



Received on 23 July, 2016; received in revised form, 25 November, 2016; accepted, 28 November, 2016; published 01 February, 2017

EVALUATION OF THALASSEMIA AWARENESS AMONG THE FUTURE HEALTHCARE PROVIDERS OF UNITED ARAB EMIRATES

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Keywords:

Thalassemia, Awareness, Healthcare Providers, United Arab Emirates

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ABSTRACT: Thalassemia is among the most common genetic disorders worldwide. It constitutes a major public health problem in the United Arab Emirates (UAE). The present study assessed the level of awareness regarding thalassemia among the students of RAK Medical and Health Sciences University, Ras Al Khaimah, UAE. A specially designed, pretested and validated questionnaire was distributed to the students and their responses were recorded. Out of the total 200 students, 51.5% were from pharmacy college, 29.5% were from medical college whereas 16% and 3% were from nursing and dental colleges respectively. Majority (62.5%) of respondents were female. The mean knowledge score of pharmacy students was highest 5.66 ± 2.02 out of a maximum of 7, as compared to 5.16 ± 0.81 of dental students, 4.47 ± 1.97 of medical students and 4.34 ± 2.26 of nursing students. However, mean attitude score of dental students was the highest 3.83 ± 0.40 out of a maximum of 4, but was not much different when compared to 3.64 ± 0.66 of medical students and 3.46 ± 0.97 of pharmacy students. Male students had higher level of knowledge regarding thalassemia as compared to female students. However, female students possessed better attitude towards thalassemia when compared to male students. The level of knowledge and attitude improved as the year of study advanced. The study showed that as the level of knowledge regarding thalassemia increased the attitude of the students towards thalassemia improved fortifying the importance of knowledge in changing perception of people towards diseases like thalassemia.

INTRODUCTION: Thalassemias are a group of autosomal recessive disorders caused by reduction or absent production of one or more of the globin chains making up the hemoglobin (Hb) ¹. Two main types i.e., the α - and β -thalassemias are identified based on the type of globin chain involved.

Both the types may occur in the major (homozygous), intermediate, and minor (heterozygous) genetic forms. $\delta\beta$ -, $\gamma\delta\beta$ -, and $\epsilon\gamma\delta\beta$ -thalassemias are complex types resulting from defective production of two to four different globin ^{2, 3, 4}.

Clinically significant forms of α -thalassemia are Hb Bart hydrops fetalis (Hb Bart) syndrome and HbH disease with former being the more severe resulting in fetal onset of generalized edema, pleural and pericardial effusions, and severe hypochromic anemia. HbH disease is characterized by microcytic hypochromic hemolytic anemia,

QUICK RESPONSE CODE 	DOI: 10.13040/IJPSR.0975-8232.8(2).908-14
	Article can be accessed online on: www.ijpsr.com
DOI link: http://dx.doi.org/10.13040/IJPSR.0975-8232.8(2).908-14	

hepatosplenomegaly, mild jaundice, and bone changes^{4,5}.

β -thalassemia can be distinguished into three main forms namely; β -thalassemia major, referred to as "Cooley's anemia", β -thalassemia intermedia and β -thalassemia minor also known as " β -thalassemia carrier" or " β -thalassemia trait"⁶. β -thalassemia major is presented between 6 and 24 months with affected infants failing to thrive and becoming progressively pale along with feeding problem, recurrent bouts of fever, and progressive enlargement of the abdomen caused by spleen and liver enlargement. Carriers of β -thalassemia minor are usually clinically asymptomatic but sometimes have a mild anemia. When both parents are carriers there is a 25% risk at each pregnancy of having children with β -thalassemia major^{7,8,9}.

Thalassemias are among the most common genetic disorders worldwide, affecting individuals originating from the Mediterranean region, Middle East, Central Asia, Indian subcontinent, and Southeast Asia^{10,11}. As the disorders require long-term care, prevention of the homozygous state forms a major goal in the management¹². β -thalassemia constitutes a major public health problem in the United Arab Emirates (UAE)¹³. According to the Dubai Health Authority (DHA), one in 12 persons in UAE carries the gene for thalassemia¹⁴. Public awareness programs, education and preventive measures have recently been implemented¹⁵ and seem to be showing positive effect but still there is a long way to go. The future health care providers play a pivotal role in creating awareness about these disorders and their preventive measures.

There have been very few published studies on the awareness of thalassemia among medical and health sciences university students. The paucity in research data on awareness of thalassemia in UAE has led to this study, which was conducted to determine the level of thalassemia awareness among the students of Ras Al Khaimah (RAK) Medical and Health Sciences University, UAE.

METHODS:

Study design: This cross sectional study was carried out to assess the level of awareness regarding thalassemia among the students of RAK

Medical and Health Sciences University, Ras Al Khaimah, UAE.

Study population: All the students studying in medical, pharmacy, dental and nursing colleges of RAK Medical and Health Sciences University were considered for the study. Only those respondents who were available for data collection and who gave written informed consent were included in the study.

Sample size: To select the study participants, a convenience sampling technique was used. Two hundred and twenty students agreed to participate in the study and signed the informed consent form. Out of the total 220 students, 200 students completed and returned the questionnaires.

Data collection: A specially designed, pretested and validated questionnaire comprising of three sections; Demographic Data, Knowledge of Thalassemia, Attitude towards Thalassemia was used to record the responses of the students. The questionnaire comprised of 17 questions focusing on the demographics, knowledge and attitude of the participant towards thalassemia.

Data analysis: The questionnaire comprised of 17 questions and was divided into 3 parts. First part was for demographic questions [6-item]. Second part was for assessing the participants' knowledge about thalassemia [7-item]. The knowledge was assessed across several domains: 1) general knowledge of thalassemia [3-item]; 2) knowledge of thalassemia diagnosis [1-item]; 3) knowledge of thalassemia treatment [1-item]; 4) knowledge of thalassemia clinical manifestations and prognosis [2-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 was for assessing the attitude towards thalassemia [4-item],

where the respondents were asked for their views on premarital screening, marriage between individuals who are both carriers, genetic counselling & prenatal testing and role of healthcare professionals in educating people regarding thalassemia. 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 0-4.

There was a band for the score, if the participants agreed with all the 4 questions (100%) the attitude was assessed as “Excellent”. If the participants agree with 3 questions (75%) the attitude was “Good”, 2 agree answers (50%) was “Average” attitude and if there were less than 2 agree answers (<50%) the attitude was assessed as “Poor”. Data was analyzed using SPSS 20.0 for Windows (SPSS

Inc., Chicago, IL, USA). The Pearson 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. A *P*-value of < 0.05 was considered to be statistically significant.

Ethical consideration: Approval for the study was obtained from the RAK Medical and Health Sciences University Research and Ethics Committee. Written informed consent was taken from all the study participants prior to the study. Data collected from the participants was preserved confidentially.

RESULTS: The socio-demographic characteristics of the respondents are shown in **Table 1**.

TABLE 1: DISTRIBUTION OF SOCIO-DEMOGRAPHIC CHARACTERISTICS

	Frequency n=200	Percentage (%)
Age		
18-19	67	33.5
20-21	49	24.5
22-23	61	30.5
24-25	20	10
>25	3	1.5
Gender		
Male	75	37.5
Female	125	62.5
College		
Pharmacy	103	51.5
Medical	59	29.5
Dental	6	3.0
Nursing	32	16
Year of Study		
Year 1	68	34.0
Year 2	42	21.0
Year 3	20	10.0
Year 4	67	33.5
Year 5	3	1.5
Marital Status		
Single	192	96.0
Married	8	4.0
Nationality		
Syrian	47	23.5
Emirati	35	17.5
Egyptian	27	13.5
Iraqi	23	11.5
Indian	23	11.5
Palestinian	10	5.0
Lebanese	7	3.5
Pakistani	6	3.0
Others	22	11.0

Among the study population majority of the respondents were females (62.5%) and single (96%). About 51.5% of the respondents were pharmacy students as compared to 29.5% medical students. Majority of the study population (74.5%) belonged to Middle East countries comprising of 23.5% Syrian, 17.5% Emirati, 13.5% Egyptian, 11.5% Iraqi, 5%, 3.5% Palestinian and Lebanese respectively (Table 1). The mean knowledge and attitude scores of the current study population were 4.84 ± 2.05 and 3.47 ± 1.00 respectively. The mean knowledge score of pharmacy students was highest 5.66 ± 2.02 out of a maximum of 7, as compared to 5.16 ± 0.81 of dental students, 4.47 ± 1.97 of

medical students and 4.34 ± 2.26 of nursing students. However, the mean attitude score of dental students was the highest 3.83 ± 0.40 out of a maximum of 4, but was not much different when compared to 3.64 ± 0.66 of medical students and 3.46 ± 0.97 of pharmacy students. Out of the 200 study participants, 63% of them had good to excellent knowledge regarding thalassemia whereas 87.5% of the study participants possessed good to excellent attitude towards thalassemia. Among the male study participants, 66% had good to excellent knowledge whereas only 60% of the female participants had good to excellent knowledge of thalassemia (Table 2).

TABLE 2: LEVEL OF KNOWLEDGE AND ATTITUDE VS. GENDER, COLLEGE AND YEAR OF STUDY

		Level of Knowledge (%)				Level of Attitude (%)			
		Ex	Go	Av	Po	Ex	Go	Av	Po
Gender	Male	23 (31)	26 (35)	13 (17)	13 (17)	48 (64)	16 (21)	5 (7)	6 (8)
	Female	26 (21)	49 (39)	25 (20)	25 (20)	92 (73)	19 (15)	7 (6)	7 (12)
College	Pharmacy	29 (28)	45 (44)	16 (16)	13 (12)	71 (69)	19 (18)	6 (6)	7 (7)
	Medical	12 (21)	17 (29)	22 (37)	8 (13)	43 (73)	12 (20)	3 (5)	1(2)
	Dental	1 (17)	5 (83)	0 (0)	0 (0)	5 (83)	1 (17)	0 (0)	0 (0)
	Nursing	7 (22)	10 (31)	6 (19)	9 (28)	21 (66)	3 (9)	3 (9)	5 (16)
Year of Study	Year 1	4 (6)	14 (21)	26 (38)	24 (35)	36 (53)	15 (22)	7 (10)	10 (15)
	Year 2	8 (19)	15 (36)	15 (36)	4 (10)	27 (64)	10 (24)	3 (7)	2 (5)
	Year 3	1 (5)	18 (90)	0 (0)	1 (5)	17 (85)	3 (15)	0 (0)	0 (0)
	Year 4	34 (51)	30 (45)	2 (3)	1 (2)	57 (86)	7 (10)	2 (3)	1 (1)
	Year 5	2 (67)	0 (0)	1 (33)	0 (0)	3 (100)	0 (0)	0 (0)	0 (0)

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

When it came to attitude towards thalassemia the female participants (88%) fared well than the male participants (85%). Out of the 74.5% of the study participants belonging to Middle East countries,

63.1% had good to excellent knowledge regarding thalassemia whereas 86.5% had good to excellent attitude towards thalassemia (Table 3).

TABLE 3: LEVEL OF KNOWLEDGE AND ATTITUDE VS. NATIONALITY

	Level of Knowledge (%)				Level of Attitude (%)			
	Ex	Go	Av	Po	Ex	Go	Av	Po
Syrian	13 (28)	20 (42)	7 (15)	7 (15)	37 (79)	5 (11)	1 (2)	4 (9)
Emirati	7 (20)	11 (31)	11 (31)	6 (18)	24 (69)	4 (11)	3 (9)	4 (11)
Egyptian	7 (26)	10 (37)	5 (19)	5 (19)	17 (63)	7 (26)	2 (7)	1 (4)
Iraqi	5 (22)	10 (44)	6 (26)	2 (9)	18 (78)	1 (4)	2 (9)	2 (9)
Indian	4 (17)	8 (35)	8 (35)	3 (13)	16 (70)	6 (26)	0 (0)	1 (4)
Palestinian	2 (20)	3 (30)	1 (10)	4 (40)	5 (50)	4 (40)	0 (0)	1 (10)
Lebanese	4 (57)	2 (29)	1 (14)	0 (0)	7 (100)	0 (0)	0 (0)	0 (0)
Pakistani	2 (33)	3 (50)	1 (17)	0 (0)	2 (33)	3 (50)	1 (17)	0 (0)
Others	5(23)	10 (45)	4 (18)	3 (14)	14 (64)	5 (23)	3 (14)	0 (0)

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

There was statistically significant positive correlation ($p < 0.001$) between age and level of knowledge and attitude (Table 4).

TABLE 4: CORRELATIONS BETWEEN AGE, KNOWLEDGE AND ATTITUDE SCORE OF RESPONDENTS

		Age	Knowledge Score	Attitude Score
Age	Pearson Correlation	1	.558**	.263**
	Sig. (2-tailed)		.000	.000
	N	200	200	200
Knowledge Score	Pearson Correlation	.558**	1	.353**
	Sig. (2-tailed)	.000		.000
	N	200	200	200
Attitude Score	Pearson Correlation	.263**	.353**	1
	Sig. (2-tailed)	.000	.000	
	N	200	200	200

** Correlation is significant at the 0.01 level (2-tailed).

The correlation between year of study and level of knowledge and attitude was found to be positive and statistically significant with a p value of <0.001 (Table 5).

TABLE 5: CORRELATIONS BETWEEN YEAR OF STUDY, KNOWLEDGE AND ATTITUDE SCORE OF RESPONDENTS

		Year of Study	Knowledge Score	Attitude Score
Year of Study	Pearson Correlation	1	.623**	.321**
	Sig. (2-tailed)		.000	.000
	N	200	200	200
Knowledge Score	Pearson Correlation	.623**	1	.353**
	Sig. (2-tailed)	.000		.000
	N	200	200	200
Attitude Score	Pearson Correlation	.321**	.353**	1
	Sig. (2-tailed)	.000	.000	
	N	200	200	200

** Correlation is significant at the 0.01 level (2-tailed).

The level of knowledge and level of attitude are positively correlated and this correlation is statistically significant ((p<0.001) (Table 6).

TABLE 6: CORRELATIONS BETWEEN KNOWLEDGE AND ATTITUDE SCORE OF RESPONDENTS

		Knowledge Score	Attitude Score
Knowledge Score	Pearson Correlation	1	.353**
	Sig. (2-tailed)		.000
	N	200	200
Attitude Score	Pearson Correlation	.353**	1
	Sig. (2-tailed)	.000	
	N	200	200

** Correlation is significant at the 0.01 level (2-tailed).

DISCUSSION: Our study demonstrated that more than half (63%) of our sample study had good to excellent knowledge and good to excellent attitude (87.5%) towards thalassemia. This knowledge and attitude of the future healthcare providers make us hopeful that they will play a progressive and constructive role in prevention and management of thalassemia in UAE. Our results are consistent with the findings of recent studies done in Malaysia among the future healthcare providers of a university¹⁶ and in Iran among science students¹⁷. However the knowledge level of the participants of this study is much higher than that of a study done

in Pakistan¹⁸ in which nearly half of the medical university students never heard about thalassemia. Majority of the study population showed that their knowledge and attitude levels were high which could be because they were the students of a medical and health sciences university.

The mean knowledge and attitude scores when compared between four different colleges showed that nursing students had the lowest scores, 4.34 ± 2.26 and 3.09 ± 1.48 respectively reflecting a lack of knowledge among the study respondents. These results are in line with previous studies¹⁶.

This could be attributed to the fact that 53.1 % of the respondents from nursing college were in the 1st year with only general secondary school examination as the level of their education. They might not be having any background knowledge pertaining to thalassemia.

Our study showed that the majority (63.1%) of respondents belonging to Middle East nationalities had a very good knowledge and attitude scores. This could be ascribed to the fact that thalassemia is the most common genetic disorders in the Middle East countries. These findings are encouraging as the future healthcare providers from Middle East countries with good knowledge and attitude towards thalassemia will play pivotal role in organizing effective programs for the awareness thalassemia in future.

Study participants' responses indicated that their specific knowledge regarding the management of thalassemia (33%) was not up to the mark. Judging by the result of the knowledge of the respondents regarding these aspects of the disease, more awareness programs should be directed to the target group of students to provide them with the information they need to know about thalassemia.

Our results demonstrated that there is a significant correlation between age and level of knowledge as well as attitude towards thalassemia indicating that as the age increased the knowledge and attitude also improved. These findings are consistent with previous study done to evaluate the level of awareness in future health care providers¹⁶. An important finding of our study is that a positive significant correlation existed between the level of knowledge and the level of attitude towards thalassemia. This indicates that as the knowledge of respondents pertaining to thalassemia increased, their attitude towards thalassemia also improved. These findings fortify the fact that knowledge plays a very significant role in changing the perception of people towards genetic diseases like thalassemia.

These results are in line with the previous studies which reported that as the knowledge about diseases like hypertension and HIV/AIDS increased the attitude towards these diseases also improved^{19, 20}.

CONCLUSION: In conclusion, the students showed good level of knowledge as well as attitude towards thalassemia but the challenge is that they put this knowledge and attitude into practice once they graduate from their respective colleges and take up their roles as efficient healthcare providers. In addition to this the students can further enhance their knowledge on specific aspects of thalassemia by attending various awareness campaigns and programs organized by the Ministry of Health. In a country like UAE where genetic disorders such as thalassemia pose a significant challenge to the health authorities, future healthcare providers with good knowledge base and positive attitude towards thalassemia will definitely contribute to the better prevention and management of thalassemia in the region.

ACKNOWLEDGEMENTS: The authors would like to thank students of RAK Medical and Health Sciences University for participating in the study. The authors also thank Dr. S Gurumadhva Rao, Vice Chancellor; Dr. BG Nagavi, Dean; Dr. Padma GM Rao, Associate Dean, RAK Medical and Health Sciences University for their support and encouragement.

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How to cite this article:

Rabbani SA, Ahmed A, Abdulkader B and Suliman S: Evaluation of thalassemia awareness among the future healthcare providers of United Arab Emirates. *Int J Pharm Sci Res* 2017; 8(2): 908-14. doi: 10.13040/IJPSR.0975-8232.8(2).908-14.

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