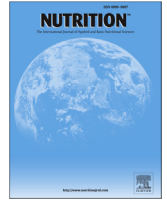


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## Is it gluten-free? Relationship between self-reported gluten-free diet adherence and knowledge of gluten content of foods



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### ABSTRACT

**Objective:** To assess the relationship between self-reported adherence to a gluten-free diet (GFD) and the ability to determine correctly the appropriateness of particular foods in a GFD.

**Methods:** Persons with celiac disease were recruited through clinics and support groups. Participants completed a questionnaire with items related to GFD information sources, gluten content of 17 common foods (food to avoid, food allowed, and food to question), GFD adherence, and demographic characteristics. Diagnosis was self-reported.

**Results:** The 82 respondents (88% female) had a median of 6 y GFD experience. Most (55%) reported strict adherence, 18% reported intentional gluten consumption and 21% acknowledged rare unintentional gluten consumption. Cookbooks, advocacy groups, and print media were the most commonly used GFD information sources (85–92%). No participant identified correctly the gluten content of all 17 foods; only 30% identified at least 14 foods correctly. The median score on the Gluten-Free Diet Knowledge Scale (GFD-KS) was 11.5 (interquartile ratio, 10–13). One in five incorrect responses put the respondent at risk of consuming gluten. GFD-KS scores did not correlate with self-reported adherence or GFD duration. Patient advocacy group members scored significantly higher on the GFD-KS than non-members (12.3 versus 10.6;  $P < 0.005$ ).

**Conclusions:** Self-report measures which do not account for the possibility of unintentional gluten ingestion overestimate GFD adherence. Individuals who believe they are following a GFD are not readily able to correctly identify foods that are GF, which suggests ongoing gluten consumption may be occurring, even among patients who believe they are “strictly” adherent. The role of patient advocacy groups and education to improve outcomes through improved adherence to a GFD requires further research.

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### Introduction

Celiac disease and dermatitis herpetiformis are chronic autoimmune conditions treated by elimination of all sources of dietary gluten [1,2]. Following a gluten-free diet (GFD) is challenging and although most patients self-report strict dietary adherence, a significant number have persistent mucosal damage 2 y after starting a GFD [3]. Even in the absence of symptoms, persistent mucosal damage is clinically significant because it is associated with greater risk of severe complications of celiac disease, including malignancy [4], as well as with increased

all-cause mortality [3]. Reasons for persistent mucosal damage are likely multifactorial. Potential reasons include occult gluten ingestion due to lack of awareness of gluten content of foods [5], contamination of allegedly gluten-free foods [6,7], and factors intrinsic to underlying celiac disease and its natural history [8,9].

Gluten ingestion due to lack of awareness of the gluten content of foods may be a significant issue for many individuals, but has the potential to be modified. Determining whether a food contains gluten is challenging. Gluten is a component of many ingredients, thus it is often not explicitly listed on product labels. Within specific food categories (e.g., potato chips), certain brands may be gluten-free while others may contain trace amounts of gluten and thus should be avoided [10]. Even within a brand, some flavors may contain gluten while others are gluten-free. The products available and the composition of particular products also changes. For example, some companies have adjusted the recipe for popular breakfast cereals to offer gluten-free versions [11]. For these reasons, following a gluten-free diet is a dynamic process that requires continuous review and reassessment.

Patients with celiac disease use many different information sources to learn about gluten-free diets [12]. These include experts (e.g., dietitians, nutritionists, and physicians), the Internet, patient support groups, and print media. There is no standardized education source for individuals requiring a GFD. Regardless of the source of a patient's technical information about gluten-free diets, this knowledge must be applied to the practical daily decisions of what to eat and, equally important, what not to eat. In practice, GFD knowledge is frequently applied in the context of attention to the content of processed foods. Few studies have assessed GFD knowledge or evaluated its relationship to self-reported adherence [13,14]. This has particular clinical relevance as misunderstandings regarding the gluten content of foods could account for (unrecognized) gluten exposure and persistent mucosal damage [5].

Efforts to maintain a stringent GFD are tempered by practical, cultural, and social realities. Individuals may choose to avoid any products that potentially contain gluten, thereby eliminating many common foods from their diet. This may result in adverse effects such as social isolation [15,16] or specific nutrient insufficiencies. This contrasts with the exponential increase in availability and diversity of gluten-free foods. Consequently, individuals trying to follow a GFD must balance vigilant avoidance of gluten containing products with awareness of new gluten-free foods as well as of alternate grains (which may or may not contain gluten) which were not previously available.

In this study, we aimed to assess the relationship between self-reported GFD adherence and the ability to determine correctly the appropriateness of particular foods in a GFD among a community sample of individuals with celiac disease and/or dermatitis herpetiformis trying to follow a GFD.

## Methods and materials

From October 2011 through October 2012, adults trying to follow a GFD were recruited through the local celiac support group, specialist clinics and advertisements at retail locations specializing in gluten-free products. Interested individuals accessed an anonymous online questionnaire. This study includes adults who reported following a GFD for a medical diagnosis of celiac disease or dermatitis herpetiformis. The questionnaire included items related to personal demographic characteristics, medical history, diet, sources of information about gluten-free diets, and the gluten content of foods (see [supplementary information](#)).

### Gluten-free eating assessment tool

Adherence to a gluten-free diet was self-reported. Specifically, respondents chose one of eight descriptors which best characterized their current diet. The descriptors were 1) unrestricted diet; 2) unrestricted gluten but other foods

restricted; 3) gluten-free diet sometimes; 4) gluten-free diet most of the time; 5) trying to follow a gluten-free diet but not always sure; 6) usually gluten-free with rare intentional gluten consumption; 7) usually gluten-free with rare unintentional gluten consumption; 8) strict gluten-free diet. "Strict adherers" were defined as those who self-reported strict adherence to a gluten-free diet whereas all other respondents were considered to be "gluten-exposed".

### Sources of gluten-free diet information

Participants were asked about their use of ten information sources to learn about gluten-free diets. For each information source, participants either rated the quality of the information obtained using a scale ranging from 1 (poor) to 5 (excellent) or indicated that they did not use this information source.

### Gluten-Free Diet Knowledge Scale (GFD-KS)

Participants completed the GFD-KS by categorizing particular foods as "allowed" (i.e., gluten-free), "foods to question" (i.e., potentially containing gluten) or "not allowed" (i.e., certainly contain gluten) in a GFD. The GFD-KS was developed by an expert panel consisting of a gastroenterologist, dietitian, and persons with celiac disease. Foods were chosen to include those that may be consumed on their own and/or appear on an ingredient list as a component of another food (e.g., milk) as well as complex foods that contain many ingredients with various recipes (e.g., sausages). Oatmeal was included because oats have recently been recognized as acceptable in a GFD [17,18]. The content was further revised following pretesting for readability and face validity by three members of the Canadian Celiac Association (CCA).

Correct classification of foods as "allowed", "not allowed", or "foods to question" was determined by a dietitian with expertise in gluten-free diets (D.W.) and verified by reviewing product labels at grocers and shops specializing in gluten-free products. The final list contained 17 foods: seven foods allowed, seven foods to question, and three foods not allowed. One point was awarded for each correct answer for a maximum total score of 17. Overrestriction was defined as questioning foods "allowed" or not allowing foods "allowed" or "foods to question." Underrestriction was defined as questioning or allowing foods "not allowed" or always allowing "foods to question."

### Statistical analysis

Statistical analyses were performed using SPSS (version 15.0; SPSS Inc., Chicago, IL, USA). Confidence intervals are typically reported in survey research and they are used here to facilitate comparisons across groups and across question items. The use of confidence intervals is recommended rather than pairwise significance tests because they help the reader focus on the magnitude of differences rather than simply concluding that a difference is statistically significant [19,20]. In making comparisons between means (between groups and across different question items) the reader should keep in mind that in one case out of 20, confidence intervals will be non-overlapping by chance.

Odds ratios (ORs) and 95% confidence intervals (CIs) were calculated using the method of Cochran and Mantel-Haenszel. Pearson correlations were performed to describe the relationships between GFD-KS scores and years on a GFD. All statistical tests were two-sided with a *P*-value <0.05 considered significant.

The study protocol was approved by the University of Manitoba Health Research Ethics Board. Completion of the anonymous survey constituted informed consent to participate in the research.

## Results

Of the 82 participants who completed the questionnaire, 76 had celiac disease and six had both celiac disease and dermatitis herpetiformis (Table 1). The majority (88%) were female and most were older than 55 y of age. Median GFD duration was 6.0 y (interquartile ratio [IQR] 2–10 y).

### Self-reported adherence

Based on the eight-item categorical self-assessment of dietary adherence, strict adherence was reported by 55%. Of the remainder, 9% followed a gluten-free diet "most of the time," 9% reported rare intentional gluten consumption, and 21% reported rare unintentional gluten consumption (Fig. 1). None reported unrestricted gluten ingestion, unrestricted gluten (other foods restricted), or gluten-free diet sometimes. About one-third (37%)

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