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Application Of Care Models To Thlassemia Children

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ABSTRACT

Thalassemia is a disease caused by a genetic syndrome where there is a synthetic decrease in one of the chains in hemoglobin (Hb A), which is often found in the world. Until now, thalassemia cannot be cured and some types of it require blood transfusions for life. One of the effects of thalassemia is changes in interacting with other people caused by physical conditions that are different from other children in general. Psychosocial problems cause complications for parents and children who suffer from thalassemia, and if the lack of support from parents has an impact on the quality of life of children with thalassemia. Therefore, children with thalassemia need special attention from families who care for them. One of the efforts that families can make in caring for children with thalassemia depends on the knowledge and abilities possessed by the family. Management of thalassemia disease is disease prevention to reduce the rate of addition of patients and improve quality of life by using preventive, promotive and curative management. The purpose of this study was to create a model for providing care to children with thalassemia

1. INTRODUCTION

Chronic disease is a condition that affects daily functioning for more than 3 months a year, leading to hospitalization for more than 1 month a year (Donna L.Wong et al., 2009). Chronic disease in children is a physical, psychological or cognitive illness that causes limitations and requires intensive care in a hospital or at home, which is expected to last at least several months (Potts, N.L. & Mandleco, 2007). The prevalence of children with chronic illnesses, for example, prolonged illness or disabilities that interfere with daily functioning, shows that around 42% of children under the age of 18 who have chronic illnesses do not receive proper care (Khikmah Ainun & Prijopranoto Sutrisno, 2022).

Thalassemia, which is a chronic disease, is an autosomal recessive inherited disease based on Mendelian laws from parents to children (Price & Wilson, 2006). Thalassemia is also a chronic disease with a high incidence in children. The results of the qualitative study show that the family has a very

big role in caring for children with chronic diseases. Caregivers or families who have children with chronic disease conditions, are faced with demands, challenges, emotional and cognitive problems, as well as changing roles in the family and society.

Thalassemia is a hereditary disease caused by the failure to form one of the four amino acid chains that make up hemoglobin, so that hemoglobin is not formed completely (Donna L.Wong et al., 2009). The body cannot form normal red blood cells, so red blood cells are easily damaged or short-lived, less than 120 days and anemia occurs (Potts, N.L. & Mandleco, 2007). Thalassemia disease until now can not be cured. WHO recommends treatment efforts that can be carried out by patients so that they can survive is by carrying out blood transfusions which can last a lifetime. Repeated blood transfusions if the hemoglobin level decreases below 6 gr/dl, besides that iron chelation therapy is also needed to remove excess iron in the body due to routine blood transfusions (Potts, N.L. & Mandleco, 2007).

The impact that occurs in a family that has a child with thalassemia, will have different situations and routines compared to a family in which there are no thalassemia sufferers. To treat individual thaller or thalassemia sufferers requires money, effort and also a lot of time. Family activities will be disrupted because they have to adjust to the routine needs of care and therapy, because caring for a thalassemia sufferer must be carried out routinely and continuously and requires a lot of time (Sukri A., 2016). Psychosocial and emotional families will be disrupted where the family will feel very anxious about and very over protective of family members who have thalassemia. The psychological condition of the family is disrupted due to worrying about the health status of sick family members. The above will cause frustration and stress in the family (Price & Wilson, 2006). The impact that occurs in thalassemia children also occurs in individual thaller and this problem is more severe in adolescents, namely when adolescents seek autonomy for themselves.

Another impact of the condition of children with thalassemia is the effect of treatment that can affect the child's appearance such as bone deformities and short stature, abnormalities in the shape of the facial bones, namely facies Cooley (slanted eyes, protrusion on the forehead, long distance between the eyes, hypertrophy of the maxilla, presence of dental malocclusion). Thus, it will affect body image which will have an impact on psychosocial problems and decrease quality of life (Fatkuriyah & Hidayati, 2022). These conditions are a separate problem for children with thalassemia and also for their families

2. METHODS

Data collection techniques in the research and development of this module use mixed research methods (mix-method). Namely conducting research on a combination of quantitative methods and qualitative methods. Mixed research methods are used because this research produces two types of data, namely quantitative data and qualitative data.

The mixed method used in this study is a concurrent mixed method, which are procedures in which the researcher brings together or combines qualitative data and quantitative data to obtain a comprehensive analysis of the research problem (Sugiyono, 2012). In this study, the first stage was to collect and analyze quantitative data through a simple descriptive approach. At the quantitative data collection stage, researchers will support parents who have children with thalassemia. The next step is to collect and analyze qualitative data using a phenomenological approach. Through this approach, natural researchers answer the formulation of the problem to be studied, namely exploring the factors that support parents with families who have thalassemia children.

The development of this model uses procedures or development steps, which are planned using three stages of research, the first stage identifies problems through qualitative research with

exploratory descriptive designs using semi-structured interviews, the second stage produces a thalassemia care model, and the third stage validates the model using pre-posttest quasi-experimental design.

The sample is part of the population selected in a certain way so that it can represent the population (Sugiyono, 2012). The population in this study were parents who had children with thalassemia major in Cirebon City. Sampling using proportional random sampling technique. Samples taken randomly from parents who have children with thalassemia major. The number of qualitative research samples used was 63 respondents and for quantitative research the researchers used 7 participants.

The time for the research was from January to December 2022 (preparation of proposals to dissemination of research results. The research was conducted in the thalassemia room at Ciremai Hospital and Gunung Jati Hospital, Cirebon City. The data analysis technique used in this study was descriptive analysis, namely by describing and interpreting the data from each aspect studied.The data from this research are in the form of quantitative data and qualitative data.The data that has been obtained is then analyzed to answer the formulation of the problem and research questions that have been made.The quantitative data obtained will then be presented in the form of data description.The data analysis technique of this study will use the help of the SPSS (Statistical Program for Social Science) 17.0 for windows program to find out the mean, median, mode, standard deviation, and range, for each aspect studied.

3. FINDINGS AND DISCUSSION

The results of the analysis of this study consist of quantitative data and qualitative data which will be described as follows;

Parent data description

The results of the first year's research focused more on how to gather information on thalassemia sufferers from both the parents' and children's aspects. This is intended to get a complete picture of Thalassemia sufferers so as to be able to develop nursing care for Thalassemia sufferers. The following parental education data is displayed in the table as follows:

Parents Age

Table 1 Distribution of Respondents Based on Parental Age

Variable	Mean	SD	Min - Mak
Mother's age	43	8,83	26 – 64

From the table above it can be informed that the lowest maternal age is 26 years and the highest maternal age is 64 years, the average maternal age is 43 years with a standard deviation of 8.83 years.

Parent Education

Table 2 Distribution of Respondents Based on Parental Education

Mother's Education	Amount	
	n	%
No school	1	1.6
SD	20	31.7
JUNIOR HIGH SCHOOL	11	17.5
SMA	19	30.2
PT	12	19

Amount	63	100

The results of the research in table 2 above can be obtained information that most of the respondents had elementary school education, namely 20 people (31.7%).

Parents' job

Table 3 Distribution of Respondents Based on Parents' Occupation

Mother's job	Amount	
	N	%
Work	37	58.7
Doesn't work	26	41.3
Amount	63	100

From table 3 above, information can be obtained that the majority of respondents are already working, namely as many as 37 people (58.7%).

Description of Children with Thalassemia

After analyzing the descriptions of parents whose children have Thalassemia sufferers, the sex descriptions of Thalassemia sufferers are as follows:

Gender of children with thalassemia

Table 4 Distribution of Respondents by Gender of Children

Gender of Child	Amount	
	N	%
Man	26	41.3
Woman	37	58.7
Amount	63	100

From table 4 above, it can be obtained information that the majority of the respondents' children were female, namely 37 people (58.7%).

Age of children with thalassemia when studied

Table 5. Distribution of Respondents by Age

Variable	Mean	SD	Min - Mak
Age of Child	14,38	7,48	3 – 42

From table 5 above it can be informed that the lowest child's age is 3 years and the highest child's age is 42 years, the average child's age is 14.38 years with a standard deviation of 7.48 years

Order of children in the family

Table 6 Data for the 3rd Child

Is this your child					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1	24	38.1	38.1	38.1
	2	21	33.3	33.3	71.4
	3	13	20.6	20.6	92.1
	4	2	3.2	3.2	95.2
	5	2	3.2	3.2	98.4
	6	1	1.6	1.6	100.0
	Total	63	100.0	100.0	

Based on these data, the highest number of sufferers occurred in the first child, namely 24 people or 38.1%, while the lowest was the 6th child with 1.6%.

Educational data taken while the child has thalassemia is as follows:

Table 7 Distribution of Thalassemia Children's Education

Education_Children					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No School	6	9.5	9.5	9.5
	Kindergarten/PAUD and equivalent	17	27.0	27.0	36.5
	SD and Equivalent	13	20.6	20.6	57.1
	Middle School and equivalent	13	20.6	20.6	77.8
	High School and Equivalent	11	17.5	17.5	95.2
	D3/S1/S2/S3	3	4.8	4.8	100.0
	Total	63	100.0	100.0	

Based on these data, the highest number of thalassemia children with final education in kindergarten/PAUD is 17 people or 27% of the total and the lowest is 4.8% who have attended college.

Time of onset or early detection of thalassemia

Table 8. Distribution based on time of detection of thalassemia children

Variable	Mean	SD	Min - Mak
Initial Diagnosis	48,73	72,16	3 – 504

From table 8 above, it can be informed that the lowest age of a child when he was first diagnosed with thalassemia was 3 months and the highest age when he was first diagnosed with thalassemia was 504 months (42 years), the average age of a child when he was first diagnosed with thalassemia was 48.7 months (4 years) with a standard deviation of 72.16 months (6 years).

At the start of the child, a blood transfusion was performed

Table 9 Distribution of children's onset of blood transfusion

Variable	Mean	SD	Min - Mak
Transfusion onset	51,39	73,16	3 – 504

From table 9 above it can be informed that the lowest age of the child for the first transfusion was 3 months and the highest age of the child for the transfusion was 504 months (42 years), the average age of the child for the first transfusion was 51.39 months (4 years 3 months) with standard deviation of 72.16 months (6 years).

Number of children with thalassemia in one family

Table 10 Distribution of the number of children in families suffering from thalassemia

Number of children in a family with thalassemia					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1	55	87.3	87.3	87.3
	2	8	12.7	12.7	100.0
	Total	63	100.0	100.0	

Based on these data that the number of children suffering from thalassemia in the family is 87.3%, only 1 person is affected who suffers from thalassemia, while 12.7% there are families who have 2 children affected by thalassemia.

Description of Family Support

Family support score

Table 11 Distribution of Respondents Based on Family Support (Score)

Variable	Mean	SD	Min - Mak
Informational Support	19,06	2,51	14 – 25
Emotional Support	29,78	3,18	21 – 35
Awards Support	16,89	3,25	13 – 25
Instrumental Support	20,73	1,66	15 – 25
Social Support	15,52	1,82	11 - 20
Family support	101,98	6,12	85 – 115

From table 11 above it can be informed that the lowest Informational Support Score is 14 and the highest Informational Support Score is 25, the average Informational Support Score is 19.06 with a standard deviation of 2.51. The lowest Emotional Support Score is 21 and the highest Emotional Support Score is 35, the average Emotional Support Score is 29.78 with a standard deviation of 3.18. The lowest Award Support Score is 13 and the highest Award Support Score is 25, the average Award Support Score is 16.89 with a standard deviation of 3.25. The lowest Instrumental Support Score is 15

and the highest Instrumental Support Score is 25, the average Instrumental Support Score is 20.73 with a standard deviation of 1.66. The lowest Social Support Score is 11 and the highest Social Support Score is 20, the average Social Support Score is 15.52 with a standard deviation of 1.82. The lowest Family Support Score is 85 and the highest Family Support Score is 115, the average Family Support Score is 101.98 with a standard deviation of 6.12.

Results Family support by category

Table 12 Distribution of Respondents Based on Family Support (category)

Variable	Amount	
	n	%
Informational Support		
Good	5	8
Enough	46	73
Less	12	19
Emotional Support		
Good	10	15,9
Enough	43	68,3
Less	10	15,9
Award Support		
Good	10	15,9
Enough	40	63,5
Less	13	20,6
Instrumental Support		
Good	5	7,9
Enough	47	74,6
Less	11	17,5
Social Support		
Good	6	9,5
Enough	50	79,4
Less	7	11,1
Family support		
Good	8	12,7
Enough	44	69,8
Less	11	17,5

From table 12 above, information can be obtained that the majority of respondents have sufficient informational support, namely 46 respondents (73%), sufficient emotional support, namely 43 respondents (68.3%), sufficient appreciation support, namely 40 respondents (63.5%), adequate instrumental support, namely 47 respondents (74.6%), sufficient social support, namely 50 respondents (79.4%) and sufficient family support, namely 44 respondents (69.8%).

Family Anxiety Caring for Children with Thalassemia

Table 13 Distribution of Respondents Based on Anxiety in Caring for Thalassemia Children

Variable	Mean	SD	Min - Mak
Emergencies Treating Thalassemia Children	110,35	8,53	93 – 129

From table 13 above it can be informed that the lowest Anxiety score for Caring for Thalassemia Children is 93 and the highest Anxiety score for Caring for Thalassemia Children is 129, the average score for Anxiety Caring for Thalassemia Children is 110.35 with a standard deviation of 8.53.

Hypothesis Test Results

The hypothesis test that was carried out was whether the support provided was able to reduce the anxiety that occurred. This support is important so that parents do not feel anxious about their children. Based on the data obtained is ordinal data, the Friedman correlation test is carried out. The result is as follows:

Table 14 Correlation Test

Correlations				
			Support	Emergency
Spearman's rho	Support	Correlation Coefficient	1.000	.284*
		Say. (2-tailed)	.	.024
		N	63	63
	Emergency	Correlation Coefficient	.284*	1.000
		Say. (2-tailed)	.024	.
		N	63	63
*. Correlation is significant at the 0.05 level (2-tailed).				

Based on these data, the support provided has an influence on parents' anxiety in caring for children who have a history of thalassemia. This support is important so that children can be enthusiastic about living their lives and can mingle with children their age.

Qualitative Data Analysis

Qualitative data analysis was carried out in order to provide an overview of parents' responses to children suffering from thalassemia. The analysis was carried out on aspects of interviews that had been carried out by researchers who had previously been prepared using semi-structured interviews. The results of the qualitative analysis will get an overview of the Care Model which will be developed in further research. The results of the qualitative data analysis focused on the following aspects:

Table 15 Qualitative results

Question	Office	The view
The first response when a child is exposed to Thalassemia	Sad, confused, confused, but still have to be enthusiastic	There has not been good education for parents and there is no knowledge about caring for children with Thalassemia
Obtain information provided about the condition of the child experiencing thalassemia	Double-checking because you don't believe it, contacting relatives to solve the problem, looking for other alternative treatments in the hope of recovery	
How to provide information on the condition of the child to the	Keep it secret, tell the school teacher only	

people around him		
Expectations of parents with children's conditions	Completely recovered, pursued the highest possible education, waiting for a miracle	
How to take care of the child's condition	Letting children eat as much and as they like, given honey	
If the child does not want to do a transfusion and iron food	Given promises, invited to travel, moved hospitals	
Efforts to provide treatment other than medical	Giving chlorophyll, treatment to ustad, duck egg oil	

Based on the results of these interviews, there is no model of care for parents to assist children with thalassemia.

Based on these results, supporting factors are very important for families in dealing with children who have thalassemia. An important component of nursing care is understanding the family's perception of the situation and existing needs, concerns, and coping strategies (Halter, 2018). Based on the results of research on the support given by parents, namely instrumental support in the form of full fulfillment of physiological needs for children, informational support in the form of giving includes seeking information about children's problems, and then emotional support in the form of increasing children's self-confidence when carrying out social interactions. The role and support of parents for children with thalassemia is to provide the basis for internal support, namely the family and externally obtained from peers, nurses, doctors and people around them.

There needs to be education for parents so they are able to understand the position of the child in conditions with thalassemia. Broadly speaking one of the forms of Thalassemia prevention is based*Health Technology Assessment Indonesi*a (2010) namely in the form of education about Thalassemia in families and communities, education in families about Thalassemia plays a very important role in prevention programs. The impact of Thalassemia disease on family psychosocial conditions can have negative consequences if not accompanied by good education. Therefore family education is the first step in the Thalassemia prevention program.

Education conducted by medical personnel is needed so that parents remain enthusiastic in living life with their children. This support is important so that the child remains enthusiastic about living a daily life full of joy

4. CONCLUSION

Based on these data, the support provided has an influence on parents' anxiety in caring for children who have a history of thalassemia. This support is important so that children can be enthusiastic about living their lives and can mingle with children their age. Based on the research results obtained, it can be recommended that there is a need for nursing care for parents, especially children suffering from Thalassemia Major, in this case the support of the family and the surrounding environment is important so that children can live and develop properly.

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