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Digital Monitoring and Family Support for Thalassemia Therapy Adherence: An Initial Implementation of the SEHAT Thaller Model

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Abstract. Thalassemia requires lifelong transfusion and iron chelation therapy, making treatment adherence and family involvement essential for long-term therapy management. Conventional monitoring through patient-held records may be limited by incomplete documentation, the absence of the monitoring book during healthcare visits, and limited use as an active monitoring tool. The SEHAT Thaller Model integrates family support, education, hope, awareness, and tracking through simple digital technology to strengthen therapy management. This preliminary descriptive study involved 64 respondents recruited through POPTI Kota Tegal (n = 38) and the Thalassemia Nusantara community network (n = 26). Data were collected using structured questionnaires assessing therapy adherence, family support, and knowledge regarding thalassemia therapy. The initial implementation included direct education, educational videos, optimization of the Thalassemia Therapy Monitoring Book, development of a digital spreadsheet for therapy and ferritin monitoring, and WhatsApp-based reminders for therapy schedules. The mean therapy adherence score was 8.83 ± 2.00 out of 12; 52 respondents (81.3%) had high adherence, 9 (14.1%) moderate adherence, and 3 (4.7%) low adherence. Family support was high in 60 respondents (93.8%). However, 38 respondents (59.4%) reported forgetting to take or administer iron chelation medication and 36 (56.3%) reported not bringing medication when travelling. The initial implementation provided a practical basis for strengthening education, awareness, reminders, and digital tracking. Further evaluation is required to determine the model's effectiveness, acceptability, and implementation outcomes.
Keywords: thalassemia; iron chelation; therapy adherence; family support; digital monitoring

1. INTRODUCTION

Thalassemia is a chronic inherited blood disorder that requires lifelong transfusion therapy and iron chelation. In transfusion-dependent thalassemia, repeated blood transfusions result in progressive iron accumulation, making effective iron chelation and regular monitoring essential to prevent iron-related organ complications. The 2025 Thalassaemia International Federation (TIF) guidelines emphasize comprehensive monitoring and management of iron overload as an essential component of long-term care for transfusion-dependent β-thalassemia. Cardiac iron overload is of particular clinical concern because it may contribute to cardiac dysfunction and heart failure [1].

The effectiveness of iron chelation therapy depends substantially on treatment adherence. However, maintaining adherence to a lifelong treatment regimen remains challenging, particularly among children and adolescents who depend on parents or caregivers for medication management. A systematic review of 37 studies involving children and adolescents with thalassemia found considerable variation in adherence to iron chelation therapy and identified factors such as social support, age, treatment burden, and treatment-related factors as being associated with adherence. Better adherence was also associated with more favorable clinical indicators, including lower serum ferritin and improved cardiac, hepatic, and endocrine outcomes [2]. Other studies have reported suboptimal adherence among transfusion-dependent thalassemia patients. In a study of adolescents, only 51.4% of participants demonstrated good adherence to iron chelation therapy, highlighting the need for regular assessment and strategies to address barriers to adherence [3].

Forgetfulness represents one practical barrier to maintaining regular chelation therapy. Theppornpitak et al. [4] found that forgetfulness was the most common reported obstacle to adherence among transfusion-dependent thalassemia patients. Their study also demonstrated that patients with higher adherence had lower recent serum ferritin levels, emphasizing the clinical relevance of maintaining consistent chelation therapy. Family involvement is also relevant to long-term treatment management in children with thalassemia. Previous research has examined factors influencing compliance with desferrioxamine therapy among children with transfusion-dependent thalassemia, including family-related factors, indicating the importance of considering the family context when addressing treatment adherence.

Digital health technology provides an opportunity to strengthen family-based treatment monitoring rather than replace conventional healthcare services. Previous research has demonstrated the feasibility of mobile technology to support medication management and disease knowledge among pediatric patients receiving chronic iron chelation therapy. Leonard et al. [5], for example, developed a mobile health intervention combining provider-led education, daily medication-recording videos, and provider feedback. The intervention was feasible to implement and was associated with high medication-tracking participation and sustained disease knowledge, although the study was small

and did not establish definitive effectiveness. Simple reminder and tracking approaches may also be useful. Chawsamtong et al. [6] found that providing a drug-use calendar improved adherence to iron chelation therapy among young patients with thalassemia and was associated with a reduction in serum ferritin compared with standard counselling alone.

Nevertheless, evidence regarding the effectiveness of digital interventions for improving adherence and disease management in thalassemia remains limited. A Cochrane review identified no eligible randomized or quasi-randomized trials evaluating computer- or mobile-based interventions for improving adherence to iron chelation therapy in people with thalassemia at the time of the review. Consequently, the authors concluded that the effectiveness of such interventions could not be determined and recommended further well-designed studies [7]. This evidence gap supports the development and evaluation of accessible, contextually appropriate digital approaches that can be integrated with family-based treatment management.

In the present setting, the Thalassemia Therapy Monitoring Book provides information related to transfusion, iron chelation medication, supplementation, and periodic laboratory monitoring, including ferritin and other biochemical parameters. However, practical implementation has identified several limitations: the book may not always be available during healthcare visits, some entries may be incomplete, and its use by families may remain primarily procedural or administrative. Furthermore, documenting a scheduled laboratory examination does not necessarily ensure that the examination is performed or that the results are appropriately followed up by the healthcare facility. These practical limitations indicate the need to complement conventional documentation with more accessible and continuous monitoring mechanisms.

Based on these needs, the SEHAT Thaller Model was developed as a holistic family-based approach integrating Support, Education, Hope, Awareness, and Tracking. In its initial implementation, the model combines direct education, educational videos, optimization of the existing Thalassemia Therapy Monitoring Book, a digital spreadsheet for therapy and ferritin monitoring, and WhatsApp-based reminders for therapy schedules. Rather than replacing conventional monitoring or clinical care, these components are intended to strengthen continuity, accessibility, and active family participation in therapy management. Therefore, this study aimed to describe therapy adherence and family support among thalassemia survivors and their parents and to report the initial implementation of the SEHAT Thaller Model through family-based education and simple digital monitoring. The findings are expected to provide baseline information for the further development and evaluation of the SEHAT Thaller Model in the subsequent stage of the research.

2. METHODS

2.1 Study Design and Setting

This article reports preliminary findings from the first year of a two-year research project developing the SEHAT Thaller Model. A descriptive quantitative approach was used to describe therapy adherence, family support, and knowledge regarding thalassemia therapy, followed by the initial implementation of the model. The study was conducted through thalassemia community networks in Tegal City, Indonesia.

2.2 Participants and Data Collection

A total of 64 respondents participated in the first-year data collection. Thirty-eight respondents were recruited through POPTI Kota Tegal, while 26 additional respondents were reached through the Thalassemia Nusantara community network. The respondents consisted of parents of children with thalassemia and thalassemia survivors who participated in the study and completed the questionnaire. Data were collected using a structured questionnaire covering three domains: therapy adherence, family support, and knowledge regarding thalassemia therapy.

2.3 Measurement and Data Analysis

Therapy adherence was assessed using 12 items addressing medication-taking and medication-management behaviors. Items were scored according to their direction, with positive and negative items scored appropriately so that higher total scores represented better adherence. The total adherence score was calculated by summing the item scores. Family support was assessed using items addressing family involvement in thalassemia therapy management. Knowledge regarding thalassemia therapy was assessed using five items related to therapy and its management. Quantitative data were analyzed descriptively using frequencies, percentages, means, and standard deviations as appropriate.

2.4 Initial Implementation of the SEHAT Thaller Model

Following the identification of treatment-management needs, the initial implementation of the SEHAT Thaller Model was conducted using a family-centered and technology-supported approach. The model integrates five components: Support, Education, Hope, Awareness, and Tracking. The first-year implementation consisted of direct education, educational videos, optimization of the existing Thalassemia Therapy Monitoring Book, development of a digital spreadsheet for therapy and ferritin monitoring, and utilization of a WhatsApp group for therapy-schedule reminders. The monitoring book was optimized to support active therapy monitoring rather than functioning solely as a procedural record. The digital spreadsheet was developed as a complementary tracking tool, while WhatsApp was used to provide reminders related to therapy schedules. These components were implemented to strengthen family participation, continuity of monitoring, and accessibility of treatment information.

2.5 Ethical Considerations

The study was conducted in accordance with ethical principles for research involving human participants. Participation was voluntary, and informed consent was obtained from respondents before data collection. Personal information was kept confidential and used only for research purposes.

3. RESULTS AND DISCUSSION

3.1 Respondent Characteristics and Therapy Adherence

A total of 64 respondents participated in the first-year data collection. Of these, 41 respondents (64.1%) were parents of children with thalassemia and 23 (35.9%) were thalassemia survivors. Thirty-eight respondents were recruited through POPTI Kota Tegal, while 26 additional respondents were reached through the Thalassemia Nusantara community network. The mean therapy adherence score was 8.83 ± 2.00 out of 12. Fifty-two respondents (81.3%) were categorized as having high adherence, 9 (14.1%) had moderate adherence, and 3 (4.7%) had low adherence. Observed adherence scores ranged from 4 to 12, with higher scores indicating better adherence.

Table 1. Distribution of therapy adherence among respondents

Therapy adherence category	Score	n	%
High	8–12	52	81.3
Moderate	5–7	9	14.1
Low	≤4	3	4.7
Total	—	64	100.0

Despite the relatively favorable overall adherence score, several specific treatment-management problems were identified. Thirty-eight respondents (59.4%) reported having forgotten to take or administer iron chelation medication, while 36 (56.3%) reported not bringing their medication when travelling. In addition, 40 respondents (62.5%) reported that they did not consistently avoid mixing the medication with tea, milk, or syrup. Other treatment behaviors were relatively favorable: 62 respondents (96.9%) reported not stopping medication when feeling healthy or asymptomatic, 63 (98.4%) reported not taking medication only after blood transfusion, 57 (89.1%) reported taking medication at the same time each day, and 51 (79.7%) reported dissolving the medication in the recommended 100–200 mL of water.

Table 2. Selected therapy-management behaviors

Therapy-management behavior	n	%
Ever forgot chelation medication	38	59.4
Did not bring medication when travelling	36	56.3
Did not consistently avoid mixing medication with tea/milk/syrup	40	62.5
Did not stop medication when feeling healthy	62	96.9
Did not take medication only after transfusion	63	98.4
Took medication at the same time every day	57	89.1
Dissolved medication in 100–200 mL water as recommended	51	79.7

3.2 Family Support and Knowledge

Family support was generally high. The mean family support score was 28.14 ± 4.56 out of 32. Sixty respondents (93.8%) were categorized as having high family support, while 2 (3.1%) had moderate support and 2 (3.1%) had low support.

Table 3. Distribution of family support

Family support category	n	%
High	60	93.8
Moderate	2	3.1
Low	2	3.1
Total	64	100.0

Knowledge regarding thalassemia therapy was generally favorable. The mean knowledge score was 17.41 ± 2.85 out of 20, with observed scores ranging from 5 to 20. The mean score per item was 3.48 ± 0.57.

Table 4. Knowledge regarding thalassemia therapy

Indicator	Mean ± SD	Minimum–Maximum
Knowledge score	17.41 ± 2.85	5–20
Mean score per item	3.48 ± 0.57	—

3.3 Initial Implementation of the SEHAT Thaller Model

The initial implementation of the SEHAT Thaller Model was conducted through an integrated family-based and technology-supported approach. The implementation included direct education, educational videos, optimization of the Thalassemia Therapy Monitoring Book, development of a digital spreadsheet for therapy and ferritin monitoring, and utilization of a WhatsApp group for therapy-schedule reminders.

The optimization of the therapy monitoring book was undertaken in response to practical limitations identified during implementation. The book was not always brought by patients during healthcare visits, some sections were incompletely documented, and its use by parents or families tended to remain procedural or administrative. In addition, documentation of scheduled ferritin and other laboratory examinations did not necessarily ensure that the examinations were performed or that the results were followed up by the healthcare facility. The digital spreadsheet was developed as a complementary tracking tool for therapy and ferritin monitoring, while WhatsApp was utilized to provide reminders regarding therapy schedules. Direct education and educational videos were used to strengthen family understanding and awareness regarding therapy management. These components represented the initial implementation of the SEHAT Thaller Model.

Overall, the first-year findings showed that reported therapy adherence and family support were generally favorable, but specific treatment-management challenges remained, particularly forgetting chelation medication and not bringing medication when travelling. These findings provided the basis for strengthening the tracking and reminder components of the SEHAT Thaller Model. The findings represent preliminary first-year results and do not establish the final effectiveness of the model.

3.4 Discussion

The present study found that overall reported therapy adherence among thalassemia survivors was relatively favorable, with a mean adherence score of 8.83 out of 12 and 81.3% of respondents categorized as having high adherence. However, the overall adherence category should be interpreted alongside specific treatment-management behaviors. More than half of the respondents reported having forgotten to take or administer iron chelation medication, while 56.3% reported not bringing medication when travelling. These findings suggest that a relatively favorable overall adherence score does not necessarily indicate consistent adherence across all daily treatment-management behaviors.

The finding regarding forgetfulness is consistent with previous evidence. A systematic review of children and adolescents with thalassemia identified forgetfulness, lack of family support, tiredness, age, treatment-related discomfort, and other personal and treatment-related factors among the factors reported to influence adherence to iron chelation therapy [2]. Theppornpitak et al. [4] similarly reported forgetfulness as an important barrier to adherence among transfusion-dependent thalassemia patients and found that better adherence was associated with lower serum ferritin levels. These findings indicate that adherence management should address not only knowledge but also practical barriers that occur during daily treatment routines.

An important finding in the present study was the high level of reported family support. Although 93.8% of respondents were categorized as having high family support, 59.4% reported having forgotten chelation medication and 56.3% reported not bringing medication when travelling. This finding suggests that family support alone may not automatically translate into consistent treatment-management behavior. The systematic review by Reddy et al. [2] indicates that social and family-related factors are relevant to adherence, but adherence is influenced by multiple

individual and treatment-related factors. Thus, family involvement needs to be accompanied by practical strategies that help families translate support into consistent treatment behaviors [11].

The discrepancy between high family support and persistent treatment-management challenges provides an important rationale for the SEHAT Thaller Model. Rather than positioning family support as an isolated intervention, the model integrates Support, Education, Hope, Awareness, and Tracking. This approach is intended to help families translate their willingness to support the child into practical treatment-management behaviors. Education and awareness can strengthen understanding of the importance of continuous chelation therapy, while tracking and reminder mechanisms can help address practical barriers such as forgetfulness and failure to prepare medication before travelling.

Parental knowledge was also relatively favorable in the present study, with a mean score of 17.41 out of 20. However, the coexistence of relatively good knowledge and specific adherence problems suggests that knowledge alone may not be sufficient to ensure consistent treatment behavior. This interpretation is consistent with the broader adherence literature in thalassemia, in which adherence is influenced by multiple factors beyond knowledge, including treatment burden, side effects, psychological factors, social factors, and forgetfulness [2], [8]–[10]. Consequently, educational interventions may be more useful when combined with mechanisms that support daily implementation of treatment recommendations.

The present study also identified practical limitations in the use of the conventional Thalassemia Therapy Monitoring Book. Although the book provides an important mechanism for documenting transfusion, medication, and laboratory monitoring, observations during implementation indicated that it was not always brought to healthcare visits, some entries were incomplete, and its use could remain primarily procedural or administrative. Furthermore, documenting a planned ferritin or other laboratory examination does not necessarily ensure that the examination is completed or that the result is appropriately followed up by the healthcare facility. This issue is important because current TIF guidance recommends regular monitoring of serum ferritin and other indicators of iron overload and emphasizes the importance of working with patients and families to optimize adherence to chelation therapy [1].

The use of simple digital technologies in the initial implementation of the SEHAT Thaller Model was therefore intended to complement rather than replace the existing monitoring system. The digital spreadsheet provides an additional mechanism for tracking therapy and ferritin data, while WhatsApp provides an accessible channel for therapy-schedule reminders [13]. Previous research supports the potential usefulness of simple reminder and tracking strategies. Chawsamtong et al. [6] found that provision of a drug-use calendar improved adherence to iron chelation therapy among young patients with thalassemia and was associated with a reduction in serum ferritin compared with standard counselling. This finding is relevant to the present model because both approaches use a simple mechanism to support treatment scheduling and reduce reliance on memory alone.

Mobile health interventions have also demonstrated potential in pediatric patients receiving chronic iron chelation therapy. Leonard et al. [5] reported the feasibility of a mobile health intervention that incorporated education, medication recording, and provider feedback among pediatric patients receiving chronic transfusions. However, the study did not provide definitive evidence of effectiveness, emphasizing that digital interventions should be further evaluated before being considered established adherence interventions.

Nevertheless, digital technology should be regarded as a supporting mechanism rather than a substitute for clinical care, family involvement, or healthcare-provider follow-up. Evidence specifically evaluating computer- and mobile-based interventions for iron-chelation adherence in thalassemia remains limited. The Cochrane review by Badawy et al. [7] found no eligible randomized or quasi-randomized trials evaluating computer- or mobile-based interventions for improving iron-chelation adherence in people with thalassemia at the time of the review. Consequently, the effectiveness of such interventions could not be determined, and further well-designed studies were recommended. This evidence gap supports the continued development and evaluation of accessible digital approaches such as those incorporated into the SEHAT Thaller Model.

From a nursing perspective, the initial implementation of the SEHAT Thaller Model illustrates the potential role of nurses in integrating education, family engagement, treatment monitoring, and digital communication into long-term thalassemia care. The model positions the family not merely as a recipient of education but as an active partner in monitoring treatment and responding to potential adherence problems. This family-centered and technology-supported approach is particularly relevant in pediatric thalassemia because treatment management extends beyond healthcare facilities into the daily routines of children and their families.

The connection between treatment adherence and iron-overload monitoring is also clinically important [12]. Current TIF guidelines emphasize that iron chelation is essential for controlling transfusional iron accumulation and that uncontrolled iron overload increases the risk of heart failure and other organ complications. The guidelines also emphasize that chelation therapy will not be effective if it is not taken regularly and recommend working with patients and their families to optimize adherence [1], [14], [15]. However, the present study did not directly measure changes in serum ferritin following implementation or assess cardiovascular outcomes. Therefore, any potential contribution of improved therapy monitoring to the prevention of cardiovascular complications should be regarded as a clinical rationale for the model rather than an outcome demonstrated by this study.

This study has several limitations. First, the findings represent the first-year stage of a two-year research project and therefore do not establish the final effectiveness of the SEHAT Thaller Model. Second, the present analysis is

primarily descriptive and does not establish a causal relationship between the initial implementation and therapy adherence. Third, respondents were recruited through POPTI Kota Tegal and the Thalassemia Nusantara community network, which may limit the generalizability of the findings to the broader thalassemia population. Fourth, the study relies substantially on self-reported treatment behaviors, which may be affected by recall or social desirability bias. Finally, qualitative interviews and thematic analysis planned for the second year have not yet been conducted. These subsequent stages are expected to provide deeper information regarding family experiences, barriers, facilitators, and the acceptability and implementation of the SEHAT Thaller Model.

4. CONCLUSIONS

The first-year findings indicate that reported therapy adherence among thalassemia survivors was generally favorable, with 81.3% of respondents categorized as having high adherence and 93.8% reporting high family support. However, specific treatment-management challenges remained, particularly forgetting iron chelation medication and not bringing medication when travelling. These findings indicate that favorable family support and overall adherence do not necessarily ensure consistent treatment-management behaviors in daily life.

The initial implementation of the SEHAT Thaller Model, integrating family support, education, awareness, therapy tracking, and simple digital technologies, provides a practical approach to strengthening continuous therapy management. The use of educational videos, optimization of the therapy monitoring book, digital spreadsheet-based monitoring of therapy and ferritin, and WhatsApp reminders was intended to complement conventional monitoring and facilitate active family participation.

These findings provide a baseline for further development and evaluation of the SEHAT Thaller Model. However, the present study does not establish the effectiveness of the model because the findings represent the first-year stage of a two-year research project. Further quantitative and qualitative evaluation is required to determine the model's effectiveness, acceptability, and applicability in long-term thalassemia care.

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