

Letter to the Editor (Viewer's Choice)

FINANCIAL BURDEN ON THE FAMILIES OF TRANSFUSION DEPENDENT THALASSEMIC CHILDREN

Karanjit Singh, Karnail Singh, Ravikaran Singh, Dilnoor Kaur

There are about 25 million carrier of beta thalassemia genes and over 9000 children of thalassemia major born every year. (1,2) The mainstay of the supportive treatment of thalassemia major is regular blood transfusion accompanied by iron chelating therapy. Hematopoietic stem cell transplantation, a curative therapy costs Rupees (Rs) one million which is very expensive and few can afford. The cost of optimal transfusion and chelation treatment in India is Rs 125,000 per year which only 10-15% could afford. (3,4) The immense medical cost makes a huge financial burden on the families of thalassemic children, which is of a major concern for the poor families.

We undertook a retrospective study to estimate the monthly expenditure and financial burden on the families of 59 regularly transfused thalassemic children. Per month expenditure was calculated by dividing total expenditure on investigations, transportation, logistics, iron chelation therapy and other supportive therapies by total period in months (starting from time of diagnosis till the conclusion of the study). Twenty-five of 59 (42.4%) parents were small-scale shopkeepers, 3 (5.1%) were in government jobs, 9 (15.3%) were in private jobs, 4 (6.8%) were professionals, 4 (6.8%) were farmers, 9 (15.3%) were laborers/skilled workers, 2 (3.4%) parents were not living together and 3 (5.1%) children were fatherless. Monthly family income in 27 (45.8%) was between Rs. 3500-7000, in 4(6.8%) was less than Rs. 3500, in 19 (32.2%) was Rs 7000-12500 and only 9 (15.3%) were earning more than Rs 12500 per month. The monthly expenditure for the patient is depicted in Figure 1. Those who spent less than Rs. 700 per month spent only for blood transfusion, in those who spent between more than Rs. 2100 per month, iron chelation therapy as well as other supportive therapy in the form of folic acid and calcium was given to the thalassemic children.

Regarding expenditure on investigations at the time diagnosis and follow up, 34 (57.7%) spent less than Rs. 6000, 5 (8.5%) spent between Rs. 6000-12000 and 20 (33.8%) spent Rs. 12000 and above. No amount was spent for investigations on other family members to detect carrier stage in 34 (57.6%) families citing poor economic conditions.

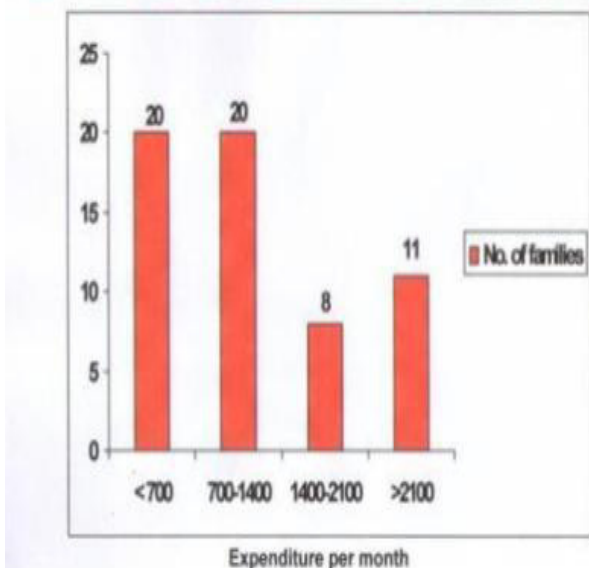
Fifty three (89.8%) patients received more than 25 units of blood thus requiring iron chelation therapy but only 21 patients (35.6%) were able to afford it. Thirty eight patients (64.4%) have never taken treatment for iron chelation. The only reason was high cost of treatment.

Ideally, a regularly transfused patient should take iron chelation, periodic relevant laboratory investigations, use of leucocyte filtration blood set, proper immunization and treatment for complications. The approximate expenditure in this way came out to be Rs. 2500 per month in a government set up, which only a few have afforded in this study. The Immense medical cost makes a huge financial burden on the families of thalassemic children, which is of a major concern for the poor families.

REFERENCES

1. Thakur (Mahadik) C, Vaz F, Banerjee M, Kapadia C, Natrajan PG, Yagnik H, Gangal S. Prenatal diagnosis of beta-thalassaemia and other haemoglobinopathies in India. *Prenat Diagn.* 2000; 20: 194-201.
2. Verma IC, Choudhry VP, Jain PK. Prevention of thalassemia: a necessity in India. *Indian J Pediatr.* 1992; 59: 649-654.
3. Sheth JJ, Sheth FJ, Pandya P, Priya R, Davla S, Thakur C, Flavin V. Beta-thalassemia mutations in western India. *Indian J Pediatr.* 2008; 75: 567-570
4. Karnon J, Zeuner D, Brown J, Ades AE, Wonke B, Modell B. Lifetime treatment costs of beta-thalassaemia major. *Clin Lab Haematol.* 1999; 21: 377-385

MONTHLY EXPENDITURE OF THE FAMILY (in Rs)



From: Department of Health and Family Welfare, Punjab, India.

Address for Correspondence: Dr Karanjit Singh, D-124, Ranjit Avenue, Amritsar (Punjab) - 143001. India. Email: kjspatti@yahoo.co.in.

E-published: 1st January 2013 **Art#**2

DOI No. 10.7199/ped.oncall.2013.2



Quick Response Code