Original Article

# Comparative Analysis of the Cost of Thalassemia Screening VS Treatment in Different Healthcare Sectors in Delhi National Capital Region

**Ritu Gupta[1], Nita Radhakrishnan[2], Ravi Shankar[3], Shomik Ray[4]**

**[1]Senior Analyst, ICON Plc, [2]Additional Professor, Department of Pediatric Hematology Oncology, Post Graduate Institute of Child Health, Noida, [3]Consultant, Pediatric Hematology Oncology and BMT, Sanar Hospitals, Gurgaon, [4]Associate Professor, Indian Institute of Public Health Delhi, India.**

**How to cite this article**: Ritu Gupta, Nita Radhakrishnan, Ravi Shankar et. al. Comparative Analysis of the Cost of Thalassemia Screening VS Treatment in Different Healthcare Sectors in Delhi National Capital Region. Indian Journal of Public Health Research and Development / Vol. 16 No. 2, April-June 2025.

**Abstract**

**Background:** Thalassemia is a single gene disorder that is passed on from parents to children. According to the World Health Organization, the carrier rate of thalassemia is between 3-7%. Treatment and management of a thalassemia major patient costs the family around USD 5389-13474 per year (INR 100,000–250,000) depending on the age and presence of complications. Screening of antenatal women have the potential to reduce the burden of thalassemia and could offer a much effective strategy.

**Methods:** A hospital based cross-sectional study was conducted to assess the cost of treatment and screening. Patients visiting thalassemia treatment centres in the National Capital Region were asked questions to assess the annual cost of treatment incurred.

**Results:** The annual treatment of thalassemia patients in government, non-governmental/charitable and private sector hospitals is being reported here. When analyzing the cost for the population at large, screening costs only 0.01% of the treatment cost.

**Conclusion:** Therefore, we can infer that screening in whole population is much more efficacious as compared to treatment in 10,000 people. Thus, screening and prevention not only reduces the morbidity and mortality associated with the disease, but also is a better public health model for countries with high prevalence of thalassemia.

**Key Words:** Thalassemia screening, cost analysis, single gene disorder

## Introduction

Thalassemia is a single gene disorder which is inherited in an autosomal recessive pattern[1,2]. Thalassemia major usually presents early; within the first 2 years of the life of the child and is fatal unless started on a regular transfusion regimen[3]. Based on the clinical severity, thalassemia is divided into transfusion dependent and non-transfusion dependent states[4]. As it is inheritedin autosomal

**Corresponding Author: Nita Radhakrishnan,** Additional Professor, Department of Pediatric Hematology Oncology, Post Graduate Institute of Child Health, Noida.

**E-mail:** nitaradhakrishnan@yahoo.com

**Submission date:** August 25, 2024 **Acceptance date**: September 30, 2024 **Published date: March 11, 2025**

This is an Open Access journal, and articles are distributed under a Creative Commons license- CC BY-NC 4.0 DEED. This license permits the use, distribution, and reproduction of the work in any medium, provided that proper citation is given to the original work and its source. It allows for attribution, non-commercial use, and the creation of derivative work.

recessive manner, the parents of the affected child are carriers who pass on the defective gene to the child[4].

Among inherited conditions, thalassemia is one of the most prevalent disorders, affecting nearly 200 million people globally[5,6]. The carrier frequency of beta thalassemia in India is estimated to be 3% to 7%, thus posing a major public health concern[7]. In India, approximately 8000-10,000 children every year are born with beta-thalassemia major, which represents 10% of the thalassemia-major burden around the world[8]. Across India, as the thalassemia prevalence vary between 0.6% and 15% in different populations, it is estimated that there are approximately 42 million beta thalassemia carriers[9,10]. There are multiple strategies that have been suggested for reducing the burden of thalassemia in the country. Detection of carriers through population-based screening (e.g. in schools, colleges etc), focused group screening (antenatal women in first trimester) and cascade screening of extended family members of an affected child are strategies that have been suggested. Of these, mandatory antenatal screening is probably the most cost-effective method of detecting carrier state, as antenatal period offers a captive period where the pregnant lady is expected to return to the healthcare facility desirous of healthcare.

## Methods

A hospital based cross-sectional survey was conducted after receiving Institutional Ethics Committee approval (reference no IIPHD_IEC_S_33_2019 dated 10 December 2019) among the parents of thalassemia patients to assess the annual treatment cost at a government institute (Post Graduate Institute of Child Health, Noida), a non-governmental organization (Red Cross Society) and patients visiting a private hospital in Delhi. The study was conducted over a period time of three months starting from December 2019 to March 2020. The study participants were thalassemic patients and their families. After taking written consent from the parents of patients aged ≤ 25 years and patients aged >25 years, interviewer administered questionnaire was administered. Participants were approached through the respective hospitals and the Red Cross Society helped in contacting patients who were under their support. Based on the objective of the study, purposive sampling was done to select participants from the hospitals from where permission was granted. To assess the cost of treatment, using 7% prevalence and 5% precision, the sample size of 100 was calculated. Considering 10% non-response rate, the final sample size estimated was 110 and were balanced between the 3 groups. Anonymous, interviewer administered questionnaire was prepared to assess treatment cost. A similar questionnaire by Thalassaemia International Federation has been used as a guidance document[10]. The questionnaire was pretested and piloted before finalization to ensure appropriateness and completeness.

The study participants were asked about their annual cost of treatment. Costs were collected by components and presented separately as well as in aggregate. User costs were collected and presented separately from treatment costs. Non-medical user costs included cost of transportation and cost of wage loss. The study has not included cost of complications beyond treatment of primary condition of thalassemia.

For screening,costs associated with prenatal screening of thalassemia among antenatal women during their first trimester using hemoglobin electrophoresis was examined. Screening in thalassemia patients is done by (antenatal women in their first trimester) by HPLC test (high performance liquid chromatography) followed by confirmatory test in the spouses of thalassemic females to see whether the couple is “at risk” or not. After detection of “at risk” couples, couples are referred to genetic counseling. Finally, those who agree for genetic counseling are advised to have prenatal genetic diagnosis of the fetus by chorionic villus sampling (CVS) at around 12 weeks of gestation. After prenatal genetic diagnosis, most couples with thalassemia major affected fetus opt for termination of pregnancy. Screening costs assessed in this study is an aggregate of all the above tests. Cost of prenatal screening was assessed from various private laboratories in Delhi NCR (Lal Path labs, House of Diagnostics, SRL, Prognosis lab, Niramaya, BLK Hospital, GangaRam Hospital, Apollo Hospital) and government hospitals (All India Institute of Medical Sciences, Kalawati Children’s Hospital and Safdarjung Hospital) in Delhi and laboratories where screening of thalassemia and genetic counselling is

being done. Purposive sampling was done for cost of prenatal screening tests as all labs and hospitals do not provide genetic counselling and pre-natal diagnosis tests. Cost of prenatal screening tests was asked from private hospitals and laboratories based on convenience and mean costs were calculated. The costs were presented separately by individual tests as well as in aggregate, separately for each type of provider. It is to be noted that only cost of treatment incurred by the patient's family is calculated and not that was incurred by the hospital since they receive free treatment through government schemes. The out of pocket expenses incurred by family such as caretaker salary loss also has not been calculated. Ethical approval for conducting the research was taken from Institutional Ethics Committee of Indian Institute of Public Health, Delhi.

## Results

Background characteristics of the respondents (parents of thalassemia patients) are displayed in Table 1. 50 patients attending government hospital, 20 attending NGO and 30 attending private hospital were enrolled. 10 families who underwent prenatal were interviewed for the costs. The overall response rate was 88% (97/110). The age of patients included in the study ranged from 1 to 39 years (mean 13 years and SD 6.5). Around 56% of the patients were females. The majority of parents of the patients (40%) were salaried followed by unemployed (29%). Homemakers constituted about 17% of the total participants while only 12% accounted for daily wage workers. Forty-three percent completed their education up to school or equivalent, 34% studied up to the fifth standard while15% had not attended school at all. The monthly household income of the respondents ranged from USD 36 (INR 3,000) to USD 4,268(INR 3,50,000). The mean and median monthly income of the respondent was around USD 900 (INR 73947) and USD 304 (INR 25000) respectively with interquartile range USD 121- 1433 (INR 10000-117500).

Components of cost of screening/couple

Screening cost included the cost of HPLC test which was considered as the first test to check the carrier status of the parents. The test was found to cost an average of USD 4.27(INR 350) in government institutes and about USD 14 (INR 1153) in private institutes. If both the parents were tested positive, they are advised to go for genetic counseling which costs USD 16.6 (INR 1360) on an average in private hospitals and labs. There was no fee for genetic counseling in government hospitals. If the parents agree then they undergo prenatal diagnosis to know whether the baby is thalassemic or not. This test costs about USD 24.3 (INR 2000) in government and USD 233(INR 19116) in private institutes. If the baby turns out to be thalassemic major, then most couples would opt for termination of the pregnancy which costs USD298 (INR 24500) in private and USD 6 (INR 500) in government hospitals. Overall, the average cost of screening in government hospitals amounts to USD 34.7(INR 2850) per couple; in private hospitals, the average cost for screening is USD 563 (INR 46170) per couple. Difference in private and government screening cost was USD 132 (INR 10830) but is not statistically significant.

Components of annual government and private treatment cost

Current recommendation states that transfusion therapy should be started as soon as the patient is diagnosed with haemoglobin level less than 7gm/dl at least on two consecutive tests(12)varying methods of obtaining blood, different practices in screening for blood pathogens and different costs of drugs and equipment. It is evident that all countries would benefit from the sharing of experience and expertise in order to harmonize and optimize the quality of treatment as much as possible. The need for management guidelines for Transfusion Dependent Thalassaemias (TDT. After the thalassemia patient has been diagnosed with thalassemia major, pre transfusion haemoglobin level test needs to be done to maintain the haemoglobin level above 9.5-10gm/dl(13)including Germany, due to immigration.\n\nMethod\nSelective review of the literature with consideration of national guidelines.\n\nResults\nThe hemoglobinopathies encompass all genetic diseases of hemoglobin. They fall into two main groups: thalassemia syndromes and structural hemoglobin variants (abnormal hemoglobins. Chelation therapy (removal of excess iron from the body with drugs) needs to be initiated along with the transfusion of blood to maintain serum ferritin level below 1000 ng/ml(12)varying methods of obtaining blood, different practices in screening for

blood pathogens and different costs of drugs and equipment. It is evident that all countries would benefit from the sharing of experience and expertise in order to harmonize and optimize the quality of treatment as much as possible. The need for management guidelines for Transfusion Dependent Thalassaemias (TDT.

Treatment for thalassemia includes the cost of regular transfusion of leukodepleted blood, medical treatment such as chelation therapy and investigations at each hospital visit and annually to monitor for complications. In government hospitals such as PGICH, Noida which is supported by National Health Mission, Blood Cell, Uttar Pradesh, all patients are provided free of cost NAT tested and leukoreduced blood and chelation therapy. All routine investigations are also provided free of cost to the patient through the NHM budget. At such centres, the cost incurred by the patient would only be for their travel to the hospital and additional investigations. The cost incurred by the hospital is borne by the budget for hemoglobinopathies under the National Health Mission, Ministry of Health and Family Welfare.

In the case of non-governmental organizations and government institutions, maximum proportion is spent by the patients on laboratory tests followed by cost of referral at NGOs. Cardiology, endocrinology and hepatology evaluation is done once annually and on sos basis and referral to specialist involves multiple visits to different specialists. In government setup, physician fee is usually free and it constitutes USD 12 (Rs. 1000) to patients visiting NGOs.

Chelation and leukodepleted blood were given free of cost to patients at the government hospital and NGOs. In the case of private hospitals, chelation constitutes the highest cost component (75%) although it also includes physician cost, and drug cost. It accounts for USD 3,016 (INR 2, 47,323) annually. After this, 10% is accounted for by specialist cost, 7% is spent on hospitalisation while 6% on transfusion. Cardiac evaluation and ferritin test accounts for only 1% of the components of the treatment cost.

Overall, the average annual cost per thalassemia patient was USD 32 (INR 2681) and USD3840(INR 3,14,906) in government vs private sector respectively for transfusion and chelation as shown in table 3. It is again highlighted that in government centres, this cost is borne by the state government either directly or through National Health Mission as the case may be whereas in NGO and private hospitals, the cost is borne by the family.

**Table 1: Background characteristics of participants (N=97)**

| **Background characteristics** | **N=97** |
|---|---|
| **Age of Patients (years), Mean(SD)** | 13(6.55) |
| **Sex of Patients, n(%)** | |
| • Male | 55(56.70) |
| • Female | 42 (43.30) |
| **Employment status of parents, n(%)** | |
| • Unemployed | 28(29.17) |
| • Daily wage worker | 12(12.50) |
| • Salaried | 39(40.63) |
| • Homemaker | 17(17.71)* |
| **Education level of parents, n(%)** | |
| • No schooling | 15(15.46) |
| • Upto class 5 | 34(35.05) |
| • High school | 42(43.30) |
| • Graduate and above | 6(6.18) |
| **Monthly family income in rupees, Median(IQR)** | 25000(10000-117500) |

*One respondent did not disclose her/his employment status

**Table 2: Difference in treatment cost between government, NGO and private sector**

| | Difference in means | P-value | Confidence Interval | T-Statistics |
|---|---|---|---|---|
| Cost difference between government and NGO vs. private treatment | -314906 | <0.001 | (-347479.1,-282332.9) | -19.50 |
| Cost difference between government and NGO vs. private screening | -10830 | 0.17 | (-29950.63-8290.63) | -1.79 |

**Table 3: Estimated cost of treatment of thalassemia (INR)**

| | Government and NGO | | Private | |
|---|---|---|---|---|
| | Monthly Range (Average cost) | Annual | Monthly Range (Average cost) | Annual |
| Cost of Transfusion | 300-1650 (771) | 3305 | 500-4400(1584) | 19010 |
| Cost of Chelation | 250-6000 (1861) | 3190 | 9000-35000(20600) | 247323 |
| Cost of Physician | 100-200 (106) | 342 | Included in chelation therapy cost | |
| Cost of Referrals | 100-2000 (942) | 2885 | 1200-7500(2875) | 32093 |
| Cost of Laboratory tests | | | | |
| 1.Ferritin | 150-500(254) | 1020 | 300-550(460) | 1843 |
| 2.Cardiac | 1500-6500(4046) | 4046 | 1900-6000(4677) | 4677 |
| Total average cost of treatment per year | | 14161 | | 314906 |
| Mean percentage of annual income spent on treatment | 7.19% | | 18.11% | |

In government center, all services were provided free to the patient and the cost incurred was borne by the government whereas in NGO and Private, the cost was borne by the patient's family.

## Discussions

The annual cost of treatment per patient, amounts to USD 32 (INR 2681) in government hospitals and USD 3840 (INR 3,14,906) in private hospitals (Table 2). This expenditure will increase year after year as treatment is required for lifetime and can reach up to USD 292(INR 24006) in government and USD 34,391(INR 28,19,764) in private over 24 years (mean life expectancy of thalassemia patients)[14]by only considering a 10% annual inflation rate. It may be noted that the study does not calculate the rate of development of complications and additional investigations and treatment costs for these complications. The highest cost component in private settings is chelation therapy. As it acquires the highest cost component and is required very frequently, every effort has been made by the government to make it free for the patient. NGOs and private hospitals also have been providing this at subsidised rates to the patients who cannot afford.

As compared to these costs, the screening cost were only USD 4.2 (INR 350) in government facilities and USD 14.5 (INR 1,193) in private facilities. Hence, screening during the first trimester should be encouraged irrespective of the fact that parents are thalassemic or not. Parents are usually willing to undergo tests during this period for the well-being of the baby(15).

We also report that 18% of the annual family income was spent by families belonging to the upper class households. Poorer patients have to spend a significant fraction of their earnings on travel, cost of medicines and investigations when not supported in government centers. Even 11-22% of their annual income can have a huge impact as many families already had less resources.

"Prevention is indeed better than cure. A majority of studies done in this genre have reported screening of antenatal women to be cost-effective as compared to the treatment done in thalassemia patients[16]. We can conclude that screening for all pregnant women of India will cost around USD 67,24,57 (INR 55,135,150) considering USD 4.2 (INR 350) as primary screening test cost and that India would have around 1,57,529 pregnant women annually (according to NFHS 4)[17]. The treatment costs on the other hand for a year in 10,000 individuals[18] will cost around USD39.6 million (INR 3250 million). Screening cost is thus only 0.01% of the treatment costs int the country. Therefore, from a public health perspective, we conclude that the investment for screening in antenatal period is an investment that should be mandated as a compulsory activity. Although there are government initiatives encouraging antenatal screening for thalassemia, currently they are not mandatory and hence the antenatal testing is currently purely voluntary which makes the acceptance poor. There is an urgent need to increase awareness and also to promote such activities through the government so as to improve the acceptance for this activity.

The studies reviewed also confirm the same findings. Kantharaj et al, 2014 reported that the cost of preventing the birth of 10,000 patients every year by screening of antenatal women is estimated to be USD 395 million (INR 6175 million). In contrast, the cost of treating these 10,000 patients over an estimated life span of 40 years is USD 4274 million (INR 66,800 million) thus highlighting that prevention is only one-tenth of the treatment costs[4].Koren et al reported in a study done in Northern Isreal in the year 2014 that the cost of preventing one affected newborn was USD 63,660 compared to USD 1,971,380 for treatment of a patient during 50 years (mean annual cost: USD 39,427)[19]. Ahmadzenhad et al from Iran also reported that the total cost of preventing one case of Thalassemia (100 USD) is less than a single year of optimum treatment for a case with major Thalassemia (6500 USD)[16]. Our study is unique we did this costing exercise for India which has the largest burden of thalassemia and that considering the healthcare delivery heterogeneity, we evaluated each economic strata separately and still showed benefit of prevention.

## Conclusions

This study provides a practical and convenient approach to evaluate policies, laws and other factors such as family income, education level and employment status influencing access to health facilities. This study provides evidence regarding the impact of prenatal screening. There is an urgent need for the mandatory inclusion of antenatal screening and prenatal diagnosis in at-risk couples after proper genetic counseling as part of the thalassemia control program in India. The role of civil societies is paramount in this regard. It is noteworthy that a significant fraction of annual income is spent on treatment by families from any economic strata. India thus is in dire need for a dedicated centrally co-ordinated thalassemia screening and treatment program which engages all stakeholders for sustainability.

**Source of funding:** None

**Conflicts of interest:** None

## References

1. Verma IC, Choudhry VP, Jain PK. Prevention of thalassemia: A necessity in India. Indian J Pediatr. 1992 Nov 1;59(6):649–54.
2. Ansari SH, Shamsi TS, Ashraf M, Farzana T, Bohray M, Perveen K, et al. Molecular epidemiology of β-thalassemia in Pakistan: Far reaching implications. Indian J Hum Genet. 2012;18(2):193–7.
3. Fucharoen S, Winichagoon P. Haemoglobinopathies in Southeast Asia. Indian J Med Res. 2011 Oct;134(4):498–506.
4. Kantharaj A, Chandrashekar S. Coping with the burden of thalassemia: Aiming for a thalassemia free world. Glob J Transfus Med 2018;3:1-5.
5. Modell B, Darlison M. Global epidemiology of haemoglobin disorders and derived service indicators. Bull World Health Organ. 2008 Jun;86(6):480-7.
6. Thiyagarajan A, Bhattacharya S, Sharma N, Srivastava A, Dhar DK. Need for a universal thalassemia screening programme in India? A public health perspective. J Family Med Prim Care. 2019 May;8(5):1528–32.
7. Colah R, Italia K, Gorakshakar A. Burden of thalassemia in India: The road map for control. Pediatric Hematology Oncology Journal. 2017 Dec 1;2(4):79–84.

8. Modell B, Darlison M. Global epidemiology of haemoglobin disorders and derived service indicators. Bull World Health Organ. 2008 Jun;86(6):480–7.

9. Madan N, Sharma S, Sood SK, Colah R, Bhatia LHM. Frequency of β-thalassemia trait and other hemoglobinopathies in northern and western India. Indian J Hum Genet. 2010 Jan;16(1):16–25.

10. Eleftheriou A, Antoniou E, Darbà J, Ascanio M, Angastiniotis M, Farmakis D. Estimating the Cost of Thalassemia Care across the World: A Thalassemia International Federation Model. Hemoglobin. 2022 Nov;46(6):308-311.

11. CCEMG - EPPI-Centre Cost Converter v.1.4 [Internet]. [cited 2020 Apr 25]. Available from: https://eppi.ioe.ac.uk/costconversion/default.aspx

12. Cappellini MD, Cohen A, Porter J, Taher A, Viprakasit V, editors. Guidelines for the Management of Transfusion Dependent Thalassaemia (TDT) [Internet]. 3rd ed. Nicosia (CY): Thalassaemia International Federation; 2014. PMID: 25610943.

13. Kohne E. Hemoglobinopathies. Dtsch Arztebl Int. 2011 Aug;108(31–32):532–40.

14. Ansari-Moghaddam A, Adineh HA, Zareban I, Mohammadi M, Maghsoodlu M. The survival rate of patients with beta-thalassemia major and intermedia and its trends in recent years in Iran. Epidemiol Health. 2018;40:e2018048.

15. Cousens NE, Gaff CL, Metcalfe SA, Delatycki MB. Carrier screening for Beta-thalassaemia: a review of international practice. Eur J Hum Genet. 2010 Oct;18(10):1077–83.

16. Ahmadnezhad E, Sepehrvand N, Jahani FF, Hatami S, Kargar C, Mirmohammadkhani M, et al. Evaluation and Cost Analysis of National Health Policy of Thalassaemia Screening in West-Azerbaijan Province of Iran. Int J Prev Med. 2012 Oct;3(10):687–92.

17. National Family Health Survey (NFHS-4), 2015-16 [Internet] Dec 2017. Available from http://rchiips.org/nfhs/NFHS-4Reports/India.pdf on 15 July 2023

18. Dolai TK, Dutta S, Bhattacharyya M, Ghosh MK. Prevalence of hemoglobinopathies in rural Bengal, India. Hemoglobin. 2012;36(1):57–63.

19. Koren A, Profeta L, Zalman L, Palmor H, Levin C, Zamir RB, Shalev S, Blondheim O. Prevention of β Thalassemia in Northern Israel - a Cost-Benefit Analysis. Mediterr J Hematol Infect Dis. 2014 Feb 17;6(1):e2014012.