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Exploring the Realities of Self-Management among Adolescents with Thalassaemia and their Caregivers in Malaysia: A qualitative study

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Abstract

Adolescents with thalassaemia face unique self-management challenges amid emotional and social changes. This research explored how Malaysian adolescents and their caregivers navigate self-management through in-depth interviews with 30 participants, analyzed thematically using Atlas. ti software. Three main themes emerged: knowledge and beliefs, self-regulation and adaptation, and communication and interaction. Findings highlight adolescents' awareness of their condition, motivation for health management, coping strategies, and the importance of open communication and social support. The study emphasizes the need for practical self-management tools and interventions to enhance adolescents' quality of life.

Keywords: Self-management; Adolescent; Thalassaemia; Caregiver

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1.0 Introduction

Reduced or absent haemoglobin production is the hallmark of thalassaemia, a genetic blood disorder that causes chronic anaemia and necessitates lifelong treatments such as iron chelation therapy and regular blood transfusions. Managing symptoms, adhering to treatment, monitoring health, and maintaining emotional and social well-being amid growing independence and developmental changes are key components of effective self-management for adolescents.

Recent research highlights both opportunities and challenges in adolescent self-management. Dhawan et al. (2021) emphasized the need for psychological support as adolescents with thalassaemia face body image issues affecting self-concept and social interactions. Kharaman-Nia et al. (2023) demonstrated that digital self-care tools, such as smartphone applications, significantly improve self-efficacy, adherence, and health behaviours—showing the potential of digital platforms to enhance engagement. Likewise, Baelen et al. (2022) discovered positive results from mobile health interventions but raised concerns regarding usability and accessibility. Mardhiyah et al. (2024) investigated the experiences of adolescents with transfusion-dependent β-thalassaemia, highlighting unmet needs associated with fatigue, pain, stigma, and interruptions to daily life. These findings emphasise the necessity of creating culturally appropriate interventions and practical tools to aid adolescent self-management and enhance their quality of life.

In light of these gaps, the current study aimed to investigate the lived experiences of self-management among Malaysian adolescents with thalassaemia and their caregivers. Specifically, it sought to comprehend how adolescents and their caregivers perceive and engage in self-management while identifying the psychosocial and contextual factors that influence their experiences within family and healthcare environments.

2.0 Literature Review

Thalassemia is a genetic blood disorder that leads to chronic anaemia due to insufficient haemoglobin production. Those affected require lifelong treatment, including blood transfusions and iron chelation therapy (Dhawan et al., 2021). For adolescents, self-management involves managing symptoms, adhering to treatment plans, monitoring health, and maintaining emotional well-being and relationships while becoming more independent (Pinto & Forni, 2020). Effective self-management enhances quality of life, academic performance, and social connections while reducing anxiety and depression (Seo & Kim, 2025). Digital tools, such as mobile health apps, can improve adherence to treatment, although challenges with accessibility and costs remain (Villalobos et al., 2020). Conversely, poor self-management can lead to long-term mental health issues and social difficulties (Kharaman-nia et al., 2023).

The Individual and Family Self-Management Theory (IFSMT) highlights that adolescents' self-management is influenced by their environment, processes, and outcomes (Ryan & Sawin, 2019). Key contextual factors include psychological aspects like anxiety, social support, physical challenges from treatment, and access to digital resources. The self-management process encompasses knowledge of their condition, treatment adherence, and support networks. Family caregivers experience their own emotional stressors, which can impact their ability to assist adolescents (Catarino et al., 2021). Applying IFSMT provides a structured framework for understanding these dynamics and improving self-management within families of adolescents with thalassaemia in Malaysia.

In summary, this study builds its foundation on the IFSMT, focusing on the interaction among context, process, and outcomes. It views adolescent self-management as a dynamic process influenced by beliefs, family support, and sociocultural communication. This framework guides the exploration of how adolescents and their caregivers practice self-management daily.

3.0 Methods

This research employs a qualitative phenomenological approach to investigate how adolescents and their caregivers in Malaysia manage self-management. The study was conducted from November 2023 to March 2024 at a thalassaemia association in the northern region, which ranks third in Malaysia for the highest population of thalassaemia patients. Additionally, there is a specific reason for choosing this association. For this phenomenological study, purposive sampling was employed to select participants, and semi-structured, in-depth interviews were utilized to explore the meanings individuals attribute to their lived experiences (Greening, 2019). Inclusion criteria included: (a) adolescents aged 10 to 19 diagnosed with any type of thalassaemia who have undergone conventional treatment for at least six months, and (b) the ability to communicate in English and/ or Bahasa Malaysia. For parents or guardians, inclusion criteria further stipulated being the primary caregiver and having lived with the adolescent for a minimum of one year. Individuals who could not communicate due to thalassaemia or other reasons were excluded from the study.

A total of 30 participants, consisting of adolescents and caregivers, were interviewed until data saturation was reached, indicating that no new themes were emerging from the collected information (Francis et al., 2010). Before recruiting participants, the researcher consulted with the presidents of thalassaemia associations, who provided a list of potential participants. After inviting them, appointments for interviews were scheduled. Consent was obtained from both the adolescents and one parent. The interviews were conducted informally in a semi-structured, conversational style. Qualitative interviews enable an in-depth exploration of complex social phenomena (Chong, 2022). This aligns with previous qualitative studies on thalassemia, which have similarly utilized in-depth interviews to understand the biological and psychosocial experiences of patients and their caregivers (Drahos et al., 2024).

The interview sessions were conducted privately to ensure confidentiality, with audio recordings made with permission and field notes taken. The recordings were transcribed verbatim and analyzed thematically using Atlas.ti, with all quotes translated into English. Member checking was used for data trustworthiness by sharing initial findings with participants for validation (Korstjens & Moser, 2018). Additionally, team discussions served as peer reviews to enhance the research process. Data analysis focused on accurately understanding the phenomenon and cross-checking findings to strengthen the study's rigor (Kaminski & Pitney, 2004).

4.0 Findings

Data saturation was achieved after interviewing thirty participants, split evenly between fifteen adolescents and fifteen caregivers. The demographic of the participants is summarised in Table 1.

Table 1: *Demographic and clinical characteristics of adolescents and caregivers*

Variable	Adolescents (n = 15)	Caregivers (n = 15)
Age, years, M (SD)	14.2 (2.6)	46.7 (4.2)
Gender, n (%)		
Male	5 (33)	4 (27)
Female	10 (67)	11 (73)
Race: Malay, n (%)	15 (100)	15 (100)
Religion: Islam, n (%)	15 (100)	15 (100)
Education, n (%)		
No formal schooling	0 (0)	0 (0)
Primary school	4 (27)	0 (0)
High school	7 (47)	5 (33)
College or university	4 (27)	10 (67)
Not sure / don’t know	0 (0)	0 (0)
Monthly household income, n (%)	-	
Low (< RM 1 000)	-	5 (33)
Middle (RM 1 000 – 3 000)	-	7 (47)
High (> RM 3 100)	-	3 (20)
Type of thalassemia, n (%)		
β-Thalassemia major	11 (73)	0 (0)
HbE β-Thalassemia	3 (20)	0 (0)
Intermedia	1 (7)	2 (13)
α-Thalassemia	0 (0)	0 (0)
Thalassemia carrier	0 (0)	13 (87)

From the thematic analysis, three main themes were identified related to exploring the realities of self-management among adolescents with thalassaemia and their caregivers: (1) Knowledge and Beliefs, (2) Self-regulation and Adaptation, and (3) Communication and Interaction. The main themes and sub-themes that generated are summarized in Table 2.

Table 2: *Main themes and sub-themes generated from the findings of this study*

Main theme	Sub-theme
Knowledge and Beliefs	Knowing and understanding Believing and valuing Self-management knowledge and importance
Self-regulation and Adaptation	Self-regulation Coping with Challenges
Communication and Interaction	Communication and Disclosure Social Facilitation

4.1 Main Theme 1: Knowledge and Beliefs

Self-management for individuals with thalassemia involves using knowledge, beliefs, and behaviours to effectively manage their condition. By exploring the interconnected themes of knowledge, belief, and the importance of self-management, this perspective highlights how individuals and caregivers navigate the challenges of thalassemia.

4.1.1 Subtheme- Knowing and Understanding

Understanding develops through ongoing conversations and knowledge sharing, especially when caregivers explain the illness and its management. Adolescents gradually grasp their condition as they grow, particularly with consistent, age-appropriate explanations from caregivers.

"When my daughter was four or five years old, I started telling her about her illness. By that time, she was starting to understand a little bit. When she started primary school, I told my daughter what treatment she needed." [Caregiver 7, Mother]

Notably, the knowledge of being a thalassemia patient should empower adolescents to take control of their health rather than leave them feeling distressed or overwhelmed. A caregiver underscored this balance, stating:

“These children with thalassemia need to know about the disease itself. When they know, they will be good at taking care of themselves. [Caregiver 3, Mother]

“Oh, as far as I remember, when I was seven. They explained to me every detail; only when I was 10 years old did mom explain what medicine I needed to take daily”. [PA13, 17 years, female, Malay, β- thalassemia major]

4.1.2 Subtheme: Believing and Valuing

Adolescents' beliefs about treatment adherence greatly influence their commitment to regular transfusions, chelation therapy, and medication. Family support, personal experiences, and medical advice help reinforce these beliefs. Many recognize the importance of sticking to transfusion schedules for their health.

"No, because thalassemia patients need blood transfusions for the rest of their lives". [PA3, 18 years, female, Malay, β-thalassaemia major]

These statements highlight adolescents' acceptance and responsibility in their treatment journey. As they navigate identity formation, thalassemia becomes a part of their identity, making them feel different from their peers and potentially causing prolonged role confusion. However, many adolescents experience improved acceptance as they grow older.

"Yes, I can still "handle" myself. Like accepting yourself, being open, and talking, you won't have a problem managing yourself if you willingly accept it". [PA2, 18 years, male, Malay, β-thalassaemia major]

4.1.3 Subtheme: Self-management knowledge and importance

Self-management relies on adolescents and caregivers sharing clear and developmentally appropriate knowledge about the disease and its treatments. Adolescents emphasize that this knowledge is essential. As one adolescent stated:

"Yes, self-management is important because it lets me build my own routine and feel more in control of my health without always relying on my parents." [PA1, 17 years, male, Malay, β-thalassaemia major]

This sense of agency helps sustain energy for school and encourages participation in social activities. Caregivers emphasize the importance of adherence.

"Yes. They don't simply want to miss [a transfusion] unless they have a bad fever." [Caregiver 13, Mother]

Most participants identified late childhood (ages 10–12) as the optimal window for assuming self-management.

"In 10- or 11-year age, you can do it yourself." [PA11, 18 years, male, Malay, β-thalassaemia major]

Some argued for even earlier initiation:

"Well, the perfect age was 7 years old… daily life routine, as well as what we understand about thalassemia." [PA8, 16 years, male, Malay, β-thalassaemia major]

Parents also highlighted the emotional labor involved:

"*Food. Parents of thalassemia children must be patient… the most challenging is the psychology, their behavior.*" [Caregiver 11, Mother]

To achieve success, interventions must integrate straightforward, age-appropriate education regarding medication and transfusion schedules with family-centered emotional support—ensuring that understanding leads to enduring self-management and promotes lasting independence. Additionally, incorporating questionnaire tools to assess their self-management can enhance this process.

4.2 Main Theme: Self-Regulation and Adaptation

Self-Regulation and Adaptation include two related subthemes: Self-Regulation and Coping with Challenges. Self-Regulation involves deliberate actions like planning and goal-setting to manage chronic illness. In contrast, Coping focuses on adolescents' emotional and psychological strategies to handle stress, stigma, and daily ups and downs.

4.2.1 Subtheme: Self-Regulation

Participants recognized the significance of self-regulation in managing chronic conditions like thalassemia. Adolescents showed varying levels of independence and utilized practical strategies, such as medication reminders and pill organizers, to integrate their medication routines into daily activities.

"*My method is my medicine box: morning, noon and night. It helps me to remember and maintain my routine."* [PA7, 14 years, female, HbE β-Thalassemia]

Even with their successes, adolescents pointed out challenges such as forgetfulness and competing social commitments, which often resulted in missed doses of medication.

"*I always have to remember when to take medicine. Sometimes, if I'm busy with friends, I just forget*." [PA12, 15 years, female, HbE β-Thalassemia]

Caregivers and healthcare providers were crucial in facilitating adolescents' self-regulation, providing structured support, supervision, and reminders.

"*My daughter took her own medicine when she was around 11, but I still check every day if she's actually taking it. Trusting her completely is difficult, but necessary.*" [Caregiver 6, Mother]

Enhancing adolescents' self-regulation requires collaborative efforts among adolescents, caregivers, and healthcare professionals to foster autonomy, resilience, and effective health management practices.

4.2.2 Subtheme: Coping with Challenges

Coping was described as crucial for managing chronic illness-related emotional stress, stigma, and adherence challenges. Adolescents frequently used distraction techniques such as playing games, listening to music, and engaging in hobbies to manage emotional stress.

"*Most of the time I will sleep. After that, I play games or listen to music. It helps calm my mind when things get overwhelming."* [PA1, 17 years, male, HbE β-Thalassemia]

Caregivers' emotional and practical support was essential, though caregivers acknowledged the emotional challenges of their supportive roles.

"*As caregivers, we need patience because training adolescents in managing their medication and routines is not easy. The psychological part is especially challenging."* [Caregiver12, Father]

Spirituality and meditation emerged as significant emotional coping strategies.

"*When I feel stressed or overwhelmed, I usually turn to prayer or meditation. It brings me peace and helps me manage difficult emotions*." [PA12, 15 years, female, HbE β-Thalassemia]

These coping strategies, supported by family, peers, healthcare workers, and spirituality, are integral to adolescents' overall emotional and psychological well-being.

4.3 Main Theme: Communication and Interaction

Communication and Interaction focuses on how adolescents manage their chronic illnesses through effective interactions and support systems involving caregivers, peers, healthcare providers, and the broader community.

4.3.1 Subtheme: Communication and Disclosure

Effective communication and disclosure significantly influenced adolescents' self-management and emotional well-being. Participants reported varying levels of openness and trust in communication with caregivers, healthcare workers, and peers.

Adolescents generally appreciated clear and supportive communication from healthcare providers, enhancing their engagement in health management.

"*Yes, doctors and nurses have ever asked. Only then did I feel comfortable to tell them about my actual symptoms and experiences*." (PA2)

Family communication ranged widely, from supportive and open to limited and strained, significantly affecting adolescents' emotional security and self-management behaviours.

"*My mom always accompanies me or sends me to the hospital. Her presence makes me feel more secure and supported*." (PA1)

Open and honest family communication notably enhanced adolescents' willingness to engage in effective self-management and emotional coping.

"*From the age of eight and up, we have trained them to understand their condition clearly and always communicate openly about their health needs."* [Caregiver3, Mother]

Open communication channels significantly improved adolescents' emotional resilience and health management, underscoring the necessity for trust-based communication networks.

4.3.2 Subtheme: Social Facilitation

Social facilitation was described as essential to managing chronic illnesses, emphasising the role of family, peer networks, healthcare systems, and community interactions in adolescents' daily health management.

Family support was frequently cited as pivotal, providing emotional reassurance, practical assistance, and consistent medication reminders.

"My mom always reminds me about appointments and taking my medication. Her support makes it much easier for me to manage my illness." [PA1, 17 years, male, HbE β-Thalassemia]

Healthcare professionals provided crucial support, offering safe and open environments for adolescents to discuss health concerns freely.

"Nurses and doctors at the clinic are supportive. They always check on how I'm feeling and remind me about important things regarding my health." [PA3, 18 years, female, Malay, β-thalassaemia major]

Consistent social support was identified as critical to successful illness management, highlighting the need for stable, stigma-free support systems across family, peer, and community contexts.

In conclusion, adolescents with chronic illnesses like thalassemia greatly benefit from structured self-regulation, diverse coping strategies, open communication, and strong social support. Effective management involves collaboration among adolescents, caregivers, healthcare providers, and community resources to promote well-being.

5.0 Discussion

The qualitative findings of this study highlight key themes in managing chronic illnesses, particularly thalassemia, among adolescents. The themes include Knowledge and Beliefs, Self-Regulation and Adaptation, and Communication and Interaction. These themes emphasize that adolescents need to understand illness, believe in their independence, achieve their goals, and communicate effectively to maintain self-management.

The first main theme, adolescents' knowledge and beliefs significantly shape their self-management behaviours. This is aligned with the Individual and Family Self-Management Theory, which emphasizes that understanding one's illness and treatment impacts adherence and health outcomes (Ryan & Sawin, 2009; Lee et al., 2020). Age-appropriate information from caregivers enhances adolescents' understanding, empowering them to manage their health independently(Bravo et al., 2020). Otherwise, beliefs about treatment adherence are critical. Modi et al. (2021) found that adolescents who recognize the importance of adherence often achieve better health outcomes. Family support reinforces these beliefs and encourages resilience in self-management practices (Dutta & Salamon, 2020).

The second main theme, "Self-regulation", emerged as a vital element in managing illnesses. Adolescents displayed varying degrees of autonomy by employing structured routines like medication reminders and integrating treatments into daily activities. Recent studies confirm that organized self-management practices substantially improve adherence and health outcomes in chronic illness (Lee et al., 2020). However, challenges like forgetfulness and social distractions persist, necessitating targeted interventions to improve self-regulation skills (Gao et al., 2025). Collaborative support from caregivers and healthcare professionals enhances adherence and fosters independence (Yıldırım, 2020). Emotional coping strategies were essential for managing stress, stigma, and adherence challenges.

Techniques such as distraction and emotional support from family and peers were crucial, with literature indicating that positive family dynamics significantly bolster coping abilities and resilience (Adams et al., 2022). Additionally, spirituality and meditation emerged as beneficial coping strategies (Saputro et al., 2021).

The final main theme, “Communication and interaction”, plays a significant role in adolescents’ emotional well-being and self-management. Supportive communication from healthcare providers and family openness fosters better health management. Open communication channels are essential for managing chronic conditions effectively (Srinivas et al., 2022). Social facilitation through family and peer support enhances adherence and emotional stability. Robust support systems in family, healthcare, and community contexts are vital for effective chronic illness management (Luo et al., 2024).

Thus, these findings underscore the importance of collaborative strategies involving adolescents, caregivers, healthcare professionals, and community resources to improve self-management, emotional resilience, and overall well-being in managing chronic illnesses like thalassemia.

6.0 Conclusion & Recommendations

This study identifies key factors influencing how adolescents manage chronic illnesses, such as thalassaemia, including comprehensive knowledge, adaptive beliefs, structured self-regulation, effective coping strategies, clear communication, and strong social support. While these findings primarily apply to adolescents with thalassaemia, cultural differences may affect their relevance to other groups. The research has numerous limitations, including the possibility of selection bias due to recruiting participants through thalassaemia associations, as it may have attracted more engaged or motivated families. Additionally, the reliance on self-reported interviews might have resulted in social desirability or recall bias. Nevertheless, the credibility of the study was improved through member checking and peer debriefing. The findings suggest that healthcare providers and policymakers should implement holistic, age-appropriate education and structured psychosocial and peer-support programs to improve adherence, resilience, and quality of life. Future research should explore innovative approaches, such as digital self-management tools and mindfulness-based interventions, to strengthen adolescents’ self-regulation and emotional well-being within diverse cultural contexts.

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Paper Contribution to Related Field of Study

This paper contributes to understanding self-management needs among adolescents with thalassemia in Malaysia, providing suitable tools or interventions to promote their independence and well-being.

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