

Abstract: *The study was executed to know the socio-economic impacts of TB on patients and their families in rural areas of district Multan, Pakistan. It was a qualitative research conducted from February to September 2018. The data was collected through In-depth Interviews (IDIs) with 30 TB patients (aged ≥ 16 years) using an open-ended interview guide and five focus group discussions with the medical personnel who were dealing with TB. Thematic analysis was carried out to analyze data. The study resulted in the majority of TB patients and their family members being illiterate or less educated. Being unfamiliar with TB, its prevention, and treatment protocol, the majority of respondents were under great stress. They were facing various socio-economic issues like deaths, denial in marriage proposals, divorce/separation, hatred, social isolation, social stigma, and increased economic burden due to long treatment duration. To resolve this life-threatening issue, awareness was found inevitable.*

Key Words: Socio-economic Impacts, Tuberculosis, Multan, Pakistan

Background of the study

A state of complete physical, mental and social well-being and not merely the absence of disease or infirmity [WHO, 2019]. Health does not simply mean that a person who is not suffering from any illness is healthy, it also means that a person is entirely physically, mentally, and socially pleased and satisfied. There are certain socio-economic determinants that directly or indirectly affect health: Income - high income and social status, which are positively associated with good health. Education, illiteracy, and lesser education are associated with bad health, too [Bystritsky, 2000].

TB is a leading communicable disease causing deaths in the world [Mandell et al., 2009]. According to national vital registration systems, even in European countries, TB was one of the foremost diseases causing deaths till the late 1800. But gradually, TB cases and the number of deaths decreased until the 20th century in Western Europe, North America, and some other countries of the world as a result of socio-economic development like increasing income, better housing, and nutritional level [Zumla, 2010]. It is a reality that TB could be controlled by timely diagnosis and proper treatment. WHO affirmed TB emergency since 1993 globally. Since that, an evident progress was observed in control over TB. But on the other hand, TB is still

prevalent as a social health problem, and yet it is much far away to end TB as an outbreak in a lot of parts of the world. Nonetheless, about ten million people in the world still become victims of TB, and it is one of the ten most reasons for death. Amongst them, the majority are males with respect to gender and adults with respect to age [Grange et al., 2001].

In Pakistan, a large population lives in rural areas where most of the people either have no or little access to proper information and health care system, adequate treatment facility, better economic opportunities, quality education, or sanitation system. Mostly, people of the rural areas suffer from improper treatment of TB, which leads them towards MDR-TB and ultimate death. Pakistan is a developing country with a low literacy rate, poor socio-economic conditions, and an unhygienic environment, which are resulting in the generation of various acute and chronic diseases. TB is one of the most deadliest and communicable diseases among them. Behind TB, there are many social, psychological, economic, and medical factors, which are a hindrance in controlling this disease in spite of TB-DOTS and many other treatment schemes introduced by the government of Pakistan. The present study focused on digging out the socio-economic dynamics and impacts regarding TB in the

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Multan district of the Punjab province of Pakistan, where TB patients are found at the maximum number and escalating day by day [\[Akhtar et al., 2011\]](#).

The prevalence of Tuberculosis (TB) is a huge menace. It is the deadliest and communicable disease, but in fact, it is curable and preventable. Being contagious in nature and possessing a long-term treatment duration, it has destructive socio-economic effects on society [\[Walter et al., 2012\]](#). Its treatment duration lasts for six to nine months normally. During this period, TB patients and their whole family suffers a lot not only socially but economically as well [\[Waheed et al., 2011\]](#).

TB is found very common among people having low or poor socio-economic backgrounds. Being a contagious disease, it affects the social environment of patients [\[Abegunde & Stanciole, 2008\]](#). TB always brings financial burden in one way or the other, not only a burden on the individuals but also for the family and the society. It is one of the diseases that are specially and exclusively associated with poverty that brings disaster for the patients and families. So medicine expenses are a huge problem that increases the burden of finances to the disease-stricken families. This is only the pocket of the poor person or the family who has to spend money to cure the told disease. The treatment cost of this disease is also quite expensive, and the thing which makes it even worse is that the treatment of TB is a long process that takes six months to almost a year. The TB expenses push further down the person who is already having very low income and living a very poor life. TB also takes patients further to the depth of poverty which makes their lives even more difficult and harder for them to live. Long treatment duration of TB and expenses push down the family who is already having a low income [\[Saqib et al., 2018\]](#). The purpose of the present study was to bring socio-economic impacts that TB patients face after the diagnosis of their disease.

Methodology

It was a cross-sectional and qualitative study. The data were collected from February to September 2019. In-depth Interviews (IDIs) were performed for data collection with 30 TB patients (aged ≥ 16 years) using an open-ended interview guide, and five focus group discussions were organized with the medical personnel who were dealing with TB. Pseudo names of the respondents were used, keeping in view the privacy of respondents. The data was analyzed thematically after identification of sub-themes and major themes through jotting down.

Results and Discussion

TB was negatively affecting the patients socially as well as economically and leading them towards a poorer circumstances.

Social Profile

The present study found that tuberculosis (TB) is commonly diagnosed in the most prolific age group (20 to 40 years). With respect to gender, the majority were males. TB is communicable in nature it is commonly found among married people. The study also found that majority of TB patients were illiterates and less educated. Commonly heads of the families were also suffering from this disease.

Family Stress

The majority of medical personnel had the view that even a single TB patient caused stress for the whole family. All TB patients exposed to that stress of their disease wrapped up the whole of their family members. Fear of spread of TB within family members, other people will hate them, economic burden, fear of death were certain reasons of their stress.

A patient, Samia, expressed:

“When I was diagnosed with TB, it caused stress not only for my whole family but particularly for me. Because I was under stress due to unfavorable, disgusting and hating behavior of my in-laws with me”.

Another study also supports the current study that the majority (i.e. 73%) of the TB patients revealed that they were experienced stress and anxiety severely. Their families were under stress in several ways, such as weaker social bonds, social distancing, isolation, etc. Their study also proclaimed a strong relationship between stress and TB. They also informed that there was stress among all TB patients, either at low level or high. Further, they added that the level of stress was similar both among the male and female TB patients. In rural areas, there were strong bonding among the family members [\[Bhat & Shah, 2015\]](#).

High fertility

Medical personnel stated that many patients seemed despairing and thought they would die soon due to TB. The majority patients, according to their opinion they were feeling as helpless and scared of TB that they would die of it. Some of the patients were fearful and worried because any of their family member/s had already died due to TB. A study conducted in rural areas of Gujrat, India, on the identification of TB found that the patients were

worried regarding long term treatment and fearful of death as for them, TB was an absolute call of death [Thakker & Upadhyay, 2014].

Domestic affairs: (Higher divorce rate, Hurdle in marriage proposals, Less/no interaction, other people avoid having a meal with the patient)

Same domestic affairs that were affected by TB were disclosed by both medical personnel and the patients as well. First of all, they said that if the patient was the head of the household, then it would be of major concern. All their social and domestic matters were affected. They were unable to participate in any family or friends function. Their whole economic system was also disturbed. Because the head was unable to go to work, so the fulfilment of the needs became impossible.

Furthermore, they added that their marital affairs were also badly affected. Young females as well as the male had to face denial for their marriage proposals if it was disclosed that he or she was a TB patient. Similarly, it was also told that when the disease TB was disclosed after marriage, females had to face more stress and stigma as compared to males.

One female married TB patient Saima expressed that:

"After my marriage, when it was diagnosed that I was a TB patient, the behavior of my whole family as well as my husband had entirely changed. Their hatred and ignoring behavior was quite unbearable for me because I was unable to perform household chores. Finally, the circumstances reached up to divorce. He had destroyed my life instead of caring."

She expressed that after her marriage, TB was diagnosed. At this the behaviour of their whole family, even her husband, totally changed with her. They started ignoring her, and the reason was this she was unable to perform her household chores. In the end, she was divorced forcefully by her husband with the consultation of his family. The study conducted in South India also supports the above results that over all domestic affairs were under distress if any of the better halves were TB patients. They further found that women TB patients were more marginalized as compared to men. Similarly, the matter of marriage proposals was found even impossible for particularly unmarried women if it was prior known to others that she was TB patients. Similarly, married women were more worried about being rejected and stigmatized by their husbands and in-laws [Sudha et al., 2008].

A study in South India revealed that in the societal opinion, TB also seemed to be diversely influential on either gender in marriage-related issues. As compared to men, women faced more stigmatization at the time of marriage. It was quite harder for a woman who had TB to get married as compared to a man. In the current study, many other reviews also highlighted the same findings. It was also found that due to TB, married women were worried and fearful of being rejected by their husbands and persecution by in-laws while the unmarried woman was worried because of having lesser chances of marriage. People also showed their apprehension about women having TB for conceiving a baby and breastfeeding [Dolla et al., 2017].

Social Isolation

Medical personnel also had the view that commonly people isolated the TB patients. A similar response came from the TB patients as well.

One of the TB patients informed that.

"Since I has been diagnosed as a confirmed TB patient, my family members had isolated and confined me in quite a separate place. Nobody bothered to sit and talk with me. This kind of behavior made me guilty."

The study also supported the same results that many patients from socioeconomically underprivileged areas had no information at all about the diseases like TB. The condition became more challenging and worse when individuals were even qualified but did not know about TB, its modes of transmission, and preventive measures. The condition was more challenging for the patient of TB. They became victims of isolation in society due to lack of awareness and not being sensitized about TB. The isolation added the misery of the patient to a great extent. The patients were suffering from deadly disease, but all at once, they forcefully had to face isolation and stigmatization not only from the society but from their kith and kin and close friends as well, which made their life even impossible with respect to recovery and keep them hopeful for recovery from this fatal disease. Again the lack of education and awareness was the root of isolation. By the sensitization of the community other healthy people could be prevented from this double-sided trouble [Courtwright & Turner, 2010].

People have their own perspective about different diseases, and especially epidemiological diseases are socially secluded/neglected. Therefore, TB is also stigmatized by the community that's why most patients refute if TB is diagnosed. Due to the

stigma that is associated with TB, patients often try to hide it even if they have TB. They feel shame on exposing their disease, sharing with others, and getting proper treatment. Stigmatization and isolation from family members, friends, colleagues at a work place and society have negative effects on their social and economic life and their role performance ([Watkins & Plant, 2004](#)).

Social Stigma

Much medical personnel had the view that social stigma was prevailing in the rural community because there were many people who were quite unaware. Therefore TB patient showed their interest to hide their disease from others. Because did not want to be victim of social stigma. Many of the patients expressed that in their area the TB patients were hated. They were so stigmatized and discriminated. Patients had the view even their own family members and friends were neither sitting with them nor dining with them. They said that they were not getting any kind of social support. Other people were stigmatizing the TB patients because they themselves were fearful that they might be the victim of TB. Many studies depicted that TB patients were being stigmatized by the illiterate or rural society. Further studies found that deficient understanding about TB paved the way for stigmatization for patient. Rather his whole family also had to face this stigmatization by their community in one way or the other. This produced many difficulties for the patient of TB to interact with the society where people had less or no understanding about TB. The major reason behind it was that the society and family members had fear of being transmission of TB. Majority population was suffering from illiteracy which added up the problem of TB dissemination so rapidly ([Courtwright & Turner, 2010](#); [Omar et al., 2017](#)).

Women are stigmatized more in many countries of the world because of many reasons. These reasons can be precise as women face economic dependency on men, less preference of health, social isolation and finally, hindrance in marriage. Therefore females are more distressed due to the consequences of TB. In Pakistan women TB patients are also associated with infertile and weakened marriageability. Similarly in some countries like Bangladesh women feel embarrassment and thus are neglected by others. Females have to face more stigmatization due to its vulnerability ([Chang & Cataldo, 2014](#)).

Economic Burden

The majority of medical personnel and the patients almost had the same response that TB had negative

impacts on the economic condition of the patients and his family. As previously has been discussed that TB was chiefly common among the age group (i.e. 20-40 years) which was very much prolific and earning for their family and usually they were the heads of their family. Their family had to get more and more debt to run their house. This scenario drifted them towards poverty even they did not have money to fulfil their even basic needs such as food, medicine, clothing, utility bills, and many other expenses. A study resulted that the family of the TB Patients had to face considerable and unexpected expenses, one due to an increase in unpredicted health expenditures of a long term treatment, secondly due to not working for a long time. These circumstances affected functioning and economically productive ability of the whole family. TB found the most vital cause of wretched and scarcely irreversible economic circumstances of the affected family ([Abegunde & Stanciole, 2008](#)). Another study concluded that TB had met the situation just like the plague in many of the developing countries like Pakistan, Nepal & India etc. Not the disease TB had made the patients physically sick, but it too had played its role in bringing economic sufferings for many families, societies and the nations ([Khan et al., 2006](#)).

Conclusion

Thus after this empirical study, it is concluded that the whole family was under a great stress although there was a single TB patient or more. They were under stress due to weaker social bonds, social distancing and isolation. Furthermore, the level of stress was similar both among the male and female TB patients. TB was also found causing deaths among those families where TB found very common. TB was also creating domestic issues within a family-like, higher divorce rate, hurdle in marriage proposals, Less or no interaction of family members with the patient, other people avoid having meal with patient. This situation was also creating the situation of social isolation and social stigma. Likewise TB also affected the economic system of the TB patients and their families. TB is commonly found in the most economically prolific age group (i.e. 20-40 years) who were the breadwinner for their whole large family. Sometimes they had to get debt not only for their treatment but to bear many other domestic expenses. Usually it became difficult for them to fulfil their basic needs. The society should be made well aware that it should support the patients to come out of such challenges and complete their treatment adequately.

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