Poltekita: Jurnal Ilmu Kesehatan
http://jurnal.poltekkespalu.ac.id/index.php/JIK

Vol.17 No.3 November 2023: Hal. 598-604
p-ISSN: 1907-459X e-ISSN: 2527-7170

Original Article

Family Psychoeducation to Improve Parents' Coping Strategies in Caring for Thalassemia Children

Dini Mariani[1*], **Annisa Salwa Muffidah**[1], **Ida Rosdiana**[1]

[1] Poltekkes Kemenkes Tasikmalaya, Tasikmalaya, West Java, Indonesia

(Correspondence author email, dini.mariani77@gmail.com)

ABSTRACT

Thalassemia is a genetic disorder of the synthesis of alpha or beta globin chains, either in whole or in part. Families who care for children with thalassemia will experience psychosocial problems. Ignorance is the reason why families find it difficult to adapt. Therefore, it is necessary to provide knowledge and the ability to adapt to stressors so that family coping is positive. This study aims to determine the effect of Family Psychoeducation on parents' coping strategies in caring for children with thalassemia. The research design used a "Quasi experiment pre-post-test with a control group." The purposive sampling technique was used with a sample of 44 people divided into two groups. The instrument used is Brief COPE. The results showed that in the intervention group, there was a significant difference in the average score with a p-value of 0.000. Meanwhile, in the control group, there was no significant difference in the average score with a p-value of 0.492. There is a difference in the average score between the intervention group and the control group, with a p-value of 0.023. In conclusion, there is an influence of family psychoeducation on parents' coping strategies in caring for children with thalassemia.

Keywords: *Family, Coping, Psychoeducation, Thalassemia*

https://doi.org/10.33860/jik.v17i3.2527

INTRODUCTION

Thalassemia is a hereditary disease that affects a significant number of people worldwide. One of the countries within the world's thalassemia belt is Indonesia, indicating a high frequency of thalassemia carrier genes[1]. According to data from the Indonesian Thalassemia Foundation, the prevalence of thalassemia cases in Indonesia is projected to reach 10,973 in 2021[2]. The province with the highest contribution to the number of people affected by thalassemia is West Java, accounting for 40% of cases[3]. The Chairperson of the Association of Indonesian Thalassemia Parents (POPTI) Tasikmalaya said there were 280 people with thalassemia in Tasikmalaya, many of whom were dominated by children[3]. Until now, it is known that a definitive treatment that completely cures thalassemia has not been found. One way to maintain the quality of life of Thalassemia patients is through supportive therapy with routine blood transfusions[4].

People with thalassemia will face an impact on physical health due to their lifelong need for blood transfusions. In addition to physical challenges, individuals with thalassemia also experience psychosocial issues. According to qualitative research conducted by Mariani et al. (2020), children with thalassemia often report instances of bullying and face limitations in their interactions with the environment[5].

This psychosocial problem has many effects, not only on people with thalassemia but also on their parents or families who have

children with thalassemia. Families must be willing to sacrifice money, energy, and time to care for and accompany their children for lifelong treatment[6].

Simple interviews conducted by researchers with Thalassemia Center officers at RSU Prasetya Bunda Tasikmalaya and 4 parents of children with thalassemia obtained information that when parents heard that their child was diagnosed with thalassemia, they would experience a stage of rejection, which eventually led to cases of non-compliance with transfusions and medication because parents were reluctant to accompany their children. In addition, 3 out of 4 parents said they had not fully reached the acceptance stage. Sometimes, families still find it difficult to accept reality when faced with problems. This statement follows research conducted by (Ulfa & Hasyim, 2018) that families experience the grieving process repeatedly when their child is diagnosed with thalassemia. Even families often return to the denial phase every time they take their child for a transfusion [7]. Ignorance of the family regarding the concept of illness, how to treat it, and the fear of loss also make it difficult for families to adapt[8]. The efforts that the family can make to reduce the threat or pressure caused by the stressor depend on how the family uses coping mechanisms [9]. However, in dealing with difficult situations, individuals tend to use faulty or maladaptive coping mechanisms. If these coping mechanisms are continuously used, they can result in higher stress levels and can cause depression[10]. This phenomenon illustrates that the family needs to be equipped with knowledge and the ability to deal with stressors so that coping is positive [9] because the family has an important role in making decisions about caring for sick family members[7].

One effort that can help the family acceptance process in carrying out its functions in patients with chronic illnesses is psychoeducation. Family psychoeducation is an intervention that provides educative information regarding the problems faced by families in caring for children with thalassemia[7]. The results of a study conducted on 21 families with children with thalassemia major showed that psychoeducational interventions affected parents' anxiety[9]. Therefore, researchers are interested in researching to know the effects of family psychoeducation on parents' coping strategies in caring for children with thalassemia at RSU Prasetya Bunda Tasikmalaya. From this background, the issue of how effective psychoeducation is in improving coping strategies for families with children with thalassemia can be raised.

METHOD

The type of research used in this study was quantitative with a quasi-experimental design method employing a pre-post test with a control group design. The research was conducted in May 2023 at Prasetya Bunda General Hospital in Tasikmalaya City. This hospital serves as a thalassemia center and a referral hospital for thalassemia cases. The population for this study consisted of parents who had children with thalassemia major, aged 6-17 years, and undergoing treatment at RSU Prasetya Bunda Tasikmalaya, totalling 95 respondents. The sample size was determined using the Slovin formula, resulting in 22 respondents per group. Purposive sampling was employed as the sampling technique.

Data retrieval involved the use of demographic sheets and the COPE brief coping strategies questionnaire, which had been translated into Indonesian [11]. The reliability of the questionnaire was tested using Cronbach's Alpha, yielding a result above 0.6 (Carver, 1997). Additionally, the reliability test Apriska (2016) conducted resulted in $\alpha = 0.746$ [11].

The research began by sorting and collecting respondents who met the inclusion criteria. Informed consent was obtained from the respondents as approval for their participation, followed by the completion of the demographic sheet. Subsequently, the respondents were given a questionnaire to assess the coping strategies they used when dealing with stressors while caring for children with thalassemia. This was followed by Session I, which involved providing educative information about thalassemia. After Session I, the parents were given a 15-minute rest period, after which Session II commenced. Session II focused on sharing coping strategies among natural parents to manage stressors associated with caring for children with thalassemia. The researchers also provided tips and tricks for stress management and effective coping strategies. Following the two sessions, the respondents received a digital pocketbook on psychoeducation, which had been delivered

earlier via WhatsApp. The post-test was conducted >14 days after providing the family psychoeducation. Eight methods can be used in implementing psychoeducation methods, namely training methods, case discussions, role plays, group discussions exercises individual, presentation and behavioral modelling consisting of four sessions in this study, the data were tested for normality using the Shapiro-Wilk analysis due to the small sample size (<50 per group) and a homogeneity test. The normality test results indicated that the data were normally distributed, enabling a paired sample t-test to determine the effect of family psychoeducation before and after the intervention and education groups, as per Prasetya Bunda General Hospital procedures in the control group. Additionally, an independent t-test was performed to ascertain whether there was a difference in the average coping strategy scores between the intervention group and the control group.

The Ethics Committee approved this study of the Poltekkes Kemenkes Tasikmalaya, with the number No.DP.04.03/16/65/2023.

RESULTS

Table 1. Distribution of respondents by age

	Intervention			Control		
	N	Mean	SD	N	Mean	SD
Age	22	37.09	7.892	22	36.41	7.062

Table 2. Distribution of respondents based on gender

Gender	Intervention		Control	
	N	%	N	%
Male	6	27.3	4	18.2
Female	16	72.7	18	81.8
Amount	22	100.0	22	100.0

Table 3. Distribution of respondents based on education

	Intervention		Control	
Education	N	%	N	%
Elementary School	6	27.3	5	22.2
Junior High School	7	31.8	7	31.8
Senior High School	7	31.8	8	36.4
University	2	9.1	2	9.1
Amount	22	100.0	22	100.0

Table 4. Distribution of respondents by occupation

Profession	Intervention		Control	
	N	%	N	%
Unemployment	6	27.3	14	63.6
Labour	16	72.7	3	13.6
Self Employed	7	31.8	4	18.2
Civil Servant	0	0.0	1	4.5
Amount	22	100.0	22	100.0

Table 5. Distribution of respondents based on family income

Profession	Intervention		Control	
	N	%	N	%
<Rp.1.000.000	8	36.4	7	31.8
Rp.1.000.000-2.500.000	9	40.9	10	45.5
Rp.2.500.000-5.000.000	3	13.6	1	4.5
>Rp.5.000.000	2	9.1	4	18.2
Amount	22	100.0	22	100.0

Table 6. The distribution of respondents is based on the total number of children and the number of children suffering from thalassemia at RSU Prasetya Bunda Tasikmalaya

	Intervention			Control		
	Media	Min	Max	Media	Min	Max
Number of Children	2.00	1	4	2.00	1	4
Number of Thalassemia Children	1.00	1	1	1.00	1	2

Table 7. Differences in average scores before and after giving family psychoeducation in the intervention group

	Paired Samples T Test				
	Mean	N	SD	SE	p-*Value*
Pretest	80.39	22	6.521	1.390	0.000
Postest	85.73	22	6.453	1.376	0.000

Table 8. Differences in average scores before and after providing education according to the procedures of RSU Prasetya Bunda Tasikmalaya in the control group

	Paired Samples T Test				
	Mean	N	SD	SE	p-Value
Pretest	80.91	22	7.603	1.621	0.427
Postest	80.73	22	7.548	1.609	0.427

Table 9. Differences in the average score after providing education between the

intervention group and the control group

	Independent Samples T Test			
	Mean	**SD**	**SE**	**p-Value**
Intervention	85.73	6.453	1.376	0.023
Control	80.73	7.548	1.609	0.023

DISCUSSION

Characteristics of Respondents

The results showed that the average age of parents caring for children with thalassemia at Prasetya Bunda General Hospital in the intervention group was 37.09 in the control group, the average age was 36.41. This age is included in early adulthood, namely the age of 26-45 years. One's mindset and strength would mature with age. According to Notoatmodjo's theory, as a person age, their level of knowledge also increases because of their life experiences[12].

The results showed that most of the respondents or parents of children with thalassemia were female, namely 16 people in the intervention group (72.7%) and 18 people in the control group (81.8%). Overall, 34 people (77.3%) were female. Meanwhile 10 people (22.7%) were male. In this study, most of the parents who accompanied their children to carry out blood transfusions at Prasetya Bunda General Hospital were mothers. This statement is in line with research by Marnis et.al. (2018) that in undergoing the process of treating thalassemia children are more often accompanied by their mothers[13]. Research (Widadi & Oktaviani, 2018) says that mothers will try and do anything for the sake of their child's recovery[14]. The mother's role is to provide emotional support, direct assistance, and appropriate and accurate information, while the father's is to provide direct and material assistance. According to (Thahir, 2014) coping used by women is also more constructive, which means looking for efforts to solve problems, while men are more likely to use destructive coping, which means prioritizing feelings[15].

The results showed that the education of the parents was mostly up to the high school stage, namely 8 people (36.4%) in the control group while in the intervention group, there was the same number, namely 7 people (31.8%) between the junior and senior high school stages. According to (Fijianto et al., 2021) higher education can affect emotional intelligence, so people who have a high level of education will adapt more quickly [16]. The results of research on the experiences of mothers caring for thalassemia children also state that when someone has extensive knowledge they are more aware of the importance of maintaining the health and welfare of the family[14]. So that it can support in improving the quality of life of children during the treatment process.

The results showed that most of the parent's employment status did not work either in the intervention group of 9 people (40.9%) or in the control group of 14 people (63.6%). This happens because most of those who accompany their children are mothers who work as housewives. Mothers who take their children for treatment have the opportunity to socialize and exchange information to increase knowledge with health workers and other parents who have the same problem [17].

The results showed that most of the income levels of families of children with thalassemia were equivalent to the Tasikmalaya UMR, namely around Rp. 1,000,000 – 2,500,000 both in the intervention group of 9 people (40.9%) and in the control group of 10 people (45.5%). Income is the cause of psychosocial problems in thalassemia families, even though BPJS covers the thalassemia treatment itself, the family also needs transportation costs and expenses for unexpected matters[18]. According to Bulan, one of the factors that can improve the quality of life for thalassemia children is the family's economic status. Because, the better the economic status of the family, the more attention the family pays to the health of the child, including sources of funds and treatment[19].

The results showed that most of the parents with thalassemia had two children altogether and one child who had thalassemia. This is because some parents are traumatized and ultimately reluctant to have more children[6].

Differences in average scores before and after providing education in the intervention and control groups.

Based on the results, the average score of the intervention group's coping strategies before giving family psychoeducation was 80.36 and after gived family psychoeducation was 85.73. The results of the analysis using the paired sample t-test in the intervention group obtained a p-value of 0.000 ($p < 0.05$), which means that there was a significant difference

between before and after giving family psychoeducation. As for the results of the study, the average score of the control group's coping strategies before providing education according to the procedures of Prasetya Bunda General Hospital was 80.91 and after providing education according to the procedures of Prasetya Bunda Hospital, it was 80.73. The difference in the average score of these results is -0.18. Results of analysis of paired samples t-test in the control group obtained a P-value of 0.427 (p> 0.05), meaning that there was no significant difference in the average score of coping strategies.

The difference in these results can be influenced by confounding variables that researchers cannot control. At the time of implementation, several respondents said that stress arose when the family had difficulty getting blood bags and ultimately did not focus on solving problems so that coping became ineffective. Economic problems are also a complaint for some families because caring for a thalassemia child requires money. The results of the study were also influenced by families who were unable to express the feelings they experienced. In addition, there is no psychoeducation program about treating children with thalassemia from the hospital which can be used as a source of information and support for parents so that the coping used by families can still change when faced with problems during the treatment process.

The problems respondents complain about are in accordance with Lazarus and Folkman's theory that materials, social support, social skills, and problem-solving skills can affect individual coping. Meanwhile, factors that can influence coping strategies are age, education, and experience.

Family psychoeducation is a form of providing health information to families to improve the family's ability to solve problems faced by the family [20]. Psychoeducation is an intervention that can improve or enhance positive responses from parents or families that are expected to maintain psychosocial and role function changes. Psychoeducation aims to rehabilitate families so that when faced with the same problems or other challenges the family will not experience disturbances[21].

In psychoeducation, there is a process of socialization and exchange of opinions that it contributes to the destigmatization of psychological disorders that are at risk of hindering treatment. Psychoeducation gives them the advantage of overcoming problems and preventing emotional disturbances with effective coping strategies [22].

Differences in average scores of coping strategies after providing education between the intervention group and the control group.

The results of the independent samples t-test statistic showed a p-value of 0.023 (p<0.05), which means that there was a significant difference in the average score before and after being given education between the intervention group and the control group. Based on the results of the study, the difference in the average score of coping strategies in the intervention group was 5.37 while in the control group, it was -0.18. This shows that the intervention group that was given family psychoeducation was more effective than the control group that was only given general education according to standard hospital procedures.

The results of this study are in line with Nurhasanah's research, (2017) that there is a significant difference after giving psychoeducation, namely a p-value of 0.001 [9]. Other research also shows that psychoeducation can improve self-care abilities in families caring for children with thalassemia with a p-value of 0.000 [7]. Psychoeducation also has the effect of increasing the ability of families to deal with anxiety in parents who have children with thalassemia [2]. In psychoeducational research, it has also been shown to influence the level of knowledge, attitudes, actions, and beliefs in preventing coronary heart disease in families who are at risk of experiencing coronary heart disease[23,24]. In the case of mental health, psychoeducation also influences the burden and support of families treating schizophrenia [22].

Research (Hendrawati, 2018) shows that there is an influence of family psychoeducation in increasing the socialization of schizophrenia [25]. Family psychoeducation can reduce the stigma that appears in the family so that if the stigma is reduced or even disappears, the family will easily train sufferers to socialize. For parents who have mental retardation, psychoeducation can increase the knowledge of children who have mental retardation with a p-value of 0.012.

Based on the results of data processing, it can be concluded that there is an influence of

family psychoeducation on parents' coping strategies in caring for children with thalassemia at RSU Prasetya Bunda Tasikmalaya

CONCLUSION

Based on the characteristics of the respondents, the average age was 36-37 years, and they were educated up to high school. Most of the respondents did not work because the majority of respondents were women. The family income of children with thalassemia ranged from Rp. 1,000,000 to 2,500,000. Additionally, the majority of respondents had two children, and one of them suffered from thalassemia.

There was a difference in the average score before and after providing family psychoeducation in the intervention group, with a p-value of 0.000. However, there was no difference in the average score before and after providing education according to Prasetya Bunda General Hospital procedures, with a p-value of 0.427. Furthermore, there was a difference in the average score between the intervention and control groups, with a P-value of 0.023. Therefore, it can be concluded that family psychoeducation influences parents' coping strategies in caring for children with thalassemia at RSU Prasetya Bunda Tasikmalaya.

As a result, it is recommended that parents develop and utilize effective coping strategies to ensure optimal care for their children who suffer from thalassemia. Parents are also encouraged to express their feelings to other family members, which can help reduce the burden of stress. Health services should consider making family psychoeducation an educational program or supportive therapy for families, enabling them to better navigate life as a thalassemia-affected family.

The study's findings indicate that the scores of family coping strategies were different between those who received psychoeducational interventions and those who received education according to standard hospital procedures. Thalassemia centre officers are urged to promote the importance of participating in POPTI as a platform for addressing issues faced by individuals with thalassemia. Future researchers are advised to conduct further studies on the psychosocial problems faced by families with thalassemia or other chronic illnesses, as well as the influence of confounding variables on the coping strategies employed by parents or families with children affected by thalassemia.

ACKNOWLEDGMENTS

The researchers would like to express their gratitude to the director of Prasetya Bunda Hospital for granting permission to conduct the research and to the parents of thalassemia children who willingly participated as respondents in this study.

CONFLICT OF INTERESTS

The authors have no conflict of interests to declare, financial or otherwise.

REFERENCE

1. Biro Komunikasi Dan Pelayanan Masyarakat Kementeria Kesehatan RI. Angka Pembawa Sifat Talasemia Tergolong Tinggi. Kementerian Kesehatan Republik Indonesia; 2019.
2. Rokom. Talasemia Penyakit Keturunan, Hindari Dengan Deteksi Dini. Sehat Negeriku; 2022.
3. Puspita R. 40 Persen Pengidap Thalasemia Di Indonesia Ada Di Jabar. Republika; 2021.
4. Rujito L. Talasemia: genetik dasar dan pengelolaan terkini. Purwokerto: Universitas Jenderal Soedirman. 2019.
5. Mariani D, Mulatsih S, Haryanti F. Life Experience of Adolescents with Thalassemia: A Qualitative Research with Phenomenological Approach. Indian Journal of Public Health Research & Development. 2020 Jan 1;11(1).
6. Sukri A. Thalasemia: mengenal, mendampingi & merawat. Bee Media Pustaka; 2016.
7. Ulfa AF, Hasyim M. Pengaruh Family Psikoedukasi terhadap Peningkatan Self Care dalam Merawat Anak Thalasemia. Jurnal Ners dan Kebidanan (Journal of Ners and Midwifery). 2018 Apr 1;5(1):053-7.
8. Hijriani H. Pengaruh Psychoeducational Parenting terhadap Kecemasan Orangtua yang Mempunyai Anak Penyandang Thalassemia Mayor. Jurnal Keperawatan Silampari. 2018 Dec 3;2(1):385-98.

9. Nurhasanah N. Pengaruh psikoedukasi terhadap koping orang tua dalam merawat anak dengan Thalasemia Di Kota Banda. Idea Nursing Journal. 2017;8(2):56-62.
10. Mesuri RP, Huriani E, Sumarsih G. Hubungan mekanisme koping dengan tingkat stres pada pasien fraktur. Ners Jurnal Keperawatan. 2014;10(1):66-74.
11. Apriska RAD. Hubungan Antara Tingkat Kesepian Dengan Mekanisme Koping Pada Lansia Di Unit Pelayanan Lanjur Usia "Wening Wardoyo" Ungaran. Skripsi. Univeristas Diponegoro; 2016.
12. Oktaria V, Kurniawati D. Hubungan Pengetahuan Talasemia Dengan Kepatuhan Keluarga Membawa Anak Menjalani Tranfusi Darah. Jurnal Ilmiah Kesehatan. 2020 Jul 10;9(2):94-7.
13. Marnis D, Indriati G, Nauli FA. Hubungan Tingkat Pengetahuan Ibu Dengan Kualitas Hidup Anak Thalasemia. Jurnal Keperawatan Sriwijaya. 2018;5(2):31-41.
14. Widadi SY, Oktaviani S. Pengalaman Ibu Merawat Anak Thalasemia di RSUD Dr. Slamet Garut. Jurnal Medika Cendikia. 2019 Dec 18;6(2):88-96.
15. Thahir A. Perbedaan Mekanisme Koping Antara Mahasiswa Laki-Laki dan Perempuan dalam Menghadapi Ujian Semester pada Fakultas Tarbiyah Iain Raden Intan Lampung. KONSELI: Jurnal Bimbingan dan Konseling (E-Journal). 2014;1(1):11-8.
16. Fijianto D, Rejeki H, Aryati DP. Hubungan Tingkat Pendidikan dengan Strategi Koping Warga Binaan Pemasyarakatan di Lapas Kelas II B Brebes. Jurnal Keperawatan Muhammadiyah. 2021 Mar 27;6(1).
17. Rachmaniah D. Pengaruh Psikoedukasi Terhadap Kecemasan Dan Koping Orang Tua Dalam Merawat Anak Dengan Thalasemia Mayor Di Rsu Kabupaten Tangerang Banten. Tesis. Universitas Indonesia; 2012.
18. Hastuti RP. Analisis faktor yang berhubungan dengan tingkat kecemasan orang tua anak thalasemia di RSUD Ahmad Yani Metro. Jurnal Kesehatan Metro Sai Wawai. 2016 Sep 14;8(2):49-54.
19. Yanitawati Y, Mardhiyah AI, Widianti E. Hubungan Perilaku Sakit Dalam Aspek Psikososial Dengan Kualitas Hidup Remaja Thalasemia. Jurnal Keperawatan BSI. 2017 Apr 15;5(1).
20. Kamalah AD, Ahsan A, Kristianto H. Efektivitas Psikoedukasi Keluarga dalam Menurunkan Beban Keluarga pada Keluarga Pasien Ulkus Diabetes Melitus. Jurnal Ilmu Keperawatan Jiwa. 2020 Feb 17;3(1):9-16.
21. Umami U. Psikoedukasi Untuk Pembentukan Sikap Positif Orang Tua Dalam Pemberian Pendidikan Seks Pada Anak Usia 10-11 Tahun. Skripsi. Univeristas Muhammadiyah Malang; 2017
22. Nurmalisyah F. Pengaruh Psikoedukasi Keluarga Terhadap Beban Dan Dukungan Keluarga Dalam Merawat Penderita Skizofrenia Di Rumah. Tesis. Universitas Airlangga; 2018.
23. Harniawan O. Thalasemia Di Kota Tasikmalaya Capai 280 Orang, Kebutuhan Darah Bulanan Tinggi. Times Indonesia; 2022.
24. Alfianto AG. Pengaruh Psikoedukasi Keluarga Terhadap Tingkat Pengetahuan, Sikap, Tindakandan Keyakinan Dalam Pencegahan Penyakitjantung Koroner Pada Keluarga Berisiko Di Desa Talokkecamatan Turen Kabupaten Malang. Tesis. Universitas Brawijaya; 2018.
25. Hendrawati GW. Pengaruh Family Psychoeduvation Berbasis Caring Terhadap Kemampuan Keluarga Dalam Meingkatkan Activity Daily Living Dan Sosialisasi Penderita Skizofrenia Di Wilayah Kerja Puskesmas Balong Ponorogo. Thesis. Universitas Airlangga; 2018.