

National survey on the experiences of people with celiac disease in Spain. The CELIAC-SPAIN project

Francesc Casellas¹, Federico Argüelles², Rosa Burgos³ and María van der Hofstadt Rovira⁴

¹Gastroenterology Department. Hospital Universitari Vall d'Hebron. Barcelona, Spain. ²Gastroenterology Department. Hospital Universitario Virgen Macarena. Sevilla, Spain. ³Nutritional Support Unit. Hospital Universitari Vall d'Hebron. Barcelona, Spain. ⁴Research Area, Food Quality and Safety Department. Federación de Asociaciones de Celíacos de España, FACE

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Correspondence: Francesc Casellas. Gastroenterology Department. Hospital Universitari Vall d'Hebron. Passeig de la Vall d'Hebron 119. 08035 Barcelona, Spain. e-mail: fcasellas@vhebron.net

ABSTRACT

Introduction: coeliac disease (CD) is well known, but not so its impact on the patient's life.

Objective: to determine the impact of CD in the life of celiac patients on different aspects such as diagnosis, follow-up and treatment.

Material and methods: associates of FACE participated in an auto-administered, telematic survey conducted between May and July, 2019. Three participant profiles have been defined: adults diagnosed in adulthood, adults diagnosed in childhood and parents/guardians of celiac children.

Results: 540 surveys (343 adult celiacs, 58 celiacs from children and 139 parents/guardians) from all autonomous communities have been included. In the diagnostic process highlights the diagnostic delay (up to 2 years) and the limitations to screening of family members. After diagnosis, about 20 % of adults do not refer to follow any control. Having a CD generates different reactions, but concern and quality of life limitation are very common. As for the gluten-free diet, 90 % of patients referred good adherence to treatment, which is accompanied by improved symptoms and weight gain. Diet tracking limits patients' daily lives. Gluten-free manufactured products are considered expensive, with unclear and unappealing labeling.

Conclusions: the results of the "CELIAC-SPAIN" project show that there are still many aspects to be improved in CD, both diagnosis and follow-up and in facilitating access to gluten-free products.

Keywords: Celiac disease. Impact. Epidemiology. Relatives. Survey. Gluten-free diet.

Conflict of interest: This survey was fostered by the Sociedad Española de Patología Digestiva together with the Federación de Asociaciones de Celíacos de España. The authors declare no conflicts of interest concerning this project.

INTRODUCTION

The prevalence and epidemiology of celiac disease (CeD) in our setting has been thoroughly studied (1-5). However, available information on the impact of CeD on health and daily living remains sparse. Numerous studies discuss the fact that celiac patients report a significant impairment in health-related quality of life, particularly those who have symptoms or fail to adequately adhere to a gluten-free diet. Furthermore, strict adherence to such diet improves symptoms and quality of life scores (6,7). However, correctly complying with gluten exclusion from the diet is challenging, and absence of alternatives limits quality of life for celiac patients (8). In the pediatric population the impact on quality of life seems less relevant than in adults, at least according to patient perception since parents do consider important the condition's effects (9,10).

A recent project promoted by the Spanish Ombudsman provided relevant data on the impact of CeD (11), particularly regarding treatment-related issues, diet adherence, guidelines, awareness raising in sectors such as the food-restaurant industry, costs, etc. Of the multiple recommendations included in that document we wish to highlight two that are directly related to the grounds for the present project: "Promote new research projects to gain more knowledge about celiac disease" and "Study the social needs associated with celiac disease"

In response to the meager amount of information available on the impact of CeD and the needs the condition entails, the "CELIAC-SPAIN" project was designed consisting of a survey developed by the Fundación Española de Aparato Digestivo (FEAD), specifically its Nutrition Committee, to

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be delivered online to members of the Federación de Asociaciones de Celíacos de España (FACE) with the aim of collecting the views of both patients and their families on various topics related to celiac disease, unsatisfied needs concerning its diagnosis and management, and difficulties patients encounter for diet adherence. Another novel aspect of the present project is its definition of three participant profiles: adults diagnosed in adulthood, adults diagnosed in childhood, and parents/guardians of celiac children.

MATERIALS AND METHODS

The "CELIAC-SPAIN" initiative represents a prospective, observational research based on a structured online survey conducted by FACE and FEAD. For the development of the "CELIAC-SPAIN" survey the authors designed a set of items dealing with various CeD-related issues concerning patient perceptions, attitudes, needs, and experiences. Following internal discussion in work meetings including gastroenterologists, nutritionists, and FACE representatives, the authors censored all item contents. The definitive survey, with a total of 43 questions (Annex 1), was structured according to three scenarios:

1. Adults over 18 years of age diagnosed in adulthood (a group representing shorter evolution times and possibly less adaptation).
2. Adults over 18 years of age diagnosed in childhood (a group representing longer evolution times and possibly greater adaptation).
3. Parents or guardians of celiac children (a group representing the impact of CeD during childhood).

The same survey was delivered to the three groups. To differentiate between groups the first question established the group in which the respondent belonged:

- Question 1. Please indicate which of the following statements best fits your case: a) I'm an adult but I was diagnosed with celiac disease during childhood; b) I'm an adult and was diagnosed with celiac disease in adulthood; c) I don't have celiac disease but care for my celiac children. Instructions: if you are a caregiver in charge of children with celiac disease, please answer the following questions according to your personal experience. If you are a celiac patient, please answer the following questions according to your personal experience.

After this first question four survey domains were defined: demography, diagnosis, follow-up, and impact on daily life plus difficulties in gluten-free diet adherence.

Procedure

From FACE and its constituent associations an invitation was sent to their members by e-mail. Also, the online survey was publicized through telematic channels (web, social networks, newsletters, *Mazorca* magazine). It was to be accessed via the Formularios-SEPD platform, and to be filled out between May and July, 2019. All completed surveys during this period were processed.

Statistical analysis

Quantitative variables were expressed as median and percentile [25th-75th]. Qualitative variables were expressed as relative frequency and percentage.

An inferential study of different qualitative variables was performed using homogeneity tests based on the chi-squared distribution when expected values allowed. Statistical comparisons for quantitative variables were made according to the appropriate nonparametric analysis using either the Mann-Whitney test or Kruskal-Wallis test as needed. A significance levels of 0.05 was used for all tests. The statistical analysis was performed using the GraphPad Prism version 5.03 software package.

RESULTS

A total of 730 surveys were submitted, of which 540 were completely filled out (inclusion rate, 74 %) and included in the study. Only incomplete or incorrectly filled out surveys were excluded. Respondents from virtually all Autonomous Communities were included (Fig. 1). Figure 2 shows the flowchart of the submitted surveys.

Demography

The sociodemographic characteristics of participants in each group are listed in table 1. Of note, in the parents/guardians group some results (age, gender, etc.) are not reported as it could not be discerned whether inputs corresponded to the celiac child or to the parent/guardian who answered. The rate of celiac relatives oscillated between 35 % and 48 % of cases, the former being mostly children, siblings and parents in all three groups.

Diagnosis

Regarding CeD diagnosis the results revealed highly relevant data (Table 2). Diagnostic delay for celiac patients diagnosed in childhood was longer than 6 months; how-



Fig. 1. Geographical distribution of the surveys included in the study.

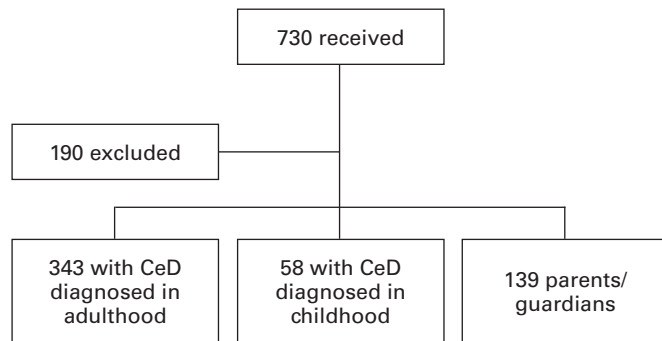


Fig. 2. Flowchart of the completed surveys received.

ever, for those diagnosed in adulthood it was significantly longer at 2 years ($p < 0.001$). As is to be expected, the diagnosis was usually made by a specialist (gastroenterol-

ogist or pediatrician according to age), with family doctors also playing a significant role particularly in the group of patients diagnosed in adulthood. In the pediatric population family screening was not recommended for 20 % of cases according to patients or parents/guardians, whereas in the adult population family screening failed to be recommended for 40 % of cases.

Of special interest during survey design was patient response to diagnosis. Table 3 lists the results obtained. Reactions at the time of diagnosis were similar across the three study groups. Most common was a feeling of relief ("At last I know what's going on, now I can start treatment..."). Other patients reported feeling overwhelmed, weighed down by the disease. Fewer individuals reported sadness (depressive responses cannot be ruled out since this could not be assessed on methodological grounds) or even anger or annoyance. As was to be expected, the least common response was aloofness or "no big deal."

Table 1. Sociodemographic characteristics of the participants in the CELIAC-SPAIN survey

	Adults with CeD diagnosed in adulthood	Adults with CeD diagnosed in childhood	Parents/guardians
Number	343	58	139
Age	40 [32-47]**	23.5 [20-33]	
Female	298 (86.8 %)	45 (77.6 %)	
Education	32 / 96 / 214	9 / 12 / 37	
Age at diagnosis	36 [27-42] ^{ss}	3 [1-12]	3 [2-6]
Evolution time (years)	1 [3-6]**	19.5 [10-26]	
Celiac relatives	168 (48.9 %)	24 (41.3 %)	50 (35.9 %) [#]
Member of an association	193 (56.4 %) ^{##}	42 (73.7 %) [#]	113 (81.3 %)
Body mass index	22.3 [20.5-24.9]	22.3 [20.5-24.2]	
Associated autoimmune disease	83 (24.2 %) ^{##}	5 (8.6 %)	10 (7.2 %)

Results are expressed in absolute value, median, 25th-75th percentile or percentage as needed. Education level is expressed as the absolute number of participants with primary / secondary / tertiary education. Statistical significance corresponds to: ** $p < 0.001$, Mann-Whitney test for CeD diagnosed in adulthood vs CeD diagnosed in childhood. ^{ss} $p < 0.001$, Kruskal-Wallis test. [#] $p < 0.05$. ^{##} $p < 0.01$, Chi-squared test.

Table 2. Results related to the diagnosis of CeD

	Adults with CeD diagnosed in adulthood	Adults with CeD diagnosed in childhood	Parents/guardians
Number	343	58	139
Diagnostic delay (months)	24.0 [6.5-60.0] ^{ss}	9.0 [5.0-16.5]	6.0 [3.0-12.0]
Advised family screening (yes)	208 (60.6 %) ^{##}	47 (81.0 %)	118 (84.9 %)
Family screening difficulties	97/246 (39.4%)	7/58 (12.0%) [#]	33/139 (23.7%)
Who made the diagnosis	239 Gastroenterologists 46 Family physicians 4 Endocrinologists 4 Nutritionists 3 Pediatricians 47 Others	31 Gastroenterologists 2 Family physicians 1 Endocrinologist 0 Nutritionists 20 Pediatricians 4 Others	74 Gastroenterologists 1 Family physician 0 Endocrinologists 0 Nutritionist 55 Pediatricians 9 Others

Results are expressed in absolute value, median, 25th-75th percentile or percentage as needed. Education level is expressed as the absolute number of participants with primary / secondary / tertiary education. Statistical significance corresponds to: ^{ss} $p < 0.001$, Kruskal-Wallis test. [#] $p < 0.05$. ^{##} $p < 0.01$, Chi-squared test.

Follow-up

Table 4 lists the main results obtained regarding patient follow-up. Of note, most patients undergo some sort of follow-up, particularly in the parents/guardians group. However, nearly 20 % of adults reported no follow-up for CeD. The practitioner involved in patient monitoring was a gastroenterologist in all groups. This is consistent with the preferences reported by patients, who consider that follow-up should be conducted by the specialist (a pediatrician in the case of children). A cause of concern revealed by the study was the reasons adduced by patients for not undergoing follow-up. The primary reason was that the patient considered he/she had been discharged, followed

by perceiving follow-up as unnecessary in the absence of symptoms.

Impact on daily life

The topic that was next assessed was that of daily living for the celiac patient. First off, respondents were asked to report their concerns regarding CeD. Most reported being worried about some aspect of the condition (65 % of celiacs diagnosed in adulthood, 51 % of celiacs diagnosed in childhood, 67 % of parents/guardians), with the three major concerns, from greatest to least, including fear of developing cancer, fear of having symptoms again, and fear of transmitting the disease to offspring.

Table 3. How respondents reacted when they were diagnosed with CeD

	Adults with CeD diagnosed in adulthood	Adults with CeD diagnosed in childhood	Parents/guardians
How did you feel when diagnosed with CeD?			
Relieved	242	17	77
Overwhelmed	143	9	77
Sad	125	9	73
Angry	83	6	33
No problem	71	12	19
Can't remember	21	37	10

Since more than one reaction could be marked, the number of responses is greater than the number of respondents.

Table 4. Results related to the follow-up of patients with CeD

	Adults with CeD diagnosed in adulthood	Adults with CeD diagnosed in childhood	Parents/guardians
On follow-up? (yes)	272 (79.3 %)	46 (79.3 %)	137 (98.5 %)
Who does the follow-up?			
Gastroenterologist	232	32	120
Family physician	33	15	5
Pediatrician	0	2	28
Surgeon	0	0	0
Endocrinologist	6	0	6
Nutritionist	10	0	1
Other	10	0	1
Why not on follow-up?	"Was discharged" in 22 "Don't think it's necessary" or "Don't have symptoms anymore" in 12	"Was discharged" in 6 "Don't think it's necessary" or "Don't have symptoms anymore" in 3	"Was discharged" in 1 "Have no specialist care" in 1
Who do you think should do the follow-up?			
Gastroenterologist	272 (79.3 %)	46 (79.3 %)	112 (80.5 %)
Family physician	30 (8.7 %)	9 (15.6 %)	3 (2.1 %)
Endocrinologist	12 (3.5 %)	0	4 (4.2 %)
Nutritionist	11 (3.2 %)	1 (1.7 %)	5 (3.6 %)
Other	18 (5.3 %)	1 (1.7 %)	15 (9.6 %)
Noone	0	1 (1.7 %)	0

Results are expressed as absolute value or percentage as needed.

Self-perceived health-related quality of life was also assessed using a visual analogue scale from 0 (worst) to 10 (best). Results are shown in figure 3, which conspicuously reveals a significantly worse perceived quality of life among celiac patients diagnosed in adulthood.

Exclusion of gluten from the diet

A highly relevant aspect of the survey has to do with gluten exclusion from the diet, adherence to gluten-free food, difficulties, opinions, impact, etc. Table 5 lists the major results

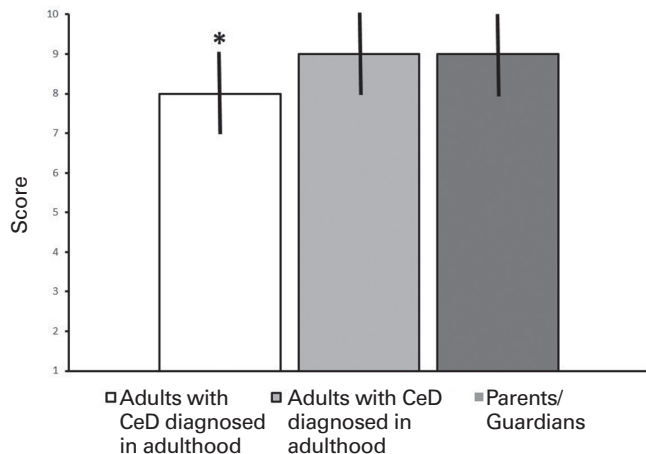


Fig. 3. Results of perceived quality of life expressed as analogue visual scale score from 0 (worst) to 10 (best). Of note the worse quality of life in the group of celiac patients diagnosed in adulthood ($p < 0.01$).

obtained. A vast majority of patients considered that gluten exclusion from the diet is very important. Respondents were also asked whether, besides gluten, they also avoided milk or dairy products. Most respondents reported they did consume dairy products (288 celiacs diagnosed in adulthood (84 %), 55 celiacs diagnosed in childhood (98 %), and 136 parents/guardians (98 %). Patients who avoided dairy products did so because of intolerance complaints ($n = 37$) or having been advised against them ($n = 18$). A high adherence to gluten-free food is to be highlighted since over 90 % of patients consider themselves good adherents in all three groups. When asked about adherence details, virtually all patients reported they stringently adhered to a gluten-free diet. Another aspect that was deemed relevant is where do patients acquire gluten-free products. Most patients in the three groups answered in supermarkets or specialized food shops.

The results obtained with gluten-free diet as perceived by respondents are listed in table 6. Of note, in virtually all cases it manages to improve symptoms, either partially or completely, which is accompanied by weight gain in almost one half of cases. Needing a gluten-free diet moderately or significantly limits daily living for one third of patients diagnosed in childhood, and two thirds of those diagnosed in adulthood. However, when asked about limitations in leisure, traveling, etc., over 50 % of patients report quite some or many limitations.

A factor that may influence gluten-free diet adherence is access to gluten-free foods. Interestingly, fewer than 10 % of patients find it difficult to seek out these products. There is also a highly significant agreement in reporting that the need to buy gluten-free products increases the cost of the average shopping basket, a fact reported by 90 % of

Table 5. Results related to gluten exclusion from the diet

	Adults with CeD diagnosed in adulthood	Adults with CeD diagnosed in childhood	Parents/guardians
Are you a good adherent to your diet? (Yes)	313 (91.2 %)	55 (94.8 %)	133 (95.6 %)
Is diet adherence important to you?:			
Very much	316 (82.1 %)	54 (94.7 %)	137 (98.5 %)
Moderately	25 (7.3 %)	3 (5.3 %)	2 (1.5 %)
Not much	2 (0.6 %)	0	0
How well do you adhere to your diet?:			
Always strictly	319 (93.3 %)	53 (92.9 %)	136 (97.8 %)
Forget sometimes	7 (2.0 %)	1 (1.8 %)	3 (2.2 %)
Carelessly at times	12 (3.5 %)	2 (3.5 %)	0
Stop it when not feeling well	1 (0.3 %)	0	0
Stop it when I feel fine	3 (0.9 %)	1 (1.8 %)	0
Where do you buy gluten-free products?:			
Supermarket	332	57	135
Specialized store	102	20	31
Internet	58	3	13
Herbalist's shop	49	11	13
Pharmacy/Parapharmacy	15	3	6

Results are expressed as absolute value or percentage as needed.

Table 6. Results regarding the consequences of gluten exclusion from the diet

	Adults with CeD diagnosed in adulthood	Adults with CeD diagnosed in childhood	Parents/guardians
How did symptoms respond to GFD?:			
They disappeared	113 (32.9 %)##	37 (64.9 %)	78 (56.9 %)
They improved	218 (63.5 %)	20 (35.1 %)	58 (42.3 %)
They didn't improve	12 (3.6 %)	0	1 (0.8 %)
How has your body weight changed since GFD onset?:			
I've regained my weight	43 (12.5 %)	14 (25.0 %)	36 (25.9 %)
I've put on weight	115 (33.5 %)	11 (19.6 %)	50 (35.9 %)
I weigh the same	110 (32.1 %)	25 (44.6 %)	49 (35.2 %)
I've lost weight	75 (21.9 %)	6 (10.8 %)	4 (3.0 %)
Do you feel limited in your daily life?:			
Not at all	22 (6.4 %)	3 (5.2 %)	15 (10.9 %)
Slightly	94 (27.4 %)	32 (56.1 %)	59 (42.4 %)
Moderately	148 (43.1 %)	16 (28.1 %)	54 (38.8 %)
A lot	79 (23.1 %)	6 (10.6 %)	11 (7.9 %)
Do you feel isolated or rejected?:			
Not at all	121 (35.2 %)	21 (36.8 %)	61 (44.2 %)
Slightly	120 (34.9 %)	26 (45.6 %)	50 (36.2 %)
Moderately	75 (21.8 %)	9 (15.9 %)	22 (15.9 %)
A lot	27 (8.1 %)	1 (1.7 %)	5 (3.7 %)
Does GFD limit your free time, travelling, etc.?			
Not at all	10 (2.9 %)	4 (7.1 %)	3 (2.1%)
A little	96 (27.9 %)	28 (49.1 %)	44 (31.6 %)
Quite a bit	136 (39.6 %)	19 (33.3 %)	71 (51.1 %)
A lot	101 (29.6 %)	6 (10.5 %)	21 (15.2 %)
How much do bars and restaurants know?:			
Quite a bit	27 (7.8 %)	11 (19.3 %)	15 (10.8 %)
Little	244 (71.1 %)	40 (70.1 %)	101 (72.6 %)
Nothing	72 (21.1 %)	6 (10.6 %)	23 (16.6 %)
Following a GFD is:			
Very easy	17 (4.9 %)	1 (1.7 %)	11 (7.9 %)
Easy	158 (46.1 %)	41 (69.5 %)	66 (47.5 %)
Quite challenging	130 (37.9 %)	12 (20.3 %)	53 (38.1 %)
Very difficult	27 (7.8 %)	1 (1.7 %)	6 (4.3 %)
Don't know	11 (3.3 %)	4 (6.8 %)	3 (2.2 %)
How do you like gluten-free products?:			
Like them, eat them regularly	20 (5.8 %)	11 (19.3 %)	12 (8.6 %)
Not bad, eat them often	121 (35.3 %)	26 (45.6 %)	45 (32.4 %)
Don't like them but eat them	144 (41.9 %)	18 (31.6 %)	57 (41.0 %)
Don't like them at all	53 (15.5 %)	2 (3.5 %)	20 (14.4 %)
Haven't tried them yet	5 (1.5 %)	0	5 (3.6 %)
How well are you informed about CeD and diet?:			
Well informed, no doubts	167 (48.7 %)	40 (70.2 %)##	65 (47.1 %)
Fairly well, some doubts	158 (46.0 %)	15 (26.3 %)	69 (50.0 %)
Not much, many doubts	18 (5.3 %)	2 (3.5 %)	4 (2.9 %)

(Continue in the next page)

Table 6 (Cont.). Results regarding the consequences of gluten exclusion from the diet

	Adults with CeD diagnosed in adulthood	Adults with CeD diagnosed in childhood	Parents/guardians
When in doubt, whom do you consult with?:			
Patient association	130 (37.9 %)	25 (43.8 %)	62 (44.7 %)
Gastroenterologist	108 (31.5 %)	8 (14.1 %)	44 (31.7 %)
Family physician	43 (12.5 %)	18 (31.5%)	3 (2.1 %)
Nutritionist	7 (2.0 %)	1 (1.8 %)	2 (1.4 %)
Pediatrician	1 (0.3 %)	0	19 (13.6 %)
I've nobody to consult with	54 (15.8 %)	5 (8.8 %)	9 (6.5 %)
Would you like some drug therapy better than GFD?:			
Yes	173 (50.4 %)	28 (49.1 %)	74 (53.2 %)
No	59 (17.2 %)	9 (15.8 %)	16 (11.5 %)
Don't know	111 (32.4 %)	20 (35.1 %)	49 (35.3 %)

Results are expressed as absolute value and percentage. * $p < 0.05$. ** $p < 0.001$, Chi-squared test.

respondents (89 % of celiacs diagnosed in adulthood, 94 % of celiacs diagnosed in childhood, and 88 % of parents/guardians). An issue that was identified with regard to gluten-free diet that leaves room for improvement is gluten content labeling, since 74 % of celiacs diagnosed in adulthood, 75 % of parents/guardians, and 14 % of celiacs diagnosed in childhood reported having problems to find out. Another improvable aspect of these products is that they seem scarcely appetizing. Despite this, when patients were asked if they would like some drug therapy rather than gluten-free diet only one half answered in the affirmative.

Another remarkable aspect of the study is related to dietary information. Although 70 % of celiacs diagnosed in childhood have few doubts, half of celiacs diagnosed in adulthood as well as parents/guardians do have many. Therefore, we asked them whom they consulted with when in doubt. The most widely used resource in all groups was patient associations, followed by the gastroenterologist or family doctor (pediatrician in the group of parents/guardians). Regrettably, 15 % of celiac patients diagnosed in adulthood reported they had nobody to consult with.

DISCUSSION

The "CELIAC SPAIN" project, promoted by SEPD in collaboration with FACE, has revealed the experiences of patients with CeD in different domains, such as diagnosis, follow-up, reactions, concerns, dietary results, issues derived from gluten exclusion, treatment preferences, limitations, etc.

Participants included subjects from across the country in three domains: adults diagnosed in adulthood, adults diagnosed in childhood, and parents/guardians for a specific assessment of the pediatric population. We consider this differentiation may help better understand the impact of CeD, providing both novel and expectable results such as the fact that the median age —both presently and at diagnosis— of those where CeD was identified during childhood was younger and follow-up time shorter than for those diagnosed in adulthood. Possibly because of the characteristics of patient enrollment a high rate of patient

association members was identified, particularly in the parents/guardians group, which amounts up to 80 % of respondents, which may represent a bias in our results. The group with fewest association members was that of patients diagnosed in adulthood, however with a highly relevant rate of 56 %. In the Ombudsman Survey (11) the rate of association members was 71 %, similar to the present study.

Different aspects of the disease were explored from a patient's perspective, hence information highly representative of the reality of CeD in our setting. One of the many remarkable results obtained is that diagnostic delay in adults still leaves a lot to be desired, and only the patient is taken into account, with no ensuing screening for potential celiac relatives. Fortunately though, results are better for the pediatric population. While other surveys have revealed delays of up to 11 years (12), the results of the present study show confirm a need for increased awareness about celiac disease both among professionals and the general population in order to minimize the time from symptom onset to consultation. In this regard, stressing the role of initiatives such as the "Protocol for the early diagnosis of celiac disease" by the Spanish Ministry of Health, seems an important thing to do (13). Another aspect that leaves room for improvement, identified at diagnosis, is the study of first-degree relatives, which often fails to be recommended and may leave without a diagnosis, or delay it unnecessarily for, a significant number of potential celiac patients. This reflects the fact that information and awareness raising work remains a need, particularly for gastroenterologists and family physicians/pediatricians, the practitioners most commonly involved in the diagnosis and management of CeD.

When someone is diagnosed with CeD adjustments need to be made in his or her daily living. How do patients react? The results obtained show a wide variety of responses, with relief, strain, and sadness being most common in all groups. Therefore, that positive coping strategies be favored at diagnosis, facilitated by support from professionals, family, and associations, is warranted (14).

After diagnosis virtually all children are followed up by a professional whereas 20 % of adults reported undergoing

no monitoring. According to patients, the reason is that they had been discharged or had deemed it unnecessary. This is an additional argument supporting an enhancement of patient information and practitioner education, particularly regarding gastroenterologists as they are the specialists patients prefer for their follow-up.

A highly positive result of the study is the high level of awareness about gluten-free diet found in all groups. A vast majority of patients consider that diet is very important, and adhere to it stringently in an ongoing manner. In fact, this self-reported adherence is better than expected with the use of measuring questionnaires in our setting (15). This is likely related to the positive response of symptoms and weight reported by the patients themselves. A survey similar to the "CELIAC-SPAIN" project that was administered in Chile found that diet adherence was incomplete in 30 % of patients, which was associated with worse clinical response (16). This does not mean that diet adherence is straightforward as it limits moderately or significantly daily living, free time activities, etc. Furthermore, consistent with the aforementioned report by the Spanish Ombudsman (11), diet entails a relevant increase in costs. This is why we wondered whether patient quality of life on treatment could be influenced by daily living limitations associated with diet and lifestyle. Our results show that when CeD is diagnosed in childhood its impact on quality of life is significantly lower than for those who are diagnosed in adulthood. This is

possibly because of a better adjustment to CeD when the condition is diagnosed early in life.

Another relevant aspect that was identified by this nationwide survey is a lack of societal awareness about the celiac disease issue. Since most patients purchase gluten-free foods in supermarkets, these should have available and facilitate product identification. The food industry should become aware of the potentially high number of customers that demand gluten-free products, as over two thirds of patients report that food venues have a scarce or nil understanding of CeD.

Although the information unveiled by the "CELIAC-SPAIN" project is clearly new, the study had a number of issues. An inclusion bias cannot be ruled out since most participants were members of associations included in FACE. The study was cross-sectional in design, hence it provided a lot of information on a specific point in time but did not allow discernment of potential response changes over time.

In summary, the results of the present study allow a better understanding of CeD patient experiences, upon which strategies to muffle the impact of the condition will be set up either by educating professionals and health care policy makers or by raising awareness among the social groups involved, such as the restaurant and food industries.

Annex 1

1. Please indicate which of the following options best describes your case:

- I'm an adult but was diagnosed with celiac disease during childhood.
- I'm an adult and was diagnosed with celiac disease in adulthood.
- I don't have celiac disease but care for my celiac children.

If you're the caregiver of a child/children with celiac disease, please answer the following questions according to your knowledge and opinion.

If you're a celiac patient, please answer the following questions according to your knowledge and opinion.

2. How old are you?:

3. Sex:

- Male.
- Female.

4. Your body weight:

[] kg

5. Your height:

[] cm at present.

6. In which Autonomous Community do you live?:

7. Your education level:

- No formal education.
- Basic education.
- High school.
- College/University degree.

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- 8. At what age were you diagnosed with celiac disease?:**
- 9. How much time (in months) elapsed from symptom onset to diagnosis?:**
- 10. Who made the diagnosis?:**
- Family Physician.
 - Pediatrician.
 - Gastroenterologist.
 - Surgeon.
 - Endocrinologist.
 - Nutritionist.
 - Other.
- 11. Do you have any relatives affected by the disease?:**
- Some of my siblings.
 - One of my parents.
 - Some of my grandparents.
 - Some cousins, aunts/uncles.
 - None.
 - Other.
- 12. Were your relatives advised to undergo testing for celiac disease?:**
- Yes.
 - No.
- 13. Were any objections/obstacles raised when requesting tests for your relatives?:**
- Yes.
 - No.
- 14. Do you remember how you felt when you received the diagnosis of celiac disease?:**
- Sad.
 - Relieved, for at last I had a diagnosis.
 - Overwhelmed.
 - Angry.
 - Good, no big deal for me.
 - Can't remember.
- 15. Are you being followed up for your disease?:**
- Yes.
 - No.
- 16. Who's doing follow-up?:**
- Family Physician.
 - Pediatrician.
 - Gastroenterologist.
 - Surgeon.
 - Endocrinologist.
 - Nutritionist.
 - Other.
- 17. Who do you think should be doing the follow-up?:**
- Family Physician.
 - Pediatrician.
 - Gastroenterologist.
 - Surgeon.
 - Endocrinologist.
 - Nutritionist.
 - Other.
- 18. Do you have any other autoimmune diseases such as thyroid or liver conditions?:**
- Yes.
 - No.

(Continue in the next page)

- 19. Is there any aspect of your disease that worries you?:**
- Yes.
 - No.
- 20. What worries you most about your disease?:**
- Fear of developing some form of cancer.
 - Fear of having symptoms again.
 - Fear of transmitting it to my children.
 - (open field).
- 21. How do you perceive the way your symptoms have evolved?:**
- My symptoms disappeared completely.
 - My symptoms have improved a lot.
 - My symptoms have improved a bit.
 - My symptoms have not improved.
- 22. Do you feel limited in daily life by your disease?:**
- Not at all.
 - Slightly.
 - Moderately.
 - A lot.
- 23. Do you feel socially rejected, isolated because of your disease?:**
- Not at all.
 - Slightly.
 - Moderately.
 - A lot.
- 24. To what extent is your disease affecting your daily life?:**
- Not at all.
 - Slightly.
 - Moderately.
 - A lot.
- 25. Do you think it's important to strictly adhere to a gluten-free diet?:**
- Very important.
 - Fairly important.
 - Hardly important.
 - Not important at all.
- 26. Does your need for a gluten-free diet represent a limitation to enjoy free time, travel, go out, etc.?:**
- Not at all.
 - Slightly.
 - Quite a bit.
 - A lot.
- 27. To what extent are you informed about the disease and gluten-free diet?:**
- Very well informed, with no doubts.
 - Well informed, with some doubts.
 - Poorly informed, with many doubts.
- 28. Are you a member of any patient associations?:**
- Yes.
 - No.
- 29. When in doubt about your disease or diet, whom do you consult?:**
- Family Physician.
 - Gastroenterologist.
 - Nutritionist.
 - Pediatrician.
 - Patient association.
 - I've nobody to consult with.

(Continue in the next page)

- 30. How much do you think bars and restaurants know about celiac disease?:**
- A lot.
 - Quite a bit.
 - A little.
 - Nothing.
- 31. Would you like to have some drug therapy that made gluten-free diet unnecessary?:**
- Yes.
 - No.
 - Don't know.
- 32. How difficult is it, in your opinion, to follow a gluten-free diet in our country?:**
- Very difficult.
 - Quite difficult.
 - Easy.
 - Very easy.
 - Don't know.
- 33. How do you consider food labeling regarding gluten content?:**
- I can check for gluten content on labels without trouble.
 - I find it difficult at times to check for gluten content.
 - I have lots of trouble trying to check for gluten content.
 - I can't identify on labels whether a product contains gluten.
- 34. Do you understand the differences between the various gluten content statements in the labeling of food products?:**
- I can't understand their meaning.
 - I have many doubts about their meaning.
 - I usually understand them without trouble.
 - I understand them without difficulty.
- 35. Where do you buy gluten-free products?:**
- Supermarket.
 - Specialized store.
 - Pharmacy or parapharmacy.
 - Internet.
 - Herbalist's shop.
- 36. If you buy gluten-free products, what impact do they have on your shopping costs?:**
- Costs remain the same.
 - Slightly more expensive.
 - Far more expensive.
 - Can't afford gluten-free products.
- 37. How do you like the gluten-free bread and pastries available in Spain?:**
- Don't like them at all.
 - Don't like them but I do eat them.
 - They're not bad, I eat them often.
 - I like them, I eat them regularly.
 - Don't know, never tried them.
- 38. Have you been diagnosed with any of the following conditions since you were diagnosed with celiac disease? (Please mark all that apply):**
- Dyslipidemia, elevated cholesterol or triglycerides.
 - High blood pressure.
 - Diabetes.
 - Overweight.
 - Allergy to some food.
 - Lactose intolerance.

(Continue in the next page)

39. Under usual conditions, how would you rate your quality of life or wellbeing when following a gluten-free diet?:

Please select the appropriate response for each concept; 1 = worst, 10 = best:

	1	2	3	4	5	6	7	8	9	10
Quality of life / wellbeing										

40. How well do you adhere to gluten-free diet?:

- Always strictly.
- I forget occasionally.
- Carelessly at times.
- Sometimes I stop it when I feel fine.
- Sometimes I stop it when I'm not feeling fine.

41. Do you consume milk or dairy products such as yogurt?:

- Yes.
- No.

42. If you abstain from or avoid milk and/or dairy products, please indicate the reason why:

- Makes me ill.
- Don't like them.
- Doctors have advised me against them.
- I think abstaining from milk is better for health.

43. How has your body weight changed since you started a gluten-free diet?:

- I weigh the same.
- I've lost weight.
- I've regained my usual weight.
- I've put on weight.

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