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AN INVESTIGATION OF FAMILY IMPACT OF CHILDREN WITH CONGENITAL AND ACQUIRED BRAIN INJURY

ORIGINAL ARTICLE

ABSTRACT

Purpose: This study aimed to investigate the family impact of children with congenital and acquired brain injury, the levels of depression in mothers, and the factors that might affect family functioning.

Methods: This study included 42 children with brain injury (20 congenital, 22 acquired) and their caregiver mothers. Impact on Family Scale (IFS) was used to evaluate family impact and the Beck Depression Inventory for the level of depression in the mothers. The Functional Oral Intake Scale for the status of oral intake of children.

Results: This study illustrated that the levels of family impact ($z=-1.161$, $p=0.246$) and mothers' depression ($z=-0.177$, $p=0.860$) were similar in children with congenital and acquired brain injury. In this study, a relationship was found between the child's feeding position ($z=-0.684$, $p=0.043$) and family income level ($z=5.981$, $p=0.046$) with family impact.

Conclusion: The family impact of having children with disabilities may be related to many factors. In order to understand this mechanism, future studies should be planned with a holistic approach. The results of these studies, provide information to be used in the development of interventions for parents of children with disabilities.

Key Words: Brain Injury; Family; Child.

KONJENİTAL VE EDİNSEL BEYİN HASARI OLAN ÇOCUKLARIN AİLE ETKİLENİMLERİNİN İNCELENMESİ

ARAŞTIRMA MAKALESİ

ÖZ

Amaç: Çalışmanın amacı, konjenital ve edinsel beyin hasarı olan çocukların aile etkilenimlerini, annelerin depresyon düzeylerini ve aile etkilenimlerini etkileyebilecek faktörleri araştırmaktır.

Yöntem: Çalışmaya 42 beyin hasarı tanısı almış çocuk (20 konjenital, 22 edinsel) ve onlara bakım veren anneleri dahil edildi. Ailelerin etkilenimi ölçmek için Aile Etki Ölçeği (AEÖ) ve annelerin depresyon düzeyini belirlemek için Beck Depresyon Ölçeği kullanıldı. Çocukların oral alım durumları Fonksiyonel Oral Alım Skalası kullanılarak belirlendi.

Sonuçlar: Çalışma konjenital ve edinsel beyin hasarı tanısı olan çocuklarda aile etkilenimini ($z=-1.161$, $p=0.246$) ve annelerin depresyon düzeylerinin ($z=-0.177$, $p=0.860$) benzer olduğunu gösterdi. Çalışmada ayrıca çocuğun beslenme pozisyonu ($z=-0.684$, $p=0.043$) ve ailenin gelir düzeyinin ($z=5.981$, $p=0.046$) aile etkilenimi ile ilişkisi olduğunu saptandı.

Tartışma: Engelli çocuğa sahibi olmanın aile üzerindeki etkisi pek çok faktörle ilişkili olabilir. Bu mekanizmayı anlamak için gelecekteki çalışmaların holistik bir yaklaşımla planlanması gerekir. Bu çalışmaların sonuçları; engelli çocukların ailelerine yönelik müdahalelerin geliştirilmesinde kullanılacak bilgiler sağlayacaktır.

Anahtar Kelimeler: Beyin Hasarı; Aile; Çocuk.

INTRODUCTION

Brain injury in children may occur due to congenital, neurodevelopmental or acquired causes. Childhood brain injury may adversely affect the child's development in many respects (physical, cognitive, social, and behavioral). In addition to the effects of brain injury on the child, it has several implications on the family. It is a general view that having a member with a deficiency leads to significant jolts of the whole family system (1,2). Parents can be affected in different ways due to the consequences of pediatric brain injury. Disintegration, divorce, job and role loss, failure to cope, problem solving and communication problems are some of the negative impacts on the family (3). Finally, some families adjust better than others, but factors promoting this adaptation are poorly known (4).

It was shown that individuals with acquired disabilities and his family's capability of adaptation to the new situation and the transition to the admission process last longer than individuals with congenital disabilities. Individuals with congenital disabilities and families accept the situation more easily, and the transition between stages becomes faster (5). Although there are many studies in the literature showing that families of children with disabilities are affected by this situation (6,7), to our knowledge, there is no study to compare the family impact of children with congenital or acquired brain injury. By studying family impact in different conditions, more information can be obtained about the effects of families in this process. This new information would guide to determine the content of the support programs to be established for families. In this study, we planned to investigate the hypothesis that families with acquired disability and congenital disability who have children with disabilities will have different family impacts. This study aimed to investigate the family impact of children with congenital and acquired brain injury, the levels of depression in mothers and the factors that might affect family functioning.

METHODS

This study was carried out at Hacettepe University, Faculty of Health Sciences, Department of Occupational Therapy. Forty-four children who have been diagnosed by a pediatric neurologist as brain

injury due to congenital or acquired reasons were included in this study. Inclusion criteria for children were having a history of brain injury (>1 year). For mothers, the inclusion criteria were (a) not caring for any other individual, (b) being nineteen years of age and over, (c) illiterate, and (d) being without any known systemic, neurological, psychiatric disease, and physical problems. The only exclusion criterion was to refuse to participate the study. Information (e.g., visual problem, caregiving duration time) was obtained for each child from medical record and family. Written informed consent was obtained from the parents participated in this study. Children included in the study were divided into two groups as congenital and acquired. The necessary ethics committee approval (GO-17/838) was obtained from Hacettepe University Non-Interventional Research Ethics Committee.

The demographic data of the participant children and the family and the information about the diagnosis of the child were obtained from the general information form. In addition, the information about the diagnosis of children's hospital files was recorded.

Impact on Family Scale (IFS), which was validated in Turkish, was used to measure the impact of families (8). The IFS examines the level of influence of the family on four main headings as with financial burden, familial and social impact, personal strain, coping and total burden which is the sum of these parameters. At least 24 and a maximum of 96 points could be obtained from the scale. Higher item scores indicate a higher family impact.

The severity of depression was assessed using the Beck Depression Inventory (BDI) which was validated in Turkish (9,10). This inventory was created by Aaron Beck (11). It includes 21 item self-report using a four-point scale ranging from 0-3 and takes approximately 5-10 minutes to complete. According to the BDI, high scores indicate the increase in depression level.

The Gross Motor Function Classification System (GMFCS) was used to determine the level of gross motor function in children with cerebral palsy (CP) (12,13).

Table 1: Descriptive Characteristics of Children.

Characteristics of Children		Congenital Group (n=20)	Acquired Group (n=22)	p
Age (months) ^ϕ		89.05±36.62	93.04±38.64	0.811
Sex (n, %) ^ϕ	Girls	7 (35.0%)	8 (36.4%)	1.000
	Boys	13 (65.0%)	14 (63.6%)	
Visual Problems (n,%) ^ϕ	Yes	5(25.0%)	9 (40.9%)	0.444
	No	15 (75.0%)	13 (59.1%)	
Speech Problems (n,%) ^ϕ	Yes	20 (100%)	19 (86.4%)	0.233
	No	0 (0%)	3 (13.6%)	
Duration of Disease (months) ^δ		89.15±36.77	19.81±7.69	<0.001*

*p<0.05. ^ϕx² test. ^δMann-Whitney U.

The Functional Oral Intake Scale (FOIS), which is a valid, reliable and sensitive scale (14,15), was used to determine the oral intake of children. The FOIS is a two-part scale consisting of 7 levels (1: no oral intake, 7: unrestricted oral intake). Level 1-3 shows the tube feeding levels, while level 4-7 shows the oral intake levels. Required permissions

were obtained for all scales used in the study.

Statistical Analysis

Sample size calculation was done by G*Power Version 3.1.9.2 program (Franz Faul, Universitat Kiel, Germany). There were no similar studies in the literature. At the level of 5% type I error rate

Table 2: Demographic and Care-Giving Characteristics of Families.

Family Characteristics		Congenital Group (Mean±SD)	Acquired Group (Mean±SD)	p
Age of Mothers' (years) ^π		37.55±6.87	34.86±7.06	0.220
Mothers' Education (n,%) ^ϕ	Elementary/Secondary Schools	7 (35.0%)	8 (36.4%)	1.000
	High School/University	13 (65.0%)	14 (63.6%)	
Parents' Marital Status (n,%)	Married	19 (95.0%)	20 (90.9%)	NA
	Divorced	1 (5.0%)	1 (4.5%)	
	Widow	0 (0)	1 (4.5%)	
Mothers' Work Status (n,%)	Working	3 (15.0%)	3 (13.6%)	NA
	Not Working	15 (75.0%)	15 (68.2%)	
	Leaving Work due to Care	1 (5.0%)	4 (18.2%)	
	Retired	1 (5.0%)	0 (0)	
	None	17 (85.0%)	22 (100%)	
Caregiving Duration (n,%) ^ϕ	3-6 hours	6 (30.0%)	4 (18.2%)	0.131
	6-9 hours	4 (20.0%)	1 (4.5%)	
	≥9 hours	10 (50.0%)	17 (77.3%)	
Care Training (n,%) ^δ	Yes	0 (0)	1 (4.5%)	1.000
	No	20 (100%)	21 (95.5%)	
Care Salary (n,%) ^ϕ	Yes	9 (45.0%)	8 (36.4%)	0.799
	No	11 (55.0%)	14 (63.6%)	
Family Income Level (n,%) ^ϕ	0-2000 TL	5 (25.0%)	8 (36.4%)	0.331
	2000-4000 TL	10 (50.0%)	11 (50.0%)	
	4000-6000 TL	2 (10.0%)	0 (0)	
	>6000 TL	3 (15.0%)	3 (13.6%)	

^ϕx² test. ^πFisher's Exact test. ^δStudent's t test.

and 44% power, the study was performed with a total of 42 individuals. Statistical analysis was performed with IBM SPSS for Windows (version 22.0, Armonk, NY, USA). Numerical variables were expressed as mean±standard deviation or median (min-max), as appropriate. Nonparametric variables were expressed as frequencies and percentages. Chi-square test or Fisher's exact test was used to determine whether there were any differences between the independent groups according to categorical variables. The normal distribution was evaluated using Shapiro Wilks test, and the homogeneity of the variances by Levene test. When the parametric test assumptions were provided, independent groups were tested using Student t-test. Mann Whitney U test or Kruskal Wallis test was used for independent group comparisons when parametric test assumptions were not met. Descriptive levels of significance was $p < 0.05$.

RESULTS

This study was completed with 42 children and their mothers. Considering the characteristics of children, except for the disease and feeding duration, sex, visual and speech problems, and nutritional status were found to be statistically similar in terms of both groups ($p > 0.05$). Children in the congenital group was diagnosed with CP (n=20). According to GMFCS, 20% of children with CP were in level II, 10% in level III, 50% in level IV, and 20% in level V. Children in acquired group had traffic accident (n=14), cerebrovascular accident (n=5), brain tumor (n=2), and encephalitis (n=1). Four of the children were able to walk with restrictions, three were able to walk by using an assistive device, 12 were transported by wheelchair in the community, and

three were carried by wheelchair in all settings. The descriptive characteristics of children are shown in Table 1. The demographic and caregiving characteristics of families in the congenital and acquired group were statistically similar ($p > 0.05$, Table 2).

The IFS and BDI scores were similar between the mothers of children with congenital and acquired brain injury ($p > 0.05$, Table 3). When the factors that affect the IFS scores are examined, a significant relationship between feeding position with coping subscale ($p = 0.043$) and a significant relationship between family income level with personal strain subscale ($p = 0.046$, Table 4).

DISCUSSION

This study showed that the family impacts and mothers' depression levels were similar in children with congenital and acquired brain injury. In addition, a relationship was found between the child's feeding position and family income level with family impact.

The birth of a child with a disability or a diagnosis that leads to disability is a crisis that disrupts parents' expectations. After the diagnosis is verified, parents undergo many reactions and adaptations, such as shock, denial, anger, shame, anxiety, refusal, depression, grief, and acceptance (16). Understanding family adaptation to disability is crucial for promoting well-being in disabled children (4). One of the determining factors in the adaptation of families to disability is family dysfunction (17).

Although there was a substantial difference between the two groups in terms of duration of

Table 3: Comparison of the Results of the Impact on Family Scale and Mothers' Depression Level.

Parameters	Congenital Group (n=20) Median (min-max)	Acquired Group (n=22) Median (min-max)	p	
Beck Depression Inventory	14.50 (0-31.00)	14.00 (1.00-27.00)	0.860	
Impact on Family Scale	Financial Burden	9.50 (3.00-12.00)	10.00 (3.00-12.00)	0.838
	Familial and Social Impact	26.00 (9.00-35.00)	26.50 (9.00-34.00)	0.448
	Personal Strain	33.00 (12.00-59.00)	28.00 (10.00-40.00)	0.067
	Coping	6.50 (4.00-16.00)	6.00 (4.00-13.00)	0.990
	Total Impact	58.00 (21.00-84.00)	52.00 (24.00-71.00)	0.246

Mann-Whitney-u test.

Table 4: Factors Related to the Impact on Family Scale Scores.

Factors	Financial Burden		Familial and Social Impact		Personal Strain		Coping		Total Impact	
	Effect Size	p	Effect Size	p	Effect Size	p	Effect Size	p	Effect Size	p
Sex ^φ	0.181	0.247	0.169	0.280	0.212	0.175	0.056	0.720	0.164	0.293
Age ^η	0.112	0.480	0.112	0.482	0.010	0.948	0.089	0.575	0.054	0.732
Length of Time since Brain Injury ^η	0.013	0.932	0.081	0.611	0.210	0.181	0.105	0.508	0.098	0.537
Visual Problem ^φ	0.018	0.119	0.150	0.968	0.033	0.218	0.077	0.501	0.109	0.702
Speech Problem ^φ	0.153	1.000	0.106	0.712	0.126	0.818	0.147	0.963	0.111	0.747
FOIS ^φ	0.056	0.371	0.125	0.815	0.051	0.342	0.066	0.433	0.079	0.518
Feeding Position ^φ	0.150	0.975	0.084	0.545	0.025	0.167	0.006	0.043*	0.036	0.235
Feeding Duration Time ^φ	0.080	0.535	0.026	0.182	0.013	0.092	0.041	0.276	0.065	0.447
Mothers' Age ^η	0.046	0.774	0.109	0.493	0.269	0.085	-0.19	0.229	0.181	0.252
Mothers' Education ^φ	0.033	0.831	0.072	0.645	0.055	0.722	0.246	0.115	0.058	0.713
Mothers' Work Status ^φ	0.039	0.260	0.024	0.154	0.070	0.457	0.035	0.236	0.021	0.138
Caregiving Duration Time ^φ	0.127	0.827	0.113	0.738	0.156	1.000	0.049	0.328	0.060	0.390
Care Salary ^φ	0.213	0.173	0.060	0.700	0.193	0.218	0.139	0.372	0.257	0.100
Family Income Level ^δ	0.074	0.330	0.293	0.069	0.326	0.046*	0.226	1.000	0.290	0.071
Beck Depression Inventory ^η	0.126	0.427	0.055	0.729	0.185	0.241	0.092	0.563	0.205	0.193

Mann-Whitney U Test, ^φKruskal Wallis Test, ^ηSpearman Correlation Coefficient. FOIS: Functional Oral Intake Scale.

disease, this study did not make any difference in terms of family impact. It is common in the literature that individuals with a congenital disability develop a better adaptation than individuals with acquired disabilities (5,6), but the reasons for better adaptation of individuals according to congenital and acquired conditions are not adequately explained. However, the lack of adequate literature on congenital conditions may reflect an implicit assumption that people with this condition have less difficulty in adapting (18).

One study determined that family impact was related to the children's existing level of functioning two years after acquired brain injury (19). Another study, followed children with mild, moderate, and severe traumatic brain injury (TBI) at three, 12, and 36 months after injury (20). They found that deterioration in family functioning and relationships between 3 and 36 months after injury among the families of children with severe traumatic brain injury. However, these two studies only include individuals with acquired brain injury. Wade et al., followed children with moderate and severe traumatic brain injury and orthopedic injuries at a follow-up conducted an average of four years after

injury (21). They found no differences between the moderate and severe traumatic brain injury and orthopedic injuries groups on parents psychological symptoms and also family functioning.

Many studies have been conducted on the family effects of children with disabilities, but there is a limited study examining the impact of pediatric feeding problems on the family (22,23). The relationship between child's feeding position and family impact was determined in this study. Children with physical disabilities and cerebral palsy have a difficulties in participating to their daily routines/activities because of impairments in mobility and positioning (24). For instance, the families with disabled children stated that it was hard to play with their children in certain positions (lie on the floor or sit with the support) (25). Therefore, it is important to teach the family how to position a child with disabilities in the simplest and optimal way for their different daily activities. In addition, if necessary, also suitable adaptive devices and environmental modifications for positioning should be recommended in the rehabilitation program. This allows family to cope with these problems more easily. In further studies, it would be useful to

examine this issue thoroughly.

A disabled child is dependent on varying degrees to his parents. This is a source of stress for the family. Determining the stress level of parents who are responsible for the care of the child with functional disorders is an important variable that needs to be evaluated (26). Stress can be harmful when it is continuous and exceeds tolerable limits and can lead to depression-like situations. Mothers who are primarily responsible for the child's care take a more active role and make more efforts in solving these difficulties. The level of depression increases in caregivers associated with neurodevelopmental disorders and acquired diseases (16,27). In this study, mothers' had similar levels of mild depressive symptoms in both groups. The similarity of scores perhaps indicates that mothers' depressive symptoms have not decreased since diagnosis.

Thirty-five mothers who participated in this study were not working. Mothers reported that time requirements for providing care for a disabled child, and the absence of adequate budgetary and adequate child care restrict employment opportunities (28). In one study, mothers of children with severe disorders reported many employment problems related to their caregiving responsibilities: reduction of working hours, separation of work time, and the necessity for a change in mother's professional career. Many of the mothers of children with chronic health problems have linked their unemployment to the care needs of their children (29). However, it is stated that the financial situation is a priority for the family in families with disabled children (7). Therefore, it is essential to plan the studies on the long-term economic effects of families with disabled children.

In this study, only a few factors founded to have an impact on the family. To get more in-depth knowledge about the thoughts, feelings, and experiences of the families with a disabled child, further study using qualitative research methods is needed to provide a detailed and advanced analysis.

To our knowledge, this was the first study in the literature examining the family impacts of children with brain injury with different etiologies. The limitation of the study was not including the

impact of the acute period on families. Further study is needed to investigate the effects of family impact and depression on different periods of caregiving. Investigation of the possible factors related to family effects is of great importance to determine the needs of the family. The findings may be referenced in the future development of family interventions for families of children with brain injury.

In conclusion, having a disabled child is a unique experience for families and can affect all aspects of family functioning. This study showed that the family impacts and mothers' depression levels were similar in children with congenital and acquired brain injury. The study also pointed out the negative impact of difficulties to feeding a disabled child on the family. However, the impact of children's disability on the family seems to be related not only to the child's health status but also with economic, personal, social and contextual variables of the family. Therefore, it is crucial that future studies be carried out in a holistic perspective.

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Conflict of Interest: None.

Ethical Approval: Hacettepe University Non-Interventional Research Ethics Committee (No: GO-17/838).

Informed Consent: Written informed consent form was obtained.

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