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Gendered Dimensions of Caregiver Burden Among Person with Disability in India: A Cross-Sectional Analysis of Psychosocial Outcomes Across Disability Types

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Abstract

Background: Caregiving for person with disability (PwD) imposes substantial psychosocial demands on family members, with these demands varying according to the type of disability. Identifying such differences is critical for developing targeted caregiver support interventions.

Objectives: This study examined PSW, caregiver burden, stress, and support domains among caregivers of individuals with different types of disabilities.

Methods: A cross-sectional study was conducted with 335 caregivers of individuals with intellectual, multiple, physical, and sensory disabilities attending a tertiary care hospital. Caregivers completed a structured questionnaire assessing psychosocial wellbeing (PSW), including psychological wellbeing, physical and emotional burden, financial strain, social and cultural challenges, perceived stress, and support systems. Descriptive statistics were calculated, and comparisons across disability types were made using the Kruskal–Wallis test, with significance defined as $p < 0.05$.

Results: Significant differences were observed across disability types in several psychosocial domains. Physical and emotional burden was highest among caregivers of persons with sensory (21.43 ± 2.95) and multiple disabilities (21.41 ± 2.87) ($p = 0.029$). Social and cultural challenges were significantly greater among caregivers of persons with sensory disabilities (17.28 ± 3.15) ($p = 0.001$). Support systems and services differed significantly, with caregivers of persons with intellectual disabilities reporting higher support (19.32 ± 4.01) ($p = 0.025$). No significant differences were found in psychological wellbeing, financial strain, or perceived stress.

Conclusion: Psychosocial experiences among caregivers vary substantially by disability type, highlighting the necessity for disability-specific caregiver support strategies.

Keywords: Caregiver Burden, Psychosocial Wellbeing, Disability Types, Gendered Caregiving

Introduction

India has an overall adult disability prevalence of 4.52%, affecting more than 26 million individuals. Locomotor disabilities are most common at 44.7%, followed by mental (20.3%), speech, visual, hearing, and multiple impairments. Data from the National Family Health Survey-5 (2019-21) indicate that 5.11% of households include at least one PwD, with the highest rates for locomotor disabilities observed in states such as Lakshadweep (1.68%) and Delhi. These trends place significant strain on family caregiving systems, notably in the context of urbanization and an aging population (Pattnaik et al., 2023). Caregiver burden includes physical exhaustion, emotional distress, monetary pressure, and social isolation resulting from sustained care for PwD. In rural India, 71.4% of caregivers report fatigue, which is associated with providing care for more than six hours daily, patient severity, and lack of respite. The burden is correlated with the level of disability, presence of psychopathology, and duration of treatment for PwD, frequently resulting in a decline in caregiver health (Baliga et al., n.d.; Goyal-Honavar et al., 2025)

Globally and in India, female caregivers report a higher burden than their male counterparts, attributable to increased emotional and bodily demands. Women, who are most often spouses or mothers (68-76%), undergo strain because of cultural expectations, unemployment, and isolation inside nuclear families (Barusch & Spaid, 1989). While male caregivers generally report lower levels of burden, they may experience higher stress in particular contexts, illustrating the influence of gendered caregiving roles.

India does not have comprehensive respite care, counseling services, and accessible government benefits for caregivers. Despite 78% of caregivers being aware of available schemes, only 44% utilize them. Rural-urban disparities, inadequate disability services, and a tenfold greater reliance on family members compared to professionals further worsen these challenges. Interventions for adult PwD caregivers remain insufficiently studied (Baliga et al., n.d.; Barusch & Spaid, 1989; Lillekroken et al., 2024). This cross-sectional analysis of caregivers with balanced gender representation addresses gaps in gender-disaggregated and cross-disability (intellectual, multiple, physical, sensory).

Method

Study Design

A cross-sectional descriptive-analytical design was utilized to address the following objectives.

1. To describe the socio-demographic characteristics of caregivers of PwD.
2. To assess the physical and emotional burden, financial hardship, social and cultural challenges, perceived stress, psychological well-being, and support systems among caregivers.
3. To examine gender differences in caregiving burden, psychosocial well-being, stress, and support systems.
4. To compare psychosocial domains across several types of disability among care recipients.

Sample

The sample comprised 335 caregivers of PwD (168 males, 167 females). Caregivers were defined as those who had provided primary care for a minimum of six months. Participants were recruited through convenience sampling from healthcare and rehabilitation settings. Inclusion criteria required willingness to participate and the ability to provide informed consent.

Tools

A structured, interviewer-administered questionnaire was utilized to assess the burden and challenges experienced by caregivers of PwD.

Section A: Socio-Demographic Information

This section collected background characteristics of caregivers using categorical response options. Variables included age, gender, marital status, family type, area of residence, relationship to the individual with disability, duration of caregiving, type of disability of the care recipient, educational attainment, employment status, and monthly household income. These variables were included to describe the study sample and to examine their associations with caregiving burden and related outcomes.

Section B: Physical and Emotional Burden

This section assessed the physical and emotional impact of caregiving. Seven items addressed physical exhaustion, pain or fatigue, sleep disturbances, health issues related to caregiving, neglect of self-care, emotional stress, and decline in quality of life. Responses were recorded on a 5-point Likert scale, with higher scores indicating greater burden.

Section C: Financial Strain

The financial consequences of caregiving were measured using seven items that focused on caregiving-related expenses, work disruption, use of savings or borrowing, reduction in household or personal expenditures, financial preparedness for long-term caregiving, and adequacy of financial support from family, government, or non-governmental organizations. Higher scores reflected greater perceived financial strain, except for positively worded items assessing financial preparedness and support.

Section D: Social and Cultural Challenges

This section comprised five items addressing social and cultural challenges. These included perceived stigma, cultural beliefs about caregiving, gender norms, social isolation, and avoidance of social activities due to caregiving. Higher scores indicated greater social and cultural challenges.

Section E: Support Systems and Services

Support availability and access were measured using six items: awareness of government schemes, access to caregiver services, satisfaction with emotional and psychological support, workplace policies, assistance from community or non-governmental organizations, and access to medical care for caregivers. Higher scores indicated better support.

Section F: Psychological Measures

TWHO-5 Well-Being Index was used to measure subjective psychological well-being during the past two weeks. It included five positively worded items assessing cheerfulness, calmness, vitality, restfulness, and interest in daily life. Higher scores indicated better psychological well-being.

The Perceived Stress Scale (short form) measured the degree of stress experienced by caregivers. Five items assessed stress, loss of control, difficulty managing problems, and coping ability. Two positively worded items were reverse scored. Higher scores indicated greater perceived stress.

Scoring

All items in Sections B to F utilized a 5-point Likert scale (1 = strongly disagree to 5 = strongly agree). Reverse-scored items were recoded prior to analysis. The standardized format facilitated optimal data entry and analysis in SPSS, Excel, or R, and enabled comparison across caregiving domains.

Data Collection Procedure

Data were collected through interviewer-administered questionnaires. After informed consent, caregivers were interviewed individually in a private setting, in a language comfortable to them. Interviewers explained items as needed, ensuring responses reflected the caregiver’s own views. Each interview lasted 25–30 minutes. Data were collected between January 2025 to August 2025.

Statistical Analysis

Data were entered and analyzed in SPSS version 26. Socio-demographic variables and psychosocial domain scores were summarized using frequencies, percentages, means, and standard deviations. Gender differences in categorical variables were examined using the Chi-square test. The Mann–Whitney U test was used to compare psychosocial domain scores between male and female caregivers, and the Kruskal–Wallis test was used to compare these scores across different types of disability. Effect sizes were calculated using Cohen's d. Statistical significance was considered at $p < 0.05$.

Results

Table 1: Demographic profile of the caregivers of person with disability

Variable		**Male n=168 (%)**	**Female n=167 (%)**	**χ^2**	**df**	**p-value**
Marital status	Divorced	7 (4.2)	52 (31.1)	107.421	3	0.001
	Married	43 (25.6)	37 (22.2)			
	Single	51 (30.4)	78 (46.7)			
	Widowed	67 (39.9)	0 (0.0)			
Family type	Extended	54 (32.1)	42 (25.1)	2.19	2	0.335
	Joint	57 (33.9)	59 (35.3)			
	Nuclear	57 (33.9)	66 (39.5)			
Domicile	Rural	74 (44.0)	42 (25.1)	13.413	2	0.001
	Semi-Urban	37 (22.0)	53 (31.7)			
	Urban	57 (33.9)	72 (43.1)			
Relationship	Caretaker	29 (17.3)	21 (12.6)	24.992	5	0.001
	Other	24 (14.3)	15 (9.0)			
	Parent	30 (17.9)	23 (13.8)			
	Relative	42 (25.0)	22 (13.2)			
	Sibling	16 (9.5)	35 (21.0)			
	Spouse	27 (16.1)	51 (30.5)			
Duration of caregiving (in years)	<1 year	23 (13.7)	21 (12.6)	54.771	3	0.001
	1–3	75 (44.6)	19 (11.4)			
	4–6	34 (20.2)	83 (49.7)			
	7+ years	36 (21.4)	44 (26.3)			
Disability type of person	Intellectual	30 (17.9)	44 (26.3)	15.218	3	0.002
	Multiple	54 (32.1)	62 (37.1)			
	Physical	51 (30.4)	22 (13.2)			
	Sensory	33 (19.6)	39 (23.4)			
Education	Illiterate	27 (16.1)	7 (4.2)	63.551	4	0.001
	PG	36 (21.4)	28 (16.8)			
	Primary	53 (31.5)	15 (9.0)			
	Secondary	37 (22.0)	61 (36.5)			
	UG	15 (8.9)	56 (33.5)			
Employment	Fulltime	46 (27.4)	57 (34.1)	16.065	2	0.001
	Parttime	58 (34.5)	26 (15.6)			
	Unemployed	64 (38.1)	84 (50.3)			

Income	<Rs.10k	50 (29.8)	56 (33.5)	15.044	3	0.002
	Rs.10k–30k	58 (34.5)	28 (16.8)			
	Rs.30k–60k	37 (22.0)	46 (27.5)			
	Rs.60k+	23 (13.7)	37 (22.2)			

Table 1 shows the demographic differences between male and female caregivers of persons with disability. Among female caregivers, 31.1% were divorced and 46.7% were single, compared to 4.2% and 30.4% among males. More males were widowed (39.9%) than females. Family type was similar in both groups. Rural residence was higher among males (44.0%) than females (25.1%), while more females lived in urban areas (43.1% vs. 33.9%). Female caregivers were more often spouses (30.5% vs. 16.1%) or siblings (21.0% vs. 9.5%), while males were more likely to be relatives (25.0% vs. 13.2%) or caretakers (17.3% vs. 12.6%). Duration of caregiving differed, with 44.6% of males providing care for 1–3 years and 49.7% of females for 4–6 years. Female caregivers more often cared for persons with intellectual (26.3% vs. 17.9%) or multiple disabilities (37.1% vs. 32.1%), while males cared more for those with physical disabilities (30.4% vs. 13.2%). More male caregivers were illiterate (16.1% vs. 4.2%) or had only primary education (31.5% vs. 9.0%). More females completed secondary (36.5% vs. 22.0%) or undergraduate education (33.5% vs. 8.9%). Unemployment was higher among females (50.3% vs. 38.1%), and more females were employed full-time (34.1% vs. 27.4%). Part-time work was more common among males (34.5% vs. 15.6%). More female caregivers were in the lowest income group (<Rs.10k: 33.5% vs. 29.8%), while more males were in the Rs.10k–30k group (34.5% vs. 16.8%). A higher proportion of females were in the highest income group (Rs.60k+: 22.2% vs. 13.7%). Significant differences were found in marital status, domicile, relationship to the person with disability, duration of caregiving, type of disability, education, employment, and income (p = .001 or p = .002).

Table 2: Gender Differences in PSW, Stress, and Support Domains

Variable	**Female (n=168) Mean ± SD**	**Male (n=167) Mean ± SD**	**Cohen's d Effect size**	**P value**
Psychological Wellbeing	29.02 ± 4.37	30.10 ± 4.43	0.25	0.018*
Physical & Emotional Burden	21.93 ± 2.94	20.26 ± 2.73	−0.59	0.001**
Financial Strain	20.61 ± 3.17	20.95 ± 4.01	0.09	0.41
Social & Cultural Challenges	16.49 ± 3.41	15.51 ± 2.83	−0.31	0.011*
Perceived Stress	14.39 ± 3.33	15.58 ± 3.49	0.35	0.001**
Support Systems & Services	17.82 ± 3.00	17.88 ± 3.56	0.02	0.63

Interpretation guide (for manuscript use): ~0.20 = small effect, ~0.50 = moderate effect, ~0.80 = large effect

Table 2 shows the gender differences in PSW, stress, and support among caregivers. Male caregivers had higher psychological wellbeing than females (30.10 ± 4.43 vs. 29.02 ± 4.37, p = .018). Female caregivers reported greater physical and emotional burden (21.93 ± 2.94 vs. 20.26 ± 2.73, p = .001) and higher social and cultural challenges (16.49 ± 3.41 vs. 15.51 ± 2.83, p = .011) compared to males. Male caregivers had higher perceived stress than females (15.58 ± 3.49 vs. 14.39 ± 3.33, p = .001). No significant differences were found in financial strain (p = .41) or perceived support from systems and services (p = .63) between genders.

Table 3: Comparison of Caregivers PSW Domains Across Types of Disability

Variable	**Intellectual (n = 74) Mean ± SD**	**Multiple (n = 116) Mean ± SD**	**Physical (n = 73) Mean ± SD**	**Sensory (n = 72) Mean ± SD**	**p value**
Psychological Wellbeing	29.01 ± 3.72	29.68 ± 5.33	29.11 ± 3.23	30.37 ± 4.47	0.292
Physical & Emotional Burden	20.23 ± 3.50	21.41 ± 2.87	21.15 ± 2.25	21.43 ± 2.95	0.029*
Financial Strain	21.28 ± 2.69	20.50 ± 3.83	20.05 ± 4.05	21.44 ± 3.50	0.268
Social & Cultural Challenges	16.36 ± 2.91	15.45 ± 2.86	15.26 ± 3.52	17.28 ± 3.15	0.001**
Perceived Stress	15.26 ± 2.54	14.68 ± 3.82	14.27 ± 3.02	15.90 ± 3.87	0.105
Support Systems & Services	19.32 ± 4.01	17.52 ± 2.58	17.12 ± 2.20	17.60 ± 3.94	0.025*

Table 3 shows the differences in psychosocial domains among caregivers of persons with different types of disability. Caregivers of persons with sensory disabilities had the highest mean psychological wellbeing score (30.37 ± 4.47, p = 0.292). Physical and emotional burden was higher among caregivers of persons with multiple (21.41 ± 2.87), sensory (21.43 ± 2.95), and physical disabilities (21.15 ± 2.25) compared to those caring for individuals with intellectual disabilities (20.23 ± 3.50, p = 0.029). Social and cultural challenges were also higher among caregivers of persons with sensory disabilities (17.28 ± 3.15, p = 0.001). No significant difference was found in financial strain (p = 0.268) and perceived stress (p = 0.105) across groups. Caregivers of persons with intellectual disabilities reported the highest support systems and services score (19.32 ± 4.01), and this difference was significant (p = 0.025).

Discussion

The present study identifies distinct gender-based differences in the demographic and caregiving profiles of caregivers of PwD. Notably, marital status varied by gender, with a greater proportion of female caregivers being single or divorced, while widowed caregivers were exclusively male. This pattern likely reflects prevailing social norms in India, where women frequently maintain caregiving roles following marital disruption, whereas widowed men may assume caregiving responsibilities in the absence of a spouse. Previous studies have similarly reported that caregiving responsibilities are shaped by gender roles and family expectations (Bains & Minhas, 2011; Boralingiah et al., 2018). No significant gender differences were observed in family type, indicating that caregiving occurs across nuclear, joint, and extended families, consistent with earlier Indian research (Boralingiah et al., 2018). Domicile differences were also evident, with male caregivers more often residing in rural areas and female caregivers in urban or semi-urban settings. This may be attributed to employment-related migration and improved access to health services in urban areas, as documented in prior research (Gnanaselvam et al., 2020).

Female caregivers were more frequently spouses or siblings and provided care for longer durations, particularly for individuals with intellectual and multiple disabilities. This finding is consistent with existing evidence that women often assume long-term and intensive caregiving roles, which are associated with increased burden and fatigue (Goyal-Honavar et al., 2025; Ramachandran et al., 2020). The observed educational differences, with female caregivers exhibiting higher levels of formal education, contrast with earlier studies that reported high illiteracy rates among caregivers, especially women (Boralingiah et al., 2018). This suggests evolving trends in caregiver education. The higher unemployment rate among female caregivers reflects the impact of caregiving responsibilities on workforce participation, a phenomenon widely documented in Indian literature (Ajay et al., 2017; Murthy et al., 2024). Collectively, these findings highlight the necessity for gender-sensitive caregiver support, including employment flexibility, social support, and access to formal services.

The study further investigated gender differences in PSW, stress, and support among caregivers of PwD, revealing several notable patterns. Male caregivers demonstrated significantly better psychological wellbeing than female caregivers, although the effect size was small. This result aligns with previous Indian and international research indicating that women caregivers experience greater psychological distress due to increased caregiving demands, emotional involvement, and socially prescribed gender roles (Mathias et al., 2019; Pinquart & Sörensen, 2006). Female caregivers experienced significantly greater physical and emotional burden, with a moderate effect size. This finding is consistent with evidence that women typically spend more time on direct caregiving activities, including personal care, which contributes to increased fatigue and strain (Madavanakadu et al., 2022; Ramachandran et al., 2020). Additionally, female caregivers faced more pronounced social and cultural challenges, such as restrictions on mobility, decision-making, and social participation, which are well documented in the Indian sociocultural context (Gailits et al., 2019).

In this study, male caregivers reported significantly higher perceived stress levels, with a small-to-moderate effect size. This result contrasts with much of the existing literature, which typically finds higher stress among women caregivers (Bueno & Chase, 2023; Gnanaselvam et al., 2020). A possible explanation is that men may experience stress associated with role adjustment, financial responsibility, and balancing employment with caregiving, especially during the initial or transitional phases of caregiving. No significant gender differences emerged in financial strain or perceived support systems and services. This finding suggests that economic challenges and limited access to formal support affect caregivers irrespective of gender, which is supported by previous Indian studies highlighting systemic gaps in caregiver support (Madavanakadu et al., 2022). these findings highlight the necessity for gender-sensitive interventions that address the distinct psychosocial needs of male and female caregivers. Particular emphasis should be placed on reducing burden among women and enhancing stress management and role support for men.

Further, this study identified significant differences in caregivers' PSW based on the type of disability. Physical and emotional burden varied across disability groups, with caregivers of individuals with multiple, physical, and sensory disabilities experiencing greater burden than those caring for persons with intellectual disabilities. These results align with previous research demonstrating that caregiving demands intensify when disabilities involve physical dependence, long-term care requirements, or multiple impairments, which contribute to increased fatigue and strain (Madavanakadu et al., 2022; Pinquart & Sörensen, 2006). Social and cultural challenges differed significantly according to disability type, with caregivers of individuals with sensory disabilities reporting the highest levels of difficulty. Communication barriers, social stigma, and limited community awareness associated with sensory impairments may restrict social participation and heighten caregiver isolation. These challenges have been documented in both Indian and international literature, underscoring the influence of societal attitudes and

cultural expectations on caregiver experiences (Bueno & Chase, 2023; Mathias et al., 2019).
Support systems and services also varied significantly by disability type, with caregivers of individuals with intellectual disabilities perceiving greater support. This likely reflects the broader availability of specialized services, educational programs, and targeted interventions for intellectual disabilities compared to other conditions. Prior research has identified an uneven distribution of formal support services across disability categories, which has a direct impact on caregiver wellbeing (Provencher et al., 2003). No significant differences emerged in psychological wellbeing, financial strain, or perceived stress across disability types. These results indicate that emotional distress, financial challenges, and stress are prevalent among caregivers irrespective of the specific disability, supporting previous findings that caregiving is inherently a major source of psychosocial strain (Gnanaselvam et al., 2020). These findings underscore the necessity for disability-specific caregiver interventions. Targeted strategies are required to reduce caregiver burden, address social challenges, and enhance support systems tailored to the unique contexts of different disabilities.

Strength, Limitation and Future Research Direction

A key strength of this study is its comprehensive evaluation of multiple psychosocial domains among caregivers from diverse disability groups within a clinical context. The relatively large sample size and inclusion of under-represented disability categories enhance the robustness and external validity of the findings. The use of standardized, domain-specific comparisons allows for a more detailed understanding of caregiver experiences. However, the cross-sectional design limits the ability to establish causality, and reliance on self-reported measures may introduce recall and social desirability biases. Furthermore, as the research was conducted in a tertiary care hospital, the generalizability of the results to caregivers in community settings may be limited. Future studies should utilize longitudinal designs to assess changes in caregiver wellbeing over time and explore the interactions among gender, caregiving duration, and disability severity. Qualitative or mixed-methods research could also elucidate contextual and cultural factors that shape caregiver burden and coping mechanisms.

Conclusion

This study observed substantial differences in PSW among caregivers according to the type of disability of the care recipient. Caregivers supporting individuals with sensory and multiple disabilities face more pronounced physical, emotional, and social challenges, whereas those caring for individuals with intellectual disabilities report relatively stronger support systems. These findings demonstrate that caregiving experiences are heterogeneous and influenced by the specific demands associated with each disability. Implementing tailored psychosocial interventions, enhancing support services, and developing caregiver-sensitive policies are essential for improving caregiver wellbeing and ensuring the sustainability of long-term caregiving.

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