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Research Article

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Psychosocial Predictors of Caregiver-Burden among the Caretakers of Children with Neurodevelopmental Disorders

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Abstract: Parenting a child with neurodevelopmental disorder (NDD) is related to higher rate of anxiety, depression, stress, and reduced quality of life but there is a lack of knowledge about the psychosocial predictors of psychological distress among these caregivers. To investigate the relationship between psychosocial predictors and caregiver-burden having children with NDD. In a Cross-Sectional study, data was collected from 100 primary caregivers of children aged 2-12 years from various cities of Pakistan (Rawalpindi, Islamabad, Lahore and Karachi) during the period from June 2020 to February 2021. Sample included 55females and 45males, of 15–68 years (M=36.92 SD=1.55). Socio–Demographic Form and Care–giver Burden Inventory was employed. Majority of participants (30%) accomplished 14 years of education, were married (77%) with mean number of 2children. 25% were mothers, 54% lived in a joint family system and 47% reported having been the caretaker for 1–5 years. Mean score of caregiver burden inventory was 35.88 (SD=20) showing mild level of burnout. No significant mean difference of caregiver burden surfaced between males and females, shown by independent sample t-test (197.98 = -.179, p > 0.05). Results of multiple regression with participant's education, gender, age, family system, marital status, duration of caretaking showed that these did not significantly predict caregiver burden F (7, 91) = .817, p>0.05. Interventions aimed at improving the wellbeing of caretakers should be made part of treatment of children with NDD. Future studies should include larger sample and study the stigma in exploring the psychosocial predictors of burnout among such caretakers.

Key Words: Burnout, Burden, Caretakers, Children, Neurodevelopmental Disorders, Psychosocial Predictors

Introduction

Neurodevelopmental disorders (NDD) encompass an assortment of conditions that can be labelled as a syndrome involving genetic disorders, certain impairments in the brain possibly occurring during the developmental period such as cerebral palsy, intellectual disability with probable conditions that lead to functional limitations (Rahman, et al., 2002; Behrman, et al., 2007). Children suffering from such disabilities generally remain at a loss to make an official mark in the general population, either in the social context or in the echelons of decision-making hierarchy (UNICEF, 2020). Lower- and middle-income societies have a higher likelihood of having to deal with children suffering from NDD. According to World Health Organization, almost 93 to 150 million children of these countries suffer from some kind of

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disability (WHO, 2011). Limited resources for maternal and child health remain a hallmark in timely dealing with issues arising during the prenatal and postnatal period, dietary deficits and pre-birth infections (Bitta, et al., 2018).

Prior research has established those behavioral problems exhibited by children serve as a significant predictive factor, both directly and indirectly, about caregiver burden (Raina et al., 2005). Research has indicated that, although mothers predominantly assume the role of primary active caregivers, the caregiving responsibilities associated with children who have special needs can result in significant anxiety and stress for caregivers, irrespective of their gender (Toledano–Toledano, et al., 2019)This especially impacts the individual that frequently assumes the role of caregiver, commonly the mother, who bears a disproportionate amount of the stress associated with caregiving responsibilities (Walkowiak, 2025). Additionally, various demographic factors, including the gender of the child (for instance, female rather than male) and age (such as children aged 1 to 5 years), may contribute to heightened psychological challenges faced by caregivers (Ndu, et al., 2020)

Dealing with children is a very challenging task and the problems encountered during the course in limited resource societies compound the already existing issues (Carnevale, et al., 2008; Parkes, et al., 2011; Thrush & Hyder, 2014). The wholesome deal of preventive, diagnostic, and management modulation is generally ignored while placing a healthcare plan in practice. This poses a challenge to public health management. It tends to drain the healthcare system of its resources and limits the outputs that reach the caregivers in the form of replenished quality of life and mental wellbeing. The focus of most researched has concentrated upon countries with adequate healthcare resources as compared to low- and middle-income countries with the lack of knowledge thereof (Newton, 2012; Scherer, et al., 2019).

Studies based on the countries having well established healthcare resources show a higher trend in stress, fatigue, anxiety and depression among caregivers of these children (Fritz & Sewell-Roberts, 2020; Masefield, et al., 2020). Various frameworks defining involvement in caregiving and the employed practices in this sphere highlight many additional factors involved in it. Some of these factors act as buffers and reduce caregiving burden among caretakers such as family and social support, parenting styles overall functioning of the family (Majnemer, et al., 2007). All these features make it altogether important to understand the psychological factors involved in caregiving experiences. To our knowledge, no studies on the psychological burden of a child diagnosed with NDD on a caregiver have been conducted in Pakistan. So present study was designed with aim is to explore level of burnout experienced by caregivers resulting from their caretaking duties and the role of psycho-social factors.

Methodology

Objectives

The present study has the following objectives:

- 1. To determine the level of burnout experienced by caregivers resulting from their caretaking duties.
- 2. To investigate the relationship between psychosocial predictors and Caregiver-burden among the caretakers of children with neurodevelopmental disorders.

Research Design

The present study uses a cross-sectional research design through purposive convenient sampling.

Sample

The present study's participants were 100 primary caregivers of children aged between 2 and 12 suffering from NDD from various cities of Pakistan, including Rawalpindi, Islamabad, Lahore, and Karachi, with the following inclusion and exclusion criteria:

Primary caregivers of children aged 2–12 years diagnosed with NDD who could read English and had a smartphone to complete the online questionnaires were included. Individuals with some serious physical/mental health issues, had some surgery or serious traumatic event in past 6months were excluded from the study. The term 'primary caregiver' was operationally defined as the person responsible for the daily care and decision-making in the best interest of child.



Instruments

Following instruments were used in the study:

- 1. **Demographic Sheet**: It sought age, gender, education level, marital status, family system format of caretaker, duration of caretaking, status of being the only caretaker, and relationship with the child.
- 2. Care-giver Burden Inventory: It is a 24-item multi-dimensional self-report questionnaire measuring caregiver burden with 5 subscales: (a) Time Dependence; (b)Developmental; (c) Behaviour; (d) Physical Burden; (e) Social Burden; (f) Emotional Burden. Scores for each item are evaluated using a 5-point Likert scale ranging from 0 (not at all disruptive) to 4 (very disruptive). All of the scores on the 24-item scale are summed and a total score >36 indicates a risk of "burning out" whereas scores near or slightly above 24 indicate a need to seek some form of respite care. It approximately takes 10-15 minutes to complete. Internal consistency reliability of each factor 0.85, 0.86, 0.73, and 0.77, respectively (Caserta, Lund, & Wright (1996).

Procedure

Following procedural steps have been undertaken:

- 1. Before the study started, the ethical committee Psychological Research Wing, Personnel Administration Directorate (General Headquarters Rawalpindi) has been secured (Serial No. AP2/2020).
- 2. Permission from the author was sought to use the scale.
- 3. All the participants were selected using convenience-purposive sampling and the snowball sampling technique.
- 4. They were sent the assessment pack, which comprised written informed consent, demographic sheet, and Caregiver Burden Inventory, via email and WhatsApp.
- 5. They filled it and sent it back to the researcher.
- 6. Telephone calls provided any clarification and explanation needed to understand the questions.
- Participants were ensured confidentiality and privacy. The data was evaluated and analyzed in SPSS-26.

Results

Around 100 caretakers participated in study, of which 55 were females and 45 were males. The demographics of participants studied in this research with their frequency and percentages are stated in table 1 as follows.

Table 1

Demographic Characteristics of Participants (n=100)

Variable	Mean/Frequency
Age range	
15-68	M=36.92 (SD=1.55)
Gender	
Male	45
Female	55
Level of education	
Primary	9
Middle	4
Matriculation	21
Intermediate	16
Bachelors	30
Masters	15
Post-graduation	3
Marital status	
Married	77
Single	23

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Variable	Mean/Frequency
Family system	
Nuclear	54
Joint	46
Duration of caretaking	
Less than 1 year	27
1 to 5 years	47
More than 5 years	26
Are you the only caretaker?	
Yes	29
More than one	71
Relationship to child	
Mother	38
Father	29
Sibling	17
Aunt/uncle	4
Grandparents	5
Other (cousin/nephew/daughter-in-law)	8

The level of burnout faced by caregivers was determined through Caregiver burden inventory. The Cronbach's alpha reliability was found to be 0.917 which is a good level of reliability. The overall mean score of caregiver burden inventory was 35.88 (SD=20) which shows a mild level of burnout. It was observed that majority of the participants were at the risk of burning out (41%) while 26% were in need of some form of respite care.

Table 2

Reliability of Caregiver Burden Inventory (CBI) (n=100)

					Range		
Variables	N	М	S. D	α	Actual	Potential	
CBI	24	35.9	20	0.917	1-95	0-96	

Table 3

Prevalence of Burnout among Caregivers (n=100)

Scale	Minimum	Maximum	Mean (SD)
Caregiver Burden Inventory			
Total Score	0	96	35.9 (20)
0-23 (no burnout)			33%
24-35 (need respite care)			26%
36 and above (at-risk of burning out)			41%
Subscales			
Time dependency	0	20	9.69 (5.49)
Development	0	20	7.94 (5.18)
Emotional health	0	20	6.18 (5.47)
Social relationship	0	16	5.91 (4.55)
Physical health	0	16	5.89 (4.6)

Table 4 shows comparison of mean scores between males and females on caregiver burnout inventory. There was no significant mean difference of caregiver burden between males and females as shown by independent sample t-test ($t_{97.98}$ = -.179, p>0.05). Multiple regression was calculated using participant's age, gender, level of education, marital status, family system, duration of caretaking and any other caretaker. Result showed that these variables did not statistically significantly predict caregiver burden F

(7, 91) = .817, p>0.05 (Table 5). Therefore, it can be deduced that these psychosocial predictors do not cause burnout among the caretakers of children with neurodevelopmental disorders.

Table 4

Independent Sample t-test to Compare Means Across Gender (n=100)

	Male (n	Male (n=45)		Female (n=55)			95%CL		
	М	S. D	М	S. D	t	р	LL	UL	
CBI	35.49	17.95	36.2	21.7	176	.861	-8.73	7.31	

Table 5

Multiple Regression Analysis to Explore Psycho-social Predictors of Burnout among Caregiver of Children with NDD (n=100)

Variables	R	R²	ΔR^2	В	SE	β	t	Sig(p)
Model 1	.243	.059	013					.576
Age				139	.175	094	792	.431
Gender				.622	4.176	.015	.149	.882
Level of Education				936	.628	161	-1.492	.139
Marital status				-2.599	5.563	055	467	.642
Family system				4.279	4.218	.107	1.015	.313
Duration of caretaking				-1.970	2.838	072	694	.489
Any other caretaker?				174	4.748	004	037	.971

*p < 0.05, ** p< 0.01

Note. R^2 = amount of variance explained by IVs; ΔR^2 = additional variance in DV; B = Unstandardized coefficient; SE= Standard Error; β = Standardized coefficient; t = estimated coefficient

Discussion

Managing a child with neurodevelopmental delays or disorder requires significant input from their respective caregiver which, in most cases, is inherently bound to continue for a long period of time. In the present study, researcher aimed to explore level of burnout experienced by caregivers resulting from their caretaking duties and the role of psycho-social factors like age, gender, level of education etc. It was found that majority of the participants were experiencing burnout, and a moderate number of participants were in need of respite care and intervals of breather from their caretaking duties. Esezobor et. al. (2020) reported parallel conclusions in a similar study design focusing on caregivers to identify psychological distress and burden of handling children with nephrotic syndrome. They found that 17% of caregivers stated a substantial burden of caregiving while 31% experienced psychological distress. Reis et. al (2020) also reported that caregivers of children with neurodevelopmental disorders felt tired and unwell. Another study conducted in Nepal also reported higher psychological distress in caregiver of children with neurodevelopmental disorders in around 46% of caregivers. Thus, it can be noted that burnout faced by caregivers in this study is in line with findings of studies conducted on Nepal and low-middle income country like India.

Review of literature suggests that caregiver burden vary across gender however, current evidence on sex and gender differences on burden faced by caregivers of patients with mental health issues is limited therefore, current study explored gender differences in level of burden faced by caregivers however no significant difference was found. There is evidence (Schaffler–Schaden et. al. 2021) that suggests gender differences to be the predictors of caregiver burden however further research is required to substantiate the hypothesis.

Additionally, empirical finding suggested that various socio-demographic characteristics act as risk factors for caregiver burden. These factors include sex, education level, hours spent caregiving, being the primary caregiver etc. (Martínez et. al. 2012). Present study also explored the relationship between such characteristics and caregiver's burden however results of multiple regression analysis were non-

significant denoting that psychosocial predictors do not cause burnout among the caretakers of children with neurodevelopmental disorders. Based on the available evidence (Toledano-Toledano et. al. 2019), the role of psychosocial and socio-demographic factors should be studied further to advance the understanding of relationship between these factors and caregiver burden.

Limitations of study includes small sample size which makes it difficult to explore differences across various sociocultural and multi-demographic factors. Furthermore, caregiver burden and burnout are multifaceted variables that can be studied in more than one way thus, additional instruments, if used, can help attain a more in-depth exploration of these variables.

Conclusion

The study found majority of caregivers are primarily at-risk of burnout while others may be in need of some form of respite care and breathers while carrying out their caregiving duties. Therefore, interventions that include the dimension of wellbeing of caretakers are likely to have a lasting and operative effect in meeting the durability of treatment modulation. Multidimensional approaches accentuating the importance of psychological health of caregivers will have a stronger impact in the overall environment of taking care of a child with neurodevelopmental disorders. Future studies should include a relatively larger sample size to incorporate diverse perceptions over the role of social support. The cultural stigma attached to neurodevelopmental disorders should also be studied for an in-depth understanding of the processes happening in the background that effect and play a role in identifying psychosocial predictors of burnout among caretakers.



References

- Behrman, R. E., & Butler, A. S. (Eds.). (2007). Preterm birth: Causes, consequences, and prevention. National Academies Press.
- Bitta, M., Kariuki, S. M., Abubakar, A., & Newton, C. R. J. C. (2017). Burden of neurodevelopmental disorders in low- and middle-income countries: A systematic review and meta-analysis. *Wellcome Open Research*, 2, 121. <u>https://doi.org/10.12688/wellcomeopenres.13540.3</u>
- Carnevale, F. A., Rehm, R. S., Kirk, S., & McKeever, P. (2008). What we know (and do not know) about raising children with complex continuing care needs. *Journal of Child Health Care*, 12(1), 4–6. https://doi.org/10.1177/1367493508088552
- Caserta, M. S., Lund, D. A., & Wright, S. D. (1996). Exploring the Caregiver Burden Inventory (CBI): Further evidence for a multidimensional view of burden. *International Journal of Aging & Human Development*, 43(1), 21–34. <u>https://doi.org/10.2190/2DKF-292P-A53W-W0A8</u>
- Esezobor, C. I., Solarin, A. U., & Olagunju, A. T. (2020). Significant burden and psychological distress among caregivers of children with nephrotic syndrome: A cross-sectional study. *Canadian Journal of Kidney Health and Disease*, 7, 2054358119898016. <u>https://doi.org/10.1177/2054358119898016</u>
- Fritz, H., & Sewell-Roberts, C. (2020). Family stress associated with cerebral palsy. In F. Miller, S. Bachrach, N. Lennon, & M. E. O'Neil (Eds.), *Cerebral palsy* (pp. 515–545). Springer. https://doi.org/10.1007/978-3-319-74558-9_213
- Majnemer, A., Shevell, M., Rosenbaum, P., Law, M., & Poulin, C. (2007). Determinants of life quality in school-age children with cerebral palsy. *The Journal of Pediatrics*, 151(5), 470–475.e3. https://doi.org/10.1016/j.jpeds.2007.04.014
- Martínez, C. R., Ramos, N., Robles, M. T., Martínez, L. C., & Figueroa, C. G. (2012). Carga y dependencia en cuidadores primarios informales de pacientes con parálisis cerebral infantil severa (bachelor's thesis). National Autonomous University of Mexico. https://hdl.handle.net/20.500.14330/TES01000671598
- Masefield, S. C., Prady, S. L., Sheldon, T. A., Small, N., Jarvis, S., & Pickett, K. E. (2020). The caregiver health effects of caring for young children with developmental disabilities: A meta-analysis. *Maternal and Child Health Journal*, 24(5), 561–574. https://doi.org/10.1007/s10995-020-02896-5
- Ndu, I. K., Osuorah, C. D. I., Nwaneli, E. I., Ekwochi, U., Asinobi, I. N., Iloh, K. K., & Nduagubam, O. C. (2020). Psychosocial burden of caregivers taking care of children in the children's emergency room of two tertiary hospitals in Southeast Nigeria. *Asian Journal of Social Health and Behavior*, 3(4), 144–151. <u>https://doi.org/10.4103/SHB.SHB_47_20</u>
- Newton, C. R. (2012). Neurodevelopmental disorders in low- and middle-income countries. *Developmental Medicine & Child Neurology*, 54(12), 1072. <u>https://doi.org/10.1111/j.1469-8749.2012.04384.x</u>
- Parkes, J., Caravale, B., Marcelli, M., Franco, F., & Colver, A. (2011). Parenting stress and children with cerebral palsy: A European cross-sectional survey. *Developmental Medicine and Child Neurology*, 53(9), 815–821. <u>https://doi.org/10.1111/j.1469-8749.2011.04014.x</u>
- Rahman, A., Harrington, R., & Bunn, J. (2002). Can maternal depression increase infant risk of illness and growth impairment in developing countries? *Child: Care, Health and Development, 28*(1), 51–56. https://doi.org/10.1046/j.1365-2214.2002.00239.x
- Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S. D., Russell, D., Swinton, M., Zhu, B., & Wood, E. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*, 115(6), e626–e636. <u>https://doi.org/10.1542/peds.2004–1689</u>
- Reis, G. A., Zonta, J. B., Camilo, B. H. N., Fumincelli, L., Gonçalves, A. M. S., & Okido, A. C. C. (2020). Quality of life of caregivers of children with neurodevelopmental disorders. *Revista Eletrônica de Enfermagem*, 22, 59629. https://doi.org/10.5216/ree.v22.59629
- Schaffler-Schaden, D., Krutter, S., Seymer, A., Eßl-Maurer, R., Flamm, M., & Osterbrink, J. (2021). Caring for a relative with dementia: Determinants and gender differences of caregiver burden in the rural setting. *Brain Sciences*, 11(11), 1511. <u>https://doi.org/10.3390/brainsci11111511</u>
- Scherer, N., Verhey, I., & Kuper, H. (2019). Depression and anxiety in parents of children with intellectual and developmental disabilities: A systematic review and meta-analysis. *PLoS ONE*, 14(7), e0219888. https://doi.org/10.1371/journal.pone.0219888
- Thrush, A., & Hyder, A. A. (2014). The neglected burden of caregiving in low– and middle–income countries. *Disability and Health Journal*, 7(3), 262–272. <u>https://doi.org/10.1016/j.dhjo.2014.01.003</u>

- Toledano-Toledano, F., & Domínguez-Guedea, M. T. (2019). Psychosocial factors related with caregiver burden among families of children with chronic conditions. *BioPsychoSocial Medicine*, 13(1), 6. <u>https://doi.org/10.1186/s13030-019-0147-2</u>
- UNICEF. (2020). Producing disability-inclusive data: Why it matters and what it takes. United Nations Children's Fund.
- Walkowiak, D., & Domaradzki, J. (2025). Perception of psychosocial burden in mothers of children with rare pediatric neurological diseases. *Scientific Reports*, *15*, 6295. <u>https://doi.org/10.1038/s41598-025-87251-w</u>

World Health Organization, & World Bank. (2011). World report on disability 2011. World Health Organization.