

Out-of-pocket expenditure incurred by caregivers of type 1 diabetes mellitus children and adolescents attending a specialised clinic at a tertiary care hospital in North India: Reg No: 460

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ABSTRACT

Caregivers play a crucial role in the management and daily care of children and adolescents with type 1 Diabetes mellitus (T1DM). However, this responsibility often imposes a significant financial burden. There is limited evidence from LMICs on the financial burden on caregivers, which demands research in the local context. Objective: This study assesses the out-of-pocket expenditures (OOPE) incurred by caregivers of children and adolescents living with T1DM. **Method:** Caregivers of patients aged 1-19 years with T1DM attending the Diabetes of Young clinic (DOY) at All India Institute of Medical Sciences (AIIMS), New Delhi, were recruited. Data were collected using a self-designed, structured, and validated questionnaire capturing demographic details, socioeconomic status, education level, family history, medical history, and cost-related domains. Expenditure data was analysed to estimate the total annual OOPE and its components. **Results:** Out of 105 recruited participants, 32.5% belonged to the upper middle socioeconomic class, 27.9% to the lower middle class, 24.4% to the upper lower middle, 14.0% to % upper class, and 1.1 % to the lower socioeconomic class as per the Modified Kuppuswamy socioeconomic scale (2020). The average annual OOPE was Rs. 36,821 (inter-quartile range [IQR] Rs14,500-52,875). Of this, direct healthcare costs accounted for Rs. 33,503 (IQR Rs. 10,200-51,100, 91.0%), while direct non-healthcare costs amounted to Rs. 3,318 (IQR Rs 800-2,600, 9.0%). Of the direct medical costs, 82.1% was spent on medical supplies and medications.

Conclusion: This study highlights the considerable financial burden faced by the caregivers of children and adolescents with T1DM emphasizing urgent need for improved financial support mechanisms and policy interventions to reduce the cost burden associated with T1DM in India.

KEYWORDS

Type 1 diabetes mellitus economics, financial burden on caregivers, out-of-pocket expenditures-LMICs