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# Nutritional problems in inflammatory bowel disease: The patient perspective

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# **KEYWORDS**

Inflammatory bowel disease; Crohn's Disease; Ulcerative colitis; Food; Nutrition; Patient experience

#### Abstract

Background and aims: Crohn's Disease (CD) and ulcerative colitis (UC) are inflammatory bowel diseases (IBD), which may result in nutrition problems that impact on patient health, nutritional status and quality of life. Subjective reports of how IBD patients experience these problems as part of their disease process, including comparisons between patient groups, or the need for tailored nutrition advice as perceived by these patients, have not been widely studied. This survey aimed to identify and explore nutritional problems that are important to CD and UC patients and to investigate their views on the IBD health services provided to help them with these.

*Methods*: Eighty-seven IBD patients were invited to take part in a nutrition survey using face-to-face questionnaire interviews. The survey asked about food and nutrition problems that patients have experienced, identifying which were most significant and the extent to which they had been addressed by the clinical service.

Results: Seventy-two IBD patients completed the evaluation (47 CD, 25 UC). Of these, 45 (62.5%) felt that food and nutrition were either 'important' or 'extremely important' in their experience of IBD, and 59 (82%) reported problems with food and nutrition. Patients with CD and UC reported similar frequencies of most nutritional problems. However, 44 (94%) CD vs. 16 (64%) UC patients reported problems with weight (p=0.002). Less than half of patients had seen a dietitian for tailored nutritional advice to address these problems.

Conclusions: Nutritional problems experienced and reported by IBD patients are numerous and varied. They are considered important by patients with CD and UC, both of whom would generally value specific dietary counselling, highlighting a need for further research in this area and adequate and equal provision of services for both groups.

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## 1. Introduction

Inflammatory bowel disease (IBD) can have a major impact on patients' lives, including disruption of daily activities, social interactions, intimacy, psychological function and physical health. <sup>1,2</sup> Food and nutrition are important aspects of peoples' lives, and these may be disturbed in patients with IBD.

Nutritional problems, measured using objective clinical indices, are common and vary depending on disease location, pattern and activity, surgical resection, stoma and associated complications. Between 20 and 85% of IBD patients have nutritional deficiencies. 3 with protein energy malnutrition being the most common, 4 occurring in both Crohn's Disease (CD) and ulcerative colitis (UC). <sup>5</sup> The cause of malnutrition is multifactorial and includes poor dietary intake, increased nutrient requirements and malabsorption.<sup>6</sup> Furthermore, the factors affecting each of these are numerous, for example, inadequate dietary intake may be the result of symptoms, medication side effects and the psychological impact of IBD, with evidence of impairments in appetite sensing. 7 These nutritional problems are not merely isolated to periods of active disease, with a variety of nutritional and functional deficiencies in IBD even following long periods of remission and despite macronutrient requirements being met.<sup>8–11</sup>

Although the interaction between IBD and nutritional status has been extensively researched, there is far less information on the role of food and nutrition as perceived by IBD patients themselves. The role of diet is central to an individual's psychological, social and cultural wellbeing and is linked to health-related quality of life. 12 As such, diet and nutrition have been identified as issues of primary concern for IBD patients for a variety of other reasons. These include diet as a treatment, 13-15 cause or a key factor for prevention<sup>13</sup>; dietary issues associated with surgery, postsurgery relapse or presence of a stoma<sup>16</sup>; and general concern over the role of diet and ambiguity about symptom control through non-pharmaceutical means. <sup>17</sup> Some patients believe that food induces or exacerbates symptoms 16,18,21 and may modify their diet in an attempt to gain some control over the disease. 6,14,22 As such, patients' beliefs about food and nutrition may have an impact on nutritional status resulting from dietary restriction or non-compliance with prescribed vitamin or mineral supplements. 14,22,23

The British Society of Gastroenterology guidelines for the management of IBD stipulate nutrition as an integral part of the management of CD.<sup>4</sup> Many health professionals, including doctors, nurses and dietitians, can play an important role in nutritional interventions in patients with IBD,<sup>24</sup> yet may discount patients' general concerns<sup>2</sup> and provide inconsistent, inadequate or confusing advice.<sup>16,21,25</sup> Meanwhile, there is currently a lack of specialist dietetic services to specifically support IBD patients, and a recent audit identified continued deficits in nutritional assessment and highlighted this as a key priority for improvement,<sup>26</sup> a situation not restricted to the United Kingdom.<sup>27</sup>

There is an increasing drive to understand the patient perspective in modern healthcare and increase patient involvement in setting research agendas. <sup>28</sup> Objective, clinical measures of nutritional status indicate a high prevalence of food and nutrition problems in IBD, yet the patients' experience has not been extensively investigated. Previous research is limited by sample size and has not fully explored the experiences of CD patients compared to those with UC, and whether health services meet their expectations. The aim of this study was to investigate the prevalence of food and nutrition problems as perceived by patients with IBD and the factors associated with these. In addition, the study aimed to investigate the extent to which these problems are addressed by health services.

## 2. Materials and methods

#### 2.1. Patients

Patients with IBD were recruited to a structured questionnaire survey regarding food and nutrition problems in IBD. They were identified from adult outpatient gastroenterology clinics at Guy's and St Thomas' NHS Foundation Trust. Patients were approached, and those willing to participate were recruited to individual face-to-face interviews conducted by two researchers (AP and AM).

Adults (≥ 18 years) with an existing diagnosis of CD or UC and a willingness to participate were included in the study. Every effort was made to recruit all eligible patients to minimise selection bias. There were no exclusion criteria to maximise population representativeness.

The interviews were conducted prior to or immediately following each patient's medical consultation. The patient was assured of confidentiality and anonymity and all patients provided informed consent to participate. The St Thomas' Research and Ethics Committee deemed that this questionnaire survey did not require ethical approval, as it constituted a patient needs assessment and service evaluation.

#### 2.2. Questionnaire design

A standardised questionnaire was used to structure the interviews, developed using a rigorous, evidence-based process. <sup>29</sup> A literature search was undertaken to identify studies that investigated the views of patients with CD or UC on food, nutrition and health service provision. Relevant questions from existing questionnaires were pooled and new questions developed, incorporating a range of quantitative and qualitative styles. Topics relevant to the research aims and objectives were brainstormed and the selected questions were ordered and phrased appropriately. A lengthy process of refinement continued until all team members considered the questionnaire to have face validity. The questionnaire was then pre-tested using role-play of fictional patients to ensure standardisation between interviewers,

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and then piloted with a small sample of IBD patients prior to final modifications.

The final questionnaire was structured into three sections investigating: (i) patient experiences and importance of food and nutrition problems: (ii) how health services addressed these issues; and (iii) demographic and clinical information. Patients were asked to describe their experiences of IBDrelated food and nutrition problems, which they may have had at any point during their disease. Patients were asked how recently they had experienced these problems and to report them in their own words through open questioning, to allow a richer narrative exploring the breadth of food and nutrition problems, as perceived by the patient. Following this, closed questions were used to ask about specific food and nutrition problems that the research team had identified in the literature search (i.e. weight issues, tiredness, trigger foods, gut problems, impaired social activities and nutrient deficiencies, all related to food). Closed questions were also used to identify patients who had previously received nutritional advice as part of their IBD care and scaled questions captured patient satisfaction ratings with these health services. Patient reported responses were not verified against objective sources, such as medical records.

# 2.3. Statistical analysis

All statistical analyses were performed using SPSS® 17.0 software (SPSS Inc., Chicago, IL, US). Quantitative data was entered directly and qualitative data was interpreted, coded and then entered into SPSS. To minimise data entry bias, a process of complete double data entry was undertaken,

which was checked for accuracy and consistency. Continuous data (e.g. age) are presented as mean (SD) and were compared between sub-groups (e.g. CD vs. UC) using unpaired t-tests. Categorical data are presented as n (%) or n/N (%) and were compared between sub-groups using the chi-squared test. However, where >20% of cells had expected counts of less than five, the Fisher's exact test was used.

# 3. Results

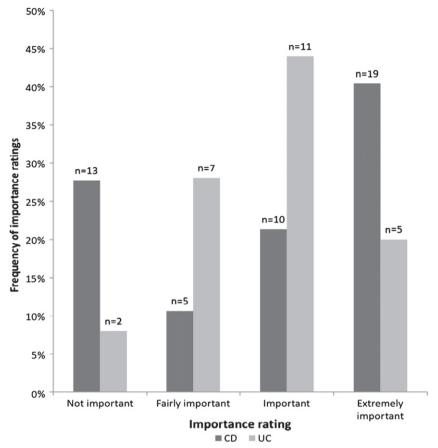
Seventy-two patients with IBD completed the interviewer-administered questionnaire, representing a response rate of 83%. Fifteen patients declined because (a) they did not want to participate (n=9); (b) feared missing their appointment (n=4); and (c) they did not have time (n=2). Demographic and clinical characteristics (Table 1) were similar between CD and UC groups, with the exception of previous surgery, which was higher in CD than UC (p<0.001).

## 3.1. Food and nutrition: importance and problems

Forty-five (62.5%) patients with IBD rated food and nutrition as either 'important' or 'extremely important' with respect to their disease. There were differences between CD and UC (p=0.012). Patients with CD were more polarised, with a greater proportion reporting food and nutrition as either 'not important' or 'extremely important', compared with UC, who were more likely to rate food and nutrition as 'fairly important' or 'important' (Fig. 1). Patients who reported themselves as having severe symptoms over the past year

Characteristic		CD (N=47)	UC (N=25)	Total IBD (N=72)
Age: mean (SD) yrs		38.7 (11.5)	40.1 (12.8)	39.2 (11.9)
Gender: n (%)	Female	29 (62)	11 (44)	40 (56)
	Male	18 (38)	14 (56)	32 (44)
Ethnicity: n (%)	White	38 (81)	18 (72)	56 (78)
, ,	Non-White	9 (19)	7 (28)	16 (22)
Time since diagnosis: n (%)		` '	` '	, ,
≤10 years		22 (47)	14 (56)	36 (50)
>10 years		25 (53)	11 (44)	36 (50)
Symptoms ( $\leq$ 12 months): $n$ (%)		, ,	, ,	` ´
None		4 (9)	4 (16)	8 (11)
Some always present		18 (38)	9 (36)	27 (38)
Flare-ups/symptom free periods		25 (53)	12 (48)	37 (51)
General disease severity in last year: n (%)		(N = 44)	(N=21)	(N = 65)
Mild		9 (21)	6 (29)	15 (23)
Moderate		15 (34)	9 (43)	24 (37)
Severe		20 (46)	6 (29)	26 (40)
Remission: n (%)		24 (52)	15 (65)	39 (57)
Hospital stay in previous 12 months: n (%)		21 (45)	6 (24)	27 (38)
History of nutrition support: <i>n</i> (%)		22 (47)	0 (0)	22 (31)
Plus normal diet		10 (21)	0 (0)	10 (14)
Sole source of nutrition		12 (25)	0 (0)	12 (17)
Previous surgery †: n (%)		28 (60)	3 (12)	31 (43)
Previous or current stoma: <i>n</i> (%)		9 (19)	3 (12)	12 (17)

 $<sup>^{\</sup>dagger}$  Significant difference CD vs. UC: (p < 0.001).



Significant difference CD vs UC responses:  $\chi^2$  (df 3, n = 72) = 10.911, p = 0.012

**Figure 1** Importance of food and nutrition to IBD patients. Significant difference CD vs. UC responses:  $\chi^2$  (df 3, n=72)=10.911, p=0.012.

were more likely to rate food and nutrition as important with respect to their disease than those with mild or moderate symptoms (p=0.013). However, there was no difference in importance ratings depending upon surgical history (previous surgery vs. no previous surgery, p=0.509), current disease state (remission vs. relapse, p=0.660) or disease duration ( $\leq$ 10 years vs. >10 years, p=0.308).

Overall, 59 (82%) patients with IBD reported experiencing problems with food and nutrition, of which 39 (83%) had CD and 20 (80%) had UC. Thirty-five (49%) had experienced problems within the last month and 49 (68%) within the last year. When asked to describe the specific types of food and nutrition problems experienced in their own words, 34 (47%) patients recalled 'trigger foods and drinks' as a problem, listing a range of items that may induce or exacerbate symptoms. Eighteen (25%) recalled 'gut problems related to diet' and eight (11%) recalled 'body weight issues'.

The clinical and demographic factors associated with the prevalence of food and nutrition problems as perceived by patients were investigated. People with CD and UC reported with similar frequency experiencing different types of food and nutrition problems related to their disease when asked specifically about each problem in turn (Table 2). However, more patients with CD (44/47, 94%) reported problems with body weight, particularly unintentional weight loss, than those with UC (16/25, 64%, p=0.002). Where problems of

excessive weight gain were cited (CD: 3/44, UC: 3/16) and a reason given as perceived by the patients (n=2), these were attributed to steroid treatment (n=1) and impaired ability to exercise due to IBD symptoms (n=1). There were no differences in the food and nutrition problems experienced between genders.

More patients who had previous surgery (29/31, 93.5%) reported problems with body weight (mostly unintentional weight loss) than those with no surgical history (31/41, 76%, p=0.043). Those with a stoma reported 'gut problems related to diet' less frequently (7/12, 58%) than those without (52/57, 91%, p=0.011). In terms of disease duration, there were no differences in the frequency of total food and nutrition problems (p=0.759) or types of nutrition problems reported, with the exception of 'micronutrient deficiencies', which were more common in patients diagnosed for more than 10 years (>10 years: 26/36, 72%,  $\leq$ 10 years 16/36, 44%, p=0.017). The most common of these reported by both CD and UC patients was iron deficiency.

Where patients cited 'trigger foods and drinks' as a problem (Table 3), those with CD most frequently reported problems with milk, alcohol, vegetables and high fibre foods. In contrast, patients with UC most frequently reported problems with spicy foods, as well as milk, alcohol, fruit and vegetables. Two patients with UC reported foods they considered to be 'helpful' in alleviating symptoms, including

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Problems, n (%)	Food and nutrition problems experienced			Most significant food and nutrition problem experienced		
	CD (N=47)	UC (N=25)	IBD (N=72)	CD (N=39)	UC (N=16)	IBD (N=55)
Weight	44 (94) *	16 (64)*	60 (83)	5 (13)	3 (19)	8 (15)
Lethargy	42 (89)	19 (76)	61 (85)	2 (5)	1 (6)	3 (5)
Trigger foods	36 (77)	21 (84)	57 (79)	5 (13)	4 (23)	9 (16)
Gut problems	40 (85)	21 (84)	61 (85)	16 (41)	3 (18)	19 (35)
Social activities	33 (70)	13 (52)	46 (64)	10 (26)	4 (23)	14 (25)
Micronutrient deficiency	28 (60)	14 (56)	42 (58)	1 (3)	1 (6)	2 (4)

brown foods and bran, lentils and VSL#3 probiotics. Among the patients who reported 'gut problems associated with

diet' these problems were predominantly with diarrhoea and pain specifically associated with eating.

Fig. 2 shows the 'social activities' that patients with IBD reported as being affected by food. Patients with CD most frequently reported problems with 'going out' (25/33, 76%), 'eating out' (21/33, 64%) and 'work' (18/33, 54.5%), and UC with 'going out' (10/13, 77%) and 'work' (9/13, 69%). Twenty-four (41%) patients with IBD reported that they alter what they eat before going out, the majority of whom said they do so by restricting food intake when outside of home, with no difference between CD and UC (p=0.297).

#### 3.2. Health service provision

Thirty-four (47%) patients reported they had seen a dietitian for IBD, of which 22 (65%) did so as an outpatient. Significantly more patients with CD (29, 62%) had seen a dietitian compared with UC (5, 20%; p=0.001). Of the 38 patients who had not seen a dietitian, 31 (82%) would like to,

Table 3 Trigger foods and drinks reported by IBD patients. CD (N = 36)UC (N=21)Total (N = 57)n (%) n (%) n (%) Milk 14 (39) 7 (33) 21 (37) Alcohol 10 (28) 7 (33) 17 (30) Spicy foods 7 (19) 9 (43) 16 (28) Vegetables 10 (28) 5 (24) 15 (26) Fresh fruit 8 (22) 5 (24) 13 (23) Fibre 10 (28) 3 (14) 13 (23) Yoghurt 7 (19) 4 (19) 11 (19) High fat foods 9 (25) 2 (9) 11 (19) 10 (17) Cheese 6(17)4 (19) Wheat 7 (19) 3 (14) 10 (17) Red meat 3 (8) 4 (19) 7 (12) Nuts or seeds 7 (19) 0 (0) 7 (12) Fizzy drinks 5 (14) 2 (9) 7 (12) Fruit juice 2 (6) 5 (24) 7 (12) Caffeine 2 (6) 3 (14) 5 (9) Dried fruit 1 (3) 3 (14) 4 (7) Large meals 2 (6) 2 (9) 4 (7) 2 (9) Sugar 2 (6) 4 (7) Sweet snacks 2 (6) 2 (9) 4 (7)

and these included 23 (85%) who rated food and nutrition as 'important' or 'extremely important' in their disease. Twenty-four (33%) patients reported they would be interested in attending a support group where they could discuss food and nutrition if it was offered as part of the service, with no difference between CD (15/47, 32%) and UC (9/25, 36%) (p=0.926).

## 4. Discussion

This study investigated the prevalence of food and nutrition problems as perceived by patients with IBD and the factors associated with them. There is a limited amount of previous research exploring CD and UC patients' subjective and shared experiences of IBD, and issues that are important to them, particularly in relation to food and nutrition and associated health services.

#### 4.1. Food and nutrition: importance and problems

Patients with CD were more polarised than those with UC in the importance assigned to food and nutrition in their disease, and this could be reflected by a greater recognition of nutrition in the treatment of CD than UC. This in turn may translate into reduced knowledge and awareness among UC patients, who are less certain about the role of diet in their disease; however, this has not previously been investigated. There were no differences in the perceived importance of food and nutrition between patients currently in remission and those in relapse, perhaps suggesting that its importance did not merely relate to managing active disease, but also for the maintenance of remission or perhaps simply for general health and quality of life.

The majority of patients reported food and nutrition problems as a result of their disease, consistent with previous research. <sup>18,20,21,30</sup> Patients with CD most frequently reported 'gut problems associated with diet' as being most significant, followed by 'impaired social activities', whereas patients with UC most frequently reported 'impaired social activities' and 'micronutrient alteration' as most the significant problems.

Comparisons of problems experienced by CD and UC patients that could be statistically analysed revealed no significant differences, with the exception of 'weight issues'. Existing research directly comparing food and nutrition problems experienced by these two groups is limited and inconsistent. Ballegaard et al. observed no

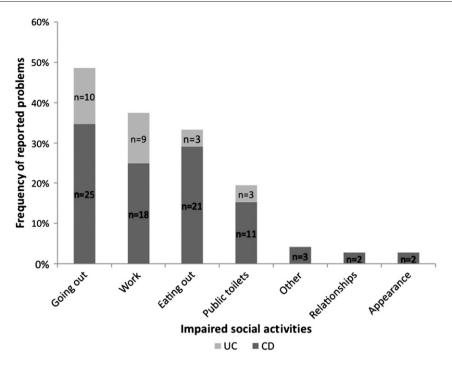


Figure 2 Problems with impaired social activities reported by IBD patients.

differences between patient groups when investigating food intolerances in IBD, <sup>23</sup> consistent with the findings here. However, in a survey conducted by Joachim, people with UC reported less adverse reactions to food than people with CD. <sup>19</sup> Despite this, studies of CD<sup>15,16</sup> and UC patients alone <sup>13,14,18</sup> and the present study suggest that both groups, as perceived by the patients themselves, experience similar prevalence and types of problems.

Weight loss was the most commonly reported 'weight issue', in line with the literature reporting high rates of malnutrition in IBD.<sup>4,5,10</sup> However, more patients with CD reported having experienced weight loss than patients with UC, as would be expected based upon the potential for inflammation at the site of macronutrient absorption. In addition, more patients with a history of surgery reported problems with weight loss, consistent with the evidence for a higher prevalence of malnutrition in those who have undergone gastrointestinal resection or have short bowel syndrome.<sup>31,32</sup>

Functional gut symptoms are common in IBD affecting 57% and 33% of patients with CD and UC respectively. <sup>33</sup> The diet may contribute to such symptoms, particularly poorly absorbed short chain, fermentable carbohydrates. <sup>34</sup> 'Trigger foods' that induce or exacerbate symptoms was the most commonly reported food and nutrition problem during openended questioning. Identifying and manipulating 'trigger foods' is a common strategy used by patients to manage their symptoms. <sup>6,14,22</sup> A patient's relationship with food can be described as a learning process to identify items that trigger episodes and, as such, patients require individualised, tailored advice to help them manage and alleviate symptoms safely and effectively, without detrimental effects on dietary quality and nutrient intake.

Physiological mechanisms underpinning how foods act as triggers for symptoms or relapse are largely unknown, although a variety of theories have been proposed. It has been suggested that microparticles (e.g. food additives) act

as antigens to the gastrointestinal tract in CD. 35,36 Meanwhile, there is some evidence that high intakes of dairy products or reduced fibre are associated with increased relapse in UC, with the strongest evidence being for sulphurrich foods (e.g. red meat, cheese, milk, fish, nuts and eggs) and alcoholic drinks, many of which contain high levels of sulphate additives. 30 Although the current study does not confirm the role of sulphur specifically, the fact that patients reported many of these foods and drinks as being problematic warrants further investigation. There is also growing evidence for a link between functional GI symptoms and intake of fermentable oligosaccharides, disaccharides, monosaccharides and polyols (FODMAPs), 37 with a reduction of these in the diet resulting in an improvement in abdominal symptoms in patients with IBD, including pain, bloating, wind and diarrhoea.<sup>34</sup> Interestingly, some of the trigger foods identified by patients in this survey contain FODMAPs (e.g. milk, wheat and fruit) and further research into the efficacy and application of this approach is also warranted.

The most commonly reported gut symptom related to eating was diarrhoea, consistent with Waljee et al. (2009). <sup>18</sup> Forty one percent of patients altered what they ate before going out and whilst away from home, and food restriction is a common theme, <sup>20</sup> and has potential implications for nutritional status. Pain and bloating were also commonly reported symptoms following eating and the extent to which they were perceived to be associated with diet varied between individuals. Patients reporting gut problems related to diet might have been experiencing functional symptoms rather than those related to active inflammation. <sup>33</sup>

'Going out' was the most commonly reported impairment in social activities related to food, in particular during active disease, and was related to 'gut problems' as described earlier. Many patients expressed concerns about needing to find a toilet after eating whilst out, often describing this as difficult and embarrassing; with many reporting they only go

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to familiar places where the location of public toilets is known. These findings reflect those of a previous focus group study in patients with UC.<sup>18</sup>

Iron deficiency was the most frequently reported micronutrient deficiency, followed by vitamin  $B_{12}$  and calcium, all of which have been confirmed using objective clinical assessment.  $^{3,38,39}$  Despite this, patients with UC and CD tended not to consider these problems to be as significant to them in their experience of IBD as those that had a direct impact on symptoms or behaviour (e.g. 'trigger foods', impaired social activities'). Patients diagnosed for more than 10 years were more likely to experience such deficiencies, compared with those diagnosed for less, possibly due to prolonged malnutrition or long-term use of pharmacological agents (e.g. steroids and sulfasalazine). Lethargy, another commonly reported problem by both CD and UC patients, was often associated with iron deficiency or poor overall nutritional intake.

#### 4.2. Health service provision

There is a dearth of literature regarding health services available to patients with respect to food and nutrition. In this evaluation, just under half of all IBD patients reported having seen a dietitian as part of their treatment. This is better than the national average of 33% as reported in the UK IBD 2008 Audit findings. However, many patients who reported they had not seen a dietitian stated that they were unaware of and had not been offered this service, which falls short of the National IBD Service Standards which state that all IBD patients should have access to a dietitian. However, and the service is a dietitian and the service of the National IBD Service Standards which state that all IBD patients should have access to a dietitian.

Significantly more CD patients had seen a dietitian for specialist dietary counselling than those with UC. Some patients with UC commented that following diagnosis they were told diet has nothing to do with it. In objective studies diet has not been highlighted as such an important factor in UC compared with CD, which may result in the fewer referrals for specialist dietary counselling by doctors. This is contrary to the experiences of UC patients here who described similar food and nutrition problems as CD patients. The findings of this study demonstrate that, despite a lack of evidence supporting nutritional intervention in UC, these patients still perceive this to be an important area of care. Clinicians wishing to adopt a more patient-focused approach should offer specialist nutritional care to both patient groups.

In addition, the results suggest that patients often avoid foods they perceive to exacerbate their condition, putting them at risk of deficiency of key nutrients. However, the foods avoided varied greatly between patients, limiting the possibility of screening for a limited number of specific nutrients. This highlights the need for tailored assessment and advice to ensure nutritional adequacy, whilst maintaining optimal symptom control and quality of life.

# 4.3. Limitations

The sample was restricted to one large tertiary referral centre in the United Kingdom and as such the findings should be interpreted cautiously as they may not apply to a wider population. However, we avoided restrictive inclusion and exclusion criteria in order to maximize the diversity and

representativeness of the patient sample. In total, 72 patients were recruited and this compares favourably with studies that objectively measure nutritional status in IBD. A strength of this study is that all patients with IBD attending out-patient clinics during this period were approached and therefore the sample reflects the actual patient mix, which consisted of more patients with CD than UC. This in turn reflects the greater utilisation of out-patient appointments by this group. 41 The structured interview format tends to yield fewer participants than alternative methods, such as postal or telephone surveys, however, it allows for more accurate and detailed data collection, another strength of this study. Therefore, whilst acknowledging the limitations of our sample, our findings provide insights into patient experiences of food and nutrition that will enable comparative research to be undertaken. Such research could assess food and nutrition problems between patients with IBD at different centres, or could compare these between different gastrointestinal disorders.

Triangulation of methods to verify qualitative data increases validity. A combination of focus groups and indepth interviews would be the most appropriate method by which to do this. A future study based at more than one clinical service, with a larger sample size and using a combination of data collection approaches, is needed to build the knowledge base in this important area of IBD care.

# 4.4. Conclusions

Food and nutrition are important to IBD patients, who have a wide range of concerns regarding how they affect their quality of life, nutritional status and disease. The food and nutrition problems experienced by CD and UC patients are similar, numerous and varied, and are generally considered important by both groups, who would value specialist and tailored nutritional input.

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AP participated in the design of the study, undertook patient recruitment, data analyses and interpretation and drafted the manuscript. AM participated in the design of the study and undertook patient recruitment. KW, MCEL and DR participated in the design of the study, data interpretation and contributed to drafting the manuscript. All authors read and approved the final manuscript.

#### References

- Magro F, Portela F, Lago P, Deus J, Cotter J, Cremers I, Vieira A, Peixe P, Caldeira P, Lopes H, Goncalves R, Reis J, Cravo M, Barros L, Ministro P, Lurdes Tavares M, Duarte A, Campos M, Carvalho L. Portuguese Study Group of IBD (GEDII), Association of Portuguese Patients with IBD (APDI) Inflammatory bowel disease: a patient's and caregiver's perspective. *Dig Dis Sci* 2009 Jan 9.
- 2. Ghosh S, Mitchell R. Impact of inflammatory bowel disease on quality of life: results of the European Federation of Crohn's and

- Ulcerative Colitis Associations (EFCCA) patient survey. *Journal of Crohn's and Colitis* 2007;1:10–20.
- Lucendo AJ, De Rezende LC. Importance of nutrition in inflammatory bowel disease. World J Gastroenterol 2009 May 7;15(17):2081–8.
- Carter MJ, Lobo AJ, Travis SP. IBD Section, British Society of Gastroenterology. Guidelines for the management of inflammatory bowel disease in adults. Gut 2004 Sep;53(Suppl 5):V1–16.
- Yamamoto T, Nakahigashi M, Saniabadi AR. Review article: diet and inflammatory bowel disease—epidemiology and treatment. Aliment Pharmacol Ther 2009 Jul 1;30(2):99–112.
- O'Sullivan M, O'Morain C. Nutrition in inflammatory bowel disease. Best Pract Res Clin Gastroenterol 2006; 20(3):561–73.
- Bannerman E, Davidson I, Conway C, Culley D, Aldhous MC, Ghosh S. Altered subjective appetite parameters in Crohn's disease patients. Clin Nutr 2001 Oct; 20(5):399–405.
- Geerling BJ, Badart-Smook A, Stockbrugger RW, Brummer RJ. Comprehensive nutritional status in patients with long-standing Crohn disease currently in remission. Am J Clin Nutr 1998 May;67(5):919–26.
- Filippi J, Al-Jaouni R, Wiroth JB, Hebuterne X, Schneider SM. Nutritional deficiencies in patients with Crohn's disease in remission. *Inflamm Bowel Dis* 2006 Mar;12(3):185–91.
- Vaisman N, Dotan I, Halack A, Niv E. Malabsorption is a major contributor to underweight in Crohn's disease patients in remission. *Nutrition* 2006 Sep;22(9):855–9.
- 11. Hengstermann S, Valentini L, Schaper L, Buning C, Koernicke T, Maritschnegg M, et al. Altered status of antioxidant vitamins and fatty acids in patients with inactive inflammatory bowel disease. *Clin Nutr* 2008 Aug; 27(4):571–8.
- 12. Barr JT, Schumacher GE. The need for a nutrition-related quality-of-life measure. *J Am Diet Assoc* 2003 Feb; **103**(2):177–80.
- 13. Welfare MR, Colligan J, Molyneux S, Pearson P, Barton JR. The identification of topics for research that are important to people with ulcerative colitis. *Eur J Gastroenterol Hepatol* 2006 Sep: **18**(9):939–44.
- 14. Jowett SL, Seal CJ, Phillips E, Gregory W, Barton JR, Welfare MR. Dietary beliefs of people with ulcerative colitis and their effect on relapse and nutrient intake. *Clin Nutr* 2004 Apr;23(2):161–70.
- 15. Kennedy ED, To T, Steinhart AH, Detsky A, Llewellyn-Thomas HA, McLeod RS. Do patients consider postoperative maintenance therapy for Crohn's disease worthwhile? *Inflamm Bowel Dis* 2008 Feb; 14(2):224–35.
- 16. Zutshi M, Hull TL, Hammel J. Crohn's disease: a patient's perspective. *Int J Colorectal Dis* 2007 Dec; **22**(12):1437–44.
- Hall NJ, Rubin GP, Dougall A, Hungin AP, Neely J. The fight for 'health-related normality': a qualitative study of the experiences of individuals living with established Inflammatory Bowel Disease (IBD). J Health Psychol 2005 May; 10(3):443–55.
- Waljee AK, Joyce JC, Wren PA, Khan TM, Higgins PD. Patient reported symptoms during an ulcerative colitis flare: a Qualitative Focus Group Study. Eur J Gastroenterol Hepatol 2009 May;21(5):558–64.
- 19. Joachim G. Responses of people with inflammatory bowel disease to foods consumed. *Gastroenterol Nurs* 2000 Jul-Aug; 23(4):160–7.
- Fletcher PC, Schneider MA. Is there any food I can eat? Living with inflammatory bowel disease and/or irritable bowel syndrome. Clin Nurse Spec 2006 Sep—Oct; 20(5):241—7.
- Jamieson AE, Fletcher PC, Schneider MA. Seeking control through the determination of diet: a qualitative investigation of women with irritable bowel syndrome and inflammatory bowel disease. Clin Nurse Spec 2007 May—Jun;21(3):152–60.
- 22. Fletcher PC, Jamieson AE, Schneider MA, Harry RJ. "I know this is bad for me, but...": a qualitative investigation of women with irritable bowel syndrome and inflammatory bowel disease: part II. Clin Nurse Spec 2008 Jul—Aug; 22(4):184—91.
- Ballegaard M, Bjergstrom A, Brondum S, Hylander E, Jensen L, Ladefoged K. Self-reported food intolerance in chronic inflammatory bowel disease. Scand J Gastroenterol 1997 Jun; 32(6):569–71.

24. Hernandez-Sampelayo P, Seoane M, Oltra L, Marin L, Torrejon A, Vera MI, et al. Contribution of nurses to the quality of care in management of inflammatory bowel disease: a synthesis of the evidence. *J Crohns Colitis* 2010 Dec;4(6):611–22.

- Morris A, Leach B. An exploration of dietary advice for individuals with an ileostomy and Crohn's disease. J Hum Nutr Diet 2009;22(3):271–2.
- 26. UK IBD Audit Steering Group. IBD Audit 2008: National Results for the Organisation and Process of IBD Care in the UK. Available at: http://www.rcplondon.ac.uk/clinical-standards/ceeu/current-work/documents/UK-IBD-Audit-2nd-Round-Full-National-Report-Appendices.pdf2009 Accessed 1/5, 2010.
- 27. Cassinotti A, Keshav S, Ardizzone S, Mortensen N, Sampietro G, Fociani P, et al. IBD care in Europe: a comparative audit of the inpatient management of Crohn's disease and ulcerative colitis using the national UK IBD audit tool. *J Crohns Colitis* 2009 Dec;3(4):291–301.
- 28. Oliver S. Patient involvement in setting research agendas. *Eur J Gastroenterol Hepatol* 2006 Sep; **18**(9): 935–8.
- 29. McColl E, Jacoby A, Thomas L, Soutter J, Bamford C, Steen N, et al. Design and use of questionnaires: a review of best practice applicable to surveys of health service staff and patients. *Health Technol Assess* 2001;5(31):1–256.
- Jowett SL, Seal CJ, Pearce MS, Phillips E, Gregory W, Barton JR, et al. Influence of dietary factors on the clinical course of ulcerative colitis: a prospective cohort study. Gut 2004 Oct; 53(10):1479–84.
- 31. Nguyen GC, Munsell M, Harris ML. Nationwide prevalence and prognostic significance of clinically diagnosable protein-calorie malnutrition in hospitalized inflammatory bowel disease patients. *Inflamm Bowel Dis* 2008 Aug;14(8):1105–11.
- 32. Nightingale J, Woodward JM. Small Bowel and Nutrition Committee of the British Society of Gastroenterology. Guidelines for management of patients with a short bowel. *Gut* 2006 Aug;55(Suppl 4):iv1–12.
- Simren M, Axelsson J, Gillberg R, Abrahamsson H, Svedlund J, Bjornsson ES. Quality of life in inflammatory bowel disease in remission: the impact of IBS-like symptoms and associated psychological factors. Am J Gastroenterol 2002;97:389–96.
- 34. Gearry RB, Irving PM, Barrett JS, Nathan DM, Shepherd SJ, Gibson PR. Reduction of dietary poorly absorbed short-chain carbohydrates (FODMAPs) improves abdominal symptoms in patients with inflammatory bowel disease a pilot study. *Journal of Crohn's and Colitis* 2009;3:8–14.
- 35. Rajendran N, Kumar D. Role of diet in the management of inflammatory bowel disease. *World J Gastroenterol* 2010 Mar 28;16(12):1442–8.
- 36. Lomer MC, Thompson RP, Powell JJ. Fine and ultrafine particles of the diet: influence on the mucosal immune response and association with Crohn's disease. *Proc Nutr Soc* 2002 Feb;**61**(1):123–30.
- 37. Gibson PR, Shepherd SJ. Evidence-based dietary management of functional gastrointestinal symptoms: the FODMAP approach. *J Gastroenterol Hepatol* 2010 Feb; 25(2):252–8.
- 38. Lomer MC, Kodjabashia K, Hutchinson C, Greenfield SM, Thompson RP, Powell JJ. Intake of dietary iron is low in patients with Crohn's disease: a case—control study. *Br J Nutr* 2004 Jan; 91(1):141–8.
- Voegtlin M, Vavricka SR, Schoepfer AM, Straumann A, Voegtlin J, Rogler G, et al. Prevalence of anaemia in inflammatory bowel disease in Switzerland: a cross-sectional study in patients from private practices and university hospitals. *J Crohns Colitis* 2010 Dec;4(6):642–8.
- IBD Standards Working Group. Quality Care: Service Standards for the Healthcare of People who have Inflammatory Bowel Disease (IBD). Available at:http://www.ibdstandards.org.uk/uploaded\_ 1files/IBDstandards.pdf2009 Accessed 1/5, 2010.
- 41. Bassi A, Dodd S, Williamson P, Bodger K. Cost of illness of inflammatory bowel disease in the UK: a single centre retrospective study. *Gut* 2004 Apr;53:1471–8.