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PROBLEMS FACED BY GUARDIANS OF THALASSEMIA MAJOR PATIENTS IN DISTRICT SAHIWAL

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ABSTRACT

Introduction: Thalassemia is inherited genetic blood disorder in which patient needs lifelong regular blood transfusion along with medicines in order to survive. So the treatment associated with lifelong financial, social and physical problems for the patients and care givers**. Objective:** This study aimed to assess medical treatment and blood transfusion faculties available to thalassemia patients, problems faced by their guardians/ parents and to suggest some policy measures to eradicate the their problems. **Study Design:** Cross sectional study. **Place and Duration of Study:** Ali Zaib Blood Transfusion Services Sahiwal. **Methodology:** this study was conducted among the parents/ guardians of Thalassemia Major Patients. A sample of 464 respondents through simple random technique was selected and the data was collected by well designed interview schedule. Data analysis and interpretation using descriptive statistics through SPSS (Statistical Package for Social Sciences) 21.0 version software was carried out. **Conclusion:** The study explored that there are less number of Thalassemia centers as compared to the numbers of patients. Long travelling enhances the problems of the patients as well as their caregivers. All the medicines were not available free of cost whereas majority of the patients are unable to purchase a prescribed medicine which results in increase of morbidity. There is a need to make Thalassemia centers at district level and to ensure the provision of all medicines on zero cost to Thalassemia patients**.**

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INTRODUCTION

High prevalence made thalassemia a major health problem worldwide. Every year about 50,000 to 100,000 thalassemia patients die in low and middle income countries.[1] In Pakistan thalassemia disease load was 90,000 to 100,000 patients.[2] Thalassemia patients need regular blood transfusions lifelong, which cause other complications such as iron overload that damage important organ such as heart, kidneys, liver, pancreas and even lead to death.[3] The patients and care givers have to bear all indirect and direct costs of therapy like medical consultation, diagnostic tests, and side effects of therapies, traveling expenses, socio-economic problems such as poor relations within society, avoid social get-together, and depression.[4,5]

OBJECTIVES OF THE STUDY

The present study was based on the following objectives:

1. To assess the medical treatment and blood transfusion options available to the patients
2. To explore the problems faced by the guardians of the patients
3. To suggest some policy measures to improve the medical treatment and blood transfusion infrastructure for the Thalassemia patients

METHODOLOGY

This study was carried out in Ali Zaib Blood

Transfusion Services (a Thalassemia center), situated at Sahiwal. The population of the study was composed of the parents/ guardians of the Thalassemia Major Patients registered or their treatment in the said transfusion center. This transfusion center was selected for the research because it was the only transfusion center situated in the area and the patients from surrounding cities, tehsils and villages are receiving blood transfusion from the said Transfusion Center. Cross sectional study was conducted and quantitative approach was used. A sample of 464 respondents was collected through simple random technique and data was collected by well designed interview schedule. Data were analyzed and interpreted by using descriptive statistics through SPSS (Statistical Package for Social Sciences) 21.0 version software. A self-designed interview schedule in accordance to the medical treatment and the process of blood transfusion was developed and revised after discussion with 2 senior doctor (>6 years' experience) and the Director of the organization.

Results and discussions

Total numbers of 464 respondents were selected in the sample in the current study. Majority of the respondents 280 (60.3%) were from age group 31-42 years, 52 (11.2%) between 18- 30 years, 124 (26.7) from 43-55 and 4 (0.9%) respondent was above 55 years of age. Demographic data shows that 208(44.8%) were male and 256 (55.2%) were female. Data shows that 320 (70.7%) respondents belonged to rural area and the remaining 136 (29.3%) belonged to urban area.

Table 1. Distance of Thalassemia center from Residence of Respondents

Distance of Thalassemia center from residence	Frequency	Percentage
Up to 20km	8	1.7
21km to 40km	44	9.5
41km to 60km	120	25.9
more than 60km	292	62.9
Total	**464**	**100**

The table above describes that 292 (62.9%) people lived more than 60km, 120 (25.9%) from 41 to 60km, 44 (9.5%) from 21 to 40km 8 (1.7%) were less than 20km far from the transfusion center. It is too much difficult for any person to travel towards miles away situated thalassemia center along with a patient twice or thrice a month on regular basis. Because it not only time consuming but also expensive because of travelling costs, such as bus, taxi, train fare and meal expenditures.

Table 2. Cost of Traveling towards Thalassemia center on each visit

Traveling cost of each visit	Frequency	Percentage
Up to Rs. 1,000	248	53.5
from Rs. 1,001 to Rs. 2,000	168	36.2
Above Rs. 2,000	48	10.3
Total	**464**	**100**

Table-2 shows that traveling cost to thalassemia center on each visit was up to Rs. 1,000/- to 248 (53.5%) respondents, Rs. 1001 to Rs. 2000 to 168 (36.2%) respondents, and above Rs. 2001 to 48 (10.3%) respondents. These costs were only the traveling costs, the blood transfusion, chelation therapy cost and the other medicines needed on regular basis were not included in it. Each patient needs to visit transfusion center at least two times in a month. Khattak ST *et al,* (2004) also mentioned that beside blood arrangements the average monthly cost of thalassemia treatment was around 10,000 PKR which is very high for a poor family.[6]

Table 3. Respondents' ability to purchase prescribed medicine

Response	Frequency	Percentage
Respondents able to purchase prescribed medicine	52	11.2%
Respondents unable to purchase prescribed medicine	412	88.8%
Total	**464**	**100.0%**

All the medicines were not available to the patents free of cost so they compelled to purchase them from the market. Rehman et al (2004) also mentioned that treatment of thalassemia major was a great challenge to health services in the developing countries due to the lack of facilities.[7]

But all the patients were not able to purchase them as table-4 shows that 52 (11.2%) people were able to purchase all the medicines prescribed to their patients however 412 (88.8%) respondents were unable to purchase it. Chelation therapy is needed for survivals but majority of respondents were unable to afford prescribed medicine.

Regardless of financial costs, the guardians were also facing social, and family problems due to permanent illness of their children as our study showed that 180 (38.8%) respondents responded that the morbidity of their children affected their relationship with their spouse.

416 (89.7%) of the respondents were of the view that there was no Thalassemia center nearby their city/ village so they were unable to get medical and blood transfusion services from the public sector hospitals. 48 (10.3%) responded that the Government hospital had a Thalassemia center but sufficient blood is not available at the government hospital.

The transfusion centers for thalassemia patients are situated in the big cities so the patients as well as their guardians belong to small cities, villages, and far flung areas have to travel long which is a big problem for them. Inability of patient to cover disease cost is a major issue for them. Ahmed (2002) also stated that approximately 4% of national health budget devoted to Thalassemia care in Pakistan, which would elevated to 40% if proper treatment was provided to all thalassemia patients.[8] So there is dire need to address the problems associated with the treatment of Thalassemia in Pakistan.

CONCLUSION

It is concluded that there is less number of Thalassemia centers in Punjab as compared to high number of patients. So guardians of the patients are facing many other problems along with morbidity of their children. Long traveling and non-availability of free medicine was creating problems to the respondents and lesson the life expectancy of the patients as majority of parents were not able to purchase prescribed medicines. There is dire need to establish more Thalassemia centers at that provide free blood transfusion and also ensure the provision of necessary medicines to all Thalassemia patients at zero cost in each Tehsil Headquarter Hospital.

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AUTHORSHIP AND CONTRIBUTION DECLARATION

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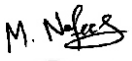
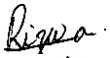
1	Muhammad Nafees	Write up	
2	Zahira Batool	Analysis of Data	
3	Rizwan Ashraf	Proof reading	
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