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Original article

Food avoidance in outpatients with Inflammatory Bowel Disease – Who, what and why

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SUMMARY

Background and aims: Food avoidance is common with Inflammatory Bowel Disease (IBD) and adherence to dietary guidelines is poor, contributing to under and over nutrition. Reasons for food avoidance have not been previously explored in detail. This study of IBD outpatients aimed to describe food avoidance patterns and rationale behind this, and describe source and confidence with dietary advice.

Methods: A prospective cross-sectional study using structured interview, nutritional assessment and medical record review was conducted in patients with confirmed diagnosis of IBD (n = 117) attending outpatient clinics over a six-month period. Participants were interviewed on foods avoided, rationale for food avoidance and previous dietary advice (source and confidence). Means ± SD or medians (IQR), percentages and counts were used to describe participant characteristics, food avoidance, and source and confidence in dietary advice. Bivariate analysis was used to explore relationships between food avoidance and disease factors (IBD subtype; disease activity: active disease vs remission), and between confidence in dietary advice and disease activity.

Results: Almost all participants reported food avoidance (90%), with more foods avoided during active disease (5.2 ± 3.6 foods/food categories, versus remission 2.9 ± 2.5, $p < 0.001$). Lactose-containing foods were avoided by 40% of patients in active disease and 33% in remission. Pain/cramping, increased bowel motions and diarrhea were the most common reasons for avoiding foods/food categories during both active disease and remission. Participants were most confident in advice received from the internet (3.3 ± 1.2; dietitian: 2.8 ± 1.5) in active disease; in remission participants had greatest confidence in advice received from gastroenterologists (4.1 ± 0.8; dietitian: 3.5 ± 1.2).

Conclusion: High prevalence of avoidance of nutritious foods and low confidence in dietetic advice amongst people with IBD is of concern. Further work is needed to build trust and ensure patients are provided with evidence-based nutrition recommendations to manage their symptoms whilst optimizing nutritional quality of their diet.

1. Introduction

Inflammatory bowel disease (IBD) is an umbrella term referring to chronic relapsing diseases of the gastrointestinal tract such as ulcerative colitis (UC) and Crohn's disease (CD) [1]. The cause of IBD is undefined; however, disease onset is often early in life with a typical age in the twenties [1,2]. The etiology of the disease is multifactorial with environmental factors such as diet hypothesized as a contributor to disease risk [1]. After a diagnosis of IBD, disease progression can lead to many nutritional challenges both

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during remission and active disease [3]. Chronic inflammation related to active disease can lead to protracted diarrhea and nutrient malabsorption in conjunction with decreased dietary intake placing IBD sufferers at risk of protein-energy malnutrition and/or micronutrient deficiencies [3,4]. Of concern, recent studies have shown poor adherence to dietary guidelines and higher prevalence of food avoidance among people with IBD than the general population, with 72–85% avoiding specific foods to manage symptoms of IBD [3,5–8].

There has been limited research to understand how people with IBD make decisions about food avoidance. Having the CD sub-type of IBD, severe disease and previous abdominal surgery appear to increase likelihood of food avoidance, with other factors such as ethnicity and education levels also influencing food avoidance behaviors [5–11]. Many patients avoid foods due to fear of exacerbating IBD symptoms such as diarrhea, abdominal pain and bloating [12]. Worsening of these symptoms is reported by 30–60% of patients in apparent remission from their IBD [13–16]. Abdominal symptoms in this population may be directly related to intestinal inflammation, and hence disease activity, and/or a co-existent disorders such as irritable bowel syndrome (IBS), and/or symptoms related to resection surgery (for example, bile salt malabsorption, significant loss of intestinal length) or post-inflammatory mechanical changes (for example, small bowel bacterial overgrowth, loss of colonic wall compliance) [17,18]. Hence, IBD patients need to be assessed carefully using validated clinical activity indices together with objective biomarkers (for example, hemoglobin, platelets, CRP, faecal calprotectin), and detailed clinical data relating to each patients' natural history. Another influencing factor for food avoidance may be limited or unclear dietary guidance [11], or conflicting and/or non-evidence based dietary advice from alternative health practitioners that is often sought by this patient group [5,8,10,11]. The role of dietary advice in the decision to avoid certain foods or food categories, or the confidence in dietary advice provided by different practitioners has not been previously explored in the IBD population.

The aim of the current study was to describe food avoidance patterns in outpatients with IBD, the relationships between food avoidance and disease factors (such as IBD subtype and disease activity) and understand why patients avoid specific foods or food categories. This study also aimed to describe the source of dietary information sought by patients with IBD, and their confidence in this advice.

2. Research methods (& Analysis)

2.1. Participant recruitment

This prospective cross-sectional study was conducted in IBD outpatient clinics at a single hospital that provides secondary care for over 1300 patients with IBD each year across north Brisbane in Queensland, Australia. All patients attending the IBD outpatient clinics over a six-month period were screened by the lead IBD physician for inclusion in the study. Eligibility criteria consisted of a confirmed diagnosis of IBD (CD, UC or IBD type unspecified) by a gastroenterologist, age greater than 18 years and no cognitive impairment that would prevent the patient being able to provide informed consent. Eligible participants were invited to participate in the study and written consent was obtained. The hospital and university Human Research Ethics Committees approved the study.

2.2. Data collection

Data was collected from participants via structured interview, nutritional assessment and review of medical records by a final year Masters of Dietetics student (AM). The following information was obtained from medical records: age, gender, disease subtype (CD, UC or IBD type unspecified), medications and additional IBS diagnosis made by the treating gastroenterologist. Disease activity (i.e. active disease vs. remission) was classified according to the Harvey Bradshaw Index for CD [19,20] and Simple Clinical Colitis Activity Index [21] determined from the IBD database clinic forms and from clinic notes in collaboration with the IBD nurse and/or registrar. Participants were asked to provide information on previous surgery related to their IBD (i.e. surgery for abscesses and/or fistulas, bowel resection, ileostomy, J-pouch, dilation of stricture or colostomy), and hospital admissions in the previous 12 months. All participants underwent a comprehensive nutrition assessment using the Subjective Global Assessment (SGA) [22]. SGA is a valid and reliable tool used to assess nutritional status based on medical history and physical examination features. It was used to classify subjects as well nourished (SGA A); moderately, or suspected of being, malnourished (SGA B); or severely malnourished (SGA C) [22].

2.3. Food avoidance/Dietary advice

All participants underwent a structured interview by AM. Table 1 provides a summary of questions relating to dietary habits (during active disease and remission), reasons for food avoidance, previous dietary advice and confidence in advice obtained. Questions relating to dietary habits were based on the study by Lmidi et al. (2016) [7]. Where more detail or clarification was required, the interviewer prompted participants to provide further information related to dairy intake (to allow classification of lactose-containing vs. low lactose dairy e.g. lactose-free milks and yoghurts) and the rationale for avoiding foods or food categories. Food categories were determined from common food items avoided in previous literature [7,23,24]. The structured interview was piloted with three inpatients with IBD prior to commencement of study and consequently modified to improve clarity.

2.4. Data analysis

Characteristics of participants were tested for normality using the Shapiro–Wilk test. Data that was normally distributed was assessed using parametric tests, while non-parametric equivalents were used for non-normally distributed data. Means ± SD or medians (IQR), percentages and counts were used to describe participant characteristics, food avoidance (number and type of food groups avoided, reasons for food avoidance) and source and confidence in dietary advice. Bivariate analysis (x^2 test for categorical data and Welch sample t test for continuous data) was used to explore relationships between food avoidance and disease factors (IBD subtype: CD vs. UC; disease activity), and between confidence in dietary advice and disease activity. All statistical analyses were performed using SPSS 10.0 for Windows package (SPSS Inc., Chicago, IL) or R 3.1.4 with $p < 0.05$ level considered statistically significant.

3. Results

A total of 172 patients were screened for inclusion in the study. From these, 32 patients could not be seen due to other clinic appointments, 18 were excluded due to uncertain IBD diagnosis and 5 declined to participate in the study. Characteristics of the final sample (n = 117) are displayed in Table 2. On average, participants were 45 years (SD 15), Caucasian (90%) and overweight (BMI 27.0 kg/m^2; SD 5.5). Active disease was present in 27% of participants, and 12% had an additional diagnosis of IBS. Almost all participants (97%, n = 114) were assessed as well nourished. There

Table 1
Structured interview guide.

1. Do you follow any special dietary pattern? (e.g. low FODMAP, gluten free, lactose free, paleo, vegetarian, vegan, other)[a]
2. Do you take any vitamin or food supplements? (e.g. vitamins/minerals, prebiotics, probiotics, fiber, superfood (e.g. turmeric capsules, goji berries), oral nutrition supplement (e.g. Sustagen, Ensure), herbal medicine, other)[a]
3. Do you consider dietary habits to have a more important role than medicines in the control of IBD?
4. Do you think that IBD affects your appetite and pleasure in eating?[a]
5. Do you feel some foods trigger a flare?[a]
6. Do you ever avoid eating certain foods because of your IBD?[a]
7/8. **During a Flare/During Remission** do you avoid the following foods (and if so, why)? (e.g. lactose-containing foods/dairy alternatives, wheat products, spicy foods, deep fried/fatty foods, alcohol, caffeine, other)
9/10. **During a Flare/During Remission:**
a) Do you ever skip whole meals due to symptoms of your IBD?
b) Do certain foods improve your symptoms? (Please list)
11. Have you previously received dietary or nutritional advice? Who did you receive this advice from?[a] (e.g. GP, gastroenterologist, dietitian, IBD nurse, family member, other IBD sufferers, other) How long ago? On a 5-point scale, how confident you feel about this advice?
12. Have you sought out your own dietary advice? Where did you receive this advice? (e.g. Internet – website/forum, TV, magazine, pamphlet/flyer, other) How long ago? On a 5-point scale, how confident you feel about this advice?

IBD: Inflammatory Bowel Disease; FODMAP: Fermentable Oligosaccharides, Disaccharides, Monosaccharides and Polyols; GP: general practitioner.
[a] Questions related to dietary information modified from study be Limidi et al. (2016) [7].

Table 2
Demographic and clinical characteristics of participants (n = 117, by IBD sub-type).

Characteristics	All participants, split by IBD[b] sub-type			All participants
	CD (n = 50)	UC (n = 61)	IBD– type unspecified (n = 6) (n = 6)	IBD – all (n = 117)
Male, n (%)	23 (46)	27 (44)	3 (50)	53 (45)
Age, years; mean (SD)	43 (14)	44 (14)	62 (19)	45 (15)
BMI[c], kg/m^2; mean (SD)	27.8 (6)	27.0 (6)	28.2 (6)	27.0 (6)
Ethnicity, n (%)				
Caucasian/European	46 (92)	54 (88)	6 (100)	106 (90)
Aboriginal	0 (0)	3 (5)	0 (0)	3 (3)
Asian	4 (8)	2 (3)	0 (0)	6 (5)
Other	0 (0)	2 (3)	0 (0)	2 (2)
Education, n (%)	10 (20)	14 (22)	4 (8)	28 (24)
Completed Primary School	9 (18)	7 (11)	0 (0)	16 (14)
Completed high school (Year 12)	15 (30)	18 (30)	1 (2)	34 (29)
Vocational training/Certificate/Diploma				
University Degree	16 (32)	22 (36)	1 (2)	39 (33)
Current Medication, n (%)				
Corticosteroids	1 (2)	5 (8)	2 (33)	8 (7)
Aminosalicylates	3 (6)	35 (57)	3 (50)	41 (35)
Immunomodulators	37 (74)	16 (26)	0 (0)	53 (45)
Biological Therapy	15 (30)	11 (18)	1 (17)	27 (23)
Other IBD medications	14 (28)	22 (38)	3 (50)	39 (33)
None	4 (8)	9 (15)	1 (17)	14 (12)
Alternate Medicine, n (%)				
Vitamin/mineral	23 (46)	20 (33)	4 (67)	47 (40)
Pre or Probiotic	13 (26)	13 (21)	1 (17)	27 (23)
Fiber Supplement	4 (8)	6 (10)	0	10 (8)
Other (superfoods, nutritional supplements, herbal medicine)	11 (22)	13 (21)	1 (17)	25 (21)
History of intestinal resection, n (%)	28 (56)	8 (13)	1 (17)	37 (32)
Ileostomy, n (%)	5 (10)	3 (5)	0 (0)	8 (7)
Colostomy, n (%)	2 (4)	0 (0)	0 (0)	2 (2)
Other IBD related procedures[a], n (%)	9 (18)	3 (5)	1 (17)	13 (11)
Additional IBS[d] Diagnosis, n (%)	6 (12)	6 (10)	2 (33)	14 (12)
Active Disease, n (%)	10 (20)	24 (39)	2 (33)	36 (27)
IBD related hospital admission last 12 months, n (%)	13 (26)	9 (15)	1 (17)	23 (20)
Well-nourished (SGA[e] A)	50 (100)	59 (97)	5 (83)	114 (97)
Malnourished (SGA[e] B/C)	0 (0)	2 (3)	1 (17)	3 (26)

[a] Including procedures such as surgery for abscesses/fistula, dilation of stricture.
[b] IBD: Inflammatory Bowel Disease.
[c] BMI: Body Mass Index.
[d] IBS: Irritable Bowel Syndrome.
[e] Subjective Global Assessment (SGA).

were no significant differences between participants with CD and UC with regard to standard demographic characteristics or use of alternative medicines, but treatment and history of bowel resection differed between disease sub-types. Almost half (45%, n = 57) of participants felt that having IBD affected their appetite and pleasure in eating and 21% (n = 25) of participants thought dietary habits had a more important role than medicine in the control of their IBD.

3.1. Description of food avoidance

Most participants (n = 91, 87%) reported not following a specific dietary pattern (e.g. vegetarian, low FODMAP or gluten free diet). Yet, most participants (n = 105, 90%) reported avoiding one or more foods/food categories due to their IBD, with more participants restricting foods during active disease (active: 90%, remission: 85%; $p < 0.001$). Participants also restricted a higher number of foods/

food categories during active disease (active: 5.2 ± 3.6, remission 2.9 ± 2.5; $p < 0.001$).

Participants most frequently reported avoiding spicy foods (46%), lactose-containing foods (41%), deep fried/fatty foods (39%) and alcohol (38%) during active disease, and spicy foods (39%) and lactose-containing foods (39%) during remission. Foods/food categories such as wheat products, legumes, nuts and seeds, and brassica vegetables were also commonly avoided (Fig. 1).

Patients with CD avoided significantly more foods or food categories than participants with UC in both active disease (CD: 6.2 ± 3.7, UC: 4.4 ± 3.3; $p < 0.01$) and remission (CD: 3.5 ± 2.5, UC 2.5 ± 2.4; $p = 0.03$). In remission, lactose-containing foods were most commonly avoided amongst people with CD (44%), whereas wheat products were most commonly avoided in UC (26%). In active disease, spicy foods were the most commonly avoided food/food category for both disease sub-types (CD: 46%, UC: 39%).

3.2. Rationale behind food avoidance

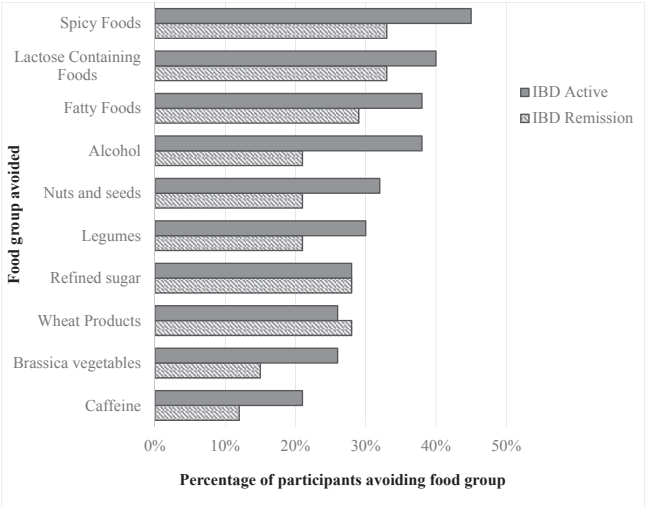
During active disease and remission, pain/cramping, increased bowel motions and diarrhea were the most commonly reported reasons for avoiding foods or food categories. Table 3 lists common patient reported reasons for food avoidance during active disease and remission. Avoiding specific foods due to dietary advice or health reasons was less common, and only cited as reasons for avoiding high fat foods, refined sugar and alcohol. Patients rarely stated that dietary advice was the reason for avoiding common foods or food categories such as lactose, wheat or spicy foods.

3.3. Information on dietary knowledge

Three quarters of participants ($n = 87$, 74%) reported previously receiving dietary advice from a health practitioner (Dietitian, Gastroenterologist, GP, IBD nurse). This advice was obtained predominantly from a dietitian ($n = 61$, 54%) followed by gastroenterologist ($n = 25$, 20%). Participants reported frequently seeking out their own dietary advice ($n = 83$, 71%), with common sources including websites $n = 63$, 53%, online forums ($n = 20$, 17%) or other sources such as books or nutrition courses ($n = 18$, 15%).

Confidence in dietary advice was assessed on a 0–5 scale and was consistently rated as low, Participants with active disease had the greatest confidence in advice received from the internet (Facebook groups, Crohn's and Colitis Australia website and Google searching) (3.3 ± 1.2), followed by a Gastroenterologist (3.0 ± 1.9), Dietitian (2.8 ± 1.5) and GP (1.3 ± 0.6). Confidence in dietary advice received from a GP was significantly lower compared to the internet, Gastroenterologists and Dietitians ($p < 0.01$); however reported confidence was not statistically different between other sources of dietary advice.

Patients currently in remission had the greatest confidence in advice received from Gastroenterologists (4.1 ± 0.8), followed by GPs (4.0 ± 1.0), Dietitians (3.5 ± 1.2) and the internet (3.3 ± 0.9). Confidence in advice received from Gastroenterologists was significantly greater compared to both Dietitians ($p < 0.01$) and the internet ($p < 0.01$).



IBD: Inflammatory Bowel Disease

Fig. 1. Percentage of participants avoiding food groups by disease activity (active disease, remission).

4. Discussion

Aligning with previous research, the present study found that almost all (90%) individuals with IBD avoid foods in an attempt to manage their IBD symptoms [8,23]. Additionally, participants were more likely to avoid a greater number of foods/food categories during active disease, regardless of disease subtype. High food avoidance raises concerns in relation to overall diet quality and variation. In both active CD and remission, participants were also found to avoid significantly more food categories than those with UC, consistent with previous Canadian studies [6,7,9,24]. Interestingly, three European studies found no difference between disease subtype, which may be explained by cultural differences in dietary patterns and/or different study methods used to assess food avoidance [25–27].

Previous research has described a range of food avoidance behaviors in patients with IBD. Consistent with previous literature, participants with active disease most frequently reported avoiding common gut irritants including spicy foods, alcohol and deep fried/fatty foods [9,24,26,27]. Of higher concern, when in disease remission, a notable number of participants avoid lactose-containing foods, wheat products, nuts and seeds, legumes, and brassica vegetables. This aligns with previous research reporting that raw vegetables and high fiber foods are avoided by many patients with IBD in both active disease and remission [6,9,12,24]. This suggests that participants avoiding these foods/food categories could be potentially at risk for inadequate intake of key nutrients including fiber, calcium, protein and B vitamins. Further research is needed to explore potential micronutrient deficiencies in this patient group.

Prior to this study the rationale behind food avoidance behavior in patients with IBD had not been explored in great depth. Previous research found reasons given for avoiding foods/food categories included fear of exacerbating symptoms, triggering a disease flare or due to advice to avoid specific foods [6,9,12,28]. A study by Zallot et al. found over half, 57.8%, of participants believed that food can play a role in causing a relapse and as mentioned previously avoided consumption of gut irritants such as spicy food (81%) and fatty foods (49%) in fear of triggering a flare [25]. This contradicts our findings with only one food category (refined sugar) commonly avoided due to fear of triggering a flare. The present study found that the most predominant reasons for avoiding most foods/or food categories in both remission and active disease were related to exacerbation of gastrointestinal symptoms such as pain/cramps, increased bowel motions/urgency and diarrhea. In remission, these symptoms are consistent with symptoms of IBS, supporting previous research indicating that IBS symptoms are commonly (33% of patients with UC and in 42–57% with CD) experienced in IBD patients in remission, as a response to the ingestion of certain foods [29–31]. Additionally foods or food categories commonly avoided

Table 3
Participant reported reasons for avoiding specific foods or food groups during active disease (n = 115) and during remission (n = 99).

Foods/food groups	Active disease (n = 115)		Remission (n = 99)	
	Avoided (n, %)	Reasons for avoiding	Avoided (n, %)	Reasons for avoiding
Spicy foods	53 (46)	Pain/cramps (n = 26, 50%) Increased bowel motions/urgency (n = 26, 50%) Diarrhea (n = 25, 47%)	39 (39)	Pain/cramps (n = 26, 50%) Dislike (n = 10, 26%) Diarrhea (n = 25, 47%)
Lactose-containing foods	47 (41)	Diarrhea (n = 22, 47%) Pain/cramps (n = 16, 34%) Bloating (n = 15, 32%)	39 (39)	Diarrhea (n = 14, 36%) Pain/cramps (n = 10, 26%) Increased bowel motions/urgency; bloating (both n = 9, 23%)
Deep fried/high fat foods	45 (39)	Increased bowel motions/urgency (n = 22, 49%) Diarrhea (n = 18, 40%) Pain/cramps (n = 16, 36%)	32 (32)	Dislike/general health (n = 11, 32%) Pain/cramps; Increased bowel motions/urgency; Diarrhea (all n = 9, 23%)
Alcohol	44 (38)	Increased bowel motions/urgency (n = 10, 23%) Diarrhea (n = 9, 20%) Dislike/general health (n = 8, 18%)	25 (25)	Dislike/general health (n = 12, 48%) Diarrhea (n = 6, 24%) Dietary advice (n = 5, 20%)
Nuts and seed	36 (31)	Pain/cramps (n = 15, 42%) Increased bowel motions/urgency (n = 12, 33%) Diarrhea (n = 10, 28%)	25 (25)	Pain/cramps (n = 8, 32%) Trigger an IBD flare; diarrhea; gas; dietary advice (all n = 4, 16%)
Legumes	35 (30)	Gas (n = 14, 40%) Pain/cramping (n = 12, 34%) Increased bowel motions/urgency (n = 11, 31%)	25 (25)	Pain/cramping (n = 9, 36%) Gas (n = 8, 32%) Increased bowel motions/urgency (n = 5, 20%)
Refined Sugar	33 (29)	Dislike/general health (n = 13, 40%) Diarrhea (n = 8, 24%) Increased bowel motions/urgency (n = 8, 24%)	33 (33)	Dislike/general health (n = 12, 36%) Dietary advice (n = 6, 18%) Trigger an IBD flare (n = 5, 15%)
Wheat	31 (27)	Bloating (n = 17, 31%) Increased bowel motions/urgency (n = 9, 30%) Pain/cramping (n = 9, 30%)	33 (33)	Bloating (n = 16, 48%) Pain/cramping (n = 8, 24%) Dietary advice (n = 7, 21%)
Brassica vegetables	31 (27)	Gas (n = 11, 36%) Pain/cramping (n = 10, 32%) Increased bowel motions/urgency (n = 9, 29%)	18 (18)	Pain/cramping (n = 8, 44%) Increased bowel motions/urgency (n = 5, 28%) Bloating (n = 4, 22%)
Caffeine	24 (21)	Diarrhea (n = 9, 38%) Increased bowel motions/urgency (n = 7, 29%) Pain/cramping (n = 7, 29%)	14 (14)	Dislike/general health (n = 5, 42%) Diarrhea (n = 4, 33%) Pain/cramping (n = 3, 25%)

by participants when in remission (i.e. wheat, lactose, legumes, nuts and seed) are also those foods known to be higher in fermentable carbohydrates which are known to be problematic for people with IBS. Yet, only one in ten participants had a confirmed diagnosis of IBS, suggesting that diagnosing concurrent IBS in people with IBD is challenging [29], particularly where they may also be ongoing but subclinical IBD activity. With respect to this important clinical issue, blood and faecal tests, including full blood count, CRP, albumin, and faecal calprotectin, are routinely used in our center's IBD clinics to monitor disease control, and thus to differentiate between active IBD, co-existent IBS, and spurious diarrhea related to previous surgery or post-inflammatory tissue damage [18]. Another explanation for the presentation of IBS-like symptoms in IBD patients is a hypersensitivity to certain food or food category. A study by Gonlachanvit et al. [32] (2009) found patients with diarrhea-predominant IBS exhibited gut hypersensitivity to chili. Subsequently, chili ingestion produced increased abdominal pain and burning in this population compared to healthy controls, supporting this idea [32]. IBS-like symptoms may also be due to the specific food components causing an abnormal response in this patient group, such as inflammation; however further research is needed to confirm this response and determine its mechanism [32].

This study found that around half of IBD participants have received dietary advice by a dietitian, but that they were neutral in their confidence in this advice. Participants were more confident in the dietary advice if they were in disease remission, while confidence was notably reduced in participants with active disease. This is not an uncommon phenomenon among people with IBD with multiple studies reporting patients are frequently unsatisfied or confused with dietary advice [5,8,11,33]. Previous research in a general chronic disease population similarly found a preference to receive nutrition advice from a medical profession compared with dietitians, related to perceptions that this would better account for disease factors and be more practice and relatable when coming from a GP [34]. However in this study of people with IBD, there was a preference for nutrition advice from their specialist medical professional (i.e. gastroenterologist), rather than GP, perhaps reinforcing the strong link between nutrition and disease amongst patients. Furthermore, in participants with active disease (likely to be most at risk of malnutrition [1]) were found to have greater confidence in the internet than health professionals. People with IBD frequently access health information and support from the internet and social media [35,36], therefore making it of critical importance for dietitians to be proactive in creating and disseminating evidence-based online information that is easily accessible by people with IBD and other health professionals to ensure that people with IBD can make informed choices about their food choices if they are seeking advice from online sources. Additionally, this study suggests that further work is needed to understand the

perception of dietitians from the perspective of people with IBD, and to establish credibility to position dietitians as experts in providing dietary advice for people with IBD.

In this study, protein-energy malnutrition was rare, with only three participants assessed as malnourished using SGA. Previous research examining the nutritional status of people with IBD has reported malnutrition prevalence between 18 and 75% [4,37], with lower rates in the outpatient population (0–40%) [23,24,38]. Advancements in IBD therapies have improved disease remission rates [1], evident in this sample of outpatients where three quarters of participants were in remission, which may also explain the low malnutrition prevalence.

This is the first Australian study to describe food avoidance in IBD patients. More, it is the first study to investigate the rationale behind food item avoidance through utilizing a structured interview approach, giving the opportunity to elicit more information about rationale for food avoidance than questionnaire methods. Utilizing this method also enhances patient comprehension of questions as participants are given an opportunity to seek clarification on areas of confusion. However, this study does have limitations to acknowledge. The cross-sectional design limits the ability to determine a cause and effect; for example, whether IBS-like symptoms reported by participants are related to IBD disease activity or in response to food item ingestion. In this study, assessment of nutritional status was limited to protein-energy malnutrition using SGA; therefore, prevalence of micronutrient deficiencies and sarcopenia, and the role of food avoidance in the development of these conditions could not be explored. The sample size and lack of sample diversity in relation to ethnicity, surgical procedures and IBD-related hospital admissions means that the impact of these factors previously shown to impact on food avoidance (e.g. ethnicity and education level) could not be examined in the present study [6,7]. There is also no validated tool for assessing food avoidance in Westernized IBD patients, thus the instrument used in this study was locally developed and not validated. Consequently, the food categories defined were based on past research and clinical experience, and therefore may not completely represent all key food items commonly avoided among people with IBD. Another challenge is determining if a patient is in active disease or remission. In future studies, use of fecal calprotectin or assessment using colonoscopy could be used to more accurately diagnosis disease remission.

From this study, it is evident that further work is needed to determine the etiology of function bowel symptoms experienced by people with IBD in remission, and to provide an evidence base from which clinicians can draw upon to deliver dietary advice. This would be assisted through the development of a validated questionnaire to identify food avoidance behaviors and subsequent symptoms experienced by people with IBD. However, this is challenging as diet is highly complex and the specific effects of an individual dietary constituent can be affected by that of others [31]. Thus it has been suggested that controlled feeding trials, coupled with biomarker approaches and nutrigenomics studies are needed to establish the true relationship between foods, inflammation and symptomology [12,32]. Currently, personalized diets implemented in collaboration with a skilled dietitian appear to be most appropriate for people with IBD to alleviate symptoms, minimize food avoidance and optimize nutritional status.

5. Conclusion

In conclusion, food avoidance is common amongst people with IBD. Food avoidance increased during periods of disease activity, and during active disease, participants with CD avoided more food items than those with UC. Participants frequently reported avoiding spicy foods, lactose-containing foods and other foods such as fruits and raw vegetables, and this varied slightly in accordance with disease subtype and activity. Increased bowel motions/urgency, diarrhea and pain/cramps were listed as the main reasons for food avoidance, with these being problematic during remission and active disease. Overall there is low confidence in advice from health professionals, particularly in active disease, with people being more confident in advice received from the internet. It is apparent that further work is needed to increase trust and confidence in dietetic advice and increase access to evidence-based information to assist people with IBD to manage their symptoms whilst minimizing food restrictions and maximizing the nutritional quality of their diet [39].

Statement of authorship

TR, JK and AY were responsible for developing the study design and obtaining ethics to undertake the study. AM was responsible for collecting the data and finalizing data collection tools. AM, AY and AL completed the data analysis. AM was responsible for writing and preparing the manuscript for publication. All authors reviewed and commented on subsequent drafts of the manuscript.

Conflict of interest statement

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