

Celiac Disease: Not So Rare, Mostly Undiagnosed

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August 1, 2012 — The prevalence of celiac disease (CD) in the United States may be more common than originally thought, according to findings from the first large population-based study that sampled people from a variety of ethnic groups.

Among the survey's key findings are that nearly 2 million people have CD, but most of them are unaware of it.

The study was authored by Alberto Rubio-Tapia, MD, from the Division of Gastroenterology and Hepatology, Mayo Clinic, Rochester, Minnesota, and colleagues, and was [published online](#) July 31 in the *American Journal of Gastroenterology*.

"The prevalence of [CD] in the United States is unknown," the authors write. Population studies from diverse groups have suggested that CD may be underdiagnosed, and some estimates have indicated that the prevalence of the disorder in non-Hispanic whites in the United States may be as high as 1.1%.

Even so, the authors emphasize, "No prior study has been designed to provide a robust estimate of the prevalence of CD for the entire US population."

To address that lack of information, the researchers analyzed data on a representative sample of 7798 people older than 6 years who during 2009-2010 took part in the National Health and Nutrition Examination Survey (NHANES), an ongoing cross-sectional study that includes physical exams, laboratory work, and interviews with participants. The NHANES is being conducted by the US Centers for Diseases Control and Prevention's National Center for Health Statistics.

The researchers screened all participants' serum for immunoglobulin A (IgA) tissue transglutaminase antibodies. The sensitivity of that test is about 98%, the authors note.

If findings from that screen were abnormal, the serum was also tested for IgA endomysial antibodies. That test has a specificity of between 99% and 100%.

Patients were also interviewed to find out whether they had ever been diagnosed with CD or, regardless of whether they had been diagnosed, whether they were following a gluten-free diet.

The investigators report that as a result of the survey, CD was diagnosed in 35 of the participants. However, only 6 of the 35 had been previously aware of their status. The median age of participants diagnosed with CD was 45 years.

The researchers report that CD was much more common among non-Hispanic whites than among other ethnic groups.

More specifically, although the overall prevalence of CD among people surveyed was 0.71% (95% confidence interval [CI], 0.58% - 0.86%), prevalence among non-Hispanic whites was 1.01 % (95% CI, 0.78% - 1.31%).

"CD was rare among minority groups but affected 1% of non-Hispanic whites," the authors write. If that 0.71% figure for overall prevalence is correct, it would translate to at least 1.8 million people with CD nationwide.

Those findings on ethnic/racial disparities are generally in line with results from several surveys conducted in European countries. "Further studies are needed to better understand the possible genetic and/or environmental reasons underlying this difference," the authors write.

The researchers also report that in the cohort as a whole, 55 of the patients were on gluten-free diets (GFDs). "The weighted prevalence of persons on a GFD in the United States was 0.63% (95 % CI, 0.36–1.07%), which equates to an estimated number of at least 1.6 million persons nationwide," the authors write.

About 80% of the participants who were following a GFD had not received a diagnosis of CD. "This finding may simply reflect the growing popularity of a GFD in the United States in recent years," the authors note. In addition, members of some

households affected by CD may all follow GFDs just to keep food preparation simple.

Even so, the authors emphasize that embarking on a GFD without first confirming the diagnosis of CD is not a good idea.

"Symptomatic improvement of gastrointestinal symptoms after gluten withdrawal is considered a poor predictor of a CD diagnosis," the authors note. "Self-treatment with a GFD is not recommended and should be discouraged."

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