Ars Artium: An International Refereed Research Journal of English Studies and Culture
ISSN (Print) : 2319-7889 • ISSN (Online) : 2395-2423
Vol. 9, January 2021
Pp. 93-104
https://www.arsartium.org

Social Insight, Stigma and Social Suffering in Contemporary Society: Insights from Regional Tuberculosis Centre, Pokhara, Nepal

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Abstract

Still in this era of nanotechnology, tuberculosis is a stigma in traditional societies, consequently the people infected with tuberculosis suffer from two-fold experiences – suffering from the disease and the social suffering. This paper tries to assess the social insight on tuberculosis and the suffering of tuberculous infected people in Nepal. The study method was quantitative and qualitative. Interview schedule, P-scale and case study guidelines were used to obtain primary data from 35 respondents. Social insight on tuberculosis as the most stigmatized and discriminated disease has resulted in the intensification of belief on faith healer, loss of income, job discontinuity, social restriction, mental stress, discrimination by family, and treatment delay. Social restriction is stern for female and elderly people, but high-caste Hindu has fewer restrictions. Restriction increased with the increase in age. The sociocultural construction and the community instituted meanings and insights on tuberculosis as a 'polluted stigma' has regulated the clinical realities and added to the social suffering of the infected. The stigma attached to tuberculosis should be regarded as a biosocial and psycho-cultural phenomenon that requires the recognition and adoption of biological and sociocultural lenses of culture and health in health policy planning.

Keywords: Medical anthropology, Socially constructed, Caste-ridden, Infodemic

Background

As one of the top ten causes of death and the leading cause from a single infectious agent that killed 1.5 million people worldwide in 2018, Tuberculosis (TB) caused by

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bacteria *Mycobacterium tuberculosis* is a top infectious killer disease which effects lungs and causes pulmonary tuberculosis which can affect intestine, bones, joints, lymph glands, skin and body tissues. According to WHO (2011) the symptoms of active tuberculosis of the lung are coughing, sometimes with sputum or blood, chest pains, weakness, weight loss, fever and night sweats. Tuberculosis is treatable with a six-month course of antibiotics. GTR (2019) affirms that an estimated 10 million people fell ill with tuberculosis worldwide in 2018 including 5.7 million men, 3.2 million women and 1.1 million children. Ending the tuberculosis by 2030 is among the health targets of the Sustainable Development Goals. According to NTP (2018), tuberculosis ranked as the sixth leading cause of death in Nepal, killed 6000 people in 2018. During 2018, 31764 tuberculosis cases were registered including all forms of cases, which includes 30,957 cases (new and relapse). Out of total registered cases 11400 (36%) were female and 20364 (64%) were male. Each day 123 new TB cases are reported.

Park (2009) confirmed that following the improvements in living conditions and the development of antibiotics, the prevalence of tuberculosis fell dramatically in industrialized countries attributed mainly to improvements in the quality of life. However, in the 1980s, the number started to rise again mainly in least developed countries. For Yang and Kong (2015), the clinical manifestations of tuberculosis are quite variable and depend on host factors such as age, immune status, coexisting diseases, immunization with BCG (Bacillus Calmette Guerin), and microbial factors such as virulence of the organism and predilection for specific tissues. Beyond medical factors, there are diverse social factors liable for higher tuberculosis risk that includes many of non-medical factors such as poor quality of life, underprivileged housing, homelessness, poverty, tobacco use, alcohol/drug abuse, under nutrition, lack of education and awareness and large families etc. Embedded with social experience of illness, social insight is the social awareness and understanding of the origins and meaning, feelings, behaviour, motives and knowledge related to any disease. Conrad and Barker (2010) posit that medical sociologists use constructionist theory to interpret social experience of illness which holds that individuals and groups produce their own conceptions of reality, and knowledge itself is product of social dynamics and illness can reshape individual/community identity.

Embedded with community's sociocultural norms, social insight perceives tuberculosis as a stigmatized and discriminated disease. The lenses of medical anthropology acknowledge, understand, and question the sociocultural norms, beliefs and stigma embedded with health, illness and health behaviours. Upadhyay (2016) affirms that sociocultural norms and beliefs entrenched to human cultural discourses and institutions are expressed through diverse taboos and activities that shape how people perceive health and disease. Pedestal on *social suffering approach,* Farmer (2003) substantiates that structural violence and social suffering construct the social relations of everyday life, the causes of suffering as collectively rooted social experience with the close linkage of personal problems with societal problems. The

interpretive approach by Kleinman (1978) affirms that disease is not an entity but an explanatory model. Disease belongs to culture and culture is not only a means of representing disease but is essential to its very constitution as a human reality involving interaction of biology, social practices and culturally constituted frames of meanings in different contexts, through which clinical realities are constructed. For Good (1994), that is: how meaning and interpretive practices interact with social, psychological, and physiological processes to produce distinctive forms of illness and illness trajectories. Meanings and symbols attached to symptoms compress a reflection and, at the same time, both motivate experiences of illness, social relations and the social stigma.

Goffman (1963) has conceptualized *stigma* as a deeply discreditable attribute of an individual or a group. Parker and Aggleton (2003) affirm and acknowledge the influence of social interactions used to create and maintain social control and to produce and reproduce social inequality. For Scrambler and Hopkins (1986) overt acts of discrimination is often called *enacted stigma* that denotes inflicting blemishes and suffering on people who are regarded as undesirable by the society. Dodor (2008) posits that tuberculosis stigmatization may be both real and perceived e.g. in Ghana individuals with tuberculosis are banned from attending public gatherings. Stigma towards tuberculosis may result in delays in seeking treatment, lower treatment compliance, and family members keeping cause of death secret allowing the disease to spread further. Dimitrova (2006) informs that in Russia tuberculosis patients' fear of unemployment is a major obstacle to patients seeking care and a reason for delays in diagnosis. People are afraid of losing their jobs, and that's why they don't seek help. For Alterado (2013), stigma contributes to suffering from illness and may delay presentation and treatment leading to prolonged transmission of infectious diseases, drug resistance or complications that increase treatment costs for this treatable health problem. Dhingra and Khan (2010) observed widespread stigma at society level with 60% of the patients hiding their disease from friends and neighbours in New Delhi.

In Nepal it is a general belief that tuberculosis is not curable, and people do not seek treatment so that to avoid shame and unfair treatment from the people living around them. Aryal et al. (2012) argue that social stigma is a barrier for successful care of people because tuberculosis is considered as a filthy disease, a death punishment or as affecting guilty people that impair self-esteem, bring shame or embarrassment with less respect from others in the society. Banstola (2012) affirms that accessing DOTS (Directly Observed Treatment) strategy medications can be particularly difficult for women, the poor and backward caste people in Nepal. Baral et al. (2007) opine that the causes of self-discrimination of tuberculosis patients include the fear of transmitting tuberculosis, and avoiding gossip and potential discrimination. For Andrew and Norris (2010), discriminatory misconceptions lead to stigmatization of tuberculosis that hinder tuberculosis control and increase diagnostic delay and treatment noncompliance. Cremer et al. (2015) squabble that

consequences of stigma include low self-esteem, insults, ridicule, discrimination, social exclusion, and isolation leading to a decreased quality of life and social status, non-disclosure, and difficulties with treatment compliance and adherence.

The stigma is worse than the disease, and healthcare providers may unintentionally reinforce stigma, as those with tuberculosis are often perceived as difficult or otherwise undesirable. Despite this, anthropological studies on relationship between tuberculosis, stigma and suffering and ramifications on treatment are rare, and the similar efforts to decrease stigma surrounding have been minimally effective. Medicine may work effectively to treat physical pain but for the treatment of psychological pain (a subset of suffering); it is necessary to contemplate on sociocultural dimensions. As the social insights and suffering from tuberculosis are the outcome of cultural understandings hence medical anthropological perusal is relevant to understand the stigma of tuberculosis, so as to develop strategies to minimize the effects on patients. Lönnroth et al. (2009) affirm that addressing the social determinants of health is a shared responsibility across disease programmes and other stakeholders within and beyond the health sector. For Dahal (2013), to deepen the understanding of tuberculosis-related stigma and to develop improved theories to explain its causes or mechanisms in least developed countries, it is necessary to understand the mechanisms, then we will be in a better position to develop strategies to sustainably reduce tuberculosis related stigma.

Objective and Methods

The key objective of this paper is to explore the social insight on tuberculosis and the suffering of tuberculous infected people in Nepal. The primary data was congregated from 35 registered tuberculosis infected people of Regional Tuberculosis Centre, Pokhara, Nepal. Nature of data was quantitative and qualitative obtained through primary sources viz. interview schedule, case study and participation scale (P-scale). Interview schedule included 45 questions which explored data on social insights, stigma and suffering. Case study guidelines included different dimensions of discrimination and distress.

For controlling the validity and reliability, a generic assessment checklist was designed on the magnitude of stigma and discriminations related to tuberculosis and pre-test was consummated at about 10% of sample size at one another tuberculosis center - Shisuwa Primary Health Care Centre of Kaski district, Nepal that assisted in maintaining consistency of reliability across time, items and respondents. This facilitated in assisting validation of measurement tools so that to represent the variables they are intended to. Ethical approval in the form of verbal consent was obtained from each respondent before administering the interview and they were convinced of the confidentiality of their identity. The field study was conducted during September 3 to 29, 2019.

Conceptual Framework of the Study

Community's social insights on tuberculosis produce stigma and discrimination for curative tuberculosis, consequently stigma and suffering become grimmer than tuberculosis. Building on anthropologist Douglas (1966) notion of *purity and pollution*, insolent social insight considering tuberculosis as a *pollution (impure)*, stigma, and the subsequent social discriminations contribute to social sufferings. Consequently, the people infected with tuberculosis try to conceal their health problem which leads to relapse of cases and alter the health seeking behaviour resulting in the treatment failure, death or severe future health problems. The conceptual framework of the study illustrates in aspect.

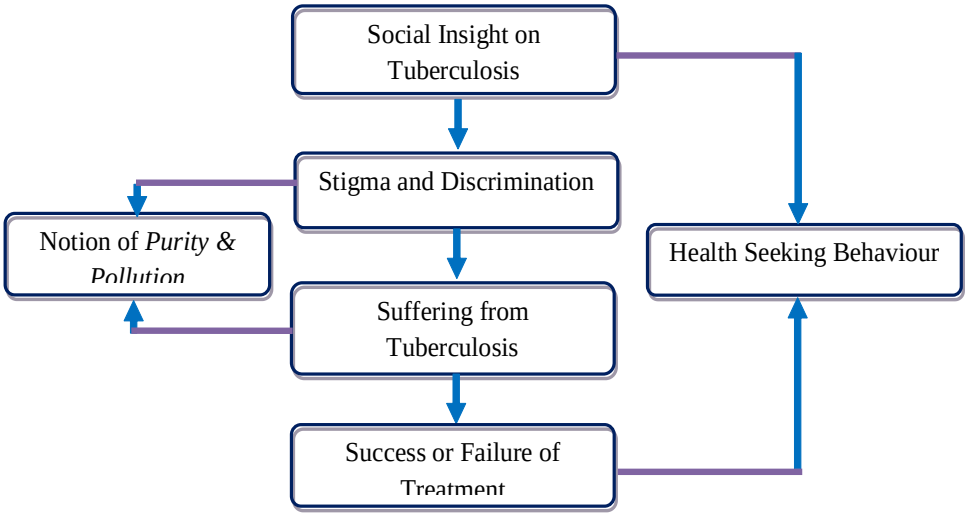


Figure 1: Conceptual Framework

Discernment on Tuberculosis

Of the 35 tuberculosis infected people registered in Regional Tuberculosis Centre Pokhara, 37 percent are *Janajati* (ethnic groups) followed by 29 percent *Kshetri*, 23 percent low-caste *Dalit* and 11 percent high-caste *Brahmin*. The majority 77 percent tuberculosis infected people are Hindus, 20 percent Buddhists and 3 percent Christians. About 54 percent infected are less than 30-years age, followed by 31 percent between 30-60 years and 14 percent above 60 years. The minimum age and maximum age is 14 years and 72 years respectively. Around 54.3 percent infected are male and rest are female (45.7%), 51 percent are married, 40 percent single and the rest are widow (er). About 33 percent tuberculosis infected are the professionals like teachers, officers, clerks, bus/taxi drivers, carpenters and ironsmiths, 29 percent are housewives, 23 percent students, and the rest are the farmers. Majority 94 percent are literate. Among the literate, 69 percent are formally educated.

The preponderance 83 percent infected contemplate tuberculosis as an infectious disease followed by 11 percent considering tuberculosis as a lung disease caused by bacteria and only 6 percent regarded tuberculosis as a general disease. For 77 percent infected, persistence cough for a month is a major sign and symptom of tuberculosis. Other infected perceived continuous fever, haemoptysis (coughing up of blood), chest pain, sweating and anorexia (loss of appetite) as the major symptoms of tuberculosis. About 75 percent professed that tuberculosis is caused by bacteria, 19 percent regarded poor hygiene and 6 percent infected took virus as the cause of tuberculosis which is incorrect.

About 71 percent infected hold the notion that tuberculosis could be transmitted through droplet, and the rest perceive eating together, using fomites and hand shaking as the major transmitter of tuberculosis. Most of them had the right answer and the only few had wrong perception (eating together, using fomites, hand shaking) regarding the mode of transmission. Around 67 percent infected had a misconception that tuberculosis is a hereditary disease. About 94 percent were convinced that tuberculosis can be treated by drugs and only 6 percent had the misapprehension that tuberculosis can be cured by worshiping god and by seeking the help of shamans and faith healers (*Dhami, Jhankri and Lama* in Nepali lexis) which validate tuberculosis patients' belief on supernatural power. Around 40 percent infected were convinced that there is the availability of traditional healers in their community for the treatment of tuberculosis. Belief on faith healers is illogical social insight that leads patients to visit a traditional faith healer which delays the medical treatment, aggravates the tuberculosis stigma and leads to severity of the disease.

A major bulk i.e. 64 percent infected were convinced that they can get treatment at any DOTS center. With multiple responses, about 86 percent of them insisted that tuberculosis can be prevented by avoiding smoking followed by 37 percent who focused on the use of face mask, 31 percent stated BCG vaccination and 20 percent focused on to get the treatment immediately. Around 71 percent of them had the easily accessibility of health workers as the source of information, the rest of the patients had the media sources like radio, television, and the relatives/ friends as the main sources of information on tuberculosis.

Social Insight, Stigmatization and Suffering

With multiple responses, around 86 percent infected acknowledged that social insight on tuberculosis is such that it is the most discriminated and polluted ailment in the community. According to Douglas (1966) the concept of *Purity* and *Pollution* exists in every society and pollution beliefs debar people from various kinds of social activities. The labeling of tuberculosis as a pollution or impure disease has structured the social insight on tuberculosis in Nepali society. Deleterious social insight regarding tuberculosis as a discriminatory sensitivity and disgrace has resulted in the subservience of the infected person, consequently for them tuberculosis is stained and similar to leprosy. It is chronic, bigoted, extortionate and the utmost stigmatized

disease in the society. This discriminatory social insight has determined the infected person's ability of making scientific judgements on tuberculosis. Hindu religion based cultural webbing of meanings associated to notions of pollution and purity has shaped the social insight on tuberculosis which is linked with fallacies, superstitions and unfriendly practices on tuberculosis. Socially constructed stigma of tuberculosis identified as unwanted by the community has led to stigmatization of tuberculosis and the resulting deflation of the infected based on a recognition of a difference on discrete characteristics of the infected person. About 81 percent patients sensed vacillation and humiliation owing to the embarrassing social insight on tuberculosis which is more social and cultural than biological.

Around 57 percent infected person's family members were infested from tuberculosis transmitted by the infected member that made the infected person feel remorseful of his disease. About 91 percent infected were living a dejected life due to the stigma attached to tuberculosis. Among those who had tuberculosis affliction, 65 percent had economic burden owing to the direct and indirect cost of treatment, 59 percent were physically weak, and 41 percent accredited mental stress along with social disgrace, discrimination by the family members, disturbance in family and marital relationship, pessimism, social distancing, and restricted occupational opportunities, unexciting life and travel restriction. Further, the tuberculosis stigma has hampered the income, daily life and has added manifold problems in the lives of infected patient that points to an association between tuberculosis stigma and variables such as monthly income, occupation, mental stress, discrimination and suffering. About 77 percent tuberculosis infected had direct cost of Nepali Rupees (NRs) 10,000 in private hospital/clinic. This health service they can get free of cost in government DOTS centre but due to the lack of awareness they paid the direct cost of preliminary treatment in private hospital and clinic. But they were ultimately referred to government DOTS for the treatment of tuberculosis. About 66 percent infected incurred indirect cost of NRs 15000 and 34 percent had NRs 15000 for getting treatment at DOTS centre. The indirect cost includes travelling cost, accommodation, snacks and meal cost, fruits, etc.

Bourdieu (2000) asserts that suffering is the collective and individual human problems associated with life conditions shaped by powerful social forces or the state of severe distress associated with events that threaten the intactness of the person. For the tuberculosis infected, in a constricted sense, suffering is a physical pain and mental/emotional pain in wide sense with distress, sorrow, misery, grief, affliction and discomfort, fear of transmission of tuberculosis to family members, economic burden, stigma and prejudice.

> As a tuberculosis victim, I left my job and started to live an impoverished lonely life, my girlfriend left me. I have not participated in social activities. I am impoverished, distressed and created distance from the society that has added to my physical and mental suffering. (Distress of a tuberculosis patient)

About 51 percent tuberculosis infected patients were suffering from tuberculosis since more than 6 months and 49 percent were tormented by tuberculosis for less than 6 months. The minimum and maximum suffering months from tuberculosis were two months and thirty-six months. Since the culture and society is organized and influenced by the issues of health, disgrace and prejudice, the tuberculosis infected were stigmatized by their family member, neighbours, friends and relatives. False notion and cultural fallacies on tuberculosis exacerbated their suffering. Most of them experienced the stigma due to the filthy (polluted) disease tuberculosis – as ascribed by their community.

> In my journey of suffering from tuberculosis, I am undergoing DOTS treatment. My mother-in-law criticizes tuberculosis as polluted. In my community there is a saying that tuberculosis is filthy due to the sin of previous birth. I did not share my agony; I am a silent sufferer. (A housewife experiencing tuberculosis)

Social disgrace attached to tuberculosis and the resulting restriction on social participation has added to the despair of tuberculosis infected. Around 74 percent of them had significant restriction, 23 percent had experienced mild restriction and 3 percent had moderate restriction on social participation. Participation restriction differs for different age groups. Around 64 percent elderly people above the age of 60 years experienced more restrictions on social participation which depicts that restriction on participation increases with the increase in age. With more access to media and education, young adults have fewer restrictions on social participation. Females have severe restriction on participation than male. About 33 percent female patients had participation restriction compared to 21 percent males. There is a variation in participation restriction by caste and ethnicity consequently 30.8 percent *Janajati* had severe restriction on participation, 30 percent for *Kshetri* followed by 25 percent for *Dalit* and 12.5 percent for *Brahmin*. The high caste Hindu *Brahmin* had less social restriction than other ethnic group. Except for treatment, the tuberculosis infected had restrictions on visit outside their village and neighborhood viz. market, public places as school, shops, offices, market and tea and coffee shops. Almost half of the infected people had restriction on equal opportunity in taking part in casual recreational and social activities as sports, meetings and in visiting people in the community, religious/community affairs, on helping neighbour/ friends, and relatives. There were restrictions on meeting people, to learn new things as other normal people do, and to start/maintain a long term relationship with life partner owing to the stigmatization related to tuberculosis as a grubby disease.

Ascription of tuberculosis as a polluted disease, ensuing stigma and social sufferings have made patients life worthless and has forced them to conceal their health problem that may delay the treatment phase and the history of illness. Connotations and proscriptions attached to tuberculosis has enthused the experiences of illness, social relations and the social stigma. The collectively rooted social relations

of everyday life and the suffering as an experience divulge the plight of tuberculosis patient and the violence of their human rights.

> I do not share about my tuberculosis ailment to others due to fear what they will say. They will not allow me to stay in the community. Society's view on tuberculosis is extremely negative, discriminatory and against the human rights. I feel remorse for being a tuberculosis patient. (Anguish of a sufferer)

In a *caste-ridden* and *priest-ridden* Hindu society, discrimination by the community is due to the fear of the risk of infection and perceived links between tuberculosis and disgraceful behaviour and the perception that tuberculosis is pollution and a divine punishment of the previous life. This perception itself is the product of social dynamics and tuberculosis as filthy illness has reshaped individual and community's identity which is expressed through assorted taboos and activities that shape how people observe tuberculosis. False notion based socially constructed community norms, the disgrace of tuberculosis and the downgrading of tuberculosis patient have made stigma more dangerous than tuberculosis infection. Both *social stigma* (public perception of stigma) and *self-stigma* (infected persons'self-judgement and mortification) generate negative stereotypes and define tuberculosis infected people as different and prevent them from being seen as a normal human. Many infected people internalize the community enacted stigma as a sociocultural phenomenon that relegates, stigmatize and constrain their life chances consequently contributing to suffering in various ways that delay presentation and treatment leading to prolonged transmission of infectious agent, drug resistance or complications that increase treatment costs for this treatable health menace.

Conclusion

The well-being of tuberculosis infected person is reliant on the perception of the sociocultural meanings of the infectious agent and disgrace attached to it that has led to discrediting community, restricted social interactions and detrimental impacts on diagnosis and treatment seeking behaviour. The orthodox sociocultural meanings of tuberculosis, dogmas and fallacies based socially constructed illogical social insight considering tuberculosis as the most perilous disease in the community has contributed to stigma, discrimination and suffering of the infected person. The sociocultural molds and meanings stemming from the notion of purity and pollution (tuberculosis as a polluted or impure disease) have shaped the local society that has deleteriously influenced health, well-being and human rights of the tuberculosis infected person.

Since the sociocultural constructions of health and the community's culturally established frames of meanings configure the clinical realities and standardize the ways in which the people experience and suffer from diseases, the tuberculosis stigma should be deliberated as a biosocial and psycho-cultural phenomenon requiring comprehension of biological and sociocultural lenses of culture and health. The dangerous and false information based *infodemic* fallacy on tuberculosis needs to be clogged by developing community ability to distinguish real information from the

false so that tuberculosis may be virtuously considered a normal macrobiotic phenomenon. Further, it is indispensable to consider sociocultural information in tuberculosis healthcare planning, policy making and programme implementation.

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