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Thalassaemia: Level of awareness among the future health care providers of Malaysia

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ABSTRACT

Thalassaemia is a hereditary disorder which results in reduced production of haemoglobin. This disease is a major public health problem. It was reported from Malaysia in 2011 that there were nearly 4,800 registered thalassaemics. The current study was carried out to determine the level of awareness on thalassaemia among the students of Royal College of Medicine Perak, University Kuala Lumpur, Ipoh, Malaysia. This is a cross-sectional study. Students were then distributed a pretested questionnaire about thalassaemia. The results were analyzed using SPSS 17.0. Out of 281 students, 41%, 41% and 18% were pharmacy students, MBBS students and nursing students respectively. Most (72%) of the respondents were female. The mean knowledge score of nursing students was highest 5.39±1.51, out of a maximum of 7, compared to MBBS students 5.18±1.15 and pharmacy students 3.76±1.57. However, the mean attitude score of nursing (2.98±1.14) and MBBS (2.98±1.26) students was highest and same out of maximum of 5, but not much different compared to pharmacy students 2.69±1.25. Male students had higher level of knowledge on thalassaemia compared to female students. However, female students possessed better attitude when compared to male students. Only 8 students (3%) had an excellent knowledge and attitude. Most of them showed high knowledge level but lack of attitude. Although, current study population level of knowledge is not directly proportional to level of attitude. Since Malaysia is a multiracial country with different cultural and religious believe should be carefully taken into consideration for the prevention of thalassaemia.

Key words: Thalassemia, Awareness, Health Care Providers, Malaysia

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INTRODUCTION

"The term thalassemia is derived from the Greek, thalassa (sea) and haima (blood)" [1]. Thalassaemia is a red blood cell (RBC) hereditary autosomal recessive disorder which involves the lack of or faults in genes accountable for construction of haemoglobin [2]. Thalassemia is a major public health delinquent in Malaysia. About 4% of Malaysian national are carriers [3-4]. But global carriers' rate is about 7% [5-6]. Although there are enormous development regarding molecular understanding about inherited disorders of haemoglobin still lot of children die from haemoglobinopathies due to lack of appropriate care [5-6]. "The thalassaemias are a group of inherited disorders of haemoglobin, first reported independently from the United States and Italy in 1925. The word thalassaemia, derived from Greek roots for the sea and blood, was invented under the mistaken belief that these disorders were confined to the Mediterranean region" [7].

Hereditary disorders of haemoglobin fall into two main groups: the structural haemoglobin variants and the thalassaemias. The structural haemoglobin variants mostly result from single amino-acid substitutions in α or β chains [8]. The thalassaemias are categorized according to the specific globin chains that are vainly made into α, β, δβ, and εδβ thalassaemias [9-10]. Alpha and β thalassaemias are more common with life threatening potential

according to public health point of view[9-10]. In beta thalassaemia there is either reduced or not at all production of the "beta globin chains of the haemoglobin tetramer" [11]. Beta thalassaemia can be further divided into three, beta thalassaemia minor, intermediate and major [11-13]. Beta thalassaemia minor is very often called as beta-thalassemia trait and the patients have mild symptoms even remain clinically asymptomatic with mild anaemia. The intermediate one causes moderate anaemia but the thalassaemia major has fatal anaemia [12]. Majority of the intermediate group are of moderate severity and usually do not need blood transfusion [14]. Two genes are involved in making the beta haemoglobin chain but only one gene will affected in minor and these individuals are carriers [12,15]. In β-thalassemia intermedia or major (Cooley's anemia), both the genes possess anomaly. β-thalassaemia major is the most severe form and results from the inheritance of the homozygous state for the phenotype [16]. Paediatric patients of thalassaemias present as early as 3 months. Patients become increasingly "pale, difficulty in feeding and irritable" [17]. These patients even have substantial "hepatosplenomegaly due to haemolysis and extra medullary haematopoiesis"[17]. At this stage urgent medical intervention is absolutely necessary for prevention of a number complications [17].

Thalassaemia is one of the most common genetic blood disorders in the world [1,18]. Congenital haemoglobin disorders are unique physiognomies of tropical and sub-tropical countries but now has become a global problem because of massive immigration of people from one country to another [1,6,18-19]. Beta-thalassemia is most prevalent in Mediterranean countries, the Middle East, Central Asia, India, Southern China, and the Far East as well as countries along the north coast of Africa and in South America. The highest carrier frequency is reported in Cyprus (14%), Sardinia (10.3%), and Southeast Asia [6,20-21]. There are approximately 240 million people worldwide who are heterozygous for β-thalassaemia and approximately 200,000 affected homozygotes are born annually [22]. Asia and Middle Eastern regions account for 95% of thalassaemia births [23]. Three hundred thousands to 500,000 children with severe forms of such sicknesses are born each year [24]. The countries largely affected are those in the Mediterranean, such as Italy, Greece and Cyprus and in Asia countries like China, India and countries in South East Asia as well as Malaysia [25-27].

Malaysia has diverse multicultural and multi-ethnic inhabitants of 28.3 million, consisting of 65.1% Malays and other Bumiputera groups, 26% Chinese, 7.7% Indians, and 1.2% of other ethnic groups [28]. Thalassaemia is the commonest single gene inherited blood disorder in Malaysia [29]. β -thalassemia affected child births per annum are assessed at 2.1 per 1,000 with an appraised 5,600 patients with transfusion reliant on β-thalassemia in Malaysia [3]. There have been very few published studies on the awareness of thalassaemia among University students. The dearth in research on awareness of thalassaemia has led to this study, which was conducted with the objective to determine the level of thalassemia awareness among the students of University Kuala Lumpur-Royal College of Medical Perak (UniKL-RCMP).

EXPERIMENTAL SECTION

This was a cross-sectional descriptive study towards the knowledge and attitude about thalassaemia. The study population was Year I and II medical, pharmacy and nursing students of University Kuala Lumpur Royal College of Medicine Perak (UniKL-RCMP). Using the built in STATCALC of the Epi Info statistical software version 3.3.2, the sample was calculated on a population size of 933, with worst acceptable value of 5% that gave a minimum sample size of 272 at 95% confidence level. Convenience sampling technique was used. A total of 300 questionnaires were distributed to the students. Target students were informed about the study and their consent was taken in a consent form. The questionnaires were pretested on several pupil of this University and validated. Questionnaires were distributed among students for response. It consisted of 18 questions related to the socio-demographic data, and knowledge and attitude towards thalassaemia. Medical and pharmacy students (Year I and II) as well as nursing students (Year I, II, and III) who agreed to participate were included in this study.

The questionnaire comprised of 18 questions, divided into 3 parts. Firstly, demographic questions [6-item) were asked. The second part, participants' knowledge about thalassaemia was assessed across several domains: 1) general knowledge of thalassaemia (2-item); 2) knowledge of thalassaemia diagnosis (1-item); 3) knowledge of thalassaemia treatment (1-item); 4) knowledge of thalassemia prognosis (3-item). For each question, "I know" response was given a score of one, and "I don't know" was scored as zero, for a total possible score of 0-7, with higher scores indicating better knowledge. There was a band for the score, if the participant answers all the 7 questions "I know" (100%) the knowledge level was assessed as "Excellent". If the participants answer 5 to 6 questions "I know" (>71% - <100%) the knowledge level was "Good", 3 to 4 "I know" answers (>28% - 71%) was "Average" knowledge level and if there were less than 3 "I know" answers (<28%) the knowledge level was assessed as "Poor".

The third part assessed attitudes toward thalassaemia (5-item), where participants were asked for their views on premarital screening, marriage between individuals who are both carriers, pregnancy of carrier couples, termination

of pregnancies affected with thalassaemia major and role of mass media to educate people about thalassaemia. For each question, an agree response was given a score of one, and disagree response was scored as zero, for a total possible score of 0-5. There was a band for the score, if the participants agreed with all the 5 questions (100%) the attitude was assessed as "Excellent". If the participants agree with 4 questions (80%) the attitude was "Good", 3 agree answer (60%) was "Average" attitude and if there were less than 3 agree answers (<60%) the attitude was assessed as "Poor".

Data was analysed using SPSS 17.0 for Windows. Values of $P < 0.05$ were considered significant. The chi-square test was used to test the significance of differences in percentages. Descriptive statistics such as mean, mode and standard deviation were generated as well.

RESULTS

Two hundred eighty one students completed questionnaires were returned back. A total of 19 were found to be incomplete. Therefore the response rate was 94%. Demographic data of the current study has been described in Table 1. Among the study participants, there were with excellent [11% (30)], good [46% (131)], average [32% (90)], and poor [11% (30)] knowledge about thalassemia (Figure 1). Similarly, there were respondents with excellent [9% (27)], good [22% (62)], average [28% (78)], and poor [41% (114)] attitude about thalassemia (Figure 1).

Table 1: Distribution of Socio-Demographic Characteristics

	Frequency n = 281	**Percentage (%)**
Age		
18-19	149	53.0
20-21	102	36.3
22-23	22	7.8
24-25	7	2.5
>25	1	0.4
Year of Study		
I	138	49.1
II	107	38.1
III	36	12.8
Course		
Medicine/ MBBS	114	40.6
Pharmacy	116	41.3
Nursing	51	18.1
Gender		
Male	78	27.8
Female	203	72.2
Ethnicity		
Malay	255	90.7
Chinese	8	2.9
Indian	13	4.6
Other	5	1.8
Previous Education		
SPM	125	44.5
Foundation	99	35.3
Matriculation	16	5.7
A level	17	6.1
IB	6	0.004
STPM	18	6.4

Table 2: Level of Knowledge and Attitude vs. Gender and Ethnicity

		Level of Knowledge (%)				**Level of Attitude (%)**			
		Av	Ex	Go	Po	Av	Ex	Go	Po
Gender	Female	68 (34)	21 (10)	96 (48)	18 (9)	62 (31)	20 (10)	51 (25)	70 (34)
	Male	22 (28)	9 (12)	35 (45)	12 (15)	16 (21)	7 (9)	11 (14)	44 (56)
Ethnicity	Chinese	2 (25)	1 (12.5)	4 (50)	1 (12.5)	0	1 (12.5)	4 (50)	3 (37.5)
	Indian	3 (23)	3 (23)	3 (23)	4 (31)	2 (15)	3 (23)	4 (31)	4 (31)
	Malay	82 (32)	26 (10)	122 (48)	25 (10)	74 (29)	23 (9)	53 (21)	105 (41)
	Others	3(60)	0	2 (40)	0	3(60)	0	1 (20)	1(20)

Av= Average, Ex=Excellent, Go=Good, Po=Poor

Table 3: Correlations between Knowledge and Attitude Score of Respondents

		Knowledge Score	Attitude Score
Knowledge Score	Pearson Correlation	1	.304**
	Sig. (2-tailed)		.000
	N	281	281
Attitude Score	Pearson Correlation	.304**	1
	Sig. (2-tailed)	.000	
	N	281	281

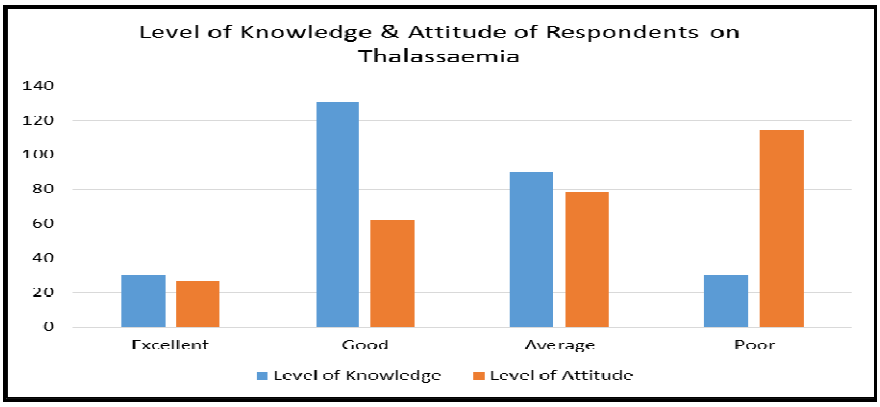

Figure 1: Level of Knowledge and Attitude of Respondents on Thalassaemia

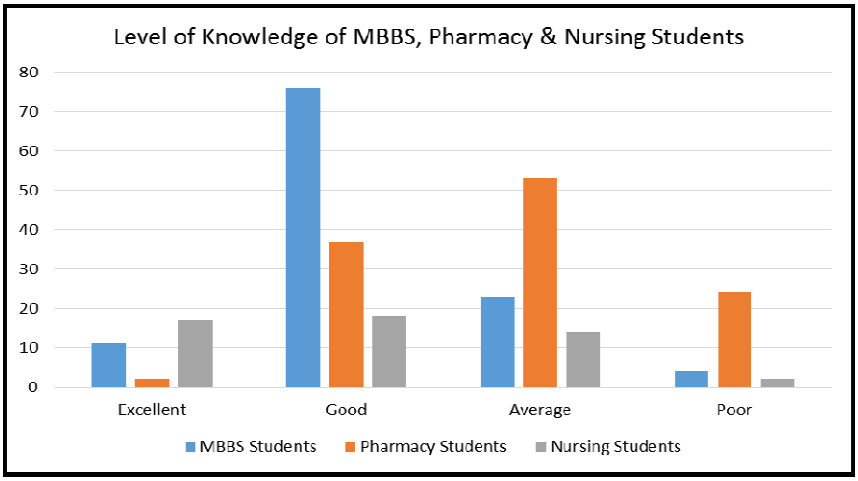

Figure 2: Level of Knowledge in Percentage of MBBS, Pharmacy, Nursing Students

Among female participants (203) of the study majority (91%) has either average or above average knowledge about thalassemia but regarding attitude although majority (64%) attain similar level (Table 2). Regarding their male counterparts was quite similar 85% of them have average or above average (Table 2).

Current study populations were divided into four major ethnic groups: Malay, Chinese, Indian and Others (Indian Muslim, Kadazan Dusan, and Sikh). Obviously, Malay was the predominant population. Knowledge of majority (90%) of Malay population regarding thalassemia was above average (Table 2). But regarding attitude the figure reached to 59%. Therefore, 41% of Malay population had poor attitude towards thalassemia (Table 2). Indians (59-69%) held quite good level of knowledge and attitude. Chinese (62.5-87.5%) also possessed good level of knowledge and attitude. In contrary, all three major ethnic group Malay (41%), Indians (31%) and Chinese (37.5%) held poor attitude regarding thalassemia (Table 2).

Current study participants mean knowledge and attitude score were 4.63±1.58 and 2.86±1.239 respectively. The mean knowledge score of nursing students was highest (5.39± 1.51), out of a maximum of 7, compared to MBBS (5.18±1.15) and pharmacy students (3.76± 1.57). However, the mean attitude score of nursing (2.98± 1.14) and MBBS (2.98± 1.26) students was highest and same, out of maximum of 5, but not much different compared to pharmacy students (2.69±1.25). Most of the participants were good in knowledge but poor in attitude. Pearson

correlation between knowledge and attitude score was 1 which showed perfect positive correlation. Therefore there was statistically significant (p=0.00) correlation between knowledge and attitude.

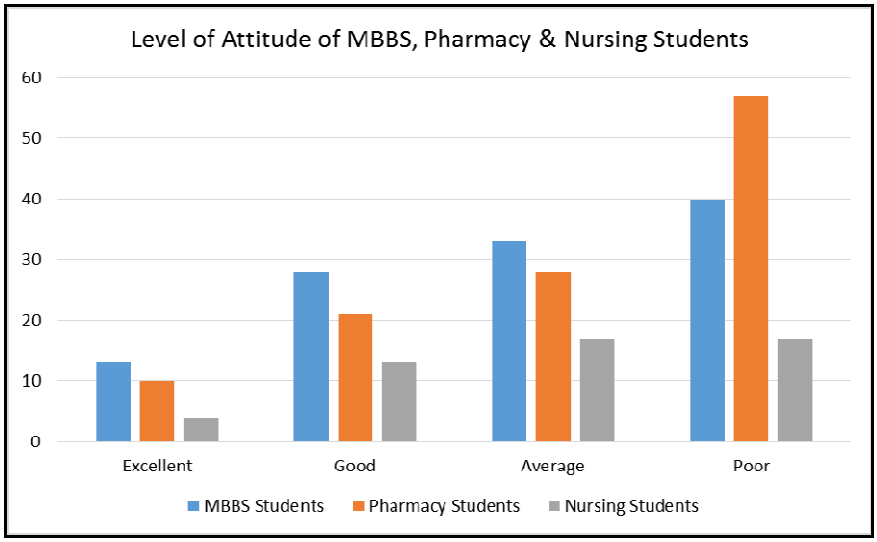

Figure 3: Level of Attitude in percentage of MBBS, Pharmacy and Nursing students

Very interestingly of nursing students showed highest (%) knowledge level among 3 group (Figure 2). But it was totally different scenario regarding attitude where medical students (13.11%) showed the highest; followed by pharmacy (10.9%) and nursing (4.8%) students (Figure 3). The Pearson correlation between knowledge and attitude score was 1 and p=0.000. Therefore, there was statistically significant correlation between knowledge and attitude (Table 3). The Pearson correlation between the age of the students and their attitude level score was 1 and p=0.043.

DISCUSSION

The knowledge level of the current study population (around 90%) was quite good which is much higher than that of a study done recently in Pakistani [30]. In that study, nearly half of the medical university student never heard about thalassemia whereas Malaysian villagers (47%) also know about thalassemia [27]. In another study using telephonic interview 77% of Malaysian population knows about thalassemia even of its' genetic origin [13]. Majority of the Malay population in this study showed their knowledge level high which could be because they were the students of a medical campus.

The mean knowledge score compared between three different courses showed that pharmacy students had the lowest 3.76 out of a possible score of 7 that reflected a lack of knowledge among the study respondents. This could be due to the 23.1% of the respondents from pharmacy course are in the 1st year with SPM (Sijil Pelajaran Malaysia, the Malaysian Certificate of Education, is a national examination taken by all fifth-year secondary school students in Malaysia, equivalent to eleventh grade in American's K-12 education) as the level of their education. They might not really know what thalassemia is and might not have strong knowledge regarding thalassaemia.

Participants' responses indicated that their specific knowledge regarding the treatment and prognosis of the disease, and its pattern of inheritance was poor. However, as compared to the study on public perceptions and attitude towards thalassaemia done in 2011 [13], UniKL-RCMP students had better knowledge on thalassaemia as perhaps they are future health care providers. Judging by the result of the knowledge of the respondents, more awareness programs should be directed to the target group of student to provide them with the information they need to know about thalassaemia so that they realise the importance of thalassaemia awareness. The Pearson correlation between the age of the students and their attitude level showed perfect positive correlation, and was considered significant since the P value ($P<0.05$) was 0.043.

The Pearson correlation found statistically significant (p=0.043) positive correlation between the age of the students and their attitude. Therefore, current study revealed that as the student's age increases, their attitude awareness towards thalassemia also increases. This is proven by the attitude level of the third year students of Nursing and second year students of MBBS. These groups of students were among 20-25 year old. The mean attitude score of nursing and MBBS students was highest and same 2.98 (SD ± 1.14, SD ± 1.26), out of maximum of 5.

In this study more than half [66 (57%)] of the Pharmacy students expressed their attitude towards thalassaemia poor. Majority of them are 18 year old (88%). Here, we can see the strong correlation between age and their attitude awareness of thalassaemia. Hence, the student's attitude towards thalassaemia very much related to the level of education on this disease.

Even though the students have high level of knowledge but they lack of proper attitude towards thalassaemia. This was supported by the study on public perceptions and attitude towards thalassaemia done in 2011 [13]. Perhaps it was because they neither studied the disease properly nor they experienced being close to the patients who suffer from this disease. They might have learnt theoretically but not yet put their knowledge into practice. But poor level of knowledge may influence to have poor level of attitude. Therefore, to gain some knowledge on this disease by the future health care providers during their early years of study is a must as thalassaemia is a common blood disorder in Malaysia.

CONCLUSION

In conclusion, level of knowledge is not directly proportional to the level of attitude. A student who has high level of knowledge not necessarily has high level of attitude. The mass media is greatly encouraged to make more programs such as films, dramas and talk shows to help increase the attitude by showing the real patients who suffer from this disorder. Besides, the Health Ministry can make the screening test for thalassaemia a compulsory for every student so that at least they know why they learn this type of blood disorder.

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