

UNDERSTANDING TB WITHIN COMMUNITY STRUCTURES

Integrating the most vulnerable

Notes from the webinar

Introduction

Community structures are established community organizations that have immense potential to collectivize efforts and initiatives to conduct activities that strengthen tuberculosis (TB) awareness in the community, improve the recognition of symptoms, and promote appropriate health seeking behaviour. Due to their significant influence as organizations with social welfare as part of their mandate, they have the ability to help TB patients in various ways, starting from one-on-one counselling and patient visits to mobilizing resources for extending monetary and/or nutrition support through the treatment period. This could create an enabling environment in the community to foster TB control initiatives and support TB patients through stigma mitigation and resource mobilization efforts.

KHPT engages with community structures such as self-help groups, youth associations, labour unions and faith-based organizations, through the Breaking the Barriers (BTB) project, funded by the United States Agency for International Development (USAID), which aims to empower vulnerable communities to access quality healthcare services, thereby accelerating the elimination of TB in India.

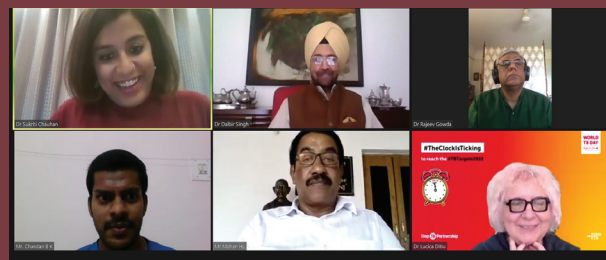
As part of the project and in the lead up to World TB Day 2021, KHPT and USAID held a webinar, 'Understanding TB within Community Structures: Integrating the Most Vulnerable', which engaged public health experts, parliamentarians, Central TB Division (CTD) representatives and TB survivors. The discussion focused on how we can accelerate India's TB response with a community-centred approach that can aid the scaling up of access to TB prevention and treatment measures. The panellists discussed the need to delve into the community as a resource to strengthen and sustain efforts to improve health seeking behaviour and treatment adherence, as well as address social issues such as stigma and discrimination.

Panellists

Opening remarks were made by Dr Raghuram Rao, Deputy Director, CTD, Ministry of Health and Family Welfare (MoHFW); Dr Reuben Swamickan, Division Chief, Tuberculosis and Infectious Diseases, USAID and Mr Mohan H L, Chief Executive Officer, KHPT.

Panellists included Dr Dalbir Singh, President, Global Coalition Against TB; Dr Rajeev Gowda, Parliamentarian, Indian National Congress; Dr Lucica Ditiu, Executive Director, Stop TB Partnership; Mr Chandan BK, TB Champion, IT professional, Bangalore.

This document highlights key points of discussion from the webinar, the recording of which may be accessed here <https://www.youtube.com/watch?v=4vb0-1ztW1g&t=4698s>



Top left to right: Dr Sukriti Chauhan, KHPT; Dr Dalbir Singh, Global Coalition Against TB; Dr Rajeev Gowda, Indian National Congress.

Bottom left to right: Mr Chandan B K, TB Champion; Mr Mohan H L, KHPT; Dr Lucica Ditiu, Stop TB Partnership.

Introductory remarks

In his opening remarks, Dr. Raghuram Rao highlighted the importance of community structures, saying that the role of communities will be critical in turning all efforts of ending TB into a Jan Andolan. The involvement of these structures will be instrumental in achieving India's goal of eliminating TB by 2025, he added.

“Communities have been an integral part of this journey, and in subsequent years, their engagement and ownership will be essential to sustain the momentum of TB elimination through the adoption of TB and COVID appropriate behaviour. - **Dr. Raghuram Rao, Deputy Director TB, CTD, MoHFW**”

In his keynote address, speaking about the role of the community structures and informal networks in meeting the End TB goal, Dr Reuben Swamickan underscored the critical role played by communities, as they emerge as the backbone of any public health intervention. He added that there has been a paradigm shift with TB survivors and champions coming forth and making themselves heard. Communities are defining themselves, he said, and there is an urgent need to recognize the power of people to turn the tide and reach out to a much larger population with messages of TB prevention, treatment and adherence.

“We cannot only depend upon the government system alone for TB treatment outcomes. It is time to empower community with solutions, so that they are able to not only help themselves but also other TB patients and the community at large. - **Dr Reuben Swamickan, Division Chief, Tuberculosis and Infectious Diseases, USAID**”

In his welcome address, Mr Mohan H L spoke about how KHPT as an organization has always kept community engagement at the centre of all its activities for over a decade now. Projects such as the USAID-funded. Tuberculosis Health Action Learning Initiative (THALI) have demonstrated how community engagement can result in increased case notification and improvement in quality of referrals, he said. He also spoke briefly about the Breaking the Barriers (BTB) project, supported by USAID, which leverages the THALI experience to work with vulnerable communities across the four geographies of Karnataka, Telangana, Assam and Bihar.

“We will be using, along with community engagement strategies, behavioural change solutions to improve case identification and case holding of these vulnerable segments - the urban poor, tribals, mining and industrial workers and migrants. - **Mr. Mohan H L, CEO, KHPT**”

Key discussions

Creating a favourable policy and programme environment for deeper community engagement

About a million people lack access to TB care as there is a gap between their needs and health processes and systems. This gap can be filled only by the communities and community structures, in the midst of whom TB thrives. Community engagement is indispensable as it facilitates the participation of the larger community in the mission to End TB, while strengthening patient support mechanisms. The National Strategic Plan (2017-25) for TB elimination recognizes the important role that communities can play, and speaks of communities not as passive recipients of care but as active and motivated stakeholders in the nation's response to TB. The recently-launched 'Jan Andolan' or 'mass movement' against TB involving advocacy, communication and social

mobilization (ACSM) is an example of policy makers recognizing that the complete participation and cooperation of communities and community-based groups at various stages of the TB response are foundational in reaching the unreached populations.

Community structures as support systems for the larger community

The real work and solution to meet the end TB goal lies with the communities. Well-established, and well-informed community structures at the grassroots level can help the larger community and the government to respond better to not only TB, but to any future pandemic.

“Through empowering communities with the right tools, information and remuneration, we can establish them as primary link and communicators between the larger communities and public health systems. Well informed and equipped community networks can be drivers of change. - **Dr. Lucica Ditiu, Executive Director, Stop TB Partnership**”

“Community engagement strengthens institutional platforms at all levels for deeper engagement with affected community and NGOs. They can help mitigate very effectively issues like stigma, discrimination and ostracization within the community and at the workplace. Active community involvement can also ensure the health system becomes more resilient, responsive and people-centric. - **Dr. Dalbir Singh, President, Global Coalition Against TB**”

The financial implications of TB for India

At an individual level, a TB patient's inability to earn sufficiently has financial implications on them and their families. At a macro level, they are unable to participate in and contribute to the economy.

This economic impact is compounded by factors such as Drug Resistant TB (DRTB), which is more difficult and expensive to treat, and malnutrition among the vulnerable populations, which affects their productivity. There is, thus, a strong need to allocate adequate resources for healthcare services which reach the worst affected and most vulnerable patients. Resources also need to be allocated to communication to spread accurate information on TB, and to address stigma and discrimination associated with the disease.

“The government needs to keep the TB control programme adequately funded. This, coupled with community interventions, can help turn the tide for the vulnerable populations when it comes to TB. - **Dr Rajeev Gowda, Parliamentarian, Indian National Congress**”

Local governments can play a critical role in the TB response

The 73rd and 74 Amendments (1992) of the Constitution ushered in the formation of local governments in India as the third tier to our federal structure. India has 2,50,000 such institutions at district, block and village levels, and public health is one of the fundamental responsibilities of the local government. Given the kind of health care that India needs, the larger objective of affordable, equitable and universal healthcare for TB care can only be achieved by building synergy between the government apparatus, local governments and society, and through a deeper engagement of local communities.

“We need synergy between the Health Ministry, Panchayati Raj, local government, society and local communities under the supervision of elected representatives at every level. We need to treat them all as equals so we can get a response from them. - **Dr. Dalbir Singh, President, Global Coalition Against TB**”

Improving the status of public sector health services in resource-poor settings key to end TB

The national government has already started investing heavily in strengthening grassroots systems. This is best explicated in the strengthening of the Health and Wellness Centres (HWCs). The MoHFW has envisaged converting existing Sub-centres - covering a population of 3000-5000 - into Health and Wellness Centres ensuring the delivery of comprehensive primary health care services in no more than 30 minutes. Community Health Officers (CHOs) at the Sub Health Centres are being trained on TB; this will enable them to support diagnosis by transporting sputum samples, ensuring test results come back in the shortest time possible, as well as support the treatment adherence of TB patients.

“We need not build new systems, rather (we should) enable and reorganize the existing systems to support the entire TB response in the country. - **Dr Reuben Swamickan, Division Chief, Tuberculosis and Infectious Diseases, USAID**”

Actively involving and engaging TB Champions

There is ample opportunity to enable and empower TB Champions to be the bridge between the community and the health system. TB Champions from within the community are either current TB patients (who are undergoing treatment), cured TB patients, or caregivers and are willing to publicly disclose that they have TB, and share their challenges and how they have overcome them to inspire other patients. Being TB survivors and caregivers themselves, their involvement can benefit both the TB patients and the government by bringing to the fore challenges being faced by the TB patients and putting forth solutions to the government.

“TB Champions can be seen as the next big force that will bridge the gap between the government and the TB patients. - **Dr Reuben Swamickan, Division Chief, Tuberculosis and Infectious Diseases, USAID**”

“It took me some time to confirm that I had TB. I only learnt about it when I went for a COVID-19 test. After multiple tests, I was diagnosed with bone TB. The doctor then advised me to undergo a surgery for my infection. I had learnt about TB when I was in school and thought it had already been eliminated, which I was shocked to learn is not really the case. I later learnt that government provides free medicines for treating TB, which earlier I was not aware of. I also learnt that there are designated centres from where I could access these medicines. As a survivor, I would strongly suggest that information dissemination be done through public service campaigns and advertisements about TB as a disease, the treatment and the various services being provided by the government, to ensure reach to a much larger population. - **Mr. Chandan BK, TB Champion, IT professional, Bangalore**”

Recommendations on the integration of community structures into the TB response

- Community structures and networks can play an important role in prevention, diagnosis, improved treatment adherence and care that can positively influence TB treatment outcomes. Increased community participation leads to deeper engagement with TB patients, and provides much needed psychological comfort. Community structures must be used as an entry point for spreading information related to TB through their networks and have a clear understanding about TB to prevent misinformation. There is a need to equip these networks of communities with tools and provide them remuneration so they work as drivers towards meeting the end TB goal.
- A well-trained and remunerated cadre of frontline workers is important to respond to the TB crisis in the country. The creation of Health and Wellness Centres as the first point of public interface for TB, which can provide support in diagnosis, treatment adherence and care, in turn supported by technology, can enable us to change the ways we work with TB patients, specifically the vulnerable communities.
- The onus is on government and civil society alike to increase TB literacy among TB patients, communities and civil society. Historically, TB has been dealt with more as a medical issue, but it is time for all state and non-state actors to address it from a social lens too.
- The civil society and the donor community through its interventions needs to ensure that it is not only merely listening to the TB patients and survivors, but is also enabling them to speak.
- The donor fraternity and the national governments need to ensure consistent funding for TB interventions, specifically for those that focus on community interventions. Given that there is a lopsided funding pattern, with a majority of funds for TB-related work going to big organizations from the Global North, there is a need to review donor funding patterns for the grassroots organizations of the Global South.
- The government should allocate adequate resources for awareness building and communication. Compelling public service campaigns and advertisements that persuade and appeal to the larger public and communities can help fight the stigma and discrimination associated with TB.

For more information, please contact Shramana Majumder, Communications Specialist, Breaking the Barriers project at shramana.majumder@khpt.org

Disclaimer: This report is made possible by the generous support of the American people through the United States Agency for International Development (USAID). The contents are the responsibility of KHPT and do not necessarily reflect the views of USAID or the United States Government.

KHPT

IT Park, 5th Floor, 1-4, Rajajinagar Industrial Area, Behind KSSIDC
Admin office, Rajajinagar, Bengaluru, Karnataka - 560 044

Ph: + 91 80 4040 0200, Fax: + 91 80 4040 0300
Email: khptblr@khpt.org | Website: www.khpt.org