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# YouTube as a Source of Information for Food, Diet-Related Items, and Advisory Comments for the Management of **Inflammatory Bowel Disease**

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### **Abstract**

Background: Patients with inflammatory bowel disease (IBD) often use the Internet to seek information beyond that received from healthcare professionals. This study assessed the perceptions of YouTube presenters on the role of diet in the management of IBD.

Methods: Videos discussing dietary aspects (food, diet-related items, and advisory comments [FODRIACs]) in the management of IBD were included. The perceptions of presenters toward each FODRIAC were labeled as positive, negative, or neutral/intermediate, and FODRIACs were classified according to their underlying role in the management of IBD (eg, symptom management, gut inflammation). Subgroup analysis was performed by type of video presenter (patients vs healthcare professionals), type of IBD (Crohn's disease vs ulcerative colitis), and reporting of scientific evidence supporting presenters' perceptions.

Results: We identified 122 FODRIACs within 160 videos. Patient videos received a higher number of likes (median 85 [interquartile range, 35-156]) than healthcare professional videos (median 44 [interquartile range, 16-1440]) (P = .01). Scientific evidence was cited in 2 (3%) of 76 patient videos compared with 25 (35%) of 71 healthcare professional videos (P < .001). Positive perceptions were expressed about avocadoes, salmon, bananas, white bread, and rice, whereas negative perceptions were reported for processed, high-fat and high-sugar foods and carbonated drinks. Fewer negative perceptions were expressed in videos supported by scientific evidence than in videos that lacked evidence (scientific: 4 positive, 0 negative vs nonscientific: 7 positive, 20 negative; P = .01).

Conclusions: We have identified FODRIACs proposed as beneficial or detrimental in the management of IBD. The effect this information has on dietary practice as patients with IBD self-manage their condition needs further exploration.

**Keywords:** inflammatory bowel disease, diet, nutrition, YouTube, perceptions

## Introduction

Inflammatory bowel disease (IBD) comprises a spectrum of chronic, debilitating disorders of the gastrointestinal tract including Crohn's disease (CD) and ulcerative colitis (UC). While the cause of IBD remains unknown, nutritional epidemiology and evidence from animal experiments implicate dietary ingredients and patterns including a diet high in fat, protein (mainly of animal origin), and ultra-processed food and low in fiber as important environmental factors in IBD onset.1-4

Currently, the only well-established dietary treatment in IBD is exclusive enteral nutrition (EEN), which is used for induction of remission mostly in pediatric CD.<sup>5,6</sup> Over the past 2 decades, several food-based exclusion diets have been suggested as potential treatments for CD and UC, some of which demonstrated promising efficacy signals

such as the CD-TREAT (Crohn's disease treatment with eating) diet and the CDED (Crohn's disease exclusion diet). 7-9 Nonetheless, current societal guidelines do not recommend the use of any solid food-based exclusion diet as a treatment option for the induction or maintenance of clinical remission in IBD.6

Although the use of EEN as a primary induction treatment is well established in children, and recently has become so in adults with active CD,10 patients often believe that some healthcare professionals may disregard the role of diet in the management of IBD. In turn, this may prompt patients to modify their diet to self-manage their symptoms and control their disease. 11,12 Such dietary modifications may range from the exclusion of specific foods perceived to provoke symptoms<sup>13</sup> to the use of dietary complementary and alternative therapies.14

#### **Key Messages**

#### What is already known?

Diet is implicated in the development and management of inflammatory bowel disease (IBD). Subsequently, patients with IBD often use the Internet as a primary source of health-related information.

#### What is new here?

Over 100 different food and dietary patterns were positively or negatively related to the management of IBD, as evidenced by perceptions of patients and healthcare professionals on YouTube. Western-type dietary patterns were perceived as detrimental, but most claims, both by patients and healthcare professionals, lacked scientific rigor.

#### How can this study help patient care?

This study highlighted the unmet need to develop evidence-based dietary guidelines for the management of IBD and to disseminate those effectively in the patient community.

Due to its ease of use and readily accessible information, the Internet and its social media and communication platforms have now become prominent sources of health-related information for patients and their families. In 2 previous surveys, the Internet and advice from gastroenterologists were the most frequent sources of health-related information for patients with IBD. In another survey, the use of the Internet as a source of IBD-related information was positively associated with disease severity, potentially suggesting that patients with treatment-refractory disease are more likely to seek alternative treatment options beyond those provided by their healthcare providers. Is

YouTube is the largest video-sharing platform, with over 2 billion people accessing its content at least once per month. 19 Previous studies have assessed YouTube as a source of healthrelated information for various conditions, such as pulmonary fibrosis,<sup>20</sup> oral cancer,<sup>21</sup> and the use of blended feeds for patients on long-term tube feeding.<sup>22</sup> In one of the very few studies that evaluated the content and quality of IBD-related YouTube videos and patients' experiences with IBD treatment regimes, Mukewar et al<sup>23</sup> concluded that the quality of information was poor and in most cases lacked scientific base. This lack of scientific rigor in the information presented on YouTube videos is likely to urge patients to follow nonevidence-based dietary advice, hence potentially increasing the risk of poor disease management, increasing the risk of development of nutritional deficiencies, reducing foodrelated quality of life, and increasing the risk of disordered eating.24-26

The main objective of this study was to characterize the content of YouTube videos related to the nutritional management of IBD. As YouTube is an important source of health-related information for patients with IBD, it is important to evaluate that information in order to better understand patients' perceptions, compare this with the existing evidence base, and identify areas that require further research. A secondary aim was to explore whether perceptions toward the role of specific foods on the management of IBD differed according to the designation of the video presenter (patients vs healthcare

professionals), type of IBD (CD vs UC), and reporting or not of scientific evidence corroborating these perceptions.

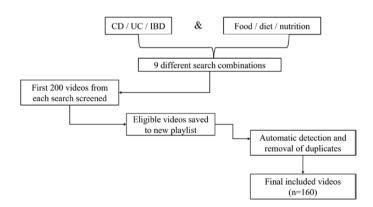
### Methods

#### Video search

A YouTube video search was performed on June 2, 2020. Boolean operators were not applied to this search, as they are unlikely to be used by the general public, and their use might have introduced video selection bias. A new YouTube account was created to minimize any potential influence of previous browsing history in the algorithm employed by YouTube. The keywords "food," "diet," and "nutrition" were used in combination with the terms "inflammatory bowel disease," "ulcerative colitis," and "Crohn's disease," which resulted in 9 separate searches. As the YouTube algorithm automatically sorts videos based on the relevance to the search terms, no specific filter was applied. The first 200 videos from each search (a total of N = 1800) were saved in separate video groups for later viewing and eligibility screening, a method that has been previously described in the literature (Figure 1).<sup>20</sup>

## Inclusion and exclusion criteria

Videos in English with good audio quality and a duration of <60 minutes that discussed the use of different food components in the nutritional management of IBD were selected. These food components were defined as food, dietrelated items, and advisory comments (FODRIACs). These FODRIACs included individual foods and food groups, food-based therapies, nonpharmaceutical food supplements, and alternative or complementary dietary therapies. Cluster videos, YouTube channels, or videos that included links leading to other webpages were excluded. Videos in languages other than English, without audio, or with poor sound quality were also excluded. As the main objective of this study was to characterize FODRIACs for the management of IBD, videos reporting the use of diet for the prevention of IBD, or videos that discussed established forms of nutritional management of IBD (ie, exclusive enteral/parenteral nutrition) were also excluded following viewing of all videos. Following screening, eligible videos were saved in a new video playlist that included all eligible videos from the 9 individual searches. This allowed for instant detection and subsequent removal of duplicate videos.



**Figure 1** Flowchart of the YouTube video search. CD, Crohn's disease; IBD, inflammatory bowel disease; UC, ulcerative colitis.

Table 1. Descriptive characteristics of YouTube videos discussing the use of FODRIACs in the management of IBD

Video features	All (n = 160)	Healthcare professionals (n = 71)	Patients (n = 76)	Undefined (n = 13)	P value
Views	3708 (1324-13 413)	4320 (1494-21 183)	3398 (1370-10 807)	1814 (725-15 753)	.273
Likes	59 (22-184)	44 (16-1440)	85 (35-256)	15 (4.5-72.5)	.01
Dislikes	4 (0-13.3)	4 (0-17.5)	4 (0.3-12.8)	1 (0-9.5)	.831
Duration	6.6 (3.3-10.9)	5.4 (2.7-10.3)	7.5 (4.89-12.0)	5 (2.1-8.1)	.043
Subscriptions	10 300 (1660-21 600)	16 150 (2613-139 000)	10 400 (1610-14 800)	5110 (647-10 105)	.035
Days since upload	941 (529-1563)	1532 (896-2179)	704 (337-1087)	827 (494-960)	<.001
Viewing rate	5.1 (1.5-15.9)	3.59 (1.43-16.6)	5.7 (2.2-15.9)	6.6 (0.7-18.1)	.257
Video interaction rate	1.59 (0.69-2.92)	0.88 (0.49-1.47)	2.73 (1.87-3.79)	0.51 (0.33-1)	<.001
Disease type	54/160 (34)	35/71 (49)	14/76 (18)	5/13 (38)	
CD	48/160 (30)	20/71 (28)	27/76 (35)	1/13 (8)	
UC	58/160 (36)	16/71 (23)	35/76 (46)	7/13 (54)	
Scientific evidence	28/160 (18)	25/71 (35)	2/76 (3)	1/13 (8)	<.001
No evidence	132/160 (83)	46/71 (65)	74/76 (97)	12/13 (92)	

Values are median (interquartile range) or n/n (%). P value shows the comparison between patients and healthcare professionals. Abbreviations: CD, Crohn's disease; FODRIAC = food, diet-related item, and advisory comment; IBD, inflammatory bowel disease; UC, ulcerative colitis.

### Data retrieval

Videos were viewed between June 2, 2020, and July 31, 2020. Two authors (K.Gk. and M.W.) assessed and transcribed half of the videos each. Initially, video information was recorded in free text in a Microsoft Excel spreadsheet (version 2013). Information captured included title: URL; number of views, likes, dislikes, and channel subscriptions; upload date; duration; and disease type (CD, UC, or IBD). Videos in which different opinions about the same FODRIAC were presented between CD and UC were considered as 2 separate video entries in downstream analysis. Analysis of each video's demographics (eg, number of views, likes, dislikes, and channel subscriptions) was performed on the same day (August 17, 2020). The viewing rate of each video was calculated as the ratio of number of views divided by the time elapsed since the video was uploaded.<sup>21</sup> The interaction rate of a video was calculated as the ratio of the difference between likes and dislikes divided over the total number of views and multiplied by 100. Video presenters were classified as healthcare professional, patient, or other/undefined. Healthcare professionals included doctors, nurses, and dietitian/nutritionists.

For each video, FODRIACs were recorded in the spreadsheet and were subsequently arranged in similar food groups. The perceived attitude of each video presenter toward the role of a FODRIAC in the management of IBD was assigned as positive, negative, or neutral/intermediate by the 2 researchers independently, and any discrepancies were resolved through consensus. Claims that suggested that a FODRIAC might not play a specific role or might neither be beneficial nor detrimental for the management of IBD were assigned in the neutral/intermediate category. FODRIACs were also classified according to their reported role in the management of IBD, including symptom management, gut inflammation, microbiome manipulation, and other non-IBD related. The latter group included reports on predominantly general nutritional benefits such as beneficial effects on bone metabolism and provision of bioactive compounds (ie, polyphenols). Information on any scientific evidence reported in the videos to support speakers' claims was also recorded. Scientific evidence was defined as a direct mention of peer-reviewed

literature and societal and authoritative guidelines by the video presenters.

## Statistical analysis

Continuous data were presented as median and interquartile range (IQR) and categorical data as count and frequency. Comparisons between groups were performed using general linear regression and Fisher's least significant difference post hoc test following Box-Cox transformation. Crosstabulations were performed for FODRIACs reported in more than 10 videos. Fisher's exact test was used to compare the number of presenters' positive over the number of negative perceptions for those FODRIACs according to disease type (CD against UC), presenter category (patients against healthcare professionals), and presence against absence of scientific evidence corroborating presenters' FODRIAC claims. Minitab (version 20) and R (version 4.1.2; R Foundation for Statistical Computing) were used for statistical analysis and visualization.

## Results

## Descriptive characteristics

Of 1800 videos screened, a total of 160 were included in the final analysis. The median number of views was 3708 (interquartile range [IQR], 1324-13 414), with a median video duration of 6.6 (IQR, 3.3-11) minutes (Table 1). Slightly more video presenters were patients with IBD (n = 76 of 160, 48%), followed by healthcare professionals (n = 71 of 160, 44%). Patient videos had longer duration (median duration 7.53 [IQR, 4.89-12.0] minutes among patient videos vs 5.4 [IQR, 2.7-10.3] minutes among healthcare professional videos; P = .043), and YouTube channels from patients had fewer subscriptions compared with healthcare professional channels (median 10 400 [IQR, 1610-14 800] channel subscriptions among patients vs 16 150 [IOR, 2613-139 000] channel subscriptions among healthcare professionals; P = .035) (Table 1). Although the median number of video views did not differ between the 2 groups, both the number of

likes and the video interaction rate were significantly higher in videos from patients compared with videos from health-care professionals (number of likes: median 85 [IQR, 35-256] among patient videos vs 44 [IQR, 16-1440] among healthcare professional videos; P = .01; video interaction rate: median 2.73 [IQR, 1.87-2.39] among patient videos vs 0.88 [IQR, 0.49-1.47] among healthcare professional videos; P < .001).

Out of 160 videos, 58 discussed FODRIACs in relation to the management of UC (36%), 48 discussed FODRIACs in relation to CD (30%), and 54 (34%) discussed both conditions (Table 1). Two (3%) of 76 videos created by patients cited scientific evidence compared with 25 (35%) of 71 videos created by healthcare professionals (P < .001). Objective markers of inflammation (ie, fecal calprotectin, blood inflammatory markers, and endoscopic indices) were discussed in 16 (10%) of 160 videos, all of which were created by healthcare professionals. The number of videos discussing FODRIACs pertinent to the management of IBD increased over the last 10 years (Supplementary Figure 1).

## Type of FODRIACs

In these 160 videos, a total of 122 FODRIACs were identified: 109 (89%) of 122 referred to individual foods or food groups and 13 (11%) of 122 were pertinent to specific dietary therapies. The most discussed FODRIACs were lactose/ dairy products (n = 61), followed by vegetables (n = 55), dietary fiber (n = 47), and probiotics/fermented foods (n = 46). In terms of defined dietary therapies for the management of IBD, the most frequently reported were the specific carbohydrate diet (SCD) (n = 17), followed by vegan and low-fiber diets (n = 15), and the low fermentable oligosaccharides, disaccharides, monosaccharides, and polyols (FODMAP) diet (n = 9). In a subsequent analysis, we chose to present the perceptions of video presenters toward the 40 most discussed FODRIACs (mentioned in more than 10 videos) as well as present the rationale underlying their perceptions. Perceptions of video presenters toward all 160 FODRIACs are presented, along with their underlying rationale, in Supplementary File 1.

# FODRIACs with predominantly positive perceptions in relation to IBD management

Figure 2 presents the proportion of videos describing positive and negative perceptions toward the 40 most reported FODRIACs. Avocadoes and salmon were viewed as positive in all videos in which these were mentioned (n = 13 of 13 and n = 11 of 11, respectively) (Figure 2). Bananas, bread, and rice products were perceived positively in the majority of videos in which these foods were reported (96% [n = 26 of 27], 91% [n = 10 of 11], and 87% [n = 21 of 24], respectively). Other FODRIACs that were predominantly perceived as positive included fish/seafood (n = 24 of 30, 82%), blueberries (n = 9 of 11, 82%), chicken (n = 12 of 17, 71%), eggs (n = 19 of 28, 68%), fruits (n = 21 of 32, 66%), and potatoes (n = 12 of 19, 63%). Likewise, both the low-fiber and vegan diets (n = 13 of 15, 87% for both) and the SCD (n = 13 of 17, 76%) were perceived positively in the majority of videos.

While in most videos presenters expressed positive perceptions about probiotics/fermented foods (n = 36 of 46, 78%), prebiotics (n = 9 of 13, 69%), turmeric/curcumin (n = 8 of 12, 67%), turkey (n = 6 of 11, 55%), and vegetables (28 of 55, 51%), there were also a considerable number of videos that reported neutral/intermediate perceptions for those FODRIACs

(prebiotics: n = 4 of 13, 31%; turmeric/curcumin: n = 3 of 12, 25%; probiotics/fermented foods: n = 10 of 46, 22%; turkey: n = 2 of 11, 18%; vegetables: n = 22 of 55, 40%) (Figure 2).

Among the FODRIACs that were perceived positively, a low-fiber diet (n = 11 of 15, 73%), bread (n = 8 of 11, 73%), bananas (n = 16 of 27, 59%), rice (n = 13 of 24, 54%), and chicken (n = 9 of 17, 53%) were associated with improvement of disease symptoms (Figure 3, 4). Conversely, blueberries (n = 7 of 11, 64%), turmeric/curcumin (n = 7 of 12, 58%), and salmon (n = 6 of 11, 55%) were thought to possess anti-inflammatory properties in most of the videos in which they were mentioned. Video presenters had positive perceptions about the SCD and vegan diets regarding their role in the management of gut inflammation in 9 (53%) of 17 and 13 (87%) of 15 videos, respectively (Figure 3).

Probiotics/fermented foods, potatoes, and turkey were associated with both amelioration of gut inflammation and control of disease symptoms (Figure 3). Conversely, consumption of avocadoes and eggs was thought to exert positive effects on the management of both symptoms and inflammation in addition to their other non–IBD-related benefits. FODRIACs that were associated with enhancement of the gut microbiome were mainly prebiotics (n = 3 of 13, 23%) and probiotics/fermented foods (n = 5 of 46, 11%) (Figures 3 and 4). Other, non–IBD-related health benefits, including nutritional benefits, were attributed to fruits (n = 9 of 32, 28%) and vegetables (n = 15 of 55, 27%). While consumption of raw vegetables was unanimously perceived as negative in all videos in which this was mentioned (n = 11 of 11, 100%), consumption of cooked vegetables was considered positive (n = 24 of 24, 100%).

# FODRIACs with predominantly negative perceptions in IBD management

Processed, high-fat foods, food additives, tomatoes, and carbonated drinks were unanimously perceived as harmful in the management of IBD (n = 100% for all) (Figure 2). Similarly, the consumption of corn, alcohol, spicy foods, high-sugar foods, caffeine, skin from vegetables or fruits, and gluten was considered harmful in over 90% of the videos in which these FODRIACs were mentioned. Most videos reported a negative role in IBD management for lactose/dairy products (n = 52 of 61, 85%), seeds (n = 15 of 19, 79%), nuts (n = 25 of 35, 71%), beans (n = 11 of 16, 69%), and both whole-grain and total grain products (n = 11 of 16, 69%, and n = 20 of 25, 80%, respectively) (Figure 2). Interestingly, although video presenters expressed negative perceptions against meat in just over half of the videos in which it was mentioned (n = 12 of 22, 55%), this proportion rose to 82% (n = 18 of 22) when the role of red meat was discussed. While presenters had negative perceptions against dietary fiber in 20 (43%) of 47 videos, a similar proportion expressed neutral/intermediate perceptions in 16 (34%) of 47 videos (Figure 2).

Corn (n = 16 of 19, 84%) and spicy foods (n = 15 of 18, 83%) were reported as the 2 most detrimental FODRIACs on disease symptom exacerbation, followed by carbonated drinks (n = 8 of 11, 72%), vegetable/fruit skin, and caffeine (both n = 10 of 14, 71%) (Figures 3 and 4). Consumption of alcohol (n = 12 of 18, 67%), high-fat foods (n = 19 of 31, 61%), spicy foods and seeds (both n = 11 of 19, 58%), nuts (n = 20 of 35, 57%), lactose/dairy (n = 34 of 62, 55%), red meat (n = 12 of 22, 55%), and beans (n = 8 of 16, 50%) was also perceived to trigger disease symptoms (Figure 3).

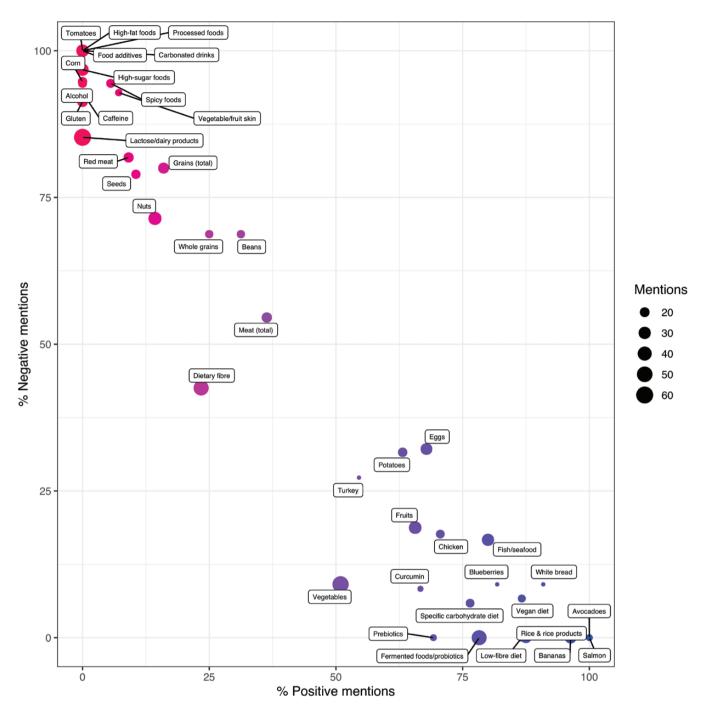


Figure 2 Proportion of YouTube videos showing presenters' positive and negative perceptions toward the top 40 most discussed food, diet-related items, and advisory comments.

Aggravation of gut inflammation was mostly attributed to food additives (n = 20 of 24, 83%) and processed foods (n = 20 of 32, 63%), followed by high-sugar foods (n = 17 of 31, 55%) (Figures 3 and 4). Gluten, tomatoes, whole grains, and total grains were perceived to trigger both exacerbation of gut inflammation and disease symptoms (Figure 3).

Detrimental effects to the gut microbiome were only attributed to food additives in 1 video (n = 1 of 24, 4%) (Figures 3 and 4). Most of the negative perceptions pertinent to dietary fiber were related to symptom exacerbation (n = 17 of 47, 36%), with neutral/intermediate perceptions expressed about its role in the management of gut inflammation (n = 10

of 47, 21%) (Figure 3). Of note, while insoluble fiber was perceived as negative in all videos in which it was mentioned (n = 9 of 9, 100%), soluble fiber was unanimously perceived as positive (n = 7 of 7, 100%) in the management of IBD when discussed. Some speakers also recommended the avoidance of dietary fiber during disease flares (n = 6 of 6, 100%).

# Comparisons of FODRIACs across different categories

The perceptions of video presenters toward FODRIACs were compared according to disease type, speaker category,

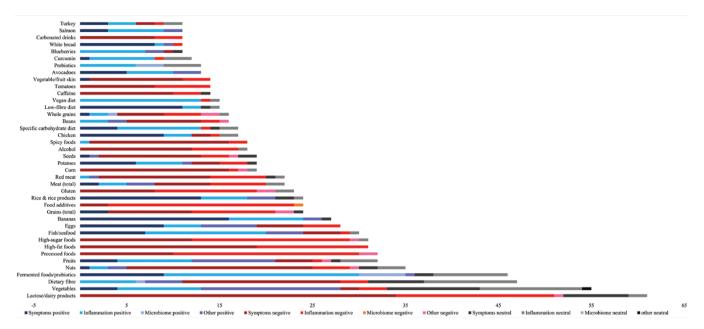


Figure 3 Top 40 food, diet-related items, and advisory comments from YouTube videos with positive, negative, and neutral perceptions in the management of inflammatory bowel disease along with presenters' underlying rationale.

		SYMPTO	MS		
FODRIACs	Total positive mentions (%)	Proportion of videos	FODRIACs	Total negative mentions (%)	Proportion of video
Low-fibre diet		11/15	Corn		16/19
White bread		8/11	Spicy foods		15/18
Bananas		16/27	Carbonated drinks		8/11
Rice and rice products		13/24	Vegetable/fruitskin		10/14
Chicken		9/17	Caffeine		10/14
		INFLAMMA	ATION		
FODRIACs	Total positive mentions (%)	Proportion of videos	FODRIACs	Total negative mentions (%)	Proportion of video
/egan diet		13/15	Food additives		20/24
Blueberries		7/11	Processed foods		20/32
Curcumin		7/12	High-sugar foods		17/31
almon		6/11	Gluten		11/23
Specific carbohydrate diet		9/17	Tomatoes		6/14
		OTHER	R		
ODRIACs	Total positive mentions (%)	Proportion of videos	FODRIACs	Total negative mentions (%)	Proportion of video
ruits		9/32	Whole grains		2/16
egetables egetables		15/55	Gluten		2/23
vocadoes		3/13	Grains		2/25
ggs		6/28	Beans		1/16
lueberries		2/11	Processed foods		2/32
		MICROBIO	OME		
ODRIACs	Total positive mentions (%)	Proportion of videos	FODRIACs	Total negative mentions (%)	Proportion of video
rebiotics		3/13	Food additives		1/14
ermented foods/probiotics		5/46			
Vhole grains		1/6			·
Fibra		1/47	·-	·	·

Figure 4 Top 5 food, diet-related items, and advisory comments (FODRIACs) with positive and negative perceptions toward inflammatory bowel disease management according to YouTube presenters' rationale (including FODRIACs with >10 mentions).

and presence vs absence of scientific evidence corroborating these perceptions. No significant differences were observed in the proportion of videos displaying positive over negative perceptions toward different FODRIACs according to disease type (CD vs UC) or speaker category (patient vs healthcare professional) (Supplementary Tables 1 and 2).

Videos supported by scientific evidence reported significantly fewer negative claims for dietary fiber compared with videos that lacked evidence (presence of evidence: 4 positive perceptions and 0 negative perceptions vs lack of evidence: 7 positive perceptions and 20 negative perceptions; P = .01) (Supplementary Table 3). All evidence-based videos that showed positive perceptions for dietary fiber were presented by healthcare professionals.

## **Discussion**

This study evaluated YouTube as an information source for the dietary management of IBD. We identified 2 distinct clusters of FODRIACs: one that included food and dietary therapies considered beneficial in the management of IBD and another that included foods associated with detrimental effects. Among them, foods pertinent to a prudent dietary pattern (ie, fish, chicken, avocado, blueberries), foods high in pre- and probiotics, and certain food exclusion diets (eg, SCD) were primarily portrayed as beneficial. Conversely, foods often associated with a Western dietary pattern, including processed foods, high-sugar foods and high-fat foods, red meat, and alcohol, were considered detrimental for disease outcomes in

patients with IBD. Neutral opinions were expressed about fiber and vegetables.

The findings of this study are in accordance with those from previous questionnaire surveys in patients and healthcare professionals that demonstrated that spicy foods, highfat foods, corn, dairy, alcohol, vegetables (particularly raw and rich in FODMAPs), and red meat are often reported as potentially detrimental in the management of IBD. 12,13,27-30 Processed and high-sugar foods were among the most common FODRIACs perceived to exacerbate gut inflammation, while gluten and tomato were linked with aggravation of both inflammation and gastrointestinal symptoms in the current study. While several patient surveys have described symptom-triggering foods, only a few studies have assessed the opinions of patients on foods that can specifically exacerbate gut inflammation and initiate a disease flare.<sup>27,29</sup> In a questionnaire survey answered by 144 patients with IBD in France, spicy foods, high-fat foods, raw vegetables, and carbonated beverages were reported as likely to trigger a disease flare.<sup>27</sup> Another cross-sectional study, using structured interviews, demonstrated that increased consumption of refined sugars was positively associated with the risk of a disease flare.25

Although it is often difficult to discern organic from functional gastrointestinal symptoms, we tried to collect separate information for the role of the various FODRIACs in the management of gut inflammation and disease symptoms. Of interest, over 50% of video presenters reported that foods that are known modifiers of gastrointestinal motility (ie, corn, spicy foods, carbonated beverages, dairy, raw vegetables, and high-fat foods) were associated with aggravation of IBD symptoms. This association may prove important as we try to unravel the role of diet in IBD etiology and management, as dietary alteration of physiological mechanisms may impact symptoms but not influence disease activity per se. It will be important going forward to dissociate these 2 by the use of objective biomarkers like fecal calprotectin.

Adherence to low-fiber and low-FODMAP diets and consumption of rice, bananas, chicken, and white bread were perceived as beneficial in the management of disease symptoms, which concurs with findings from previous questionnaire surveys. 13,27,30,34 Furthermore, exclusion diets such as plant-based diets, SCD, and foods such as salmon, blueberries, and turmeric, were thought to alleviate inflammation in the current study. Adherence to exclusion diets is one of the most common dietary modifications among patients with IBD.14,35 Interestingly, in a recent survey among healthcare professionals, Crooks et al<sup>30</sup> demonstrated that over 20% of healthcare professionals recommended exclusion diets and specifically a low-FODMAP diet as a strategy to reduce the risk of an IBD flare, a finding that is of concern in the absence of evidence proposing any benefit for a low-FODMAP diet in the management of active or quiescent IBD. Likewise, although there is ongoing research exploring novel solid food-based dietary therapies for IBD management, current guidelines do not yet recommend their use. Early data for certain dietary therapies, such as CDED7,9 and CD-TREAT,8 await further replication in larger independent studies.

Collectively, our findings are in accordance with the current nutritional epidemiology doctrine that suggests that a Western-type diet, high in processed food, animal protein, and pro-inflammatory foods, is positively associated with the risk of IBD onset, while a Mediterranean-type diet, high in fruits

and vegetables, might protect against IBD development.<sup>1,2</sup> However, foods and dietary patterns that are involved in the development of a disease may not necessarily play the same role in its management. Furthermore, epidemiological and preclinical evidence implicating diets high in sugar, saturated fat, and food additives as triggers of gut inflammation in IBD have not been confirmed in studies excluding those dietary components as a strategy to control gut inflammation.<sup>36-38</sup> As a prime example, a recent study demonstrated that the efficacy of EEN in patients with active CD was independent of the total amount and composition of fat, carbohydrates, and protein in those EEN formulas, and also the presence or absence of food additives that have been implicated in the pathogenesis of IBD within preclinical research and nutritional epidemiology.<sup>39</sup> Likewise, while red meat has been implicated as a potential dietary trigger for disease relapse in observational studies in both CD40 and UC,37 a recent randomized controlled trial failed to show differences in relapse rates between patients consuming red meat frequently, compared with patients consuming <1 portion per month.<sup>41</sup> Increased consumption of gluten-containing cereals was associated with higher levels of fecal calprotectin in a pilot study of children with CD during food reintroduction following induction treatment with EEN.40 Interestingly, even though gluten is abundant in white bread, most video presenters in our study considered white bread to be beneficial in the management of IBD, thus highlighting the complexity of dietary research and the risk of placebo bias.

Dietary fiber received neutral to negative opinions in the present study. However, fiber was presented as detrimental in the management of IBD only in videos that did not cite any form of scientific evidence. The negative perceptions against fiber could be attributed to its physiochemical properties, as fiber consumption increases fecal mass and fecal water content, thus stimulating gastrointestinal functional symptoms. Larthermore, the long-standing, anecdotal recommendations by healthcare professionals to exclude dietary fiber, particularly in active disease, may have led video presenters to express mainly neutral/negative claims. While there is epidemiological evidence to suggest that fiber might be protective against IBD onset, the evidence with regard to induction and maintenance of remission is negative in CD and inconclusive in UC.

Probiotics and prebiotics, foods high in n-3 polyunsaturated fatty acids (eg, salmon) and other foods that contain presumably anti-inflammatory compounds, such as blueberries and turmeric, were perceived to ameliorate gut inflammation in the current study. Cumulative evidence does not support the use of n-3 polyunsaturated fatty acid-rich foods or supplements in any aspect of the management of either CD or UC.45 Similarly, there is no evidence to show efficacy of pro- or prebiotic consumption in CD46,47; limited evidence suggests that selected probiotics might be effective in active UC and prevention of pouchitis.<sup>48</sup> Nonetheless, there is growing interest in the role of bioactive compounds, such as anthocyanins and curcumin in the management of IBD; curcumin in particular might be a safe, adjunctive treatment to conventional drug therapy in maintaining remission in patients with UC.49,50

Patients' perceptions against FODRIACs did not differ according to disease type in the current study. This finding is against the weight of evidence showing discrepancies between the efficacy of certain dietary therapies between the

2 diseases, such as the established efficacy of EEN in active CD and the lack of efficacy in UC.<sup>6,48</sup> Similar to our findings, Guida et al<sup>27</sup> and Zallot et al<sup>51</sup> did not observe differences in the proportion of foods avoided as a means to control disease symptoms between patients with CD and UC. In contrast, 2 other cross-sectional, questionnaire surveys reported a higher food avoidance rate from patients with CD compared with patients with UC.<sup>12,52</sup>

Interestingly, we observed a higher video interaction rate and number of likes in patient-generated videos compared with videos from healthcare professionals, irrespective of the number of views, potentially showing that patients are more comfortable interacting with content from other patients compared with healthcare professionals. Although the perceptions of video presenters did not differ between patients and healthcare professionals, only 3% of all patient videos and 35% of videos from healthcare professionals cited any form of scientific evidence. Adherence to dietary practices derived from anecdotal claims, particularly during active disease, could negatively influence short- and long-term disease outcomes and may increase risk of malnutrition and nutrient deficiencies. 14,53 Nutritional inadequacy is important to tackle in children, particularly during rapid growth phases, which often overlap with the age of incident IBD in the pediatric population. Selfimposed dietary restrictions could also lead to diminished social interactions and may have a detrimental impact on foodrelated quality of life and well-being. 12,25,27 In conjunction with the increased rates of anxiety and mental health disorders often reported in patients with IBD,54,55 extensive dietary restrictions and adherence to extreme diets may lead to the development of disordered eating.<sup>56</sup> This highlights an often unmet need to discuss both dietary and psychological aspects that extend beyond the direct management of active disease in the clinical setting.

This study is not without limitations. The cross-sectional design of this study presents a static overview of diet perceptions and does not account for the dynamic content of YouTube, as new, emerging information is uploaded every day. It is also possible that replication of this video search outside of the United Kingdom or in non–English-speaking countries might generate different results or that YouTube video findings may depend on the search history of the end user.

### **Conclusions**

This study identified food and dietary ingredients that were perceived as detrimental in the management of IBD and other dietary components related to certain elements of a Mediterranean and vegetarian type of diet as positive. Because there is a dearth of quality scientific evidence to corroborate these claims, it is of critical importance that health-care professionals discuss the role of diet in IBD etiology and management in the clinic and offer informed advice.

## Supplementary data

Supplementary data is available at *Inflammatory Bowel Diseases* online.

## **Acknowledgments**

Because the data used for this study are available on the public domain, no ethical approval was required.

### **Author Contribution**

K.Gk. carried out the video search, data retrieval, and data and statistical analysis; produced the first draft for publication; and approved the final version of the manuscript. M.W. contributed to the video search, data retrieval and data analysis, critical revision of the manuscript, and final approval. B.N. contributed to the statistical analysis and critical revision of the manuscript and final approval. V.S., R.H., and R.K.R. contributed to study concept, critical revision of the manuscript, and final approval of the manuscript. K.Ge. conceived and developed the study design, supervised the main researcher throughout the study period, and contributed to critical revision of the manuscript and final approval of the manuscript.

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## **Conflict of Interest**

R.K.R. has received speaker fees or travel support from or has performed consultancy work for Nestlé Health Sciences, AbbVie, Takeda, Pharmacosmos, Lilly, Celltrion Healthcare, and Janssen. K.Ge. has received research grants and personal fees from Nestlé Health Science; and personal fees from Nutricia, Dr. Falk Pharma, Abbott, Servier, Mylan, Janssen, and Baxter. The other authors have no conflicts of interest to declare.

## References

- Narula N, Wong ECL, Dehghan M, et al. Association of ultraprocessed food intake with risk of inflammatory bowel disease: prospective cohort study. BMJ. 2021;374:n1554. doi:10.1136/bmj. n1554
- Milajerdi A, Ebrahimi-Daryani N, Dieleman LA, Larijani B, Esmaillzadeh A. Association of dietary fiber, fruit, and vegetable consumption with risk of inflammatory bowel disease: a systematic review and meta-analysis. Adv Nutr. 2021;12(3):735-743. doi:10.1093/advances/nmaa145
- 3. Zhao M, Feng R, Ben-Horin S, et al. Systematic review with meta-analysis: environmental and dietary differences of inflammatory bowel disease in Eastern and Western populations. *Aliment Pharmacol Ther.* 2022;55(3):266-276. doi:10.1111/apt.16703
- Peters V, Bolte L, Schuttert EM, et al. Western and carnivorous dietary patterns are associated with greater likelihood of IBD development in a large prospective population-based cohort. *J Crohns Colitis*. 2022;16(6):931-939. doi:10.1093/ecco-jcc/jjab219
- Narula N, Dhillon A, Zhang D, Sherlock ME, Tondeur M, Zachos M. Enteral nutritional therapy for induction of remission in Crohn's disease. Cochrane Database Syst Rev. 2018;4(4):Cd000542. doi:10.1002 of 14651858.CD000542.pub3
- van Rheenen PF, Aloi M, Assa A, et al. The medical management of paediatric Crohn's disease: an ECCO-ESPGHAN guideline update. *J Crohns Colitis*. 2021;15(2):171-194. doi:10.1093/ecco-jcc/ jjaa161
- Levine A, Wine E, Assa A, et al. Crohn's disease exclusion diet plus partial enteral nutrition induces sustained remission in a randomized controlled trial. *Gastroenterology*. 2019;157(2):440-450.e8. doi:10.1053/j.gastro.2019.04.021
- Svolos V, Hansen R, Nichols B, et al. Treatment of active Crohn's disease with an ordinary food-based diet that replicates exclusive enteral nutrition. *Gastroenterology*. 2019;156(5):1354-1367.e6. doi:10.1053/j.gastro.2018.12.002

- Yanai H, Levine A, Hirsch A, et al. The Crohn's disease exclusion diet for induction and maintenance of remission in adults with mildto-moderate Crohn's disease (CDED-AD): an open-label, pilot, randomised trial. *Lancet Gastroenterol Hepatol*. 2022;7(1):49-59. doi:10.1016/s2468-1253(21)00299-5
- Lamb CA, Kennedy NA, Raine T, et al.; IBD guidelines eDelphi consensus group. British Society of Gastroenterology consensus guidelines on the management of inflammatory bowel disease in adults. *Gut.* 2019;68(Suppl 3):s1-s106. doi:10.1136/ gutjnl-2019-318484
- 11. Holt DQ, Strauss BJ, Moore GT. Patients with inflammatory bowel disease and their treating clinicians have different views regarding diet. *J Hum Nutr Diet*. 2017;30(1):66-72. doi:10.1111/jhn.12400
- Limdi JK, Aggarwal D, McLaughlin JT. Dietary practices and beliefs in patients with inflammatory bowel disease. *Inflamm Bowel Dis*. 2016;22(1):164-170. doi:10.1097/mib.000000000000585
- Triggs CM, Munday K, Hu R, et al. Dietary factors in chronic inflammation: food tolerances and intolerances of a New Zealand Caucasian Crohn's disease population. *Mutat Res.* 2010;690(1-2):123-138. doi:10.1016/j.mrfmmm.2010.01.020
- Gerasimidis K, McGrogan P, Hassan K, Edwards CA. Dietary modifications, nutritional supplements and alternative medicine in paediatric patients with inflammatory bowel disease. *Aliment Pharmacol Ther.* 2008;27(2):155-165. doi:10.1111/ j.1365-2036.2007.03552.x
- Amante DJ, Hogan TP, Pagoto SL, English TM, Lapane KL. Access to care and use of the Internet to search for health information: results from the US National Health Interview Survey. J Med Internet Res. 2015;17(4):e106. doi:10.2196/jmir.4126
- Bernstein KI, Promislow S, Carr R, Rawsthorne P, Walker JR, Bernstein CN. Information needs and preferences of recently diagnosed patients with inflammatory bowel disease. *Inflamm Bowel Dis.* 2010;17(2):590-598. doi:10.1002/ibd.21363
- Cima RR, Anderson KJ, Larson DW, et al. Internet use by patients in an inflammatory bowel disease specialty clinic. *Inflamm Bowel Dis*. 2007;13(10):1266-1270. doi:10.1002/ibd.20198
- 18. Angelucci E, Orlando A, Ardizzone S, et al. Internet use among inflammatory bowel disease patients: an Italian multicenter survey. *Eur J Gastroenterol Hepatol*. 2009;21(9):1036-1041. doi:10.1097/MEG.0b013e328321b112
- 19. Alexa Internet. The top 500 sites on the web. Accessed October 13, 2021. https://www.alexa.com/topsites
- Goobie GC, Guler SA, Johannson KA, Fisher JH, Ryerson CJ. You-Tube videos as a source of misinformation on idiopathic pulmonary fibrosis. *Ann Am Thorac Soc.* 2019;16(5):572-579. doi:10.1513/ AnnalsATS.201809-644OC
- Hassona Y, Taimeh D, Marahleh A, Scully C. YouTube as a source of information on mouth (oral) cancer. *Oral Dis.* 2016;22(3):202-208. doi:10.1111/odi.12434
- Walsh A, Bamkole O, Gerasimidis K. YouTube as a source of information on blenderised tube feeding. *J Pediatr Gastroenterol Nutr.* 2022;74(4):541-545. doi:10.1097/mpg.00000000000003342
- Mukewar S, Mani P, Wu X, Lopez R, Shen B. YouTube and inflammatory bowel disease. *J Crohns Colitis*. 2013;7(5):392-402. doi:10.1016/j.crohns.2012.07.011
- 24. Day AS, Yao CK, Costello SP, Andrews JM, Bryant RV. Food-related quality of life in adults with inflammatory bowel disease is associated with restrictive eating behaviour, disease activity and surgery: a prospective multicentre observational study. *J Hum Nutr Diet.* 2022;35(1):234-244. doi:10.1111/jhn.12920
- 25. Czuber-Dochan W, Morgan M, Hughes LD, Lomer MCE, Lindsay JO, Whelan K. Perceptions and psychosocial impact of food, nutrition, eating and drinking in people with inflammatory bowel disease: a qualitative investigation of food-related quality of life. J Hum Nutr Diet. 2020;33(1):115-127. doi:10.1111/jhn.12668
- Wardle RA, Thapaliya G, Nowak A, et al. An examination of appetite and disordered eating in active Crohn's disease. J Crohns Colitis. 2018;12(7):819-825. doi:10.1093/ecco-jcc/jjy041

- Zallot C, Quilliot D, Chevaux JB, et al. Dietary beliefs and behavior among inflammatory bowel disease patients. *Inflamm Bowel Dis*. 2013;19(1):66-72. doi:10.1002/ibd.22965
- Bergeron F, Bouin M, D'Aoust L, Lemoyne M, Presse N. Food avoidance in patients with inflammatory bowel disease: what, when and who? Clin Nutr. 2018;37(3):884-889. doi:10.1016/j. clnu.2017.03.010
- Marsh A, Kinneally J, Robertson T, Lord A, Young A, Radford-Smith G. Food avoidance in outpatients with inflammatory bowel disease who, what and why. *Clin Nutr ESPEN*. 2019;31:10-16. doi:10.1016/j.clnesp.2019.03.018
- 30. Crooks B, McLaughlin J, Limdi J. Dietary beliefs and recommendations in inflammatory bowel disease: a national survey of healthcare professionals in the UK. *Frontline Gastroenterol*. 2022;13(1):25-31. doi:10.1136/flgastro-2020-101723
- 31. Komperød MJ, Sommer C, Mellin-Olsen T, Iversen PO, Røseth AG, Valeur J. Persistent symptoms in patients with Crohn's disease in remission: an exploratory study on the role of diet. *Scand J Gastroenterol*. 2018;53(5):573-578. doi:10.1080/00365521.2017. 1397736
- 32. Cox SR, Lindsay JO, Fromentin S, et al. Effects of low FODMAP diet on symptoms, fecal microbiome, and markers of inflammation in patients with quiescent inflammatory bowel disease in a randomized trial. *Gastroenterology*. 2020;158(1):176-188.e7. doi:10.1053/j.gastro.2019.09.024
- 33. Szilagyi A, Galiatsatos P, Xue X. Systematic review and metaanalysis of lactose digestion, its impact on intolerance and nutritional effects of dairy food restriction in inflammatory bowel diseases. *Nutr J.* 2016;15(1):67. doi:10.1186/s12937-016-0183-8
- 34. Morton H, Pedley KC, Stewart RJC, Coad J. Inflammatory bowel disease: are symptoms and diet linked? *Nutrients*. 2020;12(10):2975. doi:10.3390/nu12102975
- de Vries JHM, Dijkhuizen M, Tap P, Witteman BJM. Patient's dietary beliefs and behaviours in inflammatory bowel disease. *Dig Dis.* 2019;37(2):131-139. doi:10.1159/000494022
- 36. Ritchie JK, Wadsworth J, Lennard-Jones JE, Rogers E. Controlled multicentre therapeutic trial of an unrefined carbohydrate, fibre rich diet in Crohn's disease. *Br Med J (Clin Res Ed)*. 1987;295(6597):517-520. doi:10.1136/bmj.295.6597.517
- 37. Jowett SL, Seal CJ, Pearce MS, et al. Influence of dietary factors on the clinical course of ulcerative colitis: a prospective cohort study. *Gut.* 2004;53(10):1479-1484. doi:10.1136/gut.2003.024828
- 38. Barnes EL, Nestor M, Onyewadume L, de Silva PS, Korzenik JR; DREAM Investigators. High dietary intake of specific fatty acids increases risk of flares in patients with ulcerative colitis in remission during treatment with aminosalicylates. *Clin Gastroenterol Hepatol.* 2017;15(9):1390-1396.e1. doi:10.1016/j.cgh.2016.12.036
- 39. Logan M, Gkikas K, Svolos V, et al. Analysis of 61 exclusive enteral nutrition formulas used in the management of active Crohn's disease—new insights into dietary disease triggers. *Aliment Pharmacol Ther*. 2020;51(10):935-947. doi:10.1111/apt.15695
- 40. Gkikas K, Logan M, Nichols B, et al. Dietary triggers of gut inflammation following exclusive enteral nutrition in children with Crohn's disease: a pilot study. *BMC Gastroenterol*. 2021;21(1):454. doi:10.1186/s12876-021-02029-4
- 41. Albenberg L, Brensinger CM, Wu Q, et al. A diet low in red and processed meat does not reduce rate of Crohn's disease flares. *Gastroenterology.* 2019;157(1):128-136.e5. doi:10.1053/j. gastro.2019.03.015
- 42. Müller M, Canfora EE, Blaak EE. Gastrointestinal transit time, glucose homeostasis and metabolic health: modulation by dietary fibers. *Nutrients*. 2018;10(3):275. doi:10.3390/nu10030275
- Ananthakrishnan AN, Khalili H, Konijeti GG, et al. A prospective study of long-term intake of dietary fiber and risk of Crohn's disease and ulcerative colitis. *Gastroenterology*. 2013;145(5):970-977. doi:10.1053/j.gastro.2013.07.050

44. Wedlake L, Slack N, Andreyev HJ, Whelan K. Fiber in the treatment and maintenance of inflammatory bowel disease: a systematic review of randomized controlled trials. *Inflamm Bowel Dis*. 2014;20(3):576-586. doi:10.1097/01.Mib.0000437984.92565.31

- Lev-Tzion R, Griffiths AM, Leder O, Turner D. Omega 3 fatty acids (fish oil) for maintenance of remission in Crohn's disease. *Cochrane Database Syst Rev.* 2014(2):Cd006320. doi:10.1002 of 14651858. CD006320.pub4
- 46. Limketkai BN, Akobeng AK, Gordon M, Adepoju AA. Probiotics for induction of remission in Crohn's disease. *Cochrane Data-base Syst Rev.* 2020;7(7):Cd006634. doi:10.1002 of 14651858. CD006634.pub3
- 47. Naseer M, Poola S, Ali S, Samiullah S, Tahan V. Prebiotics and probiotics in inflammatory bowel disease: where are we now and where are we going? *Curr Clin Pharmacol*. 2020;15(3):216-233. doi:10.2174 of 1574884715666200312100237
- 48. Oka A, Sartor RB. Microbial-based and microbial-targeted therapies for inflammatory bowel diseases. *Dig Dis Sci.* 2020;65(3):757-788. doi:10.1007/s10620-020-06090-z
- Coelho MR, Romi MD, Ferreira D, Zaltman C, Soares-Mota M. The use of curcumin as a complementary therapy in ulcerative colitis: a systematic review of randomized controlled clinical trials. Nutrients. 2020;12(8):2296. doi:10.3390/nu12082296
- 50. Kumar S, Ahuja V, Sankar MJ, Kumar A, Moss AC. Curcumin for maintenance of remission in ulcerative colitis. *Cochrane*

- *Database Syst Rev.* 2012;10:CD008424. doi:10.1002 of 14651858. CD008424.pub2
- 51. Guida L, Di Giorgio FM, Busacca A, et al. Perception of the role of food and dietary modifications in patients with inflammatory bowel disease: impact on lifestyle. *Nutrients*. 2021;13(3):759.
- 52. Cohen AB, Lee D, Long MD, et al. Dietary patterns and self-reported associations of diet with symptoms of inflammatory bowel disease. *Dig Dis Sci.* 2013;58(5):1322-1328. doi:10.1007/s10620-012-2373-3
- Kamp KJ, Pennings B, Javelli D, Wyatt G, Given B. Dietary patterns, beliefs and behaviours among individuals with inflammatory bowel disease: a cross-sectional study. J Hum Nutr Diet. 2021;34(2):257-264. doi:10.1111/jhn.12786
- 54. Byrne G, Rosenfeld G, Leung Y, et al. Prevalence of anxiety and depression in patients with inflammatory bowel disease. Can J Gastroenterol Hepatol. 2017;2017:6496727. doi:10.1155/2017/6496727
- 55. Dubinsky MC, Dotan I, Rubin DT, et al. Burden of comorbid anxiety and depression in patients with inflammatory bowel disease: a systematic literature review. Expert Rev Gastroenterol Hepatol. 2021;15(9):985-997. doi:10.1080 of 17474124.2021.1911644
- 56. Wardle RA, Thapaliya G, Nowak A, et al. An examination of appetite and disordered eating in active Crohn's disease. *J Crohns Colitis*. 2018;12(7):819-825. doi:10.1093/ecco-jcc/jjy041