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Coeliac disease knowledge and treatment: Potential factors associated with adherence to gluten-free diet

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ABSTRACT

Introduction: Lack of adherence to a strict gluten-free diet (GFD) is the main reason for poorly controlled disease in patients with coeliac disease (CD). This study aimed to assess the association between knowledge of CD and its medical diet to the adherence of GFD among adult patients with CD. **Methods:** A cross-sectional study was carried out with a total of 90 adult patients with CD (aged between 18-65 years). The data collecting instruments were a combination of four questionnaires as follows: assessment of knowledge of coeliac disease (AKCD), gluten-free diet knowledge scale (GFD-KS), coeliac disease adherence test (CDAT), and questions on potential factors influencing GFD adherence among patients. **Results:** An average knowledge score of five points out of seven was obtained from 46 participants (51%). Mean score for knowledge on gluten-free diet was seven points out of 17 in 59 participants (65%). Adequate adherence to GFD was observed in 56% of the participants. No association was found between knowledge of CD and GFD to the adherence of GFD ($p>0.050$). Participants who had higher adherence scores were discussing GFD with a specialist, obtaining educational materials, had enhanced symptoms associated with CD, and did not complain about the taste of GFD ($p<0.050$). **Conclusion:** Patients with CD has adequate knowledge of CD and adherence of GFD. No association was found between the knowledge of CD and GFD to the adherence of GFD. Further research might explore other potential factors influencing the adherence to GFD.

Key words: adherence, coeliac disease, gluten-free diet, knowledge

INTRODUCTION

Coeliac disease (CD) is an autoimmune disorder that occurs in genetically predisposed people where the ingestion of gluten leads to damage in the small intestine (Guandalini & Assiri, 2014). Coeliac disease is considered the most commonly genetically-based food

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intolerance worldwide, with prevalence of 1% in the general population (Guandalini & Assiri, 2014). A meta-analysis revealed that the seroprevalence of CD in Saudi Arabia is 2.7%, while the prevalence of CD in Saudi Arabia using biopsy is 1.4% (Safi, 2018). The symptoms of CD varies from one person to another (Guandalini & Assiri, 2014). Coeliac disease is broadly described with classic symptoms in which patients may develop symptoms of malabsorption, including diarrhoea and weight loss, or non-classical symptoms such as poor bone health (Parzanese *et al.*, 2017; Volta *et al.*, 2016).

The only efficient treatment for patients with CD so far is a life-long elimination of gluten from the diet (Guandalini & Assiri, 2014). Gluten is a protein found in wheat, rye and barley. Adherence to a strict gluten-free diet (GFD) has been shown to have benefits to CD patients in terms of improvements in depression and infertility, and decrease in the risk of gastrointestinal malignancies (Hallert *et al.*, 2002; Nenna *et al.*, 2011). Adherence to GFD in adult patients varies between 40-90% (Hall *et al.*, 2009). Many factors influencing the adherence to GFD have been explored, including the cost of GFD, eating outside of home, and knowledge of GFD (Ciacci *et al.*, 2002; Hall *et al.*, 2009; Lamontagne *et al.*, 2001; Leffler *et al.*, 2008). In addition, limited studies have reported an association between the adherence to GFD with the knowledge of CD and GFD (Ciacci *et al.*, 1998; Kokkonen *et al.*, 1989; Leffler *et al.*, 2008).

An adequate knowledge on GFD and CD is important to understand the presentations of the disease and to be more aware about the treatment, as well as how to follow a GFD (Ukkola *et al.*, 2012). A previous study reported that 76-85% of patients with CD were educated about GFD by physicians or dietitians (Ukkola *et al.*, 2012). Surprisingly, one out of four patients with CD was dissatisfied with the information regarding CD and GFD offered by their physician, and only 12% of patients with CD were not satisfied of the gluten-free information provided by dietitians (Ukkola *et al.*, 2012). One of the reasons of non-satisfaction was the low-quality information from health practitioners as it was associated with negative attitudes towards having CD (Ukkola *et al.*, 2012). Another study found that poor knowledge of GFD may lead to poor adherence to GFD (Halmos *et al.*, 2018). In addition, it was demonstrated that CD patients with self-perceived insufficient knowledge in reading gluten-free labels were more likely to misidentify gluten-free foods and were reported as non-adherent patients (Halmos *et al.*, 2018).

Up till now, limited studies have emphasised on the importance of disease knowledge and its treatment in influencing adherence to GFD in adult patients with CD. Hence, the objective of the current study was to assess the association between knowledge of CD and GFD with the adherence to GFD in patients with CD, as well as to explore any potential factors that might influence the adherence to GFD among adult patients in Saudi Arabia.

MATERIALS & METHODS

Study setting and population

This cross-sectional study initially included 222 adult patients with CD, after a screening through the Security Force Hospital in the Riyadh database. The inclusion criteria were adult patients (aged between 18 – 65 years old) with confirmed duodenal biopsy-proven CD ≥1 year. Patients with CD undergoing dietary treatment for an underlying medical issue (e.g., type 1 diabetes and multiple food allergies) and those with other chronic diseases (e.g., Down's syndrome, inflammatory bowel

disease, cystic fibrosis, short bowel syndrome, and mental disabilities) were excluded. After reviewing the database, 130 patients met the inclusion criteria. Of these, 26 patients had wrong contact information and 14 patients did not give their consent to enrol in the study. The final number of participants who met the criteria and completed the survey were 90 patients (Figure 1). All participants received phone calls explaining the objectives of the study and the study survey. Participants were also informed that participation in the study was voluntary, anonymous, and confidential, and that they could withdraw at any moment without any penalty. Data collection was conducted for six months between November 2019 to April 2020. After obtaining consent, data were collected from participants. Ethical approval of the current study was obtained from the institutional review board (IRB) of the Security Force Hospital in Riyadh (Saudi Arabia) (IRB number 19-324-22).

Data collection tools

Section 1: General characteristics and medical history

General information contained information that included age, gender, weight and height, monthly income, marital status, level of education, family history of CD, and food allergies. Data related to medical history (age at diagnosis, duration of the disease, and existing co-morbidities) were obtained from patient's medical file. Other information were collected using a self-reported questionnaire. The questionnaire was administrated in Arabic and composed of 4 sections as follows:

Section 2: Assessment of knowledge on coeliac disease (AKCD)

This section aimed to assess the

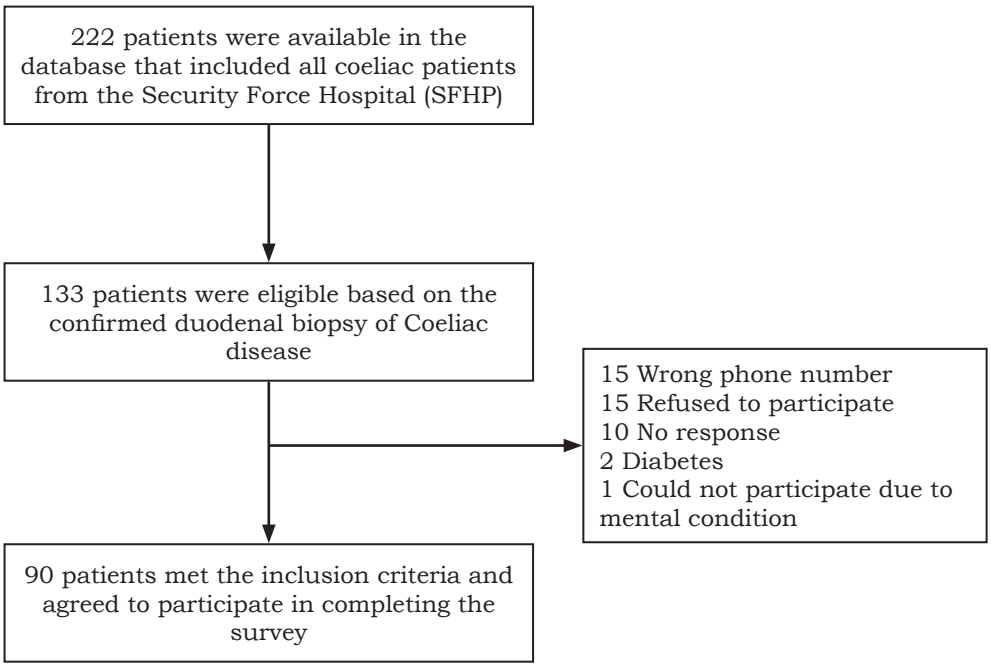

Figure 1. Flow chart of the patient sampling

knowledge about CD (AKCD). It was composed of seven questions. The questions were focused on the physiological, medical, and nutritional aspects of CD. There were no questions about the type of CD or its symptoms, as the manifestation of the disease differs from one person to another. The questionnaire was developed by three clinical dietitians in Arabic. Before being used, the questionnaire was piloted for ease of understanding and use among 50 patients with CD through an online support group for coeliac patients in Saudi Arabia. Participants in the pilot study were not included in the current study. Several feedback and comments were received regarding the clarity of the questions, which were all addressed. The revised and finalised version was used for the survey. The maximum score a participant could obtain was seven points. The mean AKCD score of all participants was five; therefore, an AKCD score of ≥5 indicated good knowledge and an AKCD score of <5 was considered as poor knowledge.

Section 3: Gluten-free diet knowledge scale (GFD-KS)

The GFD knowledge scale (GFD-KS) was used to assess the knowledge of GFD (Silvester *et al.*, 2016). The questionnaire included various foods that have been listed in the GFD as "allowed", "foods to question" or "not allowed" in a GFD (Silvester *et al.*, 2016). The scale included 17 food items, seven foods allowed, seven foods to question, and three not permitted foods. The GFD-KS questionnaire was translated to Arabic and back translated to English to ensure the accuracy of the language. Minor modifications were made to the food options in the questionnaire that were commonly consumed food items among the Saudi population (Ahmed, Salih & Khan, 2014). The modifications consisted of substituting chickpea flour, croutons, and spelt with hummus tahini, pieces of toast, and black wheat, respectively. One point was given for each correct answer to a maximum score of 17 points (Silvester *et al.*, 2016). The mean GFD-KS score of all participants was seven; therefore, a GFD-KS score of ≥7 indicated good knowledge and a GFD-KS score of <7 was considered poor knowledge.

Section 4: Self-reported adherence to gluten-free diet (CDAT)

Adherence to GFD was assessed using a validated tool (coeliac disease adherence test, CDAT) and administrated in Arabic to the participants (Leffler *et al.*, 2009). The CDAT questionnaire was translated to Arabic and back translated to English by two experts to ensure the accuracy of the language. The questionnaire consisted of seven questions ranked on a Likert scale (1 to 5) (Leffler *et al.*, 2009). The sum of the numeric values for the seven items ranged between 7 to 35, in which lower scores reflected better adherence to GFD (Leffler *et al.*, 2009). The mean score obtained from study participants was 13. Adherence to GFD scores (CDAT) of >13 was considered "inadequate adherence to GFD" and CDAT scores of £13 reflected "adequate adherence to GFD". The same cut-off point for good GFD adherence was also applied by a similar study (Leffler *et al.*, 2009).

Section 5: Factors potentially associated with adherence to GFD

Eight questions were included in the questionnaire to assess the potential factors that were associated with the adherence to GFD. As published by Butterworth *et al.* (2004), these factors included an evaluation of the information discussed with the hospital doctor and dietitian, whether the patient was

satisfied with the information given or not, was he/she part of an online support group, and if he/she had any difficulties in following the GFD. Participants were asked to choose more than one relevant answer. The questionnaire was translated to Arabic and back translated to English.

Statistical analysis

All data analysis was performed using the JMP Statistical software (North Carolina, America) for Mac, version 15. Descriptive analyses were presented as frequencies and percentages for categorical variables and means and standard deviations for continuous variables. All assessments on the association between knowledge of CD and GFD with the adherence to GFD were done using an analytical statistical test that included *t*-test and one-way ANOVA. *T*-test was performed to assess the association between a set of potential factors to the adherence of GFD (CDAT). Results were considered significantly different at a *p*-value of <0.05.

Table 1. Socio-demographic characteristics and medical history of patients with coeliac disease (*n*=90)

Socio-demographic characteristics	*n (%)*	*mean±SD or median (inter-quartile range)*
Age in years		
< 30 years old	39 (43.3)	
30 – 60 years old	46 (51.1)	
> 60 years old	5 (5.6)	
Gender		
Male	16 (17.8)	
Female	74 (82.2)	
Duration of CD (years)		4 (2-8)
Age at diagnosis of CD (years)		25.4±10.8
BMI (kg/m^2)		24.0±5.2
Marital status[†]		
Single	19 (25.0)	
Married	56 (73.7)	
Divorced	1 (1.3)	
Monthly income[‡]		
<10000 SAR	46 (51.1)	
>10000 SAR	44 (48.9)	
Level of education		
School graduate/ Diploma degree	45 (50.0)	
Bachelor's/Master's/Doctorate degree	45 (50.0)	
Food allergy and/or lactose intolerance		
Yes	10 (11.1)	
No	80 (88.9)	
Family history of CD		
Yes	22 (24.4)	
No	68 (75.6)	
Dietitian consultation		
Yes	79 (87.8)	
No	11 (12.2)	

BMI, body mass index; CD, coeliac disease; GFD, gluten-free diet

[†]*n*=76

[‡]USD 1=SAR 3.76 (as of 25 November 2022)

RESULTS

Socio-demographic characteristics and medical history

The socio-demographic characteristics and medical history of patients with CD are presented in Table 1. Majority of the participants were females (*n*=74, 82%). The average duration of the disease was 5.5 years. Mean body mass index (BMI) was within the normal range (24 kg/m^2). The majority of participants (*n*=80, 88%) did not report suffering from any other additional conditions, such as other food allergy or lactose intolerance, that might restrict them following a medical diet for the disease.

Association between knowledge of CD and GFD (AKCD and GFD-KS) and adherence to GFD (CDAT)

Table 2 shows the response rate of each item in the knowledge of CD questionnaire. The average score of the assessment on knowledge of coeliac disease was five points out of seven (71%). Only one patient had answered

Table 2. Assessment of knowledge on coeliac disease (AKCD)

AKCD	†*n (%)*
Coeliac disease is an auto-immune disease	
Yes‡	57 (63.3)
No	7 (7.8)
I don't know	26 (28.9)
Coeliac disease is a	
Chronic‡	78 (86.7)
Acute	4 (4.4)
I don't know	8 (8.9)
Coeliac disease is a genetic disease	
Yes‡	22 (24.4)
No	33 (36.7)
I don't know	35 (38.9)
The available treatment for CD	
Gluten-free-diet‡	27 (30.0)
Medications	61 (67.8)
Gluten-free-diet and medications	1 (1.1)
I don't know	1 (1.1)
The affected part of body from gluten	
Stomach	19 (21.1)
Small intestine‡	61 (67.8)
Large intestine	10 (11.1)
The gluten-free diet is	
A lifelong diet‡	83 (92.2)
A temporary diet	2 (2.2)
I don't know	5 (5.6)
I don't need to see a doctor or a registered dietitian if I'm following the GFD	
True	31 (34.4)
False‡	59 (65.6)

CD, coeliac disease; GFD, gluten-free diet
†Patients with coeliac disease (*n*=90)
‡Represents the correct answer

all the questions correctly and two patients had answered only one question correctly. For the gluten-free diet knowledge scale (GFD-KS), respondents identifying the food items correctly ranged from 3-11 out of 17. The highest score was obtained by two patients (11 out of 17) and the lowest score was obtained by seven patients (three out of 17). The mean GFD-KS score was seven points out of 17 (41%), with around 65% of the participants (n=58) having scored above the mean score. The average score for self-reported adherence to gluten-free diet (CDAT) was 13.3±4.1 (ranged between 7-24). Majority of the participants were classified as adequate (good) adherence to GFD (n= 50, 56%) (Figure 2). No associations were found between knowledge of CD and adherence to GFD (p=0.490) or knowledge of GFD and adherence to GFD (p=0.423) (Figure 3).

Factors associated with the adherence to GFD

Table 3 represents the factors that may be associated with the adherence to GFD. Participants who discussed GFD with a health care provider (e.g., dietitian) were more adherent to the GFD compared to those who did not (p=0.034) (Table 3). Patients who did not receive educational materials, such as starter packs, food list, educational brochure, etc., were more adherent to the GFD compared to those who did (p=0.010). More than half of the participants (66%) reported that they had never included a gluten food into their diet since they have been diagnosed with CD and they were more adherent to the GFD compared to those who reported daily, weekly, and monthly ingestion of gluten (p<0.001). Adequate adherence to GFD was observed in patients who found that GFD had a similar taste to non-gluten-free items compared to participants who had an unpleasant taste with GFD (p=0.043). Majority of the participants (88%) who adhered to GFD reported that they felt different after following GFD (p=0.003).

DISCUSSION

Different variables have been explored as factors influencing adherence to GFD, including knowledge of CD

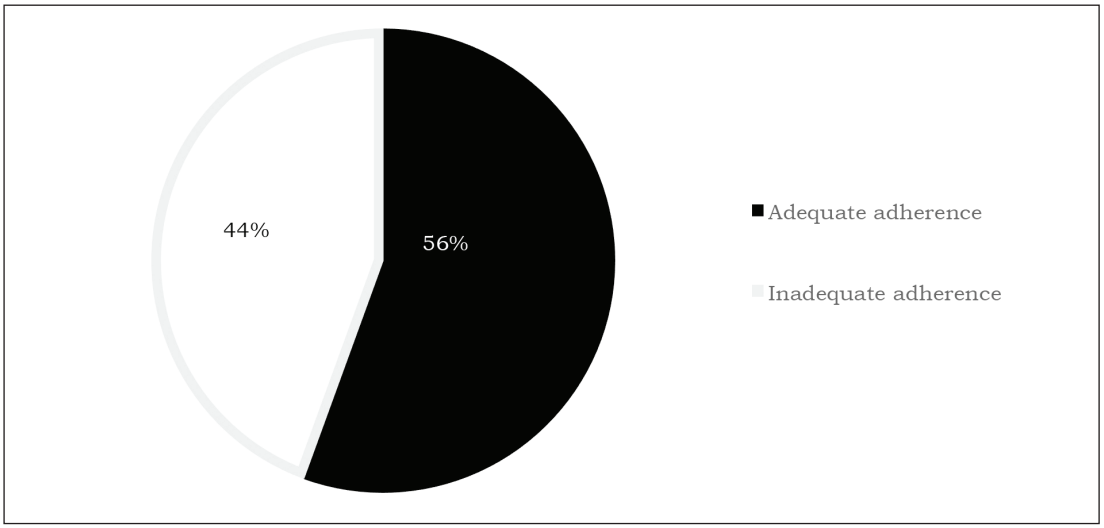

Figure 2. Adherence to gluten-free diet (GFD) using the coeliac disease adherence test (CDAT) in patients with coeliac disease (n=90). Adequate adherence to GFD was considered as CDAT scores ≤13 and inadequate adherence to GFD was considered as CADT scores >13.

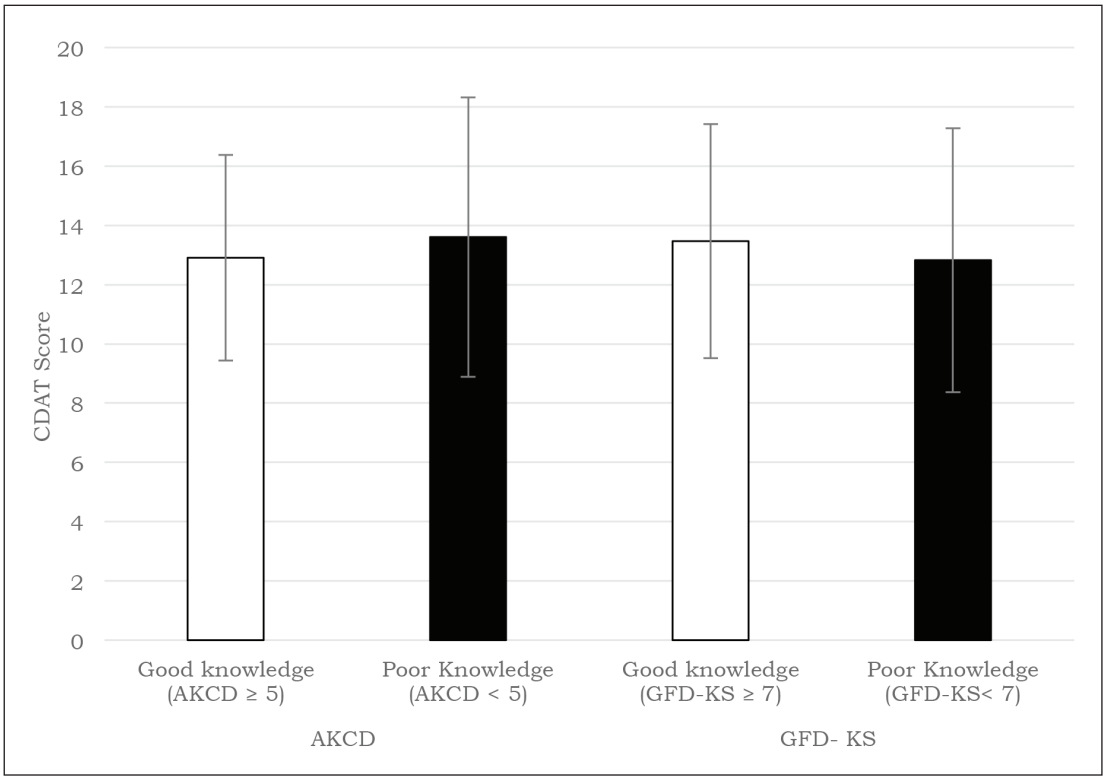

Figure 3. Associations between assessment of knowledge of coeliac disease (AKCD) and gluten-free diet knowledge scale (GFD-KS) with adherence to gluten-free Diet (CDAT) in patients with coeliac disease (*n*=90). Lower CDAT scores reflect higher adherence to a gluten-free diet (GFD). Results are presented as mean±*SD*.

and GFD (Abu-Janb & Jaana, 2020; Butterworth *et al.*, 2004; Kurppa *et al.*, 2012; Villafuerte-Galvez *et al.*, 2015). In this study, self-reported adherence to GFD was found in 50 adult patients with CD (56%), but no association was obtained between knowledge of CD and GFD with adherence to GFD. However, the present study indicated that other factors played a role in influencing the adherence to GFD in patients with CD such as discussing GFD with a specialist (registered dietitian), obtaining educational materials, perceived effectiveness of GFD, self-effectiveness (frequency of gluten ingestion), and the taste of GFD.

The current study found that study participants had adequate knowledge about CD (five points out of seven, 71%). On the other hand, the mean GFD-KS score was seven points out of 17 (41%), which was not different than other study (Silvester *et al.*, 2016). The knowledge of CD and GFD could be attributed to patients being a part of advocate or social support groups in which patients have the opportunity to frequently obtain information related to their condition, as the current study found that 63% of respondents were part of support groups or following advocate accounts though social media. In addition, the average duration of the disease among the study participants was five and a half years, which is considered as an adequate duration for a patient to be knowledgeable about the disease

Table 3. Factors that may influence the adherence to gluten-free diet in patients with coeliac disease (*n*=90)

Factors that may influence GFD adherence	*Factors that may influence GFD adherence*				*CDAT score (mean±SD)*		*p-value t-test*
	Yes		*No*		*Yes*	*No*	
	n	*%*	*n*	*%*			
At the time of your diagnosis, what was discussed at your consultation with your hospital doctor? †							
Explained what coeliac disease was	50	55.5	40	44.4	13.4±4.4	13.1±3.7	0.707
Told me to follow a strict gluten-free diet	59	65.5	31	34.4	13.1±3.8	13.1±4.7	0.616
Referred me to a dietitian	45	50.0	45	50.0	13.2±4.1	13.4±4.2	0.819
Arranged a follow-up appointment	31	34.4	59	65.5	13.9±4.2	13.3±4.1	0.919
Gave written information	17	18.8	73	81.1	12.6±1.0	13.4±0.5	0.538
Were you satisfied with the information given?	73	81.1	17	18.8	13.0±0.5	14.2±1.0	0.263
If you were referred to a dietitian, what advices were you given? †							
Explained the diagnosis and the reasons for the diet	34	37.7	56	62.2	12.6±0.7	13.7±0.5	0.199
Discussed a gluten-free diet	50	55.5	40	44.4	12.4±0.6	14.3±0.6	0.034
Provided an information pack (containing diet sheet, food list, starter packs)	41	45.5	49	54.4	14.5±4.1	12.2±3.9	0.010
Discussed the coeliac society and local groups	8	8.8	82	91.1	13.5±1.5	13.2±0.5	0.861
Discussed the prescribing of gluten-free products	24	26.6	66	73.3	13.6±0.8	13.1±0.5	0.677
A follow-up appointment was made	25	27.7	65	72.2	13.9±0.8	13.0±4.3	0.331
Given a contact telephone number for advice, if needed	7	7.7	83	92.2	13.0±1.7	13.3±0.6	0.904
Were you satisfied with the information given?	78	86.6	12	13.3	13.2±4.1	13.9±1.9	0.586
Do you think the dietician should play an important role in the long-term management of coeliac disease?	77	85.5	13	14.4	13.3±0.5	12.8±3.7	0.677
I'm a part of an online support group for coeliac patients?	57	63.3	33	36.6	12.8±0.5	14.0±0.7	0.176
How many times you include gluten food in your diet?							
Never	60	66.6			11.9±3.6		<0.001
Once a month	17	18.8			14.7±0.9		
Once a week	8	8.8			16.9±1.3		
Daily	5	5.5			18.6±1.6		
What are the difficulties you face when following gluten free diet? †							
I don't understand what foods I can and cannot eat	14	15.5	76	84.4	13.5±1.3	13.2±0.5	0.858
I don't have the time to prepare different meals	39	43.3	51	56.6	14.1±0.7	12.6±0.6	0.088
Gluten-free foods have an unpleasant taste	40	44.4	50	55.5	14.3±0.6	12.5±0.6	0.043
Gluten-free foods are expensive to buy	65	72.2	25	27.7	13.1±0.5	13.6±0.8	0.685
My General Practitioner does not prescribe sufficient amounts of gluten-free	17	18.8	73	81.1	14.6±1.0	12.9±0.5	0.173
I don't feel any different on a gluten-free diet	10	11.1	80	88.8	9.9±1.3	13.8±0.4	0.003
I don't understand the labelling on foods	10	11.1	80	88.8	14.9±1.1	13.0±4.0	0.146

†Participants were asked to choose more than one relevant answer.

and how to manage its symptoms by following the treatment. Not to mention that 79% of the study population had a consultation regarding GFD treatment from a dietitian. Additionally, majority of the respondents expressed satisfaction with the information they have received from both their primary physician and the dietitian.

A number of studies have assessed the adherence to GFD in children with CD in Saudi Arabia (Saadah, 2011; Safi, 2019; Sarkhy *et al.*, 2015). However, limited studies have assessed the adherence to GFD and its relation to knowledge on CD and GFD. More than 50% of the participants were adhering to GFD in this study. The prevalence of adherence to GFD varies in the literature, ranging from 42-91% (Hall *et al.*, 2009). The varying changes could be explained by the use of different methods in assessing adherence (serology versus self-reported) and the tools used to assess self-reported adherence to GFD. The result of the current study was not different than the literature. Knowledge on CD complications may be a factor that make patients understand the consequence of not adhering to GFD, which consequently improves the awareness and adherence to GFD. However, the current study did not observe any association between knowledge and adherence to GFD. This result was not consistent with a previous study conducted in Italy, which investigated the association between knowledge of CD and GFD with adherence to the diet in adults with CD (Paganizza *et al.*, 2019). The Italian study had no validated instrument for that purpose; the authors developed an instrument to assess the knowledge of CD and GFD via a collaboration between a gastroenterologist and a dietitian with expertise in GFD. The study found that knowledge of CD and GFD was strongly associated with adherence to GFD (Paganizza *et al.*, 2019). Possible reasons for the inconsistency in results between the current study and the Italian study were the sample size and the duration of the disease. Also, the average duration of the disease was 5 years in the current study compared to a duration of 10 years in the Italian study (Paganizza *et al.*, 2019).

Previous studies have explored various factors associated with the adherence to the GFD such as the taste and cost of GFD (Butterworth *et al.*, 2004; Kurppa *et al.*, 2012; Leffler *et al.*, 2008; Paganizza *et al.*, 2019; Villafuerte-Galvez *et al.*, 2015). Our findings were broadly consistent with other literature on self-effectiveness (the frequency of gluten ingestion) as a factor related to GFD among white Caucasian and South Asian patients (Butterworth *et al.*, 2004). Additional factors, such as the perceived effectiveness of GFD, was also indicated in previous study findings (Villafuerte-Galvez *et al.*, 2015). In addition, the unpleasant taste was observed to be a significant factor associated with a lower likelihood of following the GFD. This finding was reported in various studies in different countries; therefore, numerous studies have been conducted to enhance the taste of processed gluten-free products (Mazzeo *et al.*, 2014; Muhammad *et al.*, 2017; Padalino, Conte & Del Nobile, 2016). Furthermore, there was no significant positive association between the cost of GFD and adherence to GFD, as shown in a previous study (Villafuerte-Galvez *et al.*, 2015). Around 70% of the respondents reported that GF foods being expensive as one of the difficulties they faced when following GFD, but this did not influence their adherence to GFD.

The findings of the current study showed the influence of healthcare providers, especially registered dietitian on the adherence to GFD. Registered dietitians have remarkable responsibilities in teaching the gluten-

free diet to patients with CD, including reading food labels, cooking skills, and providing written materials. One unanticipated finding of the current study was that patients who did not receive educational materials about GFD, such as diet sheet, food list, starter packs, from their general practitioner were more adherent compared to those who did. This could be attributed to the influence of educational materials and sessions that were provided by the Coeliac Association (Paganizza *et al.*, 2019).

Two main limitations of the current study need to be reported. Firstly, majority of the patients were female. However, this limitation is overcame by the fact that CD is more common in females than males with an occurrence ratio of 2:1. Secondly, the serology test to assess adherence to GFD was not collected because majority of the participants did not follow-up with their primary physician for more than three to six months. Therefore, a serology test did not reflect the current adherence to GFD.

CONCLUSION

In conclusion, no association was found between knowledge of CD and GFD with the adherence to GFD among adult patients with CD. Factors influencing adherence to GFD were: discussing GFD with a specialist, obtaining educational materials, enhance symptoms associated with CD, and the taste of GFD. Further research is needed to explore other potential factors related to the adherence to GFD.

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Authors' contributions

Alorayyidh N, designed research, conducted research, led data collection, analysed data, wrote the manuscript; Alswaji MH, Almujammamy E & Alhujairy B, conducted research, collected the data, and wrote the first version of the manuscript; Benajiba N & Alzaben AS, led data collection, analysed data and data interpretation, assisted in drafting of the manuscript, reviewed the manuscript and supervised the whole study. All authors read and approved the final manuscript.

Conflict of interest

The authors declare no potential conflicts of interest.

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