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EXPLORING THE LEVEL OF AWARENESS REGARDING BETA THALASEMIA AMONG THE PARENTS OF PATIENTS IN DISTRICT SWAT

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ABSTRACT

Background: Thalassemia is a hereditary condition that affects globin chain synthesis in varying ways, and affect the hemoglobin production. The study objective was to determine the level of awareness among the parents of patients diagnosed with beta-thalesemia (βT).

Methodology: A cross sectional descriptive study design was used to collect data from the parents of patient that regularly visit the blood transfusion centers in district swat from February to March 2024. The sample size of the study was 235 using purposive sampling technique, while data was collected through reliable and valid questionnaire. The study was approved by the ethical review committee while informed consent were taken from each participant. Data were analyzed through SPSS 22 as descriptive and inferential statistics.

Results: In the current study majority of the parents were female 146 (62.1%), age group 31-40 years 164 (69.8%), house wife's 67 (28.5%), having monthly income 21000 to 50000 107 (45.5%), and parents with no education and matric 60 (25.5%). The majority of the patient level of awareness was good (42%), followed by poor awareness (31%), while 27% of the participant answer were neutral. Most parents are aware of prohibited foods, thalassemia signs, prevention tests, complications, drug avoidance, regular lab investigations, thalassemia genetic disorder, blood-related marriages, and HIV as blood-borne diseases.

Conclusion: The study concluded that majority of the participant level of awareness was good, but a national basis campaign is required that address the preventive strategies to prevent thalassemia.

INTRODUCTION

Thalassemia are inherited blood illnesses that minimize the level of hemoglobin (Hb) production, that are divided as alpha (α) and beta (βT). it is common among Italian, Greek, Middle Eastern, South Asian, and African people [1]. Alpha and βT are frequently passed down in an inherited manner. A child cannot develop thalassemia unless both parents are carriers. Parents with trait carrier of Thalassemia can results as twenty five percent of possibility may affect the baby in pregnancy that leads to hemoglobinopathy. Thalassemia was reported in 280

million people worldwide in 2015, accounting for 16,800 fatalities [2, 3]. βT is a prevalent single-gene hereditary disease worldwide [4]. Every year, around 70,000 newborns worldwide are born with βT, and 270 million people carry haemoglobinopathies, according to various research.Thalassaemia is a public health issue worldwide because to its high frequency [5].βT is a hereditary condition that affects globin chain synthesis in varying ways. This disease is avoidable, as proved in Italy, Greece, and Cyprus [6]. Pakistan is among the low-income countries with high population and with no reliable data on the incidence, prevalence, or fatality rates of hereditary blood diseases [7]. βT is the most frequent genetically transmitted blood condition in Pakistan, affecting practically the whole country. [8] While official data is unavailable in Pakistan, estimates of the number of babies with βT each year range from 5000 to 9000.Research indicates that the average carrier rate for βT in the general population is somewhat more than 5%. [7,9]. The increased frequency of βT cases can be attributed to inadequate education efforts and a lack of awareness [10]. Many mothers with thalassemia trait are not aware that they are carriers, which can lead to the birth of a child with thalassemia major [11]. Given the autosomal recessive inheritance pattern, pre-marital carrier screening can be beneficial in prevention, and mandated programs have been implemented in numerous afflicted countries [12]. In many countries it is being mandatory to analyzed the couple to screen and detect them from mutation causative age to take preventive measures as a part of patient therapy [13]. Globally many nations have initiate educational and diagnostic campaigns to prevent illness, while in Pakistan only two provinces have passed bills to provide financial support to national program that should be implemented to evaluate awareness and diagnostic screenings [14]. Therefore the aim of the study was to evaluate the level of awareness of the patient parents diagnosed with beta thalasemia.

METHADOLOGY

Study design: This was a descriptive cross-sectional study carried out in various thalasemia centers in Swat. KPK The study was carried out in two thalassemia centers in Swat, which provide blood transfusion care facilities and services to all KPK-diagnosed patients in those centers. The study design was descriptive cross-sectional and was completed from February to March 2024. The study population consisted of the parents of patients diagnosed with beta-thalassemia who received blood transfusions in the study setting on a regular basis. Assuming the total patients that were registered in both centers were the population, then using a 95% confidence level, a 5% margin of error and an 80% prevalence, the final sample size was 235 using purposive sampling technique.

Data collection procedure: The study objective and purpose were explained to each participant before informed consent. The questionnaire was translated into Urdu (a local language) for better understanding of the questions, which were validated by subject specialists. I asked them and ticked the option . we stayed with the patient until all questions were answered, and we gave at least 20 minutes to each patient for a questionnaire.

Inclusion and exclusion criteria: The inclusion criteria for the patient were: patient having a blood transfusion and diagnosed with beta-thalassemia after one year. Parents with cultural restrictions on communicating with the primary investigator or who are not willing to be voluntary participants are excluded from the study.

Data collection procedure: The data collection process was started after getting permission from the administration of the study setting. Patients who were admitted for blood transfusions were approached and evaluated for inclusion criteria. The data was collected in two steps: In the first step, we collect the demographic data of the participants, which includes age, gender, and living status. In the second step, we collected data regarding awareness of informed consent. A valid and reliable questionnaire was adopted for data collection. The checklist contains 16 items with a dichotomous response (agree, neutral/disagree) [15].

Microsoft Excel and SPSS version 22 were used for the data analysis, which included descriptive statistics. For continuous variables, mean and standard deviation were computed; for categorical variables, frequency and percentages were used. Pearson correlation test was used to identify the association of awareness with demographic data.

The study was approved by the ethical review committee of Tasleem College of Nursing and Health Sciences, while permission was granted from the study setting for data collection, and informed consent was obtained from each participant to protect their ethical rights.

Results

Socioeconomic status of the participants: In the current study majority of the parents were female 146 (62.1%), age group 31-40 years 164 (69.8%), house wife's 67 (28.5%), having monthly income 21000 to 50000 107 (45.5%), and parents with no education and matric 60 (25.5%), 60 (25.5%) respectively. (See table 1).

Table 1: Demographic data of the participants		
	Frequency (235)	%
Gender		
Male	89	37.9
Female	146	62.1

Age		
21 - 30 years	29	12.3
31 - 40 years	164	69.8
41 - 50 years	34	14.5
51 and above	8	3.4
Occupation		
shopkeeper	46	19.6
Farmer	14	6.0
Worker	72	30.6
Teacher	20	8.5
House wife	67	28.5
Driver	4	1.7
Overseas	4	1.7
Businessman	8	3.4
Monthly income		
20k and below	88	37.4
21 to 50k	107	45.5
51 to 100k	40	17.0
Education		
No education	60	25.5
Middle	37	15.7
Matric	60	25.5
intermediate	43	18.3
Bachelor	27	11.5
Masters and above	8	3.4

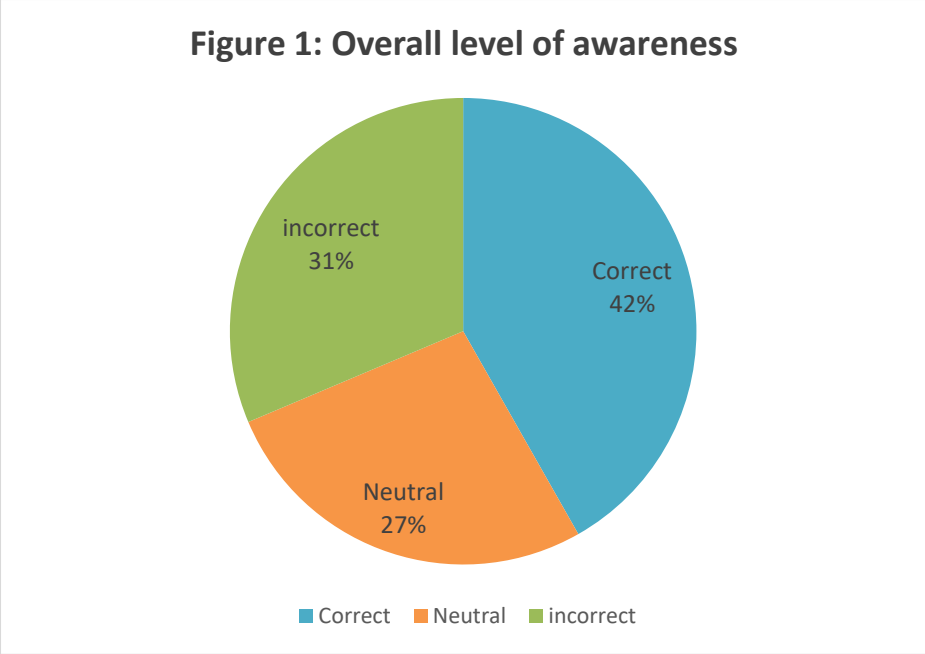
Level of awareness regarding thalasemia among parents of study participant

Table 2 illustrates that majority of the parents were aware regarding prohibited foods 124 (52%), first sign of thalassemia 153 (65.1%), tests for prevention 104 (44.3%), complications regarding thalassemia 90 (38.3%), drugs not be taken by thalasemia patients 101 (43.0%), Regular lab investigation for the patient 128 (54.5%), thalassemia is genetic disorder 118 (50.2%), marriages in blood relations increase risk of Thalassemia 136 (57.9%), and HIV is blood borne diseases 88 (37.4%). (See table 2).

Table 2: Level of awareness among thalassemia patients' parents				
	Questions	Correct	Don't,t know	Incorrect
1	Know prohibited foods for thalassemia patient	124 (52%)	69 (29.4%)	42 (17.9%)
2.	Yellowish discoloration of skin is first sign of Thalassemia patient.	153 (65.1%)	24 (10.2%)	58 (24.7%)
3.	For prevention method know the genetic investigation	104 (44.3%)	66 (28.1%)	65 (27.7%)
4.	Patients may experience splenomegaly as an outcome of their illness.	90 (38.3%)	65 (27.7%)	80 (34.0%)
5.	Are you aware of bone marrow transplantation procedure?	84 (35.7%)	88 (37.4%)	63 (26.8%)
6.	Transmission of Thalassemia is not occur through contact and food.	77 (32.8%)	53 (22.6%)	105 (44.7%)
7.	Are there any drugs that the Thalassemia patients should not take?	101 (43.0%)	77 (32.8%)	57 (24.3%)
8.	Through blood diabetes is not transmitted	67 (28.5%)	53 (22.6%)	115 (48.9%)
9	Hemoglobin, liver and kidney function test is required regularly for their patients.	128 (54.5%)	42 (17.9%)	65 (27.7%)
10	You are considered as a carrier for Thalassemia	79 (33.6%)	88 (37.4%)	68 (28.9%)
11	Hepatitis can be transmitted *via* blood transfusion	72 (30.6%)	72 (30.6%)	91 (38.7%)
12	Hepatomegaly occurs as a outcome of their disease	86 (36.6%)	42 (17.9%)	107 (45.5%)
13	Is Thalassemia a genetic disease?	118 (50.2%)	53 (22.6%)	64 (27.2%)
14	Within the family marriage rises the likelihood of having an affected child	136 (57.9%)	50 (21.3%)	49 (20.9%)
15	HIV can be transmitted by blood transfusion	88 (37.4%)	85 (36.2%)	62 (26.4%)
16	If both of the carrier parents become pregnant, the chance of having an afflicted kid is 25%.	63 (26.8%)	83 (35.3%)	89 (37.9%)

Overall awareness of the participants

Figure 1 illustrates that majority of the patient level of awareness was good (42%), followed by poor awareness (31%), while 27% of the participant answer were neutral.



Relationship of parent's awareness with demographic variables

Table 3 illustrates that Parents awareness is significantly mild positive associated with gender, occupation and education, while negative mild associated with income while moderate negative with age. (See table 3).

Table 3: Association of awareness with demographic variables

	1	2	3	4	5	6
1: Gender	-	-.210**	.199**	.023	-.002	.185**
2: Age		-	-.109	-.121	.017	-.302**
3: occupation			-	.163*	.276**	.185**
4: Income				-	.395**	-.033
5: Education					-	.156*
6: Awareness						-

****. Correlation is significant at the 0.01 level (2-tailed).**

***. Correlation is significant at the 0.05 level (2-tailed).**

Discussion

The current study was conducted with the aim to collect the insight information of parents of Beta thalasemia patients regarding the diseases in Khyber Pakhtunkhwa. In the present study majority of the parents were female 146 (62.1%), age group 31-40 years 164 (69.8%), house wife's 67 (28.5%), having monthly income 21000 to 50000 107 (45.5%), and parents with no education and matric 60 (25.5%), 60 (25.5%) respectively. Mothers have more access to the

departmental resources as most of the attendant during transfusion with patient are mothers and uneducated mothers are due to cultural restrains in past. A similar study conducted in Khyber Pakhtunkhwa Pakistan shows that the total participant were 220, where 252 (74.3%) were mothers, while 44 (25.7%). Higher number of parents were having poor level of knowledge regarding screening 237 (80.1%), while 265 (89.5%) were have no education level [16]. In study conducted Pakistan shows that Of the 88 patients that visited the Thalassemia Center, 76.5 percent were accompanied by their mothers, while the remaining patients were accompanied by their fathers. Out of 230 parents (both mothers and fathers), 74 (32.1%) were illiterate, 60 had 1-8 years of schooling (26%), 50 had 9-10 years of schooling (21.7%), 25 had 11- 12 years. year of schooling, 14 (6.0%) had 13-14 years (10.7%) and only 7 had more than 15 years of schooling (3%). Of the 115 families surveyed, 39.1% earned less than PKR 6,000, 47% earned between PKR 6,000 and 15,000, and only 13.9% earned more than PKR 15,000 every month [6]. A study conducted in Lahore Pakistan reveals that among the total 410 families, 300 (73.2%) coming from public and 110 (26.8%) from private centers. There were 179 (43.7%) fathers and 231 (56.3%) moms who attended with their children, ranging in age from 20 to 60 years. There were 279 rural families (69%) and 127 urban families (31%).In terms of parental education, 18.3% (75 out of 179) fathers and 32.9% (135 out of 231) women did not receive a formal education [17]. In the current study 118 (50.2%) of the participant were aware that thalassemia is genetic disorder, it may be due to minor cases in towns that concern the family member to know about the diseases and also when the child is diagnosed first time. Moreover the majority of the parents were aware regarding prohibited foods 124 (52%), first sign of thalassemia 153 (65.1%), tests for prevention 104 (44.3%), complications regarding thalassemia 90 (38.3%), drugs not to be taken by thalassemia patients 101 (43.0%), regular lab investigation for the patient 128 (54.5%), marriages in blood relations increase the risk of thalassemia 136 (57.9%), and HIV is a blood-borne disease. A study completed in Multan Pakistan support our findings were 60(50.0%) of the participants were aware that it is inherited diseases, approximately 29.2% (n=35) of the parents believed that a thalassemia patient may survive without therapy, while most parents did not know about it. 64.2% (n=77) and 6.7% (n=8) of parents answered that they did not know. Similarly, 89.2% (n = 107) of parents know that this disease can be identified through blood tests, and a majority of 91.7% (n = 110) believe that blood transfusion is a treatment for this disease, while 49.2% (n =59) respondents believed that marriage is an important risk factor for thalassemia in their children [18]. Another Pakistani study reveals that Out of the accompanying parents, 52 (44.6%) were aware that thalassemia is an inherited blood illness. However, 63 (55.6%) were unaware of its

etiology. Only 37 (32.2%) were aware that both parents could be carriers for the condition in their children [6]. A study conducted in Iraq shows different findings from our study where 54% of the parents were not aware that it is hereditary diseases, moreover majority 94.8% of the parents were aware regarding type of food should not be taken, 86% about the sign of thalassemic patient, 83.7% about genetic tests, 80.1% about bone marrow transplantation, 78.2% about transmission of diseases, 77.7% about drugs not to be used by the patient [15].

In the current study majority of the participant level of awareness was good (42%), followed by poor awareness (31%), while 27% of the participant answer were neutral. It may be due to regular transfusion session attended in blood transfusion centers, interaction with doctors and being a special patient in the community. A Pakistani study found that 82% of parents were aware of their child's thalassemia diagnosis and 80% knew it was a blood illness [19]. A study conducted in Islamabad Pakistan reports that the majority of the parents, 274 (66.8%), were unaware of thalassaemia prior to their first affected kid.Similarly, 333 (81.2%) participants held the incorrect belief that the disease was genetic [17]. A study conducted in Khyber pukhtankhwa shows that only 16 out of 162 patients with family history of thalassemia major were aware of prenatal screening. As a result, many families with beta-thalassemia major are unaware of their condition [16]. In the current study, parental awareness is significantly moderate positive related to gender, occupation and education, while negative moderate related to income, while moderate negative related to age. A Pakistani study found a significant association between education of parents of beta-thalassemia patients and awareness of prenatal screening. The majority of clueless parents (80.1%) were uneducated [16]. Ghafoor et al. found that 60% of parents knew nothing about thalassemia and 69% were uninformed [20]. The majority of women (89.5%) were uneducated, which explains the lack of information on prenatal screening for beta-thalassemia major. Our survey found that the literacy rate is higher than in Karachi (57%) and Turkey (67%) [21,22]. There were certain limitation in form of sampling technique, study design and limited to a province that could be generalizable to all the country.

Conclusion

The study concluded that majority of the parents level of awareness is good regarding common factors that are associated with beta Thalassemia. Parents' understanding regarding thalassemia carrier screening and prenatal diagnosis was inadequate. To address the issue, it's crucial to start a national level education campaign for the public to raise the awareness among families with thalassemic conditions.

Conflict of interest: The authors declare that there is no conflict of interest.

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