Colorectal Cancer

Edited by **Elaine Swan** BN(HONS), RGN, RM

Advanced Nurse Practitioner: Colorectal,
Manor Hospital, Walsall

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Preface

Colorectal Cancer covers all aspects of this subject that will benefit the nurse when caring for this group of patients.

Chapter 1 deals with the developing role of the colorectal nurse specialist to include professional accountability, managing change, assessing health care needs, specialist nurse/practitioner debate, specialist nursing practice and how this has evolved and changed over recent years. Chapter 2 explains the aetiology of colorectal cancer, how genes function, and the cancer/polyp multistep theory of colorectal carcinogenesis. Chapter 3 is concerned with epidemiology and genetics to include incidence of colorectal cancer, who is at increased risk, and the role of the clinical geneticist. Chapter 4 describes the diagnosis and investigations. Chapter 5 deals with treatment, surgery, mortality and follow-up. Chapter 6 is concerned with the consequences of rectal surgery, covering patient choice, informed consent, body image and sexuality. Chapter 7 relates to chemotherapy and radiotherapy and the oncology team. Finally, Chapter 8 is devoted to palliative care nursing and the support that can be offered to patients in the final stages of illness.

The aim of this book is to explain colorectal cancer to nurses in order to allow them to follow the patient's journey through diagnosis, treatment and aftercare. Bowels are a very sensitive area for many people to discuss, and the approach of the nurse within the multi-disciplinary team is all-important.

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> It does not matter how much or how little we achieve. If we don't jump for joy about it, we don't feel the emotional mileage.
>
> Astarius Reik-Om

Thank you to Sylvia, my secretary, without whose help I would not have been able to compile this book. Also many thanks to Maiya who gave me the strength and confidence to continue my work.

> Success is a journey, not a destination.
>
> Milton Erikson

Chapter 1

The role of the colorectal nurse specialist

Elaine Swan

The role of the clinical nurse specialist (CNS) remains an area of debate. Following the Briggs Report (Department of Health or DoH, 1972) the role of the CNS was introduced with the intention of improving the quality of patient care while also developing the career of senior nurses at existing ward sister level, to encourage them to stay within the clinical field of practice. The introduction of specialist nursing courses by the Joint Board of Clinical Studies, founded in 1970, provided the knowledge base and training for these nurses to develop. There are now a plethora of nurse specialists in all areas of practice with different titles, roles, levels of education and responsibility, and varying grades; this has led to much confusion within the profession and also for the general public.

McGee (1998) describes the specialist role as multidimensional; she says that there are a number of separate elements – care-giver, teacher, researcher, consultant, leader and manager – that can be identified; in reality they overlap and inform one another. She concludes that, although specialist practice should be regarded as a single entity, each practitioner has different strengths and develops the role in a way that suits both them and their employers. It is this freedom, she hypothesizes, that may be the essential ingredient in making such roles successful.

The role of the colorectal nurse specialist has developed and extended considerably. The UKCC document, *The Scope of Professional Practice* (UKCC, 1992), has allowed nurses to expand practice and take on new roles that may combine medical and nursing practice in order to promote a more holistic and effective approach to patient care. Fox (1995) suggested the notion of expansion of practice as acceptable when assisting in creating a comprehensive system of patient care. Collins (1989) noted that this should occur only where there are unmet needs of clients that are identified, or gaps in existing health care.

Professional accountability

As expansion of practice increases the workload, nurses must not compromise the service already established. Although Dyson (1990) felt that nurses would be able to undertake complex and challenging roles, it was highlighted by Autar (1996) that the nurse must be aware of not abdicating professional accountability by inappropriately delegating to others; nurses are legally accountable for their actions or omissions in care delivery (Nursing and Midwifery Council, 2002). A negligent practitioner may be subject to a professional conduct committee and/or local disciplinary proceedings. To cope with these developments and responsibilities in practice, the Nursing and Midwifery Council (NMC) emphasizes that all individual nurses, midwives and health visitors should carefully refer to their own personal experience, education and skill.

Hunt and Wainwright (1994) raise concerns of a professional and legal nature about the UKCC's (1992) document *The Scope of Professional Practice* and the possibilities of nurses developing their role and taking on activities that were previously the domain of other professionals. They highlight the lack of guidance concerning the competency levels of the practitioner and the expertise required to achieve this, leaving these decisions to be decided at an individual and hospital level. The law will judge anyone carrying out a medical procedure in comparison with a reasonable medical practitioner skilled in the procedure (*Bolam* v *Friern Hospital Management Committee,* 1957). By expanding roles, nurses must keep up to date with legal implications and the accountability that they must exercise. Tingle (1993) claimed that nurses must be aware of major areas of the law that relate to their sphere of professional practice, and that ignorance of the law is not acceptable.

For the nurse to develop successfully, a supportive management structure is required. The employer is legally responsible for its employees under vicarious liability. However, should the nurse undertake responsibilities outside the role, the nurse and not the employer is liable and can be sued for damages resulting from alleged negligence. Practitioners should, therefore, belong to an organization such as the Royal College of Nursing, or the Nursing branch of the Medical Defence Union, which have accepted the implications of the developing roles of nurses and can assist if problems arise and offer legal liability insurance to their members. Certainly, with increased autonomy, the nurse would assume greater legal responsibility, although Wright (1995) points out that the law is unclear and in need of clarification.

Managing change

Land et al. (1996) state that health care reform has emphasized that services should be flexible and ordered on the basis of the needs of individuals and client groups. This requires the efficient use of health care personnel and should also demonstrate clear and positive patient outcomes. Since the National Health Service Community Care Act 1990, which led to the separation between purchasing and providing health care, the responsibility of purchasers to assess health needs of their patients has been increasingly emphasized. Purchasers are evaluating the extent to which health care providers are meeting those needs and improving health.

Change is a necessary condition of survival, but we as individuals or organizations, with our differences, are a necessary ingredient in the change – the never-ending search for improvement. The challenge for the manager is to harness the energy and thrust of the differences so that the organization does not disintegrate but develops (Handy, 1993). Constant 'feedback' is necessary from patients, medical and nursing staff, and management. This can be gained through informal discussions, patient satisfaction surveys and independent performance review with management. Constant review of clinical practice within an annual report and within business plans allows for monitoring of progress, highlighting areas of concern and further developments planned, and also reporting on progress and achievements.

In the light of the White Paper, *Working for Patients* (DoH, 1989), the issue of auditing care has never been more important than it is today. The Government is firmly committed to efficiency, representing value for money; quality care can be achieved only through good management and regular audits of care. The purpose of quality assurance is to assure the consumer of nursing a specified degree of excellence through continuous measurement and evaluation (Schmadl, 1979). Auditing and evaluation of the service are essential. Auditing should be ongoing with the use of patient evaluation forms and the collection of statistical data on the efficiency, quality and effectiveness of the service.

The modernization of the NHS as set out in *The New NHS – Modern, Dependable* (DoH, 1997a) and *A First Class Service: Quality in the New NHS* (DoH, 1998) identify that providing effective nursing care to patients is essential. Nursing care should be evidence based, efficient and cost-effective. The introduction of clinical governance provides a framework for continuous improvement of the quality of services in the NHS and to safeguard high standards. There are seven pillars that need to be established within health care organizations in order to provide this environment:

- patient and public involvement
- clinical audit
- clinical risk management
- information
- staffing and staff management
- education, training and continuous personal and professional development
- research and clinical effectiveness.

Health care needs

The RCN document, *Public Health: Nursing rises to the challenge* (RCN, 1994), confirmed that health analysis is the first stage of taking public health perspectives forward into nursing practice. It stated that nurses are often closer to clients and their communities than other health workers, and so are uniquely placed to gain insight into local views and priorities. It suggested that nurses also have an important role as advocates for patients who may be unable to express their own views adequately from an informed perspective. Working with and alongside doctors, nurse specialists will be in an ideal position to act as advocates within the multidisciplinary team.

Demands for health care are ever increasing and are expected to rise further with an increasingly elderly population who are more dependent and have a greater tendency to ill-health. Interest in the environment, health issues and quality of service is growing. More people will take an active and responsible attitude to their own health, becoming less accepting of ill-health and more thoughtful and demanding consumers of health services (Heathrow Debate, 1993). In the past, health services have been very illness oriented; cure has traditionally been the province of medicine, care that of nurses. Increasingly nurses are becoming involved with those who are relatively healthy, aiming to raise the level of public health across society through health promotion, monitoring and support.

The Health of the Nation (DoH, 1992) strategy defined the aim of health education as being 'to ensure that individuals are able to exercise informed choice when selecting the lifestyle which they adopt'. Nursing is changing accordingly to meet these needs, making careful, thoughtful needs assessments using a methodical framework, but in a personal way offering information, advice and comfort to patients and carers, while acknowledging their individual identities and delivering effective care. Evaluation, effectiveness and value for money are key issues, and nurses and other health care professionals are much more accountable for the service they provide.

Nurse practitioner

With the reduction of junior doctors' hours in 1991, the NHS Management Executive suggested that nurses could be trained to take on work that was previously carried out by junior doctors. It is interesting to note that Nemes (1994) described the nurse practitioner role as not a doctor's substitute but a role that strengthens and promotes a multidisciplinary approach to patient care. Nevertheless, this change to junior doctors' hours has provided a focus for change. A partnership approach between medical and nursing staff would establish teamwork rather than a hierarchical structure in a multidisciplinary team, but Wright (1995) states that nurses should not be protective towards their practice, or argue about professional boundaries, because this indicates a power struggle rather than acting in the best interest of the patient. Marsden (1995) stresses the importance of communication with medical colleagues in order to assess their response, gain their support and identify areas where a nurse practitioner role would be effective, and what he or she would be able to do.

The British Society of Gastroenterology's Working Party (1995) supported the proposition that suitably trained and supervised nurses should carry out certain types of diagnostic endoscopy, i.e. flexible sigmoidoscopy. Also stressed in this document is that medico-legally a nurse may perform an endoscopy provided that she or he has received the appropriate training, has the support of the health authority/trust and is adequately supervised by the responsible consultant. There are several established posts in the USA where nurses perform screening flexible sigmoidoscopy and this has demonstrated that nurses can develop practical skills in medical procedures comparable to those of their medical colleagues (Disario and Sanowski, 1993; Maule, 1994). There are now many nurses in the UK who perform endoscopies and have done so for several years. They have expanded their roles to include therapeutics, managing their own lists and running services. The impetus for the training and recruitment of nurse endoscopists has been the 2-week waiting time rule for suspected cancer: in 2000, in response to long waiting lists, the Government pledged that a specialist would see patients with suspected cancer within two weeks of referral by their GP.

The definition of a specialist was open to interpretation, which meant that they could be seen by a nurse specialist or a doctor. Some nurses have set up open-access endoscopy clinics for these urgent cases and refer patients if they need further investigations. Other specialist nurses have set up similar clinics for non-urgent cases to relieve the burden on the consultant colorectal clinics by dealing with the more minor referrals, enabling them to see cancer cases more quickly.

Improving patient care

There is a growing need for colorectal nurse specialists to provide continuity of care in the patient's pathway from diagnosis to surgical, adjuvant and palliative treatments, and to liaise among the patient, primary care doctor and the hospital services (Association of Coloproctology of Great Britain and Ireland or ACPGB&I, 2001). The Calman Report (Calman and Hine, 1995), 'A policy framework for commissioning cancer services', advised a multidisciplinary team working approach to patient and carers as being central to the service. Current Government policy emphasizes the need for improved communication with patients and their families and good continuity of care, and they recognize the role that nurses have in improving care (DoH, 2000a).

The publication of *Improving Outcomes in Colorectal Cancer: The manual* (DoH, 1997b) provides good evidence that specialist nurses working as part of a multidisciplinary palliative care team can reduce patients' distress, improve pain control, and increase satisfaction and information flow to patients. They recommended that there were a number of operational possibilities for fulfilling this nurse specialist role and that this nurse should be available to all colorectal cancer patients. The Commission for Health Improvement (CHI, 2001) reviewed cancer services throughout the UK; they reported that some progress had been made but there was scope for improving interprofessional communication.

The NHS Plan: A plan for investment, a plan for reform (DoH, 2000b, 2000c) – for improving nurses' role and numbers – sets out the requirement that NHS employers empower appropriately qualified nurses, midwives and therapists to undertake a wider range of clinical tasks, including the right to make referrals, admit and discharge patients, order investigations and diagnostic tests, run clinics and prescribe drugs.

Specialist nursing practice

The role of the colorectal nurse specialist encompasses many aspects, i.e. clinical, teaching, research and management. Specialist nursing practice was defined by the UKCC (1994) in its document of standards for post-registration education and practice as:

> practice for which the nurse is required to possess additional knowledge and skill in order to exercise a higher level of clinical judgement and discretion in clinical care and to provide expert clinical care and leadership, teaching and supporting others.

The specialist nurse/practitioner is expected to be at first-degree level. The UKCC did not give a definition of 'an advanced nursing practitioner'. Castledine (1994) comments that this person will be expected to have higher knowledge and skills than a specialist nursing practitioner. Such an individual should be able to provide expert clinical care, clinical leadership, management, teaching, supervision and support. The UKCC document *Prep and You* (1993) acknowledges that practitioners are acquiring advanced skills and undertaking studies that are likely to be at Masters and PhD level. The recording of such qualifications may be considered in due course. The nurse practitioners' role developed in the USA in the mid-1960s as a response to a shortage of doctors available to provide primary care. The initiative developed and expanded and led to a number of education programmes, mainly at Masters level.

There is some confusion in the UK surrounding the term 'nurse practitioner' and its relationship to other nursing titles such as clinical nurse specialist, advanced practitioner, nurse clinical, etc.; the debate within the profession has yet to come to a conclusion about definition and educational level requirements. Castledine (1993) suggests that the primary activities of nurse practitioners include screening, physical and psychosocial assessment, health promotion, health education, patient teaching, medical techniques, drug prescribing, medical and diagnostic testing, certification of inevitable death, counselling and co-ordination of care.

In the 'Scope' document, the UKCC (1992) rejects the notion of 'role extension' which limited the parameters of practice. It was envisaged that, through role expansion, professional discretion can be enhanced. Nurses can take their own initiative, do their own thinking and make their own decisions based on their own experience and education, to improve practice for the benefit of patients and clients. Role expansion should progress in recognition of the health care needs of society/communities, and this purposeful progression will lead to the acceptance of new responsibilities that are appropriate to this end (Hunt and Wainwright, 1994).

Over 34 000 new cases of bowel cancer are diagnosed in the UK each year. Colorectal cancer is the third most common cause of cancer death, accounting for one in eight of all cancers (Cancer Research Campaign, 2001). More resources are being directed to cancer services by the Government; through multidisciplinary team management, colorectal cancer patients will benefit.

Greater public awareness of the symptoms of bowel disorders and increased public demand for quicker, more responsive services and information has increased pressure on health service professionals (ACPGB&I, 2001). Colorectal cancer follow-up is one area of care that has been identified to be developed by colorectal nurse specialists; consultant staff will