

ARTICLE



Barriers at various levels of human ecosystem for maintaining adherence to gluten free diet in adult patients with celiac disease

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INTRODUCTION: While lifelong and strict adherence to gluten-free diet (GFD) is essential for the successful treatment of celiac disease (CeD), only 30–50% of patients are able to maintain a good adherence to GFD. We determined factors influencing the adherence to GFD at various ecological levels including intra-personal, inter-personal, organizational, community and system-based levels in adult patients with CeD.

METHODS: A questionnaire to assess the adherence was developed and it was administered in the CeD clinic to patients with CeD on GFD for >1 year. Adherence to GFD was assessed in a subset of patients ($n = 320$) using Celiac Disease Adherence Test (CDAT).

RESULTS: Overall, 978 patients [median age: 29 years; females: 592] with CeD on GFD were recruited. They reported many barriers to adherence to GFD including *intra-personal barriers* such as lack of knowledge about GFD (19%), inadequate financial resources (27.2%) and lack of self-motivation/confidence (55.3%); *inter-personal barriers* such as intake of gluten-containing food upon forceful insistence of friends/family (23.4%); *organizational barriers* such as high cost (70.8%) and non-availability of GF-food products (48.6%); *community-based barriers* like consumption of gluten-containing food at religious occasions/festivals (11.1%) and social occasions (27.2%); and *system-based barriers* such as non-referral to dietitian for counseling (21.9%). As per CDAT, 204 (63.7%), 73(22.8%) and 43(13.4%) patients had good, average, and poor adherence to GFD, respectively. On multivariable analysis, occasional consumption of gluten, non-availability of GF-food while dining out and coercing by family and friends for consumption of GC-food were found to have highest odds for poor adherence to GFD.

CONCLUSIONS: Non-referral to a dietitian for counseling, irregular follow-up visits, unavailability of flour mill, non-supportive family/friends, high cost and limited availability of GF-food are the most common barriers to adherence to GFD. There is a need to create infrastructure and develop strategies to overcome these diverse barriers at various levels of ecosystem and thereby facilitate better adherence to GFD.

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INTRODUCTION

Celiac disease (CeD) is an immune-mediated enteropathy induced by dietary gluten in genetically susceptible individuals. The prevalence of CeD is increasing worldwide, making it one of the most common and lifelong food-related autoimmune disorders [1, 2]. Previously considered uncommon in Asia, CeD is now widely being recognized in the Middle East and in the Indian subcontinent, with prevalence equivalent to that of Western countries [3]. At present, strict adherence to gluten-free diet (GFD) is the only definitive and effective treatment for patients with CeD [2]. The adherence to GFD is not just a dietary-based intervention for controlling symptoms and for reversal and maintenance of pathophysiological abnormalities, but also requires behavioral change for adopting a gluten-free (GF) lifestyle. Owing to the ubiquitous nature of gluten, patients with CeD report multiple

challenges in maintaining the adherence to GFD in different arenas of their lives including schools, colleges, workplace, traveling, dining out of the home, or social functions [4]. In order to explore the challenges faced by patients with CeD in maintaining a good adherence to GFD, we need to understand the core facilities required such as knowledge and attitude, family support, financial status and affordability of additional cost of GF-food products, availability and quality of GF-food products and membership in Celiac Support Groups.

While multiple studies from across the globe have shown the rate of adherence to GFD in adult patients with CeD between 45 and 90% [5–10], very few have reported the barriers faced by patients in maintaining good adherence to GFD [4, 11–16]. Furthermore, only a few studies have reported the challenges faced by individuals with CeD in adhering to GFD at multiple

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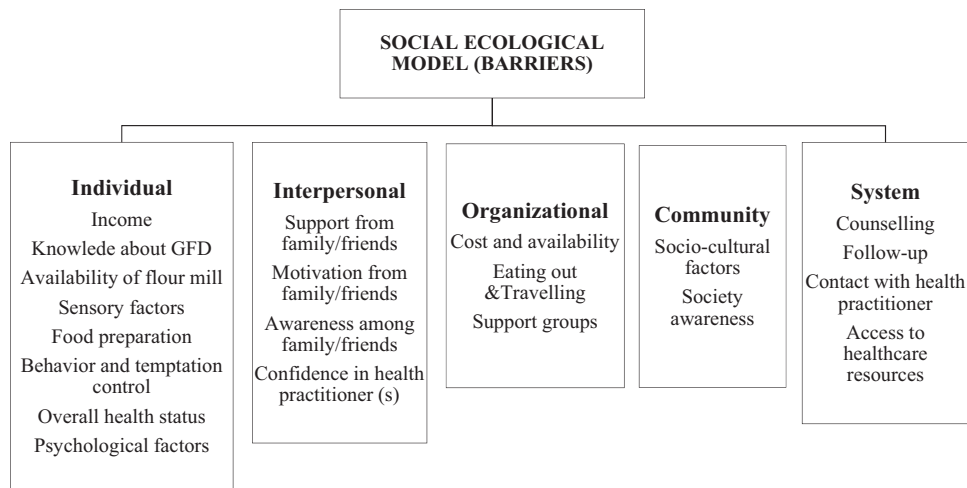


Fig. 1 Factors influencing adherence to gluten-free diet under different levels of Social-Ecological Model.

levels of ecosystem [17, 18]. One of them is a systematic review by Abu-Janb N, et al. which has described the barriers based on Social Ecological Model (SEM) [18]. The SEM covers five levels of network of integral relationship between an individual's health behavior and his/her environment such as intrapersonal level (e.g. knowledge, income, skills, attitudes, self-efficacy and self-confidence); the interpersonal level (e.g. family, spouse, in-laws, parenting and personal relationships, peer pressure/support, motivation from others); the community level (e.g. social network, cultural factors, and workplace settings); the organizational level (e.g. food environment, service, community and recreational facilities) and the system level (e.g. hospital care, adequacy of dietary counseling, evaluation on follow up and re-counseling, educational resources, quality of GF food products, food supply-chain, labeling of food items, financial support, and taxation) [19, 20].

With a burden of 1% of population having CeD [21], and a large number of patients following GFD, it is thus essential for health professionals, regulatory bodies and the food industry to understand the challenges faced by patients with CeD. Since there is a paucity of detailed data on the barriers to maintenance of adherence to GFD from Asia, we conducted a questionnaire-based survey to assess the barriers faced by adult patients with CeD in maintaining good adherence to GFD at various levels of ecological system.

PATIENTS AND METHODS

The present observational study was conducted at our institute between January 2021 and August 2022. The study was approved by the Ethics Committee of the institute

Development of the study questionnaire

An exhaustive review of current literature was carried out to identify the existing evidences on the factors affecting adherence to GFD in adult patients with CeD across the globe. Further, six sessions of group discussion with an expert panel consisting of three gastroenterologists (AA, AC, GM), four dieticians (WM, AB, NS, AM), one-hundred and twenty adult patients with CeD (females – 68 (56.7%)) and their family members were conducted to discuss the factors influencing the adherence to GFD at multiple levels of ecosystem (intrapersonal, interpersonal, community, organizational and system). After a detailed review of literature and group discussions with expert panel, the following domains (Fig. 1) were identified under five levels of SEM and a bank of questionnaire items was developed. The final questionnaire consisted of 72 questions, with 10 questions in demographics section and 62 questions relating to the domains selected (Supplementary table 1). Kuppaswamy scale 2020 was used for assessing the socio-economic status (SES) of the participants [22].

Administration of questionnaire

Prior to survey distribution, the questionnaire was administered to a group of 15 patients for pilot testing and was subsequently modified for removing the discrepancies and for providing more clarity to the respondents. The patients registered in the Celiac Clinic were reviewed and eligible participants were contacted through phone call or electronic-mail. The questionnaire was administered in a face-to-face interview to those who agreed or were scheduled for a follow-up visit in the Celiac Clinic. For others not agreeing to visit the clinic, detailed interview of patients and their close relatives were conducted telephonically and the responses were recorded in the questionnaire sheet.

The inclusion criteria were – a definite diagnosis of CeD as per standard guidelines and those who were following GFD for more than 1 year. Recruited participants were adults (age range: 19–55 years), having no other diet related disorder and any associated co-morbid illness (e.g., liver cirrhosis, inflammatory bowel disease, cardiovascular disease, any type of cancer, etc.). Eligible patients volunteering to participate in the study signed the consent form and were provided with written information sheet about the study conducted.

Adherence to gluten-free diet

The adherence to GFD was also assessed in a subset of patients ($n = 320$) using a standardized tool named "Celiac disease adherence test (CDAT)". CDAT is a 7-item questionnaire, having five responses, with score ranging from 1 to 5. Scores of less than 13 are associated with good GFD adherence, 13–17 with average and greater than 17 are associated with poor GFD adherence [23].

Statistical analysis

The data are presented as median, inter-quartile range (IQR), proportions and percentages as appropriate. The frequencies and descriptive statistics were examined for each variable. Univariate and multivariate logistic regression analysis was conducted to identify factors affecting adherence to GFD and to assess barriers which influenced the adherence independently from each other, respectively. Relevant tests of factor analysis (KMO test, Bartlett's Test of Sphericity, principal component analysis (PCA), varimax rotation with Kaiser normalization) were conducted to confirm the domains included in the questionnaire. A p-value less than 0.05 is taken as statistically significant. Statistical analysis has been performed using Software Program Stata System (SPSS) v20.0 (SPSS Inc., IBM Corporation, Chicago, Illinois).

RESULTS

Nine hundred and seventy-eight patients with CeD following GFD for more than 1 year with median age of 32 years (IQR: 20–41 years, female: 60.5%) were included in this study. More than half of the patients ($n = 510$, 52.1%) were following GFD for 1–5 years and around one-third ($n = 296$, 30.3%) of patients belonged to

Table 1. Socio-demographic characteristics of patients with CeD.

Socio-demographic characteristics		n (%)
Gender	Male	386 (39.5%)
	Female	592 (60.5%)
Follow-up since diagnosis of CeD	1–5 years	510 (52.1%)
	5.1–10 years	273 (28%)
	10.1–15 years	138 (14.1%)
	>15.1 years	57 (5.8%)
Marital status	Married	748 (76.4%)
	Unmarried	230 (23.5%)
Family history of CeD		169 (17.3%)
First degree relatives	Father	11 (1.1%)
	Mother	35 (3.5%)
	Brother	22 (2.2%)
	Sister	38 (3.8%)
	Son	13 (1.3%)
	Daughter	30 (3.1%)
Other relatives		20 (2.0%)
Educational qualification	Professional or postgraduate	208 (21.3%)
	Graduate	405 (41.4%)
	Intermediate or diploma	192 (19.6%)
	High school	103 (10.5%)
	Middle school	32 (3.3%)
	Primary school	12 (1.2%)
	No formal education	26 (2.6%)
Socio-economic status	Upper	81 (8.3%)
	Upper middle	219 (22.4%)
	Lower middle	296 (30.3%)
	Upper lower	204 (20.8%)
	Lower	178 (18.2%)

lower-middle income group as per the Kuppuswamy scale. One hundred and sixty-nine (17.3%) patients had a family history of CeD with a predominance of female relatives (mothers: 20.7%, sisters: 22.5%, and daughters: 17.7%) (Table 1).

Barriers to adherence to GFD

Intra-personal level. At the intra-personal or individual level, income, knowledge about GFD, availability of flour mill, sensory factors, food preparation and behavior and temptation control were the main factors related to adherence to GFD in adult patients with CeD (Table 2).

Other factors influencing adherence to GFD at intrapersonal level included overall health status and psychological factors.

Overall health status: While on one hand, 195 (20%) and 109 (11.1%) patients suffered moderate and severe weight loss, respectively, on the other hand 353 (36.1%) and 188 (19.2%) patients reported moderate and excessive weight gain. Further, 133 (13.6%) patients reported no change in weight after following GFD. Approximately, 207 (21.2%) patients reported moderate to severe decrease in appetite while 544 (55.6%) patients reported moderate to severe increase in appetite. Also, 227 (23.2%) patients reported no change in appetite after following the GFD.

Psychological factors: Overall, 394 (40.3%) patients believed that they were making mistakes in their dietary choices and were not

following the GFD properly while 541 (55.3%) patients were not self-willing and self-motivated to follow the GFD strictly. Further, 231 (23.6%) patients felt that they had lost their self-esteem due to the disease itself and the extra efforts required to maintain the special dietary needs whereas 480 (49.1%) patients felt no change in their self-confidence while on GFD. Furthermore, 304 (31.1%) patients felt embarrassed in refusing food at religious places/marriages/festivals/birthdays, etc.

Inter-personal level. At the inter-personal level, support and motivation from friends/family, awareness among friends/family and confidence in health practitioner(s) were the main factors found to be influencing adherence to GFD in adult patients with CeD (Table 3).

Community level. At the community level, socio-cultural factors and lack of awareness in the society about CeD and its treatment were major factors which were impediment to maintenance of appropriate adherence to GFD.

Socio-cultural factors: Amongst all, 65 (6.6%) patients with CeD admitted eating GC "religious offerings (prashad, often made up of wheat)" at religious places because they could not refuse. Religious offering is considered very sacred in India, and further, 109 (11.1%) and 266 (27.2%) patients admitted consuming GC-food items at religious occasions/festivals and social occasions such as marriages, birthdays etc., respectively. Seventy-eight (7.9%) patients reported that they had to consume GC-food items because of forceful insistence by relatives and friends.

Lack of awareness about the disease in the society: Overall, 267 (27.3%) patients reported that their relatives were unaware about CeD while 419 (42.8%) patients mentioned that their relatives did not understand the consequences of eating gluten despite knowing about their disease.

Organizational level. At the organizational level, cost and availability of GFD, eating out and traveling and membership to the Celiac Support Groups were the main factors related to adherence to GFD in adult patients with CeD (Table 4).

System level. At the system level, counseling for GFD, facilitation of follow-up visits, contact with health practitioner(s) and access to healthcare resources were main factors influencing adherence to GFD in patients with CeD (Table 4).

Rate of adherence to GFD. The adherence to GFD was assessed via Celiac Disease Adherence Test (CDAT) in a subset of patients ($n = 320$). Based on the scores of CDAT, 204 (63.7%), 73 (22.8%) and 43 (13.4%) patients were found to have good, average, and poor adherence to GFD, respectively.

Factors affecting adherence to GFD

Univariate logistic regression: On univariate logistic regression analysis, the rates of non-adherence to GFD were high (CDAT score >17) in those patients with CeD who considered occasional intake of gluten as normal and those who were forced by family members, spouse, friends, and colleagues to eat GC-food at multiple occasions and social events (Odds ratio (OR) >5) (Table 5). The odds of poor or average adherence to GFD were also higher among those who considered GF-foods to be expensive, faced non-availability of GF-food while dining out, and traveling, etc. and who were not counseled by a dietitian (Table 5).

Multivariate logistic regression: Since it is probable that some barriers cluster in the same individuals and have overlapping relations with the adherence to the GFD, a multivariate logistic

Table 2. Intra-personal factors influencing adherence to GFD in adult patients with CeD.

Theme	Sub-theme	n (%)	95% Confidence interval
Income	Income did not support their diet	266 (27.2%)	24.4%–30.1%
	Takes financial help to procure GF-food products	81 (8.3%)	6.6%–10.2%
Knowledge about GFD	Not reading food labels before purchasing/consuming	546 (55.8%)	52.6%–58.9%
	Not able to differentiate between GF and GC-food despite reading the food label	353 (36.1%)	33.1%–39.2%
	Believes GFD can be stopped once symptoms have subsided, or serological or histological parameters have come to normal	186 (19%)	16.6% - 21.6%
	Considers occasional intake of gluten as normal	261 (26.7%)	23.9%–29.6%
Availability of flour mill	Non-availability of separate and dedicated GF flour mill	441 (45.1%)	41.2%–48.3%
	Purchase of GF flour from regular wheat-based flour mill	228 (23.3%)	20.7%–26.1%
Sensory characteristics	Dislikes taste of GF-food	264 (26.9%)	24.2%–29.9%
	Dislikes mouth-feel of GF-food	217 (22.2%)	19.6%–24.9%
Food preparation	Finds cooking of GF-food difficult	206 (21.1%)	18.5%–23.8%
	Considers cooking of GF-food as a burden	148 (15.1%)	12.9%–17.5%
	Limited food choices	470 (48.1%)	44.9%–51.2%
Behavior and temptation control	Unable to control temptation and consume GC food during family gatherings/ marriages/ Socials	440 (45%)	41.8%–48.2%
	Feels depressed for not being able to consume favorite GC foods at social gatherings	234 (24%)	21.3%–26.7%
	Temptation/ depression makes them consume GC foods secretly	128 (13.1%)	11%–15.4%

GF gluten free, GC gluten containing.

regression was also performed to assess which barriers influence the adherence independently from each other. The R-squared for overall model obtained from multivariate analysis was 0.74 which shows a high level of correlation between the adherence and the barriers to GFD. Through this model, we identified some other barriers to GFD (OR > 3) in addition to those obtained from univariate analysis. The odds of poor adherence to GFD were also high among patients who had lack of provision of detailed list of dietary do's and don'ts, non-membership in celiac support groups and among those whose family members were non-counseled for GFD (Table 5). The other factors obtained were similar to those obtained from univariate analysis.

Factor analysis. We also conducted factor analysis to see if all the barriers explored could be reduced to few factors. The data was found to be appropriate for conducting factor analysis (KMO value = 0.861; Bartlett's test of sphericity, $p < 0.01$) suggesting proportion of variance and interrelationship among variables that might be due to various underlying factors. We conducted factor analysis under each ecological level as well as for the overall questionnaire (Table 6). Although, the overall questionnaire consisted of twenty separate domains which were initially postulated, but after PCA, nine different factors were extracted (eigenvalues > 1) with a cumulative variance of 68.6% (Table 6) and a different combination of items. Variables were loaded into extracted factors using varimax rotation with Kaiser Normalization, obtaining a component loading of greater than 0.50 for each variable. The expert panel reviewed the factors identified and by consensus renamed them based on their clinical features: 1) Socio-cultural factors, 2) Financial factors and purchasing power, 3) Psychological and behavioral factors, 4) Counseling of GFD and post treatment care, 5) Access to healthcare system, 6) Availability of GFD while eating out and traveling, 7) Awareness about the disease and treatment, 8) Support from friends/ family members and 9) Miscellaneous other factors.

However, the results are presented based on the initial domains postulated under each ecological level.

DISCUSSION

Non-adherence to GFD is considered as one of the major significant obstacles in the successful treatment of CeD. Since CeD is relatively a new disease, the awareness about the disease amongst health-care professionals and patients varies from country to country. Unlike treatment of many other diseases, the only treatment of CeD is strict dietary restriction, however the delivery of dietary treatment is very heterogenous. Successful institution of GFD requires proper infrastructure having well informed patients, celiac expert dietician, availability of affordable and wide varieties of GF-food, knowledge about and use of naturally GF grains, appropriate supply chain of GF-food closer to patients living, labeling of GF-food items, and quality assurance etc. However, availability of such infrastructure is not uniform, and varies from region to region. Non-availability of adequate infrastructure acts as an impediment in the adherence to GFD. While prescribing a GFD is easy, it is extremely challenging for patients with CeD to maintain a strict and prolonged adherence to GFD.

The present study is the first known quantitative survey to assess the challenges faced by adult patients with CeD in adhering to GFD, at different domains of human ecosystem including intrapersonal, interpersonal, organizational, community, and system level. At the intrapersonal level, at least one-fourth patients reported that their income did not support their diet and around 10% of patients had to take financial help to buy GF-food items. Studies from Iran [24] and United Kingdom [25, 26] also reports higher cost of living for patients on GFD. Further, around one-fourth of patients considered occasional intake of gluten as acceptable, hence a better understanding of adverse outcomes of gluten consumption amongst CeD patients is likely to impact the adequacy of adherence to GFD [27].

At the intrapersonal level, a home-based separate flour mill was not available to 45% of patients. Patients with low income rely on grinding naturally occurring GF grains using home-based mills. Non-availability of home-based flour mills compels them to get these grains grinded at the commercial mills where they ground

Table 3. Factors influencing adherence to GFD in adult patients with CeD at inter-personal level.

Theme	Sub-theme	n (%)	95% Confidence interval
Support from friends/family	Number of family members/siblings affect the diet	158 (16.2%)	13.9%–18.6%
	Family members/spouse force to eat GC foods	178 (18.1%)	15.8%–20.8%
	Friends/colleagues force to eat GC foods	229 (23.4%)	20.8%–26.2%
	In-laws are unaware of the special dietary needs	97 (12.9%)	8.1%–11.9%
	In-laws do not support the special dietary needs	598 (20.1%)	58%–64.2%
Motivation from friends/family	Friends/family does not motivate them to follow GFD	283 (28.9%)	26.1%–31.9%
Awareness among friends/family	Friends/family are unaware about CeD	171 (17.5%)	15.2%–20%
	Friends/family are unaware about consequences of eating gluten	325 (33.2%)	30.3%–36.3%
Confidence in health practitioner(s)	Not confident in their respective gastroenterologists for getting the right treatment	103 (10.5%)	8.7%–12.6%
	Not confident in their dietitian for providing the adequate counseling and guidance	97 (14.1%)	8.1%–11.9%

GFD gluten free diet, GC gluten containing, CeD celiac disease.

all kinds of grains, and hence exposing GF-flour to gluten contamination. Among the psychological and behavioral factors, more than half of patients were non-motivated to follow GFD, one-fourth of patients lost their self-esteem due to the disease and about one-fourth of them were depressed because of their inability to consume GC-food served at social functions (GF-food items are most often not served at such occasions). Furthermore, depression and anxiety in patients with CeD have been associated with reduced adherence to GFD [15, 28–30]. The findings of the present study along with data from previous studies suggest that psychological support should be an integral part of counseling of patients with CeD in order to enhance adherence to GFD.

At the interpersonal level, approximately 20% of patients with CeD reported lack of awareness about their disease amongst family/friends and non-supportive in-laws. In the present study, forceful consumption of GC-food upon insistence of family/friends has also been reported as a major factor for poor adherence to GFD. High level of support from family and friends lowers the risk of isolation and feeling of being alienated, thereby, improving the adherence to GFD [4, 16, 31]. Thus, it is important to counsel both the patient and their family members to make them understand about the importance of GFD for patients with CeD.

At the organizational level, more than half of patients in the present study reported GF-food products to be expensive and unavailable in markets/stores, leading to consumption of GC-food products by approximately 10% of patients. Studies from Italy [32], Australia [33], Austria [34], Brazil [35], Canada [36], Chile [37], Greece [38] and USA [39] stand in consonance with the observation of the present study that GF-foods are expensive than their GC-counterparts. Limited ability to afford GF-food has been associated with poor adherence to GFD as reported from studies from many Western countries [15, 16, 40]. Interestingly, around three-fourth (77%) patients of the present study expressed their concern towards non-supportive restaurant staff in catering GF-foods while around one-third and one-fourth of patients mentioned their inability to find GF-food while dining out and traveling, respectively. Having better access to GF-food products while eating out or shopping leads to increased adherence to GFD [11, 41]. Thus, there is a need to spread awareness about cooking of GF-food among restaurant chefs and the general public in order to ensure safe supply of GF-food in public eateries. Further, one-third patients of the present study reported non-membership in Celiac Support Groups. Membership in Celiac Support Groups results in increased likelihood of adhering to GFD [4, 26]. These Celiac Support Groups allow patients to get connected with experienced patients, which allow them to share their personal

experiences, sharing of coping strategies, GF recipes, safe shopping of GF products, and safe dining out places, etc.

At the system level, more than one-fifth of patients in the present study were not referred to a dietitian for counseling, and around one-third of patients started GFD without any counseling by a dietitian. Another study from USA also reported non-referral to a dietitian for counseling and difficulty in finding a celiac specialist dietitian in 21% and 40% of patients, respectively [42]. Further, more than 50% of patients in the present study reported irregular follow-up visits with both physician and dietitian and no contact details of their concerned healthcare provider. Other studies from USA [42], Australia [43] and Olmsted county [44] have also reported irregularity in follow-up visits after first counseling. Getting counseled by a celiac expert dietitian, having access to a health-care practitioner in case of emergencies and regular follow-up with a dietitian has been positively correlated with better adherence to GFD [26, 41]. Also, more than one-third of patients in the present study were not given any detailed GFD chart. Provision of detailed description of CeD, treatment, GFD and its benefits to newly diagnosed patients allows them to follow GFD accurately [18].

In the present study, specific factors responsible for poor adherence to GFD were also identified through regression analysis which included occasional consumption of gluten, forceful intake of gluten through family members, spouse, friends, and colleagues to eat GC-food at multiple occasions and social events, considering GF-foods to be expensive, non-availability of GF-food while dining out and traveling, non-counseling of GFD by a dietitian, lack of provision of detailed list of dietary do's and don'ts and non-membership in celiac support groups.

The factors or domains identified from factor analysis including socio-cultural factors, financial factors and purchasing power, psychological and behavioral factors, counseling of GFD and post treatment care, access to healthcare system, availability of GFD while eating out and traveling, awareness about the disease and treatment, support from friends/ family members and miscellaneous other factors are wholesome and includes all aspects of human ecosystem.

The strengths of the present study include development of the questionnaire based on extensive review of the relevant literature and multiple group meetings including patients, inclusion of relatively large number of patients with experience of challenges faced over a prolonged period of time, involvement of patients with various socioeconomic statuses and administration of the questionnaire by a celiac expert dietitian in face-to-face interview setting. To the best of our knowledge, the present study is the first quantitative survey to look at the challenges faced by patients

Table 4. Organizational and system level factors influencing adherence to GFD in adult patients with CeD.

Ecological level	Theme	Sub-theme	n (%)	95% Confidence interval	
Organizational level	Cost and availability	GF-foods are expensive	693 (70.8%)	67.9%–73.7%	
		Cost of GF-food limits regular purchase	461 (47.1%)	44%–50.3%	
		Purchase uncertified and less expensive GF-food because of high cost of certified GF-food	67 (6.8%)	5.3%–8.6%	
		Lack of knowledge about the stores/places where GF-food products are available	363 (37.1%)	34.1%–40.2%	
System level	Eating out and traveling	Improper supply chain of GF-food and scarce availability	475 (48.6%)	45.4%–51.7%	
		Non-availability of varieties of GF-food creates monotony in diet and hence consume GC-foods at occasions	79 (8.1%)	6.4%–10%	
		Non-supportive restaurant staff in catering GF-food	753 (76.9%)	74.2%–79.6%	
		Unable to procure GF-food while dining-out	324 (33.1%)	30.2%–36.2%	
	Support Groups	Counseling for GFD	Unable to procure GF-food while traveling	265 (27.1%)	24.3%–30%
			Non-membership in Celiac Support Groups	322 (32.9%)	30%–40%
	Facilitation of follow-up visits	Contact with health practitioner	Non-referral to a dietitian	215 (21.9%)	19.4%–24.7%
			Not counseled by a dietitian	289 (29.5%)	26.7%–32.5%
			Non-counseling of Family members	539 (55.1%)	51.9%–58.3%
			Irregular follow-up visits with doctor	560 (57.2%)	54.1%–60.4%
Access to healthcare resources	Access to healthcare resources	Irregular follow-up visits with dietitian	499 (51.1%)	47.8%–54.2%	
		Unable to get appointment for follow-up visits	260 (26.6%)	23.8%–29.5%	
		No contact details of concerned physician/ gastroenterologist	517 (52.8%)	49.7%–56%	
		No contact details of concerned dietitian	431 (44.1%)	41%–47.2%	
		Detailed diet chart, What to eat and what not, not provided	360 (36.8%)	33.8%–39.9%	
		Educational material to learn about CeD and GFD not provided	870 (88.9%)	86.8%–90.8%	

GF gluten free, GC gluten containing, CeD celiac disease.

Table 5. Factors affecting the adherence to gluten-free diet based on univariate and multivariate logistic regression.

Variables	Univariate logistic regression		Multivariate logistic regression	
	Odds ratio (95% Confidence interval)	P value	Odds ratio (95% Confidence interval)	P value
Considers occasional intake of gluten as normal	7.1 (3.6–15.7)	0.001	6.2 (2.7–13.8)	0.002
Non-availability of home-based small flour mill	3.2 (1.3–6.8)	0.04	3.5 (1.4–7.2)	0.006
Detailed diet chart, what to eat and what not, not provided	–	–	4.1 (1.8–8.9)	0.03
Temped to eat GC-food during family gatherings/ marriages/ parties	5.8 (2.1–9.8)	0.02	4.7 (2.1–10.7)	0.01
Non-membership in Celiac Support Groups	–	–	3.3 (1.3–8.4)	0.04
Forced to consume GC-food by the family members/ spouse	5.6 (2.01–10.2)	0.03	–	–
Forced to consume GC-food by friends/ colleagues	6.1 (3.1–16.2)	0.01	5.8 (2.6–12.9)	<0.001
Non-counseling of family members	–	–	3.9 (1.9–7.8)	0.04
Inability to procure GF-food while dining-out	6.8 (2.9–12.7)	0.001	5.1 (2.1–10.1)	0.02
Inability to procure GF-food while traveling	2.3 (1.4–4.5)	0.04	–	–
Improper supply chain of GF-food and scarce availability	3.9 (1.5–6.3)	0.03	4.3 (1.7–9.4)	<0.001
Non-counseling by a dietitian	2.8 (1.1–3.9)	0.01	–	–

Only those factors are mentioned which have OR > 2.

Table 6. Factor analysis.

Ecological level	Total no. of factors obtained (with eigenvalues > 1)	Cumulative % of variance contributed by extracted factors
Intra-personal	4	64.7%
Interpersonal	2	62.8%
Organizational	2	67.1%
Community	1	59.3%
System	2	67.5%
Overall questionnaire	9	68.6%

with CeD in adhering to GFD, at different levels of ecosystem. The outcome of the present study is limited by lack of validation of the questionnaire developed by us. Also, the barriers explored by the questionnaire have not been analyzed in relation to hard clinical outcomes including anti-tTG antibodies or symptoms. Further, every country/region have their own social structure and challenges, and thus, region and country specific barriers have not been addressed in the present study.

In conclusion, the present study indicates multiple barriers to the adherence of GF lifestyle at all levels of human ecosystem. Non-referral to a dietitian for counseling, lack of knowledge about GFD, irregular follow-up visits, lack of self-motivation, non-supportive family/friends, high cost and decreased availability of GF-food, non-provision of educational material to learn about GFD and non-membership in celiac support groups are the most common barriers to adherence to GFD. Forceful consumption of GC-food upon insistence of family/friends has been reported as a major factor for poor adherence to GFD. There is a need to create infrastructure for removal of these barriers at various levels of ecosystem for a better adherence to GFD by patients with CeD. At the governmental and societal level, gluten appropriate policies should be adopted for the overall improvement in the adherence to GFD.

DATA AVAILABILITY

The data generated and analyzed during this study can be found within the published article, or from the corresponding author on reasonable request.

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AUTHOR CONTRIBUTIONS

WM: Review of literature, questionnaire development, data collection, data analysis, drafting of manuscript; **AA:** Review of literature, questionnaire development, data proofing, critical review of the paper; **AC:** Review of literature, questionnaire development, critical review of the paper; **SA:** Data analysis; **AS:** Data proofing, data analysis, critical review of the paper; **AA:** Data collection, data proofing; **AB:** Questionnaire development, data proofing, critical review of the paper; **NS:** Questionnaire development, critical review of the paper; **VA:** Critical review of the paper; **AM:** Questionnaire development, study supervision, critical review of the paper; **GKM:** Overall guarantor of the paper, designed the study concept, study supervision, data analysis, and finalization of the paper. All authors revised and approved the final version.

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The authors declare no competing interests.

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