Empirical Articles

The Tale of Seeking Treatment: A Qualitative Study of Pulmonary Tuberculosis Patients

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Abstract

Aim: The aims of the study were unravelling patients' health-seeking behaviour pathways to seek medication in healthcare facilities and key factors that determined patients' immediacy in seeking medical treatment.

Method: By involving 5 pulmonary TB patients who were undertaking treatment at Pegirian Primary Health Centre, Surabaya, Indonesia, the research was carried out using an explorative qualitative research design, and the chosen data collection technique was semi-structured interview.

Results: The research findings demonstrated that all participants showed five rather similar health-seeking behaviour sequences, such as: (a) defining symptoms; (b) asking laypeople opinions on symptoms; (c) undertaking non-medical treatment to reduce the symptoms; (d) taking laypeople's suggestions to visit healthcare facilities into consideration; (e) deciding to undergo treatment process. Several barriers that caused treatment delay were inaccurate symptom definition and poor health-related risk perception. Meanwhile, reinforcing factors were relatives' appeal to seek treatment, the existence of comorbid/previous diseases, access to healthcare facilities, and increasing perceived severity of the symptoms.

Conclusion: Research findings showed that participants performed similar health-seeking pathways. Hindering factors that caused treatment delay were mostly related to cultural-based illness definition and knowledge. Research findings would be potentially beneficial to local primary healthcare for designing interventions that encourage patients to seek professional help and reduce treatment delay.

Keywords: determinant factors, health-seeking behaviour, pulmonary tuberculosis

Introduction

Pulmonary tuberculosis (TB) prevalence in Indonesia has shown a promising trend by experiencing a moderate fall every year since 2010. Case notification (CNR) and detection rate (CDR) in Indonesia have also improved significantly and even surpassed World Health Organisation (WHO) standard in 2012. However, Indonesian Ministry of Health realised that such achievement has not been completely optimal. Even if CDR had reached 82.4% in 2012, there were still 17.6% predicted pulmonary TB patients who had not had access to healthcare facilities or received proper treatment. Also, Indonesia is placed fourth worldwide as the country with the highest burden TB ("Indonesia Menjadi Contoh," 2013; Indonesian Ministry of Health, 2013; National Institute of Health Research and Development [NIHRD], 2013; WHO, 2013).

On the national scope, East Java Province obtained a rather appalling record in controlling TB. In East Java alone, there were 42.222 cases and 1308 patients died of pulmonary TB in 2013 (Andriansyah, 2013; Ardiantofani, 2014; Surabaya Local Health Affairs [SLHA], 2012). Meanwhile, Surabaya - the second biggest city in Indonesia as well as the capital city of East Java - is ranked first on having the highest number of pulmonary TB cases in East Java. As recorded by SLHA, in 2013 alone, there were 17.758 cases of pulmonary TB. Additionally, pulmonary TB was on the list of the ten most common diseases in Surabaya area (SLHA, 2013).

Case finding is the crucial key to control pulmonary TB (Wahyuni et al., 2007), so that it becomes a widely popular research topic among researchers in developing countries with high burden of TB. Case finding method is relatively weak and passive as it solely depends on the patients' awareness of the symptoms and their initiative to immediately seek professionals' help at healthcare facilities. Another problem related to case detection is patient delay, which implies an overly long-time interval between the occurrences of the first symptoms and the patient's first visit to healthcare facilities (Hooi, 1994). People with pulmonary TB should be diagnosed as soon as possible to minimize the risk of spreading (Jaramillo, 1998; Jurcev-Savicevic & Kardum, 2012).

The health behaviour of patients and healthcare workers (HCWs) directly affects the rapidity of case detection (Hooi, 1994; Johansson, Long, Diwan, & Winkvist, 2000). How the patients recognize the early symptoms, whether they seek professional help and are compliant to the medication schedule are crucial aspects in controlling the disease. Therefore, research related to health-seeking behaviour (HSB) of pulmonary TB patients has been growing rapidly, especially in developing countries. The research on HSB covered the discussion of the patients' decision making process in choosing healthcare facilities (traditional/modern healthcare facilities), the steps of undertaking treatment process and all determinant factors that underlie this process, and patient's perception of healthcare services (Kroeger, 1983). This research proven theoretically and practically useful in controlling and restraining the spreading of infectious diseases as investigating HSB helps health scientists and practitioners identify factors that hinder pulmonary patients to seek professional help (Abubakar et al., 2013; Jaramillo, 1998).

In Indonesia, there has been few research concerning the case detection rate (Karyadi et al., 2002; Rintiswati et al., 2009; Wahyuni et al., 2007; Widjanarko, Gompelman, Dijkers, & van der Werf, 2009). However, this research was mostly focused on the difficulties of finding TB cases in the eyes of HCWs, thus subsequent research on the side of patients is urgently needed. Apart from that, similar research on patient delay or patient's HSB has been very little.

Health-Seeking Behaviour and Pulmonary TB

HSB is defined as a series of steps that are taken by the patients when they feel the urge to seek medical treatment (Chrisman, 1977; Mahmood, Iqbal, & Hanifi, 2009). It is a concept that has been widely used to comprehend individual's response to their health conditions and the extent to which they are willing to take actions in treating their illness. Explaining health behaviour using a health-seeking model can be fruitful as it is a form of integration between health sciences, psychological aspects of human behaviour, and other social and cultural factors of illness, offering a more comprehensive view on explaining health behaviour. The health-seeking model is mainly focused on exploring the relation between health-related behaviours and sociocultural context, so it contributes to add a picture of the effect of human behaviour and its social context on health-related behaviour (Jaramillo, 1998). Moreover, the health-seeking model accommodates the ethnographic profile of the patient, and it is developed from laypeople's perspective, serving as a focal point in many health behaviour research (Chrisman, 1977). The health-seeking model is also useful as a basis for designing social interventions to reduce delayed diagnosis, increase

patient's compliance with HCWs' suggestions, and develop health promotion strategies in various contexts (Mackian, Bedri, & Lovel, 2004).

Generally, there are two existing models that explain patient's HSB, which are *pathway* and *determinants* models (Chrisman, 1977). Pathway model covers five sequential steps; (a) symptoms definition, which refers to the condition when the patient recognizes several changes on their physical conditions related to the illness; (b) illness-related shifts in the role of behaviour, which me and changes of patients' social relation with their surroundings due to their health conditions; (c) treatment action, which refers to several therapeutic activities conducted by patients to reduce their symptoms; (d) lay consultation, which deals with patient's effort to ask advice from their friends or relatives about their health conditions; and (d) adherence, which means a series of medical treatments conducted by health professionals in order to cure the diseases (Chrisman, 1977; Jaramillo, 1998; Kroeger, 1983).

Determinants model focuses on the exploration of explanatory variables that affect patient's decision making in choosing healthcare facilities and consists of three sets of variables; (a) predisposing factors, which are demographic variables, family size and composition, smoking behaviour, educational level, attitudes, sense of responsibility when taking health-related decision, etc.; (b) enabling factors, such as healthcare facilities' accessibility, health insurance membership, income security, etc.; and (c) healthcare system service factors, which refers to a set of variables that covers healthcare system and policies as well as political factors of the countries (Kroeger, 1983).

The debate over which model is better at explaining and predicting health behaviour has produced imbalanced views on HSB and caused stagnation of health-seeking studies. This means that HSB studies stop in the stage of understanding health-behaviour without being able to formulate strategic solutions in managing and controlling the disease, whereas it can be done by designing proper health-policies or social intervention programmes (Mackian, 2001; Mackian et al., 2004). By taking sociocultural factors into account, HCWs are able to solve twin problems in managing pulmonary TB, delay in seeking treatment, and patients' lack of commitment to undertake long-term treatment (Rubel & Garro, 1992).

The Present Study

This research aimed to investigate pulmonary patients' HSB pathways as well as determinant factors that hinder them to seek immediate medical attention by using qualitative exploratory design. Therefore, both models of HSB were used as the primary theoretical approach. Research findings could be used by primary healthcare providers to design suitable interventions that encourage people to choose professional help when pulmonary TB symptoms arise.

An exploratory qualitative research was conducted in order to investigate the pattern of HSB of pulmonary TB patients. The health-seeking model used in the research was pathways, so this research aimed to look at the paths taken by the patient in order to cope with the symptoms as well as sociocultural factors that hinder or reinforce seeking help. Exploratory qualitative design was chosen as the most suitable method because we did not intend to limit research framework to a specific scope (theory confirmation or accepting/rejecting hypothesis), yet we strived for describing phenomena as it truly is (Bryman, 2012; Lambert & Lambert, 2012). Meanwhile, quantitative design may have limitations in discovering specific sociocultural themes in regards to pulmonary TB patients' HSB.

Method

Participants

Research participants were pulmonary TB patients who: (a) had been diagnosed with active pulmonary TB for less than four months; (b) were aged over 25 years old; and (c) had been undertaking direct-observe-treatment-short course (DOTS) routinely at Pegirian Primary Health Center. Pegirian sub-district was chosen because Pegirian Primary Health Centre is one of the two Primary Health Centres that provide lung specialist clinic in Surabaya. Pegirian sub-district is a part of Semampir district, which was mentioned by Suherni and Maduratna (2013) as one of the most vulnerable areas of pulmonary TB transmission due to the high percentage of poor people, high number of children with malnutrition, high number of people with HIV, and high number of immigrants. This research was narrowed to the area of *Kampong* Sawah Pulo and Sidotopo.

Kampong Sawah Pulo and Sidotopo are slum areas in the North part of Surabaya. Most of the residents are not Surabaya official residents, but immigrants from Madura Island, thus the largest ethnic group in this area is Madurese. Based on ecological and physical conditions of the houses, the environment can be described as filthy and unhealthy. Sawah Pulo and Sidotopo have numerous narrow alleys and most of houses in these *Kampongs* are shanty houses, which are built from unsuitable materials for housing (used paper, plastics, wood, etc.). Some of the houses are built from permanent materials like brick and cement, but those are poorly built. Some of the walls are dim and in a bad shape.

The houses of our research participants showed rather similar conditions; they were overcrowded, and the air inside the houses was humid and stuffy. Ventilation was poorly designed, and some houses did not even have any ventilation. As a consequence of poor ventilation, the sunshine barely entered the houses, so the houses were rather dark and humid.

Cleanliness was an almost insolvable problem in this area. Rubbish was scattered everywhere around this area. Most households let their rubbish bins uncovered, so flies were everywhere. We saw the carcass of dead chickens and rats, yet people just let it unnoticed. Drainage system was also improper and smelled horrific, as those were severely clogged by a pile of rubbish. A nearby medium-sized river wherein river mouth is on Madura Strait was fully covered in rubbish.

Four female and one male patient were chosen to be interviewed for this research. All of them were native Madurese and had very small monthly income (less than US$160) with some degree of variation on age, level of education, and job status. They were all undertaking pulmonary TB treatment at Pegirian Primary Health Center and had been diagnosed less than four months before the interview. Two participants had to be accompanied by their significant other due to language barrier. Below are detailed descriptions of research participants and their names are all fictionalized.

1. Karin was a 65-year-old widow of a retired civil servant. When interviewing Karin, she had to be accompanied by her daughter-in-law, Rina who are was in her thirties, due to language barrier. She lived alone and was no longer working. However, she still received a sum of regular pension from her deceased husband. Karin had three grandchildren to be brought up from her pension money. Before getting sick, Karin was a *rujak* (Javanese fruit salad) seller, but had quitted since being diagnosed with pulmonary TB. Karin was a Madurese and had been living in *Kampong* Sawah Pulo since shortly after her marriage.

2. Dinda was a 30-year-old housewife who lived with her husband and three children. Before being diagnosed with pulmonary TB, she got a job at a fabric distributor. After being diagnosed, her husband asked her to stop working, and all household burden was borne by her husband who worked as a shopkeeper assistant in a drugstore.

3. Cici was a 60-year-old housewife who lived with her husband and two children. Cici was a native Madurese, but she did not remember when she first came to the area. Cici was a bread and cake seller, but shortly after being diagnosed with pulmonary TB, she stopped working as her daughter forbade her to do so. Despite being jobless, Cici occasionally collected used mineral water cups to sell for a living without her relatives' approval. During interview, Cici had to be accompanied by her eldest daughter, who was 48 years-old, due to language barrier.

4. Sari was a 25-year-old housewife and had one child. She lived with Dina, her mother, who was working as *gorengan* (traditional Indonesian fried snacks) seller. In her daily routines, she helped her mother to sell *gorengan*, while her husband worked as a street vendor at Suramadu Bridge. Sari had five siblings who also lived with Sari and her mother. After being diagnosed with pulmonary TB, Sari rarely helped her mother at work, but when she felt a bit better, she joined her mother to serve her customers.

5. Joko was a 50-year-old married man who was once a *becak* (Pedicab) driver. He lived with his wife and an adopted son. His wife worked in a printing company, while his adopted son was jobless as he was mentally ill since he was 20. After being diagnosed with pulmonary TB, Joko was unable to work, so he stopped driving *becak* and stayed at home. Joko was a native Madurese who had been living in Sidotopo for years.

Measures

An interview guide was structured by the research team using pathways and determinants model of HSB as the theoretical basis and consisted of 35 primary questions regarding the paths taken by patients, as well as the identification of sociocultural factors related to HSB. Some of the interview questions are presented in Table 1.

Table 1

Sample Interview Questions

Topic	Sample Questions
Rapport phase	When you were first diagnosed with pulmonary TB? Were there any of your relatives, families, neighbours or co-workers who have been diagnosed with pulmonary TB? Before being diagnosed with pulmonary TB, had you ever heard or been given any information about pulmonary TB?
Symptoms recognition	What were the symptoms that first arise? When were the symptoms first recognised? In what circumstances did the symptoms occur? Did they occur at any time or in a particular time?
Self-diagnosis	What did you think about your illness when the symptoms were firstly recognised? What was your guess in regards of your disease's name and its cause?
Illness-related shifts	How severe were your symptoms in disrupting your daily activities? When did your symptoms feel extremely unbearable?

Topic	Sample Questions
Seeking professional help	What were your steps in seeking professional help to cure your symptoms?
	What factors supported or hindered you to seek professional medical help?
Lay consultation	Did you tell your significant others about your symptoms and how did you tell them?
	How did they react and how important were their comments and thoughts about your illness?
	How did your significant others' advice encourage you to seek medical attention immediately?
Current treatment	What were the doctor's advice to treat your illness?
	Apart from your medical treatment, please describe in detail all your undergone treatment that were intended to cure the disease.
	What factors motivated and demotivated you to recover from your illness?
Other factors	Did you find yourself being treated differently by your circumstances after being diagnosed with pulmonary TB?
	Was there any negative comments from neighbours, relatives or co-workers related to your illness?
	Did you know that pulmonary TB is highly infectious? What are your efforts to keep your illness away from people around you?

Procedure

Semi-structured interview was undertaken to collect the data. Before starting the interview process, we undertook preliminary interviews to verify inclusion criteria. We initially interviewed 10 patients about their social-economic status, health status and their willingness to participate in the research. It was rather difficult to recruit participants as they were very reluctant due to their job inflexibility, as most of them were still working during the day and, due to safety reasons, it was not possible to conduct interviews at night.

All 10 registered patients were initially contacted, shortly interviewed and volunteered to participate; yet only five patients met the inclusion criteria and provided their agreement to participate in our research. Five others were excluded due to several reasons; one patient refused to participate without any specific reason, three patients were diagnosed with gland tuberculosis, and/or two patient had been diagnosed with pulmonary TB for more than four months. Interview process was conducted from July to September 2014.

Access to participants was formally proposed to Surabaya Local Health Affairs and Pegirian Primary Healthcare Centre. All respondents had been given informed consent forms and proper information about the research, as well as opportunities to raise questions or concerns. They also signed a consent form before interview process. Participants were informed prior to the interview that the information, which they given during interview process would be kept confidential as well as their personal information. They were also told that their names would be fictionalised in order to ensure anonymity. Ethical clearance and research's authorization were granted by Surabaya Local Health Affairs.

Data Analysis

The collected data was analysed using thematic analysis. Thematic analysis is an information coding process that produces a list of themes, theme models, complex indicator, classification related to the themes, etc. (Corbetta, 2003). Thematic analysis involves careful interviews' transcriptions reading, so that the researcher may be able to recognise the meaning pattern beyond the data (Fereday & Muir-Cochrane, 2006). The pattern is later translated to categories and/or subcategories in order to draw conclusion from data (Braun & Clarke, 2006).

Thematic analysis and theme coding were conducted by a coding team, which consisted of a researcher with the help of three research assistants. Each coding team member read the transcriptions several times and, using the thematic analysis technique, the transcripts were individually coded. Theme and definition raised in research findings were mutually agreed by the coding team after a series of discussion sessions, to align differences in interpreting and data coding.

Results

Table 2 provides a general summary of the research findings. It should be taken into consideration that the steps chosen by the participants were slightly different from Chrisman's (1977) description. According to supporting research conducted by Jaramillo (1998), HSB pathways cannot be translated as a linear sequence, as the paths are sometimes intertwined and vary from patient to patient. However, we presented the results in a logical sequence to provide better understanding of the process. Some of sociocultural factors were identified - such as symptoms naming (*anginen*) and respondents' false beliefs about the illness - yet this research only provides an early indication, thus subsequent exploratory research on determinant factors of HSB is still urgently needed.

Table 2

Paths Taken by the Research Participants Before Being Diagnosed With Pulmonary TB

Path Taken	Description
Symptom definition	All participants misrecognised their symptoms as common cold and/or *masuk angin*. Even though the symptoms appeared to be extremely threatening (ex., blood vomiting), participants did not have any idea that they were infected by pulmonary TB.
Lay consultation in regards to the symptoms	Participants' definition of the symptoms was reaffirmed by their relatives, friends and/or neighbours, so participants were mostly convinced that it was nothing serious, as it was just a common *masuk angin*. However, laypeople who had knowledge/previous experiences with pulmonary TB, advised participants to seek immeadiate treatment from health professionals.
Non-medical treatment	Most participants chose to ask someone to do *kerokan* (a popular indigenous Javanese health therapy which is performed by smearing one's back with medicinal oil then rubbing it with a coin), consumed *jamu* (traditional herbal drink), or visited traditional healer (alternative medication) to reduce their symptoms. However, participants who had had previous knowledge and direct experience with pulmonary TB straightforwardly visited healthcare facilities/professionals.
Laypeople suggestion to visit health facilities	As the symptoms were unbearable and getting intense, relatives, friends and/or neighbours strongly recommended the patient to visit formal healthcare facilities (General Practitioner [GP], Primary Health Centre, Hospital, etc.).
Decision to visit health facilities and undergo treatment	When the patients arrived at healthcare facilities they were in a very severe condition, and the HCWs conducted a sputum check, in order to recognise the symptoms of pulmonary TB straightaway. All patients who were admitted to Primary Health Centre had to sign a contract paper that bound them to regularly undergo treatment; otherwise they would be fined US$ 1550. The treatment cost was zero, as local government allocated a high amount of money to fund pulmonary TB treatment. Respondents with previous health conditions took a shorter amount of time to arrive at healthcare facilities, as they were already aware of their condition.

Symptoms Definition and Lay Consultation of the Symptoms

All respondents reported similar symptoms, which were severe coughing, chest tightness and shortness of breath, as described in Table 2. However, those particular symptoms were not yet recognized as a serious symptom as most patients reported that it did not disrupt their daily activities, and the cough sometimes disappeared even though it had lasted for a long-time period. Karin, for example, admitted that she had been coughing for 20 years. Meanwhile, other participants went to healthcare facilities for suffering from severe cough for around three weeks to four months.

Some respondents reported flu-like syndrome, which involved high fever, feeling tired, muscles pain and sore throat. Interestingly, most respondents initially defined pulmonary TB as *masuk angin* or *anginen,* which are an indication of general feeling of sickness and the excess of wind inside one's body. Four participants initially pointed *masuk angin* as the cause of their illness. In East Java, *masuk angin* or *anginen* is not considered as a dangerous or life-threatening situation, so people rarely ask HCWs to run a check on their health condition. Therefore, in this initial stage, four respondents associated cough and other symptoms as part of *anginen* or flu-like syndrome. However, Joko was the only respondent who strongly believed that he did not feel any changes in his health condition until one day he vomited blood.

Laypeople, including friends, relatives and neighbours, reaffirmed respondents' definition of their symptoms as a mere *anginen* or common cold, which reinforced respondents not to go to health facilities. They considered *anginen* as a satisfying self-diagnosis of the symptoms. However, as the symptoms got more severe and life-threatening, all participants agreed that their relatives strongly encouraged them to seek medical attention.

> "Yes it perhaps *masuk angin* (common cold), as it was rainy season so that I coughed." (Karin)

> "Yes it probably *masuk angin* (common cold)." (Sari)

Non-Medical Treatment and Making First Visit to Healthcare Facilities

Anginen is usually treated by performing a traditional *kerokan* therapy, which means scraping one's back ribs and neck with the edge of an oiled-coin until it shows a color of bright red. When the skin colour turns red, it is believed that the wind inside one's body has gone away. Therefore, *kerokan* is the treatment that four respondents admitted to have had before seeing the doctor. They mostly asked their relatives to perform *kerokan* and they reported that the symptoms slightly reduced afterwards. Thus they believed that *kerokan* was a potent treatment for their illness. A participant reported that she consumed *jamu* or traditional herbal medicine, and went to a traditional healer (*dukun* or *orang pintar*) to get a traditional body massage. However, these treatments were only temporarily effective, so the symptoms were not completely cured. Therefore, when the symptoms came back, they kept doing the treatments mentioned above until they felt that the symptoms were unbearable.

> "So *jamu* (traditional herbal medicine) (was consumed) before I went to Karang Tembok (Primary Healthcare Centre). Then I was told not to consume it again or to be massaged again. But prior to getting medical attention, I consumed *jamu* everyday." (Cici)

> "To alternative *dukun* (healer) three times, (I was) given *jamu*. Then I went to Chinese alternative (healer) in Kenjeran." (Cici)

> "Yes, powdered (*jamu*). I stirred and drunk it." (Sari)

> "Yes, I was prayed upon (by traditional healer)." (Karin)

> "Yes, I asked for *kerokan* but then (after getting more severe), I went to doctor." (Sari)

In this stage, respondents received suggestions to immediately seek help from HCWs. Karin's daughter, for example, brought her mother to a GP and admitted that her mother had been injected with a substance. When asked about the substance, both said they had no idea. Sari, on the other hand, went to a *Mantri* (an orderly who does not receive medical training) and got an injection with an unknown substance. Subsequently, she visited a midwife with her mother and she was given antibiotics for reducing her symptoms. What the midwife did indeed violated the code of ethics as a midwife should not have had authorization to prescribe antibiotics to non-obstetric patients, but it is a common practice in Indonesia. When Sari made the second visit, the midwife referred her to the Pegirian Primary Health Centre.

Although most respondents had already decided to see HCWs in this stage, three of them were not well-informed about the disease and/or the treatment undertaken by HCWs. It is also common in Indonesia to see midwives for all medical conditions, not just maternity issues, so midwives often perform medical treatments that they are not trained or authorized to do.

> "In the beginning, I coughed a lot. I tried to seek medical attention, but it was not working. There is a primary healthcare centre nearby and (I went to) midwife four times, but I still coughed a lot. I was afraid of getting lung disease, and yes I truly got lung disease." (Sari)

> "No, I have no idea. Yes, that Amoxcillin (antibiotics)." (Sari)

When the symptoms were getting intense, extremely disturbing and involved coughing up blood, respondents started to consider visiting formal healthcare facilities, even though some of them were reluctant at first due to its high cost. Cici, for example, was forced to be admitted to a public hospital due to her worsening health condition. She did not have health insurance, so she had to pay US$82 for her treatment and chest X-ray. The hospital bill was almost unaffordable for her as the hospital cost was more than she earned in a month. However, she had no choice but to seek help at a public hospital as she had been coughing severely for two weeks with some blood spotting, which made it impossible for her to sleep.

> "Yes, I begged for loan for performing X-ray. I paid Rp540.000 if I'm not mistaken, since I wanted to be cured. I should pay Rp100.000 eh… Rp190.000 only for medication." (Cici)

However, most respondents had poor knowledge about the disease they were suffering from; on the other hand, some respondents like Dinda, who had had direct contact with a pulmonary TB patient, would more easily recognise the disease. Dinda's deceased mother and aunt were also infected with pulmonary TB, so shortly after finding out that she coughed up blood, she instantly related her disease to the same disease that had infected her deceased mother and aunt. Other symptoms that reinforced respondents to be admitted to formal healthcare services were drastic weight loss, severe chest tightness and blood vomiting.

Respondents with comorbidity responded more promptly when dealing with the symptoms. Taking Dinda and Cici as examples, they took less than one month to come to health facilities. Dinda had a history of asthma and bronchitis, while Cici suffered from brain tumor and an unknown neural disease. Dinda and Cici went to Pegirian Primary Health Center due to their neighbours' suggestion knowing that it had a lung clinic.

When being admitted to Pegirian Primary Health Center, all respondents got sputum check and were obliged to come at least twice a month for at least six months to check their health condition, as well as to receive free medications and a free box of powdered milk. They had to sign a contract paper, which stated that they would be

fined US$1550, if they dropped out of the treatment process. However, free medications often got delayed, so the patients had to use their own money to buy medications. All participants were very determined to complete the treatment as they wanted to be able to work and live their normal lives.

False Beliefs of the Illness and Poor Health-Related Risk Understanding

Four respondents admitted that they knew very little about pulmonary TB and its transmission. Dinda was the only patient who got the name of her illness right, while other respondents only mentioned that they had 'lung disease'. However, when being told that they suffered from pulmonary TB, which is more specific than just lung disease, most patient accepted the fact. Joko was the only respondent who insisted to reject pulmonary TB as the name of his disease, as he was satisfied enough with lung disease as the explanation of his illness.

Despite knowing the fact that pulmonary TB is highly infectious, all respondents said that they did not wear a mask or separate their cutleries from other family members, even though the nurse at Pegirian Primary Health Care had told them to do so. Cici's daughter even firmly stated that she would not separate her mother's cutleries as she did not want to hurt her mother's feelings. Sari said that she did not wear a mask when selling *gorengan* nor considered the probability of transmitting her disease to her customers, while Joko strongly believed that pulmonary TB was only infectious for children, but not adults, so wearing a mask was unnecessary. The respondents knew that they were supposed to follow the nurse's suggestions, but chose not to as they thought it was unnecessary.

> "I have no idea. It is contagious, some said. I don't quite understand. People said and I heard that pulmonary TB cannot be transmitted to adults, is it right? But children can pick it up, is it right? I asked you." (Joko)

> "Others (can) not pick it up if I cover (covering his mouth with his hands) my mouth like this. I think it's the same, so others cannot be infected." (Joko)

> "Daily (mask usage)? No." (Sari)

> "When I sell (*gorengan* – traditional snacks)? No, I didn't wear mask. People don't seem disturbed by that." (Sari)

When asked about the origins of the disease, only Dinda provided an accurate answer as Dinda was the only patient who had had direct contact with pulmonary TB patients (her mother and her aunt). Dinda also obtained the highest educational qualification compared to other participants. Dinda finished high school, while the other obtained junior high school qualification or did not have any educational qualifications at all. Cici, Sari and Joko answered that they did not know the cause of the disease, while Karin mentioned cigarette smoke as the cause of pulmonary TB. They stated that the information given by HCWs was poor, but posters attached to Primary Health Center walls were considered quite helpful.

> "Yes, I was shocked. How can I get pulmonary TB as I thought only smokers can get it, or non-smokers who inhale cigarette smoke." (Cici)

Joko was the only patient with magical thinking. When he vomited blood, he stepped on his vomit because he believed that it would make his disease go away. However, the similar mind-set was not found in other respondents.

> "Yes, I thought so. I thought that if I stepped on my blood vomit, my disease would go away." (Joko)

> "I then washed my hands and feet in doctor's office next to my house. (What made) you vomit blood? asked the doctor. I said I was feeling unwell, but sir, my disease has gone away (as) I stepped on the

vomit. The doctor laughed, offered to examine me and diagnosed that I might had lung disease. Oh no, how can I inherit (get) that?" (Joko)

According to the respondents, there were slight significant changes on their social relations, but those were mostly positive – their relatives, friends and families were more caring to them after than before the diagnosis. Stigma was not found in this research as all respondents admitted that they did not face any discrimination or felt social embarrassment in regards to the disease.

Discussion

Our research provides a description of paths followed by pulmonary TB patients and an early indication of socio-cultural factors that reinforce and/or hinder the patients when seeking professional help. Health-seeking pattern showed by research participants demonstrated that health-seeking process, even though being similar to a model described by Chrisman (1977), the process is not a sequential path but rather a series of steps that can vary and overlap in each participant.

Research findings demonstrated that cultural-based definition of illness was one of the factors that caused delay in seeking treatment. Cultural-based symptom naming of pulmonary TB is *masuk angin* or *anginen,* which is never seen as a serious illness. *Anginen* represents East Javanese concept of illness, which is a result of an imbalance between four fundamental elements of the body: wind, fire, water, and earth (Triratnawati, 2011; Wessing, 2010). Inaccurate interpretation of the symptoms leads to the simplification of the illness, so patients will not seek professional help until their perceived severity of the illness increases. It is supported in many previous researches that mentioned that cultural definitions of pulmonary TB symptoms lead to lack of search of professional help and it is the main cause of delay in seeking treatment (Jaramillo, 1998; Rubel & Garro, 1992).

Most respondents chose formal healthcare facilities over traditional healer as their first choice when seeking professional help for their illness. However, some of HCWs performed unstandardized treatments. Additionally, HCWs did not provide adequate information to the patients about their illness as it was clear that most respondents had poor knowledge of the illness. Several previous researches have confirmed that healthcare service-related factors affected symptom definitions and shaped health behaviour of the patients (Jaramillo, 1998; Kasse et al., 2006).

Poor health-related risk understanding seems to be a serious obstacle that needs proper attention. As the research findings showed, even though all respondents were compliant to the medication process, they did not know the risk of transmitting their disease to healthy people. Hence, even though the respondents managed to fully recover from pulmonary TB, there was still a large risk of spreading the disease to healthy people. Proper understanding of pulmonary TB also strongly correlates to treatment decision making and compliance to the treatment (Abebe et al., 2010; Barnhoorn & Adriaanse, 1992). Results shown in this research support previous research that mentioned the level of education and prior direct contact with other pulmonary TB as factors that affect the knowledge and attitude towards pulmonary TB (Abebe et al., 2010; Ukwaja, Alobu, Nweke, & Onyenwe, 2013). Patients with higher educational qualification have higher self-awareness, tend to independently apply self-discipline during medication process and more easily in absorb information related to the illness given by HCWs (Jurcev-Savicevic & Kardum, 2012).

Accessibility to healthcare service providers, the existence of comorbidity, and laypeople suggestions to seek help at healthcare facilities are important motivational factors that reinforce patients to immediately visit healthcare worker. According to the research findings, all respondents admitted that they were brought by their relatives or got an advice from their neighbours or friends to visit healthcare facilities. Therefore, patient's family and community play an important role in increasing awareness and patient's decision to seek help at healthcare facilities. It was also found in Ethiopia that community is a main source of information about the illness, influences the patient's decision making as well as provides cultural definition and several simple therapies as the first aid for the illness (Abebe et al., 2010). In this research, community did not only provide cultural definition of the illness and simple therapies to temporarily cope with the symptoms, but also reinforced the patient to look for medical help at healthcare facilities.

Unlike most previous research, stigma was not found in this research as all participants did not report any negative changes in their social relations. All changes in their social relations were surprisingly positive, as they reported that their relatives became more caring than before the sickness. However, we suspect that it does not mean that stigma does not exist at all, as most laypeople have relatively low understanding about pulmonary TB. When *gorengan* seller participant was asked about her customers' reactions when they found out that she was suffering from pulmonary TB, she answered that nothing changed. None of her customers were concerned about her disease, her cough or her uncovered face.

Research findings are beneficial in providing better understanding on patients' delay in seeking professional help in Indonesia. The findings supported several previous research, which mentioned a combination of predisposing, enabling, health-system related factors as well as sociocultural factors as key variables in determining sequential process of pulmonary TB patients' HSB, as well as their immediacy in seeking medical treatment (Izza & Roosi-hermiatie, 2013; Mahendradhata, Syahrizal, & Utarini, 2008; Rintiswati et al., 2009).

However, there are some limitations in this research. The small number of participants may yet be able to result in a comprehensive description of pulmonary TB patients' HSB. Therefore, future research involving a larger number of participants may offer a wider perspective in understanding how pulmonary TB patients seek help to cure their disease. Involving participants from various cultural backgrounds could also be beneficial to add a wider understanding of pulmonary TB patients' HSB.

Nevertheless, research findings might also be beneficial to local primary healthcare and local health authorities as the basis for the implementation of suitable approaches and practices to fight pulmonary TB. Motivating pulmonary TB patients to complete their medication may not be enough as they are still in high risk of spreading the disease. Local health authorities should encourage them to adopt healthier lifestyles and behaviours, especially behaviour and precautions to prevent infections in the surrounding environments. Provide laypeople with knowledge about pulmonary TB and how to prevent it is urgently required as all participants were proven to have poor knowledge about pulmonary TB, its risks and TB preventive behaviours.

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Competing Interests

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