LIFE EXPERIENCES OF PULMONARY TUBERCULOSIS PATIENTS AFFECTED BY DELAYS IN TREATMENT, IN THAILAND

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Abstract

A qualitative research aimed to describe life experiences of pulmonary tuberculosis (TB) patients affected by delays in treatment among 25 pulmonary TB patients in Nakhon Ratchasima, Thailand from October to December 2018. The data were collected by in-depth interviews, analyzed by the content analysis, and managed with the NVivo version 12. The findings found there were two major consequences: patient-related and community-related consequences. For the patient-related consequences, patients claimed that they had more severe symptoms before getting treatment. It affected their daily-life including work that led them to stop working or leave their job. The result of having a longer duration of delays in treatment increased the severity of the disease which may result in death. For the community-related consequences, patients had opinions that they could spread TB to other people. However, some patients felt that they could not spread TB germs because the TB screening test results were not found in the infection. These findings can be used for improving the TB controlling strategies by exchanging knowledge and experience of these TB patients which may help to reduce the severity of the disease, mortality rate, and transmission rate in the community.

Keywords

Delays in Treatment, Life Experiences, Pulmonary Tuberculosis

1. Introduction

Tuberculosis (TB), an infectious disease in the respiratory system caused by the airborne bacillus called Mycobacterium tuberculosis complex, has been revealed to be not only the greatest plague of humans but also adjustable to altering conditions (Vaidya et al., 2015). TB is increasingly becoming a major global health problem with a thousand million new people infected. The World Health Organization (WHO) probably estimated the number of patients from 2002 to 2020 worldwide, there will have been approximately 1,000 million people being new infections, 150 million people being new patients, and 36 million people killed by TB (WHO, 2017). Thailand is one of 194 countries facing a serious problem with a number of Thai people infected about 91,000 cases per year as well as around half of them having the bacillus in their lungs called smear-positive or active TB cases (Department of Disease Control, 2017). Moreover, in 2016 – 2020, a new era of global TB monitoring, WHO has noted that there are three issues of high burden countries namely TB, TB with human immunodeficiency virus (HIV), and multidrug-resistant TB (MDR-TB). Thailand is one of 14 countries where faces all three mentioned issues (WHO, 2017).

In cases of TB suspected cases who do not get treatment initially, TB germs will increase and destroy their lungs until showing cavities on them (Ponticiello et al., 2001) which may cause of transmission of the disease (Cheng et al., 2013) as well as may cause of death (Meintjes et al., 2008; Virenfeldt et al., 2014). Generally, TB symptoms may progress slowly and may not appear in the early stage thus it can result in patients having a longer period from any symptom onsets to the first visit at health care facility called delays in treatment. If TB suspected cases do not go to get the specific treatment, it will also increase the prolonged duration of delays in treatment which may result in an increase in mortality rate and transmission rate as well (Chaychoowong and Suggaravetsiri, 2009).

The absence of TB suspected for a long period without proper treatment may lead to a delay in TB control. A delay in treatment among pulmonary TB patients may cause them to spread widely the germs via coughing, sneezing, or talking in the community due to most pulmonary TB patients with delay may have the more bacillus in their lungs (El-Sony et al., 2002). As well as, the delay may increase the risk of death among the patients with delay rather than patients getting treatment initially (Lienhardt et al., 2001).

According to the consequences of delays in treatment among pulmonary TB patients, it may lead to many consequences as mentioned above. In addition, an undetected and untreated patient has an ability to infect and spread TB to other people around them (Ngadaya et al., 2009; Saqib et al., 2011). The following consequences from delays in treatment may result in more advanced and severe

disease, higher mortality and increasing TB transmission (Huong et al., 2007; Buregyeya et al., 2014). Thus, the researcher is interested in to explore the life experiences of pulmonary TB patients affected by delays in treatment as more than 30 days since their symptom onset to the first visit at the health care facility. The expected findings will be useful to explain more details about their experiences such as their feelings or thoughts while they suffered from TB. Moreover, there is no previous study exploring the experiences on the effects of delays in treatment among pulmonary TB patients. The findings of this study will be useful to develop strategies by the gathered information and find better ways to solve problems. As well as, it will help the health provider create the appropriate, specific, and effective TB screening or detecting system in order to result in patients accessing treatment initially and continuously.

2. Objective

- To explain the life experiences of pulmonary TB patients affected by delays in treatment in Thailand.

3. Methodology

This research was a qualitative research aimed to explain life experiences of pulmonary TB patients affected by delays in treatment by using in-depth interview.

3.1 Population and Samples

- Population were new patients diagnosed with pulmonary TB who came to get treatment at the TB clinic in hospitals under the Nakhon Ratchasima Provincial Health Office.
- Samples were recruited by using purposive sampling. Samples were selected by being pulmonary TB patients who came to get TB treatment with the duration between their symptom onset and the first visit at health facility as more than 30 days. The samples were chosen from 3 selected hospitals: Sikhio Hospital, Dan Khun Thot Hospital, and Chaloem Phra Kiat Hospital during October 1 – December 30, 2018. The sample size was 25 resulted from the saturation of the data or the information obtained were the same (Malterud et al., 2016; Dworkin, 2012).

3.2 Research Tools

Research tools which were used in this study consisted of a questionnaire about personal information, a semi-structured interview guide created according to the conceptual framework based on the literature review and related research, a data recording form, and a tape recorder. The questionnaire

was prepared in English language and subsequently translated to the Thai language which were checked the correct of back translation by 4 bilingual experts. The tools were accordance with the objectives of the research which were checked the content validation by 2 nursing experts, 2 pharmacy experts, a public health expert, and a qualitative research expert.

3.3 Data Collection

Data were collected in Thai language by individual in-depth interviews based on a semi-structured interview guide. Moreover, further questions were asked according to the answers arising from the interview in order to detail about their life experiences of affected by delays in treatment. The interview was taken about 25 – 30minutes per case. Triangulation was used to increase the credibility and validity of the findings (Denzin, 2006) by using more than one method including interviews, observations, questionnaires, and documents. After the interview, the researcher did transcripts in Thai language from tape-recorders and data recording forms to explore whether the information was completed or not, to maintain the meanings of patients' statement, and to improve in the next interview. The researcher also reviewed the data gathered from the patients to recheck the understanding that was consistent with the received information as well as to verify the accuracy and clarity of the information.

3.4 Data Analysis

Data were prepared in English transcript forms before analysing. The researcher did transcripts from tape-recorders and the data recording forms carefully without interpretation in Thai language first, and then translated to English language. Both Thai and English transcripts were back translated by researcher and checked by 4 bilingual experts before analysis. The NVivo version 12 which is a programme for assisting the researcher to deal with huge qualitative data (Hilal & Alabri, 2013) was used to manage the data in terms of coding, categorising, and theming. Data were analysed by the content analysis as the following steps:

1. Transcripts in Thai language were done from tape-recorders and data recording forms. According to doing transcripts, the researcher did transcripts with the verbatim in order to keep the meanings and feelings of each patient. Then, Thai transcripts were translated to English language and checked by 4 bilingual experts.

2. English transcripts were put into the programme for qualitative data management, NVivo version 12, by entering the code of each transcript instead entering any information that could be linked to each patient.

3. All transcripts were read thoroughly in order to understand all contents and feelings according to the messages gathered from each patient.

4. All important messages related to life experiences were described, then categorised the similar messages into the same category (sub-node) in the programme. The Important messages were given meanings by using the messages which were classified and categorised by each patient in order to mean in the context of the phenomena studied.

5. The same sub-node were set into main points (nodes) which were classified by using the meanings which were provided to reread, then grouped the categories which were counted in the similar way into each theme.

6. Important experiences obtained from the research were described by summarising the life experiences of pulmonary TB patient affected by delays in treatment as themes in accordance with the research objective.

3.5 Ethical Consideration

This research was approved by the Ethics Committee on Human Research, Nakhon Ratchasima Provincial Health Office, No. KHE 2018-043. The researcher explained the research objective, data collection, data analysis, benefits, and consent form to participates in research. The researcher then requested consent for conducting the research by requesting permission to interview and do tape-record. All patients had signed the consent form with notice and willingness. Patients had known the right to withdraw from this research project at any time when needed which this study did not have any impact on them. In addition, there was the confidentiality of information while interview. The patient's name would not be disclosed by using the code instead patient-related information. The data were kept in a safe place where outsiders could not access to the information and they would be destroyed when the research results were published.

4. Findings

In this part, findings will be described into two main parts including general information and life experiences of pulmonary TB patients affected by delays in treatment as shown in below.

4.1 General Information

The findings found that there were 25 pulmonary TB Patients with delays in treatment (more than 30 days) who came to get treatment at TB clinic in hospitals under the Nakhon Ratchasima Provincial Public Health Office. The majority of them were male (80.00%), the median age was 57 years (the maximum age was 83 years - the lowest age was 25 years). Most of them graduated in primary school level (68.00%), married (72.00%), were general employment (36.00%), and the median income was 5,000 Baht per month (highest income was 25,000 Baht - lowest income was 0Baht). In addition, there were some of them living with HIV (16.00%), as shown in Table 1.

Table 1: *General Information about Participants*

General Information	Number (%)
Gender	
Male	20 (80.00)
Female	5 (20.00)
Age (Years)	
Median (Maximum – Minimum)	57 (83 – 25)
The Highest Education	
Illiterate	2 (8.00)
Primary education	17 (68.00)
Lower secondary education	1 (4.00)
Upper secondary education	4 (16.00)
Under graduation	1 (4.00)
Marital Status	
Single	2 (8.00)
Married	18 (72.00)
Widow	3 (12.00)
Divorced	2 (8.00)
Occupation	
Unemployed	5 (20.00)
Farmer	8 (32.00)
Labour	9 (36.00)
Government officer	1 (4.00)
Student	1 (4.00)
Monk	1 (4.00)
Monthly income (Baht)	
Median (Maximum – Minimum)	5,000 (25,000 – 0)
HIV status	
Positive	4 (16.00)
Negative	11 (44.00)
Unknown	10 (40.00)

4.2 Life Experiences of Pulmonary TB Patients

The qualitative data were analysed by the content analysis and managed by using Nvivo version 12. The findings of management with Nvivo will be described into two main themes: patient-related and community-related consequence. These themes were categorised by grouping the same meanings of patients' messages into the same group called sub-node. Relevant sub-nodes were addressed into node. Finally, relevant nodes were set into each theme, as shown in Table 2.

Table 2: *The Themes of Qualitative Findings*

Themes	Nodes	Sub-nodes
Patient-related consequence	Current consequences	Health-related consequence
		Work-related consequence
	Future consequences	Health-related consequence
		Work-related consequence
Community-related consequence	Transmission consequence	Able to transmit
		Unable to transmit

As shown in the above table, the findings of qualitative data were categorised into two main themes. Patient-related consequence consisted of two nodes: current consequence and future consequence while community-related consequence included only one node namely transmission consequence. These findings will be detailed in the following sections.

4.2.1 Patient-Related Consequence

4.2.1.1 Current Consequences

1) Health-Related Consequence

According to the findings, patients did not want to go to the hospital and tried to do self-medication by using antibiotics before going to the hospital thus it made them have a longer duration of delays in treatment. They then felt that the delays in treatment caused of having advanced symptoms or more severity of the disease. Some patients said that they had a lot of symptoms before coming to get treatment, as the following statements:

"I feared that the disease would get more depth. It showed that my symptoms were very severe, I did not know until my wife told me that I pissed out in my clothes. The doctor took me into the emergency room, then checked me up. In the x-ray film, it showed that my lungs were destroyed and had more cavities. I could feel that I breathed with some sound." (A 75-year-old man)

"Oh! I just thought that it was just cough, only cough, just only this. Bleeding was from broken capillaries. Umm, I just thought like this. Oh! Bad, bad, too bad." (A 61-years-old man)

"Huh, it was very bad, too bad. I thought that I might have cough up blood and other symptoms but it showed about tiredness before other symptoms. Thus, I called to the ambulance to pick me at my home. At that time, I just tried to hold everything in the air, I could not live." (A 61-year-old man living with HIV)

2) Work-Related Consequence

The consequence associated with health problems was the patients could not able to use their daily-life normally. Moreover, it affected the current work which caused to stop working or leave from their jobs, as the following statement:

"I thought that it… it… it was very severe. I had a bad cough that I had to stop working for 3-4 days. Since my aunt told me that I had to come back home to see the doctor. I then stopped working after that time. After that, I did not go back to work anymore and moved to work other job which was not involved with dusts." (A 25-year-old-man)

"I thought that I did not want it to be a big matter because I might be stopped from working. If it was similar to this time again, I thought that I just took medicines and the symptoms would be cured." (A 25-year-old man living with HIV)

4.2.1.1 Future Consequences

1) Health-Related Consequence

According to the findings, patients said that the consequences which may occur in the future if they had longer duration of delays in treatment. It may increase the severity of the disease. Moreover, there will be an impact on an increase of mortality rate among pulmonary TB patients, as the following statements:

"I thought that if I leaved my symptoms for a long time, I might not be alive." (A 62-year-old man)

"It might not be better, might be very severe, and might get worst at the end because I could not endure for this time. It might make me get worst or kill me." (A 44-year-old woman)

"Oho! If I did not come to the doctor, I would die. For me, if I leaved it for a longer time just only one month, I would be in the crematorium. I thought that Oh! I really could not live anymore. Since having seen the example, if it was not reached the doctor or not met the medicine, it would be only death and death." (A 61-year-old man)

"If I came to the hospital late, it would be difficult to recover. So, I thought if I came late, I might not resurrect. I thought that if I came to treatment late, it would be more severe and could not resurrect." (A 59-year-old man with haemoptysis)

2) Work-Related Consequence

As patients claimed that they may have problems which will affect their future life as they cannot go to get their previous work. They needed to stop working and waited until they were cured from TB, as the following statement:

> "In the previous time I could work. Since I had this disease, I could not work at all as I did not have energy. I just feel better in this month, better than previous period. I can eat, can eat anything. However, I do not still go to work as I am just waiting for being cured." (A 59-year-old man)

4.2.2 Community-Related Consequences

4.2.2.1 Transmission Consequence

1) Able to Transmit the Disease in Community

According to another consequence which should be strictly monitored is community-related consequences. It consisted of close contact in family, community, or society of patients. They felt that having delays in treatment will be a cause of TB transmission in their family, community, or society, as the following statements:

> "They might get the disease from me because we had lived together. As well as, I previously did not protect at all. When I coughed, I did not protect, or cover my mouth at all. I thought that they might contact the disease." (A 44-year-old woman)
>
> "Umm… I recognised that. Err… If I did not come to see the doctor or knew as being TB patient late, others who lived in the same house or closed to me might get the disease as well. They might be the same. I had thought, thought, thought about this as well." (A 48-year-old man)
>
> "Umm, they would get the disease from me because each other did not know. I did not know and they did not know as well. We still did all activities in family together, it might transmit." (A 48-year-old man living with DM)
>
> "About TB, they might get it. I might die and spread the germs to other people. As well as I thought that if I died, the disease would be out of my body. I thought as this." (A 61-year0old man living with HIV)
>
> "Someone who were close to me might contact the disease from me." (A 25-year-old man living with HIV)

2) Unable to Transmit the Disease in Community

On the other hands, some patients described their feelings about the consequence on the community that they could not able to spread TB to other people, as the following statements:

"I knew that there would not be anything because I had already separated living in myself. I did not involve with my wife and children. I also separated food and water for myself. As well as, the crockery was also used separately. There was no society nearby my home. I just was tired, did not want to be confused with anyone. I did not want to associate anything with anyone as well thus it was quiet life." (A 61-year-old man)

"About infection, I thought that it was impossible. It was not us as we lived together. For instance, other people who lived together with me were not sick. I noticed my wife that she just was in her area. I was just careful, kept some space with her as well." (A 52-year-old man)

5. Discussion

This qualitative study aimed to describe life experiences of pulmonary TB patients affected by delays in treatment among pulmonary TB patients which was undertaken in rural areas in Nakhon Ratchasima Province. The majority of the samples overall was male and elderly. Most of them graduated in primary education and got married. For economic feature, most of them were labour and farmer, and had monthly income about 5,000 Baht. There were only four patients having HIV infection. In fact, TB patients especially older people did not want to go to the hospital involving with their health seeking behaviour due to their low level of knowledge and lack of family support. This finding is consistent with a report by Kitreerawutiwo and Mekrungrongwong (2015) which showed that the importance of education level and social support play a role in the health behaviour among elderly. Moreover, most patients used antibiotics by themselves before going to get an appropriate treatment thus it also made them have a longer duration of delays in treatment and get advanced symptoms as a study of Barakh and others (2016) showed that there was a significant number of people around the world using antibiotics incorrectly which led them have a risk instead of being cured. In addition, the delays in treatment lead patients have many following consequences including patient-related and community-related consequences.

Firstly, the current patient-related consequences, the delays in treatment can affect their life in terms of health-related and work-related. The patient having delays had more advanced and severe TB symptoms. Some of them had coughing up blood or unconscious. This finding corresponds to many researches which found the delays in treatment affecting the clinical severity of TB (Virenfeldt et al., 2014; Greenaway et al., 2002) or an increase of referral rate to specialised hospitals for TB which could represent more severity of the symptoms among patients having the delays (Meintjes et

al., 2008). In addition, it also might increase the number of TB germs in patient's sputum or cause of cavities in patient's lungs (Cheng et al., 2013). Moreover, the delays can affect on patients in terms of work-related. It also resulted in patient being unable to perform normal daily activities which affected their ability of work as well. The findings found that some patients had to stop working for a while or have to stop working all the time which made them lack of income. The delays can also result in patients needing to take longer treatment time which made them deal additional costs including treatment, transportation, and living costs. This finding corresponds to research in Yemen that found patients with delays in treatment would have a significantly higher cost. (Aldhubhani et al., 2017)

Secondly, the future patient-related consequences, they commented that if they had a longer delays in treatment, it may cause them have the worse symptoms or lead them to death. This opinion was come from their own previous experiences while they faced the disease progression before getting treatment. Furthermore, patients had experiences while they have been encountered from other patients in the community. Delays in treatment may result in life-threatening. This result is consistent with the research that found the relationship between delays in treatment and an increase of mortality (Meintjes et al., 2008; Lienhardt et al., 2001).

Lastly, the community-related consequence, TB patients thought that they would be able to spread TB germs to other people such as close contact in their family, community, or society. This finding is consistent with a study shown the period of delays in treatment can predict TB patients in the home-exposed person (El-Sony et al., 2002). In addition, there was another study showing that delays in treatment was the risk of an increase of TB infection (Ponticiello et al., 2001). However, especially the elderly, some patients thought that they could not spread TB to others because there was no any family member having TB infection. This finding is consistent with the study of the difference in the number of close-contact infections between patients with long and short delays in admission (Aldhubhani et al., 2013).

6. Conclusion

The delays in treatment can affect both individual and community. The consequences on patients could result in morbidity and mortality rate among pulmonary TB patients. Moreover, it could affect their economic status because they have to stop working or leave from their job as well as to spend more money in treatment, transportation, and living cost when they come to the hospital. In terms of consequences on community, the delays in treatment also results in transmission rate among close contacts as well as communities.

Moreover, it could be seen that most patients live in the rural area, lack money, and have low level of correct knowledge and experiences about TB which make them cannot access the appropriate treatment early. While, some patients try to get an appropriate treatment but it is difficult to access because of economic background and distance barrier. Thus, the better way to decrease the delays in treatment is an improvement of the primary care unit where is the nearest health facility to their residences. Primary care unit should be improved in terms of educating people in their area to have more knowledge about TB. Moreover, it should be improved on TB screening strategies in order to detect TB patient at the early stage. If health provider and people have adequate knowledge and good attitude about TB, it will help them to detect TB suspected cases initially. Therefore, TB suspected will be diagnosed and treated early which will help to reduce the consequences on patients and communities.

For scope of future research, the researcher should investigate further about the impacts of an improvement of health care service in the primary care unit as the first health facility chosen by most people after improving health education and TB detection strategies. As well as, the study about the life experiences of people living with TB patient should be investigated further in order to compare and contrast from both viewpoints among TB patient and people living with TB patient. These mentioned future research will be useful to provide the best way to eradicate the delays in treatment and its consequences.

For research limitation, as in-depth interview was used to collect data in this study. Thus, the sample size was small, with only 25 participants selected by purposive sampling method which could have introduced bias into the findings. However, participants were carefully selected only pulmonary TB patients having delays in treatment. They were recruited in the study until the information obtained was saturated as showing the same findings. Moreover, recall bias was controlled by triangulation methods. As well as, it also was tried to reduce by including only patients who came to get treatment at the clinic no more than 2 months before the interview.

7. Suggestions from the Research

- Health education and TB detection strategies should be improved in any primary care unit. The provider and people should be gained more knowledge and awareness about TB signs and symptoms which will help the provider detect and treat TB patient in the early stage.
- People should be encouraged to exchange knowledge and experiences about the consequences of delays in treatment from real-life experiences in both impacts on patient and community.

Therefore, they may recognise the importance of severity of the disease which may occur among TB patients in the future.

- Correct information about pulmonary TB should be more provided through various media especially social media. It should be concentrated on TB signs and symptoms as well as adding more information about the impacts of delays in treatment. People will be able to consider themselves when they have adequate knowledge about the disease. Therefore, they then will come to get the examination at the health centre initially which results in reduce its consequences.

- People should be provided to access pulmonary TB screening tests at least once a year. They should be screened for pulmonary TB with questionnaire to screen by risk factors of TB infection, then sputum examination and chest x-ray. If people will be screened for pulmonary TB, it will make them more aware and better monitor on their symptoms which will allow them to get an initial diagnosis.

Acknowledgments

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