



Factors Associated with the Quality of Life of Children with Major Thalassemia

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Abstract

Thalassemia is one of the blood disorders that affects the quality of life of its sufferers, including children. Several factors are associated with the quality of life of children with major thalassemia, including family support, parenting patterns, transfusion adherence, and economic status. This study aimed to determine the factors associated with the quality of life of children with major thalassemia. This correlational study used a cross-sectional approach involving 62 children with thalassemia aged 10–19 years at Bhayangkara Setukpa Lemdikpol Sukabumi Hospital, selected through total sampling. Data were collected using the Perceived Social Support Questionnaire–Family (PSS-Fa), the Parenting Styles and Dimensions Questionnaire–Short Version (PSDQ), a respondent characteristics questionnaire for transfusion adherence and economic status, and the Pediatric Quality of Life Inventory (PedsQL). Data were analyzed using the chi-square test and logistic regression. The results showed that family support ($p=0.001$), parenting style ($p=0.005$), transfusion adherence ($p=0.002$), and economic status ($p=0.002$) were significantly associated with the quality of life of children with major thalassemia in bivariate analysis. In multivariate analysis, economic status as the strongest associated factor ($OR = 11.628$). Family support, parenting style, transfusion adherence, and economic status were associated with the quality of life of children with major thalassemia in bivariate analysis, while economic status remained the strongest associated factor in the multivariate model. Hospitals are expected to improve patients' quality of life by involving families through health education.

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1. INTRODUCTION

Thalassemia is a group of inherited blood disorders characterized by reduced or absent hemoglobin synthesis, resulting in chronic anemia and lifelong treatment requirements. According to the Thalassaemia International Federation (TIF), an estimated 5–7% of the world's population carries a mutated gene affecting hemoglobin production or function. More than 330,000 infants are born annually with severe hemoglobin disorders, of whom approximately 17% (around 56,000 infants) are affected by thalassemia (Thalassaemia International Federation, 2024). Indonesia is located within the "thalassemia belt," with an estimated prevalence of β -thalassemia carriers ranging from 3.0% to 10.0% and α -thalassemia carriers ranging from 2.6% to 11.0%. Furthermore, approximately 2,500 infants are born with β -thalassemia major each year, indicating that thalassemia remains a significant public health problem in Indonesia (Wahidiyat et al., 2022).

Thalassemia is a hereditary disease caused by a deficiency of one of the substances that form hemoglobin, resulting in reduced production. Clinically, thalassemia is divided into three types: thalassemia intermedia, minor, and thalassemia major. Alpha thalassemia occurs due to a defect in the alpha-globin gene, which causes a reduction or absence of alpha-globin chains. Meanwhile, beta thalassemia is caused by mutations in the beta-globin gene, which can result in beta thalassemia minor in heterozygous mutations and beta thalassemia major in homozygous mutations, leading to the absence of beta chains (Adyanti et al., 2020; Wibowo, 2019).

Treatment of thalassemia major through repeated blood transfusions and iron chelation therapy can cause iron accumulation, which can interfere with digestive function in nutrient absorption and affect the nutritional status of patients. Children with thalassemia major often experience growth disorders, hepatomegaly, and limited physical activity. In addition, patients also show characteristic features such as a Mongoloid face, pale yellowish skin due to increased bilirubin, and grayish skin discoloration due to iron accumulation in the tissues (Adyanti et al., 2020).

Thalassemia has a significant impact on the quality of life of those affected. In school-aged children, this condition can affect their ability to think and attend school due to the treatment they must undergo and the possibility of complications. In addition, the physical changes that occur often reduce productivity in daily activities and make sufferers feel different, causing them to withdraw from their social environment (Rediyanto, 2023).

In addition to the physical effects that impact the quality of life of thalassemia patients, there are many factors that influence the quality of life of children with thalassemia, including family support, parenting styles, transfusion compliance, and economic status (Armina & Pebriyanti, 2021; Budiarti et al., 2023; Febriani et al., 2023; Utami & Anggraeni, 2023).

One factor that affects the quality of life of children with thalassemia is family support. This is supported by research conducted by Putri & Purwati (2023) and Budiarti et al. (2023), which concluded that family support is closely related to the quality of life of children with thalassemia. Family support is the provision of support, both verbal and nonverbal, to each member of the family. Thalassemia patients who receive good family support will find it easier to maintain emotional well-being. The presence of love, attention, and other psychosocial support from the family can help patients cope with the stress and pressure arising from chronic health conditions (Santi et al., 2021).

Another factor that affects the quality of life of children with thalassemia is parenting styles. This is evidenced in studies conducted by Febriani et al. (2023) and Nuraeni et al. (2022) which show that the parenting styles used by parents of children with thalassemia have a significant impact on the quality of life of children with thalassemia. Every parent

has different characteristics, so the parenting style given to their children also varies. This will have an impact on the child's attitude and behavior, which in turn will affect the child's attitude in facing decisions, interacting with the social environment, and responding to the disease they suffer from (Aslan, 2019).

In addition to parenting patterns and family support, transfusion compliance is also one of the factors that affect the quality of life of children with thalassemia. Research by Armina & Pebriyanti (2021) shows that transfusion compliance plays an important role in improving the quality of life of children with thalassemia. Transfusion compliance is the behavior of patients in following transfusion recommendations according to the frequency determined for each patient. The transfusion process provides new energy for patients, because the transfused blood has normal hemoglobin levels that meet their body's needs (Dewi et al., 2019).

Another factor that affects the quality of life of children with thalassemia is economic status. This is supported by research conducted by Utami & Anggraeni (2023) which found that economic status contributes to the quality of life of children with thalassemia. Economic status is the source of income for parents to meet the needs of their families. Higher parental income may enable them to cover medical expenses, including routine blood transfusions, medications, and other healthcare costs, without experiencing significant financial strain (Sigalingging & Sianturi, 2019).

Several previous studies have investigated factors related to the quality of life of children with thalassemia major. Putri & Purwati (2023) and Budiarti et al. (2023) focused on the relationship between family support and quality of life, while Febriani et al. (2023) and Nuraeni et al. (2022) examined the role of parenting styles. Armina & Pebriyanti (2021) analyzed transfusion adherence, and Utami & Anggraeni (2023) investigated economic status as a contributing factor to quality of life. However, these studies generally assessed each factor separately and did not simultaneously evaluate the combined contribution of family support, parenting style, transfusion adherence, and economic status in children with major thalassemia. This study aims to identify factors associated with the quality of life of children with major thalassemia.

2. METHODS

This research uses correlational research with a cross-sectional approach. The research location was conducted at Bhayangkara Setukpa Lemdikpol Sukabumi Hospital. This study analyzes the influence of family support, parenting patterns, transfusion adherence, and economic status on the quality of life of children with major thalassemia at Bhayangkara Setukpa Lemdikpol Sukabumi Hospital.

The population in this study consisted of all children with thalassemia at Bhayangkara Setukpa Lemdikpol Hospital in Sukabumi City aged 10-19 years, totaling 62 individuals using total sampling. The inclusion criteria were children with thalassemia aged 10-19 years, children with thalassemia willing to participate as respondents, children with thalassemia undergoing transfusion visits, and children with thalassemia who were cooperative. The exclusion criteria were children with thalassemia who were in intensive care during the study.

Data were collected through questionnaires with independent variables including family support, parenting style, blood transfusion adherence, and economic status, while the dependent variable was quality of life. The data collection procedure was carried out at Bhayangkara Setukpa Lemdikpol Hospital Sukabumi from February to August 2024. The family support instrument was adapted from the Perceived Social Support-Family Scale (PSS-Fa) and modified to suit the age characteristics of the respondents. Following the modification, the instrument underwent content validation by experts and empirical

validity testing on the study respondents. The parenting style instrument was adapted from the Parenting Styles and Dimensions Questionnaire-Short Version (PSDQ) and was also subjected to content validation and empirical validity testing after modification. The blood transfusion adherence and economic status variables refer to the “Yes” and “No” options on the respondent characteristics questionnaire sheet. The quality of life instrument refers to the Pediatric Quality of Life Inventory (PedsQL) instrument. Validity testing on the standard quality of life instrument was conducted by Varni et al. (2017) and obtained r-values ranging from 0.237-0.814. Empirical validity testing of the modified PSS-Fa and PSDQ instruments showed that all items had p-values < 0.05, indicating that the instruments were valid. Reliability testing on the standard quality of life instrument was conducted by Varni et al. (2017) and obtained a Cronbach's alpha of 0.900. Reliability testing demonstrated Cronbach's alpha values of 0.864 for the family support instrument and 0.848 for the parenting style instrument, indicating good reliability.

The classification of research variables was determined based on the measurement results of the instruments used. Family support was categorized as supportive and less supportive based on the total score of the PSS-Fa instrument according to the predetermined cut-off value. Parenting style was categorized based on the highest score among the PSDQ dimensions, with the highest score in the authoritative dimension classified as democratic parenting. Economic status was classified based on the family income criteria established in the study. Quality of life was categorized as good and poor based on the total PedsQL score according to the applied cut-off value.

Data were analyzed using SPSS software version 27.0. The analysis consisted of describing respondents' characteristics and conducting univariate analysis presented in frequency distribution tables. Bivariate analysis was performed using the chi-square test, while multivariate analysis was carried out using logistic regression analysis. The level of statistical significance applied in this study was 0.05.

In this research, ethical principles including beneficence, confidentiality, and justice were strictly upheld. Ethical clearance was granted by the Ethics Committee from The Highest School for Health Sciences of Sukabumi with approval number 000541/KEP STIKES SUKABUMI/2024. All participant information was kept private and used exclusively for research purposes.

3. RESULTS AND DISCUSSION

Table 1. Characteristics of respondents (n = 62).

Characteristics	Category	Frequency (n)	Percentage (%)
Age	10 – 13	33	53.3%
	14 – 16	13	21.0%
	17 – 19	16	25.8%
Gender	Male	38	61.3%
	Femal	24	38.7%
Education	Primary School	27	43.5%
	Secondary School	20	32.3%
	High School	11	17.7%
	University	4	6.5%
Mother's Education	Primary School	17	27.4%
	Secondary School	20	32.3%
	High School	18	25.8%
	University	9	14.5%
Mother's occupation	Working	24	38.7%

	Not Working	38	61.3%
Father's Education	Primary School	18	29.0%
	Secondary School	20	32.2%
	High School	14	22.7%
	University	10	16.1%
Father's occupation	Working	54	87.1%
	Not Working	8	12.9%
Length of time receiving blood transfusions	<2 years	6	9.7%
	2 – 4 years	1	1.6%
	>4 years	55	88.7%

Table 1 shows that most respondents were aged 10–13 years old, numbering 33 people (53.3%), male, numbering 38 people (61.35%), with primary school education, numbering 27 people (43.5%), mothers with junior high school education, numbering 20 people (32.3%), 38 respondents (61.3%) had mothers who were unemployed, 20 respondents (32.3%) had fathers with a junior high school education, 54 respondents (87.1%) had fathers who were employed, and 55 respondents (88.7%) had received transfusions for more than 4 years

Table 2. Univariate analysis (n = 62).

Variable	Category	Frequency (n)	Percentage (%)
Family Support	Supportive	38	61.3%
	Not Supportive	24	38.7%
Parenting Style	Democratic	46	74.2%
	Non-Democratic	16	25.8%
Transfusion Compliance	Compliant	47	75.8%
	Non-Compliant	15	24.2%
Economic Status	High	26	41.9%
	Low	36	58.1%
Quality of Life	Good	44	71.0%
	Poor	18	29.0%

Table 2 shows that some respondents had supportive families (38 people, 61.3%), received democratic parenting (46 people, 74.2%), compliant with transfusions (47 respondents, 75.8%), have low economic status (36 respondents, 58.1%), and have a good quality of life (44 respondents, 71.05%).

Table 3. Bivariate analysis.

Variable	Category	Quality of Life				Total	%	p-value
		Good	%	Poor	%			
Family Support	Supportive	33	86.8	5	13.2	28	100	0.001
	Not Supportive	11	45.8	13	54.2	24	100	
Parenting Style	Democratic	37	80.4	9	19.6	46	100	0.005

	Non-Democratic	7	43.8	9	56.3	16	100	
Transfusion Compliance	Compliant	38	80.9	9	19.1	47	100	0.002
	Non-Compliant	6	40.0	9	60.0	15	100	
Economic Status	High	24	92.3	2	7.7	26	100	0.002
	Low	20	55.6	16	44.4	36	100	

Based on Table 3, the chi-square statistical test results show a p-value <0.05, which means that family support, parenting patterns, transfusion compliance, and economic status have an influence on the quality of life of children with major thalassaemia.

Table 4. Multivariate analysis.

Variable	B	P-Value	OR
Family Support	0.820	0.299	2.271
Parenting Style	2.064	0.023	7.880
Transfusion Compliance	1.440	0.073	4.222
Economic Status	2.453	0.024	11.628
<i>Constant</i>	-2.708	0.007	0.067
<i>R Square</i> = 0.505			

Based on Table 4, the Nagelkerke R Square value was 0.505, indicating that family support, parenting style, transfusion adherence, and economic status collectively explained 50.5% of the variation in the quality of life of children with major thalassemia, while the remaining 49.5% was explained by other factors not examined in this study. The results of the multivariate logistic regression analysis showed that only parenting style and economic status remained significantly associated with the quality of life of children with major thalassemia, whereas family support and transfusion adherence were not statistically significant in the final model. Economic status was identified as the most dominant factor associated with quality of life, with an OR of 11.628, indicating that children from families with higher economic status were 11.628 times more likely to have a good quality of life compared with children from families with lower economic status.

DISCUSSION

Based on the chi-square test results, a p-value of 0.001 and an OR of 7.8 were obtained, indicating a significant association between family support and the quality of life of children with thalassemia major. This finding is consistent with the study by Budiarti et al., (2022), which shows a significant relationship between family support and the quality of life of children with thalassemia. Children who receive support from their families have a better quality of life than those who do not receive support.

Regular blood transfusions in patients with thalassemia major can also cause various side effects, such as the risk of infection or excess iron accumulation in the body. These side effects require management that is not easy for children, so family involvement is essential. Treatment that minimizes side effects usually requires considerable costs (Febriani et al., 2023). Therefore, families can provide financial support by ensuring access to appropriate care, including the costs of transfusions, medications, medical consultations, and other medical care needed by children with thalassemia major (Hijriani & Septiani, 2020).

Based on the chi-square test results, a p-value of 0.005 and an OR of 5.286 were obtained, indicating a significant association between parenting style and the quality of life of children with thalassemia major. This finding is supported by (Ningning & Wenguang, 2023), which showed that democratic parenting styles are very effective when applied by parents. By giving children freedom with boundaries, as well as full support for their wishes, the quality of life of children with thalassemia can improve significantly.

In general, parents always try to give their children the best, especially when it comes to medical care (Sadiq et al., 2024). However, children's behavior can vary depending on how parents apply the parenting style they know or want. Parents who apply democratic or authoritative parenting styles to children with thalassemia major will ensure that their children receive the necessary medical care in a timely and regular manner, understand the importance of such medical care, and strive to comply with medical instructions properly (Rahimzadeh et al., 2024; Simangunsong & Sihotang, 2022).

Based on the chi-square test results, a p-value of 0.002 and an OR of 6.333 were obtained, indicating a significant association between transfusion compliance and the quality of life of children with thalassemia major. Several previous studies have reported a relationship between transfusion adherence and health-related quality of life in children with thalassemia, finding that transfusion frequency, pre-transfusion hemoglobin levels, and adherence to chelation therapy correlate with better HRQoL scores (Maheri et al., 2020; Mariam, 2022).

Regular and timely blood transfusions help reduce the risk of medical complications that can arise from thalassemia major, such as growth disorders and heart problems (Ali et al., 2021; Hu et al., 2024). Children who adhere to their transfusion schedule are more likely to avoid long-term health problems that can affect their quality of life. By reducing the risk of complications, children can lead healthier and more productive lives (Malay et al., 2024). Children who understand the importance of adhering to blood transfusions and other treatments tend to develop better self-awareness of their own health condition (Sarinengsih et al., 2025).

Based on the chi-square test results, a p-value of 0.002 and an OR of 9.6 were obtained, indicating a significant association between economic status and the quality of life of children with thalassemia major. This is in line with the findings by (Hossain et al., 2023), who reported a significant relationship between economic status (family income/economic class and parents' occupation) and quality of life scores in thalassemia patients.

Children with thalassemia major require regular, high-quality medical care to maintain their health. Families with good economic status can easily access the necessary health services, including hospitals with complete facilities and competent medical personnel. Conversely, families with low economic status may have difficulty obtaining adequate care, putting their children at risk of more serious health complications. The availability of medications needed for thalassemia treatment, such as chelation therapy drugs, is also influenced by economic status. Families with good economic conditions can easily and regularly purchase medications, while families with financial constraints may not be able to afford the necessary drugs (Hu et al., 2024; Zabadi et al., 2025).

The multivariate analysis showed that parenting style and economic status remained significantly associated with the quality of life of children with major thalassemia at Bhayangkara Setukpa Lemdikpol Sukabumi Hospital after adjustment for other variables. These findings indicate that both factors were more strongly associated with quality of life than family support and transfusion adherence in the multivariate model.

Conceptually, positive parenting patterns can shape children's coping skills, independence, and psychosocial adaptation in dealing with chronic illness (Sadiq et al.,

2024), while economic status determines the family's ability to access adequate health services, treatment, and social support, thereby contributing directly to improved quality of life (Malay et al., 2024). The absence of a significant association between family support and transfusion compliance with quality of life in the multivariate analysis may be explained by several factors. The relatively homogeneous characteristics of respondents may have reduced the variability of family support and transfusion compliance scores. In addition, both variables were measured using self-reported questionnaires, which may be influenced by respondents' perceptions and recall bias. Furthermore, the quality of life of children with thalassemia major is a complex outcome influenced by multiple factors, so the contribution of individual factors may not remain significant when analyzed simultaneously with other variables.

From a family-centered care perspective, parents play an essential role as partners in the care process of children with chronic illness. Family involvement through guidance, emotional regulation, and decision-making support can help children adapt to the challenges associated with thalassemia major. In addition, psychosocial adaptation and coping theory suggest that positive parenting patterns can facilitate children's coping abilities, independence, and psychological adjustment in managing chronic illness. Therefore, a supportive family environment and appropriate parenting approaches may contribute to better quality of life among children with thalassemia major (Seniwati et al., 2023).

This study has several limitations. First, the cross-sectional design limits the ability to draw causal conclusions regarding the relationships between family support, parenting style, transfusion adherence, economic status, and quality of life. Second, the relatively small sample size ($n=62$) and the use of a single service center may reduce the external validity and limit the generalizability of the findings to a broader population. Although economic status emerged as the strongest associated factor in the multivariate analysis, the relatively small sample size may have affected the precision of the odds ratio estimate; therefore, the odds ratio should be interpreted with caution. In addition, transfusion adherence and economic status were measured using dichotomous (Yes/No) responses, which may have reduced the variability and accuracy of the data and limited the ability to capture differences in the intensity or level of adherence and socioeconomic conditions among participants. Finally, the multivariate model explained approximately 50.5% of the variance in quality of life (Nagelkerke R Square = 0.505), indicating that other unmeasured factors may also contribute to the quality of life of children with major thalassemia.

The findings of this study highlight the important role of nurses in providing a holistic and family-centered approach to children with major thalassemia. Nurses can use these findings as a basis for developing educational interventions, parenting guidance, and family support programs aimed at improving children's quality of life while considering socioeconomic conditions that may affect treatment access and continuity of care. For future research, several limitations of the present study should be addressed. Longitudinal study designs are recommended to better examine causal relationships between variables. Future studies should also include objective clinical indicators, such as pre-transfusion hemoglobin and ferritin levels, to explore biological pathways related to quality of life. In addition, larger sample sizes and multicenter data collection are needed to improve the generalizability of the findings. Advanced statistical approaches, including structural equation modelling, are also recommended to examine potential mediating and moderating effects as well as hierarchical data structures.

4. CONCLUSION

Parenting style and economic status were identified as independent factors associated with the quality of life of children with major thalassemia at Bhayangkara Setukpa Lemdikpol Hospital in Sukabumi. Children who experience supportive and well-structured parenting and who come from families with adequate economic conditions tend to have a better quality of life. Family support and transfusion adherence were significantly associated with quality of life in the bivariate analysis; however, they did not remain statistically significant in the multivariate model. Future studies are recommended to develop structured family-based nursing interventions that incorporate parenting approaches and socioeconomic considerations in order to improve the quality of life of children with major thalassemia, as well as to use longitudinal and multicenter study designs to obtain broader and more robust evidence.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

AUTHOR CONTRIBUTIONS

Sri Janatri conceived and designed the study, conducted the literature review, coordinated data collection, and drafted the initial manuscript. Ghulam Ahmad contributed to data collection, literature review, interpretation of the findings, and manuscript revision. Asmarawanti contributed to data collection, literature review, interpretation of the findings, and refinement of the manuscript. Johan Budhiana contributed to the development of the research methodology, supervised the research process, conducted the data analysis and statistical analysis, and critically revised the manuscript for intellectual content. All authors reviewed and approved the final version of the manuscript for submission.

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DECLARATION OF ARTIFICIAL INTELLIGENCE USE

The author used an AI-assisted language tool (ChatGPT) solely to improve the language, grammar, readability, and organization of the manuscript. The AI tool was not used for data collection, data analysis, interpretation of results, or generation of scientific conclusions. The author takes full responsibility for the accuracy, originality, and integrity of the manuscript.

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