

## Family Support in Premarital Screening: Efforts to Prevent Thalassemia



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**ABSTRACT:** Thalassemia is an inherited disorder syndrome and is included in the hemoglobinopathy group, which is a disorder caused by impaired hemoglobin synthesis due to mutations in or near globin genes. Thalassemia disease has no cure, so early prevention is more important than treatment. The World Health Organization recommends two ways of prevention, namely pregnancy screening and population screening to look for carriers of thalassemia traits. This study aims to determine the relationship between family support and premarital screening decision-making in thalassemia adolescents at Banyumas Regional General Hospital. The method used is quantitative descriptive. This study is a correlation study with a cross-sectional design. The sample in this study was thalassemia adolescents with an age range of 12 to 21 years in the thalassemia room of Banyumas Regional General Hospital as many as 75 people. This study used a sampling technique, namely purposive sampling. The research instrument used family support questionnaires and decision-making. The data were analyzed using the Chi-Square test. Univariate test results found that most respondents had high family support as many as 52 people (69.3%), and most respondents decided to conduct premarital screening as many as 54 people (72.0%). The results of the bivariate test obtained a relationship between family support and premarital screening decision-making in thalassemia adolescents in the thalassemia room of Banyumas Regional General Hospital (p-value 0.047). Family support can also be an influential factor in determining an individual's beliefs and decisions. The higher the family support, the more supportive the thalassemia adolescent to make premarital screening decisions.

**KEYWORDS:** Family support, premarital screening, thalassemia

### I. INTRODUCTION

Thalassemia is an inherited disorder syndrome and is included in the hemoglobinopathy group, which is a disorder caused by hemoglobin synthesis disorders due to mutations in or near globin genes [1]. In Indonesia, the number of carriers of thalassemia  $\beta$  and thalassemia traits  $\alpha$  3-10% and 1.2-11% respectively. Based on these data and taking into account the current birth rate and population of Indonesia, it is estimated that 2500 thalassemia  $\beta$  major children will be born every year [2]. Based on data from the Indonesian Thalassemia Foundation (2018), the prevalence in Central Java province is 15.4% (1,308) of thalassemia sufferers. While research at the Banyumas branch of the Indonesian Thalassemia Foundation found 90.6% of patients were  $\beta$  thalassemia patients, 7.8% of thalassemia  $\beta$  minor patients, and 1.6% of thalassemia patients  $\beta$  intermedia [3]. Banyumas has been one of the thalassemia treatment centers in southern Central Java since 2009. The number of patients increased sharply from 60 people in 2010 to approximately 415 in 2017 or an increase of almost 600% [4].

Thalassemia disease has no cure, so early prevention is more important than treatment. WHO recommends two ways of prevention, namely pregnancy screening and population screening to look for carriers of thalassemia traits. That program is expected to be incorporated into the government's national program. The thalassemia prevention program consists of several strategies, namely (1) screening of Thalassemia trait carriers, (2) genetic counseling, and (3) prenatal diagnosis [5]. The process of making decisions or attitudes for adolescents to decide whether to do screening or not, it cannot be separated from the participation of family support, especially parents. Another study was also conducted by Sabila [6] who said there was a strong relationship between social support or family support and resilience. From the supporting research above, we can conclude that in preventive efforts to reduce the incidence of thalassemia, one way is to do screening. Screening can be done if the child is willing to make a decision, and the decision to do screening one of the factors that influence it is family support [7].

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Based on the results of a preliminary survey taken at the Banyumas Regional General Hospital, data on thalassemia patients in 2016 were obtained from as many as 387 people, 2017 as many as 415 people in 2018 as many as 469 people (313 of them were adolescents). In June 2019, 480 people with thalassemia were recorded. From the data above, it can be seen that every year thalassemia patients experience an increase and the majority of patients are adolescent patients. Based on the results of interviews conducted in the thalassemia room with thalassemia patients from 10 respondents, 7 people were not willing to do screening for fear and worry, and 3 other respondents were willing to do screening because they felt more comfortable and there was no fear of their baby, especially after marriage. Based on the above phenomenon, researchers are interested in conducting research in making efforts so that this action can be maximally applied, especially with this screening action. This document is a template. An electronic copy can be downloaded from the conference website. For questions on paper guidelines, please contact the conference publications committee as indicated on the conference website. Information about final paper submission is available from the conference website.

### METHOD

This study is a correlation study with a cross-sectional design. The study sample was 75 people. Test the analysis using Chi-Square.[8]

### RESULTS AND DISCUSSION

#### Frequency distribution of age, gender, education, and occupation of thalassemia adolescents at Banyumas Regional General Hospital

Characteristic	F	%
Age		
1. Early adolescence (12-14 years)	4	5,3
2. Medium teenagers (15-17 years old)	26	34,7
3. Late adolescence (18-21 years)	45	60,0
Sum	75	100
Gender		
1. male	30	40
2. Female	45	60
Sum	75	100
Education		
1. SD	7	9,3
2. JUNIOR	20	26,7
3. SMA	42	56,0
4. Higher Education	6	8,0
Sum	75	100.0
Work		
1. Private	13	17,3
2. Merchant	6	8,0
3. Farmer	4	5,3
4. Not working yet	38	50,7
5. Does not work	14	18,7
Sum	75	100.0

Source : Primary Data processed, 2019

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### Distribution of family support frequency of thalassemia adolescents at Banyumas Regional General Hospital

No	Family Support	F	%
1.	Low	23	30,7
2.	Tall	52	69,3
	Total	75	100,0

### Distribution of premarital screening decision-making frequency in thalassemia adolescents at Banyumas Regional General Hospital

No	Decision	F	%
1.	Screening	54	72,0
2.	Not screening	21	28,0
	Total	75	100,0

### The Relationship between Family Support and Premarital Screening Decision Making in Thalassemia Adolescents at Banyumas Regional General Hospital

No	Family Support	Decision				Total	
		Screening		Not screening		F	%
		F	%	F	%		
1	Low	1	56,	10	43,	23	10
.		3	5		5		0
2	Tall	4	78,	11	21,	52	10
.		1	8		2		0
	Total	5	72,	21	28,	40	10
		4	0		0		0
	X <sup>2</sup>	=	p-value				
	2.913	=	0.047				

The results of the study found that the characteristics of respondents based on age were mostly late adolescence (18 -21 years) with respondents 45 people (60.0%). In contrast to the research of Maghfiroh et al [9] which explained that most thalassemia sufferers at Dr. Hasan Sadikin Bandung Hospital were in their middle teens (16-18 years) (46.3%). Age greatly affects a person's ability to make decisions. The more mature a person is, the more mature his mindset and insight will be so that it will affect his decision-making ability [10].

The female sex characteristics of 45 respondents (45.0%) were greater than those of 30 male respondents (40.0%). In line with Maghfiroh et al who explained that most thalassemia sufferers at Dr. Hasan Sadikin Bandung Hospital were gender Women (58.5%). Women tend to have high levels of anxiety and worry [6]. Concerns about disease transmission to offspring, attention to personal health, and the desire to have children are the biggest things to consider in making decisions to conduct premarital screening[11]. Women tend to pay more attention to health and think about health developments in the future, both themselves, others and offspring[12].

Respondents with high school education are the largest number, namely as many as 42 respondents (56.0%), this is because the majority are aged 18-21 years, in line with the research of Paratika S and Ernawaty [13] which explains that there is a significant relationship between the level of education and decision making. The higher the level of education a person is, the more likely to do the flow of the decision-making process and do more consideration before choosing and deciding on a course of action.

Based on the work of respondents who have not worked 38 people (50.7%), this is because most respondents are still in school, namely high school. Most respondents' jobs were private as many as 13 people (17.3%). Napitupulu [14] explained that there is a relationship between respondents who do not work and respondents who work in the utilization of health services. The use of health services includes treatment, health checks, immunizations and health screening. There is a tendency for someone who works more actively to seek health services than those who do not work, because in addition to their higher knowledge also because they are more economically independent so they seek more complete services.

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The results showed that most respondents had high family support (69.3%). In line with research by Gharaati, Fatemeh Aghamolaei, all. [9] which explains that some respondents received family support (81.0%). Family support in question is internal support such as support from parents, husband / wife, in-laws, and support from biological family (Friedman, 2010). Family support according to Friedman [15], is an attitude of family acceptance towards family members in the form of informational support, assessment support, instrumental and emotional support. This is in accordance with the theory of Amiruddin [10] by Gilliss, Catherine L. explaining that the existence of the family as a support needed as a resource that provides a sense of psychological comfort, makes the individual loved, cared for, valued and the existence recognized by group members.

The results showed that most respondents made the decision to conduct premarital screening (72.0%). Premarital screening is a mandatory action to prevent the occurrence of couples and offspring with thalassemia[7]. Premarital screening is carried out on adolescents of productive age 12-21 years. Premarital screening measures aim to reduce the number of births of babies with thalassemia. Thalassemia is a type of disease that cannot be cured and is expensive but can be prevented. One of the things that can be done is to screen couples who will marry and it is the most effective way[16].

The results of the analysis test showed that there was a relationship between family support and premarital screening decision-making in thalassemia adolescents at the Banyumas Regional General Hospital (pV 0.047). In line with Viprakasit [17] research on the existence of a significant relationship between family support and decision making to screen for cervical cancer. Family support is defined as verbal or non-verbal information, advice, real assistance or behavior provided by people closest to the subject in his environment or in the form of presence and things that can provide emotional benefits and affect the behavior of the recipient [1]. Family support can also be an influential factor in determining individual beliefs and decisions[18]. Thanarattanakorn et al [19] explained in their research that family functions in children with thalassemia consist of 7 themes, namely problem-solving patterns, communication, role as parents, response to love, the role of love, behavioral control and the role of parents in decision making. This includes the decision to conduct premarital screening to identify thalassemia carriers. Premarital screening and pregnant women are the most effective ways to break thalassemia. By screening couples can find out the severe risks that will be faced after marriage and having children[16].

## CONCLUSION

Based on the results of research and discussion, the characteristics of thalassemia adolescents at RSUD Banyumas are mostly late adolescence, have a high school education, work as a private sector, and have not worked. Thalassemia will be passed on to children if one or both parents of the patient are a carriers of Thalassemia. Screening in thalassemia patients aims to reduce mortality and morbidity due to thalassemia. Screening is done mainly in couples who are at risk of having offspring with thalassemia syndrome.

## CONFLICTS OF INTEREST

The authors declare no conflict of interest

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