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Family and Peer Group Support Related to The Quality of Life of Thalassemic Adolescents in Outpatient Settings

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ABSTRACT

Thalassemia in Indonesia is dominated by teens. Thalassemic adolescents often experience psychosocial problems. The role of family and peer group support in the quality of life of thalassemic adolescents is still inconclusive. This study aim to determine the association between family and peer group support on the quality of life of thalassemic adolescents in one government hospital in Jakarta, Indonesia. An analytical observational study with a cross-sectional approach on β-thalassemia sufferers aged 12-18 years who came to the Children's Polyclinic and intervention room in November-December 2023. Family and peer group support was measured using the Social Support Scale, while quality of life was measured using the validated Generic Pediatric Quality of Life Inventory Version 4.0 (PedsQL). The data obtained were analyzed using Chi-Square and logistic regression tests. Forty-three patients were involved in this study. The average age of respondents was 14.4 years (range 13.8 – 15.1), the average time of diagnosis was 9.49 years (range 8.0 – 11.0), the average hemoglobin (Hb) level was 9.2 gr/dl (range 8.7 – 9.6 gr/dl). The majority of respondents were male (65.1%), had low education (60.5%), and had a good adherence to iron chelation therapy (100%). The association between family and peer group support on quality of life obtained a p-value of 0.014 and 0.006 with an Odd Ratio (OR) of 4.976 and 7.333 respectively. There is a significant relationship between family and peer group support on the quality of life of thalassemic adolescents. It is recommended for health workers to improve the quality of life of thalassemic adolescents with a family and peer group support approach. Further studies are needed to confirm the results of this study.

Keywords: adolescent; family support; peer group; quality of life; thalassemia.

1. INTRODUCTION

Thalassemia is an acquired anemia disease caused by abnormalities in forming hemoglobin (Hb) in erythrocytes (1). Thalassemia belongs to a heterogeneous group of genetic disorders of Hb function. Hemoglobin carries oxygen in erythrocytes and is divided into 2 proteins, alpha, and beta, as is also the basis for classification in Thalassemia (2,3).

The World Health Organization (WHO) states that 7% of the world's population are carriers of thalassemia. Approximately 300,000-500,000 babies are born with severe hemoglobin defects, and 50,000-100,000 children die from β-thalassemia every year, 80% of whom come from developing countries (4). Epidemiological studies in Indonesia found that the frequency of the β-thalassemia gene ranges from 3-10% (2). Jakarta is one of the top three regions with the largest number of thalassemia sufferers in Indonesia, namely 864 sufferers or 7.87% (5). According to the Indonesian Pediatrician Association, in 2023 thalassemia sufferers in Indonesia will be dominated by adolescents (6).

Adolescence is a time of self-formation through various activities, as well as a time to gain various knowledge and abilities needed in adulthood (7, 8). Quality of life is related to the development of human resources. Quality of life is a concept regarding the condition and ability of individuals to carry out various activities to meet their needs (9). Quality of life is also closely related to the happiness felt by individuals (10). Improving the quality of life is important because of its implications for improving welfare. The better a person's quality of life, the more prosperous he will feel (1).

Thalassemic adolescents face various social, psychological, and physical problems that cause the quality of life of thalassemic children and adolescents to be lower than normal. This is due to the restrictions on physical activity, physical changes, feelings of discrimination, and decreased achievement at school (11). The quality of life of thalassemic adolescents was low, mainly in the emotional aspect, followed by the physical and social aspects. The main impact on adolescents with thalassemia was depression, fear of physical activity, and sleep disorders (12–14).

Several studies show a relationship between family and peer group support with quality of life. However, several other studies have shown contradictory results (13, 15–18). This study aims to confirm the relationship between the support of family and peer groups and the quality of life in thalassemia adolescents in outpatient settings. This research also examines several factors that are thought to be confounding in this relationship, including education level, Hb levels, and length of illness since diagnosis.

2. METHOD

The design of this research is an observational analytic with a cross-sectional approach study. The research was conducted at a government children and maternal hospital in Jakarta, Indonesia in November-December 2023. The population in this study was 122 thalassemia patients based on the number of visits by thalassemia patients to the Children's Polyclinic in the previous month.

The number of samples was determined using a total sampling technique with inclusion criteria for β-thalassemia adolescents (major) aged 12-18 years who came to the children's polyclinic and treatment room at the research center. Patients with decreased consciousness, complications, mental retardation, disability, undergone splenectomy, and were currently undergoing inpatient care were excluded from the study.

Family and peer group support variables were measured using the Social Support Scale (19). Meanwhile, quality of life variables were measured using PedsQL 4.0 (20). Both of these instruments have been validated. Data collection was carried out by filling out a self-report questionnaire. The collected data was then processed using descriptive analysis, Chi-Square test, and logistic regression test using the SPSS version 26 for Windows application.

This research has been through a review process and permission from the Independent Review Board (Number IRB/48/11/ETIK/2023) on November 21, 2023. All involved respondents were informed about the study and signed informed consent.

3. RESULTS AND DISCUSSION

RESULT

A total of 43 respondents were involved in this study. The average age of respondents was 14.4 years (range 13.8 – 15.1), the average time of diagnosis was 9.49 years (range 8.0 – 11.0), and the average Hb level was 9.2 gr/dl (range 8.7 – 9.6 gr/dl). The majority of respondents were male (65.1%), had low education (lower than senior high school level or equivalent) (60.5%), and had a good adherence to iron chelation therapy (100%). The majority of family and peer group support was in the good category (60.5% and 71.1%), and the majority of respondents' quality of life was in the good category (58.1%) (Table 1).

Table 1. Characteristic of the respondent (N=43)

Variable		n (%)	Mean±SD (Range)
Age (year)			14.4 ± 2.1 (13.8-15.1)
Duration of treatment since diagnosis (year)			9.5 ± 4.8 (8.0-11.0)
Hb level (g/dL)			9.2 ± 1.5 (8.7-9.6)
Gender	Male	28 (65.1)	
	Female	15 (34.9)	
Education	High (at least at senior high school level)	17 (39.5)	
	Low (less than senior high school level)	26 (60.5)	
	Good	43 (100)	

Variable		n (%)	Mean±SD (Range)
Iron chelation therapy adherence	Poor	0 (0.0)	
Family support	Good	26 (60.5)	
	Poor	17 (39.5)	
Peer group support	Good	31 (72.1)	
	Poor	12 (27.9)	
Quality of Life	Good	25 (58.1)	
	Poor	18 (41.9)	

Abbreviation: SD, Standard Deviation; Hb, Hemoglobin; g/dL, gram per deciliters.

The analysis results using the chi-square test on family support variables and quality of life obtained a p-value of 0.014 (< α 0.05), with an odds ratio (OR) of 4.976. This means that family supports are significantly related to the quality of life of thalassemia adolescents. Good family support is 4.976 times more likely to have a good quality of life than respondents who receive poor family support (Table 2).

Table 2. Data analysis (N=43)

Variable		Quality of life n (%)		[a]p-value	OR (95% CI)
		Good	Poor		
Family support	Good	21 (80.8)	5 (19.2)	[b]0.014	4.976 (1.3-18.6)
	Poor	4 (23.5)	13 (76.5)		
Peer group support	Good	22 (71.0)	9 (29.0)	[b]0.006	7.333 (1.6-33.5)
	Poor	3 (25.0)	9 (75.0)		

[a] bivariate analysis with the Chi-Square test; [b] significant (less than α 0.05)

Abbreviation: OR, Odds Ratio; CI, Confidence Intervals

The analysis results of the chi-square test on peer group support and quality of life obtained a p-value of 0.006 (< α 0.05) with OR 7.333. This means that peer group supports are significantly related to the quality of life of thalassemic adolescents in this study. Respondents who received good peer group support were 7.333 times more likely to have a good quality of life compared to respondents who received poor peer group support (Table 2).

Multivariate analysis using logistic regression is carried out through several stages. In the process, age and sex variables are not eligible for multivariate testing. While the educational variable, duration of treatment since diagnosis was eliminated in the multivariate analysis process. Although the variable Hb level in the initial calculation does not qualify for multivariate testing, because of its important role in thalassemia, we still analyze to find out its role scale in this study. Multivariate final results show that family support and peer group variables had a significant relationship with quality of life, each of which has a p-value <0.05. Meanwhile, the Hb level variable is a confounding variable. The largest OR value obtained by the family support variable was 9.692, which means this variable has the greatest influence on quality of life, followed by the peer group variable with an OR of 8.427, and Hb level with an OR of 1.621 (Table 3).

Table 3. Multivariate analysis (N=43)

Variable	B	[a]p-value	OR	95% CI	
				Lower	Upper
Family support	2.271	[b]0,009	9.692	1.748	53.730
Peer Group support	2.131	[b]0,015	8.427	1.512	46.973
Hb level	0,483	0,105	1,621	0,903	2.910

[a] Multivariate analysis using logistic regression; [b] significant (less than α 0.05)

Abbreviation: B, Beta Coefficient; OR, Odds Ratio; CI, Confidence Interval

DISCUSSION

The relationship between family support and the quality of life of Thalassemia adolescent

The results of the analysis show that there is a significant relationship between family support and the quality of life of thalassemia in adolescents. All dimensions of family support, like emotional, appreciation, information, and instrumental support are related to the quality of life of thalassemic adolescents. The quality of life of thalassemic children and adolescents depends on family support (21). Family empowerment interventions are needed because they have a great impact on overcoming the effects of chronic diseases on children, namely improving quality of life, family care, and personal abilities (12,15,18,22).

Several research results generally state that thalassemia in children and adolescents with good family support shows a better life quality than thalassemia in adolescents with poor family support. Practical family support is related to the way the family accepts the disease and undergoes treatment (21).

Psychological support, like receiving and providing assistance to adolescents with thalassemia in carrying out treatment, is an important thing for them. Without any understanding and acceptance of thalassemia and its implications will lead to an increased risk of disease complications and poorer survival (23–26). Specifically the relationship between parents and children that psychologically has a big influence on children's development. Kathryn Barnard's nursing model theory states that there is an important connection in the parent-child relationship. Parental support can create positive behavior in adolescents to adapt to the illness they face (27,28).

Family support in the form of financial support implies a large influence on the family's ability from an economic perspective to maintain the quality of life of thalassemic adolescents (29). This means that thalassemia adolescents who are economically well supported by their families will have a better and more secure quality of life than thalassemic adolescents who are not.

The relationship between peer group support and quality of life in thalassemia adolescent

Peer groups function as social mobilizers, supporting new social functions, sharing information, interdependence, and efforts to achieve freedom in expressing opinions (30). Support and acceptance from peer groups are important for thalassemia adolescents because they can facilitate thalassemic adolescents in carrying out social integration (31–33). This peer group support can prevent thalassemia adolescents from depression and other mental disorders (34,35).

A good peer group gives hope to thalassemic adolescents to have a good quality of life. Peer groups can be one method of therapy in improving the hope of thalassemic adolescents. Hope improvement can improve their quality of life (32,36). Peer groups are also a source of knowledge for thalassemia adolescents about the diseases they suffer. This knowledge is important in maintaining their quality of life (28,32,37).

A qualified friendship will have a positive effect on the members of the group (35). A good peer group is important for thalassemia adolescents. They will receive support, both physical and non-physical, which can improve the quality of life of thalassemia adolescents (36). However, in this study, it has not been analyzed which dimensions of support affect the quality of life of thalassemic adolescents most. This is one of the limitations of this study.

Family support, peer group, Hb, and quality of life

Family support is more dominant than peer group support in maintaining the quality of life of thalassemia adolescents (38). Every challenge faced by thalassemia sufferers has a direct impact on their families rather than their peer group (15,18,21,39). Therefore, it is also important to pay attention to the psychological and financial conditions of the family.

Indirectly, the psychological and financial conditions of the family also affect the quality of life of a thalassemic person. Poor psychological conditions in the family will make it difficult to provide optimal psychological support to thalassemia sufferers. Likewise in financial matters. Thalassemia has a negative impact on family members in the form of mental, social, financial, and even physical suffering (40,41). Caring for thalassemia sufferers has a significant impact on the lives of parents as caregivers (17).

Thus, it can be concluded that the treatment for thalassemia adolescents should not only focus on the sufferer but also on the psychological and financial conditions of their family, who care for and accompany them every day. Assistance for medical and care costs from the government is also important, especially for poor families (42).

The quality of life of thalassemia adolescents also depends on blood Hb levels (43,44). If the Hb level is in the normal range (≥ 9.17 g/dL), thalassemia adolescents can grow and do normal activities (45,46). This means their quality of life is in a good category. Conversely, when Hb levels are low, sufferers will show symptoms of general weakness and decreased consciousness which can cause disturbances in several domains of quality of life (45,47,48). Therefore, Hb is a confounding factor in the quality of life of thalassemia adolescents as found in this study (49). Even though the sufferer has received adequate family and peer group support, if the Hb level is low, the sufferer's quality of life will be disrupted (47).

Limitation

This research has a narrow scope of generalization because it was conducted in one center only. The research design which uses a cross-sectional approach is also another limitation in this study. Several variables measured in this study such as Hb levels, therapy compliance, family support, peer group, and quality of life are dynamic variables that can change over time. So the results obtained in this study only describe the condition of the respondents at the time of data collection and do not show changes over time. Further research is needed to confirm the results of this study.

4. CONCLUSION

There is a significant relationship between the level of support from family and peers and the quality of life experienced by thalassemic adolescents who receive outpatient care. Of the two, family support has more influence on quality of life. Health workers should focus on improving the quality of life of thalassemic adolescents by emphasizing both family and peer group support.

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