



CAREGIVER BURDEN, BURNOUT, AND RESILIENCE AMONG CAREGIVERS OF ADOLESCENTS WITH DISABILITIES: A CROSS-SECTIONAL STUDY

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ABSTRACT

Background: Long-term caregiving for adolescents with locomotor disabilities imposes significant emotional and physical demands on family caregivers. Prolonged exposure to such stressors often results in caregiver burnout, which negatively affects both caregiver well-being and quality of care. Emotional resilience—the ability to recover from adversity—has been identified as a key protective factor reducing caregiver stress. However, limited research in the Indian context has explored the relationship between resilience and burnout among caregivers of adolescents with physical disability. **Objectives:** To assess levels of emotional resilience, caregiver burden, and burnout in long-term caregivers of adolescents with locomotor disabilities and to examine their interrelationships. **Methods:** A cross-sectional, descriptive correlational study was conducted among 83 primary family caregivers of adolescents (aged 13–19 years) with locomotor disabilities, recruited from the indoor and out-patient department of National Institute for Locomotor Disabilities, Kolkata, West Bengal, India. Data were collected using a Sociodemographic and Caregiving Questionnaire, the Brief Resilience Scale (BRS), Zarit Burden Interview (ZBI) scale, and Copenhagen Burnout Inventory (CBI). Descriptive statistics summarized participant characteristics and scale scores. Pearson's correlation, t-tests were used to explore associations and relationship among variables. **Results:** The study found substantial caregiver burden and burnout among caregivers of adolescents with disabilities, with 69.9% showing low resilience, 38.6% reporting moderate personal exhaustion, and 4.8% reporting high personal exhaustion. Caregiver burden and personal burnout were inversely associated with resilience ($r = -0.302$ and -0.470 , respectively; $p < 0.001$). **Conclusion:** Emotional resilience helps protect caregivers of adolescents with physical disability from burnout. Support programs that are designed to fit the Indian culture and focus on building resilience and reducing caregiver burden can improve the health and well-being of these caregivers, especially in areas with limited resources. The study highlights the need for family-centred rehabilitation, psychosocial support, and resilience-enhancing interventions for caregivers.

KEYWORDS

Emotional Resilience, Caregiver Burnout, Physical Disability, Adolescence, Brief Resilience Scale, India

INTRODUCTION

Disability results from the interaction between individuals with a health condition, such as cerebral palsy, Down syndrome and depression, with personal and environmental factors including negative attitudes, inaccessible transportation and public buildings, and limited social support (WHO). The Centers for Disease Control and Prevention (CDC) defines disability as a physical or mental impairment, whether congenital or acquired, that for any reason limits an individual's ability to perform daily living activities. "Person with disability" means a person with long term physical, mental, intellectual or sensory impairment which, in interaction with barriers, hinders his full and effective participation in society equally with others (RPWD ACT, 2016).¹

Locomotor disability (a person's inability to execute distinctive activities associated with movement of self and objects resulting from affliction of musculoskeletal or nervous system or both), including cerebral palsy, leprosy cured, dwarfism, acid attack victims and muscular dystrophy.¹

The 2011 Census indicates that locomotor (movement) disability is the most common form of physical disability in India. Out of the 26.8 million disabled persons nationwide, approximately 20% (about 5.4 million people) reported having a locomotor disability (census, 2011).²

The presence of locomotor disabilities in children and adolescents has a negative impact on children and their families, which creates several challenges for families, including difficulties related to the care and support of their children. In addition to the challenges faced by parents of children with disabilities, another important issue is the caregiver burden experienced.

"Care-giver" means any person including parents and other family Members who with or without payment provides care, support or assistance to a person with disability (RPwD Act, 2016)¹. Family caregivers often play a crucial role in the well-being of adolescents with locomotor disabilities, particularly in India, where formal support services remain limited and caregiving roles are deeply embedded in cultural expectations (Sharma et al., 2023)³. Adolescence introduces unique caregiving challenges, including managing developmental changes, evolving emotional needs, and increased functional care demands.

Caregiver burnout and burden is substantial in handling adolescents with locomotor disabilities. Burnout, encompassing emotional exhaustion, depersonalization, and diminished personal accomplishment, disproportionately affects long-term caregivers (Maslach & Jackson, 1981)⁴. Studies in India among caregivers of intellectually disabled children report 39% experiencing severe burden and 23–19% showing moderate to severe depression and anxiety (Math & Srinivasaraghavan, 2021; Sharma et al., 2023)⁵. Female caregivers, often mothers, report higher levels of strain due to gendered expectations and limited external support (Math & Srinivasaraghavan, 2021)⁵.

Emotional Resilience as a Protective Factor

In contrast, emotional resilience or the capacity to adapt positively despite adversity is a key protective factor. Studies among Indian parents of adolescents with intellectual disabilities demonstrate that positive cognitive appraisal of the child's condition strongly predicts resilience, whereas negative appraisal reduces it (Rajan et al., 2016)⁶. One Kerala-based study (N=174 mothers) found a robust inverse correlation ($r = -0.69$) between resilience and parental stress, with resilience explaining 65% of the variance in stress scores (Arakkathara & Bance, 2020)⁷. These results point to the importance of resilience promotion in caregiver well-being interventions.

Gaps in Research: Adolescents with Locomotor Disabilities

Although many research exists on caregivers of younger or intellectually disabled children, fewer studies focus on those caring for adolescents with locomotor disabilities. Adolescence brings its own psychosocial and care complexities like bodily changes, increased personal care, behavioral shifts that may exacerbate caregiver stress and burnout differently than caregiving for younger children. Yet Indian research in this specific subgroup remains scarce.

Rationale and Significance

Understanding how emotional resilience interplays with caregiver burnout among those caring for physically disabled adolescents is vital. It allows for:

1. Identifying resilience and burnout levels
2. Pinpointing factors such as appraisal styles, social support, financial burden, and gender that influence these outcomes.
3. Informing contextually appropriate interventions, such as psychoeducation, resilience training, or community support groups.

This study is responsive to policy and service gaps identified by Indian health experts, calling for integrated psychosocial support for caregivers of adolescents with disabilities (Devassy et al., 2022)⁸.

Study Objectives

1. Quantify emotional resilience and burnout among long-term caregivers (≥ 12 months) of adolescents (13–19 years) with locomotor disabilities in India.
2. Examine the relationship between emotional resilience and burnout.
3. Identify demographic (e.g., gender, income, education) and caregiving variables (e.g., duration, daily care hours) that predict resilience and burnout.

These insights can guide development of multi-level interventions (e.g., caregiver skills workshops, peer networks) to promote caregiver well-being and sustainability of home-based care for physically disabled adolescents.

METHODOLOGY

Study Design

This study used a cross-sectional, descriptive, and correlational design to investigate emotional resilience and burnout among long-term caregivers of adolescents with locomotor disabilities. The design was chosen to provide a clear picture of caregiver resilience and burnout levels, while exploring relationships between resilience, caregiver burden, burnout and socio-demographic variables.

Study Setting

The research was conducted in a national institute where caregivers from both urban and semi-urban areas of the state of West Bengal, Odisha and Bihar comes with their children with disabilities.

Population and Sampling

The target population comprised primary family caregivers (parents or guardians) of adolescents aged 13–19 years diagnosed with locomotor disabilities.

Inclusion Criteria were primary caregivers aged 25–70 years, caregivers providing unpaid care to an adolescent with physical disability (e.g., cerebral palsy, spina bifida, muscular dystrophy etc) for at least 1 year and able to communicate in English, Hindi, or Bengali. Paid or professional caregivers, caregivers with diagnosed psychiatric illness or cognitive impairment, caregivers of adolescents with co-existing intellectual disability (to isolate physical disability-specific caregiving challenges) were excluded from the study.

Sampling Technique

A purposive sampling strategy was adopted to recruit eligible caregivers from the Indoor and outdoor services areas of the Institute.

Data Collection Tools

Four instruments were used in this study:

1. Sociodemographic and Caregiving Questionnaire

A structured questionnaire was developed to collect data on caregiver variables such as age, gender, marital status, education, occupation, income, relationship to adolescent, duration of caregiving, daily caregiving hours. Adolescent variables like age, gender, diagnosis, severity of disability (as per Gross Motor Function Classification System – GMFCS) and social support availability (yes/no) was also evaluated.

2. Brief Resilience Scale (BRS)

The BRS (Smith et al., 2008)⁹ is a 6-item scale assessing the ability to recover from stress (“bounce back”). Each item is scored on a 5-point Likert scale (1 = strongly disagree; 5 = strongly agree). Hindi and Bengali translations were prepared using forward–backward translation by bilingual experts. The questions on the BRS are meant to capture various aspects of resilience, including the ability to cope with stress, adapt to change, and maintain a positive outlook in the face of adversity. The scoring is obtained by adding the responses, and then dividing the total sum by the total number of questions answered. A score of 1.00 to 2.99 suggests low resilience, 3.00 to 4.30 suggests normal and 4.30 to 5.00 suggests high resilience. Each caregiver was interviewed during their facility visit along with the patient.

3. Zarit Caregiver Burden Interview (ZBI) Scale

Caregiver burden was assessed with the Zarit Caregiver Burden (ZBI) scale, which has 22 questions that are scored with a five-point Likert scale. The scores range from 0 to 88, with higher scores indicating a higher caregiver burden. It has an internal consistency coefficient of

0.95 and a test-retest stability coefficient of 0.90 (Javalkar et al., 2017)¹⁰. The internal consistency coefficient was calculated as 0.86 in this study.

4. Copenhagen Burnout Inventory (CBI)

The Copenhagen Burnout Inventory (CBI) is a 19-item survey tool designed to measure physical and psychological fatigue and exhaustion. The CBI (Kristensen et al., 2005)¹¹ has 19 items divided into: Personal burnout (6 items), Work-related burnout (7 items; adapted for unpaid caregiving context), Client-related burnout (6 items; adolescent care adapted context) Responses are scored 0–100; higher scores indicate greater burnout. Hindi and Bengali versions were prepared and validated.

Data Collection Procedure

Recruitment and data collection were carried out between January 2025 to March, 2026. Eligible caregivers were approached during routine visits. After explaining the study objectives, informed written consent was obtained. Interviews were conducted in the department on assigned days and in a private setting to ensure confidentiality. On average, each session lasted for 30–45 minutes.

Data Analysis

Data were analysed using IBM SPSS Statistics (Version 25)¹². Descriptive statistics: Means, standard deviations, frequencies, and percentages. For Inferential statistics, Pearson's correlation was used to assess relationships between resilience (BRS), burden (ZBA), and burnout (CBI). Independent t-test was used to compare mean scores across demographic variables and BRS, ZBI and CBI scores. Significance level was set at $p < 0.05$.

Ethical Considerations

This study adhered to the Declaration of Helsinki principles. Participants were informed of their voluntary participation, confidentiality of responses, and right to withdraw at any point without consequences.

RESULTS

Table 1: Socio-demographic Details of Caregivers

Caregiver details	Total (n=83) frequency	Percentage (%)
Age		
30–40	13	16
41–50	48	58
>50	22	26
Gender		
Male	21	25
Female	62	75
Relation to child		
Mother	64	77
Father	11	13
Grandparents	08	10
Duration of caregiving		
<5 year	16	19
5-10 years	39	46
>10 years	28	35
Time spent in caregiving per day		
1–5 hrs	19	22
6–10 hrs	44	53
>10 hrs	20	25
Education		
Less than secondary	37	44
Secondary	29	34
University	17	22
Occupation		
Non-worker	49	60
Worker	34	40
Caregiver status		
Single parent	29	34
Both parents	54	66
Socioeconomic status		
Very low/low	37	44
Moderate	28	33
High	18	23
Family residence		
Rural	47	56
Urban	36	44

Table 1 presents the socio-demographic characteristics of the 83 caregivers included in the study. Regarding age, the majority of caregivers were aged 41–50 years (58%), followed by those aged >50 years (26%) and 30–40 years (16%).

With respect to gender, 62 caregivers (75%) were female, whereas 21 (25%) were male, indicating a predominance of female caregivers in the study population. In terms of relationship with the child, mothers constituted the largest group (77%), followed by fathers (13%), and grandparents (10%). Other details are provided in table No. 1.

Overall, the caregiver profile was characterized by a predominance of middle-aged caregivers, females, mothers, caregivers with several years of caregiving experience, substantial daily caregiving time, non-working status, and rural residence.

Table 2: Clinical Profile of Adolescents with Disabilities

Characteristics of Adolescents	Total (n=83) Frequency	Percentage (%)
Age		
13-15	30	36.14
16-19	53	63.86
Gender		
Male	55	66.26
Female	28	33.74
Diagnoses		
Cerebral Palsy	41	49.40
Downs Syndrome	14	16.87
Post Meningitis sequelae	07	8.43
Post encephalitis sequelae	05	6.02
Neurodegenerative disorders	01	1.20
Genetic disorders	02	2.41
Congenital malformations	02	2.41
Spina Bifida	03	3.61
Muscular Dystrophy	05	6.02
Others	03	3.61
Access to Rehabilitation services		
Yes	56	67.46
Break in continuity of care	21	25.30
No access at all	06	7.22
Limitation in mobility		
Mild	23	27.71
moderate	39	46.98
severe	21	25.30
Participation in school		
No difficulty	19	22.89
Moderate difficulty	43	51.80
Severe Difficulty	21	25.30

The clinical and functional characteristics of the 83 adolescents with disabilities are presented in Table No.2. The majority of adolescents (63.86%) were aged 16–19 years, while 36.14% were aged 13–15 years. Males constituted a larger proportion of the sample (66.26%) compared with females (33.74%). Cerebral palsy was the most frequently reported diagnosis (49.40%), followed by Down syndrome (16.87%), post-meningitis sequelae (8.43%), post-encephalitis sequelae and muscular dystrophy (6.02% each). Regarding access to rehabilitation services, 67.46% had access to rehabilitation, whereas 25.30% experienced a break in continuity of care and 7.22% had no access to rehabilitation services.

In terms of mobility, nearly half of the adolescents (46.98%) had moderate limitations, while 27.71% had mild and 25.30% had severe mobility limitations. With regard to school participation, 51.80% experienced moderate difficulty, 25.30% experienced severe difficulty, and only 22.89% reported no difficulty.

Table 3: Burden of Care of Primary Caregivers of Adolescents as per Zarit Burden Interview

Burden category	Total (n=83) Frequency	(%)
Little or no burden	09	10.84
Mild to Moderate burden	57	68.67
Moderate to severe burden	15	18.07
Severe burden	02	2.40

As shown in Table 3, the majority of primary caregivers (68.67%) experienced mild to moderate burden according to the Zarit Burden

Interview. A further 18.07% reported moderate to severe burden, while 2.40% experienced severe burden. Only 10.84% of caregivers reported little or no burden. Overall, the findings indicate that most caregivers experienced some degree of caregiving burden.

Table 4: Zarit Caregiver Burden Interview Score and Copenhagen Burnout Inventory Score of Caregivers Across Different Diagnoses

Diagnoses	Zarit Caregiver Burden Score Mean $\pm$ SD	Copenhagen Burnout Inventory Score Mean $\pm$ SD	p Value
Cerebral Palsy	46 $\pm$ 5.02	48.34 $\pm$ 19.72	0.022
Downs Syndrome	34 $\pm$ 3.07	41.31 $\pm$ 15.12	0.022
Post Meningitis sequelae	33 $\pm$ 2.01	40.33 $\pm$ 12.13	0.022
Post encephalitis sequelae	26 $\pm$ 4.12	42.34 $\pm$ 11.75	0.022
Neurodegenerative disorders	24 $\pm$ 4.02	40.21 $\pm$ 15.21	0.022
Genetic disorders	37 $\pm$ 5.04	44.33 $\pm$ 16.13	0.022
Congenital malformations	28 $\pm$ 4.07	40.34 $\pm$ 11.72	0.022
Spina Bifida	35 $\pm$ 5.03	42.21 $\pm$ 15.21	0.022
Muscular Dystrophy	43 $\pm$ 5.03	44.33 $\pm$ 16.13	0.022
Others	22 $\pm$ 3.02	40.34 $\pm$ 11.75	0.022

Table 4 presents the mean Zarit Caregiver Burden Interview (ZBI) and Copenhagen Burnout Inventory (CBI) scores among caregivers according to the diagnosis of the adolescent with disability. Caregiver burden differed significantly across diagnostic groups ($p = 0.022$). The highest mean ZBI score was observed among caregivers of adolescents with cerebral palsy (46 $\pm$ 5.02), followed by muscular dystrophy (43 $\pm$ 5.03) and Down syndrome (34 $\pm$ 3.07). The lowest burden score was observed among caregivers of adolescents with other diagnoses (22 $\pm$ 3.02) and neurodegenerative disorders (24 $\pm$ 4.02). CBI scores were highest among caregivers of adolescents with cerebral palsy (48.34 $\pm$ 19.72), followed by genetic disorders and muscular dystrophy (both 44.33 $\pm$ 16.13). Thus, cerebral palsy was associated with comparatively higher caregiver burden and burnout in the present sample.

Table 5: Prevalence of Burnout (CBI) Among Caregivers of Adolescents with Disabilities.

Burnout sub-domain of Copenhagen Burnout Inventory (CBI)	Number of Caregivers (n=83)	Prevalence (%)
Personal Burnout		
Yes (Mean Score > 50)	44	53.01
No (Mean Score < 50),	39	46.09
Work burnout		
Yes (Mean Score > 50)	33	39.75
No (Mean Score < 50),	50	60.25
Client burnout		
Yes (Mean Score > 50)	38	45.78
No (Mean Score < 50),	45	54.22
Total burnout		
Yes (Mean Score > 50)	28	33.73
No (Mean Score < 50),	55	66.27

* Burnout = mean score for component in each specific subdomain > 50

Total Burnout = mean score for all component > 50

Among the 83 caregivers, personal burnout (PBS) was the most prevalent, affecting 44 caregivers (53.01%). Client-related burnout was observed in 38 caregivers (45.78%), while work-related burnout (WRBS) was reported by 33 caregivers (39.75%). Overall, 33.73% met the study criterion for total burnout, whereas 66.27% did not. Thus, approximately one in three caregivers experienced burnout across the assessed CBI components.

Table 6: The Level of Exhaustion in Terms of the PBS and WBS Among the Respondents

Level of Exhaustion	Personal Burnout (PBS*) Score (%) (n = 83)	Work Related Burnout (WRBS**) Score (%) (n = 83)
Slightly	47	58
Moderately	32	23
Highest	04	02

*PBS level scoring: slightly exhausted: ≤ 50 , moderately exhausted: 50–70, highest exhausted: ≥ 70 .

****WBS level scoring:** slightly exhausted: ≤ 45 , moderately exhausted: 45–60, highest exhausted: ≥ 60 .

Table 6 shows among the 83 caregivers, 47 (56.6%) reported slight personal exhaustion, 32 (38.6%) reported moderate exhaustion, and 4 (4.8%) reported the highest level of personal exhaustion based on the Personal Burnout Score (PBS). Regarding work-related burnout, 58 (69.9%) caregivers had slight exhaustion, 23 (27.7%) had moderate exhaustion, and 2 (2.4%) had the highest level of exhaustion. Thus, most caregivers experienced slight levels of both personal and work-related exhaustion, while a smaller proportion experienced moderate to high exhaustion.

Table 7: Burnout (PBS & WRBS) Score and Caregiver Socio-demographic Characteristics and

Caregiver characteristics	Personal Burnout (PBS*) Score Mean $\pm$ SD	p Value	Work Related Burnout (WRBS**) Score Mean $\pm$ SD	p Value
Age				
30–40	43.34 $\pm$ 11.72	0.454	39.14 $\pm$ 15.67	0.025
41–50	41.21 $\pm$ 15.11		34.64 $\pm$ 15.56	
>50	44.33 $\pm$ 16.13		30.68 $\pm$ 15.31	
Gender				
Male	41.77 $\pm$ 12.23	0.023	36.19 $\pm$ 15.67	0.044
Female	52.23 $\pm$ 16.44		33.14 $\pm$ 19.37	
Relation to child				
Mother	49.11 $\pm$ 17.43	0.036	30.13 $\pm$ 18.32	0.024
Father	41.53 $\pm$ 11.22		38.17 $\pm$ 19.61	
Grandparents			26.18 $\pm$ 19.33	
Duration of caregiving				
<5 year	36.11 $\pm$ 17.52	0.045	24.43 $\pm$ 19.35	0.043
5–10 years	41.64 $\pm$ 13.73		33.18 $\pm$ 11.58	
>10 years	44.39 $\pm$ 13.45		36.11 $\pm$ 12.43	
Time spent in caregiving per day				
1–5 hrs	43.34 $\pm$ 11.72	0.022	23.44 $\pm$ 18.21	0.033
6–10 hrs	47.15 $\pm$ 15.59		32.22 $\pm$ 15.18	
>10 hrs	51.33 $\pm$ 12.24		38.72 $\pm$ 15.34	
Education				
Less than secondary	33.42 $\pm$ 12.22	0.855	33.52 $\pm$ 19.21	0.561
Secondary	36.44 $\pm$ 17.32		32.29 $\pm$ 25.38	
University	35.33 $\pm$ 10.65		30.62 $\pm$ 13.38	
Occupation				
Non-worker	41.23 $\pm$ 13.47	0.432	31.59 $\pm$ 23.34	0.658
Worker	46.34 $\pm$ 17.23		39.22 $\pm$ 17.33	
Caregiver status				
Single parent	49.19 $\pm$ 18.56	0.043	38.34 $\pm$ 13.72	
Both parents	41.14 $\pm$ 16.42		28.54 $\pm$ 11.84	
Socioeconomic status				
Very low/low	53.54 $\pm$ 14.45	0.021	39.64 $\pm$ 18.63	0.034
Moderate	42.94 $\pm$ 23.27		33.55 $\pm$ 14.51	
High	41.76 $\pm$ 14.85		30.44 $\pm$ 12.31	
Family residence				
Rural	40.38 $\pm$ 18.56	0.561	32.64 $\pm$ 18.62	0.456
Urban	39.38 $\pm$ 19.73		30.94 $\pm$ 21.32	

Table 7 demonstrates the association between caregiver socio-demographic characteristics and personal burnout (PBS) and work-related burnout (WRBS). Significant associations with personal burnout were observed for gender ($p=0.023$), relationship to the child ($p=0.036$), duration of caregiving ($p=0.045$), daily caregiving time ($p=0.022$), caregiver status ($p=0.043$), and socioeconomic status ($p=0.021$). Personal burnout scores were higher among female caregivers (52.23 $\pm$ 16.44), mothers (49.11 $\pm$ 17.43), caregivers providing care for >10 years (44.39 $\pm$ 13.45), those spending >10 hours/day in caregiving (51.33 $\pm$ 12.24), single parents (49.19 $\pm$ 18.56), and caregivers from very low/low socioeconomic groups (53.54 $\pm$ 14.45). Age, education, occupation, and place of residence were not significantly associated with PBS ($p>0.05$).

For work-related burnout, significant associations were found with age ($p=0.025$), gender ($p=0.044$), relationship to the child ($p=0.024$), duration of caregiving ($p=0.043$), daily caregiving time ($p=0.033$), and

socioeconomic status ($p=0.034$). The highest WRBS scores were observed among caregivers aged 30–40 years (39.14 $\pm$ 15.67), fathers (38.17 $\pm$ 19.61), those providing care for >10 years (36.11 $\pm$ 12.43), spending >10 hours/day in caregiving (38.72 $\pm$ 15.34), and those from very low/low socioeconomic groups (39.64 $\pm$ 18.63). Education, occupation, caregiver status, and rural/urban residence were not significantly associated with WRBS.

Table 8: Distribution of Resilience Score Among Caregivers of Adolescents with Disabilities

Brief resilience score	Total (n=83) Frequency	(%)
Low resilience	58	69.87
Normal resilience	16	19.27
High resilience	09	10.84

As shown in Table 8, the majority of caregivers demonstrated low resilience. Of the 83 caregivers assessed, 58 (69.87%) had low resilience, while 16 (19.27%) had normal resilience and only 9 (10.84%) demonstrated high resilience. Thus, nearly seven out of ten caregivers had low resilience scores, indicating limited psychological capacity to adapt positively to the ongoing demands associated with caring for adolescents with disabilities.

Table 9: Distribution of Burden Score and Resilience Score Among Caregivers

Caregiver Characteristics	Burden Score Mean $\pm$ SD	Resilience Score Mean $\pm$ SD
Gender		
Male	44 $\pm$ 3.17	2.99 $\pm$ 0.49
Female	53 $\pm$ 6.01	1.03 $\pm$ 0.21
Income status		
Very low/low income	44 $\pm$ 4.03	2.03 $\pm$ 0.02
Moderate income	38 $\pm$ 5.04	2.99 $\pm$ 0.56
High income	28 $\pm$ 4.07	3.03 $\pm$ 0.72
Duration of caregiving		
1–5 hrs	32 $\pm$ 2.11	3.01 $\pm$ 0.02
6–10 hrs	37 $\pm$ 3.07	1.99 $\pm$ 0.76
>10 hrs	46 $\pm$ 5.02	1.03 $\pm$ 0.02

Table 9 presents the distribution of caregiver burden and resilience scores according to selected caregiver characteristics. Female caregivers had higher mean burden scores than male caregivers (53 $\pm$ 6.01 vs. 44 $\pm$ 3.17), while their mean resilience score was lower (1.03 $\pm$ 0.21 vs. 2.99 $\pm$ 0.49). A socioeconomic gradient was also observed: caregivers from very low/low-income households had the highest mean burden score (44 $\pm$ 4.03) and comparatively lower resilience (2.03 $\pm$ 0.02), whereas caregivers with high income had the lowest burden score (28 $\pm$ 4.07) and the highest resilience score (3.03 $\pm$ 0.72). Caregiving time showed a similar pattern, with increasing daily caregiving hours associated with progressively higher burden and lower resilience. Caregivers spending >10 hours/day had the highest burden (46 $\pm$ 5.02) and lowest resilience (1.03 $\pm$ 0.02), compared with those providing care for 1–5 hours/day (32 $\pm$ 2.11 and 3.01 $\pm$ 0.02, respectively).

Table 10: Correlation Between Caregiver Burden and Psychological Resilience

	Zarit Burden Interview Score	Brief Resilience Score	Personal Burnout Score
Correlation coefficient	-0.302	-0.340	-0.470
p value	<0.001	<0.001	<0.001

Table 10 demonstrates a statistically significant negative correlation between caregiver burden, psychological resilience, and personal burnout. Zarit Burden Interview (ZBI) scores showed a moderate negative correlation with Brief Resilience Scale scores ($r=-0.302$, $p<0.001$), indicating that higher caregiver burden was associated with lower resilience. A similar negative correlation was observed between personal burnout and resilience ($r=-0.470$, $p<0.001$). The correlation between resilience and personal burnout was stronger than that between resilience and ZBI burden.

DISCUSSION

The present study examined caregiver burden, burnout, exhaustion, and psychological resilience among caregivers of adolescents with physical disabilities. Overall, the findings indicate that caregiving was predominantly undertaken by women, particularly mothers, and was characterized by prolonged duration and substantial daily caregiving

demands. These contextual characteristics provide an important basis for understanding the burden and psychological outcomes observed in the study. The predominance of mothers is consistent with the greater involvement of mothers in personal care, healthcare management, rehabilitation, education, and supervision of children with chronic disabilities. Previous research has similarly identified substantial physical, emotional, social, and practical demands among parents caring for children with cerebral palsy and other developmental disabilities.^{13,14}

A notable feature of the present sample was the prolonged duration and intensity of caregiving. A considerable proportion of caregivers had provided care for 5–10 years or more than 10 years, and approximately three-fourths reported spending at least six hours per day in caregiving activities. Such sustained caregiving may restrict opportunities for employment, leisure, social participation, rest, and self-care. The cumulative nature of these demands may be particularly important during adolescence, when functional needs, educational participation, and expectations for increasing independence continue to evolve. Research has demonstrated that greater severity of disability and increased caregiving demands are associated with greater caregiver burden and poorer caregiver well-being.¹⁴

The socioeconomic characteristics of the sample further contextualize the findings. A relatively large proportion of caregivers belonged to very low or low socioeconomic groups, while many were not engaged in paid employment. Long-term disability care may involve recurring expenses related to rehabilitation, transportation, medication, assistive devices, education, and other support services, while intensive caregiving may simultaneously limit opportunities for employment. Evidence from studies of families of children with disabilities has identified financial difficulties, reduced employment opportunities, and limited access to services as important components of caregiver stress.^{13,15} However, the cross-sectional design of the present study does not allow determination of whether unemployment or socioeconomic disadvantage resulted from caregiving or contributed to caregiving difficulties.

The findings concerning caregiver burden suggest that long-term caregiving places a substantial practical and emotional demand on families. Although many caregivers experienced mild-to-moderate burden, a subgroup experienced moderate-to-severe or severe burden, indicating considerable individual variation. This pattern is consistent with systematic evidence showing that caregiver burden among families of children with cerebral palsy is associated with the severity of the child's disability, caregiver psychological well-being, and quality of life.¹⁵ Parents caring for children with cerebral palsy have also described physical and emotional demands, restrictions on family and social life, difficulties accessing healthcare and financial resources, and reduced freedom.^{13,16} These findings support the need to assess caregiver well-being alongside the functional status of the adolescent rather than focusing exclusively on the child.

Caregiver burden also varied across diagnostic groups. Caregivers of adolescents with cerebral palsy had the highest ZBI and overall CBI scores, with a statistically significant difference observed across diagnostic groups ($p = 0.022$). Higher burden among caregivers of adolescents with cerebral palsy may reflect persistent motor and functional limitations, dependence in activities of daily living, and the continuing need for assistance across multiple settings. Systematic review evidence indicates that greater physical disability in children with cerebral palsy is associated with increased caregiver burden.¹⁵ Caregivers of adolescents with muscular dystrophy and genetic disorders also demonstrated relatively high burden and burnout, which may reflect progressive functional limitations and increasing dependence. Nevertheless, diagnostic category should not be interpreted as an independent cause of caregiver burden because functional severity, caregiving duration, daily caregiving time, family support, and socioeconomic resources may differ between diagnostic groups.

Burnout was another important finding of the study. Personal burnout was more frequently observed than work-related burnout, suggesting that caregivers' overall physical and psychological exhaustion may be more prominent than exhaustion specifically attributed to employment or work-related activities. This finding is understandable in a sample in which caregiving was predominantly family-based and a substantial proportion of caregivers were not engaged in paid employment. Previous research has demonstrated considerable burnout and

psychological strain among informal caregivers of children with disabilities, particularly when caregiving is prolonged and demanding.^{16,17} The present findings therefore reinforce the importance of considering personal exhaustion even when caregivers do not have formal employment.

The distribution of exhaustion further supports this interpretation. Most caregivers reported slight personal and work-related exhaustion; however, a substantial minority experienced moderate or higher personal exhaustion. This suggests that although severe exhaustion was relatively uncommon, cumulative fatigue may already be present in a considerable proportion of caregivers. Long-term caregiving can involve repeated physical assistance, supervision, transportation, healthcare management, and emotional support, which may contribute to progressive fatigue. Meta-analytic evidence indicates that caregivers of children with developmental disabilities may experience adverse effects on physical and psychological health.¹⁸ Consequently, early identification of exhaustion may be preferable to waiting until caregivers develop severe burnout or significant psychological distress.

Caregiver characteristics were also associated with burnout. Female caregivers demonstrated higher personal and work-related burnout than male caregivers, and mothers had higher personal burnout than fathers. These findings are consistent with research indicating that mothers frequently assume a greater proportion of routine caregiving responsibilities and may consequently experience greater physical and psychological demands.^{13,19} The present study also found higher burnout among caregivers with longer caregiving duration and those spending more than 10 hours per day providing care. These findings suggest that the intensity and cumulative duration of caregiving may be more directly relevant to burnout than demographic characteristics alone.

Socioeconomic status was significantly associated with both personal and work-related burnout, with higher burnout observed among caregivers from very low or low socioeconomic backgrounds. Financial strain may compound caregiving demands through treatment expenses, transportation costs, reduced employment opportunities, and limited access to supportive services. Previous research has identified socioeconomic circumstances and access to resources as important determinants of caregiver well-being.^{13,16} The present findings therefore highlight the importance of addressing social and economic factors when developing caregiver interventions rather than relying solely on individual coping strategies.

In contrast, education, occupation, and rural or urban residence were not significantly associated with burnout in the present study. These findings suggest that caregiver exhaustion may be influenced more strongly by the intensity and duration of caregiving and by available resources than by educational or residential characteristics alone. However, these non-significant findings should be interpreted cautiously because the sample size was relatively small and the study was cross-sectional. The rural representation of the sample nevertheless remains clinically relevant because geographical accessibility, transportation, continuity of rehabilitation, and availability of specialized services can influence the overall caregiving experience.

A particularly important finding was the high prevalence of low psychological resilience. Most caregivers were classified as having low resilience, whereas only a small proportion demonstrated high resilience. Resilience represents an important psychological resource in the context of prolonged caregiving because it may support adaptation to continuing stress and changing care demands. A meta-analysis of familial caregivers of children with developmental disabilities found that resilience was associated with coping, social support, perceived health, and life satisfaction.¹⁹ Similarly, systematic evidence indicates that resilience is relevant to adaptation and psychological well-being among caregivers experiencing chronic caregiving demands.²⁰

The high proportion of caregivers with low resilience may therefore reflect the cumulative effects of prolonged caregiving, limited opportunities for self-care, financial constraints, and reduced participation in meaningful social and occupational activities. Importantly, low resilience should not be interpreted as an individual deficit. Resilience is influenced by both personal and environmental resources, including social support, coping strategies, family

relationships, access to healthcare, and socioeconomic circumstances.^{19,20} This perspective is particularly relevant in rehabilitation, where caregiver support should address both individual coping and the environmental conditions in which caregiving occurs.

The relationship between caregiver burden and resilience provides further insight into the findings. The present study demonstrated a significant negative correlation between ZBI scores and resilience ($r = -0.302$, $p < 0.001$), indicating that greater perceived burden was associated with lower resilience. A stronger negative correlation was observed between personal burnout and resilience ($r = -0.470$, $p < 0.001$). These findings suggest that resilience may be particularly relevant to caregivers' experience of personal exhaustion. Previous literature similarly identifies resilience as an important psychological resource associated with better adaptation and reduced effects of caregiving stress.^{21,22}

The relationship between resilience and caregiver burden should, however, be interpreted cautiously. The present cross-sectional design demonstrates an association rather than causation. Lower resilience may contribute to greater perceived burden, but prolonged burden and burnout may also reduce psychological resources and resilience. It is also possible that both are influenced by common factors such as disability severity, social support, socioeconomic status, and caregiving intensity. Longitudinal research is therefore required to clarify the direction of these relationships and determine whether strengthening resilience can subsequently reduce caregiver burden and burnout.

The findings have important implications for rehabilitation practice. Caregiver assessment should extend beyond the assessment of the adolescent's functional limitations to include caregiver burden, burnout, exhaustion, resilience, and available social resources. Family-centred rehabilitation may incorporate caregiver education, training in safe and efficient caregiving techniques, problem-solving and coping strategies, stress-management approaches, shared caregiving arrangements, and opportunities for respite. Occupational therapists may have a particularly relevant role in analysing caregiver routines, facilitating task distribution, recommending environmental and adaptive modifications, promoting energy conservation, and supporting caregivers' participation in meaningful occupations alongside their caregiving role.

Social and peer support may also be useful components of caregiver-focused rehabilitation. A systematic review found that peer-support programmes may reduce distress and improve well-being and quality of life among parents and caregivers of children with disabilities, although the evidence base remains limited by methodological weaknesses.²³ Resilience-focused interventions involving psychoeducation, mindfulness-based approaches, and cognitive-behavioural strategies have also shown emerging benefits, although further high-quality trials are required.¹⁴ Such interventions may be particularly relevant for caregivers with prolonged caregiving duration, high daily caregiving hours, low socioeconomic resources, and elevated burnout.

Overall, the present study highlights the multidimensional nature of caregiving among families of adolescents with physical disabilities. Caregiving was predominantly undertaken by mothers and female family members and was frequently prolonged and time-intensive. Higher caregiver burden and burnout were observed in association with several caregiving characteristics, while low resilience was common and was inversely related to both caregiver burden and personal burnout. These findings support a shift from child-focused rehabilitation alone toward a more comprehensive family-centred approach that recognizes caregiver well-being as an important component of rehabilitation outcomes.

The study should be interpreted in light of its limitations. The cross-sectional design prevents causal conclusions regarding the relationships between burden, burnout, and resilience. The relatively small sample and representation of multiple diagnostic groups may limit generalizability and reduce the ability to examine diagnosis-specific factors in detail. Caregiver outcomes were also based on self-reported measures and may therefore be influenced by individual perceptions and reporting. Future longitudinal and multicentre studies with larger samples should examine the contribution of disability severity, functional dependence, social support, financial burden, and

caregiving intensity to caregiver outcomes. Intervention studies are also needed to determine whether targeted resilience-building, psychosocial, peer-support, and occupational therapy interventions can reduce caregiver burden and burnout while improving caregiver well-being and sustained participation in family life.

CONCLUSION

The present study indicates that caregivers of adolescents with disabilities experience substantial caregiver burden and burnout, accompanied by predominantly low levels of psychological resilience. Female caregivers, caregivers from lower-income households, and those with longer and more intensive caregiving responsibilities demonstrated greater burden and burnout and comparatively lower resilience. A significant inverse relationship was observed between resilience and both caregiver burden and personal burnout, suggesting that greater psychological resilience is associated with better adaptation to caregiving demands. These findings highlight the importance of incorporating caregiver-focused psychosocial and resilience-enhancing interventions, including coping-skills training, social support, caregiver education, and respite opportunities, into comprehensive rehabilitation services. Further longitudinal research is warranted to examine whether strengthening resilience can reduce caregiver burden and burnout over time. The findings indicate that rehabilitation needs to extend beyond the adolescent with disability to include the caregiver and family system, with emphasis on interventions that reduce the time and effort required for daily caregiving.

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