Lived Experiences of Patients with Pulmonary Tuberculosis

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Abstract - **Tuberculosis (TB) is one of the dreadful disease of the modern era. Till date many of the diseases have been conquered and some have been eradicated from the community. Despite achieving many milestones in various fields of medicine, the incidence of tuberculosis remains as high and it is the one of the top 10 causes of death globally1. The causative organism of tuberculosis was discovered more than 100 years ago and highly effective drugs and vaccine were available making tuberculosis a preventable and curable disease. Though, the current global picture of tuberculosis shows continued progress, yet tuberculosis continuous to be major public health problem2.India has highly diversified population with notable socioeconomic and cultural differences. Regardless of the differences, short course directly observed treatment, where patients should take drugs under direct observation of health care providers, is uniformly applied all over the country. In order to gain a better understanding of being a patient taking tuberculosis treatment and to improve adherence to treatment, this phenomenological study was conducted to explore the lived experience of patients on tuberculosis treatment. Patients underwent treatment from Primary health centre were included. Twenty-one patients, who consented to in the study, were selected by a convenience sampling method. In-depth interview was conducted using a semi-structured interview guide. The interview was audio recorded; and field notes were also taken. Data analysis was done concurrently with the data collection using a word processor designed for qualitative text analysis. Inductive Thematic analysis was undertaken and some of the main themes as influence of personal social situation, good social support and disclosure, experience of taking medication daily and knowledge about tuberculosis treatment. The findings revealed that the personal social situations of the participants which include accommodation, unemployment and nutritional requirements influenced the adherence of the participants to treatment. It was discovered that good social support had an influence on adherence which could only be enjoyed when the treatment and diagnosis of tuberculosis is disclosed to the family members and friends. Some of the participants also reported knowledge about tuberculosis, its causes, treatment and prevention, as crucial for adherence to treatment.**

INTRODUCTION AND BACKGROUND

Tuberculosis (TB) is one of the dreadful disease of the modern era. Till date many of the diseases have been conquered and some have been eradicated from the community. Despite achieving many milestones in various fields of medicine, the incidence of tuberculosis remains as high and it is the one of the top 10 causes of death globally1.India is the highest tuberculosis burden country globally accounting for one fifth of the global Incidence of tuberculosis cases in the list of developing countries. Due to this heavy burden more than 900 people in India die of Tuberculosis which is accounted for 2 deaths in every 3 minutes which has paramount importance. A single untreated patient with pulmonary tuberculosis can infect around 10 – 15 persons or more in a year 3.

But due to the rise in the incidence of tuberculosis, the Millennium Developmental Goals were formed with the global target to reduce the burden of tuberculosis disease in terms of incidence, prevalence and mortality. Stop tuberculosis partnership was considered to be the key apostle in the Millennium Development Goals (MDGs) to reduce the incidence of tuberculosis by 2015. The other two additional targets added were to halve tuberculosis prevalence and death rates by 2015 to the prevalence of the disease during the early 1990, and successfully eliminate tuberculosis by 2050 from the Global Scenario4.Standards for Tuberculosis Care in India (STCI) reiterates that surveillance system can be strengthened by implementing appropriate measures for quality diagnosis of tuberculosis and ensuring free treatment to all 5.

PROBLEM STATEMENT AND OBJECTIVES

Studies have shown that people diagnosed with tuberculosis and who are on treatment tend to discontinue their medication once they start feeling better, especially if they are not on directly observed treatment. The purpose of the study was to explore and describe the lived experiences of patients on tuberculosis treatment. The objective of the study was to generate evidence which can be used to improve patients' adherence to tuberculosis treatment, in order to help to enhance tuberculosis cure and control. The research question therefore was: What is the lived experience of patients who have been on tuberculosis treatment for at least four months?

DEFINITION OF KEYWORDS

Adherence to treatment means following the recommended course of treatment by taking all the medication, as prescribed, for the entire length of time necessary6.

Lived experience refers to the way individuals or groups make sense of a phenomenon, their world or situation 7

Non-adherence refers to the failure of a patient to comply with or follow the treatment program and medication regimen as prescribed 8

Treatment is defined as the medical or surgical management of a patient 9

In this study, treatment is the anti-tuberculosis drugs administered to the patient to destroy the tuberculosis bacilli.

RESEARCH DESIGN AND METHODS

The design used for the study was exploratory, phenomenological, and qualitative. Qualitative study is a form of social inquiry that focuses on the way people make sense of their experiences and the world they live in10.

A number of different approaches exist within the wider framework of this type of research and many of these shares the same aim: to understand, describe and interpret social phenomenon as perceive by an individual, group, or culture .10

Qualitative research methods of gathering data are ways of gaining insights through discovering meanings and also helps to obtain in-depth information on sensitive issues which otherwise might not be revealed in quantitative studies11.

Phenomenological research identifies the essence of human experiences concerning a phenomenon as described by the participants in the study 12

Lived experience of the world of everyday life is the central focus of phenomenological study, gives meaning to each individual perception of a particular phenomenon and is influence by everything internal and external to the individual 7

Phenomenological method also identifies the way of thinking or perceiving a situation, event or phenomenon.

TARGET POPULATION AND SAMPLING

A purposive sampling method was used for selection of participants from the target population. The target population were the patients with tuberculosis underwent treatment in primary health center under RNTCP and patients that met the criteria were invited to participate in the study. The inclusion criteria include patients who have been on tuberculosis treatment for at least four months, who use the selected Primary health center, Lawspet, 18 years above, able to communicate in English and willing to participate.

DATA COLLECTION

In-depth interviews were conducted by the principal investigator with the question “please, can you tell me from your own perspective, what has been your lived experience since you started tuberculosis treatment four months ago?” The patients that met all the criteria were approached after their visit in Primary health centre and were then invited to participate in the study. Sample size was 21 determined by saturation of data and the interviews were conducted in one of the consulting rooms in the health centre.The interviews were recorded and field notes taken. Each interview lasted between 30 and 45 min. A total of 21 participants participated in the study and all the participants were new cases on treatment for the first time.

ETHICAL CONSIDERATIONS

The study was approved by the Institute Ethical Committee and Written consent was sought from the participants after the study and its purpose had been explained to them. Confidentiality and anonymity were ensured by protecting the participants' identity,

privacy, worth and dignity. Participants were informed about their right to withdraw from the research at any time.

DATA ANALYSIS

The interviews were transcribed verbatim by the principal researcher with the coders. Each interview was coded with a defined coding frame to ensure confidentiality and limit bias. Data analysis was done using the three steps identified by Speziale and Carpenter (2007)7. The first step was the naive reading of each text to gain an impression and formulate ideas for further analysis. The second step was structural analysis to identify meaningful statements through revealing the structure and internal dependent relations that constitute the static state of the text. The third step was the understanding of the interpreted whole from reflection on the naive reading and structural analysis. From each transcript, the significant statements pertaining directly to the lived experience of tuberculosis were identified. Meanings were then formulated from the significant statements. The formulated meanings were then clustered together into themes, allowing for the emergence of themes common to all the participants transcripts. The result was then integrated into an in-depth exhaustive description of the phenomenon.

FINDINGS

A number of themes and subthemes emerged from the data as reflected.

Main themes and sub-themes generated from the data.

Main themes	Sub-themes
History leading to diagnosis	Reasons for seeking treatment
	Experience of being diagnosed with tuberculosis
	Reaction to diagnosis
Influence of personal social situation	Accommodation
	Unemployment
	Nutritional requirements
Influence of good social support and disclosure	Family support
	Friends support
	Community support
	Disclosure to family and friends
	Non-disclosure to family and friends
Experience of taking daily medication	Experiencing better health
	Experience of side effects
	Behaviour modification
	Using a reminder system
Experiencing self-efficacy to complete treatment regimen	Intention to complete treatment
	Determination to be cured
Knowledge related to tuberculosis and treatment	Knowledge about tuberculosis and treatment
	Source of knowledge
	Knowledge about side effects
	Importance of being knowledgeable about tuberculosis and treatment

DEMOGRAPHIC INFORMATION

About half the participants were in the 20–30 years age group while some were aged between 31 and 45 years. Most of the participants were married and residing in urban slum,poor ventilated areas. Most of the participants were alcoholics and smokers. Half of the participants were unskilled workers and some were unemployed.

History leading to diagnosis

History of diagnosis emerged as the first theme and consisted of the sub-themes reasons for seeking treatment, the experience of being diagnosed with tuberculosis and reaction to diagnosis.

1)Reason(s) for seeking treatment

Most of the participants sought treatment when the symptoms of tuberculosis became unbearable and they decided to seek a cure. A participant narrated:

‘I was very tired, lost weight more than 5 kg and I couldn't eat. I went to the doctor and after the investigationst, I was told that I have tuberculosis.’

2)Experience of being diagnosed with tuberculosis

Most of the participants were weak and did not have energy to do anything, some participants had haemoptysis and loss of appetite, and most were coughing with shortness of breath and night sweats. A participant narrated:

‘At first, I thought it was just an ordinary cough that will soon go away. So I took some cough medication and I waited for it to stop. When it got to one month and I was still coughing, I knew it was something serious.’

3)Reaction to diagnosis

Some of the participants felt sad to be diagnosed with tuberculosis and even denied it, a little more than half

of the participants were surprised but calmly accepted the diagnosis, while a few were not happy or angry with the diagnosis. One of the participants reported:
'Well I was not coughing, but I was losing weight and did not have an appetite. After the test, I was diagnosed with tuberculosis. I was surprised to hear that.'

Influence of personal social situation

Personal social situation encompassed the sub-themes accommodation, unemployment, and nutritional requirements.

1)Accommodation

Lack of accommodation was prevalent among the participants, as about half of them lacked proper accommodation. One response was:
'I stopped taking my treatment because I was having accommodation problems and could no longer stay where I was staying then, and I moved to another place.'

2)Unemployment

Slightly less than half of the participants were unemployed as narrated by a participant:
'If I diagnose as tuberculosis, I don't even have a job, I only get piece job once in a while.'

3)Nutritional requirements

Some of the participants found it difficult to get food and adhere to the nutritional requirement. The unemployed participants were sometimes unable to get food especially the right kind of nutritious food to eat. A participant responded:
'I don't usually eat the fruit and vegetables that they told me to eat lot of vegetables and fruits in the health centre because I don't have money to buy food. I just eat any food that I can get from people.'

Influence of good social support and disclosure

Influence of social support was explored through family support, friends' support, and community support, as well as the kind of support and disclosure or non-disclosure to family members and friends.

1)Family support

Majority of the participants were able to get family support. One participant narrated:
'My wife reminds me to take my medication and my sisters come to the health centre with me to get medications.'

The kind of support experienced by the participants was mostly encouragement to continue and complete treatment, provision of food and money where necessary and reminders to take medication daily. One participant responded:
'Yes, my girlfriend supports me. She reminds me to take my medication after eating breakfast. She also comes to the clinic in my place to get the medication whenever I am unable to come…'

2)Friends' and community support

Majority of the participants' friends had a positive influence on the participants, although one-fifth of the participants' friends tried to exert negative influences by encouraging participants to take medication irregularly and even to consume alcohol. A participant stated:
'Yes, I told them and though they did not abandon me, they advised me not to take the medicine sometimes so that I can have drinks with them. But, I do not drink anymore since I started the treatment'

3)Disclosure to family and friends

Majority of the participants disclosed the tuberculosis diagnosis to their family and friends and were able to enjoy some support from them. One of the responses was:
"Yes, I told my husband and children and they are supporting me. They always remind me to take my pills and also encourage me to continue with it until I finish."

4)Non-disclosure to family and friends

Some of the participants did not disclose their illness to their family and friends. The reasons included that the participants did not want their families to be worried, were afraid of how their families would receive the news and thought their families would blame them for getting sick. The responses included:
"Yes, I never told to my wife and children and if I disclose, they will not support me. They always want to be with me. I personally take my pills and continue treatment without fail. Please u just call me by phone and don't visit to my home."
'I don't want my mother to worry about me too, if I tell her that I am on tuberculosis treatment. Also, I don't know how she will react'.

Experience of taking daily medication

The experience of taking daily medication was identified as a theme and included the following sub-themes: experiencing better health, experience of side effects, behaviour modification, keeping clinic appointment and refilling of prescriptions, and use of reminders.

1)Experiencing better health

All the participants started to experience better health with the commencement of treatment as narrated by a participant:

'I am much better now as I am gaining weight and eating well now. I have been getting better since I started taking the treatment'.

2)Experience of side effects

Less than half of the participants experienced side effects. A participant stated:

'The joint pain was unbearable for me, I was much better then and I could not continue to cope with the joint pain.'

3)Behaviour modification

Behaviour modification was interpreted through taking medication daily, practicing healthy habits and engaging in moderate exercise.

All participants said that they took their medication every day without missing any, as narrated:

'Immediately after breakfast, I take them. I never miss taking them on any day.'

Some of the participants started to practice healthy habits which they did not do before the diagnosis and treatment. One participant responded:

'I open the window for fresh air to come and I make sure that I take my medicine at the same time every day. I also don't share my plate and cutleries with anyone including my children.'

One-third of the participants among those who were unemployed started doing some form of exercise since they had started treatment. A participant narrated:

'Yes, l do more exercise now than before. I walk more and I am more active'.

4)Use of reminders

All of the participants had set up systems to remind them to take their medication. The systems included putting the medication where the food is kept so that they would see it and be reminded when they got the food and putting reminders/or alarms on their phones. One participant narrated:

'I put a reminder on my phone, so when it goes off, I know it is time to take my medication.

Experiencing self-efficacy to complete treatment regimen

Experiencing self-efficacy to complete treatment regimen was also identified as a theme with the following sub-themes: intention to complete treatment and the determination to be cured.

1)Intention to complete treatment

All participants had the intention of completing treatment which they started. A participant narrated:

'I intend to complete my treatment, even if I move to another area.

2)Determination to be cured

All participants were ready do all that was required for them to be cured from tuberculosis, so that they could get back to good health. A participant responded:

'Because I want to get well to be able to take care of my children, then I have to do what I am told to get well. Taking the treatment is the way to get well, so that is why I must do it.'

Knowledge related to tuberculosis and treatment

Knowledge related to tuberculosis and treatment emerged as a theme and including the following sub-themes knowledge about tuberculosis and treatment, source of knowledge, knowledge about side effects of medication and importance of being knowledgeable about tuberculosis and treatment.

1)Knowledge about tuberculosis and treatment

The participants who had never defaulted on treatment had adequate knowledge about tuberculosis. All of these participants were given health education about tuberculosis at the health facilities, were compliant with health advice and also had knowledge about the consequences of interruption of treatment. A participant narrated:

'The doctor told me and then he explained to me all that I had to do to be cured. I started taking the treatment and I have never missed a day.'

2)Knowledge about the side effects of the medication

Half of participants had some knowledge about the side effects of the medication while the other half did

not have any knowledge about the side effects. One participant responded:
'Yes I did. I was always dizzy, but because the sister had told me when I was getting the medicine the first time that it can happen.

3)Source of knowledge regarding side effects of the medication
All the participants who had some knowledge about the side effects of the medication were able to access the knowledge through the health education given to them at the health facilities. One response was:
'I just felt like vomiting and since the nurse had told me before that it can happen, I was not surprised and then it passed with time. Since I was okay whenever I took them, I just continued taking them.'

4)Importance of being knowledgeable about tuberculosis and treatment.
All the participants had understanding about the importance of being knowledgeable about tuberculosis and treatment. A participant responded:
'Eating the right food and taking my medicine like I am supposed to. I decided to do whatever I have to do to get well and be free from tuberculosis.'

DISCUSSION

The findings from the study revealed that though tuberculosis is such a prevalent disease, the participants did not expect a diagnosis of tuberculosis. Most of the participants started seeking treatment as soon as they started having serious symptoms such as fatigue, apathy, loss of appetite, persistent coughing with shortness of breath, and haemoptysis. The findings of this study are similar to those conducted in Brazil by Hino, Takahashi, Bertolozzi, and Yoshikawa (2011)13 who explored the health needs and vulnerabilities of tuberculosis patients according to the accessibility, attachment, and adherence dimensions. Evidence was found that the signs and symptoms of tuberculosis forced the participants to seek diagnosis and treatment.
There is need for disclosure, therefore disclosure should be encouraged. Disclosure usually precipitates support, which is essential for adherence, as revealed by the participants in the study. The participants who did not disclose their tuberculosis diagnosis and treatment to their families and friends could not get any form of support from them. The participants in this study attested to the fact that social support is essential if the therapeutic regimen is to be adhered to and non-disclosure means no support from these quarters. A study conducted by Jaiswal et al. (2003)14, revealed that issues such as poor communication and lack of attention and support from the family as well as health provider to the patient sometimes precipitated default. Health professionals should therefore support patients on treatment by encouraging them to disclose their tuberculosis diagnosis and treatment to their family members and friends, so that they can get some help and support during their treatment period.
In taking the medication daily, the participants were able to enjoy better health as long as they were able to maintain adherence. A qualitative study in China (Xu et al. 2009)15 reported that side effects of the medication impacted on the adherence of participants in that study. Findings from the current study suggest that adherence counseling is necessary for all patients prior to the commencement of treatment, which might facilitate adherence. Patients need to be informed beforehand about the potential side effects so that they can be prepared and not be taken unawares by the side effects when they do manifest.
The knowledge related to tuberculosis and treatment had a significant impact on the adherence of the participants. The participants who had adequate health literacy level in this study indicated they acquired their knowledge from health education and talks from health professionals in the clinic. Molapo (2013)16 found evidence that health education related to a specific condition, such as tuberculosis, improves a patient's knowledge regarding that condition. Patients who have low knowledge about tuberculosis and treatment are usually non-adherent (Kaona, Tuba, Siziya, & Sikaona, 2004)17. Moreover, if there is adequate knowledge about the disease condition, it tends to have a relevant impact on the health behaviour and adherence of the patients. There is need for improve communication and health education in health facilities, clinics and in the communities.

CONCLUSIONS

The study revealed that tuberculosis patients on treatment had different experiences in adhering to their treatment. The personal social situations of the participants influenced the adherence of the

participants to treatment. Furthermore, knowledge about tuberculosis and support from family and friends influenced adherence positively. Side effects of the medicine were identified as a major cause of non-adherence by the participants who had been non-adherent in the past.

RECOMMENDATIONS

Professional nurses can facilitate adherence through improved communication and counselling by exploring the socio-economic background of each patient. Therefore, the care offered by health professionals must be marked by quality listening, appreciation of patient complaints and identification of their needs. Tuberculosis treatment, its side effects and duration should be discussed before the commencement of treatment. In addition, patients should always be encouraged to inform and include family members, friends and, where appropriate, their significant others in their diagnosis and treatment.

LIMITATIONS OF THE STUDY

The study was limited to a purposive sample of tuberculosis patients who have been on treatment for at least four months and residing in Lawspet area and taking treatment under RNTCP. The study was also limited to voluntary participation; therefore, because the nature of the topic material was sensitive and personal; the participants' level of honesty may have been compromised.

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