Diagnosis and Treatment of Celiac Disease Among Adults: A Qualitative Study Among Gastroenterologists

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Abstract

Introduction

Gastroenterologists (GI) play a key role in the diagnosis and treatment of persons with celiac disease (CeD). Data is lacking regarding the management of CeD among GI. We conducted a qualitative study to assess the management of CeD among US-based GI. While the abstract accounts for GI only, PCP were also interviewed, and findings beyond the abstract reflect both groups.

Methods

- In-depth 1-on-1 phone interviews with board certified GI (minimum 70% of time in direct patient care; minimum of 50 CeD patients/year). To reduce bias, the study was conducted by Cadence, an independent market research firm. Prior to the interviews, a list was prepared that covered the topics of interest. Data was coded and categorized, and a general description of each theme was formulated.
- Participants: 18 GI, mean practice experience 14.1 ± 7.7 years, mean annual CeD patients treated 119 ± 97.

Results

- Theme 1: Typical Patient: Patients are diverse in their demographic characteristics, and are predominantly white and female, with ages ranging from 18 to 55 years. They typically present with abdominal symptoms that are also consistent with irritable bowel syndrome or ulcerative colitis. Some present with nutrient deficiencies.
- Theme 2: Referral Patterns: Most patients are referred from primary care physicians (PCP), and about 25% of referrals received a prior diagnosis of CeD.
- Theme 3: Diagnostic Workup: The typical diagnostic process for GI begins with serological tests, followed by endoscopy.
- Theme 4: Patient Categorization: Although duodenal biopsies are graded by pathologists (Marsh scale), this is not useful for patient management. Categorization of patients by disease severity is not typically used, but patients may be informally classified based on the number and nature of their symptoms.
- Theme 5: Therapeutic Approach: The primary therapeutic approach for patients with CeD is a gluten free diet (GFD). Patients might also be treated to address acute symptoms (e.g., anti-diarrheals, anti-nausea) and 50% of GI use steroids for severe or refractory cases.
- Theme 6: Biggest Challenge in Treating CeD Patients: The biggest challenge is compliance with a GFD, which is of concern in about 40% of patients. GI believe that there is a major unmet need for CeD treatments beyond a GFD.

Discussion

More patients are now being evaluated for CeD, driven by increasing awareness of the disease. GI respondents consider CeD to be a straightforward disease to diagnose and treat, and the primary therapeutic approach is a GFD. However, compliance with a GFD is challenging for many patients, and new treatment options for CeD are needed.

"The main challenge is, the treatment is diet. I really, really feel that most people can do really well on a strict diet, but it's again a lot easier said than done." -GI

Background

- Although the prevalence of CeD in Western countries is approximately 0.5-1.0% of the general population, the majority of these patients go undiagnosed.[1,2]
- Diagnosis of CeD can be challenging due to lack of symptoms, an extensive range of symptoms, or overlap of symptoms with other disorders, like irritable bowel syndrome.
- The only long-term treatment at this time is a gluten-free diet for the lifetime of CeD patients.
- Large collections of data regarding CeD diagnosis and management are generally lacking.

Objectives

- Understand the current diagnostic, referral, and treatment processes for adult patients suffering from CeD.
- Gain insights regarding the current adult CeD patient population.

Methodology

- Cadence conducted a series of one-on-one interviews with GI and PCP to gain a better understanding regarding the diagnosis and management of celiac disease among adults.
- Format: one-on-one web-assisted telephone interviews; interview length: 45 minutes
- Fielding Dates: 2/15/22 – 3/4/22
- Key screening criteria: Board-certified, minimum 70% of time spent in direct patient care, must treat adult celiac patients
- Respondent sample: total sample: 32
  - GI: n = 18
  - PCP: n = 14

"If the patients follow the diet and change their lifestyle modifications, they do fairly well. This group, I am satisfied with the outcome and with the treatment modalities. The other population are the problem patients, and we don't have much tools to treat them accurately and provide symptom relief. They get discouraged, if they don't get symptom relief, they stop it -- my life is not good either way." -PCP

"Pathology and clinical characteristics don't typically correlate that excellently. You'd be surprised. Somebody with very mild findings on pathology would have severe symptoms clinically." -GI

Results

- The CeD market holds great potential for new therapies, as it currently only has one treatment option: GFD.
  - GI and PCP believe there is a major unmet need for CeD treatments beyond a GFD.
  - Although they are somewhat satisfied with GFD, they are concerned with patient compliance and accidental exposure to gluten.
- While increasingly diverse, CeD patients tend to be more similar in terms of demographics and symptomatology.
  - The typical CeD patient is predominantly white, female and 18-55 years old.
  - Patients tend to present with abdominal symptoms (e.g., pain, bloating, gas) that are also consistent with irritable bowel syndrome or ulcerative colitis; in addition, patients may present with secondary symptoms such as headaches, hair or skin changes, neurological deficiencies, or nausea.
  - If GI and PCP informally categorize their CeD patients by severity of symptoms, they will still treat them all with GFD.
- Most physician referrals are from PCP to GI.
  - All PCP respondents refer their patients to the GI for CeD diagnosis.
  - GI are responsible for diagnosing CeD; the typical diagnostic process begins with serological tests, followed by an endoscopy.
  - Nutritionists are routinely consulted.
- Diagnosing and managing CeD varies by physician type.
  - PCP experience challenges in determining when to diagnose CeD patients, especially early on in a patient's disease.
  - PCP do not typically consider CeD to be a straight-forward disease to manage.
  - GI consider CeD as straightforward with a clear but limited therapeutic approach.
  - GI are challenged to treat GFD-refractory patients due to lack of treatment options.

"The fact that gluten [is] in everything, not literally but essentially. And so, I think people struggle with compliance. I think that's the biggest, people coming in with persistent symptoms, not realizing that they're still being exposed, patient frustration that they're modifying things in their mind, quite extensively and still having persistent symptoms and wanting some other treatment that I don't necessarily have to give them. I think that's the struggle." -PCP

References

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2. Rubio-Tapia A, Ludvigsson JF, Brantner TL, et al. (2012). The prevalence of celiac disease in the United States. *Am. J. Gastroenterol.,* 107(10); 1538-1544. https://doi.org/10.1038/ajg.2012.219

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