



IBD: a guide for general nurses

Summary

- ❖ Ulcerative Colitis (UC) and Crohn's Disease (CD) are chronic inflammatory bowel diseases (IBDs) that have no proven cause. UC can only be cured by total colectomy. CD has no cure – yet.
- ❖ UC only affects the lining of the large bowel, causing inflammation that extends for a variable distance upwards from the rectum.
- ❖ CD can affect any part of the gastrointestinal tract, but most often the distal small intestine and/or the large intestine. Fistulae and abscesses, particularly around the anus, occur quite commonly.
- ❖ Features of UC include diarrhoea, mucus, rectal bleeding and fatigue. In the long term, the risk of bowel cancer is increased in those with more extensive inflammation.
- ❖ Features of CD include diarrhoea, abdominal pain, weight loss and fatigue. Cigarette smoking is very detrimental.
- ❖ 5-ASA (e.g. mesalazine) drugs reduce bowel inflammation and are usually taken indefinitely.
- ❖ Severe attacks require steroids and/or immunosuppressants and sometimes hospital admission for intravenous treatment and nutrition and possibly surgery.
- ❖ Changing the diet has little effect on UC, but can be very useful in treating CD both to correct nutritional deficiencies and to reduce inflammation.
- ❖ IBD greatly affects people's lives. With skilful medical care and surgery when necessary, most people with IBD lead a full, productive life. Good understanding of their condition and psychological support are essential.

❖ Inflammatory Bowel Disease - a Guide for General Nurses

Introduction

Ulcerative Colitis (UC) and Crohn's Disease (CD) are the two common forms of Inflammatory Bowel Disease (IBD) that affect the gastrointestinal (GI) tract. Although patients' symptoms are varied, urgent and frequent bowel movements are the major features. The effects of IBD range from mild to life-threatening.

This guide has been produced to give non-specialist nurses information about IBD, to enhance their role in the care of people with UC and CD. Further copies can be downloaded from the NACC web-site (www.nacc.org.uk) and shared with colleagues.

The main characteristics of IBD

Although precise figures are not available, the prevalence of IBD in the UK is approximately 1 in 500 people. The causes of IBD are unknown; however, there is evidence of an interaction between genetic susceptibility and as yet undetermined factors in the environment. Between 5% and 35% of people with UC and CD have a family member who is also affected.

In addition to altered bowel movements, IBD causes bleeding, cramping abdominal pain, a lack of energy and tiredness. Any age group may be affected, but most people present between 10 and 40 years, when often they are studying, establishing personal relationships or starting work. Comprehensive care should consider these psychosocial factors as well as the medical symptoms. Patients require accurate information about their condition and with the aid of the healthcare team should be enabled to stay in control of their lives as far as possible.

An attack of UC or CD can vary from mild symptoms to acute severe illness requiring hospital admission and, in some cases, surgery. UC affects only the inner lining (mucosa) of the colon, extending upwards from the rectum for a variable distance, whereas CD affects all the layers of the bowel wall and can occur in any part of the gastrointestinal tract from the mouth to the anus. Despite these differences, sometimes the two conditions are difficult to distinguish when only the colon is involved. In CD, the small bowel alone is likely to be affected in about 30% of cases, the large bowel alone in 25% of cases, and both small and large bowel in 40% of cases. Disease around the anus – abscess, fissure, fistula and fleshy skin tags – occurs in up to 50% of cases and can be very troublesome.

IBD is usually a chronic condition with episodes of relapse and remission. In UC only about 10% of patients remain in long-term remission after their first attack. The majority are affected for many years, although with time most patients experience fewer relapses. It is rarely fatal, with mortality associated with a severe attack now being less than 3%. Patients with stable disease have a normal life expectancy.

In CD, irrespective of the site of disease, half of all patients relapse in the first year after diagnosis. Approximately 80% of patients will require surgery at some time and half of these require further surgery as the years pass. Smoking has been found to increase the risk of severe disease and frequency of relapse. Children and young adults may have retarded growth and delayed sexual development.

Extra-intestinal Manifestations of IBD

A minority of people with IBD also have extra-intestinal inflammation, possibly due to altered immune function. Some manifestations parallel disease activity, and respond to medical treatment of the bowel inflammation. However, some occur independently of the bowel disease and require specific treatment.

The main manifestations are:-

- ❖ Inflammation of the joints (arthritis, sacro-iliitis and ankylosing spondylitis)
- ❖ Inflammation of the skin (erythema nodosum and pyoderma gangrenosum)
- ❖ Inflammation of the eye (uveitis and iritis)
- ❖ Inflammation of the liver (fatty liver and sclerosing cholangitis).

Investigations

Due to the chronic nature of IBD, investigations may be frequent, but the results may not always be conclusive. This can be frustrating for the patient, who may spend large amounts of time at hospital, sometimes without obvious benefit. There is a NACC booklet describing the main types of investigations for IBD.

Blood tests are required to assess anaemia, nutrition and the severity of inflammation (ESR and CRP), and are supplemented by information from barium X-rays, endoscopy or radioisotope scanning to assess the distribution and activity of the disease.

Treatment

Drugs

Most patients are prescribed 5-aminosalicylic acid (5-ASA) derivatives, sulphasalazine, mesalazine, olsalazine and balsalazide, which reduce inflammation, to control mild attacks and to maintain remission. Some of these drugs can be given rectally by suppository or enema when disease is confined to the rectum or lower colon. Patients should be encouraged to continue treatment, even when in remission, as 5-ASA drugs reduce the number of relapses and possibly reduce the risk of bowel cancer. However a small number of patients can be intolerant of these drugs causing worsening of their diarrhoea.

In more severe attacks, corticosteroids such as hydrocortisone, prednisolone and budesonide (Entocort) are needed, and sometimes immunosuppressive agents (azathioprine, 6-mercaptopurine, methotrexate, ciclosporin) are added to treat difficult disease or to reduce the duration of steroid therapy. Some immunosuppressants can take up to four months to be fully effective. In CD, antibiotics and anti-TNF α antibodies (infliximab) can provide additional, effective treatment.

Corticosteroids can have serious side effects on skin, bones, blood sugar and blood pressure and all immunosuppressants increase the risk of infections.

Analgesic, anti-diarrhoeal and anti-spasmodic drugs may be prescribed with caution and supplements of iron, calcium and vitamins D and B₁₂ may be needed.

Further information on drugs for IBD is contained in a NACC booklet on the subject.

Nutrition

All GI disorders can lead to anorexia because patients associate eating with unpleasant symptoms and so eat less. Also, in CD, the damaged small intestine may not fully absorb all the nutrients from food.

If a patient finds hospital food unpalatable, favourite foods from home, soups and supplement feeds (e.g. Ensure, Fortisip, Complan) should be considered, as well as snacks between meals.

Special Diets

An elemental or polymeric diet (complete nutrition in very easily digested liquid form) may be used to treat the intestinal inflammation in CD, and to encourage growth in children. It is not especially palatable, but can be administered by nasogastric tube, if necessary. Intravenous feeding may be needed in very ill patients or in the peri-operative period.

Adequate intake of a balanced diet is the goal of patients with IBD. Foods valuable to the diet such as dairy products may have been avoided, as some patients find their symptoms worsened, resulting in deficiency of calcium, protein and vitamin D. A low-fibre diet may reduce pain and lessen the chance of obstruction in patients with CD affecting the small intestine. Because of the range of dietary issues that may affect people with IBD, it is often useful for patients to be advised by a registered dietitian.

Indications for Surgery

Surgery can be very effective in carefully selected patients. Indications for surgery are:

<i>Ulcerative Colitis</i>	<i>Crohn's Disease</i>
Unresponsive to medical therapy	Unresponsive to medical therapy
Toxic dilatation of the colon	Severe perianal infection
Precancerous changes (dysplasia)	Intestinal stricture
Colorectal cancer	Intestinal perforation
	Bleeding
	Obstruction
	Fistula
	Abscess

Most surgery is elective, and is a typical part of treatment. There is usually plenty of time for the patient and relatives to discuss the options with their doctor and/or surgeon.

Major Concerns of Patients

Access to toilets

It is important for all hospital staff to appreciate that patients with IBD have urgency of defaecation. Those needing help to the lavatory need it immediately. Bowel actions are often explosive, noisy and malodorous. The use of a commode behind a curtain in an open ward can be embarrassing. Whenever possible, patients should have a single room with *en suite* facilities or their bed as close as possible to a lavatory.

Intimacy/Fertility/Pregnancy

Most people develop IBD during their reproductive years and so fertility, pregnancy and genetic predisposition to the disease are frequent concerns. Fortunately, the majority will have normal reproductive function and normal healthy babies. Salazopyrin (sulphasalazine) can lead to a temporary loss of fertility in males, although this is now seen less, due to the increased use of mesalazine instead. Decreased fertility of women is associated with severe disease, malnutrition and avoidance of sexual intercourse because of pain or fear of intimacy and bowel incontinence.

The most important factors for a successful pregnancy are preservation of good nutritional status and achieving disease quiescence. The continuation of medication during pregnancy is usually desirable. The majority of medications used to treat IBD are safe in pregnancy and during breast feeding, but methotrexate is absolutely contra-indicated during conception and pregnancy. Taking immunosuppressants during pregnancy should be considered carefully by the patient and doctor, but there is very little evidence that these drugs are harmful. Infliximab treatment should also be avoided, as there is insufficient evidence about its safety during pregnancy and breastfeeding.

Stomas

There are many distressing factors to having IBD, but the constant threat of surgery and formation of a stoma is the greatest. Some people reach the stage of having no option. After years of weight loss, pain and anxiety, the only solution may be the one they have been dreading for many years. The stoma care team should be involved early on to discuss anxieties and coping mechanisms, but many patients are surprised how much better their quality of life is when the diseased bowel has been removed. People with UC may be offered an ileo-anal pouch as an alternative to a stoma.

Emotional Disturbance

As with any chronic disease, personal relationships, recreational activities and employment opportunities may all be affected. Patients should be encouraged to talk to their doctor and/or nurse specialist about their worries, but some sufferers may not be able to cope independently with the burden of their disease. Specialist practitioners (e.g. stoma nurse, GI nurse) can help by discussing problem-solving techniques to reduce stress and anxiety. However, additional pharmacotherapy or psychotherapy may be required for people with significant anxiety or depression.

Further information

People with IBD often have more knowledge of their disease than non-specialist healthcare practitioners, therefore do not be afraid to ask the patient for information about how they manage their symptoms, or food preferences. For people with IBD, and their spouses, partners or relatives, there are national and regional groups such as NACC that can give support and guidance. Regular newsletters and correspondence ensure that members are up to date with new developments. Local meetings provide the opportunity to meet people with similar problems. For patients with an ileostomy or ileo-anal pouch (after removal of the colon) there is the support organisation **ia***. Nurses may also find membership of such groups useful.

Your hospital may have specialist GI or IBD nurses, who can give support and information to patients and the healthcare team.

* **ia** (Ileostomy and Internal Pouch Support Group)

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☎ 0800 018 4724 or 028 9334 4043 Fax: 028 9332 4606.

Website: www.the-ia.org.uk Email: info@the-ia.org.uk

Your local specialist nurse is:-

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This document has been prepared by NACC as general information on the subject and is not intended to replace specific advice from your own doctor.

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Responsibility for overseeing the production of the document lies with the NACC Publications Committee.

NACC is a voluntary Association which has 30,000 members and 65 Groups throughout the United Kingdom. The Association also provides a supportive listening service called NACC-in-Contact which is available to anyone affected by Inflammatory Bowel Disease. Membership of the Association costs £12 for the first year and £10 subsequently. Additional donations to help the work of the Association are always welcomed.

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