Integrating cancer and supportive services: The progress and the challenges

OVERVIEW

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In this edition of Cancer Forum, five authors examine the interface between oncology services and palliative services from differing perspectives. The interface has changed substantially as both areas have developed in the past three decades. For optimal patient, family and staff outcomes, there is more that can be done to effectively utilise the expertise of the wide range of clinicians and disciplines that should be involved in the care of people with cancer.

Although there have been advances in changing the course of cancer, for the population at large, the diagnosis of cancer is still inextricably linked with death. For 50% of people with cancer (other than non-melanocytic skin cancers) this is still the case. Although for many cancers, increased rates of cure have occurred in the past 25 years, living longer with cancer is one of the outcomes with which we have yet to come to terms fully.

Thinking beyond terminal care alone, many palliative clinicians have the ability to support people through their fears at and around the time of diagnosis. Talking of symptoms to a palliative care clinician is less likely to be seen as something which will result in curative or life-prolonging treatment being withdrawn. Talking to someone other than your primary treating oncologist (who may be perceived as the gatekeeper to active anti-cancer treatment) may be a safer place to reflect on fears. This role of supportive care is growing around the world.

The right combination of professional carers is also very important. Few of us in clinical practice would pretend that we can provide all of the care ourselves, yet many of us are still reticent to explore the breadth of the impact that cancer, its treatment and ultimate outcomes has on patients, their families and our fellow staff. We have often not been strong enough advocates for a true interdisciplinary approach to patients and their families at this challenging time. The opportunity afforded by involving and learning from different disciplines as a quality improvement mechanism is not fully utilised by many cancer services that remain fragmented and uncoordinated. Unless the mechanisms have been negotiated for excellent communication, such teamwork is unlikely to be established or survive.

In thinking about the disciplines that need to be involved, the comments are not limited to different brands of oncologists or the inclusion of a nurse in the discussions. The inclusion of rehabilitation and pain specialists are such examples. The nexus between pain and cancer is not as widely understood as we may think. When the National Health and Medical Research Centre (NHMRC) Acute Pain Guidelines were distributed, oncologists and palliative physicians were not included in the mail out. If you would like to look at chapters relevant to cancer or supportive care (chapters 4 and 8), please go to the website.

The involvement of occupational and physiotherapists, dietitians, speech pathologists and social workers still does not have enough emphasis. Sharon Bover and Tracey Quamby reflect on some of the models and potential benefits from the better involvement of allied health in this clinical setting.

The inclusion of a psychologist with their contributions to this area of clinical care emerging in the literature is still seen as a luxury for many services, not an integral part of care. Psychiatrists have a wealth of experience to add to the care of people with cancer, yet the links are still ad hoc for many cancer services nationally. With mounting evidence for a change in outcomes from adequate psychological support and, where appropriate, psychiatric support, in people facing cancer, resources need to be examined in the broad context of cancer services. Where does a unit spend $50,000 of new recurrent funding? More chemotherapy? Another member of the administrative team? A clinical psychologist with a broad palate of interventions and a special interest in cancer to bring to the bedside?

In practice, how can this interface be generated? Patient-defined needs are complex. People bring to the crisis of the diagnosis of cancer all the baggage of their life—their hopes and fears, successes and failures. Support at this time requires a detailed focus on the whole person. Communication is everything in this process and mechanisms that support this should be fostered.

Generating a team that can cope with the complex and changing needs of patients and their families is at the crux of good care in the twenty-first century. Paul Glare and Stephen Clarke outline some of the models for the interface between cancer services and palliative or supportive services. Sanchia Aranda and Donna Milne suggest further refinements to the interface. Formal evaluation of these models, their benefits, burdens and cost effectiveness have yet to be done.
The role of the primary clinical carers (nursing and medical) is highlighted by Greg Crawford. Recognising from the outset their pivotal role in providing care to which other health professionals can contribute changes the way care is offered. Often, general practitioners have enjoyed a long relationship with the patient, and are able to provide continuity and, when oncologists (medical, surgical and radiation) don’t coordinate care with each, fill this role too.

Within the broader community, there are groups for which health outcomes are not as good. In many communities, the rates of cancer are higher per head of population, rates of early detection and presentation lower, and treatment options limited. In Australia, geography alone will almost certainly limit choices for early detection, multi-modality treatment and community-based support. There are additional challenges addressing communities where cancer may have a particular negative meaning. For example, in some cultures, it is seen to be a specific curse. Confirmation of this diagnosis in this setting may be difficult, even late in the clinical course of the disease. If there are cultural and language barriers that influence options available to the population, then outcomes will not improve without these issues being addressed in a sensitive but systematic way. Ofra Fried, whose day-to-day work encompasses many of these challenges, writes for this edition of Cancer Forum.

At the same time, it is not enough for palliative service providers to ask that patients and their families are referred earlier (and hopefully not in crisis) without ensuring that they are up-to-date with the clinical decisions and service provision of the referring oncologists. Palliative service providers have an onus on them to be excellent clinicians; up-to-date not only with the symptom control and psychosocial issues, but also disease modifying treatments, their benefits and morbidities. Interdisciplinary clinics demand not only expertise in one’s own area, but current knowledge of the other disciplines represented. Patient advocacy in such a setting is a balance of the available evidence for the cancer being treated, the co-morbidities that the patient has and the patient’s own preference.

A fresh set of eyes can be a wonderful thing. The longer we know a patient, the more is assumed and often we fail to have a fresh set of eyes. As health care professionals, trying to influence the process of healing is often difficult given the constraints that our service models inherently have. If we are committed to the care of the whole person, where every interaction has the opportunity to improve health, then we will continue to better meet the needs of those whom we are here to serve.

Optimising the relationship between oncology, supportive and palliative services can only add to the quality of the care that we offer. Teams, as living organisms, need energy and commitment. As with any team, recognising the strengths and weaknesses that each player brings to the care of that particular patient is an essential part of planning care. Providing structure and support for teams to work together is something that will pay dividends.

The continued evolution of both oncology and palliative services dictate that the interface will need to continue to change. Properly structured, both add greatly to the care of patients, their families and staff with cancer.

References

Optimal care is now dependent on careful planning across different settings to ensure a continuum of care. This article will outline the model of service delivery that has been adopted by Central Gippsland Health Service (CGHC). A case study will be used to illustrate how this system operates.

This system uses a single assessment process, a single care coordinator as well as involvement of all stakeholders utilising processes, protocols, co-location and effective methods of communication. The concepts of shared/managed care are well-recognised.

**This is the story of Mr T and his journey through CGHS**

In 1998 at 59 years of age Mr T was diagnosed with throat cancer; he was transferred to a Metropolitan hospital for surgery and radiotherapy and was transferred to CGHS as an inpatient. At this point his details were taken and a UR number issued. He was referred to the dietitian and speech pathologist; then discharged to a supportive family, requiring no further services.

Fifteen months later Mr T sustained a left CVA resulting in a dense right hemiparesis. During the lengthy rehabilitation process Mr T received services from medical and nursing staff, a physiotherapist, occupational therapists, dietitian and speech pathologist. Mr T’s voice had been affected by previous surgery and radiotherapy and he often resorted to writing for communication system to enable clients to participate in their own care decisions and staff to be kept abreast of changes across settings. A “complex care meeting” enables team members from both inpatient and outpatient areas to provide information relevant to clients who are needing further care, eg impending discharges, impending admissions or for rehabilitation needs. Case conferences facilitate communication between clients, carers and their health care team. This enables appropriate care planning, and care planning around the “unique responses of people concerned”.

Central Gippsland Health Service is a multifaceted organisation of six service sites including acute and community-based health care as well as co-located services such as the Aged Care Assessment Team.

The organisation has also achieved a structure whereby an assessment officer is also a care coordinator, no matter which division (ie acute, community or residential care) is involved, and has developed a series of protocols with other agencies such as the Aged Care Assessment Team to ensure that assessment is not a repetitive and duplicative process but a building process where information is collated into a centralised document.

Our palliative care coordinator is the case manager (across all service sectors) for the client, and the community care services department head of assessment is the discharge planner of acute services. There is a single referral form, a single consent form for information exchange and a single client file along with secure/confidential electronic storage/transfer of client service delivery information, which can be accessed only by password/client consent from multiple sites/program staff.
How does this work for Mr T? Under this model the palliative care coordinator conducts the holistic assessment and acts as case manager. The care plan involves all of the service providers working with Mr T and his family to achieve the best possible outcomes for the remaining part of his life.

Utilising the single assessment tool, the palliative care coordinator is able to coordinate and access services. It means that by contact of only one person Mr T can have a “fast tracked admission” as well as a smooth transition back into community care, and that all service providers have a mechanism for communication and are involved in developing the case plan.

The family can feel confident that they only have to tell their story once. The doctor only has to communicate his directions to one person and they will be communicated to all. Provision of care from multiple sectors, for people like Mr T, requires seamless care to make his life a little more bearable.

How does this process work from an Occupational Therapy perspective? I was introduced to Mr T when he was admitted with his CVA.

We were involved with retraining in self-care, home modifications and return to work. Mr T was an accountant, and minor modifications of his workstation and connection to the Internet allowed him to return to part time work. This became far more important when he became palliative as it allowed him to complete his case load and retire with his work complete.

As the occupational therapy case load is based geographically rather than programatically it allowed us to be involved with Mr T as an inpatient, outpatient, community and palliatively; it allowed us to build rapport and provide a consistent service. It also was a big issue for Mr T in his palliative phase. He had been a very busy man and struggled with boredom. His main leisure interest was following horseracing, and with a little modification, a little patience and lots of laughter we were able to set up an Internet betting account for Mr T. It filled in his days in a way that was meaningful to him (and I learned how to pick first, second and fourth in a trifecta).

As Mr T’s health altered, care could be provided that was timely and appropriate. This was achieved by regular reviews from the palliative care coordinator and involvement of a comprehensive health care team. While physical function may not be restored, a carefully planned rehabilitation program has a positive impact on dignity and self-esteem. As seen with Mr T, by implementing an integrated approach to care, not only did his quality of life improve, but also confidence was instilled in his family, choices were provided for health care settings and treatments, and the anxieties of multiple assessments were avoided. Mr T was able to make decisions about his own health care needs, and to plan and set goals which enabled him to die peacefully at home surrounded by his family.

References

Other references (not cited)
THE INTERFACE OF ONCOLOGY AND PALLIATIVE CARE IN TERTIARY HOSPITALS: A CONCEPT IN EVOLUTION

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Introduction

Thinking back to high school science, we learnt that an interface was a term used in chemistry to mean “the surface separating two phases”. That the concept of an interface – with its implication of barriers and immiscibility – has been applied to the oncology-palliative care nexus is not surprising, as historically the two have always been separate. Contemporary palliative care services have their origin in the British Hospice Movement (BHM), which arose in the 1960s out of a reaction to the sense of abandonment created by oncologists-of-the-day when they told their incurable patients “Sorry, there’s nothing more we can do for you”.

We now live in the electronic era, and the word interface has taken on a somewhat different meaning to describe “the point at which two systems interact”, such as between a computer and some machine that it controls. In everyday parlance, interface is now used to reflect this sense of interactivity and usually refers to communicating and exchanging ideas. The relationship between oncology and palliative care has also moved in this way, particularly in tertiary hospitals in Australia, where the plane of interaction between the two disciplines is broad.

The “mixed management model” of end-of-life care, proposed by the US Institute of Medicine (IOM) in its monograph *Approaching Death* takes this evolving concept further, seeing control of disease, symptom control, psychosocial support and advance care planning as the four components of a single endeavour. In such a model of care, which is advocated for patients with eventually fatal illnesses from the time of diagnosis, any interface between oncology and palliative care is removed completely as the two concepts mix freely. It is unclear what the implications will be for oncology and palliative medicine will be if the mixed management model was to be adopted widely.

In this paper, these concepts are discussed in more detail.

1960s-1970s: An interface separating two phases – the sequential model of palliative care

The standard World Health Organisation model of cancer care has four phases: prevention, early detection, treatment and palliative care. Ideally, cancer should be prevented; if not, hopefully it can be detected early. Failing that, when it is detected at an advanced stage, effective treatment should be available. When this no longer works, there is pain relief and palliative care (see Figure 1). This is the traditional “sequential” model of palliative care, with palliative care becoming part of cancer care only after anti-tumour treatment options have been exhausted. In combination with the sense of abandonment of patients by the mainstream health care system, the sequential model led to the BHM being established outside the UK National Health Service (NHS). The issue of abandonment is raised here not to cause offense but merely to help understand why things happened the way they did. Thus, there has been a clear distinction between oncology and palliative care from the outset, and a chemistry-type interface has been easy to identify.

While the sequential model of palliative care was a definite improvement on the situation before the 1960s, it is extremely
Figure 3

“Mixed management” model of care for patients with life threatening illnesses

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limited in the way in which palliative care is able to help patients, especially when palliative care services are situated outside the mainstream hospital setting:

- Access to palliative care is restricted to people until after anti-cancer treatment options are exhausted. As a result, the median survival of patients referred to palliative care services is then only a few weeks. In this short period of time it may be possible to control pain and other physical symptoms but it does not provide the time for psychosocial support of the patient and family, or for preparation for death to occur. On the contrary, for many patients a sudden referral to previously unknown staff and loss of contact with the doctors and nurses who have dealt with them over often long periods may cause enormous distress, regardless of the quality of care they receive.

- Access is limited at a population level. It was estimated in the 1980s in Britain that only 20% of patients dying of cancer had contact with palliative care services. In many parts of the world this situation persists today, but in others it is changing.

- Access to medical management from other specialty units is usually discouraged under this model.

1980s-present: Exchanging ideas across an interface – the concurrent model of palliative care

Over the past 20 years, the limitations of the sequential model of palliative care have been recognised, and this has given way to more of a “concurrent” model. Pain, symptom control, psychosocial support and advance care planning are acknowledged as having a role at an earlier stage of disease and are provided concurrently with anti-cancer therapy (see Figure 2). The concurrent model has flourished where mainstream specialist palliative care services (SPCS) are available, such as in Australia’s tertiary hospitals, because these SPCS are made up of health care professionals who have some training in oncology and are therefore able to communicate and exchange ideas with the oncologists from the time of diagnosis. Advice on the palliative care needs of patients undergoing cancer treatment in hospital is given, and in addition, palliative care is provided for those cancer patients who are admitted to hospital but for whom further anti-cancer treatment is not possible.

The realities of the concurrent model are reflected in the current situation of the Palliative Care Service at Royal Prince Alfred Hospital where approximately one-third of patients referred to the service are still pursuing disease-controlling therapy, the median survival after referral approaches two months and approximately 10% of patients survive more than six months. Reflecting the training of the SPCS personnel, biomedical aspects of the illness are emphasised under this model: physical symptoms are given priority and a mechanistic approach to assessment and therapy is adopted. Invasive procedures are carried out in many cases. Patients are even admitted to the tertiary hospital to receive palliative care.

Despite the interchange of ideas between the disciplines, the concurrent model is similar to the sequential model in some ways. The two disciplines are separate and there is still a linear sequence to thinking. Oncology and the emphasis on disease control dominate patient care in the earlier stages of the patient’s illness, while palliative care dominates in the latter stages. While the hospital’s Palliative Care Department is part of the Cancer Services clinical grouping administratively, it is clinically separate and is not involved in multidisciplinary clinics designed to plan cancer treatment.

The future?: Removing the interface – the “mixed management” model for patients with incurable disease

For various complex reasons, mainstreamed SPCS as we understand them have never really caught on in the USA. Community-based multidisciplinary palliative care teams (usually comprising a nurse and a social worker and little or no medical input), which the Americans call “hospice”, are widespread but fit very much in the old sequential model: patients have to acknowledge they have a very poor prognosis (officially less than six months to live) and agree to forgo further anti-cancer treatment or hospital care to receive hospice services. Not surprisingly, the median survival after referral to hospice in the US is three weeks.

In 1996, the IOM convened a committee to address the deficiencies of end-of-life care in the US. As a result, the IOM published the committee’s report in the monograph Approaching Death. In the report a “mixed management model” of end-of-life care is proposed (see Figure 3). Essentially, it is predicated on three basic assumptions that affect the interface of oncology and palliative care:

1. The traditional transition of “cure to comfort” inherent in the sequential model rarely occurs anymore in the real world – patients want to pursue disease control and palliative care
concurrently and equally throughout the duration of their illness, whatever its outcome.

2. Distinctions between treatments that are preventative, curative, rehabilitative and palliative are arbitrary. Bisphosphonates to prevent fractures, treat hypercalcemia and relieve pain are a good example of this.

3. High quality end-of-life care is the responsibility of all health care professionals and should not be left to specialists in palliative care to provide. Consequently this report has not recommended the recognition of palliative care/palliative medicine as a specialty in the US at this time but rather the education of all clinicians in the specifics of symptom control, psychosocial support and death preparation, as well as the delivery of disease-controlling therapies. In such a model of care, which is advocated for patients with eventually fatal illnesses from the time of diagnosis, the concept of interface is removed completely as the two “phases” mix freely.

While the first two points are indisputable and apply under the prevailing concurrent model the third point is contentious. Can the present interface be totally removed? Can oncologists be expected to be experts in end-of-life care? Can oncologists try to control disease and prepare patients for death at the same time? Do patients and their families want to prepare for death while they are having anti-cancer therapy? What happens to SPCS in this model?

While the Royal Australasian College of Physicians has recently recognised palliative medicine as a specialty and created a Chapter of Palliative Medicine under its auspices, it is true that a small number of individuals in Australia are seeking dual qualifications in medical oncology and palliative medicine. Is this the beginning of the mixed management model here? We suspect that it is not and that for the foreseeable future the two will remain distinct. While that means there will always be an interface between the two, it needs to be an interface based on communication and the exchange of ideas and not a barrier between two inmiscible substances.

References

THE INTERFACE BETWEEN PALLIATIVE CARE AND CANCER CARE: A NURSING PERSPECTIVE

On the surface at least the key interface between palliative and cancer nursing centres on the similarities of the patient population served – people with cancer. Other images appear to imply vastly different knowledge and skills: the palliative care nurse exuding quiet calm and peaceful nurturing of the patient and family as death approaches; the cancer nurse skilled in the delivery of toxic substances, the management of complex central lines and dealing with life-threatening complications such as gram-negative sepsis. This image of the palliative care nurse as nurturer rather than skilled professional is reinforced by descriptions of palliative care nursing as epitomising the ‘quintessential’ spirit of nursing.

While it is rightfully accepted that palliative care nursing offers patients excellence in good nursing care, this is not the same as suggesting that highly technical skills and physiological knowledge are not required to deliver good palliative nursing. However, the unskilled nurturer image was recently reinforced when a nurse seeking to enter palliative care after a life-time in the operating suite could not understand why she could not get a job in community palliative care and was advised to initially work in an inpatient hospice unit where she would be better supported to gain the necessary skills before working alone in the community. Her response – “But isn’t it mainly holding hands and giving comfort?” Thus the common image of the interface between palliative and cancer nursing is that the former picks up when skilled care is no longer required. In contrast cancer nurses are often portrayed as unable to provide for the palliative needs of dying patients and indeed acute cancer services are often criticised for ‘hanging on to their patients’ and for ‘treating beyond any reasonable expectation of benefit’.

To challenge these images this short paper will explore the changing nature of cancer care by examining traditional and contemporary views from a nursing perspective. The aim is to demonstrate that what separates these two areas of nursing is increasingly less important than what they share and that the ultimate aim of any consideration of the interface between cancer and palliative care services must be a closer working relationship for the benefit of people with cancer.

The traditional view

The goal of care, cure or palliation, used to be the key to determining the difference between cancer and palliative care nursing. Cancer care was about cure and has been defined as the application of “knowledge and understanding of the biology of malignant disease, its natural history, and the efficacy of different treatment modalities to the clinical management of malignant disease”. The aim of this work and the expectation of the patient is that everything possible will be done to cure the disease or prolong life, despite the reality that this will not always be possible. The nurse’s role was principally to deliver curative treatments safely, to prevent and detect treatment complications, to educate the patient and family about self-care to minimise the negative sequela of treatment and to provide supportive care to assist the patient to cope, both physically and emotionally, with the effects of cancer and its treatment. More recently this role has extended to include prevention and early detection activities. While cancer nursing is not itself focused on the cure of disease but on the care of people experiencing treatment, nurses do contribute to survival outcomes. Nurses play a key role in the prevention and early detection of life-threatening complications of cancer treatment, a role that has contributed significantly to lower mortality rates in areas such as bone marrow transplantation and high dose chemotherapy.

In contrast to the cure focus of cancer care, palliative care is defined as “the active total care of patients whose disease is not responsive to curative treatment”. The early hospice movement, the precursor to palliative care, largely developed as a reaction against the tendency to see death as avoidable, with the dying person cast as a failure of modern medicine. However, increasingly palliative care is understood as having a role in the care of people earlier in the disease trajectory when outcome is unknown. This role centres on the reality that many people undergoing curative treatment still experience complex symptoms and face issues of meaning that may benefit from palliative expertise. Nurses working in palliative care have predominantly understood their role as commencing when curative attempts cease. Indeed some commentators argue for a clear separation between palliative and terminal care so that there is clarity of goal and a clear confrontation of the reality that the individual is going to die. Palliative nurses therefore have principally undertaken roles in symptom assessment and management, therapeutic communication to assist dying people and their families to face their impending death, provision of physical care as the patient becomes more incapacitated, assisting the family to manage this care, and support of the family following the death of the patient.

Thus cancer and palliative care nursing were complementary, located at different ends of the disease trajectory, the latter becoming increasingly important as curative treatment options became exhausted. Palliative care nurses working in hospital consultancy teams had the most interaction with patients receiving active disease-modifying treatment and hospice nurses the least. However, there were and remain some significant tensions between the two fields of care and between nurses working in them. These tensions largely surround issues such as:

1. When is a cancer treatment such as chemotherapy or radiotherapy warranted in the palliation of someone no longer able to be cured?
2. Is it appropriate to refer a patient with a high need for palliative expertise to palliative services when active attempts to control or even cure the disease continue?
3. How can appropriate palliation be undertaken with minimal understanding of the underlying disease process?

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The cancer treatment system is often criticised for treating beyond the possibility of benefit and for denying the reality that the patient is going to die. The palliative care system is often criticised for failing to understand the difficulties, for patients, family members and health professionals, associated with treatment cessation or for failing to draw on cancer-treatment expertise when appropriate for palliation, eg the use of radiotherapy for a painful bone metastasis.

A contemporary view

The various views of palliative care traditionally represent either an add on once cure is no longer possible, or an increasing involvement over time (see Glare in this issue). These views fail to capture the changed trajectory of cancer to one of ongoing involvement over time. This changing disease trajectory portrays disease control as a key focus of cancer treatment, makes the transition to palliative care less distinct than ever and necessitates an increasing presence of specialist palliative care within acute cancer services. The distinction between cancer and palliative nursing also becomes increasingly blurred as palliative care is increasingly required by patients who continue to have life-prolonging treatments, yet face living with all of the complications of having advanced disease while preparing for a future death.

What does this mean for nursing in cancer and palliative care? For cancer nurses there is an increasing need to incorporate palliative care skills as core aspects of practice competence. The patients who present for cancer treatment are sicker, more physically dependent and face their impending death over longer periods of time with a chronic cycle of hope and uncertainty. This type of disease trajectory calls for a high level of continuity in service provision, the ability to recognise the limits of practice knowledge and a willingness to refer patients to those with greater skill in some aspects of the patient’s care. It also means an increasing need for routine integration of allied health support into cancer care provision. Perhaps most important is a willingness by the cancer team to examine the outcomes of care in those situations where the transition to palliative care is imprecise, for example in bone marrow transplantation and paediatric oncology. Cancer care practitioners need to hear the questioning voice who asks why Mrs Jones, the 35 year old with metastatic melanoma, is being offered more treatment when there was no response to the last treatment and her cancer continues to advance rapidly. They must also not be frustrated when an answer of “because she is 35” is thought to be insufficient justification for treatment continuation and willing to learn from others how to talk to the patient about reaching the end of disease-modifying options. A key benefit of true integration of palliative care in the acute cancer treatment setting is the provision of this kind of questioning, not as criticism, but as an opportunity to sit back and reconsider our approach to assisting patients with their treatment decisions.

For palliative care nurses this changing cancer trajectory brings challenges around the disease and treatment knowledge needed to provide safe and informed care for patients who might be receiving palliative care while continuing with disease-modifying treatments. This also involves accepting that patients and their families may want to continue with active treatment, perhaps in the form of a phase 1 or 2 clinical trial, despite knowing it is unlikely to benefit them directly.

The key to enhancing the care of patients, particularly those with advanced cancer, is improved communication between practitioners in cancer and palliative care. In addition, increased communication will be required between the two service systems to ensure that the patient’s needs are fully communicated and that the patient is skilfully assisted to make decisions regarding ongoing treatment. These changes will also necessitate the development of roles that work across both service systems, particularly ensuring continuity of care into the patient’s home.

Some professional challenges

Some professional challenges arise as this increasingly integrated care system evolves. Specialist nursing education is largely separate, with little crossover between cancer and palliative care. Education of cancer and palliative care nurses into the future will require a flexible curriculum that both allows subspecialisation (for example in malignant haematology or community-based palliative care) but also enables nurses wishing to work at the intersection of the two specialisations to be adequately prepared to do so.

A further challenge is the current difference in professional status between cancer and palliative care nursing. Cancer nursing in Australia is well organised and well represented in both cancer and nursing policy development. Palliative nursing is far less organised and is professionally isolated with the voices of palliative care being around service delivery (through Palliative Care Australia (PCA)) or medically-focused (through the Australian and New Zealand Society of Palliative Medicine). Palliative care nurses have been loathe to build their identity outside of PCA, laudably reinforcing the multidisciplinary nature of palliative care and the need to offer a united voice. However, this emphasis on a united voice has been at a cost to palliative nursing and contributes to the specialisation’s low profile in nursing and lack of national voice in healthcare. A partnership between cancer and palliative nurses at a national and local level is essential for the future development of palliative nursing and for both specialisations to retain contemporary relevance in the care of people with cancer.
Summary

The interface between cancer and palliative care nursing has traditionally centred on caring for a similar population of patients but at different parts of the disease trajectory. Changes in the cancer disease trajectory, brought about by an increased ability to provide non-curative but disease-modifying treatments has increased both the length of the disease trajectory and its chronic nature. This is also an area of increasing consumer participation in healthcare decision-making and improved patient access to information that increases their expectations around quality care, including service continuity. As a consequence future health services will require closer integration of cancer and palliative services that allows patients receiving disease-modifying treatments equal access to the benefits of specialist palliative care. Thus nurses in cancer and palliative care will need to work more closely together if continuity and excellence of care are to be achieved.

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References

Abstract
The majority of people living with a life-limiting illness spend most of their time in the community and would prefer to die at home. General practitioners and generic community nursing service are the lynchpins of primary care. The effectiveness of the interdisciplinary palliative team care has been well demonstrated. What are the challenges for people living with a life-limiting illness when changing sites of care, and what are the difficulties in providing care in the community? How do primary care and specialist teams interface? There are differing models of care. Mechanisms to foster relationships of respect and trust, and to facilitate effective communication are vital if optimal coordinated community care for people living with a life-limiting illness is to occur.

Introduction
One of the aims of palliative care is to facilitate “seamless care”, however reality may not always mirror rhetoric. What are the challenges for people living with a life-limiting illness when changing sites of care, and what are the difficulties in providing timely, supportive care in the community that is sustainable, appropriate and not duplicating or disempowering of existing services?

Primary care
In Australia, the general practitioner and the generic community nursing service are the lynchpins of primary care. There is, however, no formal contract between family doctors and patients. Medical registration boards have requirements that adequate after-hours provisions are made and there are incentives for family doctors to offer after hours and home visiting services. However, there is insufficient financial incentive for prolonged consultations – often needed by the person living with a life-limiting illness or for house calls. Until quite recently funders have not recognised the time and skills required to coordinate care. Enhanced primary care reimbursement items were introduced by the Health Insurance Commission in 1999; however Australian general practitioners have been slow to embrace these – partly perhaps because of their apparent bureaucratic complexity.

General practitioners are community-based, may have a long-standing relationship with the patient and can be ideally placed to offer care from before diagnosis, continuing to prolonged bereavement support for the family. They are likely to be more accessible, visible and approachable. There are, however, many competing demands on general practitioner time. The provision of a sustainable service that meets the needs of patients, balances the many demands on the doctor’s time and provides the practitioner with adequate personal time is a very large challenge. And considering that the average general practitioner is likely to care for only five patients per year who might die with a protracted illness, it is not surprising that problems of skill maintenance and inadequate access to community resources are well-recognised issues. Access to home-visits and after-hours care are concerns for families. And perceived or real delays in diagnosis may also cloud the trust of the therapeutic relationship with the general practitioner.

The majority of people living with a life-limiting illness spend most of their time in the community. Most people when asked would prefer to die at home, however there are challenges and burdens associated with home care. There is the need for increasing support and supervision: the need for a carer. There are the physical difficulties for the patient and the carer. Emotional needs and anxieties about medications and changes in physical condition are real concerns, as are fears about the time of death. Death at home may not be possible or even preferable. Even if death does not occur at home, over 90% of the last year of life is spent at home and in the community.

Specialist palliative care teams
Specialist community palliative care teams have grown as a natural extension of in-patient hospice facilities. In countries including the United Kingdom, Canada and Australia there are interdisciplinary teams of specialist palliative care practitioners working to support people with life-limiting illnesses. Hearn and Higginson have demonstrated improved patient and carer satisfaction when specialist palliative care teams are involved. More patient and family needs are identified and dealt with, time in acute hospitals is reduced and costs of overall care are reduced.

Unlike the United Kingdom, in Australia, palliative care services have developed mainly within mainstream health services. However, service provision is still quite patchy. Rural and remote areas are generally poorly served. There is a scarcity of access to proximate specialist medical assessment and advice, and even access to specialist palliative nursing expertise is limited. Specialist psychological and allied health care is even more scarce. Major cities are generally better served but there are areas of specific need and inequities in access to services.

There is a dearth of high quality research into specialist models of palliative care and its impact on consumer satisfaction. Almost all has occurred in the United Kingdom and is not necessarily transferable to Australia, especially considering the significantly different models of general practice. Evidence of improved continuity of care provision by teams in other areas of health care is available, but inferences cannot be safely made.

Hospital services
Hospital services frequently may see their care as central. Medical and radiation oncologists, surgeons and other involved physicians may request continuing follow-up consultations when active therapies have ceased. The intention may be to provide support and surveillance, and to avoid a sense of abandonment for the patient. This may also be easier than closing the relationship, dealing with what this means for the patient and family, and facilitating a referral to a palliative care service. Even better would be an earlier introduction to palliative services, collaborative care and continuing involvement by the general practitioner. Continuing oncology reviews may give subliminal messages of hope for further treatment options or even cure, when all avenues have been explored. However the
complexity of modern treatments may mean that some general practitioners may have difficulties in being able to provide current and comprehensive care coordination.

The interface

So, what is the interface between primary care and specialist teams? And if care is to be coordinated, by whom?

These are not easy questions and opinions and solutions will vary. The full spectrum of models of care exists. There are palliative care services that take over all medical and nursing services, and models that are entirely consultative, only accepting referrals with the general practitioner’s consent and contracted support in-hours and after-hours. There are general practitioners who expect and are the sole medical expertise for their patients in the community, controlling all external referrals and service provisions.

Use of language such as “case manager” is not uncommon within some palliative care teams, domiciliary services and generic nursing agencies, yet do they really mean and provide this? Or are general practitioners the “gatekeepers to care” or might this role reside with another specialist doctor or even another professional?

Team care in the community has been demonstrated to reduce overall costs, reduce time spent in the acute hospital setting, to meet more patient and family needs and to be rated as highly satisfactory by consumers. The challenge is to assess the strengths and weaknesses of the specific primary care resources, the specialist palliative care team and available service agencies and to work together.

Sensible use of available resources within and outside of the team is important. Models of care may risk being designed to meet provider staffing rather than consumer needs. Rather than gate-keeping or case-management, if care is to be coordinated, there needs to be an overview. Different issues and aspects of care will involve different professionals or members of the team. Yet issues of professional responsibility cannot be avoided by arguments of “team decision-making.” There is a need for flexibility in care planning.

General practitioners and community nurses will continue to provide the greater part of care for patients. All need exposure to the philosophy, knowledge and skills that specialist palliative care has to offer. Palliative care has a social responsibility to continue educating all groups of health professionals and the general public. And if resources or practitioner attitudes or skills are lacking to actively work for change.

Primary carers may need to be taught how to work in a team and roles and responsibilities will need to be explored. The challenge for specialist teams is to support primary carers collaboratively, ensuring that patients receive optimal care; modeling good behaviours and allowing the acquisition of new knowledge and skills in a safe environment.

A challenge for the family doctor is to prepare the patient and family for a palliative focus and supports. Ideally this might be promoted at diagnosis or relapse as one part of the care package. To know when it is the “right time” to make a referral may not always be apparent. Facilitating cordial relationships with an interdisciplinary palliative care team should assist informal discussions about possible referrals, to explore what additional value the team might be able to provide to the current situation.

General practitioners may need to find a way of expressing their view of the clinical scenario and for feeding back their reactions and assessments to the team. Difficulties with the specialist team from the primary care perspective may not be frequently expressed or heard. The general practitioner may need to be active in demonstrating their preparedness to provide not only reactive care, but to adopt a more supervisory stance – to schedule regular review. Teams may need to learn the strengths of nurturing, interfacing and trusting general practitioners.

Communication is a core requirement. This begins with a dialogue at referral to set guidelines and to explore specific issues and needs. A well-constructed formal summary of the assessment is a valuable basis for collaborative care; not an exhaustive document that is in reality a summary for the specialist practitioner’s own records. This responsibility is not only from specialist to general practitioner. Primary carers need to be aware of their mutual obligation for communication and to have developed systems to facilitate this. Teams should try to develop some continuity in who interfaces with a specific primary carer, to assist in developing predictable contacts for primary carers and to allow relationships to develop.

The essence for team members is to foster not only relationships of respect and trust within the specialist team, but also with the hospital communities and primary care practitioners with whom they interact. Clear plans for assessment, review and after-hours support need to be made. And the highest priority and greatest challenge for all providers is effective, succinct, timely mutual communication.

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TREATMENT AND PALLIATION OF CANCER IN THE REMOTE SETTING

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Introduction

This paper examines the interface between cancer treatment and palliation for patients living in remote areas, using an example from central Australia. Issues identified include the variable distribution of health care resources, cultural and language differences between Aboriginal clients and health care staff, and consideration of the benefits and burdens of treatment.

Alice Springs provides regional health services for nearly 50,000 people living in remote inland Australia, of whom approximately one-third live on small communities scattered across the southern Northern Territory and cross-border regions of South Australia and West Australia, and one-third are Aboriginal people from a wide range of language and cultural groups. The Royal Adelaide Hospital runs an outreach medical oncology clinic at Alice Springs Hospital three times a year. The regional palliative care service is based in Alice Springs; one third of its referrals are from remote areas and one third of returning for terminal care. Parenteral medications, a syringe driver and other equipment were sent to the community to support changing needs. Jane was cared for at home until she died some days later.

Remoteness is a relative concept. Many patients being medically managed from Alice Springs live hundreds of kilometres from the town. Coming to town means being in a different country, where different languages are spoken, and the patient may be alienated physically, culturally and spiritually. Cancer diagnosis and treatment may require a further journey 1,500km south to major centres in Adelaide. Distance may have an enormous practical impact on the diagnosis, medical decision-making, care planning, treatment and palliation of cancer.

Case History

Jane, a 49 year old, married, Aboriginal woman living at Community X, 350 km east of Alice Springs, presented to the Aboriginal Medical Service in Town Y, 500 km north, with symptoms of weight loss, abdominal pain and dysphagia. In Alice Springs, CT revealed mediastinal lymphadenopathy and metastases in liver and bone, and a histopathological diagnosis of oesophageal cancer was later made.

Following oncology advice, Jane was offered palliative radiotherapy, chemotherapy and a palliative care referral. Jane spoke little English, and palliative care staff were concerned that she had not fully understood her prognosis and the nature and purpose of treatment, however no interpreter in her language was available. A final treatment decision was deferred until the arrival of family members from X and Y, who acted as both advisers and interpreters.

Jane accepted treatment, travelled to Adelaide with a family escort, and underwent radiotherapy and her first two cycles of chemotherapy (Cisplatin and 5FU). The third cycle was completed successfully in Alice Springs, despite a prolonged admission due to a pyrexial illness. Unfortunately, the fourth cycle was not given when Jane next presented, presumably due to a misunderstanding, and during a subsequent visit for specialist review, she was not seen by the oncologist. At a family meeting convened at X, Jane decided against further chemotherapy (although the doctor again doubted her comprehension), and opted to remain there for terminal care.

She moved near to the clinic and her family gathered from Y and outstations of X to provide home care and support. Coordinated palliative care was planned, involving regular multidisciplinary telephone reviews between the palliative care service in Alice Springs and the primary care team at X, assistance with medications and equipment, and the option of a remote community visit for palliative assessment and staff education.

Several weeks later, Jane was evacuated to Alice Springs Hospital for management of increased pain, vomiting and dehydration. Clinic staff indicated that her family were worried about her dying on the community. She was treated for a UTI and severe constipation, her symptom control was improved, and she was discharged on oral medications, with the option of returning for terminal care. Parenteral medications, a syringe driver and other equipment were sent to the community to support changing needs. Jane was cared for at home until she ceased oral intake, and then re-admitted to hospital where she died some days later.

Diagram 1: Health care provision for Jane

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Issues arising from the case:

1. **Late presentation for treatment.** Jane presented quite ill and cachectic, with advanced disease, having put up with pain and dysphagia for some considerable time. Arguably, an earlier referral may have led to different treatment options and an improved outcome.

2. **Understanding of treatment options.** Communication difficulties were recognised at several points in Jane’s illness. These may have hindered initial assessment and diagnosis, and were pertinent to her acceptance of treatment, and probably instrumental in her ceasing it.

3. **Need for appropriate decision makers.** For cultural reasons, Jane could not make her treatment decision alone. One wonders to what extent her change of mind resulted from further family input once she returned home.

4. **Access to treatment.** Jane had to travel nearly 2,000km from her home for radiotherapy in Adelaide, and subsequently several hundred kilometers by road every four weeks for chemotherapy. These journeys would have been particularly difficult because she was frail and unwell.

5. **Social isolation during treatment.** Jane was ill, probably worried or afraid, and knew that she had limited time. While she did have a family companion (the only other person who spoke her language) in Adelaide, during her Alice Springs admissions she was alone.

6. **Place of care negotiations.** While terminally ill patients can be well cared for on remote communities with appropriate support, care preferences are determined on personal, social and cultural grounds. Jane’s family decided where she should be cared for, by whom, and for how long, and those choices were respected and supported.

**Discussion**

In central Australia, treatment decisions and outcomes are determined by a constellation of geographical, resource, cultural and communication factors. While Jane was offered best practice management of her cancer, and attempted valiantly to undertake her treatment, these issues impacted at every stage of her interaction with the health care system.

**a) Diagnosis**

Delays in illness presentation may reduce treatment options. It has been suggested that delayed identification may contribute to the significantly increased mortality rates from cancer amongst Indigenous Australians5-8. Presentation for health care depends on patient factors, including their conceptions of illness and their level of trust in the health care system, and systemic factors, including physical access to and cultural acceptability of services.

There is considerable Australian1,4,6,7 and international8,9,10 evidence that Indigenous people in formerly colonised countries may distrust government services such as health care institutions. This results from previous experiences of discrimination and disempowerment11-13. Although Aboriginal people do not access mainstream services well14, acceptability may be enhanced within Aboriginal medical services, and by improving access to Aboriginal clinical, liaison and interpreter staff14,15.

The distribution of health services in the Northern Territory is skewed towards urban areas16, and in remote regions, where 69% of the Aboriginal population lives17, equity of access is not being achieved14,15. For logistic reasons, some diagnostic facilities can be provided only in larger centres. Thus CT is available in Alice Springs and Darwin, whereas MRI is available only in Adelaide.

Geography is immutable, but patients’ access to, and acceptance of, diagnostic services are not. Addressing these should improve their treatment options and may shift the balance away from palliation and towards more curative treatment. For patients, the potential benefits of this shift will depend on the quality of care planning.

**b) Care planning**

Successful care planning requires appropriate decision-making. This should include the input of the patient, family caregivers, and health professionals at each level of the health care system. The burdens and benefits of treatment need to be balanced from the patient’s perspective.

For patients whose first language is not English, information giving and important treatment decisions require professional interpreting. The adverse impact of poor communication on health care for Aboriginal people is well documented20,21,22. The use of family interpreters, while common, is fraught with difficulties23. Cultural requirements for family decision-making should be respected. Western notions of patient autonomy may be inappropriate in some cultural contexts24,25. In Aboriginal societies, as with some other cultural groups, important decisions are generally made collaboratively26,27,28. The Aboriginal kinship system will determine the correct person to take on a decision-making or spokesperson role.

In terms of professional input, both primary care workers, who know the practicalities of the patient’s situation, and specialist oncology providers offer equally important advice. Liaison between care providers is considered an important function of the palliative care service in central Australia; service workers attend oncology clinics and hospital ward rounds, convene multidisciplinary care planning meetings, and try to maintain a palliative care perspective in the care planning agenda. This requires a patient and family centred approach, and an emphasis on quality of life.

For some remote clients, the difficulties of travelling long distances for treatment and spending extended periods of time away from family29,30 may outweigh the perceived benefits of treatment. As exemplified in the case history, the care plan must sometimes be revised. Both physical distance and socio-cultural alienation are important influences on the interface between cancer treatment and palliation.

**c) Cancer treatment**

The concentration of oncology treatment in specialist cancer treatment centres (and of palliative care expertise in major metropolitan palliative care units) facilitates excellence in care and rational use of resources. Access to such expertise is, however, more difficult for remote clients. While some technologies cannot be made available in remote settings, improved planning can reduce unnecessary journeys and the time away from home. A program of teleoncology case reviews between the Royal Darwin Hospital and the Royal Adelaide Hospital reduced the duration of Darwin patients’ treatment in Adelaide (and associated costs) by approximately eight days*.

For central Australian patients, chemotherapy may be initiated in Adelaide, but is generally completed in Alice Springs. The provision of chemotherapy in smaller and more remote centres raises issues of training, supervision, and supply.

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* Professor Ian Olver, Royal Adelaide Hospital, personal communication, November 2001.
Radiotherapy is only available in Adelaide. Travelling long distances for radiotherapy results in considerable social, cultural and financial costs to patients, which must be balanced against its potential benefits for improving quantity and quality of life. This becomes particularly important in the palliative phase, when patients are frail and time increasingly precious. Distance from treatment centres, lack of financial and psychosocial support to travel there, and the ensuing social and family dislocation contribute to low radiotherapy treatment rates in Australia\(^3\). Cancer status at the time of presentation and treatment duration are important factors in deciding between treatments (for example, palliative versus curative treatment; radiotherapy versus surgery).

General surgery is available in Alice Springs, but specialist procedures only in Adelaide. For many cancer patients from remote communities, the prospect of a prolonged stay for surgical management in Adelaide is understandably daunting. In order to provide informed consent, the patient needs to understand, preferably prior to transfer, not only the rationale for and nature of the surgery, but its sequela (eg laryngectomy care, colostomy care). Patients undergoing such procedures who live in situations of poverty or isolation face particular difficulties in returning to community care.

When a patient decides against, or withdraws from, active treatment, they should be supported in accordance with recognised standards of palliative care\(^4\), regardless of their preferred place of care.

d) Palliation

The palliative care service based in Alice Springs has a regional responsibility to a dispersed and multicultural clientele. Its challenge is to overcome geographical, institutional and cultural impediments to care provision.

International data has shown that members of minority ethnic communities do not access palliative care services in numbers commensurate with their proportion in the mainstream population\(^5,13,14\). Ways of overcoming barriers to Aboriginal patients’ access to mainstream palliative care services have been previously described\(^6\). Many Aboriginal patients have expressed a wish to die on their traditional country, however access to appropriate support resources has been problematic in remote areas\(^5,7\), including the Northern Territory\(^13,17\). Poverty and lack of access to health hardware\(^8\) are important factors influencing the success of home palliative care\(^9\). If palliative care is to be delivered in the environment of the patient’s choice, in remote areas it needs to remain decentralised and flexible\(^5,8\). It also needs to be delivered in a manner that meets the cultural needs of Aboriginal patients and families\(^10\).

In a practical sense, this means building trust, and listening to those whose business it is to transmit cultural and family information. Good palliative care is not measured by the whiteness of one’s sheets or the frequency with which the patient is turned, but by maximising quality of life, in the patient’s terms, and fulfilling their wishes. In my experience, with adequate planning and liaison, good symptom control can generally be provided for patients living in remote communities.

Conclusion

The interface between cancer treatment and palliative care will shift depending on patients’ circumstances. These are not mutually exclusive management options, but interlocking methods of healing (here used in its broadest sense). Both treatment and palliation of cancer may be more difficult for patients living in remote Australia, due to their physical isolation from many services. In central Australia, Aboriginal patients face additional cultural and language barriers to cancer care. Best practice care can still be given, provided that it takes into consideration patients’ expressed needs and informed treatment choices. This type of cancer care is in accordance with the principles of palliative care, which emphasises quality of life, holistic care, and patient and family centred management\(^13,40\).

Acknowledgement

I would like to thank Professor Ian Olver for his helpful comments on this paper.

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DEVELOPMENT OF EVIDENCE-BASED CLINICAL PRACTICE GUIDELINES FOR BEST PRACTICE: TOWARDS BETTER OUTCOMES

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Professor Reeve is the recipient of the MOG/Merck, Sharp and Dohme Cancer Achievement Award for 2001. The award recognises outstanding Australian contributions to and achievements in cancer research or control. This paper was presented at the award ceremony.

“They are called wise who put things in their right order.” – Thomas Aquinas

Medicine ranks among the very earliest of professions and continues to hold a high but somewhat challenged place in our community. However, to remain relevant in an increasingly sceptical and demanding society, the profession has been required to probe and review its structure and the quality and outcomes of the services it provides. Medicine clearly needs to embrace new structural opportunities and reduce risks in its processes, while continuing to deliver the highest quality of clinical care to the community.

Accelerated societal change began to cause some discomfort for the medical profession several decades ago; renewed interest in evidence-based medicine was observed at about the same time. In a proactive step, professional leaders began to assess the successful response of business and industry to variation and quality, and review the relevance of these activities to clinical practice1,2. This has meant embracing change where appropriate after careful review, reinforcing clinical activities that were supportable, shedding those that were marginal or dubious, and aiming to bring evidentiary material of a high level into clinical practice within a reasonable time frame3.

This activity led to the embracing of evidence-based medicine, which has been defined as “the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients”4.

The use of evidence in clinical practice requires a marriage of clinical skill and experience with the best evidence that has been accrued from a systematic search of the literature5, or even by carefully reviewing the structure of practice, process and outcomes in a quality milieu6. This requires constant review and response to perceived variables if quality is to be reinforced and maintained.

The acknowledgment of these dynamic situations led to the elaboration of evidentiary material in areas related to clinical practice. These became crafted into “Guidelines”.

At this stage, late 1993, the Australian Cancer Network (ACN) was established and began to address guideline development as a major activity. The aim was to bring accurate material relating to the clinical care of cancer to clinicians, medical students and other interested people in a timely fashion.

Involvement with National Health and Medical Research Centre (NHMRC) guidelines7, which had just commenced their development8, was a useful supplementary activity. Pursuing this path the ACN has had some success in developing evidence-based documents (list of publications follows).

The National Breast Cancer Centre (NBCC) was established in 1994 and ACN has had involvement in several of the guidelines developed by the centre. This interaction has been of benefit to both bodies.

In the same time frame, NHMRC, through its Quality of Care and Health Outcomes Committee, established a working party to develop criteria for guidelines, and in 1995, “Guidelines for the Development of Clinical Practice Guidelines”9 were published. These have since been substantially revised and expanded10 and now represent the standard against which clinical practice guidelines endorsed by NHMRC are developed.

A prime purpose for guideline development was to establish not only an evidence-base, but also to provide a resource base against which personal outcomes would be monitored through an audit process.

“A good culture is maintained by designing a way for people to monitor their own behaviour. Everyone must know how they are doing if we expect them to assume accountability.” – James Champy.

The expanding issue of audit at a personal level and as group comparators is another clear advance in addressing variation in practice as has been seen and widely embraced in the Royal Australasian College of Surgeons breast audit11. The ACN has been and continues to be highly supportive of this College endeavour.

What are clinical practice guidelines?

The most widely accepted definition is that of The Institute of Medicine: “Systematically developed statements to assist practitioner and patient decisions about appropriate healthcare for specific clinical circumstances”12. This definition provided the benchmark which ACN has established for its guideline development program.

What guidelines are not

While being a valuable resource of tested evidence and contemporary information, guidelines do not cover every aspect of medicine.

They leave room for, and in fact require, clinical experience and good doctoring if they are to be implemented effectively. Clinicians and others are encouraged to draw on their personal and communal reservoirs of clinical knowledge and not to ‘throw out the baby with the bath water’ by playing down these valuable skills.

Guidelines are not:

- Replacements for clinical decision-making
- Prescriptive – not a cook book, to be slavishly followed
- Coercive for patients
- Comprehensive
- Total cover for all clinical situations

Why clinicians benefit from guidelines?

Guidelines are likely to be helpful when there is a large health burden; when current clinical practice varies widely, when there are large cost differentials between alternatives; and when there is new evidence not yet widely implemented or
being slowly embraced”. If, however, it is viewed as a cookbook, reasoned application of the Guidelines should produce a “cordon bleu” result.

Their application is limited and their availability is of reduced relevance if the current forms of practice are of uniformly good quality, or if no effective evidence is available to raise the quality of clinical practice.

Guidelines are useful in addressing cost and quality issues, where good quality care is expensive and poor quality more expensive.

Variations in clinical practice require monitoring, review and comparison of resource use if their effect is to be fully evaluated and changes introduced when necessary.

**What types of guidelines are available?**

There are several types of guidelines; two are more or less laid down and directive whereas the third results from systematic review of peer reviewed literature and provides the basis for best practice. This approach has added value when it identifies areas in which research would be appropriate to underpin areas of deficiency in clinical practice. All ACN guidelines have been based on available evidence.

**Types of guidelines**

*Prescriptive*: these direct specific action, are developed by a controlling group and are not necessarily evidence-based.

*Consensus*: usually developed by a knowledgeable group, from personal preference and selected evidence.

*Evidence-based*: these are based on systematic review of scientific data with input from knowledgeable clinicians.

**Guidelines and clinical decision making**

For guidelines to be useful in clinical decision making they must meet criteria that relate to the level, quality and strength of evidence and be relevant to the clinical problem under review. Clinical experience and decision-making skills add further value in the introduction of guidelines to clinical situations. The levels of evidence as now applied to guideline development have been clearly defined by the NHMRC in 1998 and are listed in Figure 1.

**Figure 1: Levels of Evidence**

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Evidence obtained from a systematic review of all relevant randomised controlled trials</td>
</tr>
<tr>
<td>II</td>
<td>Evidence obtained from at least one properly designed randomised controlled trial</td>
</tr>
<tr>
<td>III-1</td>
<td>Evidence obtained from well-designed pseudo-randomised controlled trials (alternate allocation etc.)</td>
</tr>
<tr>
<td>III-2</td>
<td>Evidence obtained from comparative studies with concurrent controls and allocation not randomised (cohort studies), case-control studies or interrupted time series with a control group</td>
</tr>
<tr>
<td>III-3</td>
<td>Evidence obtained from comparative studies with historical control, two or more single arm studies or interrupted time series without a parallel control group</td>
</tr>
<tr>
<td>IV</td>
<td>Evidence obtained from case series, either post-test or pre-test and post-test</td>
</tr>
</tbody>
</table>

Not all guidelines will be at this “gold standard”, but it is necessary to have a commitment to eliciting the best available evidence and Figure 2 provides a range of approaches to achieving levels of evidence ranged in their order of strength. In 1998 level IV evidence was raised in strength as against that propounded in 1995. Level IV evidence still abounds in guidelines and indicates the clear need for research in many areas of clinical practice where a low level of strength of evidence leads to expression of opinion only.

Observing the rules for developing evidence through systematic review can be a most demanding process and one wonders whether Peter Mere Latham was preparing guidelines when he made the following observation:

“Truth in all its kinds is most difficult to win; and truth in medicine is the most difficult of all ... People in general have no notion of the sort and amount of evidence needed to prove the simplest matter of fact.” — Peter Mere Latham (1789-1875).

**Guideline development and implementation process**

Having recognised the value of applying evidence in clinical practice and choosing the type of guidelines to introduce, it is necessary to establish a working group to develop them. This group should meet a number of criteria: skill, representative role, gender and geography. The group needs to be committed to the work program, appreciate what is expected of it, members who get along with each other and allow leadership to be evinced through the Chair. It is a tall order and in the process “Justice should not only be done, but should manifestly and undoubtedly be seen to be done” (Lord Hewitt (1870-1943)). To demur or deviate can be fatal to the development process.

A suggested multidisciplinary panel would encompass at least the following range of contributors:

- Specialist clinicians
- General practitioners
- Consumer representative
- Allied health professionals
- Research methodologist
- Health economists
- Public policy analyst
- Other experts
- NGO representative
- Industry representatives
- Bioethicist
- Regulators

Working together, they make a powerful multidisciplinary group. It is preferable to promote sub-committee activity than have a large and unwieldy main panel.

The multidisciplinary working party has significant activity in systematically reviewing current literature, particularly when the 20,000 journals and 200,000 papers published annually is the possible review base. This explosion has led to development of special literature searches and collaborations (Cochrane), but there remains a substantial task for each working party to systematically search literature to draft the guideline documents. The drafting procedure is demanding and may require a number of revisions before going to public consultation, when they will be revised again. This work has
been done pro-bono by a large body of devoted professionals from professional organisations or as individuals, and all should be recognised for their significant contributions.

The processes outlined in Figure 2 require to be followed if the guidelines are to be endorsed by the NHMRC and each is an important component if a quality document is to be prepared. There is no quick path and a lot remains to be learned about dissemination and implementation. Monitorig activities, e.g. patterns of care studies measured at or before the publication of the guidelines (Hill and Spigelman), have yet to be repeated at a time following guideline publication and comparisons will be valuable documents when available.

**Concerns about guidelines**

The major concerns are that guidelines could compromise clinicians if patients choose a course of litigation when an outcome is less than satisfactory. There have been concerns raised from time to time all of which are realistic and cogent. Legal concerns have been raised in a highly litigious medical environment and have increased clinicians’ concerns of their vulnerability. However, with time the concern is diminishing and comfort with the guideline process and the resultant guidelines is increasing.

The view is being taken that the accrual of evidence in a transparent manner by a well-established multidisciplinary working group provides significant protection, and the view outlined by Crown Law authorities is also supportive. The paper by Peter Dwyer also has been helpful; viz “in considering the acceptance and use of clinical practice guidelines, the medical profession should not be distracted by speculation about legal implications”.

Concerns regarding loss of professional freedom are to a certain extent in the eye of the beholder, but at no point should guidelines be promulgated without the disclaimer prefaced in each set: “This document is a general guide to appropriate practice, to be followed only subject to the clinicians’ judgement in each individual case”.

The guidelines are designed to assist decision-making and are based on the best information available at the date of compilation and should allow the level of flexibility outlined in the disclaimer.

There is not and has never been any attempt to reduce the importance of clinical experience and decision-making in patient management.

For some, the introduction of guidelines will lead to a review of their practices, e.g. over half of surgeons answering a questionnaire would change practice in some way after reading the Guidelines for the Prevention, Early Detection and Management of Colorectal Cancer. This may lead to a shift of practice emphasis (as noted with the introduction of laparoscopic surgery, or reduction of gastric surgery with knowledge of H. Pylori) and as a result, may lead to some reduction of income. It needs be said, however, that new strong evidence could expand the clinician’s role, but may increase cost to produce better outcomes through expanding use of technology and more focused care. It is not a necessary outcome for guidelines to cut cost.

**Do guidelines work?**

There is evidence that clinical practice guidelines have had wide acceptance, e.g. Melanoma Guidelines 1995 were distributed on request and 25,000 volumes were requested. The same guidelines were requested to be translated into Spanish by the Argentine Institute of Piel and disseminated in both Argentina and Spain. The 1999 revision has enjoyed similar acceptance.

Furthermore Carrick et al revealed that more than 80% of surgeons who had read all or most of the Early Breast Cancer Guidelines believed “them useful in improving women’s management and well being, easy to understand, evidence-based, a good summary of recent evidence and that they would assist agreement between women and health care providers.”

There have been comparisons of guidelines, but none of cancer outcomes. There has been insufficient time to assess the effects on cancer outcomes of locally produced guidelines.

Overseas studies have shown some influence on practice. Grimshaw and Russell, in 59 studies evaluating impact on...
process, demonstrated improvement in 55, and in 11 studies evaluating outcome, demonstrated nine improvements.

Ward 1997 studied responses from 69 (of 90) surgeons sent questionnaires on the NHMRC Clinical Practice Guidelines for Management of Early Breast Cancer and found that they had been relatively well received by the group of clinicians answering the questionnaire.

Grimshaw and Russell and Ward comment that careful dissemination and implementation are required to make any substantial impact with practitioners.

**Dissemination**

Guidelines should be made as available as possible to relevant groups of clinicians, clinical training programs and undergraduate programs, cancer organisations, professional colleges and consumer organisations.

General practitioners find a specially formatted laminated double sided A4 document to be readily accessible when consulting. In many instances a GP may see only one or two patients in a specific guideline category each year, eg breast cancer.

It is not sufficient to simply mail a document. There needs to be follow through to ensure not only that the document has been delivered, but that it has been received and read.

Telephone enquiry, academic detailing, presentations at hospital and local medical associations are useful measures to promote this activity.

**Implementation**

Some guidelines are purely clinical, being either observational or behavioural, and require no specific aids or technology for their acceptance. If they are not readily assessed, they may not have registered as part of a mind set to improve clinical practice. Guideline developers need to penetrate this barrier.

Some guidelines will be resisted as they attack the comfort zone of established behaviour, eg those for auxiliary management in breast cancer will require incentive(s), education and persuasion for them to be accepted.

Other guidelines will require cooperation with wide collaboration, the embracing of other disciplines and perhaps the relinquishment of the clinician’s own role in a particular activity to enhance a clinical process and outcome.

There are still system barriers to be overcome and incentives, persuasion and education will all play a role in effectively implementing guidelines as they are produced.

**How guidelines help in practice**

- The evidentiary base provides a sound foundation on which to introduce changes to resource allocation.
- The guideline process identifies hiati in knowledge or processes and so identifies opportunities for clinical research.
- To definitively change established treatment or define new treatment requires the highest level of evidence applicable to the problem, preferably level I or II evidence.

**Clinical best practice**

Guidelines are built on three pillars:

- Evidence
- Clinical Expertise
- Patient Choice

These principles, when introduced and reinforced at a high level, should help meet the demands modern society places on its clinicians.

In May 2001 the NBCC held a workshop on the guidelines process and developed conclusions to be considered in planning the way ahead.

**Focus issues**

- How can we best develop guidelines? (Embrace systematic reviews and evidence)
- How can we overcome system barriers to best practice? (Remember the Berlin Wall)
- How can we best implement and render guidelines accountable? (Open the gates to each other – now)
- How can we encourage best practice by “generalists”? (By adoption of multidisciplinary practices)

**Challenges**

- Best wording of guidelines (No ambiguity – simple)
- Identify groups who need the guidelines (Us as well as them)
- Appropriate information for all women and men (Of course!)
- Identify priorities for implementation strategies (Will not always avoid toes)
- Best way to revise guidelines in timely fashion (Running review, don’t delay)
- Managing the cost issues (Continue to give our time freely or lose leadership)

(The bracketed remarks are the personal views of the author.)

Guidelines in the future must address some of these issues if they are to remain relevant, the current processes for development are too slow and yet NHMRC endorsement is seen as an imperative if they are to be implemented. The NHMRC imprimatur is important to Australian clinicians.

More rapid updating may be achieved by circulating new evidence once evaluated by fax, email, Internet, phone calls, etc.

More rapid revision processes must be developed to ensure that guidelines remain contemporary. Revision probably should commence on the day guidelines are published. Development of easily accessed data banks is another option.

Guidelines and their evidentiary base could be directed into critical pathways and we should continue the effort to produce gold standard evidence.

**Conclusion**

The preparation of clinical practice guidelines from systematically reviewed literature and the marshalling of the evidence so it can be used effectively by clinicians has provided a new resource for clinical care in some cancers. With widening acceptance, clinicians will have found a ready source of sound information for guidance when making a diagnosis and caring for patients.

They will hopefully change in a constructive way and put an end to Bertrand Russell’s claim that “… the most savage controversies are about these matters as to which there is no good evidence either way”.
Acknowledgments
The author wishes to acknowledge the support and discussion time of Professor Alan Coates, Professor Sally Redman, Professor Bruce Barralough, Professor Leigh Delbridge and Dr Karen Luxford and Mrs Christine Vuletich for her exemplary care with preparing guidelines for publication.

He is also grateful to all members of working parties and those who have taken time to assist the Australian Cancer Network in its guideline development program.

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2 The Pathology Reporting of Breast Cancer – ACN, May 1997
3 Guidelines for the Management of Cutaneous Melanoma – ACN, June 1997
4 Guidelines for the Prevention, Early Detection and Management of Colorectal Cancer (CRC) – NHMRC endorsed, March 1999
5 Clinical Practice Guidelines - The Management of Cutaneous Melanoma – NHMRC endorsed, December 1999
7 The Pathology Reporting of Breast Cancer – ACN, October 2001
8 Familial Aspects of Bowel Cancer: a guide for health professionals – ACN, 2002
9 Guidelines for the Management of Localised Prostate Cancer (to be published)
10 Guidelines for the Management of Non-Melanoma Skin Cancer (at first stage public consultation)
11 Guidelines for the Management of Epithelial Ovarian Cancer (in preparation)
12 Guidelines for the Management of Lung Cancer (in preparation)
13 Guidelines for the Management of Non-Hodgkin’s Lymphoma (in preparation)
The Chinese Cancer Society of Victoria (CCSOV) began in 1996 with a Chinese social worker, a group of four Chinese people with cancer, and support from three other Chinese health workers. It has grown to an organisation of about 100 people, comprising people with cancer and their families, and is run entirely by volunteers from within this membership, including some health professionals.

Within Chinese culture, cancer is hidden and not spoken of, as it is seen as a stigma on the family. Immigration and lack of familiarity with the language and the health system in Australia impose further difficulties for many Chinese people with cancer in this country. In this context, the CCSOV provides not only a place where people can talk openly, but strong social networks and a raft of other support and education services. Fund raising, always a challenge, has provided another focus for recreational and social activities, while the Society’s publications offer an outlet for the stories of people with cancer. Overall, the CCSOV has contributed substantially to the quality of life of Chinese people with cancer and their families, and it provides a possible model for other organisations of this nature.

Introduction

This paper traces the development of a unique cancer support organisation in Melbourne – the Chinese Cancer Society of Victoria Inc (CCSOV). The Society, which began simply as a support group affiliated with The Cancer Council Victoria (TCCV), adopted its present name in 2000 in recognition of its original impetus was a request from a woman from mainland China, who arrived a decade or more ago came from Hong Kong, a proportion with some experience of western culture and English language. Most of these people are now well settled in Australia, with some knowledge of how to use the health and community support systems. Chinese immigrants from Malaysia and Singapore also tend to speak English. Many of the more recent arrivals, however, are from mainland China, have less experience of western culture, and speak little or no English when they arrive. Paradoxically, however, experience in the field suggests that these mainlanders, often from a harsher background, appear less concerned with “face” and more open and willing to ask for help.

Mok and Martinson, writing about cancer support groups in Hong Kong, identified two aspects of Chinese culture that strongly influence attitudes to cancer and help seeking within the Chinese community. Firstly, a high priority in personal relationships is to maintain strength and harmony, in contrast to the fragmentation that can result from individualism. This is related to the concept of “face”. It leads to a group-oriented culture that emphasises the homogenous nature of society, where difference makes people feel ashamed and embarrassed. People with an illness are reluctant to talk to friends about it because illness sets them apart as “different”. Secondly, Mok and Martinson pointed out that Chinese culture distinguishes between “insiders” (family members and familiar people) and “outsiders” (everybody else). Social dealings within the family group are invested with trust, giving, and feelings of belonging. Social dealings with outsiders are based largely on consideration of personal gain and loss, and interaction tends to involve meticulous and detailed calculations of potential results from transactions, with unwillingness to make even the smallest sacrifice. Reciprocity is important: one should not owe any favours, either tangible or intangible, and should make every effort to pay back any favours owed. Such reciprocity helps to maintain social harmony. In the context of cancer or any life-threatening illness, however, this “economic” approach to relationships makes people unwilling to invest in a relationship with someone who is dying.

Meeting the need – evolution of the CCSOV

This is the context within which the CCSOV evolved. The original impetus was a request from a woman from mainland China with cancer, herself a nurse, to Chinese social worker Dorothy Yiu, who was then working in a centre for older Chinese people in the inner suburb of West Melbourne. The woman with cancer knew of the existence of other support groups and recognised their potential value for combating the isolation she was experiencing.

The first group began in 1996 with only a few people with cancer. The group met at the North Yarra Community Health Service under Dorothy Yiu’s guidance, with help from two
Chinese nurses and a Chinese health educator. Its monthly meetings provided an opportunity for these people to sit and chat, in their own language, with people of the same cultural background, about things that were taboo in the wider Chinese community.

The value these early participants gained from the group highlighted the need to offer such opportunities more widely within the Chinese community. Letters were sent to nurses on oncology wards, but numbers grew only very slowly until, 18 months later, the fledgling organisation moved to the suburb of Box Hill, a centre for the Chinese community.

In November 1998, the Group was incorporated and two years later, in November 2000, it adopted its new name, the Chinese Cancer Society of Victoria. The Society defined its aims as follows:

- To provide compassion, care and counselling to all people from Chinese background who are affected by cancer.
- To attempt to alleviate suffering, fear and distress in all people from Chinese background who are affected by cancer.
- To raise awareness in the community of the specific needs of people from Chinese background who are affected by cancer.
- To provide printed and non-printed resources in the Chinese language about cancer.
- To offer bereavement support to bereaved families.
- To facilitate communication between patients and their families to cope with the stresses of illness.

Since that time, the CCSOV has grown to about 100 people. About half of these are people with cancer, with families and some cancer-free volunteers making up the other half. CCSOV now runs support groups at two community health services in the Box Hill and Fitzroy areas. Many people hear of the Society by word of mouth, but increasing publicity has also seen an increase in referrals from hospitals, palliative care services, and State Trustees.

Building support networks in the Chinese community

The CCSOV remains an TCCV-accredited support group and works closely with TCCV's Living with Cancer Education Program. The support group meetings, however, are only a part, albeit an important one, of the Society's achievements and activities.

CCSOV has generated strong social and support networks. Many members have become friends and meet often and informally. The Society's office, located in the Box Hill shopping centre, provides a well-used drop-in centre with tea, coffee and comfortable chairs, and it houses the Society's growing library of Chinese language cancer resources.

The environment is one where people can make friends, both give and receive support, and not feel threatened. The prohibition on talking about cancer is irrelevant. With everyone in the same situation, there is a freedom to talk, and symptoms that would draw attention outside the group – things such as loss of hair or extreme slowness in eating – are simply accepted.

Within the Society, people have come to see each other as “insiders” or family, as described by Mok and Martinson\(^1\). They will give openly of themselves without expecting something in return. The opportunity to offer support and help to others is therapy in itself and fosters a sense of meaning and purpose. Many say after coming to the group that they feel brighter and have found meaning in life again. They no longer want to sit hidden at home.

With careful facilitation and discussion within the support groups, members have also come, gradually, to be able to deal positively with death; to talk about it, acknowledge and respect it, grieve, and move on. This attitude has become pervasive with the Society.

The CCSOV is run entirely by volunteers among its membership. There are currently about 30 volunteers, and together they provide a wide range of services to Chinese people who are touched by cancer. A number of the volunteers have a professional background in social work, nursing, physiotherapy or teaching; others have no formal training. The services they provide are matched to their particular interests and skills, but as a whole, the Society provides home and hospital visits, telephone support, counselling by social work or nurse volunteers (to patients, carers or bereaved families), and urgent practical assistance, such as transport, cooking, interpreting, home duties, and bereavement support.

There are a number of recreational, social and educational activities. Barbecues and festival celebrations (such as Yum Cha for Mother's Day) are regular events, and there is an annual visit to the country. The Society runs short courses with the aim of helping to alleviate pain and anxiety. Topics vary according to the interests of those in the Society, and have included classes in a range of supportive and interest areas such as T'ai Chi and art. Regular Chinese language community education sessions are publicised by Chinese language radio and press, and have covered topics such as breast health, various cancers, and information sessions on other services such as Centrelink and State Trustees.

Finding the funds – a team effort

Donations, bequests, fund raising and some small grants have enabled the Society to provide one-off financial assistance, including help to people who cannot access social security benefits due to residency status (benefits are not available for the first two years in Australia) or other unforeseen circumstances.

All services are free of charge and, while overheads are low (everything is achieved with volunteer labour), fund raising is extremely important. This has provided a focus for many recreational and social activities, and has involved large numbers of people. The fund raising is a team effort, and again, people see they can contribute, and are important and useful. Fund raising efforts have been helped by the Society's recent recognition as a charity with tax deductibility status, and a subcommittee is currently working towards corporate sponsorship as well, with promise of success.

The most exciting and profitable of the fund-raising activities has been the Society's concerts, held in 1999 and 2001, which each raised some $20,000. The strength of these events was their strong community base and the team effort they fostered. Each concert involved almost all members of the Society, showcased many musical and other acts by people within the Chinese community – a highlight being the Society's own choir – and attracted an audience of some 400 people. This success has provided a major boost to members' sense of confidence as a society, as well as a significant contribution to funds, and this has been reflected in a considerable increase in involvement, activities and commitment since the first concert.
Telling people’s stories

The Society’s quarterly newsletter features people’s stories of their experiences with cancer, and these have been compiled into a book, Hope, which was launched by Professor Robert Burton, Director of TCCV, at the Society’s concert in August, 2001, to mark the International Year of Volunteers.

Both the book and the newsletters have given volunteers, cancer survivors and carers the opportunity to write of their experiences. The book has been received with great enthusiasm by the Chinese community, and a number of experiences. The book has been received with great language newspapers, both state-wide and national, by the Chinese community, and a number of extracts. It has had a considerable impact in Chinese language newspapers, both state-wide and national, by the Chinese community, and a number of Chinese language newspapers, both state-wide and national, have published extracts. It has had a considerable impact in terms of raising the profile of the Society and raising awareness of the issues faced by Chinese people with cancer.

Challenges ahead

The success and growth of the CCSOV have generated a number of challenges that need to be addressed in the immediate future.

The demand on volunteer time and, in particular, on the time of the small core of volunteers with health and community support qualifications, has grown hugely; as has the administrative workload related to company law, taxation and the like. Funding is needed to support the employment of a professional and/or administrative worker; but this in itself will bring major changes within the Society that will require adjustment. It has the potential to change the whole philosophy and direction of CCSOV, and will need to be managed with great care.

Publicity remains an ongoing challenge. While CCSOV has many members, there are many other Chinese people with cancer in the community who are isolated, may not know of the Society, and need encouragement to come. Many are not being actively referred. Others may have transport problems. The new CCSOV website will provide another channel of communication, to complement the newsletters and the use of Chinese language press and radio.

In particular, the Society needs to project more widely and clearly the message that no medical advice of any kind is given, either about Western or Chinese medicine. The only advice given is that people should talk with their own doctor; and if they want to use traditional Chinese medicine, they should do so only in conjunction with the treatment advised by their oncologist, and keep their oncologist informed.

The most pressing issues facing CCSOV at the moment, however, are the effective coordination of volunteers and organising an appropriate training package for them. Volunteers will remain an integral part of the Society, and volunteer training is of critical importance. No untrained volunteers are sent by the Society to visit patients or families. Volunteers who speak sufficient English have undergone training through the standard programs run by TCCV or other peak volunteer organisations. The majority of volunteers, however, do not have sufficient English for this, and the approach to date has been to provide training from a volunteer social worker and health educator, as needed. Developing the Society’s own training is a priority.

Nevertheless, over only five years of operation, the CCSOV has grown from a single small support group to a large and thriving organisation that has contributed significantly to the quality of life of Chinese people with cancer in Melbourne. The Society welcomes new members and enquiries about the organisation or the services it offers.

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Reference
A GROUP CANCER EDUCATION SESSION IN VIETNAMESE

A Epifanio and K Todd
Living With Cancer Education Program
The Cancer Council Victoria, Melbourne, Vic

Abstract

Being diagnosed with cancer is potentially a distressing experience, but timely information can help patients to cope. Groups offering education and support have been shown to be effective in helping patients to deal with the diagnosis. People whose English is not fluent are less likely to join such groups, and also are less likely to have access to sources of information about cancer in their first language. This article describes a one-off information session for a small group of Vietnamese-speaking patients and families in the Western health region of Melbourne. A team from The Cancer Council Victoria collaborated with health professionals in the public and private sectors to develop and deliver this brief education program. Although most of the presenters were Vietnamese-speaking, a hospital interpreter was available throughout the session. Participants were generally willing to ask questions, and afterwards expressed satisfaction with the content covered. While a single session was too brief to meet many of the needs of those present, it proved to be an acceptable format for Vietnamese-speaking patients and families and pointed to the need for further educational programs for this group.

Introduction

Cancer education programs delivered to groups offer a number of benefits. These include increased coping skills and better basic comprehension of cancer and its treatments. For patients who lack fluency in English, it may be especially important to have access to programs allowing them to learn more about cancer and to share experiences with others who understand their culture. More than one-fifth of people diagnosed with cancer in Victoria were born in countries where English is not their first language. Over the past decade in Victoria, the Living With Cancer Education Program has been adapted for presentation in various languages: Spanish, Greek, Italian, Chinese, Polish and Turkish. Participants in these programs have confirmed that they face specific problems in dealing with cancer when their English is not fluent and the health system is unresponsive to their culture and beliefs.

Immigrant groups arriving in recent decades may be particularly vulnerable, since they are less likely to have access to health professionals who speak their first language, and more likely to come from countries where cancer care is very different from that in Australia. One such group is the Vietnam-born community in Victoria. This article describes the development and delivery of a single-session cancer information program in Vietnamese, presented as a collaborative venture between two western suburban hospitals and The Cancer Council Victoria.

The background

Three workers in two hospitals in the Western health region of Melbourne approached the Cancer Council in 2000 about the problems they were seeing among Vietnam-born people with cancer and their families. All three were trained group leaders (facilitators) of the Living With Cancer Education Program and believed that, as one way of meeting their needs, these patients and families should be offered a program of education and support in a small group format.

The Western metropolitan health region in Melbourne is home to over half a million people (548,799), including 24,326 who were born in Vietnam. This figure represents around one half of Victoria’s Vietnam-born population. Of all the new cancers diagnosed in Vietnam-born Victorians, 45% occur in this region, as do 51% of the cancer deaths.

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<th>TABLE 1</th>
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<td><strong>New cancer cases in proportion to population size (%)</strong></td>
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<td><strong>Vietnam-born compared to other residents of the Western health region.</strong></td>
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<th>Age group</th>
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<td>&lt;20</td>
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<td>40-59</td>
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The experience of cancer is likely to be different for those born in Vietnam. For example, their median age at diagnosis is 52 years in the Western region, compared to 66 years for others in this region. Many of those diagnosed in the middle years (40-59, see Table 1) will be in the workforce and may be supporting wider family networks. The median age at death from cancer in the Western region is 63 years among those born in Vietnam and 71 for those born elsewhere (see Table 2).

<table>
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<td><strong>Cancer deaths in proportion to population size (%)</strong></td>
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Aim and method

Interested workers from the two hospitals and staff from The Cancer Council Victoria decided to gather resource material about cancer in Vietnamese and offer this to a group of patients and families. The aim was to provide basic facts in a way that would encourage questions from participants. They might then raise issues about their own experience of treatment if they wished to do so.

A working group was formed to develop and offer a one-off information session based on segments of the Living With Cancer Education Program, including an hour-long question time with a panel of experts. The single session would be run as a pilot project to check the acceptability and usefulness of this format and to help build a larger network of interested health professionals.

Although a Vietnamese-speaking nurse and a radiation therapist soon offered their services, no oncologist could be found. Eventually a Chinese-speaking specialist from the area agreed to join the panel, assisted by an interpreter from the Western Hospital. The Community Language Program of The Cancer Council Victoria provided a Vietnamese speaker to open the session with a talk on the basics of cancer. To publicise the session, flyers in Vietnamese were distributed widely to community agencies and health professionals in the area, and advertisements were broadcast in Vietnamese on SBS radio. The Western Hospital in Footscray, a landmark in the western suburbs, was chosen as the location for the information session. The Living With Cancer Information Session was scheduled for a Saturday afternoon to coincide with the major shopping day at the busy Footscray market nearby.

Results

The working party had been advised that Vietnam-born families did not like to discuss cancer, and so they were unsure if anyone at all would arrive. However, a dozen participants came, half of whom lived some distance away. One had travelled from a distant suburb after hearing the publicity on the radio.

Men formed over half the group and asked more questions than the women present. There was no shortage of questions, even on difficult topics, but it was clear that carers were much more vocal than patients. Some family members and friends expressed concern about lack of access to expensive treatments for patients with more advanced cancer. Others talked about end-of-life decision-making where they felt their own wishes had been ignored.

Communication difficulties seemed to underlie most of the situations described, and so a list of strategies was written on the whiteboard and translated by the interpreter; “Where you feel uncertain or unhappy about a situation, ask for an interpreter; ask questions; make another appointment; get a second opinion if you wish” and finally, “Ask to talk to the nurse or social worker, or arrange a family meeting with staff”.

These approaches were intended as tools for participants to use as they made their way through the treatment system. However, there was little time left to reinforce or discuss these ideas, and the hospital staff present decided that they would prepare a statement in Vietnamese outlining their own roles and the various services that are available, including allied health, pastoral care, and palliative care.

Half of the participants filled out an evaluation form afterwards, and these expressed satisfaction with the session. Both content and format were rated as being culturally appropriate, and all said they wished to be notified of any future session. Several of those who did not fill out a form spoke of their appreciation of the program. Although the evaluation form was anonymous, the respondents may have been displaying the positive bias seen in many patient satisfaction surveys.

For a different view, the hospital interpreter was also asked to offer an evaluation. Since it was the first session ever offered at the hospital, he had been uncertain what response to expect. He was impressed by the interest shown by the participants and the openness of the discussion: “Culturally speaking, Vietnamese people don’t even let anybody outside of the family know if their relative has cancer, let alone talk about it in public.”

He felt the session showed the importance of having accurate medical information available in the patients’ and families’ own language. Finally, he would have liked more time spent on different treatments and also some attention paid to the traditional cancer remedies favoured in Vietnamese culture, such as herbal preparations.

For the non-Vietnam-born health professionals who took part, one benefit was an increase in our level of understanding of the impact of cancer in the lives of Vietnamese-speaking patients and families. Contact between patients, families and staff within the oncology service is usually constrained by various pressures such as time and the immediate situation faced by the patient. The information session reinforced the value of interaction in a setting outside the oncology unit.

Discussion

The Vietnamese-born population in the western suburbs of Melbourne, Victoria, experience particular disadvantages when diagnosed with cancer. Problems include the burden on the families of those diagnosed in their middle years; their very limited access to health professionals who speak their language; and the paucity of cancer-related information in Vietnamese.

A search of various databases was carried out using combinations of the terms ‘Vietnamese’, ‘cancer’, ‘cancer services’, ‘Australia’, and ‘public health’, but no reports were found of a program offering group cancer education in Vietnamese. It is possible that our program was the first one to be planned and run in Australia, and so the lessons learnt may be of interest to other service providers.

From the evaluation forms and organisers’ observations, the information session appeared to meet some of the needs of those attending. Contrary to expectations, most participants were open in expressing feelings. Unfortunately, the single session format was too short to allow participants to raise all their concerns or to be confident of knowing how to get help when the need arises in the future.

Regularly scheduled single sessions would give participants the chance to re-attend and try out better ways of communicating with hospital staff. But to provide the opportunity for social support to develop over time, a full Living With Cancer Education Program would be preferable.

However, it generally takes a year to adapt and translate program content, train facilitators who speak the language, and locate health professionals to act as guest speakers. If this development is beyond current resources, the Program’s facilitator training course may still be relevant. It would be a useful preparation for any Vietnamese-speaking health worker wishing to present future cancer information sessions. The pilot session would have benefited by having a person who...
could welcome participants, introduce the various speakers, and sum up in Vietnamese.

Researchers on cultural diversity and health care have noted the need for a two-pronged approach to make health services more responsive. One prong is internal to the organisation: the initiation of change towards “culturally competent service delivery”. The second is directed outside the organisation: the building of relationships in the locality. Health care organisations must “form partnerships proactively with diverse groups to help identify service needs, participate in the planning and development of programs and services, and recruit members as employees from the communities they serve”.

These two objectives motivated the working party in planning the Living With Cancer Information Session in Vietnamese, and some progress was made in each direction. Within the hospital, awareness of Vietnamese cultural attitudes to cancer has increased among the staff involved in organising the information session. If the program was to be offered on an ongoing basis with the participation of oncology staff, there is likely to be a gradual move towards a more ‘culturally competent’ service for Vietnam-born patients.

In the local community, a Vietnamese agency was identified as being a promising partner in a cancer information program, since it worked with families. Unfortunately, its scope for involvement was limited because cancer care for families fell outside its funders’ guidelines. In a similar way, Vietnamese-speaking hospital staff offered their help on a volunteer basis, since group work and program planning were not part of their job description. The working party is now seeking funding to enable both the local agency and interested hospital staff to take part in future cancer information sessions.

Acknowledgments

The authors thank the hospital staff who approached us with their ideas and collaborated in the planning and running of the Vietnamese language program: Maureen McInerney and Ha Tran (Western Hospital), and Amanda Hebenton and Moss Arnott (Western Private Hospital).

We also thank Vicky Thursfield from the Victorian Cancer Registry for her reporting of data on Vietnam-born patients in the Western Metropolitan Health Region of Melbourne.

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3. Figures quoted are for 1994-98, the most recent available from the Victorian Cancer Registry.
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Over the past decade in Victoria, the Living With Cancer Education Program has been adapted for presentation in various languages: Spanish, Greek, Italian, Chinese, Polish and Turkish. Participants in these programs have confirmed that they face specific problems in dealing with cancer when their English is not fluent and the health system is unresponsive to their culture and beliefs.

Immigrant groups arriving in recent decades may be particularly vulnerable, since they are less likely to have access to health professionals who speak their first language, and more likely to come from countries where cancer care is very different from that in Australia. One such group is the Vietnam-born community in Victoria. This article describes the development and delivery of a single-session cancer information program in Vietnamese, presented as a collaborative venture between two western suburban hospitals and The Cancer Council Victoria.

The background
Three workers in two hospitals in the Western health region of Melbourne approached the Cancer Council in 2000 about the problems they were seeing among Vietnam-born people with cancer and their families. All three were trained group leaders (facilitators) of the Living With Cancer Education Program and believed that, as one way of meeting their needs, these patients and families should be offered a program of education and support in a small group format.

The Western metropolitan health region in Melbourne is home to over half a million people (548,799), including 24,326 who were born in Vietnam. This figure represents around one half of Victoria’s Vietnam-born population. Of all the new cancers diagnosed in Vietnam-born Victorians, 45% occur in this region, as do 51% of the cancer deaths.

<table>
<thead>
<tr>
<th>TABLE 1</th>
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</thead>
<tbody>
<tr>
<td>New cancer cases in proportion to population size (%)</td>
</tr>
<tr>
<td>Vietnam-born compared to other residents of the Western health region.</td>
</tr>
</tbody>
</table>

![Table 1](image)

The experience of cancer is likely to be different for those born in Vietnam. For example, their median age at diagnosis is 52 years in the Western region, compared to 66 years for others in this region. Many of those diagnosed in the middle years (40-59, see Table 1) will be in the workforce and may be supporting wider family networks. The median age at death from cancer in the Western region is 63 years among those born in Vietnam and 71 for those born elsewhere (see Table 2).

<table>
<thead>
<tr>
<th>TABLE 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer deaths in proportion to population size (%)</td>
</tr>
<tr>
<td>Vietnam-born compared to other residents of the Western health region.</td>
</tr>
</tbody>
</table>

![Table 2](image)
Aim and method

Interested workers from the two hospitals and staff from The Cancer Council Victoria decided to gather resource material about cancer in Vietnamese and offer this to a group of patients and families. The aim was to provide basic facts in a way that would encourage questions from participants. They might then raise issues about their own experience of treatment if they wished to do so.

A working group was formed to develop and offer a one-off information session based on segments of the Living With Cancer Education Program, including an hour-long question time with a panel of expert speakers. The single session would be run as a pilot project to check the acceptability and usefulness of this format and to help build a larger network of interested health professionals.

Although a Vietnamese-speaking nurse and a radiation therapist soon offered their services, no oncologist could be found. Eventually a Chinese-speaking specialist from the area agreed to join the panel, assisted by an interpreter from the Western Hospital. The Community Language Program of The Cancer Council Victoria provided a Vietnamese speaker to open the session with a talk on the basics of cancer. To publicise the session, flyers in Vietnamese were distributed widely to community agencies and health professionals in the area, and advertisements were broadcast in Vietnamese on SBS radio. The Western Hospital in Footscray, a landmark in the western suburbs, was chosen as the location for the information session. The Living With Cancer Information Session was scheduled for a Saturday afternoon to coincide with the major shopping day at the busy Footscray market nearby.

Results

The working party had been advised that Vietnam-born families did not like to discuss cancer, and so they were unsure if anyone at all would arrive. However, a dozen participants came, half of whom lived some distance away. One had travelled from a distant suburb after hearing the publicity on the radio.

Men formed over half the group and asked more questions than the women present. There was no shortage of questions, even on difficult topics, but it was clear that carers were much more vocal than patients. Some family members and friends expressed concern about lack of access to expensive treatments for patients with more advanced cancer. Others talked about end-of-life decision-making where they felt their own wishes had been ignored.

Communication difficulties seemed to underlie most of the situations described, and so a list of strategies was written on the whiteboard and translated by the interpreter; “Where you feel uncertain or unhappy about a situation, ask for an interpreter; ask questions; make another appointment; get a second opinion if you wish” and finally, “Ask to talk to the nurse or social worker, or arrange a family meeting with staff”.

These approaches were intended as tools for participants to use as they made their way through the treatment system. However, there was little time left to reinforce or discuss these ideas, and the hospital staff present decided that they would prepare a statement in Vietnamese outlining their own roles and the various services that are available, including allied health, pastoral care, and palliative care.

Half of the participants filled out an evaluation form afterwards, and these expressed satisfaction with the session. Both content and format were rated as being culturally appropriate, and all said they wished to be notified of any future session. Several of those who did not fill out a form spoke of their appreciation of the program. Although the evaluation form was anonymous, the respondents may have been displaying the positive bias seen in many patient satisfaction surveys.

For a different view, the hospital interpreter was also asked to offer an evaluation. Since it was the first session ever offered at the hospital, he had been uncertain what response to expect. He was impressed by the interest shown by the participants and the openness of the discussion: “Culturally speaking, Vietnamese people don’t even let anybody outside of the family know if their relative has cancer, let alone talk about it in public.” He felt the session showed the importance of having accurate medical information available in the patients’ and families’ own language. Finally, he would have liked more time spent on different treatments and also some attention paid to the traditional cancer remedies favoured in Vietnamese culture, such as herbal preparations.

For the non-Vietnam-born health professionals who took part, one benefit was an increase in our level of understanding of the impact of cancer in the lives of Vietnamese-speaking patients and families. Contact between patients, families and staff within the oncology service is usually constrained by various pressures such as time and the immediate situation faced by the patient. The information session reinforced the value of interaction in a setting outside the oncology unit.

Discussion

The Vietnamese-born population in the western suburbs of Melbourne, Victoria, experience particular disadvantages when diagnosed with cancer. Problems include the burden on the families of those diagnosed in their middle years; their very limited access to health professionals who speak their language; and the paucity of cancer-related information in Vietnamese.

A search of various databases was carried out using combinations of the terms ‘Vietnamese’, ‘cancer’, ‘cancer services’, ‘Australia’, and ‘public health’, but no reports were found of a program offering group cancer education in Vietnamese. It is possible that our program was the first one to be planned and run in Australia, and so the lessons learnt may be of interest to other service providers.

From the evaluation forms and organisers’ observations, the information session appeared to meet some of the needs of those attending. Contrary to expectations, most participants were open in expressing feelings. Unfortunately, the single session format was too short to allow participants to raise all their concerns or to be confident of knowing how to get help when the need arises in the future.

Regularly scheduled single sessions would give participants the chance to re-attend and try out better ways of communicating with hospital staff. But to provide the opportunity for social support to develop over time, a full Living With Cancer Education Program would be preferable.

However, it generally takes a year to adapt and translate program content, train facilitators who speak the language, and locate health professionals to act as guest speakers. If this development is beyond current resources, the Program’s facilitator training course may still be relevant. It would be a useful preparation for any Vietnamese-speaking health worker wishing to present future cancer information sessions. The pilot session would have benefited by having a person who...
could welcome participants, introduce the various speakers, and sum up in Vietnamese.

Researchers on cultural diversity and health care have noted the need for a two-pronged approach to make health services more responsive. One prong is internal to the organisation: the initiation of change towards “culturally competent service delivery”. The second is directed outside the organisation: the building of relationships in the locality. Health care organisations must “form partnerships proactively with diverse groups to help identify service needs, participate in the planning and development of programs and services, and recruit members as employees from the communities they serve”.

These two objectives motivated the working party in planning the Living With Cancer Information Session in Vietnamese, and some progress was made in each direction. Within the hospital, awareness of Vietnamese cultural attitudes to cancer has increased among the staff involved in organising the information session. If the program was to be offered on an ongoing basis with the participation of oncology staff, there is likely to be a gradual move towards a more ‘culturally competent’ service for Vietnam-born patients.

In the local community, a Vietnamese agency was identified as being a promising partner in a cancer information program, since it worked with families. Unfortunately, its scope for involvement was limited because cancer care for families fell outside its funders’ guidelines. In a similar way, Vietnamese-speaking hospital staff offered their help on a volunteer basis, since group work and program planning were not part of their job description. The working party is now seeking funding to enable both the local agency and interested hospital staff to take part in future cancer information sessions.

Acknowledgments

The authors thank the hospital staff who approached us with their ideas and collaborated in the planning and running of the Vietnamese language program: Maureen McInerney and Ha Tran (Western Hospital), and Amanda Hebenton and Moss Arnott (Western Private Hospital).

We also thank Vicky Thursfield from the Victorian Cancer Registry for her reporting of data on Vietnam-born patients in the Western Metropolitan Health Region of Melbourne.

References


3. Figures quoted are for 1994-98, the most recent available from the Victorian Cancer Registry.


The 28th Annual Scientific Meeting of COSA, held at the Brisbane Exhibition and Convention Centre from 28-30 November 2001, addressed broad issues in cancer care policy as well as the traditional break-out sessions focused on cancer site specific and craft groups. The theme of the meeting, From Global to Local, looked at health care issues from the perspective of globalisation. In particular, international speakers were asked to address their topics from this global perspective. The result was a mix of presentations evaluating the themes of quality and access in cancer care, the use of the electronic super-highway as a means of professional and patient support and education, funding of cancer care in the US and Australia, examples of the new molecular biology, and finally an assessment of the future of cancer care.

COSA 2001 was opened by Paul de Jersey, Chief Justice of Queensland and past President of The Cancer Council Australia. Chief Justice de Jersey addressed the opportunities and challenges of globalisation, and provided a brief summary of issues that would be addressed over the next three days. The first session set the theme of Access and Quality of Cancer Care in a Globalised World. Professor Tom Reeve was this year’s recipient of the MSD Cancer Achievement Award and his lecture during the first plenary session on the development of clinical practice guidelines for best practice summarised the achievements of the evidence-based movement in Australia to date. The increasing importance of electronic communication in patient counselling and professional education were elegantly portrayed by Diane Blum, Director of Cancer Care Incorporated, and Michael Giode, the Editor-in-Chief of ASCO on-line during the second and third sessions on the first day. As a result of the tragedies of September 11, Diane Blum was unable to attend, but a last minute video of her presentation illustrated how high quality lectures can be delivered (at significant expense) through this medium.

The most sobering plenary session, and perhaps the most important for the COSA community, addressed the crisis of funding of cancer care in Australia. By comparison with the US, Australia fares poorly in funding of cytotoxic drugs and there is an urgent need for the medical oncology community to address this issue. Professor Lloyd Sansom, Chairman of the Pharmaceutical Benefits Advisory Committee, provided an important historical perspective of the PBAC and an overview of the principles by which the PBAC conducts its business. He flagged that dialogue with relevant organisations will be an important future initiative, and both MOG and the pharmaceutical industry need to develop an open working relationship with the PBAC. The crisis in radiation oncology funding was addressed from both US and Australian perspectives. Manpower deficiencies are critical in both countries and it would appear that the US is moving along the same pathway as Australia towards crisis. Funding of palliative care appears to be, at best chaotic and rudimentary, while there is no funding for psychosocial care whatsoever.

In response to the dramatic advances in cancer research technology in recent years, COSA held a Cancer Research Symposium to address the new technologies underpinning fundamental biomedical cancer research. The translational potential of these technologies is an important issue for the medical oncology community to strategically target since future opportunities for participation in high quality cancer research will require collaboration with laboratory scientists. The natural partner of these initiatives is clinical trials and, on the last day of COSA, a “nuts and bolts” symposium addressed the methodologies and roles of the various contributors to the clinical trials process.

Breakout sessions once again evaluated practice and research at a number of cancer sites by different craft groups. This year’s recipient of the Neupogen Young Investigators Award was Dr Crystal Laurvick, who presented a population based study of the clinical epidemiology, treatment and outcomes of women in Western Australia with ovarian cancer (see below).

Medical oncologists continue to be the strongest medical supporters of COSA. Medical oncology sessions were well attended and were characterised by presentations of high quality data. The continuing contribution by medical oncologists to COSA should not be underestimated and MOG needs to continue its leadership role to create viable annual scientific meetings. Next year’s annual scientific meeting, convened by David Goldstein, requires vigorous support by the medical oncology community and I encourage members to start evaluating data for presentation.

Registration for the 28th COSA meeting was disappointing, given the diversity of speakers at this meeting. From the outset of planning, the Program and Organising Committee set the goal of inviting speakers representing different craft interests and, despite the late withdrawals as a result of the events of September 11, the programming was still diverse. To that extent, the Program and Organising Committee largely achieved its goals for the meeting.

G Beadle
Convener

THE 2001 NEUPogen YOUNG INVESTIGATOR’S AWARD

Each year AMGEN Australia offers a prize of $1,000 for the best original work by a young investigator at the COSA Annual Scientific Meeting. The award is decided by a panel of judges appointed by the Organising Committee.

The award in 2001 was won by Crystal Laurvick from the University of Western Australia’s Centre for Health Services Research. Her abstract follows.

A population-based study of the trends and outcomes following a diagnosis of ovarian cancer in Western Australia, 1982-98.

C Laurvick, J Semmens, Y Leung, A McCartney, I Hammond

1 Centre for Health Services Research, The Department of Public Health, The University of Western Australia, Nedlands, WA

2 WA Gynaecological Oncology Service, King Edward Memorial Hospital, Subiaco, WA

The present study used a population-based data linkage system to access the clinical epidemiology, treatment pathways and outcomes for women diagnosed with ovarian cancer in Western Australia. The WA Data Linkage System was used to obtain cancer, morbidity and death records for all patients with a diagnosis of ovarian cancer in 1982-98. Patients were identified using the International Classification for Diseases diagnosis and procedure codes pertaining to ovarian cancer.
During the study period, 1,336 women were diagnosed with ovarian cancer. The mean age at diagnosis was 62 years (SD+15). The incidence rate decreased on average 1% per year (p=0.05) and the mortality rate remained stable. Rates of surgical intervention increased. The majority of women (77%) received surgery to manage the disease, with a median inpatient stay of 14 days (IQR:10-19) and an in-hospital mortality of 4.4%. The overall relative survival at five years was 38% (95% CI:34-41). The present study demonstrated that there has been little change in the incidence and mortality from ovarian cancer. Women with the disease consume a considerable amount of health care resources.
FROM GLOBAL TO LOCAL: 
COSA 28TH ANNUAL SCIENTIFIC MEETING

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Minutes of the Annual General Meeting
Of the Clinical Oncological Society of Australia Inc., Held at the Brisbane Convention and Exhibition Centre on Friday 30 November 2001

Chair: Professor John Zalcberg (President)
Members Present: 37
The meeting was opened at 12.40pm.

1. President’s Report

Prof Zalcberg congratulated Dr Beadle and Dr Kenny on providing a meeting program that was provocative and challenging. He reminded the members that COSA was the peak, multi-disciplinary body in cancer care and within that charter it engaged in a diversity of projects as part of its total aim. He mentioned –

- The Workload Measurement Study (Data Managers Group)
- Psychosocial Guidelines in Communication (CNSA & Psycho-oncology Group)
- Feasibility Study on Infrastructure Support for Clinical Trials
  A study funded jointly by DHAC, COSA, NCCI and Victorian Dept of Health. Draft report presented to a workshop.
- Cancer Advocacy Network (CAN)
  A peak body for cancer consumer groups, auspiced by COSA and about to be launched as an independent body. Once established, CAN will be the logical source of consumer representation and advice for COSA Council and its working groups.
- Clinical Trials Awareness Week
  A joint project with TCCA to promote public awareness of the importance of clinical trials in improving outcomes, and to encourage patient enrolment in trials.
- Tobacco Control
  Support for the initiatives of anti-tobacco groups in reducing the burden of tobacco use on the community.
- Palliative Care Drugs
  Joint initiative with PCA and ANZSPM in lobbying for better access to drugs. Plans for a summit on access to all anti-cancer drugs in mid 2002.
- National Cancer Care Plan
  Support for an initiative of the MSC to prepare a model cancer treatment plan with assistance from the NCCI.

2. Composition of the Executive Committee

Prof Zalcberg said that under the Rules the Executive Committee comprised the President, the President-elect and three nominees of Council appointed each year. A convention had been adopted that one of these nominees would be the Chair of the numerically largest Group of the Society. This Group is the CNSA at present.

For 2002 the Executive Committee will comprise –
  Dr Liz Kenny
  Prof Stephen Ackland
  Prof Phyllis Butow
  Dr David Goldstein
  Prof Patsy Yates (CNSA)

3. Amendment to the Constitution – Rule 10(2)

The Secretary informed the members that the proposed rule change had been notified to members in the August issue of “The Marryaliyan”. The proposal removed the provision in the present Rules limiting voting membership to two Groups only.

Prof Zalcberg said that Council had endorsed the change.

* A motion to amend rule 10(2) was proposed and seconded, and passed unanimously.


The Secretary presented the audited balance sheet and profit & loss for the year 1 July 2000 – 30 June 2001.

He commented on the negative result and cautioned that the Society could not sustain a further drain on its cash reserves and should limit its expenditure and look to returning its Annual Scientific Meetings to profit.

5. Fees

Prof Zalcberg said that Council would manage its finances more conservatively but did not recommend an increase in fees in 2002.

He recommended that fees should remain:

- Ordinary $110
- Associate $60
- Sustaining $700

(all GST inclusive)

The recommendation was adopted by unanimous vote.

6. Concluding Remarks

Prof Zalcberg said that as he would step down from the President’s office at the end of 2001 this would be his last official function.

He thanked the members for their support during his term of office. He said that he had not completed all that he had hoped to but was satisfied that things in progress would be finalised. He said that achieving change had been a slow process and more difficult than he had anticipated.

On behalf of the membership Dr Kenny thanked Prof Zalcberg for his energetic and persistent leadership and presented him with a Silver Marryaliyan to mark his term of office.

The meeting closed at 1.00pm.
NATIONAL COLLABORATION FOR SKIN CANCER CONTROL IN AUSTRALIA:
OUTCOMES OF THE CANCER COUNCIL AUSTRALIA NATIONAL SKIN CANCER STEERING COMMITTEE

B Kirke and C Sinclair, on behalf of the National Skin Cancer Steering Committee

The National Skin Cancer Steering Committee (NSCSC) is a sub-committee of The Cancer Council Australia’s (TCCA) Public Health Committee and has existed since 1985. The committee was initially established to coordinate national activities for National Skin Cancer Awareness Week (NSCAW). NSCAW arose from a proposal for a national campaign by the then Anti-Cancer Council of Victoria and the Australasian College of Dermatologists (ACD) in 1985.

Membership of the committee includes a representative from each state cancer council, the ACD and scientific and behavioural research disciplines.

The role of the NSCSC has developed over the 17 years from one of campaign coordination to a broader one with the key functions being to:

- Draft position statements relating to issues associated with skin cancer and sun protection;
- Develop skin cancer control program guidelines consistent with TCCA cancer control policies; and
- Facilitate national collaboration of TCCA member organisations on skin cancer control issues.

The committee meets face-to-face once a year and teleconferences bi-monthly.

This paper reports the key activities and achievements of the NSCSC during the period 1998-2001.

SunSmart Primary Schools Program

<table>
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<tr>
<th>TABLE 1</th>
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<tr>
<td><strong>Total number of primary schools and percentage with SunSmart accreditation by state/territory</strong></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>State/territory</th>
<th>Total number of primary schools</th>
<th>Percentage SunSmart accredited primary schools</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australian Capital Territory</td>
<td>102</td>
<td>24%</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>230</td>
<td>2%</td>
</tr>
<tr>
<td>Queensland</td>
<td>1,471</td>
<td>14%</td>
</tr>
<tr>
<td>South Australia</td>
<td>575</td>
<td>28%</td>
</tr>
<tr>
<td>Tasmania</td>
<td>174</td>
<td>32%</td>
</tr>
<tr>
<td>Victoria</td>
<td>1,734</td>
<td>72%</td>
</tr>
<tr>
<td>Western Australia</td>
<td>738</td>
<td>3%</td>
</tr>
</tbody>
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The SunSmart Schools Program is an accreditation program which recognises primary schools that have adopted comprehensive sun protection policies covering curriculum, behaviour and the environment that meet prescribed standards. The program was initially developed and implemented in Victoria in 1994. A modified version of the Victorian program was subsequently introduced in South Australia and Tasmania in 1996.

Through the NSCSC, state cancer councils collaborated on fine-tuning the program and all other states and territories, with the exception of New South Wales, began offering the program to primary schools in 1998. Table 1 shows the percentage of accredited SunSmart schools in each participating state and territory at the time of printing. Many of the remaining schools are participating in the program but have not yet reached the standard to achieve SunSmart status. Cost-efficiencies were achieved in the development and printing of resources through this collaboration which also included the development of a specially designed computer software package to meet the recording and documentation needs of the program. State/territory-based staff responsible for implementing the program were provided with training in the use of the software.

Collaboration between the cancer councils through the NSCSC enabled a base-line survey to be conducted in all states/territories (except NSW) prior to the implementation of the program in 1998. A follow-up survey is currently being conducted.

The degree to which cancer councils have been able to implement the program differs and reflects the variation in fiscal and personnel resources available to each council.

Best practice guidelines

Following a NSCSC strategic planning workshop in 1999, two working groups were established to develop best practice guidelines for the implementation of sun protection programs for early childhood centres and secondary schools.

These working groups comprised state-based cancer council staff with appropriate expertise led by a member of the NSCSC. State/territory cancer councils were regularly consulted during the production phase to take account of the specific needs states/territories might have.

UV Risk Reduction: A Planning Guide for Secondary School Communities was launched in November 2001. In some states/territories cancer council staff responsible for working with secondary schools do not have experience in the workings of the secondary school system. Consequently, guidelines for working with this sector have also been developed to assist these staff.

Guidelines For Working With Australian Early Childhood Services To Improve Skin Cancer Prevention Practices were released in December 2001. Again these were complemented by guidelines for cancer council staff responsible for implementing the program.

Publicity

National Skin Cancer Action Week (formerly National Skin Cancer Awareness Week) is held in the third week in November each year and is a focus for media activity to publicise issues associated with skin cancer and sun protection.

Apart from the national and regional print and electronic media, the media strategy has included targeting popular magazines, particularly those with a fashion focus. The success of this strategy has been largely due to a coordinated approach to the media led by the teamwork of the public relations experts available through TCCA and its member organisations.
In 1999 a television advertisement was produced by the NSCSC funded by TCCA, ACD and state/territory cancer councils. The advertisement, aimed at 17-25 year olds, underwent extensive formative research. Advertising concepts were focus tested in three states, Victoria, New South Wales and South Australia, coordinated by members of the NSCSC. This resulted in the production of a highly successful advertisement known as Timebomb that has been broadcast in Victoria, Western Australia and South Australia, these being the only states able to fund a media campaign.

Target Audience Rating Points (TARPs) are the standard advertising industry measure of the weekly volume of television advertising weight. One TARP represents 1% of the target audience who have had the opportunity to see an advertisement on television. Evaluation of the South Australian advertising campaign showed a peak recall rate of 85.6% with average weekly TARPs of 290. This compares very favourably with other television advertising campaigns of health issues. How to Remove a Skin Cancer, a graphic advertisement that showed a skin cancer being removed and aimed at the 16-24 year old age group was screened in Victoria in 1997 and again in 1998. Recall of this advertisement was 72% in 1997 and 75% in 1998. The TARPs were 485 and 267 respectively.

By comparison, the 1999 Evaluation Report of the National Tobacco Campaign shows that recall of the most prominent of three advertisements peaked at approximately 90% in week four of the campaign. This campaign was held mid year, when television viewing rates are generally higher than the summer months, and the TARPs for that week were a little over 400.

Almost all respondents in the South Australian evaluation survey (98.1%) thought the advertisement was believable and 88.5% said it was thought-provoking. Also, a high proportion (85.1%) thought it was relevant to them. These results indicate that the creative execution met the criteria identified in the focus testing conducted during the development of the advertisement.

Fifty-one percent of the target age group reported having increased their level of sun protection as a result of seeing the advertisement. A well-executed advertising campaign is an important strategy in a multi-faceted program aimed at bringing about behaviour change, however, it is expensive in terms of production and advertising costs. The production of the advertisement through the NSCSC provided cancer councils with an excellent resource to complement their state-based programs. Where a paid advertising campaign was not possible, there was some free community service advertising using the Timebomb advertisement.

Development of position statements

There are many issues associated with skin cancer and sun protection that require an opinion from The Cancer Council Australia and its members. The NSCSC has been responsible for identifying the issues and over the past four years has developed the drafts of the position statements for consideration by the Public Health Committee and final endorsement by the Board of TCCA.

The various position statements, which are available on TCCA’s website at www.cancer.org.au/skin have resulted in consistent, evidence-based information being provided across the nation. They are an important aspect of the public information role of TCCA as they form the basis of policies and advice given by other non-government and government agencies.

Conclusion

The NSCSC links the state and territory cancer councils at the health promotion practitioner level providing peer support, in-service training and resource support to the smaller state cancer councils. This network is important in ensuring that educational messages and responses to skin cancer and sun protection issues that arise in the media are consistent across the nation.

It is through this state and territory collaboration that SunSmart has now become a highly respected trademark in Australia. SunSmart has also become part of the Australian language with the term used to describe behaviour, clothes, organisations and activities.

References

2 A Peipers. National SunSmart Schools Program – A Project of the National Skin Cancer Steering Committee. Report for the Australian Cancer Society (1999).
This is a regular feature in *Cancer Forum* describing behavioural applications in cancer prevention.

Australian has five behavioural research centres: the Centre for Health Promotion and Cancer Prevention Research (CHPCPR) of the University of Queensland, the Cancer Education Research Program (CERP) of The Cancer Council New South Wales, the Centre for Behavioural Research in Cancer (CBRC) of The Cancer Council Victoria, the Centre for Behavioural Research in Cancer Control (CBRCC) at Curtin University of Technology Perth, and the Centre for Cancer Control Research (CCCR), of the Anti-Cancer Foundation of South Australia.

This report has been edited by Alison Boyes (CERP) from the reports received.

**New Results**

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<th>Centre for Health Promotion and Cancer Prevention Research (CHPCPR), NSW</th>
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<td>Reasons for presentation and treatment of non-melanocytic skin cancers at an advanced stage</td>
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While most non-melanocytic skin cancers (NMSC) are easily treatable, a proportion is not given effective treatment until the cancer is advanced. Approximately 324 people died from NMSC in Australia in 1997 and these were all potentially preventable deaths. Michele Bandaranayake, a CERP PhD student, and supervisors Prof Bruce Armstrong and A/Prof Afaf Girgis undertook a prospective case-control study of people with histopathologically diagnosed NMSC to examine the patient, practitioner and disease factors contributing to delay in presentation and treatment of NMSC at an advanced stage. Cases were patients classified as having advanced NMSC based on set criteria. Computer-assisted telephone interviews were conducted with patients to explore issues relating to the NMSC that they had been treated for, especially in relation to determinants of delay. The nature of the treatment given was ascertained by a survey of the primary treating practitioners.

Information about the histopathology of the primary NMSC was abstracted from pathology records. Of the 1,221 cases and 1,279 controls contacted for consent, 79% of cases and 80% of controls consented to participate. Data analysis was carried out on 723 eligible cases and 789 controls. Some of the preliminary findings suggest that more cases (47.4%) compared to controls (44.4%) had presentation delay greater than four weeks. Cases who were employed were more likely to delay seeing their doctor than those not in paid employment, (59.1% employed versus 44.2% unemployed). A similar finding was seen amongst controls (55.5% and 40.8%). A similar proportion of cases and controls lived alone, however of those cases that lived alone, a higher proportion had greater delay compared to controls (47.9% versus 36.9%). Future analysis will focus on the possible determinants of presentation delay and the different types of delay related to advanced stage NMSC.

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<tr>
<th>Centre for Behavioural Research in Cancer (CBRC), VIC</th>
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<td>Impact of the SunSmart media campaign</td>
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Australia has the highest incidence of skin cancer in the world. Exposure to UV in sunlight is considered to be the main cause of skin cancer in Australia. A main component of the evaluation of the SunSmart campaign in Victoria includes a regular assessment of the impact of media and other specific strategies on the sun-related knowledge, attitudes and behaviours of the population. Over the summer months of 2001/2002 a telephone survey of 1,426 adults in Victoria was conducted on Monday evenings about the previous weekend’s outdoor activities. Although the media buy for the latest SunSmart commercial Timebomb was limited by funds, awareness levels were similar to those achieved in the previous year by the end of the campaign. A small increase in pro-tan attitudes and behaviour was cause for concern, while in general more people chose to avoid the sun to protect themselves on summer weekends. The prevalence of use of other sun protection behaviours on summer weekends appeared to be stable. Nonetheless, a small proportion of the population suffered sunburn on summer weekends. Moreover, questions about the reasons for the sunburn experienced suggest that there is a continued need for prompts for protection and messages about the limitations of sunscreens and promotion of other forms of protection.

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<tr>
<th>Centre for Behavioural Research in Cancer Control (CBRCC), WA</th>
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<tr>
<td>Review of breast cancer screening messages</td>
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Sandra Jones has completed a review of breast cancer screening messages targeted to women in Australia. This included a review of pamphlets produced by health professionals and a review of media coverage of breast cancer.

The pamphlet study found a number of inconsistencies in terms of the stated lifetime risk of breast cancer, risk factors (other than being a woman and increasing age), and the specific representation of symptoms. On a positive note, the majority of the pamphlets included information on breast self-
examination, clinical breast examination and mammography, and the information provided was quite consistent. The media study covered all items (advertising and editorial) appearing in the 10 top-selling Australian women's magazines and three weekend newspapers over the six-month period from December 2000 to May 2001 which included any reference to breast cancer. A total of 31 advertisements and 42 non-advertising items were identified. There was considerable misinformation, particularly in relation to the apparent age of breast cancer sufferers, with less than 40% of the women written about, and less than 10% of photographs used, being women over the age of 50.

**Centre for Cancer Control Research (CCCR), SA**

**Cancer statistics monograph series**

The Centre released the first publication in its cancer statistics monograph series, entitled Cancers of the digestive system. Cancers of the digestive system have received little publicity in South Australia, although accounting for around 30% of cancer deaths. The published behavioural research was reviewed for cancers of each organ site and the conclusion drawn that at least 40% of them could be prevented, principally through dietary change, not smoking, not drinking excess alcohol, having moderate levels of exercise, and in some instances, through proper food storage and hygiene, and infection control measures.

The Centre has also completed preparation of its second release in this series, entitled Sun-related cancers of the skin and lip. While the age-sex standardised incidence of invasive melanoma has almost doubled in South Australia since 1977-81, a plateau has occurred in 1992-2000. It likely that sun-protection programs have made an important contribution to arresting the incidence incline. A detailed comparison of 1992-96 and 1997-99 data point to a downturn in melanoma incidence in South Australians under 50 years of age. Early detection initiatives have been accompanied by an increase in proportion of invasive melanomas diagnosed when thin (<0.75mm thickness) from approximately 40% in South Australia in 1980-83 to 57% in 1996-2000. Case survivals have increased and a downward trend is now apparent in melanoma mortality in residents under 70 years of age. The monograph has highlighted sectors of the South Australian population that warrant special attention in further sun-protection and early-detection initiatives.

**SunSmart evaluation**

Data were collected on sun-protective behaviours and attitudes of South Australian 12-17 year olds as an adjunct to the triennial Australian School Students Alcohol and Drug survey. While knowledge of the link between UV exposure and skin cancer was fairly high, there was less certainty about the importance of sunburn. Sun protection practices fell short of knowledge and a sharp rise in reported sunburn in the previous summer. While the results showed a decline in perceived desirability of a tan, and a less frequent deliberate use of briefer clothing, there was the indication of a trend away from some protective behaviours in recent years. Other data collected in the South Australian Health Omnibus and Health Monitor surveys for residents aged 15 years and over indicated that risk of being burnt once or more during summer was higher in the younger age groups, males, people with skin types that were prone to burning, those born in Australia or the United Kingdom, and those who did not regularly wear a hat or clothing that could be protective. These results highlight the importance of targeting young people, in addition to other high-risk groups, in promotional campaigns. Data collected in 1990, 1993, 1996 and 1999 indicated that sunscreen use by adults increased, whereas hat wearing declined. While use of protective clothing increased initially, it then declined. These data are being used to plan ongoing sun-protection initiatives.

**Fake tan lotions and sunburn**

Staff of the Centre were authors of a report on the use of fake tanning lotions in South Australia that was published in the *Medical Journal of Australia*. Data collected by household interview for 2,005 adults indicated that use of fake tans was more common in young women and people with household incomes over $40,000. While users of fake tans were more likely to use sunscreens, they were less likely to take other precautions, like wearing hats or protective clothing. Also, they were more likely to report repeated sunburn during the prior summer. Based on the results, the Foundation considered that there was no justification for altering its policy of not promoting fake tan lotions to reduce sunburn.

**Evaluation of support for and compliance with smoke-free dining**

The Tobacco Control Research and Evaluation Program has completed an evaluation of levels of support and compliance among the South Australian community and restaurateurs in relation to smoke-free dining. Two data sets were analysed. The first was collected in 1997, 1998 and 1999 in cross-sectional Health Omnibus Surveys of more than 3,000 South Australians. The second was obtained through face-to-face interviews of restaurateurs and venue inspections. Data were collected after legislation was introduced, and replicated in June 2000, to check for changes over time. Results included evidence of consistent increases in community support (smokers and non-smokers) for smoke-free dining, as well as increased support among restaurant owners and managers. South Australians reported that their enjoyment of dining out had increased since the legislation took effect. High rates of compliance with the legislation were evident, as well as in the provision of totally smoke-free dining among sectors (such as hotels) where exemptions to the legislation could have been sought.

**Research in the Pipeline**

**CERP**

**Population based study of cancer survivors’ physical and psychosocial well being**

Improvements in the treatment and early detection of cancer have contributed to an increase in the long-term survival rate of cancer patients. However, little is known about the later effects that cancer and its treatment has on cancer survivors, their ongoing concerns, how the issues they face change over time and the type of support they need. Allison Boyes and colleagues are undertaking a population-based study to identify the prevalence and predictors of the physical and psychosocial outcomes reported by cancer survivors, and how these outcomes change with time since diagnosis. This includes a cross-sectional study of long-term survivors who are five years post-diagnosis and a longitudinal study of recent cancer survivors who will be followed for five years from six months post-diagnosis. Information about the survivors will be obtained from their cancer notification to the Central Cancer Registry as well as a self-report survey which includes reliable and valid instruments assessing anxiety, depression, quality of life, supportive care needs, coping and social support. These data will help guide the development of policies and services that are tailored to the needs of Australian cancer survivors at various stages of recovery or disease progression.

**CBRC**

**Direct mail cervical screening intervention**

As part of PapScreen Victoria's communication and recruitment strategy, over 200,000 under-screened women aged between...
50 and 69 years will be sent a personalised letter inviting them to have a Pap test. Two versions of the letter will be randomly assigned to the women; one with a gain-framed message and one with a loss-framed message. A subset of women will be monitored to assess the impact of message framing on cervical screening behaviour. The study, conducted by Madeline Fernbach, will continue until October.

**Evaluation of the SunSmart Schools Program**

The SunSmart Schools program has been a promising strategy promoting the development of policy on sun protection in the primary school setting. In 1997 and 1998 an evaluation study of the SunSmart Schools program underway in most states was initiated to assess the impact on sun protection policy and practices in primary schools. A follow-up survey has recently been conducted with data collection coordinated by Suzanne Dobbinson. A total of 970 questionnaires were sent out to schools in October and November 2001, with response rates to date fairly high in most states. Preliminary results are expected to be available in April.

**CHPCPR**

**Assessment of Queensland secondary schools’ requirements for supporting sun protective behaviour**

The documented decrease in sun protective behaviours from primary school to senior secondary school illustrates the need for sun protection programs in secondary school settings. Schools can play a major role in reducing students’ exposure to ultraviolet (UV) radiation. However, a standard approach of education, skills training and social support is less effective and innovative approaches, which address behaviour, curriculum and environment are required. Dr Warren Stanton and colleagues are conducting a Queensland Health funded project to assess the requirements of Queensland secondary schools for supporting sun protective behaviour. A statewide survey will be conducted to assess the level of implementation of sun protection policies and explore facilitators and inhibitors to the implementation of these policies. Qualitative research with principals, teachers, students and parents will also be conducted to explore innovative methods for improving the sun protective knowledge, awareness and behaviours of Queensland secondary school communities. The project will contribute to the implementation of strategies identified for the secondary school setting in the recently finalised Queensland Skin Cancer Prevention Strategic Plan 2001-2005.

**CBRCC**

**Evaluation of the Me No Fry media campaign**

In December 2001, the Cancer Foundation of WA implemented the first year of a three-year mass media campaign, “Me No Fry”. The objective of the campaign is to promote and reinforce the importance of sun protective behaviour among Western Australian children aged 12 to 17 years. A series of cross-sectional telephone surveys of the target population will be conducted to assess campaign outcomes. Six post-surveys will be conducted at two-weekly intervals following commencement of the campaign. In each survey, approximately 75 respondents will be interviewed, and males and females will be equally represented. A baseline survey was conducted with a total of 150 respondents prior to the implementation of the campaign.

**CCCR**

**Cancer risk factors and behaviours**

Interview surveys of the South Australian adult population were conducted in relation to diet, physical activity, alcohol consumption, perceptions of cancer risk, and effects of SunSmart media advertisements on awareness, recall and intention to change behaviour.

**Sun-protection practices in early childhood**

A survey was undertaken in 2001 of preschools and child care centres to assess sun-protection policies, shade levels, the promotion of personal protection, and rescheduling of outdoor activities to reduce UV exposure. Data from these surveys will be analysed in 2002.

**Participation in the Breast Cancer Support Service**

A study is being undertaken to identify population sectors in South Australia with limited coverage by the Breast Cancer Support Service. It will be assessed through follow-up inquiry whether these sectors are receiving appropriate support through other means, and if not, the nature of barriers to service acquisition, including psychosocial barriers.

**Cancer incidence by country of birth**

Compilation of data from 153 cancer registries around the world, and of Australian data by country of birth, is well advanced. The purpose is to determine risk profiles of Australians to different cancers according to their countries of birth, and in the context of the risks experienced in their countries of origin. Results will be used to target: investigations into the cultural and behavioural factors that underpin these differences; and health promotion and screening endeavours to reduce elevations in risk.

**Assessment of public support for smoking bans**

The Tobacco Control Research and Evaluation Program is examining data from a recent population survey to check for changes over time in levels of public support for smoking bans in bars and gaming venues.

**News**

**CERP**

CERP has had a number of recent grant successes. In collaboration with researchers at the Hunter Centre for Health Advancement, CERP was awarded funding from the NSW Health Promotion Demonstration Research Grants Scheme to evaluate the implementation of the NSW Health Guide for the treatment of nicotine dependent inpatients. In collaboration with researchers from the Newcastle Institute of Public Health, CERP was also awarded a consultancy to develop the NSW Health Cancer Services Framework. Dr Chris Paul has been awarded a one-year grant from the University of Newcastle Early Career Researcher Grants scheme to identify the potential for increased support for smoking cessation in pharmacies.

**CBRC**

CBRC is delighted to announce that Victoria White, Senior Behavioural Scientist, submitted and received her PhD from the University of Melbourne in 2001. Vicki’s research thesis used a longitudinal twin design to study the roles of genes and environment in determining variation in smoking behaviours from adolescence through to early adulthood. The study found no evidence that genetic factors influenced the initiation or maintenance of smoking behaviours at this stage of life, except in females where the effect was small. Environmental factors shared by twins in the same pair explained the greatest amount of variation in the initiation of smoking, and a substantial part of this was explained by the smoking behaviour of friends and parents.

**CHPCPR**

The Centre welcomed two new staff members this month. Professor Neville Owen has now settled into his new position as Director of the Centre and Professor of Health Promotion,
School of Population Health. Eva Leslie has also joined the Centre as a Research Fellow, from the University of Wollongong and will be working closely with Professor Owen on a number of projects, primarily a newly funded NHMRC project investigating how people’s environments influence their habitual physical activity.

CBRCC

We had a busy time with conference presentations during the latter part of 2001. Nadine, Sandra and Geoffrey attended the 2001 Australia and New Zealand Marketing Academy Conference in Auckland in December, where Nadine and Sandra each presented three papers. Sandra also presented three papers at the American Psychological Association Conference in San Francisco, and two papers and a workshop at the Public Health Association Conference in Sydney. Nadine presented a paper at the WA State Cancer Conference and at the Multidisciplinary Meeting on Behavioural Research in Cancer Control at Curtin University.

CCCR

The Centre for Cancer Control Research (CCCR) was recently established by the Anti-Cancer Foundation of South Australia. The Centre presently comprises of David Roder (epidemiologist), Kerri Beckmann (health researcher) and Jennifer Owen (administrative assistant). A key function is behavioural research, although the Centre’s role is broader, namely, the application of epidemiology and behavioural sciences in applied research and service delivery. The Centre works in partnership with the Tobacco Control Research and Evaluation Program and other staff of the Foundation, covering a broad field of behavioural research with a focus on tobacco control, sun protection, diet, alcohol consumption, physical activity, and psychosocial aspects of cancer management.
ACUTE LEUKAEMIA VIII - PROGNOSTIC FACTORS AND TREATMENT STRATEGIES

T Buchner et al (Eds)

Published by Springer-Verlag Berlin (2001)
RRP: US$225.00

This is the eighth volume in a series of monographs published by Springer on acute leukaemia. The first was published 13 years ago.

It is a multi-author, multi-chapter book of over 700 pages. Of more than 100 authors, 50 per cent are working in Germany so that the flavour of the book is dominated by this German perspective. The other authors are predominately from Western Europe with a few from North America.

The topics covered are wide and varied and include the following chapter headings: Leukaemia Cell Biology, Monitoring and Prognosis, Recent Antileukaemic Strategies, Recent Strategies against Opportunistic Infections, ALL in Children, ALL in Adults, AML in Adults, AML in Children, Acute Promyelocytic Leukaemia, AML in Elderly Patients, and Allogeneic and Autologous Transplantation.

In total 114 papers are presented and within each chapter there are anywhere from five to 30 papers discussing a specific topic relevant to the particular heading. Some of the papers provide a general review of a topic whereas others simply provide a description of local experience.

Like any book of this nature it is like the curate’s egg, there are “good” bits and “not so good” bits, and it is impossible to detail every paper, however in this review a few highlights are worth mentioning.

In the chapter on leukaemia cell biology the papers on the mechanisms of chromosomal breakpoints, RT-PCR monitoring of transcripts in AML and the expression of AC133 and CD34 on leukaemic cells, were informative and interesting.

The chapter on recent antileukaemic strategies discussed the use of idarubicin and liposomal daunorubicin in some detail and touched on aspects of immunomodulation including dendritic cell therapy and adoptive immunotherapy. It would have been helpful to have had some perspective on the use of anti-CD33 monoclonal antibodies and deacetylase inhibitors in this chapter but none is provided.

Nine papers on opportunistic infection follow and include a review of the role of newer quinolones, fungal infections in paediatric patients and a discussion of the experience in Hannover of central venous catheter infections in leukaemic patients, a cause of ongoing concern in all haematology units.

The chapters on acute lymphoblastic leukaemia include updates from the BFM Group in Germany on their childhood trials and reports on adult trials from the French (LALA) and US (CALGB) groups.

Similarly, chapters on AML include papers from the US and Germany on the significance of genetic abnormalities on the outcome of adult patients and there is an update of MRC trials in children. Again, it is a pity that there are no specific papers from the Australian Leukaemia Study Group (ALSG), now ALLG, which has made significant contributions in this area, nor anything from the adult MRC trials.

Acute promyelocytic leukaemia (APML) holds a unique place in the hearts and minds of haematological oncologists as an early example of the use of targeted therapy, and the papers in this chapter range from a discussion of basic biology to updates from major groups in Italy, US and Germany. Arsenic trioxide therapy is also covered by a paper from China where a lot of the pioneering work on the therapy of this disease originated.

The six papers on elderly patients with AML highlight the fact that the median age for this disease is over 60 years. Comments from major groups in the US (ECOG, MD Anderson and CALGB) as well as Germany and Italy are provided and remind the reader that this is still a very difficult disease to treat. Although aggressive therapy may be the best option for prolonged survival, only certain patients will be able to tolerate such treatment.

Finally, there are 12 papers on allogeneic and autologous transplantation. Perhaps the highlight of this chapter is the short review by Slavin’s group of the shift towards non-myeloablative conditioning for patients undergoing transplantation for leukaemia.

All in all, this is an interesting book, and certainly contains relevant information for specialists treating leukaemia. Whether they will be prepared to spend this amount of money to buy this book when most of the information can be found in the original literature remains to be seen.

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ADVANCES IN BREAST CANCER MANAGEMENT

W Gradishar et al (Eds)
RRP: US$165.00

This is one in the series entitled Cancer Treatment and Research published by Kluwer Academic with Steven T Rosen as series editor. In this volume, Advances in Breast Cancer Management, nine clinically important topics are the subject of short reviews by eminent US and Canadian experts. The management of menopausal problems, sentinel lymph node biopsy, post mastectomy radiotherapy, HER2, high dose chemotherapy x 2, preoperative chemotherapy, randomised trials of systemic adjuvant therapy and breast cancer chemo-prevention are covered.

Generally the reviews are pithy and pertinent, there is good use made of tables to summarise complex data and the references are extensive and as current as can be expected for a book published in 2000.

As always the field has moved on since the authors did their work. The editor notes cryptically that the “Bezwoda study has come under scrutiny”. Doubtless, the high dose chemotherapy papers would be drafted differently if written now. Newer data on herceptin and taxanes in metastatic disease and randomised data on the effects of venlafaxine on menopausal symptoms could now be added. A chapter on the aromatase inhibitors would have been of value.

However, as the basis for, a personal update, preparation for a lecture or as a quick reference for patient management, these are excellent reviews. I am pleased to have a copy of this little book. At US$165.00 others may prefer to twist the librarian’s arm.

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This volume comprises five review articles. Two articles, written by the same authors, address the role of HHV-8 in initiation and progression of Kaposi's sarcoma. One article covers the field of immunotoxins as therapy for cancer, focusing on production of recombinant proteins. One article reviews a possible role for illegitimate V(D)J recombinant events as instigators of chromosomal translocations in lymphoma. The longest article reviews allogeneic bone marrow transplantation over the past 10 years.

The marrow transplant review is well referenced (about 250 references) and includes a useful set of figures of expected outcomes for the various conditions for which allogeneic transplant is one option for management. There is a good review of the utility of MUD, of umbilical cord cells, and of haploidentical donors, and a balanced discussion of the prevention of GVHD, and the management of PTLD and of CMV infection. Given the strong focus on molecular methods throughout the rest of this volume, mention might have been made in the “future directions” section of the role of molecular detection and monitoring of potential relapse following chemotherapy as a determinant of the timing of marrow allografting for some hematopoetic malignancies.

The article on VDJ recombination gives a comprehensive review of the molecular mechanisms of this particular somatic DNA rearrangement, and its place in B and T cell development, although this is perhaps a little dated given the rapid generation of data on RAG gene function over the last couple of years. The link proposed between tumourigenesis in germinal centre derived cells and illegitimate VDJ enhanced recombination remains somewhat speculative, given the other genomic rearrangements also occurring in B cells at this site, though the molecular evidence is well reviewed.

The article on recombinant immunotoxins is predominantly a practical review of the hows and wherefores of construction of such molecules using recombinant DNA technology. Given that many patients may need multiple treatments, and that recombinant immunoglobulin fragments are also of potential use as diagnostic agents, discussion on potential (cross-) immunogenicity as a limitation to therapy is fairly brief. The review of clinical applications of immunotoxins is exemplary rather than comprehensive, and doesn’t give the reader a strong feeling for the actual efficacy that has been observed or might be expected in different clinical situations, or of the practical limitations to immunotoxin therapy caused by soluble antigen and by cross reactivity.

The two articles on HHV-8 review the molecular evidence supporting the role for this virus in the pathogenesis of Kaposi’s sarcoma, and discuss the means by which the virus contributes to cellular transformation, and by which disease is enhanced by immunosuppression. The articles come complete with multiple colour pictures of histology and of in situ hybridisation of lesions and of cultured spindle cells, and serve as a comprehensive and readable introduction to the field for those new to the area or needing an update.

Each of the articles is up-to-date, with many 1999 and a smattering of 2000 articles referenced, and while the articles might not quite meet the series titles of “Advances in cancer research”, they would assist an educated physician scientist to bring themselves up to speed in the reviewed field. At $75.00 a review, it is a book to borrow rather than purchase, unless the reader has need of all four major topics at their fingertips.

I Frazer
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Knowledge of clinical outcome, or prognosis, is integral to medical decision-making and resource prioritisation. The automated analysis of an individual patient's records and genomic data to extract prognostic factors may be enhanced by the development of new statistical techniques and artificial intelligence methods. But can the application of artificial intelligence techniques improve diagnosis and prognostic estimates in the domain of breast cancer research? Has there been enough progress in the past decade to justify a first book on this subject? The editors of the series in Machine Perception and Artificial Intelligence obviously believe so, and they have done an excellent job of putting together a book that highlights the advances and controversies that surround the subject. Contributors from Australia, Germany, Italy and the USA combine the pathological, intelligent and statistical approaches to enable more precise definition of disease extent and prediction of tumour behaviour and response to treatment.

The first three chapters are keys to these approaches. Two chapters provide a brief introduction to breast cancer diagnosis, risk assessment and image feature extraction. The third chapter describes recent advances in prognostic and predictive techniques in breast cancer research. It demonstrates the ability of neural networks to effectively recognise and represent the complicated dependence of the disease on the range of demographic and clinical factors and to distinguish this dependence from the noise. These chapters are clear, concise, and potentially useful for teaching of both medical informatics and computer science.

A whole chapter is devoted to the MammoNet, a Bayesian networks-based tool for breast cancer. Authors spend a good deal of time carefully explaining its topology, system architecture and the use of its decision support features. The next chapter deals mainly with the use of continuous and categorical biological variables as prognostic biomarkers for breast cancer patients. The last three chapters review the application of artificial intelligence paradigms to computer-assisted interpretation of mammograms and cytodiagnosis of breast cancer, including computer vision techniques and the current state of the ongoing research program in the USA on Xcyt, a new system for remote cytological diagnosis of breast cancer. Perhaps one of the most interesting issues arising from this collection is the examination of different decision support technologies for their application in laboratory medicine.

A degree of knowledge in algebra, cancer biology and probability theory is assumed, but there is nothing much in here to frighten the non-computer scientist and the writing is easy to follow. The book will be of particular interest to clinical decision support systems designers and academic oncologists.

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ATLAS OF CANCER SURGERY

N Bloock et al (Eds)

Published by A WB Saunders (2000)
RRP: A$355.30

To cover the technical aspects of cancer surgery, in atlas form, in one book is a challenge. In considering this book for the Australian scene one needs to look at the group to whom it will be aimed. In the USA and some areas of Europe there are surgeons who will be involved in the care of patients with many different types of cancer involving such diverse sites such as the chest and the whole abdomen. In Australia where the specialisation tends to be into different cancer sites, the broad nature of this book loses its relevance to the experienced surgeon. I think the authors have tried to cover too many different operations across too many specialities.

The illustrations are outstanding. The separate operations that are represented carry a different amount of technical written detail. In the preface, the statement “a picture is worth a thousand words” is used as justification for brevity in the legends. This is fine for the experienced surgeon but for the less experienced surgeon, trainee or student some of the legends were too brief, eg thyroidectomy and neck dissection. It is unfortunate that the opportunity to add “pearls of wisdom” to the excellent illustrations was not used by the authors.

In some of the sections there are steps in some of the illustrated procedures that I would not consider routine approaches. At the end of a number of sections operative surgery case reports are used as illustrations. These tended to be technically challenging cases. Although interesting I am not sure of the value as the preceding standard operative illustrations were usually not detailed enough with technical descriptions to allow one the insight to the intricacies of the procedure used as an illustrative case report.

Overall the book aims to cover too much. The Australian surgeon with a subspecialty interest is not going to buy this book because the descriptions in their area of interest is too brief, only offering an overview of the operations used. The Australian general surgeon will not gain enough detailed information about procedures to use this as a reference for those procedures they may perform intermittently.

For the reasons outlined above it is difficult to recommend this book to individual surgeons as a useful operative surgery reference ahead of the many other books available that cover different specialities in more depth. For the surgical trainee interested in cancer this book would be a useful reference to use for discussions with their subspecialty mentors because the illustrations are very good. For centres specialising in cancer it may be a useful text for the library as a surgical technique reference for trainees, students, non surgeon cancer specialists and patients because it does cover so much in a single text.

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This book of some 400 pages is a comprehensive text covering the modern management of bladder cancer. In addition to dealing with the clinical aspects of the disease, there are substantial chapters that focus on the epidemiology and the molecular biology of urothelial malignancy. This is timely — since, in common with other tumours, there has been a great deal of research in this area in recent years.

Almost a quarter of the book is taken up with chapters dealing with the imaging and diagnosis of bladder cancer. Whilst having this background information presented in detail is important in a reference work, I suspect it may be a little more detail than will be required for readers of the book. The central portion of the book deals with the surgical management of bladder cancer, extending from early disease through to issues relating to the use of neoadjuvant chemotherapy. These chapters are well written and provide a concise yet thorough summary of the state of the art of the treatment of bladder cancer. They are followed by a chapter on the management of metastatic bladder cancer. The book concludes with an interesting section on the design considerations for phase II trials of new therapies in bladder cancer. This a well written and interesting section of the book, though it seems somewhat out of place. The level of the discussion here is more appropriate for a reader with a specific interest in clinical trials, and, indeed, assumes a good deal of background knowledge.

Overall this is a useful book that summarises modern thinking on the management of bladder cancer. It would be a useful addition to the collection of anyone involved in the management of this disease.

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Cancer and Autoimmunity

Y Shoenfeld and M E Gershwin (Eds)

Published by Elsevier (2000)
RRP: US$196.50

This book contains a very broad coverage of the relationship between cancer and autoimmunity. At first glance these two subjects could be viewed as immunological opposites; autoimmunity is a pathological over-reaction of the immune system, whereas cancer, at least in some cases, may be associated with an insufficient immune response to the tumor. Despite this apparent incongruity, there are many instances where the two types of diseases are found in the one patient, and the book contains extensive documentation of these associations. The editors, immunologists from Israel and the USA, have assembled a volume of over 40 chapters, mostly written by European authors. A minor complaint is that in some chapters, English is obviously not the first language of the authors. Although the meaning is usually clear, it is a pity the text was not edited into more fluent English.

The book is divided into four major sections. The first is on malignancies that arise in autoimmune diseases. These chapters provide comprehensive reviews of clinical data, and some chapters also contain good overviews of pathogenesis. The section concludes with a chapter reviewing, from a clinical point of view, evidence for a causal association between autoimmune diseases and cancer. The second section covers the opposite phenomenon, autoimmunity arising in malignant conditions, again with comprehensive reviews of clinical associations. The third section is a miscellaneous collection under the heading “Mechanisms in Cancer and Autoimmunity”. The final section is on therapy of autoimmunity and cancer, and some of its chapters attempt to identify issues in treatment that are common to both conditions.

Inevitably, there is repetition and overlap between chapters. The broad scope of the topic leads to inconsistencies as to what has been included. For example a chapter on Hepatitis C virus and its association with autoimmunity and cancer is clearly justified; it is less clear why a chapter has been included on the neurotropic virus JCV, which is oncogenic but lacks association with autoimmunity, whereas other oncogenic viruses are omitted. While the clinical aspects of the book are strong, it is harder to discern unifying themes that identify underlying mechanisms in autoimmunity and cancer. The introductory chapter provides a short overview of the immune system and autoimmunity. This may not be very helpful to readers unfamiliar with contemporary immunology, as it emphasises older theories such as the idiotype network, and neglects more modern concepts such as peripheral tolerance. However in the third section, the chapter “Cancer Immunity: A Problem of Self-Tolerance” provides an excellent review of peripheral tolerance. It argues that immunological tolerance is an active process, and that inhibition of peripheral tolerance may be useful in the therapy of certain types of cancer.

The major strength of this book is its documentation of associations between cancer and autoimmunity. Interested clinicians will find this a handy reference work, and the book contains a depth of information that would be difficult to access elsewhere.

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CANCER AND YOU: HOW TO STACK THE ODDS IN YOUR FAVOUR

M Goyns (Ed)

Published by Harwood (1999)
RRP: A$33.00

Written in, and drawing on data from, the UK the first section of the book provides a general background to cancer, while the second section examines risk factors associated with common cancers. The emphasis on common cancers using UK data means cancers which do not always figure prominently in Australia (eg stomach cancer) are discussed while others are given little prominence, for example, skin cancer. To illustrate the point, the brief reference to melanoma is in a section titled ‘Less common cancers’.

The author holds a Chair in Molecular Gerontology and this background is evident in the depth and emphasis of the book. Chapter two, “Some basic biology”, and chapter three, “What is cancer”, are likely to be somewhat inaccessible to a large proportion of the lay audience at whom the book is aimed. Another concern is that the “background” component of the book, covering the aetiology of cancers, as well as diagnosis and treatment methods, occupies close to two-thirds of the book – somewhat belying the title.

On the theme of “stacking the odds in your favour” the author tackles the task through chapters on “Cancer and lifestyle”, “Your body and cancer awareness”, “Radiation risks”, “Diet, obesity and cancer”, “Tobacco and alcohol”, and “Viruses and cancer”. In general terms the material provided here is consistent with current recommendations, however is sometimes provided with differences of emphasis compared to current Australian practice (an example being a rather tepid summary of the evidence recommending the avoidance of sunbeds).

The chapter relating to early detection, titled “Your body and cancer awareness” commences with a focus on genetics as a major determinant of cancer risk. This emphasis may lead to an impression that genetics is a more predominant factor in cancer causality than the current evidence suggests.

There is no reference to the challenges in screening or the potential “costs” of “over vigorous” screening pursuits, which may have been a worthwhile theme with which to open, or at least address. The limited coverage of screening issues is suboptimal and a weakness of the book.

The chapter on “Diet, obesity and cancer” was probably consistent with thinking at the time of writing but perhaps somewhat overstates the strength of evidence linking nutrition factors and cancer outcomes based on what current evidence might allow. The absence of referencing is a problem highlighted here, as source material is not nominated.

While there is considerable care given to explaining terms as they are introduced, to be of greater use to a lay audience the book could benefit from the addition of a glossary. It is, however, well indexed.

This 151-page book is a useful general and introductory text with broadly sound advice and a wide-ranging coverage of cancer issues. It does however suffer from a lack of referencing, limiting its use for tertiary education and professional purposes. In the first section in particular, it is written in a somewhat formal and complex manner. This along with a lack of a glossary renders it of limited use to a less technically literate or lay audience.

T Slevin
Director, Education and Research
Cancer Foundation of Western Australia
Perth, WA
This is a comprehensive text on chemotherapy and biological therapies. A quite voluminous work, clearly designed as a reference book.

The initial chapters deal with the principles of chemotherapy in oncology and the rationale of its use. There is a chapter on development of new agents, which introduces the topic succinctly but not venturing into the complexity of this quite separate issue. Further chapters deal with general side effects of chemotherapy and explain the pharmacokinetics and the scientific background of the chemotherapy and biotherapy.

The book is subtly divided into three parts where a second one deals with chemotherapeutic agents by groups. This explores significant details and deals with all aspects of agents used in today’s chemotherapeutic regimens. Pleasingly there are special administration routes reviewed such as intraperitoneal use, intraarterial infusion, etc. A good description of the side effect, interactions and synergism will complete a thorough understanding of various groups and individual agents.

Further on, there are chapters on Retinoids, Biphosphonates and radiation therapy modifiers, before the book devotes itself into the realms of biological therapies. These include cytokines, growth factors, antibodies and genetically targeted therapies. The topic of vaccines is organised into very readable form, followed by anio genesis inhibitors. The end of this exhaustive work is devoted to chemokine databases, which are very extensive but perhaps of somewhat limited use for clinicians.

In summary, Cancer Chemotherapy & Biotherapy is a laudable work. It is lacking little in practical issues such as dosing and combination regimens, but there are plenty of resources available concentrating on that part. However, it would be beneficial to summarise some of the most used schedules for completion. It is an excellent reference text, which should easily find its place in the library of institutions dealing with chemotherapy and biotherapy whether on practical or scientific level.

M Slancar
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Cancer Nursing Practice: A Textbook for the Specialist Nurse

N Kearney et al (Eds)
Published by Churchill Livingstone (2000)
RRP: A$108.35

Cancer Nursing Practice attempts a review of the current complexities of modern cancer nursing given societal changes across Europe and recent significant developments in the management of cancer. This text is for cancer nurses operating at an advanced level; it is not a prescriptive text for the beginning practitioner. This, together with its Eurocentric view, makes it a welcome text in the limited market place of materials for senior clinical cancer nurses in management and education, post-graduate students, researchers and academics.

The editors are highly respected cancer nurses from Europe and the United Kingdom. The additional contributors are similarly recognisable nurses from a range of clinical practice settings and academic perspectives.

The basis for the text is the World Health Organisation’s new health policy for Europe, ‘Health 21’. This document purportedly identifies nurses “as having a key role to play throughout the whole continuum of care”. The text draws heavily on published nursing literature and evidence, and on the activities of the European Oncology Nursing Society (EONS).

There are nine chapters in the book: Cancer Nursing as a Specialty, The Practice Base of Cancer Nursing, Leadership and Management, Influencing the Shape of Advanced Cancer Nursing Practice, Clinical Decision-Making, Nursing Education in Cancer Care, Nursing Research in Cancer Care, Information and Education for Patients and Families, Some Ethical Issues in Cancer Nursing, and Towards a European Framework for Cancer Nursing Services. The chapters that were of particular interest to me in my current role included leadership and management, and information and education for patients and families.

In the final chapter, the authors intelligently reflect on the vast differences in the state of play regarding the scope and delivery of cancer care and cancer nursing in the many countries that comprise Europe, and discuss in a most articulate manner the gaps in nursing knowledge and research. Given the strategies and resources dedicated to core curricula for cancer nursing education in some countries and the admirable collaborative efforts of the EONS, gaps are being addressed to ensure that nurses can demonstrate valuable contributions to cancer care and can demonstrate the importance to the wider community of developing and enabling this speciality area of nursing practice.

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Leukaemia Foundation
Sydney, NSW
Cancer of the Lower Gastrointestinal Tract

C Willett (Ed)

Published by Harcourt (2001)
RRP: A$311.47

This book is one of a series of atlases produced by the American Cancer Society on the cancers of all the major regions of the body. This one examines all aspects of lower GIT cancers. There are chapters on epidemiology and chemoprevention, genetics, screening, pathology and staging, endoscopic management, diagnostic radiology, primary surgery, radiation, chemotherapy, surgical management of metastatic disease, treatment of anal cancer and palliative care.

Many chapters are written by a senior clinician with acknowledged experience. Each chapter gives a broad overview of the issues. The term atlas is something of a misnomer in that although the illustrations are excellent and often in vivid colour, it is principally a textbook with illustrations rather than an atlas with commentary. Like all texts with multiple authors chosen by the editor there is some variability. Most chapters review their area well, in particular the surgical chapters provide considerable detail on technique, perhaps slightly more than the non-surgeon needs but worth reading once and having available for reference. The exception being the screening chapter which consists mainly of the author’s expert opinion with little in depth review of the evidence and does not have any discussion of the relative cost benefit of the modalities promoted in this still controversial area.

Like all such texts it has a very North American perspective but does represent practice as conducted in Australia in general. The book comes with a CD-ROM that allows one to download illustrations and tables. It inevitably suffers from the same problem as all such texts. The most recent references are 1999 and subsequent information has changed a few of the conclusions, although not that many. It seems a shame in 2002 that such texts do not come with a website updated annually by the writers with the newest practice-changing information. Given that the ACS has an excellent website it would not seem to be an insurmountable task!

The book was an enjoyable read for me to review and revise basic concepts but is clearly designed to be an overview not an exhaustive, in depth, definitive text. As such it is most suitable for trainees or oncologists of any discipline who are involved in other areas and wish to dip into such a text to refresh their understanding. Those actively working in GIT malignancies may not find enough new or in depth information to challenge them although the illustrations will be useful.

I suspect that every oncology department should have a copy as a useful reference text and source of lecture material rather than recommending it for the individual oncologist’s library.

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The third edition of this book provides a current and comprehensive reference text on issues related to chemotherapy. The format is not dramatically different from the original publication in 1992. The book is divided into six sections that cover the principles of chemotherapy, the chemotherapy drugs, management of drug toxicity, drug administration, current therapy of specific solid tumours and the chemotherapy of haematological malignancies. The section on chemotherapy protocols has now been placed in a separate appendix that will undoubtedly facilitate access to this information.

While there is some new material in the third edition, the text is not substantially different from previous editions. There is additional information on high dose therapy and five new drugs approved since the second edition. The current edition also includes new chapters on clinical trials and monoclonal antibodies. The latter chapter was disappointingly brief however the use of some of the antibodies was revisited in the disease specific chapters.

A particular strength of this book is the comprehensive section on the management of drug toxicity. Since combination chemotherapy is often used for the treatment of malignancies it is extremely useful to present both the side effects of drugs and the likely “culprits” in a problem based format. In this regard, the sections on dermatological, hypersensitivity and ocular reactions are especially informative.

The chapter on investigational drugs was eminently readable and was one of the most interesting chapters in this edition. This book would serve as a valuable resource in any library or oncology department. Individuals with personal copies of earlier editions may not however feel that upgrading is value for money.

R Ward
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It is not very often that you come across a book to review that is as good as this. I think this book is superb (not perfect, but none the less, superb) and I would recommend it to any practicing haematologist and physician who deals with leukaemia.

This is a multi-author (50), multi-chapter (27), book of over 600 pages, with an international cast of contributors, a veritable “who’s who” in the field. The authors are predominately from Western Europe and North America and include Daniel Catovsky, Carlo Croce, Michael Grever, John Gribben, Terry Hamblin, Michael Keating, Thomas Loughran, William Plunkett and Kanti Rai, with a notable contribution from John Seymour and Janine Campbell from the Peter MacCallum Cancer Institute in Melbourne on Richter’s Syndrome.

The topics covered are wide, varied and comprehensive, and include history, molecular biology, epidemiology, the nature of the CLL lymphocyte, genetic approaches to therapy, prognostic factors and several chapters on different aspects of therapy of CLL. In addition, prolymphocytic leukaemia, hairy cell leukaemia and chronic T cell and NK cell leukaemias are discussed in separate chapters. The final chapter discusses the psychological aspects of CLL.

If I were to offer one constructive criticism, it would be to say that colour (rather than black and white) plates of the morphology of the lymphoid malignancies would have been useful in the chapter on differential diagnosis of the chronic B-cell lymphoid leukaemias.

Nevertheless this is an excellent book. The editor is to be congratulated on bringing together a superb group of experts who have covered the field comprehensively and in an up-to-date fashion.

I recommend this book without reservation.

G Young
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DIFFERENTIAL DIAGNOSIS IN NEURO-ONCOLOGY

J Hildebrand and M Brada (Eds)

Published by Oxford University Press (2001)
RRP: A$270.00

This is an interesting book that delineates a rational approach to the diagnosis of disorders encompassed in the field of neuro-oncology. A number of books have been recently published in the field of neuro-oncology, such as Posner’s book detailing the neurologic complications of systemic cancer, and others dealing with the diagnosis and management of brain tumours. While the other monographs usually deal with discreet defined entities, Hildebrand and Brada start with the clinical scenarios with which the clinician is faced, and deal in an orderly way with the potential diagnoses.

Their aim is to allow the physician to deal with a clinical problem, with diagnostic pathways including the relevant clinical clues to look for, appropriate imaging modalities and ancillary investigations. In addition, therapeutic recommendations are made. The chapters are supported with useful tables and decision trees. Good use is made of illustrations, including CT and MRI scans, together with a selection of colour plates. The causes are categorised as neoplastic, therapy-related, infectious, vascular and paraneoplastic in each chapter. Topics covered include altered consciousness, cognitive and behavioural disorders, seizures, cerebellar and visual disturbances, lesions of cranial nerves and spinal cord, peripheral nerve disorders and disturbances of muscle.

This approach is useful, although does mean that discussion of different diseases is scattered throughout the book. The last chapter summarises the management of primary brain tumours, cerebral and leptomeningeal metastases, and epidural spinal cord compression. The discussion is brief, and many of the references are not up-to-date. This limits the value of this section.

This book will be useful for those working in the areas of oncology and neurology, as it brings together in an approachable format the tools to diagnose disorders that bridge the intersection between the two disciplines. It will be particularly useful for registrars in oncology and neurology, as well as for oncologists who need help with assessing patients with neurologic complaints.

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ESTROGENS, ESTROGEN RECEPTOR AND BREAST CANCER

F Parl (Ed)

Published by IOS Press (2000)
RRP: A$180.92

This small book of seven chapters and 263 pages contains an astonishing amount of information.

The first chapter covers the history of the field from George Beatson through to the present day, with brief biographies and major discoveries of eight major researchers. Chapters two through six cover estrogen synthesis and metabolism, the estrogen receptor, estrogen action, estrogen receptor expression in breast cancer, and estrogens as a breast cancer risk factor. In the final chapter the author proposes a unified model of estrogens, the estrogen receptor and breast cancer. While some may not agree with his postulates, they may well stimulate thought and discussion. The emphasis in chapters two to five is very much on molecular biology. Chapter six deals more with clinical factors, such as the effects of endogenous and exogenous estrogens, including phyto and xeno estrogens on breast cancer risk.

Each paragraph is so crammed with detailed information (the author states that he diligently reviewed over 1,900 references) that, to some extent, reading can be slow and difficult. Nevertheless this is a valuable book.

While of limited interest to the clinician, it will prove an excellent reference book in the libraries of institutes involved in aspects of breast cancer and estrogen action.

R Murray
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HEPATOCELLULAR CARCINOMA: METHODS AND PROTOCOLS

N Habib (Ed)

Published by Humana Press (2000)
RRP: US$99.50

This book is an overview of laboratory methods that have been applied in the investigation of hepatocellular carcinoma. It covers many different aspects including methods for investigating the carcinogenesis of the disease, as well as its molecular and biological characteristics and methods for use in gene therapy. Its contributors are drawn from Europe the United States, and Japan, providing a truly global view of the methods that are in common use in laboratories working on this disease.

The book begins with two chapters dealing with the clinical aspects of hepatocellular carcinoma. These chapters provide a valuable background to the pathology and staging of the disease as well as the treatment that is currently in use. Treatment approaches that are considered include surgery, loco-regional therapies, and systemic therapies.

The remainder of the book is a reference work that provides detailed descriptions of laboratory protocols. A large range of methods is covered, and these will be of value to laboratory investigators working in this area.

The major problems with the book are its cost (particularly since the fall in value of the Australian dollar) and the fact that many of the methods described may become outdated as newer methods are developed. Nonetheless it would likely be a useful resource for a laboratory working on hepatocellular carcinoma.

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Royal Prince Alfred Hospital
Camperdown, NSW
HIV AND HTLV-1 ASSOCIATED MALIGNANCIES

J Sparano (Ed)
Published by Kluwer (2001)
RRP: US$200

This relatively small but not inexpensive textbook comprehensively examines biological and clinical aspects of malignancies associated with the retroviral infections, HIV and HTLV-1. Malignancy associated with HIV infection may present in many unusual and at times dramatic forms to many different types of clinician. While complications of HIV infection, especially opportunistic infections and Kaposi’s sarcoma have dramatically declined with improvements in anti-retroviral therapy there has been a lesser decline in the incidence of NHL, to the extent it has become a common initial presentation of AIDS. A number of other malignancies have been associated with HIV infection and the clinical manifestations of HIV infection itself may complicate the management of cancer in these patients. It is important cancer therapists be aware of these issues. Somewhat in contrast HTLV-1 associated leukaemia/lymphoma remains an exceptionally rare disease except in certain geographical areas such as the Caribbean and southern Japan with a more typical presentation for the cancer clinician. Why other cancers associated with infection such as MALT lymphoma or other forms of chronic immunosuppression such as the congenital immunodeficiency disorders with their high incidence of malignancy were not included remains unknown.

The editor gives no introduction or overview chapter to explain the rationale for the text. Be that as it may the quality of the content delivered is excellent. All chapters seem up-to-date and well referenced, highlight controversies in the area without ambiguity and are easy to read. The clinical chapters in particular are excellent and give clear and sensible recommendations regarding management. Their principle based approach makes it unlikely they will quickly become out-of-date. The chapter on mechanisms of lymphomagenesis has a surfeit of good content but disappoints by not giving the reader a more general overview to help understand the interplay of the many and varied factors discussed.

Any criticisms are relatively minor. It would have been helpful to have included a chapter on the protean presentations of malignancy associated with HIV infection and the appropriate diagnostic work-up. Occasionally a reference seems lacking and the contextual editing falls down with missed typographical errors and repetitive information across some chapters. Perhaps this is a problem for the ageing, hypermetropic reviewer but the system of referencing seems particularly galling as it varies the line spacing making the text more difficult to follow.

For the clinician involved in the treatment of HIV infection or the cancer specialist who may at some time be involved in the management of these conditions this would be an excellent addition to their library and would ably augment a more general library in a hospital or clinic.

S Millicken
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Hydrazines are an interesting class of chemicals due to their ubiquity in the environment. This book appears to be a comprehensive compilation of available toxicological data on the carcinogenicity of hydrazines and related chemicals. In particular, the studies are well summarised for use in cancer hazard assessment.

The inclusion of studies relevant to ‘mode of action’ is also useful to cancer risk assessment conclusions. Similarly the inclusion of chemical structures is extremely useful in facilitating identification of the different types of chemicals considered.

The information is set out in a clear and concise format, although it may have been made clearer from a ‘structure-activity’ point of view to have grouped chemicals by structure (eg functional group) rather than addressing them in alphabetical order.

The proposed supplementary publication of a volume on other toxic effects is strongly encouraged. Further information on mechanism of action would provide insight into the issue of the relevance of toxic effects seen in animals for humans.

Due to the number of chemicals (~ 100) considered in the book, it would have been useful to have an index by CAS number in addition to chemical name. Other names (synonyms) might confound the use of the chemical index. Although it is apparently envisaged to write a paper/book on “use, production and natural occurrence”, it would have added to the coverage to have provided a brief description of use and occurrence preceding each chemical profile.

Where a number of studies are presented for a specific chemical, the conclusions regarding overall carcinogenic hazard would be enhanced by inclusion of conclusions (and classification) by recognised international bodies where available. For example, a number of agencies have assessed the toxicity (including cancer potential) of a number of hydrazines, including the WHO’s International Agency for Research on Cancer (IARC) and International Programme on Chemical Safety (IPCS) and the UN’s International Register of Potentially Toxic Chemicals (IRPTC).

It is noted that the expression “carcinogenicities” is used throughout the book to describe the occurrence of both benign and malignant tumours. For accuracy, it is recommended that future publications, either provide a definition of commonly used terms or use the terms “neoplasia” or “tumours” when referring to combined tumour types.

Notwithstanding the author’s comments on the lack of statistical evaluations (see page 10 of the book), it would have been useful to include significance data where available.

Overall, the book provides a useful compilation of available carcinogenicity data on over 100 hydrazines and related chemicals and makes a valuable resource for researchers and regulators alike.

S Batt
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B Nickoloff (Ed)

Published by Humana Press (2001)
RRP: US$125.00

This book on the biology, immunology, pathology and microbiology of melanoma deserves a place in the library of all units with a specific interest in melanoma research and management. The aim of the book as stated by the editor is to provide a comprehensive and up-to-date summary of the most important advances in the field pertaining to melanoma.

Each author was asked to provide an overview of their area of research and a detailed experimental protocol to allow investigators outside the field to successfully use their techniques in their own laboratories. The subject matter of the book is very broad, ranging from molecular biology through to surgical treatment techniques in the treatment of primary melanoma. The wide-ranging nature of the contributions to this book makes an assessment of its value difficult for a general reader.

Without considerable understanding of basic microbiological techniques many of the chapters would be incomprehensible. However, to experts in the field, many chapters provide a good overview of the current status of progress in that area and a detailed description of the methodologies currently in use for molecular analysis of melanoma tissue. Some of the chapters are extremely detailed, eg the chapter on the role of molecular biology in diagnostic pathology of melanoma, while some chapters provide only a one or two page overview followed by many pages of detailed methodology, ie the chapter on isolation of tumour suppressive genes in melanoma by gene array analysis.

For the general reader the introductory chapter on the many molecular mysteries of melanoma by Brian J Nickoloff is an excellent overview of current approaches to the molecular biology of melanoma.

The chapter on surgical techniques seems somewhat out of place in a text on molecular biology but provides a reasonable overview of the management of primary cutaneous melanoma. Unfortunately the book was printed prior to the new AJCC//JCC classification system and thus does not reflect the new understandings developed from the recent detailed analysis of 30,000 melanoma case records by the AJCC melanoma committee.

This book can certainly be recommended for anybody working in the field of microbiology. It gives a good overview of the entire field of melanoma microbiology and enables those with a specialised interest in a specific area of microbiology to review and utilise the work of other researchers in this important and rapidly developing field.

W McCarthy AM
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Mendlesohn (Ed)

Published by W B Saunders (2001)
Distributed by Harcourt Australia
RRP: A$386.65

This second edition is a comprehensive up-to-date summary of the known molecular genetics in relation to cancer as at the year 2000. It would function as an excellent literature resource for research laboratories, academic teaching hospitals, cancer centres, and specialist departments. There are 62 authors, mainly from the USA and Canada. The edition is divided into four sections covering the areas of malignant transformation, growth and spread of cancer, molecular pathogenesis of specific malignancies, and about 200 pages on the molecular basis of cancer treatment. In addition, there are chapters on molecular mechanisms of chemo-prevention and differentiation therapy, and counselling for heredity cancer risk. Figures, diagrams and tables are plentiful. Chapters are well set out with appropriate headings and sub-headings and each chapter has an extensive reference list. Chapters tend to focus on data indicating what is currently known and what isn’t, without undue speculation. The section on “specific malignancies” is limited to lymphomas, leukaemias, childhood cancers, lung, colorectal, breast, prostate, ovarian cancers and melanoma, with no specific chapters on rarer malignancies. However, specific molecular genetic abnormalities involved in rarer malignancies are referenced in other sections.

The section on the “molecular basis of cancer therapy” is quite comprehensive with chapters on drug resistance, radiation, monoclonal antibodies, cytokines, cancer-specific vaccines and gene therapy.

In summary, this book would serve as an ideal reference point for scientists and clinicians in training as well as providing valuable reviews and updates for established clinicians and scientists.

S Ackland
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It is not hard to see how such a comprehensive text fits best into the reference library of diagnostic histopathologists. One is more likely to read the Yellow Pages cover-to-cover than this text, even in one’s formative years. It is destined to sit on the upper shelf and occasionally be pulled down to address specific issues in the diagnosis of early cancer. This is how it was reviewed over a three-month period and I must say it fulfilled my every expectation.

Put together from the collective wisdom of 43 contributors, including the co-editors, and mostly household names in their respective fields, it is divided into 31 chapters, including an introduction, and follows a familiar organ-based taxonomy. There are 714 numbered figures, approximately 50% in colour, and of variable quality.

The focus of the book is on the precursor lesions of human malignancy – the lesions we see more frequently as screening programs and more sophisticated patient surveillance yield biopsy specimens of progressively earlier and earlier cancers – their morphology (occasionally including diagnostic cytology), molecular genetics and epidemiology. All chapters are well referenced, mostly from the ’80s and ’90s. The very best chapters are on incipient carcinoma of the female breast and the urinary bladder. A chapter on salivary glands, new to the third edition, is an eye-opener to the reviewer not familiar with the field.

If you wanted to know about dysplasia in hepatic cirrhosis and its small cell variant, this is the book. Equally, if you need to follow and understand the adenoma-carcinoma sequence in colonic carcinoma or the genetic basis for dysplasia in Crohn’s disease, it is all there. Precursor lesions for esophageal squamous carcinoma get equivalent analysis to the dysplasia in Barrett’s esophagus. How about the relationship of melorheostosis and osteopoikilosis to bone cancer?

Subspecialty pathologists will pick at minor parochialisms such as “endometrial carcinoma is the most common malignant neoplasm of the female genital tract”. This is certainly the case in North America and Western Europe, which collectively account for almost 10% of the World’s population. The other 90% presumably do not count or do not read such books. This notwithstanding, there is a balance that will guarantee satisfaction to the reader.

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**Review of Cancer Immunology**

*R Robins and R Lees (Eds)*

Published by Kluwer academic publishers (2001)
297 pages plus index.
RRP: US$74.00

This book is a timely summary of recent knowledge in cancer immunology. This is a field which has evolved very rapidly in the past 10 years with the identification of an increasing number of tumour antigen which can service targets for immunotherapy, as well as a deep understanding of immunological process which can be exploited more effectively for therapeutic purposes. The book is divided into 13 chapters, which cover considerable new territory. The first chapter is entitled “immunogenicity of tumour associated antigens” and focuses on tolerance antigen processing, dendritic cell biology and the induction of immune responses in cancer patients using dendritic cell based vaccines. Tumour antigens are covered in chapters two to 10 which focus on the Cancer-Testis family of antigens, the use of Serex to identify tumour antigens, the differentiation antigens which are recognised by the immune system in malignant melanoma, CEA, viral antigens including EBV, HPV and other viral antigens potentially capable of serving as targets in the context of cancer immunotherapy.

Additional chapters cover fusion proteins such as bcr-abl, heat shock proteins and idiotypes which are potential targets for cancer immunotherapy and have been subject to clinical trials using a variety of different approaches in recent years.

Although defined antigens are held by many to be crucial for the further development of effective anti-cancer vaccines, there is a long history using systems aimed at stimulating immune responses in the absence of a clearly recognised antigen or series of antigens. This includes the use of tumour cells transfected with genes encoding cytokines or co-stimulatory molecules. These approaches are also discussed together with reference to some of the key clinical trials, which have used these approaches.

Given that some of the more impressive clinical successors in recent years have been achieved using monoclonal antibodies (for example Herceptin and MabThera) it is a little disappointing that the chapter describing antibody approaches is very brief (22 pages out of a total of 250 pages). The discussion largely centres on strategies and approaches rather than the results of trials with specific antibodies. Although antigens which can be recognised by antibodies are covered in earlier chapters (for example idiotypes), the broad thrust of this volume is largely about antigens recognised by the cellular immune system. The final chapter relates to mechanisms of tumour escape – an important phenomenon which can render tumours resistant to effective immune therapies. This is an important hurdle if immunotherapy of cancer is to succeed in the clinic.

This book provides a very useful introduction to readers who are unfamiliar with cancer immunotherapy. It is also good reading for those who work in the field. In particular the chapters on tumour antigens contain extensive tables listing peptide epitopes, HLA restricting elements and references. This serves as very helpful reference material.

The authors have been drawn from a number of well-recognised laboratories and institutes from Europe and the US, a number of which have made important contributions to the field over a number of years. Nonetheless some of the pioneers in modern tumour immunology, particularly those associated with the identification of the first human tumour antigens, are not represented. The focus of this publication is experimental with some discussion of progress in clinical immunotherapy. Nonetheless the book is primarily aimed at providing a review for post-graduate and post-doctoral scientists. Its value to clinicians will be limited, apart from those who work in the field.

J Cebon
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Professor Rosen is well known to surgical pathologists whether or not they are interested in breast pathology. He has published extensively on the subject and has been a leader in the field for over 20 years. He has written the definitive single author book on breast pathology and this is the revised second edition of that book. As the author describes it in the preface, the book is a “comprehensive, extensively illustrated description of breast pathology in a clinical context”. It is exactly that, and I would add that it is the best text on breast pathology available and is required buying for any pathologist interested in breast pathology. The 990 pages of the book are beautifully illustrated mainly in colour. Unlike many current pathology texts in which the colour reproduction is often of variable quality throughout the work, in this book the colour illustrations are of uniformly high quality.

The 46 chapters commence with a description of breast anatomy and physiology and then progress through all the categories of breast disease from benign through pre-cancerous lesions to in-situ and invasive carcinoma. In each of these chapters there is much more than just a description of the pathology features and differential diagnosis. The clinical significance, appropriate treatment and prognosis of the various pathological conditions are all discussed, and at the end of each chapter there is a complete reference list with citations up to the year 2000.

Immunohistochemistry, ultrastructure and molecular studies are also covered. Current areas of investigation or new techniques such as sentinel lymph node biopsy and conventional and vacuum-assisted core biopsy are discussed in depth both in their own right and also referred to in the context of the interpretation of pathology findings. Conditions that are being increasingly recognised such as “columnar cell change” are well described and beautifully illustrated. I particularly liked the chapters on lobular carcinoma in-situ and atypical lobular hyperplasia, and invasive lobular carcinoma because of their clarity, practical emphasis and discussion of risk factors. The last chapter addresses practical issues such as specimen handling, frozen sections, specimen radiography and the pathological changes in the breast following needle biopsy. Professor Rosen has had a particular interest in the latter and illustrates a number of interpretive problems such as displaced epithelium. Those seeking detailed information and illustrations on the cytology of breast disease may be disappointed as although addressed, the details are less comprehensive that those available in other specific cytology texts.

If you are a pathologist encountering breast pathology on a regular basis and even if you already have the first edition of Rosen’s Breast Pathology, buy the second edition as it is better. The historical section on in-situ disease and the overlong section on slide packaging in the first edition have gone and the information is right up-to-date.

A surgeon or oncologist wishing to have a means of learning more about breast pathology should also consider buying this book. For trainees in all the above disciplines particularly those considering specialising in breast disease, this is the ideal reference for you.

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Fifteen authors, from both sides of the Atlantic, have contributed to this text. The content has been updated and new chapters added since the first edition was published eight years ago, to reflect, as noted in the preface, the many diagnostic technical advances that have occurred in recent years as well as attitude changes towards multidisciplinary diagnosis and management.

The essential methods of breast disease diagnosis are discussed – clinical examination and history, imaging (mammography and ultrasound) and needle biopsy – with, as expected from the title, an emphasis on mammography.

Technical aspects of mammography – equipment physical factors, equipment quality assurance and positioning technique – are comprehensively described, with an emphasis on quality aspects. Normal anatomy, benign breast disease, malignant disease and post-surgical changes are described and their mammographic findings detailed. The common findings are extensively illustrated.

Normal and abnormal ultrasound imaging findings are described. Artefacts and pitfalls of the technique are discussed, as is the increasing role for the use of ultrasound. The use of echo-enhancing contrast agents for Doppler examination is one of the new techniques outlined.

Interventional procedures including cyst aspiration, needle biopsy (fine needle and core), needle localisation and ductography are covered not just from the technical point of view but also discussed are indications, accuracy, technique and guidance selection, complications etc. The pathology interpretation of the cytology and core biopsy material is well illustrated and discussed.

Further chapters describe the role of magnetic resonance imaging and potential contribution of digital mammography, aspects of population-based mammography screening, the male breast and epidemiological aspects of breast cancer.

Generally the text is comprehensive, easy to read and is well illustrated. Unfortunately the mammographic image quality in the book suffers from the high contrast nature of the original images. An appropriate emphasis has been placed on quality aspects in general and on the important features of breast disease and accurate differential diagnosis. This book is a valuable text for radiologists in particular as well as for other clinicians working in the field of breast disease diagnosis.

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Thoracic Oncology is the latest in the Cancer Treatment and Research series, published in 2001. It is a concise, well-referenced book of just over 400 pages consisting of six parts: lung cancer, non small cell lung cancer, small cell lung cancer, mediastinal tumours, malignancies of the pleura, and oesophageal cancer. All the sections are written by specialists in their field who obviously know the current questions and problems in management. While there are many books just on management of lung cancer alone, there are few such as this that cover the whole spectrum of intrathoracic disease.

As a specialist managing patients with all the diseases mentioned, I have found this book extremely interesting. It is common now, instead of going to a book, to search an Internet database for information. But how often do we find an overload of non-peer-reviewed information which is time consuming to sift through? This book is for the practicing thoracic surgeon or clinician, who already knows how to make the cut and do all the operations. Well-referenced material is discussed to give a broad scope for practice, and gives ideas for difficult situations which one might not have read about before, or didn’t understand from an evidence-based approach, without having to sift out unwanted information.

The book initially looks very dry, with few photos or drawings but, for the clinician who is currently practicing, one doesn’t need the black and white photos of shadows and masses commonly seen in the more basic texts. The actual body of information is very well put together. Each chapter has a very large reference section and this saves searching the Internet.

Overall I think this book delivers what it sets out to do – “provide the reader with an understandable, concise and comprehensive review of thoracic oncology”. I would think it is the type of book every practicing thoracic surgeon needs for quick reference for day-to-day, as well as rare, cases. It is good value and I highly recommend it.

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