

Article

The Relationship of Family Support with Compliance with Blood Transfusion in Thalassemia Children in the Children's Care Room, Pasteur Hospital, Bandung

Andri Nurmansyah¹, Roganda Situmorang¹, Fifi Siti Fauziah Yani²

¹ Faculty of Nursing, Bhakti Kencana University Bandung, Indonesia, 40614.

² Faculty of Health Sciences, Universitas Jenderal Achmad Yani Cimahi, Indonesia, 40614.

* Correspondence: andri.nurmansyah@bku.ac.id

Received: 20 January 2024; Accepted: 30 February 2024; Published: 30 March 2024.

Abstract: Background: Patient compliance in carrying out blood transfusions is important in the management of people with thalassemia. The family has a strong influence on determining treatment, the support provided is instrumental support, assessment support, informational support and emotional support. To determine the relationship between family support and blood transfusion compliance in children suffering from thalassemia major

Methods: This research is quantitative research that is correlational in nature. The sampling technique in this research used total sampling, where samples were taken from the entire available population, namely 55 people. This study used measuring instruments in the form of a family support questionnaire and an observation sheet by looking at the thalassemia patient's book in the room.

Results: Most or around 90.9% of children with thalassemia are guardians in the Children's Care Room at Pasteur Regional Hospital, Bandung, and receive good family support. Most or around 65.5% of children suffering from thalassemia major in the Children's Care Room at Pasteur Hospital Bandung are obedient to undergoing blood transfusions.

Conclusion: There is a relationship between family support and blood transfusion compliance in children with thalassemia in the Children's Care Room at Pasteur Hospital, Bandung, with a p-value of 0.043.

Keywords: Family support, Compliance, Thalassemia.

How to cite: Andri Nurmansyah, et al., (2024). The Relationship of Family Support with Compliance with Blood Transfusion in Thalassemia Children in the Children's Care Room, Pasteur Hospital, Bandung. IAR Jr Clnc Res. page no. 01-08-2024

1. Introduction

Thalassemia is an autosomal recessive genetic disorder that results in reduced production of hemoglobin which is an iron-rich protein found in red blood cells which functions to transport oxygen from the lungs to all parts of the body [1]. The prevalence of thalassemia in the world is around 20% of the population carrying thalassemia and 5.2% carrying a significant variety of hemoglobin disorders including β thalassemia and thalassemia [2]. Every year around 56,000 babies are born with thalassemia major [1]. According to the Thalassemia International Federation (TIF), around 68,000 children are born with thalassemia every year in the world. The most common thalassemia is beta thalassemia with 80 to 90 million people (1.5% of the global population) reported to be carriers of this thalassemia trait. It is also reported that around 23,000 children are born in the world with beta thalassemia every year [3]. The prevalence of beta thalassemia carriers in the Maldives is 18%, Free 14%, Sardinia 10.3% and Southeast Asia 3-5%. In Southeast Asia, the high number of thalassemia carriers causes quite serious public health problems because it is related to human survival [4].

The Indonesian Thalassemia Foundation (YTI) and the Indonesian Association of Parents of Thalassemia Sufferers (POPTI) conducted thalassemia screening in the community from 2009 to 2017 with the results

of screening 1,184 people as thalassemia carriers. Meanwhile, based on data from Cipto Mangunkusumo Hospital, as of October 2016, there were 9,131 thalassemia patients recorded throughout Indonesia [4]. According to Dr. Mohammad, Hoesin General Hospital (RSMH) registration data between June 2010 and April 2018 showed 287 patients suffering from thalassemia, and 145 (50.5%) of them were aged 7 to 18 years [1]. West Java Province has the highest number of thalassemia sufferers in Indonesia. There are as many as thalassemia sufferers in Indonesia 5,501 patients. 1,751 or around 35% came from West Java. There are around 300 people who care for thalassemia in the city of Bandung. Meanwhile for Greater Bandung around the 800s. Most patients seek treatment at the hospital. Hasan Sadikin and RSUD in their respective areas. This was reported by the Indonesian Thalassemia Foundation-Association of Parents of Thalassemia Sufferers [5].

Thalassemia causes children to experience mental retardation, physical deformities, growth retardation, and delayed puberty. The impact on physical appearance, namely bone deformities and short stature, and poor self-image. Apart from that, it can cause serious complications such as heart failure, cardiac arrhythmias, liver disease, endocrine complications and patients are easily infected [3]. One of the therapies given to thalassemia patients is blood transfusion. Blood transfusion is the mainstay treatment for sufferers of thalassemia major and intermedia. Chronic transfusion prevents most of the serious growth, skeletal, and neurologic complications in thalassemia major [4]. The results of this study also emphasize the importance of maintaining pre-transfusion Hb levels of at least 9-10.5 g/dL [6].

Artamia et al (2019) [7] wrote that 83.8% of the 63 respondents studied did not comply with blood transfusions. This non-compliance has an impact on the child's growth and development, oxygenation to the brain, resulting in a decrease in the child's cognitive abilities. One of the reasons why children do not comply with transfusions is because of financial conditions [6]. The results of research by Abolwafa et al (2019) [8] found that non-compliance with blood transfusions in thalassemia children was caused by low family support. Family support is the most influential thing because family support is a situation that can be beneficial for an individual that is obtained from other people who can be trusted so that a person will know that there are other people who pay attention, appreciate and love him. Family support Refers to the actions taken by others when providing assistance, and is understood to be of four types namely: emotional support; information support; and assessment support, and instrumental support [5].

Children with thalassemia experience physical, emotional, social and school dysfunction. Therefore, family support is very necessary for children suffering from thalassemia. The role of the family, especially parents, is very influential in undergoing continuous treatment and there is no certainty of recovery, especially for young children who need protection and love from their parents, so that children have confidence that their parents will not neglect them. about their illness. Family support, especially from parents of thalassemia sufferers, is the presence of the family as the support needed by parents of thalassemia sufferers, that there are resources that provide a sense of psychological comfort, make individuals loved, cared for, appreciated and have their true nature. its existence is recognized by group members.

The family has a strong influence in determining treatment, the support provided is instrumental support, assessment support, informational support and emotional support. Therefore, the support provided by families in the form of recommendations for regular blood transfusions has an impact on improving the welfare of parents who have children with thalassemia to take their children to health services [9]. Based on the results of research by Nazari et al (2022) [10] in Pakistan, 60% of parents are not aware of the basic things about thalassemia in children because these parents are illiterate, live in rural areas, and have a low level of knowledge.

Influences family support for their children Based on the research results of Rohimah & Puspasari (2020) [1] said that this was an encouragement or motivation so that the majority of parents were obedient in taking them to undergo blood transfusion treatment. This shows that the support provided by the family will reduce parental non-compliance in patients. Based on the results of preliminary research, thalassemia sufferers on average receive blood transfusions for 50 children every month at Pasteur Bandung Regional Hospital. Researchers' observations of thalassemia families in hospitals showed that the families accompanying the child for blood transfusions were mostly parents. Judging from compliance, families take their children for transfusions according to the predetermined schedule. Apart from that, there are also families who take their children for transfusions later than the specified time for various reasons.

The lack of family support provided is assessment support, where families should give praise and appreciation to thalassemia children who undergo blood transfusions. Apart from that, based on data in

October 2022, there were 10 children out of 50 who did not have blood transfusions according to schedule. Blood transfusion is in the form of red blood cells which have the function of increasing Hb (Hemoglobin) so that oxygenation in tissues can be optimally improved. Continuous and regular transfusions can help replace dead cells. This transfusion must be carried out throughout life for sufferers of thalassemia major and is carried out periodically and continuously over a period of every 4-5 weeks [1].

According to Rahayu et al (2016) [1] in patients who do not undergo regular transfusions, there is an increase in erythropoiesis more than normal and a decrease in hemoglobin levels which can cause symptoms such as dizziness, lethargy, fatigue caused by chronic anemia due to not having regular transfusions. Patient compliance with blood transfusions is important in the management of thalassemia sufferers. Factors that influence compliance include; socio-economic factors, side effects of treatment, health service facilities, and family support. In these four factors, family support cannot be ignored, because family support is one of the factors that has a significant contribution and acts as a reinforcement that influences patient compliance [4].

Based on the background above, the author is interested in conducting research on the relationship between family support and blood transfusion compliance in children with thalassemia.

Research Purposes To determine the relationship between family support and blood transfusion compliance in children suffering from thalassemia major

2. Research Methodology

This research is non-experimental research, namely quantitative research that is correlational in nature, including a systematic investigation of the relationship between variables where the research is carried out by developing the relationship between existing variables, namely the independent variable and the dependent variable [11].

This research was conducted to determine the relationship between family support and blood transfusion compliance in children with thalassemia major in the Children's Care Room at Pasteur Regional Hospital, Bandung. This research design uses a cross sectional method, where this research only uses one time to measure or observe data on the independent and dependent variables only once at a predetermined time. Not all subjects in this study had to be observed on the same day or time, but both the independent variable and the dependent variable were only assessed once [11]. In this study, the samples were 55 families suffering from thalassemia in the Children's Care Room at Pasteur Regional Hospital, Bandung in 2023.

Sampling in this study was non-probability sampling with a total sampling technique, namely the technique of determining samples from the total population. The instruments to determine family support used in this research consist of informational support (numbers 12, 13, 14, 15, 16), assessment or appreciation support (numbers 17, 18, 19, 20, 21, 22), instrumental support (number 7, 8, 9, 10, 11), and emotional support (numbers 1, 2, 3, 4, 5, 6). This questionnaire consists of 22 statements which are measured on a Likert scale (1-4) with good statement values: 4 = always, 3 = often, 2 = sometimes, and 1 = never, based on this scale the score given by the respondent can be achieved is a minimum of 22 to a maximum of 88. Meanwhile, the instrument used to measure blood transfusion compliance is an observation sheet in the form of a patient's schedule for carrying out blood transfusion therapy. The patient is said to be compliant if the patient has undergone a blood transfusion according to schedule in the last 3 months. Non-compliant if the patient has not had a blood transfusion according to schedule in the last 3 months one or more times. Bivariate analysis in this study used the chi square test.

All tables and figures must have caption.

3. Research Result

Table 1. Family Support for Children Suffering from Thalassemia Major in the Child Care Room at Pasteur Hospital Bandung

Family Support	N	%
Good Support	50	90,9
Support Is Not Good	5	9,1
Total	55	100,0

Based on Table 1 above, shows that the majority of respondents received family support Good 90,9

Table 2. Blood Transfusion Compliance in Children Suffering from Thalassemia Major in the Children's Treatment Room at Pasteur Hospital Bandung

Blood Transfusion Compliance	N	%
Obedient	36	65,5
Not Obedient	19	34,5
Total	55	100,0

Based on Table 2 above, shows the percentage of blood transfusions present in children with thalassemia major in the Children's Care Room at Pasteur Bandung Regional Hospital, showing that the majority of respondents are in the obedient category 65,5

Table 3. The relationship between family support and blood transfusion compliance in children with thalassemia major in the pediatric ward at Pasteur Hospital, Bandung

	Blood Transfusion Compliance				Total		p
Family Support	Obedient		Not Obedient				
	N	%	N	%	N	%	
Good Support	35	70,0	15	30,0	50	90,9	
							0,043
Support Is Not Good	1	20,0	4	80,0	5	9,1	
Total	36	65,5	19	34,5	55	100,0	

Based on table 3, the Fisher test results are obtained with a p-value of 0.043 or smaller than the alpha value $\alpha = 0.05$. So it can be concluded that there is a relationship between family support and blood transfusion compliance in children suffering from thalassemia major in the Children's Treatment Room at Pasteur Hospital Bandung.

4. Discussion

4.1. Description of family support for children suffering from thalassemia major in the Children's Care Room at Pasteur Hospital Bandung

The results of research on family support for children with thalassemia major showed that the majority of respondents, namely 50 people (90.9%) received family support in the good category. Meanwhile, 5 people (9.1%) received family support in the quite good category.

Family support is a form of service behavior provided by the family in the form of emotional, instrumental, informational and assessment support [4]. The research results showed that 90.9% of families

accompanying children undergoing blood transfusions provided good support to their children. The majority of support provided is in the form of assessment and instrumental support. Parents always accompany the child, provide the blood needed during a transfusion, provide encouragement, give praise, support the child in carrying out social activities with fellow thalassemia children and the family prays for the child's condition.

Based on the results of the analysis of respondents' answers to the family support questionnaire. The form of family support that is most often obtained by thalassemia major patients is assessment support, the mean or average score obtained is 22 with the highest score being 24 and the lowest score obtained by respondents, namely 6. This form of assessment support or appreciation includes: The family gives praise to the child when the child is enthusiastic about undergoing a blood transfusion. The family encouraged the child to continue undergoing blood transfusions continuously. The family provides understanding to the child when the child does not want to undergo a blood transfusion. Families support children in carrying out social activities with fellow children undergoing blood transfusions. Families invite children to share or share what they feel with other thalassemia children. The family prayed for the child's recovery.

The results of this research are in accordance with Marilyn's theory in research conducted by Rahayu et al (2016) [1] which states that there is a strong relationship between parents and the health status of their members where the role and support of parental appreciation are very important for every aspect of family members' health care. starting from strategies to the rehabilitation phase. As well as Amelia et al (2022) [3] which state that assessment support or appreciation is parents who act as a feedback guide, guide and mediate problem-solving, as a source and validator for family members, including providing support, appreciation, and attention.

Based on the analysis, it was found that the lowest family support obtained by thalassemia major patients was support in the form of instrumental. The average score obtained by respondents was 17.07 with the lowest score being 5 and the highest score being 20. This instrumental support was in the form of the family being ready to take the child to the hospital. for routine blood transfusions according to the schedule determined by health workers. The family accompanies the child during the blood transfusion process. Families pay BPJS contributions to cover blood transfusions given to children. The family agrees to spend funds for accommodation costs during the process of accompanying the child to/in the hospital while the transfusion is being carried out.

The family prepares the things the child will need when undergoing a blood transfusion. Low family support can be caused by family knowledge and awareness about the importance of blood transfusions for children with thalassemia major. In this condition, health workers, especially nurses, have a special role and function in accompanying families, namely as family advocates. Nurses must work together with family members in identifying goals and needs and planning interventions for problems found in caring for children with thalassemia. Providing health education and prevention is also a function of nurses that cannot be excluded from the interests of family advocates.

Based on the overall questionnaire analysis regarding information support, the average score obtained by respondents was 18. This shows that information support from families for thalassemia patients is not optimal. Meanwhile, for emotional support, an average score of 19 was obtained with the lowest score being 6 and the highest score being 24. Emotional support took the form of: The family understands if the child is bored of undergoing continuous transfusions. The family felt disappointed because the patient suffered from thalassemia and needed continuous blood transfusions. The family also feels the child's feelings when he has to undergo routine transfusions throughout his life.

The family invites the child to interact with the people around him while the child is receiving a blood transfusion. The family feels the child's discomfort due to the illness he is suffering from. The family cares about the child's feelings during the transfusion. This is also influenced by the educational level of the respondents, most of whom are at the middle level so they do not seek and understand information about thalassemia, as well as the level of employment of their parents, most of whom work as laborers. Which is an obstacle to communication between parents and children suffering from thalassemia.

This research is different from the results of previous research conducted by Rohimah & Puspasari (2020) [4] The results obtained from 25 thalassemia children were 17 (68.00%) who received good family support. The greatest support provided is emotional support and assessment. The child's parents always provide assistance in caring for the child, pay attention to and praise the child, parents always love and pay attention to the child's condition, and parents also understand that the child's illness is a disaster.

The research results show that parents of thalassemia children continue to provide information and emotional support to their children. Information support can be seen from parents who always talk about the benefits of transfusions, and transfusion schedules, some parents find out about blood transfusions and tell their children to undergo regular transfusions. The emotional support provided by the child's parents means that the parents are never disappointed because the child continues to undergo transfusions, always feels the child's feelings during the transfusion, and the family cares about the child's feelings during the transfusion.

4.2. Description of Blood Transfusion Compliance in Children Suffering from Thalassemia Major in the Children's Treatment Room at Pasteur Hospital Bandung

The percentage of fulfilled blood transfusions for children with thalassemia major in the Children's Care Room at Pasteur Hospital Bandung showed that the majority of respondents, namely 36 (65.5%) were in the compliant category, 19 respondents (34.5%) were in the non-compliant-category. obedient category. -appropriate category.

Transfusion compliance is achieving the blood transfusion schedule set by the doctor. The research results showed that there were 36 thalassemia sufferers who complied with blood transfusions. A child is said to be obedient if the patient has received a blood transfusion according to schedule in the last 3 months. On the other hand, it is said to be disobedient if the child does not receive a blood transfusion according to schedule in the last 3 months one or more times. The results of the study showed that thalassemia children missed their blood transfusion schedule because the parents forgot their child's blood transfusion schedule, the parents saw that the child was not too pale and the child's parents did not have time to take the child for a blood transfusion.

A blood transfusion is carried out after the laboratory results come out. If the laboratory results show that the Hb value is still within normal limits, then no blood transfusion will be carried out. In addition, the nurse calculates the child's need and ability to receive a transfusion. The impact of non-compliance in undergoing transfusions can reduce the child's hemoglobin levels and the accumulation of iron in the body. What is done to prevent iron buildup is that thalassemia children are given additional therapy, namely iron chelation. Thalassemia children are given additional therapy, namely iron chelation.

Based on the research results, it can be seen that the highest proportion of thalassemia sufferers was in the 3-12 year age group, 50 people (90%) and the lowest was in the >12 year age group, 5 people (10%).). The lowest age for thalassemia sufferers is 3 years. Basically, thalassemia can attack all ages. Clinical symptoms of thalassemia are generally visible at the age of 2 years, but thalassemia sufferers only come for treatment at the age of 6 years because they are getting paler so the sufferer requires treatment [12]. These results are in accordance with research by Mariam (2022) [13] at the Indonesian Red Cross Blood Transfusion Unit and dr. Kariadi Semarang stated that the highest proportion of thalassemia sufferers was in the 2-12 year age group, namely 34.5%. The results of this research are also in accordance with the results of research by Rohimah & Puspasari (2020) [4] the highest proportion of thalassemia sufferers was in the age group < 12 years at 57.6%.

Nurses have a special role and function in accompanying families, namely as family advocates. Nurses must work together with family members in identifying goals and needs and planning interventions for problems found in caring for children with thalassemia. Providing health education and prevention is also a function of nurses that cannot be excluded from their forgiving attitude as family advocates [1].

4.2.1. The relationship between family support and blood transfusion compliance in children with thalassemia major in the pediatric ward at Pasteur Hospital, Bandung

Based on the research results, it was found that 35 or 70% of children with thalassemia major who received good family support were also obedient in carrying out blood transfusions. Meanwhile, of the 5 or 9.1% of children with good family support, almost all of them, namely 4 or 80%, were not compliant with blood transfusions.

Based on the research results, it was found that 35 or 70% of children with thalassemia major who received good family support were also obedient in carrying out blood transfusions. Meanwhile, of the 5 or 9.1% of children who received good family support, almost all of them, namely 4 or 80%, were disobedient in undergoing blood transfusions. In the bivariate analysis, Fisher's test results were obtained with a p-value of 0.043 or smaller than the alpha value (= 0.05). So it can be concluded that there is a relationship between family

support and blood transfusion compliance in children suffering from thalassemia major in the Children's Treatment Room at Pasteur Hospital Bandung.

The findings in this study are in line with the results of previous research. According to (Amelia et al., 2022) [3]. Family support is very important to help patients socialize again, create supportive environmental conditions, respect the patient as a person and help solve problems. Family support will influence patient compliance in taking medication. This is reinforced by the theory put forward by Rock and Dooley in Rahayu et al (2016) [1], that the family plays a supportive role during the healing and recovery of family members so that they can achieve an optimal level of well-being.

According to Rahayu et al (2016) [1] family support is very necessary so that children can undergo transfusions at the right time. Blood transfusion is one therapy to increase the hemoglobin levels of thalassemia children. Thalassemia children who do not comply with transfusions have an impact on the child's growth and development and oxygenation to the brain, resulting in a decrease in the child's cognitive abilities. The results of this study are in line with the findings of Amelia et al (2022) [3] which shows that there is a significant relationship between family support and blood transfusion compliance in thalassemia children (p-value $0.007 < 0.01$). Family support has a moderate relationship between family support and blood transfusion compliance in thalassemia children ($r = 0.328$).

The results of this study are slightly different from the results of previous research by Amelia et al (2022) [3] stating that the support that children need does not only come from the nuclear family such as parents, but also from the support of the extended family who can provide emotional support to the parents of thalassemia children. in accompanying the child through the treatment process. The results of the research show that there is a relationship between family support and parental compliance in accompanying children with blood transfusions. Family support is very important for the compliance of parents of thalassemia children in blood transfusion therapy. Apart from being a supporter for the family's recovery, he also reports as a supervisor whose role will be to monitor and remind him continuously to regularly and at the right time take him to undergo a transfusion according to the dose determined by the officer.

5. Conclusion

Most or around 90.9% of children with thalassemia in the Children's Care Room at Pasteur Hospital Bandung receive good family support. Most or around 65.5% of children suffering from thalassemia major in the Children's Care Room at Pasteur Hospital Bandung are obedient to undergoing blood transfusions. There is a relationship between family support and blood transfusion compliance in children with thalassemia in the Children's Care Room at Pasteur Hospital Bandung with a p-value of 0.043.

Acknowledgments: Write your acknowledgment here.

Author Contributions: Write authors contribution statement or write "All authors contributed equally to the writing of this paper. All authors read and approved the final manuscript."

Conflicts of Interest: Write conflict of interests or write "The authors declare that they do not have any conflict of interests."

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