

# Prevalence and Clinician Recognition of Avoidant/Restrictive Food Intake Disorder in Patients With Inflammatory Bowel Disease

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**Abstract:** Background: Avoidant/restrictive food intake disorder (ARFID) is a newly described eating disorder. The aims of this study were to evaluate the prevalence of ARFID in patients with inflammatory bowel disease (IBD) and assess provider recognition of an eating disorder in these patients. Methods: One hundred patients with IBD seen at the Mayo Clinic subspecialty IBD practice in Jacksonville, Florida were screened for ARFID. The diagnosis of ARFID was established using the Nine-Item Avoidant/Restrictive Food Intake Disorder Screen (NIAS) questionnaire. Providers also were asked their opinion of each participating patient's disease severity and whether they believed that the patient had an eating disorder. Results: Of the 98 patients who completed the NIAS questionnaire, 10.2% scored above the clinical cutoff for ARFID. Clinician sensitivity in identifying an eating disorder was 0% and specificity was 96.5%. Conclusion: This pilot study suggests that patients with IBD are at risk for ARFID. Provider recognition of patients at risk for an eating disorder was low. Efforts to educate gastroenterology clinicians to identify and screen at-risk patients for ARFID and other eating disorders are needed.

## Keywords

Inflammatory bowel disease, eating disorders, avoidant/restrictive food intake disorder

Eating disorders, as defined by the American Psychiatric Association in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*, comprise a group of 6 distinct psychiatric disorders that are characterized by persistent disturbance in eating behavior that impairs health or psychosocial functioning.<sup>1</sup> These disorders include anorexia nervosa, avoidant/restrictive food intake disorder (ARFID), binge eating disorder, bulimia nervosa, pica, and rumination disorder. ARFID is a relatively new diagnosis included for the first time in the *DSM-5* and involves concerns regarding the aversive consequences

of eating. Some behaviors that characterize patients with ARFID include avoidant and/or restrictive eating behaviors that develop from associations of certain foods with adverse effects such as distress, disgust, pain, and/or uncomfortable sensations.<sup>2</sup> Unlike anorexia nervosa, restrictive eating in ARFID is not motivated by weight or shape concerns.

Ulcerative colitis (UC) and Crohn's disease (CD) are the 2 major disorders that comprise patients with inflammatory bowel disease (IBD). Patients with IBD experience a constellation of symptoms, including diarrhea, abdominal pain, gastrointestinal bleeding, weight loss, malnutrition, and fatigue. IBD can have a major impact on a patient's quality of life, with disturbance in daily activities, social interactions, intimacy, psychological function, and physical health.<sup>3,4</sup>

A comprehensive systematic review performed by Neuendorf and colleagues examined the prevalence of anxiety and depression in 158,371 participants with IBD.<sup>5</sup> The findings suggest high rates of depression and anxiety disorders, with prevalence rates of 15% and 21%, respectively.<sup>5</sup> As is the case for many patients with chronic medical conditions, these findings suggest that patients with IBD are at risk for comorbid psychiatric illness.

In contrast to the research on depression and anxiety in this population, only a few studies have sought to explore the relationship between patients with IBD and patients with eating disorders, and even fewer studies have focused on ARFID and IBD.<sup>6</sup> In response to aversive consequences of eating, distorted beliefs about how food affects their illness may develop in patients with IBD, leading to behaviors ranging from restrictive diets, skipping meals, binge eating, and fasting.<sup>4,7</sup> Although patients with IBD commonly use restrictive eating to manage symptoms associated with their condition, the relationship of IBD to ARFID has yet to be explored. As such, this study sought to establish the prevalence in which patients with IBD score above the clinical cutoff for ARFID on a widely used screening measure.

## Materials and Methods

This study was a single-center cross-sectional pilot study conducted at Mayo Clinic Florida. Participants in this study were patients with IBD seen during an office visit to the Inflammatory Bowel Disease Center between July 1, 2019 and July 26, 2019. The goal of this pilot study was to include 100 adult (age  $\geq 18$  years) patients with a diagnosis of IBD. Patients with ostomies or ileal pouches were eligible for inclusion in the study. Patients on total parenteral nutrition or enteral feeding were excluded.

Study recruitment consisted of providers asking new and established patients who were visiting the center

**Table 1.** Demographics and Disease Severity of Patients Who Completed the NIAS

Demographic or Disease Severity	Patients (N=98)
• Age in years, mean $\pm$ SD	44.5 $\pm$ 16.4
• Female, n	55 (56.1%)
• BMI, mean $\pm$ SD	27.3 $\pm$ 6.2
<18.5, n	3
18.5-24.9, n	36
25.0-29.9, n	29
30.0-34.9, n	17
35.0-39.9, n	10
$\geq 40.0$ , n	3
• Severity, n	65
Remission, n	40 (61.5%)
Mild, n	11 (16.9%)
Moderate, n	10 (15.4%)
Severe, n	4 (6.2%)

BMI, body mass index; NIAS, Nine-Item Avoidant/Restrictive Food Intake Disorder Screen; SD, standard deviation.

to participate in surveys to evaluate their eating habits. Patients completed the Nine-Item Avoidant/Restrictive Food Intake Disorder Screen (NIAS). The NIAS questionnaire is a validated 9-item tool used to identify ARFID-associated eating behaviors.<sup>8</sup> Patients were not asked whether they had previously received a diagnosis of an eating disorder or if they felt that they might have an eating disorder. Patients who scored 28 or higher on the NIAS questionnaire were considered a positive screen for ARFID.

Providers (physicians and nurse practitioners) who care for patients with IBD were asked to assess disease activity by ranking their patients as in remission or by severity level (mild, moderate, or severe) within 24 hours of the office visit. Providers also were asked to gauge whether they thought that their patients were at risk for an eating disorder. Providers were made aware, prior to

**Table 2.** Results of the NIAS Questionnaire

	NIAS-Positive (N=10)	NIAS-Negative (N=88)	P Value
• Age in years, mean $\pm$ SD	37.6 $\pm$ 5.17	45.3 $\pm$ 1.74	.16
• Female, n	4 (40.0%)	51 (58.0%)	.33
• BMI, mean $\pm$ SD	27.5 $\pm$ 0.67	26.3 $\pm$ 1.98	.60
• Severity, n	5	60	
Remission, n	1 (20.0%)	39 (65.0%)	.07
Mild, n	2 (40.0%)	9 (15.0%)	.20
Moderate, n	0 (0.0%)	10 (16.7%)	1.0
Severe, n	2 (40.0%)	2 (3.3%)	.027
Remission/mild (combined), n	3 (60.0%)	48 (80.0%)	.29
Moderate/severe (combined), n	2 (40.0%)	12 (20.0%)	.29

BMI, body mass index; NIAS, Nine-Item Avoidant/Restrictive Food Intake Disorder Screen; SD, standard deviation.

beginning the study, that they would be surveyed on their opinion regarding whether their patients had an eating disorder. Providers did not receive training on eating disorder recognition.

Continuous variables were summarized with the sample mean and standard deviation for the statistical analysis. Categorical variables were summarized with the number and percentage of patients. Comparisons between nonparametric groups were made using a Wilcoxon rank-sum test or Fisher's exact test. Student's *t*-test was used for comparing parametric data. All tests were 2-sided with the alpha level set at 0.05 for statistical significance. Sensitivity and specificity of the clinicians' assessments compared with the NIAS questionnaire results also were calculated. All statistical analyses were performed using JMP, Version 14.1.0 (SAS Institute Inc).

This study was approved by the Institutional Review Board at Mayo Clinic in Jacksonville, Florida.

## Results

One hundred patients with IBD provided informed consent and were surveyed. Of these, 65 had CD and 35 had UC. Owing to the small sample size, patient results were not separated by CD or UC. Results were stratified based on responses to the NIAS survey instruments.

The NIAS survey was completed by 98 patients. Of those who completed the survey, 10.2% met clinical

criteria for ARFID. The average age of patients who completed the NIAS questionnaire was 44.5  $\pm$  16.4 (mean  $\pm$  standard deviation), 56.1% were female, and the average body mass index was 27.3. Among the 65 patients for whom IBD severity was available, 40% of patients with ARFID had severe disease compared with 3.3% of patients without ARFID. Of the 95 patients for whom a provider opinion regarding an eating disorder was available, sensitivity was 0% (0/10) and specificity was 96.5% (82/85; *P*=1.0). Positive predictive value for clinician recognition of an eating disorder was 0%, whereas negative predictive value was 89.1%. Further result details can be found in Tables 1, 2, and 3.

## Discussion

This study was designed to evaluate the prevalence of patients at risk for ARFID in a cohort of patients with IBD. The prevalence of ARFID in the general population is not known, as this is a relatively new diagnosis and has not been as widely studied in the general population as other eating disorders.<sup>9</sup> This study identified 10.2% of patients screened above the cutoff, suggesting that they were at risk for ARFID. The study also found that patients with severe IBD were more likely to screen positive for ARFID. Forty percent of patients in the ARFID cohort had more severe disease compared with the non-ARFID group (3.3%). Studies in the general population

**Table 3.** Provider Recognition of an Eating Disorder

	NIAS-Positive	NIAS-Negative	Total
Provider suspects an eating disorder (positive), n	0 (0.0%)	3 (100.0%)	3
Provider does not suspect an eating disorder (negative), n	10 (10.9%)	82 (89.1%)	92
Total	10	85	95
<i>P</i> =1.0; sensitivity is 0%; specificity is 96.5%			

NIAS, Nine-Item Avoidant/Restrictive Food Intake Disorder Screen.

usually use a cutoff of 24 points for a positive screen NIAS questionnaire. It is therefore possible that this pilot study still underestimates the prevalence of ARFID in the IBD population, as a cutoff of 28 points was chosen given the baseline symptomatology of patients with IBD. Another pilot study performed at a different center found a prevalence of 17% while using the 24-point cutoff.<sup>10</sup>

Severe IBD symptomatology has been linked to poor quality of life.<sup>11</sup> Although increased physical symptoms associated with severe IBD may lead to restrictive eating, the association between symptomatology and restrictive eating behaviors remains unclear. It is also possible that malnutrition associated with restrictive eating may lead to more active disease.<sup>12-14</sup>

Because similar behaviors have been observed in patients with IBD and those with ARFID, patients with IBD should be considered at risk for ARFID. To avoid the exacerbation of IBD symptoms that are associated with eating, patients with ARFID are more likely to avoid and restrict certain foods. Similarly, patients with IBD may exclude certain foods from their diet because they associate those foods with symptoms of abdominal pain and increased defecation.<sup>12</sup> A study by Vagianos and colleagues noted that patients with IBD regularly avoid or selectively eliminate food when their disease is active, with a large percentage of participants reporting that they avoid certain foods because of gastrointestinal upset.<sup>15</sup> To help these patients with comorbid ARFID and IBD reintroduce foods and reestablish normal eating patterns, behavioral therapies may be of benefit.<sup>16</sup>

The European Society for Clinical Nutrition and Metabolism performed a systematic review combined with expert opinion to evaluate recommendations regarding nutrition in patients with IBD and to establish guidelines for nutritional management.<sup>16</sup> This study found that a special diet in IBD and/or exclusion diets were not beneficial in disease management and consequently are not recommended. However, owing to mixed findings, the authors added that it is difficult to provide evidence-based

conclusions about nutritional intervention in regard to patients with IBD.<sup>16</sup> Given that experts find it difficult to come to a clear consensus about dietary programs for patients with IBD, it is not surprising that patients with IBD are uncertain about dietary recommendations or that adverse relationships with foods may develop in these patients.

Early in their disease course, patients with IBD may establish a connection between certain foods and symptoms, and, subsequently, many feel that they receive inadequate guidance on nutrition.<sup>15,17</sup> The Manitoba IBD cohort study conducted by Wong and colleagues in 2012 noted that 80% to 89% of participants regarded dietary guidance as important, yet only 8% to 16% of participants felt adequately educated on diet.<sup>14</sup> Poor dietary guidance may be another factor that steers patients toward avoidant behavior. Future studies are needed to determine whether lack of dietary guidance contributes to avoidant and restrictive dietary behaviors.

An equally important goal of this study was to assess provider recognition of eating disorders in patients with IBD. In our practice, gastroenterology providers had low sensitivity for recognizing patients at risk for an eating disorder, with a sensitivity of 0% for recognition. This inability to recognize an eating disorder could occur for several reasons. ARFID is a newly recognized condition among eating disorders; therefore, there is no widespread awareness of its existence. A lack of knowledge and awareness of screening tools for ARFID can lead to underdiagnosis. Providers also experience significant time constraints during regular office visits that may not allow for sufficient time to address and screen for eating disorders. Further, there is symptom overlap between ARFID and IBD, including diarrhea, nausea, vomiting, reduced appetite, weight loss, malnourishment, constipation, and postprandial symptoms.<sup>2,6</sup> This overlap can lead providers to evaluate all symptoms as a sequela of IBD without consideration of other conditions that may coexist with IBD. Gastroenterology clinicians must have a higher awareness

and general knowledge to screen and identify patients with IBD who are at risk for eating disorders and ARFID.

This pilot study had several limitations. First, the sample size of 100 patients at a referral academic center is a relatively small subset that may not be generalizable to patients in the larger community. A larger study of patients with IBD with diverse demographics may help clinicians understand the true prevalence of eating disorders and ARFID and allow for further separation of IBD into CD and UC groups. Second, IBD severity was measured by clinician subjective assessment but not by an objective validated scale. Current medications (including corticosteroids), history of surgeries, and extent of disease were not systematically recorded. Third, information regarding IBD phenotype, including disease location and behavior, was not obtained for each individual patient. Fourth, food journals were not collected nor were detailed inquiries regarding restriction of specific foods and beverages. Further, patients were not requested to report whether a provider ever recommended dietary restrictions.

Finally, because the NIAS is a screening measure as opposed to a structured diagnostic interview, only patients at risk for ARFID were able to be identified. In addition, the NIAS is limited by its development and validation in a younger community sample rather than in an adult medical population. Despite it being a self-administered screening questionnaire, it is a validated tool to screen for ARFID. A visit with a provider trained in eating disorders would be needed to confirm the diagnosis.

In this pilot study, patients who screened positive for ARFID were subsequently referred to a psychologist for further evaluation, but the data from this assessment were not obtained. Despite these limitations, the data from this study present a starting point for future research and can support the development of new measures to capture disordered eating in an IBD population. This pilot study is the first to highlight the prevalence of avoidant and restrictive eating behaviors and the need to educate clinicians on this condition for improved recognition and management.

## Conclusion

This study suggests that there is a risk of comorbid ARFID in patients who have IBD. Further, studies are needed to

evaluate the actual prevalence of ARFID and associated features in patients with IBD. Provider recognition of eating disorders was low among gastroenterologists in this study. Efforts to educate clinicians are essential to appropriately screen and address ARFID in these patients.

## Disclosures

*The authors have no relevant conflicts of interest to disclose.*

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