Gluten-free diet survey: are Americans with coeliac disease consuming recommended amounts of fibre, iron, calcium and grain foods?

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Abstract

Objective This survey was conducted to assess nutrient intakes and food consumption patterns of adults with coeliac disease who adhere to a strict gluten-free diet.

Design Three-day estimated self-reported food records were used to assess daily intakes of calories, percent daily calories from carbohydrates, dietary fibre, iron, calcium and grain food servings.

Subjects Volunteers for this survey were recruited through notices placed in coeliac disease support group newsletters, as well as a national magazine for persons with coeliac disease. Forty-seven volunteers met all criteria for participation and returned useable food records.

Results Group mean daily intake of nutrients by gender: Males ($n = 8$): 2882 calories; 55% carbohydrate; 24.3 g dietary fibre; 14.7 mg iron; 1288.8 mg calcium; 6.6 grain food servings. Females ($n = 39$): 1900 calories; 52% carbohydrate; 20.2 g dietary fibre; 11.0 mg iron; 884.7 mg calcium; 4.6 grain food servings. Recommended amounts of fibre, iron and calcium were consumed by 46, 44 and 31% of women and 88, 100 and 63% of men, respectively.

Conclusions Nutrition therapy for coeliac disease has centred around food allowed/not allowed on a gluten-free diet. Emphasis also should be placed on the nutritional quality of the gluten-free diet, particularly as it concerns the iron, calcium and fibre consumption of women. The use of the estimated food record as the dietary survey method may have resulted in the under-reporting of energy intake. Due to the small sample size and possible bias of survey participants, the findings of this survey may not be representative of the larger coeliac community.

Introduction

Coeliac disease is a genetically based autoimmune disease characterized by a permanent sensitivity to certain sequences of amino acids found in the prolamin fraction of wheat, barley and rye. When persons with coeliac disease consume these grains, the mucosa of the small intestine is damaged, leading to malabsorption of nutrients. Consequently, persons with coeliac disease are advised to follow a life-long gluten-free diet, strictly avoiding the prolamins of wheat, barley and rye.

Adherence to a gluten-free diet primarily affects consumption from the grain food group. As a result, questions have been raised about the diet and its effect on B-vitamin, iron and fibre intake, as well as total carbohydrate and grain food consumption (Bjorkman *et al.*, 1985; Sabry & Okada, 1992; Mariani *et al.*, 1998; Thompson, 1999, 2000; Bardella *et al.*, 2000). While specially formulated gluten-free flours, bread products, breakfast cereals and pastas are readily available, it is unknown to what extent these foods are actually incorporated into the diets of persons with coeliac disease in the US. In addition, gluten-free cereal foods are frequently made using refined gluten-free flour or starch and generally are not enriched or fortified (Thompson, 1999). In contrast, much of the refined wheat-based flour, bread and pasta manufactured in the US are enriched (on a voluntary basis) with thiamine, riboflavin, niacin, folic acid and iron[1]. Most ready-to-eat breakfast cereals also are fortified with vitamins and minerals. As a consequence, many gluten-free grain foods do not contain the same levels of B-vitamins, iron and fibre as their wheat-containing counterparts (Thompson, 1999, 2000).

Concerns also have been expressed about the calcium consumption of persons with coeliac disease (Sabry & Okada, 1992). Persons initially diagnosed with coeliac disease may have a secondary form of lactose intolerance (Farrell & Kelley, 2002). These patients are advised to follow a lactose-free diet while their intestinal mucosa heals. In most cases, the lactose intolerance naturally resolves. However, in some patients it does not resolve and a lactose-free (or lactose-reduced) diet must be followed long-term.

A review of the published literature yielded no studies on the nutritional adequacy of the gluten-free diet as followed in the US. Therefore, it is unknown whether individuals with coeliac disease in the US are consuming recommended amounts of B-vitamins, fibre, iron, calcium, carbohydrates and grains. The purpose of this survey was to estimate nutrient intakes (from food only) and food consumption patterns of US adults with coeliac disease that adhere to a strict gluten-free diet.

Materials and methods

Survey participants

Volunteers for the survey were recruited during winter and spring 2002 through notices placed in US national and regional coeliac disease support group newsletters (e.g., Gluten Intolerance Group, Seattle, WA, USA; Celiac Sprue Association, Omaha, NE, USA; The Healthy Villi, Boston, MA, USA; The Gluten-Free Gang Columbus, OH, USA), as well as the magazine *Gluten-Free Living*, Hastings-on-Hudson, NY, USA. Criteria for participation included: (1) 20 years of age or older; (2) not pregnant or breast-feeding; (3) resident of the US; (4) coeliac disease diagnosed using intestinal biopsy and (5) strict adherence to a gluten-free diet. Individuals stating that they met these requirements were sent food record forms and detailed written instructions for completion. Participants were asked to record everything they ate and drank for three consecutive days, providing information on brand names, method of cooking and amount consumed (in household measures). If the food was cooked, they were asked to record the amount of cooked product consumed. For foods that could be counted (e.g., crackers), they were asked to record the size and count. In addition, recipes were requested for all homemade foods. Restaurant meals were to include a complete description. If commercial gluten-free foods

[1]In the UK, there is mandatory fortification of refined wheat flour with calcium, iron, thiamine and niacin. (Safe upper limits for vitamins and minerals. Food Standards Agency. Expert Group on Vitamins and Minerals, 2003. Available at: http://www.food.gov.uk.)

were consumed, participants were asked to provide food labels. Participants also were asked to complete a participant questionnaire eliciting information on the study criteria mentioned above, as well as height, weight, age at diagnosis, years on a gluten-free diet, history of lactose intolerance and supplement use.

Fifty-eight individuals volunteered to participate and returned completed food records and questionnaires. Of these, 57 met the qualifications for participation based on their participant questionnaire (one participant could not be included because she was not diagnosed via intestinal biopsy). Forty-seven of the 57 returned food records were useable. Ten food records were not useable because instructions for completing them had not been followed (e.g., food records were not kept for three consecutive days, amounts of food/beverages consumed were not provided, recipes were not provided).

Dietary assessment

Three-day (consecutive) self-reported food records recorded between January and October 2002 were used to assess individual and group mean daily intakes of calories, carbohydrates, fibre, iron and calcium. Individual mean daily servings from the grain food group also were assessed. Intakes of B-vitamins including thiamine, riboflavin, niacin and folate could not be assessed, as most US manufacturers of specially formulated gluten-free foods do not analyse their products for these nutrients because they are not required to be included on the US food label.

Food records were analysed manually by the US Registered Dietitians using the US Department of Agriculture's Nutrient Database for Standard Reference (US Department of Agriculture, Agricultural Research Service, 2003), Bowes and Church's Food Values of Portions Commonly Used, 17th edition (Pennington, 1998), manufacturer data including label information and data supplied by restaurants. Because specially formulated gluten-free foods generally are not included in nutrient databases, participants were instructed to provide food labels and/or the brand and exact name of all gluten-free products consumed. When a weight value (e.g., mg) was not available for calcium and iron, nutrition labelling information (expressed as Percent Daily Value) was used to compute a weight value. There were no missing values for the nutrients analysed. Foods to include in the grain food group and serving size determination were based on the Food Guide Pyramid Booklet (US Department of Agriculture, Center for Nutrition Policy and Promotion, 1996 revised). A dietitian not involved in the original analysis checked food records for errors.

Results

Characteristics of the survey participants are presented in Table 1. Thirty-nine of the 47 (83%) participants were female and eight were male. Based on self-reported heights and weights, 30 of the 47 (64%) participants had a Body Mass Index (BMI) in the healthy range (18.5–24.9), 13 (28%) were in the overweight range (25.0–29.9), 3 (6%) were in the underweight range (less than 18.5) and 1 (2%) was in the obese range (30.0 or more). Sixteen of the 47 (34%) respondents answered *yes* when asked if they had ever been lactose intolerant; 9 (19%) reported that they were lactose intolerant at the time they completed the survey. Forty-three of the 47 (91%) respondents answered *yes* when asked if they took a vitamin or mineral supplement: 34 (72%) respondents reported taking a multivitamin and mineral supplement, 33 (70%) reported taking a calcium supplement and 7 (15%) reported taking an iron supplement.

Group mean daily intakes of nutrients (from food only) and grain foods are presented in Table 2. Based on individual mean daily intakes, seven of eight (88%) male and 34 of 39 (87%) female participants had estimated carbohydrate

Table 1 Descriptive characteristics of survey participants ($n = 47$)

Characteristic	Mean (SD)	Range
Age in years	51 (11)	21–73
Age in years at diagnosis	46 (11)	18–66
Years on a gluten-free diet	5.3 (4.9)	0.33–23
BMI*	23.3 (3.1)	15.8–30.0

*Based on self-reported weight and height.
Formula used (English): BMI (Body Mass Index) = (weight in pounds/height in inches/height in inches) ×703.

	kcal (total)	Cho (% total kcal)	Dietary fibre (g)	Fe (mg)	Ca (mg)	Grain food servings
Male ($n = 8$)						
Mean	2882	55	24.3	14.7	1288.8	6.6
SD	739	8	5.3	5.9	670.2	2.5
Female ($n = 39$)						
Mean	1900	52	20.2	11.0	884.7	4.6
SD	401	8	6.9	3.5	371.8	2.4

Table 2 Group mean daily intakes of carbohydrates, fibre, iron, calcium and grain food servings of survey participants based on 3-day food records

intakes within the Acceptable Macronutrient Distribution Range (AMDR) of 45–65% total calories (Institute of Medicine, 2002)[2]. Seven of eight males (88%) and 18 of 39 (46%) females had estimated dietary fibre intakes that met or exceeded recommended intakes of 20–35 g/day (American Dietetic Association, 2002)[3]. All males and 17 of 39 (44%) females had estimated iron intakes that met or exceeded the Daily Recommended Intake (DRI) for iron (i.e., 8 mg or 18 mg depending upon gender and age) (Food and Nutrition Board, 2001)[4]. Five of eight (63%) males and 12 of 39 (31%) females had estimated calcium intakes that met or exceeded the DRI for calcium (i.e., 1000 mg or 1200 mg depending upon gender and age) (Food and Nutrition Board, 2001)[5].

Five of eight males (63%) and eight of 39 (21%) females consumed at least the minimum daily servings of grain foods (i.e., six) recommended by the food guide pyramid (US Department of Agriculture, US Department of Health and Human Services)[6].

Discussion

During the 3-day recording period of this survey, a minority (21%) of female respondents consumed at least the minimum daily-recommended number of servings of grain foods. In the general US population, grain foods contribute a large percentage to the adult daily intake of several nutrients including thiamine, riboflavin, niacin, folate, iron and fibre (Subar *et al.*, 1998)[7]. Based on data from the US Department of Agriculture's 1989–1991 Continuing Survey of Food Intakes by Individuals (CSFII), yeast bread, ready-to-eat cereal, pasta, cakes/cookies/quick breads/doughnuts and hot breakfast cereal contribute 32.3% to the US adult daily intake of fibre (Subar *et al.*, 1998). Ready-to-eat cereal, yeast bread, cakes/cookies/quick breads/doughnuts, pasta, flour/baking ingredients, rice/cooked grains and hot breakfast cereals contribute 46.7% to the US adult daily intake of iron (Subar *et al.*, 1998). Similarly, grain foods contribute at least 28.3, 31.4, 27.0 and 43.1%, respectively, to US adult daily intakes of folate, niacin, riboflavin and thiamine (Subar *et al.*, 1998). Consequently, not consuming recommended amounts of grain products could have

[2]In the UK it is recommended that approximately 50% of an individual's energy intake be in the form of complex carbohydrate. (COMA [1991] Dietary Reference Values for Food Energy and Nutrients for the United Kingdom. Report of the Panel on Dietary Reference Values, Committee on Medical Aspects of Food and Nutrition Policy. HMSO, London).

[3]In the UK it is recommended that adults increase their intake of nonstarch polysaccharides to 18 g a day. (COMA [1991] Dietary Reference Values for Food Energy and Nutrients for the United Kingdom. Report of the Panel on Dietary Reference Values, Committee on Medical Aspects of Food and Nutrition Policy. HMSO, London).

[4]The UK estimated average daily iron requirements for adult men is 6.7 mg, adult women 11.4 mg, post-menopausal women 6.7 mg. (COMA [1991] Dietary Reference Values for Food Energy and Nutrients for the United Kingdom. Report of the Panel on Dietary Reference Values, Committee on Medical Aspects of Food and Nutrition Policy. HMSO, London).

[5]The UK reference nutrient intake for calcium for adults is 700 mg. (COMA [1991] Dietary Reference Values for Food Energy and Nutrients for the United Kingdom. Report of the Panel on Dietary Reference Values, Committee on Medical Aspects of Food and Nutrition Policy. HMSO, London).

[6]The British Nutrition Foundation recommends that 1/3 of daily food consumption come from the bread, other cereals, and potatoes food group. (Bread, Cereals, and Potatoes. British Nutrition Foundation. Available at: http://www.nutrition.org.uk).

[7]According to the British Nutrition Foundation, wheat flour contributes significantly to the dietary intake of iron, thiamine, niacin, and fibre in the UK. (Wheat intolerance and coeliac disease. British Nutrition Foundation. Available at: http://www.nutrition.org.uk).

important implications for dietary intakes of B-vitamins, iron and fibre.

Less than half (44%) of the female respondents consumed daily-recommended amounts of iron during the 3-day recording period of this survey. In the general population, enriched/fortified grain foods are a large contributor to the US adult daily intake of iron (Subar *et al.*, 1998). However, most gluten-free flours, bread products, pastas and cold cereals are not enriched/fortified (Thompson, 1999,2000). In a study of gluten-free grain foods in the US, only 32 of 196 products made from starch or refined grain were enriched (Thompson, 2000). As a result, this major source of iron is not readily available to persons with celiac disease.

Less than half (46%) of the female survey respondents consumed daily-recommended amounts of fibre during the recording period. In the general population, yeast bread contributes almost 15% to the US adult daily intake of fibre with amounts provided by whole-grain and refined varieties split evenly (Subar *et al.*, 1998). As with gluten-containing foods, the fibre content of gluten-free grain foods varies depending upon its composition (e.g., whole grain or refined). However, in addition to whole-grain and refined varieties, gluten-free grain foods also include varieties made only from starch (e.g., rice, corn, tapioca and potato). Gluten-free products made only from starch contain little, if any, fibre (Thompson, 1999).

Less than one-third (31%) of the female survey respondents consumed daily-recommended amounts of calcium during the recording period. This finding is particularly concerning because bone disease, including osteoporosis, may be a presenting feature of coeliac disease (Farrell & Kelley, 2002). This is due to several factors including the malabsorption of calcium and Vitamin D as a result of damage to the small intestinal mucosa (Farrell & Kelley, 2002). In a study of both treated and untreated adults with coeliac disease in North America, only 28% of participants ($n = 128$) had normal bone mass densities as defined by the World Health Organization (Meyer *et al.*, 2001).

When comparing group mean intake data for calories, percent calories from carbohydrates, fibres, iron and calcium from this survey with data from the US National Health and Nutrition Examination Survey (NHANES), participants in the present survey had higher mean intakes of all measured dietary components with the exception of iron (Bialostosky *et al.*, 2002). The mean iron intake for men ages 20–59 ($n = 7$) participating in the present survey was 14.8 mg compared with 18.8 mg for similarly aged men in NHANES. The mean iron intake for women ages 20–59 ($n = 27$) participating in the present survey was 10.9 mg; for the same age range of women participating in NHANES, the mean intake was 13.0 mg. For women 60 and over ($n = 12$), the mean intake was 11.4 mg for the present survey and 12.9 mg for NHANES.

One potential limitation of this survey is the use of the three consecutive-day estimated self-reported food record as the method for assessing nutrient intake. One major limitation of this dietary survey method is the underestimation of usual energy intake due to recording error and behavioural changes during the recording period (Black *et al.*, 1991; Kretsch *et al.*, 1999). Recording error may occur as a result of inaccurate estimates of food portions consumed, not recording foods consumed in excess or viewed as unhealthy and forgetting to record some foods (Kretsch *et al.*, 1999). Individuals also may alter their eating habits during the recording period by eating differently, eating less overall, eating less of certain foods (e.g., fat) and eating more of certain foods (e.g., vegetables) (Mela & Aaron, 1997). However, individuals involved in the present survey were advised to record food intake as soon as possible after eating and cautioned against changing their eating habits during the 3-day recording period. In addition, the group mean caloric intake of men and women participating in this survey was similar to that reported by NHANES (Bialostosky *et al.*, 2002), providing some evidence that energy intake was not substantially underreported.

Another potential limitation of the three consecutive day self-reported food record is the sample-recording period. An individual's nutrient intake may fluctuate on a day-to-day basis due to a variety of factors, such as day of week and season of year (Larkin *et al.*, 1991). A three consecutive

day recording period may be inadequate to capture these fluctuations and therefore may not accurately represent an individual's usual nutrient intake (Larkin *et al.*, 1991). On the other hand, although not yet explored in previously reported research, it may be the case that an individual with celiac disease may have less day-to-day variation in nutrient intake (as compared to an individual consuming a typical American diet) due to the relatively restrictive nature of the gluten-free diet.

Other potential limitations of the survey are the small size of the study population and the use of a convenience sample that included members of coeliac support groups and/or subscribers to a national magazine on celiac disease. This subgroup of persons with coeliac disease may be relatively more knowledgeable about the gluten-free diet, including nutritional issues. Due to the small size of the sample and potential bias associated with this particular sample, survey findings may not be representative of the coeliac community as a whole. Nevertheless, survey findings suggest that the nutritional quality of the gluten-free diet may be of concern and further research is needed in this area.

Historically, nutrition therapy for coeliac disease has centred around grain food allowed/not allowed on a gluten-free diet. As is indicated from the results of this survey, emphasis also should be placed on the nutritional quality of the gluten-free diet, particularly as it concerns the iron, calcium and fibre consumption of women. While we could not directly assess nutrient intakes of thiamine, riboflavin, niacin and folate, the finding that many survey respondents (especially women) were consuming lower than recommended servings of grain foods suggests that patients should be assessed for intakes of these B-vitamins as well.

There are several recommendations dietitians can make to help persons with coeliac disease consume adequate amounts of iron, fibre, calcium and B-vitamins. Persons with coeliac disease should be encouraged to consume between 6 and 11 servings (depending on caloric intake) of gluten-free grain foods each day. These grain foods should be whole-grain or enriched whenever possible. Persons with coeliac disease also should be encouraged to increase their intake of nongrain food sources of thiamine (e.g., lean cuts of fresh pork, legumes, nuts), riboflavin (e.g., dairy products, legumes, nuts), niacin (e.g., poultry, fish, legumes), folate (e.g., legumes, fruit juices, green leafy vegetables) and iron (e.g., lean cuts of beef, dried fruits, legumes). In addition, they should be encouraged to consume three servings of low-fat or nonfat gluten-free dairy foods each day. Persons with lactose intolerance should be encouraged to consume gluten-free low lactose/lactose free dairy products and/or nondairy sources of calcium, including calcium-fortified juices, calcium-fortified soy products and calcium and vitamin D-fortified nondairy beverages. Finally, the use of gluten-free supplements (e.g., multivitamin and mineral, calcium[8]) should be considered.

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