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REFLECTIONS

Rediscovering the simple yet profound joy of breathing without pain: My experience with childhood tuberculosis

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Abstract

In this personal essay, I recount my lived experience of childhood tuberculosis, highlighting the physical, emotional, and psychological toll on myself and my family. I reflect on how tuberculosis care has since improved, but also how certain critical gaps persist, especially the challenges of inadequate financial support, post-recovery social reintegration, and insufficient psychological care for persons with tuberculosis. Drawing from my experience, I advocate measures to address stigma, invisible costs, and discrimination. Holistic care for tuberculosis must go beyond just medical recovery and ensure dignity and meaningful social healing for all.

Keywords: *tuberculosis, childhood, illness narrative, lived experience, health services*

How it all began…

I was growing up in Burla, which was then a small town on the outskirts of Sambalpur in western Odisha. At the age of ten, when I was studying in the fifth grade at a government school, I started having fevers that went on for three months. No coughing, no bloody sputum. But I do have terrible memories of sweating at night, struggling to fall asleep, and excessive sneezing while sleeping — all this felt traumatic. Fever reduced my capacity day by day, making it challenging to accomplish basic tasks. It wasn't easy to get a clear diagnosis for the illness. I remember being taken to various clinics and undergoing many tests. I specifically remember how they kept injecting my forearm (the Mantoux test), but the test repeatedly produced unclear results. This lack of explanation by doctors about my suffering created a sense of fear and agony within me and my family. I can recall how my mother used to tell her relatives about my unexplained fevers.

Coming to terms with the diagnosis

I have a vivid memory of overhearing my grandmother speaking about test results confirming tuberculosis (TB). By this time, it was already about six months from the day I started getting the initial symptoms (fevers). I was now starting my sixth grade. The news felt surreal, almost impossible to believe. TB had never affected anyone in our family before, creating an additional layer of confusion when doctors enquired about potential family history. I struggled to think that TB could be responsible for my prolonged illness. "How could this happen?" my father asked the doctor repeatedly. The doctor clarified that no specific familial background exists for TB transmission, because high-burden environments can transmit the infection to people. The doctor also explained that it would be a long treatment journey, outlining the months of medication ahead.

Profound, yet invisible, psychological impact

My primary challenge was mentally reconciling myself with the diagnosis I had never anticipated. It started impacting my identity and my relationship with my body. I had read about TB in the science textbook: it was a dangerous bug, spreading from person to person. The evening I received my diagnosis was the start of countless thoughts regarding this contagious disease.

I knew that the government used to run TB-related awareness campaigns on television. The inability to acquire a television set caused me great distress due to my persistent worrying thoughts. Whenever I visited my neighbour to watch TV, I would watch Doordarshan for the TB awareness programme. People featured in the programme demonstrate blood-tinged coughing while talking about DOTS. All the medical information overwhelmed me with anxiety. Each time I watched the TB advertisement, my heart accelerated rapidly, and a tight suffocating feeling wrapped around me, watching images associated with the disease, making it more troublesome to breathe.

I felt constant dread, fearing that my disease might affect my family members and others around me. While those TB awareness campaigns provided very useful information to me, they also created an uncontrollable, deep emotional reaction within me.

Nights brought an abundance of fearful thoughts into my restless mind. My elder sister repeatedly noticed that I stayed awake and asked me why I couldn't sleep. I shared everything with her. She gave me tremendous reassurance by telling me to stop worrying, to stop stressing myself. She assured me that medications and proper nutrition would make any disease harmless. Her words and concern were very comforting for me.

Social isolation and stigma

My family, despite a lack of formal education and any previous history of TB in the family, was able to recognise that TB spreads from person to person. They suggested I speak minimally with others and keep my illness a secret, since knowing could lead people to distance themselves from me. It established a secrecy about my health situation, which brought forth feelings of embarrassment. Engaging in outdoor games became impossible I lacked sufficient energy. My friends became annoyed with my persistent weakness and didn't want to take me into their team.

Treatment and its impact

My treatment happened at the VSS Medical College, Burla (now the Veer Surendra Sai Institute of Medical Sciences and Research), a prominent medical facility, just a half-hour's distance from my house. It started soon after my TB diagnosis and went on for six months. It ended once they saw my X-ray confirming the recovery. I recall meeting a senior woman doctor/professor. When I shared with her my vegetarian diet and a complete lack of appetite, she carefully instructed me about recovery nutrition requirements and pointed to milk and paneer, together with fruits, as my main recovery foods. She emphasised hydration together with balanced nutrition as essential to my recovery strategy.

However, back then, I remained oblivious to my family's mounting financial sacrifices for my treatment. As one of the five siblings in our already struggling household, my diagnosis became a silent destroyer of our collective dreams. The medical centre was barely half a kilometre away, yet my weakened body made this short distance feel impossible to traverse. Though some tests were free, many at private clinics required payment, with my parents unquestioningly following doctors' orders, despite the crushing costs. I watched helplessly as my father worked double shifts, returning home with exhausted eyes and trembling hands. He wanted to make the most out of the days he worked, as he had to forgo work on days he would accompany me to the hospital. My mother pushed herself, through her arthritis to continue working, and yet, the savings they managed to accumulate would quickly vanish with each new medical crisis. So, essentially, my illness infected more than just my body: it consumed the small dreams my family had, making my brother's education and my sister's college aspirations unattainable.

Over time, my interactions with my doctor became positive. She conducted regular checks, which included asking about my medication use, measuring my weight, and observing my treatment outcomes at each appointment. During the six months of treatment, which represented the hardest time of my childhood, the periodic doctor check-ups brought structure together with hope to my recovery process.

Many things have changed for good

I have now completed my postgraduation in Political Science as a first-generation learner from my family. While my brother had to contend with just school studies, my sister could complete an Intermediate of Arts. In the last fifteen years, since my TB experience, many changes have been made to government initiatives addressing the TB burden in India. TB became a notifiable disease in 2012, and TB monitoring has seen improvement [1]. In 2017, the very focus changed from providing care for and controlling TB cases to eliminating the disease itself in India. Mass campaigns like *"TB Harega Desh Jeetega"* aimed to stop social stigmatisation while encouraging treatment adherence [2]. The JEET (Joint Effort for Elimination of TB) campaign, introduced in 2018, built stronger public-private teams for TB detection and management, while the *Nikshay Poshan Yojana,* unveiled in the same year, offered financial assistance to people with TB [3]. Today's tools, such as GeneXpert/CBNAAT and TrueNat, have rapidly improved early detection. With them, people now get their results far faster than they did before. The use of both digital X-ray and AI for screening allows patients to be identified before they have symptoms, boosting the success of their treatment. Through the *Nikshay* portal, digital health has enabled an online system that makes sure care is smooth and continuous across borders, and allows regular monitoring of patients and supplies [4]. A combination of drugs has made it easier for patients to take their medications. Medications like Bedaquiline and Delamanid are new options for people who have developed drug resistance. The country seems eager to eradicate TB by connecting the TB Champions networks with communities. Hopefully, all these efforts have lessened the difficulties experienced by people with TB.

There is still some room to do better

As someone with lived experience of childhood TB and now a keen observer of health systems, I feel that despite several definite improvements in TB care over time, there are still certain deficiencies, and we can do much better on those counts.

We can still do better on the social and psychological support that people with TB and their families need. The existing financial support provided to people with TB (about a thousand rupees) would be inadequate for most families. It ought to be enhanced three to four times. There could be better coordination across health and social welfare agencies. Instead of people struggling to secure their entitlements, what if a positive TB diagnosis by the health agency itself were to start a process of issuing a ration card and provision of nutritious high-protein foods, fortified grains, and other supplements to families caring for people with TB? Assistance from community health workers (such as Auxiliary Nurse-Midwives and Accredited Social Health Activists) in setting up household or community-level kitchens, or in helping these families realise their food entitlements through the public distribution system, would be very useful.

There is some psychological support available to people getting diagnosed with TB, especially in the early stages of the treatment. But, beyond the initial mental health screening, a substantive psychological support throughout the treatment and post-treatment phases is often absent.

More importantly, people who recover from TB require support for social and economic recovery, wherein they are enabled to cope with social isolation and stigma, and they find supportive environments within workplaces and social surroundings devoid of discrimination.

Of course, not all who suffer from TB experience it the same way. Social inequities shape how one experiences both TB and the recovery from it. One of the important ways to ensure TB control/elimination efforts remain responsive to those who suffer most is for these reforms to be informed by the lived experience of people from the margins. We are yet to see this happen institutionally and substantively.

Looking back at my TB journey, I see the desperate need for the public health system, while enhancing medical care, to provide comprehensive psychological support to people with TB and their families to navigate the overwhelming feelings of fear, isolation, and uncertainty. De-stigmatising and localising TB care would significantly reduce the devastating financial impact my family silently endured, not just direct medical costs but also travel expenses, lost wages, and nutritional supplements that devoured every penny my parents earned. These invisible financial burdens created immense strain on our already vulnerable family. The double burden of draining our finances, while being physically incapable of contributing, created an emotional pain that matched the physical suffering of my disease. A truly effective TB care system must account for these hidden costs and provide support systems that address both the physical and emotional dimensions of recovery, allowing people with TB to rediscover the simple yet profound joy of breathing without pain.

After six gruelling months of medication, the transformation felt miraculous. I experienced something I had almost forgotten — the pure joy of drawing breath without that crushing weight upon my chest. The agonising pain seemed like a distant nightmare. My body regained its strength, and those terrifying TB advertisements gradually lost their power over me. When my family gathered around my final X-ray results, their tears of relief spoke volumes. Fifteen years later, I still remember that profound moment when I truly understood what it meant to breathe freely — a simple gift I'll never take for granted again.

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Reference

1. Shrivastava SR, Shrivastava PS, Ramasamy J. Notification of tuberculosis cases in India: Moving ahead in Revised National Tuberculosis Control Program. *Infect Ecol Epidemiol.* 2013 Jan 1;3(1): 23006. https://doi.org/10.3402/iee.v3i0.23006
2. Purty AJ. Detect–treat–prevent–build: Strategy for TB elimination in India by 2025. *Indian J Community Med.* 2018 Jan 1;43(1):1-4. https://doi.org/10.4103/ijcm.IJCM_321_17
3. Yadav S, Atif M, Rawal G. Nikshay Poshan Yojana- Another step to eliminate TB from India. *IP Indian J Immunol Respir Med.* 2018 Jul 13;3(2):28–9. https://doi.org/10.18231/2581-4222.2018.0010
4. Khan S, Mukhida S, Patil R, Das NK. Effective initiative to beat tuberculosis from India: Revised Nikshay Mitra support policy. *Lung India.* 2025 Feb 27;42(2):173–4. https://doi.org/10.4103/lungindia.lungindia_522_24