Thalassemia: a prevalent disease yet unknown term among college students in Saudi Arabia

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Abstract

Thalassemia is a life-threatening blood disorder that has a high prevalence in Saudi Arabia despite the implementation of mandatory premarital testing and the availability of genetic counseling. This study aimed to assess college students' knowledge of thalassemia. A cross-sectional survey of a random sample of 920 senior students enrolled at King Abdulaziz University was conducted. A self-administered questionnaire was used to collect information about thalassemia and socio-demographic characteristics. Of the 920 students, 445 (48%) had ever heard of thalassemia. Despite the mandatory premarital testing for thalassemia, only 50% of married students stated having heard of the disease. The mean thalassemia knowledge score was 4.4 ± 2.2 out of a maximum of 12. Knowledge was significantly influenced by university faculty, gender, and education outside of Saudi Arabia. Those who had heard of thalassemia had misconceptions about the disease characteristics and pattern of inheritance such as associating thalassemia with low iron levels. A substantial proportion of the participants had a low knowledge of thalassemia. This lack of awareness requires a reassessment of the goals and success of the premarital testing program, including the genetic counseling services, and also indicates the importance of emphasizing thalassemia in school curricula and promoting and scaling up existing thalassemia campaigns in the region.

Keywords Thalassemia · Knowledge · Premarital testing · Prevention

Background

Thalassemia is an inherited blood disorder that has a range of manifestations depending on the nature of the mutation (Galanello and Origa 2010; Harteveld and Higgs 2010). Although genetic testing is available and can detect thalassemia, its prevalence worldwide remains high (Nicole and Cousens 2010); thalassemia is considered the most common inherited single-gene disorder (Colah et al. 2010; Higgs et al.

2012). The high prevalence of thalassemia, its unique manifestations, and the lack of cure make it a global health concern (Wong et al. 2011). Thalassemia is unique to the Mediterranean, Sub-Saharan African, and Asian regions but is spreading to Europe and North America as a result of migration (Angastiniotis and Modell 1998). Saudi Arabia has one of the highest prevalences of thalassemia in the world, ranging from 0.4% in the Northern region to 5.9% in the Eastern region (Memish et al. 2011).

Fortunately, the incidence of thalassemia, among other inherited blood disorders, can be effectively reduced by implementing carrier detection programs that include genetic counseling (Nicole and Cousens 2010). In 2006, the World Health Organization (WHO) supported the global development of these types of programs (Angastiniotis and Modell 1998). The effectiveness of different thalassemia genetic testing and counseling programs was evaluated, and it was concluded that no single program was the most effective, as different aims and beliefs affect the targeted population (Nicole and Cousens 2010). Genetic screening programs among high school students have been found to be helpful in reducing the incidence of thalassemia, as reported by Mitchell et al., who

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found that the incidence of thalassemia decreased by 90 to 95% over two decades (Mitchell et al. 1996). “School screening” may be more advantageous than the more routinely practiced “premarital screening,” as all individuals in non-civil marriages would also receive “school screening” (Savas et al. 2010). In addition, public education about thalassemia was found to be effective in reducing the incidence of the disorder (Nicole and Cousens 2010).

Many countries have measured the public’s knowledge of and attitudes toward thalassemia in order to implement and evaluate relevant educational programs (Al Hajeri and Al Arrayed 2012; Armeli et al. 2005). For example, Italy’s education programs have been found to be effective, with Italians having more knowledge about thalassemia than Italian-Americans and non-Italian-Americans (Armeli et al. 2005). In Bahrain, assessments of the population’s knowledge of β -thalassemia indicated the need to improve the population’s basic knowledge of the disease (Al Hajeri and Al Arrayed 2012). In the literature, thalassemia knowledge was found to be associated with several factors, which vary by region and population, including gender, marital status, education, employment, and socio-economic status (Maheen et al. 2015; Okyay et al. 2016; Wong et al. 2011).

In response to the high prevalence of inherited blood disorders in Saudi Arabia, a national mandatory premarital testing detection program for thalassemia and sickle cell anemia was initiated in 2004 in all regions of the country and is free of charge (El-Hazmi 2006; “Kingdom of Saudi Arabia - Ministry of Health Portal n.d.”). Although the testing is mandatory, it is the couple’s decision to proceed with their marriage even in high-risk cases, when genetic counseling services would be offered (El-Hazmi 2006). The premarital testing program in Saudi Arabia has not significantly decreased the occurrence of high-risk couple marriages; 90% of the high-risk couples in 2007 and 98% in 2010 were later married despite receiving genetic counseling (Al Sulaiman et al. 2010; Alhamdan et al. 2007). The 2014 statistics of the Saudi Ministry of Health indicated that 3000 out of 7500 individuals who were “physically incompatible” for thalassemia or sickle cell diseases opted against medical advice and proceeded to become married (“Kingdom of Saudi Arabia - Ministry of Health Portal n.d.”). Physical incompatibility refers to both partners being carriers or infected by the disease or when one partner is a carrier and the other is infected.

Studies have found that the Saudi population is supportive of premarital testing but has a low understanding of the testing results (Al Sulaiman et al. 2008; Al-Aama et al. 2008; Olwi et al. 2016). A high percentage of high-risk couples still become married despite public health measures, suggesting a need to examine the public knowledge of the disease. Monitoring the public’s knowledge of thalassemia is important, as it will help in assessing the effectiveness of the premarital testing and other educational campaigns to ensure that

they improve thalassemia knowledge. To our knowledge, no studies have been conducted to assess the knowledge and perceptions of the public toward thalassemia in Saudi Arabia. The aims of this study were to assess the knowledge of thalassemia and the factors associated with this knowledge among a random sample of college students.

Methods

Participants

A cross-sectional study was conducted at King Abdulaziz University (KAU), which is the largest university in Saudi Arabia, between September 2014 and May 2015. KAU had 40,000 enrolled students during the 2014/2015 academic year and is divided into three fields of study: medicine, sciences, and humanities, with 18 faculties. Faculties that only enroll male or female students were not included in this study. An important aspect of the faculty comparisons was to better understand the cumulative knowledge that students gain during their college education, and this study therefore included only senior students graduating within two semesters. Undergraduate students enrolled at the main KAU campus were selected using multistage random sampling. One faculty was randomly selected from each of the three fields of study (medicine, sciences, and humanities). The selected Faculties of Dentistry, the Sciences, and Arts and Humanities were then stratified into departments, and a minimum of one senior class was randomly selected from each department.¹

Instruments and procedures

A structured self-administered questionnaire was developed from questions used in previous studies investigating the knowledge of β -thalassemia (Al Hajeri and Al Arrayed 2012; Armeli et al. 2005). The questionnaire was translated from English into Arabic using the forward-backward-forward technique (Beaton et al. 2000). The questionnaire comprised two sections: socio-demographic information and thalassemia knowledge (total of 12 questions). The final version of the questionnaire was reviewed by a medical geneticist, tested on 30 students, and modified accordingly. Appropriate arrangements were made to visit the classrooms and collect the data. During the allotted class time, the consent and questionnaire forms were distributed with a brief explanation of the aims and significance of the study. The study was approved by the Research Ethics Committee at KAU.

¹ Due to the small number of students in the Department of History in the Faculty of Humanities, it was excluded from the study.

Data analysis

Continuous variables were described using means and standard deviations, and categorical variables were described using frequencies and percentages. The responses to knowledge questions were re-categorized into two groups: (i) correct, which included the right answers, and (ii) incorrect, which included both the wrong answers and the “do not know” responses. A score of 1 was assigned to the correct responses and a score of 0 to the incorrect responses. A total knowledge score was calculated by summing the responses for students who reported having heard of thalassemia. The total score ranged between 0 and 12. A univariate analysis was performed using *t* tests or one-way ANOVA to assess the association between the predictors (age, gender, faculty, school year, GPA, education outside of Saudi Arabia, marital status, number of children, and family history of inherited disease) and knowledge of thalassemia among those who heard of the disease. Tukey’s post hoc test was used for pairwise comparisons. Data were analyzed using STATA version 13.0 (Stata Corp, College Station, Texas, USA), and $p \leq 0.05$ was considered significant.

Results

The study included 920 students, with a response rate of 90%. The socio-demographic characteristics of the study population are displayed in Table 1. The mean age was 22.4 ± 1.3 years, and the sample was 67% female. Approximately 11% of the students reported a family history of genetic diseases, of which 26, 22, 5, and 47% were sickle cell anemia, Down syndrome, thalassemia, and other diseases, respectively. Seven percent of the students had received education outside of Saudi Arabia, for an average duration of 3.5 ± 2.9 years. Of the sample of 920 students, 445 (48%) had ever heard of thalassemia, having learned about it mainly through the media (49%), their education (36%), friends (24%), and family (17%). Eight percent of the students had been tested for thalassemia, primarily through the premarital testing program, and 50% of the married students reported having heard of thalassemia.

Table 2 presents the percent of correct answers regarding thalassemia among the students who had heard of the disorder. The students answered incorrectly to the majority of the questions on thalassemia. For example, only 59% of the students knew that thalassemia causes anemia, and a small percentage (8%) associated thalassemia with higher iron levels. Although the majority (64%) identified thalassemia as being an inherited disease, only 11% knew that it required two defective genes to be transmitted.

Table 3 shows the associations between the socio-demographic variables and knowledge of thalassemia among students who reported having heard of thalassemia. The mean

Table 1 The socio-demographic characteristics of the study population

Variables	Total
	<i>N</i> (%)
Gender	
Female	619 (67)
Male	301 (38)
Age	
< 23	500 (54)
≥ 23	420 (46)
Marital status	
Never married	782 (85)
Ever married	137 (15)
Children status*	
No children	80 (59)
Have children	56 (41)
Family history of inherited diseases	
No	814 (89)
Yes	105 (11)
Academic year	
3rd/4th	453 (50)
5th/6th	459 (50)
GPA**	
A	226 (26)
B	443 (55)
C/D	210 (24)
Studied outside Saudi Arabia	
No	851 (93)
Yes	68 (7)

SD, standard deviation; *GPA*, grade point average

* Number of children reported for ever-married students

** GPA (A = 4.5–5.0, B = 3.75–4.5, C = 2.75–3.75, and D = 2.0–2.75)

knowledge score was 4.4 ± 2.2 out of a total possible score of 12. Knowledge of thalassemia varied significantly depending on faculty. Science students had the highest knowledge scores (5.2 ± 2.0), followed by arts students (4.7 ± 2.2), and then dentistry students (3.9 ± 2.3) ($p < 0.001$). Female students also had higher scores for thalassemia knowledge (4.6 ± 2.2) than males (4.0 ± 2.4) ($p = 0.018$). Students who studied outside of Saudi Arabia had lower thalassemia knowledge scores (3.6 ± 2.3) than their peers (4.5 ± 2.2) ($p = 0.03$).

Discussion

This study investigated thalassemia knowledge and its associated factors among college students in Saudi Arabia. Our main

Table 2 Percentage of students who correctly answered the 12 thalassemia knowledge questions

	Correct answer <i>N</i> (%)	Incorrect answer <i>N</i> (%)	Do not know <i>N</i> (%)
If thalassemia is left untreated, the patient's health will deteriorate. (True)	257 (60)	24 (6)	146 (34)
A person with thalassemia disease has low iron levels. (False)	37 (8)	233 (53)	172 (39)
The ideal timing to get tested for thalassemia/thalassemia trait (carrier) is before starting a family. (False)	161 (37)	64 (15)	215 (49)
Thalassemia is a disease that runs in the family. (True)	283 (64)	25 (6)	137 (31)
There is a cure for thalassemia. (False)	125 (28)	41 (9)	277 (63)
Individuals who have thalassemia cannot live normal lives even with appropriate treatment. (False)	147 (33)	69 (16)	227 (51)
Individuals who have thalassemia are anemic. (True)	260 (59)	28 (6)	156 (35)
Thalassemia is not treatable with blood transfusions. (False)	94 (21)	69 (16)	279 (63)
Thalassemia can only be treated with medications. (False)	103 (23)	48 (11)	293 (66)
A person with thalassemia trait (carrier) is otherwise healthy and shows no symptoms of the disease. (True)	160 (36)	79 (18)	203 (46)
A person with thalassemia disease has a higher risk of infections and/or illnesses. (True)	176 (40)	20 (5)	248 (56)
Having a child with thalassemia may be a consequence of one of the parents having a thalassemia trait (carrier). (False)	51 (11)	249 (57)	144 (32)

Presented are row percentages

findings indicate that there were low levels of thalassemia knowledge, with more than half of the participants never having heard of the disease. Furthermore, even those who had heard of it demonstrated inadequate knowledge of the basic concepts of thalassemia.

The results of the present study showed that less than half of the study population had heard of thalassemia. This awareness is considerably lower than that reported in other countries, including Greece (90%), Italy (85%), Bahrain (65%), and Turkey (58%) (Al Hajeri and Al Arrayed 2012; Armeli et al. 2005; Politis et al. 1991; Savas et al. 2010). These results are unfortunate, especially in a country with a high thalassemia prevalence. Of particular concern was that 50% of the married students had never heard of the disorder. This finding was unexpected, as the compulsory premarital testing, which includes thalassemia, was initiated in 2004 (“Kingdom of Saudi Arabia - Ministry of Health Portal n.d.”). Hence, all of the married participants should have been tested for thalassemia through this premarital program. This lack of knowledge supports the findings of other studies, which have indicated that couples lack awareness of the diseases included in premarital testing (Al Sulaiman et al. 2008; Al-Aama et al. 2008). This gap further emphasizes the limited availability of genetic counseling sessions offered to couples and the shortage of trained genetic counselors (Qari et al. 2013).

The most common sources of information for those who had heard about thalassemia were the media, followed by friends and family, and then one's education. Physicians contributed very little to their patients' knowledge of thalassemia. Other studies have revealed that physicians have a greater role

in informing the public about thalassemia (Armeli et al. 2005; Wong et al. 2011). Armeli et al. (2005) reported that 15% of Italians gained their knowledge of thalassemia through their physicians (Armeli et al. 2005). Similarly, Wong et al. reported that the contribution of physicians in improving Malays' knowledge of the disease was 9% (2011) (Wong et al. 2011). The low contribution of physicians in our study may reflect the nature of the study participants, as they were young, healthy college students who are less likely to have routine physician visits. The results also highlight the influence of the media on the public's knowledge of thalassemia.

The low mean level of knowledge reflects a substantial lack of understanding of thalassemia among the study participants. The current study results are considerably lower than previously reported findings (Armeli et al. 2005; Wong et al. 2011). The participants in this study were hypothesized to have higher scores on knowledge of thalassemia than the participants in other studies because Saudi Arabia has one of the highest prevalences of the disease (Al Sulaiman et al. 2008). In addition, our study participants were college students, who are expected to have higher levels of knowledge of thalassemia, as observed in previous studies (Wong et al. 2011). An interesting finding in our study was that receiving education outside of Saudi Arabia negatively affected the level of knowledge. This association might be a result of the effort Saudi Arabia has devoted to raising national awareness about thalassemia, which might not be as large an emphasis outside of the country. A similar finding was found in Italians, Italian-Americans, and non-Italian-Americans, in which Italians had substantially higher levels of thalassemia knowledge than

Table 3 Associations between socio-demographic variables and total thalassemia knowledge scores

Variables	Mean (SD)	<i>p</i> value
Faculty		
Dentistry	3.9 (2.3)	< 0.001*
Sciences	5.2 (2.0)	
Arts and Humanities	4.7 (2.2)	
Gender		
Female	4.6 (2.2)	0.018
Male	4.0 (2.4)	
Age		
< 23	4.4 (2.3)	0.512
≥ 23	4.5 (2.2)	
Marital status		
Never married	4.4 (2.3)	0.681
Ever married	4.5 (2.1)	
Children status**		
No children	4.5 (2.3)	0.842
Have children	4.6 (2.0)	
Family history of inherited diseases		
No	4.4 (2.3)	0.764
Yes	4.5 (2.2)	
Academic year		
3rd/4th	4.5 (2.2)	0.72
5th/6th	4.4 (2.3)	
GPA***		
A	4.4 (2.2)	0.78
B	4.5 (2.2)	
C/D	4.5 (2.5)	
Studied outside of Saudi Arabia		
No	4.5 (2.2)	0.03
Yes	3.6 (2.3)	

SD, standard deviation; *GPA*, grade point average

Total score of thalassemia knowledge is 12

*Dentistry < Sciences; Dentistry < Arts and Humanities

**Number of children reported for ever-married students

***GPA ($A = 4.5\text{--}5.0$, $B = 3.75\text{--}4.5$, $C = 2.75\text{--}3.75$, and $D = 2.0\text{--}2.75$)

Italian-Americans and non-Italian-Americans, reflecting the effectiveness of the community educational programs implemented in Italy (Armeli et al. 2005).

The most surprising finding in our study was that of the three surveyed faculties (Faculties of Arts and Humanities, Sciences, and Dentistry), dental students had the lowest level of knowledge, followed by arts students, and then science students. The dental students may have had the lowest level of knowledge because they had the lowest marriage rates in our sample and because they had the highest number of males. These characteristics were associated with lower knowledge levels in our study as well as in previous studies (Al Hajeri and Al Arrayed 2012; Wong et al. 2011).

Thalassemia is unique in its abnormal production of hemoglobin, leading to anemia with high accumulations of iron. The majority of participants had misconceptions about these characteristics, even among those who identified themselves as having thalassemia. Less than a tenth of the students knew that thalassemia leads to high iron levels, and only two thirds recognized that thalassemia causes anemia. Although a fair number of students recognized that thalassemia is a hereditary disease, few students understood its pattern of inheritance. Furthermore, the majority presumed that thalassemia carriers manifest the disease. Although previous studies have reported similar deficiencies (Armeli et al. 2005; Wong et al. 2011), our study participants had higher misconceptions. It is crucial to address these misconceptions, as these deficits in knowledge may lead to stigmatization and emotional burden on thalassemia carriers.

The premarital testing program implemented in Saudi Arabia aims to reduce the prevalence of thalassemia and to educate the public about the disease. As there was a substantial lack of thalassemia knowledge, we recommend a reassessment of the program and its influence. A successful program was instituted in Montreal, Canada, that aimed to educate, screen, and provide counseling for β -thalassemia among high school students of Mediterranean origin (Mitchell et al. 1996). This program found that students remembered their carrier status and followed precautionary measures later in life. The results of the high school screening program were remarkable; the incidence of β -thalassemia decreased by 90–95% over a period of 20 years.

Study limitations

This study has several limitations. First, the self-reported questionnaire may have resulted in a response bias. Second, the questionnaire was based on previous studies and was not validated. Finally, the results of the study might not be generalizable to the Saudi population, as the participants were college students at KAU, who have higher levels of education than the general public.

Conclusion

Saudi Arabia has one of the highest prevalences of thalassemia. Despite the country's efforts to reduce its incidence through premarital testing, the rates of marriages among high-risk couples have not significantly decreased. Our main findings showed a substantial lack of thalassemia knowledge among college students. We recommend a re-evaluation of the objectives and success of the premarital testing program and genetic counseling services. In addition, there is a great need to educate the public about thalassemia, as an improved knowledge would assist national efforts to reduce its

incidence. The educational system in Saudi Arabia should emphasize nationally prevalent genetic diseases such as thalassemia. These topics could be introduced in school and college curricula. Finally, policymakers might find it more effective to adopt high school screening instead of premarital testing, as high school screening has been found to be more effective in reducing the prevalence of β -thalassemia.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no competing interests.

Ethical approval The study was approved by the Research Ethics Committee at the King Abdulaziz University which is in accordance with the 1964 Helsinki declaration and its later amendments.

Informed consent Informed consent was obtained from all participants.

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