

Dietary Challenges in Adults with Celiac Disease in Saudi Arabia

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Abstract Gluten free diet is the only proven treatment for celiac disease. This study aims to investigate the dietary challenges of adults with celiac disease. A web-based survey was completed by adult patients diagnosed with CD across Saudi Arabia. The survey included questions exploring demographics, the challenges in their diet as well as questions about their behaviour of eating out. Most of the participants were females and more than half are living in Riyadh. Furthermore, 65.7% were diagnosed by bowel biopsy and 72.3% were diagnosed for more than 1 year, 95.8% are following a gluten-free diet but 51.8% are not under a nutritional program 57.1% are not following up with a dietitian. Furthermore, 96.4% of participants considered restaurants are problems in providing gluten-free food and 86.1% are avoiding restaurants. This study concluded that adults with celiac disease are following GFD without follow -up with health care providers (HCPs), this can lead to increase many complications of this disease. Moreover, increasing the awareness about CD and GFD is important among patients, HCPs and society including, families and friends and people dealing with food business.

Keywords: celiac disease, gluten-free diet, Saudi Arabia, dietary challenges

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1. Introduction

Celiac disease (CD) is a long-term autoimmune disorder that damages the small intestine. This disease can impede the absorption of nutrients [1]. Individuals with this condition are prone to developing an intolerance to gluten, the primary sources of which include grains such as wheat, barley, oat, and rye [2]. The main symptoms of this disease are abdominal pain, bloating, and diarrhea, but it can also lead to various other health conditions, such as osteoporosis [3] and deficiencies in calcium, iron, fiber, folic acid, omega-3, vitamin B12, and vitamin D [4]. This disease if not treated it can lead to morbidity and mortality [5]. This life -long disorder is known worldwide, the prevalence rate of CD ranges from 1% to 2% in western countries [6] [7] and 0.3% to 1.0% in Turkey [8] and 1% in Iran [9]. Saudi Arabia has the highest population with this condition, at 3.2% while Tunisia has the lowest, at 0.1% [10]. Moreover, globally, gluten free diet become interesting not only for CD patients but for individuals want healthy food [11]. Although a gluten-free diet (GFD) is the only treatment for CD, maintaining a strict GFD is challenging. Previous studies of indirect assessment of

GFD shows that 17-80% of CD patients are not complain with GFD [12]. Moreover, most patients that do not complain about their diet show damage in their small intestine [13]. This might explain by there are some silent symptoms that could be fined by health care providers (HCPs) follow -up. The 2004 National Institutes of Health consensus statement and 2006 American Gastroenterology Association (AGA) technical review on celiac disease both recommended that patients be evaluated at "regular intervals" or with "periodic visits" by a "physician and a dietitian [14]. Therefore, it is essential need for long-term follow-up to assure treatment and positive outcomes [5]. In addition to the difficulties of following GFD, adhering to a strict diet has a negative impact on the social lives of patients. One of the most challenging aspects of this condition is avoiding eating out. According to several reports, many people with this issue avoid restaurants [15] [16] [17]. People with this issue are worried about the lack of controlling contaminations when eating out [5], therefore, most of them are avoiding restaurants or friends' houses. Alqifari and his team demonstrate that emotional well-being and social functioning were the lowest scores in their survey on the quality of life (QOL) of celiac patients and suggest that this is due to the availability of GFD and education and not being clinically diagnosed

[18]. In Saudi Arabia, there is no previous work on the status of adults with CD adherence of GFD and the follow-up with HCPs. Also, there are only limited studies on the dietary challenges of adults with this disease. This study is important to further investigate dietary challenges facing adults with CD.

2. Methods

2.1. Study Population

The study included Saudi adults aged 18 years and above who responded and had the ability to comprehend relevant information properly. Eligibility was confirmed by their answers to explicit selection in the survey. Non-Saudi persons and those aged under 18 years were excluded from the analysis.

2.2. Ethical Consideration

Informed consent was obtained electronically from all participants included in the study. The informed consent page displayed two options: “Yes” and “No.” Only participants who chose “Yes” were taken to the questionnaire page, and allowing them to quit the process at any time. The study was conducted according to the principles outlined in the Declaration of Helsinki. All procedures performed in this study were reviewed and approved by the institutional Research Ethics Committee (King Saud University, reference no. KSU-HE-19-90).

2.3. Data Collection

In this cross-sectional study, data were collected over a period of 4 months, starting October 2019 to January 2020, using a web-based survey questionnaire. After being pre-tested for its reliability and validity, the final version was converted to an online format using an internet survey tool (Google forms). The survey was delivered in Arabic and took approximately 10 minutes to complete by the respondent. To maintain confidentiality and privacy, the responses were anonymous, and no identifiable information was collected from the respondents. An invitation containing a link to the electronic survey was posted on a social media platform. The invitation was re-posted every other day to increase the response rate and make it visible to a larger number of individuals. The survey comprised of two parts: (1) demographic characteristics: age, gender, city of residence, education level, and family monthly income; and (2) questions a related with diagnosis. (3) outside eating patterns.

2.4. Statistical Analysis

Data management and statistical analyses were conducted by using IBM SPSS Statistics (Version 23.0) for Windows. Data were cleaned for missing and invalid responses. Frequencies and percentages with 95% confidence intervals (CIs) were calculated for categorical data.

3. Results

3.1. Characteristics of Participants

The majority of participants were female (86.14%), mostly 20-30 years old (54.21%) with no participation from 31 years and older, a little more than half were at bachelor level (51.20%), residents, of Riyadh City (60.24%), and having average monthly family income of SAR 5000-15000 (43.97%) [Table 1](#).

Table 1. CDQ-Respondents' Demography

Demography		n	%
Gender			
	Male	23	13.85
	Female	143	86.14
Age Bracket			
	More than 60 y/o		
	46-60 y/o		
	31-45 y/o		
	20-30 y/o	90	54.21
	Less than 20 y/o	76	45.78
Educational Background			
	Post Graduate Level	22	13.25
	Bachelor Level	85	51.20
	High School Level and Under	59	35.54
City of Residence			
	Other Cities	66	39.75
	Riyadh	100	60.24
Average Family Month Income (SAR)			
	More than SAR 15000	44	26.50
	SAR 5000-15000	73	43.97
	Less than SAR 5000	49	29.51
N = 166			

3.2. Dietary Challenges among CD Patients

[Table 2](#) summarized the responses to the different CD-related questions. Of the total 166 respondents, majority (65.7%) claimed that their diagnosis was made through “bowel biopsy”, and about 120 (72.3%) exclaimed that their CD condition has been diagnosed more than 1 year already. On the diet-related questions, there was an almost split answer on two questions; first on whether they “undergo nutritional program” (Yes=80/48.2%), and second on “scheduled dietitian’s follow up” after diagnosis (Yes=71/42.8%). A great part of them admitted to having followed “gluten-free” diet at 159 (95.8%) with professed minor difficulty when it comes to gluten-free product’s availability (Yes=68/41.0%). CD-participants were also asked about real-world situations like being a CD patient and eating in restaurants, many (96.4%) said that it was a problem; of avoiding restaurants due to gluten-free (or the lack there of) menus, again many (86.1%) said yes; and lastly on “no choice” situation but to eat gluten-containing foods because gluten free products are not available, about 63.9% said no to that scenario but about 36.1% of them said yes it did happen to some of them. Finally, it was so pleasant to know that a great majority (84.9%) knows of the availability of some

gluten-free products in some MOH hospitals. friend's house 1 to 3 times per week and 49.3% were never taken out food. See Table 3.

Table 2. Summary Responses by CD-diagnosed Participants

Attribute		n	%
How were you diagnosed with Celiac Disease?			
	Bowel biopsy	109	65.7
	Blood analysis	48	28.91
	Endoscopy	3	1.80
	Other methods	6	3.61
When were you diagnosed with Celiac Disease?			
	Less than 1 year	46	27.71
	More than 1 year	120	72.3
Did you undergo nutritional program after you were diagnosed?			
	Yes	80	48.2
	No	86	51.80
Do you have follow up schedule with a dietitian?			
	Yes	71	42.8
	No	95	57.22
Do you follow a gluten-free diet?			
	Yes	159	95.8
	No	7	4.21
Are gluten-free products available for you to buy?			
	Yes	68	41.0
	No	98	59.0
Did you find yourself having to eat gluten-containing products due to lack of gluten-free products?			
	Yes	60	36.14
	No	106	63.9
Is Celiac Disease a problem for you when eating in restaurants?			
	Yes	160	96.4
	No	6	3.61
Do you avoid restaurants due to a gluten-free diet?			
	Yes	143	86.1
	No	23	13.9
Do you know about the availability of some gluten-free products in some MOH hospitals?			
	Yes	141	84.93
	No	25	15.06
n = 166			

Table 3. Outside Eating Patterns among Celiac Patients 166

Attribute	n (166)	%
How many times per week would you eat outside (restaurants)?		
0 (never)	75	45.1
1 to 3 times	83	50
3 to 5 times	6	3.6
5 to 7 times	2	1.2
Everyday	0	0.0
How many times per week would you eat outside (friend's house)?		
0 (never)	59	35.5
1 to 3 times	91	54.8
3 to 5 times	11	6.6
5 to 7 times	3	1.8
Everyday	2	1.2
How many times per week would you eat outside (take out)?		
0 (never)	82	49.3
1 to 3 times	70	42.1
3 to 5 times	11	6.6
5 to 7 times	2	1.2
Everyday	1	0.6

3.3. Eating Outsidess Behaviours among CD Patients

CD patients eating behaviours regarding eating outsidess, results revealed that 50% of participants were eating at restaurants 1 to 3 times per week. 54.8% were eating in a

The results of this study revealed that most patients with CD are following GFD on their own. This result was similar with previous study in US on adults with CD manage their disease without ongoing supports form HCPs follow up [19]. Moreover, previous studies have shown that patients with CD are not following up consistency after diagnosis, a study conducted in US included 122 patients with celiac and only 35% received proper follow up that was consistent with AGA recommendation [20]. Likewise, in a study in Greece, Aspasia and his team found that patients with CD are not adequate follow up [21]. The fact that even with a strict GFD, but without follow-up practice, gluten may be contained in the nutritional profile [22]. Poor follow-up with health practices is likely to have negative long-term consequences related to complications with CD. One of the main issues is nutritional deficiencies in calcium, iron, fiber, folic acid, omega-3, vitamin B12, and vitamin D [4]. Moreover, not following up with a health care provider implies other deficits, such as an increase in the risk of cardiovascular, metabolic, and weight-related diseases [4]. Although there is no compliance among CD patients, however, A previous report that 29.8% of the respondents were seen to have gluten immunogenic peptides in their stool, which is a marker for GFD [12]; this leads to a condition where their small bowel does not heal [13]. Additionally, other studies suggest that educational interventions could improve the lives of CD patients and that improved training of general practitioners, specialists, and dieticians could also help to increase adherence to the

GFD and, thus, improve the QOL of patients with CD [23]. Another factor that could affect CD patients' GFD is higher income which was associated with better biochemical indices [24]. Overall, following GFD is difficult, adults with CD are often expose to gluten in their diet, therefore, AGA guidelines recommend the need adequate follow up with HCPs to monitor their diet and prevent complications associated with this condition [5].

Being able to eat outside the home is one of the most challenging aspects for people with CD. This issue has a negative impact on QOL, especially pertaining to social and economic aspects [25,26]. Our data showed that half of the adults with CD rarely eat away from home. A possible explanation is that patients with CD findings expose to gluten while dining out is a leading cause of anxiety since they should make sure that chefs are, and restaurants team are well- informed about the need for the meal to be gluten-free and free of cross- contamination [27]. This is also has been seen in in Saudi in a previous report by Alqefari and his team, that avoiding eating out consistently may raise the low well-being and social functioning among adults with CD [18]. The lack of awareness about this issue among restaurants in Saudi Arabia is also a significant concern [28]. Previous reports show that most chefs are not aware of CD or GFD, therefore, the chance to eat food containing gluten is high,

additionally, food labelling and food contamination [16]. Prior reports believe that incomes, education, and awareness of CD are the main causes of low health-related QOL well-being and social functioning. Additionally, insufficient knowledge of CD among HCPs could contribute to this issue [30]. In Turkey, a study suggests that gluten-free product varieties in the market are inadequate a survey revealed that patients with CD are hesitant to eat out at home, also that people with this issue feel restricted from activities like holidays and travelling, moreover, this study demonstrate that the awareness of CD on public is unacceptable [17]. In general, it became clear that dietary challenges among adult patients with CD is comparable in countries such as Spain, Turkey, and Greece, in terms of high costs, restricted availability and poor-quality products [17,21,31]. However, here in Saudi Arabia, the main challenges were the lack of awareness of following GFD with clinical guidelines and worries about gluten contamination while dining out. Many studies have demonstrated that GFD is imposes a significant cost burden patients with CD, therefore, health care systems in worldwide are adopting additional costs for purchasing GFD and encouraging adherence to GFD [21]. For example, here in Saudi Arabia, CD patients are provided with a monthly allowance and packages of GF food. Embracing society can help people with this issue improve their social and emotional well-being [17], by increasing the awareness of this disease and providing the knowledge of gluten-free food preparation for individuals and societies [29]. In this study, the cross-sectional approach was used to investigate the dietary challenges for adults with CD, this approach was a limitation of this study, as no follow up study was undertaken, to identify factors that affect these challenges. Also another limitation to this study, such as the low number of participants. However, this study has given an overview of Saudi adults with CD

adherence of GFD and possibly predict their health now and in the future.

5. Conclusion

In conclusion, this study revealed that a significant majority of patients do not follow-up with HCPs. It is becoming crucial to provide clinical support guidelines follow-up for GFD to keep track of their general health. The two main challenges patients have been worried about are gluten contamination and a lack of GF food alternatives. Furthermore, this results in a decline in their social behaviours. Additionally, there is a need to raise CD and GFD awareness among patients, the general public and food catering industry in Saudi Arabia.

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