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## Experiences with Tuberculosis Management among Community-Based Care Providers in Indonesia: A Qualitative Study

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### ABSTRACT

To explore experiences with TB management among community-based care providers. Descriptive qualitative study. A total of 25 care providers were selected using purposive sampling. Data were collected by semi-structured interviews and analyzed using content analysis. Six themes emerged from this study: “various dissemination channels,” “compassionate religious volunteerism,” “shortage of resources,” “keeping TB cases hidden,” “patient impediments to care,” and “perceived economic burdens of patients.” The findings can provide an understanding that the management of tuberculosis in the community requires collaboration between various institutions as well as patients. Building a sustainable TB system would be beneficial. A TB care model can be established between government and other institutions.

### Introduction

Tuberculosis (TB) is an infectious disease that represents one of the top 10 causes of death worldwide and is the leading cause of death due to a single infectious agent (Binns & Low, 2012). Globally, an estimated 100 million people were infected with TB in 2019 (World Health Organization[WHO], 2020). Indonesia is one of eight countries that together account for two-thirds of all TB cases worldwide, with most cases identified in India (26%), Indonesia (8.5%), and China (8.4%) (WHO, 2020). TB continues to represent a major infectious disease concern in some countries, including Indonesia. The World Health Organization (WHO) Global Survey of 2019 placed Indonesia as the country with the third-highest TB case number, at 845,000 cases, with a case-fatality ratio of 12% and a treatment success rate of just 85%. India had the most cases, with more than 2.5 million cases, and China was reported with 842,000 cases (WHO, 2020). TB is among the top 5 causal diseases leading to disability-adjusted life years and is one of the most difficult infectious diseases to treat (Quaife et al., 2021). TB is strongly associated with poverty, and affected people often experience stigmatization and discrimination (WHO, 2020). In Indonesia, TB has remained a major public health issue for the past three decades (Mboi et al., 2018).

The Indonesian government implemented a TB management strategy known as directly observed treatment short-course (DOTS) in 1995. Although progress has been made, barriers continue to exist, including low adherence to treatment (Main et al., 2019). The Indonesian Ministry of Health DOTS recruits a family member or community volunteer to act as a Drug Swallow Supervisor, who observes and assists patients with taking their medication (Dewi et al., 2016). The DOTS program aims to improve adherence to the timely administration of medication and completion of the recommended treatment course, and the level of satisfaction with TB therapy has been reported to increase among patients who have a Drug Swallow Supervisor (Ashari et al., 2020).

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Several elements of the national TB management program have not been implemented optimally due to barriers that include political commitments and the failure to evaluate treatment adherence. Additionally, the dual duty of officers has resulted in incomplete records (Prameswari, 2018). The barriers have led to long delays in TB diagnosis, suboptimal case identification, low treatment course completion rates, and a lack of community involvement (Dhuria et al., 2009). Other obstacles include a lack of training for health care workers and volunteers in TB management, resulting in differences in drug administration and distribution procedures among health care facilities (Lestari et al., 2020; Prabandari et al., 2008; Reviono et al., 2017).

TB has consequential effects on individual health in addition to causing economic and social burdens for patients (Van den Hof et al., 2016). A previous study in Indonesia found that community TB task force members and patients with TB have a low level of awareness regarding their responsibility to report potential TB exposures or the possibility that they may have contracted the disease (Collins et al., 2017). A social stigma continues to exist within communities, including the idea that TB represents a form of punishment for sufferers who have done bad things in the past (Engel & Pai, 2013).

A lack of public knowledge regarding the signs and symptoms of TB and a lack of health facilities available to obtain TB examinations, diagnosis, and quality treatment are commonly encountered issues for TB management (Rakhmawati et al., 2019). Patients doubt and do not trust in the efficacy and effectiveness of treatment provided by Community Health Centers (CHCs), and many patients with TB prefer treatment by private doctors' practices and pay out of pocket, despite the availability of free health care services at CHCs, from diagnosis to treatment completion (Ruru et al., 2018).

Limited health care facilities and geographic locations remain problematic. Many TB patients live far from CHCs, and access to most TB services remains centered around CHCs at the subdistrict level in Indonesia (Karki et al., 2017). Difficulty accessing transportation can also make patient tracking and screening more difficult. To improve access to TB management services, a collaborative agreement was established with private clinics; however, these were constrained by the reporting system (Al-Hajoj & Varghese, 2013; Kusimo et al., 2015; Sissolak et al., 2011). A lack of public awareness regarding the availability of TB management resources was also identified due to limited program activities involving families and the community at large (Main et al., 2019).

24 No studies to date have focused on the TB management experiences of the community at the intersectoral organization level in Indonesia (e.g., department of health, local government, department of social welfare, civil society organizations, department of justice, and public security). Understanding the experiences and perspectives of TB care providers may identify methods for developing improved TB management strategies. This study explored community-based care providers' experiences in TB management, including the difficulties faced and the responses of patients with TB.

## 29 Methods

23 This was a descriptive qualitative study that explored the experiences of community care providers managing TB care. A descriptive qualitative study represents a comprehensive summary, presented in ordinary terms, of specific events experienced by persons or groups of persons (Lambert & Lambert, 2012). The descriptive qualitative study was considered to be the most appropriate format for the purposes of this study because it recognizes the subjective nature of the problem and the different experiences of the participants, allowing for the presentation of findings that directly reflect the terminology used in the original research question (Bradshaw et al., 2017). 5 16

## Settings

33 This study was conducted among members of the TB Task Force Team in Surabaya, Indonesia, which had the largest volume of TB cases in the province of East Java in 2018. In 2018, 3,003 new TB cases and 7,007 total TB cases were reported. The study settings were three subdistricts on the outskirts of the northwest side of Surabaya, which have had the highest TB case counts for five consecutive years.



Due to their location adjacent to another Indonesian island located on the north side of East Java, these three subdistricts also represent densely populated areas, with many temporary residents coming from other cities.

### Participants

The TB Task Force Team was established by the government within the community and consists of more than 100 community members, including official heads of villages, directors of community welfare, community nurses, and community volunteers. The team is in charge of managing TB cases within the community, including providing treatment information, planning care, and registering patients. The study participants, referred to as care providers, were selected from the TB Task Force Team. Purposive sampling was used to select participants based on the research aim and was determined by the researcher (Holloway & Wheeler, 2013). The inclusion criteria included being a member of the TB Task Force Team with working experience of at least 1 year.

### Data collection

Data were collected from March to September 2020. Semi-structured interviews were used to interview participants within the community. The interview questions focused on the community experiences associated with TB prevention, TB control, and related events. The interview questions were as follows: (a) What is your role in TB management? (b) How would you describe your experience with TB management in the community? (c) How does the community perform TB prevention and control activities? The first author, who is an experienced qualitative researcher, was responsible for conducting face-to-face interviews with all participants. Each interview lasted 45–60 minutes. All interviews were digitally (audio) recorded, transcribed, and translated for data analysis.

### Data analysis

Content analysis was applied to guide the data analysis (Merriam, 2002). The first author conducted all the interview transcribing and built a coding frame of transcripts from interviews. Researcher separated the interview contents into units so that each unit fits precisely into the categories of the coding frame (Flick & Schreier, 2014). The first author performed all translations and generated the transcriptions of all the interviews, after which the first coding frame was generated. All of the transcribed interview materials were assessed using the trial coding frame, which resulted in the first author designating 25 coding units. After finishing the coding process, the remaining three authors separated all of the interview material into the coding trial categories until all units were categorized. The first author then verified the coding units to identify those that were only suitable for describing community TB management. All authors evaluated all existing coding until they reached a mutual consensus regarding which codes were specific to the topic of community TB management. The final findings were verified for consistency by comparing against existing note fields. This study considered the appearance of no new themes to indicate data saturation (Flick & Schreier, 2014).

### Rigor

The researchers ensured rigor through the criteria of dependability, credibility, transferability, and confirmability (Lincoln & Guba, 1985). To achieve dependability, the researchers conducted all interviews with all participants, made field notes, and recorded all interviews that were then converted into transcripts. Credibility was achieved by asking the participants to verify the transcripts to ensure that they accurately represented the truth the participants conveyed, after which the transcripts were evaluated by qualitative research experts. Transferability refers to research results in a context that can be transferred to different situations and participants. The findings of this study can be transferred to

other situations or participants. This study can be applied to other situations within the framework of the context of developing countries and tuberculosis patients. This study used criteria to improve the transferability, namely thick descriptions and participant selection using purposive techniques. Confirmability is achieved by showing that the results of the interview represent the ideas that were conveyed by the participants rather than the assumptions of the researchers themselves. Confirmability was achieved by a transparent process in data collection and data analysis in this study. Participants were also involved in data analysis to confirm and review the results of the analysis conducted by the researcher to adhere to participants' perceptions.

### **Ethical considerations**

21 Institutional Review Board approval to conduct this study was granted by a public university and the  
13 Indonesia Department of Health. All participants were provided with a participant information sheet written in Bahasa Indonesia. Informed consent was obtained before initiating the interview. The principles of anonymity and confidentiality were maintained throughout the research process. During the research process, each participant was given a pseudonym to maintain confidentiality and a secure cabinet accessible only by the research team for data storage.

### **Findings**

19 A total of 25 participants were enrolled in this study, including 19 women and 6 men, with a mean age of  $37.6 \pm 4.24$  years. Twelve worked as community health volunteers, six were community health nurses, six were village officials, and one was from the Ministry of Health. Twelve graduated from high school, twelve graduated with a bachelor's degree, and one graduated with a master's degree.

17 Six themes emerged after content analysis. Detailed interview quotations are included to enrich the context and understanding of each theme.

### **Theme 1: various dissemination channels**

20 A large number of social groups and community meetings were described as being helpful for the dissemination of information to the community. These channels were used by community health volunteers (CHVs) to conduct health education sessions and distribute TB pamphlets, including the women's movement group, religious societies, and health center outreach activities. These channels became public information centers regarding TB management. Although it consists of few people, it still hopes to have a broad impact on society.

In every community meeting, such as the Family Welfare Empowerment meeting and at the CHC, we provide counseling and distribute leaflets about TB, hoping that when they return home, they will share the information with other residents. (CHV 3)

We also do this counseling opportunity at the outreach health center; although not many people come, we continue to provide health education. Because there are often community leaders who come, this is our chance for them to also share it with their residents. (Nurse 1)

### **Theme 2: compassionate religious volunteerism**

Becoming a CHV is not associated with any monetary benefits. CHVs recognized that living in a community requires cooperation and helping other community members. The reported motivations for becoming a CHV also varied. Some were previous TB patients, some were invited by other CHVs, and some were motivated by their religious beliefs, which drove them to be charitable to others. CHVs felt that they could contribute by meeting with, learning about, and being useful to the members of the community. They did not think about themselves or receiving any rewards.

As a volunteer, my highest achievement as a CHV is to help others. I am happy. When visiting patients' homes, they welcome me with joy. I feel my life is useful for them. (CHV 7)

When I find out that my patients have not recovered and have dropped out of medication, I feel like a failure as a CHV. I feel guilty about unsuccessful treatment. (CHVs 2)

I don't know [why I became a CHV]. Maybe this is my destiny in life. I have always loved this job, even though I know I might not get anything in return. [Can] you can imagine setting up an outreach health center, [and] giving green bean porridge? That is a form of contribution to CHVs, doing door-to-door inspections. I then enjoy it. (CHV 8)

### **Theme 3: shortage of resources**

The rising number of TB cases was not balanced by the number of workers available. Each worker was responsible for a large quantity of work, so the provision of services was not optimal. The TB assistance team had few active members, many of whom eventually withdrew due to a fear of becoming infected or in response to pressure from family members who did not want them to risk infection. Similar circumstances led to the small number of nurses who staffed the CHC. They were also unsure of how to pay for an increase in staff.

Perhaps because of laziness, many also for reasons of fear. Among the 10 active CHVs, only I was left behind. Many CHVs said, "I couldn't eat after seeing sputum. It made me nauseous and felt like vomiting. Even though the sputum is already in the closed container, I feel like I keep remembering it." (CHV 6)

We also feel that the work of the TB program is challenging and that we, at the health center, cannot do it optimally. We also have an obligation to provide clinical care to other visiting patients. So, our job is numerous. First, we lack CHVs, then there is a lot of work, which is not optimal. (Nurse 3)

### **Theme 4: keeping TB cases hidden**

In some communities, TB continues to be viewed as a disgrace, which is not an appropriate perception. Keeping TB cases hidden also means that the patient will remain silent and not share their disease status with family members or the community. An incorrect understanding of the disease can make providing care or visiting the patients at their homes difficult for CHVs and community nurses. The community must remain informed that TB patients live among them to prevent the spread of infection and improve the acceptance of the community of patients with all existing conditions.

For the benefit of the residents, for example, if I am going to Mr. A's house, I will not go directly to Mr. A. I will start at the surrounding houses first to guard against negative prejudice. Many residents are afraid, especially if there are officers in white uniforms from the CHC. Sometimes they close the door. (Nurse 2)

I knew that someone had TB, but I didn't tell him. Even though I had already been told the information from the CHC, I continued to visit him. I asked him how sick he was, how the medicine [effect] was, if he was okay. They thought I didn't know about the disease. This keeps them from being embarrassed so that, in the end, they will tell themselves that he has TB. (CHV 10)

### **Theme 5: patient impediments to care**

The negative perceptions of TB were thought to lead to some patients refusing to undergo TB screening by CHVs and community nurses. This presumption emerged when they experienced the symptom of a regular cough that they expected would resolve without treatment. These patients attempted to shut the door on health professionals, fearing that if they were identified as TB-positive other residents would avoid them.

I have been to a patient's house, but the person scolded me, I have shown a letter of assignment, but they did not believe that I was a TB CHV. Finally, I went home because I was not allowed to see the patient. (CHV 3)

I had an experience; I would approach her first, then I asked her why her husband was coughing. Finally, I gave him a container for his sputum. At first, the person did not want to. He was afraid that the disease would be discovered. Then, I said later, "If you come with me for the treatment, it will be free." I also told the patient later that I would take the results to his house. Besides that, later, I would help him to get the medicine from CHC until he recovered from illness. (CHV 2)

### Theme 6: perceived economic burdens of patients

5 Many patients with TB are manual laborers and factory workers. When diagnosed with TB, they are required to pay additional costs for transportation to treatment. They are also at risk of being laid off from work. These circumstances led CHVs, the Department of Health, and the Department of Social Affairs to seek assistance in alleviating the economic burdens experienced by the families of patients with TB. Patients also become physically weak after being diagnosed with TB, reducing their opportunities to work. The participants of this study felt that TB patients needed additional financial assistance.

There were patients whose economic conditions were difficult, and the CHC then helped with transportation using a pedicab. Then there was also assistance from Community Social Organizations, but only a few times. (Village officer 2)

Sometimes, the health CHVs make contributions and donate to patients. We want them to know that someone is trying to help them. We also help with their daily basic needs. (Health Official 1)

3 To be honest, if I look at the condition of TB patients, what they really need is a more decent life. Indeed, there are some patients who live in good economic conditions. But many TB patients who have recovered cannot work anymore, even though they are the backbone of the family. Those TB patients who have recovered should be given jobs that do not require a lot of manpower. They still have children and must fulfill their family needs. On average, based on my experience, they have economic problems. (Village Official 3)

## Discussion

31 This study aimed to explore care providers' experiences and difficulties in TB management. The participants in this study revealed some of their experiences and difficulties, which were categorized into themes. The first theme indicated that the community-based approach to TB management needs to be disseminated through various means and institutions. The dissemination of information is important for all members of the community, not just the patients and their families (Rakhmawati et al., 2019). All elements of the community can be used to disseminate information, including community activities and various media outlets (Kumar et al., 2019). Based on these results, the community should increase access to information about TB disease, not only through traditional channels but also through new, fresher approaches that reach wider targets, such as through social media and digital utilization.

In the second theme, participants described the importance of volunteerism. These results reflect the roles played by volunteers at the forefront of the TB elimination program, involved in early detection, screening, delivering patient sputum samples to the health center, helping patients access health services, accompanying patients when taking medication, and ensuring routine disease control until the patient is declared finished with the treatment course (Okeyo & Dowse, 2016). Further, providing incentives is expected to be able to attract young people to become health volunteers. Based on the study results, the community requires the implementation of new strategies to increase volunteer capacity. Providing attractive facilities and incentives may result in the increased desire of young people to become volunteers.

The third theme described the limited resources available for TB management, which is in line with the study reported by Shu et al. (2014), who showed that a shortage of resources results in delays in TB diagnosis and raises the danger of transmission to family members and across communities. Previous

32 research has shown that the limited number of health workers slows the process of providing health care to TB patients (Son et al., 2021). A limited number of community volunteers greatly affects the services that can be provided to a continuously increasing number of TB patients (Andrews et al., 2013). Available resources in the community should be assessed and allocated to increase the numbers of health workers, health volunteers, and access to health facilities, and collaborations should be formed with the government and the private sector to implement comprehensive strategies to stop the spread of TB.

In the theme of keeping TB cases hidden was associated with several factors, which is line with previous studies, such as those reported by Muniyandi et al. (2015) and Penalzoa et al. (2019), which indicated that a lack of comprehensive community literacy regarding TB among both patients and residents could lead to secrecy regarding TB status. In addition, several negative assumptions about TB lead to fear, shame, and refusal to seek treatment (Craig et al., 2017). Based on previous studies, an increased understanding of the disease should be prioritized to prevent TB patients from stigmatizing themselves (Nkambule et al., 2019). The community should execute a strategy that aims to eliminate false information regarding TB, involving various institutions, media, and resources. Such a strategy will make the community more inclusive and able to live harmoniously with TB patients.

27 The theme patient impediments to care involved participants describing how TB patients often obstruct the process of delivering health care, in accordance with the findings described by Gugssa Boru et al. (2017), which revealed that the patient and the patient's family are factors that can complicate the provision of health services. The patient keeps the disease a secret, and the family does not know the situation (Joloba et al., 2016). Patients and their families found it hard to accept the fact that their family members have TB. The family will close the door to health care providers and suspect their presence when they come to conduct an assessment (Joshi et al., 2018). The community needs to provide correct information to patients and their families regarding TB disease to help community members remain open to receiving health services.

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11  
11 The last theme found that patients experienced an economic burden, consistent with the studies reported by Ruan et al., (2021) and Schoeman & Sifumba (2021), who acknowledged that the conditions of the illness could lead to prolonged treatment. Prolonged treatment can negatively affect the sustainability and availability of work for the patient, disrupting the economic security of the family. Financial assistance is necessary for patients with TB, and assistance that is currently available is often not sufficient or sustainable (Fuady et al., 2019). Many patients require social and economic assistance (Watermeyer & Penn, 2019), and integrated care and social services are necessary to address the complex clinical manifestations and social needs that affect the patient's willingness to maintain treatment (Salehitali et al., 2019). Community-based strategies should be developed to ensure that patients with TB have improved their quality of life after treatment by addressing the mental and social well-being of TB patients through various community health programs.

The findings from this study showed that community-based care providers play an important role in TB management. Based on these findings, health care professionals may be inspired to improve community policies for TB management in the future.

## Implications

The following implications have emerged from this study's findings. First, the community must provide information through various media channels, including digital technology, to disseminate information across all levels of the community. Second, the government should increase the number of health workers and community health nurses available to serve the health care needs of communities. The community should encourage young people to become CHVs because most active volunteers are older adults. Moreover, the government should provide incentives, such as easy access to health and social insurance, to encourage community volunteers. Third, the government can design a policy strategy to provide an economic safety to families and TB patients to improve TB compliance with health services at CHCs.

25 Fourth, Community health nurses can collaborate with many sectors, for example, CHV, local government, health departments, and social departments in the community to improve health services for tuberculosis patients. Community health nurses can also provide comprehensive health education to the community and tuberculosis patients to eliminate inappropriate treatment, perceptions, and stigma associated with tuberculosis. Fifth, this finding can provide understanding for other communities which have tuberculosis problems to collaborate with institutions and across sectors such as health education institutions, health organizations, health care providers, and the private sector by designing effective campaigns for the prevention and treatment of tuberculosis in a more effective way. Last, future research can be performed through collaborations among government, health practitioners, and educational institutions to develop an integrative TB care model. The integrative TB care model is a health care system for groups of tuberculosis patients that involves service providers, organizations, professionals, and existing systems in the community.

## Limitations

This study did not involve patients as participants. This research was only conducted in a limited area with a small sample, which may make the generalization of these findings to other communities more difficult. Each community has unique dynamics and variations in the groups responsible for different tasks and roles. Therefore, this study may serve as a basis for conducting other research involving a wider community.

## Conclusion

This study identified the experiences and difficulties associated with TB management among care providers in the community. Some difficulties identified in TB management were similar to those described by previous studies. However, the experiences obtained from this qualitative study were comprehensive and improved understanding of the community environment for health care providers in Indonesia. TB is likely to remain a long-standing problem, and collaborative work within the community represents a potential method for managing TB. This study recommends building a community-based TB system that is resilient and sustainable. An integrative TB care model can be established through research collaborations with government and other institutions.

## 12 Disclosure statement

No potential conflict of interest was reported by the author(s).




## Ethical Statement

3 Ethical Clearance to conduct this study Institutional Review Board Ethical Committee of Airlangga University No. 634-KEPK and Surabaya Regional Department of Health.

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