



# Evaluation of Anxiety and Caregiver Burden in the Mothers of 0-2-Year-Old Children with Food Allergy

## Besin Alerjisi Olan 0-2 Yaş Çocukların Annelerinde Anksiyete ve Bakım Veren Külfetinin Değerlendirilmesi

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### ABSTRACT

**Aim:** Patients with food allergy and their families have poor quality of life, anxiety, depression, and stress compared to healthy individuals, and the Caregiver Burden is high in the parents. In our study, it was aimed to evaluate the anxiety disorder that may accompany the mothers of food allergic patients aged 0-2 years, and to examine the Caregiver Burden in the mothers of food allergic patients.

**Materials and Methods:** A questionnaire about sociodemographic data, Hospital Anxiety Depression Scale (HADS), Psychological Symptom Checklist (SCL 90-R), and Zarit Caregiver Burden Scale were administered to the mothers of food-allergic children aged 0-2 years and the mothers of healthy children (MHC) as the control group.

**Results:** Sixty seven mothers of children with food allergy and 74 MHC were enrolled in the study. Zarit Caregiver Burden Scale was significantly higher in the mothers of children with food allergy than in the MHC ( $p=0.018$ ). Mothers of food allergic children had a significantly higher overall score on the general SCL 90-R scale ( $p=0.045$ ). While the hospital anxiety scale score was significantly higher in the mothers of children with a food allergy, there was no difference in the HADS ( $p=0.045$ ,  $p=0.825$ , respectively).

**Conclusion:** Evaluation of mothers' emotional status such as burden, anxiety, and depression and coping with food allergy strategies can be neglected. Therefore, the requirement of psychosocial support for the mothers of children with food allergy, especially in the young age group, should be evaluated and provided when necessary.

**Keywords:** Anxiety, burden, food allergy, quality of life, Zarit Caregiver Burden Scale

### ÖZ

**Amaç:** Besin alerjisi olan hastalar ve aileleri sağlıklı bireylere göre düşük yaşam kalitesi, anksiyete, depresyon ve strese sahip olup, ebeveynlerde bakım veren külfeti yüksektir. Çalışmamızda 0-2 yaş arası gıda alerjisi hastalarının annelerine eşlik edebilecek anksiyete bozukluğunun değerlendirilmesi ve gıda alerjisi olan hastaların annelerinde külfetin incelenmesi amaçlandı.

**Gereç ve Yöntem:** Gıda alerjisi olan 0-2 yaş arası çocukların annelerine ve kontrol grubu olarak sağlıklı çocukların annelerine sosyodemografik veriler, Hastane Anksiyete ve Depresyon Ölçeği (HADÖ), Psikolojik Belirti Tarama Listesi (SCL 90-R) ve Zarit Bakıcı Yükü Ölçeği ile ilgili anket uygulandı.

**Bulgular:** Çalışmaya gıda alerjisi olan 67 çocuk annesi ve sağlıklı çocuğu olan 74 anne alındı. Zarit Bakım Veren Külfet Ölçeği puanı, gıda alerjisi olan çocukların annelerinde sağlıklı çocukların annelerine göre anlamlı olarak daha yüksekti ( $p=0,018$ ). Besin alerjisi olan çocukların anneleri, genel SCL 90-R ölçeğinde anlamlı olarak daha yüksek bir genel puana sahipti ( $p=0,045$ ). Besin alerjisi olan çocukların annelerinde HADÖ puanı anlamlı olarak yüksekken, Hastane Depresyon Ölçeği puanında fark yoktu (sırasıyla  $p=0,045$ ,  $p=0,825$ ).

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**Sonuç:** Annelerin külfet, anksiyete, depresyon gibi duygusal durumlarının değerlendirilmesi ve besin alerjisi ile baş etmeye çalışma stratejileri ihmal edilebilir. Bu nedenle besin alerjisi olan özellikle küçük yaştaki çocukların annelerinin psikososyal destek gereksinimleri değerlendirilmeli ve gerekli yönlendirme sağlanmalıdır.

**Anahtar Kelimeler:** Anksiyete, besin alerjisi, külfet, hayat kalitesi, Zarit Bakım Veren Külfet Ölçeği

## INTRODUCTION

The prevalence of food allergy varies between 5% and 10%, and it has increased over the last few decades<sup>1</sup>. The main principles of the treatment are the elimination of the culprit food, prevention from accidental ingestions, and treating acute reactions<sup>2</sup>. Studies have reported that patients with food allergies and their families have decreased quality of life, increased psychological disorders such as anxiety, depression, stress, and social isolation compared to healthy people<sup>3</sup>. Generally, studies have evaluated patients in the older age group, adolescents, and their families. There are a limited number of studies evaluating the mothers of patients with a diagnosis of food allergy aged 0-2 years<sup>4,5</sup>.

Nutrition in the first two years is very important for the physical and neurological development of the baby. Elimination of food due to food allergy and restrictions in daily and social activities cause a decrease in the quality of life for both the patient and their family, and especially for caregiving mothers<sup>3,6,7</sup>.

When the child and in some cases the nursing mother are recommended an elimination diet, a new era begins. During this period, the mother often seeks an answer to "What should I eat, what should my baby eat?" questions. The idea of living with the food allergy, elimination of the culprit food from diet, reading of the labels and preparation of allergen-free meals, the risk of sudden and life-threatening reactions, and the possibility of persistence can affect this anxiety and stress situation<sup>3,8</sup>.

The caregiver burden scale was evaluated in mothers of children with chronic diseases such as cystic fibrosis and cerebral palsy, and the burden was found to be high<sup>9,10</sup>. Food allergy, like other chronic diseases, can last for a long time and the development of tolerance may not occur immediately. Close attention is required during the care of the food allergic patient. The only difference from chronic diseases is that the patient's health condition is generally good in periods when there is no reaction. However, these reactions can be sudden and life-threatening at unexpected times, and the dependence of the baby on the mother who provides primary care may cause a burden especially on the mother.

Although stress and anxiety disorders have been shown in the mothers of children with food allergies in the literature, they were not evaluated with the caregiver burden scale<sup>3</sup>.

In our study, we aimed to evaluate the anxiety disorder that may accompany the mothers of patients with a diagnosis of food allergy aged 0-2 years. We aimed to evaluate the burden caused by the existing food allergy in the caregiving mother.

## MATERIALS AND METHODS

### Patients and Control Group

The mothers of patients who were diagnosed with food allergy between the ages of 0 and 2 years, admitted to our hospital's Pediatric Allergy and Immunology outpatient clinics, were included in the study. Mothers of healthy 0-2-year-old children who were admitted to our hospital's well child outpatient clinic were enrolled as the control group. Mothers of children with other chronic diseases were not enrolled to the study.

### Sample Size Calculation

The number of participants participating in the study was calculated in the Minitab program using anxiety scores obtained in a similar study<sup>11</sup>. When Type I error was taken by 0.05 and the strength of the study was 80%, the number of people to be taken in each group was calculated as at least 70 (if assumed standard deviation=4.15 and differences=1.99).

### Diagnosis of Food Allergy

Food allergy was diagnosed as a compatible clinical history with a wheal diameter >3 mm in the skin prick test and/or specific IgE  $\geq 0.35$  kU/L, and/or positive oral provocation test for the culprit food<sup>1,2,12</sup>.

### Exclusion Criteria

Mothers of patients older than 2 years, without a diagnosis of food allergy, and mothers who did not want to participate were excluded. Besides, mothers who declared that they had a psychiatric illness or underlying medical conditions during the evaluation and illiterate mothers were not included in the study.

### Socio-Demographic Characteristics

All mothers in the patient and control groups were filled out a questionnaire containing questions regarding their educational status, family structure, number of people living at home, education, occupation, and monthly income. As a pilot study, the questionnaire was administered to ten mothers selected randomly and tested for clarity at the beginning of the study.

## Psychosocial Assessment

To evaluate the stress and anxiety disorders of the mothers, all mothers were asked to complete the Psychological Symptom Checklist (SCL 90-R) and the Hospital Anxiety and Depression Scale (HADS). These scales were filled under the supervision of the investigators.

### Hospital Anxiety and Depression Scale

The HADS is a self-report test that includes 14 items and is used to evaluate anxiety and depression symptoms. Each item is scored according to the Likert scale, and the total score is between 0 and 21 for both anxiety and depression subscales. The Turkish validity and reliability study was performed for Turkish society, the threshold values were found to be 7 for depression and 10 for anxiety<sup>13</sup>.

### Psychological Symptom Checklist

The SCL 90-R psychological symptom screening test is a self-assessment test consisting of 90 items. Each item scored with a Likert-type scale is used to screen the psychological symptoms. The primary symptom dimensions that are assessed are somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, psychoticism, and a category of "additional items", which helps clinicians assess other aspects of the client's symptoms. It has been translated and validated into Turkish<sup>14</sup>.

### Zarit Caregiver Burden Scale

The Zarit Caregiver Burden Scale was used to assess the caregiver's burden. This scale has been translated and validated into Turkish<sup>15</sup>. It consists of 22 items rated on a 5-point Likert scale that ranges from 0 (never) to 4 (nearly always) with the sum of scores between 0 and 88. Higher scores indicate a greater burden. 0-20 points indicate low burden. In our study, it was accepted that mothers who scored 20 or less did not have a burden, and those who scored above had a burden<sup>16</sup>.

The scoring and evaluation of the scales were made by the pediatric psychiatry clinic of our hospital, and the mothers deemed necessary were referred for additional psychiatric evaluation.

## Ethics

This study has been conducted in accordance with the principles of Helsinki Declaration. Written informed consent was taken from all participants. This study was approved by the Ethics Committee of University of Health Sciences Turkey, Okmeydanı Training and Research Hospital (protocol no: 740, date: 24.10.2017).

## Statistical Analysis

Statistical Package for the Social Sciences 22.1 was used for data analysis. The distribution of the data was analyzed using the Shapiro-Wilk's normality test. Since data did not conform to the normal distribution, median (minimum-maximum) and quantitative data were presented as numbers and percentages (%). The Mann-Whitney U test was used for paired groups since the data did not show normal distribution when compared to qualitative data. Quantitative data were compared using the chi-square test. Linear correlations between the Zarit Caregiver Burden Scale and others were analyzed by the Spearman correlation test. Statistical significance was evaluated as  $p < 0.05$ .

## RESULTS

The study included the mothers of 67 patients and the mothers of 74 healthy children as the age and sex-matched control group. The mean age of the mothers was also similar in both groups. The socio-demographic characteristics of the patient and control groups are given in Table 1.

The Zarit Caregiver Burden Scale scores of the mothers of the patients diagnosed with food allergy were significantly higher than those of the mothers of healthy children ( $p=0.018$ ). The general score of the psychological symptom screening list (SCL 90-R) was found to be significantly higher in the mothers of children with food allergy ( $p=0.045$ ). When the subtitles of the SCL 90-R scale were evaluated separately, no significant difference was found between the groups. While the HADS was significantly higher in the mothers of children with a food allergy, there was no difference in the hospital depression scale score ( $p=0.045$ ,  $p=0.825$ , respectively). The results of all scales applied in the mothers of food-allergic children (MFAC) and controls are given in Table 2. There was no significant difference in all scores when compared according to the onset of symptoms. There was a statistically significant positive correlation coefficient ( $r$ ) value between 0.46 and 0.66 with Zarit Caregiver Burden and all other scales ( $p=0.001$ ).

Zarit Caregiver Burden Scale was found to be positive as having a burden in 42 (62.6%) MFAC and 35 (47.3%) mothers with healthy children (MHC). Among the mothers with positive Zarit Caregiver Burden Scale, the unemployment was higher and the monthly income of the family was significantly lower in MFAC ( $p=0.040$  and  $p=0.024$ , respectively). The comparison of the socio-demographic characteristics of MFAC and MHC with positive Zarit Caregiver Burden Scale is given in Table 3.

## DISCUSSION

Food allergy is a global health problem that affects many children and their families. In addition to its financial burden, the decrease in quality of life causes a burden to both the

patients and family members<sup>17,18</sup>. In our study, the burden was found to be higher in the MFAC aged 0–2 years compared to the MHC in the same age group. Besides, the HADS and SCL 90-R general score were found to be significantly higher in these mothers.

Studies have shown that the families of children with food allergies experience social and emotional deterioration and

that parents experience fear and anxiety. It was found that mothers also experience more stress and anxiety than fathers<sup>19</sup>. It has been shown that some parents also transfer their anxiety to the child and this situation was especially observed in the parents of children with previous anaphylaxis history<sup>20</sup>.

Many parents report that they hesitate to try new foods for their children and healthy siblings and felt anxious after food

**Table 1. The socio-demographic characteristics of the patient and control groups**

		MFAC (n=67)	MHC (n=74)	p value
Age (month) (median, min-max)		9 (3.0-23.0)	8.0 (1.0-24.0)	0.076 <sup>¥</sup>
Gender (n, %)	Boy	38 (56.0)	39 (50.0)	0.845 <sup>#</sup>
	Girl	29 (44.0)	35 (53.0)	
Parents are not divorced (n, %)		67 (100)	72 (97.3)	0.950 <sup>#</sup>
Number of siblings (median, min-max)		1.0 (0.0-4.0)	1.0 (0.0-4.0)	0.575 <sup>¥</sup>
Household population (median, min-max)		4.0 (3.0-10.0)	4.0 (3.0-7.0)	0.242 <sup>¥</sup>
Age of the mother (year) (median, min-max)		28.0 (18.0-49.0)	30.0 (19.0-39.0)	0.078 <sup>¥</sup>
Education of the mothers (n, %)	Primary school	11 (16.4)	15 (57.7)	0.104 <sup>#</sup>
	Junior high school	19 (28.3)	11 (36.7)	
	High school	16 (23.8)	14 (46.7)	
	University	17 (25.3)	23 (57.3)	
Mother's employment status (n, %)	Employer	13 (19.5)	32 (71.1)	0.004 <sup>#</sup>
	Unemployed	54 (80.5)	42 (43.8)	
Father's employment status (n, %)	Employer	66 (98.5)	71 (95.9)	0.684 <sup>#</sup>
	Unemployed	1 (1.5)	3 (0.04)	
Total family income (n, %)	0-1000 TL	16 (23.9)	16 (50.0)	0.058 <sup>#</sup>
	1000-2000	33 (49.2)	26 (44.1)	
	>2000 TL	16 (23.9)	32 (66.7)	

<sup>#</sup>Chi-square test, TL: Turkish liras, <sup>¥</sup>Mann-Whitney U test, min-max: Minimum-maximum, SD: Standard deviation, MFAC: Mothers of food-allergic children, MHC: Mothers of healthy children

**Table 2. Comparison of the results of all scales applied in the mothers of food allergic children and controls**

	MFAC (n=67)	MHC (n=74)	p value <sup>¥</sup>
Zarit Caregiver Burden Scale	22.0 (2.0-53.0)	18.0 (0.0-59.0)	0.018
SCL somatization	0.67 (0.0-3.33)	0.50 (0.0-3.42)	0.111
SCL obsession	0.80 (0.0-3.20)	0.50 (0.0-3.30)	0.113
SCL interpersonal sensitivity	0.56 (0.0-3.67)	0.33 (0.0-3.89)	0.131
SCL depression	0.54 (0.0-3.62)	0.54 (0.0-3.69)	0.846
SCL anxiety	0.35 (0.0-3.50)	0.20 (0.0-2.90)	0.104
SCL hostility	0.33 (0.0-3.83)	0.33 (0.0-3.17)	0.442
SCL phobia	0.14 (0.0-3.0)	0.00 (0.0-2.71)	0.155
SCL paranoid ideation	0.50 (0.0-3.83)	0.33 (0.0-3.17)	0.114
SCL psychoticism	0.10 (0.0-2.40)	0.10 (0.0-2.70)	0.465
SCL addition	0.71 (0.0-3.14)	0.43 (0.0-11.4)	0.065
SCL general	0.60 (0.03-3.10)	0.37 (0.0-2.84)	0.045
HAD anxiety	6.00 (0.0-19.0)	4.00 (0.0-16.0)	0.045
HAD depression	5.00 (0.0-20.0)	5.00 (0.0-15.0)	0.825

<sup>¥</sup>Mann-Whitney U test, HAD: Hospital Anxiety and Depression Scale, SCL: Psychological Symptom Screening List, MFAC: Mothers of food-allergic children, MHC: Mothers of healthy children

allergy was diagnosed<sup>21,22</sup>. Mothers stated that they were more anxious especially on the day of the oral food provocation test compared to the other days<sup>23</sup>. However, in cases where the diagnosis of food allergy is confirmed, parental anxiety has been shown to decrease as necessary avoidance measures are taken<sup>24,25</sup>. Prescription of an adrenaline autoinjector has been shown to reduce anxiety in some mothers of children with food allergy<sup>26</sup>. However, parental anxiety for whom an avoidance diet was recommended did not affect the increasing compliance with adrenaline auto-injector carrying and treatment<sup>27</sup>. Also, no anxiety can result in accidental encounters and risky behaviors during follow-up. Fedele et al.<sup>28</sup> evaluated food allergy coping behaviors with four different adaptation models. They found that anxiety and psychosocial influence was less in families that gave a balanced response to this process. It was observed that compliance with the treatment was less and psychosocial involvement was higher in anxious high responder families.

Most studies involve older children and adolescents with food allergy. There is a limited number of studies evaluating anxiety in the parents of the food allergic patients aged 0-2 years. Cortes et al.<sup>29</sup> evaluated the mothers of the children with an average age of 26 months with the HADS and they found the anxiety scores high in 42.6% of the mothers. In our study, 14.3% of mothers of children with food allergies had higher anxiety scores and 40.6% had higher depression scores.

In the studies, parental anxiety related to food allergy was evaluated with the quality of life questionnaire and psychosocial symptom screening questionnaires. The variability of the results was attributed to the child's age group, the timeline of the food allergy diagnosis, and the disease course, and it was thought that it should also be evaluated during the follow-up period<sup>3</sup>.

Parental anxiety was generally evaluated in both mothers and fathers in the studies. Zarit Burden Scale was found to be higher in the mothers of patients with chronic lung disease than in their fathers<sup>10</sup>. In our study, only mothers were evaluated because the caregivers in the first two years of age were mainly the mothers of the children.

Approximately 60% of the parents of children with chronic illness reported that they were in good emotional and physical conditions<sup>9</sup>. In the studies evaluating the burden in the families of food-allergic children, Food Allergy Quality of Life -Parental Burden questionnaire was generally used<sup>30,31</sup>. This questionnaire has not been translated and validated into Turkish. Therefore, in our study, the presence of burden in mothers was evaluated with the Zarit Caregiver Burden Scale, which was validated for Turkish<sup>15</sup>. The Zarit Caregiver Burden Scale was applied to family members caring for children with chronic diseases such as cystic fibrosis and cerebral palsy, and the burden was found to be high in these disease groups<sup>9,10</sup>. In our study, burden in the mothers of

**Table 3. The comparison of socio-demographic characteristics of the mothers with food allergic and healthy children whose Zarit Caregiver Burden Scale was found to be positive**

		MFAC (n=42)	MHC (n=35)	p value
Age (month) (median, min-max)		8.5 (3.0-23.0)	9.0 (1.0-24.0)	0.87 <sup>¥</sup>
Gender (n, %)	Boy	24 (57.1)	21 (60.0)	0.983 <sup>¥</sup>
	Girl	18 (42.9)	14 (40.0)	
Number of siblings (median, min-max)		1.0 (0.0-4.0)	0.0 (0.0-4.0)	0.160 <sup>¥</sup>
Household population (median, min-max)		4.0 (3.0-10.0)	3.0 (3.0-7.0)	<b>0.048<sup>¥</sup></b>
Age of the mother (year) (median, min-max)		28.0 (18.0-37.0)	30.0 (20.0-38.0)	0.084 <sup>¥</sup>
Education of the mothers (n, %)	Primary school	7 (17.9)	4 (11.4)	0.43 <sup>#</sup>
	Junior high school	11 (28.2)	6 (17.1)	
	High school	9 (23.1)	6 (17.1)	
	University	10 (25.6)	15 (42.9)	
Mother's employment status (n, %)	Employer	9 (23.1)	17 (48.6)	<b>0.040<sup>#</sup></b>
	Unemployed	30 (76.9)	18 (51.4)	
Father's employment status (n, %)	Employer	38 (97.4)	33 (94.3)	0.924 <sup>#</sup>
	Unemployed	1 (2.6)	2 (5.7)	
Family income (n, %)	0-1000 TL <sup>a</sup>	12 (31.6)	3 (8.6)	0.024 <sup>#</sup> a-b: 0.09 a-c: 0.007 b-c: 0.21
	1000-2000 TL <sup>b</sup>	14 (36.8)	12 (34.3)	
	>2000 TL <sup>c</sup>	12 (31.6)	20 (57.1)	

TL: Turkish liras, <sup>#</sup>chi-square test, <sup>¥</sup>Mann-Whitney U test, min-max: Minimum-maximum, MFAC: Mothers of food-allergic children, MHC: Mothers of healthy children

children with food allergy was found to be significantly higher than in the MHC.

In our study, the rate of unemployment in the mothers of children with food allergy was found to be significantly higher than in the MHC. Also, the rate of unemployment was found to be higher in mothers with a high score of Zarit Caregiver Burden Scale. Therefore, the unemployment was thought to be a factor that would increase the caregiver burden of the mother.

### Study Limitations

The course of food allergy, the culprit allergen, the age group, the type of food allergy can affect the anxiety and burden in the family. The limitation of our study is that the mothers were evaluated in terms of anxiety and burden after a cross-sectional diagnosis of food allergy and no comparison was made in terms of these sub-parameters. Its strength is that it is the first study in our country evaluating the burden in the MFAC aged in the first two years.

### CONCLUSION

In conclusion, the management of food allergy usually includes strict avoidance, patient education and provision of emergency medication (adrenaline–autoinjectors). However, in our clinical practice, the evaluation of mothers' emotional status such as coping with a food allergy, burden, and anxiety–depression can be neglected. For this reason, the psychosocial support needs of mothers of children with a food allergy, especially in the young age group, should be evaluated and obtained when necessary because psychological, emotional, and social well-being of the caregivers increases the quality of care the child receives.

### Ethics

**Ethics Committee Approval:** This study was approved by the Ethics Committee of University of Health Sciences Turkey, Okmeydanı Training and Research Hospital (protocol no: 740, date: 24.10.2017).

**Informed Consent:** Consent form was filled out by all participants.

**Peer-review:** Externally peer-reviewed.

### Authorship Contributions

Surgical and Medical Practices: E.Y., S.E., N.P.Y., D.Ö., Concept: E.Y., S.E., N.P.Y., Design: E.Y., N.P.Y., Data Collection or Processing: E.Y., D.Ö., S.E., N.P.Y., Ö.T., Analysis or Interpretation: Ö.T., E.Y., D.Ö., Literature Search: Ö.T., E.Y., D.Ö., S.E., Writing: D.Ö., Ö.T., E.Y., N.P.Y.

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