

Level of Adherence to Gluten-free diet among Celiac Disease patients in Qassim region

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INTRODUCTION:

Celiac disease is an autoimmune disorder characterized by hypersensitivity to gluten, a protein found in certain foods like wheat and rye, in genetically susceptible individuals and leads to enteropathy and villous atrophy[1].The prevalence of celiac disease ranges from 0.15% to 2.67% by serologic testing with variation across different countries [2]. There are no published national statistics about the prevalence of CD in Saudi Arabia. However a recent study was conducted by Al Jabreen included a number of 1,167 of healthy adolescents in three different regions: Aseer , Al-Madinah, and Al-Qassim and concluded a seroprevalence of 2.2% [3] which correlate with other studies done in other countries. The only effective treatment for celiac disease is a lifelong adherence to gluten-free diet (GFD) [4]. A strict compliance to this diet can promise better results in the health-related quality of life and significant improvement in subsequent complications such as anemia[4] osteoporosis [5] and certain types of

lymphomas [6]. Many barriers can negatively affect the adherence of the participants to GFD. Availability of commercial GFD, cost and product labeling are major barriers to adherence to a Gluten-free diet [7]. For these different reasons, we intended to conduct this study to identify the different factors impacting the rate of adherence to GFD among CD participants in Saudi Arabia and the subsequent effect on their health.

OBJECTIVES OF THE STUDY:

- Measure the level of adherence to GFD among celiac disease participants and to identify possible causes of lack of commitment.

METHODOLOGY: A questionnaire was developed and administered to 161 patients, targeting special social media groups and Coeliac disease-related accounts. With the help of the 7-item CDAT tool we managed to develop a 25-item more concise form of questionnaire to assess the level of adherence and Identify various barriers.

STUDY DESIGN : A cross sectional study

Study Population: The population includes patients diagnosed with celiac disease in Qassim region.

STUDY SETTING: The study will be Twitter accounts and WhatsApp groups of celiac disease patients living in Qassim region.

INCLUSION CRITERIA: All celiac disease participants living in Qassim region regardless of their age, gender, ethnicity, or occupation.

SAMPLING TECHNIQUE: is a simple random sampling technique.

DATA COLLECTION: data will be collected using an online questionnaire, measuring both the level of adherence using the the 7-item (CDAT tool) and a 28-item questionnaire to study the various barriers for GFD adherence,made using Google

Forms website. the questionnaire will be distributed to celiac patient groups through social media.

ETHICAL REVIEW: The participants going to be aware of the study content and objective. The questionnaire distributed will be nameless, and the Responses will be confidential. Also, to be a part of our study will not be obligatory. we will start distributing the questionnaire after we get the Ethical approval from the regional ethical committee in Qassim.

DATA ANALYSIS: The statistical package for social science (SPSS) software is suggested to be utilized for statistical analysis.

STATISTICAL ANALYSIS :

Descriptive statistics were used to describe the baseline characteristics and various GFD related questions. All the responses were presented as frequencies and percentages.

Data analysis was performed using Statistical Package for Social Science (SPSS), version 20 (IBM, Armonk, NY, USA).

LIMITATIONS OF THE STUDY: adherence was not confirmed with concurrent histological evaluation. However it is not clear if biopsy provides a better assessment of long-term adherence than nutritionist evaluation

KEY WORDS : coeliac, Gluten-free, GFD, adherence, Qassim, barriers, GFD programs

RESULTS: This cross-sectional study included 161 participants from different areas of Saudi Arabia and was held to assess the level of knowledge and identify different barriers to the adherence to gluten-free diet among celiac disease patients. On our enquiry , Almost two thirds of the participants did not consume gluten-containing food in the past 2 months while 38 (24.2%) and 11 (7.0%) consumed it once and twice respectively. Majority of the participants (56.4%) received a proper training regarding gluten-free diet from a support group. Little more than one-third of patients (37.6%) did not receive any written literature or reference about GFD. In our sample 49 (30.8%)

respondents were high school graduate and 65 (40.9%) had Bachelor's or Master's degree. 39.1% participants discussed their disease with their families, 34.2% discussed

Characteristics	N	Valid %
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it with everybody while only 25.5% did not feel comfortable discussing their condition with anybody. Most of our participants 88.6% (n =140) live in owned houses, and Almost half of them (57.2%) report complete self dependence In terms of preparing and cooking their own food . (Table 1)

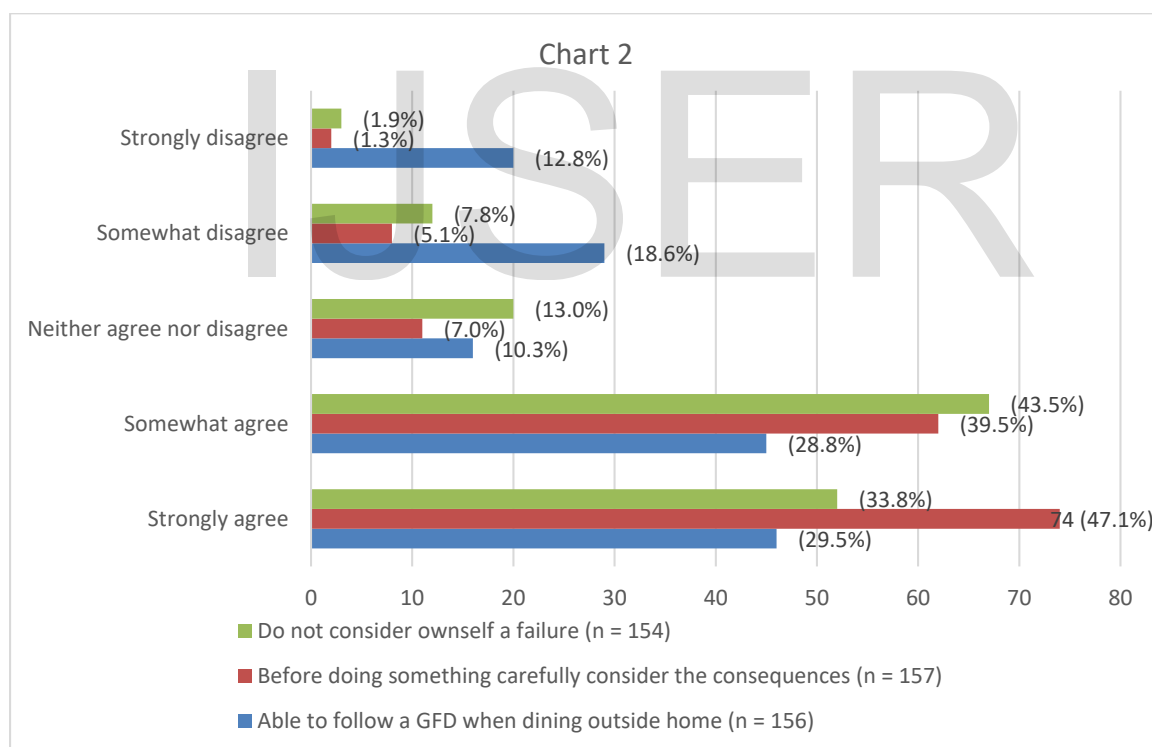
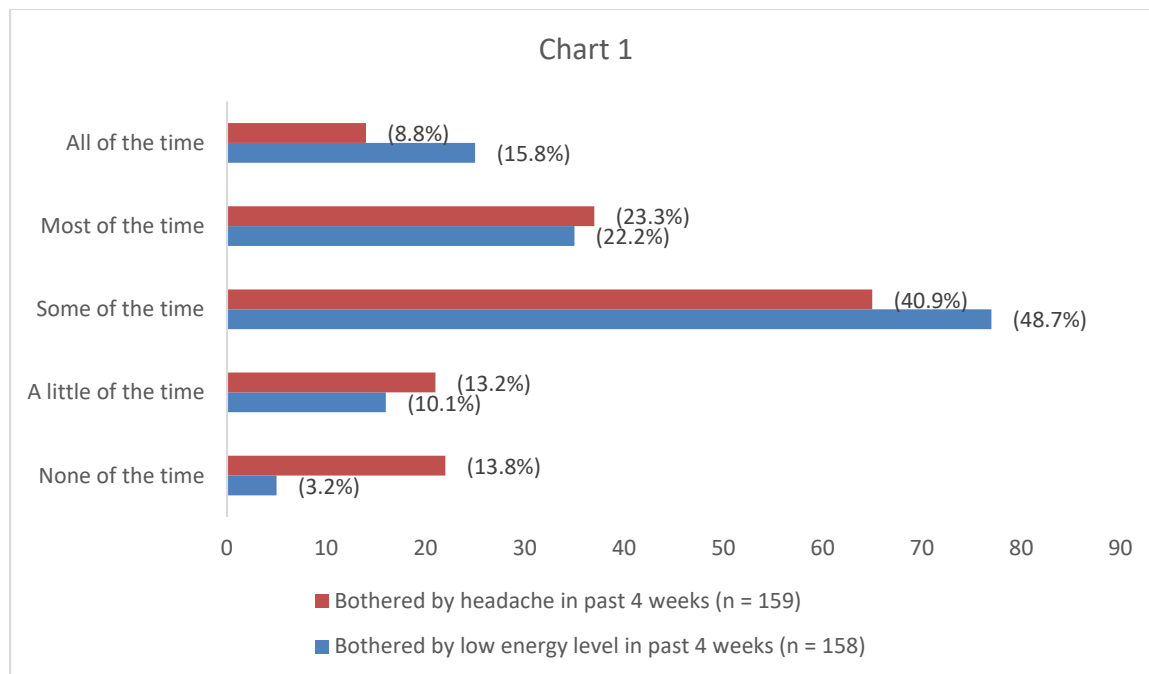
Table 1: GFD related different questions and various answers are expressed in frequencies and percentages.

Importance of health in accidental gluten exposure (n = 157)		
	104	65.8
Very important	31	19.6
Somewhat important	12	7.6
Neutral/unsure	9	5.7
A little important	2	1.3
Not at all important		
Number of times gluten containing food eaten in last 4 weeks (n = 157)		
	103	65.6
Never	38	24.2
Once	11	7.0
Twice	1	0.6
Thrice	4	2.5
Four times		
Trained about GFD by (n = 156)		
	19	12.2
Doctor	24	15.4
Internet/ web	88	56.4
Support group	10	6.4
Dietitian	15	9.6
Other sources		
Level of education (n = 159)		
	25	15.7
Primary school	17	10.7
Elementary school	49	30.8
High school graduate	65	40.9

Bachelor's/ Master's degree	3	1.9
No schooling completed		
Received any written literature/ reference (n = 157)	43	27.4
Diet chart	24	15.3
Do's and don'ts	31	19.7
Web information	59	37.6
Nothing		
Discussed your disease with (n = 159)	55	34.2
Everybody	63	39.1
Only family	41	25.5
Did not discuss		
Where stay (n = 158)	140	88.6
Home	16	10.1
Hostel	2	1.2
Others		
Who cooks food for you (n = 159)	54	34.0
Mother/ sister	3	1.9
Wife	11	6.9
Servant/ Maid	91	57.2
Self		

From where GFD is obtained (n = 159)	48	30.2
Self-grinding of gluten free cereals	43	27.0
Purchase GFD from market	68	42.8
Readymade gluten free flour		
Who purchases gluten purchase food for you (n = 158)	74	46.8
Family member	5	3.2
Home delivery	1	0.6
Servant/ Maid	78	49.4
Self		

While investigating possible symptoms contributing to the inadherence to GFD, 8.8% participants had episodes of headache almost always, 23.3% had episodes most of the time, 40.9% experienced them some of the time, 13.2% had fewer times and 13.8% reported no headaches. 77 (48.7%) participants reported to have felt low energy level sometimes in the past month, 35 (22.2%) felt it most of the time and 25 (15.8%) felt it all of the time. almost half of our participants are self-aware and considered health consequences prior to compromising their diet. 45 (28.8%) respondents somewhat agreed that they follow a GFD when dining outside and 46 (29.5%) strongly agreed it. (Chart 1 & 2)



almost all patients were convinced about GFD and its benefits and goals. 131 (83%) participants reported that GFD was difficult to find. Almost two-third of the participants (68%) reported that it is hard to know hidden gluten in purchased food. Most of the

participant reported that GFD does not taste good compared to regular food. 76% participants carried food to the workplace and 59% did not report feelings of embarrassment while eating their GFD at workplace. 74% reported that their adherence to GFD was compromised while dining outside their homes. Restaurants were avoided by 82% of the respondents and traveling was avoided by 52% of them. 87 (56%) felt like rejecting invitation for social gatherings. Almost half (52%) of participants shared their GFD with colleagues at least once. 99% of the respondents reported GFD was expensive. (Figure 1)

DISCUSSION:

in our study we concluded that GFD adherence is altered by many factors, including availability, ease of access, concern of cost, concern with accidental gluten exposure, perception of gluten-free diet and the willingness and capability to follow a GFD in places outside the patient's home. Many of our participants weren't content with the services provided to them by their health care team aimed at providing them with optimal help they need to manage coeliac disease and its consequences.

Regardless of the obvious evidence of poor adherence and anecdotal information about different barriers to the adherence to GFD, there is a huge gap in terms of published data regarding the factors that actually negatively influence GFD adherence. Only few studies acknowledged this issue and measured the level of adherence through self-report and/or questionnaires(10, 11, 12). However, these questionnaires weren't validated and self-reporting is reported to be inaccurate(13). Most of our participants reported difficulty knowing products ingredients that could possibly contain gluten owing possibly to improper labeling. The same problem was reported by a previous study in adults(16). Similarly, the high cost of GFD compared to regular gluten-containing food seems to be a common issue to coeliac disease patients world wide, several studies conducted in Europe and North America have reported the same issue (17,18,19)

A notable limitation to our study is that the adherence level was not confirmed with concurrent histological evaluation. However, prior studies showed a slight correlation of histology with clinical presentation or assessed dietary adherence(14,15)

This study has shed the light on clear areas of resistance that need to be enhanced and to facilitate future interventions to optimize the quality of life among CD patients. For example the fair percentage of individuals lacking proper knowledge about the disease, GFD, and/or their health-related consequences should urge the future implementation of educational programs aiming at filling all defects and answering every enquiry. Similarly, providing training to improve the ability to adhere to GFD when dining outside the home or when traveling is crucial and can tremendously enhance the patient's psychological and social functioning. Our future study will aim at confirming these associations and provide interventions capable of improving the patient's level of adherence.

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CONFLICT OF INTEREST : None declared

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