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ASSESSMENT OF BURDEN AMONG CAREGIVERS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES: A HOSPITAL BASED CROSS-SECTIONAL STUDY

Psychiatry

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ABSTRACT

Background: Developmental disabilities comprise a wide range of lifelong conditions that begin in early childhood and interfere with the normal progression of physical, cognitive, language, and social development. Children with developmental disability often require sustained medical, rehabilitative, and emotional support. This long-term care places a significant psychological and physical burden on caregivers. Understanding the extent and determinants of caregiver burden is essential for developing targeted psychosocial and community-based interventions. **Methodology:** This descriptive, cross-sectional study was carried out in the Department of Psychiatry at a tertiary care teaching hospital in Chennai between June 2023 and July 2024. A total of 82 primary caregivers of children with different developmental disabilities were selected through purposive sampling. Information on socio-demographic and clinical variables was obtained using a predesigned structured proforma, while the level of caregiver burden was evaluated using the Zarit Burden Interview (ZBI). Data analysis was performed using SPSS version 25.0, and associations between categorical variables were examined using the Chi-square test. A p-value of less than 0.05 was taken as statistically significant. **Results:** Of the 82 caregivers included in the study, the majority were women (87.8%). According to the Zarit Burden Interview (ZBI) scores, 56.1% of participants reported a severe level of burden, 26.8% experienced a moderate burden, and 17.1% had a mild burden. A significant association was identified between the level of caregiver burden and factors such as socioeconomic status ($p = 0.028$), educational attainment ($p = 0.021$), employment status ($p = 0.041$), and the specific type of developmental disability ($p < 0.001$). Caregivers looking after children with cerebral palsy, autism spectrum disorder, and hearing impairment experienced the greatest levels of burden. **Conclusion:** Significant psychological and social stress is experienced by carers of children with developmental disabilities, especially those from lower socioeconomic origins who have less education and are unemployed. Early identification of caregiver distress and incorporation of psychosocial counseling, financial assistance, and community-based rehabilitation into child care programs are essential to alleviate burden and improve caregiver well-being.

KEYWORDS

Developmental disability, Caregiver burden, Zarit burden interview, Mental health

INTRODUCTION

Developmental disability encompass a diverse group of conditions originating in early childhood that affect multiple domains of functioning, including cognition, behavior, motor coordination, and communication. Common examples include Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Cerebral Palsy, Intellectual Disabilities, Down Syndrome, Vision Loss, and Hearing Loss [1]. These conditions often require long-term medical care, rehabilitation, and social support, imposing a considerable strain not only on affected children but also on their caregivers [2].

In order to provide daily care, oversee treatment plans, and coordinate various therapies, caregivers typically parents or other family members play a crucial role. This prolonged responsibility frequently leads to physical exhaustion, financial burden, and emotional distress, collectively termed **caregiver burden** [3]. Anxiety, despair, and social isolation are some of the psychological effects that can appear, especially in low- and middle-income environments where access to specialised treatment and financial resources are scarce [4]. Numerous studies have demonstrated how sociodemographic and clinical factors, including the severity of the child's disability, socioeconomic situation, carer education, and work status, affect the level of carer burden [5,6].

One of the most extensively used and validated tools for determining carers' perceived burden is the Zarit Burden Interview (ZBI). It captures multiple domains emotional, social, and financial providing a comprehensive measure of strain experienced in long-term care situations [7]. Understanding the patterns and determinants of caregiver burden is crucial for developing targeted psychosocial interventions. In the Indian context, where extended family systems and limited institutional support coexist, such insights are essential for strengthening community-based rehabilitation and caregiver support programs [8]. Hence, the present study aimed to evaluate the extent of burden experienced by primary caregivers of children with developmental disabilities and to determine the socio-demographic and clinical factors linked to this burden in a tertiary care hospital setting.

MATERIAL AND METHODS

This cross-sectional, hospital-based study was conducted in the Department of Psychiatry at a tertiary care teaching hospital in Chennai over a one-year period (June 2023 - July 2024). The study included 82 primary caregivers of children diagnosed with various developmental disabilities who attended outpatient or inpatient services during the study period.

Study Design And Population

Eligible participants were caregivers of children with clinically established developmental disorders such as ADHD, ASD, Intellectual Disabilities, Down Syndrome, Cerebral Palsy, Vision Loss, or Hearing Loss. Caregivers of these children, defined as the primary family member responsible for day-to-day care, were enrolled after obtaining written informed consent. Caregivers with known psychiatric disorders, substance dependence, or those unwilling to participate were excluded from the study.

Sampling Method

A **non-probability purposive sampling technique** was adopted for the study. Caregivers who met the inclusion criteria and were available during the study period were consecutively recruited from both the outpatient and inpatient departments. This approach ensured adequate representation of different developmental disabilities and caregiver profiles commonly seen in a tertiary care setup.

Ethical Considerations

Approval for the study was obtained from the Institutional Ethics Committee prior to data collection. Participation was voluntary, and confidentiality of the participants was maintained throughout the study.

Data Collection Tools

A structured proforma was used to collect socio-demographic and clinical details of the child and caregiver, including age, gender, diagnosis, socioeconomic class, and parental education and employment status.

The Zarit Burden Interview (ZBI) was employed to assess the level of caregiver burden. This standardized tool comprises 22 items rated on a 5-point Likert scale ranging from 0 (never) to 4 (nearly always). The total score varies from 0 to 88, with higher scores indicating a greater degree of perceived burden. The instrument assesses multiple dimensions of burden such as physical, emotional, social, and financial

stress. The ZBI has demonstrated high reliability, with a Cronbach's alpha coefficient of 0.93 and test-retest reliability of 0.89.

Data Analysis

Responses from the questionnaires were coded and entered into Microsoft Excel and analyzed using SPSS software (version 25.0). Descriptive statistics were used to summarize the demographic variables. Associations between caregiver burden and clinical or socio-demographic factors were tested using the Chi-square test. A p-value of less than 0.05 was considered statistically significant.

RESULTS

A total of 82 primary caregivers of children with developmental disabilities were included in the study. The socio demographic distribution of the caregivers is presented in **(Table 1).** Most caregivers (41.5%) were aged 31-40 years, followed by 26.8% aged 41-50 years. Females predominated (87.8%). The majority belonged to the upper-lower (42.7%) and lower-middle (31.7%) socioeconomic classes. Regarding education, 43.9% had secondary and 24.4% had higher secondary or above qualifications, while 11% were illiterate. Nearly two-thirds (64.6%) were unemployed.

Table 1: Socio-demographic Characteristics Of Caregivers (N = 82)

Variable	Category	Frequency (n)	Percentage (%)
Age (years)	20 – 30	18	22.0
	31 – 40	34	41.5
	41 – 50	22	26.8
	> 50	8	9.7
Gender	Male	10	12.2
	Female	72	87.8
Socioeconomic Class (Modified BG Prasad)	Upper	3	3.7
	Upper-middle	6	7.3
	Lower-middle	26	31.7
	Upper-lower	35	42.7
	Lower	12	14.6
Education of Caregivers	Illiterate	9	11.0
	Primary education	17	20.7
	Secondary education	36	43.9
	Higher secondary & above	20	24.4
Employment Status	Employed	29	35.4
	Unemployed	53	64.6

The clinical details of the children are summarized in **(Table 2).** More than half of the children (56.1%) were aged ≤ 5 years, and 43.9% were older than five years. A slight male predominance was observed 54.9% males. Regarding the distribution of developmental disabilities, **cerebral palsy** was the most frequently encountered condition (24.4%), followed by **autism spectrum disorder (17.1%)** and **intellectual disabilities (15.9%)**.

Table 2: Clinical Profile Of Children With Developmental Disability (N = 82)

Variable	Category	Frequency (n)	Percentage (%)
Age of Child (years)	≤ 5 years	46	56.1
	> 5 years	36	43.9
Gender of Child	Male	45	54.9
	Female	37	45.1
Type of Developmental Disability	Cerebral palsy	20	24.4
	Autism Spectrum Disorder	14	17.1
	Intellectual Disabilities	13	15.9
	Attention Deficit Hyperactivity Disorder (ADHD)	10	12.2
	Down Syndrome	9	11
	Vision loss	8	9.8
	Hearing loss	8	9.8

The distribution of caregiver burden, assessed using the Zarit Burden Interview (ZBI), is depicted in **(Figure 1).** Among the 82 caregivers, a majority 46 of them experienced severe burden, while 22 reported moderate and 14 experienced mild burden. This indicates that most caregivers of children with developmental disability perceived a high degree of burden

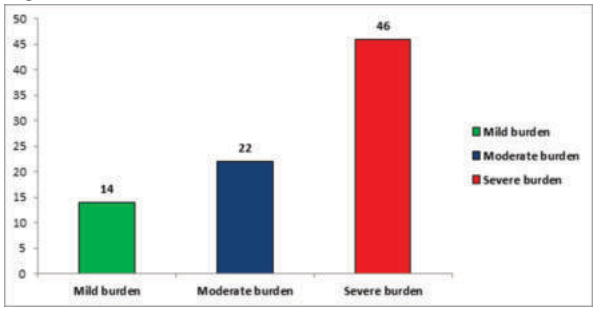

Figure 1: Distribution of Zarit Burden Categories (N = 82)

The association between caregiver burden and socio-demographic characteristics is presented in (**Table 3**). No statistically significant association was observed between caregiver age and burden levels ($p = 0.46$). However, caregivers in the 31-40 year age group reported higher proportions of severe burden (61.8%) compared to other age categories. Socioeconomic class showed a significant association with caregiver burden ($\chi^2 = 10.27$, $p = 0.028$). Caregivers belonging to lower socioeconomic strata experienced markedly higher levels of burden 83.3% of those in the lower class reported severe burden compared to only one-third among the upper and upper-middle classes. Education also had a statistically significant association with burden ($\chi^2 = 9.67$, $p = 0.021$). Severe burden was more prevalent among illiterate caregivers (66.7%) and those with only primary schooling (58.8%). Employment status was another determinant ($\chi^2 = 6.39$, $p = 0.041$), with unemployed caregivers reporting greater strain 64.1% had severe burden compared with 41.4% among those who were employed.

Table 3: Association Between ZBI Scores And Sociodemographic Characteristics Of Caregivers

Variable	Category	Mild Burden (≤40)	Moderate Burden (41-60)	Severe Burden (>60)	χ^2 value	p-value
Age of Caregiver (years)	20–30	4 (22.2)	5 (27.8)	9 (50.0)	1.57	0.46
	31–40	5 (14.7)	8 (23.5)	21 (61.8)		
	41–50	3 (13.6)	7 (31.8)	12 (54.6)		
	>50	2 (25.0)	2 (25.0)	4 (50.0)		
Socioeconomic Class (Modified BG Prasad)	Upper	1 (33.3)	1 (33.3)	1 (33.3)	10.27	0.028*
	Upper-middle	2 (33.3)	2 (33.3)	2 (33.3)		
	Lower-middle	5 (19.2)	9 (34.6)	12 (46.2)		
	Upper-lower	6 (17.1)	8 (22.9)	21 (60.0)		
	Lower	0 (0)	2 (16.7)	10 (83.3)		
Education of Caregiver	Illiterate	1 (11.1)	2 (22.2)	6 (66.7)	9.67	0.021*
	Primary education	2 (11.8)	5 (29.4)	10 (58.8)		
	Secondary education	6 (16.7)	10 (27.8)	20 (55.5)		
	Higher secondary & above	5 (25.0)	5 (25.0)	10 (50.0)		
Employment Status	Employed	6 (20.7)	11 (37.9)	12 (41.4)	6.39	0.041*
	Unemployed	8 (15.1)	11 (20.8)	34 (64.1)		

*Statistically significant ($p < 0.05$)

(Table 4) demonstrates the association between caregiver burden and the type of developmental disability. A statistically significant association was observed between the type of developmental disability and caregiver burden ($\chi^2 = 22.63$, $p < 0.001$). The majority of caregivers of children with **cerebral palsy (55%), autism spectrum disorder (57.1%),** and **hearing loss (62.5%)** reported severe levels of burden.

DISCUSSION

The present study explored the extent of burden experienced by caregivers of children with developmental disability and the factors influencing it. A considerable proportion of participants reported severe levels of burden, which is comparable to the observations made by Dambi et al. and Raina et al., who documented similar findings among caregivers of children with cerebral palsy and other developmental disabilities [4,6]. The demanding and continuous care needs of these children, their dependence on caregivers, and the scarcity of structured support systems in low-resource settings contribute substantially to this burden.

Table 4: Association Between ZBI Scores And Developmental Disability

Variable	Category	Mild Burden (≤40)	Moderate Burden (41-60)	Severe Burden (>60)	χ^2 value	p-value
Type of Disorder	Cerebral palsy	3 (15.0)	6 (30.0)	11 (55.0)	22.63	<0.001*
	Autism Spectrum Disorder	2 (14.3)	4 (28.6)	8 (57.1)		
	Intellectual Disabilities	2 (15.4)	5 (38.5)	6 (46.1)		
	Attention Deficit Hyperactivity Disorder (ADHD)	3 (30.0)	4 (40.0)	3 (30.0)		
	Down Syndrome	4 (44.4)	3 (33.3)	2 (22.3)		
	Vision loss	2 (25.0)	3 (37.5)	3 (37.5)		
	Hearing loss	1 (12.5)	2 (25.0)	5 (62.5)		

*Statistically significant ($p < 0.05$)

In this study, the majority of caregivers were females, primarily mothers, who reported higher levels of stress. This aligns with findings by Yamaoka et al., who demonstrated that caregiving responsibilities often fall disproportionately on women, leading to heightened emotional distress and physical exhaustion [9]. Similarly, Thomas et al. reported that mothers of children with psychiatric and developmental disorders in Kerala experienced significant psychological strain, influenced by cultural and social expectations [3].

A significant association was identified between socioeconomic status and caregiver burden. Participants from lower-income groups exhibited greater stress levels, a pattern consistent with the findings of El-Deen et al., who observed that limited financial means and restricted access to services intensified caregiver strain among families of children with Down syndrome [10]. Barlow et al. also reported that financial hardship and income loss due to caregiving responsibilities compound the emotional toll experienced by caregivers [11]. Educational attainment emerged as another determinant, as caregivers with lower educational levels reported higher burden. Dambi et al. suggested that caregivers with better education demonstrate stronger coping abilities, greater awareness of available health resources, and improved problem-solving skills, which can mitigate perceived stress [4]. Conversely, limited education restricts access to information and effective coping mechanisms, thereby amplifying the perceived difficulty of caregiving.

Employment status was another factor influencing burden. Unemployed caregivers experienced higher levels of distress, likely due to economic dependence and social isolation. Barlow and Ellard noted that occupational engagement often provides caregivers with psychological respite, social interaction, and a sense of self-efficacy [11]. However, balancing employment and caregiving can be challenging in the absence of family or institutional support systems.

When considering clinical variables, the type of developmental disability had a statistically significant relationship with caregiver burden. Caregivers of children with cerebral palsy, **autism spectrum disorder,** and **hearing loss** experienced more severe burden. This is consistent with findings by Narayan et al., who reported that caregivers of children with neurodevelopmental disorder tend to experience higher Zarit Burden Interview scores [12].

The findings of the present study emphasize the urgent need for structured psychosocial and rehabilitative interventions for caregivers. Integrating these interventions into existing pediatric and rehabilitation frameworks, supported by community participation and financial assistance, could significantly improve the quality of life of caregivers and the children they care for.

CONCLUSION

The present study revealed that caregivers of children with developmental disability experience substantial levels of burden, particularly those from lower socioeconomic backgrounds, with limited education, and without employment. Caregivers of children with cerebral palsy, ASD and hearing loss were found to be more affected. These findings emphasize the need for early identification of caregiver stress and the incorporation of psychosocial counseling, financial assistance, and community-based rehabilitation into routine pediatric and mental health services. Strengthening caregiver support networks and implementing targeted interventions can significantly reduce distress, enhance coping ability, and ultimately improve the overall well-being of both caregivers and their children.

REFERENCES

1. Chukwuemeka NA, Obioha WC. Burden of care and mental health of informal caregivers of children with developmental disabilities in Sub-Saharan Africa: the moderating role of resilience. *Discover Psychology.* 2024;4:77. doi:10.1007/s44202-024-00178-7.
2. Thapar A, Cooper M, Rutter M. Neurodevelopmental disorders. Lancet Psychiatry. 2017;4(4):339-46. doi:10.1016/S2215-0366(16)30376-5.
3. Thomas KS, Venkateswaran C, Alexander AV. Quality of life, perceived stress and caregiver burden in mothers of children with childhood psychiatric disorders in Kerala, India. Int J Res Med Sci. 2020;8(8):2791–7. doi:10.18203/2320-6012.ijrms20203043.
4. Dambi JM, Jelsma J, Mlambo T, Chiwaridzo M, Dangarembizi-Munambah N, Corten L. An evaluation of psychometric properties of caregiver burden outcome measures used in caregivers of children with cerebral palsy: a systematic review protocol. Syst Rev. 2016 Mar 9;5:42. doi:10.1186/s13643-016-0219-3.
5. Mugno D, Ruta L, D'Arrigo VG, Mazzone L. Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder. Health Qual Life Outcomes. 2007;5:22. doi:10.1186/1477-7525-5-22.
6. Raina P, O'Donnell M, Rosenbaum P, Brehaut J, Walter SD, Russell D, et al. The health and well-being of caregivers of children with cerebral palsy. Pediatrics. 2005;115(6):e626-36. doi:10.1542/peds.2004-1689.
7. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist.* 1980;20(6):649-55. doi:10.1093/geront/20.6.649.
8. Lee EY, Neil N, Friesen DC. Support needs, coping, and stress among parents and caregivers of people with Down syndrome. Res Dev Disabil. 2021;119:104113. doi:10.1016/j.ridd.2021.104113.
9. Yamaoka Y, Tamiya N, Moriyama Y, Sandoval Garrido FA, Sumazaki R, Noguchi H (2015) Mental Health of Parents as Caregivers of Children with Disabilities: Based on Japanese Nationwide Survey. PLoS ONE 10(12): e0145200. doi:10.1371/journal.pone.0145200.
10. El-Deen, N. A., Alwakeel, A. A., El-Gilany, A., & Wahba, Y. (2020). Burden of family caregivers of Down syndrome children: a cross-sectional study. Family Practice, 38(2), 159-164. doi:10.1093/fampra/cmaa097
11. Barlow JH, Ellard DR. The psychosocial well-being of children with chronic disease, their parents and siblings: an overview of the research evidence base. Child Care Health Dev. 2006;32(1):19-31. doi:10.1111/j.1365-2214.2006.00591.x.
12. Narayan A, T.M.AK. Caregiver burden assessment of children with neurodevelopmental disorders in a tertiary care centre. IP Int J Med Paediatr Oncol. 2023;9(2):56-61. doi:10.18231/j.ijmpo.2023.011