

CASE STUDY SERIES IN IBD

Multidisciplinary Inflammatory Bowel Disease Care to Manage Medication Nonadherence and History of Anorexia Nervosa: A Case Report

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Background

A 52-year-old woman was evaluated through an integrated, multidisciplinary virtual inflammatory bowel disease (IBD) clinic at Dartmouth Hitchcock Medical Center. This specialty clinic is designed to improve health care for people with IBD living in rural areas through both a multidisciplinary consultation and a provider mentorship program called RADIUS (which stands for Rural APPs Delivering IBD Care in the United States). This program operates on a hub-and-spoke model, with a central provider team connecting with a range of surrounding clinics. This patient was referred to the RADIUS program by her primary gastroenterologist for evaluation of ulcerative colitis (UC) because of her difficulty with medication adherence leading to frequent flares.

During the consultative visit with the RADIUS team, each patient follows a standard care pathway. Several days before the visit, records are reviewed by the program manager and the nurse, who reaches out to the patient before the visit to help him or her understand the program. On the day of the visit, the patient logs into a 2-hour video visit session through the patient portal to meet with an IBD specialist gastroenterologist, clinical psychologist, dietitian, pharmacist, and IBD nurse. Every RADIUS patient sees all providers individually, and each provider transitions every patient to the next provider, giving a brief introduction and summary of the patient's presentation, as the provider comes and goes from each clinical encounter. At the end of the video session, the program nurse then reconnects with the patient to review

all recommendations and ensure no important topics or questions were missed. The multidisciplinary team meets to review input from all providers and exchange suggestions and considerations for this new patient. After this team discussion, recommendations are sent electronically to the patient's primary gastroenterologist and the program nurse follows up with the patient a final time.

Importantly, this multidisciplinary clinic not only provides co-located care but also creates a setting within which a diverse team can interface with varied perspectives on a patient's needs to guide disease management. This model uniquely provides virtual IBD care, integrating multiple disciplines to develop a comprehensive plan. Further, this team-based care improves overall patient satisfaction and is consistent with recent calls for the integration of other specialties into IBD care, including psychology.¹

Patient History

The patient's symptoms began in 1998, when she was 28 years old. Initial symptoms included rectal bleeding and abdominal pain. A colonoscopy did not find any evidence of disease, yet her symptoms continued. She connected with her current primary gastroenterologist in 2011, presenting with rectal bleeding and abdominal pain. A colonoscopy in 2011 diagnosed mild distal ulcerative proctitis, and she started treatment with oral and topical mesalamine; however, she was not adherent to regular dosing. A colonoscopy in 2015 indicated moderate-to-severe UC involving the entire colon. A colonoscopy in 2016 indicated mildly active colitis in the sigmoid colon and moderately active proctitis in the rectum. She was inconsistently taking 4.8 g daily of oral mesalamine through 2016.

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In 2017, the patient participated in a clinical trial for fecal microbiota transplantation. She experienced substantial improvement, but symptoms returned after the study concluded. A colonoscopy in 2018 found proctosigmoiditis and otherwise normal colon and ileum. A sigmoidoscopy was performed in August 2021 and described mild colitis involving the rectum and colon up to 30 cm from the anus, and pathology indicated mild active colitis. Stool studies conducted in April 2022 were all negative. A sigmoidoscopy in May 2022 found active inflammation in the rectum. She had no history of oral, ocular, rheumatologic, dermatologic, or hepatobiliary manifestations of IBD.

The patient previously received and was responsive to occasional short courses of prednisone to treat flares. At the time of the RADIUS visit, she was reportedly treated with nine 750 mg oral balsalazide capsules daily and one 4 g/60 mL mesalamine enema daily. She noted that she experienced flares approximately 3 times per year, each of which took 1 to 2 months to resolve. In addition to UC, she had a history of sesamoiditis and carpal tunnel syndrome. Otherwise, she was healthy and able to navigate her personal and professional responsibilities.

For social history, she is successful and well-organized in both her personal and professional life. She is in a strong marriage. She is also passionate about her leadership position at an organization, yet described it as intense and stressful.

RADIUS Visit

At the time of the patient's RADIUS visit, she reported that her greatest concern was rectal bleeding and that she was experiencing blood in her stool more than 50% of the time. In the past week, she also reported experiencing greater than 5 stools more than her typical amount per day, including 4 liquid stools per day, and moderate abdominal pain. On a scale from 0 (no confidence) to 10 (full confidence), she rated her ability to control and manage her IBD-related health problems as a 6. Other notable concerns at the time of the visit included severe fatigue, poor overall well-being, and fair mental health. She had no emergency department visits or hospitalizations related to IBD in the 3 months prior to her visit.

When meeting with the IBD specialist gastroenterologist, she noted that she was prescribed 9 balsalazide capsules daily (750 mg each; 6.75 g daily total) and 1 mesalamine enema daily (4 g/60 mL). She recently had a flare after not taking her prescribed doses. At the start of the flare, she returned to her regular doses of balsalazide and mesalamine enemas, and began 4 days of prednisone. She indicated that she had not returned to her baseline bowel movement patterns and was still symptomatic. She

shared that when she was taking her medications as prescribed, she typically felt well. Flares frequently happened after a period when she had limited or no symptoms and she would start to take lower than her recommended dose of medication (eg, 6 capsules daily rather than the prescribed 9 capsules daily).

When meeting with the clinical psychologist, the patient struggled to explain or understand her challenges with medication nonadherence and her delays in contacting her physician during a flare. She characterized herself as a smart, logical, and driven person and stated that she understood the severity of her UC. Given her personal and professional success, high-achieving personality, strong organization, understanding of IBD, and agreement with her treatment plan, the patient did not mirror the characteristics typically leading to nonadherence (eg, psychiatric complexity, disease nonacceptance, rejection of Western medicine, socioeconomic disadvantage or hardship). She explained that she would notice the alarm she set for taking her medication, but frequently she would forget to take it if she was focused on another task. After missing a dose, she worried about the impact of not precisely following medication instructions. Thus, she would often skip a dose because of this rigidity about timing, and after skipping doses repeatedly, she would stop taking her medication altogether. She also indicated that she had a high pain tolerance, which often resulted in her enduring multiple weeks with moderate-to-severe UC symptoms before contacting her primary gastroenterologist. Although pain is not a core symptom for all IBD patients, this patient frequently experienced abdominal pain with her UC flares.

Given the patient's self-reported inflexibility and profound disconnect from her body, the psychologist probed for a history of trauma or other similar previous experiences of distress. The patient endorsed a history of anorexia nervosa in high school, explaining that controlling her food helped her to manage a chaotic and often highly critical home environment. She had attended therapy at that time and believed she was fully recovered from her eating disorder. The psychologist identified a connection between the rigidity and disengagement from one's body in anorexia nervosa and the patient's current IBD management. Literature on this topic highlights that eating disorders can be associated with IBD and can interfere with treatment.^{2,3}

In a follow-up visit with the RADIUS psychologist, the patient noted that the idea of disconnect from her body deeply resonated with her, and she saw this manifesting in many aspects of her life. She found that her different roles were all-consuming, and she experienced ongoing self-criticism. This control of pain and experience reminded her of her history with anorexia

Table. RADIUS Treatment Plan

| Treatment Recommendations | Accountable Provider | Psychiatric Considerations |
|---|-----------------------------------|--|
| Start an 8-week course of prednisone (followed by taper) and continue 9 balsalazide doses and 1 mesalamine enema daily | IBD specialist gastroenterologist | Support relief of current flare symptoms causing significant physical, emotional, and mental health distress. Avoid aggravation of symptoms with disconnect from body |
| Advise flexibility in oral balsalazide dosing, such as 5 capsules in the morning and 4 capsules in the evening or all 9 capsules together | IBD specialist gastroenterologist | Provide a flexible daily medication approach to prevent medication nonadherence from the patient's rigid mindset |
| Identify more advanced treatments (eg, IV therapy, biologics, small molecules) if symptoms do not improve | IBD specialist gastroenterologist | Significantly improve symptoms to avoid delayed care for flares. Provide a clinically stronger medication at a less frequent schedule, which is less likely to be skipped because of the rigid mindset |
| Meet to discuss TNF- α inhibitors or other advanced therapies with the patient | Pharmacist | Reduce anxiety that the patient expressed about more advanced treatment. Coordinate a regular, provider-supported schedule to address rigidity and medication adherence challenges |
| Reintroduce gluten into diet to incorporate more whole grains. (Note: the patient was avoiding gluten at the time of the RADIUS visit) | Dietitian | Move toward a more comprehensive diet and avoid the strict, rigid exclusion diets associated with the patient's history of disordered eating |
| Incorporate more soluble fiber into diet | Dietitian | N/A |
| Meet with a registered dietitian, if needed | Dietitian | Provide more longitudinal support for healthy dietary habits and avoid strict, rigid exclusion diets from the patient's history |

IBD, inflammatory bowel disease; IV, intravenous; N/A, not applicable; RADIUS, Rural APPs Delivering IBD Care in the United States; TNF, tumor necrosis factor.

nervosa and how control felt safe to her. Since her first RADIUS visit and the treatment recommendations, she did not miss any medication doses, started taking her full balsalazide doses daily, and shared that learning about flexibility and understanding the sources of her adherence difficulties had helped her significantly. She also focused on recommended updates to her diet and was making consistent attempts to pause during the day and respond to what her body needs.

Treatment and Future Management

The multidisciplinary team of clinicians discussed this patient and developed a comprehensive treatment plan that incorporated her psychiatric history and how it was interfering with her disease management.

The RADIUS team recommendations are outlined in the Table. This plan was also shared and coordinated with the patient and her primary gastroenterologist.

Furthering the psychological care that the RADIUS team recommended, the providers identified the importance of supplying behavioral and mental health-

informed disease management recommendations. The psychologist identified 2 approaches to care management: a medication-based treatment change to accommodate disease-interfering behaviors, or a talk therapy-based approach to identify causes of her current behavior and develop strategies to change these patterns.

For the medication-based treatment change, the integrated team suggested that a medication that does not require strict daily oral administration (such as an IBD biologic medication that is injected or infused every 2 to 8 weeks by the patient or provider) may enable better adherence for this patient. The patient would not experience as much difficulty continuing treatment in case she misses oral medication doses and is not able to continue her dosing in her rigid schedule. Moreover, by shifting to a provider-administered treatment, provider partners would support consistent treatment schedules. Benefits of this approach included a less active disease management schedule, which would decrease the likelihood that the patient would ignore symptoms or skip doses. This in turn could provide a short- and long-term solution to IBD symptoms, reduce disease activity, and prevent

recurring flares. However, this approach would enable the patient to continue engaging in avoidance-based behavior patterns (ie, disconnect from her body and needs) and ultimately could lead to the worsening of overall mental health or disease management (eg, restrictive diets leading to malnutrition). Further challenges included difficulty in identifying the correct biologic to use, significantly higher costs of biologic medications compared with oral balsalazide, insurance coverage and access issues, and potential continued nonadherence to other medications. For this patient, continuing with oral balsalazide and mesalamine enemas would be preferable based on their proven efficacy for her, excellent safety, and substantially lower cost than escalating to a biologic.

The therapy-based approach for this patient was intended to alter the core behavioral challenges that were causing her to not adhere to her treatment regimen. Along these lines, the patient had an important realization during the RADIUS visit and was very motivated to address the role that her anorexia nervosa history had on her current self-care and disease management. In this case, long-term therapy focused on behavioral habits resulting from the patient's history of anorexia nervosa could help her overcome her rigid approach to medications. This could facilitate flexibility when taking medications, particularly to continue with treatment after accidentally missing a dose and thus avoid flares. Benefits of this approach included providing her with an opportunity for growth in managing her body's needs, targeting the root cause of the medication nonadherence, and improving other actions and behaviors impacted by the history of anorexia nervosa. Challenges of this approach included the duration required for ongoing talk therapy and the chance that behaviors may not resolve quickly, resulting in more medication nonadherence and flares.

The patient and psychologist discussed the benefits and drawbacks to each of these approaches, and the patient elected to continue the balsalazide with an intention to flexibly restart routines that had helped her maintain a better connection with her mental health and body in the past (eg, meditation). She also elected to enroll in a brief therapy skills group based on the principles of acceptance and commitment therapy, as this therapy prioritizes flexibility and authenticity.

Two months after her visit with the interdisciplinary team, she noted in a psychology follow-up visit that she was feeling very well. She switched to a plant-based diet while prioritizing flexibility with her approach to eating—a behavior change of which she was quite proud. She shared that she was now taking her disease more

seriously, she was living more authentically than she had in a long time, and, with current medication adherence and dietary choices, her UC symptoms had resolved.

Conclusion

This case illustrates the ways in which both patients and providers can benefit from participation in a multidisciplinary team. Building a team with an IBD specialist gastroenterologist, clinical psychologist, pharmacist, dietitian, and IBD nurse collaborating on patient care enables providers to introduce unique perspectives and approaches to complex patient cases. In this case, each provider interfacing with the patient shared a crucial perspective for the diverse team to ensure that the medication, behavioral, and diet plan complemented the patient's needs. The clinical psychologist identified a root cause of medication nonadherence outside this patient's standard IBD care, treatment, or diet.

Beyond the discussed case, these findings apply to disease management for many other chronic conditions. First, when treating a patient with medication nonadherence, exploring a history of disordered eating or other psychiatric history can uncover prior experiences that impact adherence behaviors. Identifying these root causes can help physicians alter treatments to accommodate patients' behaviors and advise psychological treatment to better manage the root cause. Second, expanding integrated, multidisciplinary, hub-and-spoke care models to other diseases will allow more patients to benefit from this innovative approach. Complementing physicians' and nurses' roles with expertise from psychologists, pharmacists, dietitians, and clinical trial researchers can help deliver thorough and higher-quality care to patients.

Disclosures

Dr Siegel has served as a consultant to AbbVie, BMS, Lilly, Janssen, Pfizer, Prometheus, and Takeda; as a speaker for continuing medical education activities for AbbVie, Janssen, Pfizer, and Takeda; and received grant support from AbbVie, Janssen, Pfizer, and Takeda. The other authors have no relevant conflicts of interest to disclose.

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