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Identifying and improving adherence to the gluten-free diet in people with coeliac disease

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Coeliac disease (CD) is an autoimmune gastrointestinal disorder whereby the ingestion of gluten, a storage protein found in wheat, barley and rye, causes damage to intestinal mucosa with resultant malabsorption, increased risk of anaemia and osteoporosis. Worldwide estimates suggest 1 % of the population have CD. With no cure, the only treatment is a gluten-free diet (GFD). Adhering to a GFD can be very challenging; it requires knowledge, motivation and modified behaviours. Assessing adherence to a GFD is methodologically challenging. This review aims to provide an overview of the literature reporting adherence to a GFD in people with CD and the methodological challenges encountered. From six studies it has been reported that rates of adherence to a GFD range between 45 and 90 % in patients of different ethnicities with CD. GF dietary adherence can be influenced by age at diagnosis, coexisting depression, symptoms on ingestion of gluten, nutrition counselling, knowledge of GF foods, understanding of food labels, cost and availability of GF foods, receiving GF foods on prescription and membership of a coeliac society. To date only five intervention studies in adults with CD have been undertaken to improve GF dietary adherence. These have included dietary and psychological counselling, and the use of online training programmes, apps, text messages and telephonic clinics. Future interventions should include people of all ethnicities, consider patient convenience and the cost-effectiveness for the healthcare environment.

Coeliac disease: Adherence: Gluten-free diet

Coeliac disease (CD) develops in response to unknown environmental factors in genetically susceptible individuals[1]. It is a T cell-mediated autoimmune chronic gastrointestinal disorder characterised by permanent intolerance to gluten, a protein composite found in wheat, barley and rye[2]. It is histologically characterised by villous atrophy of the small bowel mucosa[3], leading to malabsorption of micronutrients[4,5] and when symptomatic leads to diarrhoea, weight loss and abdominal pain[6]. Duodenal biopsy and serology offers objective classification of the severity of CD based on research-established criteria[7,8].

CD is a multi-systemic disorder[9] and can include other organs such as the skin, liver, thyroid, pancreas, heart and brain[10–14] and has potential for long-term complications, which might include osteoporosis[15], anaemia[16] and more serious complications such as intestinal lymphoma[17]. In the majority of cases, the condition responds to a gluten-free (GF) diet (GFD)[18] only to relapse after reintroduction of gluten[19,20]. An association between CD and increased mortality has been documented, whereby disease related mortality reduced after diagnosis and treatment with a GFD[21,22].

Worldwide prevalence of CD is estimated at 1·4 % and presently there is no known cure[23]. Once considered a disorder of Europeans and people of European descent, it is now known to be a global condition with variations in presentation in people of different ethnicities, with some studies reporting a higher prevalence, for example approximately 3 % of patients from the Punjab region

Abbreviations: anti-tTG, anti-transglutaminase antibodies; CD, coeliac disease; GF, gluten-free; GFD, gluten-free diet.
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residing in the UK or the USA were reported as having CD[24–26]. Rates in other countries that have reported the incidence of CD appear slightly lower; in Libya[27] and Iran. Additionally, there has been a reported prevalence of 0·8 % in Tunisia[28] and Turkey[29]. Furthermore, prevalence ranging between 0·5 and 0·6 % has been reported in Egypt[30]. Interestingly, CD has been described as being less evident in South East Asian countries[31].

Dietary adherence to a GFD is paramount as this is the only treatment available for CD. Duodenal histological improvement, after removal of gluten from the diet[32], reverses the malabsorption state related to CD. Annibale *et al.*[33] noted that recovery was dependant on various factors such as time between biopsies and starting GFD, severity of histopathologic changes at diagnosis, and age of the patients. Iron deficiency anaemia has been shown to improve following a GFD, suggesting increased iron absorption[33,34]. Histological recovery can take a long time and because CD can result in patchy villous atrophy of the duodenum of variable severity, hence, variable degrees of malabsorption is seen[35]. Adhering to a GFD can be very challenging[36]; it requires knowledge, skills and modified behaviours to undertake the substantial changes to dietary habits.

In CD there are two key aspects related to dietary adherence: patient focused aspects such as the challenges encountered when following the GFD[37,38] and healthcare professional perspectives, whereby it is difficult to determine if patients are adhering to the diet. The WHO defines adherence as 'the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider'[39]. Over the years research has shown that following a GFD not only reverses the duodenal pathology, but also improves quality of life, and reduces CD-related morbidity[40,41].

Methodological challenges of assessing dietary adherence

Histology from a duodenal biopsy is the gold standard when assessing GF dietary adherence, as villous atrophy due to ingested gluten is visible. However, due to the invasive, costly and time-consuming nature of the procedure a variety of other methods are used in clinical and research settings: serology, faecal or urine tests, dietitian's assessment, interviews, validated and non-validated questionnaires and patient reported adherence. On its own, symptomatic improvement may not present an accurate picture of dietary adherence as there is a subset of the coeliac population with significant villus atrophy and no symptoms[42,43]. Examination of haematological markers such as blood count, folate, vitamin B_{12}, iron studies and liver biochemistry[44] with improvement in parameters such as anaemia may indirectly result in improvement in absorption of micronutrients[45].

Among the serology, antibodies in response to gluten consumption are measured; for example levels of anti-transglutaminase antibodies (anti-tTG) are used extensively in clinical practice for assessing GFD adherence. There is also evidence to suggest that persistently elevated anti-tTG denotes non-adherence with GFD[46] and falling anti-tTG indicates adherence[47]. There are studies which have examined the reliability of anti-tTG for this purpose, and reported a discrepancy between serological improvement and mucosal recovery[48–50]. Other serological markers, such as endomysial antibodies and antibodies against deamidated gliadin peptides, also have reliability concerns in relation to measuring adherence to a GFD[51–53]. Although these may not be reliable markers of histological recovery their base-line levels are important as they remain elevated with persistent dietary transgressions[46]. A promising advancement is the development of tests to measure gluten immunogenic peptides[54]. These peptides are involved in the immunogenic reaction of CD and anti-α-gliadin G12 antibody may be detected in body fluids, such as faeces and urine, of patients[55] and this has been used to monitor adherence to GFD in research settings[56].

An assessment of GF dietary adherence by a dietitian is considered highly effective and is inclusive of assessing knowledge, behaviour while dining out, and intent to adhere[57,58], indeed it is considered a gold standard by some authors[59,60]. Leffler *et al.*[59] suggest that although serologic tests have very high sensitivities and specificities for the diagnosis of CD, they cannot replace dietitian evaluation in the assessment of GFD adherence. However, without a standard process it is difficult to replicate in clinical trials and as such an association between dietetic assessment and duodenal biopsy is yet to be published.

Differing questionnaire-based methodologies have been used to measure dietary adherence in patients with CD in several studies[59,61–64]. Leffler *et al.*[59] validated a seven item, CD-specific questionnaire to measure adherence with GF, the Coeliac Disease Adherence Test; with a score >13 deemed as not adhering to the GFD[65]. This questionnaire has been subsequently used in several studies, allowing for comparison between population groups[63–65]. A Birmingham-based study evaluated adherence with the GFD with a 20-item questionnaire that holistically approached adherence employing clinical, social and economic terms[61]. The drawbacks of questionnaire-based studies include their inability to explore particular responses in depth, thereby giving it a static look in comparison to an interview. Some studies have used questionnaires to separate intentional and inadvertent gluten ingestion[41,66].

GFD adherence rates are variable depending on the methodology used and the population studied. Studies have defined adherence to a GFD using a range of terminology inclusive of: strict, partially or fairly strict and non-adherent. Hall *et al.*[41] reported adherence ranged from 42 to 91 % from thirty-eight studies published up to 2007, since then at least a further twelve studies have been published with adherence rate ranging from 53 to 76 %[25,41,59,63,65–72]. The reported variability in the adherence rate may be explained by the variability in the methodologies used by the studies. Three of them used dietitian assessment, the other three used validated questionaries and the remaining four used a non-validated self-reported measure of adherence.

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Table 1. Studies reporting gluten-free (GF) dietary adherence in Caucasian and South Asian adults

Author	Sample and recruitment source	Methods of adherence	% adherence	Factors associated with adherence
Muhammad *et al.*[63], UK	*n* 375 *n* 337 Caucasians *n* 38 South Asians Hospital records	Coeliac disease adherence test Self-reported	All 53 % Caucasians 53 % South Asians 53 % $P > 0{\cdot}05$ All 62 %	All participants: membership of coeliac UK, understanding food labels and receiving prescribed GF foods
Rajpoot *et al.*[70], India	*n* 146 All Indian Hospital records	Self-reported	53 %	Dietary counselling
Muhammad[104], UK	*n* 185 Caucasians = 160 Asians = 25 Hospital records	Butterworth	63·8 % Caucasians 64 Asians 71	All: understanding of food labelling and coeliac UK members
Holmes *et al.*[25], UK	*n* 158 Clinic records *n* 82 Asians *n* 76 White	Dietitian	Caucasians 71 % South Asians 45 % $P < 0{\cdot}01$	Not assessed
Butterworth *et al.*[61], UK	*n* 87 Hospital clinic *n* 66 Caucasian *n* 21 South Asian	Biopsy Self-reported	Caucasian 63 % Asians 66 % $P > 0{\cdot}05$	Caucasians only: coeliac society membership, understanding food labels, obtaining sufficient GF, explanation of physician, regular dietetic follow-up

Many studies do not report ethnicity of the participants and in particular there is a very limited body of literature about the dietary adherence of different ethnic groups with CD. Table 1 highlights six studies that report GFD adherence in different ethnic groups. In order to evaluate adherence rates and barriers to adherence in this population, a study in India recruited treatment-naive participants and those already following a GFD (*n* 146) and using a questionnaire; it was reported that the former group had an adherence rate of 65 % and the latter group 53 %. The main cause of non-adherence was reported to be poor availability of GF foods[70]. However, the study may well have been affected by selection bias as patients were drawn from specialised CD clinics, which are attended by motivated patients and may not truly reflect the adherence of patients who do not regularly attend clinics. Garg & Gupta[73] reported Indian children had slightly higher values for adherence (66 %) and this was related to age at presentation, nuclear families, mother's education, and parents having better knowledge of CD. Table 1 summarises studies concerning adherence in patients.

Factors impacting upon dietary adherence

Research has indicated that causes of adherence and non-adherence to a GFD are numerous and multifactorial; these include socio-demographics, age of diagnosis, whether symptoms are present with gluten ingestion, practical difficulties associated with the GFD, and membership of advocacy groups[63,67,74].

Among the socio-demographic factors, age is significant and shows variability in the adherence rate as in childhood it tends to be higher. However, adolescents often have issues with adherence[75] as they may have concerns about isolation and stigmatisation for following a GFD[76]. In contrast, it has been reported that patients diagnosed later in life have relatively good adherence (77–90 %)[77,78]. Hall *et al.*[41] reported no difference between genders in relation to adherence with GFD from a systematic review of thirty-eight studies up to 2007, however, in 2018 a large study reported being male was associated with better adherence[79]. This study of more than 5000 Australians with CD demonstrated 'symptoms after gluten ingestion' was an independent predictor of GF dietary adherence.

Strict adherence to a GFD has been associated with patients reporting 'feelings of desperation' or a need to gain or lose weight[80], for these patients as well as patients who are struggling with adherence, dietetic counselling can be beneficial. Furthermore, dietary counselling and follow-up reviews for people with CD have been associated with better GF dietary adherence, resolution of disease specific symptoms, and improved quality of life[61,70,81–83]. The studies, exploring the impact of follow-up reviews, do have methodological weaknesses and as such there remains a paucity of good quality studies.

Mental health conditions such as depression are common among patients with CD[84] and this may have a negative effect on adherence as suggested by a systematic review[85]; however, the quality of the systematic review is limited by the low number of studies included. Psychological traits associated with adherence include greater self-regulation, habit, self-efficacy, priority, facilitation and support, lower psychological distress, lower levels of conflict and fewer self-control lapses[25,72]. One

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qualitative study highlighted that 54 % of people who reported their ethnicity as White (*n* 21) indicated motivation being a challenge compared with just 33 % of South Asian patients (*n* 7)[86].

An important, but potentially modifiable, cause of low adherence is lack of knowledge about gluten-containing foods; studies have reported a positive association between food knowledge and dietary adherence[64,65,67]. Coeliac support groups offer practical advice and support to patients with CD, membership of such groups has consistently been associated with good adherence[61,67,87]. In Canada, members had better knowledge of GF foods than non-members[71]. However, members are a self-selected group of patients who may exhibit greater motivation to adhere to the GFD, which may in itself represent a confounding variable.

The ability to read and interpret food labels is a key skill patients need to master to enable them to choose appropriate GF foods. Patients who conveyed an understanding of food labels were more likely to adhere to the GFD[63,83,88]. One of our own studies[63] reported 76 % of South Asian patients agreed with the statement 'I don't understand what foods I can eat' and 53 % agreed with 'I don't understand food labelling' (*n* 38), a cause for concern and an area for clinicians to be aware of. There exists a paucity of food labelling in some countries including India with the exception of the main cities, and knowledge about a particular food item is often only a best guess as to whether it is GF or otherwise[89,90]. In addition comprehension of food labels has been reported as being low in India[91]. Assessment of health literacy has not been studied in CD but could give valuable insight in to the ability of some patients to adhere to a GFD.

A GFD does also have associated financial costs[92,93] and the perceived affordability of GF foods is associated with dietary adherence[61,65,67,69]. In the UK, GF foods have been available through prescriptions since the 1960s to enable access to GF foods and reduce the financial burden to patients. Receiving GF foods on prescription has been shown to be associated with dietary adherence[41,61,63]; however, these studies have not collected data on the amount of GF food received on prescription nor the reasons why patients were not receiving GF foods on prescription, thus there is scope for more detailed studies to be undertaken to explore this area. This research is time critical as the availability of prescribed GF foods is not uniform across the UK, with a general decline in availability over recent years due to the financial pressures within the National Health System, this is despite national guidance that GF foods should be available on prescription[94].

The ability to access GF food for the home, at work and whilst travelling have been reported as barriers to adhering to the GFD[65,69,95]. Qualitative interviews have revealed both South Asian and Caucasian patients found eating out difficult (80 and 86 %, respectively), with the majority of each group indicating a lack of confidence in information from restaurant staff[86]. Surveys within the UK have indicated manufactured GF food staples (such as GF bread, starch or pasta) are rarely stocked in convenience stores, disproportionately increasing the burden of the GFD in socioeconomically disadvantaged areas, for people who do not drive, the isolated elderly and those with physical disabilities[92]. Interviews with South Asians with CD who were not adhering to the GFD revealed 85 % were unable to find GF foods in their local Asian food stores[86]. Cross contamination of foods with gluten was also highlighted as a concern by South Asians[86], since certain practices in grinding mills may encourage cross-contamination of GF products with gluten, and such starch could reach the UK and be sold in Asian shops[96]. Studies exploring factors specific to South Asians in other health conditions, that can be extrapolated to adherence to the GFD, and these include dietary counselling not inclusive of specific details of the typical South Asian diet and social responsibilities to continue with a traditional diet[97] for example cultural pressure when visiting family members' homes or attending celebratory events with 'feelings of having to live up to cultural expectations of food and eating practises to avoid being alienated'[98].

Causes of low adherence are diverse and affected by many factors, and may even be different for particular ethnic groups. The evidence for different causes of low adherence, as suggested by the studies reported here is limited by the methodologies utilised and because the studies have used unreliable or non-validated instruments including subjective reports by patients about their own perceived adherence or non-adherence.

Interventions to improve adherence with GFD

It has been reported that there is a need to develop resources to help people with CD follow a GFD[80]. To date, only four well-designed interventions are reported in the literature, with two more underway, which target improving adherence to a GFD in adults with CD and Table 2 shows the details of the studies involving intervention to increase adherence to a GFD. Addolorato *et al.*[99] conducted a study of sixty-six CD patients with state anxiety and depression and reported a greater proportion of participants adhered to a GFD after psychological counselling compared with a control group who received no counselling[100]. This study was conducted in Italy and no mention of the ethnicity of the participants was reported. Sainsbury and colleagues[64] devised a web-based intervention to improve dietary adherence to a GFD in adults with CD residing in Australia; the ethnicity of participants was not reported. All patients had biopsy-confirmed CD, and completed the intervention (*n* 46) or were on a wait list (*n* 64) and after 3 months completed a validated dietary adherence questionnaire[59]. The intervention consisted of six, 30 min, online modules completed over a period of 6 weeks. The modules encompassed education, behaviour change and cognitive behaviour therapy to treat anxiety and depression and improve coping behaviour. This online course demonstrated a significant improvement in GF dietary knowledge and dietary adherence score

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Table 2. Intervention studies to improve gluten-free dietary adherence

Author	Country	Population studies	Adherence method	Intervention	Duration	Follow-up
Addolorato *et al.*[100]	Italy	CD with state anxiety and depression *n* 66 Ethnicity not stated	Self-reported, a family member interview, clinical symptoms, histological recovery and serology	Psychological counselling compared with no counselling control	6 months	At follow-up significantly greater GFD adherence in intervention group
Sainsbury *et al.*[64] Sainsbury *et al.*[60]	Australia	Adults Members of coeliac society		6-week online course	Follow-up after 3 (and 6 months – unable to find %)	At follow-up significantly greater GFD adherence in intervention group
Rajpoot *et al.*[70]	India	Adults		Nutrition counselling	6 month follow-up	Follow-up significantly increases GFD adherence
Haas *et al.*[102]		Children	Serology anti-tTG and deamidated gliadin peptide	45 text messages	3 month intervention	
Dowd *et al.*[80]	USA	Not yet assessed		App developed		

CD, coeliac disease; anti-tTG, anti-transglutaminase antibodies; GFD, gluten-free diet.

among participants, and was sustained at 3 months from baseline. The improvements observed were greatest in those not previous adhering to the GFD (Coeliac Disease Adherence Test score <13 at baseline; *n* 18). The participants were recruited predominately through coeliac societies, of which membership is also associated with dietary adherence[63], and thus could have introduced selection bias. The study employed web-based methodology and hence computer literacy might well be an issue in a groups of older adults that form a significant proportion of the adult UK population with CD[101].

Rajpoot and colleagues[70] aim to improve dietary adherence to a GFD in adults with CD through face-to-face nutrition counselling with a dietitian. The 45 min long counselling sessions were attended at 1, 3 and 6 month intervals for each patient and family member from baseline. The study recruited participants through hospital clinics in India, ethnicity of participants was not specified, 146 participants completed the intervention and 6-month follow-up period. Dietary adherence was assessed by participants completing a non-validated questionnaire. Dietary counselling increased the proportion of participants adhering to a GFD over time; adherence rates increased from 64 to 94 % at 6 months in the newly diagnosed group, and from 53 to 92 % in a group of patients with established CD. A limitation of the study was the lack of a control group, thus additional influences could have impacted upon the dietary adherence.

A recent study aimed to evaluate the role of text messages in relation to increasing adherence to the GFD in patients aged 12–24 years with CD living in the USA. The text message group received forty-five unique text messages over a 3-month study period, while the control group received standard care treatment[102]. Adherence was measured with serum anti-tTG and deamidated gliadin peptide levels and no significant difference was noted in either group. The study, however, could be criticised for the over-reliance on serology to detect dietary adherence.

Additional interventions have aimed to increase knowledge of patients about CD in general and GF foods[103], although these studies did not assess dietary adherence. Associations between better knowledge and adherence have been reported[79], thus is could be inferred that increasing patients knowledge is likely to improve dietary adherence.

Conclusions

It is clear from the above discussion that a proportion of people with CD are not adhering to a GFD which is compromising their short- and long-term health. A range of methods are available to assess dietary adherence in the clinical and research setting, including serological tests, questionnaires and interviews, however it remains an area where validation studies are still needed. It has been shown that GF dietary adherence is affected by age at diagnosis, the symptoms experienced, dietetic counselling, mental health status, membership of a local support group or society, understanding and knowledge of food labels, the economic cost and availability of GF foods and currently whether GF foods are available on prescription.

Adhering to a GFD has its difficulties and there are a wide range of barriers for patients to overcome. Robust studies are needed to accurately assess the social and economic burden of undertaking a lifelong GFD in ethnically diverse populations of people with CD. Very few intervention studies have been conducted in adults with

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CD to improve GF dietary adherence. Such interventions have been traditionally based on both dietary and psychological counselling. Increasingly technological based solutions have been adopted with online module based training programmes, apps, text messages and telephone clinics presenting promising results. However further developments in this area would be welcomed.

Future interventions should include people of all ethnicities, with a focus on decreasing barriers to knowledge transfer, increase understanding and enabling behavioural change. These interventions should consider how they can be undertaken in clinical practice and consider cost-effectiveness in the healthcare environment.

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Conflict of Interest

The authors have previously received Dr Schär's coeliac disease award for the year 2016.

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