Gender Responsiveness and Stigma Redressal Workshop on Tuberculosis

June 4, 2021

A Brief Report

Introduction

Tuberculosis (TB) affects an estimated 10 million people globally every year, of which around 3.2 million are women.[1] Gender differences and inequalities play a significant role in how people of all genders access and receive healthcare in the public and private sectors.

Women are especially constrained by social norms which prevent prioritizing of their nutrition, health and wellbeing. Undernutrition, their role as caretakers and the use of solid fuel for cooking puts women at risk for TB. While the fear of loss of income and the consequences of absence from work hinder care seeking in men, women face difficulties due to perceived stigma, prioritization of household chores, lack of money or financial dependence.

Besides gender differences influencing care-seeking, health system factors such as limited access, lower index of suspicion of TB for women; provision of inadequate information to care-seekers also significantly affect the access to services. Yet another critical factor that adversely influences health seeking behaviour of women is the stigma associated with the disease. More often than not women tend to not disclose their status both within and outside the family. As the woman feels the stigma associated with the disease will not only affect her family members' attitude towards her, but also may have a negative impact on her family, especially her children. She fears that her family and children may be ostracized by the neighbours and larger community if they come to know of her disease.

Karnataka Health Promotion Trust (KHPT) being cognizant of these challenges, and in alignment with the Jan Andolan theme for the month of June- Gender and TB, organised a virtual workshop titled **'Gender Responsiveness and Stigma Redressal Workshop on Tuberculosis,** on June 4, 2021, in collaboration with USAID and National TB Elimination Programme (NTEP)

The workshop enabled a discussion on barriers such as gender and stigma to accessing healthcare and completing TB treatment. The workshop comprised of expert resource persons with varied work experience in public health, women's issues and rights, TB and allied fields.

[1]National Framework for a Gender-Responsive Approach to TB in India, Central TB Division of India, Ministry of Health and Family Welfare, Government of India, 2019

Opening remarks were made by Dr Nishant Kumar, Deputy Director, Central TB Division, Ministry of Health and Family Welfare, Government of India, Ms. Amrita Goswami, Project Management Specialist,USAID, India and Dr. Prarthana BS, Strategic Lead, Tuberculosis Theme, KHPT.

Panelists included, Dr. Oommen George, Team Lead,NTSU - TB ACSM, NTEP, MoHFW, Ms. Blessina Kumar, CEO, Global Coalition of TB Activists, Dr. Dalbir Singh, President, Global Coalition Against TB and Ms. Mallika Biddappa-Tharakan, Results Delivery Officer &Lead, Knowledge Management, KHPT. Dr Sukriti Chauhan, Advocacy Lead, Breaking the Barriers moderated the discussion.
https://www.youtube.com/watch?v=TnxpcSXKd2M

Dr. Dalbir Singh, President, Global Coalition Against TB, **Ms. Blessina Kumar,** CEO, Global Coalition of TB Activists, **Dr. Oommen George,** Team Lead,NTSU - TB ACSM, NTEP, MoHFW,s, **Amrita Goswami,** Project Management Specialist,USAID, India, **STO Bihar, Dr Nishant Kumar,** Deputy Director, Central TB Division, Ministry of Health and Family Welfare, Government of India, **Dr Sukriti Chauhan,** Advocacy Lead, **Ms. Mamatha M R,** Project Director, Breaking the Barriers, KHPT, **Dr. Rehana** KHPT, **Dr. Prathana** KHPT, **Dr. N.J Das.**

Introductory remarks

Delivering the keynote address at the workshop, Dr. Nishant Kumar, Joint Director (Public Health), Central TB Division (CTD), MoHFW, emphasized that in line with the highest ever level of political commitment to eliminate TB, CTD is pledged to address all barriers that prevent people from seeking care and completing treatment. Bearing in mind the gender related challenges, CTD's gender-inclusive framework aims to develop equitable right-based services for TB patients at all levels. He also spoke of the importance of Jan Andolan in involving a cross-section of stakeholders to ensure a holistic TB response.

> "We are working towards making the care cascade friendly, and creating an environment where both the community and healthcare providers are having a dialogue. The only way to end TB in India is to make it a public movement **- Dr Nishant Kumar, Joint Director (Public Health), CTD**"

In her opening remarks Ms. Amrita Goswami, Project Management Specialist, USAID, India reiterated that USAID is committed to work with all our partners including KHPT to take on the identification and correction of gender-based inequities, especially in the TB portfolio. She also underscored the need for a collaborative approach in creating models for equitable access to TB services at national and state level.

> "Going forward, we need to build the capacities, knowledge, attitudes and practices of program staff to institute sensitive and gender friendly TB services **- Ms. Amrita Goswami, Project Management Specialist, USAID India**"

Key discussions

TB, stigma and discrimination

Stigma primarily stems from fear of TB, and of the disastrous health, financial, personal, and social consequences of the disease on affected individuals and families. Stigma exacerbates the medical and social hardships of TB, and is responsible for delays in diagnosis and treatment initiation, treatment interruptions, and poor outcomes. Stigma is a barrier to TB elimination. Stigma around TB is latent, surfacing when the disease status is known.

The primary reasons for stigma associated with TB include, fear of infection, and of economic disaster, fears from myths; e.g. "TB is hereditary", "TB only affects the poor", belief that it afflicts people who do 'bad things', societal norm, in other words people do what they see others doing.

Stigma can assume various forms

- Internalized or self-stigma or where TB affected individuals endorse negative stereotypes.
- Anticipated stigma (perceived stigma): The worry that one will be devalued after a TB diagnosis. For the person with TB, this is the fear that stigma will affect access to TB services.
- Enacted or experienced stigma: Reflects stigmatizing behaviors, messages, and effects experienced by the persons with TB or their families and/or that drive others to acts of discrimination, rejection, or isolation. This is seen from the perspective of the stigmatizer (enacted) or the stigmatized (experienced).

- **Secondary stigma:** Refers to caregivers, friends or family expecting negative attitudes or rejection because of association with the disease, or person with TB.
- **Community/public stigma:** Describes negative attitudes, beliefs and behaviors held by the wider community.
- **Structural stigma:** Laws, policies, media and institutional architecture that may be stigmatizing; includes cultural norms and institutional practices.

> "The weak link here is the way people behave towards people with TB. We need healthcare providers, families, friends and the community to demonstrate positive behaviours towards people with TB. All this can happen through behaviour change communication **- Dr Oommen George, Team Lead, NTSU - TB ACSM**"

Need for proper implementation of policies

Every change emanates from policy. The current TB framework is in alignment with the principles of equality and human rights. There is ample evidence to show gender has a significant impact on TB. For instance, mothers with TB give birth to pre-mature children. However, the implementation of the gender framework in TB is yet to be intensified. When it comes to TB notification, women are under-notified even now and this is something that needs to be overcome.

> "When fighting at the front, it is women who are the warriors. They are our first responders in any health crisis. However, very little attention is paid to them. We must provide them the support they need and remuneration **- Dr Dalbir Singh, President, Global Coalition Against TB**"

Need for establishing a global best practice

There are no best practices in place when it comes to addressing stigma. This in a way paves the way to document the best practices across the globe. The need is to focus on the issues at the regional level, and documenting the experiences of women and children who are TB survivors can be the first step towards creation of a best practice. Bringing together such lived realities and experiences can act as evidence towards building of best practice, that can have real impact.

> "We have the paradigm shift from a medicalized response to a people-centred rights-based response, we even have the tools. When we have tailor made programs, the impact is much more. What is needed right now is action **- Ms Blessina Kumar, CEO, Global Coalition of TB Activists**"

Understanding how gender and power interplay is important

It is common to see that perceptions on who women should be, how much value should be ascribed by them and their boundaries are determined by people in positions of power. How we are to integrate gender into programs is determined by how power plays out and how to transfer power from those who hold it. Gender should be positioned as a cross-cutting theme. People need to be at the forefront of discrimination to guide programs, empowering the frontline who are themselves disempowered with no redressal mechanisms is also a critical aspect.

> "We have a critical responsibility to challenge gender norms one family at a time. We have to see what empowerment means for women and not what we mean for them. We have to create safe spaces to collectivize **- Ms Mallika Biddappa, Results Delivery Officer and Lead, Knowledge Management, KHPT**"

Sharing of state experiences

A specific segment in the workshop had State Tuberculosis Officers (STOs) from Karnataka, Telangana, Assam and Bihar share their state specific experiences around the issue of gender and stigma. The STOs present at the workshop included, Dr. N. J. Das, STO, Assam; Dr.B.K.Mishra, STO, Bihar; Dr. A. Rajesham; STO, Telangana; The Karnataka STO office was represented by Parashuram Patil, DRTB and HIV Coordinator, NTEP, Belagavi, Karnataka. This session was moderated by Ms. Mamatha M.R., Project Lead, Breaking the Barriers project.

Telangana: Dr.A. Rajesham, STO, Telangana, shared that the STO office has developed a module called DISHA TB for training TB survivors as champions. Using the module 200 TB survivors have been trained as champions and are regularly engaged to talk about TB during community engagement activities.

Bihar: Dr.B.K.Mishra, STO, Bihar, shared, the STO office recognizes that they have not done enough to make TB more gender-sensitive as yet. They are cognizant that whenever women TB patients are diagnosed, there is a delay in coming to the healthcare centres for consultation. However, going forward the team is enlisting the help of women TB Champions on the ground to ensure improved outreach among women TB patients.

Karnataka: Representatives from the STO office in Karnataka, shared that involvement of frontline workers and active district NTEP staff has brought about relief to a number of TB patients. Their effort has been to focus on the vulnerable segments. The team also put forth an example of a DRTB patient who was persistently reached out to and counselled for completion of her treatment.

Assam: Dr. N. J. Das, STO, Assam, said that the situation in Assam has not been very promising either. Male notification in the State is much higher in comparison to women notification, owing to restrictive social norms that does not allow women to take decisions. However, the STO office recognizes the need to focus more on women going forward.

Key Recommendations

- It is important to start building evidence from the ground realities and experiences of people with TB to actually have an impact.
- Reaching out and involving the immediate family of TB patients, in TB response will be critical to make it more gender responsive.
- Going forward, there is need to build the capacities, knowledge, attitudes and practices of program staff to institute sensitive and gender friendly TB services.

Way forward for States

KHPT and its Breaking the Barriers (BTB) team across the States of Assam, Bihar, Telanagana and Karnataka are committed to actively collaborate with CTD and STOs in operationalizing stigma redressal and gendered response. Some of the critical steps for way forward will include:

- Integrate gender approaches by building perspectives among all BTB state and district implementation teams including the community coordinators.
- Across BTB geographies work with the state and district NTEP, organize gender sensitization trainings including the wide network of frontline health workers
- In every BTB state KHPT will closely work with state and district NTEP in developing a gender integration and stigma mitigation action plan based on National Gender Responsive Framework and the Strategy to end Stigma and Discrimination released by the Central TB Division (CTD)
- As a project the BTB teams will continue to engage with the most vulnerable groups with gender specific strategies for promoting health seeking behaviours and tackling barriers to access. In doing so also reach out to the community structures that the projects are working with on issues of TB, gender and associated stigma.
- Adapt, translate NTEP stigma videos in Telugu, Kannada, Assam and Bhojpuri, and widely disseminate in various digital media channels
- While working on Active Case Finding and other activities ensure that the focus is on women, men in distress, transgender persons with multiple vulnerabilities such as tribal women, migrant women workforce, women working in industries and mining areas, among others.
- Engage with local policymakers to bring in redressal of gender and stigma barriers to TB in their constituencies

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