

# The impact of a gluten-free diet on adults with coeliac disease: results of a national survey

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## Abstract

**Objective** We sought to evaluate the impact of the gluten-free diet on the 5,240 members of the Canadian Celiac Association (CCA). Data are presented on 2,681 adults ( $\geq 16$  years) with biopsy-proven celiac disease (CD).

**Methods** A mail-out survey was used. Quality of life was evaluated using the 'SF12', and celiac-specific questions.

**Results** Mean age was 56 years, mean age at diagnosis was 45 years, and 75% were female. The 'SF12' summary scores were similar to normative Canadian data, but were significantly lower for females and newly diagnosed patients.

Respondents reported: following a gluten-free (GF) diet (90%), improvement on the diet (83%), and difficulties following the diet (44%), which included: determining if foods were GF (85%), finding GF foods in stores (83%), avoiding restaurants (79%), and avoiding travel (38%). Most common reactions to consumed gluten (among 73%) included pain, diarrhea, bloating, fatigue, nausea, and headache.

Excellent information on CD and its treatment was provided by the CCA (64%), gastroenterologists (28%), dietitians (26%) and family doctor (12%).

**Conclusions** Quality of life in those with CD could be increased with early diagnosis, increased availability of gluten-free foods, improved food labelling, and better dietary instruction. Education of physicians and dietitians about CD and its treatment is essential.

## Introduction

Coeliac disease (CD) or gluten-sensitive enteropathy (GSE) is a genetically based autoimmune disease characterized by a life-long intolerance to specific storage proteins in wheat (gliadin), rye (secalin) and barley (hordein), which are collectively called 'gluten'. In CD, gluten triggers the progressive damage to the mucosal villi of the small intestine (Fasano & Catassi, 2001). Malabsorption of iron, folate and calcium is common as these nutrients are absorbed in the proximal small bowel. As the disease progresses along the intestine, malabsorption of carbohydrate, fat and the fat-soluble vitamins A, D, E and K, and other micronutrients occurs. Secondary lactose intolerance resulting from decreased lactase production by the damaged villi is also common (Ojetti *et al.*, 2005). While the symptoms of CD can develop in infancy after the introduction of gluten-containing cereals, it is very common for the disease to manifest itself during adulthood (Fasano & Catassi, 2001).

Research indicates that CD is much more prevalent than once thought. A large epidemiological study of the United States population estimated a prevalence rate of one of 133 (Fasano *et al.*, 2003). The National Institutes of Health Consensus Development Conference Statement estimated that CD affects 3 millions Americans, which is slightly <1% of the population, and is similar to prevalence estimates in Europe (NIH, 2004).

Untreated CD is associated with an increased risk of developing other diseases, such as osteoporosis (Meyer *et al.*, 2001; Corazza *et al.*, 2005), reproductive problems in both women and men (Nørgård *et al.*, 1999; Gasbarrini *et al.*, 2000; Stazi & Mantovani, 2000; Ludvigsson & Ludvigsson, 2001), neurological illness (Collin *et al.*, 1991; Hadjivassiliou *et al.*, 1996), cancer (Holmes *et al.*, 1989; Green *et al.*, 2001; Smedby *et al.*, 2005) and possibly the development of other autoimmune diseases (Ventura *et al.*, 1999; Hakanen *et al.*, 2001; Sategna Guidetti *et al.*, 2001). Early diagnosis and treatment usually result in mucosal recovery and a reduced risk of developing associated conditions (Holmes *et al.*, 1989; Nørgård *et al.*, 1999; Martinelli *et al.*, 2000; Corazza *et al.*, 2005).

Currently, the only treatment for CD is a strict gluten-free (GF) diet for life. Although this gives the individual with CD the opportunity to assume control over his or her own treatment, changing life-long dietary patterns, especially in adults, is not easy (Sverker *et al.*, 2005). The GF diet is complex and difficult to follow (Mäki & Collin, 1997). For many patients with CD, following a GF diet involves significant negative changes in lifestyle (Hallert *et al.*, 1998; Green *et al.*, 2001; Dennis & Case, 2004; Sverker *et al.*, 2005).

There is little Canadian data on the impact of the GF diet on the quality of life of individuals with CD. To obtain such data, the Canadian Celiac Association (CCA) developed the Canadian Celiac Health Survey, which included an extensive section on the GF diet and its impact on quality of life. The objectives of the dietary survey were:

- 1 to determine the impact of having to follow a GF diet on the quality of life of individuals with CD;
- 2 to assess compliance with the diet and identify difficulties experienced with following such a diet and
- 3 to evaluate sources of information about the disease and its treatment.

This study reports the dietary results of this survey among respondents 16 years and older. The paediatric results from this survey have been published (Rashid *et al.*, 2005). The medical results will be published separately.

## Materials and methods

The Canadian Celiac Health Survey was developed as a mail-out questionnaire by the Professional Advisory Board of the CCA, in collaboration with faculty from the Department of Epidemiology and Community Medicine of the University of Ottawa. Of the 76 questions included in the survey, half were related to the GF diet. Quality of life was evaluated using the generic quality of life instrument the Short Form 12 ('SF-12') (Riddle *et al.*, 2001) and a series of coeliac-specific questions. The questionnaire was reviewed by two international experts in CD. The questionnaire carried no respondent identification, to ensure anonymity. Only one family member with CD, per household, was instructed to complete the questionnaire

because memberships in the CCA are family memberships.

Ethics approval was received from Queen's University, Kingston, Ontario. The Canadian Celiac Health Survey was piloted by the Ottawa Chapter of the CCA in October 2001 (Cranney *et al.*, 2003).

Requests for CCA members to take part in the national Canadian Celiac Health Survey were made at meetings of the local chapters, and in the CCA newsletter. The questionnaire was mailed to all CCA members ( $N = 5240$ ) in October 2002, along with a letter of introduction and a self-addressed, postage-paid envelope for returning the questionnaire to the University of Ottawa for analysis of results. The respondents were requested to return their completed questionnaires by the end of October 2002.

### Analysis

Data were analysed using SPSS v10 for Windows. Logic checks were performed using cross-tabulations for key variables. The proportion of respondents choosing different options was calculated for each question. Where relevant, Student's *t*-test for continuous variables and chi-squared test for discrete variables were performed when comparing two groups.

### Results

A 65% response rate ( $n = 3408$ ) was received after one mail-out, and included respondents from all 10 provinces. Five hundred and four (15%) of the respondents did not have biopsy-proven CD and were excluded from the analysis. Another 55 were

excluded because they did not complete the questionnaire adequately. Data from 2681 adults and 168 children (under 16 years) with biopsy-proven CD were analysed.

Of the 2681 adult respondents, 74.5% were female, and 25.5% were male (ratio 3/1), and their mean age was 56 years (SD: 15, range: 16–90). The majority of participants (69%) had some post-secondary education. The mean age at diagnosis was 46 years and the mean duration of disease after diagnosis was 10 years. Seven percentage were first diagnosed as children, and of these 57% (i.e. 4% of total respondents) reported that their symptoms disappeared and then reoccurred during adulthood.

### Impact of gluten-free diet

Ninety-seven percentage of the respondents had been instructed to follow a GF diet for life. Eighty-six percentage were referred to a dietitian. When asked if they followed a GF diet, 90% described their diets as strictly GF. Eight percentage reported following a 'partial gluten-free' diet. Reported changes in health after the introduction of a GF diet were 'improved a lot' (83%), moderate improvement (13%), little improvement (3%) and no improvement (1%).

Difficulties identified in following a GF diet included lifestyle changes such as avoiding travel and eating outside the home. Other problems included finding GF foods, especially those of good quality, determining whether foods were GF, and not being invited out because of the diet. Maintaining a GF diet when in hospital was also identified as a concern. These difficulties are summarized in Table 1.

**Table 1** Impact of a gluten-free diet

	All of the time (%)	Most of the time (%)	Some of the time (%)	Never (%)	N/A or do not know	<i>N</i>
Brought gluten-free foods when travelling	53	22	19	6	0.2	2590
Avoided restaurants	6	27	48	19	–	2631
Had difficulty finding good quality gluten-free foods	8	22	53	17	–	2597
Had difficulty finding gluten-free foods	6	19	60	15	–	2608
Could not determine if foods were gluten-free	5	13	67	15	–	2631
Avoided travelling	3	10	25	62	0	2611
Worried about staying in hospital because of CD	8	5	14	72	1	2546
Felt left out of meal invitations because of CD	2	6	28	63	1.0	2591

### Quality of gluten-free information

The perceived quality of GF information received varied depending on the source. Seventy-nine percentage reported receiving information from a dietitian. Twenty-six percentage reported that this information was excellent and 28% reported it was very good, which was similar to ratings for information provided by gastroenterologists (28% excellent and 27% very good). The CCA and its local chapters were reported to be the best sources of information (64% excellent, 27% very good). Information from family doctors was rated lowest (12% excellent, 20% very good). The quality of information provided by these sources is summarized in Table 2.

### Sensitivity to gluten

Sensitivity to gluten varied greatly from one individual to another, with 73% (1943 of 2645) reporting clinical symptoms when they knowingly consumed gluten. Symptoms included: abdominal pain (80%), diarrhoea (77%), bloating or flatulence (74%), extreme weakness or fatigue (40%), nausea and vomiting (26%), headache (23%), itchy skin (21%), constipation (15%), insomnia (12%), mouth ulcers (8%). The mean time of onset of the first symptom after gluten ingestion was 6.4 h (median 2.5 h;  $n = 1812$ ).

### Quality of life

Short Form 12 Health Survey scores (Ware *et al.*, 1995; Riddle *et al.*, 2001) were used to estimate overall generic health-related quality of life, and the results were compared with normative Canadian data on the SF-36 (Hopman *et al.*, 2000). The

mean scores ( $N = 2421$ ) were very similar to the summary scores for the Canadian population. However, when analysed according to gender, the mean scores were significantly lower in women than in men. In addition, respondents diagnosed within the last year ( $N = 298$ ) reported lower scores than those who had been diagnosed for more than a year (Case & Zarkadas, 2004).

### Recommendations from the respondents

In the present survey, CCA members were asked what would contribute most to improving the lives of individuals with CD. The most frequent responses in descending order were early diagnosis (60.5%), better food labelling (52%), more GF foods in the supermarket (39.8%), more GF choices on restaurant menus (27.5%) and better dietary counselling (12.9%).

## Discussion

### Impact of a gluten-free diet

Ninety percentage of the respondents reported following a totally GF diet all the time. This figure was higher than that reported in a Quebec survey, in which 90% of respondents avoided all GF foods as much as possible, whereas many admitted eating GF foods by mistake (65%), by choice (36%) and by obligation (27%; Lamontagne *et al.*, 2001). A recent US survey ( $n = 1138$ ) reported that 68% followed a strict GF diet all the time and 30% most of the time (Green *et al.*, 2001).

Once on a GF diet, 83% of respondents reported feeling 'a lot better', which is similar to the 77% reported by Green *et al.* (2001). Although recovery from many coeliac symptoms can be very rapid, not all individuals respond fully to the diet (Murray, 1999; Fasano & Catassi, 2001). In a recent study on the aetiology of nonresponsive CD, investigators concluded that gluten consumption (either intentional or unintentional) caused continued symptoms among more than 50% of patients studied (Abdulkarim *et al.*, 2002; Green & Jabri, 2003). Among the remaining respondents, associated conditions that accounted for persistent symptoms included pancreatic insufficiency,

**Table 2** Quality of information received according to source

Source	Excellent (%)	Very good (%)	Good (%)	Fair/poor (%)	<i>N</i>
CCA	64	27	8	1	2512
Local CCA chapter	64	26	7	3	2256
Gastroenterologist	28	27	23	22	1670
Dietitian	26	28	22	24	2047
Family doctor	12	20	28	40	790

irritable bowel syndrome, bacterial overgrowth and collagenous colitis (Abdulkarim *et al.*, 2002). Patients with nonresponsive CD require close follow up by doctors and dietitians with expertise in CD to ensure that no other conditions are present, that the diet is followed carefully (NIH, 2004; Case, 2005a; Pietzak, 2005), and the advantages of following the diet are well understood (Ciclitira *et al.*, 2005).

Learning to follow a GF diet is challenging and often involves major changes in life-long dietary patterns (Hallert *et al.*, 1998; Green *et al.*, 2001; Dennis & Case, 2004; Sverker *et al.*, 2005). The three cereals that must be avoided on this diet are wheat, rye and barley (Kasarda, 1994). These cereals serve as the primary grains in most cereal-based foods in North America and Europe, including breads, cakes, cookies, pastries, pasta products, breakfast cereals and many snack foods. In addition, wheat is frequently used as a thickener/binder in many soups, sauces and dressings, deli meats, sausages, meat patties and artificial seafood, and as a coating on meat, poultry and fish (Zarkadas & Case, 2005). Most soy sauce is wheat-based, and barley malt is used in the manufacture of beer. Although corn and rice are permitted in the diet, many corn and rice-based breakfast cereals contain barley malt, and cannot be included in the GF diet (Case, 2005a).

Manufacturers often change product formulations, and ingredient lists must be checked at each purchase, even on frequently purchased foods. Newly diagnosed patients with CD must learn where hidden sources of gluten might be present in foods, and must become expert label readers. This was reflected by the 85% of respondents in this survey who reported having problems determining whether foods are GF. This is higher than the 80% reported in the CCA survey of 1989 (Campbell *et al.*, 1991), possibly because of the greater number of GF foods now available on the market.

Gluten is sometimes present in foods as a 'hidden' ingredient (Zarkadas *et al.*, 1999; Lee, 2005). For example, hydrolysed proteins and modified starches are sometimes made from wheat, and seasonings sometimes contain wheat flour or wheat starch. Labelling regulations requiring the identification of all gluten-containing ingredients

in foods will come into effect in Europe and the UK in November 2005 (European Union, 2003). In the United States new regulations requiring the identification of all wheat-containing ingredients in foods will become mandatory in January 2006 (USFDA, 2004). In Canada, GF foods are defined under the Food and Drug Regulations (Health Canada) and amendments requiring the declaration of the plant source of hydrolysed proteins and modified starches, and gluten-containing ingredients in seasonings and other mixtures, are being drafted in preparation for publication (written communication).

In this survey, respondents reported difficulty in finding GF foods (83%), especially GF foods of good quality (85%), even though a much wider variety of GF foods has become available in recent years (Case, 2005b). To help its members determine which food ingredients are safe and which must be avoided, the CCA has developed a *Pocket Dictionary: Acceptability of Foods and Food Ingredients for the Gluten-free Diet* (Canadian Celiac Association, 2005), which is available from <http://www.celiac.ca>.

#### Sources of dietary information

In the present study, 86% of the respondents were referred to a nutritionist, compared with 66% in a recent US survey (Green *et al.*, 2001). The CCA and its chapters received the highest rating as an excellent source of information on CD and the GF diet, in both this survey and in the CCA survey of 1989 (Campbell *et al.*, 1991). Although sponsorship of this survey by the CCA may introduce bias in its ratings as an information source, it is known that patients who are active in a support group are often more compliant and knowledgeable about the diet (Murray, 1999), and role of local advocacy groups has been recognized as essential (NIH, 2004).

Ratings of the quality of information provided by dietitians and doctors in the present survey were low (Table 2). The low number of respondents reporting on the quality of information from gastroenterologists and family doctors, in Table 2, may reflect that few respondents received dietary information from these practitioners.

A survey of individuals with CD from Quebec ( $n = 234$ ) indicated that only 44% of the respondents rated dietitians as a knowledgeable source of information, and only 55% of the respondents had a high level of confidence in the information provided by dietitians (Lamontagne *et al.*, 2001). In a study of the attitudes of 160 patients with CD, 75% had been referred to a dietitian, and 53% found the dietitian helpful and 54% said the dietitian was knowledgeable about the disease and its treatment (Tidwell & Bomba, 2001). In another recent survey, only 13% of respondents ( $n = 253$ ) reported that they had received information from a dietitian, and of those only 21% found it useful (Lee & Newman, 2003).

Medical nutrition therapy, in the form of a strict GF diet for life, is currently the only treatment for CD. Because of improved screening methods, and a greater recognition by the medical profession of the extra-intestinal symptoms associated with CD, diagnosis of CD is improving. However, it is essential that doctors and dietitians become more knowledgeable about this disorder and the GF diet (Dennis & Case, 2004; NIH, 2004). Earlier diagnosis, effective counselling and careful follow up of patients with CD can greatly improve their health and reduce their risk of developing complications such as osteoporosis, reproductive problems, autoimmune diseases and other associated conditions (Pietzak, 2005).

### Reactions to gluten

Reactions to consumed gluten among respondents ranged from no clinical symptoms to severe reactions. Gastrointestinal symptoms were the most common, but fatigue, headaches, itchy skin, insomnia and mouth ulcers were frequently reported. Reported reactions to gluten were almost identical with those reported in the pilot study, with the exception of abdominal pain which affected 80% of the national respondents, compared with 66% in the pilot test (Cranney *et al.*, 2003). Avoidance of symptoms, rather than avoidance of complications of untreated CD, is reported to be the main motivating factor in individuals with CD (O'Leary *et al.*, 2004). Among those who travelled, 94% reported carrying food

with them some or all of the time, possibly to help avoid such reactions.

### Quality of life

The perceived quality of life scores reported were similar to those of the general Canadian population. These scores differed from a Swedish study (Hallert *et al.*, 1998) in which patients with CD on a GF diet for 10 years scored significantly lower on the SF-36 than the general population. However, in both this Canadian survey and the Swedish study, lower quality of life scores were reported by women. A follow-up study in Sweden reported that women with CD perceived the disease burden to be worse than men do, and suggested that inquiry is warranted into the way men and women with CD cope with the disorder (Hallert *et al.*, 2002).

The lower scores reported in the first year after diagnosis were not unexpected, because the difficulties encountered in learning and following a GF diet, and the lifestyle changes that it imposes, especially in the initial stages, can often be overwhelming (Murray, 1999).

The results of the present survey were compared with those of the 1989 CCA National Survey (Campbell *et al.*, 1991). Over the last 13 years concern about eating in restaurants has dropped from 93% to 79%, and avoiding travel has dropped from 93% to 38%. The results of this survey are more positive than those reported in a recent US coeliac survey ( $n = 274$ ) in which difficulties in eating out were reported by 86%, and in travelling by 82% of the respondents (Lee & Newman, 2003). These authors postulated that when a diet limits a person's ability to dine out or travel it impacts negatively on quality of life, as socializing is greatly affected.

Another concern is whether GF foods will be available during a hospital stay. The results were similar to reports by patients who had received gluten-containing foods during their stays in hospital, and whose primary concern was for dietitians to fully understand the GF diet and all its complexities (Tidwell & Bomba, 2001).

One additional concern associated with following a GF diet was being left out of social situations involving food. This was discussed in a recent

study from Sweden in which a number of life experiences of individuals with CD proved to be much more varied and profound than expected. The authors stressed the importance of taking into consideration a variety of social aspects of having to follow a GF diet, including isolation, fear of gluten contamination, and worries about being a bother to others, when treating patients with CD (Sverker *et al.*, 2005).

#### Limitations of the survey

There was no control group because the purpose of the survey was to describe the impact of the GF diet on the members of the CCA. Surveying only members of the CCA could result in selection bias, because individuals diagnosed in Canada with CD are not tracked, and not all individuals with CD choose to become, or to remain, members of the CCA. The data are self-reported which may bias answers to sensitive questions such as dietary compliance. However, anonymity of the data was ensured to attempt to minimize such bias. Sponsorship of the survey by the CCA might have biased the responses regarding the quality of the sources of information.

#### Conclusions

Although the quality of life scores using the SF-12 were similar to those of the general Canadian population, the reasons for lower scores among women need further study.

Following a GF diet imposes a large number of restrictions which can impact on the quality of life of individuals with CD. Strategies to help individuals cope with these restrictions should be included in education programmes for both the patients and the medical team treating them.

The health and quality of life of persons with CD could be further enhanced by: early diagnosis of CD; increased availability of good quality GF foods in the marketplace, in restaurants and during hospital stays, and more complete labelling of food ingredients.

Although most respondents report following a strict GF diet, incomplete recovery in many individuals suggests the possibility of continued con-

sumption of gluten. Careful follow up by the doctors and dietitians with expertise in CD is essential to ensure that recovery is complete, the diet is carefully followed and the risk of complications from continued consumption of gluten is understood.

It is recommended that comprehensive programmes on CD and its treatment be developed for doctors and dietitians, both at the undergraduate level and during their continuing professional training, to help speed up diagnosis and reduce the risk of many of the serious conditions associated with untreated CD.

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