ORİJİNAL ARAŞTIRMA ORIGINAL RESEARCH

DOI: 10.5336/medsci.2018-62949

A Comparison of Family Attention and Burnout in Families of Children with Disabilities and Families of Children without Disabilities

Engelli Çocuk Ailelerinin Aile İlgi ve Tükenmişlik Durumlarının Engelli Çocuğu Bulunmayan Ailelerle Karşılaştırılması

Haluk Habib KURTOĞLU[a],
Birgül ÖZÇIRPICI[a]

[a]Department of Public Health, Gaziantep University Faculty of Medicine, Gaziantep, TURKEY

Received: 01 Oct 2018
Received in revised form: 17 Sep 2019
Accepted: 02 Oct 2019
Available online: 07 Oct 2019

Correspondence:
Haluk Habib KURTOĞLU
Gaziantep University Faculty of Medicine, Department of Public Health, Gaziantep, TURKEY/TÜRKİYE
halukhabib@hotmail.com

ABSTRACT Objective: The aim of this descriptive-cross-sectional study was to compare interest and burnout levels in mothers of children with disabilities to the mothers of children without disabilities. **Materials and Methods:** A total of 194 people were selected representing mothers of children with disabilities (n=97) and mothers of children without disabilities (n=97) living in Gaziantep. The collected data was analyzed using descriptive statistics, and the Kruskal Wallis, Mann-Whitney U, Chi-Square and t-Tests. **Results:** The mean age of the mothers of children with disabilities was 32.71 ± 6.20, while the mean age of the mothers of children without disabilities was 34.65±7.96 (p=0.06). Of the mothers of children with disabilities, 10.3% were illiterate or had not completed primary school, while this figure was 9.30% among mothers of children without disabilities (p=0.841). Of the mothers of children with disabilities and children without disabilities, 94.90% and 95.90%, respectively, were housewives. Of the children with disabilities, 64.90% had intellectual disabilities, 18.60% had physical disabilities, and 16.50% had both intellectual and physical disabilities. Mothers of children with disabilities were more likely to have consanguineous marriages (55.80%) compared to mothers of children without disabilities (42.20%) (p=0.055). According to the average score of the Maslach Burnout Inventory-Emotional Exhaustion Subscale, the mothers of children with disabilities were more likely to have a high average (13.33±9.64) than mothers of children without disabilities (7.43±7.56) (p=0.000). There was no statistically significant difference between the scores of the Maslach Burnout Inventory-Personal Achievement subscale of the mothers of children with disabilities (27.79 ± 5.24) and mothers of children without disabilities (26.86±4.82) (p=0.201). There was no statistically significant difference between the scores of the McMaster Family Assessment Device-General Functioning sub-dimension of the mothers of children with disabilities (1.76±0.52) and mothers of children without disabilities (1.68±0.55) (p=0.342). **Conclusion:** If a child is diagnosed as having a disability, the family counseling process should be initiated and the family should be given correct information about the process. Providing family and couple therapy for all families may be beneficial in reducing stress and burnout.

Keywords: Mothers of children with disabilities; burnout; Maslach; McMaster

ÖZET Amaç: Bu çalışmada engelli çocuğa sahip annelerin ilgi ve tükenmişlik durumlarının normal çocuğa sahip annelerle karşılaştırılması amaçlandı. **Gereç ve Yöntemler:** Tanımlayıcı-kesitsel tipteki bu çalışmaya Gaziantep ilinde yaşayan engelli (n=97) ve sağlıklı (n=97) çocuğa sahip annelerden örneklem seçerek 194 kişi alındı. Toplanan veriler tanımlayıcı istatistikler, Kruskal Wallis, ki-kare ve t testleri kullanılarak analiz edildi. **Bulgular:** Çalışmamızda engelli çocuğa sahip annelerin yaş ortalaması 32,71±6,201 iken sağlıklı çocuğa sahip annelerin yaş ortalaması 34,65±7,956 (p=0,06) idi. Engelli çocuk annelerinin %10,30'u okuryazar değildi veya ilkokulu bitirmemişti. Sağlıklı çocuk annelerinin %9,30'u okuryazar değildi veya ilkokulu bitirmemişti (p=0,841). Engelli çocuk annelerinin %94,80'i ev hanım idi. Sağlıklı çocuk annelerinin %95,90'ı ev hanımıydı. Çalışmamızda engelli çocukların %64,90'ının bedensel engelli, %18,60'ının zihinsel engelli, %16,50'sinin hem zihinsel hem bedensel engelli oldukları tespit edildi. Engelli çocuk annelerinin %55,80'i akraba evliliği yapmışken, sağlıklı çocuk annelerinin %42,20'si akraba evliliği yapmış olarak belirlendi (p=0,055). Maslach Tükenmişlik Ölçeği-Duygusal Tükenmişlik alt boyutundan aldıkları puan ortalamalarına göre engelli çocuğu olan annelerin duygusal tükenmişliği (13,33±9,64), sağlıklı çocuğu olan annelere (7,43±7,56) göre istatistiksel olarak anlamlı düzeyde yüksek bulundu (p=0,000). Engelli (27,79±5,24) ve sağlıklı (26,86±4,82) çocuğu olan annelerin Maslach Tükenmişlik Ölçeği-Kişisel Başarı alt boyutundan aldıkları puan ortalamaları arasında istatistiksel olarak anlamlı bir fark saptanmadı (p=0,201). Engelli (1,76±0,52) ve sağlıklı (1,68±0,55) çocuğu olan annelerin McMaster Aile Değerlendirme Ölçeği-Genel İşlevler alt boyutundan aldıkları puan ortalamaları arasında istatistiksel olarak anlamlı bir fark saptanmadı (p=0,342). **Sonuç:** Çocuğun engelli olduğu tespit edilir edilmez aile danışmanlığı süreci başlatılarak çocuğun engeli hakkında ailelere doğru bilgilerin verilmesi gerekmektedir. Tüm ailelere aile ve çift terapisi uygulamasının yapılması, stres ve tükenmişliği azaltmada fayda sağlayabilir.

Anahtar Kelimeler: Engelli çocuk annesi; tükenmişlik; Maslach; McMaster

Families constitute the smallest unit of society and children have an important place in them. The child is generally regarded as the product of the mother and the father, a means by which to continue the family line and to ensure the future security of the parents.[1]

While even the birth of a healthy child brings about many changes and challenges, having a child with disabilities at birth or later in life can cause strains on family life leading to a deterioration of the relationship between the spouses. Having a child with disabilities brings with it a number of particular challenges, whatever the nature of the disability. These challenges can be categorized as psychological, financial, educational and lifestyle challenges (socio-cultural and leisure activities, etc.), as well as strains on the family environment and interactions with the social environment. Mothers usually take a more active role in overcoming these challenges and show more effort.[2]

Counseling provided to families with children with disabilities can help parents cultivate more realistic expectations with regards to their children and reduce stress in the family. Informing mothers about their children's rehabilitation process will help to increase their self-confidence and reduce anxiety, stress and burnout as the family learns to deal with the requirements of their child.[3]

As a healthy society can only be achieved with healthy families, the goal should be to improve the physical, spiritual and social well-being of families of children with disabilities. For this reason, it is important to identify the problems and challenges faced by families of children with disabilities and offer them social support accordingly.

This study aims to compare the burnout levels of mothers of children with disabilities to that of mothers of children without disabilities, as well as identifying the challenges faced by mothers of children with disabilities and coming up with targeted solutions to help removing those challenges.

MATERIAL AND METHODS

The population of this descriptive, cross-sectional study is made up of individuals in Gaziantep with children with disabilities. The prevalence of burnout syndrome in the whole population was accepted as 4.2%, with a formula of n: $Z^2\alpha_{/2} \times P\ (1\text{-}P)/d^2$ as the sample size and at least 97 individuals per each group and at least 194 families in total were targeted whereby the prevalence was accepted as α: 0.05, d: 0.04 in the 95% confidence interval.[4] In this study, questionnaires prepared by examining the current literature were used. The questionnaire contains questions about the socio-demographic characteristics of the family, the degree of kinship of the spouses, how many children they have, the child's type of disability, support given to the spouse caring for the child with a disability, and concerns about their child's future. In order to carry out the research in 20 rehabilitation centers selected from 54 rehabilitation centers in the province with the help of random numbers table, Governorate consent was taken from the Gaziantep Provincial National Education Directorate.

Rehabilitation centers were visited and information about the research was given to mothers who brought their children to the training center with a free transport service. Individuals with children with disabilities who were accepted to participate in our research were interviewed one by one, verbal approvals were obtained and face-to-face interviews were conducted using the questionnaires. Data concerning the age, educational levels, occupations, total number of children and socioeconomic characteristics of the mothers of children with disabilities were examined. Through data-matching and picking using a random number of tables, home visits were made to families in various neighborhoods of Gaziantep (Merveşehir St., Boyno St., Mimar Sinan St., Güneykent St.) on the basis of their socio-economic status to recruit mothers of children without disabilities to the survey. Individuals with children without disabilities who were accepted to participate in our research were interviewed one by one and verbal approvals were obtained and face-to-face interviews were conducted using the questionnaires. The educational levels of the parents were classified according to the International Standard Classification of Education (ISCED, 1997) and their professions ac-

cording to the International Standard Classification of Occupations (ISCO, 2008).

In addition, the McMaster Family Assessment Scale (FAS) and Maslach Burnout Scale (MBS) were applied to the mothers.

McMASTER FAMILY ASSESSMENT SCALE

A scale developed by Epstein in 1983 as a result of the clinical application of the McMaster Family Function Model on families, this is a self-assessment scale that determines whether the family fulfills its functions and assesses them according to the perceptions of family members. The scale consists of a total of 60 items and seven sub-scales. The sub-scales are problem solving, communication, roles, emotional response, showing attention, behavior control and general functions. In our study, only the General Functions sub-scale was applied. Scale scores range from 1.00 to 4.00, and an increase in scores (>2.00) suggests a disorder in family functions.[5] The adaptation, validity and reliability of the scale were tested by Bulut. For the Turkish version of the scale, it is stated that the test-retest reliability coefficients of the sub-scales range from 0.62 to 0.90 and the internal consistency coefficients range from 0.38 to 0.86.[6]

In our study, the Cronbach Alpha internal consistency coefficients for the General Functions sub-scales of the McMaster FAS, which we applied to mothers of children with disabilities and mothers of children without disabilities, were 0.73 for "healthy family questions" (question numbers 6, 16, 26, 36, 46, 56) and 0.76 for "unhealthy family questions" (question numbers 1, 11, 21, 31, 41, 51).

THE MASLACH BURNOUT SCALE

The Maslach Burnout Scale was developed by Maslach and Jackson in 1981. There are 22 items in the original form of the scale grouped under three main dimensions. There are 9 items in the Emotional Burnout dimension, 8 in the Personal Achievements dimension, and 5 in the Desensitization dimension. Each sub-scale is scored separately. High scores from the Emotional Burnout and Desensitization sub-scales and low scores from the Personal Achievements sub-scale indicate high levels of burnout. Average scores from all three scales point to moderate exhaustion.[7]

The MBS was adapted to Turkish by Ergin. During a study with a sample group of 235 individuals from six different professions during the adaptation process, it was seen that the six-step response options in the original form were not suitable for the Turkish culture and so the number of options was reduced to five. The validity studies conducted for the Turkish form of the scale have shown that the three-factor structure is valid in our culture. The Cronbach Alpha internal consistency coefficients for the sub-scales of the scale were calculated as 0.83 for Emotional Burnout, 0.72 for Personal Achievements, 0.65 for Desensitization, and the test-retest reliability coefficients were 0.83 for Emotional Burnout, 0.67 for Personal Achievement and 0.72 for Desensitization.[8]

Pelsma, Roland, Tollefson, and Wigington examined the validity of the MBS when evaluating parental exhaustion in housewives with young children and found that two of the three dimensions were consistent with the original factor's structure. Findings show that parental and job burnout differs in terms of the desensitization dimension, but that there is an important similarity in terms of emotional exhaustion and the sensation of decreasing personal success.[9]

Similar to the research conducted by Duygun, Pelsma et al., the phrases "people I come across as part of my job" and the term "job" in the adapted version of the MBS were replaced with the phrases "my child's care" and "my child" as needed. In order to determine whether the three factors of emotional burnout, desensitization and personal achievements, which are the sub-scales in the original form of the MBS, apply to the sample of mothers of children with intellectual disabilities and mothers of children without disabilities, Duygun did a factor analysis of data from the sample of both groups. Following the analysis, he reported that the MBS items were collated under the two factors of "emotional burnout (items 1, 2, 3, 5, 6, 8, 10, 11, 13, 14, 16, 20, 22)" and "personal achievements (items 4, 7, 9, 12 , 17, 18, 19, 21)" and that the 15th item in its original form was removed from the scale be-

cause it was below the factor loading of 0.30, and did not load on the two factors. The Cronbach Alpha internal consistency coefficients for the subscales of the scale were 0.80 for Emotional Exhaustion and 0.80 for Personal Achievement. A high score of "emotional burnout" and a low score of "personal achievement" from the scale comprising of 21 items are considered to point towards high levels of burnout.[3]

The Cronbach Alpha internal consistency coefficients for the sub-scales of the MBS we applied to both groups of mothers were 0.84 for Emotional Exhaustion and 0.73 for Personal Achievement.

The obtained data was uploaded to the SPSS (Statistical Package for the Social Sciences) 21.0 statistical package program. The descriptive statistics were determined and Kruskal-Wallis, Chi-Square and t-Test were used for analyzing data. The P value <0.05 was accepted as statistically significant in the analyses.

The study was carried out in accordance with the Declaration of Helsinki 2008 Principles and an ethics committee approval numbered 2017/270 was obtained from Gaziantep University Clinical Trials Ethics Committee.

RESULTS

The mean age of mothers of children with disabilities was 32.71±6.201 (range 21-53), while the mean age of mothers of children without disabilities was 34.65±7.956 (range 21-61) and there was no significant difference between the groups' mean age (p=0.06). Of the mothers of children with disabilities, 41.20% had no blood ties with their spouses, while this rate was 57.80% for the mothers of children without disabilities. Although there was no significant difference between the two groups in terms of consanguineous marriage, the percentage of 1st degree consanguineous marriage (uncle, aunt, cousins from the mother's side) was 33.00% in families of children with disabilities, while this ratio was 20.60% (p=0.055) in families of children without disabilities.

Both groups of mothers were found to have been "secondary school, vocational secondary school and primary school" (43.30% and 41.40%) graduates. There was no significant difference between the educational levels of the groups (p=0.841).

It was determined that both groups of mothers were included in the group of "unskilled workers" (housewives) (94.90% and 95.90%). There was no significant difference between the occupational classification of the two mother groups (p=0.720) (Table 1).

It was determined that 49.50% of fathers of children with disabilities had graduated from "secondary school, vocational secondary school and primary school", while 21.60% of them had graduated from high school. It was also determined that 45.40% of fathers of children without disabilities had graduated from "secondary school, vocational secondary school and primary school", while 26.80% of them had graduated from high school. There was no significant difference between the educational levels of the groups (p= 0.558).

The economic status perceptions of the two groups of mothers were significantly different (p = 0.008). In a further analysis, it was found that this difference was due to the fact that it was mostly the mothers of children with disabilities who stated that their economic situation was 'bad' (Table 2).

Of the mothers who participated in the study, 90 (92.80%) had one child with a disability, while 7 (7.20%) had two children with disabilities.

In our study, it was found that 11.40% of mothers of children with disabilities had 1 child, 37.10% 2 children and 51.50% 3 or more children, while 3.10% of mothers of children without disabilities had 1 child, 28.90% 2 children and 68.00% 3 or more children. The distribution of the number of children of the mothers in both groups was significantly different (p=0.02). In a further analysis, it was found that this difference was due to the fact that more mothers of a child with a disability had one child (Table 2).

24.80% of mothers of children with disabilities rated the support they got from their spouses in the care of their children with disabilities as "good",

TABLE 1: Distributions of the mothers of children with disabilities and the mothers of children without disabilities according to some socio-demographic variables.

Variable	Mothers of children with disability		Mothers of children without disability		
	Mean	Min-Max	Mean	Min-Max	p*
Age	32.71±6.20	21-53	34.65±7.96	21-61	p=0.06
	Number	%	Number	%	χ^2 p
Marital Status					
Married	93	95.90	96	99.00	χ^2=1.848
Not Married	4	4.10	1	1.00	p=0.174
Consanguineous Marriage					
1.Degree relative	32	33.00	20	20.60	χ^2=5.784
1. Degree distant relative	25	25.80	21	21.60	p=0.055
Not marry a relative	40	41.20	56	57.80	
The Level of Education (ISCED)					
Illiterate	6	6.20	3	3.10	
Literate but had not finished school	4	4.10	6	6.20	
Primary school	14	14.40	12	12.20	χ^2=2.057
Secondary school, vocational secondary school	42	43.30	40	41.40	p=0.841
High school	25	25.80	30	30.90	
University	6	6.20	6	6.20	
Occupation (ISCO)					
Professional occupational groups	3	3.10	1	1.00	
Employees working in office services	1	1.00	1	1.00	χ^2=1.339
Service and sales staff	1	1.00	2	2.10	p=0.720
Unskilled workers**	92	94.90	93	95.90	
Total	97	100.00	97	100.00	

*t-Test, **Being a housewife has been classified as a non-qualified job.

23.70% as "average", 19.60% as "very good", 17.50% as "none" and 14.40% as "little". In addition, 51.60% of mothers of children with disabilities answered "yes" and 48.40% answered "no" to the question of whether they received support for the care of their children with disabilities from the other family members (grandmothers, aunts, siblings, etc.).

The mothers stated that they spent an average of 12.72±9.28 hours per day (min: 1 hour, max: 24 hours) on caring for their children with disabilities. The mean age of the children with disabilities (n: 104) in our study was 5.71±3.91 years (range 1-24).

In our study, 57.70% of the mothers answered "congenital", while 42.30% answered "following birth" in response to the question "How long has your child had a disability?" 75.00% of mothers who responded "congenital" stated that they received prenatal care during their pregnancy (minimum 4 medical checks, blood pressure measurement, blood-urine analysis, etc.), while 25.00% stated they did not.

It was determined that 64.90% of the children with disabilities had a physical disability, 18.60% had an intellectual disability, and 16.50% had both intellectual and physical disabilities.

While 68.00% of mothers of children with disabilities stated they were not receiving any sort of state aid (disability benefit, care pension, etc.), 32.00% stated that they received state aid.

TABLE 2: Comparison of the economic status, the number of children, and psychiatric drug usage of the mothers of children with disabilities and the mothers of children without disabilities.

Economic status	Mothers of children with disability		Mothers of children without disability		χ^2	p
	Number	%	Number	%		
Bad	20	20.60	7	7.30	χ^2=9.763	p=0.008
Normal	73	75.30	79	81.40		
Good	4	4.10	11	11.30		
Total	97	100.00	97	100.00		
Number of children	***Mothers of children with disability**		**Mothers of children without disability**		χ^2	p
	Number	%	Number	%		
1	11	11.40	3	3.10		
2	36	37.10	28	28.90	χ^2=7.778	p=0.02
3 and up	50	51.50	66	68.00		
	Total	97	100.00	97	100.00	
Psychiatric drug usage	**Mothers of children with disability**		**Mothers of children without disability**		χ^2	p
	Number	%	Number	%		
Yes	22	22.70	10	10.30	χ^2=5.389	p=0.02
No	75	77.30	87	89.70		
Total	97	100.00	97	100.00		

*This refers to the sum of children with disabilities along with their siblings who do not have disabilities.

The use of psychiatric medication at least once in their lifetime was found to be significantly higher among the mothers of children with disabilities (p=0.02) (Table 2).

In our study, 56.70% of mothers of children with disabilities stated they did not want to have children again, while 43.30% stated that they wanted to have children again.

Of mothers of children with disabilities, the wish of those with one child to have children again was significantly higher (p=0.015) (Table 3).

The two groups of families were in the category of healthy functioning families according to the FAS-General Functions scale (score average <2). The emotional burnout levels of the mothers of children with disabilities was found to be significantly higher than that of the mothers of children without disabilities according to the Emotional Burnout sub-scale (p=0.000) of the MBS. There was no statistically significant difference between the mean MBS-Personal Achievements sub-scale scores of the two groups of mothers (p=0.201) (Table 4).

There was no significant difference between the average scores of mothers from the sub-scales of the FAS and the MBS in terms of spousal support with the care of the child with a disability, support from other family members, age of the child with a disability and additional costs to the family budget through the child with a disability (p>0.05) (Table 5).

There was no significant difference between the scores obtained for mothers of children with disabilities from the sub-scales of the FAS-General Functions, MBS-Emotional Burnout, MBS-Personal Achievements according to their economic status ("bad", "average", "good") (Kruskal-Wallis; p=0.884, p=0.460, p=0.289).

While there was no significant difference between the scores obtained for the mothers from the sub-scales of the FAS-General Functions and the MBS-Emotional Burnout (Kruskal-Wallis, p=0.285, p=0.193) according to their child's type of disability (intellectual, physical and both), there was a significant difference between the scores they received from the MBS-Personal Achievements sub-scale (Kruskal-Wallis; p=0.012). In a further

TABLE 3: Distribution of the desire of mothers of children with disabilities to have another child according to their current number of children.

	Yes		No		Total		χ^2
Number of Children	Number	%	Number	%	Number	%	p
1	9	81.80	2	18.20	11	100.00	
2	16	44.40	20	55.60	36	100.00	χ^2=8.428
3 and up	17	34.00	33	66.00	50	100.00	p=0.015
Total	42	43.30	55	56.70	97	100.00	

TABLE 4: Distribution of average points scored by the mothers of children with disabilities and the mothers of children without disabilities from the sub-scales of FAS and the MBS.

Rating Scale	Average points by the mothers of children with disabilities ±S	Average points by the mothers of children without disabilities ±S	p*
FAS-General Functions	1.76±0.52	1.68±0.55	0.342
MBS-Emotional Burnout	13.33±9.64	7.43±7.56	0.000
MBS-Personal Achievements	27.79±5.24	26.86±4.82	0.201

*t-Test.

FAS: Family Assessment Scale, MBS: Maslach Burnout Scale.

TABLE 5: Distribution of the scores from the sub-scales of the FAS and the MBS in terms of spousal support in the care of the child with a disability, support from the other family members, age of the child with a disability, and additional costs to the family budget through the child with a disability

	Spousal Support, X±S		
Rating Scale	Very Good-Good	Normal-Few-Never	p*
FAS-General Functions	1.65±0.47	1.84±0.55	0.086
MBS-Emotional Burnout	14.14±9.78	12.69±9.58	0.464
MBS-Personal Achievements	26.74±6.27	28.61±4.13	0.081
	Support from Other Family Members, X±S		
	Yes	No	
FAS-General Functions	1.73±0.52	1.78±0.53	0.627
MBS-Emotional Burnout	12.96±8.99	13.72±10.37	0.699
MBS-Personal Achievements	28.12±5.12	27.42±5.40	0.517
Age of the Child with a Disability. X±S			
	Age of the Child with a Disability, X±S		
	≤5 age	≥6 age	
FAS-General Functions	1.79±0.49	1.72±0.56	0.499
MBS-Emotional Burnout	13.00±10.01	13.67±9.35	0.736
MBS-Personal Achievements	27.57±5.21	28.00±5.32	0.689
	Additional Costs through the Child with a Disability, X±S		
	Too much/more	Medium/Less/Too little	
FAS-General Functions	1.72±0.53	1.79±0.52	0.459
MBS-Emotional Burnout	14.31±10.63	12.37±8.57	0.323
MBS-Personal Achievements	28.31±4.52	27.27±5.87	0.328

*t-Test.

FAS: Family Assessment Scale, MBS: Maslach Burnout Scale.

analysis, it was determined that this difference was due to the fact that mothers with children with intellectual disabilities had lower scores on the subscale of the MBS-Personal Achievements.

Mothers of children with disabilities were found to be significantly more concerned about the future of their children than the mothers of children without disabilities (p=0.02) (Table 6).

When we asked the mothers about their concerns about the future of their children the open-ended questions such as "What concerns do you have about your child's future?", the mothers of children with disabilities responded as follows:

- "Will he be able to walk? Will he be able to talk? Will he be able to keep up with his peers?"

- "Will she be able to talk properly? Will she be able to overcome her shyness?"

- "How well will my ex-husband's new wife look after him?"

- "Will her hearing problems get worse?"

- "How will he manage at school? Will he be able to express himself?"

- "I want her to receive a good education and make her way in life without being dependent on anyone else."

- "I am worried about his language development, education, what he will feel like in his teenage years, whether he will marry, whether he will have any children."

- "I am worried that she might not get the education she needs, get a proper job or end up single."

- "Will he able to get to the same level as his or peers?"

- "Who will look after her if something happens to me? Will there ever be a time when she'll be able to look after herself?"

- "Will he be able to talk? Will he be able to go to school? Will he be able to manage by himself? Will he be able to socialize with others?"

- "Who can we trust in our current situation?"

- "Will she be able to walk properly? How will she manage at school? Will she be able to get a job?"

- "I am concerned about my child's introversion due to the problem with his arm, he always gets unwanted attention and I fear that his arm might never get back to being how it once was."

- "I'm concerned that my child may not be able to walk again."

- "My child will always need someone to look after him."

- "Will she be able to manage by herself?"

- "Will my child be able to act like a normal child? Will she find it easy to socialize with others?"

- "Will he be able to continue his education and get a job? Will he be able to get a driver's license and drive a car?"

- "Will her blindness cause issues with her education or social life?"

- "I am concerned that he may be bullied at school or may lose his hearing aid."

- "I fear that she may be looked down upon by society."

- "How will he manage at school when I am not around with the current state of his legs?"

- "Will he be able to go to school? Will my child have friends?"

TABLE 6: Distribution of the mothers of children with disabilities and the mothers of children without disabilities according to their concerns about the future of their children.

	Mothers of children with disability		Mothers of children without disability		
Concerns about the Future of their Children	Number	%	Number	%	p
Yes	90	92.80	55	56.70	χ^2=5.389
No	7	7.20	42	43.30	p=0.02
Total	97	100.00	97	100.00	

- "Will she be able to walk? Will my child be able to manage by herself? Will society accept her?"

- "My child suffered from West syndrome once, and overcame it. Now I am worried that the condition might return someday."

- "I am concerned about what the future holds for my twins."

- "Will my child be able to tend to his personal needs on his own and will he have a future?"

- "I am worried that my child will lose his self-confidence and become a recluse, not being able to manage on his own."

- "I am worried that I may not be able to meet all my child's needs."

- "I am concerned that my child might be looked down upon and excluded from society."

Meanwhile, mothers of children without disabilities responded:

- "I am worried that I may not be able to meet all my child's needs."

- "All my concern is giving them a good education and teaching them good morals."

- "Will my child get a good education and be healthy?"

- "I am concerned that my child is growing up in these tough times. What if something bad happens to him?"

- "What will my child's financial situation be like, and her lifestyle and education?"

- "There are terror attacks all the time, and we live in a climate of war."

- "Will my child get a good education and a good job?"

- "I am concerned about the worsening of the economy, about my child having the wrong sort of friends and receiving a bad education."

- "I am concerned about family problems."

- "I am concerned about my child taking up with the wrong sort of people and developing bad morals."

- "Will my child experience financial hardships? I am concerned about whether my husband can be the kind of father that my child needs."

- "I am concerned about the area we live in."

- "The constant climate of war makes me nervous, and the new generation are antisocial and addicted to the internet."

- "I am concerned about the constant environment of instability in the country and social media addictions."

- "I have serious doubts about justice being served in the case of those who commit crimes against children."

As a result of our binary comparisons, there were significant differences between the mothers of children with disabilities and the mothers of children without disabilities for some variables. These variables were economic status, number of children, psychiatric drug usage and concerns about the future of their children.

Because binary comparisons may cause some effects to be overlooked, these variables were evaluated by multivariate regression analysis. The effects of these variables on emotional burnout were examined.

Regression analysis revealed a statistically significant model. (p=0.000). According to the model, having a child with a disability alone increased the mean score of MBS-Emotional Burnout by 4.698 points (p=0.01). Psychiatric drug usage increased the mean score of MBS-Emotional Burnout by 5.072 points (p=0.03). It was found that the economic status (p=0.448), the number of children (p=0.087) and concerns about the future of their children (p=0.160) did not make a significant difference on the average score of MBS-Emotional Burnout scores.

DISCUSSION

In this study, which we conducted with a sample of mothers of children with disabilities and mothers of children without disabilities in the city center of Gaziantep, according to ISCO, most mothers of children both with and without disabilities are un-

skilled workers or housewives (94.80% and 95.90%). The similarity between the two groups is due to the pairings made during data collection. Taşdemir et al. in Ankara revealed that 90.60% of mothers of children with disabilities were housewives, 4.20% workers, 3.10% public sector workers and 2.10% self-employed.[10] According to the Turkey Population and Health Survey 2013, 69.00 of women do not actively work.[11] Having children with disabilities may be preventing women from pursuing careers.

As for consanguineous marriage among mothers of children with disabilities, 33.00% of them married a first degree relative, 25.80% of them married a first degree distant relative and 41.20% of them did not marry a relative. Regarding consanguineous marriage among mothers of children with disabilities, 20.60% of them married a first degree relative, 21.60% of them married a first degree distant relative and 57.80% of them did not marry a relative. In a study conducted by Sertel et al. with mothers of children with disabilities in Düzce, it was determined that 14.50% were married their relatives, while 85.50% were not married their relatives.[12] The prevalence of consanguineous marriage across Turkey is 23.20%.[13] In our study, this rate was 58.80% in total. It is thought that the prevalence of consanguineous marriages can vary according to the cultural characteristics of the region where the study is conducted. Consanguineous marriage increases the likelihood of disability, especially through autosomal recessive genetic diseases. For this reason, the prevention of consanguineous marriages is an important area of intervention to reduce disabilities.

It was found that the maximum percentage of mothers of children with disabilities and mothers of children without disabilities with 3 or more children were 51.50% and 68.00% respectively. In a study conducted by Şentürk et al. in Tekirdağ, it was found that 37.50% of mothers of children with disabilities had 1 child, 60.00% 2 children and 2.50% 3 or more children, while 30.00% of mothers of children without disabilities in the same study group were found to have 1 child, 62.50% 2 children and 7.50% 3 or more children.[14] In many studies, it has been observed that the fertility rate in our country increases gradually from west to east.[14-16] Difficulties associated with the treatment and care of children with disabilities and the fear of having another child with a disability suggest that families of children with disabilities tend to have fewer children than those of children without disabilities.

In our study, 24.80% of mothers of children with disabilities rated the support they got from their spouses in the care of their children with disabilities as “good”, 23.70% as “average”, 19.60% as “very good”, 17.50% as “none” and 14.40% as “little”. In a study conducted in our country, 12.50% of mothers of children with disabilities rated the amount of support they got from their spouses in the care of their children with disabilities as “none”, 30.00% as “very little”, 45.00% as “little”, 10.00% as “a lot” and 2.50% as “a great deal”.[14] It can be argued that childcare and housework in areas with a dominant patriarchal society structure are considered to be the main duties of the woman and that this situation has further increased the burden on the mother with regards to the care of a child with a disability.

In our study, 40.30% of the mothers were found to spend 0-6 hours, 13.50% 7-12 hours and 46.20% 13-24 hours on their children with disabilities. According to these results, mothers spend a major part of their daily lives taking care of their children with disabilities. Not having any leisure time can be a significant cause of stress and exhaustion.

In the present study, 22.70% of mothers of children with disabilities were found to have used psychiatric medication at least once in their lifetime, as opposed to 10.30% of mothers of children without disabilities. In a study conducted by Özcanarslan et al. in Şanlıurfa, 31.00% of the children with disabilities had “no depression”, 32.20% had “moderate depression”and 36.80% had “severe depression” according to the Beck Depression Scale scores.[17] In a study conducted in our country, the Beck Depression Scale scores of the mothers of children with disabilities were significantly higher than those of mothers of children without disabil-

ities.[14] Having a child with a disability may cause parents to use more psychiatric medications than the normal population by disrupting their mental health.

In our study, 56.70% of mothers of children with disabilities stated they did not want to have children again, while 43.30% stated that they wanted to have children again. According to a study conducted in Turkey, 66.20% of mothers of children with disabilities stated they did not want to have children again, while 33.80% stated that they wanted to have children again.[18] In our study, 79.30% of mothers whose first child had a disability wanted to have more children, while 74.60% of mothers whose last child had a disability did not want to have more children. When those with one child were excluded from the group of parents whose first child had a disability, the percentage of those not wanting to have more children rose to 86.70%. The desire to have a child without disabilities by those whose first child has a disability can be explained by the parents' reasoning that a second child might help with the development of the first child with a disability.

In our study, both family groups were accepted as healthily functioning families according to the FAS-General functions sub-scale (1.76±0.52/1.68±0.55). In a study conducted by Özşenol et al. on mothers of children with disabilities in Ankara, the mean scores of mothers from the FAS-General Functions sub-scale ranged from 1.57 to 1.93 according to some variables and they were placed in the healthily functioning families category.[2] In a study conducted by Kırbaş et al. on mothers of children with Down Syndrome in Erzurum, the mean scores from the FAS-General Functions sub-scale ranged from 1.26 to 1.83 according to some variables and were placed in the healthily functioning families category.[19] The FAS-General functions sub-scale aims to measure healthy communication within the family. Having a child with a disability can help strengthen family ties and the amount of support given.

The emotional burnout levels of the mothers with children with disabilities was found to be statistically higher than that of mothers who had children without disabilities according to the Emotional Burnout sub-scale of the MBS (13.33±9.64/7.43±7.56). The disappointment in having a child with a disability, limited improvements in the child's condition despite all the effort shown and isolation from society may explain the emotional exhaustion of mothers. There was no statistically significant difference between the mean MBS-Personal Achievements sub-scale scores of mothers of children with disabilities and mothers of children without disabilities (27.79±5.24/26.86±4.82). Shocked as most mothers are at finding out that their child has a disability, they then tend to accept the situation and motivate themselves to provide their child with the best care and attention. This may explain the high scores obtained by mothers of children with disabilities in the MBS-Personal achievements sub-scale. In a study conducted by Duygun on mothers with healthy children and children with disabilities, the emotional burnout levels of mothers of children with disabilities was found to be statistically higher than that of the mothers who had children without disabilities according to the Emotional Burnout sub-scale of the MBS (16.42±9.48/12.50±8.59), while there was no statistically significant difference between the two groups in terms of their scores from the MBS-Personal Achievements sub-scale (24.65±5.62/25.68±5.90).[3] The results in this study are similar to those in our study.

While there was no significant difference between the scores of the sub-scales of the FAS and the MBS-Emotional Burnout according to their child's type of disability (intellectual, physical and both), there was a significant difference between the scores they received from the MBS-Personal Achievements sub-scale. In a further analysis, it was determined that this difference was due to the fact that mothers with children with intellectual disabilities had lower scores on the sub-scale of the MBS-Personal Achievements. When compared to a physical disability, intellectual disabilities could prevent mothers more from being successful with the maintenance and care of their children.

In our study, 92.80% of mothers of children with disabilities were concerned about their child's

future, while 56.70% of mothers of children without disabilities were worried about their child's future. While the concerns of the mothers of children with disabilities mainly focus on meeting the child's basic care and needs and his or her future situation, the concerns of mothers of children without disabilities focus on the child's education and prospects of having a prosperous life. In addition, the climate of war during the time when the study was conducted, increasing terrorist incidents, and security concerns were the hallmarks of the mothers' anxieties.

CONCLUSION

It has been found that mothers of children with disabilities tend to have fewer children than mothers of children without disabilities. It has also been determined that the mothers of children with disabilities are less likely to be married than mothers of children without disabilities and that mothers of children with disabilities have more consanguineous marriages than mothers of children without disabilities. The frequency of consanguineous marriages among mothers of chil dren with disabilities has been found to be higher than the general population. Consanguineous marriages are one of the most important risk factors causing child disabilities that can be avoided. It is important that health policies are developed in a way that reduces the frequency of consanguineous marriages.

It has been determined that the participation of the mothers of children with disabilities in working life is low when compared to the Turkey Population and Health Survey 2013. The establishment of appropriate employment areas for mothers of children with disabilities taking into account their children's care needs can be an important contribution to the family budget. It is thought that giving priority to the employment of fathers of children with disabilities in the public sector is something a social state should do.

According to the McMaster FAS, the mothers of children with disabilities were found to be in a similar situation to the mothers of children without disabilities in terms of family communication and the general functioning of the family.

According to the Maslach Burnout Questionnaire, it has been found that the self-sufficiency and success of mothers of children with disabilities in child care were similar to those of mothers of children without disabilities.

It has been found that the emotional exhaustion of mothers of children with disabilities was higher than that of the mothers of children without disabilities according to the MBS.

Mothers of children with disabilities have been found to be more concerned about the future of their children than the mothers of children without disabilities. While the concerns of mothers of children with disabilities mainly focus on meeting the child's basic care and needs, the concerns of mothers of children without disabilities focus on the child's education and prospects of a prosperous life. Initiating the family counseling process if the child is identified to have a disability and giving correct information to the family, giving psychiatric support to all families as a public service, and providing family and couple therapy can help coping with the current problem and reduce stress and exhaustion. Providing counseling to individuals under risk by extending the reach of prenatal care services could be significant in preventing child disability.

Having the state provide special education to people with disabilities from all age groups and over longer periods to help with their integration into society using professional staff and modern equipment will help people with disabilities to develop while reducing the burden on mothers and the family.

While the state's supporting private education institutions with the education of children with disabilities and their integration into society will be a step in the right direction, it is also important that these institutions are monitored regularly so that a good education can be given and the abuse of the financial support given is prevented.

Acknowledgements

We would like to thank Osman AYDIN who is an English instructor at Gaziantep University for translating our article into English.

Source of Finance

During this study, no financial or spiritual support was received neither from any pharmaceutical company that has a direct connection with the research subject, nor from a company that provides or produces medical instruments and materials which may negatively affect the evaluation process of this study.

Conflict of Interest

No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.

Authorship Contributions

Idea/Concept: *Haluk Habib Kurtoğlu, Birgül Özçırpıcı;* ***Design:*** *Haluk Habib Kurtoğlu, Birgül Özçırpıcı;* ***Control/Supervision:*** *Haluk Habib Kurtoğlu, Birgül Özçırpıcı;* ***Data Collection and/or Processing:*** *Haluk Habib Kurtoğlu;* ***Analysis and/or Interpretation:*** *Haluk Habib Kurtoğlu, Birgül Özçırpıcı;* ***Literature Review:*** *Haluk Habib Kurtoğlu;* ***Writing the Article:*** *Haluk Habib Kurtoğlu;* ***Critical Review:*** *Birgül Özçırpıcı;* ***References and Fundings:*** *Haluk Habib Kurtoğlu;* ***Materials:*** *Haluk Habib Kurtoğlu.*

REFERENCES

1. Ataman A. [Reasons for needing special education]. Ataman A, editör. Özel Gereksinimli Çocuklar ve Özel Eğitime Giriş. 1. Baskı. Ankara: Gündüz Eğitim ve Yayıncılık; 2003. p.29-41.
2. Özşenol F, Işıkhan V, Ünay B, Aydın Hİ, Akın R, Gökçay E. [The evaluation of family functions of families with handicapped children]. Gülhane Tıp Dergisi. 2003;45(2):156-64.
3. Duygun T, Sezgin N. [The effects of stress symptoms, coping styles and perceived social support on burnout level of mentally handicapped and healthy children's mothers]. Türk Psikoloji Dergisi. 2003;18(52):37-52.
4. Maske UE, Riedel-Heller SG, Seiffert I, Jacobi F, Hapke U. Prevalence and comorbidity of self-reported diagnosis of burnout syndrome in the general population. Psychiatr Prax. 2016;43(1):18-24. [Crossref] [PubMed]
5. Miller AC, Gordon RM, Danielle RJ, Diller L. Stress, apraisal and coping in mothers of disabled and nondisabled children. J Pediatr Psychol. 1992;17(5):587-605. [Crossref] [PubMed]
6. Bulut I. [McMaster family assessment device]. Şahin T, editör. Ruh Hastalığının Aile İşlevlerine Etkisi. 1. Baskı. Ankara: Başbakanlık Kadın ve Sosyal Hizmetler Müsteşarlığı Yayınları; 1993. p.41-8.
7. Maslach C, Jackson SE, Leiter MP. Scale description. Maslach Burnout Inventory Manual. 3rd ed. Palo Alto, CA: Consulting Psychologist Press; 1996. p.193-5.
8. Ergin C. [Burnout and maslach burnout scale adaptation in doctors and nurses]. Bayraktar R, Dağ İ, editörler. VII. Ulusal Psikoloji Kongresi Bilimsel Çalışmaları. 1. Baskı. Ankara: Türk Psikologlar Derneği; 1992. p.143-54.
9. Pelsma DM, Roland B, Tollefson N, Wigington H. Parent burnout: validation of the maslach burnout inventory with samples of mothers. Meas Eval Couns Dev. 1989;22(2): 81-7. [Crossref]
10. Taşdemir H, Özbesler C. [Assessment of the problems encountered by children in mainstreaming education from social work practice in school settings]. The Journal of International Social Research. 2017;10(4):9307-581.
11. Hacettepe Üniversitesi Nüfus Etütleri Enstitüsü. Türkiye Nüfus ve Sağlık Araştırması 2013. T.C. Kalkınma Bakanlığı, T.C. Sağlık Bakanlığı, TÜBİTAK. Ankara: Elma Teknik Basım Matbaacılık Ltd Şti; 2013. p.343. Erişim Tarihi: 13.06.2017 [Link]
12. Sertel M, Tarsuslu Şimşek T, Tütün Yümin E, Bayraktaroğlu F. [The effect of fatigue and stres-anxiety levels on quality of life in mothers who have chronically disabled children]. Sağlık ve Toplum. 2016;26(2):29-35.
13. Türkiye İstatistik Kurumu (TÜİK). İstatistiklerle Aile, 2016. Sayı: 24646. Erişim Tarihi: 14.06.2017 [Link]
14. Şentürk M, Saraçoğlu GV. [A comparison between mothers having healthy children and mothers having physically and mentally handicapped educable children in terms of their perceived familial social support and depression levels]. Int J Basic Clin Med. 2013;1(1): 40-9.
15. Türkiye İstatistik Kurumu (TÜİK). Doğum İstatistikleri, 2016. Sayı: 24647. Erişim Tarihi: 30.05.2017 [Link]
16. Türkyılmaz AS, Çavlin A. 2013 Türkiye Nüfus ve Sağlık Araştırması. Hacettepe Üniversitesi Nüfus Etütleri Enstitüsü, T.C. Kalkınma Bakanlığı, TÜBİTAK. Ankara: p.71. Erişim Tarihi: 30.05.2017. [Link]
17. Özcanarslan F, Karataş H, Aydın D. [Determination of the depression status of mother having child with disabilities in Sanliurfa]. Journal of Harran University Medical Faculty. 2014;11(2):75-82.
18. Tarsuslu Şimşek T, Taşçı M, Karabulut D. Desire to have other children in families with a chronically disabled child and its effect on the relationship of the parents. Turk Pediatri Ars. 2015;50(3):163-9. [Crossref] [PubMed] [PMC]
19. Kırbaş ZÖ, Özkan H. [Assessment of the family function perception and social support levels of mothers of the children with down syndrome]. İzmir Dr. Behçet Uz Çocuk Hast. Dergisi. 2013;3(3):171-80. [Crossref]