

GENERAL

SOCIO-ECONOMIC CONSTRAINS FACED BY TB PATIENTS THAT LEAD TO NON-COMPLIANCE – A CROSS SECTIONAL STUDY IN SOUTHERN PUNJAB, PAKISTAN

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Abstract: Tuberculosis (TB) is an infectious disease that is communicable from one person to another. Pakistan stands forefront among few unfortunate countries that still have heavy burden of TB infection. Being a developing country, TB patients in Pakistan have to face different socio-economic constraints that upset life of the patients as well as their families. A cross sectional survey was conducted in three selected districts, Lodharan, Bahawalpur and Bahawalnagar during February 2011 to June 2011. From three hundred selected patients 210 were enrolled in study after receiving written consents. Data were collected through structured questionnaire and verbal interviews and statistically analyzed by using the univariate analysis. The survey results showed that the low educational status ($p < 0.0012$, CI 95%), unawareness of disease (88.7%), crowded population ($p = 0.0000$, CI, 95%), poverty, high treatment cost and distant access to public health facilities were directly related to prevalence of TB. Different disease related constraints including poor attitude of family members, colleagues, society and even health care professionals ($p = 0.0000$, CI 95%) were also found to be major social factors leading to non-compliance and denial of TB treatment. Socio-economic constraints such as low literacy rate, unemployment, unawareness of disease, high treatment cost, poor attitude of family, society and healthcare professionals were directly related to noncompliance and should be given high priority consideration for achieving better TB management and mitigation.

Keywords: tuberculosis in Pakistan, non-compliance, socio-economic, social stigma.

Tuberculosis (TB) is a contagious disease caused by a bacterium, *Mycobacterium tuberculosis*. TB mainly molests lungs but severe infection can also involve vital body organs such as kidney, spine and brain. Upon coughing or sneezing, the TB patient expels small aerosol droplets in air that carry infectious bacteria. In this way, a TB carrier can contaminate the healthy surrounding and inducts his fellows on the risk of being infected by TB (1). Every year, around 9 million new TB cases are reported and approximately 2 million of these patients die (2). As reported by stop TB partnership in 2010, 85% TB cases were reported in Africa (30%) and Asia (85%) although per capita incidence was found to be falling 1% per year and death rate has reduced to one third since 1990 (3). Cost of TB treatment is related to sex, age, stage of TB and insurance coverage. If the annual income is considered near 8000 \$ in 2008, the expenditure of TB could pose catastrophic financial constraints for any family (4).

Pakistan is a developing country and TB has posed a serious health challenge. Pakistan is ranked 5th in the high TB burden countries and estimated to have 4th highest prevalence of multidrug resistance (MDR) TB. In Pakistan, 420,000 new TB cases appear each year and mortality rate is 39 per 100,000 people (6). Most Pakistani population belong to lower middle class thus direct and indirect costs associated with TB treatment may appear to be a key concern for them. In Pakistan, 75% TB patients have age between 19 to 50 years who are mostly responsible for earning family livelihood (8). Thus, TB could have far-reaching economic and social consequences for the infected individuals, their families and communities. The study of Ali et al. showed that majority of TB patients were poor and consulted conventional health care professionals initially. The correct diagnosis of TB was discovered only after repeated visits. This resulted in advancement of illness which tend to increase the cost of treatment by many folds (9).

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Social contact with family, friends and relatives constitutes a very essential part of social life. In Pakistan, people avoid TB patients due to fear of getting infection. The social life of TB patients is stigmatized and affected negatively due to poor knowledge of disease, different socio-cultural myths and misconceptions in general public. In a study, around 57% respondents proposed that separating dishes of TB patients could be a good preventive strategy (10), while in another study, 76% respondents proposed that patients of TB should be treated in hospitals or sanatoriums (11). Almost 40% respondents claimed that they would not marry a person who had active TB or even history of TB in the past. Due to all these fears, most TB patients kept their disease hidden from their friends, relatives or from both. This defiant behavior of the patient led to denial of the treatment, represented by 50% to 70% defaulting rate in different treatment regimens that led to emergence of drug resistance and new TB cases (12, 13). Muynck et al. comprehensively reviewed Pakistan national TB control program (NTP) and concluded that NTP has not been implemented to required extent and may not be able to fulfill its objective (14, 15).

The economic impact of TB and fear of social stigma tend to drive the patients away from seeking treatment. An insight into different socio-economic constraints may help to find the answer to the most bitter question associated with TB; why patients of such a horrible disease commit non-compliance?

Objective of the present study was to identify and evaluate different socio-economic constraints that a TB patient has to face over the course of treatment. The study has also aimed to find the sig-

nificance association among the different socio-economic variables and emergence of non-compliance during the course of TB therapy.

METHODOLOGY

Cross sectional descriptive study design was adopted to study socioeconomic factors of non-compliance in TB patients from February 2011 to June 2011. Structured questionnaire and verbal interview were used as most suitable data collection tool because of unavailability of complete medical record and patient's history in the selected clinical settings. Sample size for the present study was calculated based on disease prevalence in the study area (15). In the present study, 300 TB patients were contacted by using the convenience sampling technique from the TB population registered under provincial tuberculosis program in Bahawalnagar, Lodharan and Bahawalpur districts of Southern Punjab. Only 210 patients provide written consent for survey and were enrolled in the study. These districts were selected due to high prevalence of, and being indicated as hotspot of tuberculosis by national tuberculosis program. The survey questionnaire inquired information about; 1. previous disease history; 2. family size; 3. position in family; 4. information of infection during treatment; 5. nature of dependents; 6. source and extent of monthly income; 7. family attitude/behavior to the patients; 8). attitude of close friends/colleagues/health physician to the patient; 9. support or motivation from government or any NGOs; 10. change of mood after start of medication; 11. acquisition of TB drugs and processes of the TB treatment; 12. prevalence of

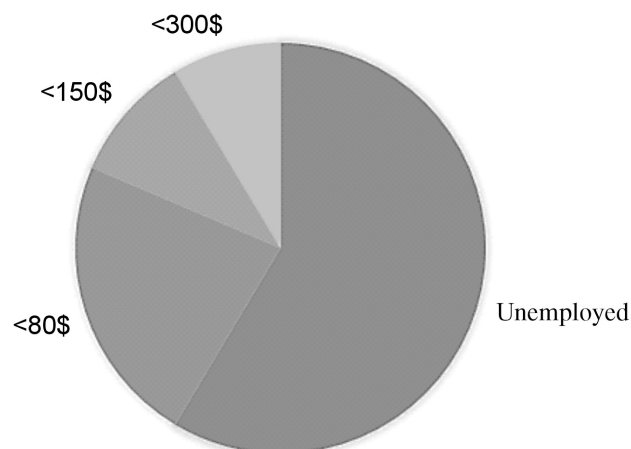


Figure 1. Employment status and monthly income (USD per month) of TB patients

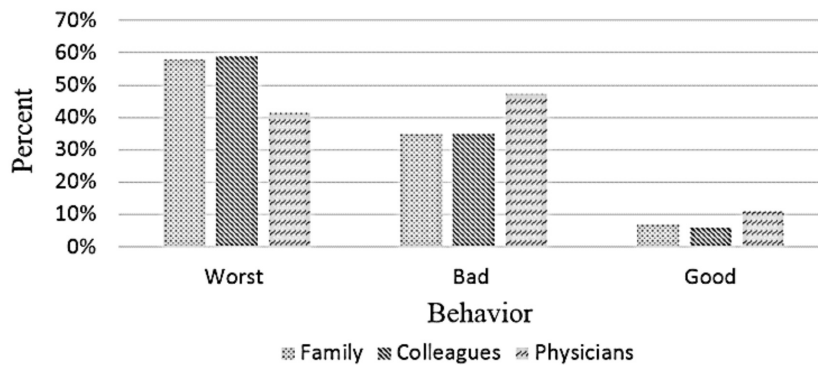


Figure 2. Behavior of family, colleagues and health physician towards TB patients.

common adverse effects; 13. access to TB Health Care Centers; 14. constraints in drugs receiving process; and 15. quantity of available drugs from health Centers. Data entry was done by using MS Excel 2007 and analyzed with SPSS version 10.0. Means and standard deviation (SD) were computed for the continuous variables i.e., age and treatment duration before noncompliance. The independent association and important risk factors were determined using the univariate regression analysis by taking p -value ≤ 0.05 as statistically significant with a confidence interval (CI) of 95%.

RESULTS

The survey involved active TB patients with the aim to identify and evaluate different socio-economic constraints that TB patients had to face in Southern Punjab, Pakistan. Demographic characteristics and their statistical significance are shown in Table 1. No significant difference was found in gender ($p > 0.05$) as both males and females had similar prevalence. Difference in age groups, marital status, treatment duration before noncompliance and literacy rate were found to be highly significant ($p < 0.0012$). Present study indicated that TB awareness was very poor in general public as well as patients. Most of the patients believed that TB is a contagious and almost half of them correctly described the symptoms of the TB. However, 88.7% patients were not familiar with the risk factors and the precautions that should be adopted during the course of the treatment.

With respect to economic status, we found that 51% patients had more than 8 family members. 40% patients had 4-8 family members, 8% patients had 2-4 family members while only one patients (0.5%)

had one family members ($p = 0.0000$, CI, 95%). A majority of TB patients (92%) were heads of the family and responsible for all the liabilities of their families. Of the 193 head of families, 52% patients had more than 8 dependents. In this study, 203 (96.7%) patients claimed that they were already suffering from miserable economic conditions before contracting TB. Results regarding employment status of TB patients showed that 75.3% patients were unemployed (Fig. 1). Of the remaining 23.7% employed patients, 17.3% had monthly income less than 80 USD, 3.3% had monthly income less than 150 USD and only 2.9% had monthly income more than 150 USD and less than 300 USD ($p = 0.0000$, CI 95%). Results of this study also identified delayed diagnosis as key factor; almost 44.3% patients were diagnosed with TB after 1 year while 33.9% patients took more than 2 years to be diagnosed properly.

With regards to social status, all TB patients complained that they have been facing bad to worst behavior of the society (Fig. 2). 58% patients complained that the behavior of their family turned to worst after they were identified with TB ($p = 0.0000$, CI 95%). When questioned about behavior of society, 59% patients complained worst and hateful behavior of their colleagues ($p = 0.0000$). From healthcare providers prospective, results showed that 41.7% patients complained worst behavior of physicians and health care worker ($p = 0.0090$, CI 95%). In addition, 92.9% patients under study responded that they neither received any motivation from the society nor any support from governments and non-government organizations. Most patients reported change in their attitude with the disease; 92.3% patients felt that they had developed different types of feelings and attitude ($p = 0.0045$).

Another important aspect was patients reported problems with drugs and drug seeking process. Most patients reported that drugs were unbearable (90%), partially available (82%) and have difficult treatment procedure (73%). Patients reported high prevalence of common adverse effects of TB drugs such as insomnia (62.9%), nausea (22.8%) and headache (14.3%). Distance to the nearest health care facility was also found to be a treatment limiting factor in 74% patients.

DISCUSSION

Pakistan is a populous country and most of its population (almost 68%) resides in rural areas that lack sufficient health care facilities. Southern Punjab areas of Pakistan mainly consists of villages and underdeveloped areas with inadequate education. The study in the three different hospitals of Greek indicate that the non-compliance was contributed by the low literacy in 71.80% patients (16) that strengthen the results of present study. Due to low literacy rate the patients just knew the signs and symptoms of disease, but were unaware of different risk factors and precautions that should be adopted during the course of the treatment. This lack of awareness lead to poor control of disease and its spread to the society (10). These findings are in accordance with the results of Reshmi et al. which find that a majority of the patients in Mysuru were unaware of the contagious nature and other risk factors associated with the transmission of the disease (17). The study results also demonstrated that a majority of patients had populous families and did not care if they were spreading disease to others. This was a very alarming situation in terms of safety. According to World Health Organization, one untreated TB patient may spread the disease to 10-15 healthy persons including those who are taking care TB patients and their children (18). Various studies in Pakistan and India showed that health workers and media stood the major source of information regarding health related problems (19, 20). Thus, health care centers should be establishing dedicated information sections that provide information politely on various risk factors, precautions and treatment associated complication in order to develop a comprehensive control strategy.

Social life and behavior have been correlated with prevalence of TB and its effects were estimated in different studies. We found that more than half of the patients reported bad to worst behavior from family and colleagues alike. This behavior of hater resulted in loss of confidence and self-worth occa-

sioned by rejection from people who were very important to them (21). Fox et al. (2015) found that the discriminative behavior of the family and society (47%, OR 1.55, adjusted 0.95-2.53) was a more common perception in the TB patients of Vietnam (22). In addition, more than one third patients pointed out that behavior of physician has been worst at health care centers. Many patients claimed that they stopped visiting health care centers because of depraved behavior of the society. Compliance with treatment regimen cannot be ensured without physician's belief of an obligation to facilitate potential noncompliance of patients. A physician's role is to politely make the patients informed of benefits of compliance and aware of the risk factors for nonadherence. Any feeling of hater or avoidance would make adherence more difficult to patients than it has to be (12). These results supported the need of implementation of National TB Control Program (NTP) guidelines which urge physicians and health care workers to develop, alter or modify their behavior in order to motivate TB patients and ensure patients compliance with treatment regimen (23).

Present study indicates that economic constraints play a major role in emergence of non-compliance and associated denial of treatment. Most patients were poor. Patients initially spend hefty sums on treatment from conventional under-qualified general health practitioners and conventional medicine practitioners. When TB was diagnosed, patients had to face various socio-economic constraints including unemployment. Many patients also claimed that they had to face cut-off in working hours due to disease. This makes patients tempted to hide the disease from colleagues and employers. These results also confirm the status of TB as "the disease of poor". In Pakistan, a patient averagely pays direct cost of PKR 1500-1800 per month for TB treatments (24). Unfortunately, a majority of patients were earning less than this. These economic factors may ultimately lead to malnutrition, which is itself a risk factor of non-compliance (24). Conditions could be especially awful for women who are dependents on their family for food and medicines. TB infection in girls was found to be associated with denial of marriages. Some married women also told that they were separated from their children due to fear of spreading infection to children and other family members. In Southern Punjab, there were no effective financial aid schemes from government or non-government organizations (NGOs) and such families were mostly supported by the kinships network (termed as Beradri in Urdu). Such support, if luckily available, could also help in

increasing patient compliance or adherence with treatment (25).

All patients reported change in behavior including different forms of anxiety or depression. Such mental stresses have been previously reported as predisposing factor to infectious diseases such as TB (26). Common adverse effects of TB drugs were also prevalent in all patients. Overall, TB drugs were unbearable for most patients who tend to quit the treatment for some days, or forever. Shameer et al. endorse the finding of this study that adverse drug reactions (OR 2.46, CI 95%) results in the noncompliance and interruption of the therapy (27). Scarcity of TB treatment centers and complexity of treatment seeking process were also identified to be key factor for delayed diagnosis and non-compliance with treatment regimen. Herrero et al. explain that travelling cost (OR 2.5; CL 95%) may increase the financial burden on the patients that already facing the high therapy cost (28). In many cases, patients had to borrow money to pay the high travel costs to and from the treatment centers. Drugs were partially available and patients had to wait up to 4 hours to receive drug. All these factors can stop treatment process partially or completely for a period of time. If continuously occurring, the issues related to availability of drugs and treatment process may lead to emergence of noncompliance (29). WHO (25) as well as Stop TB Partnership (26), a global collaboration of TB health workers community, have hailed recent efforts of national and provincial TB control programs but also stressed that such programs need to be speed up and expanded in order to envision complete eradication of disease. Investment in health sector to effectively control TB will not only prevent loss of money in term of treatment expenses but also generates revenue due to improved health (30). Such big segment of population can participate actively in the development of society rather than being a burden on them (31).

CONCLUSION

Life of TB patients was stigmatized due to miserable economic conditions as well as worst attitude of family and colleagues. Loss of job, malnutrition, highly populous housing and treatment costs were the distressful economic constraints confronted by TB patients. Lack of knowledge, poor attitude of society and predominance of myths and misconceptions about the disease also accounted for the emergence of non-compliance. Health care centers must ensure availability of TB drugs and dedicated patients education sections for complete eradication of TB from Southern Punjab, Pakistan.

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