ASYMPTOMATIC CELIAC DOCS: DOES TREATMENT HELP OR HURT?

BY KATE JOHNSON

NEW YORK — Symptomatic celiac disease is a clear indication for treatment with a gluten-free diet, but debate about the necessity of diagnosing and treating asymptomatic celiac disease was lively at an international symposium on celiac disease.

“IF we are going to diagnose this disease [in asymptomatic people], we have to be certain it will be of benefit,” said Dr. Richard Logan of the University of Nottingham (England).

Experts believe that diagnosed, symptomatic celiac disease represents only the tip of the iceberg of gluten sensitivity, while below the waterline is a spectrum of asymptomatic disease, which includes people with positive serology and histology (silent disease), as well as those with positive serology but negative histology (latent disease).

Such asymptomatic patients are often diagnosed during family screening, because it is now recognized that genetic predisposition plays an important role in the development of the disorder; almost all celiac patients carry the DQ2 or DQ8 genes.

But the uncertain clinical benefit of labeling asymptomatic individuals and prescribing them a lifelong gluten-free diet should be carefully weighed against the potential psychological and economic risks, warned several experts at the meeting, which was cosponsored by the AGA Institute.

Reducing Long-Term Risk

A gluten-free diet can dramatically reduce or eliminate symptoms, and this treatment has also been considered protective against the increased risks of malignancy and osteoporosis that have been associated with celiac disease—even its asymptomatic form. However, new research suggests that these long-term risks might be lower than previously believed, said Dr. Joe West of the University of Nottingham (England).

His study of almost 5,000 treated celiac patients and more than 25,000 controls revealed a 10% increase in overall malignancies among the celiac patients (BMJ 2004;329:716-9), but a closer analysis revealed a detection bias in that most cancers were diagnosed in the first year after the celiac diagnosis.

After controlling for this phenomenon, the difference in overall cancer rate between the two groups was no longer significant. However, further analysis of individual cancers did reveal a fivefold increase in non-Hodgkin’s lymphoma among the celiac patients, and a 40-fold increase in small bowel lymphoma (Alim Ment.) 2004;20:769-75). Interestingly, breast cancers were 70% less common in the celiac population. “This is a pretty robust and intriguing finding for which I have no explanation,” Dr. West said.

His research also found a 30% increase in osteoporosis among celiac patients, with a twofold increase in hip fracture; however, the numbers were not entirely pleasing small. These results were restricted to diagnosed celiac patients who were being treated with a gluten-free diet, and therefore their relevance for undiagnosed, untreated individuals is not clear, he said. “One way to look at it is to say that in an untreated group the risks could be much higher. The other way of looking at it is to say that people with undetected celiac may have less severe disease and therefore perhaps less risk,” he said.

Another argument for screening and treating asymptomatic celiac disease comes from evidence that it might progress to overt disease with continued gluten exposure, other experts said. Early treatment with a gluten-free diet could halt the progression from latent to silent and then to symptomatic disease, they suggested, although this is still widely debated.

The Psychological Toll

But the psychological price of a lifelong gluten-free diet is often underappreciated by physicians who prescribe it, Dr. Logan said. A recent survey of patients diagnosed with celiac disease revealed that one-third felt the gluten-free diet greatly reduced their enjoyment of food, and a quarter were not entirely pleased to have been diagnosed, he said. Despite experiencing relief of symptoms, many celiac patients (particularly women) on a gluten-free diet report a reduced quality of life, according to research by Dr. Claes Hallert of Linköping (Sweden). "We used to say celiac was a very treatable disorder, but that is not entirely true," he said in an interview. "Many patients react psychologically to the restrictive diet—the social problems, societal problems, problems at work, problems with travel—and this may lead to depression.”

In a study of 40 celiac patients, his research group identified 195 situational dilemmas faced by patients dealing with a gluten-free diet. Specific situations that were identified included isolation, shame, fear of gluten, and worry about inconveniencing others. Patients also reported unwanted visibility, neglect, disclosure avoidance, and risk-taking, as well as restrictions on food choice and extra work involved in food preparation (J Hum. Nutr. Diet. 2005;18:171-80).

Such barriers might be important contributors to noncompliance with the diet, suggested Dr. Carolina Ciacci, whose research showed that anger is the predomi- nant emotion in roughly 40% of diagnosed patients with treatment of the disease (J Hum. Nutr. Diet. 2005;18:171-80).

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