

ORIGINAL ARTICLE

Factors Affecting the Quality of Life of Children with Thalassemia Major

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ABSTRACT

Introduction: Thalassemia major is a life-threatening genetic disorder that demands regular blood transfusions, placing a heavy physical and emotional burden on affected children. This chronic treatment not only disrupts daily life but also compromises their overall quality of life. Addressing this issue is important, as various factors such as family support, parenting, the role of health workers, and peers may influence how children cope. This study aims to determine the effect of family support, parenting, the role of health workers, and peers and simultaneously on the quality of life of children with thalassemia major. **Methods:** Type of correlational research with a cross sectional approach. The sample in this study amounted to 62 respondents. The population in this study were thalassemia patients who were undergoing transfusion, aged 10-19 years, cooperative, willing to become respondents. Data collection techniques used PSS-Fa, PSDQ, SPS, and PedsQL questionnaires. Data analysis used logistic regression. **Results:** There is an influence of family support ($p=0.001$), parenting patterns ($p=0.005$), the role of health workers ($p=0.017$), peers ($p=0.002$) on the quality of life of children with thalassemia major. There is a simultaneous influence of family support and peers on the quality of life of children with thalassemia major ($p<0,05$). **Conclusion:** The conclusion is that there is an influence of family support, parenting, the role of health workers, and peers on the quality of life of children with thalassemia major. It is expected that the hospital can organize social activities, and education involving families, health workers, and peers.

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INTRODUCTION

Thalassemia is a blood cell disorder with the main causative factor being familial genetics. Apart from that, thalassemia can also occur due to the body's inability to produce hemoglobin, a protein in red blood cells that results in a decreased amount of oxygen being distributed from the lungs (1). In Indonesia, thalassemia is the most common hereditary disease. The prevalence of thalassemia gene carriers in various regions in Indonesia ranges from 3-10%. Every year, the number of patients with beta major thalassemia continues to increase (2).

An in-depth understanding of thalassemia is becoming increasingly important as the number of cases increases every year. Thalassemia is a genetic disease caused by a deficiency of one of the components that make up hemoglobin, resulting in hemoglobin production being

disrupted (3). According to Budhiana et al., people with thalassemia major generally do not reach the age of three decades (4). Thalassemia major is a serious chronic disease, and if not managed properly or left untreated, can lead to death. Management of this disease requires regular blood transfusions throughout the patient's life to maintain a healthy balance and the amount of blood in someone body.

Without blood transfusions, patients will develop severe anemia which often cause a wide range of serious complications, like organ damage or even heart failure. So far, the longest recorded lifespan for people with thalassemia major has an average lifespan of about 24 years. This shows how critical the medical management and treatment needed to improving quality of life among people with thalassemia (5).

Alternative treatments for children with thalassemia major, such as repeated blood transfusions and the use of iron chelation therapy can result in iron build-up (hemochromatosis) in the organs. This affects the function of the digestive organs in absorbing and maintaining the balance of nutrients. This also causes

them to often experience growth delays compared to other children, which affects their mobility and limits physical activity (6).

The quality of life of patients with thalassemia tends to be influenced by the disease. School-aged thalassemia patients often have difficulty in thinking and are often absent due to the treatment they have to undergo or complications that arise. This also affects their productivity while performing activities daily living, thus lowering the overall productivity level (7).

Given the complex challenges faced by children with thalassemia major, psychosocial factors such as family support, parenting, the role of health workers, and peer relationships are important to consider. These factors have been shown to influence emotional well-being, treatment adherence, and social acceptance, all of which significantly affect quality of life. Therefore, this study focuses on these key aspects to better understand their impact on the quality of life of children with thalassemia major.

In addition to the physical effects that related with quality of life among people with thalassemia, there are other aspects that are significant in influencing the quality of life of children suffering from this condition. Research conducted Putri & Puwari and Budiarti et al. Family support has a huge impact on the quality of life of children with thalassemia (3,8). Various studies explain that patients will feel more loved and loved if they get good family support. This helps to increase thalassemia sufferers' confidence in accepting themselves, which eventually has a great effect on their emotional well-being (9).

One of the the next aspect that is considered to affecting the quality of life of children with thalassemia is parenting. Research Febriani et al. and Nuraeni et al., shows that the way parents parent has a significant impact on the quality of life of children with thalassemia (10,11). The adoption of democratic parenting is considered to be particularly relevant for parents of adolescent children with thalassemia. This pattern allows them to care for and educate their children by paying attention to the freedom and interaction that the child already has in the school environment, as well as in the context of thalassemia treatment. This can better improve the quality of life of thalassemia children, as it facilitates positive support and builds a positive relationship between parents and children.

The role of health workers also affect the quality of life of children with thalassemia. Research conducted by Nuraeni et al and Ulfa & Hasyim shows that health workers have an important role in improving the quality of life of both patients and parents of children with thalassemia (6,11). Health workers who are open, accepting of patients' complaints, and providing motivation can increase patients' morale and happiness

in undergoing their treatment. Thus, positive interactions between health workers and thalassemia patients can help improve their overall quality of life. (12).

Other aspect that affecting the quality of life of children with thalassemia are relationships with peers. Research Lusiani shows that the support and role of peers has a significant contribution to the quality of life of children with thalassemia (13). Acceptance from peers can provide satisfaction and happiness, and support their social and psychological well-being. Acceptance from the group can also strengthen self-image and positive self-evaluation for children with thalassemia, because they feel recognized and accepted by the surrounding environment (14). Therefore, this study aims to examine the effects of family support, parenting patterns, the role of health workers, and peer relationships on the quality of life of children with thalassemia major at Bhayangkara Setukpa Lemdikpol Hospital in Sukabumi.

MATERIALS AND METHODS

Study Design

This study used a correlational research method with a cross sectional approach. This study was conducted at Bhayangkara Setukpa Lemdikpol Sukabumi Hospital from February to July 2024. Before data collection, ethical permission was obtained (No: 000885/KEP STIKES SUKABUMI/2024).

Sample

The population in this study were thalassemia patients who were undergoing transfusion, aged 10-19 years, cooperative, willing to become respondents. The sample in this study amounted to 62 respondents using total sampling.

Instrument

The instrument in the study used a questionnaire. The questionnaire for family support variables refers to a standardized instrument, namely the Perceived Social Support Questionnaire Family (PSS-Fa) with a validity test based on the calculated r value of 0.361 so that it is declared valid and the reliability test is based on the Cronbach alpha value of 0.752 so that it is declared reliable (15). The questionnaire for parenting variables refers to a standardized instrument, namely the Parenting Styles and Dimension Questionnaire (PSDQ) with a validity test based on the calculated r value of 0.422 so that it is declared valid and the reliability test is based on the Cronbach alpha value of 0.912 so that it is declared reliable (16). The questionnaire for the role of health workers variable refers to a Likert scale with a validity test using Pearson product moment conducted on 62 children with thalassemia at Bhayangkara Setukpa Lemdikpol Sukabumi Hospital. The validity test results obtained a p -value <0.05 so that it is declared valid for all items and the reliability test is based on the Cronbach alpha value > 0.7 so that it is declared reliable. The

questionnaire for peer variables refers to a standardized instrument, namely The Social Provision Scale (SPS) with validity test based on the calculated r value of 0.280-0.310 so that it is declared valid and reliability test based on Cronbach alpha value of 0.60-0.70 so that it is declared reliable (17). The questionnaire for quality of life variables refers to a standardized instrument, namely the Pediatric Quality of Life Inventory (PedsQL) with a validity test based on the calculated r value of 0.237-0.814 so that it is declared valid and the reliability test is based on the Cronbach alpha value of 0.900 so that it is declared reliable (18).

Data Analysis

Univariate analysis in this study used frequency distribution. Statistical analysis used chi square and logistic regression with a significance value of 0.05. All statistical analyses were performed using the SPSS statistical software package (version 26).

RESULTS

The characteristics of the respondents are presented in Table I. Most respondents were aged 10–13 years, comprising 33 participants (53.2%). The majority were male, with 38 participants (61.3%). In terms of education, most respondents had completed elementary school, accounting for 27 participants (43.5%). Most mothers had completed junior high school, with 20 participants (32.3%), and most were unemployed, comprising 38 participants (61.3%). Similarly, most fathers had completed junior high school, with 20 participants (32.3%), while 54 fathers (87.1%) were employed. Most parents had a monthly income below the regional minimum wage, namely <UMR (Rp. 2,562,434), with 36 participants (58.1%). Most respondents had undergone blood transfusion for more than four years, comprising 55 participants (88.7%), and 47 participants (75.8%) had received transfusion within the last three months. Most respondents had a family history of thalassemia, with 53 participants, and all respondents used national health insurance (BPJS).

As shown in Table II, most respondents received family support, comprising 38 participants (61.3%). Most respondents were raised using a democratic parenting pattern, with 46 participants (74.2%). The role of healthcare workers was reported as good by 47 participants (75.8%), while 36 participants (58.1%) received peer support. In terms of quality of life, most respondents had a good quality of life, comprising 44 participants (71.0%).

The bivariate and multivariate analyses are presented in Table III. The chi-square test showed significant relationships between quality of life and family support ($p = 0.001$; OR = 7.800), parenting pattern ($p = 0.005$;

Table I: Characteristics of respondents

	F	%
Age (y.o)		
10-13	33	53.2
14-16	13	21.0
17-19	16	25.8
Gender		
Male	38	61.3
Female	24	38.7
Respondent's Last Education		
Elementary School	27	43.5
Junior High School	20	32.3
Senior High School	11	17.7
College	4	6.5
Mother's Last Education		
Elementary School	17	27.4
Junior High School	20	32.3
Senior High School	18	25.8
College	9	14.5
Mother's Job		
Employed	24	38.7
Unemployed	38	61.3
Father's Last Education		
Elementary School	18	29.0
Junior High School	20	32.2
Senior High School	14	22.7
College	10	16.1
Father's Job		
Employed	54	87.1
Unemployed	8	12.9
Parent Income		
≥UMR (Rp. 2.562.434.-.)	26	41.9
<UMR (Rp. 2.562.434.-.)	36	58.1
Length of time Receiving Blood Transfusions		
<2 tahun	6	9.7
2-4 tahun	1	1.6
>4 tahun	55	88.7
Recent transfusion on the last 3 months		
Yes	47	75.8
No	15	24.2
Thalassemia History		
Yes	53	85.5
No	9	14.5
Insurance Use		
National (BPJS)	62	100
Total	62	100.0

Table II: Distribution of family support, parenting pattern, healthcare role, peer support, and quality of life

	F	%
Family Support		
Support	38	61.3
Unsupport	24	38.7
Parenting Patterns		
Democratics	46	74.2
Non Democratics	16	25.8
Healthcare Role		
Good	47	75.8
Less Good	15	24.2
Peer Support		
Support	36	58.1
Unsupport	26	41.9
Quality of Life		
Good	44	71
Less Good	18	29
Total	62	100.0

OR = 5.286), healthcare worker role ($p = 0.017$; OR = 4.229), and peer support ($p = 0.002$; OR = 6.000). In the multivariate analysis, family support and peer support remained significantly associated with quality of life among children with thalassemia major, after considering parenting pattern and the role of healthcare workers. The model explained 46.0% of the variation in quality of life, while the remaining 54.0% may be explained by other factors not examined in this study. Family support was the most dominant factor, with an OR value of 7.076, indicating that children who received family support were approximately 7.1 times more likely to have a good quality of life than those who did not receive family support.

DISCUSSION

The Effect of Family Support on the Quality of Life of Children with Thalassemia Major

The results of this study indicate that there is a significant relationship between family support and the quality of life of children with thalassemia major. These results are supported by research conducted by

Katiment et al, who found a significant relationship between family support and the quality of life of children with thalassemia (19). The quality of life of a child with thalassemia major is greatly influenced by family support, which includes physical, emotional and financial assistance. These children have to undergo regular blood transfusions which often leads to burnout, fatigue, and various side effects such as risk of infection and excess iron accumulation, which require complex management and high costs. (3,20,21). Families play an important role in ensuring access to adequate care, organizing medical schedules, and providing emotional support that helps the child feel loved and cared for. In addition, family involvement in the education and social aspects of the child helps to overcome the impact of school absenteeism and limited playtime, so that the child does not feel isolated or inferior (22).

The Effect of Parenting on the Quality of Life of Children with Thalassemia Major

The results of this study indicate that there is a significant relationship between parenting and the quality of life of children with thalassemia major. The appropriate research is Febriani et al that democratic parenting is very appropriate for parents of thalassemia children (10). Parenting patterns greatly affect the quality of life of children with thalassemia major because it plays an important role in meeting the medical, emotional, and social needs of children. Children with thalassemia major are subjected to lifelong treatment, such as regular blood transfusions and iron chelation therapy, which requires parental support in health-related decision-making (4,23). Democratic parenting, where parents provide clear but flexible rules, supports a child's emotional health by providing strong emotional support and encouraging the child to manage their emotions independently. It also ensures the child receives timely treatment, understands the importance of the treatment regimen, and stays engaged in education and social activities, which are important for transitioning to a more independent adulthood (24,25). In contrast, authoritarian or permissive parenting tends to inhibit children's emotional development and responsibility for their health care, which can negatively impact their mental health and well-being (24,26).

Table III. Bivariate and multivariate analysis of factors associated with quality of life among children with thalassemia major

Variable	Category	Quality of life			Bivariate analysis		Multivariate analysis		
		Good n (%)	Less good n (%)	Total n (%)	p-value	Crude OR	B	p-value	Adjusted OR
Family support	Support	33 (86.8)	5 (13.2)	38 (100)	0.001	7.800	1.957	0.007	7.076
	Unsupport	11 (45.8)	13 (54.2)	24 (100)					
Parenting pattern	Democratic	37 (80.4)	9 (19.6)	46 (100)	0.005	5.286	1.345	0.082	3.837
	Non-democratic	7 (43.8)	9 (56.3)	16 (100)					
Healthcare role	Good	37 (78.7)	10 (21.3)	47 (100)	0.017	4.229	0.541	0.513	1.717
	Less good	7 (46.7)	8 (53.3)	15 (100)					
Peer support	Support	33 (84.6)	6 (15.4)	39 (100)	0.002	6.000	1.650	0.029	5.206
	Unsupport	11 (47.8)	12 (52.2)	23 (100)					

Notes: OR = odds ratio; B = regression coefficient. The multivariate model R Square was 0.460. The constant was B = -2.382, $p = 0.013$, OR = 0.092.

The Effect of the Role of Health Workers on the Quality of Life of Children with Thalassemia Major

The results of this study indicate that there is a significant relationship between the role of officers and the quality of life of children with thalassemia major. Research conducted by Nurmaliyati et al mentioned that health workers, including nurses, have an influence on the quality of life of thalassemia patients (27). Children with thalassemia major require regular blood transfusions, iron chelation therapy, and a range of other medical treatments that create close interactions with healthcare workers, which play a crucial role in improving their quality of life. Healthcare workers such as doctors, nurses, nutritionists, pharmacists, child psychologists, and physical therapists are involved in early diagnosis, management of the transfusion schedule, and monitoring of patient response, all of which help reduce the risk of complications such as severe anemia and iron overload (28). In addition, health workers provide education on thalassemia disease management, the importance of medication adherence and adopting a healthy lifestyle, and provide psychosocial support to cope with stress and anxiety due to chronic illness. Multidisciplinary care coordination by health workers ensures comprehensive treatment and good hospitalization management, which is important to reduce complications and improve the child's long-term quality of life, enabling them to actively participate in daily activities (29).

The Effect of Peers on the Quality of Life of Children with Thalassemia Major

The results of this study indicate that there is a significant relationship between family support and the quality of life of children with thalassemia major. A suitable study is Lusiani's, which shows that peer support can play a role in improving the quality of life of children with thalassemia major (13). Children with thalassemia major often have to miss school due to regular medication schedules such as blood transfusions and iron chelation therapy, which can affect their social interactions. Different physical conditions such as a bulging belly and grayish skin are often the subject of teasing, although some children still have close friends and are actively involved in school activities (30). Peer support is important to their quality of life, providing comfort, understanding and encouragement that helps children cope with the anxiety and pain of medical procedures. Good relationships with peers can improve a child's psychological health, self-confidence and self-esteem. Peers also support participation in social and physical activities that improve physical and mental well-being, and encourage adherence to medical treatment (31).

The Effect of Family Support, Parenting, the Role of Health Workers, and Peers on the Quality of Life of Children with Thalassemia Major

Among the various psychosocial factors that influence the quality of life in children with thalassemia major, family support emerges as the most dominant

contributor. Children suffering from a chronic illness such as thalassemia major require not only lifelong medical treatment but also consistent emotional and psychological support from their closest environment primarily their families.

Several studies affirm that emotional bonding, financial assistance, encouragement, and care from family members significantly affect the child's ability to cope with the illness, which in turn enhances their overall well-being and perception of life quality. For instance, Budiarti et al (3) and Putri & Purwati (8), found that children who received strong family support reported better emotional stability, higher levels of happiness, and more active social interactions compared to those who did not. Katimenta et al (19) also emphasized that family involvement in daily care routines helps reduce anxiety, increase adherence to treatment, and foster a sense of security in children.

While parenting style, peer relationships, and support from health workers also contribute meaningfully, their influence appears to be less impactful than family support when examined simultaneously. For example, although democratic parenting can improve a child's autonomy and confidence (10,24), its effect is often shaped by the broader emotional environment provided by the family unit. Similarly, while peers offer social acceptance and emotional comfort (13), and healthcare providers deliver vital information and clinical care (6), these supports typically function more effectively when complemented by strong familial involvement.

The study's findings suggest that family support acts as a foundation, upon which the effects of other supportive factors can be strengthened. Children who feel loved, valued, and understood at home are more likely to respond positively to external support and exhibit better psychosocial outcomes, including treatment adherence and emotional resilience.

CONCLUSION

There is a significant influence between family support, parenting, the role of health workers, peers, and simultaneously on the quality of life of children with thalassemia major at Bhayangkara Setukpa Lemdikpol Sukabumi Hospital. It is hoped that the hospital can organize social activities, and education involving families, health workers, and peers.

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