ORIGINAL RESEARCH ARTICLE

Healthcare Costs and Financial Burden Among Informal Caregivers of Children with Down Syndrome in Karnataka, India: A Cross-Sectional Study

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ABSTRACT

Background: Parents of children with Down syndrome (DS) often face greater challenges due to the need for specialized childcare and treatment, which incurs significant and sustained costs. The objective of the study was to identify the direct healthcare costs, direct education and living cost, and financial burden associated with caregiving for children with DS.

Methods: A cross-sectional study was conducted in special schools in six districts of Karnataka where caregivers of children with medically diagnosed DS (0-18 years) were recruited. Using multistage sampling, a sample of 400 was recruited for the study.

Results: The majority of the spending was out-of-pocket expenditure. Caregivers had to bear additional costs associated with caring for hospitalized children. Four-fifth participants reported that they spend more than INR 1000 yearly to consult private practitioners, about 95% spend more than INR 1000 to consult physicians in a hospital and 94% spend more than INR 1000 to consult specialists. Apart from these, there are out-of-pocket expenses for medications, other therapies and rehabilitations.

Conclusion: Considering the absence of or inadequate health insurance cover, healthcare spending is mostly out-of-pocket. Furthermore, with meagre income, healthcare cost, special education, rehabilitation and other expenses for managing children with DS adds financial strain on the family. These findings suggest the need for future assessment of healthcare and other costs caring for DS children in comparison to children without DS and with other disabilities.

Keywords: Caregivers, Cross-sectional study, Down Syndrome, Direct costs, Financial burden

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INTRODUCTION

Down syndrome (DS), also known as trisomy 21, is a genetic disorder caused by the presence of an extra copy of chromosome 21, leading to developmental and intellectual delays as well as a distinct clinical risk profile.[1] The prevalence rates of DS range from approximately 1 in 1,000 to 1 in 1,100 live births, with a significant variation across different socio-demographic regions.[2] The increase in Down syndrome cases is primarily attributed to advanced maternal age, as the likelihood of having a child with DS rises with maternal age.[3,4] Additionally, factors such as people living in rural areas, consanguineous marriage, and socioeconomically marginalized families contribute to the chances of having a DS child.[5]

Parents of children with DS often face multiple challenges in terms of financial strain, health issues, physical and emotional stress,[6] in addition they also experience difficulties in various domains such as mental health, sleep disruption, social support, and housing stability.[7] Additionally, caregiving responsibilities lead to reduced working hours for caregivers or cause them to leave their job, further increasing the family's financial burden and weakening social support, which is consistent with previous research on caregivers' burden and associated factors among primary caregivers.[8] Parenting pressure among caregivers of DS children can lead to increased mental and physical stress, emphasizing the need for better support systems and developing targeted interventions that may reduce stress among caregivers and improve their overall quality of life.[9] Caregivers of children with DS face significant financial challenges, including high direct healthcare costs for medical treatments, therapies, and routine check-ups, as well as indirect costs such as lost income due to reduced work hours or job loss.[10] Direct healthcare cost refers to medical, non-medical, and developmental expenses incurred by caregivers or parents of DS children. Expenses, such as direct costs related to special education services, long-term care, and developmental services, and the indirect costs associated with lost wages, are not reimbursed as most of these expenses are not covered under medical insurance, and they impose a significant financial burden on families.[11] Various studies emphasised on experiences of caregivers' burden on disabled children.[12,13]

However, there is a paucity of literature on the financial burden of caregivers for DS children in India. With this research, we aim to explore and quantify the direct medical costs, direct non-medical costs, developmental costs, and financial burden associated with caregiving for children and adolescents with DS in Karnataka, India.

METHODOLOGY

Study design and setting: A cross-sectional study was conducted in Karnataka, India and the data were collected from January 2025 to March 2025.

Participants: Children clinically diagnosed with DS within the age group of 0 to 18 years were recruited from special schools in Karnataka. The lead researcher verified the children's clinical diagnosis by referring to the medical records maintained by the special schools. Informal caregivers of DS children were recruited to collect data for this study. An informal caregiver is a person who coordinates and provides most of the unpaid day-to-day care for raising and managing the health and well-being of a child with DS. School teachers or heads acted as gatekeepers to identify the caregivers of DS and supported researchers. The caregivers were selected by the lead researcher by attending parent-teacher meetings. All caregivers attending parent-teacher meetings were invited to take part in the study. Those caregivers who refused to participate, did not attend the parent-teacher meeting when the researcher visited, or whose DS children are not enrolled in any of the special schools selected by the researcher, are not part of this study.

Data sources, measurement and variables: Data were collected using a structured, self-administered questionnaire developed by the research team and completed by informal caregivers of children diagnosed with Down syndrome (DS). The questionnaire gathered information on caregiver characteristics such as age, employment type, education, marital status, family structure, residence, and child characteristics such as age group, DS severity based on school medical records, birth order, number of siblings, and care-related aspects such as the presence of medical conditions (as reported by caregivers), use of health insurance, and participation in rehabilitation or special education.

Data pertaining to annual household income was collected directly from participants by means of self-administered questionnaire where predefined income bracket is mentioned. This method was chosen so that the participants can mention the income range and the data will be consistent across population with diverse characteristics. Nevertheless, it may lead to potential biases. Reporting bias might arise if participants misinterpret the income brackets or if they consider rough estimation of income. Social desirability bias may also lead to some extent if participants select higher or lower income brackets instead of their actual income. Also, recall bias might affect the accuracy of income, especially those who have fluctuating incomes. Using the income range instead of actual figure, might affect the accuracy of measuring financial burden and should be considered when interpreting income-related results.

To reduce recall bias in providing information about caregiving costs, participants were provided with a predefined list of cost categories, including hospitalization cost (with and without surgery) medication cost, education cost, physician consultation cost, therapy cost, general practitioner visit, specialist visit, transportation cost and caregiver support expenses. This approach helped the caregivers to recollect all the possible type of potential costs and also reduces the risk of omitting or misreporting specific expenses. Although this approach helped reduce recall bias, there can be a possibility of forgoing some expenses that may still have been overlooked.

Questionnaire Design, Development and Validation: A well-structured survey was designed to capture detailed cost related information and also socio-demographic data of caregiver as well of DS child through informal caregivers. To verify whether the instrument captured all the variables pertaining to financial burden, the questionnaire was reviewed by a panel of six experts: two experts in health economics, paediatric care, and public health. The feedback was used to assess the relevance and comprehensiveness of the cost categories included.

Face validity was conducted among five informal caregivers from the target population. They were asked to assess the clarity, ease of understanding, and relevance of the questionnaire items. Based on the feedback of experts, minor revisions were carried out to enhance the clarity and structure of questionnaire. A pilot test was carried out with fifteen caregivers to assess the simplicity of the questionnaire. The feedback was used to refine the final version of the instrument.

Sampling methods: We used multistage sampling to recruit caregivers of DS children. Karnataka, is one of the South Indian states having 30 districts. There are 220 taluks in Karnataka with an average of seven taluks per district. There are 178 special schools in Karnataka, of these 25 were selected. As a first step, we purposively selected six districts based on a range of development indicators, such as the availability of special education services, healthcare infrastructure, and economic status, using data from the Karnataka State Development Report and the Department of Health and Family Welfare. We opted to include one taluk from each district, except Udupi district from where three taluks were selected. We used convenience sampling across three taluks due to logistical feasibility, established partnerships with institutions, and the availability of special schools willing to participate. In the later stage, within each selected district, we identified special schools for children with intellectual disabilities. This approach allowed us to efficiently reach eligible participants while maintaining consistency in data collection methods.

A questionnaire was distributed to all parents of DS who attended parent-teacher meetings. School teachers and heads assisted researchers in getting back filled questionnaires from the caregivers.

Scope of the Study: This study was conducted to measure the direct healthcare costs associated with caregiving for children with DS, which includes medical, educational, and caregiver costs. Indirect costs, such as lost income, productivity losses, emotional or social costs, impact on family life and relationships, were not included in this study due to difficulty in measuring these variables in the study context, and also the study focuses on direct expenditure costs which are quantifiable in measuring the financial burdens are only considered. This limitation is acknowledged, and future research may explore the impact of both direct and indirect costs on caregivers.

Study size: To determine their role in the financial strain on informal caregivers the study's quantitative variables - such as the number of hours spent providing care, related costs, and the caregiver's income levels - were examined. To capture differences between income groups, caring intensities, and other important metrics, variables were categorised using quartiles. The sample size was calculated using Cochran`s formula to determine the required sample size.[14]

$$n_0 = Z^2pq/e^2$$

Where, n_0 is required sample size; Z is Z-score corresponding to the desired confidence level (1.96 for 95%); p is estimated proportion of the population (0.5 used for maximum variability), q is 1-p; and e is acceptable margin of error (0.05 for 5%)

Using these parameters the calculated required sample size n_0 was 384.16. Thus, a sample size of approximately 384 to 400 respondents was established, guaranteeing a 95% confidence level and a 5% margin of error. There is enough statistical power in this sample size to identify significant patterns and differences in the data. Groupings were selected to account for the variety of caregiving circumstances and guarantee clarity in the interpretation of the results.

Statistical methods: For the purpose of quantitative data analysis, initially the data were compiled using Microsoft Excel and then converted into SPSS data file. The statistical analysis was performed using SPSS (v26). We reported data as frequencies and percentages, median and IQR. All costs are in Indian National Rupees (INR); USD 1 is equivalent to INR 85.88 in April 2025. Furthermore, we explored association of selected socio-demographic variables and financial burden by using Chi Square test. We computed the financial burden as total direct cost ÷ annual income × 100. Total direct cost includes costs such as direct medical cost, direct non-medical cost, outpatient medical cost, transportation and accommodation and caregiver support cost. We then categorized the financial burden into three categories, low (<10), medium (10-29.99) and high (30 or more).

The Shapiro-Wilk test was used to assess the normality of continuous cost variables. As the distribution of all cost variables was found to be non-normal ($p < 0.05$), non-parametric tests were used for further analysis. The Kruskal-Wallis test was chosen to compare median differences across more than two independent groups (age groups, annual income and DS severity), due to the skewed nature of the cost data. The Chi-Square test was used to analyse associations between categorical variable financial burden categories and annual income levels, as it is appropriate for evaluating relationships between variables.

Ethical Review Board: The study was approved by the institutional Ethical committee -Kasturba Medical College and Kasturba Hospital Institutional Ethics Committee (IEC-484/2020), Manipal and also registered under the Clinical Trial Registry, India: CTRI/2022/03/041403.

RESULTS

Participants: We collected data from 423 participants of which there was missing data from 23 participants, which were excluded; hence, final analysis was conducted on n = 400 participants.

Descriptive data: Table1 illustrates characteristics of the participants (n = 400). Approximately 70 % of the DS children were more than five years old. Of all children, 54.75% were females, 58.75% were only children of the parents, and 65.25% were first born. 41.20% children were diagnosed with moderate DS, followed by mild DS (35%). Most children (95.25%) received physiotherapy or occupational therapy, more than two-third (70.25%) received language and speech therapy, while few (7.75%) received special education in addition to attending special schools. The majority (71.25%) of children lived in a joint family system. With regards to caregiver characteristics, most (63.75%) were married, more than half (53.25%) were graduate or post-graduate, and almost quarter (24.50%) were not working.

Health status of Down syndrome children: In this study, we assessed the prevalence of health conditions reported by the caregivers of the DS children. As seen in Figure 1, most children (n = 211) had respiratory problems, followed by eye or ear problems (n = 204), heart problems (n = 142) and so on. Some of these children suffered from more than one health condition adding more caregiver burden.

Government aid or health insurance status: Three-fourth children received government scholarship in terms of monetary support; of which majority (279 of 294) received a meagre amount of INR 800 (equivalent to $ 9.31) per month. Fewer children (01.75%) were supported by non-governmental organizations. Three-fourth of children were registered with Niramaya Health Insurance by paying a premium of less than INR 1000 per year. 12.75% children were registered with Ayushman Bharat yojana, a central government sponsored health insurance for below poverty line status families. There were eight percent of children with some form of private health insurance. More details are presented in Annexure 1.

Direct Healthcare and Related Costs Among Caregivers: Shapiro-Wilk Test was conducted due to non-normal distribution of direct healthcare cost data(p<0.001). The data are presented as median values along with Interquartile Range (IQR) 25th-75th percentiles. The direct cost includes various cost components which plays a crucial role in assessing the cost burden as reported by caregivers of DS children.

Table 1: Socio-demographic variables (n = 400)

Variables	Children (%)
Down Syndrome child's characteristics	
Child's age	
0 to 5 years	105 (26.2)
6 to 12 years	164 (41)
13 to 18 years	131 (32.8)
Child's sex	
Female	219 (54.75)
Male	181 (45.25)
No. of siblings	
Only child	235 (58.75)
One	161 (40.25)
Two or higher	4 (1)
Birth order of Down Syndrome child	
First	261 (65.25)
Second	135 (33.75)
Third	4 (1)
Down Syndrome severity	
Mild	140 (35)
Moderate	165 (41.2)
Severe	95 (23.8)
Children receiving rehabilitation or special education	
Medical intervention	71 (17.75)
Physiotherapy or occupational therapy	381 (95.25)
Speech and language therapy	281 (70.25)
Diet modifications	5 (1.25)
Special education	31 (7.75)
Applied behaviour analysis	33 (8.25)
Caregiver characteristics	
Family type	
Joint	285 (71.25)
Nuclear	115 (28.75)
Marital status	
Married	255 (63.75)
Divorced	67 (16.75)
Separated	73 (18.25)
Widowed	5 (1.25)
Education	
Elementary	76 (19)
Secondary	111 (27.75)
Graduate	165 (41.25)
Post-graduate	48 (12)
Job type	
Full-time	145 (36.25)
Part-time	157 (39.25)
Not working	98 (24.5)
Type of income source	
Both parents working	160 (40)
Single parent working	240 (60)
Annual household income (INR) (USD 1 is equivalent to INR 85.88 in April 2025)	
Low Income Group (0 to 200000)	122 (30.5)
Middle Income (200000 to 500000)	149 (37.3)
High Income Group (Above 500000)	129 (32.2)

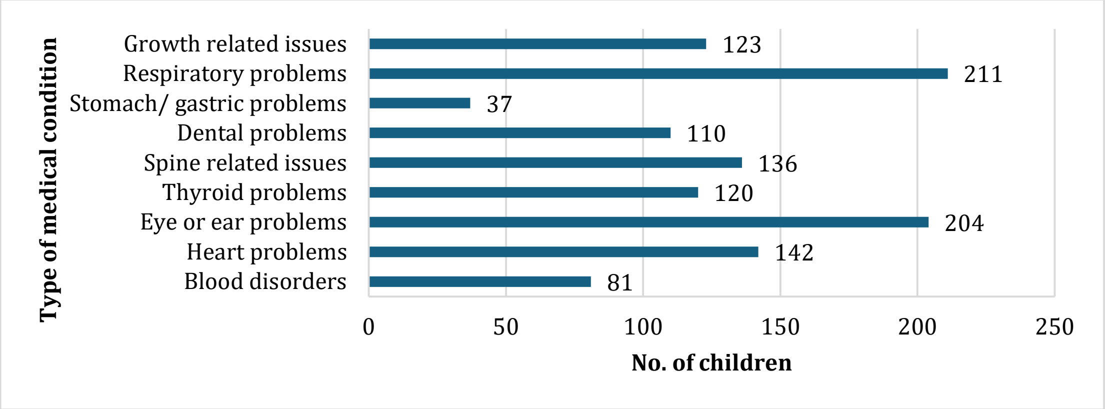

Figure 1: Frequency of Down syndrome children with medical conditions (n = 400)

Table 2: Descriptive Summary of Direct Healthcare-Related Costs (N = 400)

Cost Category	Median (INR)	IQR(Q1-Q3)* (INR)
Direct Medical Cost	23000	7500-25000
Surgical Cost	15000	6500-18375
Non-Surgical Cost	8000	0-14000
Direct Non-Medical Cost	22000	18000-28200
Living Cost	6000	3600-9600
Childcare Cost	11400	7200-15000
Special Education Cost	7200	6000-12000
Outpatient Medical Cost	15000	11150-21000
General Practitioner`s Visit	500	400-800
Specialists Consultation	1000	800-1500
Medication and supplement expenses	500	400-800
Private therapy expenses	1200	1000-2000
Outpatient Services	1000	600-1200
Transport and Accommodation Cost	6800	5000-8000
Cost of Transportation	6000	5000-8000
Cost of Accommodation	0	0-2000
Caregiver Support Cost	1000	0-3000
Skills training and workshop expenses	0	0-500
Cost of Counselling	0	0-400
Respite Care Cost	0	0-500

*Interquartile Range (IQR) 25th-75th percentiles

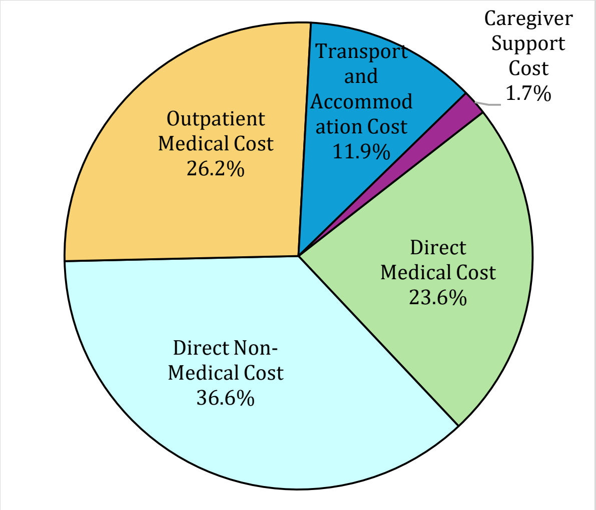

Figure 2: Distribution of Direct Costs Incurred by Informal Caregivers of Children with DS

Among the reported cost highest financial burden were attributed to direct medical cost (median INR 23000) which includes surgical and non-surgical cost, the second highest burden being direct non-medical cost (Median INR 22000) which includes childcare cost(care during school term, holidays, daycare service), living cost (special dietary needs, Personal Care, Home Modifications) while Transport and accommodation cost and Caregiver support costs showed considerable less burden with median (INR 6800 and INR 1000) respectively.

Direct Non-Medical Costs account for the largest share (37%) of the total financial burden, reflecting the substantial impact of recurring expenses such as special education, childcare, and daily living costs. Outpatient Medical Costs (26%) and Direct Medical Costs (23%) primarily driven by the ongoing need for therapy, follow-up visits, medications, and surgical care. Transport and Accommodation Costs constitute 12%, highlighting additional logistical challenges caregivers face when accessing specialized care, Caregiver Support Costs, by contrast, comprise only 2%, services such as caregiver counselling, training, and peer support are often provided at low cost or free of charge through public programs, NGOs, or hospital-based support initiatives.

A Comparative analysis of cost across various socio-demographic variables – Child Age, Down Syndrome Severity and Annual Income of Caregiver

Table 3 shows Direct Medical Cost and Outpatient medical cost significant different in pairwise comparison between 0-5 and 13-18 age group and 6-12 and 13-18 age group whereas 0-5 and 6-12 age group was not statistically significant, which indicates early and middle age children incur higher medical cost.

There were no statistically significant differences in transport and accommodation costs across the child age groups (0–5 years, 6–12 years, and 13–18 years).

Table 4 shows significant increase in cost between 3 pairwise comparison group for Direct Medical Cost, Direct non-medical cost and outpatient medical cost. Specifically, caregivers of children with severe condition incur Direct medical cost (INR 20000), Direct non-medical cost (INR 43200) and outpatient medical cost (INR 38400) when compared with mild and moderate groups.

Transportation and accommodation and Caregiver support cost were significantly higher in the severe group compared to mild and moderate groups ($p < 0.05$ for B, C), though no significant difference was observed between mild and moderate levels.

Table 5 shows significant increase in all cost categories for high income group when compared with low- and middle-income group. It shows clearly that low- and middle-income groups are not able to access or spend on health cost due to their financial constraints.

Table 6 shows no statistically significant differences between the two groups (all $p > 0.05$). The Mann–Whitney U test was conducted to examine potential gender-based differences in various direct healthcare cost categories among caregivers of children with Down syndrome. The results indicated no statistically significant differences between the two groups (all $p > 0.05$).

Table 3: Median (IQR) of Direct Healthcare Cost by age group of children with DS and Pairwise Group Comparison (all cost values in INR)

Cost Category	Age categories			Comparison#
	0 - 5 years (n=105) Median (IQR@)	6 - 12 years (n=164) Median (IQR@)	13 - 18 years (n=131) Median (IQR@)	
Direct Medical Cost*	28000 (11000-30500)	16000 (13200-30375)	12500 (6500-19500)	B, C
Direct Non-Medical Cost*	30000 (25200-31200)	39000 (36600-42000)	34800 (33000-38400)	A, B, C
Outpatient Medical Cost*	75600 (63000-81600)	75000 (63500-83750)	60000 (50000-80000)	B, C
Transport & Accommodation Cost	13600 (9600-15600)	11600 (11600-14400)	11600 (11600-14400)	None
Caregiver Support Cost*	0 (0-3800)	3000 (0-6000)	3000 (0-6000)	A, B

*Significance at p<0.05
@ Interquartile Range (IQR) Q1–Q3 (25th-75th percentiles)
#Pairwise Comparison: A = 0 to 5 vs 6 to 12, B = 0 to 5 vs 13 to 18, C = 6 to 12 vs 13 to 18

Table 4: Median (IQR) of Direct Healthcare Cost by Down Syndrome Severity and Pairwise Group Comparison (all cost values in INR)

Cost Category	Down Syndrome Severity			Comparisons#
	Mild (n=140) Median (IQR@)	Moderate (n=165) Median (IQR@)	Severe (n=95) Median (IQR@)	
Direct Medical Cost*	11000(7050-19500)	17000(10000-16250)	20000(16500-50000)	A,B,C
Direct Non-Medical Cost*	22800(16800-36900)	21600(16800-40200)	43200(31200-49800)	A,B,C
Outpatient Medical Cost*	15500(9400- 17875)	19200(14400- 23600)	38400(10800- 56600)	A,B,C
Transport & Accommodation Cost	8000(6800- 11600)	9200(7200-11600)	11600(9600- 14500)	B,C
Caregiver Support Cost	0(0-2000)	0(0-2000)	2000(0-3000)	B,C

*Significance at P<0.05
@Interquartile Range (IQR) Q1–Q3 (25th-75th percentiles)
#Pairwise Comparison: A = Mild Vs Moderate, B = Mild Vs Severe C =Moderate Vs Severe

Table 5: Median (IQR) of Direct Healthcare Cost by Annual Income of Caregivers and Pairwise Group Comparison between Income Groups

Cost Category	Annual Income Categories			Comparisons#
	Low (n=122) Median (IQR@)	Middle (n=149) Median (IQR@)	High (n=129) Median (IQR@)	
Direct Medical Cost*	0(0-6500)	20000(12000-25000)	25000(15000-30000)	A, B, C
Direct Non-Medical Cost*	18000(15000-21000)	22800(18000-27900)	28200(20000-30300)	A, B, C
Outpatient Medical Cost*	10800(9400-12800)	15000(12000-17800)	22000(13600-29300)	A, B, C
Transport & Accommodation Cost*	5000(4000-6000)	6800(6000-8300)	8000(7200-10500)	A, B, C
Caregiver Support Cost*	0(0-0)	1800(0-2550)	3000(2000-5000)	A, B, C

* - significance at P<0.05
@Interquartile Range (IQR) Q1–Q3 (25th-75th percentiles)
#Pairwise Comparison: A = Low Income Vs Middle Income, B = Low Income Vs High Income, C =Middle Income Vs High Income

Table 6: Gender-Based Comparison of Cost Categories Using the Mann–Whitney U Test (all cost values in INR)

Direct Cost Category	Group1*(Median, IQR@)	Group2*(Median, IQR@)	Mann–Whitney U	Z-Score	P Value
Direct Medical Cost	15000 (8000-25000)	12000 (7000-25000)	18274	-1.35	>0.05
Direct Non-Medical Cost	21000 (18000-28100)	22000 (18000-28200)	19439	-0.33	>0.05
Outpatient Medical Cost	15000 (12000-21000)	13800 (10600- 21000)	18549	-1.11	>0.05
Transport & Accommodation Cost	6800 (5000-8300)	7000 (5000-8000)	19612	-0.18	>0.05
Caregiver Support Cost	1000 (0-3000)	800 (0-3000)	19136	-0.62	>0.05

*Group1 – Male Children, Group2 – Female Children
@Interquartile Range (IQR) 25th-75th percentiles

Table 7: Cross-tabulation of Financial Burden Levels by Annual Household Income (N=400)

Annual Household Income Group	Low Burden n(%)	Medium Burden n(%)	High Burden n(%)	Total
Low Income	0(0%)	20(16.4%)	102(83.6%)	122
Middle Income	28(18.8%)	107(71.8%)	14(9.4%)	149
High Income	88(68.2%)	41(31.8%)	0	129

Table 7 shows a strong relationship between annual household income group and financial burden level. 83.6% of caregivers of low-Income group are facing higher financial burden and 71.8% of caregivers in middle income group are facing medium burden whereas among high income families 31.8% are suffering from medium burden and less with minimal burden.

DISCUSSION

The present study aimed to understand the direct healthcare cost distributions incurred by caregivers of DS children by emphasising the economic burden faced by these families of various socio-demographic groups. By analysing various costs like direct medical costs, direct non-medical costs, outpatient medical costs, and caregiver support costs, we explore the economic burden faced by families of DS children in Karnataka. There is an evident decrease in direct healthcare costs for low-income families with an annual income of less than INR 2 lakh, as they depend more on government-funded health schemes like Ayushman Bharat – Arogya Karnataka for availing medical treatment. Oftentimes, due to a lack of community or government response or delay in treatment, families have to rely on private therapeutic centres or hospitals in emergencies, which then leads to out-of-pocket spending.

While the financial burden is lower for these families, the relative burden, when compared to their annual income, is substantially higher. Our findings are in line with previous studies[15,16] which signifies that caregivers of the low-income group often experience financial stress as the out-of-pocket expenditures are not covered under public insurance schemes. Direct medical costs and direct non-medical costs were the most significant expenses that contribute to the financial burden of low and middle-income families. The study findings are in line with a study, where families of children below the age of six years face a huge financial burden due to the need for intensive medical interventions, surgeries, and therapy.[17] Early interventions are essential for improving developmental outcomes in children, which place considerable financial demands on families. For low and middle-income families, limited financial resources, limited awareness, and lack of access to continuous therapy services contribute to high financial burden.

The study shows that 54.75% of children with Down Syndrome were female. However, further analysis discovered that no significant gender-based differences were found in the financial burden faced by caregivers. Both male and female gender groups appeared to result in comparable levels of direct medical and direct non-medical costs, including medical interventions, therapies, and childcare expenses. This articulates that though the sample had a marginally higher proportion of female children (approximately 10%), gender did not play a substantial role in determining gender-wise financial burden experienced by caregivers.

The study shows that majority (75.5%) of children received government scholarships ₹800 per month, which is inadequate to cover their medical cost, NGO support was minimal (<2%) while 74.75% were enrolled in Niramaya scheme where the annual coverage limit is INR 1 lakh and this scheme has restricted benefits which do not adequately cover the costs of regular therapeutic expenses and special education cost. 12.75% of families were covered under Ayushman Bharat Yojana, and 12.5% had no government-sponsored insurance due to a lack of information available about the available schemes and facilities. The private health insurance scheme was opted by only 8% of the study population, as most of the families are not able to afford the annual premium, which is approximately ₹5000.

The above-mentioned observation discloses considerable gaps in the area of health insurance coverage and financial support mechanisms that are available to families of DS children, especially among the low-income demographic, while also highlighting their continued reliance on out-of-pocket expenses. Families of adult children with Down syndrome often face difficulties in accessing essential services such as occupational, speech, or physical therapy, due to restriction in insurance caps, cost variation among insurance plans, and inconsistency in coverage of benefits between private and public insurance policy.[18] The existing schemes with insufficient benefits leave the families vulnerable to economic strain and emphasize the need for more inclusive and provide financial protection mechanisms tailored to the needs of children with DS.

The financial burden assessed in our study used a set of six questions that were closely related to the challenges in the lives of caregivers taking care of DS children. The questions were based on the last item from the 22-item Zarit Burden interview which asks about "not having enough money to care".[19] To delve deeper into the understanding of the financial burden, the questions assessed if the caregivers were able to meet daily expenses, pay for themselves or their child's medical bills, spend on important occasions in a year and also have some savings. This is the first study in India to assess the financial burden of caregivers with DS children using a six-item questionnaire. This questionnaire can be used as a basis for measuring financial burden, as there are tools for assessing caregiver burden, but not specifically for financial burden of caregivers.

IMPLICATIONS

In India, families of children with DS very often face financial, emotional, and social pressure due to a lack of support from the government, community, Support groups, and their relatives and friends. This has become a challenge to face society and also a burden. These challenges are more intensified in low and middle-income groups. Caregivers are facing issues with respect to specialized care, financial aid, and community support, where all these facilities are limited or non-existent. To address these complex issues faced by caregivers, a cohesive framework is essential by leveraging digital innovation, financial tools, community networks, and policy reform. Furthermore, one best practice would be developing micro-insurance products designed specifically for children with developmental disabilities.

Firstly, there is an urgent need to broaden the coverage and raise the financial threshold of the Niramaya Health Insurance Scheme, as the current reimbursement doesn't give enough financial support to cover the ongoing costs of essential therapies such as speech, occupational, and behavioral therapies. Enhancing such schemes can improve healthcare access to many families, just like Pradhan Mantri Jan Arogya Yojana (PMJAY), which has increased the reach of medical treatment to the underserved population in rural areas. Second, the Rashtriya Bal Swasthya Karyakram (RBSK) should be strengthened or given more importance by integrating a structured pathway for children diagnosed with DS, providing continuous care and follow-up beyond the initial phase. Third, to bridge geographic and infrastructural gaps, the Government should collaborate with private clinics and organizations through public-private partnerships (PPPs) to subsidize and spread out their services in rural areas. Finally, it is also required to train frontline workers like ASHAs **(Accredited Social Health Activists)** and Anganwadi staff in providing basic therapy so that the children can get the required therapies in areas where specialists are not available. Together, these strategies offer a multilevel approach to reducing financial and transportation challenges while enhancing inclusive and sustainable development care within India's healthcare system.

However, these insurance schemes are developed with a partnership of private and public sector insurers by providing reasonable premiums and coverage for clinical therapies, health screening, childhood support services, and interim care support. This new insurance scheme fills a significant gap in the existing insurance framework, which often neglects the hidden or indirect costs of special needs care, such as transportation costs to the therapy center, specialized learning material costs, or assistive devices.

Additionally, trained professionals such as special educators and physiotherapists can provide frequent visits to rural places where they can provide basic services using assistive therapy materials, and sensory support items where every child in the remote locations receive all the required treatments without traveling a long distance. This will be beneficial to caregivers also, as they observe and learn the basic therapy methods during these sessions, allowing them to follow the same practice at home, which in turn reduces opportunity cost. Caregivers also receive support on legal matters, financial decisions, health care and also guidance to support services.

Finally, it explains the importance of strengthening and supporting the caregivers. Programs such as caregiver peer networks, where long-term caregivers train the new caregivers and also provide emotional support and practical guidance. Together, these strategies form an innovative and expandable community-based model that admires caregivers as essential contributors in the development journey of DS children by enhancing their economic, emotional, and social condition.

LIMITATIONS AND DIRECTION FOR FUTURE RESEARCH

There are a few limitations of this study. The data were collected in a self-reported questionnaire for the previous year. Although efforts were made to mitigate recall bias by providing caregivers with a predefined list of direct healthcare cost categories, some degree of recall bias may still be present. Caregivers with irregular or fluctuating costs may have found it difficult to report all expenses accurately.

This study did not include a comparator group to assess the difference in direct healthcare and other expenditures among DS children and children without DS. The participants were selected non-randomly from special education schools of select districts of Karnataka, and only those caregivers were recruited who attended parent-teacher meetings, which were also attended by the researcher. This approach was chosen for practical reasons, such as the ease of access to caregivers who were already engaged in their child's education and caregiving, also it provides a centralized hub which helps the researcher in collecting sufficient responses at one time where purpose and aim of data collection can be informed to all caregivers in the presence of special school teachers which gives confidence in caregivers to respond for the questionnaire. e rate. The sample may not be the actual representation. Considering the above limitations, we refrained from generalizability of this study to a wider population. Furthermore, future studies should contemplate towards inclusive approaches like household, community-based samples, to get a better understanding of caregivers' financial burden, reflecting diverse families of DS children.

In this study sensitivity analysis was not performed to assess the impact of income variability. This gap is an opportunity for future researchers to understand how differences in income may impact changes in financial burden.

This study emphasised more on the caregivers' direct costs of caring for children with DS. Subsequent studies in the future should address indirect caregiving costs, including lost income, decreased productivity, and emotional or social costs.

CONCLUSION

The study shows that the families of children suffering from DS face severe direct medical and direct non-healthcare costs. To help the caregivers reduce the burden, the government needs to implement these findings into reality. The major action to be taken is the Niramaya Health Insurance Scheme by increasing the scheme's coverage cost to the actual cost and making it easier for families to undergo the required therapy. Moreover, the government and policymakers should include private therapy centres within the scope of the Niramaya scheme with is currently lacking in the scheme, and also simplify the claim process, making it easier to access better services to low and middle-income families. Additionally, Rashtriya Bal Swasthya Karyakrama (RBSK), should include more inclusive and accessible services beyond the current facilities by providing follow-up care and continuous therapy for all age groups. Families residing in remote areas are not able to access healthcare facilities due to various reasons such as poor transportation, limited awareness about the schemes and the available facilities, lack of outreach services by health care workers that are available to reach families in remote areas, mobile therapy clinics, and community-based rehabilitation programs should be initiated. Capacity-building initiatives should be undertaken by district health authorities to train frontline workers such as ASHAs and Anganwadi staff, which helps to provide basic home-based therapy. Overall, taking these measures can help in reducing the financial pressure on low and middle-income groups and promote more inclusive and accessible developmental care across different communities.

Further studies are required to determine the financial burden of caring for children with Down Syndrome in comparison with children without Down syndrome, associated with managing health and other conditions. The data gathered in the study provides significant insights into multiple areas, including service delivery gaps, social welfare programs, financial protection, and subsidies.

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REFERENCES

1. Johnstone A, Mobley W. Current advances in the study of Down Syndrome: From development to aging. Front Neurosci. 2023;17:1161147. DOI: https://doi.org/10.3389/fnins.2023.1161147 PMid:37021132 PMCid:PMC10067897
2. Chen L, Wang L, Wang Y, Hu H, Zhan Y, Zeng Z, et al. Global, Regional, and National Burden and Trends of Down Syndrome From 1990 to 2019. Front Genet. 2022;13:908482. DOI: https://doi.org/10.3389/fgene.2022.908482 PMid:35910218 PMCid:PMC9337874
3. Panigrahi I, Bhatt Y, Malik S, Kaur P, Kaur A. Clinical profile of Indian children with Down syndrome. J Pediatr Genet. 2021; 12(1):53-57. DOI: https://doi.org/10.1055/s-0041-1732475 PMid:36684542 PMCid:PMC9848754
4. Ghosh S, Bhaumik P, Ghosh P, Dey SK. Chromosome 21 nondisjunction and Down syndrome birth in an Indian cohort: analysis of incidence and aetiology from family linkage data. Genet Res. 2010;92(3):189-197. DOI: https://doi.org/10.1017/S0016672310000224 PMid:20667163

5. El-Attar LM, Issa NM, Mahrous HS. The demographic data and the high frequency of chromosome/chromatid breaks as biomarkers for genome integrity have a role in predicting the susceptibility to have Down syndrome in a cohort of Egyptian young-aged mothers. Egypt J Med Hum Genet. 2019;20:16. DOI: https://doi.org/10.1186/s43042-019-0020-7

6. Barros ALO, Barros AO, Barros GLM, Santos MTBR. Burden of caregivers of children and adolescents with Down Syndrome. Cien Saude Colet. 2017;22(12):3625-3634. DOI: https://doi.org/10.1590/1413-812320172211.31102016

7. Chow K, Rezvan PH, Kazerooni L, Nguyen L, Boyd NK, Vogel BN, et al. Caregiver burden and familial impact in Down Syndrome Regression Disorder. Orphanet J Rare Dis. 2025; 20(1): 126. DOI: https://doi.org/10.1186/s13023-025-03644-0

8. Yu Y, Yang L, Liu Y, Fang J, Wang H, Luo D. Caregiver burden and associated factors among primary caregivers of children with congenital disorders: a comparative cross-sectional study in Hunan Province, China. BMC Nurs. 2025;24:491. DOI: https://doi.org/10.1186/s12912-025-03114-9 PMid:40319317

9. Zhang XN, Zhang S, Liu CY, Ni ZH, Lv HT. Caregivers' experience of having a child with Down syndrome: a meta-synthesis. BMC Nurs. 2025;24:66. DOI: https://doi.org/10.1186/s12912-024-02652-y PMid:39833779 PMCid:PMC11744819

10. Gunn, P., & Berry, P. Some Financial Costs of Caring for Children with Down Syndrome at Home. *Australia and New Zealand Journal of Developmental Disabilities*, 1987; *13*(4), 187–194. https://doi.org/10.3109/13668258709049921

11. Kageleiry A, Samuelson D, Duh MS, Lefebvre P, Campbell J, Skotko BG. Out-of-pocket medical costs and third-party healthcare costs for children with Down syndrome. Am J Med Genet A. 2017;173(3):627-637. DOI: https://doi.org/10.1002/ajmg.a.38050 PMid:27966292

12. Dada S, Bastable K, Schlebusch L, Halder S. The Participation of Children with Intellectual Disabilities: Including the Voices of Children and Their Caregivers in India and South Africa. Int J Environ Res Public Health. 2020;17(18):6706. DOI: https://doi.org/10.3390/ijerph17186706 PMid:32942575.

13. Mohandas A, Bhat D, Kumar S, Murthy MN. Quality of life and mental health status among the caregivers of genetic disease patients in Southern Karnataka, India. Clin Epidemiol Glob Health. 2021;11:100795. DOI: https://doi.org/10.1016/j.cegh.2021.100795

14. Cochran WG. Sampling techniques. 3rd ed. New York: John Wiley & Sons; 1977.

15. Galbraith AA, Wong ST, Kim SE, Newacheck PW. Out-of-pocket financial burden for low-income families with children: socioeconomic disparities and effects of insurance. Health Serv Res. 2005;40(6 Pt 1):1722-1736. DOI: https://doi.org/10.1111/j.1475-6773.2005.00421.x PMid:16336545

16. Martinez-Valverde S, Salinas-Escudero G, García-Delgado C, Garduno-Espinosa J, Moran-Barroso VF, Granados-Garcia V, et al. Out-of-pocket expenditures and care time for children with Down Syndrome: A single-hospital study in Mexico City. PLoS One. 2019;14(1):e0208076. DOI: https://doi.org/10.1371/journal.pone.0208076 PMid:30629602 PMCid:PMC6328117

17. Dawson AL, Cassell CH, Oster ME, Olney RS, Tanner JP, Kirby RS, et al. Hospitalizations and associated costs in a population-based study of children with Down syndrome born in Florida. Birth Defects Res A Clin Mol Teratol. 2014;100(11):826-836. DOI: https://doi.org/10.1002/bdra.23295 PMid:25124730 PMCid:PMC4617639

18. King E, Remington M, Berger H. Family perspectives on gaps in health care for people with Down syndrome. Am J Med Genet A. 2022;188(4):1160-1169. DOI: https://doi.org/10.1002/ajmg.a.62635 PMid:34994519

19. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: Correlates of feelings of burden. Gerontologist. 1980;20(6):649-655. DOI: https://doi.org/10.1093/geront/20.6.649 PMid:7203086

Annexure

Annexure 1: Financial support and insurance (n = 400)

Variables	**Frequency (%)**	**Amount in INR**	**Frequency (%)**
Proportion of children receiving government scholarship	294 (75.50)	800/ month	279 (94.90)
		1200/ month	15 (05.10)
Proportion of children receiving aid from NGO	07 (01.75)	1000 – 3000/ year	05
		3001 – 5000/ year	02
Proportion of children with Niramaya Health Insurance	299 (74.75)	Premium amount 300 or less /year	70
		Premium amount 301 to 1000 / year	229
Proportion of children registered with Ayushman Bharat scheme	51 (12.75)	Premium amount nil	-
Proportion of children with no government sponsored health insurance	50 (12.5)	-	-
Proportion of children with private health insurance	32 (08.00)	Premium amount 3001 to 5000 / year	02
		Premium amount 5001 to 10000 per year	30