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ASSESSMENT OF THALASSEMIC CHILDREN' PARENTS KNOWLEDGE REGARDING THALASSEMIA

Sehrish Naz[1], Anayat Jan[2], Shabnam[3]

ABSTRACT

OBJECTIVES

To assess the thalassemic children's parents' knowledge level regarding Thalassemia.

METHODOLOGY

A cross-sectional descriptive study was carried out in two tertiary care hospitals in Peshawar from February 2019 to July 2019. Informed consent was taken from 100 participants before data collection. A validated and reliable questionnaire was used as a data collection tool. SPSS version 22.0 was used for data analysis.

RESULTS

Out of 100 participants, the majority (n=77) were female. The majority were unemployed and 47 were illiterate. Most of the parents had poor knowledge regarding thalassemia 28% were unaware that patients who have thalassemia are anemic, 89% had the opinion that thalassemia cannot be treated only with medications, 78% had replied to thalassemia cannot be treated with surgery and 56% were not aware that chelation is a treatment modality for thalassemia. The mean knowledge score of the total participants regarding thalassemia was 16.65±2.94.

CONCLUSION

Based on findings there is ample need for attention by the government and health care providers to provide education to the masses and must have to launch an awareness campaign about thalassemia. Furthermore, government and health care providers and society may encourage the preventive program to decrease the prevalence of this disease in Pakistan.

KEYWORDS: *Knowledge, Parents, Thalassemia, Thalassemic Children*

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Correspondence
[1]Sehrish Naz, Lecturer INS, Khyber Medical University
🖂: Sehrish.ins@kmu.edu.pk
✆: +92-311-9464648
[2]Charge Nurse, Khyber Teaching Hospital
[3]Demonstrator, INS, Khyber Medical University

INTRODUCTION

Thalassemia is a sum of hereditary disorders characterized by the low level of production or synthesis of one of the globin chains which leads to ineffective erythropoiesis and anemia. Shortness of breath, hemolytic anemia, iron overload, tissue hypoxia, delayed puberty, dark urine, bone deformities, slowed growth, jaundice, and enlarged spleen, liver and heart all are included in the sign and symptoms of anemia.[1] Around 60000 babies are born each year in the world with thalassemia and 3 per cent of the world's estimated population possesses the genes for beta-thalassemia. High prevalence of Beta-Thalassemia is present in the Indian sub-continent, Far East, Central Asia, Transcaucasia and Mediterranean. The high incidence rate has been seen in South East Asia, Sardina (12%) and Cyprus (14%). With the reference to Pakistan, the carrier rate is 5 to 8% and 5000 children are diagnosed each year with beta-thalassemia.[2,3] To execute and promote relevant education, knowledge of the masses and attitude toward thalassemia have been assessed by most countries. For example, an education program for Italian-American and non-Italian-Americans is not as effective as Italy‟s education program having more knowledge about Thalassemia. In Bahrain basic knowledge of the population needs improvement about thalassemia. In Saudi Arabia, knowledge about thalassemia was low and above 50% of the participants had not even heard about the disease. Inadequate knowledge of the basic concepts of thalassemia was demonstrated in those who heard of it.[4] More attention is needed on issues related to knowledge and understanding of the illness, lifelong compliance and adherence to chronic treatment regime and attitudes of patients and family members as well as the quality of interpersonal relationships.[5] Most of the parents were concerned about the well-being of their children and compliance with medication.[6,7]Parents of Thalassemia patients were embarrassed, stressed, strained and scared of their child‟s future.[8,9]By increasing the thalassemia patients and their caregiver‟s knowledge, attitude and awareness about the disease and management the complications of thalassemia may be effectively decreased and will impact positively on their quality of life.[10,12] A study conducted in Karachi Pakistan shows, that people have poor knowledge of the disease despite being the population at high risk for Thalassemia. Religious preferences, literacy rate, social factors and cultural boundaries influence the lack of awareness. Psychosocial and cultural issues along with lack of knowledge and awareness act as a hurdle for the prevention.[13] Nevertheless, the level of education plays a remarkable role in the awareness of thalassemia.[14,15,16]Awareness is important in the prevention of thalassemia which is contributed frequently by the parent‟s educational level.[17,18] the current study aimed to assess the knowledge of parents‟ having thalassemic children at district Peshawar where there is no study conducted previously to assess the burden of the problem. The results of the current study may be helpful in the awareness campaign about thalassemia and seek evaluation and improvement as compared to previous studies conducted in the region and provide room for future researchers.

METHODOLOGY

A cross-sectional descriptive study was conducted in two tertiary care hospitals in district Peshawar for a six-month duration (February 2019-July 2019). The target population was parents of thalassemic children. A total of 134 thalassemic children were admitted to both hospitals so by using the Raosoft online sample size calculator a sample of 100 thalassemic children was taken whose parents were there in the hospital for taking care of them. An adopted and previously validated questionnaire with a Cronbach‟s alpha value of 0.8 was used to collect the data.[19] The questionnaire had two parts; the first part consisted of socio-demographic information of the study participants such as gender, age, sex and marital status etc. while the second part consisted of the questions regarding knowledge assessment about thalassemia. Before data collection consent was obtained from the participants and they were assured that their anonymity to information, privacy and identity would be kept confidential. The study was ethically approved by the ethics committee of the Institute of Nursing Sciences (Khyber medical University) and permission was also taken from the institutional heads of both hospitals. Data analysis was done using SPSS version 22.0. Descriptive statistics i.e. frequency, percentages, mean and standard deviation were applied for all variables of the study.

RESULTS

Out of 100 participants majority were female. According to the age; 58% were 18-30 years old, and 47% were uneducated. The monthly income of 50% of the participants was below 15000.

Table 1: Socio-Demographic Information of the Participants

Characteristics Frequency	%Age
Gender	
Male	23%
Female	77%
Age	
18-30	58%
31-40	30%
41-50	07%
50 and above	05%
Education	
Illiterate	47%
Primary level	14%
Middle level	05%
Metric level	11%
Intermediate	23%
Monthly Income	
5000 to 10000	30%
10000 to 15000	20%
15000 to 20000	17%
20000 to 250000	11%
25000 and above	22%

Table: 2 Awareness of Parents Regarding Thalassemia

Questions Regarding Thalassemia	Aware F(%)	Not Aware F(%)
Have you ever heard of Thalassemia?	64(64%)	36(36%)
Individuals, who have Thalassemia major are anemic?	28(28%)	72(72%)
Can a Patient survive if Thalassemia is left untreated?	26(26%)	74(74%)
Can Thalassemia be identified by a blood test?	88(88%)	12(12%)
Inter family marriages may lead to thalassemia?	81(81%)	19(19%)
Can conditions like fainting, fever, anemia, diarrhea, and vomiting worsen Thalassemia major?	85(85%)	15(15%)
Is blood transfusion a treatment modality for Thalassemia?	85(85%)	15(15%)
Individuals, who have Thalassemia major, lead normal lives with appropriate treatment?	58(58%)	42(42%)
Is Thalassemia a disease of the blood?	90(90%)	10(10%)
Can Thalassemia be only treated with medications?	11(11%)	89(89%)
Do both parents need to have Thalassemia minor for the baby to be born with Thalassemia major?	60(60%)	40(40%)
If one parent has Thalassemia minor (is a carrier), the couple has a chance of having a child with Thalassemia disease?	59(59%)	41(41%)
Do you think Thalassemia is preventable?	45(45%)	55(55%)
Thalassemia is a contagious disease (you can catch it like a cold)?	23(23%)	77(77%)
Is chelation a treatment modality for Thalassemia?	44(44%)	56(56%)
Is Thalassemia an inherited disorder?	73(73%)	27(27%)
Would you say that children with Thalassemia major are more likely to develop (transfusion-related reactions, kidney failure and stroke)?	87(87%)	13(13%)
Are there different types of Thalassemia?	64(64%)	36(36%)
Does a person with Thalassemia minor lead a healthy life?	40(40%)	60(60%)
Thalassemia can be treated with surgery?	22(22%)	78(78%)
Is a specific type of food a treatment modality for Thalassemia?	27(27%)	73(73%)
Is bed rest a treatment modality for Thalassemia?	24(24%)	76(76%)
Is there a cure for Thalassemia major?	49(49%)	51(51%)
The problems in thalassemia major are due to iron overload and low blood transfusion?	65(65%)	35(35%)
Does Thalassemia lead to other diseases like diseases of the heart, liver, bones, spleen and lungs?	79(79%)	21(21%)

Table 3: Knowledge Level of the Study Participants

Knowledge Level	F	%Age	Mean	Standard Deviation
Good	69	69%	16.65	2.94
Poor	31	31%		

DISCUSSION

The prevention of thalassemia depends on awareness, which is frequently affected by the educational level of the guardians.[16] In this study 47% of the participants were illiterate as compared to a study conducted in Rawalpindi Pakistan in which 69% of the study participants were illiterate.[15] Regarding inter-family marriages majority of the caregivers were aware in this study while in a similar study conducted in Kolkata India most of the participants believed that consanguineous marriages have a positive role in thalassemia.[3] In this study, a very little percentage of the study participants were aware that those individuals are anemic who have thalassemia major while a study from Saudi Arabia shows that the study participants knew that thalassemia cause anemia. In this study majority of the participants knew that thalassemia is an inherited disorder as compared to another study.[4] In this study, most of the participants were aware that a treatment modality for thalassemia is blood transfusion and knew about chelation therapy. These findings were consistent with previous studies.[6,10,12] In this study, only the majority of the respondent had heard of thalassemia which is discouraging a figure as compared to a study conducted in Quetta Pakistan which show that (100%) of the participants had heard of thalassemia.[13] In developing countries health services face major challenges due to thalassemia major.[18] In the present study some caregivers were aware of thalassemia and has good results. To some extent, these findings of the study harmonize this study with other studies conducted in Pakistan and other countries in the world. Although the scope of this is limited to only one set-up; and may not provide sufficient evidence about the whole prospects of knowledge regarding thalassemia; even then, has some consistency with other studies being carried out in Pakistan and other parts of the world. Still, there is a need for more elaborate research toward this end; and more variables should have to be researched and analyzed vigorously. If disseminated well it still has some information for the stakeholders to implement certain strategies to enhance the knowledge of parents. So, there is ample need for attention by the government and health care providers. The government must provide quality education to the masses and must have to launch an awareness campaign about thalassemia. Furthermore, it is the responsibility of the government, health care providers and society to encourage the preventive program to decrease the prevalence of this disease in Pakistan.

LIMITATIONS

This study has some methodological limitations such as non-probability sampling, small sample size, and descriptive level of analysis. These limitations need to be controlled in future research..

CONCLUSION

The finding of this study shows that more than half of the parents were good knowledge regarding thalassemia while some parents were poor knowledge. This means that overall knowledge about the disease and its likely causes such as inter-family marriages and other variables which are of importance for the family and public to know is insufficient. Based on findings there is ample need for attention by the government and health care providers to provide education to the masses and must have to launch an awareness campaign about thalassemia. Furthermore, government and health care providers and society may encourage the preventive program to decrease the prevalence of this disease in Pakistan.

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CONTRIBUTORS

1. **Sehrish Naz -** Concept & Design; Data Analysis/Interpretation; Drafting Manuscript; Critical Revision; Final Approval
2. **Anayat Jan -** Concept & Design; Data Acquisition; Drafting Manuscript
3. **Shabnam -** Data Acquisition; Drafting Manuscript; Critical Revision; Final Approval