

ARAŞTIRMA MAKALESİ/RESEARCH ARTICLE

ASSESSMENT OF NUTRITIONAL ADHERENCE IN ADULT PATIENTS WITH CELIAC DISEASE USING THE CELIAC DIET ADHERENCE TEST: A PILOT STUDYNuran ÖZİL¹, Hande SEVEN AVUK²,

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ABSTRACT

Backgrounds: Celiac disease, an autoimmune disorder triggered by gluten in genetically predisposed individuals, necessitates lifelong adherence to a gluten-free diet for optimal health and management. This study aimed to assess adherence to a gluten-free diet among individuals with celiac disease. **Material and Method:** Forty-four participants (Female: 54.5%; Male: 45.5%), with a mean age of 33.9±9.9 years and belonging to the Life with Celiac Association, were included. An online questionnaire was administered to collect participants' sociodemographic information, body mass index (BMI), and celiac-related symptoms. The Celiac Diet Adherence Test (CDAT) was conducted to evaluate adherence to gluten-free diet. **Results:** Participants had a median BMI of 22.7 kg/m², and the median CDAT score was 13.5. According to CDAT, 45.5% of participants demonstrated inadequate adherence to the gluten-free diet, 29.5% exhibited good, 18.2% had poor, and 6.8% showed excellent adherence. Single individuals had a median CDAT score of 15, whereas married individuals had a score of 11 (p = 0.048). Participants with excellent adherence to a gluten-free diet reported no celiac-related symptoms, while participants with good, poor, and poor adherence experienced symptoms such as fatigue, diarrhea, gas, and bloating. **Conclusion:** The results of this study demonstrate the importance of continuous nutritional support in the management of celiac disease, where almost half of adult celiac individuals have difficulty complying with the only treatment option, the gluten-free diet.

Keywords: Celiac, Gastrointestinal Diseases, Gluten, Gluten-free diet.

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INTRODUCTION

Celiac disease, characterized by immune-mediated enteropathy, manifests various symptoms caused by gluten intake in genetically susceptible individuals (1). These symptoms include diarrhea, weight loss, abdominal pain, anemia, metabolic bone issues, and infertility (2). A prevalent global condition, its primary treatment involves a strict, lifelong gluten-free diet. Accurate assessment of dietary adherence is essential from a clinical perspective to mitigate complications (3).

Adherence to a gluten-free diet has been reported to range from 45% to 90% (4). In Italy, 81.5% of individuals with celiac disease demonstrated adequate compliance according to the Celiac Diet Adherence Test (CDAT), with histological improvement observed over a 1-year follow-up (5). Another study evaluating long-term gluten-free diet compliance with CDAT in adults diagnosed for >5 years found 75.5% of the participants to have adequate dietary compliance (6).

Persistent gluten consumption in individuals with celiac disease worsens symptoms, damages the intestines, and elevates cancer risks (7). These risks include adenocarcinoma of the small intestine, lymphomas, and enteropathy-associated T-cell lymphoma (8). Proper assessment of dietary adherence is critical, as non-compliance increases the risk of complications. Adhering to a gluten-free diet is essential for symptom relief and for preventing long-term complications (9). This study aimed to evaluate dietary compliance and its relationship with celiac-related symptoms in adult individuals with celiac disease.

MATERIALS AND METHOD

Study Design

This cross-sectional intervention study was conducted between January and April 2022 with volunteer adult individuals aged 18-65 years who were members of the Life with Celiac Association and met the participation criteria. Due to the inadequacy of similar scientific studies conducted in Turkey, the sample size was determined by a pilot study. The sample calculation was made using the MedCalc® Statistical Software version 19.7.2 program. In the study, the number of samples was determined as 41, with type 1 error $\alpha = 0.05$ and $1-\beta = 0.80$, and 44



people were included in the study with a loss of 20%. All procedures involving human participants adhered to the ethical standards of the İstanbul Bilgi University on Human Research Ethics Committee, following the 1964 Helsinki declaration and its subsequent amendments or comparable ethical standards (project number: 2022-20034-2, date: 12.02.2022). Informed consent was obtained from all individual participants included in the study.

Inclusion and exclusion criteria:

The study included adults aged 18-65 years, diagnosed with celiac disease through serological tests and small intestine biopsy by a doctor. Excluded were individuals with other health problems, those regularly using medication or dietary supplements in the last year, regular alcohol consumers, those under the age of 18 years, and those over the age of 65 years.

Data Collections

Socio-demographic information, height and body weight, and disease-related symptom status were questioned with the help of an online platform, using a questionnaire developed by the researcher by reviewing similar literature. Compliance with the gluten-free diet was assessed with CDAT.

Survey form:

Participants responded to inquiries about their age, gender, marital status, educational background, employment status, previous gluten-free nutrition training, adherence to the gluten-free diet, and celiac disease-related symptoms using a questionnaire developed by the researcher.

Anthropometric measurements:

Participants were instructed to weigh themselves in the morning, on an empty stomach and barefoot, and to measure their height with feet together and head in the Frankfort plane. Subsequently, body mass index (BMI) was calculated using the formula: $BMI = \text{body weight (kg)}/\text{height (m}^2\text{)}$ (10).



Celiac Diet Adherence Test (CDAT):

In evaluating individuals' dietary adherence, CDAT, developed by Leffler et al. was employed (11). This clinically significant and easily applicable scale comprises seven items. Known for its clinical relevance and simplicity, CDAT consists of seven key components, offering a standardized approach for assessing adherence to the gluten-free diet and being superior to tissue transglutaminase serology in efficacy. It has proven valuable in both research and clinical settings (12). This test comprises 7-item to which participants respond using a 5-point Likert scale. The numerical values assigned to the responses range from 7 to 35. CDAT interprets a total score of 7 points as indicating excellent adherence, 8-12 points as very good adherence, 13-17 points as inadequate adherence, and >17 points as poor adherence to the gluten-free diet (11).

Statistical Analysis

Descriptive statistics were used to analyze continuous variables. Mean and standard deviation were used for normally distributed parameters, and median with range (min-max) were used for non-normally distributed variables. Normality was determined using the Shapiro-Wilk test. Dependent continuous variables were analyzed using the Wilcoxon signed-rank test, whereas independent continuous variables were assessed using the Mann–Whitney U test. Categorical variables were analyzed using the chi-square test, and, in some cases, using Fisher's exact test with Yates continuity correction. Significance was set at $p < 0.05$. The analysis was performed using MedCalc Statistical Software versions 12.7.7 and 19.1. Participants' symptoms related to celiac disease were categorized into excellent and very good adherence versus inadequate and poor adherence to increase statistical power.



RESULTS

The median age of the study participants was 33.5 years, ranging from 20 to 62 years. Among the participants, 54.5% were female and 45.5% were male, 52.3% were married, 68.2% held a university degree, and 77.3% were employed ($p>0.05$). Regarding the duration of celiac diagnosis, 56.8% of the participants had been diagnosed for <1 year, 11.4% for 1–2 years, 27.3% for 3–5 years, and 4.5% for >5 years.

Table 1. Characteristics of the participants

Variable	Female (n=24)	Male (n=20)	Total (n=44)	p
Age (years)	34.5 (20–48)	31.0 (21–62)	33.5 (20–62)	0.671 [†]
Marital status (n, %)				
Single	8 (33.3)	13 (65)	21 (47.7)	0.073 [‡]
Married	16 (66.7)	7 (35)	23 (52.3)	
Educational level (n, %)				
Primary school	1 (4.2)	-	1 (2.3)	0.240 [§]
High school	4 (16.7)	6 (30)	10 (22.7)	
University	16 (66.7)	14 (70)	30 (68.2)	
Master's degree	3 (12.5)	-	3 (6.8)	
Working status (n, %)				
Employed	18 (75)	16 (80)	34 (77.3)	0.734 [¶]
Unemployed	6 (25)	4 (20)	10 (22.7)	
Celiac disease age (n, %)				
<1 years	11 (45.9)	14 (70)	25 (56.8)	NA
1–2 years	2 (8.3)	3 (15)	5 (11.4)	
3–5 years	9 (37.5)	3 (15)	12 (27.3)	
>5 years	2 (8.3)	-	2 (4.5)	
Status of receiving gluten-free nutrition education (n, %)				
Yes	8 (33.3)	9 (45)	17 (38.6)	0.626 [§]
No	16 (66.7)	11 (55)	27 (61.4)	
Gluten-free diet adherence status (n, %)				
Often	8 (33.3)	14 (70)	22 (50)	0.015[§]
Always	16 (66.7)	6 (30)	22 (50)	
Food label reading status (n, %)				
Yes	22 (91.7)	16 (80)	38 (86.4)	NA
No	2 (8.3)	4 (20)	6 (13.6)	
Anthropometric values				
Body weight (kg)	58.0 (48–75)	77.0 (55–110)	61.5 (48–110)	0.005[†]
Height (cm)	165.0 (153–177)	172.0 (160–189)	166.5 (153–189)	0.002[†]
BMI (kg/m²)	21.6 (18–27)	24.0 (20–33)	22.7 (18–33)	0.027[†]

[†]Mann–Whitney U test, [‡]Continuity correction, [§]Pearson chi-square, [¶]Fisher's exact test, Median (Minimum-Maximum), BMI: body mass index, NA: not assessed.



Approximately 61.4% of participants had not received prior nutrition education on gluten-free diets ($p=0.626$). Half of the participants (50.0%) reported “often” adhering to a gluten-free diet, whereas the other half (50.0%) reported “always” adhering to it ($p=0.015$). Regarding food label-reading habits, 86.4% of participants indicated that they read food labels, whereas 13.6% stated that they did not. The median BMI for female participants was 21.6 kg/m² (range: 18-27 kg/m²), whereas for male participants, it was 24.0 kg/m² (range: 20–33 kg/m²), resulting in a total median BMI of 22.7 kg/m² (range: 18–33 kg/m²). This difference in BMI between gender was statistically significant ($p=0.027$) (Table 1).

Table 2. Assessment of celiac diet adherence status

Celiac diet adherence test	Female (n=24)	Male (n=20)	Total (n=44)	p
Excellent adherence (n,%)	3 (12.5)	-	3 (6.8)	0.267 [†]
Very good adherence (n,%)	8 (33.3)	5 (25)	13 (29.5)	
Inadequate adherence (n,%)	8 (33.3)	11 (60)	19 (45.5)	
Poor adherence (n,%)	5 (20.8)	4 (15)	9 (18.2)	

[†]Pearson chi-square test.

CDAT findings revealed that 45.5% of participants had insufficient adherence, 29.5% had good adherence, 18.2% had poor adherence, and 6.8% had excellent adherence ($p>0.05$; Table 2).



Table 3. Gluten-free diet adherence scores according to sociodemographic characteristics

Variable		p
CDAT total score	13.5 (7–24)	
Gender		
Female	13.0 (7–24)	0.193
Male	15.0 (9–19)	
Marital status		
Single	15.0 (9–19)	0.048[†]
Married	11.0 (7–24)	
Education level		
Primary school	23.0	
High school	16.0 (8–22)	NA
University	13.0 (7–24)	
Master degree	13.0 (11–13)	
Working status		
Yes	13.0 (7–24)	0.048[†]
No	15.5 (8–23)	

[†]Mann–Whitney U test, Median (Minimum-Maximum), CDAT: Celiac Diet Adherence Test, NA: not assessed.

The median total CDAT score for the participants was 13.5 (range: 7-24). There was no statistically significant difference in the total CDAT scores between gender ($p>0.05$). However, unmarried individuals had a statistically significantly higher median CDAT score than married individuals (unmarried: 15, range: 9-19 vs. married: 11, range: 7-24; $p=0.048$). Participants who were not employed had a statistically significantly higher median CDAT total score than those who were employed (not employed: 15.5, range: 8-23 vs. employed: 13, range: 7-24; $p=0.048$; Table 3).



Table 4. Relationship between celiac-related symptoms and celiac diet adherence test

	Excellent adherence (n=3)	Very good adherence (n=13)	Inadequate adherence (n=20)	Poor adherence (n=8)
Tiredness (n, %)				
Yes	-	6 (46.2)	18 (90)	8 (100)
No	3 (100)	7 (53.8)	2 (10)	-
Attention deficit (n, %)				
Yes	-	8 (61.5)	15 (75)	4 (50)
No	3 (100)	5 (38.5)	5 (25)	4 (50)
Weight loss (n, %)				
Yes	-	2 (15.4)	6 (30)	5 (62.5)
No	3 (100)	11 (84.6)	14 (70)	3 (37.5)
Anorexia (n, %)				
Yes	-	1 (7.7)	9 (45)	4 (50)
No	3 (100)	12 (93.3)	11 (55)	4 (50)
Nausea and vomiting (n, %)				
Yes	-	-	6 (30)	4 (50)
No	3 (100)	13 (100)	14 (70)	4 (50)
Stomach ache (n, %)				
Yes	-	1 (7.7)	12 (60)	8 (100)
No	3 (100)	12 (92.3)	8 (40)	-
Diarrhea (n, %)				
Yes	-	2 (15.4)	8 (40)	6 (75)
No	3 (100)	11 (84.6)	12 (60)	2 (25)
Constipation (n, %)				
Yes	-	1 (7.7)	12 (60)	3 (37.5)
No	3 (100)	12 (92.3)	8 (40)	5 (62.5)
Gas (n, %)				
Yes	-	4 (30.8)	16 (80)	7 (87.5)
No	3 (100)	9 (69.2)	4 (20)	1 (12.5)
Dermatitis herpetiformis (n, %)				
Yes	-	-	2 (10)	-
No	3 (100)	13 (100)	18 (90)	8 (100)
Anemia (n, %)				
Yes	-	3 (23.1)	6 (30)	4 (50)
No	3 (100)	10 (76.9)	14 (70)	4 (50)
Osteoporosis (n, %)				
Yes	-	-	2 (10)	-
No	3 (100)	13 (100)	18 (90)	8 (100)
Reflux (n, %)				
Yes	-	1 (7.7)	10 (50)	5 (62.5)
No	3 (100)	12 (92.3)	10 (50)	3 (37.5)
Hair loss (n, %)				
Yes	-	4 (30.8)	7 (35)	5 (62.5)
No	3 (100)	9 (69.2)	13 (65)	3 (37.5)
Asthma (n, %)				
Yes	-	-	1 (5)	-
No	3 (100)	13 (100)	19 (95)	8 (100)
Headache (n, %)				
Yes	-	2 (15.4)	9 (45)	3 (37.5)
No	3 (100)	11 (84.6)	11 (55)	5 (62.5)
Muscle pain (n, %)				
Yes	-	2 (15.4)	11 (55)	1 (12.5)
No	3 (100)	11 (84.6)	9 (45)	7 (87.5)



Individuals who demonstrated excellent adherence to the gluten-free diet reported no symptoms related to celiac disease. According to CDAT, among participants with very good adherence to the gluten-free diet, the majority reported attention deficit (61.5%), and other symptoms were less frequent. Among individuals with insufficient adherence to the gluten-free diet, the majority reported fatigue (90%), gas (80%), attention deficit (75%), constipation (60%), abdominal pain (60%), and muscle pain (55%), with half of them reporting symptoms such as diarrhea (75%), weight loss (62.5%), reflux (62.5%), and hair loss (62.5%). Among individuals with poor adherence to the gluten-free diet, fatigue (100%) and abdominal pain (100%) were reported by all, and most experienced symptoms such as diarrhea (75%), gas (87.5%), weight loss (62.5%), reflux (62.5%), and hair loss (62.5%). Additionally, symptoms such as attention deficit (50%), loss of appetite (50%), nausea/vomiting (50%), and anemia (50%) were reported by half of the participants. CDAT revealed that symptoms of fatigue, loss of appetite, nausea and vomiting, abdominal pain, diarrhea, constipation, gas, and reflux were significantly more common in individuals with poor and insufficient adherence than in those with excellent and very good adherence ($p < 0.05$; Table 4).

DISCUSSION

Celiac disease, a chronic immune-mediated enteropathy of the small intestine, affects approximately 1% of the population (13). This study aimed to evaluate dietary adherence and celiac related symptoms in adult individuals with celiac disease. The majority of the individuals participating in the study (54.5%) were female. Previous research has indicated a higher prevalence of celiac disease among women than among men (14, 15).

When examining self-adherence to the gluten-free diet, 50% of participants reported adherence to the diet most of the time, and the remaining 50% reported adherence all the time. The majority of participants were adults diagnosed with celiac disease in < 1 year, with 61.4% of them indicating that they had not received any education on gluten-free nutrition before. This suggests that decreasing adherence to a gluten-free diet can potentially be prevented by providing gluten-free nutrition education to patients with celiac disease shortly after their diagnosis. In another study, participants had been following a gluten-free diet for an average of 9.4 ± 6.4 years, and 75.5% of the participants adhered to the diet adequately, whereas 24.5% did not (6). Various individual factors, including lack of knowledge about the gluten-free diet, the taste of gluten-free food, social phobias related to the disease, awareness, educational level, and



income inadequacies, can influence adherence to the gluten-free diet. Additionally, environmental and societal factors such as dining out, high cost, low availability, lack of information on food labels, cultural factors, and residing in an urban area can pose challenges to adherence (16).

Celiac disease does not appear to have a significant effect on body weight; however, there is a higher likelihood of women having greater body weight (17). The BMI values of female and male participants in our study fell within the normal range. In a previous study, 18% of patients with celiac disease were underweight (18). Another study reported that 16% of newly diagnosed patients with celiac disease experienced unintentional weight loss, 7.5% had malnutrition, and 30% were mildly overweight (19). In contrast, a different study found that both male and female patients with celiac disease tended to experience an increase in BMI after starting a gluten-free diet, although the increase resulted in BMI values remaining within the normal range (18). Discrepancies between our study results and the scientific literature may stem from differences in sample size and the diversity of patient profiles.

CDAT has been found to exhibit high validity, reliability, and internal consistency, with a higher CDAT score generally indicating improved adherence to the gluten-free diet and a lower score indicating more frequent gluten exposure (11). In our study, 45.5% of participants showed inadequate adherence, 29.5% showed good adherence, 18.2% showed poor adherence, and 6.8% showed excellent adherence. Similar to our study, research conducted on adults has shown adherence rates to the gluten-free diet ranging from 17% to 45% (20). A systematic review noted that adherence to the gluten-free diet in patients with celiac disease ranged from 42% to 91% (21). In another study, the adherence rate to the gluten-free diet among 306 individuals with celiac disease was reported as 72.3% (22). The results of studies analyzing adherence to the gluten-free diet vary widely, which can be attributed to factors such as age, age at diagnosis, gender, and duration of illness (21). Full adherence to a gluten-free diet has been shown to provide significant benefits to the quality of life of individuals with celiac disease, but it can also lead to concerns and limitations in daily activities for these individuals (23).

A study has shown that women tend to adhere better to the gluten-free diet than men (24). Consistent with this research, all individuals who demonstrated excellent adherence in our study were women, and 61.5% of women exhibited very good adherence. In a study evaluating adherence to the gluten-free diet in adult patients with celiac disease, married participants were



found to be more adherent to the diet than unmarried individuals, but demographic factors such as gender, age at diagnosis, duration of adherence to the gluten-free diet, education, and employment status were not associated (20). In contrast to these findings, our study indicated that single individuals or those not employed had statistically higher total celiac scores than married or employed individuals. This discrepancy could be attributed to employed individuals spending more time outside the home, potentially facing challenges in adhering to the gluten-free diet when dining away from home. Similarly, lower adherence to the gluten-free diet for married individuals may have been influenced by the difficulties of preparing gluten-free meals in the same kitchen without cross-contamination when living with family members without celiac disease. Our study found no statistically significant correlation of gender and age with adherence to the gluten-free diet.

Adherence to a gluten-free diet for a minimum of 3 months has been demonstrated to reduce celiac-related symptoms and enhance the quality of life, especially for patients with atypical celiac disease (25). Those with celiac disease who strictly followed a gluten-free diet reported reduced fatigue and dizziness, a 65% decrease in gastrointestinal symptoms, and overall well-being improvements (26). Additionally, the gluten-free diet has proven effective in addressing most extraintestinal manifestations of celiac disease while also reducing the risk of complications (12). Leffler et al. reported that 30% of cases with no clinical improvement were linked to continuous gluten exposure in the diet (27). Consistent with this body of research, our study found that individuals who achieved excellent and very good adherence had significantly lower rates of key celiac-related symptoms than those with poor adherence.

The widespread use of gluten-containing food additives in the food industry poses challenges in maintaining a strict gluten-free diet among individuals with celiac disease. Food label comprehension remains a genuine concern for these individuals (28). For example, in one study, 75% of participants made at least one error when distinguishing between gluten-free and gluten-containing foods, potentially resulting in inadvertent gluten consumption or unnecessary restrictions on safe foods (29). Another study noted that individuals generally had limited knowledge about the gluten content of foods, and this lack of knowledge was strongly associated with adherence to a gluten-free diet (30). In our study, 86.4% of participants were observed to read food label information.

Lack of knowledge is linked to suboptimal adherence to a gluten-free diet. Our study also



revealed that a significant portion of individuals with celiac disease had not received previous education on gluten-free nutrition. Namvar et al. conducted a study that showed significant improvements in knowledge following nutrition education for individuals with celiac disease (31). The intervention group exhibited higher average knowledge scores immediately after the education and sustained these improvements over 3 months compared with the control group. Moreover, group education was found to be advantageous in increasing knowledge about gluten-free food items. Notably, group education for individuals with celiac disease significantly improved their quality of life and reduced gastrointestinal symptoms compared with individual education (24). To enhance adherence to a gluten-free diet among individuals with celiac disease, thereby alleviating symptoms and improving their quality of life, it is advisable to incorporate group-based educational programs alongside individual education (31).

CONCLUSION

Celiac disease is usually diagnosed in childhood and requires lifelong adherence to a gluten-free diet. Inadequate education about nutritional support for individuals with celiac disease has been shown to lead to intentional or unintentional failure to adhere to a gluten-free diet (32). Poor adherence has been associated with lack of knowledge (33). In conclusion, increasing knowledge about gluten-free nutrition in celiac disease is one of the most important factors that improve adherence to the diet. To prevent nutritional knowledge deficiencies in adult patients with celiac disease, continuous individual and group-based nutrition education should be provided by dietitians. In future research, addressing these limitations by incorporating a larger and more diverse sample, a control group, long-term follow-up, and more frequent and varied educational interventions could enhance the understanding and effectiveness of strategies to improve dietary adherence among individuals with celiac disease.

Limitation

This study also has some limitations. Firstly, the study relied on self-reported data for dietary adherence and symptom reporting. Participants might overestimate their adherence to the gluten-free diet or underreport symptoms.



Abbreviations

CDAT: Celiac Diet Adherence Test

BMI: body mass index

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