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## RESEARCH ARTICLE

## THE EFFECT OF HEALTH LITERACY LEVEL AND SOME GROWTH PARAMETERS ON QUALITY OF LIFE OF CELIAC ADOLESCENTS

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**Abstract**

**Background:** Celiac is an autoimmune disease that occurs as hypersensitivity to gluten and affects the intestinal system. This disease also negatively affects the quality of life of individuals. This study, it was aimed to investigate the effect of health literacy level and Body Mass Index (BMI) on the quality of life of adolescents with celiac disease.

**Method and Material:** All participants between the ages of 15-18 in the study completed the Turkish Health Literacy Scale (THLS-32) and Celiac Disease-Specific Pediatric Quality of Life (CDPQOL) Scale online. The data of this study was analyzed with the IBM SPSS Statistics 23 software package program.

**Results:** More than half (59%) of adolescents with an average age of  $16.44 \pm 1.17$  years had celiac disease for 3 years or more. CDPQOL mean total score was  $41.44 \pm 14.33$ , and 44.4% of the participants had inadequate or problematic levels of health literacy. It was determined that the mean of total score of quality of life was not related to THLS-32 sub-dimensions but had a moderate negative relationship with diagnostic time and BMI ( $r=-0.376$ ,  $p=0.005$ ;  $r=-0.602$ ,  $p=0.00$ , respectively). At the same time, it was found that the decrease in BMI was a predictive factor for poor quality of life ( $B=-0.218$ ,  $p=0.003$ ).

**Conclusions:** It has been shown that the health literacy levels of celiac adolescents are not related to the quality of life, and it is recommended to examine the quality of life with other variables that can be affected by many factors.

**Keywords:** Celiac disease, adolescent, quality of life, health literacy, Body Mass Index.

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## INTRODUCTION

Celiac, an immune disease, is characterized by clinical manifestations associated with gluten and the presence of disease-specific antibodies. It occurs as a systemic disorder in genetically susceptible individuals.<sup>1</sup> Singh et al., reported the worldwide prevalence of celiac disease as 1.4% according to serological test results and 0.7% according to biopsy results in their meta-analysis study.<sup>2</sup> In our country, the prevalence of celiac was determined as 0.47% in a screening of 20.190 healthy children between the ages of 6-18.<sup>3</sup>

The additional expense of gluten-free foods consumed outside and sold in the grocery store, the lack of knowledge of the staff in the restaurant, the tastelessness of gluten-free foods, limited restaurant options, concerns that the gluten-free diet (GFD) may cause stigma during adolescence make it difficult for adolescents to adhere to GFD.<sup>4,5,6</sup> In patients who are well adhered to GFD, it is easier to control the symptoms of the disease and prevent complications. On the contrary, in cases where GFD is not adhered to in celiac patients, growth and development are delayed in addition to psychological effects such as anxiety, depression, and fatigue. At the same time, it has been shown in studies that the quality of life of patients who do not comply with GFD is adversely affected.<sup>7,8,9</sup> While ESPGHAN recommends assessing the quality of life of children and adolescents with celiac disease during clinical follow-up, a worldwide study found that 35% of physicians never assessed their quality of life and 33% occasionally assessed their quality of life.<sup>10,11</sup>

Health literacy is examined in 3 main themes as health and health services knowledge, the ability to analyze and use this information correctly and to protect health through self-management or collaboration with health care providers.<sup>12</sup> Studies have shown that inadequate health literacy in children may lead to lower quality of life and increases in health literacy levels in chronically ill adolescents may facilitate adaptation to the disease.<sup>13,14</sup> Adolescent period is a process in which children begin to gain autonomy in disease management, and this study was planned to examine how health literacy levels and growth parameters affect quality of life in this process.

## METHODOLOGY

### Study design and sample group

This study is a cross-sectional type and was conducted between May 10 and August 10, 2022. In this study, it was planned to examine the relationships between two independent scales and the sample size was calculated at the 95% confidence level by using the "G. Power-3.1.9.2" program according to the statistical method to be used in the research. As a result of the analysis,  $\alpha = 0.05$ , standardized effect size was calculated effect size of 0.40 (moderate) due to the lack of similar studies in this area, and with a theoretical power of 0.80, the minimum sample size was calculated as 44. Inclusion criteria for this study were determined by the researchers as follows: participants should be between the ages of 15-18, be diagnosed with Celiac by a specialist physician, have the ability to understand and respond to what they read, volunteer to participate in the study, and obtain consent from their parents.

### Data collection

10 Celiac Associations in different cities in Turkey, whose contact address can be reached, were identified. Questionnaires prepared with Google forms were shared in the on-line communication groups of the members of these associations. Before filling out the questionnaires, the volunteer participants were provided with a short information about the study.

### Data collection tools

*Information form of adolescents with celiac disease:* The studies conducted with celiac patients under the age of 18 were examined in detail, and this form was prepared by the researchers as a result of the review.<sup>15,16,17</sup> In this form, there are 7 questions that examine the characteristics of the participant such as age, duration of diagnosis, whether there is an existing complaint about celiac, etc..

*Celiac disease-specific pediatric quality of life scale (CDPQOL):* This scale, which was developed in 2013 by Jordan et al.,<sup>16</sup> was adapted to Turkish children by Koçak et al.<sup>18</sup> In this study, the scale belonging to the 13-18 age group from the scale, which has 2 different formats, was used. This scale consists of four sub-dimensions and 17 items: social, uncertainty, isolation, and constraints. While the total score that can be taken from the scale varies between 0-68, the quality of life decreases as the total

score increases. In the validity reliability study, the reliability coefficient of the scale was calculated as 0.88, while Cronbach's alpha was found to be 0.92 in this study.

**Turkish health literacy scale-32 (THLS-32):** This scale was developed by Okyay et al.<sup>19</sup> on the basis of the European Health Literacy Scale (HLS-EU). There are 4 processes treatment and services at scale and prevention of diseases/health promotion, 2 dimensions, access to health-related information, understanding health-related information, evaluating health-related information, using/applying health-related information. In the evaluation of the scale, the index is calculated with the formula (average-1) x (50/3). In the index calculation, 0-25 points indicate inadequate health literacy; >25-33 points represent problematic/limited health literacy; >33-42 points represent adequate health literacy; >42-50 points represent excellent health literacy. The scale is suitable for use for people 15 years of age and older. The general internal consistency coefficient of the scale was calculated as 0.92, in this study, this coefficient was found to be 0.93.

#### Compliance with ethical standards

Ethical approval was received from the Non-Interventional Clinical Studies Ethics Committee of the relevant university on 07.04.2022 with the approval number E.192952. The consent of the adolescents before starting the work was obtained with the written consent of the parents. Permission was obtained from the authors who conducted the validity-reliability study of the scales used to use the scales in this study. All procedures of the study were carried out in accordance with the Declaration of Helsinki.

#### Data analysis

Data were analyzed with IBM SPSS version 23. Continuous variables were given as mean  $\pm$  standard deviation, and categorical variables were given as n and percentages. Skewness-flatness values were taken as a reference to determine whether the data examined had a normal distribution. While the Pearson correlation test was used to examine the relationship between the scales, the predictors of quality of life were determined by linear regression analysis.

## RESULTS

#### Participant characteristics

A total of 54 participants were included in this study. Three-quarters of the adolescents with celiac who participated in the study were female, and the mean age was determined as  $16.44 \pm 1.17$ . More than half of all participants had a diagnosis period of 3 years or more. 25.9% of adolescents stated that they had an existing complaint (abdominal swelling, nausea, abdominal pain, etc.) at the time of the study. In addition, about three-quarters of the group had another chronic disease. (Table 1).

#### Levels of quality of life and health literacy

The mean of quality of life of the adolescents who participated in the study was found to be at a moderate level as  $41.44 \pm 14.33$ . While 44.4% of the group had inadequate or problematic levels of health literacy, the total index was calculated as 21.88 (problematic/limited health literacy) (Table 2).

#### Some variables affecting and related to quality of life

It was determined that quality of life was not related to THLS-32 ( $r=0.137$ ,  $p=0.325$ ) and its sub-dimensions but had a moderate negative relationship with diagnosis time ( $r=-0.602$ ,  $p=0.00$ ) and BMI ( $r=-0.376$ ,  $p=0.05$ ) (Table 3). In the regression analysis, 12.3% of the dependent variable could be explained (Adjusted  $R^2=0.123$ ). According to this model, it was determined that the sub-dimensions of the THLS-32 scale were not predictors of the quality of life, while the one-unit increase in BMI provided a 0.28-fold decrease in the average quality of life score (Table 4).

## DISCUSSION

Celiac disease is a chronic disease that is very difficult to manage for both the child and the family. In this process, a number of factors can affect the quality of life in sick individuals. In this study, the hypothesis that children's quality of life may be related to health literacy, and BMI was examined.

When the sociodemographic characteristics are examined, it is seen that the percentile values of adolescents according to BMI are between the values of 5 and 88. In children, percentile values between 5 and 85 are considered normal, while those on the 85th percentile curve are considered overweight.<sup>20</sup> This shows the presence of overweight adolescents among the participants of the study. Although celiac disease is known to cause malnutrition, the presence of overweight or obese children should not

be ignored.<sup>21</sup> In the study, it was seen that 25.9% of celiac adolescents had any of the symptoms of GIS. If the gluten-free diet is not adhered to, mild to severe gastrointestinal symptoms such as abdominal pain, diarrhea, gas, belching, stearrhea may occur.<sup>21</sup> In studies conducted, it has been found that celiac disease is associated with Type 1 diabetes, as well as Down syndrome and Turner syndrome. In these populations, the prevalence of celiac disease is notably higher.<sup>22</sup> The fact that 77.8% of the adolescents in this study stated that they had another chronic disease is in line with this information in the literature.

When the average score of quality of life is examined, it is seen that the quality of life of adolescents is worse than the intermediate level. Koçak et al.,<sup>18</sup> in their study conducted with children between the ages of 13-18, the mean CDPQOL score was determined as  $29.28 \pm 13.93$ . The presence of younger age groups in this study may have led to a better quality of life score. In the literature, many studies have evaluated quality of life in different age groups and have generally achieved moderate or poor results.<sup>23,24</sup> When the HL scores of adolescents are examined, it is seen that 44% of them are insufficient or problematic. In another study conducted in healthy adolescents with the same age group, it was determined that 95% of the participants had insufficient or problematic HL.<sup>25</sup> It is thought that access to and use of health-related information may be better in adolescents with any diseases.

In this study, it is seen that there is no correlation between quality of life and HL total score mean and its sub-dimensions. In the study conducted by Guo et al.<sup>26</sup> with healthy children, it was found that health-related quality of life was not related to HL. On the other hand, Ran et al. (2018)<sup>13</sup> found out that high levels of health literacy in healthy children aged 12-15 years are associated with good quality of life. In the literature, quality of life in children with celiac disease has been associated with many factors, but no studies have been found that fully explain the effect of HL. Therefore, when other chronic diseases are examined, it has been determined that the level of HL in adolescents with asthma disease is related to asthma control.<sup>27</sup> In the light of this information, it is thought that the quality of life of celiac adolescents is not related to HL levels.

It is known that the most effective method of disease management, for which there is no definitive treatment for celiac disease, is compliance with a gluten-free diet. Patients who adhere to a gluten-free diet have better quality of life (Enaud et al., 2022). In this study, it was determined that there was a relationship between the BMI and quality of life of adolescents. In other words, as the BMI decreases, the quality of life deteriorates. Low BMI suggests malnutrition or risk and therefore disruptions in compliance with gluten-free diet. In short, the negative relationship between BMI and quality of life may be caused by malnutrition caused by GFD mismatch and the resulting GIS symptoms. The increase in diagnosis time, which is one of the striking findings, is associated with the improvement of quality of life. In studies with celiac and other chronic diseases, quality of life is generally better as the duration of diagnosis increases.<sup>28,29</sup> This shows that the changes in lifestyle caused by chronic disease are adapted over time.

In this study, the health literacy levels of adolescents were examined because of the idea that following dietary recommendations, being able to monitor the presence of gluten in packaged foods, and other health behaviors, including taking medication or exercising, may positively affect the quality of life related to celiac. However, as a result of the regression analysis, it was determined that none of the health literacy sub-dimensions were predictors of quality of life. In the study conducted by Altobelli et al. (2013)<sup>15</sup>, it was determined that characteristics such as gender, age, duration of diagnosis, delay in diagnosis were not predictive factors for quality of life. Although the level of health literacy is necessary in disease management, gluten-related problems, as the main factor of celiac disease, should be eliminated to improve quality of life. For example, in a study, the question of what can be done to improve the quality of life of celiac patients and their families in adolescence was asked. 68.8% of respondents said "gluten-free options in restaurants"; 36.0% said "gluten-free options in supermarkets" and 36.6% "in all social areas (e.g., schools, restaurants) information campaigns".<sup>15</sup>

The weight of celiac patients at the time of diagnosis is variable, including overweight and obese.<sup>30</sup> Growth retardation in terms of height or weight may be the earliest sign of the disease, but

recent studies have shown that CD may be associated with overweight and obesity as well as normal weight.<sup>31,32</sup> In another systematic review, it was found that the prevalence of obesity in children with celiac ages 6-17 was between 3.5% and 20%.<sup>33</sup> In this study, the one-unit increase in BMI causes the total quality of life score to decrease by 0.218 times. In other words, it found as decrease in BMI was a predictive factor for poor quality of life. Accordingly, it can be said that deviations from normal in BMI affect the quality of life and appear as a risk factor.

### Limitations

The HL scale used in this study is suitable for use in the sample group aged 15 years and older. Although the adolescent period included children in the 12-18 age group, the sample group had to be limited to 15-18 years.

### CONCLUSIONS

As with all chronic diseases, Celiac disease leads to negative effects in many areas of life as well as its physical effects. As recommended by ESPGHAN, the quality of life of children and adolescents with celiac disease should be evaluated by health professionals with appropriate tools during clinical follow-up. In addition, since deviations from normal in height and weight, which are physical parameters of growth, may adversely affect the quality of life, BMI assessment follow-up should be added to clinical follow-ups for these patients. It is important that a multidisciplinary study is conducted by health professionals in order to maintain GFD adherence and prevent accidental gluten transmissions. In addition, variables that may affect the quality of life in patients should be considered and examined as a whole.

As a result, in this study, it is seen that the quality of life specific to celiac disease in adolescence, which is a developmental crisis period, is not as high as in the desired levels. While it was seen that diagnosis time and BMI affected the quality of life, it was found that health literacy did not have an effect. It is known that the quality of life is multidimensional and is affected by many factors. Therefore, it is recommended that other variables that may affect the quality of life specific to celiac should be investigated in future studies.

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## ANNEX

**TABLE 1.** Distribution of Sociodemographic Characteristics of Celiac Adolescents

<b>Sociodemographic Characteristics</b>		<b>Mean± SD (Min-Max)</b>	
		<b>n</b>	<b>%</b>
Age		16.44±1.17 (15-18)	
Height		163.92±9.92 (145-188)	
Weight		52.48±14.08 (36-93)	
BMI (percentile)		33.85±28.09 (5-88)	
<b>Gender</b>			
Female	40		74.1
Male	14		25.9
<b>Diagnosis duration</b>			
0-6 month	8		14.8
6-12 month	6		11.1
1-3 years	8		14.8
3 years and over	32		59.3
<b>Family's income Level</b>			
Income<Expense	26		48.2
Balanced (equal)	24		44.4
Income>Expense	4		7.4
<b>Current symptom</b>			
No symptom	40		74.1
Yes (abdominal swelling, nausea, abdominal pain, diarrhea, other)	14		25.9
<b>Additional chronic disease</b>			
Yes	42		77.8
No	14		22.2

**TABLE 2.** Leves of CDPQOL with sub-dimensions and THLS-32

	Mean	SD	Min-Max
Limitations	8.22	2.65	3-12
Isolation	7.96	4.38	0-16
Uncertainty	8.0	2.62	2-12
Social	17.25	6.32	5-27
CDPQOL total score	41.44	14.33	18-65
% 3.7 inadequate levels of HL			
% 40.7 limited levels of HL	35.06	7.11	21.88-49.48
% 33.3 adequate levels of HL			
THLS-32 % 22.2 excellent levels of HL			

Note. CDPQOL= Celiac Disease-Specific Pediatric Quality of Life; THLS-32= Turkish Health Literacy Scale; HL=Health Literacy.

**TABLE 3.** Correlations between sub-dimensions of THLS-32, BMI, diagnosis duration and CDPQOL: Pearson Correlation Analysis

	r	p
THLS-32	0.137	0.325
Access to health-related information	0.325	0.295
Understanding health-related information	0.158	0.255
Using/applying health-related information	0.011	0.939
Evaluating health-related information	0.139	0.315
BMI	<b>-0.376</b>	0.005
Diagnosis duration	<b>-0.602</b>	0.000

Note. THLS-32= Turkish Health Literacy Scale; BMI= Body Mass Index.

**TABLE 4.** Effect of sub-dimensions of THLS-32, BMI and age on CDPQOL: Multiple linear regression model

	Unstandardized Coefficients		Standardized Coefficients		% 95 Confidence Interval for B		
	B	Std. Error	Beta	t	Sig.	Lower Bound	Upper Bound
Constant	36.322	35.525		1.022	0.312	-35.145	107.788
Access to health-related information	0.33	0.604	0.014	0.055	0.956	-1.182	1.249
Understanding health-related information	1.103	0.668	0.436	1.652	0.105	-0.241	2.447
Using/applying health-related information	-1.002	0.754	-0.269	-1.330	0.190	-2.519	0.514
Evaluating health-related information	-0.165	0.504	-0.092	-0.327	0.745	-1.178	0.849
Age	0.731	1.807	0.060	0.405	0.688	-2.905	4.367
BMI	-0.218	0.069	-0.426	-3.130	<b>0.003</b>	-0.357	-0.078

Note.  $R=0.471$ ;  $R^2= 0.222$ ; Adjusted  $R^2=0.123$ ; BMI= Body Mass Index.