



Financial burden for families of children with type 1 diabetes: a cross-sectional survey from North India

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Abstract

Introduction Type 1 diabetes (T1D) incurs substantial out-of-pocket expenses (OOPE) on insulin and diabetes-related supplies. The information on OOPE is scarce from low- and middle-income countries. We aimed to estimate annual OOPE for children with T1D attending our diabetes clinic located in North India.

Methods An online survey was conducted among parents of 380 children with T1D (mean age: 10.3 ± 4.6 years). Modified BG Prasad scale was used to estimate the socioeconomic status (SES).

Results The mean duration of T1D was 3.6 ± 2.6 years; 54.9% of children were boys. The median HbA1c (IQR) was 7.9% (5–15%). 51.9% belonged to lower or lower-middle SES. Mean annual spending on glucose monitoring, insulin administration, and laboratory investigations were Indian Rupee (INR) 21,576, INR 28,965, and INR 5069, respectively (total INR 55,185, IQR: 26,575–105,027). The cost of a single visit to the doctor was approximately INR 2889. Thirty children required hospitalization during the last year, which costs INR 27,495 on average. 30.3% had more than 50% of their total family income spent on diabetes care, with a significant negative correlation with their SES ($r = -0.738$, $p = 0.00$). Only 11.6% were receiving financial support from any agency. 36.6% of families had to borrow money; the OOPE exceeded income from all sources in 8.2% of families.

Conclusions There is a high financial burden of T1D care for North Indian children, almost on the verge of losing sustainability. Further studies are warranted to furnish larger OOPE data to guide policy decisions aimed at reducing direct costs to patients.

Keywords Type 1 diabetes · Children · Cross-sectional survey · Out-of-pocket expenditure · Diabetes care · Low-income countries

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Introduction

The international health agencies prioritize strengthening health systems and access to health services. Achieving universal health coverage, including financial risk protection, is also a target of the 3rd Sustainable Development Goal of good health and well-being. According to the USAID's Vision for Health Systems Strengthening (2015–2019), out-of-pocket health expenditure is a crucial financial protection indicator. Measuring this, particularly for low-income countries, is the first step towards improving health financing and protection [1].

Diabetes is a chronic condition that requires a lifelong commitment for close monitoring, both from the patient and the healthcare provider. The cost implications of diabetes care include direct medical costs such as money spent on consultations, investigations, medicines, hospitalizations,

and management of complications, and indirect costs such as money spent on transport, lifestyle modification, income lost due to absenteeism from work [2]. Several previous studies have also shown high out-of-pocket expense (OOPE) in patients with type 2 diabetes (T2D) from India, amounting to nearly 70% of their total spending on health [3–10].

The economic burden of type 1 diabetes (T1D) care is considered much higher as compared to T2D [11]. The need for intensive treatment that reduces the risk of long-term complications is obvious. Along with the intensive treatment, a family having a child with T1D suffers a more severe economic impact than T2D for several other reasons. First, insulin replacement therapy is to be taken for a lifetime. Second, there is a higher risk of hospitalization due to severe hypoglycemic or ketoacidosis events. Third, the time dedicated to childcare because of diabetes is considerable, and the burden of care can be a highly relevant cost from the perspective of society [12, 13]. Fourth, in view of rapid developments in the treatment innovations with ever-increasing use of high-tech devices, the costs of treating T1D are expected to increase in the future [14]. Further, unlike T2D, which receives financial support from the national government, the same is not true for T1D [15].

The healthcare system of India comprises of public and private healthcare with a heavy reliance on the latter; only one fifth of healthcare is publicly financed [16]. The healthcare services are also differentially distributed across India's geographical regions especially urban and rural areas that often leads to inequalities in healthcare access [17]. Barring a few federally funded tertiary care hospitals, the facilities and medical care in the public-funded hospitals are poor, forcing people to approach private hospitals for their medical needs. The burden of expenditure on healthcare is thus high in households with high healthcare needs especially those in the lower socioeconomic strata [18].

The scientific literature shows an uneven focus on the economic burden of T2D compared to T1D, probably due to a higher prevalence of T2D. Worldwide, previous studies on the economic burden of T2D diabetes care far outnumber the studies among T1D in the pediatric population [12, 14, 19–21]. Data from India on the financial burden of diabetes care are also skewed towards T2D [22]. A previous Indian study conducted almost 2 decades back had reported that direct T1D care amounted to 22% of the family income [23]. Another study on 88 children and young adults showed high direct costs of T1D care. The costs were greater in the lower socioeconomic status (SES) in proportion to their family income [24]. A large scale data on the use of resources and the expenses of T1D can lead to a better understanding of the disease effects, defining management strategies, and appropriately allocating the resources [13]. Assessment of the healthcare costs can also lead to better strategies aimed at reducing OOPE expenditure for diabetes care of children

[4]. Furthermore, studies on the economic impact of T1D are also warranted to provide data to guide economic policy decisions aimed at reducing direct costs of diabetes care by reallocating available resources [13]. The present study was thus undertaken to determine the direct and indirect costs of diabetes care among families of children with T1D.

Methods

A cross-sectional study was conducted among the parents of children with T1D attending the diabetes clinic of Advanced Pediatrics Centre, Post Graduate Institute of Medical Education and Research, Chandigarh, which is a government-funded tertiary care academic hospital located in North India. The hospital is a high-volume center and receives referred patients mainly from the adjoining four federal states and three union territories of North India [25]. The hospital charges for indoor admissions and investigations at nominal rates and routinely waives off charges for patients belonging to low SES. The hospital takes care of patients with and without insurance; the indoor admission charges of insured patients are reimbursed later by the insurance providers. A majority of the patients visiting our hospital belong to low- and middle-income groups; only 5% were found to belong to upper-income category in a recent study [26]. The study was approved by the Institute Ethics Committee, PGIMER, Chandigarh, which is an independent body (INT/OEC/2021/SPL-390 dated March 12, 2021). Informed consent was taken from all participants. The sample size was calculated using the formula, $n = z^2 p(1-p)/d^2$, where $z = 1.96$ (taking alpha to be 0.05), $p =$ prevalence: $1020/100,000 = 0.01\%$ [27], $d =$ precision, 0.01 [28], giving a sample size of 380. The data were collected using an online 'Google' form circulated through the Smartphone app WhatsApp to the parents of children registered with the diabetes clinic. There are two WhatsApp groups created for addressing patients' queries related to diabetes management at home. The phone number of either parent is added to the WhatsApp group at the time of initial encounter with the diabetes team. We encourage parents to self-exit the WhatsApp group when they feel sufficiently confident in handling their child's problems; this is done to accommodate parents of children with a new diagnosis of T1D. The characteristics of patients in the two WhatsApp groups are similar; the second group was created due to the WhatsApp's limit of a maximum of 256 participants in a single group. Currently, the two WhatsApp groups have more than 400 active participants and are extensively used for virtual diabetes care at our center [29]. The current survey was closed when the desired participant numbers, i.e., 380 were achieved.

The questionnaire developed for this study included socio-demographic details such as age, educational

qualification, type of residence, disease-related information, and cost estimation inquiry. The modified BG Prasad scale [30] was used to estimate the SES of the participants.

A telephonic or in-person interview was conducted to collect data from the participants (180 out of 380) who were unable to fill out the Google form themselves. The clinical and expenditure details collected from the participants were cross-checked with proxy sources like bills, medical records, prescriptions, and lab reports. The cost of various consumables (insulin vials/cartridges, glucostrips, pen needles, and lancets) was calculated based on their unit price and yearly consumption as estimated from their diabetes logbooks. For example, if the child was receiving 15 units of bolus insulin per day, the number of vials required annually was calculated considering the wastage of 30 units per vial. The annual cost was estimated by the number of vials per year multiplied by the cost of one vial. The statistical analysis was conducted using SPSS software for Windows (version 22.0; SPSS Inc, Chicago, Illinois).

Results

Parents of 380 T1D children (mean age: 10.3 ± 4.6 years) participated in the survey. The age groups of patients were 6–11 years (42.6%), 12–14 years (23.7%), 15–18 years (14.7%), 4–5 years (11.6%), and less than 3 years (7.4%). The gender ratio was almost equal, with 51.1% males and 48.9% females. The socio-demographic characteristics of the families are presented in Table 1. The majority of the families (51.9%) belonged to lower or lower-middle SES groups, 31.8% belonged to the middle SES, and only 16.3% belonged to the upper SES. There were 19.5% of participants who reported that the head of the family was not earning.

The overall medical condition and treatment of the enrolled children with T1D are presented in Table 2. The median HbA1c (IQR) was 7.9% (5–15%); 8.4% of children could not get an HbA1c test during the last year due to financial constraints. The majority of the children were using multiple daily insulin (MDI) regimens; 5 each (1.3%) were using insulin pumps and split-mix regimens. The most used (53.4%) bolus insulin was lispro, while glargine was the most commonly used (92.7%) basal insulin.

Figure 1a and b describes the participants' financial support system and coping mechanisms. The majority of the parents (88.4%) reported having no financial support for the treatment of their child. More than one-third of parents (34.5%) resorted to borrowing loans to bear the medical emergencies in their children. One parent reported that their child is also working part-time to meet the expenses of his treatment.

The self-monitoring of blood glucose (SMBG) practice of the enrolled children is described in Fig. 2. Almost 80%

Table 1 Socioeconomic characteristics of the study participants (n = 380)

Variable	Total	
	n	%
<i>Socioeconomic status (as per modified BG Prasad scale 2021)</i>		
Lower class	60	15.8
Lower middle	137	36.1
Middle class	59	15.5
Upper middle	62	16.3
Upper class	62	16.3
<i>Gender of the child</i>		
Male	194	51.1
Female	186	48.9
<i>Housing</i>		
Rural	221	58.2
Urban	159	41.8
<i>Education of head of the family</i>		
Illiterate	15	3.9
Primary	17	4.5
Middle	47	12.4
Secondary	66	17.4
Sr. secondary	91	23.9
Graduate	85	22.4
Post graduate	59	15.5
<i>Occupation of the head of the family (as per Kuppuswamy classification)</i>		
Unemployed	74	19.5
Unskilled	49	12.9
Semi-skilled	49	12.9
Skilled	30	7.9
Arithmetic job /shop-owner	91	23.9
Semi profession	22	5.8
Profession	65	17.1

practiced SMBG 4–7 times a day; only 6.2% were performing SMBG less than two times a day. The frequency of needle reuse among the children is described in Fig. 3a and b. Most of the parents (61%) reported using pen needles up to three times; 2.6% were using the needles, sometimes even more than 20 times. For lancet use, 33.1% were using it up to three times, whereas 7.1% used it even more than 20 times.

The details of the diabetes-related OPE and their relation with the total family income are presented in Table 3. Among the various direct expenses, the mean insulin administration cost was found to be the highest (INR 28,965), followed by blood glucose monitoring (INR 21,576) and HbA1c testing (INR 5069). More than a quarter (28.7%) of children were admitted in the last year due to other comorbidities or diabetic ketoacidosis. The mean expenses for hospitalization were INR 27,495, with wide variation (range: INR 800–170,000). On average, the diabetes-related

Table 2 Description of treatment-related practices of the children

	Total	
	Mean	SD
HbA1C (%) Median: 7.95, range: 5–15%	8.2*	1.76
Duration of diabetes (yrs)	3.6	2.6
<i>Insulin regimen</i>		
Basal bolus with pen	362	95.3
Basal bolus (with pen for basal and syringe for bolus)	8	2.1
Split mix (with syringe)	5	1.3
Insulin pump	5	1.3
<i>Bolus insulin used</i>		
Glulisine	7	1.8
Lispro	203	53.4
Aspart	120	31.6
Regular	50	13.2
<i>Basal insulin used</i>		
Glargine	352	92.7
Degludec	20	5.2
Determir	3	0.8
NPH	5	1.3
Presence of coeliac disease	57	15
Presence of hypothyroidism	33	8.7

*n = 348, as 32 children had no HbA1C test during last year

expenses were 49% (SD: 42), (median 41.8%) of the total family income of the participating families. Overall, 11.8% spent up to 10%, 21.6% spent up to 25%, 26.8% spent up to 50%, and 22.1% spent up to 75% of the total family income for T1D care. Few families (8.2%) had these expenses beyond (more than 100%) their total annual family income.

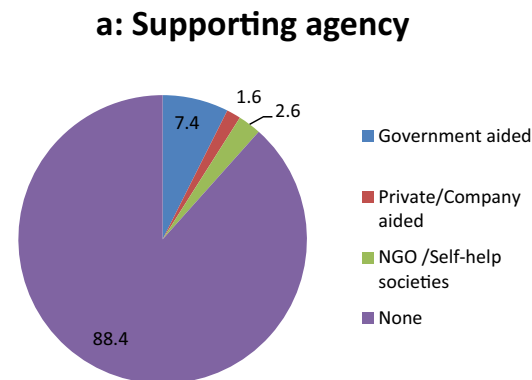


Fig. 1 Description of financial support availability and financial coping mechanisms of participants

Frequency of SMBG per day (%)

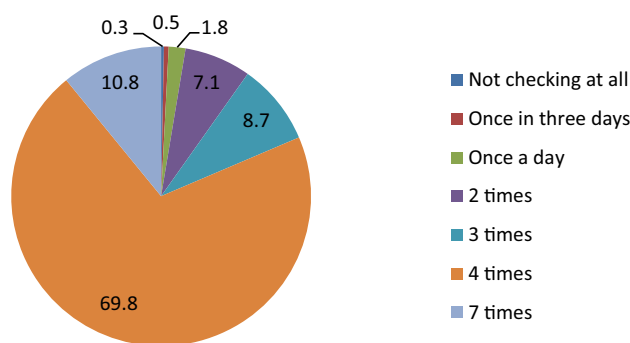


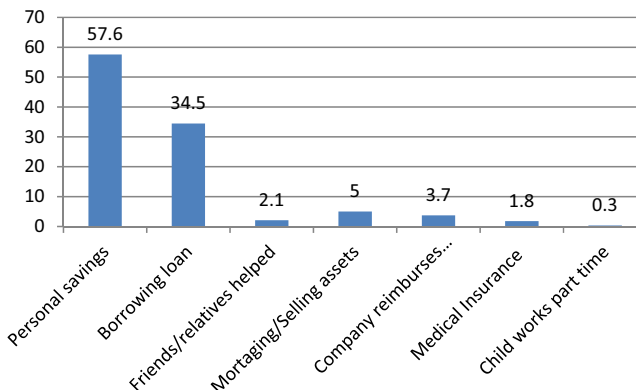
Fig. 2 Self-monitoring of blood glucose (SMBG) practice among participants

The diabetes-related expenses as a percentage of total family income varied among various SES groups; 110% in the lower SES group, 61% in the lower-middle, 34% in the middle, 20% in the upper-middle, and 9% in the higher SES group. The socioeconomic status and the percentage of family income spent on diabetes care were found to have a significant negative correlation ($r = -0.738, p = 0.00$).

Discussion

This cross-sectional study describes the enormous financial burden of diabetes management among the families of children with T1D in a low-resource setup. It was found that the majority of the families were struggling to maintain the expenses related to the essential tasks of insulin

b: Coping Mechanisms to deal with financial emergencies



administration and blood glucose monitoring. This is despite many of them not following the recent recommendations for better glycemic control, such as seven-point SMBG profiles, use of continuous glucose monitoring devices, and insulin pumps. Even the average needle use in many children was far more than recommended; similar to our earlier observations [31]. This infers that the diabetes-related expenses are affecting the sustainability of diabetes care for several families in our setup. The high OOPE correlates with lower treatment adherence leading to a poor prognosis of T1D in low-resource circumstances [4, 6].

The health-related spending on diabetes care varies vastly among high- and low-income countries. This is because high-income countries generally enjoy universal healthcare, better health insurance provisions, regularly reviewed treatment guidelines, and active diabetes associations advocating for diabetes care [19]. Governments in these countries usually provide diabetes supplies for free or subsidized. On the

other hand, in lower-income countries with under-resourced medical systems, even minimal diabetes care is beyond many families' means. In such countries, management of T1D poses a significant financial burden for the family having a child with T1D, which leads to compromised healthcare and treatment adherence, poor glycemic control, early development of chronic complications, and sometimes unpredicted death [19].

Our study also revealed a significant negative correlation between SES and diabetes expenditure as a percentage of total family income; lower SES groups spent a higher percentage of their total income on diabetes care. This assumes significance as the most underprivileged families face the highest financial burden and can potentially worsen the treatment adherence. In our study, the median percentage of total family income spent on diabetes care was 41% which is higher than the previous study from South India (22%) among adults with T1D [23], as well as another study

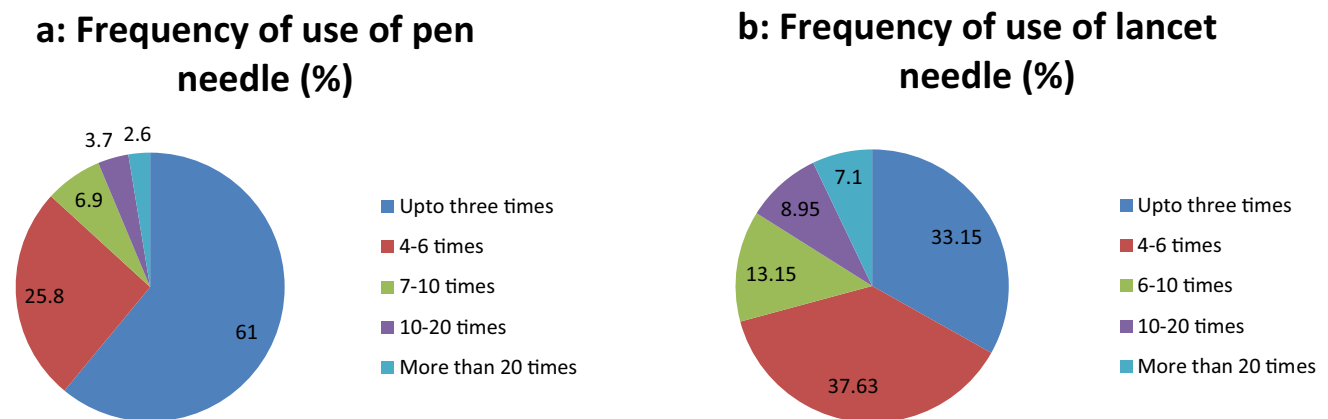


Fig. 3 Needle reuse practice among participants

Table 3 Description of expenses related to diabetes management (median, range)

Expenditure head	Mean (SD)	Median (Range)	IQR
<i>Direct expenses</i>			
Insulin administration (Rs.)	28,965 (10,081)	26,381 (12,420–67,971)	13,118
Blood glucose monitoring (Rs.)	21,576 (8119)	19,990 (1000–59,264)	9698
HbA1C tests per year (n = 348*) (Rs.)	5069 (1971)	5000 (250–8400)	3400
Single visit to the clinic for follow-up (travel, food and accommodation, if needed) (Rs.)	2889 (3185)	1825 (0–15,000)	3300
<i>Indirect expenses</i>			
Hospitalization expenses if the child was admitted in the last 1 year (n = 109) (Rs.)	27,495 (28,604)	20,000 (800–170,000)	25,500
Total family income (RS.)	19,021 (18,257)	10,000 (1500–100,000)	18,000
Total diabetes care (1 + 2 + 3) (Rs.)	55,185 (11,486)	53,396 (26,575–105,027)	14,619
Expenditure on child's diabetes care (% of family income (%))	49 (42)	41 (3.5–314.9)	46.1

*32 had no tests done due to lack of resources, ignorance or both; 36 had their expenditure more than 100% of their income

from North India (mean = 18.6%) [24]. This difference could partly be due to more patients from lower and lower-middle SES in our centre which is the largest government hospital in North India compared to the other studies that had more patients belonging to the middle SES. Nevertheless, both previous Indian studies also indicated the high economic burden on families of patients with T1D. Other studies from similar resource-constrained regions of the world have revealed similar findings [13, 32].

Few children could not get any HbA1c test done during the last year due to resource constraints. Although the test was available at subsidized rates at secondary and tertiary level hospitals, the cost of traveling to these centers was beyond their capacity; especially during the COVID-19 pandemic-related financial crunch. The wide variation among the hospitalization expenses also depicts the uneven access to healthcare. Only a few had access to free-of-cost in-patient treatment for their child, from a medical insurance or fee waiver from the hospital. Along with the tangible costs estimated in our study, other intangible costs like loss of wages, absence from school, college, office, etc., which also contribute to the overall costs of diabetes care, are expected to be high in similar proportions.

The present study has some limitations. The family income data are based on parents' reporting and may not be completely accurate. More than 90% of India's employment is in the unorganized sector making it extremely difficult to get income data verifiable by salary slips or employers' records [33]. Second, this being a single centric study, the results may not be generalizable to other patient populations. Third, there are chances of respondent bias, towards projecting more or less financial burden. To minimise this bias, the market costs of consumable items were verified to those reported by the participants. The estimated costs of diabetes consumables (insulin vials, needles, glucostrips, lancets, etc.) were determined as per costs and consumptions reported by the parents. Further, although the units of items were calculated based on consumption shown in their diabetes logbook, it was not possible to verify the cost of these items actually paid by caregivers. Similarly, it was not possible to verify the hospital bills, as most of them were admitted in various hospitals close to their residences spread across the entire region of northwest India.

Conclusions

There is high financial burden of diabetes care among families of children with T1D. Costs related to SMBG and insulin constitutes the largest share of OOPE. In addition, the expenses on hospitalization were high. Families with low SES urgently need support to sustain diabetes care for their children with T1D. Larger studies are required to provide

OOPE data to guide policy decisions aimed at reducing direct costs to patients.

Author contributions LR and DD conceived and designed the study. LR, NG, GK and PW collected data. LR conducted the data analysis. DD validated the interpretation of the data. LR wrote the first draft and DD revised the manuscript. NG, GK and PW approved the final interpretation of data, and provided important intellectual inputs during manuscript preparation. All authors approved the final version manuscript.

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Declarations

Conflict of interest None.

Ethical statement All relevant ethical guidelines have been followed for data collection and reporting.

Human rights statement Institutional Ethics Committee, Post Graduate Institute of Medical Education and Research, Chandigarh, India.

Informed consent All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and/or with the Helsinki Declaration of 1964 and later versions. Informed consent or substitute for it was obtained from all patients for being included in the study.

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