International Journal of School and Cognitive Psychology

Masood, et al, Int J Sch Cog Psychol 2015, 2:1
DOI: 10.4172/2469-9837.1000119

Research Article Open Access

Families of Children with Cerebral Palsy: Family Functioning Domains

Afsheen Masood*, Rabia Arshad and Shama Mazahir

Institute of Applied Psychology, University of the Punjab, Punjab, Pakistan

***Corresponding author:** Afsheen Masood, Assistant Professor, Institute of Applied Psychology, University of the Punjab, Pakistan, Tel: 92-03424225572; E-mail: afshen1402@gmail.com

Rec date: Jan 24, 2015, **Acc date:** Mar 24, 2015, **Pub date:** Mar 26, 2015

Abstract

The present research study was designed to investigate the family functioning of the families having children with cerebral palsy. It was hypothesized that there would be significant differences in the family functioning of families having children with cerebral palsy and families having normal children. The case-control research design was used. The sample of the study was accessed from the special needs institutions (N=50). The measure used in the current research was the Family Adaptability and Cohesion Evaluation Scale (FACES IV) by Olson, 2011. The findings from the current research reveal that there are significant differences in some of the dimensions of the family functioning of families having children with cerebral palsy in comparison to the families having normal children. The family cohesion, flexibility, communication were found to have better accounted for family functioning. The enlightening findings from the current research carry strong implications for the researchers, psychologists, family therapists, community workers and for psychiatrists.

Keywords: Cerebral palsy; Family functioning; Family cohesion; Flexibility; Communication; Satisfaction

Introduction

Family has been strong institution in every society. This strong institute carries special significance in Pakistani culture as being a strong base for upbringing of children and for ensuring their well-being. Families are very beneficial, healthy yet complex and ever changing systems that serve the purposes of development of generations. The family system is required for the development of healthy individuals. Within the family set up, the family dynamics play important role as the end result of behaviors of all family members as a family system result from it. Family dynamics have been very important in the past but in recent times, the modern world's digitally transformed interactions, family dynamics have led to marked deterioration. Sometimes the dynamics of the family create complexities especially when some special needs member is there within the family. Such complexity creates many challenges for all the family members especially the parents. The presence of a child with disability at home posits challenges for the family so much so the whole nature and dynamics of family interactions change. Due to this, the family sometimes faces multifarious challenges and adverse outcomes. Any significant child's disability like cerebral palsy not only mars his/her daily life functioning but also impairs its family's social, psychological and emotional domains of life. In present study, the major aim was to investigate the differences in functioning patterns of families of children with cerebral palsy and families with healthy children [1].

Cerebral palsy is a neurological disorder that includes a group of disabilities which influence a child's ability to move and uphold equilibrium and position. Cerebral palsy is also illustrated as a loss or inability to control over the body movements; or motor problems in regulating the hand and arms during attainment of manual tasks. These difficulties with the timings of motor movements arise due to abnormal or incomplete brain development [1]. Cerebral palsy is one of the most commonly found disorder in the developing countries and its prevalence is cited as 1 or 2/1000 in live birth [2]. Failure in achievement of milestones of motor development from birth to five years like, rolling, sitting, standing, holding or walking etc., are likely to be the significant indicators of Cerebral palsy. Signs and symptoms of cerebral palsy vary from person to person. This tends to worsen in relation to advancement in age. Not only the severity rather sometimes, the symptoms change in their nature and trends. As one grows older for instance before six months of age, a child may feel stiff or floppy but can roll around as the same child grows older than six months, he/she may not even be able to roll in any direction at all. Cerebral palsy can be diagnosed with thorough clinical assessment by an authentic physician and paeditrician in conjoining reports and observations of developmental psychologists and parents [2]. Spastic and dyskinetic are two major subtypes of cerebral palsy. Spastic refers to effect tone in which physical forces are unbending (abrupt), and movements are uncomfortable, tense and jerky. This category of cerebral palsy affects poles apart of the corpse confidential by these parts of the body like hemiplegic (one side of the body), diplegia (both legs), quadriplegia (the entire body), 70-80% cases of cerebral palsy falls in this type. Spasticity can be assessed by increase in muscles tone that is referring to resistance to elasticity, by evaluating joint angle. Second type of cerebral palsy is dyskinetic which affects association and coordination of arrangements. Dystonia refers to hypertonia and decrease motion; choreoathetosis, to asymmetrical, irregular, involuntary movements of the appendages or facial muscles [3]. The caregiving is a normal function of being the parent of a young child. However this role takes up new form when the child is experiencing some impairment that si functional in nature. In such cases, the parents have to cope with the challenges of health issues that are confronted by their child's physical or intellectual disability status. The caregiving requirements of everyday living increase the toll of burden for the parents and they consequently face various changes in their physical and psychological well-being, which indirectly affects the family functioning patterns and family dynamics in which all members directly or indirectly get influenced. This is an intricate phenomenon

to be investigated how family dynamics get subtly changed due to the presence of special needs member in the family. The approach of estimating the "independent" or "direct" effects of the care-recipient's disability on the family functioning may not appear sufficient. A more detailed analytical approach is needed to understand both direct and indirect effects simultaneously [4]. Problem with any one of the child produces marked effects on whole family functioning, which describes as the forms of relations associating members of a family system to each other [5]. Families develop patterns for managing basic, developmental, and crisis-related tasks [6]. Healthy families uphold the emotional, somatic and communal welfare of every member of family. Among the many elements that participate in this process are a family's internal strengths and the stability of the family unit. Unlike any other social group, families are competent to deliver the close emotional livelihood needed to yield self-possessed and well-adjusted children and adults. Likewise, families that function in a healthy manner are well armed to deal with the many routine variations and unanticipated catastrophes that challenge them throughout their lifetime. Thus primary function of the family is to provide opportunities to grow and develop to each member of the family [6].

The theoretical frame work of the current research has been based on the family circumflex model describes family behavior in terms of family cohesion and adaptability/flexibility as continuum, which are further divided into four categories. According to this model cohesiveness referred to emotion bond among family members, while adapted is explained as leadership, management roles and headship rules and family ability to change these rules or remain strike with them in stressful situations [7]. It means that when child in a family face difficulty in motor activities, then due to its emotional bond with other family members and that child show inability to follow family leadership and rules, hence in this way functioning of whole family gets effected.

Using the Typology Model of Adjustment and Adaptation, a family stress model, relationships surrounded by family stamina, family stressors, family appraisal, coping, social support, and fulfillment with family functioning were examined in a sample of 57 families of children with developmental disabilities. Higher satisfaction with family functioning was connected with coping-integration, network support, functional support, and hardiness. Lower fulfillment with folks functioning was associated with higher family stressor scores, social support loss, and increased parental age. The results underline the value of continual investigations of resoluteness in families [8]. Guillamon et al. [9] investigated effect of self-efficacy and coping strategies, Quality of life and mental health in parents of children with cerebral palsy. Study was done on 62 parents and results of this study reflected low quality of life and self-esteem which result into low family functioning.

Olawale et al. [10] investigated the psychological impact on families with cerebral palsy children. 52 parents of cerebral palsy children participate in this research. Findings of this research reflected that children with disability increased their responsibility for taking care of them, also accursing of people for wrongdoing and other personal problems that include loss of job, loss of family joy, and derangements of family finances influenced their family functioning. Most of the prior researches investigated the quality of life of family of parents having a child with cerebral palsy, but this study is conducted specifically to focus on the family functioning patterns of family, having a child with cerebral palsy in comparison to the families having normal children.

Hypothesis

Following hypotheses have been investigated: There are likely to be systematic difference in the family functioning and its dimensions, i.e communication, satisfaction, balanced functioning etc. of families having children with cerebral palsy in comparison to the families having normal children

Method

Research design

The research design used in current study was case-control research design as parents carrying the burdens of care for children with cerebral palsy were compared with the parents having normal children.

Sampling strategy

Non-probability purposive sampling strategy was used as the selection of the sample was contingent upon certain characteristics of the participants.

Sample

The sample of the study consisted of (N=100) families both mother and father who had children with cerebral palsy (n=50) and parents having normal children (n=50). The age range of the children in this study was from 8 to 18 years for children with cerebral palsy and for their normal children cohort. The data was be collected from special needs institutions either private or government who have been extended their services in the field of special education. There were certain factors on the basis of which control group was matched like gender of the child, number of children and family system etc.

Operational definitions of variables

Family communication: Family communication has been defined by Olson [11] as Family communication is defined as the deed of making evidence, concepts, opinions and feelings known among members of a family unit. Family communication can array from poor to very effective [11].

Family satisfaction: Family satisfaction by Olson [11] has been defined as the degree to which family members feel happy and fulfilled with each other. The operational definition includes the three dimensions that are related to the Circumplex Model; cohesion, flexibility and communication. So items in the family satisfaction scale assess the satisfaction.

Family functioning: Family Functioning is operationally defined in two terms of cohesion and flexibility, which are described as elements of balanced family. Cohesion is defined as the emotional link among all family members. Flexibility in the past has been defined as the quantity of variation in family headship, role relationships and relationship rules. Stable levels of cohesion and flexibility (low to high levels) are most favorable to healthy family functioning, while unbalanced levels of cohesion and flexibility (very low or very high levels) are associated with problematic family functioning [11].

Assessment measures: Following measures were used in the current study:

Demographic information questionnaire

A self-constructed demographic questionnaire was used in the study to seek the demographic data. First demographic sheet was constructed which provided necessary information about participants including age, no. of children, patient age, education of parents of the child and family system. The sample characteristics are reported in (Table 1).

Variables	Parents having normal children (n=50).	Parents having children with cerebral palsy (n=50).
	f (%)	f (%)
Father education		
Below metric	19 (38%)	21 (42%)
Metric	19 (38%)	12 (24%)
Intermediate	9 (18%)	10 (20%)
Bachelors	2 (4%)	6 (12%)
Masters	1 (2%)	1 (2%)
Mothers education		
Below metric	11 (22%)	14 (28%)
Metric	30 (60%)	32 (64%)
Intermediate	9 (18%)	4 (8%)
Gender of baby		
Male	31 (62%)	3174%
Female	19 (38%)	1926%
Father occupation		
Business Daily wages	20 (40%) 5 (10%)	17 (34%) 15 (30%)
Govt. job	13 (26%)	14 (28%)
Jobless	2 (4%)	3 (6%)
Private job	10 (20%)	1 (2%)
Mother occupation		
Housewife	43 (86%)	45 (90%)
Working	7 (14%)	5 (10%)
Family system		
Nuclear	13 (26%)	13 (22%)
Joint	37 (74%)	37 (78%)
No. of children		
1-3	37 (74%)	37 (78%)
4-6	13 (26%)	13 (22%)
Note. f=Frequency, %: Percentage; M: Mean; SD: Standard Deviation		

Table 1: Frequency, percentage, mean and standard deviation of demographic data of parents having normal children and parents having children with cerebral palsy (N=100).

Family functioning scale (FACES IV, 2010)

The Family Adaptability and Cohesion Evaluation Scale (FACES IV) is a variable measure by David Olson [11]. The FACES is capable of differentiate between different forms of family functioning. Its simplicity of administration and the evidence it provides, should applaud it for greater use in clinical settings. The scale has 30 items which are answered on a rating scale from 1-5. Two scores are attained, one for adaptability and one for cohesion. Based on evaluations with reference to the norm groups, the family can be scored on a circumflex model involving 16 different family types. FACES IV is a self-report evaluation completed by one or more family members. The reliability of family communication scale was .61. The reliability of family satisfaction sub scale was .88 which shows a high reliability and strength for the psychometric property of the tool for indigenous population.

Procedure

Permission of the authors was taken to use the measure through online printed form. The Family Adaptability and Cohesion Evaluation Scale (FACES IV) Olson, 2011 was used to assess the family functioning of the parents having children with cerebral palsy and families having normal children. These tools were translated in Urdu language for the convenience of the sample. In the first step forward translation was done, two translators which included the examiner and a professional, familiar with terminology of the English and Urdu languages did this task. The second step was backward translation in which the forward translated version of tool was translated back into the original language by the examiner and a bilingual (proficient in English and the Urdu language for translation) expert panel and then these both translations were first compared with each other and then compared with original version. At the end the tool was pre-tested on the target population which was taken from special institutes, the sample consisted of 10 parents of children with cerebral palsy and 10 parents of normal healthy children. The pilot study was conducted before final collection of the data. After receiving permission from the chairperson/director of the respective special needs departments, the questionnaire was administered on parents of the children who fulfilled the inclusion/exclusion criteria. To undertake research on family functioning of families having children with cerebral palsy and to collect data from various special needs institutions, the public as well as private sector special needs institutes were accessed. A consent form was given to the participants and they were ensured that the information acquired from them was held confidential and was not used for any purpose other than the research. The scale along with the demographic questionnaire was administered on each participate on face to face manner. It took about 20 to 25 minutes on average to complete the questionnaire. The data collected was analyzed through SPSS (Statistical Package for Social Sciences) software version 21.0. Descriptive analysis was carried out. Independent Sample t-test was used to analyze the family functioning in families having children with cerebral palsy. The control group was taken after matching some of the variable like parent' s age, parent' s education and the family system. For control group 50 parents of normal children were taken from schools after matching them on major features.

Results

This section presents the findings. The data analytic strategy involved performing (a) Cronbach alpha reliability that is presented in (Table 2) (b) the execution of independent sample t-test to demonstrate the difference between the family functioning of families having children with cerebral palsy and the families having normal children as shown in (Table 3).

Variables	Total item	M	SD	a
Balanced				
Cohesion	7	4.036	.204	.655
Flexibility	7	3.781	.281	.793
Unbalanced				
Disengaged	7	3.744	.444	.588
Enmeshed	7			.507
Rigid	7	3.268	.608	.760
Chaotic	7	2.366	.538	.960
Family communication	10	3.910	.043	.605
Family satisfaction	10	3.995	.045	.879

Table 2: Cronbach alpha reliabilities of FACES IV

Variables	Normal (n=50)		CP (n=50)		t	p	95% CI	
	M	SD	M	SD	LL	UL		
Balanced Family	11.04	4.56	10.8	6.25	1.62	.031	-.39	3.95
Unbalanced	17.6	4.79	1.79	5.81	-2.55	.012	-4.83	-.61
Family communication	79.76	4.51	76.62	6.07	2.93	.004	1.02	5.06
Family satisfaction	79.40	5.24	80.40	10.68	-.59	.054	-4.34	2.34
Family functioning	4.97	10.88	4.01	10.66	.093	.031	-4.77	7.17

Table 3: Independent Sample T-test comparing family functioning of families mainly parents having children with cerebral palsy (n=50) and Families having normal children (n=50).

Discussion

The present research was conducted to investigate the difference of family functioning of families having children with cerebral palsy and families having normal children. It was hypothesized that family functioning of families having children with cerebral palsy was worsened when compared to the families having normal children. The findings revealed that the family functioning of families having normal children is better as compared to the family functioning of families having children with cerebral palsy. The findings also reflect that families with normal children are more balanced, have better communication still do not differ much on the dimension of satisfaction from the families having normal children.

The first analysis supports the main hypothesis of the study that there is a significant difference in the family functioning of families having children with cerebral palsy and families having normal children. This might be due to the fact that as parents give more time to their special needs child, they do not pay sufficient attention to other activities at home. Most of such parents show extraordinary concern about the care giving towards their special needs child which somehow affects the normal and typical family functioning of the families. This finding is in line with other previous studies wherein it was found that family patterns varied between families of children with cerebral palsy and those with normal children and depression had manifested itself as an important predictor of caregiver burden, showing a significant positive linear association [12].

The next analysis contained detailed analyses of differences on dimensions of family functioning that revealed that family functioning of families having children with cerebral palsy on balanced scale of flexibility and cohesion was better when compared with the families of normal children. There was likewise significant difference on unbalanced and family communication sub scales of family functioning of families having child with cerebral palsy compared with the families having normal children. It was further revealed that the family functioning of families having children with cerebral palsy was greater on unbalanced scales of disengaged, enmeshed, rigid and chaotic when compared with the family functioning of normal children this revealing more maladaptive patterns. The findings also show that there is a significant difference in the communication domain of family functioning of two groups of families. Better communication patterns existed in families having normal children than families having children with cerebral palsy. Communications difficulties appeared to exert further contributory effect in deteriorating the psychological well-being of children. It has been observed that the families that lack open communication negatively influenced children with some disability or impairment and in some cases the children had been found to have lost their confidence and maintained poorer patterns of communication with other peers and adults; resultantly this was found to affects their interpersonal relationship and performance in school [13]. The current research corroborated the results that there is significant difference in the family communication of families having children with cerebral palsy or any other physical or mental disability and the families having normal children. As the parents of the child having any physical or mental disability pay more attention to their special child and spend more time with that child, the more of their communication with the spouse and other children decreased and this was found somehow to impair the communication dimension of the family functioning of the family [14].

There was no difference observed on the sub scales of satisfaction for the families having children with cerebral palsy. This stands in contrast to the earlier findings where the family satisfaction differed in families having children with special needs and those that do not have. Another such investigation revealed the hampering impact of child with disability on different families. This study reflected inconsistent findings from the current one where the results showed that status of having a child with disability negatively associated with family satisfaction because parents need to be more attentive towards them therefore they neglected other work areas and hence this led them in marked decrease in their satisfaction level. The contradiction is probably due to the fact that In Pakistan, families have many more avenues for satisfaction attainment.

Hence, the study highlights that decrease in functioning levels of family take place due to that fact that some family is having children with cerebral palsy. Also important is the fact that the presence of impaired child influences family communication patterns. These are the significant findings for the clinical psychologists, family therapists and community social workers. The findings from the current research study have not only contributed in bringing onto surface the scenario of family functioning for children with such debilitating special need like cerebral palsy but have also helped in exposing the dynamics of family life that should be worked on by family therapists in order to improve the quality of life of families that have member with special needs. The findings from the current research can guide future researchers in undertaking better in-depth analyses of the phenomenon of family functioning of families having child with cerebral palsy by conjoining the quantitative and qualitative methods in order to get more representative and comprehensive empirical scenarios.

This research has some limitations as well that include limitation of resources like time and cost; and assessment procedure can be indigenously developed in order to tap certain society related sensitive social aspects. In order to evaluate family functioning, both qualitative and quantitative self- report assessment procedures can yield better results. In order to increase the accuracy of results, the sibling of the children with cerebral palsy may also be assessed. Future researchers are suggested to expand this analysis to include a comparison group of other developmental disabilities in order to seek a comparison scenario of some parallel population.

References

1. Miller F (2005) Cerebral Palsy. Springer Science business media. Inc.
2. Arneson CL, Durkin MS, Benedict RE, Kirby RS, Yeargin-Allsopp M, et al. (2009) Prevalence of cerebral palsy: Autism and Developmental Disabilities Monitoring Network, three sites, United States (2004) Disabil Health J 2: 45-48.
3. O'Shea TM (2008) Diagnosis, treatment, and prevention of cerebral palsy. Clin Obstet Gynecol 51: 816-828.
4. Paterson JM, Garwick AW (2003) Levels of meaning in family stress theory. In: Boss P, Mulligan C (eds), Family Stress: Classic and Contemporary Readings. Thousand Oaks CA Sage Publishers.
5. Skinner H, Steinhauser P, Santa-Barbara J (1983) The family assessment measure. Canadian Journal of Community Mental Health 2: 91-10.
6. Olson DH (1999) Empirical approaches to family assessment circumplex model of marital & family systems. The journal of family therapy.
7. Failla S, Jones LC (1991) Families of children with developmental disabilities: an examination of family hardiness. Res Nurs Health 14: 41-50.
8. Guillamon N, Nieto R, Pousada M, Redolar D, Munoz E, et al. (2013) Quality of life and mental health among parents of children with cerebral palsy: the influence of self-efficacy and coping strategies. Journal of Clinical Nursing.
9. Olson DH, Gorall DM, Tiesel JW (2011) FACES-IV package: Administration. Minneapolis, MN: Life Innovations, Inc.
10. Resnick MD, Bearman PS, Blum RW, Bauman KE, Harris KM, et al. (1997) Protecting adolescents from harm. Findings from the National Longitudinal Study on Adolescent Health. JAMA 278: 823-832.
11. Mohoney C, Robinson C, Sullivan P (1992) Parents education in early intervention: a call for renewed focus. Retrieved on 21 June 2012.
12. Epstein NB, Bishop D, Ryan C, Miller, Keitner G (1993) The mcmaster model view of healthy family functioning. The Guilford Press, New York.
13. Eddy LL, Engel JM (2008) The impact of child disability type on the family. Rehabil Nurs 33: 98-103.

14. Falvo DR (2005) Medical and psychosocial aspects of chronic illness and disability. Johns and Bartlett Publishers.