

Original Article

Adherence to Gluten-Free Diet and Affecting Factors in Adolescents with Celiac Disease during the COVID-19 Pandemic

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Abstract

Introduction: Adolescents with celiac disease were affected differently by the restrictions during the COVID-19 pandemic. The aim of this study was to determine the adherence to a gluten-free diet during in adolescents with celiac disease during the COVID-19 pandemic and identify the associated factors.

Methods: The sample of this study consisted of 85 adolescents in the 10-19 age group diagnosed with celiac disease.

Result: Adolescents who were non-adherence with a gluten-free diet during the pandemic had difficulty finding gluten-free products, and this was most commonly due to not being able to find gluten-free products in the markets. Diet adherence was significantly higher in the younger age group ($P < 0.01$).

Discussion: Adolescents with celiac disease face difficulties adhering to a gluten-free diet during the pandemic. It is therefore important that clinicians, pediatric nurses, and dietitians encourage adolescents to adhere to their diets.

Keywords: Adolescence, celiac disease, gluten free diet

Introduction

Celiac disease (CD) is an autoimmune disorder characterized by involvement of the small intestine caused by gluten consumption (Ludvigsson et al., 2016; Sample & Turner, 2021). The most important treatment modality for CD is adherence with a gluten-free diet (GFD) (Dowhaniuk et al., 2020; Hardy & Tye-Din, 2016). Problems such as high prices of gluten-free products (GFP) and lack of information are encountered in adherence with the GFD (Jnawali et al., 2016; Paganizza et al., 2019; Samasca et al., 2017).

Preventive measures taken during the COVID-19 pandemic have affected people's lifestyles and changed their quality of life. These changes are important for adolescents with chronic diseases (Kendzierska et al., 2021; Monzani et al., 2020). In a previous study, it was observed that adolescents with CD exhibited correct nutritional behaviors during the limitations imposed by pandemic measures, at the same time, it was also determined that adolescents had difficulties in finding GFP (Monzani et al., 2020). The results of another study showed that the habit

of eating out decreased during the COVID-19 pandemic and healthy eating increased due to cooking and eating at home (Flanagan et al., 2021). In a study conducted with adults with celiac disease during the Greek pandemic period, eating outside the home was reported to be the most difficult domain (Bathrellou et al., 2023). The impact of the COVID-19 pandemic on dietary habits is controversial. While some studies report healthy eating behaviors during the COVID-19 pandemic, there are also studies observing an increase in unhealthy eating behaviors (Flanagan et al., 2021; Monzani et al., 2020; Pietrobelli et al., 2020). When following-up patients with CD, adherence with a GFD is recommended to protect health and prevent complications (Fok et al., 2016). Health professionals should identify adolescents' deficiencies in adherence to a gluten-free diet and support them. Since GFD is the only treatment for CD, more research is needed on how the availability of gluten-free foods, cost, and other factors affect diet adherence. Therefore, the aim of this study was to determine gluten-free diet adherence of adolescents with CD during the COVID-19 pandemic and identify the associated factors.

Methods

Study Design: The population of this cross-sectional study consisted of adolescents diagnosed with CD in the 10-19 age group, registered to the Association of Living with Celiac.

The sample of the research was created using the accessible sampling method. The study sample consisted of 85 participants who met the inclusion criteria and agreed to participate in the study. Data was collected by an online questionnaire prepared with Google forms and shared in social media (Facebook) or WhatsApp groups through the Association of Living with Celiac between January and April 2022. A questionnaire form prepared by the researchers in line with the relevant literature and consisting of questions related to sociodemographic characteristics, accompanying chronic diseases, disease-related symptoms and factors affecting adherence with a gluten-free diet during the COVID-19 pandemic was used to collect data. Inclusion criteria were determined as being in the 10-19 age group, being diagnosed with CD according to the revised ESPGHAN

criteria, consenting to participate in the study by the adolescents and their parents, and following a gluten-free diet for at least 6 months before the COVID-19 lockdown.

The hypotheses of this study are as follows: Hypothesis 1 (H1): GFD adherence is significantly higher among females compared to males among adolescents during the COVID-19 pandemic.

Hypothesis 2 (H2): GFD adherence varies significantly among different age groups of adolescents during the COVID-19 pandemic.

Hypothesis 3 (H3): GFD adherence is significantly associated with experiencing symptoms of CD during the COVID-19 pandemic among adolescents.

Hypothesis 4 (H4): There is a significant difference in symptoms experienced between compliant and non-compliant adolescents during the COVID-19 pandemic.

Sociodemographic Data Collection Form:

Sociodemographic characteristics such as gender and age were questioned. Adolescents' body mass indexes (BMI) were recorded by self-declaration, and BMI-for-age was evaluated according to WHO's growth reference data for 5-19 years. Between the 3rd and 97th percentiles was categorized as normal, above 97th percentile was categorized as high, and below 3rd percentile was categorized as low BMI (World Health Organization, 2022).

Gluten-Free Diet Adherence Form: In line with the literature, researchers added gluten-containing foods that celiac patients can consume most frequently to the survey. Participants who declared that they consumed any of these foods were considered non-compliant, while the others were considered compliant. Ready-made meatballs, flour-fried chicken/fish, sausages, sweets with wheat flour, bulgur pilaf/pasta/noodles, bagels, biscuits/crackers/pastry/pies, instant tomato paste/ketchup/sauces, chocolate, breakfast cereals and traditional foods (boza, tarhana) were questioned.

Factors Affecting Gluten-Free Diet

Adherence Form: This form consists of questions prepared by the researchers in line with the relevant literature in order to determine the GFD adherence of adolescents with CD during the COVID-19 pandemic and the affecting factors. In this form; difficulty finding GFP, the reason for the difficulty in finding GFP, consumption of homemade

products made with GFP, GFD is better than it was before, reason of better adherence to a GFD, reason of worse adherence to a GFD, GFD is worse than it was before questions were included.

Data Analysis: Sociodemographic characteristics of the participants and their data on adherence with a gluten-free diet were presented as numbers and percentages. Mann Whitney U and Pearson χ^2 tests were used for comparisons between groups. SPSS for Windows version 23.0 (IBM Corp, Armonk, New York) was used for data analysis.

Ethical Issues: Ethics approval was obtained from the Research and Publication Ethics Committee, of the Faculty of Health Science Bursa Uludag University. The clinical trial registration number NCT05474976

([https://clinicaltrials.gov/ct2/show/NCT05474976?term=NCT05474976&draw=2&rank=](https://clinicaltrials.gov/ct2/show/NCT05474976?term=NCT05474976&draw=2&rank=1)

1) Consenting to participate in the study was taken by the participating adolescents and their parents, informed consent was obtained from participants and their parents before enrollment. Data was anonymous and network secured via google forms. Subjects were informed about the purpose of the study, about their anonymity and their right to withdraw from the study at any stage. Subjects who agreed to participate in the study were treaded according to the Declaration of Helsinki.

Results

Personal characteristics of the adolescents participating in the study are shown in Table 1. Of the adolescents who complied with a gluten-free diet, 64.4% were girls. GFD adherence was higher among girls compared to boys, but the difference was not statistically significant ($P > 0.05$). Adolescents in the 10-14 age group constituted 82.2% of the compliant adolescents. A statistically significant difference was found in diet adherence with respect to age groups ($P < 0.05$). No statistically significant difference was found in diet adherence with respect to

having a family member with CD, presence of additional disease, disease duration, use of vitamin and mineral supplements, and body mass index ($P > 0.05$). 66.7% of the compliant adolescents and 77.5 % of the non-compliant adolescents stated that they experienced at least one symptom of CD during the COVID-19 pandemic. There was no statistically significant difference between adolescents reporting a symptom and diet adherence ($P > 0.05$).

Data on GFD during the COVID-19 pandemic are shown in Table 2. 67.5% of the non-compliant adolescents had difficulty in finding GFP during the pandemic, the reason most commonly stated by the adolescents was not being able to find GFP in the markets (74.2%). While 91.1% of the compliant adolescents reported that their consumption of homemade meals made with GFP did not change. 20% of compliant adolescents who reported that their diet adherence was better during the pandemic stated that this was because they or their mother had more time to prepare meals at home. Of the adolescents who reported that their diet adherence was worse than it was before the pandemic, 26.8% reported this was due to difficulties in finding GFP.

Gluten-containing food consumption frequency of adolescents is included in figure 1. The most frequently consumed foods by adolescents during the pandemic were determined as chocolate, ready-made tomato paste, ketchup and sauces, and sausage.

Stress, constipation, fatigue, and bone and joint pain were among the symptoms frequently experienced by the adolescents participating in the study (Figure 2). Incidence of symptoms was lower among compliant adolescents. Non-compliant adolescents described a higher rate of bone-joint pain and abdominal pain compared to compliant adolescents ($P < 0.05$).

Table 1. Sociodemographic characteristics of adolescents

	Total group n(%)	Adherence group n(%)	Non-adherence group n(%)	P value
Gender				
Female	48(56.5)	29(64.4)	19(47.5)	0.116
Male	37(43.5)	16(35.6)	21(52.5)	
Age group				
10-14 age	59(69.4)	37(82.2)	22(55)	0.007*
15-19 age	26(30.6)	8(17.8)	18(45)	
BMI				
Underweight	69(81.2)	36(80)	33(82.5)	0.381
Normal	10(11.8)	7(15.6)	3(7.5)	
Overweight	6(7)	2(4.4)	4(10)	
CD in the family				
Yes	18(21.2)	7(15.6)	11(27.5)	0.179
No	67(78.8)	38(84.4)	29(72.5)	
Disease duration				
0-5 year	50(58.8)	28(62.2)	22(55)	0.499
> 5 year	35(41.2)	17(37.8)	18(45)	
Vitamin-mineral support				
Yes	40(47.1)	21(46.7)	19(47.5)	0.939
No	45(52.9)	24(53.3)	21(52.5)	
CD Symptom				
Yes	61(71.8)	30(66.7)	31(77.5)	0.268
No	24(28.2)	15(33.3)	9(22.5)	

* $P < 0.01$

Table 2. Data on adolescents' adherence to a GFD during the COVID-19 pandemic

	Adherence group n(%)	Non-adherence group n(%)	P value
Difficulty finding GFP			
Yes	25(55.6)	27(67.5)	0.259
No	20(44.4)	13(32.5)	
The reason for the difficulty in finding GFP†			
Inability to find GFP in markets	17(54.8)	23(74.2)	0.062
No access to GFP due to home quarantine	12(38.7)	4(12.9)	
Other	2(6.5)	4(12.9)	
Consumption of homemade products made with GFP			
No change	41(91.1)	34(85)	0.505
More than normal	4(8.9)	6(15)	
Reason of better adherence to a GFD†			
I don't believe my adherence to a GFD is better than it was before	13(28.9)	14(35)	0.873
Having more time to prepare meals at home	9(20)	10(25)	
Going out less	7(15.6)	5(12.5)	
Eating at home	6(13.3)	4(10)	
Other	10(22.2)	7(17.5)	
Reason of worse adherence to a GFD†			
I don't believe my adherence to a GFD is worse than it was before	20(52.6)	16(41)	0.117
I don't know	11(28.9)	9(23.1)	
Difficulties finding GFP	6(15.8)	5(12.8)	
Other (distress or concern)	1(2.6)	9(23.1)	

† The variables were multiple answers in the table.

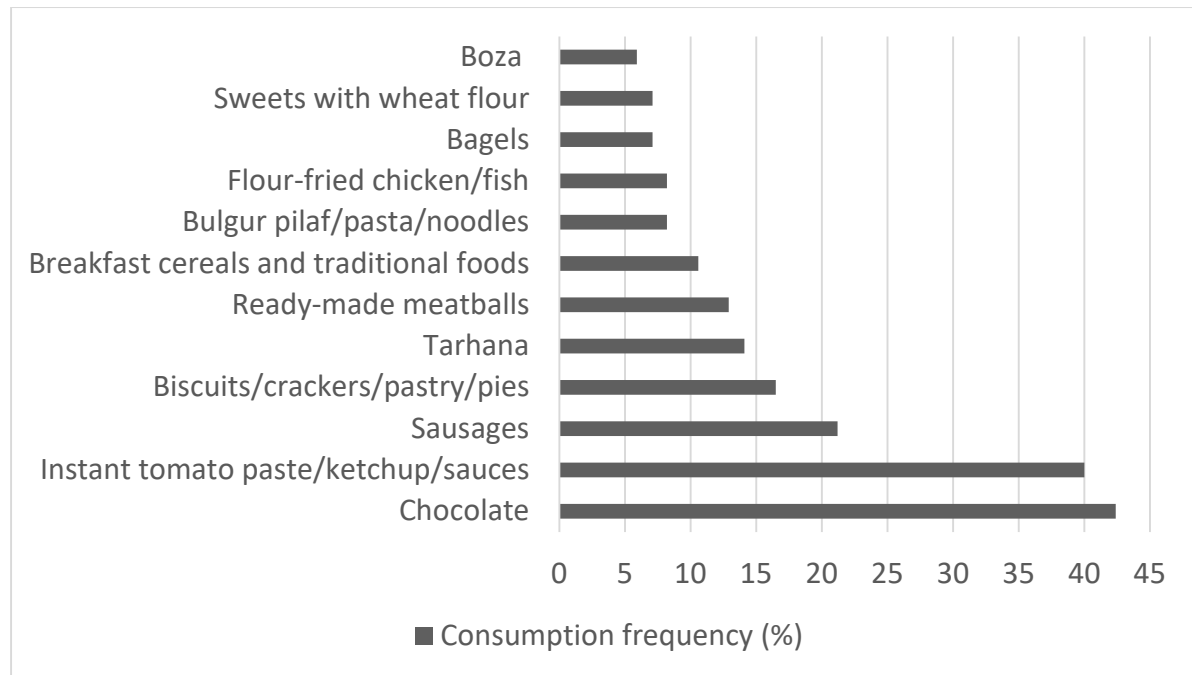


Figure 1. Frequency of gluten-containing food consumption in diet-adherence adolescents

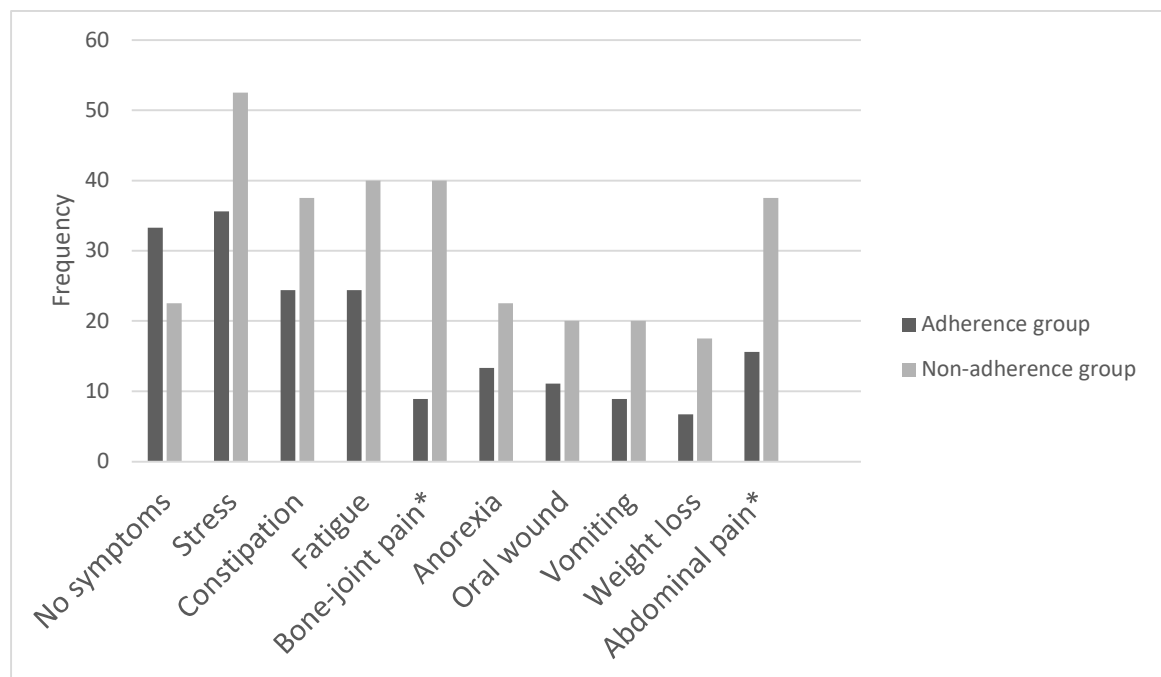


Figure 2. Disease symptoms in adherence and non- adherence adolescents

Discussion

This study is one of the few studies evaluating diet adherence among adolescents with CD during the COVID-19 pandemic. The present study examined how adherence with GFD changed during the pandemic and the factors affecting adherence. More than half of the participants (52.9%) were compliant with the diet. Adherence with a GFD is affected by many factors such as age, gender, disease duration, and availability of GFP (Fernández Miaja et al., 2021). While no difference was found in adherence with the diet with respect to gender, family history of celiac disease, duration of disease and BMI, it was found that diet adherence was significantly higher in the younger age group ($P < 0.01$). In a study on adherence with a GFD, adolescents reported lower adherence compared to younger individuals (MacCulloch & Rashid, 2014). In another study, it was determined that the diet adherence of the teenager group was lower than the adolescent group, which supports the results of the present study. This is because teenagers believed that systematic low gluten intake did not cause the intestinal symptoms they had before and their health was not adversely affected (Czaja-Bulsa & Bulsa, 2018). However, as seen in the present study, non-adherence with a GFD causes some CD symptoms (Figure 2).

The effect of a GFD on body mass index in adolescents with CD is controversial. In a longitudinal study, it was determined that approximately half of overweight children with celiac disease returned to normal BMI levels on a GFD (Anafy et al., 2021). However, other studies point out that GFD leads to predisposition to weight gain or obesity (Brambilla et al., 2013; Marciniak et al., 2021). In the present study, no relationship was found between adherence with a GFD and BMI; however, it should not be overlooked that the majority of the adolescents included in the study were at low BMI levels.

Adolescents with CD may face certain challenges brought by the pandemic and mandatory restriction measures. In the present study, one of the problems experienced by the adolescents in relation with diet adherence during the pandemic was the difficulty in finding GFP. Adolescents reported that this

was due to not being able to find GFP in the markets and not being able to leave the house (Table 2). Similar to the results of the present study, in a study conducted in Italy during the COVID-19 pandemic, 28% of children stated that they had difficulty in finding GFP (Monzani et al., 2020). In a study conducted before the COVID-19 pandemic, it was reported that the high price and limited availability of products affected adherence with a GFD (MacCulloch & Rashid, 2014). In a recent review, limited availability of products and high prices were listed among the most important problems faced by celiac patients (Demirkesen & Ozkaya, 2022). Another study highlighted that adolescents with celiac disease face challenges with the cost, access, and availability of gluten-free foods, as well as with eating out, traveling, and socializing with friends (White et al., 2016). The difficulty in finding GFP has been reported in studies conducted before and during the COVID-19 pandemic. It can be said that the restrictive measures during the pandemic negatively affect access to GFP.

In the present study, adolescents who reported that their diet adherence was better during the pandemic stated that this was due to having more time to prepare meals at home, going out less, eating at home, and paying more attention to their health during the Covid-19 pandemic (Table 2). In a similar study conducted during the COVID-19 pandemic, children who had better adherence during the pandemic primarily attributed this to not eating outside the home and having more time at home to prepare meals (Monzani et al., 2020). Going out less and having more time to eat at home can be considered as opportunities brought by the restrictive measures taken during the pandemic. In the present study, the majority of adolescents who reported worse adherence during the pandemic stated that they did not know the reason for this, and that it could be due to difficulty in finding GFP and distress or concern (Table 2). In another similar study, the majority of children who reported worse adherence stated that the reason for this was migraines and sadness (Monzani et al., 2020). In a study investigating adherence with a GFD, it was reported that psychological problems may be encountered in compliant and non-compliant children alike (Garg &

Gupta, 2014). In a review examining the effect of the COVID-19 pandemic on adolescent mental health, it was determined that the mental problems experienced by adolescents increased during this period (Panchal et al., 2021). These results may indicate that the pandemic harmed adolescents' mental health. It can also be said that symptoms of distress or concern are a factor that worsens diet adherence in adolescents with CD and psychological symptoms experienced during the pandemic have a negative effect on adherence to GFD. Nurses can guide adolescents with celiac disease on stress management, coping mechanisms, and maintaining a healthy diet during challenging times such as pandemics. It can be said that the psychological symptoms experienced during the pandemic have a negative effect on adherence with GFD.

Gluten is found in some industrially processed foods (Falcomer et al., 2020). Patients can unintentionally consume foods containing gluten. In a previous study, it was determined that the most problematic foods for celiac patients are processed meat products (sausage, salami, sausage, etc.), ready-made tomato paste, chocolate, and ketchup (Aydın et al., 2019). Similarly, in the present study, it was determined that non-adherence with diet was mostly due to the consumption of chocolate, ready-made tomato paste/ketchup/sauce, sausage. This may be because gluten content is ignored for these products or consumers have a hard time resisting these foods. In line with these results, it is recommended that healthy food alternatives for adolescents with CD should be encouraged by dietitians, pediatric nurses and other health professionals.

In CD, psychological symptoms can also be seen in addition to gastrointestinal symptoms such as abdominal pain, diarrhea, vomiting, and abdominal distension (Castillo et al., 2015; Germone et al., 2022). In the present study, adolescents most frequently reported symptoms such as stress, constipation, and fatigue. It was determined that the symptoms of abdominal pain and bone-joint pain were significantly higher in non-compliant adolescents compared to compliant adolescents (Figure 2). It is expected that the symptoms subside with diet adherence after 6

months to 2 years, and the individuals return to normal (Demirkesen & Ozkaya, 2022). In a study conducted in children with CD, it was reported that the most common presenting symptoms were chronic abdominal pain, insufficient weight gain, and symptoms of abdominal bloating (Sarkhy et al., 2015). In another study, abdominal pain, diarrhea, and growth retardation were the most frequently reported symptoms (Sansotta et al., 2018). Unlike these studies, the most frequently reported symptom was stress in the present study. This shows that adolescents with CD are primarily affected by psychological factors during the pandemic. The results of the present study suggest that during pandemics, mental symptoms should be evaluated primarily as well as physical symptoms in adolescents with CD. Not only physical, but also psychological support should be provided by pediatric nurses and other health professionals to adolescents who must adhere to a GFD throughout their lives.

The present study is one of the limited studies in the literature evaluating diet adherence among adolescents with CD during the COVID-19 pandemic. There are certain limitations of the study. Adherence with a GFD could not be examined using a serological test or small intestine biopsy. Furthermore, the study was conducted in a single region. Further multi-center prospective studies should be conducted to examine GFD adherence among adolescents with CD.

Conclusions: Based on the results obtained in the present study, it was found that the majority of adolescents with CD complied with their diet during the Covid-19 process. Diet adherence was significantly higher in the younger age group. While adolescents faced difficulties finding GFP in the markets during the pandemic; the decrease in the habit of eating out and having more time to cook at home also reinforced positive eating behaviors. It was found that the most common symptoms reported by adolescents with CD during the pandemic were stress, constipation, and fatigue. Adolescents who did not comply with their diet most frequently consumed foods such as chocolate, ready-made tomato paste/ketchup/sauce, sausage. When the restrictions and limitations brought by the pandemic are added to adolescence,

which is an important developmental period, adherence with a GFD can be challenging. Adherence with a GFD requires a multidisciplinary team approach.

Health professionals should be aware of the potential challenges that children with celiac disease may face during pandemic periods. Research and collaborations need to be conducted locally regarding the obstacles faced by adolescents with celiac disease during the pandemic. It is also thought that strengthening the collaboration between dietitians, nurses, and gastroenterologists will contribute positively to the adaptation of celiac adolescents to a gluten-free diet. Health professionals can offer adolescents with celiac disease nutritional counseling on adherence to a gluten-free diet, practical guidance in daily living, psychosocial support, and pandemic-specific support.

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