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Original Article

Level of Awareness about Thalassemia among Parents of Thalassaemic Children

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Abstract

Background: To determine the level of awareness about thalassaemia among parents of thalassaemic children.

Methods: In this cross sectional study parents (n=150) of patients suffering from beta thalassaemia major were included. Information was collected on a questionnaire consisting of all the necessary information regarding thalassemia . Eight questions related to knowledge regarding thalassaemia were included. Finally the questionnaires from different parents were analyzed and the result was interpreted. The data was analyzed by SPSS version 16.

Results: Sixty percent parents were unaware about the disease, 25% had a little knowledge about the disease and only 15% knew about Thalassemia and its complications.

Conclusion: Parental knowledge about thalassaemia was inadequate. It is required to educate not only parents but also general public to create awareness about thalassaemia so that the disease can be eradicated .

Key Words: Thalassaemia, Awareness, Parents

Introduction

Thalassaemia is a hereditary haemoglobinopathy resulting from the absence or reduced synthesis of either alpha or beta globin chain.[1] Depending upon the globin chain involvement, thalassaemia is categorized into Alpha-thalassaemia and Beta thalassaemia. Beta-thalassaemia is further classified as beta-thalassaemia major, intermedia and minor, on the basis of clinical severity and inheritance pattern .[2]

Thalassaemia has an autosomal recessive inheritance. Individuals suffering from beta-thalassaemia major are homozygous while beta-thalassaemia minor (trait) are heterozygous and are asymptomatic with mild anemia.[2,3] Among the inherited disorders, thalassaemia is the most common inherited diseases in Pakistan.[4] Beta-thalassaemia major is more common in South China Mediterranean, Arab countries, South Asia, Africa and Iran.[5] The highest carrier frequency is reported in Cyprus (14%), Sardinia (10.3%), and Southeast Asia (1-9%)[6]. Carrier parents (thalassaemia minor) have a 25% risk of producing thalassemia major child in every pregnancy. The carrier status of parents can be identified through tests, like blood C/P, Hb electrophoresis and genetic analysis.[7,8]

In Pakistan the gene frequency of β-thalassemia is 5-8% and is present in all ethnic groups. It is estimated that there are approximately 9 million carriers of β-thalassaemia, producing more than 5000 births of transfusion-dependent thalassemia (TDT) every year in Pakistan.[8-12] Presently Pakistan has 100,000 estimated cases of thalassaemia, which makes up for almost 5% of total cases in world.[13] These figures are increasing because of the lack of awareness and insufficient education campaigns.[14] It has been noticed that most mothers with thalassaemia trait do not know about their carrier status and give birth to a thalassaemia major child.[11-15]

Beta-thalassemia major patients require regular blood transfusions and iron chelation for survival The permanent cure of this illness is only possible with bone marrow transplantation or gene therapy.[16,17] Thalassaemia is a serious disease with many life threatening complications in addition to psychosocial and financial problems. Increasing incidence, inadequate management and failure of preventive attempts are primarily due to lack of knowledge and due to lack of inadequate awareness among both professionals and public at large.[18]

Public education programs for patients and their families about thalassaemia and proper communication of health staff and doctors with them is very effective to reduce the frequency of this

disease.[19-22] The prevalence of disease is more in rural areas signifying the lack of education and awareness about the disease and its prevention.[23]The low literacy rate in Pakistan is the main obstacles in improving the level of awareness which has been supported in various studies.[20,23,24]

Subjects and Methods

In this cross sectional study data was collected from 150 consecutive parents of registered Thalassemia children in Center for Thalassaemia Care, Sheikh Zayed Medical College/Hospital Rahim Yar Khan. A structured questionnaire was used in this study for collection of data, including information of residence (rural/urban) and literacy . Questionnaire also contained different questions related to thalassaemia. The purpose of using this questionnaire was to get detailed information about the level of awareness among the parents. It contained eight questions related to knowledge regarding thalassemia gene, transfer of gene, detection during pregnancy, detection before marriage, permanent treatment, transmission of illness through food, medicine or infection, treatment by blood transfusion and role of iron containing food. Level of awareness was labelled as "unaware" when the study subjects answered 0-2 questions correctly," limited knowledge" was labelled when study subjects correctly answered 3-5 questions whereas "well aware" was labelled those study subjects who answered 6-8 questions correctly.

Results

Out of 150 parents 69% were illiterate and the occupation of 70% was in rural areas (Table 1). Only 35% parents knew about their gene career status.

Table 1: Frequency distribution of socio-demographic variables (n=150)

Variables	No	Percentage
Education level		
Literate	46	31%
Illiterate	104	69%
Residence		
Rural	105	70%
Urban	45	30%

Sixty five percent did not know about the transfer of defective gene from parents to children. Knowledge about prenatal diagnosis, pre- marital screening and permanent cure of thalassaemia was known to 39%, 29% and 25% respectively (Table 2). About 60% of the parents were unaware about the basic things regarding thalassaemia disease, 25% had a little knowledge and only 15% knew almost everything about basics of thalassaemia disease (Table 3).

Table 2: Response of questions regarding thalassaemia awareness

Questions	Yes	No
	No(%)	No (%)
Do you have thalassemia gene?	53 (35)	97 (67)
Do you know that you are responsible for transfer of thalassemia gene to your child?	53 (35)	97 (65)
Do you know thalassemia can be detected during pregnancy?	59 (39)	91(61)
Do you know about screening test for thalassemia gene detection before marriage?	43(29)	107 (71)
Is there any permanent treatment of thalassemia?	38(25)	112 (75)
Can thalassemia be spread by food, medicine or infection?	17(11)	133(89)
Do you think regular blood transfusion is the only treatment?	112(75)	38 (25)
Is iron containing food healthy for thalassemic child?	27(82)	123 (18)
Total	150(100)	150 (100)

Table 3:Level of awareness among parents of children with Thalassemia major

Level of awareness	No(%)
Unaware	90(60)
Limited knowledge	37(25)
Well aware	23(15)

Discussion

Majority (60%) of the parents did not know anything about thalassaemia. Results are comparable to the study conducted in Karachi 2008 and in Turkey 2014.[25,26] The reason for inadequate awareness of parents is the mainly illiteracy (69%) in our study compared to 57% in Karachi and 67% in Turkey. Most of the parents belonged to rural area (70%) which is very high as compared to 34% in Karachi. Another study conducted by Fouzia Ishaq et al (2012) showed illiteracy 32%, 7% highly educated, 45% knew that thalassaemia is a hereditary disease while in present study 35% were aware of the disease. [27] Pre-marital screening was known only by 29% in present study, which is quite opposite to the study which showed 84% awareness.[27] Study conducted by Safila Naveed et al (2014) revealed that only 22% of people have a good knowledge of thalassaemia.[28] The current study results also correlate with other studies which showed lack of

knowledge, practice of pre-marital screenings, illiteracy and ignorance were the main reasons for the prevalence of the disease.[29-31]This study also highlights some false beliefs like blood transfusion is the only treatment for this disease. These misconceptions are a source of unnecessary anxiety for the family. Thalassaemia is controlled successfully in many countries like Iran, Greece, Italy and Cyprus by educational campaigns and raising awareness about the disease and highlighting its preventive measures to get rid of it.[31] Our country needs similar preventive measures employing educational institutions, masjids/madarsas, print and electroinc media and through seminars, symposia and workshops . Public health messages should be spread to clear the misconceptions and promote the screening of carriers and prenatal diagnosis that will eventually lead to a reduction in thalassemia births and will ultimately eradicate this fatal disease.

Conclusion

1.Parents of thalassaemia patients lack adequate knowledge about thalassaemia.

2.It is the responsibility of government, health professionals and society to support and encourage preventive programs, in order to reduce the burden of this disease in Pakistan.

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