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Knowledge and Attitudes Towards Thalassemia Screening Awareness: A Study on Teenagers From Extended Families Affected by Thalassemia

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ABSTRACT

Currently, there is no cure for Thalassemia; however, preventing marriages between carriers can help reduce the birth of children with thalassemia major. Early screening for Thalassemia is essential for this preventive measure. This study employs a quantitative analytical observational design with a cross-sectional approach. The sample comprises 120 teenagers from Tegal City, Central Java, selected through purposive sampling. Data were collected via a questionnaire assessing knowledge and attitudes towards thalassemia screening and analyzed using univariate and bivariate methods with SPSS software. The results show that 52.7% of participants demonstrated exemplary knowledge about thalassemia, while the majority (80.5%) displayed a positive attitude toward thalassemia screening. Furthermore, 86.4% of respondents expressed their intention to check their carrier status though 58.3% preferred to delay the screening until just before marriage. The study concludes that there is a critical need to enhance awareness about the importance of early thalassemia screening. This can be achieved through targeted education and strategic interventions, aiming to promote early screening and ultimately prevent the birth of children with thalassemia major.

Keywords: *awareness; knowledge; attitude; screening; thalassemia*

1. INTRODUCTION

Thalassemia, a chronic and degenerative condition, presents a significant threat to public health in Indonesia. Achieving the goal of preventing the birth of babies with thalassemia major requires collaborative efforts from all stakeholders. Although there is currently no cure for Thalassemia, the condition can be prevented by avoiding marriages between two carriers. One practical solution is to prevent two thalassemia carriers from marrying (Lantip , 2019)

Thalassemia is an increasingly concerning condition, with 2019 data showing a significant rise to approximately 10,500 patients. This number is expected to grow by around 1,500 new cases annually. However, these figures underestimate the true prevalence due to underdiagnosed cases and limited laboratory diagnostics. The prevalence of thalassemia carriers ranges from 3% to 10% of the total population. According to data from the Indonesian Thalassemia Foundation (YTI) and the Indonesian Association of Parents of Thalassemia Sufferers (POPTI), general public screenings conducted between 2008 and 2017 revealed a carrier rate of 5.8%, while family screenings during 2009-2017 indicated a carrier rate of 28.61%. The number of thalassemia cases continues to rise. Since 2012, cases have increased from 4,896 to 10,973 in 2021. As of 2020, the distribution of thalassemia major cases across Indonesia included 10,647 individuals, with notable concentrations in West Java Province (4,199), Central Java (1,377), and DKI Jakarta (864), among others. Annually, approximately 50 to 70 new cases are reported. A 2012 study by Eijkman estimated that, with a birth rate of 20% in a population of 240 million, Indonesia sees around 2,500 new cases of Thalassemia major each year. There is no cure for Thalassemia, but it can be prevented. Research highlights that prevention programs are far more beneficial than treatment. Given the outlined issues, thalassemia management programs should focus on preventing the birth of new Thalassemia major cases (Angela N Barrett Ramasamy Saminathan, 2017; Ministry of Health, 2018)

Efforts have been made to prevent the birth of individuals with Thalassemia and to evaluate the cost-effectiveness of nationwide prevention programs. An Iranian study found that the cost of thalassemia prevention was 16 times lower than the cost of treatment. Similarly, Ostrowsky et al. from Quebec, Canada, reported that the overall cost per case avoided was less than the annual cost of therapy for an individual with the disease. Research by a World Health Organization committee highlighted that the annual cost of operating a prenatal screening and diagnosis program in Cyprus was nearly equivalent to treating all existing patients over five years. The committee projected that within three years of initiating such services, the incidence of Thalassemia in Sardinia could decrease by 90%, covering the costs of establishing the prevention program. Beyond this point, the overall treatment costs would continue to decline over the following five years, eventually reaching about one-fifth of the estimated treatment costs (Ministry of Health of the Republic of Indonesia, 2022)

Several Southeast Asian countries have successfully implemented screening and early detection programs for at-risk populations to combat thalassemia. For example, Singapore has operated a screening program for over 20 years, reducing the number of babies born with Thalassemia major to just three per year. Similarly, Thailand has conducted thalassemia screening for 13 years, reducing the birth rates of affected babies to 5.4 per 1,000 live births. Notably, the cost of treating Thalassemia is estimated to be 72 times higher than that of screening. In Indonesia, the cost of a single screening using peripheral blood examination and hemoglobin (Hb) electrophoresis is approximately 550,000 IDR per person, significantly less than the annual treatment cost of one patient, which RSCM data in 2017 estimated to be around 450 million IDR, excluding additional expenses for complications.

Beyond the financial burden, patients with Thalassemia face lifelong therapy, psychological challenges, and physical changes caused by the disease. The World Health Organization (WHO) highlights that the cost of a national thalassemia prevention program is equivalent to the annual treatment cost for one patient. While prevention costs remain relatively stable, treatment expenses tend to rise annually (Ministry of Health of the Republic of Indonesia, 2022).

Effective prevention strategies are essential to mitigating the financial burden of managing Thalassemia at the national level. Indonesia has initiated a structured prevention program, including the Health Technology Assessment (HTA) in 2010 for population-level interventions and the Thalassemia Treatment Service Guarantee for patient care. The financial expenditure for thalassemia management was reported to range from IDR 1.7–2 million per patient monthly in 2011, increasing to IDR 5–10 million per child by 2018. Over an estimated 30-year patient lifespan, the cumulative cost amounts to IDR 720–1,400 million per patient, assuming constant expenses. These substantial costs pose significant challenges for both government health budgets and affected families (Lantip& Mulyanto, 2019).

Indonesia established a prevention initiative in 2010 to mitigate the financial strain on national healthcare systems, through the Health Technology Assessment (HTA) alongside the Thalassemia Treatment Service Guarantee for patient management. Between 2011 and 2018, monthly costs for thalassemia treatment per patient increased from 1.7–2 million IDR to 5–10 million IDR. Given an average lifespan of 30 years for individuals with Thalassemia, total lifetime treatment costs can range from 720 million to 1.4 billion IDR per patient, placing a substantial burden on both government resources and affected families (Hoffmann et al., 2015).

Thalassemia is a national health problem that needs to be handled with structured and systemic planning. Efforts to detect mutation carriers through thalassemia screening efforts in healthy individuals are an important step in national prevention. Carrier screening *for* early detection of Thalassemia in the community requires a careful approach, especially in areas with limited health services. Screening is needed to prevent new cases of Thalassemia. Early screening of thalassemia carriers using Hb-electrophoresis and DNA testing to confirm the diagnosis by laboratory examination of peripheral blood smears (Ministry of Health of the Republic of Indonesia, 2022).

Thalassemia is a pressing national health issue requiring structured and systemic approaches. Early detection of mutation carriers through targeted screening is vital for prevention. Carrier screening is essential to prevent new cases, especially in areas with limited healthcare services. Early detection techniques such as Hb-electrophoresis and DNA testing remain the gold standards despite their higher costs and limited accessibility. Ideally, screening should be conducted before individuals have children, with family members of thalassemia patients (ring 1) prioritized. Premarital screening can help achieve zero births of new thalassemia major cases (Ministry of Health, 2018; Roth et al., 2018).

Numerous studies demonstrate that prevention programs for thalassemia screening are far more advantageous than treatment. There are several ways to do screening, including screening both special and broader populations. There are currently no specific screening recommendations targeting high-risk groups. However, The study by Susanah et al.,(2022) revealed that 42.7% of 150 subjects from extended families with an index case of severe thalassemia were identified as thalassemia carriers. This underscores the importance of systematic screening within extended families with a history of thalassemia to detect carriers and raise awareness about thalassemia prevention.

Similarly, a study by Sari et al., (2020) reported among the 117 extended family members of children with thalassemia major, 35% were identified as carriers of thalassemia traits, highlighting the significance of family-based screening for effective

prevention strategies. Estimates provided by WHO, which state that the prevalence of thalassemia carriers among the general population in Indonesia ranges from 6-10% (Ministry of Health, 2019), underscoring the need for more targeted screening strategies. In nations with low health facility expenditures and resources, case screening is more feasible and efficient than population screening.

Early screening of thalassemia carriers with erythrocyte indices such as means blood cell volume (MCV) and means hemoglobin of blood cells (MCH) is more commonly used because of its quick procedure and cost-effectiveness. According to the Ministry of Health in Indonesia, these values are parameters for early screening of thalassemia carriers. However, in the blood smear of beta-thalassemia carriers, there are microcytic hypochromic erythrocytes, causing low MCV and MCH and having the same picture as iron deficiency anemia. A definite diagnosis to differentiate carriers of Thalassemia and iron deficiency anemia is based on hemoglobin analysis (Hb-electrophoresis) and DNA examination as the gold standard (Surjawan et al., 2017). However, all these tests are expensive, time-consuming, and not widely available in every health service in Indonesia. Various formulas using a combination of erythrocyte indices have been used to screen thalassemia and differentiate it from iron deficiency anemia to prevent unnecessary iron therapy for thalassemia.

Multilevel screening is a valuable and efficient substitute for population screening in nations with few healthcare resources and expenses. Many nations with high thalassemia rates use preventive screening programs to find disease carriers. The methods include prenatal diagnosis, big family (cascade) screening, high-risk group screening, premarital genetic counseling, and public education regarding thalassaemia. Prenatal screening and diagnosis programs are good in 9–13 countries, including Cyprus, Italy, the UK, Greece, Iran, Turkey, Sri Lanka, China, Tunisia, Thailand, and Malaysia. Cyprus, Italy, and Greece have achieved 100% success with prenatal screening and diagnosis programs, and there is currently no birth prevalence of homozygous β-thalassemia (Surjawan et al., 2017).

High-risk population screening was carried out on thalassemia patients (index case). Cascade/extended family examination *is a* good filtration option with cost efficiency. Ahmed et al. found that using this approach, 31% of family carriers could be identified (Sari et al., 2020). Indonesia does not yet have definite guidelines for screening for Thalassemia, especially in children. As one of the countries with a reasonably high incidence and burden of Thalassemia, Indonesia needs to start screening for Thalassemia to help reduce the incidence of thalassemia. Several studies have concluded that cascade screening is an effective and practical method that can be applied in countries with limited health costs and facilities like Indonesia. Therefore, in the context of limited resources and budget, screening can be focused on siblings of thalassemia patients identified by physicians using extended family screening methods. Prevention of Thalassemia through genetic screening and counseling for fertile couples in areas with a high incidence of Thalassemia is an effective measure (Ministry of Health of the Republic of Indonesia, 2022).

Prenatal diagnosis, extended family carrier screening, and thalassemia awareness are all very beneficial in avoiding and managing Thalassemia. A key component of an effective thalassemia prevention plan is increasing awareness. Sari et al.,(2020) Implementing preventive control measures requires utilizing sociocultural variables and the degree of public health awareness. Identifying information gaps and educating the public about screening should be top priorities, particularly in regions with a high illness burden. For the entire family to accept the risk of having a kid with Thalassemia, effective communication needs to be increased. The general public and parents of children with thalassemia must be attentive to the low level of parental awareness of thalassemia. Raising awareness of thalassemia screening for Thaler extended families is necessary to encourage high-risk populations and make screening more accessible

Collaboration between health professionals and volunteers at integrated service posts, preventative orientation for first-degree relatives of thalassemia patients with carrier screening measures, and optimization of promotional and preventive initiatives. Therefore, focusing on the siblings of identified thalassemia patients might be more practicable in a setting with limited resources and money. It is practical and economical to screen one's immediate family members for career counseling and identification (Susanah et al., 2022).

Health workers, as counselors, have the authority to do this; a detailed explanation of the risks arising from the marriage between thalassemia carriers is a strong consideration for couples (Ministry of Health of the Republic of Indonesia, 2022). The search begins with the family tree of those suffering from thalassemia major. Drawing a family tree involves a minimum of three generations in one family, and then thorough identification is carried out, including genetic counseling planning. Parents who have children with Thalassemia should be suspected of being carriers, as well as family members who have the same genealogy; this does not rule out the possibility of carriers of Thalassemia (Li et al., 2023). However, further examination, such as electrophoresis, still needs to be carried out because there are other possible causes of mutations (Ministry of Health of the Republic of Indonesia, 2018). Thalassemia is a genetic disease quite common in various communities, including Indonesia. This disease is characterized by disruption of the production of hemoglobin, a protein in red blood cells that functions to transport oxygen. People need to understand thalassemia well to carry out appropriate prevention and treatment. The research aims to identify factors (knowledge and attitudes) that are associated with awareness of thalassemia screening in adolescents.

2. METHOD

A quantitative analytical observational design with a cross-sectional approach is being used in this study. The sample comprised 120 adolescents from Tegal, Central Java Province, selected through purposive sampling. Data were collected using structured questionnaires assessing knowledge, attitudes, and awareness of thalassemia screening. The questionnaire consisted of five sections: respondent demographics, knowledge, attitudes, actions, and timing of thalassemia status checks. Demographic variables included age, gender, ethnicity, place of birth, consanguinity within the family, and marital status. The knowledge and attitude sections were adapted from previously validated questionnaires and translated into Indonesian.

Respondents voluntarily participated in the study after being informed of its objectives and providing signed informed consent. Ethics approval was obtained from the Faculty of Public Health Ethics Commission, Diponegoro University, Semarang. Data were analyzed using SPSS version 23.0. The Kolmogorov-Smirnov test was used to assess data normality—non-parametric tests, such as the Kruskal-Wallis test, followed by the Mann-Whitney test. Data processing was done with computer assistance using the SPSS computer program with a significance limit of $p \leq 0.05$ and CI 95%. The relationship between attitude and action scores and knowledge level scores was tested using simple linear regression. The data source in this research is primary data obtained using data collection techniques, such as direct interviews and questionnaires with respondents. Respondents had previously been explained the aims and objectives of the research and agreed to it by signing *informed consent*. Ethics in this research are stated as follows*:* The ethical clearance was issued by the ethics commission of the Faculty of Public Health, Diponegoro University, Semarang, Indonesia (Number 388/EA/KEPK-FKM/2024).

3. RESULTS

The age range of the subjects was from 13 years to 21 years. Of the total 120 research subjects, 32 people (26.6%) were aged 10-13 years, 44 people (36.7%) were aged 14-17 years, and 44 people (36.7%) were aged 18-21 years. Of the 120 respondents, 82 (68.3%) were female and 38 (31.7%) were male. The results show that 52.7% of participants demonstrated exemplary knowledge about thalassemia, while the majority (80.5%) displayed a positive attitude toward thalassemia screening. Furthermore, 86.4% of respondents expressed their intention to check their carrier statusthalassemia.

A disease's degree of societal knowledge is directly correlated with its prevalence. The current study aimed to determine the general public's awareness of Thalassaemia in the Tegal City region of Central Java Province, Indonesia. A study by Ghafoor et al. (2020) in Rahim Yar Khan, a district in Southern Punjab, Pakistan, revealed a low level of public awareness about Thalassemia. Out of 400 randomly selected adults, only 131 reported being familiar with the term "Thalassemia." Data were collected using a structured questionnaire that included demographic details (age and gender) and 24 questions to assess knowledge of the disease. The analysis, conducted with SPSS version 20, categorized awareness levels as poor (fewer than 12 correct answers), average (13–18 correct answers), and good (more than 18 correct answers). Among the 131 respondents, only 7 (5.4%) demonstrated good knowledge, 27 (20.6%) had average knowledge, and the majority, 97 (74%), exhibited poor knowledge. The study concluded that public awareness about Thalassemia in Rahim Yar Khan remains significantly low.

Many of the people questioned were ignorant of having beta-thalassemia as they had a first-degree relative with it, which was not the case in this study. While awareness is partly determined by education, age and sex seem to have a negligible effect on the awareness of the disease (Patel et al., 2016)

In this research, however, the level of awareness was slightly higher than that in Kolkata when compared to Basu Mausumi's study. In Kolkata, based on the cross-sectional study the proportion of individuals with adequate knowledge of thalassemia was 14.02 percent. (Basu, 2015) This is the reason that ignorance of the people concerning the causes of the disease is one of the major factors that are responsible for its spread. Also, data obtained from Muhammad Bilal Ghafoor strengthens this problem. According to his study of 2016 on awareness about thalassemia among parents of thalassemia children, only 15 % of the parents were sufficiently knowledgeable about the disease. In the same vein, Fozia Ishaq, Sabir H B, Liaqat I et al studied the prevalence and knowledge of Thalassemia in parents attending the Sir Ganga Ram Hospital Lahore Pakistan and in this study, out of 230 parents only fifty-two (44.6%) knew that Thalassemia was an inherited charge. Also, in this group, more than half, thirty-eight of the parents tested (33%) were aware of carrier testing showing their lack of knowledge of the disease (Ghafoor et al., 2020).

A study conducted in Bangladesh by Hossain et al. (2022) involved 660 students who participated in an online survey. The average age of the respondents was 21.97 years, with a standard deviation of 2.9. While most students (611 or 89.72%) had heard about Thalassemia, only 248 (36.42%) demonstrated good knowledge about the condition. Public health campaigns and thalassemia awareness programs must target cultural, educational, and religious settings to inform the community. Media platforms, both electronic and print, should actively disseminate accurate information to eliminate misconceptions. Promoting carrier screening and prenatal diagnosis effectively reduces the prevalence of this life-threatening disease.

The knowledge section of the study comprised 15 questions, with nine requiring "True" or "False" answers. These questions covered general knowledge about Thalassemia inheritance, diagnosis, treatment, and prevention. Each correct answer was

scored 1, with a maximum score of 15. Knowledge levels were categorized as excellent (13–15), good (10–12), fair (7–9), and poor (<6). The attitude section included nine questions assessing respondents' reactions to preventive measures such as premarital and prenatal screening, as well as contributions to helping Thalassemia patients. Responses were scored 1 for correct answers, with a maximum score of 9. Attitudes were classified as positive if the score was >5 and negative if the score was <5. The action section consisted of nine questions analyzing respondents' behaviors toward situations like having a family member with Thalassemia, consanguineous marriage, or marrying a Thalassemia carrier. Additional questions addressed actions regarding prenatal diagnosis and termination of pregnancy. Similar to the attitude section, correct answers were scored 1, and total scores were grouped into good actions (>5) or poor actions (<5).

This study emphasized the importance of knowledge, attitudes, and actions of health professionals, particularly doctors, in Thalassemia prevention strategies. As key disseminators of public information, doctors play a vital role in educating the population. The research aimed to assess adolescents' knowledge, attitudes, and awareness of thalassemia screening. A cross-sectional approach was used, involving 135 teenagers from extended families affected by Thalassemia. Conducted between October and December 2024, the study employed a structured questionnaire to evaluate knowledge, attitudes, and actions. Scores for each variable were compared using the Kruskal-Wallis test, while the relationships between knowledge, attitudes, and actions were analyzed using simple linear regression. The findings provide valuable insights into adolescents' understanding of Thalassemia screening, emphasizing the need for targeted interventions to improve awareness and preventive behaviors.

The following table shows knowledge, attitudes, and awareness of thalassemia screening in adolescents from extended families with thalassemia.

Table 1. Knowledge, Attitudes, and Awareness of Thalassemia Screening in Teenagers

Thalassemia Knowledge	**Correct**	**FALSE**
Thalassemia is a hereditary disease in the family	89,6%	10,4%
Blood test as a way to find out whether you are a carrier of Thalassemia	97,7%	2,3%
People who appear healthy may have the thalassemia gene.	44,8%	45,2%
Thalassemia babies are born to two Thalassemia parents.	60,4%	39,6%
Thalassemia is inherited from both parents, who are thalassemia carriers.	62,5%	37,5%
Management of Thalassemia is by carrying out regular blood transfusions.	78,2%	22,8%
One way to prevent babies from getting Thalassemia is through fetal diagnostic examination.	36,5%	63,5%
Thalassemia sufferers experience anemia	94,8%	5,2%
Marriage of two carriers causes Thalassemia major	87,43%	12,7%
Thalassemia is a disease that can be prevented	70,8%	29,2%
Anyone can be a carrier of Thalassemia	69,8%	30,2%
Thalassemia Screening Attitude	**Agree**	**Don't agree**
I will have a blood test even if I am healthy	9 4,8%	5,2%
I will do a blood test even if no family/relatives have Thalassemia.	15,6%	84,4%
I will consult a doctor if I have a child with Thalassemia	9 5, 6%	5, 2%
I regret not having a premarital examination	84,4%	15,6%
I want to get premarital screening information	99,2%	1,8%

Thalassemia screening is carried out in adolescence	92,7%	7,3%
I support thalassemia screening in nuclear families.	9 5,6%	4,4%
All family members underwent a thalassemia examination	89,4%	10,6%
Reasons for Thalassemia Screening		
Reasons for thalassemia screening	Requires detailed information regarding the purpose and results of the examination (70%) Health worker advice (10%) Family support (15%) Fee support (10%)	
Reasons for not screening for Thalassemia	40.4% (don't know location) 12.6% (fear of screening results) High cost (10.4 %) Not necessary (5%) Others (30.6 %)	
Health facilities of choice for thalassemia screening	RS (76%) Case lab (20%) Community Health Center (4%)	
If the screening results of both are thalassemia carriers, is it better to get married?	Doubtful (50%) Continuing marriage (30%) Did not continue (20%)	
Thalassemia Information and Education Source		
Thalassemia Information	Never (72%) Never (28%)	
The need for educational material about Thalassemia	Agree (98%) Disagree (2%)	
The Thalassemia screening process is simpler and more accessible	Agree (97%) Disagree (3%)	
Personal support as a motivator for thalassemia screening	Health profesionals (60%) Family (20%) Health cadres (10%) Partners (10%) Educational institutions (5%)	
Source of Thalassemia information	Internet (50%) Health profesionals (40%) Family (10% Educational institutions (10) Print media (5%)	

As many as 52.7% of teenagers have good knowledge; the majority have a positive attitude (80.5%). The majority (82.4%) had plans to have their thalassemia carrier status checked but preferred to postpone the test until they were about to get married (58.3%).

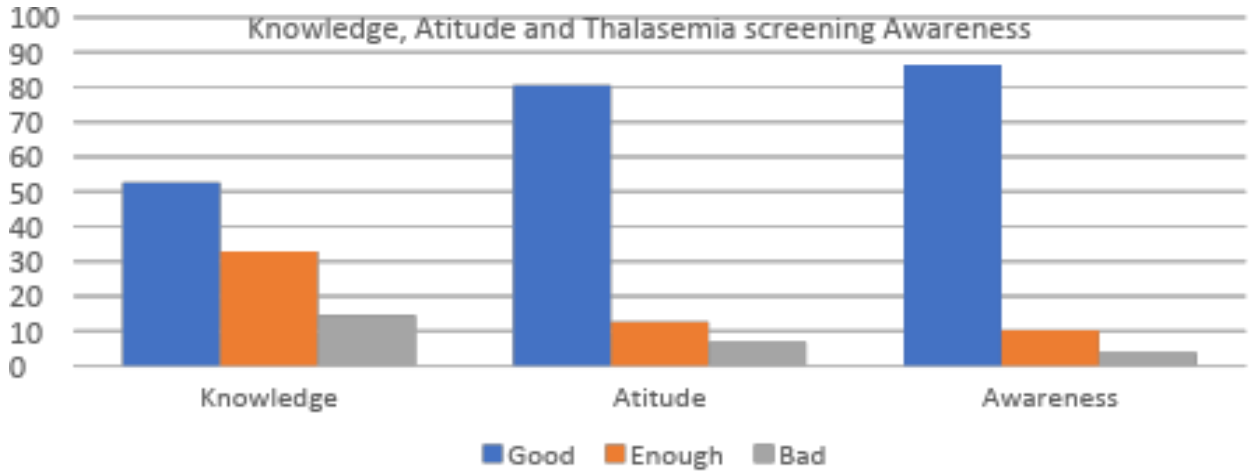

Figure 1 Knowledge, Attitude, and Thalassemia Screening Awareness

Based on surveys, the level of public knowledge about Thalassemia still varies. Several studies show that many people still do not fully understand this disease, especially how to prevent it. The research results showed that 52.7% of respondents knew about Thalassemia, and more than half were in the poor category.

4. DISCUSSION

Knowledge results from knowledge obtained through a sensing process, becoming a skill that can be used in an activity. Sensing occurs through the five human senses, namely the senses of sight, smell, taste, and touch (Soekidjo, 2018). Various factors can influence knowledge, including education, experience, age, and information. Having good educational support can make it easier for someone to receive information so that their knowledge tends to be relatively better than those with low education. Therefore, it is necessary to provide information about Thalassemia and all its problems, as well as preventive efforts that can be carried out by families/parents and adolescents through ongoing health education. Thalassemia is a congenital disorder in hemoglobin production (Dinh & Bonner, 2023).

Meanwhile, according to the MERC Manual Professional Version, (2019), Thalassemia is a genetic disease that disrupts the synthesis of globin chains, the main component of the hemoglobin (Hb) molecule. Providing information about Thalassemia is very necessary because it can increase family/parent knowledge, thus increasing the ability of families/parents to prevent thalamus. Increasing family/parent knowledge about thalaemia can motivate them to take more targeted and beneficial actions for the family so that a new generation of thalamus sufferers does not emerge. Good knowledge can mobilize families to act more effectively. This is in line with what Listyaningsih said. Aryani & Herawati, (2023) stated that good education would help treat Thalassemia well, too. The study results showed that the respondents' knowledge about the thalamus was in the poor category, so it tended to have a poor impact on efforts to prevent the thalamus. Knowledge will also affect controlling a person's psychological condition.

Relationship between family history factors and the incidence of beta thalassemia major in children. Family history in genetics is defined as the presence of genetic factors and family history. Family illness. Through the relationships and dynamics of a person's life, the family has a strong relationship with a person's health and illness. Environment, lifestyle, and genes all play a role in families. Significant medical conditions that may run in the family can be caused by these factors. The results of this study prove that there is a relationship between family history factors (p-value = 0.000), parental consanguinity (p-value = 0.000), and ethnicity (p-value = 0.007) with the incidence of beta thalassemia major in children (Nurvinanda., 2023)

This is in line with Hanifah, (2020) that parents with genetic Thalassemia will give birth to children with beta-thalassemia major. There is a relationship between the incidence of beta thalassemia major in children and a family history of Thalassemia. Based on Mendel's laws, Wildani et al., (2021) research findings show that Thalassemia is a genetic or hereditary condition. According to Wildani et al., (2021), Mendel's law regarding Thalassemia states that a child has a 25% chance of being healthy, a 25% chance of suffering from Thalassemia, and a 50% chance of being a carrier or bearer of this trait. If both parents have it, then he carries these traits. This is supported by the research findings of Susanah et al., (2022),

which show a relationship between the prevalence of beta thalassemia significance and family history.

It can be confirmed that both parents are carriers of Thalassemia if it is known that children in the same family have 26 of these diseases. Therefore, if it is known that both parents are carriers of Thalassemia, it is very likely that members of the extended family of parents, uncles, aunts, nephews, nieces, and cousins can also be carriers of Thalassemia. Cascade screening, which focuses on identifying carriers within the families of thalassemia patients, offers a practical and affordable solution for Indonesia. Health profesionals, as counselors, play a crucial role in explaining the risks associated with marriages between carriers and encouraging genetic counseling. Collaboration between health cadres, integrated service posts, and family health programs is vital for optimizing preventive efforts (Susanah et al., 2022).

Raising awareness and strengthening screening programs are key to addressing Thalassemia in Indonesia. Public education, genetic counseling, and targeted prevention strategies can significantly reduce the disease burden. Collaboration between stakeholders, including government agencies, healthcare providers, and the community, is essential to ensure the success of these initiatives (Ministry of Health of the Republic of Indonesia, 2022;Tuo et al., 2024).

Researchers assume that family history plays an important role in determining risk. A child suffers from beta thalassemia major. Beta thalassemia major is caused by gene mutations in a pair of genes that control the production of beta globin, an essential protein for the formation of hemoglobin. If one or both parents carry the mutated gene, they become carriers of beta thalassemia minor. If both parents are carriers, there is a 25% chance that the child will suffer from beta thalassemia major. Beta thalassemia major is inherited in an autosomal recessive manner, meaning both parents must have it. Carry the same mutated gene so that their child suffers from this disease. If only one parent carries the mutated gene, the child will only be a carrier of beta thalassemia minor without severe symptoms.

The relationship between parents' family closeness and the incidence of beta thalassemia is major in children. The closeness of the parents' family relationship is the relationship between a husband and wife who have a sibling relationship from the same biological parents in two generations (Hastuti, 2016). The results of this study show that children with Thalassemia have 10 (83.3%) close family relationships between their parents compared to children with Thalassemia whose parents do not have close family relationships. The results of data analysis using the Chi-Square test obtained a p-value (0.000) < α (0.05), which means there is a relationship between the closeness of the parents' family relationship and the incidence of beta thalassemia major in children.

This aligns with research conducted by Saeed, (2016), which shows a relationship between the prevalence of Thalassemia and the closeness of the parents' family relationships. The percentage of children at risk of developing Thalassemia can increase if two generations relate to the parents. Inbreeding should be avoided because it can increase the chance of developing Thalassemia. The premarital screening program can detect an individual's overall body condition to prevent or minimize the occurrence of congenital disorders, including Thalassemia, according to research by Utami & Kusumaningrum, (2020), which states that couples who are still in contact for two generations can increase the percentage risk of having thalassemia offspring. Researchers assume that marriage within a close family or blood relationship can increase the risk of having a child with beta-thalassemia major. If the parents are related, for example, cousins or nephews, they likely have similar genetics and can carry the same mutated gene.

Another critical factor is the lack of awareness and education regarding beta thalassemia, which is prominent in several regions in Indonesia. This can lead to a lack of knowledge regarding the risks and prevention of this disease, so marriages between carriers of beta thalassemia minor can occur without considering the existing related risks. Likewise, it is important for tribes that are not at risk to have a health check before marriage. Some factors that influence knowledge about Thalassemia are: 1) Education: A higher level of education tends to be associated with better knowledge about Thalassemia; 2) Access to Information: The availability of accurate and easily accessible information is very important to increase public knowledge; 3) Personal Experience: People who have family or friends suffering from Thalassemia tend to have better knowledge (Cheng et al., 2018).

Increasing public awareness about Thalassemia is very important for 1) prevention efforts, namely by understanding the risks and how to prevent them, prospective married couples can conduct genetic counseling before marriage. 2) Early Diagnosis: Good knowledge allows early detection of newborns so that treatment can be carried out earlier. 3) Disease Management: Thalassemia sufferers and their families can be more active in managing the disease and improving the quality of life. 4) Social Support: People who understand Thalassemia better will provide better social support to sufferers (Singh et al., 2022).

Efforts to increase public awareness regarding thalassemia screening include: 1) Educational Campaign: through mass media, social media, and outreach activities, information about Thalassemia can be disseminated to the public; 2) Genetic Counseling: genetic counseling is very important for prospective married couples having a family history of Thalassemia; 3) Increasing the Role of Health Workers: health workers, especially doctors and nurses, are essential in providing accurate information to patients and families. 4) Development of educational materials: educational materials about thalassemia must be prepared in easy-to-understand and interesting language (Angastiniotis et al., 2021)

Discussion of Attitudes Towards Thalassemia Screening

Thalassemia screening is an essential step in preventing and treating this disease. However, public acceptance of this film screening varies. Let's discuss the attitudes towards thalassemia screening, the factors influencing it, and the implications.

Many individuals and communities have a positive attitude towards thalassemia screening. Some of the reasons are: Prevention: Thalassemia screening allows early detection in prospective brides so that better genetic counseling and family planning can be carried out; Quality of Life: With early detection, thalassemia treatment can be carried out early, thereby improving the sufferer's quality of life; Social Responsibility: Through screening, individuals contribute to efforts to reduce the prevalence of Thalassemia in society.

However, some people still have a negative or ambivalent attitude towards thalassemia examination. Some reasons include: Lack of Information: Lack of accurate information about Thalassemia and the benefits of screening can raise doubts and concerns; Stigma: Social stigma surrounding genetic diseases can discourage people from getting tested; Cost: The high cost of screening can be a barrier for some people; Privacy: Concerns about the privacy of screening results may also be a reason to refuse screening (Hossain et al, 2019).

Education is one aspect that affects a person's attitude towards thalassemia screening; more positive attitudes towards screening are typically linked to higher levels of education. Socioeconomic level: People with higher socioeconomic levels typically have easier access to screening facilities and health information. Personal Experience: People with first-hand knowledge of Thalassemia or family members with the condition are more likely to support screening. Culture and Values: A person's attitude towards screening may be influenced by their cultural and religious beliefs (Angastiniotis et al., 2021).

To increase public acceptance of thalassemia screening, several strategies can be implemented: Education Campaign: Through mass media, social media, and outreach activities, the public needs to be given accurate and easy-to-understand information about Thalassemia and the benefits of screening; Genetic Counseling: Genetic counseling can help brides-to-be understand the risks and benefits of screening and make informed decisions. Making Examinations Easier and Affordable: Efforts must be made to make examinations more accessible and affordable, for example, by providing adequate examination facilities in various regions. Changing Public Perception: Efforts to change perceptions about genetic diseases and eliminate stigma must be carried out continuously (Mat et al., 2020).

5. CONCLUSIONS AND RECOMMENDATIONS

Most teenagers (80.5%) have a positive attitude, and as many as 52.7% have substantial knowledge. The majority (86.4%) intended to determine if they were thalassemia carriers. However, they would rather wait until they were getting married (58.3%). Attitude and knowledge are significantly associated ($p = 0.02$), as does awareness and understanding ($p = 0.03$).

Thalassemia is a genetic disease that can be prevented and treated well if people have sufficient knowledge. Efforts to increase public awareness must continue to be carried out on an ongoing basis through various means, such as educational campaigns, genetic counseling, and increasing the role of health workers. Public attitudes towards thalassemia screening vary widely. To increase public acceptance, comprehensive efforts are needed, from educational campaigns and genetic counseling to developing supportive policies. In this way, it is hoped that the prevalence of Thalassemia can be reduced and the quality of life of sufferers can be improved. Thalassemia is preventable through education, early screening, and genetic counseling. Addressing barriers such as cost, stigma, and accessibility while leveraging community support and healthcare infrastructure can significantly reduce its prevalence. By increasing public knowledge and fostering positive attitudes toward screening, policymakers can improve disease prevention and management, enhancing the quality of life for affected individuals and their families.

REFERENCES

[1] Angastiniotis, M., Petrou, M., Loukopoulos, D., Modell, B., Farmakis, D., Englezos, P., & Eleftheriou, A. (2021). The Prevention of Thalassemia Revisited: A Historical and Ethical Perspective by the Thalassemia International Federation. *Hemoglobin*, *45*(1), 5–12. https://doi.org/10.1080/03630269.2021.1872612

[2] Angela N Barrett Ramasamy Saminathan, M. C. (2017). Thalassaemia screening and confirmation of carriers in parents. *Best Practice & Research Clinical Obstetrics & Gynaecology*, *39*, 27–49. https://www.sciencedirect.com/science/article/abs/pii/S1521693416301237?via%3Dihub

[3] Basu, M. (2015). A Study on Knowledge, Attitude and Practice about Thalassemia among General Population in Out Patient Department at a Tertiary Care Hospital of Kolkata. *Journal of Preventive Medicine and Holistic Health*, *1*(1), 5–12. https://www.researchgate.net/publication/282657666

[4] Cheng, K., Fucharoen, S., Sanchaisuriya, K., Fucharoen, G., Sanchaisuriya, P., & Jetsrisuparb, A. (2018). Effect of health education on severe thalassemia prevention and control in communities in Cambodia. *Archives of Public Health*, *76*(1), 1–8. https://doi.org/10.1186/s13690-018-0259-3

[5] Dinh, T. T. H., & Bonner, A. (2023). Exploring the relationships between health literacy, social support, self-efficacy and self-management in adults with multiple chronic diseases. *BMC Health Services Research*, *23*(1), 1–10. https://doi.org/10.1186/s12913-023-09907-5

[6] Ghafoor, M. B., Iqbal, J., Muhammad, G., Shahbaz, M., Mustafa, G., & Saleem, M. (2020). Awareness Regarding Thalassemia in General Population of Rahim Yar Khan , Pakistan. *International Journal of Medical Research & Health Sciences.*, *9*(6), 79–84. www.ijmrhs.com

[7] Hanifah, M. R. (2020). Description of Thalassemia C*hildren at Regional General Hospital Dr. Soediran Mangun Sumarso Wonogiri. ASJN (Aisyiyah Surakarta Journal of Nursing), 1(1), 16–20. https://doi.org/10.30787/asjn.v1i1.64*

[8] Hastuti. (2016). Analysis Of Factors Related To The Level Of Anxiety Of Parents Of Children With Thalassemia At Ahmad Yani General Hospital, Metro. *Kesehatan Metro Sai Wawai*, *8*(2), 49–54. https://ejurnal.poltekkestjk.ac.id/index.php/JKM/issue/view/20

[9] Hoffmann, J. J. M. L., Urrechaga, E., & Aguirre, U. (2015). Discriminant Indices for Distinguishing Thalassemia and Iron Deficiency in Patients with Microcytic Anemia: A Meta-Analysis. *Clinical Chemistry and Laboratory Medicine*, *53*(12), 1883–1894.https://doi.org/10.1515/cclm-2015-0179

[10] Hossain et al. (2019). *Lack of knowledge and misperceptions about thalassemia among college students in Bangladesh: A community-level cross-sectional study*. 1–10.

[11] Lantip Rujito, J. M. (2019). Adopting mass thalassemia prevention program in Indonesia. *Indonesian Journal of Medicine and Health*, *7*(3), 109–114. https://journal.uii.ac.id/JKKI

[12] Li, H., Wang, J., Wang, D., Gan, Y., & Xiong, Y. (2023). Ten Years' Experience in Prenatal Diagnosis of α-thalassemia in a Municipal Hospital and Retrospective Analysis of Ultrasonic Abnormalities. *International Journal of Hematology*, *118*(3), 355–363.

[13] Listyaningsih. Aryani., & Herawati. (2023). The Influence of the Family Empowerment Program on Parents' Knowledge about the Care of Thalassemia Children. *Repositori Universitas Sahid Surakarta*. http://repository.usahidsolo.ac.id/id/eprint/2552

[14] Mat, M. A. C., Yaacob, L. H., & Zakaria, R. (2020). Parental knowledge on thalassaemia and factors associated with refusal to screen their children. *Malaysian Journal of Medical Sciences*, *27*(1), 124–133. https://doi.org/10.21315/mjms2020.27.1.13

[15] MERC Manual Professional Version. (2019). Pathophysiology of Thalassemias.https://www.merckmanuals.com/professional/hematology and-oncology/anemias-caused-by-hemolysis/thalassemias?

[16] Ministry of Health. (2018). *Prevent New Sufferers, Ministry of Health Formulates Thalassemia Screening Rules*. https://p2ptm.kemkes.go.id/

[17] Ministry of Health of the Republic of Indonesia. (2018). *National Guidelines for Medical Services for Handling Thalassemia*. http://hukor.kemkes.go.id/uploads/produk_hukum/KMK_No._HK_.01_.07-MENKES2018_

[18] Ministry of Health of the Republic of Indonesia. (2022). *Thalassemia Management Guidelines*. https://p2ptm.kemkes.go.id/uploads/VHcrbkVobjRzUDN3UCs4eUJ0dVBndz09/2024/05/Fix_281222_15x21

[19] Notoatmodjo Soekidjo. (2018). *Health Promotion Theory and Application*. Rineka Cipta. https://perpus.poltekkesjkt2.ac.id/index.php

[20] Nurvinanda., S. H. K. R. (2023). Factors Associated with the Incident of Beta Thalassemia Major in Children. *Journal of Professional Nursing Research*, *5*(November), 1713–1724.

[21] P2PTM Ministry of Health. (2019). *Break the Chain of Thalassemia, for a Healthier Indonesia*. https://p2ptm.kemkes.go.id/

[22] Patel, A. P., Parmar, P. H., Patel, R. B., Trivedi, N. M., Bhartiya, N. A., & Ashwin, P. P. (2016). Factors Influencing Beta-Thalassemia Awareness in West-ern India. *National Journal of Community Medicine*│*Volume*, *7*(3), 193–197. www.njcmindia.org

[23] Roth, I. L., Lachover, B., Koren, G., Levin, C., Zalman, L., & Koren, A. (2018). Detection of β-thalassemia carriers by red cell parameters obtained from automatic counters using mathematical formulas. *Mediterranean Journal of Hematology and Infectious Diseases*, *10*(1), 1–10. https://doi.org/10.4084/MJHID.2018.008

[24] Saeed, U. Z. Z. (2016). Thalassemia: Impact of consanguineous marriages on most prevalent monogenic disorders of humans. *Asian Pacific Journal of Tropical Disease*, *6*(10). https://www.sciencedirect.com/science/article/abs/pii/S2222180816611428

[25] Sari, N. M., Arini, I., Suryawan, N., Susanah, S., Reniarti, L., Achmad, H. R., & Idjradinata, P. (2020a). Evidence-Based Case Report: Screening Guidelines for Populations at High Risk for Thalassemia. *Sari Pediatri*, *21*(5), 322. https://doi.org/10.14238/sp21.5.2020.322-8

[26] Sari, N. M., Arini, I., Suryawan, N., Susanah, S., Reniarti, L., Achmad, H. R., & Idjradinata, P. (2020b). Evidence Based Case Report: Thalassemia Screening Guidelines for High Risk Population. *Sari Pediatri*, *21*(5), 322. https://doi.org/10.14238/sp21.5.2020.322-8

[27] Singh, R. K., Jha, N. K., Panigrahi, I., & Sinha, A. K. (2022). Awareness about thalassemia and its management among the caregivers of the thalassemia patients of Punjab and Chandigarh, India. *International Journal of Health Sciences*, *6*(March), 258–271. https://doi.org/10.53730/ijhs.v6ns3.5182

[28] Surjawan, Y., Tan, H. L., Setiabudy, R. D., & Rositawati, W. (2017). Early Screening of Hemoglobinopathy in Indonesia using Erythrocyte Indices. *Indonesian Biomedical Journal*, *9*(2), 99–105. https://doi.org/10.18585/inabj.v9i2.313

[29] Susanah, S., Sari, N. M., Prihatni, D., Sinaga, P., Trisaputra, J. O., Rakhmilla, L. E., & Sribudiani, Y. (2022). Extended family thalassemia screening as a feasible alternative method to be implemented in identifying carriers in West Java, Indonesia. *Journal of Community Genetics*, *13*(1), 103–112. https://doi.org/10.1007/s12687-021-00565-w

[30] Tuo, Y., Li, Y., Li, Y., Ma, J., Yang, X., Wu, S., Jin, J., & He, Z. (2024). Global, regional, and national burden of thalassemia, 1990–2021: a systematic analysis for the global burden of disease study 2021. *EClinicalMedicine*, *72*, 102619. https://doi.org/10.1016/j.eclinm.2024.102619

[31] Utami, S. T., & Kusumaningrum, N. S. D. (2020). Knowledge of Premarital Couples Regarding Premarital Screening Thalassemia. *Jurnal Keperawatan*, *11*(2), 180–187. https://doi.org/10.22219/jk.v11i2.10740

[32] Wildani, M. M., Triatmono, V. R., Yo, E. C., Mikhael, Yosia, & Wahidiyat, P. A. (2021). *Study protocol for a cross-sectional study on knowledge, attitude, and practice towards thalassemia among Indonesian youth*