# Inflammatory bowel disease: The patient experience

Inflammatory bowel diseases, including Crohn disease and ulcerative colitis, have traditionally been diagnosed by performing an endoscopy. This approach is the standard method for diagnostics, but this invasive procedure isn't always the patient's preferred method.

**By Thureiyya Rodriguez, DHA, MSN, COCN, WCN**

Inflammatory bowel disease (IBD), encompassing Crohn disease and ulcerative colitis, is characterized by inflammation of the digestive tract. Crohn disease and ulcerative colitis can occur at any age. The diseases are chronic and recurrent with periods of remission, but their effect on the colon is vastly different. Crohn disease is discernible by skip lesions with healthy intestine in-between, involvement of all layers of the intestine, the potential for the entire digestive tract to be affected, cobblestone appearance

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in the intestines, aphthous ulcers, or swollen longitudinal folds traversed by linear furrows on the lesser curvature of the gastric body and cardia ("a bamboo, joint-like" appearance). Ulcerative colitis has continuous inflammation and affects the innermost lining of the colon.[1] (See *Crohn disease* and *Ulcerative colitis*.)

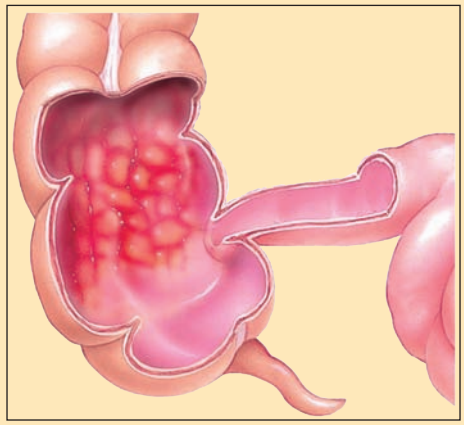
The conventional diagnostic procedure for IBD is an intestinal endoscopy, which visually examines the intestines for signs of disease such as Crohn disease and ulcerative colitis.[2] An endoscopy is the standard diagnostic procedure for detecting Crohn disease and ulcerative colitis. An endoscopy allows the physician to view the colon's interior and locate any intestinal complications. The procedure is currently the most effective approach to diagnosing Crohn disease.[2]

Individuals with Crohn disease and ulcerative colitis require ongoing monitoring and routine diagnostics to assess inflammation in the colon. They're at considerable risk for colon cancer due to the continuous turnover of the cells from the inflammation. When determining the appropriate care for a patient, consideration of the patient's mental well-being is important. Endoscopy procedures can be uncomfortable, and, for some patients, it can be frightening.

Proper bowel preparation is designed to help remove fecal waste from the intestinal tract before an endoscopy procedure. The process can involve laxatives, oral solutions, or a change in the diet to help facilitate bowel movements until the patient is only eliminating a clear, light-yellow liquid. The process can take up to 3 days; occasionally, some patients still have stool in the colon by the third day. The bowel preparation process can cause nausea or discomfort, especially when a patient is constipated and has difficulty passing stool.

Considering the patient's experience and preference, the noninvasive has been explored as an alternative approach to identifying Crohn disease and ulcerative colitis. Emerging studies on noninvasive methods have shown positive results in identifying Crohn disease and ulcerative colitis. Noninvasive testing is useful when an endoscopy exam can't be used due to a lesion in the lumen or stenosis. This article discusses noninvasive approaches in diagnosing Crohn disease and ulcerative colitis that the nurse should be aware of, considering their impact on the patient experience and mental well-being while maintaining diagnostic accuracy.

**Crohn disease**



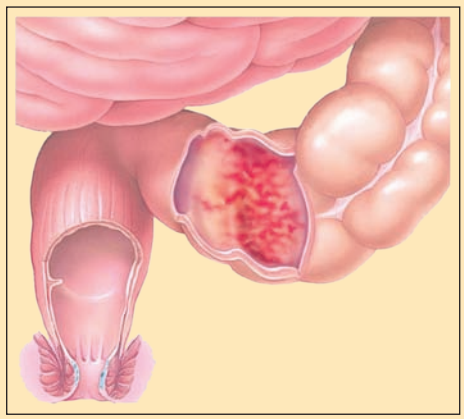
IBD: Crohn disease inflammation

Source: Anatomical Chart Company. Women's Health and Wellness. Philadelphia, PA: Wolters Kluwer Health and Pharma (LWW); 2002.

## The patient experience

As someone who's lived with Crohn disease and diversion colitis (see *Did you know?*) since childhood, I have firsthand experience with the diagnostic processes associated with these conditions. Discomfort and anxiety often accompany endoscopic procedures, which is why nurses must understand the patient's perspective. A patient's first endoscopy can be mentally stressful because of the unknowns and the associated discomfort after the procedure.

## Ulcerative colitis



IBD: Ulcerative colitis showing inflammation and ulceration.

Source: Anatomical Chart Company. Women's Health and Wellness. Philadelphia, PA: Wolters Kluwer Health and Pharma (LWW); 2002.

### Considerations for children

For children, diagnostic procedures for IBD can be a scary experience. Beyond the symptoms of unexplained abdominal pain, diarrhea, and mucus in the stool, physicians will ask several questions about the patient's stool and perform physical exams. The overall experience can be overwhelming because it's uncomfortable to be exposed to an unfamiliar adult, who often won't be the patient's primary care provider but rather a specialist. If an endoscopy is needed, the physician will explain the process to the child's parents in terms that the patient may not understand. When it's time to explain the procedure to the child, the healthcare team must use simple language. Consider that a child's imagination may envision a "tube with a camera" to be more frightening than it is. Specify the minimal size of the endoscopy instrument to mitigate fear. The procedure, coupled with the bowel preparation process, can be particularly challenging for pediatric patients. A lack of clear communication and understanding about the process can add to the anxiety and discomfort of this experience for young patients.

## Did you know?

Diversion colitis isn't the same as ulcerative colitis. Unlike ulcerative colitis, which is an autoimmune disease where the immune system attacks healthy tissue, diversion colitis isn't immune-mediated and doesn't progress over time. Most patients with diversion colitis experience resolution without long-term impacts on their quality of life.

### Bowel preparation

The day before the procedure, patients will be instructed to drink a bowel-prep solution. From experience, the healthcare team should explain to the patient that the solution may have an unpleasant taste and to be prepared to visit the bathroom regularly. If the patient is already feeling uncomfortable from the disease, the bowel-prep solution may worsen the patient's experience. On the day of the procedure, after a night of multiple trips to the bathroom, expect that the patient will be tired. After the procedure, the patient's stomach may feel "tight" (from the air pumped inside of the patient during the endoscopy) and the patient will need to visit the toilet frequently (passing bloody stool if biopsies were taken).

Bowel preparation can't be avoided unless the patient has an ileostomy. Bowel preparation is designed to eliminate stool from the colon and increase bowel movements until the patient passes clear liquid stool. Patients with an ileostomy normally have liquid output and don't create formed stools. Once a patient with an ileostomy has abstained from eating, the small intestines will have minimal liquid output. Patients with an ileostomy won't drink the bowel preparation. Instead, they must abstain from eating after 11:00 p.m. the day before the procedure. Patients with a colostomy, however, are still required to take the bowel-prep solution because their small and large

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intestines are intact, enabling the patient to pass soft-formed stool.

### Patient fears and discomfort

Patients with lifelong IBD may retain some of the fears they had as a child. For example, patients may fear test results or whether they'll experience complications with the anesthesia. Patients may fear the unknown, as well as potential pain from the procedure. Experienced patients may not exhibit fear; however, the nurse and the healthcare team need to monitor their experience, which, from personal experience, can worsen into adulthood.

Menstruating patients should also be made aware that, regardless of the point in their menstrual cycle, clinicians can still proceed with the exam. We're not fazed by "Mother Nature" making a house call. The nurse may give the patient a sanitary napkin or pad and the diagnostic team can move forward with the procedure.

Although patients with an ileostomy don't need to take the bowel-prep solution, once they wake from the procedure, their stomach will be bloated, and they will need to make frequent trips to the bathroom. The nurse should consider the particular discomfort that patients endure, as they've just been scoped through the mouth and stoma, and, if the patient has a rectum and anus, the team will perform the endoscopy there, too. For patients who are frequently prescribed endoscopies, the healthcare team must consider these areas of discomfort, and the mental load that comes with it.

### The mental load

Patients who need frequent endoscopies carry a heavy mental load. Each time, the procedure requires not only physical preparation, but also mental preparation. Knowing how they will feel afterward, over time the annual exam can be daunting. (See *Consider this*.)

It's crucial for healthcare professionals to acknowledge the physical and emotional challenges that patients may face during diagnostic procedures and to explore alternative, patient-centered approaches to ensure a more positive and supportive experience for individuals living with IBD. Let's look at how researchers are testing diagnostic alternatives to improve the exam process for patients.

## Diagnostic alternatives: An overview

Although traditional methods remain the standard, noninvasive diagnostic approaches, such as the use of inflammatory biomarkers, ultrasounds, video capsule endoscopy (VCE), and computed tomography (CT) scans, have shown promise in enhancing the diagnostic process.[3] In 2001, researchers in Canada tested colon mucosal biopsies from ulcerative colitis and Crohn disease patients. The mucosal biopsies were sent to 1H magnetic resonance spectroscopy and a multivariate analysis was performed.[3] The second study tested endoscopically and histologically normal biopsies. The results showed 98.6%

## Consider this

Mr. X, an 85-year-old male with a long-standing history of ulcerative colitis (UC), discontinued his routine annual exams at the age of 85. After a 2-year hiatus, he returned for a follow-up exam, during which he was diagnosed with colon cancer. As a result of the cancer diagnosis, Mr. X required a permanent colostomy.

Upon inquiry from the healthcare team, Mr. X explained his decision to delay the exam. He stated, "I went to see my primary care physician, and they said I only needed to get the procedure done every 2 years because of my age. I never wanted to go from the start because it was a pain, so I didn't go. I don't like the way I feel after. But after all these years of having UC, I now see the result of not going."

Although it remains uncertain whether an earlier exam would have altered the outcome, it's clear that earlier detection of the malignancy would have been possible.

accuracy in classifying ulcerative colitis and Crohn disease using this method. The testing opened the potential for another approach to identifying IBD.[3]

Despite the accuracy of an endoscopy, there are limitations to the procedure. These limitations warrant alternate methods to distinguish Crohn disease and ulcerative colitis. Endoscopy exams limit the provider to evaluating lesions only in the lumen. If a patient has extramural and intestinal wall complications or intestinal stenosis, the endoscopy exam won't be useful. CT enterography and magnetic resonance enterography are used to evaluate soft tissue, but sometimes patients don't meet the criteria to use these other diagnostic tests. As an alternative for these patients, researchers tested inflammatory biomarkers and ultrasounds as a diagnostic approach to distinguishing Crohn disease and ulcerative colitis.[4] C-reactive protein, fecal calprotectin, and erythrocyte sedimentation rate are common biomarkers to assess systemic inflammation.[4]

Patients' mental health should be considered for those who need an annual checkup. A noninvasive approach to assessing the colon for Crohn disease and ulcerative colitis has the potential to calm the patient and reduce anxiety while performing diagnostics. For example, a study conducted on children with IBD assessed the child's perspective of the monitoring test and their level of comfort with each exam. The study showed that the children preferred the noninvasive test (ultrasound) over the invasive procedure. The children stated the endoscopy had caused them the most discomfort.[5]

Data from a systematic review of adults with IBD indicated that gastrointestinal (GI) endoscopy was one of the least preferred methods for testing, along with venipuncture.[5] The discomfort the children reported was from nervousness and fright that may have resulted before the procedure. The perception of discomfort may vary between an adult and child, but both groups preferred the noninvasive approach to monitoring and assessing IBD.

Researchers are studying the use of artificial intelligence and VCE to assess Crohn disease and ulcerative colitis and eliminate cross-sectional images.[6] Video capsule endoscopy is the use of a vitamin-sized capsule with a camera to take images of the digestive tract. The capsule is swallowed and allows images of the intestinal tract to be taken. VCE has been compared with ileo-colonoscopy combined with MRI. The capsule has shown significant ability to diagnose Crohn disease.[7] Ultrasounds have recently evolved to include auxiliary data on GI complications. Elastography (sono-elastography) uses sound waves to assess stiffness, elasticity, or pathologies in soft tissue. CT scans and CT enterography are other noninvasive approaches to obtain an image of the GI tract and look for signs of Crohn disease and ulcerative colitis.

## Considerations for nurses

By supporting patients with Crohn disease and ulcerative colitis, the nurse plays a crucial role within the interdisciplinary healthcare team. Patients' mental well-being is equally important in healthcare. Invasive procedures like endoscopies can be uncomfortable and anxiety-inducing, especially for children. Taking patient preferences into account and communicating with patients can minimize anxiety to improve the overall well-being and satisfaction of individuals with IBD, ultimately improving patient outcomes.

When the nurse provides patient education about the diagnostic procedure, the nurse can gather information on the patient's emotions and identify any potential emotional issues that may arise from the procedure. This information should be relayed to the physician performing the procedure to ensure the patient is comfortable proceeding with the testing. If the patient has resistance to being examined, then the physician may be able to suggest an alternative approach to achieve the results while taking the patient's feelings into account.

IBD can be challenging to diagnose. The standard method is intestinal endoscopy, but despite this procedure's accuracy, it does have limitations. The limitations include the physician's ability to view the entire colon and the patient's experience of discomfort and anxiety. Researchers have explored noninvasive alternatives, such as inflammatory biomarkers, ultrasounds, VCE, and CT scans, to improve the diagnostic process. These methods can provide valuable information for diagnosis and ongoing management of ulcerative colitis and Crohn disease.

## Promoting the patient experience

Although traditional endoscopic procedures remain integral in diagnosing IBD, the integration of noninvasive testing methods should be further explored to offer patients a more comfortable and less anxiety-inducing diagnostic experience. Through an understanding of the patient's journey, nurses can work toward improving the overall care and well-being of individuals affected by IBD.

By integrating advancements in technology, providers can gather additional information for a clinical diagnosis. Considering the mental well-being of patients and their preferences for noninvasive approaches can significantly impact overall comfort and satisfaction. Nurses should remain updated on the latest diagnostic approaches and advocate for patient-centered care to ensure the best outcomes for individuals with Crohn disease and ulcerative colitis. ■

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Thureiyya Rodriguez currently works as an independent nurse consultant and is the owner and founder of Agni NY and Thureiyya Rodriguez Consulting Services in New York, N.Y.

Dedication: This heartfelt acknowledgment is dedicated to the remarkable Vashti Livingston, CWOCN. Her unwavering ability to adapt to changing times and her relentless drive for innovation have ignited a fire within me to push the boundaries of my own career.

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