

New study finds low rates of biopsy contribute to celiac disease underdiagnosis in US

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Under-performance of small bowel biopsy during endoscopy may be a major reason that celiac disease remains underdiagnosed in the United States, according to a new study published online recently in *Gastrointestinal Endoscopy*. Investigators at the Celiac Disease Center at Columbia University Medical Center (CUMC) found that the rate of small bowel biopsy is low in this country.

"The vast majority of people with celiac disease in the United States remain undiagnosed," said lead author Benjamin Lebwohl, MD, MS, assistant professor of clinical medicine in the Division of Digestive and Liver Diseases, and a gastroenterologist and [epidemiologist](#) at the Celiac Disease Center, CUMC. "This stands in contrast to countries in Western Europe and Scandinavia, where patients with celiac disease are much more likely to be diagnosed. Are patients with celiac disease in the United States not seeking medical attention? Actually, this study shows that some of these undiagnosed patients may be coming to see a gastroenterologist and still are not getting the biopsy they need for a diagnosis."

Dr. Lebwohl and colleagues analyzed the Clinical Outcomes Research Initiative National [Endoscopy](#) Database (CORI-NED), a multicenter database that represents a broad section of endoscopy centers throughout the country, including community-based as well as academic settings. They identified all patients who underwent [upper gastrointestinal](#)

[endoscopy](#) during the years 2004-2009 for one of the following reasons: Weight loss, [iron deficiency](#), anemia, or diarrhea. "Any one of these symptoms could be compatible with celiac disease. We know that the blood tests for making this diagnosis are not perfect, and so we argue that most patients having an endoscopy for one of these reasons should have a biopsy of the [small intestine](#) to test for celiac disease."

In fact, physicians did a small bowel biopsy in only 43 percent of the more than 13,000 patients having an endoscopy during this 6 year period.

"We thought that biopsy rates would be higher, especially considering the increased public awareness of celiac disease," said Dr. Lebwohl. Although the rates increased somewhat over time, in the most recent year of the study (2009) the biopsy rate remained only 51 percent. "As a result, it remains possible that a patient with celiac disease may seek health care, see a gastroenterologist, and have an endoscopy, and yet may still remain undiagnosed."

These low biopsy rates were not uniform: men were less likely to have a biopsy as compared to women. This may provide a clue to understanding a long-observed curiosity: the lopsided gender ratio among patients with celiac disease.

"Men are just as likely as women to develop celiac disease, but women are much more likely to be diagnosed," said Peter H.R. Green, MD, professor of clinical medicine in the Division of Digestive and Liver Diseases, director of CUMC's Celiac Disease Center, and senior author of the study.

"Perhaps men aren't being diagnosed because their doctors aren't biopsying them, even when symptoms are compatible with celiac disease. This becomes a self-fulfilling prophecy: men aren't being

biopsied, diagnosis rates in men remain low, and so doctors erroneously think that celiac disease is a 'woman's disease,'" said Dr. Green.

Biopsy rates were also lower among older patients, African-Americans, and Hispanics. Dr. Green added, "We know that celiac disease can occur at any age, and is not limited to Caucasians; but here again this [celiac disease](#) stereotype of the young Caucasian is reflected in the biopsy practices of gastroenterologists nationwide."

The authors are planning follow-up studies that aim to educate physicians regarding the benefits of performing [small bowel biopsy](#).

Provided by Columbia University Medical Center

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