

FIGHTING TB IN TIMES OF COVID-19

Understanding Disruptions in TB Care
due to COVID-19 Pandemic



A PROSPECTIVE OBSERVATIONAL ANALYSIS OF PATIENT QUERIES

As received on the SATB virtual help desk
between March 20th, 2020 and October 15th, 2020

CONTEXT



HOW HAS COVID-19 IMPACTED TB?

COVID-19 has disrupted life across India as we know it. Attempts to control this pandemic have impacted health services overall, and have resulted in reducing healthcare access and support services for the co-morbidities of COVID-19. Of these, Tuberculosis (TB) is the most significant.

TB and COVID-19 together present a deadly challenge for India's health system. Though curable, TB remains one of India's severest health issues, killing over 1,200 Indians every day on an average. During the COVID-19 pandemic, TB services have been widely disrupted, leading to delays in diagnosis, treatment, and increased suffering for patients, thereby creating greater anxiety and mental health issues for those affected.

TB - A CRISIS WITHIN A PANDEMIC

Based on data consisting of 200 cases, this brief examines the impact of the COVID-19 pandemic on TB services in India, the challenges faced by patients, and the implications for TB care in India. It also presents some possible solutions for addressing the issues around TB through systemic change, community based interventions as well as effective use of technologies. All data presented in this note is based on an analysis of the experiences and narratives of TB-affected individuals who have contacted Survivors Against TB over the last 8 months.

Objective: Knowing what aspects of queries are likely to be relevant for the NTEP and other stakeholders, both, to address gaps in care, but also to increase the effectiveness of services, the objectives of this study were to identify the kind of challenges and queries that patients and communities have and how they can be addressed.

Method: This was a prospective observational study of queries regarding patient-related problems sent to SATB helpdesk through patient networks and social media. We classified queries into general and specific and comprehensively analysed both the queries and the program gaps.

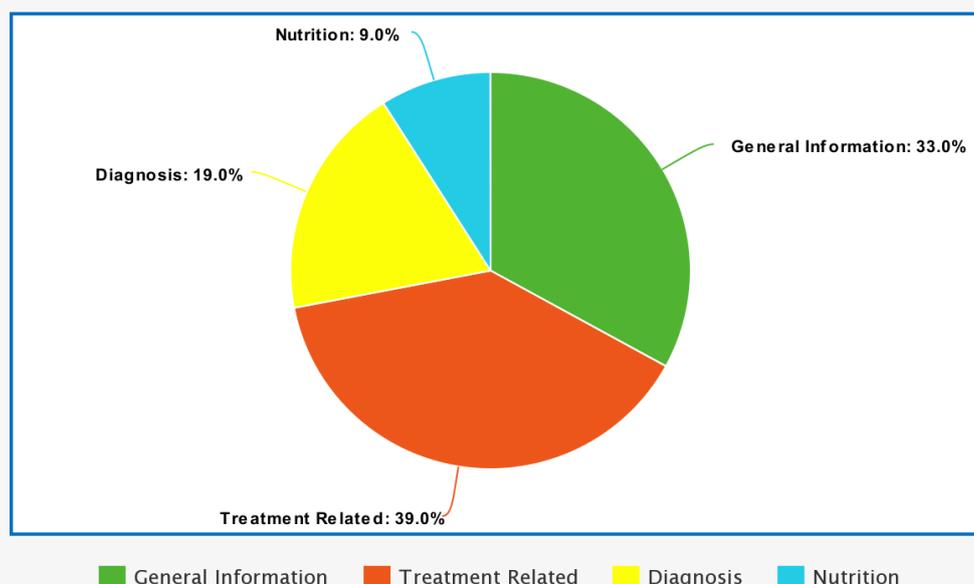
OUR VIRTUAL HELPDESK FOR PATIENTS

Around March 2020, as a response to this crisis, SATB launched a virtual survivor and expert-led response to the disruptions in TB services. This took the form of a multilingual help desk administered through local in-person networks and social media channels. The aim was to provide peer-to-peer and expert support to TB patients and affected communities on the issues they were facing during the pandemic. Over the past seven months, the help desk has recorded numerous queries. We have selected over 200 distinct queries from patients nationwide, on issues ranging from diagnosis and treatment, side-effect management, treatment adherence, nutrition and mental health, to analyze and represent the challenges faced by patients and affected communities.



ANALYSIS

NATURE OF QUERIES



We were able to identify four distinct kinds of queries and challenges that had been raised by various patients/ caregivers through patient networks and online, via various social media channels. These include the following categories:

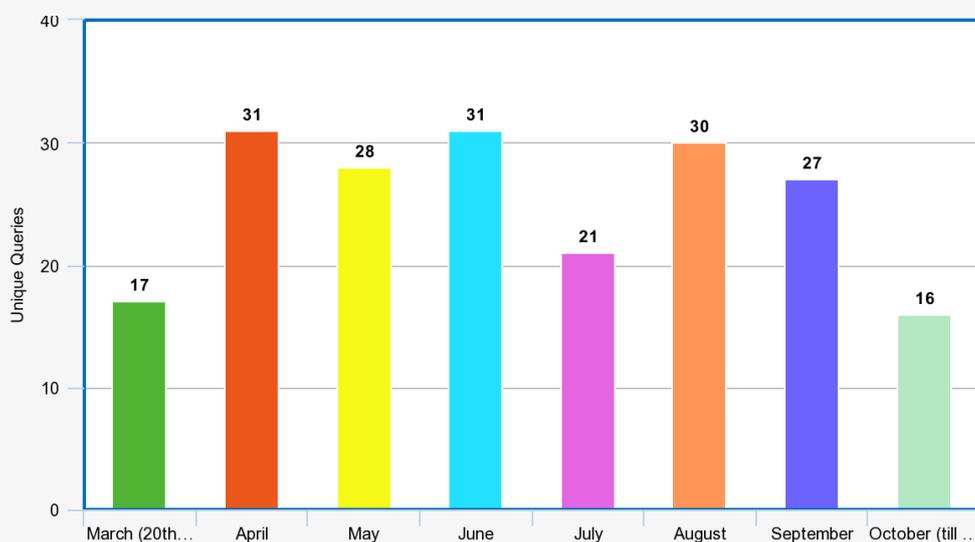
- **General Information:** A fearful climate around COVID-19, along with the inability to access health services and workers due to the nation-wide disruption of services, has led to numerous queries on information around TB, its symptoms, interpretation of diagnosis and how to access services (for both TB and COVID-19). Some came from people with symptoms, others from those recently diagnosed but unable to get appropriate treatment. Several queries were about the vulnerability of TB patients to COVID-19, and the need to take special precautions to self-protect, etc.

Two oft-repeated queries were about how TB treatment and COVID-19 infection interact, and how to address the infectiousness of both.

- **Diagnosis:** One of the primary areas of concern has been diagnosis. Queries include where to get tested (geographic availability, as well as whether to go to a public or private centre), what tests to get done (i.e.: what are the most reliable tests for TB and DR-TB), worries about the situation (safety of testing, challenges in access to testing), as well as queries pertaining to the appropriate tests and interpretation of results (testing methods for pulmonary and extra-pulmonary TB, accurate diagnosis for DR TB, meaning of results) and next steps.

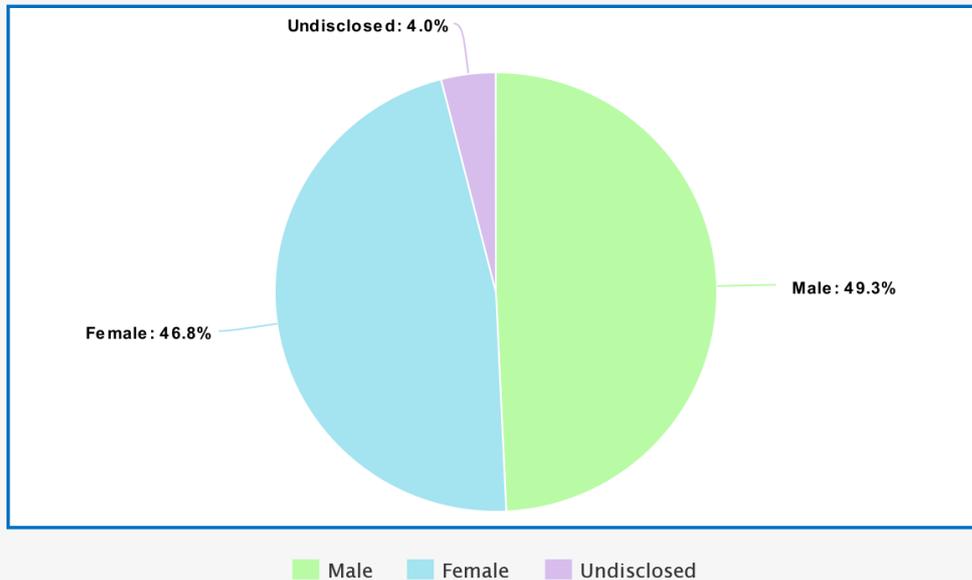
- Treatment:** These queries covered a host of issues, including gaps in treatment availability, lack of access to certain medications (Cycloserine, Clofazimine)* and questions about access to treatment facilities (inability to reach facilities, costs of transport, etc). There were also several queries involving patient literacy (what is the right regimen, is my regimen correct). There were also queries related to Side Effect Management, these included some severe and urgent issues such as neuropathy and bleeding while coughing, lack of appetite etc., as well as some about possibility of reinfection, and how to manage it, etc.
- Nutrition:** A slowing economic climate, mass exodus of migrant workers from urban centres, and job losses across sectors have caused the loss of income and greater anxiety, leading to food insecurity. Among the TB affected, this has direct health outcomes, and there have been a number of queries on access to economic support and sufficient nutrition and what foods one must eat/avoid eating etc. Recurrent queries about the lack of access to Nikshay Poshan Yojna (NPY) and its delayed payments were common in several states, and many registered patients who were enrolled in the program complained of not receiving payments until several months into treatment.

MONTH-WISE QUERY DISTRIBUTION



We have observed that the number of queries has remained high from March 2020 (20th onwards on graph) till the present day (till October 15th on graph), despite the lockdown gradually being lifted in most places and claims from various states that TB-related health services have been restored to normal. This indicates that problems are still persisting, or that patients are still anxious about visiting facilities/meeting health workers and prefer to reach out to the helpdesk instead.

GENDER-WISE DISTRIBUTION OF QUERIES



While in absolute numbers, TB affects more men than women, TB claims the lives of a huge number of women in India, even more so than causes of maternal mortality. Yet, we rarely view this disease as a gendered one. In the context of the virtual helpdesk, men and women had almost equal numbers of queries; however, the apprehension is that the number of women being represented may be low, simply because access to internet-enabled devices is still not available to women in many areas. In general, such devices are owned by men or often shared between all family members within the household. An additional reason is stigma which often limits women from using these devices for personal health issues.

OVERALL ANALYSIS

The queries highlight that gaps remain in access to diagnosis and treatment both in the public and private sector and need to be focused on. Patients lack access to supportive supervision and adherence remains an issue. Patient support, patient literacy and education was virtually absent and the pandemic has underlined the importance of including these and making these accessible remotely as a part of the care cascade. Finally stigma mitigation, gender sensitive care and mental health support remained absent as well indicating a critical need to focus on these areas.

The queries also highlight that communication around TB and COVID-19 together suffers from numerous gaps, since there is still a lot of fear and anxiety about both diseases. 30 percent of the queries about both diseases were basic and highlighted the gaps that exist in the understanding of these diseases and how they may interact for people. It also highlights that the lockdown caused major hindrances in seeking and continuing care for patients, especially those who could not consult doctors.



RECOMMENDATIONS



India's TB epidemic is not just a biological challenge, but a broader manifestation of numerous other factors. As a result, addressing TB is determined by social, economic, cultural, religious, caste and political factors. In response to the COVID-19 pandemic, charting a strategic new course for TB needs an understanding of these numerous complex factors and participation of all the stakeholders involved. Based on our work with TB-affected communities, interviews and survivor experiences, SATB has listed some recommendations to the NTEP to address TB in the time of COVID-19.

- Prioritize Case Detection:** It is critical that TB testing is not slowed down. TB programs must continue to provide and expand access to high-quality diagnosis through reliable diagnostics such as the Xpert MTB/RIF TB test, which are critical for early detection of MDR-TB. Active case finding within communities and in high-density geographies must be initiated for both TB and COVID-19, to actively identify, isolate and treat cases. Kerala has already been following this strategy. While bi-directional screening has been announced it needs to be strengthened by investing adequate resources in it.
- Address Treatment Challenges:** India needs to address treatment challenges for ongoing and new patients in both the public and private sectors. India needs to provide all TB patients with at least 2-3 months' supply of medications at one time, to decrease inconvenience, costs of travel, and exposure to possible infection at facilities. At this time, India should empower patients by hastening the switch to all-oral treatment regimens, as recommended by the WHO, so that patients do not have to undertake high-risk and costly travel for injectables. Considering the high possibility of stockouts, the NTEP must create an independent and inclusive way of tracking and forecasting drug supplies, which should include representatives from communities. Finally, access to new and novel regimens and technologies must be increased in the public and also the private sector, the latter through the creation of centres of excellence in the private sector nationwide.
- Address Mental Health & Stigma, While Increasing Peer Support:** The Government should consider urgently integrating social and mental health support aspects as an essential part of treatment support. India should implement a stigma-mitigation strategy aimed at affected individuals and families in their communities for both COVID-19 and TB. An essential aspect is to build skills among the health force, to reduce stigma and provide basic mental health support, leading to better quality care. This must include mental health screening and ongoing support. Another important aspect is to institute mechanisms for peer support, in the form of virtual and local networks etc., where patients can connect with other TB-affected patients and survivors. A final key aspect is patient education and literacy. We urge the government to consider multilingual patient education and information programs to assist patients in understanding and managing their disease.
- Deploy Strategic Communications:** Credible and reliable communication and information remains a critical challenge for both TB and COVID-19. India needs an overarching strategic communication plan drafted and executed with support from key stakeholders that helps with the delivery of the above interventions in a phased manner. A comprehensive people-centred and people-led information campaign on every aspect of the crisis, covering the components of TB care from prevention, to where and how to access government services, testing, economic and nutritional support etc. needs to be rolled out for TB immediately.

- **Create and Initiate Accessible Remote Treatment Support:** With the fear of infection from clinical environments, in person routine care has to be replaced by remote support. SATB has been providing some support of this nature to patients. This is particularly relevant for both TB and COVID-19 patients, at their quarantine sites. A helpline is important but needs to be expanded to ensure it reaches larger numbers, especially those in remote areas, and provides multilingual support. This is also needed for the government's use of telemedicine, and adherence technologies to support TB patients. In the absence of one-on-one engagement, these will allow for consultations and query resolution. These should be multilingual, broad based and easily accessible for all through multiple user-friendly social media platforms.
- **Create and Emphasize Community-based Care:** Community-based care is a critical need in TB. At this time, when facility-based TB services are increasingly not feasible, community capacity can be built to deliver community-based TB services for support and supervision. These can include community-based diagnosis using new technologies such as AI, infection control in households; supporting treatment adherence, ensuring psycho-social support and referrals for the management of adverse effects. A key aspect is effectively using community-based groups that include TB survivors, since they are credible to new patients, to provide support. The community-based care can also use social media platforms and mobile phones to ensure deeper and more effective outreach and follow-ups, both with patients and with health authorities.
- **Engage Private Health Services:** According to the National Family and Health Survey, over 60 percent of all Indians seek care in the private sector at some point or another. In the case of TB, this number remains reasonably high, even though the government provides free treatment and diagnosis. Clearly, TB or COVID-19 in India cannot be comprehensively addressed until the private sector is engaged effectively as an equal partner. This means that the government needs to employ new and innovative strategies to engage and work with the private health sector on TB, mobilizing it to deliver bi-directional diagnosis, treatment, patient support, and awareness in local communities. The government needs to create centres of excellence in the private sector and work with them to ensure that there is a collective COVID-19 and TB response via the private sector.
- **Strengthen Implementation of Direct Benefit Transfers (DBT):** DBT under NPY can play a crucial role for patients helping mitigate the challenges they face regarding nutrition. In addition, DBT incentivizes private providers to notify and facilitate treatment completion. Over the past 7 months, numerous gaps and delays have been reported in the implementation of the DBT schemes. Improving their coverage and implementation benefits patients, their families, communities and, in turn, the program. Effective implementation in the private sector will improve reporting and treatment outcomes. The government should ensure timely and regular payments for NPY, tribal and private provider schemes. In these times, staff training and use of digital technologies would help.
- **Gender-Responsive Care and Solutions:** An equal number of queries to the helpdesk from both genders as well as many from the transgender community and the LGBQIA++ communities indicate the lack of access, challenges and stigma faced across vulnerable genders and sexual orientations. The government needs to make its care more relevant and responsive to issues faced by sexual and gender minorities, and ensure that care is accessible and stigma-free for them. We need to ensure that all solutions and care are not just person-centred, but also sexuality and gender inclusive. Sexuality and gender responsive training for staff and communities is needed to ensure these factors do not hinder a person's ability to access care.



CONCLUSION

As the world and India grapple with the COVID-19 crisis, TB must not be forgotten. TB kills more than 1,200 Indians every day. Moreover, it also destroys lives, pushing millions into poverty and debt. This happens despite the fact that even its more dangerous forms such as DR TB remain curable.

While India is working hard to contain the spread of COVID-19, we cannot afford to lose the gains and momentum achieved in fighting the TB epidemic. The gaps in TB care, be it in terms of information, lockdown-related issues, unavailability and delay in accessing TB services, and the difficulty of seeking advice from medical practitioners, have all been highlighted in our findings via the virtual helpdesk through the duration of the pandemic so far.

We need to focus on TB and COVID-19 simultaneously, and to include communities and survivors as key stakeholders along every step of the way. We need to ensure that we have strategies that work for both TB and COVID-19. This crisis presents an opportunity to improve access to health services, and implement innovative tools, strategies and community-based interventions that have been ignored for too long.

ABOUT US

Survivors Against TB is a group of TB survivors, advocates and experts who are working to strengthen India's fight against TB. These communities and partner organizations advocate with key stakeholders on the changes necessary to make TB care person-centered in India.

For press queries contact: Vashita Madan,
Email: survivorsagainsttb@gmail.com
Phone: +91 9599729932

