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# Financial burden in the form of medical and non-medical out-of-pocket expenses on the family of children admitted to a pediatric intensive care unit in India

Varun Ravindra Jagtap<sup>1</sup>, Sushma Save<sup>2</sup> and Praveen Unki<sup>2\*</sup>

## Abstract

**Background** Pediatric intensive care unit (PICU) admissions can have significant repercussions on families, including financial burdens and psychological distress. Not only do they face the overwhelming concern for their child's health and well-being, but they are also confronted with a range of practical and financial difficulties. Coping strategies play a vital role in mitigating the negative impact of PICU admissions on families. Various coping mechanisms, such as seeking social support, engaging in problem-solving, and utilizing emotional regulation techniques, can help families navigate the challenges they face. The objectives of the study are to understand the array of financial implications in the form of out-of-pocket expenses (OOPE) and to quantify with a better understanding of the composition of out-of-pocket expenses in the form of medical and non-medical expenses. It also aimed to determine the loss of productive hours in a family and to understand the burden of OOPE in relation to the income of the family.

**Methods** This prospective observational study was conducted in the pediatric intensive care unit (PICU) of a tertiary care hospital over a period of 6 months after obtaining permission from the institutional ethics committee. Data pertaining to financial burden was collected with the help of Structured questionnaires which included the following categories travel, meals, accommodation, and incidental expenses were considered as non-medical expenses while all medicine costs and investigations were considered as medical expenses. The quantitative data were presented as the means  $\pm$  SD as median with 25th and 75th percentiles (interquartile range) and were analyzed using ANOVA (for more than two groups) and independent *t* test (for two groups).

**Results** More than half of the children (39(55.71%)) were not enrolled under any government scheme. The mean value of total medical and non-medical costs was  $2525 \pm 4035.28$  and  $2234.29 \pm 846.84$  Indian rupees. The mean value of total out-of-pocket expenses incurred per day (Indian rupees) on day 1, day 2, day 3, day 4, and day 5 were  $1304 \pm 587.2$ ,  $1208.86 \pm 3773.84$ ,  $814.57 \pm 565.03$ ,  $807.71 \pm 522.76$ , and  $699.86 \pm 807.02$  respectively.

**Conclusion** Families of children admitted to the pediatric intensive care unit incurred catastrophic health expenditure with the cost of medicine contributing a major share. The lowest income brackets had much higher, more than twice the financial burden compared to the higher income group. Almost all families experienced a high loss of productivity in the form of a number of days lost due to the PICU admission of a child. Enrolment in government schemes helped to reduce OOPEs though better coverage of these schemes is needed.

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**Keywords** Financial burden, Out-of-pocket expenses, Medical expenses, Non-medical expenses

## Background

Pediatric critical care has grown exponentially over the last decade in India. The hospitalization of a child to the pediatric intensive care unit (PICU) involves major stress for the child and his parents and leads to extra financial burdens on the family [1]. Direct and indirect expenses that a family has to bear as a result of critical care push the already poor classes into further deterioration [2]. It is also well known that a parent's presence during critical care helps in the speedy recovery of the child and is also important for facilitating medical and nursing care. To give time to the child who is under treatment parents have to change their lifestyle and also at the same time stay away from work, and take care of other children at home. These situations inevitably lead to extra financial burdens and loss of productive hours [3]. These expenses cause the depletion of a family's savings made over the years and are a major cause of people being driven into poverty. In developed countries, most of the families are under the cover of insurance companies, and major medical expenses are taken care of by insurance companies [4]. In a developing middle-income country like India, there are large socioeconomic differences and very few people can afford insurance coverage [5]. In India, out-of-pocket expenses (OOPE) pushed 55 million additional people into poverty in 2017 because more than three-quarters of the financial burden of health care is met by households. This was revealed in a study by the Public Health Foundation of India (PHFI) [6]. The health expenditure included expenditure on 'Family welfare', 'Water Supply and Sanitation' other than 'Medical and Public Health'. Owing to poor insurance coverage and low public health expenditure families tend to exhaust their savings and the financial burden is much higher. OOPE is a direct payment of money made from own personal resources which includes both medical and non-medical out-of-pocket expenses. Medical costs include medicine costs, investigations, consultant fees, and PICU charges while non-medical costs include travel, meals, accommodation, expenses incurred on the care of a sibling, and any incidental expenses [2]. Effect of the PICU admission on a family's financial health has rarely been studied in the Indian setting. There are many government schemes aimed at helping families on the financial front. Recent studies have shown that families with children admitted to the pediatric intensive care unit incurred significant out-of-pocket expenses. The results have also demonstrated work absenteeism and inability

to perform daily activities [7]. Most of the studies also concluded that the lowest income brackets bore the highest burden. The aim of the study was to understand the array of financial implications in the form of out-of-pocket Expenses and to quantify and better understand the composition of out-of-pocket expenses in the form of medical and non-medical expenses. It also aimed to determine the loss of productive hours in a family and to understand the burden of out-of-pocket expenses in relation to the income of the family.

## Methods

### Patient and public involvement: not involved

This was a prospective observational study conducted in the PICU of a tertiary care hospital over a period of 6 months from June 2021 to January 2022 after obtaining permission from the institutional ethics committee. All children admitted to PICU from 1 month to 12 years of age of either gender with  $\geq 2$  days of PICU stay were included in the study after obtaining consent from parents/guardians.

Structured questionnaires (Table 1) were used to collect data on financial burden. To measure the OOPEs data was collected in the following categories including all possible expenses viz. travel, meals, accommodation, caring for siblings, incidental expenses considered as non-medical expenses while all medicine costs and investigations are considered as medical expenses. (a) Actual medical cost incurred post hospitalization (including medicine, investigations), (b) Approximate non-medical cost incurred post hospitalization. Data was also collected from parents who lost productivity in terms of the number of days family members had to stay away from work. These questionnaires were administered daily to the participants in this study for consecutive 5 days.

The presentation of the Categorical variables was done in the form of numbers and percentages. On the other hand, the quantitative data were presented as the means  $\pm$  SD as the median with 25th and 75th percentiles (interquartile range). The association of the variables which were quantitative in nature were analyzed using ANOVA (for more than two groups) and Independent t test (for two groups). The data entry was done in the Microsoft EXCEL spreadsheet and the final analysis was done with the use of Statistical Package for Social Sciences (SPSS) software, IBM manufacturer, Chicago, USA, version 21.0. *P* value less than 0.05 was considered statistically significant.

**Table 1** Case record form

Study number:						
Demographic data:						
Age:						
Gender:						
Inpatient number:						
Date and time of admission:						
Contact number:						
Weight on admission:						
Indication for admission:						
Diagnosis on admission:						
Final Diagnosis:						
Total no of days of PICU stay:						
Mechanical ventilation:						
Any Government Programme under which patient is enrolled:						
Actual medical cost incurred during PICU stay:						
	D1	D2	D3	D4	D5	Total
Medicine						
Investigations						
Consultation fees						
PICU Charges						
Others						
Total						
Approximate non-medical cost incurred post-hospitalization:						
	D1	D2	D3	D4	D5	Total
Travel						
Meals						
Accommodation						
Communication						
Caring for Siblings						
Any other Incidental expenses						
Total						
Total Out Of Pocket Expenses= [Actual medical cost+ non-medical cost] =						
Total no. of days family member had to stay away from work=						
Monthly income of the family=						
The Group under which the Family falls depending on Monthly Income =						
Average daily expenditure = Medical OOPE/total days of PICU stay=						
Estimated Daily Budget=						
Percentage Daily Expenditure /Daily Budget =						

**Results**

The study was carried out at the pediatric intensive care unit of a tertiary care center. Seventy children admitted to PICU from 1 month to 12 years of age of either gender were included. 27 (38.57%) children were of the 1–5 year age group. In the majority (50(71.43%)) of children, mechanical ventilation was not required. More than half of the children (39(55.71%)) were not enrolled under any government scheme. The mean value of the cost of medicine, Investigations, PICU charges and total medical cost in rupees was 1501.57 ± 3742.76, 527 ± 1049.4, 552.86 ± 485.95 and 2525 ± 4035.28 with median (25th–75th percentile) of 800(500–1500), 195(0–707.5), 1000(0–1000), and 1870(600–2887.5) respectively as shown in Fig. 1

and Table 2. Similarly, mean value of travel, meals, incidental expenses, total non-medical cost, and caring for siblings in rupees was 711.43 ± 469.52, 761.43 ± 486.5, 728.57 ± 383.69, 2234.29 ± 846.84, and 26.43 ± 128.74 with median (25th–75th percentile) of 1000(262.5–1000), 1000(412.5–1000), 600(500–1000), 2200(1600–2750), and 0(0–0) respectively (Table 3 and Fig. 2). Furthermore, Mean value of total out of pocket expenses incurred per day (rupees) at day 1, day 2, day 3, day 4, and day 5 was 1304 ± 587.2, 1208.86 ± 3773.84, 814.57 ± 565.03, 807.71 ± 522.76 and 699.86 ± 807.02 with median (25th–75th percentile) of 1250(902.5–1575), 575(412.5–1100), 725(462.5–960), 700(500–1037.5), and 550(400–822.5) respectively (Table 4 and Fig. 3). Majority (64(91.43%)) of family members had

### Descriptive statistics of Medicine, Investigations, PICU charges and total medical cost in rupees

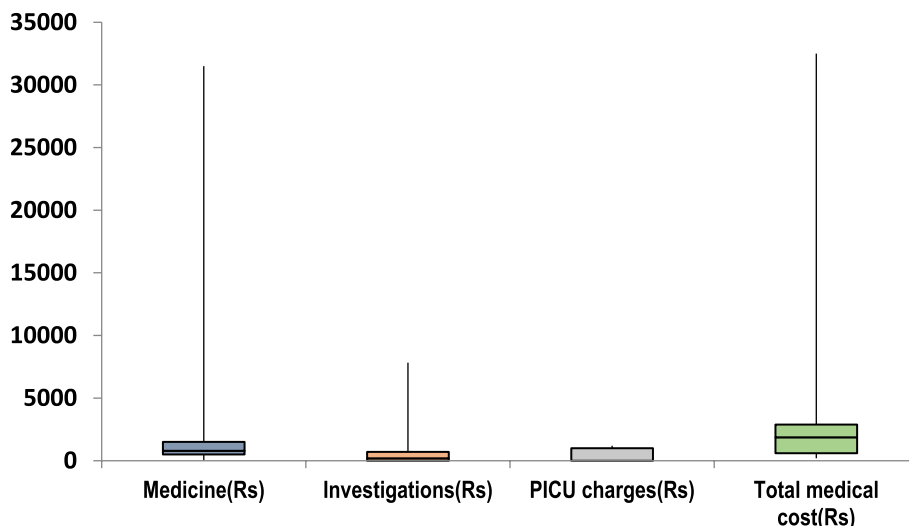


Fig. 1 Descriptive statistics of medicine, investigations, PICU charges, and total medical cost in rupees

Table 2 Descriptive statistics of medical cost

Medical cost	Mean ± SD	Median (25th–75th percentile)	Range
Medicine (Rs)	1501.57 ± 3742.76	800(500–1500)	0–31500
Investigations (Rs)	527 ± 1049.4	195(0–707.5)	0–7830
PICU charges (Rs)	552.86 ± 485.95	1000(0–1000)	0–1200
Total medical cost (Rs)	2525 ± 4035.28	1870(600–2887.5)	200–32500

Table 3 Descriptive statistics of non-medical cost

Non-medical cost	Mean ± SD	Median (25th–75th percentile)	Range
Travel (Rs)	711.43 ± 469.52	1000(262.5–1000)	0–1500
Meals (Rs)	761.43 ± 486.5	1000(412.5–1000)	0–1500
Incidental expenses (Rs)	728.57 ± 383.69	600(500–1000)	0–2000
Total non-medical cost (Rs)	2234.29 ± 846.84	2200(1600–2750)	500–5000
Caring for siblings (Rs)	26.43 ± 128.74	0(0–0)	0–800

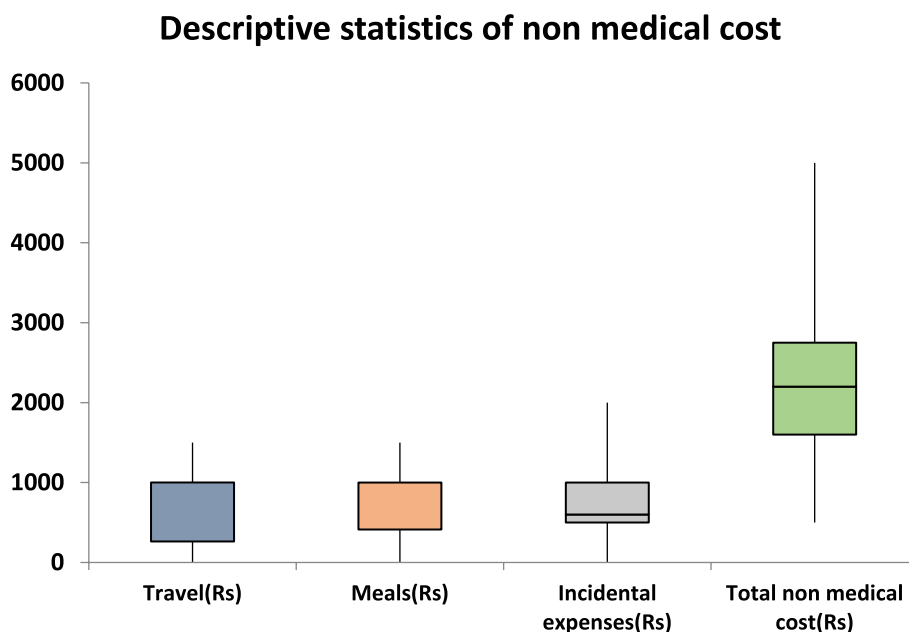
to stay away from work for 5 days followed by 3 days (5(7.14%)). Only 1 family member had to stay away from work for 2 days. The Mean value of the estimated daily budget (rupees) was 348.09 ± 225.7 with a median

(25th–75th percentile) of 330(200–483.25) and the mean value of daily expenditure/daily budget (%) was 364.56 ± 270.49 with median (25th–75th percentile) of 301(174.75–456.25).

#### Discussion

Globally PICU admissions are the most expensive and cause a major disruption to the financial dynamics of families of patients. India, being a lower middle-income country, this financial burden incurred is significantly higher than family income and inevitably leads to the deterioration of already poor classes. In our study, 70 families were studied and their OOPE for the first 5 days of PICU admission were documented. Of these 70 children, the majority 38.57% children belonged to the age group 1–5 years followed by 6–12 years consisting 34.29% of children. A study done by Wasserfallen J et al. [3], shows that the children’s mean age was 2.9 ± 3.8 years. This value is less than the mean age in our study. In our study, for 71.43% of children, mechanical ventilation was not required. Mechanical ventilation was required in only 28.57% of children. A study done by Kaur et al. [8] shows that about 55.9% of patients required mechanical ventilation and the remaining 44.1% of patients do not require ventilation. This study shows that there is more demand for mechanical ventilation as compared to our study.

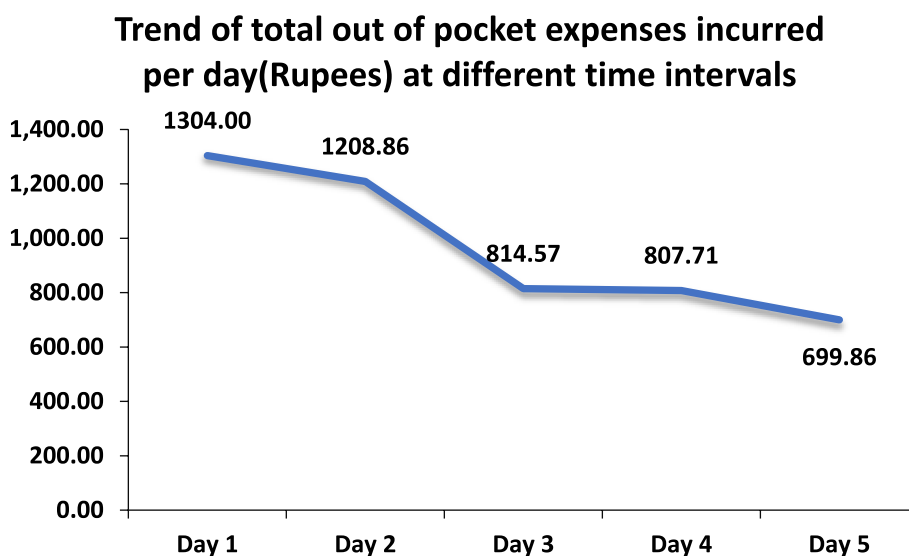
In our study, the majority of children about 55.71% were not enrolled under any government scheme. In our study, the mean value of the cost of medicine, investigations, PICU charges, and total medical cost in rupees was



**Fig. 2** Descriptive statistics of travel, meals, incidental expenses, and total non-medical cost in rupees

**Table 4** Descriptive statistics of total out-of-pocket expenses incurred per day (rupees)

Total out-of-pocket expenses incurred per day (rupees)	Mean ± SD	Median (25th-75th percentile)	Range
Day 1	1304 ± 587.2	1250(902.5–1575)	300–3400
Day 2	1208.86 ± 3773.84	575(412.5–1100)	0–32000
Day 3	814.57 ± 565.03	725(462.5–960)	0–3350
Day 4	807.71 ± 522.76	700(500–1037.5)	0–3300
Day 5	699.86 ± 807.02	550(400–822.5)	0–6800



**Fig. 3** Descriptive statistics of total out-of-pocket expenses incurred per day (rupees)

1501.57 ± 3742.76, 527 ± 1049.4, 552.86 ± 485.95, and 2525 ± 4035.28 respectively. This showed that out of total medical costs, the largest contributor was the cost of medicines (59%) followed by others. A study done by Kaur et al. [9] shows that the total mean cost per patient treated and per bed-day in the PICU was found to be US\$ 2078 (₹144,566) and US\$ 415 (₹ 28, 871) respectively. Of this, the mean health system cost per patient and per bed day was US\$ 1731 (₹120,425) and US\$ 346 (₹24,071) respectively. 80% of the total cost incurred by a patient when cared for in PICU was borne by the hospital and only 20% by the patient. A major share of OOP expenditure was contributed by medicine and consumables (79%). Being a public health care facility, patients are provided drugs free of cost so a large OOPE on medicines was not expected. According to National Health Accounts for India (2013–2014), an estimated ₹ 1331 per capita was spent on medicines, while households alone contributed ₹ 1200, i.e., 90% of all medicine expenditure in the country [10]. Severe underspending by several state governments with many reportedly spending less than 5%, leads to inadequate drug procurement and inefficient supply chains [11]. This finally leads to acute shortages of key essential medicines in public health care facilities causing a rise in OOPE. In our study, the mean value of travel, meals, incidental expenses, total non-medical cost, and caring for siblings in rupees was 711.43 ± 469.52, 761.43 ± 486.5, 728.57 ± 383.69, 2234.29 ± 846.84, and 26.43 ± 128.74 respectively. A study done by Wasserfallen J et al. [3] in Switzerland carried out in a very different system and setting, the two most important cost categories were meals and travel i.e., the non-medical OOPE. The results showed that over the whole hospital stay, families spent an average of Euro 2720 as direct out-of-pocket expenses for visiting/staying with their hospitalized child. Families spent an average out of-pocket amount of Euro 57 per day or Euro 1710 per month for travel and/or meals and communication costs. This is a very heavy burden for them which may be worsened by additional significant loss of earnings. In our study, the mean value of total out-of-pocket expenses incurred per day (rupees) on day 1, day 2, day 3, day 4, and day 5 was 1304 ± 587.2, 1208.86 ± 3773.84, 814.57 ± 565.03, 807.71 ± 522.76, and 699.86 ± 807.02 respectively. Comparing individual OOPE on each day leads to the conclusion that the first 2 days of the PICU admission incurred significant costs compared to days 3, 4, and 5. In our study, the mean value of total out-of-pocket expenses (rupees) was 4770 ± 4039.75. A study done by Kaur et al. [8], shows that the mean out-of-pocket expenditures for treatment in PICU was US\$ 352 (95% CI 315–390). Medicines and consumables accounted for a major share of out-of-pocket expenditure, i.e., 79%. Mean out-of-pocket

expenditures per patient and per patient bed day were US\$352 (₹ 24,535) and US\$70 (₹4897). Mean out-of-pocket expenditures for ventilated patient was significantly higher than a non-ventilated [US\$ 466 (₹32,482) vs US\$ 208 (₹14, 482);  $p < 0.001$ ]. Similarly, the OOP expenditure in patients with a PICU stay of ≤ 2 days was US\$ 210 (₹14,653), which was almost one-third of the OOPE among patients with a PICU stay of > 2 days, i.e., US\$ 503 (₹ 35,032). The OOPE per patient constituted approximately 20% of the total PICU cost per patient. Compared to international standards OOPE in our study appears to be low. However, most of them were in lower socioeconomic strata and had low purchasing power. So, to quantify the financial burden in effective terms how much % of the daily budget of the family was spent in the form of OOPE as a result of PICU admission was calculated. This gave a better perspective of the financial burden in relation to their income levels. Families participating in the study were stratified according to the monthly income in 3 groupings: (1) from 0 to Rs. 15,000/- per annum, (2) From Rs. 15,000/- to Rs. 100,000/- per annum, (3) more than 100,000/- per annum. In our study, the family monthly income of 54.29% of children was more than 100,000/- per annum followed by Rs. 15,000/- to Rs. 100,000/- per annum in 41.43% of patients. Findings in our study suggest that a PICU admission resulted in catastrophic health expenditure for all families. Findings show that the monetary sum spent might be the same for the different income groups. However, it effectively translates into a much higher financial burden for lower socioeconomic classes and remains a major cause for their further deterioration. A poor household paying 1000 Rs. could mean pulling a child out of school or foregoing a meal, whereas a richer household spending the same amount would have no immediate consequences. In our study, the mean ± SD of daily expenditure/daily budget (%) in patients who did not require mechanical ventilation was 386.71 ± 301.07 and who required mechanical ventilation was 309.2 ± 165.64 with no significant association between them ( $p$  value = 0.282). This was in contrast to a study done by Kaur et al. [8], which showed that the OOPE in a ventilated patient was double that of a non-ventilated child. Mechanical ventilation requires increased diagnostic and therapeutic procedures, invasive monitoring, and drugs and other consumables, thus escalating the cost per patient. Shweta et al. [11] had shown that at all levels of care, the most expensive were those requiring mechanical ventilation. In our study, the majority of family members constituting 91.43% had to stay away from work for 5 days followed by 3 days in 7.14% of patients. Only 1 family member had to stay away from work for 2 days. These showed that the majority of the families experienced the loss of earnings

directly as a result of the hospitalization of a child. A study done by Kaur et al. [8] shows that length of ventilation and PICU stay correlated with out-of-pocket expenditure; average out-of-pocket expenditure in a patient with PICU stay of <2 days was almost one-third of the average cost of patients with a PICU stay of >2 days. Compared to the cost of intensive care in developed nations, ICU costs are low in developing countries. A study from a teaching university hospital in Thessaly, Greece, done by Geitone et al. [12] showed the mean actual cost per ICU patient to be €16,516 (INR13,86,683), actual reimbursement from social funds was only €1671. The low cost of ICU care in India is partly attributed to the low cost of drugs, recycling of consumables, and lower staff salaries. Two disease-specific studies were published. The first addressed the psychosocial and economic problems of parents of children suffering from epilepsy in India. A structured questionnaire administered to parents of 50 children aged 5 to 10 years and suffering from epilepsy of more than one year's duration showed a decline in social activities in 80% of the parents, a significant impact on daily routines in over 75%, and financial difficulties in 60%. A study done by Madsen H et al. [13], shows that the average illness cost per illness episode at a secondary care center was 41.34\$ out of which 68% was medical cost, 20% was non-medical cost and the remaining 12% was loss of income. The average illness cost per illness episode at tertiary care center was 134.62\$ (INR 10,214) out of which 79.5% was medical cost, 16% was non-medical cost and the remaining 4.5% was loss of income. There are a few limitations to our study. The study was carried out at a single center. In view of decreased admissions due to the Covid pandemic, there was a small sample size and a limited period of evaluation. In addition, it did not study the reasons behind families spending decisions and coping strategies for financial burdens. Therefore, this type of study should be repeated on larger samples and different hospitalization settings, i.e., both public and private. However, the financial burden expressed in this study is troubling and warrants an urgent need to provide help for families of children admitted to PICU.

## Conclusion

Families of children admitted in pediatric intensive care units incurred significant out-of-pocket expenses with the majority of medical costs spent on medicine. Costs incurred were significantly higher on days 1 and 2 of PICU admission. Though intensive care in public health hospitals in India is much less expensive than in developed countries, when compared with income strata it is translated to significant Catastrophic Health Expenditure for families. The lowest income brackets

had much higher, more than twice the financial burden compared to higher income groups. Almost all families experienced a high loss of productivity in the form of a number of days lost due to the PICU admission of a child. Enrolment in government schemes helped to reduce OOPes though better coverage of these schemes is needed.

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None.

## Authors' contributions

VRJ contributed to the conceptualization of the study with preparation of the design of the work, collected data and subsequently analyzed, drafted the manuscript and substantively revised it, approved the submitted version, agreed both to be personally accountable and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature. SS advised on revision and subsequently approved the submitted version, agreed both to be personally accountable and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature. PU contributed to the interpretation of data with appropriate statistical method and advised on drafting the work and substant revision, approved the submitted version, agreed both to be personally accountable and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature. All authors read and approved the final manuscript.

## Funding

None.

## Availability of data and materials

The datasets used and/or analyzed during this study are available from the corresponding author on reasonable request.

## Declarations

### Ethics approval and consent to participate

Ethical approval was obtained from the institutional ethics committee ECARP (IEC) of Topiwala National Medical College.

Written informed consent was obtained from parents/guardians of the children enrolled in the study.

### Consent for publication

Not applicable.

### Competing interests

The authors declare that they have no competing interests.

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