

Disordered eating patterns in coeliac disease:

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1 **Disordered Eating Patterns in Coeliac Disease: A Framework Analysis**

2 **OBJECTIVE:** The need for dietary-management in coeliac disease may lead to the
3 development of disordered eating patterns. A theoretical model of disordered eating has
4 been proposed to explain disordered eating in coeliac disease. The aim of this study was to
5 explore the experiences of typical and disordered eating in coeliac disease to gain a greater
6 understanding of these processes and explore specific pathways within this model.

7 **METHODS:** We interviewed 21 individuals with coeliac disease, recruited from a previous
8 database, about their experiences with food and food environments. Information about
9 disordered eating status was assessed via questionnaire. The interviews were analysed
10 qualitatively using Framework analysis, which was underpinned by the theoretical model of
11 disordered eating in coeliac disease.

12 **RESULTS:** Experiences differed between participants scoring high on measures of disordered
13 eating and those who scored low (typical eaters). Participants scoring high on measures of
14 disordered eating were concerned about the consequences of their gluten-free diet on body
15 image and they described eating patterns similar to binge/restrict cycles. Typical eaters
16 reported being able to integrate their dietary self-management into their daily lives;
17 however, general concerns around food and cross-contamination were associated with a
18 restriction in food intake.

19 **CONCLUSIONS:** Coeliac disease has a varied impact on eating patterns. The need to follow a
20 gluten-free diet and to be vigilant around food has to be balanced with concerns around
21 food availability and cross-contamination which have the potential to contribute towards
22 disordered eating attitudes and behaviours. The findings suggest that the theoretical model
23 of disordered eating provides an adequate explanation of disordered eating patterns in
24 coeliac disease.

25

26 Coeliac disease (CD) is a life-long condition characterised by flattened villi (villous atrophy)
27 and inflammation of the small intestine ⁽¹⁾. These intestinal changes occur in response to
28 the ingestion of gluten, which is formed from two proteins: gliadin and glutenin ⁽²⁾. Gliadin
29 is the toxic protein for individuals with CD, as are structurally similar proteins hordein and
30 secalin that are found in barley and rye. The symptoms of CD can be both gastrointestinal
31 and non-gastrointestinal and include nausea, bloating, cognitive impairments and weight
32 changes ⁽¹⁾. There is no cure for CD but the condition is managed by following a life-long
33 gluten-free diet (GFD), which requires the exclusion of wheat, rye, barley and sometimes
34 oats from the diet. Management of the GFD also requires vigilance around cross-
35 contamination of food products, as small amounts of gluten can cause symptoms in some
36 individuals ⁽³⁾.

37 In the majority of people with CD, successful management of the GFD reverses damage to
38 the gut and reduces symptoms. However, the GFD can be challenging to follow and can
39 create concerns around eating outside the home and cross-contamination of food products
40 ⁽³⁾. Although the GFD is physically beneficial for the individual, its restrictive nature may
41 impact quality of life and result in maladaptive behaviours, including disordered eating
42 patterns ⁽⁴⁻⁶⁾.

43 The majority of individuals with CD score in the healthy range on self-report measures of
44 disordered eating ^(7,8). However, for some, CD may act as a risk factor for the development
45 of disordered eating via a number of mechanisms. Factors essential in managing the GFD,
46 including food preoccupation and awareness, may harm relationships with food ⁽⁹⁾.

47 Additionally, factors relating to the diagnostic experience, including gastrointestinal
48 symptoms and changes in weight, may affect body image and eating patterns ⁽¹⁰⁾.

49 Alternatively, the non-specific burden of chronic illness may account for the presence of
50 disordered eating in this population. Satherley, Howard and Higgs ⁽⁸⁾ suggest that factors
51 both unique to the CD diagnosis (gastrointestinal symptoms, dietary management) and
52 nonspecific factors (psychological distress) are important factors in disordered eating and
53 CD.

54 This study was theoretically informed by Satherley, Howard and Higgs' ⁽⁶⁾ model of
55 disordered eating in gastrointestinal disease (see Figure One). Central to this model are two
56 pathways; the first pathway describes individuals who experience anxiety around food and

57 cope with this by consuming a limited variety of gluten-free foods. The second pathway
58 describes those who struggle with weight changes experienced after diagnosis (usually
59 weight gain) and engage in poor dietary self-management to promote gastrointestinal
60 symptoms and associated weight loss. In an evaluation of this model, dietary-management
61 and gastrointestinal symptoms were associated with disordered eating scores, lending some
62 support to pathway two (⁸). However, the relationships between gastrointestinal symptoms,
63 dietary-management and disordered eating were not clear. Furthermore, no evidence was
64 found to support pathway one, the role of anxiety in disordered eating. This was attributed
65 to a lack of appropriate tools to measure concerns around food in individuals with CD.
66 Understanding these factors and their role in the development of disordered eating is
67 essential if appropriate supportive strategies are to be adopted by healthcare professionals.

68 The present study aimed to gain a holistic view of the experiences of typical and disordered
69 eating in CD. This was done by exploring the pathways of the Satherley, Howard and Higgs
70 (⁶) model by using a structured framework. According to the model, the type of disordered
71 eating pattern that develops will depend on beliefs about CD and the GFD, as well as the
72 psychological response to weight changes after CD diagnosis. By using this model to create
73 the framework for the interviews, we were able to assess how well this model was
74 supported by qualitative data.

75

77 Participants (18-69 years) with a self-reported biopsy-confirmed diagnosis of CD, for at least
78 2 years, without additional food allergies or health conditions, were eligible to participate.
79 Purposive sampling was used to recruit both typical and disordered eaters from a previous
80 database. Participants who scored above 20 on the EAT-26 or above 17 on the BES were
81 categorised as disordered eaters (DE), participants scoring below were classified as typical
82 eaters (non-DE; ^{11,12}). The EAT-26 is a screening tool that measures symptoms and concerns
83 characteristic of eating disorders and the BES screens for the presence of binge eating
84 behaviour, high scores are associated with more disordered eating symptoms and
85 behaviours. These are not diagnostic tools but screen for the presence of disordered eating
86 behaviours. The measures of disordered eating were taken between 18-63 days (mean = 41
87 days) prior to the interviews.

88 Sample size was based on data saturation, by repeatedly comparing data across
89 participants, which occurred when no new information was obtained from the interviews
90 (¹³). Twenty-five participants were invited to take part in the interviews but three withdrew
91 their data and one was removed from analysis, as the inclusion criteria were not met.
92 Individuals who withdrew their data were all classified as disordered eaters, no other
93 demographic differences were found in this group. Participants were informed that the
94 interview would explore eating patterns in CD. Demographic information (gender, age, years
95 since diagnosis, body mass index (BMI)) and health information (EAT-26 and BES scores)
96 were taken from the existing database; these measures were all based on self-report.

97 A semi-structured interview schedule allowed us to frame questions to fit the theoretical
98 model of disordered eating (⁶). The interview explored key themes concerning the diagnosis
99 of CD, the daily management of the GFD and how CD has affected participants' relationship
100 with food and body image.

101 *Procedure:* Participants provided written consent before their interviews. The first author
102 conducted and audiotaped the interviews. Each interview lasted between 30 and 45
103 minutes and was conducted in the participant's home. If any current or past disordered
104 eating was reported, participants were asked to discuss this in more detail, and reflect on

105 any links with their CD diagnosis. The interviewer encouraged participants to elaborate on
106 relevant themes.

107 *Data Analysis:* Ritchie and Spencer's (¹⁴) Framework methodology was used as it allows the
108 use of a theoretically-driven framework to structure and explore the data. Framework
109 analysis was beneficial for this study because it can include *a priori* themes drawn directly
110 from the model of disordered eating (⁶), as well as emergent concepts.

111 Interviews were transcribed verbatim by the first author, and read repeatedly in order to
112 identify key themes. These themes were developed into a framework for coding the entire
113 dataset. Additional categories were created for data that did not fit into the framework. To
114 enhance reliability, the coding process and emerging themes were discussed among the
115 authors until consensus was achieved. Trustworthiness of the data was enhanced using a
116 decision trail to ensure transparency (¹⁵).

117 *Ethical Approval:* Ethical approval was granted by the Research Ethics Committee, University
118 of Birmingham.

119

Results

120 Five males and 16 females took part in the interviews, (mean age = 39 years; mean time
121 since diagnosis = 5 years). Of these, 10 participants scored above EAT-26 and BES cut-offs
122 resulting in them being classified as "disordered eaters". Participant information can be
123 found in Table 1. Illustrative quotes presented are annotated with pseudonyms and
124 participants' disordered eating status (DE or non-DE). 'Disordered eaters' and 'typical eaters'
125 displayed significantly different BES ($t(19)=-7.09, p<.001$) and EAT-26 ($t(19)=-.61, p<.001$)
126 scores. There were no significant differences between participants for age, BMI or years
127 since diagnosis. There were also no significant differences across gender for EAT-26 and BES
128 scores.

129 The theoretical model of disordered eating in gastrointestinal disease (⁶), describes three
130 stages in the development of disordered eating: adaptation to diagnosis, illness beliefs and
131 dietary management. These stages provided the analytic framework for the hierarchical
132 themes. Each hierarchical theme was coded in depth to identify subordinate themes. Each
133 of these subordinate themes were explored, resulting in 17 sub-themes (see Table 2). All

134 themes were reported across participants but experiences and opinions differed across
135 individuals.

136 **1) Thoughts, Feelings and Behaviours Underlying Disordered Eating**

137 **(i) Adaptation to Diagnosis**

138 *The New Self*

139 The diagnostic process was related to physical changes in body image, which were
140 important in the adoption of disordered eating patterns. Disordered eaters described
141 distress around weight changes after diagnosis. This was linked with a desire to lose weight
142 by restricting food intake.

143 *I liked being thin. I was over 30 and I wasn't putting on weight. I've definitely got a big belly*
144 *now, I've put on weight and it's really bothering me. I really have lost a lot of confidence in*
145 *terms of the way I look. So I go on more diets now, to try and get back to how I was. I'd like*
146 *to be back to my pre-diagnosis weight. (Georgia, DE)*

147 These weight changes were challenging for disordered eaters and Dan felt that more
148 support could have been provided from healthcare professionals.

149 *Associating thinness with unhealthiness is strange. Putting on weight but being healthy, it*
150 *goes against the things you read about. I think the dietician could have explained that once*
151 *your stomach goes back to normal there will be a process where you start to gain weight. I*
152 *don't remember her explaining that. That may have helped me feel better. (Dan, DE)*

153 Some individuals did not experience post-diagnosis weight changes and others felt happier
154 with their weight once they were following the GFD. Typical eaters felt better after
155 diagnosis because of their increased energy, which was associated with an improved body
156 image.

157 *The thing I've really noticed is that when I'm feeling ok, I've got so much more strength and*
158 *energy. And that makes me perceive my body better. (Amy, non-DE)*

159

160

161 *Mourning Gluten*

162 Participants described the challenging process of mourning gluten-containing foods after
163 diagnosis, which was accompanied by distress. Twelve participants described a ritualistic
164 consumption of gluten “for the last time”. These feelings of loss were still present in
165 disordered eaters and were associated with a desire to consume gluten-containing foods.

166 *There’s a certain food that I’d normally eat, I remember I cried when I ate that for the last*
167 *time. I ate loads of it, to try and say goodbye. That was really upsetting. I still miss the food,*
168 *it’s really hard. I just want to eat it again. I get upset seeing friends eat it. (Paula, DE)*

169 For typical eaters, this mourning process was brief and no longer occupied their thoughts.

170 *There is a sort of grieving process for maybe a few months. But now it’s just a part of life.*
171 *There’s no reason to miss food that made me ill. (Colette, non-DE)*

172 After the adjustment process and acceptance of their diagnosis, participants began to
173 develop beliefs about their CD and the GFD.

174 **(ii) Illness Beliefs**

175 *The Dangers of Cross Contamination*

176 Cross-contamination was frequently referred to during the interviews. However, disordered
177 eaters were less concerned about cross-contamination than were typical eaters, and
178 believed that accidental gluten ingestion would not impact their long-term health.

179 *I’m rarely ill from cross-contamination, so I take risks and deal with the consequences. A tiny*
180 *amount of gluten every so often won’t have adverse effects on your long-term health; it just*
181 *might make you feel sick. (Julie, DE)*

182 Typical eaters had greater concerns around cross-contamination and went to greater
183 lengths to avoid cross-contamination than did the disordered eaters. Louise coped with
184 these concerns by limiting her food intake when outside of her home environment.

185 *Sitting in the staff room with everyone else eating food, that’s scary. Um, I know they’re not*
186 *going to touch me or make me eat it or anything but I won’t eat anything. There’s just too*

187 *much risk. I only eat my own foods in my own home... if I'm out shopping all day, I won't eat*
188 *but I'll eat my own safe food when I get home. (Louise, non-DE)*

189 For three individuals, these cross-contamination concerns extended into their own home:
190 the kitchen was viewed as an unsafe environment and resulted in a restricted food intake.

191 *The kitchen isn't safe. It's gluten-free, but it's more that food in general isn't safe. I get*
192 *worried around food. I have a few safe things that I do eat but food has become the enemy*
193 *now. It's just safer not to eat. (Mel, non-DE)*

194 *Response to Weight Changes due to GFD*

195 Participants were asked about the causes of any weight changes experienced after
196 commencing the GFD. Seventeen participants experienced weight gain after starting the
197 GFD whereas the remainder experienced no change or weight loss. Disordered eaters
198 attributed weight changes to the GFD and the poor nutritional quality of gluten-free foods;
199 they responded by restricting their food intake.

200 *And the gluten-free foods, if it's not super fatty, it's super sugary. Eating gluten-free food*
201 *made me really fat. It's hard to stay slim on a gluten-free diet. I've had to go on diets to lose*
202 *the weight but it's hard. (Paula, DE)*

203 For typical eaters, weight changes were attributed to the recovery of the intestine and
204 improved health.

205 *My weight has been quite stable, I put on a bit at first but I was really underweight. I read all*
206 *the books and they said that when your body recovers your weight should be normal. And*
207 *that's what happened. (Mel, non-DE)*

208 **(iii) Dietary Management**

209 *Risk Taking*

210 The majority of participants managed their GFD well. However, five disordered eaters
211 reported consuming small amounts of gluten.

212 *There was this really good sauce and I did take a really small piece of crusty bread. Because*
213 *crusty bread is the thing I miss the most. And I very gingerly sort of scooped up all the sauces*

214 *and ate it. It would be a small piece that hopefully I'm going to sort of eat without my*
215 *stomach noticing. (Dan, DE)*

216 Not all individuals with disordered eating reported deliberate gluten ingestion and this was
217 not recognised as a technique to promote weight loss.

218 For typical eaters, their concerns around cross-contamination and the fear of re-
219 experiencing unpleasant symptoms meant that risk taking was not tolerated.

220 *I don't take risks. I can't take risks. Gluten poisons me, why would you risk being poisoned?*
221 *(Sue, non-DE)*

222 **2) Patterns of Disordered Eating**

223 **(i) Eating Knowledge and Practices**

224 All participants felt that their eating patterns and the way they thought about food had
225 changed since their diagnosis. Their thoughts and feelings about their CD affected both their
226 attitudes towards food and the way they consumed food. Three sub-themes emerged
227 related to these changes in eating patterns and beliefs: *food preoccupation, eating for*
228 *pleasure and new eating patterns.*

229 *Food Preoccupation*

230 All participants reported that their diagnosis of CD had made them more aware of the foods
231 they were consuming and more aware of the nutritional content of food. This awareness
232 arose from the need to manage the GFD and the preparation and planning that this
233 involved. Participants were always thinking about food, what meal they were having next
234 and where this food was coming from. For disordered eaters, this food preoccupation
235 dominated their thoughts.

236 *You've got to think about the range of colours you're eating, the nutrients and about the*
237 *quantity, you're thinking about a whole range of stuff. I'm a bit obsessive about food. It does*
238 *change your relationship with food. You're always thinking about food. (Paula, DE)*

239 This awareness of food often led to an increased awareness of the calorific content of food.
240 Seven individuals became dissatisfied with the amount of calories they were consuming and
241 became dissatisfied with their body image.

242 *Since becoming coeliac I'm also a lot more calorie conscious as well. And the gluten free*
243 *foods. They're full of calories and fat, and that has made me, well, fat. Now I'm much more*
244 *conscious, about everything I eat. (Georgia, DE)*

245 Typical eaters described an awareness of food, but they were able to integrate these
246 thoughts around food into their life.

247 *I'm a lot more aware of food now, it's on my mind a lot but that doesn't bother me. I might*
248 *see a Chinese recipe but I'd just wonder how I could make it gluten-free. It's just a part of*
249 *life. (Richard, non-DE)*

250 *Eating for Pleasure*

251 After CD diagnosis, emotional relationships with food had changed. Meal times were
252 described as challenging and eating was no longer enjoyable. For disordered eaters, a loss of
253 pleasure around eating was common and was strongly interlinked with emotions: food
254 became a source of distress.

255 *Initially I was anxious. Finding out all these foods you couldn't have and thinking why the hell*
256 *does that have gluten in it, was upsetting. Food is now my enemy, food kills me, food attacks*
257 *me. I know that sounds really melodramatic but that's how it feels. (Dan, DE)*

258 A lack of enjoyment in the eating process resulted in typical eaters simply viewing food as
259 fuel for the body.

260 *I've gone off food really. Food is the baddie in my life at the moment. I just eat what I have*
261 *to; I've lost the enjoyment of sitting down and going out for a meal. (Amy, non-DE)*

262 In comparison, the majority of typical eaters enjoyed eating outside the home, whilst
263 managing their GFD.

264 *It's harder to eat out but you can't let that dictate your life. I still enjoy going out with friends*
265 *for a meal, I just have to be careful. (Richard, non-DE)*

266 *New Eating Patterns*

267 Some participants reported an improvement in their diet since diagnosis; however, others
268 reported eating patterns that appeared disordered in nature.

269 For eight disordered eaters, overconsumption of food was reported and this was linked with
270 emotional distress. The restrictive nature of the GFD made participants long for certain
271 foods. When these foods were available, they would be bought in bulk and consumed in a
272 short space of time, indicating a binge-type eating pattern. However, the consumption of
273 this food was not associated with guilt.

274 *When you're unable to eat certain foods, you then overcompensate with other things like*
275 *wine, chocolate, biscuits. It's depressing not getting these foods, so when you do, you just*
276 *enjoy it. And eat loads of it. I don't feel guilty, when I eat it, I feel happy again. The cakes*
277 *aren't going to be there tomorrow, so eat it while you can. (Paula, DE)*

278 Some disordered eaters felt that because of the restrictive nature of their GFD they
279 deserved to indulge in certain foods. Some participants hoarded gluten-free foods and ate
280 them at a fast rate.

281 *When the gluten-free Kit Kat bars first came out, I hoarded those because they were*
282 *delicious. If it's good, I'll be hoarding. Sometimes I eat them all myself. I think that's probably*
283 *my way of dealing with it. And I eat faster than I used to, I just eat it quickly before*
284 *someone's like – no you can't eat that. (Julie, DE)*

285 Other disordered eaters felt a need to limit their food intake due to concerns around weight
286 increase since their CD diagnosis.

287 *It's like being on several diets at once. I can't eat gluten, I eat naturally gluten-free because*
288 *of all the calories in gluten-free breads and pasta, and I'm on a Slimming World diet because*
289 *of all the weight I put on after my diagnosis. I just want to lose the weight. (Martha, DE)*

290 Typical eaters used strategies to improve food availability. This included cooking large
291 quantities of food and storing them to consume during the week.

292 *I kind of, I think I make up for the fact that I can't eat gluten by baking a lot of gluten free*
293 *cookies and meals. I portion them and freeze them for later in the week. (Katy, non-DE)*

294 Five typical eaters developed a fear of trying new foods or trying foods in new
295 environments. This stemmed from concerns around cross-contamination and the belief that
296 it was dangerous to eat foods outside the home. Some typical eaters reported going for long
297 periods of time without eating outside the home. These participants no longer enjoyed

298 eating in general and felt more at ease when they were not around food, which resulted in
299 restricted food intake.

300 *If I'm out shopping all day, I prefer not to eat. It's just not safe to eat. Eating has become*
301 *scary because of my coeliac. I only eat if I'm desperate. Food is too dangerous now, when I'm*
302 *not eating I feel safe. (Richard, non-DE)*

303 Others felt that their eating patterns were not affected by their CD diagnosis. They were still
304 able to maintain a nutritionally balanced diet. These participants were able to consume a
305 range of foods both inside and outside the home, despite sticking to their GFD.

306 *As long as I know it is gluten free, I'll try anything. I'm not a fussy eater at all. I've always*
307 *been that way. The only restriction to that is whether it's gluten free or not. (Katy, non-DE)*

308 Discussion

309 This study investigated the experiences of disordered eating in CD, in order to test a
310 theoretical model (⁶). Disordered eaters reported eating patterns suggestive of a
311 binge/restrict cycle, which was associated with psychological distress, poor dietary-
312 management and a preoccupation with food.

313 *Disordered Eaters*

314 Disordered eaters, as determined by the EAT-26 and the BES, developed eating beliefs that
315 stemmed from concerns around weight changes associated with commencing the GFD.
316 These weight changes caused distress and participants found it challenging to adapt to their
317 new body image. They described a desire to reach their pre-diagnostic weight and
318 responded by restricting their dietary intake. Weight increase is a known trigger for
319 disordered eating behaviours that may be viewed positively by those who are underweight
320 at diagnosis but may be unwelcome in those who begin at a normal or higher weight (¹⁶).
321 These findings are in line with Leffler et al. (⁴) who described three cases where concerns
322 around weight increased after starting the GFD which led to disordered eating behaviours.

323 Distress and mourning the loss of gluten-containing foods were associated with disordered
324 eating status. All participants experienced a mourning period, but for disordered eaters,
325 there was an extended period of distress surrounding the loss of gluten-containing foods,
326 that lasted for years after diagnosis. Participants coped with these feelings by

327 overcompensating with high energy-dense, gluten-free foods such as cakes and biscuits.
328 Consumption of high-energy dense foods has frequently been reported in those with CD ⁽¹⁷⁾,
329 but our results indicate that this may occur to help manage distress. Participants reported
330 no guilt around the consumption of these foods because they felt they “deserved” to eat
331 them. This resulted in the hoarding of foods and fast food consumption. This could be an
332 indication of binge-eating type behaviour in a sub-group of participants, all of whom were
333 classified as disordered eaters according to the BES ⁽¹⁸⁾.

334 Disordered eaters reported that overconsumption occurred in combination with restrictive
335 eating: weight loss was promoted by restricting food intake but this resulted in a
336 preoccupation with food and psychological distress, which resulted in binge eating. These
337 findings are in line with Herman and Polivy’s ⁽¹⁹⁾ Boundary Model, which suggests that those
338 who restrict their intake are more responsive to external stimuli and at risk for both under
339 and overconsumption of food. Similar patterns of eating have been described in people with
340 Type Two Diabetics who also follow a prescribed dietary regimen ⁽²⁰⁾. These findings
341 highlight the complex interplay of emotions and food, which may alter eating patterns and
342 beliefs in CD. An increased intake of high-density gluten free foods may be used to cope
343 with feelings of distress that arise from the restrictive nature of the GFD. Mazzeo and Bulik
344 ⁽²¹⁾ suggested that disordered eating arises after a stressful event as a way to manage
345 emotions and acts as a coping mechanism.

346 Intentional gluten consumption to promote weight loss was not reported. When asked
347 about gluten-consumption in an anonymised web-mediated survey, poor dietary
348 management was associated with disordered eating ⁽⁸⁾. In addition, case studies have
349 documented the interaction between intentional gluten consumption and a desire to
350 promote weight loss through villous atrophy ^(4,7). However, only four participants,
351 categorised as ‘disordered eaters’, described occasional gluten ingestion or risk-taking
352 behaviours. However, participants may not have been willing to talk about intentional
353 gluten consumption as a way of losing weight with the interviewer due to perceived lack of
354 anonymity.

355

356

357 *Low Risk Disordered Eaters*

358 Typical eaters differed from disordered eaters in thoughts, feelings and behaviours. Despite
359 experiencing weight changes after diagnosis, typical eaters felt healthy and energetic with
360 increased confidence. This is in line with findings suggesting that quality of life increases
361 after initiation of the GFD (^{22,23}). Typical eaters also experienced a mourning period after
362 diagnosis but these feelings of loss were no longer present at the time of interview. Typical
363 eaters associated gluten-containing foods with the symptoms they had experienced prior to
364 commencing the GFD and had no desire to consume these items again.

365 Caution around cross-contamination is essential for those with CD but may contribute to
366 limited food consumption, both inside and outside the home. Some typical eaters reported
367 going for long periods of time without consuming food because they believed that limiting
368 food consumption was keeping them safe, particularly when outside the home. Neither the
369 EAT-26 nor the BES captured the consequences of these cross-contamination beliefs on
370 eating patterns. However, this form of dietary self-management may result in eating
371 behaviours that could be considered 'disordered' (i.e. restricting and bingeing behaviours)
372 as they deviate from the norm (²⁴).

373 Importantly, not all participants displayed high levels of concern around food. Twelve
374 individuals were happy to try new foods that they believed were gluten-free. These
375 individuals described a healthy eating style and adaptive beliefs about food, with the caveat
376 that their diet was gluten-free.

377 *The Theoretical Model of Disordered Eating*

378 These findings provide support for the two-pathway theoretical model of disordered eating
379 in CD (⁶). The first pathway of the model suggests that an unwanted increase in weight after
380 diagnosis results in the belief that the GFD is responsible for this weight gain, which results
381 in poor dietary self-management to lose weight. Although our data suggests that distress
382 around weight change is associated with disordered eating attitudes and behaviours, there
383 was no evidence for the role of intentional gluten ingestion to promote weight loss. In
384 addition, the mourning and distress around the loss of gluten-containing foods was
385 associated with a desire to consume gluten. These findings are closely in line with the CD
386 grief process described by Rose and Howard, whereby the benefits of following a GFD were

387 not always viewed as beneficial, resulting in problems with dietary management ⁽²⁵⁾. Future
388 revisions of the theoretical model should consider the role of distress and feelings of loss in
389 relation to gluten-containing foods.

390 The second pathway describes those who adapt well to their CD diagnosis and have good
391 dietary self-management but overly extreme concerns around cross-contamination may
392 develop. Our findings suggest that some participants developed an extreme vigilance
393 around food, which was associated with limited food intake and concerns around food
394 preparation and consumption. However, these individuals did not score above clinical cut-
395 offs on measures of disordered eating. Vigilance around cross-contamination is essential for
396 GFD management but it is unclear from the current data whether these extreme concerns
397 around cross-contamination are maladaptive. Future revisions of the theoretical model
398 need to consider the types of concerns around food in those with CD to identify factors that
399 may promote maladaptive concerns.

400 *Strengths and Limitations*

401 All participants were diagnosed at 16 years of age or older; however, age of diagnosis may
402 have an impact on interactions with food, and this is often associated with the development
403 of disordered eating in chronic health conditions ⁽²⁶⁾. Childhood diagnosis may differ from
404 adolescent and adult diagnosis in the risk for disordered eating patterns, as diagnosis under
405 four years has been associated with better dietary-management and better psychological
406 well-being whereas those diagnosed in adolescence show more problems with social
407 interactions and more physical health problems ^(27,28). Furthermore, disordered eating
408 attitudes and behaviours tend to be more common in healthy females ⁽²⁹⁾. Although our
409 sample contained both males and females, the samples were too small to explore the
410 influence of gender on disordered eating attitudes and behaviours. Future research should
411 explore the relationship between gender and disordered eating in CD.

412 The assessment of disordered eating and BMI were all based on self-report. This may be
413 unreliable when assessing individuals who are motivated to keep their eating patterns and
414 weight secret, as is the case in disordered eating ⁽³⁰⁾. Furthermore, we recognise that the
415 EAT-26 and the BES allow screening of disordered eating but cannot be used as diagnostic
416 tools. Future research could focus on looking at those who display clinically significant

417 disordered eating patterns, assessed through clinical interview and the use of diagnostic
418 tools. Furthermore, EAT-26 and BES scores were assessed between 18-63 days prior to the
419 interview. Given the unstable nature of disordered eating attitudes and behaviours and
420 their tendency to change over time (³¹), it would be beneficial to verify disordered eating
421 status immediately before the interview. Additionally, the use of the EAT-26 and BES has not
422 been validated in individuals with CD. The scales contain items such as “I find myself
423 preoccupied with food” and “Sometimes I do not eat what I want around others because I
424 am aware of my problem with food”. As a result, there is potential for individuals with CD to
425 be misclassified as disordered eaters on these tools, particularly as management of CD
426 requires a focus on food intake (³²). However, these behaviours may represent a skill used to
427 manage the GFD as opposed to a disordered eating attitude or behaviour. At present, there
428 is no validated tool to assess disordered eating attitudes and behaviours in CD. There is a
429 need to consider the development of tools that may be more appropriate individuals with
430 CD and other dietary controlled health conditions.

431 Despite these limitations, this qualitative study was guided by the model of disordered
432 eating in gastrointestinal disease and allowed us to gain in-depth understanding into the
433 application of this model to CD (⁶). The study provides insight into the types of disordered
434 eating attitudes and behaviours and motivations behind these behaviours in CD. The BES
435 and EAT-26 appear to be effective in screening individuals who display binge/restrict-eating
436 patterns. However, these tools were not able to select individuals who limited their food
437 intake due to concerns around cross-contamination. Directions for future research should
438 focus on tools to assess concerns around food and cross-contamination in CD.

439 *Clinical Implications*

440 Individuals expressed a desire for more information regarding potential weight change after
441 commencing the GFD. This is in line with previous research, which highlights the value of
442 dietician-led services and the desire for more dietetic support in individuals with CD (^{33,34}).
443 Furthermore, disordered eaters discussed distress surrounding weight changes at CD
444 diagnosis. The current NICE guidelines do not recommend that individuals newly diagnosed
445 with CD are consulted about the benefits of a nutritionally balanced GFD and how the
446 initiation of the GFD may influence weight change and body shape, despite individuals with
447 CD explaining the benefits of this type of support (³⁴). It is recommended that research

448 informing clinical guidelines should focus on the role of educating all newly diagnosed
449 individuals with CD about the nutritional content of gluten-free foods and possible weight
450 changes after starting the GFD, as well as how to manage these weight changes.

451 *Conclusions*

452 This study has provided insight into the factors that may contribute to the development of
453 disordered eating patterns in CD. The results suggest that experiences of disordered eating
454 differ across individuals with CD but relate closely to the CD diagnosis and management of
455 the GFD. Greater understanding is still needed, especially in regards to atypical eating
456 patterns, which are not detected by current measures of disordered eating.

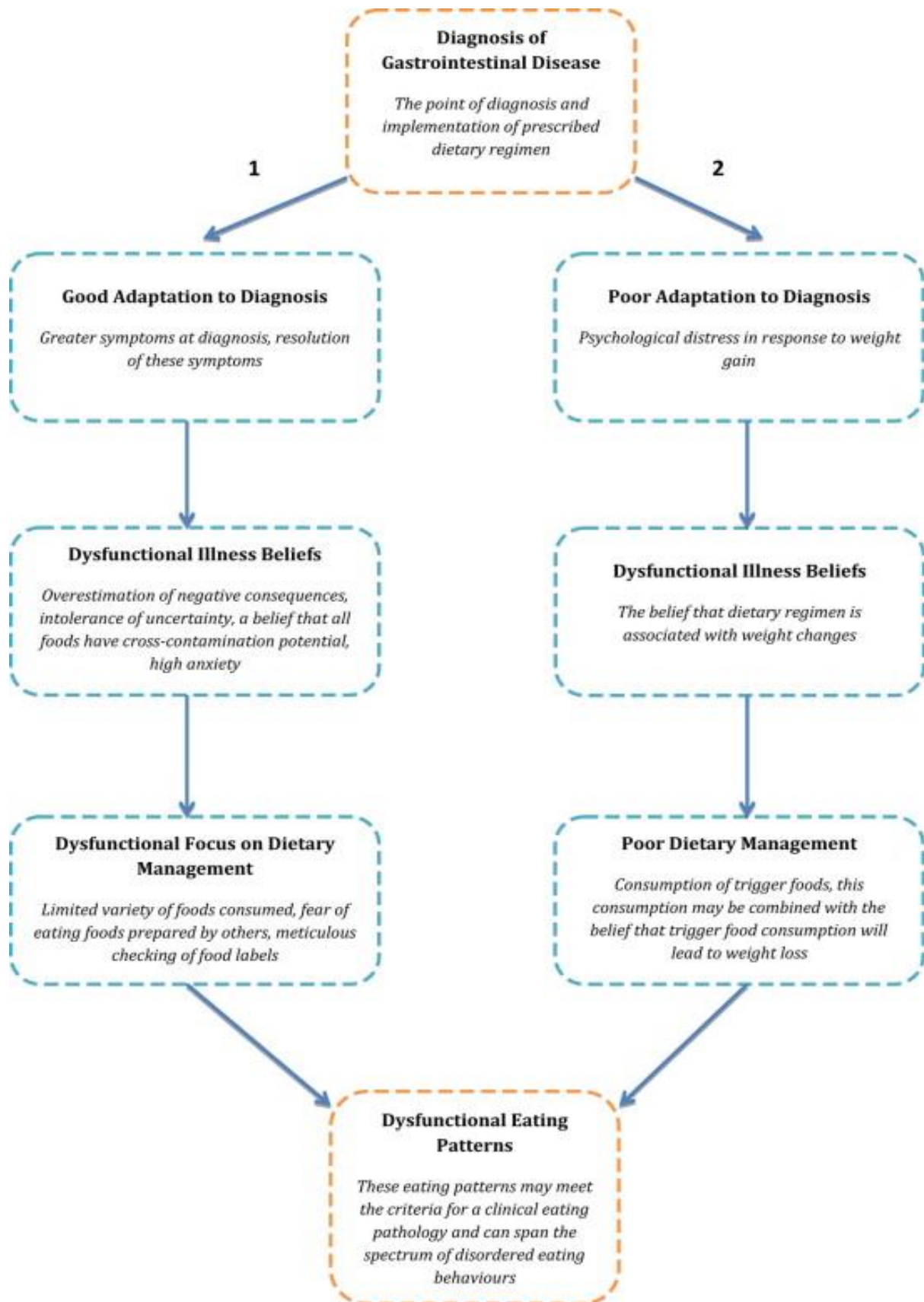
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458 *funding of this project.*

459 *Transparency Statement: The lead author affirms that this manuscript is an honest,*
460 *accurate, and transparent account of the study being reported; that no important aspects of*
461 *the study have been omitted and that any discrepancies from the study as planned (and*
462 *registered with) have been explained. The reporting of this work is compliant with STROBE*
463 *guidelines.*

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550



551

552 Figure One. The Satherley, Howard and Higgs' model of disordered eating in gastrointestinal
 553 disease. Figure taken with permission from: Satherley R, Howard R, Higgs S. Disordered
 554 eating in gastrointestinal disorders. *Appetite* 2015; **84**: 240-250.

555 Table 1

556 *Participant Characteristics and Disordered Eating Scores*

	Pseudonym	Age (years)	Years since Diagnosis	EAT-26 Score	BES Score
<i>'Typical Eaters'</i>	Katy	19	3	6	8
	John	53	2	3	3
	Mel	26	2	0	3
	Louise	29	10	8	1
	Sue	49	5	0	11
	Colette	59	19	5	2
	Richard	49	4	4	5
	Anna	28	3	7	1
	Katherine	32	3	9	5
	George	36	7	0	2
	Andrea	29	6	3	3
	<i>Mean</i>	<i>37.2</i>	<i>5.8</i>	<i>4.1</i>	<i>4</i>
<i>'Disordered Eaters'</i>	Caroline	48	3	12	23**
	Amy	48	3	26*	18**
	Paula	41	3	26*	8
	Georgia	48	2	26*	30**
	Dan	40	6	21*	25**
	Julie	22	4	30*	13
	Martha	35	4	27*	14
	Steve	38	6	19	22**
	Holly	29	2	26*	21**
	Lisa	54	8	27*	19**
	<i>Mean</i>	<i>40.3</i>	<i>4.1</i>	<i>24</i>	<i>19.3</i>

557 *Note.* * >20 on EAT-26; ** >17 on BES

558

Superordinate Theme	Sub-Theme	Example Quotes from Disordered Eaters	Example Quotes from Typical Eaters
Adaptation	<i>The New Self</i>	<p>Caroline: I've lost a lot of confidence in the way I look.</p> <p>Julie: My stomach is a lot bigger now, it's hard to accept that that's healthier.</p> <p>Dan: My weight kept going up and down, I found that very difficult.</p>	<p>Sue: I have more strength and energy, so I perceive myself as better.</p> <p>John: My weight hasn't changed much at all.</p> <p>Richard: I've lost some weight, I think that's one of the benefits of being a Coeliac.</p>
	<i>Mourning of Gluten</i>	<p>Julie: Viennese whirls. I miss them, they were my favourite and I get sad thinking about them.</p> <p>Dan: I ate a lot of gluten, to say goodbye to the foods I wouldn't be able to eat anymore.</p> <p>Caroline: My diet is so restrictive, it's impossible not to miss old foods.</p>	<p>Richard: I don't really miss any foods because they made me so ill.</p> <p>Louise: It felt like a mourning for what you couldn't have, I was angry but made peace with it in the end.</p> <p>Sue: I feel so much better now, I don't think I could miss gluten.</p>
Illness Beliefs	<i>The Dangers of Cross Contamination</i>	<p>Amy: I clean the surfaces before cooking and reduce the contamination risk.</p> <p>Georgia: I don't let cross-contamination control me, I just do a quick check before eating.</p> <p>Julie: It doesn't overly concern me, I might get ill but a small bit of gluten won't kill me.</p>	<p>Sue: I'm worried about the crumbs, if my husband's bread is in my kitchen, I won't eat.</p> <p>Louise: Sometimes it's safer not to eat because cross-contamination is everywhere.</p> <p>Mel: I have a gluten radar on at all times, if that radar is activated, it's best not to eat.</p>
	<i>My GFD Makes me Fat</i>	<p>Georgia: Gluten-free foods are full of calories, they make me feel fat.</p> <p>Caroline: Gluten-free food is full of rubbish, it definitely contributed to my weight gain.</p>	<p>Katy: Gluten-free cakes are unhealthy but I limit them like anyone else would limit cakes.</p> <p>Richard: I knew that I would gain weight as my body healed.</p>

Dietary Management	<i>Risk-Taking</i>	<p>Paula: Sometimes I'll take a very small risk.</p> <p>Georgia: I think I should probably be more careful than I am.</p> <p>Caroline: It's hard outside the home, I may take some risks then.</p>	<p>Mel: Gluten is poison, I would never cheat.</p> <p>Richard: I'm very ill when I make mistakes, I can't let it happen.</p> <p>Louise: I haven't had gluten. I just don't allow it.</p>
Eating Knowledge and Practices	<i>Eating for Pleasure</i>	<p>Georgia: Food is my enemy at the moment.</p> <p>Paula: Food makes me upset. It makes me scared. It makes me jealous.</p> <p>Amy: Eating isn't enjoyable anymore, it causes a lot of stress, particularly outside the home</p>	<p>John: Food is just a tool for my body now.</p> <p>Sue: I've gone off food, it causes me a lot of anxiety.</p> <p>Richard: Eating is a lot more difficult than it used to be, it can be done but it involves a lot more planning and isn't as relaxed.</p>
	<i>Food Preoccupation</i>	<p>Caroline: I'm a lot more aware of the calories in food now and more careful about what I eat.</p> <p>Julie: The gluten-free foods are full of fat and calories, I just avoid them.</p> <p>Georgia: Food is always on my mind, I think I'm a little bit obsessive about food.</p>	<p>Katy: You're always thinking about food. You're always cooking food.</p> <p>Mel: It does make you a bit conscious about how you are with foods.</p> <p>Richard: Food is always on my mind but it motivates me to cook and I now want to make a gluten free cake shop.</p>
	<i>New Eating Patterns</i>	<p>Julie: I overcompensate with cakes and cookies.</p> <p>Caroline: I eat a limited range of foods but it works for me.</p> <p>Dan: I always search for the new gluten-free treats. They're hard to find, so I feel like I deserve them when I can have them.</p>	<p>Colette: I will eat anything, as long as it's gluten-free.</p> <p>Richard: I cook a lot more now and I'm more interested in cooking, which makes sourcing food a lot easier.</p> <p>Sue: I don't eat out as much now, but in my home it's just the same as it used to be.</p>

561 **Appendix A – STROBE Assessment**

562 STROBE Statement

	Item No	Recommendation
Title and abstract	1	(a) Indicate the study’s design with a commonly used term in the title or the abstract – see study title “A Framework Analysis”
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found - see Abstract
Introduction		
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported – see lines 54-74
Objectives	3	State specific objectives, including any prespecified hypotheses – see lines 68-74
Methods		
Study design	4	Present key elements of study design early in the paper – see lines 72-74; 97-100
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection – see lines 86-87; 103
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants – see lines 77-82
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable – see lines 80-85; 94-96; 98-100
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group –see lines 80-85; 94-96; 98-100
Bias	9	Describe any efforts to address potential sources of bias – N/A
Study size	10	Explain how the study size was arrived at – see lines 88-90
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why – see table one; see lines MIGHT NEED TO ADDRESS THIS
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding – see lines 112-121
		(b) Describe any methods used to examine subgroups and interactions N/A?
		(c) Explain how missing data were addressed – see lines 90-93
		(d) If applicable, describe analytical methods taking account of sampling strategy – see lines 88-90

(e) Describe any sensitivity analyses N/A

Results		
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed – see lines 88-90 <hr/> (b) Give reasons for non-participation at each stage – see lines 88-90 <hr/> (c) Consider use of a flow diagram
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders – see lines 125-128 and Table One <hr/> (b) Indicate number of participants with missing data for each variable of interest – see line 88-90
Outcome data	15*	Report numbers of outcome events or summary measures – missing data was not analysed so numbers are the same throughout
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included N/A <hr/> (b) Report category boundaries when continuous variables were categorized – lines 80-82 <hr/> (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period N/A
17Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses N/A
Discussion		
Key results	18	Summarise key results with reference to study objectives – see lines 312-315
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias – see lines 402-428
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence – see lines 438-442.
Generalisability	21	Discuss the generalisability (external validity) of the study results – see line 399 ???
Other information		
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is

based x- see lines 443-444
