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Original article

The Relationship Between Family Support and Compliance with Iron Chelation Medication in Thalassemia Adolescents

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Abstract

Introduction: Treatment adherence is a significant challenge for thalassemia patients. Iron chelation medication must be taken for life, and therefore, family support is essential to achieve adherence. To determine the relationship between family support and iron chelation medication adherence in thalassemia patients.

Method: This study used a quantitative cross-sectional approach. Data was collected using a questionnaire from a sample of 120 respondents.

Results: The statistical test yielded a p-value of 0.027 <0.05, concluding that there is a significant relationship between family support and iron chelation medication adherence in adolescents with thalassemia. Most family support was categorized as good, and on average, adolescent thalassemia patients were considered compliant

Conclusion: Family support is related to medication adherence. Therefore, families are expected to continuously monitor and provide attention to their sick family members and consistently remind them to take their medication.

Keywords: Family support, Iron chelation, Compliance, Thalassemia

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INTRODUCTION

Thalassemia is a genetic or inherited blood disorder also known as Cooley's or Mediterranean anemia (Rochman et al., 2019). According to the 2019 Indonesian health profile data, the prevalence of thalassemia patients was 9,121 cases, or approximately 0.38% of the total child population. In 2020, the number of thalassemia sufferers reached 10,531 cases, or approximately 3.21% of the child population. In 2021, the number of beta thalassemia major sufferers in Indonesia was 10,973, or approximately 3.59% of the child population (Faturrohman., 2020). West Java has 3,264 thalassemia sufferers, representing 40% of the total number of thalassemia sufferers in Indonesia. West Java has one of the highest thalassemia cases in the world (Kamil et al., 2020).

Management of thalassemia major patients involves regular, repeated blood transfusions due to the short lifespan of cells, less than 120 days. Blood transfusions are given when the hemoglobin level is less than 6 g/dL (Daud et al., 2020). Adolescent thalassemia patients receive repeated transfusions from an early age. Long-term transfusions can cause several complications and can be dangerous for thalassemia patients due to the amount of iron accumulated in several organs (Sartika & Allenidekania, 2020). Therefore, iron chelation therapy is needed, such as deferioxamine, deferiprone, or deferasirox. With the help of iron chelation therapy, iron can be bound and then excreted from the body through urine and feces (Ramadhanti et al., 2022).

The majority of thalassemia patients require lifelong treatment, making adherence to treatment a significant challenge. Non-adherence to treatment can negatively impact a patient's physical health. Successful treatment requires several factors, one of which is family support (Rojas & Wahid, 2020). According to Friedman (2010), family support consists of instrumental support, informational support, appraisal support, and emotional support. The results of Made et al.'s (2020) study of 90 respondents showed that 10% had low medication adherence and 2.22% had insufficient family support. The test results between the two variables obtained a significance value of 0.000 (p<0.05), indicating a significant

relationship between the two variables. The person correlation value obtained was 0.751, indicating a strong, significant relationship between family support and patient medication adherence.

Based on a preliminary study on November 20, 2023, observations and interviews with the head of the thalassemia clinic revealed that there were 150 adolescents with thalassemia, and approximately 80%, or 120, were non-compliant with iron chelation medication. Researchers then interviewed 10 adolescents with thalassemia, and found that 8 were non-compliant. Thalassemia adolescents were non-compliant with medication due to a lack of family support. The purpose of this research is to determine the relationship between family support and compliance in taking iron chelation medication in adolescents with thalassemia at the thalassemia polyclinic at Karawang Regional Hospital.

METHOD

This type of research uses quantitative and cross-sectional approach with descriptive analytical design. This study was conducted on May 21 - June 6, 2024, in the thalassemia polyclinic of Karawang Regional Hospital. The sample used purposive sampling, obtained 120 adolescents with thalassemia who met the inclusion criteria: adolescents aged 10 - 18 years, have had a blood transfusion for at least one month and received a prescription for iron chelation drugs in the thalassemia ward of Karawang Regional Hospital. No adolescents experienced complications during data collection, so no respondents were excluded. The questionnaire used was standardized, the family support questionnaire with the lowest validity value of 0.301 and a reliability value of 0.628. Morisky medication adherence questionnaire (MMAS) with the lowest validity value of 0.576 and a reliability value of 0.795 (Mulyasari, 2016). This research has obtained permission and passed ethical approval from Horizon Indonesia University (No. 803/041127/IV/KM) and Karawang Regional Hospital (No. 800.2/0647).

RESULTS

Characteristics of Thalassemia Respondents in Thalassemia Clinic at Karawang Regional Hospital

Table 1. Characteristics of Respondents (n=120)

Characteristics	n	%
Gender		
Male	58	48,3%
Female	62	51,7%
Age		
10 – 12 years old	52	43,3%
13 – 15 years old	28	23,3%
16 – 18 years old	40	33,3%
Education		
No	6	5,0%
Elementery School	50	41,7%
Middle School	27	22,5%
High School	32	26,7%
College	5	4,2%
Period of Illness since diagnosis		
< 10 years	47	39,3%
≥ 10 years	73	60,8%
Duration of treatment		
< 10 years	70	58,3%
≥ 10 years	50	41,7%
Compliance		
Obey	55	45,8%
No	65	54,2%
Family Support		
Poor	8	6,7%
Moderate	10	8,3%
Good	102	85,0%
	120	100%

Characteristics of adolescent thalassemia patients at Karawang Regional General Hospital based on gender were predominantly female, 62 (51.7%). The age range of respondents was 10-12 years, namely 52 (43.4%). Regarding the education of adolescent respondents with thalassemia, the most education was elementary school, namely 50 (41.7%). There were 73 (60.8%) respondents who had suffered from the

disease for more than 10 years, while the duration of treatment with chelating drugs was predominantly <10 years, namely 70 (58.3%).

The Relationship Between Family Support and Adherence to Chelation Medication in Thalassemia Patients in the Thalassemia Clinic at Karawang Regional Hospital

According to Table 2, of the eight respondents with insufficient family support, eight (6.67%) were non-compliant with their medication. Of the ten respondents with moderate family support, five (4.16%) were non-compliant, and five (4.16%) were compliant. Of the 102 respondents with good family support, 52 (43.36%) were non-compliant, and 50 (41.63%) were compliant. The Chi-Square test yielded a p-value of 0.027 ($p < \alpha$ 0.05), indicating a relationship between family support and adherence to compliance medication in thalassemia patients in the Thalassemia Clinic at Karawang Regional Hospital.

Table 2. Relationship between Family Support and Compliance with Taking Blesional Lesion Medication in Thalassemia Adolescents

Family Support	Compliance				Total		P Value
	No		Obey				
	n	%	n	%	n	%	
Poor	8	6,67%	0	0%	8	6,67%	0,027
Moderate	5	4,16%	5	4,16%	10	8,32%	
Good	52	43,36%	50	41,63%	102	84,99%	
Total	65	54,2%	55	45,8%	120	100%	

DISCUSSION

The results of this study indicate that respondents were predominantly non-compliant with iron chelation medication. Research conducted at Dr. Hasan Sadikin Hospital also found that the majority of children with beta thalassemia major were non-compliant with iron chelation (Triwardhani et al., 2022). Research conducted by Gustiana et al., (2019) at Al-Ihsan Regional Hospital in Bandung also showed that the majority of beta thalassemia major patients were low in compliance. In contrast, a study conducted at Abdul Manap Hospital in Jambi City found that most patients were compliant (18 patients (64.3%). Similarly, a study by Dewi et al., (2022) also found that the majority of patients were compliant with iron chelation medication. This illustrates the variation in adherence levels among thalassemia patients at each healthcare facility.

Respondent non-compliance in this study may be due to a lack of understanding of the importance of medication (Heldawati et al., 2023). In addition, it can be caused by prolonged treatment, the regimen and type of medication administered, age, and the lack of a trusting relationship with healthcare professionals (Kannan & Singh, 2017). Patient non-compliance can also be caused by medication side effects such as dizziness, nausea, vomiting, hearing loss, and seizures (Dharmayanti et al., 2021; Wahidayat, 2016). Knowledge, family support, and support from healthcare professionals can also influence patient compliance (Adiratna et al., 2020). Therefore, factors influencing patient compliance stem from both internal and external factors.

Iron accumulation in the liver and heart of thalassemia patients is caused by blood transfusions. When this occurs, it can increase serum ferritin levels (Gustiana et al., 2019). In adolescent patients, non-compliance with iron chelation medication can result in stunted growth, susceptibility to infection, and even death (Daud, 2020; Dharmayanti et al., 2021; Wahidayat, 2016). Therefore, it is crucial to pay attention to the compliance of adolescents with thalassemia in taking iron chelation medication.

The compliant group had lower serum ferritin levels compared to the non-compliant group (Triwardhani et al., 2022). Research by Pebriyanti (2021) showed that chelation therapy was effective in reducing serum ferritin levels. This means that adherence in thalassemia patients with iron chelation medication can improve their quality of life. This is reflected in studies (Mediani et al., 2022; Supartini et al., 2013) that showed a good quality of life for thalassemia patients who adhere to their treatment.

Research findings regarding family support indicate that adolescents with thalassemia generally experience positive outcomes. This means that respondents receive emotional, instrumental, and esteem support from their families. Family support encompasses attitudes and actions, including acceptance of family members (Friedman et al., 2010). Family support includes accompanying and providing care to respondents during the treatment process. Family support includes reminders for patients to follow the rules (Prayudhistya et al., 2023).

Children with thalassemia require encouragement and support during their treatment (Febriani et al., 2023). Family support impacts individual decision-making (Dewi et al., 2022). Family attitudes toward

caring for children significantly impact the child's quality of life. The stronger the family, the better the quality of life for children with thalassemia (Supartini et al., 2013).

This study shows that good family support is directly proportional to adolescent patient compliance in taking iron chelation medication. Therefore, there is a significant relationship between family support and adherence to chelation medication. This research aligns with research conducted by Adiratna et al., (2020) that found a significant relationship between family support and iron chelation medication adherence scores in thalassemia patients. Research conducted by (Prayudhistya et al., 2023) also aligns with the results of this study, which showed a relationship between family support and medication adherence.

Family support has a positive relationship with iron chelation medication adherence scores in thalassemia patients (Adiratna et al., 2020). Individual support for thalassemia patients has increased adherence to chelation medication (Heldawati et al., 2023). This individual support can be provided by the family as the closest person after the family receives information from healthcare professionals. Having good family support will make someone more likely to be compliant (Ningtyas et al., 2021).

Adolescents who receive family support tend to be more compliant than those who do not. Family support for adolescents serves as a reminder to comply and not forget to take their antidepressant medication. Because adolescents are often prone to unstable behavior, without family support, they are more likely to be non-compliant with antidepressant medication. Without family support, the success rate of treatment or recovery is very low for patients (Dharmayanti et al., 2021). This can lead to negative consequences, including complications.

CONCLUSION

A total of 120 adolescent thalassemia patients participated in this study. Most respondents were female (51.7%), most respondents were aged 10–12 years (43.3%), just 4,2% college and those with no formal education (5.0%). Based on the duration of illness, most respondents had been diagnosed with thalassemia for more than 10 years (60.8%), regarding treatment duration 41.7% had received treatment for more than 10 years. In terms of medication adherence, more than half of the respondents were non-compliant (54.2%), while 45.8% were compliant with iron chelation therapy. Meanwhile, family support was predominantly categorized as good (85.0%), followed by moderate (8.3%) and poor (6.7%). This study concludes that there is a statistically significant relationship between family support and adherence to iron chelation medication among adolescents with thalassemia, as evidenced by a p-value of ($p < 0.05$). This study contributes to the development of nursing and family-based care interventions, emphasizing that enhancing family support can improve treatment adherence and ultimately the quality of life of adolescents with thalassemia.

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