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Original Research

Parental Experiences in Caring for Children with Thalassemia Major in Tangerang: A Phenomenology Study

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ABSTRACT

Thalassemia major can lead to significant physical, psychological, and social challenges that reduce a child's quality of life and increase the burden on the family. Parents play a crucial role in the care of children with thalassemia major; however, they often face significant challenges. This study aimed to explore the lived experiences of parents whose children have been diagnosed with thalassemia major at a private hospital in Tangerang. This research employed a descriptive phenomenological qualitative design conducted between October and November 2024. Participants were selected through purposive sampling and included 10 parents of children with thalassemia major receiving care at a private hospital in Tangerang. Data were collected through in-depth interviews guided by seven open-ended questions. All interviews were audio-recorded and transcribed verbatim. Data analysis was conducted using Colaizzi's 1978 method. The study's findings the analysis revealed four major themes: 1) Psychological upheaval, 2) Burdens of caring, 3) Affirmative attitudes, and 4) Psychosocial support for the child. Conclusion this study highlights the significant experiences of parents caring for children with thalassemia major. Recommendation is, understanding parents' experiences can help nurses and healthcare providers offer more comprehensive support and develop holistic interventions that assist parents in adapting more effectively and improving their overall quality of life.

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INTRODUCTION

According to the Centers for Disease Control and Prevention (CDC), thalassemia is an inherited blood disorder that leads to the body generating inadequate levels of hemoglobin (CDC, 2024). It is one of the most common chronic genetic disorders, affecting populations in more than 60 countries worldwide, with an estimated 100,000 babies born each year with the disease (Nabavian et al., 2022). Thalassemia is particularly prevalent in tropical regions, including the Mediterranean, the Middle East, and Southeast Asia, where the incidence can reach up to 10% (Ali et al., 2021). Indonesia is part of the global "thalassemia belt," a region with a high prevalence of thalassemia carriers.

It is estimated that between 3% and 10% of the Indonesian population are carriers of the thalassemia gene (Kemenkes, 2023).

The number of thalassemia cases in Indonesia showed an increasing trend from 4,896 cases in 2012 to 8,761 cases in 2018. By 2019, the number had risen to 10,500, and approximately 1,500 new cases are diagnosed each year (Wahidiyat et al., 2022). Based on data from the Indonesian Thalassemia Foundation in June 2021, there were 10,973 cases of people with thalassemia in Indonesia (Kemenkes, 2022). In Indonesia, the highest prevalence of thalassemia was found in West Java Province, with around 3,300 children affected, followed by DKI Jakarta with 2,200 children affected (Sabono et al., 2020).

Individuals with thalassemia require ongoing medical treatment, primarily through regular blood transfusions to compensate for the reduced production of red blood cells and desferal injections to manage the iron overload that results from repeated blood transfusions (Wahidiyat et al., 2022). Despite treatment, children with beta-thalassemia major often experience reduced quality of life (Sharma et al., 2017). Therefore, as primary caregivers, parents play a crucial role in providing care and support.

However, caring for a child with thalassemia often presents parents with numerous challenges. These include emotional and social stress (Nabavian et al., 2022). Previous studies have documented the significant pressure faced by parents as they attempt to manage their child's medical care (Biswas et al., 2018; Mashayekhi et al., 2016). Parents frequently experience intense psychological stress, including feelings of frustration, sadness, helplessness, and hopelessness (Nabavian et al., 2022a). The study found that 82% of parents of people with thalassemia felt anxious about the future, while 66% of them stated that their lives had lost their joy (Abu Shosha & Al Kalaldeh, 2018). Therefore, understanding parents' experiences in caring for a child with thalassemia is essential for nurses to deliver comprehensive and holistic care that addresses the needs of both the patient and their family. Given the limited research on this subject in Indonesia, this study aimed to explore the issue more thoroughly.

METHOD

This study used a descriptive qualitative method with a phenomenological approach to explore the experiences of parents caring for children with thalassemia major. Phenomenology is a research approach that seeks to understand the essence of a phenomenon by examining it through the lens of individuals who have personally experienced it. The goal of phenomenology is to ascertain the significance of this experience, both in terms of what was experienced and how it was experienced (Teherani et al., 2015). The participants in this study were parents of children diagnosed with thalassemia major who were receiving care in the One Day Care (ODC) unit at a private hospital in Tangerang. A purposive sampling was employed to recruit participants based on the following inclusion criteria: (1) biological parents (either father or mother) of a child with thalassemia major, (2) physically and mentally healthy, and (3) able to communicate in Indonesian. The participant recruitment process began after obtaining ethical approval and official permission from the hospital. The researchers initially coordinated with the head of the ODC unit, explaining the study's objectives and data collection procedures. Following this, the second and third researchers approached eligible parents, provided detailed information about the study, and invited them to participate. Those who expressed interest and consented were personally contacted to arrange a suitable time and location for the interview.

This study was conducted from October to November 2024. Ten parents of children with thalassemia major were recruited, scheduled, and interviewed in a private room within the hospital, away from noise and distractions, as agreed upon by both parties. To ensure the validity and clarity of the interview guide, a pilot interview was conducted with one participant prior to the data collection process. Based on the pilot, some questions were revised for better clarity and logical flow. Since the pilot's purpose was to test the interview tool, the data from this interview was not included in the main analysis. Data was collected through semi-structured, in-depth interviews using seven guiding questions (Table 1). Field notes were taken to capture the researchers' observations, and all interviews were audio-recorded. Before the interview, the researchers introduced themselves and provided a detailed explanation of the study, including its objectives, confidentiality, and potential benefits and risks to participants. Those who agreed to participate completed a demographic questionnaire, including age, gender, educational background, ethnicity, and number of children with thalassemia, followed by signing the informed consent form. Meanwhile, those who chose not to participate were not interviewed. All participants approached by the researchers agreed to participate in this study.

Each interview lasted approximately 20 to 25 minutes and was audio-recorded. Each interview was conducted by the second and third researchers during the data collection phase. The third researcher served as the main interviewer during the interviews, and the second researcher recorded non-verbal clues and asked questions that had not been addressed. Ten participants in all were enlisted, and as the interviews yielded no new information, data collection was stopped after saturation was achieved. Data collection and analysis were done at the same time. After each interview, the data was examined by first, second, and third researchers to look for any new trends in the transcript and see whether the fresh data had any new information. The researcher team decided that data saturation had been achieved when the interviews yielded no new information.

Table 1. Interview Questions

No	Questions
1	When was your child diagnosed with thalassemia major? What came to your mind when you first heard that your child was diagnosed with thalassemia major?

2	How do you feel when your child is undergoing treatment?
3	What challenges do you face in this regard?
4	What are your concerns about your child's condition?
5	What is your experience of having a child with thalassemia major?
6	Has having a child with thalassemia majorly affected your life?
7	How do you deal with your child's emotional instability when they have to follow routine medication such as blood transfusions and taking desferal medication?

Data Analysis

All recorded interviews were transcribed verbatim in Indonesian. To ensure transcript accuracy, the first, second, and third researchers independently listened to the recordings multiple times and compared them against the transcripts for consistency and completeness. Data analysis was carried out by the first, second, and third researchers using the steps of the phenomenological analysis method, according to Colaizzi 1978, cited in Edward & Welch (2011). The steps include thoroughly reading data transcripts, marking relevant statements, interpreting the meaning of statements, clustering meanings into sub-themes and themes, developing phenomenological descriptions, and condensing the complex information into a concise, clear, and meaningful statement that sums it up. The analysis resulted in four main themes that were elaborated into 13 sub-themes.

This research applied four criteria to maintain the rigor of the analysis, namely credibility, dependability, confirmability, and transferability (Polit & Beck, 2012). Credibility was maintained by determining the location of the interviews with the respondents so that they felt safe and comfortable. Dependability was achieved by using the same interview guide and explaining the data collection and analysis process in detail. Using field notes and recordings that were available to the entire team, as well as collaborative data evaluation and consensus among the researchers, confirmability was guaranteed. Confirmability was ensured by collaborative data evaluation and consensus among the researchers, as well as the use of field notes and recordings that were accessible to the entire team. To ensure the transferability of this study, participants' data and background information were presented, therefore, other researchers were able to evaluate the results' applicability and extrapolate them to similar populations.

Ethical Consideration

This study has been approved by the ethical committee of the Faculty of Nursing, Universitas Pelita Harapan, with number No.014/KEP-FON/VIII/2024. All participants have been informed that their involvement is voluntary without any coercion from any party, as evidenced by the signed informed consent. To maintain confidentiality, each participant was assigned a unique code to replace their real name. All data were securely stored on password-protected devices, accessible only to the research team, and used solely for research purposes.

RESULT

As seen in table 2, a total of 10 participants, all of whom were parents of children with thalassemia major, participated in this study. Most of the participants were female comprising 70 % of the participants. In terms of age distribution, 40% of the participants were within the age ranges of 36–40 and 46–50 years. Majority of participants completed their education at university level as much as 60 %. Regarding ethnicity, 30% of the participants were of Sundanese or Tionghoa backgrounds. Additionally, 80% of participants had at least one child diagnosed with thalassemia major.

After examining the data obtained from the interviews, the researchers discovered four main themes about parental experiences caring for children with thalassemia major: 1) psychological upheaval, 2) burdens of caring, 3) affirmative attitudes, and 4) psychosocial support for the child. As seen in table 3, these four themes were further developed into thirteen subthemes.

Table 2. Participants' sociodemographic characteristics (n=10)

Characteristics	Frequency (n)	Percentage (%)
Age		
30-40	4	40
41-45	1	10
46-50	4	40
50	1	10
Gender		
Female	7	70
Male	3	30
Education Level		
University level	6	60
Senior high school	2	20
Junior High School	1	10
Elementary School	1	10
Ethnicity		
Jawa	2	20
Sundanese	3	30
Tionghoa	3	30
Betawi	1	10
Palembang	1	10
Number of children with Thalassemia Major		
1	8	80
>1	2	20

Table 3. Themes and Sub-themes of Parental Experience of Caring for Children with Thalassemia Major

Theme	Sub-theme
Psychological upheaval	Uncontrollable feelings Uncertainty of Children's Future
Burdens Of Caring	Giving up on professional or personal roles Family conflict Financial hardship Limitations in social lives.
Affirmative Attitudes	Gratitude Acceptance Spousal connection Communion with God
Psychosocial support for the child	Communication technique Fostering self-confidence Parental fairness

Theme 1. Psychological Upheaval

Upon receiving the diagnosis of thalassemia major from the doctor, the parents reported experiencing intense psychological upheaval. Two subthemes emerged from their responses: 1) uncontrollable feelings, and 2) uncertainty about children's future.

Sub Theme 1.1 Uncontrollable feelings

Uncontrollable feeling is an important sub-theme that refers to the feelings that parents felt when their child was first diagnosed by a doctor with major thalassemia. Most parents revealed that they experienced various kinds of emotional turmoil due to the treatment and actions that their child would undergo.

> *"When I first found out about the diagnosis...it was like the world collapsed... I was hopeless..." (Participant 1).*
> *"… As a new parent, I was still in denial and struggling to accept the diagnosis..." (Participant 6).*
> *" As a mother, I felt heartbroken and overwhelmed…I couldn't hold back my tears… It was an emotional mix…it was so difficult to bear" (Participant 9).*

Parents expressed that, upon first hearing the diagnosis that their child had thalassemia major, they were overwhelmed with shock, confused, and in denial because they had no prior understanding of what thalassemia was.

> *" …I didn't know what thalassemia was ... I read about it ... it turns out it's hereditary ... I was shocked at that time ... I was confused …" (Participant 7)*
> *" … At first, I didn't understand...I didn't accept it...I couldn't believe it...how could my child be like this?" (Participant 8)*

Sub-theme 1.2 Uncertainty of children's future

Many parents shared worries about the uncertainty surrounding their children's future. Parents stated concerns that their children might have to halt their education and miss the chance to attend university. One parent was especially anxious about the child's development, fearing it wasn't progressing typically compared to other children. There were also concerns about inadequate blood supply, the potential loss of their children, and fears about their children's life expectancy.

> *" …because of illness... prevented from entering... a big company... he (patient) wanted to go to a public university outside the city" (Participant 2)*
> *" …I'm afraid he (the patient) is weak... can't play like other children... growth problems... his height is not normal... hair loss continues to be red" (Participant 6)*
> *" …Worried about not getting the blood, sometimes the stock of blood is empty…" (Participant 4).*
> *" ...very worried...about his future...can he live a long life? can he be healthy like everyone else?" (Participant 5).*

Theme 2. Burdens of Caring

While caring for children with thalassemia major, parents reported facing challenges across multiple areas of life, which were categorized into four key sub-themes: (1) giving up on professional or personal roles, (2) family conflicts, (3) financial difficulties, and (4) limitations in social lives.

Sub-theme 2.1 Giving up on professional roles.

Three out of ten parents said they decided to quit their jobs so they could care for their children.

> *"…I resigned because I'm a single parent...I'm the only one who is relied on… "(Participant 10)*
> *"…In the past I worked, but having a child like this...I stopped…" (Participant 7)*
> *"...I resigned…because I knew my child... was positive for thalassemia major.... very dilemma…I can't be a working mother…because the best helper is the mother" (Participant 6).*

Sub-theme 2.2 Family conflicts

Two parents also shared that caring for children with thalassemia major also brought them into conflict with their partners because they blamed each other and even asked their partners to remarry someone else.

> *"...At first, we (the parents) stayed quiet…there was tension between us. Since it's a hereditary condition, he (the husband) said... "it's from your side of the family" (referring to the wife) (Participant 4).*
> *"…In the early days of our marriage, it was quite difficult...almost like something was constantly weighing on us. There was even talk from my husband about wanting to remarry someone who doesn't carry thalassemia… If we didn't have strong faith, things could've fallen apart… our marriage might not have survived (Participant 6).*

Sub-theme 2.3 Financial hardship

Some parents also complained that the money spent on medical expenses and transportation was quite expensive.

> *"…The financial aspect is a concern... it makes us a bit anxious. The treatment is costly due to lifelong blood transfusions, expensive medications". (Participant 4)*
>
> *"…The financial burden was significant... we used to spend around seven to eight million rupiah each month. We had to travel back and forth to the hospital". (Participant 5).*

Sub-theme 2.4 Limitations in social lives

Parents shared that when their children were first diagnosed with thalassemia major, they felt unprepared and chose to withdraw, often keeping their child's condition hidden from others.

> *"…I distanced myself from friends…I don't want to be asked about my child's condition" (Participant 1).*
>
> *"I still keep it a secret... only close relatives know that my child has thalassemia. My child feels ashamed about it" (Participant 7).*

Theme 3. Affirmative Attitudes

Despite the burden of care felt by parents, they showed affirmative attitudes that they felt because of caring for children with thalassemia major. This theme includes four sub-themes consisting of: 1) Gratitude, 2) Acceptance, 3) Communion with God, and 4) Spousal connection.

Sub-theme 3.1 Gratitude

Parents stated that taking care of children with thalassemia major made their gratitude increase because it turned out that there are still other people who are more difficult than they are.

> *"…I've learned to be grateful... it has allowed me to better understand the struggles that others face." (Participant 9)*
>
> *"…Grateful that my child's condition is like this...there are still many other children who are in worse condition than him (the patient)." (Participant 4).*
>
> *"...I've become more thankful, as I've come to realize that many others are facing even greater challenges than we are…" (Participant 1).*

Sub-theme 3.2 Acceptance

Parents of children with thalassemia major experienced a journey from fear and anxiety to acceptance. Although parents initially felt out of control, they now focus on their child's health and happiness by living life with a positive attitude.

> *"Over time...Eventually, we accepted it and now we feel at peace" (Participant 4).*
>
> *"For our family, it doesn't feel like a burden at all because we've accepted it. We just live our lives and keep moving forward."(Participant 6).*
>
> *"Lately, I've just been choosing to stay positive. I try to enjoy things and not stress. As long as my child (the patient) is healthy and growing well, that's what matters. I've come to accept everything wholeheartedly" (Participant 8).*

Sub-theme 3.3 Communion with God

Two parents expressed that caring for children with thalassemia major made them feel grateful because they believe God entrusted and chose them to care for this child. It also led them to pray more often.

> *"…I fully surrender to Your will, O Allah. Thank You for blessing me with the trust of raising my child…" (Participant 8).*

"…This is a test from Allah… our children are merely entrusted to us… which is why, as parents, we need to pray even more…" (Participant 4).

Sub-theme 3.4 Spousal Connection

Several mothers shared that facing their child's illness has brought them closer to their partners, strengthening their bond and mutual support in the healing journey.

> *"...My husband and I feel that this experience has made our relationship stronger and more united. We know we must keep supporting each other and face everything together." (Participant 9).*
>
> *"…Working alongside my husband, staying motivated, so that we can achieve our dreams and see our child (the patient) heal." (Participant 8).*

Theme 4. Psychosocial Support for The Child

Parents shared various strategies they use to help their children cope emotionally with the effects of treatment. The support given by parents to children consists of psychosocial and spiritual support, described in three sub-themes: 1) communication techniques, 2) fostering self-confidence, and 3) parental fairness.

Sub-theme. 4.1 Communication technique

Effective communication between parents and children with thalassemia is expressed by parents as an important form of support. Parents stated that when communicating with their child, the strategy used is to give the child space to share, provide understanding, and allow the patient to make decisions.

> *"…For me, the most important thing is the support from parents...being close to your child and maintaining good communication." (Participant 9).*
>
> *"...I keep quiet for a bit... Let them talk when they're ready... Nowadays, they're more open about their school... starting to share more with me" (Participant 3).*
>
> *"I simply say... It's your choice... You (the patient) know yourself best, you understand your condition… we just try to be understanding... It's all about how we approach them (Participant 4).*
>
> *"…just remind to stay consistent with the transfusions… Let the child make their own choices." (Participant 2).*

Sub-theme 4.2 Fostering self-confidence

Building self-confidence in children with thalassemia is a crucial aspect of parental support. Parents assisted their children by allowing them to participate in activities while also managing how long they can engage in them, helping the child feel more assured in their daily life. This is proven in the following statement.

> *"I... always nurture his (the patient's) self-confidence. Whatever activity he wants to do, I allow it, but... I limit the duration. (Participant 9).*

Sub-theme 4.3 Parental fairness

Being fair to all the children in the family is important for creating a harmonious environment. By treating the children with major thalassemia, the same way as their siblings, parents show that all children have equal value, without any discrimination.

> *"I have a better understanding of his condition. I treat him just like his siblings, without making any difference between them..." (Participant 5).*

DISCUSSION

Using a phenomenological approach, this study offers a unique and in-depth understanding of parents' lived experiences in caring for children with thalassemia major. Four themes were identified: 1) psychological upheaval, 2) burdens of caring, 3) affirmative attitudes, and 4) psychosocial support for the child.

Psychological upheaval was commonly experienced by parents following early diagnosis, the initiation of lifelong medical treatment, limited access to information, and uncertainty about their child's future. These findings align with Abu Shosha & Al Kalaldeh (2018), who reported that mothers of children with thalassemia often face psychological distress, especially regarding concerns about their children's education, career, and marriage prospects (Nabavian et al., 2021). Pouraboli et al. (2017) further highlighted that persistent feelings of anxiety, fear, and despair regarding their child's future are significant sources of emotional turmoil. These emotions can severely affect mental health and strain family relationships (Behdani et al., 2015). Hood et al. (2024) also emphasized that parents who struggle to accept their child's diagnosis often suffer from poor mental well-being, which can impact their daily functioning. Therefore, holistic interventions are needed to support parents' mental health and equip them with adaptive coping strategies (Punaglom et al., 2019).

This study shows that parents of children with thalassemia face various burdens, such as job loss, family conflict, financial difficulties, and social limitations. Caring for a child often forces parents to take leave or stop working, which can trigger a loss of identity and purpose (Abu Shosha et al., 2022; Nabavian et al., 2022; Suryani & Murniati, 2020). Financial difficulties are a recurring issue in low-income households, given the costs associated with long-term treatment and hospitalizations (Biswas et al., 2018; Nabavian et al., 2022; Shahraki-Vahed et al., 2017). These difficulties can lead to family conflict and reduced quality of life (Biswas et al., 2018), often triggered by differences in views and values (Madmoli et al., 2017; Pouraboli et al., 2017). Some parents also withdraw from social settings due to shame and fear of criticism. In line with a study in Iran conducted by Nabavian et al. (2022) where counseling was suggested as a form of support to ease the burden on families.

Despite these challenges, many parents demonstrated affirmative attitudes, such as gratitude, acceptance, strengthened marital relationships, and spiritual growth. Gratitude serves as a powerful coping mechanism, enabling individuals to find meaning and maintain psychological well-being amidst adversity by appreciating small and positive aspects of life (Edward & Welch, 2011; Gray et al., 2017). Acceptance of their child's condition was also associated with greater emotional stability, particularly when parents received encouragement from peers facing similar situations (Karakul et al., 2022). Spirituality, through practices such as prayer and religious reflection, was a key source of comfort and strength, echoing previous studies on the role of faith in promoting resilience among caregivers (Sujana et al., 2017; Andriyani et al., 2022). Furthermore, strong spousal relationships, characterized by open communication and mutual support, were found to be essential in promoting emotional well-being and facilitating effective coping with the challenges of caregiving (Ginanjar et al., 2021).

Children with thalassemia also face psychological challenges due to invasive medical procedures and long-term treatment demands. Their psychological well-being largely depends on their ability to adapt to this condition (Elzaree et al., 2018). Effective communication emerged as an essential component of parental support (Stein et al., 2019). Parents mentioned the importance of giving space, time, and explaining the condition honestly while allowing the child to be involved in decision-making. This is in line with Ayoub (2024) findings that effective communication includes empathy, age-appropriate language, and support for the independence of adolescent patients. Other psychosocial support includes encouraging children to actively participate in daily activities to build confidence and coping skills (Elzaree et al., 2018; Mashayekhi et al., 2016). Fair treatment of sick and healthy children in the family is also considered important, although there has not been much explicit research on this. However, the study by Leeman et al. (2016) emphasized that family dynamics, including communication and conflict resolution, influence children's psychological health.

This research has some limitations. First, the small sample size limited the diversity of parental experiences captured, potentially affecting the representativeness of the findings. Second, the unique contextual and cultural background of each family means that the findings may not be generalizable to broader populations. Third, the data relied on self-reported experiences, which may be influenced by subjective emotions such as fear, hope, or expectation, making them difficult to quantify objectively.

CONCLUSION

This study explored the lived experiences of parents caring for a child with thalassemia major. Although caring for children with this condition is a challenging experience and can cause difficulties in their lives, many parents remain positive and affirmative in their role. However, comprehensive support and a holistic approach are essential to help families adapt more effectively and enhance their overall quality of life. The findings of this study have important implications for nursing practice and hospital-based care. Nurses should be equipped with effective communication skills to ensure that parents and children with thalassemia receive clear, accurate information regarding diagnosis, treatment, and long-term care. It is also essential for nurses to be attuned to the emotional well-being of both parents and patients, offering psychosocial support or referrals to mental health services as needed. Furthermore, hospitals can collaborate with spiritual departments, counselors, or psychologists to provide holistic support to patients and families, especially during the initial diagnosis and treatment process.

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