

Anxiety, depression and quality of life in mothers of disabled children

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Özet

Özürlü çocukların annelerinde anksiyete, depresyon ve yaşam kalitesi

Amaç: Bu çalışmanın amacı özürlü çocukların annelerinde anksiyete, depresyon ve yaşam kalitesi arasındaki ilişkiyi incelemektir. **Yöntem:** Çalışma Ankara'da 3 ayrı rehabilitasyon merkezinde yapıldı. Çalışmaya 107 özürlü çocuk annesi dahil edildi. Depresyon düzeyini değerlendirmek için Beck Depresyon Ölçeği (BDÖ), anksiyete düzeyini değerlendirmek için Durumluluk-Süreklilik Kaygı Ölçeği (DSKÖ) ve yaşam kalitesini değerlendirmek için Nottingham Sağlık Profili (NSP) uygulandı. Değerlendirmeler çocukların rehabilitasyon merkezlerinde tedavileri esnasında yapıldı. **Bulgular:** BDÖ verilerine göre ortalama puan 14.22, SD:13.03, DKÖ puanı 41.95, SD: 6.55 ve SKÖ puanı 47.27, SD:7.94 idi. BDÖ ile SKÖ arasında ($r:0.348$, $p0.01$) ve BDÖ ile NSP'nin tüm alt maddeleri arasında anlamlı bir ilişki bulundu (emosyonel reaksiyon-ER $r:0.622$, enerji düzeyi-ED $r:0.416$, ağrı $r: 0.463$, uyku $r:0.429$, fiziksel yetenekler-FY $r:0.422$, sosyal izolasyon-Sİ $r:0.587$, $p0.01$). SKÖ ile NSP arasında anlamlı bir ilişki vardı (ER $r:0.271$, $p0.01$, ED $r:0.206$, $p0.05$, uyku $r:0.252$, $p0.01$). Ayrıca annelerin eğitim düzeyi ile SKÖ arasında ($r:-0.209$, $p0.05$) ve NSP arasında negatif bir ilişki vardı ($r:-0.240$, $p0.05$). **Sonuçlar:** Çalışmamızın sonuçları özürlü çocukların annelerinde önemli derecede anksiyete ve depresyon olduğunu gösterdi. Depresyon ve anksiyete düzeyinin artması annelerin yaşam kalitesini olumsuz yönde etkilemekteydi. Etkili rehabilitasyon programları yalnızca çocukların özür düzeyleri ile ilgili bilgilendirme değil aynı zamanda anneler için psikolojik destek sağlayacak tekrarlı takipleri içermelidir.

Anahtar kelimeler: Depresyon, anksiyete, yaşam kalitesi, özürlü çocuk anneleri

Abstract

Objectives: The purpose of this study was to investigate the relationship among anxiety and depression with quality of life in mothers with disabled children. **Methods:** The study was performed three rehabilitation centers in Ankara. One hundred and seven disabled children's mothers included of the study. Beck Depression Inventory (BDI), State Trait Anxiety Inventory (STAI) and Nottingham Health Profile's Part -1 (NHP) were used to assess depression, anxiety and quality of life of mothers. The assessments were performed during children's treatment in rehabilitation centers. **Results:** The mean score on the BDI was 14.22, SD:13.03, SAI was 41.95, SD: 6.55 and TAI was 47.27, SD:7.94. There was a significant correlation between BDI and TAI ($r: 0.348$, $p0.01$) and all subscales of NHP (emotional reaction-ER $r: 0.622$, energy level-EL $r: 0.416$, pain $r: 0.463$, sleep $r: 0.429$, physical mobility-PM $r: 0.422$, social isolation-SI $r: 0.587$, $p0.01$). There was a significant correlation between TAI and ER ($r: 0.271$, $p0.01$) EL ($r: 0.206$, $p0.05$) sleep ($r: 0.252$, $p0.01$) of NHP. There was a significant correlation between mother's education level and TAI ($r:-0.209$, $p0.05$). There was a significant correlation between mother's education level and NHP pain scale ($r:-0.240$, $p0.05$). **Conclusions:** The findings of this study indicated that mothers with disabled children have anxiety and depression. Increased depression and anxiety level affected with badly in mother's quality of life. The effective rehabilitation programs should provide sufficient opportunities for repeated follow-up interviews which offer not only information on the children's disabilities but also psychological support for the mothers.

Keywords: Depression, anxiety, mothers have disabled children, quality of life.

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Introduction

Having disability brings about different hardness for child and his/her parents. This condition commonly starts with a shock. Sometimes there are feelings of guilt, sorrow and helplessness. When children are diagnosed with developmental delays, their parents may experience psychological turmoil similar to that experienced by suicidal individuals (1). On the other hand, obligation in dependent daily living activities demolishes dynamics in family. Consequently, family members' roles have to change. These different responsibilities cause stress, anxiety and depression. Depression among parents of children having disabilities is an important symptom for therapists and other professionals to consider when providing treatment for a child or family (2). Children whose mothers are depressed show a variety of problems in cognitive, linguistic and social functioning when compared to children whose mothers are not depressed (3).

The most affected person in the family is usually mother in such a situation. Mothers of children with disabilities often experience greater stress and emotional demands than do other mothers (2). Mothers have to undertake too much stress because they are alone with their children in daily life. Not all mothers of children with disabilities have difficulties of adaptation even when they have to face highly stressful life situations. However, it has been explained that children and mothers are at risk of stress-related problems when mothers are overburdened by the demands of care giving, earning a living, and other responsibilities (4).

Children with different disabilities cause different levels of stress in their mothers. Mothers of children with epilepsy show increased levels of expressed emotion towards their children. Maternal over-involvement being significantly positively correlated with maternal stress suggests that concern and worry about children with epilepsy is an extra burden for mothers (5). Also mental retardation in the epileptic child had the significant impact on the mothers' depression symptom (6).

The mothers of children with impairments of speech met criteria for depression better as compared to mothers of healthy children (7). Parents of autistic children have described stressful conditions in their families (8-10). Anxiety and depression were significantly higher among the mothers of psychotic children (11). It was demonstrated that the mothers of children with cerebral palsy experienced higher

levels of stress than mothers of healthy children (12,13).

On the other hand, maternal mental situations affect the quality of life in mothers. Quality of life is an overall sense of well-being with a strong relation to a person's health perceptions and ability to function. On a larger scale, quality of life can be viewed as including all aspects of community life that have a direct and quantifiable on the physical and mental health of its members (14).

In the literature, there have been studies about quality of life of parents who have children with chronic diseases. In mothers of children with congenital heart disease, cancer, atopic dermatitis and type I diabetes, quality of life levels were found significantly lower. But, mothers of children with asthma, juvenile chronic arthritis and cleft lip/palate findings indicate no impact in quality of life (15-21).

Despite to these studies, depression and anxiety effect on quality of life in mothers of children with different disabilities has not been investigated enough. The aim of our study is to determine the relationship among anxiety and depression with quality of life on mothers with disabled children.

Methods

Participants and Procedures

170 mothers of children with different types of disabilities participated to study. Participation is voluntary and data would be handled confidentially. 107 of 170 mothers accepted participating in the present study. The procedures and purpose of study were described in detail to the mothers and written informed consents were obtained. The mothers were solicited for participation through special education and rehabilitation centers, in the different regions of Ankara.

Beck Depression Inventory (BDI) was used to assess depression (22,23). State-Trait Anxiety Inventory (STAI) was used to assess anxiety (24,25) and Nottingham Health Profile (NHP) (26,27) was used to assess quality of life of the mothers. As a rule these mothers had each completed the BDI, STAI and NHP in a silent and separate room. Two physiotherapists worked for the study. Each of the physiotherapists made a brief explanation about the questionnaires to mothers, in the rehabilitation centers.

Measures

1.State- Trait Anxiety Inventory (STAI)

STAI (Spielberger,Gorsuch and Lushene -1970) has

been used extensively in research with both adults and adolescents. STAI is a 20- item self report rating scale for measuring state and trait anxiety. The SAI requires people to describe how they feel right now, and increases in response to situational stress and declines under relaxed conditions. The TAI asks people to describe how they generally feel, and reflects relatively stable individual differences in anxiety and proneness that are impervious to situational stress. The items are rated on a scale of 1-4. Total scores range from 20 to 80. The mean score (SD) for working adult men is 34.89 with a 9.2 standard deviation and that for working adult women, 34.79 with a 9.2 standard deviation. The STAI has high internal consistency and high test-retest reliability. The Turkish version of STAI (Öner and LeCompte-1985) was used in this study (25).

2.Beck Depression Inventory (BDI)

BDI (Beck, Ward, Mendelson, Mock, & Erbaugh - 1961) is a 21- item self-report measure of the cognitive, affective, and somatic dimensions of depression. Each item contains four statements, ranging from no indication of depression (I am so sad or unhappy that I can't stand it). Items sum to a total score that can range from 0 to 63. The symptoms in the inventory are divided into mood, thought, motivational and physical sets. According to Beck (1967) the mean BDI scores for the minimal, mild, moderate and severe classifications are 10.9 (SD= 8.1), 18.7 (SD= 10.2), 25.4 (SD= 9.6), and 30.0 (SD= 10.4), respectively. The Turkish version of BDI (Tegin -1980) was used in this study (23).

3.Nottingham Health Profile (NHP)

This test is a generic health related quality of life measure. The instrument is used to evaluate perceived distress across various populations. It consists of two parts. Part 1 contains 38 yes/no items in 6 dimensions: pain, physical mobility (PM), emotional reactions (ER), energy level (EL), social isolation (SI) and sleep. Part 2 contains 7 general yes/no questions concerning daily living problems. The two parts may be used independently and part 2 is not analyzed in this study. We calculated scores for each NHP dimension in these studies by adding all the answers to the items in the dimension, giving the value of 0 for answers of "no" and 1 for answers of "yes". To obtain a final score in each dimension, and to overcome the fact of having a different number of items in some of the dimensions, each sum was multiplied by 100 and divided by the number of items in the dimension. Possible scores ranged from 0 (all

answers of "no" in the dimension, denoting absence of distress) to 100 (all answers of "yes", denoting maximal distress). The Turkish version of NHP was used in this study. The reliability and validity of Turkish NHP have been demonstrated in previous study (27).

Data analyses

The data was analyzed using SPSS for Windows 11.5 (SPSS Inc., 1989- 2002). Variables were presented with descriptive statistics and analyzed with Pearson Correlation Coefficient.

Results

Mean age of the children in this study was 10.2 with a 6.5 standard deviation. There were 33.6 % girls, and 66.4 % boys in the children. These children have 23 different diagnoses with a 24.5 % cerebral palsy, 17.0 % autism, 10.4 % mental retardation, 9.4 % mental-motor retardation and 38.7 % other disabilities. The characteristics of the mothers were presented in Table 1.

Table 1. Characteristics of the sample

	n (107)	%
Age (years)		
22- 30	36	33.6
31- 39	45	42.1
40- 48	19	17.8
49- 67	7	6.5
Marital Status		
Married	101	94.4
Divorced	5	4.7
Widowed	1	0.9
Level of Education		
Primary School	33	30.8
Secondary School	8	7.5
High School	46	43.0
University	20	18.7
Income		
Low	20	18.7
Middle- High	87	81.3
Mother employed		
Yes	12	11.2
No	92	86.0
Retired	3	2.8
Number of children		
One	24	22.4
Two	53	49.5
Three or more	30	30.1
Number of disabled children		
One	102	95.3
Two or more	5	4.7

Mean age of the mothers was 34.8 with a 7.8 standard deviation. 94.4 % of the mothers (n= 101) were married and the only 11.2 % of them were employed (n= 12). 81.3 % of the families (n= 87) had an enough level of income. Mothers education level is 30.8 % from primary school (n= 33), 7.5 % from secondary school (n= 8), 43 % from high school (n= 46) and

18.7 % from university (n= 20) 22.4 % of the mothers (n= 24) had one child, 49.5 % had two children (n= 53), and 30.1 % had three or more children (n= 30). 102 of the mothers had one disabled child and 5 of the mothers had two or more disabled children. Descriptive statistics of mothers' BDI, STAI and NHP scores are given in Table 2.

Table 2. Sample scores of BDI, STAI and NHP

Questionnaires	Mean	SD	Median	IQR*
BDI	14.22	13.03	11.0	6.0- 18.0
SAI	41.95	6.55	42.0	39.0- 46.0
TAI	47.27	7.94	47.0	41.0- 53.0
NHP Section				
Sleep	26.91	25.78	20.0	0.0- 40.0
PM	19.62	17.35	12.5	0.0- 37.5
EL	40.59	38.75	33.33	0.0- 66.66
SI	24.3	29.72	20.0	0.0- 40.0
ER	34.87	30.94	33.33	0.0- 55.55
Pain	22.75	29.06	12.5	0.0- 37.5

*Inter- quartile range

The mean score for the study sample on BDI was 14.22 (SD = 13.03). These results represent minimal to mild depression in the mothers. The mean score was 41.95 (SD = 6.55) for SAI and 47.27 (SD = 7.94) for TAI. These results represent especially higher trait anxiety in the sample group. The highest mean score in NHP was EL with 40.59 (SD = 38.75) and then ER with 34.87 (SD = 30.94). The other sections were sleep with 26.91 (SD = 25.78), SI with 24.3 (SD = 29.72), pain with 22.75 (SD = 29.06) and PM with 19.62 (SD = 17.35).

Bivariate Pearson correlation coefficients among BDI, STAI and NHP sections are given in Table 3.

Table 3. Correlations between BDI, STAI and NHP sections

	BDI	SAI	TAI	Sleep	PM	EL	SI	ER	Pain
BDI	1								
SAI	-.048	1							
TAI	.348**	-.029	1						
Sleep	.429**	.115	.252**	1					
PM	.422**	-.008	.156	.237*	1				
EL	.416**	-.098	.206*	.176	.583**	1			
SI	.587**	-.088	.147	.424**	.333**	.344**	1		
ER	.622**	-.064	.271**	.428**	.438**	.573**	.637**	1	
Pain	.463**	-.009	.163	.296**	.622**	.431**	.260**	.343**	1

* p < 0.05

** p < 0.01

Out of the 36 possible correlations of BDI, STAI and NHP sections, 24 were significant. There was a significant correlation between BDI and all NHP sections: sleep (r = 0.429), PM (r = 0.422), EL (r = 0.416), SI (r = 0.587), ER (r = 0.622) and pain (r = 0.463) significant at 0.01 levels. Between TAI and BDI (r = 0.348) correlation coefficient was significant

at 0.01 level. SAI was not correlated with any of the questionnaires. TAI was positively correlated with sleep (r = 0.252) and ER (r = 0.271) at 0.01 level and with EL (r = 0.206) at 0.05 level.

Between NHP sections, almost every section was positively correlated with each other. Sleep was correlated with SI (r = 0.424), ER (r = 0.428) and pain (r = 0.296) at 0.01 level, and with PM at 0.05 level. There were significant correlations between PM and EL (r = 0.583), SI (r = 0.333), ER (r = 0.438) and pain (r = 0.622) at 0.01 level. EL was correlated with SI (r = 0.344), ER (r = 0.573) and pain (r = 0.431) at 0.01 level. SI was significantly correlated with ER (r = 0.637) and pain (r = 0.260) at 0.01 level. There was a relation between ER and pain (r = 0.343) significant at 0.01 level.

It was found that mothers' educational level were negatively correlated with TAI (r = -0.209) and pain (r = -0.240) at 0.05 level. Between SAI and number of children that a mother has, there was a positive correlation (r = 0.399) significant at 0.05 level. There was no relationship between child's age and depression, anxiety and quality of life of mothers.

Discussion

The findings of this study indicated that mothers with disabled children have higher anxiety, depression and lower quality of life. Anxiety and depression affect negatively quality of life of mothers. Although TAI scores were higher, SAI scores were not significant for anxiety. This situation made us think that mothers of disabled children accept living with disabled children in life time. Finally, trait anxiety exists in this population.

Giving birth to and bringing up a child with a mental or physical handicap may give rise shock and denial, guilt, sorrow and helplessness occur in times. Spending more time with disabled children anxiety exists in all family members (11). 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 level and sleep disturbance accompanied with increased emotional reactions in mothers with trait anxiety. Similarly, Brandt explained that mothers of psychotic children had anxiety level indicating morbidity (11).

Depression accompanied with this anxiety in mothers. In our study, a significant correlation was found between depression scores and trait anxiety scores. Constantly, Baker et al. found dense anxiety and higher level of depression in mothers of children with severe behavioral problems (28). Manne et al. also showed that high level of correlation between depression and anxiety level in mothers of children undergoing bone marrow transplant (29). However, Brandt showed that anxiety and depression scores were significantly higher among the mothers of psychotic children, although he explained that no definite sign of depression were recorded (11). In our study, significant correlation was found between depression scores and all subscales of quality of life. In case of increased depression scores, we found increased emotional reactions in mothers. Similarly, Baker found higher scores both of emotional scores and depression scores in mothers of child with severe behavioral problems (28).

In our study, we found significant correlation between depression and social isolation in mothers. Depend on over responsibilities in daily life mothers don't have enough time for social activities. Barnett showed that both parents of a child with Down syndrome devoted more time to child care and spend less time in social activities. Mothers of children with Down syndrome allocated less time to paid employment (30). Consequently, low level of income suggests low level of quality of life. In contrast to this, Taanila et al. explained that mothers' hobbies change because of the child, but it doesn't affect directly to social isolation (31).

Lawoko et al. indicated that the multivariate analyses revealed however that variables such as distress, hopelessness and financial situation were more important in explaining the reduced quality of life than parental gender and the presence/severity of the children's heart diseases (15). Severity of disease, age and gender of the child, social and financial conditions are identified as factors that affect quality of life in most of the studies. We didn't find any relationship between depression, anxiety, quality of life and child's age. Similarly, Warschburger et al.

showed that neither the child's gender nor the age had affected the quality of life in mothers of children with atopic dermatitis, but severity of disease affected quality of life in mothers (17). On the other hand, in mothers of children with type 1 diabetes, child's age is a factor that decreases quality of life (18). Quality of life levels decreases while child is growing up. Mu et al. showed that mothers' educational level did significantly affect maternal depression symptoms (6). Similarly, we found that mothers with lower educational level had highest trait anxiety and pain scale of NHP.

In our study, we found a positive correlation between pain and depression. Similarly, a study done by Geerlings indicated that depression was accompanied with pain (32). We found that in case of increased depression scores, energy level and physical activity level decrease. Wallander et al showed that limitations on mothers' roles occur when having a child with physical disability (33). However, sleep disturbance was seen when depression scores were higher. The findings of this study indicated that mothers with disabled children have anxiety and depression. Increased depression and anxiety level affected with badly in mother's quality of life. We thought that effective rehabilitation programs should provide sufficient opportunities for repeated follow-up interviews which offer not only information on the children's disabilities but also psychological support for the mothers.

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