Original Article

Adherence to a Gluten-free Diet and Identification of Barriers in Adult Celiac Population in Shiraz, Iran

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ABSTRACT

Background:
Despite the importance of a gluten-free diet (GFD) in the management of celiac disease (CD), non-adherence is quite common and varies in different societies. The aim of this study was to survey adherence to a GFD and identify the barriers in the adult celiac population in Shiraz.

Materials and Methods:
In this cross-sectional study, the patients diagnosed with CD were determined through serum levels of tissue transglutaminase IgA (tTg-IgA) and immunoglobulin A (IgA). In patients with positive anti-tTG, small bowel biopsies were taken. A gastroenterologist routinely assesses CD patients at Shiraz Celiac Clinic. Also, an expert general practitioner describes a list of forbidden food to patients. Adherence to a gluten-free diet was evaluated using interview and tTg-IgA level.

Results:
Adherence to a gluten-free diet was 58.2% among 170 participating patients aged 15 to 71 years. There was no significant difference in sex ($P=0.730$), current age, and age at the time of diagnosis ($P>0.05$) between the adherent and non-adherent groups. However, the adherence among the unemployed ($P=0.036$) and highly educated ones was significantly higher than others. More patients adhered to the gluten-free diet for 1-3 years (63.7%), so after three years, less adherence was seen (50%). The most reason for non-adherence was lack of proper access and labeling, cost, and feeling different from others.

Conclusion:
Advances in the catering/food industry, increasing economic support and awareness about CD, GFD, and gluten-free products, as well as removing barriers such as inaccessibility and cost, can improve adherence to a GFD.

Keywords: Celiac, Adherence, Adult

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INTRODUCTION

Celiac disease (CD) is a permanent, inflammatory small intestinal, autoimmune disorder that appears in response to the gluten protein intake in genetically predisposed individuals. The protein is mainly found in wheat, rye, and barley (1,2). Frequently, with atrophy of the intestinal villi due to the immune system's reaction to gluten consumption, symptoms of malabsorption such as weight loss, and diarrhea present. CD may be associated with extra-intestinal manifestations like osteoporosis, infertility, anemia, and dietary deficiencies; or else, it may manifest symptomless (3-5). Except for areas where people are less genetically susceptible to CD, the prevalence rate is estimated to be 0.5- 1% in the general population, with a 2:1 in female to male ratio (6,7). A meta-analysis has shown that the CD prevalence in Iran is similar and even more than global statistics. This high prevalence may be due to the cereal diet, particularly wheat, which is one of the main meals among the Iranian population (8). Today, adherence to a strict gluten-free diet (GFD) is the only known effective therapy for CD patients (9,10). Compliance with a GFD can improve clinical and histological manifestations, and also reduce the chance of serious and long-term complications of CD such as malignancy, anemia, liver diseases, mental illness, and other CD-related problems (10-13). However, low adherence to a GFD has been reported among CD patients in the range of 42%-91% (9). In adults with CD, multiple factors affect GFD disobedience at the individual level (e.g. insufficient knowledge about CD and GFD, careless attention, low education status, low-income level, improper taste of food) and the interpersonal level (e.g. social fear/lack of awareness). Other factors may also contribute to non-compliance with a GFD at the environmental and community levels (e.g. eating in a restaurant/outside the home, high cost, low availability, unspecified food label, cultural factors, traveling, residing in an urban area) and the system level (e.g. lack of education to patients, poor labeling system) (14). The high cost of GFD is also a barrier to compliance in Iran (15). Hence, identifying barriers to compliance with a GFD can enhance compliance and improve the patients' health status. Despite the benefits of following a GFD in patients with CD, it may increase the risk of metabolic syndrome, hepatic disorders, and cardiovascular diseases. Patients on a GFD consume more high-calorie foods including fats and simple carbohydrates (6,16-18).

Given the challenges of following a GFD and the wide differences in adherence to a GFD, we aimed to study the adherence to a GFD and identify barriers in the adult celiac population in Shiraz.

METHODS AND MATERIALS

Usually, when a patient is diagnosed with CD, he/she is referred to Shiraz Celiac Clinic, a referral clinic in southern Iran. Diagnosis of CD is based on serum levels of tissue transglutaminase IgA (tTg-IgA), and immunoglobulin A (IgA) levels. Patients with IgA levels less than 0.006 g/dL, known as immunoglobulin A deficiency, were excluded from the study. The estimation of IgA anti-tTG was carried out using the Aeskulisa kit (Germany), along with the ELISA method. A titer of 18 IU/mL or higher was considered positive tTg-Ig A. Documentation of small-bowel biopsies was taken in all positive anti-tTG patients. The histological findings were classified according to the Oberhuber-modified Marsh classification (19).

The diagnosed patients are under routine follow-up at Shiraz Celiac Clinic, where a gastroenterologist visits CD patients and explains the details of the illness and their treatment process. An expert general practitioner explains a list of foods that must be avoided, and they receive food subsidies every month.

This cross-sectional study was conducted between 2018 and 2019 among patients diagnosed with CD that were under the care of Shiraz Celiac Clinic. The inclusion criteria were outpatients, age over 15 years, and consumption of GFD for at least one year. Exclusion criteria were participants with incomplete records and unwillingness to participate in our study. A highly skilled staff working in the celiac clinic evaluated the GFD adherence in adult celiac population. After obtaining written informed consent, they were enrolled in this study by census method.

Adherence to a GFD was determined by an interview and tTg-IgA level. The data collection form contained items with sections on demographics, disease history, history of disease in the family, time since diagnosis, and comorbid conditions such as type I diabetes.

This study was approved by the Ethics Committee of Shiraz University of Medical Sciences. (IR.SUMS.REC.1398.730)

Data are presented as mean±SD and number (percentage), for continuous and categorical variables, respectively. Chi-square and *t* tests were used to examine the statistical significance of the differences between adherent and non-adherent groups. The data were analyzed using SPSS software, version 18 (SPSS Inc., Chicago, IL, USA). The $P<0.05$ was considered statistically significant.

RESULTS

In this study, 170 patients in the age range of 15 to 71 years participated; of them, 41.8% (71 cases) did not adhere to GFD. Demographic characteristics based on the two groups of adherence and non-adherence are listed in Table 1. According to the results, there was no statistically significant difference in the current age and age at the time of diagnosis between the two groups ($P>0.05$). There was also no statistically significant difference between the two groups according to sex ($P=0.730$), while non-employed patients were significantly more adherent than others (adherence was higher in non-employed patients) ($P=0.036$). Also, at higher education levels, adherence was significantly higher, so in patients with undergraduate education (high school and lower) it was 50.8%, and in those with diploma 53.4%, but in people with university education, adherence was 73.3% ($P=0.046$). The results of the presence of any symptoms (gastrointestinal (GI) and non-GI symptoms) and the durations of symptoms are also summarized in Table 1. Significantly more symptoms were seen in patients with no adherence (52.1% vs. 35.4%) ($P=0.029$). There was no significant difference between the two groups based on the diagnosis time. The patients were more adherent to GFD between 1-3 years, and less adherent after three years (63.7%, 50% respectively, $P=0.074$).

Of all the patients who did not adhere, most (53.5%) stated that the reason for non-adherence was lack of proper access and others stated other reasons such as cost, lack of proper food labels, and feeling different from others (Table 2). The most non-adherence was observed in parties (31.9%). The result of the comparison of tTG-lgA (we used the logarithm of tTG-lgA due to non-normality) showed that there was no significant difference between the two groups at the diagnosis time and study time. Also, there was no significant difference in the changes between the two groups, while within each group there was a significant decrease (Table 3).

DISCUSSION

GFD is the only useful and effective solution for celiac disease. This diet is multifaceted and involves all food-related activities; therefore, a sustainable diet for lifespan is challenging (20,21). In this study, we decided to investigate the factors that are most commonly related to GFD adherence. The adherence level was 58.2% in our study. That is comparable with other studies conducted by other researchers (36% to 96%) in patients of different ethnicities with CD, and at different times (12,22-24). This variability may attribute to different types of research methods, different adherence questionnaires, and the source of the study population.

Adherent patients were more educated, non-employed, and experienced fewer symptoms than non-adherent patients. The difference between the two groups was significant in our study (Table 1). The role of education and the symptoms experienced has been reported by other authors (14,23-26), but Leffler and others reported that employment status was not associated with adherence (5). On other hand, employed individuals are less likely to follow a healthy diet (27).

GFD adherence may result from the patient's knowledge and understanding of the rules of GFD, so educating the patient about the disease and diet (how to read labels) should be a solution for low adherence (26).

Although 30% of patients with GFD experience intermittent or persistent symptoms because of sustained or periodic, definite or unintentional gluten consumption (25). On other hand, assessment of symptoms alone is insufficient to measure adherence (28).

Factors such as current age, age at diagnosis, sex, and median household income were not associated with GFD adherence in our study (Table 1), which is comparable with other studies (5,23,29). Although other studies reported that female sex and age at diagnosis were associated with more adherence (21,24,28).

Table 1. Demographic and clinical characteristics of adult patients with celiac disease population

Variables		Group		*P* value
		Adherent (n=99)	Non-adherent (n=71)	
Current age, years		33.16±13.58	32.19±14.93	0.662
Age at diagnosis, years		28.57±13.88	27.50±15.58	0.640
Sex (Male)		63 (63.6)	47 (66.2)	0.730
Job	Employed	33 (48.5)	35 (51.5)	0.036
	Not Employed	66 (64.7)	36 (35.3)	
Education	Under high school diploma	32 (50.8)	31 (49.2)	0.046
	High school diploma	31 (53.4)	27 (46.6)	
	College	33 (73.3)	12 (26.7)	
Residency	Urban	88 (57.9)	64 (42.1)	0.589
	Rural	11 (64.7)	6 (35.3)	
Housing situation	Proprietary	67 (59.8)	45 (40.2)	0.217
	Leased	24 (51.1)	23 (48.9)	
	Others	8 (80.0)	2 (20.0)	
Income, Rails (per million)	<=15	57 (59.4)	39 (40.6)	0.731
	>15	42 (56.8)	32 (43.2)	
Having any symptom	Yes	35 (35.4)	37 (52.1)	0.029
	No	64 (64.6)	34 (47.9)	
Time from Having symptoms to diagnosis	< 1 year	79 (80.6)	61 (85.9)	0.551
	1-3	8 (8.2)	3 (4.2)	
	>3	11 (11.2)	7 (9.9)	
Time from diagnosis till now	1-3	58 (63.7)	33 (36.3)	0.074
	>3	38 (50.0)	38 (50.0)	
Accompanying disease	Diarrhea	22 (59.5)	15 (40.5)	0.092
	Diabetic type 1	10 (62.5)	6 (37.5)	
	Thyroid	6 (54.5)	5 (45.5)	
	Other	10 (100)	0	
Family member with celiac disease	Yes	11 (64.7)	6 (35.5)	0.589
	No	88 (57.9)	64 (42.1)	
Recommendation	Yes	88 (60.3)	58 (39.7)	0.791
	No	11 (39.7)	13 (60.3)	

Our patients were more adherent to GFD between 1-3 years, and less adherent after three years. It means when celiac disease gets chronic, patients are less adherent to the GFD. Mucosal recovery in celiac patients was seen after two years or more (28). That should justify lower adherence after three years.

The existence of accompanying disease and celiac disease in other members of the family did not have a significant difference between the adherent and non-adherent patients in our study. The results of other studies were comparable with our findings in this issue (12,30). The number of CD patients may have adverse effects on family finances (31), which may be the reason for the non-significant result.

Although studies have confirmed the effect of education on the knowledge of celiac patients (13,14,32), there was no significant difference between adherent and non-adherent patients regarding food instruction in our study.

The instruction provided may have not been sufficient to increase the patients' knowledge, or other factors such as lack of access, food label, and social fear may affect this result.

There was no significant difference in changes in tTg-IgA between the two groups, while there was a significant decrease within each group in our study. A review survey reported that the level of tTg-IgA could predict adherence to GFD although there was inconsistency between the decrease in the serological level and mucosal recovery. Different factors such as the time between biopsies and starting GFD, the severity of histopathologic changes at diagnosis, and the age of the patients affect duodenal histological improvement (24).

The most mentioned reasons for non-adherence were lack of suitable access, cost, lack of food labeling, and feeling different from others. At parties, during trips, and in the restaurant were the most occasions that our participants did not have adherence (Table 2). Similar reasons were reported by other researchers (21,24,29). The strategies recommended to overcome these problems include improvement in the food industry to produce healthier, less expensive, tastier GFDs, and enhancement of food labeling. GFD should be available in supermarkets (33).

The limitation of this study was its cross-sectional and self-reported design. Up to now, this is the first survey conducted to find GFD adherence and associated factors among adult celiac patients in Shiraz.

Table 2. Self-reported reasons and condition of non-adherence among adult celiac patients

Reason	Out of the non-adherent group (n=71)
Forgetfulness	3 (4.2)
Inaccessibility	38 (53.5)
Taste	7 (4.1)
Feeling needless	3 (1.8)
Cost	18 (25.4)
Shortage of prescription by a physician	2 (1.2)
Feeling different from other	9 (5.3)
Lack of food labels	9 (5.3)
Lake of knowledge about labels	4 (2.4)
Lake of education	1 (0.6)
Condition	
Restaurant	13 (18.8)
School	9 (13.0)
In traveling	16 (23.2)
Parties	22 (31.9)
Picnic	0
Other	9 (13.0)

CONCLUSION

Our study found that occupation, education, and presence of symptoms were significantly different between the adherent and non-adherent groups. Lack of access to GFD, especially while traveling, or at parties, and cost were mentioned as barriers to adherence. It is recommended that authorities develop the catering/food industry and increase economic support by expanding food subsidies. Increasing awareness about CD, GFD, and gluten-free products within the catering/food industry is also suggested. This study could be a cornerstone for interventional studies because identifying the influencing factors of non-adherence is helpful in dietary self-management among celiac patients. Future studies should focus on developing and testing interventions for this non-adherent group.

Table 3. Comparison of anthropometric and lab data in adherent and non-adherent patients

Variables		Group		P value
		Adherent (n=99)	Non-adherent (n=71)	
Log (tTG-lgA)	At diagnostic time	4.81±1.18	4.86±0.94	0.793
	At study time	2.21±1.14	2.43±1.37	0.249
	Change	-2.60±1.67	-2.42±1.57	0.481
	P value	<0.001	<0.001	-

tTG-lgA: tissue transglutaminase IgA

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