

The Dynamics of the Quality of Life of Tuberculosis Patients in Palembang City: A Phenomenological Study

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Keywords:

Quality of Life; Tuberculosis;
Phenomenology

ABSTRACT

This study aims to explore the dynamics of the quality of life of tuberculosis (TB) patients in Palembang City through a phenomenological study. Tuberculosis is not merely a physical disease that attacks the respiratory system, but also has a significant impact on the psychological aspects and overall well-being of patients. The high incidence of TB in Palembang City, which records the highest cases in South Sumatra Province, underscores the importance of understanding the perceptions and lived experiences of those affected. The method used in this study is descriptive qualitative with a phenomenological approach. The research subjects consisted of two TB patients with a history of disease relapse (initials AS and F), supported by two knowledgeable informants from the family and Patient Support Group. Data were collected through in-depth interviews and documentation techniques. Data analysis was conducted using the Miles and Huberman model and the Spradley model to draw systematic conclusions. The results of the study indicate that both subjects were able to achieve an adequate level of quality of life despite having to face physical challenges due to treatment side effects and psychosocial burdens in the form of stigma and limited social interaction. The dynamics of a patient's quality of life are significantly influenced by several key factors, including microsystem (family) support, access to government health services, and spiritual strength and internal motivation to recover. Adaptability and effective emotional regulation have been shown to be crucial elements in maintaining well-being throughout long-term treatment.

INTRODUCTION

Mycobacterium tuberculosis (M.tb) is the causative agent of tuberculosis (TB), a disease transmitted through the air that attacks the lungs and other organs of the body (extrapulmonary TB). TB remains a global health problem, including in Indonesia, which ranks second in the world in TB incidence. In Palembang City, TB cases recorded in 2023 were notably high, affecting both the physical and psychological health of patients, including psychological well-being and quality of life (QOL). Psychological well-being encompasses the ability to accept oneself, manage one's environment, build positive relationships, and achieve life goals, all of which are strongly linked to a patient's quality of life (Ryff & Keyes, 2016; Syaiful & Sariyah, 2018).

The research urgency of this study stems from several critical factors. First, Palembang City has the highest TB incidence rate in South Sumatra Province, making it a priority area for TB control programs. Second, relapsed TB patients face unique challenges compared to new

patients, including longer treatment duration, potential drug resistance, and a greater psychological burden, making an understanding of their quality of life dynamics essential for designing targeted support interventions (Dookie et al., 2022; Lange et al., 2018). Third, TB is not merely a medical condition but a biopsychosocial phenomenon that affects patients' physical health, mental well-being, social relationships, and economic productivity. Fourth, without a qualitative understanding of patients' lived experiences, health programs may focus narrowly on medical compliance while neglecting psychosocial support needs. Fifth, the Indonesian National TB Program emphasizes patient-centered care, but evidence-based understanding of patient quality of life dynamics remains limited (Cipta et al., 2024; Eklund & Kapoor, 2019; Sudastra et al., 2026). This study addresses this urgency by providing rich phenomenological data that can inform more holistic, patient-centered TB care in Palembang and beyond.

The novelty of this research lies in five aspects. First, this study specifically focuses on relapsed TB patients in Palembang City, a population not previously studied using phenomenological methods. Second, this study applies a comprehensive quality of life framework integrating physical, psychological, social, and environmental dimensions with Bronfenbrenner's Ecological Systems Theory to analyze how multiple levels of influence — individual, family, healthcare, and community — interact to shape patient quality of life. Third, this study compares two patients with different social support structures (AS with strong spousal support, and F with a separated marital status and extended family support), revealing how differences in family structure affect quality of life dynamics. Fourth, this study identifies spirituality and religious coping as dominant internal forces for Indonesian TB patients, reflecting the cultural and religious context of Palembang. Fifth, this study integrates multiple theoretical perspectives — including the Health Belief Model (HBM), Coping Theory (Lazarus & Folkman), and Ecological Systems Theory (Bronfenbrenner) — to provide a comprehensive understanding of TB patient quality of life.

This study employed in-depth interviews with two subjects who were pulmonary TB patients with a history of relapse: subject AS and subject F. Subject AS, a 39-year-old male working as a market laborer and exposed to poultry dust, experienced TB twice, including a Drug-Resistant (DR-TB) type in 2023. Throughout treatment, AS demonstrated a positive mindset and high adherence to OAT (anti-TB drugs), despite facing isolation in the hospital and psychological distress. Family support, social involvement, and an understanding of treatment procedures play an important role in his motivation to recover. The subject maintains social interaction with neighbors and remains compliant with health protocols, demonstrating a balance between social needs and awareness of transmission risk.

Subject F, a 40-year-old male construction worker, comes from a family with a history of TB. Early symptoms in the form of a prolonged cough and weight loss led him to seek examination and he was subsequently diagnosed with TB in 2017. Subject F experienced emotional distress, fear of death, and changes in social relationships due to stigma. Nevertheless, F remains resilient, maintains a reasonable distance from others, and strives to preserve social relationships with friends to support his motivation and mental health.

The case analysis of these two patients shows that the quality of life of TB patients is not only influenced by physical conditions and adherence to treatment, but also by psychological factors, social support, and adaptation strategies in response to stigma. Awareness, family

support, and social involvement can improve psychological well-being and strengthen the effectiveness of long-term treatment.

METHOD

This research employs a qualitative method, defined as a scientific approach carried out to collect data in a structured manner, classify it based on certain categories, and describe and interpret information obtained through interviews, informal conversations, observations, and documentation. The data collected may take the form of words, images, photographs, meeting minutes, notes, memos, and other narrative or visual forms (Ratnaningtyas, 2023).

According to Creswell, qualitative research is a set of methods used to trace and understand the meaning constructed by individuals and groups regarding problems related to social or humanitarian aspects (Ulfiyatun Rochmah & Lubabin Nuqul, 2015). Qualitative research is an approach used to understand events related to the lived experiences of research subjects, with the aim of gaining a deep understanding of social and humanitarian issues. In addition, this approach is considered more responsive to current environmental conditions due to its flexible nature, allowing for adjustments to data collection concepts, instruments, and techniques to support further research development (Oktaviany & Ramadan, 2023).

The approach employed in this study is a phenomenological approach. Phenomenology is a research approach used to explore and understand the essence of human experience in relation to a particular phenomenon. In this process, the researcher seeks to describe the phenomenon as it presents itself in observation — that is, by tracing the data that emerges through the direct experience of the research subject. This approach emphasizes a deep understanding of the meaning contained in the subjective experience of the individual (Ulfiyatun Rochmah & Lubabin Nuqul, 2015).

This research applies a qualitative method with a phenomenological approach, wherein phenomenological inquiry aims to decipher the meaning contained in an individual's lived experience in relation to a particular concept or phenomenon (Rachmatunisa & Rahmandani, 2023). Phenomenology is often understood in general terms as an approach that refers to the subjective experiences of various types and categories of subjects. However, in a more specific context, the term refers to the systematic study of consciousness as seen from a first-person perspective. The phenomenological approach focuses on the direct experiences that individuals undergo, as well as on how individuals assign meaning to experiences related to phenomena considered significant in their lives (Munandar, 2022). This study employs a qualitative descriptive design with a phenomenological approach to examine the dynamics of the quality of life of tuberculosis patients. The researcher interpreted the data obtained in detail and identified patterns that are continuous with the quality of life experiences of tuberculosis patients.

This research was conducted in Palembang City, which was selected on the basis of statistical data from BPS South Sumatra Province indicating that the rate of TB cases in this city is relatively high compared to other cities and districts in the province. The research involved four data sources: two research subjects and one informant from each subject's family. The first subject, with the initials AS, is a 39-year-old man from a lower-middle-class background who has been suffering from tuberculosis since 2017, recovered in 2018, but relapsed in 2023 until he was declared cured in January 2025, and works as a manual laborer

in the market. The second subject, F, is a 40-year-old man with a similar background who had tuberculosis since 2017, recovered, but relapsed from August 2023 to December 2024, works as a construction worker, and lives with his brother and father. The third informant is S, the wife of AS, who works as a housewife, while the fourth informant is D, F's older brother, who is self-employed. The data sources of this study include primary data, in the form of direct information from the subjects regarding their experience of TB treatment at Bari Hospital Palembang, and secondary data, in the form of indirect information from the subjects' families regarding treatment history, consultation schedules, and documentation of the patients' treatment journeys. The data were obtained through in-depth interviews, observations, and documentation, then analyzed systematically to capture underlying meanings and organized into interrelated categories or themes.

RESULT AND DISCUSSION

Themes of Quality of Life Aspects of Tuberculosis Patients in U.S. Subjects

The US subject explained that at the beginning of his diagnosis of tuberculosis his physical condition underwent significant changes, especially related to drastic weight loss. The US subject felt his body shrink far from normal before falling ill, where his body was sharply reduced to a dozen kilograms. This weight measurement is the most visible and felt physical indicator by US subjects as a result of the TB disease they suffer. Here is the US subject's story:

"Yo if I go to keno I want my body to be thin and it's not quite far from 50kg, it's 38kg, right, so that's what is this crew, right" (W3/S1/12-16).

As the treatment process progressed and the recovery period, the U.S. subject said that his current physical condition had improved much better. The US subject said that his weight had gradually increased again until he reached 50kg, which was the total weight of the US subject before he suffered from tuberculosis. Despite being declared cured for almost a year, the US subject still routinely goes to the hospital every six months for a check-up which is a directive from the doctor to ensure his physical condition remains stable. Here is the US subject's story:

"Alhamdulillah, if it's quite a bit of a pain now, I've gained quite a lot of weight, right. Initially, when I was treated it was 38kg, sometimes I went to jugo, but at most 45kg, now it's 50kg. This man has been cured for almost a year, even if every 6 months he still has to apo namonyo.. control to the hospital" (W3/S1/20-28).

Regarding physical obstacles or challenges faced during illness, the US subject admitted that the weakening of the body's condition had an impact on his productivity in daily activities. Weak physical condition required U.S. subjects to undergo hospital quarantine that lasted approximately ten days. After the quarantine period in the hospital is over, the US subjects are advised to undergo complete rest at home and are not allowed to work. The main obstacle he felt was physical limitations that directly stopped his economic activities. Here is the US subject's story:

"If you want to be told to go to the bathroom, your body will become thin and finally you will be quarantined in the hospital for about 10 days and then you will be told to rest first at home and told to work, that's the most difficult thing because I can't do that, right" (W3/S1/31-38).

Lamba said in his writing, body image represents the process of subjective evaluation of individuals on aesthetic dimensions and physical morphology that are manifested in a spectrum of positive and negative assessments. Analysis of various age groups in the female population showed significant divergences in aspects of body appreciation; The older age group tends to have a higher degree of physical acceptance compared to the young adult and middle adult cohorts. The phenomenon of body dissatisfaction is also observed in the male population, which is triggered by the strengthening of sociocultural norms regarding masculine body image. This increase in men's awareness of the aesthetics of appearance is driven cumulatively by the intensive exposure of advertising of diet care and management products in public spaces (Lamba, 2025).

Body image is related to various determinants that include physical, psychological, sociocultural, and interpersonal factors. As one of the crucial components of self-concept, body image plays an important role in facilitating individuals to achieve optimal physical and mental health conditions. Perception of the body not only affects self-concept, but also has a significant impact on self-esteem. Excessive worry as well as a high dependence on body image have a mutually beneficial relationship with an individual's level of self-esteem. The two constructs are closely interrelated, where individuals who have a negative body image tend to show lower levels of self-esteem (Lamba, 2025).

According to Toselli et al, body image is a multidimensional construct that includes perceptual, affective, and cognitive aspects of one's own and others' physical characteristics. Perception in body image integrates evaluation of the dimensions of body size, assessment of physical attractiveness, and mental representation of body shape and volume. Thus, the formation of body image is the result of a complex interaction between physiological processes, cognitive function, and individual social dynamics (Janita et al., 2025).

Based on the data of the study, it can be concluded that the US subjects experienced significant fluctuations in physical condition due to tuberculosis, which was characterized by a drastic weight loss from 50 kg to 38 kg and limited economic activity due to the quarantine and recovery period. Although the subjects have reached the phase of clinical recovery with a stable weight and regularly undergo medical check-ups, this phenomenon of physical changes is closely related to the concept of body image as a multidimensional construct that includes perceptual, affective, and cognitive aspects. Theoretically, these changes in physical morphology affect an individual's subjective evaluation of oneself, where the perception of body size and shape plays a crucial role in determining the patient's level of self-esteem and psychological well-being during the transition from illness to recovery.

Psychological Aspects

U.S. subjects experienced major psychological distress during TB treatment related to adherence to a long drug regimen and the risk of having to repeat the procedure in case of dose neglect. After treatment, the U.S. is relieved to be free of drugs, but remains worried about the possibility of relapse, so it becomes more vigilant about its lifestyle and diet. U.S. confidence increased moderately with the return of normal activity and work ability, indicating post-treatment emotional stability. The U.S. experience reflects the concept of resilience, which is the ability of individuals to adapt positively to stressors through the use of personal resources to bounce back and adjust after facing significant challenges.

Social Aspects

During the TB treatment period, U.S. subjects did not experience discrimination or social exclusion; Interactions with neighbors remain normal, and families provide moral support as well as practical assistance. The U.S. is actively maintaining communication and openness, as well as adhering to health protocols such as mask use, which aids social acceptance and turns family concerns into support. Stable social support from family and the environment has been shown to play a protective factor, facilitating medication adherence, improving self-esteem, and building a more optimistic outlook on life, in line with the literature that emphasizes the importance of emotional and practical support for TB patients.

Environmental Aspects

During the TB treatment period, U.S. subjects showed strong emotional readiness and psychological resilience. Despite experiencing a decline in physical condition, vomiting, and fatigue, the U.S. remained calm, focused on treatment, and made clear decisions, supported by previous experience of undergoing TB treatment. Significant support from the wife helps to undergo medical and administrative procedures, including the management of KIS, which is crucial for the sustainability of treatment amid financial constraints. The U.S. also maintains emotional interaction with children despite implementing health protocols, and taking preventive measures such as getting enough rest. This phenomenon is in line with the Health Belief Model and the concept of coping, where perceptions of disease threats and the benefits of preventive measures encourage adaptive behavior and focus on recovery.

Aspects of Quality of Life of Subject F Tuberculosis Patients

Subject F was initially unaware of the deterioration in his physical condition due to tuberculosis, which was detected by family and neighbors through observation of body weight and somatic symptoms such as respiratory distress and night chills, prompting him to undergo a medical examination until a positive diagnosis was confirmed. During treatment, the subject continued to engage in light household activities to maintain stamina, even though he was unable to perform heavy physical work, and experienced significant recovery marked by weight gain from 44 kg to 55 kg and changes in his preventive diet.

Psychological distress arose from loss of productivity and physical distance from family, but peer support, reading, and personal determination encouraged resilience, independence, and medication adherence, while social interaction was maintained through persuasive communication and a positive reframing of social distancing measures. Access to health services was carried out independently with professional responses from healthcare officers, as well as financial support through BPJS and hospital assistance to help maintain economic stability despite reduced productivity. Theoretically, this experience reflects the principles of Ecological Systems Theory, wherein the interaction of microsystems (family and friends) and exosystems (healthcare and social assistance) plays a crucial role in the physical, psychological, and social recovery of TB patients, as well as underscoring the importance of stigma-free, inclusive environments in supporting compliance and healing.

Quality of life is a multidimensional concept that reflects an individual's subjective assessment of physical, mental, social, and environmental aspects of their life (Novitri Jalaham et al., 2021). Based on the results of the study on subjects AS and F, the process of achieving an optimal quality of life for post-TB patients is greatly influenced by various determinant factors, both internal and external. According to Harefa (Oktafini, 2024), factors such as age,

gender, education level, occupation, and economic status interact with one another in shaping an individual's perception of their well-being. Both subjects demonstrated that maturity in age (39 and 40 years) provided better mental readiness in facing chronic health challenges, although their economic conditions as manual laborers created obstacles to financial stability.

First, the physical aspect is strongly influenced by disease condition and health behavior. Relapsed tuberculosis has a significant impact on the subject's physical capacity, characterized by drastic weight loss and limited energy for work. In accordance with the relevant theory (K. P. Sari, 2017), physical capacity to carry out daily activities is the primary indicator of quality of life. From the interview results, the nature of manual labor requires excellent physical condition, such that when health status declines, subjects AS and F experienced a noticeable decrease in quality of life in the productivity domain. Physical recovery for both subjects is not merely the disappearance of medical symptoms, but the restoration of functional ability to meet the economic needs of the family.

Second, the psychological aspect in this study is closely related to factors of emotional maturity and mental stability. A person's positive affect is obtained from the individual's success in managing the stress of long-term illness. Subject AS demonstrated stable psychological qualities by being able to accept his situation, which is theoretically influenced by the adult age factor that tends to be more adaptive in times of crisis. Subject F, on the other hand, showed anxiety about the risk of disease recurrence. The component of life satisfaction is highly dependent on the dominance of positive affect over negative affect. Mental distress such as the anxiety experienced by subject F is an obstacle to achieving full emotional well-being, requiring more intensive psychological coping than that of subject AS.

Third, the social aspect is greatly influenced by social support factors and the value systems within the family. Family support is a crucial protective factor for patients with chronic diseases (Buheji et al., 2019). This is evident in how marital status and interpersonal relationships shape each subject's experience; subject AS, who is fully supported by his wife, demonstrates higher social stability than subject F, who has separated from his wife. Nevertheless, external environmental factors such as the acceptance of neighbors in Palembang City make a positive contribution to reducing the potential for social isolation. Hassan et al. explained that a supportive environmental situation has a significant influence on the well-being of adolescents and adults, particularly in building a sense of security and social involvement following treatment (Amanda, 2022).

Fourth, environmental aspects and health access are directly influenced by economic status and public policy factors. According to Harefa, a well-established economic status generally facilitates access to quality health services (Oktafini, 2024). Although both subjects came from low economic backgrounds, external factors in the form of government health insurance (KIS/BPJS) were key variables that maintained their quality of life in the environmental domain. In addition, environmental safety factors and the availability of health facilities near the subjects' residences in Palembang helped mitigate their financial limitations. According to Putri, quality of life reflects how individuals interpret an ideal life amid the constraints of their physical and economic environment (Putri et al., 2016).

Finally, religious and spiritual factors emerged as particularly dominant internal forces in shaping the quality of life of both subjects. According to Cho, spiritual beliefs provide meaning and direction in life, especially for patients with serious illnesses (Cho, 2013).

Subjects AS and F employ religious coping to find serenity and hope amid medical uncertainty. Based on Pargament's theory, positive religious coping — such as surrender and the search for meaning behind illness — helps individuals reduce anxiety and build deeper emotional connections (Fadilpa & Male, 2017). This spirituality factor acts as a compensatory mechanism that enhances the subjects' overall life satisfaction, even when their physical and economic circumstances remain challenging.

The quality of life of post-TB patients in both subjects showed both similarities and differences, reflecting their respective recovery adaptations. The similarities lie in their demographic profile and socioeconomic background: subjects AS and F are adult men of productive age (39 and 40 years) from middle-to-lower economic backgrounds who work as manual laborers and share a similar medical history of tuberculosis recurrence, having first been diagnosed in 2017 and relapsing in 2023. Both experienced a significant decline in physical condition, including low body weight (55 kg and 56 kg) and a thin build, yet remained disciplined in undergoing treatment to recover and resume their roles as breadwinners.

The differences are evident in their sources of social support and domestic status. Subject AS receives full support from his wife and two children who live in the same household, facilitating medical compliance and administrative matters, while subject F lives with his brother and father following a separation from his wife, making him more independent in the recovery process even though he remains monitored by his family. In addition, the manifestation of physical complaints and psychological responses also differs: subject AS is notably affected by drastic weight loss and obstacles to work productivity, but remains more emotionally stable and accepts his condition as a trial, while subject F experiences sensory disturbances such as chills and excessive sweating and exhibits greater anxiety about relapse, relying on cognitive and spiritual reflection to interpret his post-illness quality of life. As such, subject AS emphasizes physical coping, while subject F relies more heavily on psychological and spiritual coping.

CONCLUSION

Based on the research conducted, it can be concluded that both subjects in this study — AS and F — have achieved an adequate level of quality of life despite having to face the challenges of disease recurrence. This is evident from the description of the aspects and factors that affect the quality of life of both subjects, as revealed through the themes of the interview results and observations. Both subjects were able to maintain their quality of life by adapting to the physical and psychosocial challenges that occurred in their lives. The description of each subject's quality of life is reflected through four main dimensions with different dynamics for each subject.

In subjects AS and F, the physical aspect was characterized by efforts to restore the body's capacity so as to return to productive work as manual laborers. The psychological aspect is reflected in genuine self-acceptance and the management of anxiety regarding the risk of treatment failure. The social aspect is demonstrated through the utilization of support from the family microsystem, where subject AS is greatly assisted by the role of his wife, and subject F by the support of his extended family. In addition, there are several factors that influence the quality of life of both subjects, including maturity in responding to health problems, economic

constraints alleviated through government health insurance (KIS/BPJS), and spiritual factors that serve as the primary strategy for assigning positive meaning to the illness experienced.

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