Indonesian Journal of Global Health Research
Volume 6 Number 5, October 2024
e-ISSN 2715-1972; p-ISSN 2714-9749
http://jurnal.globalhealthsciencegroup.com/index.php/IJGHR

ILLNESS PERCEPTION AND QUALITY OF LIFE OF PARENTS WITH THALASSEMIC ADOLESCENTS

Andini Tri Lestari*, Ai Mardhiyah, Tuti Pahria, Henny Suzana Mediani, Hendrawati
Faculty of Nursing, Universitas Padjadjaran, Jl. Raya Bandung Sumedang KM.21, Sumedang, West Java 45363, Indonesia
*andini20005@mail.unpad.ac.id

ABSTRACT

Thalassemia major necessitates routine treatment that affects the physical, psychological, and social capacities of both the sufferers and their parents. In these circumstances, the way parents perceive their child's illness significantly influences their quality of life, making this a crucial aspect to consider.Objective: This study aims to explore the relationship between illness perception and quality of life in parents of adolescents with thalassemia major at RSUD dr. Slamet Garut. Method: The study employed a cross-sectional approach, including 64 parents of adolescents with thalassemia major (aged 10-18 years) selected through consecutive sampling. The Brief Illness Perception Questionnaire (BIPQ) was used to measure illness perception, and the World Health Organization Quality of Life Brief Version (WHOQoL-BREF) was used to assess quality of life. Both instruments are validated and reliable, with BIPQ having reliability coefficients of r=0.40-0.78 (α=0.74) and WHOQoL-BREF having r=0.39-0.79 (α=0.94). The Spearman correlation test was utilized for bivariate analysis. Results: The findings indicated that 55 respondents (85.9%) had a positive illness perception of thalassemia, and 61 respondents (95.3%) reported a high quality of life. The correlation analysis revealed a significant relationship between illness perception and the quality of life of parents, with a correlation coefficient of 0.548 ($p<0.05$). Conclusions: This concludes that there is a significant relationship between illness perception and quality of life in parents of adolescents with thalassemia major at RSUD dr. Slamet Garut.

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

First Received	Revised	Accepted
28 March 2024	28 April 2024	30 April 2024

Final Proof Received	Published
05 July 2024	01 October 2024

How to cite (in APA style)
Lestari, A. T., Mardhiyah, A., Pahria, T., Mediani, H. S., & Hendrawati, H. (2024). Illness Perception and Quality of Life of Parents with Thalassemic Adolescents. Indonesian Journal of Global Health Research, 6(5), 2977-2986. https://doi.org/10.37287/ijghr.v6i5.3678.

INTRODUCTION

Thalassemia is a hereditary hemolytic genetic disorder characterized by impaired hemoglobin synthesis due to a genetic mutation, resulting in damaged hemoglobin within red blood cells (Salsabila et al., 2019). It is the most prevalent hemolytic hereditary disease globally, causing significant child mortality annually (Rujito, 2019). In Indonesia, 6-10% of the population is affected, with the highest cases in West Java (KEMENKES, 2019). As of May 2018, Garut Regency reported over 270 residents with major thalassemia (Dinkes, 2018). A December 2023 study at RSUD dr. Slamet Garut found 80 adolescents aged 10-18 undergoing treatment, which includes managing physical and psychological impacts such as stunted growth, bone deformities, fear, anxiety, and loss of self-confidence (Mardhiyah et al., 2023).

Parents of children with thalassemia face significant challenges, including depression, stress, and compromised quality of life (Hamsyah & Sakti, 2015; Murali et al., 2022). While most parents report good physical health, their psychological, social, and environmental well-being is moderate (Jacob & Sandjaya, 2018; Fitrilliani et al., 2020). Common issues include high anxiety, inadequate understanding of the disease, financial burdens, and social isolation (Saleem et al., 2021; Nabavian et al., 2022). Illness perception, encompassing beliefs about the disease's characteristics, causes, duration, and treatment, significantly influences parents' quality of life and emotions (Chilcot et al., 2021; Papadopoulos et al., 2023). Interviews with nurses and parents in Garut revealed that parents' social and emotional lives are significantly affected by their children's conditions. Despite feeling tired, parents strive to maintain a positive quality of life. However, there is limited research on the relationship between parents' illness perception and their quality of life when they have adolescents with major thalassemia. This study aims to explore this relationship to better understand how parents' beliefs about the illness influence their overall well-being and quality of life.

METHOD

This research is a descriptive study with a quantitative approach that produces data in numerical form. The statistical technique used to assess the relationship between variables is the correlational technique with a cross-sectional approach. The subjects of the research are parents with teenage children (10-18 years old) who have major thalassemia and undergo blood transfusions at dr. Slamet Garut Regional Hospital. The sampling technique used is consecutive sampling with a total population of 77 people and a tolerance level of 5%. This research has received ethical approval from the Health Ethics Committee with the approval letter number 016/KEPK/FITKes-Unjani/III/2024. The Indonesian version of the WHOQoL-BREF questionnaire was used to measure the quality of life of the parents. The questionnaire statements cover the dimensions with a total of 26 statements. Each item is rated on a scale from 1 to 5. The validity and reliability of this instrument have been previously tested on 30 respondents at the Talun Health Center with an r value ranging from 0.390 to 0.798 and a reliability value of 0.941, indicating that the instrument is valid and reliable. Disease perception was measured using the Indonesian version of the B-IPQ (The Brief Illness Perception Questionnaire). This instrument consists of 9 items, each measuring a dimension of disease perception on a scale from 0 to 10. This instrument was tested by Robiyanto et al. (2016) and was declared valid and reliable with a Cronbach's Alpha value of 0.74. Data analysis was carried out through univariate and bivariate analysis. Univariate analysis was performed by calculating the frequency distribution of categorical data, while bivariate analysis used Spearman's rank correlation to test the relationship between variables. This research was conducted in the thalassemia outpatient clinic at dr. Slamet Garut Regional Hospital in March 2024.

RESULTS

Table 1 shows that the majority of respondent were dominated by female (70.3%), in the age of 19-44 (54.7%), and married (92.2%). Most of the respondents were an elementary school graduate (35.9%) also currently not working (62.5%). Based on family income, most respondents were categorize as below the minimum wage (67.2%). Respondents also dominated by parents who only have 1 thalassemic child (76.6%), also most of them were statin that they didn’t have any chronic disease (85.9%).

Table 2 shows that most respondents have a positive perception towards thalassemia major as their child illnesses, unfortunately on a most of them still have negative perception in a few domain which were consequences (62.5%), duration (95.3%), identity (51.6%) and concern (96.9%).

Table 1.
Respondent characteristics (n= 64)

Respondent characteristics	f	%
Gender		
Male	19	29.7
Female	45	70.3
Age		
19-44 years old	35	54.7
45-59 years old	29	45.3
Marital state		
Married	59	92.2
Divorced	1	1.6
Widowed	4	6.3
Education		
Primary school graduate	23	35.9
Junior high school graduate	19	29.7
Senior high school graduate	17	26.6
Diploma or University graduate	5	7.8
Occupation		
Unemployed	40	62.5
Labor	7	10.9
Farmer/rancher/entrepreneur	6	9.4
Private Employees/Employees	8	12.5
Military/police/civil servants	3	4.7
Income level		
Below regional minimum wage (<Rp 2.150.000)	43	67.2
Equals to regional minimum wage (Rp 2.150.000)	17	26.6
Above regional minimum wage (>Rp 2.150.000)	4	6.3
Number of thalassemic children		
1	49	76.6
2	12	18.8
>2	3	4.7
Parent’s illnesses		
None	55	85.9
Heart disease (history of heart disease)	1	1.6
Hypertension	3	4.7
others	5	7.8

Table 2.
Frequency distribution of illness perception domains (n= 64)

Illness perception domains	f	%
Consecuences		
Positive	24	37.5
Negative	40	62.5
Duration		
Positive	3	4.7
Negative	61	95.3
Personal control		
Positive	60	93.8
Negative	4	6.3
Treatment control		
Positive	59	92.2
Negative	5	7.8
Identity		
Positive	31	48.4
Negative	33	51.6
Concern		
Positive	2	3.1
Negative	62	96.9

Illness perception domains	f	%
Coherence		
Positive	57	89.1
Negative	7	10.9
Emotional representation		
Positive	35	54.7
Negative	29	45.3

Table 3.
Frequency distribution of illness perception causal(n= 64)

Illness perception causal	f	%
Don’t Know	17	27
Genetic	41	64
Anemia	3	5
Premature	2	3
Fever	2	3
Incest	1	2
Parents had chronic illness	1	2
No appetite	1	2
Colostomi	1	2
Parents eat too much education	1	2
Parents too tired	1	2
Flu	1	2

Table 3 shows that even though there is still parents who state they don’t know what is the cause of thalassemia on their child (27%), most parents were agreed that thalassemia was caused by Genetic (64%).

Table 4.
Frequency distribution of illness perception (n= 64)

Illness Perception	f	%
Positive	55	85.9
Negative	9	14.1

Table 4 shows that most parents who had an adolescents with thalassemic major have a positive illness perception towards thalassemia as their child illnesses.

Table 5.
Frequency distribution of quality of life domain (n= 64)

Quality of life domains	f	%
Physical health factor		
High	57	89.1
Low	7	10.9
Psycological factor		
High	59	92.2
Low	5	7.8
Social relationship factor		
High	60	93.8
Low	4	6.3
Environmental factors		
High	59	92.2
Low	5	7.8

Table 6.
Frequency distribution of quality of life (n= 64)

Quality of life	f	%
High	61	95.3
Low	3	4.7

Table 5 and table 6 we can see that almost every respondent have a high quality of life (95.3%) even when we look at each domain, its still dominated by respondents that have a high quality of life with the highest quality of life was the social relationship (93.8%).

Table 7.
Crosstabs frequency distribution illness perception and quality of life (n= 64)

		Total Score WHOQOL					
		High		Low		Total	
		f	%	f	%	f	%
Total score BIPQ	Positive	55	100	0	0	55	100
	Negative	6	66.7	3	33.3	9	100
Total		61	95.3	3	4.7	64	100

Table 8.
Correlation test of illness perception and quality of life (n= 64)

			Skor Total WHOQOL	Skor Total BIPQ
Spearman’s rho	Skor Total WHOQOL	Correlation coefficient	1.000	.548**
		Sig. (2-tailed)	.	.000
		n	64	64
	Skor Total BIPQ	Correlation coefficient	.548**	1.000
		Sig. (2-tailed)	.000	.
		n	64	64

Table 7 and 8 shows the relations between illness perception and quality of life. The results of spearman rank correlation test obtain a significance value of 0, which means that there is a significant relationship between illness perception and quality of life of parents with thalassemic adolescents. The correlation coefficient is 0.548 which means that the level of correlation strength is categorized as strong.

DISCUSSION

Illness Perception

In this study, the results indicate that most parents of adolescents with thalassemia major at RSUD dr. Slamet Garut have a positive illness perception, with 89.1% of respondents holding positive views and only 10.9% having negative perceptions. This suggests a good understanding of thalassemia major, its causes, consequences, and management among the majority of parents, aligning with previous research by Dahlia & Oktiviyari (2011) which found mostly positive or neutral perceptions among parents. However, other studies show differing results. Szentes et al. (2017) reported that some parents had negative perceptions associated with high anxiety, and Salvador et al. (2015) found that parents of children undergoing treatment had more negative perceptions and lower quality of life. These variations may be due to differences in cultural context, educational level, and access to health information. Most respondents in this study were aged 19-44, a demographic typically more adaptable and optimistic when facing health challenges. Interestingly, despite most respondents being elementary school graduates, they still had a positive illness perception, possibly due to strong social support and community involvement. This community support, along with continuous education from healthcare professionals, helps parents manage their adolescent's condition effectively. This education is crucial in shaping positive illness perceptions and reducing fears and anxieties, as supported by studies from Osman (2019). Only 10.9% of parents had a negative illness perception, likely due to lack of information, negative healthcare experiences, or high stress and anxiety related to their adolescent's condition.

Quality of Life

The study results indicate that most parents of adolescents with thalassemia major at RSUD dr. Slamet Garut have a high quality of life, with 95.3% reporting high quality and only 4.7% reporting low quality. This finding aligns with Estiarti's (2010) study on families at Poli Talasemia RSUP Dr. Hasan Sadikin Bandung. Research consistently shows that parents of children with chronic illnesses face significant emotional and social challenges, but good social support and adaptation can help maintain a high quality of life (Yıldırım, 2021). Cultural, healthcare, and social policy contexts also influence quality of life. In Indonesian culture, where the majority are Muslim, acceptance and gratitude are core values that contribute to better quality of life (Sulistyarini, 2019). Most respondents were aged 19-44, a period where individuals are typically more resilient and capable of adapting to stress. Cognitive and emotional flexibility, along with social support and healthcare access, plays a significant role in maintaining a high quality of life despite low income (Toledano-Toledano, 2020). Married respondents reported higher quality of life, supported by emotional, practical, and financial assistance from spouses (Lohare, 2021; Biswas, 2020). Interestingly, having more than one child with thalassemia did not lower the parents' quality of life, as the experience enhanced their adaptability and confidence in managing the disease.

Correlation between illness perception and quality of life

In this study, the relationship between illness perception and the quality of life of parents of adolescents with thalassemia major at RSUD dr. Slamet Garut was analyzed using the Spearman rank correlation test. The results show a significant positive relationship, with a correlation coefficient of 0.548 and a p-value of 0.000. This indicates that the more positive the illness perception held by the parents, the higher their quality of life. A positive perception, including a clear understanding of the disease and its management, contributes significantly to a better quality of life, consistent with previous research by Terrasson (2018). Various factors influence this relationship, such as parents' education levels, experiences with the disease, and access to health resources. Parents who believe they have control over managing their adolescent’s illness and see hope in medical treatments tend to have better coping mechanisms (Szentes, 2018). Higher education improves parents' understanding and coping strategies. Encouragement and optimism from believing in effective treatment enhance quality of life, making parents more likely to engage actively in their adolescent’s care and build strong social support networks, which are crucial for coping with challenges and reducing isolation, ultimately enhancing their quality of life (Levinger & Alhuzail, 2018). Conversely, a negative perception of thalassemia major, viewing it as highly threatening and prolonged, leads to higher stress and anxiety (Yengil et al., 2014). This negativity can result in mental health issues like depression, lowering quality of life. In RSUD Kota Garut, where resources might be limited, a positive illness perception encourages parents to seek additional resources and information, enhancing their confidence and reducing their psychological burden. This study underscores the importance of nurses focusing on educating and emotionally supporting parents, enhancing their understanding and perception of the disease to ultimately improve their quality of life. Limitations of this studies include the relatively small sample size and unmeasured factors such as economic conditions, social support, access to healthcare, and mental health status. Future research should explore these variables more comprehensively to provide a deeper understanding of their impact on the quality of life of parents of adolescents with major thalassemia.

CONCLUSION

This study shows that the majority of parents of adolescents with major thalassemia at RSUD dr. Slamet Garut have a positive illness perception. Additionally, the respondents' quality of life is mostly in the high category, even when looking at individual dimensions of quality of life such as physical health, psychological well-being, social relationships, and environment, all are predominantly in the high category. The results indicate that there is a positive relationship between illness perception and quality of life among parents of adolescents with thalassemia, meaning that the more positive the illness perception, the higher the quality of life. This can occur because parents with a positive illness perception will have motivation, optimism, good coping abilities, and a better social network compared to those with a negative illness perception. These factors directly enhance the quality of life scores of the parents. Future research is expected to use larger and more diverse samples and to consider various other factors that may influence the quality of life.

REFERENCES

Biswas, D., Sarkar, A.P., Haldar, D., Sarkar, G.N., & Saha, I. (2020). Quality of life among parents of Thalassemic Children in Eastern India.

Chilcot, J., Weinman, J., & Farrington, K. (2021). Chapter 14 - Adherence and illness perceptions in patients with CKD and ESRD (D. Cukor, S. D. Cohen, & P. L. B. T.-P. A. of C. K. D. Kimmel, Eds.; pp. 297–309). Academic Press. https://doi.org/https://doi.org/10.1016/B978-0-12-817080-9.00014-2

Dahlia, & Oktiviyari, A. (2011). Persepsi Orang Tua Penyandang Autisme Terhadap Autisme Di Wilayah Banda Aceh. Jurnal Kedokteran Syiah Kuala, 11(2), 78–83.

Estiarti, A., L. (2010). Gambaran kualitas hidup keluarga yang merawat anak thalassemia di Poli Thalasemia RSUP Dr. Hasan Sadikin Bandung. Skripsi Fakultas Keperawatan Universitas Padjajaran.

Fitriliani KH, P., Rakhmawati, W., Rukmasari, E. A., & Mardhiyah, A. (2020). Gambaran Kualitas Hidup Orang Tua Yang Merawat Remaja Talasemia di Kabupaten Garut. Jurnal Keperawatan BSI, 8(2), 173-182. Retrieved from https://ejurnal.ars.ac.id/index.php/keperawatan/article/view/295

Jacob, D. E., & Sandjaya. (2018). Faktor faktor yang mempengaruhi kualitas hidup masyarakat Karubaga district sub district Tolikara propinsi Papua. Jurnal Nasional Ilmu Kesehatan (JNIK), 1(69), 1–16. https://journal.unhas.ac.id/index.php/jnik/index

KEMENKES. (2019). Putuskan Mata Rantai Talasemia, untuk Indonesia Lebih Sehat. Kemkes.Go.Id. https://p2ptm.kemkes.go.id/tag/putuskan-mata-rantai-talasemia-untuk-indonesia-lebih-sehat

Levinger, M., & Alhuzail, N. A. (2018). Bedouin Hearing Parents of Children With Hearing Loss: Stress, Coping, and Quality of Life. American Annals of the Deaf, 163(3), 328–355. https:/li /doi.org/10.1353/aad.2018.0022

Lohare, B. S., & Gokhe, S. S. B. (2021). A cross-sectional study to assess quality of life in 2-18 years children and adolescent living with beta thalassemia major registered at comprehensive thalassemia care centre attached to tertiary care hospital in a metropolitan city. International Journal of Community Medicine and Public Health, 8(9), 4513. https://doi.org/10.18203/2394-6040.ijcmph20213561

Mardhiyah, A., Suzana Mediani, H., Letcmi Panduragan, S., & Yosep, I. (2023). Psychosocial Problems on Adolescents with Thalassemia Major: A Systematic Scoping Review. KnE Social Sciences. https://doi.org/10.18502/kss.v8i14.13834

Murali, C. N., Lalani, S. R., Azamian, M. S., Miyake, C. Y., & Smith, H. S. (2022). Quality of life, illness perceptions, and parental lived experiences in TANGO2-related metabolic encephalopathy and arrhythmias. European Journal of Human Genetics, 30(9), 1044–1050. https://doi.org/10.1038/s41431-022-01127-5

Nabavian, M., Cheraghi, F., Shamsaei, F., Tapak, L., & Ahmad, T. (2022). The psychosocial challenges of mothers of children with thalassemia: A qualitative study. Journal of Education and Health Promotion, 11(37). https://doi.org/10.4103/jehp.jehp_163_21

Osman, A., Cambers, B., Potter, S., & Sykes, K. (2019). Parental Experiences of Healthcare Education During Critical Illness. MedEdPublish, 8(1). https://doi.org/10.15694/mep.2019.000010.1

Papadopoulos, A., Siafaka, V., Tsapara, A., Tafiadis, D., Kotsis, K., Skapinakis, P., & Tzoufi, M. (2023). Measuring parental stress, illness perceptions, coping and quality of life in families of children newly diagnosed with autism spectrum disorder. BJPsych Open, 9(3), 1–9. https://doi.org/10.1192/bjo.2023.55

Robiyanto, Prayuda, A. O., & Nansy, E. (2016). Uji Validitas Instrumen B-Ipq Versi Indonesia Pada Pasien Hipertensi Di Rsud Sultan Syarif Mohamad Alkadrie Pontianak. Social Clinical Pharmacy Indonesia Journal, 1(1), 41–49.

Rujito, L. (2019). Talasemia : Genetik Dasar dan Pengelolaan Terkini. In D. W. D. Lestari (Ed.), Universitas Jenderal Soedirman (1st ed.). Universitas Jenderal Soedirman.

Saleem, N., Anwar, A., Shahid, N. U. A., Saleem, R., Saleem, Z., Asghar, H., Zubair, M., Ellahi, H., & Iqbal, S. (2021). Perception of Parents of Thalassemic Child to Thalassemia in Pakistan. Cureus. https://doi.org/10.7759/cureus.17615

Salsabila, N., Perdani, R. R. W., & Irawati, N. A. V. (2019). Nutrisi Pasien Thalassemia. Medical Journal Of Lampung University, 8(1), 178–182.

Salvador, Á., Crespo, C., Martins, A. R., Santos, S., & Canavarro, M. C. (2015). Parents' Perceptions About Their Child's Illness in Pediatric Cancer: Links with Caregiving Burden and Quality of Life. Journal of Child and Family Studies, 24(4). https://doi.org/10.1007/s10826-014-9921-8

Siafaka, V., Zioga, A., Evrenoglou, T., Mavridis, D., & Tsabouri, S. (2020). Illness perceptions and quality of life in families with child with atopic dermatitis. Allergologia et Immunopathologia, 48(6), 603–611. https://doi.org/10.1016/j.aller.2020.03.003

Sulistyarini, R.I., & Andriansyah, Y. (2019). Social Support, Gratitude, and Quality of Life of Patients with Chronic Disease in Yogyakarta, Indonesia.

Szentes, A., Kökönyei, G., Békési, A., Bokrétás, I., & Török, S. (2017). Differences in illness perception between children with cancer and other chronic diseases and their parents. Clinical Child Psychology and Psychiatry, 23(3), 365–380. https://doi.org/10.1177/1359104517731899

Terrasson, J., Terrade, F., Somat, A., Nivot-Adamiak, S., Guitteny, M.-A., & de Kerdanet, M. (2017). Association between quality of life of adolescents with type 1 diabetes and parents' illness perception as evaluated by adolescents. Psychology, Health & Medicine, 23(3), 347–359. https://doi.org/10.1080/13548506.2017.1348608

The WHOQOL Group. (1995). The World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization. Social Science & Medicine, 41(10), 1403–1409. https://doi.org/10.1016/0277-9536(95)00112-K

Toledano-Toledano, F., Moral de la Rubia, J., Nabors, L. A., Domínguez-Guedea, M. T., Salinas Escudero, G., Rocha Pérez, E., Luna, D., & Leyva López, A. (2020). Predictors of Quality of Life among Parents of Children with Chronic Diseases: A Cross-Sectional Study. Healthcare, 8(4), 456. https://doi.org/10.3390/healthcare8040456

Yildirim, M., Yayan, E. H., Suna Dağ, Y., Sülün, A., & Akyay, A. (2021). The relationship between the care burden and quality of life of parents who have children with hematological problems and their perceived social support. Journal of Pediatric Nursing. https://doi.org/10.1016/j.pedn.2021.10.004.