

REFLECTIONS

Public healthcare (in)accessibility for TB patients: a slum's-eye view

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Abstract

The government healthcare system unintentionally excludes the destitute in several ways. In this article, a "slum's-eye" perspective on the public healthcare system is offered through reflections on stories of tuberculosis patients in urban poor neighbourhoods. We hope these stories contribute to discourse on how to strengthen the public healthcare system and make it more accessible for all, especially the poor.

Keywords: public healthcare, poverty, tuberculosis, access

Introduction

"Why didn't you show her at the government hospital?" I (TD) asked, exasperated.

Taiba (all names changed to protect privacy), 18, is extremely weak, little more than skin and bones. Her mother-in-law supports her as she walks back from an appointment with a private practitioner. The family, who live in a bamboo-and-plastic shack by the side of a railway track, is paying Rs 100 per day for consultation plus tuberculosis (TB) medicines. It's hard to understand why they don't seek care from a government hospital instead, where TB treatment is free and patients are entitled to a payment of Rs 500 per month from the Nikshay Poshan Yojna (NPY).

"Sarkari me gareebon ki koi sunwaahi nahi." (The poor are given no attention in government hospitals).

Taiba's perception of government hospitals as complex, unfriendly bureaucracies is extremely common, and not without reason. Sobered by their response, I agree to go with them to the local government hospital, where Taiba, after some difficulty, gets onto the standard anti-tuberculosis treatment.

In this article, we outline some of the ways in which the government healthcare system unintentionally excludes the destitute. We take a few case studies of TB patients because it is a classic disease of the poor, with malnutrition, crowded living conditions and indoor air pollution as some of its major risk factors.

First, we examine the extreme challenges faced by the poor in seeking healthcare during the pandemic period. All other healthcare concerns, including TB, took a backseat at this time. As usual, the socio-economically marginalised were the biggest losers. We go on to consider the difficulties of many of the poor in getting the correct documentation required to access key government services. Finally, we reflect on the complexity of the healthcare system, often requiring impoverished people to make multiple trips to hospital and waste a lot of time waiting in long queues.

We are Australian community development workers, with no medical background, who have lived and worked in North Indian urban poor communities for many years. In this article, we seek to offer a "slum's-eye" perspective on the public healthcare system. While many schemes and policies look good on paper, the way they unfold on the ground is often different. We write not to criticise government hospitals or espouse privatisation — a "solution" that further disempowers the poor — but rather in the hope that these stories prompt reflections on how to strengthen the public healthcare system and make it inclusive for all, especially those who most rely on it.

Tuberculosis and Covid-19: A tale of two pathogens

Aliya, 16, had persistent and terrible stomach pain and vomiting, which was eventually diagnosed as abdominal tuberculosis. Her family had spent around Rs 40,000 on various private doctors, with no relief. When I (TD) met Aliya for the first time, her large intestine was extremely swollen and in danger of rupturing, requiring an emergency ileostomy. Unfortunately, she contracted Covid-19 while in hospital, and was shifted to the Covid ward just two days after this major abdominal surgery. As a close contact, I also got tested and was found to be Covid-positive. Though asymptomatic, I shifted into the Covid ward to help Aliya's mother care for her.^a

Aliya's condition deteriorated over the first 48 hours in the Covid ward. Unfortunately, she received little specialist attention; the clear focus was on containing the spread of Covid, not on ensuring patients received the care they needed. For instance, her post-surgery wound was not

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cleaned and bandaged for the first 24 hours in the ward. After repeatedly requesting for a doctor to attend to it, I was told to do it myself. While initially reluctant, I received instructions and did what I could. After a few days in the ward, I quickly realised that the doctors were limited in their mobility and even vision by their bulky personal protective equipment (PPE). Given the sweltering heat, they understandably wanted to minimise their time in the (non-air-conditioned) ward. On a typical day, there used to be only one doctor in the 40-bedded ward, that too for a total of two to three hours.

Aliya stabilised and was ultimately discharged, but countless others perished in that first wave — some from Covid itself, but probably just as many from other illnesses that went untreated as a result of the diversion of medical resources and exclusive focus on containing the spread of Covid [1]. Entire wards and sometimes whole hospitals were turned into holding pens and quarantine zones. This huge diversion of public health resources to contain the pandemic had severe consequences for those who would normally have accessed healthcare through the public health system. Many people simultaneously faced severely reduced income due to lockdowns, and the choice between private healthcare or none, due to diverted public health resources [2].

On the other hand, the mobilisation of resources for the Covid response also inspires hope about what can be achieved in a short span of time, with an injection of resources, political will, and a sense of urgency. Economic orthodoxies were sacrificed and governments throughout the world borrowed huge amounts of money. We can only wonder what such an infusion of resources would do to the fight against TB, where the rhetorical shift from the national tuberculosis “control” to “elimination” programme has not been accompanied by a commensurate increase in funding [3].

Many journal articles and other reports highlight the impact of Covid on efforts to end TB. Experts deduce that the significant drop in new cases reported during the first lockdown in March-May 2020 was not because fewer people contracted TB, but because many remained undiagnosed. For example, in Uttar Pradesh, there was a whopping 73% reduction in diagnosed cases during the 8-week lockdown, compared to the previous 8 weeks [4]. Epidemiologists are modelling the predicted impact of missed cases of active TB, along with increased rates of undernutrition and poverty. Meanwhile, TB deaths in India have increased for the first time in decades [5]. At the local level, in the urban poor neighbourhood where we live, we are witnessing the reality on the ground for the poor. Each person's story is multi-faceted, and the ripple effects of the Covid waves combine with pre-existing factors limiting access to treatment, as we describe next.

Documentation difficulties: The curse of paperwork

Walking through our neighbourhood one day, a friend greeted me (CD) enthusiastically and called me in for chai. As we chatted, she told me her mother Farzana's tale of woe. Farzana

was widowed shortly before Covid, and was not yet receiving her pension, despite making repeated payments in attempts to open a bank account and submit the application. Then she fell ill. Now, she had been on TB treatment from a nearby private doctor for several months, and was progressively becoming weaker while the family struggled to pay for the medicines and diagnostics. After a few weeks, we managed to get her transferred to the Directly Observed Treatment, Short-course (DOTS) centre at a nearby government hospital. When enrolling for tuberculosis treatment, she needed to provide her Aadhaar and bank details. However, her Aadhaar card had her late husband's phone number as she didn't have a phone, and her biometric details were outdated resulting in failure to open her bank account. She was later enrolled in the National TB Elimination Programme (NTEP) and after slow months of little progress, is now significantly improved. Finally, she is able to focus on updating her Aadhaar card, opening her own bank account, and applying for her widows' pension.

Meanwhile Soni, a neighbour of Farzana and a young mother of two, has had a lump on her neck for over a year, which was diagnosed as TB. However, she was refused treatment because she did not have an Aadhaar card, which was destroyed in a fire at her village home. Due to increasing neck pain, Soni wanted to be treated, but the DOTS centre insisted for her Aadhaar card in order to register for NTEP. Officially, a patient cannot be refused treatment for lack of an Aadhaar card, but in practice this is quite common. Eventually, we were able to help her get an Aadhaar and enrol for treatment. In both these cases, the patient did not have a bank account^b but officials were willing to use a family member's account.

Like most large-scale programmes, the NTEP works best for people who conform to the programme designers' perceptions of the public, ie by 2023, everyone would have a functioning mobile phone, an up-to-date Aadhaar card and a bank account! However, this is not a certainty for the very people who are most at risk of contracting active TB — the undernourished poor, living in overcrowded under-ventilated homes, people with addictions, and those living with HIV. For anyone struggling to live day-to-day, repairing a broken mobile phone, updating an Aadhaar card or opening a bank account are expenses that often must wait.

Another frequent problem is that many recent urban migrants have village-based identity documents. Those who are less educated and lack personal connections in the city are easy targets for scams; too often they pay “fees” for updating their Aadhaar and ration cards but their work is never done. It can also be difficult to obtain any kind of address proof when renting a room in a *basti* without legal land title. Several times doctors have advised our friend Aliya to take a high-protein diet, but her family is perpetually strapped for cash, and their village-based ration card is refused by the local ration shops.

Aliya's struggle for adequate nutrition was further exacerbated by the much-delayed arrival of her NPY payments into her mother's bank account in the village. The first payment of Rs 1000 appeared in the bank account about six months after treatment began, and the subsequent monthly payments of Rs 500 arrived in the account as a lump sum six months after the completion of treatment. Aliya's family is glad to have the money — better late than never — but it did not help at all in giving her adequate nutrition during the treatment.

Complexity and discoordination of the healthcare system

"Have you been taking TB medicines for a while?" I (TD) asked Parveen.

"Yes, for two months," she responded and added "But there's been no improvement, my cough is still just as bad."

Puzzled and concerned, I asked her to show me the medicine wrappers. When she pulled out some paracetamol and multivitamins, I didn't know whether to laugh or cry. Examining her *parcha* (prescription), I saw that the doctor had scrawled a reference to the DOTS centre in barely legible English. Parveen can't read (even Hindi), and nobody had taken the time to explain to her where the DOTS centre is or how to get on the correct treatment. Parveen, meanwhile, assumed that the medicines she had been prescribed for symptomatic relief were "TB medicines".

This year, Aliya is once again on TB treatment, after her previous abdominal TB episode in 2020-21. Recently, she had been experiencing a lot of nausea, fevers and weakness, so I (CD) accompanied her on several hospital visits. One Thursday, after hours of waiting outside and dodging heavy downpours, she received the following advice: carry out sputum test, blood test, abdominal ultrasound, chest x-ray, and add various vitamin supplements to the regular tuberculosis medications. Happy that the doctor has carefully investigated her problems, we bought the medicines, did the chest x-ray, and booked the ultrasound. Unfortunately, we were too late to do the blood test that day. We returned on Saturday morning to submit her sputum sample and do the blood test. Aliya waited several hours for the ultrasound, since sputum collection is only between 10 and 12, the ultrasound was booked for 4pm, and she didn't have cash to go home in between. She returned once more on Tuesday afternoon to pick up the blood test and ultrasound reports at the prescribed times, ready to visit the doctor again on Thursday morning. This was a typical experience; one visit to the doctor may generate two or three further trips to the hospital before the next consultation. Each blood test, ultrasound or x-ray often involves two or three queues — to register, pay and then to do the diagnostic procedure. In large city hospitals, sometimes the doctor's consulting room, the counters for various payments, the laboratories and procedure rooms are all in different buildings. The whole experience is complicated and exhausting to navigate even for the highly educated and able-bodied, let alone for patients who are poorly educated, under-confident,

or quite sick. For chronically ill teenagers like Aliya, study is continually disrupted, postponed or simply terminated.

In short, the physical and organisational structures of government hospitals in India are not designed to be patient-friendly. Perhaps the problem is that they were designed decades ago, before the advent of online booking portals, Aadhaar cards, computerised registration systems, digital radiography and much more. Much of the physical infrastructure and the administrative systems have been built up incrementally, tweaked and updated, but not re-designed from the ground up. Our nearby Government Medical University is so large and complex that even staff and doctors sometimes give incorrect directions about where to go for a particular task. Generally, the crowds are such that doctors and other staff have limited time to explain the advice they give or hand-hold patients through the maze, and some things are learned only after standing in the wrong queue for an hour.

The system produces weary, confused patients, and stressed doctors and staff — lost patients, lost patience. An unfortunate consequence of the difficulty and inconvenience of accessing public healthcare is that many people are driven to the private sector, hoping that the added expense will be compensated by effective treatment, friendlier staff, and quicker service, resulting in less disruption to work or study. Some private practitioners do provide high-quality and cost-effective services. However, catastrophic healthcare expenses are common when patients are squeezed into the private system, further keeping the poor trapped in cycles of debt, undernutrition, and illness.

Concluding reflections

Imagine this scene: August 15, 2025. The Prime Minister proudly declares that India has ended TB. True, it is not eradicated, but cases are down 90%. Just three years earlier, the task seemed impossible, as the nation emerged from the Covid pandemic. How has this remarkable transformation been achieved?

Senior government officials have started taking a serious interest in the functioning of the public health system. From the health minister down, officials are making unannounced hospital visits in disguise, to understand the system from a patients' perspective. Hospitals are reorganised and simplified to ease the flow from diagnosis to treatment.

The infusion of political will is accompanied by a massive financial boost. Government spending on health has doubled to 2% of Gross Domestic Product. New hospitals have been built, and more doctors hired. Doctors and a legion of community health workers are mobilised to find tuberculosis patients and help them start treatment. Simultaneously, the public distribution system has been strengthened and universalised; everyone now collects rations using just their Aadhar card. Lentils are brought into

the system to help provide protein. Malnutrition is now rapidly receding.

Some private doctors have gone out of business — many more have taken up jobs in the new government hospitals. The phrase “*sarkaari me koi sunwaahi nahi*” (no attention is given in government hospitals), once so ubiquitous, has faded.

Is this a pipe dream? We hope not.

Let's listen to the stories of those who are falling through the cracks in the current system and build something better for their sake.

Note:

- a) *It was a fascinating experience to share the Covid ward with some 40 other patients experiencing a diverse array of ailments. For the first time in my life, I lived behind locked doors. Barely ten minutes after I arrived in the ward, two staff entered with a stretcher bearing a patient whose leg was in a cast. As they struggled to get him onto a bed, they motioned for me to come over and help. I did; and very quickly I became an unofficial Ward boy. The*

doctor on duty would often ring me up or even put an announcement over the PA: “check the vitals of patient in bed 18”.

- b) *All patients registering on NTEP are encouraged to also give their bank details, to register for Nikshay Poshan Yojana, to receive direct transfers into their bank account to support better nutrition during treatment.*

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