

**SOCIAL EXCLUSION AND THE REVISED NATIONAL  
TUBERCULOSIS CONTROL PROGRAMME (RNTCP)**

**Developed by**

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## SOCIAL EXCLUSION AND THE RNTCP

### 1. INTRODUCTION

Tuberculosis (TB), sometimes referred to as the *White Plague* is one of the oldest diseases of the human race. Evidence of its history was detected as far back as Egyptian times, where the spines of mummies showed decay due to the disease. Since its discovery, and after going through many stages of trying to understand its causes and cures, science has made advancements in the discovery of the tuberculosis mycobacterium and the development of the BCG vaccine and other therapies for its treatment<sup>1</sup>.

Despite these progresses, however, TB has persisted as one of the leading infectious diseases around the world today, partly due to its neglect as a major public health priority for many decades<sup>2</sup>. Tuberculosis disproportionately affects the poorer and marginalized sections of society, and until recently there has been a lack of political will and commitment by governments to ensure effective treatment for those who are affected<sup>3</sup>.

The last decade and a half witnessed an invigoration of concern and funding towards anti-TB efforts. Driven predominately by the emergence of the HIV/TB co-infection and the rising prevalence of drug-resistance strains, the containment and elimination of Tuberculosis was announced as a global health priority through the United Nations' 6<sup>th</sup> Millennium Development Goal, with the intention to "combat HIV/AIDS, Malaria, and Tuberculosis by 2015"<sup>4</sup>.

Prior to this global commitment to eradicate Tuberculosis, India had introduced the Revised National Tuberculosis Containment Program (RNTCP) in the mid-1990s for the prevention, containment, and cure of TB infections in the country through the utilization of the World Health Organization (WHO) endorsed DOTS strategy. The RNTCP currently works in conjunction with the Stop TB Partnership also to further the goal of worldwide TB elimination by 2015<sup>5</sup>.

The RNTCP's overarching objective is to "achieve and maintain a cure rate of at least 85 percent in new cases, and to achieve and maintain detection of at least 70 percent of sputum positive pulmonary TB patients"<sup>6</sup>. Considered to be vertically-oriented<sup>7</sup>, the RNTCP is characterized to focus more on program targets, without much consideration for the social, psycho-social, cultural, political, and logistical factors that make Tuberculosis endemic in poor populations.

In the case of tuberculosis, the prevalence of the disease and an individual's ability to seek and complete an anti-TB treatment regimen is strongly linked with factors of his/her physical, social, and cultural environment. Disregard or a lack of understanding for these factors on the part of the health system can lead to the voluntary and involuntarily exclusion of individuals from treatment services, especially from the most vulnerable and marginalized sections of society, in lieu of meeting program goals. The action of exclusion and the consequences of inaccessible services can give way to a cycle of poverty at the individual, household, and community level.

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<sup>1</sup> Herzog H. *History of tuberculosis*. Respiration (Herrlisheim) 1998;65: 5-15.

<sup>2</sup> Murray C J L. *Social, economic and operational research on tuberculosis. Recent studies and some priority questions*. Bull Int Union Tuberc Lung Dis 1991; 66(4): 149-156.

<sup>3</sup> T. Rosenberg. "The Scandal of 'poor people's disease' March 29, 2006 The New York Times

<sup>4</sup> Combat HIV/AIDS, Malaria and Other Diseases. MDG Monitor <http://www.mdgmonitor.org/goal6.cfm>

<sup>5</sup> *TB Control India*. Directorate General of Health Services Ministry of Health and Family Welfare <http://www.tbcindia.org/>

<sup>6</sup> *Strategic Vision for the country for TB control up to 2015*. TB Control India. Directorate General of Health Services Ministry of Health and Family Welfare <http://www.tbcindia.org/pdfs/Strategic%20Vision%20for%20the%20country%202005-2015%20%20Final.pdf>

<sup>7</sup> V. Singh, O. Mittal Significance of Foreign Funding in developing health programmes in India - The case study of RNTCP in the overall context of north-south Cooperation. Health Administrator Vol : XV, Numbers : 1-2, pg. 52-60

The aim of this paper is to outline various social and programmatic barriers that can exclude communities from gaining access, utilizing, and completing the RNTCP's DOTS program. The paper is interested to explore the experiences of various sub-groups of the poor section of India's society including Dalits, Adivasis, and Muslims. The paper will do this in a linear fashion by highlighting factors of tuberculosis susceptibility of different groups, experiences in seeking and utilization of treatment services, and challenges associated with treatment adherence. The rationale for this effort is to help highlight the elements of the RNTCP that hinder treatment access, retention, and completion. In the face of an epidemiological emergency through the re-emergence of tuberculosis and multi-drug resistance, it is equally imperative to ensure that the rights and dignity of all people are upheld through the provision of accessible and non-discriminatory health care services.

## 2. THE REVISED NATIONAL TUBERCULOSIS CONTROL PROGRAM

Beginning in the mid-20<sup>th</sup> century, as a response to the overwhelming prevalence and incidence of tuberculosis in India, the National TB Control Program (NTP) was started in 1962 (<http://mohfw.nic.in/kk/95/i9/95i90701.htm>) It was launched on a half-sharing basis between the central and state government, with the objective to detect as many cases as possible and effectively treat them to make them non-infectious<sup>8</sup>. However, the NTP failed to make any significant epidemiological impact due to various shortcomings, which included inadequate ownership of the program by the states, managerial weaknesses, insufficient funding, an over-reliance on x-ray for diagnosis, interrupted drug supply, and low rates of treatment completion<sup>9,10</sup>.

In 1992, in an attempt to revitalize the TB program, the Government of India, along with WHO and SIDA reviewed the NTP and the factors that contributed to its demise<sup>11</sup>. This collaboration recognized the need for a new thrust to TB control activities, and planned for the introduction of the new Revised National TB Control Program<sup>12</sup>. The RNTCP adopted the internationally recommended Directly Observed Treatment Short-course (DOTS) strategy as one of its core strategies, and viewed it as the most systematic and cost-effective approach to revitalize the TB control program in India<sup>13</sup>. The DOTS strategy has the objective of curing at least 85 percent of new smear positive TB patients, and detecting at least 70 percent of such patients. It involves direct observation of the patient by a health care provider to ensure that regular treatment is maintained. The RNTCP was launched as a national program in 1997, in a phased manner, and by 2006, all of India had come under it<sup>14</sup>.

Given the shortcomings of the original NTP, the emphasis of the RNTCP has been to focus on the logistical and administrative aspects to ensure vast availability of treatment services throughout the country, and un-interrupted treatment regimen<sup>15</sup>. In its efforts to expand the availability of tuberculosis treatment services and facilities, by March 2006, the RNTCP was implemented nationwide in 633 districts, covering 1114 million (100%) population with 440 district TB centers<sup>16</sup>. RNTCP established across the country more than 12,000 quality assured designated microscopy centers (DMC) providing sputum microscopy services, each DMC covering roughly a population of 100,000 (50,000 in tribal and difficult areas).

In order to ensure that un-interrupted treatment was provided to patients with Tuberculosis, DOTS was to be provided at the dispensaries. Under the DOTS program, the entire course of anti-TB drugs for individual patients is to be packaged in a 'patient wise box', to simplify drug logistics and to ensure continuity of drug supplies<sup>17</sup>.

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<sup>8</sup> National TB Control Program. Ministry of Health and Family Welfare. <http://mohfw.nic.in/kk/95/i9/95i90701.htm>

<sup>9</sup> National TB Control Program. Ministry of Health and Family Welfare. <http://mohfw.nic.in/kk/95/i9/95i90701.htm>

<sup>10</sup> Nagpaul D R 1997. Editorial - *Evolution of Indian NTP*. Indian Journal of Tuberculosis; 44:59-60

<sup>11</sup> A. Sahni. *TB Management in India: Critical Issues* Health Administrator Vol : XV, Numbers : 1-2, pg. 192 -193

<sup>12</sup> Revised National Tuberculosis Control Programme, Government of India (1997b) Operational Guidelines for Tuberculosis Control. Central TB Division, Directorate General Health Services, New Delhi.

<sup>13</sup> S.P. Agarwal, L.S. Chauhan *Tuberculosis Control in India* Directorate General of Health Services Ministry of Health and Family Welfare New Delhi 2005

<sup>14</sup> Revised National Tuberculosis Control Programme, Government of India (1997b) Operational Guidelines for Tuberculosis Control. Central TB Division, Directorate General Health Services, New Delhi.

<sup>15</sup> Ibid, Sahni.

<sup>16</sup> RNTCP Status Report 2009 Central TB Division Directorate General of Health Services Ministry of Health and Family Welfare Nirman Bhawan, New Delhi <http://www.tbcindia.org>

<sup>17</sup> Tuberculosis. Communicable Diseases and Disease Surveillance. Country Office for India, World Health Organization <http://www.whoindia.org/en/Section3/Section123.htm>

Since its inception, the program boasts treatment initiation of more than 7.9 million patients and a treatment success rate of more than 85 percent among new TB cases. In 2008 alone, the program claims that it has treated about 10 million TB patients, with over 1.5 million registered for treatment. The same year it achieved a treatment success rate of over 86% in new smear positive cases and a case detection rate of 72%<sup>18</sup>.

### 3. BURDEN OF TUBERCULOSIS DISEASE

Despite the efforts made and the progress claimed by the RNTCP, the burden of the tuberculosis disease continues to overwhelm individuals and communities. In regards to India, according to the WHO's Global TB Report 2009, the country ranks first among the 22 high-burden TB countries worldwide with the highest *number* of TB cases annually. In 2007, it was reported that there were 331,000 deaths and approximately 1.96 million new TB cases, which represented more than 21 percent of all TB cases worldwide<sup>19</sup>. The prevalence of Tuberculosis in 2000 was quoted as 3.8 million cases, with 1.7 million new smear positive cases<sup>20</sup>.

At the macro level, tuberculosis is second only to HIV as the leading infectious killer of adults worldwide. It accounts for more deaths among women than all other causes of maternal mortality combined. In 2007 it was reported that the number of new cases of tuberculosis per capita appeared to have reduced since 2003 in various regions, where the WHO's strategy to reduce TB was implemented<sup>21</sup>. While the incidence of tuberculosis is stable or reducing in many parts of the world, the global rates of new infections continue to rise in many endemic areas where TB goes hand-in-hand with the effects of poverty.

Some level of uncertainty should be assumed with these reported figures, as the true prevalence of the disease is not known. Various factors that include poor data collection mechanisms, absence of a reporting culture, the lack of consensus on the measurement and estimation of prevalence, and the simple fact that not everyone with tuberculosis seeks treatment from the RNTCP all contribute to this uncertainty<sup>22</sup>. Given this dearth of reliable data on the spread and distribution of the tuberculosis disease it is challenging to understand its epidemiology, which can hinder effective planning for prevention and treatment services for the diverse needs of India's large population.

### 4. CONSEQUENCES OF THE TUBERCULOSIS DISEASE

At the individual level, tuberculosis has the ability to hinder the physical, social, and economic well-being. Many *Quality of Life*<sup>23 24 25</sup> studies which have been conducted to understand the impact of TB on an individual and the broader sense of well-being show that the disease negatively affects an individual's perception of his/her own health in various domains, including physical, mental, psycho-social, and economic well-being.

#### 4.1 Physical

Poverty, characterized by poor health, compromised immunity, exposure to unhygienic conditions, and inadequate nutritional intake, can increase one's susceptibility to the tuberculosis disease. Once acquired, the physical effects of tuberculosis can have a debilitating impact through its affect on the lungs, loss of appetite, weakness and weight-loss. The manifestation of the disease can significantly hinder an individual's physical capacity to engage in routine activities, including those related to livelihood and income generation.

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<sup>18</sup> Tuberculosis. Communicable Diseases and Disease Surveillance. Country Office for India, World Health Organization <http://www.whoindia.org/en/Section3/Section123.htm>

<sup>19</sup> WHO Report 2009 *Global Tuberculosis Control Epidemiology, Strategy, Financing* [http://www.who.int/tb/publications/global\\_report/2009/pdf/full\\_report.pdf](http://www.who.int/tb/publications/global_report/2009/pdf/full_report.pdf)

<sup>20</sup> *Key Facts and Concepts About Tuberculosis*. Central TB Division, Directorate General Health Services, New Delhi [www.tbcindia.org/pdfs/KeyFactsandConcepts.ppt](http://www.tbcindia.org/pdfs/KeyFactsandConcepts.ppt)

<sup>21</sup> WHO Report 2008 *Global Tuberculosis Control Epidemiology, Strategy, Financing* [http://www.who.int/tb/publications/global\\_report/2008/pdf/fullreport.pdf](http://www.who.int/tb/publications/global_report/2008/pdf/fullreport.pdf)

<sup>22</sup> C. Dye, S. Scheele, P. Dolin, V. Pathania, M. C. Raviglione, *Global Burden of Tuberculosis Estimated Incidence, Prevalence, and Mortality by Country* WHO Global Surveillance and Monitoring Project

<sup>23</sup> M. Dhuria, N. Sharma, GK Ingle *Impact of Tuberculosis on the Quality of Life* Indian J Community Med > v.33(1); Jan 2008

<sup>24</sup> Dhuria M, Sharma N, Narender Pal Singh, Ram Chander Jiloha, Saha R, Gopal Krishan Ingle *A study of the impact of tuberculosis on the quality of life and the effect after treatment with DOTS* Asia Pac J Public Health. 2009 Jul;21(3):312-20

<sup>25</sup> R. Rajeswari, M. Muniyandi, R. Balasubramanian and P.R. Narayanan *Perceptions of tuberculosis patients about their physical, mental and social well-being: a field report from south India* Social Science & Medicine Volume 60, Issue 8, April 2005, Pages 1845-1853

## 4.2 Economic

Tuberculosis sabotages one's ability to work. It often affects individuals between the ages of 20 and 50, which are considered the most economically productive years of one's life<sup>26</sup>. Tuberculosis not only threatens the loss of income and the potential loss of a job, but it also generates indirect expenses associated with treatment for the disease, transportation, fees for the provider, and medicines. The Tuberculosis Research Centre (TRC) in Chennai, which undertook a study to estimate the socio-economic impact of tuberculosis in the country, estimated that TB costs the country more than \$300 million annually in direct costs alone<sup>27</sup>. Out of this amount, more than \$100 million is incurred in the form of debt by patients and their families; and more than 100 million productive workdays are lost annually on account of tuberculosis<sup>28</sup>.

The impact of TB often extends beyond the individual level, and to the dependents of that individual. For instance, when a woman is affected with tuberculosis, the welfare of the children in the household is also impacted<sup>29</sup>. This is seen in a study by Ramachandran, which estimated that more than 3,00,000 children may have left school permanently because of their parents' TB.

## 4.3 Social

While there is a relationship between one's physical and economic well-being in the context of tuberculosis, the issue of stigma plays a pivotal role in the social well-being of an individual with tuberculosis. Despite the continued and wide prevalence of this disease, awareness about its causes, transmission, and curability is very limited. The lack of understanding of TB's curability often leads to shunning or abandonment of the individual, and loss of a support network, which can lead to hiding or denial of the disease and/or delay in seeking treatment, or abandonment of existing treatment regimen<sup>30</sup>.

## 5. PREVALANCE OF TUBERCULOSIS

Understanding the epidemiology of tuberculosis across different regions and sub-populations is a challenge, as accurate data is not readily available. In the 1950s, the Indian Council of Medical Research (ICMR) conducted a large-scale study to estimate the prevalence of tuberculosis nation-wide<sup>31</sup>. Following this, half a decade later in 2000-2003, there was another survey that was conducted to study the prevalence of infection in different regions of the country<sup>32</sup>. Aside from these two macro efforts, other studies have focused on understanding tuberculosis prevalence and annual risk for tuberculosis on a smaller scale. One of the most recent sources of nation-wide TB prevalence is the National Family Health Survey-3 (NFHS), which has made a systematic effort to assess the prevalence of tuberculosis among its surveyed population. The numbers quoted below from the NFHS outline the prevalence of tuberculosis based on the number of people who sought out medical treatment for the disease (medical treatment does not necessarily mean services under the RNTCP).

NFHS shows that the prevalence of TB is higher in rural areas than urban areas. Reports show that 469 out of every 100,000 persons have been medically treated for TB in rural areas as compared to 307 in urban areas<sup>33</sup>. Other studies also support this and show that one third of total TB cases in India are located in urban areas<sup>34</sup>. This regional disparity is sometimes attributed to the lack of clinical facilities and personnel in rural areas for the treatment of

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<sup>26</sup> *Socio-economic impact of tuberculosis on patients and family in India* R. Rajeswari; R. Balasubramanian; M. Muniyandi; S. Geetharamani; X. Thresa; P. Venkatesan *The International Journal of Tuberculosis and Lung Disease*, Volume 3, Number 10, October 1999, pp. 869-877(9)

<sup>27</sup> S. Geetharamani, M. Muniyandi, R. Rajeswari, R. Balasubramanian, X. Theresa and P. Venkatesan *Socio-Economic Impact of Parental Tuberculosis on Children* *Ind. J Tub.*, 2001,48, 91

<sup>28</sup> *Ibid*, Rajeswari

<sup>29</sup> *Ibid*, Geetharamani.

<sup>30</sup> *Ibid*, Ramachandran.

<sup>31</sup> Indian Council of Medical Research. *Tuberculosis in India – A sample survey 1955–58*, Special report series No. 34, ICMR; New Delhi: 1–21.

<sup>32</sup> J. Bhat, V.G. Rao, P.G. Gopi, R. Yadav, N. Selvakumar, B. Tiwari, V. Gadge, M.K. Bhondelay, F. Wares. *Prevalence of pulmonary tuberculosis amongst the tribal population of Madhya Pradesh, central India* *Int J Epidemiol.* 2009 Aug;38(4):1026-32

<sup>33</sup> National Family Health Survey-3 Volume 1 2005-2006 – International Institute for Population Sciences, Deonar Mumbai

<sup>34</sup> D. Nair, A. George, K.T. Chacko *Tuberculosis in Bombay: New Insights from Poor Urban Patients* [Health Policy Plan](#). 1997 Mar;12(1):77-8

tuberculosis<sup>35</sup>. In urban areas and slums, close living quarters, overcrowding, and poor access to clean water and sanitation<sup>36</sup> is the typical environment where the TB infection is said to thrive. Unlike rural areas, however, there is generally a concentration of health facilities in the urban setting.

Apart from a regional differential, the prevalence of TB also varies by gender. It shows that it is higher among men (526/100,000) as compared to women (309/100,000)<sup>37</sup>. Several studies have pointed out that this differential might be due to underreporting by women, and others have suggested the figures are lower because care for women with tuberculosis is sought less frequently and sought much later, as compared to men<sup>38</sup>. The impact of TB on women is more intense with problems of malnutrition, ill health, repeated childbirth, fear, and stigma attached to the disease and the delay in seeking medical care<sup>39</sup>.

From the perspective of age, TB prevalence is said to increase with age as demonstrated by the NFHS where persons over 60 years (998) are twice as likely to suffer as those between 15 and 59 years. According to the given NFHS data, all these differentials that exist between age and sex are more prominent in rural areas over urban areas.

## 6. FACTORS AFFECTING ACCESS, UTILIZATION AND ADHERENCE TO THE RNTCP'S DOTS PROGRAM

TB is a disease that is usually rooted in populations where human rights and dignity are limited, and while anyone can contract tuberculosis the disease is most prevalent among members of populations who are marginalized, discriminated against, and living in poverty<sup>40</sup>. Time has shown that Tuberculosis predominately affects those who are situated in the lower rungs of the socio-economic ladder. Tuberculosis is a disease that exacerbates poverty, which in turn increases the likelihood of contracting the disease<sup>41</sup>

Archbishop Desmond Tutu aptly stated that "TB is the child of poverty, and also its parent and provider"<sup>42</sup>, stating that poverty causes TB, and TB causes poverty.

Some populations are more vulnerable than others to infection and its effects, simply because of the relative levels of poverty and disadvantage that characterize them<sup>43 44</sup>. In this context, the Dalits, Adivasis, and Muslims are considered to have a relatively vulnerable status within the poor strata of society. The following section will address the disease from the point of susceptibility to the point of DOTS treatment acquisition from the perspective of the poor and marginalized. It will address the issues faced by vulnerable populations in the context of the RNTCP, and outline some of the factors that lead their relative vulnerability and potential social exclusion, starting from the point of disease susceptibility to the point of treatment utilization and completion.

The following figure aims to do this in a simplistic and logical fashion. It broadly highlights the three different stages (rectangles) that an individual will go through in the course of seeking treatment from the RNTCP – starting from susceptibility to the disease, to experiences in seeking out DOTS treatment services, to the utilization of the DOTS treatment regimen. The bottom section of the diagram outlines four overarching factors (ovals) that a) influence the each of the three stages and b) the relationships between the stages (solid arrows) throughout the entire

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<sup>35</sup> Rubel AJ Garro LC *Social and Cultural Factors in the Successful Control of TB*. Public Health Reports Pg 626 - 636

<sup>36</sup> S. K. Karn, S. Shikura, H. Harada *Living Environment and Health of Urban Poor A Study in Mumbai* Economic and Political Weekly August 23, 2003 3575-3586

<sup>37</sup> National Family Health Survey-3 Volume 1 2005-2006 – International Institute for Population Sciences, Deonar Mumbai

<sup>38</sup> F. Karim, A. Islam, AMR Chowdhury, E. Johansson and V. K Diwan *Gender differences in delays in diagnosis and treatment of tuberculosis*. Health Policy and Planning 2007 22(5):329-334;

<sup>39</sup> Kaulagekar A, Radkar A. 2006. *Social Status Makes A Difference: Tuberculosis Scenario During National Family Health Survey – 2*. Indian Journal of Tuberculosis. Pg 17-23.

<sup>40</sup> *A Human Rights Approach to Tuberculosis: Guidelines for Social Mobilization*. 2001. The Stop TB Partnership Secretariat. WHO. <http://www.who.int/hhr/information/A%20Human%20Rights%20Approach%20to%20Tuberculosis.pdf>

<sup>41</sup> Ibid, Kaulagekar.

<sup>42</sup> Tuberculosis and Poverty. <http://www.tbalert.org/worldwide/TBandpoverty.php>

<sup>43</sup> J. Ogden; S. Rangan; M. Uplekar; J. Porter; R. Brugha; A. Zwi; D. Nyheim *Shifting the paradigm in tuberculosis control: illustrations from India* The International Journal of Tuberculosis and Lung Disease, Volume 3, Number 10, October 1999 , pp. 855-861

<sup>44</sup> P. Farmer *Social Inequalities and Emerging Infectious Diseases* Vol. 2, No. 4 – October-December 1996 Emerging Infectious Diseases pg. 259-269

process. These overarching factors act independently, as well as in combination with each other in their influence. As indicated by the diagram, not all of these overarching factors are applicable to the each of the stages.

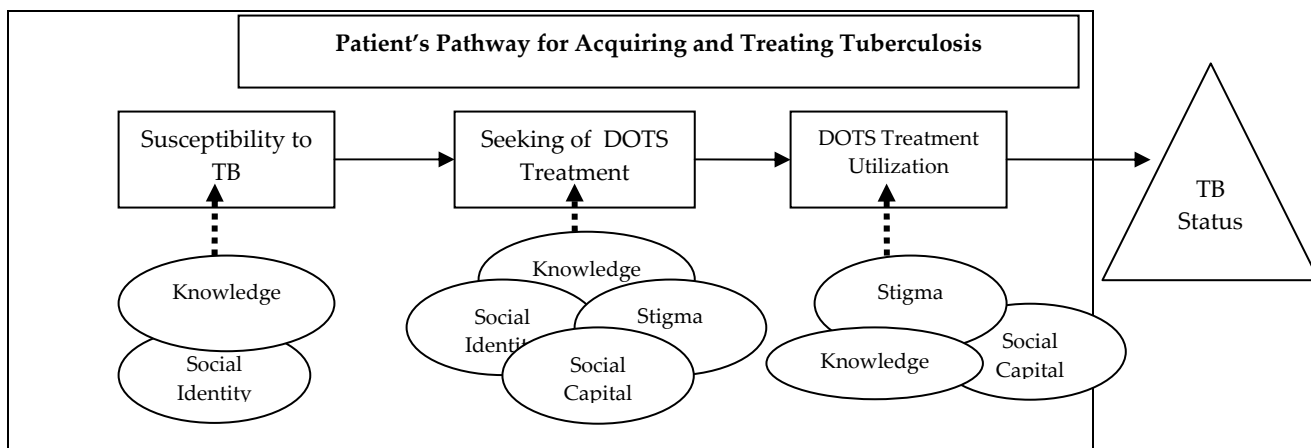


Figure 1: Pathway for Tuberculosis: From Susceptibility to Treatment Outcome

### 6.1. PHASE 1: FACTORS FOR TUBERCULOSIS SUSCEPTIBILITY

Table 1: Factors that affect TB susceptibility

FACTORS THAT AFFECT TB SUCEPTIBILITY	Description
<b>Elements of poverty in the context of TB</b>	
<ul style="list-style-type: none"> <li>Immunity (Nutrition/ Alcohol/Substance Abuse)</li> </ul>	Compromised immunity due to poor nutrition and/or the abuse of drugs/alcohol
<ul style="list-style-type: none"> <li>Type of Job</li> </ul>	Daily-wage physical labor and its impact on weakening an individual's body
<ul style="list-style-type: none"> <li>Living Conditions</li> </ul>	Overcrowded and unhygienic living/working conditions increase susceptibility
<ul style="list-style-type: none"> <li>Region - Urban/Rural</li> </ul>	Prevalence of TB in rural areas and urban slums
<b>Social Identity</b>	
<ul style="list-style-type: none"> <li>Caste</li> <li>Religion</li> </ul>	Caste has been used as a proxy for poverty in many studies in India, especially in the case of Dalits
	Religion in the case of Muslims has been suggested as a proxy for poverty, however, this theory has yet to be established.
FACTORS THAT MODERATE TB SUCEPTIBILITY	Description
<b>Knowledge about disease transmission</b>	Poor knowledge about tuberculosis, its symptoms, causes, transmission, and cure influence the prevalence of tuberculosis
<b>Social Identity (in the context of poverty)</b>	
<ul style="list-style-type: none"> <li>Caste</li> </ul>	Caste determines the severity of the impact of the <i>direct</i> factors on susceptibility (Dalits)
<ul style="list-style-type: none"> <li>Religion</li> </ul>	Religion determines the severity of the impact of the <i>direct</i> factors on susceptibility (Muslims)
<ul style="list-style-type: none"> <li>Gender</li> </ul>	Gender modifies one's risk for acquiring tuberculosis
<ul style="list-style-type: none"> <li>Age</li> </ul>	Age modifies one's risk for acquiring tuberculosis

#### 6.1.1 Factors that affect TB susceptibility

As stated previously, tuberculosis is generally said to make an appearance in circumstances where the individual has a low immunodeficiency status, he/she has poor nutritional intake, works and/or lives in areas where there is poor ventilation, hygiene, and air quality, engages hard physical labor on a regular basis, and engages in the abuse of drugs and alcohol<sup>45 46 47</sup>.

<sup>45</sup> V. Gajalakshmi, R. Peto *Smoking, drinking and incident tuberculosis in rural India: population-based case-control study*. Int J Epidemiol. 2009 Aug;38(4):1018-25.

<sup>46</sup> Ibid, Rajeswari.

<sup>47</sup> P. C. Hopewell, M. Pai *Tuberculosis, Vulnerability, and Access to Quality Care* JAMA. 2005;293:2790-2793.

In addition to these factors, *knowledge* and *social identity* (which in this case includes caste, religion, gender, and age) are also important in their influence in this phase. Social identity has a unique dual role. Firstly, social identity, particularly caste (and possibly religion, in the context of poor Muslims), directly influences the level of an individual's vulnerability to acquire the tuberculosis disease. Caste has been considered broadly as a proxy for socio-economic status and poverty<sup>48 49</sup>, however, the concept of religion as a proxy for poverty, although suggested is yet to be established<sup>50</sup>. Additional factors associated with social identity in the context of tuberculosis, such as gender and age are not primary determinants of susceptibility, but can act in combination with social identity to moderate the level of susceptibility to tuberculosis.

Secondly, social identity also serves as one of two overarching factors in this stage, and where knowledge is the other. This relationship can be illustrated with the following example, where a poor Dalit might be relatively more susceptible to TB, because the Dalit-identity has been associated with some assumption of poverty. Therefore, poverty can be substituted with caste as a risk factor for acquiring tuberculosis. Similarly, if we are speaking of a poor person's susceptibility to TB then we can say that caste might moderate one's susceptibility to TB, and a Dalit identity could affect a person's relative likelihood to acquire tuberculosis.

The population of India according to the Census in 2001 is 1,028 million<sup>51</sup>. The percent of the Indian population that lived in urban areas at the time was 28 percent in 2001. 16 percent of India's population belonged to scheduled castes and 8 percent belonged to scheduled tribes. In terms of religious affiliation, a majority of the Indians, 82 percent, identified as Hindus and approximately 12 percent identified as Islam<sup>52</sup>. The Planning Commission of India, using its own criteria estimated that 27.5 percent of the population was living below the poverty line in 2004-2005<sup>53</sup>. According to the NFHS-3 survey, a caste based breakdown shows that a higher proportion of SCs, STs, and OBCs live in rural areas than in urban areas. Close to 43% of urban households belong to the general caste, as compared to 27% of rural households<sup>54</sup>.

Dalits, who have been persistently discriminated against in Indian society for many years are left in a large state of poverty and marginalization from basic human development resources<sup>55 56</sup>. A large percentage of Dalits reside in the rural parts of India, where, as stated earlier, there is higher prevalence of TB. Dalits are typically engaged in daily wage labor, work as manual scavengers, and are said to have poor health indicators in relation to nutrition<sup>57</sup>. Based on factors such as housing, region, labor, nutrition, and exclusion from public health services, or encounters with poor quality health services, Dalits are very susceptible to acquiring TB.

Muslims are another sub-population in Indian society who has faced a long history of continued discrimination based on their social identity. Poor Muslim communities normally reside in clusters in their communities, which are characterized as ghettos that lack access to basic services like water, schools, and health services<sup>58 59 60</sup>. The culture of Muslim communities lends itself mostly to religious education conducted in community-based schools called madrasahs<sup>61</sup>. Similarly, in the context of health services Muslims are likely to adopt local health traditions,

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<sup>48</sup> Nayar K.R. *Social exclusion, caste & health: A review based on the social determinants framework*. Indian J Med Res 126, October 2007, pp 355-363

<sup>49</sup> Kothari DI, & Krishnamswamy S. (1998). *Poverty, family planning and fertility vis-à-vis Management of family planning services in India. A case study*. Report on seminar. "Poverty fertility and family planning" organized by CIRCED and IISUANAM, Mexico, June 2-4, 1998

<sup>50</sup> R.M. John, R. Mutatkar. *Statewise Estimates of Poverty among Religious Groups in India* Economic and Political Weekly March 26, 2005 1337-1344

<sup>51</sup> Census 2001

<sup>52</sup> Registrar General, 2006a

<sup>53</sup> 2004-2005 - <http://planningcommission.nic.in/reports/genrep/reportsf.htm>

<sup>54</sup> National Family Health Survey-3 Volume 1 2005-2006 - International Institute for Population Sciences, Deonar Mumbai

<sup>55</sup> B.B. Mohanty. *Land Distribution among Scheduled Castes and Tribes* Economic and Political Weekly October 6, 2001 pg 3857-3868

<sup>56</sup> K Sundaram, S. D. Tendulkar *Poverty among Social and Economic Groups in India* in 1990s Economic and Political Weekly December 13, 2003

<sup>57</sup> Ramiah

<sup>58</sup> Sachar Committee 2006; *Social, Economics and Education Status of Muslim Community in India: A Report*. Prime Minister's High Level Committee, Cabinet Secreteriat. Government of India [http://minorityaffairs.gov.in/newsite/sachar/sachar\\_comm.pdf](http://minorityaffairs.gov.in/newsite/sachar/sachar_comm.pdf)

<sup>59</sup> Vithal

<sup>60</sup> Bandhukwala

<sup>61</sup> B. Aleaz, *Madrasa Education, State and Community Consciousness Muslims in West Bengal* Economic and Political Weekly February 5, 2005 pg 555-564



particularly the practice of Unani to address their health needs. The self- and forced- identity-based isolation of poor Muslims in India result in various elements of poverty that influence this group's susceptibility to tuberculosis.

Adivasis, or Scheduled Tribes (STs) are another population who are often marginalized by and from mainstream society. While they have not been discriminated against on the basis of caste, their marginalization is based on ethnicity. The poverty associated with STs has resulted in low levels of education, poor health and reduced access to health care services<sup>62</sup>. Adivasis typically live in areas that are hard to reach and access, and they constitute a large proportion of laborers<sup>63</sup>. They belong to the poorest strata of the society and have severe health problems<sup>64</sup>. They are less likely to afford and get access to healthcare services when required, and their health outcomes are very poor even as compared to the Scheduled Castes<sup>65</sup>. The tribal population is in a transition phase right now from their primitive lifestyle to a modern lifestyle, which has resulted in drastic changes in various aspects of their life including economic activities. This demands the health delivery system to meet the population's changing needs as more people engage in migration and the use of drugs and alcohol, which are both risk factors for TB<sup>66</sup>. A study of TB prevalence based on NFHS-2 data showed that the disease is highest among STs, and almost doubly worse for the women of these STs<sup>67</sup>. The knowledge about TB prevalence of STs at the national level is unknown. Even in the 1955 ICMR tuberculosis prevalence survey ST groups were not included<sup>68</sup>. While comprehensive information on the health of STs, especially in the case of TB prevalence is not readily available, a few studies have been conducted to determine the prevalence and annual risk among Tribals<sup>69</sup>. They show contradictory scenarios where some show that despite the lack of health services and the remote location of STs, the prevalence and annual risk of tuberculosis in this area is no different from the situation of non-tribal populations.

We can consider migrants a sub-group of these various populations, who are faced with their own unique challenges. In this context we consider migrants to be those individuals of the poor socio-economic strata who move away from their native place for the sake of finding better economic opportunities to sustain their livelihood. 14.4 million people migrated within the country with the hopes to find employment and to make money to sustain their livelihood<sup>70</sup>. Poor migrants work as casual laborers as part of the informal sector. This population is at high risk for diseases and faces reduced access to health services<sup>71</sup>. They have the additional factor of being located in an area that is unfamiliar, which leaves them more vulnerable and with less access to even the most minimal services like proper housing, food, water, and sanitation facilities. In addition to these factors that increase vulnerability to acquiring tuberculosis, these populations tend to have worse-off educational outcomes, which could correlate with a decrease in the knowledge about the cause, symptoms and transmission of TB. The study of migrants is still a new and emerging topic, but they are a population that is viewed negatively by many public health professionals in the context of communicable diseases.

### 6.1.2 Knowledge about Tuberculosis and Transmission

The level of knowledge about tuberculosis and its transmission has shown to have a relationship with the level of education of an individual. As education level increases, so does awareness about tuberculosis and its transmission and its curability<sup>72</sup>. One exception to this is that the percent of misconceptions about tuberculosis transmission does not decrease with education level; instead it is randomly distributed across educational strata.

Table 2: Knowledge about TB across caste (NFHS-3)

CASTE	Men who have heard of TB (%)	Men who have knowledge of transmission	Misconception of transmission (%)	Believe it can be cured (%)
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<sup>62</sup> Women's Health, Booklet for National Health Assembly II, Compiled by Sama Resource Group for Women and Health, New Delhi, October 2006

<sup>63</sup> C. Chatterjee, G. Sheoran. *Vulnerable Groups in India* The Center for Enquiry into Health and Allied Themes, Mumbai May 2007

<sup>64</sup> National Family Health Survey-3 Volume 1 2005-2006 - International Institute for Population Sciences, Deonar Mumbai

<sup>65</sup> Ibid, Chatterjee

<sup>66</sup> Ibid, Chatterjee

<sup>67</sup> Ibid, Kaulkegar.

<sup>68</sup> Ibid, Bhat.

<sup>69</sup> Narang, Rajamma *Prevalence of pulmonary tuberculosis amongst the tribal population of Madhya Pradesh, central India & Annual risk of tuberculosis infection among tribal population of central India,*

<sup>70</sup> 2001 census

<sup>71</sup> Ibid, Chatterjee

<sup>72</sup> National Family Health Survey-3 Volume 1 2005-2006 - International Institute for Population Sciences, Deonar Mumbai

SC	91.6	51.3	51.7	85.1
ST	83.0	44.3	50.5	76.9
OBC	91.7	56.4	52.6	85.8
Other	94.4	58.3	50.4	88.0

Across various caste groups, Adivasis/STs consistently rank the lowest in having heard of the disease, having knowledge of its transmission, and believing that there is a cure<sup>73</sup>. These findings are supported by a qualitative study that showed how tribal patients who were affected by TB were not sure of the causes of the disease. For instance, some of the reported causes included excess work, coughing, sharing food, liquor, black gram and the intake of maize<sup>74</sup>. In the case of religion, a comparison of Muslims and Hindus does not give us sufficient insight about the relationship of religion with knowledge about TB and its transmission, as it does not take into account regional, educational, and wealth differences.

**Table 3: Knowledge about TB across religion (NFHS-3)**

RELIGION	Men who have heard of TB (%)	Men who have knowledge of transmission	Misconception of transmission (%)	Believe it can be cured (%)
Hindu	91.6	55.6	51.9	86.1
Muslim	93.7	50.7	51.6	83.9

By looking at the breakdown of religion by caste groups (table not included) in terms of educational attainment, NFHS-3 data shows that Muslim men are less likely than men of most other religions to have ever been to school and to have completed 10 years or more of education. By caste/tribe, educational attainment is lowest among men belonging to the scheduled tribes, followed by men belonging to the scheduled castes, compared with other men who know their caste/tribe status. The proportion of men who have completed at least 12 years of education among men who do not belong to a scheduled caste, scheduled tribe, or other backward class, at 28 percent, is three times the proportion of scheduled tribe men and twice the proportion of scheduled caste men who have this level of education<sup>75</sup>.

In the case of literacy, Muslim women and men, followed by Hindu women and men, are less likely to be literate than women and men of most other religions, although the differentials by religion are much greater for women than for men. Literacy is least among women and men from the scheduled tribes, somewhat higher among women and men from scheduled castes, followed by those who belong to the other backward classes. Those who do not belong to any of these groups have the highest literacy rates.

**Table 4: Knowledge about TB across region, education level, and wealth index (NFHS-3)**

REGION	Men who have heard of TB (%)	Men who have knowledge of transmission	Misconception of transmission (%)	Believe it can be cured (%)
Urban	95.4	63.6	51.1	89.3
Rural	89.7	49.9	51.7	83.6
<b>EDUCATION</b>				
No Education	81.6	37.1	48.9	75.2
<5 years	85.9	42.4	46.6	78.3
5-7	90.3	48.5	48.9	82.8
8-9	94.9	55.3	51.8	86.8
10-11	96.3	62.2	50.9	90.0
12+	98.7	74.0	57.8	95.2
<b>WEALTH</b>				
Lowest	84.6	38.0	52.1	77.0
Second	89.1	44.9	53.1	81.6
Middle	90.2	53.4	51.7	84.3
4 <sup>th</sup>	94.4	59.6	49.0	88.2
Highest	97.7	69.6	52.0	92.7

<sup>73</sup> National Family Health Survey-3 Volume 1 2005-2006 - International Institute for Population Sciences, Deonar Mumbai

<sup>74</sup> *Social Assessment Study for RNTCP*. Central TB Division. Ministry of Health and Family Welfare

<http://www.tbcindia.org/pdfs/Social%20Assessment%20Study%20for%20RNTCP%20-%20Final%20Report%20-%20ORC%20CSR.pdf>

<sup>75</sup> National Family Health Survey-3 Volume 1 2005-2006 - International Institute for Population Sciences, Deonar Mumbai

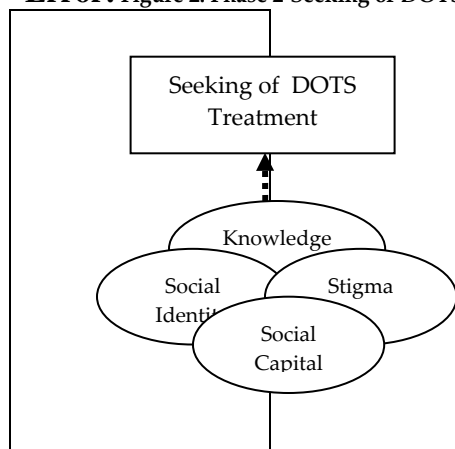
## 6.2 PHASE 2: Seeking RNTCP Treatment

**Table 5: Factors that directly influence seeking of DOTS treatment**

Factors that directly influence seeking of DOTS treatment	Description
<b>Individual Factors</b>	
<ul style="list-style-type: none"> <li>Lack of time due to busy schedule</li> </ul>	Work and household responsibilities can be a limiting factor in getting testing and treatment for
<ul style="list-style-type: none"> <li>Need for instant relief/ disease vs. symptom</li> </ul>	Need for instant relief that can enable one's ability to continue with routine tasks and work is prioritized over long-term disease treatment
<b>Availability of Services</b>	
<ul style="list-style-type: none"> <li>Preference for local provider</li> </ul>	Local private provider and private hospitals are generally preferred over public health services
<ul style="list-style-type: none"> <li>Lack of time off, distance of facility, lack of money for transport</li> </ul>	Sometimes the unavailability of RNTCP services (in one place) makes it a less appealing option for treatment
<ul style="list-style-type: none"> <li>Health Visitor</li> </ul>	The role of the health visitor is an important determinant of whether a person is able to enroll for DOTS treatment.
<b>Factors that moderate susceptibility to TB</b>	
<b>Knowledge</b>	
<ul style="list-style-type: none"> <li>Knowledge about disease, cure, and services</li> </ul>	A lack of knowledge about the disease and its symptoms, whether there is a cure and where to seek services all result in a delay in treatment for tuberculosis.
<b>Stigma</b>	
<ul style="list-style-type: none"> <li>Afraid to seek treatment for fear of rejection/ostracization</li> </ul>	Identification and acknowledgement of one's own disease status could lead to rejection from the household and community. These could lead to a delay or avoidance of seeking services
<b>Social Capital</b>	
<ul style="list-style-type: none"> <li>Lack of social support in helping to go seek out treatment</li> </ul>	Social support is an important factor that can determine whether one is able to seek treatment. This also takes place in the form of permission - whether those of lower social standing within the family are given the endorsement to see services.
<b>Social Identity</b>	
	Factors of caste, religion, and gender influence one's ability to seek and acquire RNTCP health services

The impact of delaying treatment for tuberculosis can have damaging consequences on an individual. It can lead to permanent lung damage, and also affect other parts of the body including the central nervous system, brain, circulatory system, and lymphatic system. When it goes undiagnosed and untreated its impacts can be potentially fatal and lead to death. Untreated pulmonary TB leads to death in 60 to 70 percent of cases<sup>76</sup>. Delay in treatment can also promote the transmission of tuberculosis to others. The pathway for seeking DOTS treatment from the RNTCP is circuitous and depicted by many barriers.

**Error! Figure 2: Phase 2-Seeking of DOTS treatment**



<sup>76</sup> 1993 World Development Report published by World Bank, quoted in Borgdorff et al (2001) pg 30

## 6.2.1 Factors that directly influence the seeking of DOTS

At the point that an individual begins to experience symptoms of the disease he/she will either a) seek care for the symptoms of tuberculosis, which include persistent coughing and fatigue, or b) will seek treatment for the disease itself. Evidence shows that the former is more likely<sup>77</sup>. Many studies have shown that people living in poverty, who rely on daily wage labor for their livelihood often seek out instant relief for their symptoms. The daily demands in the lives of the poor determine how much time and money they can invest into their own health.

While many members of the groups in question engage in daily-wage jobs it presents them with a huge limitation to be able to take time off from work to go out to seek medical services. These limitations often affect the decision of many people to seek care for the symptoms of TB, rather than for the disease itself, and to seek services from a provider that is locally accessible and familiar.

The private medical sector remains the primary source of health care for the majority of households in both urban areas at 70% and rural areas at 63 %. Households in the lowest three wealth quintiles rely on the public and private medical sector in about equal proportions. It is among the fourth and particularly the highest wealth quintiles that reliance on the public sector declines and reliance on the private sector increases<sup>78</sup>.

Private practitioners are often preferred due to their easy accessibility and the patient's confidence in the effectiveness of the provider<sup>79</sup>. Even when the condition worsens, people prefer to access private health services, and only use the public health system as a last resort, because they find that public health facilities are inaccessible, although less expensive than private services.

**Table 6: Availability and Access to Tuberculosis Treatment Services**

	Region		Wealth Index				
	Urban	Rural	Lowest	Second	Middle	Fourth	Highest
Public	29.6	36.8	39.4	37.1	39.0	33.9	22.6
Private	69.5	62.5	59.9	62.2	60.4	65.3	76.4

A large scale qualitative study that was conducted in 4 different regions of India on tuberculosis found that for common ailments, slum dwellers and industrial migrants seek treatment from a chemist/any private medical practitioners located in or around their area because of easy accessibility. Migrants utilize government providers only when they did not get cured after visiting private providers. This was also the case for the TB infection where they visited chemists, private dispensaries and private local providers first and then were referred to government hospitals by local private doctors themselves, employers, family members and health workers. Due to this tendency to seek out private and local providers first, patients delayed their treatments by 1 to 5 months in trying other treatments. The study showed that for the most part slum/migrants/industrial workers were aware of government TB hospitals in the town where TB treatment is available<sup>80</sup>.

In the case of the RNTCP service availability, despite the progress put forth by the revised program, a lack of cohesion between the microscopy and treatment centers continues to exist. When an individual approaches a facility, he/she has to undergo a sputum examination and chest X-ray<sup>81 82</sup> due to the lack of equipment to get tested in a given place, however, the patient might be referred elsewhere first for the testing purpose. For instance, a study

<sup>77</sup> Ogden J. 2000 The Resurgence of TB in the Tropics: Improving TB Control – Social Science Inputs. Transactions of the Royal Society of Tropical Medicine and Hygiene 94; 135-140

<sup>78</sup> National Family Health Survey-3 Volume 1 2005-2006 – International Institute for Population Sciences, Deonar Mumbai

<sup>79</sup> S. R. Atre , A. M. Kudale , S. N. Morankar , S. G. Rangan and M. G. Weiss *Cultural concepts of tuberculosis and gender among the general population without tuberculosis in rural Maharashtra*. Tropical Medicine & International Health Volume 9 Issue 11, Pages 1228-1238 Nov 2004

<sup>80</sup> *Social Assessment Study for RNTCP*. Central TB Division. Ministry of Health and Family Welfare  
<http://www.tbcindia.org/pdfs/Social%20Assessment%20Study%20for%20RNTCP%20-%20Final%20Report%20-%20ORG%20CSR.pdf>

<sup>81</sup> Revised National Tuberculosis Control Programme, Government of India (1997b) Operational Guidelines for Tuberculosis Control. Central TB Division, Directorate General Health Services, New Delhi.

<sup>82</sup> V. Singh, A. Jaiswal, J. D. H. Porter, J. A. Ogden, R. Sarin, P. P. Sharma, V. K. Arora & R. C. Jain *TB control, poverty, and vulnerability in Delhi, India* Tropical Medicine & International Health Volume 7 Issue 8, Pages 693 - 700

conducted by IHRM, on accessibility and utilization of TB services from SC/STs found that the average distance traveled for availing diagnosing services was 16kms for testing, and 3km for treatment<sup>83</sup>.

Once an individual access and undergoes testing, positive patients are subsequently classified as 'area' or 'non-area' cases, depending on whether they reside in or outside the clinic coverage area<sup>84</sup>. The DOTS treatment regimens are offered only to 'area' patients, while 'non-area' patients are either sent to their own local chest clinic or offered standard chemotherapy (12–18 month unsupervised regimens)<sup>85</sup>. After the patient is categorized, a Treatment Card and Patient Identity Card are created and the patient is registered with the clinic. At this point, the doctor is supposed to explain the treatment schedule and to refer the patient to the area treatment centre for DOTS<sup>86</sup>. At this point, a TB Health Visitor is supposed to visit the home of the patient, and speak with the patient and his or her family about the importance of the treatment and its completion. In addition, the health visitor is supposed to ensure the verification of address of the diagnosed patient before he/she enrolls into the DOTS program<sup>87</sup>.

Given these requirements, several studies have found a clear division between the practices of the staff employed by the clinic and those designated for the RNTCP work in the clinic. The TB Health Visitor has the final authority to decide the enrolment of the patient, and determine whether they were considered suitable for DOTS. Various studies have revealed that Health Visitors often utilize a pre-determined algorithm that will qualify or disqualify individuals from the DOTS program<sup>88 89 90</sup>. This algorithm helps them identify those individuals who are more likely to be able to complete treatment. Therefore, patients who would anyway comply with TB treatment were subsequently registered under the DOTS system, and those considered least likely to achieve cure, who needed DOTS treatment the most were usually given standard regimen treatment and not followed up consistently<sup>91</sup>.

The patient characteristics that were identified as a hindrance to treatment completion included social marginalization (abandoned or widowed mothers, alcoholics, poor, low caste); low level of integration in the city (new migrants, some women – especially newly married women from the villages who have come to their natal homes because of sickness); absolute poverty; past history of irregular treatment; and wage laboring which require regular trips out of the area. In summary, those denied treatment could be classified as among the poor and socially marginalized, and least likely to be able to afford private sector treatment<sup>92 93</sup>. Additionally, in the first place, some individuals would not be able to qualify as 'area' patients due to a lack of an identity card. Migrants are especially vulnerable to this problem and fall through the crack when needing to access DOTS services.

## 6.2.2 Stigma and Knowledge of the Tuberculosis disease and its Treatment

Aside from the accessibility of health services, knowledge is another factor that can influence the choice of an individual in seeking or not seeking treatment. Knowledge in this context refers to knowledge of the disease, its cure, and about where to seek treatment and that RNTCP offers free and comprehensive treatment services.

In one respect, the lack of knowledge about the disease, which fuels stigma, can lead to the refusal to seek out treatment from the RNTCP. According to the NFHS-3 as education level increases, peoples' desire to keep tuberculosis a secret from their neighbors decreases, from 20.4 percent of men with no education as compared to 13.7 percent of men with more than 12 years of education. This level of secrecy is generally seen across all population subgroups. The lack of understanding about the disease and its curability can dilute the possibility of a social support network for an individual that has tuberculosis. "Many patients had not mentioned to those with whom they had

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<sup>83</sup> *Social Assessment Study for RNTCP*. Central TB Division. Ministry of Health and Family Welfare  
<http://www.tbcindia.org/pdfs/Social%20Assessment%20Study%20for%20RNTCP%20-%20Final%20Report%20-%20ORC%20CSR.pdf>

<sup>84</sup> Ibid, Singh.

<sup>85</sup> Ibid, Singh.

<sup>86</sup> Ibid, Singh.

<sup>87</sup> Revised National Tuberculosis Control Programme, Government of India (1997b) Operational Guidelines for Tuberculosis Control. Central TB Division, Directorate General Health Services, New Delhi.

<sup>88</sup> Ibid, Singh.

<sup>89</sup> Ibid, Chatterjee.

<sup>90</sup> Ogden J. 2000 *The Resurgence of TB in the Tropics: Improving TB Control* – Social Science Inputs. Transactions of the Royal Society of Tropical Medicine and Hygiene 94; 135-140

<sup>91</sup> Ibid, Ogden.

<sup>92</sup> Ibid, Singh.

<sup>93</sup> Tuberculosis in India. <http://www.dantb.org/hypoaalbuminemia.html>

lived the nature of their illness, others curtailed contacts with family and friends, and still others expressed fear that a spouse would discover their illness. One of the most striking features of these interviews was the systematic avoidance by respondents of the term “tuberculosis”<sup>94</sup>.

The consequences of this stigma can lead to expulsion from a job to rejection from the household, and vary between women and men. The illness destroys a woman’s ability to marry, abandoned if she is married due to the fear that it will spread to the children, and blamed for acquiring the disease. In the case of men, they might lose their jobs due to the disease, and might experience some social or self-isolation, however, it has been proven unlikely that a man with tuberculosis will be abandoned by his wife or family, and that the consequences for women are more drastic<sup>95 96</sup>.

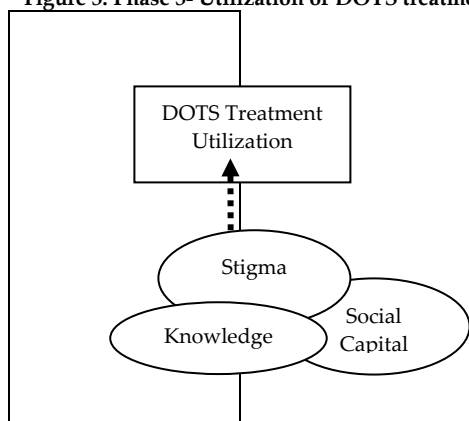
The factor of support is important for an individual to seek out treatment for tuberculosis, however this point correlates directly with that of an individual’s social standing in the household, and his/her ability to seek treatment from the RNTCP. The ability to make decisions for health and utilization of health services is not the same for everyone. Women are often at a disadvantage when they contract tuberculosis due to the lack of autonomy and power to seek services treatment services.

### 6.3 PHASE 3: Adherence to RNTCP Treatment Regimen

**Table 7: Factors that directly influence utilization of DOTS**

Factors that directly influence utilization of DOTS	Description
<b>Logistics</b>	
<ul style="list-style-type: none"> <li>Distance and timing of dots provider</li> </ul>	Whether the DOTS provider is available at a location and time that is convenient and accessible to the patient, without being a hindrance to the individual’s routine responsibilities.
<b>Factors that moderate susceptibility to TB</b>	
<b>Social capital</b>	Support from spouse, family, DOTS provider in adhering to and completing treatment
<b>Knowledge</b>	Knowledge of the importance of treatment and to not stop when feeling better
<b>Stigma</b>	Ostracization against a person with tuberculosis could

**Figure 3: Phase 3- Utilization of DOTS treatment**



Early drop out from an anti-tuberculosis treatment regimen has negative consequences at an individual, community, and population level. The issue of multi-drug resistance TB has come about as a consequence and so has re-incidence of cases that were avoidable. With the increasing prevalence of TB and HIV/ AIDS cases, the need for successful TB treatment utilization and completion has become more of an emergency (TB Alliance, P Farmer). Treatment adherence and completion is one of the key concerns of the RNTCP (RNTCP), however efforts to understand why patients default or drop-out from the treatment has not been understood and addressed to the necessary extent.

<sup>94</sup> Ibid, Rubel.

<sup>95</sup> Ibid, Atre.

<sup>96</sup> M. Uplekar, S. Rangan, J. Ogden. *Gender and Tuberculosis Control: Towards a strategy for research and action*. Draft strategy paper prepared for Communicable Disease Prevention, Control, and Eradication. World Health Organization December 1999

In a study that was conducted to understand why people did not accept treatment in first place it was found that the most important reason given by patients for not accepting treatment under the RNTCP was logistical: they did not feel they could manage to meet the requirement for alternate day attendance at the DOT centre given the competing priorities and demands of their daily lives. It was perceived particularly difficult for those patients engaged in daily wage labor and for children still in school.

In the DOTS program making regular visits is an important component – to ensure that this happens regularly there needs to be a convenience in terms of time and location. Some of the DOTS dispensaries are only open from 9 to 1, which makes it difficult for people with daily wage jobs to go there regularly. One study showed that in some dispensaries people show up in the early hours to take their treatment, and because they all show up at once and to deal with the rush the providers hand out the medicines without actually doing the direct observation part. Additionally, the TB Health Visitor is supposed to monitor the therapy, manages drug reactions and takes ‘defaulter retrieval action’<sup>97</sup>. If a patient fails to appear for DOTS on more than two occasions, the health visitor must go back to the patient’s home and bring him/her in for treatment. This is often seen as a time-consuming and difficult task, particularly in the very low-income ‘slum’ areas in which many patients live. While the RNTCP strategy clearly outlines the role of the provider and the health visitor in informing the patient of the importance of successful adherence and treatment completion, whether this is being done in reality has to be investigated more thoroughly.

Stigma is another factor that can prevent completion of treatment because a person might not want others to know that they are receiving treatment for tuberculosis (NFHS has some data on this). Sometimes this is tied in with social capital, where if a person with TB does not have support and if they feel socially ostracized or isolated they might not complete the treatment.

## 7. DISCUSSION

TB is a product of structural inequity, and those individuals who acquire tuberculosis and have the greatest need for free and comprehensive treatment services have been demonstrated as most often being from the poorest and most marginalized sections of society. It has also been demonstrated that those who face the most difficulty in accessing DOTS treatment and completing the regimen are often always the same group of people who are the most vulnerable to the disease.

Tuberculosis is an issue of growing importance, especially in reference to the barriers to its containment, such as the emergence of HIV/TB co-infection and increasing multi-drug-resistant cases. TB poses a tremendous challenge from an infectious disease and an endemic point of view, however, it is necessary to keep in mind that this disease cannot be sustainably curbed or eradicated by using a strategy that is focused purely on a ‘catch and cure’ approach. Due to its nature and transmission, tuberculosis necessitates a broader approach to be utilized by the RNTCP, one that recognizes and acknowledges that a) some groups are more vulnerable to TB based on characteristics aligned with extreme poverty, b) that RNTCP services (particularly DOTS) cannot be easily accessed by those who need them the most, and c) if/when accessed, tuberculosis treatment adherence and completion is subject to a diverse set of factors that must be faced by the patient.

The RNTCP prioritizes identification of cases and their cure as one of its main objectives to “achieve universal access to quality and patient-centered treatment” (TB PPT), and focuses on the increasing of service availability as one of its key strategies. Beyond outlining the need for basic physical infrastructure, the RNTCP, with help from NGOs and other stakeholders, has identified areas for improvement to address service inaccessibility. One such example is the creation of the PPM. Another example is the program for industrial laborers to help bring tb services closer to the worksite. While these policies exist on paper systematic investigation is needed to understand how it translates into action at the community level.

While this goal of case identification and cure sounds logical and straightforward, the vertical nature of the RNTCP characterized by its structuring, funding, and disease-centric focuses can promote a narrow approach to tuberculosis control which not only ignores components critical to TB utilization and completion, but can also slow down attainment of TB containment and eradication itself. The RNTCP has ambitious goals and a tremendous amount of pressure riding on it. This makes the program very target-driven, and through direct association it puts employees of

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<sup>97</sup> Ogden J. 2000 *The Resurgence of TB in the Tropics: Improving TB Control – Social Science Inputs*. Transactions of the Royal Society of Tropical Medicine and Hygiene 94; 135-140

the program, under pressure to achieve these goals. This causes two problems as we see – the first is that people, the poorest and most marginalized, are getting left out of the program because they are seen as a compromise the program's performance; and secondly it removes focus from the patient's needs and shifts it to the program's needs. This makes the program less patient-centric with a reduced focus on the socio-cultural aspects that are responsible for tuberculosis susceptibility, access to RNTCP services and complete utilization of the treatment. From a disease control point of view, by excluding people from services who need them the most, and the spread of disease is furthered.

As discussed throughout the paper, there are many diverse factors that play out in each stage of acquiring tuberculosis and its treatment which determine one's TB-related health outcome, and ultimately the health of those who share the same space. In order to understand how these factors play out in different settings an understanding of the social and cultural perspective is imperative, especially in the context of tuberculosis susceptibility, treatment access and completion – that the health seeking behavior of different groups of people varies across different stages of the process. The RNTCP must keep in mind that treatment does not take place in a vacuum, and if treatment is successful most patients are being sent back to the same conditions where they contracted the disease. This shows that tuberculosis extends beyond just the RNTCP and has direct correlation with food, living conditions, type of work, access to health services etc. and that with a vertical disease-centered approach it is difficult to touch upon all these other issues.

In the context of marginalized communities, these populations lose out because the policies of the RNTCP operate in a way that is blind to the inequities that exist in Indian society. The program also falsely assumes that those working under the purview of the RNTCP are also completely blind to these inequities. Therefore the program does not factor in additional provisions or conditions that can help create better access to the RNTCP program for these typically marginalized communities. The reality, however, is that inequities do exist and despite what is outlined in its policies, at the point of implementation, different people from different communities are oftentimes on the receiving end of discrimination due to their social identity, or they are discriminated against based on the social conditions, which are a consequence of their social identity. Although discrimination at the level of implementation was not thoroughly discussed in this paper, there is a need to document how social-identity based discrimination at the point of service delivery occurs in the context of the RNTCP.

Based on the data that was found through this paper, some of the following suggestions could help make the program better suited to the needs of the diverse populations. Data pointed out that there is a dearth of knowledge among different sub-groups about the tuberculosis disease, as well as where treatment services can be sought. Whatever the reasons for poor knowledge about TB, it cannot be denied, based on presented data that a lack of knowledge provokes Stigma and loss of Social Capital. Emphasis on increasing awareness of people about the transmission of the disease and its curability could help dilute the stigma and ostracization that one experiences from the disease. It is important to keep in mind however, that knowledge does not always translate into action or behavior change, and if the aim is to increase the number of users at the RNTCP then the availability of services should also be increased. Service availability and knowledge should work hand-in-hand to help fuel action both at the supply and demand side.

The RNTCP's second claim to “reduce human suffering and socio-economic burden associated with TB” needs to be more specifically defined. If the program believes that free treatment is the panacea for human suffering and socio-economic burden associated with tuberculosis, it is sadly mistaken. The program cannot ignore that despite no-cost services, quality of services matters in an individual's decision to seek health care, that this decision is loaded with indirect expenses such as time off from work, transportation, permission to seek care, and social stigma. All these factors influence the physical, mental and social well-being of an individual, and extend well beyond what is currently provided at a DOTS treatment facility.

## **8. CONCLUSION**

The RNTCP has the potential to be an instrument to truly reduce the suffering caused by this debilitating disease. With deeper consideration of its diverse patient base and their respective needs, the program can be better suited to handle its task with an equitable approach. An equity-oriented approach by the RNTCP is necessary for the treatment of TB in India to address the disparities that exist and have existed across different social groups for many generations. There is a great sense of urgency for policy makers and program implementers to not only recognize and understand, but also acknowledge the challenges and barriers to TB treatment services experienced by these



populations. Furthermore, it is necessary to understand that many barriers that exist as a product of deeply embedded social norms and society's opportunity structure, and are beyond the scope of the individual's agency or ability. The time has come for program developers and implementers to take the necessary measures for TB containment by first understanding the intricacies of the circuitous pathway that currently exists for TB services, which excludes many groups of people from accessing necessary care.