

## The Sociological dimension of Tuberculosis: a Case Study

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**Abstract:** The Greeks named it 'phthisis' (meaning to waste); in the Roman times, this condition was referred to as 'tabes' (a near equivalent to phthisis); in the Vedic literature it is called 'sosha' or 'rajayakshma'. Once the English-speaking world developed, the familiar term 'consumption' - derived from the Latin term 'consumere' (meaning to, consume or wear away) - entered the literature. No matter whatever the label, tuberculosis (TB) till date remains the largest, single infectious cause of death in the world, despite the fact that it was almost a half century ago that the first antibiotic, streptomycin, was found to be effective against it. Almost all researches made till now have had a very limited focus, concentrating on tuberculosis as a mere 'medical phenomena'. In the current study an attempt has been made to render visibility to the passive, mute bodies of the patients and those who constitute their significant and generalized others. The focus has been to study the popular social perceptions held about disease.

**Keywords:** Directly Observed Treatment (Short-course), Others, Perceptions, Sosha, Stigma,

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### I. Introduction

Until the industrial revolution, tuberculosis was a much-desired state of death associated with creative genius. 'Spes phthisica' was the term coined by the Greeks to describe the nervous energy that led to special creativity. In a quote, Elizabeth Barrett Browning is said to have cried, "Is it possible that genius is only scrofula?"<sup>2</sup> Peaks of emotional sufferings were dramatically presented in the form of various symptoms associated with it. At the height of the romantic era of the disease, Alexander Dumas wrote, "It was the fashion to suffer from the lungs; everybody was consumptive, poets especially; it was good form to spit blood after each emotion that was at all sensational and to die before reaching the age of thirty"<sup>3</sup>.

This romantically ordained perception was carried over into the 20<sup>th</sup> century even after the identification of the cause of tuberculosis. Eugene O'Neill wrote in a message to patients with tuberculosis:

"But let me add a warning: Don't get snobbish. I remember I used to despise the untutored, ignorant folk who did not have or had not had TB. I looked down upon such unfortunates as an inexperienced, inferior lot, who after all, couldn't know much about life or anything else. They simply didn't belong, thought I with a superior sniff - until one day a friend, an eminent TB specialist, sensing my attitude, maliciously told me that truth - that autopsies reveal the democratic fact that nearly everyone has had it! Which leaves us only one point of superiority to brag about: We know it and the rest of them don't"<sup>4</sup>.

The literature written around mid-1700s reflects a myriad of such emotional experiences and associated romanticism. The best sellers of the Victorian Era are full of fictional characters that suffered from tuberculosis. Charles Dickens depicts the sufferings of Little Blossom in 'David Copperfield'<sup>5</sup>. Perhaps the most renowned description of the sanatorium is that of Davos, vividly depicted in 'The Magic Mountain'<sup>6</sup> by Thomas Mann. American literature is also not without its consumptive heroes or heroines; Little Eva in 'Uncle Tom's Cabin'<sup>7</sup> and Milly Theale in 'The Wings of the Dove'<sup>8</sup> both died from tuberculosis.

Tuberculosis was rarely presented as something disgusting and repugnant. It was used as a device to enlist the sympathies of the reader, for it was believed to mainly affect those who were of a sensitive nature. The disease was also shown to confer some kind of a 'refined physical charm' on the patient, especially the heroines, before they succumbed to it. This, romanticism associated with the tuberculosis, and the charm associated with the tubercular patient, began to decline in the latter part of the 19<sup>th</sup> century. Probably due to the public health problems associated with the industrial revolution because of which a keen interest in the social and cultural dimensions of the disease arose<sup>9</sup>. The advance of scientific concepts led to the loss of vision of illness as a romantic disease. It no more

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<sup>2</sup> R. Dubos and J. Dubos, *The White Plague*, p. 5 (New Brunswick, NJ: Rutgers University Press, 1987).

<sup>3</sup> *id.*, p. 185.

<sup>4</sup> J.A. Myers, *Fighters of Fate*, p.317 (Baltimore: Waverly Press, 1927).

<sup>5</sup> C. Dickens. *David Copperfield* (UK: Bradbury and Evans, 1850).

<sup>6</sup> T. Mann, *The Magic Mountain* (tr. by J. E. Woods) (Publication and place of publication not known, 1924).

<sup>7</sup> H. B. Stowe, *Uncle Tom's Cabin* (Cleveland, Ohio: Jewett, Proctor & Worthington, 1852).

<sup>8</sup> H. James, *The Wings of the Dove* (NY: Charles Scribner's Sons, 1902).

<sup>9</sup> R. Dubos, *Mirage of Health* (New York: Harper & Row, Publishers, Inc, 1959).

won sympathy for the sufferer but rather was an epitome of profanity, contagion, and dirt. As knowledge of tuberculosis grew, the mystique decreased. Susan Sontag in her work notes,

“For as long as its cause was not understood and the ministrations of doctors remained so ineffective, tuberculosis was thought to be an insidious, implacable theft of a life”<sup>10</sup>. .... “TB is disintegration, febrilization, dematerialization; it is a disease of liquids - the body turning to phlegm and mucus and sputum and, finally, blood - and of air, of the need for better air”<sup>11</sup>. .... “TB is a disease of time; it speeds up life, highlights it, spiritualizes it.”<sup>12</sup> .... “TB is often imagined as a disease of poverty and deprivation - of thin garments, thin bodies, unheated rooms, poor hygiene, inadequate food”<sup>13</sup>.

## II. Tuberculosis in India

In India, tuberculosis was never seen in a colourful realm but rather was always perceived in shades of grey. Since the times of *Ayurveda*, tuberculosis was a disease always associated with deep indent, dirt, pollution, and by extension was perceived as unholy. This is apparent from the terms used as reference for it, such as *sosha* and *rajyayakshma*.

The term *sosha* is derived from the word ‘*sosh*’ meaning ‘exploitation’. In *Ayurveda*, tuberculosis was believed to act like a parasite upon the fluid-blood system and was referred to as, *sosha*. The term *rajyayakshma* has two meanings attached to it. One is where it is referred to as the ‘disease of the king’, wherein the term ‘*rajya*’ refers to the king and ‘*yakshma*’ refers to disease.

It is believed that since Moon, the king of the planets, was the first one to get afflicted by the disease, therefore it is referred to as the ‘disease of the king’. The second connotation, whereby it is referred to as the ‘king of diseases’, is derived from the fact that just like the king is protected by his security guards, tuberculosis also is preceded, and even accompanied and followed by other diseases/ailments like fever, cough, respiratory infections, etc. In certain texts, tuberculosis has also been referred to as *kshaya* (literally meaning dilapidation, declension) because of its power to destroy the internal and external vital systems of the body. These perceptions do not exist in isolation but rather have an associated style in which the disease is managed. This style is tailored not medically but rather socially and holds relevance even under strict medical surveillance.

## III. Institutional management

In India, erstwhile seven Municipal Committees were merged in 1957 to form Municipal Corporation of Delhi (MCD), India. Chapter XVII of MCD Act dealing with sanitation and public health includes prevention and control of ‘dangerous diseases’ under Sections 371 to 386. Tuberculosis is included as one of the ‘dangerous diseases’ in section 2(9) (a) of Chapter I of MCD Act.

Measures for preventing and checking the spread of dangerous diseases, the establishment and maintenance of dispensaries and maternity and child welfare centres, and the carrying out of other measure necessary for public medical relief are listed as Obligatory functions of the Corporation under Section 42 (i) and (j) of Chapter III of MCD Act. To discharge these functions in respect of tuberculosis, MCD established 11 chest clinics in its jurisdiction. Subsequently, New Delhi Municipal Committee (NDMC) also opened a chest clinic in its jurisdiction and in 2002 Delhi Administration also established chest clinics bringing their total number in Delhi to 24. Each of these clinics have, a number of Microscopic Centres (MC’s) undertaking sputum examination and directly observed treatment (DOT) centres located in its defined coverage area.

Tuberculosis threatens the health of millions across the globe. Statistically speaking, of the 8.6 million cases, 2.2 (25%) million cases occurred in India, in 2013-14. Annually, 1/4<sup>th</sup> of the global incident TB cases occur in India, making it the highest burden country in the world.

## IV. Background

Tuberculosis is an infectious disease which in order to be cured, demands a diligently followed and rigorously complied with drug regime. Quite often, the medical technicality associated with diseases such as TB, cancer, leprosy, epilepsy and the like, creates a mystery for those on the other side. It seems as if some secrecy is concealed in the medical jargon used, since almost all of it goes much beyond the understanding of the patient. The setting, the medical décor, the stiff non-smile of the doctor and the feigned smile of the para-medical staff are all a significant part of the ‘presentation of self’ in a medical organization which add to the aura of high empowerment created through specialization and super-specialization.

With all the lights focused on this biomedical stage, the only part of the patient which remains is her/his shadow. S/he is categorized as an insignificant, passive, and mute spectator (if not an invisible being).

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<sup>10</sup> S. Sontag, *Illness as Metaphor and AIDS and its Metaphor*, p.5 (New York: Farrar, Strauss and Giroux, 1990).

<sup>11</sup> *id.*, p.13.

<sup>12</sup> *id.*, p.14.

<sup>13</sup> *id.*, p.15.

During the course of diagnosis and treatment, this faceless, colourless patient gets snapped in the files and receives a code or a number, which henceforth conceals her/his identity. S/he becomes a raw material, the unwitting bearer of a disease or a lesion. It is only what the doctor does to and for the patient that counts.

In the current study an attempt has been made to render visibility to these passive, mute bodies. The focus has been to study the various social perceptions held about tuberculosis. Contrary to Foucault's argument that the experience of the patient has no role in the biomedical sciences, the present study emphasizes that the biomedical system, in order to sustain its grounds, has to be sensitive to the social system and in fact needs to build the demands of the social system into its structure. To ignore or even undermine the role of the patient, and to treat him as a mere passive recipient of medical care (as portrayed by Parsons) is a very incorrect and myopic perspective. This has been quite well substantiated by Byron Good, Goffman and, Coe. The current study strives to give a strong meaning to Blaxter's statement that patient's conception of his illness and of its causes "*may be very individual, but... they will be to some extent socially patterned....Cause is multifactorial, processes are interconnected, manifestations are multi-faceted...*"<sup>14</sup>.

The locus of the study has been a Chest Clinic in Delhi (India) established under Municipal Corporation of Delhi (MCD) in 1981, and has henceforth been referred to as either the MCD Chest Clinic, or the Chest Clinic. The respondents included patients, their 'significant others' who accompanied them to the clinic and also the 'generalized others', who resided in the zonal parameters covered by the MCD Chest Clinic.

To discharge tasks specific to tuberculosis, all of the 11 chest clinics falling under the jurisdiction of Municipal Corporation of Delhi (and the other 13 chest clinics which did not fall under the jurisdiction of MCD) irrespective of their ownership, have a management committee called the, *Tapedik Niantran* Committee. Funds for salary of the staff specially recruited for Revised National TB Control Programme (RNTCP) and all activities undertaken for promoting RNTCP are released through these management committees which in turn receive funds from Delhi *Tapedik Unmulan Samiti* (DTUS). DTUS is a state level society under the chairmanship of the Principal Secretary (Health), NCT of Delhi with State TB Officer (STO) as its member secretary. It, in turn, receives its funds directly from Central TB Division of Directorate General of Health Services (DGHS), Ministry of Health, Government of India. Drugs for Directly Observed Treatment, Short-course (DOTS), and other Conventional TB drugs (prescribed under the National TB Control Programme (NTP)) are procured by the Central TB Division, and are distributed to the chest clinics through Delhi *Tapedik Unmulan Samiti*.

Under DOTS (RNTCP), the patients were required to take the prescribed drugs diligently and intermittently i.e. every alternate day (thrice a week). Mondays, Wednesdays, and Fridays were the assigned days for patients receiving treatment under RNTCP. Those who failed to take their drugs on the prescribed day were to be visited by the Health Visitor the next day to retrieve the defaulters from their homes. For those who were receiving treatment under the Conventional Regime (NTP), there existed no such privilege or attention. They were issued drugs for a period of 15 days.

The identity of the patients, at the Clinic was codified in terms of her/his 'Identity Card Number'. In fact the entire system, revealed itself in terms of labels and numbers. From the identity of the doctors, to the investigation rooms/windows, everything was numbers.

## V. Methodology

The approach of the author was primarily interpretative in nature. The qualitative data determined the 'ontology' to be a function of the human thought, analysis and perception. This ontological assumption has implications for the selected epistemological position which is non-positivist in nature.

Phenomenological perspective in sociology offers a radical alternative to the positivist methodology, and has been the methodological plan employed for data-analysis in the current study.

The current analytical plan also includes interactionist as well as the ethnomethodological perspective. The relevance of the interactionism in the context of the present study lies in viewing human beings as 'symbol-manipulating' beings who are capable of producing culture and transmitting a complex history through symbols. The social world in which they live is a dynamic and dialectical web, in which the situations reveal themselves as encounters with unstable outcomes. Because of this, the lives and their biographies are never fixed and immutable; instead they are always in the process of shifting and becoming. In short, the study highlights that the social world is interactive, as humans are always connected to the 'others'.

While analyzing the data, conscious efforts have been made to look beneath the symbols, processes and interactions in order to determine the underlying patterns or forms of social life.

The data has been collected primarily through the tool of interviews both structured as well as unstructured. Efforts have been made to report the meanings of the experiences as interpreted by the respondents

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<sup>14</sup> Blaxter, M. 'The Causes of Diseases: Women Talking', *Social Science and Medicine*, 17(2), 1983, p.68

themselves. Care has been taken to be 'non-directive' and refrain maintained from offering opinions, avoiding expressions of approval or disapproval etc. Apart from interviews, quite a few focus group discussions were also organized, some of which were unsuccessful because of 'stigma'. The case-study method also proved to be quite productive in eliciting data as it was not too large. This enabled the author to observe minutely and focus in detail, on every respondent.

The data has been analyzed inductively i.e. from the particular to the general. Under the applied epistemology (interpretative), the research design involves the development of a theory, which started from the collection of data, arose of, and is grounded in that data.

## VI. TB beyond the biomedical perspective

In the current study almost all of the respondents (except those who were either a victim of extra-pulmonary TB or were associated with such a patient) knew about only one form of tuberculosis, i.e. pulmonary tuberculosis. *Chaati ya gala, yeh hi do jagah hain jahan par yeh bimari apnee pakad jamati hain...esi leye to doctor sahib bhi, x-ray ya balgum ki janch batate hain* (literally, chest or throat, these are the two places where the disease establishes itself...this is why call for either an x-ray or sputum examination), said Dev Raj (62 years). Pulmonary TB was further subdivided into two:

- (a) '*jisme khon ki ulti hoti hai*' (literally, the one in which blood is vomited out), and
- (b) '*jo balgum wali TB hoti hai*' (literally, the one in which mucus comes out).

The form in which one coughs out blood was also known as '*sindhoori*' TB. Mangu Lal (28 years), a carpenter, despite being illiterate, insisted on knowing a lot about the disease because of his father, who was a *vaid* (indigenous healer). He asserted, that initially the *khonwali* (the one with blood) TB, which is quite *bhayanak* (serious) was cured only at Agra, his hometown. He added that it is only now that this form of TB has become a common disease (*aam bimari ban gayee hai*).

*Balgumwali* (literally, the one with mucus) TB, was believed to be non- infectious and therefore had no fear associated with it.

Some respondents added a third form and referred to it as the

(c) '*alag tarah ki*' (literally, different type of) TB. The characteristics associated with this lay category drew a connect with what is referred to as the extra-pulmonary form of tuberculosis in the medical parlance. Those who were or are suffering from this form, justified their diagnosis by viewing TB as predestined and henceforth unalterable but at the same time they were also quick to assertively add that the blessed ones are those who are ordained with a this form of TB as it is not stigmatized.

In a comparative perspective, those with extra-pulmonary TB were seen to be in a better position to pass off as 'normal', un-stigmatized individuals. Goffman has also stressed that people with stigmas that are not clearly visible to others have the option of concealing or not disclosing the stigma. However, Smart and Wegner claim that even a concealable stigma can be costly, since "In the effort to hide their true identities, those with concealable stigmas must face an internal struggle that leads to anguish and perhaps even to psycho-pathology". It is in this context that the patients with extra-pulmonary tuberculosis were perturbed and disturbed when they were required to visit the MCD Chest Clinic as a part of their treatment. It was argued that these visits revealed their otherwise hidden tubercular status which was not immediately perceivable. To use Goffman's terms, the fear was that the discreditable might step across the thin line and enter into the world of the discredited. *Alah miyan ne bimari dali to hai par shukar hai uska ki bande ko kam se kam chipa sakne ki ijazat to di hai...esi ley to main kahta tha ki jahan sarkari elaj shoori kiya to museebaton ka pahad gir padega...ghar mein char kuwari betion ka bhi to sochna hai* (literally, God has given the disease but one should be thankful to him for granting the permission/making it possible to hide it...this is why I use to say that once you begin governmental treatment then troubles will fall upon you...one has to also think about the four unmarried daughters at home), said Afzal (49 years).

In a similar tone, Sonia (25 years) despite her much dreaded and feared tubercular diagnosis, sighed relief because of the fact that she had '*alag tarah ki*' (different type of) TB. *Bhagwan ki daya se mera TB dekhta nahin hai* (literally, by God's grace my TB is not visible), she sighed. She was a very confident girl, who when asked whether she enjoyed the 'patient-role comfort', promptly replied that *admi bas ek he cheez chahata hai...saas kee sewa main acche se karti hoon...vaise bhi main bade ghar se hoon, mera khayal to rakhenge hee* (literally, husband's just wants one thing...I look after my mother-in-law well...otherwise also I belong to an upper class, they will take care of me).

It can be observed from cases such as that of Afzal and Sonia that the intensity of stigma loosened its grip in the case of patients with extra-pulmonary form of tuberculosis. Goffman, in his work has identified different types of stigma/stigmatizing conditions such as "abominations of the body", like physical deformities; "blemishes of individual character", like addictions, unemployment; and "tribal identities", like race, nation, and caste. In pulmonary form of TB, especially in cases of haemoptysis, the body starts to show the signs which the

lay man is familiar with, while in the extra-pulmonary forms, despite the probability of “abominations of the body” it reflects neither on the patient nor on his/her family.

A more exhaustive theoretical framework has been given by Jones et.al, in their study where they have identified six dimensions of stigmatizing conditions. These are:

1. ‘Concealability’, which refers to the extent to which the stigmatizing characteristic is necessarily visible, such as in the case of a patient with excessive haemoptysis versus the patient who can pass off with his extra-pulmonary condition;
2. ‘Course of the mark’, which refers to the mark becoming more salient or progressively debilitating over a period of time for example in the case of lymph node TB;
3. ‘Disruptiveness’, which alludes/refers to the degree to which the stigmatizing characteristic like, acute bouts of coughing, interfere with the flow of interpersonal interaction;
4. ‘Aesthetics’, which symbolizes subjective reactions to the unattractiveness of the stigma, for example the non-cooperative and dismissing attitude of the lower staff at the MCD Chest Clinic when compared with the empathetic attitude of the Chief Medical Officer there;
5. ‘Origin of the stigmatizing mark’, such as the fact whether the disease runs in the family or is it a result of the tensions and mental pressures especially those associated with marriage;
6. ‘Peril’, which symbolizes the perceived danger of the stigmatizing conditions to the others, for example the infectious versus the non-infectious forms of TB.

Sohan Pal (80 years old), Hindu thakur from Uttranchal, not only regarded his form of (extra-pulmonary) tuberculosis to be superior to that of the other TB patients, but even went to the extreme of regarding it as an ‘endowment of the Almighty’. He proudly said that *prabhu ki maya dekho, kissi ko maloom bhi nahin hai ki bimari kahan hai* (literally, look at God’s play, nobody knows as to where is the disease). Similar tones are highlighted in the words of Shashi (35 years) who argued that earlier TB use to hit only those who had committed *bure karam* (bad deeds) in their previous births but today it hits almost everyone. Her natal family, she said, is financially better off, substantiating her statement by showing her bangles, earnings, and *mangalsutra*, which she claimed was of pure gold (by implication, prized). Her wedding, she further elaborated, was hosted at a community centre, and her parents gave lots of gifts and sweets and continue to give gifts on every festivity. It was this higher economic edge along with the extra-pulmonary form of her disease which gave her a normalcy in her everyday life.

She perceived herself to be a very pious and a religious lady because of which she had the power to take over herself the curse of TB predestined on her affinal family. Further, since God was aware of her positive karmas (deeds), therefore she was “blessed” with a hidden, curable and hence a “superior” form of tuberculosis instead of the lowly ‘*khoon wali*’ (the one with blood) TB.

Unlike the patient respondents, most of the ‘other respondents’ (i.e. those who were not patients) came very strongly against viewing a repulsive disease such as tuberculosis (no matter whatever its form) in a ritually sacred context. Satya Devi (40 years), a widow who swept the area in and around the local temple claimed the responsibility to maintain the sanctity of the temple and also attended to small ailments such as cold, temperature, injuries, and sometimes even deliveries. She rebuked those who associated any form of blessings with the disease and regarded TB as a curse. The gravity of the disease increases if, in the family of the sufferer, there also happens to be a daughter and that too of a marriageable age. Satya Devi was prompt to advise that no ‘sensible parent’ should ever go for his/her treatment in a “*sarkari*” (public) set up, like the MCD Chest Clinic and all possible measures to conceal the disease should be taken.

Even in the medical parlance, the element of distance from the disease, and by extension the diseased, is apparent from the fact that tuberculosis has been categorized as a “dangerous” disease in Section 2(9) (a) of Chapter I of MCD Act (as mentioned earlier). The only difference between the two perceptions i.e. that of the common man (in the current context, to be read as the respondents) and that of the medical fraternity, was that of approach. For the common man, the disease was dangerous because it is highly infectious and is difficult to cure. For the medical fraternity the element of danger lies in the fact that despite the efforts, a disease which once had almost vanished, has lashed back with such a force that despite their ‘consistent efforts’, it is the single largest infectious cause of death. Further, because of its course, it contributes heavily to the reservoir of infection, thereby standing as a threat to the community.

An evaluation of an infection or a disease, by a member of the medical fraternity say, the physician, contains the medical definition of what is good, desirable, and normal as opposed to what is bad, undesirable, and abnormal. This evaluation is interpreted within the context of existing medical knowledge and the physician’s experience. On this basis medical science formulates medical rules defining biological deviance and the fraternity seeks to enforce them by virtue of their authority to treat those persons defined as diseased.

In the current study, as mentioned earlier, the focus is not on what is medically labeled as diseased but rather on what is sociologically recognized as sick, and by extension, deviant. In sociology, one of the early definitions of sickness as a form of deviant behaviour was formulated by Parsons in his concept of the ‘sick role’. He saw being sick as a disturbance in the “normal” condition of the human being, both biologically and socially. The basis for describing

sickness/illness as a form of socially deviant behaviour lies in the (sociological) definition of deviance; according to which any act or behaviour, that violates the social norms within a given social system, is a form of social deviance.

Erikson claims that *“Deviance is not a property inherent in certain forms of behaviour; it is a property conferred upon these forms by the audiences which directly or indirectly witness them”* (emphasis in original). Thus seen, it is not only the act of deviance on part of the individual actor but rather the social audience which labels the act such, which is equally important.

Sociologically speaking, deviant behaviour is not simply a variation from a statistical average. A pronouncement of deviant behaviour involves making a ‘social judgment’ about what is right and proper behaviour according to a social norm. Here norms reflect expectations of appropriate behaviour shared by people in specific social settings. We find the echo of the same perspective in Archer’s definition of deviance as *“a perceived behaviour or condition that is thought to involve an undesirable departure in a compelling way from a putative standard”*.

Being sick, Parsons argues, is not just experiencing the physical condition of a sick state; rather it constitutes a social role because it involves behaviour based on institutional expectations and reinforced by the norms of society corresponding to these expectations. A major expectation concerning the sick is that they are unable to take care of themselves. This makes it necessary for them to seek (medical) advice and to cooperate with (medical) experts, so as to return to normal roles.

One such center of advice and expertise was the MCD Chest Clinic which over a period of time came to be popularly termed as ‘TB Clinic’. Till the time it was a Chest Clinic, in general terms, no label or stigma was attached to it but as the spread of tuberculosis became extensive, the label became significant and the connotation derogatory. The phase of change has been very subtle to the extent that even the staff at the Chest Clinic did not realize it. In all probability this change might have occurred sometime around October 1993, when it was recognized as one of the five pilot project sites of Directly Observed Treatment, Short-course (DOTS), under the Revised National TB Control Programme, by Government of India.

In the current study, the respondents were a more or less economically homogeneous section, all belonging to different sub-segments of the lower income group. This economic homogeneity of the respondents stood no opposition to their geographic heterogeneity in regarding tuberculosis as “serious”, which, it was collectively believed, if not treated immediately, would ruin the entire *“khandan”* (household). This belief has two undertones to it. Firstly, the disease is considered so stigmatized that its occurrence was a trauma so deep and powerful, having the ability to ruin the entire family’s social status. Secondly, TB was regarded as “serious” because of its highly infectious nature which was feared to engulf the entire family, in its tentacles. It was this ability/capacity to infect which made the respondents perceive tuberculosis as serious.

## **VII. TB: A Stigma**

Let us first discuss the significance and relevance of stigma, in regarding the disease as “serious”. The origin of the term ‘stigma’ can be traced back to the ancient Greeks. The criminals and traitors were cut or branded so as to mark them for their immorality or their deviance from societal norms. Such a mark was called a “stigma”. The stigmatized was ostracized, insulted and scorned. Goffman, in his classic monograph on stigma describes stigma as a sign or mark that designates the bearer as “spoiled” and therefore as valued less than “normal” people. This labeling and subsequent devaluation of an individual is explained by Crocker et.al. who contend that *“a person who is stigmatized is a person whose social identity or membership in some social category, calls into question his or her full humanity -the person is devalued, spoiled, or flawed in the eyes of others”*. Neuberg et.al. also argue that, *“Stigmatization thus represents one end of the continuum of the process of assigning positive or negative labels to those we come across, and then valuing and devaluing them as their labels warrant.”*

Few would disagree that there is a universal social stigma attached to tuberculosis. It is evident from the present study that stigmatization costs heavily in terms of personal, interpersonal and social context. The label ‘TB’, respondents claimed, acted as an annexure to the personality of the patient and followed her/him like a shadow throughout her/his life. It played a major role in worsening the quality of life for the tubercular. Stigma came into frame from the time the symptoms were acknowledged, continued during the phase when care was sought, and continued even after the patient was declared to have been ‘cured’ of the disease, justifying with the argument that predestined, other-worldly curse such as TB, can never have a this-worldly cure.

Kirti (14 years) was receiving her treatment under DOTS from the MCD Chest Clinic and was studying in Xth class at Kendriya School. Her mother (a widow) ran a beauty parlour from a shop given by her father. They were Punjabi Hindus from Amritsar and had come to Delhi after the 1984 riots. After Kirti’s diagnosis, her mother was threatened by her maternal uncle to throw her out of the shop, as it was located in the same building in which he was living with his family. His justification lay in the fact that since his daughters were mature and he was on a look out for a good match for them, a tubercular relative would be a hindrance.

Further, since the treatment schedule under DOTS demanded a visit every day during the initial phase and on alternate days during the continuation phase, the *biradari* (associates/kin group) had started questioning their (Kirti and her mother's) frequent visits to the MCD Chest Clinic. The visits to the Chest Clinic were constraining not only on their pocket and time but were also a source of social stigma. *Logon ko mooh kholne ka mouka mil jata hai* (literally, people get an opportunity to, open their mouth/speak), she said. Moreover, the health worker's visits to the residence of those receiving DOTS, made their life worse as it was suggestive of the disease and therefore the stigma. As a result, the *halat* (circumstances) forced the widowed mother to stop Kirti's treatment for about 1½ months. During this phase, extreme bouts of cough and expectoration were suppressed by taking popular cough syrups from the local pharmacists. It was only when she started coughing out blood and was too weak to even go to the toilet that her treatment was restarted and she was put on the Conventional Regime, under which drugs were issued for a period of 15 days. This came as a relief to the mother-daughter because of less frequent visits to the Clinic and also by the Health Visitor.

Dibya (15 years) was a student of 10<sup>th</sup> class, studying in a government school had two sisters; one elder and the other younger. She was sent to her mother's brother's (mama) house in Andhra Pradesh because of her disease. *Beiton wala ghar hai, sabki tekreeban beyanewali umar hai, dur to bejana hi padega* (literally, with daughters in the house, all of whom are around the marriageable age, she will have to be sent/we will have to send her away), her mother rationalized. The intense stigma necessitates the diseased to be physically distanced. *Bahut namurad bimari hai yeh, pure ghar ko duba deti hai* (literally, this is a very cursed disease, it ruins/sinks the entire house). It has the power to taint the entire family.

Dibya had not disclosed her tubercular status in the school. But due to the unavoidable holidays, she was forced to produce a medical certificate. She had requested her teacher-in-charge to keep it a secret but soon the teachers started sending her out of the class on some pretext or the other such as her inability to comprehend a question, etc. Her friends also stopped sitting with her. This treatment, she felt, produced pain which was more acute than the biological disabilities associated with tuberculosis. Stigma has an underlying ideology, created to explain the patients' inferiority, accounting for the danger s/he represents, sometimes rationalizing an animosity based on other differences. This devaluation is one of the functions that the socially relevant 'others' perform for the diseased/the stigmatized. Dovidio et.al. refer to these socially relevant 'others' as the 'stigmatizing others', such as the teachers and friends in Dibya's case. Apart from devaluation, these 'stigmatizing others' also perform certain positive functions such as self-esteem enhancement, control enhancement, and anxiety buffering.

The marital status of the respondents was particularly relevant in the study because those in the marriageable age 'could never even dream' of a visit to the MCD Chest Clinic because of it having earned the label of a 'TB clinic'. In fact none of the unmarried females were 'permitted' to be even a part of our focus group discussions. Respondents having daughters or sisters in that age group took all possible measures to conceal their 'diseased identity'.

After sputum examination of unmarried female patients, it was preferred to put them on the Conventional Regime. This was because of two reasons: firstly it called for a dissipated supervision, and secondly, the drugs under the Conventional Regime could be procured without the physical presence of the female patient at the Clinic.

The stigma associated with tuberculosis is intense because it is considered a family disease. If one family member gets afflicted, the chances to find a suitable match for other sons and daughters is greatly reduced and the present engagements to marry may also be at stake. Quite often, the disease of a parent or brother/sister was not reported so that the chances of the other family members' finding a marriage partner or job is not reduced. Reenu (31 years) was warned by her parents to keep her disease a secret so as to successfully accomplish her pending marriage (which was initially stopped because of insufficient dowry). Dhananjay (22 years) got married, keeping his disease a secret from, his wife and even his own parents. This conscious decision was taken understanding his rural territoriality, which he argued, was locked in fear attached to the disease. *Gaon mein sab TB se asse darte hain jaise koyi bhoot ho...bimari hai dawa khane se theek ho jayegi* (literally, in the village, people fear the disease as if it is a ghost...it is a disease and will get cured with medicine), he said with extreme comfort.

Bharat Singh (27 years), a Hindu Rajput recollected with extreme bitterness the marital separation of his elder sister, on being diagnosed as tubercular, despite her (2 months) pregnancy, which he wept, suffered the cost of the stigma, for soon she had a miscarriage. The disease, Bharat Singh emphatically said, threw his sister's entire life into scatters. D.C. Pandey (45 years), a government school teacher opined that the disease should never be revealed, for *mohalledari bhi to dekхни hai* (literally, one has to maintain cordial ties within ones neighbourhood also). He believed that TB takes even those closest to us, far away from us.

### **VIII. Stigma: Rural/Urban perspective**

Stigma surrounding tuberculosis was believed by most of the respondents to be more acute in the villages. This was because people there lacked awareness about the fact that it is to a large extent curable. It is in this context that Kishan (34 years) was told by his mother not to reveal his diagnosis and keep it a secret, lest it might have repercussions in terms of the marriage proposals coming from the village for him.

Raju (30 years) was employed as a sweeper by the Municipal Corporation of Delhi on daily wages. He belonged to Dhanbad, Bihar and was currently living in a one room *jhuggi* (slum). He admitted to be an alcoholic since 10 years, though he claimed to have left it since the time his treatment (under the Conventional regime) began. He disassociated stigma with *shahari* TB (the TB that occurs in the city). His statement, *yahan sab samajhte hain* (literally, here everyone understands), needs to be interpreted in two totally distinct and ironical ways. One is that the people in the city understand that the disease is curable and therefore do not associate any destructive form of stigma with it. The other interpretation is that since all the respondents came from the similar socio-economic/macro-environment which was quite conducive to the spread/infection, TB was very common.

It was argued that there was a time when it was a dreaded disease affecting only few, but today it affects every other common man. *Yeh ek aam bimari ban gayi hai* (literally, this has become a common disease). During one of the unstructured interviews, Raju revealed that his father was also suffering from tuberculosis and they shared drugs issued by the Chest Clinic. This drew attention to three issues:

- i. TB seen as a family disease,
- ii. role of the unhealthy conditions in precipitating infection and
- iii. sanctity of drug management at the Clinic

Tuberculosis was primarily seen by the respondents as a disease affecting those living in the cities - especially those living in crowded places, unhygienic surroundings, damp and dark places – all of which was atypical of the migrant population coming in search for work and money. This role of the macro-environment is apparent from the fact that tuberculosis, in the current study, was perceived to be miles away from the villages. It was the suffocating life and living conditions of the cities which were seen as precipitators of the disease. Shriram (50 years) separated from his wife because, he claimed, she was barren. Soon his younger brother developed some problem in his lungs because of heavy drinking. To treat him, due to financial constraints, he had to sell off his agricultural land. But soon after his brother's marriage, he forgot of all the sacrifices made and switched his loyalties because of which Shriram had to migrate to Delhi and look out for employment opportunities to sustain himself. He argued that in the villages there is so much of freshness and everyone gets proper food at the right time. It was his inability to adjust because of environmental suffocation along with the pain of being cheated by the dear ones which made him succumb to the disease.

The perception of TB as a highly infectious disease was apparent even amongst the peon and the *safai karamchhari* (literally, sweepers) at the Chest Clinic, for they were often heard screaming at the patients to cover their mouths.

In general, majority of the respondents perceived tuberculosis (to be read as pulmonary tuberculosis) to be highly infectious and contagious. Meenu (22 years) had an 11 month old baby whom she did not breast-feed due to the fear of her milk being infected because of her tubercular status. As a result of which the child was extremely weak and malnourished. Anju (27 years), like Meenu, also perceived tuberculosis as contagious. Her *devar* (husband's younger brother) lived with them and was perceived as a major liability by Anju (probably because he was unemployed). She claimed that quite often he use to feel breathless and concluded that he suffered from TB. This suspicion, made her maintain separate utensils for him though she had to wash them. This caused in her the fear of contracting the 'infection'. She proudly added that would she not have threatened her husband of consuming poison, he would not have thrown his brother out of their house and if otherwise, soon the entire family would have been in the clutches of TB.

Manju (52 years) on knowing of her daughter-in-law's tubercular status, took away her grandchildren (one girl and, one boy who was barely 6-7 months old) from their mother. She justified her move in terms of her fear of the high probability of the disease spreading in the veins of 'her blood' (*hamare khoon mein TB na aa jaye*).

Saroj (38 years) regarded the infection to be powerful in its manifestation with the ability to engulf every family member of the diseased. This was considered to be acute especially under 'conditions of poverty' where there is no food and people are too weak to fight out diseases such as TB. This view showed reflections of knowing the role played by immunity or lack of it in terms of the disease.

### **IX. TB and weak immunity**

During the focus-group discussions, four reasons were identified to lessen the immune system, and by extension, attract tuberculosis. First, was identified as excessive physical strain. It was argued that if a person, especially who is weak, took up physically stressful work - like pulling heavy objects, labouring from morning to evening, overindulges in sexual intercourse, frequent pregnancies, (especially those resulting in delivering lesser sex (girls)), masturbation, visiting prostitutes quite often, etc. – would suffer from acute body pain, temperature, cough, weight loss, and even insomnia.

Geeta (25 years), a TB patient, maintained that frequent pregnancies with fewer intervals weaken one's body, and this precipitates TB. Immediately after her marriage she got pregnant and there was hardly any gap between her children. The eldest was a girl of 10 years, followed another girl aged 9 years, and a boy of 7 years.

The second reason causing harm to the immune system was the suppression of the desires and urges and this is why, the respondents maintained, TB was quite common amongst the poor. When the poor look around, they too wish to enjoy the pleasures of life but their wishes, due to paucity of resources, cannot be fulfilled. This forced suppression of the desires, weakens their immune system and attracts tuberculosis.

Not only is the suppression of worldly pleasures a painful cause but also the suppression of the urge to urinate, or defecate, or release gas due to various reasons, were regarded to be responsible for the disease, in the long run. It was believed that the suppressed bad wind goes to different parts of the body and induces pain in the back, shoulders, throat, chest, and head. The body is then affected by cough, fever, sore throat, and weakness. The male respondents argued that those women who did not fulfill the sexual urges of their husbands were responsible in converting those urges into weakness and later into TB. In fact the continuous uses of contraceptive measures like Mala D or Nirodh were considered hurdles in satisfaction of sexual desires.

The above mentioned association between indulgence in a sexual relationship and tuberculosis is in fact contradictory, for in contrast to the above discussed belief there was yet another belief according to which a TB patient is required to observe celibacy. It was argued that because of cohabitation, hard work, fear, jealousy, etc., the body heat increased (especially in the afternoon), which precipitated tuberculosis.

The third reason which was regarded to weaken the immune system was mental strain. When a person worried or grieved a lot; is troubled by negative emotions such as jealousy, fear, anger, etc.; and despite being weak, does not take nutritious diet, does fasting or eats little, then, it was believed that, her/his blood gets thinned and s/he succumbs to TB.

Reenu (31 years) opined that one should not overwork one's brain. *Socha mat karo, sochne se bimari barti hai* (literally, do not think, thinking increases the disease). Akhtari (52 years) lived in a one room house with her husband, four sons, and one daughter. Her husband had lost sensation in his lower limbs during a fight with his brothers over property. Two of her daughters had succumbed to dowry pressures exerted by their in-laws. She insisted that TB occurred because of tensions. *Jiske naseeb mein aaram ho, usse bimari ka dar kaisa? Aik to yeh garibi, upeer se makan malik ke tane, betiyon ka gum, admi ki majboori...jab zindagi mein dukh hi dukh ho to bimari to aayegi hi*, (literally, the ones who have been destined to relax have no reason to fear the disease. One is poverty, the other are the taunts by the landlord, sorrows because of daughters deaths, limitations of her husband...when there are sorrows in life, disease shall follow). She added that the disease usually inflicts the females because they are the weaker sex. *Kyonki aurate kamzor hoti hain, aur un par sabka bojh hai, is ley zayada tar unhe hi TB hoti hai* (literally, because females are weak and they bear everybody's burden, that is why TB mostly affects them).

The male respondents on the other hand argued that since they have greater work to do, more stress to bear, and by extension, more tensions, therefore it afflicts them more often. Since the household and the family burdens (*ghar aur parivar ka bojh*, they said) are on their shoulders, therefore tuberculosis hits men more often than the females.

Veer Singh (50 years) was a scrap-dealer and argued that TB more often affected the poor because *chhote log bahut laparwahi se rahte hain* (literally, poor people live in a very irresponsible way). He belonged to Aligarh and was currently living in a *pucca* rented room shared by two people. These glimpses, along with the association of the disease with the city conditions discussed above, reflect the role of the environment in TB causation.

Manju (25 years) was a victim of domestic violence. Her second child was a cesarean. This surgery had made her very weak, and was followed by fever in the evenings (especially after 4:00 p.m.). Because of her ill health, the milk in her breasts dried up and quite often had bouts of excessive cough. It was immense interference by her in-laws along with her husband's insensitivity which culminated in family fights and tensions, causing TB. She also agreed in the gender bias which the disease maintained. *Museebatiyan to auraton ko hi ati hain* (literally, difficulties come only to females) she said.

Phool Chand (32 years) believed that diseases like TB do not occur all of a sudden. It is an episodic development, usually precipitated by some tension or depression. Anger and sadness lead to a loss in the appetite (*gum bhook kha jata hai*) and the resultant mental agony starts speaking on one's physical well-being, as a result of which, *khatarnak* (dangerous) diseases such as TB develop. He claimed to know of a lady who developed TB because of the *sadma* (shock) of her young son's death. During one of the interviews, it was revealed that this woman was none other but his own wife.

The fourth reason lessening one's immunity is indulgence in bad/wrong dietary habits which disturbs the balance in the body and weakens the immune system. Smoking tobacco, ganja, and charas, drinking cheap liquor, practicing occupations in which bad odour is emitted such as leather business and the like, lessen the (*shakti*) power to fight diseases such as tuberculosis.

D. C. Pandey revealed that working the entire day at the school made him very tired and for relief, he used to drink in the evenings. This overindulgence in alcohol resulted in tuberculosis. Bharat Singh could not establish the cause of his tubercular status, for he did not indulge in any addictions. To this there was an interesting suggestion offered by some of his acquaintances, who had suffered from TB before. They suggested him to start drinking and smoking because it had the power to kill the tubercular germs. Paresh (46 years) was a Hindu Brahman and argued that tuberculosis occurred due to various indulgences and addictions such as, *tambaku* (tobacco), alcohol, chicken, eggs, etc. reflecting lack of self-control.

To receive the complete benefit from the treatment, two things were regarded as most significant. One was a purely vegetarian diet which is 'rich and healthy' and the other was God's grace, for which the patients should regularly visit the temple. Tuberculosis, more quite a few respondents, meant end of life, as it occurs amongst those who abuse one's body, be it mentally or physically.

The disease was perceived to enter our body through our respiratory system, blood system, and from the mouth. Upon entering the body, it spreads through the skin, blood, and air. Because it spreads through the skin therefore one should avoid the touch of a tubercular; because it passes through blood therefore it runs in the family and is hereditary. Its infectiousness was regarded as so acute that even the air around the tubercular, especially the one with *sindhoori* TB, can infect the other person, especially if her/his immunity is low. The disease, it was claimed, is not easy to control for neither does it have a system nor does it have any time duration. The manner, in which it spreads, according to the respondents, cannot be universally established. Its development, progress, and duration are believed to depend upon the intensity of the infection, the resistance power of the patient, her/his financial status, and her/his overall position in the society.

Thus the respondents, in different perspectives, highlighted the association between the lessening of the immune system (due to physical stress, mental stress, overindulgences, and suppression of urges) and tuberculosis.

## **X. TB and magic**

Apart from the immunity, another factor perceived to be a causative agent was magic (popularly referred to as *jadoo-tona* (literally, black magic)), and religion. In the context of magic, TB was unanimously agreed upon to be inflicted by others due to some animosity or jealousy. In the context of religion, it was agreed upon as a curse or punishment, afflicted by God, for the past *karmas* (deeds).

The circumstances wherein either magic or religion were believed to have caused TB, the immediate recourse was sought in terms of some oblations (*havan*) or sacred ash (*vibhuti*)/herbal drugs (*jadi-booti*) available with the traditional healers. During the course of study, it was apparent that modern medicine and its prescribed regimes, were of any significance only when the 'other sources' of relief/treatment, including the private physician, failed.

Akhtari perceived her tubercular status in context of her and her family's sour relationship with the owner of the house, who (she insisted to note) was a Hindu while she was a Muslim. She vehemently asserted that TB in her house was a result of the *jadoo-tona* done by the *makan-malik* (landlord). Discussions with her also revealed that mental agony and tensions precipitate tuberculosis. *Doosron ka pata nahin par hume to makan-malik ki di huin takleephon ne bimari de di* (literally, I do not know about others, but to us, the disease has been a result of the sufferings given by the landlord), she said. *Do bar ghar mein taveez mili hai* (literally, twice amulet has been found in the house), and sometimes a cock was found in a pool of blood in front of her door, she added. Being extremely insensitive, the landlord quite often forcibly cut off the electricity connection, leaving them to sweat in excessive heat. In fact it was this heat stroke, which worsened her daughter's tuberculosis, she believed.

Md. Jafir (27 years) was not in good terms with her wife and without any medical examination declared his wife to be barren. He also suspected her of infidelity justifying, *yeh purdah cum dalti hai*, (literally, she veils less often). He believed the cause behind his tubercular status was the magic played by his parents-in-law on him. Once he had gone to their place and was served tea and eggs laced with *jadoo* (magic), (they had never invited him before nor had they ever served the delicacies which a son-in-law deserves, he complained). That night itself he coughed blood and was soon diagnosed with TB.

Bharat Singh's tubercular status was believed to be a result of being under the siege of a *devata* (God), for which prayers had to be offered. While walking, he had spat on the ground where Peer Baba (head of a denomination) resided. To get rid of the curse, he was required to visit the dargah (an Islamic Shrine) in summers. Reenu perceived the disease as *kali mata ka prakop* (literally, influence of a Hindu female Goddess) resulting from the unholy *karmas* of one's previous births.

According to the ideology underlying the theory of stigma, cases wherein the sufferer or her/his guardian came up with a defensive response with regard to her/his diseased condition, it was perceived as a direct exposure of her/his defect. Both, the defect and the response were seen as retribution for something s/he or his/her parents or her/his group (such as, caste, religion) did and hence a justification of the way s/he is

treated. This was true of Akhtari's tubercular status. On the one hand it was she who kept on blaming her landlord for the disease while her landlord had his own side of the story. He was desperate in throwing her and her family out of his accommodation and insisted on never keeping a Muslim as his tenant for, he believed they have dirt in their blood, spreading highly infectious and fast spreading diseases such as tuberculosis.

Such perceptions are not just typical of the current study. Literature reveals that throughout the world, much before the 16<sup>th</sup> century i.e. the onset of Enlightenment, diseases were seen as having causes internal to the individual, his family, his community. Diseased were those whose deeds bestowed upon them the 'curse'. They were stigmatized in religious terms and were referred to as 'witches' or 'possessed'. In fact the then bestowed medical labeling was no better where in they were defined as masturbators, mad or epileptics.

## **XI. Gender and TB**

"For the virgin no marriage, for the married no pregnancy, for the pregnant no confinement, and for the mother no suckling"; this perception stands quite true and appropriate in the current study. The perceptions of the society, the female respondents argued, were quite harsh when the patient happened to be a female or when she is married to a man who turns tubercular. Belonging to the lesser gender was quite debilitating, involving various patriarchal complexes such as dowry etc. and worse came if she fell prey to the power of the disease. It acted as a double punishment for her and her parents, 'a curse upon a curse'.

When a man is afflicted after marriage, it is the women/wife whose *karmas* against the *dharma*s (religious path) were believed to have made the entire family suffer the curse. In fact it was believed that a lapse in her dedication towards serving the male members made the females suffer and also pass it to the others.

The female body was believed to be a curse and those who did not perform their *karma* i.e. duty/service succumbed to the disease. Divorce and broken engagements were regarded as the possible consequences of the disease, more so for the females than for the males.

## **XII. Conclusion**

The above mentioned perceptions highlight the need to go beyond the biomedical understanding of TB and venture into the multi-behavioural approach as an integral part of its treatment. In fact what characterizes the sociological approach is the fact that it is derived from a social interaction or social systems perspective where the abstractions used do not just relate to individuals alone but to individuals in interaction.

Author believes that a study which does not locate the individual in her/his macro-environment structure would never reveal the actual situation because the organism and the environment are one unitary phenomenon.

The complex relationship between the culture, health-related beliefs and health behaviours needs to be well grasped and imbibed so as to lay a treatment plan which is not merely biologically efficacious but also socially acceptable. Once the treatment is enmeshed with the existing socio-cultural scenario, there is bound to be a wider acceptability.

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