Microscopic Colitis Foundation

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Wayne's Blog

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My Doctor Says I Have an Eating Disorder. Do I?

by Wayne Persky

The defining feature of inflammatory bowel disease (IBD) is chronic inflammation of the gastrointestinal tract. This persistent inflammation leads to various symptoms, including abdominal pain, diarrhea, weight loss, and for IBDs such as Crohn's disease and ulcerative colitis (UC), rectal bleeding. Because they are far more familiar with Crohn's disease and UC, and have a relatively poor understanding of microscopic colitis (MC), many medical professionals tend to ignore the fact that MC meets the definition of an IBD, and because MC is treated like the proverbial redheaded stepchild, MC patients are typically excluded from IBD research projects.

Medical professionals seem to be confused by the definition of IBD.

Similar to the way they view MC, many medical professionals consider celiac disease to be a unique syndrome, and they fail to recognize it as an IBD, although it certainly meets the medical criteria for classification as an IBD. Due to the food sensitivities associated with the development of IBD (which many medical professionals still do not recognize, because of the lack of definitive research), diet changes by IBD patients are becoming increasingly common.

MC causes chronic inflammation of the entire digestive tract.

Diet changes can help with symptoms.

Many IBD patients have discovered that diet changes are very beneficial.

Individuals who have IBD frequently modify their diets in an effort to manage symptoms, often avoiding certain foods or adopting restrictive eating behaviors. However, the medical community tends to view this trend quite differently from the way most IBD patients consider the issue. Indeed, a recent article based on a survey and published in Appetite, highlights the widespread prevalence of food avoidance among IBD patients and raises concerns about its potential negative impact on quality of life (Day, Yao, Costello, Andrews, and Bryant, 2021)[1].

In this review, the researchers conducted a systematic review analyzing 29 studies examining dietary beliefs, food avoidance, and their relationship with quality of life in adults with IBD. The review found that:

- 28% to 89% of individuals with IBD engage in food avoidance to manage symptoms.
- 41% to 93% report restrictive eating behaviors, which may contribute to nutritional deficiencies
- Women were more likely to restrict food intake than men.
- Dietary misinformation often leads to unnecessary restrictions.
- The primary reason for dietary changes was fear of triggering symptoms, even without scientific validation (inferring that scientific validation of a food sensitivity is essential).

Another study based on a more recent survey,

found that eating disorders are increasing rapidly. This dietary trend among IBD patients is emphasized by a recently published FAIR Health study of eating disorder. Based on data from the years of 2018 through 2022, eating disorders in general (including binge eating, anorexia, and bulimia), increased by about 65% in the U.S. (FAIR Health, 2023, November 15)[2]. But interestingly, by comparison, avoidant/restrictive food intake disorder (ARFID) increased by 305% (inferring that eating disorders are a major issue (therefore, a major problem), among IBD patients).

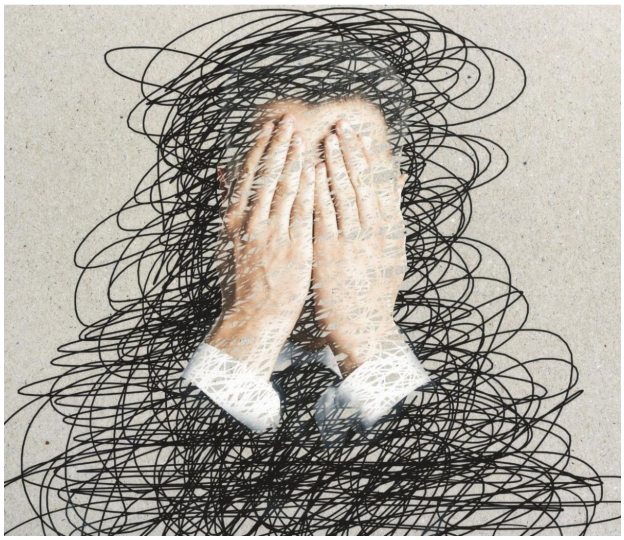
Unfortunately, the problem with this study is that it apparently only looked at associated mental health

issues such as anxiety and depression, without even considering that the eating "disorder" might be due to a physical issue, such as attempting to minimize gastrointestinal symptoms.

As usual, these studies focus on patients who have Crohn's disease and ulcerative colitis (UC), rather than microscopic colitis (MC), but there's no reason to doubt that the findings should apply to MC patients, also.

> **Restricting certain foods is common with MC and other IBDs**

> **This is an attempt to minimize physical symptoms, not a mental health issue.**



IBD patients have relatively high rates of depression and anxiety.

By coincidence, an article published this past summer, titled *"Searching for links between IBD and mental health, through the gut microbiome"*, found that up to 40% of IBD patients are diagnosed with depression, and up to 30% of them are diagnosed with anxiety, at some point during their lives (Wood, 2023, June 14)[3].

Although many websites discuss the fact that many IBD patients experience eating disorders, few of them mention the numbers that are involved. An article published less than a year ago on the HealthCentral website states that up to 93% of IBD patients "struggle with unhealthy eating patterns" (Taylor, 2023, May 8)[4]. And the article lists two "red flags" that are indicative of "disordered eating", as suggested by a clinical psychologist at the University of Pennsylvania in Philadelphia. Those two "red flags" are:

- Constantly worrying about what you're eating
- Avoiding entire food groups for an extended period of time, even when your symptoms aren't flaring

Does that sound familiar?

Of course it does, because it describes most of us who are using diet changes to put or keep our MC in remission. And note that those two red flag warnings in the above quote totally, and specifically, define dietary treatments such as the type that we are using to keep our MC in remission, as "unhealthy eating patterns", which places them in the category of mental health issues. Although that article specifically refers to Crohn's patients, it certainly doesn't seem to apply only to patients who have Crohn's disease. Why wouldn't it apply to anyone who has any other IBD, and for that matter, anyone who has food

sensitivities as a result of some other digestive issue, regardless of the origin?

Restrictive eating can lead to some deficiencies.

But MC symptoms can cause deficiencies too.

Malnutrition is indeed common among IBD patients.

According to a recent Medical Xpress article, probably about 15% of Crohn's disease patients, and 12% of ulcerative colitis patients have malnutrition. Research shows that approximately 28% of those who have active disease, and 8% of those who are in remission are likely to have malnutrition (Solomon, 2024, January 15)[5]. The chronic inflammation characteristic of IBD can lead to various nutritional deficiencies, impacting patients' overall health and quality of life.

Several issues contribute to the malnutrition risk.

1. Inflammation in the gastrointestinal tract leads to a malabsorption problem that compromises the absorption of essential nutrients, leading to deficiencies in certain vitamins and minerals.
2. Symptoms such as abdominal pain, diarrhea, and loss of appetite often cause patients to decrease their food consumption, increasing the likelihood of nutrient deficiencies.
3. The chronic diarrhea that's typically associated with IBD, often leads to the loss of electrolytes (in addition to the other vital nutrients).
4. Certain treatments for IBD, particularly corticosteroids and immunosuppressants, can interfere with nutrient absorption and metabolism.

IBD patients are particularly susceptible to certain deficiencies.

- Vitamin D is depleted by IBDs, and common treatments, such as corticosteroids and immunosuppressants.
- Magnesium is depleted by IBDs, and common treatments, such as corticosteroids and immunosuppressants.
- Vitamin B-12 — vitamin B-12 is absorbed in the terminal ileum. Since the terminal ileum is often highly inflamed in both Crohn's disease and MC, patients who have those IBDs are highly susceptible to a vitamin B-12 deficiency. B-12 deficiency can cause anemia and neurological issues.
- Calcium — although most diets (even restricted diets) contain more than adequate amounts of calcium, deficiencies of vitamin D and/or magnesium can prevent the proper absorption of calcium (vitamin D deficiency) or its transportation from the bloodstream to the cells in the body where it's needed (magnesium deficiency), resulting in osteoporosis.
- Iron deficiency is especially common with Crohn's and UC, due to the chronic blood loss associated with those IBDs, but it's uncommon (although not rare) among MC patients.

These deficiencies can negatively affect our quality of life.

- Increased fatigue — nutrient deficiencies can lead to increased tiredness, affecting daily activities and overall well-being.
- Impaired immune function — lack of essential nutrients can weaken the immune system, making patients more susceptible to infections.
- Delays in recovery — proper nutrition is crucial for healing, and deficiencies can slow down recovery from flare-ups or surgeries.

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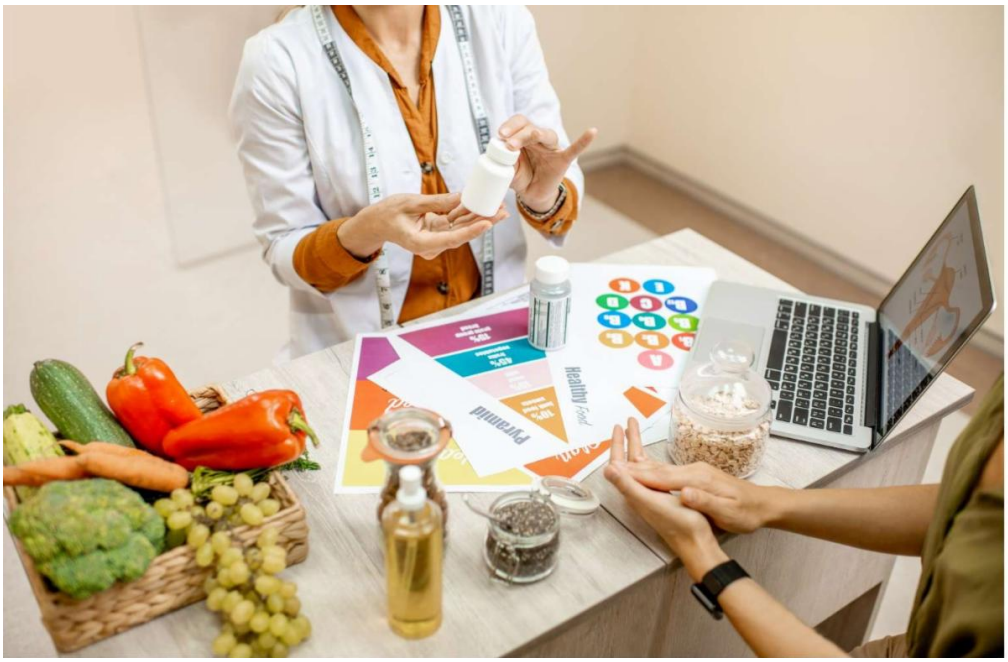

Managing the nutrient deficiency risks of IBD patients:

Although dietitians almost never understand the dietary needs and limitations of MC patients, consultations with a dietitian may be beneficial for patients who do understand their own needs and limitations, and are able to communicate those needs and limitations to the dietitian, who can then help to formulate personalized meal plans to ensure adequate nutrient intake and address deficiencies.

But before we consult with a dietitian,

we have to be in remission. Otherwise, we will almost certainly allow a dietitian to talk us into taking unnecessary risks. The reason we have to be in remission, is because if we add a food that a dietitian recommends, and it causes us to react, we'll never know that it's not a safe food, because we're already reacting, and therefore we won't be able to make an accurate judgment.

Remember, the bottom line regarding dietitians, is that we have to be the final judge of the "safety" of any dietary recommendations they make, because we understand our dietary needs better than anyone else in the world. If we don't understand our needs and limitations, the sooner we learn them, the sooner we will be able to put the disease into remission. And the sooner we might be able to consult with a dietitian and accurately describe our needs and limitations, and make accurate and safe judgments regarding any dietary recommendations.

Remember to check the labels carefully on any and all supplements.

Supplementing vitamins and minerals to correct deficiencies should be beneficial, but make sure that they don't contain any ingredients that might trigger a reaction. Remember, the labeling laws (at least in the US) require that labels must show the active ingredients and the amounts of those ingredients, but the FDA does not require labels to show the inactive ingredients. Fortunately, most manufacturers voluntarily list inactive ingredients on their labels, also, but some do not list all inactive ingredients. Hopefully, by proactively addressing known nutritional issues, IBD patients can improve their health outcomes and enhance their quality of life.

Is food avoidance by IBD patients actually a psychological problem?

While it's certainly true that restrictive eating is widespread among IBD patients, whether or not this actually has any psychosocial impact remains poorly understood, because the data appear to be improperly analyzed, due to the studies being designed with a biased agenda. In fact, any psychological impact associated with IBD patient diet changes may well be primarily due to a legitimate physical reason for the diet change — not the actual diet change. Such research projects are therefore confounded due to their initial design. They need to be more carefully designed so that they actually reflect the realities of living with an IBD.

From the viewpoint of an IBD patient with incontinence,

quality of life is a concept that we are not likely to waste much time considering when we find ourselves dreaming about lying in a warm, relaxing pool, and suddenly wake up to discover that we're lying in our bed in a pool of our own liquid diarrhea. Nor has even one among us likely to have given much thought to quality of life as we're rushing down a supermarket aisle, heading toward a bathroom, and suddenly experience the unpleasant, humiliating surprise of feeling something warm and wet running down one or both of our legs.

As MC patients, most of us are well aware of the incontinence risks associated with MC, and all IBD patients surely share these concerns. And unfortunately, virtually all of us had to learn about this risk in the school of hard knocks. We had to learn the hard way, by personal experience, because our gastroenterologist never mentioned even so much as a possibility of incontinence (as if incontinence is a trivial issue, not even worth mentioning.

Why do studies such as these seem to be designed to prove eating disorders?

Skilled researchers are usually able to prove what they set out to prove, assuming that they've designed the study correctly. The concept of analyzing and diagnosing eating disorders is a somewhat popular and growing trend in healthcare. And the main reason that IBD patients have been caught up in that net is because researchers don't take seriously our claims that chronic intestinal inflammation is perpetuated by food sensitivities, and dietary changes are effective for treating IBD. In other words, without existing published medical research to verify our claims, researchers simply assume that they have no basis in fact. And this is probably a reflection of the attitudes of most clinicians, also.

And so, because convincing research hasn't been published, naturally the concept of diagnosing food sensitivities and designing treatment programs based on dietary changes is not covered in medical school. Therefore, clinicians have no incentive to consider our claims, and by default, they choose to recognize the finding of published research studies that refer to these issues as eating disorders.

Naturally, this does not benefit patients.

In most cases, policies such as this do a grave disservice to IBD patients, because the findings of the studies, while correct, are rather misleading. Rather than being "disordered" eating, diet changes by IBD patients are typically more accurately described as "reordered" eating. And the resulting diet changes chosen by IBD patients are usually selected for a very valid reason, contrary to the available published research

These studies appear to be designed to prove disordered behavior.

And the reason they are designed to prove disordered behavior is because that is the current prevailing medical opinion. But in designing the studies this way, researchers chose to ignore the reasons why their

study subjects made these changes in their diets, and this implies that the researchers had to have made the assumption that diet changes by IBD patients are made for irrational reasons, when they initially designed the studies.

But the overall findings of these studies are typically only a "half truth".

Although the findings of the studies conclude that in general, the dietary changes made by IBD patients negatively affect their quality of life (and maybe their health), this is only a half truth. It totally ignores the reality of living with an IBD. Many IBD patients find themselves afraid to stray very far from a bathroom, and afraid to leave their home, because of the very real risk of incontinence. Since this obviously might negatively affect IBD patients' quality of life, it's only fair that it should at least be mentioned in research claiming to show so-called "eating disorders", and associated issues.

Why don't gastroenterologists responsibly advise new IBD patients about their diagnoses?

Why should there be such a huge disconnect between IBD patients' perceptions of priorities, and gastroenterologists' (and IBD researchers') perceptions of priorities. This situation brings to mind the old Proverb, "When you're up to your neck (or some other body part) in alligators, it's hard to remember that your initial objective was to drain the swamp." Even if gastroenterologists fail to acknowledge the value of diet changes when treating IBD, they should at the very least, warn newly diagnosed IBD patients about the risk of incontinence, and IBD researchers need to consider the priorities of IBD patients when analyzing survey data regarding "eating disorders". If that change is not made in future research projects, then gastroenterologists will continue to fail to recognize the value of safe food choices when treating IBD.

The classification of food avoidance in IBD patients as an eating disorder is highly problematic.

In most cases, the dietary choices (or diet changes) made by IBD patients are not due to an "eating disorder" or a "psychological issue". Claims to that effect are simply unfair, and they're typically harmful oversimplifications. While it's likely to be true that some IBD patients may develop "disordered eating patterns" because of their anxiety regarding food, the primary motivation for avoiding certain foods is usually practical and medically driven, in order to prevent incontinence, pain, and other severe gastrointestinal distress. The choice by medical professionals to label this logical coping mechanism as a psychological issue is not only disingenuous, but it can have serious negative consequences for patients' physical and mental health.

Here are some reasons why food avoidance in IBD is not an eating disorder:

- Eating disorders, such as anorexia or avoidant/restrictive food intake disorder (ARFID) involve distorted body image, fear of weight gain, or extreme anxiety around food.
- IBD-related food avoidance is based on real, painful, and embarrassing physical consequences such as diarrhea, cramping, and fecal incontinence.
- IBD patients are not avoiding food to lose weight or due to irrational fears, but rather to maintain dignity, social functioning, and symptom control.
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The "real" quality of life considerations are these:

- IBD patients often experience unpredictable bowel urgency. Avoiding trigger foods can prevent

  socially embarrassing situations, workplace disruptions, and unnecessary suffering.
- Expecting patients to "just eat everything" despite well-documented food-induced symptom exacerbations dismisses their lived experience.
- Blaming them for avoiding certain foods invalidates their symptoms and can erode trust in medical professionals.

Misclassifying IBD patients as having eating disorders creates problems.

According to a University of South Australia study, eating disorders are more heavily stigmatized than depression (University of South Australia, 2025, March 13)[6]. If an IBD patient is incorrectly labeled as

having an eating disorder, they may face social judgment, medical dismissal, and a lack of serious consideration for their physical symptoms. This stigma may discourage patients from seeking help, fearing they won't be believed about their pain, weight loss, or difficulty eating.

Misclassification can even cause insurance problems.

If an IBD patient is wrongly diagnosed with an eating disorder, insurance companies may deny coverage for necessary treatments, such as:

- Biologic medications
- Colonoscopies
- Nutritional support (e.g., enteral nutrition or IV therapy)

Instead, they may only approve mental health interventions, which do not address the underlying gastrointestinal inflammation.

> **Food avoidance with MC is not an eating disorder.**

> **Misclassifying food avoidence as psychological creates problems.**

SUMMARY

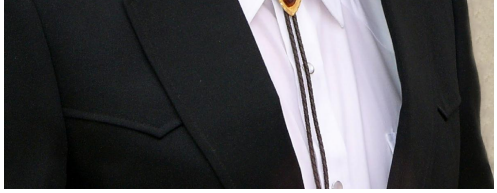
Both IBD and eating disorders can lead to malnutrition, weight loss, and vitamin/mineral deficiencies, but the causes are vastly different. In IBD patients, these deficiencies result from malabsorption, chronic diarrhea, or inflammation, rather than restrictive eating behaviors. Misclassification could lead to inappropriate dietary recommendations, such as forcing an IBD patient to eat foods that trigger flares (e.g., fiber-rich or dairy-based foods) under the assumption that their avoidance is psychologically driven rather than medically necessary.

While some IBD patients may develop disordered eating patterns due to food-related distress, this is usually a response to their disease, rather than a primary psychiatric disorder. Labeling an IBD patient as having an eating disorder can lead to biased behavior by healthcare professionals, where patients are told their concerns are psychological rather than physiological. This can result in increased anxiety, depression, and distrust in medical providers, further complicating the patient's overall well-being.

Check Out Wayne's Blog

He posts a new blog about once a week. Here are the titles of the most recent. Click the button at the top of the newsletter to access.

New blogs are temporarily on hold while the final touches are being made to our website renovation. We are close to revealing the new site.



The Microscopic Colitis Foundation Website is Undergoing an Update

If you visit our website, you will no doubt notice that it is in the middle of a renovation, and looking messy. You can still find Wayne's blogs, and back issues of the newsletters. We hope to have it completed soon, but web design changes always seem to take longer than planned.

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Contact Us: Wayne Persky: wayne@perskyfarms.com

Rosalyn Upson (Newsletter Editor): rosalyn.upson@gmail.com