

Care Burden of Care Givers of Children with Cerebral Palsy

Sibin Joy Vayalil^{1*} and Jayarani Premkumar²

¹Lourdes College of Nursing Kochi (Kerala), India

²Indian Nursing Council Consortium, CMC Hospital, Vellore (Tamil Nadu), India

Abstract

The purpose of the study was to assess the care burden among caregivers of children with cerebral palsy. The presentation of cerebral palsy can be global, mental and physical dysfunction or isolated disturbances in gait, cognition, growth, or sensation. It is frequently frightening for the family to hear the diagnosis of cerebral palsy. It excites powerful emotions in both parents. It reshapes the organization of the family. Unfortunately, in Kerala, special schools and rehabilitation centers exclusively for children with cerebral palsy are very few in numbers. Children with cerebral palsy are in most cases, clubbed along with mentally retarded children. Until now, very few studies were reported on the care burden of care givers of children with cerebral palsy from this southern state of India. The care givers are heavily involved in self-care activities which may add an additional challenges and stress to the care givers. The study was conducted in selected rehabilitation centres in Kerala. The research design used was quasi experimental pre-test post-test control group design. The study sample comprised 100 care givers of cerebral palsy children. Subjects were selected with total enumeration sampling method. The care giver-child social and emotional relationship was assessed by structured observation. The care burden was assessed by care burden assessment tool. It was a self-rating five point scale. The reliability of the tools were developed by interclass correlation coefficient (0.90) and Cronch's alpha (0.82) respectively. Majority of caregivers had weak bonding, (82%) and (84%) in experimental and comparison group respectively. None of the subjects had strong social and emotional relationship with their children. There is significant association between care burden of caregiver's of children with cerebral palsy and selected back ground variables of child, birth order ($F^2=11.64^*$, $p=0.020$) and ability to walk independently ($F^2=6.93^*$, $p=0.031$). Two weeks after the intervention there is significant difference in the care burden level between the experimental and comparison group. (Z score=2.9**, $p=0.004$). Two weeks after the intervention the mean score is (33.2) and (47.8) in experimental group and comparison group respectively with (Z score=7.62**, $p=0.001$). Three months after the intervention the mean score becomes (20.3) and (47.4) in experimental group and comparison group respectively with (Z score=8.29**, $p=0.001$).

Keywords: Cerebral palsy, care burden, care givers, nursing interventions

***Author for Correspondence:** Email ID: sibirrejee@yahoo.co.in

INTRODUCTION

The presentation of cerebral palsy can be global, mental and physical dysfunction or isolated disturbances in gait, cognition, growth, or sensation. A common misconception about those born with

cerebral palsy is that they are less intelligent than those born without it. It is frequently frightening for the family to hear the diagnosis of cerebral palsy. It is important for families to understand the vast spectrum of cerebral palsy ^[1].

According to World Health Survey and Global burden of disease the disability rate as in the year 2010 below fifteen years 5.04 billion and above fifteen years it was 1.86 billion. But in the year 2004 it was 975 million and 785 million respectively [2]. According to 2001 census disability statistics in India 2.1% of the population had different kinds of disabilities far behind WHO figures of 5 to 10%. But as per UN around 10% of the Indian population was disabled.

Global burden of disease estimates moderate and severe prevalence are 11% higher for females than males. Burden of disability for children (0–14 years) is expressed as 5.1% (93 million) suffering with moderate to severe disability and 0.70% (13 million) with severe disability [3]. Gupta conducted a study in the cities of New Delhi and Faridabad regions of Northern India through six non-governmental organizations (NGOs) that serve children with disabling conditions. The purpose of the study was to determine the parenting stress and its determinants among parents of children with disabling conditions in India. The Parenting Stress Index short form and a few open ended questions were administered to a convenience sample of 66 patient families in July, 2009. The results showed that female sex of the child ($F=0.52$, $\text{sig}=0.76$) was associated with higher stress related to failure of the child to meet parent's expectations and to satisfy the parents in their parenting role. Parents engaged in more lucrative and prestigious occupations had more stress than parents engaged in less prestigious and lucrative occupations irrespective of their income. Occupation of the parent was significantly correlated with parental distress and total stress after adjustment for joint family status, education of the parents, and sex of the child ($T=2.84$, $\text{sig}=0.006$, $T=2.13$, $\text{sig}=0.037$) [4].

Glenn conducted a randomized controlled study to investigate factors predicting

parenting stress in mothers of pre-school children with cerebral palsy. The sample consisted of 80 children with CP and their mothers referred from 11 child development centres in the north-west of England. Mothers completed the Parenting Stress Index (PSI) and the following measures of family functioning: family support, family cohesion and adaptability, coping strategies, family needs and locus of control. Children were assessed using the Griffiths Scales and the Gross Motor Function measure. The child's home environment was assessed using home observation for measuring the environment. Study results revealed that high scores were significantly correlated with high family needs ($r=0.58$, $P=0.000$), high maladaptive coping ($r=0.25$, $P=0.041$), high life stressors ($r=0.26$, $P=0.032$), low family cohesion ($r=-0.27$, $P=0.024$), low family adaptability ($r=0.32$, $P=0.007$), external locus of control ($r=0.35$, $P=0.003$). In multiple regression, a set of three factors emerged as significant, with 33% of the variance in total stress accounted for by family needs ($\text{beta}=0.489$, $P=0.000$), 6.5% by family adaptability ($\text{beta}=-0.325$, $P=0.001$) and 5.7% by cognitive impairment ($\text{beta}=-0.266$, $P=0.006$) [5].

STATEMENT OF THE PROBLEM

A Study to assess the effect of nursing intervention on the care burden of the care givers of children with cerebral palsy in selected rehabilitation centers of Ernakulum District, Kerala.

OBJECTIVES OF THE STUDY

1. To assess the care burden of caregivers' of children with cerebral palsy by using care burden assessment scale.
2. To evaluate the effect of nursing intervention on the care burden of caregivers of children with cerebral palsy by comparing the post test scores of experimental and comparison group.

- To find the association between the care burden and selected demographic variables.

ASSUMPTIONS

- Cerebral palsy is a non-curable disease.
- Children with CP are at increased risk of behavioural and emotional problems and their parents experience increased parental stress.
- The implementation of nursing interventions can reduce the caregiver's burden and enhance the quality of life of caregivers.

HYPOTHESES

All hypotheses will be tested at the level of 0.05 level of significance.

- The care burden of the care givers of children with cerebral palsy in the experimental group will be lesser than the comparison group.
- There will be significant association between the care burden of caregiver's of children with cerebral palsy with selected demographic variables

METHODOLOGY

Research Approach

The researcher used a quantitative experimental approach in the present study.

Research Design

In this study the researcher adopted a quasi-experimental pre-test post-test control group design. The symbolic representation of the study was as follows,
 $O_1 \times O_2$
 $O_3 \quad O_4$

Variables

The variables under the present study were: independent variable: nursing intervention; dependent variable: care burden; and socio-demographic variables of child and care giver.

Setting

Selected rehabilitation centers at Ernakulam district.

POPULATION

Target Population

Care givers of children with cerebral palsy residing in Ernakulam district.

Accessible Population

Care givers of children with cerebral palsy in selected rehabilitation centers at Ernakulam district

Sample

100 Care givers of children with cerebral palsy between three and ten years of age were taken.

Sample Selection Criteria

Inclusion Criteria

The care giver is a person who is:

- A person who cares the children with cerebral palsy between the age group of three and ten years of age.
- A close relative either father, mother or grandparents who takes care of the child with cerebral palsy.
- Taking care of the child for more than six months.
- Support the child in all their needs in the day care.
- Living with the child.
- Willing to disclose their unique experiences.

Exclusion Criteria

Care givers who care the children with cerebral palsy between the age group of three and ten years of age having associated problems like mental retardation, epilepsy etc.

Sampling Technique

Total enumeration sampling.

Instruments

Tool I: Background information of caregiver and child.

Tool II: Observational checklist to assess the care giver-child social and emotional relationship.

Tool III: Self-reported rating scale to assess the care burden.

Reliability of the Tool

The tool II reliability was developed by interclass correlation co-efficient. It was 0.90. Tool III reliability was developed by Cronbachs Alpha, It was 0.82.

Ethical Considerations

Ethical clearance was obtained from the institutional ethics committee followed by permission from the rehabilitation centres. Informed written consent was obtained from the subjects; they were assured of the confidentiality and anonymity of the information provided.

Data Collection Process

Data collection was started after obtaining permission from Institutional Ethics Committee and rehabilitation centers' authority. The experimental and comparison group was selected by random assignment. Based on sample selection criteria, 50 subjects were selected from experimental and comparison group by total enumeration sampling. Total sample size was 100. The investigator introduced herself, and the objectives of the study were explained to each subject. Individual informed consent was obtained from the subjects after explaining the objectives and purposes.

In both experimental and comparison group the respondents were assured anonymity and confidentiality of the information provided by them. Data collection was in Malayalam and doubts were clarified after each question. The nursing intervention, which includes needs of care recipients, causes of caregiver stress, warning signs of high stress, barriers to manage stress, steps to prevent caregiver burn out and coping skills for caregivers was implemented immediately

after the pre-test. The duration of the session was two hours. The session was repeated after one week. The post-test one was conducted after two weeks of the intervention. The post-test two was conducted three months after the intervention.

RESULTS

The data was compiled and analyzed using descriptive and inferential statistics. The analysis of the data are organized and presented as:

Socio Demographic Background of Care Giver and Characteristics of Children with Cerebral Palsy

Majority of the sample (64%) in experimental group and (60%) in comparison group fell in the category of 30 to 39 years. Out of the total sample (20%) of the subjects have professional education in comparison group, whereas (14%) only in experimental group. Taking into account the monthly income (34%) of the caregivers in the experimental group have 5000 to 10,000 whereas (46%) subjects in comparison group have more than 20,000 monthly income. On the total of 100 subjects (60%) of the subjects in experimental group belong to Hindu religion, at the same time (40%) in comparison group are Christians.

Regarding type of family both the group are equally distributed such as (54%) of caregivers have nuclear family and (56%) have joint family in comparison group. Considering the number of children (50%) of care givers in both groups have two children. For majority of caregivers the main source of knowledge was from rehabilitation centers (68%) and (62%) in experimental and comparison group respectively.

The analysis of the characteristics of children with cerebral palsy depicts that, majority of the children (48%) in

experimental group and (54%) in comparison group fell in the category of 3 to 5 years. When coming to the type of cerebral palsy, spastic cerebral palsy is more prevalent in experimental and comparison groups (54%) and (44%) respectively.

In both group children have diplegic cerebral palsy, (50%) in experimental group and (60%) in comparison group. While out of the total children (68%) of the children in experimental group and (62%) in comparison group are male.

Taking into account the ordinal position of the child (54%) in the experimental group and (66%) in comparison group children are the first child in their family. Considering the use of medication (34%)

of children in comparison group is not taking any prescribed medications, whereas (52%) of children are taking antispasmodics in experimental group and (64%) in comparison group is taking anticonvulsants.

Regarding the ability to walk independently majority in both the group are unable to walk independently, (94%) in experimental group and (80%) in comparison group. Majority of children are getting frequent episodes of respiratory infections (62%) and (64%) in experimental and comparison group respectively.

Assess the Care Burden of Care Givers of Children with Cerebral Palsy

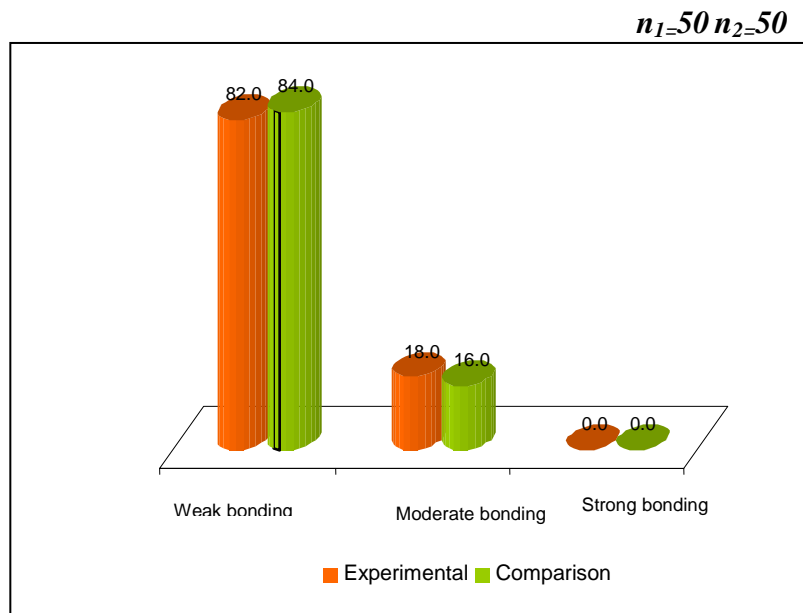


Fig. 1: Distribution of Caregiver-Child Social and Emotional Relationship Based on Group.

Figure 1 depicts the distribution of caregiver-child social and emotional relationship. Majority have weak bonding, 82 and 84% in experimental and

comparison group respectively. None of the subjects have strong social and emotional relationship with their children.

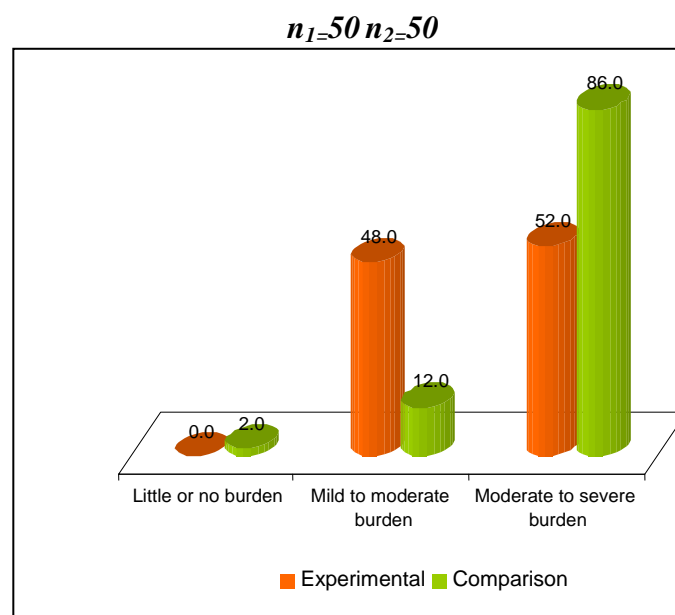


Fig. 2: Distribution of Care Burden Based on Group.

Figure 2 depicts the distribution of care burden of caregivers. Majority (86%) of caregivers have moderate to severe burden, whereas (52%) in experimental group. About (48%) caregivers in experimental have mild to moderate care burden, but in comparison group (12%) only. None of the caregivers fell in the category of little or no care burden, whereas (2%) of comparison group has little or no care burden.

Effect of Nursing Intervention on Care Burden of Caregivers of Children with Cerebral Palsy

The effect of intervention on care giver-child social and emotional relationship was assessed by Mann-Whitney U Test. Two weeks after the intervention there is significant difference in the caregiver-child bonding between the experimental and comparison group. (Z score = 3.17**, $p = 0.002$). The caregiver-child bonding in experimental group becomes stronger than the comparison group three months after intervention. (Z score = 8.25**, $p = 0.001$).

So the null hypothesis is rejected and the research hypothesis the care giver-child social and emotional relationship in experimental group will be higher than the comparison group is accepted.

Table 1 depicts the effect of intervention on care burden of caregivers of children with cerebral palsy. Two weeks after the intervention there is significant difference in the care burden level between the experimental and comparison group. (Z score = 2.9**, $p = 0.004$). Two weeks after the intervention the mean score is (33.2) and (47.8) in experimental group and comparison group respectively with (Z score = 7.62**, $p = 0.001$). Three months after the intervention the mean score becomes (20.3) and (47.4) in experimental group and comparison group respectively with (Z score = 8.29**, $p = 0.001$). So the null hypothesis is rejected and the research hypothesis the care burden of the care givers of children with cerebral palsy in the experimental group will be lesser than the comparison group is accepted.

Assessment	Group	Mean	Median	SD	Z#	p
Pre test	Experimental	43.2	43.0	7.0	2.9**	0.004
	Comparison	46.2	46.0	8.3		
2 Weeks after intervention	Experimental	33.2	32.5	5.1	7.62**	0.001
	Comparison	47.8	48.5	8.2		
3 Months after intervention	Experimental	20.3	20.0	3.7	8.29**	0.001
	Comparison	47.4	48.0	8.2		

#Mann-Whitney U Test.

** Significant at 0.01 Level.

Association between the Care Burden of Caregiver's of Children with Cerebral Palsy and Selected Demographic Variables

The association between caregiver-child social and emotional relationship and selected socio demographic variables of care giver was analyzed by χ^2 . Except number of children ($\chi^2=9.04^*$, $p=0.001$) none of the socio demographic variables have significant association with caregiver-child social and emotional relationship. On account of association between care burden of caregiver's of children with cerebral palsy and selected back ground variables of care givers, except religion ($\chi^2=15.81^{**}$, $p=0.003$) none of the background variables have significant association with care burden of caregivers. Whereas, analyzing the association between care burden of caregiver's of children with cerebral palsy and selected back ground variables of child, there is significant association with birth order ($\chi^2=11.64^*$, $p=0.020$) and ability to walk independently ($\chi^2=6.93^*$, $p=0.031$).

DISCUSSION

It is commonly believed that parents of children with disabilities have high levels of stress associated with parenting. However, Byrne and Cunningham (1985) argued that many studies assumed, and so focused on finding stress, but failed to look at those families that did not experience heightened levels of stress. Majority (86%) of caregivers in comparison group have moderate to severe burden, whereas (52%) in experimental group. About (48%) caregivers in experimental have mild to moderate care

burden, but in comparison group (12%) only. None of the caregivers in experimental group fell in the category of little or no care burden, whereas (2%) of comparison group have little or no care burden. The study result was supported by Glenn [5]. In this study high stress items were role restriction, isolation and poor spouse support, and having a child who was perceived as less adaptable and more demanding. There was significant association between care burden of caregivers and religion ($\chi^2=15.81^{**}$, $p=0.003$). Many researchers from India have reported that people often find relief in religious propitiation and surrender to the will of God when faced with intractable disease and disability [6, 7]. Since people often turn to religion, it may be advisable for religious institutions and preachers to be trained to provide pastoral counselling to help families cope with the condition of disability.

The amount of stress and the lack of support measures in the family may in turn affect not only the condition of the child, but the family as a whole. The severity of an intellectually disabled child's condition impacts his or her ability to engage in daily living activities. The family needs to spend more time; energy and money to take care of their child, thus, the level of caregiver strain will be higher. The present study results revealed this. There is significant association between care burden and ability to walk independently ($\chi^2=6.93^*$, $p=0.031$).

This was supported by study results of Tsai and Wang [8]. The dependent degree

of daily living activity of the children had a positive correlation with strain, indicating that the mothers who had children with a higher dependent degree of daily living activity perceived a higher level of strain ($r = 0.250^{**}$, $p = <0.01$). The present study result shows that the nursing intervention was effective for reducing care burden of caregivers of children with cerebral palsy. Two weeks after the intervention there is significant difference in the care burden level between the experimental and comparison group. (Z score = 2.9^{**} , $p = 0.004$).

Two weeks after the intervention the mean score is (33.2) and (47.8) in experimental group and comparison group respectively with (Z score = 7.62^{**} , $p = 0.001$). Three months after the intervention the mean score becomes (20.3) and (47.4) in experimental group and comparison group respectively with (Z score = 8.29^{**} , $p = 0.001$). The specific sources of parenting stress among parents of different socioeconomic status should be explored in future studies so that appropriate interventions can be planned.

CONCLUSION

While parenting stress has been studied in many developed countries, few formal studies have been conducted in developing countries. Shortage of resources, including food, medication, durable medical equipment, and apparel can add to the stress of raising children with disabilities. In conditions of poverty, a child with a disability is regarded as a burden, an evil spirit, and an object of charity without rights, rather than as an unfortunate child^[9]. Present study sheds light on the wide range of social and psychological problems experienced by the care givers of children with CP. While planning a family-centred program for such children, these problems should be considered and addressed in order to make care of the child more effective.

REFERENCES

1. The Truth about Cerebral Palsy. Available from: URL: E:/cerebral palsy% 20 palsy %20 india.htm.
2. Summary World Report on Disability. <http://www.who.int/disabilities/world-report/2011>.
3. Disability Statics in India. www.india.gov.in/social-sector/social-vulnerable.../persons-with-disability-2001
4. Vidya Bhushan Gupta, Priyanka Mehrotra, Naveen Mehrotra. Parental Stress in Raising a Child with Disabilities in India. *www.eparent.com/EP Magazine*. Dec 2012; 42–46p.
5. Glenn S, Cunningham C, Poole H, *et al*. Maternal Parenting Stress and its Correlates in Families with a Young Child with Cerebral Palsy. *Child Care Health Dev*. 2008; 35(1): 71–80p.
6. Dalal AK. Living with Chronic Disease: Healing and Psychological Adjustment in Indian Society. *Psychol. Dev. Soc. J*. 2000; 12: 67–82p.
7. Brown I, Anand S, Fung A, *et al*. Family Quality of Life: Canadian Results from an International Study. *J. Dev. Phys. Disabil*. 2003; 15(3): 207–230p.
8. Shu-Mei Tsai, Hsiu-Hung Wang. The Relationship between Caregiver's Strain and Social Support among Mothers with Intellectually Disabled Children. *J. Clin. Nurs*. 2009; 18: 539–548p.
9. Pal DK, Choudhury G. Preliminary Validation of a Parental Adjustment Measure for Use with Families of Disabled Children in Rural India. *Child Care Health Dev*. 1998; 24: 315–324p.