Qualitative Assessment of Adherence to Anti-Tuberculosis Medication Among Active Tuberculosis Patients

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ABSTRACT

Background: Non- adherence is one of the major risk factors for the emergence of MDR and XDR TB. It is also one of the key factors responsible for treatment failure, disease relapse, prolonged infection and death. This study was conducted to explore the various factors contributing to non-adherence to the Anti-TB medication.

Methods: A qualitative study was done on Adult Pulmonary and extra pulmonary TB patients who were in course of the treatment. A total of 20 patients were enrolled. Socio –demographic details and specific questions regarding TB were collected using a semi-structured questionnaire. In depth telephonic interviews were conducted among all participants.

Results: The participants comprised between 15 to 68 years of age with a mean age of 36 ±14.9years. Factors influencing non-adherence to medication were grouped under patient, medication, Socio-economic and Health care related factors, Motive. Almost all patients reported more than one factor.

Conclusion: Increasing the awareness of various TB services in the community may increase knowledge and improve attitude among the patients. Providing more information about the effects of medication may reduce the risk of being non adherent. TB anonymous groups can be organized for patients to discuss their challenges while on treatment.

Keywords: Tuberculosis, DOTS, Barriers to treatment adherence, In-depth interview

INTRODUCTION

Tuberculosis (TB) is caused by Mycobacterium tuberculosis that utmost frequently affects the lungs. When patients with pulmonary TB cough, sneeze or spit, transmission occurs through droplet nuclei containing millions of TB bacilli. Globally,10 million new cases and 1.24 million deaths have been reported. In India, the incidence of new (TB+HIV) is 2.640 million cases. Among them, 124,000 are MDR-TB cases. The total number of deaths due to TB was 4, 36,000 in 2020. [1] Worldwide, the infectivity rate and death rate of tuberculosis are slowly decreasing. However, TB remains as a great challenge for the community health [2]

The National Tuberculosis control program was implemented in 1960.Then came the Revised National Tuberculosis Control Program (RNTCP) and Directly Observed Therapy Short course (DOTS) which included weekly thrice intermittent regimen. DOTS were fully implemented all over India by 2006. At end of 2006, reviews conducted by Government of India revealed that less than 30% who have been enrolled have completed the treatment. [3] Taking TB medication is a cumbersome process for the patients.

Such long term, compulsory treatment results in non- adherence to the prescribed medication. [4]

Non- adherence is one of the major risk factors for the emergence of MDR and XDR TB. It is also one of the key factors responsible for treatment failure, disease relapse, prolonged infection and death. It poses as one of the main obstacles in the control of TB globally. [5]

Many studies have shown different factors for the non-adherence in TB patients. Several studies indicate that the adverse effects of the medications are an important cause for development of non- adherence to medication. However other factors that plays a major role in contributing to non- adherence are social stigma, lack of knowledge, depression, poor accessibility, vulnerable housing. [6] Hence this study was conducted to explore the various factors contributing to non-adherence to the Anti-TB medication.

OBJECTIVE

The objectives of the study was to explore the factors responsible for adherence to anti- Tuberculosis (TB) medication

METHODOLOGY

A qualitative study to assess the factors contributing to non-adherence to anti-Tuberculosis medication among TB patients. The duration of the study was 6 months (From March 2021- August 2021). Both Adult Pulmonary and extra pulmonary TB patients who are in course of the treatment, irrespective of the phase of treatment, who were diagnosed and registered in TB and Chest Medicine department in Saveetha Medical College and Hospital were included in the study. All pediatric TB cases and those who did not give consent to participate in the study were excluded. Purposive sampling method was used to select the participants in the study. A total of 20 patients were enrolled in the study. The contact details of the TB patients registered from March 2021 to August 2021 were obtained from Chest Medicine dept. of a tertiary care hospital. A total of 20 patients who were willing to participate were included in the study. In depth telephonic interviews were conducted for all 20 patients. The background characteristics of TB patients (socio–demographic details) and the specific details related to TB (Type of TB, date of diagnosis and phase of treatment, number of pills per day, BCG vaccination and presence of any co-morbid condition) were collected using a semi-structured questionnaire. Participants were also asked about adherence to their TB medications and factors responsible for it. The interviews were tape recorded and each interview took about 25-30 minutes. Questions were posed in a neutral manner to all the participants and their responses were heard attentively and participants were not shown approval or disapproval of what they said. Bulletin key words have been noted to aid investigator in remembering all participants.

Statistical Analysis: Descriptive statistics were computed for the background variables. Data collection and analysis was performed simultaneously. The keywords, phrases were documented. The documented patients own words (verbatim) has been translated and transcribed to English from Tamil to the nearest verbatim as articulated by the patients. The transcribed interview was then coded. The transcribed data was analyzed by using seven stage Colazzi Thematic Analysis. The various codes were categorized into subthemes and themes were generated.

Ethical Considerations: The study got ethical clearance from the Institutional Ethics Committee (IEC) of Tertiary Medical Hospital.

RESULTS

Background characteristics of study participants: The mean age of the TB patients was 36 ±14.9 years. The study included 12 (60%) males and 8 (40%) females. Educational level of the patients revealed that 1(5%) was illiterate, 7(35%) had completed secondary and 2(10%) had completed senior secondary level of education. 10(50%) participants completed their graduation. Among the participants, 7(35%) were unemployed. All the participants were vaccinated with BCG. 10(50%) patients had pulmonary TB and 10(50%) had extra-pulmonary TB. 5(25%) patients were in phase 1 treatment and 15(75%) in phase 2 treatment. Among the participants, 12 (60%) patients did not have any co-morbidity. 2(10%) patients had Diabetes mellitus and 5(25%) patients had both Diabetes and Hypertension.

Factors Influencing Non-Adherence to Medication: From the participant perspective, factors influencing non-adherence to medication were grouped under 5 Themes (Table 1)

1. Patient-related factors

Patient related factors included lack of knowledge regarding TB treatment, Forgetfulness to take the medications and psychological effect on taking medications.

Lack of knowledge of TB Treatment

Out of 20 patients, 19 patients lacked knowledge regarding TB treatment. 4 patients did not know why they were affected with the disease or the mode of disease transmission, since none of their family members were affected with the disease before as they thought the disease was hereditary. After the diagnosis of the disease, majority of the patients were aware of the dangers of not taking their medications consistently. Participants admitted that doctors had comprehended the management of TB.

Table1: Themes with related categories and codes. (Seven Stage Colazzi process)

THEMES	CATEGORIES	CODES
Patient related factors	Lack of knowledge of TB Treatment	Inadequate knowledge, not knowing about the transmission, treatment of TB
	Psychological state	Stress, feeling low due to presence of disease
	Forgetfulness	Difficulty to remember and take medicines on time
Medication related factors	Pill burden	Swallowing more number of medicines on daily basis
	Side effects	Felt worse on treatment
		Could not perform day to day activities
Socio-economic related factors	Financial cost	Cost of transportation to clinic, cost of additional medicines to decrease side effects
	Stigma	Friends avoided interaction
		Neighbors gossiped and avoided interactions
Health care related factors	Interactions with the health care system	Provider being kind and helpful
		Reassurance by doctors and utmost care from hospital staffs
Motive	Factors that influenced to take medicines	Supportive family
		Family administered medications and reinforced adherence

A 35-year-old female patient who was undergoing teachers training said that

"I did not know why I got this disease, as none of my family members were affected with this disease before (Patient 1)

Another patient, who was 18 years old and is an allied health science student, had adequate knowledge of TB treatment and he said that:

"Since I'm an allied health student, I had adequate knowledge regarding the disease and knew I could have some complications, if I don't take medicines." (Patient 4)

Psychological state:

Since few patients had other co-morbidities, being newly diagnosed with tuberculosis, made them feel emotionally low. Facing the psychological pressure caused by the disease, poor self-regulation capability has also led to medication non-adherence. This was mentioned by a patient who told:

I was newly diagnosed with diabetes mellitus, when I already had tuberculosis, which made my life even more difficult (Patient 1)

Another patient who was a Housewife told that

I'm working in a private centre, when I got diagnosed with the disease, I felt very low, as I had so many symptoms and I couldn't continue my job. (Patient 19)

In contrast, few participants reported that they were more worried about the problems that might occur in future if they don't take medicines, than feeling worried.

Forgetfulness:

All the patients confessed that they never forgot to take medicines, even though at times if they tend to forget, their family members would always remind them to take the medications.

"Even though I forget to take my medicines, my husband used to remind me every time, so that I don't miss any dose. (Patient 10)

2. Therapy related:

Pill burden:

Majority of the patients found difficulty in swallowing too many pills at once and for long duration. Patients with co morbidities, found even more difficult to take medications, as they were already on many medicines. 9 patients listed out the size of the tablet as an issue, as it was difficult to swallow.

Taking medication for both TB and thyroid simultaneously was difficult and it was also difficult to remember and take it on time. The TB tablet was large in size and it was not easy to swallow- (Patient 6)

I'm working in a private company, since the duration of the treatment is longer, I had to quit the job, it was really frustrating (Patient 17)

Side effects:

Medication side effects were a primary reason for stopping medication. When patients defaulted due to side effects it was because their symptoms were severe and made them feel worse than their TB-related symptoms did.

Due to the side effects as well as other reasons described below, 4 patients stopped taking medicines in our study.

A patient told that:

I had tingling sensation, discoloration of urine, in between felt cured so I discontinued the medications- (Patient 2)

After taking tablets, I had severe side effects like swelling in hands and legs, nausea, heartburns and abdominal pain. I skipped tablets twice when I had side effects (Patient 6)

3. Socio-economic factors:

Financial cost:

Though TB medicines are given at free of cost, patients reported that they still need to pay for few medical examinations, hospitalizations. Additional

cost is regarded as an issue related to treatment adherence.

I had to spend more for travelling to the TB centre and hospital. Furthermore, it was highly difficult for me to spend on the consultation charges, which was charged by other doctors. I lost my job, because I was bedridden, which made me financially weak- (Patient 2)

Stigma:

Many patients believed that, because of the disease they were predisposed to stigma. Few of them felt that they have been socially isolated from their neighbours also shared their experiences saying they were being pointed in their neighbourhoods and were excluded from social events.

Neighbours did not talk with me, and they did not even come close to me, which made me emotionally down - (Patient 3)

I'm working in a private company, I felt left out from my friend's group and colleagues at times, I was totally ignored by my colleagues and relatives when I took medications in front of them. -(Patient 8)

4. Health care related:

Patient provider relationship, distance from the health care facility, communication between health care personnel and patient appeared to have a major impact on patients' adherence.

Doctors and the health care team supported me to take the medicines and reassured me every time, when I had any issues and doubts regarding the disease. - (Patient 4)

Health workers are guiding me to take the medication through a regular weekly inspection through phone. Even for other ailments, doctors helped a lot, to get cured. - (Patient 5)

5. Motive:

Many of the patients listed out various factors which made them to take medications. Some of the responses are as follows:

At a very earlier stage after marriage, I lost my husband, being a single parent, I had to take care of the baby, for whom I had to take medicines, to get cured (Patient 1)

I have to recover from the disease as soon as possible and resume to day-to-day activities, and I did not want to depend on anyone- (Patient 14)

DISCUSSION

This study had explored the reasons for adherence to TB treatment. Our results show that the positive factors that led to adherence was supportive family, family members reinforcing to take medications, provider being kind and helpful, reassurance by doctors and utmost care from hospital staffs and the negative factors that led to non-adherence is loss of income, stigma, lack of social support, lack of knowledge, cost and side effects of TB medications.

Our results show that patient default is most often due to loss of income, stigma, lack of social support, lack of knowledge, cost and side effects of TB medications, and also various factors that act as barriers to adherence, rather than a disinclination to receive therapy.

Health care providers should be trained to provide health education to patients, which may increase awareness and improve adherence. Some of the respondent's concern were the distance between the health care facility and their home, which may in turn lead to non- adherence and it was similar to a study conducted in Ethiopia. [7].

In our study, we found that majority of the participants lacked adequate knowledge regarding TB and the mode of transmission. Many patients did not know that the conventional period for treatment is 6 months. Similar findings were obtained from a study conducted among the TB patients in Pakistan. [8]. Studies have found that educating the patients will significantly reduce the risk of treatment non-adherence [9, 10].

Many of the patients had lost their job, due to the disease. As they were unemployed, they did not have their family or relatives support, and had faced financial constraints. Similar studies have found that TB patients have experienced problems due to shortage of funds, and they are not able to spend more money for travelling to the health care facility. [11,12.] In our study, family and community support has shown to be a main reason for treatment adherence, which was also evident from several studies [13, 14, 15]. This study found that interaction between health care professionals and patients has a positive attitude and reassuring the patients have been a great source of motivation.

Extended duration of TB treatment has affected the patient's daily routine as stated by the patients in our study, influencing non adherence to treatment. Similar studies have also found that prolonged duration of TB challenges both patient and their families, emotionally and financially, leading to non-adherence. [16,17].

Under the National Tuberculosis Elimination Program (NTEP), adherence is kept on check by wide network of DOTS-Providers and also family DOTS for bedridden patients. To improve adherence to treatment, family members should be included, to understand the treatment plan, as it will improve treatment adherence. From 2018, 99 DOTS and Medication Event Reminder Monitor System (MERM) are being introduced in the program. A randomized control trial study has also shown that MERM is highly feasible in resource- limited settings and acceptable to patients and providers in improving adherence to TB medications. [18,19]

In 2021, "TB AarogyaSathi" app was introduced in Telangana which provides more access to patients on Tb services available and also helps patient to track their progress on treatment and also ensures adherence. [20]

Further improvement in adherence can be accomplished with Video Directly Observed Therapy (VDOT) which showed remarkable improvement in treatment completion and adherence as evidence from a study done in Vietnam. SMS reminders combined with TB education also proved to be an effective intervention in completion of TB treatment in active TB patients [21].

Electronic reminders like text messaging and medication monitor were found to be effective in treatment adherence as evidence by controlled trail conducted in China. The main strength of the study is the study design itself, as qualitative study is most suitable to identify the perceptions or reason behind any behavior. [22]

CONCLUSION

Increasing the awareness of various TB services in the community may increase knowledge and improve attitude among the patients. Providing more information about the effects of medication may reduce the risk of being non adherent. Furthermore, TB anonymous groups can be organized for patients to discuss their challenges while on treatment. Prompt identification and measures to mitigate structural barriers can reduce the defaulters and improve the adherence in the future.

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