

ORIGINAL RESEARCH—CLINICAL

Avoidant/Restrictive Food Intake Disorder Characteristics and Prevalence in Adult Celiac Disease Patients



Audrey Bennett,¹ Alexandra Bery,² Patricia Esposito,¹ Hana Zickgraf,³ and Dawn W. Adams¹

¹Department of Gastroenterology, Hepatology, and Nutrition, Vanderbilt University Medical Center, Nashville, Tennessee; ²Department of Internal Medicine, Vanderbilt University Medical Center, Nashville, Tennessee; and ³Department of Psychology, University of South Alabama, Mobile, Alabama

BACKGROUND AND AIMS: The objective of this study was to identify the prevalence of avoidant/restrictive food intake disorder (ARFID) in patients with celiac disease (CD) and assess metabolic complications, disease control, diet adherence, and correlation with symptom and quality-of-life metrics. **METHODS:** This was a retrospective study of 137 adult patients with CD who completed an ARFID survey in the CD clinic between 2018 and 2020. Demographics, clinical results, standardized diet assessment, and results of Celiac Disease Symptom Diary and Impact of a Gluten-free Diet Questionnaire were reviewed. The primary outcome measured was the rate of suspected ARFID based on patient-reported survey responses. **RESULTS:** Seventy-eight patients (57%) met suspected ARFID criteria. There were no differences in age, gender, body mass index, micronutrient deficiencies, or bone disease in those with or without ARFID. Patients with ARFID did not have a difference in biopsy activity or better adherence to a gluten-free diet compared with non-ARFID patients. Food and social burden on Impact of a Gluten-free Diet Questionnaire was most predictive of ARFID. **CONCLUSION:** ARFID is common and has a high impact in patients with CD. Although some eating behavior is certainly due to their CD, there was no distinct difference in disease control between those with or without suspected ARFID, suggesting these maladaptive behaviors are not necessary for disease control. We did not find increased metabolic complications, but this was a 2-year snapshot. We need to further understand the social and food impacts on patients who score high on this survey to prevent further deficiencies and impaired, long-term detrimental eating behaviors.

Keywords: Celiac Disease; ARFID; Eating Disorder

Introduction

Celiac disease (CD) is an autoimmune disease resulting in intolerance to gluten, a protein found in wheat, barley, and rye.¹ Once diagnosed, CD is a lifelong, chronic condition. For patients with CD, exposure to gluten leads to chronic inflammation in the small bowel, with symptoms that can include diarrhea, nausea, abdominal pain, bloating, weight loss, fatigue, depression, and cognitive impairment.² Effects of chronic small bowel inflammation in

CD can include micronutrient deficiency due to malabsorption, bone disease including osteopenia or osteoporosis, and rarely, the development of CD-associated malignancies, including enteropathy-associated T cell lymphoma, non-Hodgkin's lymphoma, and adenocarcinoma of the small intestine.^{2,3} It is estimated that close to 1% of the US population has CD.⁴ At this time, the only treatment for CD is a strict gluten-free diet.^{3,5} The gluten-free diet promotes intestinal healing and symptom improvement, but is a restrictive diet that can be difficult for patients to follow, mentally taxing, and socially isolating.²

Some patients with CD develop dysfunctional beliefs regarding gluten-free foods, gluten-free products, or fear of gastrointestinal (GI) symptoms or neophobia of eating certain gluten-free foods.⁵ These eating patterns, characterized by fear of negative consequences from eating, food neophobia, and low motivation to eat may lead to avoidant/restrictive food intake disorder (ARFID). The diagnosis of ARFID was added to the Diagnostic and Statistical Manual, 5th Edition (DSM-5) in 2013 as a way to identify patients who were unable to meet their nutritional needs, but unlike anorexia nervosa or bulimia nervosa, did not fear weight gain or experience body image distortion.⁶ Patients with ARFID have limited food intake or a narrow diet which leads to nutritional deficiencies, dependence on nutritional supplements, or significant impairment with daily functioning.^{7,8} ARFID is diagnosed when a patient's eating restrictions are not due to fear of body weight or shape, but rather by other factors, which include excessively picky eating, limited appetite or lack of interest in eating, and fear

Abbreviations used in this paper: ARFID, avoidant/restrictive food intake disorder; BMI, body mass index; CD, celiac disease; CDS, Celiac Disease Symptom Diary; DEXA, dual-energy x-ray absorptiometry; EGD, esophagogastroduodenoscopy; GI, gastrointestinal; IBS, irritable bowel syndrome; IGF, Impact of a Gluten-free Diet Questionnaire; NIAS, Nine-item Avoidant Restrictive Food Intake Disorder Screen; SDE, Standardized Dietitian Evaluation.

Most current article

Copyright © 2022 The Authors. Published by Elsevier Inc. on behalf of the AGA Institute. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

2772-5723

<https://doi.org/10.1016/j.gastha.2022.01.002>

of negative consequences, such as choking, vomiting, or GI distress from eating.^{7,8} In the Diagnostic and Statistical Manual, 5th Edition, there are 3 distinct eating patterns that can lead to ARFID, including avoidance of foods due to aversion to their sensory properties, poor appetite or limited interest in eating, or fear of negative consequences from eating.⁸

This study was a retrospective chart review of patients with CD who followed with the Center for Human Nutrition at Vanderbilt University Medical Center for management of their CD from January 2018 to November 2020 and completed an ARFID assessment survey. The aim of the study was to understand the prevalence of ARFID in the adult CD population and identify if disease activity, diet adherence, and metabolic complications were associated with ARFID.

Materials and Methods

This descriptive retrospective study included adult patients with CD who were evaluated in the Center for Human Nutrition at Vanderbilt University Medical Center. All patients included in this study had confirmed, biopsy-proven CD. The Center for Human Nutrition at Vanderbilt University Medical Center maintains a panel of patients with CD who are evaluated in the clinic. Clinic visits include laboratory testing, bone density screening, and standardized diet adherence assessment by a single dietitian. In addition, patients complete clinical surveys for assessment of disease activity, impact of the gluten-free diet on quality of life, and an ARFID screening assessment. We identified patients who had completed at least one ARFID survey between January 2018 and August 2020. For patients who had completed more than one ARFID survey during this time period, their first ARFID survey results were included. There were no exclusion criteria for this study.

Patients' charts were reviewed to extract date of birth, gender, height, weight, body mass index (BMI), date of CD diagnosis, and history of bone disease including osteoporosis or osteopenia as measured by dual-energy x-ray absorptiometry scan. History of anxiety or depression was noted in chart review of the past medical history, or patients reported in celiac clinic notes. Supplement use was noted in chart review of medication list and dietitian notes, or patients reported in celiac clinic notes. Celiac serologies, including tissue transglutaminase antibodies (IgG and IgA) and deaminated gliadin antibodies (IgG and IgA), were collected as part of routine care and were categorized as positive or negative per our laboratory's reference range. Micronutrient levels collected included iron, folic acid, zinc, copper, magnesium, vitamin B12, vitamin B6, and vitamin D. If any of these micronutrient levels were low, the patient was marked as having a micronutrient deficiency. Laboratory results were only included if patients had laboratory values collected within 1 year of their ARFID survey. Follow-up duodenal biopsy results from esophagogastroduodenoscopy with the Marsh score, a standardized histologic marker of CD activity, were reported.^{9,10} Biopsy results included in this study were from the most recent surveillance biopsy; biopsy results from index endoscopy at the time of CD diagnosis were not included as all patients had active disease at diagnosis. Finally, survey data collected for

this study included Standardized Dietitian Evaluation (SDE), Celiac Disease Symptom Diary (CDS), Impact of a Gluten-free Diet Questionnaire (IGFDQ), and ARFID symptom checklist (ARFID-cl).¹¹⁻¹³ All surveys were completed by the patient at the clinic visit. The SDE is a validated survey of a 3-day food record to assess quantity and frequency of exposure to gluten as measured on a 6-point Likert scale, with 1 being 'excellent adherence' to 6 being 'not following a gluten-free diet'.¹¹ The CDS is a validated patient-reported outcome survey that assesses, over the last 7 days, the presence of CD symptoms such as diarrhea, constipation, abdominal pain, bloating, flatulence, nausea, rash, fatigue, headache, and difficulty thinking. If these symptoms are present, patients then rank the severity and amount of interference with activities of daily living.¹² The CDS survey is scored from 0 to 40, with higher scores representing more symptoms.¹² The IGFDQ is a survey that assesses, over the past 7 days, the burden of a gluten-free diet including limited food choices, interference with social activities, and impact on emotional well-being.¹² For each of these subcategories within the IGFDQ survey, scores range from 1 to 5, with 1 representing 'no burden or interference' and 5 representing 'always a burden or a complete interference'.¹²

The ARFID screening assessment used for this study was the ARFID-cl. This validated survey was created by Zickgraf, Franklin, and Rozin and published in the *Journal for Eating Disorders* in 2016.¹³ The ARFID-cl is similar to the Nine-item Avoidant/Restrictive Food Intake Survey (NIAS) created by Zickgraf and Ellis, but the ARFID-cl was designed to discriminate between restrictive eating driven by medical illness and restrictive eating driven by fear of consequences that are excessive to the real risks or likely consequences of a medical condition that is appropriately managed.⁸ For the ARFID screening assessment, patients were asked to report whether 'limited interest in eating', 'limited appetite', 'selective or picky eating—not willing to try new foods', and 'fear of negative consequences from eating (choking, vomiting, discomfort)' led to any of the 4 diagnostic ARFID symptoms: weight loss, nutritional deficiencies, dependence on nutritional supplements, or impairment in daily life.¹³ Participants who endorsed any of these symptoms as present to 'some' or 'a significant' degree (vs 'not at all' on a 3-point scale) were asked to rate the degree to which potential drivers of restrictive eating are present, including the 3 ARFID-related eating restrictions, poor appetite, picky eating, or fear of negative consequences from eating, with separate questions to assess fear of abdominal pain or bowel discomfort including irritable bowel syndrome (IBS), fear of choking or food becoming stuck in the throat, or fear of vomiting. The ARFID-cl survey also evaluated if restrictive eating was driven by a desire to lose weight or control shape, a drive to eat exclusively "clean" or "healthy" food (eg, orthorexia nervosa), or pain, discomfort, or metabolic problems caused by a medical illness, excluding IBS. Each driver for restrictive eating was rated on a 4-point scale, with anchors 'this did not contribute', 'this did not contribute much', 'this made a contribution', and 'this was the sole or primary contributor'. Only participants who attributed their ARFID symptoms to 1 of the 3 ARFID restrictions by rating at least one of them as the 'sole or primary contributor' were included in the suspected clinical or subclinical ARFID categories. Participants who rated other reasons for restriction as 'sole or primary' in addition to at least one ARFID restriction were included in the suspected ARFID group.

Patients were determined to not have ARFID if they denied any subclinical or significant ARFID symptoms or if they reported subclinical or significant ARFID symptoms but attributed them to a non-ARFID cause. Patients were diagnosed with subclinical ARFID if they reported one or more ARFID symptoms as present 'to some degree' but did not report any symptom as present 'to a significant degree'. Patients were determined to have clinical ARFID if they reported one or more ARFID symptoms as present 'to a significant degree' and attributed the ARFID symptoms to an ARFID cause. In this study, both clinical and subclinical ARFID cases were counted as ARFID. All ARFID symptoms and manifestations in this study were based on patient-reported survey responses in the ARFID-cl and were not based on formal clinical assessment.

Continuous variables were summarized using median, 25th percentile, and 75th percentile and categorical variables, using percentages. The Wilcoxon rank sum test (continuous variables) and Pearson's chi-squared test were used to test for unadjusted associations with ARFID status. We also used multivariable logistic regression to estimate the odds of ARFID per one-point increase in IGFQ food, social, and emotional scores.

Results

There were 137 adult patients with CD included in this study who completed an ARFID survey between January 2018 and August 2020. The study included 107 women and 30 men. The median age at the time of CD diagnosis was 37 years (lower quartile = 25 years, upper quartile = 56 years). At the time of ARFID survey, the median patient age was 43 years (lower quartile = 28 years, upper quartile = 60 years). The median BMI of all patients was 26 (lower quartile = 23, upper quartile = 32). Of the 137 patients included in the study, 8 (5.8%) had a diagnosis of type I diabetes mellitus, and 7 (5%) had a diagnosis of type II diabetes mellitus. Within the group, there were 10 patients (7%) with microscopic colitis, 1 (0.7%) with ulcerative colitis, 1 (0.7%) with Crohn's disease, and 1 (0.7%) with indeterminate colitis. No patients in this study were on enteral nutrition support.

There were 78 patients (57%) in this study with suspected ARFID based on patient-reported survey response. Of these 78 patients, 30 were identified as clinical ARFID and 48 were identified as subclinical ARFID. There was no significant difference in duration of illness with CD between those with or without ARFID; the median duration from diagnosis of CD to the time of ARFID survey in the non-ARFID group was 1260 days (3.45 years) compared with 978 days (2.68 years) in the ARFID group. As outlined in [Table 1](#), there was no significant difference in age, gender, or BMI between patients with or without ARFID. The median BMI of the non-ARFID group was 25 (lower quartile = 23, upper quartile = 33), and the median BMI of the ARFID group was 27 (lower quartile = 23, upper quartile = 32) ($P = .98$). There was no significant difference in comorbid GI diseases, but these numbers were small in both groups. There was no significant difference in the prevalence of

anxiety and/or depression between the 2 groups. Of the 137 patients in this study, 45 patients (33%) had a diagnosis of anxiety and/or depression. Within the ARFID group, 23 of 78 (30%) had a diagnosis of anxiety and/or depression, and within the non-ARFID group, 22 of 59 (38%) had a diagnosis of anxiety and/or depression. There was no difference in the rate of bone disease between the 2 groups; 19 (39%) patients with ARFID and 22 (46%) patients without ARFID had bone disease, defined as osteopenia or osteoporosis based on dual-energy x-ray absorptiometry imaging ($P = .48$). Thirty-three (42%) patients with ARFID had a vitamin or micronutrient deficiency compared with 22 (37%) non-ARFID patients ($P = .55$). Overall, for the 137 patients in this study, 91 patients (66%) were taking supplements. Of the 59 patients without ARFID, 38 patients (64%) were taking supplements, and of the 78 patients with ARFID, 53 patients (69%) were taking supplements.

Celiac serologies, checked within 1 year of the ARFID survey, showed only the tissue transglutaminase IgG antibody was statistically different between the ARFID (15% positive) and non-ARFID groups (2% positive) ($P = .007$). The other serology laboratory results are outlined in [Table 1](#). There were 35 patients (59%) in the non-ARFID group who had at least one positive celiac serology compared with 43 patients (55%) in the ARFID group ($P = .62$). All patients had at least one positive celiac serology at the time of CD diagnosis.

Eighty-four of 137 patients (61%) had a follow-up duodenal biopsy after their diagnosis of CD. There was no significant difference in duodenal biopsy activity between patients with ARFID and non-ARFID patients as measured by the Marsh score. There were 18 of 45 (40%) patients with ARFID with Marsh 0 disease compared with 23 of 39 (59%) non-ARFID patients with Marsh 0 disease ($P = .20$). Patients with ARFID did not have better compliance with the gluten-free diet; the median SDE score was 2 for both groups ($P = .34$). An SDE score of 2 corresponds with 'good gluten-free diet adherence'.¹¹

In the ARFID survey, patients were asked if limited interest in eating, limited appetite, selective/picky eating, or fear of negative consequences from eating led to any of the 4 diagnostic ARFID symptoms which include unintended weight loss, nutritional deficiencies, dependence on nutritional supplements, or impairment in daily life. Within the 78 patients with suspected ARFID, 4 patients (5%) reported their only ARFID symptom was nutritional deficiency, 28 patients (36%) reported their only ARFID symptom was impairment in daily life, and no patients reported unintended weight loss or dependence on nutritional supplements as their only ARFID symptom. There were 46 of 78 patients (59%) who reported multiple ARFID symptoms as outlined in [Table A1](#). Overall, 69 of 78 patients (89%) reported impairment in daily life as an ARFID symptom.

In the ARFID survey, patients were asked to report if poor appetite/limited interest in eating, picky eating, fear of GI discomfort including IBS, fear of vomiting, fear of choking, fear of GI discomfort from a medical condition/

Table 1. Characteristics for Adult Patients With Celiac Disease and With and Without Avoidant/Restrictive Food Intake Disorder (ARFID)

Characteristic	Patients without ARFID (n = 59)	Patients with ARFID (n = 78)	P-value
Age at ARFID survey (y)	46 (29, 66)	42 (28, 55)	.20
Age at celiac diagnosis	41 (25, 61)	36 (26, 49)	.20
Gender (female)	46 (78%)	61 (78%)	.97
Body mass index	25 (23, 33)	27 (23, 32)	.98
Microscopic colitis	4 (7%)	6 (8%)	.84
Nondiabetic	51 (86%)	71 (91%)	.29
Type I diabetes mellitus	3 (5%)	5 (6%)	
Type II diabetes mellitus	5 (8%)	2 (3%)	
Osteoporosis or osteopenia	22/48 (46%)	19/49 (39%)	.48
Micronutrient deficiency	22 (37%)	33 (42%)	.55
Tissue transglutaminase IgG positive on surveillance laboratory values	1 (2%)	12 (15%)	.007
Tissue transglutaminase IgA positive on surveillance laboratory values	24 (41%)	33 (42%)	.85
Deaminated gliadin IgG positive on surveillance laboratory values	14 (24%)	26 (33%)	.22
Deaminated gliadin IgA positive on surveillance laboratory values	21 (36%)	28 (36%)	.97
Impact of a Gluten-free Diet Questionnaire (IGFDQ), emotional	1.5 (1.2, 2)	1.9 (1.4, 2.4)	.013
Impact of a Gluten-free Diet Questionnaire (IGFDQ), social	1.5 (1, 2)	2.5 (1.5, 3)	.002
Impact of a Gluten-free Diet Questionnaire (IGFDQ), food	2.3 (1.7, 3)	3 (2.3, 3.3)	.008
Celiac Disease Symptom Diary (CDS) nonstool score	3.2 (0.5, 10)	7.2 (5.2, 13)	.016
Celiac Disease Symptom Diary (CDS) diarrhea score	0 (0, 0)	0 (0, 2)	.062
Standardized Dietician Evaluation (SDE) score	2 (1.5, 3)	2 (1, 3)	.34
Surveillance duodenal biopsy Marsh score			.20
Marsh score 0	23/39 (59%)	18/45 (40%)	
Marsh score 1	2/39 (5%)	5/45 (11%)	
Marsh score 2	0 (0%)	0 (%)	
Marsh score 3	14/39 (36%)	22/45 (49%)	

Values are expressed as median (lower and upper quartile range).

excluding IBS, fear of weight gain, or desire to eat only healthy foods/orthorexia contributed to restrictive eating and led to ARFID symptoms of unintended weight loss, nutritional deficiencies, dependence on nutritional supplements, or impairment in daily life. As outlined in [Table A1](#), many patients reported more than one cause for their restrictive eating behavior. Overall, 18 of 78 patients (23%) identified poor appetite as a reason for restrictive eating, 16 of 78 (21%) identified picky eating, 55 of 78 (71%) reported fear of GI discomfort including IBS as a reason for restriction, 8 of 78 (10%) reported fear of vomiting, 6 of 78 (8%) reported fear of choking, 19 of 78 (24%) reported fear of GI discomfort from a medical condition/excluding IBS, 8 of 78 (10%) reported fear of weight gain, and 15 of 78 (19%) reported a desire to eat only healthy foods/orthorexia.

Notably, for patients who reported fear of weight gain, desire to eat only healthy foods/orthorexia, or GI discomfort from a medical condition/excluding IBS as reasons for their restrictive behavior, they all equally reported other reasons for restriction (poor appetite, picky eating, fear of negative consequences from eating) to qualify for a suspected ARFID diagnosis. After patients reported whether the above-mentioned reasons contributed to restrictive eating ('this did not contribute', 'this did not contribute much', 'this made

a contribution', and 'this was the sole or primary contributor'), they were then asked to rank those 8 reasons for restriction on a scale from 1 to 8. Among the 78 patients in this study with suspected ARFID, 65 patients completed this ranking. Reasons for their restriction are outlined in [Table 2](#). The self-reported top reason for restrictive eating was fear of GI discomfort including IBS (31/65, 48%), followed by picky eating (9/65, 14%), poor appetite (7/65, 11%), fear of GI discomfort caused by a medical illness/excluding IBS (7/65, 11%), fear of choking (3/65, 5%), fear of gaining weight (3/65, 5%), strong desire to eat only healthy foods/orthorexia (3/65, 5%), and fear of vomiting (2/65, 3%). Notably, for the 6 patients who reported their top reason for restrictive eating was either fear of gaining weight or strong desire to eat only healthy foods/orthorexia, all of these patients also equally ranked other reasons for restrictive eating habits in the survey. For the 3 patients who reported a strong desire to eat only healthy foods/orthorexia, they also reported additional reasons for restriction including either picky eating or fear of GI discomfort. For the 3 patients who reported fear of weight gain, they also reported additional reasons for restriction including either poor appetite or fear of GI discomfort.

The presence of ARFID correlated highly with the IGFDQ. Patients had a higher probability of having ARFID if they

Table 2. Self-reported Top Contributing Reason for Restrictive Eating in Adult Patients With Celiac Disease and With Avoidant/Restrictive Food Intake Disorder (ARFID)

Top reason for restrictive eating	n = 65
Fear of GI discomfort including irritable bowel syndrome	48% (31/65)
Picky eating	14% (9/65)
Poor appetite	11% (7/65)
Fear of gastrointestinal discomfort excluding irritable bowel syndrome	11% (7/65)
Fear of choking	5% (3/65)
Fear of gaining weight	5% (3/65)
Strong desire to eat only healthy foods/orthorexia	5% (3/65)
Fear of vomiting	3% (2/65)

scored higher on the social and food components of the questionnaire as compared with the emotional component. The IGFDDQ was the only predictor of ARFID in multivariable analysis with odds ratio of 1.64 ($P = .01$), 1.66 ($P = .05$), and 1.59 ($P = .01$) for food, emotional, and social components, respectively. In modeling, food and social parameters mattered more than emotional in predicting ARFID. Interestingly, despite being predictive of ARFID, subjects overall ranked the impact of a gluten-free diet on their food choices as only sometimes limiting (median = 3 out of 5) and avoiding social activities slightly to moderately (median = 2.5 out of 5).

Discussion

Because the only current treatment for CD is a strict gluten-free diet, there is an increased awareness of food in this patient population that can lead to disordered eating habits such as ARFID. The diagnosis of ARFID is not restricted to any age group, but has most often been diagnosed in young adolescents.⁶ Prior studies have demonstrated that compared with other eating disorders, patients with ARFID are more likely to have a comorbid medical condition or anxiety disorder.¹⁴⁻¹⁶ As a diagnosis that was only recently identified in 2013 and with a higher prevalence in adolescent patients, less is known about prevalence and outcomes of ARFID in adult patients, especially those with comorbid conditions, such as CD.

Our study found a high prevalence of adult patients with CD who met criteria for suspected ARFID based on patient-reported survey response. Although we cannot completely separate true celiac symptoms from nonceliac GI symptoms as a contributor to this phenomenon, it is notable that there was no significant difference in disease control or standardized diet assessment in patients with and without suspected ARFID. This supports that this degree of restriction is not required nor should be accepted to achieve celiac treatment targets. A recent, similar study by Fink et al used

the NIAS to screen for ARFID in 76 adult patients with CD and found 37 (49%) of patients had a positive NIAS, concerning for possible ARFID. In their study, they also found that patients who reported more ARFID symptoms had higher rates of anxiety, depression, and lower quality of life.¹⁷

Studies have demonstrated that up to 90% of patients with newly diagnosed CD may have a micronutrient deficiency and up to 75% may have some form of metabolic bone disease.¹⁸⁻²⁰ Our study was not limited to newly diagnosed patients but found that 40% of patients had a micronutrient deficiency at some point during their care in our center with a median BMI of 26 (overweight). To our surprise, the BMI did not differ between patients with and without restrictive eating attributed to ARFID. In addition, there was no difference in rates of bone disease. We hypothesized to see more evidence of micronutrient deficiencies, low BMI, and higher rates of bone disease in patients with ARFID. Our findings are limited by the short follow-up, and it will be interesting to follow these patients over time to see if any divergence occurs.

Patients with CD may achieve disease control with a gluten-free diet but can suffer psychosocial consequences related to this treatment. Patients with CD have higher rates of anxiety and depression and higher risk for the development of eating disorders.^{14,15} In a study completed in Vienna of 259 adolescent females (32 with CD and an eating disorder, 174 with CD but without an eating disorder, and 53 as healthy controls), overall quality of life was lower in patients with CD and an eating disorder than that in patients with CD without an associated eating disorder and in healthy controls.¹⁵ This decreased quality of life included lower positive attitude toward life, lower self-esteem, higher depressed mood, and less joy in life.¹⁵ Subjects in our study with suspected ARFID scored higher on the IGFDDQ with respect to food and social parameters more than emotional, but had a median score of only 2.5-3 (out of 5 as most severe). Emotional aspects of the IGFDDQ were the least predictive for the presence of ARFID, with median scores of 1.9 vs 1.5. We had anticipated higher scores in these areas if the main reason for restrictive eating was due to the impact of a gluten-free diet. Similar to findings in other studies, fear of GI discomfort (specified not to be fully attributable to an illness or metabolic condition, ie, CD) was the predominant reason for restrictive eating, but 34 of 65 patients (52%) identified other etiologies for their restrictive eating such as pickiness and poor appetite.²¹ There were 6 patients whose self-reported primary reason for restrictive eating was fear of weight gain or desire to eat only healthy foods/orthorexia, but these patients also equally identified other drivers for restriction which met ARFID criteria, such as poor appetite, picky eating, or fear of GI discomfort. Although fear of weight gain is not a symptom of ARFID, fear of weight gain and body image concerns are common in the general population, and people who want to lose

weight or avoid weight gain can still be diagnosed with ARFID. These concepts need to be taken into consideration as we counsel our patients with CD. Clinicians commonly focus on controlling GI symptoms and improving celiac laboratory parameters through a strict gluten-free diet without considering the impact of their recommendations on a patient's psychological well-being and food options. In addition to the gluten-free diet, some patients may explore various elimination diets based on the advice of a clinician or from personal research to further decrease GI symptoms. The combination of these elimination diets with the gluten-free diet can significantly restrict food options. Specialized counseling with a celiac-trained dietitian who is aware of these tendencies should be included in all CD follow-up visits. A protocol to screen for restrictive eating with an ARFID survey could better direct a dietitian in the counseling session and, if needed, prompt a referral to behavioral health.

Our study is limited by the nature of survey and data collection. Patients were not personally instructed on how to fill out the surveys, and there is the possibility for misinterpretation. A limitation of this study may be that ARFID-cl was not used in conjunction with the NIAS. We elected not to use the NIAS in this patient population as the patients in this study had an identified motivation (gluten-free diet) for restrictive eating. An additional limitation of this study was that patients were not asked if they had lack of access to gluten-free foods—this is an important distinction because the diagnosis of ARFID requires that their eating disturbance not be due to lack of available food options. This, however, was assessed in the IGFDDQ and, as mentioned, was not ranked as high as would be expected if this was the main limitation.

This is a snapshot assessment of a 2-year period, and we may find more differences over time. Because many patients with CD only come to clinic once a year, most of our patients did not have a follow-up survey, and therefore, we did not include follow-up surveys. We did not have follow-up duodenal biopsies on all patients in the cohort, and not all patients had a bone density assessment.

Conclusion

Overall, this study is significant for reinforcing the high prevalence of restrictive eating in patients with CD and supporting a validated tool that can be used in this patient population to screen for suspected ARFID. Identification of patients who struggle with this disorder can guide the physician and dietitian in dietary and behavioral management.

Supplementary Materials

Material associated with this article can be found in the online version at <https://doi.org/10.1016/j.gastha.2022.01.002>.

References

1. Green PH, Cellier C. Celiac disease. *N Engl J Med* 2007; 357:1731–1743.
2. Satherley RM, Higgs S, Howard R. Disordered eating patterns in coeliac disease: a framework analysis. *J Hum Nutr Diet* 2017;30:724–736.
3. Marafini I, Monteleone G, Stolfi C. Association between celiac disease and cancer. *Int J Mol Sci* 2020;21:4155.
4. Catassi C, Gatti S, Fasano A. The new epidemiology of celiac disease. *J Pediatr Gastroenterol Nutr* 2014;59 Suppl 1:S7–S9.
5. Zysk W, Glabska D, Guzek D. Food neophobia in celiac disease and other gluten-free diet individuals. *Nutrients* 2019;11:1762.
6. Zimmerman J, Fisher M. Avoidant/restrictive food intake disorder (ARFID). *Curr Probl Pediatr Adolesc Health Care* 2017;47:95–103.
7. Schmidt R, Kirsten T, Hiemisch A, et al. Interview-based assessment of avoidant/restrictive food intake disorder (ARFID): a pilot study evaluating an ARFID module for the eating disorder examination. *Int J Eat Disord* 2019; 52:388–397.
8. Zickgraf HF, Ellis JM. Initial validation of the Nine Item Avoidant/Restrictive Food Intake disorder screen (NIAS): a measure of three restrictive eating patterns. *Appetite* 2018;123:32–42.
9. Walker MM, Murray JA. An update in the diagnosis of coeliac disease. *Histopathology* 2011;59:166–179.
10. Oberhuber G, Granditsch G, Vogelsang H. The histopathology of coeliac disease: time for a standardized report scheme for pathologists. *Eur J Gastroenterol Hepatol* 1999;11:1185–1194.
11. Leffler DA, Dennis M, Edwards George JB, et al. A simple validated gluten-free diet adherence survey for adults with celiac disease. *Clin Gastroenterol Hepatol* 2009; 7:530–536, 536.e1-2.
12. Canestaro WJ, Edwards TC, Patrick DL. Systematic review: patient-reported outcome measures in coeliac disease for regulatory submissions. *Aliment Pharmacol Ther* 2016;44:313–331.
13. Zickgraf HF, Franklin ME, Rozin P. Adult picky eaters with symptoms of avoidant/restrictive food intake disorder: comparable distress and comorbidity but different eating behaviors compared to those with disordered eating symptoms. *J Eat Disord* 2016;4:1–11.
14. Karwautz A, Wagner G, Berger G, et al. Eating pathology in adolescents with celiac disease. *Psychosomatics* 2008;49:399–406.
15. Wagner G, Zeiler M, Berger G, et al. Eating disorders in adolescents with celiac disease: influence of personality characteristics and coping. *Eur Eat Disord Rev* 2015; 23:361–370.
16. Nicely T, Lane-Loney S, Masciulli E, et al. Prevalence and characteristics of avoidant/restrictive food intake disorder in a cohort of young patients in day treatment for eating disorders. *J Eat Disord* 2014;2:21.
17. Fink M, Simons M, Tomasino K, et al. When is patient behavior indicative of avoidant restrictive food intake disorder (ARFID) vs reasonable response to digestive disease? *Clin Gastroenterol Hepatol* 2021. <http://doi.org/10.1016/j.cgh.2021.07.045>.

18. Grace-Farfaglia P. Bones of contention: bone mineral density recovery in celiac disease—a systematic review. *Nutrients* 2015;7:3347–3369.
19. Dahele A, Ghosh S. Vitamin B12 deficiency in untreated celiac disease. *Am J Gastroenterol* 2001;96:745–750.
20. Wierdsma N, van Bokhorst-de van der Schueren M, Berkenpas M, et al. Vitamin and mineral deficiencies are highly prevalent in newly diagnosed celiac disease patients. *Nutrients* 2013;5:3975–3992.
21. Murray H, Bailey A, Keshishian A, et al. Prevalence and characteristics of avoidant/restrictive intake disorder in adult neurogastroenterology patients. *Clin Gastroenterol Hepatol* 2020;18:1995–2002.e1.

Received July 9, 2021. Accepted January 10, 2022.

Correspondence:

Address correspondence to: Audrey Bennett, MD, Vanderbilt Gastroenterology, 1301 Medical Center Drive, 1600 The Vanderbilt Clinic, Nashville, Tennessee 37232. e-mail: audrey.l.bennett@vumc.org.

Authors' Contributions:

Dawn Adams was the guarantor of the article. Audrey Bennett contributed to design, acquisition of data, interpretation of data, and drafting and critically revising the manuscript, gave approval, and agreed to be accountable for all

aspects of the work. Alexandra Bery contributed to acquisition of data, interpretation of data, and critically revising the manuscript, gave approval, and agreed to be accountable for all aspects of the work. Patricia Esposito contributed to acquisition of data, interpretation of data, and critically revising the manuscript, gave approval, and agreed to be accountable for all aspects of the work. Hana Zickgraf contributed to conception and design, interpretation and analysis of data, and drafting and critically revising the manuscript, gave approval, and agreed to be accountable for all aspects of the work. Dawn Adams contributed to conception and design, acquisition of data, and analysis and interpretation of data, involved in drafting and critically revising the manuscript, gave approval, and agreed to be accountable for all aspects of the work.

Conflicts of Interest:

The authors disclose no conflicts.

Funding:

The authors report no funding.

Ethical Statement:

The corresponding author, on behalf of all authors, jointly and severally, certifies that their institution has approved the protocol for any investigation involving humans or animals and that all experimentation was conducted in conformity with ethical and humane principles of research.

Data Transparency Statement:

The data, analytic methods, and study materials underlying this article will be shared on reasonable request to the corresponding author.

Author Approval:

All authors had access to the study data and reviewed and approved the final manuscript.