Establishing an inflammatory bowel disease service

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Specialist nurses make a valuable contribution to the care of the individual with inflammatory bowel disease yet there are still relatively few of these nurses in post. This article discusses the development of the role within the Bolton Hospitals NHS Trust.

Inflammatory bowel disease (IBD) is an umbrella term for the chronic conditions ulcerative colitis and Crohn’s disease. The management of IBD involves a number of approaches, all of which necessitate huge physiological, psychological and sociological adjustments for the individual (Pearson, 2004).

**Background**

Specialist nurses for patients with IBD make a valuable contribution to care (National Association for Colitis and Crohn’s disease, 2005). However, there are relatively few of these posts around the country. Bolton Hospitals NHS Trust has developed this role. Its gastroenterology team consists of three consultant gastroenterologists, dietitians, psychologists, social workers, endoscopy ward nurses and a nurse specialist in inflammatory bowel disease, who was appointed to improve the quality of care of patients with IBD.

The trust serves a population of 300,000 and has 756 patients with IBD who have been identified and included on a database. The work of Nightingale et al (2001) in evaluating the effectiveness of the specialist nurse role in managing IBD was used to guide the development of a telephone helpline and nurse-led clinics to improve patient education and support.

**Development of the role**

A patient questionnaire, focus groups and process mapping informed the development of the service. These identified that access to the gastroenterology team during periods of exacerbation was poor and that prolonged periods of ill health had an impact on patients’ home lives, sexual relationships and work life. The level of understanding that patients with IBD had about their condition and its management was poor. A considerable number of patients were unable to describe the pathology of their condition and the rationale of their therapeutic management.

**Rapid access service**

To improve access to the gastroenterology team a telephone helpline was established, run by the nurse specialist. Patients could seek general advice around IBD, while those who had an exacerbation of their condition could contact the team, and additional clinic spaces were created to enable rapid access review. This enabled patients with exacerbating IBD to be reviewed within five working days. Over the past four years 2,800 contacts have been recorded, 1,600 for general advice and 1,200 related to the management of an exacerbation.

**Outpatient clinic**

It is well documented that nurse-led clinics increase support and education for patients (Rowlinson, 1999), improve compliance with medication (Nyatanga, 1997) and promote self management (Robinson et al, 2003). The service was developed to include three outpatient clinics each week, reviewing nine patients – normally seven follow-up patients and two with exacerbating disease.

During the review patients are educated around coping mechanisms, pregnancy, lifestyle choices, holiday and travel, smoking cessation, nutritional status, compliance with medication, colorectal cancer and osteoporosis awareness.

Patients with exacerbating disease are assessed holistically and clinical examination undertaken. Medication is then prescribed under the supplementary prescribing guidelines (DH, 2003).

**Telephone clinics**

A telephone clinic was established twice monthly to review patients with quiescent disease. It was set up in response to concerns raised by the gastroenterology team regarding the care of patients discharged to primary care, and patients who identified that attending hospital appointments when well was unsatisfactory, as they had to take time off work, arrange childcare and face long waits in clinic. These outcomes were also identified by Miller et al (2002).

Colorectal cancer surveillance is recommended in patients with IBD, who are considered to have an increased risk of developing colorectal cancer. This is considered in the telephone review and, with the patient’s agreement, a colonoscopy is requested in accordance with British Society of Gastroenterology guidelines (Carter et al, 2004). The frequency of this test is determined by the length of diagnosis, for

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example patients with ulcerative colitis affecting the whole colon would have a colonoscopy every nine years in the first decade, every five years in the second decade and annually thereafter.

Compliance with medication is also assessed in the telephone clinic review. For follow-up appointments patients are given the choice to attend an outpatient clinic or to have a further telephone clinic review. The telephone clinic is supported with the telephone helpline, enabling rapid review if necessary.

**Immunosuppression therapy**

An increasing part of the role of an IBD nurse is the coordination of immunosuppression therapy (Buckton, 2003). Approximately 20% of patients receiving immunosuppression therapy experience side-effects (Carter et al, 2004). Gastrointestinal disturbances, hepatitis, renal impairment, myalgia and bone marrow suppression are the most common (Forbes, 1997). As a result, careful monitoring is essential.

The IBD nurse assumes responsibility for the coordination of haematological monitoring and counsels and educates patients regarding the rationale for therapy, potential side-effects and necessity of ongoing monitoring. The nurse is also responsible for ensuring safe administration of infliximab or anti-tumour necrosis factor (anti-TNF).

The IBD nurse’s role includes supporting other nurses through education to ensure patients make an informed choice when considering infliximab.

**Inpatient care**

On average six IBD patients are admitted each month. The specialist nurse visits on alternate days, providing expert advice and support. An IBD multidisciplinary team meeting – consisting of gastroenterologists, colorectal surgeons, histopathologists, radiologists, dietitians and nurse specialists – has been established to discuss complicated IBD patients.

**Evaluation of the role**

Measuring the difference an IBD nurse specialist makes is difficult. Evaluation in regard of corporate objectives shows:

- Over the past 12 months the IBD nurse specialist has undertaken 950 follow-up reviews;
- This has freed consultant time to be spent reviewing new patients and helping achieve political targets;
- Improved communication within the team;
- Reduced inpatient stays (mean 24 days prior to changes, 20 days following the nurse-led service).

Focus groups demonstrate that patients feel nurse-led clinics have increased the level of support and education available. Themes that emerged include:

- Feelings of empowerment;
- Self-management;
- Equal partnerships in care.

Patients place a huge value on access to expert advice during periods of exacerbation. The impact of this is a reduction in time spent off work and an impact on their family life and relationships.

From a risk management view, immunosuppression therapy is given in a safe and supportive environment and administered under the same process in both primary and secondary care. Patients are now able to state why therapy was commenced and the potential side-effects of therapy (Figs 1–2). An increase in patients’ awareness of side-effects through a systematic approach to education has seen side-effects detected on average 21 days earlier (mean 24 days prior to changes, 20 days following the nurse-led service).

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**The future**

Nurse specialists in diabetes, coronary heart disease and asthma have for many years demonstrated their effectiveness. IBD patients have yet to receive this as a standard component of their care. However, the value of the role cannot be underestimated in improving the quality of life for patients with IBD.

**REFERENCES**


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