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Exploring experiences of mothers of children with thalassemia major in Indonesia: A descriptive phenomenological study

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Abstract

Background: Thalassemia is a hereditary blood disorder that poses significant challenges for affected children and their families. Caregivers, particularly mothers, often experience difficulties in managing their child's condition. Understanding their current experience is crucial for improving care and support.

Objective: This study aimed to explore the experiences of mothers caring for children with thalassemia in Banten, Indonesia.

Methods: A qualitative descriptive approach was employed, involving semi-structured in-depth interviews with eleven mothers of children diagnosed with thalassemia. Data were collected from April to May 2023. The interviews were audio recorded, and the data were analyzed verbatim using Colaizzi's method to identify key themes related to the experiences.

Results: Three themes were developed: 1) Perception of thalassemia as a genetic condition, 2) Emotional, logistical, and practical caregiving challenges, and 3) Support received by mothers in caring for children with thalassemia.

Conclusion: The findings highlight the multifaceted challenges faced by mothers of children with thalassemia and emphasize the need for improved communication, emotional support, and care coordination from nurses and healthcare providers. Future research should focus on expanding support systems and exploring effective interventions to enhance the quality of life for families navigating the complexities of chronic illness.

Keywords

Indonesia; thalassemia; child; caregivers; hematologic diseases; chronic disease

Background

Thalassemia is a hereditary blood disorder characterized by reduced or absent synthesis of hemoglobin, leading to chronic anemia and requiring lifelong medical management (Widyawati, 2022). Children have the right to receive treatment for health problems, including chronic diseases that last one year or more and necessitate ongoing medical intervention, resulting in limitations in daily living activities (Centers for Disease Control (CDC), 2022). Chronic diseases, such as thalassemia, affect children's long-term health and can have significant sequelae (Nóbrega et al., 2017). In Indonesia, prevalent chronic diseases include bronchial asthma, nephrotic syndrome, and thalassemia (Ministry of Health, 2020).

The global prevalence of thalassemia varies by region. According to World Health Organization 2019 data, approximately 5% of the world's population are carriers, with 300,000 to 400,000 new cases diagnosed yearly (Makkawi et al., 2021). In the United States, about 5% of the population has alpha and major thalassemia, and these conditions can be transmitted genetically (Smith, 2022). For patients with thalassemia major who receive blood transfusions and iron chelation therapy, life expectancy can exceed 50 years (Weidlich et al., 2016). In Indonesia, thalassemia carriers constitute about 3-8% of the population, leading to an estimated 3,000 births of affected children annually. There are 10,973 thalassemia patients in Indonesia, with 843 in Banten (Widyawati, 2022).

Primary treatment for major thalassemia includes blood transfusion and iron chelation therapy. Blood transfusions aim to prevent extramedullary hematopoiesis and optimize children's growth and development (Osataphan et al., 2023). The timing of these transfusions varies by patient, and complications from continuous transfusions, such as iron overload, require careful management to avoid severe health issues, including liver fibrosis (El-Beshlawy et al., 2023; Manara et al., 2019).

Thalassemia significantly impacts both children and their families. The disease has been shown to cause physical, psychosocial, and economic challenges (Kharyal et al., 2021). A study by Sen et al. (2019) revealed that 43% of children with thalassemia aged six years and older experienced mental health issues, including anxiety and mood disorders. Research by Chong et al. (2019) found that mothers of children with thalassemia experience psychological stress but

often develop positive coping mechanisms, such as engaging in religious activities.

Effective management of thalassemia requires coordinated care, which is particularly relevant to nursing practice. Nurses play a crucial role in supporting families through education, care coordination, and emotional support (Mardhiyah et al., 2023). They can help parents navigate the complexities of ongoing treatment, ensure adherence to medical regimens, and facilitate communication between families and healthcare providers. Understanding the experiences of mothers caring for children with thalassemia can inform nursing strategies aimed at improving family-centered care and addressing the emotional and practical challenges faced by these caregivers.

Several local studies have explored the challenges faced by mothers of children with thalassemia in Indonesia. Andriani et al. (2022) conducted a qualitative study that examined the fortitude of mothers caring for children with thalassemia, identifying themes such as denial, surrender, and acceptance through religious means. While the study provided valuable insights into maternal resilience, its focus was limited to six mothers, which restricted the generalizability of the findings. In addition, Utami et al. (2024) explored the relationship between parental support and the quality of life in children with thalassemia. This quantitative study found a significant correlation between family support and the child's well-being. However, this study was limited by its cross-sectional design, which only provided a snapshot of parental support at one point without examining changes in support over the long term. Additionally, the study did not explore the emotional and psychosocial challenges faced by mothers themselves, focusing solely on the children.

Apriani et al. (2024) investigated the relationship between social support and quality of life among parents of adolescents with thalassemia. The study concluded that social support significantly improves the quality of life for parents. While this study highlighted the importance of social networks, it was focused on adolescent caregivers and did not account for mothers of younger children. Yunike and Eprila (2022) studied the psychological conditions of mothers as caregivers for children with thalassemia. This case study revealed that many mothers suffer psychological stress due to the constant demands of caregiving. The research provided critical insights into maternal mental health, but its findings were based on a small, localized sample, which limits its generalizability to broader populations.

Despite these valuable contributions, significant gaps remain in understanding the broader challenges faced by mothers of children with thalassemia in Indonesia. Most existing studies either focus on a single aspect of caregiving or address only the mothers' resilience without providing a holistic view of their overall experiences. Additionally, many studies are limited by small sample sizes or cross-sectional designs, restricting the depth and applicability of the findings. Therefore, this study seeks to fill these gaps by investigating the experiences of mothers caring for children suffering from thalassemia. This study aims to offer comprehensive insights that will inform better healthcare.

Methods

Study Design

This study was conducted using a descriptive-phenomenological approach, with the primary aim of exploring the experiences of mothers of children affected by thalassemia. This approach was essential for exploring the unique individual phenomena, specific responses, and interactions among the participants. The research process involved several steps: bracketing, which required setting aside preconceptions or judgments; intuiting, remaining open to the meanings expressed by the participants; analyzing, which involved identifying significant statements, categorizing them, and assigning core meanings; and describing, which entailed understanding and articulating the essence of the phenomenon (Creswell & Creswell, 2018; Polit & Beck, 2018). Consolidated criteria for reporting qualitative research (COREQ) checklist (Tong et al., 2007) was used in this study.

Participants

Purposive sampling was employed to select participants based on the conceptual needs of the research. In qualitative studies, sample size is determined by achieving data saturation and redundancy (Polit & Beck, 2017). The selection process involved collaboration between the researchers and nurses in the children's ward to identify potential participants by screening parents of children with thalassemia. These prospective participants were further screened to ensure they met the inclusion criteria. The study population included parents whose children received thalassemia treatment at Dr. Adjiramo Regional Public Hospital in Banten, Indonesia. For the purpose of this study, eleven mothers were selected based on specific inclusion criteria: being the mother of a child with thalassemia, the child undergoing both blood transfusions and iron chelation therapy at the hospital, and the mother's willingness to participate. The final number of participants was determined once data saturation was reached, with no new information emerging from the interviews.

Data Collection

Data were collected from April to May 2023 through semi-structured in-depth interviews with each participant using interview questions (see **Table 1**), with the researcher applying bracketing, encouraging openness, and actively listening while preparing follow-up questions (Polit & Beck, 2017). Semi-structured in-depth interviews mean using open-ended questions to explore participants' experiences and emotions in detail. While guided by key topics, the interviewer follows the participant's responses, allowing for flexibility and more profound insights as the conversation flows naturally. The researchers developed the interview questions, drawing on their expertise in thalassemia and qualitative research. Pilot testing was not conducted, as the questions were based on established knowledge and prior research in the field, which was deemed adequate to guide in-depth exploration of the participants' experiences.

Prior to the interviews, the environment was set up to ensure comfort and a conducive atmosphere. The interviews were held in a meeting room at the hospital, and an audio recording device was used to capture the interaction between the researcher and participants. The device was placed on the

table between the researcher and participant to ensure clear audio quality. No one else was presented in the interviews. The interviews were conducted in Bahasa Indonesia. Each session of the interviews lasted 20–30 minutes, as agreed upon in advance. Participants' experiences were validated in the final phase, and there were no repeated interviews. Field notes were not made in this study.

Table 1 Interview questions

Interview Questions
• What do you know about major thalassemia?
• How did you feel when you learned that your child was diagnosed with major thalassemia?
• How do you feel about your child having to undergo repeated treatments at the hospital?
• What do you know about the blood transfusions your child receives for the treatment of major thalassemia?
• What do you know about the iron chelation therapy your child receives for the treatment of major thalassemia?
• What do you do at home regarding the care of your child with major thalassemia?
• Does your financial situation affect the management of your child with major thalassemia? Please explain how.
• What difficulties or challenges have you experienced?
• How do relatives, family, friends, and teachers contribute to the care of your child with major thalassemia? Please share your experiences.
• How do relatives, family, friends, and teachers hinder the care of your child with major thalassemia? Please share your experiences.
• What habits support the care of your child with major thalassemia?

Reflexivity

The interviews were conducted by the first female author (NHD), a nursing lecturer, with guidance and support from the other female authors—two professors and two lecturers—all holding PhDs in nursing with extensive experience and expertise in qualitative research. Importantly, there was no prior relationship between the authors and the participants; the participants only knew the authors in the context of conducting the study. This helped minimize potential bias.

Data Analysis

The data in this study were transcribed verbatim and then analyzed using Colaizzi's method. (Colaizzi, 1978). The analysis began with a thorough reading and re-reading of all transcribed interviews to gain a deep understanding of the participants' experiences. Significant statements directly related to the phenomenon were then identified and extracted from the transcripts, highlighting key elements of the participants' experiences. Following this, the researchers interpreted the significant statements, formulating meanings that captured the essence of what the participants intended to convey. These meanings were then organized into clusters of categories and themes, which revealed common patterns and shared experiences among the participants. Next, an exhaustive description was developed, integrating all the themes and significant statements to understand the phenomenon comprehensively. This detailed description was then distilled into a concise summary, capturing the fundamental structure or essence of the participants' experiences. Finally, the basic structure was returned to the participants for validation, ensuring that the analysis accurately reflected their perspectives. Any discrepancies identified during this process were addressed and incorporated into the final analysis (Colaizzi, 1978).

The analysis did not involve data coders or the creation of coding trees. Instead, the researchers directly examined the transcripts, highlighting relevant statements through careful reading and annotation. This approach allowed for a thorough understanding of the participants' experiences and perspectives, ensuring that the analysis remained closely tied to the original narratives. By prioritizing direct engagement with the data, the researchers aimed to capture the depth of the mothers' experiences, enhancing the richness and validity of the findings. This method reflects the qualitative nature of the study, emphasizing the importance of context in interpreting the participants' responses.

Please note that all data were analyzed in Bahasa Indonesia, and the English translation was provided solely for publication purposes. No software was also used for analysis.

Trustworthiness

The trustworthiness in this study was achieved through member checking, where each participant was invited to validate the interview results. This process involved sharing the findings and interpretations with the participants to ensure their experiences were accurately represented. Participants were encouraged to provide feedback and suggest any necessary adjustments, thereby enhancing the credibility of the research. The participants agreed with the findings; no changes were needed.

Ethical Considerations

Ethical approval for this study was granted by the Health Research Ethics Committee of the Faculty of Medicine, Universitas Sultan Ageng Tirtayasa (Approval number: 382 /UN43.20/KEPK/2023). Adherence to ethical principles was prioritized throughout the research. Autonomy was respected by obtaining informed consent from all participants, allowing them to share their experiences freely. Beneficence was ensured by fostering a comfortable and supportive environment during interactions, prioritizing the well-being of participants. Confidentiality and anonymity were maintained using initials and codes instead of personal identifiers. Finally, fairness was upheld by treating all participants equally throughout the research process.

Results

Table 2 presents the characteristics of eleven mothers of children with thalassemia, detailing participant demographics. Their ages range from 26 to 45 years, with educational levels varying from junior high to bachelor's degrees. All participants are married. The children's ages range from 3 to 15 years, with a near-equal gender distribution of six males and five females.

Table 2 Characteristics of the participants

Participant's Code	Mother	Mother's Age (Years)	Mother's Educational Level	Mother's Marital Status	Children's Age (Years)	Children's Gender
P1	Mother	36	Junior High School	Married	12	Male
P2	Mother	37	High School	Married	12	Male
P3	Mother	45	Bachelor's Degree	Married	13	Female
P4	Mother	28	Junior High School	Married	5	Male
P5	Mother	26	High School	Married	3	Female
P6	Mother	45	High School	Married	15	Female
P7	Mother	31	Bachelor's Degree	Married	5	Female
P8	Mother	29	High School	Married	8	Male
P9	Mother	44	High School	Married	11	Female
P10	Mother	28	High School	Married	8	Female
P11	Mother	31	High School	Married	7	Male

Three themes were developed from the analysis: 1) Perception of thalassemia as a genetic condition, 2) Emotional, logistical, and practical caregiving challenges, and 3) Support received by mothers.

Theme 1: Perception of Thalassemia as a Genetic Condition

Mothers' understanding of thalassemia was gathered from their expressions. A prominent theme emerged: the perception of thalassemia as a hereditary blood disorder characterized by weakness and paleness. This perception can be divided into two categories: 1) Anemia and Hereditary Disease and 2) Physical Symptoms: Fatigue, Dizziness, and Paleness. The first category highlights thalassemia as an inherited condition that is considered incurable. Participants expressed this view with statements such as:

"...red blood cells don't function properly, so they can't produce their red blood cells themselves..." (P1)
"...anemia, fatigue, paleness, requiring blood transfusions every two weeks, sometimes depending on the hemoglobin levels..." (P2)
"…it's said to have a lack of red blood cells..." (P6)
"...a genetic disease, genetic means it's hereditary..." (P4)
"...from their parents, from their DNA..." (P7)

The second category focuses on the symptoms associated with thalassemia, as expressed by the following statements:

"...regular transfusions are necessary, as without them, one can become fatigued and experience drops in health, and dizziness and so on..." (P1)
"...they appear pale, but you wouldn't suspect it because even though they're pale, they never look sick, like having a fever..." (P10)
"...they don't want to eat, they don't want to drink milk, they look pale..." (P9)
"...paleness, continued yellowing, and their stomach becomes hard..." (P3)

Theme 2: Emotional, Logistical, and Practical Caregiving Challenges

Mothers of children with thalassemia experience a range of emotional, logistical, and practical caregiving challenges that profoundly impact their daily lives. This theme includes emotional distress, logistical difficulties in accessing care, and practical issues related to medication management and dietary restrictions.

Emotional Challenges. Mothers express deep sadness and emotional turmoil associated with their child's diagnosis and ongoing treatment:

"...as a parent, I feel overwhelmed, a mixture of feelings, especially knowing that my child has thalassemia..." (P8)
"...my feelings are filled with sadness, and I wonder why it's my child who has to go through this..." (P5)
"...it's a mix of emotions, sadness, heartache, and everything; it feels like, 'Why me, Allah?' especially when we were told it's a lifelong condition (cries)…" (P3)
"...I felt like I was struck by lightning in broad daylight, sad for sure, especially when told it's a lifelong disease..." (P9)
"...just sadness, wondering why my child has thalassemia when it's not in our genes..." (P7)
"...sometimes he cries, wondering why he has to go to the hospital all the time, but his friends don't have to. He's tired of going to the hospital, saying it's exhausting, going back and forth to the hospital..." (P4)
"...he also gets angry when it's time to go to the hospital; he often doesn't want to go. He gets upset, doesn't want to go..." (P2)
"...whatever he asks for must be fulfilled; if he asks for something that day, it has to be done..." (P7)

Logistical Challenges. Mothers face significant logistical hurdles in managing their child's care, including difficulties in accessing treatment facilities:

"...the hospital is far, and getting there is expensive..." (P3)
"...it's challenging to coordinate appointments and treatments while managing daily life..." (P2)
"...we often have to miss work to take our child to the hospital, which adds to our stress..." (P4)

Practical Caregiving Challenges. Mothers encounter various practical difficulties ensuring adequate care, particularly in medication management, dietary restrictions, and communication with healthcare professionals.

The mothers struggle with adhering to medication schedules:

"...we used to give medication, back when we were in Tangerang; now we don't give medication anymore..." (P1)
"...we still have the medication; it should have run out last month because it's been a month..." (P3)
"...the medication is supposed to be taken three times a day, but it's a big pill, so it's challenging. Yes, it needs to be crushed, and sometimes we need to give candy to make it more palatable..." (P9)
"...not taking medication regularly..." (P11)

The mothers report confusion and inconsistency regarding dietary guidelines:

"...they shouldn't eat a lot of stuff, like offal. It's not that they can't eat it, but it's just not too much, and sodas are a no-no..." (P10)
"...yes, it's mostly about not drinking certain things, that's it..." (P7)
"...the doctor rarely mentions restrictions; maybe green, leafy vegetables like spinach..." (P3)
"...there's been no information at home about what should or shouldn't be done..." (P5)

The mothers highlight gaps in information and support from healthcare providers:

"...they didn't inform us..." (P6)
"...the doctor said the medication is expensive, but it must be taken; it's important..." (P2)
"...it has to be taken (the medication) because blood transfusions are not the best solution; we're afraid there won't be enough iron, and it might affect the heart, liver, and other things..." (P8)
"...we haven't been given information about the medication; we only looked it up on Google..." (P5)

Theme 3: The Support Received by Mothers in Caring for Children with Thalassemia

Mothers caring for children with thalassemia receive vital support from their husbands, teachers, and healthcare professionals. This support is essential for managing both the emotional and practical aspects of caregiving. The theme of support is categorized into three categories:

Husbands' Involvement in Medical Treatment and Blood Donor Searches. Husbands play a significant role in supporting mothers by taking their children to medical appointments, persuading them to undergo treatment, and searching for blood donors. Participants shared their experiences:

"...Support from the husband, he persuades the child, takes them to the hospital, and searches for blood donors. For instance, I accompanied them back then because I didn't fully understand the situation, so we would go together. Nowadays, I go alone to save costs." (P9)
"...He persuades their child to go to the hospital..." (P11)
"...Thankfully, he helps and actively seeks blood donors..." (P3)
"He willingly takes them to the hospital. Earlier, when I was working, he would go with the child, but for the past two years, he often goes alone on a motorcycle..." (P10)
"...Sometimes, he goes with (them to the hospital) because I have work, and I can't always accompany them to the hospital..." (P2)

Teachers' Support for Children's Activities. Teachers also provide support by adjusting school activities to accommodate the physical limitations of children with thalassemia. This ensures that children can participate in school life without overexerting themselves. As described by a participant:

"...Teachers ask for parental consent for school activities, so they are not as strenuous as, for example, sports or other physically demanding activities..." (P1)

Friendly and Supportive Healthcare Providers. Doctors and nurses play an instrumental role by offering medical care in a friendly, compassionate manner. They adhere to proper procedures, refer patients to hospitals with specialized care, and provide emotional encouragement to parents. Participants reflected on the support from healthcare professionals:

"...The medical staff are friendly, and they follow the proper procedures..." (P6)
"...At one point, a doctor visited our home to conduct an examination, and they recommended going to the community health centers for a comprehensive check-up..." (P3)
"...Here at this hospital, and at times, the child was referred to (another hospital) in Tangerang, on two occasions, to receive Ferriprox..." (P9)
"...The doctor encouraged me not to lose hope, saying, 'If you give up, who will take care of your child? You will meet other parents who face similar challenges and won't be alone. Insha'Allah, you'll find many friends to support you..." (P8)
"...When the child was nine months old, they were referred to (another hospital) Kartini, and their hemoglobin was at 6..." (P4)
"...They were referred to Adjidarmo Hospital just to ensure that it was only thalassemia and not a more severe condition..." (P11)

Discussion

Summary of the Findings

The first theme highlights the perception among mothers that thalassemia is a hereditary and incurable genetic condition. This understanding aligns with the scientific definition of thalassemia as a genetic blood disorder, specifically an autosomal recessive hereditary anemia characterized by impaired or absent synthesis of globin chains. As outlined by Fucharoen and Weatherall (2016), thalassemia involves the intracellular precipitation of unpaired globin chains, leading to ineffective erythropoiesis, increased destruction of erythroid progenitors during their maturation, and intramedullary hemolysis. De Simone et al. (2022) further explain how this leads to severe anemia requiring long-term treatment, often with blood transfusions and iron chelation therapy, reflecting parents' recognition of the genetic and chronic nature of the disease.

The first category, *Anemia and Hereditary Disease*, reflects mothers' understanding that thalassemia is an inherited condition passed down through families and is incurable. This perception corresponds with the findings of Chuncharunee et al. (2019), who discuss the complications associated with blood transfusion-dependent thalassemia, such as severe iron overload, splenectomy-related risks, and pulmonary hypertension. These complications reinforce the parents' view of thalassemia as a serious, lifelong condition with complex health challenges. The second category, *Physical Symptoms: Fatigue, Dizziness, and Paleness*, is characterized by physical symptoms observed by parents in their children, such as fatigue, pallor, and dizziness. These symptoms align with medical descriptions of thalassemia, where ineffective erythropoiesis results in hypochromic, microcytic red blood cells, leading to chronic anemia and related symptoms (De Simone et al., 2022). The common manifestations of fatigue and pallor reflect the weakened state of children with thalassemia, which often require regular transfusions to manage these symptoms (Freedman, 1988). Thus, the parents' understanding of thalassemia as a genetic, chronic disease causing weakness and requiring continuous medical intervention is consistent with clinical literature. Their observations and lived experiences align closely with the medical understanding of the condition.

The second theme reveals that mothers of children with thalassemia face a wide range of emotional, logistical, and practical caregiving challenges that significantly impact their

daily lives. These challenges include emotional distress, difficulties in accessing healthcare, and issues related to medication management and dietary restrictions. These experiences align with existing literature on the impact of chronic childhood illnesses on caregivers. Emotionally, parents often experience deep sadness, grief, and helplessness following their child's diagnosis of thalassemia, a common reaction to chronic childhood illnesses (Binbay et al., 2013; Yunike & Eprila, 2022). These emotional responses are also reflected in the findings of Andriani et al. (2022), where mothers reported emotional stress, sadness, fear, and difficulty managing their emotions. The emotional burden is intensified when children express reluctance to undergo treatments or visit hospitals, adding further strain on the parents. In addition to the emotional challenges, children themselves may experience psychological symptoms in response to the limitations imposed by thalassemia. Participants noted that children sometimes have frustration, tantrums, or withdrawal, reflecting the emotional and psychological toll of their condition. This aligns with the findings of Cappellini et al. (2017), who noted that children with thalassemia often experience lower emotional well-being compared to their peers without chronic illness.

Logistically, families face significant challenges in accessing care. High costs, long distances to medical facilities, and the need for frequent hospital visits contribute to parental stress. These logistical hurdles are exacerbated by the requirement for ongoing treatments like blood transfusions and iron chelation therapy (Wensing et al., 2021). The time commitment and financial strain often lead to feelings of burnout among caregivers, complicating their ability to manage both caregiving and work responsibilities.

Practically, managing a child's thalassemia treatment poses additional difficulties. Medication adherence and understanding dietary restrictions are frequent sources of confusion, especially when healthcare providers provide inconsistent guidance. This highlights the importance of effective communication between healthcare providers and families to ensure proper care coordination (Wensing et al., 2021). Participants reported inconsistent communication, further complicating managing their child's condition. Overall, mothers experience a multifaceted burden involving emotional distress, logistical difficulties, and practical caregiving challenges. Improved communication from healthcare providers, better logistical support, and emotional resources are essential to alleviate these burdens and enhance the quality of life for the children and their caregivers.

The third theme focuses on the support systems available to mothers of children with thalassemia. Support from husbands, teachers, and healthcare providers is crucial in managing the emotional and practical aspects of caregiving, reducing the burden on mothers, and enhancing their caregiving capacity. Husbands play a pivotal role in supporting their children's medical care by accompanying them to hospital appointments and actively searching for blood donors. This involvement helps reduce the emotional and logistical burdens faced by mothers. Research by Yildirim et al. (2022) highlights that families with higher levels of social support, including spouses, perceive a lower caregiving burden and report better quality of life, highlighting the importance of engaged partners in managing thalassemia care.

In addition, teachers provide support by modifying school activities to accommodate the physical limitations of children with thalassemia. This ensures that children can still participate in school without overexerting themselves, which is essential for their psychosocial development. As noted by Cappellini et al. (2017), maintaining age-appropriate activities and a positive outlook on life significantly contributes to a higher quality of life for children with thalassemia. The support provided by teachers allows children to navigate school life while managing their condition, reinforcing the critical role of a supportive educational environment.

Support from healthcare providers is another crucial factor in managing thalassemia care. Participants reported that friendly, compassionate healthcare professionals helped them navigate the complexities of their child's treatment. Continuity of care, especially for chronic conditions like thalassemia, is an essential aspect of integrated care. García-Vivar et al. (2022) and Boyer et al. (2020) emphasize that effective care coordination improves patient safety and quality of life. Healthcare providers who offer both medical and emotional support greatly enhance the well-being of both children and their caregivers.

Culturally sensitive care also contributes to more effective treatment outcomes. Studies by Narayan and Mallinson (2022) and Larsen et al. (2021) suggest that cultural sensitivity improves communication between healthcare providers and patients, leading to better treatment adherence and greater trust in the healthcare system. This aligns with the experiences of the mothers in this study, who appreciated the empathy and support from healthcare providers who understood their challenges.

It is noted that the support received by mothers of children with thalassemia from their husbands, teachers, and healthcare providers is essential in managing the complex challenges of caregiving. This support reduces emotional burdens, enhances care coordination, and improves outcomes for both children and their caregivers. Research indicates that strong social support systems significantly reduce caregiving stress and improve the quality of life for families managing chronic illness (Yildirim et al., 2022).

Implications of this Study for Nursing Practice

The findings from this study highlight important implications for nursing practice in the context of caring for children with thalassemia and their families: 1) Enhanced communication strategies are essential, allowing nurses to provide clear, consistent information about thalassemia, treatment options, and potential complications; 2) Regular updates regarding the child's health and treatment plans, along with addressing any questions or concerns, can significantly benefit families; 3) Emotional support is another critical aspect, given the emotional distress reported by parents, particularly mothers. Nurses should not only focus on medical care but also offer emotional encouragement, actively listening and validating parents' feelings. Connecting families with mental health resources when necessary can further support their well-being; 4) Care coordination is a pivotal role for nurses, ensuring that all aspects of a child's treatment—such as medication management, dietary restrictions, and follow-up appointments—are effectively managed. Liaising with other healthcare professionals will help ensure comprehensive care

for the child; 5) Providing educational resources tailored to the needs of families can empower them to manage their child's condition more effectively. Practical guides on medication adherence, dietary management, and coping strategies for emotional challenges can be invaluable; 6) adopting a family-centered approach in nursing practice can enhance support systems for children and their caregivers. Engaging fathers, teachers, and other caregivers in the treatment process creates a more supportive environment for the child.

Strengths and Limitations of the Study

The study's novelty lies in its comprehensive exploration of mothers' perceptions of thalassemia as a hereditary, incurable condition, highlighting their emotional, logistical, and practical caregiving challenges. It uniquely emphasizes the interconnectedness of these challenges and the critical role of support systems, including healthcare providers and educators, in alleviating mothers' burdens. Strengths of the study include its qualitative approach, which captures the nuanced experiences of mothers, and its potential to inform targeted interventions that enhance care coordination. By integrating these insights, the findings contribute to a deeper understanding of the complexities of caregiving in thalassemia, improving the quality of life for affected families.

However, several limitations must be acknowledged. The sample size may restrict the generalizability of the findings. Future research should aim to include a larger and more diverse group of participants to capture a wider range of experiences and perspectives. This study was conducted in a specific geographic area; the findings may not be applicable to families in different regions or countries. Future studies should explore the experiences of families in various cultural and socioeconomic contexts to broaden the understanding of caregiving in thalassemia. This study also primarily focuses on the current experiences of caregivers. Longitudinal research could provide deeper insights into how caregiving experiences evolve over time and how interventions may affect caregivers' emotional well-being. Additionally, considering the perspectives of children with thalassemia in future research could provide a more holistic view of the impact of the disease on family dynamics. Understanding their experiences and emotional responses is essential. Lastly, further studies should evaluate the effectiveness of specific interventions aimed at improving emotional support, care coordination, and educational resources for families. Identifying best practices for nursing care in this population can lead to more effective strategies for supporting families facing the challenges of chronic illness.

Conclusion

This study highlights the significant challenges faced by mothers caring for children with thalassemia, emphasizing the need for comprehensive support systems and effective communication from healthcare providers. The findings reveal the emotional, logistical, and practical burdens of caregiving, as well as the critical role that support from husbands, teachers, and healthcare providers plays in alleviating these challenges. Nursing practice must adapt to these insights by prioritizing family-centered care, enhancing communication, and providing emotional and logistical support. Future research should focus on expanding the understanding of these experiences across diverse populations and exploring interventions that can improve the quality of life for children with thalassemia and their caregivers. By addressing the multifaceted needs of these families, healthcare providers can contribute to better health outcomes and improved well-being for all involved.

Declaration of Conflicting Interest

The authors declared no conflict of interest.

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Authors' Contributions

Nelly Hermala Dewi came up with the research idea, determined the research design, collected and analyzed research data, and drafted the manuscript. The other authors (Setyowati, Enie Novieastari, Rr. Tutik Sri Hariyati, and Allenidekania) contributed to research design, literature review, data analysis, and manuscript review. All authors met the authorship criteria and approved the final version of the article to be published.

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Data Availability

Supporting data for qualitative analysis are available upon reasonable request to the corresponding author.

Declaration of Use of AI in Scientific Writing

None to declare.

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