ORIGINAL ARTICLE

OUT OF POCKET EXPENDITURE ON THALASSEMIA MAJOR AND ITS IMPLICATIONS ON THE HOUSEHOLD ECONOMICS

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Background: Pakistan faces a considerable burden of disease with regard to inherited blood disorder, i.e., Thalassemia Major. Its economic implications are least studied before, particularly when it comes to ascertaining a household's out of pocket expense on treating the disease. This study was carried out to understand the current estimate of Out-of-pocket expenditure (OOP) expense and its implications on the household and livelihood, while seeking treatment for a child suffering from thalassemia. **Methods:** It was a descriptive cross-sectional study of 3 months' duration. Patients were selected from Fauji Foundation Hospital (FFH) and Pakistan Institute of Medical Sciences (PIMS), through. The descriptive quantitative analysis and inferential analysis was carried through purposive sampling. **Results:** Treatment expense of entitled patients from FFH hospital (a public hospital which offers entitlement to the families of retired army personnel) was compared with that of non-entitled patients coming to PIMS (a public sector general hospital). Total expense incurred on treatment by the end of the month was PKR. 5000–10,000 (USD31-62) in FFH, while at PIMS, the total expense incurred on treatment by the end of the month was around PKR 80,000 (USD500). Around 37% families having an average monthly income of PkRs25000 (USD150) only, sold their livelihoods, 31% compromised on their children's education expenses and 23% percent curtailed the health expenses of the other children. **Conclusion:** The out-of-pocket expenditure on treating TM is quite high and compels the families to borrow money and sell or mortgage their property, which puts a great deal monetary pressure given their socio-economic status. A practical solution would be to cover these families under the health safety net supported by the government.

Keywords: Thalassemia major; Out of pocket expenditure; Catastrophic expenditure; Direct cost; Indirect cost; Household economics.

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INTRODUCTION

Many a times, out of pocket (OOP) expenditure on health pushes the poor segments of population into an imminent threat of poverty; and therefore, they will either forgo or delay seeking the health care. The non-affording prices of health care and the financial constraint add to their impoverished state and the families will be further driven into the vicious cycle of poverty.[1]

This state of affairs has a detrimental effect on the individual family members also.[2] Among other chronic childhood diseases, Thalassemia major (TM) is one which is expensive to treat and it's cost of treatment has been expensive all over the world. Besides direct treatment costs, there are significant indirect costs associated also.[3,4] The costs of thalassemia treatment are not only the concern of the health system but also of the affected individuals and their families because the treatment decisions and coping mechanisms usually take place at the household level. In many low- and middle-income countries, the families caring for a child with β-thalassemia require financial support to mitigate adverse financial hardship.[5]

Thalassemia is the most common inherited blood disorder in Pakistan. An estimated 5000-7000[6] children are born each year suffering from thalassemia with a carrier rate of 5–7%.[6] These children are dependent on blood transfusions and iron chelation at a very early age of life.[7,8] However, unfortunately there are very few studies conducted in Pakistan to estimate the OOP expenditure and its implications on the households with children suffering from TM.[9,10] In one study conducted in 2017, the cost of treating a thalassemia child per month was PKR 9,626 (USD60) per month.[11] Management of thalassemia major mainly requires regular and safe blood transfusion with adequate iron chelation for a better quality of life. Although there are many institutions and organizations to provide blood free of cost but there are still other expenses for these patients. As they grow older due to repeated blood transfusion, they develop alloantibodies that cause destruction of the normal transfused red cells and reduce the interval between subsequent transfusions. The increased transfusion demands lead to shortage of blood supply for these patients. Yet, there are still other expenses such as leucodepletion,

processing, screening and testing of blood products. Hepatitis B and C is also common in these patients from chronic blood transfusion. This kind of treatment and medical maintenance demands considerable expenditure. Hence the high cost of treating such patients is not affordable by majority of the families

Our study was conducted in two different settings, i.e., Fauji Foundation Hospital (FFH) Rawalpindi and Pakistan Institute of Medial Sciences (PIMS) Islamabad with the aim to ascertain the out-of-pocket expenditure on Thalassemia major and its implications on the household economics and to weigh if it leads to a catastrophic expenditure. FFH is a public hospital which offers entitlement to the families of retired junior commissioned army personnel and PIMS is a public sector general hospital.

MATERIAL AND METHODS

It was a descriptive cross-sectional study, conducted in the Paediatric Unit of FFH and Thalassemia center of PIMS hospital. The duration of the study was from September to December 2019. The study population comprised patients of Thalassemia major and the respondents were the parents of Thalassemia children. A systematic random sampling was done to recruit 100 Thalassemia major patients from each site. Sample size was calculated using the following formula:

$$N = Z^2\,1\text{-}\alpha/2\ P\ (1\text{-}p)\ N/d^2\ (N\text{-}1) + Z^2\,1\text{-}\alpha/2P\ (1\text{-}P)$$
$$= 1.96^2 \times 0.06 \times 0.94 \times 165000 / (0.05)^2\ (165000) + (1.96)^2 \times 0.06 \times 0.96$$

Z = confidence interval
P =Prevalence of thalassemia. (5%)
N = Number of thalassemia major cases
d = Error which is 5%
10% additional sample were included to overcome loss of data.
n= 100
Patients with other haemoglobinopathies such as thalassemia intermedia and thalassemia minor were excluded from the study. The data was collected in the form of structured questionnaire and was filled by the principal researcher. Interviews were taken from the parents/care takers of the patients after obtaining the written consent signed from them. Questions regarding the OOP expense and the implications of expenditure on the household were asked in detail through a small interview from the parents of the TM patients.

Quantitative statistical analysis of variables from the questionnaire was carried out after the data in SPSS version 21.0. The descriptive analysis included frequencies and percentages of the categorical variables. The dependent variables were expense on treatment, blood transfusions, iron chelation, OPD visits, food, travel, medications and the blood tests. The independent variables will be the age, gender and the cousin marriage. The inferential analysis was carried out using the chi-square test along with cross-tabulation to assess the level of association.

Institutional Review Board of the Health Services Academy granted the ethical approval to conduct the study. Permissions to conduct study was sought from the Hospital Research Committees of both hospitals. Written consent was taken from the study respondents, after explaining to them the objectives of the study.

RESULTS

Out of 100 thalassemia major patients, 55% were males and 45% were females. Thirty-five were in between 6 months-10 years, 63% were in between the age of 11–20 years and 2% were in between 20–30 years. These patients belonged to a poor socioeconomic group. The results of the study showed us that 75% of the families had monthly income in between the range of Rs 21,000–30,000. Eighteen percent had in between the range of PKR 11,000–20,000. Eighty-two percent parents of the thalassemia major children had to pay PKR 6000–10,000 per month for acquiring blood products to compensate for the anaemia. This amount varied depending on the center from where they took the blood and blood bag screening. The expense incurred on iron chelation per month was less than PKR 5000 for 68% of the respondents. Only 13% had to pay PKR 21,000–40,000. The expense incurred on food was less than PKR 5000. 67% paid PKR 6000–10,000 and 23% paid PKR 11,000–20,000 per month for their OPD visits. This included the money paid on the medical consultation, OPD slip and basic investigations for disease monitoring including CBC and Serum Ferritin. Total 56% paid PKR 41% paid PKR 11,000–20,000 followed by 29% paid PKR 6000–10,000 per month for the medications. Only 17% had to pay PKR 21,000–40,000. It included hydrae for the augmentation of HbF and antibiotics in case of infections.

Figure-1 shows the total expense on treatment of TM by the end of last month with 76% spending Rs > 80,000/ month. Comparison of the treatment expense between the two hospitals show that at FFH where entitled patients and families of the retired army personnel are seeking treatment are getting relief to some extent as far as the total expenditure on treating TM is concerned. However, at PIMS where there is no entitlement by and large, the monthly expense is quite high (PKR

80,000/USD500) as compared to FFH (PKR 5,000-10,000/USD31–62), as shown in figure 2 and 3. When p value was computed for assessing any significant association between the expenses incurred at two health facilities, it came out to be significant as shown in table-1.

When families were asked about the effect of thalassemia on the other family members of the house, 37% of the respondent report that they sold livelihood, 31% compromised on their children's education and 33% compromised on the health expenses of the other children, as shown in figure-4. Around 98% of the respondents said that they borrowed money from their relatives, friends and colleagues at their work place to cope up with the costs incurred on the treatment of TM.

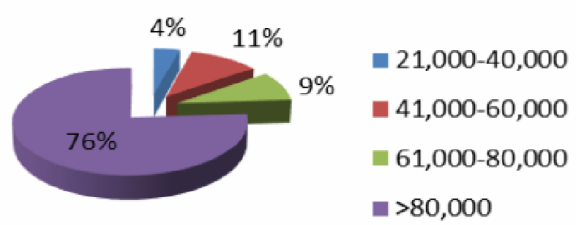

Figure-1: Total expense in Rupee on treatment of thalassemia major by the last month.
N(total)=100

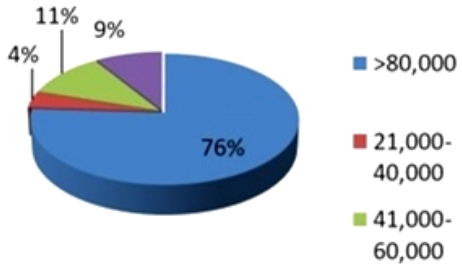

Figure-2: Total expense on treatment in the last month of PIMS.

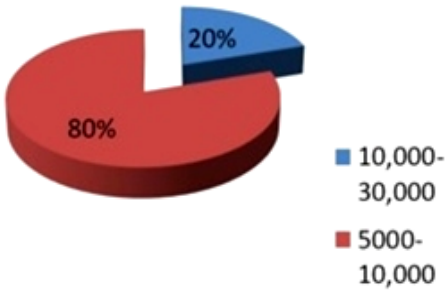

Figure-3: Total expense on treatment in the last month of FFH

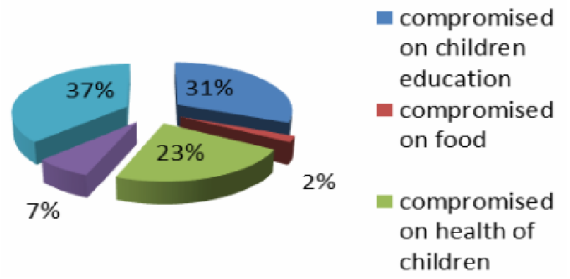

Figure-4: Major economic implications on household. n%(total)=100

Table-1: Total expense incurred on patients with n=100

Total expense (Rs)	FFH	PIMS	*p*-value
5000-10,000	80%	0%	
10,000-30,000	20%	4%	
30,000-40,000	0%	11%	
40,00-50,000	0%	9%	
>50,000	0%	76%	0.000*

p<0.05* =statistically significant.

DISCUSSION

Our study was conducted with the aim to explore the out-of-pocket expenditure on thalassemia major and its implications on the household economics such that it leads to a catastrophic expenditure. Thalassemia major is an inherited disorder which can be prevented. Various other studies have been conducted showing similar findings.[12] a study in Iran also shows similar results of screening and treatment of TM. They found the cost of managing a patient with thalassemia major was about US$ 136 532 per year.[13] a study in Malaysia to find the life time cost of treating a tm child was found to be USD 561,208 and the main cause of this cost was iron chelation therapy (56.9%) followed by blood transfusion cost at 13.1%.[14] Another study in Sri Lanka shows similar findings where total cost per year to the hospital was calculated to be $US 2601 of which $US 2092 were direct costs and $US 509 were indirect costs. The mean household expenditure was found to be $US 206 per year with food and transport per transfusion ($US 7.57 and $US 4.26 respectively) being the highest cost items.[4] However the cost on food in our study was lowest as most of the patient's bought food from their homes. The same study also showed that 9 (26.5%) families experienced catastrophic levels of healthcare expenditure (>10% of income) in care of TM child.[4] A literature review on economic burden of TM children shows similar findings were direct medical cost from transfusion and iron chelation drug cost represents the largest portion of total cost of TM therapy.[15] As TM is a disease which requires regular medical care and blood transfusions to keep the children thriving. This sort of treatment costs significant amount which should either is covered by an entitlement, insurance and safety net.[16] Our study confirmed that the families of thalassaemic children having a service entitlement are saved to quite an extent

from the catastrophic expenditure. Others not having any medical entitlement or coverage by a safety net had to face high OOP expense. These families eventually compromised on other aspects of their livelihood and end up incurring a catastrophic expenditure, i.e., nearly 10% of their total monthly income. The poorest households were the most likely to experience such levels of expenditure. Our results corroborate with other studies which recorded the economic implications of TM treatment such as borrowing of money, selling or mortgaging the property which led to a catastrophic end for the family. Governments do provide financial safety net to the families with marginal income so that they can seek health care without any delay.[16]

CONCLUSION

The families of children suffering from thalassemia major face a significant out of pocket expenditure on the treatment, which puts a great deal monetary pressure given their socio-economic status. This evidence calls for the provision of safety net to the families of TM children.

Limitations: Sample size is small for generalizability across all districts of the country /province. Limited time period for study and only quantitative method is used.

Way forward: We recommend the need to spread more awareness on thalassemia major treatment organizations to help out these poor households. Private sectors also have a social responsibility. We recommend them to join hands with the government and non-government organizations to make the treatment more accessible and affordable to these families.

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AUTHORS' CONTRIBUTION

MKQ conceived the research question, designed the study, collected data and analyzed it. She drafted the manuscript. BTS supervised her research, helped in in designing the data collection tool, provided oversight to the data collection and analysis, and later contributed to the development and finalization of the draft of the manuscript.

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