



PRACTICE

WHAT YOUR PATIENT IS THINKING

Fighting TB requires empowered patients

In this article from India, Deepti Chavan describes the differences in health outcomes when patients are able to access the information they need

Deepti Chavan

I was 16 when I first started coughing. It was in the middle of school exams. After months of coughing non-stop, I had a chest x ray and it was confirmed. “You have TB,” my general practitioner said. These three words changed my life. I didn’t know anything about this disease. I was about to start university. Everything changed. From a young person filled with hope I became an anxious patient.

No information

I went to one doctor after another. At first I went where I was referred. Later I undertook my own search for a doctor who would be able to help. They did not tell me about the disease or its progression. I felt I just had to trust them—like God; you never see her but you have to believe. Everyone promised a cure and would experiment with my medication, but I didn’t get better. No one told me about the horrific side effects; nobody directed me to any resources that would help. I felt lost, angry, and helpless. After a year my doctor told me that I had multidrug resistant TB and required surgery.

My family and I had no clue what that meant and no other options were discussed. A decade later I wonder why no doctor ever advised me to get a drug susceptibility test earlier, instead of just changing medicines.

Post-surgery I had to continue with medicines and injections, but my condition deteriorated. Desperate, I started surfing the net to find a doctor who could help me. Three years after my first diagnosis, I found one in the UK who referred me to a specialist in Mumbai.

Treatment beyond drugs or surgery

Under this new doctor’s care I realised for the first time that a patient could ask questions, and could frankly share their apprehensions. I was used to doctors rejecting what I said; when I told them that I was suffering from a side effect, they just dismissed it saying that nothing of that sort happens, that it was just in my mind. Because of this I became hesitant to voice my

concerns to any doctor because I knew I would get the same answer.

But with the new doctor it was different. He told me that he understood how difficult it is to consume so many medications and that I was being very brave. He explained to me that my case was difficult, but he motivated me at the same time, reassuring me that I could fight it.

When a doctor says that he has faith in his patients and understands their struggle it gives them confidence; it is part of good treatment.

By now my health had become much worse and I required further surgery, which was potentially life threatening. Eventually I found a surgeon who, although he believed I would most likely die on the operating table, was willing to try. In fact, I was out of the intensive care unit the next day—faith, miracles, who knows?

Survivors do wonder

Today I am cured of TB but it took six years of medicines, 400 injections, and two major surgeries.

TB is as much a mental fight as it is a physical one. As the doctor you are my most trustworthy ally and you need to know that until you empower me I will either give up this fight or lose. You need to listen to me when I say a medicine isn’t working or that I am experiencing side effects. If I have a disease like TB or HIV, you need to test me for drug resistance up front, not change medicines without offering a good reason. Perhaps if my doctors had done the test earlier, my lung could have been saved.

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What you need to know

- Help patients and their families understand the detail of what might happen in the course of their disease, including medication side effects
- Don't change treatments without a clearly explained reason
- Patients need information, empathy, and encouragement as well as drugs

Notes for international readers

Deepti Chavan was mainly treated in private practice, starting with a doctor in a primary care clinic, but was advised to seek a second opinion from a doctor in the public sector before surgery took place