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Knowledge, Awareness and Participation of Medical and Non-medical Students in the Malaysia National Thalassemia Prevention Programme

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KEYWORDS Screening. Attitudes. Thalassemia. Multi-racial Population

ABSTRACT There are about 1 in 20 Malaysians who are carriers of the thalassemia gene and the prevalence of this disease in Malaysia is 6-10 percent. This study was conducted to assess knowledge, awareness and participation of medical and non-medical students in the Malaysia National Thalassemia Prevention Programme. The design of the study was a cross-sectional study. A total of 300 questionnaires were distributed to selected students from the university. The collected data was analysed using SPSS version 20.0. Data analysis revealed a highly significant difference in total knowledge between medical students and non-medical students and the thalassemia awareness also showed significant statistical association between medical and non-medical students. In conclusion, medical students have better knowledge, awareness and screening rate of thalassemia.

INTRODUCTION

Thalassemia is one of the most common genetic blood disorders in the world. There are approximately 240 million people worldwide who are heterozygous for β-thalassemia and approximately 200,000 affected homozygotes are born annually (Haque et al. 2015). It is a genetic disorder which involves the absence of or errors in genes that affect the body's ability to produce a protein in the red blood cells called haemoglobin, a protein present in the red blood cells. Generally, these groups of single gene disorders have an estimated 5 percent prevalence as carriers. Like in many other countries, thalassemia also poses an important public health problem in Malaysia. Approximately 4.5 of Malaysians are carriers of ß-thalassemia, and annually the affected births are estimated at 2.1 per 1,000 with an estimated 5,600 patients with transfusion dependent ß-thalassemia in Malaysia (George and Tan 2010). The Malaysian Chinese possess the Southeast Asian deletion that causes Bart's hydropsfetalis, a fatal condition in α-thalassemia (Fucharoen and Vip 2009). Lifelong treatment is needed for those affected with symptomatic thalassemia major and intermedia. Population screening for detection of carriers is the best way to reduce its occurrence and is being practiced in many countries. The best mechanism for screening varies as it covers various areas such as the genetic examination and analysis as well as genetic counselling.

In several countries, carrier screening programs are being conducted using various approaches. They include cascade screening, screening of 'high-risk' communities, screening of the general population and antenatal screening. The percentage of β-thalassemia carriers identified using a cascade screening approach is 5-6 times higher. It has been shown earlier that in communities where consanguinity is common, one can identify even more number of carriers. More than 90 percent of the "at risk" couples were identified in Sardinia using cascade screening by examining only 11percent of the population (Sazlina et al. 2015).Thalassemia carrier screening programmes can be divided into largely mandatory programmes and voluntary pro-

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grammes. They can also be divided by the timing of testing in relation to pregnancy, being either pre-pregnancy or in the early stages of pregnancy. There are many options available to a couple, if screening is done before conception. They can decide to end their relationship, adopt a child, use donor egg or sperm, conceive through in-vitro fertilization using pre-implantation genetic diagnosis or they can choose to go ahead with prenatal diagnosis after conception and elect to terminate the pregnancy if the foetus is affected with β-thalassemia major (Amato et al. 2014). It is estimated that 56,100 infants are born yearly with thalassemia in the world. This figure is expected to rise in the next 20 years to 900,000 births of clinically significant thalassemia disorders. Asia and Middle Eastern regions account for 95 percent of thalassemia births. The countries mainly affected by thalassemia are those in the Mediterranean region such as Italy, Greece and Cyprus and in Asia countries like China, India and countries in South East Asia including (Khodaei et al. 2013). The population of Malaysia is 28.3 million comprising mainly of Malays (50.8%) who make up the majority followed by the Chinese (23%), indigenous people of Sabah and Sarawak (11%) and Indians (6.9%). The remaining population is made up by the ethnic minority groups who account for 8.3 percent of the population. In Malaysia, most health centres, including the community health centres are equipped with a blood cell analyser, and it is therefore feasible to adopt the screening method based on the MCV of <80fL or MCH of <27 pg (Ezaliaet al. 2014).Though it is not necessarily thalassemia, it may be an indicator and further investigations can be performed for certainty. Prior to controlling thalassemia, the Malaysian government through its Ministry of Health tried to cultivate awareness through advertisements in the mass media as well as the alternative media, the internet by its resource centre website, My Thalassemia.

It is stated that screening of thalassemia is compulsory for a couple before marriage and are then advised a thorough counselling service (Al-Farsiet al. 2014). It was found that women who had undergone antenatal carrier screening in the United Kingdom were overall glad to be made aware of their carrier status. While in Pakistan, medical practitioners, lawyers, politicians and parents of children affected by thalassemia are trying determining people's attitudes towards thalassemia carrier screening and found that over 95 percent of the parents and 90 percent of the doctors supported genetic screening; however, only one-third of politicians were in favour of screening. It is often considered as heavy burden for affected families and the health care system. Moreover, social stigma associated with thalassemia also impact on patients and their families. In India, being a thalassemia carrier caused social isolation, marital tensions and stigmatization. There are many proven studies which indicate that prenatal diagnosis has dramatically reduced the disease burden but lot of barriers such as lack of knowledge, awareness about the disorder, its consequences, and deep psychosocial, cultural issues may serve as barriers to prevention. Additionally, a number of studies worldwide showed that attitudes toward prenatal diagnosis were related to religious convictions. Muslim couples, for instance, have been reported to refuse prenatal diagnosis on religious grounds. Studies on knowledge, attitudes and practices related to thalassemia are relatively scarce in Malaysian context (Cousens et al. 2010). A Malaysian study, which conducted the first nationwide population based survey of thalassemia in Malaysia, aimed to determine differences in public awareness, perceptions and attitudes toward thalassaemia in the multi-racial population in Malaysia (Wong et al. 2011).

This study aimed to assess knowledge, awareness and participation of medical and non-medical students in the Malaysian National Thalassemia prevention programme.

Objectives of the Study

To evaluate the awareness and knowledge of thalassemia disease, attitude and participation of medical and non-medical students in the Malaysia National Thalassemia Prevention Programme.

MATERIAL AND METHODS

The study was done in the Management and Science University, Seksyen 13 Campus and was conducted from November 2011 until March 2012.The study design is a descriptive cross sectional study.

Study Population and Sample

The populations of this study were students of Management and Science University, Seksyen 13 Campus Shah Alam, Selangor. The population was divided into two groups; the medical students from Faculty of International Medical School and non-medical group of Faculty of Business Management and Professionals. (FBMP)

Sample Size

The sample size was 300 students. 150 respondents were medical students of International Medical School and 150 respondents were non-medical students of Faculty of Business Management and Professionals.

Sampling Technique

Choosing of Sample

The choice of sampling was random and was purposive convenience sampling. The questionnaires were distributed to about 150 medical students of International Medical School and 150 non-medical students of Faculty of Business Management and Professionals.

The study was approached by using a designed questionnaire of the Thalassemia Disease and screening programme. This questionnaire was developed by the authors of this study. The questionnaires included three sections as below:

Section 1: Socio-demographic

The questions contained the basic socio-demographic questions. These included the respondent's age, sex, education level, marital status, race and religion. This is important because it may relate to the awareness and knowledge about thalassemia.

Section 2: Awareness, knowledge and attitude relating to the thalassemia disease and its screening.

In this section the respondents were asked about their awareness and knowledge about thalassemia disease and its screening. Their knowledge about the disease and whether it could be fatal or not, could be cured or not, the treatment and symptoms was a part of this section of the questionnaire. This section was important to know the level of awareness and knowledge about thalassemia disease.

Section 3: Participation in the Malaysia National Thalassemia Prevention Programme

In this section, the respondents were asked about the participation in health campaign and opinions about place of screening.

Data Collection

Ethical Approval

Ethical approval was obtained from ethical committee of International Medical School, MSU.

Questionnaire

The place of distribution was in Management and Science University, Seksyen 13 Campus, Shah Alam, Selangor. Before distributing the questionnaire, permission was asked from the respondent directly, the respondent would fill the consent form to prove their consent. The survey was kept anonymous and the participation of students was voluntary.

Dependent Factors

1. Awareness of thalassemia disease and its screening
2. Knowledge of thalassemia disease and its screening
3. Attitude towards thalassemia disease and its screening
4. Participation in the Malaysia National Thalassemia Prevention Programme.

Independent Factors

These were mainly socio-demographic - gender, religion, races, ages, marital status, time usage and media preference.

Data Analysis

The raw data was calculated using the Statistical Package for Social Science (SPSS) program. The statistical tests that were used on the raw data was the Chi-square test and Spearman's rank correlation coefficient. This can explain the

descriptive and bivariate analysis from the data collected.

RESULTS

Participation of Medical and Non-medical Students in the Malaysia National Thalassemia Prevention Programme

Of the total respondents, 60.5 percent of medical students had heard about 1-2 health campaigns throughout 2011 whereas 65.1 percent of non-medical students had heard about less than one health campaign throughout 2011. A significant differencewas observed between the two groups for the number of health campaigns that they had heard throughout 2011 (p=0.0046).

45.9 percent of medical students who responded to the question on the most preferable health institution said they preferred to visit private hospitals once in a year to get screened for thalassemia whereas 54.1 percent of non-medical students who responded to the question on the most preferable health institution said they preferred to visit private hospitals once a year to get screened for thalassemia. 66.7 percent of medical students who responded to the question on the most preferable health institution said they preferred to visit private clinics once in a three months to get screened for thalassemia whereas 46.7 percent of non-medical students who responded to the question on the most preferable health institution said they preferred to visit private clinics once in six months to get screened for thalassemia. A significant difference was observed between the two groups for those who visited private hospitals (p=0.0369) and private clinics (p=0.0459). However, it was also noticed that there was a significant difference between the two groups who responded to government clinics (p=0.0025) and private clinics (p=0.0193) as the least preferable health institution. 77 percent of the medical students who responded to the question on the least preferable health institution said that it took a lot of time to get screened at the Government clinics whereas only 29 percent of the non-medical students who responded to the question on the least preferable health institution also said that time was a crucial factor while attending these clinics (Table 1).

The following questions on: promotions regarding thalassemia in 2011, accessing government internet websites regarding thalassemia and its prevention, promotion regarding thalassemia prevention in MSU campus, having seen promotion regarding thalassemia in leisure places, willingness to participate in thalassemia programme if introduced by someone (p=0.0162), asking friends or family members to participate in health campaigns and willingness to tell friends about the thalassemia after completion of this survey were all statistically significant (p=0.0001). Sixty-eight percent of medical students had never heard of any Thalassemia promotions in 2011 whereas only 38 percent of non-medical students answered "No" to this question. Majority of the students had never accessed a Government website regarding thalassemia and its prevention (61 percent of medical students and 39.1 percent of non-medical students). The majority of students also had not seen any thalassemia promotion at public leisure places (62.6% of Medical students and 37.4% of non-medical students respectively). 55% of medical students and 45% of non-medical students were willing to participate in the National Thalassemia Prevention Programme if someone introduced them to it. Only a small number of students (31 medical students and 25 non-medical students) were tested for Thalassemia/Thalassemia trait (Table 2).

Awareness and Knowledge Regarding Thalassemia among Medical and Non-medical Students in the Malaysia National Thalassemia Prevention Programme

Medical students (65.7%) knew that Thalassemia was associated with fewer red blood cells whereas 72.8 percent of non-medical students did not know about Thalassemia. 78.5 percent of medical students knew that Thalassemia is associated with low iron levels whereas 82.7 percent of non-medical students did not know the iron levels in thalassemia. About thirty-five percent of medical students and 64.1 percent of non-medical students did not know the prevalence of thalassemia among Malaysians. Medical students (61.3%) responded that the best time to get screened for thalassemia or thalassemia trait would be as an infant or small child whereas 60.4 percent of non-medical students said that teenage would be best time to get

Table 1: Number and percentage related to participation of medical and non-medical students in the Malaysia National Thalassemia Prevention Programme – 2011

S. No.	*Groups*	*Medical (IMS) n (%)*	*Non-medical (FBMP) n (%)*	*Chi-square*	*p-value*
1	Numbers of health campaigns heard throughout the year 2011				
	<1	29 (34.90)	54 (65.10)	13.0	0.0046*
	1-2	75 (60.49)	49 (39.51)		
	3-4	25 (50)	25 (50)		
	>5	21 (48.85)	22 (51.15)		
2a	*Most Preferable Health Institutions to Get Screened for Thalassemia and Its Reasons*				
2.1	*Private Hospital*				
	>3 times per month	7 (87.50)	1 (12.50)	10.22	0.0369*
	1-3 times per month	2 (28.57)	5 (71.43)		
	Once in three month	16 (72.72)	6 (27.28)		
	Once in six month	6 (42.85)	8 (57.15)		
	Once in year	17 (45.94)	20 (54.06)		
2.2	*Private Clinic*				
	>3 times per month	2 (33.33)	4 (66.67)	9.69	0.0459*
	1-3 times per month	2 (16.66)	10 (83.34)		
	Once in three month	18 (66.66)	9 (33.34)		
	Once in six month	16 (53.33)	14 (46.67)		
	Once in year	6 (40)	9 (60)		
				0.687	0.4074
2b	*Least Preferable Health Institutions to Get Screened for Thalassemia and Its Reasons*				
2.3	*Government Clinics*				
	Time	22 (70.96)	9 (29.04)	14.33	0.0025*
	Comfort	15 (71.42)	6 (28.58)		
	Cost	3 (33.33)	6 (66.67)		
	Location	0 (0)	6 (100)		
2.4	*Private Clinic*				
	Time	1 (16.66)	5 (83.34)	9.91	0.0193*
	Comfort	6 (50)	6 (50)		
	Cost	11 (73.33)	4 (26.67)		
	Location	0 (0)	4 (100)		
3	If the test is conducted before married and both of you are carriers will you proceed with marriage?				
	Yes	65 (71.42)	26 (28.58)	61.21	0.0001*
	No	58 (65.16)	31 (34.84)		
	I Don't Know	27 (22.50)	93 (77.50)		

Analysis of data was done using Chi-square test.
p <0.005 was considered as statistically significant.

screened for thalassemia or thalassemia trait. It has been observed that 66.3 percent of medical students and 36.7 percent of non-medical students knew that thalassemia is a familial disease. Seventy-one percent of medical students knew that thalassemic patients suffer from anemia whereas 76.5 percent of non-medical students did not know whether thalassemic patients were anaemic or not.A large proportion of non-medical students surveyed (82.9%) were not aware that Thalassemia patients could be treated with blood transfusions .When asked whether *if a person is born with thalassemia trait, he/she will always be a carrier as the trait is inherited from parents,* 84 percent of non-medical students said that they did not know the answer.49.1 percent of medical students and 50.9 percent of non-medical students did not know that *the screening test service for thalassemia trait is fully subsidized in Malaysia.* There was statistically significant differences ($p<0.005$) between the two groups on the awareness and knowledge of the following questions: thalassemia sources, problems of thalassemia,untreated thalassemia, iron levels in untreated thalassemia,the ideal time to get tested for thalassemia/thalassemia trait, whether thalassemia is a contagious disease/ familial disease/sexually transmitted disease and an allergic reaction,whether thalassemic individuals lead normal lives with appropriate

Table 2: Number and percentage related to participation of medical and non-medical students in the Malaysia National Thalassemia Prevention Programme – 2011

S. No.	*Groups*	*Medical (IMS) n (%)*	*Non-medical (FBMP) n (%)*	*Chi-square*	*p-value*
1	*Heard of Any Promotions Regarding Thalassemia in the Year 2011?*				
	Yes	68 (57.14)	51 (42.86)	45.05	0.0001*
	No	68 (66.02)	35 (33.98)		
	I Don't Know	14 (17.94)	64 (82.06)		
2	*Accessed Any Government Internet Website Regarding Thalassemia and Its Prevention?*				
	Yes	44 (58.66)	31 (41.34)	45.86	0.0001*
	No	98 (60.86)	63 (39.14)		
	I Don't Know	8 (12.50)	56 (87.50)		
3	*Heard of Any Promotion Regarding Thalassemia Prevention in MSU Campus?*				
	Yes	33 (51.56)	31 (48.44)	31.62	0.0001*
	No	102 (61.44)	64 (38.56)		
	I Don't Know	15 (21.42)	55 (78.56)		
4	*Seen Any Promotion Regarding Thalassemia in Leisure Places?*				
	Yes	46 (54.76)	38 (45.24)	46.79	0.0001*
	No	97 (62.58)	58 (37.42)		
	I Don't Know	7 (11.47)	54 (88.53)		
5	*Willing to Participate in the Thalassemia Prevention Programme if Someone Introduces You?*				
	Yes	92 (55.08)	75 (44.92)	8.25	0.0162*
	No	22 (57.89)	16 (42.11)		
	I Don't Know	36 (37.89)	59 (62.11)		
6	*Have You Asked Your Friends or Family Members to Participate in Any Health Campaigns?*				
	Yes	76 (53.90)	65 (46.10)	43.65	0.0001*
	No	63 (68.47)	29 (31.53)		
	I Don't Know	11 (16.41)	56 (83.59)		
7	*Willing to Tell Friends about Thalassemia After Completing This Survey*				
	Yes	116 (59.18)	80 (40.82)	24.13	0.0001*
	No	15 (50)	15 (50)		
	I Don't Know	19 (25.67)	55 (74.33)		
8	*Tested for Thalassemia / Thalassemia Trait*				
	No	119 (48.73)	125(51.27)	0.55	0.4588
	Yes	31 (55.35)	25(44.65)		

Analysis of data was done using Chi-square test.
p <0.005 was considered as statistically significant.

treatment,whether thalassemic individuals are anaemic,whether thalassemia can be treated with blood transfusions/medications,whether appropriate treatment can cure thalassemia/thalassemia trait,a person with thalassemia trait will always be a carrier as the trait is inherited from parents/will require blood transfusion (Tables 3,4 and 5).

Socio-demographic Data of Medical and Non-medical Students in the Malaysia National Thalassemia Prevention Programme

Three hundred respondents participated in the study. There were one hundred and fifty Medical and Non-medical students each in both the groups. There were 111 females (74%) and 39 males (26%) in the medical group and 104 females (69.33%) and 46 males (30.67%) in the non-medical group.The age of the respondents was in the range of 18-28 years. Majority of the students in both groups were Malay. The marital status of majority of the students was single (96% in the medical group and 97.33 percent in the non-medical group). Only 4 percent of medical students and 5.3 percent of non-medical students reported that they had a family member or blood relative who were suffering from thalassemia.

There were statistically significant differences ($p<0.005$) between the races of the respondents, religions of the respondents and between the years of study of the respondents. However there were no significant differences between the two groups in terms of gender, age, marital status, self-diagnosis of thalassemia, family diagnosis of thalassemia, places where most time was spent, number of hours spent on the mass

Table 3: Number and percentage related to awareness and knowledge regarding thalassemia among medical and non-medical students in the Malaysia National Thalassemia Prevention Programme – 2011

S. No.	*Groups*	*Medical (IMS) n (%)*	*Non-medical (FBMP) n (%)*	*Chi-square*	*p-value*
1	*Thalassemia Sources*				
	Never heard about it	8 (21.62)	29 (78.38)	12.33	0.0004*
	Yes	142 (53.99)	121 (46.01)		
2	*Problems of Thalassemia*				
	Having too many red blood cells	20 (48.78)	21 (51.22)	36.28	0.0001*
	Not having enough red blood cells	90 (65.69)	47 (15.7)		
	Having an extra chromosome	12 (63.15)	7 (36.85)		
	I Don't Know	28 (27.28)	75 (72.82)		
3	*Untreated Thalassemia*				
	The person will get worse	120 (66.66)	60 (33.34)	76.21	0.0001*
	The person will get better	2 (15.38)	11 (84.62)		
	The person will not get any better or not get any worse	20 (64.51)	11 (35.48)		
	I Don't Know	8 (10.52)	68 (89.48)		
4	*Iron level of Untreated Thalassemia*				
	Low iron levels	102 (78.46)	28 (21.54)	103.10	0.0001*
	High iron levels	24 (68.57)	11 (31.43)		
	Normal iron levels	3 (21.42)	11 (78.58)		
	I Don't Know	21 (17.35)	100 (82.65)		
5	*Probability of Thalassemia among Malaysians*				
	1:1000	41 (78.84)	11 (21.16)	33.90	0.0001*
	1:250	32 (58.18)	23 (41.82)		
	1:25	24 (58.53)	17 (41.47)		
	I Don't Know	53 (34.86)	99 (65.14)		
6	*Ideal Time to Get Tested for Thalassemia/Thalassemia Trait*				
	As an infant or small child	84 (61.31)	53 (38.69)	12.99	0.0015*
	As a teenager	38 (39.58)	58 (60.42)		
	When ready to have children	28 (41.79)	39 (58.21)		

Analysis of data was done using Chi-square test.
P<0.005 was considered as statistically significant.

media, number of hours spent on the internet daily and the most accessed internet content (Tables 6 and 7).

DISCUSSION

In Malaysia, most participants do not know the incidence of thalassemia in the country, as nearly half of the participants perceive thalassemia as a very rare, not serious, or not a common disease. Both the groups perceived a lack of information to be the main cause of unawareness about thalassemia among the general public. Some pointed out that educational material about Thalassemia were lacking in public places and health care centres. There was confusion between the terms "thalassemia major" and "carriers"across all groups as participants were not able to tell the difference between the two. The majority of participants were unaware that there are different types of thalassemia and that α- and β-thalassemia are the two most common types. Knowledge about the genetics of thalassemia was also very poor especially among the non-medical students. Many were unaware that both parents must be carriers in order to produce an affected child and that carrier parents have a chance of 1:2:1 of having children who are normal, carrier, and thalassemia major. A study in Malaysia on the public perceptions and attitudes towards Thalassemia also show similar data (Wong et al. 2011).Studies in Iran have shown that 39 percent of thalassemic patients had poor information about the disease, 32.5 percent had little information and 28.5 percent had satisfying information (Kourorian et al. 2014). This data is also comparable with our study where the knowledge of Thalassemia is poor among the non-medical students.

Table 4: Number and percentage related to awareness and knowledge regarding thalassemia among medical and non-medical students in the Malaysia National Thalassemia Prevention Programme – 2011

S. No.	*Groups*	*Medical (IMS) n (%)*	*Non-medical (FBMP) n (%)*	*Chi-square*	*p-value*
1	*Thalassemia is a Contagious Disease*				
	Yes	11 (32.35)	23 (67.65)	70.19	0.0001*
	No	114 (73.07)	42 (26.93)		
	I Don't Know	25 (22.72)	85 (77.28)		
2	*Thalassemia Is A Disease That Runs In The Family*				
	Yes	133 (66.33)	77 (36.67)	50.54	0.0001*
	No	7 (25.92)	20 (74.08)		
	I Don't Know	10 (84.13)	53 (15.87)		
3	*Thalassemia Is A Sexually Transmitted Disease*				
	Yes	5 (25)	15 (75)	67.62	0.0001*
	No	135 (66.17)	69 (33.83)		
	I Don't Know	10 (13.15)	66 (86.85)		
4	*Thalassemia Is An Allergic Reaction*				
	Yes	7 (24.13)	22 (75.87)	84.11	0.0001*
	No	127 (72.15)	49 (27.85)		
	I Don't Know	16 (16.84)	79 (83.16)		
5	*Individuals Who Have Thalassemia Lead Normal Lives With Appropriate Treatment*				
	Yes	109 (66.06)	56 (33.94)	65.72	0.0001
	No	30 (60)	20 (40)		
	I Don't Know	11 (12.94)	74 (87.06)		
6	*Individuals who have thalassemia are anaemic*				
	Yes	105 (71.91)	41 (28.09)	60.64	0.0001*
	No	18 (46.15)	21 (53.85)		
	I Don't Know	27 (23.47)	88 (76.53)		

Analysis of data was done using Chi-square test.
$p<0.005$ was considered as statistically significant.

This study detected a high acceptability for premarital screening for thalassemia. The main reason as to why Malaysians do not undergo screening is a lack of awareness and limited availability of information about the disorder, rather than unwillingness to undergo the test. Many were also supportive of mandatory premarital screening for thalassemia. Some participants felt that they may become depressed, resentful, or embarrassed in the event of a positive test result and a few expressed genuine concerns regarding partner's reaction if they were confirmed to be carriers. Thus, participants felt that it would be more fitting for carrier screening to start in secondary school (13–17 years).A study in Malaysia showed that 89.8 percent of the public were aware that the partner of a thalassemia carrier should undergo blood tests (Wong et al. 2011).

Knowledge on thalassemia plays an important role in the determining the success of thalassemia prevention. With knowledge reaching the people, the awareness will increase, thus increasing the number of people getting screened and participating in the national thalassemia prevention programme.

The knowledge among medical students is better than the non-medical students. Medical students were taught in the lectures about thalassemia and sickle cell disease and thus scored well. Otherwise, the public and non-medical students depend on parents, friends, medical personnel, informational campaigns and media to improve their knowledge on thalassemia. However, the campaigns in the media in 2009 on awareness of thalassemia were not successful enough (Gorakshakar and Colah 2009).

The knowledge component also has strong significant association with awareness where the p value score is less than 0.01. Those who scored more in the knowledge questions on thalassemia have better awareness. Knowledge deficits result in unnecessary anxiety among the general public and thus has a serious emotional effect on the thalassemia carriers. Public health messages should mainly focus on disseminating in-

Table 6: Number and percentage of socio-demographic data of medical and non-medical students in the Malaysia National Thalassemia Prevention Programme – 2011

S.No.	*Groups*	*Medical (IMS) n (%)*	*Non-medical (FBMP) n (%)*	*Chi-square*	*p-value*
1	*No. of Subjects (N)*	150 (50.0)	150 (50.0)		
2	*Gender*				
	Female	111(74)	104 (69.33)	0.59	0.4420
	Male	39 (26)	46 (30.67)		
3	*Age*				
	18-20	59 (48.36)	63 (51.63)	3.39	0.3348
	21-23	64 (49.61)	65 (50.38)		
	24-26	26 (59.09)	18 (40.90)		
	>27	1 (20)	4 (80)		
4	*Race*				
	Malay	89 (42.78)	119 (57.21)	19.4	0.0002*
	Chinese	18 (85.71)	3 (14.29)		
	Indian	38 (63.33)	22 (36.66)		
	Others	5 (45.45)	6 (54.54)		
5	*Religion*				
	Muslim	93 (43.86)	119 (56.13)	14.66	0.0021*
	Buddhist	13 (85.71)	4 (23.52)		
	Christian	10 (83.33)	2 (16.66)		
	Others	34 (57.62)	25 (42.37)		
6	*Marital Status*				
	Single(Unmarried/separated/ divorced/widowed)	144 (49.65)	146 (50.34)	0.10	0.7477
	Married	6 (60)	4 (40)		

Analysis of data was done using Chi-square test.
p<0.005 was considered as statistically significant.

formation about differences between the various types of thalassemia and that the disorder is more severe among the homozygotic individuals. It has been suggested that effective audio-visual communication can be established with audio-visual aids and personal experience sharing (Saxena and Phadke 2002). Thus, the knowledge among Malaysians on thalassemia must be instilled seriously to increase the awareness towards thalassemia and screening rate.

Awareness towards Thalassemia

The courses have significant association with awareness where the p value is less than 0.01. This shows that medical students have better awareness than the non-medical students. The pathophysiology for haemopoietic and lymphoid systems and genetics were taught to both medical and non-medical students at different depths, this factor mainly lead to awareness. For the non-medical students, the awareness can arise from parents, friends, media and internet. Therefore reaching out to the non-medical students is important to ensure that they have knowledge and awareness on this disease and later participate in the National thalassemia prevention programme. In general, awareness of thalassemia is higher among the higher education categories. This indicates that educational programmes to increase awareness of thalassemia should be more concentrated in the low education groups.There was statistical significance for the first 17 questions regarding the knowledge and awareness of thalassemia with p value ranging from 0.0001 to 0.0015.

Screening of Thalassemia

The number of students that were screened for thalassemia was 29 out of 300 students. This is merely only a 1:10 ratio. In general, those who were screened have better knowledge, awareness and better attitude in making the national thalassemia prevention programme successful. For a country with a prevalence of 6-10 percent or 1:20 ratio of thalassemia disease, it is not acceptable that the screening is not made mandatory. There is a need to visualise and make improvements from several models of programmes

Table 7: Number and percentage of socio-demographic data of medical and non-medical students in the Malaysia National Thalassemia Prevention Programme – 2011

S. No.	*Groups*	*Medical (IMS) n (%)*	*Non-medical (FBMP) n (%)*	*Chi-square*	*p-value*
1	*Year of Studies*				
	Year 1	63 (43.75)	81 (56.25)	36.88	0.0001*
	Year 2	17 (27.86)	44 (72.13)		
	Year 3	61 (71.76)	24 (28.23)		
	Year 4	2 (100)	0 (0.0)		
	Year 5	1 (100)	0 (0.0)		
	Year 6	6 (87.10)	1 (14.28)		
2	*Self-diagnosis of Thalassemia*				
	Yes	6 (75)	2 (25)	1.16	0.2824
	No	144 (49.31)	148 (50.69)		
3	*Family diagnosis of Thalassemia*				
	Yes	6 (42.85)	8 (57.14)	0.07	0.7843
	No	144 (50.34)	142 (49.66)		
4	*Places Where Most Time Spent*				
	House	75 (54.74)	62 (45.26)	5.62	0.1315
	Campus	65 (43.91)	83 (56.09)		
	Shopping centres	4 (80)	1 (20)		
	Library	6 (60)	4 (40)		
5	*No. of Hours Spent on The Mass Media (TV,Radio,Newspapers)*				
	<1	28 (45.90)	33 (54.10)	3.55	0.4698
	1-3	75 (54.34)	63 (43.66)		
	3-5	38 (49.35)	39 (50.65)		
	5-10	9 (39.13)	14 (60.87)		
	>10	0(0.0)	1 (100)		
6	*No. of Hours Spend on Internet Daily*				
	<1	15 (50.0)	15 (50.0)	3.92	0.4163
	1-3	54 (47.78)	59 (52.22)		
	3-5	42 (47.72)	46 (52.28)		
	5-10	23 (50)	23 (50)		
	>10	16 (69.56)	7 (30.43)		
7	*Most Accessed Internet Content*				
	Resource and information	33 (50.76)	32 (49.34)	1.81	0.6128
	Games	9 (39.13)	14 (60.87)		
	Social network page	84 (52.50)	76 (47.50)		
	Entertainment	24 (46.15)	28 (53.85)		

Analysis of data was done using Chi-square test.
$p<0.005$ was considered as statistically significant.

that have already taken place and achieved a high rate of success. There is a need to make premarital screening mandatory or improve our genetic counselling system which is almost unheard of in Malaysia. A study done in Malaysia in 2011 which had 3723 respondents noted that if we give better counselling the knowledge and awareness will increase. They were also concerned that a significant minority considered that premarital screening was unnecessary for the general public (Wong et al. 2011). The places of screening also must be taken into attention. Anotherstudy detected a significant proportion of the subjects in both Li and Han populations of the Hainan Island in Southern China who carried both α- and β-globinmutations and suggested that careful screening of both α- and β-thalassemia mutations in all couples during premarital and prenatal examinationcan be used to counsel couples regarding risk to their offspring. During a period ranging from March 2010 to June 2012, they screened 8600 individuals of the Li people who sought health examination, premarital medical checkups, and genetic counseling, prenatal diagnosis, in health care centers or hospitals in Baoting, Baisha, Qiongzhong, Tunchang, Dongfang, and Wuzhishan in the Hainan province of China (Hongxia et al. 2014).

This study has compiled the satisfaction of the subjects towards the health institutions in

Malaysia and the frequency of visiting so in the future, it can really make the test screening easy to access and convenient for any Malaysian to do the test. With regard to time, if the screening took place in a short period, more people will get screened for thalassemia. However, most time is consumed especially in public health facilities making it a bad reputation for the public to attend. The screening or counselling place should be comfortable which means that it should be hassle free and equipped with good facilities as well as good hospitality from the staff. A special section for this purpose would be favourable. The cost of the screening must be also very reasonable or made free so that people will not hesitate to do the test. Many of the students think that the government does not fully subsidise the screening for thalassemia and that it affects the rate of screening. Furthermore in some places in Malaysia, the public health facilities are beyond the reach of people, so a few rural areas do not have full access to health services and for the urban setting, the private facilities seems to be very expensive and thus burdens the public. Location is another factor that could be a problem for health settings. For urban areas, there are still not many public health settings that have much equipment and a delay in sample screening occurs unless special kits were made available in these settings. This is important as the Kadazandusuns community in Sabah have more prevalence of sickle cell disease. For urban settings, the lack of parking space, access of transport and the time taken to reach the facilities are the major constraints in providing better health access.

Attitude in Malaysia National Thalassemia Prevention Programme

The attitude studied in this research was to mainly see their awareness towards health campaigns; whether they wanted to hear more about these health campaigns and whether they would tell others about any campaigns held especially on health. For knowledge and awareness, it seems to have a better association as can be seen in the p value of <0.05. However, when it comes to promoting awareness to others, the students became more hesitant and did not want to tell others about this disease. This factor could be a worrying one as the public health awareness would not rise if such mannerisms occur. This leaves the media and education medium alone to reach the people regarding health issues. A study in 2011 in Malaysia has shown that the majority of participants have very positive attitudes towards screening for Thalassemia and they concluded that efforts to promote screening are more likely to receive a favourable response from the general Malaysian Public (Wong et al. 2011).

CONCLUSION

From the study, medical students are more knowledgeable, more aware, have better rate of screening and better attitude in participation of the Malaysia National Thalassemia Prevention Programme. This exact evidence is because they were taught about the details of thalassemia in their curriculum. In contrast the non-medical students focus more on other subjects and have quite limited exposure to medical knowledge. Therefore their knowledge and awareness is not high and it gives effect to screening rate and the attitude in the prevention programme.

In conclusion, this study fulfils the objective set up for this research, and that was to assess the knowledge, awareness and participation of undergraduate (medical and non-medical) students in the Malaysian National Thalassemia prevention programme. We have identified key areas which need to be emphasized and highlighted in any awareness campaigns and public education programmes for Thalassemia screening in Malaysia.The data has revealed that there is a knowledge deficit in the genetics and pattern inheritance of Thalassemia, thus, any public interventional programme should include the information about the molecular basis of Thalassemia.

RECOMMENDATIONS

By determining the health institutions and their preferences, the Malaysian government can improve the facilities and attract people to undergo health screening, particularly thalassemia screening. This holds important implications for the university and the government to educate the public especially the students, so that the prevention of thalassemia is a success and its prevalence among Malaysians can be reduced.

LIMITATIONS OF THE STUDY

The limitation of the number of respondents and the design of the questionnaire could cause

varying results compared to what was noticed in other studies.

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