

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

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ABSTRACT

Background: Thalassemia is an inherited hemoglobin disorder and an important public health concern in Indonesia. Adolescents from families affected by thalassemia may have an increased risk of carrying the thalassemia trait. Awareness of thalassemia screening is important for understanding carrier status and supporting informed reproductive health decisions. However, screening awareness may be associated with individual knowledge, attitudes, family support, caregiving experience, and access to health information.

Objective: This study aimed to analyze factors associated with thalassemia screening awareness among adolescents from families affected by thalassemia in Tegal, Central Java, Indonesia.

Methods: This quantitative analytical study used a cross-sectional design and purposive sampling. The manuscript reports 210 respondents in the results tables. Data were collected using questionnaires assessing knowledge of thalassemia, attitudes toward screening, perceived vulnerability, perceived severity, perceived benefits, screening barriers, family support, access to health information, caregiving experience, and screening awareness. Descriptive statistics, chi-square tests, and multivariable logistic regression were used to examine associations between the measured factors and screening awareness.

Results: Of the 210 respondents reported in the results tables, 121 (57.6%) had good screening awareness, while 89 (42.4%) had low screening awareness. Bivariate analysis showed significant associations between screening awareness and knowledge ($p = 0.001$), attitudes toward screening ($p = 0.003$), perceived benefits ($p = 0.041$), access to health information ($p = 0.002$), caregiving experience ($p = 0.008$), and family support ($p < 0.001$). In the multivariable logistic regression model, family support (adjusted odds ratio [AOR] = 3.62; 95% confidence interval [CI]: 2.01–6.51; $p < 0.001$), knowledge (AOR = 2.19; 95% CI: 1.24–3.84; $p = 0.006$), attitudes toward screening (AOR = 1.71; 95% CI: 1.02–2.89; $p = 0.041$), access to health information (AOR = 1.58; 95% CI: 1.01–2.71; $p = 0.049$), and caregiving experience (AOR = 1.74; 95% CI: 1.12–3.02; $p = 0.033$) were reported to be independently associated with screening awareness. Family support had the largest adjusted odds ratio among the variables included in the reported final model.

Conclusion: Thalassemia screening awareness among adolescents from families affected by thalassemia was associated with knowledge, attitudes toward screening, family support, access to health information, and caregiving experience. Family-inclusive education and accessible adolescent health information may be considered in the development of screening awareness initiatives. Further studies using verified datasets and more representative samples are needed to confirm these findings.

INTRODUCTION

Thalassemia is an inherited blood disorder characterized by reduced or absent production of one or more globin chains that make up hemoglobin. The condition can lead to anemia and, in more severe forms, may require long-term medical care and regular blood transfusions (Centers for Disease Control and Prevention [CDC], 2024; Mensah & Sheth, 2021). Thalassemia is an important public health concern because its clinical burden extends beyond individual patients to their families and health care systems. Although treatment and supportive care have improved, prevention through carrier identification, appropriate screening, and genetic counseling remains an important strategy for reducing the risk of severe thalassemia in future generations (Mensah & Sheth, 2021). Carrier screening can help identify individuals who carry thalassemia-associated genetic variants, including those who may have few or no symptoms. Therefore, awareness of thalassemia and the availability of screening services is an important component of public health education and prevention (CDC, 2024; Wahidiat et al., 2021).

The importance of thalassemia prevention is particularly relevant in Indonesia. A nationwide study of Indonesian youth found that knowledge and screening-related practices were not consistently adequate, despite generally favorable attitudes toward thalassemia prevention. In that study, 878 respondents were included in the analysis; 62.1% had poor knowledge, 83.3% had a positive attitude, and 54.4% had poor practices related to thalassemia (Wahidiat et al., 2021). The findings suggest that positive attitudes alone may not be sufficient to ensure that young people understand their carrier status or pursue screening. The study also reported that many respondents had never undergone thalassemia testing and that some misunderstood the distinction between being a carrier and having the disease (Wahidiat et al., 2021). These findings highlight the need for accessible and understandable information about thalassemia, genetic inheritance, and screening options. However, results from a nationwide youth sample do not necessarily describe the specific needs of adolescents who have family members affected by thalassemia, whose experiences and family circumstances may differ.

Adolescents from families affected by thalassemia are an important population for focused education and screening awareness. A family history of thalassemia can be relevant when health professionals assess whether an individual should receive further information or testing for a hemoglobin disorder (CDC, 2024; Mensah & Sheth, 2021). Nevertheless, having a family member with thalassemia does not automatically mean that an adolescent is a carrier; the level of genetic risk depends on the family relationship and the inheritance pattern. Accurate information is therefore essential to prevent both unnecessary anxiety and false reassurance. Adolescence also provides an opportunity to develop health knowledge and make informed decisions about personal health. Education delivered through families, schools, and health services may help adolescents understand the purpose of screening and the importance of discussing family health history with qualified health professionals. Research on Indonesian youth has emphasized that schools, parents, health professionals, and accessible information channels can all contribute to thalassemia education (Wahidiat et al., 2021).

Awareness of thalassemia screening may be associated with several individual, family, and health service factors. Knowledge is one potential factor because adolescents need to understand the disease, how it is inherited, the difference between carriers and affected individuals, and the purpose of screening before they can make informed decisions. Evidence from Indonesian youth indicates that gaps in knowledge remain an important concern, even among respondents who express favorable attitudes toward prevention (Wahidiat et al., 2021). Attitudes toward screening may also be relevant because an adolescent who views screening as useful and acceptable may be more willing to seek information or discuss testing with family members or health professionals. The Health Belief Model provides a useful theoretical perspective for examining these relationships. It proposes that health-related action may be influenced by perceived susceptibility, perceived severity, perceived benefits, perceived barriers, and cues to action (Rosenstock, 1974; Janz & Becker, 1984). In the context of thalassemia screening, these concepts may help explain why adolescents differ in their awareness of screening and their perceptions of its importance. However, these theoretical factors should be evaluated empirically rather than assumed to influence every adolescent in the same way.

Family support may be especially relevant for adolescents who live in families affected by thalassemia. Family members may help adolescents recognize the importance of screening, provide information about family history, encourage communication with health professionals, and assist them in accessing health services. Conversely, limited discussion of thalassemia within the family may leave adolescents uncertain about their own potential risk or the purpose of screening. Experience caring for a family member with thalassemia may also shape adolescents' understanding of the condition, although direct experience does not necessarily guarantee accurate knowledge or awareness of carrier screening. Access to health information is another potentially important factor. Information obtained through health professionals, schools, educational materials, and credible digital sources may help adolescents understand thalassemia and identify where screening services are available. The findings of Wahidiat et al. (2021) support the need to strengthen youth-focused education and consider the social and demographic factors associated with knowledge, attitudes, and practices. Together, these considerations indicate that screening awareness should be

examined in relation to knowledge, attitudes, family support, caregiving experience, and access to health information rather than being treated as a consequence of knowledge alone.

Although previous research has examined knowledge, attitudes, and practices related to thalassemia among Indonesian youth, further investigation is needed to understand factors associated specifically with screening awareness among adolescents from families affected by thalassemia. General youth studies provide valuable national context, but they do not fully establish how family support, caregiving experience, perceived benefits and barriers, and access to health information relate to awareness within this particular population. In addition, awareness of screening is distinct from actual screening uptake: an adolescent may know about screening without having undergone testing, while another may have undergone testing without demonstrating comprehensive knowledge of the procedure. This distinction is important when interpreting screening-related outcomes and designing appropriate educational interventions. A focused assessment of adolescents from families affected by thalassemia may therefore provide locally relevant evidence to guide family-centered education and adolescent health communication.

Accordingly, this study aimed to analyze factors associated with thalassemia screening awareness among adolescents from families affected by thalassemia in Tegal, Central Java, Indonesia. The study examined knowledge, attitudes toward screening, perceived vulnerability, perceived severity, perceived benefits, perceived barriers, access to health information, experience caring for a family member with thalassemia, and family support. By examining these factors together, the study sought to identify which characteristics were associated with screening awareness in the study population. The findings may help inform the development of educational approaches that involve families, improve access to reliable health information, and support informed discussions about thalassemia screening. Because the study used a cross-sectional design, the findings are interpreted as associations rather than evidence of causal relationships.

RESEARCH METHODS

Study Design

This study employed a quantitative analytical cross-sectional design to examine factors associated with thalassemia screening awareness among adolescents from families affected by thalassemia. This design enabled the researchers to assess screening awareness and its association with individual, family, and information-related factors within the study population. The study was conducted in Tegal, Central Java, Indonesia.

Population and Sample

The study population consisted of adolescents from families with a history of thalassemia. Participants were recruited using purposive sampling based on the study eligibility criteria. The original study protocol described eligible participants as adolescents aged 15–24 years who had family members with thalassemia. Participants were selected because their family history was relevant to the assessment of thalassemia screening awareness.

The original Methods section reported a sample of 150 respondents, whereas the Results section presented respondent characteristics and outcome distributions for 210 respondents. The final sample size should be established from the original research dataset to ensure consistency throughout the manuscript. The age eligibility criteria should likewise be reconciled with the age categories reported in the Results section before publication.

Study Variables

The dependent variable was thalassemia screening awareness. The independent variables included knowledge of thalassemia, attitudes toward screening, perceived vulnerability, perceived severity, perceived benefits, perceived barriers, access to health information, experience caring for a family member with thalassemia, and family support.

Knowledge referred to participants' understanding of thalassemia and screening. Attitudes represented participants' views toward screening. Perceived vulnerability and perceived severity reflected their perceptions of thalassemia-related susceptibility and seriousness. Perceived benefits and barriers represented their views of the potential advantages and obstacles associated with screening. Access to health information referred to exposure to information through media, education, and health services. Family support included emotional, informational, and instrumental support. Caregiving experience indicated whether participants had experience caring for a family member with thalassemia.

Screening awareness was described in the original manuscript as including knowledge, perceived need, and interest in screening. The scoring procedures and cutoff values used to classify awareness and the independent variables should follow the original questionnaire and analysis protocol.

Research Instruments

Data were collected using questionnaires covering respondent characteristics, knowledge, attitudes toward thalassemia screening, family support, access to health information, and screening awareness. The knowledge questionnaire consisted of 15 items. Attitudes toward screening were assessed using a Likert-type questionnaire. Family support was assessed through emotional, informational, and instrumental support, while access to health information covered information obtained through media, educational settings, and health services.

The screening awareness questionnaire addressed participants' knowledge, perceived need, and interest in screening. The original manuscript reported that instrument validity and reliability were assessed, with Cronbach's alpha greater than 0.70. Detailed information about the validity-testing procedures, the reliability coefficient for each instrument, the questionnaire sources, and the scoring criteria should be reported according to the original research documentation.

Data Collection

Data were collected from adolescents who met the study eligibility criteria using the research questionnaires. Participation was voluntary, and participant anonymity and confidentiality were considered throughout the research process. The exact data collection period, questionnaire administration procedures, and procedures for handling incomplete responses should be reported in accordance with the original study records.

Data Analysis

Data analysis consisted of univariate, bivariate, and multivariable analyses. Univariate analysis was used to describe respondent characteristics and the distribution of study variables using frequencies and percentages. Bivariate analysis was performed using the chi-square test to examine associations between the independent variables and thalassemia screening awareness.

Multivariable logistic regression was used to examine the associations between selected explanatory variables and screening awareness while accounting for the other variables included in the model. The results were reported as adjusted odds ratios (AORs), 95% confidence intervals (CIs), and p-values. According to the original Results section, family support had the largest adjusted odds ratio (AOR = 3.62; 95% CI: 2.01–6.51; $p < 0.001$).

The statistical software, significance threshold, variable-selection criteria, outcome coding, missing-data procedures, and model-fit assessment should be specified based on the original statistical analysis. Given the cross-sectional design, the results are interpreted as associations rather than causal relationships.

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

The univariate analysis described the respondents' demographic characteristics, predisposing factors, enabling and reinforcing factors, and thalassemia screening awareness. The original results tables reported a total of 210 respondents. However, this number needs to be verified against the final analytical dataset because the sample sizes reported in the Abstract and Methods sections differ from the number presented in the Results section.

Table 1. Respondent Characteristics (n = 210)

Variables	n (%)
Age group	
12–15 years	81 (38.6)
16–18 years	89 (42.4)
19–21 years	40 (19.0)
Sex	
Female	128 (60.9)
Male	82 (39.1)
Caregiving experience	
Reported having cared for a family member with thalassemia	92 (43.8)

Note: Values are reproduced from the original manuscript. The age categories should be checked against the eligibility criteria and original participant records. The caregiving variable is presented as reported in the original table; the frequency for the comparison category was not separately provided in that table.

As shown in Table 1, the largest age group comprised respondents aged 16–18 years (89; 42.4%), followed by those aged 12–15 years (81; 38.6%) and 19–21 years (40; 19.0%). Female respondents accounted for 128 (60.9%) of the reported sample, while male respondents accounted for 82 (39.1%). A total of 92 respondents (43.8%) were reported to have caregiving experience involving a family member with thalassemia. These demographic findings should be interpreted in conjunction with the final verified eligibility criteria and sample size.

Table 2. Distribution of Predisposing Variables (n = 210)

Variables	Adequate, n (%)	Inadequate, n (%)
Knowledge	120 (57.1)	90 (42.9)
Attitude	124 (59.0)	86 (41.0)
Perceived vulnerability	96 (45.7)	114 (54.3)
Perceived severity	136 (64.8)	74 (35.2)

Note: The labels “Adequate” and “Inadequate” are used to improve clarity. The original scoring criteria and cut-off points for each variable should be specified in the Methods section and checked against the study instruments.

Table 2 presents the distribution of the predisposing variables. Adequate knowledge was reported among 120 respondents (57.1%), while 90 (42.9%) were categorized as having inadequate knowledge. A favorable attitude category was reported for 124 respondents (59.0%), compared with 86 (41.0%) in the lower category. Regarding perceived vulnerability, 96 respondents (45.7%) were categorized in the higher or adequate category, whereas 114 (54.3%) were in the lower category. Perceived severity was categorized as adequate for 136 respondents (64.8%) and inadequate for 74 (35.2%). These results describe the distribution of the measured variables; the interpretation of each category depends on the operational definitions and scoring criteria used in the study.

Table 3. Distribution of Enabling and Reinforcing Variables (n = 210)

Variables	High/Adequate, n (%)	Low/Inadequate, n (%)
Perceived benefits	148 (70.5)	62 (29.5)
Screening barriers	103 (49.1)	107 (50.9)
Access to health information	118 (56.2)	92 (43.8)
Caregiving experience	92 (43.8)	118 (56.2)
Family support	132 (62.9)	78 (37.1)

Note: Category labels have been standardized for readability. For screening barriers, the interpretation of the categories should follow the original questionnaire and scoring direction. The caregiving-experience categories should be checked against the original coding to confirm that they represent the presence and absence of such experience.

As shown in Table 3, perceived benefits were categorized as high or adequate for 148 respondents (70.5%). Screening barriers were categorized in the first reported category for 103 respondents (49.1%) and the second category for 107 (50.9%). Access to health information was categorized as adequate for 118 respondents (56.2%), while 92 (43.8%) were in the lower category. A total of 92 respondents (43.8%) were classified in the first caregiving-experience category, while 118 (56.2%) were classified in the second. Family support was categorized as high or adequate for 132 respondents (62.9%), whereas 78 (37.1%) were categorized as low or inadequate. These descriptive results indicate that the distribution varied across the enabling and reinforcing variables.

Table 4. Distribution of Thalassemia Screening Awareness (n = 210)

Screening awareness	n (%)
Good	121 (57.6)
Low	89 (42.4)
Total	210 (100.0)

Note: The cut-off used to classify screening awareness as good or low should be stated in the Methods section. Table 4 shows that 121 respondents (57.6%) were classified as having good awareness of thalassemia screening, while 89 (42.4%) were classified as having low awareness. Thus, the good-awareness category accounted for a larger proportion of the sample than the low-awareness category. This outcome reflects the awareness measure used in the study and should not be interpreted as the proportion of respondents who had actually undergone thalassemia screening unless screening uptake was measured separately.

Bivariate Analysis

The bivariate analysis examined the reported associations between the independent variables and thalassemia screening awareness. The original manuscript presented prevalence ratios (PRs) and p-values in Table 5. The values below are retained from the original table; the PR estimates and statistical results must be checked against the final analysis output before publication.

Table 5. Bivariate Analysis of Factors Associated with Thalassemia Screening Awareness

Variables	PR (as reported)	p-value	Reported result
Knowledge	2.11	0.001	Significant
Attitude	1.78	0.003	Significant
Perceived vulnerability	1.22	0.188	Not significant
Perceived severity	1.31	0.072	Not significant
Perceived benefits	1.44	0.041	Significant
Screening barriers	0.87	0.211	Not significant
Access to health information	1.63	0.002	Significant
Caregiving experience	1.95	0.008	Significant
Family support	2.89	<0.001	Significant

Note: The significance level should be specified in the Methods section. The “PR” column is reproduced as reported in the original manuscript and requires verification against the statistical output. A chi-square test provides a test of association but does not, by itself, produce a PR estimate. The authors should confirm which model generated these estimates and report the effect measure appropriate to that model.

According to the original bivariate results, knowledge, attitude, perceived benefits, access to health information, caregiving experience, and family support were statistically associated with thalassemia screening awareness at the reported significance threshold. The strongest reported bivariate association was for family support (PR = 2.89; $p < 0.001$). In contrast, perceived vulnerability ($p = 0.188$), perceived severity ($p = 0.072$), and screening barriers ($p = 0.211$) were not statistically significant at the conventional 0.05 threshold. These findings describe the unadjusted analyses and do not establish independent associations after accounting for other variables.

Multivariable Analysis

Multivariable logistic regression was reported to assess which factors remained associated with thalassemia screening awareness after adjustment for other variables included in the final model. Table 6 retains the adjusted odds ratios (AORs), 95% confidence intervals, and p-values reported in the original manuscript.

Table 6. Multivariable Logistic Regression Analysis of Factors Associated with Thalassemia Screening Awareness

Variables	AOR	95% CI	p-value
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 health information	1.58	1.01–2.71	0.049
Caregiving experience	1.74	1.12–3.02	0.033

Abbreviations: AOR, adjusted odds ratio; CI, confidence interval.

Note: The estimates are reproduced from the original manuscript and must be verified against the final regression output. The final report should state the number of respondents included in the model, the reference categories and coding of each variable, the covariates entered into the model, and relevant model-fit or diagnostic information.

As presented in Table 6, family support had the largest adjusted odds ratio among the variables listed (AOR = 3.62; 95% CI: 2.01–6.51; $p < 0.001$). Knowledge was also associated with screening awareness (AOR = 2.19; 95% CI: 1.24–3.84; $p = 0.006$). Significant adjusted associations were additionally reported for attitude (AOR = 1.71; 95% CI: 1.02–2.89; $p = 0.041$), access to health information (AOR = 1.58; 95% CI: 1.01–2.71; $p = 0.049$), and caregiving experience (AOR = 1.74; 95% CI: 1.12–3.02; $p = 0.033$).

Family support had the largest point estimate in the reported final model. It may therefore be described as having the largest adjusted association among the variables presented, provided that the model and estimates are confirmed. The confidence interval indicates uncertainty around the estimated association, and the cross-sectional design does not establish causality. The findings should consequently be interpreted as associations with screening awareness rather than evidence that these factors caused awareness or increased actual screening uptake.

DISCUSSION

Overall Interpretation of the Main Findings

This study examined factors associated with thalassemia screening awareness among adolescents from families affected by thalassemia in Tegal, Central Java, Indonesia. The reported results indicated that 57.6% of respondents had good screening awareness, whereas 42.4% had low awareness. Although the proportion with good awareness was higher, the findings demonstrate that awareness was not uniformly adequate within the study population. This distinction is important because familiarity with thalassemia does not necessarily indicate a comprehensive understanding of carrier status, inheritance patterns, screening procedures, or the availability of appropriate health services. Research among Indonesian youth has similarly identified substantial gaps in thalassemia knowledge, despite generally favorable attitudes toward prevention (Wahidiyat et al., 2021).

The most notable finding was the adjusted association between family support and screening awareness, with an adjusted odds ratio (AOR) of 3.62 (95% confidence interval [CI]: 2.01–6.51; $p < 0.001$). Knowledge, attitudes toward screening, access to health information, and caregiving experience were also reported to be independently associated with awareness in the final regression model. These findings suggest that screening awareness should be considered in relation to individual understanding, family communication, personal experience, and the information environment rather than knowledge alone. This interpretation is consistent with broader approaches to health promotion that recognize the interaction between individual capabilities and social and environmental conditions (Green & Kreuter, 2005; Glanz & Bishop, 2010).

Nevertheless, the results require cautious interpretation. The study used a cross-sectional design, meaning that the exposure variables and screening awareness were assessed within the same general study period. Consequently, the findings cannot establish whether family support, knowledge, favorable attitudes, information access, or caregiving experience preceded the development of awareness. Furthermore, screening awareness was the measured outcome; the findings should not be interpreted as demonstrating that these factors increased actual screening uptake or reduced the incidence of thalassemia.

Knowledge and Awareness of Thalassemia Screening

Knowledge was significantly associated with screening awareness in both the bivariate analysis (reported PR = 2.11; $p = 0.001$) and the multivariable analysis (AOR = 2.19; 95% CI: 1.24–3.84; $p = 0.006$). The adjusted estimate indicates that respondents in the category coded as having better knowledge had approximately 2.19 times the odds of good screening awareness compared with respondents in the reference category, assuming the model coding and reported estimates are correct. This association supports the relevance of disease-specific knowledge when examining adolescents' understanding of screening.

A plausible explanation is that adolescents who understand thalassemia, its hereditary nature, and the distinction between carriers and affected individuals may be better able to recognize the purpose of screening. Knowledge may also help them formulate questions about family history and identify when consultation with a qualified health professional is appropriate. However, these mechanisms were not directly tested in the present study and should therefore be regarded as possible explanations rather than established pathways. The importance of distinguishing carriers from affected individuals is particularly relevant because people carrying thalassemia-associated variants may have few or no symptoms (Centers for Disease Control and Prevention [CDC], 2024; Mensah & Sheth, 2021).

The present findings are broadly consistent with the nationwide study by Wahidiyat et al. (2021), which found that 62.1% of Indonesian youth had poor thalassemia knowledge and that 95.7% of respondents had never undergone testing. That study also identified misunderstandings regarding carrier status. Similarly, Mirza et al. (2013) reported limited background knowledge of β -thalassemia among university students in Pakistan, although many respondents expressed interest in knowing their carrier status. These findings indicate that awareness of a screening concept and an accurate understanding of the condition are related but distinct dimensions.

Differences between the present findings and previous studies may reflect differences in participant characteristics, recruitment settings, questionnaire content, and the operational definitions of knowledge and awareness. The current study focused specifically on adolescents from families affected by thalassemia, whereas Wahidiyat et al. (2021) investigated a broader youth population. Family exposure may provide additional opportunities to encounter disease-related information, but it may also result in uneven knowledge depending on how openly family members discuss the condition and whether accurate information is available.

The adjusted association should not be interpreted as proof that increasing knowledge alone will necessarily improve screening awareness. Health literacy research among adolescents suggests that the relationship between knowledge and health-related outcomes depends partly on the ability to understand, evaluate, and apply health information (Fleary et al., 2018). Accordingly, educational materials may need to address not only factual knowledge but also the practical meaning of carrier testing, the interpretation of results, confidentiality, and access to professional counseling.

Attitudes Toward Screening

Attitudes toward screening were associated with awareness in the bivariate analysis (reported PR = 1.78; $p = 0.003$) and remained statistically significant in the adjusted model (AOR = 1.71; 95% CI: 1.02–2.89; $p = 0.041$). The confidence interval is relatively wide, and its lower bound is close to 1.00. Therefore, although the reported result meets the conventional 0.05 significance threshold, the precision of the estimated association is limited and the magnitude should not be overstated.

One possible explanation is that adolescents who regard screening as relevant or beneficial may be more attentive to information about thalassemia. Favorable attitudes may also encourage discussion with parents, relatives, teachers, or health professionals. However, because attitudes and awareness were measured in a cross-sectional study, their temporal relationship cannot be determined. Greater awareness may be associated with more favorable attitudes just as favorable attitudes may coexist with greater awareness.

This interpretation is compatible with the Health Belief Model (HBM), which proposes that health-related decisions may be associated with perceived susceptibility, perceived severity, perceived benefits, perceived barriers, and cues to action (Rosenstock, 1974; Janz & Becker, 1984). In this study, attitudes toward screening and perceived benefits may overlap conceptually with positive evaluations of screening. Nevertheless, the questionnaire's actual item content and scoring procedures must be examined before concluding that these variables fully represent specific HBM constructs.

Evidence from other settings also illustrates the distinction between attitudes and practical behavior. Mirza et al. (2013) found that providing written information was associated with more favorable responses to some premarital screening questions among university students in Pakistan. However, that study's intervention context and outcomes differ from those of the present cross-sectional study. Likewise, Durrani et al. (2023) identified gaps in knowledge of prenatal and premarital thalassemia screening among Pakistani university students. Together, these studies support the relevance of understandable screening information while also showing why attitudes, awareness, and actual testing should be measured separately.

The present results therefore suggest that attitudes are a relevant correlate of screening awareness, but they do not establish that changing attitudes will lead to testing. Future research could examine whether attitudes remain associated with awareness after using clearly differentiated measures of knowledge, perceived benefits, perceived barriers, and willingness to seek screening information.

Family Support as the Strongest Reported Adjusted Association

Family support had the largest adjusted odds ratio among the factors included in the reported final model (AOR = 3.62; 95% CI: 2.01–6.51; $p < 0.001$). This result indicates a comparatively strong adjusted association with screening awareness within the fitted model. The confidence interval excludes 1.00, supporting statistical evidence of an association under the assumptions of the analysis. Nevertheless, the interval extends from approximately twofold to more than sixfold odds, indicating meaningful uncertainty about the precise magnitude.

The adjusted estimate of 3.62 should be used consistently throughout the manuscript. The earlier discussion's estimate of OR = 3.9 should not be retained unless it can be verified as a separate crude estimate from the original statistical output. An unadjusted odds ratio and an adjusted odds ratio represent different analyses and should be explicitly identified if both are reported. The bivariate table currently gives a reported PR of 2.89, which is a different effect measure and should not be directly equated with the adjusted odds ratio.

Family support may be associated with awareness through several plausible mechanisms. Relatives may share information about the condition, explain aspects of family medical history, encourage adolescents to ask questions, and help them identify appropriate sources of health information. Families with direct experience of thalassemia may also have more opportunities to discuss its treatment and implications. These mechanisms are plausible, but the present study did not establish which specific dimensions of support were responsible for the observed association.

The finding is consistent with a social-contextual understanding of health behavior. House (1981) described social support in terms of emotional, informational, and instrumental dimensions, while Cohen and Wills (1985) discussed how support may help individuals manage demands and stress. In the context of hereditary conditions, family communication may also shape how individuals understand genetic information and evaluate the relevance of testing. However, these broader theories do not establish the mechanism operating in the present sample.

Family involvement in thalassemia-related knowledge has also been examined in studies involving affected families. The study of parents of children with β -thalassemia in Pakistan by Ansari et al. (2017) reported substantial awareness of screening and genetic counseling among families receiving care through thalassemia centers. Their population differed from the adolescents studied here, and their findings cannot be assumed to apply directly to adolescents in Tegal. Nevertheless, the study illustrates how repeated contact with health services and family experience may provide opportunities to acquire disease-related information.

Family support should not be understood as uniformly beneficial or as a substitute for adolescents' own understanding and informed participation. Family discussions may be incomplete, inaccurate, or shaped by concerns about stigma, marriage, confidentiality, and the implications of carrier status. In addition, a family history of thalassemia does not automatically establish that every adolescent is a carrier. Appropriate genetic information and professional counseling remain important to avoid unnecessary anxiety or false reassurance (CDC, 2024; Mensah & Sheth, 2021).

Accordingly, family support can be considered a priority for further investigation and for the development of carefully evaluated educational approaches. The current findings do not demonstrate that family-based education is more effective than school-based or individual education, nor do they establish that increasing family support would produce a particular change in screening behavior.

Access to Health Information

Access to health information was associated with screening awareness in the bivariate analysis (reported PR = 1.63; $p = 0.002$) and remained statistically significant in the adjusted model (AOR = 1.58; 95% CI: 1.01–2.71; $p = 0.049$). The estimated association was smaller than those reported for family support and knowledge, and the confidence interval approached the null value. The result therefore provides comparatively limited precision and should be interpreted cautiously.

Access to information may be relevant because adolescents need opportunities to encounter, understand, and evaluate information about thalassemia and screening. Potential sources include family members, schools, health professionals, printed educational materials, and digital platforms. However, access to information is not equivalent to information quality, comprehension, or the ability to use information in health-related decisions. The questionnaire's operational definition of access should therefore be considered when interpreting the result.

Wahidiyat et al. (2021) identified social media and educational settings among the sources through which Indonesian youth encountered thalassemia information. Their findings support the relevance of multiple information channels but do not establish that exposure to any particular channel is necessarily associated with more accurate knowledge or greater screening uptake. Fleary et al. (2018) similarly emphasized the relevance of adolescent health literacy while identifying variation in how health literacy and health-related outcomes are defined and measured.

The present study did not establish which information sources were most influential, whether respondents received consistent information, or whether the information was medically accurate. It would therefore be inappropriate to conclude that social media campaigns or digital education necessarily improve screening participation. Instead, the finding supports further assessment of accessible, age-appropriate, and clinically accurate information, together with evaluation of whether adolescents understand the material and know where to obtain appropriate advice.

Information access may also overlap with family support and knowledge. Adolescents with greater family support may have more opportunities to discuss health information, while adolescents with better baseline knowledge may actively seek additional information. Although multivariable analysis attempts to account for included variables, it cannot eliminate confounding by factors that were not measured or were measured inadequately.

Caregiving Experience and Screening Awareness

Caregiving experience was associated with awareness in the bivariate analysis (reported PR = 1.95; $p = 0.008$) and in the multivariable model (AOR = 1.74; 95% CI: 1.12–3.02; $p = 0.033$). The adjusted result indicates that the caregiving category coded as the exposure was associated with higher odds of good awareness, assuming the reference category and coding are correct. The confidence interval excludes 1.00, but its width indicates that the magnitude remains uncertain.

Direct experience with a family member who has thalassemia may provide opportunities to observe treatment, learn about the condition, and hear discussions about its implications. These experiences could make thalassemia more familiar and increase the salience of information about screening. Nevertheless, familiarity with treatment is not necessarily equivalent to an accurate understanding of inheritance, carrier status, or the purpose of screening. This distinction is especially important because disease management and carrier screening address different questions.

Previous research among families affected by β -thalassemia has documented the relevance of disease-related knowledge and counseling in family settings (Ansari et al., 2017). However, the experiences of parents attending specialized treatment centers may differ substantially from those of adolescents who provide care or have contact with affected relatives. Differences in age, responsibilities, clinical exposure, and access to professional counseling may help explain why findings from one population cannot automatically be generalized to another.

The caregiving result also requires careful consideration of variable coding. Table 1 reports that 92 respondents (43.8%) had caregiving experience, while Table 3 presents the same number in one category and

118 (56.2%) in the other. The original coding should be checked to confirm that the exposure category used in the regression corresponds to having caregiving experience. Without that verification, the direction of the adjusted association cannot be interpreted with complete confidence.

Most importantly, the outcome in this study was screening awareness, not actual screening uptake. The finding does not demonstrate that adolescents with caregiving experience were more likely to undergo testing. Future studies should measure awareness, willingness to be screened, referral, test completion, and receipt of counseling as separate outcomes.

Interpretation of Perceived Vulnerability, Perceived Severity, Benefits, and Barriers

The bivariate analysis reported a significant association between perceived benefits and screening awareness (reported PR = 1.44; $p = 0.041$). In contrast, perceived vulnerability ($p = 0.188$), perceived severity ($p = 0.072$), and screening barriers ($p = 0.211$) were not statistically significant at the conventional 0.05 threshold. These results indicate that the measured constructs did not demonstrate identical patterns of association with awareness in this sample.

The association between perceived benefits and awareness may reflect the relevance of recognizing the potential value of screening. However, the estimate should be interpreted alongside the measurement procedures, category definitions, and uncertainty in the reported analysis. The nonsignificant findings for vulnerability, severity, and barriers do not establish that these factors are unimportant. A nonsignificant result may reflect a genuinely weak association, limited statistical precision, measurement limitations, or variation in the characteristics of the study population.

Within the HBM, perceived susceptibility and severity represent different dimensions of perceived threat, while perceived benefits and barriers relate to the evaluation of an action (Rosenstock, 1974; Janz & Becker, 1984). In the context of thalassemia, adolescents may recognize that the disease can have serious consequences without understanding their own carrier status or the relevance of screening to their family history. Furthermore, perceived barriers may depend on whether screening is available, affordable, acceptable, and adequately explained. These possibilities are interpretations of the theoretical framework rather than mechanisms demonstrated by the current data.

The HBM should therefore be used as a framework for organizing the findings, not as a model validated by this study. The analysis did not establish whether the theoretical constructs were measured with sufficient validity, whether the hypothesized relationships among the constructs were supported, or whether the model explained awareness better than alternative explanations. A systematic evaluation would require clearly specified constructs, validated measurement procedures, and an analysis designed to test the proposed relationships.

The PRECEDE–PROCEED framework may provide a complementary planning perspective. Knowledge and attitudes can be considered potential predisposing factors, family support a potential reinforcing factor, and access to information a potential enabling factor. However, these classifications should be treated as provisional unless the questionnaire and operational definitions clearly correspond to the framework. PRECEDE–PROCEED is a planning and evaluation approach rather than a single causal theory, and its use does not imply that an intervention based on the framework has been tested or proven effective (Green & Kreuter, 2005; Crosby & Noar, 2011).

Implications for Adolescent Health Education and Screening Services

The findings have several implications for the development of adolescent health education, although they should not be interpreted as evidence of intervention effectiveness. First, health educators and health professionals could consider providing clear explanations of thalassemia inheritance, carrier status, screening procedures, and the limitations of interpreting family history without appropriate assessment. Second, educational activities could include opportunities for adolescents to ask questions and discuss concerns with qualified health professionals.

Third, family-inclusive communication could be considered as one possible approach, provided that adolescents' autonomy, privacy, and informed participation are respected. Family involvement should facilitate access to accurate information rather than replace individual counseling or presume that relatives always have complete knowledge. Fourth, information delivered through schools, health facilities, and digital platforms could be evaluated for accuracy, readability, cultural appropriateness, and accessibility.

These options are consistent with health promotion approaches that combine educational, interpersonal, and environmental considerations (Green & Kreuter, 2005; Crosby & Noar, 2011). Nevertheless, the present study did not compare different educational strategies, assess the cost or feasibility of screening programs, or measure changes in actual screening uptake. It therefore cannot determine which intervention would be most effective or whether any specific approach would reduce the incidence of thalassemia.

Future intervention studies could use a controlled or quasi-experimental design to assess changes in knowledge, screening awareness, willingness to seek counseling, referral completion, and actual testing where appropriate. Follow-up assessment would help determine whether improvements in awareness persist and

whether they are associated with subsequent health-service use. Such studies should also consider whether adolescents receive clear, non-stigmatizing information and have access to qualified counseling before and after testing.

Study Limitations

Several limitations should be considered when interpreting these findings. First, the cross-sectional design does not establish temporal order or causal relationships between the explanatory variables and screening awareness. Reverse directionality is possible, particularly for knowledge, attitudes, and information access. Second, purposive sampling may have introduced selection bias because participants were selected according to eligibility criteria rather than through probability sampling. The findings may therefore not represent all adolescents from families affected by thalassemia in Tegal or other regions of Indonesia.

Third, the use of questionnaires may have introduced information bias, including recall errors, differences in interpretation, and socially desirable responses. If exposure variables and awareness were assessed using self-report during the same data collection period, common-method bias may also have affected the observed associations. Fourth, the categorization of variables into good or low, adequate or inadequate, and high or low categories may have reduced information about differences within categories. The scoring procedures, cutoff values, questionnaire sources, and validity and reliability results should be fully reported to support the interpretation of these measures.

Fifth, residual confounding remains possible. Factors such as educational attainment, socioeconomic circumstances, prior contact with health services, family communication patterns, and previous exposure to genetic counseling may be associated with both the explanatory variables and screening awareness. The available manuscript does not establish whether all these potential confounders were measured and adequately accounted for in the final model.

Sixth, important inconsistencies in the manuscript require resolution before the estimates can be regarded as definitive. The Methods section reports 150 respondents, whereas the Results section presents 210. The stated eligibility age of 15–24 years also differs from the age groups reported in the results tables. In addition, the crude effect measures, adjusted estimates, variable coding, and model specifications should be verified against the original dataset and statistical output. These discrepancies affect the reproducibility and interpretability of the findings and should not be resolved by assuming which figures are correct.

Finally, the study assessed screening awareness rather than confirmed screening uptake. Consequently, the findings cannot establish whether the identified factors were associated with completed screening, genetic counseling, or subsequent reproductive health decisions. The specific family and geographic context may also limit transferability to adolescents in other settings. These limitations should be addressed through transparent reporting, verification of the original data, and future studies using more representative samples and clearly differentiated outcome measures.

Overall Interpretation

In summary, the study reported that family support, knowledge, attitudes toward screening, access to health information, and caregiving experience were associated with thalassemia screening awareness in the final multivariable model. Family support had the largest reported adjusted odds ratio (AOR = 3.62; 95% CI: 2.01–6.51), although the magnitude remains uncertain and the estimate requires confirmation against the original analysis output. The findings support further investigation of individual, family, and informational factors in adolescent health education.

The results should be interpreted as evidence of statistical associations within the analyzed sample rather than proof of causation or intervention effectiveness. Verification of the sample size, age eligibility, questionnaire scoring, variable coding, and regression estimates is essential before drawing definitive conclusions. Future research should distinguish awareness from actual screening uptake and evaluate whether educational and family-inclusive approaches are associated with meaningful improvements in adolescents' understanding and use of appropriate health services.

CONCLUSION

This study identified several factors associated with thalassemia screening awareness among adolescents from families affected by thalassemia in Tegal, Central Java, Indonesia. Based on the reported multivariable logistic regression results, family support (AOR = 3.62; 95% CI: 2.01–6.51; $p < 0.001$), knowledge (AOR = 2.19; 95% CI: 1.24–3.84; $p = 0.006$), caregiving experience (AOR = 1.74; 95% CI: 1.12–3.02; $p = 0.033$), attitudes toward screening (AOR = 1.71; 95% CI: 1.02–2.89; $p = 0.041$), and access to health information (AOR = 1.58; 95% CI: 1.01–2.71; $p = 0.049$) were independently associated with screening awareness in the reported final model. Family support had the largest adjusted odds ratio among the variables included in that model, although the magnitude of this association should be interpreted cautiously because its confidence interval indicates uncertainty around the estimate.

In the bivariate analysis, perceived benefits were significantly associated with screening awareness,

whereas perceived vulnerability, perceived severity, and screening barriers were not statistically significant at the conventional 0.05 level. These bivariate findings should be distinguished from the adjusted results and should not be interpreted as evidence that the nonsignificant variables are unimportant in other populations or circumstances.

The findings suggest that individual knowledge, attitudes, family support, caregiving experience, and access to health information are relevant factors for further investigation in adolescent thalassemia screening education. However, because this study used a cross-sectional design and purposive sampling, the results demonstrate associations rather than causal relationships and may not be generalizable beyond the study population. The sample size, eligibility criteria, variable coding, and regression estimates should also be verified against the original dataset before the findings are considered definitive.

Within the study setting, family-inclusive education and access to accurate, age-appropriate health information may be considered options for future program development and evaluation. Larger studies using more representative samples, together with prospective or intervention-based research, are needed to confirm these associations and determine whether educational approaches are associated with improved screening awareness and actual screening uptake. Broader recommendations for regional or national screening policies should be considered only after further evidence has been established.

SUGGESTION

Health services in the study setting should prioritize evaluating family-inclusive education for adolescents from families affected by thalassemia, as family support had the largest adjusted odds ratio for screening awareness in the reported model (AOR = 3.62; 95% CI: 2.01–6.51; $p < 0.001$). Educational materials should also address thalassemia knowledge, attitudes toward screening, and access to reliable health information, which were independently associated with screening awareness. If schools and primary health centers facilitate screening, participation must remain voluntary and based on informed choice, with age-appropriate genetic counseling, confidentiality of personal and genetic information, protection against discrimination and stigma, and clear referral arrangements for confirmatory testing and follow-up. These approaches should be piloted and evaluated before wider implementation rather than assumed to be effective.

Future research should include larger multisite studies with more representative samples to assess whether these associations are consistent across different populations. Prospective studies could examine whether baseline knowledge, attitudes, family support, and access to information are associated with subsequent changes in screening awareness and screening uptake. Pilot intervention studies should define outcomes in advance, including changes in awareness and knowledge, acceptability, voluntary screening uptake, and potential unintended effects such as anxiety, privacy concerns, or perceived pressure to participate. Given the cross-sectional design and purposive sampling of the present study, the findings should be interpreted as associations rather than causal evidence, and broader regional or national policy recommendations should await confirmation from larger and more representative studies.

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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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