

Awareness of Celiac Disease among the General Public in Saudi Arabia

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Abstract Background: Celiac disease (CD) is an immune-mediated systemic disorder triggered by dietary gluten and is considered one of the most common lifelong food-related disorders worldwide. The knowledge of CD among the general public in Saudi Arabia remains limited. Therefore, we aimed to assess the awareness and knowledge of CD among the general public in Saudi Arabia. Methods: A cross-sectional online survey including members of the general public was conducted in Saudi Arabia. The survey included questions assessing the public's awareness about CD, gluten sensitivity, and peanut allergy, as well as celiac disease-related knowledge. Results: From a total of 1230 responses received, 76.7% (95% confidence interval [CI], 74.0%–79.4%) were females, 42.0% (95% CI, 37.7–46.3) were aged between 31–45 years, and 64.3% (95% CI, 61.0%–67.6%) had Bachelor's degree. Less than half of the participants had heard of CD (48.4%; 95% CI, 44.4%–52.4%), but the majority had heard of peanut allergy (80.1%; 95% CI, 77.6%–82.6%) and gluten sensitivity (72.4%; 95% CI, 69.5%–75.3%). The prevalence of CD was estimated incorrectly by more than 80% of participants. Other questions on participants' knowledge associated with CD were answered "Do not know" by the majority. Females demonstrated a greater awareness of CD, peanut allergy, and gluten sensitivity, and had a higher percentage of correct responses to questions related to CD than males. Conclusion: This study highlights the need to increase the awareness and knowledge of CD, especially in the recognition of its symptoms. Educational efforts toward increasing the awareness of the general public about CD could help optimize its diagnosis and management.

Keywords: Celiac Disease, Gluten-Free Diet, Gluten Sensitivity, Saudi Arabia, questionnaire

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1. Introduction

Celiac disease (CD) is an immune-mediated systemic disorder characterized by mucosal damage of the small intestine. This disease is capable of impeding the absorption of nutrients [1]. Celiac disease develops in genetically susceptible individuals exposed to gliadin proteins and related prolamines (defined as gluten, which is present in grains, including wheat, rye, and barley) [2]. A lifelong strict adherence to a gluten-free diet (GFD) is the only currently available treatment for CD, allowing the restoration of the structure and function of the small intestinal mucosa [3,4,5].

A wide range of clinical symptoms, including gastrointestinal issues (e.g., chronic constipation, diarrhea, vomiting, and abdominal pain and distention), malabsorption, delayed puberty, amenorrhea, chronic iron-deficiency anemia, and osteoporosis may be associated with CD [1,6]. CD could be hard to recognize, owing to variations in the presentation and intensity of its symptoms. It can also be asymptomatic at presentation [4]. Historically, CD was thought to primarily affect children; however, it is now recognized that the initial symptoms of this disease may present at any age from childhood to late

in adult life [7]. Further, it is now considered to be one of the most common lifelong food-related disorders worldwide.

The estimated prevalence of CD is approximately 1% in the US and Europe [8]. Studies from South-East Asia and the Middle East show a similar prevalence [9,10]. Comparable epidemiological studies conducted among the Saudi population are limited, wherein CD is broadly perceived as being uncommon. Some descriptive small studies were conducted to determine the prevalence of CD in some regions of Saudi Arabia. In a study carried out by Aljebreen et al. [11], healthy adolescent students selected from three regions of Saudi Arabia were included, and the prevalence of CD by region was as follows: Madinah, 1.8%; Aseer, 2.1%; and Al-Qaseem, 3.2%. A more recent study reported a high prevalence of CD in Saudi school-aged children in Riyadh (1.5%) [12]. It has been proposed that there is an amplified possibility of CD epidemics, particularly in countries with gluten-rich dietary patterns, including Saudi Arabia [13].

Although the prevalence of CD is increasing worldwide [14,15,16], the rate of diagnosis increases more slowly [17]. A large number of patients with CD remain undiagnosed and more likely to develop complications of the latent disease, including severe health complications, morbidity, and mortality [18,19,20]. Increasing the

awareness of CD and its varied gastrointestinal and extra-intestinal manifestations is crucial in minimizing the undiagnosed burden of CD. A similar condition to CD is peanut allergy. Peanut allergy is reported by nearly 1% of the US population, and appears to be increasing in children over the past decade [21].

In Saudi Arabia, there is no information on the knowledge of gluten-related health issues and CD among the general public. Therefore, the objectives of this study were to assess the level of awareness and knowledge with regard to CD among the general public in Saudi Arabia. The awareness of gluten sensitivity and peanut allergy conditions was also assessed.

2. Methods

2.1. Study Population

The sample of this study comprised 1230 members (23.3% males and 76.7% females) of the general Saudi population. We included Saudi adults aged 18 years and above who responded to the announcement and had the ability to comprehend relevant information properly. Eligibility was confirmed by answers to explicit selection questions 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 they could 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, October 2019 to January 2020, using a self-administered survey questionnaire. After being pre-tested for clarity and efficiency, 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 min to complete. 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 two parts: (1) demographic characteristics: age, gender, city of residence, education level, and family monthly income; and (2) awareness of CD, gluten sensitivity, and peanut allergy, and knowledge related to CD. The survey included the following questions: How many people do you think are affected by

CD? Do you think that CD affects children only? Can CD occur without symptoms? Does CD, if not treated, lead to other diseases? Can patients with CD eat foods containing gluten if they do not show any symptoms?

2.4. Statistical Analyses

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. Participants’ awareness and knowledge of CD were compared by gender with chi-square analysis with a two-tailed p-value. Values of $p < 0.05$ were considered statistically significant.

3. Results

3.1. Descriptive Characteristics

By the end of the data collection (4 months), 1230 adults in the general public completed the survey. The descriptive demographic characteristics of the participants are shown in Table 1. The majority of the participants were females ($n = 944$ [76.7%; 95% CI, 74.0%–79.4%]), with males making up the minority ($n = 268$ [23.3%; 95% CI, 18.4%–28.2%]). The age range of approximately half of the participants was 31–45 years. The majority of the study participants indicated that their permanent residence was the capital city of Saudi Arabia, Riyadh ($n = 874$ [71.1%; 95% CI, 68.1%–74.1%]). More than half of the participants ($n = 791$ [64.3%; 95% CI, 61.0%–67.6%]) had at least a bachelor’s degree. With respect to the average family monthly income, the least represented category came from the “less than SAR 5000” category, whereas the highest and second highest categories came close, at 523 (42.5%; 95% CI, 38.3%–46.7%) and 501 (40.7%; 95% CI, 36.4–45.0%), respectively, for the SAR 5000–15,000 category and the more than SAR 15,000 category.

Table 1. Demographic characteristics of the study participants

Variables	N	%* (95% CI)
Gender		
Male	286	23.3 (18.4–28.2)
Female	944	76.7 (74.0–79.4)
Age (years)		
18–20	67	5.4 (4.2–6.6)
21–30	355	28.9 (24.1–33.6)
31–45	516	42.0 (37.7–46.3)
46–60	266	21.6 (16.7–26.5)
More than 60	26	2.1 (3.4–7.6)
City of residence		
Riyadh	874	71.1 (68.1–74.1)
Other than Riyadh	356	28.9 (24.2–33.6)
Educational level		
Postgraduate	195	15.9 (10.8–21.0)
Bachelor’s degree	791	64.3 (61.0–67.6)
High school and under	244	19.8 (14.8–24.8)
Family income (SAR)		
Less than 5000	206	16.7 (11.6–21.8)
5000–15,000	523	42.5 (38.3–46.7)
More than 15,000	501	40.7 (36.4–45.0)

$n = 1230$. *Percentages may not add up to 100 because of rounding.

3.2. Awareness of Peanut Allergy, Gluten Sensitivity, and Celiac Disease

The awareness of peanut allergy, gluten sensitivity, and CD is shown in Figure 1. The majority of the participants had heard of peanut allergy ($n = 985$ [80.1%; 95% CI, 77.6%–82.6%]) and gluten sensitivity ($n = 890$ [72.4%; 95% CI, 69.5%–75.3%]). In contrast, less than half of the participants had heard of CD ($n = 595$ [48.4%; 95% CI, 44.4%–52.4%]). The numbers of participants who had not heard of peanut allergy, gluten sensitivity, and CD were 245 (19.9%; 95% CI, 14.9%–24.9%), 340 (27.6%; 95% CI, 22.8%–32.4%), and 635 (51.6%; 95% CI, 47.7%–55.5%), respectively.

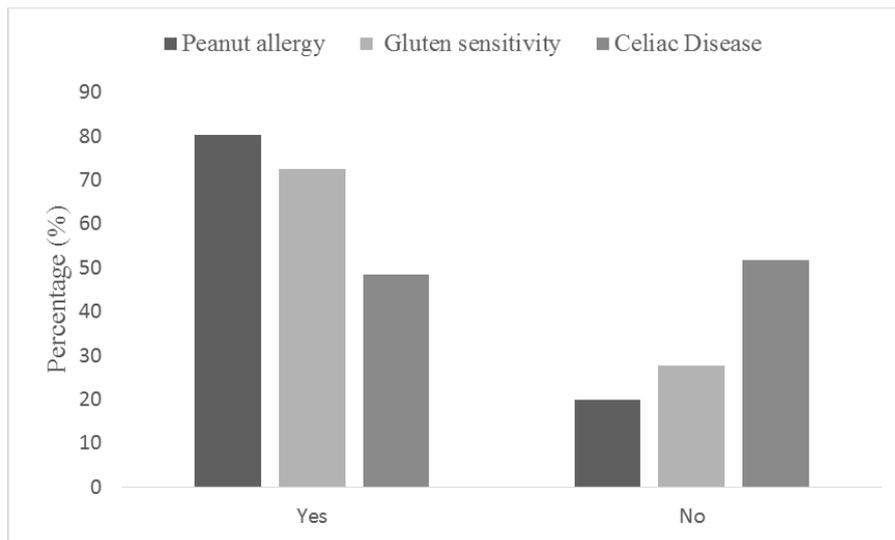


Figure 1. Awareness of peanut allergy, gluten sensitivity, and celiac disease among the study participants

Table 2. Participants' knowledge of celiac disease

Variables	n	%* (95% CI)
How many people do you think are affected by celiac disease?		
1 in 10	211	17.2 (12.1–22.3)
1 in 50	199	16.2 (11.1–21.3)
1 in 100	208	16.9 (11.8–22.0)
1 in 200	125	10.2 (4.9–15.9)
1 in 500	150	12.2 (7.0–17.4)
1 in 1000	337	27.4 (22.6–32.2)
Do you think that celiac disease affects children only?		
Yes	100	8.1 (7.3–8.7)
No	536	43.6 (39.4–47.8)
Do not know	594	48.3 (44.3–52.3)
Can celiac disease occur without symptoms?		
Yes	299	24.3 (19.4–29.2)
No	350	28.5 (23.8–33.2)
Do not know	581	47.2 (43.1–51.3)
Does celiac disease, if not treated, lead to other diseases?		
Yes	462	37.6 (33.2–42.0)
No	193	15.7 (10.6–20.8)
Do not know	575	46.7 (24.6–50.8)
Can patients with celiac disease eat foods containing gluten if they do not show any symptoms?		
Yes	79	6.4 (5.3–7.5)
No	455	37.0 (32.6–41.4)
Do not know	696	56.6 (52.9–60.3)

$n = 1230$. *Percentages may not add up to 100 because of rounding.

3.3. Knowledge of Celiac Disease

Table 2 displays responses to questions on the participants' knowledge of CD. When we asked participants to estimate the prevalence of CD, more than 80% of them estimated it incorrectly. CD was underestimated by 33.4% of participants, but it was overestimated by approximately half of the participants (49.8%). Other questions on the participants' knowledge of CD, including "Do you think that CD affects children only? Does CD have symptoms? Does CD, if not treated, lead to other diseases? Can patients with CD eat foods containing gluten if they do not show any symptoms?" were answered with a response of "Do not know" by the majority.

Table 3. Participants' knowledge of celiac disease according to gender

Variables	Gender		P-value
	Male n (%)*	Female n (%)	
N	286 (23.3)	944 (76.7)	
Have you heard of peanut allergy			
Yes	184 (64.3)	801 (84.9)	0.000
No	102 (35.7)	143 (15.1)	
Have you heard of gluten sensitivity?			
Yes	145 (50.7)	745 (78.9)	0.000
No	141 (49.3)	199 (21.1)	
Have you heard of celiac disease?			
Yes	81 (28.3)	514 (54.4)	0.000
No	205 (71.7)	430 (45.6)	
How many people do you think are affected by celiac disease?			
1 in 10	48 (16.8)	163 (17.3)	0.706
1 in 50	40 (14.0)	159 (16.8)	
1 in 100	56 (19.6)	152 (16.1)	
1 in 200	28 (9.8)	97 (10.2)	
1 in 500	37 (12.9)	113 (12.0)	
1 in 1000	77 (26.9)	260 (27.5)	
Do you think that celiac disease affects children only?			
Yes	16 (5.6)	84 (8.9)	0.000
No	65 (22.7)	471 (49.9)	
Do not know	205 (71.7)	389 (41.2)	
Can celiac disease occur without symptoms?			
Yes	48 (16.8)	251 (26.6)	0.000
No	54 (18.9)	296 (31.4)	
Do not know	184 (64.3)	397 (42.1)	
Does celiac disease, if not treated, lead to other diseases?			
Yes	67 (23.4)	395 (41.8)	0.000
No	50 (17.5)	143 (15.1)	
Do not know	169 (59.1)	406 (43.0)	
Can patients with celiac disease eat foods containing gluten if they do not show any symptoms?			
Yes	13 (4.5)	66 (7.0)	0.000
No	61 (21.3)	394 (41.7)	
Do not know	212 (74.1)	484 (51.3)	

*Percentages may not add up to 100 because of rounding.

The knowledge of CD among participants according to gender is shown in Table 3. Gender was associated significantly with all questions on CD perception, except for the question, "How many people do you think are affected by CD?" The percentages of females who had heard about peanut allergy, gluten sensitivity, and CD were greater than those of males. "Do not know" was the predominant male response to the questions, "Do you think that CD affects children only? Does CD have symptoms? "Does CD, if not treated, lead to other diseases?" and "Can patients with CD eat foods containing gluten if they do not show any symptoms?"

4. Discussion

The present study aimed to evaluate the level of awareness of CD among the general public in Saudi Arabia. Among those surveyed, we found that less than half (48.4%) had heard of CD. Our findings are consistent with those of a previous study conducted in the US, which reported that among 861 adults of the general public, 47% had heard of CD [22]. However, the awareness of the

general public of CD in this study was greater than that reported in a study conducted in the UK among 513 adults from the general public, wherein 44.2% had heard of CD [23].

In the current study, participants were more likely to have heard of peanut allergy and gluten sensitivity than CD. This finding is in agreement with the two previous studies conducted in the US and the UK, which reported a greater awareness of peanut allergy and gluten sensitivity than of CD [22,23].

Approximately 1% of the population is reportedly affected by CD [19,24]. In this study, only a small percentage (16.9%) of the participants estimated the prevalence of CD correctly. Similarly, CD was estimated incorrectly by the majority of people who participated in the US study [22]. Other questions on the knowledge associated with CD were answered with a response of "Do not know" by the majority. We found that males are less aware of peanut allergy, gluten sensitivity, and CD than females. Furthermore, females had a higher percentage of correct responses to questions related to CD than males.

Despite the increasing prevalence of CD worldwide, the disease still remains heavily underdiagnosed. The

diagnosis of CD is a challenge, as this disease has a multifaceted clinical presentation [25]. Moreover, the diagnostic rate relies mainly on the level of awareness of the disease. The variations in the presentation of CD and the limited awareness of this condition could result in diagnostic delays exceeding 10 years [26,27]. Hence, the increased awareness and knowledge of CD and its broad spectrum of symptoms among the general public are warranted. Improved awareness of CD among healthcare professionals is also recommended. A previous study [28] conducted in Saudi Arabia assessed the knowledge of CD and reported poor knowledge among a significant proportion of healthcare professionals, including consultants.

Delays in the diagnosis of CD could negatively affect patients' health and cause. The untreated condition can lead to numerous complications, such as nutritional deficiencies (e.g., anemia and osteoporosis), an increased risk of developing other autoimmune disorders, and small intestinal lymphoma [3].

Gluten is the main environmental risk factor for the development of CD [20]. At present, the only proven treatment for CD is a lifelong strict GFD, which shows overall excellent results. Early adherence to a GFD has been demonstrated to eliminate symptoms and to halt the progression of several complications of CD. A GFD seems to remain a crucial aspect of disease management in the future, as no medications have been approved for the disease so far [20,25]. Good adherence to a GFD is associated with the level of knowledge and motivation of patients [25]. It should be mentioned that knowledge about a GFD is essential, not only of the hidden sources of gluten but also of healthy gluten-free substitute grains that supply sufficient amount of nutrients and fiber.

Some limitations of our study should be considered: a self-administered electronic questionnaire was used, which increases the likelihood of recall bias. The study might evaluate the level of awareness and knowledge less accurately, as it was delivered online, meaning that only people who have access to social media networks have been included in the study. One of the major strengths of the current study is that this is the first study to assess the awareness of CD among the general public in Saudi Arabia.

5. Conclusion

The present study demonstrated gaps in knowledge with regard to CD among the general public. These findings support a need to increase the awareness and knowledge of CD, especially in the recognition of its symptoms. Educational efforts are needed to increase the awareness of the general public about CD, which could help optimize its diagnosis and care.

Ethics Approval and Consent to Participate

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). Informed

consent was obtained electronically from all participants included in the study.

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Not applicable.

Conflict of Interest

Authors declare no conflict of interest.

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