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Hemoglobinopathy Awareness Among Middle and High School Students in Karataş, Turkey

Hemoglobinopathy Awareness Among Middle and High School Students

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Abstract: **Objective:** Hemoglobinopathies are complex and inherited genetic disorders with no definitive cure; however, preventive measures such as genetic counseling and premarital screening may dramatically reduce their prevalence. Therefore, having sufficient information about the mentioned preventive measures is crucial.

Methods: All students attending middle and high schools were included without a sample selection. A survey form was administered to students in order to evaluate their knowledge level and attitudes regarding hemoglobinopathies. The results were evaluated using Chi-square and logistic regression analysis with 95% confidence interval (CI).

Results: The total number of students agreeing to participate in the study was 877. The mean age of the participants was 14.8 ± 1.5 years; 50.5% of them were male.Of the participating students, 40.3% were previously informed about hemoglobinopathies.The lowest correct response rate among questions in terms of students' knowledge about hemoglobinopathies was observed in the question that asked the transmission route of the disorders with 13.7%.In the multivariate analysis, maternal education level (OR=1.417; 95% CI) and knowing an affected patient (OR=4.215; 95% CI) were associated with a greater likelihood of being previously informed.

Conclusions: The correct rates of the responses given by the participating students to the questions about hemoglobinopathies varied. Students who were previously informed about hemoglobinopathies gave a higher rate of correct answers. Organizing and sustaining educational particularly genetic basics of the disorders to students, who are the parents of the future, may be useful in combating hemoglobinopathies.

Keywords: Hemoglobinopathies, Awareness, School Health, Middle School Students, High School Students

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INTRODUCTION

Hemoglobinopathies (sickle-cell disorders and thalassemias) refer to a group of diseases caused by genetic disorders that affect the formation of the normal hemoglobin chain (1). According to the World Health Organization (WHO), about 5% of the world population are healthy carriers of a gene for thalassemia or sickle-cell anemia. However, there are more than 300,000 annual births with severe forms of these diseases worldwide, the majority being in countries with low or middle income (2). According to data of the Turkish National Hemoglobinopathy Council and the Ministry of Health, there were 1.4 million thalassemia carriers in Turkey in 2006. Additionally, the prevalence of both β-thalassemia and sickle cell anemia carriers was particularly high in cities such as Hatay, Antalya and Adana, which are located on the Mediterranean shore (3,4). A control program has been recommended by the WHO for hemoglobinopathies because there is no definitive cure. The control program comprises prenatal diagnosis, raising awareness of the public, carrier screening and genetic counseling (5). Henceforward, in many of the affected countries worldwide, premarital screening programs have been put into practice. Countries such as Italy, Canada, Greece, the United Kingdom and Cyprus have used such programs. As a striking example, the thalassemia prevalence in Cyprus has been reduced from very high levels to trifling levels after the implementation of a screening program (6).The achievements in these programs have also shown the importance of enlightenment about the diseases because insufficient awareness and knowledge regarding hemoglobinopathies may act as obstacles to prevention and testing for hemoglobinopathies. Cultural and psychosocial concerns may lead to disclosure of disease status (7,8). All these suggest that, increasing awareness about the nature and transmission of these disorders may help individuals to make healthy decisions in terms of risky situations. Therefore, in this paper, our goal was to investigate the knowledge of middle and high school students towards hemoglobinopathies and to determine their preventive behaviors in Karataş, Adana, where the disorders are prevalent.

METHODS

Design and data collection

The study was planned in a cross-sectional design and it took place in Karataş, Adana, which is a city in the Çukurova Region. In this study, a survey form evaluating the knowledge level and attitudes of students in terms of hemoglobinopathies and their status of being previously informed about the disorders was used. In Karataş, there were 3 middle schools and 2 high schools at the time of the study. The total number of students attending these 5 schools was 1058. We opted not to choose a sample and aimed to reach all students between the 7^{th} and 12^{th} class. Before the questionnaires were given to the students, all classes were visited by the researcher with a guidance teacher and information about the questionnaire was given. In addition, an illuminated proclamation paper was distributed to the students to be completed by their parents. The questionnaire was administered to students who brought the illuminated proclamation paper the next day. For the ones who forgot to bring the illuminated proclamation paper, one last survey was conducted the day after. Of the 1058 students, 877 (82.9 %) agreed to participate in the study. The data were collected during October-December 2015.

Statistical analysis

Statistical Package for the Social Sciences (SPSS) for Windows software was used in order to manage data and perform statistical analysis. The results were evaluated using Chi-square and logistic regression analysis, assuming $p<0.05$ to be statistically significant.

Ethical considerations

Official approvals were obtained from the Provincial Directorate of Education and the Governorship of Adana for the study.

RESULTS

The total number of students agreeing to participate in the study was 877. The mean age of the participants was 14.8 ± 1.5 years; 50.5% of them were male. It was found that 10.7% (n=94) of the students' mothers and 4.3% (n=38) of the students' fathers were illiterate. One hundred twenty-five (14.3%) of the participants perceived their economic status as very bad or bad, 61.5% (n=539) were perceived it as moderate, and 24.2% (n=213) perceived it as good or very good. Of the participants, 11.1% (n=97) expressed that they knew a patient with hemoglobinopathy around them, 77.4% (n=679) did not know a patient with hemoglobinopathy and 11.5% (n=101) were unsure whether there was a hemoglobinopathy patient around them (Table 1).

Table 1. Sociodemographic characteristics of the participants

Sociodemographic Characteristics	n	%
Sex		
Female	434	49.5
Male	443	50.5
Age group (years)		
12 to 14	384	43.8
15 to 17	463	52.8
18 or above	30	3.4
Educational status of the students' mothers		
Illiterate	94	10.7
Literate only (not primary school graduate)	116	13.2
Primary school graduate	372	42.4
Middle school graduate	173	19.8
High school graduate	95	10.8
University graduate	27	3.1
Educational status of the students' fathers		
Illiterate	38	4.3
Literate only (not primary school graduate)	102	11.7
Primary school graduate	338	38.5
Middle school graduate	214	24.4
High school graduate	145	16.5
University graduate	40	4.6
Perceived economic status		
Very bad	20	2.3
Bad	105	12.0
Moderate	539	61.5
Good	196	22.3
Very good	17	1.9
Existence of a known hemoglobinopathy patient		
Yes	97	11.1
No	979	77.4
Unsure	101	11.5

Of the participating students, 40.3% (n=353) were previously informed about hemoglobinopathies, the remainder was not. The lowest correct response rate among questions in terms of students' knowledge about hemoglobinopathies was observed in the question that asked the transmission route of the disorders with 13.7% (n=120). This indicates that vast majority of the participants did not know that the disorders were inherited. On the other hand, 70.8% (n=621) of the participating students correctly stated that the diseases affected both males and females. The distributions of accurate answers about hemoglobinopathies are shown in Chart 1. The accurate answer rates were significantly altered according to their status of being previously informed. These findings show that informing students about the disorders plays an important role in their knowledge level regarding hemoglobinopathies (Table 2). Of the participants, 80.7% (n=663) were willing to gain knowledge about hemoglobinopathies at schools, and 74.6% (n=607) were keen to learn whether they were carriers. Of the participants, 72.0% (n=559) expressed that they would change their future decisions in case of a risky situation caused by these disorders. A significant difference was found between participants who were and were not previously informed in terms of changing their future decisions in case they were affected by the disorders (Table 3).

Our results revealed that informing participants may play a key role in altering their level of knowledge and attitudes. Considering this fact, we performed a regression analysis to determine which factors affected the status of being previously informed. The following variables were associated with a greater likelihood of being previously informed: maternal education level and presence of a known affected patient. However, being a middle or high school student, fathers' education level, and economic status perception were not found to be associated with being previously informed about hemoglobinopathies in the regression model (Table 4).

Table 2. Students' accurate answer rates according to status of being previously informed

Questions	Correct answer of not previously informed(n=524)		Correct answer of previously informed(n=353)		P-value**
	n	%*	n	%*	
Which system of body do these disorders affect?	191	36.5	256	72.5	<0.001
How do these disorders transmit?	42	8.0	78	22.1	<0.001
Is it possible to be a carrier of these disorders ?	213	40.6	237	67.1	<0.001
Which sexes do these disorders affect?	359	68.5	262	74.2	0.068
Where do these disorders occur mostly in Turkey?	189	36.1	216	61.2	<0.001
Do you think these disorders are preventable?	199	38.0	178	50.4	<0.001
What is an important risk for the disorders ?	115	21.9	187	53.0	<0.001
Are these disorders are curable?	157	30.0	143	40.5	0.01

*The values are in n (%)
**Calculated using Pearson's Chi-square test

Table 3. Attitude and behavioral pattern of students about hemoglobinopathies according to being previously informed

Attitudes and Behaviors	Not previously informed		Previously informed		P-value**
	n	%*	n	%*	
Willing to be informed at school [a]	390	80.4	273	81.0	0.831
Willing to learn their carrier status [b]	347	73.4	260	76.2	0.351
Would change future plans in case of a risky situation [c]	293	65.7	266	80.6	<0.001

*The values are in column percentage of valid answers
**Calculated using Pearson's Chi-square test
[a] 55 missing data
[b] 63 missing data
[c] 101 missing data

Table 4. Factors affecting the status of being previously informed

Factors				95% C.I.for O.R.	
	B	p	O.R.	Lower	Upper
Education (middle school-high school)	0.259	0.102	1.296	0.950	1.768
Mothers' education level	**0.349**	**0.049**	**1.417**	**1.001**	**2.007**
Fathers' education level	0.026	0.878	1.026	0.736	1.431
Economic status perception	0.059	0.725	1.061	0.762	1.477
Presence of a patient around	**1.439**	**<0.001**	**4.215**	**2.640**	**6.731**

DISCUSSION

Our aim in this study was to emphasize the importance of raising knowledge and awareness about hemoglobinopathies beacuse insufficient knowledge and awareness are major obstacles in regards to prevention (6,7,8).As mentioned before both thalassemias and sickle cell anemia is prevalent in Adana (3,4).Therefore, we decided to conduct the study in Karataş, Adana which is in the Çukurova region of Turkey. By doing this, we aimed to measure the level of knowledge and awareness in a region where the disorders are common.Our results indicate that the lowest level of knowledge regarding hemoglobinopathies was about the transmission of the disorders. Only 13.7% of students knew that hemoglobinopathies were inherited disorders. This rate was even lower for students who had not been informed about hemoglobinopathies before. In a survey of high school students in Hatay in 2009, 18.5% of students with no previous education about hemoglobinopathies and 44.8% of students previously informed about hemoglobinopathies knew that the diseases were inherited (9). Later in 2016, a similar study conducted on 8th and 9th graders in Hatay reported that about 30% of the students could specify that hemoglobinopathies were inherited disorders (10). In a study conducted in Antalya between 1998 and 1999, 10.7% of 11th graders stated that thalassemia was a result of carrier marriage (11). Another study conducted on 8th graders in Burdur reported that over 80% of the students knew that thalassemia was not contagious (12). Although the rate seems higher in the Çatak et

al. study than in other studies, the question asked in the study was whether thalassemia was contagious or not, which may explain why the rate was higher. Except for the study conducted in Burdur, it would not be wrong to state that knowledge levels about the transmission of hemoglobinopathies in middle school and high school students in Turkey are low. Another remarkable finding in our study is that nearly two thirds of the students did not know that the consanguineous marriage was a risk for hemoglobinopathies. Similar findings were also found in two studies conducted in Hatay (9,10). This is particularly important in our country where consanguineous marriage is frequent. Consanguineous marriage is a risk factor for many genetic disorders, including sickle cell anemia and thalassemia (13,14,15). Consanguineous marriage rates in Turkey have been between 20% and 25% over the last 25 years (16). Taken together, the lack of knowledge about the transmission of the disorders and not recognizing consanguineous marriage as a risk, may obstruct the path to screening and health consultancy and hinder using preventive measures. We believe educational interventions regarding the genetic transmission of common inherited disorders are necessary, especially in regions where consanguineous marriages are frequent. In our study, previously informed students gave more accurate answers to questions regarding the level of knowledge about illnesses than previously uninformed students (see Table 2). A study conducted on university students in Kocaeli reported that there was an evident augmentation in knowledge level regarding hemoglobinopathies after an informative course (17). Likewise, a study conducted on risk groups in 2009 reported that, after an infotainment session, participants understood the genetic transmission of hemoglobinopathies (18). All these suggest that it is important to inform students to raise awareness about the disorders.In our study, when students' attitudes towards hemoglobinopathies were evaluated, the percentages of students who were willing to gain knowledge, establish whether or not they were carriers, and be alert to risky situations in the future were 80.7%, 74.6%, and 72.0%, respectively. The rates found in our study were slightly lower than those observed in two studies conducted in Hatay (9,10). The rate of previously informed students who stated that they would change their future decisions in case of a risky situation was significantly higher than those who were not previously informed. Likewise, in a study performed in Iran, it was found that the desired attitudes of high school students towards diseases were increasing with higher knowledge levels (19). It may be useful to include courses into schools' curricula regarding these diseases because it is a prerequisite to raise awareness among the public to develop preventive behaviors.Informing students about hemoglobinopathies plays a key role in both students' level of knowledge and positive attitudes. In this study, higher maternal education levels and existence of a known patient with hemoglobinopathy were found as independent factors that positively affected the status of being previously informed. Consistent with our findings, Miri-Moghaddam et al. also reported that as parents' educational level increases, the students' positive attitude level towards hemoglobinopathies became augmented (19). Similarly,(9) and (10) reported that the rate of students' being previously informed status were significantly higher in those who knew an affected person. The fact that positive attitudes of the students were augmented with higher maternal education levels suggests that educating mothers about the disorders may also be beneficial in raising the awareness of students.This study was conducted in a region where the disorders are prevalent. Also, all middle and high schools in Karataş were included in the study. However the study has some limitations. Since the data were collected using a questionnaire, memory factors may affect the responses to the questionnaires. Additionally, the carrier status of the students was not questioned.

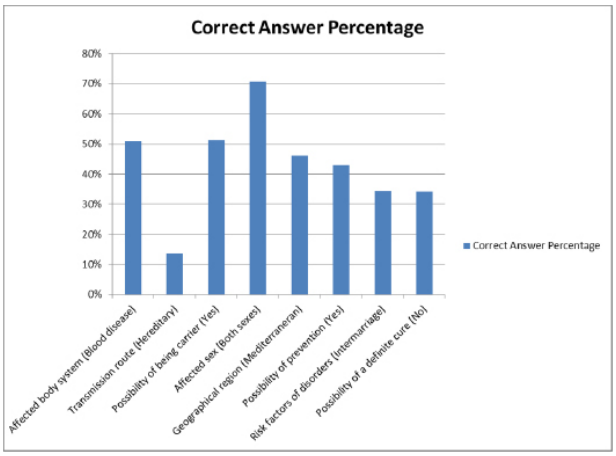

Chart 1. Students' accurate answer rates to questions about hemoglobinopathies

Limitations

This study only provides an idea about the awareness of students in Karataş, a district of Adana, and cannot be generalized. If a more appropriate sample representing Adana is selected, the representativeness will increase. In addition, the fact that a scale measuring knowledge or awareness about hemoglobinopathy was not used in the study causes limitations when interpreting the results.

CONCLUSIONS

The rate of correct responses of the participating students to questions about hemoglobinopathies varied between 13.7% and 70.8%. The subject they were least informed about was the transmission route of the disease, and the subject they were most informed about was that it could affect both genders. Students who had previously been informed about hemoglobinopathies gave a higher rate of correct responses. Students with a higher level of maternal education and those who knew about the existence of a person affected by the disease increased the likelihood of having been informed before. It may be recommended that training be planned on this subject in order to increase students' awareness of this issue.

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