



Experience of Pediatric Nurses Caring for Tuberculosis Children from Different Ethnic Groups in the New Normal Life

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ABSTRACT

The cases of Tuberculosis (TB) children in Indonesia increased in 2023 due to the impact of the new normal life. This increase was attributed to delayed immunization, poor nutrition, restrictions on activities, and disruptions to treatment services. The new normal life also affected the increasing number of TB children, in addition to certain ethnic beliefs and culture, causing a significant rise in hospitalized patients and deaths. Therefore, this study aims to explore the experience of pediatric nurses in caring for TB children from various ethnic groups during the new normal life. This study used a phenomenological method, consisting of 12 nurses working in a pediatric ward who were interviewed in an isolated room. The purposive sampling method was used to collect data through semi-structured and in-depth interviews. Data analysis was carried out using the 7-step Colaizzi method. The results showed that a total of 5 themes were identified, namely 1) nurses challenged by patients condition, 2) focus on safety care, 3) the influence of local culture in TB treatment, 4) differences in perceptions of TB between nurses as well as parents, and 5) understanding the perceptions of ethnic beliefs and culture of parents towards the disease. There are still challenges that pediatric nurses must overcome in providing care to patients in hospitals. The results could serve as initial data for developing guidelines or protocols incorporating a cultural competency method, thereby minimizing differences in the provision of nursing care for children with TB.

Keyword: Children, Ethnic group, Pediatric nurses, Tuberculosis, Parents



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1. Introduction

Tuberculosis (TB) is one of the leading causes of child death in Indonesia (Wijaya et al., 2021). Approximately 1.25 million children suffer from the disease, with 214,000 deaths that can be prevented and cured if patients and parents had a proper understanding. TB causes 12% of the global occurrence and 17% of deaths (WHO, 2023). According to the Indonesian Ministry of Health (2022), TB cases in children under 15 years of age were estimated to reach 110,881, or approximately 15.3% of the total cases in Indonesia, including 143 drug-resistant events (Kementerian Kesehatan RI, 2023). The causes of death in children due to the disease cannot be separated from sociocultural factors, including ethnic beliefs that influence access to treatment, stigma, and compliance with treatment. Some ethnic have certain stigma or myths that prevent seeking or adhering to proper treatment (Fitri & Krianto, 2023). Another factor is the perception of certain ethnic groups

and culture that can influence behavior in seeking treatment and adherence to treatment (Sajodin et al., 2022). In certain ethnic groups, stigmatizing and discriminating against patients has an impact on health-seeking behavior and treatment adherence (Joseph et al., 2019).

Another factor that causes an increase in the number of TB children being treated in hospitals is the ignorance of parents as companions in caring for and complying with treatment regulations in Indonesia (Sarifuddin & Sabir, 2023). The most common reason found for children to be hospitalized is TB drug resistance, which is the major cause of death, accompanied by malnutrition (Munthali et al., 2017). The predominant factors responsible for hospitalization are complications, fever, malnutrition, and cough (Kané et al., 2022). Generally, children are the most susceptible age group to TB, which causes a high death rate (Marais et al., 2019). This causes patients to delay seeking treatment at healthcare facilities for fear of contracting COVID-19 (Janah et al., 2022). Additionally, there are resistance drugs, which serve as growing global health problem (Zhuang et al., 2023).

Da Silva et al. (2023) stated that the new normal life affected TB control in children, particularly in the context of morbidity and mortality associated with drug resistance and withdrawal. As health workers, nurses are often affected by the new normal life and face various challenges in providing care to patients (Mackay et al., 2023). According to Pegorin and Angelo (2024), nurses face challenges in responding to frightening situations, adapting to new situations, and adjusting to changing rules because of the COVID-19 pandemic, as well as shifting expectations for care and work processes. Fadare et al. (2020) reported inadequate personal protective equipment, insufficient isolation rooms, delegation of care for TB patients, unclear policies to protect nurses, and minimal training. Nurses are highly susceptible to contracting the disease because of being at the front lines of patient care (Akande, 2020). Another challenge faced by nurses in caring for patients is poor working conditions that endanger occupational safety and mental health (Baluku et al., 2023).

Nurses face various obstacles in caring for TB children in hospitals due to 1) socio-demographic and economic factors, 2) knowledge and perception, as well as 3) TB treatment (Pradipta et al., 2021). Harichander et al. (2024) found that the lack of evidence-based guidelines could lead to errors in drug calculations and dosages. Furthermore, patients reported poor nursing behavior and high levels of TB-related stigma (Nkambule et al., 2019). An et al. (2023) found that nurses discovered inadequate TB isolation rooms, limited knowledge about children history, poor collaboration between health workers, lack of availability of examination tools, and a limited supply of drugs. Other factors were fear of contracting TB and experiencing stigmatization, lack of psychosocial support, stress, anxiety, frustration, stressful work environments, and understaffing (Baluku et al., 2023).

Nurses who understand experience of caring for patients can support children and families, improve treatment adherence, and contribute to better outcomes. This is because there are limitations in the research related to experience of nurses in caring for TB children from different ethnic groups and during the new normal life. Therefore, this research aimed to explore experience of pediatric nurses in caring for TB children from diverse ethnic backgrounds during the new normal life using a phenomenological method.

2. Methods

2.1 Research design

This qualitative research was carried out using a phenomenological method with a descriptive design. The method was used to explore and describe the essence of a particular experience, focusing on individuals perception (Polit & Beck, 2018)

2.2 Participants

Participants in this research were nurses who cared for TB children at one of the Government General Hospitals in Medan. The purposive sampling method was used to select participants by initially determining the inclusion criteria (Polit & Beck, 2018). These criteria were 1) nurses who had cared for TB children, 2) had a minimum of 2 years of clinical experience, and 3) given their consent to participate. Sampling in qualitative research did not depend on the number of participants but rather on achieving data saturation (Polit & Beck, 2018). Therefore, saturation was reached for this with the 12th participant.

2.3 Data collection

This research was conducted from May to July 2021 in a hospital that provided inpatient isolation rooms for TB children. In the data collection process, 7 steps were taken to ensure good data quality, including prolonged engagement, persistent observation, making field notes, recording voice and verbal transcripts,

triangulation, data saturation, and member checking (Polit & Beck, 2018). Guided by the principles of qualitative research, a sample rich in information was selected to explore in depth the phenomenon of nurses caring for TB children from different ethnic backgrounds during the new normal life period. Interviews were conducted until saturation was reached, followed by cessation of sampling. Data saturation showed that no new data was obtained (Polit & Beck, 2018).

Interviews were conducted in a semi-structured and in-depth manner to obtain data directly from participants. The guide was specially created in consultation with experts in the field of pediatric nursing and refined through a trial of interviews and structured for this research. The process for interviews started with an open question, which included 1) Can you tell us about the experience in caring for TB children during the new normal life, 2) What are the activities performed when caring for patients, 3) What are the obstacles that limit treating children from different ethnic groups in the new normal life, 4) What do you experience when caring for patients with different ethnic groups and culture, and 5) What are the activities performed in caring for TB children with different ethnic groups and culture in the new normal life. The interview lasted between 45 and 60 minutes and was recorded simultaneously. The results were recorded in a Word-format transcript. Subsequently, the transcript, which had been prepared in script form, was given to the participants for clarification. This was followed by a coding process and extraction was continued, alongside collection and analysis processes.

In qualitative research, subjectivity is inherent as the interpretations and analyses shape the results (Polit & Beck, 2018). This can introduce bias, where the personal experience, beliefs, and values of the research team unconsciously influence the results. To mitigate bias, qualitative research focused on rigor, trustworthiness, and reflexivity, actively acknowledging and addressing their biases throughout the process

2.4 Data analysis

The data in this research were analyzed using the Colaizzi 7-step method. These included 1) data introduction, 2) extraction of important statements, 3) formulation of meaning, 4) organizing themes, 5) providing a comprehensive description of the phenomenon, 6) identifying the basic structure of the phenomenon, and 7) returning to participants (Polit & Beck, 2018).

2.5 Trustworthiness

In this research, to ensure the credibility of the data, Lincoln and Guba's evaluative criteria were used, including credibility, dependability, confirmability, and transferability (Polit & Beck, 2018). Credibility was established through prolonged engagement and member checking. Dependability was ensured by conducting interviews with the research team. Confirmability was established through discussions with key participants. Furthermore, transferability was assessed with other pediatric nurses who were not involved in the research process.

2.6 Ethical considerations

This research obtained ethical approval from the Research Ethics Committee of the University of North Sumatra (No.433/KEP/USU/2021).

3. Results

3.1. Characteristics of Participants

As shown in Table 1, a total of 12 nurses working in pediatric patient ward were selected, with the majority consisting of 6 participants aged 36–45 years. All participants were female, consisting of 11 married nurses, 10 Christians, and 12 undergraduates, 6 had 5 to 10 years of experience, and 6 were Bataknese. The characteristics of participants are shown in Table 1.

Table 1 Characteristics of participants

Characteristics	f	%
Age		
25-35	2	16.7
36-45	6	50.0
46 -55	4	33.3

Table 1 Continued

Characteristics	f	%
Gender		
Female	12	100
Marital Status		
Married	11	91.7
Single	1	8.3
Religion		
Muslim	2	16.7
Christian	10	83.3
Education		
Bachelor degree	12	100
Years of experience		
Less than 5 years	2	16.7
5 to 10 years	6	50.0
More than 10 years	4	33.3
Ethnic		
Batakese	6	50.0
Karonese	4	33.3
Javanese	2	16.7

3.2. Themes and Subthemes

After analyzing the data using the Colaizzi method, 5 themes and 13 sub-themes were identified, as shown in Table 2.

Table 2 Main summary themes and sub-themes

Themes	Subthemes
Theme 1: Nurses challenged by the patient's condition	-Complicated conditions - Drug-resistant TB -Discontinuation of medication
Theme 2: Focus on safety care	-Implementation of patient safety -Implementation of nurses safety
Theme 3: The influence of local culture on TB treatment	-TB a hidden disease -TB only attacks people who have an unhealthy lifestyle -TB is an inherited disease
Theme 4: Differences in perceptions of TB between nurses and parents	-Belief in traditional medicine -TB can only attack the lungs -A common cough that requires no treatment
Themes 5: Trying to understand the perceptions of ethnic and culture of parents towards TB	-Using local languages -Local cultural method

Theme 1: Nurses challenged by the condition of patients

The majority of nurses experienced challenges in caring for TB children. These included conditions that were already complicated, drug-resistant TB, and drug withdrawal.

Sub-theme 1: Complicated conditions

Complicated conditions were among the most important sub-themes in this research, as the first thing encountered by nurses when caring for patients during the new normal life. Participants described complicated conditions as follows:

“Most of the time, I found that the condition of patients when they were admitted to the children isolation room was already very poor, with complications such as decreased consciousness, malnutrition, meningitis, and bronchopneumonia” (P 7)

Sub-theme 2: Drug-resistant TB

Drug resistance in TB patients increased during the new normal life due to fear of contracting COVID-19 while taking drugs, not taking medication regularly, and stigma. Participants described the majority of TB patients treated in hospitals who had experienced drug resistance as follows:

“The majority of patients and their families explained that they were afraid of contracting COVID-19, leading to laziness about taking medicine at the health center. Because of the side

effects, which also made patients experience nausea and vomiting, patients did not complete TB treatment. This worsened the condition and caused hospitalization” (P5)

Sub-theme 3: Discontinuation of medication

TB drug withdrawal in patients can be caused by various factors, such as forgetting to take medication, cessation of treatment due to the feeling that symptoms have disappeared, and side effects. Several participants provided narratives about the impact of the new normal life:

“From what parents told me, they stopped giving their patients medication because of the difficulty in accessing health facilities during the new normal life, and the side effects of TB drugs were considered very painful. Parents felt sorry for their children who were experiencing nausea or vomiting and had no appetite” (P12)

Theme 2: Focus on safety care

The majority of nurses did not practice patient safety when caring for TB children during the new normal life.

Sub-theme 1: Implementation of patient safety

Patient safety can be implemented by improving communication, staff training, and reducing the risk of infection. The objective is to minimize the risk of adverse events associated with medical care. Participants in implementing patient safety are as follows:

“The new normal life makes me more frequent and disciplined in implementing hand washing with soap and running water before and after providing nursing care to TB patients” (P7)

Sub-theme 2: Implementation of nurses' safety

The implementation of nurses safety includes preventing injuries, infections, and medication errors, as well as creating a safe and supportive workplace. Participants in implementing nurses' safety as follows:

“Before taking any action that risks endangering my safety, I will first wear a mask, gown, face shield, and gloves. The process serves as a safety precaution to protect myself during the new normal life” (P12)

Theme 3: The influence of local culture on TB treatment

A major challenge that can hinder nurses when caring for patients is the persistent stigma surrounding the disease. TB only attacks people who have unhealthy and dirty lifestyles, and the disease is inherited.

Sub-theme 1: TB is a disease that must be hidden

Patients and parents consider TB as a feared disease associated with negative stigma. This can affect how patients and parents search for treatment, the level of participation in prevention programs, and the openness to share information regarding the disease. The majority of participants provided a narrative about TB as a shameful disease by stating:

“Almost all TB patients and their parents told me that they felt ashamed to bring their children for treatment. The majority hide the disease from others because of shame and fear of being ostracized from families and neighbors. This was because TB was still believed to be a shameful disease for the family” (P10)

Sub-theme 2: TB only attacks people who have an unhealthy lifestyle

The perception that TB only attacks people with low socioeconomic status can trigger stigma and discrimination against patients. Several participants provided narratives about TB only attacking people with unhealthy lifestyles by stating that:

“From my perspective, the wrong perception of TB is still believed by many patients and parents. I try to correct their misconceptions about TB in patients. I explain that the disease is an infection caused by the bacteria Mycobacterium TB that could attack everyone, including those with unhealthy behavior” (P6)

Sub-theme 3: TB is an inherited disease

Local culture also influences patients and parents perceptions, which causes delayed treatment and transmission. Some participants provided narratives about TB as a hereditary disease by stating that:

“From what patients and parents said, TB is a common disease because many of their families have TB. Therefore, parents consider TB as a hereditary disease that makes them feel ashamed when children are taken to the health center or hospital for treatment. Parents decide to undergo traditional medicine” (P1)

Theme 4: Differences in perceptions of TB between nurses and parents

Nurses found differences in perceptions of TB regarding the use of traditional medicine. This is because the majority of parents assume that TB only attacks the lungs and common coughs, requiring no treatment.

Sub-theme 1: Belief in traditional medicine

Parents have an inaccurate perception towards TB, considering the disease as hereditary based on beliefs, tribes, and culture. In this research, several participants provided narratives about TB being curable with traditional medicine by stating that:

“There are certain tribes of parents whose children are treated and continue to strongly hold their beliefs. Efforts to correct these beliefs are often met with frustration. Cultural ties believed by parents and patients have led to a preference for traditional medicine in the form of potions, herbs, and massage methods” (P 11)

Sub-theme 2: TB can only attack the lungs

The assumption that TB only attacks the lungs is wrong. Participants described the parents' opinions regarding TB disease that only attacks the lungs as follows:

“I have explained that TB is caused by infection with the bacteria Mycobacterium tuberculosis. The bacteria can spread through the air when patients cough, sneeze, and talk. However, most people believe that TB only attacks the lungs because TB patients often experience shortness of breath”(P4)

Sub-theme 3: A common cough that requires no treatment

The majority of participants gave a narrative about cough in TB patients as a common symptom requiring no treatment by stating that:

“I tried to explain that cough in TB patients needs to be treated with anti-tuberculosis drugs and must be taken regularly and completely. However, patients and parents believe that coughing is a common thing that requires no treatment. This is because, around their place of residence, there are many TB patients with coughs, none of whom seek treatment but recover without medical intervention (P2)”

Theme 5: Trying to understand the perceptions of ethnic and culture of parents towards TB

Nurses can understand ethnic and culture of TB patients by using local languages and cultural method.

Sub-theme 1: Using local languages

Nurses can use local languages to care for patients when fluent. Some participants provided narratives about the use of local languages by stating that:

“I try to use local languages when communicating with patients and parents. If not available, I look for a friend in the room who can speak the same local language as the parents and patients. The objective is to make it easier for them to understand what I explain regarding TB and the condition” (P 8)

Sub-theme 2: Local cultural method

The diversity of ethnic groups and culture in Indonesia served as a consideration for nurses in providing care to TB children. Several participants provided narratives about the use of local cultural methods by stating that:

“Initially, I asked about ethnic groups, religion, and language used daily by parents and patients. Based on experience, parents and patients are usually more open and cooperative when I try to prepare a nursing plan according to their cultural background and religious values, particularly when providing information about TB disease” (P9)

4. Discussion

4.1 Nurses challenged by the condition of patients

The new normal life causes nurses to face tough challenges in caring for TB children in hospitals, such as the risk of infection, violence, and limited equipment. (Baluku et al., 2023). Ichsan et al. (2023) found that the new normal life was a major factor contributing to the increase in multidrug-resistant TB among patients. According to Wahyuni et al. (2021), complications occur due to discontinuation of drugs, poor nutrition, low immunity, comorbidities, and lack of knowledge related to TB. Nurses who do not understand how to care for TB children in the new normal life face various problems, such as a lack of cooperation between health service providers for screening and treatment, inadequate quality of diagnostic tools, and the cessation of the

availability of drugs (An et al., 2023). Other challenges include infection control, resource constraints, communication gaps, and problems related to patients education and adherence. Addressing these challenges is crucial to improving TB control, and ensuring the safety and well-being of both nurses and patients.

4.2 Focus on safety care

The new normal life has a significant impact on nurses' ability to provide safe care. This is due to several factors, including an excessive workload, limited equipment, and disease transmission (Gnatta et al., 2023). According to Mehboodi et al. (2024), the new normal life affects the quality of care in hospitals, and concerns about safety, the supply of personal protective equipment, and changes in policies related to personal protective equipment (Simonovich et al., 2022). Nurses have increased risks related to patients safety and fragmentation of care (Stayt et al., 2022). Lee and Kim (2024) identified challenges to nursing patient safety in children, attributing these to factors originating from both patients and caregivers. Generally, nurses play an essential role in ensuring the safety of TB patients during the new normal life by implementing stringent infection control measures, providing thorough patient education, as well as actively monitoring and supporting treatment adherence.

4.3 The influence of local culture on TB treatment

The local culture and beliefs of patients and their parents can influence TB treatment in children in hospitals (Yetti et al., 2023). The level of stigmatization believed by patients and parents has the potential to cause obstacles in seeking treatment (Chaychoowong et al., 2023). The research conducted by Mindu et al. (2017) found misunderstandings about TB in children. Beliefs from patients and parents that TB disease is caused by evil spirits and can be cured through spiritual rituals are factors restricting patients from visiting the hospital (Msoka et al., 2021). Also, local culture got belief that TB spreads from kissing, plates sharing, same toilet use, air spit drops, and some culture rules make it hard for women to get help (Adeoye et al., 2024). Give et al. (2024) found that sociocultural beliefs often implied certain actions as causes of TB symptoms, such as social stigma, not believing positive TB test results, seeking traditional alternative treatments, and belief in the supernatural. Juma et al. (2022) reported that TB was inherited from ancestors, religious beliefs, and buying drugs freely. Cultural can stop treatment for TB, showing the need to understanding these influences for developing effective control strategies that are good.

4.4 Differences in perceptions of TB between nurses and parents

Nurses and parents may have different perceptions about TB due to factors such as education, experience, and cultural beliefs (Adeoye et al., 2024). In this case, nurses need to have a positive perception to provide effective care and emotional support, be aware of the risk of contracting TB in the workplace, and possess basic knowledge regarding the disease (Jamaludin et al., 2019). However, parents have limited knowledge, beliefs, and misperceptions about TB and treatment (Matakanye et al., 2019). Spruijt et al. (2020) stated that the inability to distinguish latent TB infection and the fear of being infected by patients could lead to stigma and misunderstandings in cultural beliefs regarding transmission and prevention. Nurses caring for TB patients have diverse perceptions, including challenges, support, and a need for further training (Baluku et al., 2023). There are also varying perspectives on transmission and prevention (Madzinga et al., 2022). Meanwhile, parental perceptions influence acceptance of TB patients treatment (Wademan et al., 2022). According to Vericat-Ferrer et al. (2022), parents believed that TB was a stigma, felt guilty and ashamed, limiting the ability to get social support, and lacked knowledge regarding treatment. Huaman et al. (2021) found that nurses with MDR-TB had difficulty complying with treatment, thereby drug administration was not carried out completely because of wrong perception. By addressing the differences in perceptions and fostering a more positive as well as supportive environment for both nurses and parents, there is a tendency to enhance TB prevention and care, leading to improved health outcomes for patients and families.

4.5 Trying to understand the perceptions of ethnic and culture of parents towards TB

Machmud et al. (2020) found that inappropriate cultural practices in patients could negatively impact care due to different ethnic and communication barriers. Ethnic groups and cultures do stigma and discrimination to patients, making treatment and health-seeking not occurred properly (Joseph et al., 2019). Beliefs about TB in some culture come from spiritual, social, and traditional values that are part of the thinking (Joseph et al., 2019). Use of language from the local area during care helps more understanding from nurses happen and give better treatment (Anandita & Krianto, 2023). The study by Hussen et al. (2020) showed respect for different

beliefs and culture, suggesting the important of culture humbleness. There are views on TB change in different ethnic backgrounds, like causes, how to treat, and spreading. These beliefs can influence how people seek care, which delays treatment and hinders progress toward ending the disease (Tabong et al., 2021). Nyasulu et al. (2018) found that cultural beliefs, poverty, and stigma could influence how children were diagnosed and treated. This shows the need to understand parents' ethnic and culture perceptions to improve management and prevention. Parents often have views influenced by traditional beliefs, cultural practices, and understandings of health, which can affect their behavior related to TB.

5. Conclusion

In conclusion, experience of pediatric nurses caring for TB children from different ethnic groups in the new normal life shows several challenges. These include a focus on safety care, the influence of local culture, differences in perceptions about the disease between nurses and parents, as well as trying to understand ethnic and culture perceptions of parents towards TB. Nursing education regarding TB in children should include a comprehensive understanding of the disease, such as transmission, diagnosis, treatment, and prevention. Furthermore, nurses should be equipped to educate families about TB, promote treatment adherence, and prevent further transmission. As the number of TB cases in children continues to increase in Indonesia, ethnographic research is needed to gain deeper insight into the underlying causes associated with the disease.

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