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Strategies used by perinatally infected adolescents to protect their HIV status: qualitative data from South Africa.

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Background

- The increasing availability and provision of free antiretroviral treatment (ART) have resulted in a significant reduction in mortality of HIV-infected children, surviving through childhood into adolescence in low income countries [1, 2]
- The increased survival of children and adolescents with perinatally acquired HIV (PAH) has been accompanied by unique needs and specialized management [3].
- Their needs are more sensitive and varied than those of adults; they must simultaneously deal with adult issues, such as disclosure, stigma, and practicing safe sex [4].

Background

- While adolescents and children with HIV prefer to be informed about their diagnosis, studies that examine self-disclosure by adolescents suggest that disclosure to sexual partners and friends remains low [5-7].
- Self-disclosure to sexual partners is considered an important process in preventing HIV transmission.
- The importance of self-disclosure increases as children with PAH progress into adolescence, and concerns regarding HIV transmission intensify [8].
- The benefits of self-disclosure among adolescents with PAH increases condom negotiation and use, improves ART adherence, and reduces levels of unprotected sexual activities.

Purpose of the study

The primary study explored motherhood desires, motivations, and concerns of adolescents with PAH and assessed their awareness and understanding of perinatal transmission of HIV.

We further analyzed data from the study to establish strategies used by perinatally infected adolescents to protect the HIV status.

Methodology

Study design

- ❑ A qualitative descriptive approach was used to conduct in-depth interviews with 30 female adolescents with PAH 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.

Methodology

Participant recruitment

- ❑ Adolescents were recruited during their scheduled treatment and follow-up visits at the hospital wellness clinic while they waited their turn to consult.
- ❑ 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 confirmed disclosure was subsequently requested permission to interview the adolescent.



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Methodology

Ethical considerations

- ❑ Caregivers and PAH were informed about the study objectives, confidentiality of the interview, and voluntary participation prior to requesting consent/assent.
- ❑ 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.



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Findings

QSR NVivo 10 software for qualitative data analysis was used to aid data organization and analysis.

Themes

The themes that emerged during qualitative data analysis were; experiences of disclosure , secrecy of HIV status, Predicament of self-disclosure, disclosure in romantic relationships (current and future partners).



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Experiences of disclosure

Finding out about the HIV status

The nurses in the clinic asked me if I know the reasons why I take the pills and I said no. That's when they explained to me. They told me that I am HIV positive and got it from my mother when I was born

I found out a few years back, before my father passed away that I am HIV positive as I got sick and weak. At hospital they tested me and communicated the results to my mother and me.

The social worker gave me the hospital file, told me to read and check any illness that I know and can identify from the file. I saw HIV and then she took the file and closed it and told me that I have HIV that I saw in the file



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Secrecy about HIV status

Themes

The participants said they would disclose only when they were promised that the information would remain a secret:

I want it to be secret. Why should people know? I cannot trust anyone about my status except my family

My mother will never tell anyone about my status because she loves to keep it a secret

I will tell them that this is their deep secret and they are not supposed to tell anyone at all



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Predicament of self-disclosure

Those who had not disclosed and were not willing to disclose their status had various reasons:

*I do not know if I would tell my partner because I am **scared** of his **reaction** to my status and if he will still want to be with me. I am not too sure as yet on what I will do as I am **scared of being rejected** (Participant 21; 15 years old, living with her father, doing Grade 8).*

*It is my secret as I am still **scared** of the reaction when my partner finds out (Participant 12; 18 years old, living with her stepmother, doing Grade 11).*

*I do not **trust** them enough to tell them about my status as this is my biggest **secret**. I plan to tell my partner when I can trust him or if he can **commit to me by marrying** me. (Participant 13; 17 years old, living with her father, doing Grade 8).*

Context of disclosure to romantic partners

- 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.

Tactics to delay or avoid disclosure

Forceful negotiation of condoms

I did not tell him but we used protection when we have sex. I forced him to use protection because I wanted to protect him as I am not ready to tell him about my status (Participant 5; 18 years old, living with her grandmother, doing Grade 10).



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Tactics to delay or avoid disclosure

Declaring non-readiness

*The first boyfriend I dated from 2009-2012 and we broke up because he wanted us to have sex and **I was not ready** at that time. The second one was from 2012-2014. I always tell him that **I am not ready** and **they need to respect that**.*

*When I am ready I will to communicate whoever I will be with at that time but **I need to trust the person** first before we become sexually active (Participant 12; 18 years old, living with her stepmother, doing Grade 11).*

Tactics to delay or avoid disclosure

Postponing in romantic relationship

I have never and will not be in a relationship soon, as my mother made it clear that she is against me being in a relationship because I am still young. (Participant 14; 16 years old, living with her mother, doing Grade 10)

Tactics to delay or avoid disclosure

Waiting for the right time to tell

*We have been together since 2008 so it is almost 8 years now **I did not tell him then**. I only decided to tell him two years back. I told him the reasons why I did not tell him then that was **because we were both still young not responsible** (Participant 30; 18 years old, living with her mother, doing Grade 10).*

Tactics to delay or avoid disclosure

Avoiding of disclosure beyond adolescence

*HIV it is not curable and you live with it for the rest of your life. It lives in your body and it makes it difficult to have your own kids 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** (Participant 12; 18 years old, living with her stepmother, doing Grade 11).*



Discussion

- 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, and some reported that by avoiding penetrative sex, they were not forced to disclose the HIV status to their partners and face possible rejection.
- Similar behavior was reported in a study conducted in the US, where adolescents and young adults with PHIV avoided penetrative sex through delaying sexual onset [28].



Discussion

- 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 PAH 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.



Study limitations

- The sample was limited to female adolescent with PAH 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 views presented in the study are limited to female adolescent and cannot represent the views of their counterpart. It is important that future studies take this into consideration.



Conclusion

- The adolescent's disclosure experiences influenced their consideration for disclosure to peers and romantic partners.
- The tactics used by the PAH although perpetuating non-disclosure are in a way protective towards risky sexual behaviour, early sexual debut and unplanned sex.
- There is a need to implement interventions for encouraging disclosure among PAH since there is no guarantee that the current strategies they use to conceal the HIV status are sustainable given relationship dynamics and sexual partner character differences.



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Thank You

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