

# Lived-in Experiences of Tuberculosis Patients

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**Abstract:** ***Introduction:** It is an important public health problem. WHO (World Health Organization) estimates that 2 billion people, or a third of the world's population, are infected with M. tuberculosis and new infections occur at a rate of about one per second. TB patients, in addition to clinical symptoms, has to deal with several physiological, financial and psychological problems. It is also associated with stigma and discriminations in the society. This study was done to explore the lived-in experiences of tuberculosis patients. **Aim of the study:** To explore the lived in experience of tuberculosis patient various dimensions. **Methods:** The research approach adopted was qualitative and the design was phenomenology. purposive sampling technique was used to select a sample size of 15 till data saturation. an in-depth interview was conducted using open ended questions. The audio taped interviews were transcribed, meanings were formulated and emerging themes were identified. **Results:** Six themes emerged which brought out the fear, emotions and experiences of patients having tuberculosis. **Conclusions:** The study revealed the physical, psychological, social, economical, vocational and spiritual effects of tuberculosis on patients. It has brought out many issues; the main issue was the need for education and awareness programs to make public aware of the disease. The study also concluded that there is a need to plan for addressing the psychological and social needs of tuberculosis patients along with medical treatment.*

**Keywords:** Tuberculosis patients, DOTs

## 1. Introduction

Tuberculosis (TB) is an infectious disease caused by Mycobacterium tuberculosis. Tuberculosis is one of the oldest diseases known to humankind, and it is the second leading cause of death from an infection worldwide today. The World Health Organization (WHO) estimates that the global incidence of TB in 2012 was 8.6 million cases, with 1.3 million deaths, predominantly occurring in developing countries. Tuberculosis is the second cause of death from infectious diseases after HIV in the world. It is the leading cause of mortality worldwide.<sup>1</sup>

Aimed at reducing morbidity and mortality from TB, DOTS (Directly Observed Treatment Short-Course) is highly recommended by WHO to control the disease.<sup>2</sup> With the development of effective treatment strategies, the focus of TB management has been shifted from the prevention of mortality to the avoidance of morbidity. As such, there is increased interest in the quality of life (QOL) experienced by individuals being treated for TB. There are numerous aspects of active TB that may lead to a reduction in QOL. Treatment of active TB requires prolonged therapy with multiple potentially toxic drugs that may lead to adverse reactions in a significant number of patients.<sup>3,4</sup>

TB patients, in addition to clinical symptoms, has to deal with several physiological, financial and psychological problems. The symptoms and clinical burden of disease often extend beyond the duration of treatment. Also the treatment may be related with several side effects. All these aspects of disease and its management have a huge impact on the overall well being of the patient and burden of these factors can equal and even exceed the physical impact of illness.<sup>5</sup>

Despite TB being a curable disease in almost all of new cases, professionals such as psychologists, anthropologists, sociologists, and TB analysts have repeatedly indicated that

talking about the disease still causes discomfort and unease in the population, especially within the poorer communities. Understanding the meanings conferred to TB by patients within their social settings enables one to approach this disease beyond clinical and conventional care. Patients' lifestyles and thinking modes have an effect on how they respond to healthcare workers' interventions and actions.<sup>5</sup> TB is surrounded by intense grief, with implications to different spheres of life, including social relationships. This is due to long-standing negative representations about this disease, which result in stigma and discrimination.<sup>6</sup> Since Ancient Greece, the term 'stigma' has stood for bodily signs denoting something rare and evil about the signifier's moral standing. From patients' and healthcare professionals' perspective, TB dimensions indicate that besides its physical impact on patients' lives, this disease has also a strong emotional impact, given that debilitating symptoms evoke disability, impotence, and self-discrimination.<sup>7</sup>

Even after successful completion of treatment, many patients inhibit to visit their acquiesces and from revealing their diagnosis to colleagues and even to their spouses.<sup>8</sup> Such discriminations with TB patients are a key determinant of non-adherence to ATT. Patients are seen of even providing wrong address at ATT centers to avoid stigmatization of them and to their entire family. Patients are also afraid of informing their employers about their diagnosis to avoid losing of job or wages.<sup>26</sup> Women participation is lessened in household activities and they avoid seeking treatment unless and until the disease is far advanced and beyond control. In India, it is also common for women with TB to be rejected by their husbands or be sent away until cured.<sup>9</sup>

## 2. Objectives

- 1) To explore the lived-in experiences of tuberculosis patients.
- 2) To explore the various dimensions of the lived-in experiences of tuberculosis patients.

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### 3. Methodology

The research approach adopted was qualitative and design was phenomenology. Purposive sampling technique was used to select the subjects. The inclusion criteria included all patients who have completed full course of anti tuberculosis treatment regimen within the duration of 6 months. The exclusion Criteria included Patients who have undergone treatment for MDR-TB, completed tuberculosis treatment regimen but have other co-morbid conditions such as HIV/AIDS or others and patients who are not willing to participate or share their experiences. The sample size was 15 till the data saturation. Formal permission was obtained from the concerned authorities and ATT centre, K.C. General Hospital. Participants were identified from the DOTS registers. The purpose of the study was explained and informed consent was obtained from the participants to audio tape the conversation. After filling the demographic proforma, an in-depth interview was conducted with open ended questions. Semi structured questions were directed towards their reaction, thoughts, emotions with the diagnosis of TB and their experiences while undergoing anti tubercular treatment. The audio-taped interviews were transcribed into verbatim and coding was done and emerging themes were identified.

### 4. Results and Discussions

Modified Colizzi's Analysis Framework was used. All interviews was transcribed into verbatim and read in order to get an understanding of the verbatim. Significant selected phrases pertaining to the experience of patient under investigation were extracted. Meaning was formulated from these significant statements and statements were organized into cluster of themes. The themes which emerged from the data are as follows:

### 5. Themes

#### Theme 1: Lived Time (before and after being diagnosed as having tuberculosis)

The subtheme identified were denial and difficulty to accept the disease condition, fear, anger, confusion, shock and uncertainty regarding future. The feelings were universal to all the clients during the early period of being diagnosed as having tuberculosis. Some of the causes of fear were the fear of stigma and discriminations from the spouses, family members and friends; fear of passing the disease to their family members; fear of taking anti tubercular treatment and side effects of the medicines. Participants have also expressed concern regarding their future. They were worried about their image in the society. *"I was worried about my future. Whether after being recovered, people will talk to me or treat me as before whether they will look at me as they used to."*

#### Theme 2: Lived Body

Participants' lives were changed after being diagnosed as having disease. They had to face several health related issues. This disease had affected their daily activities.

Almost all of them had become dependent on others in the first few months of the illness. Most of them had expressed alteration in their normal pattern of living. The subthemes identified were physical symptoms and change in daily activities. All the participants had expressed that they have suffered from various physical symptoms due to the disease such as vigorous cough, blood in sputum, weakness, weight loss etc. they had also expressed that it was difficult for them to manage their daily activities by themselves.

#### Theme 3: Lived relationship

This theme has been highlighted as all the clients lived in the family. Their lives were affected by the behavior and support of their family members. For the clients the important relations in the family were their wife, children, parents, social relationships and etc. Most of the participants were married and they stated that their wives had supported them during the period of illness. All of them stated that their wives were concerned about them and have taken good care of them. One of the participants told that his wife left him when he was suffering from tuberculosis. All of the participants have expressed that their parents were supportive to them during the time of their sufferings. Four of the participants said that their children could understand that they are sick. Most of them said that they used to avoid talking to them because they did not want them to suffer from tuberculosis. One participant expressed, *"I used to stay away from my children and did not allow them to come near me. Sometimes my son would come near me and ask why I am not talking to him. I would just say it is for few days only. After I become well everything will be just like before."*

The sub theme of social relationship was full of stigma. This was a phenomenon that ran through all the participants though some described it explicitly- the rejecting neighbors, relatives and a section of the community saw the clients and their families as blameworthy, dangerous and guilty. One participant expressed, *"They stopped inviting me to their home for any occasions. They did not say anything to me directly, but they were talking behind my back. I have heard them talking to my wife outside my room. They told, "He must be taking drugs, that is why he is suffering from tuberculosis."*

Another participant expressed, *"Neighbors also behaved like the relatives only. They thought they will also suffer from the disease if they talk to us. They used to tell my mother, "Your son must be onto something wrong, he must be drinking alcohol, which is why he got this disease. Do not let him come out of his room. Do not touch him. Keep your daughters away from him, or they will also suffer. Their future will be spoiled"*.

A cross-sectional study was conducted on the self-evaluation of tuberculosis patients about their illness at Ankara Atatürk Sanatorium Training and Research Hospital, Turkey. Most of the patients (91.8%) stated that it was their own decision to visit the sanatorium, 32 out of 74 unemployed patients said that they had to leave their jobs because of their illness, 4 patients were dismissed from their job, majority (57.7%) of patients stated that they had to change their relations with their children. The study concluded that TB greatly

influence the social and psychological aspects of life of the patients and health workers has to plan for social care along with physical and biological care for the patients.<sup>10</sup>

#### Theme 4: Lived economical

This theme has emerged in most of the interview transcripts. Most of the participants have expressed the experience of suffering financial difficulties during their period of illness. The subthemes identified were loss of job and salary, difficulties in meeting family needs, need for family members to work to manage financial difficulties and reactions of family members on expenses on treatment.. Most of the participants have expressed that they had lost their job due to illness. Some of the participants have stated that they had to suffer loss of pay as they were not able to go for job. Most of them were working in private companies and some were drivers. One of them expressed, *"I was the only working member in the family. There was no other source of income. When I was sick, I could not go for work. I lost my job"*.

Most of the participants have stated that they had to face difficulties in meeting the needs of the family because of the expenditure on treatment. They have also stated that they had to borrow money from others in order to manage family. *"I had some savings, from that only we managed somehow. My sisters are studying. I had to spend money on their education. My father is sick; he is suffering from heart problems, that also I had to take care of. We had to reduce our expenses. We had to manage with limited money. I was also worried about my sister's marriage. I had to keep money for that also. There was a lot of pressure."*

One of the participants told that his wife had to go for work as he was unable to continue his job. *"She used to go for work at other houses, cleaning utensils, washing clothes, she used to work hard"*. Almost all of the participants have stated that their family members were quite supportive to them.

#### Theme 5: Lived Vocational

This theme was highlighted as most of all of the participants were working and they had to suffer discrimination in their work places and also their ability to perform job was affected by their health condition. The sub themes identified were low standard of performance and Changes in relationship with colleagues. Most of the participants have stated that they were not able to perform their work as effectively as before due to their health conditions. *"When I got sick, it was not possible for me to me go to work. I was not able to stand for long time. How could I go for delivering products?"*

Most of the participants have expressed that they had to face discriminations at their workplace and the behavior of their colleagues was also changed towards them. One had expressed, *"When my co-workers came to know about my condition, their behavior was changed. They would not look at me if I would go and talk to them. I used to wear mask, even then also they would say, "You should not talk to us, it is dangerous. You can infect us. Stay away." Even one of my*

*co-worker said, "I think you will not survive". I was really hurt. I felt very bad."*

#### Theme 6: Lived spiritual

In Karnataka and in Bangalore also, people use to have faith in God to an extent they relate to God almost in everything. They believe that health and illness is caused by the blessings and curse of the God respectively. They also believe that if someone has committed any sin, God will punish him in one way or the other. The following subthemes have arisen from the interviews that explain the spiritual aspect of the participants' experiences: Change in belief towards God, high intensified belief towards God and alternative methods to satisfy spiritual distress. Participants have expressed that after suffering from tuberculosis, their belief towards God has changed. Some stated that they believe in God but they do not think that God can do anything for them. *"At some point I felt that God does not exist. If he was there, he would not have let me suffer like this."*

One of them expressed, *"Previously, I did not use to go to temple; I did not use to pray every day. I think for that only God was not happy with me. My wife used to tell me, Have faith in God. Worship God. He will listen to our prayers and take away all our sufferings. I used to pray to God everyday and ask forgiveness for my sin"*.

Some of the participants stated that they think that they were being punished by God for their mistakes. *"I thought I had committed some mistake so that God was punishing me. So I used to pray for forgiveness."*

Few of them have expressed that they think they were destined to this. *"I think it was my fate. You cannot escape your fate". I had accepted this. I do not blame God for what has happened to me."*

## 6. Conclusion and Recommendations

Being diagnosed as having tuberculosis brings fear and frustration among the patients. The physical sufferings of the patients worsen with the side effects of the drugs. The disease not only affects the person physically but it also causes them to suffer from fear of transmission, social prejudice, and death. The patients become emotionally disturbed and psychologically imbalanced. They lose their confidence in themselves. The stigma related to the disease also affected the patient socially. Patients are mostly neglected by the people in the society. The financial constraints faced by the patients were one of the major reasons for sufferings caused by tuberculosis. This disease also affects patients vocationally. The participants reported that family support is essential in bearing the burden of the disease. There is a need to initiate an education programme regarding prevention and treatment of tuberculosis which should address the needs of the tuberculosis patients and their families. The Revised National Tuberculosis Control Programme in Bangalore should strengthen the awareness programme focusing on the various dimensions of health being affected by the disease. There should be adequate provision for teaching the lay people regarding the

prevention and treatment of tuberculosis including the services provided to them and how to access those services. Financial assistance in the form of social grant from the government would help to lessen the financial constraints faced by the tuberculosis patients. There should be provision for rehabilitation of the tuberculosis patients. Self help group can be initiated in order to provide for vocational guidance for the tuberculosis patients after their recovery.

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