Indonesian Journal of Global Health Research
Volume 6 Number 4, Agustus 2024
e-ISSN 2715-1972; p-ISSN 2714-9749
http://jurnal.globalhealthsciencegroup.com/index.php/IJGHR

THE RELATIONSHIP BETWEEN QUALITY OF LIFE OF ADOLESCENTS WITH THALASSEMIA AND PARENTS' QUALITY OF LIFE: A CROSS SECTIONAL STUDY

Sri Yenni Br Tarigan*, Ai Mardhiyah, Witdiawati
Faculty of Nursing, Universitas Padjadjaran, Jl. Raya Bandung Sumedang KM.21, Hegarmanah, Jatinangor, Sumedang, West Jawa 45363, Indonesia
*sri20011@mail.unpad.ac.id

ABSTRACT

Thalassemia is a lifelong genetic disorder that requires regular and routine treatment. Adolescents with thalassemia major experience changes in physical, emotional, school, and family. Parents of thalassemia adolescents are the ones who care for and are always involved in the process of caring for their children, this condition can affect the quality of life. This study aims to identify the relationship between the quality of life of adolescents with thalassemia major and the quality of life of parents at RSUD Dr Slamet Garut. This study is a quantitative study with a cross-sectional approach. The sampling technique was consecutive sampling. Respondents of this study were 64 adolescents with thalassemia major and parents. Data collection was carried out at the time before the patient had a blood transfusion using the TranQol questionnaire and WHOQOL-BREF. TranQol to measure the quality of life of adolescents that has been tested for validity and reliability with a value of r=0,112-0,743 and α=0,806. WHOQOL-BREF to measure the quality of life of parents that has been testet for validity and reliability with a value of r=0,5-0,7 and α=0,41-0,77. The data analysis used was univariate analysis and bivariate analysis using the spearman rank correlation test. The results of this study found that the quality of life of adolescents with thalassemia major at RSUD Dr. Slamet Garut as many as 53 respondents (82.8%) was good, as many as 11 respondents (17.2%) was bad. While the quality of life of parents as many as 61 respondents (95.3%) is good, as many as 3 respondents (4.7%) was bad. Based on the results of the spearman rank test, the results obtained p=0.001 (p<0.05) which means that there is a significant relationship between the quality of life of adolescents with thalassemia major and the quality of life of parents. So it can be concluded that the better the quality of life of adolescents with thalassemia major, the better the quality of life of parents.

Keywords: parents; quality of life; thalassemia; thalassemia adolescent

First Received	Revised	Accepted
12 March 2024	23 April 2024	24 April 2024
Final Proof Received		**Published**
14 May 2024		01 August 2024

How to cite (in APA style)
Tarigan, S. Y. B., Mardhiyah, A., & Witdiawati, W. (2024). The Relationship Between Quality of Life of Adolescents with Thalassemia and Parents' Quality of Life: A Cross Sectional Study. Indonesian Journal of Global Health Research, 6(4), 2015-2024. https://doi.org/10.37287/ijghr.v6i4.3360.

INTRODUCTION

Thalassemia is one of the most common genetic blood disorders in the world. Indonesia is one of the countries in the world thalassemia belt, meaning that Indonesia is one of the countries with a fairly high frequency of thalassemia genes (trait carrier numbers). The World Health Organization (WHO) states that the incidence of thalassemia trait carriers in Indonesia ranges from 6-10%, this means that out of every 100 people in the population there are 6-10 people who are carriers of thalassemia traits (Kemenkes, 2019). Garut City is also one of the areas with high thalassemia cases. Looking at the medical record data at RSUD Dr. Slamet Garut from January to March 2022, there were 261 pediatric patients suffering from thalassemia (Widadi et al., 2023). According to the Indonesian Ministry of Health, adolescents are a group with an age range of 10-18 years (Kemenkes, 2018). Adolescence is a transitional period from

children to adulthood. An adolescent's success in transitioning from childhood to adulthood is influenced by biological and environmental factors, such as family, peers and society. A biological factor that affects adolescent growth and development is chronic illness. Chronic illness can affect the physical, social and emotional development of adolescents. This will lead to a decrease in the quality of life of adolescents (Rusmil, 2013). Wong (2009) in Nurhasanah (2017) states that thalassemia has an impact on both children and their parents.

Thalassemia is a disease that cannot be cured permanently. People with thalassemia major require thalassemia care management, namely regular lifelong blood transfusions (Septyana, Mardhiyah, & Widianti, 2019), he intensity or dependence of children with parents is getting higher during treatment, potentially reducing the level of psychological well-being of parents (Nuraeni et al., 2022). The emotional condition of caregivers needs further attention because it plays an important role in providing medical support to children affected by diseases that last a lifetime (Astarani & Siburian, 2016). The impact that occurs on the physical problems of children with thalassemia major, namely experiencing chronic anemia that can make them tired, weak, difficulty in daily activities (Astarani & Siburian, 2016). In social function, people with thalassemia also experience problems, namely limitations in interacting with their peers or with the surrounding environment because they have to do medical care and treatment (Pratiwi, 2017). In addition, the emotional function of people with thalassemia is also disrupted and is influenced by various things, namely feeling depressed when diagnosed, therapy that must be undergone every month regularly, and having to miss school because of undergoing therapy (Raj et al., 2017).

In a study conducted by Yengil et al (2014), it was found that there was a significant disturbance in parents who had thalassemia adolescents in terms of physical health, including lack of energy due to fatigue, pain, discomfort, and difficulty sleeping due to anxiety and worry about the child's condition. Couture et al (2020) in Rahmi & Putri (2021) stated that the patient's impaired physical (behavioral) and emotional quality of life will affect the caregiver's quality of life because they will experience chronic stress so that their physical and mental health deteriorates and causes a decrease in their quality of life. From some of the problems that occur in parents of adolescents with thalassemia major can affect the quality of life of parents. From the above problems, the purpose of this study is whether there is a relationship between the quality of adolescents with thalassemia major and the quality of life of parents.

METHOD

This study is a quantitative study with a cross sectional approach. The population in this study were adolescents with thalassemia major aged 10-18 years and parents at Dr. Slamet Garut Hospital. The sampling technique used was consecutive sampling with inclusion criteria, namely mothers or fathers who take care of adolescents with thalassemia major who live in one house with thalassemia adolescents and take care of them in their daily lives, all parents who have adolescents with thalassemia major who routinely do blood transfusions, parents and adolescents aged 10-18 years with thalassemia major who are willing to be respondents. The sample in this study amounted to 64 adolescents with thalassemia major aged 10-18 years and their parents. The instruments used were TranQol to measure the quality of life of adolescents with thalassemia major and WHOQOL-BREF to measure the quality of life of parents. The TranQol questionnaire was developed by Dr. Robert Klaassen and distributed by Mapi Research Trust. This questionnaire consists of 28 items and 4 domains, namely physical, emotional, family, and school domains. This questionnaire has been tested for validity with a value of r=0,112-0,743 and reliability test with a value of α=0,806 (Poengoet et al., 2017). Meanwhile, WHOQOL-BREF is an instrument developed by the World Health

Organization (WHO) and adapted into Indonesian by Riza Sarasvati and Dr. Satya Joewana. This questionnaire consists of 26 items and 4 domains, namely physical health, psychological, social relationships, and the environment. This questionnaire has been tested for validity with a score of *r*=0,5-0,7 and reliability test with a score of α=0,41-0,77 (Salim et al., 2007). The ethical feasibility test has been carried out at the Ethics Committee of 'Aisyiyah University with letter number 728/KEP. 01/UNISA-BANDUNG/II/2024. Data collection was carried out on March 1-22, 2024. The data analysis used was univariate to see the frequency distribution or proportion and bivariate analysis to see the relationship between the quality of life of adolescents with thalassemia major and the quality of life of parents at RSUD Dr. Slamet Garut. The bivariate analysis used was the Spearman rho test.

RESULTS

Table 1.
Respondent characteristics (n=64)

Adolescent characteristics	f	%
Age		
10-13 years	30	46,9
14-16 years	22	34,4
17-18 years	12	18,8
Gender		
Men	36	56,3
Woman	28	43,8
Education		
No school	2	3,1
Elementary school	24	37,5
Junior high school	17	26,6
Senior high school	21	32,8
Age at diagnosis of thalassemia		
0-1 year	36	56,3
1-5 year	20	31,3
>5 year	8	12,5
Frequency of blood transfusions		
1 time in 1 month	12	18,8
2 times in 1 month	40	62,5
3 times in 1 month	4	6,3
4 times in 1 month	8	12,5
Disease suffered except thalassemia		
No disease	64	100
Parents characteristics		
Age		
19-44 years	35	54,7
45-59 years	29	45,3
Relationship with child		
Father	19	29,7
Mother	45	70,3
Last education		
No school	0	0
Elementary school	23	35,9
Junior high school	19	29,7
Senior high school	17	26,6
Bachelor	5	7,8
Number of thalassemia children		
1 child	49	76,6
2 children	12	18,8
>2 children	3	4,7

Adolescent characteristics	f	%
Job		
No work	40	62,5
Laborer	7	10,9
Farmer/breeder/entrepreneur	6	9,4
Employee	8	12,5
Military/police/civil servant	3	4,7
Marital status		
Married	59	92,2
Divorced	1	1,6
Death divorce	4	6,3
Income		
<Garut minimum wage (Rp2.117.318)	43	67,2
=Garut minimum wage (Rp2.117.318)	17	26,6
>Garut minimum wage (Rp2.117.318)	4	6,3
Disease suffered		
No disease	55	85,9
Hypertension	3	4,7
Other	6	9,4

Table 1 shows that adolescents with thalassemia major aged 10-18 years at Dr. Slamet Garut Hospital are mostly male, as many as 36 respondents (56.3%) and predominantly aged 10-13 years (46.9%). Based on education, most were elementary school students, as many as 24 respondents. Most of them were diagnosed at the age of 0-12 months (56.3%) and all adolescents did not have other diseases besides thalassemia (100%). The most dominant parent caring for thalassemia adolescents aged 10-18 years at Dr. Slamet Garut Hospital is the mother (70.3%). The dominant parents did not work or housewives (62.5%) and the average age was adult (19-44 years). Most were elementary school graduates (35.9%) and almost all were married (92.2%). A total of 55 respondents (85.9%) had no disease, 3 respondents (4.7%) had hypertension, and 6 respondents (9.4%) had other diseases, namely vertigo, gastritis, hypotension, and prostate disease. Most of the respondents (67.2%) had a monthly family income of <Rp2,117,318.31.

Table 2.
Quality of Life of Adolescents with Thalassemia Major (n=64)

Category	f	%
Physical domain		
Bad	17	26,6
Good	47	73,4
Emotional domain		
Bad	9	14,1
Good	55	85,9
Family domain		
Bad	14	21,9
Good	50	78,1
School domain		
Bad	27	42,2
Good	37	57,8
Total Quality of Life of Adolescents		
Bad	11	17,2
Good	53	82,8

Table 2 shows that most adolescents with thalassemia major aged 10-18 years at Dr. Slamet Garut Hospital have a good quality of life (82.8%). In the physical domain (73.4%), emotional domain (85.9%), and family domain (78.1%), while the school domain has the lowest quality of life (57.8%). The emotional domain of the quality of life of adolescents with thalassemia major aged 10-18 years at Dr. Slamet Garut Hospital is the domain with the highest score (good). While the school domain is the domain with the lowest score (bad).

Table 3.
Quality of Life of Parents (n=64)

Kategori	f	%
Physical domain		
Bad	7	10,9
Good	57	89,1
Domain Psikologis		
Bad	5	7,8
Good	59	92,2
Social relationship domain		
Bad	4	6,3
Good	60	93,8
Environmental domain		
Bad	5	7,8
Good	59	92,2
Total Quality of Life of Parents		
Bad	3	4,7
Good	61	95,3

Table 3 shows that the majority of parents have a good quality of life (95.3%). The social relationship domain of the quality of life of parents of adolescents with thalassemia major aged 10-18 years at Dr. Slamet Garut Hospital is the domain with the highest score of 93.8% (good category). In the environmental domain and psychological domain, the same results were obtained, namely 92.2% and were in the good category. While the physical domain obtained a result of 89.1% is in the good category.

Table 4.
The Relationship between Quality of Life of Adolescents with Thalassemia Major and Quality of Life of Parents (n=64)

Variable	Total Quality of Life of Parents (WHOQOL)	
	Correlation coefficient	P-value
Total Quality of Life of Adolescents	0,406	0,001

Table 4 shows the results of the analysis of the relationship between the quality of life of adolescents with thalassemia major with the quality of life of parents, it is found that there is a significant relationship between the quality of life of adolescents with thalassemia major with the quality of life of parents. Judging from the sig value. (2-tailed) results obtained <0.05 which means that there is a significant relationship between the quality of life of adolescents with thalassemia major with the quality of life of parents. And the correlation coefficient value of 0.406 shows that there is a fairly strong relationship between the two variables

DISCUSSION

Demographic Characteristics of the Adolescents with Thalassemia Major and Parents

Adolescents with thalassemia major at RSUD Dr. Slamet Garut are predominantly male (56.3%). The results of this study are in line with Kamil et al (2020) who stated that most of the respondents were male. Meanwhile, research conducted by Putranto et al (2021) states that most respondents are female. This shows that thalassemia major is inherited autosomal recessively from the carrier parents and does not depend on the sex of the child (Bulan, 2009; Dahnil et al., 2017). The most dominant age of respondents was in the age range of 10-13 years (46.9%). According to research conducted by Supartini, Sulastri, & Sianturi (2017) there is a significant relationship between age and children's quality of life. The older the child's age, the more prepared and persistent the child will be in undergoing treatment. This is reinforced by research conducted by Thavorncharoensap et al (2010) in Lusiani et al (2017) which states that adolescents have a higher quality of life than younger children due to the adjustment process to their illness. Most respondents' education was elementary school

(37.5%) followed by high school (32.8%) then junior high school (26.6%) and 3.1% did not attend school. The initial age of respondents when diagnosed with thalassemia major was dominant at the age of 0-12 months, as many as 56.3%. This is in line with the research of Trehan et al (2015) in India which states that the majority of children who need transfusions are in the first year of life, but only diagnosed after the age of 2 years due to the symptoms of thalassemia. The frequency of blood transfusions was predominantly 2 times in 1 month. This is in line with the research of Mariani et al (2014) explaining that there is no significant relationship between the frequency of transfusions and the quality of life of beta major thalassemia children. All respondents (100%) did not have other diseases besides thalassemia. Based on research conducted by Utami & Anggraeni (2023) this study shows the results of no significant relationship between comorbidities and the quality of life of children suffering from thalassemia major.

The parents of the most dominant in this study were mothers (70.3%). This is in line with research conducted by (Fitriliani et al., 2020) that parents who care for adolescents with thalassemia are dominated by mothers and do not work or as housewives. Parents of adolescents with thalassemia major at RSUD Dr. Slamet Garut are dominated by adults aged 19-44 years (56.3%). The last education of most respondents is elementary school graduates (35.9%). This is in line with research conducted by Mariani et al (2014) which revealed that the education level of parents is mostly elementary school graduates. This is reinforced by research conducted by Utami & Anggraeni (2023) which states that low education causes low social function and disease knowledge is also influenced by high education so that it contributes to knowledge of the course of the disease. The most dominant family income is below the minimum wage of Garut Regency, which is IDR 2,117,318 (67.2%). This is in line with the research of Mariani et al (2014) which explains family income and thalassemia history affect the quality of life of children. The better the parents' income, the better the quality of life of children with thalassemia major because the care provided will be better. The number of children with thalassemia in the family is dominantly 1 child (76.6%). Based on research Hanifah (2020), parents with genetic thalassemia will give birth to children with beta thalassemia major. There is a relationship between the incidence of beta thalassemia major in children with a family history of thalassemia. The majority of parents were married (92.2%). A total of 55 respondents (85.9%) had no disease, 3 respondents (4.7%) had hypertension, and 6 respondents (9.4%) had other diseases, such as vertigo, gastritis, hypotension, and prostate.

Quality of Life of Adolescents with Thalassemia Major

The total score of the quality of life of adolescents with thalassemia major aged 10-18 years is in the good category (82.8%). The results of this study are in line with Utami & Anggraeni (2023) which explains that the quality of life of children with major thalassemia at RSPAD Gatsu and RASAB Harkit Jakarta has a good quality of life as many as 50 (60.2%). Research by Mediani et al (2022) showed that children's quality of life based on the emotional domain was in the good category. Mediani et al (2022) revealed that this high emotional domain score could be due to starting to adapt and depending on the learning process towards emotional control in children. The school domain (57.8%) is the domain that has the lowest value compared to other quality of life domains. According to Thavorncharoensap et al (2010) in Ali et al (2021), this can occur due to the fact that thalassemia children often do not go to school because they have to go to the hospital to do transfusions and lack of energy when doing academic activities can have a negative impact on the learning process. Adolescents are often absent from school because they have to do blood transfusions at the hospital. The family domain quality of life score from this study was 78.1% below the emotional domain. Research conducted by Mazzone et al (2009) in Putri & Purwati (2019) explains that psychosocial support from families reduces emotional problems in children with thalassemia.

The role of the family, especially parents, is very important in supporting the quality of life of adolescents by providing medical support such as transfusions for adolescents, the quality of life of children with thalassemia will be better if the family provides good support as well. The physical domain quality of life score was 73.4%. Nikmah & Mauliza (2018) showed that the quality of life of children with thalassemia major was in the bad category with an average quality of life score in the physical domain of 55.67%. This can be caused by chronic anemia conditions that cause children to often experience fatigue during activities (Widadi et al., 2023). Before transfusion, adolescents look weak but after transfusion they look fitter because the Hb before transfusion is low.

Quality of Life of Parents

The total score of parents' quality of life is in the good category (95.3%). This is in line with research conducted by Fitriliani et al (2020), showing that the majority of parents have good and moderate quality of life in each domain. Unlike the case with research conducted by Ahmed et al (2023), showing that more than half of the respondents (caregivers) (67.1%) had a bad quality of life. Fitriliani et al (2020), shows that the quality of life of parents based on the social relationship domain is mostly in the moderate category (56.6%). Fitriliani et al (2020) revealed that social support will help parents deal with the problems that are happening so that it will improve their quality of life. This is reinforced by research conducted by Habsyie et al (2022), stating that people who get social support will be able to cope with the stress experienced and their physical health will improve or be better. Parents of thalassemia adolescents get support from nurses, doctors, and other parents who have thalassemia adolescents at RSUD Dr Slamet garut. A total of 59 respondents (92.2%) had a good quality of life in the psychological domain and 54 respondents (92.2%) had a good quality of life in the environmental domain. This is in line with research conducted by Fitriliani et al (2020) which found that the majority of parents were in the moderate category in the environmental domain. Based on education, most respondents (parents) are elementary school graduates, but in this case parents still seek information related to their child's disease, namely thalassemia. Parents still look for information about thalassemia from doctors and nurses. According to Widadi & Oktaviani (2019) families or parents will try to do their best for their child's recovery by seeking information related to the child's condition and seeking help and support from inside and outside. The physical domain is the lowest domain with a score of 89.1%. Unlike the case with research conducted by Fitriliani et al (2020) explaining that the quality of life of parents of adolescents with thalassemia major in Garut Regency the majority have a good quality of life in the physical domain as many as 25 respondents (48.1%) and very good 4 respondents (7.7%).

The Relationship between Quality of Life of Adolescents with Thalassemia Major and Quality of Life of Parents

The results of the analysis of the relationship between the quality of life of adolescents with thalassemia major aged 10-18 years with the quality of life of parents at RSUD Dr. Slamet Garut obtained that there is a relationship between the total score of the quality of life of adolescents with thalassemia major with the total score of the quality of life of parents (r=0.406, p=0.001), meaning that the greater or better the quality of life of adolescents with thalassemia major, the better the quality of life of parents. This is in line with research conducted by Biswas et al (2023), finding that the quality of life of caregivers who accompany and care significantly affects the quality of life of children with thalassemia. This may occur because caregivers who have a better quality of life will provide a better quality of service in their environment so that it has a positive impact on their quality of life.

CONCLUSION

The quality of life of adolescents with thalassemia major at RSUD Dr. Slamet Garut is good as many as 53 respondents (82.8%) and bad as many as 11 respondents (17.2%). While the quality of life of parents of adolescents with thalassemia major at RSUD Dr. Slamet Garut is good as many as 61 respondents (95.3%) and bad as many as 3 respondents (4.7%). Based on the results of the spearman rank correlation test, it was found that the p value = 0.001 (p <0.05), it can be concluded that there is a significant relationship between the quality of life of adolescents with thalassemia major with the quality of life of parents so it can be concluded that the better the quality of life of adolescents with thalassemia major, the better the quality of life of parents.

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