

Psychosocial burden on caregivers of children with cerebral palsy

1. Dr. Peter Anu M*, MD, DNB Pediatrics, Government T D Medical College, Alappuzha

2. Dr. R Parvathy, MD Pediatrics, Government Medical College, Thrissur

Department(s) and institution(s):

Current :Department of Pediatrics, Government T D Medical College, Alappuzha, Kerala

At time of research:Department of Pediatrics, Government Medical College, Thrissur

Current : Amala Institute of Medical Sciences, Thrissur, Kerala

At time of research :Department of Pediatrics, Government Medical College, Thrissur

Corresponding Author : Dr. Anu Marie Peter

E mail id : anumarie@gmail.com Phone number : 9447691401

Address : Assistant Professor of Pediatrics, Govt T D Medical College, Alappuzha – 688005, Kerala

Second Author : Dr. Parvathy R

Email id : drparvathymohan@gmail.com

ABSTRACT

BACKGROUND : Caregiving for a child with Cerebral Palsy is time consuming and stressful, often leading to psychosocial burden and lowering the quality of life of the caregiver.

AIMS:

1. To assess caregiver burden and Quality of life of primary caregivers of children with Cerebral Palsy (CP)

2. To make a comparison of the Quality of life and burden among caregivers of children with different functional levels.

SETTINGS AND DESIGN: A cross sectional study was done on primary caregivers of children with Cerebral Palsy (n=60) on regular follow up in Government Medical College, Thrissur to assess their psychosocial burden and quality of life and its association with child's level of functioning.

METHODS AND MATERIAL: Functional levels were assessed by the GMFCS and MACS scores. The psychosocial burden was assessed using the Zarit Burden Interview and quality of life(QOL) was measured using the WHOQOL-BREF.

STATISTICAL ANALYSIS: Data analysis was done using Chi-square test and student t-test.



RESULTS:

All caregivers were mothers. Two third had moderate to severe psychosocial burden and QOL scores in all domains were low (<50). Mothers of children with poorer GMFCS and MACS scores had more chance of having moderate to severe psychosocial burden (p value-0.001) and had poorer quality of life (QOL) (p value-0.009). Mothers with moderate to severe psychosocial burden had poorer QOL (p value-0.01).

CONCLUSIONS:

Mothers of CP children have significant burden, and interventions to reduce burden and improve quality of life are imperative to reduce stress; which would affect both the child and the caregiver.

Key-words : *Cerebral Palsy; GMFCS; MACS; Psychosocial burden; Quality of life.*

INTRODUCTION

Raising a child with intellectual or physical disability is a challenging task for any parent. This is especially so, when the child is suffering from a condition like Cerebral Palsy where physical as well as cognitive abilities of the child are affected to varying levels [1]. This creates extensive social and economic burden on the caregivers. [2,3]The mother is still expected to fulfill all her usual roles at home, and the stress leads to psychological as well as physical health issues. Studies have identified factors influencing the psychosocial burden to be the disability level of the CP patient as well as the age, marital status and education of the caregiver.[4-6]

Most of the research on the psychological status of the primary care giver in Cerebral Palsy have come from the West whose functioning is totally different from that of our country. The level of awareness as well as the economic support from the State helps to reduce the burden in a developed country. In a country like ours, where there is a significant proportion of the population below the poverty line, the resources available for parents of children with disabilities are few. Estimating the nature of caregiver's problems will lead to better focus on caregiver interventions in the long-term care of disabled children.

Kerala has among the highest literacy rates as well as a well-established public health system[7].No studies have been conducted so far in this set up to assess the burden among mothers of children with CP. This study measured the psychosocial burden of these caregivers; as well as their quality of life. It also looked at the influencing factors with special emphasis on the functional level of the child.

MATERIALS AND METHODS:

This cross-sectional descriptive study was conducted between January 2014 to May 2015 in the Department of Pediatrics, in Government Medical College, Thrissur, a tertiary care institution in Kerala. The study was approved by the Institutional Ethics Committee. Primary caregivers of children with Cerebral Palsy attending the Pediatric Neurology Clinic were recruited after obtaining informed consent. Caregivers of children less than two years of age and caregivers with chronic illnesses were excluded. From a previous study done using WHOQOL BREF and Zarit Burden Interview among caregivers of children with CP in India, the mean and standard deviation in the psychological domain of quality of life was taken for calculation of sample size[8].

Mean = 36.6, SD = 7.35

Sample size = $\frac{Z\alpha^2 \times SD^2}{d^2}$

$z\alpha^2 = 3.84$, SD = 7.35, d is variability, taken as 2.

$$n = \frac{3.84 \times 7.35 \times 7.35}{2 \times 2} = 51$$

Taking a non-responder rate of 10%, sample size is taken as 60.

A total of 60 caregivers were included in the study. The details of affected children including age, gender, SES status, type of CP and disability pension status was collected. The health care needs of the children were assessed in terms of number of hospital visits, need for hospital admissions and chronic medication in the three months prior to interview. The functional status of the children was evaluated using the GMFCS and MACS classification.[9-12]

Caregiver details including age, gender,

education, occupation as well as family support was collected. The caregiver burden of subjects in this study was assessed using the Zarit Burden Interview [13] developed by Zarit, Reever and Bach (1980). This interview schedule contains 22 items, and for each item, caregivers were asked to respond about the impact of the patient’s illness on their life, by indicating how often they felt in a particular way, (“never”, “rarely”, “sometimes”, “quite frequently”, “nearly always”).

The caregiver quality of life was assessed by the WHOQOL-BREF – World Health Organization Quality of Life BREF – Assessment Instrument: short version which contains 26 questions divided into four domains:

- A. *Physical health.*
- B. *Mental health/Psychological*
- C. *Social relationships.*
- D. *Environment*

Each question was assigned an appropriate number of points from 1 to 5 with 1 point denoting very dissatisfied and 5 very satisfied. The mean scores of the questions pertaining to each domain was computed, which gave the raw domain score. The transformed domain score was used for analysis.[14,15]

The socioeconomic status of the caregiver was assessed using the modified Kuppuswamy scale, meant for use in urban Indian population.[16]

Data analysis :Data was analysed using SPSS version 18. Student t test was used for analysis of continuous variables and Chi square test was used for categorical variables.

RESULTS:

A total of 60 caregivers were enrolled. Of the sixty affected children, there was an almost equal male-female distribution. The study included

children with ages from two to eighteen, and 50% belonged to the five to ten years age group. Majority belonged to the upper lower socio economic class (60 percent) followed by upper middle class (37 percent) . Among the different types of Cerebral Palsy, Spastic quadriplegia (32 percent) and spastic hemiplegia (28 percent) followed by spastic diplegia (20 percent) were the most common while choreoathetoid CP was the least common (3 percent). Under the GMFCS, 27 out of the sixty children belonged to Level 5, and 25 of these children had a level five MACS as well (Table 1). Because these children have poor functioning ability, they were bedridden and required caregiver support for all activities of daily living. Only 50% of the children were receiving state provided disability pension.

Table 1: GMFCS and MACS levels of CP children

Levels	GMFCS		MACS
	Frequency	Percentage	Frequency
1	10	16.67	13
2	15	25	12
3	2	3.33	5
4	6	10	5
5	27	45	25
Total	60	100	60

17 percent of the children required frequent medical attention; atleast one visit per month. Around 40 percent of children required hospital admissions in the last 3 months with an average duration of stay of 5.6 days. The average expenditure of hospital stay was Rs. 2900. 75 percent of children were on regular medication; most of the time, the children were on anti epileptic drugs. Average cost of medicines for a month was around Rs. 300.

All the sixty primary caregivers in this study were mothers; and 60% of them were above 30 years of age. 77 percent caregivers had completed secondary education. Ten of these mothers had done graduation level studies and one had completed her post graduation. There were no illiterate mothers. Only around 17 percent of the mothers were employed; and more than half of them had only part time jobs. Seven of the mothers had given up their jobs and six of them had to cut down on working hours in order to look after the disabled child. The average income was Rs. 2000 per month. The state government aided caregiver pension was being procured by only 18 mothers. Although almost all of them were aware of this provision, they reported that the application process was tedious and they were kept waiting for more than a year before the amount got sanctioned. The payment was also reported to be irregular.

In majority of households, the spouse of the caregiver was the head of the household. Most of the caregivers were living in their own homes (90 percent) and there was overcrowding in more than half of the households. In our study, 70 percent of mothers had support from other family members in caring for their child, commonly the husband or mother-in-law. However, the help was available only for an average of two hours per day and the bulk of the caregiving was still

being handled by the mother alone. None of the caregivers had paid help- night or day.

1. Caregiver Burden

The caregiver burden assessed using the Zarit Burden Interview divides the caregivers as those with no burden, mild, moderate or severe burden. In the study group, 58 percent of mothers had moderate caregiver burden and 6 percent had severe burden ie almost two third of mothers had moderate to severe burden (Table 2).

Table 2: Caregiver Burden

Severity of burden	Frequency	Percentage
No burden	2	3.3
Mild burden	19	31.7
Moderate burden	35	58.3
Severe burden	4	6.7
Total	60	100

A positive association was seen between higher level of GMFCS and severity of caregiver burden. The difference between the two groups were highly significant with a p value of 0.001. (Table 3). Mothers of children with poorer MACS(3,4,5) had more probability of having moderate or severe burden. (p value of 0.001). In our study, no significant association was found between the primary caregiver's educational or occupational status and caregiver burden.

Table 3 : Caregiver Burden vs GMFCS and MACS

	Caregiver Burden			
GMFCS	No burden	Mild burden	Moderate burden	Severe burden
Level 1& 2	2	15 (79%)	9 (20%)	1 (25%)
Level 3,4,5	0	4 (21%)	26(80%)	3(75%)
Total	2	19	35	4
Chi Square - 17.198		p value: 0.001		
MACS	No burden	Mild burden	Moderate burden	Severe burden
Level 1& 2	2 (100%)	14 (74%)	8 (22%)	1 (25%)
Level 3,4,5	0	5 (26%)	27 (78%)	3 (75%)
Total	2	19	35	4
Chi square-16.365		p value : 0.001		

2. Quality of Life

The transformed mean score in all domains were less than 50 indicating a less than satisfactory quality of life. The worst affected was the psychological domain indicating a psychological stress related to the child’s condition (Table 4).It was found that mothers with moderate to severe burden had lower domain scores indicating

poorer quality of life. The Quality of life of the caregiver was better in all four domains when the child had good gross motor functioning (GMFCS 1&2); highly significant in the physical and psychological domains. Better fine motor functioning of the child caregivers had a better quality of life in all domains (Table 5). Caregiver Quality of life had no correlation with caregiver’s education or occupational status.

Table 4: Mean domain scores and Standard deviation

Domains	Mean ± SD	Max - Min scores
Physical health	48.03 ± 10.9	78.5 - 25
Psychological	39.79 ± 11.02	70.8 - 16.6
Social Relationships	42.77 ± 12.9	66.6 - 16.6
Environmental	41.9 ± 11.6	59.4 - 21.8

Table 5: Quality of life and functional classification

Domains	GMFCS 1&2 mean score (n = 25)	GMFCS 3,4,5 mean score (n = 35)	df	t test value	p value	
Physical	52.43	44.89	47	2.01	0.009	
Psychological	45.83	35.47	48	2.01	0.0002	
Social	46.67	40	43	2.02	0.06	
Environmental	44.63	41.69	45	2.03	0.39	
Domains	MACS 1&2 Mean(n=25)	MACS 3,4,5 mean(n=35)	df	t test value	p value	
Physical	53.43	44.18	47	2.01	0.001	
Psychological	46.33	35.12	47	2.01	0.00007	
Social	47.67	39.28	43	2.02	0.01	
Environmental	46.5	40.36	33	2.03	0.06	

Discussion:

The study found an almost equal male-female ratio among subjects. The most common types of CP were spastic quadriplegia and spastic hemiplegia. In a study done in 2002, Singhi PD had reported that spastic quadriplegia was the most common, suggesting no major changes over the past 15 years. [17]

The process of application for disability pension is tedious, as a result of which many of the children do not receive eligible support. There is a need for swift action from the policymakers in order to help improve the lives of children affected with chronic illnesses.

All the sixty caregivers enrolled in the study were mothers of the affected children. Though the spouse was the head of household in the majority, mothers had the lion’s share of responsibility in looking after children as well as managing household chores. This can be taken as a reflection of the patriarchal type of society prevalent in our

country. The youngest mother was 22 and the eldest 42 with a mean age of 32.5 years.

In contrary to the rest of the country, Kerala is acknowledged for its high literacy rate and abundance of educational institutions. 77 percent of the caregivers in this study had completed secondary level education and almost 20 percent had done higher education.

The task of caregiving for a child with disability is in itself a full time responsibility and when there is no other caregiver, an additional job is almost impossible. This could explain the low rate of employment among our study group. None of the mothers who had children with GMFCS level 5 could work; indicating the increased time demands in caring for such a child.

Mbugua[18] had identified unemployment as a risk factor for maternal depression. In this study, most of the mothers with moderate or severe burden were unemployed but the difference was not found to be significant.

The state government provides a monthly pension to caregivers of the chronically ill[19], but only 30 percent of mothers were receiving this pension. The process of application and its approval is a long drawn process and very often the mother is unable to follow it up due to the other demands on her time, leading to delay in availability of pension. Making this process an easier and transparent one could go a long way in helping these mothers.

Management of Cerebral Palsy is multidisciplinary with rehabilitation through physiotherapy, occupational therapy and drugs for management of complications. We found that this leads to a heavy burden on the caregiver, both physical and economic with hospital admissions are an additional burden. Khanna [20] and Vadivelan [2] have described similar findings.

Majority of the study group had significant psychosocial burden and this indicates the need for effective interventions to reduce the burden, as this has been proven to have a negative impact on both the caregiver as well as the child [3,5]. This could be done by forming peer groups where problems could be discussed and issues addressed.

There was a significant positive association between the caregiver's burden and level of the child's disability as measured by MACS and GMFCS. Previous investigators have found conflicting results in this regard. Glenn[21], Marx[22] and Wallander[23] had reported no significant difference in caregiver stress based on the child's GMFCS levels while Basaran [24] found a significant difference in caregiver depression with poorer functioning abilities of the child. Chavez also described a worsening of burden with severe disability [3]. Most of the studies which could find no significant difference are from Western literature where there is an

efficient state run support system for children with disabilities, as well as their caregivers. The major issue in those settings would be understanding the child's prognosis rather than the day to day exertion which mothers in our setting have to face.

Relationship of other factors like caregiver education, caregiver occupation, informal help and availability of pension with the caregiver burden was assessed. Gambhir [25] had found that higher levels of education led to a favorable attitude to Cerebral Palsy. Chavez [2] described an increased burden in caregivers with less than secondary level schooling, but our study found no significant difference based on level of education in terms of caregiver burden.

The caregivers in our study had a poor quality of life. Adenuga[26] had reported poorer QOL in CP caregivers and had found physical health, social relationships and environmental health to be more affected. Similar findings have been reported by Basaran[24], Ones [27] and Pandit [28]. Pruthi [8] had published similar results in a comparison study of caregivers of children with Cerebral Palsy, Thalassaemia and no major illnesses. However, a few studies reported a good Health Related QOL in caregivers of CP children [29].

Psychological domain was the worst affected. Mothers with moderate or severe caregiver burden had poorer quality of life in all domains, with significant difference between the two groups. This proves that there is a negative association between quality of life and caregiver burden, which emphasizes the need for interventions to reduce the caregiver burden and thereby improve their quality of life.

The caregivers of children with better GMFCS and MACS scores had a better quality of life in all

domains. With respect to GMFCS, the difference was significant in the physical and psychological domains which appear to be more affected due to the caregiving role. Similar findings were reported by Sonune et al [30]. Physical, psychological and social domains were significantly affected when the child had poor MACS scores. Previous investigators had looked into this relationship with respect to GMFCS. Adenuga [26] had found that physical health, social relationships and environmental health were more affected.

To summarize, caregivers of children with CP

have significant psychosocial burden and poor Quality of life. The medical community has to recognize the need to take care of not only the child, but also the mother.

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