

It is common for the physician (or individuals themselves) to put the patient on a trial gluten-free diet based on symptoms alone. The symptoms might improve; however, the patient soon realizes that a strict gluten-free diet is not easy to follow. The diet is costly, complex, and socially restrictive. Now the patient wants to know if celiac disease is truly present so that he or she can liberalize the diet, and a referral is made. Those of us who work in the field know how difficult this situation is for the patients, their families, and gastroenterologists.

The focus should be on improving awareness of celiac disease and advocating wider availability of serologic screening and timely access to endoscopy, rather than empirical therapy of this lifelong disorder.

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### Data needed

Rashid et al<sup>1</sup> recommend a laboratory test for tissue transglutaminase (tTG) following positive tTG home-test results. Yet they fail to provide any data or rationale to support such unnecessary delays and duplication of costs, which needlessly increase the burden on our health care system. The specificity of the tTG rapid home

test is reported to be very close to 100%.<sup>2,3</sup> Although Rashid and colleagues quite rightly decry the unfortunate practice of beginning a gluten-free diet before endoscopic biopsy, the unnecessary delays they recommend might well increase the frequency of patients beginning gluten-free diets prematurely.

As reported, false-negative test results will, predictably, increase in the absence of total immunoglobulin A measurement, owing to the increased incidence of immunoglobulin A deficiency among individuals with celiac disease. This limitation has long been recognized in association with all serology testing for antibodies suggestive of celiac disease. Home tests are, of course, similarly and equally compromised. However, Rashid et al do not provide any data suggesting that the specificity of the home test is compromised. The very study they cite to impugn the home test's sensitivity reported 100% specificity of this test in the group investigated.<sup>2</sup>

Admittedly, a reduction in sensitivity is reported for rapid tTG antibody testing when nurses who have not been trained in the administration of this test conduct population screening for celiac disease.<sup>2</sup> Rashid and colleagues point to the conclusions drawn by Korponay-Szabó et al, who mention that "extra training is needed

to improve sensitivity of the test.<sup>2</sup> This is immediately followed by Rashid et al stating, "There is little data on how well this testing will perform when carried out by the general public."<sup>1</sup> The implication is clear; however, this implicit argument ignores 2 confounding variables.

The first of these obfuscating factors is seen in the very report used to impugn home tests, which states, in part, "The design of the study may have caused further confounding—nurses sent all patients with positive results directly for endoscopy, and they may have been reluctant to do this if the test line was faint."<sup>2</sup> The nurses' reluctance might well have resulted from their awareness of the expensive and invasive nature of the endoscopic procedure.

The second variable that Rashid et al seem to overlook is that the home test availability in Canada is accompanied by an Internet link to a 5-minute instructional video (<http://celiachometest.com/en/test/video>), which provides the very training that the nurses lacked in Korponay-Szabó et al's investigation.

The lengthy delays to diagnosis, such as an average time frame of 11.7 years to diagnosis and 27% patients with celiac disease consulting 3 or more physicians before confirming diagnosis, are well documented and are reflected in the published work of many of the same authors who contributed to the Rashid et al paper.<sup>4</sup>

Further, as so ably reported by this same group, unnecessary delays can result in debilitating or deadly sequelae.<sup>4</sup> Such hazards can be mitigated when patients reduce the burden on the health care system by spending their own money on this highly specific testing that, when positive, should lead directly to endoscopic biopsy. The unnecessary cost and delays that arise from repeated serology testing, as recommended by Rashid et al, are not accompanied by any supportive data or rationale and should therefore be viewed with skepticism.

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#### References

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## Response

Consider this scenario: The brother of one of your patients with type 1 diabetes checks his blood sugar level on the home glucometer and finds it to be 17.5 mmol/L. Would you send this patient urgently to the local laboratory for confirmation of hyperglycemia or accept the diagnosis based on the glucometer test alone? Even if the concordance between home glucometer and

laboratory measure were perfect, would you not do a laboratory blood glucose measurement to confirm the diagnosis of a serious, lifelong disorder? Celiac disease should be treated no differently.

Laboratory serologic testing for celiac disease is currently funded by the provincial health care programs in all provinces except Ontario (and is available in Ontario without cost in most academic health institutions). Efforts are being made to make this universally available in that province as well. As the tests become widely available, there is little delay in getting the results back. I agree that the availability of timely upper gastrointestinal endoscopy is a problem in Canada. This should be addressed. But the answer is not to start treating individuals who have positive home blood test results for celiac disease with gluten-free diets. We expressed reservations in our article that such self-diagnosis can have serious implications, including lack of both proper medical evaluation for nutritional efficiencies and adequate counseling from a registered dietitian with expertise in gluten-free diet regimens.<sup>1</sup> It must be remembered that celiac disease is a permanent sensitivity to gluten and the treatment consists of a lifelong, strict adherence to a gluten-free diet. The cost of making a definite diagnosis would likely be less than that of unconfirmed diagnosis, as the patients in the latter group will continue to access health care services.

In Canada, home blood testing for celiac disease is uncharted territory. One needs to see how this plays out over time. The medical profession should continue to advocate even better availability of laboratory serologic screening tests and timely access to endoscopy for confirmation of diagnosis.

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