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# EXPLORING THE EXPERIENCES OF FAMILY CAREGIVERS CARING FOR PATIENT WITH TUBERCULOSIS AT HOME

**Evelyn Hemme Tambunan** ✉
Faculty of Nursing Science, Universitas Advent Indonesia, West Java, Indonesia
evelyntambunan@unai.edu

## Abstrak

Keluarga mempunyai peranan yang sangat penting dalam kesembuhan anggota keluarga yang menderita TBC. Penelitian ini bertujuan untuk mengeksplorasi pengalaman keluarga *caregiver* merawat anggota keluarga yang menderita Tuberkulosis di rumah. Penelitian ini merupakan penelitian kualitatif, yang bersifat eksploratif dan deskriptif serta menggunakan pendekatan fenomenologi. Wawancara semi terstruktur dengan pertanyaan terbuka dijawab oleh 16 peserta yang sedang merawat anggota keluarga yang menderita Tuberkulosis. Data dianalisis menggunakan Analisis Fenomenologi Interpretif yang telah disetujui oleh Komite Etik Penelitian Fakultas Keperawatan Universitas Advent Indonesia. Analisis data menghasilkan ekstraksi tiga tema yang meliputi peran keluarga dalam perawatan dan dukungan Tuberkulosis, perilaku keluarga *caregiver* dalam penularan penyakit, dan pengetahuan keluarga *caregiver* terhadap penyakit. Berbagai pengalaman digambarkan oleh keluarga *caregiver* dalam merawat anggota keluarga yang menderita Tuberkulosis. Penelitian dapat dikembangkan untuk masa mendatang dapat berupa intervensi edukasi berkelanjutan guna meningkatkan pengetahuan keluarga terkait perawatan Tuberkulosis di rumah.

**Kata Kunci:** *keluarga caregiver, tuberkulosis, pengalaman, merawat di rumah*

## *Abstract*

*The family has a very important role in the recovery of family members who suffer from Tuberculosis. This study aims to explore the experiences of family caregivers caring for family members who are suffering from Tuberculosis at home. This research is a qualitative study, where exploratory and descriptive in nature and phenomenology was followed. A semi-structured interview with open ended questions was answered by 16 participants, who are caring family members suffering from Tuberculosis. The data was analyzed using Interpretive Phenomenology Analysis that was approved by Komite Etik Penelitian Fakultas Ilmu Keperawatan Universitas Advent Indonesia. The data analysis resulted in the extraction of three themes including family role in Tuberculosis care and support, family caregivers behavior in transmission of disease and family caregivers knowledge of disease.Various experiences described by family caregivers in caring family members suffering from Tuberculosis. The future research needed to provide sustainable education to enhance family knowledge related to Tuberculosis care at home.*

***Keywords*****:** *family caregivers, tuberculosis, experiences; caring, at home*

✉ Corresponding author :
Address : UNAI Campus, Kol Masturi St. No 288, Bandung
Email : evelyntambunan@unai.edu
Phone : 087821523478

## INTRODUCTION

Tuberculosis (TB) is a communicable infectious disease that estimated around 25% of the world’s population are affected (Chakaya et al, 2021). Despite being one of the oldest diseases known to humans, TB continues to be one of the top 10 causes of death worldwide and the most lethal infectious disease. Around 1.5 million people, including 251 000 HIV-positive individuals, passed away from TB in 2018 (Reid et al, 2019). In addition, an estimated 10 million people, including 5.7 million men, 3.2 million women, and 1.1 million children, developed TB. Through its "End TB Strategy," the World Health Organization (WHO) aimed to end TB-related morbidity, mortality, and suffering by 2035. Between 2015 and 2035, WHO hopes to cut the number of new cases and fatalities from TB by 90% and ensure that no family has to bear the financial burden of catastrophic TB costs (World Health Organization, 2019).

The most common form of TB, known as pulmonary TB, affects the lungs and is contracted by inhaling airborne droplet nuclei after exposure, which normally lasts many hours. Key risk factors for the infection of tuberculin-negative people include close contact and the infectiousness of the source patient (Addo et al, 2022). The current standard of care for drug-susceptible TB is combination therapy, which entails a 2 month intensive phase of isoniazid, rifampin, pyrazinamide, and ethambutol, followed by a 4 month continuation phase of isoniazid and rifampin (WHO, 2022). The complex regimen must be adhered to in order to prevent the emergence and spread of Multidrug Resistance Tuberculosis (MDR-TB), hence Directly Observed Therapy (DOT) is advised. Following six months of therapy, approximately 85% of patients get a successful outcome (Ekpeyong et al, 2023). In addition, patient can stop being contagious two weeks after starting treatment, preventing the spread of disease. For the patient and their close friends and family, quick therapy commencement is crucial (WHO, 2022). Nevertheless, the management of TB is made more difficult by the rising frequency of MDR-TB, which necessitates protracted and sophisticated medication and is more likely to be linked with negative outcomes (Lange et al, 2019). Patients may experience persistent lung illness and a shortened life expectancy even after successful treatment (Dortois and Rubin, 2022).

A family is a group of people who have lived together for a long time and are linked to one another through blood, marriage, or adoption (Kaakinen, 2018). Those who are unable to care for themselves due to TB and other illnesses are looked after by family members. Patients who receive care at home anticipate support and assistance from family members in some capacity. In terms of the Indonesian National Health Plan, families play a significant role in caring for patients and ensuring continuity of care after they are discharged from the hospital (Siregar et al, 2020). Family care practices and family care systems have been the cornerstone of communities for generations (Kaakinen, 2018). In this regard, family members are responsible for giving emotional support, ensuring continuity of care by facilitating treatment, monitoring treatment adherence, side effects, and scheduled appointments, washing, cooking, and feeding their sick family members when they are released from the healthcare facilities (Siregar et al, 2020). Family members can be full-time students or full-time workers, among other full-time obligations. Families support their sick loved ones by advocating for them and having an impact on a patient's psychological adjustment and path to recovery. In the majority of cases, they do so without any training, assistance or acknowledgment from others, financial incentives, or other forms of compensation. They also give the sick people physical, mental, and financial support (Kristinawati, Muryadewi and Irianti, 2019).

Family caregivers may experience interruptions as a result of caring for and residing with TB infected individuals, as well as difficult-to-manage challenges and issues. Because they stayed with infected individuals, TB patient's family members experience stigma and rejection in their communities (Fana and Sotana, 2021). People who have TB are thought to be filthy, to eat poorly, and to practice poor hygiene. In addition, they go through the agony of seeing loved ones suffer from disease and the guilt, hatred, and shame that comes with it, as well as the agony of being unable to accept a family member's health problems getting worse despite their best attempts to care for them (Wu et al, 2023).

Numerous studies have shown that family caregivers frequently result in emotional, physical, social, and financial obligations, causing severe stress for families. According to other studies (Fana and Sotana, 2021; Wu et al, 2023), family caregivers are still mostly a female activity. This is because of a variety of societal and cultural expectations placed on women. Other studies that have been published have revealed that the assistance that carers offer has a favorable impact on the receivers' quality of life and saves the healthcare system a large amount of money (Kristinawati, Muryadewi and Irianti, 2019). Consequently, there aren't many studies that have used a qualitative approach, despite the fact that family caring has been the focus of research in numerous locations throughout the world. Particularly in low- and middle-income countries like Indonesia, where the burden of diseases like TB has also altered the demographic makeup of families, social structures, and norms, with men and children increasingly taking on roles as caregivers, there is still much to learn about why people take on demanding caregivers duties, how they approach their caregivers responsibilities, and the effects of doing so. Therefore, this study was performed to explore the experiences of family caregivers with disease and treatment of patients with TB in an Indonesian family context.

## METHOD

The design for this study was qualitative, exploratory and descriptive in nature, and the phenomenological approach was followed. The researchers looked at the experiences of volunteers who looked after TB patients. The participants' accounts of their lived experiences were noted, observed, and later recorded by the researchers. The descriptive research approach was selected by the researchers because it provides an overview of the problem's results (Creswell and Creswell, 2018).

The population consisted of all family members from Karyawangi Village, Parongpong District, West Bandung regency, in the West Java province of Indonesia, who were caring for TB patients at home. The researcher involved in site selection applied purposive sampling to select Karyawangi village as the site for research, because statistics from Parongpong Community Health Center in this area indicated one of high prevalence of TB patients. TB patients were selected from the health center register and traced to their families through a Directly Observed Treatment Strategy (DOTS) supporter. A sample of 16 family members for the village were chosen to participate in the study.

A sample is a subset of the population selected for a particular study (Creswell and Creswell, 2018). The sample in this study research consisted of only one or two members of each family depending on the size of the family. Males and females were chosen. The inclusion criteria followed were that: 1) participants were chosen from families where there was a TB patient on treatment during the time of data collection; 2) participants were family members caring for the patient.

Data was collected using the unstructured interview method. The interviews were conducted as normal conversations with the purpose of producing more in-depth information on the subjects concerned (Polit and Beck, 2018). The unstructured interview is also called a non-scheduled interview. The researchers established rapport with the participants by paying attention to what they were saying. The interviewer did not interrupt the participants, was non-judgemental and developed a healthy appreciation for silence. Discussion proceeded in a relaxed, conversational manner, with questions asked such as: 1) Can you tell me about your experiences in caring for the patient with TB at home?; 2) how can you describe your caring behaviors towards your family member who suffer for TB; 3) What challenges do you experience when caring for the TB patient?

The conversations were recorded and transcribed verbatim. In order to look for nonverbal clues, the researcher carefully watched the individuals. In the residences of the patients, interviews were performed. Following the achievement of saturation, data collecting was stopped. The information was evaluated and sorted into the predetermined goal or subjects. First, the interviews were read to become familiar with the text. The next step was to identify key issues in the text related to the topics. The third phase involved classifying the important issues based on the five main themes. Lastly, new categories were created inside each topic using the session data. To get an agreement regarding the material and the categories, all three authors talked about the categorization (Polit and Beck, 2018).

The principles of credibility, transferability, dependability, and confirmability were upheld in order to keep this study credible. Member checking was used to ensure that the data were highly credible for the study's findings. This method was utilized to determine the appropriate data collected from participants by providing the interview outcomes to all participants in the form of transcripts. Through thorough description and deliberate sampling, transferability was attained. Participants were chosen purposefully to aid in the transferability of the inquiry and were used to provide a detailed explanation of the exploratory themes. Step-by-step replication and peer review were used to establish dependability. Researchers compared the outcomes of their various analyses of the same data using stepwise replication. Additionally, the research procedure and results were discussed with other coworkers who had conducted qualitative research as part of the peer examination process. Last but not least, confirmability was attained by reflective journals. In order to accurately comprehend findings produced from data, researchers retained the reflective texts (Licoln and Guba, 1985).

The Ethics Committee of the Faculty of Nursing at University Advent Indonesia as well as the Chief of the village where the research was done, all granted the researcher permission to carry out this study. An informed consent form was also used to get the participants' permission. Participants were informed about the use of an audiotape for interview recording and the presence of a research assistant. They were also shown a stop button so they may halt the recording if they didn't want some data to be captured. Aside from being made aware of the study's voluntary nature, participants were also told that they might withdraw from it at any time without fear of retaliation. The recordings were kept under lock and key, and no one else was given access to the information collected from the participants. Participants were advised on the value of identifying the difficulties they faced when providing at-home care for TB patients.

## RESULTS AND DICSUSSION

Based on the study results, an in-depth unstructured interviews were conducted with 16 family caregivers from one village in the Parongpong District. Seven of participants were males aged between 19 and 49. One male caregiver was employed as a teacher who had worked only morning to afternoon in order to care his father during the rest of the day. The rest of males caregivers were employed as freelance farmers. The rest of the participants were females aged between 20 and 66. Most of the female caregivers were a housewife, whose main occupation is caring for her family.

Family members described different experiences related to caring for patients with TB at home. Three major themes emerged from the data with sub-themes are the following: 1) Family role in TB care and support; 2) Family caregivers behavior to transmission of disease; 3) Family caregivers knowledge of disease

1. Family role in TB care and support

This theme contained experiences of family caregivers caring for their family member who suffers for TB. In the interviews, family caregivers attempt to assist the recovery of family members who are suffering from TB. Two major sub-themes were identified including encouraging adherence with taking medication and providing environmental health and hygiene. The role of the family is pivotal in ensuring patient compliance in the medication program. The caregivers described their role as that of assisting patients to take their medicine. The participants explained that one of their responsibilities is to help patients take their prescribed medications on time. The participants elucidated that patients' ability to recover is contingent upon their adherence to the prescribed drug regimen for the entire prescribed duration. Likewise, the role of the family in controlling the environment, including good air circulation and nutrition, is very necessary for family members who suffer from TB.

Example of excerpts of encourage the adherence with taking medication are as follows:

"*I try to comply with the rules of getting medicine from the community health center, Parongpong...free service. The schedule for taking the medicine has been informed by the officers there*." *(P13)*

*"In the morning, I usually help my mother take her medicine. My mother's treatment has been going on for months. I feel sorry for my mother too." (P5)*

*"As a mother, I really hope my child recovers soon. Every morning I wake my child up to take his medicine. At first, my child was very, very annoying, but after 4 months of treatment, it has become easier for us." (P10)*

The statements regarding environmental controls are given:

*"Since my child was sick with TB, I have been diligent in cleaning the house. Every day I clean*

*the house, especially now that it's the dry season, dust flies around." (P3)*

*"A few months ago, during the rainy season, every day it rained and the air was very cold, so we rarely opened the windows. And indeed there are only 2 windows that can be opened. The other one is a patent window, so it cannot be opened every day. But I try to open every day a door or window that can be opened for air circulation." (P13)*

*"my child has difficulty eating, but I still try to give him the food recommended by the nurse at the health center, such as milk, eggs, tofu, chicken meat" (P8)*

2. Family caregivers behavior to transmission of disease

Two major sub-themes were identified from the family caregivers behavior to transmission while caring for family members with TB. The sub-themes including ignoring the clinical importance of screening and underestimating household transmission. From the interview in this present study show that participants refuse and are reluctant to carry out screening. Families who provide care for TB patients believe screening is not really necessary. unwilling to comply with health officials' orders requiring family members to get screened. In addition, the behavior of underestimating household transmission explained by family members to interviewers.

The explanation two of family caregivers regarding to ignoring the clinical importance of screening as follows:

"*Though I haven't noticed any symptoms yet, my father has tuberculosis, so why does it need to be screened?" (P11)*

*"As a family, we don't need to be screened, even though health workers have recommended that we be screened, to collect phlegm, we don't cough." (P9)*

The expression of family caregivers related to underestimate the household transmission are given:

"*Yes, health officials have explained TB transmission, but it has not been fully implemented, for example my mother sometimes forgets how to cough properly, haaaa." (P5)*

*" We didn't get infected, even though our father had TB. How about it...not to chat closely with my father, it's a pity he's old," (P8)*

3. Family caregivers knowledge of Tuberculosis

The study's participants lacked general understanding about tuberculosis and health care service which has an impact on the management of family members when initially diagnosed with TB. The majority of family caregivers were unaware of the disease's source, its route of transmission, or the duration of their treatment. However, after some time of treatment, understanding has been gained and the community health center was used for treatment. Some family caregivers are also afraid of being discriminated against if it becomes known to the community around them.

The example of comments given related to deficient knowledge about TB disease are as follow:

*"At first, my child coughed continuously, I thought it was a normal cough. and it's hard to eat. He was indeed underweight when he was weighed at the integrated service post (Posyandu). Turned out to be suffering TB"(P12)*

"*I don't understand why my sister has TB. At first I didn't really know what TB and how my little brother could get TB." (P11)*

*"Why does TB treatment take so long? Is there any medicine to take for just 2-3 weeks? I feel sorry for my father" (P3)*

Excerpts example expressed by the participants related to health care service for TB disease are as follow:

"*At the beginning of my mother's illness, my father and I did not understand how my mother should undergo treatment." (P12)*

*"When the health worker initially visited our village for tracking program, they said. I didn't know how my wife to take medicine that will take six months to complete the treatment. Now it has been 5 months, According to the schedule determined by the health worker, I took the medicine to the community health center." (P14)*

*Family caregivers experience their predisposed to stigma because of the disease as expressed by statements below:*

*"At the beginning of my mother's diagnosis, we were very worried that the neighbors would find out that a member of our family was sick with TB, so we were very close to our neighbors." (P2)*
*"they often gossip, and talk about the cause of my child getting TB, our livestock is said to be the cause." (P4)*

*" Since they learned that my child had TB, my neighbors have become less inclined to visit my home." (P7)*

Since tuberculosis is a chronic illness that requires ongoing care, families play an important role in treating the disease. The family is crucial in the course of the infection, the appearance of signs and symptoms, the behavior of seeking medical attention, and the resolution of the therapy (Chakaya et al, 2021). This is related to the condition that DOTs (directly observed treatment, short course) is the internationally recommended control strategy for TB (WHO, 2022). This strategy includes the delivery of a standard short course of drugs, lasting 6 months for new patients and 8 months for re-treatment patients, to individuals diagnosed with TB. The delivery includes the direct observation of therapy (DOT), either by a health worker or by someone nominated by the health worker such as family caregivers and the patient for this purpose, sometimes called a DOT supporter (WHO, 2022). This strategy has been promoted widely and implemented globally including Indonesia (Kemenkes, 2020).

The decision to discontinue or continue treatment may be influenced by the family member's attitude (Mardi, Parellangi and Purwanto, 2023). Supporting, monitoring, and urging the patient to take their medication are vital roles played by family members, particularly spouses. Our study also found that patients with frequent medication supervision by family caregivers who often encouraged them mentally were more likely adherence in taking medication. This result could be attributed to the psychological burden that TB patients typically bear, which prevents them from adhering to their treatment plans due to their lack of trust in the disease's ability to be cured (Addo et al, 2022). In addition, the patient's confidence may rise due to the family's unwavering support and care, which may have an impact on the patient's adherence to their drug regimen. Family members' assistance in resolving issues in their lives did not affect adherence during the illness (Chen et al, 2020).

Environmental controls and family economics play a major role in whether tuberculosis treatment is successful or not. The purpose of environmental controls is to lower the amount of infectious bacteria in the air in locations where contamination is likely to occur (Grigoryan et al, 2022). Several studies found that contacts dwelling in the house with poor ventilation were four times more likely at risk of getting TB than those dwelling in the house with good ventilation in Sub Saharan Africa, Pakistan and Ethiopia (Banda, 2022; Madebo, Balta, Daka, 2023). This might be because of inadequate ventilation in homes, which raises the concentration of tuberculosis bacteria in homes and increases the risk of contracting the disease. Nonetheless, adequate ventilation lowers the amount of TB germs present, which will lessen the disease's ability to spread (Addo et al, 2022).

The results of this study are in line with several countries where the prevalence of adhering to family contact screening was indicated to be very low (Jember, Hailu and Wassie, 2023; Barroso, 2018). Household contacts are the priority for TB screening because HC screening not only helps trace cases but also offers various benefits, including early diagnosis, a lower rate of morbidity, a lower risk of transmission to others, and an enhanced high yield (Shiferaw, Mekonnen and Abate, 2019). In fact, the World Health Organization (WHO) defines systematic screening for TB as a systematic identification of people with suspected active TB, in a predetermined target group, using tests, examinations or other procedures that can be applied rapidly (WHO, 2013). In order to protect family members, especially children from contracting TB, early screening is crucial. If it turns out that a child has contracted the infection from an adult patient, treatment can start sooner and diagnosis delays can be avoided, which will help stop the illness from getting worse and from developing problems (Gebretnsae et al., 2020). Additionally, one of the responsibilities of the family to preserve health and create a prosperous family is family screening. Utilizing the health resources that are currently available is another obligation placed on the family. In the event that a family member has tuberculosis, the other family members should be screened as a preventative step using the current health services (Tesfaye et al, 2020).

Studies of social contacts suggest that large proportions of indoor meeting time between people occur between household members or close social contacts. The main factors contributing to tuberculosis transmission were sharing air from a closed-circuit ventilation system or residing in the same compartment as an infectious TB patient. There was no indication of any noteworthy transmission from any other type of interaction on board, including passing conversation in various sections or coming into contact with fomites (....). Several studies have actually shown that although household of TB cases represents a setting for intense transmission Mycobacterium tuberculosis, household exposure accounts for about similar among the majority of extra-household case contacts of transmission within a community (Kakaire et al, 2021; Fox, Nhung and Marks, 2018). However, the administrative controls recommended by WHO are a guide in preventing transmission to family members of TB sufferers. On the other hand the various factors including relate to the recipient and the bacterial strain or the the environment may influence the transmission (WHO, 2019).

Numerous research focused on how patients' comprehension and their caregivers of TB therapy, particularly how long it would last and what happens if the patients don't follow through, affects their adherence to it (Grigoyan, 2022; Mardi, Parellangi, Purwanto, 2023). Patients and family caregivers had a poor understanding of the extended treatment term, and adherence seemed to be easier when they recognized the significance of finishing treatment. According to a study on prophylactic adherence, patients and family caregivers who were not adhering to the therapy had limited knowledge about tuberculosis (TB) as a disease but were highly conscious of the possible side effects of their medication (Madebo, Balta and Daka, 2023). Therefore health education has an important role in adherence to TB treatment. This may due to the fact that it favors a better understanding of the side effects, duration of treatment, and facilitates the procedure for receiving the treatment (Bashorum, 2020).

The synthesis revealed a substantial presence of factors associated with the delivery of health care services. Treatment strategies that preserve patient autonomy and offer flexibility and choice seemed to go against the conventional way that many TB clinics are organized (Kemenkes, 2020). Failures of the programs, such as insufficient prescription supply and trouble contacting doctors, made these issues worse (WHO, 2022). A patient's working day would frequently be cut short to attend DOT at a medical facility. That being said, patients may prioritize their family's needs over adhering to their treatment plan (Chen et al, 2020). Family and patient financial hardship and social disruption are exacerbated by other health care service variables, such as lengthy wait times and awkward clinic operating hours (Kristinawati, Muryadewi and Irianti, 2019), which also have a detrimental effect on adherence. There is evidence that individuals intentionally assess the opportunity costs of receiving treatment, and the findings indicate that patients frequently have to choose between working and taking their TB medicine (Wu et al, 2023).

A community's or a family's internalized bias toward TB patients as a result of societal standards is known as stigma connected to TB. Depending on the cultural setting and degree of awareness in the community, it has been shown that the poor, women, ethnic minorities, migrants, and refugees are most affected by TB-related stigma and its associated effects, which include isolation, lack of support, and job loss (Rakhmawati, Nilmanat, Hatthakit, 2019). The community's or family’s attitudes, views, and behaviors toward TB patients have hindered service delivery and could cause patients to delay seeking treatment, which could have an impact on treatment outcomes, even in the presence of free and decentralized TB services (Datiko, Jerene, Suarez, 2020). In fact, TB remains a highly stigmatized disease, primarily due to false beliefs about its transmission and its link to HIV. Qualitative research confirms that housing was denied to tuberculosis sufferers and that the illness was occasionally viewed as a curse. Patients in these communities typically choose to stay at home when they experience symptoms rather than seeking medical attention, making it difficult for them to get care (Mbuthia et al, 2020).

## CONCLUSION

This qualitative study has explored the different experiences of family caregivers in Karyawangi Village, Parongpong District, West Bandung regency, in the West Java province of Indonesia, who were caring for family members suffering from TB at home. Three major themes emerged from the data including family role in TB care and support, family caregivers behavior to transmission of disease and family caregivers knowledge of disease. This study suggests for further research to provide sustainable educational interventions to enhance family knowledge related to TB care at home.

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