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Factors Affecting the Quality of Life of Children With Transfusion-Dependent Thalassemia: A Cross-Sectional Study

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Abstract

Objective. This study aimed to identify the factors affecting the quality of life (QoL) of children with transfusion-dependent thalassemia. **Materials and Methods.** A cross-sectional study was conducted on 38 hospitalized pediatric patients with thalassemia at two regional hospitals in Indonesia. We used demographic and anthropometric data, as well as the Pediatric Quality of Life Inventory 4.0 Generic Core Scales (PedsQL), to collect the data. **Results.** The median age of the participants was 11 years (range, 2–18), with a median age at diagnosis of 12.5 months (2 – 84). The average hemoglobin (Hb) level was 8.47 g/dl, and 34% of the patients had blood type O. The interval between blood transfusions was 23.74 days, with a median number of transfusions of 200.5 (range, 22 – 405). The median current weight was 25 kg (range, 9.5 – 50 kg). More than half of the fathers (52.6%) and mothers (50%) of the children with thalassemia had completed only elementary school. The mean total QoL score reported by children was 82.69±13.38, and by parents, 82.6±11.27. Among the PedsQL domains, the children reported the highest scores in social functioning (89.86±15.48) and the lowest in school functioning (74.21±18.06). Similarly, parents reported the highest score in social functioning (91.05±12.95) and the lowest in school functioning (78.42±13.9). Multivariable analysis showed that Hb level and current weight were significantly associated with QoL in children with thalassemia. **Conclusions.** The QoL of children with thalassemia is generally good and is influenced by their current body weight and Hb levels.

Key Words: Children ▪ Quality of Life ▪ PedsQL ▪ Thalassemia.

Introduction

Thalassemia is a genetic disease of blood cells that causes damage to hemoglobin (Hb), the main component of red blood cells, and an oxygen carrier. It leads to a shorter lifespan of red blood cells - 120 days - resulting in below-normal Hb levels (1)which leads to anemia. It is caused by mutation in the DNA of cells that make hemoglobin. Thalassemia should be prevented by premarital screening and prenatal diagnosis which is helpful in decreasing prevalence and future incidence of thalassemia. The most important problem in thalassemia patients are iron overload, cardiac arrhythmia, hepatitis, osteoporosis and endocrine disorder however there are typical signs and symptoms of anemia. People with thalassemia can get treatment as indicated by the degree of seriousness of their condition. Blood transfusion is the common treatment for thalassemia. This review presents the types, diagnosis, prevalence, complications and treatment of thalassemia. Thalassemias are a major public health issue in many populations which many health authorities fail to address. These requirements are notrecognized by measures such as the Global Burden of Disease project, which ranks thalassemia very low in terms of disability-adjusted life years (DALYs. This causes chronic anemia, which significantly affects children's growth, development, and quality of life (QoL). The QoL of children with thalassemia

is affected by the disease itself and its long-term therapy (2). Long-term therapy requires repeated transfusions to treat severe anemia. Repeat transfusions can also lead to hemosiderosis, which is destructive to organs such as the heart, liver, kidneys, and endocrine glands. Patients with hemosiderosis require iron chelation therapy to maintain a long-term prognosis (3). Thalassemia is classified into two main categories based on transfusion requirements: transfusion-dependent thalassemia (TDT) and non-transfusion-dependent thalassemia (NTDT) (4).

World Bank data show that 7% of the global population carries the thalassemia trait. Every year, 300.000-500.000 babies are born with severe Hb disorders, and 50,000 to 100,000 children die due to thalassemia. Indonesia has one of the highest rates of thalassemia trait carriers (3). The 2021 data from the Health Minister of the Republic of Indonesia reported 10,973 thalassemia cases. Children with thalassemia are prone to various complications and challenges that affect their QoL. These include physical and psychosocial aspects such as social, emotional, and school functioning. The factors that affect the QoL of children with thalassemia require attention (5)passed from parents to children, which can be mitigated through screening programs. Inconsistencies in blood transfusions and iron chelation therapy result in physical changes that can cause psychological problems, with anxiety being the most prominent. This study aimed to examine the factors influencing anxiety levels among adolescent thalassemia major survivors. Methods: The research utilized a quantitative approach with a correlational analytic design and cross-sectional method. It included a population of 122 adolescent survivors, all of whom were included using a total sampling technique. Data analysis involved univariate analysis by frequency distribution, bivariate analysis using the chi-square test, and multivariate analysis with logistic regression. Results: The findings of the study showed that adolescent thalassemia survivors experienced varying levels of anxiety: mild anxiety in 70.5%, moderate anxiety in 9.8%, and severe anxiety in 19.7%. Significant associations were observed between anxiety levels and factors such as body image ($P<0.001$).

Age plays an important role in determining the QoL of children with thalassemia. Each developmental stage has its own growth and developmental tasks; hence, the challenges faced also vary accordingly. Age determines children's ability to cope with these tasks and challenges, which, in turn, affects their QoL (6). When children are diagnosed at a young age, this often causes anxiety, fear, and emotional stress in both parents and children. Children also face activity restrictions, changes in physical appearance, and social interactions resulting from the treatment they must undergo, such as repeated transfusions and regular iron chelation drugs (7). Hb level is an essential parameter in thalassemia management, as it may affect the symptoms and complications experienced by the patient (8). Transfusion frequency is also an important element in thalassemia treatment, as regular blood transfusions are necessary to maintain Hb levels within a safe range (9, 10). Additionally, nutritional status plays an integral role in optimizing the health and QoL of patients with thalassemia. Nutritional deficiencies can exacerbate symptoms and increase the risk of complications. Poor nutritional status in children with thalassemia significantly impacts QoL (11). Nutritional deficiencies can lead to decreased energy, lowered resistance to infection, impaired growth and development, and a decline in overall QoL.

This study aimed to determine the QoL of children with thalassemia and to identify and analyze the factors affecting the QoL of children with thalassemia, focusing on the children's age, age at diagnosis, blood type, parents' education degree, pre-transfusion Hb level, transfusion frequency, and nutritional status, and analyzing which factors are the most dominant in influencing it.

Materials and Methods

Research Design, Setting, and Study Population

This cross-sectional study was conducted at two regional hospitals, Temanggung Regional Hospital and KRT Setjonegoro Wonosobo Regional Hospital, between May and June 2024. The sample size was calculated using G*Power 3.1. Based on an expected medium effect size of 0.5, significance level (Type I error, α) of 0.05, and power of 0.90 for a two-tailed test, the minimum required sample size was 34 children with thalassemia. However, 38 participants were studied to account for a 10% attrition rate. Of the 38 participants, 16 were from the Temanggung Regional Hospital and 22 were from KRT Setjonegoro. The inclusion criteria were children aged 2 to 18 years with beta-thalassemia major or intermedia who were receiving routine blood transfusions. A total sampling technique was applied, meaning all eligible patients available during the data collection period were included in the study. The exclusion criteria were children with thalassemia with severe cognitive impairment and parents and children with thalassemia who refused to participate in the study.

Data Collection and Instrument

Data collection was carried out using a questionnaire that covered the patient's characteristics, including initials, date of birth, birth weight, birth length, sex, blood type, parents' education, age at first diagnosis, transfusion frequency, current Hb level, and anthropometric measurements, including the child's current weight and height to determine nutritional status. The children's QoL was measured using the Pediatric Quality of Life Inventory 4.0 Generic Core Scales (PedQL) instrument, which contains 23 question items within the QoL domain. They were divided into 4 domains: physical, social, emotional, and school functioning. The domain of physical functioning consisted of 8 questions assessing the child's ability to perform daily physical activities such as walking, running, lifting objects, bathing, and participating in sports or active play. The social functioning domain assesses the child's ability to interact with peers, maintain friendships, and avoid social exclusion. Items include questions about getting along with other children, being teased, or having difficulties in group activities. The emotional functioning domain includes 5 items addressing the child's feelings of anxiety, sadness, anger, and fear, as well as difficulty sleeping due to emotional distress. The school functioning domain consists of five items related to academic engagement and school performance, such as paying attention in class, forgetting things, keeping up with schoolwork, and missing school due to health problems or doctor visits. The instrument was completed by both the children and their parents. Respondents were asked to choose from "never" (score 0 and worth 100) to "always" (score 4 and worth 0). The scale score is calculated as the sum of the item scores divided by the number of items answered. Domain scores are scaled in a positive direction, which means that higher scores indicate better QoL. The scores are divided into two categories: if the total score is less than 70, the child's QoL is considered poor, and vice versa (12).

Ethical Consideration

This study obtained a research permit and research ethics approval from the Chairperson of the Research Ethics Commission of the Institute for Research, Publishing, and Community Service (LP3M) of Universitas Sains Al-Qur'an (number 018/EC/LP3M-UNSIQ/V/2024). The researcher explained the study to the patients and their parents and requested that they sign an informed consent form as proof of the patients' approval.

Statistical Analysis

The data were statistically analyzed using the IBM SPSS Statistical Package version 26. Descriptive statistics, including frequency, percentage, mean, and standard deviation (SD), were calculated to identify the characteristics of the respondents. Bivariate analysis was performed using Spearman's correlation test to analyze the relationships between age,

birth weight, birth length, sex, blood type, parents' education, age at diagnosis, transfusion frequency, current Hb level, nutritional status, and QoL. A multiple logistic regression analysis was performed to assess the impact of various factors on the QoL of children with thalassemia.

Results

Characteristics of the Respondents

The respondents' characteristics are presented in Table 1. Regarding blood type distribution, the majority of participants had blood type O (34.2%),

Table 1. Respondents' Characteristics

Variable	Frequency	%	Mean ± SD*	Median (min – max‡)
Sex				
Male	22	57.9	-	-
Female	16	42.1		-
Nutritional status				
Underweight	10	26.3	-	-
Normal	25	65.8	-	-
Overweight	2	5.3	-	-
Obesity	1	2.6	-	-
Blood type				
A	7	18.4	-	-
B	11	28.9	-	-
AB	7	18.4	-	-
O	13	34.2	-	-
Fathers' education				
Elementary school	20	52.6	-	-
Junior high school	9	23.7	-	-
Senior/vocational high school	6	15.8	-	-
Diploma 3	2	5.3	-	-
Bachelor degree	1	2.6	-	-
Mothers' education				
Elementary school	19	50	-	-
Junior high school	9	23.7	-	-
Senior/vocational high school	6	15.8	-	-
Diploma 3	3	7.9	-	-
Bachelor degree	1	2.6	-	-
Clinical Characteristics Factors				
Age (year)	-	-	9.76±4.23	11 (2-18)
Birth weight (grams)	-	-	2865.8±465.7	2850 (1500-4000)
Birth length (cm)	-	-	47.55±1.69	47 (45-52)
Current weight (kg)	-	P20-P100‖	26.47±10.19	25 (9.5-50)
Current height (cm)	-	P20-P100‖	123.55±20.37	129.5 (68-150)
BMI†	-	-	16.74±2.95	15.59 (12.64-25.51)
Age at diagnosis (months)	-	-	23.17±20.35	12.5 (2-84)
Hb§ (g/dl)	-	-	8.37±1.39	8.35 (5.6-12.0)
Transfusion frequency (days)	-	-	23.74±9.71	21 (14-60)

*Standard deviation; †Body mass index; ‡Minimum – maximum values; §Hemoglobin; ‖Between the 20th and 100th percentiles of reference growth charts.

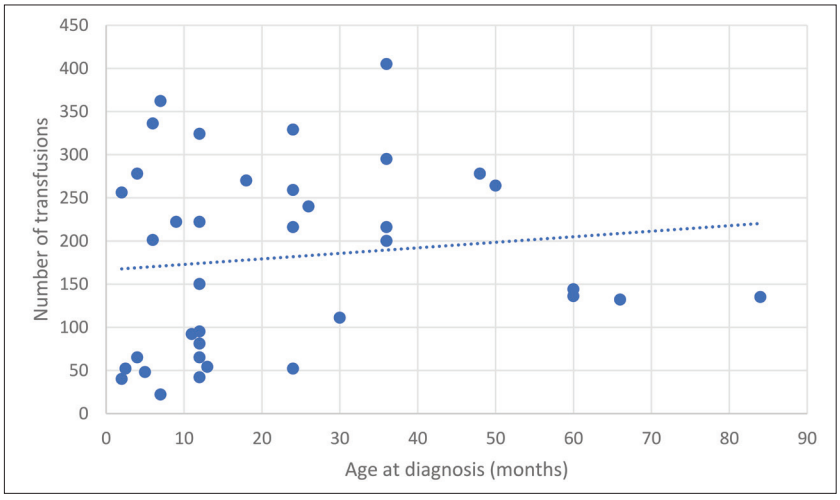

Figure 1. Distribution of age at diagnosis and number of transfusions.

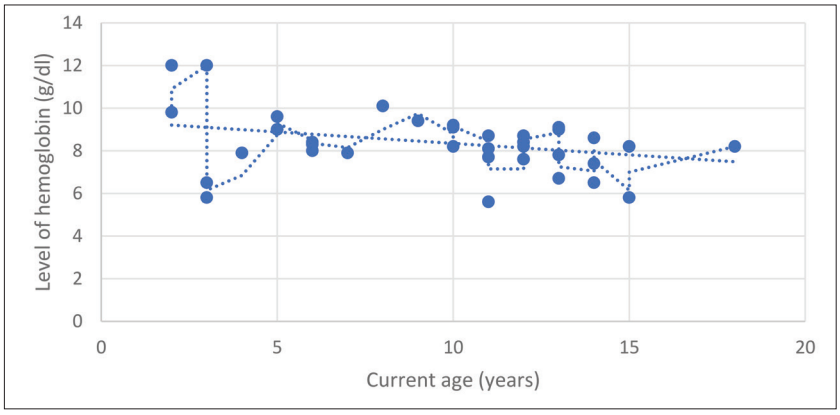

Figure 2. Distribution of hemoglobin levels and age.

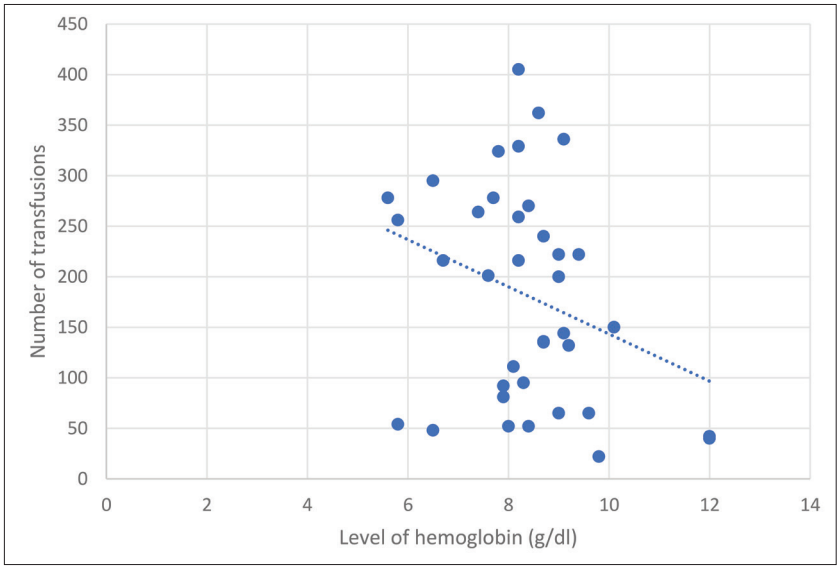

Figure 3. Distribution of hemoglobin levels and number of transfusions.

followed by blood types B (28.9%), A (18.4%), and AB (18.4%). The majority of patients were boys (22 patients, 57.9%). In terms of nutritional status, the majority of participants had a normal weight (65.8%), while 26.3% were underweight. A smaller proportion was classified as overweight (5.3%) and obese (2.6%). Most of the parents of the children with thalassemia had primary school education (20 fathers (52.6%) and 19 mothers (50%)). The respondents had an average age of 9.76 years and were in the school-age category. They also had normal birth weight (2500-4000 grams) and birth length (45-53 cm). The current weight and height averaged 26.47±10.19 kg and 123.55±20.37 cm, respectively. The age of the children at diagnosis ranged from 2 months to 7 years. The median Hb level was 8.35 (5.6–12.0) g/dl, with an interval between their transfusions of 23.74 days, and the median number of transfusions was 200.5 (range 22–405).

The distributions of Hb levels, age (current age and age at diagnosis), and number of transfusions received by patients with thalassemia are presented in the scatter plot diagrams in Figures 1-3. As shown in the figure, children aged 2–6 years demonstrated relatively higher and more stable Hb levels, particularly among those diagnosed

Table 2. Relationship Between Age, Hemoglobin Level, and Number in Children With Thalassemia

Variable 1	Variable 1	Pearson's r	Direction and Strength of Correlation
Current age	Current hemoglobin	–0.33	Weak negative
Current age	Number of transfusions	0.88	Strong positive
Current hemoglobin	Number of transfusions	–0.31	Weak negative

early and who received timely transfusion therapy. In contrast, patients aged 13 years and older showed a tendency toward lower or fluctuating Hb levels, despite having received a significantly greater number of transfusions. These findings indicate that Hb concentration may not be directly proportional to the transfusion quantity but is likely influenced by multiple factors, including transfusion frequency, individual physiological response, and the presence of complications. Additionally, patients diagnosed before the age of 12 months tended to achieve better Hb control when managed with regular transfusions, whereas those diagnosed later or with delayed initiation of transfusion therapy commonly exhibited lower Hb levels despite a higher transfusion burden.

According to the data presented in Table 2, a very strong positive correlation was found between the current age of the patients and the total number of transfusions received (r=0.88), indicating that older children had undergone significantly more transfusions. This finding was expected, given that patients with thalassemia major require lifelong regular transfusion therapy. In contrast, a weak negative correlation was observed between Hb levels and the number of transfusions (r=–0.31), suggesting that a greater number of transfusions does not necessarily result in higher Hb levels. This may be influenced by other factors, such as individual resistance to transfused red blood cells, delays in transfusion schedules, or secondary complications. Additionally, a weak negative correlation was found between patient age and Hb level (r=-0.33), indicating that older children tended to have lower Hb concentrations, which may be attributed to the cumulative effects of bone marrow damage or chronic disease-related complications.

The Quality of Life of Children with Thalassemia

Table 3 shows that the average QoL scores of children with thalassemia, as reported by both children and their parents, were in the "good" category, with scores of 82.69±13.38 and 82.6±11.27, respectively. The school function domain had the lowest score of 74.21±18.06 and 78.42±13.9, and the social function domain had the highest score of 89.86±15.48 and 91.05±12.95.

Factors Affecting Quality of Life

The factors influencing the QoL of children with thalassemia are presented in Table 4, which illustrates the relationships between QoL and various demographic and clinical parameters, including age, birth weight, birth length, current body weight, current height, body mass index (BMI), age at diagnosis, current Hb levels, and transfusion frequency. Spearman's correlation analysis was conducted to examine the association between

Table 3. The Quality of Life of Children with Thalassemia based on PedsQL

PedsQL Domain	Children report		Parents report	
	Mean+ SD	Median (min-max)	Mean + SD	Median (min-max)
Physical function	84.78+16.79	90.62 (40.63-100)	80.92+20.21	87.5 (40.63-100)
Emotional function	80.65+12.9	85 (45-100)	81.05+14.71	85 (45-100)
Social function	89.86+15.48	97.5 (35-100)	91.05+12.95	97.5 (35-100)
School function	74.21+18.06	80 (30-100)	78.42+13.9	82.5 (50-100)
Quality of life	82.69+13.38	86.95 (48.91-98.91)	82.6+11.27	85.3 (54.35-100)

Table 4. The Relationship Variables and Transfusion Frequency to Children's Quality of Life

Variable	Quality of Life		P*	r†
	Good	Poor		
Age	10.35±4.00	7.14±4.53	0.159	-0.233
Birth weight	2825.81±469.73	3042.86±435.34	0.278	0.181
Birth length	47.65±1.74	47.14±1.46	0.509	-0.11
Current weight	28.22±10.30	18.73±4.93	0.010*	-0.412
Current height	126.79±20.44	109.21±13.31	0.014*	-0.397
Body mass index	17.01±3.10	15.52±1.83	0.415	-0.136
Age at Diagnosis	2.17±1.74	1.51±1.07	0.479	-0.118
Hb‡	8.57± .35	7.51±1.32	0.013*	-0.295
Transfusion frequency	22.32±10.25	30	0.003*	0.476

*Significant (P<0.05); †Correlation coefficient between variable and children's quality of life; ‡Hemoglobin.

these variables and the children's QoL. The results indicated that BBS was significantly negatively correlated with QoL (r=-0.412, P=0.010). This relationship was classified as moderate in strength with a negative directional association. Similarly, TBS was found to have a significant negative correlation with QoL (r=-0.397, P=0.014), indicating a weak negative correlation. Furthermore, an analysis of age at diagnosis, Hb levels, and transfusion frequency using Spearman's correlation test revealed that transfusion frequency is significantly correlated with QoL (r=0.467, P=0.003). This suggests a moderate positive association between transfusion frequency and QoL (13).

A Multivariate logistic regression analysis was conducted to further investigate the factors influencing the QoL of children with thalassemia, as detailed in Table 5. The analysis revealed that current weight (OR=0.788; 95% CI=0.636–0.976; P=0.029) and Hb level (OR=0.365; 95% CI=0.146–0.914; P=0.031) were significantly associated with children's QoL. Specifically, lower weight and lower Hb levels were predictors of reduced QoL. Other variables, including age, current height, and transfusion frequency, did not show statistically significant associations (P>0.05).

Table 5. Results of Multivariate Logistic Regression Test on Children's Quality of Life

Variable	P	OR*	95% CI†
Age	0.902	0.945	0.386-2.316
Current weight	0.029‡	0.788	0.636-0.976
Current height	0.671	1.036	0.879-1.221
Hb§	0.031‡	0.365	0.146-0.914
Transfusion frequency	0.3	1.078	0.935-1.242

*Odds ratio; †Confidence interval provides a range within which the true result is likely to lie; ‡Significant (P<0.05); §Hemoglobin.

Discussion

This study explored the factors influencing QoL among children with transfusion-dependent thalassemia, highlighting that Hb level and current weight emerged as the most significant determinants. They were associated with four QoL domains, particularly school functioning. Various studies have shown that the QoL of children with thalassemia has a lower score than that of healthy children. The results of all studies also showed lower scores on all dimensions of the PedsQL, including physical, emotional, social, and school dimensions (14). This study is inconsistent with a previous study in which the assessment of QoL among children with thalassemia using the PedsQL revealed generally positive outcomes across multiple domains, as reported by both children and their parents. The highest scores were observed in the social functioning domain, with mean scores of 89.86 (children) and 91.05 (parents), indicating strong peer interactions and social integration. Emotional and physical functioning also showed favorable scores, although children rated their

physical function slightly higher than their parents did (15). It reflects a child's internal emotional well-being and potential psychological distress.

Notably, school functioning emerged as the lowest-rated domain, with mean scores of 74.21 (children) and 78.42 (parents), suggesting potential academic or cognitive challenges related to the condition. Overall life quality was rated similarly by both groups, with mean scores of 82.69 (children) and 82.6 (parents). These findings highlight the relatively good perceived QoL among children with thalassemia while underscoring the need for targeted support in the academic domain. Earlier studies have also shown that school and social functioning factors are highly influential in the QoL of children with thalassemia. Mediani et al. (16) our knowledge of the factors affecting the quality of life of thalassemic children is limited and some previous studies have shown contradictory results. The study aimed to analyze factors impacted to the QOL of school-age thalassemic children in Indonesia. A correlational analytic with a cross-sectional approach was conducted at a district hospital in Sumedang Indonesia from May to July 2017. The PedsQL generic core scale was used to assess 55 school-age thalassemic children with thalassemia major. Data were analyzed bivariate by using Pearson and Spearman Correlation Test and multivariate analysis used multiple linear regression to determine the factor that most impacting the QOL thalassemic children. The findings showed that the average of QOL of school-age thalassemic children was 66.54+12.85. There was a significant correlation between QOL with pretransfusion Hb level (P=0.018, α=0.05 stated that the most dominant factor affecting the QoL of school children is transfusion frequency. This is because frequent transfusions can compromise their school function; for example, they may be unable to attend school meetings, which may affect their QoL. A study conducted at Cut Meutia Hospital Aceh revealed that the average pediatric patient with thalassemia had a poor QoL, especially in terms of school functioning (17). Another study at Al Ihsan Bandung General Hospital in 2019 showed a similar result: thalassemic pediatric patients had poor QoL, which further interfered with their other life-affecting functions, such as physical, emotional, school, and social functioning. Children with thalassemia in Jeddah, Saudi Arabia, have a similar low QoL, especially prior to blood transfusion, despite significant improvement after the procedure.

Theoretically, the QoL of children with thalassemia is influenced by many factors, including age, sex, age at first transfusion, Hb level, underlying disease, and social support from family and community. These factors significantly affect the QoL of children with thalassemia (6). However, there are differences in the influencing factors in each study related to the QoL of children with thalassemia. This study indicates that children diagnosed at an older age tended to receive a higher number of transfusions. This may reflect delayed diagnosis or treatment initiation, which could lead to an accumulated transfusion requirement over time to correct prolonged anemia. Early diagnosis and timely initiation of transfusion therapy are essential to prevent complications and reduce transfusion burden. This study also showed that transfusion frequency, current weight, and Hb levels significantly impacted QoL. These findings are consistent with prior research, indicating that poor nutritional status and anemia significantly impair health-related quality of life (HRQoL) in this population. Malnutrition is highly prevalent among pediatric patients with thalassemia and has been shown to negatively affect growth, physical function, and overall QoL. In one study, approximately 48.2% of children were malnourished, and malnutrition was strongly associated with diminished QoL scores (18). A higher transfusion frequency is associated with a lower QoL in children with thalassemia, especially in the physical, psychological, social, and educational domains. It also increases the risk of transfusion-transmitted infections, which affect the physical and psychological aspects of children (18-20)physical activities, competencies, and family stability are all compromised in some way. Assessing HRQoL in individuals with thalassaemia and identifying variables that contribute to low quality of life is

crucial. Aim: To correlate HRQoL and factors affecting among different age groups in transfusion-dependent thalassaemia patients. Materials and Methods: A cross-sectional study was conducted at MGM College and Hospital, Navi Mumbai from October 2020 to August 2021, 70 thalassaemia patients aged 8-25 years registered for regular blood transfusions were included in the study and divided into three age groups: Group-I (8-12 years. The recommended transfusion frequency for children with thalassemia is every 3–4 weeks (approximately 12 times/year or more) to maintain Hb levels, prevent complications, and support QoL. However, it must be balanced with monitoring and iron chelation therapy to prevent long-term transfusion side effects, such as iron overload and organ damage (21, which results in anemia. Packed red blood cell (PRBC22).

In this study, the other factor that affected the QoL of children with thalassemia was their current body weight. Body weight is one of the indicators used to determine the nutritional status of children, in addition to length or height and other anthropometric measures. A previous study showed that the majority of children with thalassemia are underweight (23). This affects the nutritional needs of patients with thalassemia. Children with thalassemia often suffer from malnutrition due to the effects of long-term therapy, such as iron chelation therapy, multiple endocrinopathies, cellular hypoxia due to anemia, and frequent transfusions. In a 2021 study by Biswas et al., malnutrition had a very negative impact on the QoL of children with thalassemia, with a P-value of 0.009 (18). The findings of this study indicate that current body weight significantly affects the QoL of patients with thalassemia. This relationship is mediated by alterations in the nutritional status. Adolescents with thalassemia who exhibit poor nutritional status have a reduced QoL compared to their well-nourished peers. Undernutrition is also associated with growth impairment, such as short stature, and contributes to a diminished overall QoL (24) Scopus, Research gate, and Web of Sciences to evaluate the prevalence of nutritional disorders in patients with BTM worldwide in relation to their body composition and possible etiological factors. In addition, we reviewed the published nutritional intervention studies. Results: 22 studies on the prevalence of undernutrition (12 countries.

The next factor affecting the QoL of children with thalassemia in this study was Hb level. Higher Hb levels were associated with a better QoL in children with thalassemia. Children with higher Hb levels tended to have significantly better QoL scores (6). One of the most prominent manifestations of thalassemia is decreased Hb levels (25) i.e., homozygous β-thalassemia, β-thalassemia/Hb E, and Hb Bart's hydrops fetalis. Laboratory diagnosis of thalassemia requires a number of tests including red blood cell indices and Hb and DNA analyses. Thalassemic red blood cell analysis with an automated hematology analyzer is a primary screening for thalassemia since microcytosis and decreased Hb content of red blood cells are hallmarks of all thalassemic red blood cells. However, these two red blood cell indices cannot discriminate between thalassemia trait and iron deficiency or between α- and β-thalassemic conditions. Today, Hb analysis may be carried out by either automatic high-performance liquid chromatography (HPLC. The damage occurs due to structural disorders of Hb formation (abnormal Hb), characterized by the absent or decreased synthesis of one or more globin chains (26). Efforts to raise and maintain Hb levels are carried out by administering transfusions. Transfusion frequency influences the QoL of patients. However, the transfusion regimen administered to patients with thalassemia to maintain Hb levels above 9-10.5 g/dl improves QoL in children. Appropriate management of serum ferritin levels and the application of a collaborative approach to treatment have been shown to be effective in increasing life expectancy in patients with thalassemia (27). Consistent with the results of this study, blood Hb levels had the most significant relationship with the QoL of patients (P=0.03). QoL and blood transfusion also had a significant relationship (P=0.003) (28). Children with thalassemia in Jeddah, Saudi Arabia, also have a similar low QoL, especially before blood transfusion, despite significant improvement after

the procedure (29). Therefore, maintaining Hb ≥9 g/dl is very beneficial because it can prevent the emergence of various complications that may arise in children with thalassemia (30).

Children with thalassemia may experience impaired physical and psychological growth and development. Therefore, transfusion plays a crucial role in increasing blood Hb levels to maintain the stability of growth and development processes. Additionally, proper and adequate nutrition, nutritional counseling tailored to patients with thalassemia, provision of nutritional supplements, and periodic evaluation of nutritional status are suggested as interventions that should be addressed by parents and are necessary for patients with thalassemia (31). With proper nutrition, children's QoL, growth, and development are well maintained (32). This also serves as an intervention to prevent complications due to decreased Hb levels and malnutrition (33).

Overall, children receiving routine treatment have better QoL (29). A study by Mikael in Iraq (34) revealed that patients with major thalassemia have a lower QoL than those with intermediate thalassemia. The age of first diagnosis correlates positively with QoL. It is important to evaluate the QoL of children with thalassemia to enable targeted efforts to enhance it. A case in point is the provision of health education for parents of children with thalassemia (35).

Limitations of the Study

This study has limitations that should be acknowledged, including the variation in the number of samples and clinical parameters, such as serum ferritin levels, hepatomegaly, and splenomegaly, which lead to different factors affecting the QoL of children with thalassemia. Future research should focus on incorporating these clinical variables to provide a more comprehensive understanding of the factors influencing the QoL of children with thalassemia. Nevertheless, the results of this study can serve as a basis for determining interventions in children with thalassemia, especially in Hb level monitoring and nutritional interventions. Interventions to be considered based on the results of this study include maintaining Hb levels in children with thalassemia through regular blood transfusions, regular nutritional status observation (weight and height), and specific nutritional programs for children with thalassemia to improve their weight status and, ultimately, their QoL. Family involvement in therapy regimen compliance, educational and psychological programs, and counseling are also interventions that should be considered.

Conclusions

In this study, age, birth weight, birth length, BMI, and age at diagnosis were not correlated with the QoL of children with thalassemia. Transfusion frequency, current body weight, and pre-transfusion Hb levels were significantly associated with the QoL of children. Weight loss is closely related to malnutrition, which is strongly associated with health status. The overall QoL of the children with thalassemia was categorized as good.

What Is Already Known on This Topic:

The quality of life (QoL) of children with thalassemia is influenced by a combination of clinical signs, such as fatigue, pale, enlarged abdomen due to hepatomegaly or splenomegaly, and poor growth, as well as routine transfusions as the primary management of thalassemia and other factors, namely demographics and psychosocial factors, including family income, education level, and caregiving burden. These factors are interrelated and can impact a child's physical, emotional, social, and school functions.

What This Study Adds:

This study showed that transfusion frequency, current hemoglobin (Hb) levels, and body weight are significantly related to the QoL of children with thalassemia. The results of this study are basic data that can be used to determine more specific actions to improve the QoL of children, such as the innovation of appropriate nutritional interventions to maintain children's weight in normal nutritional status, maintain Hb levels through regular blood transfusions and chelation therapy, and family involvement in therapy regimen compliance. Educational, psychological, and counseling programs are also interventions that should be considered. In addition, these results can be further developed through research that modifies factors significantly related to the QoL of children.

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