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ORIGINAL ARTICLE

General disease awareness among parents of thalassemic children visiting government versus private care centers of Rawalpindi and Islamabad

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ABSTRACT

Introduction: Thalassemia Major is a hemolytic anemia which is prevalent in developing countries and is preventable by promoting awareness among the masses.

Objectives: To assess the current general disease awareness and compare the level of understanding between parents attending government versus private thalassemia care facilities.

Methods: This cross-sectional study was conducted in four thalassemia centers of Rawalpindi and Islamabad from December 2017 to January 2019. Parents/caregivers of Thalassemia Major Patients were included by non-probability purposive sampling and those having children having other blood disorders, were excluded. After taking informed consent, a pretested structured questionnaire was given to participants and awareness level was classified into ‘unaware’, ‘aware’ and ‘well-aware’ categories, based on the score achieved. Data was evaluated using SPSS version 23.0. Chi-square test was used for analysis.

Results: A total of 277 parents were included. Parents who took their children to government and private centers were 161 (58.1%) vs 116 (41.9%) respectively. There was a statistically significant difference in the know-how about mode of disease transmission (p value=0.02), blood-borne diseases (p value=0.00), method of complete cure (p value= 0.05) and harmful effects of repetitive blood transfusions (p value=0.05) among parents visiting the two different facilities. While 80.2% parents in private centers were ‘well-aware’, the corresponding percentage in government centers was 57.1%.

Conclusion: General disease awareness was average. Parents visiting private institutes have shown much better awareness. Funding and dedicated education, with focus on government organizations, which are accessible for the common man, is required.

Keywords: *Thalassemia major, awareness, Pakistan*

Introduction

Thalassemia is a hereditary, hemolytic anemia of varying severity where patients’ lives are dependent on repetitive blood transfusions in the ‘Major’ subtype.[1] the prevalence of the disease is high in developing countries, particularly in Asian and Mediterranean countries. In Pakistan, every 1–4 per 1000 infants suffer from

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Thalassemia, which makes it one of the high risk countries for Thalassemia in the world.[2] the average life expectancy of affected children is stated to be 10 years in Pakistan, which is quite lower than the global average of 10-50 years.[3]

Consanguineous marriages are a major risk factor and they are quite common in Pakistan due to the cultural beliefs prevalent in the country.[4] Pre-marital screening is not a known concept, especially in the rural areas. Majority people learn first about the disease when their own child or a close family member is affected.[5] prenatal screening is also lacking. A study done in Peshawar showed that even though 74% couples have knowledge of prenatal screening, only 11% opted for it.[6]

While blood transfusion is an essential part of management, the concept of safe blood transfusion is lacking in affected families and hence, Hepatitis C is quite prevalent in Thalassemia children. Acquisition of Hepatitis C adds to the morbidity and mortality of affected children. It has been reported as one of the top two causes of death in Thalassemia children- the second being cardiac complications, secondary to iron overload.[3]

In Pakistan, the average annual expenditure for managing disease in a child with thalassemia is US $ 4500, which is much more than the per capita revenue in Pakistan. Thalassemia contributes to an annual loss of 1.46–2.92 million disability adjusted life years (DALYs), leading to massive economic burden worldwide.[3]

Majority population finds government-based facilities more affordable and accessible. In the past, awareness assessment studies similar to this have been conducted but comparison of the level of understanding between private and government sector hospitals has not been done previously. The objective of this study was to assess the current general disease awareness and to compare the level of understanding between parents attending government versus private care facilities.

Methods

After taking IRB approval from SIH and various thalassemia centers of Rawalpindi and Islamabad, this cross-sectional study was conducted in Holy Family Hospital (HFH) Thalassemia Centre, Rawalpindi, Pakistan Institute of Medical Sciences (PIMS) Thalassemia Centre, Islamabad, Jamila Sultana Foundation (JSF), Rawalpindi and Thalassemia House, Rawalpindi from Dec 2017 to January 2019.

The sample size was calculated as 256 using the WHO sample size calculator taking 95% confidence level, 0.06% precision and approximate population size was taken as 6000. Parents/caregivers of thalassemia major patients were included, while those of children with hemolytic anemias like thalassemia minor, thalassemia intermedia, sickle cell anemia, hereditary spherocytosis and G6PD deficiency were excluded. Recruitment was done through non-probability purposive sampling after informed consent.

The pretested structured questionnaire was filled by the authors through small interview with parents/guardians in Urdu language. Later, the correct answers were communicated to all parents individually. The questionnaire consisted of 07 questions related to basic knowledge of Thalassemia and total score was calculated out of 07 depending upon number of correct answers. Participants were classified into three categories: unaware; having total score of 01 to 02. Aware; having total score of 03 to 05 and Well aware; having total score of 06 to 07. Scores of parents visiting government and private centers were compared.

Data was entered in SPSS software version 23 and analyzed. Chi-square test was applied and P-value ≤ 0.05 was considered significant.

Results

A total of 277 caregivers were included in this study. Parents who took their children to government and private centers were 161 (58.1%) vs 116 (41.9%) respectively. The responses of parents to the awareness questions about Thalassemia are shown in Table 1. Correct responses and statistically significant p-values have been highlighted in bold.

There was a statistically significant difference among government and private institutes, in the knowledge of mode of disease transmission (p value=0.02), blood-borne diseases (p value=0.00), method of complete cure (p value= 0.05) and harmful effects of repetitive blood transfusions (p value=0.05). Awareness levels of the participants are presented in Figure 1.

Table 1: Responses of parents to the awareness questions

Questions	Public sector participants	Private sector participants	P-value
Mode of Transmission:			0.02
Genetic	108 (67.1%)	95 (81.9%)	
Sexually transmitted	7 (4.3%)	0 (0%)	
Unhealthy diet	3 (1.9%)	2 (1.7%)	
Not sure	43 (26.7%)	19 (16.4%)	
Diagnostic test:			0.49
Blood test	152 (94.4%)	109 (94.0%)	
Urine test	0 (0%)	1 (0.9%)	
Not sure	9 (5.6%)	6 (5.2%)	
Should Pre-marital screening be done?			0.14
Yes	151 (93.8%)	114 (98.3%)	
No	4 (2.5%)	0 (0%)	
Not sure	6 (3.7%)	2 (1.7%)	
Is Prenatal diagnosis possible?			0.09
Yes	138 (85.7%)	107 (92.2%)	
No	1 (0.6%)	2 (1.7%)	
Not sure	22 (13.7%)	7 (6.0%)	
Diseases transmitted via repetitive blood transfusions:			0.00
AIDS and Hepatitis C	87 (54.0%)	91 (78.4%)	
Cancer	14 (8.7%)	3 (2.6%)	
Not sure	60 (37.3%)	22 (19.0%)	
Complete cure:			0.05
Blood Transfusions	41 (25.5%)	18 (15.5%)	
Healthy Diet	11 (6.8%)	13 (11.2%)	
Bone marrow transplant	100 (62.1%)	83 (71.6%)	
Medication	9 (5.6%)	2 (1.7%)	
Harmful effect of repetitive transfusions?			0.05
Iron overload	133 (82.6%)	104 (89.7%)	
Calcium overload	7 (4.3%)	0 (0%)	
Not sure	21 (13.0%)	12 (10.3%)	

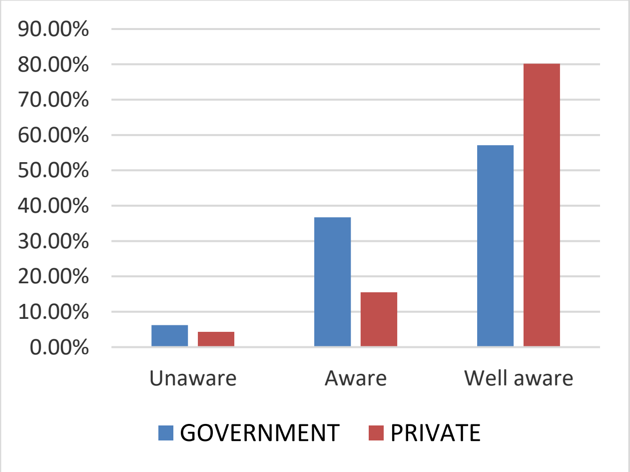

Figure 1: Awareness level of caregivers

Discussion

In our study, among government sector caregivers, 67.1% appropriately responded to the question on mode of disease transmission compared to 81.9% from the private sector, showing statistically significant difference (P-value=0.02). Knowledge was 82.6% in a 2018 study carried out in a government hospital of Rawalpindi/Islamabad.[5] Previous government hospital based studies carried out in other areas showed 47.6, 35 and 50% mindfulness sequentially.[7-9] Another study carried out in both government and private centers of the twin cities of Rawalpindi/Islamabad in 2017 reported 81.2% correct responses.[10] The previous work done in these twin cities is comparable to our work. Lastly, a study done in Rajasthan showed results of 43.3%, which is significantly lower compared to our study.[11]

When we tested the familiarity of the guardians about the diagnostic test for Thalassemia, 94.4% versus 94.0% responded correctly in government and private centers respectively and answered ‘Blood test’. Awareness was almost the same in the two groups and with inconsequential difference. A study done in a private center in Karachi showed that 93% of parents knew that Thalassemia can be identified by a blood test, which is analogous to our finding.[2] In government and private centers, subjects in favor of pre-marital screening were 93.8% versus 98.3% respectively. The comparison was statistically insignificant. The cognizance was better relative to 29% and 89% reported in former Pakistani studies, done in the years 2017 and 2016 respectively.[10,8] This shows a temporal improvement.

Regarding the possibility of prenatal diagnosis, correct response was given by 85.7% versus 92.2% interviewees in our study- again with no significant difference. Other government sector researches from India and Rahim Yar Khan, Pakistan showed 50.9 and 39% awareness in order.[7,8] Knowledge similar to ours-88.3%, was noted in a previous twin cities-based study.[10] A study done in Punjab, India showed 76% of the population were aware of it.[12] A research based in another city of India showed that 60% of the population knew the benefits of it.[13]

When the caregivers in this study were asked about the diseases transmitted by blood transfusions, 54% from government versus 78.4% from private setting replied correctly by answering AIDS &Hepatitis C. This was the most noteworthy difference in knowledge (P-value= 0.00). In the study by Mutar et al in Iraq, 37.3% and 56.9% gave correct response of AIDS and hepatitis C correspondingly.[14] Assessing awareness about the curative option for thalassemia, knowledge of bone marrow transplant was seen in 62.1% vs 71.6% government and private caregivers respectively. It was a statistically significant difference (P-value=0.05). Awareness of this aspect was much lower 2.7 and 25%, in former 2018 and 2016 studies based in India and Rahim Yar Khan, Pakistan sequentially.[7,8] Yet in a study done in Iraq, 80.1% had knowledge about it as a treatment option, but only 39.2% were cognizant of it being a complete cure.[14] However, in one more study from India (2020), only 6.78% of participants knew BMT as a treatment option and over 77.2% considered blood transfusions as the only treatment option.[15] From our results, consciousness of this aspect seems to be on the rise.

When asked about the harmful effect of multiple blood transfusions, correct response was 82.6% against 89.7% from the two groups respectively. The difference was statistically significant (p value= 0.05). This aspect was not assessed from this viewpoint in similar studies. With time, awareness is improving. The likely explanation of greater awareness level in private hospital participants is the higher doctor: patient ratio and better availability of resources. Monetary investment along with devoted education of the population needs to be done, especially in government centers, which are accessible and affordable for majority people. These measures can draw us closer to the target of a Thalassemia-free Pakistan in future.

The objectives of this study were achieved. The researchers also spent time and energy in communicating the correct answers to the study participants, once assessment was complete. However, the study has some limitations. A larger sample size may have provided a better representation of the actual disease statistics. Also, we did not inquire about factors like thalassemia screening behavior among family members and know-how about management of disease complications.

Conclusion

Overall, awareness about the disease was average, but seems to be improving. Private institutes have shown much better perception among parents as compared with government institutes. Funding along with dedicated teaching of the masses is required, especially in government organizations, for a future Thalassemia-free Pakistan.

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