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Determining Factors of Quality of Life in Tuberculosis Patients: A Qualitative Case Study in Yogyakarta

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ABSTRACT

Introduction: The second-largest tuberculosis hotspot in the world is located in Indonesia, which creates a significant threat to global health. The disease causes severe harm to patients' health status because it damages their physical health, mental state, and social relationships. The development of tuberculosis control strategies requires knowledge about elements that impact the maintenance of the health quality of tuberculosis patients. This study aims to explore the determinants of quality of life in tuberculosis patients qualitatively using thematic analysis techniques with Atlas.ti software in Yogyakarta.

Methods: This study used a qualitative design and a case study technique. Patients and TBC program holders from Yogyakarta City's primary healthcare institutions participated in the event. Nine participants were selected using a purposive sampling strategy from individuals who had recently completed treatment and were educated about TBC. In-depth interviews were conducted utilizing an interview guide to gather data. Atlas.ti was used for thematic analysis of the data. This project has been granted ethical approval under license number 369/EA/KEPK-FKM/2024.

Results: Most TBC patients have a low quality of life due to physical and psychological disorders, as well as the influence of social stigma. At the same time, the environmental health dimension is in good condition. Determining factors include intrapersonal aspects (knowledge, self-efficacy, motivation), interpersonal aspects (family knowledge and support), and environmental aspects (stigma). Therefore, psychosocial education for patients and their families is crucial for improving quality of life.

Conclusion: Tuberculosis patients in Yogyakarta City continue to have a bad quality of life in terms of physical, psychological, and social dimensions. As a result, education is required to promote awareness of TBC among patients and their families, encouraging social support to aid in the healing process, and reducing societal stigma.

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INTRODUCTION

Tuberculosis (TBC) remains a global problem and is among the top ten causes of death from infectious diseases. According to the World Health Organization, the number of TBC cases is expected to rise by 10.8 million in 2023, surpassing the number of cases discovered in 2020-2022. This rise indicates population growth and the stress placed on the country. India, Indonesia, China, the Philippines, and Pakistan have the world's most significant TBC burdens (1). In Indonesia, the number of TBC cases increased by 856,420 in 2024, compared to 821,200 in 2023 (2). Based on data from the Yogyakarta City Health Office, 741 cases were reported in 2024, with a treatment success rate of 83.10%, down from the previous year (3). The effectiveness of TBC therapy is closely linked to enhancing the patient's quality of life, particularly through medication adherence and optimal therapeutic outcomes (4–6).

Treatment success is closely tied to an improved quality of life. After comprehensive therapy, patients' quality of life scores increases dramatically, with mental health being the most affected domain. Patients who successfully finish therapy report improved physical condition and can resume regular activities (4,7,8). The majority of tuberculosis patients indicate that their quality of life is harmed by the disease's physical symptoms and medication side effects, as well as the psychological impact of the need for long-term care. The state of TBC patients with clinical symptoms such as coughing, chest discomfort, fatigue, and diminished stamina affect their daily and physical activities, resulting in a loss of the physical health component of quality of life. Psychological health issues, such as stress, anxiety, and depression, are influenced by the duration of therapy and the presence of societal stigma. Furthermore, patients' experiences with prejudice and isolation affect the social health dimension (9). Each person's quality of life varies according to how they deal with their own challenges. If individuals reply favorably, their quality of life improves; if they respond adversely, their quality of life deteriorates (10).

Many variables impact quality of life in TBC patients, including age, anxiety levels, and social support from family, patient depression (11), stress (12), and self-efficacy (13). A thorough understanding of these characteristics is crucial for developing effective therapies that prioritize not only medical aspects but also the patient's overall well-being. Quality of life in tuberculosis patients was measured using the WHO's WHOQOL-BREF, as it is applicable to all types of the disease (14).This study aims to explore the determinants of quality of life in tuberculosis patients qualitatively using thematic analysis techniques in Yogyakarta.

METHOD

Research Type

This qualitative research was used a case study approach to in-depth explore the phenomenon of quality of life in tuberculosis patients and the management of tuberculosis control in community health services. The research location is limited to Yogyakarta City, chosen because of its high TB caseload and active TBC control program. Epistemologically, this research is grounded in a constructivist paradigm that views patient experiences and service strategies as the result of the construction of social meaning.

Population and Sample/Informants

The units of analysis in this study were tuberculosis patients and TBC program participants at the community health center. Subjects were selected purposively, considering the relevance of the information and participant involvement within the research context. The criteria included patients who had completed treatment and individuals actively involved in TBC prevention and control activities in the community. Nine informants were interviewed: six patients and three TBC program participants at the Puskesmas. The number of participants was determined based on the principle of data saturation, which occurs when no new information emerges from additional interviews. Participant diversity characteristics, such as gender, age, and social background, contribute to enriching the variety of perspectives and increasing the rigor of the findings.

Research Location

This study was conducted at a community health center (Puskesmas) in Yogyakarta City, which falls within the operational area of the Yogyakarta City Health Office.

Instrumentation or Tools

This research uses an interview guide as its tool.

Data Collection Procedures

In-depth interviews were conducted to explore the research subjects' experiences and perspectives on quality of life and management in tuberculosis control. The interview guide was developed based on a literature review and discussions with tuberculosis experts and practitioners. Interviews were conducted face-to-face in a community health center consultation room, ensuring privacy and comfort. Interviews were conducted for 30 and 60 minutes and was recorded with the participants' permission. Interview results were translated into standard Indonesian for ease of understanding without altering the substance of the participants' statements.

Data Analysis

Data were analyzed thematically using Atlas.ti software to identify themes related to quality of life and its influencing factors. The analysis used the following framework: transcribing interviews, coding using an open coding system, grouping codes into categories, reviewing and refining themes, and writing a comprehensive thematic narrative. Efforts were made to ensure the trustworthiness of the results in this study through member validation with several participants to verify the researcher's interpretations of their experiences.

Ethical Approval

The Ethics Committee of Ahmad Dahlan University accepted this study (Approval Number: 369/EA/KEPK-FKM/2024). All respondents in this study were 18 years or older; therefore, consent was granted directly by the respondents rather than through their parents or guardians. The confidentiality of all participants was preserved throughout the study procedure.

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RESULTS

Research Respondent Characteristics

Interviews were conducted to investigate the factors that influence the recovery and quality of life of TBC patients. Individuals who knew TBC control, patients who had just completed treatment, were 18 years or older, lived in Yogyakarta City, and were accompanied by their families. Table 1 shows the overall characteristics of the informants.

Table 1. Characteristics of Interview Informants

Informant	Data Source	Gender	Occupation	Income
Informant 1	TBC Program Manager at the Community Health Center	Female	Civil Servants	≥ Regional Minimum Wage
Informant 2	TBC Program Manager at the Community Health Center	Female	Civil Servants	≥ Regional Minimum Wage
Informant 3	TBC Program Manager at the Community Health Center	Female	Civil Servants	≥ Regional Minimum Wage
Informant 4	TBC Patient 1	Female	Laborers	< Regional Minimum Wage
Informant 5	TBC Patient 2	Male	Self-employed	< Regional Minimum Wage
Informant 6	TBC Patient 3	Male	Freelancers	< Regional Minimum Wage
Informant 7	TBC Patient 4	Male	Freelancers	< Regional Minimum Wage
Informant 8	TBC Patient 5	Male	Self-employed	< Regional Minimum Wage
Informant 9	TBC Patient 6	Male	Private Employees	≥ Regional Minimum Wage

Table 1 shows that the nine informants comprised three tuberculosis program managers at community health centers and six TBC patients with diverse socioeconomic backgrounds. Many of the program managers were female civil servants with incomes above the regional minimum wage, while most of the patients worked in the informal sector with relatively lower incomes. This diversity of characteristics demonstrates the differences in social context between service providers and beneficiaries and provides a variety of perspectives that enrich the understanding of patients' quality of life and the implementation of tuberculosis control programs at the community level.

Quality of Life among Tuberculosis Patients in Yogyakarta City

Figure 1 presents the findings of the topic analysis, which identified four major themes regarding the quality of life of TBC patients: physical health, environmental health, psychological health, and social health. Findings from six informants on environmental health indicated satisfaction, as patients do not feel stigmatized by their surroundings. They restrict their interaction with others, resulting in little public awareness. Access to health-care facilities is satisfying and straightforward because health professionals or TBC program managers operate professionally and give system assistance. Patients believe they are obtaining therapy via fun and amusement.

Based on the interview results "TB patients have experienced many changes since being diagnosed, such as requiring assistance from others in their daily activities, difficulty sleeping and being able to sleep after taking medication, experiencing stress, anxiety and feeling lonely." Patients' physical, psychological, and social health were found to be disturbed both at the start of therapy and from the beginning to the conclusion. In terms of physical health, patients were found to be disturbed, requiring assistance from others to carry out their regular physical tasks, and they had poor sleep quality, with some informants stating that they could sleep owing to the influence of using anti-tuberculosis medicines. In terms of psychological health, some informants did not feel disturbed because they received support from their families and lived a healthy lifestyle. Still, several other patients experienced changes after being diagnosed, including feelings of anxiety, stress, depression, and loneliness because of reduced interaction with others, particularly family.

Another result of social health problems was a reduction in social interactions with both family and community. Interviews with various informants indicated that there is no stigma in society since people with TBC minimize their social activities and isolate themselves from others. Another study found that a TBC diagnosis disturbs sexual interactions owing to the worry of infecting a partner, resulting in a decrease in sexual contact with their partner.

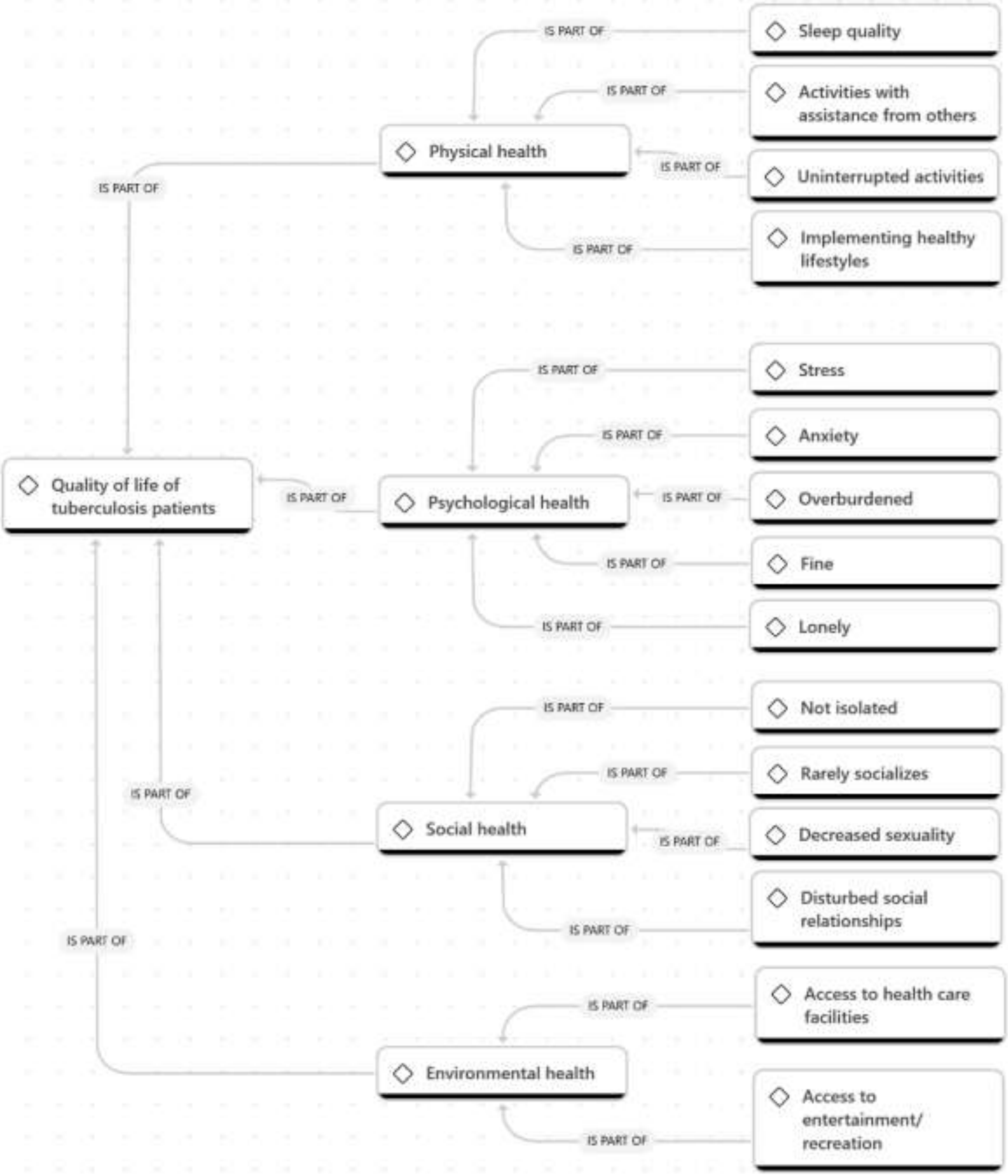

Figure 1. Overview of the quality of life of tuberculosis patients in Yogyakarta City

Factors Influencing Quality of Life

According to Figure 2, the thematic analysis identified three major themes impacting recovery and quality of life: intrapersonal variables, interpersonal factors, and environmental factors. Intrapersonal elements are an individual's internal attributes that contribute to healing and a high quality of life. According to this study, respondents had an inadequate understanding of TBC, including its definition, causes, transmission, and prevention. However, only a few informants were aware of this knowledge. Informants were aware that TBC therapy lasts six months and includes regular daily medication (Figure 2). Patients' lack of understanding about TBC might impede their rehabilitation and quality of life. An intriguing result is that some informants regard TBC as a contagious disease that is difficult to cure, which might undermine their confidence in their capacity to undertake treatment and engage in preventative practices. As a result of this inadequate understanding, some individuals isolate themselves from their families and communities, affecting social and environmental health, which are measures of quality of life. Another result showed that some patients were more self-motivated to heal than their family members. This was because they secluded themselves by not informing other members of their immediate family and removing themselves from their relatives. Family support contributes to TBC patients' recovery and quality of life (Figure 2).

Thematic analysis revealed five forms of family support for tuberculosis patients: emotional, informational, instrumental, appreciative, and spiritual. These findings align with previous research, but the spiritual dimension emerged as a distinctive aspect reflecting local cultural values. Spiritual support was realized through strengthening faith, praying together, and reminders to pray, which provided comfort and motivation for patients. All informants received emotional support, and most received instrumental support, although informational support was limited due to a lack of family knowledge. These results confirm that the spiritual aspect of family support is contextual and important to consider in family-based interventions.

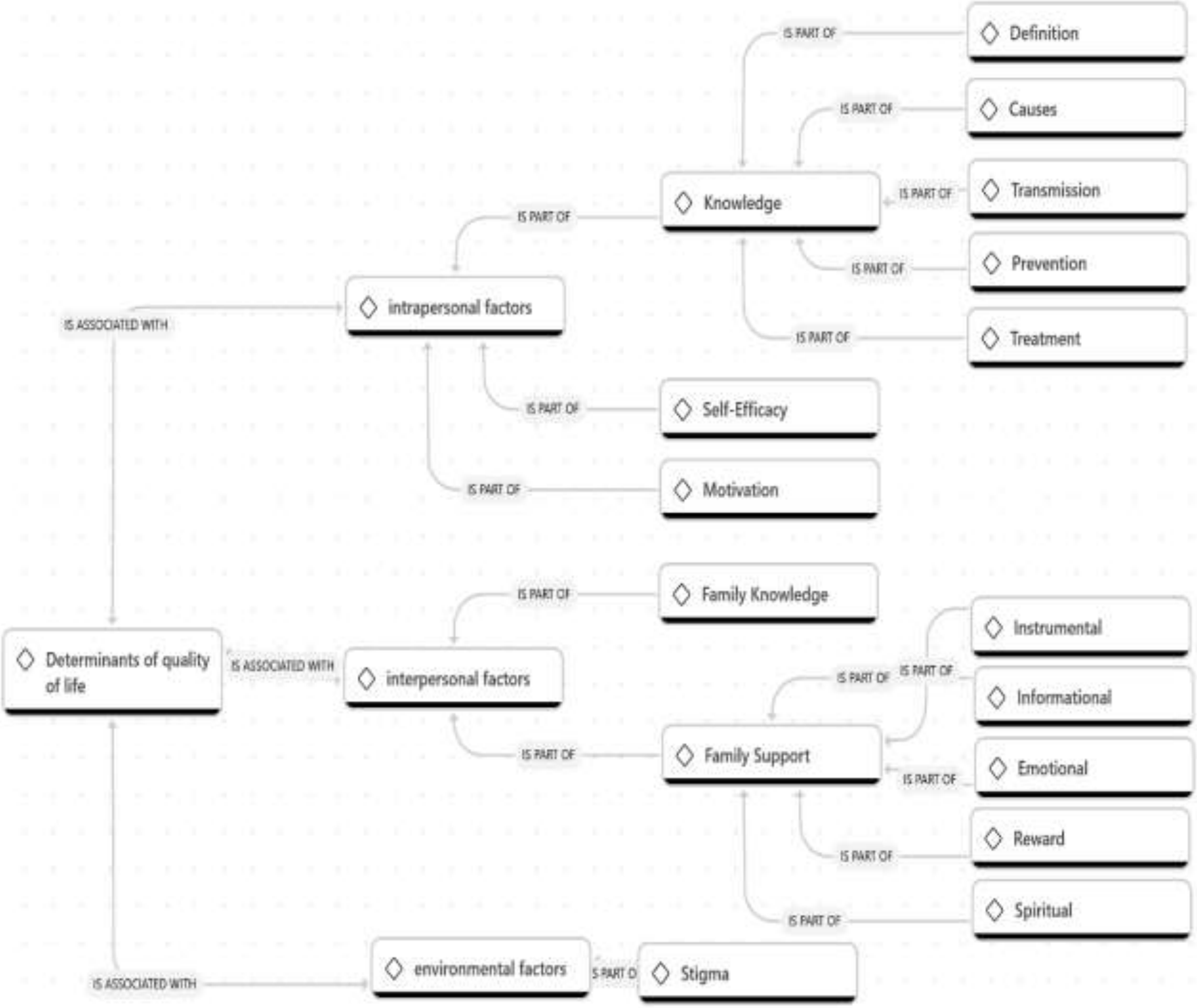

Figure 2. Results of thematic analysis of determinants of recovery and quality of life of tuberculosis patients in Yogyakarta City

Overview of Tuberculosis Control Programs

Interviews were used to investigate TBC control methods that improve patient recovery and quality of life. The interviews revealed that currently, “there are no programs specifically designed to improve the quality of life for TB patients”. Based on the findings, efforts to assist TBC eradication in the Special Region of Yogyakarta, as part of the tuberculosis program's acceleration by 2025, include case identification, treatment, and prevention. Therapy strategies to aid in recovery include increasing family and community involvement as a support structure and offering information through counseling. According to the findings of this study, programs continue to focus on delivering information, communicating, and monitoring the use of anti-tuberculosis drugs. This study's distinctive result was that numerous community health centers introduced new TBC control strategies, such as extra food and family-based treatments, through focus group discussions. However, the innovation initiative, implemented in various community health centers, faces challenges such as insufficient finances. This is owing to the rigid use of BOK funds, which are part of the regional budget, and the scarcity of cadres aiding TBC patients (Figure 3). Other issues raised by patients include boredom and absence during therapy. Family problems include resistance and family dynamics while dealing with tuberculosis-infected family members, as well as a lack of family comprehension and awareness (Figure 3).

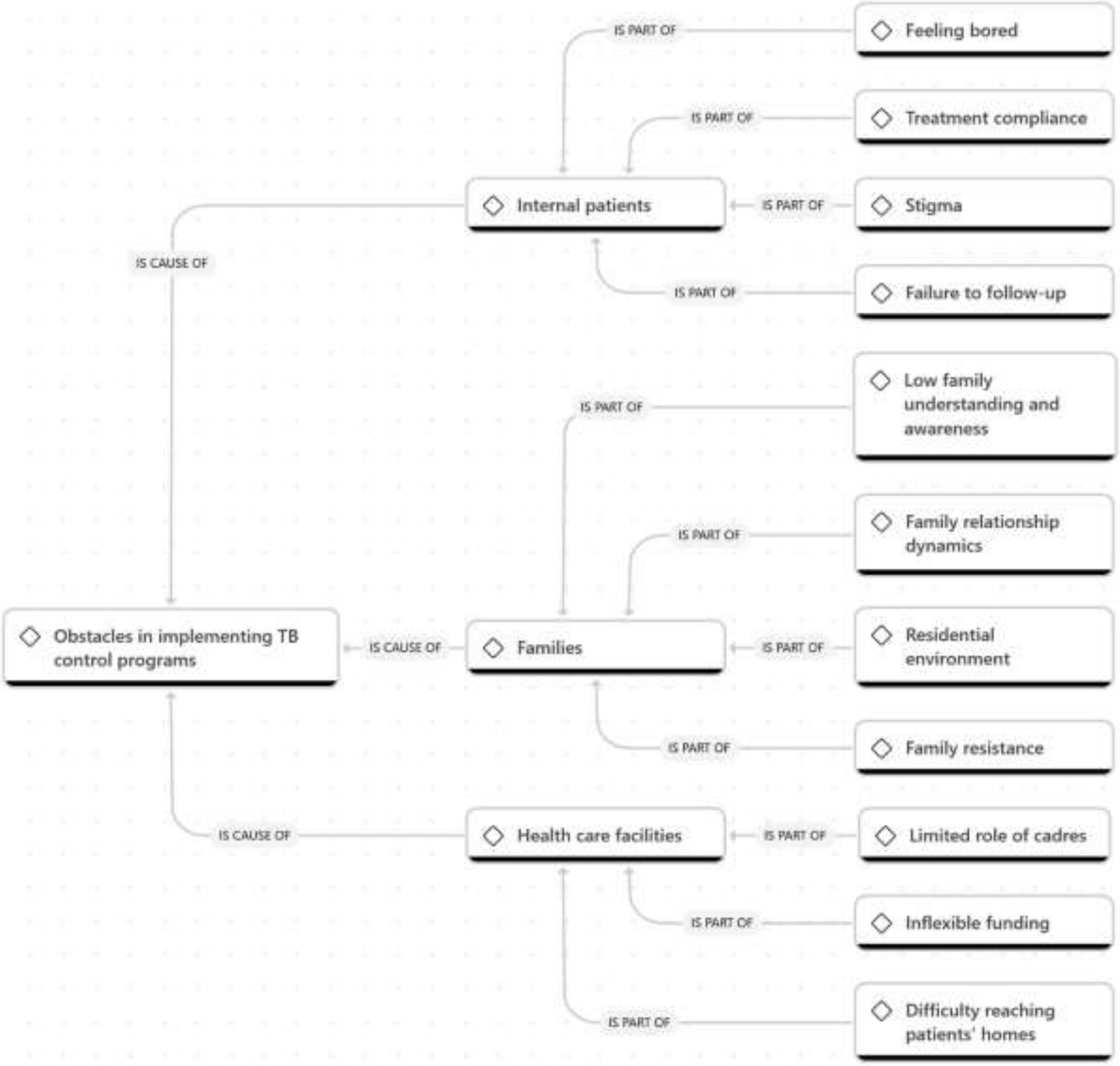

Figure 3. Obstacles to implementing the tuberculosis control program

DISCUSSION

Anti-tuberculosis therapy has been demonstrated to enhance patients' physical quality of life, particularly during the treatment phase until therapy completion (15). Nonetheless, the administration of anti-tuberculosis medications may induce side effects like nausea, discomfort, and sleep problems, which could adversely affect the patient's quality of life (16). In this study, most informants experienced decreased sleep quality, a finding consistent with several previous studies showing that sleep disturbances are common in tuberculosis patients and correlate with decreased sleep quality and treatment efficacy (17,18). Another finding showed that over 35% of patients who have undergone treatment continue to experience sleep disturbances (19).

Research suggests that stress, anxiety, and depression are typically most pronounced at the onset of treatment, followed by a notable gradual reduction during and after treatment (20). Diagnosing tuberculosis frequently induces psychological illnesses, manifesting as depression and anxiety, exemplified by findings in Pakistan, where 46% reported depression and 47% reported anxiety (21). This data aligns with existing literature indicating that mental health issues frequently co-occur in tuberculosis patients, with reported prevalence rates of depression and anxiety ranging from 30% to 45% across diverse tuberculosis patient populations (22). The psychological conditions of tuberculosis patients improve within two months and with completion of treatment (23). Recent studies reveal that roughly 15–23% of tuberculosis patients continue to endure psychological anguish, face a risk of depression, and experience anxiety disorders, both throughout treatment and post-therapy (24,25). The continuation of psychological issues in tuberculosis survivors is affected by medical factors, including inflammation, immune response, drug side effects, and residual lung function impairment, as well as social factors such as stigma, unemployment, diminished social roles, and anxiety associated with chronic health conditions (26,27). Preventive measures addressing the long-term consequences that may impede the recovery of tuberculosis patients should be implemented through comprehensive mental health interventions, encompassing counseling, psychosocial support, and the early identification of psychological disorders (28–30).

Individuals with tuberculosis often self-isolate to evade social engagement and hide their ailment, hence fostering the illusion that there is no external social stigma (31). Invisible stigma is fundamentally based on anxiety and adverse experiences from prior social interactions (32). Research in Vietnam indicates that patients engage in self-isolation, a phenomenon shaped by cultural norms and societal expectations. The social milieu frequently acknowledges this self-imposed limitation, resulting in a relatively minimal social stigma associated with tuberculosis patients (33).

Research in Bangladesh corroborates this study, indicating that stigma exacerbates sexual relationship conditions due to apprehension over disease transmission and induces household conflict (34). A survey of patient experiences revealed that they are cognizant of the potential of tuberculosis transmission. Moreover, inadequate physical condition and age-related issues contribute to their hesitance in fulfilling their sexual activity requirements, as this physical frailty stems from tuberculosis (7). Sufficient social support mitigates the adverse effects of stigma and enhances the quality of life and well-being of patients, both in familial and romantic contexts (35).

Adverse environmental circumstances might diminish the quality of life for tuberculosis patients, as they hinder the recovery process and the efficacy of treatment (36). Substandard environmental health in residential zones markedly elevates the probability of tuberculosis transmission and reinfection, attributable to extended proximity among individuals (37). Nonetheless, respondents scored other environmental variables well, especially concerning accessibility to healthcare services and the availability of leisure and recreational amenities. This factor can diminish stress levels and enhance treatment compliance, consequently affecting overall quality of life (38). Patients with service access are more likely to receive prompt treatment, demonstrate improved adherence, and attain optimal health outcomes. The availability of access contributes to diminished disease burden, expedited recovery, and enhanced quality of life (39–41). Recreational opportunities can alleviate stress, reduce feelings of isolation, and improve emotional well-being through social engagement that fosters social support, counters stigma, and fortifies mental resilience in the context of disease (40,42,43).

Thematic analysis identifies intrapersonal, interpersonal, and environmental elements as key determinants of quality of life. Despite possessing sufficient knowledge, certain patients exhibit inconsistency in treatment adherence. This is particularly true for those who perceive an improvement in their clinical state and thus discontinue medication prematurely, which eventually adversely affects long-term quality of life (44). Inadequate health literacy correlates with a heightened probability of treatment non-adherence, which adversely affects clinical outcomes and patients' quality of life (45). Ongoing education and intervention, employing interactive media and a tailored strategy, are essential for sustaining and enhancing patient comprehension. Enhanced understanding enables patients to alleviate worry and rectify misconceptions regarding tuberculosis, hence positively influencing their quality of life (40,44).

Individuals with elevated self-efficacy demonstrate a greater ability to sustain treatment adherence and engage in health-promoting behaviors that enhance treatment outcomes and overall quality of life. In contrast, diminished self-efficacy can obstruct therapy management and impair patient well-being (46). Decreased self-efficacy significantly correlates with a worse quality of life in tuberculosis patients. The inability to overcome the challenges of illness, reduced confidence in administering treatment, and the resulting emotional strain are factors that diminish patient well-being (13,47). Elevated self-efficacy enhances hope, drive, and a constructive outlook on life, hence augmenting overall quality of life. This effect is evidenced by the robust correlation between high self-efficacy and improved treatment adherence and quality of life (47,48).

Patients with tuberculosis who encounter stigma from their social surroundings are susceptible to feelings of isolation and psychological discomfort, regardless of their strong motivation to recover. The economic cost and severity of physical symptoms further deteriorate patients' quality of life (49,50). Familial and environmental support are essential for enhancing quality of life, a factor that individual motivation alone cannot adequately substitute (51,52). Psychological aspects affecting the quality of life of tuberculosis patients include motivation and social support. Familial social support constitutes the primary source of encouragement for patients, fostering enthusiasm and encouraging adherence to tuberculosis treatment and health maintenance (53). Patients with tuberculosis are at an elevated risk of depression, which diminishes their quality of life; yet, a resilient mindset can alleviate psychological stress, consequently enhancing their overall well-being (54). Research indicates that tuberculosis patients exhibiting low self-efficacy experience diminished quality of life, whereas those with elevated self-efficacy tend to enjoy an improved quality of life (13,47,55). Robust motivation enhances and elevates patients' self-efficacy, thereby influencing their quality of life (56).

Research consistently demonstrates that familial support is essential for enhancing treatment adherence, motivation, and the psychological well-being of tuberculosis patients, which are critical variables for attaining optimal health (57,58). Patients with tuberculosis typically receive help through medicine reminders and material aid. This support greatly influences treatment adherence; nevertheless, its effect on quality of life is contingent upon familial circumstances and the dynamics among family members (57). The effectiveness of support depends on how the patient perceives it. When the assistance provided meets their needs, the patient's quality of life typically improves. If the support fails to address the patient's needs or exacerbates their psychological distress, its beneficial effect on quality of life diminishes (59). The intricacy of familial ties, the existence of discord, or the stigma associated with tuberculosis can impede the efficacy of assistance. In certain circumstances, familial relationships may exacerbate stress or feelings of isolation, despite the appearance of support, thereby diminishing their positive impact on quality of life (60).

Patients reported feelings of stigma, low self-esteem, and social withdrawal. The stigma associated with tuberculosis patients is predominantly negative and might impede the healing process, as it may result in social isolation and postponed treatment (61). Individuals with tuberculosis can positively navigate stigma as a psychological coping mechanism, aiding them in confronting social pressure and preserving their mental well-being (62). Formulating effective coping techniques, along with sufficient psychological support, is crucial in alleviating the detrimental impacts of stigma. This approach constitutes the primary basis for developing mental health therapies intended to assist tuberculosis patients in preserving psychological stability throughout treatment and the recovery period (63)

The health care program at the Community Health Center includes weekly anti-tuberculosis medication collection activities to monitor patient adherence and condition. Thematic analysis showed that the existence of this mechanism positively contributes to the patient's recovery process, as it increases the regularity of medication consumption and strengthens the relationship between patients and healthcare providers. Integrated drug collection services may be amalgamated with additional initiatives, such as tele-follow-up monitoring or coordinated home visits, to enhance compliance (64). Nevertheless, the capacity of community health centers to execute innovative initiatives for tuberculosis control and rehabilitation is constrained by an inflexible financial system. The constrained financing flexibility hampers community health centers in designing and implementing new programs, including nutritional therapy assistance, screening of at-risk populations, and other public health initiatives intended to enhance tuberculosis prevention and treatment efficacy (65). Another challenge arises from relatives, whose insufficient awareness and comprehension hinder their ability to provide essential emotional and practical assistance to patients, such as reminding them to adhere to medication schedules or accompanying them to therapy sessions. The restricted familial support may diminish patient motivation, hence heightening the likelihood of therapy discontinuation and failure (66). Empowered families can function as a proficient support system, therefore enhancing the patient's likelihood of recovery (67).

Limitations and Cautions

The study's limitations include a minimal participant pool and a specialized contextual framework, which hinder the generalizability of the findings. Moreover, the potential for bias is heightened due to the reliance on the researcher's subjectivity in data interpretation.

Recommendations for Future Research

Subsequent research should utilize a more extensive sample size and adopt an alternative methodological framework, such as a longitudinal design.

CONCLUSION

Most respondents experienced a diminished quality of life, characterized by physical health issues, impaired sleep quality, and a need for assistance with daily tasks. Regarding psychological well-being, participants reported feelings of loneliness, anxiety, and depression. The determinants of quality of life encompass intrapersonal factors, which arise from the individual and include knowledge, self-efficacy, and motivation; interpersonal factors, which stem from the family and consist of familial knowledge and support; and environmental factors, which pertain to stigma originating from the social milieu. Initiatives to enhance the quality of life encompass psychosocial education for tuberculosis patients and their families. Based on these findings, the government is advised to strengthen tuberculosis control through psychosocial education programs involving families and communities to increase social support for tuberculosis patients. Furthermore, future researchers can conduct further research using longitudinal or mixed methods to gain a deeper understanding of the dynamics of family support and its impact on recovery and quality of life.

AUTHOR’S CONTRIBUTION STATEMENT

All authors contributed to this study. The first author contributed to data collection, data analysis, preparation of results and discussion. The second, third and fourth authors contributed to data analysis, preparation of results and discussion.

CONFLICTS OF INTEREST

The authors declare no conflict of interest.

DECLARATION OF GENERATIVE AI AND AI-ASSISTED TECHNOLOGIES IN THE WRITING PROCESS.

In the preparation of this manuscript, the authors used AI-assisted tools, specifically Grammarly and Quillbot, solely to improve grammar, spelling, and sentence clarity. The authors take full responsibility for the content and integrity of the manuscript.

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