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Factors Related to Thalassemia Screening Awareness in Adolescents from Families with Thallasemia

Natiqotul Fatkhiyah[1*], Fatchurrozak Himawan[2], Apoina Kartini[3]
[1]Faculty of Health, Bhamada University, Slawi, Province Central Java, Indonesia
[2]Nursing Study Program, Ministry of Health Polytechnic, Tegal, Central Java, Indonesia
[3]Doktoral of Public health, Diponegoro University Semarang, Indonesia

***Corresponding author:** natiqotul.fatkhiyah@bhamada.ac.id

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ABSTRACT

Background: Thalassemia is a hereditary blood disorder with a high prevalence in Indonesia, especially in areas with a history of consanguineous marriages and high carrier rates. Screening awareness in adolescents plays an important role in preventing the birth of children with thalassemia major.
Objective: To analyze factors related to thalassemia screening awareness in adolescents from families with thalassemia.
Methods: This quantitative analytical study used a cross-sectional design. The sample was adolescents aged 15–24 years who had family members with thalassemia (n = 120). The instruments included questionnaires on characteristics, knowledge, attitudes, family support, and access to information. Analysis used chi-square and logistic regression.
Results: Factors significantly related to thalassemia screening awareness were knowledge level ($p<0.001$), attitude towards screening ($p=0.002$), family support ($p=0.001$), experience caring for thalassemia family members ($p=0.03$), and access to health information ($p=0.004$). The most dominant factor was family support (OR=3.9).
Conclusion: Thalassemia screening awareness in adolescents is influenced by various personal, social, and environmental factors. Intensive family-based education and adolescent health services are needed to increase awareness of early thalassemia screening.

INTRODUCTION

Thalassemia is an inherited hemoglobin disorder inherited in an autosomal recessive manner. Indonesia is among the countries with a high burden of thalassemia; an estimated 3–10% of the population are carriers. An effective measure to reduce the birth rate of thalassemia major is early screening of adolescents , especially those at high risk, namely those from families with thalassemia (Nandarathna 2022).

However, in reality, many adolescents are unaware of the importance of carrier screening. Screening awareness is influenced by many factors, including knowledge, family support, experience caring for a family member with thalassemia, access to health information, and perceptions of the benefits and barriers to screening (Saeed and Piracha 2016).

Thalassemia is a hereditary blood disorder that is a global health problem, especially in countries with high carrier rates such as South Asia, Southeast Asia, the Middle East, and the Mediterranean. The World Health Organization (WHO) estimates that approximately 5–7% of the world's population carries the hemoglobinopathy trait and more than 300,000 babies are born each year with severe hemoglobin disorders. Indonesia is among the countries with a steadily increasing burden of thalassemia; as of 2024, thalassemia major was recorded as the chronic disease with the highest BPJS (Social Security) costs , making it a public health issue that requires serious attention (P2PTM Kementerian Kesehatan Indonesia 2022).

One of the most effective strategies for reducing the birth rate of thalassemia major is carrier screening, particularly for adolescents and young adults before marriage. Research by Masserini et al. (2022) shows that countries that systematically implement premarital screening programs for adolescents and couples can reduce the birth rate of thalassemia major by up to 90% . However, in Indonesia, screening is still

voluntary and utilization rates are low, including among high-risk groups such as adolescents with family members with thalassemia (Fatkhiyah et al. 2025).

Adolescents from families with thalassemia have a higher risk of becoming carriers due to the autosomal recessive inheritance trait. Although they are a priority group for screening, local and international studies indicate low awareness. Research by Al-Shahrani (2021) showed that only 32–48% of adolescents with thalassemia families understood their genetic risk status. In Indonesia, research by Sari (2020) in a community of thalassemia families showed that only 40% of adolescents had received screening information, and less than 20% had undergone the test.

Screening awareness is the result of the interaction of various personal, family, social, and health system factors. A literature review reveals several important determinants:

Knowledge about thalassemia and genetic inheritance has been shown to increase screening willingness (Khalid et al., 2021; Rahman et al., 2019). Lack of information prevents adolescents from feeling vulnerable.

Attitudes towards screening, perceived benefits and barriers According to *the Health Belief Model*, perceived susceptibility*,* perceived severity *and* perceived benefits of screening are the main predictors of health action (Rosenstock, 1974; Janz & Becker, 1984).

Family support and experience caring for thalassemia patients. Several studies have shown that family involvement, especially in families with children with thalassemia major, significantly influences adolescents' willingness to be examined (Ismail et al., 2020).

Access to health information and services. Exposure to information through social media, schools, health workers, and patient communities has been shown to increase knowledge and awareness (Latief et al., 2022).

Based on these conditions, this study was conducted to analyze factors related to thalassemia screening awareness in adolescents from families with thalassemia , which can be the basis for educational interventions and national screening programs.

Thalassemia is an inherited autosomal recessive hemoglobin disorder and is a significant global health problem, particularly in the Mediterranean, Middle East, South Asia, and Southeast Asia, including Indonesia. (Wulandari, Setijowati, and Widyaningsih 2023)In beta thalassemia, there is a decrease or absence of beta globin chain synthesis, which causes chronic anemia, growth disorders, and severe organ complications (5). The World Health Organization (WHO) reports that thalassemia is the most common group of genetic diseases with millions of carriers worldwide.

In Indonesia, thalassemia is a catastrophic disease that causes high healthcare costs and increases annually. A 2023 report from the Indonesian Ministry of Health showed that the number of people with thalassemia major continues to increase due to the low level of early detection and carrier screening in the community (4). This situation is exacerbated by the low level of knowledge among adolescents about thalassemia, even though they are of productive age and ready to marry, which puts them at risk of having children with thalassemia major (Wu et al. 2024).

RESEARCH METHODS

Study Design

This study used a cross-sectional design in adolescents aged 15–24 years who had family members with thalassemia. Sampling was conducted in cities and districts in Tegal city, Central Java Province with a high prevalence of thalassemia.

Population and Sample

Population are all adolescents from families with a history of thalassemia. Sample: 150 respondents. Sampling technique: purposive sampling based on inclusion criteria.

Study Variables

This part consists of dependent and independent variables under study. Dependent variable is awareness screening thalasemia. Independent variable are knowledge, attitude, family support and access to health information.

Study Instruments

It explains the measurement tools (for example, questionnaires or scales) designed to obtain data on a topic of interest from study subjects.

Research Instruments

Knowledge questionnaire (15 items).

Attitude questionnaire towards screening (Likert).

Family support (emotional, informational, instrumental).

Access to health information (media, health services, education).

Screening awareness (including knowledge, perception of need, and interest in screening).
The instrument was tested for validity and reliability (Cronbach's α > 0.7).

Data analysis

Univariate analysis: frequency distribution.
Bivariate analysis: Chi-square test.
Multivariate analysis: logistic regression to determine the dominant factor.

Research Ethics

Research ethical issues including informed consent, anonymity, and confidentiality, were addressed carefully during the study process. The research ethical clearance approval letter was obtained from the Research Ethics Committee of Public Health Faculty of Diponegoro University (Approval No: 2023-20034-50, Date: 25 September 2023). A voluntary informed consent form was obtained from volunteers.

RESULTS

Univariate Analysis

Table 1. Respondent Characteristics (n=210)

Variables	n (%)
Ages 12–15 years	81 (38.6)
Age 16–18 years	89 (42.4)
Age 19–21 years	40 (19.0)
Woman	128 (60.9)
Man	82 (39.1)
Status of having cared for a family member	92 (43.8)

Table 2. Predisposing Variables

Variables	Good (%)	Not enough (%)
Knowledge	120 (57.1)	90 (42.9)
Attitude	124 (59.0)	86 (41.0)
Perception of vulnerability	96 (45.7)	114 (54.3)
Perception of severity	136 (64.8)	74 (35.2)

Table 3. Enabling & Reinforcing Variables

Variables	Tall (%)	Low (%)
Perception of benefits	148 (70.5)	62 (29.5)
Screening barriers	103 (49.1)	107 (50.9)
Access to information	118 (56.2)	92 (43.8)
Experience of caring	92 (43.8)	118 (56.2)
Family support	132 (62.9)	78 (37.1)

Table 4. Screening Awareness

Awareness	n (%)
Good	121 (57.6)
Low	89 (42.4)

Table 5. Bivariate Analysis (Chi-square)

Variables	PR	p-value	Information
Knowledge → Awareness	2.11	0.001	significant
Attitude → Awareness	1.78	0.003	significant
Perception of vulnerability	1.22	0.188	insignificant

Variables	PR	p-value	Information
Perception of severity	1.31	0.072	insignificant
Perception of benefits	1.44	0.041	significant
Obstacle	0.87	0.211	insignificant
Access to information	1.63	0.002	significant
Experience of caring	1.95	0.008	significant
Family support	2.89	<0.001	significant

Table 6. Multivariate Analysis (Logistic Regression)
Final Model

Variables	AOR	95% CI	p
Family support	3.62	2.01–6.51	<0.001
Knowledge	2.19	1.24–3.84	0.006
Attitude	1.71	1.02–2.89	0.041
Access to information	1.58	1.01–2.71	0.049
Experience of caring	1.74	1.12–3.02	0.033

Dominant factors: Family support (AOR=3.62)

DISCUSSION

The study results showed that knowledge is a crucial factor in fostering awareness of thalassemia screening. Adolescents with good knowledge are more likely to understand the risks of being a carrier and the benefits of screening.

Positive attitudes towards screening also increase awareness, in line with the Health Belief Model (HBM) theory which emphasizes perceptions of benefits and susceptibility as factors in health behavior.(Larasati and Menaldi 2020)

Family support is the most dominant factor because families of thalassemia sufferers have direct experience of the burden of the disease, thus encouraging adolescents to undertake primary prevention through screening.

In addition, access to health information through social media, school education, or health facilities has been shown to increase adolescents' chances of learning about screening services.(Jaffar et al. 2021)

The results of this study indicate that awareness of thalassemia screening among adolescents from families with thalassemia is influenced by several factors, including knowledge, attitudes, family support, access to information, and experience caring for family members. These findings align with various international and national studies on genetic screening behavior.

The Influence of Knowledge on Screening Awareness

Knowledge is significantly associated with adolescents' awareness of screening. This finding aligns with research by Khalid et al. (2021) in Pakistan and Saptarshi (2020) in India, which found that adolescents with good knowledge were twice as likely to be screened. Adequate knowledge enables adolescents to understand their genetic risks, the benefits of knowing their carrier status, and the consequences of having a partner who is a carrier (Elhadi et al. 2025).

In Indonesia, Sari's (2020) research also found that low knowledge regarding autosomal recessive inheritance was a major barrier to screening awareness. This confirms the importance of family-based education for improving genetic literacy among adolescents (Sundoro 2022).

Adolescent Attitudes towards Screening

Attitudes are significantly related to screening awareness. Adolescents with positive attitudes are more likely to understand the importance of knowing their carrier status before marriage. This finding is consistent with the Health Belief Model, which states that health behavior is influenced by perceived vulnerability, perceived benefits, perceived barriers, and cues *to action* (Boardman et al. 2020).

Saeed's (2021) research showed that a positive attitude toward thalassemia prevention tripled the likelihood of screening. This aligns with current research findings that adolescents with a high perceived risk are more likely to be screened.

Family Support as a Dominant Factor

Family support was the most dominant factor in this study (OR = 3.9). This finding aligns with research by Ismail et al. (2020), which found that adolescents with thalassemia in their families experienced strong parental influence, especially those who directly experienced the burden of the disease, such as regular blood transfusions and organ complications (Alkilani et al. 2025).

Families are significant *cues to action* for adolescents, especially when parents or siblings actively encourage screening. In families active in the thalassemia community, adolescent screening awareness rates even reach >70%. This demonstrates the need for family-based interventions within national screening programs.

Access to Health Information

Adolescents who have access to thalassemia-related information through schools, health facilities, social media, or patient communities have higher screening awareness. Research by Latief et al. (2022) and Mahmud (2020) shows that exposure to information through digital media significantly increases participation in genetic screening (On and Children 2020).

In the Indonesian context, the high use of social media among adolescents presents a significant opportunity to develop a digital-based thalassemia screening education campaign.

Experience Caring for Family Members with Thalassemia

This experience provides a direct perception of the burden of the disease, thereby increasing perceived vulnerability and perceived severity—two key constructs in the Health Belief Model. This finding aligns with Singh's (2021) research, which found that adolescents who had cared for a relative with thalassemia were three times more likely to seek screening.

Implications of Theory and Program

Research findings support the use of the Health Belief Model and PRECEDE-PROCEED as intervention frameworks to increase screening awareness.

Predisposing factors: knowledge and attitude.

Reinforcing factors: family support.

Enabling factors: access to information and services.

An effective adolescent screening program should include genetic education, family empowerment, and increased access to services (Jaffar et al. 2021).

CONCLUSION

Awareness of thalassemia screening in adolescents from families with thalassemia is influenced by:Teenage knowledge, Attitudes towards screening, Family support (most dominant), Access to health information and Experience caring for a family member with thalassemia. Family-based educational interventions, adolescent education modules, and strengthening adolescent screening services are urgently needed to improve thalassemia prevention in Indonesia.

SUGGESTION

For Health Services:
Providing integrated adolescent screening services at community health centers and schools.
Develop educational media that is easy for teenagers to understand.
For Family:
Increase support, including direct referrals and mentoring to screening services.
For Further Research
Developing a screening intervention model based on PRECEDE-PROCEED and HBM.
Conduct longitudinal research to look at changes in screening behavior.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to declare. The authors declare that the study was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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