ORIGINAL ARTICLE

Caring for Carers: Biopsychosocial Burden in Caregivers of Persons with Disability- A Cross-sectional Study in Rawalpindi

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ABSTRACT

Objective: The study aimed to determine the caregiver burden experienced by caregivers of persons with disability (PWD) reporting to a tertiary care rehabilitation medicine facility.

Study Design: A cross-sectional observational study.

Place and Duration of Study: The study was conducted at the Armed Forces Institute of Rehabilitation Medicine (AFIRM), Rawalpindi, Pakistan from April 2022 to March 2023.

Methods: A total of 90 patients were enrolled in the study using a non-probability purposive sampling technique. The Caregiver Burden Inventory (CBI), a tool developed to assess the burden experienced by informal caregivers across five domains — time-dependence, developmental, physical, social, and emotional —was used to measure multidimensional aspects of caregiving and burden of care. Statistical analysis of data was done using the Statistical Package for the Social Sciences (SPSS).

Results: Total caregiver burden score amongst participants was statistically significant (*P* value: 0.046). Among the five domains used by CBI, the physical domain was most affected (*P* value: 0.004). The mean total CBI score was 26.5 (IQR 18.7 - 37). A positive correlation was found between increased age and increased total CBI score (0.231; *P*-value of 0.04). There was no correlation between the duration of care provided by caregiver and total CBI score (0.052; *P*-value = 0.625).

Conclusion: The presence of a high burden of care seen among female caregivers, older individuals, and in those providing care to persons with various comorbidities, depicts a need for structured support systems, including respite care services, financial assistance programs, and caregiver-friendly policies to alleviate this burden.

Keywords: *Caregiver*, *Caregiver Burden, Developing Country, Pakistan, Persons with Disability, Rehabilitation.*

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Introduction

Disability is any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restriction).[1] The World Health Organization (WHO) estimates the prevalence of global disability at approximately 15 percent.[2] According to a national census of 2017, the total population of Pakistan is estimated to be 207 million, and 6.2% of them include Persons with Disabilities (PWD), though under-reporting and definitional challenges likely understate the true burden**.** This refers to a significant number of individuals from all age groups and genders, suffering from a variety of neuromuscular and musculoskeletal disorders.[3]

Caregiving, the act of assisting persons with disabilities (PWDs) in activities of daily living and

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long-term care, is an essential yet demanding role.[4] In Pakistan's socio-cultural landscape, caregiving responsibilities are predominantly undertaken by family members, often in home-based informal settings. While caregiving is an essential component of support for PWDs, it remains unrecognized, unsupported, and undervalued.[4] The caregiving role, when assumed without training or formal resources, has demonstrable impacts on the caregiver's physical health, emotional well-being, social integration, financial security, self-esteem, and overall quality of life.[5]

The biopsychosocial model provides a comprehensive framework to understand caregiver burden, integrating physical demands, emotional stress from societal expectations, and social or financial stressors.[6,7]

In resource-limited developing countries like Pakistan, these stressors are amplified by factors like: (1) limited healthcare infrastructure, (2) lack of formal rehabilitation and respite services, (3) limited access to whatever rehabilitation and respite services are available, (4) absence of formal caregiver training or psychosocial support programs, (5) poor awareness and utilization of assistive technologies and (6) inadequate integration of caregiver needs into health policy frameworks[7,8]

Despite increasing international recognition of caregiver burden as a public health issue, research and policy attention to explore the lived experiences of caregivers in Pakistan remains limited.[8,9] The rationale of this study is to address this gap by systematically documenting the multidimensional burden faced by informal caregivers of PWDs using a validated tool, while contextualizing the findings within Pakistan's unique demographic, cultural, and healthcare setting. The evidence generated is expected to inform the development of caregiver support strategies, training programs, inclusive disability policies, and health system reforms in resource-constrained settings.

Methods

This cross-sectional study was carried out from March 2022 to March 2023, after taking approval from the institute Ethical Review Committee (Letter no. 03/2022/Trg /AFIRM), dated 30th February 2022 and informed consent of participants. Inclusion criteria were participants of either gender, aged 18 years or older, who are providing care to persons with disabilities (PWDs) for at least 4 hours or more per day for 4 weeks or more. Exclusion criteria included inability to communicate, age less than 18 years, or more than 60 years. A sample size of 90 was calculated using the WHO Open EPI calculator (global prevalence of disability 6.2% and confidence level of 95%).[3] Participants were recruited using convenience sampling.

Demographic characteristics of caregivers were noted, including age, gender, race, marital status, education, and relationship to the care recipient. The following parameters of the care recipient were also noted: diagnosis, type of disability, duration of disability, relation with caregiver, and level of assistance required using the Functional Independence Measure instrument (FIM).

Caregiver burden inventory (CBI) is a multidimensional tool developed to assess the burden experienced by informal caregivers across five domains: Time-Dependence Burden, Developmental Burden, Physical Burden, Social Burden, and Emotional Burden, and has already been used in different caregiver populations, including patients with physical, mental, and mixed disabilities. It consists of 24 items, each item rated on a 5-point Likert scale ranging from 0 (never/ strongly disagree) to 4 (nearly always/ strongly agree), resulting in a total score range of 0 to 96.[10.] While there is no universally fixed cut-off, higher scores indicate a greater level of perceived burden. A cumulative score exceeding 36 indicates a potential risk of caregiver burnout, whereas scores around or just above 24 may indicate the need for temporary relief through respite care.[11] In the absence of a validated Urdu version of CBI, the authors faced a challenge as the majority of our population is not well conversant with the English language. To facilitate participant comprehension, promote inclusivity, and minimize response bias, the Caregiver Burden Inventory (CBI) was translated into Urdu through an author's consensus-based translation. The final version was pilot-tested in semi-structured interviews on a sample of the first five caregivers, which successfully confirmed acceptability and comprehensibility. Only this Urdu

version was administered in semi-structured interviews across the study to maintain standardization and minimize comprehension bias. While formal psychometric validation of the Urdu version is beyond the scope of the present study, all efforts were made to preserve the integrity and intent of the original instrument, especially in low-resource settings. Semi-structured interviews were conducted in a separate room, ensuring the absence of care recipients, so that caregivers could express themselves.

Statistical Packages for Social Sciences (SPSS) version 21 was used for statistical analysis. Normality of data was assessed using the Kolmogorov-Smirnov test. Median and interquartile range were calculated for continuous variables, and percentages and frequencies were calculated for categorical variables. Mann-Whitney U test was used to compare the mean score of CBI between demographic characteristics of caregivers. A *P*-value of 0.05 or less was considered significant. Applying the Pearson correlation test, the correlation between the age of the caregiver, the duration of the care-giving period, and the total CBI scores were assessed.

Results

A total of 90 caregivers who met the inclusion criteria participated in the study. The median age was 33 years (IQR: 30–38). Caregivers included 51 (56.7%) males and 39 (43.3%) females. Regarding marital status, the majority (84.4%) were married. Regarding occupation, 40% were housewives, 34.4% were military personnel, 12.2% were unemployed, and the remaining included students, farmers, tailors, engineers, or sportsmen. Educational background included nearly half (48.9%) who matriculated and 12.2% were not educated. The majority of caregivers (84.4%) did not have any comorbidities. The mean total Caregiver Burden Inventory (CBI) score was 26.5 (IQR: 18.7-37), indicating a moderate level of perceived burden. Table 1 shows the details of the demographic characteristics of the caregivers.

The most common diseases in care recipients included neuropathies (27.8%), meningomyelocele (17.8%), Guillain-Barré syndrome (4.4%), Parkinson's disease (4.4%), Erb's palsy (4.4%), spinal cord injury (1.1%), multiple sclerosis (1.1%), stroke (1.1%), and amputation (1.1%) (Table 2).

Regarding the level of assistance required by care recipients, 33.3 % required total assistance, 26.6% maximal assistance, 17.7% required moderate assistance and 7.8% required supervision. (Table 3).

A significant positive correlation was observed between increasing age and total CBI score (r = 0.231, *P* = 0.04), indicating that older caregivers experienced higher levels of burden. However, no significant correlation was found between the duration of caregiving and the total CBI score (r = 0.052, *P* = 0.625). Female caregivers experienced higher total caregiver burden (CBI: 31.64 for females vs. 26.14 for males, *P* = 0.046) and physical health burden (3.08 for males vs. 5.18 for females, *P* = 0.004). Married caregivers had a higher total burden than unmarried caregivers (married 29.29 vs. unmarried 24.36); however, the difference was not statistically significant (*P* = 0.352). Education level did not significantly impact burden scores (*P* = 0.924). Caregivers with comorbidities reported a higher total burden (31.07 vs. 28.05); however, the difference was not statistically significant (*P* = 0.824). An important difference was observed in the emotional health domain, where caregivers with comorbidities reported higher burden (*P* = 0.041). (Table 4).

Discussion

This study provides valuable insights into the biopsychosocial burden experienced by caregivers of PWDs in Pakistan, a context where caregiver roles are often shaped by cultural expectations, limited support systems, and underdeveloped community-based rehabilitation services. The mean total Caregiver Burden Inventory (CBI) score of 26.5 (IQR: 18.7–37) reflects a moderate level of perceived burden, consistent with findings reported in similar low- and middle-income country settings where informal caregiving is predominant.[12]

A statistically significant positive correlation was observed between caregiver age and total CBI score, suggesting that older caregivers experience greater burden.[13] This aligns with prior studies indicating that aging caregivers often face physical decline, increased vulnerability to stress, and reduced coping capacity.[14]

Female caregivers reported significantly higher total and physical health burden than their male

Table 1: Demographic characteristics of caregivers

Variable	Characteristics	Frequency	Percentage (%)
Sex	Male	51	56.7
	Female	39	43.3
Marital Status	Married	76	84.4
	Un - married	14	15.6
Occupation	Housewife	36	40.0
	Student	06	6.7
	Farmer	03	3.3
	Sportsman	01	1.1
	Military Personnel	31	34.4
	Un - employed	11	12.2
	Tailor	01	1.1
	Engineer	01	1.1
Education	Non educated	11	12.2
	Under matric	11	12.2
	Matriculation	44	48.9
	Intermediate	11	12.2
	Middle	06	6.7
	Graduation	07	7.8
Comorbid	Hypertension	10	11.1
	Diabetes Mellitus	01	1.1
	Tuberculosis (TB)	01	1.1
	None	76	84.4
	Hypertension and Ischemic heart disease (both)	01	1.1
	Hypertension and Diabetes Mellitus (both)	01	1.1
Relationship with the patient	Mother	20	22.2
	Wife	04	4.4
	Daughter	07	7.8
	Brother	11	12.2
	Brother-in-law	01	1.1
	Son	10	11.1
	Workplace attendant	14	15.6
	Cousin	03	3.3
	Father	09	10.0
	Sister	06	6.7
	Nephew	02	2.2
	Niece	02	2.2
	Grand daughter	01	1.1

Table 2: Disability Diagnosis

Disability Diagnosis	Frequency	Percentage (%)
Meningomyelocele	16	17.8
Myopathy	01	1.1
Multiple sclerosis	01	1.1
Stroke	01	1.1
Bronchiectasis	01	1
Cervical myelopathy	01	1.1
Traumatic brain injury	02	2.2
Guillain-Barre Syndrome	04	4.4
Rheumatoid Arthritis (RA)	02	2.2
Ankylosing spondylitis	01	1.1
Advanced Knee Osteoarthritis	03	3.3
Spinal cord injury	01	1.1
Neuropathies	25	27.8
Amputation	01	1.1
Cervical myelopathy	02	2.2
Tuberculous meningitis	01	1.1
Erb's palsy	04	4.4
Parkinson disease	04	4.4
Bone marrow transplant	01	1.1
Severe multilevel lumbosacral radiculopathy	01	1.1

Table 3: Level of assistance required by care receiver

Level of assistance required by the patient	Frequency	Percentage (%)
Total assistance	30	33.3
Maximal assistance	24	26.6
Moderate assistance	16	17.7
Minimal assistance	13	14.4
Supervision	07	7.8

counterparts. This finding is consistent with global evidence highlighting that caregiving disproportionately affects women, both in volume and intensity, due to entrenched gender roles and expectations.[15,16] However, in the context of Pakistani society, the authors believe that low mean total CBI scores in males might represent under-reporting because acceptance of psychological distress among males is generally perceived as a sign of weakness in our society. Married caregivers exhibited higher total burden compared to unmarried caregivers, though the difference was not statistically significant. This is consistent with a study by Alves et al. and Pinquart et al. This trend may reflect the compounded responsibilities of managing both caregiving and family obligations, a pattern noted in sociocultural settings where nuclear and extended family systems coexist.[17,18]

Interestingly, education level did not significantly impact burden scores. This suggests that knowledge or literacy alone may not mitigate caregiving strain, especially in the absence of practical support or skill-based training. This is further reinforced by another study highlighting that structured training opportunities, experiential learning of caregiving knowledge and hands-on skills strengthen their positive perception of the caregiving role.[19] However, in contrast to our finding, a study reported an inverse relationship between education and caregiver burden, possibly due to better problem-solving and

Table 4: Comparison between the mean scores of total CBI score and domains of CBI scale in relation to gender, marital status, education, and comorbidities

		CBI Total Score	Five Domains of CBI scale				
			Time	Develop-ment	Physical Health	Emotional Health	Social Relationship
		Mean	Mean	Mean	Mean	Mean	Mean
Gender	Male	26.14	14.41	4.18	3.08	1.90	2.57
	Female	31.64	15.08	4.82	5.18	2.95	3.62
	P-value	0.046	0.525	0.287	0.004	0.074	0.241
Marital status	Married	29.29	14.87	4.54	4.36	2.46	3.07
	Unmarried	24.36	13.79	4.00	2.00	1.79	2.79
	P-value	0.352	0.295	0.924	0.067	0.553	0.363
Education	Under matric	27.77	14.18	4.14	4.27	2.50	2.68
	Matric & above	28.76	14.87	4.56	3.90	2.31	3.13
	P-value	0.924	0.484	0.902	0.552	0.682	0.888
Comorbids	No	28.05	14.71	4.25	4.01	2.05	3.03
	Yes	31.07	14.64	5.57	3.86	4.00	3.00
	P-value	0.824	0.712	0.577	0.870	0.041	0.570

CBI: caregiver burden inventory

coping mechanisms to manage caregiving challenges.[20] Moreover, a possible explanation for our finding is the homogeneity of our sample's educational background, which predominantly included matriculate caregivers, with very few participants holding graduate or higher degrees. This might have obscured any potential associations.

Caregivers with comorbidities reported higher total burden, with a significant difference observed in the emotional health domain. This finding is consistent with the study by Schmaderer M et al. which states that caregiver commodities and the need for self-care add additional strain on already demanding caregiving efforts.[21] This underscores the need to screen caregivers for underlying health conditions, as chronic illness among caregivers may reduce resilience and contribute to poorer mental health outcomes.

Interestingly, while caregivers of recipients requiring total or maximal assistance were familiar, the duration of caregiving did not correlate significantly with burden. This may point toward the complexity of caregiver experiences, where perceived burden may be influenced more by intensity and type of care than duration alone.

The findings of this study have important implications for policy and practice. There is a clear need for structured interventions, including respite care, mental health screening for caregivers, financial support schemes, and capacity-building programs tailored to caregivers' physical and emotional needs. Integrating caregiver support into disability rehabilitation frameworks could improve both caregiver well-being and care quality for PWDs.

However, several limitations should be acknowledged. First, including a wide range of disability types may limit the generalizability of our findings; future studies focusing on specific disability groups could yield more precise insights. Second, participants were recruited from a single hospital, which may not reflect the experiences of caregivers in other settings or those supporting individuals with different disability profiles. Third, despite efforts to minimize bias, the absence of a locally translated and culturally validated version of the Caregiver Burden Inventory (CBI) may have introduced response bias, potentially leading to over- or underestimation of specific burden components. Lastly, excluding caregivers aged 60 and above, it may have narrowed the scope of our findings, as older caregivers often face distinct challenges. Future research should aim to include a broader age range and diverse settings to enhance representation and applicability.

Conclusion

This study underscores the multifaceted biopsychosocial burden faced by caregivers of

persons with disabilities (PWDs) in Pakistan. Notably, higher levels of burden were observed among female caregivers, older individuals, and those with comorbidities - particularly in the domains of physical and emotional health. These findings highlight the urgent need for structured interventions such as respite care, financial assistance and caregiver-inclusive policies to alleviate this burden. Future research should examine the long-term effects of caregiving and evaluate targeted strategies to enhance caregiver well-being, which, in turn, may lead to improved care outcomes for PWDs.

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Author Contributions

SA: Conception and design of the work
UY: Writing the original draft, proofreading, and approval for final submission
MTK: Data acquisition, curation, and statistical analysis
KA: Revising, editing, and supervising for intellectual content
SNM: Manuscript writing for methodology design and investigation
MI: Validation of data, interpretation, and write-up of results