

The childbearing desires of perinatally infected female adolescents enrolled in an HIV clinic in Tshwane District, Gauteng Province, South Africa.

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Abstract

Background: Although there is evidence that adolescents with Perinatally-Acquired HIV (PHIV) are living into young adulthood, there is paucity of research about their fertility intentions and how the experiences of growing up with HIV influence their intentions for parenting. This is despite South Africa being the country with the largest number of children and adolescents on Antiretroviral Therapy (ART). The study explored motherhood desires, motivations, and concerns of female adolescents with PHIV and assessed their awareness and understanding of Perinatal HIV Transmission (PHT).

Methods: In-depth interviews were conducted with a purposively selected sample of 30 female adolescents with PHIV aged 14-19 years. The adolescents were enrolled in an ART program of a district hospital in Gauteng province, South Africa. Data were analyzed thematically using NVivo data analysis software.

Findings: Most female adolescents with PHIV who perceived a low risk of PHT desired to have children. The desire for motherhood superseded the fear of PHT. However, parenting related issues such as the intention to disclose their HIV-positive status to their children was a great concern. The fear of PHT during pregnancy and fear of premature death leaving their children orphaned was the greatest concern among adolescents who did not desire to have children. On the other hand, the thoughts of having children for some adolescents was farfetched, for them, completing school and having a career was more important than having children.

Conclusion: The heightened fear of PHT underscores the importance of educating children and adolescents with PHIV about the prevention of perinatal transmission of HIV. It is crucial that regular discussions on fertility desires, disclosure, and prevention of PHT are integrated in the daily counseling and support for children and adolescents with PHIV.

Keywords: Perinatally infected adolescents, Motherhood desires, disclosure, HIV transmission, South Africa.

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Background

Findings from studies conducted in the African region show that a significant proportion of HIV-positive adolescents are sexually active [1-4]. A recent study conducted in South Africa found that 14.9% of adolescents with perinatally-acquired HIV (PHIV) were sexually active [5]. Earlier findings from Uganda showed a higher prevalence of sexual activity with 33% of adolescents with PHIV aged 15-19 years having had sexual intercourse [1].

Adolescents with PHIV do desire to explore their sexuality [1,6]. They desire to love and to be loved and have plans to bear children [7-9]. However, the challenges facing adolescents with PHIV are even more complex, considering the dilemma of their being in a sexually active relationship while having to avoid HIV transmission. Several studies have reported that adolescents with PHIV are afraid of being involved in a sexual relationship because of the risk of transmitting HIV to their partners and unborn babies [10-12].

On the other hand, similar to HIV-negative adolescents, early sexual debut, multiple concurrent sexual partners, unprotected sexual intercourse, and non-disclosure have also been identified as the prevailing risky sexual behaviours among adolescents with PHIV [5,13,14]. Research further shows that adolescents with PHIV who know their HIV status are more likely to use a condom at first sexual experience than those with unknown HIV status and are less likely to engage in penetrative sex than their HIV-negative peers [4,5,15-17].

The intentions and fertility choices are central to every human being, and adolescents with PHIV are not any different [18-20]. There is evidence that adolescents and young adults with PHIV have high levels of fertility desires [20,21]. Factors related to not wanting children among adult women living with HIV vary from negative attitudes held by health care workers towards people living with HIV having children to community disapproval and stigmatization as well as mother's fears that the child will become an orphan [18]. Availability of antiretroviral treatment (ART), being of a young and child-bearing age, being in a stable relationship, not having a child with the current partner, and the partner's desire to have children, positively influence the desire for motherhood among adult HIV positive women. In most of these studies, the desire for motherhood was found to override the fear of perinatal HIV transmission (PHT) [22-25]. The knowledge of the available treatment to reduce PHT may also lead individuals to consider pregnancy.

Although there is evidence that adolescents with PHIV are living into young adulthood in developing and developed settings, little is known about their childbearing intentions and how the experiences of growing up with HIV influence their intentions for parenting [26]. There is evidence that adolescents with PHIV engage in sexual activities, that negotiating safe sexual practices is challenging for them resulting in high rates of unprotected sex, and that female adolescents are more likely to report unprotected sex [5,20,27,28]. However, there is paucity of research about their reproduction despite South Africa being the country with the largest number of children and adolescents on ART. This could be partly because the children who were initiated with ART when the country scaled up ART services are just now reaching adolescence in large enough numbers. Studies conducted in developed countries show that their knowledge of PHT is low while their fertility intentions are high [21,27]. Evangeli et al. argue that there may be differences in the fertility intentions of adolescents with PHIV in different contexts [21].

It should be noted that adolescents with PHIV often learn of their HIV status during the adolescence stage when they have to make decisions about initiating sexual relationships, disclosure to romantic partners, and having children of their own [20]. Therefore, as the population

of adolescents with PHIV enter adulthood, the health education must include discussion on fertility desires and intentions as a means to heighten the effectiveness of harm reduction strategies [29]. However, the paucity of data on their fertility desires particularly in developing countries where the highest number of adolescents with PHIV are concentrated, will hamper the development of appropriate strategies to reduce PHT. The study explored motherhood desires, motivations, and concerns of adolescents with PHIV and assessed their awareness and understanding of perinatal transmission of HIV. It is important to understand the parenting intentions and motivations of adolescents and young adults with PHIV considering that health professionals in developing countries will be managing the potential childbearing of youth with PHIV as they reach reproductive age for many years and on a much larger scale [27].

Methods and Materials

Study Design

A qualitative descriptive approach was used to conduct in-depth interviews with female adolescents with PHIV between September and December 2014. Female adolescents aged between 14-19 years were purposely selected from a population of 120 teenagers with PHIV who were enrolled in the ART program of a rural district hospital located in Tshwane Metropolitan Municipality, Gauteng Province, South Africa. Only adolescents who were informed about their HIV status were selected for participating in the study. This selection criterion was important as not all the teenagers in the ART clinic were informed about their HIV positive status.

The adolescents were purposely selected because only female adolescents for whom disclosure had occurred for about a year were eligible to participate in the study. Literature shows that after the initial shock of learning about their status, children and adolescents make informed decisions to live healthy and make future plans [30]. It was important to prevent including adolescents who recently received their disclosure and had not dealt with the shock of an HIV diagnosis. To ensure maximum variation, we sampled adolescents aged 14-19 years with different clinical and socio-demographic characteristics.

Recruitment of Participants

The researcher (second author) recruited the adolescents during their scheduled treatment and follow-up visits at the hospital wellness clinic in the mornings while they waited their turn to consult. Although the target population was the adolescents, the researcher approached individual caregivers who accompanied their adolescent child to the clinic to establish whether she has been told about her HIV positive status. The caregiver who confirms disclosure was subsequently requested permission to interview the adolescent. The caregivers were provided comprehensive

information about the study objectives, confidentiality of the interview, and voluntary participation prior to requesting consent to interview the adolescents. All the adolescents who were reported not to have been disclosed to by the caregivers were excluded from the study. We also excluded adolescents who were unaccompanied by an adult caregiver because the researchers could not establish from the caregiver if disclosure had occurred. Also excluded were adolescents whom the clinic staff indicated that they were informed of their HIV status but an informed consent could not be obtained from the caregiver. However, since the study was conducted over four months, some of the adolescents who were eligible to participate but were excluded were later interviewed when they were accompanied by their caregivers. For adolescents who were not accompanied by an adult caregiver and were 18 years and above, the clinic staff assisted in identifying those who were informed about their status to avoid accidental disclosure even though the chance for accidental disclosure among this age group was minimal. The researcher then approached the individual adolescent and requested them to participate in the study. The adolescents were also provided comprehensive information about the study objectives, confidentiality of the interview, and voluntary participation prior to requesting them to volunteer to participate in the interviews. For the adolescent who were under the age of 18 years, the accompanying caregiver provided a signed consent and the adolescent provided a written assent. Adolescents who were 18 years and older signed their own consent. The in-depth interviews (IDIs) were conducted after the clinical consultations, mostly in the afternoons in order to avoid interruptions with the clinical workflow.

Data Collection

The in-depth interviews were conducted by the second author using open-ended questions designed to elicit detailed individual responses on adolescents' understanding of perinatal HIV transmission as well as their intentions about motherhood. All the interviews were conducted in a private consulting room without the caregivers being present. Each interview took about 30 minutes, all were recorded using a digital audio-recorder with the adolescent's permission to record, and were conducted in Setswana, the local language in the area. The adolescents were given a voucher for lunch since they were kept for longer than their routine visits for the afternoon interviews.

A brief tool with closed-ended questions was used to collect socio-demographic data such as current age, age at first diagnosis, time since HIV diagnosis, time since ART initiation, orphan status, and level of education.

Data Analysis

All the audio-recordings were transcribed verbatim and then translated into English by the second author. Thematic analysis, a method used for identifying,

analysing and reporting themes within data was employed for the analysis of data. Analysis began with the authors immersing themselves in the data by repeated readings of the transcripts to familiarize with the data. This was followed by conducting manual coding to identify codes emerging from the data to develop a code book. The code book was developed from the initial list of emerging codes over several meetings during which the authors reached a consensus on the definition of themes. Transcripts were subsequently uploaded into the NVivo version 10 qualitative analysis software package for application of codes. The analysis yielded the codes which captured the feelings of the participants about their context, their sexual relationships, plans, and their desire to become mothers in future.

To ensure trustworthiness, a digital audio recorder was used to facilitate verbatim transcription and to ensure that the findings reflected the views and feelings of the adolescents. All the authors performed data analysis, and the codes were agreed upon after reaching consensus. Additionally, the QSR NVivo 10 software for qualitative data analysis was used to aid data organization and analysis.

Ethical Considerations

Ethical clearance was obtained from the Research and Ethics Committee of the University of Limpopo, Medunsa Campus. Permission was also sought from Tshwane District Health and the Hospital Management. For adolescents under the age of 18 years, the caregivers provided signed informed consent and the adolescents assented. Adolescents aged 18 years and above signed their own informed consent. The caregivers and the adolescents were informed that participation was voluntary and that the adolescents could withdraw from participation without negative consequences for them. The resident social worker and psychologist were on standby for counseling during the period of data collection and two adolescents who became emotional during the interviews were referred for counselling.

Study Findings

Characteristics of the study sample

Thirty female adolescent with PHIV participated in the in-depth interviews. The youngest were 14 years and the oldest were 19 years old. The adolescents were in Grade 5 to Grade 12 of schooling, with only seven still in primary school. Nineteen out of 30 adolescents were maternal orphans; seven adolescents lived with their mothers, three with their fathers, two with both of their parents, 12 with their grandmothers and six with other relatives.

Themes

The themes that emerged during qualitative data analysis were; future goals, disclosure in romantic relationships,

desires for motherhood, the need to protect children from PHT, and the intention to disclose to children.

Future Goals

When the adolescents were asked about their plans and dreams, most believed that they have a bright future ahead of them. They mentioned pursuing professional careers and aspired to work in professions where they would help other people.

I dream big for the future. I want to see myself working one day as a fashion artist. I also want to help people who are needy (18 years old, Grade 10 learner).

I want to study engineering as I already have the foundation from high school and love it. I am currently in a technical school. Therefore, I have a foundation in engineering (18 years old; Grade 11 learner).

I want to become a lawyer because I want to help people who are in trouble with their problems (15 years old, Grade 7 learner).

For some of the adolescents, their future goals were more important than to be involved in a romantic relationship.

I never have and will not be in a relationship soon; I am still young. I will be in a relationship once I finish matric. I do not want boys to waste my time and delay my studies (16 years old, living with her mother, doing Grade 10).

I am not in a relationship; I am still very young for that. I do not want to be involved with boys because they ruin the girl's future. I am scared of my grandmother; that is why I stay away from boys and relationships (14 years old, doing Grade 6).

Disclosure in Romantic Relationships

Some of the adolescents reported that they were involved in sexual relationships but had not disclosed their status to their partners. They stated that to avoid disclosure, those who were sexually active insisted on the use of condoms and engaged in sex without telling their boyfriends about their HIV status.

I did not tell him..., but we used protection when we had sex. I forced him to use protection because I wanted to protect him as I am not ready to tell him about my status (18 years old, Grade 11).

Other adolescents reported that although they were engaged in romantic relationships, they avoided sex for fear of revealing their status.

I started dating in 2009 when I was 15 years old. I only had two boyfriends ever since. The first boyfriend I dated from 2009-2012 and we broke up because he wanted us to be sexually active which I was not ready. When I am ready I will communicate whoever I will be with at that time but I need to trust the person first before we become sexually

active (18 years old, Grade 11 learner).

Desire for Motherhood

The participants were asked whether they wanted to have children of their own in the future. Most of those who desired to have children had these to say:

I will not let HIV stand in my way of having my children in the future because I can be able to have my own children even though I have HIV (18 years old, Grade 10 learner).

I wish to have only one child; I am not afraid as there is treatment now to take when you're pregnant to protect the child from getting HIV (14 years old, Grade 8 learner).

I wish to have one or two children. Honestly, I do not know how I will make sure they don't get HIV, but I wish they will not have it (14 years old Grade 5 learner).

Although most of the adolescents desired to have children in the future, some were concerned about the risk of HIV transmission during pregnancy.

HIV it is not curable and you live with it for the rest of your life. It [HIV] lives in your body, and it makes it difficult to have your own children in the future as that might put them at risks of getting HIV. Even getting married becomes a challenge as you have to reveal your status to your partner who might reject you at times (18 years old, Grade 11 learner).

When I give birth my child will also be HIV-positive just like what happened to my mother when she gave birth to me. My child will also experience the same pain I am experiencing right now because they will not have a normal life but always wonder about medication and death (16 years old, Grade 10).

While most of the adolescents were concerned about PHT, the decision not to have children was also influenced by living with HIV. They were worried that they might not live long to have children as reflected in what one adolescent had to say;

I know there is no future for me to live and have children, that is what is making me more emotional and angry to know that I will not live long to have my own family (16 years old, Grade 10).

An additional concern for the adolescents about having children was the issue of disclosure of their HIV status to their children. They stated that it would be difficult to disclose their own HIV status to the children and were reluctant to have children and deal with the issue of disclosure of their status to their children.

If my child comes out HIV-positive, it is going to be difficult to tell him/her about the status as it was also difficult for my mother to do so. I am scared of my

child's reaction when I tell him/her about my status as he/her might react the same way as I did, so it is better I use protection (16 years old, Grade 10 learner).

The Need to Protect Children from PHT

The data revealed that the adolescents who had intentions to have children had a comprehensive understanding of PHT during pregnancy. They were also aware of the prevention of PHT which influenced their intentions to have children in the future. The data revealed the steps they would take to ensure that the baby is not infected.

I am not afraid of infecting the baby as there is treatment now to take when you're pregnant to protect the child from getting HIV (14 years old, Grade 8 learner).

I will come to the clinic when I plan to start a family for advice; that is what they always tell us. They will tell me what to do and give me what to drink to protect my children from getting HIV (15 years old, Grade 10 learner).

I will not breastfeed my children after birth; I will give them formula milk as I heard that they could get it [HIV] through breast feeding. I will go to the clinic for their advice the minute I find out about my pregnancy to protect my baby from getting HIV (15 years old, Grade 9 learner).

The Intention to Disclose to Children

The adolescents who desired to have children intended to disclose their HIV status to their children in future. Some reflected on their own disclosure experiences which influenced their intention to disclose, when to disclose and how they thought about disclosure to their children. The age of disclosure was an important consideration for disclosure and they intended to disclose at the time or age when the child would be able to keep a secret.

I am going to tell them to accept me the way I am and they must never be ashamed of me and should continue to love me. I am going to tell them when they are 15 because they would understand better by then (18 years old, Grade 10 learner).

I will tell them when they are twelve years old and are able to understand HIV as they are taught at school by then, that's just my opinion. I think so because I also started understanding at the age of twelve when they started to teach us at school about HIV (14 years old, Grade 7 learner).

Telling them before they can understand what the disease is all about preventing them to hear it from someone else before me and to be able to keep it as a secret (15 years old, Grade 9 learner).

Discussion

The purpose of the study was to explore motherhood desires, motivations, and concerns of adolescents with PHIV and assess their awareness and understanding of perinatal HIV transmission. Over and above expressing their fertility intentions, the adolescents also reported on their sexual activities. The findings revealed that although some of the adolescents were involved in sexual relationships and were sexually active, there were those who avoided penetrative sex. Disclosure to sexual partners was not easy for most of the adolescents with PHIV, and some reported that by avoiding penetrative sex, they were not forced to disclose their HIV status to their partners and face possible rejection. Similar behaviour was reported in a study conducted in the US, where adolescents and young adults with PHIV avoided penetrative sex through delaying sexual onset [28]. We found that sexually active adolescents used a condom consistently to avoid disclosure to the sexual partner. Some reported that they forced their partners to use a condom to avoid disclosure. The practice of using condoms consistently to avoid disclosure was also reported in a recent study conducted with young adults with PHIV in the UK [31]. In contrast, adolescents who disclosed to their sexual partners reported that disclosure will make it easy to use a condom when they initiate sex.

Most of the female adolescents with PHIV desired to have children in the future irrespective of having had HIV transmitted from birth and growing up with HIV. Evangeli and colleagues in a study conducted with adolescents and young adults with PHIV in an urban London clinic also reported that living with HIV did not deter their parental intentions [21]. Studies conducted in the US among urban adolescents and young adults with PHIV also reported that HIV infection status does not deter adolescents and young women from desiring motherhood [20,32].

We found that the adolescents who intended to have children perceived a low risk of PHT compared to those who perceived it as high and did not intent to have children for fear of PHT. The adolescents who expressed the strong desire to have children believed in the strategies to prevent HIV transmission to their unborn children. Research conducted with adult women living with HIV suggest that the knowledge of the available treatment to reduce PHT may lead individuals to consider pregnancy [23]. Research further indicate that the desire for motherhood supersede the fear of PHT among HIV-positive adult women in developing and developed countries [24,25].

The adolescent's decision to have children was taken with considerations of other parenting related issues such as the intention to disclose their HIV-positive status to their children [21]. They reflected on their own HIV disclosure experiences, when and how they were told about their own HIV status as they planned to disclose to their children. The finding is consistent with those of adolescents and young

adults with PHIV conducted in a London clinic, where their own disclosure stories influenced their consideration for disclosure to their children in the future [21]. The timing of the disclosure, the ability of the child to keep a secret, and the fear of a possible negative reaction to disclosure were the main considerations for the intention to disclose to children in the future. The adolescents' disclosure experiences such as how and when they were told about their status was a motivation for them to want to disclose their own status and that of their children differently to reduce the negative impact of disclosure.

It should be noted that the disclosure concerns among adolescents with PHIV are similar to that of the current generation of HIV positive mothers and caregivers of children with PHIV. The fear of disclosure of their HIV status and that of their unborn children is influenced not only by their experiences of finding out about their HIV diagnosis but by their experiences of living with HIV. There is a need to highlight the reality of the upcoming "third generation" of children affected by HIV born to people with PHIV as more adolescents with PHIV mature into adulthood and begin to procreate. The disclosure to their children will become more commonplace [27]. This underscores the importance of the need for context focused interventions for early disclosure and education for the different population groups that are currently affected and those that will be affected by disclosure [27].

As already stated, the adolescents who perceived the risk of PHT to their unborn children to be high had no intentions to have children. Their lived experiences of being infected with HIV from birth influenced their desire for parenting. They were determined that their unborn children should not live with HIV like they had to and the only way they knew how was not to have children in the first place. The fear of PHT during pregnancy was the most prominent parenting concern among adolescents and young adults with PHIV in a study conducted in the US [29]. We found that despite the fact that the adolescents have been on ART for some time and were healthy and did not suffer from any HIV-related illness, they feared that they would die prematurely and leave their children orphaned. The fear of dying and leaving the children orphaned was also reported in the US study [29]. Adolescents with PHIV live their lives through the experiences of the adults in their lives, although most did not experience the devastating effects of AIDS, they still believed that an HIV diagnosis equals life sentence [30].

For some of the adolescents, the thoughts of having children were farfetched. These adolescents were not involved in romantic relationships, for them completing school and having a career was more important. However, their priorities might shift once they attain their future goals of completing school, Finocchiaro-Kessler et al. argue that finishing school and getting a job, are

important developmental milestones in adolescence and it is expected that they would prioritize that before thinking of parenting [33].

Study Limitations

The sample was limited to female adolescent with PHIV who were enrolled in an HIV clinic of a district hospital. A larger sample of adolescents with HIV from other settings such as primary health facilities should be considered in future in order to be able to generalize broadly. Another limitation of the study was the exclusion of boys with PHIV from participating; therefore, the perceptions of parenting in the study are limited to female adolescent and cannot represent the views of adolescents with PHIV. It is important that future studies take this into consideration. However, the study findings provide insight into childbearing desires and decisions of children with PHIV in South Africa.

Conclusion

Most female adolescents with PHIV who perceived a low risk of PHT desired to have children in the future. However, parenting related issues such as the intention to disclose their HIV-positive status to their children was a great concern.

The strong desires for parenting coupled with low intentions to disclose to sexual partners and tendency to use a condom to avoid disclosure have implications for healthcare professionals providing HIV related services to adolescents with PHIV. It is crucial that regular discussions on fertility desires, disclosure, and prevention of PHT are integrated in the provision of counseling and support for children and adolescents with PHIV. It is also critical that health professionals create an enabling environment to communicate with adolescents with PHIV on sexual and reproductive health, fertility desires, concerns, disclosure and prevention of perinatal HIV transmission.

The adolescent's disclosure experiences influenced their consideration for disclosure to their unborn children, and they were determined to approach disclosure to their children in a way to prevent negative impact of disclosure.

While for adolescents who desired to have children the desire for motherhood superseded the fear of PHT. The fear of PHT during pregnancy was the greatest concern among those who did not desire to have children. They feared that their unborn children would experience living with HIV like they had to, for which some felt was the most painful experience ever. This group of adolescents also feared that they would die and leave their children orphaned. The fear of PHT underscores the importance of educating children and adolescents about the prevention of PHT.

The data on adolescent's fertility intentions provide valuable information that should be used by health

professionals in planning and developing reproductive health education that is context appropriate to meet the needs of adolescents and children with PHIV.

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