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Tuberculosis in India: Is it just a Medical Problem?

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India features among the 30 High Tuberculosis (TB) Burden Countries that together accounted for 87 per cent of the global TB burden in 2015 in terms of the highest estimated number of incident TB cases (Global TB Report, WHO 2016), despite the prolonged operation of a disease-specific, focused national health program in the country to address TB and considerable expansion of TB care services. The disease is believed to be strongly correlated to socioeconomic gradients of the population. Also, the contagious nature of pulmonary TB coupled with misconceptions is often the source of strong social stigma that impacts health-seeking behaviour of individuals. This paper tries to track down from literature factors that might be partially offsetting the success of the conventional "diagnosis and treatment" based efforts to curb the disease in India.

Keywords: Tuberculosis, contagiousness, socio-economic vulnerability, risk factors, awareness, stigma, health-seeking behaviour, treatment default.

Introduction

Tuberculosis, a dreaded disease from ancient times, continues to haunt the global public health scenario despite efforts and interventions both at national and international levels to combat the disease. It stands as a major health challenge and a prime killer in developing countries. Often referred to as the *White Plague* in history, TB continues to thrive thousands of years after plaguing ancient cultures from Greece to Egypt, more than a century after the bacillus *Mycobacterium tuberculosis* causing the disease was first identified by Robert Koch in 1882 and decades after the first antibiotic-based treatments were introduced. It typically affects the lungs (pulmonary TB) but can affect other sites of the body as well (extra-pulmonary TB). The disease is spread in the air when people sick with pulmonary TB expel bacteria while sneezing,

talking or coughing without cover. The most common and accepted method for diagnosing TB worldwide is sputum smear microscopy as it clinches diagnosis. TB is an opportunistic infection and chances of latent disease developing into an active one diminishes with the presence of conditions like lower body immunity due to malnutrition etc., which act as catalysts. Any expected health benefit from improved diagnosis and treatment may be nullified by increase in risk factors like poor nutrition, HIV infection, diabetes, tobacco and alcohol abuse, exposure to indoor air pollution, poor ventilation, and crowded and unhygienic living conditions. The conventional treatment regimefor emerging cases of drug-susceptible TB constitutes the administration of four first-line antibiotic drugs viz. isoniazid, rifampicin, ethambutol and pyrazinamide, spanning over six months. Treatment for multi drug resistant (MDR) TB lasts for twenty months and requires the administration of more expensive and toxic second line drugs.

TB was declared as a global public health emergency in 1993 by the World Health Organization (WHO).Despite conscious attempts both at national and international fronts to fight the disease, the global burden of TB remains enormous with an estimated 10.4 million incident cases, that is new and relapse cases of TB worldwide in 2015 and 1.4 million deaths from TB. In 2015, TB ranked above HIV/AIDS as one of the leading causes of death from an infectious disease (WHO 2016) despite being treatable and largely preventable. People fall ill with TB mostly in their productive years (15-59) of life that receive greater exposure to the outside world, posing serious socio-economic hardships for the household. According to studies, India loses an estimated 23.7 billion US dollars to TB annually in the form of direct and indirect costs. 3 to 4 months of work time is lost as result of TB with an average lost potential earning of 20-30 per cent of the annual household income. This increases the burden of debt particularly among the poor and marginalized sections of the population in addition to problems of social exclusion on public revelation of TB status, etc.

Global progress in combating the disease relies heavily on major advances in TB prevention and care in particularly the high burden countries like India, Pakistan, China, Indonesia, South Africa and Nigeria, to name a few. In India, the National Tuberculosis Control

Program (NTCP), which had been operational since 1962, was reviewed in 1992 and the Revised National TB Control Program (RNTCP) was formulated with the Directly Observed Treatment, Short Course (DOTS) strategy as its cornerstone. Nationwide coverage of the RNTCP was achieved by March 2006. Nevertheless, India housed the largest number of incident TB cases (2.0 million-2.5 million) in 2011, accounting alone for more than 21 per cent of the global TB burden. Although the initiation of affected persons into the treatment trajectory has been taken care of to some extent with the advent and effective functioning of the RNTCP, the adoption of adequate preventive measures and ensuring of compulsory diagnosis of persons with symptoms and completion of treatment have not been satisfactorily attended to. Conventionally, socio-economic vulnerabilities coupled with TB related misconceptions, lack of awareness and strong social stigma are supposed to play an important role in perpetuation of TB in developing societies like India by impacting the health-seeking behaviour of people, despite all-out efforts globally from clinical and medical perspectives to bring down the burden of the disease. The paper tries to identify from literature some such socioeconomic and cultural aspects at play, without addressing which, attempts at fighting this health menace is likely to remain largely incomplete.

Literature looking into perspectives on TB beyond medical and clinical stereotypes

A dreaded disease and a threat to community health, especially in developing countries, TB has inspired many studies on broader and crucial socio-economic and cultural factors including knowledge, awareness and stigma related issues that have contributed to perpetuation of the disease in our society.

Helden (2003) emphasizes that TB is not just a medical problem, but also a problem of social inequality and poverty. The poor will remain a breeding ground for TB until it is realized that it is not only the microbe that is to be blamed for the disease but also the gross defects in social organization and management of individual lives. What is urgently needed along with ensuring methodical administration of antibiotics is counselling of the patient and family to make them correctly aware of the disease and discard

stigma. Biomedical research needs to be combined with thoughtful political, social, economic and cultural research to look for an effective means to fight the disease.

Ghosh and Kulkarni (2004) have looked into whether household and individual characteristics play a role in the pattern of causes of deaths, and more specifically, the proportion of deaths due to communicable diseases in various age-sex groups in India where both large income inequalities and social stratification have traditionally been well defined. The paper finds that epidemiological transition is in progress in India, but its advance varies along socioeconomic lines with growing prevalence of non-communicable diseases among the better-off, educated and urban population, while communicable diseases remain relatively more prevalent among the rural based, illiterate or semi-literate poor masses and the sociallyweak.

According to Lonnroth et al. (2009), while the current health program based strategy to control TB is effective in curing patients and rescuing lives, its epidemiological impact has so far been less than predicted. To reach long term epidemiological targets, additional interventions are a necessity to reduce society's vulnerabilities for TB. Risk factors that seem to play out at the population level include poor living and working conditions and factors that cripple the host's defense against TB infection like HIV, malnutrition, smoking, alcohol abuse, diabetes and indoor air pollution. Identification of such risk groups help to better target strategies for early detection of people in need of treatment. The disease follows a strong socio-economic gradient between countries, within countries, and within communities. Studies focusing on TB burden among specific vulnerable populations such as prisoners and inmates, the displaced and homeless and certain ethnic minorities hint at the existence of a strong link between social deprivation and risk of TB.

Geethakrishnan et al. (1988) attempts to assess why there are so many undetected cases of tuberculosis when diagnostic facilities are available in each and every district of India and why patients default on treatment even when drugs are freely available. A survey was carried out in the South 24 Parganas district of West Bengal, India. Misconceptions and persistence of negative attitudes towards TB, particularly the belief that TB is incurable, were

identified as factors discouraging patients from continuing treatment.

In their paper, Mathew and Takalkar (2007)highlight that in India TB patients experience rejection and social isolation. Common misconceptions that fuel stigma are that TB is incurable; drugs for TB treatment harm the patient causing impotence and sterility, etc. Beliefs that TB spreads though unsafe sex practices like the case of HIV, through shaking hands and sharing food with an infected person, etc., cause patients to become secretive of their health conditions for fear of being shunned, even by their own family members. The myths and stigma revolving around TB contribute greatly to poor, delayed and inadequate health-seeking by individuals with symptoms as well as patients.

In the study by Subramanian et al.(1999), respondents from a number of randomly selected villages of a district in Tamil Nadu, India, were interviewed to find out the initial level of TB related knowledge on symptoms, diagnostic and treatment facilities available in government health institutions, preventive measures etc. Subsequently, the community was educated on basic facts about TB by various health education methods like pamphlets, film shows, exhibitions, etc. by volunteers. When interviewed after two years with the same set of questions, the same households were found to have gained an overall improvement in knowledge varying from 31 to 58 percent under different heads. The study thus draws attention to the effectiveness of direct and indirect methods of making community more aware about the disease.

The paper by Sreeramareddy et al. (2013) observes that knowledge about TB transmission in the general population of India was very poor and misconceptions were widely prevalent. Among traditional mass media, only the frequency of listening to radio was associated with knowledge about TB transmission. Majority of the respondents had heard of the disease called 'TB', nearly half the population knew that TB transmission occurred by air when coughing or sneezing but simultaneously believed in other modes of transmission like touching a TB patient or sharing his utensils, etc, thus propagating stigma. Only a quarter had idea about the correct mode of transmission without nurturing any misconception.

Sharma et al. (2005) have made anattempt to assess the impact of an intensive Information Education Communication (IEC) campaign in connection with the RNTCP launched by the Government of Delhi on generation of awareness and improvement in self reporting in Delhi, India. Results revealed that self-reporting, though more frequent after the campaign, was still low. IEC messages had less impact on the disadvantaged sections of the city's population. They being among the groups most exposed to the threats of infection and disease, the study suggests the use of specific, more effective IEC tools to reach out to such sectors, to cater to the special needs of illiterates, lower socio-economic classes and women to ensure higher self-reporting and demand for direct sputum smears.

Jaramillo (2001) presents an evaluation of a media based health education campaign with respect to case finding for TB control in Cali, Colombia. Results showed noticeable increase after the endeavour in the number of direct smears examined, in the number of people being tested with smears and in the notification of positive pulmonary TB cases in Cali. Increasing demand for smear tests is one way to achieve an increase in diagnostic coverage which is an objective of TB control programs across the globe. This piece of research highlights that complete reliance on passive case finding driven by public health institutions is insufficient to reach targets for diagnostic coverage – providing certain basic information regarding early symptoms of TB, costs, diagnostic and treatment facilities through mass media can strongly influence health- seeking behaviour and enable people to demand direct smears thereby increasing case finding and strengthening the effect of control programs.

According to Rubel and Garro (1992), the twin problems of delay in seeking TB treatment and treatment drop-out are a result of complex factors like people's confusion regarding implication of symptoms, time and monetary costs of accessing health facilities, social stigma, uncertainty regarding curability despite medication, etc. Socio-cultural factors in connection to TB have not received adequate attention in the drive to control this disease. Salient among those factors is the health culture of the patients, that is the understanding and information people have from family, friends and neighbours as to the nature of a health problem, its

causes and implications. It is of particular importance to determine the extent to which patients' comprehension of their health condition is influenced by the education and attitude they receive from clinical staff members.

Dodor, Neal and Kelly (2008) have explored the attitude, behaviour and understanding of TB by communities in a district in the western region of Ghana, Africa. In-depth interviews with respondents revealed that primarily fear of infection gave rise to negative attitudes towards TB leading to imposition of socio-physical distance and participatory restrictions on patients. Stigma in fact led individuals with obvious symptoms of TB to attribute it to other non-stigmatizing conditions or conceal diagnosis from others as well as default on treatment. The study indicated that TB related stigma, ingrained in most developing societies, including Ghana, was a major setback to the success of the National Tuberculosis Control Program (NTCP) globally, in particular with regards to case finding and adherence to treatment.

Kelly (1999) highlights the inadequacy of an entirely disease-specific focus on TB control without simultaneously understanding the broader family, community and social context of occurrence of the illness. Interviewed patients perceived themselves as transmitter of disease and on diagnosis becoming public, most of them suffered shunning and hostile behaviour from friends and family, to which they reacted by isolating themselves, becoming secretive about their illness and even abandoning treatment midway. Awareness about symptoms of the disease, its path of transmission etc. and freedom from stigma are crucial factors determining health seeking behaviour on the part of patients.

Courtwright and Turner (2010) have reviewed available literature on ÒÂ stigma to identify the causes of stigma surrounding the disease and to assess the impact of the same on diagnosis and treatment of TB. Most authors have identified the contagiousness of tuberculosis as a leading cause of stigma. Even among people with relatively good knowledge of TB transmissibility, the perceived risk of transmission can lead to isolation of individuals with TB. Among other factors fuelling stigma are the perceived associations of TB with malnutrition, poverty, low socio-economic class, HIV and TB co-infection, etc. Several authors have also tried to capture the prevalence of perceived, internalized and actually experienced

TB related stigma and compare its extent in different geographic regions. Concern about suffering the consequences of stigma prevent at-risk individuals from undergoing TB screening and seeking medical assistance after surfacing of symptoms. Even after start of treatment, fear of revelation of positive TB status may result in treatment drop-outs. Some interventions in the form of TB clubs and other awareness-raising initiatives have been shown to decrease TB stigma and improve treatment adherence.

Findings and discussion

Available literature at large as well as pertaining to the case of India succinctly supports the adoption of a wider and more holistic view towards TB, involving an understanding of the broader socio-economic and cultural context of occurrence of the disease, rather than a conservative, purely medical outlook. Poverty in general is recognized as a major barrier to health and health care and the links between poverty and disease burden have been well documented over the years in case of TB. Poverty is not only a cause but also a consequence of the disease due to loss of productivity and earnings, associated costs, etc. Crowded living conditions as often presented by refugees and displaced population provide an ideal situation for infection spread. Level of TB among prison population has been observed to be much higher than that among civilians. Late diagnosis, inadequate treatment, overcrowding, poor ventilation and repeated prison transfers encourage easy transmission of TB infection. Gender norms and gender inequality also create barriers to TB services. In case of women who are affected by TB in their economically and reproductively active years, the impact of the disease is strongly felt by their children and families. Women may have less access to TB treatment and prevention services than men due to unwillingness among male members of the family who do not consider women's health to be as important. Again, men might be more vulnerable to TB due to gender-specific occupations like mining or blasting, with exposure to particulates. They may be more likely to migrate for work, which can both increase spread of infection and cause interruptions in treatment. Men may also smoke or use drugs more in some societies, both independent risk factors for TB. Such documentations and observations do call for

other social considerations beyond the narrow, clinical aspect of TB for a more exhaustive understanding of the causes of the disease and its consequences on society.

Inadequate knowledge base and misconceptions that build around this largely communicable disease and encourage stigma, assume an important role in partially negating efforts at national and international levels to curb the incidence of TB and cure the disease in the affected population. Stigma constitutes negative attitude towards personal characteristics or circumstances that are not in sync with the norm. Concern about suffering the consequences of stigma and fear of isolation from society may compel individuals with TB symptoms to keep their health condition secret, avoid diagnosis and even practise non-compliance to treatment, thereby exposing the community to threats of new and more resistant strains of the bacterium like MDR and extensively drug resistant (XDR) TB. Stigma, which is moulded and disseminated by institutional and community norms and interpersonal attitudes, is a social determinant of health. Perception of self as a transmitter of disease may lead patients to conceal or not avail themselves of diagnosis and even to attribute their illness to other non-stigmatizing conditions. It is more often than not fuelled by incomplete and incorrect information as well as misconceptions particularly in relation to the path of transmission of infection, uncertainty about curability of the disease, etc. Persistence of lack of awareness and thus negative attitudes towards TB cause individuals with symptoms to go without diagnosis despite availability of adequate diagnostic facilities, resulting in a significant number of undetected TB cases. This helps the disease to perpetuate, by accommodating undiagnosed, infected individuals as well as treatment non-compliant or defaulter patients in the system. Among other factors feeding stigma are the perceived associations of TB with malnutrition, poverty, low socioeconomic class, HIV and TB co-infection, etc. The issue of stigma that has crippling social consequences can however be taken care of by undertaking general awareness enhancement campaigns and devising methods of reaching out to the people, particularly the vulnerable strata of the population, with effective information relating to TB, like its correct mode of spread, symptoms, availability of concerned health facilities, treatment specifications, curability, etc. Attempts to make the general

population correctly aware about the disease through health-education endeavors and/or accepted forms of media have huge potential to generate prompt health-seeking on the part of individuals. Targeting forms of media that are more popular among sections of the population can be a particularly effective means for spread of awareness and knowledge relating to TB. A more aware and knowledgeable community can shake off stigma, be less hesitant in coming out with TB in the open and take advantage of available specific medical facilities.

Conclusion

Despite a comprehensive national TB control program in place in India for quite some time, which now guides the states regarding implementation of TB diagnosis and treatment, the country accounts for a quarter of the world's annual incidence of TB. It is therefore clear that although TB is a medical condition *per se*, the larger socio-economic and cultural context of occurrence of the disease should be an equally poignant consideration as far as addressing and elimination of this global health menace is concerned. In a developing country like India, the broader scenario constituting mass poverty, malnutrition, ill health, poor and unhygienic living conditions, displacement and marginalization of population groups, illiteracy, glaring social stratification, unequal access to health care, lack of awareness, misconceptions and irrational beliefs, strong social stigma etc. provide the most fertile environment for breeding of the TB infection and its perpetuation, often in more drug resistant and virulent strains.

Every sputum-positive case has the potential to infect 10-15 individuals in a year; therefore, there is need to make the population aware of the correct route of TB transmission, symptoms, importance of diagnostic promptness and adherence to treatment. Awareness about the path of transmission of the disease (TB infection spreads from affected individuals through air when they cough, talk or sneeze without cover) and elimination of misconceptions not only provide primary prevention from infection following cough etiquette but also ensure that people do not nurture stigma, by dispelling myths and baseless fears about the disease. Success of the tuberculosis control program in India relies heavily on passive case detection and self-reporting by

patients to the health facility. However, this largely remains as only a supply-side response to the medical havoc. Lack of knowledge and association of negative attitudes like embarrassment, isolation, self-identification as a disease transmitter, etc. with TB continue to act as deterrents to timely health-seeking and treatment adherence. Reduction in stigma can potentially increase the demand for smears for stimulating, for which effective measures need to be undertaken in the form of awareness enhancement, convincing patients about curability of the disease, etc. With such demand issues remaining grossly unaddressed, effectiveness of TB control program in India is always under cloud. Failure of efforts at curbing the disease hints at the clear inadequacy of an entirely "diagnosis and treatment'' based focus on the tubercular pandemic. TB is essentially a public health issue. Singular focus on treatment of reported cases leaves out many diseased individuals who are potential threats to community health but have not been medically diagnosed because they did not seek medical assistance by self-reporting due to fear of loss of livelihood and TB related stigma.

It is thus crucial to look beyond the eye-catching ''detection and cure rates'' as TB control programs most often tend to focus on, India being no exception. Treating the TB pandemic as merely a medical phenomenon without identifying the nexus of larger socio-economic and socio-cultural elements at play that feed the infection, appears to be a gross underestimation of the gravity of this health menace. This calls for addressing the deeper issues to arrest problems of underreporting and treatment default which cause perpetuation of the TB infection, mostly in more evolved and drug resistant strains. Lack of awareness and acute social stigma often result in violation of basic human rights curbing liberty, privacy, right to appear in public, etc. of the affected individuals. Stigma and the resulting discrimination can be devastating for patients and households as they may cause the affected to refrain from diagnosis and treatment, which is clearly a violation of the right of all to be benefitted from the highest attainable standards of available health care services. The IEC wing of the public health program relating to TB in India, which is responsible for generating community awareness, should be more consciously directed to information dissipation and delivery of TB related messages via alternative forms of media. Socio-economic

vulnerabilities like poverty, low and semi literacy levels, etc. pose further challenge to ensuring the effectiveness of awareness raising and stigma reducing efforts of such campaigns whereas the poor and disadvantaged sections of population happen to be among the most susceptible groups for TB. There is thus need for health program managers to explore and design more effective tools to reach out to such sectors with special needs, apart from meeting the information requirements of the public at large. Door to door campaigns to raise the general level of knowledge and awareness about TB and convince patients about its curability conditional on disciplined medication might improve the situation in India to a great extent.

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