"I don’t even know how to start that kind of conversation." HIV communication between mothers and adolescents with perinatally acquired HIV

Caroline Gibbsa, Diane Melvinb, Caroline Fosterb and Michael Evangelia\*

a Department of Clinical Psychology, Royal Holloway University of London, Egham, Surrey, TW20 0EX; Tel: 0044 178 444 3851; Email: [caroline.gibbs2@nhs.net](mailto:caroline.gibbs2@nhs.net) & [michael.evangeli@rhul.ac.uk](mailto:michael.evangeli@rhul.ac.uk)

b The Family Clinic, Department of Paediatrics, 6th Floor QEQM Wing, St Mary's Hospital, South Wharf Road, London, W2 1NY; Tel: 0044 203 312 6626. Email: [dianemelvin27@gmail.com](mailto:dianemelvin27@gmail.com) & [caroline.foster@imperial.nhs.uk](mailto:caroline.foster@imperial.nhs.uk)

\* Corresponding author. Dr Michael Evangeli. Email: [michael.evangeli@rhul.ac.uk](mailto:michael.evangeli@rhul.ac.uk)

**Acknowledgments**

We would like to acknowledge the young people and their mothers who took part in this project. We would like to thank staff at St. Mary’s Hospital, particularly Anita Freeman and Paula Seery for their help with participant recruitment and for being so willing to share their knowledge and experience.

**Abstract**

Young people with perinatally acquired HIV (PAH) are now surviving into late adolescence and adulthood. We explored HIV communication within mother/adolescent dyads following naming of the adolescents’ HIV. Five adolescents with PAH (14 to 16 years) and their biological mothers were interviewed separately. HIV communication between mothers and children was rare. Discussion most commonly related to biomedical aspects of HIV. Onward HIV disclosure was discouraged by mothers, which often contrasted with adolescents’ beliefs. Discussing emotional and sexual aspects of HIV was mutually avoided. Culturally sensitive support and guidance should be offered to families about discussing HIV, considering potentially differing perspectives.

**Keywords: HIV; adolescence; family; communication; qualitative methods**

# Introduction

The introduction of antiretroviral therapy (ART) has meant that the number of children surviving HIV globally has continued to rise (UNAIDS, 2014). As HIV has become a chronic health condition, new challenges have arisen, including life-long adherence to medication, consideration of sexual and reproductive health needs, making decisions about onward disclosure, and managing friendships, familial and romantic relationships (Mofenson and Cotton, 2013). This study investigates communication between adolescents with perinatally acquired HIV (PAH) and their mothers about these HIV-related issues.

## Family HIV communication following paediatric disclosure

The importance of effective family communication for individual wellbeing and family functioning has been widely investigated. Research about familial communication and both paediatric cancer (Dahlquist et al, 1991; Scott et al, 2003) and inherited genetic conditions (Metcalfe et al, 2008) suggests that the child benefits when parents talk openly and honestly about the illness, with mothers often being viewed as the best source of support and information by young people. Effective communication enables family members to express their needs and concerns and provides opportunities to share information and advice and to offer support. Ineffective family communication (e.g. communication that is unclear, involving high levels of criticism or absent) may lead to conflict and weaken emotional relationships (Olsen, 1993). In addition, young people can express feelings of anger and frustration about information about illness being kept secret. Conversations about illness can be difficult, however, and a tendency for both parents and young people to want to protect each other from distress has been reported (Metcalfe et al, 2008).

Facilitating communication about HIV and related topics is one way in which parents or family members may support a young person with PAH post paediatric disclosure (the naming of HIV for the child), creating feelings of closeness and helping in the management of HIV stigma (Proulx-Boucher et al, 2017). Indeed, a frequently used programme supporting families where a child is HIV-positive and aware of their diagnosis explicitly aims to improve familial communication (Bhana et al, 2014) with outcomes suggesting a greater ease in being able to talk about sensitive topics, including HIV.

Although there has been a significant focus on outcomes associated with paediatric disclosure (Krauss et al, 2013), there are only a limited number of accounts relating to how families naturally engage in communicating about HIV post naming. Dorrell, Earle, Katz and Reveley (2008) briefly touched on the subject whilst interviewing 20 young people (aged between 13 and 24) with PAH, in the UK. Participants described feeling unable to talk about HIV with their parents for fear of upsetting them. In a study in the Democratic Republic of Congo, eight children with PAH aged between eight and 17 years old, and their caregivers, were interviewed about family communication before, during and after paediatric disclosure (Vaz, Eng, Maman, Tshikandu and Behets, 2010). Communication following disclosure was described by children and caregivers as being one-way, with caregivers providing advice or instruction about medication adherence, appointments, protecting others from infection and offering spiritual guidance. Caregivers reported feeling uncomfortable talking about HIV, feeling only able to offer advice, rather than in-depth conversations. Caregivers were not aware that children had concerns or questions despite nearly all young people reporting that they wanted to know more about their status. Young people reported questions being ignored or deflected and frequent episodes of being told ‘not to worry.’

A study in Sweden also reported a lack of familial HIV discussion in a group of young people (aged between 15 and 21 years old) with perinatal and early-acquired HIV (Rydström, Ygge, Tingberg, Naver and Eriksson, 2013). Similarly, a French-Canadian qualitative study explored familial interactions about HIV with 29 young people aged ten to 18 years of age, the majority of whom were perinatally infected (Proulx-Boucher et al, 2011). Young people reported very rare or non-existent conversations with their families about HIV. Any conversations about HIV were focussed on clinic appointments and medical information (e.g. CD4 count) and often took place in medical settings, facilitated by clinical staff. Young people described not wanting to bring up the topic of HIV to prevent mothers feeling guilty and of avoiding conversations to prevent other family members from becoming upset. Young people living with host families spoke of feeling more able to talk about HIV and that the person in charge of the host family would raise the subject, leading the authors to conclude that the emotional connection between biological mother and child inhibited HIV discussion.

All but one of the above studies (Vaz et al, 2010) gathered information from young people only, thus excluding the mothers’ perspectives. The latter is important as adolescents with PAH and their mothers form dyads with experiences that are both shared (living with the same stigmatised condition requiring active management) and different (divergent routes of infection and sometimes having been raised in different countries with variation in cultural beliefs about health and childhood). These features also differentiate this population from families living with other chronic conditions.

Age ranges in previous studies have often been wide, making it difficult to draw conclusions across the whole sample. In addition, a proportion of the participants in these studies were not describing HIV communication with their biological (HIV positive) mothers, where specific issues of guilt and blame may be present. It is important to investigate the unique experiences of HIV communication between adolescents with HIV and their mothers given the evidence across conditions of the benefits of open, honest, sensitive and normalising familial discussion about illness. There may be particular benefits if barriers to communicating about emotional matters can be overcome.

The present study aimed to explore experiences of HIV communication between adolescents with PAH of a similar age and their biological mothers following paediatric HIV disclosure.

# Method

The study adopted a qualitative cross sectional design. A constructivist grounded theory approach was used (Charmaz, 2014).

***Sampling and Recruitment***

Ten participants were recruited from a tertiary HIV family service in an inner city London hospital. Sampling was a mixture of convenience (i.e. six of the ten were based on who had upcoming appointments) and theoretical (i.e. the remaining four were selected to investigate the perspectives of adolescents of both gender). The inclusion criteria was that adolescents must be aged between 13 and 17 and have been told their HIV status at least twelve months prior to the interview. Mothers and adolescents had to live in the same house as one another, speak English well enough to not require the use of an interpreter and be presenting without significant cognitive deficits or risk issues.

Two adolescents declined to take part when approached. Table 1 provides information about participant demographics. All five young people were fully disclosed to at the clinic between the ages of ten and twelve (mean time from HIV naming to the interview was 4.2 years). All participants reported having some discussions about HIV at home.

**Table 1 here**

***Data collection***

The interview guides (one each for adolescents and mothers) were piloted with a group of adolescents with PAH and the mother of a child with PAH to ensure the questions were relevant and understandable. The study was introduced to potential participants on the phone or in person at routine clinic appointments by members of their clinical team (who were not part of the research team). Young people were either introduced to the study before their mother or at the same time. If potential participants expressed an interest in taking part, they met with the first author to discuss the study and for consent to be taken.

Participants took part in semi-structured interviews either at the clinic or in their homes between September 2014 and February 2015. Interview questions were generally open-ended to allow participants’ experiences to emerge (Charmaz, 2014) (e.g., “What do you think has affected how you talk to your child about HIV?”; “How do you feel when mum (/other) brings up the subject of HIV?”). Questions about HIV communications were asked chronologically from HIV communication immediately after full paediatric disclosure until the present. Mothers’ interviews lasted between 43 and 72 minutes, with a mean interview length of 54 minutes. Adolescents’ interviews lasted between 28 and 59 minutes, with a mean interview length of 44 minutes.

***Data analysis***

Data analysis was conducted using Charmaz’s constructivist approach to grounded theory (Charmaz, 2014). Interviews were transcribed verbatim and coded three times (open coding, focussed coding and theoretical coding) by the first author, with codings reviewed by the second author (neither of whom were part of participants’ clinical team). The third and fourth author were part of participants’ clinical team. The interview transcriptions and initial codes were completed soon after each interview.  The first author then reviewed the interview schedules and any emerging gaps, ambiguities and key areas of interest were identified from this analysis.  These were then added to the interview guide to be explored further with subsequent participants.  The first author also met with members of the clinical team to discuss some of the initial ideas and queries that had been identified following the first four interviews and to investigate the possibility of recruiting participants from different backgrounds to test the emerging theory.

***Ethical considerations***

The project was granted ethical approval by NHS and University departmental ethics committees. All participants over the age of fifteen gave informed consent. Participants under sixteen provided assent, with mothers providing parental consent.

# Results

Eight theoretical codes were identified (see Table 2). Across codes, communication about HIV was often described as challenging, despite relationships between young people and their mothers generally being perceived positively. In particular, there was a mutual lack of confidence about talking about more emotional matters relating to HIV and differing views about sharing one’s HIV status with others. This appeared partly related to differing cultural influences on mothers and adolescents and also a greater impact of HIV stigma on mothers.

**Table 2 here**

## Triggers to HIV communication post-disclosure.

*1.1 Adolescent having specific questions about HIV*

Nine of the ten participants described occasions where the young person had approached their mother with specific questions about HIV. These questions tended to be requests for factual information such as wanting to know about HIV transmission or other virus-specific information. One adolescent also described wanting to hear more about their mother’s own experiences.

"The one time was maybe when I asked how did I get it and then she said it was from mother to daughter," (Adolescent-F)

*1.2 HIV being mentioned in the media*

Another catalyst to HIV communication was its mention in the media, usually on the television or radio. Mothers often recommended their child watched or listened, thus indirectly raising the topic.

"I tend to watch a program on it or in the paper and we start discussing it you know," (Mother-I)

*1.3 Choosing a suitable time for conversations to happen*

Certain conversations about HIV, particularly those concerning relationships, tended to happen once the adolescent was older and appearing to reflect mothers’ perceived need to initiate conversations about onward transmission. Decisions about raising this issue appeared to be culturally informed, with one mother stating that she was planning to talk to her child about relationships at a younger age than if they had lived in her country of origin.

“In this country I would [talk about relationships earlier with child] because of the society we are living in, but just comparing to people in the same position as me back home they wouldn’t, but in this country I think I have to,” (Mother-I)

*1.4 Adolescent feeling distressed*

Mothers and young people also described occasions where the adolescent’s distress had triggered HIV communication. Young people described being upset and frustrated with HIV interfering with friendships, relationships and job prospects.

“He wanted to talk to me about how it’s affecting his life and his confidence, he says it gets him down because of it and he was emotional about it," (Mother-C)

***Barriers to HIV communication post full disclosure***

Mothers and adolescents described several barriers to HIV communication. These were both motivational (i.e. citing reasons not to talk about HIV) and volitional (i.e. factors that inhibited talking despite wanting to).

*2.1 Lacking self-efficacy in communication skills (with a strong link to cultural influences for mothers)*

Mothers and adolescents reported feeling that they lacked the skills needed to initiate or participate in a conversation about HIV. This was sometimes related to particular topics (e.g. romantic relationships) but for others it limited nearly all HIV communication. Several mothers described a strong link between their own upbringing and how this had influenced their perceived ability to communicate with their child.

"I find myself at a loss of words and really unable to communicate my deepest thoughts. I feel that I’m not completing what I’m meant to do as a parent, to be more open and talk freely, because of my culture it’s, it’s something in my mind that’s keeping me back from discussing more issues… I never grew up discussing anything with my parents so it’s really difficult for me," (Mother-C)

*2.2 Lacking the time, availability or privacy to have conversations*

Seven participants described lacking the time to talk about HIV at home due to having other commitments (e.g. work or school assignments). Participants also spoke of lacking space and privacy to talk at home, either because other family members were unaware of their status or preferring to keep conversations private.

"I think he would talk to me but we don’t have that much space even to talk about [HIV] because small children are around and it’s only sometimes when we find ourselves by ourselves that we talk about it," (Mother-C)

*2.3 Anticipating (and wanting to avoid) adolescent distress*

Both mothers and adolescents described avoiding HIV communication so as to prevent the adolescent becoming distressed. Mothers described occasions where HIV communication had previously led to their child becoming upset and choosing not to raise the topic again. One mother also spoke of avoiding communication because she wanted her child to feel normal.

"I think he likes to be more open about [HIV] but when he discusses about it he gets emotional and ………a bit more down than before so he doesn’t raise it that much and I don’t want to raise it on him if he doesn’t want to discuss, I don’t want to force it on him," (Mother-C)

***HIV topics that are up for discussion***

Despite the barriers described above, participants described a set of topics that were more easily discussed.

*3.1 Mother providing medication reminders or encouragement*

All participants described frequent occasions where mothers would remind the adolescent to take their medication, either in response to reluctance from the adolescent or a wish for their child’s viral load to be undetectable. Mothers also spoke to the adolescent about the lack of medication in some parts of Africa and how lucky they were to have it so readily available.

“I will be telling them, you are lucky you’ve got the medicines, you need to take them," (Mother-I)

*3.2 Mother discouraging onward disclosure (and offering advice on how to maintain secrecy)*

Seven participants described occasions where adolescents were instructed by mothers not to share their status with anyone outside of those who already knew (mainly family members and clinic staff). Mothers tended to warn adolescents about the expected reaction they would receive, predicting negative responses and rejection from friends (i.e., anticipating HIV stigma).

"They’re completely and utterly against it. Like, they don’t want me to disclose because they don’t think that like, my friends will stay…that if things go badly that at the end of the day, you just lost a friend and like, the implications that it can have on your life like, you don’t know who that person is going to tell," (Adolescent-D)

To avoid being asked questions by others (e.g. when on school trips or having guests to stay) mothers also offered adolescents advice as to how to keep their status a secret to avoid stigmatizing responses from others.

"I would try to think of ways, how could she [take her medication], how could she, for example I say, ‘OK, instead of maybe getting it from your suitcase you could put it into your toilet bag so when you’re going to the bathroom you just say you’re going to brush your teeth before you go to bed so that you can have it,’" (Mother-G)

*3.3 HIV transmission*

Several participants recalled having conversations about HIV transmission. As well as describing how HIV had been transmitted, mothers also spoke of expressing their regret to children, explaining that they could not have prevented transmission from occurring.

"I have explained myself to her that if I had known that this is the status that I had then I would never have breastfed or if I was supposed to be breast feeding I would have taken antiretrovirals," (Mother-E)

*3.4 Mother providing reassurance to the adolescent*

This is a topic only raised by the mothers as an example of HIV communication. Several recalled providing their child with reassurance about living with HIV, particularly in the context of ‘living a normal life.’

"I always encourage her like, I will say, ‘OK you see me, you are able to work, you are able to live a normal life,’ you know those kinds, I try to be like a role model into her life and ah, she’s able to see other friends as I said…we’re living a normal life," (Mother-G)

***Experience of HIV communication***

*4.1 Experiencing conversations as difficult, stressful or awkward*

Four mothers and three adolescents described finding it hard to talk about HIV and that conversations could be stressful or awkward. Some of these experiences related to having beliefs about lacking the required skills to talk about HIV.

"When I’m talking to her about it, it’s hard for me to put it into… I try like, correctly phrase it so that it gets to her and so she understands it but, she can’t see what I’m thinking so it’s kind of difficult for me," (Adolescent-B)

*4.2 Conversations being kept to a minimum or lacking in depth*

HIV communication was described by seven participants as occurring infrequently, with conversations tending to be short and lacking in detail.

"It’s not really spoken about and then when it is spoken about it’s like... just get it over and done with and said than going into depth," (Adolescent-F)

"I think I talked to her once or twice after about it and then…I don’t think we ever talked about it again after that…it’s mostly a quick 5, 6 minute max chat yeah," (Adolescent-J)

*4.3 Level of satisfaction with amount of HIV communication*

Several participants spoke of feeling satisfied with the amount of family HIV communication, despite it being quite limited or brief in nature.

"Yeah it’s fine...we talk about it when we need to talk about it and not when we don’t need to," (Adolescent-D)

One adolescent recalled a period in which they would have liked to have more conversations with their mother, but that eventually her questions had been answered at a support group.

"I used to want to have more discussions but then now most of the questions that I wanted have been answered already," (Adolescent-F)

Some mothers, however, spoke of wanting to talk more with their children about HIV, or of only feeling satisfied once the amount of communication had increased. This appeared motivated by wanting to help their child.

"Not enough that’s what I think. I want to talk more about it. If there is anything I could put a light on, if there is anything that worries him, I want to discuss it more," (Mother-C)

*4.4 Adolescent feeling frustrated over differing beliefs to mother*

Several adolescents described having different beliefs to their parents about HIV and of feeling frustrated by conversations. Mothers would encourage their child to avoid disclosing to friends or to have relationships with people who were also HIV positive. Adolescents spoke of wanting to be more open about their status and of wanting to find a partner who accepted them for who they were. These feelings of frustration appeared to contribute to adolescents’ lack of willingness to discuss HIV with their mothers, thus perpetuating this barrier to HIV communication.

"She would say stuff like, ‘find someone alike, find someone like this, find someone like that,’ and I’ll be thinking but, is it for you to be happy or is it for me to be happy…we can’t come to a compromise so it kind of side tracks me and it kind of, for the rest of the afternoon or day or whatever, it’ll be on my mind, so I don’t really like talking about it with her," (Adolescent-B)

The three adolescents who spoke of having different beliefs about disclosure and relationships were those who attended support groups and therefore exposed to hearing about a broader range of experiences of people living with HIV.

*4.5 Adolescent perceiving mum as being supportive*

Despite disagreeing about some topics, several adolescents described feeling that their mother’s intentions behind advice given stemmed from a place of support.

""I feel like she’s enquiring cos she cares." (Adolescent-D)

***Factors that influence ongoing HIV communication***

A number of factors were found to influence both the choice of topics discussed and the experience of having these conversations.

*5.1 Having less need to talk about HIV over time*

Several adolescents and mothers spoke of having less need to discuss HIV over time, so that it became a less important or necessary topic of conversation. Both referred to the adolescent being given the right amount of factual information so that conversations were no longer necessary.

"Maybe because, I’ve got to the point where, most of the stuff I know so yeah… there ain’t really much to explain about it," (Adolescent-H)

“I don’t really see it as something that we really have to talk much about because she has…she’s got quite the right amount she’s got amount of, of knowledge about it and…I don’t see really any much to talk about it," (Mother-G)

*5.2 Mother perceiving the adolescent to be receiving enough information/support elsewhere*

Several mothers spoke of their feeling that their child was getting enough support and information about HIV elsewhere, usually at the clinic and/or support groups.

"No, she didn’t have that much question because she got a nurse that’s teaching her everything, that’s <nurse> here [at the clinic], so they are really good so I’m really happy about that and doctor as well," (Mother-A)

Some mothers also perceived their child as preferring to talk about HIV elsewhere because of the nature of the relationship between teenagers and their parents.

"It’s not always the same talking to your parents and talking to someone else about it. Because with your parent you’re scared that they might say something negative about whatever you’re trying to do…but with other people you can talk freely and yeah," (Mother-C)

*5.3 Adolescent finding it easier to talk about HIV elsewhere*

Adolescents also described finding it easier or preferring to talk about HIV with clinic staff and at the support groups. They spoke of being able to support their friends and of being supported in return.

"It’s easier because some of them [friends at support group] have grown up from the first day I went there and I’m still talking with them and all of that and then sometimes if they have a problem they tell me and if I have a problem I tell them," (Adolescent-F)

*5.4 Mother’s experience of stigma and the wish to protect her child*

Mothers’ own experiences of HIV stigma were influential in their choosing to advise their children not to tell anyone about their HIV status. Three mothers spoke of witnessing or experiencing stigma from others and described anticipating stigma from others - something they wanted to protect their child from.

"At one point I was admitted to one hospital and I could tell, the reaction I got from the nurses who were treating me was completely very horrible and very negative yep… Very very very very difficult. I wouldn’t like her to go through that but it was peoples’ comments and people what they say it just feels so bad, it just feels so bad and so sad," (Mother-G)

"Yes, I don’t want him to be bullied or to be harassed or to be…told something negative," (Mother-C)

Adolescents themselves did not describe any incidents of seeing or hearing negative responses from others in relation to HIV, although many referred to understanding their mother’s opinion and of being aware that stigma exists. Despite feeling worried about receiving a negative response and being told not to disclose, two young people felt able to do so after hearing positive experiences at support groups. Both adolescents described telling HIV-negative friends about their status and viewing these episodes as positive events.

"I mean he – surprising to me – just really didn’t really, he just asked maybe one or two questions, he wasn’t really shocked, he wasn’t really surprised, he didn’t react badly so..that’s what really strengthened us as well, like trust between us two… I felt relieved. Cos, it’s a relief to tell someone close to you. And, if that’s the way they react then... it makes you positive, you’re like, ok, so not everyone is pessimistic," (Adolescent-B)

***The impact of HIV communication***

Mothers and adolescents spoke of the impact HIV communication had on their wellbeing and on their relationships with one another, both positive and negative.

*6.1 Positive impact of HIV communication*

The dyad who reported speaking more regularly about HIV at home described several positive outcomes of HIV communication. Both the adolescent and mother spoke of how talking about HIV had strengthened their relationship and that talking about it had become easier over time. The adolescent also spoke of feeling as though she had more support available in knowing that she could talk about HIV at home.

"I feel like I’ve got more support if I need it so, I know that mum’s always there to talk about it and like, it’s just one of those things which is like, more of a common topic now rather than something which is special topic to talk about," (Adolescent-D)

*6.2 Negative impact of HIV communication*

Several participants described negative outcomes following HIV communication including greater worry or distress in mothers and adolescents.

"I worry more, I worry more [after talking about it], what’s his future going to be, how is he going to cope and down from that and start feeling bad about himself, yeah," (Mother-C)

"It was one of those things where if I did talk about it I’d end up in a really bad mood so I just used to avoid it completely," (Adolescent-D)

***The role of others***

*7.1 Recognising the important role of support groups and clinic staff in providing HIV information and support*

Every participant described the benefits of being able to talk with experienced professionals in a non-judgemental environment.

"It’s good. It’s a haven. Very good. You know, finding a place where you can easily, openly talk without getting judged, that’s….you know, you’ll be very lucky, cos there’s not a lot of them. It was only when I was, 12, 13 when I found out about <support group> and not even to the extent that I know now, and I’m very glad that I did cos it’s a very good place, yeah," (Adolescent-B)

*7.2 Receiving social support*

Mothers and adolescents described the increased level of support the young person had received from attending support groups and residential interventions, and in having the opportunity to talk to and make friends with other young people with HIV.

"She has also got friends who are in the same situation and up until last year when she went to camp it made her feel so much better because you know she is not living alone, she is not the only one," (Mother-E)

"I guess it’s like an opportunity to like..be away from family life and just be with people round your age who are like you and you can relate to which is a good environment," (Adolescent-F)

*7.3 Identifying a need for more support with family communication about HIV*

None of the participants reported that healthcare professionals had offered or provided support with family communication about HIV. Two participants described wanting support from services with HIV communication at home, either presently or in the past.

"Yeah it would have been, it would have been helpful to have someone in the middle to create a bridge between us," (Adolescent-F)

"Yeah, if there was someone to support me to do those conversations it would have flowed more, yeah," (Mother-C)

***Sex communication is off limits***

Nine participants described sex as being something they were unable to discuss with their mother or child, influenced by a range of factors.

*8.1 Mothers’ cultural experiences and beliefs about the parental role*

Several mothers spoke of the impact culture had on their decision to avoid sex communication with their children. They referred to their country of origin and of their understanding that sex was not something parents should discuss with their children, as they had not done with their own parents.

"We don’t really talk about it much. It’s like a cultural thing you wouldn’t, from back home you wouldn’t talk to your parents about, the culture is used to like if you get a girlfriend or boyfriend you talk to the aunties those kind of things," (Mother-G)

*8.2 Adolescent anticipating - and wanting to avoid – awkwardness with mother*

Adolescents also described avoiding conversations about sex with their mothers, feeling that doing so would be very awkward.

"It’s like I’m sort of scared like how’s this going to go or something…Like, be really awkward, just not be able to talk to her about it," (Adolescent-H)

Wanting to avoid sex communication also acted as a barrier to HIV communication. One adolescent spoke of not wanting to talk about HIV in case it led on to the topic of sex, something they would find too awkward or embarrassing.

“The reason I don’t want to talk about HIV with my mum is in case it leads on to talking about sex,” (AD-H)

*8.3 The role of others in sex communication*

Participants spoke about their ability to talk about sex with clinicians, friends and at support groups. Young people also spoke of finding it easier to talk to clinicians about sex, particularly in the context of HIV, as they were able to offer advice from a medical perspective and were less judgemental.

"It’s just a lot easier to talk to [clinicians] about [sex] because like, I can get more informed knowledge so it’s just easier for me to understand," (Adolescent-D)

# Discussion

This study showed that post-naming conversations about HIV between adolescents with PAH and their mothers were generally rare and, on the occasions that they did occur, short and lacking in depth. These findings are consistent with previous research (Dorrell et al, 2008; Vaz et al, 2010; Proulx-Boucher et al, 2011; Rydström et al 2013). There was no evidence of relationships generally characterized by conflict and an absence of warmth, despite the relative absence of HIV communication. There was also limited evidence of adolescents feeling ignored or of mothers not being aware of their children’s HIV-related questions and concerns, in contrast to Vaz et al’s (2010) study.

One key influence on the nature of HIV communication was the topic in question. *Biomedical* aspects of HIV (e.g., information about HIV transmission and medication issues) were discussed most frequently by both adolescents and their mothers. Adolescents sometimes triggered conversations with asking specific questions. On occasions, questions were related to topics that only mothers could answer, for example, how their mother had come to be HIV positive. Some studies have shown, however, that HIV-positive parents are reluctant to talk about details of HIV transmission with their children (Kennedy et al, 2010). In this study many mothers offered medication prompts and advice about reducing the risk of onward HIV transmission as children increased in age. In addition, mothers sometimes attempted to prompts conversations about HIV indirectly (e.g., through suggesting that their child watch a particular TV programme). These findings are in contrast to the one-way (adult to child) communication reported in a study in DRC (Vaz et al, 2010), perhaps explained by cultural differences between the two contexts. The important topic of *onward HIV disclosure* (sharing one’s HIV status with others) was also discussed but this area often revealed tension between the mother’s and adolescent’s beliefs. Mothers frequently advised against onward disclosure for fear of stigmatizing responses from others, offering suggestions for how to keep HIV a secret and reporting their own negative experiences of discrimination when their status was known. Adolescents, on the other hand, sometimes reported more pro HIV disclosure beliefs, in keeping with their conversations with peers and positive experiences of having shared their status. There remains little guidance about how to support young people with PAH and families around the issue of onward HIV disclosure (Evangeli & Foster, 2014).

*Emotional and sexual/relationship* consequences of living with HIV appeared to be rarely discussed, consistent with other studies (Proulx-Boucher et al, 2011). Conversations that might, or had previously, led to adolescent or maternal distress, in particular, tended to be mutually avoided. Fear of upsetting one’s parent has been cited as a barriers to HIV communication in young people with PAH (Dorrell et al, 2008; Proulx-Boucher et al, 2011). On some occasions, however, it was adolescents’ HIV-related distress that had prompted communication between mother and child. Many participants described experiencing HIV communication as being stressful or awkward. These experiences may have contributed to the mutual avoidance of further conversations.

Aside from a desire to avoid distress, there were a number of other *motivational barriers* to HIV communication. Both mothers and their children spoke of *not knowing how to* bring up or talk about HIV, in keeping with research reporting that parents felt lacking in the skills to tell their children that they were HIV-positive (Kouyoumdijan, Meyers and Mtshizana, 2005). Our findings demonstrate that caregivers’ difficulties in talking about HIV continue past status disclosure to the child. Mothers also cited their *culture* as a barrier to HIV communication (although it is acknowledged that this term may have had different meanings for individual participants). Several mothers described feeling both unable and unwilling to talk about certain HIV-related topics with their child (e.g. sex or relationships) either as a result of their experience with their own parents, or due to wider cultural beliefs. This supports previous findings in South Africa and DRC, that parents with HIV felt uncomfortable and emotionally unprepared to discuss HIV with their children both during and post-paediatric disclosure (Kouyoumdijan, Meyers and Mtshizana, 2005; Vaz et al, 2010). Most participants, however, did not report a *need* to discuss HIV more with their family member, consistent with findings from a previous UK study, where young people with PAH described feeling satisfied about the level of communication about their status, despite having few confidants (Sopeña, Evangeli, Dodge and Melvin, 2010). Some *volitional* barriers to discussing HIV were apparent. Finding sufficient time and space to communicate about HIV was an issue, particularly where other family members were unaware of their status. This highlights the prevalence of secrecy within families affected by HIV.

It is possible that the opportunities to discuss HIV with professional and peers (the former potentially more available than in low income contexts) fulfilled some of adolescents’ HIV communication needs. This supports findings from a Swedish study where young people with HIV relied heavily on healthcare professionals with some being described as ‘replacing family’ (Rydström et al, 2013). It was clear that mothers provided reassurance related to HIV, expressed regret about their child being HIV positive, were sensitive to their children’s distress that could result from discussing HIV, and were perceived by their children as acting on good intentions. The dyad that spoke most readily about HIV reported that this communication had strengthened their relationship. In addition, some mothers said that they would like to communicate more about HIV with their child, suggesting their own needs may not have been fully met.

Our study benefited from recruiting a homogenous sample of young people, in relation to age at interview and paediatric disclosure, whilst still recruiting both male and female participants. In addition, the response rate was good, and the sample was demographically similar to that of the broader clinic population and the national population of HIV-positive adolescents living in the UK (CHIPS, 2014). Another strength was the use of both professionals and service users to maintain quality of the research by reviewing codes and refining the interview guide (Madill, Jordan & Shirley, 2000). Limitations include the possibility that those recruited were more likely to be open to talking about HIV (particularly as the subject matter was HIV communication) than other young people, or may have closer relationships with their mother/child than non-recruited dyads. In addition, caution must be expressed about attempting to generalise findings given the small sample size (which precluded examination of whether codes differed by age and gender, for example).

Our findings suggest that mothers and young people could benefit from support to increase their confidence in HIV communication. More supported parent /child discussions about HIV pre and post naming, role-play, modelling and challenging beliefs about the perceived outcome of HIV communication are possible methods for increasing self-efficacy as has been evidenced in onward disclosure HIV interventions in other populations (e.g., Murphy, Armistead, Marelich, Payne & Herbeck, 2011). The lack of time and space to discuss HIV reported by mothers indicates that families may need support in planning for a suitable time to have conversations about HIV or the provision of a safe space (e.g. at clinics) if they are motivated to communicate more openly. Professionals have reported wanting more guidance about how to support young people with onward HIV disclosure (Bott & Obermeyer, 2013) including managing anticipated distress which is a barrier to HIV communication. Building skills in how mothers and adolescents may cope with distress may be helpful, consistent with the importance of considering both the young person’s and the mother’s emotional needs.

Support with HIV communication should be aware of cultural sensitivities, and could be topic and person-specific, and provided in a range of formats (e.g. written material on ‘talking about sex with your mum’). A combination of individual and family sessions (informed by systemic and narrative ideas) may be most effective when face to face work is indicated, for example when there are competing narratives about HIV within the family. Systemic and narrative approaches would aim to understand different experience and stories about HIV for both mothers and adolescents and may enable the understanding of each other’s perspective.

Group sessions for mothers may also be helpful so that they can share experiences, thus normalising difficulties with HIV communication – this has been shown to be effective in the ‘mothers2mothers’ programme (Teasdale and Besser, 2008). Future research could also explore HIV communication with fathers or siblings, as well evaluating HIV communication interventions, employing some of the suggestions described above.

**Declaration of Conflicting Interests**

The Authors declare that there is no conflict of interest.

**References**

Bhana, A., Mellins, C. A., Petersen, I., Alicea, S., Myeza, N., Holst, H., ... & Leu, C. S. (2014). The VUKA family program: piloting a family-based psychosocial intervention to promote health and mental health among HIV infected early adolescents in South Africa. *AIDS care, 26*(1), 1-11.

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*, 10 (Suppl 1):S5–S16.

Collaborative HIV Paediatric Study (CHIPS). (2014). *Annual Report 2013/14.* London: Medical Research Council.

Dahlquist, L. M., Czyzewski. D., Copeland, K., Jones, C., Taub, E., & Vaughan, J. (1993). Parents of children newly diagnosed with cancer: Anxiety, coping and marital distress. *Journal of Pediatric Psycholology*, *18*, 365–376.

Dorrell, J., Earle, S., Katz, J., & Reveley, S. (2008). Growing up with HIV: The experiences of young people living with HIV since birth in the UK. *Death and dying: A reader.* 237-244.

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(supplement 3), S343-346.

Imber-Black, E. (2014). Will Talking About It Make It Worse? Facilitating Family Conversations in the Context of Chronic and Life-Shortening Illness. *Journal of Family Nursing*, 20(2), 151-163.

Kennedy, C. E., Medley, A. M., Sweat, M. D., & O'Reilly, K. R. (2010). Behavioural interventions for HIV positive prevention in developing countries: a systematic review and meta-analysis. *Bulletin of the World Health Organization, 88*(8), 615-623.

Kouyoumdjian, F. G., Meyers, T., & Mtshizana, S. (2005). Barriers to disclosure to children with HIV. *Journal of Tropical Pediatrics, 51*(5), 285-287.

Krauss, B.J., Letteney, S., De Baets, A.J., Baggeley, R., & Amolo Okero, F. (2013). Disclosure of HIV status to HIV-positive children 12 and under: A systematic cross-national review of implications for health and well-being. *Vulnerable Children and Youth Studies, 8*(2), 99-119.

Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British journal of psychology*, *91*(1), 1-20.

Mellins, C. A., & Malee, K. M. (2013). Understanding the mental health of youth living with perinatal HIV infection: lessons learned and current challenges. *Journal of the International AIDS Society, 16*(1).

Metcalfe, A., Coad, J., Plumridge, G. M., Gill, P., & Farndon, P. (2008). Family communication between children and their parents about inherited genetic conditions: a meta-synthesis of the research. *Eur J Hum Genet, 16*(10), 1193-1200.

Mofenson, L. M., & Cotton, M. F. (2013). The challenges of success: adolescents with perinatal HIV infection. *Journal of the International AIDS Society, 16 (1).*

Murphy, D. A., Armistead, L., Marelich, W. D., Payne, D. L., & Herbeck, D. M. (2011). Pilot trial of a disclosure intervention for HIV+ mothers: the TRACK program. *Journal of consulting and clinical psychology, 79*(2), 203-214.

Olson, D. H. (1993). Circumplex model of marital and family systems: Assessing family functioning. In Walsh, F. (Eds). *Normal family processes. Guilford family therapy series* (pp. 104-137). New York, NY: Guilford Press.

|  |
| --- |
|  |

Patel, K., Williams, P. L., Seeger, J. D., McIntosh, K., Van Dyke, R. B., & Seage, G. R. (2008). Long-term effectiveness of highly active antiretroviral therapy on the survival of children and adolescents with HIV infection: a 10-year follow-up study. *Clinical Infectious Diseases, 46*(4), 507-515.

Proulx-Boucher, K., Blais, M., Fernet, M., Richard, M. E., Otis, J., Levy, J. J., ... & Trottier, G. (2011). Silence and disclosure in families of adolescents living with HIV since birth: A qualitative exploration. *Paediatrics and Child Health, 16*(7), 404-408.

Proulx-Boucher, K., Fernet, M., Blais, M., Lapointe, N., Samson, J., Lévy, J.J., Otis, J., Morin, G., Thériault, J. and Trottier, G., (2017). Stigma Management Trajectories in Youth with Perinatally Acquired HIV and Their Families: A Qualitative Perspective. *AIDS and Behaviour*, 1-11.

Rydström, L. L., Ygge, B. M., Tingberg, B., Naver, L., & Eriksson, L. E. (2013). Experiences of young adults growing up with innate or early acquired HIV infection–a qualitative study. *Journal of advanced nursing, 69*(6), 1357-1365.

Scott, J. T., Harmsen, M., Prictor, M. J., Sowden, A. J., & Watt, I. (2003). Interventions for improving communication with children and adolescents about their cancer. *Cochrane Database System Review, 3*, 1-33.

Sopeña, S., Evangeli, M., Dodge, J., & Melvin, D. (2010). Coping and psychological adjustment in adolescents with vertically acquired HIV. *AIDS care*, 22(10), 1252-1258.

Teasdale, C. A., & Besser, M. J. (2008). Enhancing PMTCT programmes through psychosocial support and empowerment of women: the mothers2mothers model of care: short report. *Southern African Journal of HIV Medicine*, (29), 60-62.

UNAIDS. (2014). *2014 Progress Report on the Global Plan.* Geneva: UNAIDS.

Vaz, L. M., Eng, E., Maman, S., Tshikandu, T., & Behets, F. (2010). Telling children they have HIV: lessons learned from findings of a qualitative study in sub-Saharan Africa. *AIDS Patient Care and STDs, 24*(4), 247-256.

**Table 1. Table of participants’ demographics**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **Participant** | **Age** | **Gender** | **Place of Birth** | **Age of Diagnosis1/Disclosure2** |
| Mother 1 | 49 | F | Sub-Saharan Africa | 361 |
| Adolescent 1 | 16 | F | Sub-Saharan Africa | 102 |
| Mother 2 | 39 | F | Sub-Saharan Africa | 261 |
| Adolescent 2 | 16 | M | Sub-Saharan Africa | 122 |
| Mother 3 | 41 | F | Sub-Saharan Africa | 301 |
| Adolescent 3 | 16 | F | Sub-Saharan Africa | 122 |
| Mother 4 | 40 | F | Sub-Saharan Africa | 321 |
| Adolescent 4 | 15 | F | UK | 11/122 |
| Mother 5 | 49 | F | Sub-Saharan Africa | >311 |
| Adolescent 5 | 14 | M | UK | 10/112 |

**Table 2. Theoretical and focussed codes**

|  |  |
| --- | --- |
| THEORETICAL CODES | FOCUSSED CODES |
| 1. Triggers to HIV communication post-disclosure | 1.1 Adolescent having specific questions about HIV |
| 1.2 HIV being mentioned in the media |
| 1.3 Choosing a suitable time for conversations to happen |
| 1.4 Adolescent feeling/exhibiting distress |
| 2. Barriers to HIV communication | 2.1 Lacking self-efficacy in communication skills (with strong cultural influence for mothers) |
| 2.2 Lacking the time, availability or privacy to have conversations |
| 2.3 Anticipating (and wanting to avoid) adolescent distress |
| 3. HIV topics that are up for discussion | 3.1 Mother providing medication reminders or encouragement |
| 3.2 Mother discouraging onward disclosure and advising as to how to maintain secrecy |
| 3.3 HIV transmission (perinatal infection and guilt) |
| 3.4 Mother providing reassurance to adolescent |
| 4. Experience of HIV communication | 4.1 Experiencing conversations as difficult/stressful/awkward |
|  | 4.2 Conversations being kept to a minimum / lacking depth |
| 4.3 Level of satisfaction with amount of HIV communication |
|  | 4.4 Adolescent having different beliefs to mother |
|  | 4.5 Adolescent perceiving mum as being supportive |
| 5. Factors that influence ongoing HIV communication | 5.1 Having less need to talk about HIV over time |
| 5.2 Mother perceiving the young person is getting enough info/support elsewhere |
| 5.3 Adolescent finding it easier to talk elsewhere (at clinic/support group/siblings) |
| 5.4 Mother’s experience of stigma – (anticipating, observed, enacted) and wish to protect child |
| 6. The impact of HIV communication | 6.1 Positive impact of HIV communication |
| 6.2 Negative impact of HIV communication |
| 7. The Role of Others | 7.1 Recognising the role of support groups and clinic staff in providing HIV information and support |
| 7.2 Receiving social support |
| 7.3 Role of services - identifying a need for support with family communication about HIV |
| 8. Sex communication is off limits | 8.1 Mothers’ cultural experiences and beliefs about the parental role |
| 8.2 Adolescent anticipating (and wanting to avoid) awkwardness with parent |
| 8.3 The role of others in sex communication |