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## Original article

## Awareness of gluten-related disorders: A survey of the general public, chefs and patients<sup>☆</sup>

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## SUMMARY

**Background & aims:** We sought to establish the level of knowledge of celiac disease (CD) and gluten sensitivity (GS) among the general public and chefs, and to compare dining habits of people with CD and the general public.

**Methods:** Surveys assessing knowledge of CD and GS as well as dining habits were administered through an Internet survey tool or face-to-face. The chef survey also assessed training/education.

**Results:** Among 861 persons from the general public 47% had heard of CD, 67% of GS and 88% of peanut allergy. Chefs were more likely than the general public to have heard of CD (77% vs. 47%,  $p < 0.0001$ ), though greater proportions in both groups had heard of GS (89% vs. 67%,  $p < 0.0001$ ). 63% of patients ( $n = 790$ ) reported that they avoid restaurants because of the gluten-free diet and ate take-out food and restaurant food significantly less often than the general public. Trained chefs had more knowledge than untrained chefs (83% vs. 52%,  $p < 0.0001$ ). There was a direct relationship between the average check price and chefs' awareness (<\$25: 64% vs. >\$65: 94%,  $p < 0.0001$ ).

**Conclusions:** Awareness of gluten-related issues was prominent. Surprisingly, both the public and chefs were more likely to have heard of GS than CD. Most with CD avoid restaurants, and eat outside the home less frequently than the general public. Knowledge of CD among chefs exceeds that of the general public, but varies considerably.

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### 1. Introduction

Celiac disease is an autoimmune enteropathy triggered by gluten ingestion.<sup>1</sup> The treatment is elimination of gluten from the diet. One of the most challenging aspects of a gluten-free diet is eating foods away from the home, particularly in restaurants.<sup>2,3</sup> A Canadian survey of patients with celiac disease revealed that more than 80% of those with celiac disease avoid restaurants some or most of the time.<sup>3</sup> The National Restaurant Association 2010 statistics indicate that on a typical day in the United States more than 130 million people will be foodservice patrons and 44% of

adults in the United States say that restaurants are an essential part of their lifestyle.<sup>4</sup>

Peanut allergy is reported by about 1% of the United States population, a similar prevalence to celiac disease, and appears to be increasing in children over the past decade,<sup>5</sup> however, a survey of 100 restaurant managers, chefs and servers, found that only 42% had received any food allergy training.<sup>6</sup>

There is no information as to the level of awareness of either the general public or chefs in the United States about the gluten-related health issues, celiac disease and gluten sensitivity. We therefore surveyed both chefs and members of the general public about their knowledge of celiac disease and gluten sensitivity.

### 2. Materials and methods

We used three surveys, two of which were modified from surveys used in a previous study in England.<sup>7</sup> The surveys assessed the knowledge of celiac disease and gluten sensitivity in the general public and in chefs. The surveys also queried dining habits of people with celiac disease or gluten sensitivity and the general public. The study was approved by the IRB at Columbia

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University June 2010. Surveys were administered through an internet survey tool (SurveyMonkey) or face-to-face from June until November 2010.

The survey given to the general public was modified from a survey used in a previous, similar study<sup>7</sup> and assessed awareness of celiac disease, gluten sensitivity and peanut allergy, as well dining habits. The general public was recruited by face-to-face interviews in several areas of New York City.

The patient survey was modified from a survey used in a previous, similar study<sup>7</sup> and assessed dining habits for those with celiac disease or gluten sensitivity. They were recruited through celiac disease support groups, patients of the Celiac Disease Center at Columbia University and national support group websites.

The chef survey assessed awareness of celiac disease, gluten sensitivity and peanut allergy and was designed with the help of chefs, dietitians and the authors of a similar study.<sup>7</sup> Chefs were asked about their education, training and the type of establishment they worked in (fast food/casual/fine dining, average check price of customers). In addition, chefs were provided with a list of foods and asked to identify which contained gluten. Chefs were recruited through emails, websites and face-to-face interviews in New York City. The survey was sent to the alumni of four culinary schools including the Italian Culinary Academy, the International Culinary Center, the Institute of Culinary Education and the French Culinary Institute. The New York Restaurant Association also sent the survey link in emails to chefs. Approximately 200 chefs were recruited by interviews in their restaurants (face-to-face or by phone). Geographical location of email and website respondents was not determined (Figs. 1–3).

Comparisons between chefs and the general public, and between celiac disease patients and the general public, were performed using the chi square test. The Cochran–Armitage test for trend was used where appropriate. All statistical tests were performed using SAS version 9.2 (Cary, NC).

### 3. Results

Among the 861 members of the general public (females 67%), 47% had heard of celiac disease, 67% of gluten sensitivity and 88% of peanut allergy compared to chefs ( $n = 430$ ), among whom 77% had heard of celiac disease, 89% of gluten sensitivity and 93% of peanut allergy. Chefs were significantly more likely than the general public to have heard of celiac disease and peanut allergy (Table 1). Awareness of peanut allergy and celiac disease were moderately correlated ( $r = 0.43$ ,  $p < 0.0001$ ). When we asked participants to estimate the prevalence of celiac disease and peanut allergy, greater than 70% of chefs and the general public incorrectly estimated the prevalence of both conditions. Celiac disease was underestimated by both chefs (56%) and the general public (69%) while peanut allergy was overestimated by 55% of the general public and 60% of chefs (Table 1).

Trained chefs were more likely to have heard of all three conditions than untrained chefs; 83% compared to 52% ( $p < 0.0001$ ) for celiac disease, 94% compared to 66% ( $p < 0.0001$ ) for gluten sensitivity, 82% compared to 77% for peanut allergy ( $p < 0.0001$ ). The majority of chefs correctly identified bread (90%) and pasta (90%) as gluten-containing foods, but a significant minority incorrectly implicated peanut butter (16%) wine (10%), chicken (4%), oil (3%) and salt (3%) as containing gluten. Neither length of years working in food service nor length of years since graduation was significantly correlated with awareness of celiac disease or gluten sensitivity (Table 2). There was, however, a direct relationship between the average check price and chefs' awareness of celiac disease (<\$25: 64% vs. >\$65: 94%, trend,  $p < 0.0001$ ). Of the chefs who responded to the survey, the mode of ascertainment was known in 93%. Chefs that completed the survey on the internet (69% of respondents) were significantly more likely to have heard of celiac disease (93% vs. 42%),

## CHEF QUESTIONNAIRE

Have you heard of peanut allergy? Yes  No

Have you heard of Celiac Disease? Yes  No

Have you heard of Gluten sensitivity? Yes  No

How many people do you think are affected by peanut allergy?

1 in 10  1 in 50  1 in 100   
 1 in 200  1 in 500  1 in 1000

How many people do you think are affected by celiac disease?

1 in 10  1 in 50  1 in 100   
 1 in 200  1 in 500  1 in 1000

Are you a trained chef/cook? Yes  No

How many years ago did you graduate from culinary/cooking school?

< 5 years ago  5-10 years ago  10-20 years ago   
 > 20 years ago  N/A

How many years have you worked in foodservice?

<5  5-10  10-20  >20

Check all items that contain gluten.

Chicken   
 Bread   
 Wine   
 Pasta   
 Peanut butter   
 Salt   
 Oil

What type of establishment do you work in?

Restaurant   
 Cafeteria/ Administrative   
 Catering   
 Other

What is the average check price per person in the restaurant you work in?

Less than \$25   
 26-40   
 41-65   
 Great than 65   
 N/A

What type of restaurant do you work in?

Take out/ Quick serve   
 Casual Dining   
 Fine Dining

What type of cuisine does your restaurant sell?

African  American  Asian  Bar food  Caribbean   
 Cuban  Deli  Diner  Eastern European/ Greek  French   
 Italian  Latin/Mexican  Mediterranean Middle Eastern   
 Seafood  South Asian (Indian)  Spanish  Steak  Tapas   
 Other \_\_\_\_\_

Fig. 1. Survey given to chefs.

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