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Living with Stigma: The Experience of Tuberculosis Patients and Family Caregivers in Indonesia

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ABSTRACT

Background: People with tuberculosis (TB) lead to emotional distress because of stigma. Their stigma could extend to other family members particularly caregiver. Therefore, stigma could be a hindering factor on the successful of TB control.

Objective: This study aimed to explore the experience of stigma among TB patients and family caregivers in Indonesia.

Material and Method: A qualitative study was conducted among five TB patients and four family caregivers who had experienced with TB stigma, had a previous TB diagnosis (patients) or caring TB patients (caregivers), and can speak Indonesian or Sundanese language. Data were collected by in-depth interview, and content analysis was used for the data analysis.

Findings: Three main themes emerged from participants' experiences for being stigmatized. The first theme was TB meaning, including TB is as a dreadful disease, as a severe disease, and as a dangerous disease. Second theme was psychosocial aspect of TB stigma, consisting of feeling shame and social exclusion, which were influenced by their fear of causal transmission and blame from others. Finally, strategies to cope with stigma, including isolating themselves, keeping secrecy of TB, ignoring, and convincing others.

Conclusion: These findings suggest that persons affected by TB stigma need support from health care providers. These findings will be benefits to health professionals to develop stigma reduction intervention for patients and family caregivers to cope with TB and its stigma.

Keywords: *Family caregiver, Indonesia, Patient, Stigma, Tuberculosis.*

Introduction

TB stigma has emerged as an important barrier to the control and treatment of TB. TB stigma contributes to the quality of TB management such as delays in seeking health care, TB diagnostic delay, poor treatment compliance, non-adherence to TB screening in household contacts, and consequently poor quality of life[1]. Stigma is defined as an "attribute that is deeply discrediting"[2]. Several studies reported the experiences of stigma among TB patients including isolation, discrimination, rejection, and social exclusion[3,4]. Stigma does not only affect a TB patient as an individual, but also the family caregivers who take care of and who have a close relationship with TB patients. Stigma that extends to others family members is known as "courtesy stigma"[2]. Another study also reported the positive correlation between TB courtesy stigma and health-seeking behavior[5].

TB stigma also occurs in Indonesia. Even though World Health Organization (WHO) reported that the success rate of TB treatment in Indonesia was 85% in 2015, treatment default in several areas in Indonesia is still low[6]. The misperception of TB showed a significant relationship with TB treatment default[7]one of the barriers in the TB control program is the non-compliance to treatment. Morbidity, mortality, and risk to become

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resistant to drugs are emerging among defaulters. Thus, the aim of this study is to identify the factors, especially knowledge and perceptions of TB and association with treatment default among patients treated in primary care settings, East Nusa Tenggara. METHODS: This study was part of a bigger cohort community-based controlled trial study. The subjects were newly diagnosed pulmonary TB patients from four districts in East Nusa Tenggara. Knowledge, perception of TB, and other related factors were assessed prior to the treatment. Patients who interrupted the treatment in two consecutive months were classified as defaulters, as World Health Organization stated. Odds ratio (OR. Most studies in Indonesia have focused on quantitatively measuring TB stigma and the relation of stigma on TB diagnosis and treatment. However, there are limited studies that have explored stigma among people with TB and the family caregiver. In order to reduce stigma in Indonesia and increase TB control programs, understanding about stigma within TB patients and family caregivers in Indonesia is essential. The objective was to explore the experience of stigma among TB patients and family caregivers in Indonesian.

Method

This study is a part of PhD dissertation, which used a qualitative study. This study was conducted in Bandung, Indonesia. The participants in this study were purposively recruited until data saturation. Five TB patients and four family caregivers voluntary participated. The inclusion criteria were persons who have experience with stigma related to TB, have a previous active TB diagnosis (for TB patients) or were caring for TB patients (for family caregivers), and can speak Indonesian or Sundanese language. The participants were obtained from a lung clinic, Bandung, Indonesia. TB participants are represented by codes P1-P5, while caregivers are coded by FC.1-FC.4.

Data were collected from December 2016 to July 2017 through in-depth interview. Each participant was interviewed for 2–4 times, and around 40-90 minutes was spent for each interview. The sample questions included “how do you perceive TB?” and “what were other people’s reactions when they knew that you had TB disease?” The interviews were recorded using a tape recorder and then transcribed verbatim before being translated into English. The member checking technique was applied to enhance trustworthiness. Content analysis method was used to analyze the data.

Findings

Three main themes emerged from the interview transcriptions, consisting of the meaning of TB, TB stigma experiences, and strategies to cope with stigma.

Meaning of TB: When asked how they perceived TB, the participants shared their meanings of TB in three aspects.

Dreadful disease: The perception of TB as a dreadful disease was reported by both TB patients and family caregivers. Participants perceived that having TB means persons were in a condition that approached death and only had a short life. These participants had experiences of seeing someone die because of TB. As a TB patient, P3 stated the meaning of TB:

> Having TB means only having a short life … when I was in the education room, there was someone who died because of TB. I was afraid to be like that, and it made me cry (P3)

Similarly, family caregivers also shared the same dreadful meaning of TB. FC.4 mentioned that:

> Last time, there was my neighbor who got TB in here, and she died … I still did not know anything about TB. His wife was the first person who got TB. Then, she died. Her husband also got TB, and he also died. (FC4)

Severe disease: TB patients described TB as severe disease. Having TB leads to the separation of utensils. Those who got TB would have several physical problems such as weakness, a persistent cough, and isolation by others. P3 stated:

> “I thought that TB is a severe disease, the worst disease, and it makes me feel helpless … I felt tired even when I did not do anything, I was sweatier. My condition of TB disease was severe, would I lay down, and not do anything?” (P3)

Family caregivers also perceived TB as a severe disease. Their perception of TB as severe disease was related to the long-term treatment of TB. The FC.1 as the family caregiver who took care of mother in-law with TB disease expressed their meaning of TB:

> TB seems a severe disease, it should be treated fully for 6 months. If it (treatment) does not work effectively it will lead her to be re-treated. (FC.1)

Dangerous Disease: Both TB patients and family caregivers reported their meaning of TB as a dangerous disease. Knowledge about how TB is transmitted to others and that TB patients should be isolated led them to think that TB is dangerous.

> TB is known as a disease that … dangerous, if everybody knows it, they will avoid us, (we) will be isolated … People who know someone has got TB, they will avoid him/her. If they do not know, they will not avoid him/her. (P4)

Another family caregiver described when knowing about the TB diagnosis of her mother in-law's sister, she received information about TB transmission. This information made the family caregiver think that TB was dangerous.

> The doctor said "You should take care of them (family member). Your mother in-law's sister should use a mask, because TB can transmit through respiratory or chat, and also do not spit carelessly … It (TB disease) is dangerous and can be transmitted … this illness is dangerous and can transmit." (FC2)

TB stigma experiences: The participants' experiences of TB stigma can be classified into two categories of feeling shame and social exclusion.

Feeling shame: The symptoms of TB among adults is commonly related to loss of body weight and a persistent cough. Therefore, all TB participants felt shame because of the changes in their physical appearance. TB participants stated that others could notice their TB disease from their physical symptoms. These participants explained that others perceived TB as a disgusting and scary disease because TB can be transmitted to others, which later on they will be blamed as the cause of transmission.

> I felt shame because my cough often appears. I was worried my neighbors will know of my TB and they were afraid of being infected with TB because of me (P1)

Social Exclusion: Social exclusion was experienced by both TB patients and family caregivers. Other people began to avoid and exclude them from their social life since the others knew about the TB diagnosis within the participants. For instance, one TB participant described how their neighbors behaved to her.

> [after the neighbors knew that I got TB] some of my neighbors avoided me … they said "she (participant) has TBC, it is a transmitted disease. Do not come close to her" … they did not want to talk with me (P2)

Moreover, one family caregiver also reported that the experiences of social exclusion also had impacted on their children. Exclusion from their relative was experienced by FC.4.

> She (participant's relative) did not allow her son to play with my daughter, and did not allow him to come to our home … Maybe she was worry that TB in my home can be transmitted to her son (FC.4)

Strategies to cope with stigma: Four strategies to cope with TB stigma among the participants were identified, consisting of isolating themselves, keeping a secrecy of TB, ignoring, and convincing others.

Isolating themselves: Due to the feeling of shame, most TB patients preferred to isolate themselves from their community. They mainly stayed at home, in order to prevent themselves from and avoid social life.

> I felt shame and also afraid, they may feel afraid to be close to me because I will infect them. Thus, I never went out of my home … because I was afraid they will know my TB (P1)

Keeping secrecy of TB: To avoid the exclusion from others, the participants preferred to hide the TB disease and keep it a secret. When their neighbors saw TB patients wearing masks or the caregiver with TB patients often going back and forth to the health services, they would ask about their disease. Then, the participants dissimulated their disease such as a lung disease or a common cough and/or to avoid dust.

> When I used mask, there was my neighbors who asked me, "what happened to you, why do you use a mask?" then I said, "it's only to avoid the dust" … So, I rarely went out, I often stayed in here (inside home) (P4)

Another family caregiver also expressed the same thing, which concealed the TB disease.

> We did not want everybody to know about its disease (TB), both in my residence and my husband's office (FC.3)

Ignoring: Some participants used an ignoring as a strategy to manage TB stigma. They also did not want to hear or see the reactions of others to them. One TB patient shared her story about coping with TB stigma.

> I did not listen to them (neighbors), didn't care it because I want to be cured. Let them talk about whatever they would like to say (about my disease) (P2)

Similarly, the family caregiver also ignored what other people thought about her family with TB. When the family caregiver went to hospital to pick up her husband's medicines, her neighbor mocked her family.

> When we went to the hospital. My neighbor who saw us, asked us "where are you going?" I said, "we are going to the hospital", and they said "commonly, people are going together for a walk or for picnic, while you are going to hospital." ... I don't care... they were not the persons who paid our treatment, they were not the persons who helped us. (FC.4)

Convincing others: This strategy was only reported by the family caregivers. Most of them described how to handle others' negative views about TB within their families. They attempted to explain to others that their TB family member was undergoing treatment. Through their explanation, they hoped their neighbors would not worry with TB transmission.

> They (neighbors) asked about my husband, my children and TB disease among us. I explained to them, how TB is transmitted to others, TB cannot be transmitted if only touching ... some people understand ... In here (their community), they think that TB can be transmitted only like this (touching hand) (FC.2)

Discussion

Participants perceived TB as a dreadful, severe, and dangerous disease. These meanings of TB were related to the understanding about the curability of TB, TB treatment, and the risk of TB transmission to others. This finding was similar with the previous studies that reported several perceptions of TB disease including as a dangerous, infectious, incurable disease[1,4], and scary disease related to approach death[1].

The participants' perceptions of TB contributed to their experience of stigma, which was feeling shame to be noticed as a cause of transmission. Its feeling shame was caused by poor awareness and misperceptions about TB[8]. Other previous studies also described people with TB had a fear of shame due to the TB disease and its transmission, and they also suffered because of TB disease[8–11]particularly in resource limited settings, where rates of tuberculosis are high. The objective of this study is to assess health-seeking behaviour and health care experiences among persons with pulmonary tuberculosis, and identify the reasons patients might not complete their treatment. We performed qualitative one-on-one in-depth interviews with pulmonary tuberculosis patients in nine health facilities in rural western Kenya. Thirty-one patients, 18 women and 13 men, participated in the study. All reside in an area of western Kenya with a Health and Demographic Surveillance System (HDSS. Social exclusion was not only experienced by most TB patients, but also by some family caregivers. One family caregiver also mentioned the relative and neighbors who excluded their children. Stigma among TB patients could extend to other family members[2]. Avoiding other people was contributed by other people perceptions about TB, which was as a disgusting and scary disease because it can infect them. This finding was congruent with the previous studies that reported the consequences of stigma among people with TB which included isolation and social exclusion from others[1,2,12].

The participants applied several strategies to cope with their stigma experienced. These strategies reflect the Indonesian value of family closeness, which is concerned with the loyalty of other family members' lives to protect and help each other[1]. Concealing TB disease by isolating themselves and keeping the secrecy of TB, helped them to avoid the feeling of shame and of being stigmatized. The previous studies also described hiding a TB diagnosis, keeping TB as a secret, and separating themselves were strategies to deal with discrimination from others[1,3,10,12]. However, TB patients have to receive treatment in secret this may lead to a disruption in routine treatment[13]. Ignoring was reported as a strategy to cope with stigma. The ignoring and keeping their live moved were useful to mitigate stigma among patients who have completed TB treatment[9]. The family caregiver tried to educate and explain to their neighbors and relatives about the likelihood of their family member who had TB transmitting it to them. This strategy was similar with the previous study that reported educating others help to reduce any misunderstandings[13].

Conclusion: This study identified three TB meanings, including as a dreadful, a severe, and a dangerous disease, which contributed to the experience of stigma. Shame and social exclusion were common experienced by TB patients and family caregivers. TB patients and family caregivers described the coping strategies to cope with stigma, including isolating themselves, keeping secrecy of TB, ignoring, and convincing others. The findings are of benefit to nurses and other health care providers to develop stigma reduction interventions for patients and family caregivers.

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