Inflammatory bowel disease - patient engagement and experience

Inflammatory Bowel Disease (IBD) is a collective name for a number of conditions such as Ulcerative Colitis (UC) and Crohn’s Disease (CD). It produces uncontrolled, chronic inflammation of the intestinal mucosa. IBD is characterised as a chronic illness that is punctuated by disease exacerbation and remission; patients require an individual, multidisciplinary/multimodal approach to care. There is currently no permanent cure for either CD or UC, therefore treatment strategies focus on good symptom control, modification of the disease process and improving quality of life. This article gives an overview of the condition and presents a personal patient experience.

**Key words:**
- Inflammatory bowel disease
- Chronic illness
- Patient engagement
- Self management

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**Challenges in management**

Not surprisingly, chronic disease presents an overwhelming challenge to many patients and their families, which may well span over an individual’s lifetime. It also impacts on health care professionals involved in supporting these long term patients in both hospital and community settings. An individual with IBD will journey through the health care system at different points, from initial investigation and diagnosis, through emergency care/admission, surgery (planned or emergency), post operative care and discharge, being taught to manage associated medical conditions, and finally to follow up care with routine IBD management.

Therefore, no single model of care is appropriate for all patients all the time; care may be delivered in hospital, shared between hospital and primary care, or be supported self-managed care. However, patients with IBD should have access to skilled and knowledgeable professionals who know how it affects lives both physically and emotionally.

Nursing has long been recognised as having a key role to play in helping people manage long-term conditions. Research has shown evidence of improved outcomes in patient care from specialist nurses who provide specialist care and lead the co-ordination of care for individuals affected by IBD. It is well reported that it is often nurses who are more widely favoured by patient as they are able to spend more time with people giving more detailed information in terms of the aetiology of their disease, its management and consequence of treatment modalities. It is also felt that nurses often take a more holistic approach to care delivery.

At present, a great majority of IBD care is provided by health care professionals based in secondary care; however, due to the unpredictability of the condition, aspects of management can be provided in the primary care setting, taking services
closer to the patient21. However, many outside specialist nursing roles such as the school nurse, practice nurse, and community nurse, will at some point interface with individuals affected by UC or CD in the community setting. Therefore, they need to be prepared, and have a greater understanding of the issues that individuals living with IBD have to face throughout their disease trajectory, along with an understanding of the impact this illness has on those around them. Pullen & Julian2 suggest that basic support and information can be provided by non-specialist professionals. Educating the patient to report infection or any adverse reactions to medications promptly, utilising support groups and learning more about their disease process can be helpful to patients and families. **Patient choices** Patients who are well-informed about their illness and how it can be treated, who have a clear understanding of the service being offered to them and who receive support from the IBD team in adapting to the social and psychological impact of IBD, will be able to manage their illness more effectively and have a greater chance of achieving a better quality of life within the constraints of their illness12,13. Thus, all health care professional involved in the care of patient with IBD should be aware of the impact of such an unpredictable illness, and support the patient in order to improve concordance. Patients with UC are five-times more likely to relapse if they fail to take their 5-ASA therapy14 (medication); those who require hospitalisation owing to relapse and subsequent treatment of disease complications cost the NHS 20 times more than patients in remission15. Patient information has long been seen as a key component in patient self management ideologies16 and has continued to be the foundation for many chronic disease management programmes since. A patient perspective is outlined in Box 1.

Box 1: Living with IBD; the patient experience

My name is Vanessa Denvir; I am 42 years old and single. I’m an artist, primarily working with ceramics and glass; some of my work reflecting patient experience is on exhibition at the Manchester Royal Infirmary (MRI). I am also a volunteer with the Colostomy Association and Crohns and Colitis UK.

I enjoy cycling, swimming and love to travel whenever I get the opportunity. Travelling requires a little preparation: finding adequate insurance, carrying a medical certificate from my doctor or ostomy charity (available in multiple languages) while passing through security and customs and packing at least a third more accessories than days I’ll be away. The World Alliance programme ensures that stoma products can be forwarded worldwide to the ostomy traveller in emergency circumstances such as lost or stolen luggage. For longer trips abroad it’s always worthwhile contacting the airline as additional luggage allowance may be offered to assist with medical needs.

I was progressively unwell from 24 to 34 years of age through a combination of misdiagnosis and repeat investigative referrals. Crohn’s Disease was confirmed in November 2004. Annually 10,000 people in the UK are diagnosed with IBD and up to 50 per cent require surgical intervention at some point. I should acknowledge my circumstances were very unique, and as a result of a repeat abscessing fistula, rectal cancer was diagnosed in April 2005. I required major surgery to remove my rectum, a metre of my lower bowel and to site a colostomy that functions like an ileostomy. From diagnosis to discharge and beyond, colorectal, stoma and ward nursing teams were empathetic and supportive. I was fully informed about the procedure, what to expect life to be like post-surgery, and had several visits from the stoma nurse once I’d returned home. Despite all of this, my initial experience of caring for and living with my situation were, to say the least, tearful. My stoma is permanent, and like all new patients, it took time until I became accustomed to my new altered body image and bowel function; milestones and familiarity were reached at three, six and twelve month periods.

I reached out for additional support to the Colostomy (CA) and Ileostomy (IA) Associations where I could meet and share with others, in similar circumstances, learning that life doesn’t have to stop just because I wear a bag. CA and IA are independent charities offering support and reassurance to ostomates, their families and carers. Embracing my new life, I now support others by volunteering at open days, on telephone help lines or visiting new ostomates in hospital. My Crohn’s Disease has returned twice since surgery, but with steroid and immunosuppressant medications prescribed to manage it, I can continue with my creative and voluntary roles.

I am open about having a stoma: working with medical companies sampling new products for the ostomy market, appearing on the ‘Embrassing Bodies’ series helping to dispel the myths about living with a stoma and, proving you can still be gorgeous after stoma surgery, modelling beautiful ostomy lingerie and swimwear around the UK.

I recognise the role of the community nurse is a challenging one and encouragingly, at a recent JCN Nursing event, so many nurses and students wanted to know more about how they could support their patients. Knowledge of what the charities offer aids patients in their awareness and management of their circumstances and in turn supports nursing teams with their daily workload. As cancer was a word whispered in hushed tones twenty years ago, I am hopeful that stoma awareness and conversation can be had without society’s revulsion with our very daily practice of bowel function.

Vanessa Denvir. February 2013
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Conclusion
Chronic illness has a huge affect on all aspects of life for individuals living with and affected by IBD. Patients experience both distressing physical symptoms, interruptions to everyday activities including education, work and social life and the psychological effects on life that an unpredictable disease brings. IBD patients will be faced with a number of difficult treatment decisions throughout their illness; such treatments will cause significant long term consequences to an individual’s health and well-being as well as living with the expected effect of IBD itself.

As nurses we should be empowering patients to take an active role in the decision making process during all stages of their journey through the health care system and encourage them to communicate clearly with all health care professionals. Self management is important; patients are encouraged to take responsibility for managing their illness so they are in a stronger position to deal with relapses and enjoy the periods of remission. Education regarding disease management and self help strategies are paramount to improve concordance and achieving optimal outcomes.

References
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