

## **Family Burden on Parents of the Children with Cerebral Palsy: Effectiveness of the Family Centered Psycho-Social Intervention Programme**

<sup>1</sup>Rathna kumari. S, <sup>2</sup>Dr. Mary Venus Joseph

<sup>1</sup>*Social Scientist Department of Community Health St. John's Medical College Bangalore, Karnataka 560034, India*

<sup>2</sup>*Dean and Administrative Officer Rajagiri School of Social Work, Kalamessery, Kochi Kerala 683104. India*

---

**ABSTRACT:** *This study was to measure the effectiveness of family centered psycho-social intervention on family burden among the parents of the children with cerebral palsy. A quasi experimental research design without control group was used. Parents were chosen using simple random technique from the list of children in the age group of 1-12years with cerebral palsy registered, in a tertiary care hospital for treatment. Study was carried out during June to November 2013. Data was gathered in two phases. The intervention package included the following: i. group interactive sessions on prevention and coping skills of family burden. ii. Individual and family counseling sessions to the parents and family members. Using SPSS version 17, frequency of variables, mean, standard deviation; paired 't' test and Cohen's 'd' tests were applied to find the outcome. Among the parents most of them (88.6%) were mothers. More than one third (37.1%) parents were between the age group of 26-30years. Most of the parents (91.4%) were living with their family. More than half (65.7%) of parents had consanguineous marriage. The standard of living index indicated almost half (48.6%) of the parents were from lower socio economic background. Paired sample 't' test indicated significant reduction in the level ( $t=2.95$ ,  $p<0.001$ ) of family burden. There was a very small positive effect ( $d=0.08$ ) after the intervention program on the group of parents. It showed that family centered psycho social intervention was effective in reducing family burden of the parents of the children with cerebral palsy. This intervention program was to prevent psycho-social health problems of the parents with cerebral palsy. Comparative studies were needed to ascertain the efficacy of this intervention.*

**Key words:** *Cerebral palsy, Counseling, Family burden, psycho-social intervention.*

---

### **I. Introduction:**

Damage to the brain can have a major effect on an individual. Cerebral palsy (CP) is a chronic condition defined as a group of functional limitations due to the damage in the development of central nervous system (Rethlesfsen, et al 2010). The world incidence of CP was estimated between 2 to 2.5 cases per 1000/live births (Blair 2010). Loco motor malformation is the main limitation of CP, it is also characterized by the cognitive, sensory and social developmental limitations. These limitations lead to significant influence on self care activities like eating, mobility, clothing, and personal hygiene. Therefore, Raina (2005) described in his study that CP can be considered as a unique type of disability in childhood. Care of these children, require more attention and longer duration of care compared to the care of normal children. It results in burden on parents and family. Excessive responsibility can adversely affect their physical, psychological and social health (Brehout et al, 2009, Desmong and Surrency, 2009). It also affects parent's social, cultural and professional lives (Grootenhuis and Bronner 2009). It may be subjective or objective factors. Considering these factors, intervention program can be developed and implemented to bring positive changes among the parents. Researchers found parents of the children with disabilities likely to experience more burdens (Olsson and Hwang 2001, Segur et al 2008) compared to the parents of normal children. (Barlow et al 2006; Button et al, 2001). The symptoms of burden leads to various kinds of problems among care givers.

Support by partners and related family members have been shown to greatly influence the well-being of parents for children with disabilities. According to Bennett, DeLuca, and Allen (1995), in the family life cycle, all the parents in different stages perceived family members and close friends as the main source of emotional support. Parents also perceived and experienced peer or parent support groups from outside family to be the greatest resources of social support that they receive. These groups can be a social and emotional source of support, as well as a source of getting different information, adopt coping skills and share management techniques to care for their child with multiple impairment disabilities. Some of the parents experience different kinds of burden in the family which could be affected by the level of support they get from family members or

due to the levels of frustration and support services they get for their child. The more support they receive from parents, the greater was the impact on the perception, functioning and coping with their burden.

Author has been working in preventive and social medicine in a Medical College at Bangalore Karnataka, India. Having been worked in community level with the patients of chronically and terminally ill and parents of the children with special needs made her to conceive the idea of investigating, family burden among the parents of the CP children. She perceives care giving as a process that causes different kinds of burden on caregiver, parents develop emotional burden, neglect their self care due to lack of perceived social support. They encounter difficulties in managing needs and responsibilities of the family. There are many psycho social domains other than medical intervention that requires parents to understand their care receiver's condition and different areas to intervene as well. She felt the need for implementing intervention using the techniques of medical and psychiatry social work to enable parents to reduce their family burden.

The expected outcome of the intervention program is reduced level in family burden of the parents with cerebral palsy children. This will enhance the strength of the parents in providing better care to their children as care receivers. The importance of caring for self care is encouraged.

## **II. Methodology:**

### **2.1 Selection criteria**

The criteria used to select the participants for the study were as follows:

- 1) Parents in the age group of 21 to 40 years having cerebral palsy children in the age group of 1-12 years registered during January 2008 to December 2011 to attend a clinic in a tertiary care private Hospital.
- 2) Total of 50 from the list of 108 (unit) children with cerebral palsy was chosen randomly to fulfill the criteria of social group work method for the intervention programme.
- 3) Parents should know to speak the local language and must hail from the vicinity of 30kms.
- 4) Parents who were willing to participate in the study.

A single group of parents were chosen considering the difficulties of the primary care givers to leave their child with family members to participate in the group activities of the intervention programme. As the social group work method requires a small group composing few parents to participate comfortably within the group interaction aimed for; therefore 50 primary care givers were chosen randomly from the unit of the study. Ten out of 50 parents did not give consent to participate in this study. Remaining 40 parents who gave their consent to participate in the study were included from base line assessment. Due to unavoidable reasons 5 parents could not continue in the study. The reasons were death of a primary care givers child with CP, relocation and the ill health of the primary care giver. Thus a total of 35 primary care givers participated successfully in the study which constituted the sample size.

### **2.2 Tools:**

The tools used in the study were as follows:

- i. A detailed Interview schedule was used to explain socio demographic details and other variables of the study.
  - ii. Modified Standard Of Living Index Questionnaire (Parasuraman et al 1999)
  - iii. Family burden scale (Pai and Kapur 1981):
- i. Socio Demographic details: Information on parent's age, gender, educational status, type of marriage and status on living with marriage relationship.
  - ii. Modified Standard Of Living Index Questionnaire (Parasuraman et al 1999):  
It was used to assess the socio economic status of the parents based on the material possessiveness. It consisted of - 11 number of items. It was scored on a 4point scale. The interpretation of the score was as follows: low (0-14), middle (15-24) and higher (25-67).
  - iii. Family burden scale (Pai and Kapur 1981):  
This instrument consists of seven domains and one extra category to account for any other burden on the family. The authors have included 24 items in the instrument and also have to be filled, and burden rated by skilled raters on a three point scale of sever burden-2, moderate burden- and No burden-0. Each item clearly demonstrates the intent behind it. For twenty items the inter-rater reliability coefficients were above 0.90 and this coefficient ranged between 0.87 and 0.89 for the rest four items. The scale has high amount of validity. This includes seven domains and one extra for any other burden on the family about which they were not asked. The schedule has be filled and burdens rated by skilled rates on a three point scale with sever burden-2, moderate burden-1, No burden - 0. High amount of validity for the scales is reported by the authors.

**2.3: Research design:**

Quasi experimental research design without control group was assigned. Assessments on parent’s family burden were done at the beginning of the study. The same tests were repeated after six months of intervention to find the difference before and after intervention. The intervention program consisted of interactive session on prevention, coping skills in management of family burden and counseling sessions based on the needs of the parents and their family members. During the intervention activities, parents discussed and exchanged their views on sharing of responsibilities in household chores, opportunity to get a break from continuous caring of the child, participation in decision making on treatment of the child and family matters and opportunities to share emotional burden with members of the family. Parents were asked to practice the learned techniques to cope and prevent their burden and were asked to attend the counseling sessions. Follow up on counseling sessions was done once a week. Both pre and post tests were done visiting the families of the parents at their convenient time. This study used the family burden scale (Pai and Kapur 1981) to quantify the level of family burden experienced by parents of the children with cerebral palsy. This quantification of the family burden was done before and after the intervention with the follow up period of 6 months.

**2.4 Analysis of data:**

Data was analyzed using SPSS version 17. Frequency of variables, mean, standard deviation; paired ‘t’ test and Cohen’s ‘d’ tests were used. The results are discussed based on the test findings.

**III. Results And Discussion**

**3.1 Socio demographic details of the parents**

Most of the caregivers (88.6%) were mothers of the children with cerebral palsy. They were in the age group of 21-40 years (88.6%) and more than one third (37.1%) of parents were between the age group of 26-30 years. Most of the parents (91.4%) were living with their partner and other members of family during the study period. More than half (65.7%) of the members in this group of parents had consanguineous marriage.

Findings on education level shows more than half (53.3%) of the parents completed their secondary school. Standard of living index tool indicated that almost half of the group members (48.6%) were from lower socio economic background. Applying the test of association between variables found there is significant association (<0.05) between the level of family burden and socio economic status of the parents.

In this study, result of the parent’s care giving family burden on applying test of significance has revealed that there was significant reduction on family burden. The different subscales are distribution of routine family activities, disruption of family interaction, effect on family leisure, effect on physical health of others, effect on mental health of others and overall (P<0.000). Effect size of the intervention programme had positive very small effect (d=0.08). This indicates the level of the effectiveness of intervention programme on parents in reducing their family burden while caring their cerebral palsy children.

**3.2 Comparison of Pre and Post test: Effectiveness of the family centered psycho social intervention on family burden:**

| Family burden Sub domains          | Pre and post test | No | Mean score | SD   | Mean difference | t-Value | P- Value |
|------------------------------------|-------------------|----|------------|------|-----------------|---------|----------|
| Financial burden                   | Pre               | 35 | 9.23       | 2.16 | 3.06            | 11.65   | <0.000   |
|                                    | Post              |    | 6.17       | 2.08 |                 |         |          |
| Distribution of routine activities | Pre               | 35 | 6.54       | 1.86 | 1.80            | 10.71   | <0.000   |
|                                    | Post              |    | 4.74       | 2.10 |                 |         |          |
| Distribution of family leisure     | Pre               | 35 | 4.68       | 1.89 | 1.54            | 7.78    | <0.000   |
|                                    | Post              |    | 3.14       | 1.83 |                 |         |          |
| Distribution of family Interaction | Pre               | 35 | 5.11       | 2.38 | 1.74            | 7.71    | <0.000   |
|                                    | Post              |    | 3.37       | 2.01 |                 |         |          |
| Effect on physical health          | Pre               | 35 | 2.22       | 1.11 | 0.77            | 5.92    | <0.000   |
|                                    | Post              |    | 1.45       | 1.03 |                 |         |          |
| Effect on mental health            | Pre               | 35 | 1.65       | 0.96 | 0.57            | 5.16    | <0.000   |
|                                    | Post              |    | 1.08       | 0.85 |                 |         |          |
| Any other burden on family         | Pre               | 35 | 1.17       | 0.45 | 0.47            | 6.73    | <0.000   |
|                                    | Post              |    | 0.60       | 0.60 |                 |         |          |
| Subjective burden                  | Pre               | 35 | 1.37       | 0.54 | 0.49            | 6.59    | <0.000   |
|                                    | Post              |    | 0.60       | 0.75 |                 |         |          |
| Over all burden                    | Pre               | 35 | 1.91       | 0.70 | 0.69            | 6.00    | <0.000   |
|                                    | Post              |    | 1.22       | 0.77 |                 |         |          |

Results of this particular study are added information to the research on family burden among the parents of the children with CP. This study results supports a study done by Franziska Kuhne et al (2012) on a systematic review of psychosocial family intervention for the palliative parents and their children. Family centered intervention with counseling of the children of palliative parents resulted in reduced parent family burden. The pre intervention score was greater than the post intervention scores on the subscales of family burden.

In this study individual and family counseling proved to be therapeutic to most of the parents with family burden. It is supported by a study done by Kanaka Latha et al (2013) on the effectiveness of counseling for the parents of the children of autistic; the results showed that parents felt empowered by counseling. Intervention in this study helped parents to cope with family burden and make family members to contribute to the responsibilities in caring for their CP child.

Parents shared their experience during the intervention program which enhanced their ability in terms of sharing responsibilities in household chores and imparted opportunities to share their feeling with other members of the family. It indicated that most of the parents were able to cope with family burden after psycho social intervention. The group sessions helped mothers to feel less isolated as they continued to interact with other care givers who attended the interactive sessions. These outcomes resulted in the effect size of intervention programme on parents in reducing their family burden.

#### **IV. Conclusion**

This study shows the possibility of reducing family burden among the parents of children with Cerebral palsy. It was achieved through the interactive sessions on improving and sharing the responsibilities of the family chores and other members caring for the child. Interactions made the members to learn practical coping skills on family burden. Counseling parents enabled them to prevent and cope with their family burden. Results of the tests demonstrated the effectiveness of the intervention program in all the areas of family burden. This model can be applied to the care givers of the people with chronic illness to reduce their family burden.

#### **References:**

- [1]. Rethlefsen, S. A., Ryan, D. D., & Kay, R. M. (2010). Classification systems in cerebral palsy. *Orthopedic Clinics of North America*, 41(4), 457-467.
- [2]. Blair, E. (2010). Epidemiology of the cerebral palsies- *Orthopedic Clinic of North America* Volume 41, Issue 4 – October, 2010; (41(4); 441-455
- [3]. Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S. D., Russell, D., et al. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*, 115(6), 626-636.
- [4]. Brehaut, J. C., Kohen, D. E., Garner, R. E., Miller, A. R., Lach, L. M., Klassen, A. F., et al. (2009). Health among caregivers of children with health problems: Findings from a Canadian population-based study. *American Journal of Public Health*, 99(7), 1254-1262.
- [5]. Grootenhuis, M. A., & Bronner, M. B. (2009). Paediatric illness! Family matters. *Acta Paediatrica*, 98, 940-941.
- [6]. Olsson MB, Hwang CP. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal Disability Research* 45 (part 6):535-43.
- [7]. Button et al, Pianta, R. C., & Marvin, R. S. (2001); Partner support and maternal support in families raising young child with cerebral palsy *journal of development and disability* 13(1) 61-81.
- [8]. Bennett, T., DeLuca, D. A., & Allen, R. W. (1995). Religion and children with disabilities. *Journal of Religion and Health*, 34, 301-312.
- [9]. Franziska Kühne, M.Sc., Thomas Krattenmacher, M.Sc. (2012). Minor childrderen of palliative patients- A systematic review of psycho social family intervention. *Palliat Med. Aug*; 15(8): 931-945.
- [10]. Kanaka Latha Abbagani, Usha S Naik & Hannah Anandaraj Use of the parenting stress index (psi) in mothers of children with autism.(2013), *The official journal of Indian Acedemy of Cerebral Play. July, IJCP:1 (1)30-34*