Sexual and Reproductive health of young people living with HIV

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Shalini is 21 years old girl born with HIV in a rural village in Namakkal district. Shalini is the 3rd girl child in her family and was diagnosed with HIV when her father got very sick when she was 3 years old. Shalini lost her father at the age of 4 and has been growing up with her widow mother who is also HIV positive. Shalini came first to Buds of Christ Centre, when she was 13 years old with suicidal thoughts, later through counselling, encouragement and participation in support group meeting for children living with HIV, she overcame the struggles in her mind and now has found a purpose for her life by completing B.Sc Nutrition and Dietetics. During these last 6 years, Shalini has learnt everything about HIV, including ways of transmission, menstrual hygiene and safety, sexual and reproductive health and is now a peer educator for other children and teenagers who are born with HIV like herself.

Buds of Christ is founded with a vision to empower children and enable wellbeing. Shalini is one such example of children being empowered at the centre which is based in Tiruchengode Taluk of Namakkal district. Buds of Christ operates with a strategy of H.E.A.L (Health, Education, Advocacy and Leadership development) among children living with HIV and orphans and vulnerable children with an aim to empower and enable wellbeing. More than 70 children living with HIV from 6 years to 22 years old are accessing the centre for the past 5 years for its services.

Though efforts have been taken to create major awareness among the public about HIV and AIDS, the self stigma among HIV positive young people still prevails. Access to care is irregular among HIV positive young people (born HIV positive), especially orphan children under the care of grandparents, as the fear of being identified as HIV positive starts at the adolescent stage. Services for sexual and reproductive health in the current government system for HIV positive people are focussed on condom distribution and positive prevention for adults. Sexual and reproductive health needs of HIV positive adolescents are nowhere on the agenda of any service delivery point.

The issues that we find in the context of sexual and reproductive health among HIV positive adolescents include lack of proper support systems and services. Most of the young
people are brought up by widowed mothers and grandparents, who have limited education and are employed as casual workers.

Our experiences show that we need to talk about sexual and reproductive health at an early age of 11 and 12 years. With the early onset of puberty among young people living with HIV, preparing them with the right information prevents unnecessary fears. One of the key concerns of HIV positive young people is the choice of marriage and sexual life. Thus, information and education with a focus on behaviour change helps them to take care of themselves, especially in positive prevention, maintaining menstrual hygiene and also understanding the need for safe disposal of napkins. Such information is not shared even by their mothers because menstruation is a taboo subject in the community.

“I did not understand about blood spots, but because I used to attend the sessions, I was prepared when I attained my puberty and I called up the Akka (Of our centre) and informed her first. Then she shared the information with my grandfather. I did not know that it was essential to keep our private parts also clean. In the session they taught us about changing napkins more often and also the importance of disposing the napkins safely” - expressed by an adolescent living with her widowed mother.

Government ART (Ante-Retroviral Therapy) Centre is the only point of contact for children and young people living with HIV. The core focus of this centre is on diagnosis, medication and treatment counseling. Currently more than 14000 people living with HIV are followed up for treatment at Namakkal ART Centre and sexual and reproductive health education, literacy or focused counseling on these areas are least considered because of the patient load. This has resulted in limited information about sexuality and reproduction among young people living with HIV with and some of them making decisions that could have serious adverse consequences for themselves and the people they marry or enter into sexual relations with. The need for positive prevention is realised, but there is no focus on implementing a programme for information and counselling.

In one instance an orphan girl living with HIV and staying with her grandparents fell in love with a boy in her neighbourhood. She was not on ARV medications due to good immunity, and so her understanding of HIV transmission was limited. Yielding to her pressure, her grandparents made arrangements for the marriage. The boy did not know about her HIV status, but knew that the girl’s parents and her sister had died of HIV. He had limited understanding of HIV. The two got married and later challenges emerged when they considered planning a family. His fear of contracting the infection was very high. They approached the community-based organisation for counselling, and were referred to the specialised counselling services. This helped them have a safe delivery and both the child and the husband are negative. Such instances are rare as in this case, the girl was able to access the services at the right time when she was followed up by the community based organisation.
In another instance an orphan girl aged 18 years married a young boy of 21 years without disclosing her HIV status. She discontinued her ARV treatment due to the fear of being identified as HIV positive, and this affected her health. She conceived in this state of compromised health and during the 7th month of pregnancy, when she was routinely screened for HIV, her husband also was tested. This affected their marital relationships and the girl had to experience severe violence from her in-laws. Her CD4 count at the time of delivery was only 125 and she was severely anaemic. The child was born underweight, and now is experiencing delayed milestones.

A successful story is of Nadiya, a young person living with HIV. A school dropout aged 23 years, she is looked after by her widowed mother who is also HIV positive. She had faced extreme forms of stigma due to her status and her mother’s status. She had even received proposal for marriage from boys who are not HIV positive, but accepting her HIV status. She had endured the pressures of older men (15-20 years older to her) for marriage, offering her bride price (instead of the dowry claimed from the woman). Through the sessions conducted at the centre, she has understood the risk of HIV transmission. Having faced extreme discrimination personally she is very firm in marrying a person who is open for adoption rather than having a child through marriage. She is a peer leader for young people of the centre and now she has vocationally trained and practicing beautician.

Though this article presents stories of young girls living with HIV, there is a need for interventions on sexual and reproductive for young boys as well to prevent new infections and also to make the voices of young people heard and make right choices towards their future.

by Jeyapaul