ORIGINAL ARTICLE

Knowledge and Attitude of University Students in Perak, Malaysia towards Pre-Marital Screening for Thalassaemia.

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Abstract

Introduction: In Malaysia, thalassaemia is regarded as one of the important public health problems. The studies showed that a high number of children had thalassaemia as it was one of the most common autosomal recessive disorders that was genetically passed down from their parents. The lack of awareness of thalassaemia itself may have contributed to this as several mothers were unaware of their thalassaemia trait until they gave birth to a thalassaemia major child. Although thalassaemia is incurable, it is controllable with an effective prevention strategy that could decrease the percentage of affected births by approximately 95%. Therefore, this study was done to assess the knowledge, awareness, and participation of university students toward pre-marital screening for thalassaemia in Perak. **Materials and Methods:** This was a cross-sectional study and 333 students from eight universities in Perak State answered the online questionnaire. Multistage sampling method - quota sampling followed by convenience sampling - was used. The questionnaire was composed of 3 sections: Sociodemographic data of the participants, Knowledge on thalassaemia and Attitude towards premarital thalassaemia screening. **Results:** Our results highlighted the knowledge and attitude towards premarital screening of thalassemia. Majority of the respondents had a high level of knowledge (63.1%) and a high level of attitude (98.8%). A statistically significant association was found between the level of knowledge and some demographic characteristics, such as gender, the university the participants were enrolled in, level of study and their educational background. However, there was no association found between the level of attitude and the demographic features. **Conclusion:** Majority of the participants had a high level of knowledge on thalassaemia and a good attitude towards premarital thalassaemia screening. Moreover, the students who were studying in bachelor and masterprograms had 1.8 times the chance to have higher knowledge of thalassemia than the students from foundation and diploma programs.

Keywords: *Premarital screening, thalassaemia, University students in Perak*

Introduction

Thalassaemia, which the term itself shares the greek roots of thalassa for “sea” and haima for “blood.”, is known to be one of the most common genetic blood disorders in the world [1]. It is a hereditary disorder which involves approximately 240 million people across the globe who are heterozygous for β-thalassaemia whereas an approximate of 200,000 affected homozygotes are born annually [2]. This disease is not infectious as it only transmits genetically to children from the parents. Thalassaemia is a disease that involves a decrease as well as defective production of haemoglobin. According to a journal published in 2021, it was stated that about 80 to 90 million people were found to be β-thalassaemia carriers globally. It was also indicated that higher rates were found in the Mediterranean, Middle East, Central Asia, and the Indian subcontinent as well as North America [3].

The lack of awareness of thalassaemia resulted in approximately 4.5% of Malaysians were carriers of β-thalassaemia, whereas the affected births annually are estimated at 2.1 per 1,000 population. In Malaysia, there are 5,600 patients with transfusion dependent β-thalassaemia. Moreover, it was found that the Chinese population in Malaysia dominated the Southeast Asian deletion which caused a fatal condition in α-thalassaemia, known as the Bart's hydrops foetalis [4]. Past studies found that a number of mothers with a thalassaemia trait had been unaware of their carrier status until they gave birth to thalassaemia major children. Across the globe, the factors which include high gene frequency, low literacy rates, consanguine marriages, high birth rate as well as the population size were the major risk factors leading to a high incidence of β-thalassaemia. They were responsible for the large number of children with thalassaemia-dependent transfusion in the world. On top of that, economically the cost of the disease was high as patients with a thalassaemia major will need a monthly or even twice monthly blood transfusion as well as iron chelation treatment. However, in a lot of countries including Iran, Greece, Italy and Cyprus, this disease had been successfully controlled as there were many education campaigns as well awareness programs launched, making it a necessary approach to make people aware of the severity and difficulties when one or their family members had thalassaemia [1].

Thalassaemia is an incurable and severe disease yet was found to be manageable when there is an effective prevention programme that could decrease the percentage of the affected births by approximately 95%. Moreover, it was stated that a thalassaemia carrier couple had a 25% chance to produce a thalassaemia major child.

Thus, a premarital screening remained as one of the prevention measures as it had been proven as an effective approach to reduce the incidence of thalassaemia in many countries across the globe. In history, the first pre-marital thalassaemia screening was carried out back in 1975 by Silvestroni and colleagues in Latium, Italy, as a part of a school prevention programme following a screening for sickle cell anaemia in 1970, in Virginia. Following that, a number of nationwide screening programmes were also done in Greece, Italy, Canada, Cyprus and the UK during the 1970s, which was proven to be a success [5].

In Cyprus, Greece and Italy, a pre-marital screening for thalassaemia had been practised for decades as the consanguinity rate was high. Although screening for thalassaemia had been known and widely implemented in several countries, not everyone is aware of the importance of it in preventing thalassaemia [5]. As a preventive measure, a premarital or carrier screening before marriage should be done to detect defective or diseased genes which would cause an autosomal or X-linked recessive genetic disease in the offspring. This is important to avoid pregnancy which have a significant morbidity and reduced life expectancy after birth [6]. Through a simple blood test, the healthy carriers of β-thalassaemia could be easily identified. However, to implement an educational intervention

program of a disease, it may require a deeper understanding as well as the attitudes of their knowledge of that disease. Most medical undergraduate students may have a good knowledge and a positive attitude towards thalassaemia but a nonmedical student may have a limited exposure to medical knowledge on thalassaemia[1]. So, this study was done in order to assess the knowledge, awareness and participation of university students on pre-marital screening for Thalassaemia in Perak.

Current estimation showed that 6.8% of Malaysians were thalassemia carriers who might be affected with various degrees of anaemia. The majority of registered patients with thalassemia were Malay (63.9%), followed by Chinese (11.75%) and the rest are Indians and other ethnicities in Malaysia. Malay ethnicity had the highest prevalence of β-thalassemia than others [7]. The largest number of registered patients with thalassemia came from Sabah (22.72%), followed by Selangor state (14.64%), Kedah (8.69%), Johor (7.98%) and Perak (7.06%). Majority of the patients that had thalassemia were in the group age of 5-25 years (64.45%) [8].

Methodology

A cross-sectional study was conducted in June till July 2023 for 6 weeks to assess the level of knowledge and attitude among students studying at eight universities in Perak on premarital screening of thalassaemia. Online data collection was performed by using structured self-administered questionnaires. The estimated total number of university students in Perak was 59,768. Based on a previous study (Haque et al, 2015), the anticipated frequency is 32% with a precision of 5% for 95% confidence limit and 333 sample size was obtained. Multistage sampling method was used and the inclusion and exclusion criteria were applied. First, quota sampling was used to make sure the questionnaire was equally distributed among the universities, followed by convenience sampling. This questionnaire was pretested before distributing it to the respondents to uncover biases in question wording, and was corrected. Informed consent was taken from all the participants before answering the questionnaire. The identity of the respondents and their personal data was kept anonymous, and confidential. Questionnaires used in survey research were clear and well presented. The questionnaire was composed of 3 sections: sociodemographic data of the participants, knowledge on thalassaemia and attitude towards premarital thalassaemia screening.

Data Analysis

The data was tabulated and analysed using Microsoft Excel and IBM Statistical Package for Social Sciences (SPSS) 2015. The 3 sections of the questionnaire (socio-demographic, knowledge of thalassaemia and attitude towards premarital thalassaemia screening), were of categorical variables. The frequency and the percentage of each variable were calculated. The raw score for knowledge on thalassaemia was calculated by summing up the correct answers with a total score of 12, while the raw score for attitude towards premarital thalassaemia screening was calculated by summing up the correct answers with a total score of 8. The level of knowledge and level of attitude was divided into two categories (high/low, and good/poor) by using the median scores (50^{th} percentile). For inferential statistics, we perform a chi-square test to find out the relationship between socio-demographic with knowledge on thalassaemia and attitude towards premarital thalassaemia screening.

Ethical Considerations

The study had been submitted for review and was approved by the UniKL RCMP Medical Research Ethics Committee (MREC). Respondents were informed about the research and confidentiality of their responses. They were requested to tick the online consent form if they agree.

Results

The online questionnaires were distributed to 420 university students in Perak and, 333 (79.3%) answered our questionnaire. Table 1 showed the sociodemographic of 333 respondents.

Majority of the respondents were less than and equal to 23 years old (63.4%) and predominantly female (59.5%). Most of the respondents were Malay (81.4%). The respondents were equally distributed among 8 universities. Among 333 respondents, most of them were from bachelor and master programs (78.4%) and Medicine and Health Sciences was the highest among the courses (25.8%).

Concerning the knowledge on thalassemia among university students in Perak, most of them agreed that thalassemia was not a contagious disease (62.8%). Majority of the respondents knew that thalassemia was a genetic disease (93.1%). Only 107 respondents believed that thalassemia could not be transmitted through blood transfusion from a person with thalassemia (32.1%). Half of the respondents knew that individuals who had thalassemia were anaemic (56.8%). More than half of the respondents agreed that thalassemia carriers were as healthy as normal people (63.4%). 84.1% of respondents believed that marriage between two carriers could lead to a child with thalassemia major. Only 61 (18.3%) respondents believed that if one parent was a carrier, the couple had a chance of having a child with thalassemia. More than half of the respondents agreed that marriage between close relatives could increase the chance of thalassemia (55.6%). Only 91 (27.3%) respondents believed that thalassemia was a preventable disease. Then, 46.2% of respondents did not agree that thalassemia was a completely curable disease. 72.4% of respondents agreed that anyone could be a thalassemia carrier. Majority of the respondents (93.1%) knew that thalassemia could be identified by blood test. Table 3 showed frequency and percentage level of knowledge. Majority of the respondents had a high level of knowledge (63.1%).

Table 4 showed frequency and percentage of attitude towards premarital thalassemia screening. For attitude, the majority of the respondents agreed to take the necessary blood test before marriage to prevent the birth of a thalassaemic child (98.2%). Most of them would like to encourage family members to perform the blood testing for thalassemia before marriage (97.9%). 97.6% of the respondents encouraged their friends to do premarital screening for thalassemia. 67.3% of respondents had relationship with thalassemia persons. Only 196 (58.9%) respondents had intention to marry their partner if they were tested as thalassemia carriers. 76.9% of them agreed that testing for thalassemia before marriage would not do more harm than good for society. Next, 77.8% of respondents believed that if both of them are thalassemia carriers, they would try not to have children together. All of the respondents agreed that their universities should take initiative to create awareness among students about thalassemia.

Table 5 showed frequency and percentage level of attitude towards premarital thalassemia screening. Majority of the respondents had a high level of attitude (98.8%).

Table 6 displayed the association between level of knowledge on thalassemia screening and all sociodemographics. There was no association between level of knowledge on thalassemia screening and age (p=0.338), which suggested that regardless of age of the respondents, all havehigh level of knowledge on thalassemia. Female students were more d knowledgeable on thalassemia compared to male students (p=0.005). With regards to ethnicity, no association was found between level of knowledge on thalassaemia and ethnicity (p=0.749). Respondents from all ethnicities have a high level of knowledge on thalassemia. There was an association found between knowledge on thalassaemia and the university, students were

enrolled in (p =0.005). Students from UniKL RCMP have the highest level of knowledge on thalassemia with 88.1% scoring high. An association was found between knowledge on thalassaemia and the level of study (p=0.02), which meant that students from bachelor's and master's programs have 1.8 times higher knowledge on thalassemia compared with students from foundation and diploma. There was also an association found between the knowledge on thalassaemia and educational background (p=0.005). Respondents with medicine and health science education have a higher level of knowledge on thalassemia compared with students in other courses.

Table 7 showed that there was no association between level of attitude towards premarital thalassemia screening and all sociodemographics (p-value>0.05).

Discussion

Based on the results, it was observed that frequency and level of knowledge of participants on thalassemia were high, which was 63.1%. This was far better than a study by Samina Perven et al, conducted among undergraduate students in Bangladesh which showed 49.5%, 43.6%, and 7.1% had poor, average and good knowledge about premarital screening of thalassemia respectively [3]. In Malaysia, a study in Kota Bharu, Kelantan, showed that knowledge of thalassemia among unmarried individuals who were not professionals, was low [12]. Majority of the respondents in current study knew that thalassemia was a genetic disease (93.1%) and this is much higher than the study done in Selangor which showed that 66.3% of medical students and 36.7% of nonmedical students knew that thalassemia is a familial disease [2]. This study showed that slightly more than half (56.8%) of respondents knew that individuals with thalassaemia are anaemic, while the study in Selangor showed 71.9% of medical students and only 28.1% of nonmedical students knew this fact [2]. There is still a gap in understanding thalassaemia in Malaysia. There is a need to address this gap with more rigorous educational campaign.

For the level of attitude towards premarital thalassemia screening, it was shown that the majority of the respondents had a high level of attitude (98.8%). Majority of the respondents agreed to take blood test for thalassaemia before marriage (98.2%) at the same time encouraged their family members to do the same (97.9%). This results were better than the study in Selangor, where 55.1% of medical students and 44.9% of nonmedical students were willing to be screened for thalassaemia [2]. A study in Qatar 78.2% respondents agreed that premarital screening was important for future married life [10]. All of the respondents in current study wanted their university to take initiative to create awareness among students about thalassaemia, reflecting their very positive attitudes towards screening for thalassaemia.

This study also revealed more females (69.2%) than males (54.1%) have knowledge on thalassaemia, which was in contrast to the study conducted in Kolkata, India which found that more males (61.7%) had adequate knowledge on thalassemia than females (42%) [11].

This study showed similar findings with the study in Selangor, that more students from universities with Medicine and Health Sciences courses have knowledge on thalassaemia [12]. This emphasised the inequality on knowledge of thalassaemia that need to be addressed by either Ministry of Health (MoH) and the Ministry of Education (MoE) to ensure the awareness and screening campaign on thalassaemia, that was launched in January 2021, will reach its target [13].

Limitation and Suggestion

The limitation in this study was utilization of a web-based non-probability convenience sampling method. Most of the university students were their semester break, hence, only active internet users could be recruited in this study.

Conclusion

This study showed that students in Perak, had good knowledge on thalassaemia and good attitude towards thalaasaemia screening. These findings were similar to students in Selangor[2]. Nevertheless, there was a difference in knowledge among nonmedical and nonhealth background students, which requires stakeholders (MoH and MoE) to improve the deliverance on understanding and awareness of thalassemia and screening of thalassaemia, to the general public especially those without medicine and health sciences background.

Table 1. Frequency and percentage of sociodemographic characteristics of the students

Variables	Frequency (n)	Percentage (%)
Age		
• Less than and equal to 23 years old	211	63.4
• More than 23 years old	122	36.6
Gender		
• Female	198	59.5
• Male	135	40.5
Ethnic group		
• Malay	271	81.4
• Chinese, Indian and Others	62	18.6
University Studying		
• UniKL RCMP	42	12.6
• UTP	42	12.6
• UTAR	42	12.6
• UITM Tapah	42	12.6
• UITM Seri Iskandar	42	12.6
• Quest University	41	12.3
• USAS	41	12.3
• UPSI	41	12.3
Level of study		
• Bachelor and master	261	78.4
• Foundation and diploma	72	21.6
Educational Background		
• Medicine and health science	86	25.8
• Engineering and applied science	55	16.5
• IT, information system and management	43	12.9
• Education and language	49	14.7
• Islamic studies	32	9.6
• Business, economic and accounting	36	10.8
• Architecture, planning and surveying	32	9.6

Table 2. Frequency and percentage of knowledge on thalassemia

Questions	Options					
	Yes		No		Not Sure	
	n	%	n	%	n	%
Thalassemia is a contagious disease	106	31.8	209	62.8	18	5.4
Thalassemia is a genetic disease	310	93.1	4	1.2	19	5.7
Thalassemia can be transmitted through blood transfusion from a person with thalassemia	155	46.5	107	32.1	71	21.3
Individuals who have thalassemia are anaemic	189	56.8	23	6.9	121	36.3
Thalassemia carriers are as healthy as normal people	211	63.4	46	13.8	76	22.8
Marriage between two carriers can lead to a child with thalassemia major	280	84.1	9	2.7	44	13.2
If one parent is a carrier, the couple has a chance of having a child with thalassemia	208	62.5	61	18.3	64	19.2
Marriage between close relatives can increase the chance of thalassemia	185	55.6	33	9.9	115	34.5
Thalassemia is a preventable disease	164	49.2	91	27.3	78	23.4
Thalassemia is a completely curable disease	71	21.3	154	46.2	108	32.4
Anyone could be a thalassemia carrier	241	72.4	38	11.4	54	16.2
Thalassemia can be identified by blood test	310	93.1	0	0	23	6.9

Table 3. Frequency and percentage level of knowledge.

Level of Knowledge	Frequency (n)	Percentage (%)
High	210	63.1
Low	123	36.9
Total	333	100

Table 4. Frequency and percentage of attitude towards premarital thalassemia screening.

Questions	Options			
	Yes		No	
	n	%	n	%
I would take the necessary blood test before marriage to prevent the birth of a thalassemic child.	327	98.2	6	1.8
I would like to encourage my family members to perform the blood testing for thalassemia before marriage.	326	97.9	7	2.1
I would encourage my friends to do premarital screening for thalassemia.	325	97.6	8	2.4
I would like to have a relationship with a thalassemia person.	109	32.7	224	67.3
If my partner was tested as a thalassemia carrier, I would still want to marry him/her.	196	58.9	137	41.1
Testing for thalassemia before marriage will do more harm than good for society.	77	23.1	256	76.9
I believe that if both my partner and I are thalassemia carriers, we will try not to have children together.	256	77.8	74	22.2
I want my university to take initiative to create awareness among students about thalassemia.	333	100	0	0

Table 5. Frequency and percentage of level of attitude towards premarital thalassemia screening.

Level of Attitude	**Frequency (n)**	**Percentage (%)**
Good	329	98.8
Poor	4	1.2
Total	333	100

Table 6. Association between level of knowledge on thalassemia and sociodemographics.

Variables	Level of knowledge							
	High n (%)	Low n(%)	χ^2 value	df	POR	95% Confidence Interval		P-value
						Lower	Upper	
Age								
-Less than and equal to 23 years old	129 (61.1)	82 (38.9)	0.917	1	-	-	-	0.338
-More than 23 years old	81 (66.4)	41 (33.6)						
Gender								
-Female	137 (69.2)	61 (30.8)	7.876	1	1.907	1.212	3.002	*0.005**
-Male	73 (54.1)	62 (45.9)						
Ethnic group								
-Malay	172 (63.5)	99 (36.5)						
-Chinese, Indian and Others	38 (61.3)	24 (38.7)	0.103	1	-	-	-	0.749
University currently studying								
-UniKL RCMP	37 (88.1)	5 (11.9)						
-UTP	24 (57.1)	18 (42.9)						
-UTAR	27 (64.3)	15 (35.7)						
-UITM Tapah	27 (64.3)	15 (35.7)	20.28	7	-	-	-	*0.005**
-UITM Seri Iskandar	22 (52.4)	20 (47.6)						
-Quest University	30 (73.2)	11 (26.8)						
-USAS	20 (48.8)	21 (51.2)						
-UPSI	23 (56.1)	18 (43.9)						
Level of study								
-Bachelor and masters	173 (66.3)	88 (33.7)	5.375	1	1.860	1.096	3.155	*0.02**
-Foundation and diploma	37 (51.4)	35 (48.6)						
Educational Background								
-Medicine and Health Science	68 (79.1)	18 (20.9)						
-Engineering and applied science	33 (60.0)	22 (40.0)						
-IT, information system and management	23 (53.5)	20 (46.5)						
-Education and language			18.56	6	-	-	-	*0.005**
-Islamic studies	30 (61.2)	19 (38.8)						
-Business, economic and accounting	14 (43.8)	18 (56.3)						
-Architecture, planning and surveying	25 (69.4)	11 (30.6)						
	17 (53.1)	15 (46.9)						

Chi-square test was performed, *level of significant at p<0.05*;* POR = Prevalence Odds Ratio, df = degree of freedom

Table 7. Association between level of attitude towards premarital thalassemia screening and sociodemographics.

Variables	Level of attitude				
	High n(%)	Low n(%)	χ^2 value	df	P-value
Age					
-Less than and equal to 23 years old	208 (98.6)	3 (1.4)			
-More than 23 years old			0.236	1	0.627
	121 (99.2)	1 (0.8)			
Gender					
-Female	195 (98.5)	3 (1.5)	0.406	1	0.524
-Male	134 (99.3)	1 (0.7)			
Ethnic group					
-Malay	267 (98.5)	4 (1.5)			
-Chinese, Indian and Others	62 (100)	0 (0)	0.926	1	0.336
University currently studying					
-UniKL RCMP	42 (100)	0 (0)			
-UTP	42 (100)	0 (0)			
-UTAR	41 (97.6)	1 (2.4)			
-UITM Tapah	42 (100)	0 (0)			
-UITM Seri Iskandar	41 (97.6)	1 (2.4)	8.185	7	0.317
-Quest University	39 (95.1)	2 (4.9)			
-USAS	41 (100)	0 (0)			
-UPSI	41 (100)	0 (0)			
Level of study					
-Bachelor and masters	259 (99.2)	2 (0.8)	1.924	1	0.165
-Foundation and diploma	70 (97.2)	2 (2.8)			
Educational Background					
-Medicine and health science	84 (97.7)	2 (2.3)			
-Engineering and applied science	53 (96.4)	2 (3.6)			
-IT, information system and management	43 (100)	0 (0)			
-Education and language	49 (100)	0 (0)			
-Islamic studies	32 (100)	0 (0)			
-Business, economic and accounting	36 (100)	0 (0)			
-Architecture, planning and surveying	32 (100)	0 (0)	5.999	6	0.423

Chi-square test was performed, df = degree of freedom

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