The Effect of Parental Support on the Quality of Life of Children with Thalassemia

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KEYWORDS

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ABSTRACT

Introduction: Thalassaemia is a blood disorder that is passed down from parents to their children. Patients should receive blood transfusions regularly. Children with thalassaemia will undergo treatment for a long time. These extreme impacts cause various physical, emotional, social, and environmental disorders that can reduce the quality of life of people with persistent thalassaemia major. Objectives: This study aims to determine the effect of family support on the quality of life in children with thalassaemia major. Methods: This research is a type of quantitative correlation with the cross-sectional approach. The sample of all thalassemia patients in April-August 2022 until 2024 Agustus, was 120 pediatric patients selected using the total sampling technique. Bivariate analysis using chi square. Results: The age characteristics of children with thalassaemia were 83 (69.2%), the majority of females were 65 (54.2%). Family support was mostly positive for 63 (52.5%) and the quality of life of children with thalassaemia was mostly for 64 respondents (65.8%) in the normal category. There is a relationship of family support for the quality of life of children with thalassaemia at the Dr. Soedirman Regional General Hospital, Kebumen. Conclusions: Support family and friends, as well as providing a adequate for parents is very important in improving the quality of life of children Thalassaemia.

1. Introduction

Chronic anemia and a high death rate in children are the results of thalassemia, a genetically inherited blood illness marked by the absence or reduction in the synthesis of one or more of the hemoglobin molecule's four globin chains.

It has been demonstrated that thalassaemia diagnoses have an impact on patients' quality of life (Teffler P, at allet al., 2005). One nation where thalassaemia is highly prevalent is Indonesia. The Hematology Skills Competency Test results from the Indonesian Pediatrician Association in 2016 show that the prevalence of thalassaemia major in Indonesia was 9,121, according to the Ministry of Health of the Republic of Indonesia (2019) (1).

According to data from the Parents Association of Thalassemia Patients and the Thalassemia Indonesia Foundation, the number of thalassemia patients in Indonesia climbed from 4,896 in 2012 to 9,028 in 2018 (2).

Disease-related physical alterations include hepatosplenomegaly, growth retardation, paleness, muscle hypotrophy, and bone abnormalities (such as craniofacial or mongoloid facial deformities) brought on by bone that increases the marrow (3).

Additional issues may impact the child's capacity to perform regularly. Long infusion times for iron chelation therapy, frequent hospital stays for blood transfusions, and anemia-related exhaustion can all interfere with a child's daily schedule and attendance at school (4). Children with thalassaemia experience psychosocial impacts such as low self-esteem, shyness, helplessness, and social disengagement due to the physical changes and impairments they experience (5).

For the majority of thalassemia patients, parents play a crucial role in their ongoing therapy, and recovery is not guaranteed, particularly for young children who depend on their parents for warmth and care (6). Families who have children affected by thalassemia need to be aware of e

very clinical symptom that the patient faces because it poses a risk to their health and life.

The intensity of the emotions increases with the severity of the clinical symptoms. To help care for the child and satisfactorily address the youngster's inquiries regarding the illness, families require the assistance of health professionals. Parents must help their children through difficult times (7).

Age, the children's education, the father's education, the father's employment, and the support of family or parents are all associated with the quality of life of children with thalassemia, according to research by Pranajaya & Nurchairina (2016).

Due to the fact thatBecause children with chronic illnesses require significant care, the family—especially the parents—will be greatly impacted by their quality of life, which may lead to stress. It can occasionally be difficult for parents or other family members to accept, get used to, and get ready for the terminal illness conditions that children face (8).

Objectives

Given the foregoing context, the researcher set out to determine how family support affected the children with thalassemia major's quality of life.

2. Methodology

Study design

Quantitative correlation research, or research to ascertain the link between variables, is the methodology used in this study. The methodology employed is cross-sectional.

Population and sample.

The pediatric patients at the Dr. Soedirman Regional General Hospital Kebumen who have thalassemia between April and August of 2022 make up the study's population. In this study, a total of 120 respondents were sampled using a certain technique.

Patients between the ages of 6 and 18 who have been receiving red blood cell transfusions for the last six months and who have been diagnosed with thalassaemia major based on a history, clinical examination, and Hb electrophoresis results meet the study's inclusion criteria. The exclusion criteria include the presence of additional chronic illnesses, mental impairment that can interfere with everyday activities, and anamnesis based on medical record data.

Tool

Two measures are used in this research: quality of life and family support. With scores of r = 0.632 (Aniswati, 2017) and 0.821 (Fatmasyithah & Rahayu, 2014), the 12-item family support questionnaire is a valid and reliable tool. The parent support questionnaire employed the following assessments: Disagreement less (KS) = 3, Strongly disagree (STS) = 1, Strongly agree (SS) = 5, Agree (S) = 4, and Disagreement less (TS) = 2. The evaluation is determined by multiplying the total number of statements by three.

Based on the categories of good, sufficient, and poor votes, the multiplication result is separated into three groups. In 1988, Zimet et al. designed this questionnaire. A high score denotes increased support from friends, family, and other significant individuals in one's life. According to reports, the alpha questionnaire's overall correlation with Cronbach's Alpha was 0.91, and it ranged from 0.90 to 0.95 for each dimension independently.17.

There were 23 questions on the Peds QL quality of life test, which were divided into three categories: social (5 questions), emotional (5 questions), and physical (8 questions).

Mariani (2011) conducted a study titled "Analysis of factors that affect the quality of life of children with beta thalassemiabeta-thalassemia major at Tasikmalaya Hospital and Ciamis City," using the PedsQL Generic Core Scale Questionnaire version 4.0. 23 questions were deemed valid based on the validity test results, with each item's significance ($p < 0.05$) and Cronbach alpha = 0.904 (>0.7).

According to the Likert scale, the assessment score is as follows: Continually (0): each day; Often (1):

once every week; Infrequently (2): once every month; Seldom (3): once every two to three months; Never (4): never in the previous three months.

Data collection

With the permission of guardians, data were gathered in pediatric inpatient rooms occupied by thalassaemia patients between August and November of 2023.

Data analysis

Quantitative correlation research, or research to ascertain the link between variables, is the methodology used in this study. The methodology employed is cross-sectional. Utilizing the chi squarechi-square test in bivariate analysis.

Ethical considerations

On May 8, 2023, the University of Muhammadiyah Gombong's Research Ethics Committee accepted this study under the letter ethics number: 104.6/II.3.AU/F/KEPK/V/2023. Prior to beginning, this study was approved and permitted by Dr. Soedirman Kebumen, the hospital's director.

The researcher gave participants notice of the study's goal, information confidentiality, and their right to withdraw from participation at any time before any data was gathered. Informed consent forms were filled out by participants on behalf of their parents or guardians, and they were requested to grant permission to complete questionnaires on their quality of life, family support, and demographic data gathering. In order toTo maintain anonymity while analyzing the data, researchers.

3. Results and Discussion

Univariate Analysis

Characteristics of Respondents

The following table provides information about the respondents' age, gender, and educational background in relation to thalassemia patients:(9)

Table 1. Frequency Distribution of Characteristics of Respondents with Thalassemia in the Melati Room of Dr. Soedirman Kebumen Hospital (N=120)

Characteristic	Frequency	Percentage (%)
Age		
7-11 Years	23	**19.2**
12-14 Years	14	**11.6**
15-18 years old	83	**69.2**
Gender		
Man	55	**45.8**
Woman	**65**	**54.2**

Source: Authors

Distribution of Family Support

Table 2. Distribution of Thalassemia Family Support Frequency in the Melati Room of Dr. Soedirman Kebumen Hospital (N=120)

Family Support	Frequency	Percentage (%)
Negative	57	**47.5**
Positive	**63**	**52.5**

Source: Author

Quality of Life Distribution

Table 3. Distribution of Frequency of Thalassemia Children's Quality of Life in the Melati Room of Dr. Soedirman Hospital, Kebumen (N=120)

Quality of lif	Frequency	Percentage (%)
Usual	64	53.3
Risk	56	46.7

Source: Authors

Bivariate Analysis

Table 4. Frequency Distribution of Family Support Relationship with the Quality of Life of Thalassemia Children at Dr. Soedirman Hospital, Kebumen 2023

Backing		Children's quality of life			TOTAL	
Family	Usual	%	Risk	%	N	**%**
Positive	63	52.5	0	0	63	**52.5**
Negative	1	0.83	56	16	57	**47.5**
Total	64	53.3	46.7	16	120	**100**
			P value = 0.003			

Source: Authors

Discussion

Parental support for children with Thalassaemia

Table 1.2 presents the findings of a study including 120 participants, the majority of whom are caregivers of children diagnosed with thalassaemia in the hospital's Jasmine Room.(10) Positive feedback from Dr. Soedirman was given by 63 (52.5%) people.
Parental support is crucial for the health care of family members during the treatment process and the rehabilitation phase of thalassemia-affected children. It also helps solve problems by demonstrating appreciation and attention to the children.(11) Children require emotional support and appreciation from their families in the form of constant presence during therapy, as well as facility assistance in the form of accommodations such as time and treatment facilities.(12)

Parental support is crucial for a person to have when dealing with health issues and as a preventative measure to lessen stress when the individual's perspective on life broadens and they become less anxious.(13) For children with thalassemia to maintain a normal quality of life—physical, emotional, social, and academic—parental care is necessary. For children with thalassemia, family emotional support is crucial as their primary source of compassion and empathy.(14) Every child evaluates parental support in a unique way, ranging from good to negative.

Quality of life of children with thalassaemia

Table 1.3 presents the findings of a study conducted on the quality of life of children with thalassemia in the hospital's Jasmine Room, with 120 respondents—the majority of them were from the research sample. The typical rate for Dr. Soedirman is 64 (53.3%).(15)

According to the study's findings, children with thalassemia generally have a normal quality of life because they have supportive friends and family members who help them understand and accept their illness, even though their overall health is not good.(16)

Age is another aspect that affects quality of life; it is generally greater, with the biggest age range being 15–18 years. At this point, a person has reached adolescence and must psychologically accept that their physical state will differ from that of an earlier age.(17) Thalassemia affects a patient's bodily as well as their psychological well-being.(18)

The relationship between family support and the quality of life of thalassemia children

According to the study's findings, 63 (52.5%) of the respondents reported receiving positive support, and 64 (53.3%) reported having a normal quality of life.(19) The chi-square correlation test results showed a value of p = 0.03 indicating a relationship between the parental support variable and the

child's quality of life, with the child's quality of life being more normal the more positive the parental support is.(20)

Throughout life, parental support is a process.(21) In terms of their acceptance of sick patients and their supportive attitudes and behaviors, parents serve as a source of support for other family members.(22) According to Yani, W., Andriani, R., & Novhriyanti, D. (2023) research findings, parental support plays a crucial role in bolstering an individual's quality of life, which is perceived in terms of their abilities, limitations, and psychosocial symptoms about their role in society and the cultural milieu.(23)

By assisting in behavior management and assisting kids in adjusting to psychological and physical changes, families play a psychosocial role in the lives of their children.(24) According to research by Lusiani et al. (2017), familial support has an impact on the quality of life for children with thalassemia because it helps these youngsters become stronger, make better decisions, and maintain normal patterns in their everyday lives.(25)

Psychosocial support from the family lowers emotional problems in patients with thalassemia beta major, according to Mazzone et al., 2009 in Pranajaya & Nurchairina, (2016). It also increases the effectiveness of iron chelation, strengthens coping mechanisms for better daily living, and lowers emotional distress

4. Conclusion and future scope

Based on the results of the study, it can be concluded that Most most of the school-age children who suffering from thalassemia who and undergo underwent blood transfusions at Dr. Soedirman Kebumen Hospital have had good family support, . most Most of the school-age children who suffer from thalassemia who undergo blood transfusions at Dr. Soedirman Kebumen Hospital have a normal quality of life, and family support is significantly related to the quality of life of school-age children with thalassemia at Dr. Soedirman Kebumen Hospital. From the results of this study, it is necessary if for the hospital to motivates or informs inform the family regarding the importance of family support through continuous health education and can also provide information to the family about the importance of transfusion according to the schedule set by the hospital

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