

GLUTEN-FREE DIET AMONG PORTUGUESE COELIAC ADULTS: PERCEIVED DIFFICULTIES



A DIETA ISENTA DE GLÚTEN EM CELÍACOS ADULTOS PORTUGUESES: DIFICULDADES PERCECIONADAS

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ABSTRACT

INTRODUCTION: Coeliac disease can cause a great burden in the coeliacs' life. Therefore, it is important to assess the difficulties that coeliacs face in their daily life.

OBJECTIVES: To evaluate the perceived difficulties of self-reported compliance with the gluten-free diet and with out-of-home eating aspects in a convenience sample of Portuguese coeliac adults.

METHODOLOGY: It was performed a transversal observational study where Portuguese coeliac adults were inquired, filling out an online questionnaire. It comprised three sections: sociodemographic and disease characteristics, self-reported compliance with the gluten-free diet and out-of-home eating aspects.

RESULTS: The final sample included 339 participants, where 76.4% were members of Associação Portuguesa de Celíacos, 84.1% were female and the age of coeliac disease diagnosis ranged from 1 to 70 years old. The difficulties identified by the participants in self-reported compliance with the gluten-free diet were "Risk of gluten cross-contamination" (84.1%), "Availability of gluten-free products in public places (coffee shops, hospitals, restaurants, ...) (83.8%), "Absence of the gluten-free symbol in the products' label" (52.2%) and the "Lack of gluten-free food products offer, at an affordable price" (45.7%). In out-of-home eating, the main difficulty was the "Lack of information and unconcern of the establishments' staff" (44.0%).

CONCLUSIONS: Coeliacs face a lot of challenges in terms of daily food choices. The role of patient support groups and education provided by a follow-up team with professional skills in coeliac disease are vital for its management and long-term outcome.

KEYWORDS

Coeliac disease, Compliance, Gluten-free, Survey

RESUMO

INTRODUÇÃO: A doença celíaca pode ser uma grande sobrecarga na vida dos celíacos. Assim, é importante examinar as dificuldades que os celíacos enfrentam no seu dia a dia.

OBJETIVOS: Avaliar as dificuldades percecionadas na adesão autorreportada à dieta isenta de glúten e na realização de refeições fora de casa numa amostra de conveniência de celíacos adultos portugueses.

METODOLOGIA: Foi realizado um estudo observacional transversal onde se inquiriram celíacos adultos portugueses, através do preenchimento de um questionário *online*. Este continha três secções: características sociodemográficas e relacionadas com a doença, cumprimento autorreportado da dieta isenta de glúten e aspetos da realização de refeições fora de casa.

RESULTADOS: A amostra final incluiu 339 participantes, em que 76,4% eram membros da Associação Portuguesa de Celíacos, 84,1% eram do sexo feminino e a idade de diagnóstico de doença celíaca variou entre os 1 e 70 anos. As dificuldades identificadas pelos participantes no cumprimento autorreportado da dieta isenta de glúten foram "Risco de contaminação cruzada por glúten" (84,1%), "Disponibilidade de produtos sem glúten em espaços públicos (cafés, hospitais, restaurantes, ...) (83,8%), a "Ausência de símbolo identificador do produto como isento de glúten no rótulo alimentar" (52,2%) e "Ausência de oferta de produtos alimentares sem glúten e a preço acessível" (45,7%). Na realização de refeições fora de casa, a maior dificuldade encontrada foi a "Falta de informação e despreocupação por parte do staff dos estabelecimentos" (44,0%).

CONCLUSÕES: Os celíacos enfrentam muitos desafios em termos de escolhas alimentares diárias. O papel dos grupos de apoio destes pacientes e a educação fornecida por uma equipa de seguimento com competências profissionais na doença celíaca são cruciais para a sua gestão e resultados a longo prazo.

PALAVRAS-CHAVE

Doença celíaca, Cumprimento, Sem glúten, Questionário

INTRODUCTION

Coeliac Disease (CD) is a chronic enteropathy and an immunemediated disease. It occurs in genetically predisposed individuals when they ingest gluten, a group of proteins rich in prolamins present in wheat, rye, and barley (1-3). Currently, the only treatment for CD is a strict permanent gluten-free diet (GFD), implying that exposure to trace amounts of gluten is harmful. This way, coeliacs must eliminate from their diet gluten-containing (GC) foods as well as gluten cross-contamination (GCC) (1, 2, 4). CD can cause a great burden in the coeliacs' quality of life and in social, cultural, economic and working contexts, due to its need for a permanent treatment, its chronic nature and its impact on health (4, 5). In Portugal, there is only one study that reflects the perception of health status and quality of life in coeliacs (6). This way, this is the first study in Portugal that focuses on the difficulties that Portuguese coeliac adults face daily, and it is important to identify and understand them as they influence health outcomes and the ability to maintain a GFD in a long-term (7).

OBJECTIVES

The aim of this study was to evaluate the perceived difficulties in the daily life of a convenience sample of Portuguese coeliac adults.

METHODOLOGY

We have conducted a transversal observational study. An online questionnaire was applied, which was sent to every member of Associação Portuguesa de Celíacos (APC) through newsletter and it was disseminated through social media, in coeliac support groups. The following inclusion criteria were considered: a) individuals with self-reported correct diagnosis for CD (according to the European Society Paediatric Gastroenterology, Hepatology and Nutrition criteria (3)), b) adults (over 18 years old) and c) resident in "Portugal". This way, the final sample consisted of 339 individuals. The study was authorized by the Ethics Committee of the University of Porto, "Parecer n°73/CEUP/2019". The developed questionnaire was based on a tool developed by Coeliac UK and the University of Oxford, called "Coeliac Disease Assessment Questionnaire" (8), having been asked for authorization to use it. A pre-test was performed by 3 adult coeliac individuals. The questionnaire was filled out through an online platform, Google Forms. It comprised 23 questions and it encompassed the following dimensions: sociodemographic and diseaserelated, self-reported compliance with the GFD and out-of-home eating aspects. Data were analysed in IBM® SPSS® Statistics version 25.0 for Windows®. Descriptive analysis used were means and standard deviations (SD) for quantitative variables and absolute (n) and relative frequencies (%) for qualitative variables.

RESULTS

Sociodemographic and disease characteristics

Out of 339 participants, 76.4% were members of APC, 84.1% were female and the age ranged from 18 until 77 years old, with 37 years old being the mean. Most of the participants had higher education (73.5%) and were employed or employers (76.1%). The majority resided in "Área Metropolitana de Lisboa" (41.0%) and the age of CD diagnosis ranged from 1 to 70 years old with 25 years old being the mean (Table 1).

Self-reported compliance with the gluten-free diet

Since their CD diagnosis, 76.4% self-reportedly never ingested gluten whilst 41.9% considered the compliance with the GFD acceptable. A total of 82.9% stated that the GF foods' offer improved, since their diagnosis. Plus, considering this section, the participants considered that

Table 1

Sociodemographic and disease characterization of the participants

SO	CIODEMOGRAPHIC AND DISEASE CHARACTERISTIC	cs
Member of APC	Yes n (%)	259 (76.4)
Sex	Female n (%)	285 (84.1)
	Male n (%)	54 (15.9)
Age (years)	Mean (SD)	37 (12)
Education level	Primary school n (%)	7 (2.0)
	Secondary school n (%)	83 (24.5)
	Higher education n (%)	249 (73.5)
Economic and professional situation	Employed, employers n (%)	258 (76.1)
	Unemployed, domestic n (%)	21 (6.2)
	Student n (%)	43 (12.7)
	Retired n (%)	17 (5.0)
Region of residence	"Alentejo" n (%)	15 (4.4)
	"Algarve" n (%)	13 (3.8)
	"Centro" n (%)	73 (21.5)
	"Área Metropolitana de Lisboa" n (%)	139 (41.0)
	"Norte" n (%)	87 (25.7)
	"Região Autónoma dos Açores" n (%)	6 (1.8)
	"Região Autónoma da Madeira" n (%)	6 (1.8)
Age of CD diagnosis (years)	Mean (SD)	25 (17)

APC: Associação Portuguesa de Celíacos

CD: Coeliac disease

SD: Standard deviation

the most difficult factors were the "Risk of gluten cross-contamination" (84.1%), the "Availability of GF products in public places (coffee shops, hospitals, restaurants, ...) (83.8%), the "Absence of the GF-symbol in the products' label" (52.2%) and the "Lack of GF food products offer, at an affordable price" (45.7%) (Table 2).

Out-of-home eating aspects

When asked about "How often do you eat outside home", most of the participants (36.0%) answered in the frequency of "Sometimes (2 to 3 times/month). The most answered option was "often", when the participants were asked about whether it is difficult to order a secure GF meal outside home (38.6%), if they considered that there's lack of knowledge about CD and regarding the precautions to adopt in the handling of GF food by the employees (54.9%) and if they felt frustrated about the GF meals' price (28.6%).

A total of 27.7% revealed that they always preoccupied they might become ill after eating outside home and 27.1% stated they rarely feel uncomfortable at the table, during meals.

A total of 76.4% ate less frequently out-of-home, since the CD diagnosis, and the main difficulty faced, in this section, was the "Lack of information and unconcern of the establishments' staff", with 44.0% responses (Table 3).

DISCUSSION OF RESULTS

A total of 76.4% of the sample were a member of APC, which is a positive aspect to be considered. APC is an non-profit association that defends the interests and rights of Portuguese coeliacs (9): it is proved that being a member of associations of patients with CD is correlated to higher adherence with the GFD and they perform an important communication role between coeliacs and industries (5, 10, 11). A total of 84.1% of the sample is female and CD was once considered a paediatric disease however the age gap of diagnosis of the present analysis showed the opposite: both results are in accordance with the results found in several other studies (4, 6).

The European rate of GFD compliance is 44-97% (4, 5). Even though in this study the rate of gluten ingestion is rather lower - 23.6% - this is still very serious. Non-adherence to GFD leads to damage of the

Table 2

Characterization of the participants' self-reported compliance with the gluten-free diet

SELF-REPORTED COMPLIANCE WITH THE GFD							
Do you ingest gluten?		Never n (%) Rarely n (%) Sometimes n (%) Often n (%) Always n (%)	259 (76.4) 56 (16.5) 19 (5.6) 5 (1.5) 0 (0.0)				
Do you consider the compliance with the GFD:		Very easy n (%) Easy n (%) Acceptable n (%) Difficult n (%) Very difficult n (%)	16 (4.7) 90 (26.5) 142 (41.9) 74 (21.8) 17 (5.0)				
Worsened n (%) Do you consider that since your CD diagnosis, the GF foods' offer: Remained equal n (%) Improved n (%)			2 (0.6) 56 (16.5) 281 (82.9)				
What do you consider most difficult in compliance with the GFD?	Lack of support of family and friends n (% of	33 (9.7)					
	Lack of GF food products offer, at an affordable	155 (45.7)					
	Impossibility of doing home-made meals n (%	53 (15.6)					
	Lack of information concerning CD n (% of ca	111 (32.7)					
	Absence of the GF-symbol in the products' lab	177 (52.2)					
	Lack of support from health professionals (doc	46 (13.6)					
	Lack of culinary skills to cook GF meals n (%	29 (8.6)					
	Desire to eat gluten-containing foods n (% of	92 (27.1)					
	Availability of GF products in public places (co	284 (83.8)					
	Risk of gluten cross-contamination n (% of ca	285 (84.1)					
	GF foods' flavour and texture n (% of cases)	83 (24.5)					

CD: Coeliac disease GF: Gluten-free GFD: Gluten-free diet

Table 3

Characterization of the participants' out-of-home eating aspects

(ONLY MEALS EATEN		T-OF-HOME EATING JCH AS RESTAURANTS,	CANTEENS, BARS, AMONG	OTHERS)	
Never n (%) Rarely (less than or equal to 1 time/month) n (%) How often do you eat outside home? Sometimes (2 to 3 times/month) n (%) Often (1 to 6 times/week) n (%) Daily n (%)					
How often:	Never n(%)	Rarely n(%)	Sometimes n(%)	Often n(%)	Always n(%)
Have you found it difficult to order a secure GF meal outside home?	12 (3.5)	27 (8.0)	96 (28.3)	131 (38.6)	73 (21.5)
Have you considered that there's lack of knowledge about CD and regarding the precautions to adopt in the handling of GF foods by the employees?	1 (0.3)	9 (2.7)	25 (7.4)	186 (54.9)	118 (34.8)
Have you preoccupied that you might become ill after eating outside home?	22 (6.5)	54 (15.9)	81 (23.9)	88 (26.0)	94 (27.7)
Have you felt frustrated about the GF meals' price?	12 (3.5)	39 (11.5)	96 (28.3)	97 (28.6)	95 (28.0)
Have you felt uncomfortable at the table, during meals?	83 (24.5)	92 (27.1)	89 (26.3)	54 (15.9)	21 (6.2)
Do you feel that you eat less frequently out-of-home since your CD diagnosis?	Yes n (%)				259 (76.4)
Select the main difficulty faced when eating outside home:	Mistrust in the safety of Limited offer of suitable Lack of information and Discomfort and embarr High cost and limited o	52 (15.3) 83 (24.5) 149 (44.0) 7 (2.1) 48 (14.2)			

CD: Coeliac disease GF: Gluten-free GFD: Gluten-free diet

intestinal mucosa, reappearance of symptoms and development of complications such as anaemia and osteoporosis (1, 2). Moreover, a study conducted in Spanish hospitals concluded that patients with complete adherence with the GFD reported a better quality of life whereas patients who didn't adhere to GFD had a lower quality of life and a greater severity of symptoms (12). Also, a study in Italy, that aimed to investigate adherence to a gluten-free diet and potentially

associated factors, reported that 19% of the sample did not adhere to a GFD, however recognizing that the GFD is the only treatment for CD, and that strict adherence is essential (11).

Nearly all individuals of the sample acknowledge that the GF foods' offer improved, since their CD diagnosis. In fact, the GF foods' market has been growing, as it is estimated that from 2012 to 2014, in the United States of America, it grew about 63% (13). In Portugal there's

a rising variety of brands and products launched in the market in the past few years (14).

Concerning the difficulties faced in self-reported compliance with the GFD, the participants chose the risk of GCC as the most difficult item. GCC may explain the mucosal atrophy and symptoms of patients who self-reportedly follow a strict GFD. Coeliacs face it daily as it might occur in a number of scenarios such as in the field, in the factory, in restaurants or at home, through shared production areas, inadequate hygiene of kitchenware, through spreads used with other GC foods (4, 15, 16). The Regulation (EU) No 1169/2011 states that it is mandatory by law to provide information to the consumer regarding all the ingredients, processing aids and other substances with allergenic or intolerance effect, such as GC ingredients, in the composition of pre-packaged products, including products sold in catering establishments. However, this is insufficient to ensure that GCC doesn't occur so separate production zones for GF and GC foods would be a first step (15, 17, 18). In the future, it would be important to implement security measures and to provide educational training to the staff in establishments such as schools, canteens, restaurants, among others, in order to improve the knowledge regarding this topic, so the coeliac consumer would have a safe meal. The option "availability of GF products in public places (coffee shops, hospitals, restaurants)" also stands an obstacle in this segment. A study conducted by Associação dos Celíacos do Brasil in eight retail stores concluded that there was low availability and variety of GF food products when compared to GC products available to the consumer. In addition, it reveals a situation that restricts food choices and interferes on the daily management of coeliacs (19). Also, 52.2% of the participants considered the absence of the GF-symbol in the products label a difficulty, which is in line with the literature (6, 7, 20, 21). This way, it can be concluded that inadequate labelling is one of the biggest barriers in strict compliance with a GFD. Conformingly, a study performed in England settled that not understanding the foods label increased the risk of not following a GFD (22). In fact, coeliacs spend on average about an extra 10 to 20 hours per month in grocery shopping when analyzing food labels regarding gluten content (13, 22, 23). Likewise, a total of 45.7% of the participants considered the "Lack of GF food products offer, at an affordable price" as one of the difficulties. In line with this, APC conducted a study that settled that GF food products are 2,5 times more expensive comparing to GC products (14). Analyzing this economic burden, we must reflect its consequences in strict compliance with the GFD as several studies show that the price of GF products may be related to nonadherence to the GFD (7, 13, 19).

About the main difficulty faced by the participants when out-of-home eating, the most selected option was the "Lack of information and unconcern of the establishments' staff". A study in 58 bakeries in Brazil stated that, in most cases, the bakery employees informed verbally that certain products were GF although 23,7% of them were contaminated (24). A literature review showed that, as proved in multiple studies, dining establishments were unable to provide a secure experience for coeliacs, leading to the occurrence of GCC (7).

This study has some limitations to be considered. The survey was conducted online which biased the sample as it required digital literacy skills. Moreover, it was online for only one month and there is no unequivocal proof of the correct diagnosis of CD, as well as the compliance with the GFD. The compliance is difficult to measure, but it has been suggested that it should be achieved via a combination of assessing clinical symptoms, serum antibodies and a follow-up biopsy (10). Yet, more studies are needed to define it. Plus, a convenience

sample was used leading to sampling bias as it is not representative of the entire population. Also, a mixed tool was applied however based in two previously validated questionnaires. Nevertheless, this is the first study in Portugal that identifies the major difficulties that Portuguese coeliac adults' face daily. Also, there was a significative number of participants to the online questionnaire, which means that Portuguese coeliac adults are interested in this topic. Likewise, there was a representative sample of all Portugal's regions. In the future, it would be noteworthy to apply this questionnaire in other countries to reflect and compare the results between them.

CONCLUSIONS

Reflecting on the results obtained, it can be concluded that the major difficulties that Portuguese coeliac adults confront every day, concerning the self-reported compliance with the GFD are the absence of the GF-symbol in the products label, the risk of GCC, the availability of GF products in public places, the lack of GF food products offer, at an affordable price whereas regarding out-of-home eating it is the lack of information and unconcern of the establishments' staff.

The role of patient support groups and education provided by a followup team with professional skills in CD should always be considered as they are vital for its management and its long-term outcome as it enhances compliance and maintenance of a healthy diet and way of living, preventing potential nutritional deficiencies and other associated complications of CD.

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