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Application of the Parenting Model in Children with Thalassemia

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Abstract

Thalassemia can be hereditary within a family. Individuals with Thalassaemia, an inherited condition, require specific medical attention and care. The primary objective of this study is to provide families with knowledge about how thalassemia plays a crucial role in the preventive program. By doing so, we want to address the potential negative implications of thalassemia on the mental well-being of families. This education initiative serves as the initial step in the thalassemia prevention program. The approach employed in this module's research and development involves using a mixed research method (mixed-method) for data collection. They are explicitly doing research using a blend of quantitative and qualitative methodologies. The mixed research method is employed due of its ability to generate both quantitative and qualitative data. The study's findings demonstrated that the assistance provided had an impact on the anxiety levels of parents who were responsible for the care of children with a history of thalassemia. According to the research findings, it is advisable to provide nursing care for parents, particularly for children with Thalassemia Major. In this situation, it is crucial to have support from the family and the surrounding environment to ensure the correct growth and development of these children.

Keywords: *Thalassaemia, Support, Education, Family, Well-Being.*

INTRODUCTION

Thalassemia major is a chronic condition that significantly impairs affected children's physical, emotional, social, and academic functioning, diminishing their overall quality of life. A chronic disease is a long-term medical condition that significantly hampers daily functioning for more than three months in a year, leading to hospitalization for more than one month within the same year (Donna et al., 2009). Chronic illness in children is a persistent physical, psychological, or cognitive disorder that imposes limitations and requires substantial medical care, either in a hospital or at home. This condition is expected to endure for at least several months (Potts et al., 2007). According to Khikmah et al. (2022), almost 42% of children below the age of 18 with chronic diseases, which refer to ongoing illnesses or impairments that affect their daily functioning, do not receive sufficient treatment.

Thalassemia, classified as a chronic condition, is an autosomal recessive disorder that is inherited from parents to offspring according to Mendel's law (Price & Wilson, 2006). Thalassemia is a prevalent chronic condition in youngsters. A qualitative study suggests that the family has a substantial impact on the care of children with chronic diseases. Those tasked with caring for children with chronic illnesses face a range of challenges, including physical and mental demands, emotional and cognitive impairments, and changes in their roles within the family and community.

Thalassemia predominantly impacts infants of Mediterranean descent, including persons from Italy and Greece, as well as those from the Arabian peninsula, Iran, Africa, Southeast Asia, and southern China. Thalassemia major, also referred to as Cooley's anemia, is a condition marked by a life-threatening kind of severe anemia that requires frequent blood transfusions and ongoing medical attention. Cardiovascular deaths commonly occur in individuals between the ages of 20 and 30 years

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(Potts & Mandleco, 2007). Thalassemia is an inherited disorder resulting from the inability to produce one of the four amino acid chains necessary for the formation of hemoglobin, leading to incomplete hemoglobin formation (Donna et al., 2009). The body cannot produce red blood cells of normal quality, resulting in red blood cells that are easily destroyed or have a shorter lifespan of fewer than 120 days. This leads to anemia (Potts et al., 2007).

The disease of thalassemia remains incurable to this day. According to the World Health Organization (WHO), patients who want to increase their chances of survival may consider receiving lifelong blood transfusions as part of their treatment. Regular blood transfusions are necessary when hemoglobin levels fall below 6 g/dl. Iron chelation therapy is also required to eliminate excess iron in the body resulting from frequent blood transfusions (Potts et al., 2007).

The presence of a child with thalassemia in a family significantly alters their circumstances and daily routine, distinguishing them from families without any individuals affected by thalassemia. Providing treatment for individuals with thalassemia necessitates financial resources, effort, and a significant amount of time. Family activities will be disrupted as they must accommodate the demands of treatment and therapy routines, as the care of a thalassemia patient necessitates regular and uninterrupted attention, which consumes a significant amount of time.

The family's psychosocial and emotional well-being will be disrupted, leading to heightened anxiety and excessive protectiveness towards family members affected by thalassemia. The family's psychological state is disrupted due to concerns about the health of sick family members. This will result in both irritation and stress within the family. The impact experienced by children with thalassemia is also observed in persons with thalassemia, and the severity of the issue is heightened throughout adolescence, a period when individuals strive for independence.

Children diagnosed with thalassemia may undergo physical alterations due to their medical intervention. These alterations may encompass skeletal malformations, reduced height, and distortions in the structure of their facial bones, referred to as facies cooley. Facies cooley is characterized by narrow eyes, a protrusion on the forehead, increased distance between the eyes, hypertrophy of the maxilla, and dental malocclusion. As a result, this will impact their impression of their physical appearance, resulting in psychological problems and a decrease in overall welfare (Fatkuriyah & Hidayati, 2022). These conditions present a difficulty for children with thalassemia and their family members.

In accordance with the Health Technology Assessment Indonesia (2010), the primary approach to avoiding thalassemia entails providing education to families and communities regarding the disease. More precisely, the education of families regarding thalassemia plays a pivotal role in prevention endeavors. Insufficient education regarding thalassemia illness can potentially have adverse impacts on the psychological well-being of the family. Therefore, family education functions as the primary stage of the thalassemia prevention program.

In the near term, education involves imparting information to a specific population. Furthermore, in the long run, education aims to enhance the comprehension and consciousness of families and the community regarding Thalassemia disease. This will be achieved by incorporating Thalassemia-related content into the secondary school education curriculum, spreading information through mass media and internet networks, distributing brochures and leaflets, and arranging events to observe World Thalassemia Day that involve all segments of society.

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METHOD

The data collection strategy employed in the research and development of this module utilizes a mixed research method, often known as a mixed method. Specifically, it engages in research that utilizes both quantitative and qualitative methodologies. The mixed research method is employed because it can generate both quantitative and qualitative data. The study employs the concurrent mixed method, a research approach that integrates qualitative and quantitative data to fully analyze the research problem (Sugiyono, 2012).

For this investigation, numerical data was gathered and examined using a straightforward descriptive method in the initial phase. During the phase of gathering quantitative data, the researcher will assist parents with children diagnosed with thalassemia. The subsequent phase involves collecting and examining qualitative data with a phenomenological methodology. In this approach, researchers in the field of nature investigate the phrasing of the problem at hand to explore the variables that assist parents and families with children who have thalassemia. The construction of this model follows a systematic process consisting of three distinct stages of research. In the initial stage, the problem is identified through qualitative research employing an exploratory, descriptive design utilizing semi-structured interviews. The subsequent stage involves the creation of a thalassemia care model. Finally, the model is validated in the third stage through a pre-posttest experimental quasi-design.

The study focuses on parents living in Cirebon City who have children diagnosed with thalassemia major. The sample was obtained by the method of proportionate random sampling. The sample was assigned to parents with children diagnosed with thalassemia major using a random selection process. The qualitative study sample consisted of 63 respondents, whereas the quantitative research included seven participants. The research term extends from January to December 2022, covering activities ranging from the drafting of the proposal to the dissemination of research conclusions. The research was conducted at the thalassemia ward located at Ciremai Hospital and Gunung Jati Hospital in the city of Cirebon. The data gathering instruments utilized in this study consist of interview sheets and questionnaires. These techniques are used to determine the characteristics of the respondents and identify the problems faced by the research participants.

The study uses a descriptive analysis methodology to describe and interpret data from each investigated component. The data collected in this study can be classified into quantitative and qualitative data. The obtained data is then analyzed to address the research problem and inquiries. The quantitative data collected will be described using the SPSS 17.0 for Windows program, calculating the mean, median, mode, standard deviation, and range for each aspect studied.

RESULTS AND DISCUSSION

This study's outcomes comprise quantitative and qualitative data, which will be delineated as follows: parent data refers to information or data higher in hierarchy or level than other data. It typically represents a broader category or a more extensive set of data. The initial year of research primarily focuses on investigating the methods of gathering information about individuals affected by Thalassemia, considering both the perspectives of parents and the affected children. This study aims to obtain a comprehensive understanding of individuals affected by Thalassemia to facilitate the development of specialized nursing care for this population. The table below presents the parental education data:

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Table 1 Distribution of Respondents Based on Age of Parents

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

Table 1 presents data regarding the age of the mother. The minimum recorded age is 26, and the maximum is 64. The mean maternal age is 43, with a standard deviation of 8.83 years.

Table 2 Distribution of Respondents Based on Parents' Education

Maternal Education	n	Sum	%
	N		%
Not in school	1		1.6
SD	20		31.7
JUNIOR	11		17.5
SMA	19		30.2
PT	12		19
Sum	63		100

The data shown in table 2 reveals that the primary level of education is held by the majority of respondents, particularly 20 individuals (31.7%).

Table 3 Distribution of Respondents Based on Parents' Occupation

Mother's Work	Sum	
	N	%
Work	37	58.7
Not Working	26	41.3
Sum	63	100

The data presented in Table 3 clearly show that the majority of the respondents, 37 persons (58.7%), possess prior work experience.

Upon examining the description of parents with children affected by Thalassaemia, the gender distribution of individuals with Thalassemia is as follows:

Gender of children with thalassemia

Table 4 Distribution of respondents by gender of children

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

Based on the information in table 4, it can be deduced that the more significant portion of the participants' offspring are female. More specifically, 37 individuals represent 58.7% of the total.

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Table 5. Distribution of Respondents Based on Child Age

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

Table 5 indicates that the children's minimum age is 3 years old, while their maximum age is 42. The mean age of the children is 14.38, with a standard deviation of 7.48.

Order of children in the family

Table 6 Data of Children

Child to	Frequency	Percent
1	24	38.1
2	21	33.3
3	13	20.6
4	2	3.2
5	2	3.2
6	1	1.6
Total	63	100.0

Based on the statistics, the initial kid experienced the highest impact, affecting 24 individuals, which accounts for 38.1%. In contrast, the impact on the sixth kid was minimal, with a mere 1.6%.

Table 7 Distribution of Thalassemia Children's Education

Education of Child	Frequency	Percent
No School	6	9.5
Kindergarten/Early Childhood Education and equivalent	17	27.0
Elementary and Equivalent	13	20.6
Junior High School and Equivalent	13	20.6
High School and Equivalent	11	17.5
D3/S1/S2/S3	3	4.8
Total	63	100.0

According to the data, the majority of children with thalassemia have completed their education at the kindergarten or early childhood education level. This accounts for 17 individuals, which is equivalent to 27% of the total. On the other hand, the smallest proportion, representing 4.8%, have attained a college education.

When thalassemia is detected

Table 8 Distribution Based on Time of Detection of Thalassemia Children

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

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According to the information presented in Table 8, the earliest age at which children are initially diagnosed with Thalassemia is three months. In comparison, the latest age is 504 months (which is comparable to 42 years). The mean age of diagnosis is 48.7 months, equivalent to 4 years, with a standard deviation of 72.16 months, equivalent to 6 years.

The child is introduced to a blood transfusion.

Table 9 Distribution of Children Undergoing Blood Transfusion

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

According to the information in Table 9, we can conclude that the youngest child who had the initial transfusion was three months old, while the oldest child was 504 months old, comparable to 42 years. The mean age of the children who received the first transfusion was 51.39 months, similar to 4 years and three months. The standard variation of their ages was 72.16 months, equivalent to 6 years.

Table 10 Distribution of the Number of Children in Families Suffering from Thalassemia

Sum	Frequency	Percent
1	55	87.3
2	8	12.7
Total	63	100.0

According to the statistics, 87.3% of the children in the family are affected by thalassemia. Thalassemia affects only one individual in each home; however, 12.7% of families have two children affected by thalassemia.

Family Support

Table 11 clearly shows that the Informational Support Score ranges from a minimum of 14 to a maximum of 25. The mean Score is 19.06, with a standard deviation of 2.51.

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
Award 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

The Emotional Support Scores vary from a minimum of 21 to a high of 35. The mean Emotional Support Score is 29.78, with a standard deviation 3.18. The minimum Award Support Score is 13, while the maximum Award Support Score is 25. The mean Award Support Score is 16.89, with a standard deviation 3.25. The lowest score for Instrumental Support is 15, while the maximum score is 25. The mean Instrumental Support Score is 20.73, with a standard deviation 1.66. The Social Support Scores vary from a minimum of 11 to a maximum of 20. The mean Social Support Score is 15.52, with a standard deviation 1.82. The minimum score for Family Support is 85, while the maximum score is 115. The mean Family Support Score is 101.98, with a standard deviation of 6.12.

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

Variable	Sum	
	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
Good Instrumental		
Support	5	7,9
Quite	47	74,6
Less	11	17,5
Good Social		
Support	6	9,5
Quite	50	79,4
Less	7	11,1
Good Family		
Support	8	12,7
Quite	44	69,8
Less	11	17,5

According to the data from Table 12, a significant majority of respondents, precisely 46 individuals (73%), reported having sufficient informational support. In the same vein, 68.3% of the respondents reported having adequate emotional support, 63.5% reported having sufficient appreciation support, 74.6% reported having adequate instrumental support, 79.4% reported having sufficient social support, and 69.8% reported having sufficient family support.

Family Anxiety Caring for a Child with Thalassemia

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

Variable	Mean	SD	Min – Mak
Anxiety of Caring for a Child with Thalassemia	110,35	8,53	93 – 129

According to the information provided in Table 13, the minimum score for Anxiety Caring for Children with Thalassemia is 93, while the maximum score is 129. The mean score is 110.35, with a standard deviation of 8.53. The hypothesis test investigates whether the provided support can reduce the occurrence of anxiety. This support is essential to reduce parental distress concerning their children. An ordinal data set was used to run a Friedman correlation test. The results are as indicated:

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Table 14 Correlation Test

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

According to this data, the assistance given has an impact on the anxiety experienced by parents when taking care of children with a history of thalassemia. This assistance is crucial to foster children's enthusiasm in embracing their lives and facilitating their integration with peers of the same age.

Analysis of qualitative data

A complete qualitative analysis was performed to thoroughly understand parents' responses to children affected by thalassemia. The study centered on the researcher's prearranged semi-structured interviews. The qualitative analysis will comprehensively examine the Parenting Model constructed in the forthcoming research. The analysis of the qualitative data focuses on the following aspects:

Table 15 Qualitative results

Question	Responses	View
First response when Children affected by Thalassemia	Sad, confused, chaotic, but still have to spirit	There is no good education for parents and no knowledge about parenting in Thalassemia children
Get information provided about the condition of the child with thalassemia	Re-checking because they don't believe it, contacting relatives to solve the problem, look for other alternative treatments in the hope of being cured	
How to provide information on the condition of children to people in Surrounding	Confidential, only inform the school teacher	
Parents' expectations with Children's Condition	Fully recovered, pursuing the highest education- high, waiting for a miracle	
How to maintain conditions child	Let the child eat as much as he wants and As you like, be given honey	
If the child is transfused and food Iron unwilling	Promised, invited to travel, moved to a hospital	
Efforts to provide Other treatments other than medical	Give chlorophyll, treat ustad, oil duck eggs	

According to the interview results, no established parenting style is available for parents who want to support children affected by Thalassaemia.

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DISCUSSION

Thalassemia is an inherited condition resulting from a genetic abnormality affecting red blood cells. The condition results in aberrant hemoglobin synthesis, leading to impaired oxygen transportation by red blood cells. Thalassemia is caused by an inherited genetic condition transmitted by both parents. This condition creates aberrant hemoglobin, leading to a lack of oxygen transportation by red blood cells throughout the body. Typical symptoms include of tiredness, lightheadedness, difficulty breathing, pale complexion, and an accelerated heart rate. Severe cases may result in stunted growth, skeletal issues, and recurring infections. People with thalassemia major require regular lifelong blood transfusions, but people with thalassemia intermedia require blood transfusions, but not on a routine basis. Thalassemia can be classified into different types. Thalassemia Major necessitates lifelong regular blood transfusions. Thalassaemia Intermedia: Blood transfusions are necessary but not done regularly. Thalassemia mild, also known as Carrier Trait, refers to individuals who are clinically healthy, show no symptoms, and do not need blood transfusions (Widyawati, 2022).

Treatment for thalassemia patients must undergo repeated blood transfusions to replenish the lack of blood cells. In patients with severe thalassemia, the doctor will recommend a bone marrow transplant procedure. Prevention: Thalassemia is not curable. However, it can be prevented by avoiding marriage between carriers of the trait or preventing pregnancy in couples who carry the trait thalassemia, which can be detected through early detection. Pre-marital genetic testing can help prevent the spread of this disease Increase in cases. There has been an increase in thalassemia cases in Indonesia, with data from the Indonesian Thalassemia Foundation showing that as many as 10,973 cases of thalassemia in Indonesia as of June 2021 (Widyawati, 2022). According to BPJS Kesehatan 2020 data, the burden of health financing for thalassemia reached 2.78 trillion, which occupies the 5th position among non-communicable diseases after heart disease, kidney failure, cancer, and stroke. Early detection is critical to identify carriers of thalassemia so that marriage between carriers of the trait does not occur. Blood tests and hemoglobin analysis can help detect this disease. Thalassemia is a disease that requires lifelong treatment and can lead to serious complications if not treated properly. Prevention and early detection are key in reducing the risk of developing this disease.

These results indicate that supporting variables are crucial in assisting families coping with children diagnosed with Thalassaemia. An essential aspect of nursing care involves comprehending the family's perception of the situation and their existing demands, attention, and coping techniques (Halter, 2018). The research findings indicate that parental support is crucial in meeting children's physiological needs, providing information about their problems, and boosting their confidence in social interactions. The role and support of parents in children with thalassemia is to provide internal and external support. Internally, parents offer the foundation of support within the family. Externally, support is acquired from peers, nurses, doctors, and individuals in their immediate environment.

Parents require education to comprehend the circumstances of children affected by thalassemia. A practical method of preventing thalassemia, as outlined in the Health Technology Assessment Indonesia (2010), involves educating families and communities about the disease. Specifically, educating families about thalassemia plays a crucial role in prevention efforts. Insufficient education might exacerbate the harmful repercussions of thalassemia sickness on family psychosocial situations. Thus, family education serves as the initial phase of the thalassemia preventive program. The activities encompass media briefings, webinars, and early detection initiatives targeted toward families.

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The Ministry of Health urges the government, commercial sector, and public to actively engage and provide assistance in preventing and managing thalassemia through:

1. Increase promotive and preventive efforts to prevent the birth of babies with Thalassemia Major by increasing information and education to the public and carrying out screening/early detection of Thalassemia for families with thalassemia.
2. Carry out early detection on prospective brides who do not have an early detection card.
3. Carry out health screenings for schoolchildren by integrating the School Health Business (UKS) program.
4. Encourage relevant ministries (Ministry of Religion and Ministry of Education and Culture) and other related cross-sectors to increase cooperation in overcoming health problems so that all existing policies favor health.

The way to prevent marriage between two carriers of thalassemia is to do genetic screening before marriage. This screening involves examining peripheral blood and analyzing hemoglobin to determine if a person is a carrier of thalassemia major, intermedia, or minor. Here are some steps that can be taken to prevent marriage between two carriers of thalassemia:

1. Genetic Screening: Before getting married, couples who want to get married should undergo genetic screening to find out if they are carriers of the thalassemia trait. This screening involves a peripheral blood test and hemoglobin analysis to determine their genetic status
2. Genetic Counseling: After the screening results, couples carriers of the trait thalassemia should receive genetic counseling to understand the risks associated with their marriage. This counseling helps couples understand the medical, family, and psychological consequences of this genetic disease
3. Birth Control: When a spouse who carries thalassemia is married, it is essential to inform them about the potential danger of having a child with thalassemia major. Couples should have the choice to either prevent pregnancy or assume the possibility of having a child with thalassemia major.
4. Prenatal Diagnosis: For couples who already have children, a prenatal diagnosis may be made to determine if the unborn baby has thalassemia. Methods used include chorion villus biopsy, PCR, and genetic or DNA analysis
5. Implementing these strategies might diminish the likelihood of a marriage between two individuals with thalassemia, thereby decreasing the probability of having a child with thalassemia major.

Medical personnel's education is urgently needed so that parents remain enthusiastic about living life with their children. This support is essential so that children remain enthusiastic about living a daily life full of joy.

CONCLUSIONS AND SUGGESTIONS

The study findings indicated that individuals with thalassemia commenced receiving blood transfusions at the age of 4 years and three months after being diagnosed at the age of three. Support for individuals with thalassemia encompasses various forms, including informational, emotional, financial, practical, social, and familial assistance. These statistics indicate that the support given has an impact on the anxiety experienced by parents when caring for children with a history of thalassemia. According to the research findings, it is advisable to provide nursing care for parents,

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particularly for children with Thalassemia Major. In this situation, it is crucial to have support from the family and the surrounding environment to ensure these children's correct growth and development.

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References

1) Anonymous. 2032. Thalassaemia: Causes, Symptoms and How to Treat. Siloam Medical Hospital Team. https://www.siloamhospitals.com/en/informasi-siloam/artikel/apa-itu-talasemia
2) Chavarina, K. K., Faradiba, D., Sari, E. N., Wang, Y., & Teerawattananon, Y. (2023). Health economic evaluations for Indonesia: a systematic review assessing evidence quality and adherence to the Indonesian Health Technology Assessment (HTA) Guideline. *The Lancet Regional Health-Southeast Asia*, *13*.
3) Fatkuriyah, L., & Hidayati, A. (2022). Factors Related To Quality Of Life Among Children With Thalassemia Major: A Literature Review. *Nurse and Health: Journal of Nursing*, *11*(1), 47-56.
4) Halter, M. J. (2018). Varcarolis' Foundations of Psychatric Mental Health Nursing: A clinical approach.
5) Ministry of Health. 2024. Information about Thalassaemia. https://p2ptm.kemkes.go.id/informasi-p2ptm/thalassemia
6) Khikmah, F. A., & Prijopranoto, H. S. (2022). Prevalence of thalassemia beta minor using the mentzer index in methamphetamine anemia patients at Sabu Raijua Hospital. *Journals of Ners Community*, *13*(2), 301-306.
7) Meva Nareja. 2022. Definition of Thalassaemia. https://www.alodokter.com/thalassemia
8) Potts, N. ., & Mandleco, B. . . (2007). *Pediatric Nursing: caring for children and their families* (2nd ed.).
9) Rejeki, D. S. S., Nurhayati, N., Supriyanto, S., & Kartikasari, E. (2012). Descriptive epidemiological study of thalassaemia. *Kesmas*, *7*(3), 139-144.
10) Healthy Homes for Jakarta. 2023. Getting to Know Thalassemia Disease and How to Reduce Its Risk. https://dinkes.jakarta.go.id/berita/read/mengenal-penyakit-talasemia-dan-cara-mengurangi-risikonya
11) Sugiyono. (2012). *Understanding Qualitative Research*. ALFABETA.
12) *Varcarolis' Foundations of Psychatric Mental Health Nursing: A Clinical Approach*, 1–1500.
13) Widyawati. 2022. Thalassaemia, a hereditary disease, avoid it with early detection. https://sehatnegeriku.kemkes.go.id/baca/rilis-media/20220510/5739792/talasemia-penyakit-keturunan-hindari-dengan-deteksi-dini/
14) Wong, D. L. (2009). Pediatric nursing textbook.