

# Family-Centered Approaches to Pediatric Tuberculosis and Nutritional Challenges in North Aceh: A Qualitative Study

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## ABSTRACT

**Background:** Pediatric tuberculosis (TB) remains a major global health issue, particularly in low- and middle-income countries. In areas such as Aceh, the nutritional needs of pediatric TB patients are frequently neglected, with treatment primarily addressing the causes of infection and insufficient family involvement. This study aimed to analyze the nutritional problems related to pediatric TB in North Aceh Regency, Aceh Province, Indonesia.

**Methodology:** This qualitative study employed phenomenological analysis through in-depth face-to-face interviews with pediatric patients, their guardians, healthcare professionals, and hospital administrative staff at Cut Meutia General Hospital, North Aceh, from July to September 2024. Conducted in Indonesian, the interviews were audio-recorded with consent and analyzed using thematic analysis.

**Results:** This study examined 28 pediatric TB patients, equally divided by sex, with a mean age of 2.6 years. Most were normally nourished, and nearly half had pulmonary TB, primarily contracted from household contact. This study identified five key themes: increasing TB incidence, pediatric TB treatment challenges, nutritional concerns, inadequate sanitation, and strategies to address treatment and nutritional issues in children with TB.

**Conclusions:** The proposed interventions include increasing TB awareness, promoting BCG vaccination, considering socioeconomic factors, enhancing treatment adherence, and integrating nutritional support into management strategies.

**Keywords:** Pediatric Tuberculosis, Family-center Approach, Nutritional Status, North Aceh

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## INTRODUCTION

Tuberculosis (TB), which is caused by *Mycobacterium tuberculosis*, remains a significant global health issue, particularly in developing countries. The World Health Organization (WHO) Global Report for Tuberculosis 2023 identified tuberculosis as the second leading cause of death from a single infectious agent worldwide. Southeast Asia consistently had the highest incidence of new TB cases from 2010 to 2022. Indonesia ranks second globally, comprising more than 60% of cases below India.<sup>1</sup> Pediatric TB poses a significant global health challenge, particularly in low- and middle-income countries, where it disproportionately affects children. The prevalence of TB among children and young adolescents (0-14 years) increased from 2014 to 2019, with around 1.25 million diagnosed by 2022, 47% of whom are aged 0-5 years.<sup>2,3</sup>

TB in children under 5 years of age is alarming due to the rapid progression from infection to severe forms such as miliary TB and TB meningitis, often fatal without prompt diagnosis and treatment.<sup>4</sup> TB is closely related to poor nutrition and weakened immunity, with persistent immune impairment worsening nutritional status through decreased food intake and malabsorption.<sup>5</sup> Nutritional status, assessed using weight and height measurements, reflects the balance between nutrient needs and intake.<sup>6</sup> Malnutrition and inadequate weight gain during treatment are associated with higher mortality, disease recurrence, poor therapeutic response, increased severity, and comorbidities.<sup>7</sup>

The association between nutritional status and pediatric TB represents an expanding area of research, and malnutrition has been identified as a significant risk factor for pediatric TB. Malnutrition alters immune function and increases susceptibility to TB infection and disease progression.<sup>8,9</sup> Aketi et al. (2017) emphasized that adequate nutrition is crucial for immune competence, which is essential to resist infections, such as TB.<sup>10,11</sup> Furthermore, TB can exacerbate nutritional deficiencies, creating a cycle that complicates recovery and treatment.<sup>12</sup>

According to the WHO, children exhibit increased susceptibility to TB, with the disease demonstrating rapid progression from infection to an active state, potentially resulting in severe morbidity and mortality. The challenges in diagnosing and treating TB in pediatric patients are further exacerbated by factors such as infrequent bacteriological confirmation of diagnoses and the limited availability of child-friendly anti-TB medications.<sup>13</sup> Furthermore, the nutritional status of pediatric patients plays a critical role in their overall health and recovery from TB, as malnutrition is prevalent among affected children.<sup>12</sup>

A family centered approach to healthcare is increasingly being recognized as a vital strategy for managing pediatric TB. This approach emphasizes the involvement of families in the care process, acknowl-

edging that family dynamics and support systems significantly influence health outcomes. Research indicates that family-centered care can enhance the quality of care provided to pediatric patients, leading to improved satisfaction and better health outcomes.<sup>14</sup> A family-centered approach not only addresses the medical needs of pediatric TB patients but also incorporates the family's role in prevention, management, and nutritional support.

Integrating nutritional support into TB prevention and control strategies is crucial, especially in regions with high prevalence. Therefore, this study aimed to evaluate the nutritional problems related to pediatric tuberculosis in the North Aceh Regency, Aceh Province, Indonesia.

## METHODOLOGY

**Study design:** This qualitative study employed a phenomenological approach. Qualitative research interviews in healthcare employ a phenomenological approach to extract insights and comprehend the lived experiences of participants. These interviews were aimed at gathering conceptual and theoretical knowledge about individuals' life experiences.<sup>15,16</sup> The study involved in-depth interviews with pediatric TB patients, guardians of children diagnosed with tuberculosis, healthcare providers (including nutritionists and directly observed treatment providers (DOT)), and hospital administrations (including staff from the Medical Services Department and Director of Cut Meutia General Hospital, North Aceh Regency).

**Study population and participants:** The participants were recruited through purposive sampling. The inclusion criteria for the study were pediatric patients diagnosed with tuberculosis who were either receiving treatment or were new TB cases that had undergone therapy for at least 1 month. The exclusion criteria were pediatric TB patients with HIV infection or diabetes, and oedema cause by nephrotic syndrome. Guardians, healthcare providers (nutritionists and DOT providers), and hospital management facilities also included healthcare providers who described their experiences in caring for children with TB and their perceptions of the challenges faced by the children.

**Data collection:** The investigators initially conducted a preliminary study on the challenges encountered by pediatric tuberculosis patients within the community. Subsequently, an analysis of the strengths, weaknesses, opportunities, and threats potentially affecting pediatric tuberculosis patients was performed. This information was used to develop a semi-structured topic guide. However, the interview was not piloted and validated, because the principal investigator has the experience and expertise in the field. The principal investigator conducted in-depth face-to-face interviews using a semi-structured interview guide in Indonesian and in the local language (Acehnese) from July to September

2024. The principal investigator was a female medical doctor (MD), a pediatrician proficient in local languages, with experience in qualitative research. The interviews were recorded after informed consent was obtained and transcribed verbatim. The average duration of the interviews was 45 min.

Three groups of participants were interviewed: guardians of children (referred to as "Parent"), healthcare providers (nutritionist and DOT providers; referred to as "Healthcare providers"), and hospital management (Health Services Department staff and Director of Cut Meutia General Hospital, North Aceh Regency; referred to as "Hospital management"). Nutritionists play a role in supplementary feeding programs and monitoring the nutritional status of pediatric patients with TB, whereas DOT providers are responsible for the follow-up of treatment adherence in pediatric TB patients. In this study, we consider both were "Healthcare providers." The interviews addressed factors associated with pediatric TB, nutritional status of children, and challenges encountered during TB treatment. Daily records of medication adherence, medication availability, and treatment follow-up schedules were obtained from the family logbooks of tuberculosis patients. Nutritional status was classified based on WHO charts (weight-for-height).

**Data management and analysis:** The transcripts were completed within two weeks of conducting the interviews. The research team evaluated the reliability of the transcripts to ensure translation accuracy. This study used phenomenological analysis that included descriptions and themes. To obtain a comprehensive understanding of the complexities of the case, the researchers extracted themes from the transcribed and interview texts.<sup>17</sup>

**Approval of Institutional Ethical Committee:** Ethical approval was obtained from the Ethics Research Commission of the Faculty of Medicine, Universitas Malikussaleh, Aceh, Indonesia (No. 26/KEPK/FKUNIMAL-RSUCM/2024; May 20, 2024).

## RESULTS

**Characteristics of pediatric patients with TB:** The study involved 28 pediatric tuberculosis patients with a mean age of  $2.6 \pm 1.2$  years, ranging from 7 months to 4.7 years. The gender distributions were equal. Most patients had normal nutritional status, and 46.4% had pulmonary tuberculosis. A significant number of infected children had household contact with family members who also had pulmonary TB (Table 1).

**Pediatric tuberculosis-related nutritional problems:** Qualitative analysis yielded five primary themes addressing pediatric tuberculosis-related nutritional issues. These themes were further divided into five subthemes: 1) increased TB incidence, 2) challenges in treating pediatric TB, 3) nutritional problems in TB-affected children, 4) basic sanitation

practices, and 5) strategies to address treatment and nutritional challenges in children with TB. A summary of the themes and subthemes derived from this analysis is shown in Figure 1.

**Table 1: Characteristics of Pediatric TB Patients**

Variable	Patients (n=20) (%)
<b>Age (year)</b> , mean $\pm$ SD	2.6 $\pm$ 1.2
<b>Gender</b>	
Male	14 (50.0)
Female	14 (50.0)
<b>Nutritional Status</b>	
Undernutrition	4 (14.3)
Normal	22 (78.6)
Overweight	2 (7.1)
<b>Diagnosis</b>	
Pulmonary TB	13 (46.4)
Gland TB	8 (28.6)
Ocular TB	1 (3.6)
Meningoencephalitis TB	2 (7.1)
Bone TB	1 (3.6)
Meningitis TB	1 (3.6)
Isoniazid (INH) prophylaxis	2 (7.1)
<b>Education Level of Parent</b>	
Low	24 (85.71)
High	4 (14.29)
<b>Parent Occupation</b>	
Civil servant	4 (14.29)
Self-employed	10 (35.71)
Housewife	14 (50.0)

**Increase in the number of TB cases:** The increase in the number of TB cases among children in the North Aceh District is attributed to contact with TB-positive family members. Consequently, the increasing incidence of adult TB cases in North Aceh Regency has resulted in a corresponding increase in tuberculosis cases among children.

*"I have a family member who had TB too, but it's been a while now, and she completed her six-month treatment."* (Parent 1)

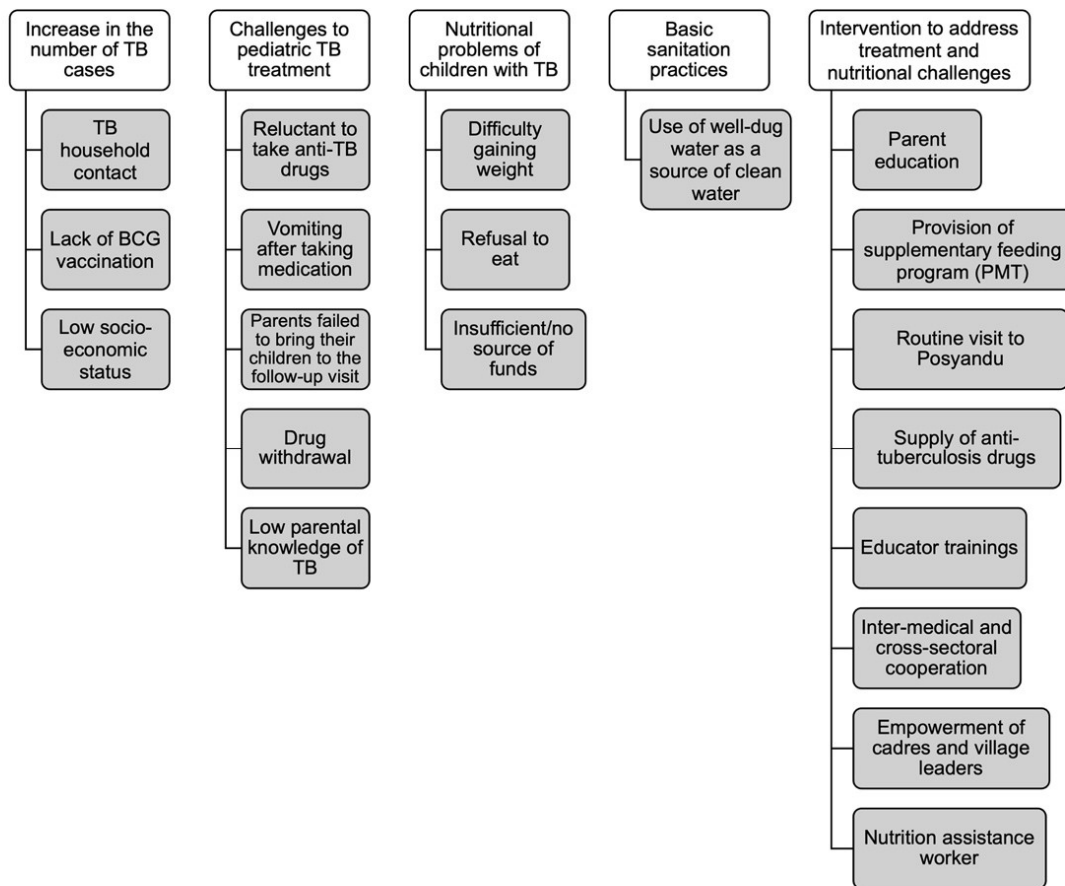
The present study also found that none of the pediatric patients with TB received BCG immunization.

*"I chose not to vaccinate my child when they were little, and their father felt the same way. I simply thought immunization wasn't essential."* (Parent 2)

The increased number of pediatric TB patients also occurs because there are still many community members with a low socioeconomic status.

*"Pediatric tuberculosis in our community mainly affects children from low-income families, who often face difficulties in fulfilling their daily nutritional needs. For these children, finding enough food to satisfy their hunger is quite a challenge, and simply having a meal is something they are truly thankful for."* (Healthcare provider 1)

**Challenges to pediatric TB treatment:** Various barriers are encountered in the treatment of pediatric tuberculosis at Cut Meutia General Hospital, including medication adherence among children.



**Figure 1: Themes and subthemes from the analysis**

*“My child is having a tough time with his anti-tuberculosis medication and often ends up vomiting it. At first, he did fairly well, but now he has refused. It seems that he got tired of the daily routines. I have tried various ways to encourage him, but he still manages to spit it out.”* (Parent 3)

Parental involvement significantly influences adherence to pediatric TB treatment. In this study, parents did not return their children to scheduled follow-up appointments.

*“Managing pediatric TB can be quite challenging. Some parents missed their scheduled follow-up visits, which unfortunately led to treatment interruption. Additionally, many parents face educational hurdles because they haven't had the opportunity to attend school.”* (Healthcare provider 2)

**Nutritional problems of children with TB:** This study also identified nutritional problems in pediatric patients with tuberculosis infection.

*“Another challenge is that children with TB often deal with nutritional problems. Many of them are malnourished, and only a few have a healthy nutritional status.”* (Healthcare provider 2)

Parent 4 also mentioned the following.

*“My child has been having a tough time gaining weight, even though I've been giving him milk and encouraging him to eat. Despite all my efforts, it seems like his weight hasn't changed.”* (Parent 4)

**Basic sanitation practice:** This study identified inadequate basic sanitation practices among families of children with tuberculosis infection. Most participants reported using water sources from dug wells that they considered clean.

*“We purchase water for drinking, but for everyday tasks such as bathing and washing, we continue to use the water from our well. Occasionally, we boil that well water before drinking it.”* (Parent 5)

**Management solutions for treatment and nutrition problems in TB children:** Multiple efforts are needed to control childhood tuberculosis in the North Aceh Regency.

*“In my opinion, addressing the issue of TB in children should include the entire family and not just health care professionals. TB is closely tied to a child's nutrition, so what can we do to help? We can support parents in understanding the significance of monitoring their children's nutrition when dealing with TB. Recovery can be challenging for these children if nutrition is not prioritized. Who provides the closest support to the child? Exactly—the family! Parents have a vital role in helping their children heal, regain their health, and eventually return to school just like their peers.”* (Health provider 3)

Regarding additional interventions that can be implemented in the management of childhood tuberculosis and its associated nutritional improvement, the government has established an existing supplement-

tary feeding program (PMT).

*“Currently, we’re focusing on enhancing the nutrition of children with TB. We have been providing supplementary feeding (PMT); although we know that this alone might not be sufficient, we have been providing supplementary feeding. It is also important that children consistently receive anti-TB medication. I am hopeful that mothers will bring their children to Posyandu regularly for weighing, so that we can monitor their nutritional health. Additionally, our nutrition educators have received training to better support families.”* (Health provider 1)

The present study found that some mothers did not take their children to the Integrated Health Service Post (Posyandu), a community health service that affects the nutritional status of children with tuberculosis. Many mothers of malnourished children skip these visits due to discouragement from their children's conditions, and some believe that health services are unnecessary when children are sick, opting for over-the-counter medications and natural remedies.

*“I never took my child to Posyandu to weigh him. Instead, I checked his weight during the hospital visit. That’s how I discovered how much he weighed.”* (Parent 6)

Another subtheme of this study was the provision of anti-tuberculosis drugs and the responsibility of the government through health offices. Although the provision of anti-tuberculosis drugs in the North Aceh Regency is currently optimal, availability alone is not sufficient for effective prevention of childhood tuberculosis. Collaboration between healthcare professionals and cross-sector agencies is crucial to achieve this goal.

*“To address tuberculosis in children is truly a group effort, not just the job of healthcare professionals. We need teamwork among medical experts and support from community leaders such as village leaders and local volunteers. Unfortunately, many parents do not realize the importance of proper nutrition during their child’s illness. They often think, ‘My child is sick, so I just need to give them medicine.’”* (Hospital management 1)

## DISCUSSION

This study identified several factors associated with pediatric tuberculosis-related nutritional issues at Cut Meutia General Hospital, North Aceh Regency. These factors include an increase in the incidence of TB, challenges in pediatric TB treatment, nutritional deficiencies in children with TB, inadequate basic sanitation, management strategies for addressing TB treatment, and nutritional problems in pediatric patients.

This qualitative study identified key factors contributing to the increase in pediatric TB cases, including

household contact with adult TB patients, lack of BCG vaccination, and low socioeconomic status. North Aceh Regency reported 1247 adult pulmonary TB cases, leading to a rise in pediatric TB due to household exposure to active TB family members.<sup>18</sup> Poor adherence to TB treatment in adults exacerbates pediatric cases, as children frequently contact AFB-positive TB family members, heightening their infection risk through respiratory droplets from coughing or sneezing. Previous studies indicated that children exposed to adults with pulmonary TB for over six months have a 27 times higher risk of developing pediatric TB.<sup>19</sup> Non-adherence to TB treatment by family members prolongs children's exposure, increasing pediatric TB incidence. Studies reveal that children with household TB contact are more likely to develop active TB than those without such contact.<sup>20</sup> A recent study found that 86.7% of pediatric TB cases involved contact with adult TB patients, underscoring the significance of household transmission.<sup>21</sup>

This study identified a correlation between the absence of BCG vaccination and increased TB susceptibility in children, especially in North Aceh Regency. This aligns with a prior study at Cut Meutia Hospital, which found that lack of BCG vaccination is a risk factor for pediatric TB in high-prevalence areas, where the vaccine protects against severe disease forms.<sup>22</sup> A study among Indonesian children showed that those without BCG scars had a higher TB diagnosis rate than vaccinated children.<sup>23</sup> Despite debates on BCG vaccine efficacy in children, it significantly prevents TB in those under five.<sup>24</sup> The evidence underscores the need for improved vaccination coverage to reduce TB incidence in children.<sup>25</sup>

The association between tuberculosis and low SES is well-established, with children from low-income households being 0.3 times more likely to develop TB.<sup>26</sup> Lack of access to healthcare, proper nutrition, and safe living conditions contribute to the increased risk of TB among children from low-income families.<sup>27</sup> A South African study demonstrated a direct correlation between poverty and TB incidence, highlighting the significant impact of socioeconomic deprivation on the disease burden.<sup>28</sup> Children from low-SES backgrounds may experience malnutrition, affect immune function and increase susceptibility to TB.<sup>27</sup> The association between family socioeconomic status (SES) and healthcare access in pediatric TB is vital as it affects health outcomes and treatment adherence. Low SES is associated with financial constraints, a lack of transportation, and inadequate health literacy. Wanahari et al. (2022) found that cash transfer and microfinance interventions can improve TB outcomes by enhancing healthcare access and economic well-being, especially for vulnerable groups. This highlights the importance of addressing socioeconomic barriers in TB management to break the poverty-disease cycle.<sup>29</sup> Additionally, the stigma associated with TB complicates the SES-healthcare access relationship, and delays medical

care. Andom (2023) found that food insecurity hinders treatment adherence, as patients may avoid medication because of fear of worsened side effects without proper nutrition.<sup>30</sup>

Children's reluctance to take anti-TB drugs, vomiting post-medication, parental neglect during follow-up visits, drug withdrawal, and low parental knowledge significantly hinder pediatric tuberculosis treatment adherence and outcomes. Prolonged treatment can induce boredom, while medication reluctance stems from bitter taste, complex dosing regimens, and psychological impact.<sup>31</sup> Furthermore, anti-TB drug side effects such as nausea and vomiting dissuade children from completing treatment.<sup>32</sup> Vomiting post-medication also contributes to treatment interruptions, non-adherence, and potential drug resistance.<sup>33</sup>

Effective communication between healthcare providers and families is crucial to address concerns about side effects and ensure completion of TB treatment, as low parental knowledge of TB and its treatment exacerbates these challenges. Parental understanding of tuberculosis and its treatment is essential for adherence to treatment regimens and improving children's health, especially for children under 5 years of age who rely on their parents for adherence.<sup>34</sup> Educational interventions to boost parental understanding of TB transmission and treatment are necessary for better treatment outcomes.<sup>35</sup> Moreover, disparities in diagnosing and providing services for pediatric TB contribute to higher mortality rates in children.<sup>36</sup> A recent study identified several challenges in diagnosing childhood TB, including caregivers' knowledge and experience, the case-finding process, community mobilization, healthcare providers' diagnostic methods and service provision, and the lack of necessary logistics at healthcare facilities.<sup>37</sup>

This study found that most of the patients had a normal nutritional status and only 14,3% of the participants were undernourished. We assumed that, at the time of sampling, some patients were undergoing treatment. At the commencement of treatment, pediatric TB patients are monitored for nutritional status by the attending physician and nutritionist at the hospital or community health center. In cases where malnutrition was identified, the patient was recommended to participate in a supplementary feeding program. It is probable that the nutritional status of pediatric patients improved by the time this study was conducted. However, the present study highlights the critical link between nutritional issues and pediatric tuberculosis (TB), noting problems such as difficulty gaining weight, refusal to eat, and financial constraints. These interconnected factors significantly influence the nutritional status, which is a crucial determinant of TB outcomes. Children with TB often struggle to gain weight because of the metabolic demands of infection. Previous studies have indicated a high prevalence (85%) of malnutrition among these children, correlating with disease progression and

poor clinical outcomes.<sup>38,39</sup> The metabolic demands of TB perpetuate a cycle that hinders recovery.<sup>40,41</sup> The link between TB and nutritional status is well-documented, with malnutrition being a major risk factor for developing and progressing the disease. Studies indicate that malnourished children are more susceptible to TB, with a high prevalence of poor nutritional status among pediatric TB patients.<sup>38,42</sup> A case-control study revealed that 68.6% of children with TB had poor nutritional status, compared to 14.3% in the control group, underscoring the impact of nutrition on TB incidence.<sup>42</sup> Additionally, malnourished children not only have a higher risk of contracting TB but also experience worse treatment outcomes, including delayed recovery and increased mortality rates.<sup>43</sup>

This study found deficient basic sanitation in families of children with TB. Studies showed that environmental factors such as water quality significantly impact TB epidemiology.<sup>44</sup> Water contaminants can cause malnutrition and weakened immune responses, increasing children's TB susceptibility.<sup>11</sup> Improving these essential conditions may reduce pediatric TB incidence and enhance health outcomes in vulnerable communities.

Efforts to control childhood tuberculosis in North Aceh Regency emphasize the family's crucial role. A study found that a family-based approach led to 71% of children receiving effective treatment with positive outcomes.<sup>45</sup> Tuberculosis control must address improved nutrition, as poor nutrition hinders recovery and increases the risks of comorbidities and mortality.<sup>46</sup> Enhancing children's nutritional status requires active parental involvement, with fathers especially responsible as primary providers.<sup>47</sup> In the context of TB, this family centered approach is particularly relevant as it allows for the integration of nutritional support and education within the family unit, addressing both the medical and psychosocial needs of the child.<sup>14,48</sup> Moreover, the epidemiological profile of pediatric TB often reveals a strong association with adult TB cases within the household, highlighting the importance of contact tracing and family involvement in prevention strategies.<sup>49</sup> The management of latent TB infection (LTBI) in children, especially those who have been in contact with active TB cases, is crucial for preventing the progression to active disease (Won et al., 2022). Family-centered interventions can facilitate the identification and treatment of LTBI, thereby reducing transmission rates and improving long-term health outcomes for children.<sup>50</sup>

In Indonesia, programs such as the Family Nutrition Awareness Program (KADARZI) involve family members, but do not specifically target the nutritional management of children with tuberculosis. The Supplementary Feeding Program (PMT) seeks to improve the nutritional status of children under five by providing food suited to their needs.<sup>51</sup> The target of the PMT is a malnutrition-prone group that includes underweight toddlers aged 6-59 months.<sup>52</sup>

The PMT targets underweight toddlers aged 6-59 months at risk of malnutrition.<sup>53</sup> Benefits for mothers who bring their children to Posyandu include regular monitoring of their children's weight and nutritional status, receiving pediatric health education, and accessing supplementary feeding programs. It is advised that all family members, including grandmothers, participate in this program.<sup>54</sup>

The government ensures the quality of anti-TB drugs via health offices. While drug provision in the North Aceh Regency is currently optimal, availability alone does not ensure a successful childhood tuberculosis prevention program. Effective implementation requires collaboration between healthcare professionals and cross-sectoral agencies. The Indonesian government has outlined six technical strategies for tuberculosis control, focusing on case-finding, treatment, and prevention. Thus, the involvement of multiple stakeholders, including cadres and village heads, is essential for tuberculosis control.<sup>55</sup> Limitations of this study warrant mentioned. First, the sample size of this study was small. Additionally, this study only included pediatric TB patients at one hospital, whereas TB patients could also receive treatment at a community health center.

## CONCLUSION

This study identified five themes related to pediatric tuberculosis in the North Aceh Regency: increasing TB cases, treatment challenges, nutritional issues, basic sanitation problems, and potential solutions. The increase in TB cases was linked to household tuberculosis contact, lack of BCG vaccination, and low socioeconomic status. Treatment adherence is hampered by medication side effects, parental neglect during follow-up visits, and limited parental knowledge. Nutritional and basic sanitation issues were common among the affected families. These findings emphasize the need for a family centered approach to pediatric TB management, emphasizing parental involvement in treatment adherence and nutritional support. Furthermore, government nutrition improvement initiatives should be tailored to TB infected children. Effective TB control requires collaboration among healthcare professionals, cross-sectoral agencies, and community stakeholders. Future interventions should focus on enhancing TB awareness, promoting BCG vaccination, addressing socioeconomic factors, improving treatment adherence strategies, and integrating nutritional support into TB management programmes. Recommendations included the involvement of family members, DOT providers, nutritionists, and hospital management in intervention the nutritional status of patients during TB treatment.

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**Availability of Data:** The data that support the findings of this study are available from the corresponding author upon reasonable request.

**Declaration of Generative AI and AI-assisted Technologies:** During the preparation of this study, the author(s) did not use Generative AI and AI-assisted technologies.

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