

Bowel Cancer

Foundations for Practice

Edited by **Barbara Borwell** MA(ED), RGN, DIP COUNSELLING
Specialist Nurse Consultant/Associate Lecturer, Institute of Health
and Community Studies, Bournemouth University



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Foreword

Thirteen years ago, when I was presenter of the BBC's *Watchdog* programme, I was diagnosed with advanced bowel cancer after nearly a year of medical delay. I had never heard of the disease – I had no idea that it was the second biggest cancer killer in the UK and, a decade later, set to become the most common cancer across Europe.

I welcome this book and urge health professionals to read it for the support that it will give you both in understanding this dreadful disease and in your efforts to help us, your patients, at whatever stage of our journey to survive it, live with it, die from it with understanding and dignity.

Lynn Faulds-Wood

September 2004

Preface

Bowel (or colorectal) cancer is a significant health problem of the twenty-first century. On a worldwide scale, it is the fourth most common cancer, associated with substantial morbidity and mortality (Boyle, 1998).

For a health-care system to meet the demands of a patient suffering from bowel cancer, it is vital that a good working relationship is established between those engaged in the different aspects of care.

Development of readers' knowledge and skills in both theory and practice will enable nurses to demonstrate knowledge acquisition and understanding of the challenges posed by cancer in their area of nursing practice. This increased awareness will provide opportunities for nurses to develop strategies that can further enhance the quality and effectiveness of patient care.

Having worked in the field of specialist nursing for over 20 years, with the major component being in the field of cancer care, I have a total commitment to patient-focused care and multidisciplinary team working. My involvement in oncology nurse education reflects these principles and provides opportunities to utilize past experience, and current and political debate for the benefit of nursing practice.

The purpose of this book is to provide a comprehensive introduction to bowel cancer for all health professionals involved in the care of these patients and their families, empowering patients to cope with the challenges newly imposed by a cancer diagnosis, supported by a multiprofessional team with a shared commitment to maximizing the quality of the patient's experience.

This book has been designed and written to assist the reader in embarking on a bowel cancer journey from its evolution and treatment, to patient- and family-centred care including consideration of an individual's social, spiritual and psychological needs, in either the hospital or the community setting.

The contributors to this volume reflect this philosophy, and bring together a wealth of experience and specialist knowledge, thus providing a concise and readable foundation on which to base current health-care practice.

Barbara Borwell

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Introduction

Helena Bridgman

Between 1985 and 1989, a comparison of cancer survival rates across 17 European countries, using data collected from both national and regional registries, was conducted (Eurocare Study: WHO, IARC, EC 1995). This indicated that outcomes of care in the UK were poor despite an advanced health-care economy. A further study comparing outcomes of care specifically for colorectal cancer patients in the western world (Cancer Research Campaign 1999) also demonstrated significant differences in 5-year survival between the whole of Europe (47%) and the UK (40.9%).

It is important to consider methodological differences in data collection when using international comparisons to distinguish between what is reality and what may be artefact (Woodman et al. 2001), but substantial evidence remains that the most recent data for England and Wales demonstrate that over 30 000 individuals are diagnosed with colorectal cancer per annum, many of whom present with advanced disease (Quinn et al. 2001). In addition, about half of these patients will die of their disease whereas survival rates are now between 40.9 and 45% at 5 years after diagnosis (National Cancer Guidance Steering Group or NCGSG 2004). Identified reasons for this have been multiple but have included ignorance of risk factors or fear of their implication, delays in communication between primary and secondary care, timeliness and national parity of investigations and treatment regimens, and equity of access to supportive and palliative care.

The challenge for government health policy and the multidisciplinary teams that directly deliver care in the twenty-first century has been to develop a framework that reduces inequalities in cancer care. This is being achieved by providing service models based on locally identified needs' assessment and evidence-based treatment guidance, and the redesign of existent services to improve cure rates and quality of life for all individuals with a diagnosis of colorectal cancer.

Historical background

The Calman–Hine Report (Expert Advisory Group on Cancer 1995) set the agenda for significant organizational and cultural change, which continues to evolve within the context of The NHS Cancer Plan (Department of Health or DoH 2000b) and improving outcomes guidance (IOG). This, the first of the National Service Frameworks, prioritized continuity and coordination of cancer care through the creation of managed clinical networks charged with providing patient-centred services. For the first time, service commissioners and providers, voluntary organizations and local authorities would work as a team to provide ‘seamless’ care throughout the patient cancer journey, from diagnosis to cure or into palliative care. They would develop joint service delivery plans which exercised a consensus when identifying and funding common resource needs and creating solutions for filling perceived gaps in service provision.

These teams would be representative of an integrated three-tier structure of care led by primary care and supported by secondary and tertiary care. Primary care would be responsible for the rapid referral of individuals with a suspected cancer and would manage the day-to-day care of patients in their own homes, where most individuals spend most of their time while living with cancer and its effects. The most common cancers, which include colorectal cancer, would be treated in secondary care cancer units, usually district general hospitals, by teams with sufficient expertise and facilities. The final level of care would be provided by tertiary care cancer centres, for both common and less common cancers, which would also provide specialist diagnostic and therapeutic techniques, such as radiotherapy, to support the local clinical teams. Crucially, for outcomes of care to improve, it would be necessary for all teams to receive appropriate and ongoing training in cancer- and site-specific care in order to provide clinically effective care based on the most up-to-date research evidence.

In 1997, the NHS Clinical Outcomes Group (COG) published the clinical outcomes guidance for colorectal cancer. This guidance acknowledged that, although there was a growing body of scientific evidence to generate improvements in colorectal/bowel cancer outcomes, uncertainty remained in many areas of care. These included the effectiveness of population screening and existent follow-up, and whether cancer of the colon and cancer of the rectum required care under different clinical and organizational structures as a result of the complexity and associated morbidity of surgical interventions for the latter. It was also acknowledged that the vagueness of presenting symptoms meant that many colorectal cancer patients either presented as emergencies with associated morbidity or were referred by a variety of routes, which could

cause significant delays in treatment. The quality and availability of diagnostic services were known to be variable and existent clinical practice needed review using targeted clinical trials to clarify the most effective future treatment modalities. Crucially, qualitative outcomes relating to the patient's experience of care needed to be identified. The IOG (NHS Clinical Outcomes Group 1997, updated to NICE 2004) demonstrated that much of the original content is valid but there have been a few important areas of new evidence and the 2004 edition now includes the management of anal cancer as a separate entity.

The implications of the IOG for existing teams could not and cannot be overestimated because, despite achievements to date, more remains to be done. Care delivery based on performance targets places all individuals under the spotlight because a core requirement continues to be the need for audit, to establish which teams are achieving the best care outcomes and whether 'fitness to provide services' should be based on recorded outcomes and a stated minimum level of service activity. Accurate retrospective data have been hard to clarify using an information technology (IT) infrastructure which has been the victim of chronic under-investment, so original figures have been at best arbitrary but have still been used in some cases to make significant changes in the way teams work and relate to specialist centres. The interpretation of the IOG has caused controversy within some local teams with its potential to undermine the practice of senior skilled clinicians, however unintentionally. This unfortunate aspect of its impact has threatened the key to successful organizational change, namely collaborative working and partnership between all providers of care.

The appointment of a National Cancer Director in 1999 sent a clear signal that cancer would be a top priority within the government's modernization agenda for the NHS, presented in The NHS Plan (DoH 2000a). This was closely followed in September 2000 by the publication of The NHS Cancer Plan (DoH 2000b) and the appointment of a Cancer Taskforce to oversee its implementation. This 10-year comprehensive strategy, building on the foundations set by The Calman-Hine Report (Expert Advisory Group on Cancer 1995), aimed to improve the survival and quality of life of all cancer patients, with the target of reducing the death rate from cancer in people under 75 years by at least a fifth by 2010, to compare with the best outcomes in Europe. Advances and service improvements were to be made in the patient cancer journey, through prevention, screening, diagnosis, treatment, supportive and palliative care. This would be achieved by tackling health inequalities, providing clinically effective treatments with equal access to them nationwide, and also, uncommonly for a politically driven vehicle, to plan long term by investing in an infrastructure that would sustain a sufficient and knowledgeable workforce, supported by the latest equipment.

Underpinning all this was the priority to be given to the patient experience, which would influence the redesign of services and the creation of new roles. The Cancer Services Collaborative, more recently known as the Cancer Services Collaborative Service Improvement Partnership (CSC ‘IP’), was to spearhead this, bringing ‘users’ of cancer services, represented by patients, carers, managers and health professionals, together in Partnership Groups to examine the systems by which care was currently delivered. The patient cancer journey would be ‘mapped’ to aid communication and patient satisfaction with services, prioritizing patient preference and informed decision-making; the plan was to change ways of working to prevent duplication of workload that sometimes leads to significant time delays, and to develop new roles to provide dedicated expertise, availability and consistency in care delivery.

There are now 37 clinically managed cancer networks in place. These work alongside the CSC ‘IP’ and Partnership Groups, with the aim of delivering consistent levels of care across primary, secondary and tertiary settings. There is an inevitability that, in a health service that delivers care free at the point of delivery, the challenge in making the patient choice agenda a reality and understanding what that really means to the individual will continue to grow because pragmatism vies with idealism in a cash-strapped health economy. However, it has been clear that some changes in service delivery have not been costly. The results of the National Cancer Survey (Airey et al. 2002) found that most patients reported very positively on their experience of care, but access to both clear and accurate written and verbal information about their condition, and also a named professional who could promote continuity of care, were identified as immediate priorities. Information pathways, integrated care pathways and the evolving role of nurse-led services are all examples of significant patient-driven developments and the first national Peer Review of Cancer Services in 2001–2 recognized the many improvements that had been made in services for colorectal cancer patients. Work, however, still remains to be done in standardizing and improving the provision of appropriately trained staff and resources across the country, at all stages of the patient pathway.

Opportunities and challenges for the multidisciplinary team

One of the major objectives in compiling *Bowel Cancer: Foundations for Practice* has been to provide a review of the contribution of the multidisciplinary team (MDT) to patient management and care outcomes and of

the developments allied to the implementation of The NHS Cancer Plan, following the patient through defined stages of the cancer journey.

Facilitating changes in health-related behaviours to reduce the risk of developing colorectal cancer are key to improving survival rates and form the basis of the National Service Framework for Cancer. The implementation of primary preventive strategies, such as Bowel Cancer Awareness Month and the UK's leading colorectal cancer charity, Colon Cancer Concern, is a complex process where an individual's freedom to access help has psychological, social and environmental factors. In a health service that has often been accused of being a 'sickness service' driven by the financial demands placed on secondary care, this requires a major shift in culture as well as training and support for health professionals to promote changes in lifestyle and attitudes. The comprehensive guidance on cancer prevention produced by the Health Development Agency (2002) gives direction to primary care trusts and their cancer leads, together with their partners, in the strategic planning and delivery of cancer services, because the guidance can be interpreted in the context of local needs, resources and circumstances. Changes to the GP contract, which include rewards for services tailored to the local community, may also benefit areas of deprivation or where special needs have been identified.

For outcomes to improve, earlier detection of colorectal cancer not only will be dependent on raising public awareness, but will also require targeted secondary prevention for high-risk and at-risk groups. This has significant implications for future workforce planning and training to meet the increased demand for screening techniques. Inconclusive data resulting from the national screening pilots for detecting colorectal cancer have led to a further option appraisal, which has serious implications for already stretched and under-resourced services, but may herald opportunities for new and advanced practice roles (DoH 1999). In October 2003, it was announced that three national and seven regional endoscopy training centres will train nurses, GPs and allied health professionals (AHPs) in endoscopic procedures, as the focus of diagnostic effort moves from barium enemas to endoscopy. This is one example of the potential for innovation in cancer care roles and responsibilities, which continues to evolve.

Rapid and accurate diagnosis and care of cancer patients, with a maximum 2-month wait from urgent referral to commencement of treatment cited for all cancers by 2008, except for sound clinical reasons or through patient choice, will rely on proactive primary and secondary prevention, robust systems for tracking referrals and a workforce to support this. Systems should also be in place for emergency patients (particularly those with intestinal obstruction) to be promptly referred to and managed by colorectal cancer MDTs. Efficacy of care will rely on the streamlining of

services led by the MDT, a growing evidence base for effective drugs and technologies that will be available wherever the patient is treated, national datasets that will inform on the process and outcomes of care, and monitoring of progress, based on regular peer review. Controversy and ethical debate now centre on the knock-on effect that these developments may have on patients with illnesses other than cancer, with the potential for delays in timely treatments. There is also the potential for tensions to develop as the different National Service Frameworks compete for limited resources and achievement of performance indicators. Only time and accurate data will clarify the reality of these concerns.

Ironically, the greatest challenge facing the health professional will probably be directly associated with the drive to improve outcomes. The increasing knowledge base and availability of treatments mean that individuals requiring supportive and palliative care are now generally living longer, often with complex problems in the community. The Supportive and Palliative Care Guidance (National Institute for Clinical Excellence or NICE 2004) defines service models in 12 topic areas which will be needed to ensure that patients, their families and their carers live as well as possible with the effects of their illness from pre-diagnosis and treatment, to cure, continuing illness or death and into bereavement. The key message is that delivery of high-quality care is the responsibility of all and promotes the importance of a partnership approach. What this means in reality is a collective responsibility to undertake a baseline assessment of existent services, a gap analysis leading to short-, medium- and long-term actions dependent on local needs and ongoing research and evaluation of the proposed service models. In primary care, the Gold Standards Framework (Thomas 2003), and in secondary care the Integrated Care Pathway for Care of the Dying (Ellershaw and Ward 2003), are two initiatives that are working towards filling gaps in the consistency of multiprofessional care. For the patient with colorectal cancer, reliant on both specialist and generic support services, coordinated care tailored to meet individual needs will contribute to bringing cancer services up to the levels experienced elsewhere in Europe.

Vision for the future

As cancer continues to be the UK's biggest killer, with one in three people diagnosed and one in four people dying from cancer, 60% of patients will continue to be cared for in the community or generic settings in secondary care (Royal College of Nursing or RCN 2003). A major challenge highlighted by the most recent National Cancer Guidance Steering Group