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The policy of Cancer Forum is to provide a forum for debate and the exchange of medical, scientific, political, social and educational comment related to cancer research, treatment, prevention and control. Cancer Forum invites submissions of original research articles, reports and letters relating to these themes.

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Cancer Forum
GPO Box 4708
Sydney NSW 2001

Telephone: 02 8063 4100
Facsimile: 02 8063 4101
Email: info@cancerforum.org.au
Website: www.cancerforum.org.au

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Symptom management in supportive care

PALLIATIVE CARE: COMPASSION, CARE AND COMPLEXITY

Meera Agar
Palliative Care, Braeside Hospital, Hope Healthcare, Sydney; Department of Palliative and Supportive Services, Flinders University; South West Sydney Clinical School, University of NSW
Email: meera.agar@sswahs.nsw.gov.au

Palliative care is a complex arena, where basic science and sensitive compassion have an equal footing, reflecting the ever broadening scope and diversity of disciplines involved in maximising function, controlling symptoms and providing support for patients with advanced illness and their families.[1] In the setting of active progressive far advanced disease, multidisciplinary care has never been so crucial. This issue of *Cancer Forum* highlights some of the more challenging areas for multidisciplinary palliative care and bringing the role of the multidisciplinary team into focus, but also the other services (such as rehabilitation) that support them. Somogyi et al bring the laboratory to the bedside as we broaden our understanding of how the most efficacious pharmacological approaches to pain could be assisted by utilising pharmaco-genomics,[2] and Sanderson et al outline the progress in knowledge of the patho-physiology of delirium in advanced cancer.[3-5]

Delirium, despite being a medical emergency, is under-recognised and undertreated, associated with significant morbidity and is an independent predictor of mortality in advanced cancer patients. Delirium incidence has been posed as a marker of the quality of healthcare and rightly so, as focus on delirium prevention and rapid management has potential to reduce functional and cognitive decline and provide a survival advantage in advanced cancer.[6,7]

Hewitt et al describe the challenges of lymphoedema management in palliative care.[8] Intractable breathlessness is a complex and multi-factorial symptom, where severity cannot be determined by the degree of pulmonary function abnormalities or extent of disease; its prevalence increases as disease advances.[9,10] It is paramount all cancer professionals have an understanding of the state of the field in the therapeutics for breathlessness. Davidson et al provides us an up-to-date review, so the situation that a person is left to endure their escalating breathlessness does not occur.[9,11]

In discussing the carer experience in end of life caregiving, Wilkinson cites that the annual replacement value of the vital role carers play in caring for family or friends is over $30.5 billion annually.[12,13] A survey of family carers found a phenomenal number - 2.6 million people, (13% of Australians living in households) provided some assistance to those who needed help because of disability or age.[14] A national health strategy must pay attention to service models that: support caregivers as those for whom they provide care experience symptom exacerbations and hospitalisations; empower them to manage situations in the home environment to avoid unnecessary hospitalisations; and reduce end-of-life carer burden, stress, anxiety and burnout, and complicated bereavement. The focus should be on proactively assisting the cancer carer and patient to live life as fully as possible in the time they have left.

Rehabilitation, according to Cole, has much to offer cancer patients with physical functioning issues related to nervous and musculoskeletal problems due to cancer or its treatment, as well as the general debility that may be a feature of advanced cancer and its acute medical complications.[15] Specialist rehabilitation teams bring their skills to bear to improve the ability of patients to live their daily lives as independently as possible, while the sub-specialty of cancer rehabilitation continues to evolve. As Cole states eloquently: "There is no place for therapeutic nihilism in the presence of physical disability in cancer patients, any more than there is in the presence of disability due to 'benign' illnesses".[15] Equally, lymphoedema in patients with advanced disease associated with worsening levels of function and dependence, as well as feelings of hopelessness, disgust and social isolation, requires professionals skilled in management strategies that can be provided across inpatient, outpatient and community settings.[16]

In an article that delves into the essence of suffering, Kearsley challenges health professionals to better understand their patients' perspective, encouraging us to reflect on the nature of suffering and the patient stories we are privileged to bear witness to every day.[17] Kearsley cites the poet Lesley Marmon Silko: "I will tell you something about stories, they aren't just entertainment. Don't be fooled. They are all we have, you see, all we have to fight off illness and death".[17,18]

The articles in this Forum put forward the challenge to escalate the evidence-base to: provide high quality palliation of complex symptoms of dyspnoea, delirium and lymphoedema; better understand their patho-physiology

and; ask us to deepen our individual capacity to be with suffering. The unforgotten primary caregivers who contribute much to the quality of experience of the person with advanced cancer need the right support, information and services, and the person living with advanced cancer needs us to put much focus in maintaining and regaining function for as long as possible.

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Role of pharmacogenomics in pain therapy: focus on opioids

Andrew A Somogyi[1] and Janet Hardy[2]

1. Discipline of Pharmacology, Faculty of Health Sciences, University of Adelaide.
2. Department of Palliative Care, Mater Health Services, Brisbane, Queensland.

Email: andrew.somogyi@adelaide.edu.au

Abstract

Analgesics, especially opioids, show remarkable inter-individual variability in both efficacy and adverse effect profile. There are many factors that contribute to this variability, including renal and liver function, co-morbidity and concomitant medications. Another source of interpatient variability in response to analgesics is the patients' genetic profile that controls their drug metabolism, drug transport out of the brain and target site activity. The cytochrome P450 2D6 poor metaboliser phenotype reduces the effects of some opioids, such as tramadol. In contrast, in ultra-rapid metabolisers, adverse effects are seen with codeine and antidepressants. The efflux transporter p-glycoprotein located at the blood brain barrier limits the access of these drug classes to the brain. Genetic polymorphisms in ABCB1 result in enhanced efficacy, but also increased adverse effects to many drugs used widely in palliative care. For opioids, a mu receptor polymorphism leads to reduced efficacy and for Non Steroidal Anti-inflammatory Drugs, CYP2C9 polymorphisms are associated with a higher risk of bleeding. These genetic factors might explain why some drugs 'don't work' or 'work too well' in routine clinical practice.

In palliative care, patients receive multiple medications for symptom management and to reduce adverse effects from medications. Until recently, it was difficult to carry out rigorous studies to determine the contribution of pharmacokinetic (eg. metabolism and transport) and/or pharmacodynamic (eg. receptors) factors to interpatient variability in response and the potentially pivotal role that could be played by pharmacogenomics. Since the early part of this century, advances in population pharmacokinetics, objective measures of drug effect and the technology to easily, rapidly and cheaply genotype for any drug metabolising enzyme, transporter and receptor/target, has allowed for valuable insights into explaining why some patients respond poorly, why others experience unacceptable adverse effects necessitating drug withdrawal and why dosage requirements vary substantially between patients. This paper will cover the role of pharmacogenomics as a key factor in the wide range in dosage requirements and the occurrence of adverse effects to analgesics, especially the opioids.

The reasons why a patient may respond differently to a

medicine can be due to polymorphisms in genes encoding for proteins controlling the enzymatic metabolism of drugs (eg. CYP2D6 and codeine), the transport of drugs out of their target organ (eg. p-glycoprotein and fentanyl) and the target receptor (eg. mu opioid receptor and morphine). One should appreciate that in many instances, the phenotypic response (low response or moderate-severe side-effects) may be a combination of one or more different gene variants. Also, not all gene variants result in a reduced drug effect. Some patients may have multiple copies of the "normal" or wildtype gene of a drug metabolising enzyme, which in the case of codeine results in adverse effects, whereas genetic variants for efflux transporters at the blood-brain barrier may result in increased and not decreased effects. Moreover, there are multiple other factors that influence how individual patients react to different drugs. These include renal function (relevant in the elimination of many drugs including morphine), liver function (important for the elimination of oxycodone), other medications (such as CYP450 inducers and inhibitors) and age.

Pharmacogenetics of analgesics

Opioids

The mu opioid receptor is the major target for all opioids and although there are a large number of variants to its gene OPRM1, the c.118A>G single-nucleotide polymorphism (SNP) in which the G variant allele has a frequency of 10-15% in Caucasians but almost 50% in Asians and results in reduced opioid effects, has been the most widely studied. For example, in healthy subjects administered alfentanil, those with one or two copies of the G variant allele showed a threefold reduced effect to experimentally induced pain from electrical stimulation and 10 fold reduced respiratory depressant effect.[1] It is difficult to quantify analgesic response and the variability in response to opioids in patients with pain. As a consequence, this is often assessed as dosage requirements. In cancer patients on morphine for chronic pain, four patients who had two copies of the G variant gene required a higher dose (mean±SD 225±143 mg/day) compared to 78 with no copy, or 17 with one copy of the variant (97±89 and 66±50 mg/day respectively).[2] However, the small numbers of patients with both alleles variant (homozygous variant), the large interpatient variability in dosage requirements per se and the non gene-dose effect make interpretation difficult.

In a much larger population of 175 cancer patients commencing morphine, while there was no difference in dosage requirements between those with zero, one or two copies of the G variant allele, those with two copies had a significantly lower change in pain as measured on a numerical rating scale (mean 0.2 unit change), compared to those with one copy (1.8) and those with no copies (3.8), after one week of dosing. When those with one or two copies of the variant allele were combined, the result was significant in that those with the G variant allele had a much lower change in pain rating.[3] Thus, the mu opioid receptor gene variant c.118A>G appears to lead to a reduced opioid effect.

This was confirmed in a recent study in postoperative pain conducted in almost 1000 Asian patients in Singapore, noting that the G variant allele has a much higher frequency in this population.[4] The authors found a difference in morphine PCA dosage used in that the homozygous variant group required almost double that of the wildtype group, with intermediate use in the heterozygotes (10.9, 5.8, 8.8 dosage units, respectively). In a recent meta-analysis, Walter and Lötsch (2009) reported that the c.118A>G SNP showed no consistent association with phenotype.[5] However, the data were from a combined analysis of postoperative patients, women in labour and patients with chronic cancer pain and chronic non-cancer persistent pain. As mentioned above, one of the major problems in human studies in this area has been low patient numbers in most of the studies included in the analyses.

The COMT (catechol-O-methytransferase) enzyme system metabolises noradrenaline, adrenaline and dopamine, and can effect morphine dosage requirements. In 207 cancer patients, those with two copies of the COMT A variant at c.474G>A required 95±99 (mean±SD) mg/day, those with one copy required 117±100 mg/day and those with no variant allele (G wildtype) 155±160 mg/day (P=0.025).[6] Although the mechanism remains unclear, the A variant causes upregulation of the mu opioid receptor, so that endogenous opioids have a greater effect, resulting in less dosage required of exogenous opioids (eg. morphine).

Opioids must cross the blood-brain barrier for the majority of their effects. P-glycoprotein is an efflux transporter found on the luminal membrane of many organs and tissues. It is located on the apical membrane of the capillary endothelial cells at the blood-brain barrier and functions to limit drug entry into the brain. A lowered function of the transporter allows more drug to be present in the brain. Theoretically, this should lead to an enhanced antinociceptive effect. Some opioids such as fentanyl, morphine and methadone are p-glycoprotein substrates. In acute pain, a variant of the gene ABCB1 (that encodes for p-glycoprotein) causes enhanced respiratory depression following a single intravenous dose of fentanyl.[7] Haplotype (multiple SNP) analysis for ABCB1 showed that dosage requirements of methadone used in maintenance treatment for opioid dependence were related to the number of copies of the variant haplotype. Those patients with two wildtype alleles required a higher dose than those with both alleles variant.[8] In the study cited above for morphine by Campa and colleagues (2008), those patients with two copies of the most common ABCB1 variant allele c.3435C>T had an increased analgesic effect (increase in pain score of 4.4 units), compared to those with one variant (3.15) and those with wildtype (2.31).[3] These findings indicate that several of the opioids that have been tested are p-glycoprotein substrates, and that there will be an enhanced analgesic and adverse effect to standard doses of opioids in patients who have variants in ABCB1.

It is intriguing that the combination of variants in OPRM1 and ABCB1 can have opposite effects on response, with the former lowering analgesic response while the latter enhances analgesia. Thus, overall response will depend on which combination of these two gene variants a patient

has. For example, Campa et al (2008) showed that the best response to morphine in their cancer patients was in those with a combination of wildtype OPRM1 plus ABCB1 variant (4.8 unit change in pain score) and the worst response was in those with a combination of OPRM1 variant and wildtype ABCB1 (1.3).[3]

Opioids such as codeine, tramadol and oxycodone that are O-demethylated to more potent opioid metabolites such as morphine, O-desmethyltramadol and oxymorphone, respectively by the highly polymorphic cytochrome P450 CYP2D6 enzyme, show reduced effects to the parent drug in subjects with mutations in the CYP2D6 gene, resulting in the poor metaboliser (PM) phenotype. For example, CYP2D6 PMs given codeine show a substantially reduced response to cold pressor pain and reduced respiratory depression and lower psychomotor performance.[9] However, there have been no large clinical pain studies to test this premise. Similarly with oxycodone, in a small study in palliative care, the one PM patient required the highest dose of oxycodone and greatest number of breakthrough analgesic doses.[10] Finally, for tramadol in postoperative patients following abdominal surgery, there was a significantly higher number of non-responders in PMs (81%) compared to extensive metabolisers (EMs 17%).[11] In addition to PMs, who comprise about 7% of the Caucasian population, about 2% of Caucasians are ultrarapid metabolisers (UMs) mainly through having multiple copies (up to 13) of the CYP2D6 gene. In such people, enhanced adverse effects such as euphoria and dizziness have been reported due to increased conversion of codeine to morphine.[12] Adverse psychiatric reactions have been reported to oxycodone and hydrocodone in patients with the UM phenotype.[13]

In summary, people with variants in the mu opioid receptor gene OPRM1 have a reduced response, those with variants in the p-glycoprotein efflux transporter gene ABCB1 an enhanced response and those with poor metaboliser variants in the CYP2D6 gene have a reduced response to some opioids that produce metabolites with substantially enhanced mu opioid activity.[14]

Non Steroidal Anti-inflammatory Drugs (NSAIDs)

The major polymorphic enzymes involved in the metabolism of NSAIDs are CYP2C9 (primarily) and CYP2C8 (less so). Plasma concentrations of flurbiprofen, ibuprofen, diclofenac (minor effect), lornoxicam, piroxicam and celecoxib are increased in subjects with the CYP2C9*3 variant (loss of function) allele, however the magnitude is less than two fold in most cases.[15] For celecoxib, those who were homozygous for CYP2C9*3 had a seven fold increase in drug exposure,[16] but this has not been confirmed. For the active S-ibuprofen and piroxicam, such increased exposure results in greater thromboxane A2 concentrations, raising the potential that the CYP2C9 polymorphisms might reduce its COX-2 selectivity.[17] In terms of NSAID induced gut toxicity, NSAID induced bleeding is higher in those with the CYP2C9*3 variant allele.[18]

Some NSAIDs are also UGT substrates for glucuronidation, with diclofenac induced hepatotoxicity being more common in those with UGT2B7*2 variant alleles compared with controls.[19]

In regard to genetic polymorphisms in the COX1 and COX2 enzymes and NSAID effects, in patients following dental surgery given rofecoxib, ibuprofen or placebo, those homozygous for the G allele of c.-765G>C of COX2 had a significantly lower pain intensity score from rofecoxib at 48 hours compared with those on ibuprofen, whereas those homozygous or heterozygous for the minor allele variant had a significantly higher pain intensity score compared to the wildtype.[20] The mechanisms underpinning these findings and their clinical importance remain to be established.

Tricyclic antidepressants

Amitriptyline, nortriptyline and doxepin are metabolised by CYP enzymes. CYP2D6 contributes about 50% to the overall metabolism of amitriptyline and its active metabolite nortriptyline, Loss of function of CYP2D6 alleles result in an approximate doubling in plasma concentrations of the drug.[17] It is uncertain to what extent the CYP2D6 phenotype contributes to enhanced efficacy, especially in neuropathic pain. It is generally considered that dose reductions are unnecessary in these patients, and the practice has not been adopted in the psychiatric and pain palliative care communities. Nortriptyline CYP2D6 ultrarapid metabolisers have plasma concentrations of only 20-50% of those with two functioning alleles and this could lead to drug resistance;[21] a higher incidence (25%) of postural hypotension was reported in ultrarapid metabolisers (25%) compared to extensive metabolisers (0%).[22]

Conclusion

Pain response to analgesia remains unsatisfactory in 10-30% of patients. Dose requirements required in order to obtain adequate pain relief vary considerably, especially with opioid therapy, where the inter-patient variation can be as high as 40%.[9] There are many pharmacogenetics factors that can contribute to the efficacy and adverse effects of analgesics, especially the opioids. It is as yet unclear however, how significant these factors are in routine clinical practice. The number of patients included in many of the studies has been low, and some studies have shown no, or only borderline value in pharmacogenetic testing for predicting the response to opioids.[23,24] It seems likely however, that genetic testing will in the future at least contribute to inter-individualised pain management.

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DELIRIUM IN ADVANCED CANCER

Christine Sanderson[1] and Meera Agar[2]

1. Palliative Medicine, Calvary Healthcare, Kogarah, Sydney; and CareSearch, Flinders University of South Australia.

2. Palliative Care, Braeside Hospital, Hope Healthcare, Sydney; Department of Palliative and Supportive Services, Flinders University; and South Western Sydney Clinical School, University of NSW.

Email: christinersanderson@gmail.com

Abstract

Delirium is a distressing and under-diagnosed syndrome of acute alteration in mental state. It occurs frequently in patients with advanced cancer and is often associated with a worsening of prognosis and difficult challenges in symptom management. Given its associations with older age, recognition and management of delirious patients are likely to become an even more important aspect of oncological practice in the future. The potential for prevention of delirium is being studied, and protocols which involve modifications in hospital care, in addition to screening and rapid identification and treatment of precipitants, may reduce the burden of the condition. However, such approaches require further study and validation in an advanced cancer population. Routine use of appropriate and validated screening tools is a low burden strategy which is likely to improve diagnosis, care and understanding of delirium. The evidence to guide pharmacological management is not strong. Well designed clinical trials are urgently needed in order to improve supportive care outcomes for delirious patients and to clarify the role of antipsychotic and other medications in symptomatic management.

For cancer patients and their families, delirium is a devastating, frequent and often under-recognised complication of their disease.[1] Delirium is a complex neuropsychiatric syndrome causing acute alteration in mental status.

Core features of the condition as described in the Diagnostic and Statistical Manual IV[2] are:

- disturbed consciousness, with reduced ability to focus, sustain or shift attention
- altered cognition (memory, orientation, language) or the development of a perceptual disturbance that is not better accounted for by dementia
- disturbance develops over hours to days and tends to fluctuate during the course of the day
- there is evidence of an aetiological cause.

There is no pathognomonic feature of delirium. Presentations include diverse cognitive and non-cognitive symptoms (table 1).[3]

Table 1. *Delirium symptomatology*

Features	Hypoactive delirium	Hyperactive delirium
Disturbance of arousal	Hypoaroused, hypoalert, drowsy, reduced awareness of surroundings.	Hypervigilant, distractible, easy startling.
Temporal onset	Abrupt onset, fluctuating course.	Abrupt onset, fluctuating course.
Perceptual disturbance	Visual hallucinations, misperceptions, illusions.	Visual hallucinations, misperceptions, illusions.
Disturbance of thought content	Paranoid delusions. Vague and not systematised.	Persistent thoughts and delusions more common in hyperactive delirium.
Mood symptoms	Sad, depressed irritable, mood labile, disinhibition.	Mood lability – may include a wide range of mood states from combative or impatient through to euphoric.
Psychomotor activity	Hypoactive, withdrawn, quiet.	Restless, agitated.
Past psychiatric history	Previous episode of delirium may be present.	Correlated with alcohol and/or drug withdrawal. Previous episode of delirium may be present.
Sleep wake disturbance	Increased daytime sleepiness.	Prominent sleep-wake cycle disturbance, nightmares.
Neurological examination	Asterixis, frontal release signs may be elicited; EEG may show slowing.	Asterixis, frontal release signs may be elicited; EEG may show slowing.

The existence of hyperactive, hypoactive and mixed subtypes is clinically significant, as delirium can range from subtle hypoactivity or altered mood through to dramatic onset of psychosis. Hypoactive delirium is a diagnosis which is frequently missed, but nonetheless causes significant distress to patients and may be associated with worse outcomes than hyperactive presentations.[4,5] Of all the potential features of delirium, inattention is crucial to the diagnosis, occurring in 97-100% of cases.[6]

Despite the frequency and severity of delirium, it is not well studied and current clinical management strategies lack a robust evidence base. This review addresses evolving understandings of the condition, potential for prevention, outcomes of delirium and how it impacts on prognosis, clinical strategies for screening and assessment, and emerging clinical approaches to pharmacological management.

Epidemiology

The prevalence of delirium at admission to hospital for patients with advanced cancer has been estimated at between 28% and 48%, rising to around 90% in the last days of life.[7] However, evaluation of the degree of error in recognition and diagnosis in such settings has been limited.[8,9] Due to poor ascertainment of delirium in routine clinical practice,[10] these prevalence figures are likely to underestimate the true burden of the problem.

Delirium is conceptualised as having predisposing and precipitating features.[11,12] The threshold for an episode relates to the interplay of these factors. Vulnerable patients with many predisposing factors, particularly the elderly, require fewer, less noxious precipitants to trigger an episode of delirium. In clinical practice, the epidemiology is consistent with this model, with delirium occurring predominantly in older patients or the most severely ill. Also increasingly recognised is the overlap with dementia, with both pre-existing cognitive impairment predisposing to delirium occurrence and ongoing cognitive change common after delirium resolution.[13-17] As one of the most important predisposing factors is cognitive impairment, delirium has been identified as a "geriatric syndrome."[18]

Advanced cancer brings specific vulnerability and precipitating factors for delirium. Chemotherapy and its complications are potential precipitants,[19] while some treatments, such as stem cell transplants and high dose interferon, are recognised as being associated with a particularly high risk of delirium.[20-22] Given that improved treatment of cancer has led to more frequent and prolonged active treatment of elderly patients, who may have pre-existing cognitive fragility or even dementia, these distinct epidemiologies of delirium – as geriatric syndrome and as comorbid with cancer – can be expected to increasingly overlap in oncological practice in future.

Observational studies in palliative care settings have shown that, when carefully screened for, the hypoactive subtype predominates – occurring in as many as 86% of patients with delirium.[23] A series of studies looking at potential for delirium reversibility in palliative care have demonstrated that up to 50% of cases may be reversible.[9,24,25] However, in those patients in whom delirium persists, mortality is higher and outcomes are worse.[9,25,26] The impact of hospital practices on the incidence of delirium have led to the suggestion of using delirium as a marker of quality of care.[27,28]

Pathophysiology – current understandings

The physiological basis of delirium is not well understood, and the syndrome is likely to be the final common pathway of a diverse group of pathophysiological mechanisms.[29]

The best studied hypothesis proposes that delirium can be caused by relative neurotransmitter imbalance, with decreased cholinergic transmission and corresponding overactivity of dopaminergic pathways. Central nervous system cholinergic pathways are involved in arousal, attention, memory and sleep, all functions affected in delirium. Supporting evidence for this model includes demonstration of a dose response relationship between exposure to anticholinergic medications and delirium in vulnerable populations and the discovery of endogenous anticholinergic activity in sera and cerebrospinal fluid of delirious patients.[30-32] This hypothesis also suggests a theoretical link with the cholinergic deficit model for dementia, perhaps accounting for the frequent co-occurrence of these two conditions. Finally, the model provides theoretical support for the use of dopamine blocking neuroleptic agents as treatments for delirium. There is also evidence for dysregulation of other neurotransmitter pathways in delirium. These include serotonin, melatonin, cortisol, endogenous opioids and glutamate.[33-35]

The role of inflammatory mediators and cytokines within the delirium process are also being explored.[34]

The evidence related to these is less well established, however these mechanisms may potentially explain how diverse (and sometimes seemingly trivial) precipitants without obvious link to central neurotransmission (for example mild urinary tract infection), might trigger the often disproportionate and global neuropsychiatric response of delirium. Another important area of research attempts to identify biomarkers and/or physiological predictors of delirium. Attention has focused on inflammatory mediators such as interleukins IL-6 and IL-8, markers of neuronal injury such as neuron-specific enolase and S 100 beta, presence of APOE4 genotype, cerebral blood flow, neuropeptide Y, brain-derived neurotrophic factor and glutamate transport.[36] A consistent picture has yet to emerge from the literature.

Modifiable versus non-modifiable factors

In considering the potential for both prevention and reversibility of delirium, distinguishing between modifiable and non-modifiable factors is useful (table 2). The presence of numerous non-modifiable predisposing factors defines a high risk population. It is suggested that these patients require routine screening for cognitive changes, with a high level of clinical alertness for onset of delirium, careful attention to their environment, to minimising polypharmacy, and rapid identification and treatment of reversible problems.[37]

Table 2. *Risk factors for delirium*

Non-modifiable individual factors	Potentially modifiable individual factors	Institutional factors[38]
Age >65	Treatable medical condition (eg. infection, metabolic syndrome, anaemia, uncontrolled cardiovascular or respiratory condition)	Number of room changes
Known/documented cognitive impairment	Psychoactive medications: ■ opioids ■ benzodiazepines ■ steroids ■ SSRIs ■ tricyclic antidepressants ■ neuroleptics	Absence of clock or watch
Severe underlying illness eg. advanced cancer, trauma, end-stage organ failure	Anticholinergic load	Absence of usual visual aids
Intracranial disease / damage: ■ primary and metastatic brain neoplasms ■ leptomeningeal metastases ■ paraneoplastic encephalitis ■ cerebrovascular accident ■ postictal state ■ CNS radiotherapy	Poorly treated pain	Absence of a family member
Low albumin	Dehydration	Use of restraints (physical or pharmacological)
Post-operative state	Malnutrition	Catheterisation

It is important to recognise that most cases of delirium, particularly in older patients, are likely to have multiple precipitants.[39,40] In a study of causes of delirium in a cohort of patients with advanced cancer, a median of three precipitants was identified for each episode (range 1 – 6). Potential for reversibility was associated with specific aetiologies. Episodes related to opioids or other psychoactive medications (corticosteroids and benzodiazepines), or dehydration, were more likely to be treatable, while delirium attributed to hypoxic encephalopathy or metabolic causes was associated with refractoriness.[9] Managing psychoactive medication and delirium is a fine balance between adequate symptom control and contribution to delirium. While medications used for supportive care are often implicated in the onset of delirium, there may be limited alternatives to these if they are being used to treat distressing symptoms such as pain. Strategies such as opioid rotation,[41] gentle hydration, and attempting to select adjuvant medications with less psychoactive or anticholinergic properties, or use of more specific therapies such as radiation for bone pain, may all be used to try to alter the balance between analgesia and adverse effects. Pharmacovigilance is especially required in caring for the deteriorating patient.

Potential for preventability

Evidence has been accumulating in relation to the potential preventability of delirium. A number factors which may be amenable to primary prevention approaches have been identified (see box).[42]

Elements of multicomponent interventions to prevent delirium

- Modifying processes of care: minimising room changes and staff changes; providing regular re-orientation to time and place and access to a clock; ensuring cognitive stimulation; ensuring access to aids such as glasses, hearing aids and dentures.
- Minimisation of polypharmacy - medication review
- Focus on maintaining mobility, hydration and nutrition, preventing constipation and promoting natural sleep.
- Treat infection and other precipitants.

Clinical trials testing this concept have shown that multicomponent interventions addressing delirium risk factors may reduce the incidence of delirium by up to a third, while in some studies there were reductions in severity of delirium.[37] These findings have led to considerable interest in developing clinical protocols for primary prevention of delirium, focusing on minimisation of risk factors. A multicomponent intervention protocol addressing major geriatric delirium risk factors (sleep deprivation, cognitive function, reduced mobility, visual impairment, dehydration) using a case control study method (N = 852) reduced the incidence of delirium (9.9% v 15% p = 0.02), the number of delirium episodes (62 v 90 p = 0.03) and the total number of days of delirium (105 v 161 days p = 0.02).[42]

The possibility of using neuroleptics and other medications for prophylaxis for delirium is also being explored, however has not yet shown definitive results.[43-45] Studies relating to delirium prevention have so far been performed in aged care and orthopaedic surgical populations almost exclusively. The extent to which similar benefits could be expected if prevention strategies were implemented in in-patient cancer care has not been studied. As in aged care, for patients with advanced cancer the balance of predisposing and precipitating factors and the extent to which the dominant precipitants are ultimately reversible, determine the outcomes. For example, risk factors identified in a population of patients receiving haematapoietic stem cell transplant included poor cognitive function, increased creatinine, type of malignancy, total body irradiation, older age and history of drug or alcohol misuse, most of which are not easily reversible.[20,46] However, any strategies that raise the threshold at which delirium may be triggered may still deliver overall benefits across a population.

Screening and diagnostic tools

Under-diagnosis of delirium is a significant barrier to improvements in care and to improving our understanding of the problem. Identifying acute alterations in mental state often does not carry the sense of clinical urgency which the problem merits. Delirium is frequently described with one of a multitude of synonyms which have no diagnostic specificity – 'confused,' 'agitated,' 'muddled' or 'drowsy'. Under-diagnosis and under-treatment go hand in hand. As the diagnosis of delirium is a clinical one, and its presentation is so varied, healthcare providers need to maintain a high index of suspicion, especially in high risk patients. This is particularly true for the hypoactive subtype, which may commonly be mistaken for depression.[8,47]

Screening for baseline cognitive function and acute alterations in mental state have been shown to improve outcomes for patients with delirium in terms of length of hospital stay and mortality.[48] However, there are challenges in using some of the available cognitive assessment tools, especially in unwell patients with advanced cancer. For instance the Mini-Mental Status Examination is widely used, but provides a non-specific assessment of cognitive function, and is physically difficult for sick patients to complete. Several tools which are more specific for delirium and less burdensome for both patients and staff have been developed (table 3), and can potentially be recommended for routine clinical use in cancer care settings.[19]

Table 3. *Cognitive assessment tools*

Tool	Description	Comments
Confusion Assessment Method (CAM)[49]	A brief four-item tool, validated in a variety of settings for the screening and diagnosis delirium.	Despite good psychometric properties when used by trained clinicians, the tool is less specific if used by those who are untrained. Versions of the CAM exist for ICU patients. Does not include an item to specifically capture hypoactive delirium.
Memorial Delirium Assessment Scale (MDAS)[50]	A 10 item instrument for diagnosis and monitoring severity of delirium.	Developed and validated in cancer care settings. The score can also be used as a measure of the degree of confidence with which a diagnosis of delirium can be made. Scoring is standardised, but the assessment is intrusive and may be impossible to complete with an unwell patient.
Blessed Orientation Memory and Concentration Test (BOMCT)[51]	A brief oral test which is able to be used both for screening and monitoring severity of delirium.	Excellent psychometric characteristics. Less burdensome than the Mini-Mental State Examination in a cancer population.
Nursing Delirium Screening Scale (NuDESC)[52]	An observational five-item scale useful for both screening and monitoring severity.	Sensitivity 85.7% and specificity 86.8% in a palliative care validation study. High degree of clinical utility and acceptability to staff, and a non-intrusive assessment.

Management strategies for delirium symptomatology

As well as appropriate non-pharmacological management, patients experiencing delirium symptoms may require pharmacological treatment to reduce distress and prevent injury to themselves or caregivers. Whether such treatment may also modify the underlying condition is not yet well established by evidence, despite an increase in trials undertaken in recent years. Many are methodologically flawed (non-blinded, not placebo controlled or not adequately powered).[16,45] Both typical and atypical antipsychotics have been studied, and most evidence is from retrospective or open label studies and case reports. While these studies appear to support a clinical role for antipsychotic medications, due to lack of any placebo arm demonstrated improvements cannot be clearly separated from the natural history of delirium itself.[53] Benzodiazepines are frequently given in caring for delirious patients to reduce symptoms of agitation, but no evidence supports their use in delirium, except if due to benzodiazepine or alcohol withdrawal, and a single trial has been done which suggests they may worsen cognitive function.[54]

Therefore pharmacological management of delirium, including which drug to use and how to titrate, continues to be based on expert opinion, and continues to be controversial. There is enormous variation in practice between different disciplines in medicine and different settings of care.[55] Due to the fluctuating nature of delirium, well designed, adequately powered, randomised placebo-controlled trials are required.[56] Studies designed to separate the impact of various antipsychotics and other medications on distressing target symptoms versus overall delirium severity, as well as the impact on duration and mortality outcomes from delirium, are greatly needed. They should be able to ascertain the frequency and effect of any adverse effects of these medications in patients with advanced cancer, or perhaps on various specific aetiologies of delirium.

Outcomes for patients with delirium

For patients with advanced cancer, even with careful management of all reversible precipitants, delirium is a generally reliable marker of poorer prognosis.[3] Hypoactive subtype and severity of cognitive impairment are correlated with worse outcomes, and for refractory delirium the life expectancy in advanced cancer is likely to be days or weeks. One study in a palliative care unit showed that for patients with reversible delirium (n=33) the mean time to death was 39.7 days, while for refractory delirium (n=88) it was 16.8 days.[26] The costs of delirium are substantial – both to the patient and to health services. Although not quantified for cancer patients specifically, these include loss of ability to communicate and reduced quality of life, increased length of stay in hospital with requirement for more intense nursing care, and admission to hospital for patients who can no longer be cared for at home by their families. The suffering of families of delirious patients is also significant, and witnessing severe or terminal delirium may add to their distress in the bereavement period,[1,3,4] while unrelieved and distressing symptoms of delirium at the end of life may be an ethically appropriate justification for initiating palliative sedation.[57]

Given the prevalence and impact of delirium in cancer, it is remarkable how little evidence is available to support clinicians in making the difficult decisions required in

caring for delirious patients. These include: how much to investigate and what burden of tests and treatments is appropriate and acceptable for a given episode of delirium; when and how to manage pharmacologically the kinds of psychological care and institutional arrangements needed by delirious patients; and how best to support their families. Research focused on the cancer population is urgently required in order to improve screening, diagnosis, and management of delirious patients and to minimise avoidable distress.

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LYMPHOEDEMA MANAGEMENT IN PALLIATIVE CARE

Bronwen Hewitt, Erin Bugden and Polly Levinson
Physiotherapy Department, Sacred Heart Palliative Care Service, St Vincent's Hospital, Darlinghurst, Sydney.
Email: bhewitt@stvincents.com.au

Abstract

In palliative care, the presence of lymphoedema poses an interesting challenge for both patients and clinicians. When determining an appropriate management plan for a patient with advanced disease and lymphoedema, a number of factors need to be considered. These include: the extent of the oedema; the impact of the oedema and its management on other symptoms such as pain, breathlessness and fatigue; the expectations of the patient; and the patient's tolerance of different treatment modalities. Current evidence suggests that combined with good skin care, the modalities most effective in the management of lymphoedema include massage (manual lymphatic drainage), compression (multilayer compression bandaging or compression garments) and exercise. This paper discusses how these modalities can be effectively modified for use in a palliative care setting and presents two case studies to illustrate some of the practical considerations of lymphoedema management in palliative care.

Lymphoedema is a high protein oedema that occurs when there is a build-up of fluid in the lymphatic system as a result of damage to lymphatic vessels or nodes through either trauma or disease.[1-4] Lymphoedema is characterised by changes to both the skin and underlying tissues.[5] While lymphoedema most commonly manifests in the limbs, in advanced disease oedema may also present in the trunk, face and genital regions.[6] A number of factors have been identified as contributing to the development of lymphoedema, with cancer and its treatment (surgery, chemotherapy and radiotherapy) identified as one of the leading causes.[5]

In palliative care, the spread of disease to surrounding lymph nodes, the development of fungating lesions, ongoing nutritional deficiencies, recurrent infections, reduced mobility and function, progressive organ failure and prolonged use of medications such as Non Steroidal Anti-inflammatory Drugs (NSAIDs), corticosteroids or chemotherapy, have all been associated with an increased risk of either developing or exacerbating lymphoedema.[3,7,8] Estimates of the prevalence of lymphoedema in cancer patients have been found to vary according to location of the primary malignancy. However, it is estimated that 20% of patients with melanoma or primary breast, gynaecological or prostate cancer will experience lymphoedema.[9-11] The impact of lymphoedema on patients has been found to be quite profound, with both physical and psychological implications.[10,12] In patients with advanced disease, the impact is even more pronounced, with the presence of lymphoedema associated with worsening levels of function and dependence, as well as feelings of hopelessness, disgust and social isolation.[8] For these reasons, the development and utilisation of appropriate strategies to manage lymphoedema are necessary to maintain the quality of life in palliative patients.

Management of lymphoedema

There have been a number of different strategies proposed for the management of lymphoedema.[9,12] These have ranged from surgical debulking,[13] or subcutaneous drainage,[14,15] to pneumatic pumps,[16] medications,[12] massage, compression, exercise, low-level laser therapy and complementary therapies.[4,9] However, to date the evidence to support the use of any of these modalities is limited.[9,17,18] The modalities that have the strongest evidence to support their use are massage, compression and exercise.[4,9]

Assessment of the patient is required prior to the instigation of a lymphoedema management plan.[4,9] In conjunction with a full medical history and examination of the extent and quality of the oedema, other useful information includes the impact of the oedema on other symptoms such as pain, breathlessness and fatigue, and the expectations of the patient.[19] If possible, it is also useful to ascertain the patient's tolerance to different treatment modalities, namely compression.[4] Armed with this information, it is possible to develop a management plan in conjunction with the patient that will not only optimise the control of his or her oedema, but also improve the patient's quality of life.

Skin care is considered one of the cornerstones of comprehensive lymphoedema management.[20] Maintaining skin integrity is crucial not only for patient comfort, but also to prevent recurrent infections, such as cellulitis, which are not only problematic to treat but may contribute to worsening oedema.[21,22] In advanced disease, skin integrity can be further compromised by the presence of lymphorrhoea, the leaking of lymphatic fluid through the skin,[23] or fungating lesions.[24] The presence of either of these adds complexity to the management of lymphoedema and requires a co-ordinated approach from the multidisciplinary team.[25]

The aim of massage, or manual lymphatic drainage (MLD), in lymphoedema management is to facilitate the movement of lymphatic fluid, reducing congestion and ongoing oedema.[20] The effectiveness of this modality is reliant on a number of factors. First is the integrity of the skin. Although MLD is a gentle massage technique, if a patient's skin is fragile, inflamed or leaking, massage

may be contra-indicated.[4] The second factor to consider is the extent of damage to the lymphatic system. If the lymphatic system (vessels and nodes) is significantly compromised, by either underlying disease or cancer treatment (surgery and radiotherapy), then MLD may not be effective in decongesting a limb. In this case, MLD may focus on softening the oedema, especially around joints to enable movement.[19,20] The final factor to consider is the frequency of MLD. It is unclear how frequently MLD needs to be performed.[17] Current consensus suggests patients and/or their carers be taught self-lymphatic massage, a simplified version of MLD, to optimise the effectiveness of massage.[4]

Graduated compression of an oedematous limb aims to increase lymphatic absorption and facilitate the movement of lymphatic fluid.[19,26] Compression can be applied either through the use of multi-layer bandaging or a specially fitted compression garment.[4] Multi-layer bandaging consists of layers of protective padding combined with low stretch bandages.[4] Compression garments are recommended for use once the volume of oedema in the limb has stabilised.[20] In palliative care, the decision to use compression is again based on a number of factors. The region of the body affected will dictate what method of compression can be used, with oedema to the face and genital regions the most difficult to compress.[27] Patient comfort is another factor to consider. For instance, reducing the level of compression has been shown to dramatically improve patient tolerance of both bandages and garments.[26] Finally, the risk of exacerbating other conditions such as ascities and superior vena cava obstruction needs to be taken into consideration.

Exercise is thought to facilitate the movement of lymphatic fluid through utilisation of the extrinsic muscle pump.[12,20] While specific exercise regimes have been developed,[16] there is anecdotal evidence to suggest that participation in activities of daily living may be sufficient to improve lymphatic flow. In palliative care, the ability to maintain independence has been identified as important for quality of life. The introduction of a general exercise program, including joint range of motion exercises, may facilitate not only a reduction of lymphoedema, but enable patients to return to activities they enjoy.[4]

Case studies

The following two case studies illustrate some of the practical considerations and complexity of upper limb and lower limb lymphoedema management for patients with advanced disease. In both cases, the patients were referred to a multidisciplinary specialist palliative care team, where the physiotherapists are trained in, and provide, lymphoedema management.

Ms G

Ms G is a 48 year-old lady with right sided breast cancer. Her initial treatment was neo-adjuvant chemotherapy and hormonal treatment prior to right mastectomy in May 2006, followed by radiotherapy. She then developed metastatic disease to her brain, liver, lung, cervical lymphadenopathy and a fungating wound of her right anterior chest wall. Ms G developed right upper limb lymphoedema two years after her primary treatment. At this time she was measured for a custom fit garment consisting of a glove and sleeve. She was also taught self-lymphatic drainage massage, which she performed twice daily.

One year later she had increased cervical lymphadenopathy, progressive right upper limb lymphoedema, a sharp stabbing pain in her arm and hand, and she was no longer tolerating wearing her compression garment. On initial examination by our physiotherapist, Ms G had gross lymphoedema of her right upper limb, extending from her fingers to her right chest wall area. Her limb was very fibrotic in texture, and her skin was intact. Circumferential measurements were taken of her wrist 20cm, elbow 34.5cm and axilla 54cm.

She was initially treated with multi-layer compression bandaging of the right upper limb, with only one layer of low stretch bandage, and given range of movement exercises. She was to continue her daily self-lymphatic massage and moisturise her skin. This treatment was not tolerated by the patient for more than six hours and resulted in neurological compromise with reported pins and needles and numbness. The next line of treatment that was trialled was again multi-layer bandaging, using one layer of crepe instead of short stretch bandages. This time the patient tolerated the bandages for less than three hours before neurological compromise started, at which point she removed them. On both occasions neurological signs resolved with removal of the bandages. Ms G reverted to wearing her compression glove and Tubigrip. Her treating physiotherapist then commenced lymphoedema massage of the right upper limb in an attempt to soften the fibrotic nature of the limb. Ms G also requested being measured for a new compression glove. There was a good response to the lymphoedema massage over time, with the limb reducing in size and woodiness.

Ms G reported improved upper limb function, namely she was able to resume some cooking preparation, feeding with her right arm, typing, sewing and knitting. Her axilla circumference decreased to 49cm. She had some lymphorrhoea at times that ceased with massage. Despite the reducing size of her right upper limb, Ms G was unable to be fitted for an off-the-shelf compression glove and continued to be managed with massage and Tubigrip, as this was the only form of compression she could tolerate. The goals of treatment identified for this patient were to improve her upper limb function, maintain her skin condition and prevent infection.

Ms D

Ms D is a 51 year-old lady with metastatic non-small cell lung cancer. Ms D suffered two episodes

of cellulitis in both her lower limbs, treated with intravenous antibiotics and knee length anti-embolic (TED) stockings, which she did not wear as they cut in behind her knees. Ms D was referred to the community palliative care physiotherapist to manage her oedematous legs. On initial examination, oedema was gross, hard and pitting extending the length of her legs to the thigh (left right), with fibrotic areas on the left lower limb. She had pressure areas at both anterior ankle creases and forefeet.

On the first occasion, treatment consisted of lymphatic drainage massage, education in how to perform daily self-massage and education in maintaining skin integrity, to prevent infection. It was decided to try modified compression bandaging using low stretch bandages that would stay on for approximately 36 hours, and to do this twice a week. This would allow Ms D to continue to go out and maintain an active lifestyle, while attempting to manage and reduce her oedematous legs. Ms D was also instructed on active ankle and knee exercises to perform while the bandages were on, and advised to keep her legs elevated when resting. Ms D was happy with the results, exclaiming that she "had ankles again!" This continued twice weekly for two weeks. She had a third episode of cellulitis, likely from the broken skin of a fungal infection in her toes.

On discharge, treatment resumed as it had prior to her hospital admission, and extra emphasis was placed on the importance of maintaining skin integrity to avoid further episodes of cellulitis. Ms D was finding that her legs were reduced in size after the bandages came off, but that they would return to their larger size within a day or so. She found the heat/humidity of summer made the bandages very uncomfortable and she was often not able to tolerate them for very long. She was then maintained with weekly to twice weekly massage to her legs by the community physiotherapist, continuation of self-massage and TED stockings at night. Her right leg size reduced markedly and the left leg is still moderately oedematous, but has no fibrotic areas and skin is very well nourished, with no pressure areas.

Conclusion

Although lymphoedema can be challenging to manage in palliative populations, it is possible to modify existing modalities to effectively reduce oedema and improve quality of life. Care does need to be taken though to ensure that patient comfort is maintained in the assessment and treatment process. For this reason it is advisable to utilise clinicians who not only possess appropriate training in lymphoedema management, but who also employ a holistic view to patient care.

While the focus of this paper has been on the physical management of lymphoedema, it is important not to discount the psychological impact of swollen limbs on patients and their carers. Hopefully, as the body of research in this area develops, clinicians will be able to offer patients evidence-based treatment strategies to effectively manage the physical and psychological consequences of lymphoedema.

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MANAGEMENT OF REFRACTORY DYSPNOEA: EVIDENCE-BASED INTERVENTIONS

Patricia M Davidson[1] and David C Currow[2]
1. Centre for Cardiovascular and Chronic Care, Curtin Health Innovation Research Institute, Curtin University, Western Australia.
2. Palliative and Supportive Services, Flinders University; Flinders Centre for Clinical Change, Flinders University and Institute of Palliative and Supportive Care Research, Australia.
Email: p.davidson@curtin.edu.au

Abstract

Breathlessness is a common and distressing symptom in both malignant and non-malignant conditions. Both pharmacological and non-pharmacological strategies are necessary to minimise symptom burden and distress. Assessing the individual's needs and clarifying the goals of treatment is an important first step in determining an effective treatment plan. Although the evidence supporting the use of some of these therapies is variable, there is an increasing evidence base to inform clinical decision making and treatment plans. Pharmacotherapy with opioids is a common and effective strategy for managing breathlessness, yet requires judicious titration and management. The adverse effects of opioid therapy, including constipation and drowsiness, can be anticipated and managed with adjunctive therapies. The use of oxygen in people who are hypoxaemic is supported, but is of limited value in people who are not hypoxaemic. Individualised strategies and advance care planning is important to avoid unnecessary hospitalisations and futile treatments at the end of life. There is a clear mismatch between the prevalence and burden of this problem and data to inform evidence-based guidelines. Refractory breathlessness is a fertile area for ongoing research and requires increased attention to address the burden of this highly prevalent symptom.

Breathlessness is a common and distressing symptom for patients and carers, occurring in 50-90% of individuals in both malignant and non-malignant conditions.[1] In palliative care, the intensity of breathlessness frequently worsens as death is imminent.[2] In spite of the prevalence of this symptom, patho-physiological processes remain poorly understood and the sensation is highly subjective, challenging development of evidence-based approaches.[3] Available data suggest that there is more than one mechanism involved in the pathogenesis and manifestation of breathlessness.[4]

An important consideration for health professionals is that in the real world of clinical practice, it is rare for an individual to have a single condition responsible for inducing the sensation of breathlessness. Breathlessness may be related to a prior condition, disease progression or it may be iatrogenic. In addition to causes of refractory breathlessness, commonly chronic obstructive pulmonary disease (COPD) and chronic heart failure (CHF) are comorbid conditions of individuals with cancer.[5-7] Furthermore, breathlessness can also be associated with deconditioning associated with advanced illness.[8,9] This means that the diagnosis, management and treatment of dyspnoea is complex and multifaceted and requires an appreciation of the biological, psychological and social impacts of breathlessness. Importantly, this requires appraisal of the individual's needs and establishing the goals of therapy.[10]

Much of the data derived for recommendations relating to management of refractory breathlessness in cancer is derived from non-malignant populations.[11] However, when disease is advanced and there is a need to focus on symptom management, these data provide an important foundation for empirical treatment. The heterogeneity of both patient populations and the symptom challenge evidence-based guidelines. In spite of these challenges, it is important that the clinician takes a systematic approach to the diagnosis and management of this symptom.

Assessment and planning: foundation of effective treatment

In order to develop an effective treatment plan it is important to identify the cause, where possible, and identify reversible causes such as pleural effusions, heart failure exacerbations or anaemia. Implementing strategies for monitoring the severity of breathlessness across the illness trajectory can assist in monitoring and managing exacerbations.[1] Implementing a valid and reliable strategy for assessing breathlessness, such as a Visual Analogue Scale, Numerical Rating Scale or modified Borg Scale, can assist in monitoring and evaluating symptomatic treatment.[12,13] Although there can be challenges in administering these instruments, implementing a measure routinely in clinical practice can assist in treatment and management. Although self-report is optimal, objective assessment using tools such as the Respiratory Distress Observation Scale may be useful.[14] Calls for consensus of the choice of instruments for dyspnoea trials is an important consideration, particularly in the palliative care population.[15]

Unfortunately, once breathlessness is refractory, many non-pharmacological interventions have been trialled and reversible causes assessed. As both malignant and non-malignant diseases progress, pharmacotherapy is an essential part of treatment integrated within a supportive care plan, recognising the physical, social, psychological and spiritual needs of patients and their families. As breathlessness is a common cause for hospitalisation, pre-empting hospital presentations with action plans in the event of sudden worsening of breathlessness is contingent upon effective palliative strategies. Evidence-based recommendations are limited by the current data available to inform decisions, underscoring the importance of ongoing research. Although there is increasing and emerging data in managing breathlessness,[16] we are still limited by the absence of adequately powered clinical trials to definitively define treatment for many of the options currently used.[1,17]

Opioids

Although the mechanisms of action remain unclear, opioids are a frequently used and effective strategy for managing refractory breathlessness.[17,18] Apart from morphine, which can be administered in immediate or sustained release oral preparations, subcutaneously or intravenously, other preparations include dihydrocodeine, hydromorphone and fentanyl. Opioids cause vasodilation and decrease the chemoreceptor response to hypercapnia and hypoxia. These responses may decrease the sensation of breathlessness through reducing preload and pulmonary congestion. The effect of opioids through decreasing anxiety and the subjective sensation of breathlessness, contributes to decreasing the respiratory rate and oxygen consumption.

Encouraging results have been found in the use of opioids in both malignant and non-malignant populations for relieving dyspnoea.[17,19,20] Stigma and scepticism regarding opioids are important factors in the low uptake of opioid therapy.[21] The commonly cited reasons for avoiding opioids, such as causing respiratory depression and reducing life expectancy, are not substantiated by available data when used chronologically in low doses. Minimising physical and psychological distress is not associated with shortening life expectancy. The optimal type, dose and mode of administration remain less clear and are the focus of ongoing research. Growing clinical experience indicates that judicious titration of dosage and anticipation of adverse effects, such as constipation, improves compliance with opiates. Adverse effects of opioids such as sleepiness or nausea are infrequent, and can be overcome by dose titration. Each patient should be assessed individually and appropriate dose adjustments made based on the patient's current medical condition. Starting with a low dose and up titrating slowly can allow the monitoring of adverse events and the tailoring of dosage. Constipation does not readily respond to dose titration and requires proactive bowel management and adjunctive administration of regular laxatives. For clinicians less experienced in opioid therapy prescription and management, enlisting the support of a more experienced colleague for mentorship and a pharmacist to assist with dosing is an important consideration.[22] Although conceptually alluring, the use of nebulised opioids in the treatment of dyspnoea is not supported by individual studies nor a meta analysis.[18]

Diverse pharmacological agents

Corticosteroids can be effective in the treatment of dyspnoea related to carcinomatous lymphangitis, superior vena cava syndrome, tracheal obstruction and bronchospasm associated with COPD and asthma.[23]

Bronchodilators are used in the management of bronchospasm and may provide relief of breathlessness caused by airflow obstruction through relaxing the muscles around airways and increasing muscle tone.[20] Common bronchodilators include the short acting agents albuterol sulfate, levalbuterol and pirbuterol acetate, and the long-acting agents ipratropium bromide, salmeterol xinafoate, formoterol, tiotropium and terbutaline sulfate. Metered dose inhalers should be used with a spacer to improve the patient's ability to receive the full dose. Proper dosing is often dependent on perfecting the technique of these technically challenging devices. Failure to achieve therapeutic doses due to poor usage of the delivery system is not uncommon. Considering administration by a nebuliser may be a more reliable alternative, particularly if the patient is highly symptomatic.

Diuretics may be useful in the treatment of breathlessness caused by oedema. Generally loop diuretics, such as frusemide, are prescribed. Standard dosing for frusemide is 20-40mg orally, subcutaneously or intravenously once or twice a day. In individuals where heart failure is advanced or diuretics have been administered over a long period of time, diuretic resistance may be a problem requiring tailoring of the timing of dosage and the addition of a thiazide diuretic.[24] Diuretics must be used cautiously given the potential for hypovolemia and electrolyte disturbances, particularly hypokalaemia. Consideration of electrolyte substitution, particularly potassium and magnesium should be considered.[24] Importantly, if the patient is incontinent, strategies to maintain patient comfort, dignity and preserve skin function should be implemented.

A recent meta-analysis conducted by Simon and colleagues did not show a beneficial effect of benzodiazepines for the relief of breathlessness in patients with advanced cancer and chronic obstructive pulmonary disease. These authors concluded that there was a small, non-significant trend towards a beneficial effect. Benzodiazepines caused more drowsiness compared to placebo, but less compared to morphine. They recommend considering benzodiazepines when opioids and non-pharmacological measures have failed to control breathlessness.[25] The decision to

prescribe these agents should be based on the presence of anxiety impacting on the sensation of breathlessness.[10] Benzodiazepines reduce the sensation of breathlessness through decreasing the anxiety associated with breathlessness. As benzodiazepines are metabolised in the liver to long-acting metabolites, short-acting drugs such as lorazepam are preferred, especially in the elderly or in patients with impaired liver function. Midazolam, when administered either subcutaneously or intravenously as an addition to an opioid, has been shown to reduce the terminal agitation and anxiety that may be associated with dyspnoea.

There is some data to suggest that phenothiazines can be beneficial in the treatment of breathlessness.[26] In addition to reducing anxiety, phenothiazines possess anticholinergic properties that can be useful in managing increased respiratory secretions or in controlling nausea. Chlorpromazine has been found to be effective for the relief of dyspnoea in advanced cancer patients and also relieves terminal restlessness.[27] Side-effects of phenothiazines may include hypotension and extrapyramidal effects, which may limit tolerability of these agents.

Agents such as aminophylline and theophylline have been found to dilate the bronchi and improve diaphragmatic contractility in individuals with COPD, irrespective of any bronchoconstriction. There have also been reports of use in the palliative care setting.[28] Theophylline can also be useful in managing dyspnoea when combined with albuterol and ipratropium. Adverse effects include vomiting, hypokalaemia, hyperglycemia, tachycardia, cardiac dysrhythmias, neuromuscular irritability and seizures. Given the narrow therapeutic index, frequency of side-effects and the lack of evidence for efficacy, these agents are often not well tolerated in patients with advanced illness and their use should be reserved for people already established on these therapies.

Nebulised frusemide has been identified as a novel approach to dyspnoea management. The precise mode of action is unclear and it is thought to have multiple pathways of action. Potential modes of action are on the pulmonary stretch receptors and vasculature. A recent review has shown that this agent had a positive influence on dyspnoea and physiological measurements. However, the authors provide the caveat that findings are mixed and data to date comes from small trials and observational studies.[29] Further investigation into the mechanistic and therapeutic actions of nebulised frusemide is warranted.

Oxygen therapy

Oxygen therapy continues to be very controversial in the management of dyspnoea, as there is little data supporting its use in the nonhypoxic patient,[30] although the role in people who transiently desaturate, particularly on exertion or overnight, can be made more easily. In patients who are hypoxic on room air, the benefit of supplemental oxygen is most likely related to flow of gas over the face. Currently, guidelines only recommend oxygen for dyspnoeic patients, with hypoxaemia of less than PaO2 of 55-60mm Hg. A recently published systematic review of short-term oxygen in people with cancer who did not qualify for domiciliary oxygen, showed no symptomatic benefit.[31] A recent international, multicentre, randomised comparator control study assessed long-term oxygen (≥15 hours/day) therapy versus air in a palliative care population, who had intractable dyspnoea at rest and on minimal exertion and did not qualify for home oxygen (NHMRC 375127/NIH R01 AG026469-01). It showed that both oxygen and air delivered symptomatic benefit when used at two litres per minute via nasal prongs for more than 15 hours a day.[32]

Non-pharmacological therapies

Both invasive and non-invasive ventilation can be considered for progressive illnesses when the symptom is refractory to other therapies.[33] However, the purpose and goals of treatment need to be carefully considered.[34] There is an increasing concern of the futility of some decisions to provide mechanical ventilation.[35] Escalation of symptom burden avoiding such scenarios can be achieved by careful planning and the institution of an action plan,[36] providing strategies for self-management and instructions to health professionals where there is a deterioration in status about the person's wishes. In life limiting illness, advance care planning is important to document the patient's wishes and outline a clear plan for care.[37]

There is a wide array of non-pharmacological therapies to manage dyspnoea, by either changing physiologic factors or modifying the subsequent emotional response associated with the sensation of breathlessness, as shown in table 1. Current research has been geared primarily toward patients with COPD, however the utility of this modality for both malignant and non-malignant disease is increasingly evident. Increasingly in cancer, there is an interest in rehabilitation programs similar to those seen in cardiac and respiratory rehabilitation.[38,39] The aims of structured rehabilitation programs are to facilitate the coordination of care, provide information and facilitate access to resources, optimise physical and social function and provide psychosocial and peer support.

The purpose of rehabilitation for patients with cancer is similar to that for patients with other diseases. The anticipated progression of disease, and any associated treatments must be considered carefully when goals are formed. When tumour progression and treatment causes a functional decline, or when the disease causes a fluctuation in abilities, rehabilitation assumes a supportive role of seeking to minimise the rate of decline, and goals should be adjusted to meet the needs of the patient and their families. The strong evidence for appropriate exercise in decreasing the symptom burden of dyspnoea and the increased adherence obtained from group settings is an important consideration.[40,41]

Table 1: *Nonpharmacologic therapies for dyspnoea*

- Reassurance and strategies to minimise the anxiety/dyspnoea cycle.
- General supportive measures such as optimising nutritional status.
- Positioning to support ventilation – sitting up or leaning forward.
- Muscle strengthening through exercise and respiratory muscle training.
- Energy conservation techniques to minimise exertion and optimise activities of daily living.
- Relaxation through techniques such as guided imagery and progressive muscle relaxation.
- Breathing training through pursed lips and diaphragmatic breathing.
- Counselling techniques such as mindfulness therapy.
- Cool air and moving air across the face through use of a fan or gas administration via nasal cannula or mask.
- Non-invasive ventilation.
- Acupuncture/acupressure.
- Massage to promote relaxation and posture.

The use of complementary and alternative treatments, such as massage, to decrease anxiety is increasing. Emotional responses to illness, such as anxiety and anger, can precipitate and worsen breathlessness.[42] Although some studies have assessed these therapies, the widespread recommendation is limited due to methodological factors such as small sample sizes.[13] Relaxation and biofeedback techniques have demonstrated some efficacy in breathlessness in COPD and in patients with CHF. A critical strategy is addressing anxiety before it escalates into a situation of panic.[43] Distraction is a useful technique and the playing of music and getting the patient to watch a movie can be useful. Breathing exercises and meditation strategies such as Buteyko and Pranyama, that use diaphragmatic breathing, can relieve the sensation of dyspnoea and promote a sense of control, however require a motivated and cognitively intact person.[44,45] Bernardi and colleagues demonstrated in a small study that training using the Ave Maria (in Latin), or a yoga mantra, improved psychological responses and increased baroreflex sensitivity.[46] For these strategies to be effective, it is important to introduce these early in the illness, as when patients become highly symptomatic or drowsy, it is difficult to teach these techniques.

Some studies have suggested there is a benefit from acupuncture.[47,48] Strategies that promote a sense of control are likely to improve the patient's sense of wellbeing and minimise feelings of hopelessness. A recent trial of mindfulness therapy has shown benefits in relieving dyspnoea.[49] It is important that patients and their families feel comfortable discussing alternative approaches and disclosing treatments they are undertaking.[50] The potential for deleterious drug interactions with herbs and vitamins increases as metabolic derangements occur in the advanced stages of disease at the end of life.

An important strategy in managing refractory breathlessness and maximising quality of life are energy conservation techniques.[51] As symptoms worsen, activities of daily living become increasingly difficult. Implementing strategies and devices, such as walkers, to reduce energy expenditure can be useful.[52] Involving allied health professionals, particularly occupational therapists, can contribute effectively to the dyspnoea management plan.

Palliative care

When increasing disability is evident and advanced disease processes are present, interventions and goals that focus on minimising or eliminating complications and providing comfort and support are important. Psychological and social support for the patient and family members are integral. Although a palliative approach can be provided by a range of health care professionals, particularly general practitioners, when breathlessness is refractory and front line treatments have been trialled unsuccessfully, specialist palliative care services should be accessed. It is not uncommon for existential distress to exacerbate symptoms, particularly dyspnoea.

Conclusion

Dyspnoea is a difficult and challenging symptom to manage for patients, their families and clinicians. Management of refractory breathlessness in patients with advanced disease remains challenging and further research is required to develop evidence-based strategies. Although there is a growing evidence base for interventions to manage dyspnoea, issues in clinical trial design challenge translation to evidence-based guidelines. Adequately powered, well controlled clinical trials are urgently needed to address the burden of this distressing symptom. A salient consideration in contemplating evidence-based interventions is that dyspnoea is a highly individualised and subjective symptom. As a consequence, the optimal treatment of dyspnoea will involve appraisal of the pathophysiological basis of the symptom, weighing of the potential risks and benefits of treatment and overall prognosis. Implicitly, this will entail an understanding of psychosocial, spiritual, and existential needs of the patient and their family.

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THE CARER EXPERIENCE IN END-OF-LIFE CANCER CAREGIVING: A DISCUSSION OF THE LITERATURE

Anne M Wilkinson
Chair in Palliative and Supportive Care, Cancer Council Western Australia (WA); WA Centre for Cancer and Palliative Care, Edith Cowan University.
Email: anne.wilkinson@ecu.edu.au

Abstract

Research into the experience of unpaid caregiving has been growing since the 1980s with the introduction of 'community care' policies in Australia and in other Western societies. There is now a large body of research that sheds light on various aspects of the experience of cancer end-of-life caregiving. The aim of this article is to explore what is known about the roles, needs, adverse impacts and concerns of family caregivers providing care to advanced cancer patients at the end of life. Reviewed literature, published between 1990 and 2010, focused on end-of-life cancer caring in the home, but includes in-patient palliative care interventions. Where relevant, general end-of-life caregiving literature to supplement the cancer specific research is included. Five major dimensions of the end-of-life cancer carer experience are identified: the end-of-life cancer carer role, impact of end-of-life caregiving; positive aspects of caregiving; carer perceptions of need; and access to palliative care.

In 2004-5 (the latest year for which we have national data), 2% of the Australian population, or about 390,000 people, reported that they currently had cancer and 87% reported that their cancer was malignant.[1] Moreover, cancer was the cause of over 40,000 deaths in 2007, or just over 29% of all deaths in Australia.[1] The most common cancers in Australia (excluding non-melanoma skin cancer) are prostate, colorectal (large bowel), breast, melanoma and lung cancer.[2] Although cancer incidence increases with age, improvement in cancer survival rates has meant that people are living with the disease longer and receiving successful outpatient treatment. Nevertheless, despite advances in the early detection and treatment of cancer, half of all cancer patients either present with, or eventually develop, incurable metastatic disease.[3]

Carers are essential for ensuring treatment compliance, continuity of care, social support and assisting the healthcare system in achieving the patient's treatment goals. It has been estimated that the annual replacement value of the vital role carers play in caring for family or friends is over $30.5 billion annually.[4] A survey of family carers found that almost 2.6 million people, or 13% of Australians living in households, provided some assistance to those who needed help because of disability or age. About one in five carers, or 474,600, self-identified as the primary carer, that is, someone who provided the majority of informal help to a person with a disability. Just over half (54%) of all carers were women, but women were more likely (71%) to be the primary carer. Most primary carers (78%) cared for a person living in the same household. Twenty-four per cent of primary carers were aged 65 years and over, compared to 13% of the total population.[5] Nearly two million of these carers were of workforce age, but many have had to leave the workforce, reduce the hours they work, or work below their skill capacity because of their caring responsibility. In addition, one million, or 39% of carers were simultaneously caring for children, partners and/or ageing parents.[2] On average, carers were found to spend around 40 hours a week providing care.[6]

End-of-life cancer carer role

The increased use of outpatient services for cancer treatment, shortened hospital stays, longer survival and the trend to accommodate patients' desire to be cared for at home, and when possible, to die at home, has resulted in up to 90% of terminally ill cancer patients spending much of their last year of life in the community cared for by lay carers.[7-9] Irrespective of the underlying type of malignancy, most patients with advanced cancer experience a prolonged period of gradual decline before a short phase of accelerated decline and intense need in the last month or two.[10] Several of the issues cancer patients and their carers face at the end of life are similar, regardless of their illness or initial type of cancer. Patients are likely to experience physical and emotional symptoms from the treatment as well as from the disease itself, including pain, dyspnea, anorexia, depression, fatigue, nausea and delirium.[11,12] Advanced cancer patients have been reported to experience an average of 11-13 symptoms and frequently have other comorbid illness burden.[13,14]

Studies examining end-of-life caregiving have tended to focus on research exploring the adverse effects and needs for assistance associated with end-of-life caring, patients' and carers' views of communication with their physician and obstacles to care, the perceptions of surrogate decision makers about end-of-life care, or retrospective studies of the end-of-life experience of families.[15-17] As patients move through the cancer trajectory, and as disease progresses, the needs of patients and their carers increase exponentially. The role of the cancer carer has been transformed from the simple provision of custodial care into a multifaceted role with responsibilities that can be complex and burdensome. Caregiving now

includes a variety of direct, hands-on care activities, including carrying out nursing and medical procedures, as well as indirect care activities ie. activities carried out on behalf of the patient. Indirect care include activities such as transportation to health care appointments, accessing needed services or resources, supervising unpaid care workers, coordinating care among healthcare professionals and facilitating care transitions (eg. hospital to home or to hospice or residential aged care), making medical decisions when the patient cannot, and throughout the course of illness, serving as the patient's advocate in response to a rapidly changing array of healthcare professionals, settings and medical circumstances to ensure that the patient's needs are adequately met. One of the most important roles of the family carer is to assist the cancer patient with symptom management. Carers are expected to assess and monitor patients for changes in hallmark symptoms, to identify side-effects from therapy as well as any new symptoms, to administer and supervise the cancer patient's medications (eg. which medication, when to dispense it, at what dosage, when to refill), and to handle symptom exacerbation emergencies. Furthermore, technological advances in pain management require caregivers to engage in more complex care tasks, including managing patient controlled analgesia pumps, epidural catheters and home infusions.[12,18-21]

However, family carers may be ill prepared to assume these tasks. As Burridge et al report,[22] family carers regularly report feeling unprepared for the role of carer and 'overwhelmed' by their responsibilities, particularly when providing end-of-life care. For many, caregiving must be balanced against already established roles and role responsibilities. Carers may feel anything from highly committed to not at all interested in caregiving, yet powerful social norms pressure them to accept the role. Indeed, carer reluctance may be hidden in order to avoid censure. However, this 'inner conflict' may be an intrinsic element of caring due to the inherent conflict between the needs of the patient and the carer's own needs and/or those of other family members. Choice appears to be the major factor in carer reluctance, however reluctance may not remain static over the caregiving trajectory.[22] For the most part, those who assume the carer role are motivated by love and concern. Indeed, most carers appear to view caregiving as an extension of the family relationship, where increasing caregiving responsibilities evolve over time and are seen as a normal part of family life.[23]

Impact of end-of-life cancer caregiving

Extensive international and Australian research has confirmed that caregiving places far reaching demands on the carer, physically, emotionally, financially, in existential and social domains, and can negatively impact the carer's health, well-being, immune system, risk for disease (eg. heart disease and metabolic syndromes) and life expectancy when compared to non-carers.[15,17,24-32] The physical and psychological wellbeing of the patient and carer have been found to be interrelated and patient psychological and physical suffering, particularly at the end of life, affect the carer's psychological adjustment and morbidity during caregiving and in bereavement. Between 32% to 70% of advanced cancer patient carers have been found to experience a high level of distress or depressive symptoms at a level suggesting clinical depression.[33-35] Schultz and Beach (1999) found a 63% higher mortality risk in bereaved elderly carers experiencing distress, compared to those who provided care but did not feel stressed.[36] Caregiver burden and depression are also associated with family dissatisfaction with end-of-life health care services, including hospice and palliative care.[37]

Carer characteristics associated with negative caregiving impacts include carer age (eg. younger carers report more depressive symptoms), ethnicity (eg. non-white populations report more negative effects although the evidence is mixed), gender (female carers report more negative effects), socioeconomic status (lower income), and carer health and functional status. Other factors include the duration and intensity of caring demands, carer mood and physical health, a recurrence of the illness, the caregivers' subjective burden (or, feeling overwhelmed) and entrapment. Cancer patient characteristics include the patient's age and gender (older, female), patient functional impairment and need for assistance. Patients who display more symptom distress or depressed mood all appear more likely to have caregivers who report greater depressive symptoms and negative perceptions of health.[38-40]

Positive aspects of end-of-life caregiving

Despite the challenges of caring for a terminally ill patient, the majority of family caregivers are able to identify positive aspects of the role. Positive elements of end-of-life caring include: the discovery of emotional strength, physical abilities and personal growth through adversity; acceptance of uncontrolled situations, in managing care, and out of necessity; the deepening of the relationship with the person for whom they care; altered relationships with others; and altered perspectives on living.[41] While many carers give accounts of positive benefits from caregiving, the extent to which the positive aspects of caring buffer the negative aspects of the role is unclear. The long-term impact of the caregiver role on those who are unable to recognise positive elements warrants further exploration.[42]

Carer perceptions of need

The ability of families to assume caregiving responsibilities is contingent on the material, informational and educational, social and professional guidance and support they receive from their healthcare professionals. Inadequate or inappropriate support to the terminally ill and their carers can result in the misuse of resources and added burden to the family. Studies consistently identify carer unmet needs in information, education, skills training and communication with healthcare professionals regarding care for the dying patient. Specifically, end-of-life carers require information about: the patient's prognosis and disease progression; practical and nursing patient care education; understanding of the goals of medical treatment and awareness of approaching death; better access to social support services; and more information about what to expect at the patient's death.[16,43-47] However, health

professionals appear to consistently underestimate the level of carer need, as well as the availability of services when compared to their patient and carer reports.[8,48-50]

Access to palliative care services

Although patients, caregivers and healthcare professionals have clear and highly convergent ideas about the care needed at the end of life and how it should be delivered,[51-54] specific elements of this care are often different at any one time and may shift throughout the course of the patient's terminal illness, especially as patients move from curative to supportive or comfort care. A majority of patients report that they want to 'die at home', however access to palliative care and a home death is highly dependent on the availability of a willing and able carer and a variety of patient, healthcare professional and health system factors (eg. availability of home based hospice, hospital bed capacity, physician referral practice patterns, patient diagnosis).[55-57]

The primary intervention for advanced cancer patients and their carers has been in-patient and community based palliative care services. Evidence regarding the positive impact of palliative care services is strongest in cancer care, reflecting the degree to which palliative care has been integrated into oncology practice.[16] Studies demonstrate strong associations between patient and carer satisfaction with: accessibility to and care coordination by the healthcare team; competence in symptom management and comfort with dying; the manner and extent of communication with family and practical education concerning patient care; emotional support for both the patient and carer; personalisation of care; and support of patients' decision making.[16,58] However, accumulating evidence suggests that a sizeable portion of cancer patients are not referred or are referred to specialist palliative care and/or community based palliative care late in the course of their illness.[59-62] Schockett et al found almost 15% of patients were referred too late to receive services, while Adams et al found fully one third of patients or families in community palliative care reported that they wished they had been referred 'earlier'.[63,64]

Johnson et al investigated cancer specialists referral practices to specialised palliative care and found specialists mainly referred people with advanced cancer for symptom related reasons, but that patient or carer psychosocial, emotional, cultural and spiritual issues rarely triggered referral.[59] Sekelja et al examined bereaved cancer carers' palliative care experiences and views on optimal timing of referral, finding that carers were grateful for the support, practical help and the respect shown to them and their loved one, however they also acknowledged the limits of hospice.[65] Carers generally would like palliative care to be introduced when patients or carers first need help at home, or when symptoms become difficult to control, rather than when patients are told that their cancer is incurable.

Conclusion

Most of the research on cancer end-of-life caring has been qualitative, cross-sectional and conducted on small, fairly homogeneous samples, limiting our understanding of the precursors of and changes in carer needs over time, setting or populations. It has tended to focus on the identification of people at risk for adverse outcomes potentially needing therapeutic intervention, rather than on the appropriate type or timing of specific interventions for specific groups of carers, or on how to support carers so as to prevent or limit adverse effects in the first place. Support services for carers are greatly influenced by the available resources and carer needs are often neglected or under-appreciated, by most, including palliative care health professionals. More attention needs to be paid to exploring preventative interventions that address: avoidable symptom exacerbations and hospitalisations; end-of-life carer burden, stress, anxiety and burnout; and complicated bereavement; and that proactively assist the cancer carer and patient to live life as fully as possible in the time they have left. Questions that still need to be addressed include: what are the differences and similarities in cancer end-of-life caregiving with other forms of caregiving; when and for which populations of caregivers to intervene; ethnic differences in end-of-life caregiving; the economic burden and consequences of various forms of end of life caregiving; and finally, how to better organise the delivery of good palliative and supportive cancer care. There is an urgent unmet need for innovative solutions to the challenges involved with providing high quality, compassionate care to the terminally ill and their carers.

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REHABILITATION IN ADVANCED CANCER

Andrew MD Cole
Hammond Care, Sydney, New South Wales; Hope Healthcare, Greenwich, New South Wales; University of New South Wales, Sydney.
Email: acole@hammond.com.au

Abstract

Rehabilitation has much to offer cancer patients with physical functioning issues related to nervous and musculoskeletal problems, as well as the general debility that may be a feature of advanced cancer. Individual members of the rehabilitation team bring their skills to bear to improve the ability of patients to live their daily lives as independently as possible. Rehabilitation outcomes can be measured with standardised assessments, including the Barthel Index and the Functional Independence Measure, which may form part of casemix algorithms. There are no randomised control studies of rehabilitation in advanced cancer. However, there are observational studies that provide level III evidence for the efficacy of rehabilitation programs for residual physical disability that may be present in patients after acute treatment of brain tumours, spinal tumours, bony metastases with fractures, and in patients with debility. Patients with brain tumours and spinal tumours can expect a response to therapy that is entirely comparable with that seen in 'benign' lesions, such as strokes, brain trauma or spinal trauma in similar anatomical locations. Rehabilitation also has a useful role to play in the debility that may be a feature of advanced cancer. Particular attention must be paid to rehabilitation for return to safe driving of motor vehicles after treatment of brain tumours, and the program generally involves medical and psychological review, as well as occupational therapy assessment of the patient in off-road and on-road settings. There is no place for therapeutic nihilism in the presence of physical disability in cancer patients, any more than there is in the presence of disability due to 'benign' illnesses.

Serious problems with physical function are fortunately not a universal feature of most cancer journeys. Such problems do however, occur relatively commonly with advanced primary and secondary tumours involving the nervous and musculoskeletal systems. This review will focus on the evidence for the place of rehabilitation programs in patients with significant functional disability associated with brain and spinal tumours, tumours in bone and patients with general debility associated with sepsis or other sequelae of cancer treatment.

In all these settings, deficits may include: various combinations of weakness and sensory loss; cognitive, visual and perceptual deficits; and problems with bladder and bowel dysfunction. While much attention in cancer care is focused on direct tumour related matters such as the pathology and staging of a tumour, imaging, laboratory test data and side-effects from drug and radiation treatment, rehabilitation clinicians have a primary focus on the impact of cancer and its treatment on the patient's ordinary daily living function and social participation.

A patient with physical and functional problems present in the post-acute stage of cancer care will, in general, respond to rehabilitation therapies as well as a patient with similar problems due to a more 'benign' cause, provided there is adequate ongoing control of the underlying cancer.

Rehabilitation environment

As with many other services for cancer patients, care in the rehabilitation environment is multi-disciplinary, with an appropriate range of nursing, allied health and medical staff available, with the team's care supervised and coordinated by a medical specialist in rehabilitation medicine. Expert rehabilitation nurses support patients and carers by integrating individualised nursing programs with continuing reinforcement of the skills learnt in formal allied health therapy sessions at other times.

While the core roles of individual allied health therapists are defined, there are often considerable areas of co-operative overlap. Physiotherapists have a primary focus on impairments of motor function, coordination and strength, together with problems of balance and mobility. In contrast, occupational therapists focus on problems in self-care function, including daily personal care and feeding, with assessment of both the individual and their home environment. Speech pathologists focus on therapy for swallowing problems and issues with communication and verbal interaction, and memory problems, with support from psychologists. Social workers counsel and support patients as they resume family and social relationships, and particularly address concerns around housing and financial matters.

Critically, all of this team activity is aimed at restoring the individual patient's sense that they are regaining some control of their lives. As each patient sets and achieves goals in a rehabilitation program, they progress towards greater independence in life, even if it is not the same life as was the case before.

Rehabilitation approach

Weakness is a very common deficit,[1] especially in brain and spinal tumour patients where it may be quite focal and associated with other neurological signs, but is often a prominent part of the general deconditioning that may accompany sepsis or weight loss in other cancers.

Clearly, this can affect transferring from laying or sitting to standing, ambulation and dressing, toileting and bathing. All of these problems can be addressed by and benefit from rehabilitation, that is entirely analogous in scope with programs developed for use with benign diagnoses.[2] Frequent reassessment and flexibility in program delivery are required however, if there is a possibility of reappearance or progression of the underlying cancer.[3] As described in detail later, studies have shown that brain and spinal tumour patients with physical disability can achieve functional gains and discharge outcomes that are comparable with stroke, brain and spinal trauma patients, and often with a shorter length of hospital stay.

Towards the end of a rehabilitation admission, the team assesses whether it is safe to discharge a patient, or whether supervised care is indicated. For many patients going home, especially those with brain and spinal tumours, the ability to resume driving a car is a central icon of adult social independence, and it is mandatory that this is addressed and managed as a specific issue.

Measurement of rehabilitation outcomes

There are two common overview measures of overall rehabilitation functional outcomes. The Barthel Index is the simpler and older of the two,[4] focusing on basic mobility function and personal activities of daily living. Each of the 10 task items is rated at three levels of patient function – independent, need for assistance and dependent – and the patient's task scores are added to produce a total between 0 and 100. The higher the score, the better the patient's ability to function independently. The scale has been shown to have excellent internal consistency,[5] and good inter-rater and test-retest reliability.[6] While making good sense intuitively, the Barthel scale does however, assume all rated tasks have equal impact on a person's ability or inability to live independently, which is not necessarily the case.

The Functional Independence Measure (FIM)* is the present standard outcome measure for rehabilitation therapy.[7] It has 18 items, each one being rated from one (complete dependence) to seven (independence), with full-scale scores ranging from 18 to 126. Items are grouped by motor function (transfers, walking, stairs, bladder and bowel control), activities of daily living (eating, grooming, bathing, dressing and toileting) and cognition-communication (speech ability, social interaction, problem solving and memory function). Where assessors are correctly trained, the scale has excellent internal consistency,[8] inter-rater and test-retest reliability.[9] In its raw ordinal form, statistical manipulation of the FIM can be somewhat complex, and Rasch transformation of the FIM to a continuously variable metric has been employed to circumvent this particular difficulty.[10]

Where cost weighted funding of individual episodes of rehabilitation care has been introduced in inpatient settings, FIM measurements are a fundamental component of the funding algorithm. Although many other scales can be used to measure multiple different aspects of physical functioning in the cancer survivor,[11] the pragmatic approach taken here is to focus on evidence coming from the use of the FIM, both because of its global scope and its use in such funding algorithms.

Rehabilitation outcomes for brain tumour patients

There are no randomised control trials of outcomes of rehabilitation therapy for individuals with brain tumours. Seven observational studies describe rehabilitation of individuals with significant brain tumour associated disability. Four of these are non-comparative,[12-15] and three compare brain tumour patients with stroke or brain trauma patients.[16-18] All seven studies use the FIM to show improvement in patients' functional status with rehabilitation therapy. One study separated out patients by the grade and type of the underlying brain tumour, and found no difference in average improvement in functional outcome or length of stay between the groups studied.[14]

There is level III evidence that participation in a rehabilitation program is associated with improved mobility function in brain tumours,[12,14,15] at a rate comparable to that seen with therapy of benign neurological diagnoses.[16-18] Likewise, there is level III evidence for improvement in personal activities of daily living, with appropriate therapy.[15] There is level III evidence that cognitive-communication function improves with rehabilitation therapy, with efficiency rates similar between a group of patients who have had a high-grade glioma, compared with other brain tumour groups.[14]

There is currently no evidence for the efficacy of speech therapy in managing swallowing disorders in brain tumour patients, however the advice of a speech pathologist should be sought to assist in managing residual problems related to swallowing function. Similarly, there is no evidence relating neuropsychological interventions to improved outcomes in therapy programs in this setting. Observational evidence however, clearly supports the importance of neuropsychological evaluation of cognitive impairment after brain tumour treatment.[19-21]

Rehabilitation outcomes for patients with spinal tumours

As with brain tumours, there are no randomised control trials of outcomes of rehabilitation therapy for individuals with spinal tumours. Five observational studies, all using the FIM to assess changes in patients' ability to function, describe rehabilitation of individuals with significant disability related to spinal tumours. Three of these are non-comparative [22-24] while two compare spinal tumour patients with spinal trauma patients.[25,26]

There is level III evidence that participation in a rehabilitation program is associated with improved mobility function in spinal tumours comparable to that achieved in rehabilitation of benign disorders.[25,26] There is level III evidence that rehabilitation therapy improves function in ordinary activities of daily living in spinal tumour patients.[22]

*FIM is a trademark of the Uniform Data System for Medical Rehabilitation, a division of UB Foundation Activities, Inc.

Rehabilitation outcomes for patients with tumours in bone

As with brain and spinal tumours, there are no randomised control trials of rehabilitation therapy in this setting. Two observational studies, neither of them comparing cancer patients with patients with benign orthopaedic lesions, describe rehabilitation outcomes for patients who have had bony metastatic disease with pathological fracture.[12,27] There is level III evidence that patients who have had a pathological fracture fixed, improve their mobility function with rehabilitation, as measured by the FIM scale.[12]

Rehabilitation outcomes for patients with cancer related debility

Again, there are no randomised control trials of rehabilitation therapy in this setting. A single retrospective non-comparative study examines the effects of rehabilitation therapy in individuals with late stage disease, where asthenia is the diagnostic category accounting for hospital admission of individuals with advanced cancer.[12] This study provides level III evidence for improvements in the motor and cognitive components of the FIM with rehabilitation therapy.

A parallel paper discusses the value of such rehabilitation therapy in assisting the transition of these patients from curative to palliative care,[28] mapping from the functional improvements gained in these patients to an estimate of the reduced number of hours of hands-on care needed to support these patients in home care settings.

Driving after onset of cancer related disability

The ability to drive a motor vehicle is a central icon of social independence. It is a particular issue in one area of cancer rehabilitation, namely brain tumour patient care, where the individual may not have the insight to appreciate the extent to which their possible cognitive and motor problems interfere with the very complex task of safe driving.

Return to driving a motor vehicle after treatment for a brain tumour is covered by a set of national guidelines with regulatory force in all Australian jurisdictions.[29] If there is any evidence for the presence of residual malignant brain tumour (eg. on a brain scan), or presence of neurological signs such as hemianopia, quadrantanopia or impaired judgment, the individual does not satisfy the criteria for holding an unrestricted driver's licence.

The best way to manage potential risks in a brain tumour patient who expects to return to driving as part of a rehabilitation program, is to undertake a full assessment that should include medical, ophthalmological, psychological and occupational therapy assessments, initially in an off-road setting and then in a controlled on-road setting.

The outcome may be that the person is not safe to drive at all, or is safe to drive with some restrictions, or is safe to drive an adapted vehicle, or may drive without restriction. These recommended outcomes are communicated to the driver licensing authority, for its determination and endorsement of the person's driving licence, and it is incumbent on the patient that they obey this outcome of the process.

In other areas of cancer related disability, where the difficulty with driving is more of a physical nature, the assessment process is much less complex, and a positive outcome that may involve some adaptation of the vehicle driven is more likely.

In any case, formal assessment of suitability for return to driving a car is recommended as the best way of managing the risk that an unsafe driver otherwise presents to those around them.

Conclusion

Despite the lack of randomised control studies of rehabilitation for cancer patients with significant physical disability, the evidence that is currently available clearly shows the benefit of providing rehabilitation therapy for these patients. With adequate control of the underlying cancer, there is no ground for rehabilitation therapeutic nihilism in these patients, any more than there is in other individuals disabled as a result of their experience with comparable 'benign' diseases.

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THERAPEUTIC USE OF SELF AND THE RELIEF OF SUFFERING

John H Kearsley
Faculty of Medicine, University of NSW; Radiation Oncology, Cancer Care Centre, St George Hospital, New South Wales.
Email: john.kearsley@sesiahs.health.nsw.gov.au

Abstract

Suffering is a universal human experience, which may be engendered by the onset of illness, especially if illness is perceived to be life threatening. This paper examines the essence of suffering and the common sources of suffering in the setting of illness and the health system. It is proposed that many health care professionals, despite mastering the diagnosis and treatment of physiologic dysfunction, may be at a loss when it comes to helping to relieve patient suffering. At an existential level, suffering arises from the meaning ascribed by patients to events of illness, and is commonly expressed as a personal narrative. In order to help alleviate suffering and to promote healing, clinicians are encouraged to recognise themselves as therapeutic tools in understanding the nature of suffering, listening proactively to the narratives that patients need to tell so that narratives with new meanings can be created.

Nature of suffering

Suffering is a universal experience whose boundaries extend beyond the horizon of our understanding and its depth may be unfathomable to our enquiry. According to Cassell, suffering "arises from perceptions of impending destruction of an individual's personhood and continues until the threat of disintegration has passed or the integrity of the person is restored".[1] Life threatening illness represents an assault on the whole person, the physical, psychological and spiritual. Furthermore, suffering is experienced by whole persons, not bodies. Coulehan suggests that suffering "is the experience of distress or disharmony caused by the loss, or threatened loss, of what we most cherish".[2] The experience of suffering is idiosyncratic, mysterious and may vary in terms of intensity and duration. Reed characterises the intensity of suffering as a continuum extending from distress, through misery, anguish to agony.[3] Perhaps the major themes of suffering are expressed most succinctly by Manon in Puccini's eponymous opera, when she tearfully declares herself to be "sola, perduta, abandonata",[4] – alone, lost, adandoned. The four great themes of suffering, variably expressed in their intensity, are isolation, hopelessness, helplessness and loss. Concomitant with all suffering is some element of fear because according to Reed, "the patient's world view and sometimes his or her very existence are threatened by the disease or circumstances".[3] According to Gillies and Neimeyer,[5] it is a common observation that "illness threatens the integrity of personhood, isolating the patient and engendering suffering". Furthermore, suffering alienates the sufferer from self and society, and may engender a "crisis of meaning".[6] As restated by Neimeyer, "profound loss perturbs these taken-for-granted constructions about life, sometimes traumatically shaking the very foundation of one's assumptive world".[5] For many of our patients, drained of meaning and abandoned in the foreign world of sickness, "this is never how it was meant to be".

The experience of suffering is often idiosyncratic, intensely personal; the expression of suffering to clinicians includes patients describing themselves as being shattered, broken and disconnected. For many, their world simply falls apart and they fall to pieces. They become like "broken pottery".[7] Suffering is therefore associated with a disintegration of self, a disintegration of values, belief systems, traditions and even daily routines. There is also disintegration of hope. Kearney considers suffering as "the experience of an individual who has become disconnected and alienated from the deepest and most fundamental aspects of him or herself".[8] Kissane refers to this constellation of feelings and perceptions as the "demoralisation syndrome", in which hopelessness is the core construct, and involves negative cognitive attitudes such as pessimism, stoicism and fatalism, despair, loss of purpose, sense of failure and meaninglessness.[9] Disintegration of interpersonal and community connectedness is common. Others refer to the condition as "spiritual pain".[10]

Sources of suffering in the context of illness

Of the many sources of suffering, the distressing effect of physical pain and other somatic symptoms cannot be over-emphasised. However, suffering may exist in the absence of significant physical symptoms,[11] and suffering may even continue despite careful attention to physical distress. The suffering which may result from survivorship after cure of cancer has been recently highlighted,[12] as has been reported the finding that a significant percentage of patients with advanced cancer do not consider themselves to be suffering.[13] Undiagnosed depressive and anxiety disorders, unrecognised family dysfunction, fatigue, communication breakdown and emotional distress have been found to be additional important sources of suffering in palliative care patients.[14] Wilson's recently reported study of suffering in patients with advanced cancer found that there was a dominant physical component in those with significant suffering (especially pain, malaise, functional loss, weakness and inability to eat).[13] The major non-physical sources were grouped around the dimensions of social-relational concerns (especially dependence, isolation, concerns for others), psychological morbidity (especially anxiety, depression, hopelessness, loss of pleasure) and existential worries (especially loss of dignity, loss of resilience, loss of control, spiritual crisis).[13]

Problem of suffering for clinicians

Despite the universal expectation that healthcare professionals have a central (core) role in relieving suffering, it is acknowledged that healthcare professionals are poorly trained and unprepared to diagnose, assess and manage patient suffering, even though pain management, psychological issues and psychiatric diagnoses are often covered.[15] Since suffering frequently has an existential component, related to a shattering of meaning, purpose and hope, physicians cannot rely solely on theory, knowledge and skills that address physiologic dysfunction. Rather, as Coulehan suggests, "we must learn to engage the patient at an existential level".[2]

Therapeutic use of self: a wholly communion

The starting point in attempting to engage with the suffering of our patients stems from our readiness to develop a deep awareness of illness, its meaning and symbolism to our patients and to recognise both mute and expressive phases of the suffering which may result from illness.[16] That is, we need to be awake or alive to the other person, and to develop a readiness to connect with the 'person' of the patient.[17] As Sassall says, the good doctor "must come close enough to recognise the patient fully".[18]

To be physically present during another's personal illness and distress is important. Our training places little emphasis on the importance of 'being there' and 'listening' in times of turmoil. Silences can often penetrate those places where words cannot go. In one of her earlier essays, Saunders suggests that it is sometimes simply enough for our patients to perceive that we are with them in their struggles and that we are on their side. Accordingly, "we are not there to take away, or explain or even understand it".[10] It is important for our patients to know that we are witness to their suffering and that they are not abandoned.[19] However, even when we dare to remain physically present, it is sometimes more comfortable to remain detached or to withdraw to the confines of the traditional medical history and unknowingly, conceal and imprison the distress of our patients within it.[2]

The theologian Henri Nouwen uses the term 'self emptying' to describe the process of being there, fully present in order to "pay attention to others in such a way that they begin to recognise their own value".[17] However, as health professionals we tend to be in a state of preoccupation with emphasis on diagnosing, investigating and curing the physical aspects of disease; "curers of disease" rather than "healers of the sick".[20] Nouwen continues: "Every time we pay attention we become emptier and the more empty we are the more healing space we have to offer".[17]

Dobkin and Stewart emphasise the importance that physicians develop 'mindfulness' as an initial step in fostering healing in their patients,[21,22] and many commentators stress the need for physicians to better understand their own beliefs, feelings, attitudes and response patterns.[23] Mindfulness is characterised by learned mental habits, such as attentive observation of self, patient and context - critical curiosity, a fresh mind and presence ('being there').[23,24] Mindfulness enhances the physician's ability to bring awareness to the treatment of another human being. It is not what is done, but how it is done that matters most. It is not how much time is spent with a patient, but rather what transpires within that time.[24] It has been recommended that mindfulness be introduced early in medical education, recognising the need to broaden training such that curing and caring are equally valued.[23] Mental preparation in order to fully exercise compassion is a prominent teaching in Buddhism,[24,25] as well as other followings.[17]

We therefore connect by emptying ourselves and listening actively. It has been said that the most valuable thing we can give each other is our attention (our emptiness), taking the time, being genuinely interested and not being distracted by professional title, by what I think I have to offer or what I want to be the outcomes. My essential self is sufficient.[24]

The recent interest in teaching communication skills to healthcare professionals is both encouraging and overdue.[26,27] However, the communication techniques which are taught do not necessarily guarantee connection and better communication. The teaching of communication skills alone without true underlying communion, will predictably be seen by patients as gratuitous and superficial at best, and demeaning at worst. For many patients, communication techniques will only be of benefit when they are used in the context of a deep awareness that has already been established. Saunders suggests that patients "need someone who will come to this meeting not bearing any kind of technique, be it therapeutic, pastoral or evangelistic, but just as another person".[10] As observed by Sackett, widely regarded as a father figure of evidence-based medicine, "the most powerful therapeutic tool you'll ever have is your own personality".[27]

The importance of connecting with patients and becoming aware of the therapeutic use of ourselves is usually not taught formally in medical schools.[28] Instead, many aspiring young doctors might see that to be 'professional' also means becoming detached.[2,25] Providing a listening ear may risk opening up our own vulnerabilities. There has been an unwritten caveat that getting too close to patients can be dangerous, both personally and professionally, because so

much perceived pain, negativity, fear and loneliness can prove to be overwhelming and may lead to emotional exhaustion and compromise good sound clinical decision-making and on the job learning. As Shlim describes it: "The only way they (doctors) feel they can care more for patients is by not caring too much".[25] Remen has contrasted the important clinical roles that doctors have in fixing, helping and serving patients.[29] In discussing the clinical role of service, Remen suggests that "we can only serve that to which we are profoundly connected, that which we are willing to touch".[29]

In the beginning was the word, then came the stories

While it has been said that 'everyone has his or her own story', it is equally true that 'everyone is a story'. Each story is unique. I particularly enjoy Allen's opinion that "a human being is nothing but a story with skin around it".[30]

Our own stories define who we are. Human experience is framed and interpreted in terms of our life stories. Amato has said that "with no story to tell, we are no people at all".[31] It has been said that we live in stories not in statistics; we "continually author our own life stories as we reflect, interpret and re-interpret what happens in our lives, and tell and re-tell our stories to other people and to ourselves".[5] Stories help us to make sense of the insensible, to explain our view of the world. Storytelling can be regarded as one of the oldest healing arts.

Stories also allow us to tap into the state of suffering. Suffering arises from the meaning ascribed to events and is commonly expressed as a personal narrative - the only things about ourselves that cannot be taken away, the only things that remain coherent and intact. And from our stories, hope may gently trickle into our pools of pain. The poet Lesley Marmon Silko wrote: "I will tell you something about stories, they aren't just entertainment. Don't be fooled. They are all we have, you see, all we have to fight off illness and death".[32] Stories, according to Mount et al, are one conduit through which "healing connections" may be created, so that patients may be able to move from suffering to a sense of wellbeing.[33]

How can we as health care professionals assess and relieve suffering of our patients and their families?

In the health system, there are a large number of parameters and outcomes which are assessed – outcomes such as length of stay, infection rates, waiting times, responses to treatment, survival times and treatment-related toxicity. However, if it is accepted that a core activity of the health care system is about the relief of suffering, what is really known about the prevalence of suffering in our health system?

More than a quarter of a century ago, Cassell argued that physicians do, in fact, have a professional responsibility to understand and to treat suffering at an existential level.[1] In addition to attending meticulously to physical symptoms and seeking other sources of suffering, listening to the stories of patients is one conduit by which clinicians can tap into that state of suffering; the telling of stories is the conduit by which patients endure, reflect on, redefine and may finally transcend their state of suffering.[34,35] There is no agony like bearing an untold story inside of you; health care professionals can increase or prolong the state of suffering by ignoring it, by walking away and by ignoring the stories that need to be told. The cartoonist Leunig encourages "teach us to embrace sadness lest it turn to despair".[36] Of course, many clinicians do not even get past the standard medical history; unwittingly, we may imprison our patients within the confines of the medical history. The direct question: "Do you feel that you are suffering?" does not yet appear to have found its way into our routine assessment of patients. A recent Consensus Conference provided strong recommendations for the implementation of a spiritual history and spiritual care in patients with life threatening illness.[37]

To be a witness to a person's story is a validating and re-personalising activity. Yes, this is really happening to you - no, it is not a dream. And I am a witness to your story. And, I will tell your story. "Besides talking himself", Broyard suggested, "the doctor ought to bleed the patient of talk".[38] The physician-healer, according to Egnew, becomes a therapeutic instrument by drawing out the patient's narrative experience, and then "helps the patient to create or discover a healing narrative with new meanings that transcend suffering".[35] As observed by Frankl, "suffering ceases to be suffering in some way at the moment it finds a meaning".[39]

Stories have healing power - not only in the content, but in the telling comes healing. Unlike the predictability of many clinical outcomes in medicine, the outcomes resulting from interpersonal communion may be neither predictable nor understandable. When we do listen to people's stories, we make room for mystery and healing to occur. A healing effect on the teller, as well as a healing effect on the listener (see Wal's story).

Wal's story

Wal came in to see me the other week. Wal is 79 years in the shade. He lives on his own in Sans Souci in the sun. I treated Wal eight years ago for prostate cancer. I think he is cured. Wal shuffles in; his fair skin makes him look anaemic. Wal has a problem with his weight, but he doesn't care. What he lacks in teeth he compensates with a big thirst for his favourite VB stubbies. Wal wears old faded fawn shorts and green thongs. Wal has good knees. In my honour, Wal has not shaven for a week. I sit with my two students; it is 11.30am on a Friday, the end of a long follow-up clinic. And so close to lunch.

"How are you doc?" "How are you mate, what's news?" Wal and I are friends. We talk. He reaches back into the half-full pockets of his colourful past. The stories come, they start to flow. His stories about the war, his stories about life in the tropics, his work as an engineer, Mr Fixit; how he could make things work when others couldn't. A cheeky smile breaks across his ancient seafarer face; a toothless grin.

The students shuffle their feet. One looks at her watch, the other at the floor. They look at me (how much longer?). We finish – I thank Wal for his stories and for coming. "Your prostate cancer is under good control Wal, and your PSA is normal. See you in another six months time".

Wal stands, we shake hands, he turns to leave – and dissolves in tears. "All I wanted was someone to listen". No one speaks. He hugs me. None of us can speak.

Wal left. We were no longer hungry. There was silence. We have communed over the broken bread of Wal's life stories. And we were sustained. We sensed a healing had occurred for all of us.

Remen makes the common observation that "dying people often have the power to heal the rest of us in powerful ways. Years afterwards, many people can remember what a dying person has said to them, and carry it with them, woven into the fabric of their being".[40]

Finally, stories may represent a patient's quest for 'immortality', and they remain a legacy for others.[34] Our patients may therefore say, as if in the words of Byron: "But I have lived, and have not lived in vain; My mind may lose its force, my blood its fire, and my frame perish, Even in conquering pain; But, there is that within me which shall tire torture and time, and breathe when I expire".[41]

In the end, the value of our patients' lives may not be measured so much by what they knew, nor by their possessions, but by what they have to tell in their stories, enabling them to know at last who they are and how to come to peace with life and death. Our patients live on in their stories; our story becomes woven with theirs – two, but also one. We then, become custodians of what we have heard and witnessed.

In his letter of 1549, Michaelangelo Buonarotti suggested that sculpting is a process of 'taking away', in contrast to painting which was seen as 'adding on'.[42] It is up to the sculptor to reveal the soul imprisoned within the stone. Michaelangelo carved in order to liberate, to set free, the figure imprisoned within the marble. We see this effect most powerfully in some of the unfinished statues of Slaves. The figures seem to explode from the stone. In fact, the power of the figures is enhanced by the very fact that the statues are unfinished on purpose. Complete, though unfinished; whole, though imperfect.

Conclusion

In conclusion, three recommendations appear appropriate. Firstly, understand and appreciate suffering. As a result, you will learn more about yourself. Secondly, understand and appreciate the stories that your patients need to tell you. As a result, you may become healers. Finally, never underestimate the therapeutic potential of who you are, whether student, intern or senior consultant. In the words of Remen, "who you are may affect your patients as deeply as what you know. You will often heal with your understanding and your presence things you cannot cure with your scientific knowledge".[43]

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SARCOMA CAPABILITY AUDIT: A REGISTER OF CENTRES OF EXCELLENCE

Sally Whyte and Sophie Gatenby
Australasian Sarcoma Study Group, Melbourne, Victoria.
Email: sally.whyte@petermac.org

Abstract

The Australasian Sarcoma Study Group was formed in 2008 to improve the outcomes for sarcomas and related tumours in the Australian community through research and development. The group provides the infrastructure for collaboration between multi-disciplinary teams; to establish this framework, an audit of existing sarcoma treatment centres within Australia was undertaken. An online survey of 15 centres was designed primarily to compile a register of sarcoma treatment centres of excellence and to determine the services offered at those sites. A secondary purpose was to gain knowledge about infrastructure and the capability of sites to conduct sarcoma research. This information has been transformed into a website resource for sarcoma patients, their family and friends, clinicians and other health care professionals, and the general community. Four key features of the website are: 'Find a Specialist', 'Find a Clinical Study', 'Find Someone to Talk to' and 'Ask a Question'. This audit has provided the foundation knowledge and information required to create a reliable, useful resource for patients and the scientific community. The immediate utility realised from this audit suggests that replication of the survey for international sarcoma treatment centres may prove equally advantageous.

The Australasian Sarcoma Study Group was formed in January 2008 to improve the outcomes for sarcomas and related tumours in the Australian community through research and development. Given the aggressive nature and rarity of sarcoma, it was recognised that a collaborative approach was needed to fight the disease. One strategy was to use multi-disciplinary teams in the clinical sense to create a network of clinicians, allied health workers, nurses and researchers within Australia and internationally, all of whom share the common goal of finding solutions to treat sarcoma. The group provides the infrastructure for collaboration between multi-disciplinary teams and to establish this framework, an audit of existing sarcoma treatment centres within Australia was undertaken. The outcome of the audit has been translated into a resource: the Australasian Sarcoma Study Group website www.australiansarcomagroup.org. In this paper, the foundation and membership of the group is described, an outline of the survey is provided and the results are presented as they relate to the key features of the website.

Australasian Sarcoma Study Group: foundation and membership

In January 2008, with funding from Cancer Australia, the Australasian Sarcoma Study Group established itself as a national cooperative cancer clinical research group and commenced operation. From 2009, the University of Melbourne became the administering institution for the group through Cancer Australia's 'Support for Cancer Clinical Research Program'.[1] Under this program, the Australian Government provides funding to build Australia's capacity to conduct cancer clinical research. The Australasian Sarcoma Study Group is one of 13 multisite collaborative national cancer clinical trials groups supported under the program. Groups were established to help reduce the impact of cancer in the community through facilitating coordination of and collaboration between all stakeholders, including people affected through cancer, health professionals, researchers, cancer organisations and governments. The group has grown significantly in a short period in both membership and achievement, with work focusing on three areas: research, engagement and organisation.

The broad aim of the group is to improve outcomes for sarcoma and related tumours in the Australian community by undertaking basic, translational, clinical and supportive care research. The foundation goals include: taking a leadership role nationally and internationally in this research; identifying unique strengths and opportunities in the Australian environment; developing a particular focus on

adolescents and young adults; and building bridges with local, national and international communities.[2]

The strategic principles that underpin this work include: developing a deep commitment within the group to all aspects of sarcoma research, care and education; integrating both paediatric and adult sarcoma communities; participating in global research collaborations encompassing strengths in basic, translational and clinical research; investing in the infrastructure that builds basic and clinical research capacity; and partnering with the wider community through government and philanthropic bodies to focus greater awareness and support for sarcoma research.

Specifically, the objectives are to: develop a collaborative network of specialist sarcoma units conducting research; establish a national, integrated clinical database and biospecimen bank to support research; foster an emphasis on translational research between bench and bedside; build specific bridges between paediatric and adult sarcoma communities; increase capacity by developing partnerships between the scientific, clinical and wider community; and undertake ethically sound and academically rigorous research in collaboration with the pharmaceutical industry. Achieving these goals relies on a network of committed individuals across Australasia.

The current membership of the group stands at 161 and comprises representatives from the range of health related disciplines and consumers/supporters from the general community. The predominant medical disciplines are: medical oncology (n=24); radiation oncology (n=22); surgical/orthopaedic oncology and general surgery (n= 27); paediatric oncology (n=22); pathology (n=15); radiology (n=5) and nuclear medicine (n=2). Twenty seven members are engaged in full-time research/biostatistics, nine are nurses, six are from allied health fields and four are consumers.

Capability audit: survey and results

An online survey was designed primarily to compile a register of sarcoma treatment centres of excellence and to determine the services that were offered at those sites. A secondary purpose was to gain knowledge about infrastructure and the capability of sites to conduct sarcoma research. Overall, this information was collected to assist the group to function as a coordinated, national, collaborative research group. Each site was asked to complete a survey comprising eight questions addressing: sarcoma centre details; disciplines offered; service types; centre facilities; multi-disciplinary sarcoma teams; research program; request for other relevant information; and expression of interest in receiving information about the group. In total, 15 centres were invited to complete the survey and all 15 responded with a complete data set. Table 1 displays the sites that participated in the survey.

Table 1: *Sarcoma treatment centres - capability audit sites*

Sarcoma Treatment Centres		
State	**n**	**Site**
Australian Capital Territory	1	Canberra Hospital
New South Wales	5	Sydney Children's Hospital Children's Hospital Westmead St Vincent's Hospital Sydney Westmead Hospital Prince of Wales Hospital
Queensland	3	Princess Alexandra Hospital Royal Children's Hospital Brisbane Wesley Medical Centre
South Australia	2	Royal Adelaide Hospital Adelaide Cancer Centre
Victoria	2	Royal Children's Hospital Melbourne Peter MacCallum Cancer Centre
Western Australia	2	Princess Margaret Hospital for Children Sir Charles Gardiner Hospital

Services

At all 15 sites, either a medical (80%) or paediatric oncologist (47%) practised, while most sites also employed either a surgical (93%) or radiation oncologist (93%). Similarly, all sites (100%) reported employing the range of allied health personnel - social workers, psychologists, physiotherapists, occupational therapists and nutritionists. Twelve sites (80%) offered the services of a clinical nurse consultant or co-ordinator. All sites provided access to palliative care, pathology and haematology services. Other services available included podiatry and education, with the latter being for the paediatric and adolescent populations.

Regarding diagnostic services, all sites offered MRI scanning, with 73% offering FDG-PET and 93% intervention radiology; only the Peter MacCallum Cancer Centre reported offering alternative scanning devices such as FAZA, FLT and F-MISO.

Sites treated either adults or paediatrics, or both - Prince of Wales Hospital in New South Wales and Sir Charles Gardiner Hospital in Western Australia treat both adult and paediatric patients. All sites treated out-patients and in-patients, with the exception of the Adelaide Cancer Centre. Noteworthy, the Adelaide Cancer Centre is known as a specialist outpatient centre, whereas all other sites are multi-facility hospitals.

Table 2 summarises the distributions for disciplines, diagnostics services, age range and ambulatory care.

Table 2. *Summary of sarcoma treatment centre - distributions for discipline, diagnostic services, age range and ambulatory care*

	n	%
Disciplines		
Clinical nurse consultant	12	80
Haematology	15	100
Medical oncology	12	80
Nutrition and dietetics	15	100
Occupational therapy	15	100
Paediatric oncology	7	47
Palliative care	15	100
Pathology	15	100
Physiotherapy	15	100
Psychology	15	100
Radiation oncology	14	93
Social work	15	100
Surgical oncology	14	93
Other services	7	47
Diagnostic Services		
FDG-PET	11	73
Interventional radiology	14	93
MRI	15	100
Other PET tracers	1	7
Age Range		
Adolescent Young Adult (AYA)	13	87
Adult	10	67
Paediatric	8	53
Ambulatory Care		
Home based	13	87
In-patients	14	93
Out-patients	15	100

Multidisciplinary teams

All 15 sites held multidisciplinary team meetings and of these, eight (53%) were held on a weekly basis. Of the remaining sites, three (20%) held meetings monthly and four (13%) met as required (26%).

Clinical research

All sites reported involvement in hospital run clinical trials. Moreover, all sites expressed willingness to participate in multi-centre trials and provided at least one specialist contact to receive inquiries about clinical research. Eight per cent (n=12) of sites reported recording sarcoma specific clinical data while 73% (n=11) collected sarcoma biospecimens. Table 3 highlights the scope of capability for conducting a range of clinical research.

Table 3. *Sarcoma treatment centres - clinical research capability*

Research activity	n	%
Run clinical trials	15	100
Phase I	9	60
Phase II	12	80
Phase III	11	73
Sarcoma specific trials	6	40
Have run sarcoma-specific trial in the last three years	11	73
Would consider participating in multi-centre trials	10	67
Currently participate in other research activities	15	100
Collect sarcoma biospecimens clinical data	15	100
Collect sarcoma specific clinical data	15	100

Australasian Sarcoma Study Group website

To facilitate an effective, national, collaborative research group, certain prerequisites are essential and need to be located at most participating centres. The aims of the audit were to: develop a register of sarcoma treatment centres of excellence; determine the services that were offered at those sites; and gain knowledge about infrastructure and capability to conduct sarcoma research. The results from this audit demonstrate that the foundation for multi-site, collaborative research clearly exists. Furthermore, the critical infrastructure – well functioning multidisciplinary teams – is also present in sufficient quantity at each of the 15 sites. This information has been transformed into a website resource for sarcoma patients, their families and friends, clinicians and other health care professionals, and the general community - www.australiansarcomastudygroup.org.

The 'Find a Specialist' feature on the website provides contact details for multidisciplinary teams who are members of the group and who specialise in sarcoma care and conduct specific clinical studies for sarcoma patients in each state in Australia. The group adopted recommendations for the management of patients with sarcoma from the National Cancer Control Network (US)[3] and the National Institute for Health and Clinical Excellence (UK),[4] but with modifications for the Australian setting. A critical component of these recommendations is that all patients with sarcoma should be treated at centres with appropriate expertise and relevant multidisciplinary teams.

The overarching aim of the group is to facilitate clinical research in sarcoma. Clinical research encompasses drug or intervention studies, systems of health care delivery, measures of the impact of disease on the community

(epidemiology), research into the genetic basis of cancer in a human context, as well as research into the psychosocial and quality of life impacts of cancer. The group is committed to facilitating access for all Australian sarcoma patients to a diverse range of well designed clinical research studies, where the knowledge that is generated will have a substantial international impact on outcomes in this disease. The research program comprises clinical trials, familial studies, supportive care initiatives and data analysis reviews. A search engine enables users to locate a study by tumour type, age group or location. Given the varying needs of paediatric, adolescent, young adult and adult populations, it is useful to be able to identify protocols that specifically care for these groups and potentially, also increases recruitment.

The 'Find Someone to Talk To' function offers contact numbers for a range of services such as: individual, family and group counselling; education and information; and advocacy. It also assists in providing community referrals. Many people and their families often feel fearful and anxious about their diagnosis and impending treatment - knowledge and support are important in coping with these fears. Multidisciplinary teams have members available to assist in supporting patients and their families during this time.

Modern technology has transformed the capability for and expectation of sharing information across the globe. The group website encourages users to 'Contact Us' or 'Ask A Question'. In just six months, more than 30 requests have been received through email or telephone for: information about sarcoma, the group or fundraising; assistance generally about sarcoma or particularly to locate a specialist; and from consumers wanting to participate in research, find studies that are being conducted or to inquire about potential trials that might be opening. Having a database of contact details gleaned from the audit has enabled these requests to be re-directed within 24 hours of an inquiry. Feedback about this service has been positive from both the patients and clinicians.

Communication network

Clearly the most useful outcome from the audit is the register of sarcoma treatment centres of excellence. A referral service is one benefit of the database, while another is the opportunity to conduct feasibility surveys to quickly gauge both interest in and capability to conduct specific sarcoma research. Three such feasibility surveys have been conducted in the past six months. The plan is to formally update the register every three months and correspondingly, to refresh the website. Meanwhile, the multidisciplinary teams are asked to contact the group about any changes, which are corrected on the website within 24 hours. The membership database will become web based with the next upgrade of the site planned for 2010.

Clinical database and virtual biospecimen bank

A major project for the group has been to establish a sarcoma clinical database in collaboration with BioGrid Australia,[5] and a centralised database recording the inventories of current sarcoma tissue bank sites. A collaborative effort between three major sarcoma centres (Victoria, New South Wales and the Australian Capital Territory) resulted in the development of a minimum sarcoma dataset. In 2009, a federated database, based on the Biogrid system and using the sarcoma minimum dataset, was built, tested and began being populated in Victoria at the Peter MacCallum Cancer Centre (data on 150 patients has since been recorded). Seven more sites are committed to collecting data and are in varying stages of readiness. The model ensures that each site has a server, ethics approval and a data manager employed before data collection commences. When all sites are operational a sarcoma database users group will be formed to achieve anticipated data collection outcomes, such as comparison of epidemiological data and clinical care data, and standards against international benchmarks. A longer term goal is to include paediatric data.

The sarcoma biospecimen bank project runs in parallel with establishing the database. The expected outcome is a register of sarcoma tissue storage that will be posted on the website for researchers to access.

Conclusion

The key role for the Australasian Sarcoma Study Group is to improve outcomes for sarcoma and related tumours in the Australian community by undertaking basic, translational, clinical and supportive care research. To achieve this aim, the group undertook to develop a collaborative network of specialist sarcoma units conducting research, to establish a national, integrated clinical database and biospecimen bank to support research and to increase capacity by developing partnerships between the scientific, clinical and wider community. This audit has provided the foundation knowledge to achieve these objectives and the information required to populate the website and create a reliable, useful resource for patients and the scientific community. The immediate utility realised from this audit suggests that replication of the survey for international sarcoma treatment centres may prove equally advantageous.

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AUSTRALIAN BEHAVIOURAL RESEARCH IN CANCER

Behavioural Research and Evaluation (BREU), South Australia

Staying Healthy After Cancer

Given that cancer is gaining recognition as a chronic illness, Cancer Council SA offers a six-week chronic disease self-management program for people who have been diagnosed with cancer and who are not receiving medical treatment for cancer at the time. The Staying Healthy After Cancer (SHAC) program aims to enhance participants' use of self-management behaviours and to manage the physical and emotional challenges associated with ill-health. From 2005 to 2008, SHAC program participants (n=79) completed three questionnaires; prior to participating, after the final program session and six months after completing the program. The questionnaires assessed behavioural and psychosocial outcomes addressed by the program, with responses compared to assess change. Results show that the SHAC program significantly increased participants' ability to self-manage their illness during the course of the program. Participants saw improvement during this time in levels of fatigue, self efficacy, exercise behaviours, use of stress management techniques and goal achievement. Sustained improvements in levels of distress, fatigue, self efficacy, exercise and use of stress management techniques remained at six month follow-up.

Indigenous mass media project

While smoking rates are at approximately 21% in the South Australian community, rates remain high among Indigenous South Australians (at over 50%). Mass media has been shown to be an effective strategy to reduce smoking rates in the general community, however the impact of this media among Aboriginal people is not well understood. In consultation with the SA Aboriginal Health Council, new research has been developed in collaboration with the Centre for Behavioural Research in Cancer (Cancer Council Victoria). Funded by the SA Government, the research will investigate the impact of various television commercials on Aboriginal people. The research aims to assess the comprehension, acceptability and potential effectiveness of specific television advertisements communicating anti-smoking messages among Aboriginal people compared to non Aboriginal South Australians.

Tobacco outlet density in South Australia

South Australia does not currently restrict the number of retail outlets that sell tobacco. Studies in the alcohol literature indicate that reductions in the physical availability of alcohol products are associated with positive health and behavioural outcomes, especially in low socio-economic areas. New government funded research will be undertaken by the Tobacco Control Research and Evaluation Unit to obtain profiles of tobacco retailer density and investigate relationships between smoking rates and licence density. This research may then inform future tobacco licensing models.

Centre for Behavioural Research in Cancer (CBRC), Victoria

Second-hand smoke drift: Examining the influence of indoor smoking bans on indoor and outdoor air quality at pubs and bars

In recognition of the substantial health risks associated with second-hand tobacco smoke exposure, this study aimed to examine the influence of indoor smoking bans at pubs and bars on indoor and outdoor air quality, and to assess whether second-hand tobacco smoke drifts from outdoor smoking areas to adjacent indoor areas. Data was collected from a sample of 19 pubs and bars in Victoria that had at least one indoor area with an adjacent semi-enclosed outdoor eating/drinking area. Using TSI SidePak Personal Aerosol Monitors, concentrations of second-hand tobacco smoke were measured concurrently in indoor and outdoor areas before and after implementation of the indoor smoking ban in pubs in Victoria in 2007. We found that indoor second-hand tobacco smoke concentrations significantly reduced by 65% from pre-ban to post-ban, and that outdoor exposure to second-hand tobacco smoke also reduced significantly by 39% from pre-ban to post-ban. In addition, post-ban indoor second-hand tobacco smoke concentrations were positively and significantly associated with post-ban outdoor concentrations, suggesting that second-hand tobacco smoke was drifting from outdoors to the adjacent indoor areas. Therefore, the findings from this study indicate that although indoor smoking bans are an effective means of improving indoor and outdoor air quality in pubs and bars, the air quality of smoke-free indoor areas may be compromised by smoking in adjacent outdoor areas. These findings must be considered to ensure adequate protection of the health of employees and patrons at hospitality venues.

Does the portrayal of tanning in Australian women's magazines relate to real women's tanning beliefs and behaviour?

The possible role of mass media in influencing attitudes and social norms for tanning by women has received little research attention. This study aimed to examine whether exposure to tanned models in popular women's magazines between 1987 and 2002 is associated with pro-tan attitudes, beliefs and behaviours among women in Melbourne, Australia during the same period. Content analysis data on the portrayal of tanning among 4949 female, Caucasian models sampled from spring and summer magazine issues were combined with magazine readership data to generate indices of potential exposure to social modelling of tanning via popular women's magazines. Associations between these indices and cross-sectional telephone survey data from the same

period on 5675 female teenagers' and adults' tanning attitudes, beliefs and behaviour were examined. Among young women, greater population exposure to tanning in young women's magazines was associated with increased likelihood of endorsing pro-tan attitudes and beliefs. Among women of all ages, greater exposure to tanned models via the most popular women's magazines was associated with increased likelihood of attempting to get a tan, but lower likelihood of endorsing pro-tan attitudes. These study results suggest that popular women's magazines may promote and reflect real women's tanning beliefs and behaviour. Thus, skin cancer prevention programs may need to develop strategies aimed at reducing pro-tan imagery in women's magazines.

Centre for Behavioural Research in Cancer Control (CBRCC), WA

Awareness of the harms of chronic alcohol consumption on cancer risk

A literature review, funded by Cancer Council Australia, was conducted to determine knowledge of the harms of chronic alcohol consumption and cancer in the community. Alcohol is an important modifiable risk factor for some cancers. There appears to be a dose response relationship with cancer risk increasing with higher levels of alcohol consumption. Public education campaigns on alcohol have focused on the harms of acute and binge drinking, but not on the harms of chronic alcohol consumption. The evidence from Australian studies suggests that beliefs about the link between alcohol and cancer are not salient. For example, in a series of four surveys of South Australians (2004: n=2985; 2006: n=2971; 2007: n=2507; 2008: n=2824), when asked what people could eat or drink more or less of to reduce their risk of cancer, only a small proportion of respondents nominated 'limiting or avoiding alcohol' (6–11% in each survey). However, there appears to be a moderate level of belief that alcohol increases cancer risk, with 57% of adults in Western Australian (2008: n=830) nominating 'alcohol' as doing so. This belief was not strongly held with only 21% responding 'increase a lot'. This literature review highlights the need for public education campaigns to raise public awareness of the link between alcohol consumption and cancer.

Understanding of the food industry's voluntary 'Percent Daily Intake Energy' labelling system

Currently a federal review of food labelling is underway with health organisations lobbying for a mandatory 'traffic light' nutrition labelling system to be placed front of pack on all packaged foods and beverages. The Australian Food and Grocery Council is countering with its own Percentage Daily Intake (%DI), already voluntarily adopted by 180 major brands and as of March 2010, appears on 2000 products. A newly introduced variant presents a single 'energy' thumbnail that specifies the percentage of daily recommended kilojoules represented by a single serve of a product (%DI kJ). Australian Food and Grocery Council recommends its use where "the product is low in all core nutrients" and has since emerged on soft drinks, confectionary bars and biscuits. While a number of previous researchers have compared the comparative merits of the traffic light system versus %DI, no one has investigated the recently introduced %DI kJ variant. We were curious to know whether people had noticed it, how they interpreted it and how useful they thought it was. A series of eight focus groups was conducted, stratified by age, sex and SES, to explore its merits. Few people noticed it unprompted or understood its implications. Indeed, many interpreted the term 'energy' with positive associations akin to energy sports drinks, while totally missing the point of potential contribution to weight gain. A modest quantitative follow-up study (n=58) confirmed that the %DI kJ label was deemed significantly less interpretable, noticeable, a deterrent or useful than either traffic light or %DI.

Centre for Health Research & Psycho-oncology (CHeRP), NSW

Evaluation of acceptability and impact of Cancer Council NSW telephone support groups

Emotional and social support interventions, such as support groups, can facilitate positive adjustment amongst those affected by cancer. Telephone support groups (TSGs) are now being offered as an alternative to traditional face-to-face groups. We evaluated Cancer Council NSW TSGs to determine their acceptability to participants and facilitators, impact on participants' psychosocial wellbeing and levels of burnout amongst group facilitators. One hundred and thirty six former, current or new TSG members completed a computer-assisted telephone interview assessing utility (referral sources, reasons for joining the group) and acceptability (structure, content, leadership, between member support and overall satisfaction) of the groups. New members also completed a survey assessing their psychosocial wellbeing before participating in their first group session and again 12 weeks later. All 11 group facilitators completed a burnout survey and interview exploring their experiences of the groups. Lack of access to face-to-face groups was the main reason members participated in TSG. There was a significant reduction in new members' levels of depression and improvement in overall mental health and emotional/informational support from pre to post-group assessment. Although facilitators identified challenges (workload, skills, group size), they reported significantly lower levels of burnout compared to reference values. TSGs are highly acceptable to people affected by cancer and may contribute to improvements in some aspects of emotional wellbeing. These findings emphasise the value of including telephone based support groups as part of the suite of supportive care services available to people affected by cancer.

Coping Together: Development and pilot testing of a self-directed coping skills intervention for patients and their partners

Both patients and partners describe the acute post-diagnostic phase as an emotional rollercoaster, with overlapping reactions including shock, distress, uncertainty and denial. Although patients and partners react to a cancer diagnosis as an emotional system, few psychosocial interventions target couples; those that are

available tend to be led by highly trained professionals, limiting their reach and sustainability. To overcome these limitations, researchers at CHeRP and national/international collaborators are developing a self-directed coping skills training intervention Coping-Together. Coping-Together translates the most up-to-date literature on effective coping strategies and makes it available to couples to optimise management of common physical, psychological and social cancer related challenges. The key component of Coping-Together is a workbook that presents couples with a series of behaviour therapy based worksheets, which encourage self-reflection and application of coping strategies to their current situation. For instance, it provides couples with a guide to mindfulness, tips on communication between patients and their partners and health care professionals, exercises to encourage joint problem solving and guidance for couples in the seeking and sharing of cancer information. The workbook has been presented to 12 couples, with most rating it highly and reporting that the concrete coping strategies help them work through their issues. Some participants have indicated that a self-directed format is more acceptable to them than attending support groups or workshops. The efficacy of Coping-Together in optimising couples' illness adjustment will be examined in a randomised control trial in 2011.

Viertel Centre for Research in Cancer Control (VCRCC), Queensland

Beating the blues after cancer

Approximately 35% of patients will experience persistent clinically significant distress; carers often experience even higher distress than patients. There is a need to identify patients and family members experiencing high distress and once identified, refer people to services that match their psychosocial care needs. This study is being conducted in collaboration with Cancer Council NSW to investigate support options for distressed callers to Cancer Council Helpline. It is a two control arm randomised control trial with distressed patients and carers, comparing a nurse led telephone support and education session, with subsequent provision of a self-management manual, to a tele-based, psychologist delivered cognitive behavioural intervention (five sessions). Participants' anxiety and depression, cancer specific distress, unmet supportive care needs, positive adjustment and overall quality of life are assessed at baseline and three, six and 12 months post-recruitment.

A significant outcome of this study will be recommendations about the efficacy of minimal contact self-management versus tele-based psychologist delivered cognitive behavioural intervention to facilitate better psychosocial adjustment and mental health for people effected by cancer. The results of this study will provide an evidence-based, practical and applied approach to psychosocial care that can be rapidly translated into community and acute settings. Information on the potential economic value of the intervention can be used by health planners to help achieve efficient health service delivery. Participant recruitment has been excellent and data collection is expected to be completed by September 2011. So far, the study has highlighted that Cancer Council Helpline staff (NSW and Qld) are highly effective in distress screening and participant feedback has been highly positive for the support care received.

Amazon Heart Thunder: achieving personal growth through a Harley Davidson

Amazon Heart Thunder (AHT) is a 10 day Harley Davidson motorcycle ride providing a peer support adventure event for breast cancer survivors. Anecdotal reports and an earlier qualitative study indicated that AHT is a catalyst for positive life change, or post-traumatic growth (PTG). This research aimed to identify the mechanisms for which PTG occurs in this peer support environment. Quantitative results showed that upward identification with positive role models during the ride was related to increased levels of PTG. Participants had high levels of pre and post-ride PTG, and also reported high group cohesion after the ride. Levels of cancer related distress significantly decreased after the ride. Qualitative results highlighted the challenges and benefits of the ride, and also the strong connections formed with the other women and the group. Often the challenges faced during the AHT experience were also discussed as benefits. Overcoming these challenges became an achievement and promoted a sense of personal strength. For some women a new social identity was formed through a strong sense of belonging to AHT. Women also discussed PTG that had occurred after their breast cancer and after experiencing AHT. The types of changes included enjoying life and seizing opportunities, fun and freedom, improved relationships with others, personal strength, pride in self and self-nurturing.

NEWS & ANNOUNCEMENTS

Expanding waistlines contribute to oesophageal cancer surge

Escalating obesity has contributed almost as much as smoking to a doubling of oesophageal cancer diagnoses in Australia over the past 25 years.

Highlighting the issue on World Cancer Day (4 February), Cancer Council Australia CEO, Professor Ian Olver, said more needed to be done through prevention to curb the disturbing increases in overweight and obesity.

"Oesophageal cancer is a good example of how Australia is falling short of our potential to prevent cancer through lifestyle change, with 37% of cases attributed to obesity and more than 45% caused by smoking," Professor Olver said.

According to Professor Olver, World Cancer Day 2010, with its theme of prevention, was a timely reminder in the lead-up to the Australian Health Ministers' Conference, expected to discuss the Government's chronic disease prevention agenda.

"Federal, state and territory governments must show genuine commitment to work together to reduce the impact of a disease responsible for more premature death in Australia than any other cause."

Professor Olver said the international prevention campaign, coordinated by the International Union Against Cancer (UICC), also highlighted the link between cancer and infections such as hepatitis and human papillomavirus.

Information on UICC's campaign is available at: www.worldcancercampaign.org

Cancer Council, COSA applaud US Government recommendations on gene patent policy

Cancer Council Australia and the Clinical Oncological Society of Australia (COSA) congratulated the US Government for sending a timely message to Australian policy makers, following the announcement in February of recommendations aimed at protecting the public from commercial exploitation of gene patents.

Professor Olver and COSA President, Professor Bruce Mann, welcomed the new recommendations from the US Secretary's Advisory Committee on Genetics, Health, and Society, which called for legal protection and policy reform to ensure gene patents did not restrict vital access to healthcare.

Professor Mann, a specialist breast surgeon who treats genetically at-risk patients, said the US recommendations were consistent with COSA and Cancer Council proposals to the Senate, such as establishing an advisory group for gene patents that included genetic clinicians.

"Gene patent policy needs formal clinical input, from professionals who understand the short and long-term scientific considerations in terms of patient care and future therapies," Professor Mann said.

"Human genetic material is not an invention, but the discovery of something that exists in nature, and its use in research and diagnostic services, should never be compromised by an outdated patent system."

Cancer Council's position on gene patents can be found at: www.cancer.org.au/Newsmedia/Issues_in_the_media/Gene_patents.htm

Cancer Council Australia/COSA submission to the Senate inquiry: www.cancer.org.au/policy/submissionstogovernment/GenePatentInquiry.htm

Cancer Council, COSA applaud principles of Rudd health reform agenda, but remote patient travel assistance left behind

Cancer Council Australia and COSA applauded the Rudd Government in March, for addressing the inefficiencies of Australia's fragmented health system.

However, they were disappointed remote patient travel assistance would remain a state responsibility and warned this might perpetuate geographic inequities in cancer care outcomes.

Professor Olver said the proposal to unify the health system, establish national care standards and more transparent reporting had the potential to improve outcomes for cancer patients, whose capacity to access genuine multidisciplinary care was often described as a 'lottery'.

"The plan to set national care standards by ensuring clinical practice guidelines are developed and applied locally as part of best practice is a tangible example of how improvements in care can be built into a unified system," he said.

"However, we will still need to address under-utilisation of critical services such as radiotherapy, which require infrastructure and workforce investment."

Professor Mann said he welcomed the emphasis on better engagement with clinicians in the development of care standards and guidelines.

"It is critical that this principle is backed up by formal partnerships with independent professional clinician groups, mandating our role in reforming the health system.

"In the meantime, clinicians caring for cancer patients in rural and remote areas – who have significantly poorer treatment outcomes than metropolitan patients – will be

disappointed to see no recommendation for centralised coordination of patient travel schemes."

US gene patent ruling sends message to Australian policy makers, say Cancer Council, COSA

A US court ruling in March that patents should never have been granted for the BRCA1 and BRCA2 gene mutations linked to breast and ovarian cancer reinforces a call by Cancer Council Australia and COSA for gene patenting law reform in Australia.

Professor Olver said the US judge's finding that biological materials in an isolated form are discoveries, not inventions, clarifies the ambiguity that has clouded the gene patenting debate.

"This result is not only significant to research and diagnostic uses of BRCA1 and BRCA2, it also sets a precedent for preventing the establishment of commercial monopolies over the use of many other genes and mutations that might hold the key to reducing cancer death and disease," Professor Olver said.

"It should send a message to Australian policy makers. We trust the Senate committee inquiring into this issue is watching with great interest."

Professor Mann said a similar ruling in Australia would give comfort to Australian women, whose access to public genetic testing for breast and ovarian cancer was threatened by an attempted commercial monopoly in 2008.

"Until Australian courts follow the US lead and recognise that genes should not be patented, the future of public access to genetic tests and to other vital, non-commercial uses of genetic material remains uncertain," Professor Mann said.

Plain packaging could see Australia 're-established as world leader' in reducing tobacco deaths

The Australian Government's decision in April to introduce plain packaging for tobacco products will cut cancer rates in Australia by eliminating one of the most effective remaining forms of cigarette advertising.

Professor Olver said the Government's commitment to phase out glossy branded tobacco packaging would enhance the effectiveness of graphic health warnings on packs and assist people trying to quit their deadly smoking habit.

"When tobacco products are sold in plain packs, not only will the health warnings be more prominent, but research also points to a reduction in youth smoking and an overall increase in quitting," Professor Olver said

"By committing to replacing the glossy coloured packs with plain packaging, the Government has re-established Australia as a world leader in health policy aimed at reducing the death and disease caused by smoking."

Professor Olver said reductions in premature cancer diagnoses resulting from the government's anti-smoking package would significantly reduce pressure on Australia's health system over the longer term.

Tobacco tax increase will slash cancer and cardiovascular disease deaths

Australia's future cancer and cardiovascular disease burden will be dramatically reduced as a result of the Government's decision to increase tobacco tax by 25 per cent, Cancer Council Australia and the National Heart Foundation of Australia said in April.

Professor Olver, and the CEO of the National Heart Foundation, Dr Lyn Roberts, said the tax increase in addition to the planned introduction of plain packaging for tobacco products made the announcement "a historic day for preventative health policy in Australia".

"An increase in excise of 25 per cent should prompt more than 100,000 Australian adults to quit smoking and prevent 25,000 children from becoming addicted to nicotine. That translates to saving thousands of Australians from a premature cancer death," said Professor Olver.

Professor Olver and Dr Roberts said the commitment to increase tobacco tax and introduce plain tobacco packaging showed the Government was serious about disease prevention as a pillar of health system reform.

Cancer Council, COSA welcome 'major investment' in reducing regional cancer care inequity

The Australian Government's 'Delivering better cancer care' plan released in April is the most important federal initiative for reducing geographic inequity in cancer care outcomes that Australia has seen, according to Cancer Council Australia and COSA.

Professor Olver said it was well-documented that Australians diagnosed with cancer had poorer treatment outcomes the further they lived from a city where they could receive multidisciplinary cancer care.

"Last year's federal budget announcement of $560 million for a network of regional cancer centres marked the first time an Australian Government committed to a major investment in reducing this disparity," Professor Olver said.

Professor Mann also applauded the announcement: "Funding vital infrastructure such as new radiotherapy and chemotherapy facilities, PET scanners and accommodation for remote patients, as recommended by local communities, is a groundbreaking capital investment in regional cancer care", he said.

According to Professors Olver and Mann, Cancer Council Australia and COSA had for many years promoted the concept of a network of regional cancer centres, with capital funding from the Australian Government and recurrent costs provided by jurisdictions.

It was now important to improve patient travel and accommodation schemes, to ensure that cancer patients in more remote areas were better able to benefit from the milestone funding.

The Government's commitment to introduce national standards and reporting in the health system to ensure consistent, high quality cancer care nationwide was also welcome, provided they were developed around advice from independent clinicians.

New guide on advanced prostate cancer for men and their families

A new booklet is available to support men and their families in the diagnosis and treatment of advanced prostate cancer.

Advanced Prostate Cancer - a guide for men and their families explains the advanced stages of prostate cancer, its treatments and how men and their families can manage patient health and care.

Developed by the Australian Prostate Cancer Collaboration in association with Cancer Council's Australian Cancer Network, the guide was produced as a sequel to the booklet *Local Prostate Cancer - a guide for men and their families.*

Advanced Prostate Cancer draws on the National Health and Medical Research Council's draft clinical practice guidelines, to provide a comprehensive source of information, written and reviewed by leading practitioners.

Download the guide from www.cancer.org.au/Healthprofessionals/clinicalguidelines/prostatecancer.htm or call the Cancer Council Helpline on 13 11 20 for a printed copy.

Events

Who will you buy a daffodil for?

If you like giving or receiving flowers and you think the one in two people who get cancer is one too many, then this August, please support Cancer Council's Daffodil Day.

Getting involved is easy. You can either register to receive a box of merchandise to sell, or you can purchase one of our Daffodil Day gifts at selected outlets during August, and on Daffodil Day itself (Friday, 27th August).

This year's range includes daffodil pins (ranging from $5-$30), our ever-popular pens ($5), soccer balls ($7), diamantes ($10) and this year's collectable Dougal Bear, decked out in a fetching yellow hoodie ($10). Coles have also come on board with bunches of fresh daffodils ($5) and the special Daffodil Day enviro bag ($2.50).

Funds raised support cancer research, prevention programs and support services for cancer patients and their families.

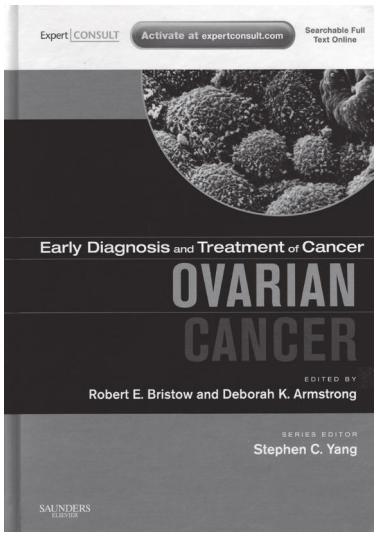
And don't forget we always need volunteers to help us sell Daffodil Day merchandise on the day. Visit www.daffodilday.com.au or phone 1300 65 65 85 for more information.



BOOK REVIEWS

Early Diagnosis and Treatment of Cancer - Ovarian Cancer

Robert E Bristow and Deborah K Armstrong (Editors)
Elsevier (2009)
ISBN-13:978-1-4160-4685-1
RRP: $170.00



This book on ovarian cancer is one of a series, *Early Diagnosis and Treatment of Cancer,* which gathers state-of-the-art research and recommendations into compact, easy to use volumes. The intention is to "make expert advice as accessible as possible to a wide variety of health care professionals."

Early Diagnosis and Treatment of Cancer - Ovarian Cancer is a well written, quality, hard copy text. It is easy to follow, with key points summarised at the beginning of each chapter. The content includes chapters on epidemiology, screening, pathology, genetics, imaging, surgery and chemotherapy, which are written by a variety of experts using recent, respected research and clinical trials. There are many high quality coloured photographs and illustrations to assist the reader, with boxes and tables to summarise recommended strategies, protocols, indications and contraindications, as well as statistics and other essential information. Throughout the book, tables and figures summarise important clinical data and support the text. Each chapter concludes with an impressive list of references providing further useful information.

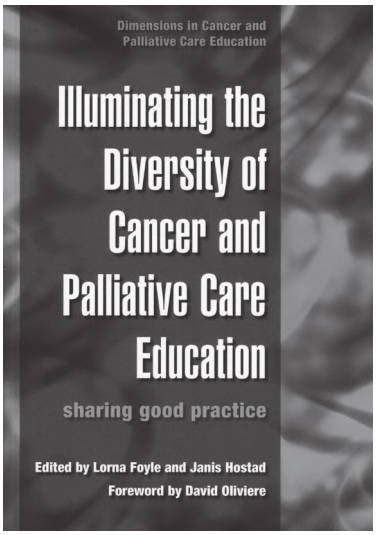
I enjoyed this book as an excellent source of reference, which despite being easy to follow, still provides a depth of information for health care professionals to better understand ovarian cancer including genetics, screening, diagnostics and treatment procedures. One limitation of the text is the omission of a chapter which describes the psychosocial impact of a diagnosis of ovarian cancer and living with a disease which has a high recurrence and mortality rate. Despite the importance of a multidisciplinary approach to care, it is only very briefly mentioned in the concluding paragraph.

Nevertheless, this book is highly relevant and I can certainly recommend it to health care professionals including clinicians, general practitioners and gynaecologic oncology nurses who want to better understand the disease, screening and staging, as well as the rationale for recommended treatment pathways. It would be a useful text for gynaecologic oncology wards and hospital libraries.

Pauline Tanner, Gynaecological Oncology Service, WA Cancer and Palliative Care Network.

Illuminating the Diversity of Cancer and Palliative Care Education – sharing good practise

Lorna Foyle and Janis Hostad (Editors)
David Oliviere (Forward)
Radcliffe Publishing (2009)
ISBN-13: 9781846190575
RRP: $99.00



This book is the third in the series on *cancer and palliative care education*. It is no light read, with 22 chapters and more than 350 pages. However, as its title indicates, it does cover a wide range of topics related to the diversity of cancer and palliative care education.

What I liked about the book was its clear organisation. The aims and learning outcomes are stated at the beginning of each chapter, with the key points re-stated at the chapter's conclusion. This layout makes it easy to dip into and out of the book. I also liked the fact that the teaching of communication skills occurred at the very beginning, highlighting its primacy in cancer and palliative care education. The chapters are clearly linked to each other, with references made to previous and forthcoming chapters. The book could have been a disparate group of 22 chapters, but instead it coalesces well into a unified whole.

The collection of topics does showcase the breadth of education, practice and research that is currently occurring in the field. However, I found that the material/ strategies within the chapters were not particularly new or innovative. Strategies such as using actors, role plays,

reflective practice and storytelling have been part of the education toolbox for some time now. What is perhaps new are the chapters on the importance of the teaching of critical thinking skills, the teaching of law applicable to cancer and palliative care contexts, the topic of patient and carer education and the use of cancer stories as a basis for communication modules.

One of my research interests is the nature of suffering and how to educate palliative care professionals to work with this subjective concept. Therefore, it was heartening to see that there was a chapter on hope and suffering written by Robert Becker. The classroom exercises will perhaps provide some useful 'hope inspiring' strategies that will assist in the area of capacity building.

Overall, the cited educational strategies can be applied to many disciplines and education levels. In my opinion, this is a strength of the book.

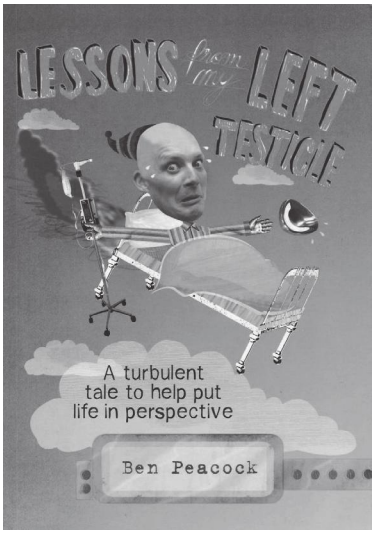
The book focuses primarily on UK based research and experiences. If you want different cultural contexts and appropriate educational strategies for these, you will not find them here.

This book would be beneficial to all educators/trainers in the field of cancer and palliative care.

Katrina Breaden, Flinders University, Course Coordinator Palliative and Supportive Studies , Adelaide SA.

Lessons from my Left Testicle

Ben Peacock
Finch Publishing (2009)
ISBN: 9781921462016
180 pages
RRP: $24.95



If you've never read a patient experience of cancer (or a 'cancer story'), then this account is for you. It is very relevant as a young Australian man shares his experience with cancer – thrown in with his travels, his relationship and subsequent marriage and of course his developing career.

What makes this account personable and engaging is Ben's skills in writing, his capture of the moment and his capacity to add a dollop of dry humour to the roller coaster ride we know cancer to be.

The title and the cover artwork remind you of Dr Karl's books and other resources that attempt to bring a more common touch to quite complex issues. It is immediately appealing because it is to the point. It may be too blunt for some and I wonder if the average younger adult male may view purchasing it in a bookshop akin to purchasing condoms at the chemist!

It is always inspiring and humbling to be exposed to someone else's confronting health crisis, however this book is different in that it doesn't get too bogged down in the clinical specifics of each medical or treatment interaction, and it reflects Ben's goal to always push through to keep a healthy perspective on elements of the journey to get to the ultimate aim.

The media release with the book lists Ben's top 10 epiphanies and from our experiences as health professionals and consumers of cancer services we recognise as truisms: "It's a good thing; having a reason to live makes life a lot easier; you can enjoy a bad moment; pain goes; 'if' means nothing; taking control is the key; you've got to get down to get up; there's always someone worse off; you probably can't do it on your own and; always finish on a positive".

There are two things I particularly enjoyed about Ben's approach in documenting his experience. The first was his inclusion of emails to and from his friends and family over time, which gives the book a modern edge and reminds us of the importance of communication with people who are special to us. The second was his wife's participation in the book with her thoughts on surviving cancer. I liked the way they talked about the experience as 'we', as a couple might getting through important life events such as pregnancy. As most carers will recognise, and especially those who are life partners will attest, his wife declared "I surrendered to an exercise in devotion".

It was no surprise to learn that Ben founded the ethical advertising agency, Republic of Everyone. It is clear that Ben learned many lessons from his experience with cancer and there are lessons for us all in here.

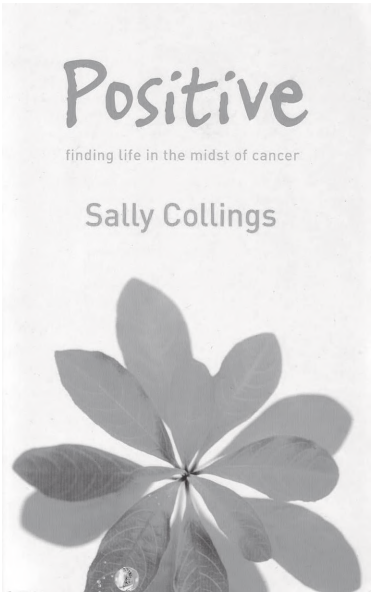
Gabrielle Prest, The College of Nursing, Burwood, NSW.

Positive – finding life in the midst of cancer

Sally Collings
HarperCollins Publishers (2009)
ISBN: 9780732287191
274 pages
RRP: $27.99

Given the recent discussions in the research and clinical community around the pressure that can be placed on cancer patients by either themselves or their family and friends to remain positive at all times throughout their cancer journey, my response to the title of this book was hesitant.

For the author, positive is defined as "the term (that) describes the 'upside' of cancer that appears against all expectations, and seemingly, against the odds". She also acknowledges that the positives are not immediate or apparent all the time or there for everyone. This is an important distinction and one that cannot be emphasised too highly.



It is a dense book. Dense in that there are many stories and many points of view expressed by those whose lives have been touched by a diagnosis of cancer. It is therefore a book that may be helpful to dip in and out of, but to read in a single sitting, or even several sittings, is overwhelming.

It illustrates well the individuality of the cancer experience. There are similarities and differences in the experiences and the stories and the reader may well find a story that fits their own. This can be reassuring, reaffirming and perhaps more importantly, an acknowledgement that a diagnosis of cancer touches everyone within the patient's circle in different ways.

Collings has interviewed a wide cross-section of cancer patients, their friends and family – the well known and the unknown. It follows their stories across the cancer continuum from diagnosis, through treatment, remission and survivorship or relapse, palliative care and bereavement, and describes the effect of this journey on the lives of the patients, their families and caregivers. Some tighter editing may have helped to create a better flow in the stories.

Perhaps the single threat throughout the stories is that for many, they have not allowed a diagnosis of cancer to define them. They have gone on to embrace fuller lives, reclaim earlier dreams or ambitions and respond to the needs of others in similar situations. What unifies the stories is that a diagnosis of cancer is a life altering experience for all concerned.

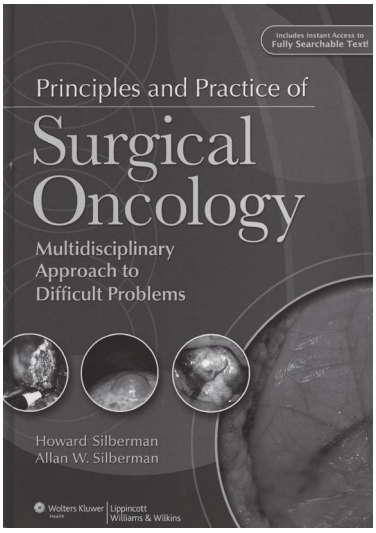
Perhaps the final word remains with Dr Jane Turner (page 19), who highlights that: "It is true that some positives can come out of cancer: however, that is at a cost. People will talk about the positive things as a way of avoiding going into the dark space to talk about what has been a difficult time for them". Collings has managed to achieve a balance through a collection of voices that express both the positives as well as the negatives.

This book is more directed towards patients and families, however the health professional who may read it will gain further insight into the psychosocial implications of a cancer diagnosis and the ripple effect created in the patient's wider circle.

Elizabeth Lobb, Calvary Health Care Sydney and Cunningham Centre for Palliative Care, Kogarah, NSW.

Principals and Practice of Surgical Oncology: Multidisciplinary Approach to Difficult Problems

Howard Silberman and Allan W. Silberman
Lippincott Williams & Wilkins (2010)
ISBN-13:978-0-7817-6546-6
1083 pages
RRP: $346.50



This text provides detailed information and data to assist the surgeon to make informative decisions when planning surgery on the cancer patient from a multidisciplinary framework.

There is discussion on the specifics of molecular biology of cancer to provide a better understanding of the therapeutic and future options in the treatment of cancer. Also included are detailed imaging and technique chapters to further assist the surgeon in their approach.

Dedicated sections on neo-adjuvant, adjuvant, monoclonal and targeted therapies provide a broad perspective on the management of individual cancers from a multi-modality stance.

There are multiple chapters on the multidisciplinary management of breast cancer, with diagrams highlighting different surgical techniques. Other cancers discussed in this text include melanoma, lung, thyroid, ovarian, sarcoma (including primary bone and soft tissue), gastrointestinal and the colorectal cancers, including small bowel, urological and the surgical approach to neuroendocrine cancers.

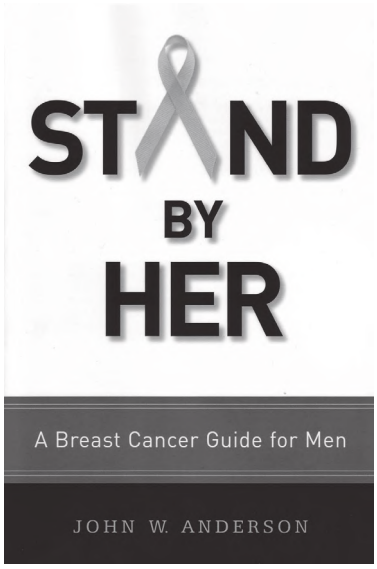
Within the text, discussion on the surgical approach of metastases is described, especially in the management of breast, melanoma and lung cancer. Other topics discussed in this text include malnutrition and cancer cachexia, stem cell transplantation for solid tumours and organ transplantation for malignancy, especially in the management of hepatocelluar cancer. Discussion on malignancy as a result of organ transplantation and its complexity is also described.

This book provides an overview of the principles and practice of surgical oncology from a multidisciplinary perspective. All disciplines involved in the management of cancer care would find this text beneficial in their practice.

Louise Nicholson, Nurse Unit Manager, Outpatient Oncology Services, Royal Hobart Hospital, Tasmania.

Stand By Her: A Breast Cancer Guide for Men

John W Anderson
McGraw Hill (2009)
ISBN-13: 9780814413913
256 pages
RRP: $35.00



Like many illnesses, breast cancer doesn't just affect the women who have been diagnosed. This book is targeted towards the men in their lives and where the breast cancer journey takes them. Based on the author's personal experiences, this resource gives an insight into their lives and the emotions and feelings they go through. From a carers approach, the reader is offered a review of the medical, psychological and social aspects of breast cancer.

The book is set out in a logical format with a heartfelt and moving aspect, providing the opportunity for the carer's journey to be explored. While trying to navigate the medical world, plus the emotional aspect of breast cancer, John Anderson suggests strategies for the carer to cope with this devastating experience. Avenues and opportunities are discussed to enlighten the carer how to be a more valuable and supportive part of their loved one's journey. Also, delicate issues surrounding breast cancer and the process involved in emotional coping and healing for the carer are addressed. Thousands of men entering the breast cancer world with their loved ones will have a guide to better face and cope with their fears, sufferings, isolation and bewildering emotions.

Finally, the text is further enhanced with four pages of web resources to relevant organisations, including group counselling, professional support services, cancer research, educational programs, exercise, diet and more.

In conclusion, the presentation was consistent from a carer's view, covering the entire spectrum from diagnosis to survivorship. Both patients and carers will appreciate this inspiring and informative read. However, the one size fits all approach to support and information for carers does not suffice, as carers' needs differ at various stages during their journey.

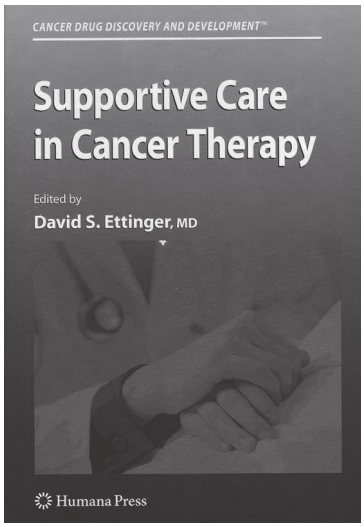
Ruth Mirto, Sydney Cancer Centre, Royal Prince Alfred Hospital, Sydney, NSW.

Supportive Care in Cancer Therapy

Edited by David S. Ettinger
Humana Press (2009)
ISBN: 9781588299413
294 pages
RRP: $US149.00

Supportive Care in Cancer Therapy is a part of the Cancer Drug Discovery and Development series. Edited by David S. Ettinger, the book comprises chapters written by North American authors on topics of their expertise.

Cancer is a prevalent disease and patients with cancer are living longer. There are more and more discoveries of new agents and more options for people with regards to curative or palliative anti-cancer therapies. This book is useful to those working in palliative medicine, which is my field of practice; we are treating patients earlier in their disease and in parallel with anti-cancer therapies. Furthermore, a large proportion of all our clinical practice relates to an ageing population.



This book would be useful for any clinician working with cancer patients. It is concise (294 pages) and covers the management of symptoms that relate to cancer and/or its treatment. Each chapter has an abstract and at the end summarises key points. It is well referenced and includes evidence-based approaches to symptoms.

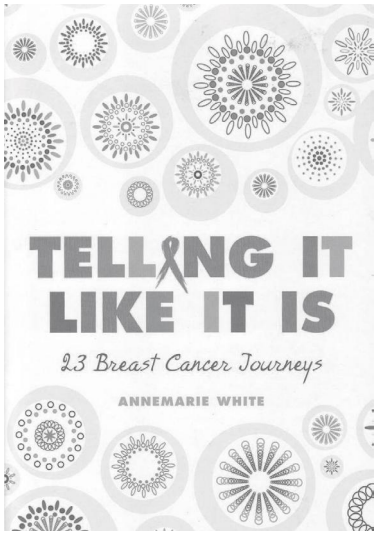
I was pleased to discover that it covered not only physical symptoms, but psychological/psychiatric comorbidities, complimentary therapies and end-of-life decisions. This underlies the importance of holistic care and the multidisciplinary approach to care for patients with cancer. Chapter 14 is specific for supportive care of the older patient and geriatric oncology is undoubtedly becoming a discipline of its own.

I would recommend this book to clinicians practising in any of the oncological fields. It can also be used as a reference for specific symptoms and their treatment.

Toula Christou, Southern Adelaide Palliative Services, Repatriation General Hospital, South Australia.

Telling It Like It Is – 23 Breast Cancer Journeys

Anne-Marie White
ABC Books - Harper Collins Publishers (2009)
ISBN: 9780733325168
273 pages
RRP: $32.99



Telling It Like It Is is an inspiring and emotional read, exploring 23 individual breast cancer journeys. Written by Anne-Marie White, a breast cancer survivor herself, the book conveys the breast cancer experiences of a range of 22 women, including Anne-Marie's, and with a remarkable account of one man's breast cancer journey.

These stories are captured and told by the author from interviews with people who have had a breast cancer diagnosis and includes thoughts and experiences from their families and friends. Throughout the book, the author shares her own story, drawing on her memories and emails to close friends during the time she had cancer. She shares with her readers her personal and confronting insights into her cancer experience, by relaying her fears, frustrations, achievements and the emotional rollercoaster ride of her cancer journey.

The book highlights how different each person's cancer experience can be. Factors influencing the individual's cancer journey include the age of diagnosis, how they were diagnosed, the type of breast cancer and the varying cancer treatments they had to endure. Each story touches on these factors in relation to the emotional stress of a cancer diagnosis and the physical and psychological ability to cope with the treatment.

If there is a common message coming from this inspirational account of breast cancer journeys, it is one of bravery, showing that individuals can seek and find unrevealed strength and can battle through a cancer diagnosis with the great support of family, friends and medical professionals.

"The cancer unleashed what was always there, but I guess it gave me the courage to be genuine. I realised that I was more resilient than I thought and that was the gift this diagnosis gave me – the discovery of my own inner power." - Dawn Leicester

These first hand accounts come from a wide range of Australians, some well-known including athlete Kerryn McCann, retired politicians Ros Kelly and Jocelyn Newman, and Margaret Stewart, a member of the ABC news team at Toowong studios.

It is undoubtedly a genuinely compelling book, guaranteed to make you laugh, cry and develop a great respect and admiration for all people experiencing a cancer journey.

Jenny Treloar, McGrath Breast Nurse, Macarthur Cancer Centre, Campbelltown, NSW.

CALENDAR OF MEETINGS

AUSTRALIA AND NEW ZEALAND

Date	Name of Meeting	Place	Secretariat
2010			
July			
14 – 16	Sydney Cancer Conference - Profiling risk, personalising treatment and predicting outcomes	Sydney NSW	Cancer Research Network Room 302, Medical Foundation Building 92-94 Parramatta Road Camperdown NSW 2050 Australia Tel: +61 2 9036 3478 Email: merilynh@health.usyd.edu.au
29 – 31	Cancer Nurses Society of Australia 13th Winter Congress	Perth WA	CNSA 2010 Congress Managers Level 10, 51 Druitt Street, Sydney NSW 2000, Australia Tel: +61 2 9265 0700 Email: cnsa2010@arinex.com.au Website: www.cnsa2010.com
August			
6 – 8	2010 Australian-Canadian Prostate Cancer Research Alliance Symposium, Annual Scientific Congress 2010	Gold Coast QLD	Australian Canadian Prostate Cancer Research Alliance Tel: +61 7 3176 7446 Email: ally.tutkaluk@qut.edu.au Website: www.aus-canprostatealliance.org/events/2010-symposium
11 – 13	11th National Prostate Cancer Symposium	Melbourne Vic	The PR Exchange Pty Ltd PO Box 27, Foster, Victoria 3960 Tel: +61 3 56841582 E-mail: prex@pacific.net.au Website: www.prostatemeeting.org.au
21 – 22	Cancer Pharmacists Group (CPG) of Clinical Oncological Society of Australia (COSA) Clinical Skills for Cancer Pharmacy Practitioners workshop	Brisbane QLD	Level 1/131 Leichardt Street Spring Hill Qld 4001 Tel: +61 7 3834 3333 Email: amy@iamevents.com.au Website:http://cpg.iamevents.com.au/index.php
September			
1 – 3	Australasian Gastro-Intestinal Trials Group (AGITG) Annual Scientific Meeting 2010	Adelaide SA	GI CANCER Institute Medical Foundation Building University of Sydney Level 6 92-94 Parramatta Road Camperdown NSW 2050 http://www.gicancer.org.au
12 – 18	Australia & Asia Pacific Clinical Oncology Research Development (ACORD) Workshop 2010	Sunshine Coast QLD	Australia & Asia Pacific Clinical Oncology Research Development (ACORD) Website: www.acordworkshop.org.au
14 – 17	Australia & New Zealand Society of Palliative Medicine	Adelaide Sa	Australia & New Zealand Society of Palliative Medicine PO Box 238 Braidwood NSW 2622 Website: www.anzspm.org.au
October			
TBC	3rd Biannual Australian Lung Cancer Conference	TBC	PO Box 847 Lutwyche QLD 4030 Email: enquiries@lungfoundation.com.au Website: www.lungfoundation.com.au

2 – 3	COGNO Annual Scientific Meeting	COGNO	6–10 Mallett Street Camperdown NSW 2050 Tel: +61 2 9562 5000 Email: cogno@ctc.usyd.edu.au Website: http://www.cogno.org.au/
November			
10 – 12	Clinical Oncological Society of Australia Annual Scientific Meeting	Melbourne VIC	Clinical Oncological Society of Australia (COSA) Level 1, 120 Chalmers Street Surry Hills NSW 2010 Tel: +61 2 8063 4100 Email: cosa@cancer.org.au Website: www.cosa.org.au

INTERNATIONAL

Date	Name of Meeting	Place	Secretariat
2010			
July			
19 – 23	International Conference on Modern Cancer Management	Abuka Nigeria	Society of Oncology and Cancer Research of Nigeria Mrs Adebola Oyewole 102 Bashorun Road, Ashi Bodija Sectariat PO Box 29822, 20000 Ibadan, Nigeria Tel: +234 802 343 1487 Fax: +234 2 241 0995 Email: info@socron.net Website: www.socron.net
August			
18 – 22	2010 World Cancer Congress	China	International Union Against Cancer (UICC) 62 Route de Frontenex 1207 Geneva, Switzerland Tel: +41 22 809 1811 Fax: +41 22 809 1810 Email: verhagen@uicc.org Website: www.worldcancercongress.org
29 Aug – 3 Sep	13th World Congress on Pain	Montréal Canada	International Association for the Study of Pain (IASP) c/o Meeting Makers 76 Southbrae Drive G13 1PP Glasgow, United Kingdom Tel: +44 141 434 1500 Fax: +44 141 434 1519 Email: iasp2008@meetingmakers.co.uk Website: www.iasp-pain.org/AM/Template.cfm?Section=Home
September			
15 – 17	15th Congress of the European Society of Surgical Oncology (ESSO)	Bordeaux France	ECCO Michel Ballieu 83 av Mounier 1200 Brussels, Belgium Email: nicola@ecco-org.eu Website: www.ecco-org.eu/Conferences-and-Events/ESSO-2010/page.aspx/1135

October			
3 – 5	IFHNOS 2010 World Tour	Frankfurt Germany	International Federation of Head and Neck Oncologic Societies (IFHNOS) Dr Jatin Shah 1275 York Avenue 10065 New York, United States Tel: +1 212 639 7233 Fax: +1 212 717 3302 Email: shahj@mskcc.org Website: www.ifhnosworldtour2010.org
6 – 10	APACT 2010	Sydney Australia	Asia Pacific Association for the Control of Tobacco c/o Event Planners Australia 547 Harris Street NSW 2007 Ultimo, Australia Email: info@apact2010.org Phone: +61 2 9213 4051 Fax: +61 2 9213 4099
7 – 9	IFHNOS 2010 World Tour	Istanbul Turkey	International Federation of Head and Neck Oncologic Societies (IFHNOS) Dr Jatin Shah 1275 York Avenue 10065 New York, United States Tel: +1 212 639 7233 Fax: +1 212 717 3302 Email: shahj@mskcc.org Website: www.ifhnosworldtour2010.org
8 – 12	35th European Society for Medical Oncology Congress	Milan Italy	ESMO Congress Via La Santa 7 6962 Viaganello-Lugano, Switzerland Tel: +41 91 973 1919 Fax: +41 91 973 1918 Email: congress@esmo.org Website: www.esmo.org
10 – 12	IFHNOS 2010 World Tour	St. Petersburg Russia	International Federation of Head and Neck Oncologic Societies (IFHNOS) Dr Jatin Shah 1275 York Avenue 10065 New York, United States Tel: +1 212 639 7233 Fax: +1 212 717 3302 Email: shahj@mskcc.org Website: www.ifhnosworldtour2010.org
14 – 16	IFHNOS 2010 World Tour	Bangalore India	International Federation of Head and Neck Oncologic Societies (IFHNOS) Dr Jatin Shah 1275 York Avenue 10065 New York, United States Tel: +1 212 639 7233 Fax: +1 212 717 3302 Email: shahj@mskcc.org Website: www.ifhnosworldtour2010.org
18 – 20	IFHNOS 2010 World Tour	Manila Philippines	International Federation of Head and Neck Oncologic Societies (IFHNOS) Dr Jatin Shah 1275 York Avenue 10065 New York, United States Tel: +1 212 639 7233 Fax: +1 212 717 3302 Email: shahj@mskcc.org Website: www.ifhnosworldtour2010.org
19 – 22	Colon Cancer in Murine Models and Humans III	Bar Harbor United States	The Jackson Laboratory Erin McDevitt 600 Main Street 04609 Bar Harbor, United States Email: erin.mcdevitt@jax.org Phone: +1 207 288 6659 Fax: +1 207 288 6080

19 – 22	16th World Congress of Senologic International Society and 29th National Congress of the Spanish Society of Senology and Breast Disease	Valencia Spain	Senologic International Society (SIS) and Spanish Society of Senology and Breast Disease (SESPM) Teresa Marti c/ D. Juan de Austria, 36 - p.8 46002 Valencia, Spain Tel: +34 96 394 2210 Fax: +34 96 394 2210 Email: sisbreast.valencia@grupoaran.com Website: www.congresomundialsis.com
21 – 23	IFHNOS 2010 World Tour	Shanghai China	International Federation of Head and Neck Oncologic Societies (IFHNOS) Dr Jatin Shah 1275 York Avenue 10065 New York, United States Tel: +1 212 639 7233 Fax: +1 212 717 3302 Email: shahj@mskcc.org Website: www.ifhnosworldtour2010.org
23 – 26	13th International Gynecologic Cancer Society Biennial Meeting	Prague Czech Republic	International Gynecologic Cancer Society Erica Bard Riley, MA PO Box 6387 40206 Louisville, United States Phone: +1 502 891 4575 Fax: +1 502 891 4576 Email: adminoffice@igcs.org Website: www.kenes.com/igcs
26 – 27	IFHNOS 2010 World Tour	Rio De Janeiro Brazil	International Federation of Head and Neck Oncologic Societies (IFHNOS) Dr Jatin Shah 1275 York Avenue 10065 New York, United States Tel: +1 212 639 7233 Fax: +1 212 717 3302 Email: shahj@mskcc.org Website: www.ifhnosworldtour2010.org
26 – 29	International Cancer Week	Abuja Nigeria	Federal Ministry of Health / Breast without Spot initiative Professor Ifeoma Okoye Centre for Continuing Education and Research in Radiology University of Nigeria Teaching Hospital, Ituku Ozalla Enugu state, Nigeria. 234 Enugu, Nigeria Email: okyeij2002@yahoo.co.uk Phone: +234 803 772 5980 Fax: +234 4 245 2813
28 – 30	IFHNOS 2010 World Tour	Mexico City Mexico	International Federation of Head and Neck Oncologic Societies (IFHNOS) Dr Jatin Shah 1275 York Avenue 10065 New York, United States Tel: +1 212 639 7233 Fax: +1 212 717 3302 Email: shahj@mskcc.org Website: www.ifhnosworldtour2010.org
28 – 30	Geriatric Oncology: Cancer in Senior Adults - 11th Meeting of the International Society of Geriatric Oncology	New York United States	International Society of Geriatric Oncology (SIOG) Matti S. Aapro, Executive Director c/o IMO - Clinique de Genolier Route du Muids 1272 Genolier, Switzerland Email: siog@genolier.net Phone: +41 22 366 9106 Fax: +41 22 366 9207
November			
7 – 10	NCRI Cancer Conference	Liverpool United Kingdom	National Cancer Research Institute Sharon Vanloo 61 Lincoln's Inn Fields PO Box 49709 WC2A 3WZ London, United Kingdom Tel: +44 207 438 5453 Email: ncriconference@ncri.org.uk Website: www.ncri.org.uk/ncriconference

16 – 19	22nd EORTC-NCI-AACR Symposium on Molecular Targets and Cancer Therapeutics	Berlin Germany	ECCO - the European Cancer Organisation Davi Kaur ECCO - the European Cancer Organisation Avenue E. Mounier 83 B-1200 Brussels, Belgium Tel: +32 2 775 0201 Fax: +32 2 775 0200 Email: ena2010@ecco-org.eu Website: www.ecco-org.eu/Conferences-and-Events/EORTC-NCI-AACR-2010/page.aspx/1386
28 Nov – 3 Dec	96th RSNA Scientific Assembly and Annual Meeting	Chicago United States	Radiological Society of North America 820 Jorie Blvd 60521 Oak Brook, United States Tel: +1 630 571 7879 Fax: +1 630 571 7837 Email: reginfo@rsna.org Website: www.rsna.org/
December			
9 – 12	33rd Annual San Antonio Breast Cancer Symposium	San Antonio United States	CTRC Research Foundation Rich Markow, Symposium Coordinator d.b.a. San Antonio Breast Cancer Symposium 7979 Wurzbach Rd., Rm. U-531 Email: Rmarkow@ctrc.net Phone: +1 210 450 5912 Fax: +1 210 450-5009
2011			
March			
16 – 19	12th International Conference Primary Therapy of Early Breast Cancer	St Gallen Switzerland	TBC
25 – 26	EORTC EANO conference 2011: Trends in Central Nervous System Malignancies	Bucharest Romania	ECCO - the European Cancer Organisation Avenue E. Mounier 1200 Brussels, Belgium Email: info@ecco-org.eu Phone: +32 2 775 0201 Fax: +32 2 775 0200

CANCER COUNCIL AUSTRALIA

Cancer Council Australia is the nation's peak cancer control organisation.

Its members are the leading state and territory Cancer Councils, working together to undertake and fund cancer research, prevent and control cancer and provide information and support for people affected by cancer.

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CLINICAL ONCOLOGICAL SOCIETY OF AUSTRALIA INC

The Clinical Oncological Society of Australia (COSA) is a multidisciplinary society for health professionals working in cancer research or the treatment, rehabilitation or palliation of cancer patients.

It conducts an annual scientific meeting, seminars and educational activities related to current cancer issues. COSA is affiliated with Cancer Council Australia.

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www.cosa.org.au or cosa@cancer.org.au

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Cancer Research
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Familial Cancer
Gastrointestinal Oncology
Gynaecological Oncology
Lung Oncology
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Radiation Oncology
Regional and Rural Oncology
Social Workers
Surgical Oncology
Urologic Oncology

Information for contributors

Cancer Forum provides an avenue for communication between all those involved in the fight against cancer and especially seeks to promote contact across disciplinary barriers.

To this end articles need to be comprehensible to as wide a section of the readership as possible. Authors should provide sufficient introductory material to place their articles in context for those outside their field of specialisation.

Format

Cancer Forum welcomes original articles about medical, scientific, political, social, educational and administrative aspects of cancer control. All manuscripts should be submitted by email to info@cancerforum.org.au as MS Word documents.

Length: 2000-2500 words.

Font: Arial - 20pt for title, 12pt for headings and 10pt for text.

Following the title, include your full name, organisation and email address.

Include an introductory heading and sub-headings that describe the content.

Number pages in the footer.

Abstract

All manuscripts must include an abstract of approximately 200 words, providing a summary of the key findings or statements.

Illustrations

Photographs and line drawings can be submitted via email or on disk, preferably in tiff or jpeg format, or as transparencies or high quality prints.

If images are not owned by the author, written permission to reproduce the images should be provided with the submission.

Referencing

Reference numbers within the text should be superscripted and placed after punctuation.

The list of references at the end of the paper should be numbered consecutively in the order in which they are first mentioned and be consistent with the National Library of Medicine's International Committee of Medical Journal Editors' *Uniform Requirements for Manuscripts Submitted to Biomedical Journals.*

> eg. Halpern SD, Ubel PA, Caplan AL. Solid-organ transplantation in HIV-infected patients. N Engl J Med. 2002 Jul 25;347(4):284-7.

A full guide is available at www.nlm.nih.gov/bsd/uniform_requirements.html

The Editorial Board will make the final decision on publication of articles and may request clarifications or additional information.

Manuscripts should be emailed to:

Executive Editor
Cancer Forum
GPO Box 4708
Sydney NSW 2001
info@cancerforum.org.au

GPO Box 4708, Sydney NSW 2001
Telephone: 02 8063 4100
Facsimile: 02 8063 4101
Website: www.cancer.org.au