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# High School Knowledge and Attitudes towards Thalassemia in Southeastern Iran

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#### **ABSTRACT**

**Objectives:** Thalassemia (thal) is the most single gene disorders in southeast of Iran. About one quarter of total Iranian new thal cases were born in the Sistan and Balouchistan province so the aim of this study is to assess knowledge level and attitudes towards thal in high school students in Zahedan, capital of Sistan and Balouchistan province in Iran.

Study design: cross- sectional descriptive survey

**Methods:** this study was conducted on 762 Zahedan high school boys and girls students in 2009. The structured questionnaires were completed by students which consisted of three parts, namely demographic characteristics, knowledge part by 20 multiple choice questions and attitude part by 9 questions.

**Results:** The results indicated that only 14.7 % students had good knowledge, good knowledge towards thal was 16.2% in boys and 29.1% in girls (P-value<0.001), positive attitude was 76.7% in boys and 84.7% in girls (P-value<0.029). Negative attitude in students who were born in villages and cities were 33.3% and 20.7% respectively (P-value=0.04). Good knowledge level in experimental field studied was between 2-4-fold more than other field students. Students in the last year high school had more knowledge and more positive attitude. Students' knowledge score had no significant relationship with father education level (P-value=0.11) but had considerable difference with mother educational level (P-value=0.03).

**Conclusions:** It is concluded that long term and target based programs are suggested for high school students and local population of Sistan and Balouchistan where the trend of family marriages is quite high. These programs would impart valuable education and improve knowledge of people towards that being couples in pre-marriage period and then after becoming parents thereby reducing the effects of disease.

Key words: Thalassemia; Student; Knowledge; Attitude; Education; Iran

## INTRODUCTION

Thalassemia (thal) is the most single-gene disorder in the world that results in a reduction or absence of globulin polypeptide chain synthesis and according to the affected chain type, divided into  $\alpha$ ,  $\beta$ ,  $\gamma$  and  $\delta$  thal. Thal disorder has more prevalence in countries which are located on thal band, tropical

and sub-tropical areas where malaria is or was endemic, such as Mediterranean, middle Asia, Central Asia, India and Southeast of Asia.<sup>2-4</sup> Iran was placed on thal band and has 25,000 major thal patients that receive blood regularly.<sup>5</sup> According to Iranian blood transfusion organization, about one-quarter of total blood donation has been used by thal patients.<sup>6</sup> Sistan and Balouchistan province, the

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largest province in Iran (about 191,785 km2), is located in southeastern Iran in a subtropical and malaria endemic area. So far, 2,500 major  $\beta$ -thal patients in Sistan and Balouchistan province have been registered by Iranian Blood Transfusion Organization (IBTO) which has become a major issue for Sistan and Balouchistan healthcare system. This province with a ratio of 1 to 27 of Iranian population hosts a high rate of about 25% of new cases of Iranian thaleach year.

Despite the efforts to develop a treatment protocol for thal patients based on gene therapy and bone marrow transplantation, so far, no effective successes have been achieved. These patients are blood transfusion-dependent for lifelong and conventional treatment involving blood transfusions and iron chelating is burdensome and highly expensive. Moreover, through blood transfusion, the risk of some complications may increase such as iron overload in different organs, alloimonuzation and transmitted infection through blood injection. <sup>6, 9, 10</sup>

In many countries where rate of thal incidences is quite high, strategies like knowledge improvement and educational courses, suitable screening and premarital diagnosis lead to a remarkable reduction in thal incidences. Following compulsory premarital screening and optional prenatal testing, from 2,000 to 2,007 there were no thal major births in Cyprus. 12

Prevention programs in Iran for controlling thal started from 1997 and some provinces have achieved remarkable success rate but in Sistan and Balouchistan province despite the significant number of prenatal diagnosis of thal (about 60-70) new affected thal patients are born every year. Thus, the level of knowledge and attitude about thal can help in reduction of such cases because today's youth (tomorrow's parents) with adequate information and awareness about diseases would overcome the effects on their matrimonial life. So the goal of this study is to assess knowledge level and attitudes towards thal in high school students in Zahedan, capital of Sistan and Balouchistan province in Iran.

#### MATERIALS AND METHODS

This cross- sectional descriptive survey was conducted on Zahedani high school students in 2009. The protocol was approved by the Ethical Committee in Deputy of Research in Zahedan Medical Sciences University; an agreement was also signed by all the education offices in the schools where the study was to be carried out. Similarly, written consents were received from all participants before this study.

The sample size was calculated using descriptive study formula with p=0.50 and d= 0.05 for which total 762 high school boys and girls were selected randomly (opportunity sampling technique). The structured questionnaires were completed by students which consisted of three parts, namely demographic characteristics, knowledge part by 16 multiple choice questions and attitude part by 9 questions (Table 1& 2). Knowledge towards thal level was calculated into scores by dividing the sum of the correct answers by the total items in each part. Knowledge score in weak, acceptable and good (correct response to be less than 33% of questions, between 33 to 67 % and more than 67% questions, respectively). Also, the attitude was assessed using 9 questions, (negative and positive attitude if the correct questions score were less than 50% and more than 50% correct scores). The content validity of the questionnaire was confirmed by a research team and its reliability was verified using test- retest methods. It is established using a pilot test by collecting data from 15 subjects. The Pearson's correlation for pre and post knowledge scores was 0.86, which is an acceptable scale (norusis 1993). Data analysis was performed by SPSS version 11 software and descriptive statistics were used with demographics characteristics, Chi-Square used to determine relationship between sex, field study, education level, ethnicity with knowledge and attitude towards thal, and P-value < 0.05 was considered statistically significant.

## **RESULTS**

We studied 762 selected Zahedani high school students, mean aged 16.9±0.8 years, amongst 377(49.5%) were males and 385(50.5%) were females. The rate of ethnicity groups among them

were 22.6 % Balouch, 49.3 % Sistani and 28.1% others. The consanguineous rates in students' parents were 50.9 %. Out of which, 70.2 % were Shiites and the remainder Sunnis.

The results indicated that 14.7 % students had good knowledge, 78.6% had positive attitude

towards thal. Knowledge score between boys and girls was significantly varying, good knowledge towards thal was 16.2% in boys and 29.1% in girls (P-value<0.05), positive attitude was 76.7% in boys and 84.7% in girls (P-value<0.05) (Table 3).

Table3. Knowledge and Attitude towards Thalassemia According to Students' Sex, Birth Place and Ethnicity in Zahedan High School Students in Southern Iran

		Knowledge				Attitude		
	weak	average	good	P Value	positive	negative	Р	
Sex								
Male	88(23.3)	252(66.8)	37(9.8)	<0.001	284(75.3)	93(24.7)	0.020	
Female	41(10.6)	269(69.9)	75(19.5)	<0.001	315(81.8)	70(18.2)	0.029	
Birth place								
City	118(16.4)	496(68.9)	106(14.7)	0.254	571(79.3)	149(20.7)	0.04	
Village	11(26.2)	25(59.5)	6(14.3)	0.251	28(66.7)	14(33.3)	0.04	
Ethnicity								
Balouch	26(15.1)	122(70.9)	24(14)		123(71.5)	49(28.5)		
Sistani	72(19.3)	256(68.4)	46(12.3)	0.111	299(79.9)	75(20.1)	0.00	
other	31(14.4)	143(66.2)	42(19.4)	0.111	177(81.9)	39(18.1)	0.03	

Negative attitude in students who were born in villages was 33.3% and 20.7% in population who were born in cities (P-value=0.04). Non local students (who were originally not from Sistan and Balouchistan) had more positive attitude as

compared to local students (P-value=0.03) (Table1). Good knowledge level in experimental field studied was 4-fold more than students who studied in technical field and 2-fold more than students in mathematical field (P-value<0.05) (Table 4).

Table4. Knowledge and Attitude towards Thalassemia According to Students' Field in Zahedan High School Students in Southern Iran

		Knowl	edge	Attitude			
	Weak	Average	Good	P value	Positive	Negative	P value
<b>Human sciences</b>	43(23.6)	127(69.8)	12(6.6)		141(77.5)	41(22.5)	
<b>Empirical sciences</b>	13(6.3)	130(62.5)	65(31.3)	<0.001	177(85.1)	31(14.9)	0.<001
mathematics	26(15.1)	123(71.5)	23(13.4)		143(83.1)	29(16.9)	
Technical sciences	47(23.5)	141(70.5)	12(6)		138(69)	62(31)	
total	129(16.9)	521(68.4)	112(14.7)		599(78.6)	163(21.4)	

Students in the last year high school had more knowledge and more positive attitude (P-value=0.001) (Table 5).

Table5. Knowledge and Attitude towards Thalassemia According to Students' Grade in Zahedan High School Students in Southern Iran

		Know	ledge	Attitude			
	weak	average	Good	P value	positive	negative	P value
Sophomore	55(19.6)	201(71.5)	25(8.9)		205(73)	76(27)	
Junior	43(15.3)	191(68)	47(16.7)	0.008	225(80.1)	56(19.9)	0.007
Senior	31(15.5)	129(64.5)	40(20)		169(84.5)	31(15.5)	
total	129(16.9)	521(68.4)	112(14.7)		599(78.6)	163(21.4)	

Students' knowledge score had no significant relationship with father education level (P-value=0.11) but had considerable difference with mother educational level (P-value=0.03). Students

whose mother had university degree had 25.2% good knowledge while students who had illiterate mother had 12.7% good knowledge. (Table 6, 7)

Table6. Knowledge and Attitude towards Thalassemia according to Father Student Education Level in Zahedan High School Students in Southern Iran

		Know	ledge	Attitude			
	weak	average	Good	P value	positive	negative	P value
Illiterate	10(18.2)	36(65.5)	9(16.4)		41(74.5)	14(25.5)	
Elemntry-highschool	26(11.3)	173(75.2)	31(13.5)	0.111	175(76.1)	55(23.9)	0.52
Diploma	57(21.3)	170(63.4)	41(15.3)		215(80.2)	53(19.8)	
University degree	36(17.2)	142(67.9)	31(14.8)		168(80.4)	41(19.6)	
total	129(16.9)	521(68.4)	112(14.7)		599(78.6)	163(21.4)	

Table7. Knowledge and Attitude toward Thalassemia according to Mother Student Education Level in Zahedan High School
Students in Southern Iran

	Knowledge				Attitude		
	weak	average	good	P value	positive	negative	P value
Illiterate	18(15.3)	85(72)	15(12.7)		83(70.3)	35(29.7)	
Elemntry-highschool	53(16.6)	224(70.2)	42(13.2)	0.03	254(79.6)	65(20.4)	0.11
Diploma	37(18)	144(69.9)	25(12.1)		165(80.1)	41(19.9)	
University degree	21(17.6)	68(57.1)	30(25.2)		97(81.5)	22(18.5)	
Total	129(16.9)	521(68.4)	112(14.7)		599(78.6)	163(21.4)	

#### **DISCUSSION**

Our result showed that more than half (68.4%) of our sample study had acceptable knowledge (average) and positive attitude (78.6%) towards thal. So with this basic knowledge and attitude we can be hopeful to have effective programs to control thal in Sistan Balouchistan with focus on pre-marriage couples (these students would be future couples). According to the Romeo study, the most important reason of thal new incidences was weak knowledge of pre-marriage couples in Cecil and reported increase in knowledge and attitude of health personnel were effective prevention. 13 According to Shrivastava, due to positive attitude towards thal, the majority of responders believe that the birth of a thal child was not because of sins that committed by parents.<sup>14</sup> Therefore, the prevalence of such stigmatization between Sistani Balouchistani, improves the knowledge and attitude which would be wrathful for thal control.

Knowledge and attitude of students in the different field study have significant variation. Students who studied in experimental field have the most knowledge and positive attitude about thal. In Afshinnia study, mostly girl students who studied at experimental field had good knowledge about thal in Ghazvin city.15 Therefore, according to our results, knowledge about disease is more in students who essentially learn and pass these courses, teaching and promotion this kind of courses amongst other high school fields and also non-medicine field at university in the high prevalence of thal is essential. Also, results showed that students in senior level had more knowledge and also more positive attitude. In some courses students gain knowledge related to the content of their books, but some of the other courses increased awareness of students increased with increasing age students, because of their ability to use books and media and social communication. It seems necessary to supplement the annual Thalassemia-related pamphlets to be distributed in schools. In agree with our results, Afshinnia and Hajian founded that increase in educational level of students leads to more significant increase in knowledge about disease nature and prevention. 15, 16 Pauisri in a study, stated that people with higher level of education are more likely to undertake self-care than those with lower level.<sup>17</sup> Since most marriages in Sistan and Balouchistan take places in younger age so continuous educational program in different level of student education is considered important. Broad educational activity in different way such as classes in their local places with local language of that area population, broadcast educational film in a place that local people mostly gather to speak or rest such as tea-shop or holly places that they gather for religious prayers, may have deep effects on their knowledge and attitude. Paholpak in a study suggested, video / audio lectures and pamphlets to improve patient's awareness. 18 Shukr in a study to examine parent knowledge about genetic transmission before and after educational videos, concluded that such videos may prove to be an effective tool in educating the population.<sup>19</sup>

Also, the results indicated that there is a significant difference between attitude and ethnicity so that students who were not originally Sistani and Balouchi have more positive attitude, therefore weak attitude may be one of the reasons that about 90% patients in this province are from Balouchpopulation. 8, 20 According to Ahmed, religion has a significant impact on decision about screening.<sup>21</sup> Wong states that because of a complex web of moral, cultural and traditional religious values of family and community, termination of pregnancy is not consideration among Asian. He also added that there are ethnic differences regarding termination of fatuous affected by thal major. He added that the Malays in comparison with Chinas and Indians support lesser the termination of fatuous.<sup>22</sup>

We found while students' knowledge and attitude has no significant relationship with their father level education but on the other hand it has a significant relationship with their mother education level. Ghazanfari in a study evaluated the needs of thal children mothers are more than father and explains because mothers feel more responsibilities so they seek more for data and the relationship between education, awareness and educational needs was significant.<sup>23</sup> Mother, who had more educational level, had more knowledgeable and more positive attitude towards thal. In Afshinnia study, with the increase in parents' educational level, the students' level towards thal becomes increased. 15 Khin in a study, low parental awareness and attitudes about thal introduced the main obstacle to preventing the disease.<sup>24</sup> Tochina in his study shows that parents' attitudes change by face to face training and their confidence was increased<sup>25</sup>

Conclusively, to improve knowledge and suitable attitude towards thal amongst high school students who will be future parents, more education and knowledge improvement programs are suggested for them, also for couples who are in pre-marriage period. Since Sistan and Balouchistan family marriage and also some believes about disease are more prevalent, so long term and target based program for these local population is essential.

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# **Table1. Awareness Questions**

Awareness Question	Yes	No	Doesn't know
1. Is thalassemia a hereditary disease?			
2. Is thalassemia a blood disease?			
3. Does thallasemia happen after malnutrition?			
4. Do the face and shape of major thalassemia change?			
5. Do consanguineous marriages have any role in incidence of thalassemia?			
6. Can thalassemia recognized by blood test?			
7. Is thalassemia predictable?			
8. Is premarriage consultation useful for refuse of a newborn with thalassemia?			
9. Is pre-marriage consultation the only way to prevent the thalassemia incidence?			
10. Is there any way to recognize major thalassemia in fetus?			
11. Does minor thalassemia recognition have any role in			
prevention of major thalassemia?			
12. Does minor thalassemia have any special sign or symptom?			
13. Does minor thalassemia curable?			
14. Can two people with minor thalassemia marry with each other?			
15. Does a marriage between a healthy person and a carrier lead to a major thalassemic child?			
16. Do thalassemia patients need blood transfusion in all of lifetime?			

**Table2. Attitude Question** 

Attitude Question	Yes	No	Doesn't know
1. Do you like to a relationship with a thalassemic person?			
2. Do you visit a consultant before marriage?			
3. Do you take necessary blood test before marriage?			
4. If after test you understand your favorite person has minor thalassemia, do you still want to marry with him/her?			
5. Do you like to donate your blood for thalassemia patients?			
6. If there was a major thalassemia patient in your family, and you are the only chance for bone marrow transplantation, do you like to do it?			
7. Do you accept the probability of a thalassemic child just because of a family marriage?			
8. If both parents have minor thalassemia and in pregnancy period and before soul inspiration, you understand the fetus is affected thalassemia, do you agree with medical abortion?			
9. If you were a major thalassemia patient, did you like to cooperate with consultation center for consulting with thalassemia patients?			