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Aiding HIV-positive with their stories

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HIV-infected members of 'So What' and activists from Prayas discuss coping with HIV, which contributed to the new booklet

A school dropout who works in a general store, 20-year-old HIV-infected Ruchi Deokar (name changed), was regularly subjected to the trauma of the taunt ‘Your death will be a relief to me!’ from her mother. She shared, “At 10, my health deteriorated; high fever and stomach pain became a routine and after two years of treatments, I was told of my HIV infection.



Till date, my mother has not been able to accept this. She was the carrier of my infection, but she is still in denial and has shrugged off all responsibility of me.” Such heartrending stories of HIV/AIDS-infected youth between 18-24 from in and around the city were published on November 3 by NGO Prayas, in a special compilation called Kalala Tevha (When I Found Out), arising from a series of discussion and therapy sessions between contributors and other victims of the infection.

Seven infected adults shared their experiences in the Marathi compilation, after they first formed a group called ‘So What’ in 2010, close on the heels of a sex-education workshop by Prayas.

Explained NGO member Neha Vaidya, “We had organized the workshop for HIV-infected children to facilitate discussions, and this led to the formation of the group ‘So What’ in October 2010, which was basically a group of HIVinfected adolescents that resolved to compile their experiences and work with other HIV0-infected kids.”

Prayas works towards awareness and training regarding HIV/AIDS, with a special emphasis on prevention of mother to child transmission (PMTCT). Interestingly, all contributors towards the book were infected by HIV due to this category of transmission.

Vaidya, who put together the voices of the contributors, told Mirror, “The Kalala Tevha booklet is dedicated to parents of the infected children, who often fail to disclose the HIV infection to their children because of their inhibitions. The book chronicles stories of people who have spoken about how they understood or were told of their condition.

The coping, challenges and complexities are portrayed in this book.” Anish Rane (name changed), a site engineer with a real estate developer, reminisced to Mirror, “ In Class 7, I got Herpes Zoster, a viral skin disease for which I visited Prayas with my mother. I noticed then that the doctor’s board read ‘Skin specialist and HIV expert’.

Even after I went back to school, I kept questioning why I was made to take medicines every day and why I had to take a blood test every six months.” An ardent reader, young Anish scrolled through awareness guides and /AIDS information pamphlets at the clinic.

After his SSC Board examination, Anish’s mother took him to a counsellor, who told him about his condition. “I kept thinking ‘why me?’. But later, I made peace with it. It was like an accident, neither karmic, nor punitive, merely a misadventure,” he said. Another contributor, Shailesh Joshi (name changed), a 21-year-old hotel management student, was first told about his infection by in Class 7. Initially, he developed animosity towards his parents for giving him the infection.

Later, when his father passed away, he was left with his mother and siblings. “Despite the fact that my

mother was an HIV patient, I felt no sympathy towards her because she had passed on the condition knowingly to me,” said Shailesh.

Gradually however, he came to terms with it and his relationship with his family improved. Initially, while battling acceptance, Joshi refused to take medicines regularly. “I skipped doses and felt that I was fine. I even ate out with friends, although I was asked not to by my doctor. I was rebellious and later my health deteriorated.

When I went to the doctor, I was told that since I had skipped my medicines, my body had stopped responding to them. I was put on second-line HIV medicines. It was an eye opener,” he narrated. Today, along with running his hotel, Joshi also works for HIVinfected children.

To summarise their collective will, Ruchi emphasised that her own enthusiasm for life would not be dulled by anyone else’s actions. “The HIV infection is a condition, it is not the end. I have learnt to embrace it as one of life’s many hues,” said Deokar.

â–° Kalala Tevha is dedicated to parents of the infected children, who often fail to disclose the HIV infection to their children because of their inhibitions

- *Neha Vaidya Member, Prayas*

