PERSPECTIVES ON CANCER CARE

Edited by Josephine (Tonks) N Fawcett and Anne McQueen

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Foreword

The original proposal for this book described it as a 'reader' and, in the era of sound-bites delivered by kilobytes, this is very welcome. I am as guilty as anyone of turning to a well-known search engine for every bit of information I need, rarely reaching for the book-shelves. In fact, I pride myself in being able to answer every question posed by my research students within minutes, by the above means; the supervision session usually ending with 'You could have done that!' With information being so readily available – but often only precisely what you needed to know and no more, and not always from a verifiable source – a reader seems the perfect antidote to the relatively recent phenomenon of 'hit and run' learning.

Perspectives on Cancer Care is described by the editors as a book that will inspire, offer insight, enhance knowledge and encourage best practice, and as one that will sit alongside more comprehensive cancer textbooks. As such, the book presents expert views that would have been unlikely to be gathered together under another cover. Had these authors been writing a textbook, they would have been less free to express their expert views, given that textbooks can often constrain writers rather than get the best out of them.

Few of us have not been touched by cancer, either as a matter of personal experience or the experience of a close family member. Despite some of the outer fringes of the 'let's be positive about the cancer experience' movement, it is a fact that more people now live with and through cancer to survival than ever before. Many reflect on the time as life-changing and on having found new resources and inner strength. However, as the first editor, Tonks Fawcett, says in her opening chapter on the cancer experience: 'Once said, in terms of a diagnosis, the word cancer cannot be unsaid.' I am not aware of anybody who has welcomed a diagnosis of cancer, nor has it elicited envy in others as a result. This opening chapter is an excellent essay on cancer and deserves to be read widely as it reflects on the medical, sociological and even the political aspects of cancer, and offers insights into the personal journey. Realistically, the book ends with end-of-life care; cancer continues to kill people who, without expert care, will suffer pain and distress which will instil fear in those close to them and, so much worse, may lead to the loss of hope.

Without some knowledge of molecular biology and the insensible second-by-second homeostatic adjustments that our bodies make – and just how close we live to cancer in our daily existence – few of us know how likely we are to develop some kind of cancer. I write this in my mid 50s, knowing full well that I harbour (as does every man of my age) cellular changes in my prostate that the prospect of longevity only makes more likely to manifest itself as cancer of the prostate. Therefore, for many, survival into old age with the decline in

the protective mechanisms which, for lack of a better metaphor, 'fight' cancer at the level of our DNA, makes the development of cancer a strong possibility. For some, however, this prospect is heightened by not choosing their parents carefully and, speaking from personal experience, I am now filmed from a particular angle that few would choose voluntarily, every five years, through my poor choice of parents. The inclusion of a chapter on genetics and cancer is, therefore, entirely appropriate.

It is impossible to mention every author in the book in the space available, and this is not a review, but three other chapters in *Perspectives on Cancer Care* deserve special attention, purely from the perspective of novelty. Rosemary Mander's chapter on the care of the childbearing woman with cancer presents a situation that few would automatically consider when they think of cancer: bringing forth new life in a body that is having its own struggle to survive. While Mander, a midwife, may not agree with me, childbearing seems sufficiently dangerous without the added stress of cancer and there is a great deal more to consider than merely the effect on the woman: what effect does treatment have on the rapidly developing fetus, and is breast-feeding possible while taking chemotherapy? Ashley Brown considers cancer and the surgeon, and even raises the possibility of surgeons becoming redundant with respect to cancer as medical treatments become more successful. Metaphors about turkeys and Christmas come to mind and Brown – a surgeon – describes the changing role of the surgeon and the new possibilities that are developing for different types and levels of surgical intervention as cancer treatment improves. The third chapter worth mentioning in this light is the one on the role of the clinical research nurse in cancer clinical trials, by Patty Campbell. Research nurses are a vital but, arguably, neglected group in clinical research, often going unnoticed. However, this is being addressed in the United Kingdom through proper training and increasing recognition by way of, for example, well-deserved co-authorship. The inclusion of this chapter in this reader is very welcome.

To learn about cancer, its effects and its treatments, this book provides me with much that I need to know, short of experiencing cancer myself. The book is a reader aimed at nurses and others learning in the context of higher education, but it could also provide a useful reader for the person suffering from or being with someone being treated for cancer. As nurses and other clinicians, we often seek insight into conditions so that we may understand them better and provide better care. This book should achieve that and it may also provide, as it did for me, a greater insight into the work of people who care for people with cancer.

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Tonks N Fawcett
August 2010

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Introduction

Tonks N. Fawcett and Anne McQueen

The real voyage of discovery consists not in seeking new lands but in seeing with new eyes.
Marcel Proust

Nursing care in the 21st century requires not only an understanding of scientific evidence on which to base care decisions, but also the sensitive appreciation of the human response to illness, the primacy of caring and the paramount skills of communication – the heart and art of nursing. The challenge for nurses, and for all heathcare professionals, is to maintain, simultaneously, their mastery of the state of the science and their capacity for the art of patient care.

This book is concerned with caring for individuals with cancer. The authors of the individual chapters write from their own particular expertise and passion on the subject of cancer care; they aim to communicate their enthusiasm for their particular topic and their commitment to the highest quality of care for those diagnosed with cancer. The styles in which the chapters are written also demonstrate the authors' perspectives. Some are writing from the perspective of 'hard' scientific evidence from which best practice emerges. Others look more qualitatively at the experiential aspects of cancer. All the chapters contribute to developing knowledge, understanding and the professional care of those experiencing cancer.

The text is considered to be a 'reader' to support commonly taught undergraduate or postgraduate programmes and courses, or can be seen as a supplementary book providing special insights from clinicians, based on their specific expertise and experience. It is not intended to be a comprehensive text on cancer care but rather (as the title suggests) to offer some perspectives on cancer care that can inspire readers and encourage high-quality care through an enhanced understanding of patients' needs and carers' skills.

In accordance with the title, *Perspectives on Cancer Care*, the text presents a series of chapters highlighting some central issues in the management of patients with cancer. Different circumstances and approaches to the complex reality of cancer care are presented. The text addresses both practical and interpersonal skills and each chapter is based on sound research findings and critical appraisal of the relevant literature. The holistic approach to total care is a prominent feature in cancer care and this is illustrated through the different cancer scenarios represented in the various chapters. The special need

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for sensitivity, trust, empathy and support in the care of patients with cancer and their families is illuminated through the book.

Purpose of the text:

- To collate and present perspectives on cancer care that highlight particular issues in cancer care;
- To provide a concise volume with some insights and experience that can be of value to others in the field.

Aims of the text:

- To inspire readers caring for individuals with cancer;
- To give insight into patients' needs and how these can be addressed;
- To enhance knowledge of literature and its relevance to practice;
- To encourage best practice and a high quality of care for individuals facing cancer.

The aim and purpose of the text is achieved by drawing on the expertise of specialist practitioners in the field of cancer care.

Cancer care: an introductory overview

Cancer is common in the United Kingdom (UK) and indeed it is prevalent worldwide. Although causes and risk factors related to our current lifestyle are associated with cancer, it is not a new disease. Around 400 BC, Hippocrates, a Greek physician and the father of medicine, is claimed to have given the name cancer to tumours whose appearance resembled a crab; and he is credited with distinguishing between benign and malignant tumours. However, Hippocrates was not the first to discover the disease since the earliest case to be documented was reported on a papyrus, in Egypt, some time between 3000 and 1500 BC (www.cancerresearchuk.org). It was not until the 19th century that the concept of metastases via the bloodstream was appreciated. However, since Francis Crick and James Watson described the structure of deoxyribonucleic acid (DNA) it has been possible to study cancers at a molecular level, and now to have the possibility of developing new and exciting treatments.

It is recognised that there are more than 200 types of cancer, originating from different causes, presenting with different symptoms and requiring different forms of treatment or management. It is estimated that more than one in three people will develop some form of cancer during their lifetime. In July 2010 Cancer Research UK reported in the region of 298,000 new cases of cancer (excluding non-melanoma skin cancer) being diagnosed each year in the UK; breast, lung, large bowel (colorectal) and prostate cancers accounting for over half (54%) of all new cases (http://info.cancerresearchuk.org/ 2010). Almost 11 million new cases of cancer are diagnosed each year worldwide, 26% of these being in Europe (http://info.cancerresearchuk.org/cancerstats/world/ 2009).

Cameron and Howard (2006: 258) state that 'the key to understanding the clinical behaviour of cancers lies in their biology'. Cancer results from an error or defect in cell division; usually resulting from defects or damage in one or more of the genes involved in cell division. The damaged or mutated genes can start to divide uncontrollably and these

defective cells multiply to form a lump of abnormal tissue, the tumour. Four main types of genes are involved in cell division, and defects of these can be seen in cancer:

- Oncogenes
- Tumour suppressor genes
- Suicide genes
- DNA repair genes

When oncogenes are activated, they speed up a cell's growth rate. When one is damaged cell division becomes uncontrolled. *Tumour suppressor genes* inhibit cell division and require to be 'switched off' by other proteins before a cell can grow. Apoptosis, or cell suicide, can occur when something goes wrong with a cell, to prevent damage to neighbouring cells. If the *suicide genes* become damaged, then a faulty cell can keep dividing and become cancerous. *DNA repair genes* enable damaged genes to be repaired. Body cells contain many proteins which are able to repair damaged DNA and the majority of DNA damage is probably repaired quickly, with no ill effects. However, if the DNA damage occurs to a gene which is responsible for making a DNA repair protein, a cell's ability to repair itself will be reduced. This can allow errors to build up in other genes over time and can result in cancer, something now thought of as genome instability.

In malignancy, for whatever reason, 'the homeostatic mechanisms related to cell division fail' (Watson & Fawcett 2003: 78) and the cancerous cells divide uncontrollably usually to form a tumour. Tumorigenesis is a multistep process, the developing tumour seen as clonal expansions. Such tumours may initially be symptomless according to their location but may press on nerves, block the digestive tract, obstruct blood vessels, or release hormones that can interfere with normal body processes. Cancers can spread to other tissues, distant to the primary source. This occurs when a single cancerous cell breaks away from the main tumour and travels via the circulatory or lymphatic system, the cerebrospinal fluid or via serous cavities to other tissues of the body. At the new site, new blood vessels grow to provide it with oxygen and nutrients (angiogenesis). Indeed, Hanahan and Weinberg (2000) identify six capabilities of cancers, acquired directly or indirectly through mutations in specific genes.

1. Self-sufficiency in growth signals, this autonomy modulated by oncogenes;
2. Insensitivity to antigrowth factors that normally regulate cell advance through the G1 phase of the cell cycle);
3. Evasion of apoptosis, programmed cell death, often associated with deactivation of the tumour suppressor gene, p53;
4. Limitless ability to replicate as a result of the above capabilities leading to uncontrolled proliferation;
5. Sustained angiogenesis via an 'angiogenic switch' in the course of cancer progression;
6. Tissue invasion and metastases which depend on all the above capabilities.

If left undetected and untreated the individual will, sometimes sooner, sometimes later, experience the consequences of this 'intimate enemy' (Marieb 2001: 142).

Cancer is recognised as a major fear by the public and this is not surprising since one in four of all deaths in the UK occurs as a result of cancer. However, half of the number of people diagnosed with cancer now survive for more than five years, and the average ten-year cancer survival rate has doubled over the last 30 years. Notably, the overall cancer death rate has fallen by 10% over the last decade (www.cancerresearchuk.org). Much of the improved prognosis is due to advances in knowledge and technology, facilitating earlier diagnosis and more refined treatments.

Although cancer affects individuals, and is not infectious, it is a disease that has effects on the whole family. Those within the family are affected by the changes cancer imposes on the individual; changes to their role within the family, the implications of ongoing treatments and their side effects, emotional upsets on a day-to-day basis, and worries about the future for their loved one and for themselves. Treatment for an individual with cancer therefore requires to include the needs of the family and this forms an important part of the nurse's role.

The prevalence of cancer means that all practising nurses will be involved in the care of individuals with cancer and will require knowledge and skills to cope with their particular needs. However, advances in cancer treatment and care have also provided opportunities for the emergence of nursing specialties such as the clinical nurse specialist in cancer care, the genetic counsellor, the genetic research nurse and the palliative care nurse, to name but a few. These specialists apply their expertise to provide the required sensitive, dedicated care to cancer patients and their families through the different stages of their cancer journey.

Such specialists are among the contributors to this book. This 'reader' is essentially written for student nurses and qualified nurses, not necessarily specialising in oncology, but who will meet patients with cancer in their varying nursing roles. However, it may also be of interest to specialist nurses in cancer care since the specialist practitioners contributing to the book express and share their passion for best practice in cancer care. The virtue of such a text is that it looks to bring together issues in cancer care that are well recognised, and some perhaps less well-recognised areas of expertise. Whilst issues such as pain management and hope are recognised as central in cancer care, they are included here together with genetic issues and the important position of the cancer research nurse. The chapter headings are intentionally selective and diverse in nature, highlighting issues that the authors believe to be significant in cancer care and where there is a need for attention to be focused in a reader. While this adds to the existing literature base, it is a unique text, 'speaking to' the readers and at the same time allowing them to explore critically the knowledge, skills and evidence presented to enhance their professional practice. As already suggested, this is not intended to provide comprehensive coverage of the domains of cancer care; rather as a 'reader' the content seeks to reflect differing perspectives of the chosen contributors, collected into a single volume for publication.

Chapter 1 explores what is meant by cancer as a journey of discovery. The developments affecting cancer care over the last several decades are examined with an appreciation of the tremendous progress that has been made, affecting a patient's cancer career. An analysis is made of the use of metaphors for discussing and understanding cancer, and consideration is given to how their meanings have changed with the social, technological and professional advances. An examination is made of how the notion of cancer and the cancer journey, from presentation to outcome, is different in the 21st century, and the relevance of

concepts such as victim, sufferer, survivor, hope, fear, courage and loss through the cancer journey.

Chapter 2 illustrates how cancer genetics is integrated into healthcare, and its value in cancer care. The authors emphasise the importance of having knowledge of cancer family history, and fundamental to this is the current guidance from government and professional bodies. The skills and knowledge required to elicit a family history and construct a three-generation pedigree using universal nomenclature is outlined, and inheritance patterns in relation to cancer predisposition gene changes are explained. An overview is included of currently known gene changes that increase the risk for common cancers and of genetic testing available in the UK. Integral to the chapter is the role of cancer genetic services in the UK. The chapter is supported with case studies to assist understanding.

In Chapter 3, the author considers the care of the childbearing woman with cancer. The prospect of having a baby is generally considered to be a happy event, but when a pregnancy is overshadowed with a diagnosis of cancer it brings with it a range of issues for the childbearing woman, her unborn baby, her family and those who provide care. Some of these issues relate to the woman's survival, as the death of the mother may need to be considered. Other issues relate to the treatment of the woman's cancer, raising questions about maternal and fetal harm and benefit. Thus, decision-making about the timing of treatment becomes significant. In this chapter the traditional role of the midwife, as being 'with woman', will be considered. This role is comparable with that of the palliative care nurse attending a person with cancer. In palliative care the concept of 'being with' assumes special importance, and the role of the midwife in caring for the childbearing woman with cancer may yet need to be addressed more explicitly through research and education.

In Chapter 4 the focus is on the importance of research in addressing the practical realities that patients with cancer are confronted with. Research into the nursing and caring needs of cancer patients is vital to their optimum management and the dissemination of best practice across professional care. In this chapter the authors illustrate the need for a methodical and comprehensive oral assessment tool for use in children with oral mucositis. In order to conduct clinical trials of mucositis prevention and treatment, reliable, valid, sensitive and easy-to-use instruments are required. Considerable effort has resulted in many different mucositis scales being developed, primarily for adults with cancer receiving chemotherapy and radiotherapy. Oral mucositis research in children receiving anticancer therapy has been impeded by the lack of an acceptable, appropriate assessment scale. The authors of this chapter are two of the experts who have been working together to produce an oral mucositis assessment scale that will be appropriate for use in children. This chapter describes the processes involved in the development of the Children's International Mucositis Evaluation Scale (ChIMES) that resulted from this research group.

In Chapter 5 the author outlines the diagnosis, symptoms and treatment of malignant brain tumours. Particular attention is given to the need for a multidisciplinary approach to care. The specific problems experienced by patients, such as physical dysfunction, communication difficulties, cognitive impairment and psychological distress, are explored. The management of seizures is discussed along with the implication of seizures for the patient's quality of life. Additionally radiotherapy, chemotherapy and other therapeutic