Assessing and supporting patients who have IBD

In this article...

- Incorporating the 6Cs into inflammatory bowel disease care
- Methods and tools used to assess IBD severity
- How nurses can best treat and support patients

5 key points

1. The signs and symptoms of inflammatory bowel disease can vary, and depend on the location of the disease
2. Patients may look well so it is crucial that nurses take a detailed history
3. Patients with IBD should be systematically assessed
4. Many patients with IBD will need surgery
5. Nurses should ensure patients have contact details for supportive organisations upon discharge from hospital

All nurses, irrespective of their role, can have a tremendous impact on the lives of patients living with inflammatory bowel disease, as well as their families.

Nursing practice is enhanced when care is underpinned by the 6Cs – care, compassion, courage, commitment, competence and communication. These values, of equal importance, facilitate an integrated, multiprofessional approach to each episode of care for patients and their families (NHS Commissioning Board, 2012).

The assessment process of IBD is dynamic and has to be adapted to:

- New diagnoses;
- Flare-ups;
- Assessments of responses to treatment;
- The location of the assessment, including acute admission wards, outpatient clinics, or those done by telephone, email or in a virtual clinic.
- The disease can have a huge psychosocial impact and a holistic, patient-centred approach to care is vital. Effective communication and listening skills, intertwined with compassion, are needed to capture a good patient history. Gathering information from patients involves asking the right questions, with a focus on attentive listening. It is important the patient perspective is explored and patients are encouraged to be involved and discuss their expectations, feelings and concerns (Kumar and Clark, 2009).

A systematic approach to assessment enables nurses to evaluate care needs and develop individualised and patient-centred care plans.

Diagnosing IBD

Signs and symptoms of IBD vary depending on the disease location and the presence of extraintestinal disease activity (Hall, 2014). Patients may look well because they are usually young and do not have any comorbidity; this is why objective tools must be used to assess the condition accurately. A full history should include:

- Risk factors (outlined in Part 1);
- Bowel function;
- Physical assessment.

<table>
<thead>
<tr>
<th>TABLE 1. SEVERITY OF INFLAMMATORY BOWEL DISEASE</th>
</tr>
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<tbody>
<tr>
<td>Symptom</td>
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<tr>
<td>-----------------------</td>
</tr>
<tr>
<td>Bloody stools per day</td>
</tr>
<tr>
<td>Temperature (°C)</td>
</tr>
<tr>
<td>Pulse (bpm)</td>
</tr>
<tr>
<td>Haemoglobin (g/dL)</td>
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<tr>
<td>C-reactive protein (mg/L)</td>
</tr>
</tbody>
</table>

Adapted from: Truelove and Witts (1955)
The presence and nature of abdominal pain should be established, along with precipitating and relieving factors. For example, a patient may tell you that pain occurs 30 minutes after eating and is relieved by opening the bowels, which suggests that there may be narrowing in the small bowel. Pain scores provide an objective measure that can be reviewed over time. Assessing malaise, fever and weight loss will help nurses to establish how aggressive the disease is. Asking patients about extraintestinal manifestations involving the eye, joints, skin and oral cavity is also important, as is using a disease activity index to establish disease severity.

### Assessing IBD

It is vital to assess symptoms as the extent and severity of IBD and its symptoms will inform treatment (National Institute for Health and Care Excellence, 2013). Disease extent and severity will also influence decisions about colorectal cancer screening.

Patients with IBD undergo many investigations, including:
- Blood tests;
- Radiological investigations;
- Endoscopy investigations, such as colonoscopy and sigmoidoscopy.

Nurses need to know about these investigations so they can give patients support and information. Leaflets can help to inform patients about what to expect.

There is no single tool to establish the severity of ulcerative colitis, a common type of IBD (Hall, 2014). Nearly 60 years ago, Truelove and Witts (1955) developed a non-invasive tool based on clinical signs; it is relevant as it differentiates between mild, moderate and severe disease (Table 1). More invasive indices include the Mayo score (Rutgeerts et al, 2005) (Table 2), which consists of the macroscopic findings at endoscopy, plus clinical manifestations such as stool frequency, rectal bleeding and a physician's global assessment. A Mayo score of six or more indicates moderate-to-severe disease (Table 2).

Colonoscopy is an accurate tool for diagnosing colonic and terminal ileal inflammation in IBD. As Crohn's disease can extend above the terminal ileum beyond the reach of a colonoscope, radiological assessment is helpful. An ordinary abdominal X-ray can reveal colonic or small bowel dilatation, as well as any mass in the right iliac fossa, which may indicate an inflamed swollen area of bowel that is adhering to other parts of the bowel and surrounding tissue. Other diagnostic investigations include:
- Pelvic ultrasound;
- Barium studies;
- Computerised tomography scans;
- Magnetic resonance imaging scans;
- Capsule endoscopy, which involves swallowing a wireless video capsule that travels through the gastrointestinal tract to access areas that are difficult to reach by endoscopy.

The Crohn's Disease Activity Index (CDAI) (Best et al, 1976) measures Crohn's disease activity based on a seven-day symptom diary, clinical examination and haemocrit value. Haemocrit is the percentage of the volume of whole blood that is made up of red blood cells; this depends on the number and size of red blood cells. The test is usually done as part of a full blood count; it can also be done with a sample from a thumb prick. Low haemocrit may correlate with active Crohn's disease and can be due to anaemia, bleeding and malnutrition. CDAI scores range from 0 to 700 according to severity, with 700 being worst.

The Harvey and Bradshaw Index (1980) is quicker and simpler to use than the CDAI. Based on a single assessment, it takes into account intestinal symptoms, the presence or absence of abdominal mass and extraintestinal manifestations.

### Bowel function

Crombie and Hall (2013) said assessing diarrhoea was challenging because it has multiple causes. Diarrhoeal symptoms cannot be assumed to be related to IBD until infection has been excluded as a cause. This applies to each flare-up.

When a patient has symptoms of diarrhoea, it is important to consider:
- Recent foreign travel;
- Medication history – diarrhoea is a side-effect of some prescribed and over-the-counter drugs. Non-steroidal drugs can trigger the onset and flare-up of IBD, although the absolute risk is low;
- Recent antibiotic use – antibiotics can cause diarrhoea and may result in Clostridium difficile infection.

Assessment of bowel function includes:
- Stool frequency;
- Consistency;
- Associated urgency;
- Presence of blood in stools.

A pictorial prompt, such as the Bristol stool chart, may reduce embarrassment when talking about stool shape and consistency and heighten objectivity. Patients should be asked about nocturnal symptoms of diarrhoea because this may indicate significant disease. It is important to describe bowel function using terms patients understand (Kurtz and Silverman, 1996).

Diarrhoeal symptoms are a major concern to people with IBD. They need access to a toilet immediately and can be embarrassed about noisy, explosive and malodorous bowel actions. They may also worry about faecal incontinence. In hospitals and clinics, they need reassurance that they will have easy access to a toilet and a place to change their clothes if required. Facilities should also be available for patients with a stoma and who need to change their appliance.

### Physical assessment

Physical assessment includes finding out about overall general wellbeing, as well as conducting systemic observations of pulse rate, blood pressure, temperature and weight. Patients with a severe attack may exhibit fever, tachycardia and weight loss.

Abdominal palpation is important to establish whether there are signs of:
- Abdominal tenderness;
- Rebound tenderness;
- Distension, or the presence of a palpable mass.

In severe ulcerative colitis and colonic

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**TABLE 2. MAYO SCORING**

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Score</th>
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<tbody>
<tr>
<td>Stool frequency</td>
<td></td>
</tr>
<tr>
<td>Normal number of stools for this patient</td>
<td>0</td>
</tr>
<tr>
<td>1-2 stools more than normal</td>
<td>1</td>
</tr>
<tr>
<td>3-4 stools more than normal</td>
<td>2</td>
</tr>
<tr>
<td>≥5 stools more than normal</td>
<td>3</td>
</tr>
<tr>
<td>Rectal bleeding</td>
<td></td>
</tr>
<tr>
<td>No blood seen</td>
<td>0</td>
</tr>
<tr>
<td>Streaks of blood with stool less than half of the time</td>
<td>1</td>
</tr>
<tr>
<td>Obvious blood with stool most of the time</td>
<td>2</td>
</tr>
<tr>
<td>Blood alone passed</td>
<td>3</td>
</tr>
<tr>
<td>Physician's global assessment</td>
<td></td>
</tr>
<tr>
<td>Normal</td>
<td>0</td>
</tr>
<tr>
<td>Mild disease</td>
<td>1</td>
</tr>
<tr>
<td>Moderate disease</td>
<td>2</td>
</tr>
<tr>
<td>Severe disease</td>
<td>3</td>
</tr>
<tr>
<td>Endoscopic findings</td>
<td></td>
</tr>
<tr>
<td>Normal or inactive disease</td>
<td>0</td>
</tr>
<tr>
<td>Mild disease (erythema, decreased vascular pattern, mild friability)</td>
<td>1</td>
</tr>
<tr>
<td>Moderate disease (marked erythema, absent vascular pattern, friability, erosions)</td>
<td>2</td>
</tr>
<tr>
<td>Severe disease (spontaneous bleeding, ulceration)</td>
<td>3</td>
</tr>
<tr>
<td>Total score</td>
<td></td>
</tr>
</tbody>
</table>

*Source: Rutgeerts et al (2005)*

For a Nursing Times Learning unit on assessment and management of diarrhoea, go to nursingtimes.net/diarrhoea

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Crohn’s disease, there may be colonic tenderness, abdominal distension and/or reduced bowel sounds. The presence of a mass in the right iliac fossa is suggestive of Crohn’s disease. Perineal disease, including abscesses, anal fissures and fistulas are common in Crohn’s disease but rarely seen in ulcerative colitis.

The nurse’s role
Nurses need to be aware of the signs and symptoms of acute, severe colitis to enable timely decisions about escalating medical therapy or predicting the need for surgery. They are in a good position to indicate to doctors that prognostic markers are present or a patient is deteriorating. Patients often do not want to face the prospect of surgery – such as colectomy and stoma formation – so courage, compassion, competency and communication skills are paramount.

The Royal College of Physicians (2012) recommends using the National Early Warning Score to identify deterioration and facilitate timely assessment. This assesses six parameters: respiratory rate; oxygen saturation; temperature; systolic blood pressure; pulse rate; and consciousness level.

Hydration and nutrition needs should be assessed and the Malnutrition Universal Screening Tool (MUST) is considered to be the gold standard in nutritional assessment (Todorovic et al, 2003). The fundamental measurement of nutritional status is weight, so assessments should document weight before illness or the latest flare-up. Weight loss indicates that the bowel is unable to maintain nutritional balance due to malabsorption; calculating body mass index is an important part of assessment (IBD Standards Group, 2013).

Patients with acute diarrhoea can experience mild dehydration due to loss of fluids. Those with severe dehydration may need intravenous fluids. Patients with severe dehydration may need intravenous therapy and medical advice should be sought.

Patient support
Providing advice and support is crucial if patients are to navigate the care pathway and feel empowered to make decisions about their care and treatment based on evidence. They need time to discuss:
- The effects of their condition;
- Its course;
- Medical treatment options;
- The effects of medication;
- What monitoring is needed.

NICE (2013) found that 90% of patients with inflammatory bowel disease reported a lack of information about drug side-effects upon discharge from hospital. Nurses can fill this gap by providing information verbally and with leaflets.

All patients with IBD should have access to specialist pharmacists for advice on current and future medical treatment. Ward nurses should ensure the ward-based pharmacist is involved with the discharge medications.

It is important to provide information to support people who are considering elective surgery. A nurse will need 6Cs qualities to provide this. Between 50% and 80% of people with Crohn’s disease will need surgery for strictures that cause bowel obstruction, other complications such as fistula formation, perforation or failure of medical therapy (NICE, 2013).

Nurses have a vital role in explaining information about surgery using a language and approach that is personalised.