

#Week1

GCTA Community Chitter Chatter on TB Stigma in Children

Chinmay Modi, a young man of 25 years from India, living openly with HIV, struggled to get a correct diagnosis for TB for one and a half years before he was finally diagnosed with TB in his lymph nodes when he was 15. He took TB treatment for a year and today he is a strong TB/ HIV advocate.



GCTA: When you were diagnosed with TB, what were your biggest challenges?

Chinmay: I first showed symptoms of TB when I was 14. Doctors simply couldn't diagnose what the matter with me was. It took one and a half years to detect that I had TB. Dealing with the fever, headaches and weight loss was hard.

I was already openly living with HIV and have dealt with stigma from HIV. So I decided that I will not tell anybody I had TB because I will then have to deal with stigma from TB as well.

For me, the most difficult part was managing both the treatments at the same time – HIV and TB. I had to take ARVs and a total of 9 tablets every day after I got TB – I found it very difficult to manage as a teenager. It really affected me psychologically taking so many TB drugs. There were no fixed dose combinations at the time for paediatric TB.

The most challenging part was managing while in school. I took the drugs to the toilet to ensure that nobody would see me taking the tablets fearing they will ask me, "Now what happened to you again, why are you taking all these medicines?"

The side effects of the medicines were difficult to cope with. I would feel dizzy and sleepy. No one understood what I was going through in class. The teachers would shout at me when I was feeling sleepy. If I took the medicines, it was a problem because I would feel sleepy. If I didn't take the medicines, that would also be a problem.

At 15 years of age, I was not mature enough to understand why I had to take all these medicines and how it would benefit me. At home, my parents supported me and ensured I took the medicines on time. But in school, there was no support at all.

GCTA: You mentioned it was tough to get diagnosed for TB, that must have been difficult, but how was the journey to recovery?

Chinmay: I was misdiagnosed for one and a half years after I started showing symptoms. I finally did the Mantoux test which revealed that I had TB.

My lymph nodes were swollen and bleeding, I had a lot of pain in my underarms. I was not even able to move my hand as it would start bleeding.

Like I mentioned, mentally, I couldn't handle taking TB medicines 4 or 5 times a day. Plus ARV tablets that had to be taken twice a day. I couldn't keep an alarm on the phone – I didn't have a phone to begin with and phones weren't even allowed in school.

Relatives would ask me why my skin had darkened so much and if I was taking my HIV medicines on time – they were convinced that the darkening of the skin and the weight loss was because of HIV.

GCTA: Can you talk a little about not revealing you had TB for the fear of stigma and discrimination?

Chinmay: I didn't tell anyone about being diagnosed with TB. The school authorities never supported me when we had shared with them openly about my HIV status so I stayed away from telling them about TB.

I already faced stigma because of HIV. When I went out with my cousins, some family members would make me eat from a separate plate and would not allow me to sit with my cousins during meals – I had to eat sitting in a corner. I didn't want to face even more stigma than I was already facing.

There were many challenges in school. Parents at school would say, "You are going to die soon anyway, so why are you coming to school and spoiling our children." Some parents were so rude, they would outrightly insult my parents by saying, "What sort of work do your parents do for you to get HIV?"

During my treatment for TB I had high fever and diarrhoea and my friends would ask questions like "Why is your face so dull, why are you taking all these medicines?" They noticed that I was not moving my hand and they would trouble me by pulling my hand and make fun of me. It was hard to deal with, and I made sure I hid the TB diagnosis from them to avoid further discrimination. You can imagine what that must have been like for a 14 year old.

It was only after I completed TB treatment that I told my friends and relatives I had TB. They then asked me why I was not covering my mouth at the time or tying a handkerchief around my face/mouth – they were not aware that TB can affect other parts of your body too, apart from the lungs.

The fear of discrimination was always on my mind. I was determined not to disclose that I had TB – I would even carry the medicines in my pocket and not leave them in my bag. Sometimes in school it was common for friends to open your bag to take out something, and I just didn't want them to see all those medicines in my bag.

I was fourteen and appearances mattered a lot and I feared people could tell something was wrong by looking at me. This troubled me a lot and I began questioning myself – I wondered why this was happening to me.

GCTA: Did you miss school because of TB?

Chinmay: I missed a week of school before diagnosis of TB. I couldn't move my hands and I was in a lot of pain. After I was diagnosed correctly, my parents went to the DOTS (Directly Observed Treatment Shortcourse) centre every day to collect the TB medicines for my daily treatment.

After I started treatment, I didn't miss school because the doctors ensured they put the dressing properly and I didn't need to miss school. But I had to go to the hospital twice every day – once after school and once after tuitions later in the evening to change the dressing. In the morning before school, my mother would change the dressing and it used to hurt so badly, because sometimes the dressing would get stuck and bleed.

Although I didn't miss school after my diagnosis, I couldn't take part in sports or extra-curricular activities as I was in pain and couldn't move my arms too much.

GCTA: How did your parents handle the situation. What was their response?

Chinmay: They took a lot of care making sure I took my TB medicines on time. They didn't know I was taking my medicines in the toilet while at school. I didn't want them to know, otherwise they would start worrying about me all over again, like they did when I was diagnosed with HIV when I was only 8 years old.

I was not scared of anything, but I worried a lot about the psychological effect TB had on my parents. I didn't want them to worry and be disturbed – they were already thinking about it 24 hours a day. They would always ask me if I was feeling okay – it was always on their minds.

GCTA: What about support groups? Were you able to find one for HIV or TB?

Chinmay: When I started treatment for HIV in 2002, I was dependent on private treatment and was exploited. The doctor would charge Rs 50,000 (approx. US\$ 800) for meeting me for one minute. I stopped HIV treatment because of this financial exploitation.

The doctor told me that I must not go out and reveal that I have HIV – they would call the media. He would write reports and prescribe unnecessary tests and charge exorbitantly for consultation.

In 2004, when the government started giving free ARVs, I began treatment again. Soon, GNP+ (Global Network of People Living with HIV) was formed, I joined and began to speak in front of people and the government about HIV. This was my support group for HIV.

But I never had a support group for TB. This is a huge gap in TB. There is a big difference when a person affected by TB openly talks about TB – it is more effective and people will listen. To say, “Yes, I am a survivor – these are my needs and expectations from the government” is so powerful.

GCTA: What about your diet? Were you eating properly?

Chinmay: I was not eating properly but I started taking care and drank lots of milk. I started feeling better once I took better care of myself, both physically and mentally.

GCTA: What could have been done to make your experience better (from the point of getting diagnosed to treatment completion)?

Chinmay: Children go through a lot. We must do something to support kids who are forced to hide and take medication, like me taking my medicines in the toilet, due to fear of stigma and discrimination.

I don't know how many children will be able to cope with all these questions that will be directed to them. We need to provide quality counselling and explain why it is important to take the treatment, otherwise it may cause fear which will lead to discontinuing treatment.

When kids are small, between 8 to 18, their mindset is such that they may forget to take medicines because they are with their friends or are busy. We need to support them.

GCTA: Do you think your experience would have been different if there was quality counselling in schools?

Chinmay: Absolutely. We definitely need counselling in schools. Had I got proper counselling, I don't think I would have hidden the fact that I had TB and would have also understood the importance of taking my medicines on time.

Apart from counselling for children, we need to counsel the school authorities – teachers and the management. School management should not treat children who have TB any differently from other kids. They need to understand why a child who is affected by TB is not feeling well and why on some days this child will not be able to come to school. They also need to have accurate information about TB, including the larger community like the parents.

GCTA: Any advice you have for the national TB programme?

Chinmay: I would stress the importance of counselling for children. It is very important. We also need to ensure that schools and the overall community is supportive of children who are affected by TB, including collection of medicines while maintaining confidentiality of the identity of the family and children.