ORIGINAL ARTICLE

Awareness, Attitude and Knowledge about Thalassemia among Students of Different Disciplines

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ABSTRACT

Objective: This study was conducted to determine awareness, attitude, and knowledge about thalassemia among the students of urban educational institutions of Rawalpindi/Islamabad.

Study Design: A cross sectional study.

Place and Duration of Study: Institutions of Rawalpindi and Islamabad from December 2018 to June 2019.

Materials and Methods: There were four major groups of students, which included newly inducted Medical students, FSC. students, Engineering students and students of Biomedical Sciences. A questionnaire consisting of 20 YES/NO responses and 6 multiple choice questions was given. SPSS 23.0 software was used for analysis of data using frequency and chi-square tests and $p<0.05$ was considered statistically significant.

Results: Among the 500 subjects recruited in this cross-sectional study, a total of 434(86.8%) had some idea about thalassemia. The p-value was less than 0.05 ($p<0.05$) The range of percentage of correct answers was between 35.6% (about iron rich diet) and 95.2% (about the affected cells). The attitudinal patterns of all the students towards thalassemia revealed that 93.2% students wanted to be informed about the disease at their respective institution. 90.6% were willing to learn their carrier status and 91.4% were ready to amend their future in case of risky prospects.

Conclusion: The awareness regarding the general aspects of thalassemia is reasonably sufficient among the students in urban educational institutions of Rawalpindi/Islamabad, there is some level of disparity in the degree of knowledge between different groups of students. There is need of sessions based on knowledge of thalassemia among non-medical students also.

Key Words: *Thalassemia, Awareness, Gene Disorder, Prevention, Premarital Screening.*

Introduction

Thalassemia is the most widespread hemoglobinopathy worldwide affecting about 5% of total population of world with gene frequencies ranging from 2.5% to 16.2%.[1,2] Worldwide there are about 240 million carriers and about 200,000 – 400,000 infants are born with severe disease annually.[3,5]

It is most common in the areas of Africa, Southeast Asia, Equator, Mediterranean, the Middle East, Central Asia, Southern China, Far East as well in South America. The maximum carrier frequency was found in Cyprus (14%), Sardinia (10.3%) and Southeast Asia (1-9%).[4,6,7]

The term thalassemia originated from the Greek, thalassa(sea) and haima (blood).[6] Thalassemia is an inherited disorder resulting from either the absence or reduced synthesis of alpha (α) or beta (β) globin chains that are integral components of Hemoglobin[2,7] an oxygen carrying protein in red blood cells (RBCs).

It is an autosomal recessive disorder and is categorized as α or β thalassemia based on the type of globin chain affected. β thalassemia is further classified as thalassemia major or minor.[7] β thalassemia occurs due to a defect in the autosomal chromosome 11. It is thalassemia major if both the copies of this chromosome are affected and if only one copy is affected it is thalassemia minor.[8]

The affected and carrier population varies in different countries. Malaysia has about 4.5% carrier frequency with 2.1 affected births out of 1000 annually with 5600 transfusion dependent patients.[3] In Turkey carrier frequency is about 4.3%.[4] Egypt has 9-10% carrier frequency with approx. 1000 out of 1.5million annual thalassemic births.[9] Netherlands

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Funding Source: NIL; Conflict of Interest: NIL
Received: August 08, 2019; Revised: May 01, 2021
Accepted: May 04, 2021

has got 140,000 carriers.[10] In Thailand, about 40% are carriers, while 1% of the population is afflicted with this disease.[11] Thalassemia gene in different regions of India varies from 1 to 17% with a mean prevalence of about 3.3%.[12] Iran has approximately 3,750,000 carriers and 20,000 persons with a diagnosis of beta thalassemia major (b-TM).[13]

In Pakistan, thalassemia is the most common inherited single gene disorder causing serious health issues.[14] The carrier frequency is about 5-8% that are more than 9 million. At present time Pakistan has 100,000 estimated cases of thalassemia, which makes up almost 5% of the total cases of the world and each year nearly 5,000-9,000 affected children are born in the country [7,15,16]

There is no therapeutic cure for thalassemia, WHO introduced control program consisting of general public awareness, screening and genetic counseling to avoid affected births.[4,17] Different countries initiated these programs and remain successful. Fortunately no thalassemic baby has been born in Cyprus since 2001.[17] Sardinia has reduced the birth rate of thalassemia major from 1:250 live births to 1:4000.[4]

The disease can only be prevented through proper screening, awareness, public enlightenment about disease and genetic counseling. Blood analysis and electrophoresis is used to identify carriers.[6,7] Lack of awareness and knowledge only fuels the increase in prevalence Of this disease.[4]

In this study, we wanted to explore the knowledge of FSc, Biomedical, Newly inducted Medical and Engineering students about thalassemia in Islamabad and Rawalpindi. Our aim was to assess the level of awareness to determine awareness, attitude, and knowledge about thalassemia among the students of urban educational institutions of Rawalpindi/Islamabad.

Materials and Methods

This was a cross sectional study aiming to gauge the knowledge and attitude about thalassemia among undergraduate students in the institutions of Islamabad and Rawalpindi conducted from December 2018 to June 2019. There were four major groups which included newly inducted Medical students, FSC students, Engineering students and students of Biomedical Sciences. A total of 500 students took part in this study. Out of which 200 of them were in their 1st year of MBBS, 100 each from FSC, Biomedical sciences and Non-Medical Undergraduates in which there were equal numbers of males and females and the average age of the subjects was around 19 years.

The data from newly inducted Medical students was collected from Rawalpindi Medical University (RMU), Islamabad Medical and Dental College and HBS Medical College. The F.SC. students were from OPF College for boys H-8/4 and Islamabad Model College for Girls G-10/4, Islamabad. The Non-Medical Undergraduates and biomedical students were from COMSATS and FAST university.

A questionnaire consisting of 20 YES/NO responses and 6 multiple choice questions regarding the disease and their attitude towards it was applied to gather data. We did not give any knowledge regarding Thalassemia while collecting data and we ensured that Medical students had not yet studied thalassemia in their curriculum as well. The data analysis was done using SPSS software and results were analyzed with frequency and chi-square tests and $p<0.05$ was statistically significant.

Results

Among the 500 subjects recruited in this cross-sectional study, a total of 434(86.8%) had some idea about thalassemia. A significant relationship between the student's academic field and their awareness regarding this disease was observed ($p<0.05$, table I). However, only 182(36.3%) students had ever seen a thalassemic patient and 36(7.2%) had a family member suffering from the disease.

Table I: General Perspective about Thalassemia

	TOTAL (N=500) [a]	MBBS STUDENTS (N=200) [a]	Non-Medical Undergraduates (N=100) [a]	F.SC (N=100) [a]	BIOMEDICAL (N=100) [a]	*p*-value
Any idea about Thalassemia	434(86.8%)	188(94%)	65(65%)	84(84%)	97(97%)	.00
Seen any Thalassemic patient.	182(36.3%)	68(43%)	31(31%)	22(22%)	61(61%)	.00
Anyone in family who suffered from Thalassemia.	36(7.2%)	18(9%)	9(9%)	4(4%)	5(5%)	.294

[a]The values are in n (%)

The level of awareness regarding the general facts about thalassemia and its complications was checked after classifying students into their respective groups. In totality, 94.8% of the students knew about the body system affected by the disease and 95.2% knew about the cells affected by it.

Moreover, 89% knew that it has a genetic mode of transmission while 88.8% were aware that cousin marriages are a risk factor in causing thalassemia. Only 39.6% students understood that it is not curable, 72.4% said that it is preventable, and 67.2% students understood that both genders have an equal risk of being affected. Regarding the relationship of iron rich diets with thalassemia, a general perception among 64.4% of the total subjects responded that iron rich diets are beneficial for thalassemic patients. Table shows the total frequency of correct responses by students of different groups along with their p values. The table also shows the expected and observed counts of the correct answers, indicating an obvious disparity between the two.

Table II: Correct Student's Responses

Question Subject	TOTAL (N=500) [a]	MBBS STUDENTS (N=200) [a]	Non-Medical Undergraduates (N=100) [a]	F.SC (N=100) [a]	BIOMEDICAL (N=100) [a]	p-value
Body system	474(94.8%)	197(98.5%)	89(89%)	89(89%)	99(99%)	**.003**
Affected cells	476(95.2%)	197(98.5%)	86(86%)	93(93%)	100(100%)	**.00**
Affected gender	336(67.2%)	128(64%)	71(71%)	79(79%)	58(58%)	**.00**
Transmission	445(89%)	193(96.5%)	71(71%)	85(85%)	96(96%)	**.00**
Risk factor	444(88.8%)	187(93.5%)	73(73%)	89(89%)	95(95%)	**.00**
Preventable	362(72.4%)	139(69.5%)	79(79%)	73(73%)	71(71%)	.371
Curable	198(39.6%)	98(49%)	22(22%)	28(28%)	50(50%)	**.00**
Blood transfusion is important	455(91%)	197(98.5)	74(74%)	85(85%)	99(99%)	**.00**
Iron rich diet	178(35.6%)	82(41%)	25(25%)	34(34%)	37(37%)	.054
Long life span	440(88%)	177(88.5)	89(89%)	87(87%)	87(87%)	.954

[a] The values are in n(%)

A total of 121(24.2%) students in the entire sample had attended a discussion or awareness seminar about thalassemia before this study was conducted and the remaining 379(75.8%) had never been to any such event. Among those who had been previously informed, 32% were MBBS undergraduates, 10% were enrolled in some non-medical graduation program, 11% were FSC students and 36% were students of Biomedical sciences as shown in table III. Another significant relationship was observed between the aforementioned academic fields of the students and their status of being previously informed with a p value of less than 0.05 as reported in table. Surprisingly, no significant relationship was recorded between the awareness of subjects after attending seminars/discussions on thalassemia and the frequency of blood donations among them. (P>0.05) as shown in table IV.

Table III: Students Who Attended Awareness Sessions Previously

Did you ever hear or attend any discussion or awareness talk regarding Thalassemia in your school?				Total	
		Yes	No		p-value
Subject's Qualification	1st Year MBBS student	64	136	200	
	Non-medical Undergraduate	10	90	100	
	Intermediate Student	11	89	100	.000
	Biomedical Undergraduates	36	64	100	
Total		121	379	500	

Table IV: Relationship Between Blood Donation and Previously Informed Students

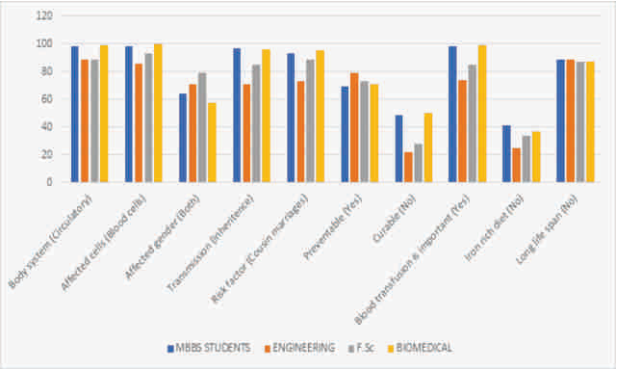
		Have you ever donated blood for a Thalassemic patient before?		Total	
		Yes	No		P-value
Did you ever hear or attend any discussion or awareness talk regarding Thalassemia in your school?	Yes	8	113	121	
	No	28	351	379	.774
TOTAL		36	464	500	

Queries associated with the attitudinal patterns of all the students towards thalassemia revealed that 93.2% students wanted to be informed about the disease at their respective institution. 90.6% were willing to learn their carrier status and 91.4% were ready to amend their future plans in case of risky prospects.

Table V: Attitude and Behavioral pattern of Students Regarding Thalassemia.

	TOTAL (N=500) [a]	MBBS STUDENTS (N=200) [a]	ENGINEERING (N=100) [a]	F.SC (N=100) [a]	BIOMEDICAL (N=100) [a]	p-value
Willing to be informed at college/university	466(93.2%)	190(95%)	87(87%)	92(92%)	97(97%)	.022
Willing to learn their carrier status	453(90.6%)	187(93.5%)	86(86%)	89(89%)	91(91%)	.189
Willing to change future in case of risky situation	457(91.4%)	183(91.5%)	86(86%)	94(94%)	94(94%)	.143

[a] The values are in n (%)



Discussion

This study began in the light of the fact that there is a high prevalence of thalassemia in rural and urban areas of Pakistan. An estimated 5000-9000 children are born with β-thalassemia in Pakistan. This shows a carrier frequency of 5-8% i.e. 9.8 million people in an approximate population 180 million.[2,15] To unravel the causes of this occurrence, awareness of young individuals was checked regarding the disease, its complications, transmission, risk factors, prevention and treatment.

We found that even though the awareness regarding the general aspects of thalassemia was reasonably sufficient among the students in urban educational institutions of Rawalpindi/Islamabad, there was some level of disparity in the degree of knowledge between different groups of students that were analyzed separately.

Even though about 86.8% of the subjects said that they had heard or had some idea about thalassemia, only 24.2% of them had actually attended a discussion or an awareness seminar about it. In a similar study conducted on students at Antioch in Turkey, 37.3% students had been previously informed about thalassemia.[17] Regarding the characteristics of thalassemia, 89% of the participants knew that this disease has hereditary mode of transmission and 39.6% gave the correct answer about its cure and 72.4% that it is preventable. These findings are comparable to the research carried out in Antioch where 82% of the previously informed students knew about the mode of transmission, only 37% gave correct answers about treatment and 60.7% knew that it is preventable.[18]

According to a research, Iron Overload in Beta Thalassemia Major and Intermedia Patients, 87.4% of thalassemic patients showed high ferritin (a protein used store iron and indicate iron levels in the body) levels.[19] In our study when asked if iron rich diets are helpful for thalassemic patients only 35.6% of the total participants responded correctly.

Moreover, a significant disparity was observed between the level of knowledge about the disease and the academic courses of the subjects. Students enrolled in medical programs i.e. MBBS and bioscience scored higher than those enrolled in non-medical programs which is comparable to a study carried out on 1st and 2nd year medical students to assess the knowledge and attitude towards thalassemia in Delhi where 75.25% of the participants had good knowledge about thalassemia.[20] Another study carried out by Mirza A in Pakistan on Thalassemia and premarital screening at non-medical universities showed that only 54.5% of the students had ever heard about beta thalassemia.[21]

The attitudinal patterns of students towards thalassemia were observed to be well above satisfactory and sufficient. 93.2% students stated that they would like to be informed about thalassemia at their college/university. 90.6% were willing to know about their carrier status checked and 91.4% agreed to change their future plans in case of a risky situation. These results are higher than other studies. 87% students wanted to be educated on hemoglobinopathies at their school in a study carried out on young students in Turkey.[4] In the same study, 81.6% students wanted to learn about their carrier status and 70.4% said that they were willing to change their future decisions in case these diseases could harm them or their families. In a study in Antioch, Turkey 89.1% participants also wanted to know about their carrier status.[17]

Conclusion

The awareness regarding the general aspects of thalassemia is reasonably sufficient among the students in urban educational institutions of Rawalpindi/Islamabad, there is some level of difference in the degree of knowledge between different groups of students. There is need of sessions based on knowledge of thalassemia among non-medical students also. Although awareness was quite sufficient but there is still high prevalence in the country that refers the need of study and awareness in rural areas of the country

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