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# How good are gastroenterologists in diagnosing and treating celiac disease?

Delays in diagnosis, uncertain information on how to handle health issues, hesitant recommendations on screening of relatives, etc. is not at all rare for celiac patients. To gain more insight into these issues, we performed a survey that was recently presented at the world's largest gathering of gastroenterologists: Digestive Disease Week (DDW) in New Orleans in May of this year. Our group (the University of Chicago Celiac Disease Center and colleagues at North Shore Health System (*) hypothesized that significant variation exists between recommendations from clinical guidelines and the clinical practices of experts in celiac disease compared to community-based gastroenterologists.

To study this hypothesis, a survey reviewing a variety of clinical concepts in the diagnosis and management of CD was created. Responses of CD experts were compared to non-experts. Cluster sampling of non-expert gastroenterologists was performed at Digestive Diseases Week 2009. There were 185 responses, and 169 were included in the final analysis.

Thirty CD experts from around the world were selected. Twenty-three responded via e-mail, 22 were included in the final analysis.

To measure variation in decision making, the suitability of diagnostic and management options were rated on a validated scientific instrument, called a
"RAND Appropriateness Scale (RAS)" that has 9 points.

- Here are some of the scenarios used for the study:
    1. How to diagnose a patient on a gluten free diet (GFD) for 5 years after a questionable diagnosis based only on a positive anti-gliadin antibody;
    2. Screening for CD in high risk groups;
    3. Screening for CD in atypical presentations.
- While there was overall good concordance in most of the scenarios proposed among CD experts, major differences between them and the non-experts were seen in half of the answer options (26 out of 54). Let's examine in more detail some of our results:
    1. Practically all experts endorsed the need for a gluten challenge as an initial step to diagnose CD; on the contrary, the favored diagnostic option among non-experts (endorsed by 63% of them) was to perform a blood test for TTG (which clearly would have not shown any abnormality).
    2. Significant differences in endorsement were seen in screening for CD in high risk groups, such as first-degree relatives, patients with Down syndrome, autoimmune conditions, etc. In fact, while between 73% and 96% of the experts favored screening for celiac disease in the various groups known to be at risk *(and one here might question why not a steady 100% for each condition ….)*, an average of only less than 50% of the non-experts endorsed the need to screen for such disorders (of note: a solid 55% of the non-experts would not screen for CD in type 1 diabetes!).
    3. Things were no better when dealing with the need to screen patients that would present with atypical manifestations, such as iron-deficient anemia, delayed puberty, unexplained infertility, elevated liver enzymes, etc. For such presentations, on the

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average only about 55% of the non-experts (compared to almost 90% of the experts) would request screening for CD.

- Thus, significant variations occur among gastroenterologists in the diagnosis and management of CD, including use of the gluten challenge and the need for screening of high risk groups and atypical presentations. These conclusions perhaps do not come as a surprise to many of the readers who may have gone through serious difficulties before being properly diagnosed, and should alert everyone caring for CD to the need to continue tirelessly efforts at spreading increased awareness and education: not just to primary care physicians, but, as sadly shown by this study, also to gastroenterology specialists.

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