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ORIGINAL ARTICLE

Thalassemia screening: Low level of knowledge among unmarried youths in Kota Bharu, Kelantan, Malaysia

Muhammad Akmal Mohd Nor, Nur Suhaila Idris, Maryam Mohd Zulkifli, Ruzilawati Abu Bakar, Imran Ahmad

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Authors:

Imran Ahmad
(Corresponding author)
MBBS, MMed (Family Medicine)
Department of Family Medicine
School of Medical Sciences, Universiti Sains Malaysia, Kubang Kerian
Kelantan, Malaysia
Email: profimran@usm.my

Muhammad Akmal Mohd Nor
MD, MMed (Family Medicine)
Department of Family Medicine
School of Medical Sciences, Universiti Sains Malaysia, Kubang Kerian
Kelantan, Malaysia

Nur Suhaila Idris
MD, MMed (Family Medicine)
Department of Family Medicine
School of Medical Sciences, Universiti Sains Malaysia, Kubang Kerian
Kelantan, Malaysia

Maryam Mohd Zulkifli
MBBS, MMed (Family Medicine)
Department of Family Medicine
School of Medical Sciences, Universiti Sains Malaysia, Kubang Kerian
Kelantan, Malaysia

Ruzilawati Abu Bakar
PhD
Department of Pharmacology
School of Medical Sciences, Universiti Sains Malaysia, Kubang Kerian
Kelantan, Malaysia

Abstract

Introduction: Thalassaemia is a common genetic blood disorder. Knowledge, awareness, attitude towards, and intention to screen for thalassaemia among Malaysians is poor. Screening for thalassaemia in unmarried individuals plays a key role in preventing thalassaemia major births.

Methods: A cross-sectional study was conducted on unmarried individuals aged 18 years and older in Kota Bharu, Kelantan, Malaysia. A questionnaire was used to collect the general data of the participants, their knowledge of thalassaemia, attitude towards thalassaemia, and intention to screen for thalassaemia.

Results: A total of 278 respondents were included in this study. The mean (SD) knowledge score was 8.8 (4.99) out of a possible score of 21, with higher scores indicating better knowledge. The factor associated with good knowledge of thalassaemia was being a professional. Most respondents agreed that unmarried individuals should be screened for thalassaemia before marriage.

Conclusion: In conclusion, knowledge of thalassaemia among unmarried individuals who were not professionals was low.

Introduction

Thalassaemia is a common genetic blood disorder. It is a heterogeneous group of genetic disorders characterised by defective synthesis of one or more globin chains (alpha or beta). Reduced globin chain synthesis causes a reduction in haemoglobin synthesis and eventually results in hypochromic microcytic anaemia.[1] Thalassaemia causes significant morbidity and mortality.[2,3] Thalassaemia also has significant psychosocial and emotional impacts on patients and their families. Being a thalassaemia carrier can lead to social isolation, marital tension, and stigmatisation.[4]

Many countries, including Iran, Bahrain, and Cyprus, employ premarital screening programmes for haemoglobinopathies, which have decreased the incidence of thalassaemia. Screening, particularly of people in the premarital phase of life, is important because it can provide early detection of thalassaemia carriers and help to prevent new cases. Premarital screening is superior to neonatal screening because the former is a primary prevention mechanism, while the latter is a secondary prevention mechanism.[5]

In Malaysia, thalassaemia continues to be a significant burden for many patients of different ethnic groups. There are also many factors that influence public perception, knowledge, and attitude towards thalassaemia and its screening.[4] The Malaysian Ministry of Health established the National Thalassaemia Prevention and Control Program in late 2004.[6]

This study aimed to determine the level of knowledge of thalassaemia, its screening programme, individual attitudes towards the programme, and intention to screen among unmarried individuals in Kota Bharu, Kelantan, Malaysia.

Methods

Study design and participants

A cross-sectional study was conducted from May 1, 2017, to May 30, 2017, with 278 unmarried participants who attended a premarital course in Kota Bharu, Kelantan, Malaysia. Respondents were aged 18 years and older. Female respondents were all premenopausal and none had undergone hysterectomy. Ethical approval for this study was obtained from the Human Research

Ethics Committee of Universiti Sains Malaysia (USM/JEPeM/16090312) and followed the principles of the Helsinki Declaration.

Research tools

The questionnaire used to collect information about the variables of interest was adapted and modified from Wong et al.,[4] with permission from Professor Wong Li Ping of the Department of Social and Preventive Medicine, Faculty of Medicine, University of Malaya, Kuala Lumpur, Malaysia. The questionnaire comprised 44 questions and was divided into 4 parts; it was administered via a computer-assisted telephone interview (CATI) system. The questionnaire was altered in view of the method of administration being changed from telephone interview to a self-administered questionnaire; a face validation study was conducted for this purpose.

The first part of the questionnaire was designed to obtain information on the sociodemographic data of the respondents, including age, gender, race, religion, locality, highest education level, and average household monthly income.

The second part of the questionnaire was used to obtain information about the respondents' knowledge of thalassaemia. The respondents were asked if they had heard of thalassaemia or a disease with low numbers of red blood cells or a deficiency of blood. The other questions addressed their knowledge of thalassaemia across several domains, including general knowledge of thalassaemia (5 items), knowledge of thalassaemia major (6 items), knowledge of thalassaemia carriers (8 items), and knowledge of the prevention of thalassaemia major (2 items). For each question, a correct response was scored as '1', and an incorrect response or 'do not know' was scored as '0', for a total possible score of 0–21, with a higher score indicating better knowledge. The maximum score of the questionnaire was 21.

The third part of the questionnaire was designed to collect information on the participants' attitude towards thalassaemia (4 items). Participants were asked for their views on premarital screening, marriage between individuals who were both carriers, pregnancy in carrier couples, and termination of pregnancies affected by thalassaemia major.

The fourth part of the questionnaire asked respondents about their intention to be screened for thalassaemia (8 items). Screening for thalassaemia referred to screening performed in Malaysia, where initial investigation consists of a full blood count (FBC) to detect a mean corpuscular haemoglobin (MCH) value less than 27 pg.

The respondents were asked whether they would be willing to abort their baby (or their partner's baby) if it had been diagnosed with thalassaemia major or as a carrier prior to 120 days of fetal life.[7] According to the 52nd Muzakarah Jawatankuasa Fatwa Majlis Kebangsaan Bagi Hal Ehwal Ugama Islam Malaysia7 that was held on July 1, 2002, for a foetus diagnosed with thalassaemia or as a thalassaemia carrier: a) it is 'makruh' (a disliked act) if abortion is performed between 1 and 40 days of foetal life, provided that it does not cause harm to the mother and both parents agree; b) it is 'harus' (a recommended act) if abortion is performed before 120 days of foetal life if the foetus is disabled or causing harm to the mother; and c) it is 'haram' (a forbidden act) if abortion is performed after 120 days of foetal life, as from the Islamic point of view, the 'roh' (soul) of the foetus has been incorporated at this point, unless the pregnancy is causing harm to the mother.

Validity and reliability

The internal consistency (Cronbach's alpha) for the 21-item, close-ended knowledge questions was 0.86.[4]

Face validation and preliminary study

A face validation study was previously conducted with 30 unmarried individuals who were over 18 years old and did not meet the exclusion criteria.

Data collection

Written consent was obtained from the participants who fulfilled the inclusion criteria. Participants who consented were provided with a set of self-administered questionnaires during the premarital course, along with an explanation of how to complete the questionnaires.

Data analysis

Data entry and statistical analyses were carried out using IBM SPSS statistics version 24.0. Simple linear regression was used to determine the potential associated factors of the mean knowledge score for thalassaemia. Multiple linear regression was used to determine two or more associated factors of mean knowledge of thalassaemia at the same time. Descriptive

analysis was conducted for attitude towards and intention regarding thalassaemia screening. A p value of <0.05 was considered statistically significant.

Results

A total of 278 participants responded to the questionnaires, for a response rate of 100%. Almost all respondents were Malay (99.6%), most were young adults with a mean (SD) age of 24.64 (4.394), and 58.6% had secondary school education. **Table 1** presents the characteristics of the respondents.

Table 2 presents a descriptive analysis of each item in the 'knowledge regarding thalassaemia' topic. The results showed that the premarital course respondents had inadequate knowledge of many aspects of thalassaemia.

Nine independent variables were tested for factors associated with a good score for knowledge of thalassaemia: sociodemographic factors (age, gender, ethnicity, monthly average household income, highest education level, background education level, and occupation), family history of thalassaemia, and prior screening for thalassaemia (**Table 3**). Multiple linear regression showed that only professional occupation was significantly associated with adequate knowledge of thalassaemia (R^2_{adj} 13.22; 95% CI [5.37, 21.07]). No multicollinearity was detected, and the model assumption was met; therefore, the findings are valid for interpretation. The coefficient of determination (R^2) was 0.038, which implies that the model explains 3.8% of the variability. The final model equation showed that respondents with a professional occupation had a knowledge score 13.22 units higher than respondents who were unemployed.

The results regarding attitude towards thalassaemia screening are shown in **Table 4**, and **Table 5** presents the intention of respondents to be screened for thalassaemia.

Table 1. Sociodemographic features of the premarital respondents.

	Mean (SD)	n (%)
Age (years)	24.6 (4.39)	
Monthly average household income (RM)	1189.6 (1043.16)	
Gender		
Male		132 (47.5)
Female		146 (52.5)
Ethnicity		
Malay		277 (99.6)
Non-Malay		1 (0.4)
Highest education level		
Secondary school		163 (58.6)
Tertiary school or higher		115 (41.4)
Education background		
Islamic stream		86 (30.9)
Conventional/science stream		192 (69.1)
Occupation		
Professional		40 (14.4)
Managerial		64 (23)
Skilled worker		41 (14.7)
Unskilled worker		68 (24.5)
Unemployed		65 (23.4)

Table 2. Participant knowledge regarding thalassaemia.

Question	Correct answer n (%)
General knowledge of thalassaemia	
Thalassaemia is a hereditary disease	173 (62.2)
A person can be a thalassaemia carrier or have thalassaemia major	121 (43.5)
Thalassaemia can be divided into two groups: alpha or beta thalassaemia	90 (32.4)
Urine test can be performed to determine if a person has thalassaemia	109 (39.2)
Blood testing can be performed to determine if a person has thalassaemia	229 (82.4)
Thalassaemia major	
The life span of a thalassaemia major patient is shortened if he/she does NOT receive appropriate treatment	130 (46.8)
Red blood cells of thalassaemia major patients break down easily and cause anaemia	125 (45)
Individuals with thalassaemia major require regular blood transfusions throughout life	94 (33.8)
All thalassaemia major individuals are mentally retarded	129 (46.4)
Individuals with thalassaemia major can lead normal and healthy lives with appropriate treatment	179 (64.4)
Individuals with thalassaemia major can be cured with bone marrow transplant	61 (21.9)
Thalassaemia carriers	
The life span of thalassaemia carrier is shortened	80 (28.8)
Thalassaemia carriers appear healthy and show no symptoms	98 (35.3)
A thalassaemia carrier shows signs of anaemia (paleness), tiredness, no appetite, and is prone to infections	24 (8.6)
A thalassaemia carrier may develop thalassaemia major	36 (12.9)
A thalassaemia carrier cannot play a normal role in society with regards to working and having a family, and needs treatment for the disease	98 (35.3)
Children born to both parents who are thalassaemia carriers will be at risk of having thalassaemia major	175 (62.9)
Children born to either one parent who is a thalassaemia carrier will be at risk of having thalassaemia major	42 (15.1)
Couples where both are thalassaemia carriers will certainly give birth to thalassaemia major children; they will not conceive any healthy children	58 (20.9)
Prevention of thalassaemia major	
The partner of a thalassaemia carrier should undergo blood tests	225 (80.9)
Prenatal diagnosis for high-risk pregnancies (both partners are thalassaemia carriers) are necessary	173 (62.2)

Table 3. Independent variable differences in mean knowledge score and simple linear regression analysis of associated factors predicting knowledge of thalassaemia.

	Total knowledge score (0–21 item scale)		Simple linear regression	
	Mean score (SD)	n	ba (95% CI)	P value
Age				
18–24	8.2 (4.69)	156		
≥25	9.7 (5.25)	122	6.85 (1.24, 12.45)	0.017
Monthly average household income				
RM0–RM499	8.5 (4.78)	65		
RM500–RM999	7.7 (4.83)	53	-6.77 (-13.88, 0.34)	0.062
RM1000–RM1499	8.1 (4.74)	70	-4.68 (-11.12, 1.77)	0.155
RM1500–RM1999	10.2 (5.18)	30	7.21 (-1.80, 16.23)	0.116
≥RM2000	10.4 (5.16)	60	9.52 (2.78, 16.25)	0.006
Gender				
Male	8.8 (5.34)	132		
Female	8.9 (4.66)	146	0.08 (-4.80, 6.45)	0.772
Ethnicity				
Malay	8.8 (4.99)	277	-10.28 (-57.20, 36.63)	0.667
Non-Malay	-	1		
Highest educational level				
Secondary school	8.2 (4.61)	163		
Tertiary school	9.8 (5.37)	115	7.44 (1.81, 13.08)	0.010

	Total knowledge score (0–21 item scale)		Simple linear regression	
	Mean score (SD)	n	ba (95% CI)	P value
Education background				
Islamic stream	8.5 (4.84)	86		
Conventional/science stream	9.0 (5.06)	192	2.24 (-3.83, 8.32)	0.467
Occupation				
Professional	11.2 (5.53)	40	13.22 (5.37, 21.07)	0.001
Managerial	8.1 (4.67)	64	-4.48 (-11.13, 2.17)	0.186
Skilled worker	8.2 (4.43)	41	-3.52 (-11.43, 4.40)	0.382
Unskilled worker	8.8 (5.10)	68	-0.16 (-6.70, 6.38)	0.962
Unemployed	8.5 (4.86)	65		
Family history of thalassaemia				
No	8.8 (4.98)			
Yes	9.0 (5.50)		0.74 (-15.13, 16.62)	0.927
Prior screening for thalassaemia				
Yes	10.8 (4.04)			
Never	8.7 (5.02)		-9.71 (-22.51, 3.08)	0.136

[a] Crude regression coefficient.

Table 4. Participant attitude regarding thalassaemia screening.

	Agreed n (%)
Premarital screening for thalassaemia is necessary for the general public.	245 (88.1)
Couples who are thalassaemia carriers should not marry	88 (31.7)
Couples who are thalassaemia carriers should not have children	74 (26.6)
Termination of pregnancy with thalassaemia major is necessary as it not only brings suffering to the affected child, but it is also a burden to the family, community, and country	92 (33.1)

Table 5. Participant intentions regarding thalassaemia screening.

Reason	n (%)
Reasons for unwillingness to undergo thalassaemia screening among premarital participants who had not been previously screened (n=67)	
Not at risk	44 (65.7)
Afraid of test results	13 (19.4)
Afraid of being discriminated against	1 (1.5)
Do not know about the test	6 (8.9)
Do not know where to get the test	3 (4.5)
Reasons for not continuing a relationship with his or her partner if unmarried couples are thalassaemia carriers (n=81)	
Do not want children with thalassaemia major	63 (77.8)
Family will not allow marriage to proceed	17 (20.99)
Others	1 (1.2)
Reasons for not wanting to abort own baby/partner's baby if the baby is diagnosed with thalassaemia major before 120 days of life (n=32)	
Abortion is against religion	160 (68.97)
God's fate	66 (28.4)
Others	6 (2.6)

Discussion

Thalassaemia continues to be one of the most common preventable haemolytic diseases that places a great burden on both the patient and the health care system in many countries, including Malaysia.[8] Despite the recent move by the Malaysian Ministry of Health (MOH) to screen secondary students for thalassaemia, it is still important to assess the level of knowledge of thalassaemia, attitude towards, and intention to screen for thalassaemia of unmarried individuals. Despite extensive health education and promotion efforts by the MOH, the results of this study showed that the level of thalassaemia knowledge remains poor. Some attitudes towards thalassaemia screening and intention to screen are also poor. It is important to analyse the possible reasons for this inadequate knowledge so that appropriate intervention measures can be taken.

In this study, most respondents had heard of thalassaemia (87.15%). In comparison, in another study on awareness of thalassaemia, only 55.3% of adults attending primary health care centres in Oman had heard of thalassaemia.[9] Another study in Pakistan, which analysed awareness of thalassaemia among university students studying management, found that only 75.2% of respondents had heard of thalassaemia.10 These findings show that the level of awareness about thalassaemia among unmarried individuals in Kota Bharu was equivalent to the level of awareness in other Middle Eastern and Asian countries where the prevalence of thalassaemia is higher.

Most respondents in this study cited mass media as their most frequent source of information for thalassaemia (31.3%), followed by health care providers (19.8%), and school (14%). In comparison, Wong et al. noted that most of the respondents in their study cited mass media as their primary source of information (83.35%), and health care providers as a minor source (8.9%).[4] Another study in Oman that involved Omani university students found that the students had heard about premarital screening primarily from school (36%) and less from health care providers (~31%).[11] A study in Pakistan involving management university students also noted that most respondents heard about thalassaemia from friends and relatives (42%) or from electronic media (26%); awareness campaigns by health authorities were only cited by 19% of respondents.[12]

The mean knowledge score of this study was 8.8 out of 21 (42.14%). This score is lower than the 11.85 out of 21 (56.43%) reported by Wong et al., who used the same questionnaire.[4] It is interesting to note that the mean score has declined despite recent extensive health promotion and education efforts focusing on thalassaemia prevention. The possible explanation for this discrepancy could be that the youths of Kelantan are more relaxed and have different ways of viewing the hardships of life, including thalassaemia. Thalassaemia knowledge levels have been assessed in other countries. A study in Turkey noted that the knowledge score of thalassaemia among premarital couples ranged from 41–50%.[12] A study in Italy found that knowledge of thalassaemia was much higher among Italians (54.9%) than Italian-Americans (16.5%) and non-Italian-Americans (23.6%).[13] Karimzaei et al. reported that, among Iranian marriage partners who were genetic carriers of thalassaemia, the mean knowledge score of thalassaemia was 11.48 out of 22 (52.18%).[14] Another study in Pakistan involving management university students noted that 72.6% of respondents had poor to slight knowledge of thalassaemia, and only 4% had excellent knowledge.[10] These findings suggest that the knowledge level of thalassaemia is still far less than satisfactory, not only in Malaysia, but also in other Asian and Middle East countries where the prevalence of thalassaemia is higher. The researcher also noted that many other studies in Middle Eastern countries assessed respondents' knowledge of premarital thalassaemia screening, rather than knowledge of thalassaemia.[9,11,15,16]

In terms of general knowledge of thalassaemia, over half of the premarital course respondents knew that thalassaemia was hereditary (62.2%); however, most of them did not know the difference between thalassaemia major and thalassaemia carrier state. Almost all the respondents were unsure whether thalassaemia carriers would manifest symptoms of the disease (91.4%). They also wrongly believed or were unsure of the following: thalassaemia carriers developed thalassaemia major (87.1%), children born to couples where either parent is a thalassaemia carrier are at risk of having thalassaemia major (84.9%), and couples who are both thalassaemia carriers will certainly give birth to thalassaemia major children, and they are unable to conceive any healthy children (79.1%). Understanding the difference between thalassaemia major and thalassaemia carrier state may be difficult for the public, particularly for individuals with lower education levels and economic status. This study did not assess the literacy level of the respondents, but they were assumed to have a satisfactory literacy level based on their educational backgrounds.

The respondents had several misconceptions that noted in this study. Many respondents incorrectly believed or were unsure whether all thalassaemia major patients were mentally handicapped (53.6%). Some respondents also falsely believed or were unsure whether a thalassaemia carrier could lead a normal life, work, or have a family (64.3%).

Knowledge about aspects of thalassaemia major diagnosis and treatment was also found to be deficient. Although most respondents

correctly responded that blood investigation is needed to diagnose thalassaemia (82.4%), more than half falsely believed or did not know that a urine test is used to diagnose thalassaemia (60.8%). Most respondents also did not know that patients with thalassaemia major need regular blood transfusions for life (66.2%), and only 21.9% knew that thalassaemia could be definitively cured by bone marrow transplant. These findings suggested that the knowledge of the diagnosis and treatment of thalassaemia was low among the respondents. However, it is important to note that some items with a low score can be considered medical knowledge of a higher level, like the difference between thalassaemia minor and major and its cure by bone marrow transplant.

Because the mean knowledge level was found to be low in this study, efforts must be made to further improve education about thalassaemia among unmarried individuals in Kota Bharu. The Malaysian MOH has produced pamphlets about thalassaemia that are available at all local health clinics as part of their health education efforts. Other ways of educating thalassaemia should be considered.

The results of this study showed that the only associated factor that significantly predicted knowledge score was professional occupation. This finding suggests that the knowledge level regarding thalassaemia is low in unmarried individuals in Kelantan, Malaysia who are not professionals; therefore, thalassaemia health promotion efforts should be targeted towards this group. This differs from a previous study by Wong et al., who reported that average household income predicted knowledge of thalassaemia.[4] Professional occupation seems self-explanatory; being professional corresponds to higher education level and having better access to sources of knowledge. An earlier study in Malaysia involving rural participants in Penang only analysed factors associated with awareness of thalassaemia, which were reported to be younger age group and higher level of education.[17] As for studies in other countries, factors that were significantly associated with increased knowledge of thalassaemia included age, educational status, and Italian race.[12–14]

In the multiple linear regression analysis, R^2 was 0.038, which indicated that the independent variables tested explained only 3.8% of the variability in the knowledge score. Other possible associated factors that were not analysed and could have been included in the analysis were: attitude towards thalassaemia screening; background of medical education[18]; location within Kota Bharu; source of thalassaemia awareness; perceived severity and susceptibility of thalassaemia[14]; perceived complications of thalassaemia in terms of affected patients; and perceived burden of thalassaemia on the patient, their family, and community.

Respondents were asked about their attitude towards thalassaemia screening. Most of the respondents agreed that thalassaemia screening was necessary for the general public (88.1%). Studies in Middle Eastern countries such as Oman, Turkey, and Saudi Arabia showed a high percentage of respondents agreeing that premarital screening was necessary, with the percentage of agreement ranging from 84.5% to 95.9%.[9,11,12,19] This finding was encouraging, as the percentage of agreement in this study was similar to the value reported by other studies. This reflects the positive attitude of unmarried individuals in Kota Bharu towards premarital thalassaemia screening.

In our study, 31.7% of the respondents agreed that two thalassaemia carriers who were a couple should not get married. In studies conducted in Turkey, Oman, and Saudi Arabia, 35–50% of respondents agreed that thalassaemia carriers should not marry each other.[11,12,19]

Only 26.6% of the respondents agreed that thalassaemia carriers should not have children. Compared with a study in Turkey, the percentage of participants that agreed that thalassaemia carriers should not have children was higher (50%).[12] The majority of premarital course respondents also did not agree with termination of pregnancy of foetuses with thalassaemia major; only 33.1% agreed. This finding implied that most respondents were not accepting of pregnancy termination, even though Islamic regulations allow termination of pregnancy for thalassaemia major cases before 120 days of gestation.[7,20] Kelantanese individuals are known for a strong stance in practicing Islam, especially the more traditional type of Islam. It is possible that some of the clerics in Kelantan reject termination of pregnancy entirely. Regarding similar data from studies

in other countries, a study in Palestine showed that 15% of pregnant mothers diagnosed with beta thalassaemia agreed to abortion, which is low.[21]

In this study, it was found that 5% of the respondents had been screened for thalassaemia. This suggests that despite the favourable attitudes of respondents regarding premarital thalassaemia screening, unmarried individuals did not undergo screening before marriage. The reasons given by those who had not been screened included perceiving themselves as not being at risk (65.7%), being afraid of the test results (19.4%), and not knowing about the test (8.9%). These fears suggest that more education and health promotion regarding knowledge and the importance of screening for thalassaemia should be provided, particularly to unmarried individuals in Kota Bharu. A study in northern Thailand showed that, when village health volunteers engaged the community about thalassaemia education, the rate of thalassaemia screening was higher.[22] Therefore, community participation can be considered an important part of thalassaemia education to encourage more voluntary thalassaemia screening.

In other countries, the percentage of premarital thalassaemia screening ranged from as low as 1.7% in Pakistan to 10.5–18.7% in Sri Lanka.[23,24] In Oman, a country with a high prevalence of thalassaemia due to a high rate of consanguineous marriage, the percentage of premarital thalassaemia screening was still quite low at 10.5%.[9] However, in Oman, the reasons for not undergoing premarital screening differed from those observed in our study; the main reasons included lack of awareness, self-perception of having no hereditary diseases in the family, and lack of interest.[9]

Respondents were asked if they would separate from their partner if both were thalassaemia carriers. Most respondents indicated that they would not separate, and only 29.1% agreed that they would separate. The final item in the questionnaire focused on willingness to abort a foetus with thalassaemia major if the pregnancy was less than 120 days, to which a small proportion of respondents agreed (16.5%). The two reasons given by respondents who would have refused abortion were: abortion is against religion (68.97%), and it is God's fate (28.4%). These reasons were given even though the question had been adjusted to include a statement about abortions for pregnancies less than 120 days fitting with the Islamic ruling of abortion for babies diagnosed with thalassaemia major.[7,20]

In conclusion, the findings of this study can be used to create further educational materials and programmes about thalassaemia, and to highlight the importance of screening. More programmes need to be designed to specifically target unmarried individuals. This study has identified various factors that influence this population, particularly in Kelantan, Malaysia.

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Conflicts of interest

The authors declare no conflicts of interest.

How does this paper make a difference to general practice?

- Thalassaemia is a common disease encountered in general practice.
- Primary care physicians should be aware of the issues pertaining to thalassaemia.
- Educating the youth regarding the condition is vital.
- Ensuring the application of obtained knowledge is even more important.
- This study provides all the information needed to help in guiding the society and the nation to minimise the number of children born with thalassaemia

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