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The Influences of Medical Students' Consent to Participate in Thalassemia Research

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Home > Journals > Faculty of Public Health > KESMAS > Vol. 19 (2024) > Iss. 2

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Case Study

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The Influences of Medical Students' Consent to Participate in Thalassemia Research

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Abstract

An effective way of learning about thalassemia, a complex public health issue with multiple perspectives, is through participating in research. This study used an inductive approach to presume the influencing factors of students' consent to participate in thalassemia research voluntarily. Nested in the preliminary stage of a research series on thalassemia, this study used a consecutive sampling to recruit 140 medical undergraduates. Their knowledge, experience, and attitude to thalassemia and the perception of self-quality life were assessed using self-administered questionnaires. Blood samples were drawn for carrier screening. Students' GPAs were collected from faculty records. Of 140 participants, only 123 had at least heard of thalassemia, and their data was used in the analysis. Most participants had fairly good but incomplete knowledge of inheritance patterns, antenatal screening, and thalassemia management. Premarital screening was known and received the most positive attitudes from participants. Inductively, academic performance and carrier status curiosity were presumed to influence students' consent to participate. With the limitation of an inductive approach, further study with a specific design is needed to closely investigate student perspectives on research and their drives to get involved.

Keywords: consent, influence, knowledge, medical student, thalassemia

Introduction

In Southeast Asia, thalassemia is known to be the most common manifestation of hemoglobinopathy.[1] Historically, this inherited blood disorder was frequently found in malarial enclaves and assumed to confer a benefit of selective survival on thalassemia heterozygotes from the severe adverse effects of malaria. This natural selection may have also placed Indonesia, the second-largest malaria endemic area in Southeast Asia, into the thalassemia belt. Until now, the magnitude of the thalassemia problem in Indonesia remains a public health concern, with the number of cases expected is expected to continue to increase from time to time.[2]

Indonesia has had a strategic plan for thalassemia prevention since 2010[3], which primarily translated into various program activities such as health promotion, formal education, carrier screening, premarital counseling, and prenatal diagnosis.[4-6] However, these efforts have not yet been able to significantly suppress new emerging cases since health service inequality is still a challenge triggered by geographic differences, socioeconomic discrepancies, and inequitable distribution of health providers and required facilities within the country.[2,7]

Approximately 2,500 babies are born with beta-thalassemia (ß-TM) mayor yearly.[8] In 2019, the annual average cost to get optimal treatment for a thalassemic patient reaches up to IDR 300-400 million (USD 1,8642.72 – 2,4856.96), and this cost will increase as the patient ages and the complications they experience.[9] Such spending burdens the individual patient or their family and causes an enormous financial burden within the government health insurance scheme, estimated at IDR 900 billion (USD 559,281.6) per year.[10]

To date, information on the magnitude of thalassemia-related public health burdens has not received proportionate public attention in Indonesia. Efforts to work on thalassemia as a type of anemia have not yet been part of the health promotion to reduce anemia cases. That being concerned, the campaign for anemia due to iron deficiency is much more intensive, far surpassing the slow outreach of the other common variants of anemia, such as thalassemia.

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In other words, public ignorance is also a major obstacle in the efforts to control thalassemia thus far.[2]

The lack of public awareness of thalassemia in Indonesia is allegedly due to inadequate general knowledge, even among prospective health workers, about what thalassemia is and how to deal with it. Within the last decade, linkages between knowledge, awareness, attitude, and behaviors related to thalassemia have been studied among different respondents in various settings in Indonesia.[11-16] Trials to elevate knowledge of thalassemia among respondents with multiple characteristics have consistently proven effective in creating awareness or adherence to certain positive attitudes and behaviors.[17-20] The act of providing relevant information could also lend psychological support,[21] reduce anxiety,[22-23] improve self-esteem,[24] and increase resilience for both thalassemia patients and those closest to them.[21]

It is fundamental to do effective promotional education activities to disseminate information on thalassemia.[25] For this purpose, the public health system needs capable, trustworthy, and easy-to-consult resource persons. There is a high expectation for a medical doctor to at least be a competent resource person to deliver education on thalassemia or even provide quality healthcare for people with thalassemia. To build up such relevant knowledge and skills during their study time, the institution should organize various teaching and learning methods, one of which is through research activities. Although it is knowledge-dense, the involvement of students in research activities is optional, especially for undergraduates; hence, it requires their consent to participate, which could sometimes be very minimal. Meanwhile, factors which could motivate medical students to participate in research, particularly those requiring somewhat invasive procedures,[26] such as blood sampling, have yet to be studied.

In 2021, the Faculty of Medicine at a university in Jakarta initiated a research series on thalassemia. In phase I of this study, participants were selected from the university medical students who voluntarily enrolled after the outreach of research. The outreach conveyed to the attendants the need for blood sampling from all participants for carrier screening. As part of the research series, this study aimed to comprehend students' knowledge and attitudes to issues related to thalassemia. An additional analysis of their profiles was also carried out to determine influential factors to the students' consent to volunteer using an inductive approach.

Method

To find out more about thalassemia from various perspectives, a series of research was planned. Carried out as a cross-sectional descriptive study in May-June 2021, this was the preliminary stage of the series. This study included undergraduate students from the 2016-2020 batches of the Faculty of Medicine of a private university in Jakarta, Indonesia, who registered voluntarily online or offline. A consecutive sampling technique was applied to correspond with the study objectives. Recruiting participants began with the outreach directly to the students, both through online and offline.

The online session was delivered on May 24, 2021, followed by consecutive offline sessions from June 23-29, 2021. These sessions allowed dialogue between the attendants and the research team members on the study objectives, methodology, and data collection process. Participants in this study must be active undergraduate medical students; domiciled in Jakarta; not suffering from chronic diseases and/or not having blood transfusion within three months prior to blood collection; healthy during data collection; had heard of thalassemia; and not having an increase in leukocytes greater than 20% of the normal value range.

A formula to estimate a single proportion of the degree of participation was applied to calculate the sample size. With a total of 619 students from batch 2016-2020, a finite population correction (FPC) was applied to adjust the final sample size. The sample size calculation formula with an FPC was:

$$n = \frac{\frac{Z^2.(1-p)}{e^2}}{1 + \frac{Z^2.(1-p)}{e^2N}}$$

For estimating 90% of the participation level with a 95% confidence level ($Z\alpha/2$ = 1.96) and a 5% margin of error (e), the minimum sample size required after the correction was 113 participants. Voluntary participation in medical-related studies that include invasive procedures might be low, even among medical students. This study showed that of 619 active students, 60.6% (n=375) attended the study outreach. Of the 375 students attending the outreach sessions, 140 voluntarily registered in the study. Of these 140 students, 17 (12.1%) had never heard of thalassemia; thus, their responses were considered irrelevant and excluded from the analysis. Yet, using non-probability sampling technique, the composition of participants still resembled the composition of the 2016-2020 student population with a male/female ratio of 1 to 2 and slightly fewer participants from the earlier batches (the year 2016-2018: 45%) than from the latest batches (the year 2019-2020: 55%).

As illustrated in Figure 1, the presumed influential factors to students' participation in research were regarded as variables under study whose indicators were collected using three different methods. Knowledge, attitude, and experience related to thalassemia, perception of quality of life, sociodemographic status, and participants' economic status were assessed using self-administered online (Google Forms) questionnaires (as coded with Q1 – Q4). The data on students' grade point average (GPA) was obtained from the faculty record. A 7 ml venous blood sample was also collected from each participant in two 3 ml etilena diamina tetra asetat (EDTA) tubes for three levels of carrier screening.

The blood sampling was done by skilled analysts from Laboratory X in six batches from June 23 to 29, 2023. The first level screening was done using a Complete Blood Count (CBC), which comprises Hb, MCV, and MCH. The CBC was assessed using the Flow Cytometry Method Using a Semiconductor Laser (Sysmex-XN®). These biochemical assessments were carried out by Laboratory X in compliance with ISO Standards (SNI ISO 15189 has been accredited by the National Accrediation Committee with certificate no LM-013- IDN). The procedures of the second and third level screening would be reported elsewhere (in progress) because only the results of the first level screening were presented here.

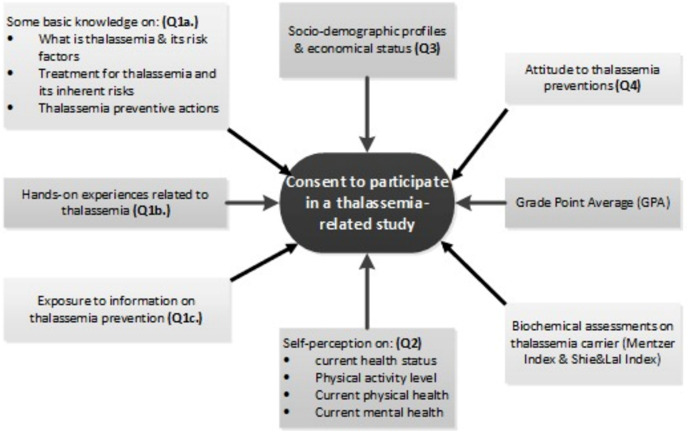


Figure 1. Conceptual Framework of the Preliminary Study

This study collected two types of data, categorical and continuous data, analyzed using SPSS Statistics for Windows version 26.0 (licensed until 2032). Responses from questionnaires were mostly categorical and presented as proportions. For responses on Q1.a, Q2, and Q4 were transformed into scores so that they could be treated as continuous data as well as regrouped into ordinal data (i.e., low, medium, and high scores). All continuous data were checked for their data distribution graphically using eye-ball observations and statistically using the Kolmogorov-Smirnov test combined to further determine the statistical tests for more analytical purposes.

The results of blood biochemical tests were used to detect the participant's pathophysiological conditions, such as anemia and/or suspected thalassemia carriers. The sex-specific World Health Organization's standards were applied to determine an anemic condition based on Hb level with <13 g/dL for anemic men and <12 g/dL for anemic women.[27] For those with anemia, further examinations were also carried out to determine whether the person concerned was suspected of thalassemia carrier. Following the national guidelines for medicine services management of thalassemia,[5] those with MCV<80 fl and/or MCH <27 pg were initially (1st level) suspected of thalassemia. A combination of the Mentzer index (MCV/RBC) and the Shine&Lal index ($MCV^2*MCH/100$) could also be utilized to sort out those with suspected thalassemia carriers.[28,29] Participants with Mentzer index <13 and Shine&Lal index <1530 were considered suspected Beta-thalassemia carriers.

Results

Analyses were performed based on only 123 datasets. The participants were 18-26 years old, with an average age of 20. None of them were married or had children. Most were Muslims (78.6%; n=97) and Christians (18.6%; n=23).

Based on the World Bank categories,[30] 22.9% (n=28) of participants came from the lower middle-income group, while more than half (77.1%; n=95) came from the upper middle to high-income group. Most students (79.7%; n=98) had been exposed to relevant information from lectures at the faculty, 13.8% (n=17) from TV, and very few (6.5%; n=8) from unspecified sources. Based on their experience, only 11.4% (n=14) have ever met a child with thalassemia or even donated blood to a child with thalassemia (3.3%; n=4). Although it could not be determined which happened first, experience or exposure to information, it was noticed that among those with backgrounds (14.6%; n=18), all had been exposed to some information, whether it be from lectures (11.4%; n=14) or news on TV (3.3%; n=4). Most participants (95.9%; n=118) also expected the government to raise public awareness of thalassemia through printed and electronic media.

The participants were dominated by those with optimal academic achievement (GPA 2.5-3.5: 69.9%; n=86), some from a less academic group (GPA <2.5: 20.3%; n=25), and even fewer from the high achievers (GPA >3.5: 9.8%; n=12). Only the 2020 batch had the number of participants equally divided between low and optimal achievers. The number of low achievers then decreased drastically in earlier batches. A significant difference in knowledge related to thalassemia prevention could only be detected between those with GPA <3.0 and those with GPA ≥3.0. Within the range of minimal and maximum scores of 0-4, the median score (4) of students with high GPAs was statistically higher than the median score (3) of those with low GPAs (p-value <0.05; Mann-Whitney U test). Besides, no other statistical differences were found between groups related to all aspects (knowledge, experience, attitude, and self-perception), including those between batches. Therefore, the overall analysis was then carried out using combined data, and the results were presented descriptively without any segregation between those with different batches or levels of GPA.

None of the participants knew whether they were thalassemia carriers or not. Of 123 participants, 13.8% (n=17)—all female—were anemic. Based on the first screening level, more than half of these anemic cases (n=10) were also suspected of thalassemia. While using MI and SLI combined, two anemic female participants were also suspected of beta-thalassemia. Three domains of knowledge were tested on the participants: a) what thalassemia is and its inherited pattern; b) prevention of thalassemia; and c) treatment for thalassemia. Overall, the participants' knowledge was high, with a median score of 10 (min-max: 1-15). As seen from Table 1, knowledge of what thalassemia is could be answered correctly by most participants (>90%). Still, the proportion sharply decreased when being asked about the roots of this condition (<60%). Only 60.2% (n=74) answered that thalassemia could be prevented, yet most participants (95.9%; n=118) answered correctly that premarital screening was equally crucial for males and females.

However, 33.5% (n=41) did not know that antenatal screening could work effectively. Compared to the first two knowledge domains, knowledge related to thalassemia treatment appeared to be much less, with the most significant proportion being 72.4% (n=89) for non-specific knowledge of thalassemia, repeating blood transfusion carries a risk. The participants could provide correct answers (60.2%; n=74) at most for 8-11 of 15 knowledge-related questions (Figure 2). This proportion was dominated by participants' correct responses on 2-5 questions on thalassemia and its causes (93.5%; n=115), 2-4 questions for thalassemia prevention (92.7%; n=114), and 2-4 questions for thalassemia treatment (61%; n=75).

Coherent with participants' knowledge of the methods to prevent thalassemia, premarital screening received the most positive attitude (98.4%; n=120) compared to the other preventive ways (Table 2). More than half of the participants were willing to undergo this kind of screening voluntarily, even though it was not mandatory. While, positive attitudes for other preventive ways only came from about two-thirds of the participants, and the proportion was even smaller (26.2%; n=32) when it related to the termination of pregnancy with a thalassemia major fetus. Most participants (81.3%; n=99) gave only one to two reasons that a pregnancy with a thalassemia major fetus would cause difficulties to the child (71.5%; n=87) or his family (33.3%; n=41) if maintained. Yet, the majority (64.8%; n=79) gave no opinion about pregnancy termination.

In this study, eight features were used to describe the quality of life as a whole, including self-assessment of the overall health (1 set of questions), physical conditions (3 sets of questions), vitality (1 set of questions), mental conditions (2 sets of questions), and even social functions (1 set of questions). As seen in Table 3, the participants' responses generally tended to be positively skewed as they valued themselves as healthy and normally functioning physically, mentally, and socially. Yet, when it comes to the self-perceived on broader or more abstract features like overall health, vitality, and mental health, their responses tended to be diverse and represented more the picture of a population's normal distribution.

Table 1. Participants' Knowledge of Thalassemia (N=123*)

Knowledge	Correct answer n (%)
What thalassemia is	
1. Thalassemia is a genetic disease	120 (97.6)
2. Thalassemia originates from a blood disorder	122 (99.2)
3. There are two types of thalassemia	71 (57.7)
4. A normal person could genetically have thalassemia minor	67 (54.5)
5. A child will not suffer from thalassemia if only one of the parents genetically has thalassemia minor	14 (11.4)
6. A normal person could marry a thalassemia carrier	86 (69.9)
Prevention of thalassemia	
1. Thalassemia could not be transmitted from food	105 (85.4)
2. Thalassemia could be detected during pregnancy	83 (67.5)
3. Thalassemia is preventable	74 (60.2)
4. Premarital screening for thalassemia needs to be done on both men and women	118 (95.9)
Treatment of thalassemia and its inherent risks	
1. Repeated blood transfusion is the way children with thalassemia can survive	69 (56.1)
2. There is a permanent solution for thalassemia	48 (39.0)
3. Repeated blood transfusion carries a risk	89 (72.4)
4. Therapy using iron chelating agents can be recommended for children with thalassemia	40 (32.5)
5. There are precautions/prohibitions for certain types of food for those with thalassemia	39 (31.7)

Table 2. Attitude to Thalassemia Prevention (N=122*)

	Attitude (%)		
Pregnancy with **a fetus detected as a carrier of thalassemia major**		**Reason**:	
- Kept it	9.0 (n=11)	Difficulties to the child (n=3); burden to the family (n=3); ethical issue (n=4) **gave no reason at all (n=1); gave only one reason (n=10)**	
- Terminated it	26.2 (n=32)	Difficulties to the child (n=30); burden to the family (n=12); burden to the country (n=3); death risk (n=1) **gave only one reason (n=21); gave more than one reasons (n=11)**	
- Do not know	64.8 (n=79)	Difficulties to the child (n=55); burden to the family (n=26); burden to the country (n=6); ethical issues (n=3); break the chain of disease (n=1) **gave no reason at all (n=12); gave only one reason (n=49); gave more than one reasons (n=18)**	
Premarital screening for thalassemia is **necessary**		M**arriage between** couples who are **both thalassemia carriers**	
- Yes	98.4	- Just fine	32.8
- No	1.6	- Should not	67.2
Want to have a premarital screening independently although it is not yet mandatory in Indonesia		**Carriers couples for getting pregnant**	
- Yes	54.9	- Just fine	33.6
- Maybe	41.8	- Should not	66.4
- No	3.3		

*one respondent gave no responses to this set of questions

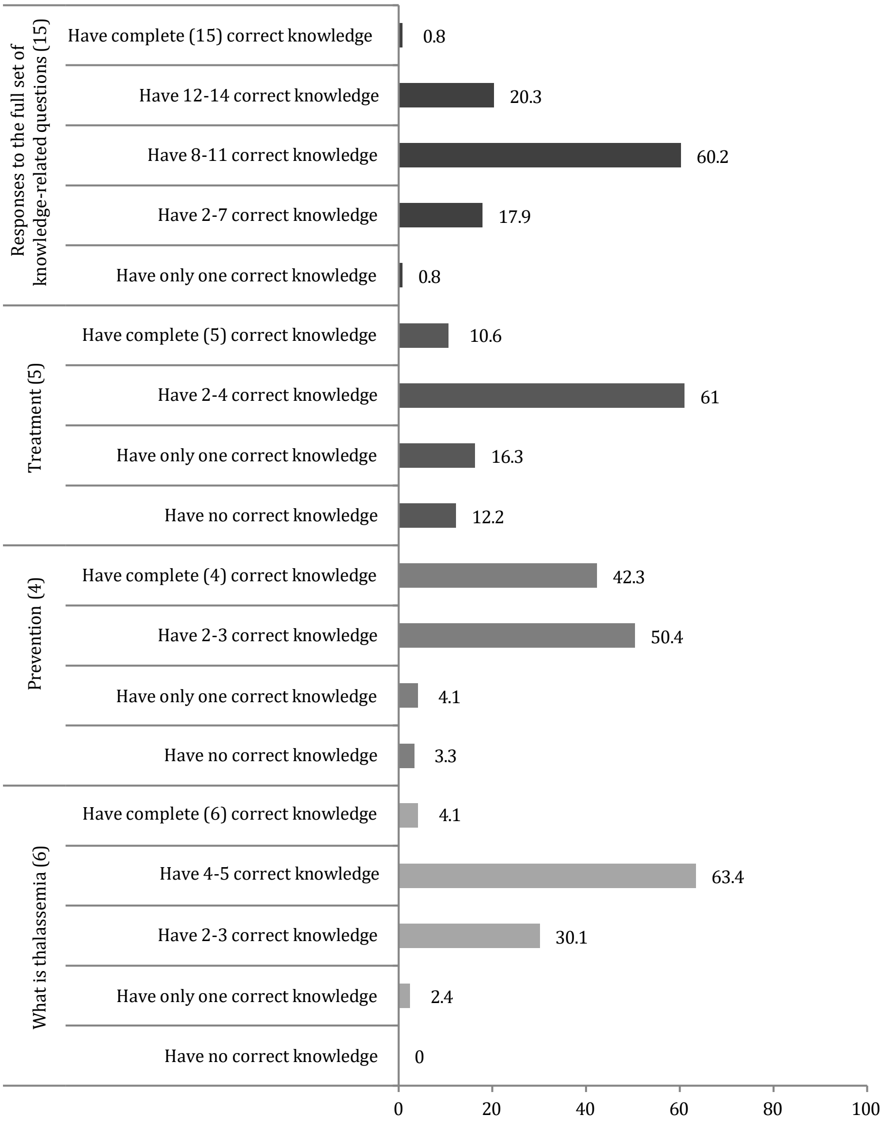
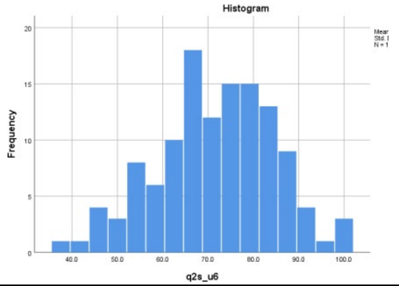
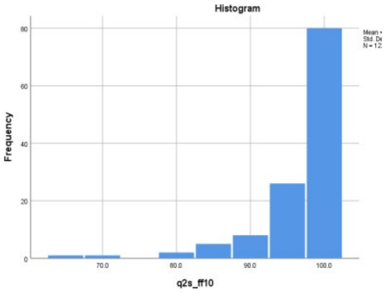
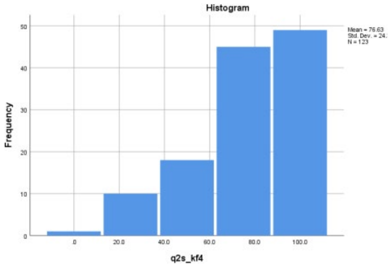
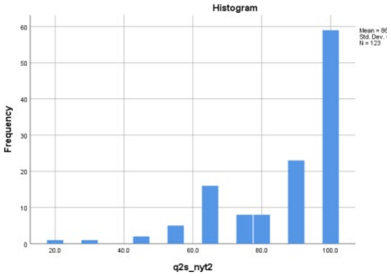
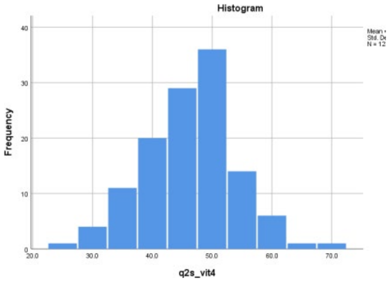
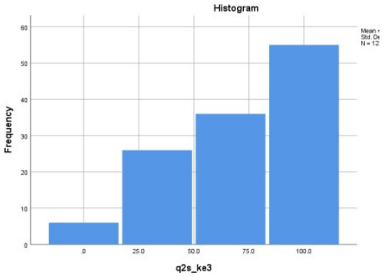
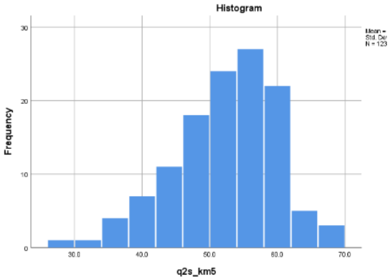
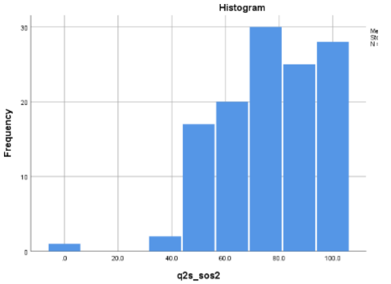


Figure 2. Proportion Distribution of Participants with Correct Knowledge of Thalassemia (N=123)

Table 3. Perception of the Self-Quality of Life (N=123)

Sub-variable	Statistics*	Score distribution
General health (6 questions) 1. How would you describe your current health condition? 2. How is your health now compared to one year ago? 3. I feel like I get sick a little easily 4. I am as healthy as anyone else 5. I feel my health is getting worse 6. My health is very good	70.8 (37.5 - 100.0)	

	Physical functions (10 questions) 1. Activities that require a lot of energy, lifting heavy objects, doing strenuous exercise 2. Light activities such as moving tables, sweeping, jogging/leisurely walking 3. Lifting or carrying light items (e.g. groceries, bags) 4. Climb some stairs 5. Climb one stair 6. Bending the neck/hands/legs, prostrating or bowing 7. Walk more than 1.5 km 8. Walk through several alleys/1km 9. Walk through one alley/0.5 km 10. Take a shower or wear your own clothes	100.0 (65.0 - 100.0)	
	Physical limitations (4 questions) 1. Spending all your time doing work or other activities. 2. Finishing work not on time. 3. Limited to some work or other activities. 4. Experiencing difficulty in doing work or other activities (for example those that require extra energy such as jacking/carpentry, washing)	75.0 (0.0 - 100.0)	
	Body soreness (2 questions) 1. How much pain have you felt in your body during the last 4 weeks? 2. In the last 4 weeks, how much did the pain interfere with your daily work (including work outside the home and work inside the home)?	87.5 (20.0 - 100.0)	
	Vitality (4 questions) 1. Do you feel full of enthusiasm? 2. Do you have a lot of energy? 3. Do you feel bored? 4. Do you feel tired quickly?	45.0 (25.0 - 75.0)	
	Emotional limitations (3 questions) 1. Spending all your time doing work or other activities 2. Finishing the job takes less time than usual 3. When carrying out work or other activities, you are not as careful as usual	66.7 (0.0 - 100.0)	

	Mental health (5 questions) 1. Are you a very nervous person? 2. Do you feel very depressed and nothing cheers you up? 3. Do you feel calm and peaceful? 4. Do you feel hopeless and sad? 5. Are you a cheerful person?	52.0 (28.0 - 68.0)	
	Social function (2 questions) 1. In the last 4 weeks, how much did your physical health or emotional problems interfere with your usual social activities with family, friends, neighbors or your group? 2. In the last 4 weeks, how often did your physical health or emotional problems affect your social activities (such as visiting friends, relatives, etc.)?	75.0 (0.0 - 100.0)	

***Median (min-max)**

Discussion

Delivering education on thalassemia takes a challenging and complex process. With the gene inheritance pattern from parents to offspring, carrier screening might create a fear of stigmatization.[25] Several prevention methods, such as avoiding or terminating a pregnancy, may arouse serious controversy and even outright rejection because they conflict with existing norms, or are invasive.[31,32] Moreover, efforts to convince thalassemia major patients or their families to strictly adhere to lifelong treatment could be hampered by many issues, such as financial problems, time constraints, resistance to pain, and mental depression.[33] In this context, more than just relevant medical knowledge is needed to enable a doctor to carry out the function of a health educator.

Solid medical knowledge may enable one to select and construct supportive fundamental messages precisely. However, concordance should be pursued regarding more delicate or sensitive issues, not just adherence or compliance.[34] Specific skills must also be mastered to verbally communicate (ideally in an understandable lay language) on thalassemia, its consequences, or the reasons for recommending a way out or solution. Also, it is a proper attitude that must objectively underlay specific medical advice whenever considered the best option.[35] Only then would the patients probably comprehend better the basis of their decision-making less clouded by incorrect or irrelevant perspectives.

That being said, only some of the participants could meet the above criteria, even just assessed by their levels of knowledge and attitude. Although their overall knowledge was good, it was patchy in some specific issues: inheritance patterns, antenatal screening, and treatment of thalassemia. However, the coherence of knowledge and attitude was noticed in this study, just like premarital screening, which was known by and received a positive attitude from most participants (>90%). This attitude might be predisposed by students' understanding that thalassemia is an inherited disorder and their unmarried status. However, the pattern of inheritance following Mendel's law for recessive genes was unknown by the majority (88.6%). Perhaps a positive attitude to premarital screening was also driven by considerations that other options, such as termination of pregnancy, were too risky, against the existing norms, conflict with their personal views or beliefs, or might give rise to ethical controversy.[31]

Age, sex, and years of education did not determine differences in knowledge and attitude on thalassemia among these undergraduate participants. A study in Semarang, Central Java, among medical students also reported similar findings, except that the year of education was significantly associated with knowledge and attitude.[13] Other studies among similar target groups reported significant associations between sex and knowledge,[36] age and attitude,[35] or age and knowledge.[37] Their educational performance, as indicated by the GPA, seemed only to differentiate the elementary level of knowledge of thalassemia prevention, but not about attitude or even experience. This association between GPA and knowledge somewhat aligned with their response that the faculty's lecture was their primary information channel on thalassemia. As a caveat, the topic of thalassemia given through lectures was very short in duration and not repetitive

(2 x 50 minutes in only one semester). Much detailed information might be forgotten when piled up with other course materials. The experience of thalassemia among the participants was too minimal to be associated with any factor aside from their rare exposure to thalassemia cases, direct or indirect. Perhaps it was because the participants were still students with no intense exposure to specific cases, including thalassemia, on top of their patchy knowledge.

One effective way to build positive attitudes and gain hands-on experience simultaneously with knowledge for medical students is through volunteering,[36] including in research. Therefore, understanding the underlying factors of students' interest in research to the point that they were willing to participate was just as important as exploring an engaging teaching method. However, this study has shown that student's willingness to participate voluntarily in research could be low regardless of their high attendance in the outreach session. There was also an indication that their interest was not necessarily driven by the proximity of their educational background to the scientific field of a given research.

An interesting finding was the dominance of students with optimal academic performance as this study participant, also found among undergraduate medical students in Dubai.[36] It was assumed that the optimal achievers' group may have different motives and attributes in viewing or responding to any existing opportunities compared to other groups. The phenomenon of the number of participants with low and optimal GPAs being equal only in the latest batch might indicate that students initially had similar attributes, which then became diverse in corresponding to the changes in learning demands and patterns in line with their studying period.

Even though it was known that a small number of participants were carriers of thalassemia, none of them knew about their condition because they had never been independently screened before, and most perceived themselves to be in reasonably good health. Curiosity to see whether they are carriers could be the driving factor for their participation in this research, even though their blood samples must be taken. However, on the other hand, it is yet to be known whether the lack of consent among non-participants was due to objections to blood sampling.

Using an inductive approach to identify influencing factors of consent to volunteers based on participants' characteristics has a limited scope of interpretation because there is no comparative data on the features of the non-participant group. Since factors such as age, sex, marital status, economic group, years of education, and perceived self-quality of life of the participants resembled the profile of the 2016-2020 students' population, no underlying factor of students' consent could be presumed within this cluster of variables as another limitation of an inductive approach.

Conclusion

In general, knowledge of thalassemia among the study participants is quite good, even though they are patchy on issues regarding inheritance patterns, antenatal screening, and treatment for thalassemia. The attitude to premarital screening is mostly positive, supported by the knowledge that thalassemia is an inherited disorder. The limitation of the inductive approach and the absence of a comparison group (non-participants) become constraints in identifying the influencing factors for student consent to participate. Academic performance and curiosity about career status are presumed to be the influential factors. Further studies must be specifically designed to analyze determinants for medical students' consent to participate, particularly in a study with complex subjects that must be understood from multiple public health perspectives, such as thalassemia.

Abbreviations

FPC: finite population correction; GPA: grade point average; CBC = complete blood count.

Ethics Approval and Consent to Participate

This research was ethically approved by the Research Ethics Committee of the Faculty of Medicine, Universitas Trisakti, Indonesia (Ethical Clearance no 011/KER/FK/IV/2021). The participation of students in the research was voluntary. All potential candidates who had met the inclusion criteria were exposed to detailed information on the research objectives and data collection procedures through outreach activities before signing consent to participate.

Competing Interest

The author declares that no significant competing financial, professional, or personal interests might have affected the performance or presentation of the work described in this article.

Availability of Data and Materials

The data used in this study is primary data taken directly from the results of filling out online questionnaires and laboratory examinations.

Authors' Contribution

RW had initiated the conception of the research, and all the other authors contributed to constructing the research plan. EXT and AK managed the data collection, DA and AK performed the statistical analysis, and RW drafted the manuscript. All authors took part in compiling references, giving insight into research implications for the near future study and policy, and finalizing the draft manuscript.

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The Influences of Medical Students' Consent to Participate in Thalassemia Research

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Abstract

An effective way of learning about thalassemia, a complex public health issue with multiple perspectives, is through participating in research. This study used an inductive approach to presume the influencing factors of students' consent to participate in thalassemia research voluntarily. Nested in the preliminary stage of a research series on thalassemia, this study used a consecutive sampling to recruit 140 medical undergraduates. Their knowledge, experience, and attitude to thalassemia and the perception of self-quality life were assessed using self-administered questionnaires. Blood samples were drawn for carrier screening. Students' GPAs were collected from faculty records. Of 140 participants, only 123 had at least heard of thalassemia, and their data was used in the analysis. Most participants had fairly good but incomplete knowledge of inheritance patterns, antenatal screening, and thalassemia management. Premarital screening was known and received the most positive attitudes from participants. Inductively, academic performance and carrier status curiosity were presumed to influence students' consent to participate. With the limitation of an inductive approach, further study with a specific design is needed to closely investigate student perspectives on research and their drives to get involved.

Keywords: consent, influence, knowledge, medical student, thalassemia

Introduction

In Southeast Asia, thalassemia is known to be the most common manifestation of hemoglobinopathy.[1] Historically, this inherited blood disorder was frequently found in malarial enclaves and assumed to confer a benefit of selective survival on thalassemia heterozygotes from the severe adverse effects of malaria. This natural selection may have also placed Indonesia, the second-largest malaria endemic area in Southeast Asia, into the thalassemia belt. Until now, the magnitude of the thalassemia problem in Indonesia remains a public health concern, with the number of cases expected is expected to continue to increase from time to time.[2]

Indonesia has had a strategic plan for thalassemia prevention since 2010[3], which primarily translated into various program activities such as health promotion, formal education, carrier screening, premarital counseling, and prenatal diagnosis.[4-6] However, these efforts have not yet been able to significantly suppress new emerging cases since health service inequality is still a challenge triggered by geographic differences, socioeconomic discrepancies, and inequitable distribution of health providers and required facilities within the country.[2,7]

Approximately 2,500 babies are born with beta-thalassemia (ß-TM) mayor yearly.[8] In 2019, the annual average cost to get optimal treatment for a thalassemic patient reaches up to IDR 300-400 million (USD 1,8642.72 – 2,4856.96), and this cost will increase as the patient ages and the complications they experience.[9] Such spending burdens the individual patient or their family and causes an enormous financial burden within the government health insurance scheme, estimated at IDR 900 billion (USD 559,281.6) per year.[10]

To date, information on the magnitude of thalassemia-related public health burdens has not received proportionate public attention in Indonesia. Efforts to work on thalassemia as a type of anemia have not yet been part of the health promotion to reduce anemia cases. That being concerned, the campaign for anemia due to iron deficiency is much more intensive, far surpassing the slow outreach of the other common variants of anemia, such as thalassemia.

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In other words, public ignorance is also a major obstacle in the efforts to control thalassemia thus far.[2]

The lack of public awareness of thalassemia in Indonesia is allegedly due to inadequate general knowledge, even among prospective health workers, about what thalassemia is and how to deal with it. Within the last decade, linkages between knowledge, awareness, attitude, and behaviors related to thalassemia have been studied among different respondents in various settings in Indonesia.[11-16] Trials to elevate knowledge of thalassemia among respondents with multiple characteristics have consistently proven effective in creating awareness or adherence to certain positive attitudes and behaviors.[17-20] The act of providing relevant information could also lend psychological support,[21] reduce anxiety,[22-23] improve self-esteem,[24] and increase resilience for both thalassemia patients and those closest to them.[21]

It is fundamental to do effective promotional education activities to disseminate information on thalassemia.[25] For this purpose, the public health system needs capable, trustworthy, and easy-to-consult resource persons. There is a high expectation for a medical doctor to at least be a competent resource person to deliver education on thalassemia or even provide quality healthcare for people with thalassemia. To build up such relevant knowledge and skills during their study time, the institution should organize various teaching and learning methods, one of which is through research activities. Although it is knowledge-dense, the involvement of students in research activities is optional, especially for undergraduates; hence, it requires their consent to participate, which could sometimes be very minimal. Meanwhile, factors which could motivate medical students to participate in research, particularly those requiring somewhat invasive procedures,[26] such as blood sampling, have yet to be studied.

In 2021, the Faculty of Medicine at a university in Jakarta initiated a research series on thalassemia. In phase I of this study, participants were selected from the university medical students who voluntarily enrolled after the outreach of research. The outreach conveyed to the attendants the need for blood sampling from all participants for carrier screening. As part of the research series, this study aimed to comprehend students' knowledge and attitudes to issues related to thalassemia. An additional analysis of their profiles was also carried out to determine influential factors to the students' consent to volunteer using an inductive approach.

Method

To find out more about thalassemia from various perspectives, a series of research was planned. Carried out as a cross-sectional descriptive study in May-June 2021, this was the preliminary stage of the series. This study included undergraduate students from the 2016-2020 batches of the Faculty of Medicine of a private university in Jakarta, Indonesia, who registered voluntarily online or offline. A consecutive sampling technique was applied to correspond with the study objectives. Recruiting participants began with the outreach directly to the students, both through online and offline.

The online session was delivered on May 24, 2021, followed by consecutive offline sessions from June 23-29, 2021. These sessions allowed dialogue between the attendants and the research team members on the study objectives, methodology, and data collection process. Participants in this study must be active undergraduate medical students; domiciled in Jakarta; not suffering from chronic diseases and/or not having blood transfusion within three months prior to blood collection; healthy during data collection; had heard of thalassemia; and not having an increase in leukocytes greater than 20% of the normal value range.

A formula to estimate a single proportion of the degree of participation was applied to calculate the sample size. With a total of 619 students from batch 2016-2020, a finite population correction (FPC) was applied to adjust the final sample size. The sample size calculation formula with an FPC was:

$$n = \frac{\frac{Z^2.(1-p)}{e^2}}{1 + \left(\frac{Z^2.(1-p)}{e^2 N}\right)}$$

For estimating 90% of the participation level with a 95% confidence level ($Z\alpha/2$ = 1.96) and a 5% margin of error (e), the minimum sample size required after the correction was 113 participants. Voluntary participation in medical-related studies that include invasive procedures might be low, even among medical students. This study showed that of 619 active students, 60.6% (n=375) attended the study outreach. Of the 375 students attending the outreach sessions, 140 voluntarily registered in the study. Of these 140 students, 17 (12.1%) had never heard of thalassemia; thus, their responses were considered irrelevant and excluded from the analysis. Yet, using non-probability sampling technique, the composition of participants still resembled the composition of the 2016-2020 student population with a male/female ratio of 1 to 2 and slightly fewer participants from the earlier batches (the year 2016-2018: 45%) than from the latest batches (the year 2019-2020: 55%).

As illustrated in Figure 1, the presumed influential factors to students' participation in research were regarded as variables under study whose indicators were collected using three different methods. Knowledge, attitude, and experience related to thalassemia, perception of quality of life, sociodemographic status, and participants' economic status were assessed using self-administered online (Google Forms) questionnaires (as coded with Q1 – Q4). The data on students' grade point average (GPA) was obtained from the faculty record. A 7 ml venous blood sample was also collected from each participant in two 3 ml etilena diamina tetra asetat (EDTA) tubes for three levels of carrier screening.

The blood sampling was done by skilled analysts from Laboratory X in six batches from June 23 to 29, 2023. The first level screening was done using a Complete Blood Count (CBC), which comprises Hb, MCV, and MCH. The CBC was assessed using the Flow Cytometry Method Using a Semiconductor Laser (Sysmex-XN®). These biochemical assessments were carried out by Laboratory X in compliance with ISO Standards (SNI ISO 15189 has been accredited by the National Accrediation Committee with certificate no LM-013- IDN). The procedures of the second and third level screening would be reported elsewhere (in progress) because only the results of the first level screening were presented here.

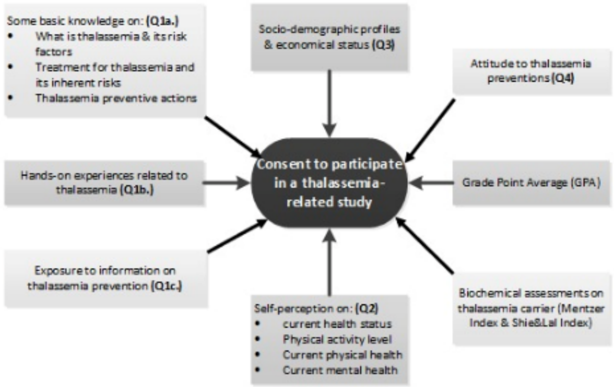


Figure 1. Conceptual Framework of the Preliminary Study

This study collected two types of data, categorical and continuous data, analyzed using SPSS Statistics for Windows version 26.0 (licensed until 2032). Responses from questionnaires were mostly categorical and presented as proportions. For responses on Q1.a, Q2, and Q4 were transformed into scores so that they could be treated as continuous data as well as regrouped into ordinal data (i.e., low, medium, and high scores). All continuous data were checked for their data distribution graphically using eye-ball observations and statistically using the Kolmogorov-Smirnov test combined to further determine the statistical tests for more analytical purposes.

The results of blood biochemical tests were used to detect the participant's pathophysiological conditions, such as anemia and/or suspected thalassemia carriers. The sex-specific World Health Organization's standards were applied to determine an anemic condition based on Hb level with <13 g/dL for anemic men and <12 g/dL for anemic women.[27] For those with anemia, further examinations were also carried out to determine whether the person concerned was suspected of thalassemia carrier. Following the national guidelines for medicine services management of thalassemia,[5] those with MCV<80 fl and/or MCH <27 pg were initially (1st level) suspected of thalassemia. A combination of the Mentzer index (MCV/RBC) and the Shine&Lal index ($MCV^2 * MCH/100$) could also be utilized to sort out those with suspected thalassemia carriers.[28,29] Participants with Mentzer index <13 and Shine&Lal index <1530 were considered suspected Beta-thalassemia carriers.

Results

Analyses were performed based on only 123 datasets. The participants were 18-26 years old, with an average age of 20. None of them were married or had children. Most were Muslims (78.6%; n=97) and Christians (18.6%; n=23).

Based on the World Bank categories,[30] 22.9% (n=28) of participants came from the lower middle-income group, while more than half (77.1%; n=95) came from the upper middle to high-income group. Most students (79.7%; n=98) had been exposed to relevant information from lectures at the faculty, 13.8% (n=17) from TV, and very few (6.5%; n=8) from unspecified sources. Based on their experience, only 11.4% (n=14) have ever met a child with thalassemia or even donated blood to a child with thalassemia (3.3%; n=4). Although it could not be determined which happened first, experience or exposure to information, it was noticed that among those with backgrounds (14.6%; n=18), all had been exposed to some information, whether it be from lectures (11.4%; n=14) or news on TV (3.3%; n=4). Most participants (95.9%; n=118) also expected the government to raise public awareness of thalassemia through printed and electronic media.

The participants were dominated by those with optimal academic achievement (GPA 2.5-3.5: 69.9%; n=86), some from a less academic group (GPA <2.5: 20.3%; n=25), and even fewer from the high achievers (GPA >3.5: 9.8%; n=12). Only the 2020 batch had the number of participants equally divided between low and optimal achievers. The number of low achievers then decreased drastically in earlier batches. A significant difference in knowledge related to thalassemia prevention could only be detected between those with GPA <3.0 and those with GPA ≥3.0. Within the range of minimal and maximum scores of 0-4, the median score (4) of students with high GPAs was statistically higher than the median score (3) of those with low GPAs (p-value <0.05; Mann-Whitney U test). Besides, no other statistical differences were found between groups related to all aspects (knowledge, experience, attitude, and self-perception), including those between batches. Therefore, the overall analysis was then carried out using combined data, and the results were presented descriptively without any segregation between those with different batches or levels of GPA.

None of the participants knew whether they were thalassemia carriers or not. Of 123 participants, 13.8% (n=17)—all female—were anemic. Based on the first screening level, more than half of these anemic cases (n=10) were also suspected of thalassemia. While using MI and SLI combined, two anemic female participants were also suspected of beta-thalassemia. Three domains of knowledge were tested on the participants: a) what thalassemia is and its inherited pattern; b) prevention of thalassemia; and c) treatment for thalassemia. Overall, the participants' knowledge was high, with a median score of 10 (min-max: 1-15). As seen from Table 1, knowledge of what thalassemia is could be answered correctly by most participants (>90%). Still, the proportion sharply decreased when being asked about the roots of this condition (<60%). Only 60.2% (n=74) answered that thalassemia could be prevented, yet most participants (95.9%; n=118) answered correctly that premarital screening was equally crucial for males and females.

However, 33.5% (n=41) did not know that antenatal screening could work effectively. Compared to the first two knowledge domains, knowledge related to thalassemia treatment appeared to be much less, with the most significant proportion being 72.4% (n=89) for non-specific knowledge of thalassemia, repeating blood transfusion carries a risk. The participants could provide correct answers (60.2%; n=74) at most for 8-11 of 15 knowledge-related questions (Figure 2). This proportion was dominated by participants' correct responses on 2-5 questions on thalassemia and its causes (93.5%; n=115), 2-4 questions for thalassemia prevention (92.7%; n=114), and 2-4 questions for thalassemia treatment (61%; n=75).

Coherent with participants' knowledge of the methods to prevent thalassemia, premarital screening received the most positive attitude (98.4%; n=120) compared to the other preventive ways (Table 2). More than half of the participants were willing to undergo this kind of screening voluntarily, even though it was not mandatory. While, positive attitudes for other preventive ways only came from about two-thirds of the participants, and the proportion was even smaller (26.2%; n=32) when it related to the termination of pregnancy with a thalassemia major fetus. Most participants (81.3%; n=99) gave only one to two reasons that a pregnancy with a thalassemia major fetus would cause difficulties to the child (71.5%; n=87) or his family (33.3%; n=41) if maintained. Yet, the majority (64.8%; n=79) gave no opinion about pregnancy termination.

In this study, eight features were used to describe the quality of life as a whole, including self-assessment of the overall health (1 set of questions), physical conditions (3 sets of questions), vitality (1 set of questions), mental conditions (2 sets of questions), and even social functions (1 set of questions). As seen in Table 3, the participants' responses generally tended to be positively skewed as they valued themselves as healthy and normally functioning physically, mentally, and socially. Yet, when it comes to the self-perceived on broader or more abstract features like overall health, vitality, and mental health, their responses tended to be diverse and represented more the picture of a population's normal distribution.

Table 1. Participants' Knowledge of Thalassemia (N=123*)

Knowledge	Correct answer n (%)
What thalassemia is	
1. Thalassemia is a genetic disease	120 (97.6)
2. Thalassemia originates from a blood disorder	122 (99.2)
3. There are two types of thalassemia	71 (57.7)
4. A normal person could genetically have thalassemia minor	67 (54.5)
5. A child will not suffer from thalassemia if only one of the parents genetically has thalassemia minor	14 (11.4)
6. A normal person could marry a thalassemia carrier	86 (69.9)
Prevention of thalassemia	
1. Thalassemia could not be transmitted from food	105 (85.4)
2. Thalassemia could be detected during pregnancy	83 (67.5)
3. Thalassemia is preventable	74 (60.2)
4. Premarital screening for thalassemia needs to be done on both men and women	118 (95.9)
Treatment of thalassemia and its inherent risks	
1. Repeated blood transfusion is the way children with thalassemia can survive	69 (56.1)
2. There is a permanent solution for thalassemia	48 (39.0)
3. Repeated blood transfusion carries a risk	89 (72.4)
4. Therapy using iron chelating agents can be recommended for children with thalassemia	40 (32.5)
5. There are precautions/prohibitions for certain types of food for those with thalassemia	39 (31.7)

Table 2. Attitude to Thalassemia Prevention (N=122*)

Attitude (%)			
Pregnancy with **a fetus detected as a carrier of thalassemia major**		**Reason**:	
• Kept it	9.0 (n=11)	Difficulties to the child (n=3); burden to the family (n=3); ethical issue (n=4) **gave no reason at all (n=1); gave only one reason (n=10)**	
• Terminated it	26.2 (n=32)	Difficulties to the child (n=30); burden to the family (n=12); burden to the country (n=3); death risk (n=1) **gave only one reason (n=21); gave more than one reasons (n=11)**	
• Do not know	64.8 (n=79)	Difficulties to the child (n=55); burden to the family (n=26); burden to the country (n=6); ethical issues (n=3); break the chain of disease (n=1) **gave no reason at all (n=12); gave only one reason (n=49); gave more than one reasons (n=18)**	
Premarital screening for thalassemia is **necessary**		**Marriage between** couples who are **both thalassemia carriers**	
• Yes	98.4	• Just fine	32.8
• No	1.6	• Should not	67.2
Want to have a premarital screening independently although it is not yet mandatory in Indonesia		**Carriers couples for getting pregnant**	
• Yes	54.9	• Just fine	33.6
• Maybe	41.8	• Should not	66.4
• No	3.3		

*one respondent gave no responses to this set of questions

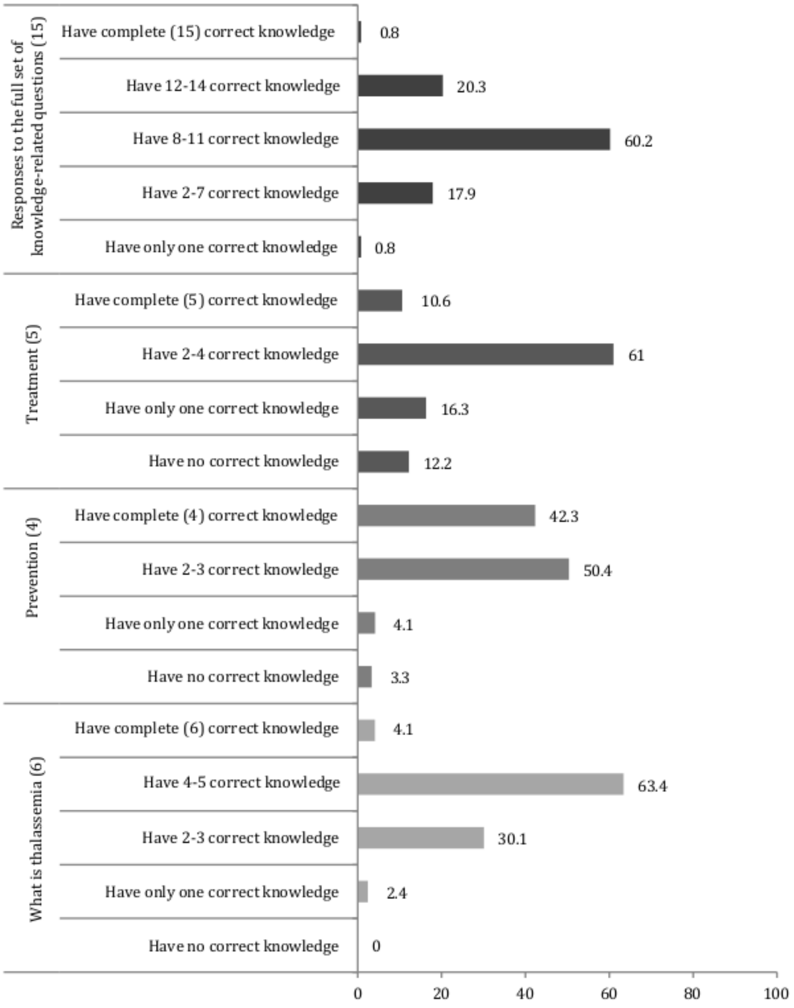
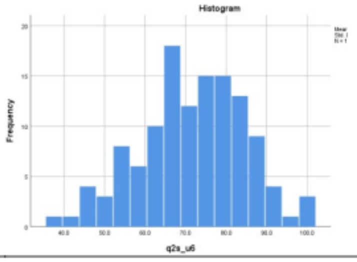
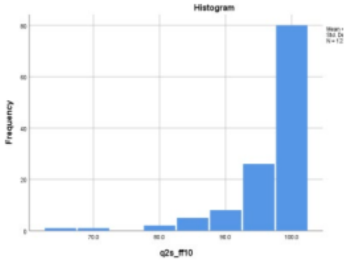
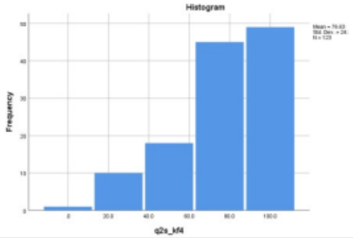
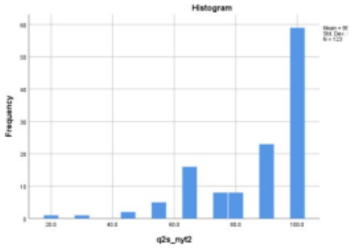
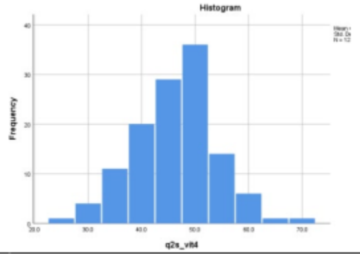
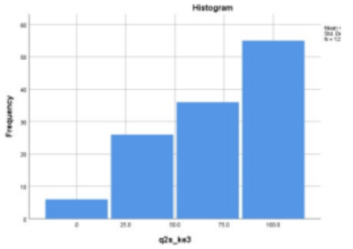
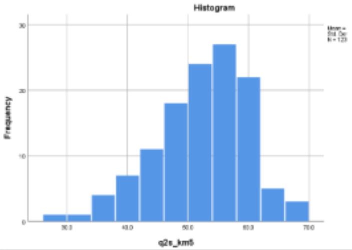
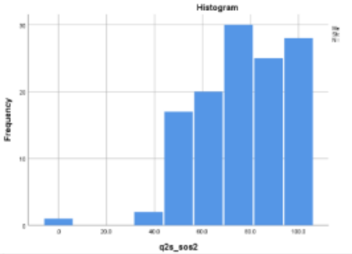


Figure 2. Proportion Distribution of Participants with Correct Knowledge of Thalassemia (N=123)

Table 3. Perception of the Self-Quality of Life (N=123)

Sub-variable	Statistics*	Score distribution
General health (6 questions) 1. How would you describe your current health condition? 2. How is your health now compared to one year ago? 3. I feel like I get sick a little easily 4. I am as healthy as anyone else 5. I feel my health is getting worse 6. My health is very good	70.8 (37.5 - 100.0)	

Physical functions (10 questions) 1. Activities that require a lot of energy, lifting heavy objects, doing strenuous exercise 2. Light activities such as moving tables, sweeping, jogging/leisurely walking 3. Lifting or carrying light items (e.g. groceries, bags) 4. Climb some stairs 5. Climb one stair 6. Bending the neck/hands/legs, prostrating or bowing 7. Walk more than 1.5 km 8. Walk through several alleys/1km 9. Walk through one alley/0.5 km 10. Take a shower or wear your own clothes	100.0 (65.0 - 100.0)	
Physical limitations (4 questions) 1. Spending all your time doing work or other activities. 2. Finishing work not on time. 3. Limited to some work or other activities. 4. Experiencing difficulty in doing work or other activities (for example those that require extra energy such as jacking/carpentry, washing)	75.0 (0.0 - 100.0)	
Body soreness (2 questions) 1. How much pain have you felt in your body during the last 4 weeks? 2. In the last 4 weeks, how much did the pain interfere with your daily work (including work outside the home and work inside the home)?	87.5 (20.0 - 100.0)	
Vitality (4 questions) 1. Do you feel full of enthusiasm? 2. Do you have a lot of energy? 3. Do you feel bored? 4. Do you feel tired quickly?	45.0 (25.0 - 75.0)	
Emotional limitations (3 questions) 1. Spending all your time doing work or other activities 2. Finishing the job takes less time than usual 3. When carrying out work or other activities, you are not as careful as usual	66.7 (0.0 - 100.0)	

Mental health (5 questions) 1. Are you a very nervous person? 2. Do you feel very depressed and nothing cheers you up? 3. Do you feel calm and peaceful? 4. Do you feel hopeless and sad? 5. Are you a cheerful person?	52.0 (28.0 - 68.0)	
Social function (2 questions) 1. [illegible] the last 4 weeks, how much did your physical health or emotional problems interfere with your usual social activities with fam[illegible] friends, neighbors or your group? 2. In the last 4 weeks, how often did your physical health or emotional problems affect your social activities (such as visiting friends, relatives, etc.)?	75.0 (0.0 - 100.0)	

***Median (min-max)**

Discussion

Delivering education on thalassemia takes a challenging and complex process. With the gene inheritance pattern from parents to offspring, carrier screening might create a fear of stigmatization.[25] Several prevention methods, such as avoiding or terminating a pregnancy, may arouse serious controversy and even outright rejection because they conflict with existing norms, or are invasive.[31,32] Moreover, efforts to convince thalassemia major patients or their families to strictly adhere to lifelong treatment could be hampered by many issues, such as financial problems, time constraints, resistance to pain, and mental depression.[33] In this context, more than just relevant medical knowledge is needed to enable a doctor to carry out the function of a health educator.

Solid medical knowledge may enable one to select and construct supportive fundamental messages precisely. However, concordance should be pursued regarding more delicate or sensitive issues, not just adherence or compliance.[34] Specific skills must also be mastered to verbally communicate (ideally in an understandable lay language) on thalassemia, its consequences, or the reasons for recommending a way out or solution. Also, it is a proper attitude that must objectively underlay specific medical advice whenever considered the best option.[35] Only then would the patients probably comprehend better the basis of their decision-making less clouded by incorrect or irrelevant perspectives.

That being said, only some of the participants could meet the above criteria, even just assessed by their levels of knowledge and attitude. Although their overall knowledge was good, it was patchy in some specific issues: inheritance patterns, antenatal screening, and treatment of thalassemia. However, the coherence of knowledge and attitude was noticed in this study, just like premarital screening, which was known by and received a positive attitude from most participants (>90%). This attitude might be predisposed by students' understanding that thalassemia is an inherited disorder and their unmarried status. However, the pattern of inheritance following Mendel's law for recessive genes was unknown by the majority (88.6%). Perhaps a positive attitude to premarital screening was also driven by considerations that other options, such as termination of pregnancy, were too risky, against the existing norms, conflict with their personal views or beliefs, or might give rise to ethical controversy.[31]

Age, sex, and years of education did not determine differences in knowledge and attitude on thalassemia among these undergraduate participants. A study in Semarang, Central Java, among medical students also reported similar findings, except that the year of education was significantly associated with knowledge and attitude.[13] Other studies among similar target groups reported significant associations between sex and knowledge,[36] age and attitude,[35] or age and knowledge.[37] Their educational performance, as indicated by the GPA, seemed only to differentiate the elementary level of knowledge of thalassemia prevention, but not about attitude or even experience. This association between GPA and knowledge somewhat aligned with their response that the faculty's lecture was their primary information channel on thalassemia. As a caveat, the topic of thalassemia given through lectures was very short in duration and not repetitive

(2 x 50 minutes in only one semester). Much detailed information might be forgotten when piled up with other course materials. The experience of thalassemia among the participants was too minimal to be associated with any factor aside from their rare exposure to thalassemia cases, direct or indirect. Perhaps it was because the participants were still students with no intense exposure to specific cases, including thalassemia, on top of their patchy knowledge.

One effective way to build positive attitudes and gain hands-on experience simultaneously with knowledge for medical students is through volunteering,[36] including in research. Therefore, understanding the underlying factors of students' interest in research to the point that they were willing to participate was just as important as exploring an engaging teaching method. However, this study has shown that student's willingness to participate voluntarily in research could be low regardless of their high attendance in the outreach session. There was also an indication that their interest was not necessarily driven by the proximity of their educational background to the scientific field of a given research.

An interesting finding was the dominance of students with optimal academic performance as this study participant, also found among undergraduate medical students in Dubai.[36] It was assumed that the optimal achievers' group may have different motives and attributes in viewing or responding to any existing opportunities compared to other groups. The phenomenon of the number of participants with low and optimal GPAs being equal only in the latest batch might indicate that students initially had similar attributes, which then became diverse in corresponding to the changes in learning demands and patterns in line with their studying period.

Even though it was known that a small number of participants were carriers of thalassemia, none of them knew about their condition because they had never been independently screened before, and most perceived themselves to be in reasonably good health. Curiosity to see whether they are carriers could be the driving factor for their participation in this research, even though their blood samples must be taken. However, on the other hand, it is yet to be known whether the lack of consent among non-participants was due to objections to blood sampling.

Using an inductive approach to identify influencing factors of consent to volunteers based on participants' characteristics has a limited scope of interpretation because there is no comparative data on the features of the non-participant group. Since factors such as age, sex, marital status, economic group, years of education, and perceived self-quality of life of the participants resembled the profile of the 2016-2020 students' population, no underlying factor of students' consent could be presumed within this cluster of variables as another limitation of an inductive approach.

Conclusion

In general, knowledge of thalassemia among the study participants is quite good, even though they are patchy on issues regarding inheritance patterns, antenatal screening, and treatment for thalassemia. The attitude to premarital screening is mostly positive, supported by the knowledge that thalassemia is an inherited disorder. The limitation of the inductive approach and the absence of a comparison group (non-participants) become constraints in identifying the influencing factors for student consent to participate. Academic performance and curiosity about career status are presumed to be the influential factors. Further studies must be specifically designed to analyze determinants for medical students' consent to participate, particularly in a study with complex subjects that must be understood from multiple public health perspectives, such as thalassemia.

Abbreviations

FPC: finite population correction; GPA: grade point average; CBC = complete blood count.

Ethics Approval and Consent to Participate

This research was ethically approved by the Research Ethics Committee of the Faculty of Medicine, Universitas Trisakti, Indonesia (Ethical Clearance no 011/KER/FK/IV/2021). The participation of students in the research was voluntary. All potential candidates who had met the inclusion criteria were exposed to detailed information on the research objectives and data collection procedures through outreach activities before signing consent to participate.

Competing Interest

The author declares that no significant competing financial, professional, or personal interests might have affected the performance or presentation of the work described in this article.

Availability of Data and Materials

The data used in this study is primary data taken directly from the results of filling out online questionnaires and laboratory examinations.

Authors' Contribution

RW had initiated the conception of the research, and all the other authors contributed to constructing the research plan. EXT and AK managed the data collection, DA and AK performed the statistical analysis, and RW drafted the manuscript. All authors took part in compiling references, giving insight into research implications for the near future study and policy, and finalizing the draft manuscript.

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