Article published online: 2025-08-26

Original Article

Economic Impact of Pediatric Hematological Cancer Treatment: Prospective Study from Western Rajasthan's Tertiary Care Center

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Ind J Med Paediatr Oncol

Abstract

Introduction Pediatric hematological cancers, which include acute leukemia, lymphoma, and other blood-related malignancies, are one of the main causes of cancer-related mortality in children worldwide. This study investigates the financial burden faced by families of pediatric patients undergoing treatment for hematological cancers at a tertiary center in Western Rajasthan.

Objective The objective of this study is to evaluate the economic impact of pediatric hematological cancer treatment at a tertiary care center in Western Rajasthan. It aims to assess the direct and indirect costs associated with treatment, including medical expenses, caregiver burden, loss of productivity, and financial strain on families. Additionally, the study aims to explore the broader economic implications for the health care system and the region, offering insights that can inform policy decisions, optimize resource allocation, and improve the affordability and accessibility of care for patients with pediatric cancer.

Materials and Methods The primary data collection approach involved interviewing families of pediatric patients with hematological cancers aged 1 month to 18 years who were treated between February 2021 and July 2021. The study assessed direct and indirect costs to understand the financial burden on families.

Results Results indicated considerable financial strain. The analysis of health care costs over the past 6 months revealed that direct costs for investigations averaged 260,922.8, with a median of250,000. The average costs for procedures during hospital admissions and medications were 48,137 and 31,818.1, respectively. Indirect costs included an average transportation cost per visit of2,324.1 and an average cost for one attendant's transportation, food, and stay of 5,593.3. A notable portion (21%) of households of patients requiring blood transfusions reported experiencing catastrophic financial consequences.

Keywords
- financial strain
- hematological neoplasm
- health care cost
- pediatric cancers
- health economics

DOI https://doi.org/10.1055/s-0045-1811525.
ISSN 0971-5851.

Thieme Medical and Scientific Publishers Pvt. Ltd., A-12, 2nd Floor, Sector 2, Noida-201301 UP, India

Conclusion Policymakers and health care providers must work together to develop strategies that reduce out-of-pocket expenses and provide financial protection for vulnerable families. Enhancing regional health care infrastructure and expanding financial aid programs are crucial steps toward alleviating the financial strain and improving the overall well-being of pediatric cancer patients and their families.

Introduction

Pediatric hematological cancers (acute leukemia, lymphoma, and other blood-related malignancies) are one of the main causes of cancer-related mortality in children worldwide. The number of new cases of childhood cancer exceeds 200,000 annually, and more than 80% of these are from the developing world.[1] In 2017, childhood cancer was the fifth leading cause of death among 5- to 14-year-olds.[2] According to the Economic Survey 2022–23, the combined expenditure of India's central and state governments on health care was 1.6% of the country's gross domestic product (GDP) in the financial year 2020–21. However, this expenditure increased to 2.1% of GDP in 2022–23, indicating a growing commitment to public health care funding. Emerging therapies and diagnostics are extremely expensive, and these costs are borne by the family, the health care sector, and society.[3] The economic burden of pediatric hematological malignancies extends beyond direct medical expenditures, incorporating indirect costs such as loss of productivity and impaired quality of life for patients and their families.

The various protocols for treating hematological malignancy in children entail intensive multiagent chemotherapy to achieve and maintain complete remission. The chemotherapy consists of induction, consolidation, central nervous system prophylaxis, delayed intensification, and maintenance therapy for up to 2 to 3 years, depending on the risk group. Nowadays, the cure rate with 5-year disease-free survival ranges from 50 to >90% at various centers in India and abroad, depending on risk stratification and the expertise of the treating center.[4] However, intensive chemotherapy carries the potential for serious complications, such as infections and bleeding requiring prolonged intensive care unit admission and hospital stay, costing a lot to the family, with a lot of financial burden on the family, society, and nation.

There is a paucity of Indian literature showing the cost implications for patients with hematological malignancies. This study aimed to perform a cost-of-illness analysis to determine the financial burden due to total direct and indirect costs incurred in the treatment of hematological malignancy in children.

Study Design and Setting

This prospective observational study was conducted over a period of 6 months, from February 2021 to July 2021. A consecutive sampling technique was used to recruit participants. The study aimed to explore the economic impact of pediatric hematological cancer treatment within a predefined time frame. Given the observational nature of the study and logistical constraints, a prior sample size calculation was not performed.

Inclusion Criteria

Patients with hematological malignancy aged 1 month to 18 years presenting to the hospital setting were enrolled.

Exclusion Criteria

1. Patients with hematological malignancy partially treated outside were excluded.
2. Families of patients who did not give consent were excluded.

Primary Outcome

The primary outcome was the total gross direct and indirect costs incurred in the treatment of pediatric hematological malignancy.

Secondary Outcome

The secondary outcome included the assessment of the proportion of direct versus indirect costs, variation in costs by diagnosis and treatment phase, catastrophic health expenditure (CHE) borne by families, and out-of-pocket expenditure.

Statistical Analysis

Direct medical costs encompassed expenses related to diagnostics, laboratory investigations, radiological imaging, outpatient and emergency consultations, supportive treatments and chemotherapy, medications for managing complications, nursing services, operating room charges, medical equipment, and care provided by nonphysician health care professionals. Indirect costs included transportation costs, accommodation costs, and the cost of care for the dependent families and caregivers. The average costs, median, and interquartile range for direct and indirect categories were calculated to assess the overall financial burden. Statistical analysis was done using Microsoft Excel.

Ethical Approval

The study was approved by the institutional ethics committee of All India Institute of Medical Sciences (AIIMS), Jodhpur (vide letter no: AIIMS/IEC/2021/3591, dated April 24, 2021). The objectives of the study were explained to all the parents/caregivers of the enrolled patients, and written consent was obtained from each. All of them were also assured of confidentiality.

Table 1 Details of the participants

Variables		*N*	%
Age group (y)	0–5	26	43.3
	6–10	14	23.3
	11–15	17	28.3
	16–18	3	5
Sex	Male	34	56.6
	Female	26	43.3
Malignancy	ALL	59	98.3
	AML	1	1.6
Average number of visits to hospital (d)	1–5	55	91.6
	6–10	3	5
	11–15	2	3.3

Abbreviations: ALL, acute lymphoblastic leukemia; AML, acute myeloid leukemia.

Results

►**Table 1** depicts the sociodemographic distribution of the patients. A total of 60 children were included in the study, with the maximum children falling in the age group of 0 to 5 years. Male pediatric patients were 34 (56.66%), and female pediatric patients were 26 (43.33%). The majority of patients (98.3%) were diagnosed with acute lymphoblastic leukemia (ALL). Hospital consultations were attended by the father, mother, siblings, and grandparents of the patients. However, the majority of the children were attended by their father. The geographic distribution of the patients is depicted by a map of Rajasthan (India) (►**Fig. 1**).

The average duration of treatment in these children was 6 months. The average expenditure on medical investigations is considerable, while costs for procedures and medications further exacerbate the financial strain on patients and their families. These factors collectively represent the direct costs associated with pediatric hematological cancers

Fig. 1 Geographic distribution of patients attending our hospital located in the Jodhpur district (each dot represents a patient).

Table 2 Expenditure for the patients in various domains (direct cost)

	Cost component	Average (INR)	Median (INR)	IQR
1	Cost incurred for investigations by patients in the last 6 months	260,922.8	250,000	335,500–153,000 = 182,500
2	Cost incurred for investigations in AIIMS by patients in the last 6 months	101,290.1	100,000	105,000–57,500 = 47,500
3	Cost incurred for any procedures during hospital admissions in the last 6 months	48,137.9	38,000	53,725–35,000 = 18,725
4	Medication cost incurred in the last 6 months	31,818.1	30,000	35,000–20,000 = 15,000

Abbreviations: AIIMS, All India Institute of Medical Sciences; IQR, interquartile range.

Table 3 Expenditure for the patients in various domains (indirect cost)

	Cost component	Average (INR)	Median (INR)	IQR
1	Cost incurred for transportation per visit in the last 6 months	2,324.1	500	525–475 = 50
2	Cost incurred for transport, food, and stay of one attendant in a single admission	5,593.3	500	1,000–500 = 500
3	Cost incurred per attendant during hospital stay	11,281.6	500	15,750–500 = 15,250

Abbreviations: INR, Indian rupee; IQR, interquartile range.

Table 4 Average number of days of work lost in a single visit for one attendant

Number of days	Number of patients
1–30	24
31–60	26
61–90	7
>90	3

(►**Table 2**). Transportation costs per visit and expenses related to attendants during hospital admissions further add to the overall costs (►**Table 3**).

On average, attendants lost a substantial number of workdays during a single visit for patients. Specifically, 26 patients reported losing between 31 and 60 days of work, and 3 patients reported losing >90 days of work. These data underscore the considerable impact of medical visits on the working lives of attendants (►**Table 4**).

Among the 60 patients analyzed, 19 required blood transfusions. The average cost of illness for these patients amounted to74,771.27. Additionally, it was observed that 21% of households experienced catastrophic financial impacts due to hematological cancers. CHE is typically defined as health care spending that significantly affects a household's ability to maintain a basic standard of living. Specific to India, a household is said to suffer from CHE if out-of-pocket expenses exceed a certain percentage (10–25%) of annual household income or total consumption expenditure. We can observe that blood transfusions substantially contribute to the overall cost of illness, and a notable percentage of households are financially devastated by the expenses associated with hematological cancers. ►**Fig. 2** depicts different types of costs for patients who underwent blood transfusions.

Discussion

The findings from this study underscore the substantial economic impact of pediatric hematological cancers on families in Western Rajasthan. The direct medical costs, including diagnostic tests, medications, and supportive care, constitute a considerable portion of the financial burden. These expenses are exacerbated by indirect costs such as transportation and accommodation for caregivers. The cumulative effect of these costs leads to considerable financial strain on families, many of whom are already economically vulnerable.

The geographic distribution of patients suggests that families from various parts of Rajasthan travel substantial distances to access specialized care, further increasing the nonmedical costs. Families living in rural or remote areas face considerable barriers in accessing these facilities, including long travel times, high transportation costs, and logistical challenges of arranging travel and accommodation. This delay can occur at initial consultation, referral to a specialist, and the actual diagnostic process involving specialized tests and procedures.[5,6] Overall, the geographical distance from advanced health care services is a critical factor in timely diagnosis and treatment for pediatric hematological cancers, where early detection and intervention are crucial for better health outcomes. This geographic factor emphasizes the importance of regional health care infrastructure improvements and telemedicine to reduce travel-related expenses.[7,8]

The expenditure on medical investigations alone demonstrates the exorbitant expense of health care services for treating pediatric hematological cancers. Our findings are coordinated with some Indian studies, which indicate that the highest expenditure is on medical expenses.[3,9] This financial burden is compounded by the indirect costs associated with travel, stay, loss of productivity and income, as caregivers often need to take extended leave from work to support their

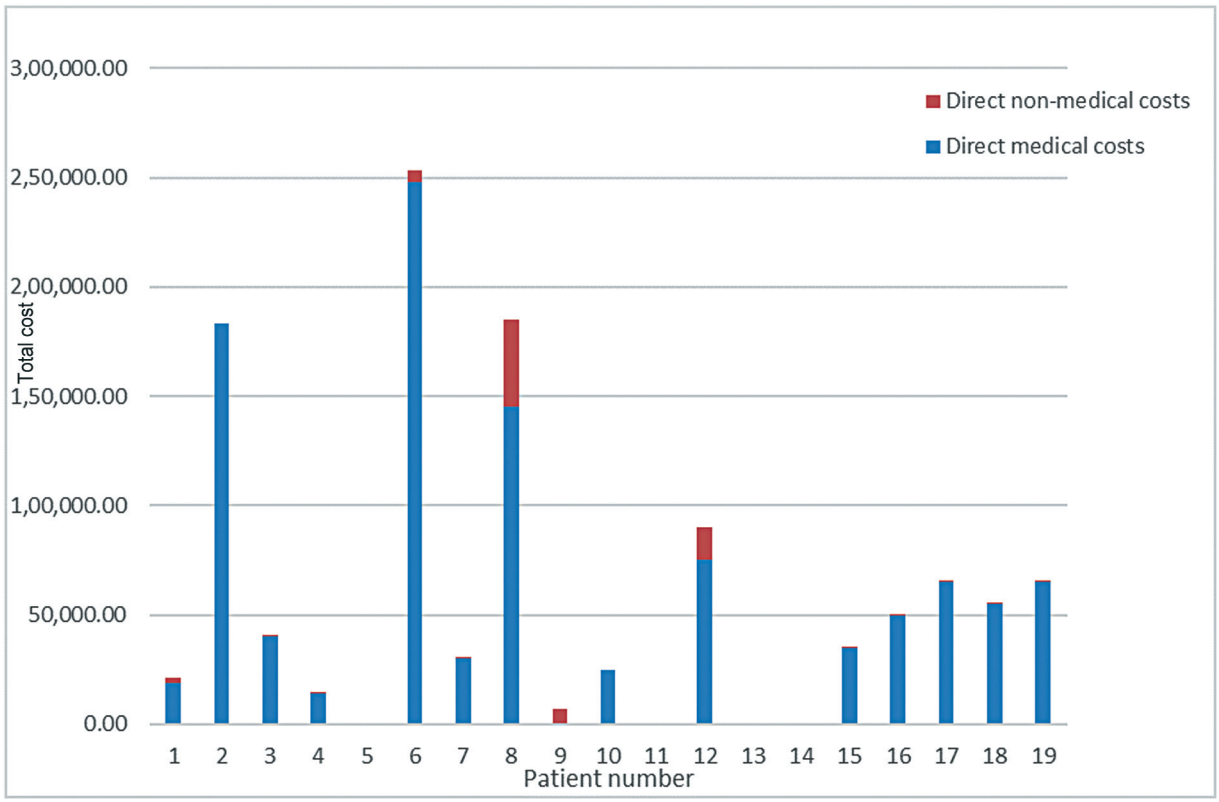

Fig. 2 Graph depicting different types of costs for patients who underwent blood transfusion.

children during treatment. Our findings are consistent with research that found that a cancer diagnosis in children had a significant influence on the productivity and duration of work of their parents.[10,11]

Several factors contribute to the rising costs associated with pediatric hematological cancers, primarily centered around the issues of late presentation and diagnosis. When patients seek medical attention at advanced stages of their illness, they often face a higher likelihood of complications. These complications can significantly worsen the patient's condition, leading to disease progression that may require more intensive and expensive treatments. As the severity of the disease increases, the need for hospital admissions becomes more frequent. Extended hospital stays, emergency interventions, and additional diagnostic tests add to the financial burden on families, ultimately escalating overall expenses.

A substantial portion of the study population required blood transfusions, which added to the overall cost of illness. The study found that these transfusions significantly contribute to the financial burden, with the average cost of illness amounting to 74,771.27. The economic impact is profound, with 21% of households experiencing catastrophic financial consequences, indicating that the cost of treating pediatric hematological cancers can lead to severe economic distress and potentially push families into poverty. Prior studies conducted in eight Southeast Asian nations found that the prevalence of CHE associated with cancer was 48%.[12] This statistic reflects the severe economic disruption caused by the costs associated with treating pediatric hematological cancers, which can lead to long-term financial instability for affected families.

The high cost of illness emphasizes the necessity for robust health insurance schemes and financial support programs specifically tailored for pediatric cancer patients. The cost of cancer care can be exceedingly burdensome, with patients often facing substantial out-of-pocket expenses that can be financially crippling. Recognizing this challenge, the Government of India has introduced the National Health Protection Scheme under the Ayushman Bharat Program. This initiative aims to provide much-needed financial relief and ensure that vulnerable populations have access to essential health care services without the burden of excessive costs. By covering a substantial portion of medical expenses, the scheme seeks to alleviate the financial strain on families affected by cancer and other serious illnesses, thereby promoting more equitable health care access across the country.[13]

Strengths

1. *Prospective Design*: The prospective nature of the study ensures real-time and accurate data collection, reducing recall bias.
2. *Focused Population*: Exclusive focus on pediatric hematological malignancies provides a specific, high-burden, and under-researched subgroup.
3. *Comprehensive Cost Analysis*: Inclusion of both direct and indirect costs offers a holistic view of the economic burden.

4. *Real-World Data*: Conducted in a tertiary care government center, it reflects real-world treatment patterns and expenditure in a resource-constrained setting.
5. *Contextual Relevance*: Provides crucial insights for policymakers and health care planners in low- and middle-income settings, particularly rural and semiurban India.

Limitations

1. *Short Study Duration*: The 6-month duration of the study may limit the ability to capture long-term economic impacts and variations in treatment costs over a more extended period, especially considering the prolonged nature of pediatric cancer treatments.
2. *Small Sample Size*: The study sample of 60 subjects may not be large enough to draw generalized conclusions about the economic impact of pediatric hematological cancer treatment across diverse populations. A larger sample would increase the statistical power and external validity of the findings.
3. *Regional Limitation*: The study focuses on a tertiary care center in Western Rajasthan, which may not be representative of other regions in India or other countries. The findings may be influenced by the regional health care infrastructure, economic conditions, and accessibility to resources, limiting the generalizability of the results.
4. *Single-Center Study*: Being based at a single tertiary care center, the study may not account for variations in treatment practices, costs, and patient experiences across different hospitals or health care settings, leading to potential bias in the results.
5. *Disease-Related limitation*: ALL was the predominant malignancy in this cohort, and it included only a few lymphoma cases.

Future Research Directions

1. *Longitudinal Multicenter Studies*: To capture variations over time and across different health care settings.
2. *Cost-Effectiveness Analyses*: Evaluating different treatment protocols or support interventions for economic efficiency.
3. *Impact of Financial Support Schemes*: Analyzing the effectiveness of government or NGO-based funding mechanisms.

Generalizability

Our findings are broadly generalizable to:

1. Government-run tertiary health care facilities in rural or semiurban India.
2. Populations with similar socioeconomic and health care access profiles in developing countries.

Less applicable to:

3. Urban private sector settings with different cost structures.
4. Regions with established universal health coverage or different economic dynamics.

Gray Areas

1. *Economic Impact on Education of the Child and Siblings*: School dropout or absenteeism due to treatment demands.
2. *Long-Term Financial Toxicity*: Extended impact on household savings, debt, and social mobility.
3. *Comparison of Cost Across Cancer Types or Risk Groups*: Not explored in the current study.
4. *Psychosocial Coping Mechanisms and Costs*: Largely missing from the analysis.
5. *Delayed Diagnosis and Its Economic Implications*: Not addressed but potentially significant in rural setups.

Suggestions

- To reduce the catastrophic financial impact of costs associated with hematological cancers and blood transfusions, several strategies can be considered:
  - *Insurance Coverage Improvements and Awareness*: These patients should be automatically enrolled in the Ayushman Bharat program, with compulsory enrollment facilitated through panchayats, particularly in rural areas. This initiative is essential at the tertiary level, as complex cases often arise during diagnosis.
  - *Cost Transparency*: Improving transparency around the costs of treatments and procedures can help patients make informed decisions and plan their finances better.
  - *Community Support Services*: Enhancing access to community support services, including counseling and financial planning, can help families navigate the financial complexities of treatment.
- *Shared-Care Options*: It will support oncology specialty services and help reduce transportation expenses. Additionally, increasing support for blood transfusions and ensuring that doctors are well-educated on the latest treatment protocols will contribute to more effective and affordable care for patients.
- *InHouse Facilities*: If all tests and investigations, such as flow cytometry, minimal residual disease assessment, molecular cytogenetics, and karyotyping, are made available in-house, overall costs could be reduced. Additionally, the Ayushman Bharat could cover these services, further alleviating financial burdens on patients.
- *Good Nutrition and Hygiene*: Effective treatment for pediatric hematological cancers relies on good nutrition and hygiene. However, the health system often focuses on arranging finances and logistics, which can compromise the quality of primary care. This highlights the need for a more integrated approach that addresses both financial and foundational health needs.

Conclusion

This study highlights the substantial financial burden faced by families of pediatric patients undergoing treatment for hematological cancers in western Rajasthan. The direct and indirect costs associated with care not only strain household finances but also contribute to significant emotional and

psychological stress. Implementing targeted strategies, such as enhancing insurance coverage through the Ayushman Bharat program, improving cost transparency, and expanding community support services, is crucial. Additionally, developing in-house diagnostic facilities and prioritizing nutrition and hygiene can improve health outcomes while alleviating financial pressures. A multifaceted approach is essential to ensure families can afford treatment and maintain their dignity during these challenging times.

Patient Consent

Institution ethical clearance taken and individual consent taken from each participants.

Funding

None.

Conflict of Interest

None declared.

Acknowledgments

The authors would like to thank the health technology assistant in the Department of Health Research (DHR), Government of India, and All India Institute of Medical Sciences, Jodhpur, India, for the support.

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