Analysis of spreading of TB in India

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***Abstract*: Tuberculosis is a treatable, communicable disease that has two general states: latent infection and active disease. With few exceptions, only those who develop active tuberculosis in the lungs or larynx can infect others, usually by coughing, sneezing, or otherwise expelling tiny infectious particles that someone else inhales. With its socio-economic implications, tuberculosis (TB) is a disease that requires the successful engagement of all levels of stakeholders in the community. However, civil society urgency in regard to TB seems to be missing. This is a great gap in India's response to TB and leaves the community more vulnerable to the disease.**

***Keywords*: tuberculosis, communicable disease, latent infection, active disease**

Introduction

Tuberculosis (TB) is caused by a bacterium called *Mycobacterium tuberculosis*. The bacteria usually attack the lungs, but TB bacteria can attack any part of the body such as the kidney, spine, and brain. Not everyone infected with TB bacteria becomes sick. As a result, two TB-related conditions exist: latent TB infection (LTBI) and TB disease. If not treated properly, TB disease can be fatal. India has the world's largest burden of TB, with 2.3 million new infections every year out of 8.6 million worldwide.[1] This infectious disease leaves a devastating socio-economic impact, with direct and indirect losses in India amounting to $23.7 billion every year.[2]

India has taken serious note of the public health challenge posed by TB, rolling out the Revised National TB Control Programme (RNTCP) in 1997, which expanded to cover the entire country by 2006.3 The RNTCP offers free treatment to TB patients through the Directly Observed Treatment, Short-course (DOTS) regime.

A treatable, curable disease, TB can successfully be cured by timely diagnosis of the patient and adherence to the prescribed course of treatment. However, the fact that the disease persists with high incidence in India, in spite of a comprehensive framework in place to address it, points towards gaps that need urgent redressal.

As a disease which disproportionately affects the poor, renders patients vulnerable to social stigma and which flourishes on account of low risk perception, lack of awareness and inadequate preventive measures, TB poses a social challenge that requires the active participation of stakeholders from outside the existing government programme. Civil society constitutes a significant section of organisations with the human resources and the reach to be able to play a transformative role in the Indian TB landscape. A strong motivation to respond better to urgent health and humanitarian needs posed by infectious diseases such as TB has engendered a debate on how to formalise the significant, at times vital, contribution of civil society organisations in global health governance.
There are significant advantages that may potentially result from the greater engagement of civil society with the RNTCP. Civil society organisations (CSOs) exercise a bidirectional influence on the general public's beliefs, behaviour, as well as on government policies, community structures and government institutions. CSOs that work for on-the-ground implementation of welfare schemes, including health, are armed with the knowledge and understanding of local circumstances to be able to adapt and implement TB care services more effectively.

In the context of TB, CSOs could also play a significant role in resource mobilisation through their influence in the policy environment. They can play a valuable role in implementation support through personnel as well as knowledge of on-the-ground circumstances. As change agents and opinion leaders, CSOs can support advocacy and communication activities to increase awareness about TB, mobilise the community to collectively work against the disease and extend physical and moral support to those suffering from it.
One of the key challenges persisting in the Indian TB landscape, in spite of the RNTCP's scale of operation, is the difficulty faced by those with TB symptoms and patients in accessing diagnosis and treatment due to geographical limitations in difficult-to-reach, remote areas and conflict zones. Many CSOs function in these challenging circumstances, and their engagement offers a unique opportunity for increased early TB case detection and treatment adherence through the generation of demand for services and scaling-up of community-based care.

While the potential benefits of increased CSO engagement in the Indian TB landscape are significant, the response by civil society to public health issues in general and TB in particular is muted and generally non-impactful, if at all it exists. The dialogue on greater civil society inclusion remains on paper. A recent example is the consultations around the Global Fund proposal development—there were hardly any inclusive and representative consultations with the affected communities or the people working close to them. Moreover, the few consultations that did emerge with civil society were more as an initiative from civil society partners working on TB rather than as an invitation from the government.

There is also no collective sense of ownership among civil society representatives apart from the grassroot-level NGOs, who truly know the difficulties faced by the patients as well as the realities of the impact of TB on patients' families and communities. Unfortunately, the power to inform and change policy does not lie with grassroot-level NGOs and community structures. NGOs at the grassroots level are required to work closely with the national programme. They hesitate to inform and raise issues experienced at the level of implementation, as they feel the need to co-exist peacefully and are willing to accept status quo. They depend on the support of the local government to allow them to work in the community, and are unwilling to take risks that may impede them in being able to do so.

Since civil society is constituted by a diverse range of individuals and institutions, with influence across different levels of the policy and implementation landscape, we need voices from other non-state actors in order to strengthen civil society dialogue around TB. We need the active support of sections of the community who wield influence and have the power to change opinion. The corporate sector, media, the film fraternity, centres of policy and think tanks hold the potential to prepare the ground and create a platform for issues related to TB control to come to the fore. These groups of civil society members have the authority and expertise as well as the confidence to initiate a dialogue with the national programme.

Another important challenge in the management of TB in India arises from the lack of patient-centric evolution of policies to address the real-world concerns that result in delayed diagnosis and lack of treatment adherence. Patient advocacy is limited and there is no platform for engagement. The recent attempts to create and sustain TB patient forums under Project Axshya of the Global Fund could be the first steps towards creating these platforms. However, these forums need to be nurtured, mentored and championed in order to create a meaningful impact.

Another challenge is the general impression that prevails of there being no patient activism being generated because of the nature of the disease. Popular belief has it that most TB patients are cured after a relatively short course of treatment unlike the HIV community that lives with the disease. However, several factors such as the emergence of drug-resistant strains of TB, the link to poverty and loss of livelihood, which have devastating effects on patients and their families, need to be recognised and brought on board while considering the impact of TB on communities.

There is therefore a need to activate and energise civil society to call on the government to act to stop TB deaths and reach India's missing million.[3, 45
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The prevalence of TB is a threat to the entire community, and brings with it significant economic losses and suffering. The inclusion of all civil society groups in TB control initiatives through an urgent call to action is needed, so as to take ownership of the problem by understanding the issues confronting TB control and its impact on fellow citizens who are affected.

The role of CSOs can be broadly divided into three categories: Firstly, as members of monitoring committees; secondly, as resource groups for capacity building and facilitation; and thirdly, as agencies helping to carry out independent collection of information.[5] The global experience of CSO engagement for TB control has seen the establishment of initiatives such as the Global Fund and the Stop TB Partnership. The six-point Stop TB Strategy, developed by the World Health Organization in 2006, seeks to builds on the successes of the DOTS regime while also explicitly addressing the key challenges facing TB. [6] On the other hand, the Global Fund to Fight AIDS, TB and Malaria is an international financing organisation that aims to attract and disburse additional resources to prevent and treat HIV and AIDS, tuberculosis and malaria globally.[7] The Global Fund also mentions the role of CSOs as "instrumental" in the furtherance of its initiatives.[8]

As discussed earlier, however, CSO engagement with TB in India has met with very limited success, characterised by a low level of engagement and participation. It was to address this shortcoming that Project Axshya (meaning 'free of TB') was launched in April 2010 as the civil society component of a five-year project funded by the Global Fund. [9] Led by the Union and World Vision India, this project works in 374 districts across 23 Indian states.
There are also other avenues of support that can be drawn upon to augment the implementation of the programme. Leading organizations in the corporate sector can be engaged with to provide support and suggest solutions as part of their corporate social responsibility mandate.

In addition to resource mobilization, there is a need for greater awareness around TB and the measures necessary for its prevention and control. While there is increasing attention around TB in the media, it is necessary to build its support for TB advocacy. A call to the media to focus on public health and social issues and to showcase nuanced personal testimonials from the community and patients is necessary to raise the profile of TB and sensitize the general public about the disease.

It is a well-established fact that the association of opinion leaders, celebrities from films and sports fraternities plays a critical role in building public support towards issues of social relevance. Reaching out to their legions of supporters, celebrity champions can take the cause of fighting TB and preventing TB deaths to a larger and wider audience.

In addition to the multiple avenues of support, there is a need to constantly evaluate the evolving TB challenge in India, and to develop newer strategies to tackle it. Public health professionals and think tanks must find ways and means to engage the

community, support and strengthen community systems to provide grassroot-level feedback on services and devise a framework to take these issues to the district, state and national levels.

The RNTCP should also critically review its record of engagement with civil society partners for impact and effectiveness. Several "schemes for civil society engagement" have been formulated, revised and reviewed, but have been implemented poorly. The problem is compounded by the fact that the revised set of schemes in the National Strategic Plan for TB control has not been rolled out. The commitment of the programme to civil society engagement exists in policy, as already mentioned, but is not reflected in the budget allocation for private sector and NGO participation, nor are there any attempts to facilitate and simplify the framework for engaging all sectors towards TB control efforts. A strategic framework for engagement needs to be implemented and accelerated.

And finally, but most importantly, we must remember that the end beneficiary of all our strategies, the patient, is the one whose welfare and convenience must be at the core of our efforts. All stakeholders in the Indian TB control scenario need to come together to provide an enabling and inclusive environment to protect patients and strengthen them to be able to voice their concerns and fight for their rights. An inclusive, well-implemented strategy that addresses both the social and the epidemiological aspects of the TB challenge is our best hope towards successfully overcoming the disease in India, and by extension, around the world.

Multidrug-resistant TB

Anti-TB medicines have been used for decades and strains that are resistant to one or more of the medicines have been documented in every country surveyed. Drug resistance emerges when anti-TB medicines are used inappropriately, through incorrect prescription by health care providers, poor quality drugs, and patients stopping treatment prematurely.

Multidrug-resistant tuberculosis (MDR-TB) is a form of TB caused by bacteria that do not respond to isoniazid and rifampicin, the 2 most effective first-line anti-TB drugs. MDR-TB is treatable and curable by using second-line drugs. However, second-line treatment options are limited and require extensive chemotherapy (up to 2 years of treatment) with medicines that are expensive and toxic.

In some cases, more severe drug resistance can develop. TB caused by bacteria that do not respond to the most effective second-line anti-TB drugs can leave patients without any further treatment options.

Conclusion and future work

Tuberculosis (TB) remains an important public health problem. With close to 10 million new cases per year, and a pool of two billion latently infected individuals, control efforts are struggling in many parts of the world. Nevertheless, the renewed interest in research and improved funding for TB give reasons for optimism. Recently, the Stop TB Partnership, a network of concerned governments, organizations, and donors lead by the WHO, outlined a global plan to halve TB prevalence and mortality by 2015 and eliminate the disease as a public health problem by 2050.Attaining these goals will depend on both strong government commitment and increased interdisciplinary research and development. As existing diagnostics, drugs, and vaccines will be insufficient to achieve these objectives, a substantial effort in both basic science and epidemiology will be necessary to develop better tools and strategies to control TB. Here we analysis the recent history of TB research and some of the latest insights into the evolutionary history of the disease. We then discuss ways in which we could benefit from a more comprehensive systems approach to control TB in the future.

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