TUBERCULOSIS IN INDIA:
EXPLORING FROM CAPABILITY PROSPECTIVE

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ABSTRACT

This paper explores the Tuberculosis control programmes after independence and the emergence of RNCTP with combined strategies i.e. direct engagement of civil society with public health care approach. In early1990s, it is not only national but international factors too played crucial role in changing discourse of Health policy and programmes. However, number of scholars has argued that there has been weakening of public health care accompanied with privatization of services have further deteriorated the condition thereby to locate it in wider socio-economic structure. In addition taking Sen's idea of 'capability' in which the realization of freedom of human being, to great extent, depends on the way state delivers services and people having ability to participate in decision making of what affect their life directly. By locating this paper in the political economy realm of health care system, it argues that unless deprivation is not tackled as multi-dimensional ways, which automatically takes account of strong Public Health Care System and effective way to control TB, there would be lesser chance of coming out of deprivation by using secondary data.

Keywords: Public health care system, tuberculosis control, deprivation, and capability

1. INTRODUCTION

Tuberculosis is an infectious disease caused by Mycobacterium tuberculosis and rarely by other organisms of the "tuberculosis Complex". Tuberculosis is most commonly transmitted by inhalation of infected droplet "nuclei" which are discharged in the air when a patient with untreated sputum positive TB coughs or sneezes. If the bacillus succeeds in infecting a person, only about 5%-10% of such infected persons (primary infection) develop active diseases. In the remaining 90%-95% of infected persons, initial infection usually goes unnoticed. Tuberculin sensitivity appears within a few weeks of infection and initial lesions commonly heal leaving no residual changes except occasional pulmonary or tracheo-bronchial lymph node classifications. Infection occurs almost exclusively through the respiratory route. The infection may then spread from the primary lung lesions to any part of the body via the blood stream, lymphatic and bronchial systems. However, patients with
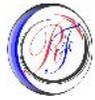
extra-pulmonary Tuberculosis hardly ever spread the disease to others. If untreated, TB leads to deaths within 2-3 years in at least half the patients.

The case of TB in India as well as on global level shows gloomy picture of uneven development, poverty, inequality and unjustness in society at large. For instance, one third of the global population is estimated to be infected with Tuberculosis bacillus. The annual incidence of new cases of all forms of TB (pulmonary and Extra-pulmonary) worldwide is estimated to be approximately 8.6 million of which about 95% occur in developing countries. Globally, it is estimated that 1.8 million people die from TB each year. The majority of them are in developing countries. (WHO Report, 2008)

Tuberculosis remains a major public health problem in India. About 40% of the population in India is estimated to be infected with TB bacillua, and India account for nearly one third of the global burden of tuberculosis. This continued burden of disease is particularly tragic because TB is nearly fully curable. Besides, control of TB with multi drug regime has been cited as one of the five highly cost-effective interventions (World Bank 1993). Drug resistance in sputum-positive patients treated with short-course chemotherapy has been shown to be low (2.1%) in India (TRC, ICMR 2001). Untreated patients can infect 10-15 patients every year. Poorly treated patients develop drug-resistant and potentially incurable TB which is known as multi-drug resistance (or MDR).

Low-income people are at higher risk of getting TB as it spreads in crowded places as households, school, workplace, marketplace, and spread among them. TB kills more women in India than any other infectious disease and causes more deaths among women than all cases of maternal mortality combined. Moreover, women with TB are stigmatized as more than 100,000 women are rejected by their families each year because of TB. The disease has also an adverse impact on children. It leads to a large number of children orphans. Every year 300,000 children leave school on account of their parents TB (GOI, 2004b).

The 1955-58 survey conducted by the Indian Council of Medical Research demonstrated a high prevalence of TB in India at 400/100,000. Annual rate of tuberculosis infection (ARTI) studies, conducted in 2002-03, showed an ARTI of 1.5% at the national level (1.9% in the North Zone, 1.6% in the West Zone, 1.3% in the East Zone and 1.0% in the South Zone), only a marginal decline from the 1.7% reported in earlier studies (GOI, 2005).

According to NFHS-2 survey, the overall prevalence of tuberculosis in India is 544 per 100,000 populations. This is 16% higher than the prevalence recorded in NFHS-1 (467 per 100,000) indicating that tuberculosis may be rise in India. The prevalence of tuberculosis is much higher in rural areas (600 per 100,000) than in urban areas (390 per 100,000). The prevalence rate is much higher for females (624 per 100,000) than for females (460 per 100,000).The sex differential in the prevalence of tuberculosis is about the same in urban and rural areas. The prevalence of tuberculosis increases rapidly with age. It is substantially higher among persons age 60 and above (1,374 per 100,000) than among those age 15-59 (675 per 100,000) or age 0-14 years (153 per 100,000) (NFHS-2).

Although it would be crude to estimates the loss of human life by TB in term of mere productive angles because it is avoidable if being treated. But, as is mention TB still causes more than million deaths in single year and imposes an enormous social and economic burden on the people. It affects all age group but has its greatest impact on productive adults.

In India, tuberculosis kills more adults in the most productive age group (15-54 years) than any other infectious disease (Table 1). On an average 3-4 months of work time are lost if an adult has TB , resulting in the loss of 20%-30% of annual household income(GOI,2004b). Almost 0.37 million people die every year. The disruption caused to society and economy is enormous. A patient of tuberculosis takes an average of three to four months to recover, losing that much income. The loss is unfortunate for those struggling against poverty and under-development. The direct cost of the disease in India is estimated at US $ 300 Million, and indirect cost is US $ 3billion (See Table 1 GOI, 2006).

Table 1
Percentage of new Smear positive cases in different age-groups (2005)

Age group(years)	Percentage
0-14	1.85
15-24	21.18
25-34	23.65
35-44	20.75
45-54	16.09
55-64	10.53
65+	5.91

Source: Government of India, 2006

Every year, TB costs India more than RS 13,000 crore. In addition, every year, TB patient spent more than RS 645 crore in seeking private care for TB. It has been estimated that if the GOI spent even US $200 Million (RS 900 crore) per year on effective implementation of Directly Observed Treatment, Short Course, the tangible benefit to the Indian economy would be worth at least US $ 750 million per year (RS 3375 crore) (WHO, 2004).Given the causes of the TB and its prevalent among most deprived people, it is important to conceptualize the health care in general and TB in particular in the realm of broader political and social arrangement under which individual freedom is realized(or restrained).

1.1.   Conceptualizing TB control strategy in "Capability approach"

As is earlier mentioned that one of the major cause of TB is low level of immunity (what, indeed, depends on nutrition and adequate food) and bad living condition. Hence, the cases of TB are closely linked with socio-economic condition of person which manifests in multiple deprivations, what Sen would call it.

The idea of capability –the ability to do things for what she has reason to value – is based on expansion of freedom; indeed the whole aim of development is the well-being of individuals .As Sen writes "freedom is taken as involving both the process as well as the actual opportunities people have, given their personal and social circumstances. Here the process means to have freedom of action and decision (p.17)".Further, he goes on and argues that lack of freedom can arise either through inadequate processes (such as violation of voting privilege or other political or civil rights) or through inadequate opportunities that some people have for achieving what they would, minimally, like to achieve (including the absence of such elementary opportunities as capability to escape premature mortality or preventable morbidity) (P.17).It is worth noting here that being healthy and avoiding premature death is

one of the fundamental component in Sen's capability approach because human life is end in itself which goes contrary to popular normative belief that human life is means to achieve certain other ends. However, Sen distinguishes five types of instrumental freedoms that directly or indirectly contribute to the overall freedom people have to live the way they would like to live (P.40).

2. Tuberculosis control in India

2.1. Monitoring and Evaluation of National Tuberculosis Programme

The expert committee formed by the ICMR in the year 1975 and from time to time, the expert of Swedish International Development Agency (SIDA) evaluated the programme on TB since beginning. The main purpose of these organizations was to evaluate the functioning of the programme. Studies have indicated that there is no clear evidence of substantial change in the prevalence of infection. It was felt that that the programme did not function as efficiently as expected.

It was evident that because of the poor state of general health services, the National Tuberculosis Programme had to suffer from most severe neglect. There could be a number of reasons for this, of which two are mentioned here. Firstly, massive "vertical" or targeted programme like malaria, family planning, mass immunization have overshadowed socially sensitive National Tuberculosis Programme (Banerji, 1995). Majority of health workers and managers of health delivery systems were found to be insensitive towards National Tuberculosis Programme and obsessed with targets of the vertical programmes, as their efficiency was determined by the fulfillment of targets laid down for the vertical programmes. Later on, the emergence of new diseases like HIV/AIDS has reinforced to move toward comprehensive programme, which would discuss in very shortly.

Therefore the reason could be given the sheer insensitive attitude and neglect of interest of people, particularly towards the poor, by the political leaders. Lack of political commitment and of public health competence contributes to the deteriorating state of government health services in India. To a large extent, therefore, the responsibility for proper functioning of National Tuberculosis Programme lies on the political leadership. The problem in the implementation of the National Tuberculosis Programme may be solved by reversing the negative trend that have crept into the health services of the country (D. Banerji, 97).

Despite the existence of the NTP, there was little impact on the TB burden till 1992. A combined review of the programme in 1992 concluded that the NTP could not achieve the objectives because of low priority, managerial weakness, over dependence on X-rays for diagnosis and inadequate funding. Apart from this, joint review of TB control activities indicated that despite the existence of a national programme, TB patients were not accurately diagnosed, and most patients did not complete treatment (GOI, 2005).

2.2. Emergence of RNTCP

On the recommendation of an expert committee, a revised strategy to control TB was pilot-tested in 1993 in a population of 2.35 million and thereafter increased in phased manner. A full-fledged programme was started in 1997 and rapidly expanded with excellent results.
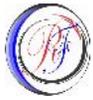
This Revised National Tuberculosis Control Programme (RNTCP) uses the DOTS (Directly Observed Treatment, Short-Course Chemotherapy) strategy, which based on results of tuberculosis research done in India. Indeed this is major turn in the case of TB control in India come while there was opening up of global economy and more integration of health policies with international institutions, namely WHO and world Bank, it is implemented on almost all so-called developing world(Quadir,1994); which would discuss little later.

It is argued that DOTS is likely to succeed as it puts the responsibility for achieving a cure on health system and not on the patient. This is because since most of tuberculosis patients give up treatment once they start feeling better. But in the DOTS the health system is required to observe that patients take all of their medications, to monitor their progress, ensure all bacilli are gone and the patient is totally cured. It is asserted by WHO that DOTS is one of the most cost-effective health interventions compared to those available for other diseases.

The RNTCP is based on the Directly Observed Treatment, Short-Course (DOTS) Strategy, which is the internationally recommended strategy of choice for TB control. The DOTS strategy has following five components-

1. Sustained political commitment to increase human and financial resources and make TB control a nation-wide activity integral to national health policy.

2. Case detection by sputum microscopy,

3. Standardized short-course Chemotherapy to all cases of TB under proper case-management conditions imply technically sound and socially supportive treatment services.

4. Uninterrupted supply of quality-assured drugs with reliable drug procurement and distribution system.

5. Systematic monitoring and accountability for every patient diagnosed (improved monitoring and supervision using the TB register).

2.3. Civil society involvement in RNTCP

Once a person is diagnosed as having TB by Sputum examination under RNTCP, he/she is put on DOTS. A DOTS provider could be any person living in the village or neighborhood of the patient- a health worker, a teacher, a sarpanch, any other local leader, an anganwadi worker (AWW), and a shopkeeper- who is willing to supervise the administration of drugs to the patient. it is observed that DOTS providers are either volunteers or the AWW.In many instances, TB drugs are not administered under the direct supervision of AWWs; in some cases they give the drugs to the patient on a weekly basis to be taken by him/ her. Occasionally, they give all the drugs to the patients for the total duration all at once. At some places, the post of Senior Treatment Supervisor (STS) and STLS are vacant and supervision is lacking. Occasionally, the AWWs, who were the DOTS providers, came across situations when the patient developed some side-effects due to the ant tuberculosis drugs, and had to take the patient to nearest PHC. In Bangalore, an NGO had even identified household's members as DOTS providers, which was contrary to the guidelines issued under the programme.

By June 2005 the RNTCP had covered more than 1 billion population (more than 90% of the country was covered) (RNTCP Report, 2006). With increasing coverage of areas
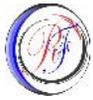
under the RNTCP, the number of deaths due to TB has declined from over 5 lakh to about 4 lakh per year-in registered patients. Further, it has been estimated that if a case detection rate of 70% and cure rate of 85% can be maintained, there would be decline of 6%-12% per annum in the incidence of new cases of TB (GOI, 2005).

However, a critical activity for the success of DOTS is monitoring and supervision to ensure a new case detection rate of at least 70% and a cure rate of 85% mentioned. Many scholars have argued that there is considerable difficulty in case detection as well as strict adherence of DOTs. It is required to ensure that patients who are put on treatment complete the full course. However, the performance under the programme shows that although as a national average the treatment success rates are over 85%, there are variations between states and some districts have cure rates of less than 40%. At the same time, case detection rates are less than 70% in many States/UTs (barring Andhra Pradesh, Chandigarh, Delhi and Sikkim), and this might be an important cause of India's failure to achieve the target of TB control. This evidence emphasizes the need to strengthen Programme monitoring and supervision of implementation at all levels (GOI, 2005).Besides, it also shows that the level of health care arrangement of particular region depends on many other factors like overemphasis on single health care programme over all or lack of staffs in concerned programme. Besides, the case detection has to be increased in order to control TB as early as possible.

3. The conception of case finding can be traced by differentiating active and passive.

3.1. Active verses Passive

Difference between active and passive case finding approaches, and problems with the effectiveness of passive case-finding, have been evident throughout the history of the NTP in India. In the 1960s, the strongly held belief was that "the extension in the work and aim of a clinic must not take place until and unless the clinic or the service is able to deal adequately with patients that report to it with symptoms…".Further,This belief is reflected in WHO's DOTS strategy. From this perspective more damage than good can be done by actively bringing patients into a programme which cannot adequately meet their needs-either for correct diagnosis or for drugs. There it is believed that active case finding leads to over-diagnosis, over-treatment, and therefore wastage and unnecessary burdens being placed on an already over- burdened system (Porter & Ogden1997).

 In essence passive case detection relies on people presenting to health facilities for TB treatment. It pre-supposes a community where people with TB will be educated sufficiently to understand the symptoms of TB and will be able to present for treatment. It also pre-supposes the accessibility and availability of a health care facility providing TB treatment and people with tuberculosis symptoms are autonomous agents. But both of the pre suppose understanding hard to entertain given the fact that many part of the country public health care system is drastically eroded and the considerable size of population is not adequately equipped in term of knowledge about being healthy simply because education among masses is lacking(Dreze & Gazdar 96,pp;33-108).
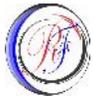
3.2. Access

Over the past decade AIDS research has made important contribution to our understanding of the relationship between illness, infectious disease and social structure. This research has demonstrated that not all people have equal access to health care structure, and that the social meanings ascribed to certain diseases also affect people unequally. In terms of ethics, this means looking at the relative autonomy of people with TB within their community, the balance between beneficence and non-maleficence, the net gain for being enrolled in the DOTS strategy, and finally whether they are treated justly. In short, the opposition to passive case-finding revolves around first, the belief that all people have the right to appropriate treatment and second, and the fear of society's most vulnerable members will not receive treatment unless actively supported by the system.

3.3. Social and cultural burden

In addition to the effect cultural meanings have on treatment –seeking and, therefore, passive case-finding, there is also evidence that broader social cultural factors may also have to role to play, but there seems a lack of study on it. Similarly, there are only a limited number of studies on the actual costs or economic consequences of TB borne by families, communities, and economies in India. Nevertheless it is apparent that not all people are equally able to access health care structure, and it is, implicitly, argued by Sen(2000) ,and poor(or deprived) people has greater problem of accessibility and decision making in what one would think as necessary thing and directly affecting that person life. Nonetheless, importance of diverse set of tools that could enable one to overcome

3.4. Standardized short-course Chemotherapy to all cases of TB under proper case-management conditions imply technically sound and socially supportive treatment services:

The development of short course chemotherapy has been an important breakthrough in tuberculosis treatment. The drugs involved enable patients to obtain cure for their diseases in the less than half the time of standard regimens. But there are involved dangerous with this type of treatment. These drugs may lead to the development of resistant strains of micro bacteria which results into untreatable disease in individuals if not carefully monitored. This has led practitioners and policy makers to require that receiving short course chemotherapy to do so under the direct observation of a trained health care worker; indeed some scholars like (Craig 2007 Harper 2005) have argued that the direct observation is necessary in order avoid the failure of treatment or being defaulted.

On the other hand, the particular control practices inherent in the DOTS strategy, for example, have invited criticism for being unethical because of its strong emphasis on controlling patients' swallowing their drugs through direct observation and argued (Narayan 1999; Ogden 2000) that the discourse of direct observation is one of the domination and control of the health care worker over the patient. It has been argued that the approach fails to respect the independence (or autonomy) of the TB Patients. Perhaps the confusion is steaming from the fact that while those who support controlling strategy see, implicitly, patients as ignorant about their own health and over rely on expert or observer but they are
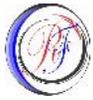
unable to realize that if a person has both sort of knowledge, namely her perceived understanding of own health and medical knowledge generated externally, she would able to determine about her health and would certainly take necessary steps to avoid becoming defaulter. Therefore, the 'care relationship' between patient and providers should be portrayed by a balance between the independence of the TB patients and the beneficence and non-maleficence of the health care worker and should led to net benefit with negligible harm. The relationship becomes coercive, if the health worker attempts to force the patient into a type of treatment which they do not understand or agree with. But the empirical evidence suggest that there is most careless relation between government health care provider and patient generally in India (Banerjii & Duflo, 2011).

Above all, many Scholars including Banerji (1997) and Singh (2002) have criticized the most important point of critics of the programme rests essentially on the fact that in the existing poor state of the general health services, one cannot expect any 'miracle' results from RNTCP. Unless primary health care services and its administration is improved drastically, it is not possible to reduce the suffering of the tuberculosis patients merely by revising the programme. Even now people with symptoms of tuberculosis are found to visit rural health institutions but are being sent back without proper diagnosis and treatment of their disease. That might be due to lack of staffs, high staff absenteeism or poor management of health care service, especially in state like Uttar Pradesh (Draze and Gazadhar, 1995).

However, one of the major players in infectious disease control, there is a debate which centers on conflicting notions about design of programmes-one informed by bio-medical values and the other by socio-political values. The bio-medical values tends to reflect programmes in terms of outcomes, number of cases treated and cures, following standardized procedures and assuming generalization. The socio-political values tend to see TB as a disease of poverty which cannot wait for economic development to change that situation. Thus, it reflects programmes which take account of patients living and working conditions, which are flexible, accessible and try to deal with treatment regimens as well as stigmatizing effects of the disease. Given the socio economic condition interwoven with TB, one may hardly escape the way general health care policy adoption and its practices; more so in the case of diseases like TB.

4. CONCLUSION

Major causes of TB is(or has been) poor living condition, namely malnourishment or living in crowded areas and what has termed as underdeveloped areas have large concentration of TB patient and cases; that is why TB has generally been linked with socio-economic condition of People and manifestation of multiple deprivation ranging from lack of ability to be well-nourished. Hence, it does apparently conceivable that this deprivation, namely TB, can be understood in Sen's idea which argues that freedom is not only an end in itself but an instrument to realize individual capability. Indeed, the instrumental aspect of freedom demands basic education and public health care to be enjoyed by individuals and society at large. In this respect, the role state and its institutional arrangement cannot be underestimated. However, almost all empirical evidence suggests that there has been deteriorating condition of public health care system.
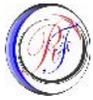
Limited public resources for health have contributed to a weak public health-care infrastructure as low salaries for health staff. Many health positions in rural areas are vacant due to the poor working and living conditions for staff. Frequent transfer of staff at all levels increase straining load and reduces quality. Staff absenteeism and practice in private clinics to increase income are other problem. Besides, Complex bureaucracies also contribute to low morale and inefficient management and supervision. Above all, the programme like family planning gets more attention and energy in health care services, particularly in the underdeveloped area of country; instead of whole health care services. Hence, it is reasonable to argue that there is less likely to control of TB at large scale.

Although the policy to control TB has changed when RNTCP adopted during early 90s in term of greater role of civil society, or early detection of TB cases and strict adherence to the DOTS, but it made the TB control as mere monitoring aspect and bypassed the larger issue of health care service improvement, or linking up with malnourishment or poor living condition. On the detection frontier, the lack of awareness and bad conditioning of public health care causes delay in case detection. Perhaps the strongest reason for lack of awareness is steaming from not having wider reach of education and ability to use information in realizing well-being. Similarly, the adopted strategy of DOTs does strongly have conflict with patient self-autonomy to take medicine; partly such conflict arises because there is complete erosion of 'care relation' between health care staff and patient as we know that the patient of TB has been stigmazed in society. But, it is largely due to the fact that there is an asymmetry between individual perception about own health and newly generated knowledge. Therefore, this conflict can be minimized (or even eliminated altogether) if there is spread of information accompany with masses education.

Overall, it can be argued that the disease like TB never become political commitment on global level as well as in India. Although the global agencies like WHO has influenced the making of RNTCP in helm of weakening state support to health care and so, and the consequence of it is to inability to tackle effectively. The growing inequalities within state and between states has made more perplexed situation. In fact, history has shown that disease control programmes lacking in governmental support are not sustainable. Yet the fact remains that tuberculosis is only one contributor to ill health in India. To combat diseases like TB, there is an urgent need of effective poverty alleviation programme like NREGA, equitable access to health care, improved housing, employment, nutrition etc. for improvement of poor section of our society. Or, taking the TB as multiple deprivation and lack of lack of freedom has to be prioritized in order to achieving TB free society which is fully curable and preventable to great extent. These issues are important than primarily on biomedical treatment. Moreover, if the disease like TB takes as part and parcel of lacking freedom, the improvement of primary health care would be an integral part of policy making as well as implementation.

To sum up, when Gautam, later known as Buddha, left princely home in search of enlightenment more than two thousand years ago, it is said that he was moved by mortality,morbidtiy and suffering of the people; Although the story of Buddha goes in other direction but it is still relevant in our age as to how a society is unable to prevent diseases

like TB which is indeed fully curable; perhaps, it can happen due to the silencing of these health problem in public discussion joined with paramount inaction of those in position to act.

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