

# The Relationship Between Quality of Life and Health Literacy in Adults with Celiac Disease: A Cross-Sectional Study

Çölyak Tanılı Yetişkinlerde Yaşam Kalitesi ve Sağlık Okuryazarlığı Arasındaki İlişki: Kesitsel Bir Çalışma



Mine Yılmaz<sup>1</sup>, Yasemin Gümüş Şekerci<sup>2</sup>

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## Abstract

**Objective:** The aim of this study was to determine the quality of life and health literacy of patients with celiac disease and to examine the relationship between these two concepts.

**Method:** This cross-sectional study was conducted on 119 adults registered with the Celiac Disease Association of Turkey in 2023. Descriptive information form, Celiac Quality of Life Questionnaire and Turkey Health Literacy Scale 32 were used for data collection.

**Results:** The mean quality of life score for celiac patients was  $75.41 \pm 15.29$  and the mean health literacy score was  $25.16 \pm 11.23$ . There was a significant moderate positive correlation between health literacy and quality of life. Health literacy explained 13.0% of the change in quality of life. The gluten-free diet was found to be an important factor that could affect the quality of life of celiac patients in terms of their emotional state, anxiety, social life, and gastrointestinal symptoms. The study identified eight risk factors for health literacy.

**Conclusion:** This study found that patients with celiac disease have a lower than average quality of life and limited health literacy. The study found that there was a positive relationship between health literacy and quality of life. It was concluded that as patients' health literacy increases, their quality of life may also increase.

**Keywords:** celiac disease; health literacy; nursing; quality of life

## Özet

**Amaç:** Bu çalışma çölyak hastalarının yaşam kalitesi ve sağlık okuryazarlık düzeyini belirlemeyi ve bu iki kavram arasındaki ilişkiyi incelemeyi amaçlamıştır.

**Yöntem:** Bu kesitsel çalışma 2023 yılında Türkiye'de Çölyak Derneği'ne kayıtlı 119 yetişkin bireyle yürütüldü. Verilerin toplanmasında tanıtıcı bilgi formu, Çölyak Hastalarında Yaşam Kalitesi Anketi ve Türkiye Sağlık Okuryazarlığı Ölçeği 32 kullanıldı.

**Bulgular:** Çölyak hastaları için yaşam kalitesi puan ortalaması  $75,41 \pm 15,29$ , sağlık okuryazarlık puan ortalaması  $25,16 \pm 11,23$  idi. Katılımcıların sağlık okuryazarlıkları ve yaşam kaliteleri arasında orta düzeyde pozitif yönlü anlamlı bir korelasyon belirlendi. Sağlık okuryazarlığı yaşam kalitesindeki değişimin %13,0'ını açıkladı. Glütensiz beslenmenin; çölyak hastalarının duygusal durumları, endişeleri, sosyal yaşamları ve gastrointestinal belirtilerine yönelik yaşam kalitelerini etkileyebilecek önemli bir faktör olduğu tespit edildi. Çalışma sağlık okuryazarlığını etkileyen sekiz risk faktörünü tanımladı.

**Sonuç:** Bu çalışma çölyak hastalarının ortalama düzeyin altında yaşam kalitesinin ve sınırlı sağlık okuryazarlığının olduğunu ortaya çıkardı. Çalışmada sağlık okuryazarlığı ile yaşam kalitesi arasında pozitif yönde bir ilişkinin olduğu belirlendi. Hastaların sağlık okuryazarlık düzeyleri arttıkça yaşam kalitelerinin de artabileceği sonucuna ulaşıldı.

**Anahtar Sözcükler:** çölyak hastalığı; hemşirelik; sağlık okuryazarlığı; yaşam kalitesi

<sup>1</sup> Selçuk Üniversitesi Hemşirelik Fakültesi (Orcid no: 0000-0003-4466-6691)

<sup>2</sup> Doç. Dr., Selçuk Üniversitesi Hemşirelik Fakültesi Halk Sağlığı Hemşireliği Anabilim Dalı (Orcid no: 0000-0002-9661-0924)

## Introduction

Celiac disease is a common disorder caused by autoimmunity to the gluten protein (1). It is one of the most common food-related diseases in recent times (2,3). The prevalence of celiac disease in the world is reported to be 0.7% according to biopsy results and 1.4% according to serological test results (4). In Turkey, the prevalence varies between 0.3-1% and the number of diagnosed celiac disease patients was reported to be 154,027 by the end of 2022 (5). Although the number of celiac disease patients is increasing, there are also some who are not diagnosed. It is reported that for every patient diagnosed with celiac disease, there are 1/3 to 1/5 undiagnosed celiac patients (6). The only effective and safe treatment for celiac disease is the elimination of gluten-containing foods and products (7).

Given the chronic nature of the disease, the quality of life (QoL) of patients with celiac disease is affected by the symptoms experienced, comorbidities, the need for a gluten-free diet (8), and the difficulty and cost of lifelong adherence to a gluten-free diet. In previous studies, age, gender, duration of gluten-free diet (9), and gluten-free diet (1) were associated with QoL. A study of 60 adult patients with celiac disease in India reported a significant increase in their reduced health-related QoL with a gluten-free diet (10). Maintaining a lifelong gluten-free diet is a difficult process due to reasons such as the high cost of gluten-free foods, limited accessibility, taste and flavor not appealing to everyone's taste buds, unaccounted-for gluten contamination, and cultural differences. The QoL of people with celiac disease can be improved through better dietary practices, early diagnosis, reading food labels, more frequent and better implementation of dietary education, and increasing health literacy (HL).

Health literacy refers to an individual's ability to interpret and understand basic health information. Increasing the level of HL can ensure that patients have information about treatment and are involved in the process, that patients correctly perceive the services and service quality provided and respond positively (11). In addition, increasing the level of HL can emphasize preventive health services, shorten the treatment process, and improve the QoL of individuals (12).

Health literacy is a known determinant of many health outcomes and helps to reduce health disparities (13). Limited HL levels negatively affect the diagnosis and treatment process of patients, leading to increased hospital readmission rates and patient care costs (14). In the European HL study conducted in eight European countries, it was found that 12% of the respondents had inadequate HL and 47% had problematic limited HL (15). The Turkey-wide study was conducted on 6,228 households and it was determined that 30.9% of the participants had insufficient HL, 38.0% had limited HL, 23.4% had adequate HL, and 7.7% had excellent HL. In the same study, it was found that 7 out of 10 people in Turkey have inadequate or limited HL (5).

The level of HL has become an important determinant of health outcomes by influencing the use of health services (16). Limited HL is a significant barrier to the delivery of health services (17). Low HL may pose a potential risk to the protection or treatment of an individual's health and may place an additional burden on healthcare by wasting limited resources on both vital and healthcare expenditures (14). Low HL is associated with lack of knowledge about medical conditions and health services received, lack of effective communication with health professionals (18), increased hospitalizations (18,19) increased use of emergency care, poor adherence to medication regimens, inability to interpret health-related information, poorer general health, increased healthcare costs (18), and higher mortality (20).

Health literacy is one of the important factors that affect patients' health-related QoL and their ability to access necessary health services. Previous studies have investigated the relationship between HL and QoL (19,21-24), but the results are not consistent. While some studies have shown a positive relationship between QoL and HL (25-27), others have reported a negative relationship (28). A recent meta-analysis and systematic review on this topic highlighted that there is a moderate correlation between HL and QoL, but this finding needs to be supported by more evidence (12). Other studies have reported no difference between HL and QoL (22,29). To our knowledge, no study conducted in Turkey has evaluated the relationship between QoL

and HL in Turkish celiac patients. Therefore, the aim of this study was to determine the QoL and HL levels of celiac patients and to examine the relationship between these two concepts.

## Methods

**Type of Research:** This is a cross-sectional study conducted between May and August 2023 among patients registered with the Celiac Disease Association in a province in Turkey.

**Study Population and Sample:** The study population consisted of adult patients with celiac disease registered with the Celiac Disease Association in one of the provinces of Turkey who met the inclusion criteria (N=160). Considering the correlation between HL and QoL ( $r=0.35$ ) based on the formula used to determine sample size (<http://sampsizem.sourceforge.net/iface/>) and a systematic review and meta-analysis study (12), the sample size was estimated to be at least 114 individuals at the 95% confidence level. A 20% attrition rate was added to improve precision and avoid bias due to the reduced sample size. As a result, 137 participants were planned to be included in the study, but since 13 participants did not want to participate in the study and 5 participants completed half of the data collection forms, the study was conducted with a total of 119 patients.

## Inclusion and Exclusion Criteria

### Inclusion criteria

- 18 years or older
- Able to speak Turkish and communicate verbally
- Registered with the Celiac Disease Association where the study is being conducted
- No neurological health problems affecting advanced mental and cognitive status
- No vision or hearing problems

### Exclusion criteria

- Under 18 years of age
- Unable to communicate in Turkish or have another native language
- Having a neurological health problem with advanced mental and cognitive status
- Problems with vision and hearing
- Individuals who initially agreed to participate in the study but later withdrew and patients who did not answer all the questions on the data collection form were excluded from the study.

**Data Collection:** The data were collected face-to-face through a questionnaire form prepared by the researchers according to the literature (12,14,23,26,30). To collect the necessary data, one of the researchers visited the Celiac Association between 08:00-17:00 on different days, distributed the questionnaires to the patients, and collected on the same day. Data was collected using the Descriptive Information Form, the Health-Related Quality of Life Questionnaire in Celiac Disease Patients and the Turkish Health Literacy Scale 32 (THLS-32).

**Descriptive Information Form:** This form was prepared by the researchers based on the literature and included information about the sociodemographic characteristics of the participants (age, gender, education level, employment status, marital status, presence of children, income level, etc.) and their health status (age at diagnosis of celiac disease, other chronic disease status, gluten-free diet, vitamin and mineral supplementation, screening test for celiac disease in family members, family history of celiac disease, regular physical activity status, etc.) (12,14,20-23,26,30).

**Health-Related Quality of Life Questionnaire for Celiac Disease Patients:** The questionnaire was developed by Häuser et al. (2007) as a short form of the SF-36 Quality of Life Scale (31). Turkish validity and reliability studies of the scale were conducted by Aksan et al. (2015) (32). The scale determines the general well-being that celiac patients need to address based on their last 15 days. It can only be applied to individuals with celiac disease who are 18 years of age or older. The scale has four sub-dimensions. "Emotional state", "worries", "social problems," and "gastrointestinal symptoms." The scale is a 7-point Likert type and consists of a total of 28 questions, seven questions in each sub-dimension. Emotional state sub-dimension consists of the 2<sup>nd</sup>, 3<sup>rd</sup>, 6<sup>th</sup>, 10<sup>th</sup>, 14<sup>th</sup>, 16<sup>th</sup>, and 21<sup>st</sup> items. The Anxiety sub-dimension consists of the 7<sup>th</sup>, 12<sup>th</sup>, 24<sup>th</sup>, 25<sup>th</sup>, 26<sup>th</sup>, 27<sup>th</sup>, and 28<sup>th</sup> items. The Social problems sub-dimension consists of the 4<sup>th</sup>, 9<sup>th</sup>, 15<sup>th</sup>, 18<sup>th</sup>, 20<sup>th</sup>, 22<sup>nd</sup>, and 23<sup>rd</sup> items. The Gastrointestinal symptoms sub-dimension consists of the 1<sup>st</sup>, 5<sup>th</sup>, 8<sup>th</sup>, 11<sup>th</sup>, 13<sup>th</sup>, 17<sup>th</sup>, and 19<sup>th</sup> items. The total score is obtained by summing the scores of all items. Subscale scores range

from 0-49 and total scores range from 0-196. The higher the score, the higher the QoL, and the lower the score, the lower the QoL. The test-retest Cronbach's alpha coefficient of the Turkish validity and reliability scale was reported to be 0.99 for all subscales (32). The Cronbach's alpha coefficient for this study was found to be 0.61 and it can be seen that the Cronbach's alpha value is at an acceptable level (33).

### **Turkish Health Literacy Scale 32 (THLS-32):**

THLS-32 is a scale developed based on the conceptual framework of the HLS-EU Consortium study. The validity and reliability study was conducted by Okyay and Abacigil (2016) (34). The scale consists of 32 statements and a 2\*4 matrix structure. The matrix consists of eight components: Two dimensions (treatment/service and disease prevention/health promotion) and four processes (accessing health-related information, understanding health-related information, evaluating health-related information, and using/applying health-related information). Access to health-related information in the treatment/service sub-dimension includes items 1, 4, 5, 7; understanding health-related information includes items 2, 8, 11, 13; evaluating health-related information includes items 3, 9, 12, 15; and using/applying health-related information includes items 6, 10, 14, and 16. In the disease prevention/health promotion subdimension, accessing health-related information includes items 18, 20, 22, and 27; understanding health-related information includes items 19, 21, 23, and 25; evaluating health-related information includes items 24, 26, 28, and 32; and using/applying health-related information includes items 17, 29, 30, and 31. The THLS-32 is based on the principle of rating how "easy" or "difficult" the behavior specified in each question is, according to the individual's own perception. The scale is a 5-point Likert scale, and each item is rated as "very easy (1), easy (2), difficult (3), very difficult (4), and no idea (5)." Before calculating the score, the codes are recoded as 1-4, 2-3, 3-2, 4-1, and 5-0. The total score that can be obtained from the scale ranges from 0-128. For ease of calculation, the total score was standardized using the formula below to take a value between 0 and 50 points as in the HLS-EU study (34).

Index = (mean-1) x (50/3).

In the above formula, the index is the individually calculated index; the mean is the average of each item answered by a person; 1 is the lowest possible value of the mean (so the index is the lowest 0); 3 is the range of the mean; 50 is the highest value chosen for the new criterion. After this calculation, 0 indicates the lowest HL and 50 the highest HL. The index is also divided into four categories. These categories correspond to the scoring:

- (0-25 points): inadequate HL
- (>25-33 points): problematic-limited HL
- (>33-42 points): adequate HL
- (>42-50 points): defined as excellent HL (34).

The Cronbach's alpha coefficient of the Turkish validity and reliability of the scale was reported as 0.92 (34). The Cronbach's alpha coefficient of this study was 0.92.

**Data Analysis:** The data of the study was analyzed using IBM SPSS Statistical Package Program 21.0. Number, percentage distribution, minimum, maximum, mean, and standard deviation values were used in the descriptive analysis of the data. The Kolmogorov-Smirnov test and histogram graph were used to determine whether the data conformed to the normal distribution. Pearson correlation coefficient was used to examine the relationship between HL and QoL. Independent samples t-test was used to determine the difference in mean scores of HL and QoL variables according to gender, marital status, employment status, education level, presence of children, presence of chronic diseases other than celiac disease, use of vitamin supplements, screening test, family history of celiac disease, and regular physical activity. One-way ANOVA test was used to examine the difference between mean scores of HL and QoL variables according to income level and gluten-free diet practices. Finally, simple linear regression was used to investigate the concurrent relationship between HL and QoL in patients. Statistical significance was accepted as  $p < 0.05$ .

**Ethical Considerations:** Ethical approval for the study was obtained from the Ethics Committee for Non-Interventional Clinical Research of the Faculty of Nursing at a university (meeting number: 2023/03, decision number: 2023/16). Additionally, institutional approval was obtained



from the Celiac Disease Association where the study was conducted. The study purpose was explained to patients who volunteered participation, and informed consent was obtained.

## Results

This study included 119 patients registered with the Celiac Disease Association in one of the provinces of Turkey. The mean age of the participants was  $54.5 \pm 21.2$  years, and the mean age at diagnosis of celiac disease was  $30.2 \pm 8.1$  years. The majority of patients with celiac disease were female, had more than 8 years of education, were employed, married, and had children. Hypertension, diabetes, thyroid diseases (hypothyroidism, Hashimoto's thyroiditis), neurological diseases, bone fractures, liver and kidney diseases were present in 35.3% of the patients. The majority of patients were compliant with their diet and 12.6% took vitamin-mineral supplements. Furthermore, 18.5% of patients had a family history of celiac disease (Table 1).

Table 1. Characteristics of the Participants	
Variables	Mean $\pm$ SD
<b>Age</b>	
Age at diagnosis of celiac disease	$54.5 \pm 21.2$ $30.2 \pm 8.1$
	n (%)
<b>Gender</b>	
Female	69 (58.0)
Male	50 (42.0)
<b>Educational level</b>	
8 years and less	56 (47.1)
Over 8 years	63 (52.9)
<b>Employment status</b>	
Employed	67 (56.3)
Not employed*	52 (43.7)
<b>Marital status</b>	
Married	94 (79.0)
Single	25 (21.0)
<b>Having a child</b>	
Yes	83 (69.7)
No	36 (30.3)
<b>Income status</b>	
Income less than expenses	50 (42.0)
Income equal to expenses	37 (31.1)
Income exceeds expenses	32 (26.9)

Chronic diseases other than celiac disease	
Yes†	42 (35.3)
No	77 (64.7)
<b>Adopting a gluten-free diet</b>	
Yes	77 (64.7)
No	25 (21.0)
I break it sometimes	17 (14.3)
<b>Vitamin and mineral supplements</b>	
Yes	15 (12.6)
No	104 (87.4)
<b>Having family members take a screening test for celiac disease</b>	
Yes	19 (16.0)
No	100 (84.0)
<b>Family history of celiac disease</b>	
Yes	22 (18.5)
No	97 (81.5)
<b>Regular physical activity status</b>	
Yes	9 (7.6)
No	110 (92.4)
<b>Total</b>	119 (100.0)
Abbreviations: SD, standard deviation; n, number; %, percentage.	
* Housewives or retired participants	
† Hypertension, diabetes, thyroid disease (hypothyroidism, Hashimoto's thyroiditis), neurological disease, bone fracture, liver and kidney disease	

The mean total QoL score of celiac patients was  $75.41 \pm 15.29$ , indicating a QoL below the moderate level. The highest mean score was  $21.94 \pm 9.14$  for the sub-dimension "emotional state," and the lowest mean score was  $16.78 \pm 6.53$  for the sub-dimension "social problems."

Additionally, the mean total score for HL was  $25.16 \pm 11.23$ , indicating limited HL. The highest average score for the "treatment and services" sub-dimension of HL was  $31.40 \pm 15.07$  for using/applying information, and the lowest average score was  $29.09 \pm 16.99$  for accessing information. Additionally, the highest average score for the "prevention and health promotion" sub-dimension of HL was  $25.84 \pm 13.36$  for evaluating information, and the lowest average score was  $15.82 \pm 12.01$  for understanding information (Table 2).

Variables		Mean ± SD
QoL	Emotional state	21.94±9.14
	Worries	17.53±6.66
	Social problems	16.78±6.53
	Gastrointestinal problems	19.13±8.77
<b>Total</b>		<b>75.41±15.29</b>
<b>HL</b>		
Treatment and services	Access to information	29.09±16.99
	Understanding knowledge	30.88±14.27
	Evaluating knowledge	31.19±14.29
	Use/Apply knowledge	31.40±15.07
Prevention and health promotion	Access to information	22.51±13.47
	Understanding knowledge	15.82±12.01
	Evaluating knowledge	25.84±13.36
	Use/Apply knowledge	25.30±13.88
<b>Total</b>		<b>25.16±11.23</b>

Abbreviations: SD, standard deviation; QoL, Quality of life; HL, Health Literacy

Variables		QoL				
		Emotional state	Worries	Social problems	Gastrointestinal problems	Total
<b>HL</b>						
Treatment and services	Access to information	r =0.251 <b>p=0.006</b>	r=-0.113 p=0.222	r=0.062 p=0.506	r=0.237 <b>p=0.010</b>	r=0.263 <b>p=0.004</b>
	Understanding knowledge	r=0.192 <b>p=0.037</b>	r=-0.109 p=0.238	r=-0.040 p=0.669	r=0.154 p=0.094	r=0.139 p=0.132
	Evaluating knowledge	r=0.284 <b>p=0.002</b>	r=-0.030 p=0.742	r=-0.114 p=0.215	r=0.081 p=0.382	r=0.154 p=0.094
	Use/Apply knowledge	r=0.257 <b>p=0.005</b>	r=-0.112 p=0.224	r=-0.80 p=0.387	r=0.157 p=0.089	r=0.161 p=0.081
Prevention and health promotion	Access to information	r=0.404 <b>p&lt;0.001</b>	r=-0.097 p=0.292	r=0.065 p=0.480	r=0.159 p=0.083	r=0.318 <b>p&lt;0.001</b>
	Understanding knowledge	r=0.181 p=0.490	r=0.204 p=0.260	r=0.305 <b>p=0.001</b>	r=0.187 <b>p=0.041</b>	r=0.435 <b>p&lt;0.001</b>
	Evaluating knowledge	r=.338 <b>p&lt;0.001</b>	r=-.054 p=0.557	r=.078 p=0.399	r=.195 p=0.034	r=.324 <b>p&lt;0.001</b>
	Use/Apply knowledge	r=0.302 <b>p=0.001</b>	r=-0.056 p=0.542	r=0.024 p=0.798	r=0.207 <b>p=0.024</b>	r=0.285 <b>p=0.002</b>
<b>Total</b>		r=0.352 <b>p&lt;0.001</b>	r=0.050 p=.590	r=0.088 p=0.342	r=0.235 <b>p=0.010</b>	r=0.361 <b>p&lt;0.001</b>

Abbreviations: QoL, Quality of Life; HL, Health Literacy

The results showed a moderately positive and significant relationship between HL and patients' QoL ( $r=0.361$ ,  $p<0.001$ ). Among the QoL sub-dimensions, "emotional state" had the highest correlation with the overall HL score ( $r=0.352$ ,  $p<0.001$ ) (Table 3).

Simple linear regression analysis was performed in the study to determine how HL affects QoL. According to this analysis, a significant relationship was observed between HL and QoL ( $R=0.361$ ,  $R^2=0.130$ ) and HL had a significant effect on QoL ( $p<0.001$ ). The regression coefficient was positive ( $\beta=0.361$ ) and it was observed that QoL increased as HL increased. Additionally, QoL explained 13.0% of the change in HL (Table 4).

The results showed that there was a significant difference between the participants' employment status ( $t=-2.192$ ,  $p=0.030$ ), presence of chronic diseases other than celiac disease ( $t=-3.208$ ,  $p=0.002$ ), and gluten-free diet ( $F=6.021$ ,  $p=0.003$ ) and QoL. In this context, those who were homemakers or retired, those who did not

have chronic diseases other than celiac disease, and those who followed a gluten-free diet had a higher QoL (Table 5).

In addition, patients' age and gender ( $t=7.818$ ,  $p<0.001$ ), education level ( $t=-6.694$ ,  $p<0.001$ ), employment status ( $t=-5.663$ ,  $p<0.001$ ), presence of children ( $t=-3.135$ ,  $p=0.002$ ), income status ( $F=3.877$ ,  $p=0.023$ ), presence of chronic diseases other than celiac disease ( $t=-2.465$ ,  $p=0.015$ ), gluten-free diet ( $F=11.158$ ,  $p<0.001$ ), and having family members screened for celiac disease ( $t=3.389$ ,  $p<0.001$ ). It was found that women had higher HL than men, those with a higher education level had higher HL than those with a lower education level, those who were housewives or retired had higher HL than those who were employed, those who had no children had higher HL than those who had children, those who had higher income had higher HL than those who had lower income, those who practiced gluten-free diet had higher HL than those who did not, and those who had family members undergo screening tests had higher HL than those who did not (Table 5).

**Table 4.** Results of Simple Linear Regression Analysis Affecting Participants' QoL

	Unstandardized coefficients		Standardized coefficients	t	R	R <sup>2</sup>	F	P value
	B	Std.Error	Beta ( $\beta$ )					
HL	0.491	0.117	0.361	4.188	0.361 <sup>a</sup>	0.130	17.542	<0.001

a. Predictors: Constant

Abbreviations: HL, Health Literacy

**Table 5.** The Relationship between QoL and HL according to Participants' Sociodemographic and Health Status

Variables	QoL			HL		
	Mean $\pm$ SD	Statistical test	p value	Mean $\pm$ SD	Statistical test	p value
<b>Gender</b>						
Female	76.31 $\pm$ 15.71	t=0.759	0.540	30.74 $\pm$ 6.20	t=7.818	<0.001
Male	74.16 $\pm$ 14.76			17.46 $\pm$ 12.10		
<b>Education level</b>						
8 years and less	72.64 $\pm$ 15.05	t=-1.882	0.062	18.76 $\pm$ 12.11	t=-6.694	<0.001
Over 8 years	77.87 $\pm$ 15.20			30.85 $\pm$ 6.34		
<b>Employment status</b>						
Employed	72.74 $\pm$ 14.33	t=-2.192	0.030	20.79 $\pm$ 11.87	t=-5.663	<0.001
Not employed*	78.84 $\pm$ 15.94			30.79 $\pm$ 7.24		

<b>Marital status</b>						
Married	75.56±15.76	t=0.209	0.834	24.21±12.33	t=-1.813	0.072
Single	74.84±13.65			28.75±3.85		
<b>Having a child</b>						
Yes	75.21±14.72	t=-0.200	0.842	23.26±11.49	t=-3.135	<b>0.002</b>
No	75.86±16.76			29.55±9.37		
<b>Income status</b>						
Income less than expenses	73.82±15.03	F=0.672	0.513	22.16±11.04	F=3.877	<b>0.023</b>
Income equal to expenses	75.45±15.53			25.92±10.68		
Income exceeds expenses	77.84±15.57			28.96±11.19 c>a		
<b>Chronic diseases other than celiac disease</b>						
Yes <sup>†</sup>	69.54±11.61	t=-3.208	<b>0.002</b>	21.79±9.68	t=-2.465	<b>0.015</b>
No	78.61±16.16			27.00±11.65		
<b>Adopting a gluten-free diet</b>						
Yes <sup>a</sup>	78.79±16.42	F=6.021	<b>0.003</b>	28.06±10.18	F=11.158	<b>&lt;0.001</b>
No <sup>b</sup>	67.92±12.69			16.81±11.77		
I break it sometimes <sup>c</sup>	71.11±6.33 a>b			24.30±8.96 a>b		
<b>Vitamin and mineral supplements</b>						
Yes	73.00±14.43	t=-0.652	0.516	23.00±9.75	t=-0.797	0.427
No	75.75±15.45			25.47±11.44		
<b>Having family members take a screening test for celiac disease</b>						
Yes	82.63±23.23	t=1.566	0.133	32.84±13.65	t=3.389	<b>0.001</b>
No	74.04±12.99			23.70±10.15		
<b>Family history of celiac disease</b>						
Yes	76.40±13.08	t=0.337	0.736	27.02±9.33	t=0.858	0.393
No	75.18±15.80			24.74±11.62		
<b>Regular physical activity status</b>						
Yes	73.88±17.51	t=-0.309	0.758	24.29±15.49	t=-0.240	0.811
No	75.53±15.18			25.23±10.91		
Abbreviations: SD, standard deviation; QoL, Quality of Life; HL, Health Literacy						
* Housewives or retired participants						
† Hypertension, diabetes, thyroid disease (hypothyroidism, Hashimoto's thyroiditis), neurological disease, bone fracture, liver and kidney disease						

## Discussion

### QoL and Related Factors

QoL is an important factor affecting health. Determining the QoL ensures that the patient's well-being is taken into consideration in the plans and evaluations related to the disease and its treatment. In this study, it was determined that celiac patients had a QoL below the middle level.

Among the QoL sub-dimensions, the highest mean belonged to "emotional state" and the lowest mean belonged to "social problems" sub-dimension. In other words, it was concluded that the disease caused the most social problems. Similarly, in the study conducted by Vázquez-Polo et al. (2023), it was observed that celiac patients reported many social difficulties such as eating



out with others (35). In addition, Deepak et al. (2018) reported that those with celiac disease had low health-related QoL (10). However, some study results showed that participants had moderate QoL (36,37). The inconsistencies in QoL between studies are thought to be due to differences in the individual, cultural, economic and social characteristics of the studied groups. It is thought that providing emotional and social support to celiac patients is an important requirement in improving QoL.

Employment is an important factor in QoL (38). In this study, it was found that patients who were not working (homemakers and retired) had a higher QoL than working patients. In the study conducted by Cakir et al. (2015), a negative relationship was found between QoL and weekly working hours (39). In the study conducted by Deger and Ordu (2022), it was reported that the QoL of the elderly receiving pensions was higher than the elderly without income (40). However, previous literature shows that the QoL of working individuals is higher (38;41). Although the factors affecting QoL vary between countries and cultures, it was thought that the economy was the most important factor that did not change. The fact that celiac patients who participated in this study received a monthly income from the state may have affected the results of this study.

Since celiac disease is an autoimmune disease, the risk of being seen with other autoimmune diseases is higher than in healthy individuals (42). In this study, patients with chronic diseases other than celiac disease had a lower QoL. More than one third of the patients had hypertension, diabetes, thyroid diseases (hypothyroidism, Hashimoto's thyroiditis), neurological diseases, bone fractures, liver and kidney diseases. Likewise, in a study conducted overseas by Deger and Ordu (2022) in Turkey, it was reported that QoL was low in elderly people with chronic diseases and pain (40). Similarly, in a study conducted abroad by Rong et al. (2020), it was reported that participants who had been physically ill in the past two weeks and hospitalized within the last year had a low QoL (43). In addition, Caio et al. (2019) reported that celiac disease may be associated with different autoimmune and idiopathic diseases (7). Similarly, Ozciftci-Ertugral (2019) reported that the risk

of celiac disease in patients with autoimmune thyroiditis is approximately 6-7 times higher than in the general population (44). From this point of view, it can be suggested that individuals with an autoimmune disease in addition to celiac disease should pay more attention to their QoL.

In the study, it was determined that gluten-free diet is an important factor that can affect the QoL of celiac patients regarding their emotional state, anxiety, social life, and gastrointestinal symptoms. Marsilio et al. (2020) reported that the QoL of celiac patients on a gluten-free diet was better than others (45). However, in the same study, it was determined that those who did not comply with the gluten-free diet experienced deep restlessness and dissatisfaction. Similarly, previous studies have shown that poor adherence to a gluten-free diet is often associated with poor QoL (1) but it has been emphasized that it is difficult to determine which is the cause and which is the effect (46). One long-term study suggested that the deterioration in QoL was associated with a lack of dietary adherence (47), while others have shown that patients who fully adhere to a gluten-free diet may also have poor QoL (48). However, the study by Barrio and Cilleruelo (2022) reported that the social and emotional effects were not completely normalized despite patients following a strict diet, thereby affecting QoL (49). The direct association of dietary adherence with QoL may be partly due to a decrease in depression (1). The attention required for a gluten-free diet can lead to an obsession with food intake and fear of eating, significantly increasing the risk of developing eating disorders. Therefore, a therapeutic intervention can increase adherence to a gluten-free diet and improve the psychological well-being as well as the concomitant QoL of individuals with celiac disease.

### **HL and Related Factors**

Good HL enables patients to make decisions about their own health and is highly relevant to the self-management of celiac patients (50). The study results showed that the HL levels of celiac patients were limited. In addition, the HL level of the participants was found to be lower in the disease prevention/health promotion dimension. Similarly, in the study conducted by Ilgaz (2021), it was reported that the

scores of disease prevention/health promotion were lower (51). Consistent with this finding, studies conducted in Turkey have reported that individuals' HL levels were insufficient (51,52). In addition, inadequate HL levels are mentioned in studies (30,53). Inadequate HL is thought to affect health behaviors as well as health service use, health outcomes and health costs. However, some studies have reported that individuals' HL levels are sufficient (54-56). In addition, Sørensen et al. (2015) reported that HL proficiency varied between 29% and 62% in eight European countries (15). The reasons for the inconsistency between studies on HL may be due to the fact that there are many factors affecting HL. Many factors such as individual characteristics, cultural status, economic and social factors may have an impact on this structure. Also, the inadequate or limited knowledge levels of celiac patients regarding their HL emphasizes the need for HL interventions in Turkey. In addition, individuals with lower levels of HL can contribute to health promotion by gaining health responsibility through health education (51).

In this study, it was revealed that the mean HL scores of the participants differed significantly according to gender. Accordingly, women had higher HL than men. Similarly, Mehralian et al. (2023) found that the HL of elderly women was higher than that of elderly men (30). In the study conducted by Ghaedi et al. (2016) on patients with type 2 diabetes over the age of 40, it was reported that the mean HL scores of women were higher than those of men (57). In the study conducted by Qasem et al. (2023), awareness of celiac disease was found to be higher in women (58). Some of the reasons for this may be that women search for more health-related content, visit doctors and health centers more frequently to participate in screening programs and receive information from health professionals, which may have increased the level of HL.

Another variable affecting HL is education level (30). In this study, as the level of education increased, the level of HL also increased. Similarly, it has been reported in the literature that there is a significant relationship between HL and education level, and it has been emphasized that HL levels increase as the education level of individuals increases (55). Individuals with a

high level of education may need to research health-related issues more. They are also able to communicate effectively with healthcare professionals, which may be effective in improving their HL. On the contrary, Ghaedi et al. (2016) obtained different results regarding the relationship between HL and education level. The HL of all elderly individuals with type 2 diabetes and those with a high diploma degree was found to be significantly lower than those with a diploma (57). The researchers concluded that a higher level of education does not guarantee higher HL. Therefore, those with lower levels of education probably have more free time to search for health-related information through virtual social networks or mass media. They may also have more opportunities to access more information and visit health centers for screening and care. This highlights the need for HL interventions to be targeted at people with lower levels of education.

In this study, it was determined that those who did not work, those who did not have children, those with higher income, and those who did not have chronic diseases in addition to celiac disease had higher HL. Additionally, those who had family members undergo screening tests also had higher HL.

One factor associated with HL is a gluten-free diet. In this study, patients who followed a gluten-free diet had higher HL levels. Similarly, Jeanes et al. (2022) reported that those with higher HL levels showed better compliance with the gluten-free diet (50). In a systematic review study by Abu Janb and Jaana (2020), in which the results of 40 studies published between 1992 and 2017 were examined; it was reported that the compliance of celiac patients with gluten-free diet varied between 42% and 91% (59). In the same study, it was reported that the reasons for the low compliance of patients with their diets may be that they do not have enough information about the gluten-free diet, physicians cannot allocate enough time to educate patients, and patients do not communicate enough with celiac associations. From this point of view, it is recommended that family physicians and nurses working in family health centers should direct celiac patients to activities that will increase their health knowledge, such as ensuring that

the patient becomes a member of the celiac association.

### **The Relationship between QoL and HL**

In this study, it was found that as patients' QoL increased, their HL levels also increased. In addition, QoL explained 13.0% of the change in HL. Wang et al. (2017) reported that high HL was significantly associated with QoL in patients with hypertension in their study in China (27). In a recent study by Vázquez-Polo et al. (2023), it was reported that the majority of participants responded positively when asked whether they believed that increased knowledge about celiac disease would improve their QoL (35). Low levels of HL are thought to be related to poor disease management and associated poorer overall health status and lower QoL. Investment in strengthening HL is likely to have a significant return on health status and QoL at both the individual and community level.

**Study Limitations:** Regarding the limitations of this study, it is important to recognize that the data collected is self-reported and may be influenced by participants' personal beliefs and opinions. Furthermore, this is a cross-sectional study and different results may be seen in different time periods. In addition, the use of questionnaires and the inability to fully generalize the results to other societies and cultures are also limitations of this study. Longitudinal studies in other regions with different cultures are highly recommended.

### **Conclusion**

The study revealed that celiac patients have below average QoL and limited HL. Health literacy explained 13.0% of the change in quality of life. Celiac patients mostly experienced problems related to social life. The gluten-free diet was found to be an important factor that could affect the quality of life of celiac patients in terms of their emotional state, anxiety, social life, and gastrointestinal symptoms. The study identified eight risk factors for health literacy. It is recommended to develop effective interventions to improve the HL skills of celiac patients and improve their QoL.

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### **Conflict of Interest**

The authors have no conflict of interest with any institution, person or organization.

### **Ethical Approval**

The study was conducted following the principles of the Declaration of Helsinki. This study was approved by the Selcuk University Faculty of Nursing Non-Interventional Clinical Research Ethics Committee (meeting number: 2023/03, decision number: 2023/16). Permission was obtained from the institution where the study was conducted. In addition, the participants were informed about the purpose and procedures of the study and their verbal and written informed consent was obtained before the start of the study.

### **Authorship Statement**

Conception - MY, YGŞ; Design - MY, YGŞ; Supervision - YGŞ; Data Collection and/or Processing - MY; Analysis and/or Interpretation - MY, YGŞ; Literature Search - MY, YGŞ; Writing - MY, YG; Critical Review - YGŞ. All authors meet the criteria for authorship. All authors agree with the content of the article.

**Contact:** Yasemin Gümüş Şekerci  
**E-Mail:** y.gumus36@hotmail.com

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