Management of Dietary Education for Children with Thalassemia at The Thalassemia Polyclinic

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Abstract

Background: Dietary education in thalassemia major is often neglected due to high nursing workloads. This case report evaluates a structured dietary education intervention using management frameworks to address this gap. Methods: A descriptive study was conducted on a family with three siblings diagnosed with thalassemia major and severe hyperferritinemia. The 3M (Man, Method, Material) analysis identified primary barriers: high procedural workload, lack of SOPs, and absence of educational media. Consequently, a POAC (Planning, Organizing, Actuating, Controlling) intervention using digital videos and leaflets was implemented to overcome these constraints. Results: The intervention effectively bypassed clinical time constraints. Family health literacy improved substantially, with dietary knowledge scores increasing from 2 out of 5 to a perfect 5 out of 5, sustained over a five month follow-up. Behavioral changes in meal preparation were reported, although immediate serum ferritin reduction was not yet observed. Conclusion: Structured education utilizing digital media effectively bridges the gap between patient needs and limited nursing resources. Integrating digital tools into routine practice and establishing SOPs are recommended to ensure comprehensive management and improve long-term patient outcomes.

Keywords: Health Education, Iron Overload, Nursing Care, Pediatrics, Thalassemia

Introductions

Thalassemia is a chronic hereditary hematological disorder characterized by impaired globin chain synthesis, resulting in defects in red blood cells (Origa, 2017). Clinically, the disease is classified into thalassemia major, intermedia, and minor. In thalassemia major, the absence of beta-globin chain production causes severe anemia, necessitating lifelong blood transfusions (Rujito, 2019). In Indonesia, the prevalence of thalassemia ranges from 6% to 10% of the national population (Widyawati, 2019). The Indonesian Thalassemia Foundation (YTI) reported 10,973 cases in 2021, with a significant annual increasing trend. Regional data from the Indonesian Society of Parents with Thalassemia (POPTI) West Java indicates that this province contributes approximately 40% (5,417 patients) of the total 13,406 national cases. At the service level, data from the Thalassemia Polyclinic at Dr. Hasan Sadikin General Hospital in January 2025 recorded 277 pediatric patients, with the majority having developed splenomegaly complications.

The management of thalassemia major requires complex medical and supportive therapies. Routine blood transfusions are indicated when Hemoglobin (Hb) levels fall below 7 g/dL (Septyana et al., 2019). Although life-saving, repeated transfusions cause inevitable complications in the form of iron overload or hemosiderosis in vital organs, triggering hepatosplenomegaly. This condition requires patients to undergo iron chelation therapy to control serum ferritin levels. In addition to pharmacotherapy, nutritional management through a low-iron diet is a crucial adjuvant therapy (Ali et al., 2021). Without dietary iron restriction, the efficacy of iron chelation therapy may be compromised due to the continuous accumulation of daily iron intake, which ultimately worsens the patient's prognosis.

Despite the clinical urgency of a low-iron diet, there is a tangible gap in the implementation of nursing education. Theoretically, nurses are responsible for facilitating clients' learning needs to achieve optimal health (DeLaune & Ladner, 2010). However, clinical reality shows that dietary education is often neglected due to the heavy service focus on transfusion and medication procedures. Consequently, family understanding of dietary management remains inadequate. Previous studies confirm that parental knowledge regarding dietary iron is still low which correlates linearly with poor nutritional status in children with thalassemia (Dict Man et al., 2019).

To date, there is no structured dietary education model in the service unit capable of optimally supporting the success of iron chelation therapy. Based on this background, this case report aims to explore the management of dietary education for children with thalassemia at the Thalassemia Polyclinic and to evaluate its impact on family knowledge and the quality of nursing care.

Research Method

This study employed a descriptive qualitative case report design focusing on nursing care management. This design was selected to provide a comprehensive overview of the care process within a real clinical setting. The study was conducted from January 17 to June 2025 at the Thalassemia Polyclinic, Bandung, West Java. Subjects were selected using purposive sampling with a familial cluster criterion. The selected subject was one family with three children suffering from thalassemia major who routinely underwent transfusions. The justification for selecting this family was based on the high caregiver burden and clinical urgency due to hyperferritinemia in all three children. Data were collected through participatory observation, interviews, and knowledge score measurements, which were then analyzed descriptively.

Management Intervention Procedure (POAC) to address the identified clinical issues, a management intervention was systematically structured using the POAC (Planning, Organizing, Actuating, Controlling) cycle. The process began with the planning phase, where the author formulated a strategic education plan based on the initial assessment that revealed a "Knowledge Deficit" regarding nutritional restrictions in the family. This planning phase involved the

formulation of a Structured Health Education Plan (Satuan Acara Penyuluhan/SAP), the development of evaluation instruments (pre-test and post-test), and the production of visual media in the form of low-iron diet leaflets and educational videos. The educational materials covered disease definitions, prohibited foods (iron-rich foods), recommended foods (iron inhibitors), and the risks of non-compliance. These materials were also consulted with the Head of the Thalassemia Polyclinic for content validation.

Subsequently, in the organizing phase, tasks were delegated, with the author collaborating with two staff nurses in the ward. The head nurse provided full authorization for the implementation of education, while ethical aspects were fulfilled by obtaining informed consent from the patient's family before the intervention commenced. The actuating phase was executed on January 22, 2025, utilizing a multichannel approach. A face-to-face session was conducted while the patients underwent blood transfusions, explaining dietary details using leaflets. Additionally, a digital session was carried out by screening the educational video and sending the digital file to the family's WhatsApp group to enable independent learning at home.

Case Description

Family Mrs. I has six children, and three of them, who are male, have been diagnosed with thalassaemia major. The three children are currently undergoing blood transfusions simultaneously. Since their initial diagnosis of thalassaemia, all three have exhibited significant signs and symptoms with relatively stable Hb levels of 9 g/dL. For An. A, transfusions are performed once a month with 300 ml of PRC and blood type O. Meanwhile, Child B and Child J typically undergo blood transfusions every two weeks with 300 ml of PRC and the same blood type. The family stated that the three children do not regularly take iron chelation medication due to difficulties in obtaining the medication, primarily due to transportation cost limitations to the hospital. Nevertheless, the family understands that medication must be taken daily. The current hospital policy for medication pickup is once a week. This poses a challenge for Mrs. I, who faces financial difficulties, resulting in medication pickup often being delayed by a week, and on one occasion, she went a month without taking medication. Ferritin levels indicate that Child B has a ferritin level of 6,000 ng/mL, Child J at 4,000 ng/mL, and Child Aat 3,500 ng/mL. All three receive iron chelation therapy with deferasirox at the same dose of 500 mg. Based on anthropometric data, Child B's weight and height were 18 kg and 106 cm with a waist measurement of 69 cm, while Child Aalso had a weight of 18 kg and height of 106 cm with a waist measurement of 63 cm. Meanwhile, Child J had a weight of 14.5 kg and height of 97 cm with a waist measurement of 65 cm.

To this day, the family has never conducted genetic testing or screening to determine the origin of thalassaemia in the family, due to fears about the testing process. The client also mentioned that their three daughters do not have thalassaemia and are growing and developing appropriately for their age. The three sons with thalassaemia, namely Child B, Child J, and An. A, are currently unable to attend school. All three have a good appetite, but when their haemoglobin levels drop, they tend to become lethargic and lose their appetite. Additionally, all three have experienced splenomegaly (enlarged spleen). The family also mentioned that during their therapy, they never received special education regarding the diet for children with thalassaemia, so they are unsure about the specific foods that should be avoided. As a result, the client often consumes foods that are not recommended for their condition. The results of problem-based analysis based on Man, Method, Material (3M) data in the implementation of nursing care related to nursing problems in clients are as follows:

1)Man

Presently, there are only two nurses responsible for treating all thalassaemia patients who come in every day, with an average of ±20 patients per day. When combined with other haematology patients, this number can increase to ±45 patients in a single day of service. The two available nurses are divided into two tasks, with one

nurse conducting the initial anamnesis of the patient and the other nurse providing nursing care, namely IV insertion and blood transfusion. This condition has actually been adjusted to the calculation of nursing staff requirements according to the Depkes (2005), which is :

Nursing staff requirement = number of nursing staff + loss days + correction

= 0.428 + 1.080 + 0.06933

= 1.577, rounded to 2 nurses per shift.

However, the nurses in the ward have not been able to provide comprehensive nursing care optimally due to the nurse-to-patient ratio and the intensity of service delivery. One important aspect that has been overlooked is patient education for thalassemia patients and their families. Nurses only provide education regarding the schedule for repeat therapy and the routine intake of iron chelation medication, without further exploring information about the patient's dietary patterns. The patient's family also does not fully understand the dietary recommendations for children with thalassemia. The family is unable to list the recommended foods, but they can list some of the foods that are prohibited for children with thalassemia. Meanwhile, in patients with thalassemia, an appropriate diet is very influential in preventing complications due to excess iron. Therefore, the implementation of dietary education for children with thalassemia at the Thalassemia Polyclinic has not been optimally carried out.

2) Material

The Paediatric Thalassaemia Polyclinic is equipped with a number of facilities in the treatment room, including two computers in the anamnesis room, one television in the procedure room, and one television in the waiting room. There is also a WhatsApp group for parents of children with thalassemia. However, to date, there are no specific standard operating procedures (SOPs) governing the implementation of dietary education for families of thalassemia patients, so this aspect has not yet been structured into the nursing care provided at the clinic. Based on the researcher's observations, nurses have not utilised the available facilities in the room to provide education to patients' families. This is evident from the lack of educational materials such as leaflets, infographic banners, and educational videos that could be used in the counselling process. Moreover, there are no other media, such as video screenings on television, for diet management education.

3) Method

Nurses at the Thalassaemia Polyclinic have never provided education on diet to patients and their families. The WhatsApp group for parents has not been utilised effectively for educational purposes. However, standard operating procedures (SOPs) are in place for the management of thalassaemia patients after blood transfusions, namely iron chelation therapy. However, monitoring of this therapy is also not optimal because nurses do not evaluate ferritin levels for each patient. Dietary monitoring for patients is also not being carried out effectively because there is no specific nursing documentation for patient diets.

Results

Based on the implementation of the educational intervention described in the methodology, the evaluation results encompassed process evaluation, knowledge improvement, and clinical outcomes, which constitute the controlling phase. The process evaluation indicated that the family responded very positively to the intervention. During the implementation session, the family demonstrated high enthusiasm and openness to receiving new information. An active two-way discussion occurred, where the family asked critical questions regarding food myths in the community and the specific risks of non-compliance with the diet. The use of leaflets and video media was assessed by the family as being very helpful because the materials could be reviewed at home without time constraints. No language barriers or resistance were encountered during the educational process.

Regarding knowledge outcomes, a significant difference was observed between pre- and post-intervention understanding. Quantitatively, the baseline pre-test results

showed that the family could only answer 2 out of 5 questions correctly regarding the thalassemia diet. Prior to the intervention, the family was unable to name foods that should be avoided and did not understand the concept of iron inhibitors. However, immediately after the education, the family was able to perform a teach-back, correctly explaining key points regarding dietary restrictions. This was reinforced by a long-term evaluation through a post-test conducted five months later (June 15, 2025) during a home visit, which showed excellent knowledge retention with the family achieving a perfect score of 5 out of 5 correct answers. This indicates that the combined educational method (verbal and digital video) successfully instilled sustained knowledge.

In terms of clinical and behavioral outcomes, the family reported having changed their shopping and food serving patterns at home in accordance with the leaflet recommendations. However, objective clinical data showed that serum ferritin levels in the three children during the three-month post-education evaluation period still indicated persistent hyperferritinemia. These findings suggest that although knowledge increased significantly, clinical improvement in the form of ferritin reduction is a multifactorial process that requires a longer time and must work synergistically with strict adherence to iron chelation medication. Therefore, periodic monitoring of serum ferritin every three months by the head nurse is recommended as a long-term success indicator.

Discussion

The management of thalassemia major presents a dual challenge: maintaining hemoglobin levels through transfusions while mitigating the inevitable consequence of iron toxicity. In this case report, the three children presented with severe iron overload, evidenced by serum ferritin levels ranging from 3,500 to 6,000 ng/mL—figures significantly exceeding the safety threshold of 1,000 ng/mL (Goldberg et al., 2022). While the patients received standard medical therapy, the analysis revealed a critical disconnect between the administration of iron chelation therapy and the family's nutritional management. The effectiveness of chelation therapy is heavily dependent on minimizing dietary iron intake. The findings of this study illustrate that pharmacotherapy alone is insufficient when caregivers lack the fundamental knowledge to implement a low-iron diet at home (Ali et al., 2021).

The root cause of this knowledge deficit, as identified through the 3M situational analysis, was not parental negligence but rather a systemic gap in nursing care delivery. Although the nurse-to-patient ratio appeared adequate based on the Ministry of Health formula Depkes (2005), the functional reality of high procedural workloads prevented nurses from providing comprehensive education. This validates the observation that the quality of care is intrinsically linked to the time allocated for patient education (Gröndahl et al., 2019). The absence of Standard Operating Procedures (SOPs) and educational media meant that the complex dietary guidelines outlined by the Thalassaemia International Federation (2021)—such as avoiding iron-rich organ meats and utilizing iron inhibitors like tea or calcium were never effectively communicated to the family. This explains the baseline pre-test finding where the family could only answer two out of five questions correctly; they were unaware of the specific dietary restrictions necessary to support the medical treatment.

The intervention implemented in this study demonstrates the efficacy of a multichannel educational approach in overcoming these systemic resource limitations. The shift from a knowledge score of 2 out of 5 to a perfect 5 out of 5 in the post-test indicates that the combination of printed leaflets and digital videos was highly effective. Critical reflection on this success suggests that the video medium was particularly impactful because it allowed the family to overcome the time constraints of clinical visits. Video-based education enhances decision-making and compliance by providing a consistent resource that families can review repeatedly (Kovoor et al., 2021). Furthermore, this intervention aligns with the Family-Centered Care (FCC) model which posits that empowering parents with accessible knowledge transforms them from passive recipients of care into active

partners in disease management (Kuo et al., 2012). By providing materials via WhatsApp, the intervention bridged the gap between the clinical setting and the patient's home environment (Setiyawati et al., 2022).

However, it is crucial to differentiate between the immediate improvement in knowledge and the long-term clinical outcomes. While the family demonstrated a significant behavioral shift evidenced by their ability to accurately recall prohibited foods and the reported changes in meal preparation the serum ferritin levels remained high during the short-term evaluation. This finding under scores that reversing hemosiderosis is a chronic process. Ferritin levels are cumulative and influenced by years of transfusion history. Therefore, the lack of immediate biochemical improvement in this single case should not be interpreted as a failure of the dietary intervention, but rather as an indication that dietary management must be sustained over the long term alongside strict adherence to chelation therapy(Mishra & Tiwari, 2013). The education provided serves as the foundational step necessary to halt further iron accumulation, which will eventually support the efficacy of chelation agents.

The implications of this study extend beyond this specific family to clinical policy and practice. The reliance on verbal education during busy transfusion sessions is evidently insufficient. Consequently, this study advocates for the integration of structured dietary education into the routine SOP s of thalassemia care. Specifically, the use of digital educational tools, such as the videos utilized in this intervention, should be standardized to ensure every family receives consistent information regardless of nursing workload intensity (Diana Dayaningsih, 2023). Strengthening institutional support through the provision of these resources is essential to uphold the Indonesian Nursing Competency Standards PPNI (2013), which mandate health education as a core nursing competency.

This study acknowledges several limitations, primarily its design as a single-case report, which restricts the generalizability of the findings to the broader thalassemia population. Additionally, the follow-up period was insufficient to observe statistically significant changes in serum ferritin levels, which requires longitudinal monitoring. Future research should involve larger cohorts with longer follow-up durations to quantitatively assess the correlation between structured dietary education and biochemical markers of iron overload. Nevertheless, this report provides compelling evidence that empowering families through targeted, accessible education is a vital, low-cost strategy to enhance the quality of nursing care and support the complex management of thalassemia major.

Conclusion

The management of dietary education at the Thalassemia Polyclinic was previously hindered by high nursing workloads and a lack of educational media, contributing to significant knowledge gaps regarding iron-restricted diets. This case report demonstrates that a structured intervention based on the POAC framework, utilizing digital videos and leaflets, effectively bridged this gap by facilitating continuous home-based learning. The approach substantially improved the family's health literacy and knowledge regarding dietary management, a positive outcome that was sustained over a five-month period. Although immediate reduction in serum ferritin was not observed due to the chronic nature of hemosiderosis, the establishment of correct dietary behaviors is a critical prerequisite for the efficacy of chelation therapy. Consequently, integrating this low-cost, media-based education into routine Standard Operating Procedures (SOPs) is strongly recommended to address both medical and nutritional needs, ultimately enhancing the long-term prognosis of children with thalassemia.

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