

FAMILY SUPPORT PATTERN FOR TREATMENT ADHERENCE AMONG TUBERCULOSIS PATIENTS IN DELI SERDANG REGENCY: A QUALITATIVE STUDY

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FAMILY SUPPORT PATTERN FOR TREATMENT ADHERENCE AMONG TUBERCULOSIS PATIENTS IN DELI SERDANG REGENCY: A QUALITATIVE STUDY

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ABSTRACT

In Indonesia, 50% of tuberculosis (TB) treatments are discontinued prematurely. The success of TB treatment depends on patient adherence to completing the treatment. Family support is crucial in enhancing TB patient adherence, particularly regarding emotional and appreciation support. This study aims to explore the complexity of family support to TB patient adherence in Deli Serdang Regency, North Sumatra ² province, Indonesia. This qualitative study employed participatory observation and in-depth interviews with TB patients and their family members. The research was conducted from February to April 2024 in Deli Serdang Regency, North Sumatra, Indonesia. Informants included 10 TB patients and 16 family members, selected purposively based on data from the public health center and the TB Program Holder. The researcher was the primary instrument of the study, focusing on two dimensions of family support: emotional and appreciation. Data validity was checked through credibility testing, including triangulation. The study findings indicate that family emotional support is reflected in expressions of empathy and caring. Sadness is evident from family members' tears upon learning that a relative tested positive for TB. Family support is shown by accompanying TB patients to the health center and reminding them to take treatment. Appreciation support is demonstrated by valuing the patient's treatment process. Family members encourage and motivate the patient to adhere to the treatment. Emotional and appreciation support from family plays a significant role in TB patient adherence to treatment. Families can significantly contribute to the success of TB treatment by demonstrating empathy, caring, and appreciation for the patient.

⁸ **Keywords:** family support, patient adherence, tuberculosis

Introduction

Tuberculosis (TB) remains a significant global health issue, with prevalence and mortality rates continuing to rise annually, both globally and in Indonesia.^{1,2} TB poses complex problems from medical, social, economic, and cultural perspectives. One significant impact is economic loss. Every year, Indonesia incurs a loss of 136.7 billion rupiah due to TB. The economic impact of TB-related deaths also results in a loss of approximately 0.7% of Indonesia's Gross Domestic Product (GDP), amounting to 123.6 billion rupiah.³⁻⁵

Adherence to TB treatment is crucial for patient recovery. About 50% of TB patients do not comply with taking anti-TB drugs. Premature cessation of treatment in Indonesia is the most significant factor in TB treatment failure. If treatment is not carried out regularly and according to the prescribed schedule, it will result in failure, relapse, and resistance to anti-TB drugs or Multi-Drug Resistance (MDR TB). It leads to continuous disease transmission and increases the risk of morbidity and mortality for patients and the wider community.⁶⁻⁸

One of the main factors for non-adherence to TB treatment is the lack of family support. The lack of family involvement in various aspects of patient care often causes non-adherence. Families often do not accompany patients to treatment, do not remind them to take medication, motivate them to stay strong and motivated, do not provide nutritious food, or remind patients to get adequate rest.⁹ Family involvement is crucial for TB patients to carry out the care plans set by healthcare providers. Although families are not always a positive source of client health, they most often play an essential role in healing.¹⁰ Family members supervise and monitor medication intake, guidance, counseling, and encouragement. Families can remind patients to take medication on schedule, provide medication at all times, ensure adequate rest, provide nutritious food, and give motivation to recover.^{11,12}

Several previous studies have examined the impact of family support on improving TB patient adherence. Emotional support, such as empathy, attention, and caring, can create a harmonious family environment. It makes patients feel comfortable and not alone, positively affecting their adherence to taking medication regularly and getting enough rest.^{10,13} Instrumental support, like financial assistance for treatment, transportation to health centers, nutritious food provision, environmental cleanliness, and reminders for medication schedules, can improve TB patient adherence in completing treatment.¹⁴ Similarly, the study stated that informational support, such as education about the disease, guidance on drug use, information about health services, and daily management during treatment, can enhance TB patient adherence in completing treatment.¹⁵

The crucial role of family support in improving TB treatment adherence is key to successful treatment and preventing drug resistance. In the Indonesian context, where treatment non-adherence rates remain high, interventions that actively involve families are highly needed. Strong family support can reduce treatment failure rates, prevent the rise of drug-resistant TB cases, and

ultimately lower TB-related morbidity and mortality rates. Therefore, understanding and optimizing the role of family support is an urgent and critical step in effectively addressing the TB epidemic. An in-depth exploration of the more complex role of family support in TB treatment adherence has not been extensively discussed in previous literature. According to quantitative research, emotional and appreciation support are the most dominant factors influencing TB patient adherence in the Deli Serdang Regency.¹⁶ The study aims to explore the complexity of family support in terms of emotional and appreciation support on TB treatment adherence in the Deli Serdang Regency to provide effective intervention recommendations for enhancing family involvement in TB patient care.

Methods

This study employs a qualitative case study approach to understand TB patients and their families' experiences and interactions regarding treatment adherence. The aim is to explore in-depth how emotional support and appreciation from the family influence TB patients' adherence to treatment. The study was conducted in the Deli Serdang Regency, North Sumatra Province, Indonesia, specifically at the homes of TB patients undergoing treatment. The research activities took place from February to April 2024.

The study informants are TB patients undergoing treatment who are over 18 years old and their accompanying family members. Purposive sampling was used to recruit TB patients and their family members with direct experience and involvement in TB treatment. Informants were recruited through coordination with the Public Health Centers and the TB program managers at the Deli Serdang Health Office, assisted by three enumerators. The enumerators played a crucial role by assisting as interviewers after achieving a shared understanding of the study's objectives. They are Public Health Center staff under 40 years old, with a diploma or bachelor's degree in health, possessing good communication skills, and experience as program holders or TB cadres. The enumerators were responsible for logistical coordination, preparing informants, and handling technical aspects such as recording and note-taking, ensuring that the interview process ran smoothly and that the data collected were accurate. The informants interviewed consisted of 10 TB patients and 16 family members, selected based on data saturation. Inclusion criteria are TB patients diagnosed and undergoing treatment at Deli Serdang health centers, over 18 years old, able to communicate well, and willing to provide written consent. Family members meeting these criteria were also included. Exclusion criteria include patients and family members having medical or mental conditions preventing participation.

Data were collected through in-depth interviews with TB patients and their family members at their homes. Interviews were recorded using mobile phones to facilitate transcription. Questions addressed aspects of emotional support and appreciation provided by the family to the TB patient.

Data from the interviews and field notes were transcribed, thematically identified, and analyzed to conclude. Data validity was ensured through data source triangulation by comparing information from expert informants, including two TB program officers, whose role was to provide expert validation and additional context regarding patient compliance and family support. These officers are responsible for overseeing TB treatment programs and monitoring patient adherence to treatment protocols. The triangulation process involved comparing information from patients, family members, and the TB officers to ensure data accuracy. This triangulation method aimed to validate the emotional support patients received, including expressions of empathy and concern from family members, as well as their actions in accompanying patients for treatment. The questions for patients and family members, which focused on emotional support and appreciation, are presented in Table 1.

Table 1. Emotional Support Questions for TB Patients and Family Members

Informant	Expression	Question
Patient	Empathy	<ol style="list-style-type: none"> 1. Do you think your family feels sympathy for you regarding your illness? 2. If so, what signs do they feel sympathetic towards you? 3. How do you perceive your family's attention to your health?
	Care	<ol style="list-style-type: none"> 1. How does your family help you go to the clinic or hospital for treatment? 2. What activities do you do together with your family? 3. What role do you play in your treatment? 4. What do you need the most right now?
Family Member	Empathy	<ol style="list-style-type: none"> 1. How did you feel when you found out a family member had TB? 2. How do you feel about your own condition? 3. Are you afraid of getting infected by them? 4. What makes you feel afraid of getting infected?
	Care	<ol style="list-style-type: none"> 1. How does your family help you get to the clinic or hospital for treatment? Who usually takes you? 2. What activities does your family often do together with you? 3. How does your family show their love and care for you? 4. How does your family support your medication regimen? Who reminds you, prepares, and stores the medicine? 5. Is there any family attention that deeply touches you? Can you provide an example?

Appreciation support was investigated in terms of positive and motivational reinforcement from the family. Positive reinforcement is observed through daily attention given to the TB patient by family members, from waking up to going to bed, especially when the patient lacks appetite or complains of pain. Providing motivation is reflected in family members' actions, encouraging patients to take their medication on time. The following questions are presented in Table 2.

The data in this study were analyzed using thematic analysis to identify and categorize patterns and themes that emerged from the in-depth interviews. The thematic analysis allowed for a detailed examination of the emotional support and appreciation provided by family members and their influence on the adherence of TB patients to treatment. The data analysis began with data collection through interviews and field notes, followed by data reduction to select, focus, and simplify relevant information. Themes and sub-themes were then identified through data categorization, and the findings were presented in narrative form and thematic matrices to facilitate

conclusions. Interpretations and conclusions were drawn based on the analyzed data. Data validity was ensured through source triangulation, comparing data from various respondents and information from expert informants such as TB program officers.

Table 2. Appreciation Support Questions for TB Patients and Family Members

Informant	Expression	Question
Patient	Positive Reinforcement	1. Do family members often get angry with you?
		2. What do family members usually do for you in the morning and at night?
		3. How do family members engage in conversations with you?
		4. What do family members do when you are feeling sick?
		5. What do family members do when you have no appetite?
	Motivation	1. How do family members take you out for walks?
		2. What did your family do after finding out you had TB?
		3. What roles do your family members play that help you recover quickly from TB?
		4. What does your family do when you want to stop taking your medication?
		5. Have you ever felt isolated by your family or community because of TB?
Family Member	Positive Reinforcement	1. What do you do for the patient in the morning and at night?
		2. How do you engage in conversations with the patient? What do you talk about?
		3. What do you do when the patient is feeling sick?
		4. What do you do when the patient has no appetite?
	Motivation	1. How do you encourage the patient to seek TB treatment?
		2. What actions do you take to help the patient recover quickly?
		3. What do you do when the patient wants to stop taking their medication?

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This study was approved by the Faculty of Medicine Universitas Andalas ethics committee, as indicated in Approval Letter No. 850/UN.16.2/KEP-FK/2022. Before conducting the research and interviews, the researchers provided informants with a thorough explanation of the study's purpose, procedures, and rights and were required to give written consent. Confidentiality was maintained by using codes or initials to protect informants' identities in the research report. Informants had the right to withdraw from the study without facing negative consequences. Data validity was ensured through source triangulation, comparing data from various respondents and information sources.

Results

The general characteristics of the informants, both TB patients and their families, are as follows: the patients' ages range from 35 to 55 years, with the duration of TB illness lasting between 1 to 3 years. Most patients and their families work as farmers, homemakers, traders, laborers, or unemployed, with education levels ranging from elementary to high school. The informants were coded for TB patients by assigning each patient a sequence from 1 to 10, followed by the patient's initials. For example, 1R represents informant 1, a patient with the initial R. For the patient's family members, the number 1 is added after the patient's code, such as 1R1, which indicates a family informant of the patient with the initial R. Meanwhile, healthcare workers were given the codes P01 and P02, representing healthcare informants 1 and 2. This coding system

facilitated the analysis of the support provided to TB patients by their families, with the validity confirmed by healthcare workers.

Emotional support from family members towards TB patients includes two criteria: expressions of empathy and care. Empathy is the ability to understand and feel what a TB patient is experiencing, allowing family members to feel the patient's suffering and emotional struggles. Care involves concrete actions showing attention and compassion for the patient's well-being, such as physical assistance and practical support. The empathy of family members towards TB patients encompasses deep care and affection, where they emotionally share the patient's suffering and difficulties. Family members expressed that they were saddened to hear that one of their members was diagnosed with pulmonary TB. This sadness was evident when family members cried upon hearing the news. This empathy makes the patients feel supported and not alone in their fight against TB, thanks to genuine and sincere emotional support from their family members. Healthcare workers noted that patients who receive such emotional support from their families tend to adhere more to treatment protocols, as the empathetic and caring environment motivates them to follow medical advice and attend regular check-ups more diligently. This emotional connection is further reflected in the patient's own words:

".....After knowing he had TB, I cried." (Informant 3A2)

".....When I returned from abroad and saw his condition, I immediately tore up. He looked thin, and his body was trembling." (Informant 2I2)

".....It felt devastating because it was my sibling." (Informant 9A1)

However, family members also expressed frustration with the TB patient's unwillingness to take advice. One family member shared their struggles:

".....Sometimes it's frustrating and tiring because he doesn't listen to his family's advice, rarely bathes, often smokes, and drinks palm wine." (Informant 9A1)

These findings have been confirmed by an expert informant from the TB program officer, who emphasized that emotional support from the family is crucial for the recovery of TB patients, especially in ensuring that they adhere to a healthy lifestyle. The expert noted:

".....Emotional support from the family is very meaningful for patients, but I understand that caring for a TB patient can be challenging, particularly when the patient struggles to maintain healthy habits essential for their recovery." (Informant P01)

".....¹⁹ family plays a key role in this process, and we need to continue supporting them by providing education and strategies to address these challenges" (Informant P01)

Regarding care, family members always accompany TB patients to the public health center or hospital because they always remember the treatment schedule. Healthcare workers have observed that this consistent accompaniment not only ensures that patients adhere to their treatment

schedules but also provides emotional support, as the presence of family members during medical visits reassures patients and alleviates their anxiety. This level of care from the family is seen as a significant factor in the success of the treatment, as noted by the healthcare providers. One family member shared:

".....My child is accompanied by his father to the health center. I also keep track and remind him of his schedule for follow-up visits." (Informant 2I1)

".....My brother took the initiative to take me to the doctor because our father had a similar illness and was taken too late for treatment." (Informant 2I1)

However, there are TB patients who go for treatment on their own, as they do not have immediate family members like a spouse or parents but live alone and eat with their married siblings. One such patient mentioned:

".....I go for treatment on my own; there's no one to accompany me." (Informant 8R)

Family members have not played a role in storing TB medication. TB patients store their medication themselves. One patient shared:

".....I store the medication myself. My sibling helps pick up the medication from the health center, and my aunt reminds me to eat before taking it." (Informant 3A)

".....My family only gives advice; the rest is up to me, like preparing and storing the medication." (Informant 7V)

Patients stated that family members always remind them to take their medication. The family members who remind them to take their medication are usually their wife or mother, the information obtained is as follows:

".....Every night my wife always reminds me." (Informant 1R)

".....My wife often reminds me; sometimes I remember on my own too." (Informant 7V)

".....My mother often advises me to take my medication." (Informant 6H)

".....Every night, my mom prepares the medication." (Informant 2I)

However, other patients stated that no family member reminds them to take their medication.

".....I store my medication myself. I take it only during the day. No one reminds me to take it." (Informant 8R)

The interview results indicate that the role of family support in ensuring TB patients' adherence to treatment varies. Most patients receive support in the form of accompaniment to medical appointments and reminders to take their medication, particularly from close family members such as a spouse or mother. However, some patients lack accompaniment or reminders from their families, which may increase the risk of non-adherence to treatment. The TB program officer has also confirmed these findings.

".....Family support is crucial, especially ensuring patients adhere to their treatment. Patients who live alone might be more vulnerable to non-adherence." (Informant P02)

".....This requires more attention. We need to consider ways to enhance the role and awareness of families in supporting TB patients." (Informant P02)

In this study, appreciation support for TB patients includes positive recognition and motivation. Positive reinforcement support from family members to TB patients involves recognizing and appreciating the patient's efforts. Providing motivation includes encouragement and motivation to ensure the patient remains committed to completing the entire course of treatment, emphasizing the importance of the TB recovery process.

Family members closely monitor the condition of TB patients. The health challenges faced by the patients prompt the family to remind them to stay fit consistently. Providing direct praise and appreciation to TB patients for their efforts and recovery progress is an effective way to enhance patient compliance in completing their treatment. Based on the interview results, the information obtained is as follows:

".....At night, we often talk about maintaining health to stay healthy and not get sick again."
(I Informant 1R1)

".....I call my child to sunbathe and do some stretching. At night, I tell him not to sit outside because the night air is not good. Also, no staying up late or smoking." (Informant 2I1)

According to the statements of patients and family members, special treatments are given to appreciate the patient, such as all family members wearing masks and accompanying the patient when they are sick. According to the following statement:

".....Interaction is normal, but we remind others to wear masks too, so he doesn't feel alone and for prevention as well." (Informant 2I2)

".....Before my wife goes to sell, she asks about my condition. If I don't feel well, she calls someone else to sell, and she stays home to accompany me." (Informant 10K)

However, during their illness, the patient only stays at home. Because of the patient's condition, the family lets the patient rest at home. However, the patient also needs a break to relieve stress and ease their illness. The family's understanding of the importance of the TB patient's mental condition is still minimal. According to the following statement:

".....No, sir. I only go out if necessary. While sick, I stay at home." (Informant 2I)

".....No, just staying in the room or sitting in front of the house." (Informant 9A)

Family members play a crucial role by providing positive reinforcement, monitoring the patient's condition closely, and offering direct praise for their recovery efforts. This support is demonstrated through actions such as wearing masks with the patient and accompanying them, which helps prevent feelings of loneliness. However, the study also found that while patients are

often encouraged to rest at home, the family's understanding of the importance of the mental condition of TB patients is still limited. According to the following statement:

".....That is true. Positive reinforcement helps patients comply with their treatment, especially when they feel appreciated". (Informant P01)

".....This is indeed an issue that needs further attention. The mental condition of TB patients is just as important as their physical condition. We might consider implementing programs to increase family awareness about the importance of mental well-being for TB patients". (Informant P01)

In terms of motivation, the family strengthens the patient by providing encouragement and support so that the patient never feels like giving up on taking medication, as expressed in the following statements:

".....My parents are sad, but they try to keep me motivated to recover and always remind me to take my medication." (Informant 2I)

".....They boost our spirits to recover." (Informant 5H)

".....I give motivation, painting a picture that if he is sick, everyone else will be affected too. When the family embraces him, his spirit is uplifted." (Informant 7V1)

".....I keep giving support, as a wife, I feel pity. I don't want to distance myself; when he's sick, we need to take care of him too." (Informant 1R1)

".....I encourage him not to give up on taking his medication." (Informant 10K1)

Besides encouragement, family members also use threats to push TB patients to remain compliant with their treatment. According to the following statement:

".....If he doesn't want to go for treatment, I won't accompany him to the doctor when he's sick. But because she's my wife, it's not possible. So, it's more like a threat. Even if it's boring, the medication must be taken." (Informant 10K1)

The family provides strong motivational support to TB patients to ensure they do not give up on their treatment. This motivation is given through encouragement, regular reminders to take their medication, and explanations about the impact of the illness on the entire family. However, in addition to positive reinforcement, some family members also use threats to ensure the patient remains compliant with the treatment, such as threatening not to accompany the patient to the doctor if they refuse treatment.

".....That is right. Family motivation is indeed crucial. Patients who feel supported and motivated tend to comply more with their treatment." (Informant P02)

".....Yes, but using threats can be a double-edged sword. While it may be effective in the short term, it could also add stress to the patient and negatively impact their mental health." (Informant P02)

".....I agree. By providing a more supportive approach and understanding the patient's condition, we can help them complete their TB treatment more effectively." (Informant P02)

The qualitative research findings indicate that expressions of empathy are evident from family members crying when they learn that a family member has TB. Care is shown by family members accompanying the TB patient for treatment because they remember the schedule for visits to the health center. However, for medication storage, the patient still stores the medication themselves. Family members only remind the patient to take the medication. Positive recognition is shown by family members accompanying the patient during treatment, such as wearing masks together as a form of solidarity. Motivation from family members comes in the form of encouragement and support. However, the threat can also be applied to ensure the TB patient complies with the treatment. Generally, this study found that female and close family members, such as the wife or mother, mostly show emotional and appreciation support.

Discussion

Family support is a support system provided through interpersonal relationships among family members to maintain social identity, fulfill material needs, promote health, and provide information and services in interacting with society. Emotional support from family gives individuals a sense of being cared for, valued, and loved.¹⁰ Family support can also influence various aspects of health, evidenced by reduced mortality, faster recovery, and improved emotional well-being.^{13,14}

Research exploring the relationship between family support as a Directly Observed Treatment (DOT) supervisor and medication adherence in tuberculosis patients found that emotional support positively correlates with TB patients' adherence to medication.¹⁷ Theoretically, the family acts as a safe and peaceful space for rest and recovery, helping individuals manage their emotions. This support involves expressions of empathy and care, providing comfort, and making individuals feel comfort. There is a significant relationship between emotional support and TB medication adherence.¹⁸ Emotional support, such as attention, affection, and care, enhances patients' motivation and comfort, making them feel valued and encouraging them to adhere to their medication regimen, ultimately speeding up the healing process. Direct family involvement in reminding patients to take their medication on time helps reduce the risk of non-adherence.¹⁸

A significant relationship exists between recognition and treatment adherence, with differences in mindset observed between urban and rural communities¹⁸. With more available time, rural communities can offer more support than urban communities, where most people are employed. This type of family recognition support can create a harmonious and loving environment, making patients feel valued, accepted, and supported by their loved ones, which boosts their confidence to adhere to the treatment until completion.¹⁹ However, no relationship was

found between recognition support and medication adherence in TB patients.¹⁷ This discrepancy is attributed to families viewing TB patients as equal to other family members so the patients do not feel isolated. Positive recognition from family through praise and acknowledgment of the patient's efforts to consistently follow the treatment schedule can enhance TB patients' motivation and self-confidence to recover.¹⁹ Moreover, this self-confidence can reduce anxiety and stress during the treatment process and increase adherence to the treatment until it is completed.^{18,20}

Family motivation enhances patients' morale, mental health, and treatment adherence and strengthens the emotional bond between the patient and the family, creating a supportive environment for the patient's recovery.²¹⁻²³ Family motivation, such as positive reinforcement and encouragement, can increase patients' adherence to treatment, making them more consistent in following the treatment schedule. These findings highlight the critical role of the family in the healing process and provide insights into effective strategies to enhance treatment adherence.¹⁸ Recognition through praise and motivation can strengthen patients' resolve to adhere to their treatment.^{24,25}

This study has several limitations, including a small sample size and a focus on TB patients and their families in a specific region (Deli Serdang Regency, North Sumatra Province), which may not be generalizable to other areas with different cultural or socioeconomic backgrounds. Using qualitative methods also risks introducing subjective biases from both participants and researchers. Additionally, the data collected are self-reported and susceptible to social desirability bias. External factors such as healthcare system access and economic constraints should have been explored in depth. Nevertheless, the findings highlight the importance of emotional and recognition support from families in enhancing TB patients' medication adherence. Public health interventions in Indonesia should involve families as part of treatment programs, considering the differences in family support between urban and rural communities.

Conclusion

Family support, which includes empathy, care, positive reinforcement, and motivation, has been proven to have a significant impact on adherence to TB treatment. This finding is consistent with previous studies showing that emotional support and encouragement from family play a crucial role in the success of treatment. The combination of these forms of support not only enhances patient adherence but also accelerates their recovery process. However, the study has limitations, such as variability in family support that may only partially capture some scenarios, the generalizability of findings to different populations or settings, and potential subjective bias in self-reported data. Additionally, family resource constraints may affect the effectiveness of the support provided. Therefore, the implications are that future clinical strategies should prioritize integrating the family role into TB treatment plans. Educational programs for patients' families are highly

recommended to emphasize the importance of emotional and practical support during treatment, and policies encouraging collaboration between healthcare providers and families should be developed. Further research is also suggested to explore the most effective methods for family involvement and apply these findings to other chronic diseases while considering the existing limitations to ensure recommendations are effectively implemented across various contexts.

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Conflict of Interest

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