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EDITORIAL

Eliminating Dietary Gluten: Don't Be a "Glutton for Punishment"

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Currently, the only proven treatment of celiac disease (CD) is lifelong, strict adherence to a gluten-free diet (GFD), which is associated with mucosal healing, which, in turn, is associated with improved bone mineral density, decreased risk of lymphoproliferative disorders and other CD-associated complications [1–3]. Although strict adherence to a GFD is essential for patients with CD, following such a restrictive diet has many practical and psychological challenges [4]. Patients with CD report treatment burden comparable to patients with severe morbidity, such as those with end-stage renal disease [5]. Adherence to a GFD can be unduly burdensome for patients: stressors include negative social consequences associated with dietary adherence, the constant vigilance required to avoid gluten, and the frustration experienced during times of accidental exposure [4]. Eating out or traveling is also complicated because of the difficulty accessing gluten-free products and constant fear about possible gluten contamination [4]. While a certain level of vigilance is needed for following a GFD, extreme vigilance could be detrimental to patients' quality-of-life (QOL). To date, negative consequences of extreme vigilance to following a GFD have not been rigorously studied.

In this issue of *Digestive Diseases and Sciences,* Wolf et al. [6] assessed disease-specific QOL, energy level, GFD knowledge level, and level of adherence to a GFD among 80 adult and teenaged patients with CD being followed at a tertiary care celiac center in an US metropolitan city. The knowledge base of and level of adherence to a GFD was assessed by a detailed interview by a skilled celiac registered dietician nutritionist (RDN); based on this assessment, patients were grouped into "extremely vigilant" or "less vigilant" categories [6]. The authors found that "extremely vigilant" adult patients had significantly lower QOL compared to those who were less vigilant. Subscale analysis showed that "extremely vigilant" patients were more likely to feel depressed/overwhelmed by CD and feel limited by CD when eating out or traveling compared to less vigilant patients [6].

This is the first study highlighting the negative impact of extreme vigilance on QOL of patients with CD. In clinical practice, physicians often focus on objective markers of strict compliance such as resolution of clinical symptoms, normalization of anti-tissue transglutaminase titers, and healing of duodenal mucosa. When these objective findings are present, these patients are encouraged to keep up the good work of following a GFD. Nevertheless, some of these patients are extremely vigilant to gluten contamination and are possibly achieving these objective goals at the cost of their QOL. It is easy for clinicians to ignore the psychological distress induced by the strict GFD in these patients as they lack the necessary training (and time) needed to differentiate between extreme vigilance and necessary vigilance. An interview with a skilled RDN remains the "gold standard" for assessing compliance to a GFD and he/she has the expertise to identify the patients with "extreme vigilance." The Celiac Toolkit, the Academy of Nutrition and Dietetics (formerly American Dietetic Association) Evidence-Based Nutrition Practice Guidelines recommends two visits with an RDN within the first month followed by additional visits depending on the patient's risk, motivation level and the dietary and lifestyle changes needed [7]. Although the American College of Gastroenterology (ACG) guidelines do not specifically recommend compulsory ongoing follow-up with RDNs for monitoring of CD unless gluten contamination is suspected, this study adds to the existing body of the literature that skilled RDNs are as important as physicians (or perhaps more) in monitoring CD [8].

As "extremely vigilant" patients were more likely to be psychologically distressed by challenges faced in following a GFD, they were also more likely to feel that treatment options for CD were limited. The burden of trying to follow the GFD and anxiety surrounding asymptomatic gluten exposure remains high in patients with CD. There is a need for pharmacological therapies that could allow consumption

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of some gluten without disease exacerbation to reduce the anxiety related to gluten exposure in patients with CD [9].

Wolf et al. [6] also tried to provide insight into factors perceived as barriers to maintaining a strict GFD. Although the number of restaurants offering gluten-free options has increased in the last few years, the majority of patients with CD still struggle with eating out. Extremely vigilant patients were more likely to avoid eating out and rely on home-cooked meals given their apprehension about gluten contamination. There is a need to streamline the steps taken to prepare and serve a gluten-free meal at restaurants. Also important is to make restaurant staff aware of these steps that could help mitigate some of the anxiety faced by patients with CD. If a restaurant serves gluten-free options, its staff should be educated that a GFD for patients with CD is a necessity, not a preference. Ultimately, a certification of quality control for gluten-free products served at restaurant might be necessary.

Patients with CD identified having support from family and friends as the single most important facilitator for successfully maintaining a GFD. As a GFD is a lifelong treatment for patients with CD, involving family members at the initial visit with the RDN might be helpful in improving the adherence to a GFD in these patients [1]. These days, patients also frequently use internet apps and sites to help them maintain a GFD; "extremely vigilant" patients are more likely to rely on these tools. Thus, celiac centers, skilled RDNs, and support groups should refer their patients with CD to patient friendly, easily accessible websites with accurate and up-to-date information about a GFD.

In summary, this study highlights the need for finding balance between adherence to a GFD and maintaining a high QOL. Prospective longitudinal studies to test the level of dietary adherence that can achieve the treatment goals of CD (none—minimal symptoms, healing of intestinal mucosa, and negligible risk of long term complications), while balancing QOL and patient satisfaction are needed. It is increasingly understood that since the GFD is an imperfect and cumbersome treatment option for patients with CD, there is an urgent need for pharmacological therapies for CD that will allow occasional/accidental consumption of gluten without worsening of disease [9]. Furthermore, further studies that investigate the relationship between the complex comorbidity of eating disorders, which could be considered an extreme state of hypervigilance, and CD, requiring strict adherence to the GFD, may also be of great use in the clinical setting [10]. It is also unclear if these is an association between hypervigilance for gluten contamination and obsessive–compulsive personality disorder or mental health disorders such as obsessive–compulsive disorder and anxiety. If there is an association, it will be interesting to see if mental health disorders are present at the time of diagnosis or they develop after initiating a GFD.

Compliance with ethical standards

Conflict of interest None.

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