Original Article

Knowledge, Attitude, and Practices of Parents of Beta Thalassemia Patients

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ABSTRACT

Objective: To evaluate the knowledge, practices, and attitude of parents of β- Thalassemia patients.
Study Design: A cross-sectional study
Place and Duration of Study: This study was conducted at the thalassemia Center of Children Hospital PIMS, Islamabad, for six months from December 2022 to May 2023.
Methods: This cross-sectional study was conducted at the thalassemia Center of Children Hospital PIMS, Islamabad, for six months from December 2022 to May 2023. Two hundred fifty parents were selected using the WHO sample size calculator through the nonprobability sampling technique. Informed consent was obtained and the questionnaire was filled from each participant. Data were analyzed by using the latest version of SPSs.
Results: About 77.6% of the participants were moms, 22.4 % were dads, and 68% were married to relatives and 32% to others. 38.8% said thalassemia is inherited, but 71.6% didn't know about pre-marital screening and 90% expressed concern. However, 97.2% supported pre-marital screening. Participants' knowledge, attitude, and habits were significantly associated with rural and urban residence ($p \leq 0.05$).
Conclusion: The study concluded that the participants lacked proper knowledge regarding pre-marital and prenatal testing. Around ninety percent of them were not in favor of cousin marriages, and anxiety was the main psychological problem of all patients. It is therefore concluded that awareness seminars and workshops could help to raise awareness and to reduce the incidence of the disease.

Key Words: Beta-thalassemia, pre-natal diagnosis, pre-marital diagnosis

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INTRODUCTION

Thalassemia has become one of the most common mon ogenic in nature situations around the globe, which is ca used by a lack of or a decrease in the chains of globin f ormation [1]. An individual might obtain a blood disorder called thalassemia trait or condition through both parents via transferring their genetic material [2]. People with beta thalassemia do not manufacture sufficient beta globin chains, resulting in an overabundance of alpha chains. The yellow colour of the skin. Slower development and teenage years, conditions like anemia, a spleen that is larger, and a greater vulnerability to pathogens are frequently seen symptoms and warning signs of thalassemic illnesses. Such persistent disabling condition impacts more than thirty-three million individuals globally, including both genders being affected at roughly the same frequency[3]. Pakistan additionally happens to be listed among the countries with a significant number of cases prevalence of beta-thalassemia. 78.5% had a relationship with 61% being closest relatives, and 17.5% being cousins from afar. Only 25% were knowledgeable about genetics psychotherapy, 65% had an understanding that thalassemia carries a hereditary way of transfer and 24% seemed knowledgeable of thalassemic diagnostic options. While around 63.55% believed that early detection can avoid thalassemia, almost all (83%) of couples reported being uninformed of thalassemia prior to pregnancy. In the poll, over fifty-two percent of those who responded (52%) nevertheless remained in supporting related weddings [4]. Since a formal official setup has not been established in Pakistan, it is projected about nearly nine thousand youngsters have been diagnosed having beta thalassemia every year. The carrier's growth frequency is projected to be 5-7%, making up nearly nine million transmitters in the population as a whole. [5]. The reason for this is a consequence of a significant number of marriages between close relatives, a lack of understanding of prenatal examinations and inherited guidance, a lack of access to preconception testing, and ending a pregnancy being regarded as unlawful and violating religious values. [6]. According to a research investigation carried out in Karachi to evaluate the parent's understanding of

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beta thalassemia, a large percentage of couples (77.6%) were having related getting married, the bulk understood that thalassemia is a genetic disease, and the overwhelming majority had been familiar with prior to marriage and diagnosis during pregnancy, but a small percentage were knowledgeable of the existence of thalassemia inherited condition. A number of the couple's children were aware of the practice of ending an unwanted pregnancy based on the results of an antenatal test, but just a minority found it spiritually permissible [7].

METHODS

Inclusion criteria:

- Parents of children having β-Thalassemia and visiting to Thalassemia Center of Children Hospital PIMS.
- Parents who were willing to be a part of the study

Exclusion criteria:

- Parents of patients with other blood disorders like alpha-thalassemia, thalassemia intermedia, aplastic anemia, Fanconi anemia, iron deficiency anemia, and lymphoblastic leukemia, etc. were excluded
- Parents not willing to be part of this study

Data collection procedure: After agreeing, parents got a well-structured questionnaire. Privacy and secrecy were assured. For each subject, proper answers scored one and erroneous answers zero. More knowledge meant higher scores. Scores over 60% indicated "adequate knowledge" while scores below 60% indicated "inadequate knowledge". A positive attitude was indicated if over 50% of queries were answered correctly, and a negative attitude if less. Furthermore, a correct answer rate of <50% was deemed poor, while >50% was deemed great.

Data Analysis: The collected data was entered in MS Excel responses were coded and analysed using Statistical Package of Social Sciences software version 24. Statistical analysis was to determine the prevalence ratio. The association of respondents' KAP scores with socio-demographic data was also analysed using the Chi-Square test. P-value ≤ 0.05 was taken as significant.

RESULTS

Table 01 shows the socio-demographic characteristics of the participants. 77.6 % were mothers, and 22.4 % were fathers. 52.4 % have an education level equal to matric and intermediate. 79.6 % of them have moderate and low incomes. Moreover, 53,.2 % of them have very good access to health care services. The mean age of the child was 8.25 years with a standard deviation of 2.82. Additionally, 68 % were married to cousins and 32 % of them were married other than cousins.

Table No. 1: Socio-demographic characteristics

Parents (gender)	**Number**	**Percentage**
Mother	194	77.6 %
Father	56	22.4 %
Parent's educational status		
Illiterate 54 Primary 20 Matric 95 Intermediate 36 Graduate 26 Postgraduate 19		
Economic status of the families in relation to the income.		
Very High High Moderate Low Very Low 0 02 52 147 49		
Access to health services		
Very good Good Moderate Bad Very Bad 133 10 10 0 0		
Age of thalassemic children (mean) 8.25 years with STD 2.82		
Thalassemic children at home **One (78.8%) Two (18.8%) Three (2.4 %)**		
Residential place **Rural 41.6 % Urban 58.4 %**		
Cousin marriages Yes (68 %) **No (32%)**		

Table No. 2: Responses of the participants regarding knowledge

Knowledge regarding thalassemia before the child's disease	**Yes 8%**	**No 92%**
Sources of information regarding the disease (thalassemia)		
Physician:	92.4 %	
Family relative	6.8 %	
Radio		
Television		
Relative	1.2 %	

Table No. 03: Perceptions of the participants regarding thalassemia

What is your perception of thalassemia?			
A genetic Disorder 38.8%, Don't know 59.65% God's will 0.8% Infectious disease 0.8%			
Which successful treatment for thalassemia Folic acid supplement blood transfusion Bone marrow transplant splenectomy			
0.8 %	59.2 %	40 %	0
Method of prevention for thalassemia Genetic counseling pre-marital screening prenatal diagnosis			
38 %		61.2 %	0.8 %
The psychological effect on parents due to their child's illness Anxiety sympathy aggression gratitude			
90 %	2 %	8 %	0

Table No. 4: Responses of the participants regarding knowledge

	Yes	No	Don't know
Does cousin marriage play a role in the transmission of thalassemia to next generation?	94.4 %	14	0
Do you have knowledge about premarital screening?	28.4 %	71.6 %	
knowledge regarding the prenatal screening of thalassemia	23.6 %	76.8 %	
Information thalassemia major is due to iron overload and low blood transfusion	52.4 %	47.6 %	0
If one parent is a carrier, the couple has a chance of having a child with Thalassemia disease	52 %	33.6 %	May be 13.6 %
Knowledge transfusion-related reactions, kidney failure, and stroke	94.4 %	2 %	maybe 3.6 %

Table No. 5: Questions regarding attitude

	Yes	No
There should be Intermarriages of thalassemia carrier	4.8 %	95. 2 %
Carrier couples should have children	31.2 %	68.8 %
There should be pre-marital screening for general public	97.2 %	2.8 %
Do u support Termination of pregnancy if fetus is thalassemia positive	90.4 %	9.6 %
There is Need of legislation of pre-marital screening	97.2 %	2.8 %
Blood should be donated for thalassemia patients	100 %	0
Consanguineous marriage should be preferred	7.6 %	92.4 %
Thalassemia is a financial burden for the family	94.8 %	5.2 %
Thalassemia as a cause of emotional distress in the family	99.2 %	0.8 %
Would you disclose about child's condition to family and society	98.8 %	1.2 %

Table No. 6: Questions regarding practices

	Yes	No
Have you both partners undergone screening before getting married	2.8 %	97.2 %
Has the female partner got her CVS test done during her pregnancy?	4 %	96 %
If CVS was positive, did you opt for Termination of pregnancy?	1.2 %	98.8 %
Are your other children screened	94 %	6 %
Have you motivated anyone for premarital screening	97.2 %	2.8 %
Do you wish for more children despite of already having sick ones	99.6 %	0.4 %
Do you encourage your child to take medicine regularly	98.4 %	1.6 %
Do you share food equally among your children	97.6 %	2.4 %
Have you ever received genetic counseling	55.2 %	44.8 %
Have you motivated anyone for pre-natal diagnosis	95.2 %	4.8 %

Table No. 7: Knowledge, Attitude and practices with respect to rural and urban participants

Residence	**Knowledge,**		**Attitude**		**practices**	
	Adequate Frequency (%)	Inadequate Frequency (%)	Positive Frequency (%)	Negative Frequency (%)	Good Frequency (%)	Bad Frequency (%)
Urban	103 (70.55%)	43 (29.45%)	131 (89.73%)	15 (10.27%)	103 (70.55%)	43 (29.45%)
Rural	52 (50%)	52 (50%)	84 (80.77%)	20 (19.23%)	52 (50%)	52 (50%)
P value	**0.001**		**0.001**		**0.001**	

DISCUSSION

The parents' knowledge, attitude, and practice were properly assessed in this study, as thalassemia is a chronic and debilitating disease and has a massive effect on the lives of the patients and their parents. In the current study, 92 % of the parents did not know about thalassemia before their child's illness, and 38.8 % answered that thalassemia is a genetic disease. Still, the study conducted by Shahzad A et al. showed that 33.2 % of the parents had knowledge before the child's illness, and 81.2 % said that thalassemia is a genetic disorder [8]. 94.2 % of them said that there should not be in-between cousin marriages; similarly, 94. 4 % of them knew the reaction of transfusion and related conditions like stroke and kidney failure, 94.4 % of the

parents thought that the child had a financial effect on the family[9,10]. In comparison, 98.8 % of them had disclosed their child's condition with family and society, however, the previously conducted studies concluded that 56.6 % of the parents said that thalassemia is more commonly due to in-between cousin marriages, 59.6 % of parents had information regarding blood transfusion reactions, and 43.07 % of the parents had shared the information with their community and family regarding their child condition.[11]. A study by Saxena A et al. concluded that 47.5 % and 62.5 % of the parents knew that thalassemia is a genetic condition and that blood transfusion can cause a reaction [12]. In the current study, 97.2 % of the participants answered that there should be pre-marital screening; in comparison, the other results show that 100 % of them should be pre-marital screening. In the current study, the knowledge regarding the prenatal diagnosis of thalassemia was 23.2 %, and 76. 8 % did not know the prenatal diagnosis of thalassemia. A study conducted by Manzoor I et al. revealed 77 % of the participants said that thalassemia is prevalent because of cousin marriages; moreover, 90 % and 89 % of the parents had information related to prenatal and premarital diagnosis of thalassemia[13]. The current show that 100 % of the participants agreed that should be a blood donation for thalassemic, and 92.4 % opposed parental cousin marriages. In contrast, the other study shows that 95.56 % of the participants believed that there should not be cousin marriages, and only 25.93 % of them were in the opinion of blood donation for thalassemic Childs[14]. The current study concluded that 94.4 4 % of parents said thalassemia patients can survive without proper treatment. However, another study shows that 95.6 % of the participants said that a patient can survive without treatment. Moreover, 63.4% and 55.2 % believe thalassemia is a preventable genetic disease. In our study, based on the association of residence with Knowledge, Attitude and practices, the knowledge of 103 (70.55%) of the participants was adequate, and 43 (29.45%) was inadequate in the urban population, while the knowledge of 52 (50%) participants was adequate and 52 (50%) was inadequate in participants from rural areas. (p=0.001) The attitude about thalassemia was positive in 131 (89.73%) participants, and it was negative in 15 (10.27%) participants from urban areas. In contrast, in the case of participants from rural areas, the attitude was positive in 84 (80.77%) participants and negative in 20 (19.23%). (p=0.001) The practices of 103 (70.55%) were good, and 43 (29.45%) were bad (poor) in participants from urban areas, while the practices were good in 52 (50%) participants and bad in 52 (50%) participants from rural areas. (p=0.001) In our study, another study by Mausumi Basu reported comparable results[15]. They reported that the participants from urban areas were more knowledgeable about thalassemia than those from rural areas. This might be due to low literacy rates in rural areas. Moreover, they reported that the attitude was positive in more urban participants than rural participants. They reported a significant association of the participants' knowledge, attitude and practices with the residency, which aligns with our findings[15]. Another study from Iran also reported comparable results to our findings. According to their findings, urban participants were observed with more knowledge about thalassemia than rural participants [16].

CONCLUSION

The study concluded that the participants lacked proper pre-marital and prenatal testing knowledge. Around ninety per cent of them did not favour cousin marriages, and anxiety was the main psychological problem of all patients. Therefore, awareness seminars and workshops could help raise awareness and reduce the incidence of the disease.

Author's Contribution:

Concept & Design of Study:	Muhammad Sa'd Masood
Drafting:	Maqbool Hussain, Iqra Rashid
Data Analysis:	Iqra Rashid
Revisiting Critically:	Muhammad Sa'd Masood, Maqbool Hussain
Final Approval of version:	Muhammad Sa'd Masood

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