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flexibility

**reflective
enthusiasm**

Roles descriptives for inflammatory bowel disease nurse specialists

RCN guidance

approachability

sensitivity



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Disclaimer

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Roles descriptives for inflammatory bowel disease nurse specialists

RCN guidance

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Foreword

The RCN Gastroenterology and Stoma Care Nursing Forum has been well established for many years, and the Crohn's and Colitis special interest group (SIG) has been a sub-section of this group since 2005. The SIG's overall purpose is to provide a forum for nurses with a special interest in Inflammatory Bowel Disease (IBD). One of its core aims was to define and publish competencies for practice for the specialist IBD nurse role.

A steering committee was established from the Crohn's and Colitis SIG. The group reviewed available literature, and met to develop a consensus document describing the role and skills required of IBD nurse specialists. The framework for the document was adapted from the RCN publication *Caring for people with colorectal problems* (2002).

This document should be used to guide the development of best practice and the creation of specialist nurse roles within local organisations. The descriptors are divided into two sections: the first part reflects generic qualities of nurses in the specialty; and the second part recognises the specialist skills needed to deliver an IBD nurse service. It is envisaged that nurses may offer all or part of the services listed, and should adapt these descriptors for their local needs and in line with the professional experience of the post holder.

Our guidance is based on the experiences of IBD, gastroenterology and colorectal nurse specialists and nurse endoscopists working in the inflammatory bowel disease specialty. The experiences are supported by an extensive literature review.

Cath Stansfield
Steering Group Chair

Introduction

Inflammatory bowel disease is used to describe ulcerative colitis (UC) and Crohn's disease (CD). It affects 1 in 400 people in the UK (NACC, 2004).

Both are chronic disorders characterised by inflammation and ulceration in various sections of the digestive tract. Common symptoms include diarrhoea (often bloody and urgent), abdominal pain, fever, tiredness and loss of weight.

Presentation of inflammatory bowel diseases

Ulcerative colitis and Crohn's disease affect all age groups and can start at any age. The highest number of new cases occurs in young people aged between 15 and 45.

Both UC and CD run a largely unpredictable relapsing and remitting course. A few patients experience chronic active symptoms despite being on various medications.

IBD may take many years to diagnose because the symptoms often resemble other conditions, such as gastrointestinal (GI) infections and irritable bowel syndrome.

Causes of IBD

The origin of IBD remains uncertain. A number of genetic and environmental influences have been considered as causes in the development and persistence of IBD. An emerging theory has been an imbalance of the inflammatory processes of the gut probably triggered by the normal intestinal flora. Other theories have looked at environmental influences such as a highly refined diet, stress and smoking. The measles virus and an atypical mycobacterium organism have also been examined, but as yet they remain unproven.

Ulcerative colitis

The inflammation in UC affects the superficial layer (the mucosa) of the large intestine (colon) only. It almost always involves the rectum and extends in continuity along the colon with a clear demarcation line between normal and inflamed tissue at its limit. In a small percentage of patients, the whole of the large bowel is involved. The most common age group for UC to be diagnosed in is 15 to 45-year-olds. There is a second peak in the 55 to 70-year-old age group. Up to 400 people per 100,000 in the UK suffer from ulcerative colitis.

Crohn's disease

Unlike UC, CD can affect any part of the GI tract, and the inflammation extends into deeper layers of the intestinal wall (Forbes, 2001). The disease most commonly affects just the small intestine (40%), although both the small and large intestine (ileo-colonic) (30%) or colon alone (30%) can be affected.

Crohn's disease affects up to 150 people per 100,000, and is most commonly diagnosed in the 15 to 45-year-old age group. Recent statistics appear to indicate a rise in the number of new cases, but it is not clear why this may be (Carter et al, 2004).

About 15 to 20 per cent of people with Crohn's disease have a close relative with some form of IBD, which suggests an inherited predisposition in these patients.

Complications of IBD

In cases where diarrhoea is prolonged, or bloody and severe, water loss and poor absorption of nutrients may occur. This leads to anaemia, dehydration and severe weight loss.

The inflammation in CD may result in strictures (narrowing) of the bowel leading to abdominal

pain. Severe cases may lead to life-threatening complications such as blockage or perforation of the bowel, and there is a definite link between IBD and an increased risk of developing colorectal cancer.

The risk of colorectal cancer increases with the extent and severity of the disease, the age of onset and duration of the disease. For patients suffering from ulcerative colitis, recent trials have shown the risk of colorectal cancer at 10, 20 and 30 years after the onset of the disease is 2, 8 and 18 per cent higher (respectively) than the incidence seen in the general population. Regular maintenance with aminosalicylates and colonic surveillance at defined intervals that looks for signs of dysplasia (pre-cancerous cell changes) can minimise the risk.

Surgery is also a common treatment option that is usually used when medical therapy has failed. In the case of Crohn's disease it is used to deal with complications due to infection such as abscesses and fistulae, or obstruction due to strictures. Surgery for Crohn's disease is typically undertaken with caution because of the high recurrence rates. In UC surgery is considered a cure because the whole colon is removed, which generally eliminates any future risk of colorectal cancer.

Managing and treating IBD

There is currently no permanent cure for either UC or CD. Therefore, the treatment goal is to control symptoms, modify the disease process and improve quality of life. This is largely achieved by medications that reduce the inflammation and suppress the body's immune response. Common medications used include aminosalicylates, corticosteroids, immunosuppressant therapy (azathioprine, mercaptopurine), methotrexate and anti-TNF. Additional lifestyle adaptations are often necessary in order to prolong remission, including dietary manipulation and avoidance of foods found to provoke symptoms. Other factors include stress management, avoidance of non-steroidal anti-inflammatory medications (NSAIDs), avoidance of GI infections and generally keeping fit.

Patients often require support and education in explaining the rationale for medical management. This promotes compliance with the medication regime, and increases the early detection of side effects.

1

The role of the IBD nurse specialist

Defining the role of the IBD nurse specialist is difficult because of the evolving nature of the specialty. In the UK, IBD nursing developed in the mid 1990s because it was recognised that local health care services did not meet the needs of patients with IBD (Phillips, 1995). The role has since been defined as essential to the provision of expert clinical care and education for both patients and health care professionals. It is also fundamental to undertaking research to evaluate the effectiveness of the role and the experience of patients with the condition, as well as having a role in consultancy and service development (Nightingale et al, 2000). The implementation of the role has varied, depending on local need, the health care trust and the individual nurse's expertise and experience.

Preparation for specialist practice continues to vary in the UK, and more recently the development of advance nurse practice roles has caused even further confusion. The separation of the roles is difficult due to the lack of clarity surrounding the definition of an advanced nurse practitioner and clinical nurse specialist. Both roles are considered to offer expert clinical advice and higher levels of clinical decision-making. They also evaluate practice, provide education and undertake research (NMC, 2005; ICN, 2003; RCN, 2005).

A recent systematic review highlighted the need for a full formal evaluation of the role of the IBD nurse specialist (McClaren et al, 2006). However, recent audits have shown that the role is cost effective and of great value to the gastroenterology team (Nightingale et al, 2000; Pearson, 2005).

Defining the role

The IBD nurse specialist is a relatively new development in gastroenterology. As a result the role encompasses a wide range of clinical areas,

and the implementation of the role varies according to local needs.

The following section gives an outline for developing new roles and the scope of practice of the IBD nurse specialist.

Developing new roles

When establishing IBD nurse specialist services the organisation should take into account local need and variation. The following issues should be considered (ENRiP, 1999):

- ◆ duration of the post and funding
- ◆ preparation for the post holder
- ◆ trust-wide agreement and support for the post holder
- ◆ publicity and explanation of the post
- ◆ building effective relationships within the team
- ◆ regular review of job description, workload, working hours, cover for sickness and leave
- ◆ assuring public safety, performance review, protocols, guidelines, professional regulation, accountability, boundaries and competencies
- ◆ remuneration and resource allocation i.e. equipment, administration, clerical support, educational plans and career development
- ◆ evaluation of the post
- ◆ future planning and role review.

Areas of practice

Specialist nurses working with patients with inflammatory bowel disease may work in a number of settings (Younge, 2003). For example:

- ◆ outpatients
- ◆ ward areas – both medical and surgical
- ◆ primary care clinics
- ◆ endoscopy.

Nursing titles

A number of job titles are used to describe the role of nurses working at a specialist level in IBD, which reflects the variety of settings where specialist nurses are based. These included:

- ◆ IBD nurse specialist
- ◆ gastroenterology clinical nurse specialist
- ◆ colorectal nurse specialist
- ◆ nurse endoscopist.

More recently the specialty has seen the development of nurse consultant and advanced nurse practitioner roles. Each of these roles has been developed in response to local health care needs.

This document refers to IBD nurse specialists, but recognises that the nurse may have other responsibilities in the role.

- ◆ providing nutritional support
- ◆ providing education and counselling
- ◆ developing and defining IBD services
- ◆ liaising with the multidisciplinary team involved in the care of patients with IBD
- ◆ undertaking endoscopy
- ◆ co-ordinating colorectal cancer surveillance for IBD patients.

Some specialist nurses working in IBD may have more than one area of responsibility. Therefore, the nurse may not adopt all of the services listed, or they may take on a more supporting role.

Scope of practice of the IBD nurse specialist

The key components of specialist practice are considered to be the provision of expert clinical care, education, research, and consultancy and service management (Porret and Daniel, 1999). These parameters are general to IBD specialist practice. More specifically, the role is seen to be pivotal in improving disease management, compliance and patient satisfaction (Nightingale, 2000). The remit of the role may include:

- ◆ telephone advice line
- ◆ follow-up clinics
- ◆ rapid access clinics
- ◆ in-patient support
- ◆ managing an immunosuppression service
- ◆ administration and monitoring of anti-TNF therapy

2

Attributes and belief systems of the IBD nurse specialist

Personal attributes

The challenging nature of IBD requires nurses to have a wide range of personal attributes. Castledine (1998) suggests that specialist nurses should have:

- ◆ motivation and enthusiasm
- ◆ sensitivity to patients needs
- ◆ assertiveness
- ◆ approachability
- ◆ flexibility
- ◆ self-awareness
- ◆ excellent interpersonal skills
- ◆ common sense
- ◆ cultural awareness
- ◆ reflective practice
- ◆ openness to criticism
- ◆ a good sense of humour
- ◆ confidence
- ◆ resilience.

Personal beliefs

In addition, the nurse should possess the following belief systems as central to the delivery of care to patients with IBD. The nurse should:

- ◆ promote and provide holistic care for patients with IBD
- ◆ recognise the importance of health promotion
- ◆ possess a high level of interpersonal skills
- ◆ develop and promote positive attitudes towards IBD and the stigmas around bowel care
- ◆ work as an advocate
- ◆ respect culture and diversity
- ◆ work as an innovator and change agent within the specialty of IBD
- ◆ aim to improve the quality of care for patients with IBD
- ◆ act as an expert role model for health care professional
- ◆ work in a complementary role to medical colleagues and other members of the multidisciplinary team.

3

Core descriptors

The NHS Knowledge and Skills Framework (NHS KSF) defines and describes the knowledge and skills which NHS staff need to apply in their work in order to deliver quality services. It provides a single, consistent, comprehensive and explicit framework on which to base review and development for all staff. The NHS KSF and its associated development review process lie at the heart of the career and pay progression strand of Agenda for Change (DH, 2004),

Preparation for practice and continuing professional development

Below we describe the relevant knowledge and skills framework references.

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- ✓ Core 2: personal and people development

The specialist nurse must be able to demonstrate the following:

- ◆ preparation for practice – essential qualifications:
 - possess or is working towards a relevant degree
 - evidence of relevant degree level education e.g. R36 IBD nursing
- ◆ preparation for practice – desirable qualifications:
 - possess a teaching qualification
 - relevant extended role qualifications e.g. nurse prescribing, endoscopy
- ◆ demonstrate evidence of continuing professional development (CPD) through a portfolio of evidence
- ◆ assume responsibility for setting and achieving own CPD needs

- ◆ set own professional boundaries within the scope of professional practice (NMC, 2002)
- ◆ provide evidence-based care through critical appraisal of current research and literature
- ◆ ability to demonstrate a high level of leadership skills
- ◆ participate in giving and receiving clinical supervision.
- ◆ develop personal objectives in line with national and local guidelines
- ◆ take an active part in education and development programmes of other health care professionals
- ◆ network at national and local level with other IBD nurses through regional groups and conferences
- ◆ attendance at one relevant conference per year e.g. British Society of Gastroenterology (BSG), Royal College of Nursing Forum.

Specialist knowledge

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- ✓ Core 2: personal and people development

The IBD nurse specialist should possess the following:

- ◆ in-depth knowledge of the gastrointestinal tract in health and disease
- ◆ an understanding of the aetiology and pathogenesis of IBD and associated conditions
- ◆ an understanding of the relevant pharmacology related to the drugs used in IBD
- ◆ in-depth knowledge of medical and surgical treatment options in IBD
- ◆ in-depth knowledge of nutrition and its role in IBD as a treatment and to provide supplementation
- ◆ ability to use knowledge to formulate and negotiate treatment plans with patients
- ◆ ability to draw on knowledge and attempt to resolve complex issues with patients e.g.

sexuality, pregnancy, altered body image, financial issues and employment

- ◆ an insight and experience of the effect of chronic illness on the individual with IBD e.g. loss of independence, loss of control, compliance and uncertainty and also the effect on family members and carers
- ◆ knowledge of extra intestinal manifestations and their management
- ◆ ability to make complex decisions (including timely referral) where patients do not follow conventional approaches to care
- ◆ ability to recognise and develop opportunities to expand practice while acknowledging own limitations.

Service development

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- ✓ Core 4: service improvement
- ✓ Core 5: quality
- ✓ G2: development and innovation
- ✓ HWB4: enablement to address health and wellbeing needs
- ✓ HWB5: provision of care to meet health and wellbeing needs,
- ✓ HWB7: interventions and treatments
- ◆ provide care for patients in an holistic framework, reflecting individuals' needs
- ◆ assess, plan and implement care programmes based on local organisational objectives, national guidelines and contemporary evidence
- ◆ ensure safe delivery of disease-modifying antirheumatic Drugs (DMARD's) and anti-TNF therapy
- ◆ provide patients with information and education to empower them to be active in the decision-making process
- ◆ adopt extended roles to contribute to enhancing the patients journey, i.e. nurse prescribing
- ◆ promote supported self-management of patients to increase compliance with medication and choice in long-term management

- ◆ undertake onward referral to other health care professionals as required
- ◆ work in a co-ordinating capacity in the multidisciplinary team, acting as the patient's advocate
- ◆ provide a telephone advice line for IBD patients
- ◆ provide rapid access clinics for patients with exacerbating IBD and those experiencing problems coping with IBD
- ◆ ability to prioritise service provision.

Management and leadership

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- ✓ Core 4: service improvement
- ✓ Core 5: quality
- ✓ G5: services and project management
- ◆ work as an autonomous practitioner
- ◆ manage own workload efficiently
- ◆ identify limitations which may affect the service, i.e. capacity and demand
- ◆ work in a clinical governance framework, ensuring safe and equitable care for all
- ◆ develop services to meet needs within resource restrictions
- ◆ have a clear vision of how an IBD nursing service should function in the local health care economy
- ◆ demonstrate a clear audit trail to evaluate service effectiveness
- ◆ co-ordinate and organise the multidisciplinary team for IBD
- ◆ act as a resource for expert advice within the IBD service across the local health economy
- ◆ identify service needs and actively participate in influencing service developments
- ◆ assume responsibility for nurse-led clinics and telephone helpline

- ◆ liaise with outside agencies to seek actively the opinions of service users e.g. NACC, patient panels
- ◆ be responsible for the production and review of clinical guidelines/protocols/care pathways in conjunction with clinical team
- ◆ implement national and local goals and strategies.

Evidence-based practice

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- ✓ IK2: information collection and analysis
- ◆ review contemporary literature that is relevant to IBD
- ◆ ability to appraise evidence critically
- ◆ evaluate practice using a clear audit trail from both clinical and user perspective
- ◆ consider the cost-effectiveness of implementing new practices based on the latest evidence
- ◆ participate in and undertakes own research
- ◆ publish best practice findings
- ◆ actively conduct and participate in audit, and disseminate best practice findings.

Education

KSF

- ✓ Core 2: personal and people development
- ✓ Core 5: quality
- ✓ HWB1: promotion of health and wellbeing and prevention of adverse effects on health and wellbeing
- ✓ HWB4: enablement to address health and wellbeing needs

National Association for Colitis and Crohn's Disease

- ◆ educate patients and carers about IBD e.g. provide written information about the National Association for Colitis and Crohn's Disease (NACC) and their literature, and other material such as information provided by pharmaceutical companies
- ◆ develop and deliver education programmes for IBD patients
- ◆ support the development of expert patient IBD programmes
- ◆ educate other health care professionals in primary and secondary care, on a one-to-one basis and formally in groups about IBD
- ◆ disseminate evidence-based practice locally and nationally
- ◆ support higher education institutions in the delivery of education programmes about IBD
- ◆ provide clinical leadership for other nurses
- ◆ provide problem-solving strategies and advice to other health care professionals about IBD-related issues.

4

Specialist descriptors

Introduction

The section outlines the descriptors for each aspect of an IBD service that the nurse specialist provides. On an individual basis, nurses should use their own expert knowledge to develop skills in their own areas of practice. This should take into account local need, patient numbers and individual practitioner preferences and organisational structures. However, we have found that not all IBD nurse specialists offer all of the services outlined below.

Examples of protocols, guidelines and patient information to support IBD services can be found on the Crohn's and Colitis Specialist Interest Group website (www.ibdnurses.com).

Medications

Immunosuppression therapy

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- ✓ HWB2: assessment and care planning to meet health and wellbeing needs
- ✓ HWB3: protection of health and wellbeing
- ✓ HWB5: provision of care to meet health and wellbeing needs
- ✓ HWB7: interventions and treatments

The following descriptors apply to nurses who have a responsibility for ensuring the safe administration of immunosuppression therapy such as azathioprine, mercaptopurine and methotrexate:

- ◆ knowledge and understanding of the pharmacology of the drugs involved in immunosuppression therapy for IBD

- ◆ knowledge and understanding of the side effects of immunosuppression therapy and their management
- ◆ ability to provide written and verbal explanations of the role of immunosuppression therapy to IBD patients to encourage informed consent
- ◆ obtain written consent to treatment
- ◆ provide pre-administration counselling to patients who may require immunosuppressant therapy
- ◆ develop protocols and guidelines to ensure a standardised approach to immunosuppression therapy by the gastroenterology team
- ◆ administer immunosuppression therapy within the NMC guidelines (2006) for the safe administration of medication
- ◆ develop local policy for the administration of immunosuppression therapy
- ◆ administer methotrexate in line with guidelines for the administration of cytotoxic medication
- ◆ ensure that shared care agreements are in place for patients requiring immunosuppressant therapy that have clear actions to take in the event of side effects or abnormalities on blood test monitoring
- ◆ ensure that strategies are in place for monitoring patients receiving immunosuppression therapy where shared care agreements are not in place
- ◆ report adverse events in line with National Prescribing Centres guidelines (NPC, 2004).

Biological therapy

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- ✓ HWB2: assessment and care planning to meet health and wellbeing needs
- ✓ HWB3: protection of health and wellbeing
- ✓ HWB5: provision of care to meet health and wellbeing needs
- ✓ HWB7: interventions and treatments

The following descriptors relate to nurses who have a responsibility for ensuring the safe administration of anti-TNF therapy to IBD patients:

- ◆ knowledge and understanding of the pharmacology of anti-TNF therapy
- ◆ knowledge and understanding of the side effects of anti-TNF therapy
- ◆ ability to provide written and verbal explanations of the role of anti-TNF therapy to encourage informed consent
- ◆ obtain written consent from patients receiving anti-TNF
- ◆ provide counselling to patients prior to receiving anti-TNF therapy
- ◆ develop protocols/guidelines/care pathways to ensure a standardised and safe approach to anti-TNF therapy by the gastroenterology team
- ◆ demonstrate a clear audit trail to demonstrate effectiveness and safety of practice
- ◆ administer anti-TNF therapy within the NMC guidelines (2006) for the safe administration of medication
- ◆ consider NICE guidelines as a framework for the administration of anti-TNF (NICE, 2000)
- ◆ provide support and education for staff involved in the administration of biological therapy
- ◆ report adverse events
- ◆ ensure effective channels of communication with the primary care team about the management of the drug therapy.

Nutrition

KSF

- ✓ HWB2: assessment and care planning to meet health and wellbeing needs

Nutrition is central to the care of the patients with IBD (Carter et al, 2004). Therefore, the IBD nurse specialist must be able to demonstrate:

- ◆ knowledge and understanding of the role of nutrition in the management of IBD patients e.g. enteral and parenteral nutrition, osteoporosis prevention, and exclusion diets

- ◆ knowledge and understanding of the range of products available
- ◆ knowledge and understanding of nutrition as both a primary and supportive treatment of Crohn's disease
- ◆ knowledge and understanding of the role of nutrition in patients requiring dietary supplements or both Crohn's disease and ulcerative colitis
- ◆ ability to identify patients who are at risk of having a poor nutritional status through taking a history and screening, and refer to a dietician for further support and guidance.

Also:

- ◆ develop close links with specialist dietician
- ◆ assess and evaluate the effectiveness of nutritional interventions
- ◆ consider NICE guidelines for nutrition in the management of IBD patients (NICE, 2006).

Disease management

Management of patients with a new diagnosis of IBD

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- ✓ HWB1: promotion of health and wellbeing and prevention of adverse effects on health and wellbeing
- ✓ HWB2: assessment and care planning to meet health and wellbeing needs
- ✓ HWB3: protection of health and wellbeing
- ✓ HWB4: enablement to address health and wellbeing needs
- ✓ HWB6: assessment and treatment planning

An IBD nurse specialist working with patients who have been newly-diagnosed with IBD must be able to demonstrate:

- ◆ ability to interpret endoscopy, histology, pathology and radiology findings and understand their significance in the management of IBD

- ◆ ability to communicate results of investigations to patients in a manner appropriate to their needs and level of understanding
- ◆ ability to provide a wide range of written information and suggestions of other sources of information to patients about IBD according to their needs and level of understanding
- ◆ ability to request further investigations under agreed protocols and guidelines according to assessment findings
- ◆ active participation in health promotion for patients in written and verbal formats regarding issues such as osteoporosis, smoking, compliance, fertility and pregnancy
- ◆ develop treatment plans in conjunction with patients based on current expert clinical practice or latest evidence
- ◆ ability to counsel and educate patients on individual management plans.

Also:

- ◆ promote the importance of compliance and self-management in patients with IBD
- ◆ arrange appropriate follow up for IBD patients
- ◆ provide a supportive and proactive service with rapid access clinics and telephone helpline
- ◆ foster a culture of support for IBD patients that helps them move towards independence
- ◆ educate patients on signs and symptoms of IBD and its management.

Management of the patient requiring long term follow-up

KSF

- ✓ HWB1: promotion of health and wellbeing and prevention of adverse effects on health and wellbeing
- ✓ HWB2: assessment and care planning to meet health and wellbeing needs
- ✓ HWB3: protection of health and wellbeing
- ◆ actively participate in the development of services that are efficient, effective and

responsive to patients' needs and other service users

- ◆ offer education and advice on treatment options to patients in order to improve understanding and to empower them to manage their condition more confidently and effectively
- ◆ actively undertake health promotion for patients in written and verbal formats regarding osteoporosis, smoking, compliance, fertility and pregnancy
- ◆ consider alternative means of efficient follow-up to make best use of available resources e.g. telephone clinics (Miller, 2002)
- ◆ offer advice to primary care staff
- ◆ develop strong and effective communication links with primary care
- ◆ develop relationships with external self-help groups and charitable organisations e.g. NACC and ia - the Ileostomy and Internal Pouch Support Group
- ◆ provide and review treatment plans in conjunction with the patients and health care professionals
- ◆ monitor clinical activity by regular audits of practice.

Colorectal cancer screening

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- ✓ HWB3: protection of health and wellbeing
- ◆ ensure that systems are in place for providing colorectal cancer screening in ulcerative colitis in line with BSG guidelines (Carter et al, 2004)
- ◆ advise and counsel patients on the role and necessity for colorectal cancer screening
- ◆ audit practice against national guidelines.

Management of patients with exacerbating disease

KSF

- ✓ HWB2: assessment and care planning to meet health and wellbeing needs
- ✓ HWB3: protection of health and wellbeing
- ✓ HWB4: enablement to address health and wellbeing needs
- ✓ HWB6: assessment and treatment planning
- ◆ educate patients on the signs and symptoms of exacerbating disease
- ◆ develop self-management strategies for patients with mild to moderate flare ups
- ◆ provide telephone advice and support to promote a proactive service
- ◆ provide rapid access clinics to facilitate early review with multidisciplinary support
- ◆ ability to undertake comprehensive nursing assessment
- ◆ ability to undertake clinical examinations (or arrange for this to happen)
- ◆ administer or prescribe medication appropriate to the needs of the patient
- ◆ develop treatment plans in conjunction with patients and other members of the health care team
- ◆ provide further follow up for patients in conjunction with members of the gastroenterology team in order to underpin practice
- ◆ provide support for inpatients and ward nurses caring for IBD patients
- ◆ educate and support the health care team in the management of patients with a flare-up
- ◆ encourage the development of a systematic evidence-based approach to care
- ◆ demonstrate a clear audit trail of outcomes.

Adolescent transition clinics

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- ✓ HWB3: protection of health and wellbeing
- ◆ experience of caring for adolescents with IBD
- ◆ develop a planned and structured *transitional service* in line with the NACC guidelines for transitional care (NACC, 2005)
- ◆ establish effective channels of communication between paediatric and adult gastroenterology services
- ◆ establish effective channels of communication between primary and secondary care
- ◆ establish good relationships between the patient and the multidisciplinary team
- ◆ ability to compromise with adolescents considering the struggle between the transitions into adulthood and living with a diagnosis of IBD
- ◆ raise awareness of IBD in the community e.g. information about medication and treatment for schools and prospective employers.

5

The next steps

This document has gone some way to describe the role of the IBD nurse specialist. The RCN Crohn's and Colitis Special Interest Group for nurses recognises the need for further development work around competencies and standards for practice.

The next stage of the project aims to develop competencies for specialist nurses' practice by examining the skills and knowledge necessary for safe and effective practice. We expect the competencies to be available to practitioners over the next two years.

6

References

- Carter MJ et al (2004) Guidelines for the management of IBD in adults, *Gut*, 53: V1-16.
- Castledine G (1998) *Advanced and specialist nursing practice*, Oxford: Blackwell Publishing.
- Department of Health (2004) *The NHS knowledge and skills framework (NHS KSF) and the department review process*. DH: London.
- ENRiP (1999) *Developing new roles in practice: an evidence-based guide*, Sheffield: School of Health and Related Research, University of Sheffield.
- Forbes A (2001) *Clinicians guide to inflammatory bowel disease*, London: Hodder Arnold.
- International Council of Nurses (2003) *Definition and characteristics of the role*, Geneva: ICN.
- Miller L et al (2002) Telephone clinic improves quality of follow-up care for chronic bowel disease, *Nursing Times*, 30 (98), pp.36-38.
- National Institute for Health and Clinical Excellence (2002) *TA40 Crohn's disease - infliximab: information for the public*, London: NICE.
- National Institute for Health and Clinical Excellence (2006) *CG32 Nutrition support in adults*, London: NICE.
- Nightingale AJ, Middleton W, Middleton SJ and Hunter JO (2000) Evaluation of the effectiveness of a specialist nurse in inflammatory bowel disease, *European Journal of Gastroenterology*, 12 (9), pp.967-973.
- National Prescribing Centre (2004) *Maintaining competency in prescribing – an outline framework to help allied health professional supplementary prescribers*, Liverpool: NPC.
- Nursing and Midwifery Council (2005) *A higher level of practice – a final report*, London: NMC.
- Nursing and Midwifery Council (2006) *Standards for prescribing medication – a final report*, London: NMC.
- Nursing and Midwifery Council (2004) *The NMC Code of professional conduct: standards for conduct, performance and ethics*, London: NMC.
- Pearson C (2005) A nurse led IBD service in a district general hospital, *Gastrointestinal Nursing*, 3 (1), pp.33-39.
- Phillips S (1995) Gut Reaction, *Nursing Times*, 91 (1), pp.44-45.
- Porret T and Daniel M (1999) *Essential coloproctology for nurses*, Chichester: John Wiley & Sons (formerly Whurr Publishing).
- Royal College of Nursing (2005) *Maxi nurses. Advanced and specialist nursing roles*, London: RCN. Available online at www.rcn.org.uk/publications
- Royal College of Nursing (2002) *Caring for people with colorectal problems. Report of the RCN/Coloplast competencies project*, London: RCN. Available online at www.rcn.org.uk/publications
- Younge L (2003) Following the form, *Gastrointestinal Nursing*, 1 (8), pp.12-13.

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Appendices

Appendix 1: Courses

The following educational institutions offer degree and masters-level education for nurses in IBD.

Burdett Institute of Gastrointestinal Nursing

St Mark's Hospital
Watford Road, Harrow
Middlesex HA1 3UJ
Tel 020 8869 5429

www.burdettinstitute.org.uk

Level 3 - IBD Nursing
Level 4 - Advancing IBD Practice

University of Bradford

Bradford
West Yorkshire BD7 1DP
Tel 01274 232323

www.bradford.ac.uk

Level 3 – Caring for individuals with inflammatory bowel disease (IBD)

Appendix 2: Further reading and resources

British Society of Gastroenterology

www.bsg.org.uk

Carter MJ et al (2004) Guidelines for the management of inflammatory bowel disease in adults, *Gut*, 53: V1-16.

British Society of Gastroenterology (2006) *Care of patients with gastrointestinal disorders in the United Kingdom. A strategy for the future*, London: BSG.

CORE (The Digestive Disorders Foundation)

www.digestivedisorders.org.uk

Crohn's & Colitis Foundation of America

www.ccfa.org

ia – the Ileostomy and Internal Pouch Support Group

www.the-ia.org.uk

National Association for Colitis and Crohn's Disease

www.nacc.org.uk

Royal College of Nursing

www.rcn.org.uk

Royal College of Nursing (2006) *Telephone advice lines for people with long-term conditions. Guidance for nursing practitioners*. London: RCN. Publication code 003 033.

Royal College of Nursing (2004) *Administering subcutaneous methotrexate for inflammatory arthritis: RCN guidance for nurses*, London: RCN.

The RCN Crohn's and Colitis Special Interest Group

www.ibdnurses.com/home



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motivation

resilience
openness