Dietary gluten avoidance in Canada: results from the 2015 Canadian Community Health Survey

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Word Count:
Abstract: 243
Full Text: 2509
Tables: 5

Author Contributions: AM, NR, JS, DD and CB were involved in the design, conceptualization and analysis/interpretation of the data. AW was involved in the analysis/interpretation of the data. AM, AW, and NR were involved in drafting the manuscript. All authors have read and agreed with the material in the manuscript. We, the authors, take full responsibility for the content of the manuscript.

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Funding/Support: This study was supported by the Canadian Celiac Association's J. A. Campbell Research Award (2018) to NR and the J. A. Campbell Young Investigator Award (2019) to AM. The study was also supplemented by start-up funds to NR from the University of Manitoba. NR is also supported by a Canadian Institutes of Health Research Early Career Investigator Award (155435).

Statement of Potential Conflict of Interest: No potential conflict of interest was reported by the authors.

Acknowledgements: We gratefully acknowledge the Manitoba Research Data Centre data analyst Dr. Ian Clara for his support in data vetting. Although the research and analysis are based on data from Statistics Canada, the opinions expressed do not represent the views of Statistics Canada. We would also like to acknowledge Melissa Secord and the Canadian Celiac Association for their support of this research and in knowledge translation. Lastly, we would like to thank Dr. Luc Clair for his assistance with the matching process.

ABSTRACT

Background: A gluten-free diet (GFD) is necessary in managing celiac disease, non-celiac gluten sensitivities, and wheat allergies, though individuals may also follow a GFD for discretionary reasons. We sought to 1) characterize dietary gluten avoidance using a nationally representative sample of Canadians and 2) describe and compare the location of food preparation among those who follow a GFD to those who do not.

Methods: We utilized cross-sectional data from the 2015 Canadian Community Health Survey, Nutrition Survey (n=20,487). Demographic variables included sex, age group, ethnicity, highest level of household education, and income adequacy. Respondents were dichotomized into those who avoid dietary gluten and those who did not. Logistic regression was used to test for predictors of a GFD.

Results: An estimated 1.9% of Canadians follow a GFD. Women had two times higher odds of reporting a GFD compared to men. People living in Ontario and Quebec had approximately half the odds of reporting a GFD as compared to other regions, independent of income adequacy, household education, sex, age group, and ethnicity. Canadians who followed a GFD consumed significantly fewer calories from foods prepared outside the home, specifically at restaurants, compared to both Canadians who reported no dietary avoidances or dietary avoidances other than gluten.

Interpretation: Results suggest that dining constraints can be difficult when eating gluten-free in Canada. The regional differences in dietary gluten avoidance suggest policies limiting access to celiac testing in Ontario may be impacting the prevalence of dietary gluten avoidance.

Celiac disease (CD) affects approximately 1% of the general western population[1], and the prevalence appears to be increasing[2]. Individuals with CD, non-celiac gluten sensitivity (NCGS), and wheat allergy must restrict gluten, a protein found in cereals such as wheat, rye and barley[3,4]. Increasingly individuals with irritable bowel syndrome (IBS) avoid gluten, though this is thought to be due to co-occurrence of NCGS[5]. It has been previously estimated that the global prevalence of the gluten-free diet (GFD) adherence is rising[1,6], including those for whom it is medically necessary, but also for a growing number of people who perceive it as a healthier diet option[3]. A GFD has been widely promoted in popular culture, rising in popularity in part, due to mass media and non-scientific reports of health and weight-loss claims, both of which are unfounded[7,8]. However, the extent to which this dietary fad may have penetrated Canadian culture is unclear. The majority of research on GFDs remains focused on CD, reflecting the seriousness of associated morbidities, as well as improvements to the diagnostic process[9,10]. However, given the multitude of reasons for adhering to a GFD, it is likely that this population will have differing demographic and socioeconomic characteristics compared to any one gluten-related disorder alone[10,11,12].

An epidemiological description of the Canadian population avoiding dietary gluten will inform our understanding of effects of different provincial health system policies specific to gluten-related disorders. Currently, Ontario is the only province in Canada that does not cover primary care testing with IgA TTG serology, the screening test necessary for detection of CD, under its provincial health insurance plan. A description of the eating patterns among those who avoid gluten will also inform our understanding of the adequacy of the Canadian food system in responding to these dietary needs. Hyper-vigilance in regard to GFD adherence presents challenges for food consumption outside the home, when travelling, and in institutional and

social settings[13,14], and can lead to a decreased quality of life[14-17]. While there has been considerable growth in the market for gluten-free foods[18], it remains unclear how current food preparation and eating location patterns may differ between Canadians following a GFD and other Canadians. Therefore, the purpose of this study was to 1) describe the demographic and socioeconomic characteristics of Canadians who adhere to a GFD; and 2) describe the location of food preparation and consumption for those who follow a GFD, and test for differences between: those following a GFD, those who report no dietary avoidances, and those reporting other, non-gluten, dietary avoidances.

METHODS

Data Source

We used data from the 2015 Canadian Community Health Survey (CCHS) Nutrition Survey. The main objective of the 2015 CCHS Nutrition Survey was to gather reliable, detailed and timely information on the dietary intake and nutritional well-being of Canadians to inform future government and health policies[19]. The 2015 CCHS included a representative sample (n=20,487) covering approximately 98% of the Canadian population, > 1-year-old, residing in the ten provinces. A detailed description of the 2015 CCHS survey sampling frame, survey, and collection methods are described elsewhere[18]. Briefly, the CCHS Nutrition Survey included a questionnaire component, as well as a 24-hour dietary recall, which followed the automated multiple pass method[19].

Variables

Adherence to a GFD was defined using self-reported responses to the question "*Do you completely exclude any of the following foods from your diet? By completely exclude, we mean you never eat it on its own or as part of a prepared dish*". Responses included meat (beef, pork,

lamb, etc.); poultry (chicken, turkey, duck, etc.); fish and shellfish; eggs, dairy products (milk, cheese, etc.); and gluten sources (wheat, barley, triticale, etc.). Adherence to a GFD was defined as an affirmative response to avoidance of gluten sources[19].

Dietary gluten avoidance was described according to sex, age group, province or region, household education, income adequacy, and ethnicity. *Sex* was dichotomized as male and female. *Age groups* were categorized as 2-17 years old, 18–49 years old, and ≥ 50 y. *Region* was grouped as British Columbia, the Prairies (Alberta, Saskatchewan and Manitoba), Ontario, Quebec, and the Atlantic provinces (New Brunswick, Newfoundland, Nova Scotia and Prince Edward Island)[20] *Highest level of household education* was categorized as less than secondary school graduation, some post-secondary, and post-secondary graduation or diploma/equivalent. *Household income adequacy*, as defined by Statistics Canada using total household income and number of individuals in the household, was classified into four categories: lowest to lower-middle income group, middle to upper-middle income group, and highest income group. *Ethnicity* was categorized as white, and racialized or Indigenous, based on the categorizations collected in the survey[19]. While missing data for income adequacy was imputed by Statistics Canada, other missing data was minimal and therefore ignored.

Dietary Avoidance Groups

For analysis related to location of food preparation and consumption (objective 2), respondents were divided into three, mutually exclusive groups based on dietary avoidances: respondents who avoid gluten, respondents who have ≥ 1 dietary avoidance other than gluten, and respondents who report no dietary avoidances. Groups were divided in this way to more fairly compare dietary gluten avoidance to other dietary avoidances, rather than no dietary avoidances alone.

Location of Food Consumption

Food consumption location was collected as part of the 24-hour dietary recall. Importantly, we wanted to distinguish between location of food *consumption* and the location of food *preparation*, as they are not necessarily the same. For example, any food that was ordered in or taken out, would be classified as prepared outside of the home, but would be consumed inside the home. As part of the 24-hour dietary recall, respondents were asked directly where the meal or snack (again, all foods and/or beverages consumed at a single eating occasion) were consumed. As such, all calories reported in the 24-hour dietary recall were attributed to one of three consumption locations: home, other, and not stated. *Home* included an individual's home or someone else's home. *Other* locations included fast food/pizza restaurants, take-out, restaurants with server; bar/tavern/lounge; vending machine; restaurants with no additional information; cafeteria not at school; cafeteria at school; child care centre; family/adult care centre; other; grocery; corner or other types of stores; or at work. Any meal or snack where a location was not reported was categorized as *not stated*.

Location of Food Preparation

Respondents were also asked directly where the meal or snack originated. Preparation is especially important for dietary gluten avoidance, as cross-contamination is a concern. Location of food preparation was categorized into five groups: *home recipe/homemade*, *restaurant* (including fast food), *other* (e.g. from a dry mix, frozen, commercially prepared), *no preparation required,* and *information not available*. Again, we calculated total calories consumed that were attributed to each location of preparation.

Statistical Analysis

Objective 1

The prevalence of dietary gluten avoidance according to the previously listed sociodemographic variables was described and chi-square analyses were used to test for differences within categories. Logistic regression was used to test for associations of socio-demographic variables as predictors of following a GFD.

Objective 2

Pregnant or breastfeeding respondents were excluded from this analysis given known effects on energy needs. We used post-estimation commands to test for differences in percent calories consumed for both food consumption location and food preparation location, according to the three dietary avoidance groups. We also determined the prevalence of consuming ***only*** food prepared at home according to each of the three dietary avoidance groups and tested for differences using post-estimation commands.

Given known differences in the sample who avoid gluten as compared to those who do not avoid gluten, we employed coarsened exact matching to correct for potential bias due to endogeneity[21]. Canadians who reported a GFD were matched by age, sex, region and household education with Canadians reporting ≥ 1 dietary avoidance other than gluten. This process resulted in a final matched sample of 2,746, with few respondents who avoid dietary gluten being pruned. Again, we tested for differences in percent calories consumed for both food consumption location and food preparation location between the two matched groups using post-estimation commands.

All analyses were performed using PASW SPSS Statistics, IBM, version 18 and STATA Statistical Analysis Software, RTI International, version 14. Given the complex survey design of the CCHS, we utilized the bootstrapping method to estimate standard errors, coefficients of variation and confidence intervals[18]. Significance was set at $p<0.05$.

Ethics Approval

All research was conducted at the Manitoba Research Data Centre, and the Social Sciences and Humanities Research Council of Canada approved our analysis, precluding the need for institutional Research Ethics Board approval.

RESULTS

Prevalence of dietary gluten avoidance and demographics

A total of 488 respondents self-reported dietary gluten avoidance, indicating an overall estimated prevalence of 1.9% among Canadians, with a higher prevalence among women than men (2.5% vs. 1.3%, respectively) (**Table 1**). Gluten avoidance was more prevalent among Canadians 18-49 years, compared with children and adolescents 2-17 years old. Ontario and Quebec had similar prevalence, which was the lowest in Canada, and residents were approximately half as likely to follow a GFD compared to Atlantic Canadians (**Table 2**). Education, income and ethnicity were not significant independent predictors of following a GFD.

Location of food consumption

Respondents consumed most of their calories at home (74-81% of total calories), regardless of dietary exclusions (**Table 3**). However, respondents who avoided dietary gluten consumed significantly more calories at home and significantly fewer calories from other locations when compared to respondents reporting any other dietary avoidance, as well as those with no dietary exclusions. Results from matched analysis revealed similar significant differences (data not shown). Almost half of respondents who followed a GFD consumed foods only at home (45.7%), compared with 36.8% and 37.8% of respondents who reported ≥ 1 dietary avoidance other than gluten and no dietary avoidances, respectively (**Table 4**).

Location of food preparation

Percent daily energy intake from homemade/home prepared recipes ranged from 11.7-12.6% of total calories for the three groups. Percent calories consumed from home-prepared foods did not differ significantly among the three groups, while the percent daily energy intake from foods prepared at restaurants (including fast food establishments) was significantly lower (2.0%) among Canadians who avoid dietary gluten compared to those with other avoidances (6.7%) and those with none (6.4%) (**Table 5**). Again, results from matched analysis revealed similar significant differences (data not shown).

DISCUSSION

We report an estimated 1.9% prevalence of Canadians who avoid dietary gluten. This prevalence likely includes individuals with CD, wheat allergy, NCGS, as well as individuals excluding gluten in the management of IBS or for reasons related to dietary trends. Unfortunately, the survey did not allow for determination of the reason for gluten avoidance. Our finding is reasonable given the 1.0% estimated prevalence of CD[1], the approximately 0.3-0.4% of Canadians with wheat allergies[23], and the prevalence of NCGS, which ranges from 0.6-6%[24]. Though at present, there remain many undiagnosed patients with CD, and therefore CD prevalence is less than this[22]. American data indicate a similar prevalence of gluten avoidance, which in 2014 was estimated at 2.1%[25]. Interestingly, the prevalence in Australia is considerably higher, which showed 3.8% total gluten avoidance, and upwards of 24.2% partial avoidance[26]; this may be partially attributed to the increasing popularity of FODMAP diets, originally theorized in Australia[27,28].

Canadian women were twice as likely as men to follow a GFD, similar to previous reports of CD, showing a female to male ratio of 2:1 or 3:1 [10,11], and NCGS, which also appears to be

female predominated[27]. In the present study, white participants had a higher proportion of gluten avoidance as compared to racialized or Indigenous participants, also similar to previous reports [29,30]; however, ethnicity was no longer significant after adjusting for other variables. CD was originally thought to be more prominent among Europeans, however more recent studies have emphasized its ethnic diversity and disproven this theory [31,32]. Income adequacy and education were not significantly associated with gluten avoidance.

In both Ontario and Quebec, the likelihood of adhering to a GFD was approximately half of what it was in the Atlantic provinces, which had the highest prevalence at 2.9%. The lower prevalence of adherence to a GFD in Quebec and higher prevalence in the Atlantic provinces, may be reflective of provincial rates in IBS[33], which suggests that those avoiding gluten includes a substantial proportion of people with IBS[34]. Limited access to serological testing for CD in Ontario through lack of Provincial funding may be contributing to disproportionately higher cases of undiagnosed CD in that province, and hence, a lower prevalence of GFD. Indeed, two of the authors (DD and CB), gastroenterologists in Manitoba, regularly provide serological testing for patients from Ontario. This is particularly concerning given that approximately 39% of the Canadian population resides in Ontario. Importantly, tTG is a highly reliable test and is recommended as the initial test to screen individuals for CD[35], a condition which overlaps with many other conditions, including IBS[34]. The lack of funding for this test may contribute to the trivialization of CD by both the public and medical professionals. Anecdotal evidence among people with CD suggests skepticism among physicians when first seeking medical help. This "health-care gaslighting", especially common among women, whose symptoms may be downplayed or ignored[36], leads to frustration and may contribute to the often long period of time before receiving a correct diagnosis[37].

Our results suggest that it is likely that the majority of Canadians reporting dietary gluten avoidance are vigilant in their avoidance. Indeed, the differences in the caloric profile by eating location/preparation of Canadians following a GFD indicate the degree of caution required, particularly from lack of control and trust over the preparation process[38]. These concerns were echoed in our engagement with patients in terms of the variation in attentiveness to which food service establishments respond to their dietary needs[39].

One of the strengths of this study is the use of CCHS data, which includes a large and representative sample size, making it the best available data of the Canadian population currently available. Nevertheless, the CCHS only included data from the ten provinces, excluding people from the territories, on-reserves, settlements, full-time members of the Canadian forces, and individuals who are institutionalized. Another limitation is that the GFD was self-reported and we cannot determine the proportion of the sample who avoid dietary gluten due to CD, non-celiac gluten sensitivity, wheat allergy, or other reasons. Lastly, we did not apply the National Cancer Institute method[40] to estimate *usual* energy intake according to location of preparation or location, as compared to *average* intake, which requires the inclusion of the second dietary recall, due to the small sample who reported dietary gluten avoidance.

CONCLUSIONS

This study offers a foundational description of dietary gluten avoidance in Canada. Provincial differences in access to CD testing may explain some regional differences in dietary gluten avoidance reported here and provide strong evidence for changes in policy to improve access to CD testing in Ontario. Results from this study may also provide credibility to Canadians who follow a GFD, as the number of Canadians reporting dietary gluten avoidance did not greatly

exceed the estimated prevalence of CD, wheat allergies, and NCGS. There are likely few Canadians following a GFD for discretionary reasons.

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Table 1. Demographic characteristics of Canadians who avoid dietary gluten based on results from the Canadian Community Health Survey, 2015.

Characteristic (n)	Percent dietary gluten avoidance (SE)	p-value
Sex		
Male (n=9,744)	1.3 (0.2)	<0.001
Female (n=10,733)	2.5 (0.3)	
Age		
2-17 y (n=5,839)	0.9 (0.2)	<0.001
18 to 49 y (n=6,543)	2.3 (0.4)	
≥ 50 y (n=7,724)	1.9 (0.2)	
Province/region		
Atlantic Provinces (n=5,308)	2.9 (0.4)	<0.01
Quebec (n=3,204)	1.5 (0.3)	
Ontario (n=4,228)	1.5 (0.3)	
Prairies (n=5,146)	2.4 (0.3)	
British Columbia (n=2,591)	2.7 (0.7)	
Household education		0.869
< Secondary School (n=1,780)	1.6 (0.5)	
Post-secondary School (n=3,754)	1.5 (0.3)	
Post-secondary degree or diploma (n=14,903)	2.0 (0.2)	
Ethnicity		
White (n=16,127)	2.1 (0.2)	<0.001
Racialized or Indigenous (n=3,369)	1.4 (0.5)	
Household income adequacy		
Low-Low Middle (m=1,318)	1.6 (0.5)	0.889
Upper to Upper Middle (n=8,496)	1.5 (0.2)	
Highest (n=10,663)	2.2 (0.3)	

SE, standard error

Table 2. Odds Ratio (95% CI) for excluding dietary gluten.

Characteristic	Odds ratio (95% CI)
Sex	
Men	Reference
Women	2.08 (1.32-3.27)**
Age (y)	
2 to 17 y	0.38 (0.23-0.63)***
18 to 49 y	Reference
≥ 50 y	0.80 (0.54-1.17)
Province/region	
Atlantic Provinces	Reference
Quebec	0.52 (0.31-0.87)*
Ontario	0.55 (0.32-0.94)*
Prairies	0.84 (0.54-1.29)
British Columbia	0.99 (0.51-1.95)
Household education	
< Secondary School	Reference
Post-secondary School	0.83 (0.35-1.93)
Post-secondary degree or diploma	1.14 (0.50-2.62)
Ethnicity	
White	Reference
Racialized or Indigenous	0.68 (0.33-1.43)
Household income adequacy	
Low-Low Middle	Reference
Upper to Upper Middle	0.83 (0.35-1.96)
Highest	1.21 (0.52-2.86)

* $p < 0.05$, ** $p < 0.01$, *** $p<0.001$

Table 3. Percent total calories by type of food consumption location according to type of dietary avoidance(s).

	Percent total kcal consumed (SE)		
	At home[a]	**Other locations[b]**	**Not stated**
Respondents who avoid dietary gluten (n=488)	81.1 (2.7)	15.4 (2.0)	3.6 (1.9)
Respondents reporting ≥ 1 dietary avoidance[c] (n=2,653)	75.3 (1.2)**	23.0 (1.2)**	1.7 (0.4)
Respondents who report no dietary avoidances (n=17,336)	74.9 (0.5)*	23.0 (0.5)**	2.1 (0.2)

SE, standard error

[a] Home refers to foods prepared at the participant's home or at someone else's home

[b] All other locations refer to the following locations: fast food/pizza restaurants; take-out; restaurants with waiter/waitress; bar/tavern/lounge; vending machine; restaurants with no additional information; cafeteria not at school; cafeteria at school; child care centre; family/adult care centre; other; grocery; corner or other types of stores; or at work.

[c] With the exception of gluten.

* $p < 0.05$, ** $p < 0.01$, *** $p<0.001$ in comparison with respondents who avoid dietary gluten.

Table 4. Prevalence of exclusive at-home food consumption[a] according to type of dietary avoidance(s).

Characteristic	Percent (SE)
Respondents who avoid dietary gluten (n=488)	45.7 (0.5)
Respondents who report one or more dietary avoidances other than gluten (n= n=2,653)	36.8 (0.2)**
Respondents who report no dietary avoidances (n=17,336)	37.8 (0.1)**

SE, standard error

[a] Home refers to foods prepared at the participant's home or at someone else's home

** $p < 0.01$ in comparison with respondents who avoid dietary gluten.

Table 5. Percent total calories for type of food preparation according to type of dietary avoidance(s).

	Percent total kcal consumed (SE)				
	Home recipe/homemade	**Restaurants[a]**	**Other[b]**	**No preparation required**	**Information not available**
Respondents who avoid dietary gluten (n=488)	12.3 (1.3)	2.0 (0.5)	10.5 (2.2)	54.9 (2.3)	20.4 (2.3)
Respondents reporting ≥ 1 dietary avoidance other than gluten (n=2,653)	11.7 (0.6)	6.7 (0.6)***	11.4 (0.6)	49.3 (0.8)**	20.9 (0.7)
Respondents who report no dietary avoidances (n=17,336)	12.6 (0.3)	6.4 (0.2)***	12.1 (0.3)	47.5 (0.3)*	21.3 (0.3)

SE, standard error

[a] Includes fast food establishments

[b] Includes dry mix, frozen or commercially packaged foods

* $p < 0.05$, ** $p < 0.01$, *** $p<0.001$ in comparison with respondents who avoid dietary gluten.