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*Research Article*

# Parents' Experiences in Managing Treatment Compliance of Children with Thalassemia: A Phenomenological Study

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**Abstract.** Background: Thalassemia major is a chronic genetic disorder that requires lifelong treatment, including routine blood transfusions and iron chelation therapy. This chronic condition demands the absolute involvement of parents as primary caregivers in managing treatment compliance to ensure an optimal quality of life for the child. Objective: This study aimed to explore in depth the subjective experiences of parents in managing treatment compliance for children with thalassemia. Methods: This study utilized a qualitative design with a descriptive phenomenological approach. Informants were selected using a purposive sampling technique at RSUD Dr. Moewardi Surakarta, involving 6 parents as primary participants. Data were gathered through in-depth interviews, non-verbal observations, and medical record documentation. The data were then analyzed using qualitative thematic analysis. Results: The analysis revealed 4 major themes: (1) Psychological shock and initial acceptance process, (2) Parents' adaptive strategies in maintaining child compliance, (3) Social support networks as a reinforcing factor, and (4) The dynamics of compliance between blood transfusion (high due to immediate clinical impact) and iron chelation therapy (low due to boredom and side effects). Conclusion: Parents of children with thalassemia face complex psychosocial and technical challenges. There is an imbalance in adherence between blood transfusion and iron chelation. These results emphasize the crucial need for family-centered nursing interventions and sustainable psychological support to mitigate caregiver burnout.

**Keywords:** Parental Experience ; Parents' Experiences; Phenomenological Study; Thalassemia Treatment Adherence; Treatment Compliance.

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## 1. Introduction

Thalassemia is a genetic disorder caused by reduced or absent production of alpha or beta chains in hemoglobin, preventing the body from producing red blood cells normally. This condition can potentially cause severe anemia that begins in childhood and persists throughout life. As an autosomal recessive inherited disease, thalassemia requires genetic participation from both carrier parents to be passed on to their children. People with thalassemia major generally begin to show symptoms of anemia, appearing pale, weak, experiencing stunted physical growth, and becoming dependent on regular blood transfusions before the age of 3.

Primary treatment for thalassemia major focuses on regular blood transfusions to maintain hemoglobin (Hb) levels within the range of 9–10 g /dL, as well as iron chelation therapy to bind and remove excess iron accumulated due to repeated transfusions. Non-compliance with iron chelation therapy can have serious clinical consequences, including damage to vital organs (heart, liver, and endocrine system) and an increased risk of death from cardiac complications. Therefore, the role of parents—especially mothers as primary caregivers—is crucial in managing children's medication adherence.

Although the role of parents is crucial, the process of raising a child with thalassemia is fraught with multidimensional burdens. Parents often experience anxiety, emotional

exhaustion, financial problems, and psychosocial stress due to the demands of long-term care. Data on visits by school-aged children (5–12 years old) at Dr. Moewardi Hospital, Surakarta, shows a high number of outpatient treatments, reaching 1,127 visits in a three-month period by the end of 2025. Based on this phenomenon, this study aims to explore in depth the subjective experiences of parents in managing treatment compliance for children with thalassemia at Dr. Moewardi Hospital, Surakarta.

## 2. Preliminaries or Related Work or Literature Review

### Children

Children are individuals aged from birth to 18 years who are undergoing a continuous process of growth and development. During this stage, children experience physical, cognitive, emotional, and social changes that lay the foundation for future health and quality of life. Children have unique biological, psychological, social, and spiritual needs that differ from those of adults, requiring a specialized approach to meeting these needs (Thubthed et al., 2022).

### Thalassemia

Haemoglobinemia is an inherited blood disorder caused by a genetic mutation. This condition prevents the body from producing hemoglobin (a protein responsible for transporting oxygen). As a result, the patient's red blood cell count is lower than normal. As a result, the red blood cells produced are not formed properly and are easily damaged, resulting in a lifespan shorter than 120 days. This leads to anemia, or a lack of blood, making the patient frequently feel tired and weak. In severe cases, patients require regular blood transfusions throughout their lives (Rediyanto, 2023).

### The Concept of Treatment Compliance

Compliance refers to behavior that emerges from the interaction between healthcare professionals and patients, ensuring that the patient understands the plan and its consequences and is willing to implement it. According to participants, compliance is following instructions from a doctor or healthcare professional and following all instructions (Jumhan & Mutmainah, 2023).

### Role and Experience of Parents

Chronic, lifelong illnesses like thalassemia place significant emotional stress on both children and parents. Sufferers often experience mental health issues such as anxiety, emotional exhaustion, and depression, ranging from limited physical activity to long-term treatment (Hastuti *et al* ., 2023).

## 3. Materials and Method

This study used a qualitative design with a descriptive phenomenological approach to deeply understand the subjective meanings and lived experiences of parents. The study was conducted in the Thalassemia Room, 6th Floor, Flamboyan Building, Dr. Moewardi Regional Hospital, Surakarta, from May to June 2026.

The subject determination was carried out using a purposive sampling technique with inclusion criteria including: biological parents of children with thalassemia aged 5–12 years who have undergone regular blood transfusions for more than 3 months. The number of participants involved until reaching data saturation was 6 people (5 mothers and 1 father, initials Mrs. W, Mrs. S, Mr. A, Mrs. I, Mrs. L, and Mrs. M).

The main instrument in this qualitative research was the researcher herself (the researcher as a key instrument), assisted by an in-depth interview guide containing 11 core questions adapted from Dewi et al. (2024), a non-verbal behavior observation sheet, and an audio recorder (smartphone and wireless microphone). The data collection procedure included three main techniques:

In-Depth Interview : Recording parents' narratives and emotional responses directly.

Systematic Observation : Recording the informant's non-verbal expressions and gestures.

Documentation Study : Examining patient medical record data to verify clinical history.

Data analysis was conducted thematically through the stages of verbatim transcription, coding, category grouping, and phenomenological theme extraction. Data validity testing (trustworthiness) applied the principles of credibility (through member checking and

technical/source triangulation), transferability (detailed description of the context), dependability (audit trail with the supervisor), and confirmability (data transparency). This study has obtained ethical approval from the Health Research Ethics Commission (KEPK) of Dr. Moewardi Surakarta Regional Hospital (No. 577/III/HREC/2026).

## 4. Results and Discussion

### Results

Participants in this study consisted of six parents (mothers/fathers) who acted as primary caregivers for children diagnosed with thalassemia who had been receiving regular treatment at Dr. Moewardi Surakarta Regional Hospital for at least one year. The following table shows the demographic data of the participants to provide a contextual understanding of the study results:

**Table 1.** Participant Characteristics

| Code | Initials | Age (Year) | Education | Work | Child Age | Diagnosis Time |
|---|---|---|---|---|---|---|
| P1 | Mrs. W | 45 | Bachelor | Teacher | 7 | 6 Years |
| P2 | Mrs. S | 48 | SENIOR HIGH SCHOOL | Laborer | 12 | 3 Years |
| P3 | Mr. A | 56 | SENIOR HIGH SCHOOL | Private | 8 | 3 Years |
| P4 | Mrs. I | 34 | SENIOR HIGH SCHOOL | Private | 2.5 | 2.5 Years |
| P5 | Mrs. L | 45 | Vocational School | housewife | 7 | 2.5 Years |
| P6 | Mrs. M | 45 | SENIOR HIGH SCHOOL | housewife | 12 | 11 Years |

Participant characteristics included parents ranging in age from 34 to 56 years, with educational backgrounds ranging from high school to bachelor's degree (S1), and a duration of thalassemia diagnosis ranging from 2.5 to 11 years. Thematic analysis yielded four main themes:

**Psychological Shock and Initial Acceptance Process**

The initial phase of diagnosis is the most difficult for parents. They experience shock, devastation, and denial before reaching acceptance. Initial denial prompted some participants to seek alternative treatments before ultimately returning to formal medical care as their child's physical condition worsened.

" I was shocked when I was diagnosed with thalassemia... It means we have to undergo regular treatment, which obviously involves transfusions." (P3 - Mr. A)

"At first I refused, I took him to alternative medicine first because I couldn't bear it... But his condition just got worse, so I finally gave in and accepted it." (P2 - Mrs. S)

**Parental Strategies for Maintaining Child Adherence**

Parents developed non-pharmacological persuasive tactics to address their children's anxiety and boredom with invasive needle procedures. These tactics included a reward system, offering recreational opportunities/rewards, and visual distraction techniques using smartphones during the transfusion procedure.

" If we go... we have to coax them first, like, 'Will we go there after we get home?'" (P4 - Mrs. I)

"When I was giving the transfusion, I did it while watching his favorite cartoon on my cellphone so his attention was diverted..." (P3 - Mr. A)

**Social Support Network as a Reinforcing Factor**

The presence of an external support system is a crucial pillar in preventing caregiver burnout. Harmonious role-sharing with partners, peer support through the POPTI community, flexible leave requirements from schools, and the friendliness of nurses at Dr. Moewardi Regional Hospital strengthen parents' emotional resilience.

" Fortunately, my husband is very understanding. We share the tasks... At Moewardi, the nurses are also friendly, so the children aren't afraid." (P6 - Mrs. M)

"Joining the community of thalassemia parents in Solo is very helpful, here we support each other..." (P1 - Mrs. W)

**The Dynamics of Compliance Between Blood Transfusion and Iron Chelation Therapy**

There is a significant disparity in compliance. Parents are highly compliant and disciplined with the monthly blood transfusion schedule because the impact of delays is immediately visible clinically (the child appears weak and pale). In contrast, compliance with daily iron chelation at home tends to be lower due to children's boredom, side effects of nausea/abdominal pain, and the long-term, preventative effects of the medication, which are not immediately apparent.

" When it comes to blood transfusion schedules... I never dare to delay... Because it's very obvious if it's late, the child immediately becomes weak and pale." (P5 - Mrs. L)

"The hardest thing is actually when I tell my child to take iron chelation medication every day... My child often gets bored, refuses, and even complains of feeling nauseous..." (P1 - Mrs. W)

**Discussion**

The study results show that the diagnosis of thalassemia major acts as a massive psychosocial crisis that triggers an initial denial response in parents. This phenomenon aligns with Kübler-Ross's psychological adjustment theory and Ververidou's (2023) study, which states that chronic childhood illness causes severe emotional distress for caregivers. Delaying medical intervention due to denial is highly detrimental to the child's safety, given that the pathophysiology of thalassemia, characterized by ineffective erythropoiesis, can lead to severe, fatal anemia.

In maintaining compliance in school-aged children (5–12 years old), the use of distraction techniques and behavior modification by parents has been shown to be effective in lowering children's anxiety thresholds. Based on child development theory (Zakiyah et al., 2024), school-aged children are highly sensitive to pain and feelings of being "different" from their peers. Emotional support and an adaptive approach from parents successfully shape children's self-care behavior.

The presence of a social support network has been shown to function as a stress buffer that prevents caregiver burnout. These results support the findings of Habsyie et al. (2022) and Andriyani et al. (2025) regarding a positive linear relationship between community support (such as POPTI) and the resilience of families with thalassemia.

The phenomenon of compliance disparity between blood transfusions and iron chelation can be analyzed using the Health Belief Model (HBM). Compliance is influenced by perceived threats. Transfusions pose an immediate, acute threat, while iron chelation is hampered by drug tolerability issues (such as nausea and daily boredom). As explained by Cappellini et al. (2024) and Mardhiyah et al. (2024), iron chelation non-compliance below 80% increases the risk of iron accumulation, which can lead to fatal cardiac complications. Therefore, ongoing education and a family-centered care approach are essential.

**Comparison**

***Psychological Shock and Initial Acceptance Process***

When a child first receives a medical diagnosis of thalassemia major, all parents go through a phase of intense emotional shock, guilt, deep sadness, and even denial.

This refusal was proven by the action of taking the child to alternative medicine first because he could not bear to see his toddler having to be injected with a needle every month.

However, after the child's physical condition continues to decline (drop), parents experience a psychological transition towards resignation and full acceptance (acceptance) for the sake of their child's survival.

***Social Support Network as a Reinforcing Factor***

Parents' physical and mental consistency and resilience in managing long-term treatment is greatly strengthened by a solid external support system.

These strengthening factors include a harmonious division of domestic tasks with a partner (husband/wife), peer group support through the POPTI Solo community to strengthen each other and exchange drug information, academic leniency from the school (teachers), and a friendly and empathetic service climate from the nursing staff in the Flamboyan Room on the 6th Floor of Dr. Moewardi Surakarta Regional General Hospital which makes children feel fearless.

This finding strengthens the theoretical basis of Habsyie et al. (2022) who stated that there is a significant positive linear relationship between social support and the level of resilience of primary caregivers (mothers) in caring for children with thalassemia.

Social support acts as a stress buffer that includes 5 vital aspects, namely emotional, instrumental, informational, esteem, and social network support.

In addition , parents' narratives regarding the benefits of the POPTI Solo community are in line with the results of a study by Andriyani et al. (2025) which confirmed that the presence of peer-group support was proven effective in reducing family anxiety levels and indirectly optimizing the quality of home care for children with thalassemia.

***The Dynamics of Compliance Between Blood Transfusion and Iron Chelation Therapy***

A striking difference in compliance behavior (disparity) was found in the implementation of the two main pillars of pediatric medical therapy.

Parents showed a very high level of compliance and discipline with the monthly blood transfusion schedule because the clinical effects of delay were immediately visible to the naked eye (child was weak, pale, had no appetite).

Conversely , compliance with monitoring daily iron chelation medication consumption at home tends to be lower and is often lax due to children's refusal due to boredom, difficulty dissolving the medication, and side effects such as nausea and abdominal pain.

This phenomenon of compliance inequality can be explained accurately through the Health Belief Model (HBM) approach to the components of perceived threats and perceived benefits.

In transfusion therapy, parents are compliant because they are driven by the high perception of acute clinical threats that appear instantly if they are late, which is in line with the findings of Purbasari & Lail (2024) that compliance with taking children for regular transfusions is positively correlated in maintaining physical status and preventing acute complications in children.

## 6. Conclusion

Parents' experiences in managing adherence to treatment for children with thalassemia are complex processes involving psychological, social, and medical-technical dimensions. Parents struggle from the crisis/emotional shock phase to acceptance. To maintain child adherence, parents actively employ persuasive and distraction strategies. Although support from family, the POPTI community, and healthcare professionals helps maintain parental resilience, significant disparities in adherence remain between blood transfusion therapy (high adherence) and daily iron chelation therapy (low/loose adherence). It is hoped that healthcare facilities and nurses can optimize visual education and ongoing psychosocial counseling to support holistic adherence.

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