





# Relationship of Diet Adherence with Levels of Depression, Anxiety, and Caregiver Burden in Parents of Children with Celiac Disease

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## ABSTRACT

**Objectives:** The aim of this study was to compare caregiver burden and the levels of depression and anxiety among mothers of children with celiac disease who are adherent or non-adherent to a gluten-free diet.

**Methods:** In this study, 92 patients diagnosed with celiac disease who were regularly followed at the Department of Pediatric Gastroenterology, Çukurova University Faculty of Medicine, and their caregiving mothers were enrolled. Demographic characteristics were captured for both patients and mothers and the Beck Anxiety Inventory, Beck Depression Inventory, and Zarit Burden Interview were completed for caregiving mothers.

**Results:** There were 69 (75%) mothers in the diet-adherent group and 23 (25%) mothers in the non-diet-adherent group. The caregiving mothers studied had a mean age of  $39.6 \pm 7.4$  years. The mean Beck Anxiety Inventory, Beck Depression Inventory, and Zarit Burden Interview scores of the caregiving mothers were  $15.4 \pm 8.2$ ,  $17.3 \pm 9.5$ , and  $37.1 \pm 13.5$  points, respectively. Compared to the mothers in the diet-adherent group, mean Beck Anxiety Inventory, Beck Depression Inventory, and Zarit Burden Interview scores were statistically significantly higher in the mothers in the non-diet-adherent group ( $P = .005$ ,  $.001$ ,  $.020$ , respectively).

**Conclusions:** It is necessary to recognize the burdens that caregivers are exposed to and identify how heavy these burdens are. Mothers of patients who do not comply with gluten-free diet may experience high levels of depression and anxiety and this should be borne in mind while treating celiac disease.

**Keywords:** anxiety, caregiver burden, celiac, depression

## INTRODUCTION

Celiac disease (CD) is defined as a chronic, immune-mediated condition caused by the ingestion of gluten in genetically predisposed individuals, which is characterized by a wide variety of gastrointestinal and/or systemic manifestations, various degrees of inflammatory enteropathy, and high levels of celiac-specific autoantibodies.<sup>1</sup> The global prevalence of CD ranges between 0.5% and 1% with variations in reported rates across countries.<sup>2</sup> In Turkey, CD prevalence has been estimated at 0.47%.<sup>3</sup> Celiac disease results from the interplay between genetic and environmental factors. Although there is ongoing research focusing on the treatment of CD, the only effective treatment continues to be lifelong adherence to a gluten-free diet (GFD). Strict adherence to this diet is important for the prognosis of the disease.<sup>4</sup>

In Turkey, the care for sick individuals is often provided by the parents and it is perceived as a family responsibility. Studies on the assessment of the quality of life in mothers of children with chronic diseases have usually involved children with neurological

problems, and there are few studies on mothers of children with CD.<sup>5,6</sup> Moreover, adherence to a GFD may be more challenging in children and it may demand extra effort from their mothers, which can negatively affect them psychosocially.<sup>7,8</sup>

In the present study, we aimed to determine how mothers of children with CD who were compliant or non-compliant with a GFD are affected physically, socially, emotionally, and economically by comparing the quality of life, depression, and anxiety levels of the mothers.

## METHODS

In this study, 92 patients diagnosed with CD who were being regularly followed at the Department of Pediatric Gastroenterology clinic and their caregiving mothers were enrolled. The sociodemographic characteristics of the caregiving mothers including age, the length of marriage, total number of children, occupation, education level, and economic status were captured using a study-specific form. Mothers with any mental illness within the

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last 12 months diagnosed either by an expert psychiatrist according to the Diagnostic and Statistical Manual of Mental Disorders, fifth Edition criteria, on the basis of history or identified through medical chart review, and mothers taking psychotropic drugs were excluded from the study.<sup>9</sup>

Sociodemographic data sheet, the Beck Anxiety Inventory (BAI), and the Beck Depression Inventory (BDI) were completed through face-to-face interviews. Each interview took about 15–20 minutes. Additionally, the adherence of the patients with CD to the diet was assessed using serological CD tests, history, and physical examination. Written consent was obtained from the parents of the patients participating in this study. The study was conducted in accordance with the principles set forth in the Declaration of Helsinki, and ethics approval was obtained from the institutional review board (Date: April 5, 2019, Decision no: 87).

#### Beck Anxiety Inventory

The BAI was developed by Beck et al.<sup>10</sup> The BAI measures the severity and frequency of anxiety symptoms experienced by the individual. It is a self-assessment tool consisting of 21 items rated on a 4-point Likert scale ranging from 0 to 3 points. The maximum possible score is 63 points. Higher total scores indicate more severe anxiety symptoms in an individual. The reliability and validity of the Turkish version of the scale had been demonstrated by Ulusoy et al.<sup>11</sup> The Cronbach alpha reliability coefficient of the scale was 0.93.

#### Beck Depression Inventory

The BDI is used to measure the physical, emotional, cognitive, and motivational symptoms experienced in depression. The BDI aims to determine the extent of depressive symptoms objectively. The scale consists of 21 questions with 4 possible responses, and each item is assigned a score from 0 to 3. The items are summed to produce a total depression score which ranges from 0 to 63 points. Higher total scores indicate more severe depressive symptoms. The reliability and validity of the Turkish version of the BDI had been demonstrated by Hisli<sup>12</sup> The Cronbach alpha reliability coefficient of the scale was 0.93.

#### Zarit Burden Interview

The Zarit Burden Interview (ZBI) was developed by Zarit et al.<sup>13</sup> in 1980. The ZBI consists of 22 items that address the impact of caregiving burden on the daily life of caregivers. Each item is rated on a 5-point Likert scale that ranges from 0 (never) to

4 (nearly always). The reliability and validity of the Turkish version of the scale had been demonstrated by Inci and Erdem in 2008, with a Cronbach alpha value of 0.95.<sup>14</sup> The items are summed to produce a total score ranging from 0 to 88 points. The total burden scores are interpreted as little/no burden (0–20), moderate burden (21–40), severe burden (41–60), and very severe burden (61–88). The ZBI items are generally related to social and emotional dimensions and higher total scores indicate greater burden and higher level of distress for the caregiver.<sup>15</sup>

#### Statistical Analysis

The study data were analyzed using the Statistical Package for the Social Sciences software version 22.0 for Windows (SPSS Inc, Chicago, Ill, USA). The Kolmogorov–Smirnov test was used to check whether continuous variables followed a normal distribution. Normally distributed variables were expressed as mean  $\pm$  standard deviation, while non-normally distributed variables were expressed as median with interquartile range. The categorical variables were presented as percentages. Differences between the 2 groups were analyzed using the Student's unpaired *t*-test or the Mann–Whitney *U* test for parameters with a normal or non-normal distribution. The frequencies of nominal variables were compared using the Fisher's exact test or chi-square test.  $P < .05$  was considered statistically significant.

#### RESULTS

In this study, 92 mothers of patients with CD were included in the study. There were 69 (75%) mothers in the diet-adherent (DA) group and 23 (25%) mothers in the non-diet-adherent (NDA) group. The caregiving mothers studied had a mean age of  $39.6 \pm 7.4$  years, 56.5% of them were primary school graduates, 73.9% were married for an average duration of  $16.6 \pm 5.9$  years, and the mean number of children was  $3.1 \pm 1.6$ . The DA group and NDA group were not statistically significantly different in terms of mean age, education status, occupation, length of marriage, and number of children ( $P > .05$ ). With regard to household income, monthly income was less than expenses in 73.9% of the NDA group and 43% of the DA group. There was a significant difference between the 2 groups in terms of monthly income ( $P = .038$ ). Patient age, sex, body weight, height, and disease duration were not significantly different between the 2 groups ( $P > .05$ ) (Table 1).

The mean BAI score was  $19.6 \pm 9.3$  for the mothers in the NDA group and  $14.0 \pm 7.4$  for the mothers in the DA group ( $P = .005$ ). The NDA group had a mean BDI score of  $23.1 \pm 7.3$  and the DA group had a mean BDI score of  $15.4 \pm 9.4$  ( $P = .001$ ). The mean ZDI score was  $42.9 \pm 9.1$  in the NDA group and  $35.3 \pm 14.3$  in the DA group ( $P = .020$ ) (Table 2). When the caregiving burden of the mothers was evaluated based on the ZDI scores, moderate caregiving burden was most common among all mothers (50%). The moderate burden was found in 55.1% of the mothers in the NDA group and 56.5% of the mothers in the DA group reported severe caregiving burden. The difference between the 2 groups in terms of the subdomains of the caregiving burden scale was of borderline significance ( $P = .057$ ).

#### Main Points

- Anxiety and depression in the mothers of children with celiac disease (CD) who require special diet and care are important for the management of the disease.
- The children with CD and their mothers should be provided with psychological support during follow-up.
- The mothers of CD children who are non-compliant with a gluten-free diet have higher levels of depression and anxiety.

**Table 1.** Sociodemographic Characteristics of Patients and Their Caregiving Mothers

Parameters	Total Number of Patients (n=92)	Diet Adherent (n=69)	Non-diet Adherent (n=23)	P
Patient's age (month)	131.3 ± 50.0	126.3 ± 49.1	146.6 ± 50.6	.91
<b>Patient's sex</b>				
Female, n (%)	61 (66.3)	46 (66.7)	15 (65.2)	.899
Male, n (%)	31 (33.7)	23 (33.3)	8 (34.8)	
Patient's body weight (kg)	34.3 ± 14.8	33.2 ± 14.4	37.4 ± 15.6	.243
Patient's height (cm)	135.9 ± 22.3	134.4 ± 22.6	140.4 ± 21.0	.266
Disease duration (months)	56.1 ± 25.8	55.2 ± 26.4	58.6 ± 24.4	.588
Adherence to diet, n (%)	92 (100)	69 (75)	23 (25)	
Caregiver age (years)	39.6 ± 7.4	39.5 ± 7.1	39.7 ± 8.6	.917
Length of marriage (years)	16.6 ± 5.9	16.8 ± 5.9	16.3 ± 6.1	.707
Total number of children	3.1 ± 1.6	3.2 ± 1.6	3.0 ± 1.4	.679
<b>Mother's occupation</b>				
Housewife, n (%)	68 (73.9)	51 (73.9)	17 (73.9)	.293
Worker, n (%)	7 (7.6)	7 (10.1)	0 (0)	
Civil servant, n (%)	3 (3.3)	2 (2.9)	1 (4.3)	
Self-employed, n (%)	11 (12.0)	8 (11.6)	3 (13.0)	
Retired, n (%)	2 (2.2)	1 (1.4)	1 (4.3)	
<b>Mother's education status</b>				
Primary school, n (%)	52 (56.5)	41 (59.4)	11 (47.8)	.408
Secondary school, n (%)	17 (18.5)	11 (15.9)	6 (26.1)	
High school, n (%)	16 (17.4)	13 (18.8)	3 (13.0)	
University, n (%)	7 (7.6)	4 (5.8)	3 (13.0)	
<b>Household income</b>				
Income less than expenses, n (%)	47 (51.1)	30 (43.5)	17 (73.9)	.038
Income equal to expenses, n (%)	34 (36.9)	29 (42.0)	5 (21.7)	
Income greater than expenses, n (%)	11 (12.0)	10 (14.5)	1 (4.3)	

**Table 2.** Levels of Anxiety, Depression, and Caregiving Burden of Caregiving Mothers

Parameters	Total Number of Patients (n=92)	Diet Adherent (n=69)	Non-diet Adherent (n=23)	P
Beck Anxiety Inventory	15.4 ± 8.2	14.0 ± 7.4	19.6 ± 9.3	.005
Beck Depression Inventory	17.3 ± 9.5	15.4 ± 9.4	23.1 ± 7.3	.001
Zarit Burden Interview	37.1 ± 13.5	35.3 ± 14.3	42.9 ± 9.1	.020

**DISCUSSION**

Family members are the ones who provide the greatest support to patients with a chronic conditions and at the same time, they feel that they bear the heaviest burden. This affects the quality

of life and mental health of all family members and puts a great deal of stress and pressure on parents. Mothers often feel the obligation to meet all the needs of their sick children and find it difficult to accept the situation.

Celiac disease causes dramatic changes in the daily lives of both the patient and the caregiver and interferes with the habitual routine of the affected individual. Many studies on the caregivers have demonstrated that caregivers experience psychological distress and have a poor quality of life. In a study by Lorenzo et al<sup>7</sup> conducted in Joana de Gusmao Children's Hospital in Brazil, significantly lower quality of life scores were found in the parents of children with CD compared to the parents of children without CD.

It has been reported that mothers of children diagnosed with CD may develop psychological problems such as depression and anxiety along with changes in the quality of life during the course of the disease.<sup>7</sup> In a study by Epifanio et al.<sup>16</sup> a higher level of parenting stress was reported in the parents of children with CD than in the parents of healthy children.

Following a lifelong diet as a treatment modality is a challenging commitment for both patients and their families. Consequently, the rate of noncompliance with the diet is quite high and adherence to a specific diet demands extra effort from the mothers, affecting their psychosocial well-being negatively.<sup>7,8</sup> Celiac disease may cause symptoms of anxiety and depression due to several factors including concerns about adherence to a GFD, high cost of food, problems with meals served at school, limitations in the time to prepare food, and having to eat out.<sup>17</sup> In line with the literature, the mothers of CD children who were noncompliant with a GFD had higher levels of depression and anxiety compared to the mothers of CD children who were compliant with the diet. The development of self-concept and identity in children during the growth period exposes the mother to greater stress due to reasons including refusing the GFD and opposition to the authority, and the physical and mental fatigue that builds over time causes deterioration of the well-being of the caregiver and increases feelings of depression and anxiety. Adolescents non-compliant with a GFD were reported to have a lower overall quality of life, more physical problems, greater burden of illness, and more family problems compared to adolescents who were compliant with a GFD.<sup>18</sup>

We believe that the management of CD should involve the evaluation of the patient and the caregiver together, an early assessment of the risk factors, as well as implementation of measures to eliminate the risks. Various factors associated with the burden on caregivers of patients with chronic conditions have been examined and demonstrated in former studies. These factors include those that are related to the patient and the disease (e.g., age, sex, severity and type of symptoms, disease duration, and treatment), those that are related to the caregiver (e.g., sex, the degree of relationship with the patient, personality traits, socio-economic, and cultural characteristics), and others (e.g., social support, degree of stigmatization by the community, quality, and accessibility of mental health services).<sup>19,20</sup>

Increased caregiver burden is associated with higher scores for depression and anxiety among caregivers. The burden of caregiving affects the mental health of the patients, and increased caregiving burden affects the quality of life of the caregiver, and this, in turn, results in an increase in the caregiver burden. Studies conducted with mothers of children with chronic illnesses reported mean caregiver burden scores that ranged between 30 and 52 points.<sup>21,22</sup> The caregiver burden scores observed in the present study are consistent with those reported in the literature. Increased caregiver burden has a negative impact on the well-being of caregivers and affects their quality of life adversely. Caregivers may feel overwhelmed and experience anxiety, depression, uncertainty about the future, feelings of inadequacy, and social isolation. Having a child with a chronic condition can cause changes in the physical, emotional, and financial stability of the family and this can take away the ability of the family members to enjoy life, resulting in poor family quality of life. We believe that early social-psychological support should be provided to caregivers to avoid the negative effects of caregiving burden on the lives of caregivers.

The burden of care for a chronic illness also brings along many financial problems, and a study by Arslantas et al<sup>23</sup> concluded that economic costs are perceived as the biggest burden by the caregivers. Removing gluten from the diet may be a challenging task due to several reasons including the high cost of and limited access to gluten-free products, cross-contamination with gluten and prolamins in many marketed products (despite having a “gluten-free label”), unavailability of GFD products, and the presence of a few alternative products such as pure corn starch and rice flour. Increasing monthly allowances for celiac patients and their families and improved access to GFD products seem important to ease the economic burden of CD.

The limitations of our study include the enrollment of only mothers as caregivers, the small sample size, assessment of mental health by looking at symptoms of anxiety and depression only, not determining the factors that cause burden on caregiving mothers, and not comparing the symptoms of psychological problems in the mothers with those in children. Future studies involving comprehensive assessments may help to better understand these relations.

## CONCLUSION

Caregiving is a long and challenging process that is associated with restrictions on the daily life of the caregivers and adverse effects on their social interactions. Therefore, it is necessary to recognize the burdens that caregivers are exposed to and to identify how severe these burdens are. Protecting caregivers should be among our primary duties while treating our patients. The quality of care will also be improved when the caregiver is healthy both mentally and physically. We may end up with a new patient population if we fail to acknowledge the difficulties experienced by caregivers.

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**Informed Consent:** Informed Consent: Informed consent was obtained from legal guardians to participate.

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