

Thalassemia awareness among Iraqi people in 2018

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Abstract

Thalassemia is an autosomal recessive disease that is common in Iraq with a prevalence of 35.7 per 100,000. It is the most common type of hereditary anemia registered in 2015. It is a life-threatening condition with many complications which if not managed could cause death in early age. This study aimed to assess the awareness of Iragi people about thalassemia transmission and prevention and to find their source of information about the disease, as developing good awareness is the first and the most advantageous road to establish a successful prevention program. This cross-sectional study involved 417 participants who were from medical and non-medical fields. It was conducted as an online survey in addition to participants interview using a self-structured questionnaire which was tested for content and face validity, unidimensionality and test-retest reliability in a pilot study of 40 participants. Each participant who had heard about the disease was given a score (0-5) based on their knowledge: 68.8% of the people had heard about the disease previously, those had a mean score of 3 out of 5; 84% claimed that thalassemia is a noncommunicable disease which resembles the highest awareness aspect. The lowest one was about the preventability of the disease. Significant correlation was found between the score of awareness and the age. People awareness about thalassemia was relatively good. A control strategy should be directed to elevate the awareness level about thalassemia in the community with the application of the national program for thalassemia control.

Introduction

Thalassemia is the most common type of hereditary anemia registered in Iraq in 16 thalassemic centers in 2015. Both males and females are equally affected by thalassemia and this disorder occurs in approximately 4.4/10,000 live births. Also, it was estimated that the prevalence of beta-thalassemia carrier state is 1.5% in general population.¹

Thalassemic patients are susceptible to many complications, like marked hepatosplenomegaly, which occurs due to excessive red cell destruction (25.8% of the patients in Iraq have splenomegaly, and 4.4% of them have hepatomegaly), extramedullary hematopoiesis, iron overload, osteoporosis (67.5% of the patients in Iraq) and osteopenia (9.4% of the patients in Iraq).^{1,2} And in a study done in 2015, 66.4% of thalassemia patients were under 15 years with splenomegaly and growth retardation representing the most frequent complications.¹

Thalassemia represents a great burden. In Iraq, a report from the Federal Board of Supreme Audit in 2016 revealed that the cost of management of each patient is 1428.00-3785.00 US\$/month.¹

In the Arabian region, high proportions of consanguineous marriages have resulted in a high incidence of genetically based disorders, particularly autosomal recessive ones, and thalassemia is one of them.^{3,4}

Thalassemia is a preventable disease, and many countries had succeeded in its prevention through a comprehensive approach starting from spreading knowledge and awareness and developing program to control the disease through premarital investigation and antenatal detection with therapeutic abortion.⁵⁻⁷

As awareness is critical in the prevention, it needs assessment in order to identify its level among the general population as well as students from the medical field because some studies showed that even the medical field required more education about the disease prevention methods.⁴

Our aim is to assess the awareness among people about this chronic genetic disease since Thalassemia awareness assessment among population represents the first step in the prevention program, and there is little data available in Iraq about this subject.

Materials and Methods

This is a cross-sectional study held for one month in august in 2018. This study included 417 participants who were from medical (185) and non-medical fields (232). Sample collection methods included using an online survey in social media sites in addition to participants interview using a self-structured questionnaire.

The questionnaire was tested for validity, unidimensionality, and reliability in a pilot study of 40 participants.

Regarding validity, the questionnaire was developed after reviewing the literature⁸⁻¹⁰ to establish both construct and face validity.

Regarding unidimensionality, it was tested using principal component analysis

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and only one factor was found to account for the finding; the result can be shown in Table 1. Regarding reliability, test-retest reliability was obtained with interclass correlation coefficient (ICC), the smallest value was 0.69, and all were statistically significant.

The questionnaire included information about sociodemographic data (age, gender, education level and job, marital status and consanguinity).

The total score was calculated for all those who have heard about the disease so that *Do not know* answers were considered as incorrect and given a score of (0), whereas the correct answer was given a score of (1). Each of them was given a score (0-5) based on their knowledge in answering the following five questions: i) *Is thalassemia a chronic disease*?; ii) *Is a consanguineous marriage related to thalassemia occurrence*?; iii) *Is thalassemia a contagious disease*?; iv) *Is thalassemia a preventable disease*?; v) *Can thalassemia be transmitted by food*?

Descriptive and analytic statistics were done in the term of mean, standard deviation, minimum, maximum, proportions, chi-



Table 1. Unidimensionality testing.

Component	Initial Eigen values			nea Extrac	Extraction sums of squared loadings			
	Total	%of variance	Cumulative%	Total	%of variance	Cumulative%		
1	2.032	40.646	40.646	2.032	40.646	40.646		
2	0.930	18.594	59.240					
3	0.817	16.340	75.580					
4	0.680	13.606	89.187					
5	0.541	10.813	100.000					

Extraction method: principal component analysis.

square, t-test, and one-way ANOVA with 95% confidence level which means that a P-value less than 0.05 is considered statistically significant.

All participants were informed about the goal of the survey, and informed consent was obtained from them.

The data was analyzed using Social Sciences program (SPSS) version 24.

Table 1 represents unidimensionality testing.

Results

Results of non-medical sample (n=232)

The mean age of the sample is 26.25 years with standard deviation of 8.53 and minimum age of 17 and maximum age of 67, 41.17% were students, 16.7% had no job, 8.6% were academic professor, and 8.14% were students in higher education.

Table 2 represents the educational degree of the participants.

59.6% were from Baghdad, 6.1% were from Al-Nasiriyah, 5.7% were from Basrah, 4.8% were from Babil, 4.4% were from Anbar and same for Dyala, and 3.9% were from Al-Najaf. the remainder were from other provinces.

68.8% of the people have heard about thalassemia previously.

The mean score of the participants who heard about the disease is 3 with a standard deviation of 1.46.

Table 3 represents the source from where the Participants have heard about the disease (only 202 participants).

A significant weak positive association was noticed between age and the score with r=0.22 and p-value of 0.04.

No significant association was found between the score and age, gender and if the couples are relatives using T-test with a Pvalue of 0.85, 0.068 and 0.198 respectively.

Results of medical sample (n=185)

The mean age is 22.3 years with stan-

Table 2. The educational degree of the participants.

		Frequency	Valid percent	
Valid	Primary	3	0.7	
vana	Intermediate	2	0.5	
	Preparatory	32	7.7	
	College	123	29.6	
	Higher education	71	17.1	
	Medical fields	185	44.5	
	Total	416	100.0	
Missing	System	1		
Total	417			

Table 3. Source of knowledge about the disease.

Source of knowledge	Valid percent	Frequency
Friends and family	28.8	58
Internet	27.7	56
School and college	22.3	45
Hospital visit	8.9	18
Others	12.3	25

dard deviation of 3.3. Minimum age was 17 and maximum was 39 years.

84.9% were medical students, 5.9% dentists, 3.2% pharmacist, 2.7% physicians, and 3.3% for other medical fields' careers.

31.4% were from Baghdad, 20% were from Basrah, 15.7% from Al-Dewaniyah, the remaining of the sample was distributed in different other provinces.

94% of the sample have heard about the disease.

The mean score of medical sample was 3.87 with standard deviation of 1.22.

Table 4 represents other sociodemographic data of the non-medical and medical group.

Table 5 demonstrates the score-based questionnaire answers among medical and non-medical group.

Among non-medical sample, of those who said that thalassemia has relation to consanguineous marriage, 84.1% of them claimed that consanguineous marriage can increase the risk of thalassemia, 2.3% claimed that it decreases the risk meanwhile

the others did not have information.

Of those who said thalassemia is preventable, 46.7% claimed that consanguineous marriage prevention is the best way, 32.2% said that doing test before marriage is the way for prevention, 13.3% said avoidance of certain foods is the way of prevention, others suggested blood transfusion restriction and avoidance of marriage from the affected ones.

There is statistically significant difference between mean score of medical sample and non-medical sample using T test of P-value of 0.0001.

Discussion

Thalassemia has a great economic burden in Iraq. It is the most common hereditary hemoglobinopathy in Iraq.¹ Knowledge and awareness about thalassemia play a significant role in the success of the national program of thalassemia prevention; for this

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reason, this study was conducted.⁴ This study aims to find awareness level among general population and among a particular group who are involved frequently with the subject who are the medical students.

Most of the participants in this study were in their twenties, and this can be confirmed by their mean of age was 26.25, which is a critical age group to be targeted for assessment and evaluation of their awareness about the disease as they are willing to get engaged or having their first child, and they should be aware about this common disease in the community and identify the best method for its prevention.

In this study (regarding non-medical sample), 68% of the participants identify the disease as a consanguineous marriage related disease, and 84% of them believed it increases the risk. Studies had shown that avoiding consanguineous marriage is a well-established and effective preventive measure which should be done by educating young couples who have a marriage desire to prevent many recessive diseases including but not limited to thalassemia.⁸⁻¹²

When both parents are carriers of a particular gene for any disorder, each child of those parents has a 25% risk of that recessive disorder. The chance that both parents will be carriers of the gene of the same disorder is influenced by the extent to which the problem is endemic in a community.¹³

The study (regarding non-medical field) shows that participants believed that the best method of prevention is to have a premarital testing. The premarital testing is an essential part in the prevention programs, and it is applied in several countries worldwide such as Cyprus,⁵ Lebanon,⁶ Saudi Arabia, Iran, and United Arab Emirates.⁷

In Iraq, the prevention program is now applied, and every couple is obliged to do premarital investigations including blood tests, but the couples are free to make their decision to proceed with their marriage or not. The WHO recommends that these tests are to be done on voluntary basis¹⁴ but the high economic burden of the blood diseases in Iraq was the rationale for making them mandatory, the situation is the same in many countries in the Mediterranean region. Some countries applied screening test among secondary school students in order to identify those at risk before they have a desire or arrangement for marriage. A study done in Duhok, in north Iraq, showed that about 54,132 couples who were willing to get engaged were tested and 130 of them were found to be at risk; 98.1% of them decided to proceed with their marriage after they knew that.¹⁵ So it is necessary to educate couples and to spread awareness about the disease.

As the contagious diseases have many impacts including stigma, it is necessary to identify Thalasssemia as a non-contagious disease to protect patients from being stigmatized. 84.5% of the non-medical people field described the disease as a non-contiguous disease, and it is known that all genetic diseases are not infectious in nature. Thalassemia is transmitted in an autosomal recessive fashion in majority of cases; in very rare cases it is associated with a dominant mutation.^{16,17}

Essential for the awareness is to assess the source of information about the disease and its prevention. The most frequent source of information was from families or friends, followed by social media sites; this might give a good indicator of raising community awareness about thalassemia if more attention is given for social media.

	Non-medical sample			Medical sample			
Category	Frequency	Proportion	Mean score	Frequency	Proportion	Mean score	
Age group <25	99	42.7%	3.1	19	10.3%	4.1	
Age group >25	133	57.3%	2.9	166	89.7%	3.8	
Male	67	28.9%	2.9	53	28.6%	4	
Females	165	71.1%	3	132	71.4%	3.7	
Married persons	72	31%	3.4	21	11.4%	4.1	
Unmarried persons	160	69%	2.8	164	88.6%	3.8	
Relative marriage	15	20.8%	3.6	15	71.4%	2.6	
Non relative marriage	57	79.2%	3.3	6	28.5%	3.3	
Family history*	32	20.1%	3.4	21	12.1%	3.9	
No family* history	127	79.9%	3.1	153	87.9%	3.9	

Table 4. Sociodemographic data in both groups.

*Of those who have heard about the disease.

Table 5. Items' answers of awareness among medical and non-medical sample.

	Non-medical sample			Medical sample		
Question	Yes (%)	No (%)	I don't know (%)	Yes (%)	No (%)	I don't know (%)
Is thalassemia a chronic disease?	136 (58.7)	22 (9.6)	74 (31.7)	159 (85.9)	7 (4.1)	19 (10)
Is consanguineous marriage related thalassemia occurrence?	160 (68.8)	21 (8.9)	51 (22.3)	163 (88.3)	5 (2.3)	17 (9.4)
Is thalassemia a contagious disease?	8 (3.6)	195 (84)	29 (12.4)	3 (1.8)	169 (91.2)	13 (7.1)
Is thalassemia a preventable disease?	100 (43.1)	38 (16.2)	94 (40.7)	104 (56.2)	29 (15)	52 (28.4)



This is different from a study done by Ahmed *et al.*¹⁸ and Abd Al Azeem *et al.*¹⁹ in which television was the most frequent source of their knowledge, followed by friends and relatives.

Medical students' awareness was the the lowest in prevention aspects, and this goes with the findings of Zulkeflle *et al.*⁴ for this reason, the college students are targeted to assess their knowledge about prevention, particularly about premarital investigation test.²⁰

Important to be mentioned in this study is that it is a complementary study to a previous study conducted among thalassemia patients' parents to assess their awareness.²¹

As a limitation, this study was conducted as an online survey and only those with internet access had the chance of participation in the study so an important part to be considered in next studies is to address those living in villages and those without internet access to involve them in the study in order to have a full clear image about the awareness of the disease in a more precise and clear way. And the authors encourage future researchers to use this questionnaire to assess thalassemia awareness in these areas as it was proved to be valid and reliable.

Conclusions

People awareness about thalassemia was relatively good, the highest awareness was for the contiguity of the disease and the lowest awareness was for the preventability. More awareness programs will be beneficial for prevention of the disease.

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