

AVAILABILITY AND FINANCIAL DEMANDS OF A GLUTEN-FREE DIET

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Abstract

Celiac disease (also known as celiac sprue or gluten-sensitive enteropathy, or gluten enteropathy) is a term for a lifelong chronic autoimmune disease. One of the primary therapeutic approaches is introducing a special gluten-free diet. This diet is demanding in terms of preparation, finances, and availability.

We cooperated with a nutritional therapist and a general nurse working in a gastroenterology surgery to achieve the goal of finding out the availability of a gluten-free diet when eating out, the reasons why patients most often violate the set diet, and the financial demands of a gluten-free diet compared to a normal diet.

We used a questionnaire to obtain information about these problems. The questionnaire was sent electronically to patients who had been diagnosed with celiac disease and confirmed that they followed a gluten-free diet. They filled in the questionnaires anonymously and sent them back to the researcher. We used 296 questionnaires for evaluation.

The results showed that 20.3% of respondents did not go to mass caterers (for many reasons). The remaining 79.7% went to such facilities despite dietary restrictions. 80% of respondents reported going to such facilities less than once a week. 11.7% of respondents go to such facilities once a week, and 8.4% go there every other day. Another reason for not going to such facilities is a higher price than a regular diet.

Keywords: *Availability of meals; Celiac disease; Dietician; Diets away from home; Financial demandingness; Gastroenterological surgeries*

INTRODUCTION

Celiac disease (gluten enteropathy, non-tropic sprue, celiac sprue, Herter's disease) is a systemic autoimmune disease caused by gluten (or its component gliadin and similar prolamins) in genetically susceptible individuals with concomitant intestinal barrier disorders (Hes et al., 2014; Kasper, 2015). Subsequently, each gluten-containing food causes an inflammatory reaction and severe damage to the mucosa of the small intestine (or entero-

cytes), with subsequent manifestations of fat malabsorption, fat-soluble vitamins, protein-energy malnutrition, and other manifestations resulting from insufficient absorption of essential nutrients. It can be clinically different and asymptomatic (Zlatohlávek et al., 2017).

The extent of clinical manifestations depends on the cause and level of malabsorption. The most common symptoms include unwanted weight loss, malnutrition, diarrhoea, steatorrhoea, swelling of the lower limbs in hypoalbuminemia,

anaemia, osteoporosis, increased risk of cancer, fertility impairment or increased abortions, foetal malformations, and premature births (Hes et al., 2014; Oliverius et al., 2017).

Celiac disease is a disease that can be affected by diet. Diet is a cure, making following a gluten-free diet a lifelong necessity. A gluten-free diet eliminates all gluten-containing foods (Hes et al., 2014; Kasper, 2015). These are mainly cereals, such as wheat, rye, barley and oats, and products made of these (Silano et al., 2007). In some countries, oats are permitted on a gluten-free diet. Oats are contaminated with wheat, rye or barley in the Czech Republic and are therefore not among the allowed foods (Kasper, 2015). It is forbidden to consume products made of selected flour (pastries, pasta, dumplings, confectionery), flakes, groats, semolina, and seitan - a vegetable meat substitute with a high gluten content (Estévez et al., 2016).

A gluten-free diet focuses on the intake of naturally gluten-free foods, such as potatoes, rice, corn, legumes, buckwheat, millet, quinoa, amaranth, soy, fruits, vegetables, meat, eggs, mushrooms, sugar, honey, coffee (not coffee substitutes), tea, cocoa, milk and dairy products (Rimárová et al., 2020). However, it is always necessary to check that the food does not contain gluten, as it often occurs even where we would not expect it (Kohout et al., 2010). People with celiac disease are notified of suitable food choices via a crossed-out ear symbol that can be found on gluten-free foods (Association of Celiacs of the Czech Republic, 2020; Kohoutková, 2018).

Disorders of disaccharidases, most commonly lactose intolerance, can also occur with celiac disease (do Nascimento et al., 2014; Lukáš et al., 2003; Zlatohlávek et al., 2016).

One of the primary therapeutic approaches is the introduction of a special gluten-free diet. It is a demanding diet in terms of preparation, finances, and the availability of raw materials (Lee et al., 2019).

We cooperated with a nutritional therapist and a general nurse working in a gastroenterology surgery to achieve the goal of finding out the availability of a gluten-free diet when eating out, the reasons why patients most often violate the set diet, the availability of gluten-free food, and the financial demands of a gluten-free diet compared to a normal diet.

MATERIALS AND METHODS

We used an interrogation method to get information about these problems. The 26 questions in the questionnaire were aimed at gathering information about the availability of a gluten-free diet, eating out, violating the diet, or its financial demands. We consulted and processed the questionnaire's content in cooperation with a general nurse working at a gastroenterology clinic. We sent the questionnaire electronically. The questionnaire was posted on the Society for Gluten-Free Diet, Association of Celiacs of the Czech Republic websites, and social networks, where data collection took place using the "snowball" method. Only respondents who have celiac disease answered. The anonymous questionnaire was completed by 406 respondents. We excluded 110 questionnaires for incompleteness and evaluated 296 questionnaires.

We processed the questionnaires individually and entered the data into the database.

The group consisted of 88.4% women and 11.6% men, i.e., 260 women and 34 men. 52.4% were aged 20–40 years, 26.4% were aged 40–60, 16.2% were aged up to 20 years, 4.7% were between 60–80 years, and 1 respondent (0.3%) was over 80.

RESULTS

Catering in establishments and school canteens

We wanted to determine whether the respondents ate in public catering establishments (restaurants, school canteens, and others). The results showed that 20.3% of respondents did not go to catering establishments. There were many reasons for this: they were uncertain of contamination, there were no establishments in the area that offered a gluten-free diet, their dietary restrictions were more extensive, or the prices were higher than for a regular diet. 79.7% of respondents continued to go to these facilities despite the nutritional limitations. Of these, 80% reported going to such facilities less than once a week, 11.7% of respondents go once a week, and the remaining respondents (i.e., 8.3%) go every other day (Table 1).

Table 1 – Catering in mass caterers

School cafeterias (96 respondents)	No catering options	30.0%		
	They have catering options	70.0%	Do not use this option (70%)	11.4%
			They use this option (70%)	88.6%
Mass caterers (296 respondents)	Do not go	20.3%		
	Do not go	79.7%	<1/a week (79.7%)	80.0%
			1/a week (79.7%)	11.7%
			3/a week (79.7%)	8.3%

School canteens are only used by children and students, while mass caterers are used by all respondents, including children and students.

We wanted to determine whether the range offered in the catering establishments was sufficient in relation to gluten-free diets. 258 respondents (87.1%) rated it as insufficient.

70% of respondents (out of 96 respondents) have the opportunity to eat in school cafeterias.

The most common reasons for respondents not using the option of eating in canteens are distrusting the accuracy of reported allergens, frequent contamination of gluten-free foods with gluten, poor taste, or having a stricter diet due to other diseases.

When evaluating the selection offered, 5.2% (i.e., 5 respondents) out of 96 respondents in school canteens stated that they were satisfied. The remaining 94.8% (i.e., 91 respondents) indicated dissatisfaction with the selection.

We looked into the attention given to diet meals at school canteens. Only 2% of respondents (i.e., 2 respondents) rated it as fully adequate, while 25% (i.e., 25 respondents) rated it as partially satisfactory. 36% (i.e., 34 respondents) evaluated it as entirely insufficient, and the remaining 37% (i.e., 35 respondents) could not assess this issue (Chart 1).

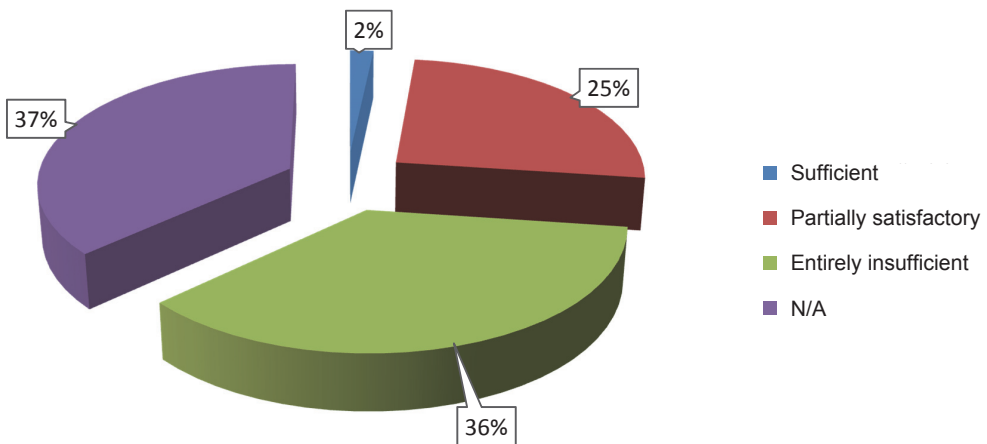


Chart 1 – Evaluation of dietary meal quality at school canteens

Respondents' diets

71% of respondents said they have never broken their diet (Chart 2). 26% reported exceptional dietary violations, and only 3% re-

ported frequent violations. The reason for the remaining 8.3% is the high price of gluten-free foods. They consider this to be a strong reason for violating the diet.

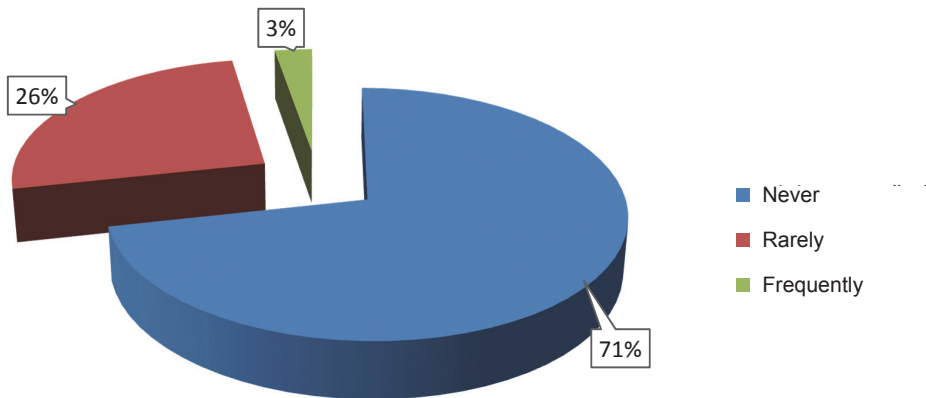


Chart 2 – Frequency of dietary violations among the respondents (296 respondents)

Financial demands of a gluten-free diet

Looking at the financial demands of gluten-free diets, the use of financial support from insurance companies is low. 53.6% of respondents do not receive any financial contributions for more expensive raw ingredients. 39% receive financial contributions from their health insurance company in various amounts, and 7.4% did not know they could obtain any.

We studied which insurance companies the respondents were registered with (Chart 3). 167 respondents (56.4%) were registered with the General Health Insurance Company, 43 (14.5%) were with the Health Insurance Company of the Ministry of the Interior of the Czech Republic, 29 (9.8%) were with the Czech Industrial Health Insurance Company, 20 (6.8%) were with the Branch Health Insurance Company of Bank, Insurance Companies and Construction Employees, 13 (4.4%) were with RBP (District Fraternal Office), 12 (4.1%) were at the Military Health Insurance Company of the Czech Republic, 9 (3.0%) were with the Škoda Employees' Insurance Company, and 3 respondents (1.0%) were insured abroad.

All contributions are up to CZK 6,000 (Chart 4). Only 16.9% of respondents received

the highest amount, 49.5% received CZK 3,000, 16.4% received CZK 500, 9.1% received CZK 4,000, and 8.1% received CZK 1,000.

Given that the right diet is a cure for celiac disease, we also asked respondents about how much the financial contribution would need to be to cover the cost of gluten-free meals per year. 52.5% of respondents would need CZK 10,000 for expenses related to gluten-free meals. 17.4% stated that CZK 6,000 would be sufficient. 5.3% needed 12,000 CZK per year, and 3.5% needed CZK 36,000. That gives a total of 78.7%. Other requirements were individual and not included in the results.

71% of respondents would welcome financial aid, while 29% find it unnecessary and would welcome such aid for raw ingredients.

62.7% of respondents state that the household financial expenditure for a gluten-free diet compared to normal diet is 50% higher than a regular diet. 37.3% state that their expenditure is less than 50% higher.

We received 157 answers to how the state cares for celiacs. 83 (53%) rated it as entirely insufficient, 5 (3%) rated it as inadequate, and 52 (33%) rated it as partially sufficient. 17 respondents (10%) could not answer this question (Chart 5).

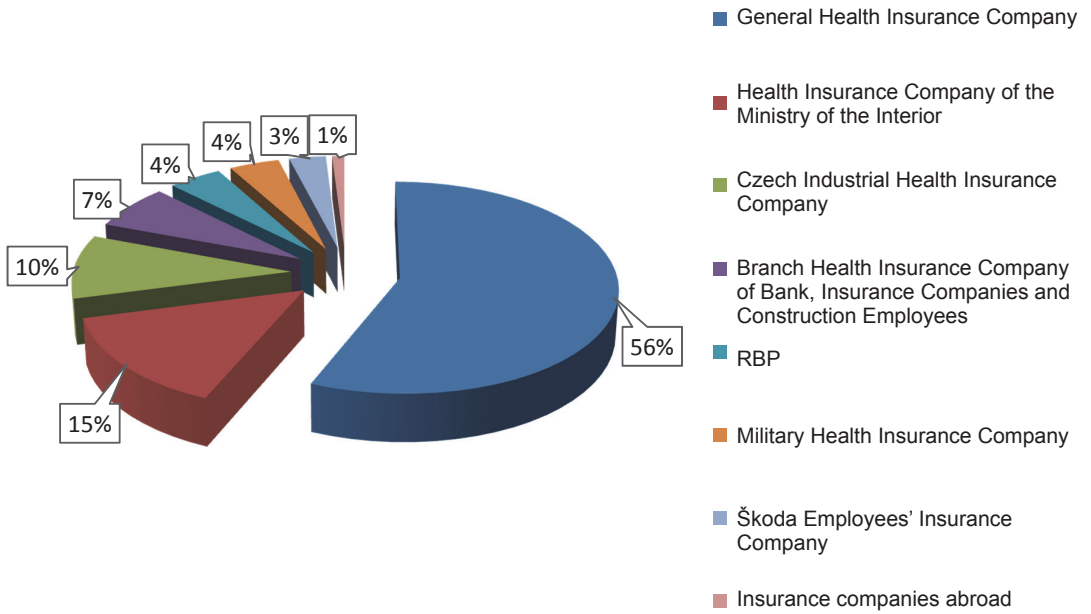


Chart 3 – Respondents' insurance companies

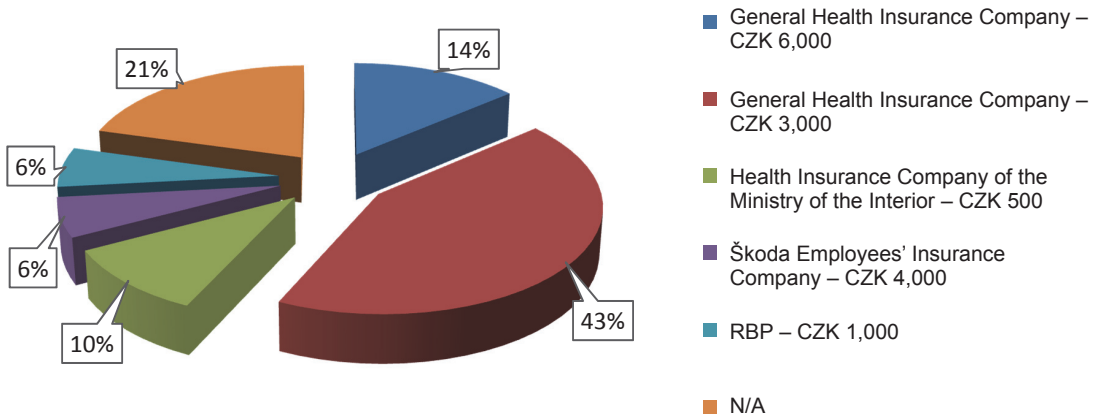


Chart 4 – Financial contributions from insurance companies (296 respondents)

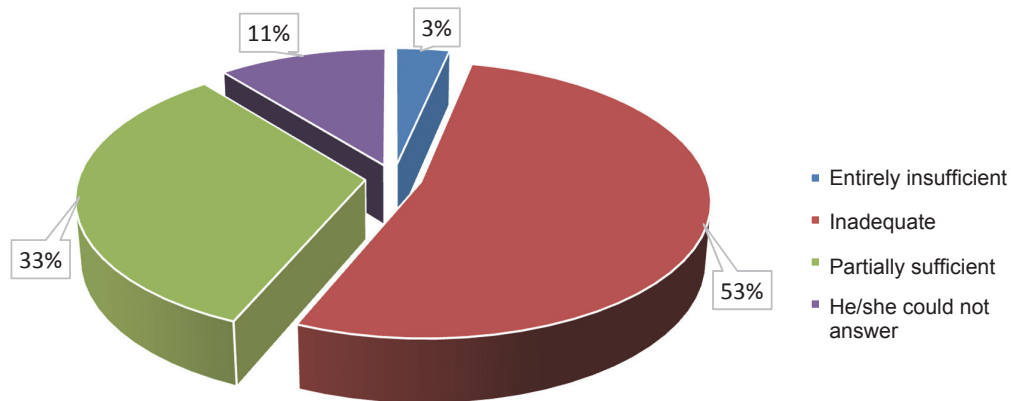


Chart 5 – State care for celiacs (157 respondents)

To evaluate patients’ approach to diet, a price list of individual foods with and without gluten is essential (Table 2).

Prices for meals in restaurants are reasonable for 51.4% of respondents, but for 48.6% they are too high in relation to their monthly expenses and income.

In conclusion, a common reason for non-compliance is that the treatment based primarily on proper adherence to dietary measures, with contributions to this type of diet being optional.

Table 2 – Price comparison of 100 grams of food with and without gluten (Singh and Whelan, 2011)

Food category (converted to 100 g)	Average price for food with gluten (CZK)	Average price for food without gluten (CZK)	Difference
Bread	3	21	700%
Pastry	5	33	660%
Pasta	5	15	300%
Flour	2	11	550%
Baguette	6	35	583%
Children’s biscuits	11	30	273%
Cake	14	33	236%
Breadcrumbs	6	18	300%

DISCUSSION

Our results show that 30% of respondents do not have the opportunity to go to school canteens due to a lack of gluten-free meals. 79.7% of respondents go to standard establishments. The main reason that people do not go to these establishments is that they distrust the offered gluten-free food (despite the mentioned allergens). This distrust stems from previous

bad experience or staff’s unawareness of such dietary needs (possible risk of contamination or selection of gluten-free ingredients). 80% of the respondents go to such establishments less than once a week. Only 8.3% go there every other day. A Canadian study (Bascañán et al., 2017) assessed contamination in 640 samples of naturally gluten-free flour and starch. The results were staggering. 9.5% showed traces of gluten at 5–7995 ppm. Due

to these results, it is recommended to measure prolamins only in ready meals. Rimárová et al. (2020) point out the issue of the purity of gluten-free products and warn of shortcomings in the composition of gluten-free foods.

Our study included why respondents did not go to establishments such as canteens. 20.3% of respondents who do not go to such establishments distrust the product purity and fear contamination (after previous experience). However, in the case of such a large amount of flour and starch contamination, going to restaurants and the preparing of food at home can be risky.

Despite gluten-free diets being the only safe and successful treatment for celiac disease, adopting the indicated dietary restrictions for patients suffering from this disease can be challenging. Such difficulties can be reflected in the work and social life. Adherence to dietary restrictions depends on the clinical and nutritional course of the disease, and the development of complications and consequences that affect the quality of life (Bascuñán et al., 2017).

When asked whether adopting and accepting new eating habits was problematic, 70.9% of respondents answered “yes” or “partially”. Thus, we can say that the intervention in eating habits is a big problem for patients with celiac disease – in their personal life, as well as the work and social environment. According to our results, 65% of respondents strictly follow their diet, 23.7% rarely violate dietary restrictions, and only 2.7% often violate the

set regime. Thus, we can say that most patients follow the gluten-free diet for fear of complications or worsening of the disease, which would subsequently reduce their quality of life.

Despite partial support from health insurance companies, this diet is costly. In many neighbouring countries, there is no support (Deleanu et al., 2014). By studying the literature related to the topic, we obtained information on the financial demands of a gluten-free diet for university students. Even in this age group, the results show the financial cost of gluten-free ingredients, as respondents reported buying cheap gluten foods rather than gluten-free foods so as not to exceed their monthly budget (Sparks et al., 2019).

We received 157 answers that point to low support in relation to state care. When we looked into the amount they receive, most respondents answered CZK 3,000, but each for a different period. It was not specified in the questionnaire, so we are unaware of the exact amount. Many respondents also commented on the amount received as symbolic or negligible. Therefore, we asked what amount they thought would be enough per year to cover the annual cost of a celiac disease diet. 157 respondents (52.5%) answered CZK 10,000. Fewer answered with CZK 6,000, CZK 12,000, CZK 24,000, or CZK 36,000. Some answered with CZK 120,000. The study of Kohout and Starnovská (2006) showed the higher financial demand of a gluten-free diet (CZK 28,800 per year) than a regular diet. Kosíková (2021)

Table 3 – Comparison of individual insurance companies’ financial contributions for gluten-free nutrition

Insurance company	Financial contribution	Conditions
General Health Insurance Company	6,000 CZK/year	Only children and students up to 26 years
Czech Industrial Health Insurance Company	1,000 CZK/year	Only children
Branch Health Insurance Company of Bank, Insurance Companies and Construction Employees	3–5% for buying GF foods	When buying GF foods online at elepek.cz
RBP	1,000 CZK/year	All with a confirmation
Military Health Insurance Company	N/A	
Škoda Employees’ Insurance Company	4,000 CZK/year, 5% for buying GF foods	All with a doctor’s confirmation and when buying GF foods online at elepek.cz
Health Insurance Company of the Ministry of the Interior	500 CZK/year	All with a doctor’s confirmation

states a gluten-free diet costs CZK 7,524 more than a normal diet.

The results are similar to those obtained in other countries. The study shows that gluten-free diets are 159% more financially demanding (Fry et al., 2017).

Table 3 (see previous page) compares gluten-free meals from individual insurance companies (Kosíková, 2021).

Our results show that most respondents are registered with the General Health Insurance Company (56.4%), which has the highest contributions under the age of 26. The next most represented is the Health Insurance Company of the Ministry of the Interior of the Czech Republic, which contributes CZK 500/year (but only with a doctor's confirmation). Many respondents do not even know the extent of contributions from competing insurance companies. This data corresponds to our results.

In our study, 62.7% of respondents stated that the price of a gluten-free diet is more than 50% higher than a regular diet. It can be seen

from the table above that the raw ingredients are many times more expensive.

CONCLUSIONS

This study is an overview of celiac disease pathogenesis. We emphasised the importance of a gluten-free diet. Unfortunately, the comprehensive provision of a gluten-free diet is not always available. The respondents' distrust the quality of so-called gluten-free foods, especially whether the food is actually gluten-free. Support from both health insurance companies, and the state is low, therefore the financial costs also determine the use of a gluten-free diet.

The results show that the situation regarding the diet of celiacs corresponds with the European standards.

Ethical aspects and conflict of interests

The authors have no conflict of interests to declare.

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