

Qualitative Assessment Of The Social Stigma And Discrimination Faced By Tuberculosis Patients Residing In Ernakulam District, Kerala

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Abstract.

Tuberculosis is one of the chronic infectious diseases which is heavily stigmatized and mostly leads to abandonment, social isolation, and condemnation from society. The study aims to qualitatively analyze the social stigma and discrimination faced by tuberculosis patients residing in the Ernakulam district using the grounded theory approach. A qualitative study was conducted among purposively selected TB patients, family members of TB patients, medical officers, senior treatment supervisors, Senior lab supervisors, and Health visitors. Qualitative data was collected till saturation was obtained. The audio recorded data was then translated, transcribed, and manually coded. Thematic analysis and data source triangulation was carried out and conclusions were made. Self-stigma was found to be more evident among the patients since they feared contempt from society, due to which the majority of the patients hide their TB status from society. The revelation of TB status to family members and at the workplace led to the isolation of a few patients. However, the friendly interaction of healthcare workers helped to reduce social stigma and discrimination. Stigma & discrimination that persist in the community, have a negative impact on treatment adherence of TB patients and thereby delay TB elimination.

Keywords: Stigma, Discrimination, TB, Qualitative analysis and grounded theory approach.

I. INTRODUCTION

Tuberculosis (TB) is an important public health concern in India. People with TB often face social stigma and discrimination (1). Stigma is a social determinant of health, found to be a major barrier to the health-seeking behavior of the patients and leads to poor disease management (2). Goffman, the pioneering author of stigma, describes stigma, as a 'situation of the individual who is disqualified from full social acceptance (3). Enacted stigma (external stigma) refers to other people's experiences of unfair treatment. Felt stigma can be as detrimental as enforced stigma as it leads to social support being withheld and limited (4). Discrimination occurs in two forms.

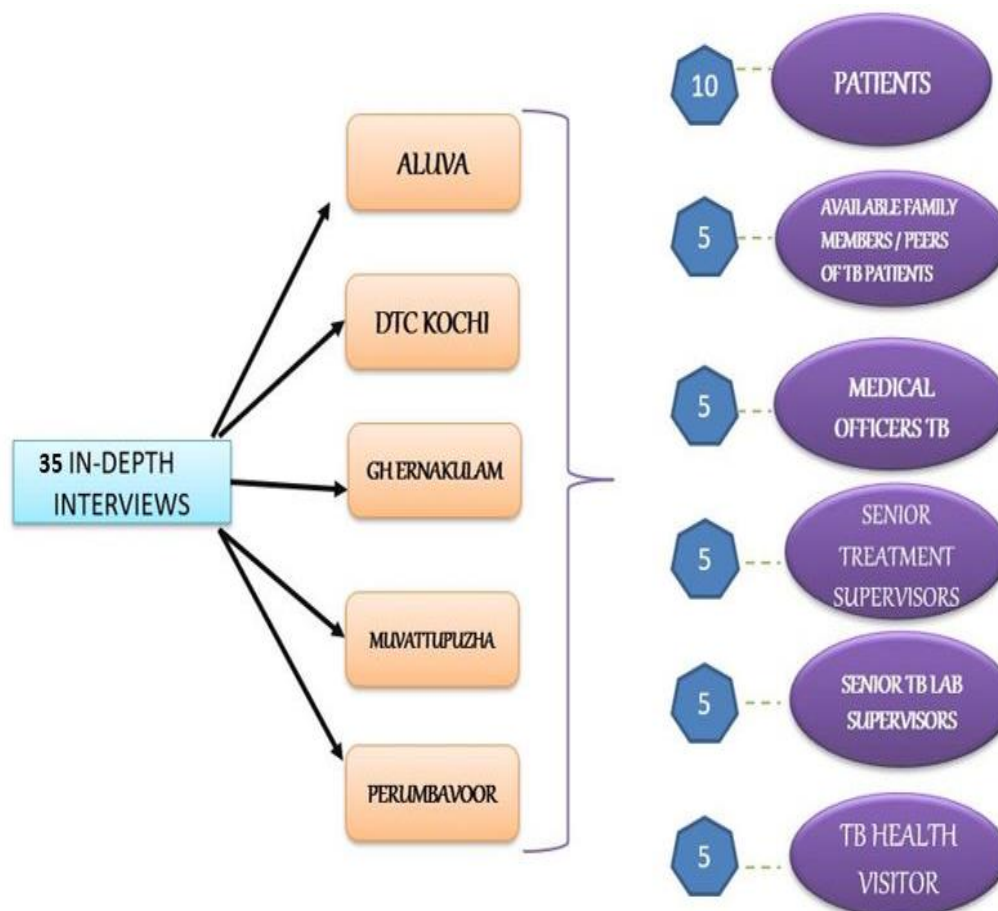
Direct discrimination occurs when, on account of their illness, a person is treated less favorably than others under the same or similar circumstances. Indirect discrimination arises when a requirement or condition is applied to all but a few of them who don't satisfy the condition will have disadvantages (5). Stigma and prejudice have a huge impact on the patient. This influence is felt in the home, workplace, schools, and culture. Stigma, discrimination, and social exclusion are regularly described by people with communicable diseases. It causes significant obstacles to the health, well-being, and quality of life of TB patients (6). Stigma and discrimination pose significant barriers to healthcare-seeking and completion of treatment. Therefore, the study aims to assess TB-related stigma and discrimination faced by the patients, so that appropriate policy recommendations can be put forward.

II. MATERIALS AND METHODS

After obtaining institutional ethical committee clearance and permission from the State TB cell, a qualitative study using the grounded theory approach was conducted among adult TB patients. Patients undertaking treatment in Ernakulam district of Kerala, from December 2019 to March 2020 were included in the study. In order to get a holistic perspective on the stigma and discrimination faced by TB patients 35 In-depth interviews were conducted among TB patients, Family members of TB patients, Medical Officers treating TB patients, Senior treatment supervisors, Senior lab supervisors, and Health visitors as depicted in

figures number 1. After obtaining informed consent, the interviews were conducted and were audio-recorded. It was then translated to English and transcribed. Following which it was manually coded and themes & sub-themes were identified. Data source triangulation was done to draw conclusions.

Fig 1. Stratification of participants in qualitative data collection



III. RESULT

10 Tuberculosis patients, 5 family members of TB patients, 5 Medical Officer, 5 Health visitors, 5 senior treatment supervisors, and 5 Senior lab supervisors were interviewed. The TB patients interviewed were in the age group ranging from 22 to 66 years of age with a mean age of 44.4+ 9.679. Out of the total patients interviewed, half of them were married, unemployed, suffered from pulmonary TB, 2 MDR TB patients and belonged to the initial phase of treatment. Stigma and discrimination faced by the patients are presented under 5 major themes- stigma and discrimination at the individual level, society, family, workplace, and health care system.

I. Self- stigma and discrimination

Almost the majority of the patients who participated in the study were facing self-stigma due to Tuberculosis. The main reason for self-stigma was the clinical presentation of tuberculosis such as weight loss, cough, etc. The majority of the TB patients were worried about others noticing them have tuberculosis. They believed that TB is a stigmatizing and disgraceful disease, which only the poor get affected. Few unmarried patients had the opinion that no one will marry them because others believe that TB patients will turn to be infertile. Few others explained that TB shows a recurrence nature due to which patients who recovered from the disease will still be discriminated by the society. These self-stigmatizing thoughts made them sad and lowered the self-esteem, which in turn forced them to hide their disease status from society.

"I wonder how I am going to get a good alliance since I am suffering from an infectious disease.

People think women with TB can't bear a child."

(22-year-old unmarried female with pulmonary TB.)

II. Societal stigma and discrimination.

The fear of disclosing the TB status to society was one of the biggest fears faced by the majority of the patients. They believed that society will isolate them and spread rumors about them. Few of the children of TB patients had to face bullying at school since one of their parents was having TB. This shows the presence of stigma and discrimination not only to the patients but also to their relatives. whereas few others, who disclosed it to their friends, received good support from them.

“once, a friend of our son, told him that your father is having a disease which is communicable, and refused to talk to my son. When my husband knew about this, he wanted to commit suicide.”

(Wife of a 45-year-old male with pulmonary TB patient)

III. Familial stigma and discrimination.

Most of the study participants had no difficulty in revealing their disease status to their family and they received support from the family. Whereas few others had to face discrimination from their family such as they were kept in a separate room & partners slept separately, and few others even left the patient after knowing about the disease status. Few patients faced discrimination while they were having food. They were not allowed to sit with the other family members and some others even if they eat together ensured to use separate utensils, in order to prevent the spread of disease. Family members explained that they were in the fear of getting the infection from the patient, therefore by doing so they were protecting themselves.

“We have fear of the spread of disease, so we kept her in the outhouse close to our house.”

(Daughter of 66 years old female pulmonary TB patient)

IV. Existence and cause of stigma and discrimination at the Workplace.

One of the main concerns of the patients were losing their jobs. Even though TB is curable, many employees still do not allow TB patients/survivors to continue with their jobs. According to the opinion of health care professionals, this seems to be the main reason for the lack of treatment adherence among migrants. They will be sent out of their jobs once the employer identifies them to have TB. This can lead to the spreading of disease as well as poor adherence to treatment. Some even though, they continued to work had to face discrimination in the workplace. They were asked to maintain a distance and many were forced to take long leaves. Some even asked them to go home and have food instead of sitting with them.

“In the case of Migrants, if they are diagnosed with TB, the employers will send them away. This made them hide their medical condition and they relocate to some other place. During their transit, they are susceptible to spread TB also. However, employers are not aware of the damage that they are doing. This should be changed”

(Medical officer, TU no. 5)

V. Stigma and discrimination in the health care system.

Almost all the participants had a very good opinion about the health care providers due to the support provided by them. The health care workers treated the patients with good respect. Since others were looking down at them seems to be one of the main reasons why they were tempted to hide their TB status from others and seek treatment. The positive interaction of the health workers helped in treatment adherence and to maintain positive mental health. To make the patients comfortable the health care professionals tried to reduce the use of masks and took extra caution not to wash hands immediately in front of the patients after treating them. Because they believe that putting on a mask will act as a sign of discrimination and patients would feel stigmatized. They used a mask only while consulting MDR TB. According to the opinion of patients, none of the health care providers hesitated to treat the patients. Instead, they had a very friendly approach towards the patients, which made them happy.

“Really great approach. When I go there, they will make me sit. They talk pleasantly and treat me by giving good respect.”

(62 years old male with pulmonary TB)

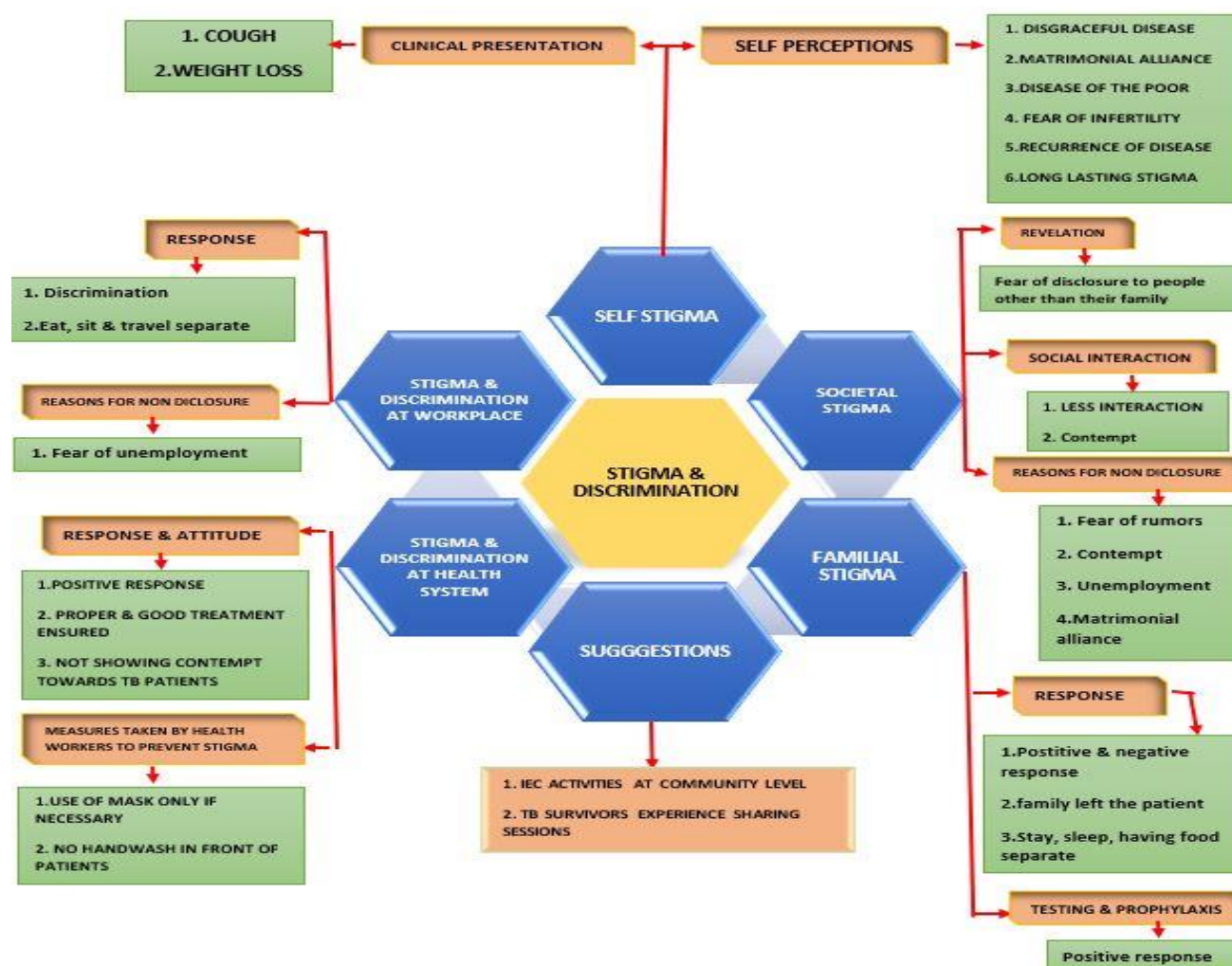
IV. DISCUSSION

The main qualitative finding of this study was described under the domains such as self, family, society, health care system and workplace. The majority of them experienced self-stigma since they were

overly concerned about their disease. Those who were employed feared that they would lose their job due to the disease, so few of them were not ready to disclose their TB status to others. In the studies done by Mukerji et al in Kolkata and Yanai et al in Thailand, the participants reported that TB stigma may result in losing job opportunities. (7), (8). This shows that stigma and discrimination are universal and it's not pertained to a particular place. In the current study, the majority of them had the fear of others looking down at them which prevented them from disclosing their disease status to society. Similar results were obtained from a study conducted in Karnataka by Padmanabhan et al, where one-fourth of patients confided that they have been made to feel ashamed or embarrassed because of this problem. (9) The major consequences on the social life of the patient include a lack of social interaction, isolation, and less interaction with neighbours. Similar results were seen in a study done in Maharashtra, where their neighbours maintain a distance from them (10). Few unmarried patients had the fear that this disease may affect their marriage and fertility which led them to hide their status from others and even their own family members. Similarly, in a study done by Mukerji et al in Kolkata, the more frequently reported issue among younger, unmarried participants was the loss of marital prospects. (8) In this study, few of the children of TB patients had to face bullying from their friends due to the condition of their parents. Similar results were obtained from a study done by Padmanabhan et al, where one-fourth of the parents of patients thought this would cause social problems for their children in the community (9).

An elder woman was forced to stay in the outhouse to avoid the spread of the disease. Similar results were observed in the study done by Somma et al, where the patients were isolated because of their disease, or forced to move away from their homes (11). In this research, the main consequences on the personal life of the TB patients were that the patient's family left the patient and started staying separately and few others, kept the patient out of their homes. Similar to these results, in a study conducted by Nagarkar et al, female patients have reported that they were frequently taunted by husbands and family members for contracting the disease (10). It was observed that the majority of the patients slept separately. The main reason was to prevent the spread of infection and a few had a worry that their partners might not like to sleep with them. So, they voluntarily slept separately. Similar results were obtained from a study done by Mukerji et al, where the partners slept separately and interacted less with the patient (8). Few of them had to eat separately at family as well as at the workplace. In the workplace, one of the participants with MDR TB was asked to have food separately.

Similar findings were observed from a study conducted in Mexico by Moya et al, where participants have reported that they experienced discrimination from colleagues, friends, and family, asking the patients to eat and drink separately (9). In this research, a few of them who were employed did not inform the employers about the disease in the fear of losing the job. Those who have revealed their status had to face discrimination. Similar results of losing a job due to TB was seen in other studies (7). We found that migrant workers with TB were also stigmatized. This resulted in the unemployment of the patients and which further makes them hide their status and move to other places for their job. This led to problems regarding treatment adherence and also the spread of the disease. Similar results were found in a study in China, where migrants were not given the job when the employers noticed that they were having Tuberculosis (12) The approach of the health care workers was quite satisfactory and patients were happy with the treatment. This indeed helped the patients to adhere to the treatment. The health care workers minimized the use of masks to prevent any kind of stigma that the patient might feel. They ensured a friendly approach to the patients. Unlike this research, a study conducted by Baral et al in Nepal showed that some patients felt they were discriminated against by health workers (6). Therefore, this is a unique finding, showcasing the lack of stigma towards TB patients by the health care providers in Kerala

Fig 2. Flowchart showing qualitative results

V. CONCLUSION

Stigma and discrimination were found at individual, family, society, workplace, and health care system levels. However, stigma and discrimination were found least in the health care system. Self-stigma was found to be more than enacted stigma. It was probably because of the good services provided by the health care providers. Provision of counselling services, patient-provider sessions, survivor's meetings, and awareness classes may all have contributed to reducing stigma. Therefore, these interventions need to be further strengthened in order to further reduce the stigma and discrimination faced by TB patients and thereby improve their quality of life.

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