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ORIGINAL ARTICLE

EDUCATIONAL INTERVENTION TO IMPROVE KNOWLEDGE AND ATTITUDES ABOUT THALASSEMIA PREMARITAL SCREENING SURVEYS AMONG MUSLIM SOCIETIES: A PILOT STUDY IN INDONESIA

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ABSTRACT

Premarital screening is an effective preventive intervention to decrease the prevalence of thalassemia. However, the use of premarital screening is still low in Indonesia. This study assesses the effect of educational interventions on the knowledge and attitudes of Muslim couples regarding premarital screening for thalassemia in Indonesia. This pilot study used a pre-posttest design that included 17 premarital couples in Banyumas District. The participant's knowledge and attitude regarding premarital screening for thalassemia were measured using a paper-based questionnaire before and after the intervention. The participants received a class-based lecture about thalassemia screening and were provided a handbook containing lecture material to read at home. The knowledge and attitude score was analyzed using Wilcoxon and Kruskal-Wallis test. The knowledge score significantly increased after the intervention, but the proportion of positive attitudes did not differ significantly. The participants knew that premarital screening for thalassemia was necessary; however, did not affect their marriage decision. Thus, educational intervention increases the knowledge and shapes the attitude of couples toward thalassemia premarital screening but is inadequate for changing their behavior. Further exploration of the factors that affect the behavior of couples is needed to increase the use of premarital screening among couples in Indonesia.

Keywords: *Attitude; education intervention; knowledge; premarital screening; thalassemia*

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INTRODUCTION

Thalassemia is an autosomal recessive genetic disorder of the blood that causes the human body to produce less hemoglobin. Genetic mutations and the level of expression influence the condition. The hereditary nature of thalassemia implies that the number of carriers will significantly affect the prevalence of the disease. Approximately 1.5% of healthy people in the global population are carriers of the mutant gene of β thalassemia, which leads to approximately 60,000 affected newborns annually (Lippi & Mattiuzzi, 2020).

The high medical costs for thalassemia treatment often form a financial barrier for its sufferers. Hematopoietic stem cell transplantation (HCT) is the only currently available procedure to cure the disease. However, it is expensive and unavailable to ordinary people (Santarone et al., 2022). This treatment includes blood transfusions, iron chelation therapy, nutritional supplementation, and surgical procedures. These procedures are resource-consuming because they must be provided for a lifetime (Chonat & Quinn, 2017). Therefore, preventive care, such as premarital screening, is the most effective and efficient way to reduce the prevalence of thalassemia. Premarital screening is one of the most frequent preventive efforts in various countries to reduce morbidity and mortality related to genetic disorders, especially thalassemia (Kisanga et al., 2021).

In Indonesian society, adequate knowledge and awareness of diseases caused by genetic disorders, including thalassemia, are still considerably low (Rujito et al., 2020). The screening of thalassemia carriers, such as premarital screening, tends to have a negative response from the community due to the low level of knowledge regarding the disease. This mainly occurs in traditional societies with rigid social norms and values, such as religious societies. Therefore, increasing people's knowledge regarding thalassemia and the related preventive efforts is crucial to preventing the disease (Angastiniotis & Lobitz, 2019). Moreover, a comprehensive understanding of thalassemia is required to reduce the mental burden felt by individuals with thalassemia when choosing a life partner (Hasanshahi & Khanjani, 2021).

Indonesia, a religious country with the world's largest Muslim population, has a relatively high incidence of thalassemia, with approximately 3-10% people being carriers, compared to Caucasian countries with below 1% prevalence (Wahidiyat et al., 2022). The Indonesian Thalassemia Foundation has conducted various efforts to increase people's knowledge of thalassemia in Indonesian society. These include providing information about thalassemia, such as brochures directly to the people, school-based education, and community empowerment, such as developing and training health cadres. Integrating thalassemia-related knowledge as part of schools' curricula is also an effective way to increase people's knowledge about the disease (Schmotzer et al., 2021).

However, the association between efforts to increase people's knowledge and premarital screening as the primary prevention of thalassemia has not been explored. Therefore, this study aims to conduct educational interventions for the targeted community to gain adequate knowledge of thalassemia and measure people's attitudes toward its screening. This study focuses on especially Muslim couples as the largest community in the country with conservative conduct regarding its religious rules. The pilot study took place in Banyumas District, Central Java, Indonesia, as one of the country's leading locations for both incident rate and service programs in Indonesia.

METHOD

Study design

This was a pilot study with a pre-posttest design. It assessed the differences in the level of knowledge and attitudes of premarital couples about thalassemia before and after the educational intervention.

Sample

The pilot study used the consecutive sampling method using the Lameshow formula $n = z1\text{-}\alpha/2P(1\text{-}P)/d^2$ with Z for 0.05 signifiance, d: 0.1, and proportion 0.23 to select 17 respondents (based on couples registered between the time frame of data collection). The inclusion criteria included newly married couples aged 19-35 years without a health statement. The exclusion criteria were respondents who have family members with genetic diseases. Couples who met the criteria and could participate in the research were then recruited. These couples planned to register their marriages at the Population and Civil Registration Office and Religious Affairs Office in Banyumas District, Central Java, Indonesia.

Instrument

The research instruments were a set of questionnaires related to premarital screening and booklets on thalassemia. The questionnaire was adopted and modified from a previous instrument (Hashemi-Soteh et al., 2019), and its validity and reliability were tested using Cronbach's alpha and Spearman tests before being administered to potential respondents. The respondents' demographic and other basic characteristic data were collected through this instrument. A tape recorder was used during the question-and-answer process to facilitate the interview.

Intervention

All participants went through the following process. Before the intervention, all participants received a questionnaire about their knowledge, attitudes, and behavior on premarital thalassemia screening. The knowledge section consists of 15 questions with a total score of 100. The questions for attitude were developed to assess how well the respondents understand, agree, and support the prevention program. The attitude section comprised of 12 questions with 6 main topics on a Likert scale with the following categories: agree, neutral, and disagree. It also consists of open-ended questions about the respondent's desire for the mass prevention program.
The education process was implemented in two steps. First, the respondents received a class-based education through a presentation of educational material about premarital screening for thalassemia, followed by an interactive discussion. This process was conducted by a physician who has expertise in thalassemia. Second, the respondents received a handbook containing educational material about premarital screening for thalassemia to read at home. The measurement of the respondents' knowledge regarding premarital screening for thalassemia and their attitude was repeated three days after the educational intervention using the same instrument.

Flowchart

Data collection

Data were collected using a structured interview instrument when the couple registered their marriage. Knowledge data were recorded on paper, while audio recordings were taken for the attitude questions.

Statistical analysis

A univariate analysis was conducted to describe the participants' basic characteristics. Data measured in a categorical scale were described using absolute frequency distribution and percentages. A non-parametric Wilcoxon sign-ranked test was employed to assess the difference in knowledge scores before and after the educational intervention. Non-parametric tests were employed because the data were not normally distributed, and data transformation failed to normalize the data distribution. For similar reasons, the Kruskal Wallis tests were performed to assess the changes in the participants' attitudes. These were categorized into three categories (agree, neutral, and disagree) before and after the intervention.

Ethical consideration

This study has been exempted from undergoing a full ethics review by the Health Research Ethics Committee, Faculty of Medicine, Universitas Jenderal Soedirman, with the reference number: 0803/UN23.07.5.1/PP.1/2019.

RESULTS

Muslim couples are the largest community that performs their marriage registration process at the religious department. This fact is correlated with the number of Muslim populations in Indonesia. The basic characteristics of this study's participants are displayed in Table 1.

Table 1. Participant's characteristics (n = 17)

Characteristics	% (n)
Gender	
Male	47.1 (8)
Female	52.9 (9)
Education level	
Low	11.8 (2)
Middle	76.4 (13)
High	11.8 (2)
Employment	
Unemployed	17.6 (3)
Formal workers	58.9 (10)
Informal workers	23.5 (4)
Place of residence	
Urban	17.6 (3)
Rural	82.4 (14)
History of genetic disorder	
Yes	-
No	100.0 (17)
Carrier attribute	
Yes	-
No	100.0 (17)
Family history of genetic disorder	
Yes	-
No	100.0 (17)
Consanguinity	
Yes	-
No	100.0 (17)
Source of screening-related information	
Internet	5.9 (1)
Social media	17.6 (3)
Unknown	76.5 (13)
History of genetic screening	
Yes	-
No	100.0 (17)

Most of the respondents are female (52.9%), have a middle level of education equal to junior and senior high school level (76.4%), work as formal workers (58.9 %), and live in rural areas (82.4%). Regarding genetic characteristics, none of the respondents have a history of genetic disorders, carrier attributes, consanguinity, and a family history of genetic disorders. Most of the respondents also have no previous knowledge or information related to genetic or thalassemia screening (76.5%), and none of them have undergone any genetic screening before.

The average knowledge score before and after the intervention, followed by both absolute and relative changes in knowledge score after the intervention are presented in Table 2. Overall, the respondent's knowledge score was higher after the intervention than before. The overall knowledge score after the intervention increased by 39% compared to before the intervention. The increase in the knowledge score varies among categories such as gender, educational level, and employment type. Female respondents had lower knowledge scores both before and after the intervention compared to the male respondents. However, the female respondents had a larger increase in knowledge score after intervention compared to male respondents. Based on socioeconomic status, the high level education group had the highest knowledge score both before and after the intervention compared to the lower groups. The same phenomenon was seen when comparing formal workers with informal workers and unemployed individuals. However, respondents who were low education level (11.8%) and unemployed (65%) experienced the largest increase of knowledge score after the intervention.

Table 2. The average knowledge score of the respondents before and after the intervention (n = 17)

	Average knowledge score (%)		Change of knowledge score (%)	
	Before the intervention	After the intervention	Absolute	Relative
Overall	56.1	78.0	21.9	39.0
Gender				
Male	63.7	82.2	18.5	29.0
Female	47.5	73.3	25.8	54.3
Education level				
Low	30.0	63.3	33.3	111.0
Middle	50.9	76.1	25.2	49.5
High	86.7	93.3	6.6	7.6
Employment				
Unemployed	44.4	73.3	28.9	65.1
Formal worker	62.7	84.0	21.3	33.9
Informal worker	48.3	68.3	20.0	41.5

The participant's attitude toward premarital screening before and after the intervention is displayed in Table 3. In general, the respondent's attitudes toward premarital screening show fewer positive results after intervention with a higher number of respondents who opted for "neutral" or "disagree" from previously choosing to "agree" on several items. For instance, the number of respondents who agreed on the importance of premarital screening decreased from 70.6% before intervention to 58.8% after intervention. Similar findings were also found in the respondent's attitudes toward the possibility of premarital screening becoming a mandatory requirement for marriage as well as the implementation of government regulation to prevent marriage with positive screening results. However, some favorable changes in the participant's attitudes were also found. For instance, the number of respondents who recommended earlier screening increased from 0% to 11.8%.

Table 3. The respondent's attitude toward premarital screening before and after the intervention (n = 17)

Attitude parameter	Respondent's attitudes	
	Before the intervention % (n)	After the intervention % (n)
Premarital screening is important		
Agree	70.6 (12)	58.8 (10)
Neutral	29.4 (5)	41.2 (7)
Disagree	0.0 (0)	0.0 (0)
Agree to do premarital screening with a partner		
Agree	88.2 (15)	88.2 (15)
Disagree	11.8 (2)	11.8 (2)
Premarital screening is a mandatory procedure		
Agree	58.8 (10)	35.3 (6)
Neutral	41.2 (7)	58.8 (10)
Disagree	0.0 (0)	5.9 (1)
Most appropriate screening time		
Before marriage	88.2 (15)	70.6 (12)
During high school	11.8 (2)	17.6 (3)
Early	0.0 (0)	11.8 (2)
Marriage decision when screening results is positive		
Continue to marriage due to faith in God	70.6 (12)	47.1 (8)
Continue to marriage and willing to take the risk	17.6 (3)	29.4 (5)
Cancel the engagement/marriage	5.9 (1)	0.0 (0)
Do not know	5.9 (1)	23.5 (4)
Government regulation to prevent marriage when screening result is positive		
Agree	17.6 (3)	11.8 (2)
Neutral	64.8 (11)	58.8 (10)
Disagree	17.6 (3)	29.4 (5)

Table 4 and Table 5 exhibit the changes in knowledge score and the percentage of the respondent's positive attitudes before and after the intervention. The participant's average knowledge about premarital screening increased significantly after the intervention (78.04) compared to the average score before the intervention (56.08), as indicated by the p-value of 0.002.

Table 4. Change of knowledge score before and after intervention

Variable	Score (average%)		p-value
	Before	After	
Knowledge	56.08	78.04	0.002

Table 5. Changes of participant's attitude toward premarital screening before and after intervention

Attitude parameter	p-value
The importance of premarital screening	0.900
Premarital screening as mandatory procedure	0.293
Most appropriate screening time	0.352
Marriage decision due to positive screening result	0.264
Regulation to prevent marriage when screening result is positive	0.696

DISCUSSION

This study assessed the effect of educational interventions on the knowledge score and attitude toward premarital screening in Muslim couples living in Banyumas, Central Java, Indonesia. This study found that the respondents' knowledge regarding premarital screening significantly increased after the educational intervention compared to their knowledge before the intervention. However, the educational intervention did not significantly affect the respondents' positive attitude toward premarital screening.

This study found that educational intervention significantly improved the knowledge of the respondents. This finding is similar to a previous study conducted in Saudi Arabia which showed that health education interventions significantly increased the level of the student's knowledge related to Sickle Cell anemia (Kotb et al., 2019). Another study on the multiethnic population in Malaysia showed a significant increase in the level of respondents' knowledge as well as the agreement to the premarital screening program after the educational intervention. Moreover, this study underlined two most important factors which may further stimulate the respondents to conduct premarital screening: comprehensive information related to screening and the availability of screening facilities (Mohd Nor et al., 2022).

In this study, the respondents' knowledge scores were relatively low before the intervention. This is understandable because information about thalassemia and their preventive programs, such as premarital screening, is still limited in public media. Those with better information access are likely to have better knowledge. This can be confirmed by the relatively high score for respondents with high educational backgrounds (university level), implying that respondents with higher education have better information access and perhaps multiple information sources, resulting in a higher knowledge score. Several studies have confirmed the important role of education in health information access, particularly for preventive healthcare (Chen et al., 2019; Soroya et al., 2021).

In terms of knowledge increase, this study showed that respondents with low socioeconomic status (e.g., low-educated and unemployed respondents) experienced a larger increase in knowledge compared to their counterparts. This finding is similar to previous studies in Oman and Saudi Arabia (Al-Kindi et al., 2019). As the lower socioeconomic groups had much lower knowledge scores before the intervention compared to the higher socioeconomic groups, the probability of having a larger increase in knowledge scores becomes higher. For the higher socioeconomic groups, because their knowledge score is already high before the intervention, the increase of the knowledge score after the intervention is likely to be lower. This phenomenon is also known as the "ceiling effect" and is commonly found in studies related to health information (Svendsen et al., 2020).

Furthermore, the results from this study showed that the respondents' positive attitudes toward premarital screening did not increase and even decreased after the educational intervention. This result is different from a previous study in Cambodia which showed that knowledge and attitude towards preventing and controlling severe thalassemia and particularly the intention to undergo premarital screening improved considerably in the intervention group (Cheng et al., 2018). This difference can be explained by assuming that the positive response before the intervention represents a standard view of a value that is considered similar among individuals. Knowledge, motivation, and information interventions would increase the understanding of the proposed value conditions (Asbjørnsen et al., 2020). As a result, this will affect the attitude and values of the subject by considering the consequences of their positive attitude contrary to other social norms such as religious values, tradition, and cultural norms, which may lead to a more negative attitude toward premarital screening. In a society with a very heterogeneous background, the variation in attitude represents the variation in the respondents' literacy and ethnic origins (Al-Qattan et al., 2019). As previously mentioned, educational intervention potentially improves people's perception of thalassemia and their preventive care. However, this is still a formidable challenge in Indonesia due to ethnic diversity, its vast region, and cultural differences (Andodo et al., 2019; Rujito & Mulyanto, 2019; Widayanti et al., 2020).

Another plausible explanation related to the insignificant effect of an educational intervention on changing respondents' attitudes toward premarital screening is that the nature of thalassemia is described as a hereditary disease, which does not directly affect the respondents' current health condition. The study showed that the absence of clear and immediate signs and symptoms of the disease tend to negatively affect people's attitude toward the disease (Widayanti et al., 2020). Moreover, based on the health belief model, obtaining knowledge of the disease is not a warranty for achieving a cure (Luquis & Kensinger, 2019). A previous study also showed that the increase in knowledge and understanding related to the disease might drive the respondents to avoid screening due to the consequences of the screening results (Jaka et al., 2019).

The complexity of factors that influence a participant's attitude toward premarital screening is clearly described by the findings related to marriage decisions after premarital screening results. Most respondents were willing to take health risks by continuing the marriage, although their screening result showed significant health risks and suggested that the marriage should be cancelled. This finding is similar to a previous study of a screening program for sickle cell disease and β-thalassemia in Saudi Arabia. Most respondents decided to continue marriage regardless of the unfavorable screening results (Al-Shroby et al., 2021). A previous study in Indonesia found that after going through premarital screening and education, couples that made individual decisions tend to have a conflict with their partners. For Muslim couples, particularly in Indonesia, the marriage decision generally involves each partner's extended family, complicating the decision-making process (Rizkianti et al., 2020).

Although premarital screening programs were unsuccessful in discouraging at-risk marriages, another study showed that it is likely to reduce the prevalence of affected births in countries given the adequate availability of prenatal detection and therapeutic abortion (Chakravorty & Dick, 2019). These options may provide opportunities for more advanced educational intervention using information technology that may suit millennials (Marshall et al., 2019). Efforts should start at the early stage to maximize the outcome of educational intervention by incorporating the program into formal education from the elementary level (Jansen et al., 2019).

Considering that attitude and behavior are heavily influenced by contextual factors such as religious values, social norms, and tradition, education interventions that aim to increase the public's knowledge of the general population and not only the specific population, such as couples, become fundamental. According to previous studies, a positive attitude relates to the health education provided. Therefore, teaching is essential for increasing public attitudes in the community and needs to be implemented as part of the formal education curriculum to promote a healthy lifestyle and prevent diseases. These efforts include counseling, interactive quizzes, and screening services (Joh et al., 2017).

This study reveals some prominent data for the Indonesian population. However, there are still several weaknesses that can be considered for further research. Future studies should improve this study's number of respondents and lack of controls.

CONCLUSION AND RECOMMENDATION

In conclusion, this study showed that the proposed educational intervention successfully increased the respondent's overall knowledge but did not positively affect their attitude toward premarital screening for thalassemia. The positive attitude toward premarital screening is likely related to the complexity of marriage decisions in the Indonesian context, which is often a collective decision of extended families influenced by religious values, social norms, and tradition rather than the participant's individual decision. Therefore, to be more effective, health campaigns are needed not only for a specific population (i.e., couples) but for the general population to increase public awareness and shape public attitudes toward the disease. A continuous, comprehensive, and integrated educational intervention that starts in the early stages of learning and is incorporated into formal education is likely to increase the public's knowledge and shape a positive attitude and behavior toward thalassemia and its prevention.

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