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Awareness Regarding Thalassemia in General Population of Rahim Yar Khan, Pakistan

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ABSTRACT

Background: *Thalassemia, an inherited blood disorder represents a significant burden for many countries across the globe and the knowledge related to this illness is very limited. The preventive practices, among people especially from developing countries. In Pakistan, Thalassemia is a serious health problem bearing 5 to 8% frequency of beta-Thalassemia gene without discrimination of ethnic groups.* ***Objective:*** *To assess the awareness level regarding Thalassemia in general population of Rahim Yar Khan, a district of Southern Punjab, Pakistan.* ***Methodology:*** *Study Design: Cross sectional study. A total of 400 adults of 18 years and above age, were selected randomly, from the households of the Rahim Yar Khan City and one Rural Union council. Out of 400 subjects, only 131, reported that they had heard the name "Thalassemia", hence for analysis of awareness, the data of only these 131 was used. A structured questionnaire was designed which included information on; gender, age and 24 questions about awareness of Thalassemia disease. Level of Awareness was ascertained by response of these 24 questions and was categorized as poor, average and good. The persons answering less than 12 questions correctly were considered to have poor knowledge, answers of 13-18 questions were labeled as possessing average knowledge and the persons were included in category of having good knowledge who answered more than 18 questions correctly. Data was analyzed by using SPSS 20.* ***Results:*** *Out of 131 study subjects , who reported to have ever heard of word Thalassemia, level of awareness about Thalassemia was found to be "Good" among 7 (5.4%) persons, 27 (20.6%) persons have an average knowledge about Thalassemia and a large number of people 97 (74%) have poor knowledge about Thalassemia disease.* ***Conclusion:*** *Public knowledge regarding Thalassemia was found to be poor among general population of Rahim Yar Khan, Pakistan.*

Keywords: Thalassemia, Awareness, Public, Rahim Yar Khan, Pakistan

INTRODUCTION

The term "Thalassemia" shares the greek roots of thalassa for "sea" and haima for "blood." Thalassemia is a diverse group of genetic blood diseases, characterized by absent or reduced production of normal hemoglobin, resulting in microcytic anemia of varying degrees [1]. This disease leads to a significant decrease

in the synthesis of one or more globin chains [2]. It is a growing public health problem around the world and the number of births with clinically significant Thalassemia disorder expected to occur in the next 20 years up to 9,00,000. This disease is classified into the alpha and beta groups, depending on the type of diminished globin chain and is transmitted as an autosomal recessive pattern [3]. When two carriers of the Thalassemia gene (Thalassemia carriers) marry, in every pregnancy there will be 25% chance of Thalassemia Major Child, 25% of normal healthy child and 50% of Thalassemia career. About 240 million people worldwide are heterozygous for beta-Thalassemia (Thalassemia carriers) and approximately 2,00,000 homozygotes (transfusion-dependent Thalassemia) are born each year [3].

The lack of awareness about Thalassemia in Pakistan, results in 5,000 transfusion-dependent Thalassemia (TBD) births every year, the reason behind is the presence of 9 million β-Thalassemia carriers. Currently, around 1,00,000 Thalassemia cases have been reported in Pakistan, representing 5% of the world's total cases [4]. β-Thalassemia is a major problem in Pakistan, with a carrier rate of 5 to 8%. Factors such as high gene frequency, consanguine marriages, high birth rate, population size and low literacy rates are the risk factor for the high incidence of β-Thalassemia and are responsible for the largest number of children with Thalassemia-dependent transfusion in the world [5].

The economic and social cost of the disease is high because the patient of Thalassemia major needs monthly or twice monthly blood transfusion and iron chelation treatment [6]. It was noted that the majority of mothers with Thalassemia trait were unaware of their carrier status and gave birth to Thalassemia major children [4]. Thalassemia has been successfully controlled in many countries, such as Iran, Greece, Italy and Cyprus, launching education campaigns, awareness programs and highlighting its preventive measures. Therefore, it is necessary to make people aware of these difficulties [4,6]. Current study was conducted to assess the level of awareness about Thalassemia among the general population of Rahim Yar Khan, Pakistan so that Thalassemia awareness programs can be amended to increase the level of awareness. It is an effort to make a Thalassemia free Pakistan.

METHODS

Study Design

It was a cross sectional study.

Inclusion Criteria

Adults of 18 years and above of both genders, present at their homes at the time of data collection.

Exclusion Criteria

Non willing study subjects and person of any medical specialty or parents of known Thalassemia child were excluded from the study.

Sample Size

A total of 400 individuals of both genders were included randomly, in the study from households of urban and rural areas of Rahim Yar Khan and level of awareness was assessed only among those subjects who knew or heard the disease Thalassemia.

Duration of Study

Eight months from June 2018 to January 2019. Level of Awareness was ascertained by asking 24 questions and was categorized as poor, average and good. The persons answering less than 12 questions correctly were considered to have poor knowledge. Answering 13-18 answers correctly were measured of having average knowledge. The persons were considered to have good knowledge who answered more than 18 questions correctly. Ethical approval was sought from Institutional Review Board. The results were analyzed by SPSS version 20.

RESULTS

Out of 400 study subjects, only 131 (32.8%) have ever heard of Thalassemia, hence data of only these study subjects was used for further knowledge analysis. The age spans of the subjects were from 18 years to 75 years. Out of total 400 study subjects, 62 persons (15.5%) were less than 25 years of age, 264 (66.0%) were in range of 25-45 years, 72 persons (18.0%) were 46-65 years and only 2 (0.5%) were above the age of 65 years. Out of 400, 242 (60.5%) were males and 158 (39.5%) were females.

In present study, out of 400, 270 study subjects (67.5%) belonged to urban area. The subjects were chosen randomly and out of these 400 subjects 39 (9.8%) were illiterate (those who can't even write and read their own name), 87 (21.8%) were of primary to middle educational level, 130 (32.5%) have done Matriculation and 144 subjects (36.0%) were possessing education above Matriculation. Out of 400 study subjects, 124 (31%) were house wives, 115 (28.8%) government servants, 50 (12.5%) labourer, 16 (4%) students, 53 (13.3%) businessman, 32 (8%) were farmers and 10 (2.5%) were unemployed.

Majority of people even did not know or heard about Thalassemia disease 258 out of 400 (64.5%). Only 131 (32.8%) study subjects heard or knew about Thalassemia disease and were further studied. Many people did not know that Thalassemia is a genetic disorder 80 out of 131 (61%) and a blood born disease 53 out of 131 (40%). People thought that it is an environmental transmitted infection which spread from food 45 out of 131(34.4%). They didn't know that it can be detected during pregnancy 93 out of 131 (70.99%) and they did not want to abort pregnancy even if it is diagnosed with Thalassemia 70 out of 131 (53.4%). They are also devoid of knowledge that either repeated transfusion could harm the child 86 out of 131 (65.6%) or iron Chelation therapy is needed to minimize iron overload after repeated blood transfusion 84 (64%) (Table 1).

Table 1 Responses to questions for assessment of Thalassemia awareness

Serial No.	Questions	Yes	No			Total
1	Have you ever heard of Thalassemia?	131 (32.8%)	269 (67.25%)			400 (100%)
2	From where you knew about Thalassemia?	Newspaper	TV	Lecture	None	Total
		11 (8.4%)	20 (15.3%)	22 (16.8%)	78 (60%)	131 (100%)
3	Do you have ever seen any thalassemic child?	Yes	No	I don't know		Total
		24 (18.3%)	85 (64.9%)	22 (16.8%)		131 (100%)
4	Do you think Thalassemia is a genetic disease?	37 (28.2%)	14 (10.6%)	80 (61%)		131 (100%)
5	Do you think it is a blood born disease?	69 (52.6%)	9 (6.8%)	53 (40.0%)		131 (100%)
6	How many types of Thalassemia are?	One	Two	Three	I don't know	Total
		4 (3%)	4 (3%)	3 (2.3%)	120 (91.6%)	131 (100%)
		Yes	No	I don't know		Total
7	Can a normal person have Thalassemia minor gene?	18 (13.7%)	28 (21.4%)	85 (64.8%)		131 (100%)
8	Do you have Thalassemia minor gene?	14 (10.6%)	65 (49.6%)	52 (39.69%)		131 (100%)
9	Could a child be thalassemic if one of the parent has Thalassemia minor gene?	78 (59.5%)	7 (5.3%)	46 (35.1%)		131 (100%)
10	Should a normal person marry with a Thalassemia carrier?	41 (31.3%)	25 (19%)	65 (49.6%)		131 (100%)
11	Do you think Thalassemia spread through food/eatables?	46 (35.1%)	40 (30.5%)	45 (34.4%)		131 (100%)

12	Do you think repeated blood transfusion is the only way of survival for a thalassemic child?	47 (35.9%)	25 (19%)	59 (45%)		131 (100%)
13	Does Thalassemia carrier need any kind of treatment?	31 (23.6%)	18 (13.7%)	82 (62.6%)		131 (100%)
14	Do you think presence of Thalassemia can be detected during pregnancy?	25 (19.0%)	13 (9.9%)	93 (70.99%)		131 (100%)
15	If the fetus is diagnosed with Thalassemia, one should carry the pregnancy or abort it?	25 (19.0%)	70 (53.4%)	36 (27.5%)		131 (100%)
16	Is there any prevention for Thalassemia?	80 (61%)	13 (10%)	38 (29.0%)		
17	Do you think Govt. should use electronic or print media for Thalassemia awareness?	103 (78.6%)	3 (2.3%)	25 (19%)		131 (100%)
18	Do you think a screening test of Thalassemia should be performed on both male and female before marriage?	73 (55.7%)	12 (9.1%)	46 (35.1%)		131 (100%)
19	Is there any permanent solution for Thalassemia?	35 (26.7%)	16 (12%)	80 (61%)		131 (100%)
20	If it is, then what it should be?	Bone marrow transplant	Gene therapy	Repeated blood transfusion	I don't know	Total
		7 (5.3%)	3 (2.3%)	12 (9.1%)	109 (83.2%)	131 (100%)
21	Is there any risk on repeated blood transfusion?	Yes	No	I don't know		Total
		24 (18.3%)	21 (16%)	86 (65.6%)		131 (100%)
22	Should iron chelating therapy be advised to a thalassemic child?	16 (12.2%)	31 (23.6%)	84 (64%)		131 (100%)
23	Is there any precaution/avoidance for some specific eatables? (iron containing food)	22 (16.8%)	50 (38%)	59 (45%)		131 (100%)
24	Do you have ever donated blood to a thalassemic child?	10 (7.6%)	121 (92.4%)			131 (100%)

Regarding Level of awareness, 27 (20.6%) people had average knowledge about Thalassemia, 7 (5.4%) people out of 131 had a good knowledge about Thalassemia and a large number of people 97 (74%) had poor knowledge regarding Thalassemia disease. It was alarming that out of 400 study subjects 269 (67.25%) did not knew or heard about Thalassemia disease (Table 2).

Table 2 Awareness level among general population of district Rahim Yar Khan

Awareness Level	Frequency	Percentage (%)
Poor (<12 questions)	97	74
Average (13-18 questions)	27	20.6
Good (≥ 19 questions)	7	5.4
Total	131	100

DISCUSSION

Prevalence of a disease has a close relation with the level of awareness of the disease in a community. The current study was conducted in the general population of district Rahim yar Khan, Pakistan to assess the level of awareness about Thalassemia. The level of awareness average to good was only 26% among those who have ever heard name of Thalassemia. Only 7 (5.4%) persons out of 131 had good knowledge about Thalassemia, 27 (20.6%) persons out of 400 had average knowledge about Thalassemia. This knowledge was insufficient as compared with the study conducted in Bahrain by Al Arrayed, et al. [7]. In that study conducted in Bahrain about level of awareness about Thalassemia, questionnaires from two thousand study

subjects were received; nevertheless, not a single person answered all the questions. One thousand two hundred and ninety-seven (65.1%) just heard of beta Thalassemia and 809 (40.5%) knew that both parents should have to be carriers for birth of an affected child [7]. The study by Patel AP et al., in western India on factors influencing awareness of beta-Thalassemia, all the participants knew that beta-Thalassemia can affect both male and female genders equally. Correct responses to various questions varied from 6.5 % to 45.2 %. The participants with a positive family history or who were already tested for beta-Thalassemia had significantly more knowledge ($p<0.0001$), but even participants with first-degree relatives of beta-Thalassemia major did not have complete knowledge. Age and gender had no impact on disease prevalence while education influenced on certain aspects [8]. A study by Behera, et al. revealed an interesting note that almost all of the educated Bengalee had heard the term 'Thalassemia' [9]. This is in contrast to our study, where only 131 (26%) have ever heard of word Thalassemia. In that study, this was true for both genders. They also knew the symptoms of this disorder. But regarding mode of inheritance and relation of this disorder with blood, the females outnumber the males and 74.17% of the females and 67.89% of the males knew that Thalassemia is an inherited disorder [9]. The awareness of Thalassemia in present study was more as compared to the study conducted by Basu Mausumi in Kolkata. In their study only 14.02% people had good knowledge about thalassaemia [10]. Low awareness level is the cause of prevalence of disease. Study conducted by Muhammad Bilal Ghafoor the author of this study, on awareness of Thalassemia among parents of Thalassemia children in 2016 demonstrated that even parents of these suffering children have very poor knowledge regarding Thalassemia (15%) [4]. Another study of Fozia Ishaq at Sir Ganga Ram Hospital Lahore, Pakistan showed only fifty- two parents (44.6%) out of 230 knew Thalassemia is an inherited disorder. Thirty-eight (33%) had heard about the test for detecting Thalassemia carrier, is responsible for limited knowledge regarding Thalassemia [11]. Study conducted in Iran by Moghaddam, et al. among high school students which also projected the image of low basic knowledge regarding Thalassemia. The results indicated that only 14.7% students had fair knowledge about Thalassemia. It was 16.2% among boys and 29.1% among girls [12].

CONCLUSION

It was concluded that knowledge regarding Thalassemia among general population in Rahim Yar Khan, Pakistan is insufficient. Public educational campaigns and Thalassemia awareness programs should be organized and practiced in cultural, teaching and religious belief sites. Public health massages through electronic and print media should be spread to clear the misconceptions. The screening of Thalassemia carriers and pre-natal diagnosis should be emphasized. Observing all these measures will ultimately reduce the prevalence of this fatal disease.

DECLARATIONS

Conflicts of Interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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