IP International Journal of Medical Paediatrics and Oncology 2023;9(2):56–61

Content available at: https://www.ipinnovative.com/open-access-journals

IP International Journal of Medical Paediatrics and Oncology

Journal homepage: https://www.ijmpo.com/

Original Research Article

Caregiver burden assessment of children with neurodevelopmental disorders in a tertiary care centre

Amrutha Narayan[1,*], **Ananda Kesavan T.M**[1]

[1] *Dept. of Paediatrics, Government Medical College, Thrissur, Kerala, India*

A R T I C L E I N F O

Article history:
Received 17-06-2023
Accepted 22-06-2023
Available online 12-07-2023

Keywords:
Caregiver burden
Neurodevelopmental delay
Cerebral Palsy
Zarit Burden Interview

A B S T R A C T

Background: Families of children with neurodevelopmental disorders have significant financial and social stressors and difficulties with coordinating medical care. Caregivers play a central role in the rehabilitation of these children.

Materials and Methods: This was a hospital based cross sectional study in the Department of Pediatrics in the year 2021-22 in a tertiary care government hospital in Kerala.Caregiver burden was assessed using Zarit Burden Interview and the clinical profile was assessed using a self made proforma. This was done for 86 children and their caregivers.

Results: A total of 86 children and caregivers were included in the study and the Zarit burden scores were compared between the categories. 55.8% of the caregivers fell into the category of severe burden. Amongst these, in caregivers of children with cerebral palsy, 68% had a burden score of >60 or categorized as severe burden. In cerebral palsy, the burden score of those caregivers of children with spastic quadriparesis showed 81% falling into the category of severe burden.

Conclusion: Caregiver burden continues to be a big concern in our setting where the families are plagued not only by factors affecting the health of their child but also with social and financial burden. Burnout of the caregivers can in turn affect the well being of their children and families.

1. Introduction

In its broadest sense, neurodevelopmental disabilities can include a wide range of disorders with significant overlap and varying causes. These include conditions that affect motor, sensory, cognitive, language and executive functions and social and behavioral disorders.[1,2]

Caregiver burden is related to the well-being of both the individual and the caregiver. Dealing with a differentially-abled child usually leads to a disequilibrium in the family and has its own set of challenges which include physical, social and financial difficulties.[3]

Caring for them requires a multidisciplinary approach – one which takes care of the medical aspects and associated co morbidities like seizures, frequent pneumonia, contractures, malnutrition, behavioural issues and also focuses on their rehabilitation and enabling them to lead a life with the least possible dependence on the caregivers.[4]

Children with established disabilities often have problems with initiating social interactions, expressing their emotions, anger outbursts, responsiveness to others, and they can exhibit unusual behavioral problems – these combined with the other disability related aspects of health can intensify the problems faced by the caregivers.[5]

The gendered aspects of care is very evident in our Indian setup in such cases. Mothers may reduce their workplace commitments, while fathers withdraw from family and

---

* *Corresponding author*.
E-mail address: amruthanarayan1995@gmail.com (A. Narayan).

https://doi.org/10.18231/j.ijmpo.2023.011

invest more in their jobs. Mothers and women in general tend to spend more time doing the household chores and caring for the disabled child irrespective of her employment status.[6] Areas that parents found hardest to cope with included children's physical dependency, lack of mobility, communication difficulties, behaviour and supervision.[7]

Studies have shown that caregivers of children with Down syndrome experience lesser burden than other neurodevelopmental diseases – this is consistent with the theory of Down Syndrome advantage – that is, these children are often easier to parent than other children with intellectual disability. The reason for this has largely been attributed to their behavioural phenotype, including an easy-going temperament, fewer problem behaviours, more compliant responses to others and more cheerful, outgoing and generally positive personality traits.[8–10]

In a study in caregivers of children with epileptic encephalopathy, majority of the caregivers reported heavy burden of care and negative emotional experiences and had a high burden of disease socially, emotionally, functionally, and economically.[11]

2. Materials and Methods

This was a hospital based cross sectional study in the Department of Pediatrics, Government Medical College Thrissur between July 2021 to June 2022. The study population comprised of children between the age groups of 6 months to 12 years with neurodevelopmental disorders and their caregivers attending the outpatient and inpatient care. Caregiver burden was assessed using Zarit Burden Interview and the clinical profile was assessed using a self made proforma. This was done for 86 children and their caregivers. The study was conducted after getting informed consent from the parents of the children.

An Ethical Committee clearance was obtained before the commencement of the study.

2.1. The zarit burden interview

The Zarit Burden interview is a comprehensive tool widely used to assess caregiver burden all over the world. It is a 22-item instrument for measuring the caregiver's perceived burden of providing family care. The 22 items are assessed on a 5-point Likert scale, ranging from 0 = never to 4 = nearly always. The scores of these items are added up to obtain a score ranging from 0 to 88, with higher scores indicating greater burden.[12] The score covers several aspects of the burden including physical,social,financial and emotional. The scale has an internal consistency of 0.93 (Cronbach's alpha) and a test-retest reliability of 0.89. The validity of the scale correlated against burden assessment scale.[12]

3. Results

86 children and their caregivers were included in the studty of which 56.98% of were below 5 years of age with a males preponderance (54.6%). The characteristics of the parents with respect to age and educational status was compared and only 12.79%(n=11) of the mothers had a college degree education. Most of the mothers (93%) were unemployed – of this 39.5% of the mothers had to quit their jobs to look after their children full time. 70.93 % of the families belonged to the Upper lower class according to the Modified Kuppuswamy Classification. 91.89% of the caretakers were mothers and the other group comprised mainly of the grandmothers. Marital discord was there in 19.7% of the families.

60.47% of children had between 1-2 hospital admissions per year. Only 18.6 % of the children had no ICU admissions. 51% of the children had 3 or more total number of ICU admissions.

81%(n=48 of the caregivers experienced severe burden 24 4%(n=21 of the caregivers had mild to moderate burden.

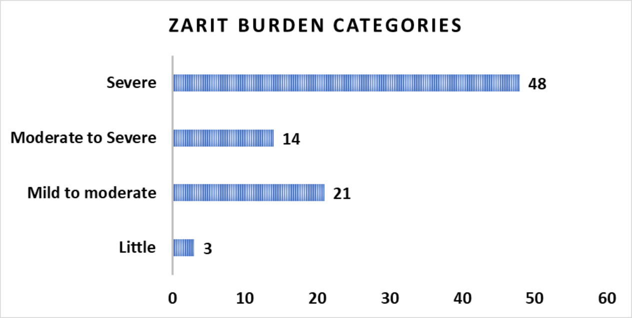

Fig. 1: Zaritburden interview ranges

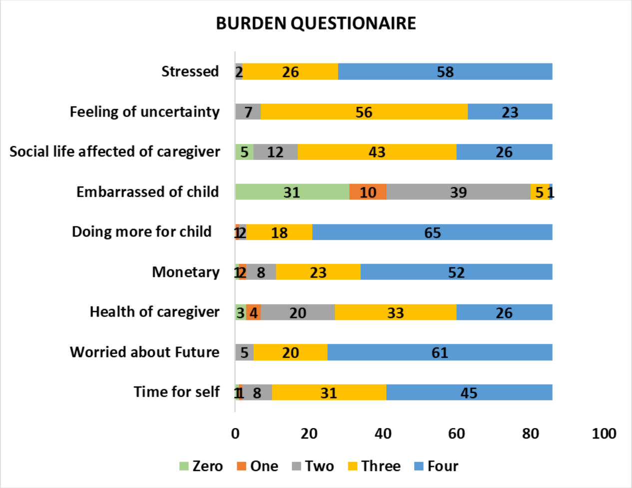

Fig. 2: Distribution of responses to specific questions on theZarit Burden Interview (0 to 4 indicate the scores on the Likert scale of ZBI)

Table 1: Clinicodemohraphical profile

Parameter	Number (n)	Percentage (%)
Age		
<= 5 years	49	56.95
>= 5 years	37	43.02
Sex		
Female	39	45.35
Male	47	54.65
Mother Occupation		
Working	6	6.98
Not working	80	93.02
Mother had to quit Job		
Yes	34	39.53
No	52	60.47
Socioeconomic Status		
Upper Lower	61	70.93
Middle Lower	20	23.36
Lower	5	5.81
Primary Caregiver		
Mother	79	91.86
Others	7	8.14
Marital Status		
Divorced	5	5.81
Married	69	80.23
Separated	12	13.95
Diagnosis		
CNS malformations	3	3.49
Cerebral Palsy	41	47.67
Down Syndrome	26	30.23
Epileptic Encephalopathy	4	4.65
Post Meningitis Sequelae	6	6.98
Neurodegenerative	6	6.98
Cerebral Palsy		
Spastic Quadriparesis	26	30.23
Hemiplegic CP	3	3.49
Hypotonic CP	6	6.98
Spastic Diplegia	6	6.98
Total no of ICU Admissions		
None	16	18.6
1-2	26	30.23
3-5	22	25.58
>5	22	25.58

Several questions of the burden interview were individually assessed and their responses tabulated. Score 0 – (Never); 1(Rarely), 2 (Sometimes), 3 (Quite frequently) and 4 (Nearly always). 52.33% of the caregivers reported that they nearly always felt that they had no time for themselves. 70.93% of the caregivers felt that they were nearly always worried about the future. 38.37% of caregivers felt that their health had been affected —quite frequently. Many of the health issues mentioned included back pain, arm pain and hypertension. Around 21% of the mothers had chronic back pain from carrying their children around.

60.47% of the caregivers were worried about not having enough money. 30 % of the caregivers remarked that their social life had —nearly always been affected.

65.12% of the caregivers most frequently had a feeling of uncertainty about the future. 67.44% of the caregivers felt that they were nearly always stressed.

The burden score between various categories of diagnosis was compared and it was found that the burden score in the cerebral palsy group- 68% had severe burden; in the CNS malformations and epileptic encephalopathy and neurodegenerative groups, 100% of the caregivers had severe burden and none had severe burden in the down syndrome group. It was seen that the burden score in caregivers of children with down syndrome was significantly lower than the caregivers of children with cerebral palsy. The results obtained were statistically significant- by chi square analysis.

The association between the ZBI scores and different categories of cerebral palsy was analyzed was found that 81 % of children with spastic quadripareisis,100 % of those with hypotonic CP and 100 % of those with hemiplegic CP had severe burden. 67% of the children with spastic diplegia had moderate to severe burden and none had severe burden. The was done by fisher's exact test and was found to be statistically significant. The maximum mean burden score was in the spastic quadriparesis group and the minimum in the spastic diplegia group – done by one way ANOVA test and the result was found to be statistically significant.

The association between ZBI scores and total ICU admissions were analyzed by chi-square test and it was found that, higher the number of admissions – higher the burden.

4. Discussion

Caregivers of children with neurodevelopmental disorders experience a range of issues and the domains of burden broadly identified include physical, social, emotional and financial. Several physical problems identified include -back pain, headache ,leg pain, disturbed sleep, fatigue, feeling drained and tired, loss of appetite and weight. Parents can feel embarrassed and ashamed by their child's behaviour when they visit relatives or friends. This results in reduced social contact. Intra - family interactions are also affected adversely.[13] The mental burden of mothers was found to be greater than the fathers- they felt pressure, anger, no personal time for themselves, lagging behind in their relationships and work and also emotionally overburdened and exhausted.[14] Caregivers of children with disability experience more parental stress and anxiety.[15]

The role of caregiving poses a huge financial strain to the family. Cost of medications, repeated hospital admissions, other supportive therapy, paying for travel to and from check ups- the list is endless. In a scenario where one parent is forced to quit the job inorder to be physically present to look

Table 2: Association between ZBI scores and diagnosis (Fisher's exact Test)

Parameter	ZBI score	Number (n)	Percentage (%)	Pvalue (<0.001)
CNS Malformations	<=40	0	0	
	41-60	0	0	
	>60	3	100	
Cerebral Palsy	<=40	3	7	
	41-60	10	24	
	>60	28	68	
Down Syndrome	<=40	20	77	
	41-60	6	23	
	>60	0	0	
Post Meningitis Sequelae	<=40	0	0	
	41-60	1	17	
	>60	5	83	
Epileptic Encephalopathy	<=40	0	0	
	41-60	0	0	
	>60	4	100	
Neurodegenerative	<=40	0	0	
	41-60	0	0	
	>=60	6	100	

Table 3: Association between Cerebral Palsy categories and ZBI scores (Fisher's Exact Test)

Parameter	ZBI	Number (n) and Percentage (%)	Mean Burden Score and (Standard deviation)	P value
Spastic Quadriparesis	<=40	1 (4%)	66.92(11.33)	0.003
	41-60	4 (15%)		
	>60	21 (81%)		
Spastic Diplegia	<=40	2 (33%)	42.67 (11.99)	
	41-60	4 (67%)		
	>=60	0 (0%)		
Hemiplegic CP	<=40	0 (0%)	65.33(2.08)	
	41-60	0 (0%)		
	>=60	3 (100%)		
Hypotonic CP	<=40	0 (0%)	62.17 (7.49)	
	41-60	2 (33%)		
	>=60	4 (67%)		

Table 4: Association between ZBI and total ICU admissions

Total ICU admissions	ZBI	Number	Percentage (%)	P value
None	<=40	12	75	<0.001
	40 to 60	4	25	
	>=60	0	0	
1-2	<=40	10	38	
	40 to 60	7	27	
	>=60	9	35	
3-5	<=40	1	5	
	40 to 60	4	18	
	>=60	17	77	
>5	<=40	0	0	
	40 to 60	2	9	
	>=60	20	91	

after the child, this burden falls heavier. Caregiver parents are expected to absorb the caregiver duties into the parental role and subsequent responsibilities indefinitely.[16]

The burden of caregiving falls mainly on the mother - many of whom while being interviewed complained of minimal or no spousal support other than the financial aspect in caring for the disabled child. In a study by Marcenko et al, it was seen that the majority of the responsibility of caring for the child was taken up by the mother and received only very little emotional or instrumental support, but those who received this help indicated that it was important to them.[17]

In a study conducted by Florian et al, mothers of children with CP reported lower marital adaptation than the control group. It was also seen that more stressful life events were associated with poor mental health and marital adaptation.[18]

The mean Zarit Burden score was compared with the following studies in caregivers of children with cerebral palsy. In the study by Fatih et al, the mean burden score was 49.77[19] and in the study by Shah et al, the mean burden score was 62.6.[20] The mean burden score in our setting was higher than the other two studies – probably because of the lower socio economic status, increased incidence of hospital admissions or a variety of social factors which have not been assessed in detail in other studies.

Parents experienced less than satisfactory time for themselves or for their social life and quoted that whenever they were taking a moment for themselves ,they would feel guilty about leaving their child alone at home or under the care of others.[21] 70.93% of the caregivers were worried about the future of their children. 38.3% of the caregivers noted that they “quite frequently” (Likert scale 3 of Zarit Burden Interview) had health problems. Few of the health problems identified by the mothers included backpain and arm pain from carrying the child over a period of time-similar to other studies.[22]

In cases where the total no of ICU admissions exceeded 5, 91% of the caregivers had severe burden. This was similar to the results seen in an Indian study assessing the caregiver burden in an ICU setup where there was a positive association between ICU admission and the burden perceived by the caregivers.[23]

5. Conclusion

Caregiver burden continues to be a big concern in our setting where the families are plagued not only by factors affecting the health of their child but also with social and financial burden. Burnout of the caregivers can in turn affect the well being of their children and families. The findings of this study have important implications for the provision of services for children with chronic disabilities, such as CP, and their families. There is a pressing need to address their burden and bring out the remedial measures such as better financial support, self help groups, professional and regular counselling sessions, closer intervention centres, better access to centres equipped to deal with these children.

6. Contributions

Dr. Ananda Kesavan conceived the idea, designed the methodology, guided the conduct of the study and critically reviewed the manuscript. Dr. Amrutha collected the data, analysed it and prepared the manuscript. All authors approved the final version of the manuscript.

7. Conflict of Interest

None.

8. Source of Funding

None.

9. Acknowledgement

Government Medical College, Thrissur.

References

1. Purpura G, Tagliabue L, Petri S, Cerroni F, Mazzarini A, Nacinovich R, et al. Burden of School-Aged Children with Neurodevelopmental Disorders: Implications for Family-Centred Care. *Brain Sci*. 2021;11(7):875. doi:10.3390/brainsci11070875.
2. Kenneth S. Swaiman‘s Pediatric Neurology : Principles and Practice (version 5th ed). Edinburgh: Elsevier Saunders; 2012.
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. Sharma R, Garadi S, Kodi SM, Jelly P. The burden of childhood epilepsy and its impact: Parental perspectives. *IP Int J Med Paediatr Oncol*. 2022;8(1):1–5.
5. Spiker D, Boyce GC, Boyce LK. Parent-child interactions when young children have disabilities. In: Glidden LM, editor. International review of research in mental retardation. vol. 25. Academic Press: Elsevier; 2002. p. 35–70. doi:10.1016/S0074-7750(02)80005-2.
6. Leslie LA, Anderson EA, Branson MP. Responsibility for Children: The Role of Gender and Employment. *J Fam Issues*. 1991;12(2):197–210.
7. Pimm PL. Some of the implications of caring for a child or adult with cerebral palsy. *Br J Occup Ther*. 1996;59(7):335–41. doi:10.1177/030802269605900714.
8. El-Deen A, Alwakeel N, El-Gilany AA, Wahba AH. Burden of family caregivers of Down syndrome children: a cross-sectional study. *Fam Pract*. 2021;38(2):159–64.
9. 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.
10. Hodapp RM, Ly TM, Fidler DJ, Ricci LA. Less Stress, More Rewarding: Parenting Children With Down Syndrome. *Parenting*. 2001;1(4):317–37. doi:10.1207/S15327922PAR0104_3.
11. Gallop K, Lloyd AJ, Olt J, Marshall J. Impact of developmental and epileptic encephalopathies on caregivers: A literature review. *Epilepsy Behav*. 2021;124:108324. doi:10.1016/j.yebeh.2021.108324.
12. Seng BK, Luo N, Ng WY, Lim J, Chionh HL, Goh J, et al. Validity and reliability of the Zarit Burden Interview in assessing caregiving burden. *Ann Acad Med Singapore*. 2010;39(10):758–63.
13. Meltzer H, Ford T, Goodman R, Vostanis P. The Burden of Caring for Children with Emotional or Conduct Disorders. *Int J Family Med*. 2011;p. 801203. doi:10.1155/2011/801203.

14. Vassilis B. Burden of parents with children diagnosed with pervasive developmental disorders and behavioural disorders. *Psychol Behav Sci Int J*. 2017;7(2):555710. doi:10.19080/PBSIJ.2017.07.555710.
15. 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.
16. Schuengel C, Rentinck ICM, Stolk J, Voorman JM, Loots GMP, Ketelaar M, et al. Parents' reactions to the diagnosis of cerebral palsy: associations between resolution, age and severity of disability. *Child Care Health Dev*. 2009;35(5):673–80. doi:10.1111/j.1365-2214.2009.00951.x.
17. Marcenko MO, Meyers JC. Mothers of Children with Developmental Disabilities: Who Shares the Burden? . *Fam Relat*. 1991;40(2):186–90. doi:10.2307/585481.
18. Florian V, Findler L. Mental health and marital adaptation among mothers of children with cerebral palsy. *Am J Orthopsychiatry*. 2001;71(3):358–67. doi:10.1037/0002-9432.71.3.358.
19. Yığman F, Yığman ZA, Akyüz E. Investigation of the relationship between disease severity, caregiver burden and emotional expression in caregivers of children with cerebral palsy. *Ir J Med Sci*. 1971;189(4):1413–19. doi:10.1007/s11845-020-02214-6.
20. Shah AN, Prajapati R, Savaliya T, Patel S, Desai D, Sinha A, et al. Zarit burden interview score in caregivers of patients of cerebral palsy and epilepsy. *J Evid Based Med Healthc [Internet]*. 2019;6(44):2869–72.
21. Schmidt J, Schmidt M, Brown I. Quality of Life Among Families of Children With Intellectual Disabilities: A Slovene Study: Quality of Life Among Families. *J Policy Pract Intellect Disabil*. 2017;14(1):87–102.
22. Sharan D, Ajeesh P, Rameshkumar R, Manjula M. Musculoskeletal disorders in caregivers of children with cerebral palsy following a multilevel surgery. *Work*. 2012;41:1891–5. doi:10.3233/WOR-2012-0403-1891.
23. Ramdurg S, Biradar S, Reddy P. Assessing caregiving burden among primary caregivers in a medical intensive care unit setup: Cross-sectional study. *Ind Psychiatry J*. 2021;30(1):36–40. doi:10.4103/ipj.ipj_27_20.

Author biography

Amrutha Narayan, Junior Resident

Ananda Kesavan T.M, Additional Professor

Cite this article: Narayan A, Ananda Kesavan T.M. Caregiver burden assessment of children with neurodevelopmental disorders in a tertiary care centre. *IP Int J Med Paediatr Oncol* 2023;9(2):56-61.