ORIGINAL ARTICLE

EVALUATION OF GROSS MEDICAL CARE EXPENDITURE ENDURED BY PARENTS OF THALASSEMIA MAJOR PATIENTS

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Background: Thalassemia major is a chronic problem and requires lifelong treatment that costs a lot to the parents directly or in directly. Objective of this study was to evaluate the gross medical care burden on the parents of thalassemia major patients visiting tertiary care hospitals for treatment. **Methods:** This cross-sectional research of six month duration (Jan–Jun 2024) was carried out in Quetta. Parents of malnourished thalassemia major patients admitted in paediatric wards were included whereas rest of the parents of thalassemia major patients with problems other than malnutrition were excluded. Systematic random sampling was used to gather data via preformed structured questionnaire. Ethical consideration was obtained from the parents and ERB of SOD before study. Descriptive statistics, i.e., frequencies and percentages were calculated and results were presented in the form of tabulation. **Results:** Among the 100 parents, more than half (65) were males and 35 were females. Majority (80%) parents had 1–5 siblings, 81% families had only a single earning member, 53% parents had 1 or 2 visits per month for blood transfusion. Ninety-seven percent and 89% parents respectively said that expenses on food and transport ranged from PKR 200–500. **Conclusion:** Parents spend about 300 rupees on food and about 300 rupees on travelling per visit so they had to spend about Rs. 1,200 (on an average) per month as most of them visit at least twice for the transfusion (some of them had to visit 3 times per month).

Keywords: Economic evaluation, expenditure, malnutrition, parents, thalassemia major.

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INTRODUCTION

Malnutrition is amongst one of effects of thalassemia because of fast erythrocyte turnover. Frequent blood transfusions are required for thalassemia patients.[1] Malnutrition or malnourishment affects individuals in every nation. Malnutrition refers to 'excesses, deficiencies, or imbalances in an individual's intake of energy or/and nutrients'.[2] Nutrition in early phases of life can have long-term health effects in adulthood.[3] Thalassemia major patients fail to thrive and required blood transfusions on regular basis and because of iron accumulate in various organs of body, it may lead to organ damage, which should be managed as part of conservative management otherwise it might lead to organ failure, which requires intravenous and oral iron chelation therapy.[4] Thalassemia is reported to be prevalent throughout Southeast Asia.[5] Approximately 12,000 babies born in India each year (10% of the world's burden) are affected with major form of this disease, and half of these children pass away before they become adults. A significant proportion of these early demises are because of malnutrition.[6,7] Thalassemia major is common in Pakistan as well. About 5,000 children are born every year with thalassemia here, and then the cost that the patients and their families have to bear is huge. Many countries worked a lot on the premarital screening and the diagnosis of the thalassemia trait cases so that they can prevent the medical catastrophe in their families.[8] Another study on 500 people of northern areas of Pakistan revealed an overall prevalence of 5.4%.[9]

Malnutrition among thalassemia children is multi-factorial. Usually these kids belong to more economically impoverished segment of the society. Parental literacy and socioeconomic status are important factors in this context[10], as socioeconomic status is also a predictor of a wide range of outcomes over the course of a person's life, including their physical and psychological health[11,12]. The aim of this study was to evaluate the gross medical care expenditure borne by the parents of thalassemia major patients visiting tertiary care hospital.

METHODOLOGY

This cross-sectional research was carried out in Sandeman Provincial Hospital, and Bolan Medical College Hospital, Quetta from Jan to June 2024. Ethical approval was obtained from ERB under No. SOD/ERB/2023/61-07, and consent of parents was taken before carrying out the study. Sample size of one hundred (100) was calculated by following formula:

$$N=Z^2\,1\text{-}\alpha/2\;P\;(1\text{-}p)\;N/d^2\;(N\text{-}1)+Z^2\;1\text{-}\alpha/2P\;(1\text{-}P)$$
$$=1.96^2\,\chi 0.06\,\chi 0.94\,\chi\,165000/(0.05)^2\,(165000)+(1.96)^2\,\chi\,0.06\,\chi\,0.94$$
$$=100\ \text{(sample size)}$$

where Z=confidence interval, P=Prevalence of thalassemia, N=Number of major thalassemia cases,

d=Error level (5%). Ten percent additional samples were included to overcome loss of data. Parents of patients having malnourishment with thalassemia major without any other systemic illness, mental confusion, talking or hearing disorders were included in this study. Parents of patients having malnourishment with thalassemia major and other additional issues of systemic illness, mental confusion, talking or hearing disorders were excluded.

Systematic random sampling was used to gather data via preformed structured questionnaire. Questionnaire was divided into several portions; quantitative section with the parents and patient's demographic data, then the financial burden on family by inquiring the various questions about the illness expenditure, parent's occupations and earnings. Descriptive statistics, i.e., frequencies and percentages were calculated and results were presented in the form of tabulation.

RESULTS

Among the 100 parents, more than half (65) were males. Majority (80%) parents had 1–5 siblings. Eighty-one percent families had only a single earning member, while 17% had 2–5 earning family members. One-fourth respondents were government servants, more than half were labourers, and 15% were shopkeepers. Almost half (49%) of the parents were uneducated, 15% were matriculate and merely 7% were graduate or above. Socio-demographics are depicted in Table-1.

Table-1: Demographic characteristics of parents of malnourished thalassemia major patients

	Number	Percentage
Number of siblings of patients		
1–5	80	80
6–10	18	18
11–15	1	1
16 and above	1	1
Number of earning members of family		
1	81	81
2 –5	17	17
6 & above	2	2
Occupation of earning members of family		
Labourer	58	58
Shopkeeper	15	15
Government servant	25	25
Others	2	2
Level of education of parents		
Uneducated	49	49
Primary school certified	7	7
Middle certified	13	13
SCC	15	15
HSSC	9	9
Graduate and above	7	7

Ninety-seven percent and 89% parents respectively said that expanses on food and transport ranged PKR 200–500. Fifty-three percent (53%) parents had 1 or 2 visits per month for blood transfusion, and 42% visited 3 or 4 times a month for their children who were malnourished thalassemia major patients. All parents had to visit hospital for chelation of their thalassemic major children every month. (Table-2).

Table-2: Gross medical care expenditure defrayed by parents visiting the hospital for treatment of their malnourished thalassemia major children

Expenses	Numbers	Percentage
Travel expenses (PKR)		
200–500	89	89
501–800	9	9
801–1200	1	1
1201–1500	1	1
Visits per month for confirmed transfusion		
1–2	53	53
3–4	42	42
5 and above	5	5
Visits per month for chelation		
Once in month	100	100
Expanses on food (PKR)		
200–500	97	97
501–1000	3	3

DISCUSSION

Thalassemia is an autosomal recessive single gene malady as a result of imbalance in the formation of α- and β-globin chains, leaving behind an advanced negative impact on the nutritional status that has become a huge problem in this era.[1] Thalassemia major is a chronic problem and required lifelong treatment that costs a lot to the parents directly or in directly. In some other countries, the parents get insurance for certain diseases where their children who are patients also gets insured for different diseases but in some cases they had to pay. At several instances, patients are supported by the government only for direct medical cost, and parents have to pay for their food, and transport, and have to sacrifice their daily wages. A study conducted in Iran in 2015 showed that there was a lot of direct medical cost burden in spite of being insured because of the payments other than direct medical bills.[13] In our study 50% of the parents were uneducated which is far better than 89.5% reported earlier[14]. Seven percent parents in our study were graduate or above which is more than 3.15% reported[15] parents. Job status of our respondents is comparable to another study[16].

Treatment of thalassemia major includes regular blood transfusion, iron chelation, bone marrow transplantation, and gene therapy.[17] In our study, 53% parents had 1 or 2 visits per month for blood transfusion, the number at which they actually got blood for transfusion. Otherwise they had to visit more as some times the blood was not available. Forty-two percent of our subjects visited 3 or 4 times a month which is comparable with another study[18] where 33% folks visited monthly and 9.60% visited 4 times a month.

In this survey, 97% of the attendants spent PKR 200–500 on food for child, and 89% spent PKR 200–500 on transportation which is comparable with another study[19] where US$ 7.57 and 4.26 were spent respectively on food and transportation per transfusion.

A research from Multan[20] found that most of the family members had an income of PKR 5,000 to 7,000 PKR and the average expanses on the treatment of

the child were about PKR 10,000. The study from the Northern Punjab[21] to find the impact on the families of the thalassemia major patients found that due to this there is huge impact (economic burden) on the financial and social life of the families of those children. Considering the higher treatment costs on thalassemia major patients, it is necessary to create new policies to lessen the expenditures that patients and parents have to pay. Because thalassemia treatment is expensive, it may be worthwhile to consider novel options for screening. Even if it involves paying more than normal but quality of life of patients can be improved.[13,22]

This study was done in public hospitals, most of patients belonged to poor socio-economic status. It was a small sample size. Direct and indirect costs were not estimated separately in this research.

CONCLUSION

Parents spend ~300 rupees on food and ~300 rupees on travelling per visit to hospital so they have to spend roughly PKR 1,200 per month as most of them visits at least twice for the transfusion (some of them had to visit 3 times per month as well).

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