

Dietary Patterns and Self-Reported Associations of Diet with Symptoms of Inflammatory Bowel Disease

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Abstract

Background There are insufficient data to make firm dietary recommendations for patients with inflammatory bowel disease (IBD). Yet patients frequently report that specific food items influence their symptoms. In this study, we describe patients' perceptions about the benefits and harms of selected foods and patients' dietary patterns.

Methods CCFA Partners is an ongoing internet-based cohort study of patients with IBD. We used a semi-quantitative food frequency questionnaire to measure dietary consumption patterns and open-ended questions to elicit responses from patients about food items they believe

ameliorate or exacerbate IBD. We categorized patients into four mutually exclusive disease categories: CD without an ostomy or pouch (CD), UC without an ostomy or pouch (UC), CD with an ostomy (CD-ostomy), and UC with a pouch (UC-pouch).

Results Yogurt, rice, and bananas were more frequently reported to improve symptoms whereas non-leafy vegetables, spicy foods, fruit, nuts, leafy vegetables, fried foods, milk, red meat, soda, popcorn, dairy, alcohol, high-fiber foods, corn, fatty foods, seeds, coffee, and beans were more frequently reported to worsen symptoms. Compared to CD patients, CD-ostomy patients reported significantly greater consumption of cheese (odds ratio [OR] 1.56, 95 % CI 1.03–2.36), sweetened beverages (OR 2.14, 95 % CI 1.02–1.03), milk (OR 1.84, 95 % CI 1.35–2.52), pizza (OR 1.57, 95 % CI 1.12–2.20), and processed meats (OR 1.40; 95 % CI 1.04–1.89).

Conclusions Patients identified foods that they believe worsen symptoms and restricted their diet. Patients with ostomies ate a more liberal diet. Prospective studies are needed to determine whether diet influences disease course.

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Introduction

Crohn's disease and ulcerative colitis can lead to poor quality of life, weight loss, and malnutrition [1–5]. Prior studies have explored the role of diet in the etiology of inflammatory bowel disease (IBD) and demonstrated the benefit of enteral nutrition in mucosal healing [6–9]. However, there are insufficient data regarding the role of diet in the management of IBD to make firm recommendations on dietary modifications. Consequently, numerous unsubstantiated recommendations exist on

dietary modifications for patients with IBD [10–13]. Likewise, there is a paucity of research in the literature describing the dietary patterns of patients with Crohn's disease and ulcerative colitis, whether these patterns differ between disease types, and whether the presence of an ostomy or pouch influences dietary intake and symptoms associated with consuming certain food items.

One approach to identifying dietary patterns that may influence the course of the disease is to query patients. However, within a single center, it is difficult to accumulate sufficiently large numbers of patients with different phenotypes to draw strong conclusions from these patient reports. CCFA Partners is an internet-based cohort study that includes a very large number of patients with IBD. By querying patients within the CCFA Partners study, we describe IBD patients' perceptions of the benefits and harms of selected foods and their dietary patterns according to disease type, disease activity, and self-reported perception of foods that ameliorate or worsen IBD.

Methods

CCFA Partners is an ongoing internet-based cohort study of patients with IBD [14]. Invitations to join the cohort were sent via email to individuals listed on rosters of the Crohn's and Colitis Foundation of America (CCFA). Respondents completed a baseline survey that included modules on disease characteristics, medications, and dietary patterns. This study used data available from June 17, 2011 through October 4, 2011. Patients with implausible age of diagnosis were excluded (3 subjects).

Disease type was recorded within CCFA Partners based on patient self-reports. For the purpose of this study, we categorized patients into four mutually exclusive disease subtypes: CD without an ostomy or pouch (referred to as CD), UC without an ostomy or pouch (referred to as UC), CD with an ostomy (CD-ostomy), and UC with a pouch (UC-pouch). Any patient with an ostomy was excluded from the UC-pouch group.

We used the semi-quantitative food frequency questionnaire developed by the National Cancer Institute to quantify average daily consumption in the prior month of red meat, fruit, leafy vegetables, other vegetables, cheese, sweetened beverages, milk, tomatoes, dessert items, potatoes, soda, beans, pizza, processed meats, ice cream, and popcorn (<http://riskfactor.cancer.gov/studies/nhanes/dietscreen/>).

The baseline CCFA Partners survey included open-ended questions to elicit responses regarding food items that patients believed exacerbated or ameliorated their symptoms. For the first 2,000 respondents and all patients who reported having an ostomy or pouch, the free text responses were manually reviewed and grouped into

categories including similar food items (i.e., steak and pork were grouped into red meat). We only report results if at least 5 % of participants within a disease subtype identified a food item as ameliorating or worsening symptoms.

Descriptive data are reported in percentages, mean, median, and interquartile range (IQR). To analyze whether food items were more commonly reported to improve or worsen symptoms, we used the sign test with the Bonferroni method to adjust for multiple comparisons ($P < 0.00039$ was required to be considered statistically significant). The Wilcoxon rank-sum or chi squared test was used to evaluate whether patients adhered to their stated dietary patterns by consuming more of the foods that improved symptoms and less of the foods that worsened symptoms. These analyses were performed on the 2,329 patients whose free text responses were manually reviewed.

The remaining statistical analyses were performed on the entire cohort of 6,768 patients. Patients were grouped into two categories of disease activity based on self-reported survey answers. Self-reported disease activity was assessed with a 5-point Likert scale with categories of remission, minimal, mild, moderate, and severe symptoms. Patients with inactive disease were those who reported being in remission or having minimal symptoms. Patients with active disease activity were those who reported having mild, moderate, or severe symptoms. Reported food consumption for each group based on the food frequency questionnaire was categorized into quartiles from least to most consumption. Logistic regression analysis adjusting for age, sex, and previous surgery was performed to determine whether disease activity was associated with the level of consumption of specific food items. Logistic regression adjusted for age, sex, and self-reported disease activity was used to compare food item consumption across IBD subtypes. We planned a priori to compare the highest quartile to the lowest quartile in the logistic regression models.

Results

The final cohort included 6,768 patients; analysis of free text responses to foods that exacerbate and ameliorate symptoms was performed on 2,329 respondents (1,121 CD, 597 UC, 206 UC-pouch, and 405 CD-ostomy; Table 1). Across each of the IBD subtypes, approximately 70 % of respondents were women, the median age was 42–49, and 58–73 % of respondents reported having minimal disease activity. The patient demographics of the larger source cohort has been previously described [14].

The most frequently reported foods that ameliorated and exacerbated symptoms are displayed in Table 2. Yogurt and rice were more frequently reported to improve symptoms within all subgroups of patients while bananas were

Table 1 Patient demographics

Demographic	CD	UC	CD-O	UC-P
Total patients	1,121	597	405	206
Female (%)	72.4 %	64.2 %	71.6 %	69.4 %
Age				
Mean	43.9	44.9	48.2	41.6
Median	44	44	49	42
IQR	24	23	21	22
Self-reported disease activity				
Remission	24.1 %	36.0 %	39.8 %	41.8 %
Minimal symptoms	33.4 %	32.2 %	32.8 %	30.6 %
Mild symptoms	21.0 %	15.9 %	13.1 %	15.1 %
Moderate symptoms	14.4 %	10.2 %	10.1 %	8.3 %
Severe symptoms	5.1 %	5.0 %	3.7 %	2.4 %
Disease location (CD) ^a				
UGI	32.0 %	N/A	39.0 %	N/A
Jejunum	21.6 %	N/A	31.6 %	N/A
Ileum	65.0 %	N/A	68.9 %	N/A
Colon	58.0 %	N/A	88.2 %	N/A
Rectum	35.3 %	N/A	78.5 %	N/A
Stricture	52.7 %	N/A	75.3 %	N/A
Fistula now	7.1 %	N/A	13.8 %	N/A
Fistula ever	39.7 %	N/A	80.5 %	N/A
Disease location (UC)				
Rectum	N/A	5.0 %	N/A	1.0 %
Rectum/sigmoid	N/A	12.2 %	N/A	1.5 %
Left-sided	N/A	28.0 %	N/A	9.7 %
Extensive colitis	N/A	7.9 %	N/A	4.9 %
Pancolitis	N/A	29.7 %	N/A	75.7 %
Uncertain	N/A	16.6 %	N/A	6.8 %

CD Crohn's disease, UC ulcerative colitis, O ostomy, P pouch

CD patients with both an ostomy and pouch were included in the CD-O group

^a Disease location categories are not mutually exclusive. If the participant answered uncertain they were assumed not to have involvement of the bowel segment. 13 participants (1.2 %) answered uncertain for all bowel locations, all within the CD no O/P group

more commonly reported to improve symptoms in the UC-pouch group. Non-leafy vegetables, spicy foods, fruit, nuts, leafy vegetables, fried foods, milk, red meat, soda, popcorn, dairy, alcohol, high-fiber foods, corn, fatty foods, seeds, coffee, and beans were more frequently reported to worsen symptoms within most disease categories.

Further analysis showed that patients ate less red meat, dairy, soda, sugar, high-fiber foods, gluten, milk, fruit, leafy vegetables, beans, non-leafy vegetables, tomatoes, pizza, cheese, chocolate, and ice cream when they reported that these items worsened their symptoms ($P < 0.05$ for all comparisons, data included in supplemental Table 1). Conversely, patients ate more vegetarian diet, organic

Table 2 Frequency of patient-reported foods that improve or worsen symptoms

Food items	CD (n = 1,121) (B, W)	UC (n = 597) (B, W)	CD-O (n = 405) (B, W)	UC-P (n = 206) (B, W)
Improved symptoms				
Yogurt	108, 7*	54, 3*	26, 0*	19, 0*
Rice	59, 3*	30, 3*	20, 3 [†]	16, 0*
Bananas	NR	NR	NR	14, 0*
Worsened symptoms				
Non-leafy vegetables	28, 221*	29, 81*	7, 90*	3, 36*
Spicy foods	1, 145*	3, 79*	0, 46*	0, 33*
Fruit	50, 136*	40, 63	22, 51 [†]	15, 24
Nuts	3, 120*	1, 33*	0, 52*	0, 21*
Leafy vegetables	6, 115*	2, 50*	2, 29*	1, 14 [†]
Fried foods	0, 105*	0, 53*	0, 22*	0, 11 [†]
Milk	6, 105*	0, 49*	5, 28*	2, 14 [†]
Red meat	6, 103*	7, 47*	2, 24*	NR
Soda	11, 99*	0, 46*	0, 33*	0, 28*
Popcorn	2, 97*	NR	0, 27*	0, 18*
Dairy	3, 94*	1, 56*	NR	0, 12 [†]
Alcohol	0, 90*	0, 54*	NR	0, 23*
High fiber	19, 87*	19, 35 [†]	7, 46*	NR
Corn	0, 77*	0, 31*	0, 29*	NR
Fatty foods	0, 62*	NR	NR	NR
Seeds	NR	NR	0, 22*	NR
Coffee	NR	4, 37*	NR	NR
Beans	NR	5, 30*	NR	NR

B number of patients who stated food item made them better, W number of patients who stated food item made them worse

A response rate of 5 % for either improvement or worsening of symptoms in at least one of the study groups was required for the food item to be included in the above table. Where the response was less than 5 %, results are not reported (NR). There were 106 additional food items reported by less than 5 % of each group.

P values were from the sign test. Using the Bonferroni method to correct for multiple comparisons, statistical significance is defined as $P < 0.00039$ (i.e., 0.05/127). Those items meeting this threshold are identified with an asterisk (*). Items with a P value between 0.05 and 0.00039 are identified with [†]

foods, cereal, milk, fruit juice, fruit, leafy vegetables, potatoes, whole grains, non-leafy vegetables, cheese, and ice cream when they reported that these items improved symptoms ($P < 0.05$ for all comparisons, data included in supplemental Table 2).

The entire patient cohort of 4,001 patients with CD, 2,156 with UC, 206 with UC-pouch, and 405 with CD-ostomy was analyzed to compare consumption rates within disease categories (Table 3). As compared to patients with CD, those with UC reported significantly greater consumption of fruit (OR 1.82, 95 % CI 1.49–2.22), leafy vegetables (OR 1.87, 95 % CI 1.59–2.20), non-leafy vegetables (OR 1.49, 95 % CI 1.27–1.74), tomatoes (OR 1.16, 95 % CI 1.02–1.33), beans (OR 1.51, 95 % CI 1.30–1.75),

Table 3 Odds ratios for food consumption between IBD subtypes

Food items	UC vs. CD	CD-O vs. CD	UC-P vs. UC
Red meat	0.87 (0.74–1.01)	1.20 (0.90–1.61)	1.13 (0.46–1.13)
Fruit	1.82 (1.49–2.22)	0.67 (0.45–1.00)	0.62 (0.36–1.09)
Leafy vegetables	1.87 (1.59–2.20)	0.72 (0.51–1.01)	0.58 (0.38–0.89)
Non-leafy vegetables	1.49 (1.27–1.74)	0.76 (0.56–1.03)	0.77 (0.51–1.18)
Cheese	0.95 (0.75–1.20)	1.56 (1.03–2.36)	1.54 (0.84–2.80)
Sweetened beverages	0.82 (0.71–0.96)	2.14 (1.02–1.03)	1.68 (1.17–2.43)
Milk	0.83 (0.69–1.01)	1.84 (1.35–2.52)	1.11 (0.67–1.82)
Tomato	1.16 (1.02–1.33)	1.05 (0.81–1.37)	1.07 (0.74–1.54)
Dessert	0.90 (0.79–1.02)	0.85 (0.66–1.09)	1.37 (0.99–1.89)
Potato	0.83 (0.72–0.96)	1.27 (0.98–1.65)	1.25 (0.84–1.86)
Soda	0.61 (0.52–0.70)	1.19 (0.91–1.54)	0.84 (0.55–1.29)
Beans	1.51 (1.30–1.75)	0.72 (0.52–0.99)	0.82 (0.55–1.23)
Pizza	0.92 (0.77–1.11)	1.57 (1.12–2.20)	1.00 (0.59–1.70)
Processed meats	0.85 (0.73–0.99)	1.40 (1.04–1.89)	0.93 (0.61–1.41)
Ice cream	0.94 (0.80–1.10)	1.09 (0.81–1.45)	1.17 (0.74–1.83)
Popcorn	1.28 (1.10–1.48)	0.82 (0.60–1.12)	0.89 (0.59–1.33)

Values are given as odds ratio (OR) and 95 % confidence interval (CI)

Odds ratios are presented for the highest quartile vs. the lowest quartile of consumption of food items among those with UC relative to CD, CD-O relative to CD, and UC-P relative to UC. Bolded items are statistically significant. Odds ratios are adjusted for age, sex, and disease activity

and popcorn (OR 1.28, 95 % CI 1.10–1.48), and significantly less consumption of sweetened beverages (OR 0.82, 95 % CI 0.71–0.96), potatoes (OR 0.83, 95 % CI 0.72–0.96), soda (OR 0.61, 95 % CI 0.52–0.70), and processed meats (OR 0.85, 95 % CI 0.73–0.99). Compared to CD patients without an ostomy, CD patients with an ostomy reported significantly greater consumption of cheese (OR 1.56, 95 % CI 1.03–2.36), sweetened beverages (OR 2.14, 95 % CI 1.02–1.03), milk (OR 1.84, 95 % CI 1.35–2.52), pizza (OR 1.57, 95 % CI 1.12–2.20), and processed meats (OR 1.40, 95 % CI 1.04–1.89), and significantly less consumption of beans (OR 0.72, 95 % CI 0.52–0.99). Compared to UC patients without a pouch, UC patients with a pouch reported significantly greater consumption of sweetened beverages (1.68, 95 % CI 1.17–2.43) and significantly less consumption of leafy vegetables (OR 0.58, 95 % CI 0.38–0.89).

Table 4 shows the odds ratios for self-reported food consumption based on self-reported disease activity. CD patients with active disease reported consuming significantly less fruit (OR 0.43, 95 % CI 0.33–0.57), leafy vegetables (OR 0.44, 95 % CI 0.36–0.54), non-leafy vegetables (OR 0.54, 95 % CI 0.44–0.65), milk (OR 0.78, 95 % CI 0.62–0.97), tomatoes (OR 0.73, 95 % CI 0.62–0.86), dessert (OR 0.71, 95 % CI 0.61–0.83), beans (OR 0.59, 95 % CI 0.48–0.71), pizza (OR 0.77, 95 % CI 0.62–0.96), processed meats (OR 0.78, 95 % CI 0.65–0.93), ice cream (OR 0.71, 95 % CI 0.59–0.86), and popcorn (OR 0.74, 95 % CI 0.61–0.89) than those without active disease. CD patients with active disease reported consuming more sweetened beverages (OR 1.29, 95 % CI

1.09–1.53) and soda (OR 1.51, 95 % CI 1.29–1.78) than those without active disease.

UC patients with active disease reported consuming significantly less fruit (OR 0.39, 95 % CI 0.27–0.55), leafy vegetables (OR 0.40, 95 % CI 0.30–0.53), non-leafy vegetables (OR 0.59, 95 % CI 0.45–0.77), tomatoes (OR 0.67, 95 % CI 0.54–0.84), beans (OR 0.49, 95 % CI 0.38–0.64), and ice cream (OR 0.66, 95 % CI 0.50–0.86) than those without active disease. UC patients with active disease reported consuming more soda (OR 1.32, 95 % CI 1.03–1.71) than those without active disease.

CD-ostomy patients with active disease reported consuming significantly less fruit (OR 0.19, 95 % CI 0.05–0.64), leafy vegetables (OR 0.34, 95 % CI 0.15–0.75), non-leafy vegetables (OR 0.32, 95 % CI 0.15–0.68), and beans (OR 0.43, 95 % CI 0.20–0.94) than those without active disease. UC-pouch patients with active disease reported significantly less consumption of red meat (OR 0.11, 95 % CI 0.02–0.54) and fruit (OR 0.14, 95 % CI 0.03–0.71) than those without active disease.

Discussion

This study comprehensively assessed dietary patterns and beliefs among a large cohort of patients with IBD. We identified numerous food groups that patients more frequently identified as worsening symptoms and a few food items that were more commonly reported to improve symptoms. While dietary patterns differed by disease type, the self-reported perception of what worsened or improved

Table 4 Adjusted odds ratios for association of dietary patterns and self-reported disease activity

Food items	CD (<i>n</i> = 4,001)	UC (<i>n</i> = 2,156)	CD-O (<i>n</i> = 405)	UC-P (<i>n</i> = 206)
Red meat	0.95 (0.79–1.14)	0.88 (0.68–1.14)	1.21(0.62–2.33)	0.11 (0.02–0.54)
Fruit	0.43 (0.33–0.57)	0.39 (0.27–0.55)	0.19 (0.05–0.64)	0.14 (0.03–0.71)
Leafy vegetables	0.44 (0.36–0.54)	0.40 (0.30–0.53)	0.34 (0.15–0.75)	0.56 (0.22–1.44)
Non-leafy vegetables	0.54 (0.44–0.65)	0.59 (0.45–0.77)	0.32 (0.15–0.68)	0.86 (0.36–2.08)
Cheese	0.77 (0.58–1.01)	1.05 (0.70–1.56)	0.56 (0.22–1.42)	0.60 (0.14–2.54)
Sweetened beverages	1.29 (1.09–1.53)	1.29 (0.99–1.66)	0.65 (0.38–1.12)	0.68 (0.29–1.61)
Milk	0.78 (0.62–0.97)	0.89 (0.64–1.22)	0.82 (0.42–1.57)	0.40 (0.12–1.35)
Tomato	0.73 (0.62–0.86)	0.67 (0.54–0.84)	0.58 (0.32–1.06)	0.83 (0.37–1.86)
Dessert	0.71 (0.61–0.83)	1.87 (0.70–1.08)	0.78 (0.45–1.36)	0.67 (0.32–1.39)
Potato	0.92 (0.77–0.09)	1.03 (0.81–1.32)	0.57 (0.32–1.01)	0.84 (0.33–2.11)
Soda	1.51 (1.29–1.78)	1.32 (1.03–1.71)	1.19 (0.69–2.07)	1.48 (0.59–3.72)
Beans	0.59 (0.48–0.71)	0.49 (0.38–0.64)	0.43 (0.20–0.94)	0.40 (0.16–1.04)
Pizza	0.77 (0.62–0.96)	0.94 (0.69–1.30)	0.97 (0.49–1.92)	0.33 (0.09–1.27)
Processed meats	0.78 (0.65–0.93)	0.97 (0.75–1.25)	1.21 (0.63–2.32)	0.64 (0.26–1.57)
Ice cream	0.71 (0.59–0.86)	0.66 (0.50–0.86)	0.84 (0.46–1.54)	0.72 (0.26–1.97)
Popcorn	0.74 (0.61–0.89)	0.79 (0.61–1.02)	0.58 (0.28–1.18)	0.72 (0.29–1.76)

Values are given as odds ratio (OR) and 95 % confidence interval (CI)

Odds ratios (OR) are presented for the highest quartile versus the lowest quartile of consumption of food items among those with active disease relative to inactive disease. Bolded items are statistically significant. Odds ratios are adjusted for age, sex, and prior surgery

symptoms was relatively consistent across disease types. We also documented that patients' dietary patterns are linked to their perceptions of how food items influence their disease course. Not surprisingly, patients with active disease reported different dietary patterns than those whose disease was quiescent. Finally, those who had undergone surgery to create an ostomy reported more liberalized dietary patterns.

Patients were far more likely to describe foods that worsened symptoms than improved them. While several food items were not ranked because fewer than 5 % of patients reported the food as helping or hurting, many of these items were still more frequently reported to worsen symptoms and a few to improve symptoms. The list of foods that patients believed worsened symptoms was broad but with some evidence of a pattern. Dairy was reported to worsen symptoms by multiple groups, which could reflect a component of lactose intolerance. Many of the food groups commonly reported to worsen symptoms were also higher in fiber (e.g., vegetables, fruits, and corn).

Past research has shown that red meat is associated with early relapse of disease in patients with UC [15]. This hypothesis was further supported in our study as red meat was more commonly reported to worsen symptoms in all disease categories except UC-pouch. When we compared UC to CD, self-reported consumption of red meat was not significantly less in the UC group, suggesting that red meat might influence the course of CD as well.

The fruit and vegetable groups included diverse items, and it is therefore difficult to generalize the impact of these

food groups on patients' symptoms. For example, bananas were more commonly reported to improve symptoms while tomatoes were more commonly reported to exacerbate symptoms.

These data provide a summary of the anecdotal perceptions of a broad cohort of patients. However, we are not able to assess whether these food items actually impact bowel inflammation or merely patients' symptoms. Food items such as milk, dairy, and high fiber, all foods that are associated with intolerances, may not exacerbate the disease process but simply lead to symptoms as they would in individuals without IBD [16–20]. The consistent pattern of foods commonly reported to worsen symptoms across the disease groups supports this hypothesis. Ultimately, as with medications, controlled trials of dietary interventions are needed to test the hypotheses that these food items influence disease course.

Although we were unable to determine what experiences led patients to believe that certain foods worsen their symptoms, our data confirmed that patients with IBD restrict their dietary pattern due to active symptoms or fear of exacerbating symptoms. We observed decreased consumption of selected food items among patients with active symptoms and among those who believed that certain food items worsen their symptoms. Furthermore, definitive surgery for Crohn's disease was associated with different dietary patterns. After adjusting for self-reported disease activity, CD-ostomy patients consumed more cheese, sweetened beverages, milk, pizza, and processed meats

than those without ostomies. These data suggest that one of the benefits of surgical approaches to managing IBD may be the ability to liberalize one's diet. Alternatively, patients who have a more inclusive diet may be more willing to undergo ostomy surgery.

Zallot et al. [21] recently assessed the dietary patterns and beliefs of 244 patients with IBD, among whom 25–80 % of patients believed eating spicy foods, vegetables, fruit, soda, fiber, dairy, and/or coffee could lead to relapse. These items were all more frequently reported as worsening symptoms in our study. The observation by Zallot et al. that UC patients seem to tolerate raw vegetables better than CD patients was also consistent with our observation that UC patients ate significantly more non-leafy and leafy vegetables than CD patients.

In Zallot's study, approximately 25 % of patients stated dairy exacerbated their symptoms, yet only 4 % adopted a dairy-free diet [21]. In contrast, our study population reported eating more of foods that made them better and less of foods that made them worse (including dairy). This suggests that while patients may not necessarily adopt a full elimination diet, they do appear to limit their intake of food items that exacerbate symptoms. Whether there is a clinical advantage to complete elimination of certain foods requires further testing in controlled studies.

Self-imposed dietary restrictions may have an important impact on nutritional status. For example, 40–78 % of IBD patients are believed to have inadequate folate intake [22, 23]. Folate is found predominately in leafy and non-leafy vegetables such as spinach, asparagus, and Brussels sprouts [1]. Patients avoiding these foods for fear of worsening symptoms may be vulnerable to inadequacies in their diet. Additionally, 80–86 % of IBD patients are reported to have inadequate dietary intake of calcium, possibly as a result of avoiding milk and dairy, which were also identified as foods thought to worsen symptoms [17, 18].

This study relied on patients' self-reported answers to survey questions to characterize disease type, dietary patterns, and symptoms. Some patients were unaware of disease location, and the reliability of self-reported disease distribution and history of fistula or strictures is unknown. Therefore, we did not attempt to subcategorize patients on these phenotypic characteristics. However, one would anticipate that self-reported disease type (i.e., CD versus UC) and the presence of an ostomy or pouch should be reliable. Food frequency questionnaires are not a perfect method to quantify dietary intake but are useful to discriminate between those with high and low levels of intake [24]. Because we categorized participants into quartiles and based our conclusions on comparisons of those in the highest and lowest quartiles, there should be relatively little misclassification. We assessed dietary intake over the prior month but disease activity at a single point in time. We

cannot state with certainty that those who reported active disease had such symptoms over the course of the prior month, and some of the patients who reported no or minimal symptoms may have had active disease during the prior month. Such misclassification would have been expected to bias us toward the null. Thus, our reported associations between disease activity and dietary patterns may be an underestimate of the magnitude of the association.

CCFA Partners is a convenience sample of patients with IBD. It is possible that this cohort differs from other populations of patients with IBD such as having particularly strong beliefs about diet and IBD. The similar results of this study and that of Zallot et al. [21] argue against such.

There are several important strengths of this study. To our knowledge, this is the largest study of IBD and diet to date. The volunteers were sufficiently interested in IBD to complete an online survey and may be more aware of their disease and symptoms than less motivated subjects. The food frequency questionnaire was meticulously developed by the National Cancer Institute and has been used in large national studies. We also had access to free text responses, thereby not limiting our food data to preselected food items. By linking free text responses with the food frequency questionnaire, we were able to confirm that participants actually followed the dietary patterns that they believed would improve their disease course.

Patients often ask about the role of diet in controlling their IBD symptoms, and physicians struggle to make evidence-based recommendations. At present there is insufficient information to make strong recommendations about diet. We have identified food items that patients commonly believe to worsen, and in a few cases, help their IBD. Planned prospective follow-up of this cohort could demonstrate whether these dietary elements are associated with disease flares or remission and provide more support for the role of diet and IBD activity. We also observed that CD-O patients had a more liberalized diet. This may be an important consideration for patients contemplating surgery with ostomy formation.

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Conflict of interest None.

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