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Nutrition Literacy Status of individuals with and without eliac disease

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ABSTRACT

Background: Celiac disease (CD) is a chronic autoimmune disorder that requires lifelong adherence to a gluten-free diet (GFD). Nutrition literacy (NL), defined as the ability to access, understand, and apply nutrition information, is crucial for achieving adequate dietary adherence and maintaining long-term health in these patients.

Objective: This study aimed to assess NL levels in adults with CD compared to healthy controls.

Methods: A cross-sectional, online survey was conducted between February and June 2024. Demographic data and NL were assessed using the Evaluation Instrument of Nutrition Literacy in Adults (EINLA). A total of 458 adults participated (228 with CD and 230 healthy controls), aged 19–64 years. Independent t-tests, chi-square tests, and regression analyses were applied to examine differences and predictors of NL.

Results: The mean age of the total sample was 36.7 ± 12.4 years; participants with CD were slightly younger (35.9 ± 11.8 years) compared to controls (37.5 ± 13.0 years). The mean EINLA score of the overall sample was 23.8 ± 5.6. Healthy controls had significantly higher scores (24.9 ± 5.4) than CD patients (22.6 ± 5.7; $p<0.05$). Most participants in both groups were classified as having borderline NL: 94.3% in the CD group and 87.8% in the control group. Adequate NL was more frequent among healthy controls (12.2%) compared to CD patients (5.7%). Regression analysis identified gender and CD status as significant predictors of NL, with women and controls showing relatively higher literacy levels.

Conclusion: Both CD patients and healthy adults demonstrated predominantly borderline NL, with significantly lower scores among CD patients. These findings underscore the need for dietitian-led, targeted education programs to strengthen nutritional knowledge, improve dietary adherence to the GFD, and enhance long-term health outcomes.

KEYWORDS

Adults nutrition literacy; celiac disease; dietary habits; gluten free diet; nutritional knowledge.

INTRODUCTION

Celiac Disease (CD) is a multisystem autoimmune disease characterized by immune-mediated damage to the small intestine following gluten consumption in genetically susceptible individuals[1,2]. CD is characterized by clinical polymorphism, with classic, asymptomatic oligosymptomatic, and extra-intestinal forms, which may lead to diagnostic delay and exposure to serious complications[3]. However, the factors that lead to the development of CD remain unknown. Once diagnosed, CD remains a lifelong medical condition with no cure. The only approved treatment is the complete elimination of gluten from foods, beverages, and medications. The main goals of celiac nutritional therapy are optimal health, growth, and development; malabsorption that may lead to accompanying diseases such as anemia, osteopenia, or osteoporosis; and nutritional deficiency that may occur in prevention and treatment[1] A gluten-free diet (GFD) should meet the recommended nutritional goals for energy and nutrients, like the general population[4]. A gluten-free diet can improve quality of life, gastrointestinal health, and treat symptoms. Improvement in antibodies and inflammatory and

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immunological indicators related to CD is achieved by adhering to this dietary model[1]. The typical intake of a patient on a gluten-free diet is generally low in complex carbohydrates and proteins, and high in fat and simple carbohydrates. Conventional gluten-free foods have a higher caloric content, causing patients to gain weight when adhering to a gluten-free diet, even though they do not change food intake. The types of flour and starch used in gluten-free foods result in high carbohydrate intake with low fiber and high sugar content in gluten-free diets[2].

Nutritional deficiencies in CD are often due to nutritional deficiencies in gluten-free foods and incorrect behavior[5]. Although a gluten-free diet is the only management strategy for CD, strict adherence to the diet varies from 42% to 91%. Inadequate education is one of the factors that affect adherence[6].

Health literacy is defined as "the degree to which individuals can obtain, process, and understand Zoellner, basic health information and services needed to make appropriate health decisions"[7]. Patients, especially in the first years after diagnosis, need expert care and guidance to navigate their dietary and treatment options and manage the disorder, as well as related social and nutritional challenges[8]. Nutrition literacy (NL) is defined as an individual's ability to access, understand, interpret, and apply basic nutrition-related information and services to promote and maintain good health. NL requires highly complex cognitive skills as it requires skills related to nutrition and food principles[9]. In a study conducted on 104 celiac patients, 65% of the patients strictly adhered to a gluten-free diet. It was determined that patients' knowledge of CD and gluten-free diets was generally inadequate. The relationship between CD and gluten-free diet knowledge and compliance with the diet has been suggested to encourage education and behavioral programs[10]. This highlights gaps that need to be addressed in current clinical practice and management of patients with CD. Counseling should include a detailed analysis of an individual's food environment rather than simply providing information about food. It is necessary to recognize and understand these barriers and support systems to help patients develop strategies to address their social situations[11]. This study aimed to examine the nutritional literacy level of individuals with and without celiac disease.

MATERIALS AND METHODS

This study is a cross-sectional, online survey developed to collect data for the study group (CD group), remote online interviews were conducted with celiac associations and foundations in some cities in Turkey. The questionnaire consists of some personel questions and the Evaluation Instrument of Nutrition Literacy on Adults (EINLA) scale with and without CD between 15 February - 15 June 2024. The study was conducted in accordance with the Declaration of Helsinki and approved by the Institutional Review Board of BASKENT UNIVERSITY (KA23/404.17.01.2024) for studies involving humans.

The study was conducted with 630 participants between the ages of 19 and 64, 107 of whom were excluded from the study because they had chronic disease, and 65 participants were excluded because they gave incomplete answers. In the power analysis conducted on the investigation of NL individuals with and without celiac disease, it was found appropriate to work with at least 328 individuals (similar in terms of age $p>0.05$) with 5% types I error probability and 95% power probability (effect size = 0.40). The study was conducted with 458 participants. The study group consisted of 228 patients with CD group, and the control group (healthy) consisted of 230 patients without CD. A flowchart of the participant recruitment process is shown in Fig. 1. The inclusion criteria were as follows; not having any chronic disease for the healthy group, not having any chronic disease except celiac disease for celiac patients and celiac disease was diagnosed by doctor, not being pregnant, not use of medications that affect nutritional status and voluntary participation. The clinical diagnosis of CD and the anthropometric data (BMI) were self-reported.

The questionnaire was divided into two primary sections as demographic, anthropometric, and diagnostic questions, and the Evaluation Instrument of Nutrition Literacy on Adults (EINLA). The Evaluation Instrument of Nutrition Literacy on Adults developed to assess the development of Nutrition Literacy was applied to 266 in Turkey. EINLA consists of 35 questions upon the completion of factor analysis conducted to assess construct validity, but one of the items (item 1) in the assessment tool was determined to have load factors greater than 0.30, and the tool was considered to have a 5-factor structure. The correlation coefficient was found to be 0.85 using the test-retest method. The Cronbach's alpha reliability coefficient of the assessment tool was 0.75. The first section included items on general nutrition information, the second section on reading comprehension and interpretation, the third section on food groups, the fourth section on serving sizes, and the fifth section on how to read food labels and the ability to do simple calculations. While each correct answer was given one point, unanswered or incorrectly answered items were given 0 points. When the nutrition literacy level was graded, a total score between 0 and 11 was considered insufficient, between 12 and 23 as borderline, and between 24 and 35 as sufficient[9].

In comparisons between groups, the characteristics of the participants were compared using the Pearson chi-square test for categorical variables and Student's t-test and analysis of variance (ANOVA) for continuous variables. Data were presented as percentages (%) and absolute values (n) for categorical variables and as mean and Standard Deviation (SD) for continuous variables. Multiple linear regression analysis was conducted with adjustments for age, gender, celiac dis-

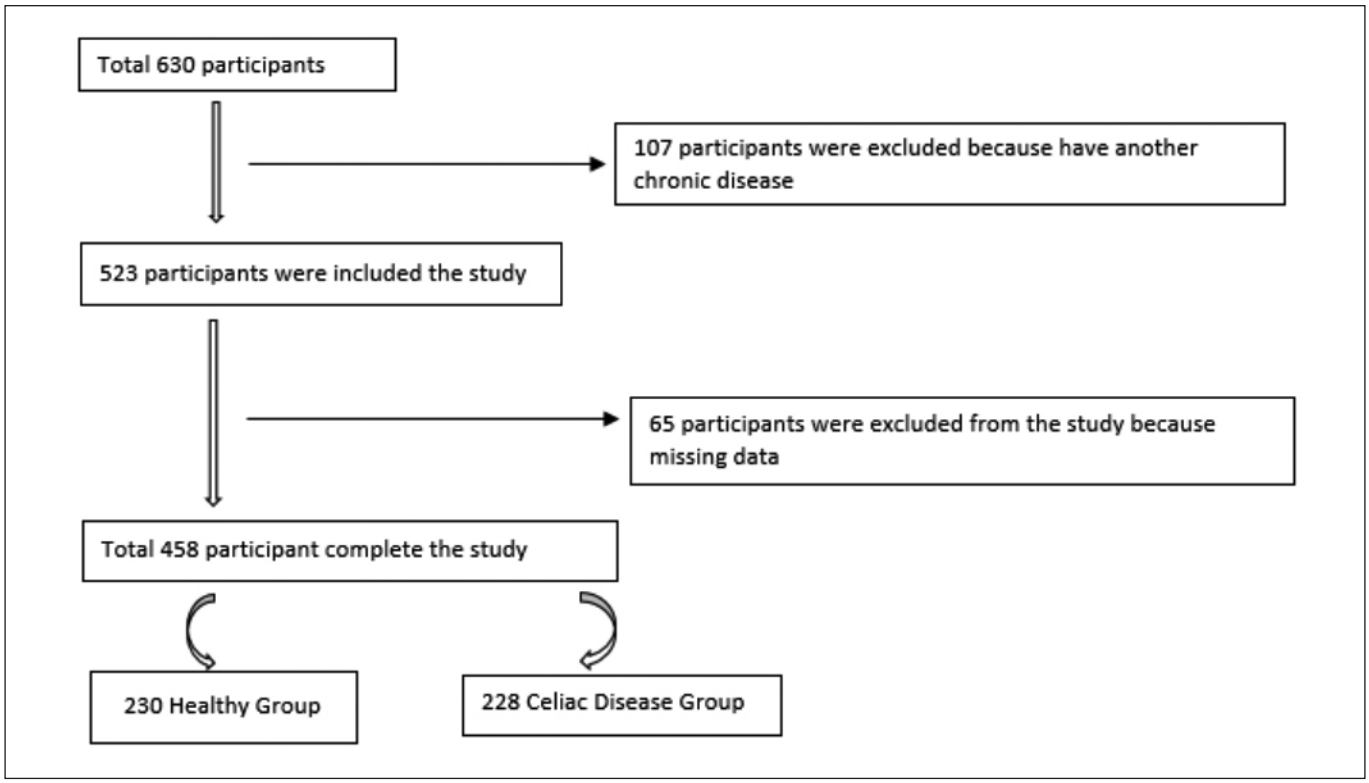

Figure 1. Flow chart of the recruitment of the participants

ease, and Body Mass Index (BMI) to assess factors related to nutrition literacy. The results from the multiple linear regression analysis are presented as β (standardized coefficients beta) ± SE (standard error).

RESULTS

Demographics of Celiac Patients and Healthy Group

The study was conducted on total 458 people, which 228 (203 women, and 25 men) with CD, and 230 (157 women and 73 men) without CD. The average age of women in the study and healthy groups was 33.9±8.65 and 3.6±11.60 years, respectively ($p>0.05$), while the average age of men was 34.8±11.48 and 34.8±12.28 years ($p>0.05$). There is no statistical difference between the body weights and BMI of men and women in the CD and healthy groups. The average height of women in the healthy group was 166.7±5.60 cm, while the average height of women in the CD group was 162.6±5.96 cm. The difference was found to be statistically significant ($p<0.05$). The anthropometric data (BMI) were self-reported and shown in Table 1.

Table 1. Age and anthropometric measurement of participants

Age and anthropometric measurement	CD Group				Healthy Group				p^1	p^2
	Women (n=203)		Men (n=25)		Women (n=157)		Men (n=73)			
	$\bar{x}$	SS	$\bar{x}$	SS	$\bar{x}$	SS	$\bar{x}$	SS		
Age (year)	33.9	8.65	34.8	11.48	32.6	11.6	34.7	12.28	0.202	0.956
Height (cm)	162.6	5.96	174.8	6.56	166.7	5.6	179.5	7.46	**0.000***	**0.006***
Weight (kg)	60.2	12.3	74.7	11.76	62.9	10.8	87.5	16.18	**0.031***	**0.000***
BMI (kg/m^2)	27.7	4.31	24.4	3.52	22.6	3.97	27.1	4.51	0.848	**0.004***

The educational status of women and men with CD was analyzed, and it was found that 71.9% and 80%, respectively, and 66.2% and 75.3% of healthy women and men, respectively, were university graduates (p>0.05).

Among the participants, 19.7% reported being diagnosed through antibody testing, 27.2% through biopsy, 3.9% through genetic testing, 45.6% through endoscopy, and 7.5% through other methods. Regarding the time since diagnosis, 18.0% of the patients had been diagnosed within the past year, 34.6% between 1 and 5 years ago, 22.4% between 6 and 10 years ago, and 25.0% more than 10 years ago. A small proportion of patients (0.9%) stated that they had not received any dietary advice. In terms of adherence, 54.4% reported difficulties in following a gluten-free diet, while 5.7% indicated that they were not following any diet at all. Dietary guidance was most commonly received from physicians (42.1%) and dietitians (39.0%), whereas 13.1% reported obtaining dietary advice from other healthcare professionals or alternative sources.

Nutrition literacy knowledge

The mean EINLA scores of individuals with and without CD were examined in Table 2. Mean scores of 'general nutrition', 'serving sizes', and 'food labels and ability to do simple calculations' were found to be lower in women with CD than in healthy women (p<0.05). Reading comprehension and interpretation and food groups were examined, and no statistically significant difference was found between or within groups. Among healthy individuals, the mean scores of 'general nutrition', 'serving sizes', and 'food labels and ability to do simple calculations' of females were found to be statistically significantly higher than men(p<0.05). When the mean total scores of NL were analyzed, it was found that females were higher than men in healthy individuals (p<0.05). The mean nutrition score was statistically significantly higher in women with CD than in healthy women (p<0.05). Healthy group has higher EINLA scores than CD group, and "the reading comprehension and interpretation", "food labels and the ability to do simple calculations points" and "total points" were higher in healthy group (p<0.05).

In Table 3, the classification of NL is analyzed. It was determined that 95.1% of women with CD and 85.4% of healthy women had borderline nutritional literacy. The difference was statistically significant (p<0.05). For HG, the percentage of those with borderline was 87.8%, while the percentage with adequate knowledge was12.2%, and for CD group, the percentage with borderline was 94.3%, while the percentage with adequate was 5.7%. The difference between the two groups was statistically significant (p < 0.05).

Table 2. EINLA scores of individuals with and without CD

EINLA scores	CD Group			Healthy Group			P^1	P^2	P^3	P^4	P^5
	Women (n=203)	Men (n=25)	Total (n=228)	Woman (n=157)	Men (n=73)	Total (n=230)					
	x̄±SS	x̄±SS	x̄±SS	x̄±SS	x̄±SS	x̄±SS					
Nutrition information	8.5±1.15	8.5±1.29	8.5±1.63	9.0±1.19	8.3±1.35	8.8±1.28	0.912	**0.000***	**0.000***	0.539	0.009
Reading comprehension and interpretation	5.3±0.87	5.3±1.02	5.3±0.89	5.5±0.64	5.4±0.81	5.6±0.69	0.914	0.222	**0.023***	0.655	**0.04***
Food groups	2.3±0.67	2.2±0.83	2.3±0.68	2.2±0.78	2.3±0.78	2.3±0.77	0.513	0.472	0.193	0.684	0.352
Serving sizes	1.3±0.54	1.2±0.66	1.3±0.54	1.49±0.55	1.3±0.51	1.43±0.55	0.665	**0.008***	**0.001***	0.711	0.06
Food labels and the ability to do simple calculations	2.8±1.08	2.8±1.10	2.8±1.08	3.09±0.92	2.8±1.12	3.0±0.99	0.789	**0.032***	**0.003***	0.861	**0.027***
Total	20.2±2.30	20.1±3.20	20.2±2.40	21.32±2.32	20.1±2.44	20.9±2.42	0.880	**0.000***	**0.000***	0.969	**0.001***

*p<0.05. Evaluation Instrument of Nutrition Literacy on Adults EINLA, CD celiac disease p^1: Difference between individuals with CD, p^2: Difference between Healthy Individuals, p^3:Difference between women, p^4: Difference between men, p^5: Difference between total.

Table 3. The classification of EINLA

EINLA classification	CD Group						Healthy Group						p1	p2	p3	p4	p5
	Women (n=203)		Men (n=25)		Total (n=228)		Women (n=157)		Men (n=73)		Total (n=230)						
	n	%	n	%	n	%	n	%	n	%	n	%					
Borderline	193	95.1	22	88.0	215	94.3	134	85.4	68	93.1	202	87.8	X2= 2.072; p= 0.150	X2= 2.836; p= 0.092	**X2= 10.053; p= 0.002***	X2= 0.659; p= 0.417	**X2= 5.884; p= 0.015***
Adequate	10	4.9	3	12.0	13	5.7	23	14.6	5	6.9	28	12.2					
Total	203	100.0	25	100	228	100	157	100.0	73	100.0	230	100					

1p<0.05; EINLA; Evaluation Instrument of Nutrition Literacy on Adults, CD; celiac disease, p^1: Difference between individuals with CD, p^2: Difference between Healthy Individuals, p^3: Difference between women, p^4: Difference between men.

Multiple linear regression examining the impact of gender, age, CD status, and BMI on NL

Table 4 displays the results of multiple linear regression examining the impact of gender, age, CD status, and BMI on NL. The modeling revealed that gender and CD status had a statistically significant effect on nutritional literacy. In all the modeling, the NL level was found to be negatively associated in men compared to women (p<0.001). Also, in model 4, it was observed that having CD status compared to not having CD status was associated statistically significantly positively with 0.194 points on NL (p<0.001).

Table 4 displays the results of multiple linear regression examining the impact of gender, age, CD status, and BMI on nutrition literacy (NL). The modeling revealed that gender and CD status had a statistically significant effect on NL. In all models, NL levels were found to be significantly lower among men compared to women ($p < 0.001$). In Model 4, having CD status (compared to not having CD) was positively associated with NL by 0.194 points ($p < 0.001$). The overall explanatory power of the models was low, with R^2 values ranging from 0.020 to 0.026 and adjusted R^2 values remaining below 0.01. This indicates that gender, age, CD status, and BMI together explained only a small proportion of the variance in NL scores, suggesting that these variables were not strong predictors of NL in this sample.

DISCUSSION

This study examined the Nutrition Literacy Status of Individuals with and without CD. CD is a common autoimmune condition that requires strict adherence to a gluten-free diet. There is insufficient information on the optimal timing and amount of information that people with celiac disease need to understand.

Table 4. The multiple linear regression examined the impact of gender, age, CD status, and BMI on NL

Gender, age, CD status, and BMI	Model 1	Model 2	Model 3	Model 4
	β±SE, *p*	**β±SE, *p***	**β±SE, *p***	**β±SE, *p***
Gender Women, Men	-0.099±0.277; **p=0.035***	-0.103±0.277; **p=0.028***	-0.153±0.282; **p=0.001***	-0.158±0.297; **p=0.002***
Age, year		0.079±0.011; p=0.090	0.089±0.011; p=0.052	0.084±0.011; p=0.088
Celiac disease Yes No			0.195±0.231; **p=0.000***	0.194±0.232; **p=0.000***
BMI, kg/m^2				0.016±0.028; p=0.752
R2	0.020	0.021	0.021	0.026

p<0.05. Body mass index BMI, Model 1 adjusted for gender; Model 2 adjusted for gender and age; Model 3 adjusted for gender, age, and celiac disease status; Model 4 adjusted for gender, age, celiac disease status, and BMI. β: Standardized coefficients beta; SE: Standard Error.

It is recommended that information on a gluten-free diet (GFD) be provided by a doctor or dietitian at the time of diagnosis. Immediately after diagnosis, patients may find it difficult to cope with the large amount of information. Inadequate advice at this stage may lead some patients to utilize the many sources of information available to them at this time in the form of brochures, books, and websites, which may at times be less reliable. A useful approach is to offer follow-up consultation shortly after diagnosis to allow patients to ask questions and clarify dietary and health-related issues[12]. Successful management of CD requires a team and individualized approach involving the person with CD, family, physicians, dietitian, celiac support group, and caregivers, understanding of quality-of-life issues, use of evidence-based, up-to-date information and resources, regular follow-up to monitor compliance and nutritional status, and additional information and support[13].

Newly diagnosed celiac patients should be referred to a dietitian to assess the nutrient, vitamin, fiber, and calcium contents of the diet, as well as to avoid gluten and use alternative products. Patients with weight loss before the diagnosis of CD may need help and support to gain weight, while others should be counseled on weight management as part of a healthy diet[12].

A previous study found no significant difference between the sexes in nutrition literacy[14]. The higher nutrition literacy scores observed in women could be explained by the fact that women are more responsible for home nutrition practices than men. In addition, the use of different nutrition literacy tools may have led to these differences. The EINLA scores of the women with CD were lower than those of the healthy women. In a study, no significant difference was found in nutrition literacy levels between individuals with and without chronic disease[15]. In another study, they reported that the nutritional literacy scores of individuals with chronic diseases were significantly high[16]. These studies have shown that the relationship between nutrition literacy and chronic diseases is contradictory. Individuals with CD should undergo dietary therapy upon diagnosis. However, the reason why they had less knowledge than the healthy individual in this study is thought to be that these patients were given one-way education only at the gluten level. Healthy eating behavior is affected by many factors, and nutrition literacy plays a crucial role in developing healthy eating behaviors[15].

Clinical CD guidelines currently provide insufficient guidance for maintaining a nutritionally adequate GFD. More people are facing the challenge of the GFD due to the increased use of this diet for other medical conditions such as non-celiac gluten sensitivity or non-celiac wheat sensitivity, wheat allergy, inflammatory bowel disease, gastrointestinal reactions to fermentable carbohydrates and polyols, fibromyalgia, and various autoimmune conditions. The strict nature of the gluten-free diet poses a challenge for patient adherence and for clinicians to provide comprehensive and personalized dietary therapy[17]. While it is generally recognized that it can be difficult to determine whether food is gluten-free, it is equally difficult for health professionals to determine whether an individual's diet is gluten-free. Traditionally, the most common approach has been patient self-reporting and assessment by a qualified dietitian trained in gluten-free diets. Participants with a higher frequency of intentional gluten consumption were more likely to respond less accurately to the food label test. Most participants made at least one error when identifying gluten-free and gluten-containing foods. The findings suggest that patients may lack adequate guidance and support within the healthcare system and community, contributing to the individual challenges of adherence to the GFD[18].

However, there are conflicting data on the nutritional adequacy of GF products and diets. In a study examining the adherence of people with celiac disease to the Mediterranean diet, a dietary regimen that is protective against major non-communicable diseases, it was found that people with celiac disease consumed significantly higher amounts of potatoes and red and processed meat compared to healthy participants, raising questions about the food choices of people with CD and suggesting that they should be encouraged to make food choices that are more compatible with an MD that will improve their nutritional status and better protect them from non-communicable diseases in the long term[19]. In a study in which parental food literacy, home food environment, and food purchasing patterns were investigated, despite parents having good food literacy, young people reported poor diet quality[20]. In a study comparing celiac disease patients with healthy volunteers, both groups were found to have a high-lipid, high-protein, low-carbohydrate diet, high sugar intake, and low intake of vitamin D, folate, vitamin E, iodine, calcium, and iron[21]. In another study, it was emphasized that compliance with the Mediterranean diet was lower in CD patients than in healthy individuals and that CD patients had nutritional deficiencies. Therefore, it was stated that it could increase the risk of normal and metabolic diseases. In addition to compliance with the Celiac diet, it is recommended that celiac patients comply with the Mediterranean diet[22].

In this study, the majority of participants were found to have borderline NL**,** with a significantly higher prevalence among women with CD compared to healthy women. These findings are in line with previous research showing that nutritional literacy is often insufficient in both clinical and healthy populations, and that chronic diseases may further influence nutritional knowledge and behaviors[23,24]. It was reported that low levels of food and nutrition literacy are common in adults and can negatively impact dietary choices and adherence to medical nutrition therapy[25].

The observed differences between the CD and healthy groups may reflect the additional dietary restrictions and challenges associated with maintaining a strict gluten-free diet.

Previous studies have highlighted that patients with CD often face difficulties in understanding food labels, identifying hidden sources of gluten, and applying practical dietary knowledge in daily life[26,27]. These barriers may partly explain why, despite greater medical contact, CD patients did not demonstrate higher rates of adequate NL compared to their healthy counterparts.

The high proportion of borderline NL in both groups underscores the need for structured nutritional education interventions. Evidence suggests that dietitian-led educational programs significantly improve dietary adherence and self-management in CD patients[28,29]. Thus, strengthening nutrition education strategies, particularly tailored to chronic disease populations such as CD, may be critical to improving both NL and long-term health outcomes.

Limitations

This study is based on participants' recall, which can introduce potential inaccuracies.

Future Directions

Longitudinal studies assessing the impact of educational interventions on awareness. Future studies can be conducted by observing the nutritional behaviors of individuals in addition to the scale. The consistency between dietary ethics and behaviors can be observed.

CONCLUSIONS

It was found that patients with celiac disease had a lower NL than healthy individuals. It was determined that most individuals with and without celiac disease had borderline scores for EINLA. Celiac patients should be provided with celiac diet education with nutrition literacy education.

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