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RESEARCH ARTICLE **OPEN ACCESS**

Exploration of Concordance Behavior between Tuberculosis Patients, Families, and Healthcare Workers in Supporting Treatment Adherence: A Qualitative Study

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Abstract:

Background: Indonesia continues to face a significant problem with Tuberculosis (TB), ranking as the country with the second highest global burden. Concordance behavior is crucial to treatment adherence. However, understanding of concordance behavior determinants remains incomplete.

Objective: This study aims to explore the understanding and experience of TB patients, their families, and health workers regarding communication in support of TB treatment concordance.

Methods: We employed a phenomenological design to explore the lived experiences of individuals involved in TB treatment. Semi-structured interviews were conducted with a purposive sample of TB patients, family members, and healthcare workers at primary healthcare centers in Padang City, Indonesia. We utilized the Braun and Clarke approach-guided thematic analysis to identify salient themes emerging from the interview data.

Results: Data analysis yielded four principal themes: understanding of concordance, the role of the family in treatment communication, communication barriers, and effective communication strategies to support the concordance. Many patients and relatives were unsure about TB treatment. Family pressure on medication adherence was significant, yet it sometimes caused patient stress. Healthcare workers' time and TB stigma hindered communication. Brochures, films, and digital media have improved knowledge and adherence.

Conclusion: Concordance behavior among patients, families, and healthcare workers is essential. Enhancing adherence necessitates ongoing education, family engagement, and reduction of stigma for TB treatment.

Keywords: Tuberculosis, Treatment concordance, Communication, Family support, Patient education, Stigma.

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1. INTRODUCTION

Tuberculosis (TB) remains a significant global health challenge, with an estimated more than 10 million people, including 5.8 million men, 3.5 million women, and 1.3 million children affected worldwide in 2022. It ranks among the top ten deadliest infectious diseases, according to the World Health Organization (WHO) [1, 2]. Despite widespread implementation of Directly Observed Treatment Short-course (DOTS) strategies, achieving sustained treatment adherence continues to be problematic, especially in high-burden countries [3]. Indonesia is ranked as the 2nd country with the highest TB burden. In 2021, the TB incidence rate is 354 per 100.000 populations [4, 5]. The country exhibits a large prevalence of Multidrug-Resistant Tuberculosis (MDR-TB), especially among patients with prior treatment, with rates markedly exceeding global averages (52.5% *vs*. 17.7%) [6]. The prevalence of tuberculosis exhibits considerable variation throughout Indonesia, with elevated rates observed in Sumatera and other islands relative to Java-Bali [7]. In Padang City, the capital of West Sumatera Province, there was an increase in the rates of pulmonary tuberculosis, treatment dropout, recurrence, and multidrug-resistant tuberculosis in 2022, recorded at 69%, 3%, and 69% [8]. One of the critical challenges in TB treatment is the lack of coordination and concordance among patients, families, and healthcare providers, which undermines adherence efforts. Patients often face barriers such as social stigma, economic hardship, and limited healthcare access, while families may lack adequate understanding of the disease and its treatment, leading to non-supportive behaviors [9]. Healthcare workers, on the other hand, may struggle with communication barriers and high workloads, limiting their ability to provide the personalized attention needed to foster adherence [10]. So far, the model of health worker-patient relations in TB treatment is limited to the concept of compliance and adherence only. Both models tend to be one-way in which patients must carry out health worker's orders throughout their treatment without establishing mutual trust and understanding between health workers and patients. The concept of concordance is a new pattern of the health worker-patient relationship that combines aspects of the partnership, sharing decision making and trust. The concept of concordance in the health worker-patient relationship is an evolving model that emphasizes partnership, shared decision-making, and mutual trust. This model aims to create a more collaborative and effective interaction between health workers and patients [11]. Concordance behavior significantly enhances treatment compliance in TB patients. A study conducted in Medan found that patients with good concordance had a 2.6 times higher probability of good compliance compared to those with poor concordance [9]. Communication between patients, their families, and healthcare workers is a key determinant of adherence to TB treatment [12, 13, 14]. Effective communication ensures that patients and families understand the importance of completing the treatment regimen, adhering to medication schedules, and overcoming barriers to concordance, such as stigma or lack of social support [14]. Inadequate communication, on the other hand, has been shown to contribute to poor treatment outcomes, as patients may misunderstand treatment instructions or be unaware of the consequences of discontinuing their medication prematurely [13]. Thus, enhancing communication strategies in TB care is crucial for improving adherence and reducing the public health burden of TB. The primary challenge in achieving high rates of treatment concordance lies in bridging the gap between medical knowledge and patient understanding [11]. Patients often face complex regimens, side effects, and logistical barriers that can lead to low adherence. Previous studies have highlighted that patients frequently experience difficulties comprehending the need for long-term treatment, especially once symptoms subside [15]. Furthermore, family dynamics and social pressures can either support or hinder a patient's adherence, making it essential to engage both the patient and their support system in the treatment process [16]. Healthcare workers are tasked with addressing these barriers, yet limited resources and high patient loads often lead to insufficient time for in-depth communication [17]. To address these challenges, recent research has focused on the development of interventions aimed at improving patient-provider communication. Solutions such as patient education programs, enhanced counseling techniques, and digital tools like mobile health applications have been proposed to improve patient understanding and engagement with their treatment [18]. However, while these strategies have shown promise in controlled settings, their effectiveness in real-world healthcare systems, especially in resource-limited environments, remains unclear. Several studies have explored the role of family involvement in improving TB treatment outcomes. Families can provide critical emotional, logistical, and financial support, and their involvement has been shown to correlate with better adherence rates [19]. This underscores the importance of involving family members in the treatment process, as their support can alleviate psychological stress and improve the overall treatment experience [20]. Additionally, healthcare workers have been encouraged to communicate not only with patients but also with family members to ensure they understand the patient's treatment regimen and how they can assist. However, some research also suggests that family pressure can lead to stress and negatively affect patient adherence when not managed properly [16, 17]. Thus, striking a balance between family support and patient autonomy is crucial. Recent literature has focused on improving communication strategies in healthcare settings, particularly in TB treatment programs [21]. Interventions such as community-based education, visual aids, and mobile applications have been tested to address communication gaps [18]. While these strategies have improved awareness, there remains a critical gap in understanding the specific dynamics between patients, families, and healthcare workers in supporting concordance. Most studies either focus solely on the patient or the provider's role, neglecting the interactional

nature of communication within the broader support network. This lack of comprehensive understanding has led to incomplete interventions that fail to address all facets of the communication process. The objective of this study is to investigate the multi-layered communication processes between patients, their families, and healthcare workers in supporting TB treatment concordance. This study is novel in its approach, integrating the perspectives of all three groups to provide a more holistic view of communication in TB treatment. Furthermore, this research aims to identify specific communication barriers and facilitators that impact concordance behavior, addressing gaps in previous studies that have focused on isolated factors. The findings from this study could inform the development of more targeted interventions that enhance communication, support family involvement, and ultimately improve patient outcomes in TB treatment.

2. MATERIALS AND METHODS

2.1. Research Design

This study employed a qualitative approach with a phenomenological study design. The phenomenological approach was chosen to capture the subjective experience and meaning given by the participant to the interactions and communication that occurred during the treatment process. The 32-item Consolidated Criteria for Reporting Qualitative Studies (COREQ) checklist was followed for reporting [22].

2.2. Setting

The study was conducted at 3 primary health cares (PHCs) with low cure success rates in Padang City that treated TB patients from September 2023 to June 2024. These PHCs provide TB services, including medical consultations, laboratory tests, and drug distribution. Participants were patients who were undergoing treatment, families involved in patient care, and health workers who were responsible for accompanying patients in treatment.

2.3. Participants

(1) Participants in this study consisted of approximately 10 individuals across three groups: TB patients: Adult patients who have been on treatment for at least one month are selected purposively to ensure they have sufficient experience in communicating with family and healthcare workers regarding TB treatment.

(2) Patient Family: Family members who are directly involved in supporting the patient's treatment, such as a spouse, parent, or adult. They were selected based on their direct involvement in the care and treatment of patients.

(3) Health Workers: Doctors and nurses who are directly responsible for providing treatment and accompanying TB patients.

2.3.1. Inclusion Criteria

(1) Adult TB patients (17-65 years old) who are undergoing treatment for at least 1 month.

(2) Family members who live with the patient or are involved in the treatment process.

(3) Health workers who have worked with TB patients for at least 6 months.

2.3.2. Exclusion Criteria

(1) Patients with comorbidities that interfere with communication (*e.g.* severe mental or cognitive impairment).

(2) Health workers who do not work directly with TB patients.

2.4. Recruitment

Participant recruitment was carried out through a direct approach by researchers at the health facility where the study was conducted. Healthcare workers helped identify patients and families who met the inclusion criteria. The researcher then explained the purpose of the study and obtained written consent after providing complete information to potential participants. No one refused to participate in the study. The sample selection in this study was purposive, with the objective of ensuring the representation of the three main groups that play a role in TB treatment: patients, families, and health workers. Variations in participant characteristics, including age, gender, and socioeconomic background, were considered to obtain a comprehensive perspective. The data obtained has reached saturation, characterized by the absence of new themes emerging after the last interview and the consistency of findings obtained from various data sources, including patients, families, and health workers. Additionally, a data triangulation process was conducted to ensure the validity and credibility of the research findings.

2.5. Data Collection

Data were collected through semi-structured interviews with three groups of participants: TB patients, their families, and health workers. Interviews were conducted face-to-face in a private room agreed upon by the participants in PHC. No one else was present besides the participants and researchers. Each interview lasted 30 to 60 minutes and was recorded using a digital voice recorder. We used field notes for capturing contextual details, non-verbal cues, and researchers' reflections. Interview transcripts were saved for further analysis.

Interviews were conducted by the first author (RP), a PhD candidate of the Faculty of Medicine, Andalas University. He is a pulmonologist with a background in qualitative research and training in in-depth interview techniques.To maintain objectivity and reduce potential bias, researchers took a neutral approach during the recruitment and interview process. The researcher introduced himself as a doctoral student and explained that the study was part of an academic study, regardless of the health service institution where the research was conducted. Before starting the interview, the researcher provided time to talk to the participants, explain the objectives of the study, and clarify that there was no direct relationship between the study and the medical care that the participants were undergoing. This to build trust and create a comfortable atmosphere, allowing participants to share their experiences openly without fear or pressure.

During the interviews, researchers maintained open and empathetic communication but avoided emotional involvement or providing medical advice that could affect participants' responses. The researcher also underlined that all information provided will be kept confidential and will not affect the health services received by participants. When no new codes could be created, the data was said to be saturated. We carried out two additional interviews to ensure data saturation.

2.6. Data Analysis

The data were analyzed using a thematic analysis approach, following the procedure from Braun and Clarke (2006) [23]. Interview transcripts were verbatim transcribed and analyzed using the qualitative analysis software NVivo. The analysis process included the following steps:

2.6.1. Familiarization with Data

Re-reading the transcript to understand the entire content.

2.6.2. Initial Encoding

Introduction of the initial themes that emerged from the data by marking important parts of the transcript. In this step, 28 codes and 13 sub-codes were retrieved.

2.6.3. Identify Key Themes

The initial codes are organized into key themes that are relevant to the research objectives.

2.6.4. Theme Review and Naming

Themes are reviewed and named according to the content and context depicted. Finally, four themes were found in this study.

2.6.5. Narrative Drafting

Key themes were developed into narratives that describe the relationship between communication, treatment concordance, and the roles of patients, families, and health workers.

2.7. Data Validity

To increase the credibility of the results, several techniques are performed, including:

2.7.1. Triangulation of Sources

Data were obtained from various groups (patients, families, health workers) to obtain diverse perspectives.

2.7.2. Member Checking

Some participants were asked to provide feedback on the preliminary findings to ensure that the researcher's interpretation was accurate and in accordance with their understanding.

2.7.3. Audit Trail

Detailed records of the decision-making process during data analysis are kept, increasing transparency.

3. RESULTS

This study involved 10 informants consisting of three main groups: TB patients, patients' family members, and health workers. The demographic characteristics of the informants are demonstrated in the Table **1**.

From interviews conducted with two TB patients, two family members, and six healthcare workers, four main themes emerged related to their experiences and understanding of communication in support of TB treatment concordance: (1) understanding of concordance, (2) the role of the family in treatment communication, (3) communication barriers, and (4) effective communication strategies to support the concordance.

Table 1. The demographic characteristics of informants.

Informant Code	Group	Gender	Age	Education	Social Economic Status
P1	TB patients	Male	45	Senior High School	Lower
P2	TB patients	Female	32	Senior High School	Middle
F1	Patient's Family	Male	28	Diploma	Middle
F2	Patient's Family	Female	55	Junior High School	Lower
H1	Health worker	Female	35	Bachelor of Nursing	Middle
H2	Health worker	Female	30	Bachelor of Nursing	Middle
H3	Health worker	Male	40	Doctor	Middle
H4	Health worker	Female	27	Diploma of nursing	Lower
H5	Health worker	Male	50	Pulmonologist	Upper
N6	Health worker	Female	34	Bachelor of Nursing	Middle

3.1. Understanding of Concordance

Most of TB patients and family members do not understand concordance as a form of partnership that is equal to that of patients. Only a few healthcare workers know it, but they do not have a comprehensive understanding.

Some TB patients and family members said that:

"Never, sir. So, I do not know yet." (P1)

"It seems that this concordance has never been heard, so I do not know what this is." (P2)

"I've never heard of concordance, so I do not know what this is." (F1)

"The doctor said I had to take medicine until I recovered, but I did not really understand why it had to take so long. I feel like I've improved after a few weeks." (F2)

Families also revealed that sometimes, the information

presented by health workers is not clear enough. One of the families said:

"*We heard about TB and how the drug should be spent, but it wasn't told in an easy-to-understand way. There are many medical terms that we find difficult to understand." (F2)*

Healthcare workers acknowledge that there is a limited time when providing explanations, particularly when dealing with many patients. Some healthcare professionals feel that this communication limitation reduces their effectiveness in supporting patient medication compliance. One of the healthcare professionals said:

"*Well, because of the limited time, we often must rush through important information. Ideally, we would like to sit down with each patient, understand their concerns, and explain everything clearly, but that's not always possible. This can make it difficult to ensure that patients fully understand their medication regimen." (H3)*

3.2. The Role of the Family in Medical Communication

The family plays an important role in supporting patient medication compliance. Many families actively communicate with patients to remind them of their medication schedules and support patients emotionally. One of the patient's family said:

"*I always remind my brother to take medicine according to the time given by the doctor. Sometimes I have to remind him, because he likes to forget." (F1)*

However, some patients feel pressure from family members regarding treatment, which sometimes worsens their experience. Another patient's family said:

"*My family is always worried, but the way they force me to take medication actually makes me stressed. I know they care, but sometimes I need space." (P2)*

Healthcare workers also acknowledged the important role of the family in supporting patient communication and compliance, but emphasized that family involvement must be managed carefully to avoid placing excessive pressure on patients. One of the healthcare workers said:

"*Yes, definitely. While family support is crucial, it needs to be balanced carefully. Sometimes, family members can unintentionally put too much pressure on the patient, which can lead to stress or even resistance. Patients need support, not control." (H2)*

3.3. Communication Barriers

Some of the communication barriers identified in this study include differences in understanding between patients and healthcare workers, lack of time for education, and stigma associated with TB. Patients from low socioeconomic backgrounds reported difficulty understanding medical terms conveyed by healthcare workers, leading to confusion about treatment.

One patient revealed:

"*Sometimes I don't really understand what the doctor says. Too fast, too much information that I don't understand." (P1)*

TB-related stigma also affects communication between patients and families. Some patients choose not to open up about their illness to other family members for fear of being ostracized. One of the patients said:

"*I didn't tell other brothers. They may not want to get close to me if they know I have TB." (P2)*

Health workers are aware of this stigma problem, and some of them are trying to overcome it by providing education to families and communities. However, stigma remains a significant barrier to open communication. One of the health workers said:

"*One of the things we try to do is provide education, both to patients and their families, as well as the wider community. We explain the nature of the condition, how it can be managed, and the importance of seeking help early. Education helps reduce misconceptions and fosters a more supportive environment." (H4)*

3.4. Effective Communication Strategies to Support Concordance

In the face of various communication challenges, patients, families, and health workers have identified several strategies that are felt to be effective in improving concordance: —ongoing education and strengthening understanding through regular visits to be helpful.

One patient stated:

"*Every time I come for control, I always remember why it's important to take medication. The doctor always reminds me, and it helps me a lot." (F1)*

Health workers also mentioned the importance of involving families in the patient education process so that they can help monitor medication compliance at home. The use of media such as brochures, educational videos, and digital intervention in the clinic is considered effective by some patients because it provides easy-to-understand explanations.

One of the health workers explained:

"*We started using short videos to explain about TB and how to treat it. This helps because the patient can see and hear the information many times, and the family also watches." (H5)*

The findings of this study show that communication between patients, families, and health workers plays a key role in supporting the concordance of TB treatment. However, there are several significant obstacles, such as differences in understanding, stigma, and time limitations owned by health workers. Participants also highlighted the importance of family involvement and ongoing education as key strategies to improve medication adherence.

4. DISCUSSION

This study explores the understanding and experiences of patients, families, and health workers related to communication in supporting the concordance of Tuberculosis (TB) treatment. Key findings reveal

variations in the quality of medical communication, the significant role of families in supporting treatment adherence, complex communication barriers, and several strategies considered effective to improve concordance. These findings add to a deeper understanding of the factors that influence the concordance of TB treatment, which could have implications for the development of communication-based interventions to improve patient compliance.

4.1. Understanding of Concordance

Findings from this study revealed a heterogeneous quality of medical communication between healthcare providers and Tuberculosis (TB) patients. A subset of patients expressed a limited comprehension of the extended duration and significance of TB treatment. These results align with existing literature demonstrating the frequent insufficiency of patient understanding of TB treatment, particularly in the context of intricate treatment regimens and the utilization of unfamiliar medical terminology [24, 25, 26]. A significant barrier to ensuring patient comprehension of the importance of treatment adherence was identified as the limited time available for healthcare providers to deliver comprehensive education [27]. Consequently, a more robust approach to patient education is warranted, encompassing both verbal instruction and accessible media formats, such as brochures, videos, or digital resources, to facilitate ongoing patient understanding.

4.2. The Role of the Family in Supporting Compliance

The family plays an important role in supporting the patient's medication concordance, especially in reminding the patient to take medication and providing emotional support. The role of the family in this context is in line with the literature that emphasizes the importance of social support as a determining factor for the success of TB treatment. However, the study also found that family involvement can create stress in patients, which sometimes contributes to increased stress [28]. This pressure, if not managed properly, can trigger resistance from patients to treatment, especially if they feel their personal control over their health is being taken away. Therefore, health workers need to educate not only patients but also families, on how to support patients in a non-invasive way and respect patient autonomy.

The importance of family support extends beyond mere adherence to medication. It also encompasses the overall well-being of patients. Emotional support from family members has been shown to enhance patients' motivation and resilience, which are critical for navigating the challenges of TB treatment [29, 30]. Furthermore, studies have indicated that patients with larger family networks tend to report higher levels of social support, which correlates with better treatment outcomes [31, 32]. This aligns with findings from Zhang *et al*., which emphasize that psychological support from family members can help patients overcome the stigma and fear associated with TB, reinforcing their belief in the treatability of the disease [33]. This underscores the necessity of integrating family dynamics into TB treatment strategies, as a supportive home environment can significantly influence patient behaviors and treatment success.

4.3. Communication Barriers and Stigma

Communication barriers found in this study, including differences in understanding, time limitations of health workers, and social stigma, have been extensively documented in the TB-related literature. One of the barriers that is often overlooked is stigma, which was found in the study to affect both patients' open communication with their families as well as patients' willingness to engage in long-term treatment. TB-related stigma often causes patients to hide their disease or avoid follow-up treatment, ultimately negatively impacting treatment outcomes [34]. The stigma surrounding TB often leads to social isolation, discrimination, and a reluctance to seek medical care, which can exacerbate the spread of the disease and hinder effective treatment [35, 36]. Interventions to reduce stigma, such as public awareness campaigns, should be considered as an integral part of strategies to improve concordance. Implementing health education programs can enhance understanding of TB while training healthcare workers to convey anti-stigma messages effectively is crucial [37]. Additionally, fostering open discussions in healthcare settings can help mitigate power dynamics and encourage collaboration. Support groups for patients and families can also provide psychosocial support, reducing stigma and improving communication pathways within the healthcare system [38, 39].

4.4. Communication Strategies to Improve Concordance

The study also identified several effective communication strategies, such as continuing education and the use of visual media to help patients and families understand the importance of treatment. These strategies have been shown to be effective in other studies, where continuing education tailored to the patient's needs and direct family involvement in treatment have been shown to improve adherence. The use of educational videos in clinics can also be a very useful tool to bridge the gap in understanding between health workers and patients, especially for those who have low health literacy. Research indicates that patient adherence to TB treatment is significantly influenced by various psychosocial factors, including the quality of communication between healthcare providers and patients. For instance, a study by Wahyuni *et al*. emphasizes the importance of establishing effective communication based on partnership, openness, empathy, and support, which can enhance concordance among TB patients [40]. This aligns with findings from Motappa *et al*., who identified that patients' perceptions of treatment length and drug efficacy significantly affect their adherence to anti-tubercular regimens [41].

The findings of this study have important implications

for improving communication strategies in the health system. First, a more personal and holistic approach is needed in communication between health workers, patients, and families. Given the limited time of healthcare workers, service providers should consider using communication aids such as brochures and videos that are simple and easy to understand to support patient education. Second, training for health workers on how to communicate effectively and sensitively with patients and families about TB and the importance of medication adherence should be strengthened. Third, campaigns to address TB stigma in the community need to be expanded to create a more supportive environment for TB patients.

This research has several limitations. First, the study was conducted in only one location, so the findings may not be fully generalizable to other regions or populations with different socio-economic characteristics. Second, this study used interviews that may be influenced by memory bias or participants' desire to provide answers that they consider desirable. Future research could expand its scope by involving more research sites as well as more diverse data collection methods, such as participant observation.

CONCLUSION

This study highlights the importance of effective communication between patients, families, and health workers in supporting the concordance of TB treatment. Family support and ongoing education strategies appear to be key factors in improving treatment adherence, while stigma and communication barriers remain significant challenges that need to be addressed. Therefore, intervention strategies that combine effective education, family involvement, and stigma reduction efforts must be integrated into TB treatment programs to achieve optimal treatment outcomes. Additionally, future research should utilize mixed-methods studies to gain a comprehensive understanding of the complex factors influencing TB treatment adherence.

AUTHORS' CONTRIBUTIONS

R.P., A., F.Y., A.B.: Study conception and design; R.P.: Data collection, analysis, and interpretation of results; R.P.: Draft manuscript. All authors reviewed the results and approved the final version of the manuscript.

LIST OF ABBREVIATIONS

TB	=	Tuberculosis
COREQ	=	The Consolidated Criteria for Reporting Qualitative Studies
PHCs	=	Primary Health Cares
DOTS	=	Directly Observed Treatment Short-course

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

This research was approved by the Research Ethics Committee of the Medicine Faculty of Andalas University, Indonesia (permit number 53/UN.16.2/KEP-FK.

HUMAN AND ANIMAL RIGHTS

All human research procedures followed were in accordance with the ethical standards of the committee responsible for human experimentation (institutional and national), and with the Helsinki Declaration of 1975, as revised in 2013.

CONSENT FOR PUBLICATION

Informed consent was obtained from all participants.

STANDARDS OF REPORTING

COREQ guidelines were followed.

AVAILABILITY OF DATA AND MATERIALS

The datasets used and analyzed during this study will be available from the corresponding authors [R.P.] upon reasonable request.

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None.

CONFLICT OF INTEREST

The authors declare no conflict of interest, financial or otherwise.

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