

Family life of caregivers: A descriptive study of disruption of family activities, leisures and interaction of caregivers of children with cerebral palsy

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Abstract: *Context:* The purpose of this research was to study family life of caregivers who provide primary care to children with Cerebral Palsy. *Aim:* To study the family activities, leisure and interaction of caregivers of children with Cerebral Palsy. *Settings and Design:* Study was conducted in Dept. of Physical Medicine and Rehabilitation, AIIMS, New Delhi. *Methods and Material:* Study sample consisted of 65 primary caregivers of children with Cerebral Palsy. Questionnaires about family activities, leisure and interaction from Family burden interview schedule were used. Descriptive statistics and multiple regressions were used for data analysis. *Results:* All three domains i.e. disruption of routine family activities, family leisure and family interaction were found to be disrupted in caregivers of children with Cerebral Palsy. Various factors like education of caregiver, total children, family income, duration of caregiving, speech disturbance in child, seizures and mental retardation were found to effect scores of disruption of family activities, leisure and interaction. *Conclusions:* Caregivers of children with Cerebral palsy experience disruption of family activities, leisure and interaction. For proper care of children caregiver's family life should be taken care of. Healthcare providers should enhance support networks to encourage and promote normal family activities, leisure and interactions of caregivers.

Keywords: Family life of caregivers, caregivers of children with Cerebral Palsy, family activities, family leisure, family interaction

Introduction

Cerebral Palsy is a disorder of movement and posture caused by a non progressive injury to immature brain [1]. It affects both children and their caregivers. Society is realizing more that the education of these children works best when family care providers actively participate. The first aspect of treating children with Cerebral Palsy is ensuring that the families have heard and come to some level of acceptance that their children have some problem called Cerebral Palsy, which is permanent and will not go away [2]. The limitations of the child with Cerebral Palsy can result in requirements for long term care, far exceeding the usual needs of children as they develop, or the expectations of their families as they parent [3].

This study is an effort to know the disruption of family activities, leisure and interaction of caregivers of children with Cerebral Palsy. A study of stress and coping - A comparison of self-

report; measures of functioning in families of young children with Cerebral Palsy or no medical diagnosis was conducted by Pristner A Britner et al [4]. They analyzed data from 87 mothers of children aged 15 to 44 months with Cerebral Palsy or no medical diagnosis who completed the dynamic adjustment scale, parenting stress index, support function scale mothers of children with Cerebral Palsy reported higher level of parenting stress than in mothers of control.

A study of "Assessment of data quality in a multicentre cross sectional study was done of participation of quality of life of children of Cerebral Palsy was done by Fauconnier J et al [5] Under this study 1174 children aged 8-12 years were selected from 8 populations based register of children with Cerebral Palsy. They found that 37% families did not respond, 12% were not traced, from those traced 24% declined to participate and 3% were not approached. McIntyre LL et al studied

'Behavior mental health disabilities in young adults with intellectual disability: impact on families [6]. Mothers of 103 young adults with intellectual disabilities were interviewed using a 2-3 hr. in depth protocol of measures designed to assess their child's adaptive functioning, maladaptive behavior, mutual health problems and negative impact on family. They made use of revised problem behavior scale and Reiss screen behavior.

A study done by Lori S Anderson et al on Mothers of Children with Special Health Care Needs: Documenting the Experience of Their Children's Care in the School Setting. Interviews were transcribed and content analysis revealed five themes: (a) communication, (b) educational system issues, (c) mother as a caregiver and expert, (d) navigating the system, and (e) strategies and coping [7]. They concluded that describing and understanding experiences of mothers of CSHCN (Children with Special Health Care Needs) is important for developing appropriate supportive interventions.

A study titled "Mental health and marital adaptation among mothers of children with Cerebral Palsy" was done by Florian et al [8] Results revealed differences between the two groups and indicated that, among mothers of children with Cerebral Palsy, self-esteem, self-mastery, and family network size were the main variables that contributed to mothers' psychological and marital adaptation. Sheeran T Marvin et al investigated the relation between maternal resolution/non-resolution of a child's diagnosis of chronic medical condition to self-reported measures of parenting stress, marital quality, and social support by conducting a study on mothers' resolution of their child's diagnosis and self-reported measures of parenting stress, marital relations, and social support [9]. Findings suggested that resolution/non-resolution of diagnosis has implications not only for individual functioning and child-parent interactions, as found in previous research, but also for other intimate familial relationships and social ecology.

A study on "How do mothers and fathers who have a child with a disability describe their adaptation/ transformation process?" was done in University of Montreal, Montreal, Quebec, Canada. by Pelchat D et al [10]. This qualitative

study explored the adaptation/transformation process in mothers and fathers at the individual, parental, marital and extra familial levels, and the similarities and differences in their experience of living with a child with Cerebral Palsy. The results showed that mothers and fathers are more likely to view the situation differently than similarly. For both parents, the situation offers the potential for transformation. Mothers' experience with their developmentally disordered children: specificity of internal representations was studied by Pukinskaite et al [11]. The purpose of this study was to examine mothers' internal representations of experience with their developmentally disordered children. Using developmental disability sample of 17-34-month-old children, they compared mothers' representations of their children in clinically referred and not referred groups, using the working model of the Child Interview. The study did not confirm relationships between maternal representation classifications and their self-perceived impact of child disability on family.

A study titled "Parents of children with Cerebral Palsy: a review of factors related to the process of adaptation" was conducted by Rentick IC et al at rehabilitation centre De Hoggstraat [12] A literature search was performed to gain a deeper insight in the process of adaptation of parents with a child with Cerebral Palsy and on factors related to this process. It was concluded that it is important to realize that parents' adaptation may change as a function of their child's development and changing stages of family life over time. Until now cross-sectional studies have dominated this area of research, but in order to understand the process of adaptation over time, longitudinal studies are needed.

Aim: To study the disruption of family activities, leisure and interaction of caregivers of children with Cerebral Palsy.

Material and Methods

Study Setting: Study was conducted in Department of Physical Medicine and Rehabilitation, All India Institute of Medical Sciences, New Delhi.

Study Population: Caregivers of children who had received a diagnosis of Cerebral Palsy and attended OPD of Department of Physical Medicine and Rehabilitation, All India Institute of Medical Sciences.

Sample Size Calculation: Considering the anticipated severe disruption of family activities, leisure and interaction among caregivers of children with Cerebral Palsy as 40%, level of confidence as 95%, absolute precision as 15%, therefore $40\% \pm 15$ i.e. 25-55, we needed to enroll 65 caregivers of children with Cerebral Palsy.

Inclusion Criteria:

- Caregivers who had already received a diagnosis of Cerebral Palsy.
- Those who wished to participate in this study.
- Caregivers who were able to communicate in Hindi or English to answer the questionnaire.
- Both caregiver and child lived in the same house and caregiver was responsible for care of the child for more than 6 months.

Exclusion Criteria:

- Those who refused to participate in study.
- Caregivers of children with disabilities those were not associated with Cerebral Palsy.
- Caregivers of children with other health problems that are not related to Cerebral Palsy such as Heart disease, Diabetes mellitus, Down syndrome.
- Caregivers who were suffering from an already diagnosed psychiatric illness.

Tools: Burden was assessed using the family burden interview schedule developed by Shaila Pai and R.L. Kapur [13]. Each item was recorded as:

Absent	Score 0
Moderate	Score 1
Severe	Score 2

The following questionnaires from this schedule were used:

Disruption of routine family activities:

1. Patient not going to work, school, college etc: How inconvenient is this for the family?
2. Patient not helping in the household work: How much does this affect the family?

3. Disruption of activities of other members of the family:
4. Patient's behavior disrupting activities:
5. Neglect of the rest of the family due to patient's illness:

Disruption of family leisure:

1. Stopping of normal recreational activities:
2. Patient's illness using up another person holiday and leisure time:
3. Lack of attention to other members of family such as children and its effect on them:
4. Has any other leisure activity had to be abandoned owing to the patient's illness or incapacity:

Disruption of family interaction:

1. Any ill effect on the general atmosphere in the house:
2. Do other members get into argument over this – How are they affected?
3. Have relatives or neighbours stopped visiting the family or reduced the frequency of their visits because of the patient's behaviour or the stigma attached to his illness? How does the family feel about this?
4. Has the family become secluded? Does it avoid mixing with others because of shame or fear of being misunderstood? How does the family feel about this?
5. Has the patient's illness had any other effect on relationships with in the family or between the family and neighbors or relatives? How does the family feel about this?

During the interview rating was noted for each individual item on the same 3 point Likert scale. Association of disruption of routine family activities, leisure and interaction with various factors like age of the caregiver, sex, child gender, relationship to the child, education of caregiver, total children, occupation, family income, duration of caregiving, duration of daily caregiving, duration of knowing the diagnosis, speech disturbance, visual disturbance, hearing trouble, seizures and mental retardation was also found. Caregivers who personally accompanied their children to the PMR OPD

were selected in sample groups as per inclusion and exclusion criteria. Those who agreed to participate signed an informed consent form. Then they were interviewed. How to answer the questionnaires was explained to them. Then they were handed over the questionnaires and were allowed to answer themselves. If they had any problem in reading or writing, questions were read and they were allowed to answer one by one. Data gathered from the questionnaires was analyzed.

Statistical Analysis: Data was recorded on a pre-described proforma and managed on an excel spread sheet. Demographic and patient’s characteristics were summarized by mean±S.D (for quantitative variables) and frequency (percentage for categorical variables). Association of different factors with scores of disruption of routine family activities, leisure and interaction was determined. Correlation coefficient between disruption of routine family activities, leisure and interaction score for each of the domains and total was computed multiple

linear regression analysis was used to determine the role of various factors on these scores.

The analysis was done as follows:

- Dependent variables as score and factors as various demographic, socioeconomic and patient characteristics.

Disruption of routine family activities, leisure and interaction score as dependent variable and factors as demographic, socioeconomic and patient characteristics. STATA 11.0 statistical software was used for data analysis. In this study p value < 0.05 was considered statistically significant.

Results

Disruption of routine family activities: Mean value for this category in the caregivers was 6.8± 1.98(moderate) with a minimum of 1 and maximum of 10.

Table-1: Association between disruption of routine family activities and various factors (numbers in bold indicate significant values)

		Correlation coef./Mean ± S.D.	Univariate Regression	P value
Age		0.085	6.024	0.498
Sex	Female	6.9± 1.89	-0.739	0.1629
	Male	6.4± 2.29		
Child gender	Female	6.2± 1.93	-2.072	0.3026
	Male	6.9± 1.99		
Relationship to the child	Mother	6.88± 1.88	-0.82	0.527
	Father	6.5± 5.12		
Education	0 to Class 8	8± 1		
	Class 8 to 12	7.5± 1.2	-1.189	0.02
	Graduate and PG	4.8± 1.8	-7.649	0.01
Total children		-0.6338	-1.18	0.01
Occupation	Non working	6.8± 1.93	-0.839	0.612
	Working	6.58± 2.18		
Family income		-0.098	-0.0000197	0.436
Duration of caregiving		0.544*	-3095	0.004
Duration of daily caregiving		0.022	0.007	0.86
Duration of knowing the diagnosis		0.525*	0.299	0.002

		Correlation coef./Mean ± S.D.	Univariate Regression	P value
Speech disturbance	No	5.37± 1.82	-3.24	0.01
	Yes	7.81± 1.39		
Visual disturbance	No	6.82± 2.00	-1.09	0.88
	Yes	6.73± 1.98		
Hearing difficulty	No	6.8± 1.8	-6.49	0.178
	Yes	5.5± 3.1		
Seizures	No	5.8± 2.06	-2.716	0.0001
	Yes	7.6± 1.45		
Mental Retardation	No	5.7± 2.11	-2.52	0.0029
	Yes	7.2± 1.73		

Disruption of family leisure: The mean value in the caregivers was recorded as 5.06± 1.87 (moderate). The minimum was 1 and maximum was 8.

Table-2: Association between disruption of family leisure and various factors

		Correlation coef./Mean ± S.D.	Univariate Regression	P value
Age		0.0001	0.000193	1
Sex	Female	5.1± 0.244	-0.895	0.75
	Male	4.9± 0.529		
Child gender	Female	4.6± 1.5	-1.77	0.38
	Male	5.14± 1.8		
Relationship to the child	Mother	5.09± 1.71	-0.919	0.756
	Father	4.92± 2.12		
Education	0 to Class 8	6.4117± 1.064		
	Class 8 to 12	5.59± 1.24	-1.089	0.003
	Graduate and PG	3.28± 1.45	-5.649	0.001
Total children		-0.6319	-1.06	0.004
Occupation	Non working	5.04± 1.73	-1.09	0.88
	Working	5.11± 1.99		
Family Income		-0.2964	-0.0000537	0.017
Duration of caregiving		0.5139*	0.2639	0.001
Duration of daily caregiving		-0.0385	-0.0117	0.761
Duration of knowing the diagnosis		0.4970*	0.2587	0.006
Speech disturbance	No	3.85± 1.5	-2.81	0.002
	Yes	5.92± 1.45		
Visual disturbance	No	5.02± 1.73	-1.24	0.736
	Yes	5.2± 2.04		
Hearing difficulty	No	5.08± 1.76	-1.53	0.7228
	Yes	4.75± 2.5		
Seizures	No	4.29± 2.00	-2.29	0.006
	Yes	5.76± 1.23		
Mental Retardation	No	4.76± 2.07	-1.35	0.002
	Yes	5.20± .65		

Disruption of family interaction: The mean value of burden in this category was 4.56 ± 2.63 (moderate) and the minimum and maximum value recorded were 0 and 10 respectively.

Table-3: Association between disruption of family interaction and various factors (numbers in bold indicate significant value)

Disruption of Family Interaction		Correlation coef./Mean \pm S.D.	Univariate Regression	P value
Age		-0.1028	-0.283	0.415
Sex	Female	5.9 \pm 1.89	-0.639	0.1629
	Male	5.4 \pm 2.29		
Child gender	Female	5.2 \pm 1.93	-1.072	0.3026
	Male	5.9 \pm 1.99		
Relationship to the child	Mother	6.88 \pm 1.88	-0.82	0.527
	Father	6.5 \pm 5.12		
Education	0 to Class 8	7.117 \pm 1.932		
	Class 8 to 12	4.481 \pm .392		
	Graduate and PG	2.61 \pm 1.499		
Total children		-0.6819	-1.6939	0
Occupation	Non working	6.8 \pm 1.93	-0.839	0.612
	Working	6.58 \pm 2.18		
Family income		-0.2667	-0.0000709	0.032
Duration of caregiving		-0.4875	3.678	0.001
Duration of daily caregiving		-0.063	-0.0282	0.618
Duration of knowing the diagnosis		0.5085	0.3843	0.003
Speech disturbance	No	5.37 \pm 1.82	-3.24	0.01
	Yes	7.81 \pm 1.39		
Visual disturbance	No	6.82 \pm 2.00	-1.09	0.88
	Yes	6.73 \pm 1.98		
Hearing difficulty	No	6.8 \pm 1.8	-6.49	0.178
	Yes	5.5 \pm 3.1		
Seizures	No	5.8 \pm 2.06	-2.716	0.0001
	Yes	7.6 \pm 1.45		
Mental Retardation	No	5.7 \pm 2.11	-2.52	0.0029
	Yes	7.2 \pm 1.73		

Discussion

Disruption of routine family activities: The mean score recorded in this study was 6.8 ± 1.98 which was quite high (min. 1 and max. 10). Caregivers were found to experience a lot of disruption of routine family activities while caring for their children with Cerebral Palsy. This was due to the reason that as the caregivers were involved in

taking care of their children with Cerebral Palsy most of the time, they had less time for performing other routine family activities. Also, most of the caregivers were mothers, who had more satisfaction in taking care of their children and thus were willing to stay with their children rather than to do other activities.

Disruption of Family leisure: The mean score in this category was 5.6 (min. 1 and max. 8) which was high. This means that caregivers no longer experienced family leisure to that extent which they earlier used to experience. This could possibly be explained by the fact that majority of caregivers feared that their children with Cerebral Palsy would not be able to perform self care when they grew up. So they had so much worries and concerns about the future of their child that they were not able to enjoy life as earlier they used to.

Disruption of Family interaction: Mean score of disruption of family interaction was low, which means that there was no much loss of family interaction after knowing that their child was suffering from Cerebral Palsy. Low score indicated that they had good family interaction, which meant that they had someone to share and consult with as well as boost their spirits in taking care of their children with Cerebral Palsy and dealing with caring problems. These findings were consistent with the findings of Martinson et al (1995), who studied Chinese mothers' reaction to their children's chronic illness and found that mother had social relationship with persons who could take care of their children [14]. Social support definitely affects burden and stress in caregivers of children with Cerebral Palsy. These were concluded by a study conducted by Al-Gamal E et al, which showed that severity of disability was not significantly related to maternal wellbeing but that perceived stress and perceived social support significantly provided wellbeing both independently and together [15].

Association with various factors: No association was found between age of caregiver, caregiver's relation, child gender and scores of disruption of family activities, leisure and interaction. Caregiver's education and total number of children they had affected scores of all three domains i.e disruption of family activities, leisure and interaction. The reason could be that the caregivers with higher education were able to understand the condition and cope up with it in a better way. On searching the literature, no studies were found to show the association between these two factors. With more number of children there was less disruption of their routine family activities, leisure and interaction. The reason could be that caregivers with normal children were less worried about the future of

their child with Cerebral Palsy and could interact with their family in a better way. No association was found between occupation of caregivers and disruption of family activities, leisure and interaction. A study by Jamie D Brehaut et al showed that majority of caregivers of children with Cerebral Palsy were non working [16].

While scores of disruption of family activities were not affected by family income but scores of disruption of family leisure and interaction were found to be significantly associated with family income. This could be explained by the fact that caregivers with higher family income could afford assistance to take care of their child with Cerebral palsy and hence could get time to interact and have some leisure time with other family members With increase in duration of caregiving there was increase in scores of disruption of family activities, interaction and leisure. This may be due to the fact that with time caregivers became more worried and concerned about the future of their child. It was shown in study titled "Long term follow up of children with Cerebral Palsy and coping behavior of parents" by Hirose T et al that the caregivers experienced the stressful period during the child's infancy due to the shock from the diagnosis [17]. Most difficult period occurred during child toddlerhood, school age and adolescence due to difficulties in terms of child's underdeveloped motor activity.

Significantly high scores of disruption of routine family activities, leisure and interaction were seen in caregivers who had children with Cerebral Palsy associated with speech disturbance. As the child was not able to communicate his needs, so the caregivers had to spent most of their time with their children and hence had less family time. No association was found between visual disturbance or hearing trouble and disruption of routine family activities, family leisure and interaction. The reason could be that in majority of children visual disturbance was mainly squint and hearing problems were also minor and these were not so much bothersome for caregivers as compared to other problems. A significant association was found between scores of disruption of routine family

activities, leisure and interaction and seizures or mental retardation. These both added to the concerns and worries of the caregivers and they were not able to interact or involve in other family matters.

Conclusions

Hence it can be concluded from this study that Caregivers of children with Cerebral palsy experience disruption of family activities, leisure

and interaction which are associated with various factors like caregiver's education, total number of children, family income, duration of caregiving, speech disturbance, seizures and mental retardation. Caregiver's family life should be taken care of in order to help them live a happy and stress free life. In this way they will be more capable of taking care of their children with Cerebral palsy.

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