



Understanding Caregiver Burden in Families of Physically Disabled Persons Insights from a Cross-sectional Study in Northern Karnataka India

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ABSTRACT

Background: Caregivers of physically disabled individuals frequently experience a multidimensional burden that affects their emotional, social, and physical well-being. Measuring caregiver burden and identifying its determinants are essential for improving support systems.

Objectives: To assess caregiver burden using the Caregiver Burden Inventory (CBI) and identify key sociodemographic determinants among caregivers of physically disabled individuals.

Methodology: A cross-sectional study was conducted among 400 caregiver–disabled individual pairs attending a District Disability Rehabilitation Centre. Data were collected using a semistructured questionnaire, the CBI, and the Perceived Stress Scale (PSS). Descriptive statistics, chi-square tests, and logistic regression were applied.

Results: Of 400 caregivers, 56% experienced a high burden. Significant determinants included low education ($p < 0.001$), low income ($p < 0.001$), unemployment ($p = 0.002$), and caring for individuals with severe disabilities. A strong positive correlation was observed between burden and caregiver stress ($r = 0.591$, $p < 0.001$).

Conclusion: Caregiver burden is substantial and is strongly influenced by socioeconomic vulnerabilities. Strengthening counseling, improving financial support, and enhancing respite services are crucial.

Keywords: Caregiver Burden Inventory scale, Caregiver burden, Disability, Economic burden, Stress.

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INTRODUCTION

Caring for a person with a physical disability represents a significant and multifaceted challenge that extends far beyond the immediate provision of physical assistance. Family caregivers navigate a complex terrain encompassing physical, emotional, social, and financial dimensions as they support their disabled relatives. The informal caregiving process, while often undertaken with dedication and compassion, frequently results in substantial adverse consequences for the caregivers themselves.¹ Caregiver burden, a term encompassing the physical, emotional, social, spiritual, and financial strain experienced by caregivers, has emerged as a critical public health concern requiring systematic investigation and targeted intervention.

The phenomenon of caregiver burden is particularly pronounced among families caring for individuals with physical disabilities. Unlike acute illness episodes that resolve relatively quickly, chronic physical disabilities demand sustained, often intensive caregiving over months and years. This prolonged engagement with caregiving responsibilities creates

a distinct risk profile for adverse health outcomes among informal caregivers.² Research consistently demonstrates that family members providing care for disabled relatives experience higher levels of psychological distress, physical health complications, and reduced quality of life compared to noncaregiving populations.

Multiple factors influence the level of burden experienced by family caregivers of physically disabled individuals. Patient-related characteristics significantly predict caregiver outcomes. The severity and nature of physical disability, particularly as reflected in limitations in activities of daily living and instrumental activities of daily living, strongly correlate with caregiver burden.³ Additionally, the presence of behavioral and psychological symptoms comorbid with physical disability, such as cognitive impairment, depression, or behavioral problems, substantially amplifies caregiver distress beyond what physical disability alone would predict.

Caregiver-related factors equally influence burden levels. These include the caregiver's age, gender, educational level, preexisting health status, and psychological characteristics such as coping style and

resilience.⁴ The relationship between the caregiver and care recipient (whether spouse, adult child, or other relative) also modifies the caregiving experience, with different relationship types associated with distinct burden patterns. Socioeconomic factors, including household income, employment status, and access to formal support services, profoundly shape caregiving burden, particularly in underresourced settings.

Understanding the determinants of caregiver burden among families of physically disabled individuals is essential for several compelling reasons. First, the global prevalence of physical disability continues to increase because of aging populations, rising rates of chronic disease, and improved survival after acute conditions such as stroke and spinal cord injury. As disability prevalence increases, the number of family members engaged in caregiving for disabled relatives will necessarily expand, magnifying the public health significance of caregiver burden. Second, recognition that caregiver burden itself constitutes a health risk—associated with depression, anxiety, cardiovascular disease, and functional impairment—positions caregiver health as a legitimate health care concern warranting direct intervention. Third, existing literature, while substantial, often focuses on specific disease populations rather than physical disability broadly, potentially obscuring common burden determinants that transcend particular diagnostic categories.

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Contemporary approaches to disability increasingly emphasize autonomy, participation, and shared decision-making, even in contexts of physical dependency, as articulated in the social and rights-based models of disability. These frameworks recognize persons with disabilities as active agents rather than passive recipients of care and highlight the relational dynamics between caregiver and care recipient. Incorporating such perspectives is essential to understanding caregiver burden not merely as a function of physical assistance but as a complex interaction shaped by autonomy, role negotiation, and psychosocial expectations.

This study aims to comprehensively assess caregiver burden among families of physically disabled individuals using the validated Caregiver Burden Inventory (CBI), thereby providing a detailed characterization of burden determinants across this diverse population.

METHODOLOGY

Study Design

All methods were conducted following relevant guidelines and regulations to ensure ethical compliance and scientific rigor. This cross-sectional study was conducted to assess caregiver burden among families of physically disabled individuals.

Study Setting

The study was carried out at the District Disability Rehabilitation Centre in Vijayapura District, Karnataka.

Study Population

Inclusion criteria: Primary caregivers aged ≥ 18 years who had been providing unpaid care to a physically disabled family member for at least 6 months, were involved in assistance with activities of daily living or mobility, and accompanied the care recipient to the rehabilitation center (family members, relatives, and friends).

Exclusion criteria: Professional or paid caregivers; caregivers providing care for < 6 months; caregivers of individuals with temporary disabilities; and caregivers unwilling to participate.

Sample Size and Sampling Technique

The study required a sample size of 359 participants with a 95% confidence level and 5% absolute precision, given the estimated 37% economic burden on caregivers of individuals with physical disabilities.⁵ Including a dropout rate of 10%, the sample size was calculated as $359 + 36 = 395$. This was rounded up to a total of 400.

Convenience sampling was utilized, including all caregivers who consented and met the study inclusion criteria.

Ethical Considerations and Consent to Participate

Before participating in the study, each participant provided informed consent to participate and for publication. Participants were made aware of the study objectives, methods, potential risks and benefits, and their freedom to discontinue participation at any time without incurring any costs. Every participant in the study provided written informed consent.

Ethical clearance was obtained from the Institutional Ethics Committee, BLDE (DU) Shri BM Patil Medical College and Research Centre, Vijayapura, ensuring adherence to ethical principles and guidelines (reference no. IEC-SBMPMC/694/2022–23).

Data Collection

Data collection utilized a semistructured questionnaire to gather sociodemographic information. The Perceived Stress Scale (PSS) was used to assess caregivers' stress levels. The CBI was used to assess caregiver burden.

The CBI, originally developed by Novak and Guest, is a multidimensional instrument consisting of 24 items across five domains (time dependence, developmental, physical, social, and emotional burden), with demonstrated good internal consistency and construct validity.⁶ The PSS, developed by Cohen et al., is a widely used 10-item scale measuring perceived stress over the previous month, with established reliability across diverse populations.⁷

Data Analysis

Statistical Package for the Social Sciences (SPSS) version 26 was used for analysis after the data were compiled into a Microsoft Excel spreadsheet. For preliminary data analysis, descriptive statistics, including frequencies, percentages, and graphs, were used. Results were presented as counts with percentages for categorical variables and as mean (median) $\pm$ standard deviation (SD) for continuous variables, with diagrams added where needed. To assess statistical significance, a significance level of $p < 0.05$ was selected. Chi-squared tests for categorical variables and logistic regression analysis to investigate predictive associations were used to evaluate statistical relationships between caregiver burden and other independent variables.

Data Availability

The datasets used during the current study are available from the corresponding author upon request.

RESULTS

In [Table 1](#), we can see that the sociodemographic profile of the 400 caregivers indicates that nearly half were aged 40–60 years (46%), followed by 20–40 years (32.5%), whereas only a very small proportion were above 80 years. Males constituted 56.3% of the participants, and most caregivers were married (96.5%). With respect to religion, the sample comprised almost equal representation of Hindus (47.8%) and Muslims (52%).

Educational attainment was generally low, with over half (51.3%) having no formal schooling and only a small proportion having completed graduation or higher. Regarding occupation, caregivers were mainly private employees (36.3%), self-employed (30.3%), or unemployed (31.3%).

Individual monthly income was low for most participants, with 58.8% earning Rs. 1,000–10,000, whereas family income predominantly fell within Rs. 10,000–20,000 (48%). Most caregivers lived in households of 5–8 members (67.3%), and the majority belonged to nuclear families (67.5%), followed by joint families (24.5%).

In [Table 2](#), the assessment of caregiver stress revealed that the majority of participants experienced moderate levels of stress. More than half of the caregivers (55.8%) scored within the moderate range (14–26). A substantial proportion (38.5%) reported high stress levels (27–40), indicating a significant burden among a sizable segment of the sample. Only a small fraction (5.8%) fell within the low-stress category (0–13).

[Figure 1](#) shows the distribution of caregivers based on their level of care needs. A little over half of the participants (56%, $n = 226$) reported having a greater need, indicating higher support requirements in their caregiving role. In contrast, 44% ($n = 174$) reported minimal need.

The correlation analysis in [Table 3](#) shows a significant positive association between caregiver burden and caregiver stress. The Spearman's rho value of 0.591 indicates a moderately strong positive correlation, meaning that as caregiver burden increases, caregiver stress also tends to rise. The p -value (< 0.001) demonstrates that this relationship is highly statistically significant. When there is a significant amount of stress among caregivers, there

Table 1: Sociodemographic details of the caregivers

S. no.	Sociodemographic characteristics		Frequency (n = 400)	Percentage
1	Age	20–40	130	32.5
		40–60	184	46.0
		60–80	84	21.0
		>80	2	0.5
2	Gender	Male	225	56.3
		Female	175	43.8
3	Marital status	Married	386	96.5
		Unmarried	4	1.0
		Widow/widower/separated	10	2.5
		Refused	–	–
4	Religion	Hindu	191	47.8
		Muslim	208	52.0
		Christian	1	0.3
5	Education	Illiterate/no formal schooling	205	51.3
		Primary school (<7th standard)	81	20.3
		High school (7th to 10th standard)	54	13.5
		Pre-university (>10th to ≤PUC2)	23	5.8
		Graduation	15	3.8
		Postgraduation	1	0.3
		Refused	21	5.3
		Government employee	5	1.3
6	Occupation	Private employee	145	36.3
		Self-employed	121	30.3
		Retired	4	1.0
		Unemployed	125	31.3
		Income (Rs)	0	115
7	Income (Rs)	1–10,000	235	58.8
		10,000–20,000	47	11.8
		>20,000	3	0.8
		Family income (Rs)	0	1
8	Family income (Rs)	1–10,000	158	39.5
		10,000–20,000	192	48.0
		>20,000	49	12.3
		Total number of family members	1–4	118
9	Total number of family members	5–8	269	67.3
		9–12	7	1.8
		>12	6	1.5
		Type of family	Nuclear	270
10	Type of family	Joint	98	24.5
		Extended	10	2.5
		Third generation	22	5.5

Table 2: Stress levels of the caregiver

S. no.	Stress level	Range	Frequency (n = 400)	Percent
1	Low	0–13	23	5.8
2	Moderate	14–26	223	55.8
3	High	27–40	154	38.5

is a corresponding increase in the level of caregiver burden.

In Table 4, we see that most variables did not show a statistically significant association with stress categories (low, moderate,

high). Age, gender, marital status, religion, occupation, individual income, family size, and type of family demonstrated no meaningful differences in stress distribution across their respective subgroups

($p > 0.05$). However, education showed a significant association with caregiver stress ($\chi^2 = 27.785, p = 0.006$). Caregivers with lower educational attainment, particularly those without formal schooling, were more likely

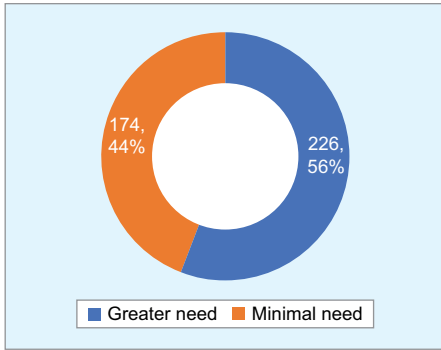


Fig. 1: Level of caregiver burden

to experience high stress levels compared to those with higher education. Likewise, family income was also significantly related to stress levels ($\chi^2 = 30.346$, $p < 0.001$). Caregivers from lower-income households showed a higher proportion of moderate to high stress.

In Table 5, most variables did not show a statistically significant relationship with respite need; however, gender, education, and family income demonstrated significant associations. Caregivers across all age-groups showed comparable levels of respite need, and no meaningful differences were observed ($p = 0.228$). Marital status, religion, occupation, household size, and type of family also showed no significant association with the need for respite care ($p > 0.05$). A significant association was noted with gender ($\chi^2 = 4.237$, $p = 0.040$). Female caregivers reported a greater need for respite compared to males, suggesting that women may experience higher caregiving demands or strain. Education was strongly associated with respite need ($\chi^2 = 26.156$, $p < 0.001$). Caregivers with no formal schooling had a much higher proportion reporting minimal need, whereas those with primary or higher education reported more need for respite, indicating that educational status may influence awareness, expectations, or perceived burden. Family income also showed a significant association ($\chi^2 = 31.719$, $p < 0.001$). Caregivers from lower-income households had a greater need for respite care, likely reflecting increased financial stress and reduced access to support systems.

DISCUSSION

In our study, the sociodemographic profile of caregivers revealed patterns both consistent with and distinct from those reported in earlier Indian research. Caregivers were predominantly middle-aged adults, paralleling findings from Goyal-Honavar et al., who also observed

Table 3: Correlation between caregiver stress and caregiver burden

		Caregiver burden
Caregiver stress	Spearman rho correlation coefficient	0.591
	Sig. (2-tailed)	<0.001

Bold value significance p -value < 0.05

that caregiving responsibilities typically fall on individuals in their most economically productive years.⁸

However, unlike previous studies in which women overwhelmingly constituted the primary caregivers, such as the 76% female caregivers reported by Goyal-Honavar et al. and the 85.9% reported among caregivers of children with disabilities in the study by R S et al., the present study documented a higher proportion of male caregivers.^{8,9} This divergence may reflect the physical demands associated with caring for individuals with mobility-related impairments or context-specific caregiving norms in the rehabilitation setting.

Educational disadvantage was more pronounced in our study, with over half of caregivers lacking formal schooling, a much higher proportion than that reported in the visual impairment study by Khare et al., in which 36.7% were illiterate, and markedly different from the relatively higher educational attainment reported among caregivers in the Chennai-based study.¹⁰

Socioeconomic vulnerability emerged as a common thread across all studies, although the income profile of our study suggested slightly better household earnings than those documented in Khare et al., in which incomes were extremely low.¹⁰

The predominance of nuclear families in our study also contrasts with the implicit support structures described in other settings, suggesting that caregivers in our study may have fewer shared responsibilities and therefore experience greater personal strain. Overall, these comparisons indicate that while caregiver burden in India consistently affects socioeconomically disadvantaged families, the demographic composition and contextual realities of caregivers may vary substantially, influencing both the caregiving experience and the resulting burden.

The stress levels of the caregivers were measured using the PSS, which showed that 38.5% experienced high levels of stress. The majority of participants exhibited moderate stress levels (55.8%). Similar results were reported in a study by Ramachandran et al., which found that 64.3% of caregivers had severe stress, 21.7% experienced high stress, and 13.8% experienced mild stress.¹¹

Furthermore, a related study by Abirami found that 89% of caregivers had moderate levels of stress and that these levels were significantly correlated with demographic characteristics such as sex, education, occupation, income, and relationship with the child. Additionally, the study examined caregiver burden and its relationship with disability.¹² In a meta-analysis evaluating the effects of caregiving across 23 samples, Vitaliano et al. found substantial but moderate differences in several health categories, including self-reported health, medication use, antibodies, and stress hormones.¹³ Similarly, participants in the eldercare groups reported poorer physical and mental health than those in other groups, with lower life satisfaction (37%) and higher levels of stress (59% high), burnout (36% high), and depression (42% high).¹⁴

According to the CBI, of the 400 participants, 56% of caregivers reported a greater need for respite and other services, whereas 44% (174 participants) reported very little need. Kaur and Arora's semistructured caregiver burden questionnaire measures the difficulty of raising children with mental disabilities, which affects all aspects of the home environment, including family life, emotional problems, and finances.¹⁵ In the study conducted by Arasu and Shanbhag, the mean caregiver burden score was 33.27 ± 13.03 , with 56% of caregivers reporting a light burden, 25% a moderate burden, and 2% a severe burden.¹⁶ In the study by Grunfeld et al., the burden score among breast cancer caregivers was 26.21.¹⁷

Caregiver stress and burden were found to be significantly positively correlated in our study (Spearman's rho, $p < 0.001$). Similarly, Arun et al. found a positive correlation (Pearson's correlation coefficient, $r = 0.588$, $p < 0.001$) between the spouse caregiver burden score and the Indian Disability Evaluation and Assessment Scale (IDEAS) global disability score.¹⁸

There was a strong association between the Zarit Caregiver Burden Inventory (ZCBI) and the Caregiver Strain Index (CSI) ($r = 0.819$; $p < 0.0001$), with mean scores of 16 ± 13.9 for the ZCBI and 2.1 ± 2.3 for the CSI. Furthermore, 5.8% of caregivers reported high stress levels (CSI ≥ 7), and 9.1% experienced a moderate-to-severe burden (ZCBI > 40).¹⁹

Table 4: Association between sociodemographic data and stress levels of the caregivers

S. no. Sociodemographic characteristics			Stress						Chi-square	p-value
			Low		Moderate		High			
			n	%	n	%	n	%		
1	Age	20–40	8	34.80	81	36.30	41	26.60	4.279	0.639
		40–60	11	47.80	96	43.00	77	50.00		
		60–80	4	17.40	45	20.20	35	22.70		
		>80	0	0.00	1	0.40	1	0.60		
2	Gender	Male	9	39.10	125	56.10	91	59.10	3.248	0.197
		Female	14	60.90	98	43.90	63	40.90		
		Others								
3	Marital status	Married	21	91.30	216	96.90	149	96.80	4.736	0.315
		Unmarried	0	0.00	3	1.30	1	0.60		
		Widow/widower/separated	2	8.70	4	1.80	4	2.60		
4	Religion	Hindu	14	60.90	116	52.00	61	39.60	8.613	0.072
		Muslim	9	39.10	107	48.00	92	59.70		
		Christian	0	0.00	0	0.00	1	0.60		
5	Education	Illiterate/no formal schooling	5	21.70	104	46.60	96	62.30	27.785	0.006*
		Primary school	7	30.40	47	21.10	27	17.50		
		High school	5	21.70	39	17.50	10	6.50		
		Pre-university	2	8.70	12	5.40	9	5.80		
		Graduation	3	13.00	9	4.00	3	1.90		
		Postgraduation	0	0.00	1	0.40	0	0.00		
		Refused	1	4.30	11	4.90	9	5.80		
6	Occupation	Government employee	0	0.00	3	1.30	2	1.30	9.859	0.275
		Private employee	7	30.40	71	31.80	67	43.50		
		Self-employed	5	21.70	77	34.50	39	25.30		
		Retired	0	0.00	2	0.90	2	1.30		
		Unemployed	11	47.80	70	31.40	44	28.60		
7	Income (Rs)	0	10	43.50	64	28.70	41	26.60	10.921	0.091
		1–10,000	9	39.10	125	56.10	101	65.60		
		10,000–20,000	4	17.40	31	13.90	12	7.80		
		>20,000	0	0.00	3	1.30	0	0.00		
8	Family income (Rs)	0	0	0.00	1	0.40	0	0.00	30.346	<0.001*
		1–10,000	4	17.40	74	33.20	80	51.90		
		10,000–20,000	11	47.80	115	51.60	66	42.90		
		>20,000	8	34.80	33	14.80	8	5.20		
9	Total number of family members	1–4	9	39.10	70	31.40	39	25.30	12.242	0.057
		5–8	11	47.80	148	66.40	110	71.40		
		9–12	2	8.70	2	0.90	3	1.90		
		>12	1	4.30	3	1.30	2	1.30		
10	Type of family	Nuclear	15	65.20	145	65.00	110	71.40	5.407	0.493
		Joint	7	30.40	60	26.90	31	20.10		
		Extended	0	0.00	4	1.80	6	3.90		
		Third generation	1	4.30	14	6.30	7	4.50		

Bold value significance p -value <0.05

While caregiving in this setting largely followed a family-centered assistive model, the findings should be interpreted in light of emerging disability frameworks that emphasize autonomy and shared decision-making. Failure to recognize these dynamics may underestimate relational tensions

and psychosocial dimensions of burden, particularly in long-term physical disability.

Limitations

This study's analysis of certain factors depended on participant self-reported data, which may have introduced reporting and recall bias.

CONCLUSION

The study highlights the increasing financial strain, stress, and burden experienced by caregivers. An improved social and psychological support system specifically designed to address these issues among caregivers is urgently needed. To enhance the overall psychosocial

Table 5: Association between sociodemographic data and caregiver burden among caregivers

S. no.	Sociodemographic characteristics		Need for respite				Chi-square	p-value
			Greater need		Minimal need			
			n	%	n	%		
1	Age	20–40	81	35.80	49	28.20	4.325	0.228
		40–60	94	41.60	90	51.70		
		60–80	50	22.10	34	19.50		
		>80	1	0.40	1	0.60		
2	Gender	Male	117	51.80	108	62.10	4.237	0.04*
		Female	109	48.20	66	37.90		
3	Marital status	Married	219	96.90	167	96.00	0.249	0.883
		Unmarried	2	0.90	2	1.10		
		Widow/widower/separated	5	2.20	5	2.90		
4	Religion	Hindu	111	49.10	80	46.00	1.626	0.444
		Muslim	115	50.90	93	53.40		
		Christian	0	0.00	1	0.60		
5	Education	Illiterate/no formal schooling	92	40.70	113	64.90	26.156	<0.001*
		Primary school (<7th standard)	57	25.20	24	13.80		
		High school (7th–10th standard)	38	16.80	16	9.20		
		Pre-university (>10th to ≤PUC2)	14	6.20	9	5.20		
		Graduation	12	5.30	3	1.70		
		Postgraduation	1	0.40	0	0.00		
		Refused	12	5.30	9	5.20		
6	Occupation	Government employee	4	1.80	1	0.60	3.985	0.408
		Private employee	74	32.70	71	40.80		
		Self-employed	70	31.00	51	29.30		
		Retired	2	0.90	2	1.10		
		Unemployed	76	33.60	49	28.20		
7	Income (Rs)	<1,000	73	32.30	42	24.10	7.506	0.057
		1–10,000	121	53.50	114	65.50		
		10,000–20,000	29	12.80	18	10.30		
		>20,000	3	1.30	0	0.00		
8	Family income (Rs)	<1,000	1	0.40	0	0.00	31.719	<0.001*
		1–10,000	64	28.30	94	54.00		
		10,000–20,000	122	54.00	70	40.20		
		>20,000	39	17.30	10	5.70		
9	Total number of family members	1–4	59	26.10	59	33.90	3.783	0.286
		5–8	160	70.80	109	62.60		
		9–12	3	1.30	4	2.30		
		>12	4	1.80	2	1.10		
10	Type of family	Nuclear	149	65.90	121	69.50	2.735	0.434
		Joint	56	24.80	42	24.10		
		Extended	5	2.20	5	2.90		
		Third generation	16	7.10	6	3.40		

Bold value significance p -value <0.05

well-being of caregivers, targeted interventions emphasizing mental health support and counseling services are required.

RECOMMENDATIONS

Routine screening for caregiver stress and burden should be integrated into

rehabilitation center services, particularly for caregivers with lower educational attainment and lower family income, as these groups demonstrated significantly higher stress levels and a greater need for respite care.

It is essential to establish mental health clinics and hotlines to provide social support

and counseling to people with physical disabilities, their caregivers, and family members.

Financial assistance schemes and linkage to social welfare programs should be strengthened for low-income caregiver households.

Supporting caregivers in managing stress through lifestyle improvement programs is essential.

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