Inflammatory bowel disease

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Inflammatory bowel disease (IBD) is a term used to describe ulcerative colitis and Crohn’s disease. Both are chronic, lifelong conditions characterised by periods of exacerbation and remission. The management of IBD is complex for the health care team. Following an exploration of the physical, psychological and sociological impact of the condition, the medications used to control the symptoms are described, together with consideration of the surgical options used in the management of IBD. Finally, the role of the nurse in meeting holistically the needs of patients with IBD is highlighted.

Inflammatory bowel disease (IBD) is an umbrella term used to describe ulcerative colitis (UC) and Crohn’s disease (CD). Both are chronic, lifelong conditions characterised by periods of exacerbation and remission. The management of IBD is complex for the health care team. Following an exploration of the physical, psychological and sociological impact of the condition, the medications used to control the symptoms are described, together with consideration of the surgical options used in the management of IBD. Finally, the role of the nurse in meeting holistically the needs of patients with IBD is highlighted.

The presentation of IBD is complex and patients are often unwell for long periods before they are finally given a diagnosis. The impact upon the individual is immense physically, psychologically and socially. Disruption to family life, work life and relationships is common. Individuals become depressed and feel isolated as they try to cope with the daily challenges that having IBD brings.

**Epidemiology**

The prevalence of UC is approximately 100–200 cases per 100,000 people and for CD it is 50–100 cases per 100,000. The incidence of UC remains stable, whereas the incidence of CD has risen. Both conditions are considered to be diseases of young people, with a peak in incidence between the ages of 10 and 40 years (British Society of Gastroenterology (BSG), 2003).

There is a marked difference in prevalence between ethnic groups, with a particularly high incidence among immigrant Ashkenazi Jews and Asians (Forbes, 1997). An estimated 120,000–150,000 people are affected with IBD in the UK.

**Pathogenesis**

The cause of IBD is unknown. However, it is believed that both conditions develop as a result of environmental factors (for example drugs and infection) in genetically susceptible individuals. These and other factors thought to be implicated in the development of IBD are summarised in Table 1.

**Physical impact of IBD**

**Ulcerative colitis**

UC is characterised by inflammation of the mucosa and submucosa of the colon. It always affects the rectum and can progress to involve all of the colon or certain parts of it to varying extents (Fig 1).

The condition is described according to the parts of the colon affected:

- Pancolitis – affects the whole of the colon;
- Left-sided colitis – affects the descending colon;
- Distal colitis – affects the rectum and sigmoid colon;
- Proctitis – affects the rectum.

The majority of patients with UC initially present with bloody diarrhoea. Other symptoms can include abdominal pain, urgency and tenesmus. UC is characterised by periods of remission and exacerbation. It is estimated that 50 per cent of patients with UC will experience relapse in any year (BSG, 2003), and that it is likely that a significant number will have frequently relapsing or continuous disease in any year. However, the majority of patients remain fully able to work.

**TABLE 1. FACTORS THOUGHT TO BE IMPLICATED IN THE DEVELOPMENT OF IBD**

<table>
<thead>
<tr>
<th>FAMILY RISK</th>
<th>ENVIRONMENTAL FACTORS</th>
<th>GENETIC FACTORS</th>
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| When considering the extended family, 20–30 per cent of patients have a positive family history of IBD | Smoking  
Ulcerative colitis  
- 1–3 per cent risk of a sibling/parent having IBD  
- 1–3 per cent risk of a child developing IBD | Ulcerative colitis  
Low incidence |
| Ulcerative colitis  
- 1–3 per cent risk of a sibling/parent having IBD  
- 1–3 per cent risk of a child developing IBD | Crohn’s disease  
Smoking increases the risk of developing the disease and doubles the risk of postoperative recurrence | Strong genetic influence |
| Crohn’s disease  
- 3–8 per cent risk of a sibling/parent having IBD  
- 1–2 per cent risk of a child developing IBD |  |  |
Sigmoid colon

Promotion opportunities and work opportunities are not symptoms from their employers to ensure that their ability to form long-term relationships with peers is affected and their social development is delayed.

Relationships

Trying to maintain a normal social life often provides many challenges for people with IBD. The fear of incontinence/diarrhoea often inhibits their social activities. They report fears of eating in public in case this increases bowel frequency and they worry about undertaking long journeys and not knowing where toilets are.

Sexuality

Little has been written on the impact of IBD on patients’ sexuality. Rowlinson (1999a) reported that up to 50 per cent of female patients with IBD reduce or abstain from sexual activity because of their fear of faecal incontinence, abdominal pain or dyspareunia. People with perianal Crohn’s disease and patients who have undergone extensive surgery also experience problems with their sexuality.

Fertility

Most females with IBD are able to conceive and achieve a normal pregnancy (Kamm, 2002). Nothing has been documented on the impact of IBD on male fertility. Most gastroenterologists will advise women with IBD to continue taking azathioprine, 6-mercaptopurine and aminosalicylates during their pregnancy, although in some cases women prefer not to be taking medication while trying to conceive or if they are pregnant. However, counselling, education and close medical supervision should be offered to reduce the chances of exacerbation of the IBD.

Stress

The stress involved in managing IBD has long been acknowledged (Forbes, 1997). Increased stress in patients with IBD has been shown to increase urgency, diarrhoea, rectal bleeding and abdominal pain, increasing feelings of social isolation and depression.

Diagnosis and investigation

A number of investigations are used to diagnose and assess the severity of IBD in the long term: biochemical, endoscopic, radiological and histological. The diagnosis of UC is made on the basis of assessment of symptoms, negative stool sample, endoscopy (sigmoidoscopy or colonoscopy) and biopsy findings.

Similarly, diagnosis of CD relies on endoscopic and barium studies to identify the extent of the disease, and the presence of granulomatous inflammation on biopsy. Both conditions require the assessment of presenting treatment needs and links to relevant website see www.nursingtimes.net

REFERENCES


Crohn’s disease

The symptoms of CD are more varied than those of UC but typically include abdominal pain, diarrhoea and weight loss. Systemically, individuals often experience malaise, anorexia, or fever. CD affects any part of the gastrointestinal tract from the mouth to the rectum. The most common sites include the terminal ileum, colon and perianal area. The condition is characterised by patchy inflammation that affects all layers of the bowel mucosa (transmural). In some patients this inflammation extends through the whole layer of the bowel mucosa, causing fistulae to develop on adjacent loops of intestine or on other structures, such as the vagina or bladder. Commonly, strictures and abscesses can develop. CD tends to cause greater disability than UC, with only 75 per cent of patients able to work in the year after diagnosis (BSG, 2003).

Extra-intestinal manifestations

The association between extra-intestinal manifestations and IBD suggests that IBD is a systemic disease. These manifestations may affect several organs distant from the bowel. None is specific to UC or CD. Symptoms may be apparent before or at the onset of intestinal symptoms. They frequently occur together: the triad of skin-eye-joint involvement is common. Examples of structures involved and their extra-intestinal manifestations are shown in Table 2.

Psychological and sociological impact

The psychological and sociological elements of IBD, such as education, employment, social development and personal relationships, are often underestimated when considering the impact of IBD upon a patient.

Education and employment

The pressures of work on patients with IBD are immense. They often feel too unwell to work but hide the extent of their symptoms from their employers to ensure that their promotion opportunities and work opportunities are not affected. The National Association for Colitis and Crohn’s Disease (1999) says that a significant number of patients with IBD are depressed because they feel that they are unable to achieve their true potential. In addition the prospect of not working poses many financial worries.

Similarly, adolescents and children with IBD often struggle to progress academically because of the physical symptoms and their lethargy. As a consequence their ability to form long-term relationships with peers is affected and their social development is delayed.
manifestations, physical findings and complications. In a certain number of cases, a definitive diagnosis of UC or CD cannot be made owing to inconclusive findings on colonoscopy and sigmoidoscopy and the failure to find granulomas on histology. In this situation, a diagnosis of indeterminate colitis is made.

History and examination
Among the many factors that need to be taken into consideration when assessing a patient with IBD are recent travel, medication, smoking and family history. A full bowel assessment should be undertaken, examining stool frequency, consistency, urgency, whether rectal bleeding is with or without mucus, abdominal pain, malaise, fever, weight loss and extra-intestinal manifestations. Additionally, pulse, blood pressure, temperature and weight should be documented.

Initial investigations
Usually a full blood count, urea and electrolyte count, liver function test, erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP) test are performed. These enable identification of anaemia, abnormal renal or hepatic function and the extent of inflammation. It should be remembered that raised ESR and CRP are indicative of active IBD, although they are not bowel-specific.

In an acute presentation of IBD, abdominal X-ray may also be appropriate in order to assess for toxic dilation of the colon. The X-ray may also enable the practitioner to assess the extent of disease in a patient with UC or the presence of proximal constipation.

Sigmoidoscopy and colonoscopy
For all patients presenting with bloody diarrhoea, a sigmoidoscopy is usually performed to assess the severity and extent of the disease. Colonoscopy may be preferred to sigmoidoscopy in patients who have mild to moderate disease as this gives a more thorough assessment of the extent of disease. In more severe cases endoscopic investigation may be deferred until the patient’s clinical condition improves to reduce the risk of perforation.

For patients with suspected CD colonoscopy is more appropriate because it enables the clinician to visualise the terminal ileum and enables a biopsy to be taken. This would allow a conclusive diagnosis of small-bowel CD to be made.

Other investigations
When assessing patients for the presence of small-bowel disease they are given a barium enema. Although this is not as efficient as colonoscopy for diagnosing IBD, as it does not allow for biopsy and may underestimate the extent of the disease, small-bowel barium meals are the only means of visualising the extent of CD in the small bowel.

White cell scans are also used to assess for active areas of IBD, but only infrequently as they tend to lack specificity. Computerised tomography (CT) scans and magnetic resonance imaging (MRI) are often used to assess the site, activity and complications of CD.

After diagnosis has been confirmed, it is essential for the disease extent to be defined, as this will determine the most appropriate route of therapy for the patient. For UC the extent is defined as the proximal margin of inflammation. For CD both the large and small bowel should be assessed.

Drugs used in the treatment of IBD
A variety of medications are used to control the symptoms of IBD. Aminosalicylates, corticosteroids and immunosuppression therapy are most commonly used. Methotrexate, antibiotics and cyclosporine have been used in patients with severe refractory disease, with varying effects (Rizzello et al., 2003).

Aminosalicylates
Aminosalicylates (mesalazine or 5-aminosalicylic acid [5-ASA]) are composed of an anti-inflammatory agent linked to an active carrier molecule. When given orally the drug is delivered to various parts of the terminal ileum or colon, where the carrier is split, either by a change in the pH value (in the case of the drug mesalazine, for example) or by the action of bacteria (for example in the case of balsalazine or olsalazine) (Sands, 2000).

Sulfasalazine is sometimes used for the management of IBD. It comprises of 5-ASA linked to sulphasalazine (the carrier molecule). Its efficiency is well documented in recent Cochrane reviews (Sutherland et al., 2000). However, tolerability of the drug remains a problem. Common side-effects include headaches, nausea, anorexia, rashes, oligospermia and blood dyscrasias. These side-effects are usually reversible once the drug has been stopped.

The newer 5-ASA compounds do not contain a sulphur component and are better tolerated. Research suggests...
that increased tolerance allows higher doses to be used, which enables a remission rate of around 60 per cent to be achieved (Rizzello, et al, 2003). The effect in CD is somewhat lower, owing to the differences in aetiology (Sciriano and Prantera, 2002).

The treatment S-ASA can be used in enema and suppository form to manage distal colitis. There the effect is topical and has been shown to spread up to the splenic flexure. Lucidarme et al (1997) suggest that clinical remission is usually achieved in 70–80 per cent of patients after four to six weeks. This suggests that such therapies should be considered first-line management for patients who have distal colitis.

### Corticosteroids

Corticosteroids, predominately prednisolone, hydrocortisone and budesonide have proven efficacy in active IBD. Essentially, they reduce the inflammatory process. They can be administered intravenously, rectally or orally (dependent upon location and severity of the disease). Steroids offer rapid and effective relief of symptoms through the inhibition of several inflammatory pathways (Forbes, 1997).

Steroids are usually given as a reducing regimen over a prolonged period but it is common for symptoms to return when doses are reduced. This may require slower reduction of steroids.

The prolonged use of steroids increases the risk of side-effects, including weight gain, mood swings, acne, osteoporosis, hypertension and hyperglycaemia. It should be explained to patients that there is a likelihood of side-effects occurring. Immunosuppression therapy should be used to replace steroids if the patient becomes steroid-dependent.

### Immunosuppression therapy

Azathioprine and 6-mercaptopurine are related immunomodulators but the mechanisms by which they work are unclear (BSG, 2003). It is estimated that 20 per cent of patients with IBD will require immunosuppression therapy (Buckton, 2003). Azathioprine and 6-mercaptopurine are usually administered to treat refractory symptoms or to reduce the need for steroid therapy in the steroid-dependent or steroid-sensitive patient. The onset of the drug is slow – the maximum benefit is seen between 12 and 26 weeks.

Many patients respond well to immunosuppression therapy although some develop side-effects, including gastrointestinal intolerance or severe myalgia and bone marrow suppression. Monitoring of regular blood counts, liver function tests, urea and electrolytes is therefore essential in the management of patients having immunosuppression therapy. The frequency is according to local guidelines.

Thiopurine methyltransferase (TPMT) activity is frequently measured to predict the likelihood of neutropenia developing. However, this test should not replace careful administration and haematological monitoring once therapy has begun.

**Infliximab**

Anti-tumour necrosis factor (anti-TNFα) is a recent addition to the management of CD. It is a monoclonal antibody that blocks the action of tumour necrosis factor, a cytokine that is thought to be one of the causes of inflammation in CD. It is used to reduce inflammation of the intestine and increase the length of time that elapses between flare-ups.

The National Institute for Clinical Excellence (NICE) (2002) recommends that only patients with severe active CD be given anti-TNFαs. In addition, the patient’s condition must be refractory to treatment with immunomodulators and corticosteroids or be inappropriate for surgery. The NICE guidance advocates that anti-TNFα drugs (such as infliximab) should not be used to treat fistulising CD.

Anti-TNFα drugs given as an intravenous infusion, either as a single dose or as maintenance therapy, are expensive, costing in the region of £500 per treatment. Numerous side-effects have been documented, including headache, nausea, upper respiratory tract infection, abdominal pain, skin rash, diarrhoea, tuberculosis, and congestive heart failure (Hanauer et al, 2002). Anti-TNFα should therefore be given in an environment where there is sufficient clinical expertise to manage patients with CD effectively and ensure that administration of the drug is undertaken safely.

### Nutrition

Nutrition is a major consideration in the management of the patient with IBD. A full nutritional assessment considering dietary intake, body mass index, current weight and weight loss should be documented. Weight loss often indicates the severity of disease activity.

Nutrition is also offered as a therapy in the management of CD. It has no benefit to the patient with UC. Elemental and polymeric diets are used to replace normal dietary intake in the form of sip feeds. An elemental diet contains pre-digested nutrients that are absorbed in the first metre of the small intestine. Such a diet is believed to restore nutritional status and allow the bowel to rest, both of which are considered the optimum conditions for the bowel to heal. They are used less commonly than polymeric diets, which contain a balance of standard nutrients. It has been demonstrated that nutritional therapy, together with appropriate physical and psychological support, can achieve a remission rate of up to 70 per cent (Pullen, 1999).

The success of nutritional therapy for the patient with IBD depends on effective support from the multi-disciplinary team. Included in the team will be medical and nursing staff, specialist dietitians, and psychologists. They will ensure that patients can cope with the therapy both emotionally and physically.

### Surgery

Patients who require surgery to manage their IBD are usually jointly managed by a colorectal surgeon and consultant gastroenterologist. Early referral should be...
made to a colorectal or stoma nurse to enable adequate emotional support, physical preparation, education and counselling to be offered to the patient before surgery.

**Crohn’s disease**

In CD, surgery is not curative and management is directed at minimising the impact of the disease. Up to 80 per cent of patients experience a recurrence of the disease at the site of re-anastomosis. Approximately 50 per cent will require surgical treatment in the first 10 years following diagnosis (BSG, 2003). Intestinal resection and strictureplasty are the most common surgical procedures undertaken in the patient with CD. The surgery aims to:

- Control symptoms while maintaining continuity of the gastrointestinal tract (Sercombe, 2001);
- Restore patients’ health by eliminating or alleviating their symptoms, such as strictures, fistulae or abscesses (Rowlinson, 1999b).

Intestinal resection usually involves the removal of a section of terminal ileum and caecum. In the majority of cases continuity is maintained but if the bowel is dilated or toxic a stoma may be formed. Strictureplasty involves excision of the stricture longitudinally and closing of the incision transversally. The benefit of this procedure is that no length of bowel is lost and the chance of short-bowel syndrome occurring is therefore reduced.

Postoperatively, patients who have undergone an ileal resection experience problems such as bile salt malabsorption. This is usually corrected with cholestyramine sachets one to two times a day. Other problems include iron, folic acid and vitamin $B_12$ deficiency. This is attributed to the terminal ileum being responsible for the absorption of these nutrients.

**Ulcerative colitis**

About 20–45 per cent of patients with UC will require surgery, almost half having it within 10 years of their diagnosis (BSG, 2003; Sercombe, 2001). The aims of surgical treatment in UC are:

- To alleviate symptoms and prevent complications;
- To restore health while improving quality of life.

Proctocolectomy is the most common procedure performed on patients with UC. Sercombe (2001) summarises the surgical process in three stages:

- A rectal stump and ileostomy are performed. The rectal stump is either sutured to the undersurface of the incisional wound or brought out as a mucous fistula;
- After several months, when the patient has recovered from the proctectomy (surgical resection of the rectum), the creation of an ileal-anal reservoir with a loop ileostomy is undertaken;
- The loop ileostomy is closed at a later time. Sometimes the creation of the ileal-anal reservoir and the closure of the loop ileostomy are undertaken at the same time.

Occasionally, a panproctocolectomy with a permanent ileostomy is undertaken in patients who do not want restorative surgery. This surgery involves the removal of the diseased colon and the creation of a permanent ileostomy in one operation. Patients often choose this operation as it seems a preferable option to putting up with chronic disease. The choice of surgery is dependent upon the severity of disease, operative risks and the expertise of the surgeon.

**The nurse’s role in managing IBD**

Physical management of IBD remains an important aspect of caring for patients with IBD. However, to achieve holistic care the social and psychological challenges of coping with IBD must be addressed. Nurses who work with patients who have IBD must clearly understand the issues the patient faces, the physical symptoms and their psychological and social impact. An awareness of basic nursing concepts is essential to beginning to understand the patient’s experience, and to the offering of support in the form of acceptance, empathy and trust, for example.

Ongoing education is also essential and should cover the topics outlined in Box 1. Education aims to empower patients to cope with the everyday symptoms of their condition, to promote self-control and concordance with medication, to facilitate self-management and reduce hospital visits and inpatient stays (Kennedy et al, 2003; Nightingale et al, 2000). Overall, the aim is to achieve a more proactive approach to the long-term management of the condition.

In some hospitals specialist nurses offer support to patients with IBD. These nurses work as part of a multi-disciplinary team to improve the management of patients with IBD, offering nurse-led clinics, open access telephone services and immunosuppression monitoring.

**Conclusion**

The key to successful management of the patient with IBD is education and emotional support. Empowering patients to make choices, educating them about their illness and the effects it is likely to have on their lifestyle, enables them to take responsibility for their condition. This has to be underpinned by effective relationship-building. The nurse’s role in facilitating all these elements cannot be underestimated.