

BRIEF REPORT: Physician Awareness of Celiac Disease

A Need for Further Education

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BACKGROUND: Celiac disease is a common disorder (up to 0.7%); however, it is uncommonly diagnosed in the United States.

OBJECTIVE: We sought to determine physician awareness of celiac disease.

DESIGN: Surveys completed by 2,440 (47%) of 5,191 patients in a support group were analyzed for frequency of diagnosis by physician specialties. Questionnaires were then sent to primary care physicians (PCPs) ($n=132$) in a southern California county to assess knowledge of celiac disease.

RESULTS: In patient surveys, only 11% were diagnosed by PCPs (internists and family physicians) versus 65% by gastroenterologists. Physician surveys (70% response) showed that only 35% of PCPs had ever diagnosed celiac disease. Almost all physicians (95%) knew of wheat intolerance, but few (32%) knew that onset of symptoms in adulthood is common. Physicians were well aware (90%) of diarrhea as a symptom, but fewer knew of common symptoms of irritable bowel syndrome (71%), chronic abdominal pain (67%), fatigue (54%), depression and irritability (24%) or of associations with diabetes (13%), anemia (45%) or osteoporosis (45%), or of diagnosis by endomysial antibody tests (44%).

CONCLUSIONS: Lack of physician awareness of adult onset of symptoms, associated disorders, and use of serology testing may contribute to the underdiagnosis of celiac disease.

KEY WORDS: celiac disease; primary care physicians; endomysial antibodies; education.

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Until recently, the typical presentation of celiac disease was thought to be a severe malabsorption disorder of childhood.¹⁻³ It is now increasingly recognized that symptoms of celiac disease may appear at any age, and several surveys have identified the peak age of onset of symptoms in the fifth or sixth decades of life.⁴⁻⁷ These symptoms range from severe malabsorption with steatorrhea to more subtle symptoms often resembling irritable bowel syndrome, fibromyalgia, chronic fatigue, depression and anxiety, or symptoms of anemia.^{1-3,5-8} Identification of celiac disease is facilitated by widely available serologic tests, particularly anti-endomysial and anti-tissue transglutaminase antibodies. However, in the United States there remains a large gap between the prevalence of celiac disease predicted by surveys using serology screening at more than 1 in 150 compared with the number of patients diagnosed in the community.^{9,10} Delays in diagnosis of symptomatic pa-

tients with celiac disease are common, often exceeding 10 years.^{6,7} A recent analysis of celiac disease diagnosis in Olmsted County (Minn) shows increasing incidence of diagnosis from 1950 to 2001, especially in the last two years, but there is still marked underdiagnosis nationwide.^{5,11} The unanswered question is why celiac disease is not diagnosed earlier and more frequently.

OBJECTIVE

Lack of physician familiarity with celiac disease may contribute to delays in diagnosis and treatment. The aim of the current study was to determine awareness of the presentations and diagnosis of celiac disease among community physicians in one geographic region.

DESIGN

The database of a nationwide patient support group, the Celiac Disease Foundation, was utilized to determine the age at diagnosis, the duration of symptoms, and the specialty of physicians and nonphysicians who diagnosed celiac disease. There were 2,440 patients (98% Caucasian; 1,844 women and 596 men; mean age 44 years) with a diagnosis of celiac disease in the database, collected from 1993 to 2004 by surveys at the time of initial membership in the support group (47% response rate). The respondents represented wide distribution from all regions of the United States and included the 1,032 patients reported earlier.⁷ Institutional Review Board approval was obtained from the Research and Education Institute of Harbor-UCLA Medical Center (Torrance, Calif) and from the Ethics Committee of San Dimas Community Hospital (San Dimas, Calif). To further assure patient privacy, all patient identifying information was deleted before the survey data were released from the patient support group to the investigators. No attempts were made to contact the patients or their physicians to confirm the diagnosis.

To further evaluate the awareness of celiac disease and the number of patients diagnosed by primary care physicians, a mail-in survey was sent to all primary care physicians ($n=132$) listed as general internal medicine, general practice, or family practice in the telephone directories of San Bernardino County (Calif). This county is adjacent to Los Angeles, encompassing approximately 20,000 square miles, 1.7 million population, one allopathic medical school, and one nearby osteopathic medical school. The survey asked years in practice and the number of patients diagnosed with celiac disease. The questionnaires asked physicians to identify those characteristics associated with celiac disease in each of the following topics: etiology, age at onset of symptoms, common symptoms, associated disorders, complications, and diagnostic tests.

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Table 1. Physician Diagnosis of Celiac Disease: Results of Patient Survey

Diagnosing Physician	Patients No. (%)	Biopsy Confirmed No. (%)	Average Duration of Symptoms (months)	Average Age at Diagnosis (years)
Primary care physicians	265 (11)	146 (55)	10	46
Gastroenterologists	1,574 (65)	1,386 (88)	86	49
Medical specialists*	97 (4)	55 (57)	105	44
Dermatologists	89 (4)	19 (21)	36	48
Pediatricians	53 (2)	28 (53)	15	6
Pediatric gastroenterologists	200 (8)	193 (97)	14	5
Nonphysicians†	37 (2)	0 (0)	206	50
Self-diagnosed	91 (4)	7 (8)	214	52
Not stated	43 (2)	13 (24)	188	53
Total	2,440 (100)	1,847 (76)	86	44

*Medical specialists: endocrinologists (35), allergists (19), hematologists (16), rheumatologists (10), neurologists (5), cardiologists (3), otolaryngologists (3), pathologists (2), surgeon (1), infectious disease (1), emergency medicine (1), radiologist (1).

†Nonphysicians: chiropractors (11), naturopaths (7), nutritionists (5), homeopaths (3), kinesiologists (2), psychologist (1), environmental (1), oriental medicine (1), holistic (1), dieticians (2), alternative (1), biochemists (2).

There were 6 to 9 choices in each of these categories, including some incorrect choices and the choice of "I don't know." The full questionnaire can be viewed from the journal's website (<http://www.blackwellpublishing.com/products/journals/suppmat/JGI/JGI05225/JGI05225sm.htm>). Data were analyzed by calculating the percentage of physicians who answered that they were aware of each characteristic known to be associated with celiac disease. The surveys were mailed two more times to physicians who did not respond. Interviews with physicians in surrounding counties were conducted to validate the questionnaire, and the project was approved by the Ethics Committee of San Dimas Community Hospital.

RESULTS

In the patient survey, only 11% of the 2,440 patients reported that their celiac disease was diagnosed by a primary care physician (8% of those confirmed by biopsy) as listed in Table 1. Patients who reported that their primary physician suspected celiac disease before referral to a gastroenterologist were categorized in the primary care physician category. The majority of patients were diagnosed by gastroenterologists, with only a small percentage of patients reporting diagnosis by other physician specialists or by nonphysicians. Those patients diagnosed by primary care physicians reported an average duration of symptoms of less than 1 year, compared with over 7 years for patients eventually diagnosed by gastroenterologists or other medical specialists, but it is not known whether the delays were attributable to the primary care or to the specialist physician.

In the physician survey, 70% of primary care physicians returned the questionnaires. Physicians were in medical practice for an average of 20 years, but only 35% had ever diagnosed a patient with celiac disease, with a median number of 3 patients diagnosed. The results of physician questionnaires are summarized in Table 2.

DISCUSSION

The survey of 2,440 patients documents that celiac disease is diagnosed primarily by gastroenterologists and uncommonly diagnosed by primary care physicians. These data contrast with a preliminary report from Northern Ireland, where over

two-thirds of all celiac disease patients are now identified by general practitioners using endomysial antibody testing.¹² This widely available antibody test has good sensitivity (75% to 98%), specificity (96% to 100%), positive predictive value (98% to 100%), and negative predictive value (80% to 95%).^{1,2} Our survey of physicians in San Bernardino County reveals that only about one-third of primary care physicians had ever diagnosed a patient with celiac disease, and only 44% were aware that endomysial antibody testing can be used for diagnosis.

Several surveys of patients with celiac disease in the United States document that the majority of patients first present with symptoms as adults.⁵⁻⁷ However, in our primary care physicians from one southern California county, only approximately one-third were aware that adult onset of symptoms is common. The physicians generally knew of the typical symptom of chronic diarrhea, but they were less aware of the common presentations of unexplained abdominal pain, myalgias, fatigue, or symptoms resembling irritable bowel syndrome (Table 2).

Several patient groups have increased risk of celiac disease, including diabetes mellitus type 1, Sjogrens syndrome, Down's syndrome, thyroiditis, patients with immunoglobulin A (IgA) deficiency, and those with a family history of celiac disease.^{1-3,13-17} Diabetes mellitus type 1 is a common disorder treated by primary care physicians, and the prevalence of celiac disease is reported at 3% to 8% in these patients; however, very few of the surveyed physicians were aware of this association. Awareness of the association of IgA deficiency is important as negative tests for IgA anti-endomysial and IgA anti-tissue transglutaminase antibodies do not exclude the diagnosis in this population. Iron-deficiency anemia or mixed anemia with folate deficiency is a common complication of celiac disease and a presenting manifestation in over 50% of patients.⁵⁻⁸ Similarly, osteopenia is found in approximately 40% of celiac patients and severe osteoporosis is an occasional presenting manifestation.¹⁸ Fewer than half of the primary care physicians were aware of these common associations. As a group, the physicians lacked awareness of the less common associations of celiac disease with seizure disorder, unexplained infertility, and lymphoma.

The patient survey relied on questionnaires returned by mail, subjecting responses to recall bias. It also did not permit

Table 2. Physician Awareness of Celiac Disease Characteristics: Results of Physician Survey

Topic	Characteristics of Celiac Disease	Prevalence in Patient Surveys (%) [*]	Physician Awareness (%) [†]
Etiology	Intolerance to wheat products	100	95
Onset of symptoms	Childhood onset of symptoms with lifelong disease	13	62
	Onset of symptoms often begins in adulthood	87	32
Common presenting symptoms	Chronic diarrhea	59	90
	Symptoms resembling irritable bowel syndrome	26	71
	Chronic abdominal pain	46	67
	Chronic fatigue	46	54
	Depression and irritability	24	46
	Muscle aches	42	37
Associated conditions	IgA deficiency	1	34
	Thyroiditis	12	23
	Diabetes mellitus type 1	5	13
	Down's syndrome	<1	4
Complications	Iron-deficiency anemia	52	45
	Osteoporosis	12	45
	Intestinal lymphoma	<1	17
	Infertility	<5	8
	Seizures	<1	8
Diagnostic tests	Small intestinal biopsy		63
	Endomysial antibodies		44

^{*}Data represent approximate mean values from 5 surveys of celiac disease patients in the United States and Canada.⁵⁻⁹

[†]Percentage of physicians responding that they were aware of this association.

review of serology or biopsy results to confirm the diagnosis. Respondents may underrepresent minority groups and patients with mild symptoms who may be less likely to join the patient support group. However, the large number of 2,440 patients and the nationwide response suggest validity of the observation that relatively few patients were diagnosed by primary care physicians. There are also limitations in extrapolating the data from physicians in one large county to physicians nationwide. Physicians not individually listed in public telephone directories were not reached by our survey, including physicians employed in industry, teaching institutions, or at Kaiser-Permanente HMO. It is not known if physicians elsewhere in the country, those more recently trained, or those in university settings would have similar responses. However, the physician survey is consistent with the patient survey suggesting infrequent diagnosis of celiac disease by primary care physicians. A recent Consensus Development Conference on celiac disease by the National Institutes of Health concluded that celiac disease is underdiagnosed, and the panel recommended education of physicians and other health providers.¹¹ Our data support a need to increase awareness of celiac disease, especially among primary care physicians, and particularly in the recognition of adult onset of symptoms, associated disorders, and the utility of antibody tests.

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