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Patients with Celiac Disease Are Not Followed Adequately

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Abstract

Background & Aims—Adherence to a gluten-free diet is the only effective treatment for celiac disease. It has been recommended that patients be followed, make regular visits to the clinic, and undergo serologic analysis for markers of celiac disease, although a follow-up procedure has not been standardized. We determined how many patients with celiac disease are actually followed.

Methods—We collected data on 122 patients with biopsy-proven celiac disease, diagnosed between 1996 and 2006 in Olmsted County, Minnesota (70% women, median age of 42 years) for whom complete medical records and verification of residency were available. We determined the frequency at which patients received follow-up examinations, from 6 months to 5 years after diagnosis. The Kaplan-Meier method was used to estimate event rates at 1 and 5 year(s). Patients were classified according to categories of follow-up procedures recommended by the American Gastroenterology Association (AGA).

Results—We estimated that by 1 and 5 year(s) after diagnosis with celiac disease, 41.0% and 88.7% of the patients had follow-up visits, 33.6% and 79.8% were assessed for compliance with a gluten-free diet, 3.3% and 15.8% met with a registered dietitian, 2.5% and 18.1% had an additional intestinal biopsy, and 22.1% and 65.6% received serologic testing for markers of celiac disease. Among 113 patients (93%) who were followed for more than 4 years, only 35% received follow-up analyses that were consistent with AGA recommendations.

Conclusions—Patients with celiac disease are not followed consistently. Follow-up examinations are often inadequate and do not follow AGA recommendations. Improving follow-up strategies for patients with celiac disease could improve management of this disease.

Keywords

food allergy; therapy; long-term; assessment

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INTRODUCTION

Celiac disease is an immune-mediated disorder that affects approximately 1% of the general population in the United States and results in permanent intolerance to gluten in the diet (1-3). Patients diagnosed with celiac disease only represent a minority, since most cases remain undiagnosed (4). In fact, for every patient diagnosed, at least 5 individuals remain undiagnosed in Olmsted County, Minnesota (4). Celiac disease patients have a modestly increased risk of mortality, and this risk may be higher in those with poor adherence to a gluten-free diet (GFD) (5-12). Furthermore, poor adherence to a GFD has been shown to have a positive association with lower quality-of-life assessments (13, 14).

Currently, the only proven treatment is strict adherence to a GFD (i.e., complete avoidance of all wheat, rye, and barley) (15). Achieving true compliance with this diet poses a considerable challenge. These cereals, staples in the Western diet, make avoidance difficult, particularly taking into account poor food labeling and frequent packaged food contamination (16-18). Measured compliance rates vary considerably, but generally have been lower than 50%, and less when GFD is strictly defined (19-21). Dietary compliance can be monitored, with varying degrees of accuracy, by four methods: skilled interview with a dietitian, serology, validated surveys, and mucosal biopsy (22-28).

The need for long-term follow-up to improve compliance with the GFD has been well established (22-25, 29). The 2004 National Institutes of Health consensus statement and 2006 American Gastroenterology Association (AGA) technical review on celiac disease both recommended that patients be evaluated at “regular intervals” or with “periodic visits” by a “physician and a dietitian” (1, 30). Practice guidelines vary greatly, and many specific recommendations are not evidence based (19, 25, 30-33). Because of this variability in guidelines, substantial variability in follow-up was expected. However, no study has systematically assessed long-term celiac disease follow-up practices in non-referral populations. This study measures these practices in a population-based cohort of patients with celiac disease from Olmsted County, Minnesota.

METHODS

Study Setting and Patients

Unique circumstances in Olmsted County, Minnesota, facilitate population-based research. The county is geographically isolated and has a limited number of medical providers. Since 1966, the Rochester Epidemiology Project (REP) has linked medical records at Mayo Clinic and Olmsted Medical Center to provide a comprehensive medical record for the population. Olmsted County has a population of 144,248 (2010 US Census; 88% non-Hispanic white). More residents are employed in the health-care field (25%, vs 8% nationwide) and the level of education is higher, but in other respects, residents are similar to the upper Midwest population (34, 35). Potential celiac disease cases were identified using the REP diagnostic index, retrieving patient charts containing celiac disease (ICD-9 code 579) or dermatitis herpetiformis (ICD-9 codes: 694, 694.2) during calendar years 1996 to 2006. Cases included patients having an intestinal biopsy with any degree of villous atrophy, associated crypt hyperplasia and an increased number of intraepithelial lymphocytes; as well as clinical or histological improvement after the introduction of a GFD, and positive endomysial or tissue transglutaminase antibodies (30). Both positive celiac disease specific serology and response to GFD were required for diagnosis of celiac disease in patients with mild enteropathy (Marsh I and Marsh II) (20, 36).

Residency Status Verification

Complete capture of celiac disease follow-up likely hinges on continuous residency status. Thus, residency in Olmsted County for patients within 5 years from the date of clinical diagnosis was systematically verified with a computer program that matches health-care encounters with county zip codes (34). This strategy has 97% congruence with manual residency status review and US census data (37). Patients without continuous Olmsted County residency verification over the 5 year observation period were excluded from analysis to prevent inclusion of patients that may be accessing health care outside of the scope of the REP.

Operational Definitions for Categories of Follow-up

To encompass the variability of available recommendations for celiac disease follow-up, (1, 3, 19, 21, 23, 30-33, 38, 39) a priori definitions for follow-up categories were established, aiming to represent AGA recommendations:

“No celiac disease follow-up”—patients who had no celiac disease follow-up serology or visit during the observation period.

“Regular follow-up”—patients who had 2 celiac disease follow-up visits and 2 serologies at least 6 months apart during the 5-year follow-up period, beginning 6 months after diagnosis.

“Irregular follow-up”—patients who had some celiac disease follow-up visits or serologies, but failed to meet the minimal follow-up criteria of the previous operational definition.

Data Abstraction

A single physician reviewer (M.L.H.) conducted the chart review process in a uniform fashion for all patients. Initial identification of the number of visits that met criteria for a follow-up visit included 1) a gastroenterology or primary care annual medical visit that addressed and documented celiac disease and 2) any other physician or midlevel provider visit in which symptoms associated with celiac disease and compliance on a GFD were documented and/or celiac disease serologies were assessed. Visits within 6 months or beyond 5 years of the date of diagnosis were excluded. Follow-up events of interest were recorded, including assessments of compliance to GFD, registered dietitian appointment, repeat duodenal biopsy, and follow-up serologies (native gliadin, tissue transglutaminase, endomysial, and deamidated gliadin) (40). In addition, other components of follow-up, including laboratory tests and dual-emission X-ray absorptiometry scans in association with the visits, were recorded. Visit-associated compliance outcomes (ie, serologic results, documentation of GFD “compliance” as perceived by providers) were also recorded. “Positive serology” included any positive serology and “Negative serology” was used only when all serologic tests were negative.

Ethical Issues

This study was approved by the institutional review boards of Mayo Clinic and Olmsted Medical Center. Patients who did not grant authorization to use their medical records for research were excluded from analyses as per Minnesota state statute.

Statistical Analysis

Patient characteristics were summarized using descriptive statistics. The Kaplan-Meier method was used to estimate cumulative incidence rates for various “first time” celiac disease related follow-up events, such as first follow-up registered dietitian appointment, at

1 and 5 year(s) after the date of diagnosis. In addition to cumulative incidence rates expressed at the patient level, the frequency of individual components of follow-up were summarized at the visit level as the percentage of total visits over the 5-year follow-up period. Among those having at least 4 years of available follow-up data, patients were categorized into groups based on the extent of celiac disease related follow-up in accordance with AGA recommendations: 1) regular, 2) irregular, and 3) no celiac disease follow-up. To test for an association with select baseline characteristics, we compared patients with “regular” versus “irregular” or “no” follow-up using a Chi-square test (or Wilcoxon Rank Sum Test for continuous variable age). A P value < 0.05 was considered statistically significant. All analyses were carried out using the SAS statistical software package (Version 9.2, SAS Institute Inc., Cary, NC).

RESULTS

Patients

From a total of 161 incident cases identified between 1996 and 2006, 39 (24%) were excluded because of 1) lack of research authorization to use their medical records ($n=7$), 2) failure to confirm Olmsted County residency over the complete 5-year observation period ($n=25$), and 3) inadequately documented or revoked diagnosis discovered during the chart review process ($n=7$). Among the 122 patients with celiac disease included in the final analysis, 86 (70.5%) were female, and the median (range) age at diagnosis was 42 years (1.7-84.4 years). Baseline clinical characteristics are summarized in Table 1.

Follow-up Events

Most follow-up events were observed in less than one-third of patients at 1 year following diagnosis. While most patients had at least one follow-up visit and assessment of GFD compliance over the observation period of 5 years, just two-thirds had a follow-up celiac disease serology of any type. Intestinal biopsy and registered dietitian appointment were infrequent follow-up events during the entire observation period. The Kaplan-Meier cumulative incidence rates for follow-up events at 1 and 5 year(s) following diagnosis are summarized in Table 2 and Figure 1.

Other Components of Celiac Disease Follow-up

The total number of celiac disease visits for the 122 patients during the 5 year follow-up period was 314 (median [25th to 75th percentile] of 2 [1, 2] visits per person). These visits were mostly conducted by primary care providers ($n=175$, 56%) and gastroenterologists ($n=122$, 39%). Complete blood count was assessed in 62% of all follow-up visits. On average, tissue transglutaminase antibodies, transaminases, thyroid-stimulating hormone, and ferritin were each assessed in about one out of every 2 to 3 visits. Other laboratory tests (ie, vitamin D, folate) were assessed less frequently. Some form of serology was tested in 147 (47%) of 314 follow-up visits (Table 3).

Across 5 years of follow-up, more than half of patients had at least one tissue transglutaminase, CBC, transaminase, or TSH test performed. Other tests of interest (namely DEXA, nutritional markers, fasting glucoses) were not performed across the 5-year follow-up in a majority of patients (Table 4).

Categories of Follow-up

Among those with at least 4 years of follow-up available after celiac disease diagnosis ($n=113$), 40 (35%) patients had “regular” follow-up consistent with AGA recommendations, 65 (58%) had “irregular” follow-up, and 8 (7%) had no celiac disease follow-up. There was a significant association between indication of diarrhea at time of diagnosis and having

“regular” follow-up ($P=0.02$). Although not statistically significant, a family history of celiac disease showed a trend toward having “irregular” or “no follow-up” ($P=0.11$). Age, sex, and indication of a dietitian consult and other gastrointestinal symptoms at diagnosis (eg, bloating, nausea/vomiting, weight loss, abdominal pain) were not significantly associated with follow-up categories (Supplemental Table 1).

Assessment of Compliance to Gluten-Free Diet

Among patients with 4 or more years of follow-up, 57 (50%) had at least one negative follow-up serology and 31 (27%) had at least one positive follow-up serology. For provider assessment of GFD compliance, 78 (69%) patients had at least one visit in which good compliance was documented, while 35 (31%) were documented at least once with poor compliance. In addition, 42 (37%) patients had at least one visit without any documentation of GFD compliance.

DISCUSSION

The principal finding of this study is that the practice of medical follow-up in patients with celiac disease is highly variable and often inadequate. Despite some high rates observed for patients having any celiac disease related follow-up events within 5 years (e.g., 88.7% for any celiac disease follow-up visit, 79.8% for assessment of compliance to the GFD), follow-up “consistent with current recommendations” was observed in only 40 (35%) of all patients, and basic features of a follow-up visit were often absent (ie, 37% of all patients had at least one celiac disease follow-up visit with no documentation of GFD compliance). Poor follow-up practices are likely to negatively impact long-term outcomes related to compliance with GFD (25).

Practice guidelines are not consistent with regards to follow-up type and timing (1, 19, 30, 31, 33, 38, 39). The AGA and National Institutes of Health simply suggest periodic visits at regular intervals with compliance assessed and reinforced with counseling by both a physician and a dietitian (1, 30). Other societies and opinion papers use terms such as “annual,” “symptoms” and “pregnancy” to determine follow-up (19, 32, 33, 38).

There is no consensus among recommendations on whether serology should be used as a means of assessing compliance (31). Pietzak and Haines et al suggest that serologies be done annually, while the National Institutes of Health and Primary Care Society for Gastroenterology merely note that these are available markers (1, 19, 25, 30, 33). Perhaps most surprising is the lack of clear advice on when to repeat small intestinal biopsy.

Many recommendations include support of laboratory assessments to monitor for nutritional deficiencies or other diseases that can be associated with celiac disease (31). Silvester and Rashid published a review article demonstrating this variability among guidelines and found that the cost variance of proposed annual laboratory tests was between \$28 and \$278 in one healthcare system (31). With the notable exception of complete blood count, laboratory tests were infrequently assessed in our study.

The considerable incongruity of guidelines posed a challenge in defining the categories of follow-up. The definition that was chosen aimed to be the most inclusive in order to ensure that our results were not an underestimation of follow-up practices. Despite this, our results confirmed that follow-up in celiac disease is less than optimal.

Research conducted on other chronic disease populations has indicated that socioeconomic and psychological factors interplay with treatment compliance (41-43). Patient preferences may impact adherence to follow-up recommendations. A survey among celiac patients in the

United Kingdom demonstrated that the preferred method of follow-up for celiac disease patients was to see a dietitian, with a doctor available as needed (38% were not under active follow-up) (29). Olmsted County is a unique population in that there is tremendous access to medical care, fewer uninsured, and overall higher degrees of education and wealth (34). These factors would likely enhance a patient's probability of receiving follow-up medical care, implying that our estimates are an overstatement of follow-up compared to other locations. Thus, it is likely that limited celiac disease follow-up may be the rule, not the exception, in the United States.

While the original cohort for this study is population based, there was a minority of patients who failed to meet study inclusion criteria (primarily related to residency status) and were thus excluded from these analyses. However, based on a comparison of those included (n=122) versus excluded (n=32, not counting the n=7 subjects that denied research authorization), the study restrictions did not appear to induce any significant selection bias with respect to age (mean, 41 vs 40 years, respectively; $P=0.82$) or sex (female, 71% vs 56%; $P=0.13$), which could be taken to mean that the study cohort is demographically representative of the larger population-based cohort.

Other limitations of the study include the relative homogenous population of Olmsted County in relation to the rest of the country. However, this limitation must be balanced against the many strengths of REP (e.g., complete case ascertainment, residency status verification) that make this population-based study feasible (35).

Currently, there are very few studies exploring actual practices of medical follow-up in celiac disease (44). Future prospective studies in larger patient populations and other settings will continue to provide useful information on how to improve upon follow-up practices and outcomes in celiac disease.

In summary, this study showed that in a population-based cohort of 122 patients diagnosed with celiac disease, very few patients had medical follow-up that would be in keeping with even the most lax interpretation of current guidelines. Understanding current follow-up practices will be of assistance in generating evidence-based recommendations for long-term follow-up of patients with celiac disease, which may improve the overall quality of medical care.

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ABBREVIATIONS

AGA	American Gastroenterology Association
GFD	gluten-free diet
REP	Rochester Epidemiology Project

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Figure 1.

5-year Kaplan-Meier curves of celiac disease-related follow-up events in a cohort of 122 patients with celiac disease:

A) Celiac disease-related follow-up visit, B) assessment of compliance to gluten-free-diet, C) registered dietitian appointment, D) repeat duodenal biopsy, and E) follow-up celiac disease serologies.

Table 1

Summary of Clinical Characteristics of a Cohort of 122 Patients with Celiac Disease

Variable	
Demographics	
Age at celiac disease diagnosis [^]	42 (1.7, 84.4)
Female sex	86/122 (70.5%)
Clinical Characteristics	
Histology	
Villous atrophy and/or intraepithelial lymphocytosis [*] in diagnostic biopsy	122/122 (100%)
Serology	
Positive tissue transglutaminase antibody or endomysial antibody	99/108 (91.7%) ^{**}
Positive tissue transglutaminase antibody	71/79 (89.9%) ^{**}
Positive endomysial antibody	66/81 (81.5%) ^{**}
Gastrointestinal Symptoms	
Diarrhea	45/122 (36.9%)
Greasy stool	10/122 (8.2%)
Abdominal distention/bloating	20/122 (16.4%)
Nausea/vomiting	19/122 (15.6%)
Weight loss	21/122 (17.2%)
Abdominal cramping	45/122 (36.9%)
Treatment	
Gluten-free diet treatment started [†]	120/122 (98.4%)
Dietitian consult at time of diagnosis	96/114 (84.2%) ^{**}

[^] Median (min, max).^{*} Only 3 patients were diagnosed on the basis of intraepithelial lymphocytosis (40 intraepithelial lymphocytes per 100 epithelial cells) without villous atrophy but positive endomysial antibodies and response to gluten-free diet (36).^{**} Due to some missingness, the number of subjects with actual data is shown and used as the denominator for all percentages.[†] Gluten-free diet was recommended at celiac disease diagnosis to all 122 patients.

Table 2

Kaplan-Meier Rates of Celiac Disease Related Follow-up Events at 1 Year and 5 Years After Diagnosis in a Cohort of 122 Patients with Celiac Disease.

Follow-up Event	1 Year % (95% CI)	5 Years % (95% CI)
Follow-up celiac disease appointment	41.0 (31.6, 49.1)	88.7 (80.1, 93.6)
Assessment of compliance to GFD	33.6 (24.7, 41.5)	79.8 (70.4, 86.2)
Follow-up dietitian appointment	3.3 (0.1, 6.4)	15.8 (9.0, 22.1)
Follow-up duodenal biopsy	2.5 (0.0, 5.2)	18.1 (11.0, 24.7)
Follow-up celiac disease serologies	22.1 (14.4, 29.2)	65.6 (55.7, 73.4)

Table 3

Percent of Visits with Follow-up Studies During 5 Years of Celiac Follow-up

Serology	(N=314) (%) of total visits
Endomysial antibody	51 (16%)
Tissue transglutaminase antibody (IgG or IgA)	127 (40%)
Gliadin antibody (IgG or IgA)	25 (8%)
Basic Laboratories and Studies	
CBC	195 (62%)
Transaminases	123 (39%)
Albumin	31 (10%)
TSH	107 (34%)
Ferritin	102 (32%)
Vitamin D	49 (16%)
Folate	35 (11%)
Vitamin B12	38 (12%)
Fasting glucose	26 (8%)
DEXA scan	68 (22%)

Table 4

Kaplan-Meier Rates of Celiac Disease-Related Follow-up Studies at 1 Year and 5 Years After Diagnosis in a Cohort of 122 Patients with Celiac Disease

Follow-up Study	1 Year % (95% CI)	5 Years % (95% CI)
Serology		
Endomysial antibody	9.8 (4.4, 15.0)	29.9 (21.0, 37.9)
Tissue transglutaminase antibody (IgG or IgA)	17.2 (10.2, 23.6)	53.5 (43.5, 61.7)
Gliadin antibody (IgG or IgA)	2.5 (0.0, 5.2)	15.9 (9.1, 22.3)
Basic Laboratories and Studies		
CBC	33.6 (24.7, 41.5)	78.9 (69.7, 85.3)
Transaminases	15.6 (8.9, 21.8)	56.2 (46.0, 64.5)
Albumin	2.5 (0.0, 5.2)	18.6 (11.2, 25.3)
TSH	12.3 (6.3, 17.9)	51.4 (41.4, 59.7)
Ferritin	19.7 (12.3, 26.4)	48.6 (38.6, 56.9)
Vitamin D	5.7 (1.5, 9.8)	28.9 (20.2, 36.7)
Folate	4.9 (1.0, 8.7)	21.6 (13.9, 28.6)
Vitamin B12	4.1 (0.5, 7.6)	24.3 (16.1, 31.6)
Fasting glucose	3.3 (0.1, 6.4)	15.9 (9.1, 22.2)
DEXA scan	6.6 (2.1, 10.8)	39.7 (30.1, 48.0)