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Impact of having a disabled child on mothers' anxiety, depression and quality of life levels

Özürlü bir çocuğa sahip olmanın annelerin kaygı, depresyon ve yaşam kalitesi düzeylerine etkisi

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Abstract

Purpose: The aim of this study is to investigate the effects of the financial burdens, familial and social life, personal strain due to psychological burdens and stress coping behaviors on the anxiety, depression and quality of life of mothers with a disabled child.

Materials and methods: Mothers (=33.32±6.31 years) of 50 disabled children (x̄±SD=7.66±3.96 years) included in the study and were evaluated with Impact on Family Scale (IFS), Hospital Anxiety and Depression Scale and Nottingham Health Profile.

Results: A moderate correlation was found between the depression and anxiety levels of the mothers and all parameters except the coping ($p<0.05$). A high degree correlation was found between quality of life of mothers and financial burden and familial and social impact, and a moderately positive correlation with personal strain and coping ($p<0.05$). Also correlations were found between the sleep and all parameters of IFS ($p<0.05$). IFS affects the anxiety and depression levels of the mothers ($p<0.05$). Quality of life of mothers were affected by the IFS.

Conclusion: Having a disabled child was inevitable for mothers to have problems in familial and social life. The psychological and physical loads cause mothers to experience personal difficulties and imbalances, and have also affected their depression and anxiety levels.

Key words: Disabled children, anxiety, depression, quality of life, impact of family scale.

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Özet

Amaç: Bu çalışmanın amacı, özürlü çocuğu olan annelerin mali, ailesel, sosyal ve psikolojik yüklere bağlı kişisel baskı ve stresle başa çıkma davranışlarının anksiyete, depresyon ve yaşam kalitesi üzerine etkilerini araştırmaktır.

Gereç ve yöntem: Çalışmaya 50 özürlü çocuğun (x̄±SS=7,66±3,96 yıl) anneleri (x̄±SS=33, 32±6,31 yıl) dahil edildi ve Aile Etki Ölçeği (AEÖ), Hastane Anksiyete ve Depresyon Ölçeği ve Nottingham Sağlık Profili ile değerlendirildi.

Bulgular: Annelerin depresyon ve anksiyete düzeyleri ile başa çıkma parametresi dışındaki tüm parametreler arasında orta düzeyde korelasyon bulundu ($p<0,05$). Annelerin yaşam kalitesi ile mali yük ve ailesel ve sosyal etki arasında yüksek derecede, kişisel zorlanma ve başa çıkma ile orta derecede pozitif korelasyon bulundu ($p<0,05$). Ayrıca uyku ile AEÖ'nün tüm parametreleri arasında korelasyon bulundu ($p<0,05$). AEÖ, annelerin anksiyete ve depresyon düzeylerini etkilemektedir ($p<0.05$). Annelerin yaşam kalitesi AEÖ'den etkilenmiştir.

Sonuç: Özürlü bir çocuğa sahip olan annelerin ailesel ve sosyal yaşamda sorun yaşamaları kaçınılmazdır. Psikolojik ve fiziksel yükler annelerin kişisel zorlanmalar ve ruhsal dengesizlikler yaşamasına neden olurken, depresyon ve kaygı düzeylerini de etkilemiştir.

Anahtar kelimeler: Özürlü çocuk, anksiyete, depresyon, yaşam kalitesi, aile etki ölçeği.

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Introduction

According to the World Health Organization, as a result of a disorder, the limitation or inability to perform the activity in the normal style and within the limits accepted as normal is defined as a disability [1]. It is estimated that approximately 100 million people in the world are congenitally disabled [2].

Parents who learn that they have disabled children experience different emotional processes such as emotional complexity, mourning, sadness, and disappointment [3]. There are studies showing that the responsibilities of having a disabled child have an impact on maternal health [4, 5]. It is well known that families of children with disabilities are under more stress than other families due to the parents' time, energy, financial condition and emotions, and possible inadequacy about their ability to meet their children's needs [4].

Being the parent of a disabled child can bring some psychological, social and economic burdens. One of the parents, usually the mother, may stop working to provide the care needed by the disabled child [5]. Although this is beneficial in terms of the quality of care that the child receives, it places an economic burden on the family. With the addition of the costs of care and treatment of the disabled child, families are in a difficult situation. While the child's disability is a psychological burden on the parent, economic problems also add to it [6]. As a result of these psychological and economic problems, social interactions in the familial and social life can also be disrupted. While the level of exposure to each individual may be different, some parents can cope with these problems, while others experience deep psychological and personal imbalances and have difficulty in dealing with this burden. As a result, anxiety-depression levels of the parents may increase and quality of life may decrease [7].

Various studies have been conducted to measure emotional states such as anxiety and depression in families with a child with disability or chronic illness. According to a study conducted in Estonia, 151 mothers with disabled children, 57 fathers and 101 mothers with children without disabilities, 55 fathers' depressive symptoms and emotional states were evaluated. According to the results of the study, families with disabled children were found to have a significantly negative emotional state and more depressive symptoms than families with children without disabilities [8].

Current studies in the literature investigate how the anxiety, depression and quality of life of parents of children with disabilities are affected, without investigating the factors [8-11]. The aim of this study is to investigate the effects of the financial burdens, familial and social life, personal strain due to psychological burdens and stress coping behaviors on the anxiety, depression and quality of life of mothers with a disabled child.

Materials and methods

This study included the mothers of disabled children attending the physiotherapy program at private training and rehabilitation centers in Manisa, Turkey. The study was conducted between the dates of 12.03.2020 and 30.03.2020. The study has been approved by the Pamukkale University Medical Ethics Committee by the date of 11.03.2020 and the number of 60116787-020/23906.

The mothers were informed regarding the aim of the study. The mothers were interviewed by the phone calls (because of the Covid-19 pandemic) in all evaluations by a single physiotherapist and the obtained data were recorded. The written inform consent was obtained from the directors of the rehabilitation centers and the mothers included in the study. The study was conducted in accordance with the principles of the Declaration of Helsinki.

Participants

The study included mothers of 50 disabled children (ages between 2-16 years), 29 with cerebral palsy, 9 with neural tube defect, 5 with Down Syndrome, 3 with neuromuscular muscle disease and 4 with obstetric brachial plexus injury. Having disabled children, being over the age of 18, having no psychological diagnosis, accepting to participate in the study and being literate were determined as the inclusion criteria of the study. Participants who were illiterate, did not want to answer questions and did not complete the questionnaires were excluded from the study.

Measures

Participants were included in the study by filling out the demographic data form. Then, the questionnaires were applied to the participants.

Impact on Family Scale

Impact on Family Scale (IFS) was developed by Stein and Riessman to easily measure the impact of families with children with chronic disabilities [12]. IFS consists of 33 items and measures the level of the family's exposure under 4 main headings: financial burden, familial and social impact, personal strain, coping and the total effect caused by the sum of these parameters [12].

In the scale, the mothers were asked to answer the questions asked in order as "strongly agree" -1-, "agree" -2-, "disagree -3-" and "strongly disagree" -4-. The scale has a Likert type rating ranging from 1 to 4. A minimum score of 24 and a maximum of 96 can be obtained from the scale. The items in the scale are generally directed towards social, financial and emotional situations, and the high scale score indicates that the problem of mothers is high [12]. The Turkish version of IFS was conducted by Beydemir et al. [4].

Hospital Anxiety And Depression Scale

The Hospital Anxiety and Depression Scale (HAD) developed by Zigmond and Snaith is used to determine the risk in terms of anxiety and depression, and to measure the level and severity change [13]. It has two subscales that evaluate anxiety and depression separately. The cutoff scores of the Turkish form of the scale were 10 for the anxiety subscale and 7 for the depression subscale. The Hospital Anxiety and Depression Scale (HAD) for which the Turkish validity and reliability study was conducted by by Aydemir et al. [14].

Nottingham Health Profile

The Nottingham Health Profile (NHP), developed by Hunt et al. [15], is in the form of a general health questioning and has been developed to measure the physical, emotional and social effects of diseases on the person. It includes 38 questions in six sections: pain (P), physical mobility (PM), energy (E), sleep (S), social isolation (SI) and emotional reaction (ER). The questions are answered as "Yes" or "No". Scores between 0-100 are made to each section. 0 indicates the best health condition, 100 indicates the worst health condition. The Turkish version of NHP was conducted by Kucukdeveci et al. [16].

Statistical analysis

In the power analysis made in line with the expectations and information obtained from the literature; Assuming that the effect size of the relationship between the variables to be examined may be at a medium level (r=0.4), it was calculated that when at least 34 people were included in the study, 80% power could be obtained at 95% confidence level. Considering that there may be data loss, the study was conducted with 50 people.

The data were analyzed with SPSS 25 (IBM SPSS Statistics 25 software (Armonk, NY: IBM Corp.)) package program. Continuous variables are given as mean ± standard deviation and categorical variables as numbers and percentages. Relationships between continuous variables were examined by Spearman correlation analysis and appropriate regression models.

Results

The mean age of the mothers participating in the study was 33.32±6.31 years and the mean age of their children was 7.66±3.96 years. Table 1 shows the demographic data of mothers and children.

In Table 2, weak and moderately positive and statistically significant correlations were found between the HAD scores of the mothers and all parameters except the coping parameter of the IFS ($p<0.05$).

In Table 3, there is a moderate and statistically significant correlation between NHP scores of mothers and "financial burden" and "familial and social impact" parameters, and a weak and statistically significant correlation with "personal strain" and "coping" parameters ($p<0.05$). Also

Table 1. Demographic data of mothers and children

Mothers		
Marital Status	**n**	**%**
Married	39	78
Divorced/Spouse Died	11	22
Employment Status	**n**	**%**
Housewife	27	54
Full Time	15	30
Part Time	8	16
Education Status	**n**	**%**
Not a highschool graduate	21	42
Highschool or higher	29	58
Children		
School	**n**	**%**
Special Education	42	84
Regular School	6	12
Not Attending School	2	4
Auxiliary Device Usage	**n**	**%**
Yes	17	34
No	33	66

n: Number of Cases **%:** Percentage Rate

Table 2. The relationship of mothers' impact level with depression and anxiety levels

		Financial Burden	**Familial and Social Impact**	**Personal Strain**	**Coping**	**Total**
Depression	**r**	0.523*	0.509*	0.400*	0.252	0.563*
	p	0.000	0.000	0.008	0.078	0.000
Anxiety	**r**	0.497*	0.519*	0.437*	-0.022	0.530*
	p	0.000	0.000	0.002	0.880	0.000

Spearman Correlation Analysis **r:** Correlation Coefficient ***p*:** Significance Level (<0.05)

Table 3. The relationship of mothers' impact level with quality of life

NHP		Financial Burden	Familial and Social Impact	Personal Strain	Coping	Total
Energy	r	0.494*	0.484*	0.427*	0.102	0.514*
	p	0.000	0.000	0.002	0.481	0.000
Pain	r	0.300*	0.179	0.112	0.378*	0.213
	p	0.034	0.213	0.440	0.007	0.138
Physical Activity	r	0.333*	0.291*	0.133	0.402*	0.284*
	p	0.018	0.040	0.356	0.004	0.045
Sleep	r	0.515*	0.583*	0.468*	0.391*	0.621*
	p	0.000	0.000	0.001	0.005	0.000
Social Isolation	r	0.350*	0.266	0.166	0.418*	0.337*
	p	0.013	0.062	0.249	0.003	0.017
Emotional Reaction	r	0.580*	0.483*	0.463*	0.213	0.465*
	p	0.000	0.000	0.001	0.137	0.001
Quality of Life Total	r	0.665*	0.605*	0.481*	0.426*	0.655*
	p	0.000	0.000	0.000	0.002	0.000

Spearman Correlation Analysis **r:** Correlation Coefficient ***p*:** Significance Level (<0.05)

a statistically significant and positive correlation was found between the sleep parameter of the NHP and the overall score and the scores of all parameters of IFS (*p*<0.05).

According to Table 4, the scores of all parameters of the IFS and the overall score affects the HAD scores (*p*<0.05); only this effect was not achieved in the "coping" parameter.

In Table 5, all parameters of the NHP scores of mothers were affected by the IFS.

Table 4. The effect of mothers' impact level on anxiety and depression

Dependent Variable (Affected)	**Independent Variable (Affecting)**	**Std. Beta**	**t**	***p***	**Lower Limit**	**Upper Limit**
Depression	Financial Burden	0.536	4.402	0.0001*	0.522	1.399
	Familial and Social Impact	0.576	4.884	0.0001*	0.200	0.481
	Personal Strain	0.443	3.424	0.001*	0.123	0.471
	Coping	0.303	2.201	0.033*	0.036	0.803
	Total	0.659	6.076	0.0001*	0.155	0.308
Anxiety	Financial Burden	0.486	3.852	0.0001*	0.423	1.346
	Familial and Social Impact	0.511	4.117	0.0001*	0.157	0.457
	Personal Strain	0.493	3.926	0.0001*	0.164	0.508
	Coping	0.044	0.306	0.761	-0.346	0.470
	Total	0.580	4.931	0.0001*	0.122	0.291

Regression Analysis 95% Confidence Interval **t:** Test Statistics ***p*:** Significance Level (<0.05)

Table 5. The effect of mothers' impact level on quality of life

Dependent Variable (Affected)	Independent Variable (Affecting)	Std. Beta	t	*p*	Lower Limit	Upper Limit
Energy	Financial Burden	0.488	3.868	0.0001*	3.210	10.158
	Familial and Social Impact	0.448	3.471	0.001*	0.853	3.202
	Personal Strain	0.391	2.947	0.005*	0.638	3.378
	Coping	0.148	1.039	0.304	-1.471	4.618
	Total	0.507	4.074	0.0001*	0.690	2.034
Pain	Financial Burden	0.290	2.096	0.041*	0.143	6.877
	Familial and Social Impact	0.281	2.032	0.048*	0.012	2.241
	Personal Strain	0.138	0.963	0.341	-0.679	1.927
	Coping	0.401	3.036	0.004*	1.271	6.257
	Total	0.288	2.081	0.043*	0.023	1.344
Physical Activity	Financial Burden	0.355	2.627	0.012*	0.879	6.611
	Familial and Social Impact	0.224	1.593	0.118	-0.205	1.768
	Personal Strain	0.179	1.257	0.215	-0.423	1.834
	Coping	0.360	2.673	0.01*	0.729	5.154
	Total	0.248	1.777	0.082	-0.067	1.096
Sleep	Financial Burden	0.537	4.411	0.0001*	3.400	9.097
	Familial and Social Impact	0.515	4.161	0.0001*	1.022	2.934
	Personal Strain	0.522	4.241	0.0001*	1.195	3.350
	Coping	0.404	3.056	0.004*	1.243	6.024
	Total	0.598	5.167	0.0001*	0.833	1.894
Social Isolation	Financial Burden	0.390	2.936	0.005*	1.913	10.229
	Familial and Social Impact	0.324	2.375	0.022*	0.256	3.077
	Personal Strain	0.216	1.535	0.131	-0.390	2.909
	Coping	0.440	3.395	0.001*	2.160	8.435
	Total	0.389	2.925	0.005*	0.371	2.001
Emotional Reaction	Financial Burden	0.609	5.326	0.0001*	4.841	10.712
	Familial and Social Impact	0.481	3.801	0.0001*	0.954	3.098
	Personal Strain	0.501	4.009	0.0001*	1.192	3.590
	Coping	0.277	1.998	0.05*	-0.017	5.488
	Total	0.509	4.092	0.0001*	0.647	1.897
Quality of Life Total	Financial Burden	0.628	5.593	0.0001*	22.079	46.863
	Familial and Social Impact	0.537	4.410	0.0001*	5.293	14.164
	Personal Strain	0.447	3.460	0.001*	3.842	14.503
	Coping	0.471	3.701	0.001*	9.139	30.876
	Total	0.601	5.213	0.0001*	3.973	8.961

Regression Analysis 95% Confidence Interval **t:** Test Statistics ***p*:** Significance Level (<0.05)

Discussion

This study was conducted with mothers to investigate the effects of financial burden, familial and social impact, personal strain and coping behaviors caused by having a disabled child on the anxiety, depression and quality of life. The results obtained showed that the effect of having a disabled child triggers anxiety and depression and decreases the quality of life in mothers, which was compatible with the hypothesis at the beginning of the study and current literature [9, 11, 13].

Contrary to expectations, the fact that the mothers included in the study were at an average young age, and the children at an average school age did not have any effect, and the level of their effectiveness was still high. In the current literature, there are studies showing that the physical and psychological burden created by younger disabled children is higher than that of older disabled children [17, 18].

According to the results of the correlation analysis between IFS and HAD, the financial burden caused by the factors such as the care and treatment costs of the disabled child, the separation of one of the parents from their job to take care of the child negatively affected the mothers and consequently increased the level of anxiety and depression of the mothers.

The fact that mothers' coping efforts were not associated with anxiety and depression suggested that these efforts were not sufficient to reduce anxiety and depression.

According to the regression analysis, the familial and social effects of having a child with a disability were the factors that affect the depression level of the mothers the most, followed by financial burdens. Because mothers had problems in the family due to their disabled children, they also lacked social participation and this caused mothers to become depressed. Likewise, the financial burden of caring for a disabled child contributed to this picture.

A study conducted by Davis et al. [19] also supports these findings. According to that study caring for a child with CP can negatively impact on parents interms of demands on physical health, distrupted sleep, difficulty in maintaining social relationships, pressure on marital relationships, difficulty in taking family holidays, limited freedom, limited time, a child's long-term dependence, difficulty inmaintaining maternal employment, financial burden, difficulty in accessing funding and insufficient support from services.

In terms of anxiety, familial and social effects were the most impacting factors in the same way, followed by personal difficulties and financial burdens. The level of anxiety of mothers has increased due to the problems experienced in the family due to having a disabled child, staying away from participation in social life, personal difficulties caused by psychological burden and financial burdens.

A study conducted by Diwan et al. [11] also supports these findings. According to that study spending more time with disabled children anxiety exists in all family members. Because of mothers' dominant roles in care giving and responsibilities at household, trait anxiety levels were higher in mothers in our study. This trait anxiety affects negatively quality of life. Our study showed that decreased energy and sleep disturbance accompanied with increased emotional reactions in mothers with trait anxiety.

As a result of the financial burdens of having a disabled child and the anxiety and depression resulting from it, the quality of life of the mothers in every sense was negatively affected. The emotional stresses caused by the deterioration of familial and social relations caused a decrease in sleep quality and, consequently, a decrease in physical activities with the decrease in energy. Personal strains also showed similar effects.

According to the results of the correlation analysis between IFS and NHP, when the relationship of mothers' efforts to cope with the burden of having a disabled child with the quality of life is examined, it was seen that it has a negative effect on the quality of life. Efforts to constantly deal with the disabled child and to deal with their problems negatively affected sleep, caused a decrease in physical activities, and therefore brought pain. As a result, mothers started to be isolated from social life.

In a study that Telci et al. [20] conducted, musculoskeletal pain was observed in mothers with disabled children and this situation was found to affect the quality of life of the mothers negatively.

When approached in terms of health related quality of life, according to the results of the regression analysis; most of the financial burdens and familial and social impact on energy, the efforts to cope with stress on pain and physical activity, the efforts to cope with stress on social isolation and financial burdens, emotional reactions on social isolation, although all factors have similar effects. It was observed that the financial burdens had an effect. When the quality of life related to health is analyzed in general, it is seen that the most influencing factor is financial burdens, followed by familial and social effects, efforts to cope with stress and personal difficulties brought by psychological burden, respectively.

Ones et al. [9] conducted a research on the mothers of 46 children diagnosed with cerebral palsy, and in parallel with the results of this study, the mothers were adversely affected about their energy, pain, physical activity, sleep, social isolation and emotional reactions, therefore their quality of life decreased. In the same study, it was found that depression levels of mothers increased significantly, but there was no significant change in anxiety levels. In our study, unlike this study, it was investigated which factors affect how much anxiety, depression and quality of life changes.

In a study investigating the relationship between the psychological well-being of mothers with children with disabilities, it was observed that mothers mostly experienced depressive symptoms; and in another study investigating the quality of life of mothers with disabled children, it was shown that all domains of NHP (sleep, energy, emotional reactions, social isolation, physical activity, and pain) were impaired [21]. Health-related quality-of-life measures tap the physical, functional, psychological, and social well-being [22, 23].

Sufficient sample size and factors measuring the effect load could be shown as the strengths of this study. In addition, studies specific to a particular diagnosis and including mentally disabled people may be stronger. However, in another study it was revealed that the level of depression and quality of life of mothers did not depend on the diagnosis of the disabled child [21]. According to the results of the study, no statistically significant difference was found between the levels of exposure of mothers of children with Cerebral Palsy, Down Syndrome and Autism.

Looking at the results obtained from the study in general, financial burden, familial and social effects, personal difficulties brought by psychological burden and efforts to cope with stress have significant effects on mothers' depression, anxiety and quality of life levels. This is an indication of the psychological and physical burden of having and giving care to a disabled child. From this point of view, the necessity of involving mothers in the rehabilitation program and helping them to cope with this burden they face by directing them to the relevant disciplines is reached. The fact that mothers are better physically and psychologically will also contribute to the rehabilitation process of their children.

When the magnitude of the impact of the financial burden on the anxiety, depression and quality of life of the disabled mothers is analyzed, it was understood that approaches are needed to improve the economic conditions of these families and to decrease the expenses related to the disabled children. Mothers with improved economic status will have a better psychology and will be able to better care for their children.

Along with the results of this study, the necessity of teaching the mothers how to deal with stress against personal difficulties due to the psychological burden of having a disabled child, and even incorporating it into a training program has emerged.

Healthcare professionals must focus on how the caregiver can be supported and rendered less exhausted. Support for the caregivers, acknowledging and participating in stress reduction, is an important consideration [24]. The caregiver interventions such as counseling and relaxation techniques may enable caregivers to adopt healthier lifestyles for themselves and their disabled child [24, 25]. Previous research has shown a significant association between family-centered services for children with disabilities and better emotional well-being of the caregiver, including less stress and greater satisfaction with their child's care and therefore better well-being of the child [26].

Increased tendency to withdraw from social activities or hobbies due to the increased demands of being a caregiver of a disabled child may impair their own quality of life while attempting to improve that of their children. Therefore, rather than targeting the child exclusively, health professionals working in this area should also consider the mental health and the quality of life of caregivers and should develop interventions that support and nurture the family as a whole [13, 26, 27].

Consequently, when factors such as the need for continuous care of the disabled child, spending most of the time at home with the care of the child and not going out, it was inevitable for mothers to have problems in familial and social life. The psychological and physical loads of all these processes also cause mothers to experience personal difficulties and imbalances, and have also affected their depression and anxiety levels. While planning the rehabilitation process of disabled children, mothers should be included in the process and the rehabilitation team should approach the mother and the child as a multidisciplinary.

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Contributions of the authors to the article

F.Y. created the main idea and hypothesis of the study, and edited the material method section. H.Ş. performed the statistical analysis of the study. M.A., İ.Ç. and S.T. conducted data collection studies. F.T. evaluated the data in the results part and wrote the discussion part. F.Y. generally reviewed the work and made the necessary corrections and approved. In addition, all authors discussed the entire study and approved its final version.