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## **Nutritional knowledge, eating habits and Quality of Life of coeliac disease patients**

**Purpose:** Coeliac Disease (CD) is a lifelong autoimmune disorder and is managed with a strict gluten-free diet. At diagnosis, an individual's nutritional status is affected by how long CD has been active, their dietary intake, intestinal inflammation, and degree of malabsorption. This study explores if age and time since diagnosis affect nutritional knowledge, eating habits and emotional wellbeing of participants.

**Methodology:** An online survey using Qualtrics was conducted. The survey consists of 4 sections exploring (i) demographics, (ii) nutritional knowledge, (iii) eating habits and (iv) Quality of life (QoL). A total of 162 valid questionnaires were completed.

**Findings:** Those who'd been diagnosed for more than 5 years demonstrated better knowledge about gluten-free or gluten containing products. Social interactions are limited by concerns about becoming ill, unwanted attention, and increased financial costs. Eighty-eight % of participants would go hungry at social events. Those aged between 40 – 59 and above 60 years felt more financially restricted compared to younger adults ( $\chi^2(4)=10.73$ ,  $p=0.01$ ). Strong emotions were experienced by participants since diagnosed with CD. Anxiety, feelings of concern, sadness, depression, and fear have declined and happiness, confidence and being accepting of coeliac disease have increased since diagnosis across all years.

**Originality:** This study is one of the first few studies to investigate time since diagnosis and age-related differences in nutritional knowledge, eating habits and QoL of adults diagnosed with CD. Over time, negative emotions could potentially be alleviated with improved knowledge and experience.

**Keywords:** coeliac disease; eating habits; gluten-free; nutrition; Quality of life

### **Introduction**

Coeliac Disease (CD) is a lifelong autoimmune disorder which can develop at any age. Currently one in 100 people in the UK are diagnosed with CD, with an estimated 500,000 undiagnosed cases (Coeliac UK, 2018a). CD damages the small intestine of genetically susceptible individuals when exposed to gluten (Lebwohl *et al.*, 2018). Common physical symptoms include, diarrhoea, constipation, anaemia, stomach cramps, chronic fatigue, and weight loss (NICE, 2015). Less typical manifestations include migraine, headaches, iron deficiency anaemia, skin rashes and bone disease (Rubio-Tapia *et al.*, 2013). New drug therapies based on increased understanding of the pathogenetic process of CD are underway, offering hope for future CD management (Kivela *et al.*, 2020). Currently, strict dietary exclusion of all foods containing gluten is the only treatment currently available (Ciacci *et al.*, 2015).

39 At diagnosis, an individual's nutritional status is affected by how long CD has been active, their dietary  
40 intake, intestinal inflammation, and degree of malabsorption (Theethira *et al.*, 2014). Post-diagnosis  
41 unintended weight gain and elevated cholesterol levels may occur because of intestinal healing and  
42 improved absorption (Welstead, 2015). Common nutritional inadequacies exist at diagnosis. Whilst  
43 some vitamin and mineral deficiencies are eliminated post-diagnosis, new deficiencies occur, excess  
44 fat intake continues, sugar intake increases, and dietary fibre and protein intake are low (Melini and  
45 Melini, 2019). In Miranda *et al.* (2014), non-gluten and gluten containing foods were compared:  
46 unfavourable differences in nutritional content were found in gluten-free (GF) foods, with higher  
47 levels of saturated fats, and lower levels of protein and fibre in non-gluten breads and pasta. When  
48 maintaining a GF diet, lack of vitamin and mineral fortification in non-gluten containing products  
49 poses a nutritional risk and increases the need for a diet rich in fruit, vegetables, nuts, seeds, meat,  
50 fish and poultry to ensure sufficient dietary requirements are achieved (Welstead, 2015). Vici *et al.*  
51 (2016) found that necessary avoidance of several grains, naturally rich in fibre, and consumption of  
52 alternative GF products made from refined flours, contributed to poor fibre intake. The inclusion of  
53 potentially unfamiliar alternative grains (AG) to diversify diet and meet nutritional needs, would require  
54 knowledge and education to raise awareness and consumption (Laheri and Soon, 2018).

55

56 Whilst excellent nutritional knowledge and eating habits are essential, and support groups helpful  
57 (Coeliac UK, 2019a), there are other reasons why people with CD struggle, notably the mental burden  
58 of day-to-day coping with dietary restriction and fear of gluten contamination (Zingone *et al.*, 2015).  
59 There are increased levels of lifetime depression amongst some people with CD, including those who  
60 practice intentional strict GF dietary adherence (van Hees *et al.*, 2013). Whilst strict adherence to a GF  
61 diet increases the chance of physical recovery, it may contribute to higher levels of anxiety and  
62 depression (Ludvigsson *et al.*, 2018). Causal links may include social anxiety (Addolorato *et al.*, 2008),  
63 fear of food contamination (Zarkadas *et al.*, 2013), and poor nutritional content (Staudacher, 2015).  
64 After diagnosis, patients may feel overwhelmed as they come to terms with the disease.  
65 This was evidenced by Zarkadas *et al.* (2006) who found lower QoL for patients in the first  
66 year after diagnosis due to greater burden to the newly diagnosed CD patient. Whilst  
67 following GF diet, patients may be overloaded with dietary information and preventative  
68 strategies to avoid gluten (Ciacci *et al.*, 2015). White *et al.* (2016) report higher costs, poorer  
69 palatability and reduced enjoyment of GF foods negatively impact psychological wellbeing. Zysk *et al.*  
70 (2018) found that the economic status of a CD patient was one of the main socio-demographic  
71 influencing. Low economic status led to lower QoL in social and emotional fears and worries. As GF  
72 products are more expensive (Singh and Whelan, 2011), this may be burdensome for low income CD  
73 patients.

74

75 In self-reported GF dietary adherence, perceived health, vitality, and Quality of Life (QoL) was  
76 reduced, despite purported compliance (Hallert *et al.*, 2003). Eating a separate diet to others, dealing

77 with un-informed catering staff, and constantly questioning the GF status of foods, imposes social  
78 restrictions, limits foreign travel, contributing to increased anxiety (White *et al.*, 2016). The  
79 symptoms of CD may therefore have a physical aetiology, e.g., malabsorption caused by a failure to  
80 achieve full physical intestinal recovery (Paarlahti *et al.*, 2013), nutritional deficiencies caused by  
81 dietary inadequacy (Shepherd and Gibson, 2013), and manifestations of a psychosocial disturbance  
82 caused by constant dietary vigilance (Ludvigsson *et al.*, 2018). Negative attitudes towards following  
83 the GF diet may harm an individual's relationship with food, leading to disordered eating habits  
84 (Satherley *et al.*, 2015), adversely impacting their QoL. When enjoyment of food is impaired,  
85 psychological distress and reduced QoL can be observed (Satherley *et al.*, 2018). Following new  
86 dietary practices, not being able to eat out, having to read food labels, and a lack of dietary  
87 alternatives contribute to the difficulties diagnosed people face (Araujo and Araujo, 2012).

88  
89 In "extreme dietary vigilance" amongst both teenagers and adults, there were lower reported energy  
90 levels, greater fatigue, and lower QoL scores than for those less vigilant (Wolf *et al.*, 2018b). By  
91 contrast, according to Marsilio *et al.* (2020), adherence to the GF diet resulted in higher QoL scores,  
92 but a significantly higher percentage of non-adherent participants reporting low scores for dysphoria.  
93 Notably, and of great concern, the greater the perceived burden of living with CD, the poorer  
94 adherence to the GF diet (Shah *et al.*, 2014). Adherence to the GF diet is influenced by several  
95 factors, including age at diagnosis and knowledge of GF foods (Muhammad *et al.*, 2019). Adults  
96 diagnosed in childhood report higher rates of non-adherence to the GF diet than those diagnosed as  
97 adults (Hall *et al.*, 2009). Wagner *et al.* (2008) notes that children moving from paediatric CD care  
98 are at greater risk of non-dietary compliance, increased physical symptoms and poorer QoL. Silvester  
99 *et al.* (2016a) report on coeliac participants' current age groups, nutritional knowledge, and gluten  
100 exposure, but did not consider how this impacts QoL. Gray and Papanicolas (2010) report on age  
101 group related levels of health and QoL, based on CD symptoms, but not on how nutritional knowledge  
102 or eating habits affect them. Paarlahti *et al.* (2013) researched factors predicting ongoing GI  
103 symptoms and reduced QoL, by current age, and time since diagnosis while Zarkadas *et al.* (2013)  
104 investigated the emotional impact and difficulties experienced by CD patients who follow a GF diet  
105 and found that women were more accepting of CD than men and negative emotions were  
106 experienced less frequently among those who'd been following GF diet for more than 5 years. There  
107 are limited studies that sought to discover in which ways current age, and time since diagnosis affect  
108 nutritional knowledge, eating habits and QoL collectively. This study aims to investigate time since  
109 diagnosis and age-related differences in nutritional knowledge, eating habits and QoL of adults  
110 diagnosed with CD. Expanding understanding of age-related differences may identify issues which, for  
111 example, only young adults or elderly adults experience, and could contribute to the development of  
112 tailored age-appropriate adult healthcare regimes and educational support.

113

## 114 **Methodology**

115 **Questionnaire Development**

116 The questionnaire had 4 sections exploring (i) demographics (gender, age and time since diagnosis),  
117 (ii) nutritional knowledge, (iii) eating habits and (iv) Quality of life (QoL). Participants were asked 5  
118 closed questions to assess GF knowledge. Questions were designed based on Silvester et al. (2016a,  
119 2016b), assessing how participants gained their understanding of CD and how they applied their  
120 nutritional knowledge to everyday living. Participants were asked about 12 everyday food items,  
121 whether they consider them 'safe', 'unsafe' or a 'food to question'. The Coeliac UK Food and  
122 Information Checker was the main reference point for correct answer verification (Coeliac UK, 2019b).  
123 Foods categorised as 'safe' are buckwheat flour, lentils, cocoa, rice, maltodextrin, and barley malt  
124 vinegar. 'Foods to question' are oats, tamari and flavoured yoghurts. 'Unsafe' foods are barleycup,  
125 spelt and bulgar wheat. There were closed questions exploring eating habits, based on early research  
126 by Lamontagne et al. (2001) and built on by Araujo and Araujo (2011). These questions aimed to  
127 identify how eating habits are affected by the requirement to consume only GF foods. There were  
128 closed questions assessing emotions and impact on daily life (Dorn *et al.*, 2010; Zarkadas *et al.*,  
129 2013). The survey was designed using Qualtrics XM software. Hertzog (2008) suggested a sample  
130 size of 10 - 40 for pilot studies and due to the inclusion criteria required for this population, a pilot  
131 sample of 10 subjects were deemed sufficient. The survey was pilot tested and subjected to face  
132 validity with 10 CD patients to assess the feasibility, clarity and time required to complete the  
133 questionnaire.

134

135 **Data collection**

136 To be eligible to take part in the survey, participants had to be  $\geq 18$  years of age. Participants had to  
137 have been clinically diagnosed with Coeliac Disease (Ludvigsson *et al.*, 2014). Clinical diagnosis of CD  
138 is achieved by serological testing to measure antibody levels in blood and small intestinal biopsy to  
139 check for damage to the gut lining (Coeliac UK, 2022; Lindfors et al., 2019). The survey was  
140 advertised on Coeliac UK's social media network, local clinics, and coeliac support groups in UK.  
141 Online survey has a response rate of 20 – 30%, hence the study was advertised as widely as  
142 possible. Based on the sample size calculation (confidence level: 95%; population size:  $\sim 670,000$   
143 [using the value of 'one in 100 UK population is affected by CD' as the basis for the calculation of the  
144 affected population] and margin of error: 5%), the study requires more than 380 patients. The  
145 survey was conducted from February to March 2019.

146

147 **Statistical analyses**

148 Descriptive statistics, Chi square ( $\chi^2$ ), Mann-Whitney U and Kruskal Wallis tests were conducted.  
149 Significant value is set a  $p < 0.05$ .

150

151 **Results and Discussion**

152 A total of 217 participants returned the survey, of which there were 162 valid responses. Similar  
153 studies had recruited between 50 – 100 participants with CD (Laheri and Soon, 2018; Lee et al.,  
154 2009). The demographics of participants' characteristics are shown in Table 1. All participants made  
155 use of all the suggested five methods of nutritional knowledge sources. Social media and websites  
156 and Coeliac support groups were the two main sources of information. Strict GF dietary adherence is  
157 reported most frequently followed by rare, unintentional consumption. Participants were asked if they  
158 still experience GI symptoms when following a GF diet of which 48.1% still experienced the  
159 symptoms. Rice, potato and gluten free bread were the most common food sources preferred by the  
160 participants whilst amaranth and buckwheat were least common.

161

162 Insert Table 1 here

163

164 Participants were asked about 12 everyday food items, whether they consider them 'safe', 'unsafe' or  
165 a 'food to question'. The Coeliac UK Food and Information Checker was the main reference point for  
166 correct answer verification (Coeliac UK, 2019b). Foods categorised as 'safe' are buckwheat flour,  
167 lentils, cocoa, rice, maltodextrin, and barley malt vinegar. 'Foods to question' are oats, tamari and  
168 flavoured yoghurts. 'Unsafe' foods are barleycup, spelt and bulgar wheat. Table 2 highlights the % of  
169 food items identified correctly as safe, questionable or unsafe by different age and years since  
170 diagnosis groups. There was significant association between age groups and whether or not the  
171 groups reported tamari as a food to question ( $\chi^2(4)=8.48$ ,  $p=0.04$ ). More than 40% of the older  
172 participants identified tamari as food to question while 23% of younger participants reported  
173 correctly. Time since diagnosis revealed significant association in identifying correct safe foods and  
174 food to question. These were buckwheat flour ( $\chi^2(4)=9.69$ ,  $p=0.04$ ), lentils ( $\chi^2(4)=10.01$ ,  
175  $p=0.04$ ), rice ( $\chi^2(4)=15.66$ ,  $p=0.01$ ) and tamari ( $\chi^2(4)=10.70$ ,  $p=0.03$ ) (Table 2). Those who'd been  
176 diagnosed for more than 5 years demonstrated better knowledge about GF or gluten containing  
177 products.

178

179 Insert Table 2 here

180

181 There were no significant differences in checking the label between gender, age groups and year of  
182 diagnosis. However, females, participants above the age of 60 and those newly diagnosed with CD  
183 were found to check for gluten free wording and Crossed Grain symbol more often. There was also  
184 strong agreement that participants' nutritional knowledge had improved since their diagnosis. Males  
185 tend to agree that they eat more healthily since diagnosed with CD. Participants also agreed that  
186 their cooking and food preparation skills had improved over time (Table 3).

187

188 Insert Table 3 here

189

190 Table 4 shows being a coeliac could restrict participants from socialising. Most participants were  
191 found to go hungry at social events, females were more likely to feel being restricted due to risk of  
192 falling ill or due to the attention brought forth by being a coeliac. There were significant association  
193 between age groups and feeling of being restricted by the financial cost of GF food. Those aged  
194 between 40 – 59 and above 60 years felt more restrictive compared to the younger adults  
195 ( $\chi^2(4)=10.73, p=0.01$ ).

196

197 Insert Table 4 here

198

199 Figure 1 contrasts the percentage point differences based on how the participants felt when first  
200 diagnosed with CD to how they feel today. Happiness, confidence and being accepting of CD have  
201 increased since diagnosis across all years. Those recently diagnosed with coeliac disease (< 1 year)  
202 showed the greatest level of acceptance (61.54%), but the same group was least confident in  
203 managing CD (15.38%). Participants were more relieved when newly diagnosed and reductions in  
204 feelings of relief were most noticeable among those who'd been diagnosed for 1 – 2 years. Feeling  
205 anxious, concerned, sad and depressed about the diagnosis have fallen across all groups.

206

207 Insert Figure 1 here

208

## 209 **Discussion**

210 The female to male participant response (n=138) females, to (n=24) males is a ratio of 5.8:1 women  
211 to men. Similar to previous studies, there is a female predominance of diagnosed coeliac disease (Dimidi  
212 *et al.*, 2021; Jansson-Knodell *et al.*, 2018; Tan *et al.*, 2021). Women are also more likely to experience  
213 abdominal pain, iron deficiency anaemia, decreased bone mineral density and were more likely to seek  
214 medical care (Ballester-Fernandez *et al.*, 2021; Castro *et al.*, 2015; O'Shaughnessy *et al.*, 2021; Tan *et*  
215 *al.*, 2021). Online data collection methods via Coeliac support groups may account for some  
216 difference, as women use social media to seek advice and offer support more frequently than men  
217 (Kimbrough *et al.*, 2012). Research suggests that the more nutritional knowledge gained about the GF  
218 diet and CD, the greater the dietary adherence achieved (Lamontage *et al.*, 2001). It is important  
219 that the sources of knowledge acquisition are both accurate and available, at the time they are  
220 needed. Findings showed that more than 80% of the participants use social media and websites to gain  
221 CD knowledge. Social media, and online health forums have an overall positive effect; with their use  
222 individuals are better able to deal with their condition both socially and practically (Tanis, 2008).  
223 Coeliac support groups were the second most preferred choice of information followed by healthcare  
224 providers. Health related online social networking and coeliac support groups offer the opportunity to  
225 share personal stories, make friends, and reduces isolation by providing emotional support from  
226 others who experience similar issues (Chung, 2013), this is important if healthcare services are  
227 limited.

228

229 Adherence to a GF diet is fundamental to the health and wellbeing of people diagnosed with CD. More  
230 than half of the participants reported strict GF diet. Similarly, Dimidi et al. (2021) found that half to  
231 three quarters of their participants adhered to GF diet. Whilst rare intentional failures to adhere to a  
232 GF diet do occur, rare unintentional gluten consumption is far greater (30.2%), consistent with  
233 findings by Hall et al. (2013) where 54% reported unintentional consumption. Despite following GF  
234 diet, almost half of the participants experienced some form of gastrointestinal symptoms. Rice was  
235 the most common food source, but participants were less likely to consume amaranth and  
236 buckwheat. This is consistent with previous studies where rice was reported as the most popular  
237 grain, but most participants reported never having consumed amaranth and buckwheat (Laheri and  
238 Soon, 2018; Nicklas *et al.*, 2013). It is possible that misconceptions about pseudo-cereals such as  
239 amaranth and buckwheat contain gluten when it is actually GF leading to lower rate of consumption  
240 (Kmietowicz, 2017). Lack of awareness as identified in this study and accessibility to alternative grains  
241 too may play a role.

242

243 Establishing the difference between safe, unsafe or foods to question is a critical skill to learn, and  
244 some foods pose more problems than others. To date, the inclusion of oat in GF diet remains a debatable  
245 topic in the scientific community. Oats remain questionable due to possible cross contamination  
246 (Colombo *et al.*, 2021; Fritz & Chen, 2018). Although pure oats were found to be well-tolerated by  
247 most CD patients in moderate amount (50 – 70 g / day for adults) (Cohen *et al.*, 2019), nevertheless  
248 the potential for sensitivity exists as oat avenins may influence the immunoreactivity of peptides at  
249 intestinal level (Kosova *et al.*, 2020). Varieties and cultivars differ in oat avenins, possibly contributing  
250 to different research findings for oats safety, and may also contribute to the confusion  
251 surrounding their consumption (Comino *et al.*, 2015). Inherently GF grains and seeds pose a dilemma  
252 for people with CD as these products may contain traces of gluten due to the growing and  
253 manufacturing processes increasing their risk of contamination and highlighting the need to consume  
254 only those which are labelled "Gluten Free" (Thompson *et al.*, 2010). This study revealed significant  
255 association between years since diagnosis and identification of safe foods especially cocoa, lentils and  
256 rice. Previous research revealed for those most recently diagnosed, it takes around 6 months to  
257 identify gluten containing and GF foods (Clerx *et al.*, 2019). Confusing unsafe foods with safe foods is  
258 also of considerable concern. Incorrect identification of bulgar wheat (25.93%) and spelt (20.37%) as  
259 safe in this study potentially puts participants at risk from gluten exposure. It is possible that because  
260 bulgar wheat (which is unsafe), sounds similar to buckwheat (which is safe), may have led to  
261 participants' confusion.

262

263 Those who were diagnosed for less than a year were found to consistently reported higher levels of  
264 checking 'Gluten-Free' wording, 'Crossed Grain' symbol and nutritional content. Checking food labels  
265 is a fundamental tool in the management of CD and label reading skills are necessary to avoid gluten



266 (Gutowski *et al.*, 2020). This study showed that newly diagnosed patients tend to be more anxious  
267 and were concerned about adhering to GF diet. This may be the key factors to why newly diagnosed  
268 patients were more likely to scrutinise the front of pack labelling for GF label. All groups were found  
269 to consistently checked for GF wording more frequently compared to Crossed Grain symbol. Sielicka-  
270 Rozynska *et al.* (2020) found their respondents paid more attention to verbal GF claims than pictures  
271 on packaging. In fact, Sielicka-Rozynska *et al.* (2020) suggested that the combination of the Crossed  
272 Grain symbol and a GF verbal statement helped to strengthen respondents' decision making. Whilst  
273 those who'd been diagnosed for longer believed their nutritional knowledge has improved, however  
274 there were no significant differences in their self-reported eating practices. Most participants also  
275 somewhat disagreed that their cooking and food preparation skills did not improve since their  
276 diagnosis.

277

278 Over 88% of all participants in this study reported often going hungry at social events, with those in  
279 the age range 30-39 reporting the highest rate (92.5%). Participants going hungry at social events  
280 may be attributed to fear of gluten contamination (Zingone *et al.*, 2015; Zarkadas *et al.*, 2005). Hiding  
281 CD from others and not wanting to place dietary burdens on friends and family may be an additional  
282 reason that going hungry is so frequently reported (Sverker *et al.*, 2005). Shah *et al.* (2014) identified  
283 that the higher the perceived importance of maintaining a GF diet, the more difficult eating away from  
284 home became.

285

286 Eating habits are also affected by the availability of GF foods and by their cost (Hopkins and Soon,  
287 2019). There were significant association between age groups with feelings of being restricted by the  
288 financial cost of gluten free foods. GF products cost on average 2 - 4 times more than gluten  
289 containing foods (Hopkins and Soon, 2019; Jegede *et al.*, 2021; Vriesekoop *et al.*, 2020). Although GF  
290 foods are increasingly available, those in budget and convenience stores, reported to be frequented  
291 by lower income people, remain limited and can affect GF dietary adherence (Hopkins and Soon,  
292 2019). Necessary changes to eating habits and a perpetual need to be vigilant during food choice is  
293 also seen to impose social restrictions and social discomfort (Satherley *et al.*, 2018, Addolorato *et al.*,  
294 2008, and Zarkadas *et al.*, 2013). Acquiring the skills to assess gluten risk, and to enquire about a  
295 food's GF status in restaurants and eating away from home is reported to take 1-2 years (Clerx *et al.*,  
296 2019).

297

298 There are often strong emotions experienced by those who must follow a GF diet. Not being able to  
299 socialise, travel and eat with others, feelings of isolation and exclusion, difficulty in finding GF foods,  
300 fear of 'being a bother', restricted food choice and hypervigilance could impact on Quality of Life  
301 (Crocker *et al.*, 2018; Silvester *et al.*, 2016b; White *et al.*, 2016; Zarkadas *et al.*, 2013). A substantial  
302 number of people with CD report reduced health related QoL whilst attempting to maintain a GF diet  
303 (Paarlahti *et al.*, 2013). Figure 1 shows the emotions experienced by participants over time. Anxiety,

304 feelings of concern, sadness, depression, and fear declined across all time periods. Wolf et al. (2018)  
305 reported that individuals with coeliac disease are extremely vigilant in adhering to a strict gluten-free  
306 diet and this may increase symptoms such as anxiety and concern. Over time, such negative  
307 emotions could potentially be alleviated with improved knowledge and experience. Our findings  
308 corroborate with Fernandes and Lopes (2022) who reported that patients' experience improves over  
309 time with regular follow up and was associated with better GF diet compliance and improved  
310 prognosis. CD is a highly complex condition, and could be considered as a hidden disability, one which  
311 impacts a broad range of areas in the lives of those diagnosed (Carrie and Chan, 2008).

312

### 313 Limitations

314 The survey was adapted from other questionnaires and was only pilot-tested and subjected to face  
315 validity. Participants included those who self-reported that they were diagnosed clinically. There is a  
316 lower share of male respondents compared to female patients, thus the responses are heavily skewed  
317 towards female respondents' perceptions. Participants were recruited from local support groups,  
318 clinics and Coeliac UK and would have received some form of help and support from such  
319 organisations and may be more knowledgeable and adherent to the diet. The survey was self-  
320 reported hence may be subjected to optimistic bias where participants overrate their adherence to a  
321 GF diet. Although participants were recruited on the basis of self-reporting their diagnosis and while  
322 they considered themselves to have been given a diagnosis of coeliac disease, it is possible that they  
323 may not have coeliac disease. Coeliac disease affects 1% of the population, there's been a rise in  
324 number of individuals self-reporting gluten-sensitivity and consume a gluten-free diet despite not  
325 being clinically diagnosed (Imran, 2018). In the absence of evaluation by a physician or a skilled  
326 dietitian with expertise on CD and GF diet, the data cannot be translated into clinical practice.

327

### 328 Conclusion

329 There is considerable complexity surrounding the acquisition of nutritional knowledge for people with  
330 CD. Acquisition of nutritional knowledge takes time; those diagnosed for longer i.e. more than 5 years  
331 demonstrated greater knowledge about gluten-free and gluten containing foods. Majority of  
332 participants report going hungry at social events. Social interactions are limited because of concerns  
333 about becoming ill, from unwanted attention, and due to increased financial costs. Although  
334 nutritional knowledge, eating habits and Quality of Life (QoL) are repeatedly researched as separate  
335 entities, it is important to remember that each one is inextricably linked to the others. People's lives  
336 are complex, and diagnosed individuals navigate CD with different knowledge, life experience,  
337 economic status, and social skills, all of which influence post-diagnosis management. It is  
338 recommended that further studies to explore the influence of social-demographics and if participants  
339 have access to clinical and dietary support to assess CD patients' adherence to GF diet and overall  
340 wellbeing.

341

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