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Psycho- Social Problems and care of Tuberculosis Patients: Need of the Hour

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Abstract

Tuberculosis (TB) is an ancient disease, described in Vedas (200 BC) as the “king of diseases”. It is a social disease with medical aspects. Worldwide 2 billion people are infected with TB. Therefore 8 million new TB cases each year and nearly 2 million death occurs annually, 40% of these people are in South East Asia. India accounts for nearly one third of the global burden. 40% of the Indian population has TB infection. Every day in India more than 20,000 people become infected with the TB bacillus and more than 5,000 people develop TB. The society does not accuse one of dependence when one is ill and is being taken care of by the members of the family. There are seems to be among some people an unconscious drive to develop a disease that would meet their needs of dependence. Consequently they overlook all precautionary measures, become careless about their health and contract the disease. During the period of treatment, such patients are not usually concerned about their recovery but about being cared for. At the times they are a headache to nurses. They want everything to be done for them and literally sulk when nurses or relatives fail to meet their needs. On the other hand, there are persons who by insistence on independence reveal their inability to accept any type of dependence. Social Work is of great help with its methods of helping people to help themselves by using its case work, group work and so on. Thus it’s the need of the hour.

Introduction: Tuberculosis (TB) is an ancient disease, described in Vedas(200 BC) as the “king of diseases”. It is a social disease with medical aspects. Worldwide 2 billion people are infected with TB. Therefore 8 million new TB cases each year and nearly 2million death occurs annually, 40% of these people are in South East Asia. India accounts for nearly one third of the global burden. 40% of the Indian population has TB infection. Every day in India more than 20,000 people become infected with the TB bacillus and more than 5,000 people develop TB. Every year twenty lakhs people develop TB in India of which at least eight lakh are infectious (sputum positive). Every year, nearly five laths die of TB; 1000

deaths per day, one TB death per minute. Untreated TB cases spread the infection to others in the community; each infectious patient can infect ten to fifteen individuals in a year unless effectively treated. In India TB kills fourteen times more people than all tropical diseases combined, twenty one times more than Malaria and four hundred times more than leprosy. Low-income people are at higher risk of getting TB as it spreads in crowded places—households, school, workplace, marketplace and commutes between them (Health and Development Initiative 2004). TB kills more women in India than any other infectious disease and causes more deaths among women than all causes of maternal mortality combined. Moreover, women with TB are stigmatized—more than 100,000 women are rejected by their families each year because of TB. The disease also has an adverse impact on children—it leads to a large number of children becoming orphans, and every year in India alone, 300,000 children leave school on account of their parents' TB (Government of India 2004). Because more than three quarters of people with active TB are in the economically productive age group (15–54 years), the economic and social costs to them and the society are huge (Health and Development Initiative 2004). On an average, 3–4 months of work time are lost if an adult has TB, resulting in the loss of 20%–30% of annual household income. An average of 15 years of income is lost if an individual dies of the disease (Government of India 2004). Every year, TB costs India more than Rs 13,000 crore. In addition, every year, TB patients spend more than Rs 645 crore in seeking private care for TB. It has been estimated that if the GOI spent even US\$ 200 million (Rs 900 crore) per year on effective implementation of Directly Observed Treatment, Short course (DOTS), the tangible benefits to the Indian economy would be worth at least US\$ 750 million per year (Rs 3375 crore) (WHO 2004).

Tuberculosis and Economic Issues: The burden of TB in India is indeed staggering by any measure. TB was declared a “global emergency” by WHO over a decade ago because of its toll on the health of individuals and its wider social and economic impact on overall development of a country. More than 80% of the burden of tuberculosis is due to premature death, as measured in terms of disability adjusted life years (DALYs) lost. In India, over 70% of the cases occur in the economically productive age group (15–54 years) and is one of the leading infectious diseases causing death. As per WHO estimates in 2004, 370,000 persons in India died of tuberculosis (mortality rate 30 per 100,000 persons), which was estimated at over 500,000 annually prior to 2000. It is not just the death figures that are startling. TB causes huge economic loss with about 17 crore workdays lost due to the disease. The annual economic cost of tuberculosis to the Indian economy is at least US\$ 3 billion (RNTCP status Report, TB India 2007).

Tuberculosis and Social Pathology: The usual victims of TB are migrant labourers, slum dwellers, residents of backward areas and tribal pockets. Known as the disease of the poor, TB often appears where malnutrition, shanty housing and overcrowding are common. It can lock the entire community into a circle of disease and poverty. Women are doubly disadvantaged. They largely ignore medical help in the initial stages, not wanting to neglect household responsibilities. A TB-affected mother can pose a threat to the entire household

as she is close to her children and has to perform household duties. In many cases, children whose mothers died of TB were found to be infected. TB deaths among women have major implications for child survival, economic productivity and family welfare. Women try to suppress TB symptoms fearing stigma and rejection. More than 100,000 women with TB are abandoned by their families every year, making it a major deterrent to women's empowerment. More than 300,000 children are forced to leave school every year, because their parents have TB. The social stigma of the disease adds to the burden for both men and women. Studies indicate that while men have to deal with the stigma at their workplaces and in the community, women are ostracized in the household and neighbourhood (RNTCP status Report, TB India 2007).

Well, TB is an infectious disease caused by the Mycobacterium Tuberculosis. TB bacilli mainly affect the lungs, causing lungs, tuberculosis (Pulmonary TB), however in some cases; other parts of the body may also be affected, leading to extra pulmonary TB. Extra pulmonary TB is more common in HIV- infected people.

TB germ usually spread through air when a patient with untreated pulmonary TB coughs, sneezes, or talks, he in voluntarily throws TB germs into the air in the form of tiny droplets. These tiny droplets when inhaled by another person may cause TB. When patients with TB begin taking effective treatment they stop spreading the germs within a few days to weeks. But unless they take the treatment regularly and complete it they are likely to develop more dangerous forms of TB, known as Drug resistant TB, which can spread to others. Once infected with M. Tuberculosis, a person stays infected for many years probably for life. The vast majority (90%) of people without HIV infection who are infected with M. tuberculosis do not develop tuberculosis disease. The bacilli remain dormant in their bodies. About 40% of our population is infected with the TB bacillus, of these about 10% will develop the disease. Infected persons can develop TB disease any time various physical or emotional stresses may trigger progression of infection to disease. The most important trigger is weakling of immune resistance, especially by HIV infection.

Causation of Tuberculosis: Private providers report that female TB patients sometimes try home remedies because of negligence and financial problems. Similar perceptions have emerged from non-affected community members. Community's perceptions of the disease TB influence their attitudes towards TB patients. Non-affected female community members believe that women patients are disturbed psychologically as they are isolated at family as well as at community level and hence try to hide the disease. They also perceive problems in arranging a marriage for unmarried girls, problems with in-laws and husband for married females. (Sudhakar Morankar, Nishi Suryawanshi 2000).

A case control study conducted to 103 tuberculosis cases and a similar number of age, sex matched controls to find out the difference in illness behaviour profile of the two groups. The tuberculosis patients were receiving treatment from two DOTS centres in East Delhi and the controls were from the same locality. The tuberculosis patients exhibited features pertaining to general hypochondnasis (GH), affective inhibi- tion (AI) and affective

disturbance (AD) more than the controls and the differences between the two groups were statistically significant. However, denial of problem (D) was seen more in controls compared to tuberculosis patients. The study assessed that Illness is a dynamic process and change in behaviour could occur at the various stages of illness. Tuberculosis causes social stigma and results in adverse psychological reactions including a higher degree of neuroticism and psycho-sexual disturbances however, present study shows that psycho-social elements have been largely ignored under DOTS. (S. K.Bhasin, Atul Mittal, O.P.Aggarwal & R.K.Chadha, 2001).

In a sociological study of Stigma among TB patients in Delhi, it was found that No Stigma at family level, and the family members by large were found supportive to the patients. At work level, the study showed that there were no any stigma, with 80.8% having disclosed their disease to their colleagues and 77.9 % to their employers. But accordingly to sex , less number of female patients shared their disease with colleagues as well as their employers as compared to males.At the society level the study revealed that there were immense stigma, i.e 60% of the patients hide or conceal their disease from the friends or neighbors . Moreover the stigma was observed to be more among females.(V.K. Dhingra and Shadab Khan ,2009).

In “neglected aspect of pulmonary tuberculosis”. The author suggested that in medical practice, the accepted method of assessing change among patients has been to focus on laboratory or clinical tests. Although these results provide important information regarding the disease, it is often impossible to separate the disease from the individual's personal and social context, especially in chronic and progressive diseases. Kaplan and Bush proposed the use of the term "**health-related quality of life**" (HRQoL) . An objective assessment of patient's HRQoL represents the functional effects of an illness and its consequent therapy on a patient, as perceived by the patient. HRQoL measures are, however, not a substitute for disease outcomes, but are an adjunct to them. Medical interventions may result in improved functional health status without evidence of physiologic improvement and vice-versa. Several generic and disease-specific questionnaires are now available for quantifying HRQoL in patients with a wide variety of clinical disorders. Almost all instruments have been developed and validated in Western societies and patient groups. A.N. Aggarwal , 2010).

Tuberculosis at a glance in Assam

To combat with Tuberculosis, Revised National Tuberculosis programme(RNTCP) was first implemented in Dibrugarh District of Assam in the year1998-1999 and now it covers 23 district of Assam. Currently there are 68 numbers of Tuberculosis Unit (TU) and 332 numbers of Designated Microscopic Centres (DMC) to control Tuberculosis in Assam.More than 500 DOTS centres are running in the state for providing Directly Observed Treatment Short Course (DOTS) to the TB patients.

If we look in to the TB scenario of Assam , controlling TB is serious challenge for us it may devastating if recovery machinaries are unable to push the break on the wheel. A Table will help us to understand the situation in more precisely.

Name of the state	Name of the year (No. of TB Patients)		
Assam	2005	2006	2007
	23,435	32,111	36,766

Source: RNTCP State Report, Assam.

Name of the District	Name of the year	Nos. of TB. Patients
Cachar	2007	1961
	2008	2183
	2009	2543
S.M.DEVCivil Hospital, Silchar	2007	537
	2008	484
	2009	552
Silchar Medical College&Hospital	2007	169
	2008	204
	2009	228

Source: District Tuberculosis Office, Cachar, Silchar Assam.

Help seeking behaviour and scope for Social Work Intervention: The help seeking behaviour of patients in this study is influenced by various cultural and social factors, such as marital status, status in the family and interpersonal relationship with family members and the community. Help seeking behaviour is also influenced by the cost, related to the treatment, such as fees of health care providers, travel cost and opportunity costs. For obvious reasons it is a more important barrier for women, who are poor and if they have lower status. Such factors often force women to stay within the governmental health care system, although the first help seeking is reported to be private providers at the village level. Ignorance, lack of awareness of treatment availability at health facilities, time and financial constraints were found to be the factors responsible for delays in the diagnosis and the beginning of treatment.

Psycho-social problems of Tuberculosis patients and Social Work Intervention:

Causation of communicable disease like Tuberculosis cannot be explained on a purely bacteriological basis, because such an explanation ignores the fact that the disease process in man depends on the characteristics of disease agents (germs), the characteristics of man and his environment. It is often stated that tuberculosis is a disease caused by the activities of tiny rod-shaped germs, i.e. tubercle bacilli. But every seed requires proper soil for its growth and tuberculosis, germs represent one of the environmental, and social factors together with personal factors in the individual patient from the soil for the seed, i.e. tubercle bacillus. Some persons owing to faulty family attitudes develop an inordinate need for affection and dependence. These needs may be openly expressed, disguised or even totally denied. For such people along drawn out disease like tuberculosis provides an opportunity for meeting their needs in a socially acceptable way. The society does not accuse one of dependence when one is ill and is being taken care of by the members of the family. There seems to be among some people an unconscious drive to develop a disease that would meet their needs of dependence. Consequently they overlook all precautionary measures, become careless about their health and contract the disease. During the period of treatment, such patients are not usually concerned about their recovery but about being cared for. At the times they are a headache to nurses. They want everything to be done for them and literally sulk when nurses or relatives fail to meet their needs. On the other hand, there are persons who by ostentatious insistence on independence reveal their inability to accept any type of dependence. They have an unconscious need for self drive. This may arise out of a basic conflict regarding compliance with demands of dominating parents under protest. In course of years, the authority against whom they had opposition is internalized. As a result, their conscience takes up the role of dominating parents and compels them to yield to its demands. As something from within goads them to overexert themselves, such people feel very uncomfortable if they are debarred from doing so. In short, they have needed to overexert themselves even at the cost of lowering their resistance to the disease. There are some varied personal factors that play a significant role in leading some persons to take steps which are suicidal in that they expose them to disease.

No less important is the fatalistic attitude towards life. If it permeates families and communities it brings in lethargy and inertia. All the responsibility of controlling the disease is shoved on to god. Attitude on the part of the individual (personal factor) as well as community (environmental factor) is a stumbling block in the way of controlling disease. Closely allied to the above cultural factor is the influence of industrialization and urbanization of our country. Consequently a large section of population facing stress and strain associated with the change over from rural to urban conditions. Due to proper housing and other facilities are provided to them, the tubercle bacilli will find a favourable soil for them. The extent of tuberculosis in a community depends largely on its standard of living. The higher the standard of living the lower is the incidence of tuberculosis.

Psycho-social and Psycho physiologic Studies of Tuberculosis have highlighted that the tuberculosis subjects to be sensitive, anxious, rigid, and emotionally labile. These patients,

when compared with the cultural norms, were in many ways marginal people at the time of onset of tuberculosis. They started life with an unfavorable social status and grew up in an environment that was for them crippling. They were, in essence, strangers attempting to find a place for themselves in the contemporary American scene. The nature of their attitudes and life experiences made it unusually difficult for them to decide what was expected of them or what they expected of themselves. As a consequence their attempts at adjustment were characterized by unrealistic striving which was not only unrewarding but also productive of cumulative conflict, anxiety, and depression.. The manifestations of the life crisis that ensued included high frequencies of broken marriages and changes in residential and occupational status. Alcoholism, frequent and persistent psychosomatic disorders, and mental illness were common. It was in this setting of increasing life stress acting on individuals whose limited capacities were no longer adequate for resolving problems or achieving satisfaction that tuberculosis developed. (Thomas. H, Norman. G, Hawkins, Charles. E, Bowerman , Edmund. R, Clarke. JR and Joy. R, Joffee., 1965).

A study on Psycho-social variations of hospitalized TB patients in TB Sanatorium named Hermitage, in Sangrur District of Punjab, the findings reveal that the peak age of the patients was in the range of 25-45 years; that most of the population of that Sanatorium was illiterate, and their socio-economic status was poor. Eighty-two percent of the patients came from the countryside. About 56% of the male patients had a habit of drinking. Only 13% of the patients had disturbed family relations. No correlation was found between the patients' attitude towards their illness and the physician's rating about the severity of their illness. The Psychological Tests indicated that TB patients did not have different neurotic scores when compared with patients with other chest diseases. (Avinash CM & Dwarkapershad ,1972).

The study aimed to determine some of the psychosocial variables of hospitalized male and female TB patients. Evidence suggesting social rejection, apprehensions about life and unhealthy family relationships were looked for among the responses to the tests. A significantly higher number of females (72%) perceived their childhood as having been difficult compared to 45% of the males. There was no difference in male and female patients with regard to indications of disturbed interpersonal relationships. More females projected fear of death and fear of being cast out of the social sphere than males. This result is probably due to the social settings, where most females are found to be economically dependent. (Dubey, B.L. 1975).

Psycho-social study on tuberculosis patients in outpatient clinic of Tuberculosis and Chest Diseases, S.R.N. Hospital, Allahabad. Findings showed that a larger number of tuberculosis patients (32%) demonstrated the presence of depression in comparison to control cases (7%). (A.K. Tandon, S.K. Jain, R.K. Tandon and Ram Asare. 1978) .

A study made on Socio-Cultural Aspects of Tuberculosis Among Women in Western rural Maharashtra, India. Findings analyzed that (77%) of the female TB-patients to seek medical help. A majority mentions "physical symptoms" as the main distress of the disease, but for 28% sadness, anxiety and worry were the most disturbing problems related to the disease.

Even patients who are treated in their natal village and who receive support from their parents reported psychological problems. Narrative accounts showed that they are worried about their husband's sexual behaviour during the period of their treatment and the risk of his marrying another woman. This worry and tension compel them to complete the treatment as soon as possible in order to go back home. They were found to be severely affected by stigma. Many of these women are treated normally by their in laws until the disease is diagnosed. Once TB is diagnosed, they are often sent back to their natal home. Those staying in joint families (30%) reported that except their husband nobody in the family was aware of the disease and that they were always under the tension and fear of disclosure. Widows (17.5%) perceive a high level of emotional, psychological and economic burden if they are suffering from TB.

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