Sexual and Reproductive Health Concerns of Adolescents Living with Perinatally Infected HIV in India

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Abstract

Background: With improved access to highly active antiretroviral treatment (ART) has increased the survival rates among perinatally HIV-infected children in low-income and high-income countries. These children are now reaching into adolescence and sexually active. This qualitative, explorative study examines the sexual and reproductive health (SRH) needs and concerns of adolescents living with HIV (ALHIV) in India. Materials and Methods: We used qualitative research design to collect the data. Twenty participants were recruited from two nongovernmental organizations which provide shelter care, education, and emotional and social support to HIV/AIDS orphan children located in Bengaluru District of Karnataka State using purposive sampling. In-depth interview guide was prepared and used to elicit the adolescents’ concerns, knowledge, and perspective related to sexuality, marriage, child bearing, and barriers in availing SRH services in the context of HIV. Results: Totally, four themes were emerged from that qualitative data based on thematic analysis, which are as follows: “Perceived challenges in relation to romantic relationship,” “Confusion regarding whether to marry person with HIV positive or HIV negative,” “Aspiration to have children,” and “Perspective of ALHIV in relation to SRH needs and concerns.” Conclusion: The findings of the research brought out the need for policies and guidelines specifically targeting the SRH needs and concerns of ALHIV.

Keywords: Adolescents, health, HIV, reproductive, sexual

Introduction

The increased availability as well as accessibility of highly active antiretroviral treatment (ART) has increased the survival rates among perinatally HIV-infected children in low-income and high-income countries. Those children born with perinatal HIV are now reaching into adolescence and sexually active. Growing up with HIV poses significant problems as adolescence living with HIV (ALHIV) begins to explore their sexuality and develop relationships with opposite sex. The desire to be “fit” and be “normal” like any other adolescent is complicated by the HIV disease itself.1

Dealing with delayed sexual maturation, poor body image due to delayed development of secondary sexual characters, fear of disclosing HIV status to other, and anxiety about HIV transmission pose huge challenges to young people with HIV moving into adulthood.2-5 Age of onset of sexual activity, growing up experiences, and experiencing events are found to be similar for both perinatally acquired HIV peer groups and uninfected peers.6-11 The existing key interventions to sexual and reproductive health (SRH) of adolescents in India focused on the prevention of disease transmission and handling high-risk behaviors such as delaying sex contact, reducing sexual relationship with multiple partners, and condom use. Moreover, the existing HIV-specific services targeted toward HIV-positive adults than HIV-positive adolescents. It is crucial to understand SRH needs of adolescents living with perinatally infected HIV in India as there are limited knowledge and gap in research in this field.11

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**Materials and Methods**

We used qualitative research design to collect the data. The application of qualitative method would be beneficial as the purpose was to understand the complexity of the participants' situation and experiences in a comprehensive manner. It helps to gain insight into the phenomenon under study, especially the SRH needs of ALHIV.

The participants for the research were recruited from two nongovernmental organizations (NGOs) that provide shelter care, education, and social support to HIV/AIDS orphans located in Bengaluru District, Karnataka State. For the current study, nonrandom purposive sampling technique was used to select participants. Twenty adolescents were recruited to participate in the research using following the inclusion and exclusion criteria: Those adolescents living with perinatally acquired HIV aged between 13 and 18 years, aware of their HIV status, and provided informed assent by their guardians/parents. Those participants who were below 13 years of age, participants with no consent and assent provided, and those unaware of their HIV statuses were excluded from the study.

**Ethical statement**

Ethical clearance was obtained from Human Behavioural and Ethics Committee of the National Institute of Mental Health and Neurosciences, Bengaluru, Karnataka, India.

**Data collection**

In-depth interview guide was prepared using predominantly open-ended questions eliciting the adolescents concerns, knowledge, and perspective related to sexuality, marriage, child bearing, and barriers in availing SRH services in the context of HIV. All the interviews were conducted in a private room without the guardians being present. Each interview lasted about 45 min to 1 h; all interviews were recorded using a digital audio-recorder with the permission of the participants and guardians. The interviews were conducted in the local language Kannada. The brief descriptions of demographic profile of ALHIV were as follows: The age of ALHIV ranged from 13 to 18 years. Forty percent were boys and 60% were girls. Eighty-five percent of adolescents were orphans whose parents were died due to HIV/AIDS and 15% of participants had single parents. Seventy percent of the participants were staying in shelter care for more than 3–6 years. With regard to education, 70% were studying in secondary schools and 30% were studying in preuniversity college. The reasons for staying in shelter homes reported by the ALHIV were loss of parents, neglect by extended family member, and stigma and ostracization by relatives and for education and ART treatment purposes.

**Data analysis**

The actual interviews were audio recorded, later transcribed, and translated into English. Thematic analysis was used to analyze the data. Notes and open codes were generated and organized manually, and similar codes were grouped into categories. We identified a hierarchical scheme of specific themes, issues, and problems that emerged from data. Themes that recurred with high frequency and strong emotional content received higher codes.**12** Analysis included thorough reading of transcripts, grouping of themes with similar information while checking for codes, and clustering codes into common themes. Totally, four themes were emerged which are as follows: “Perceived challenges in relation to romantic relationship,” “Confusion regarding whether to marry person with HIV positive or HIV negative,” “Aspiration to Have Children,” and “Perspective of ALHIV in relation to SRH needs and concerns.”

**Results**

**Perceived challenges in relation to romantic relationship**

All the adolescents expressed desire to have romantic relationship with the noninfected HIV peers. Some of the challenges of having intimate relationship secondary to their HIV status perceived by the participants were insecurity about dating due to fear of rejection and abandonment by the partners if they get to know about their HIV and fear of transmission of HIV to noninfected partners. Few older adolescents expressed desire to have intimate physical relationship before they die. HIV-related internal stigma was predominately perceived as hindrance to have romantic relationship with opposite sex.

“We too also have same feelings like others. We have right to love or to be loved. But we doubt if I disclose my HIV status, no one would want to have loving and affectionate relationship with me. I may get rejected which is more painful and fearful than living with HIV.”

**Confusion regarding whether to marry person with HIV-positive or HIV-negative status**

Regarding the marriage, nearly all the adolescents expressed that they would love to have life partner in the future. However, all of them had confusion regarding whether to marry a person with HIV positive or HIV negative. Choosing a partner with HIV positive was perceived as a way of dealing and coping with HIV-related stigma in the community. Many adolescents expressed that they would prefer to marry a person with HIV positive as both can be supportive toward each other illness and difficulties.

“I don’t like to marry because I will not get a special girl (HIV-positive girl); suppose if I marry normal girl (HIV negative), then she will get my illness. I should marry only a special girl. Isn’t it?.”

**Aspiration to have children**

All the adolescents expressed their desire to have children in the future. Girls were worried about the risk of HIV transmission during pregnancy and lacked awareness about the prevention of parent-to-child transmission. Many adolescents hoped that if they adhere to medication, they would live long to complete education, get a job, marry, and have their own
children. They even hoped that 1 day, a permanent cure for HIV might be found so that they no longer have to suffer with pain and stigma in the society.

**Perspective of adolescents living with HIV in relation to sexual and reproductive health needs and concerns**

The adolescents reported that they are not comfortable talking about sex with their parents as they had communicated to them indirectly not to discuss this issue. Girls shared their concerns related to delayed secondary sexual characteristics. One of the adolescent girls described how difficult it was to discuss with mother regarding her delayed puberty as follows: "My breasts are smaller than my friends of same age. I feel it will not become like a woman due to HIV. I feel depressed; if I marry and have a baby, I will not be able to feed my baby."

When it comes to source of information about sexuality, many reported that they discuss with their friends and peers. Adolescents were asked whether they ever discussed with service providers/parents/guardians on issues related to SRH such as menstruation, pregnancy, contraceptive methods, safer sexual practices, marriage, and having children. It was revealed that majority of the adolescents never discussed these issues with anyone and all had lots of misconception about mode of transmission of HIV and preventive strategies.

**Discussion and Conclusion**

This study was carried out to understand the SRH needs adolescents living with perinatally infected HIV in India. The current findings of the study revealed that the SRH needs of the adolescents with HIV are similar to that of noninfected groups. Majority of ALHIV in the current study were afraid to have romantic relationship either due to fear of rejection or due to fear of possible transmission of HIV to a negative partner. These adolescents’ perceptions of relationships appear to connect with feelings of shame and concerns about whether anyone would want to marry them due to their HIV-positive status. The findings are concurrence with few studies which discussed the adolescents with HIV are similar to that of noninfected adolescents living with perinatally infected HIV in India. The adolescents reported that they are not comfortable talking about sex with their parents as they had communicated to them indirectly not to discuss this issue. Girls shared their concerns related to delayed secondary sexual characteristics. One of the adolescent girls described how difficult it was to discuss with mother regarding her delayed puberty as follows: "My breasts are smaller than my friends of same age. I feel it will not become like a woman due to HIV. I feel depressed; if I marry and have a baby, I will not be able to feed my baby."

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**Implications and Conclusion**

ALHIV need youth-friendly comprehensive reproductive health services which are comprehensive, repetitive, developmentally appropriate, and tailored-made considering unique nature of their problem. Further, HIV/AIDS program should also integrate life skills training which enable adolescents to make informed choices related to sexuality. More efforts should be taken to develop IEC strategies address SRH issues of ALHIV in particular. Finally, there is need for more research to explore reproductive health needs according to different determinants such as gender, age, family background, orphanhood, HIV stage, sexual knowledge, practices, and belief system-related HIV. Such findings are essential to understand complex issue to design culturally appropriate tailored-made intervention to have desired impact on SRH of ALHIV.

One of the limitations of this study was that data were collected from two NGOs; hence, the findings may not be possible to generalize. Yet, with the limited samples, the study provided more insight into the SRH issues of ALHIV.

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**Conflicts of interest**

There are no conflicts of interest.

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