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Living with coeliac disease and a gluten-free diet: a Canadian perspective

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Abstract

Objective: Strict adherence to a gluten-free diet is the only treatment for coeliac disease. The gluten-free diet is complex, costly and impacts on all activities involving food, making it difficult to maintain for a lifetime. The purpose of this cross-sectional study was to evaluate the difficulties experienced, the strategies used and the emotional impact of following a gluten-free diet among Canadians with coeliac disease.

Methods: A questionnaire was mailed to all members (n = 10 693) of both the Canadian Celiac Association and the Fondation québécoise de la maladie cœliaque in 2008.

Results: The overall response rate was 72%. Results are presented for the 5912 respondents (≥ 18 years) reporting biopsy-confirmed coeliac disease and/or dermatitis herpetiformis. Two-thirds never intentionally consumed gluten. Women reported significantly greater emotional responses to a gluten-free diet but, with time, were more accepting of it than men. Difficulties and negative emotions were experienced less frequently by those on the diet for >5 years, although food labelling and eating away from home remained very problematic. Frustration and isolation because of the diet were the most common negative emotions experienced.

Conclusions: The present study quantifies the difficulties experienced, the strategies used and the emotional impact of following a gluten-free diet. It highlights the need to improve the training and education of dietitians, other health providers and the food service industry workers about coeliac disease and a gluten-free diet, with the aim of better helping individuals improve their adherence to a gluten-free diet and their quality of life.

Introduction

Coeliac disease is a gluten-elicited, autoimmune-enteropathy occurring in genetically predisposed individuals (Ludvigsson *et al.*, 2012; Sapone *et al.*, 2012). The estimated prevalence in developed countries is 0.5–1% and is rising worldwide, possibly as a result of environmental factors (Catassi & Fasano, 2008; Rubio-Tapia *et al.*, 2009). Newly-diagnosed patients are often relieved to learn that coeliac disease can be treated by a gluten-free diet alone (Ciacci *et al.*, 2002). Many following this diet find it challenging because gluten-containing foods, such as rye, barley and especially wheat, are widely used in the production of many processed and prepackaged foods, including baked goods, pastas, breakfast cereals, soups, sauces, snacks and processed meats. Avoiding the wide range of foods that contain gluten often necessitates significant changes in eating patterns and lifestyle that can be hard to maintain over a lifetime (Rashtak & Murray, 2009).

Dermatitis herpetiformis (DH) is a skin condition triggered by gluten that can develop among those with coeliac disease (Reunala, 2001; Zone, 2005). It is characterised by extremely itchy bilateral blistering of the elbows, knees and buttocks. Although patients with DH often present with mild or no gastrointestinal symptoms, histological changes in the small intestine occur in approximately 75% of cases (Mäki & Collin, 1997). Patients with DH require lifelong treatment with a gluten-free diet (Reunala, 2001).

Many factors can impact on an individual's desire and ability to change long-established food habits (Sverker *et al.*, 2005). Investigators agree that there is a need for a better understanding of the emotional impact of following a gluten-free diet for life and the difficulties that it entails (Hallert *et al.*, 2003; Sverker *et al.*, 2005). Such information about Canadians with coeliac disease is limited (Lamontagne *et al.*, 2001; Zarkadas *et al.*, 2006). Hence, a comprehensive survey entitled 'Living with a Gluten-Free Diet' was conducted among members of Canada's two major coeliac disease support associations: the Canadian Celiac Association (CCA) and la Fondation québécoise de la maladie cœliaque (FQMC).

The objectives of this cross-sectional study were to evaluate the emotional impact, the difficulties experienced and the strategies used in daily food-related situations by Canadian adults with coeliac disease who were following a gluten-free diet.

The present study reports the results for the dietary aspects of the survey. The results from the medical aspects of this survey will be reported elsewhere.

Materials and methods

A questionnaire was developed collaboratively by the CCA Professional Advisory Board and Health Canada, in consultation with FQMC. The study protocol was approved by the Ethics Review Board of Health Canada.

The questionnaire contained 59 questions with sections on demographics, diagnosis, symptoms, dietary adherence, information sources, knowledge of a gluten-free diet, emotional impact, difficulties experienced and strategies used when on the diet, as well as personal life situations (Lee & Newman, 2003; Leffler *et al.*, 2009).The difficulties, strategies and emotions presented for rating in the questionnaire were identified in the scientific literature (Hallert *et al.*, 2003; Sverker *et al.*, 2005) and by the CCA, the FQMC and dietitians with expertise in coeliac disease (through personal communications), and were finalised in consultation with psychometric experts. The questions about the usefulness of information sources, emotional impact, difficulties and strategies were asked on a five-point scale with the following options: never, rarely, sometimes, often and very often. The questionnaire was developed in English then translated into French; language equivalence was assessed by bilingual subject-matter and survey-methodology experts. It was pretested by CCA and FQMC members.

A total of 10 693 households with current membership of the CCA ($n = 7872$) or the FQMC ($n = 2821$) were each mailed one copy of the questionnaire in December 2008. Individuals aged 18 years or older, following a gluten-free diet, were eligible to take part in the survey. If there was more than one eligible family member in a household, they were asked to request additional questionnaire(s). To ensure respondent anonymity, the questionnaire carried no identification or coding information. Upon return, each questionnaire was assigned a unique identifying code. Questionnaire completion and return was regarded as consent.

Analysis

The data were analysed using SPSS, version 18 (SPSS Inc., Chicago, IL, USA). The results are presented as percentages. Pearson's chi-squared tests were used to test for statistical significance of differences between groups. All statistical tests were two-sided. Because of the large sample size, tests were considered statistically significant based on an alpha value of 0.01. Because not all respondents answered all questions, the number of respondents replying to each question is variable. Four data entry clerks entered the questionnaire data, verifying the accuracy of their data entry for a random 10% sample. The data entry manager randomly verified the accuracy of the data entry for 10% of the questionnaires, ensuring an error rate of 5% or less. After the data entry was completed, frequencies and cross tabulations were used to pick up inconsistencies and the data for each question were reviewed for logical consistency.

Results

A total of 7823 completed questionnaires ($n = 5857$ English and 1966 French) were received. Of these, 436 were excluded because the respondents did not meet the eligibility criteria or the questionnaires were essentially blank, resulting in an overall response rate of 72.0%. A biopsy-confirmed diagnosis was reported by 5912 respondents: 5092 had biopsy-confirmed coeliac disease, 51 had biopsy-confirmed DH and 769 had both coeliac disease and DH, with one or both confirmed by biopsy. The findings reported in the present study are based on this biopsy-confirmed subset of respondents.

Characteristics of the respondents

Respondents were from all 10 Canadian provinces, the Northwest Territories and the Yukon, with approximately equal representation from metropolitan ($\geq$500 000 population), urban (<500 000 population) and rural areas. Women represented 75.9% of respondents. The mean (SD) age of respondents was 56.4 (15.2) years. Just over 8% (8.1%) had been following a gluten-free diet for <1 year, 32.4% for between 1 and 5 years and 59.5% for more than 5 years.

Compared to the adult Canadian population, women, the age group $\geq$65 years and those with post-secondary education were over-represented; the age group 18–29 years and those with an annual household income of <$20 000 were under-represented (Statistics Canada, 2007).

Frequency of intentional gluten consumption

The majority of respondents (68.0%) indicated that they never intentionally consumed gluten. Another 18.8% of respondents indicated that they had intentionally consumed gluten once or twice during the previous year. The remaining 13.2% reported the intentional consumption of gluten at least once a month during the previous year. The percentage of respondents reporting the intentional consumption of gluten at least once in the previous year was lower among respondents who had been following a gluten-free diet for a longer period of time ($P = 0.013$). The frequency of intentional gluten consumption was not significantly different between men and women.

Rationale for avoiding gluten consumption

The majority of respondents (87.8%) indicated that they considered preventing long-term complications and avoiding immediate reactions as being equally important reasons for avoiding gluten consumption. In addition, 9.9% of respondents indicated that preventing long-term complications was the most important reason for avoiding gluten consumption and 2.2% indicated that preventing reactions was more important.

Information about a gluten-free diet

Respondents obtained information about a gluten-free diet from a variety of sources (Table 1). The perceived usefulness of this information ranged from 90.4% (coeliac support association) to 52.1% (dietitian) and to 25.3% (family doctor).

Table 1 Usefulness of information received about a gluten-free diet

Source of information	Percentage rating information as very good/excellent	*n*
Coeliac disease support association	90.4	5639
Another person with coeliac disease	66.9	3642
Cookbooks	62.0	4565
Internet	53.2	3467
Dietitian	52.1	4705
Medical books/journals	50.7	1605
Alternative medical professional	47.0	442
Gastroenterologist	42.9	3611
Newspaper/magazine	28.4	3150
Family doctor	25.3	1990

Knowledge of a gluten-free diet

When asked to review a list of 15 foods and ingredients and identify those that are NOT allowed on a gluten-free diet, 49.3% of respondents correctly identified all seven non-allowed items. An additional 32.5% correctly identified six of the seven items. A significantly higher percentage of women (52.8%) than men (38.5%) correctly identified all seven of the non-allowed items ($P < 0.001$).

The percentage of respondents who correctly identified all non-allowed items was significantly higher among respondents who had been following a gluten-free diet for a longer period of time (38.0% among respondents on a gluten-free diet <1 year, 46.5% on a gluten-free diet 1–5 years, and 52.2% on the diet >5 years; $P < 0.001$). The three non-allowed items that were most frequently identified as allowed were imitation crab meat (36.3%), egg noodles (16.0%) and spelt (11.4%). The three allowed items that were most frequently identified as non-allowed were modified corn starch (16.6%), glutinous rice (10.7%) and molasses (6.0%).

Emotions associated with following a gluten-free diet

Respondents were asked to report on their emotions during the month before the survey and their recollection of the emotions experienced in the first few months after diagnosis. The majority of respondents reported feeling relieved and accepting of the diet during the first few months after diagnosis, with a significantly larger percentage of men than women reporting these feelings (Table 2). However, at the time that the survey was taken, the percentage of respondents who reported feeling relieved was significantly lower, whereas the percentage reporting acceptance of the diet was significantly higher. The increase in acceptance was statistically significant among women but not among men.

Table 2 Emotions frequently experienced when following a gluten-free diet

Emotions experienced often or very often	During the first few months after diagnosis (%)			During the month before the survey (%)		
	Overall	Men	Women	Overall	Men	Women
Positive emotions						
Relieved	58.4	62.4	57.0*	43.6**	41.7	44.0
Accepting	57.4	65.2	55.0*	69.9**	66.3	70.8***
Negative emotions						
Frustrated	56.9	45.4	60.2*	21.3**	17.3	22.5***
Overwhelmed	48.7	34.2	52.7*	7.8**	5.5	8.5***
Isolated	41.8	30.7	45.0*	16.6**	11.6	18.1***
Confused	37.3	28.9	39.8*	5.7**	5.4	5.8
Anxious	37.0	26.9	40.0*	8.8**	6.7	9.5***
Sad	34.4	22.3	38.0*	9.0**	5.7	10.1***
Angry	30.6	21.8	33.1*	8.6**	6.9	9.1
Feeling depressed	23.3	15.3	25.6*	6.9**	4.7	7.5***

n = 5131–5518.

*Significant differences between men and women during the first few months after diagnosis ($P < 0.01$).

**Significant differences between the first few months after diagnosis and the month before the survey ($P < 0.01$).

***Significant differences between men and women during the month before the survey ($P < 0.01$).

The percentage of respondents who reported often feeling each of the negative emotions listed in Table 2 was significantly higher in the months after diagnosis than during the month before the survey. A significantly higher percentage of women than men reported often feeling each of these negative emotions during both time periods. Frustration and isolation were the two negative emotions experienced by the largest percentage of respondents during the month before the survey.

Difficulties experienced

Table 3 summarises the difficulties experienced when following a gluten-free diet. Twelve of the 39 difficulties were experienced by a significantly larger percentage of women than men. There was no significant difference in the percentage of men and women reporting the other 27 difficulties. Those on the diet for over 5 years experienced fewer difficulties overall. However, over 50% of these latter respondents still experienced, often or very often, one-third of the difficulties that were queried. These included: limited food choices in restaurants and cafeterias; limited choices of restaurants; being concerned that gluten does not always appear on food labels; the high cost of gluten-free foods; not liking others to feel sorry for them; worrying about cooks in restaurants not being trained in preparing gluten-free meals; limited choices of food for carried lunches; and a variety of food-associated difficulties experienced when travelling. The difficulty often experienced by the lowest percentage of respondents was a lack of understanding of their dietary needs by family and friends. However, 24.8% indicated that they suspected their family/friends were afraid to invite them for meals.

Other specific difficulties reported were: difficulty obtaining gluten-free meals in hospitals and retirement homes (42.6%); difficulty determining the gluten content of nonprescription drugs and vitamins (35.7%) and of prescription drugs (29.6%); limitations in religious practices (25.1%); and feeling guilty about having passed coeliac disease on to children/grandchildren (24.6%).

No association was observed between the number of difficulties experienced and dietary adherence (defined as the frequency of intentional gluten consumption). The complete results of the difficulties experienced are provided in Appendix 1.

Strategies used

Adaptive strategies used when following a gluten-free diet are reported in Table 4.

The strategies often used by the largest percentages of respondents included: reading every food ingredient list; labelling all gluten-free flours; and having snacks on hand at work or school. Seventeen of the 25 strategies were used by a significantly higher percentage of women than men. The use of four of the strategies listed was significantly higher, and the use of eight of the strategies significantly lower among respondents who had been following a gluten-free diet for a longer period of time.

Statistical analyses examining the association between strategy use and dietary adherence were restricted to the 17 strategies with the highest number of responses. These strategies fell into four categories, namely: 'Food purchasing', 'Food preparation', 'Eating with family and friends' and 'Eating in restaurants'. Overall frequencies of strategy use were: 18.1% of respondents used four or fewer strate-

Table 3 Difficulties experienced often when following a gluten-free (GF) diet

Difficulties experienced often/very often	Overall (%)	Difficulties that dropped significantly over time on GF diet	*n*
Purchasing gluten-free foods			
Concerned that gluten does not always appear on food labels*	78.9		5768
Cost of commercially prepared GF foods limits purchases*	61.1†		5754
Annoyed at having to ask companies if products are GF	43.7†	↓	4852
Think that GF information from companies may not be correct	21.8		5432
Cannot find variety of GF foods in local stores	12.2	↓	5842
Gluten-free food preparation			
Limited GF choices for carried lunches*	55.6	↓	4633
Have to cook more often*	53.9	↓	5137
GF meals more difficult to prepare	35.3$^{♂}$	↓	5307
Frustrating to bake with GF flours in favorite recipes	33.3	↓	5001
Difficult to prepare both GF and gluten-containing meals	23.7	↓	4510
Worry about making mistakes with the GF diet	20.7	↓	5278
Eating with family/friends			
Do not like others to feel sorry for me*	66.3†		5400
People think a little gluten will not hurt me	45.5†	↓	5735
Feel that I am a burden	33.4†	↓	5770
Avoid going to social events involving food	32.2		5757
Embarrassed by my dietary needs	27.4†	↓	5784
Suspect that family/friends are afraid to invite me for meals	24.8†		5733
Feel neglected	14.5†	↓	5727
Find it difficult to refuse gluten-containing foods offered to me	8.0		5723
My friends do not understand my dietary needs	5.3	↓	5786
My family does not understand my dietary needs	2.9	↓	5784
Eating in restaurants			
Limited choices at fast food restaurants*	87.5	↓	5490
Limited choice of restaurants*	76.9	↓	5776
Worry that cook is not trained in preparing GF meals*	63.7	↓	5711
Restaurants cannot provide information on gluten content of menu items	34.1	↓	5662
Cannot eat in restaurants because the food may be contaminated with gluten	30.5	↓	5458
GF foods are not as tasty as regular foods	19.1	↓	5775
Afraid of being a bother, so do not ask for changes to menu items	17.1		5574
Eating at school/work			
Limited choices in the cafeteria*	84.8		1926
Business lunches are very stressful	49.8†	↓	2259
Difficult to be spotlighted as having a problem	35.3†	↓	2938
Difficult having to bring own food for lunches	33.5		2861
Feel hurt when people are indifferent to my dietary needs	31.1†		2846
Symptoms after consuming gluten cause me to miss work/school	8.8		2782
Travelling			
Travelling abroad is difficult because I cannot tell from the label if the food is GF*	68.7	↓	3027
Sad that I cannot eat many local/national specialty dishes*	61.0†	↓	3974
Difficult to find shops and restaurants that sell GF food*	54.2	↓	5113
Restaurant personnel abroad are unaware of what GF means*	52.5	↓	3348
Difficult to carry GF food when travelling	45.9		5363

*Indicates a difficulty experienced often/very often by $\geq$50% of respondents after 5 years on the diet.
†Indicates a difficulty experienced significantly more often by women.
$^{♂}$Indicates a difficulty experienced significantly more often by men.

gies, 32.2% used five to seven strategies, 31.3% used eight to 10 strategies, 15.6% used 11–13 strategies and 2.8% of respondents used 14–17 strategies.

Figure 1 presents the results for the percentage of respondents who reported each of these five levels of strategy use (0–4, 5–7, 8–10, 11–13 and 14–17 strategies used frequently across three levels of intentional gluten consumption), namely: (i) never intentionally ate gluten; (ii) intentionally ate gluten one or two times a year; and (iii) intentionally ate gluten at least once a month. Fig-

Table 4 Adaptive strategies often used to enhance ability to follow a gluten-free (GF) diet

Strategies used often/very often	Overall (%)	Strategies that increased or decreased significantly over time on a GF diet	*n*
Purchasing gluten-free foods			
Read every ingredient list*	96.1		5835
Use the CCA pocket dictionary	55.3[†]	↓	5749
Ask local grocery store to carry certain GF products	24.6	↑	5522
Purchase GF food by mail order	13.7		5856
Gluten-free food preparation			
Label all GF flours*	83.8[†]	↑	4714
Store GF ingredients in a separate area *	74.9	↓	4939
Cook only GF foods for the whole family	48.8		4724
Make and freeze extra GF foods	47.6		5264
Eating with family/friends			
Check ingredient lists on the foods I eat*	55.1[†]		5684
Bring my own food when visiting	46.5[†]		5755
Share my best GF recipes	46.3[†]	↑	5559
It is easier to take charge of meals	38.8[†]	↓	5459
Invite friends/family to eat at my home	34.3[†]	↓	5516
Eating in restaurants			
Enquire about gluten content of all foods*	74.5		5609
Call ahead to enquire about GF menu choices	33.7[†]	↓	5576
Ask for printed information about gluten content	32.9[†]	↓	5593
Use the internet to find restaurants that serve GF foods	24.3 [†]	↓	5297
Eating at school/work			
Have snacks on hand*	78.1[†]		2937
Talk to others about coeliac disease and the GF diet*	68.2[†]	↑	2980
Offer to bring a GF dish to events involving food*	61.8[†]		2856
If an event involves food, remind people about my GF diet*	58.0		2931
Travelling			
Take translated information about the GF diet when abroad	43.7[†]		2803
Research restaurants on the internet before I leave home	27.5[†]	↓	4993
Contact local Coeliac Society about sources of GF foods	15.7[†]		3482
Carry a doctor's letter indicating that I require a GF diet	15.3[†]		5200

*Indicates the strategy is used often/very often by ≥50% of respondents after 5 years on the diet.

[†] Indicates that the strategy is used significantly more often by women.

CCA, Canadian Celiac Association.

ure 1 shows that the respondents who reported intentional gluten consumption more often used fewer strategies. For example, the frequent use of 0–4 strategies was reported by 40.1% of those who intentionally consumed gluten at least once a month compared to 22.4% of respondents who intentionally consumed gluten one or two times a year and to 12.5% of respondents who never intentionally consumed gluten.

Overall, respondents who reported a higher level of strategy use were significantly less likely to intentionally consumed gluten (P = <0.001). This association was observed among both men and women, even though, on average, men used significantly fewer strategies than women.

The complete results of the strategies used are provided in Appendix 2.

Discussion

Many factors are involved in changing health behaviour patterns, including personal and cultural influences and social interactions (Glanz & Bishop, 2010; Sainsbury & Mullan, 2011). Long-term adherence to a new health behaviour involves developing self-management and coping strategies, and feeling in control of situations as they arise (Glanz & Bishop, 2010). Many patients regard a gluten-free diet as a substantial burden even after being on the diet for several years (Whitaker *et al.*, 2009). The present study aimed to examine the difficulties experienced, the strategies used and the emotional impact of following a gluten-free diet. To our knowledge, this is the largest survey ever conducted aiming to assess the impact

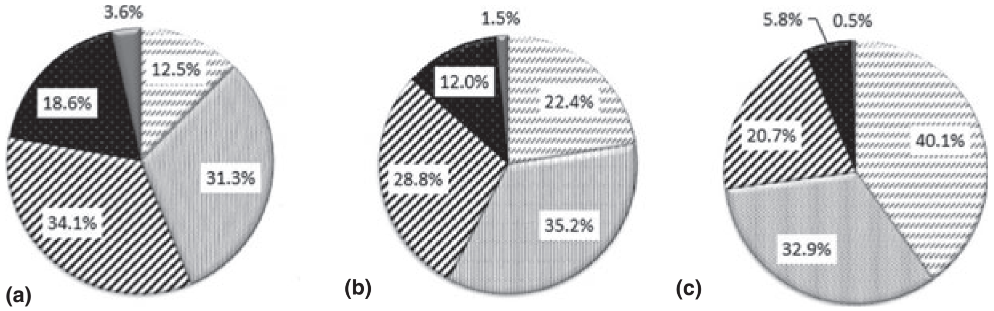

Figure 1 The relationship between level of strategy use and intentional gluten consumption. (a) Proportion of those who never intentionally ate gluten according to the number of strategies they frequently used. (b) Proportion of those who intentionally ate gluten one or two times in the past year according to the number of strategies they frequently used. (c) Proportion of those who intentionally ate gluten one or more times per month according to the number of strategies they frequently used. Level of strategies used (# of strategies, patterns used in graph): 0–4 tire marks; 5 to 7 fine vertical gray lines; 8 to 10 diagonal black lines; 11 to 13 dark stippled area; 14 to 17 solid gray area.

of a gluten-free diet on the lives of individuals with coeliac disease.

Information and knowledge about a gluten-free diet

Receiving accurate information about a gluten-free diet promptly after a diagnosis of coeliac disease is a major factor in initiating good dietary adherence, symptom recovery and improving quality of life (Ciacci *et al.*, 2002; Hallert *et al.*, 2002). Understanding the diet and learning coping skills can help reduce the burden of adapting to a gluten-free diet (MacKenzie *et al.*, 2010). The important role played by coeliac support organisations in providing emotional and social support and improving dietary adherence has been widely recognised (National Institutes of Health, 2005; Sainsbury & Mullan, 2011). In the present study, all of the respondents were members of a major Canadian coeliac support organisation which explains, at least in part, why the information provided by these organisations obtained the highest rating. The ratio of approximately 3 : 1 females to males in the present study was consistent with the results of a previous Canadian study (Zarkadas *et al.*, 2006) and other national studies conducted in the USA (Green *et al.*, 2001; Lee *et al.*, 2012) and Germany (Häuser *et al.*, 2006).

The low ratings of the usefulness of the information provided by dietitians, gastroenterologists and family physicians are similar to those reported elsewhere (Green *et al.*, 2001; Lamontagne *et al.*, 2001) and are even lower than those reported in a previous survey (Zarkadas *et al.*, 2006). The importance of awareness about coeliac disease and its treatment needs to be increased, especially among dietitians (Case, 2005; Kupper, 2005) and primary healthcare providers (Fasano, 2003), to improve care and help alleviate the social, personal and medical costs of this disease (Green *et al.*, 2008). Ideally, a team approach for support of the patient would involve his/her family, the physician, a dietitian with expertise in coeliac disease and help from a coeliac support group (Case, 2005; Pietzak, 2005; Casellas *et al.*, 2006).

In the present study, women were significantly more knowledgeable about a gluten-free diet than men, probably as a result of their greater role in all aspects of food, both at home and away from home (Hallert *et al.*, 2003; Sverker *et al.*, 2009). As anticipated, the overall knowledge of the respondents about the foods not allowed on a gluten-free diet was significantly higher among those who had been following the diet for a longer period of time.

Adherence to a gluten-free diet

At present, a strict gluten-free diet is the only treatment for coeliac disease. The two primary motivating factors for good adherence to this diet are avoiding debilitating reactions to consumed gluten (Ciacci *et al.*, 2002), and reducing the risk of other associated diseases (Fasano, 2003). Both of these factors were rated as very important by a large majority of the respondents in this survey. Others reported similar findings (Leffler *et al.*, 2008).

Many factors can negatively affect adherence to this complex diet, including poor knowledge of the diet, difficulties in changing established food habits, incomplete or confusing labelling of gluten in foods and drugs, dining outside the home and social pressures, among other factors (Green *et al.*, 2001; Lee & Newman, 2003; Sverker *et al.*, 2007; Sainsbury & Mullan, 2011).

In the present survey, two-thirds of the respondents reported that they never purposely consumed gluten, which is similar to the results of two other national surveys (Green *et al.*, 2001; Häuser *et al.*, 2006). Self-reported adherence to a gluten-free diet tends to be over-reported (Fera *et al.*, 2003). Because of the sample size and the confidentiality of our research protocol, interviewing the surveyed participants was not possible and the self-reported data may represent a significant overate of true adherence to a gluten-free diet.

All of the respondents in the present study were members of a coeliac support organisation. It is possible that individuals who have not had help and support from such an organisation may not be as knowledgeable or as adherent to the diet.

Emotional impact of following a gluten-free diet

The present study indicates that having to make lifetime changes in dietary patterns can have a significant emotional impact. It also confirms that a larger percentage of women on a gluten-free diet experience more emotional distress than men, which might explain in part the greater burden of disease experienced by women on a gluten-free diet reported by Hallert *et al.* (2003). Women's greater role in all aspects of the diet, both at home and away from home (Gregory, 2005), and innate differences between men and women (Sverker *et al.*, 2009) are other possible factors.

The most common emotion reported by both men and women when first on a gluten-free diet was relief, which is similar to the finding of Ciacci *et al.* (2002). After many years of unexplained illness, many of the respondents indicated that they were greatly relieved that they did not have a terminal illness and could be treated by diet alone. However, reported feelings of relief dropped significantly after going onto the diet.

Respondents reported feeling frustrated, overwhelmed and isolated more often than feeling anxious, sad or angry as reported by others (Ciacci *et al.*, 2002). However, just before the survey, feeling overwhelmed by the diet dropped to below 8% overall. Frustration and isolation were the most common negative emotions reported among those on the diet for more than 5 years. Worry and trust issues about the diet are also recognised as difficulties but are necessary to maintain dietary adherence (Sainsbury & Mullan, 2011). It is important that these emotions be acknowledged to allow individuals to cope with these difficulties.

Acceptance of a disease and its treatment involves a process of adjustment to new conditions and learning to live with these changes (Telford *et al.*, 2006). In the present study, acceptance of the diet was initially higher among men, as reported elsewhere (Hallert *et al.*, 2003). However, at the time of the survey, acceptance of the diet was significantly higher among women, possibly indicating their better adjustment to the diet over time.

Difficulties experienced

The present study enabled us to quantify the frequencies of a wide variety of difficulties experienced and strategies used, including differences between men and women and across individuals who had been following a gluten-free diet for different periods of time.

Women reported experiencing approximately one-third of the identified difficulties significantly more frequently than men. Each difficulty asked about was experienced by a lower percentage of respondents who had been following a gluten-free diet for a longer period of time. Lee *et al.* (2012) also reported a decrease of the negative impact of a gluten-free diet over time, although some areas such as dining out and travel remained problematic. In the present study, more than three-quarters of those on the diet for over 5 years continued to experience difficulties with food labelling and limited food choices in restaurants and cafeterias, and many other difficulties were reported to be a concern by more than half of these respondents. This finding is also reported in other studies showing that many subjects take several years to plan, prioritise and solve problems associated with chronic disease and other treatments (Whittemore & Dixon, 2008).

The high cost of prepackaged gluten-free foods was identified by over 60% of the respondents as a limiting factor in their food purchases. Prepackaged gluten-free foods have been reported to cost more than their gluten containing equivalents (Lee *et al.*, 2007; Stevens & Rashid, 2008; Singh & Whelan, 2011). A need for extra cooking was also identified as a problem by a majority of respondents. Preparing foods at home is a less expensive alternative, although it may be problematic if time or cooking skills are limited. It is hoped that, with increased competition in the marketplace, the price differential between gluten-free foods and the foods that they replace will be reduced.

Of concern was the 65.0% of respondents who had been following a gluten-free diet for over 5 years, and who reported that they disliked others feeling sorry for them because of their diet. This, along with other reported feelings, including neglect, embarrassment because of dietary needs and not wanting to be spotlighted as having a problem, need to be acknowledged and addressed through dietary counselling. Counsellors also need to take into consideration the fact that dietary adherence must be achieved within a social context that often involves interactions centered around food (Gregory, 2005; Rydén & Sydner, 2011). Encouraging individuals to develop a positive attitude about the diet and its benefits and sharing this with others should be discussed as part of dietary counselling (Rydén & Sydner, 2011).

Support from family and friends is very important for those on a gluten-free diet (Gregory, 2005), and it was very encouraging that the respondents reported that only 2.9% of their family and 5.3% of their friends did not understand their dietary needs. Of concern, however, was the 24.8% who suspected they were not being invited to family and friends because of their diet, which could be one reason for continued feelings of isolation.

Improvements in the availability and quality of commercial gluten-free foods, including yeast breads, were reported. Those reporting difficulty finding gluten-free foods (12.2%) and finding good-tasting gluten-free foods (19.1%), was much lower than the 83% and 85%, respectively, reported in a previous survey by the CCA (Zarkadas *et al.*, 2006), indicating a remarkable increase in both the quantity and quality of gluten-free foods now available on the Canadian market (Cureton & Fasano, 2009; Case, 2010).

One of the major difficulties reported by the respondents in the present study was incomplete or confusing food labelling. To ensure complete and clear labelling of gluten sources in prepackaged food, Health Canada has amended its *Food and Drug Regulations* to require a declaration of all priority allergens, gluten sources and sulphites added to prepackaged foods (http://gazette.gc.ca/rp-pr/p2/2011/2011-02-16/html/sor-dors28-eng.html). This enhanced labelling will reduce the time presently used for label reading and provide more assurance to consumers about the safety of their food choices. There have been a number of gluten-free food certification programmes developed in Canada and the USA that also provide consumers assurance that foods identified as gluten-free will meet specific criteria regarding the gluten-content of foods (Case, 2010).

Difficulties experienced in restaurants by those on a gluten-free diet could be greatly reduced by training chefs and restaurant staff about foods that are allowed and not allowed on a gluten-free diet, as well as how to ensure ingredients from their suppliers are gluten-free and how to prevent contamination of food with gluten during preparation. Such training will help those with coeliac disease maintain a normal social life (Case, 2005; Karajeh *et al.*, 2005).

Strategies used

In following a gluten-free diet, food activities both at home and away from home require a good deal of thought, planning, time and responsibility. Women tend to take more responsibility for these activities (Gregory, 2005). In the present study, the use of specific strategies differed by the length of time on a gluten-free diet. The use of the ingredient dictionary was significantly lower, whereas talking to others about coeliac disease and its treatment was significantly higher among those who had been following a gluten-free diet for a longer period of time. The latter is a very positive step in accepting one's condition and in helping to increase awareness about coeliac disease and its treatment (Glanz & Bishop, 2010).

Reading all ingredient lists, enquiring about the gluten-content of all foods when eating out, having snacks on hand at school/work and taking translated information about a gluten-free diet when travelling were used by the majority of respondents who had been on the diet for >5 years.

A key finding of the present study was that the more strategies used, the greater was the reported adherence to the diet among both men and women. This confirms that learning good coping skills can have a very positive impact on dietary adherence (Leffler *et al.*, 2009; MacKenzie *et al.*, 2010). The results from those on the diet for 5 years or longer indicate that acceptance, knowledge and management of the diet improves with time, although continuing support is still needed.

The need for further research to develop and evaluate strategies to help individuals adhere to a gluten-free diet has been identified (Hall *et al.*, 2009). The present results may contribute to an identification of such strategies. The results obtained in the present study should also be of interest to those with food allergies because the difficulties experienced by individuals avoiding gluten are very similar (Marklund *et al.*, 2007; Leftwich *et al.*, 2011).

Strengths and limitations of the present study

There is no coeliac disease registry in Canada; therefore, it was not possible to study a random sample of Canadians with coeliac disease. Participants were members of coeliac support organisations and there is no information available on the differences between members and non-members of these associations. However, by comparing the participants in the present study with the Canadian population, it was seen that the survey respondents tended to have a higher level of education and a higher annual household income than the general population. Both of these factors are significantly associated with key variables in the present study, such as the frequency of intentional gluten consumption, quality of life and knowledge of the diet. To maximise the inclusion of persons with coeliac disease with a lower socio-economic status, the questionnaire was sent to all members of the support associations rather than just a sample. The resulting sample size was larger, making the present study the largest of its kind in Canada.

It is also possible that members of coeliac support organisation may have joined because they were finding it difficult to cope with a gluten-free diet. At the same time, members may have attained higher than average levels of knowledge about this diet. These factors may decrease the extent to which respondents are representative of Canadians with coeliac disease. There is also the possibility of response bias, with members with strong opinions sending back the questionnaire. However, the sample size of the survey was large, and it was nationally representative.

Conclusions

In the present study, the low ratings received by dietitians and other health professionals as a source of information about a gluten-free diet highlights the need for further education of these professionals about coeliac disease, a gluten-free diet and its impact on daily living. It is essential for individuals with coeliac disease to receive accurate and comprehensive information about the disease and its dietary management. Timely support is especially important for those who are newly diagnosed and those who are experiencing difficulties in achieving a high level of dietary adherence.

The present study identified significant differences between men and women in a wide range of emotional experiences, difficulties encountered and strategies used when following a gluten-free diet. This information should be considered when dietary training is being provided. The finding that frustration and isolation were the most common negative emotions after more than 5 years should also be addressed.

The statistically significant inverse association between strategy use and intentional gluten consumption is an important finding to be considered by dietitians and other health professionals managing the condition.

Major difficulties experienced by more than half of the respondents who had been on the diet for over 5 years included limited food choices in restaurants, cafeterias, hospitals and nursing homes, as well as worry about the safety of foods in these establishments. Hence, greater efforts are needed to ensure that food service staffs in restaurants, cafeterias, hospitals and nursing homes receive comprehensive training in the preparation and service of gluten-free foods.

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MZ (Principal Investigator) (Canadian Celiac Association, Professional Advisory Board) initiated the project, and also participated in the study design, questionnaire development and pretesting, data interpretation and manuscript preparation. SD (Bureau of Policy, Regulatory and Governmental Affairs, Food Directorate, Health Canada) participated in the study design, and also in questionnaire development and pretesting, data analysis, data interpretation and manuscript preparation. KMI (Canadian Celiac Association) participated in the data analysis, data interpretation and manuscript review. IC (Coordinator) (Bureau of Chemical Safety, Food Directorate, Health Canada) participated in the study design, questionnaire development, pretesting and manuscript review. MR (Canadian Celiac Association, Professional Advisory Board and Faculty of Medicine, Dalhousie University, Halifax, Nova Scotia, Canada) participated in the study design, questionnaire development and pretesting and manuscript review. SLV (Bureau of Chemical Safety, Food Directorate, Health Canada) participated in the data analysis, data interpretation and manuscript review. KR (Centre for Chronic Disease Prevention and Control, Public Health Agency of Canada) participated in the study design, questionnaire development, data interpretation and manuscript review. SG (Food Directorate, Health Canada) participated in both the initiation and the roll-out of the survey and in the review of the questionnaire and the manuscript. OMP (Co-Principal Investigator) (Bureau of Chemical Safety, Food Directorate, Health Canada and Faculty of Medicine, University of Ottawa, Ottawa, Ontario, Canada) participated in the study design, questionnaire development and pretesting, and also in obtaining ethics approval, data interpretation and manuscript preparation.

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Appendix 1. Complete results of difficulties experienced often when following a gluten-free (GF) diet

		By gender (%)		By years on GF diet (%)		
	Overall (%)	Male	Female	<1	1–5	>5
Purchasing GF foods						
Concerned that gluten does not always appear on food labels	78.9	77.8	79.2	82.3	80.0	77.9
Frustrated with the variety of names for gluten on food labels	67.0	65.9	67.3	76.5	71.2	63.5[‡]
Cost of commercially prepared GF foods limits purchases	61.1	56.4	62.5[†]	65.2	60.8	60.7
Annoyed at having to ask companies if products are GF	43.7	35.7	46.4[†]	53.3	50.1	38.6[‡]
Hard to tell from ingredient list if a prepackaged food is GF	38.5	40.3	38.1	47.2	43.3	34.8[‡]
Resent time needed to read all ingredient lists	38.3	38.4	38.1	44.8	40.6	36.2[‡]
Think that GF information from companies may not be correct	21.8	23.1	21.5	24.1	23.1	20.8
Cannot find variety of GF foods in local stores	12.2	11.8	12.5	15.4	14.6	10.4[‡]
Food preparation						
Limited GF choices for carried lunches	55.6	58.5	55.1	60.3	59.6	52.5[‡]
Have to cook more often	53.9	51.8	54.5	66.7	57.7	49.8[‡]
GF meals more difficult to prepare	35.3	42.2	33.7[†]	47.4	39.3	31.4[‡]
Frustrating to bake with GF flours in favourite recipes	33.3	31.7	33.7	47.6	38.7	28.4[‡]
Do not enjoy the challenge of making GF foods	46.5	49.0	45.9	50.5	48.4	44.8
Difficult to prepare both GF and gluten-containing meals	23.7	23.8	23.7	33.0	28.0	20.0[‡]
Do not feel well adjusted to GF meal preparation	5.5	5.5	5.4	13.0	7.5	3.3[‡]
Worry about making mistakes with the GF diet	20.7	23.7	20.1	41.9	25.9	14.9[‡]
Eating with family/friends						
Do not like others to feel sorry for me	66.3	61.3	67.9[†]	67.7	68.1	65.0
People think a little gluten will not hurt me	45.5	41.3	46.8[†]	52.3	52.9	40.5[‡]
Hard to ask others to accommodate my GF diet	44.9	36.6	47.8[†]	54.9	49.1	41.3[‡]
Feel that I am a burden	33.4	28.3	35.2[†]	36.5	37.0	30.9[‡]
Avoid going to social events involving food	32.2	29.8	32.8	35.5	33.1	31.0
Embarrassed by my dietary needs	27.4	23.4	28.8[†]	34.8	30.8	24.5[‡]
Suspect that family/friends are afraid to invite me for meals	24.8	18.3	26.9[†]	22.7	27.2	23.7
Feel neglected	14.5	10.0	15.9[†]	16.1	16.9	12.9[‡]
Find it difficult to refuse gluten-containing foods offered to me	8.0	7.4	8.2	10.9	8.6	7.3
My friends do not understand my dietary needs	5.3	6.0	5.1	8.6	6.6	4.2[‡]
My family does not understand my dietary needs	2.9	2.1	3.1	4.9	3.3	2.4[‡]
Eating in restaurants						
Limited choices at fast food restaurants	87.5	87.5	87.5	91.3	89.2	86.0[‡]

Appendix 1. (Continued)

		By gender (%)		By years on GF diet (%)		
	Overall (%)	Male	Female	<1	1–5	>5
Limited choice of restaurants	76.9	75.2	77.6	84.8	80.5	73.8[‡]
Frustrated as a result of limited choices on restaurant menus	70.9	67.7	71.9[†]	81.1	75.2	67.1[‡]
Worry that cook is not trained in preparing GF meals	63.7	60.9	64.8	74.4	69.4	59.2[‡]
Resent having to decide which restaurants to go to	38.7	31.4	40.9[†]	39.8	41.9	36.8[‡]
Restaurants cannot provide information on gluten content of menu items	34.1	34.7	34.2	41.5	38.2	30.9[‡]
Cannot eat in restaurants because the food may be contaminated with gluten	30.5	30.7	30.5	41.3	34.3	26.8[‡]
GF foods are not as tasty as regular foods	19.1	18.8	19.0	25.7	20.2	17.5[‡]
Afraid of being a bother, so do not ask for changes to menu items	17.1	17.9	16.7	17.8	16.6	17.3
Eating at school/work						
Limited choices in the cafeteria	84.8	83.4	85.2	89.2	87.0	82.7
Feel badly if people make mistakes when making GF food for me	49.9	41.5	52.3[†]	51.7	51.3	48.7
Business lunches are very stressful	49.8	43.0	51.7[†]	52.8	54.9	45.9[‡]
Difficult to be spotlighted as having a problem	35.3	27.2	37.6[†]	39.2	38.1	32.7[‡]
Difficult having to bring own food for lunches	33.5	37.4	32.3	33.3	36.6	31.5
Feel hurt when people are indifferent to my dietary needs	31.1	23.8	33.2[†]	31.7	33.0	29.8
Embarrassed to tell people I must have a GF diet	15.7	15.1	15.8	20.9	17.4	13.5[‡]
Symptoms after consuming gluten cause me to miss work/school	8.8	7.9	9.1	10.2	9.2	8.2
Travelling						
Travelling abroad is difficult because I cannot tell from the label if the food is GF	68.7	65.9	69.7	77.0	72.0	66.2[‡]
Sad that I cannot eat many local/national specialty dishes	61.0	52.1	64.1[†]	65.9	63.8	59.1[‡]
Worry I will not find GF food when travelling	57.7	49.0	60.5[†]	62.6	62.3	54.5[‡]
GF diet makes me anxious about travelling	55.7	49.0	57.8[†]	59.4	58.7	53.5[‡]
Difficult to find shops and restaurants that sell GF food	54.2	52.7	54.6	60.1	58.6	51.0[‡]
Restaurant personnel abroad are unaware of what GF means	52.5	51.3	53.0	61.8	55.6	50.1[‡]
Difficult to carry GF food when travelling	45.9	42.6	47.0[†]	46.0	48.5	44.6
Do not enjoy travelling as much as before	35.0	30.5	36.5[†]	41.0	36.8	33.2[‡]
Embarrassed to have to always ask for GF foods	38.2	31.7	40.4[†]	48.9	41.8	34.9[‡]

[†] Indicates a significant difference between males and females ($P < 0.01$).

[‡] Indicates a significant difference among the three time periods ($P < 0.01$).

Appendix 2. Complete results of adaptive strategies often used to enhance ability to follow a gluten-free (GF) diet

		By gender (%)		By years on GF diet (%)		
Strategies used often/very often	Overall (%)	Male	Female	<1	1–5	>5
Purchasing GF foods						
Read every ingredient list	96.1	96.5	96.0	97.7	96.4	95.8
Use the CCA pocket dictionary	55.3	51.8	56.3[†]	71.5	63.5	48.5[‡]
Ask local grocery store to carry certain GF products	24.6	23.6	24.9	18.3	25.2	25.2[‡]
Purchase GF food by mail order	13.7	12.2	13.9	11.2	12.3	14.7
Food preparation						
Label all GF flours	83.8	79.7	84.6[†]	77.2	82.8	85.3[‡]
Store GF ingredients in a separate area	74.9	72.3	75.5	77.0	77.3	73.4[‡]
Cook only GF foods for the whole family	48.8	48.5	48.9	41.9	52.8	47.6[‡]
Make and freeze extra GF foods	47.6	49.5	47.2	42.8	47.1	48.7
Eating with friends/family						
Check ingredient lists on the foods I eat	55.1	46.4	58.0[†]	58.7	57.2	53.6
Bring my own food when visiting	46.5	35.9	50.2[†]	46.6	49.6	44.8[‡]
Share my best GF recipes	46.3	39.6	48.3[†]	38.1	44.4	48.4[‡]
It is easier to take charge of meals	38.8	26.7	42.5[†]	41.2	42.8	36.3[‡]

Appendix 2. (Continued)

		By gender (%)		By years on GF diet (%)		
Strategies used often/very often	Overall (%)	Male	Female	<1	1–5	>5
Invite friends/family to eat at my home	34.3	26.1	36.8†	37.5	37.7	32.0‡
Eating in restaurants						
Enquire about gluten content of all foods	74.5	72.8	74.9	75.1	75.4	73.9
Call ahead to enquire about GF menu choices	33.7	27.5	35.6†	33.9	37.4	31.7‡
Ask for printed information about gluten content	32.9	28.6	34.6†	38.2	36.8	30.0‡
Use the internet to find restaurants that serve GF foods	24.3	21.0	25.4†	35.4	32.5	17.9‡
Eating at school/work						
Have snacks on hand	78.1	67.2	81.1†	75.7	78.0	78.6
Talk to others about coeliac disease and the GF diet	68.2	62.2	70.0†	60.0	67.7	70.0‡
Offer to bring a GF dish to events involving food	61.8	47.5	65.9†	57.4	61.0	63.0
If an event involves food, remind people about my GF diet	58.0	62.5	56.8	53.8	57.7	58.7
Travelling						
Take translated information about the GF diet when abroad	43.7	34.0	47.4†	34.0	42.1	45.1
Research restaurants on the internet before I leave home	27.5	22.0	29.5†	32.0	36.4	21.8‡
Contact local Coeliac Society about sources of GF foods	15.7	12.6	16.9†	15.9	16.4	15.3
Carry a doctor's letter indicating that I require a GF diet	15.3	10.6	16.8†	13.1	16.0	15.1

†Indicates a significant difference between males and females ($P < 0.01$).

‡Indicates a significant difference among the three time periods ($P < 0.01$).

CCA, Canadian Celiac Association.