

Deep-Dive Directions for Dietitians (DDDDs): a roadmap for the nutritional management of poorly responsive coeliac disease patients

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ABSTRACT

A substantial number of coeliac disease patients fail to respond to treatment with a gluten-free diet. Non-responsiveness might be multifactorial and the spectrum ranges from intentional or inadvertent gluten contamination as the main aetiology, to sensitivity to other nutrients (in addition to additives and preservatives). If the diagnosis of coeliac disease is correctly made and cross contamination and other factors have been excluded, then the aetiology behind the symptoms of a small group of coeliac patients might be refractory coeliac disease. The journey to ensure gluten contamination is not behind the persistent symptoms, is very challenging and requires in-depth training and skills. We therefore present potential guidance for the healthcare professional, in particular dietitians, on how to navigate these challenges on this journey.

Keywords: Celiac disease, Non-responsive, Gluten contamination, Food sensitivity.

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Introduction

Since lifelong gluten free diet is currently the main treatment for coeliac disease (CD), thorough in-depth assessment, education, and counselling by a coeliac specialist dietitian is fundamental in the dietary management of the poorly responsive coeliac patient as supported by National Institute of Health (NIH) (1, 2).

Most patients diagnosed with coeliac disease, will usually find that their symptoms improve within weeks (and may completely resolve within months) once they have started on a gluten-free diet (GFD). Unfortunately, up to 30% of patients may still show signs, symptoms, or persistent small intestinal damage after being on a gluten-free diet for one year (3).

These patients require thorough assessment by gastroenterologists, to ensure correct diagnosis of coeliac disease and rule out other common GI aetiologies (for instance microscopic colitis, small

intestinal bacterial overgrowth, IBS, IBD, pancreatic insufficiency, and other food/sugar intolerances) which might be contributing to persistent intestinal damages (2-4).

If a diagnosis of coeliac disease is confirmed, an experienced coeliac disease dietitian plays an important role in determining whether these patients with recurrent or persistent symptoms are intentionally or inadvertently still ingesting gluten. Persistent gluten ingestion accounts for 40%–50% of patients with poorly or nonresponsive coeliac disease (4). Refractory CD is a rare disorder and only affects between 7-30 % of non-responsive CD patients (2). Hollon et al found that the presence of gluten traces and contaminated gluten free products, led to patients being incorrectly diagnosed with refractory CD, which potentially could result in unnecessary use of immunosuppressants (5). Patients with true refractory CD typically present as being very ill, with severe weight loss and other malabsorption symptoms (6).

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Since gluten exposure is the most common cause of non-responsive CD, the first step in the management of these patients, would be an in-depth dietary assessment.

In this study we show how the dietitian would need to go beyond the usual nutritional assessment of medical, family-, biochemistry, and diet history as in-depth review needs to be made around the following topics.

Patients living/ housing situation and food environment

Following initial consultation and follow-up at diagnosis that covers the content of Table 1, more in-depth assessment is required for non-responsive CD patients (Table 2).

Questions need to be asked about who takes part in

the shopping and preparation of meals; their understanding and knowledge of CD, label reading and brands. Shopping from food bins can be another area of cross contamination (7).

Sverker A et al recommended that healthcare professionals develop family-oriented information in relation to CD to inform close relatives, irrespective of gender, of the possible consequences of untreated coeliac disease (8). They also pointed out that it is important to consider the different social context that women and men report in relation to food preparations, which might also be applicable to various cultures. The kitchen is an area where a lot of inadvertent cross-contamination can take place and therefore it is important to check whether patients are storing gluten

Table 1. Checklist at initial CD diagnosis and follow-up

Assessment

- Explain the purpose of consultation.
- Take a diet history of current intake.
- Check symptoms before and after diagnosis. Some patients may not attribute any health problem specifically to their coeliac disease – you may need to help them retrospectively identify their symptoms.
- Consider any dietary restrictions for example if following a vegetarian or vegan diet, are lactose intolerant, or if they have diabetes.
- Assess iron and calcium intake. Consider other lifestyle issues which may impact on bone health, for example, regular weight bearing activity.
- Assess the patient's understanding of gluten free diet and consider involving other family members in dietary education. They may have accessed information from a variety of sources before attending the appointment.

Education

- Explain what coeliac disease is and how it affects the body.
- Explain the risks of not following a lifelong strict gluten free diet.
- Gluten free diet – explain what gluten is, where you find it and tools available to select safe foods such as gluten free labelling, allergen labelling, national and local support group resources.
- Highlight which foods are naturally gluten free.
- Explain suitable gluten free alternatives and changes needed to current diet.
- Encourage high fibre gluten free products.
- Explain how to read labels, including how to check monthly due to product changes.
- Discuss cross contamination with gluten and sensible steps on how to avoid it.
- Eating out: discuss with the patient strategies to overcome challenges when eating out.
- Provide patient with gluten free recipes as appropriate and information on available gluten free products.
- Discuss gluten free products which may be available on prescription. Making use of special offers to cut on costs.
- Discuss iron and calcium requirements. Assess whether to advise on an iron- or calcium-rich diet or if supplements are required.
- Ensure diet is balanced with general healthy eating recommendations.
- Give the patient advice on cross-contamination in medications.
- Encourage the patient to join coeliac support groups and provide contact details.
- Record weight, height, and BMI.

Review and ongoing support

- Arrange a follow up appointment for 4-6 weeks to assess compliance and understanding.
- Gain consent regarding contacting patient's healthcare provider for requesting Vit D, calcium, folate, Vit B12, iron and coeliac serology if not already done.
- Contact patient's healthcare provider regarding prescribing gluten free products in countries where appropriate.
- Provide 3 to 6 monthly appointments for first year.
- Arrange annual follow up visits once symptoms have resolved and serology has normalised.

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free (GF) products separately, using separate condiments, utensils, toasters and having a gluten free preparation area, clean counter tops; especially where kitchens are shared (7). In some countries, like New Zealand, oats might be heavily contaminated with gluten and in these countries, it would be good to determine whether patients and their relatives are aware of it. Wieser found that contaminated naturally gluten-free products seemed to be a higher health risk than certified products for patients with CD (9).

Affordability and availability of gluten free products

Sensitive questioning should be performed around

the affordability of gluten free products. Many international studies have shown that the cost of GF products may vary between being 22%-400% higher in cost than their gluten containing counterparts (2). MacCulloch K et al. found that availability, cost, and product labelling were major barriers to the adherence of GF diet (10). In our clinics, we often see patients who complain of affordability. Dietitians need to be creative in how to overcome these barriers. Recipes made with only 4 ingredients or easy meals which do not require cooking, can all be helpful to patients.

Support systems

Since the diagnosis might affect a family's food

Table 2. Cross-contamination checklist

A patient's living/ housing situation and food environment

- Who prepares and participates in meal preparation and food shopping?
- Is the person preparing the meals trained on reading labels/ understanding English/ aware of hidden sources of gluten/ in denial about the diagnosis?
- Is the kitchen shared?
- Are separate containers, condiments, utensils, toasters etc used?
- Is there a dedicated storage and preparation area in the kitchen for gluten free products and meals?
- What is the availability and affordability of safe GF foods? WINS?
- Have brands and ingredients of favourite products changed?
- Are they buying foods from open bins?
- Are they aware that oats are heavily contaminated in those applicable countries and they should be avoiding cereals with malt?
- Do they check labels for 'traces of gluten'?
- Was there a change in their living situation or household members?

Support systems

- Are close family/ friends supportive or in denial of the condition?
- What are their levels of knowledge and beliefs? "A little won't hurt much" or "surely you can have a cheat day"?
- Do they and the patient understand the consequences of 'cheating'?
- What are family and friends' reactions to the diagnosis?
- Has the diagnosis affected their food culture and norms?

Patient's emotional response

- Is the patient still struggling to come to terms with this lifelong diagnosis? Do they experience feelings of mourning, anger, loss of control, anxiety, and relief?
- Do they feel like a burden, experience feelings of guilt/ shame or isolation?
- Do they feel excluded from others/ different?
- Do they feel frustrated by the restrictions?
- Do they avoid dining out, social functions, eating with others or traveling?

Eating out and travelling

- Do they ask preparation questions? How and where?
- Is there a risk of airborne wheat flour for instance, in bakeries?
- Do they enquire as to whether staff are trained?
- Do they know/ understand the ingredients of ethnic cuisines?
- Are pizza toppings and salad bar items shared? Gloves changed? Different utensils used?

Medication and other hidden traces

- What medications and dietary supplements are patients on and what fillers are used in them?
 - Has there been a change in brand or ingredients?
 - Are children playing with wheat based play-dough?
 - Are wheat wafers used in communion?
 - What lipstick and dental fixtures are used?
 - Are baked goods purchased from shared facilities?
-

culture and norms, it is important to discuss what support systems the patient/family have in place and whether relatives/friends have accepted the diagnosis. Consultation with the whole family to assess their levels of knowledge and beliefs, whether they think “a little won’t hurt much”/ “it isn’t necessary to be so strict” or “days off are ok” and whether they understand the consequences of not adhering to a strict gluten free diet. Informing the family might be just as important as the patient themselves for creating a supportive and safe environment.

The patient’s emotional response

Patients may need time to process and come to terms with the diagnosis of CD and the lifelong commitment of a GFD. With compassionate questioning, the dietitian may need to assess where in the grieving process patients are. The Spanish project found that while it wasn’t uncommon for patients to experience feelings of relief at diagnosis, they also experienced feelings of fear; fear of cancer, fear of their symptoms returning, or fear of passing it on to their children (11). Feelings of being overwhelmed, sad, angry, anxious, and frustrated by the limitations of the diet were also expressed. They found that 41.9% of patients didn’t like gluten free products but would eat them (11).

Guilt, being a burden to others and feelings of isolation or being different to their peers are mentioned in many quality-of-life studies (2, 7) and we also see this in our clinics, especially in children. These may all be barriers to the adherence of a gluten free diet. It is important to encourage positive coping strategies and make patients feel connected to their family/friends or support groups at diagnosis (2, 11).

In MacCulloch’s study, it was found that overall adherence was lower at social events than home or school for children and adolescents, with adolescents reporting lower adherence compared with parents (10). Teenagers especially, require support to maintain adherence as this is an age group of many physical and emotional changes which can lead to risk-taking behaviours and seeking independence from parents. Embarrassment amongst their non-coeliac friends and the lack of spontaneity can be common barriers for young adults with CD. Peer mentoring and use of technology media might be ways in which strategies can be put into place to support this age group,

alongside the help of healthcare professionals and support groups (7).

In the Spanish project, 39.6% of subjects felt GF diet limited their free time and travelling ‘quite a bit’ with 29.6% subjects feeling it restricted them ‘a lot’ (11). Are patients avoiding travelling, social functions, eating out or dining with others because of their diagnosis?

Eating out and travelling

It is well known that eating at restaurants, workplaces, and schools, remain high risk environments for inadvertent gluten exposure (12). There is evidence in the literature of restaurants not always following strict gluten free guidelines (13). During an 18-month period, 804 users who were issued with portable gluten detection devices (Nima, Nima Labs, Inc., San Francisco) tested several restaurants across the US. They performed 5624 tests and gluten above 20 mg/kg was detected in 32% of products labelled as gluten-free. Gluten was detected in 53.2% of pizza samples and 50.8% of pasta samples (14). Common sources of cross contamination in restaurants are deep fryers, grills, handling of food by untrained or unaware staff, salad bars, utensils, and shared pizza toppings (7). Some airlines provide gluten free options, but the general feeling is that travelling long distances and unfamiliar destinations, might be challenging for coeliac travelers due to the suboptimal availability of gluten free foods.

Medication and other hidden traces

Gluten is often introduced (using wheat starch as a filling agent) in numerous medications and cosmetic products, in particular lipstick (9). A closer look needs to be taken at patients’ medications, dietary supplements and whether brands or ingredients had been changed and if there may be any hidden traces of gluten. Playdough in day-care facilities, have been found to be another area where cross contamination can happen in children.

If the dietitian is unable to identify any cross-contamination during this in-depth review and symptoms persist, it may be necessary to use the Gluten Contamination Elimination Diet (GCED) (3) for a short amount of time. Almost all processed foods, including those foods labelled as gluten free, are removed from the patient’s diet to eliminate any possible source of

gluten in the diet. The reasons for trialling this diet would be the following:

Labelled gluten free products

Cross contamination can happen in fields due to crop rotation, grains grown in adjacent fields or grains harvested on shared equipment (7). It is for this reason that oats are highly contaminated in certain countries.

Cross contamination can also occur in factories or retail where products are stored or processed in the same factory and products are made on shared equipment (7).

In Falcomer et al's systematic review of 24 international studies, a mean contamination prevalence of gluten above 20 mg/kg was found in 42% (17-66%) of certified gluten-free products from food services. A mean contamination of 13% (11-16%) was detected in industrial food products labelled as 'gluten-free' (12). In addition, Wieser et al have investigated gluten free products of several European countries (including Ireland, Italy, Germany, Spain, Norway, Turkey), Canada, US, Brazil, and India, and found gluten traces above 20 ppm between 0% - 36% of gluten free labelled products, with Italy having the least amount of cross contamination (9). Furthermore, similar finding was found in Christchurch study where 11-450 mg/kg gluten was detected in 9.8% of gluten-free samples (15).

Super sensitive patients

Some CD patients are very sensitive to minute amounts of gluten (5) and although most EU guidelines support gluten free as 20ppm and most patients tolerate these, the non-responsive patient might not tolerate this amount of gluten (16). For these patients, the aim

should be a gluten free diet below 20 ppm (17).

The gluten contamination elimination diet (GCED)

The gluten contamination elimination diet is very strict and should only be done under the close supervision of a trained registered dietitian to prevent weight loss and nutrient deficiencies (3). This diet should also only be followed in the short term and no more than 3-4 months in total. This diet is not suitable for newly diagnosed coeliac disease patients and is only to be implemented if a patient has followed a gluten free diet for a minimum of 12 months and correct diagnosis for coeliac disease has been confirmed. This diet can also be used to differentiate whether a patient has true refractory CD or just inadvertent gluten contamination (3) (Figure 1).

To eliminate any possible source of gluten in the diet, almost all processed foods, including those foods labelled as gluten free are removed from the patient's diet. Exceptions to foods allowed and those avoided can be made on an individual basis to aide compliance. Only whole, fresh, unprocessed gluten free foods in their natural state, are allowed. A gluten free multivitamin should be taken daily, and dietitians could recommend gluten free supplements, for instance Fortisip or Ensure Plus, for unwanted weight loss (3).

The GCED has two phases for elimination. The first phase (the first two weeks) is the strictest and excludes dairy, as this can often contribute to unwanted symptoms. The aim of the GCED is to encourage remission and heal inflammation. This is followed by a further 10 weeks of phase two of the elimination diet. One new food is re-introduced at a time, with a new

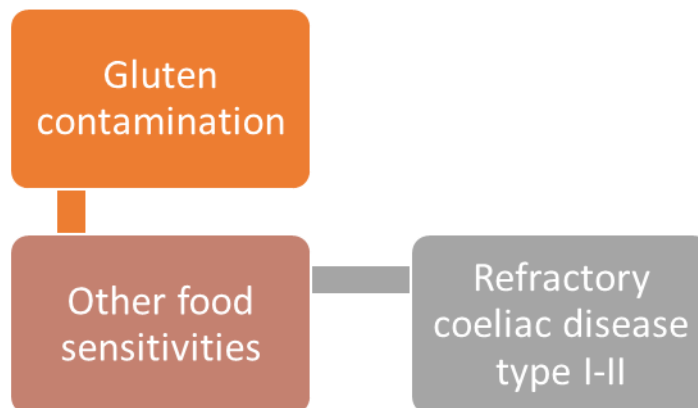


Figure 1. The major etiology for non-responsiveness is gluten contamination followed by other food sensitivity/intolerances and less frequent refractory coeliac disease.

food added every 2-3 days with close monitoring of symptoms. It is recommended that coeliac serology and gastroscopy is performed after following this diet for 3 months and symptoms have subsided, to determine whether the diet was successful (3).

Following this, processed gluten free foods are re-introduced under the supervision of a trained dietitian, with careful monitoring of foods and symptoms. The dietitian would recommend the re-introduction of least likely contaminated foods first; for instance, canned/frozen fruits, vegetables and meats, condiments, salad dressings and jarred sauces. If these foods are tolerated, the next step would be the reintroduction of gluten free grains. The patient may start with one serving of a gluten free product (for instance one slice of gluten free bread or ½ cup of gluten free pasta or cereal) per day for 3 days in a row. If this is tolerated, a second serving may be added. After a second serving of processed gluten-free grain has been tolerated for 3-4 days, it would be safe to return to a typical gluten-free diet. If symptoms occur at any time during the reintroduction, the triggering food needs to be removed and further reintroduction delayed until symptoms improve (3). This is also an opportunity for the dietitian to keep an eye out for possible food chemical intolerances.

Patients whose symptoms, serology and/or histology have improved on the GCED, should be reviewed for 3-6 months following their return to GFD to ensure they remain in remission, and yearly thereafter (3).

For those patients whose symptoms did not improve on GCED, dietitians need to consider other potential causes, for instance:

Fibre

It is well documented in the literature that GFD is known to be low in fibre (18), and more specifically, prebiotic fibre (19) which may contribute to changes in microbiota. This low fibre intake is usually due to a decreased intake of grains and the fact that many manufactured GF products rely on rice/ potato/ tapioca starch which are very refined (18, 20). In our practice, we see that patients often rely on white rice, potatoes and sweet potato/kumara as their main carbohydrate sources as they're familiar, easy and low-cost natural sources of gluten free foods. Low fibre intake can lead to constipation, bloating or wind. Some patients cut carbohydrates out of their diets completely.

High fibre intake can lead to loose stools, flatulence, or discomfort. Some patients may have an increased intake of salads, vegetables, and raw fruit as these are easy, safe meal options, especially when eating out.

It is important for the dietitian to assess whether the patient's fibre intake is consistent and if this is not the case, to adjust the patient's fibre intake through food or supplements. It may also be helpful to recommend a prebiotic fibre source which may help control symptoms and promote healthy gut microbiota.

Sugars

Lactose, fructose, and sugar alcohols may cause abdominal symptoms. These symptoms are dose dependent and can be altered by adding sucrose.

Lactose is a disaccharide of glucose and galactose and found in milk and milk products, for instance ice cream, cream, yoghurt, and certain soft cheeses. In lactose malabsorption, the small intestine is not able to digest lactose and symptoms may include diarrhoea, bloating and flatulence (21) (NIDDK and dietitians FODMAP article).

Fructose is a monosaccharide which is naturally found in fruits, honey, and some vegetables. High fructose corn syrup is also added to many products. In fructose malabsorption, the small intestine is not able to digest fructose and can also cause symptoms of diarrhoea, bloating, and flatulence (22).

Sugar alcohols are polyols which are formed through the hydrogenation of carbohydrates. Mannitol, sorbitol, erythritol, lactitol, maltitol, xylitol, isomalt and hydrogenated starch hydrolysates are all examples of polyols. Sorbitol and Erythritol are naturally found in certain fruits, vegetables and mushrooms and polyols are also used in non-digestible low-calorie sweeteners.

These polyols are not absorbed in the small intestine and pass into the large intestine where bacteria ferment these sugar alcohols. This can cause symptoms of diarrhoea, dysmotility, abdominal discomfort, bloating and flatulence (23).

FODMAP's

When reviewing FODMAP's (fermentable oligosaccharides, disaccharides, monosaccharides and polyols), it is important for the dietitian to keep in mind that many FODMAP food restrictions are dose dependent. It is important to look at the type, amount, and frequency of FODMAPs consumed and the

combination of them with well tolerated foods. As the low FODMAP diet can be very restrictive, it is worth considering the use of a simplified FODMAP plan for patients to prevent over restriction. This simplified plan (Table 3) is useful in patients whose diet histories reveal large consumption of high FODMAP foods but tolerate or have mild symptoms with amber servings of most foods. It is also useful in patients who tolerate lactose. For these patients, foods tolerated would be kept in their diet, whilst only excluding high FODMAP's and subgroups which are frequently consumed.

Management of the true refractory CD patient

Once we have exhausted all the avenues detailed above, with the support and further testing of the coeliac specialist multidisciplinary team, a diagnosis might be made for refractory coeliac disease (Table 4).

Patients with refractory coeliac disease, have persistent symptoms of malabsorption and significant small intestine mucosal lesions, despite strict adherence to a gluten-free diet for at least 12 months. Symptoms and signs may include diarrhoea, weight loss, anaemia, persistent nutritional deficiencies, malabsorption, gastrointestinal bleeding, fever, night sweats and bowel obstruction (4).

There are two subtypes of refractory CD; Type 1 and Type 2. They each have differing diagnostic criteria, prognosis, and response to therapy. Type 2 has an overall poorer prognosis than type 1 and poses a risk for development of ulcerative jejunoileitis or enteropathy-associated T-cell lymphoma (EATL) (4).

The dietitian plays an important role in completing detailed nutritional assessments on patients with either type, looking closely at any macro- and micronutrient deficiencies. These deficiencies might be corrected by using oral supplements or enteral feeding support. Parenteral nutrition may be considered in those cases where there develops severe malnutrition due to malabsorption intestinal failure (4).

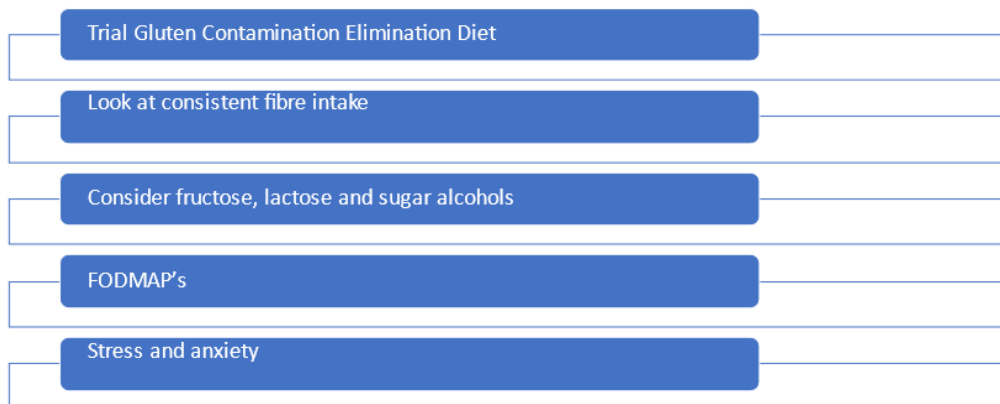
Steroids are used as a first-line therapy in both type 1 or type 2 refractory CD and these patients require regular follow up by their multidisciplinary team, including gastroenterologists and dietitians. Immunosuppressants therapy may also be used (4). Elemental diet is another potential therapy for RCD and has seen a 67% clinical response and 89% histological improvement in the literature (4). This is sometimes used as a stand-alone therapy or in combination with other drug therapies.

Where the multidisciplinary team has decided upon nutrition therapy, the dietitian plays a very important

Table 3. Simplified FODMAP (fermentable oligosaccharides, disaccharides, monosaccharides and polyols)

Group	Foods
Fructans	Garlic, onion, artichoke, wheat/rye/barley-based cereals, breads, pasta, crackers and cookies
Excessive Fructose	Apple, pear, mango, watermelon, dried fruit, honey, high fructose corn syrup, fruit juice
Lactose	Cow's milk, custard, ice cream, condensed and evaporated milk, yoghurt (large servings)
Mannitol	Mushrooms, cauliflower
Sorbitol	Stoned fruits (plum, peach, nectarine), watermelon, sugar free products
GOS	Kidney beans, split pea, falafel, baked beans, cashews, pistachios

Table 4. Checklist where no cross-contamination identified



role in educating, counselling, and providing compassionate, regular support for these patients and their families. This helps to ensure strict adherence to nutrition therapy, for the best outcome in their journeys. It is well documented in the literature that dietary adherence is increased through ongoing nutrition counselling (2).

Stress and anxiety

As dietitians, our counselling needs to include strategies for stress and anxiety management; for instance, breathing and 5 senses grounding techniques, yoga, mindfulness, exercise.

Conclusion

For successful management of coeliac disease, education, support, and follow-up are imperative (7).

We recognise that the nutrition assessment for non-responsive CD patients need to be multifaceted, covering issues such as their food environment, cost, availability of gluten free foods, social and emotional concerns, with sensitivity and compassion, to rule out any intentional or inadvertent gluten contamination. It is crucial that this very thorough assessment is done with the utmost compassion, sensitivity, and respect by the healthcare professional.

We also recognise the need for multiple dietitian visits where the dietitian can continue to assess and educate, depending on how patients' needs and responses change over time, counsel and navigate their current situations. Dietitians need to be thorough, dig deep, and evaluate all aspects of patients' lives with great empathy. We need to be creative in helping patients overcome barriers. This continuity of care and much needed support increases dietary adherence. In a quality study done by Madden et al, it was found that a patient's degree of satisfaction was impacted by the dietitians CD expertise, the consistency of the dietitian seen and the frequency and length of appointments (24). Unfortunately, currently there is a lack of resources in many countries for frequent follow up for these patients and a lack of trained coeliac dietitians. More needs to be done in terms of training, upskilling of dietitians, and raising awareness in this area.

Conflict of interests

All authors declare that they have no conflict of interest.

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