




Dietary assessments in individuals living with coeliac disease: key considerations

Anne R. Lee¹  | Melinda Dennis² | Jessica Lebovits¹  | Lori Welstead³ | Ritu Verma³ | Amelie Therrien²  | Benjamin Lewohl¹

¹Department of Medicine, Celiac Disease Center, Columbia University Medical Center, Columbia University, New York, New York, USA

²Division of Gastroenterology, Celiac Center, Beth Israel Deaconess Medical Center, Boston, Massachusetts, USA

³Divisions of Pediatric and Adult Gastroenterology, Hepatology, and Nutrition, Celiac Disease Center, University of Chicago, Chicago, Illinois, USA

Correspondence

Anne R. Lee, Celiac Disease Center, Department of Medicine, Columbia University Medical Center, Columbia University, New York, NY, USA.
Email: arl2004@cumc.columbia.edu

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Abstract

Background: Coeliac disease (CeD) is a type of enteropathy characterised by an immune-mediated reaction to ingested gluten, resulting in impaired absorption of nutrients and symptoms such as bloating, abdominal cramping and diarrhoea. Currently, the only treatment for CeD is adherence to a gluten-free diet (GFD). The latest draft guidance from the US Food and Drug Administration recommends that dietitians experienced in CeD management evaluate patients during the screening and treatment period of CeD clinical trials to assess adherence to a GFD. However, there are currently no standardised guidelines on dietary assessment of patients with CeD on a GFD and there is a lack of widespread availability of expertise in this field.

Methods: Based on the findings of a literature review conducted between April and September 2023, this article provides an overview of key points to consider in the nutritional and dietary assessment of patients with CeD who are following a GFD, with particular focus on the clinical trial setting.

Results: Based on a consensus from dietitians and gastroenterologists experienced in treating patients with CeD, we present specific recommendations for registered dietitians who manage patients with CeD. We also describe the development of a simplified tool for assessment of adherence to a GFD, the Gluten-Free Adherence Survey, based on these recommendations.

Conclusions: These guidelines cover nutritional and dietary assessment of patients with CeD, physical assessments, intake of oats, environmental considerations and the disease burden.

KEYWORDS

coeliac disease, dietary assessment, gluten-free diet

Key points

Based on findings from a literature review, a team of dietitians and gastroenterologists specialising in coeliac disease developed specific recommendations for nutritional assessment and dietary adherence in patients with coeliac disease following a gluten-free diet.

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INTRODUCTION

Coeliac disease (CeD) is a common form of enteropathy defined as a permanent immune-mediated response to gluten found in wheat, barley and rye, with a reported prevalence of 0.5%–1.0% in the general population.¹ This leads to impaired digestion and absorption of nutrients to variable degrees and gastrointestinal (GI) symptoms such as bloating, abdominal cramping, diarrhoea and nausea, among others.^{2–4} Individuals with CeD may also experience extraintestinal manifestations including osteopenia, anaemia, fatigue, headache, cognitive difficulties, joint pain and skin rash.^{1,3–6}

At the time of diagnosis, there is a need for clinical assessment of malnutrition and evaluation of levels of vitamins and minerals. In addition to the nutritional assessment, counselling by a specialist dietitian on the gluten-free diet (GFD), focusing on adherence and correction of any deficiencies, is essential.⁷

Currently, the only treatment for CeD involves adherence to a strict GFD with medical follow-up and management. Recent US Food and Drug Administration (FDA) draft guidance for the development of nondietary therapies recommends that ‘dietitians experienced in CeD management should evaluate patients during the screening period to assess for adherence to the gluten-free diet’ and that ‘dietitians experienced in CeD management be involved in evaluating patients for the adherence to the gluten-free diet during the treatment period’.⁸ This guidance poses challenges to the current landscape of CeD management due to the lack of widespread availability of expertise and standardisation of dietary assessment. As such, the aim of this report was to perform an extensive literature review to evaluate the current landscape and to establish best practices for assessing adherence to a GFD in adults with CeD based on the consensus of both gastroenterologists and dietitians specialising in CeD, with a focus on the clinical trial setting.

Based on the results of this process, a secondary objective was to develop a simple and easy-to-use tool to assess adherence to a GFD. The tool was designed to provide an insight into barriers to adherence, which provides the dietitian with an opportunity to explore topics with patients to improve adherence. The tool may also be useful in a CeD clinical trial setting to evaluate the level of GFD adherence in enrolled patients.

METHODS

A committee was formed in April 2023 that included four dietitians and three gastroenterologists (including one paediatric gastroenterologist) from three leading US-based coeliac centres. The committee met to identify current practices of nutritional assessment and identify gaps in practice and to develop a consensus on a standardised nutritional assessment. Teams of one dietitian

and one gastroenterologist were established and each team conducted a literature review. The teams were assigned responsibility for the development of recommendations for a specific area of nutritional assessment, for example, medical history and laboratory data.

Search strategy

A literature review was conducted between April 2023 and September 2023 in the PubMed and Cochrane Library databases, and included the following search terms: ‘celiac disease and nutritional assessment’, ‘nutrient needs’, ‘nutrient deficiency’, ‘anthropometric measurements’, ‘cross-contact’, ‘quality of life’, ‘anxiety’ and ‘depression’. Original research studies and review articles in adult CeD populations were included. Exclusion criteria: articles more than 10 years old (March 2013 until September 2023), articles not in English, full text unavailable, small sample size (<9 participants), paediatric population, noncoeliac gluten sensitivity or wheat allergy.

In total, 2167 articles were identified; 341 were selected for review and 190 were selected for inclusion in the study based on the criteria outlined above.

Development of recommendations

Each team drafted recommendations for their assigned section, and a complete draft was formulated by the full committee in September 2023. All comments and edits were incorporated into the review draft, which was then sent to four dietitians from coeliac centres not associated with the initial draft. A consensus meeting was held in person in October 2023, where the reviewers and committee members developed a draft of the final consensus on nutritional assessment, which is presented here.

Development of a new dietary adherence tool

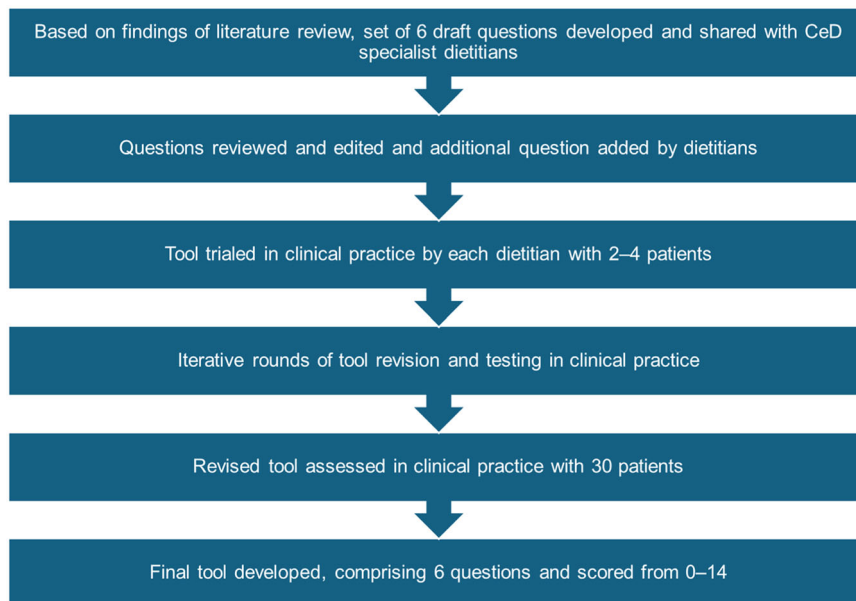
Based on the results of the literature review, a set of six draft questions with a yes/no response were developed and shared with a group of coeliac specialist dietitians (six including the authors). This questionnaire was subjected to iterative rounds of feedback and clinical assessment between January and April 2023 (Figure 1).

RECOMMENDATIONS FOR STANDARD NUTRITIONAL ASSESSMENT

Importance of assessment of nutritional status

Nutrient imbalances have been observed in both men and women with established CeD^{9,10} and may be the result of

FIGURE 1 Overview of the tool development process. CeD, coeliac disease.



inadequacy of the GFD. Given this, the need for nutritional assessment does not become obsolete once a patient has demonstrated adherence to a GFD. There is extensive literature on how the Western GFD may be high in calories and saturated fat and low in fibre,¹⁰ increasing the risk of cardiovascular disease, obesity and persistent GI symptoms. Moreover, women, in particular, may experience reproductive issues due to micronutrient deficiencies, and have a higher risk of osteopenia and osteoporosis. Finally, additional food intolerances can be linked to CeD (lactose, fructose or other fermentable oligosaccharides, disaccharides, monosaccharides and polyols [FODMAPs]). Weight and eating behaviours may change and possibly lead to bingeing, restricting or developing avoidant restrictive food intake disorder (ARFID),¹¹ supporting the need for longitudinal nutritional assessment during the life of a patient with CeD.

The role of registered dietitians (RDs) specialising in CeD

The RD, also known as an RD nutritionist, with expertise in the GFD plays a uniquely qualified role in educating patients with CeD, and assessing and monitoring the long-term nutritional status of the patient.^{7,12–14} Medical nutrition therapy (MNT) is strongly recommended for patients with CeD as part of a multidisciplinary approach to treatment^{12,15,16} and is one of the six main principles set forth by the US National Institutes of Health (NIH) Consensus Statement on Celiac Disease.¹⁷

Ongoing follow-up by the RD is critical to assess and monitor the nutritional status, knowledge level and dietary adherence of the patient, as well as to support them as they navigate the social and emotional aspects of the gluten-free (GF) lifestyle.^{12,13} By establishing a trusting rapport in the clinical setting, patients should feel

comfortable asking questions and setting health goals with their RD.¹⁸ Numerous studies have supported referral to a specialised RD for patients with CeD, not only for assessing gluten ingestion^{19,20} but also to identify and prevent or correct early signs of malnutrition or malabsorption of macro- and micronutrients,^{21–23} to support optimal eating habits and to ensure a balanced strictly GFD over the long term.^{10,15,20,21,24}

Frequency of MNT encounters with an RD

Recent information on the recommended frequency of MNT encounters with an RD for CeD is lacking. In a review article from 2005, Pietzak recommended initial counselling, followed by a 3–6-month period of regular consultation with the primary care physician (or gastroenterologist) and an RD to discuss adherence to a GFD, followed by an annual check-up. If clinical symptoms, nutritional deficiencies or elevated antibodies are present, more extensive counselling on the GFD by an RD and closer monitoring are recommended.²⁵

The Academy of Nutrition and Dietetics (AND) Celiac Toolkit suggests that education on a GFD for individuals with CeD should be ongoing and should include an initial consultation and at least two follow-up visits with a specialist RD within the first year of diagnosis.¹² The American College of Gastroenterology (ACG) guidelines recommend referral to an RD following an inadequate response to a GFD.⁷

Assessment of food/nutrition-related history

To assess adherence as well as the nutritional value of a patient's GFD, it is necessary to complete a dietary assessment. Current approaches to assess an individual's

general dietary pattern include patient-reported assessments such as 24-h diet recall, multiday food diaries and food frequency questionnaires (FFQs). Each type of dietary assessment has unique strengths and limitations. Some tools, such as diet recalls or FFQs, are limited by a patient's recall abilities.²⁶ The disadvantage of the 24-h diet recall is the length of time involved for both the patient and the dietitian, whereas FFQs can take only 20–30 min of the patient's time. A limitation of FFQs is the lack of GF foods on standard forms, which can lead to inaccuracies. Food records or food diaries are done closer to real-time intake and, therefore, may provide better estimations. However, there is still the possibility of a patient modifying intake or modifying documentation to reflect what they think providers would want to see.¹⁶

The recorded foods can be looked up in standardised databases to assess nutritional composition; however, GF products (GFPs) are poorly represented in validated databases. These methodological problems create gaps in individual assessments and hamper standardisation.^{9,24,26} A significant challenge in accurately defining the nutritional value of a GFD is that GF foods and GFP frequently use refined grains and starches, and are not enriched or fortified with B vitamins or iron and, therefore, differ in their nutrient composition compared with their gluten-containing counterparts.^{27,28} Many GFP also contain higher amounts of fat to improve taste and texture.^{27,28}

In a review by Cardo et al., the authors note that participants in studies often change their eating habits during the reporting period, which may affect research conclusions.²⁴ They also note that gender- and age-matched non-CeD controls would be beneficial. In a 2021 study by Gladys et al., which used both a 3-day food diary and a 24-h food recall with an RD, researchers cited the potential for 'random error due to the respondent not admitting to eating a certain food or forgetting to write the food in the diary'.²⁰

Although these discrepancies exist throughout the world of nutritional research, this highlights the unique challenges that healthcare practitioners in CeD face. Two studies using identical protocols cited similar limitations when conducting nutritional analysis.^{9,26} Both studies noted the limitations of standardised food databases when assessing the nutritional composition of GFP. In both studies, they used a 3-day 24-h recall administered by trained dietitians in combination with an FFQ and photographs to determine ratios and portion sizes. However, nutritional assessment of the dietary intake generally used the micronutrient content of gluten-containing counterparts owing to a lack of databases that include the specific composition of GFP.^{9,26} This limitation was echoed in the study by Ballester-Fernandez et al.,²⁹ in which recalls were analysed using the computer software DIAL with GFP taken from a GF food composition database developed within the research

group. However, even with this additional database capability, the researchers cite the limitations of data on micronutrient composition in commercially available GFP.²⁹

Most of the studies reviewed specifically highlight the benefits of having a trained RD, familiar with CeD, involved in patient follow-ups and in dietary assessments. This is useful in assessing adherence, other potential food intolerances, micronutrient deficiencies and inadequate caloric intake.^{10,24,30} Abdi et al. echo these benefits and the benefits of detailed diet review, but also highlight that there are barriers.¹⁶ They cite time constraints, increased cost to the healthcare system and limited availability of expert RDs. The various types of dietary assessments used in the research, and the limitations of only using one type of assessment, would suggest that a combination of tools may best serve the CeD community when obtaining intake information. Increased accuracy of nutrient assessments will require increased representation of GFP in nutrition composition databases, inclusion of supplement use, inclusive food intake and preparation details, and FFQs should be universally included in any intake assessment.

NUTRITION-FOCUSED PHYSICAL ASSESSMENT

Anthropometrics

CeD is a cause of protein calorie malnutrition mostly by malabsorption, but also as a result of decreased oral intake owing to GI symptoms and increased energy expenditure while regeneration of the intestines occurs. Several ways to assess protein calorie malnutrition have been described and assessments can be performed by gastroenterologists or dietitians. The AND guidelines recommend evaluating the height, weight, weight history, growth history, relationship to family stature and body mass index (BMI) at the initial encounter, and then reassessment of weight and BMI at follow-up.^{7,13}

A BMI of less than 15 kg/m² is associated with significant mortality.³¹ BMI alone, however, is not a reliable indicator of nutritional status. Instead, a history of unintentional and progressive weight loss serves as a more accurate indicator.³¹ Anthropomorphic measurements were included in recent studies and shed light on several important issues.^{9,10,15,16,20} In contrast to the generally held belief that BMI decreases for people on a GFD, it was commonly found that it may remain stable or increase in individuals on a strict GFD over time. Moreover, not all patients with CeD present with weight loss and muscular wasting; up to 43% of individuals are overweight (BMI 25–29.9 kg/m²) or obese (BMI > 30 kg/m²) at the time of diagnosis of CeD and many do not obtain the daily recommended amount of micronutrients.^{9,22} In a Polish study, obesity was

associated with sarcopenia in 30% of adults, which is also linked to inadequate physical activity.²² Waist circumference adjusted for ethnicity is also an important anthropometric measure, as it is a predictor for metabolic syndrome.³² Other anthropometric measurements recently reviewed by the McMaster University Celiac Center's team include body circumferences (waist, hip and limbs), skinfold thickness and handgrip strength using a dynamometer.¹⁶

During follow-up visits, current weight, BMI and waist circumference should be compared to the values at diagnosis, but also from the past 3 months to tailor dietary counselling.

Weight concerns with the GFD

In addition to caloric and macronutrient intake, physical activity should be assessed, especially in the presence of weight gain. Presentation of CeD is increasingly common in overweight or obese adults. Several studies reported that 15%–31% of adult patients are overweight and 6.8%–13% are obese at the time of CeD diagnosis.^{9,33,34} Moreover, patients tend to gain weight on a GFD^{35,36} and there is an increased risk of metabolic dysfunction-associated steatotic liver disease (MASLD) and metabolic syndrome.^{37,38} In addition to weight management considerations, physical activity while following a GFD was associated with significant improvement in mood among menopausal Spanish women,³⁹ possible reduction in systemic inflammation⁴⁰ and improvement in quality of life (QoL) and GI symptoms.⁴¹

Alternatively, continued weight loss on a GFD may be caused by a healthier diet, especially if the patient was overweight at baseline, or inadequate caloric intake due to avoidant and restrictive behaviours, or nonadherence and even refractory CeD, mostly seen in the elderly population with a late diagnosis of CeD (after 50 years of age).^{42,43}

GI and extraintestinal symptoms, and comorbidities

CeD comes with a myriad of GI symptoms at diagnosis, but is also often associated with other food intolerances such as to lactose, fructose and other FODMAPs, as well as dysbiosis and small intestinal bacterial overgrowth in the years following the diagnosis. This may impair the quality and diversity of the diet, and persistent symptoms are not necessarily a sign of dietary noncompliance.

Constipation is frequent, and may be mistaken for active CeD symptoms, presenting with abdominal pain and bloating. Other forms of dysmotility, such as delayed gastric emptying, have also been reported, both at the time of the diagnosis due to the ileal-brake phenomenon and later on a GFD.⁴⁴ As such, the RD should assess GI

symptoms (such as type, frequency and volume of bowel function; abdominal pain and bloating; nausea or vomiting; reduced gut motility and delayed gastric emptying).¹²

Extraintestinal manifestations of CeD may include iron deficiency anaemia, osteopenia/osteoporosis, peripheral neuropathy, mouth ulcers, dental enamel defects, dermatitis herpetiformis and liver injury.^{1,45–48} Finally, thyroid conditions, other autoimmune conditions and endocrinologic disorders, such as type 1 diabetes mellitus, are commonly seen in patients with CeD^{12,49} and may be associated with additional dietary restrictions and/or GI symptoms. Microscopic colitis is another associated diagnosis that may or may not respond to a GFD and can cause dehydration and reduced oral intake to avoid exacerbation of diarrhoea.

Medications and supplements

Conducting a comprehensive medical review proves invaluable in identifying potential causes of weight fluctuations and GI symptoms. A wide range of medications can affect weight and lead to side-effects such as constipation, nausea and dysgeusia, among others. Notably, glucagon-like peptide 1 agonists have gained popularity in the treatment of obesity; yet, their effects on the nutritional status of individuals with CeD remain an understudied area. The presence of gluten in medications remains a subject of debate, particularly, because in some countries such as the United States, there is no legislation mandating formal labelling of drugs for gluten content.⁵⁰ Despite the absence of compelling supporting evidence, some argue that any potential contamination would likely be negligible.

It is recommended to choose vitamin and mineral supplements that are labelled GF whenever possible. Owing to the malabsorption associated with active CeD and the inherent deficiencies of the GFD, it is crucial to consider the inclusion of specific supplements and their dosages in the dietary assessment of individuals on the GFD. Omission of supplement usage in the diet assessment may mask deficiencies that would be present without the support of supplementation. Evaluation of the use of supplements has been inconsistently reported in studies on nutritional assessment in CeD. In addition to the need to consider the additional intake in vitamins and minerals, a thorough review of nutritional supplements is also indicated to assess the risk of unsuspected gluten exposure. The AND recommends advising maintenance of a GFD along with daily consumption of age- and sex-appropriate vitamin and mineral supplements if dietary intake and/or laboratory tests indicate nutritional inadequacies.¹² There are several studies reporting individual micronutrient deficiency responses to supplements (Table 1). Vitamin levels should be assessed at diagnosis and every 3–6 months until the individual achieves

TABLE 1 Incidence, clinical characteristics and management of nutritional deficiencies associated with CeD.

Nutritional deficiency	Incidence in CeD	Most frequent signs and symptoms	Supplementation if deficient
Iron	28%–50%	Glossitis, koilonychia, fatigue, pallor, cognitive impairment	PO iron 325 mg, can be every other day. IV iron if anaemia and intolerance to PO iron
Folate	35%–49%	Glossitis, diarrhoea, cognitive impairment	1 mg daily
Vitamin B12	8%–41%	Posterior cord syndrome, dementia, depression, psychosis, numbness and tingling	If borderline (200–300 pg/mL), oral or sublingual vitamin B12 can be offered: 1000 µg/day. If <200 pg/mL or within borderline range (200–300 pg/mL), injection of four doses of 1000 µg until serum levels normalise
Vitamin D	4.8%–59%	Osteomalacia (deformity of bone, pathologic fractures), cognitive impairment	1000–2000 IU, vitamin D2 50,000 IU weekly if level <20 ng/mL
Zinc	54%–67%	Growth retardation, hypogonadism, dysgeusia, poor wound healing, diarrhoea, dermatitis on the extremities and periorificial, glossitis, alopecia, corneal clouding	25–50 mg/day, check copper levels and make sure the supplementation is combined with an multivitamin/mineral containing copper
<i>Less frequently occurring</i>			
Vitamin B1 (thiamine)	Unknown	Irritability, fatigue, headaches, peripheral neuropathy, wet beriberi: congestive heart failure; Wernicke: nystagmus, ophthalmoplegia, ataxia; Korsakoff: hallucinations, impaired short-term memory and confabulation	B complex vitamin
Vitamin B2 (riboflavin)	Unknown	Red eyes, loss of facial colour, sores around the mouth, sore throat, magenta colour of the tongue, red and raw lips, skin sores, rash, anaemia, nerve damage	
Vitamin B3 (niacin)	Unknown	Pellagra: diarrhoea, dementia, pigmented dermatitis; glossitis, stomatitis, vaginitis, vertigo, burning dysesthesias	
Vitamin B6 (pyridoxine)	14.5%	Stomatitis, angular cheilosis, glossitis, irritability, depression, confusion	
Vitamin A	7.5%	Follicular hyperkeratosis, night blindness, conjunctival xerosis, keratomalacia	10,000 IU daily for 7 days
Vitamin E	Unknown	Peripheral neuropathies, ophthalmoplegia, posterior cord syndrome	400 IU daily

Note: Table adapted from Therrien, Theethira et al., and Dennis et al.^{13,51,52}

Abbreviations: CeD, coeliac disease; PO, per os; IV, intravenous.

normal ranges, then yearly.⁷ Elevated serum levels, especially of vitamin B6, may be due to multivitamin/mineral intake containing a high concentration of vitamin B6. Nevertheless, considering the heterogeneity of the patient population and intake, systematic and specific supplementations for CeD are not recommended and should be based on the evaluation of dietary intake and laboratory tests (see the next section).¹²

In the papers reviewed, reporting of dietary supplement intake was variable. Several studies did not indicate whether participants were taking dietary supplements,^{14,20,21,26} whereas one specifically noted that participants were not taking supplements.²⁹ Both Wild et al. and Kostecka et al. recorded dietary supplement intake, but did not perform further analyses.^{15,19} In the Hoteit study, 50% of the Lebanese study participants were reported as taking dietary supplements.²² In the van

Megen study, dietary supplements were not included in the calculations; however, half of the women in the study with CeD reported using them.¹⁰ Similarly, in the Martin 2013 study, supplements were recorded in the questionnaire as being taken by 17.6% of the adult males and by 45.5% of adult women, but they were not added to the daily nutrient intake.²³ It is our conclusion that detailed supplement intake should be noted in a comprehensive nutritional assessment, as it can affect the overall nutritional quality of the diet being examined.

Micronutrient imbalance of the GFD

Micronutrient deficiencies are frequently found and well documented in individuals with untreated or newly diagnosed CeD (Table 1). The degree of micronutrient

deficiency depends on the length of time before the CeD diagnosis and the degree of intestinal mucosal injury. In a study of newly diagnosed adult Dutch patients, it was found that 87% had at least one vitamin or mineral deficiency; specifically, 67% had zinc deficiency, 46% had low iron stores and 32% had anaemia. In the analysis of vitamins, 20% were deficient in folate, 19% in B12, 14.5% in B6 and 7.5% in vitamin A.⁵³ It is important to note that fat maldigestion causes reduced calcium absorption through binding of intraluminal calcium, as well as liposoluble vitamin deficiencies such as vitamin A, D, E and K. Hydrosoluble vitamin deficiencies can also occur, either as a result of malabsorption or low intake as part of a GFD. Vitamin B12 can be low at diagnosis in 5%–40% of patients with CeD and in 2.9%–41% after initiation of a GFD.⁵⁴ Copper is linked to ceruloplasmin, which is involved in the transfer of iron from ferritin to transferrin. Hence, copper deficiency can cause circulating iron deficiency. Serum copper levels can be elevated despite malnutrition in some conditions and with oral contraceptives. Although not mentioned in the recent ACG guidelines, vitamin B6 deficiency may also be present at the time of diagnosis.^{7,53} Cumulative calcium intake influences bone mass and even with normal circulating values, chronic low intake can reduce bone density. Some patients will undergo a dual-energy X-ray absorptiometry scan to assess bone density at the time of diagnosis and others after 1 year on a GFD. Adults with reduced bone density or low vitamin D may need additional calcium and vitamin D.¹²

Once the mucosal lining has healed and absorption returns, most deficiencies are corrected.^{24,55} However, several studies have reported micronutrient deficiencies in individuals who are on a GFD for several years.^{24,53–56} Deficiencies of folate, iron, vitamin D, calcium and B vitamins are the most common.^{24,53–56} Although naturally GF grains can provide essential nutrients, traditionally, GFP use corn, rice, tapioca and potato as their starch base. These products do not have the same nutrient profile as wheat.⁵⁷ As the FDA requires wheat products to be enriched to restore the natural nutrient value of the wheat grain,⁵⁸ a wheat-based diet is inherently rich in iron, fibre and B complex vitamins. Dietary products such as GF breads, pastas and cereals are not required by the FDA to be enriched.⁵⁸ Therefore, GFP tend to have lower iron and B vitamin levels, as well as lower levels of other nutrients, such as calcium, zinc and magnesium.^{27,28,59,60} Therefore, to assess the micronutrient content of an individual's GFD, it is imperative to review the intake of naturally GF whole grains and the amount of GF processed products.^{57,61}

In a cross-sectional age- and gender-matched study of Spanish adults, individuals with CeD on a GFD for over 1 year were deficient in key micronutrients,²⁹ including a calcium intake of 80% below the recommended amount and iron at two-thirds of the recommended intake in females. Dietary vitamin D intake was also low, and 34%

of individuals with CeD had low serum vitamin D levels; intake of vitamin E and iodine was also below two-thirds of national recommendations.²⁹

Similarly, a case-control study by Gonzalez et al. reported a decreased intake of vitamin E, niacin, folate and magnesium in men with CeD compared with controls.⁹ Men with CeD met the daily recommended intake for iron, but only 69% of women with CeD achieved two-thirds of the daily recommended intake for iron.⁹ Similar findings were reported in the studies by Martin and Shepard.^{23,62} In these studies, women with CeD had below the daily recommended intake for iron, iodine, potassium and selenium.^{23,62}

A cross-sectional study of 20 individuals with CeD and 39 healthy controls showed significant differences ($p < 0.05$) in serum and dietary folate levels for the individuals with CeD compared with controls.⁶³ Folate levels were significantly lower for women with CeD ($p = 0.002$) compared with men with CeD and healthy control women. Intake of B6 and B12 was lower ($p < 0.05$) in the diet of individuals on a GFD compared with the healthy controls.⁶³

In conclusion, routine monitoring of at-risk vitamin and mineral levels should be part of comprehensive follow-up for patients with CeD. A patient-centred team approach including consultation and regular follow-up with a specialist dietitian is recommended to ensure optimal outcomes.

Laboratory assessment of micronutrients

The recent ACG guidelines suggest assessing several vitamins (A, D, E, folic acid, B12) and minerals (copper, zinc, ferritin, iron) at the time of diagnosis.⁷ Blood tests at follow-up (3, 6 and 12 months) should be individualised to verify correction of laboratory results that were abnormal at baseline. Not all deficiencies improve with a GFD. We can extrapolate from paediatric literature that, without supplementation, deficiencies in vitamin D, A and zinc will not change post-diagnosis with only a GFD being implemented, in comparison to vitamins E, K, B6 and B1.⁶⁴

Macronutrient imbalance of the GFD

Often, GFD education focuses on the recognition and avoidance of gluten, rather than a balanced GFD, which can lead to choosing highly processed food, which is low in nutritional value.²⁰ In addition, poor dietary habits are found in the coeliac population as in the general population.²⁴ Therefore, in addition to micronutrients, an in-depth review of macronutrient intake should be an integral part of any nutritional assessment.

A 2023 review article by Abdi et al. describes the typical GFD as often being low in complex and nutrient-

dense carbohydrates (such as whole GF grains, fruits and vegetables). Consequently, it tends to be low in fibre and protein, whereas being high in sugar, fat and calories, leading to weight gain.^{16,24,55} Both the quality (saturated, mono-unsaturated or polyunsaturated; processed or natural) and the quantity of fat are important to assess in a dietary assessment.¹⁶ This is important because diseases related to these dietary imbalances, such as cardiovascular diseases⁶⁵ and type 2 diabetes, are, therefore, more likely to occur in the CeD population.¹⁴ As noted in Theethira's 2014 review paper, however, studies from different countries do present some conflicting evidence regarding macronutrient intake as shown below.⁵¹

Removal of wheat and gluten-containing grains, particularly, whole grain cereals and breads, from the diet and consumption of processed GFP is a primary cause of several of the macronutrient imbalances mentioned above.^{10,13,19,24,62,66} Typically, GFPs are prepared with refined maize (corn) flour and white rice, which are lower in fibre than both wheat and brown rice⁶² and tend to have a higher glycaemic index.⁶⁷

In several studies, carbohydrate and energy intake was below the recommended amounts. The majority of studies distinguished between the intake of complex versus simple carbohydrates among their study participants,^{14,19,20,26,29} although a few did not.^{9,22,23} Melini et al. highlight a significant issue: GFPs are generally found to be low in protein.⁶⁸ This is concerning, as protein plays a crucial role in providing satiety, promoting thermogenesis and maintaining muscle mass.⁶⁹ Surprisingly, despite low protein levels in GFP, numerous studies report the protein intake of individuals with CeD to be in excess of the recommended amounts.^{9,29}

Gladys et al. presented a detailed dietary assessment protocol in their 2021 study that included a 3-day food diary validated by using a 24-h diet recall with additional detailed questions. Patients with CeD ate less plant-based protein (both patients with active CeD and those in remission), but more total fat and energy (especially those in CeD remission) than the control group, which may increase the risk of cardiovascular disease or obesity. Moreover, patients with CeD did not consume enough fibre and consumed excessive amounts of cholesterol.²⁰

The study by Martin et al. observed lower diet quality in individuals with CeD in Germany compared with the healthy control group.²³ Among male patients, energy and macronutrient consumptions were comparable to the control group, with the exception of significantly lower fibre intake. Conversely, females with CeD consumed significantly more fat but fewer carbohydrates compared with controls.²³ The authors highlighted the concerning trends of low fibre intake and high-fat consumption. They recommended a dietary approach that prioritises nutrient-dense foods, supplemented with special GFP as necessary.²³

In a cross-sectional age- and gender-matched study in 64 adults with CeD on a GFD in Spain, carbohydrate

intake was below recommendations, whereas protein intake exceeded recommendations (although protein intake was similar to the male control group). Lipid and cholesterol intake was higher compared with the general population. Neither group reached two-thirds of the recommended energy intake. Fibre intake in patients with CeD approached the recommendations, especially in men, which contrasts with earlier studies. Both groups ingested excess amounts of simple sugars.²⁹

Similarly, Gonzalez et al. found that intake of carbohydrates and fibre was below the recommended values and intake of protein and cholesterol was above the recommended intake in 42 Spanish men with CeD compared with male non-CeD controls. Saturated and unsaturated fatty acid recommendations were reached by both groups and daily energy intake was comparable.⁹ The authors recommended nutrition education and long-term follow-up for the general Spanish and CeD populations, specifically for men with CeD, to reduce the risk of comorbidities related to CeD. They proposed a greater intake of GF cereals or pseudocereals, vegetables and legumes and less meat.⁹

In the Churruga study of 54 Spanish women with CeD, the imbalanced macronutrient distribution of the diet was similar to the rest of the female Spanish population. Women with CeD consumed a very low amount of cereal grains (fibre) and a greater amount of pulses and legumes. Their total calorie intake was lower than the Dietary Reference Intakes and that of their female control counterparts.²⁶ The authors recommended a reduction in fat and protein, and an increase in fibre, specifically whole grain products, to increase the intake of B vitamins, iron and fibre in the GFD of their female Spanish participants.²⁶ In a British study, patients with CeD had similar intakes of energy and nutrients to the British control population, but a higher proportion of carbohydrate intake came from nonmilk extrinsic sugars, whereas nonstarch polysaccharide intake was low.¹⁹

Overall, the articles reviewed emphasised the need for an improved and balanced GFD requiring long-term monitoring. Following a GFD increases the risk of nutritional inadequacies and excesses.⁶² Some imbalances may be related to the eating habits of their general population such as in the Spanish populations cited in the Churruga and Gonzalez studies.^{9,26} Some may be due to preexisting individual eating habits,⁶² and many are related to the GFD as outlined in this paper. More investigation into these reasons for the imbalance and potential other causes has been recommended.⁶²

The RD's dietary assessment should include a detailed review of the patient's intake of both simple and complex carbohydrates (including the more nutrient-dense, GF whole grains (e.g., whole corn, brown rice, millet, sorghum, wild rice, teff), the pseudograins (amaranth, quinoa, buckwheat), fruits, vegetables, plant and lean animal sources of protein, low-fat dairy and healthy fats and oils.^{9,13,62} If dairy is avoided, the

nutritional value of plant-based beverages and food should be assessed.

Further dietary restrictions

Several studies excluded participants who had digestive conditions that needed specific dietary modification, such as eating disorders, renal disease and lactose, soy or egg intolerance.^{9,14,19,22} Although there was no mention in all but one of the studies about the specific amount of fluid consumed,²³ the reader can likely assume that fluid intake would and should be included in the dietary recall or FFQ. It is also unclear if we can assume that alcohol is included in the dietary recall or FFQ; however, it is an important question to ask. Of the reviewed articles, Churrua et al. mentioned alcohol specifically.²⁶ Smoking was not noted in any of the studies, with the exception of van Meegen et al., who recorded three different categories of smoking among participants.¹⁰

Managing two or more diseases with a dietary component adds additional restrictions for patients that will further affect the nutritional quality of the diet and may result in a higher risk of noncompliance.¹³ The RD's role is to assess for the presence of other disease states, disorders, food preferences (such as vegetarianism or veganism), food allergies and food intolerances (lactose, fructose, FODMAPs, sucrose) or any pre-existing condition that affects the patient's intake and behaviour. Equally critical is the work to then combine those dietary adjustments skilfully into one balanced meal plan, or eating pattern, to design an effective, overall disease management plan.

SPECIAL CONSIDERATION—OATS

Historically, the inclusion or exclusion of oats in a GFD has been a topic of confusion, debate and concern within the CeD community. As an alternative GF grain, oats have the potential to provide nutritional value and increased adherence to and acceptance of a GFD. Owing to its rich content of vitamins, minerals, fibres, protein, lipids and antioxidants, several studies have cited the nutritional benefits of oats.^{70–72} However, historically, oats have been associated with intolerances among some individuals with CeD.^{70–72} Past recommendations regarding oats have included full exclusion, exclusion until full mucosal healing and/or restriction to a specific daily allowance. Currently, recommendations vary from country to country. Within a diet that is restrictive and requires diligence in identifying safe foods, the murky guidance regarding oats can further exacerbate the potential for anxiety and overrestriction. Recent identification of contamination of certified GF oats has further complicated the landscape. Therefore, the current recommendations are to use only oats labelled GF, use in moderation and monitor for symptoms or elevated

coeliac serology. Individuals are encouraged to check ingredient labels as the use of oats and oat flour (which can be contaminated as well) has increased in use in many GFP including nondairy milk, cereal bars, cookies and breads. Further recommendations include initiating a trial removal of oats and retesting in 3 months if coeliac serology becomes elevated. Individual guidance and follow-up are essential to navigate this area.

Oats are frequently contaminated with gluten; therefore, individuals with CeD are recommended to consume only 'pure' or 'uncontaminated' GF oats. This has proved difficult, as the standards and reliability of these terms vary from country to country. Pinto-Sanchez et al. note that although Finland and Norway are reliably able to produce uncontaminated GF oats, North American countries have struggled with this issue. They concluded that the purity of the oats was heavily reliant on the country of origin and local regulations.⁷³ In a review of 35 studies, de Souza et al. cite five studies that showed gluten contamination in a variety of GFP-containing oats, including Canadian oat products.⁷⁴ Additional studies by Rodriguez et al. and the Gluten-Free Watchdog reported similar results, with several GF-labelled products tested as containing above 20 ppm gluten (FDA regulations stipulate that a product has to contain <20 ppm gluten to be labelled GF).⁷⁵

The study of individuals with biopsy-proven CeD or dermatitis herpetiformis⁷¹ that assessed GI symptoms, psychological well-being and dermatologic QoL reported that long-term inclusion of oats was associated with improved outcomes. Although the findings support the inclusion of GF oats in the diet, there was little specific information on the quantity of oats eaten and reasons associated with oat restriction. Similar results were reported by Aaltonen et al.⁷⁰

There is a small subset of the population with and without CeD that are intolerant to the presence of the protein avenin that may experience a reaction to even 'pure' GF oat consumption.⁷² Additionally, it is important to differentiate the potential symptoms associated with the high fibre content of oats from those due to gluten exposure. Guidance from an RD is necessary to distinguish the potential cause of the intolerance and to recommend safe ways to include GF oats in the diet.

Recommendations generally suggest that uncontaminated GF oats should be introduced with caution and regular guidance with follow-up to assess any adverse effects.^{72,76,77}

ENVIRONMENTAL CONSIDERATIONS THAT IMPACT ADHERENCE TO A GFD

Historically, inadvertent exposure to gluten was referred to as cross-contamination. As understanding has grown that potential exposure must include contact with gluten, the

terminology has transitioned to cross-contact. In 2013, the FDA defined 'cross-contact' as the unintentional incorporation of a food allergen into a food.⁷⁸

Dietary recommendations to minimise gluten cross-contact in shared kitchens and when eating out vary greatly. There are limited evidence-based studies to guide recommendations for best practices to minimise the risk of cross-contact. Historically, recommendations have been based on assumptions and, despite best intentions, may have been more restrictive than necessary.

There are several common sources of cross-contact including the field, factory, retail premises, restaurants and the home. Historically, cross-contact at home was thought to occur through shared kitchenware, countertops, cupboards and spreads commonly used with gluten-containing foods.⁷⁹ Evidence for the efficacy of using separate kitchen equipment for the preparation of GF foods is sparse.

Life-long avoidance of gluten is necessary in CeD, but there are limited studies on the amount of gluten ingestion that would cause an inflammatory response. It has been recommended in a study by Catassi et al. to reduce gluten to less than 50 mg/day.⁸⁰ A study by Silvester et al. found that 8% of the food samples eaten by individuals on a GFD during a 10-day period had gluten contamination, with an average intake of 2.1 mg of gluten and a range of 0.2–80 mg.⁸¹ In a study of gluten found in restaurant items labelled GF, gluten was detected in 32% of dishes. The items most likely to be contaminated were pizza (53.2%) and pasta (50.8%).⁸²

Clinically, some individuals may be more sensitive than others and experience overt symptoms upon small levels of cross-contact.⁸³ In the Catassi study, one individual responded to 10 mg/day of gluten.⁸⁰ Further studies are needed to determine the varying effect of exposure to small amounts of gluten. It is challenging to pinpoint inadvertent gluten ingestion, as not all individuals with CeD experience overt GI symptoms to reveal the source of cross-contact.

Cross-contact of gluten in domestic kitchens

Studerus et al.⁸⁴ led a study to determine the risk of cross-contact with shared kitchenware and the most reliable cleaning method to reduce cross-contact in a domestic kitchen. Kitchenware (wooden spoon, colander, ladle and knife) previously used to cook and/or prepare gluten-containing foods was used for the preparation of GF bread and pasta. The gluten concentration of the GF foods was determined using an established enzyme-linked immunosorbent assay (ELISA) and a polymerase chain reaction assay was used to detect the presence of wheat x-gliadin DNA in the food samples. The results of this study showed that gluten could not be detected in relevant and quantifiable amounts in the

samples. The cleaning method did not affect the gluten concentrations; all samples had gluten concentrations <10 ppm. Higher concentrations of wheat DNA were only detected on a ladle that was used in water contaminated with gluten-containing pasta. This was a small study; however, the authors did show that cross-contact of gluten-containing flour via domestic kitchen utensils during the preparation of GF meals is less critical than previously reported.⁸⁴ The authors hypothesised that shared ladles pose a higher risk for contamination of GF foods than shared wooden spoons, colanders or knives. They also proposed that despite some cross-contact with gluten, shared kitchenware in a domestic setting should not pose a risk to individuals with CeD.⁸⁴ Similarly, Weisbrod et al. reported low-level gluten transfer when cutting GF cupcakes with a knife used to cut frosted gluten-containing cupcakes. The authors reported minimal gluten transfer when using a shared toaster.⁸⁵

Parsons et al. investigated common food practices (shared fryers, toasters and spreads) that could lead to gluten cross-contact. Most samples showed no significant cross-contact. Risk of cross-contact was highest with the shared use of knives in spreads such as peanut butter, mayonnaise and jam; mayonnaise and peanut butter samples were contaminated with gluten above the FDA-designated GF limit of <20 ppm. The authors suggest that the texture, viscosity and hydrophobic nature of these spreads may facilitate gluten adherence.⁸⁶

Physical separation to avoid cross-contact

A study by Miller et al. found that when preparing a GF meal in a commercial kitchen, a minimum distance of 2 m is required between wheat flour and GF areas when standard hygiene procedures are followed (i.e., clean surfaces, utensils and equipment).⁸⁷ A similar study in Brazil found that approximately 21% of GFP from bakeries with shared production areas contained gluten and 64% of the bakeries sold at least one contaminated product.⁸⁸

Similarly, in an Italian study, researchers found that if GF food preparation specifications were adhered to in shared kitchens, cooking GF and wheat-based pizzas simultaneously is as safe as having a dedicated GF oven. The authors also reported that alternating between cooking of GF and wheat-based pizzas in the same oven was safe; however, it was noted that the results of this study may not be generalisable, as the GF preparation protocols in Italy are very stringent.⁸⁹

Cross-contact in restaurants

Historically, the varying levels of understanding and education in regard to food preparation in shared kitchens were a cause for concern among patients with

CeD when dining out. Concerns about cross-contact have been reported to decrease the frequency that individuals with CeD dine outside of the home and a study in the UK found that chefs appeared to know less about CeD and the GFD than the general population.⁹⁰

A subsequent study of chefs and the general public in the United Kingdom found that there has been a significant increase in the awareness of gluten-related disorders in both groups. Further education and advocacy are necessary to ensure safe yet realistic precautions to avoid cross-contact.⁹¹

Shared fryers may impose a risk for cross-contact.⁹² One study reported that 25% of fries cooked in a shared fryer were contaminated with gluten. The authors noted, however, that the ELISA underperforms when analysing gluten in foods that have been heated.⁹²

A study by Korth et al. confirmed that gluten transfer increased over the course of the preparation time in a shared restaurant kitchen.⁹³ Three scenarios were developed to assess gluten transfer and efficacy of washing methods during food preparation: (1) cooking pasta, (2) toasting bread and (3) slicing cupcakes.⁸⁵ Of the three scenarios tested, cooking GF pasta using shared water was the riskiest, resulting in gluten levels >20 ppm in all samples tested. The authors concluded that the risk of gluten cross-contact may be mitigated by rinsing the pasta, which reduced gluten content to <20 ppm.

A recent editorial reported that it would be premature to recommend changes to current precautionary culinary practices minimising cross-contact until there are evidence-based studies detailing safe food preparation practices to minimise gluten cross-contact.⁹⁴ Further systematic studies using gold standard testing to quantify the level of gluten transfer during all steps of food production are needed to quantify safe practices.

Food insecurity and CeD

Food insecurity negatively impacts adherence to a GFD and is associated with a decrease in health-related quality of life (HRQoL).⁹⁵ One in six patients with CeD is food insecure. Food insecurity should be considered in the management of CeD. A study by Ma et al. found that less than one-quarter of food-insecure patients adhere to a GFD.⁹⁶ The authors also found that the food-insecure CeD population was disproportionately younger, poorly educated, non-White, living in poverty, illiterate, non-English speaking and significantly less likely to adopt a GFD (24.1% vs. 67.9%, $p = 0.02$). Food insecurity was associated with significantly lower consumption of protein, carbohydrates, fat, vitamins and minerals.⁹⁶

The Food Equality Initiative (FEI) was developed to improve health and end hunger among individuals with food allergies and CeD in the United States.⁹⁷ In response to the COVID-19 pandemic in 2020, FEI

adapted their in-person collection pantries to allow contactless delivery of safe foods.⁹⁷

Households with dietary restrictions were more likely to experience prepandemic and pandemic-related incidents or worsening food insecurity compared with households without dietary restrictions. An anonymous electronic survey to assess food insecurity using the Hunger Vital Sign questions investigated dietary adherence during the COVID-19 pandemic. The study reported that the proportion of households with a child on a GFD who were food insecure (19%) was similar to national rates of households without dietary restrictions (24%).⁹⁸ Approximately 5% of families who were generally food secure reported food insecurity related to obtaining GF food. Parent-reported intentional gluten consumption due to limited GF food availability in the household increased during the pandemic by 7.5%.

CeD in education facilities

School classroom settings, specifically art and home economics, may pose risk of gluten exposure. A study by Weisbrod et al. was the first to measure gluten transfer from school supplies to GF foods.⁹⁹ The study investigated the efficacy of washing techniques to remove gluten from hands and tables in 30 participants aged 2–18 years.⁹⁹ Investigators used Play-Doh[®], papier mâché and dry and cooked pasta as potential gluten-transfer agents. Following the activities, gluten levels were measured on separate slices of GF bread rubbed on participants' hands and table surfaces. Participants were assigned one of three handwashing methods (soap and water, water alone or wet wipes). Gluten transfer measurements were taken directly from the hands and tables, from bread rubbed on the hands and tables and after washing in one of three scenarios using the R-Biopharm R7001 R5-ELISA Sandwich assay. Results indicated that papier mâché, cooked pasta in sensory tables and participation in baking resulted in rates of gluten transfer >20 ppm. Soap and water were consistently the most effective method for removing gluten.

The Voluntary Recommendations for Managing Celiac Disease in Learning Environments guide was developed in 2020 with the collaboration of the Celiac Disease Foundation and multiple CeD centres along with industry partners.¹⁰⁰ It is intended to support the implementation of a Celiac Disease Management Plan for the creation and maintenance of an environment that reduces the risk of gluten exposure for children with CeD. The guide provides information including sample letters for clinicians and recommendations for children as young as 3 years through to college-age teenagers. Collaboration between medical centres and experts is essential to create and reinforce guidelines for food allergy and chronic disease management in educational settings.

Recently, Sage developed guidelines for 504 accommodations for implementation by schools. These guidelines are used by paediatric coeliac centres across the United States to help families who have children with CeD succeed in safe school environments.

Transition to college can be a major lifestyle change for young adults. Collaboration between the medical team and university food service is key to ensuring a safe environment with options for an adequate GFD. Some universities may provide separate living options for those requiring a medical diet or already have allergen stations set up to provide for students. Beyond Celiac, a US support organisation, have developed a resource for students going away to college.¹⁰¹ This provides tools and access to pertinent information for students, parents and universities.

Cross-contact is a legitimate concern for individuals with CeD. A thorough dietary assessment must query aspects of food security, meal preparation at home and in the school environment, as well as life-stage events and transitions in the individual's life. Several studies have indicated the negative impact of food insecurity and cost and availability of GF foods on dietary adherence. Additionally, the issue of cross-contact has increased the burden of dietary adherence through recommendations that were not based on scientific findings. More studies are needed to determine safety guidelines based on scientific evidence to avoid the risks of cross-contact. This will help inform clinicians and patients of best practices and avoid cross-contact of gluten.

ASSESSMENT OF QOL AND PSYCHOSOCIAL ASPECTS

As noted above, factors affecting dietary adherence are multifaceted. Studies have historically reported on the negative impact of a GFD on an individual's QoL,^{102–104} especially the social domain. A more recent study by Lee et al. identified the impact of a GFD on social anxiety, depression and QoL.¹⁰⁵ Although a nutritional assessment may not encompass the scope of a full psychosocial assessment, clinicians need to be aware of the impact of social and emotional factors on dietary adherence. This review highlights key factors of the psychosocial impact.

Burden of disease and diet

Economic

Navigating an environment where gluten is ubiquitous can lead to a high degree of perceived burden of a GFD and CeD. The burden of a GFD as a treatment has been reported by Leffler et al. as being second only to

end-stage renal disease.¹⁰³ In particular, the time spent shopping and preparing food ($p = 0.001$), eating outside the home ($p = 0.005$) and the additional cost of the GF foods ($p = 0.001$) were key factors associated with the increased burden of the diet as treatment.⁸²

A study by Lee et al.¹⁰⁶ reported the persistent increased cost of a GFD despite an increased availability and variety of GFP. In the United States, GFP were reported to be 183% more expensive than their gluten-containing counterparts.¹⁰⁶ This increased cost has been observed in other countries, including Iran,¹⁰⁷ Greece, where the GFP were 22%–334% more expensive,¹⁰⁸ and the United Kingdom,¹⁰⁹ where GFP were 159% more expensive. A study by Oza et al. found that the patients with lower income had lower perceived health, more symptoms and increased hospitalisations and burden from the GFD.¹¹⁰

Impact on social domain

The negative impact of CeD on patient QoL, especially in the social domain areas of dining out, travel, work and partner burden, has been well documented.^{82,102,111–113}

In a study that investigated the effect of CeD and GFD on dating within the social domain, the majority of participants (68.4%) reported that CeD had a major/moderate impact on their dating life, especially those aged 23–35 years ($p = 0.002$), and those with a lower annual household income ($p = 0.019$). For example, 39.3% of those surveyed were uncomfortable explaining their dietary needs to waiters in front of their date.¹¹¹ Additionally, 22.7% of all survey participants felt that their symptoms interfered with being physically intimate, and 39.0% were hesitant to kiss their partner owing to concerns of chance gluten exposure.¹¹¹ The impact on females was significantly greater than males in the context of physical intimacy (24.5% vs. 10.7%; $p = 0.012$) or kissing (41.1% vs. 22.7%; $p = 0.005$). Indeed, overall QoL scores reflected this increased social burden, with a score of 57.8, which is in the moderate range. Furthermore, the social anxiety score, as measured on the Social Anxiety Questionnaire, was 78.8, with 23.0% of participants meeting the clinical cut-off point for social anxiety disorder.

Although the proportion who intentionally consumed gluten on a date was small (7.5%), this is relevant for clinicians, and suggests that individuals may feel inhibited at restaurants in front of their date, leading to riskier behaviours.¹¹¹ It is crucial that nutritional assessments identify the specific anxieties that patients are facing. Discussion of these real-world difficulties, the struggles of following a strict GFD, the impact on an individual's social life and strategies to navigate them should be an integral part of nutritional counselling for individuals with CeD.

Partner burden

Disease burden is not isolated to the individual with CeD.¹¹⁴ A study by Roy et al.¹¹⁴ found that partners of individuals with CeD also reported a burden of illness. In particular, 29% of the non-CeD partners reported mild to moderate burden and 8% reported moderate to severe burden associated with feelings of the CeD partner being dependent, worry of future health of the CeD partner, impaired social life and strained relationship.¹¹⁴ In a study by Ferretti et al., the impact of a GFD and CeD was highest in the social domain aspects of family life, social interactions and cost.¹¹⁵

In a study using the Swedish Total Population Register, caregivers (parents or spouses) of individuals with CeD were compared with matched controls.¹¹⁶ The authors found that depression was 11% more common in CeD caregivers than in control caregivers and anxiety was 7% more common in CeD caregivers than in control caregivers.¹¹⁶

Increased anxiety and depression

More research is needed to determine the underlying cause of the increased rates of depression, anxiety and panic disorder in individuals with CeD compared with non-CeD controls. In a meta-analysis, there was a statistically significant increased risk for individuals with CeD to develop depression ($p < 0.0001$), anxiety ($p = 0.05$) and panic disorder ($p < 0.0001$) compared with controls.¹¹⁷ In contrast, Zylberberg et al. found depression in 3.9% of individuals with CeD compared with 8.2% of controls on reviewing data from the National Health and Nutrition Examination Survey.¹¹⁸ However, on comparing QoL measures, 13.8% individuals with CeD reported physical, mental and emotional limitations compared with 2.9% of controls.¹¹⁸

Maladaptive eating behaviours

The reported increased impacts on psychosocial and emotional domains of life have caused concern regarding the potential impact on eating behaviours and patterns. In a study on biopsy-confirmed CeD in adults and adolescents, adults who were extremely vigilant in their dietary adherence had a lower QoL score (64.2) compared with adults who were less vigilant (77.2; $p = 0.004$).¹¹⁹ Among those identified as more vigilant, the top concerns were fear of contamination and the embarrassment of requesting specific foods or inquiring about food preparation.¹¹⁹ Similar trends were found in adolescents; for example, 70% of adolescents reported more barriers to QoL encompassing two main areas: eating out and GFP. With regard to eating out, adolescents reported frustration at dismissive wait staff, lack of spontaneity and the

embarrassment associated with asking questions to assure food safety.¹¹⁹ Regarding GFP, adolescents felt that available products were of poorer quality and more expensive than their wheat-based counterparts, and they did not trust the GFP labels.¹¹⁹

In a study that reviewed eating patterns in individuals with various digestive diseases, 48.7% of the individuals with CeD met the criteria for ARFID. Individuals with CeD were more likely to be described as picky eaters (17.1% vs. 7.1% of those who had eosinophilic esophagitis (EoE), or 10.8% of those with achalasia).¹²⁰ In fact, those with CeD had the lowest rate of fear of GI symptoms (25.0% vs. 70.3% with achalasia, 35.9% with IBD and 33.3% with EoE).¹²⁰

In a cross-sectional study of 50 adults with biopsy-proven CeD, 42% had QoL scores under 60 points, suggesting low QoL and 40% met the threshold for clinical diagnosis of anxiety. Additionally, the newly developed Celiac Disease Food and Behaviour questionnaire (CD-FAB), which assesses eating behaviours, revealed a mean score of 37, indicating some maladaptive eating behaviours among this patient group. The items that participants most strongly agreed with were 'I am afraid to eat outside my home' and 'I get worried when eating with strangers'. There was a high correlation between CD-FAB scores and lower QoL.¹²¹

In a cross-sectional study that assessed GFD adherence strategies in 30 teenagers, 53.3% of the study population expressed maladaptive approaches to following the diet.¹¹² The strategies were divided into four categories ranging from adaptive, mostly adaptive, some maladaptive behaviours and mostly maladaptive behaviours.¹¹² The adaptive behaviours were characterised by flexibility, trust and confidence. Maladaptive behaviours were characterised by greater rigidity, avoidance, controlling behaviour and preoccupation with maintaining the GFD, and were associated with a lower QoL score.¹¹²

Impact on QoL

In a survey of 538 adults with CeD, Lee et al. reported a mean QoL score (57.8) in the moderate range.¹⁰⁵ However, the high mean social anxiety score (78.82) was noteworthy, with 9% of participants meeting the clinical threshold for social anxiety disorder. Diminished QoL with CeD has been reported globally.^{122–124} In a Spanish adaption of the Celiac Disease Questionnaire assessment tool,¹²³ lower overall QoL scores were reported for females, with statistically significant differences seen in the emotion ($p = 0.003$) and social ($p = 0.036$) subdomains. Those on a GFD for less than 2 years also had lower overall QoL scores.¹²³ In an Italian study by Borghini et al.,¹²² individuals with CeD had significantly lower HRQoL scores ($p < 0.001$) compared with healthy controls. Using the Beck Depression Inventory, those with CeD had significantly higher depression scores

($p < 0.001$) compared with healthy controls.¹²² In a study in China,¹²⁴ patients with CeD had an overall QoL score in the moderate range (62.1); patients noted significant barriers to maintaining a GFD and socialising.

It is noteworthy that a few studies have identified interventions that positively impact overall QoL scores.^{102,125,126} In a randomised control trial using text message intervention,¹²⁶ 3 months of the intervention resulted in a statistically significant improvement in the QoL scores, 50.8 versus 53.3 ($p = 0.01$), using the NIH Patient-Reported Outcomes Measurement Information System Global Mental Health survey.¹²⁶ In the MyHealthyGut intervention,¹²⁵ the intervention group showed significant improvements in Celiac Dietary Adherence Test (CDAT) score ($p < 0.001$) and in Celiac Disease Quality of Life Measure scores ($p < 0.001$) compared with controls after using the MyHealthyGut app for 1 month.

Studies^{127–129} have also suggested the importance of healthcare professionals being aware of the impact of diet and diagnosis to improve overall QoL. In a cross-sectional study investigating the impact of social support networks,¹²⁸ Lee et al. reported improved QoL scores (72.6 vs. 66.7; $p < 0.0001$) associated with face-to-face social support compared with online versions. In a prospective study of 200 adults with CeD,¹²⁷ it was found that self-compassion enhanced QoL ($p = 0.001$) and dietary adherence ($p = 0.006$). In a qualitative study of women,¹²⁹ three major themes emerged indicating barriers in daily life: illness trajectory and treatment; socialising with others; and feelings of loneliness and invisibility. The authors in both studies concluded the importance of awareness of barriers, negative impact of diet and diagnosis in their patients with CeD.^{127–129}

As a GFD is the cornerstone of treatment for CeD, adjustments to the diet, dietary compliance and quality of the diet are imperative to assess. Additionally, many studies have noted that dietary adherence is affected by social and emotional factors.^{113,130–133} Therefore, it is imperative that healthcare practitioners look beyond clinical parameters and assess social and emotional barriers to GFD adherence and the impact on an individual's QoL. As Mulder et al. noted,¹³¹ the dietitian plays a key role in ongoing care and management of the individual with CeD. Indeed, within the nutritional assessment process, the dietitian has the ability to focus on the perceived barriers, presence or absence of support systems and any maladaptive eating behaviours. Addressing these issues will not only improve overall QoL but also dietary adherence.^{130,134}

LIMITATIONS OF DIETARY ASSESSMENT STUDIES

Several limitations in studies assessing nutrient intake were identified. Smoking and alcohol intake can have a substantial impact on patient health, but were not

consistently reported across studies; it is, therefore, unclear if they were included in nutritional assessments. There is a lack of data on micronutrient composition of commercial GFP for vitamins, such as B vitamins, and minerals (other than iron) both on the products themselves and in the nutrient databases. As a result, researchers must estimate or compare similar gluten-containing products. Selenium, iodine and vitamin E intakes were infrequently analysed in the literature, and yet, they are important to ensure the health status of people with CeD. Finally, when data are collected from individuals who are members of a CeD society, results cannot necessarily be generalised to the wider population of individuals with CeD; members of a society who are willing to take part in a study are likely to be more health conscious, demonstrate greater awareness of nutritional issues and have stricter adherence to a GFD than other individuals with CeD.

DIETARY ADHERENCE TOOLS

A dietitian consultation includes nutritional, psychosocial and anthropometric assessments. A cornerstone of a nutritional assessment in individuals with CeD is to determine adherence to a GFD. Currently, there are several methods and or tools used to determine dietary adherence. Adherence measures range from self-reported adherence, knowledge based on ingredient or grocery quizzes, self-administered questionnaires and, more recently, the use of gluten immunopeptide (GIP) testing of urine or faeces. However, there is no consensus on which tool is most effective. In fact, Weiser et al.¹³⁵ report a wide range of dietary adherence internationally: 45%–90% in adults and 23%–98% in children. Weiser et al. indicate that the potential reason for such disparity in adherence may be due in fact to the different methods used, the definition of adherence used by different groups and variations in study populations.¹³⁵

Overall, six dietary adherence measures are commonly used: the Standardised Dietitian Evaluation (SDE),¹³⁶ the CDAT,¹³⁷ the Gluten-Free Eating Assessment Tool (GF-EAT)⁸³, the Biagi tool,¹³⁸ grocery and ingredient knowledge tools⁸³ and GIP test kits.¹³⁹ Key details for each of these tools are summarised in Table 2.

In a study by Leffler et al., the CDAT, a seven-item questionnaire, was developed; the questionnaire contains an additive score and was found to correlate with the SDE ($p < 0.001$) and tissue transglutaminase immunoglobulin (Ig)A (TTG) levels ($p = 0.001$). Interestingly, the authors found that the domain of knowledge did not add substantive value to the predictive ability of the model.¹⁴¹

In a study that reviewed several of the measures together, Gutowski et al. found that the grocery and ingredient knowledge scores decreased over time.¹⁴² Additionally, the knowledge score did not correlate with the adherence scores from the CDAT or the GF-EAT and

TABLE 2 Summary of commonly used dietary adherence tools.

Measure	Description
SDE ¹³⁶	A common dietitian-led assessment
CDAT ¹³⁷	A seven-item questionnaire specifically designed to assess diet adherence in patients with coeliac disease
GF-EAT ⁸³	Self-reported measure for participants to estimate the frequency of gluten exposure (either intentional or unintentional)
Biagi tool ¹³⁸	Questionnaire led by expert personnel
Grocery and ingredient knowledge tools ¹⁴⁰	Tools measuring knowledge of gluten-free grocery items and ingredients
GIP test kits ¹³⁹	Kits using urine or stool to test for the presence of GIP

Abbreviations: CDAT, Celiac Dietary Adherence Tool; GF-EAT, Gluten-Free Eating Assessment Tool; GIP, gluten immunogenic peptide; SDE, Standard Dietitian Evaluation.

did not correlate with serology or symptoms.¹⁴² Overall, the authors concluded that the grocery quiz or knowledge assessment does not correlate to adherence.¹⁴²

A study by Rodrigo et al.¹⁴³ explored the benefits of three measures including dietitian assessment in overall compliance to a GFD, monitoring coeliac antibodies and GIP testing. The authors noted that coeliac antibodies were a poor marker of adherence, that the CDAT was easy to use but was not better than GIP testing and concluded that best practice included monitoring by a specialist dietitian using multiple monitoring measures.¹⁴³

Gladys et al. compared the CDAT to the SDE, and found that there was generally good correlation between the two adherence scores ($p = 0.008$).¹³⁶ However, they also highlighted that according to the SDE, 76% of participants had good or above adherence, whereas using the CDAT, only 48% of participants were rated as good or above for adherence. Interestingly, in the food label quiz, only 16.3% of participants who were rated as highly adherent correctly classified all items. The authors concluded that the SDE correlated better than the CDAT with serology and biopsies.¹³⁶

Silvester et al. reviewed the efficacy of the CDAT, self-reported diet adherence, the GF-EAT and TTG, and found that the CDAT correlated to symptoms ($r = 0.49$) better than serology ($r = 0.20$). In contrast, the GF-EAT did not compare favourably to serology.⁸³

The Biagi tool, which gives a simple five-point score, initially showed high correlation with the absence of persistent villous atrophy (VA).¹⁴⁴ In a subsequent study, a poor adherence score predicted ongoing mucosal damage at 1 year.¹⁴⁵ Another study by Galli et al. found that 81.5% of participants were classified as adherent according to the Biagi tool, but only 66% of these patients had complete histological recovery ($p < 0.00001$).¹⁴⁶

In a study by Schieppatti et al., VA was used as the gold standard of adherence and used to assess the Biagi tool.¹⁴⁷ The authors found that the presenting symptoms of diarrhoea and weight loss were better predictors of adherence ($p = 0.02$) than the Biagi adherence tool. The

authors noted that, in the majority of participants, the level of adherence did not change over time.¹⁴⁷

In a subsequent study by Lau, the Biagi tool did not correlate well to serology or VA. Point-of-care testing (PCOT) detects both deamidated gliadin peptide IgA and IgG using lateral flow. The authors report that in detecting VA, the PCOT had the highest predictive value of 67.1%, followed by TTG with 44.7%, antiendomysial antibody (37.7%) and the Biagi tool (24.7%).¹⁴⁸ In a study that reviewed both the CDAT and the Biagi measure of dietary adherence, Coleman et al. found that serology, CDAT and Biagi did not accurately predict VA. Overall, the CDAT did not correlate well with histological findings. In fact, 55.6% of patients with persistent VA had a good adherence score on the CDAT and 47.8% of patients with a good CDAT score had no VA. The Biagi tool correlated poorly, with 20.6% of patients with VA measured as having good adherence.¹⁴⁹ It is important to note that although VA was used as the endpoint in these studies, mucosal healing can take several years, so even highly adherent patients may still have mild VA several years later.

GIP measures are able to identify specific exposure and transgressions, and the use of GIP in clinical trials has been able to indicate positive correlations with gluten intake. The authors report poor correlation between GIP and TTG antibodies. The agreement between GIP and CDAT was acceptable ($p = 0.004$), as 92.5% reported compliance according to GIP levels compared to 86.3% who had a good or above adherence score on the CDAT. Of the 69 patients with good adherence on the CDAT, three had positive GIP results.¹³⁷

Lombardo et al.¹⁵⁰ looked at the presence of VA and found that it did not correlate with TTG serology. In fact, the TTG did not show significant correlation with either histology or urinary GIP (uGIP). A positive uGIP correlated to histology, but did not correlate with CDAT, TTG or symptoms.¹⁵⁰ In comparing the CDAT and GIP alone, the authors found that the CDAT could miss chance exposures and contamination that could be

picked up by using the GIP routinely.¹⁵⁰ The authors recommended using the GIP three times a week with at least one measure on a weekend day.

In the study by Ruiz-Carnicer et al.,¹⁵¹ it was found that the uGIP levels had good correlation with VA. In contrast, they found that the CDAT had poor correlation with VA.¹⁵¹ Similarly, measurement of faecal GIP (fGIP) also correlated well with VA. In the study by Laserna-Mendiet,¹⁵² the fGIP correlated well with biopsy results, whereas the TTG did not correlate well with biopsy results. In looking at the predictive value of the CDAT, it was found that the CDAT had no association with biopsy results, fGIP or serology.¹⁵²

In a long-term study of individuals with CeD, adequate adherence was found in 75.5% of respondents.¹⁵³ After controlling for household income, a higher level of education was associated with adequate adherence. Perceptions of cost, effectiveness of the GFD, knowledge of the GFD and self-effectiveness at following the GFD correlated with improved adherence. This study indicates that perceived cost and lower education are barriers to GFD adherence.¹⁵³

In summary, these findings indicate that no one tool is adequate in assessing GFD adherence compared with serologic and histologic markers or the role of the dietitian.¹⁴³ Indeed, there are many facets affecting dietary compliance. Several studies identified a lack of correlation between knowledge (ingredient quizzes, reading labels, etc.) cost, availability and dietary adherence.^{130,141,142} A common shortfall of the current adherence measures used is the absence of inquiry on motivators, barriers, self-efficacy and locus of control as they impact dietary adherence.^{130,154} Muhammad et al. report increased adherence with the use of GF foods on prescription, as this decreased the economic barrier to adherence.¹⁵⁵ Bellini reported increased adherence with increased QoL and greater internal locus of control.¹³⁰ Both studies highlight the multifaceted aspects of dietary adherence. It is also important to note that a firm adherence outcome measure must be agreed upon,^{130,154} whether it is normalisation of intestinal mucosa, serology or remission of symptoms. Recently, a new tool, the Celiac-SE tool, has been developed that measures self-efficacy. Fueyo-Díaz et al. noted the importance of self-efficacy in ability to be adherent.¹⁵⁶ Recommendations for dietary assessment in CeD are summarised in Table 3.

DEVELOPMENT OF THE GLUTEN-FREE DIET ADHERENCE SURVEY (GFAS)

Based on the limitations of current assessment tools for GFD adherence identified in this literature review, we undertook development of a new adherence tool that targets behaviours associated with dietary adherence or nonadherence. The ideal tool should be easy to

administer and score within a typical dietitian counselling session and enable assessment of dietary adherence barriers to guide education and counselling for improved compliance with a GFD.

As knowledge about GF labels, ingredients and GFDs was not associated with serology and histology,^{136,142,149} we determined that focusing on behaviours around food and eating may better predict dietary adherence. A set of six draft questions with a yes/no response was developed and shared with a group of six coeliac specialist dietitians (including the authors). This questionnaire was subjected to iterative rounds of feedback and clinical assessment between January and April 2023. Based on the feedback of the assessment group, an additional question was included and an additional column was added to the draft tool to include prompts to identify barriers around areas of nonadherence or lack of knowledge. The tool was trialled in clinical practice by each dietitian with two to four patients with CeD. The group reviewed their experiences and expanded the questionnaire to include 11 questions; this included a question to assess oat contamination and the scoring was adjusted accordingly. However, this version of the tool was considered to be long and repetitive. Taking this feedback into account, the final tool, the GFAS, contains six questions with a total score of 0–14: a score over 6 represents poor dietary adherence (Table 4).

Validation of this tool via correlation with biomarkers is planned in a multicentre study. As part of the validation process, the GFAS will be administered three times over a 12-month period. The scores will be compared to the CDAT, which will be administered at the same time points. Both the CDAT scores and the GFAS scores will be assessed against serology and histology findings at diagnosis and 12 months to assess reliability.

DISCUSSION

A nutritional assessment contains many essential components to the overall care of the individual with CeD. The importance of assessing nutrient status, dietary adherence, medication, supplements, symptoms and the nutritional quality of the diet cannot be emphasised enough. The reality, however, is that often, individuals with CeD are not routinely followed up.¹⁵⁷ In a study on routine follow-up visits, it was found that of the patients who were followed up for more than 4 years, only 35% received the level of care recommended by the American Gastroenterological Association's guidelines for individuals with CeD.¹⁵⁷ The authors also noted that there was no indication of any documentation on dietary adherence in 37% of the patients' follow-up visits.¹⁵⁷ In a patient-based survey administered through WhatsApp, Mehtab et al. reported that 61% of the Indian patients with CeD were referred to a dietitian for dietary counselling. In the majority of cases, the consultations lasted

TABLE 3 Summary of recommendations for nutritional assessment in CeD.

Area	Recommendation
Role of the specialised CeD RD	<ul style="list-style-type: none"> Patients with CeD should have ongoing follow-up and dietary assessment by a trained RD who is familiar with CeD.
Frequency of assessment with an RD	<ul style="list-style-type: none"> Longitudinal nutritional assessment during the life of a patient with CeD is recommended. Frequent encounters with an RD are recommended (at diagnosis, every 3–6 months in the first year, then annually, with more frequent follow-ups if clinical symptoms are present).
Assessment of food/nutrition-related history	<ul style="list-style-type: none"> Increased accuracy of nutrient assessments will require increased representation of GFP in nutrition composition databases, inclusion of supplement use, inclusive food intake and preparation details. Food frequency questionnaires/food recalls should be universally included in any intake assessment.
Anthropometrics	<ul style="list-style-type: none"> During follow-up visits, current weight, BMI and waist circumference should be compared to the values at diagnosis, but also from the past 3 months to tailor dietary counselling.
Gastrointestinal/extraintestinal symptoms and comorbidities	<ul style="list-style-type: none"> The RD should assess gastrointestinal symptoms (such as type, frequency and volume of bowel function; abdominal pain and bloating; nausea or vomiting; reduced gut motility and delayed gastric emptying). The RD should also consider any extraintestinal symptoms common in CeD such as fatigue, headache, cognitive difficulties, joint pain and skin rash, and CeD comorbidities that may be associated with additional dietary restrictions and/or GI symptoms such as thyroid conditions, other autoimmune conditions and endocrinologic disorders, such as type 1 diabetes mellitus.
Medications and supplements	<ul style="list-style-type: none"> Details of medication and supplement intake should be taken, noting if they are labelled gluten-free.
Micronutrients	<ul style="list-style-type: none"> Routine monitoring of at-risk vitamin and mineral levels should be part of a nutritional assessment.
Macronutrients	<ul style="list-style-type: none"> An in-depth review of macronutrient intake should be an integral part of any nutritional assessment. Dietary assessment by an RD should include a detailed review of the patient's intake of both simple and complex carbohydrates. If the patient is avoiding dairy, the nutritional value of plant-based beverages and food should be assessed.
Other dietary restrictions	<ul style="list-style-type: none"> The RD should assess for the presence of other disease states, disorders, food preferences, food allergies and intolerances (lactose, fructose, FODMAPs, sucrose) or any pre-existing condition that affects the patient's intake and behaviour.
Oats	<ul style="list-style-type: none"> Uncontaminated oats labelled as 'gluten-free' should be introduced with caution and with regular guidance with follow-up to assess any adverse effects.
Environment	<ul style="list-style-type: none"> A thorough dietary assessment must query aspects of food security, meal preparation at home and in the school environment, as well as life-stage events and transitions in the individual's life.
Burden of disease	<ul style="list-style-type: none"> Healthcare practitioners should look beyond clinical parameters and assess social and emotional barriers to GFD adherence and the impact on an individual's quality of life.

Abbreviations: BMI, body mass index; CeD, coeliac disease; FODMAP, fermentable oligosaccharides, disaccharides, monosaccharides and polyols; GF, gluten-free; GFD, gluten-free diet; RD, registered dietitian.

only 10–20 min, reinforcing the need for proper guidelines for the care and management of these patients.¹⁵⁸

Dietitians experienced in dealing with patients with CeD play a central role in the comprehensive nutritional assessment of the patient. Some studies used trained dietitians or nutritionists to assess gluten avoidance and/or nutritional adequacy of the GFD.^{9,10,14,20,62} Other studies did not identify the individual administering the survey.²³

There is a strong need for comprehensive nutritional assessment and counselling by an RD with expertise in CeD at the time of diagnosis and follow-up on a GFD.¹⁷ This follow-up would allow appropriate and personalised nutritional recommendations, resources, support and a quicker intestinal recovery. A standardised assessment and adherence to recommendations could eventually make nutritional measures a surrogate marker of intestinal function and recovery.

TABLE 4 Gluten-Free Diet Adherence Survey (GFAS).

Over the past month		Yes	No	Notes/prompts
GFDA1	Did you intentionally ingest gluten?	4	0	-
GFDA2	Did you always check food labels for gluten-containing ingredients?	0	3	If needed, check knowledge. Ask about ingredients like: malt, brewers yeast ... Probe deeper if patient answers 'mostly', 'X' out of 10 times': Ask patient what are the products that he/she does not check. If products are used routinely that would be considered adherent.
	Did you feel confident in identifying gluten on ingredient labels?	0	1	
	Did you consume oats without a gluten-free label?	1	0	If it is a new product, package has changed or product is used infrequently, it would be considered nonadherent.
GFDA3	Did you request that your meal be gluten-free in situations such as dining out or ordering in, at work or school and at family/friends' houses?	0	1	Probe deeper if doubtful about answers. - If patient is only dining out in a dedicated gluten-free restaurant = YES
GFDA4	Did you ask how food was prepared in all previous scenarios?	0	1	- Ingredients in a meal must be gluten-free and cross-contact must be avoided. Some examples include gluten-free sauces/marinades, changing gloves, separate utensils, separate prep boards, separate prep/serving area, separate utensils for pasta, separate toppings for pizza, waiter staff/host identifies gluten-free dish and you confirm that the meal is gluten-free.
GFDA5	Did you still eat your food if it was knowingly contaminated in all previous scenarios?	2	0	- Dedicated gluten-free fryer: a separate fryer used for gluten-free items to avoid cross-contact with gluten-containing items. - Separate toaster, colander. - Bakery/pizza: A dedicated preparation space would include separate gluten-free ingredients, pans and utensils (mixing, spreading, cutting), a separate mixing area, special cleaning between baking runs and individually packaged gluten-free items, preferably in a separate area. - Cafeteria/salad bar: separate utensils to grab food. *Answers such as 'mostly', 'maybe' = NO Answers including even one scenario = NO
GFDA6	Did you use condiments and/or spreads that may have been contaminated?	1	0	Condiments/Spreads: Peanut butter, butter, jelly/jam and other condiments are easily contaminated if they are exposed to a utensil that has touched a gluten-containing food (e.g. spreading peanut butter on wheat bread)—at home, friend/family's house, dining out. Did someone educate them that using the same knife in jar is a problem?

Note: The final score ranges from 0 to 14, where a lower score indicates greater adherence and a higher score lower adherence. Adherence rating: Excellent, 0–1; Good, 2; Fair, 3; Poor, 4–5; Not on GFD > 6. Abbreviation: GDF, gluten-free diet.

In a study by Hoteit et al., the authors underlined the essential role of experienced RDs to regularly counsel their patients on nutritional and metabolic factors of healthy diets and physical activity.²² Furthermore, Abdi et al. recommended a multidisciplinary team involving physicians and dietitians for the long-term assessment, monitoring and nutritional management of these patients.¹⁶

In line with the recommendations above, the 2023 AND Evidence-Based Nutrition Practice Guidelines and clinical experience in the field, long-term nutrition follow-up of the patient with CeD should be carried out by an RD with expertise in the GFD, who individualises the care plan based on the patient's personal response to the GFD, nutrient status, lab values, changes in adherence level and clinical signs and symptoms related to CeD.¹²

CONCLUSION

A comprehensive dietary assessment should be conducted as part of ongoing monitoring of patients with CeD (including anthropometrics, intake of vitamins, minerals, nutrients/micronutrients, supplements and oats, pre-existing conditions, food intolerances, comorbidities, food preferences [e.g., veganism], meal preparation and potential risks for cross-contact with gluten, QoL and psychosocial impacts of CeD and a GFD). It is important to note that a comprehensive nutritional assessment is only the initial step in the ongoing management of patients with CeD. Comprehensive individualised education on the GFD, including knowledge on individual nutrient needs, as well as strategies for navigating dining out, travel and social life, are imperative. In addition, the GFAS described here may provide a useful tool for the assessment of GFD adherence as part of patient monitoring visits and in CeD clinical trials. Given the limitations of existing GFD adherence tools, particularly in their ability to predict VA, implementation of this new tool will potentially enable simplified, accurate testing of adherence to a GFD in patients with CeD.

AUTHOR CONTRIBUTIONS

Anne R. Lee conceived of the presented idea and developed the theory and organised the literature review. Melinda Dennis, Jessica Lebovits, Lori Welstead, Ritu Verma, Amelie Therrien and Benjamin Lebowohl reviewed the literature and were responsible for drafting the paper. All authors discussed the review of the literature and contributed to the final manuscript. All authors were involved in the writing, critical review and approval of the manuscript.

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CONFLICT OF INTEREST STATEMENT

Melinda Dennis is a consultant for Takeda. The remaining authors declare no conflict of interest.

ORCID

Anne R. Lee  <http://orcid.org/0000-0002-3867-0910>

Jessica Lebovits  <http://orcid.org/0000-0002-2526-6011>

Amelie Therrien  <http://orcid.org/0000-0002-6911-8598>

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AUTHOR BIOGRAPHIES

Anne R. Lee is an Assistant Professor of Nutritional Medicine in the Department of Medicine at Columbia University Celiac Disease Center. The research areas that she explores include coeliac disease, diet quality and eating behaviours.

Melinda Dennis is co-founder/Nutrition Coordinator at the Celiac Center, Beth Israel Deaconess Medical Center, Boston; she is an Executive Committee member of the Celiac Research Programme, Harvard Medical School, and an international research task-force member.

Jessica Lebovits is a registered dietitian at Columbia University's Celiac Disease Center, specialising in coeliac disease and gluten-related disorders. Her research focuses on quality of life, especially related to dating and micronutrient considerations.

Lori Welstead is an adult GI dietitian at the University of Chicago Medicine and nutrition advisor of their Celiac Disease Center. A diagnosis of coeliac disease in 2015 certainly impacted her life and career.

Ritu Verma is a Professor of Pediatrics and the University of Chicago Medical Center Section Chief for Pediatric Gastroenterology, Hepatology and Nutrition. The research areas that she focuses on are coeliac disease, Crohn's disease and IBS.

Amelie Therrien is an Instructor of Medicine at Harvard Medical School and Beth Israel Deaconess Medical Center. Her areas of research include coeliac disease, IBD and small bowel diseases.

Benjamin Lebwohl is the Director of Clinical Research at the Celiac Disease Center at Columbia University. He received his MD and completed his training from Columbia College of Physicians and Surgeons.

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