

# CANCER FORUM



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FORUM: Survivorship

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Australian behavioural research in cancer

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Fuel, beds, meals and meds: out-of-pocket expenses  
for patients with cancer in rural Queensland

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# CANCER FORUM



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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](mailto:info@cancerforum.org.au)  
Website: [www.cancerforum.org.au](http://www.cancerforum.org.au)*

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# CANCER FORUM

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## Survivorship

# IMPROVING OUTCOMES FOR CANCER SURVIVORS IN AUSTRALIA

**Michael Jefford** ■ Australian Cancer Survivorship Centre and Department of Medical Oncology, Peter MacCallum Cancer Centre. Cancer Council Victoria. Faculty of Medicine, Dentistry and Health Sciences, University of Melbourne.  
Email: Michael.Jefford@petermac.org

The most recent national cancer incidence, mortality and prevalence data was reported in 2008.<sup>1</sup> In 2005, for the first time, there were over 100,000 new cases of cancer diagnosed in Australia. This number is projected to grow by over 3000 extra cases per year in 2006–2010, mainly due to the ageing of the population. In 2005 there were over 39,000 deaths from cancer in Australia. Pleasingly though, cancer survival rates have improved substantially over the past two decades.<sup>1</sup> For males, five-year relative survival increased from 41% to 58% (comparing cancer diagnoses made in 1982–1986 and those made in 1998–2004) and for females, it increased from 53% to 64%.<sup>1</sup>

Increasing survival leads to increasing prevalence. At the end of 2004, 654,977 people had been diagnosed with cancer at some time in the previous 23 years (when national data collection began), representing 3.2% of the Australian population (3.1% of males and 3.3% of females).<sup>2</sup> For those aged 50 years and over, 9% (9.3% of males and 8.7% of females) had been diagnosed with cancer during the previous 23 years and were still alive.<sup>2</sup> This proportion was further increased in people aged 65 years and over, at 14% (17% of males and 12% of females). Importantly, in older cohorts, the prevalence of other illnesses also becomes much more common. The most prevalent cancer survivors were survivors of breast cancer (130,000), melanoma (116,000), prostate (98,000) and colorectal (91,000). Next most prevalent are survivors of non Hodgkin's lymphoma, a much smaller group of 26,000.<sup>2</sup>

### Defining cancer survivorship

The term 'cancer survivor' may refer to different populations of people with an experience of cancer. In the US, the National Coalition for Cancer Survivorship suggests that "an individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life." Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition.<sup>3</sup> The US National Cancer Institute Office of Cancer Survivorship has adopted the same definition. Advantages of this broad definition are that it emphasises that cancer affects people for the duration of their lives and that family members, caregivers and others are also profoundly affected.

However, and more traditionally, a cancer survivor has been considered someone who appears cured of, or at least free from cancer. Measures such as five-year disease free (or overall) survival have marked long-term survivorship.

A more recent emphasis has been on the period of time following potentially curative treatments for cancer. The influential US Institute of Medicine (IOM) report *From cancer patient to cancer survivor: lost in transition* focuses on this period.<sup>4</sup> In Australia, the term 'cancer survivor' is generally used to refer to people who have completed initial cancer treatments, who are apparently free from cancer. As this definition does not implicitly include family and caregivers, we should be mindful of the effect of cancer on those other than the person immediately affected. Similarly, the post-treatment phase is clearly linked to the diagnostic and treatment phase of a person's cancer experience, as well as potentially, to periods of cancer recurrence, living with advanced cancer and death. It is essential to consider the phase of post-treatment survivorship as part of a continuum, frequently referred to as the cancer journey.

### This edition of *Cancer Forum*

The IOM report made a number of key recommendations, which are very relevant to cancer survivors in Australia, and elsewhere. The first recommendation of the report is to raise awareness of the needs of cancer survivors and to recognise survivorship, and particularly the period after completing treatment, as a distinct phase of cancer care.<sup>4</sup> This edition of *Cancer Forum* includes a number of papers that describe the range of issues and concerns that may be experienced by survivors and caregivers and draws attention to the need to develop strategies to reduce the consequences that cancer and its treatments may have on people. It also considers essential components of quality survivorship care and interventions to improve survivors' health and wellbeing. Papers also review current research activities in Australia and elsewhere and consider the critical issue of measurement – to identify issues affecting survivors, but also to measure the effect of interventions that intend to improve the wellbeing of survivors and carers.

### Issues for survivors

Survivors may encounter a range of potential effects as a result of the cancer itself and cancer treatments.<sup>4</sup> These issues are reviewed by Boyes and colleagues.<sup>5</sup> Cancer may cause significant physical, psychosocial, spiritual and existential impacts. There may be a range of practical consequences, including loss of income and change in roles. Effects may pass relatively quickly following completion of treatment (eg. hair loss or nausea), or may be long-term or permanent (eg. infertility). Some effects may not arise for months or years after completion of treatment, so called 'late effects' (eg. heart failure, second cancers).

Social impacts include loss of work and income, changed roles and changed friendships and networks. Physical impacts are strongly influenced by cancer type and treatments (as well as patient factors, including age and other illnesses) and may include fatigue, changed appearance (which may be associated with altered body image and esteem), cognitive changes, impaired mobility and premature menopause.

Many survivors feel anxious about leaving the safety of the hospital system when they transition from the end of treatment to long-term follow-up.<sup>6</sup> Consistent with many international reports, Australian studies indicate that fear of cancer recurrence and uncertainty about the future are common issues that survivors (and indeed caregivers) identify as needing help with.<sup>6-8</sup> In general though, studies indicate that cancer survivors' levels of anxiety and distress generally return to a level comparable to the general population (without a prior history of cancer), around two years post-treatment completion. An Australian study reported this year, found that five years following cancer diagnosis, most survivors had adjusted well and reported levels of anxiety and depression similar to Australian population norms.<sup>9</sup>

There may be additional difficulties for people from particular populations. People with backgrounds different to the dominant cultural and language groups appear to experience additional difficulties.<sup>5</sup>

While the majority of cancer survivors have very good quality of life and live healthy, satisfying and rewarding lives, it is vital that health professionals are aware of the issues that survivors may encounter and have strategies to, where possible, prevent, identify and treat these consequences. The IOM report recommends that healthcare providers "use systematically developed evidence-based clinical practice guidelines, assessment tools and screening instruments to help identify and manage late effects of cancer and its treatment."<sup>4</sup>

In the midst of potential negative consequences, many survivors (and carers) report positive feelings and describe personal growth. There is an emerging literature describing post-traumatic growth and benefit finding in oncology.<sup>10,11</sup>

### Family members and caregivers

With the shift in healthcare from hospital to more community-based care, increasing demands are placed on informal carers. Family members may find the cancer

experience more stressful than patients.<sup>12</sup> Girgis and Lambert review the issues that face caregivers of cancer survivors.<sup>13</sup> Caregivers may experience negative outcomes, including high levels of distress and depression.<sup>13,14</sup> Caregivers frequently report significant unmet needs, some of which overlap with those reported by people with cancer, including concerns about cancer recurrence and the need for accurate information and practical assistance. A meta-analysis of research studies examining the relationship between psychological distress in cancer patients and caregivers found a moderate correlation between patients' and caregivers' psychological distress.<sup>15</sup> The authors suggest that attention be given to factors other than cancer that may mediate distress in couples. Girgis and Lambert note the paucity of research studies targeting both patients and caregivers and suggest that interventions focus on areas such as information giving, communication between patients, caregivers and health professionals, emotional support, promotion of self care and peer support.<sup>13</sup>

### Issues for survivors of childhood cancers

Wheeler and colleagues review issues for survivors of childhood cancers.<sup>16</sup> As a result of improvements in cancer treatments, around 80% of children with cancer will be long-term survivors. However, such impressive survival figures are a relatively recent phenomenon, seen for only the last 40 years. There has been growing recognition, particularly over the last 20 years, of the many potential complications that may result from cancers themselves and cancer treatments for children. Much of the current data regarding long-term and late complications has derived from the Childhood Cancer Survivors Study.<sup>17,18</sup> This very impressive data set underscores the importance of data collection to allow a full assessment of issues for cancer survivors. Moreover, the studies have led to the development of comprehensive long-term follow-up guidelines (see [www.survivorguidelines.org](http://www.survivorguidelines.org)) that are becoming integrated into program delivery in the US and elsewhere.

Although not specifically addressed in this edition of *Cancer Forum*, people who develop cancer in adolescence and young adulthood (AYA) may encounter survivorship issues that overlap those seen in survivors of childhood and adult cancers, but also issues that are specific to the types of cancer encountered in this age group and linked to issues around this life stage.<sup>19</sup> Somewhat surprisingly, there is a lack of comprehensive data regarding long-term and late effects from cancer in this age group.<sup>20</sup> Adolescence is recognised as a period marked by risk-taking and experimentation.<sup>21</sup> Hudson and Findlay point out that health promotional counselling should acknowledge the educational needs of the adolescent/young adult age group, recognising the paucity of evidence to guide practice.<sup>21</sup> There is a need to develop greater understanding of survivorship issues and effective management strategies for AYA survivors.

The above brief review underscores the importance of paying attention to the post-treatment phase of the cancer journey. Health care practitioners should be aware of the health consequences of cancer and its treatment, as well

as strategies to address these issues. Comprehensive cancer control plans should include consideration of survivorship care.

### What constitutes ideal survivorship care?

Lotfi-Jam and colleagues consider this question in this edition of *Cancer Forum*.<sup>22</sup> As they describe, the IOM report defines four aims of survivorship care: prevention and detection of new cancers and recurrent cancer; surveillance for cancer spread, recurrence or second cancers; interventions to deal with the consequences of cancer and its treatment, and; coordination between specialists and primary care providers.<sup>4</sup> Arguably, current models of follow-up focus primarily on the second aim, but do not effectively address the other goals of survivorship care. As an illustration, Beaker and Luker studied the nature and content of hospital follow-up for women with early breast cancer.<sup>23</sup> Consultations were generally quite short (mean duration of six minutes) and focused on the detection of cancer recurrence. Unsurprisingly, few opportunities were available to meet supportive care needs. However, patients gained reassurance from these visits, as they were generally very optimistic. Strategies need to be explored that can more fully meet the needs of survivors.

Lotfi-Jam and colleagues suggest that optimal survivorship care should also be patient-centred, multidisciplinary, transition focused, holistic and able to be implemented.<sup>22</sup>

Importantly, optimal survivorship care does not begin as treatment ends. Optimal outcomes for cancer survivors are strongly influenced by experiences and interventions that take place much earlier in the cancer journey, including at diagnosis and during treatment. Identifying and addressing supportive care needs early may result in improved outcomes.<sup>24</sup> For example, meeting informational needs and providing necessary practical and emotional support are likely to reduce distress following treatment completion and into the survivorship phase. Similarly, medical interventions during the treatment phase may prevent later consequences. For example, with appropriate intervention it may be possible to preserve mobility and reduce the risk of premature menopause, infertility, sexual dysfunction and cognitive problems.

Health care providers need to be aware of potential issues for survivors, understanding common survivor concerns and consequences related to treatment of particular types of cancer and particular treatments. As mentioned, the IOM report encourages the development and use of evidence-based clinical practice guidelines, assessment tools and screening instruments to help identify and manage late effects of cancer and its treatment.<sup>4</sup> In Australia, we are currently struggling to routinely screen all new patients with cancer for unmet supportive care needs.<sup>24</sup> Regular rescreening presents an additional challenge. Perhaps considerations regarding screening of survivors for distress and for unmet need might be incorporated into plans to routinely implement repeat screening?

There is a growing push for government and other agencies to recognise survivorship care as an essential

component of high quality cancer care. As with other aspects of clinical care, a set of relevant metrics (that reflect quality survivorship care and survivor outcomes) need to be developed and the results made available, publicly.

### Exploring different models of care

Current models of follow-up care are inadequate and inefficient. Other models of care might more fully meet the goals of optimal survivorship care. Oeffinger and McCabe present a very useful review of models of survivorship care.<sup>25</sup> Currently, the majority of follow-up care, particularly in metropolitan areas, is provided by oncology specialists (surgical, medical, radiation oncologists). Other options might include GP care, alone or in partnership with oncology specialists (shared care), and nurse-led care. Follow-up need not be face-to-face, but may be telephone-based or, by video linkage (traditional video conferencing or using the internet). Follow-up may be according to a recommended protocol or patient initiated. Each of these models should allow easy referral to other health professionals (for example, psychology, social work, dietetics, physiotherapy) as necessary, and also allow easy referral for specialist review (for example, if there is concern regarding possible disease recurrence). There is a pressing need to develop and test different models of care. It is likely that different models will suit different settings. What works in a metropolitan setting may not be applicable or feasible in a rural environment. With this, it will be necessary to work with government to fund various models of follow-up. Current funding models favour medical and face-to-face models of review. Yet it may be more feasible, acceptable, cheaper and more effective to use non-medical models and/or models that do not require face-to-face review.

In this edition of *Cancer Forum*, Brennan and Jefford discuss GP based models of care.<sup>26</sup> Several randomised control trials have evaluated GP versus oncology specialist review for patients with a history of early breast or colorectal cancer.<sup>27,28</sup> The studies suggest that GP based review is a safe, reasonable alternative to hospital specialist review. A recent systematic review compared GP versus hospital based review of patients with cancer.<sup>29</sup> The authors found no statistically significant differences regarding cancer recurrence rates, survival, patient wellbeing or patient satisfaction.<sup>29</sup>

Gates and Krishnasamy review nurse-led models of care, particularly nurse-led clinics.<sup>30</sup> Advantages of nurse-led review include a focus on patient centred care, an emphasis on the detection and management of distress and unmet need (including provision of information and support), effective symptom management, promotion of self-care strategies and patient empowerment, and also cost considerations (relative to specialist medical staff). A systematic review of nurse-led versus hospital specialist follow-up identified four randomised control trials.<sup>31</sup> There were no statistically significant differences in cancer outcomes including survival and disease recurrence, nor regarding psychological morbidity. Beaver and colleagues have recently reported results from a randomised control trial in which women with early breast cancer were

randomised to traditional hospital follow-up or telephone follow-up with a specialist nurse.<sup>32</sup> Again, there were no differences regarding detection of cancer recurrence or levels of anxiety, though women in the telephone group reported higher levels of satisfaction. Interestingly, the telephone group was more expensive. The authors' conclusions were that this strategy may be suitable for women "at low to moderate risk of recurrence and those with long travelling distances or mobility problems" and that the intervention "decreases the burden on busy hospital clinics".<sup>32</sup>

Hospital-based multidisciplinary clinics represent another option for follow-up. This model has most commonly been utilised to follow survivors of childhood cancers considered at high risk of late effects, or with complex physical, psychosocial or practical issues. It is discussed by Wheeler and colleagues<sup>16</sup> and by Oeffinger and McCabe.<sup>25</sup>

These and other models of care need to be developed and evaluated. Furthermore, strategies to promote empowerment and greater self efficacy should be explored, where appropriate.

### Survivorship care plans

The majority of survivors want to be informed of strategies to remain well and many wish to be active partners in their long-term follow-up. GPs appear willing to manage patients in the survivorship phase.<sup>26</sup> A key requirement is that they be informed of key issues and advised regarding recommended follow-up. A key recommendation from the IOM report (indeed, the second of its 10 recommendations) is that survivors, GPs and other specialists be provided with a comprehensive care summary and follow-up plan.<sup>26</sup> This should summarise details of the cancer diagnosis, treatments, adverse reactions to treatment, current and potential future medical and supportive care issues and strategies to deal with these, strategies to maintain and improve health and a list of support services. The care plan should ideally be discussed with the person (and family/caregivers) and used as a living, working document. There are resources to assist with the development of care plans.<sup>33</sup> While the use of care plans might make intuitive sense (have good face validity), their impact has not been formally evaluated. There are a number of challenges to their routine use, most obviously who will produce the document, how can it be easily tailored to an individual person, who will discuss the document and how should it be used to enhance outcomes for survivors? Some centres have begun to use and evaluate survivorship care plans.<sup>34</sup> We await further evaluation and publication.

### Behavioural strategies

A cancer diagnosis and completion of cancer treatments can represent an opportunity to make changes to improve health and wellbeing, a so-called 'teachable moment'.<sup>35,36</sup> Stopping smoking, regular exercise, eating well and maintaining a healthy weight are all strategies that may improve wellbeing, quality of life and may reduce the risk of cancer recurrence.<sup>35,36</sup> Pollard and colleagues review the evidence regarding behavioural strategies, particularly

around exercise and diet.<sup>37</sup> Much Australian research is underway (and reviewed by the authors) to add to the evidence base, particularly regarding exercise. Physical activity recommendations for the general adult Australian population (a minimum of 30 minutes of moderate exercise per day, five days per week) appear appropriate for cancer survivors. It will be important to conduct further work to define strategies, applicable across a range of settings and to the breadth of the cancer survivor population, that lead to the adoption and maintenance of healthy lifestyle behaviours. These strategies may include advice and coaching from a broad range of health professionals, as well as from peers, volunteers or through self-directed learning.

### Measurement

Determination of survivors' concerns and needs is crucial to patient centred care. Survivors (and caregivers) are best placed to report issues that are of concern to them. However, they may not be aware of all potential consequences of their cancer and its treatments. We need assessment tools and screening instruments to help identify and manage late effects of cancer and its treatment.

Sanson-Fisher and colleagues, note that, "while there has been an expansion in the development of unmet needs scales for cancer patients, survivors and significant others, there remains a need to ensure that these measures are psychometrically robust".<sup>38</sup> Also, "a driving impetus behind the assessment of unmet need is the goal of intervening and reducing needs".<sup>38</sup> We need measures that are able to detect issues that are of importance to survivors (and carers). Interventions should be able to improve outcomes and we need to be able to measure this change, so that we can demonstrate that the intervention is effective. A major problem arises if an intervention is effective, however improvement cannot be measured using the available measures. Related to the ability to detect change on a measure, is the relationship of this change in measurement to what survivors and health professionals consider to be clinically meaningful. Although an intervention may produce a statistically significant improvement, compared to usual care, is this change actually meaningful? The authors also discuss the various instruments that have been developed to assess the needs of survivors and carers.<sup>38,39</sup>

### Research

There is a need to further understand experiences of cancer survivors from the paediatric, AYA and adult populations. We also need to further understand issues affecting people from different cultural backgrounds and other groups. Although much is known, particularly about the physical sequelae of cancer, some cancers and cancer treatments are under researched. Effective strategies to deal with the consequences of treatment and improve wellbeing need to be developed. As previously discussed, we need to investigate models of care delivery. As Girgis and Butow note, there is considerable consensus internationally regarding priority areas for research.<sup>40</sup> Priorities include: the investigation of long-term effects of



cancer diagnosis and treatment on patients, their families and caregivers, as well as needs and characteristics of unique or disadvantaged populations; the influence of lifestyle factors and behaviours on the health and wellbeing of survivors; development of evidence-based clinical practice guidelines for survivorship care; development of tools and instruments for use in clinical care and in survivorship research; development of effective care models and interventions, and the development and implementation of measures of quality of survivorship care. As the authors point out (and as illustrated in the papers in this journal), Australian researchers have been and remain, very active in cancer survivorship research. It makes good sense to define a coordinated research agenda that acknowledges internationally agreed priorities, while recognising circumstances that are particular to the Australian setting. For example, models of care that suit the US health care system may not translate effectively to an Australian setting.

We hope that you will enjoy this edition of *Cancer Forum*, that brings together papers that cover many aspects of cancer survivorship, from some of the key leaders in this area.

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## ISSUES FOR CANCER SURVIVORS IN AUSTRALIA

Allison Boyes,<sup>1</sup> Katharine Hodgkinson,<sup>2</sup> Lynley Aldridge<sup>3</sup> and Jane Turner<sup>4</sup>

1. Centre for Health Research and Psycho-oncology; Cancer Council NSW; University of Newcastle; Hunter Medical Research Institute.

2. HEADWAYhealth, NSW.

3. Psycho-Oncology Co-operative Research Group, University of Sydney, NSW.

4. Department of Psychiatry, University of Queensland.

Email: allison.boyes@newcastle.edu.au

### Abstract

As the number of people surviving cancer continues to increase, the need to know about the issues they face and how to support them becomes more urgent. Cancer is a life-changing diagnosis, with many survivors experiencing a range of both positive and negative outcomes attributed to cancer. While most survivors adjust well over time and experience relatively high quality of life, issues persist for some. Many survivors experience ongoing physical effects such as fatigue, pain and sexual problems. Some experience elevated levels of anxiety, depression or mood impairment and ongoing disruptions to daily living and social activities. New issues that emerge can include employment problems, insurance difficulties and worries about health, including cancer recurrence. Positive effects include changed values and goals, enhanced appreciation of life, improved close relationship with others, altruism and lifestyle changes. This article provides a brief overview of the psychological, physical, social and existential impact of cancer, with an emphasis on the issues faced by survivors after the completion of primary treatment.

*"Two years after diagnosis, it is hard getting used to the new me." I don't have the strength, flexibility or stamina that I used to, and have to adjust to achieving less each day than my mind expects me to... Still, I am generally not in pain and happy to still be here with my family and friends. I have down-sized my career, which has had a financial impact, but I think has achieved a better work/life balance for this stage in my recovery."*

The past three decades have seen significant improvements in the survival outcomes of those diagnosed with cancer, with more than 60% expected to be alive at least five years after their initial diagnosis.<sup>1</sup> It is estimated that about 340,000 people in Australia are living with a history of cancer, representing about 2% of the Australian population.<sup>2</sup> Many more will have an experience of cancer as a partner, family member or friend of someone with cancer. Given the multicultural nature of the Australian community, many survivors will be from culturally and linguistically diverse backgrounds (CALD). While most survivors are considered cured and/or cancer-free, others live with active disease and for many, cancer becomes a chronic disease.

The term cancer 'survivor' has varied definitions and has been used to describe those diagnosed with cancer who are alive and/or disease-free after five years, diagnosed patients who have completed primary treatment, as well as patients at any point from diagnosis.<sup>3</sup> This article adopts the widely accepted National Cancer Institute Office of Cancer Survivorship definition of a cancer 'survivor' to encompass anyone diagnosed with cancer, from the time of diagnosis to the end of life.<sup>4</sup> Mullan (1985) described survival as a three phase process: acute survival includes the diagnosis and treatment phases often dominated by fear and anxiety; extended survival starts at the

completion of active treatment or remission of disease and is characterised by fear of recurrence, physical limitations such as fatigue and monitoring for recurrence and late effects of treatment; permanent survival evolves from extended survival when the risk of recurrence is low and patterns of normal life may be re-established.<sup>5</sup>

A diagnosis of cancer is typically experienced as very distressing. Cancer treatments are often invasive and prolonged, placing significant demands on the person diagnosed, as well as their family and loved ones. While acknowledging that each individual's experience is unique, it is well accepted that cancer may have a significant psychological, physical, social and existential impact upon survivors with both positive (eg. feelings of gratitude) and negative sequelae (eg. distress, fatigue) reported. Although there are relatively few longitudinal studies, it is also known that some effects are long-term or permanent (eg. infertility) and others manifest some time after treatment completion (eg. lymphoedema). The extent to which these effects are experienced by survivors is known to vary according to characteristics such as age, gender, ethnicity, type of cancer, stage of disease, treatment modality, social support and coping style.<sup>6</sup>

In order to help the growing population of cancer survivors in Australia to 'thrive', it is important to understand the range of issues they face. Although most studies have focused on survivors in the acute survival phase, there is an emerging body of evidence describing the experience of those who have completed potentially curative treatment. Drawing on Australian research where possible, this article provides a selective and brief overview of the issues faced by cancer survivors, with an emphasis on the extended and permanent phases of survival.

## Psychological

Estimates of the prevalence of psychological morbidity experienced by cancer survivors vary widely across studies. However, it is generally agreed that distress is most common in the acute survival phase and declines over time since diagnosis; studies have found that cancer survivors' levels of distress typically return to a level comparable to the general population and individuals with no history of cancer, around two years post-diagnosis.<sup>7</sup> Consistent with international research, a recent study conducted in Australia indicated that long-term survivors of cancer often report levels of psychological wellbeing that matches or exceeds population levels.<sup>8</sup>

Nonetheless, areas of concern may persist for some survivors. For example, many survivors report a heightened sense of vulnerability, loneliness, worries about their health, concerns about burdening their loved ones, and anxiety about the possibility of cancer recurrence. Studies undertaken in Australia consistently report fear of cancer recurrence and uncertainty about the future as the most common concerns survivors need help to manage,<sup>9-11</sup> and are associated with an inability to make future plans. Adverse psychological outcomes tend to be more prevalent among female survivors compared to male survivors, and younger survivors (less than 50 years) compared to older survivors.<sup>12</sup>

Although many survivors find follow-up testing stressful, they also feel anxious about leaving the safety of the hospital system when they transition from the end of treatment to long-term follow-up.<sup>13</sup> When cancer does recur, it is often experienced as more traumatic than the first diagnosis and reinforces the importance of periodic screening for distress across the cancer trajectory, including the survivorship phase.<sup>14</sup> Anecdotally, some survivors report experiencing feelings of guilt because they survived and someone else they knew with cancer didn't, although this is not well documented in the scientific literature.

Despite the absence of evidence to support this notion, it is common for those who have experienced cancer to adopt a 'positive attitude' in the belief that this may contribute to longer survival. For some individuals, this strategy may confer a sense of control and optimism, while for others it represents a burden, especially if there is pressure, either overt or covert, to avoid discussing painful or confronting issues. Furthermore, the belief that one's force of will and attitude can influence the course of cancer poses a burden if cancer recurs, with the implication being that the individual "has not tried hard enough".

Research undertaken in Australia reveals that there are a number of issues specific to CALD communities that are an additional source of distress to CALD cancer survivors. In the Chinese, Greek and Arabic communities, cancer is perceived as incurable, sometimes connoting 'certain' and 'imminent' death, and a source of stigma for self and family that should be kept a private matter. In some parts of the Greek and Chinese communities, cancer is still viewed as contagious.<sup>15-17</sup> Survivors and their families from Arabic, Chinese and Greek backgrounds also report feelings of loss of power and control, and consequent

difficulties navigating the health system due to difficulties with both written and verbal language.<sup>18</sup>

## Physical

Fatigue is commonly experienced by survivors and can be profoundly debilitating: "At its worst, cancer-related fatigue is a draining, unrelenting exhaustion that impedes the ability to enjoy life and carry out daily activities".<sup>19</sup> Unlike other visible markers of cancer treatment such as hair loss, fatigue is not apparent to others, and survivors may be reluctant to discuss fatigue because they 'look well', or intuitively believe that rest will help. Given the evidence about the benefits of exercise in reducing fatigue in cancer survivors, exploration of fatigue and provision of information about strategies to deal with this should be part of routine clinical care.<sup>20</sup>

Although pain in advanced cancer is recognised as a management concern, there is emerging evidence that cancer survivors may experience chronic pain, and given its association with depression, is an area that merits closer attention.<sup>21</sup> Survivors' reluctance to report pain may be due to fear that the pain represents residual or recurrent cancer.

It is now recognised that cognitive changes occur in those who have been treated with chemotherapy,<sup>22</sup> although there is insufficient evidence about the precise mechanism of this, and risk factors for its development. The nature of the deficit is often subtle and not evident in casual social contact, but problems with new learning, organisation and ability to self-monitor and self-correct are commonly identified on neuropsychological testing, and can be disabling to the point of interfering with the ability to return to work. In Australia, research is being initiated to assess the effectiveness of computer-based programs designed to "retrain" affected individuals (Vardy J, personal communication).

There is an extensive literature describing the adverse impact of cancer treatment on body image and sexuality, and the former focus on breast cancer has expanded to include other cancers such as prostate cancer. Sexual difficulties are common and can impact upon other aspects of intimacy and relationship functioning. Sexual difficulties can be due to direct effects of treatment, such as gynaecological cancers treated with surgery and radiotherapy, and indirect effects such as chemotherapy-induced menopause, pain and fatigue. Effective treatments are available however, once established, problems tend to persist in the absence of active intervention.<sup>23</sup> An active approach to management is now promoted and interventions should take into account interpersonal and relationship issues, self-esteem and body image in addition to biological factors.<sup>24</sup>

The loss of fertility following treatment may represent a major setback and be associated with significant psychological distress and relationship difficulties.<sup>25</sup> The impact is obvious for a young woman or man, however for those who already have children the impact may not be apparent to extended family members or social contacts. Even women who have regarded their family as "complete" prior to the development of chemotherapy-

induced menopause may express grief and regret about the choice of future pregnancies being taken away from them.

## Social

Social relationships may change as a consequence of diagnosis; some may not provide anticipated support, others may decrease over time, while new relationships and sources of support may emerge.<sup>26</sup> Family members may rate the cancer experience as more stressful than patients,<sup>27</sup> highlighting the importance of attention to the adjustment of family members. Divergence in priorities and attitudes can result in tensions in relationships emerging, with the cancer survivor being expected to “move forward”. A strong attempt to “get back to normal” can represent the desire of family members and significant others to avoid contemplating the risk of recurrence or a less certain future.

Although most survivors function effectively in a work environment following the completion of cancer treatments, a minority may take a number of years to return to work, or will return to work in a diminished capacity. Studies indicate employment discrimination, difficulties with re-entry into the workforce, dismissal, demotion and lack of career advancement can be experienced by some cancer survivors.<sup>28,29</sup> Adverse socioeconomic and financial effects may be partly due to such difficulties in addition to out-of-pocket medical costs and difficulties borrowing from financial institutions. Access to insurance coverage for health care, sickness, disability, life and travel can also be problematic following a diagnosis of cancer.<sup>30</sup>

Some of these difficulties (eg. relationship changes) may be accentuated in CALD survivors because of the stigma and taboos surrounding cancer, and the associated reluctance to discuss this outside of the family.<sup>15,16</sup> Feelings of isolation may also be compounded by a sense of cultural isolation. Regardless of English ability, CALD survivors have described experiencing an additional level of comfort, support, and familiarity when treated by people from their own culture, and feelings of separation, isolation, and difficulty building relationships when this is absent.

## Existential

Most survivors report that life is never the same after a cancer diagnosis. Many re-evaluate and change their values, goals, priorities and outlook on life as a result of facing their own mortality.<sup>31</sup> Little et al described the process of ‘liminality’ commencing at the first experience of malignancy, whereby “each patient constructs and reconstructs meaning for their experience by means of a narrative. This phase persists, probably for the rest of the cancer patient’s life.”<sup>32</sup> Learning to adjust to a new ‘normal’ can be challenging and two recent studies conducted in Australia identified that many survivors struggle to cope with changes to their self-identity and expectations of themselves as a cancer survivors.<sup>10,13</sup> The obvious relief of survival may be tinged with sadness about the cost at which this has been achieved, for example limited functioning or inability to parent children.

Numerous positive outcomes and improvements in wellbeing have been reported in both the empirical and popular literature on cancer survivorship. Several studies have found that most survivors, including CALD survivors, perceive benefits from their cancer experience such as personal growth, enhanced appreciation for life, living fuller and more meaningful lives, closer relationships with others, existential gains, increased faith and positive lifestyle changes such as increased exercise and healthier diet.<sup>10,13,17,33,34</sup> There is some evidence suggesting that women and younger survivors are more likely to identify personal growth and other positive aspects of cancer, while men and older survivors are more likely to minimise its impact and perceive it as just a part of living.<sup>35</sup> Researchers advocate the inclusion of positive change items in outcome assessments to capture the breadth of individuals’ experiences and to identify opportunities for improving outcomes.<sup>36</sup>

## Future directions

A key perspective missing in our understanding of the issues faced by cancer survivors is longitudinal studies that follow survivors with repeated assessments to see how they fare over time. Further research exploring the specific needs of CALD survivors is also required. Recognition of the importance of this type of research has increased with the high profile report *From Cancer Patient to Cancer Survivor: Lost in Transition*,<sup>5</sup> recommending large-scale population-based studies conducted with the diversity of cancer survivors be undertaken as a matter of priority. Two studies addressing these priority areas are currently underway in Australia; the Cancer Survival Study undertaken by the Centre for Health Research and Psycho-oncology (CHeRP) is following 1455 survivors from six months to five years post-diagnosis, while the Psycho-Oncology Co-operative Research Group (PoCoG) is conducting a population based study which aims to recruit 1000 survivors from Arabic, Chinese, Greek and English speaking backgrounds from two years to five years post-diagnosis. Among other outcomes, both studies are assessing survivors’ anxiety, depression, perceived needs and quality of life. The PoCoG study will provide the first population based estimates of these outcomes in cancer survivors from CALD communities in Australia, while the CHeRP study will identify the duration, onset, frequency and severity of the positive and negative effects of cancer over the disease trajectory.

It is imperative that we are able to identify the difficulties experienced by cancer survivors and develop effective approaches to help survivors manage them. The results of these two landmark studies will make a substantial contribution to providing an evidence base upon which to develop culturally appropriate policies and practices to improve the health and wellbeing of cancer survivors in Australia.

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## CAREGIVERS OF CANCER SURVIVORS: THE STATE OF THE FIELD

**Afaf Girgis and Sylvie Lambert** ■ Centre for Health Research and Psycho-oncology, Cancer Council NSW; University of Newcastle and Hunter Medical Research Institute, NSW.  
Email: [Afaf.girgis@newcastle.edu.au](mailto:Afaf.girgis@newcastle.edu.au)

### Abstract

Increasingly, researchers and clinicians are recognising the reverberating impact of a cancer diagnosis on patients' families. Upon diagnosis, families often find themselves grappling with intense emotions and existential concerns at the same time as they are providing support to patients, taking on novel care giving roles and responsibilities and attempting to remain afloat with other competing life events. In the midst of this whirlwind, patients and their caregivers may be struggling to find optimal coping strategies and adjust to potential disruptions in routines and activities. Despite efforts to manage care giving demands, these may inadvertently exceed caregivers' capabilities and result in them feeling burdened and exhausted. This paper reviews current evidence on the impact of a cancer diagnosis on families/caregivers, with a particular focus on the survivorship stage as well as Australian research initiatives. In addition, intervention research designed to assist families/caregivers with the demands of their roles will be reviewed. Last, limitations hampering caregiver research and priorities for future research will be discussed.

Within the last five years, studies documenting the short and long-term impacts of a cancer diagnosis on families/caregivers are increasing exponentially. Three

main aspects of this literature will be reviewed, in turn: additional roles, responsibilities and skills required by caregivers; ensuring caregivers' needs for assistance and

support and; caregivers' quality of life, with a focus on burden and psychological distress.

### Caregivers roles and responsibilities: when is it too much?

Throughout the illness experience, families/caregivers provide valuable instrumental (eg. driving to medical appointments), informational (eg. searching treatment on the internet) and emotional support to patients with cancer.<sup>1,2,3</sup> Such reliance on them is only expected to continue to grow,<sup>4</sup> particularly as the course of cancer is changing from an acute to a chronic disease, and the setting for cancer care delivery is shifting from the hospital to the home.<sup>2,5,6</sup> Care giving can extend for several years and roles/tasks can involve a considerable number of hours per week, which for some is comparable to a full-time job.<sup>3</sup> According to patients' diagnosis and illness severity, care giving may require mastery of tasks typically performed by health care professionals, including symptom management, nutrition support, implementation of a treatment regimen, management of acute illness episodes and providing help with activities of daily living (eg. getting in and out of bed, feeding, getting dressed, bathing).<sup>3</sup>

In 2005, the Centre for Health Research and Psycho-oncology (CHeRP) embarked on a longitudinal study among a population-based sample (n=547) of partners and caregivers of cancer survivors with diverse cancer diagnoses to further examine the impact of care giving. This study aims to document physical, financial and psychosocial impacts of care giving six months, 12 months, two years, three and a half years and five years post-diagnosis. Early results suggest that, at six months post-diagnosis, participants identified being mostly involved in: household tasks (daily 68.5%); emotional support (daily 39.9%) and; managing money (daily 22.7%). Interestingly, providing emotional support, liaising with doctors, making appointments and assessing for and managing medication were more associated with caregiver anxiety than other tasks. Similarly, a study by Bakas et al among caregivers of patients with lung cancer also found that one of the most time consuming tasks was providing emotional support, in addition to transportation and monitoring symptoms.<sup>1</sup> Moreover, these caregivers identified emotional support, behavioural management, monitoring symptoms and household tasks as the most difficult duties. These findings highlight that caregivers' tasks go beyond personal care or activities of daily living. Attention needs to be given not only to the frequency with which tasks are performed, but also the nature of these tasks and their perceived level of difficulty.

Taking on a care giving role also means that caregivers must develop a set of sophisticated skills and aptitudes, including monitoring, interpreting, making decisions, taking action, making adjustments, accessing resources, providing hands-on care, working together with the ill person and becoming an expert at navigating the healthcare system.<sup>3</sup> Indisputably, care giving can become a daunting undertaking and involve many novelties for which caregivers, according to their previous knowledge and experience and physical and cognitive abilities,

may require additional resources to cope. Healthcare professionals need to be aware of caregivers' tasks and roles and assess the extent to which they are apt and comfortable with these to be able to offer timely and fitting assistance. For instance, as emotional support appears to be one aspect of care giving that is difficult and anxiety-provoking, it may be effective for health care professionals to design communication interventions to enhance emotional support strategies such as active listening, reassurance and validation.<sup>1</sup> In addition, as care giving responsibilities may negatively impact on carers' (and patients') illness experience, a better understanding of how caregivers acquire their skills and manage different tasks is a research avenue in need of more attention.<sup>5</sup>

### Caregiver needs: what kind of help do caregivers require?

Despite increased attention to documenting caregivers' needs, many of these reportedly remain unmet.<sup>7,8</sup> Several research groups in Australia are examining the short and long-term, unmet supportive care needs of families/caregivers. For instance, Hodgkinson et al<sup>9</sup> administered the Cancer Survivors' Partners Unmet Needs measure to partners (n=212) of a mixed group of cancer survivors (3.4 years on average post-cancer diagnosis and disease free for at least one year) and found that the top five unmet needs were: concerns about cancer recurrence; accessible hospital parking; reducing stress in the survivors' life; having an ongoing case manager and; up-to-date information.

In addition, in a study by Clavarino et al<sup>7</sup> participating caregivers (n=19), living in rural and remote Queensland, identified needing most help with fears related to the patient's physical deterioration and the cancer returning, uncertainty concerning the future, changes to usual routine and lifestyle, concerns about their financial situation and monetary allowances for travel. Most patients participating in this study were within the first year following diagnosis. Carers and patients differed on the rank ordering of their highest unmet needs. Patients' needs were concerns about the worries of those close to them, fears regarding the cancer returning or spreading, having a staff member with whom they can talk about all aspects of the illness and monetary allowances for travel.<sup>7</sup>

The Supportive Care Needs Survey – Partners and Caregivers (SCNS-P&C) was developed jointly by CHeRP and the Centre for Medical Psychology and Evidence-Based Decision Making, to facilitate identification of partners' and caregivers' unmet supportive care needs across the illness trajectory (available online at <http://www.newcastle.edu.au/research-centre/cherp/professional-resources/>). Administration of the SCNS-P&C to partners and caregivers participating in CHeRP's longitudinal study (n=481) revealed the following as the highest unmet moderate or high needs: reducing stress for the patient; concerns about recurrence; understanding the patient experience; accessible hospital parking and; information on treatment for decision-making.<sup>10</sup> Janda et al also administered the SCNS-P&C to 70 caregivers of patients with a brain tumour, recruited through the Queensland

Cancer Fund\* Brain Tumour Support Service, and found some overlap in unmet needs (moderate or high): addressing fears related to the patient's deterioration; impact of caring on working life; reducing stress in the life of the person with cancer; decision making in uncertainty, and; balancing caregiver and patient needs.<sup>8</sup>

Further research is required to document the needs of partners/caregivers, particularly regarding how these may vary as caregivers transition from the acute to the survivorship phase of the illness and determining the most optimal strategies to address these.

### Care giving outcomes

Throughout the past decade there has been a growing body of evidence documenting the negative physical, financial and psychosocial outcomes associated with care giving.<sup>11-17</sup> In a study by Kim and Schulz,<sup>3</sup> 67.3% of caregivers (n=99) reported a moderate to high level of burden. In the same study, cancer caregivers had higher levels of financial hardship, physical strain and emotional stress than caregivers of individuals with diabetes and frail elderly caregivers. Nonetheless, burden levels reported by cancer caregivers were comparable to those caring for an individual with dementia,<sup>3</sup> or AIDS,<sup>18</sup> two other highly stress-inducing and challenging illnesses for caregivers.

In addition to higher burden, care giving has been associated with poorer quality of life.<sup>9</sup> In comparison to population norms, Janda et al reported lower quality of life, as measured by the Functional Assessment of Cancer Therapy-General, among caregivers of brain tumour survivors (n=70) recruited from the brain tumour support service offered by Cancer Council Queensland.<sup>8</sup> Most studies examining the quality of life of caregivers have focused on their levels of anxiety and depression.<sup>19</sup> Typically, higher levels of anxiety are reported in comparison to depression,<sup>20</sup> with recent studies reporting anxiety levels ranging from 16% to 47% and depression levels ranging from 9.7% to 30% among caregivers of people with cancer.<sup>20,21,22</sup> These rates are slightly to moderately higher than the prevalence of anxiety disorders (14.4%) and depressive episodes (4.1%) reported in the general Australian population.<sup>23</sup> Borderline or clinical levels of anxiety and depression appear to be more prevalent post-diagnosis or in the acute phase of the illness, however a certain percentage of caregivers continues to experience significant levels of anxiety and depression well into the medium and long-term survivorship stage of the illness.<sup>19,21,24</sup>

In CHERP's longitudinal study, at six months post-diagnosis, 40% and 11% of partners/caregivers report anxiety or depression, respectively, with 15% reporting both anxiety and depression. Importantly, at one-year post-diagnosis, 30% of caregivers were still borderline/clinically anxious. Although some studies suggest that caregivers and patients have comparable levels of general quality of life and distress,<sup>21,25,26</sup> others actually report lower quality of life<sup>6</sup> and greater distress among caregivers (reaching clinical levels).<sup>27,28,19</sup>

\* Now called Cancer Council Queensland.

### Variables influencing caregiver outcomes

The literature identifies myriad variables associated with or predictive of, psychosocial outcomes among cancer caregivers, including short and less satisfactory relationships with the patient,<sup>29</sup> having concerns apropos the patient's well-being<sup>29</sup> or job-related concerns,<sup>29</sup> being uncertain about the future,<sup>29</sup> high level of unmet needs,<sup>30</sup> feeling of burden,<sup>27,3,28</sup> avoidance attachment orientation,<sup>28</sup> using avoidant coping strategies,<sup>31</sup> and lower family and social support.<sup>6,32</sup>

In addition, demographic and/or treatment/disease related variables increasing caregiver risk for distress include: lower education,<sup>3,29</sup> lower income,<sup>6</sup> being female,<sup>2,3,6</sup> being unmarried,<sup>6</sup> younger age,<sup>6,31</sup> shorter-term marriages,<sup>29</sup> less well-adjusted marriages,<sup>28,29</sup> patients with greater functional impairment,<sup>27</sup> and greater illness severity.<sup>33-35</sup>

Interestingly, several studies have found that cancer survivors' and caregivers' quality of life (or lack thereof) interact and have a mutual influence, positive or negative.<sup>6,36</sup> A recent meta-analysis examining the relationship between the psychological distress of cancer patients and their caregivers further supported the positive association between patients' and caregivers' psychological distress ( $r=.35$ ,  $p<.00001$ ).<sup>37</sup> Furthermore, it appears that this relationship is directional and that partner anxiety seems to be more influential on patient anxiety, than patient anxiety on their partner's well-being. Overall, these findings emphasise the reciprocal influence of cancer caregivers' health on patients (and vice-versa) and argue for holistic interventions targeting couples or families.

Although most research identifies variables associated with a 'negative' care giving experience, recently studies have focused on predicting 'positive' change in caregivers' life philosophy, relationships and personal growth, which has also been coined as post-traumatic growth (PTG) or benefit finding. Thornton & Perez found that PTG among 67 wives of prostate cancer survivors was predicted by less education, being with a partner who was employed, higher avoidance symptoms of stress at pre-surgery and preferring positive reframing coping.<sup>38</sup> Noteworthy, both patients and caregivers were found to have comparable levels of PTG, further emphasising the distress associated with a loved one's cancer diagnosis.<sup>38</sup> In addition, Kim et al reported that caregivers of a mixed group of cancer survivors (n=779) were more likely to report benefit finding if they were less educated, engaged in religious coping and perceived the availability of social support.<sup>39</sup> Lower education has also been related to higher levels of distress, which might explain its relationship with PTG or benefit findings.<sup>38</sup> Findings on whether PTG or benefit finding positively influence psychosocial adjustment are equivocal and additional studies are warranted to further elucidate this relationship.

### Supportive care intervention research

While psychosocial interventions have been shown to improve quality of life among cancer survivors,<sup>40</sup> few studies have examined the potential of psychosocial interventions to ease burden and optimise adjustment outcomes among caregivers. Few Australian research groups have

initiated intervention research among caregivers in the acute illness phase,<sup>41</sup> and no published studies have been found for caregivers of cancer survivors. However, a tiered model of psychosocial care, developed by Queensland researchers to guide the design and implementation of supportive care services among patients with cancer and their caregivers, may provide some guidance in prioritising scarce resources according to patient and caregiver needs.<sup>42</sup>

Internationally, few intervention studies have been undertaken with caregivers of cancer survivors. For instance, Canada et al implemented a sexual rehabilitation intervention among prostate cancer survivors and their caregivers (n=51), which led to an increase in sexual function for both patients and their caregivers three months post-intervention.<sup>43</sup> However, overall, intervention studies among caregivers of cancer survivors are scarce. Future research is needed to determine which aspects of the care giving experience warrant psychosocial intervention and might most contribute to enhancing the caregiver and patient cancer experience. The literature reviewed suggests that intervention research should ideally target both patients and caregivers and focus on such aspects of care as information sharing, communication among patients and caregivers and the treatment team, emotional support strategies, promotion of patient and caregiver empowerment and self-identification of needs, continuity and planning of care, and peer support.

### Limitations of current studies

Although much attention has been directed at understanding the impact of a cancer diagnosis on partners/caregivers, these studies are typically cross-sectional, many include partners/caregivers of women with breast cancer or men with prostate cancer, and have a limited sample size (less than 100). Consequently, studies often report correlational analyses and little can be concluded regarding predictors of the care giving experience.

### Future research priorities

Recently, Breast Cancer Network Australia published a summary report of the National Survivorship Think Tank meeting.<sup>44</sup> Among the different research priority areas discussed, appropriate measures of carer distress, considering the needs of families and caregivers, and implementing interventions to help families manage the impact of the cancer diagnosis were identified and echo the salient issues reviewed in this paper. Determining the extent to which providing care to cancer survivors contributes to burden, the unique challenges of being a caregiver in the survivorship stage and the way in which these can be addressed, are undoubtedly key research areas if we are to develop appropriate supportive services, optimise the care giving experience and maintain partners'/caregivers' ability to support patients throughout the illness trajectory.<sup>3</sup> These empirical foundations are required to provide the basis upon which to design robust intervention studies. Particularly, research examining the interaction between the quality of life of cancer survivors and their families/caregivers during the long-term survivor

phase and the factors predictive of both survivors' and family caregivers' quality of life, seems to be a promising avenue for research.<sup>6,45</sup> In addition, findings from the aforementioned studies indicate that caregivers may require guidance in fulfilling some roles, however few studies have examined how care giving skills are acquired and developed over time among partners/caregivers of individuals with cancer.<sup>5</sup> Finally, future research examining reasons and factors contributing to whether families/caregivers have a positive (eg. benefit finding) or negative experience, may contribute to better understanding caregivers' ability to care for patients, which in turn may impact on their quality of life.

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## WHAT CONSTITUTES IDEAL SURVIVORSHIP CARE?

**Kerryann Lotfi-Jam,<sup>1,2</sup> Penelope Schofield<sup>1,2</sup> and Michael Jefford<sup>1,2,3</sup>**

1. Peter MacCallum Cancer Centre, Victoria.

2. Faculty of Medicine, Dentistry and Health Sciences, University of Melbourne, Victoria.

3. Cancer Council Victoria.

Email: [Kerryann.Lotfi-Jam@petermac.org](mailto:Kerryann.Lotfi-Jam@petermac.org)

### Abstract

There is increasing recognition that cancer survivors require continued care, beyond diagnosis and treatment. They are at increased risk of second and recurrent cancers, treatment related side-effects, other co-morbid health conditions, as well as psychological and social difficulties. However, current care is suboptimal and does not adequately meet the needs of this vulnerable population. In this paper, the principles of optimal survivorship care are discussed, including: prevention and detection of new cancers and recurrent cancer; surveillance for cancer spread, recurrence or second cancers; interventions for consequences of cancer and its treatment and; coordination between specialists and primary care providers. Barriers to achieving optimal care are discussed and recommendations made for improving survivorship care.

### Importance of continued care for cancer survivors

The number of people completing curative cancer treatment is increasing, with over 60% of cancer patients in Australia surviving more than five years.<sup>1</sup> This has led to the recognition of cancer survivorship as a distinct phase in the cancer trajectory.<sup>2</sup> Despite the expectation that survivors will 'return to their normal lives', the transition into the survivorship phase can be difficult due to the physical, psychological and

social consequences of cancer and its treatment.<sup>3</sup> Cancer survivors report issues managing long-term side-effects and late effects, fears of recurrence, uncertainty about the future, difficulties returning to work/social situations, financial problems and feelings of abandonment by the treatment team.<sup>3</sup> Furthermore, survivors are at an increased risk of second or recurrent cancers, as well as co-morbidities that affect older populations, such as heart disease and arthritis.<sup>4</sup> Continued care, beyond the acute treatment phase, is essential to ensure that these

issues are appropriately managed and to improve survivor outcomes.<sup>5</sup>

### Current survivorship care

Despite the complex issues around treatment completion, survivorship care is suboptimal. Follow-up care may be fragmented between oncology specialists (surgeon, medical and radiation oncologists) and general practitioners. There can be considerable duplication of effort, or alternatively, major gaps in follow-up resulting from poorly coordinated care. Follow-up generally tends to focus on surveillance for cancer recurrence, metastases or new primary cancers, with little attention given to physical and psychosocial late effects. Health promotional advice and psychosocial strategies to improve wellbeing are rarely discussed, and when they are, this is usually ad hoc, inconsistent and lacking a sound evidence base.<sup>2</sup>

Patients commonly report a lack of necessary information and ongoing support.<sup>6</sup> Hewitt examined perspectives on post-treatment cancer care with survivors, nurses and physicians.<sup>7</sup> Most survivors reported that they were satisfied with current medical care, but felt their psychosocial needs were not met. In addition, they reported being overwhelmed at the end of treatment, but were rarely given any written information.<sup>7</sup> This has been identified as a significant problem, nationally and internationally, with few resources available for patients in this phase.<sup>2</sup> This is currently being remedied in Australia, with the development of several key resources, including a DVD and information booklet for people completing treatment.<sup>8</sup> Further consideration of the content and delivery of survivorship care is critically needed.

### Principles of ideal survivorship care

The push for improved services for cancer survivors has gained considerable momentum over the past 10 years. In 1996, the National Coalition for Cancer Survivorship established 12 principles for delivering quality cancer care.<sup>9</sup> In 2001, the US Institute of Medicine (IOM) also released a report *Crossing the Quality Chasm*,<sup>10</sup> which recommended several factors for the delivery of quality care. Together with the growing body of survivorship work, there is now broad consensus that ideal survivorship care should be:

- comprehensive, high quality health care that is accessible to all cancer survivors, including specialised survivor services
- patient-centred and tailored to meet individual needs, whilst empowering survivors to take an active role in their own health management, to the extent that they desire
- multidisciplinary and collaborative, involving a range of oncologists, primary care providers, nursing and allied health staff, as well survivors and their families
- continuing medical care that is focused on the transition from the acute setting to the community, using effective communication strategies to promote planned and coordinated follow-up
- holistic care which addresses psychological and social needs in addition to physical issues; attention should also be given to preventive, rather than solely reactive management strategies
- evidence-based and supported by appropriate guidelines, policies and research, ensuring that service delivery is outcomes focused, cost-effective and sustainable.

In 2006, the IOM released a pivotal report, *From Cancer Patient to Cancer Survivor: Lost in Transition*,<sup>2</sup> advocating for planned and coordinated care to manage the medical and psychosocial difficulties experienced by cancer survivors after completing treatment. The report attempted to further describe and 'operationalise' the content of what survivorship care should involve. Four key components were identified.

#### Prevention of new cancers and recurrent cancer

Although survivors remain at a heightened risk of developing new cancers, many risk factors are modifiable.<sup>5</sup> There is growing evidence to support many adjuvant medical treatments (not reviewed here) to reduce the likelihood of secondary cancers.<sup>2</sup> In addition, the period after treatment can be seen as a teachable moment, where changes to health and lifestyle may be more readily adopted in an attempt to prevent disease and ill health.<sup>2</sup> Improved diet, maintaining a healthy weight, ceasing smoking and increasing physical activity may prevent secondary and recurrent cancers, and may also reduce many of the physical and psychosocial consequences of cancer treatment.<sup>11</sup> Information on recommended health and lifestyle strategies should be provided to all cancer survivors.<sup>2,11</sup>

#### Surveillance for cancer spread, recurrence or second cancers

Ongoing surveillance is an essential component of follow-up care to ensure that new or recurrent cancers are detected at a time when treatment may be most effective.<sup>12</sup> Guidelines are not available for all cancer types and vary considerably in terms of their comprehensiveness. Many emphasise detection of cancer recurrence, but place little emphasis on the prevention, detection and amelioration of the consequences of cancer treatments. Many of these guidelines provide inconsistent recommendations about the frequency, duration and type of follow-up that is required for different survivor groups.<sup>12</sup>

Nevertheless, surveillance is an ideal opportunity to monitor treatment efficacy and any physical or psychosocial consequences and also to provide continuing information and support. Surveillance may also help survivors to feel less anxious about the possibility of cancer returning and more confident about what will happen to them in the future. Surveillance should be tailored, with high-risk individuals requiring a higher degree of surveillance.<sup>12</sup> Surveillance also provides an added opportunity to screen general health issues, as many patients neglect other areas of health due to a heavy focus on cancer and recurrence.<sup>13</sup>

### **Interventions for consequences of cancer and its treatment**

Cancer survivors may require further assistance managing the physical and psychosocial effects of cancer diagnosis and treatment. Patients may have persisting, even long-term effects and also be at risk of developing problems at a later time, referred to as 'late effects'.<sup>4</sup> Patients frequently report ongoing physical issues with fatigue, pain, urinary/bowel issues and hot flushes,<sup>3</sup> many of which can often be managed with medical interventions or self-care strategies. It is unknown to what extent advice regarding these strategies is provided. Furthermore, it has been suggested that a full review of psychosocial and adjustment issues should be incorporated into an optimal model of survivorship care.<sup>4</sup> A growing number of psychosocial interventions may improve symptom management and psychological issues as they arise, and should be discussed as part of a tailored survivor consultation.<sup>14</sup>

### **Coordination between specialists and primary care providers**

Follow-up care is often provided by a group of oncology specialists and primary care providers. This system has a number of strengths, if used effectively. Cancer screening services are received more reliably when specialists are involved, however preventive services for other medical illnesses tend to be neglected.<sup>4</sup> This may be greatly improved when a primary care provider is also involved.<sup>4</sup> Coordinated care between oncologists and primary care providers is essential for ensuring that all health needs are met.<sup>2</sup> Regular, effective communication strategies are crucial to the success of such an arrangement. Care plans may assist in this matter and are discussed below. Clear delineation of roles is essential. Comprehensive care means that each of the above principles (detection, surveillance and intervention) should be undertaken, however it is less clear how to optimally allocate these responsibilities in a shared care model.

### **Barriers to optimal care**

While survivors may receive follow-up care that achieves some of these components, such as adequate surveillance for cancer recurrence, there are several reasons why survivorship care may be less than comprehensive.

Firstly, there are currently insufficient means for identifying and addressing many of the diverse issues which are crucial for cancer survivors. Review appointments are often very brief such that it may not be possible to adequately address the broad range of survivorship issues, particularly in the setting of busy clinics. This problem is compounded by the lack of sound assessment tools available to clinicians that can be administered in such an environment.

Secondly, it is often unclear to both patients and health professionals exactly who is responsible for follow-up and how it should be provided. Although both oncologists and primary care providers are usually involved, the system is fragmented and it is often unclear who is accountable for each of the components of care, resulting in unmet needs

for cancer survivors or being lost to follow-up.<sup>2</sup> Even when these roles are delineated, primary care providers may not have adequate training in survivorship issues, and are generally unable to rely on communication and advice from specialists.<sup>2</sup>

Thirdly, although attempts are being made (eg. American Society of Clinical Oncology guidelines),<sup>15</sup> there is a lack of evidence to guide the frequency and content of review appointments. Existing guidelines are generally limited to detecting recurrence and second cancers and are not always readily available to clinicians. Furthermore, there is a lack of evidence for recommending self-care strategies to manage treatment side-effects.<sup>16</sup> Intervention research to date has focused almost solely on limited health promotional strategies, particularly exercise programs and the reduction of physical side-effects.<sup>11,17</sup> Further evidence-based support for psychosocial treatments would greatly improve their recommendation and uptake. The IOM report also recommended the development and testing of strategies to improve both physical and psychosocial outcomes.<sup>2</sup>

### **Recommended strategies to promote ideal survivorship care**

There is much work to be done to improve survivorship care. The IOM report made several recommendations, most of which are directly adaptable in an Australian setting. Several priority areas and strategies have been identified to implement the above principles.

#### **Clinical guidelines for follow-up**

It is clear that there is a need for long-term continuous follow-up for cancer survivors. The IOM report suggested that progress had been limited in terms of evidence-based guidance for providers of survivorship care and recommended the development of "evidence-based clinical practice guidelines, assessment tools and screening instruments to help identify and manage late effects of cancer and its treatment."<sup>2</sup> Such guidelines would include ongoing, repeat assessments and would assist clinicians with the management of the complex range of survivor issues, ensuring that any changes to health, cancer or non cancer, are detected at a time when treatment or intervention is most likely to be effective.<sup>12</sup>

#### **Screening and management of psychosocial issues**

In addition to routine physical screening, there is a need to screen all cancer survivors for distress and unmet needs, and to identify mechanisms for matching these needs to interventions and other treatments. Tailoring interventions to the level of distress experienced may further improve psychosocial outcomes and efficient use of health resources.<sup>18</sup> Work, finances and other social difficulties should be discussed, and referral pathways developed, to assist survivors to manage these issues.

#### **Education and training**

There is a need to incorporate survivorship issues into the training of all health professionals, and to upskill the current workforce. Educational opportunities should be provided to better equip health professionals to address

the physical and psychosocial issues pertinent to cancer survivorship.<sup>2</sup> Awareness of the medical and psychosocial needs that may follow cancer treatment will ensure that appropriate assessments are completed and available interventions employed. In combination with a system of increased accountability for follow-up, this strategy may enhance clinician confidence to identify and manage survivor issues directly, rather than allow patients to be lost in a system of referrals.

### Survivorship care plans

Central to overcoming the communication barriers in survivorship care, the IOM report recommended that all patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan, written by those who coordinate oncology treatment.<sup>2</sup> Such a medical summary would include all diagnosis and treatment information, as well as details regarding any toxicities and complications experienced.<sup>4</sup> The care plan should also include recommendations regarding frequency and duration of follow-up, as well as a schedule for appointments, particularly if a shared care model is applied. It would also include information on strategies to deal with current consequences of cancer and its treatments, strategies to remain well and a list of available support services. The care plan is intended for the cancer survivor as well as their GP and all other specialists. A structured care plan has the potential to significantly improve communication between specialists and primary care providers, who often must rely on patient recollection and understanding of their care. There is widespread support for tailored care plans from survivors, nurses and physicians, although further investigation is required regarding their preparation and implementation.<sup>7,19</sup>

### Conclusion

Cancer survivors require ongoing follow-up care that focuses on prevention and detection of new cancers and recurrent cancer, surveillance for cancer spread, recurrence or second cancers, interventions for consequences of cancer and its treatment and coordination between specialists and primary care providers. The delivery of survivorship care is currently inconsistent and fragmented, with many survivors reporting unmet needs and being lost to follow-up. Survivorship care needs to be patient-centred, flexible, tailored to individual needs, cost-efficient and sustainable. Currently, there are several barriers to achieving this, including poor communication, unstructured follow-up schedules, lack of clarity around roles and responsibilities, and a deficit in evidence-based strategies to address the range of issues faced by survivors. Further development of new initiatives such as care plans, screening tools, education and training programs, and the

development of evidence-based guidelines are crucial to improving the care that can be provided to this vulnerable population.

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# NURSE-LED SURVIVORSHIP CARE

**Priscilla Gates<sup>1</sup> and Meinir Krishnasamy<sup>2</sup>**

1. Nurse Consultant – Late Effects, Peter MacCallum Cancer Centre, Victoria.

2. Department of Nursing and Supportive Care Research, Peter MacCallum Cancer Centre, Victoria.

Email: meinir.krishnasamy@petermac.org

## Abstract

The goal of post treatment survivorship care is primarily to promote the health of an individual. This goal has clear resonance with theories and practice of nursing, where the essence of specialised nursing knowledge is directed towards helping individuals regain health, at a time when they are unable to, or lack an appreciation of the importance of doing so. With impressive improvements in survival rates, survivors of Hodgkin's Lymphoma constitute a large cohort of survivors who are at risk of developing long-term and late effects related to treatment. Late effects include secondary malignancies, cardiac dysfunction, endocrine dysfunction, infertility, functional decline and psychosocial morbidity. Many late effects are avoidable or amenable to amelioration by early detection or risk modification. This paper describes the development of an innovative model of nurse-led care, delivered within the context of a multi-disciplinary, haematology, late effects clinic.

The provision of follow-up care to cancer survivors is an essential component of excellent cancer care.<sup>1</sup> Essential features of high quality models of survivorship care include comprehensiveness, a coordinated approach and individualised care provision.<sup>1</sup> Models differ based on the needs or risk-determinants of specific cancer patients, however their intent is the same – the delivery of multi-disciplinary follow-up care to optimise survivor wellbeing and improve treatment outcomes.

As role boundaries between health professionals become increasingly blurred in response to a changing and diminishing workforce, an increase in numbers of cancer patients and survivors,<sup>2</sup> and a desire to deliver patient centred care,<sup>3</sup> new models of care delivery are becoming increasingly prevalent. However, the potential contribution of any new model of care must be considered according to its capacity to optimise patient outcomes during treatment and survivorship. For patients with cancer, life beyond treatment is affected by physical, psychological, social and spiritual needs.<sup>4,5</sup> Fatigue, sterility, loss of sexual function,<sup>2</sup> anxiety, uncertainty, social isolation,<sup>6,7</sup> financial hardship and search for meaning in life,<sup>6,8</sup> can all impact survivorship. This plethora of needs indicates the importance of providing effective survivorship care across a range of domains and reinforces the importance of multidisciplinary care provision. Furthermore, this complexity of need highlights the difficulty of designing and implementing models of follow-up that are both responsive to the needs of cancer survivors, but are also feasible and achievable in practice. Nurse-led services have been proposed as one means to help address some of these challenges.<sup>3,9</sup>

## Nurse-led services

Nurse-led services are characterised by the delivery of evidence based, patient-centred care, focused on patient-centred outcomes and delivered by advanced practice nurses.<sup>10</sup> Patient centred care is defined as the provision of information by a health care provider in a manner that:

educates patients; is inclusive of family and friends; meets a person's emotional and physical needs; is respectful of individuals' preferences; and is delivered in a coordinated and cohesive manner.<sup>11</sup> These characteristics have strong resonance with recommendations for survivorship care articulated in the Institute of Medicine's report, *From Cancer Patient to Survivor: Lost in Transition*.<sup>9</sup> They also resonate with an evolving paradigm of cancer survivorship in which the traditional focus on disease orientation and physical dysfunction is replaced by a multi-disciplinary, rehabilitative approach to the promotion of healthy living.<sup>5</sup> Patient centred outcomes include health related quality of life, functional status, emotional wellbeing, optimism and motivation to engage in health promoting activities.<sup>12</sup>

## Nurse-led clinics

One of the ways in which nursing is attempting to respond to the drive for new models of care is through the development of nurse-led clinics. Current treatment review appointments are generally a very brief focus on the detection of cancer recurrence and physical side-effects, but do not adequately deal with patients' needs, nor do they realise the opportunity for health promotion.<sup>13</sup> To date there have been no robust, empirical studies that report the potential of nurse-led, cancer survivorship clinics to enhance long-term survivor outcomes. There is however, a steady growth in literature that claims a positive impact from nurse-led, follow-up care on patient outcomes in the period immediately after treatment completion. Studies published over the past decade indicate that nurse-led follow-up results in:

- a greater number of referrals and liaison with other support services than traditional models of follow-up<sup>14,15</sup>
- increased satisfaction with provision of follow-up, including organisation of care, information and advice, reassurance and overall rating of support<sup>16,17,18</sup>

- greater capacity to respond to individual need through more flexible models of follow-up, for example, by telephone or patient driven needs initiated follow-up<sup>19</sup>
- capacity to maximise opportunities for behavioural change through targeting interventions to a “teachable moment”<sup>20</sup>
- provision of individualised, tailored self-care information, linked to a reduction in patient-reported physical problems.<sup>16</sup>

Crucially, nurse-led clinics have been shown to be safe, with no difference found between nurse-led and medical follow-up of patients with early stage breast cancer in terms of disease outcomes, such as overall survival or time to detection of recurrence.<sup>3,14,19</sup> In a randomised, equivalence trial of study to compare hospital versus nurse-led telephone follow-up for women with breast cancer (n=374), telephone follow-up was well received by women in the intervention arm, with no physical or psychological disadvantage.<sup>19</sup> Similarly, no statistically significant difference was reported for time to symptom detection in a sample of 400 men with prostate cancer randomised to hospital nurse-led follow-up (n=200) versus conventional follow-up (n=200),<sup>21</sup> and in a randomised control trial to compare hospital nurse-led follow-up (n=99) versus conventional follow-up (n=103) for patients with non-small cell lung cancer.<sup>17</sup> However, results from a recent systematic review of nurse-led versus conventional physician follow-up for patients with cancer concluded that the current evidence available was characterised by methodological limitations, including inadequate randomisation processes, lack of blinding, poorly reported statistical tests and underpowered studies.<sup>22</sup> Further research is needed to demonstrate benefits in terms of survival, patient wellbeing and cost-effectiveness.<sup>22</sup>

## Quality nurse-led care

A review of theoretical and descriptive papers on the evolution of nurse-led services,<sup>3,22,23</sup> led to the identification of five essential characteristics of quality, nurse-led follow-up care.

### 1. Nursing expertise

Care planned and led by specialists with cancer site/disease specific expertise.

### 2. Nurse-led care coupled to a robust evaluation framework

Care that is focused on achieving specific results. There are clearly articulated, measurable outcomes.

### 3. Driven by a theoretical framework

The nature and choice of interventions offered, their dose, frequency, intensity, duration and proposed outcomes should be based on sound theoretical propositions.

### 4. Multidisciplinary collaboration

Patient eligibility criteria for the nurse-led clinic, care pathways and protocols for the clinic should be based on an agreed, service-wide model of care delivery.

## 5. Evidence-based care

The nurse-led clinic should function according to evidence based protocols/best available evidence and practice driven by best practice guidelines.

Below, we describe how these characteristics have been applied to the development of nurse-led care for patients who have completed treatment for Hodgkin's lymphoma at the Peter MacCallum Cancer Centre in Melbourne, Victoria.

## Haematology late effects and nurse-led survivorship care

Long-term survivors of childhood, adolescent and adult Hodgkin's Lymphoma (HL) are an expanding patient group who encounter a wide range of survivorship issues. With advances in multimodality therapy, survival rates from HL now exceed 90%.<sup>24</sup> However, among patients who do not survive, approximately half die as a direct result of HL, 20% from new cancers and 14% from cardiovascular complications.<sup>25</sup> In addition to physical effects, evidence from a qualitative survey of 1024 cancer survivors of mixed diagnoses, indicated that the transition from treatment to long-term survivorship is marked by significant emotional and psychosocial concerns.<sup>26</sup> One hundred and twenty two respondents (12%) were diagnosed up to one year, 42% between two to five years and 45% over five years. Almost half, (49%), reported emotional concerns, 60% relationship problems and a third (338) having trouble coping with emotional concerns. Over half of the study sample, (53%) reported their emotional needs harder to cope with than their physical needs.<sup>26</sup>

Data from a recent study of 1040 cancer survivors, two to five years after completing treatment, (39% of whom were survivors of haematological malignancies), demonstrated a lack of awareness of heightened health risks following treatment completion and inadequate information provision to enable people to manage future health needs.<sup>8</sup> Information needs were prevalent among the total study sample, with unmet information needs reported in relation to: follow-up care and surveillance (71%); health promotion (68%); late effects of treatment (63%); psychosocial issues (54%) and sexual function and fertility (31%). Similar findings were reported from a study of 266 cancer survivors regarding their knowledge of increased vulnerability to health problems following treatment completion.<sup>27</sup> The authors concluded that the knowledge deficits identified limited survivor awareness of their health risks and the importance of adopting healthy lifestyle behaviours. As the numbers of HL survivors grow, it is imperative that they are able to adopt healthy behaviours in order to maximise quality of life and longevity.<sup>4</sup> Nurse-led care has the capacity to improve survivors' outcomes by recognising and dealing with psychosocial distress, ensuring survivors have adequate information and support and by promoting sustained behavioural change.<sup>20</sup>

## Nurse-led care in the context of a multidisciplinary, haematology late effects clinic

The Late Effects Clinic at Peter MacCallum Cancer Centre was established in 2000 and is one of three known late effects units for adult survivors in Australia. Referrals come from all over Australia and include hospitals, advocacy groups, primary care physicians and survivors who may self-refer. Patients are accepted into the unit five years after completion of treatment. Despite an acknowledgement that survivors experience unmet informational and emotional needs during early stages of survivorship (for example, from time of diagnosis or during treatment),<sup>28</sup> the clinic was developed to address the needs of the growing population of longer term survivors, who experience increased risk from and impact of late effects at a time when the frequency and intensity of follow-up decreases.<sup>5,29,30</sup> Currently, there are 396 patients on the late effects unit database, of whom 36% are survivors of haematological malignancies. The team includes a haematologist, transplant physician, radiation oncologists, fellow and registrar, cardiologist, endocrinologist, primary care liaison officer, psychologist and a specialised late effects social worker. In 2008, a late effects nurse consultant was appointed to the team to work specifically with survivors of haematological malignancies. The position was motivated by recognition of the considerable health deficits experienced by survivors of haematological malignancies.

Prior to each late effects clinic, all patients scheduled to attend are considered in detail by the multidisciplinary team in order to consider anticipated health risks, review relevant past disease and treatment issues and relevant or potential areas of risk. Any screening investigations required are identified in advance of the clinic appointment. This preparatory work is undertaken to maximise efficiency of the review appointment for the individual and multidisciplinary team. The model of care in the late effects clinic is strongly patient orientated, with outcomes directed at sustained or enhanced wellbeing of each attendee. All relevant practitioners meet with the patient on the same day. Patients remain in one location throughout the visits and are not required to move from room to room for consultations with the relevant practitioners.<sup>31</sup>

## A model of nurse-led, late effects consultations

Referral for nurse-led consultation is a core element of the late effects model of care at Peter MacCallum Cancer Centre, based on evidence that nurse-led consultations may improve survivor outcomes. Nurse-led consultations aim to address patient needs through systematic assessment of supportive needs and identification of dominant patient concerns in order to deliver individualised, comprehensive, education packages to promote a healthy lifestyle.<sup>32</sup> The structure of the nurse-led service is based on quality components of nurse-led care as defined above. Care is planned and delivered by an expert haematology nurse with 13 years experience in the specialty. All consultation interactions, interventions and patient outcomes are

recorded in a dedicated database to assess the impact of the late effects nurse consultant contribution to survivor outcomes. The choice of interventions offered are targeted at relevant, patient centred concerns and are amenable to nursing intervention (ie. there is adequate indication of the capacity of the intervention to improve patient reported outcomes). Patient eligibility criteria for nurse-led consultation, evidence based care pathways and protocols for the clinic have been developed in consultation with the multidisciplinary, late effects team.

Since the incidence of emotional distress is significant in cancer survivors,<sup>5</sup> screening for emotional distress is undertaken at every consultation, with timely referral for specialist support as needed. The late effects nurse consultant has undergone training in eliciting and responding to emotional cues and uses a locally developed supportive care needs screening tool in all her consultations.

The nursing consultation focuses on six key domains, informed by best available evidence, to indicate prominent health related needs for cancer survivors: physical activity; healthy eating; smoking status; alcohol consumption; self examination; and sun protection.<sup>3,33,34,35</sup> The information is presented to each individual within the context of an education package directed specifically at their concerns, problems or health risks. Concerns or risks are identified during completion of the screening tool and through data provided by patient self-report measures completed by each individual prior to attending the consultation. Measures include the General Health Index,<sup>35</sup> a 22 item self-report instrument that assesses perceptions of personal health and the Health Promoting Lifestyle Profile 11,<sup>36</sup> a 56 item self-report tool to assess frequency of engagement in health promoting activities. The purpose of the education package is to inform survivors about the importance of healthy lifestyle behaviors in a manner that motivates and promotes sustainable, behavioural change.<sup>37</sup> In response to evidence indicating lack of awareness of where to find additional supportive information, each individual is given details of recommended websites to access information when at home.<sup>38</sup>

As gender, age, primary diagnosis and treatment history all impact the nature of late effects experienced and risks associated with them, the ability to undertake screening and assessment is essential to the success of the nursing consultation.<sup>37</sup> Education provision is tailored to each person's social context, personal beliefs and health requirements. The interventions form part of a cohesive, multidisciplinary survivorship care package.<sup>9</sup>

Survivorship care plans are recognised as an important element of comprehensive survivorship care and as a means of raising survivors' awareness of the importance of surveillance, healthy living and a coordinated plan of follow-up care.<sup>1,5</sup> In response to evidence that indicates that as few as 30% of survivors know they are at risk of developing late effects and that as many as 15% of cancer survivors choose not to attend long-term follow-up clinics,<sup>33</sup> each survivor attending for nurse-led consultation receives an individualised care plan. This includes details of medical history, treatments received,

potential for late effects, requirements for follow-up appointments, tests and reasons for them. The care plan focuses on health promotion and highlights the need for and how to adopt healthy behaviours. It also addresses psychosocial issues, how to identify them and where to get help. A copy of the care plan is sent to each person's primary care physician to ensure they are kept up-to-date with information essential to monitoring the health of a cancer survivor and to provide the cancer survivor with a knowledgeable source of support and advice close to home.

## Conclusion

This innovative nurse-led model of survivorship follow-up is in its infancy. Data is currently being gathered to evaluate its contribution to the outcomes of survivors of haematological malignancies and findings will be published in 2010. The interventions are informed by patient reported concerns and common concerns of this survivor group, are delivered by an advanced practice haematology nurse, have been based on best available evidence and endorsed by a multidisciplinary team of experts in the field. As such, the initiative demonstrates an evolution in the thinking around the development of nurse-led follow-up and may offer a useful model for the development of other nurse-led models of cancer survivorship care.

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# GENERAL PRACTITIONER-BASED MODELS OF POST-TREATMENT FOLLOW-UP

**Meagan Brennan<sup>1,2</sup> and Michael Jefford<sup>3,4</sup>**

1. The Patricia Ritchie Centre for Cancer Care and Research, The Mater Hospital, North Sydney, NSW.
  2. Northern Clinical School, University of Sydney, NSW.
  3. Division of Haematology and Medical Oncology, Peter MacCallum Cancer Centre, Melbourne, Victoria.
  4. Faculty of Medicine, Dentistry and Health Sciences, University of Melbourne, Victoria.
- Email: m.brennan@usyd.edu.au

## Abstract

In Australia, most survivorship care is currently provided by specialist oncologists. However, the increasing numbers of cancer survivors, together with workforce issues in oncology, make the development of alternative models of care essential. Following completion of cancer treatments many survivors have significant unmet needs. As providers of comprehensive, long-term care with an intimate knowledge of the patient's health and social context, general practitioners are ideally placed to provide survivorship care. Several models involving general practitioner care have been evaluated and other potential models are yet to be fully developed and assessed. These include exclusive general practitioner care following discharge from specialist care, general practitioner led interventions and shared care programs, generally supported by the use of survivorship care plans. These will be explored and benefits and potential challenges will be discussed.

In Australia, survivorship care following cancer treatment is largely specialist based. As in the US, increasing numbers of long-term survivors combined with workforce issues, make sustainability of this model of care a challenge.<sup>1</sup> Additionally, specialist based follow-up is not cost-effective. As providers of comprehensive continuous care in the primary health care setting, GPs are ideally placed to incorporate survivorship issues into long-term care.<sup>2,3,4</sup> GPs can be integrated into oncology treatment teams to provide survivorship care in a variety of models, including exclusively providing follow-up care after discharge from specialist care, specialist and GP 'shared care' models and the development of special interest GPs with additional training in oncology and survivorship issues.

## Aims of survivorship care

The concept of survivorship care continues to evolve and the definition and aims of survivorship care are the subject of considerable debate. In 2006, the Institute of Medicine (IOM) in the US released a landmark report titled '*From cancer patient to cancer survivor – lost in transition*'.<sup>5</sup> This report described survivorship as a distinct phase of the cancer journey. It provided recommendations for long-term care after treatment for cancer with the aim of encouraging a comprehensive, coordinated approach to care that meets the many long-term needs of survivors. The four essential elements of survivorship care are prevention, surveillance, intervention and coordination.<sup>5</sup>

## GP involvement in survivorship care

A recent US study comparing the expectations of patients, oncologists and primary care physicians regarding survivorship care reported discordant views between

patients and doctors regarding the oncologist's role in long-term care.<sup>6</sup> Primary care physicians expected a high level of involvement in follow-up care and patients anticipated more involvement from the oncologist. Primary care physicians also expected to take on a high level of responsibility in domains of survivorship care such as cancer surveillance, cancer screening and preventive health care, whereas oncologists believed these areas were their responsibility.<sup>6</sup> A recently reported Canadian study found that GPs were very willing to assume exclusive responsibility for the follow-up of survivors.<sup>7</sup> Nissen and colleagues reported that many GPs lacked necessary information to enable them to feel confident regarding survivorship care.<sup>8</sup> Our own work indicates that oncologists and nurses generally believe that GPs can and should have a major role in post-treatment follow-up.<sup>9</sup> GPs were keen to participate in survivorship care. Together, these findings suggest there is general support for GP involvement in survivorship care, providing GPs receive the necessary information and training. However, there is some confusion about who might be responsible for various aspects of care. Patients also need to feel confident that their GP can provide complete survivorship care.

## Trials of GP follow-up care

Models of follow-up care involving the GP have been most comprehensively assessed in breast cancer. In 1995, Grunfeld et al reported a trial conducted in the United Kingdom involving 296 women who were randomised to receive follow-up with their general practitioner or through a district hospital clinic, according to a set protocol.<sup>10,11</sup> One hundred and fifteen general practitioners were involved in the study. During the 18 months of the study, 26 (8.8%) women presented with a recurrence of breast cancer,

with no statistically significant difference in recurrence rates between groups. Quality of life, including anxiety, was also assessed and showed no difference between the two groups.<sup>10,11</sup> A subsequent economic analysis favoured the GP group.<sup>12</sup> Costs to patients and to the health service were lower in the GP group.<sup>12</sup> A subsequent randomised trial (involving 968 patients) was conducted by the same investigators in the Canadian health setting.<sup>13</sup> Similar results were seen, with no significant difference in recurrence related serious events or health related quality of life.<sup>13</sup> General practitioner protocol based follow-up care, therefore, appears to represent a safe, reasonable alternative to hospital clinic care for women with early breast cancer.

GP follow-up has also been evaluated for people with colon cancer. In an Australian trial, 203 patients were randomised to follow-up by their surgeon or general practitioner.<sup>14</sup> There were similar rates of recurrence, time to detection of recurrence and death rates between the groups. GPs tended to order more faecal occult blood tests than surgeons, whereas surgeons ordered more colonoscopies and ultrasounds. The study concluded that while patterns of investigation were different, there was no significant difference in outcomes, including quality of life.<sup>14</sup>

### Shared care models

'Shared care' in the setting of cancer survivorship usually refers to a specialist oncologist sharing follow-up care with the patient's usual GP.<sup>15</sup> It has also been used to describe models of sharing care between an oncologist and a cancer nurse. Several models of shared care between oncologists and GPs have been proposed, most frequently consisting of a program of visits alternating between the two practitioners over a number of years.<sup>15</sup> This style of care is often used for sharing care between specialists from different disciplines, for example sharing of follow-up between a surgeon, medical oncologist and radiation oncologist for women with early stage breast cancer.

In a three-year pilot study of 133 patients in the Netherlands, adult survivors of childhood cancer were followed in a shared care program between a family physician at the cancer centre and their own GP. High levels of patient and GP satisfaction were reported, and there was adequate monitoring for late effects.<sup>16</sup>

In Australia, Jefford et al conducted a randomised trial of an intervention in which tailored information about an individual patient's prescribed chemotherapy regimen was faxed to the GP.<sup>17</sup> There was a statistically significant improvement in confidence and satisfaction with both information received and with perceptions of shared care for GPs who received this information, compared to those receiving standard correspondence.<sup>17</sup> This simple strategy of providing GPs with timely, tailored information and advice may be a useful strategy in post-treatment follow-up.

Holtedahl et al in Norway conducted a randomised trial of a counselling intervention by GPs shortly after the end of cancer treatment.<sup>18</sup> Relatives' satisfaction with

care increased over six months in the intervention group, however there were no other significant differences between the intervention and control groups regarding quality of life or satisfaction with care. This nevertheless remains a potential strategy for survivors.

### Survivorship care plans

Survivorship care plans are formal, written documents that provide details of a person's cancer diagnosis and treatment, potential late and long-term effects arising from the cancer and its treatment, recommended follow-up, and strategies to remain well.<sup>5,19</sup> The IOM report has strongly supported the routine use of care plans.<sup>5</sup> Use of care plans may facilitate shared care with GPs or exclusive care by GPs. Australian surveys in bowel and breast cancer show support by consumers and health professionals for the development and use of survivorship care plans.<sup>9,20</sup> There are no published trials specifically assessing the impact of survivorship care plans, however trials are underway in Australia and elsewhere.

### Potential benefits of GP involvement in survivorship care

As primary care providers, GPs develop long-term relationships with their patients and have an intimate knowledge of the context of a cancer diagnosis in the patient's life and overall health. The GP is well placed to integrate cancer related health care into the long-term care already being offered.<sup>2</sup> Cancer survivors frequently report unmet needs regarding psychosocial care.<sup>21,22</sup> GPs are trained to recognise and respond to psychosocial concerns and may have more time to deal with concerns. GPs also have a greater focus on health promotion and health surveillance.

The GP is often the first point of contact for healthcare and advice, even for patients also under the care of specialists. In the Grunfeld UK study, when breast cancer recurrence developed during the study period, 72% of recurrences presented with symptoms between routine visits. All of the women with recurrences in the GP group presented to the GP with their symptoms and 58% in the hospital clinic group presented to the GP with symptoms.<sup>11</sup> All specialist oncology care is essentially 'shared care', even if it is not specifically designed to be. This relationship can be used to enhance patient care. Strategies to improve communication, teamwork and confidence between medical practitioners (for example using survivorship care plans, developing formal shared care programs and faxing chemotherapy information) should be developed.

Accessibility of GPs is another potential advantage of follow-up in primary care. GP follow-up may be far more convenient for patients in rural and remote areas. Cost may also be an advantage.

### Potential challenges and barriers for GP involvement in survivorship care

Possibly the greatest challenge for developing models that include GPs in survivorship care is the diversity of cancer, clinicians, patients and health services. This means

that a model that may suit one cancer type, one health system, one geographical area, one group of patients and particular clinical teams, may be less suitable in another setting. Models of care need to be relevant and applicable to local circumstances. A range of models of follow-up will need to be developed.

General practitioner care may not be preferred or be appropriate for some patients. Some people may not have a good relationship with their GP or have confidence in the GP's ability to provide oncology-related care. Likewise, some GPs may feel they do not have the skills, time or interest to provide such care. In the Grunfeld UK trial, 33% of women declined to participate. Of the two GPs who declined participation, lack of resources and time for the required paperwork were the reasons cited. During the trial, 3% of patients in the GP group and 3% in the hospital clinic group requested change to the other group.<sup>10</sup> In the equivalent trial in Canada, there was only 55% uptake of study by patients and 83% of GPs agreed to participate.<sup>13</sup> While there may be specific reasons for not wanting to participate in the study separate to the issue of who provides the care, it is likely that a proportion of patients preferred to remain under the care of the cancer centre than be followed up by their GP.

In Australia, the preferences of bowel and breast cancer survivors and health care professionals regarding follow-up care have been evaluated. Baravelli et al found patient support for shared care programs using GPs and nurses in bowel cancer follow-up, but a desire to remain under the care of a specialist for at least some visits.<sup>9</sup> Brennan et al also found support for the concept of GP and nurse care, shared with specialist oncologists in the breast cancer setting. However, there was some concern by patients that GPs might not be able to provide the high level of specialised care that women felt they required (unpublished data).

If the GP is to become more involved in survivorship care, education of patients and GPs and provision of information and advice to GPs is essential. Direct, efficient referral pathways must also be established so GPs can refer as necessary.

Shared care programs have the added challenge of ensuring that communication between the clinicians caring for the patients is smooth and that it is clear to the patient and clinicians who has responsibility for the various aspects of care, so that care does not become fragmented and poorly coordinated. There are a number of ways that this can be optimised, such as the use of written follow-up protocols, prompt correspondence between clinicians, use of patient-held records and survivorship care plans.<sup>5</sup>

### Another alternative - 'GP specialists'

An alternative to GP or hospital specialist follow-up of breast cancer survivors in Australasia is follow-up with a breast physician. These practitioners, most with a background in general practice, undertake specialised training in breast medicine, particularly in the diagnostic phase of care. Traditionally based in private diagnostic breast clinics and BreastScreen services, breast physicians are becoming more involved in breast cancer treatment

and follow-up care.<sup>23</sup> Breast physicians bring a specialist level of knowledge to survivorship care with many of the benefits of a GP approach, including experience in the management of menopausal symptoms, bone health and general health issues. In a survey of health professionals, breast physicians expressed a high level of interest in being more involved in follow-up care.<sup>20</sup>

The breast physician model could be used to develop other GP oncology related special interest areas. Prostate cancer, colorectal cancer and childhood cancers are all examples where specialised GPs can offer invaluable support to patients and oncologists. This is already evolving in some clinical settings.

### Conclusion

As providers of health care throughout a person's life, GPs are already involved in follow-up care after cancer. There are several ways in which their role may be formalised. This includes discharging patients from specialist to GP care after treatment (with or without a period of specialist observation), shared care programs involving GPs and the development of specialised GPs, such as breast physicians. While some of these models have been assessed internationally, there is a need for more research into models of care that include GPs in Australia's unique health care system.

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## HEALTH BEHAVIOUR INTERVENTIONS FOR CANCER SURVIVORS: AN OVERVIEW OF THE EVIDENCE AND CONTEMPORARY AUSTRALIAN TRIALS

**Annabel Pollard,<sup>1</sup> Elizabeth Eakin,<sup>2</sup> Janette Vardy<sup>3</sup> and Anna Hawkes<sup>4</sup>**

1. Psycho-Oncology Research Unit, Peter MacCallum Cancer Centre, Victoria.
2. Cancer Prevention Research Centre, The University of Queensland, School of Population Health.
3. Sydney Cancer Centre, University of Sydney, NSW.
4. Viertel Centre for Research in Cancer Control, Cancer Council Queensland.

Email: Annabel.Pollard@petermac.org

### Abstract

Cancer survivors experience significant ongoing health problems, primarily as a result of cancer treatment, pre-morbid health status and lifestyle. While significant public health resources have been directed at cancer prevention via reducing health risk behaviours such as smoking, physical inactivity and excessive alcohol consumption, considerably less attention has been directed at promoting health enhancing behaviours in cancer survivors. Emerging research suggests that such a focus can significantly improve health outcomes for cancer survivors. This article reviews the evidence in more detail and highlights contemporary Australian research in the field.

Advances in the early detection and treatment of cancer, coupled with the ageing population, have resulted in a dramatic increase in the number of cancer survivors,<sup>1</sup> and the numbers are expected to grow considerably.<sup>2-5</sup> Current estimates indicate that there are over 380,000 cancer survivors in Australia,<sup>6</sup> and while the rise in cancer survivors reflects improved survival, the long-term health effects of cancer and its treatment represent a major public health concern.

Compared to the general population, cancer survivors are at a greater risk of developing secondary cancers and other chronic diseases or conditions, such as heart disease, diabetes and functional decline.<sup>7-9</sup> There are a number of possible reasons for this increased risk, including genetic predisposition, cancer treatment related sequelae and importantly, lifestyle behaviours.<sup>10</sup> Unhealthy lifestyle behaviours such as smoking, physical inactivity, poor diet, and related obesity/overweight, are associated with an increased risk of cancer, cardiovascular disease and other chronic diseases.<sup>10-13</sup> Conversely, recent cohort data suggest that post-diagnosis physical activity may reduce the risk of cancer recurrence and potentially extend survival for survivors of colorectal and breast cancer.<sup>8,9,14,15</sup> In addition, research indicates that a low-

fat diet combined with moderate weight loss, may reduce cancer recurrence in postmenopausal breast cancer survivors.<sup>16</sup> Interventions that target smoking cessation indicate that cancer survivors will experience improvements in a variety of health outcomes.<sup>17</sup>

Recent national health surveys in the US indicate that a large proportion of cancer survivors do not adhere to national physical activity and dietary guidelines.<sup>1,18</sup> Data reveals few lifestyle differences between individuals diagnosed with cancer and healthy populations, or non-cancer controls.<sup>1,18</sup> In recent Australian studies, cancer survivors and controls who did not have a cancer history had similar rates of smoking, physical inactivity and obesity.<sup>19,20</sup> Cancer survivors were more likely to report a range of co-morbid chronic medical conditions.<sup>19,20</sup>

There is a growing number of studies evaluating smoking cessation, exercise and dietary interventions in cancer survivors.<sup>21,22</sup> Many of the studies have yielded promising results, with exercise interventions showing improvements across psycho-social, quality of life and biological measures.<sup>21,23-27</sup> These interventions are outlined below in more detail and we highlight current Australian research in the field.

## Smoking cessation interventions

Smoking has a causal relationship with a number of cancers.<sup>28</sup> Continued smoking after a cancer diagnosis is associated with increased risk of second primary tumours, recurrence, other co-morbidities and death.<sup>29</sup> High spontaneous quit rates of up to 50% are reported following a cancer diagnosis.<sup>30</sup> Yet about one third of smokers continue to smoke after a cancer diagnosis.<sup>17</sup> However, smoking cessation interventions for those with cancer have reported abstinence rates of up to 70% at one year post treatment.<sup>31</sup> Combined interventions that utilise both behavioural counselling and pharmacotherapy appear to be most effective, however, this type of intervention is not routinely offered in the majority of cancer treatment centres.<sup>24</sup>

## Physical activity interventions

Recent research has provided important data on the relationship between exercise and cancer survival. Three longitudinal cohort studies examining patients with colorectal cancer or women with breast cancer, reported that increased post-diagnosis physical activity is associated with a significantly lower risk of overall mortality and, in breast cancer, with significantly lower risk of breast cancer death.<sup>8,9,14,15</sup> Among women with breast cancer, activity levels (consistent with current physical activity guidelines -150 minutes/week of moderate-level activity) were associated with significantly lower risk of death compared to low activity (RR/HR from 0.58 to 0.71)<sup>8,14</sup> and no activity (RR/HR=0.36).<sup>15</sup> Changes in activity from pre to post-diagnosis have also been shown to influence survival. Among women with breast cancer, and compared to those who were inactive before and after diagnosis, those who increased their activity by about 60 minutes/week or more of moderate-level activity, halved their risk of breast-cancer death, as well as all-cause mortality, compared with those who had no change. Conversely, women whose activity decreased by 60 minutes or more per week of moderate-level physical activity increased their risk of death four-fold.<sup>15</sup>

More than 70 intervention trials of physical activity for cancer survivors have been published, the majority focusing on breast cancer and colorectal cancer survivors.<sup>32-36</sup> Emerging evidence in other cancer groups suggests that physical activity interventions have similar benefits for men with prostate cancer.<sup>37</sup> However, further research is required across other cancer types.<sup>23,30</sup> Overall, these studies suggest that physical activity interventions implemented during or following treatment may improve: cardio-respiratory fitness; body composition (ie. muscle mass and bone health); immune function; strength and flexibility; body image; self-esteem and mood; chemotherapy completion rates; and allow for better adjustment to illness. Physical activity during and after completion of treatment has also been associated with improved quality of life and reduced fatigue.<sup>36,38-41</sup>

The now very large literature base on physical activity interventions in cancer survivors strongly supports the efficacy and safety of interventions commenced both during and following cancer treatment.<sup>23,35,42-45</sup> The general

exercise recommendation for people undertaking or having completed cancer treatment is low to moderate intensity, regular frequency (3–5 times/week) for at least 20 minutes per session involving aerobic, resistance or mixed exercise types,<sup>42</sup> which is largely consistent with recommendations for the general adult population.<sup>12,34</sup> Future work needs to more thoroughly assess what constitutes optimal exercise prescriptions including mode of delivery, cost effectiveness, frequency, duration, intensity and type, and how individual characteristics (eg. age, cancer type, treatment, presence of specific symptoms) affect this prescription.<sup>42</sup>

## Dietary and weight loss interventions

The evidence regarding the importance of weight loss and dietary interventions in cancer survival is less clear.<sup>16,46,47</sup> Findings from the *Women's Intervention Nutrition* study, suggest that reduced dietary fat intake and corresponding weight loss conferred a modest improvement on relapse-free survival in the intervention group, compared to the control group: HR of relapse events in the intervention group compared with the control group was 0.76 (95% CI = 0.60 to 0.98, P = .077 for stratified log rank and P = .034 for adjusted Cox model analysis).<sup>16</sup> Conversely, the *Women's Healthy Eating and Living* study found that dietary changes did not alter the incidence of breast cancer recurrence/new primary or death from other causes in breast cancer survivors. About 17% of women in each group experienced a new primary or recurrence and there was no difference in mortality between the two groups.<sup>47</sup>

Evidence suggests that dietary interventions may improve quality of life, although findings are limited.<sup>48</sup> Only four studies have evaluated weight loss interventions in women with breast cancer, with all reporting significant weight loss.<sup>49-52</sup> Based on the epidemiological evidence, it is suggested that weight management be an integral part of breast cancer care.<sup>12,46,53</sup>

## Contemporary Australian trials

Exercise for Health\* is a nearly completed National Breast Cancer Foundation funded randomised control trial, addressing how exercise interventions can be delivered in 'real world' contexts, with the greatest possible population reach, and in a manner that assists women to become appropriately active during breast cancer treatment and into longer term survivorship. The eight month, moderate intensity exercise intervention (aerobic and resistance based), has been delivered by exercise physiologists, either face-to-face or over the telephone, commencing at six weeks post-surgery. Two modes of delivery are being tested to evaluate the most effective (and cost-effective) modes of delivery, an issue with important implications for translating evidence into practice. The study has two settings. In the first, women who reside in the greater Brisbane area are randomised into one of two exercise intervention groups or a control 'usual care' group. In

\* Exercise for Health is being conducted by researchers from the Institute for Health and Biomedical Innovation (IHBI) at the Queensland University of Technology, in collaboration with the Cancer Prevention Research Centre, School of Population Health, at the University of Queensland. For more information, contact Dr Sandra Hayes at IHBI.

the second setting, women from regional/rural areas are randomised into telephone intervention or usual care. Baseline characteristics are assessed pre-randomisation and short and longer term compliance, as well as potential benefits assessed mid-way through the intervention (six months post-surgery) and three months following completion of the intervention. Primary outcomes are feasibility of delivery, quality of life, upper body function and physical activity.

Previous research has suggested that interventions to improve quality of life after colorectal cancer (CRC) may be most effective if they target symptom management, psychosocial and lifestyle variables, or health behaviours, in a comprehensive and integrated approach.<sup>54</sup> However, there have been few trials of behavioural interventions to address the specific needs of CRC survivors. As such, for the first time we are conducting a large-scale randomised control trial of a comprehensive telephone delivered intervention to improve lifestyle factors and health outcomes for CRC survivors, 'CanChange'.<sup>55</sup> CanChange<sup>†</sup> is being conducted at the Cancer Council Queensland and is funded by Cancer Australia (2008-2010). The trial is in collaboration with: The University of Queensland; Queensland Institute of Medical Research; University of Alberta, Canada; and Cancer Council Victoria. Three hundred and fifty people recently diagnosed with CRC are currently being recruited through the Queensland Cancer Registry and randomised to the intervention or 'usual care' control condition. The intervention assists participants to make improvements in lifestyle factors (physical activity, healthy diet, weight management and smoking cessation) and health outcomes. Intervention participants receive up to 11 telephone sessions over six months from a qualified health professional with a focus on symptom management, psychosocial and lifestyle support. Data collection occurs at baseline, post-intervention or six months follow-up, and at 12 months follow-up for longer term effects. Primary outcome measures include physical activity, cancer related fatigue and quality of life. A cost-effective analysis of the intervention is also being conducted from the perspective of health care costs to the government.

Pilot testing demonstrated that 80% of participants (n = 20) said the intervention addressed their issues, 100% said it made them more motivated to make positive life changes, and 100% said they would recommend the intervention to other CRC survivors. From baseline to post-intervention we observed improvements in all CRC specific symptoms and quality of life; a significant decrease in processed meat intake, as well as improvements in sedentary behaviour and the proportion of participants meeting the national guidelines for fruit and vegetable intake.<sup>56</sup>

Two new physical activity studies are about to commence. The first is CHALLENGE<sup>‡</sup> – a three year physical activity intervention for colon cancer survivors who are two to six months post adjuvant treatment. A multicentre

Phase III RCT study, it is being run as a collaboration between the National Cancer Institute – Canada and the Survivorship Research Group at Sydney University. The aim is to determine the efficacy of physical activity in reducing disease recurrence in patients with localised colon cancer. The primary hypothesis is that a physical activity program will improve three year disease free survival in patients with resected colon cancer. Additional hypotheses are that exercise can improve fatigue, quality of life, physical functioning and body composition. The association of cytokines and insulin axis levels with physical activity fatigue and disease free survival will be sought, as well as a health economic evaluation of the physical activity intervention.

The second RCT, Physical Activity – Lung, will determine the efficacy of physical activity in reducing fatigue and improving quality of life in patients with non-resectable thoracic cancer. This patient population has co-morbidities such as chronic obstructive pulmonary disease (COPD). Although there is a paucity of physical activity research in patients with advanced lung cancer, pulmonary rehabilitation programs in COPD populations have shown evidence of benefit from physical activity. The primary hypothesis is that a physical activity program will improve fatigue, with secondary hypotheses that exercise can improve quality of life, anxiety and depression, physical functioning, body composition and disease progression. An integral part of the intervention in both trials is a behaviour change component. Both studies will evaluate underlying biological mechanisms by which physical activity may be useful for cancer survivors.

Theory driven interventions have shown success in physical activity behaviour change research, but are not always incorporated into routine clinical care.<sup>57-60</sup> Social cognitive factors (such as attitudes) have been shown to play a significant role in behavioural choices about physical activity, thus theoretically driven studies are important, in order to ascertain how best to promote positive attitudes towards healthy behaviour and long-term behaviour change.<sup>61</sup> The aim of this randomised pilot study is to determine the role of social cognitive factors in the uptake of physical activity post-treatment. Approximately 120 breast cancer survivors will be recruited at Peter MacCallum Cancer Centre. Participants are women who have completed primary treatment for stage I-IIIa breast cancer within the preceding 12-18 months. Participants are randomised to one of two intervention groups or a control group. The intervention groups are provided with a theory-based booklet containing information and recommendations concerning physical activity in breast cancer survivors, plus/minus a goal setting intervention. Data collection and intervention occurs at baseline, at three months post-intervention and at 12 months follow-up. The primary hypothesis is that social cognitive factors, including goal setting, will be associated with an increase in self reported minutes of moderate to strenuous activity per week. Primary outcome measures include physical activity, cancer related fatigue and quality of life.<sup>5</sup>

† For more information on CanChange contact A/Prof Anna Hawkes [AnnaHawkes@cancerqld.org.au](mailto:AnnaHawkes@cancerqld.org.au).

‡ The Australian CHALLENGE (Colon Health and Life Long Exercise ChaNGE) arm and newly funded lung cancer trial. For more information contact Janette Vardy at Sydney Cancer Centre, University of Sydney.

§ The Breast Cancer Survivors Healthy Living Study is being conducted by researchers at the Peter MacCallum Cancer Centre (PMCC) and the University of Melbourne. This study is supported by a scholarship from the Victorian Cancer Agency. For more information, contact Annabel Pollard at PMCC.

## Conclusion

Lifestyle modification is an increasingly important component of cancer survivorship to ameliorate the effects of treatment, minimise the risk of associated co-morbidities and promote longer term health. Translational research that systematically implements and evaluates evidence-based interventions targeting health enhancing behaviours is an important challenge for researchers and clinicians. As one expert in the field points out: "...the longer people survive after a cancer diagnosis, the more likely it is that what they do after their diagnosis might matter."<sup>62</sup>

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## CHALLENGES FACING SURVIVORS OF CHILDHOOD AND ADOLESCENT CANCER

**Greg Wheeler,<sup>1,2,3</sup> Kate Thompson,<sup>4</sup> Josephine Samers,<sup>5</sup> John F Seymour<sup>1,3,6</sup>**

1. Division of Radiation Oncology, Peter MacCallum Cancer Centre, Victoria.
  2. Long-Term Follow-up Program, Paediatric Integrated Cancer Service, Victoria.
  3. University of Melbourne, Victoria.
  4. Victorian Adolescent and Young Adult Cancer Service, Peter MacCallum Cancer Centre, Victoria.
  5. General Practice Liaison, Alfred Hospital, Victoria.
  6. Division of Haematology and Medical Oncology, Peter MacCallum Cancer Centre, Victoria.
- Email: Greg.Wheeler@petermac.org

### Abstract

The last 40 years have seen major changes in the treatment of childhood and adolescent cancers. From a nearly uniform fatal outcome to an expectant 80% probability of cure, the number of long-term survivors has dramatically increased. During the last 20 years the significant consequences of surgery, radiotherapy and chemotherapy have become apparent. Permanent complications as a result of the tumour itself and initial surgery are aggravated by long-term effects of radiotherapy and chemotherapy. The assumption that cancer cure leads to the end of medical surveillance is being overturned as more research regarding long-term and late effects is reported. The effect on psychosocial development of children and adolescents is increasingly being recognised and this has implications well into adulthood. With the increasing number of survivors of childhood and adolescent malignancies in the community, medical and allied health professions should develop a knowledge of the implications of having had these diagnoses and their subsequent treatments. The challenges in creating a robust, sustainable model of ongoing care for these patients is significant, with options ranging from discharge to family doctors, who are provided with information, through to totally tertiary referral centre based care.

In many pursuits, the 'finishing line' is not always where you think it is. For many years the 'finishing line' for children and adolescents with cancer was being told that they were cured – usually after four to five years of disease-free survival. It is now apparent that the consequences of having had a malignancy, especially in childhood, can impact many years later. In the greater scheme of things, curing significant numbers of childhood cancers has been a relatively recent phenomenon, namely over the last 35-40 years. This period has seen a phenomenal change in outcomes for childhood malignancies. When Farber first used methotrexate to treat children with leukaemia in

1948, short remissions resulted, but ultimately all patients succumbed to the disease. His initial report in the *New England Journal of Medicine* in 1948<sup>1</sup> was met with derision, as the prevailing view was that leukaemias were incurable and that the children should be allowed to 'die in peace'. Indeed, in the 1960s parents were often told to take their children home and to love them, as there were no sustained remissions.

The use of multi-agent chemotherapy in the late 1960s led to the first reported durable remissions for children with acute leukaemias and lymphomas. The 1970s saw



a dramatic rise in cure rates for many malignancies. It is humbling to realise that many of these children are now in their 40s and 50s - in many respects still relatively young.

Until this watershed, the only long-term survivors of childhood malignancy resulted from curative surgery or curative radiation. The numbers were small, but even then there was a recognised cost seen in these long-term survivors with growth effects, neuro-cognitive and neuro-endocrine complications and the suggestion of increased second malignancies. In his seminal paper on the role of radiotherapy in medulloblastoma, Bloom noted that children under two years of age often required ongoing institutional care after receiving craniospinal radiotherapy.<sup>2</sup> Prior to this, Lampe expressed concern regarding brain damage that could result from high doses of radiation to brains of younger patients.<sup>3</sup>

It was hoped that chemotherapy would eliminate the need for radiation and be free of long-term consequences, but unfortunately this was not to be. Until the 1990s, once a patient was deemed cured they were usually discharged from the primary treating institution and told to live a normal life with reasonable expectation that they would. There has been an increasing recognition over the last 20 years of the many complications that may result from anti-cancer treatments. As a profession, we have an obligation to screen for and deal with these problems. This paper reviews the challenges facing childhood cancer survivors considering the physical, psychological, social and financial implications.

### Epidemiology of cancer in children

According to the Surveillance, Epidemiology and End Results data, the incidence of cancers in young people less than 20 in the US, has remained static between 12.9 and 16.7 per 100,000 during the last 30 years.<sup>4</sup> During this time, the mortality incidence has decreased from 5.2 to 2.6. The most common malignancies are leukaemias (45/100,000), central nervous system malignancies (28/100,000), lymphomas (24/100,000), soft tissue sarcomas (12/100,000), germcell/trophoblastic tumours/neoplasms of the gonads (11.6/100,000), malignant bone tumours (9/100,000), neuroblastomas (8/100,000) and renal tumours eg. Wilms (6/100,000).<sup>5</sup>

As a result of this improvement in treatment, it is now expected that 80% of childhood cancer patients will become long-term survivors.<sup>6</sup> One in 640 young adults 20-39 are cancer survivors and this means that the average general practice would be expected to have at least two of these patients per physician.

Treatments for childhood and adolescent cancers are diverse. The most common malignancy in this group is leukaemia (as above) and the chemotherapy for this condition can often continue over 18 months, possibly requiring total body irradiation and bone marrow transplantation. Lymphomas are treated predominantly with chemotherapy, with radiation used in a number of cooperative group protocols, albeit at much lower doses than adult patients receive. Brain tumours are usually treated with up-front surgery followed by up to 59 Gy of radiation. Sarcomas are usually treated with surgery

and subsequent chemotherapy, often with the role of radiotherapy dependant on the histology and surgical clearance pathologically. The doses of radiotherapy for this group are variable, ranging from a modest 36 Gy to a radical 50.4 (Rhabdomyosarcoma) or 55.8 Gy (Ewings). At the other end of the spectrum, Wilm's tumour in the early stages is treated with a short course of chemotherapy and radiotherapy usually of very small doses (10.8-21.6 Gy).

The gist of the European cooperative group studies has been to avoid radiation unless the local control with surgery comes with unacceptable toxicities. The North American cooperative groups in contrast have aimed to reduce the doses of radiotherapy, but the result is that more children are receiving it. Not surprisingly, over the last decade many treatment protocols for diseases such as Wilms tumour are converging on the role and dose of radiotherapy, allowing cross group studies to be entertained.

### Physical effects from the cancer itself

The tumour itself can cause significant long-lasting problems prior to any therapeutic intervention. In brain tumours, there is good evidence that having a tumour itself can cause disturbance of the hypothalamic pituitary axis prior to surgery or radiotherapy.<sup>7</sup> Likewise, the development of hydrocephalus is recognised to be an independent cause of significant neurocognitive decline in patients with brain tumours, previously attributed solely to radiation therapy.<sup>8</sup> Damage to neurones may not be repairable and so often timely intervention is crucial in the setting of cord compression (eg. osteosarcoma or Ewing's), or the optic chiasm (craniopharyngiomas and optic pathway gliomas).

### Surgery

Clearly, the need for cancer resections of bony structures may have significant cosmetic effects and impacts on growth, especially if the growth plates are involved. The issue of rehabilitation involved after amputations is significant. Those patients who have undergone splenectomy, as performed at staging laparotomy for Hodgkin's disease in the 1970s and 80s, are at risk of pneumococcal and meningococcal infections and as such require life-long surveillance and vaccinations.<sup>9</sup> Long-term neurocognitive insult and neuronal injury are a possible complication of major brain tumour resections. Nephrectomy patients develop compensatory hypertrophy of the remaining kidney and run the risk of earlier onset hypertension, with its related health issues and proteinuria.<sup>10-12</sup>

### Late effects from radiotherapy and chemotherapy

The most famous first victim of radiation late effects was probably Marie Curie, who discovered radium along with her husband Pierre. She also went on to develop the first mobile X-ray station in France in World War I. Marie died of aplastic anaemia, most likely as a result of her long-term radiation exposure. Her daughter Irene, also a Nobel Prize winning radiation physicist, developed and died from acute leukaemia. Pierre Curie however, was spared a similar fate - he was run over by a horse drawn cart on the streets of Paris in April of 1906.

The most studied modality producing late effects is radiation. The first patients were treated in the late 1890s and until the advent of chemotherapy, it was the only effective non-surgical treatment for cancer available. However, from relatively early on the effects of radiotherapy were appreciated.

*"The dangers from the use of X-rays may be grouped as immediate and remote. During the actual exposure, the possibility of making contact with a high-tension lead carrying a very high voltage has to be guarded against. An accident of this kind may easily be fatal...constitutional disorders, anaemia and sterility not infrequently arise in operators who are constantly exposed to X-rays."<sup>13</sup>*

In 1935, the concept of immediate and long-term or late effects was very simple. It is now thought that late effects refer to complications that arise many months to many years after the completion of therapy.

Indeed, much of the significant early data regarding adverse effects from radiotherapy is not from therapeutic radiation exposure - rather from the Hiroshima and Nagasaki atomic bomb data, industrial accidents and use in benign conditions. For example, in the 1940s and 50s, superficial irradiation was a commonly used treatment for tinea capitis, with doses of 0.04-0.45 Gy used.<sup>14</sup> Early reports from the 1960s suggested an increase in leukaemias, other malignancies and interestingly 'mental disorders'. The incidence of thyroid, brain and other head and neck cancers was also found to be increased in the large cohort of Israeli immigrants treated for tinea in the 1940s and 50s.<sup>15</sup>

Much of the current data regarding late effects of cancer treatments has been developed for the retrospective cohort of ~ 10,000 patients with matched sibling controls in the Childhood Cancer Survivors Study group.<sup>6,16-19</sup> Much of this data and other published literature has been brought together in the formation of the long-term follow-up guidelines of the Children's Oncology Group ([www.survivorshipguidelines.org/](http://www.survivorshipguidelines.org/)). These guidelines are used as the basis for many long-term follow-up programs both in the US and internationally.

It is beyond the scope of this paper to exhaustively detail the physical effects of chemotherapy and radiotherapy, however, a brief overview follows.

### **Head and neck region**

Alopecia is physically perhaps the most insignificant side-effect of cancer treatment, but psychosocially, one of the more distressing, particularly for teenage girls. Cranial radiation often leads to temporary hair loss in field and the degree of permanent effect relates to total dose. It is apparent that combined chemoradiation (such as in medulloblastoma) can lead to more pronounced permanent thinning of the hair, or indeed complete alopecia.<sup>20</sup>

The lens of the eye is very sensitive to the effects of radiation and to steroid administration, which both lead to cataractogenesis.<sup>21</sup> In conditions such as medulloblastoma and leukaemia requiring prophylactic cranial irradiation, it is difficult to adequately cover the cribriform plate without giving some dose to the lens. In itself, cataract removal is a fairly straightforward procedure, but the dose to the

anterior chamber of the eye also increases the later risk of developing glaucoma.<sup>22</sup>

The hypothalamic-pituitary axis is often compromised if it is involved in the surgical resection of tumours (particularly craniopharyngioma). Both surgery and radiotherapy to the hypothalamus can lead to hypothalamic obesity or metabolic syndrome, which is thought to be due to an abnormality in the normal satiety response to food. Radiotherapy effects to this axis present with a median time of three years post therapy. The thyroid axis is usually affected first, followed by growth hormone, the sex hormones (sometimes presenting as precocious puberty) and less commonly Adrenocorticotropic hormone, leading to Addisonian syndromes. The thyroid gland itself may suffer primary failure if it is in the primary radiation field. In conditions requiring cranio-spinal irradiation, it may prove difficult to distinguish between central failure and peripheral (glandular) failure. Central infertility may also result from radiation, however, this may be negated by the use of gonadotrophic releasing hormone agonists to induce gonadal stimulation.<sup>23-26</sup>

Often the most devastating long-term effects is the functional neurological compromise suffered by patients who have had brain tumours or cranial irradiation.<sup>27</sup> As mentioned previously, there is evidence that hydrocephalus itself can aggravate neurocognitive compromise.<sup>8</sup> Merchant et al have demonstrated that IQ decline is proportional to the volume of brain treated, especially the temporal lobes and the dose these volumes received.<sup>28</sup> Palmer et al found that there appears to be a constant decline until age 12, after which the IQ remains stable. There is however, a progressive reduction in short-term memory and concentration span through the teenage years.<sup>29</sup> Some evidence suggests medications such as dexamphetamine and/or cognitive remediation programs may improve academic performance and overall quality of life in some with a history of brain tumours.<sup>23,24,30,31</sup> Similar, but not as profound effects can be seen in patients who have had intrathecal methotrexate, especially if cranial radiotherapy is also given.<sup>25,32</sup>

Radiation can age the brain and there is a small risk of focal radionecrosis in high dose regions,<sup>33</sup> as well as a general increased risk of cerebrovascular accidents. Radiation to the neck and mediastinum can increase the rates of cerebrovascular disease in five-year survivors from Hodgkin's disease.<sup>34</sup> For this reason, many late effects services take an aggressive approach to management of hypercholesterolemia, hypertension and other reversible risk factors for cerebrovascular disease.

### **Cardiac effects**

Both radiotherapy and chemotherapy have significant impacts on cardiac function. High-dose anthracyclines (eg. > 350 mg/m<sup>2</sup> equivalent doxorubicin), can induce cardiac failure during treatment.<sup>35</sup> There is also a recognised decrement in cardiac function which may present years later.<sup>36,37</sup> In female patients, cardiac failure may be unmasked during pregnancy. It is advisable for pregnant women with a history of cardiac irradiation or anthracycline chemotherapy to undergo cardiac function assessment during pregnancy and monitoring during labour and delivery. Radiotherapy to the chest

increases the risk of ischaemic heart disease by 2-5%.<sup>19,38</sup> These patients also have an increased rate of valvular abnormalities, usually presenting with stenotic rather than incompetent valvular heart disease. Renal irradiation may cause cortical scarring or fibrosis, increasing the risk of Angiotensin converting enzyme driven hypertension, aggravating both the cerebral and cardiac risk profile.<sup>10</sup>

Intriguingly, there is data that implicates higher doses of cisplatin used in the treatment of testicular cancers in the development of the metabolic syndrome. This clearly has ongoing implications for the cardiovascular health of these patients.<sup>39</sup>

### **Pulmonary effects**

Radiation doses above about 20 Gy induce variable degrees of pulmonary fibrosis in the radiation field, which if marked, may lead to a restrictive pattern on lung function testing and a decrease in overall diffusing capacity.<sup>32,40</sup> This is particularly relevant in patients with mediastinal lymphoma, and needs to be considered in some with a history of neuroblastoma. Bleomycin chemotherapy is a potent inducer of interstitial fibrosis and pneumonitis.<sup>33,41</sup> These problems are aggravated by tobacco and marijuana smoking, so smoking cessation is essential for people with these prior exposures.

### **Gastrointestinal effects**

High dose radiation to the gastrointestinal tract can lead to localised strictures, gastrointestinal tract blood loss from

telangiectatic blood vessel formation in the walls and/or chronic loose motions or diarrhoea.<sup>1,42</sup> There are reports of radiation induced bowel cancers in people treated for Wilm's tumour or rhabdomyosarcoma.<sup>43</sup>

### **Genitourinary effects**

High dose cyclophosphamide may induce haemorrhagic cystitis despite routine intravenous hydration prior to chemotherapy. Cyclophosphamide in childhood increases the risk of later bladder malignancies.<sup>44</sup> High dose irradiation may induce scarring in the bladder, causing reduced bladder volume, which may result in urinary frequency and urge incontinence. Many chemotherapies, particularly potent alkylating agents (especially nitrogen mustard), can induce infertility in later life.<sup>45</sup> Chemotherapy (especially cyclophosphamide) may be associated with premature menopause. This is related to chemotherapy dose and age at treatment. Radiation has been found to reduce uterine blood flow, and in doses above 16-20 Gy may induce hypoplasia and fibrosis, resulting in miscarriage or inability to carry a pregnancy to term. Radiotherapy doses of 2-4 Gy to the testes and 4-6 Gy to the ovaries may induce sterility, and at higher levels (~20 Gy) may result in loss of hormonal function.<sup>46-48</sup>

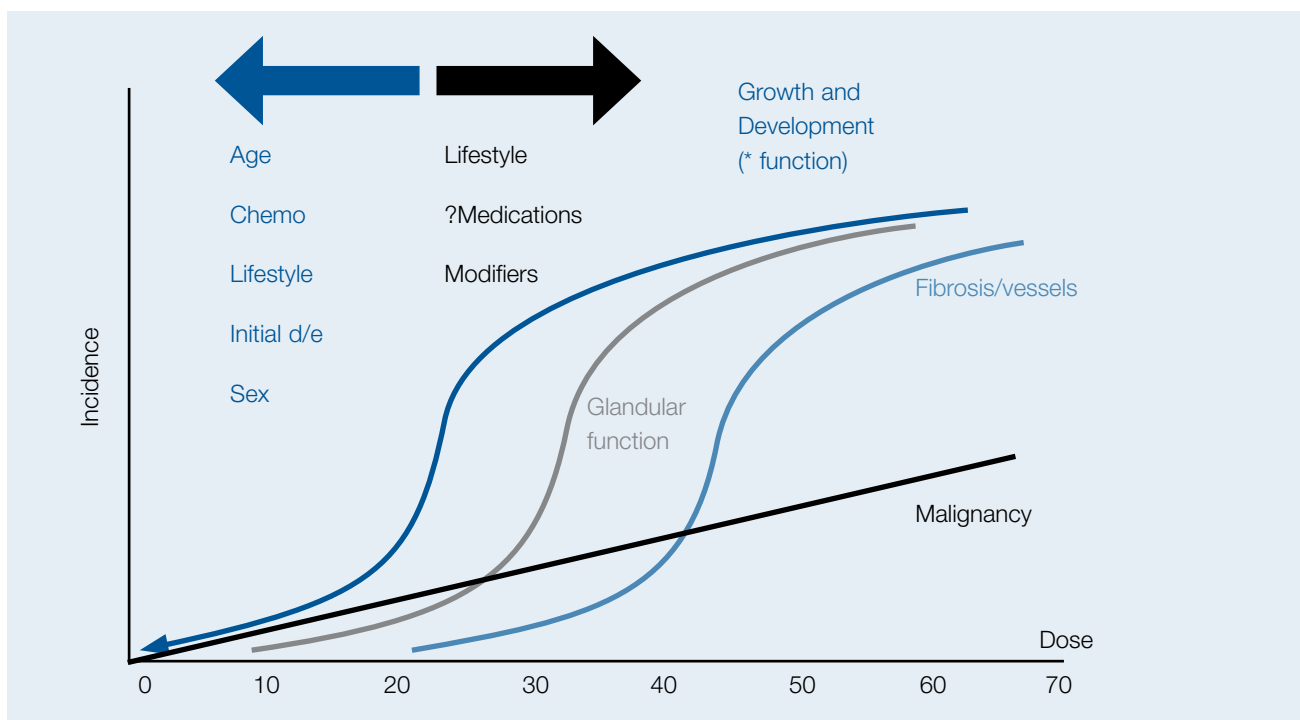
### **Musculoskeletal hypoplasia**

As depicted in figure 1, the threshold dose for hypoplasia induced by radiation appears to be about 16 Gy, with the plateauing of effect seen at about 25 Gy. If there

**Figure 1** – Schematic representation of the late effects of radiotherapy

*Legend: The shape of these curves indicate an initial gentle rise in incidence with increasing radiotherapy doses. The steeper sections represent the critical regions of dose where there is a rapid increase in the incidence of growth retardation/glandular function/fibrosis and vascular complications; at higher dose levels the incidence tends to plateau. In planning radiotherapy for children it is preferable to dose critical structures below that where the curves steepen. There is a near linear development of second malignancy to dose.*

*(Incidence – reflects the incidence or severity of the complication; Dose – in Gray; d/e – disease; Sex – male or female gender; \* function- surrogate for function; Malignancy – radiation/treatment induced second malignancy (excluding disease recurrence)).*



is inhomogeneity across growth plates (as in vertebral bodies), asymmetric growth may lead to impaired cosmetic outcomes, such as kyphoscoliosis, facial asymmetry and pelvic tilt. Associated with this could be effects on neuronal, glandular and mechanical functions as described above. Clearly another mechanism of impaired growth is from the effects on growth hormone production from hypothalamic/pituitary irradiation. Chemotherapy itself may cause overall growth failure, with twin studies showing that bone marrow transplanted patients are reliably shorter than their siblings. Radiation can lead to late osteoporosis in field and in some cases radionecrosis in high dose areas. Likewise, high total dose corticosteroids may induce osteoporosis and more worryingly avascular necrosis of the head of the femurs.

### **Second malignancies**

One of the most concerning complications of cancer treatment, both for the patient and the treating clinicians, is second malignant neoplasms.<sup>49</sup> Some primary tumours in themselves are associated with an increased risk of other malignancies, such as retinoblastoma, or lymphoma. Intensive chemotherapy, particularly etoposide-like drugs, carry a risk of induced leukaemias and myelodysplastic syndromes.<sup>50</sup> The second malignancy risk from radiotherapy has a dose response, with the exception of thyroid cancers, which seem to plateau at a dose of approximately 15 Gy. Concurrent chemotherapy, particularly doxorubicin, increases the risk of developing a radiation induced second malignancy.

It has been appreciated for many years that treatment for Hodgkin's lymphoma using mediastinal radiation increases the risk of breast cancer.<sup>51</sup> More recently, the induction of meningiomas and more rarely gliomas in the central nervous system with antimetabolite maintenance chemotherapy in acute lymphoblastic leukemia is apparent. Retinoblastoma patients who have had irradiation have a significant risk of a second malignant neoplasm, especially osteosarcomas in the treatment field. The prognosis from these tumours is grim. Development of skin cancers within a previous radiation field is common. Infield lung cancers have been reported with an observed to expected ratio of 7.0, and in this study,<sup>52</sup> all were smokers. Eighty per cent of secondary malignancies are either in the field of radiotherapy or at the margins, strongly implicating the role of radiation in the pathogenesis of these conditions.<sup>53-59</sup>

### **Psychological and social effects**

It has become increasingly apparent that having had a cancer can have a profound impact on psychosocial development. Survivors of cancer in childhood or adolescence are much less likely than their peers to marry, hold a job, reach the same socioeconomic status, hold insurance or complete tertiary education.<sup>60-64</sup> The most obvious impacts relate to failure to socialise due to brain injury, whether it be surgical insult (such as posterior fossa syndrome or hemiplegias), or failure to concentrate and follow game commands due to prior radiation. Damaged frontal lobe function often impacts on group play, and children may be ostracised as a result. More subtle impacts are seen when children lose touch with their peers during long absences caused by treatment.

Social awkwardness engendered by lack of hair or just the fact of having their peers feeling awkward about their diagnosis of cancer can impede normal interactions. They are also often caught between wanting to be 'normal', yet having a life-changing event acknowledged in some way (see Carl's story).

### **Carl's story**

Carl was found to have a medulloblastoma in his second last year of high school. He found that once the diagnosis was known, especially once his hair began to fall out, he felt cocooned from his friends, that they didn't see him in the same way and often would tiptoe around him with their jokes and stories in case they offended him.

He found however, that their conversations were more inane and juvenile: "I'd faced a life threatening illness and they were concerned about who said what to who; it just didn't seem important anymore." He repeated his second last year of school to catch up on the work he had missed out on while undergoing treatment. When he was in his final year he found it hard to be motivated as all his friends were at university and having a great time, while he was still stuck with the 'kids'.

While wanting to get on with a normal life he became increasingly concerned about minor symptoms in case they represented disease recurrence. The periods between his scans and obtaining the results were also extraordinarily stressful for him. A referral to a psychology and counselling service in concert with regular medial check-ups has helped this latter problem.

He is now in tertiary studies and pursuing a music career. His illness has given him a very different perspective on life and he remains anxious as to the possible late effects of treatment.

This can become particularly poignant once the treatment is completed and they look physically normal. Indeed, often adolescents and children find the academic dislocation hard to overcome, resulting in poor grades and worsening social isolation should they need to repeat a year of school.<sup>49</sup> As they transition into the period of adolescence and young adulthood, social awkwardness, along with the physical impact from cancer and its treatments, can provide additional stress on relationships. Having a healthy body image and self-esteem relies on accepting physical appearances, which in the maelstrom of surgery, chemotherapy and radiotherapy is hard for young people to achieve, especially with the change in the way people respond to them. Permanent physical treatment side-effects such as hair loss, amputation, scarring and fatigue, can result in reactive depression, anxiety and in some situations post-traumatic stress disorder.<sup>65,66</sup> Increased prevalence of somatic symptoms, depression and/or anxiety, attention deficit and anti-social behaviour among young cancer survivors, has been documented in those diagnosed with leukaemia. Central nervous system tumours and neuroblastoma are also deemed to be at

particular risk.<sup>66,67</sup> Brain tumour patients in particular may have profound and often debilitating fatigue, which inhibits ability to work and particularly socialise after work if they are employed. In some patients, exogenous growth hormone or stimulants such as dexamphetamine may be useful adjuncts, and of course screening for hypothyroidism (either central or due to gland damage) is an important part of long-term surveillance.

Other causes of fatigue need to be considered and it is often an early sign of more significant issues, such as a reactive depression, post-traumatic stress disorder or general anxiety. Many long-term survivors have a marked anxiety about their health.<sup>66</sup> The wait for test results can be particularly onerous, while returning to the same institution where their initial treatment was given can bring distressing flashbacks or even responsive nausea and vomiting. Minor symptoms can bring on marked agitation about the possible cause, and it is beholden upon the caring team to put the risks of long-term problems in perspective. In other cases, patients may want to completely ignore what they have been through and refuse further follow-up. The extreme of this is to engage in risk taking behaviour such as tobacco and alcohol excess or illicit drug use.

Childhood cancer survivors often find long-term consequences in later life that are not directly related to the direct physical effects of chemotherapy or radiotherapy. In many countries (such as Australia), there are enormous hurdles to cancer survivors joining the military and developing further trade opportunities that could carry on into civilian life. Short-term memory impairment and concentration span problems, which may result from cranial radiation and intrathecal chemotherapy, reduce patients' ability to complete tertiary education or even vocational training assessments.<sup>60-64</sup> More subtle issues such as altered cosmetic outcomes or personality affects, may deny survivors of childhood and adolescent cancers promotion prospects or other advancement in their fields.

Life insurance policies are often very difficult to obtain, which is frequently an issue when they start their own families. For instance, many policies issued in this setting exclude any malignancy, even if it were to develop outside the treatment field and have no obvious link to the treatment given or the primary condition. Likewise, health insurance in many spheres may be difficult to obtain and in many regions assisted fertility (eg. IVF) is not necessarily covered in public health programs. In regions where there is no universal health coverage this can carry significant implications for these patients, both for future health issues as well as the need for routine surveillance for long-term treatment related effects.

The increasing use of molecular genetics in the diagnosis of the primary tumour raises the spectre of future employers requesting the results as part of the employment process, potentially allowing discrimination. This is of most concern in jurisdictions where part of the employment conditions involve employer funded health insurance.

In the brain tumour survivor cohort treated to high doses of radiation to large volumes, or who have suffered significant initial injury from the tumour or surgery, there is the heart-rending situation where significantly neuro-

cognitively impaired patients are reliant on their now ageing parents for many of their activities of daily living. These parents often struggle with the issue of who will care for their children when they die or become too frail to do it themselves.

Finally, one of the more insidious and common problems faced by cancer survivors is the lack of knowledge about the issues by both themselves and their treating medical practitioners. Clearly there needs to be a balance in informing survivors of their long-term risk and causing unnecessary concern. Many patients feel that they are a 'time bomb' waiting to develop a second cancer or other significant complication. The majority of patients will not develop a second cancer - their relative risks mandate an appropriate screening regimen, but an understanding of the risk is critical for their peace of mind. In a busy oncology clinic, the needs of acutely unwell and newly diagnosed patients generally take precedence over those who are apparently cured and healthy. In our practice, we find that a consult in our dedicated late effects clinic - with the same patient we saw last in an acute clinic, and often in the same clinic room - is profoundly different in the scope of issues covered. Indeed, we have a number of patients in whom there is a correspondence trail between their family doctor asking for advice about issues and the oncology team answering that it is not related to their cancer and thus not appropriate for them to address. How should these patients be cared for now?

At one end of the spectrum is the concept discussed above, whereby once a patient is deemed cured they are discharged into their family physician's care. The other end is regular detailed follow-up in a multidisciplinary long-term follow-up clinic. The problem with the first option is that it places a lot of reliance on the family doctor to keep up-to-date with a wide range of potential issues for what may be only a couple of patients in their practice. Compounding this is the mobile nature of the young adult population and patients' lack of knowledge about what treatment they received, let alone the likely toxicities. The second does create its own issues. A dedicated paediatric late effects clinic can reach a steady state whereby the patients that are discharged when they reach adulthood (18 years old), are replaced by patients entering the long-term follow-up period - a revolving door concept. However, an adult clinic is more like a bucket. Patients enter the clinic either directly from their oncology team or from the paediatric long-term follow-up unit and, due to the high cure rates and low mortality from late effects, and with no ongoing plan will stay there. The clinic initially ran second monthly, but over the last 10 years is now bursting at the seams with a fully booked clinic every week.

### Shared care

Clearly a shared care model is appropriate.<sup>68</sup> The model that we are developing in our centre is based on a stratified shared care system. On entry to the clinic patients will be assessed as low, intermediate or high risk. Low risk patients would include such groups as a stage I Wilms tumour treated with surgery and simple chemotherapy. These patients would be able to be discharged into their family physician's care with important provisos.

The first is that the patients are given a survivorship care plan which outlines the treatment they have received, the risks identified as a result of the treatment and the recommended screening investigations and lifestyle modifications. This would enable the patient to change doctors without compromising their ongoing care, and would also give the family doctors guidance. The second proviso is the need to have a feedback loop, so that the long-term follow up clinic knows who the local doctor is, what tests have been ordered and what the results are. This is necessary to ensure that the appropriate care is being delivered and to allow contact with both the patient and the family doctor should new information about potential late effects become apparent. In a survey of GPs from the Netherlands, 97% of GPs were willing to participate in the long-term care of survivors and 64% felt that it was their responsibility.<sup>69</sup>

The intermediate risk group would be patients who need regular surveillance and imaging, but not on an annual basis. This would include any patients who had had radiotherapy, high dose anthracyclines or endocrinopathies. Again a passport and management plan is essential, as is the feedback loop to a robust database. For instance, structural imaging for second malignancy surveillance or echocardiograms for delayed cardiotoxicity may be done every two to three years. Subsequent review in a multidisciplinary setting could alternate with yearly bloods, blood pressure checks and lifestyle modification counselling by the GPs.

The high risk group would be those who need annual multidisciplinary review in a tertiary centre. Again the passport and database would be essential to inform the GPs for the care between visits to the long-term follow-up clinic. Patients in this group would include brain tumour/cranial irradiation patients and bone marrow transplant recipients.

In the Netherlands survey, GPs felt that to participate in a shared care program they needed availability of guidelines (64%), sufficient information about the patient's medical history (37%) and short communication lines (45%). The main barriers to participation were felt to be workload (16%), lack of knowledge (15%) and lack of communication from the parent institution.<sup>69</sup>

The challenges facing long-term follow-up programs mirror those of oncologists caring for adults, especially in diseases that have significant cure rates. Hopefully, a working model for childhood and adolescent cancer survivors will extrapolate easily to the appropriate care of cured adults.

As a profession, we have only been curing childhood cancers reliably for 30-40 years. This is the span of many of our senior colleagues' and mentors' working lives. We need to provide robust and thorough follow-up, both for our current patients' sakes, and through surveillance and research, patients that are yet to come through our doors. It may well be that in 200 years, our professional descendents look upon our crude therapies much as we look upon the gross surgeries performed without anaesthesia 200 years ago. The question for our profession is how we will be viewed with regard to the care we have provided for our patients.

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# CANCER SURVIVORSHIP: RESEARCH PRIORITIES AT THE NATIONAL AND INTERNATIONAL LEVELS

**Afaf Girgis<sup>1</sup> and Phyllis Butow<sup>2</sup>**

1. Centre for Health Research & Psycho-oncology, Cancer Council NSW. University of Newcastle & Hunter Medical Research Institute, NSW.

2. Centre for Medical Psychology and Evidence-based Decision-making, University of Sydney, NSW.

Email: Afaf.girgis@newcastle.edu.au

## Abstract

With an increasing number of people living with and beyond a cancer diagnosis, research addressing the needs of this population has consistently been identified as one of the key priorities for a global survivorship agenda. Within an international context, US, UK and Canada have been key players in priority setting activities, with the consistency across these nations lending support for a global survivorship research agenda. Priorities identified include: development of tools and instruments for use in survivorship research; development of effective care models and interventions; investigation of long-term effects of cancer diagnosis and treatment on patients, their families and caregivers; and needs and characteristics of unique or disadvantaged populations. An overview of the research being undertaken in Australia suggests a high level of congruency with international priorities, with a wide spectrum of research addressing issues across the whole survivorship continuum. However, support is needed for further work to progress our understanding of survivorship issues within an Australian context, particularly in the areas of unique populations, lifestyle factors and effective care models.

## A brief scan of international survivorship research priorities

Due to advances in early detection and treatment, the number of people living with and beyond a cancer diagnosis is growing annually and it is imperative we increase our understanding of the unique needs of this population. Research addressing the health and life of a person with a history of cancer has consistently been identified as one of the key priorities for a global survivorship agenda. The Institute of Medicine's seminal report, *From Cancer Patient to Cancer Survivor: Lost in Transition*,<sup>1</sup> includes among its 10 recommendations, three specific to survivorship research. First is a recommendation to increase support for survivorship research, including research initiatives focused on patient follow-up to help guide effective survivorship care. The second relates to the development of evidence-based clinical practice guidelines for survivorship care and the third, to the development and implementation of measures of quality of survivorship care.<sup>1</sup>

From an international perspective, the US, UK and Canada have been key players in guiding current research priority setting activities. Following is a brief overview of the survivorship areas identified for priority research from these three countries.

### From the US

In recognition of the large number of individuals now surviving cancer for long periods of time and their unique and poorly understood needs, the National Cancer Institute established the Office of Cancer Survivorship (OCS) in July of 1996. Since its inception, the OCS has spearheaded major funding initiatives geared towards the stimulation of research on long-term cancer survivorship.

The mission of the OCS is to enhance the quality and length of survival of all people diagnosed with cancer and to minimise or stabilise adverse effects experienced during cancer survivorship. This is accomplished through: a variety of funding mechanisms; liaisons with researchers health professionals and the public to build common research agendas; and through assistance to the National Cancer Institute and other organisations concerned with the educational, medical and supportive care needs of survivors.

The OCS conducts and supports research that both examines and addresses the long and short-term physical, psychological, social and economic effects of cancer and its treatment among paediatric and adult survivors of cancer and their families. As well as supporting exploratory levels of research, the OCS is seeking to expand its research portfolio to include descriptive and analytical studies documenting the physiologic, psychosocial and economic effects of cancer and its treatment on survivors, as well as intervention studies to develop and test new strategies to prevent or reduce adverse outcomes and promote optimal health and well-being after cancer treatment.

Currently, the OCS has identified a number of priority areas.<sup>2</sup> These include:

- understudied cancer sites, such as colorectal, lung, and head and neck
- health disparities in cancer survivorship among minority or disadvantaged populations
- the impact of cancer treatment, and the sequelae of cancer survivorship on family or caregivers
- economic outcomes relating to the impact of survivorship on work and financial status



- access to, and the impact of, patterns of care on the morbidity and mortality among survivors
- research addressing healthy lifestyle and behaviours such as those affecting cancer risk, promoting well-being and improve health and surveillance practices
- communication initiatives aiming to develop educational and training programs for cancer survivors and their families and friends, and exploring the information needs of cancer survivors
- development of instruments for assessing needs and health-related outcomes suitable for use with long-term cancer survivors, which permit cross-comparison with healthy or chronically ill populations.

### From the UK

In 2008, the Department of Health and Macmillan Cancer Support launched the *National Cancer Survivorship Initiative*. A think tank event, Making the Cancer Survivorship Agenda a Reality, attended by a wide variety of stakeholders including researchers, consumers and research funding organisations, highlighted that survivors of cancer have a range of physical, psychological, social, spiritual, financial and information needs. The think tank identified the following as priority areas:

#### 1. Research

Further extensive review is required to inform and improve the future assessment and outcomes for patients, including service planning and commissioning. Activities incorporated into this work stream will include:

- prevalence modelling
  - determination of the natural history for each site specific cancer
  - linking of databases and cancer registries to enable healthcare analysis
  - systematic review of existing survivorship literature
  - cohort studies
  - methodology for evaluating new service models.
2. Survivorship care plans and testing and evaluating new service approaches.
  3. Expert patient program - evaluation of new and existing approaches to care.
  4. Late effects of treatment.
  5. Management of active and progressive disease.
  6. Survivors of childhood, adolescent and young adult cancer.
  7. Work and finance.

A summary report of the think tank is available.<sup>3</sup> Seven work streams were subsequently set up to look into the health care services and support available and how these may be improved, extended and adapted to best serve the needs of survivors. The research work stream is working to bring together partners, representatives of other cancer charities, researchers and consumers in

order to identify the knowledge gaps and define the future research agenda.

### From Canada

Most recently, an environmental scan of cancer survivorship across Canada recommended identifying topics for a national research agenda as a key priority for cancer survivorship research.<sup>4</sup> The Canadian Partnership Against Cancer, an independent organisation funded by the Federal Government to accelerate action on cancer control, determined priorities in survivorship through a comprehensive approach which included an invitational workshop held in March 2008 involving 84 participants, around one-third of whom were cancer survivors. The workshop identified seven priorities for a Canadian survivorship agenda, one of which was research, including the development of stronger collaborations across institutions.<sup>5</sup>

A second workshop held in November 2008 focused on advancing the research agenda and included attendees from community treatment agencies, community-based organisations, academic institutions, policy oriented organisations and cancer survivors. Importantly, funders were invited to be involved in the planning process. An iterative process was used to prioritise unanswered questions in survivorship research identified by the participants. In total, 30 priorities were agreed from an initial pool of 250 questions identified by participants as unanswered at this stage. Strategies to address each of the priority areas were then developed.

The top five priorities identified for cancer survivorship research were:

- measurement and development of relevant and appropriate tools for use in survivorship research (seen as underpinning all the other research priorities)
- effective care models across a range of issues
- effective interventions across a range of issues
- mechanisms underlying long-term effects of cancer diagnosis and treatment (including behavioural, psychological and physical effects)
- needs and characteristics of unique populations.

Strategies recommended to address these priorities are outlined in detail in the report of the workshop.<sup>6</sup> However, some overarching themes which were seen as important for the advancement of these priority areas included:

- identification/collation of current knowledge and further refinement of key areas of investigation
- targeted funding for survivorship research
- forging partnerships across institutions to encourage collaboration between researchers/clinicians, and multidisciplinary/multi-site research
- access to clinical trials data and establishment of clinical trials groups for survivorship.

A key outcome of the workshop was identification of the need for a coordinated program of research incorporating translational aspects, to ensure best practice is implemented in the long-term.

It was recognised that the difficult task ahead was to maintain the momentum of priority setting and create action in advancing the identified priorities. While future work in this area is characterised by opportunities as well as barriers, national recognition for the importance of research in cancer survivorship is at an unprecedented level, with major funding bodies for cancer research in Canada having embraced survivorship as a key priority.

### **Australia: punching above its weight in addressing survivorship research priorities**

International cancer survivorship research priorities and current focus areas reveal a high level of consistency across the main players involved, lending support for a global survivorship research agenda. It is vital that Australian research is congruent with such an agenda, and that the research being funded helps to address the identified priorities.

Survivorship is recognised as a critical issue in most Australian cancer plans, sometimes implicitly, at other times explicitly. For example, the *National Services Improvement Framework for Cancer* states a guiding principle behind the framework is that cancer care should span “the continuum of care and life course for the condition – embracing where required prevention, screening, diagnosis, management, rehabilitation, living with the condition and palliation”.<sup>7</sup> In its conclusion regarding management and support after and between treatment, it states: “The absence of research about good practice, guidelines for service provision or data about current practice in Australia illustrates the relative lack of attention outside the treatment context. There is an urgent need for increased research data and the development of organised and co-ordinated approaches to care.”

To date, there have been no integrated Australian efforts to develop a survivorship research agenda. Individual researchers have conducted a wide spectrum of research on survivorship, ranging from qualitative to epidemiological research, addressing issues across the survivorship continuum. These have included studies on the:

#### ■ **Meaning of survivorship**

A number of qualitative studies have been conducted identifying the subjective experience of cancer survivorship. For example, concepts of liminality, hope and awareness of death as central themes to the survivorship experience have been identified.<sup>8</sup> Liminality is a state of being on the “threshold” of or between two different existential planes. In one study,<sup>8</sup> an initial acute phase of liminality was identified, marked by disorientation, a sense of loss and of loss of control, and a sense of uncertainty, followed by an adaptive, enduring phase of suspended liminality, in which each patient constructs and reconstructs meaning for their experience.

#### ■ **Unmet needs and distress in survivors and their caregivers**

Several Australian research groups have developed and validated measures of unmet needs for survivors and their carers,<sup>9-11</sup> and documented the nature,

prevalence and severity of distress and unmet needs in cancer survivors.<sup>12-16</sup> Australian research funded by the National Health and Medical Research Council and Cancer Council NSW is underway, exploring the impact of cancer over the first five years post-diagnosis, for cancer survivors and for their partners/caregivers.

#### ■ **Fear of recurrence**

Several groups have documented the prevalence of fear of recurrence in cancer survivors. For example, in one study fear of recurrence was reported as the most common unmet supportive care need in a large cohort of patients in NSW, concurring with the results of many other studies.<sup>17</sup> Australian research funded by the National Breast Cancer Foundation is underway, exploring the prevalence, predictors and outcomes of high levels of fear of recurrence.

#### ■ **Long-term side effects of cancer treatment**

Australian groups are working on the prevalence, causes and intervention to improve long-term side-effects of cancer treatments, such as cognitive dysfunction after chemotherapy,<sup>18,19</sup> lymphoedema<sup>20-23</sup> and infertility.<sup>24,25</sup>

#### ■ **Occupational and insurance issues in survivorship**

Work in occupational and insurance issues has been undertaken both in the context of those at high risk of cancer,<sup>26</sup> and those who have been diagnosed with cancer.<sup>27</sup>

#### ■ **Lifestyle interventions to improve survival and quality of life**

Several groups have explored the relationship between lifestyle factors, such as exercise and diet, and outcomes for people with cancer.<sup>28,29</sup> Studies evaluating interventions to increase exercise in cancer survivors are underway in Queensland<sup>29</sup> and NSW.

#### ■ **Models of follow-up care**

There is increasing interest in survivorship care plans and follow-up in the Australian context,<sup>15,30-31</sup> with studies underway piloting interventions to improve these.

#### ■ **Supporting patients with advanced cancer**

A small number of Australian studies have investigated strategies to support and inform patients with advanced cancer and manage their pain.<sup>32-35</sup>

#### ■ **Needs of specific populations**

Australian studies have explored the needs of specific populations experiencing cancer survival, such as migrants<sup>36</sup> and rural patients.<sup>37</sup> Other studies have explored patterns of care in Indigenous patients,<sup>38</sup> but without a specific focus on survivorship.

## **Conclusions**

The above summary highlights that the research currently undertaken nationally is well within the scope of survivorship research priority areas identified internationally. However, further work is needed to progress our understanding of

survivorship issues within an Australian context, particularly in the areas of survivorship issues in unique populations, the influence of lifestyle factors and behaviours on the health and wellbeing of survivors, and flexible and cost-effective models for providing survivorship care. Studies in these areas are underway in Australia and these need to be supported.

While it is important that our national research agenda assists in advancing our knowledge and understanding of issues faced by cancer survivors in an Australian context, it is imperative that research priorities are guided by those identified through international priority setting activities.

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# MEASURING THE UNMET NEEDS OF THOSE WITH CANCER: A CRITICAL OVERVIEW

**Rob Sanson-Fisher, Mariko Carey and Christine Paul**

Priority Research Centre for Health Behaviour, University of Newcastle. Hunter Medical Research Institute, NSW.

Email: Rob.Sanson-Fisher@newcastle.edu.au

## Abstract

Unmet needs scales are a way of eliciting cancer patients' perceptions of their need for help in order to achieve optimal psychosocial wellbeing. This represents a bottom-up approach to the assessment of psychosocial wellbeing. It may be used in conjunction with traditional top-down, expert driven methods of conceptualising psychosocial status. While there has been an expansion in the development of unmet needs scales for cancer patients, survivors and significant others, there remains a need to ensure that these measures are psychometrically robust. Predictive validity, in particular, has been largely unexamined. More work is needed to establish the clinical utility of unmet need scales and how to define what represents meaningful changes on these measures.

Over the past two decades there has been increasing interest in finding mechanisms to improve cancer patients' and survivors psychosocial wellbeing.<sup>1</sup> Such efforts require robust and effective measures in order to establish prevalence of psychosocial concerns and to evaluate the effectiveness of interventions. This has resulted in increased attention to the development and testing of measures designed to elicit psychosocial wellbeing.<sup>2</sup> Several different ways of conceptualising the impact of cancer on psychosocial wellbeing have been proposed. These approaches may be broadly classified as top-down or bottom-up methods. It is useful to consider unmet needs measures within this context.

## Top-down method of estimating patients' needs

Some attempts to estimate patients' needs have stemmed from an expert driven approach, whereby health professionals take responsibility for determining patient needs.<sup>3,4</sup> This 'top down' approach assumes that health care providers are in the position of expert and therefore are capable of making accurate judgments about the psychosocial wellbeing of a patient. This approach requires the health professional to determine whether or not the individual is depressed, anxious or has other psychosocial concerns requiring intervention. Research in a number of fields including medical oncology, suggests that the ability of health care providers to make judgments which agree with standardised measures of depression and anxiety is questionable.<sup>5</sup>

A variation of the top-down approach is reflected by the use of psychological scales which attempt to mimic clinical judgments. Responses to such scales are used to define cancer patients and survivors as being cases (eg. clinically depressed or anxious), non-cases or borderline.<sup>6,7</sup> The accuracy of this judgment is tested by making comparisons against a psychiatrist's judgement when they are using a standardised interview. Accuracy of the scale is defined by the specificity and sensitivity of the cut point used in the scale in relation to the expert judgement.<sup>8</sup> Commonly used

examples include the Hospital Anxiety and Depression Scale,<sup>6</sup> Depression Anxiety and Stress Scale,<sup>9,10</sup> Brief Symptom Inventory,<sup>11,12</sup> and Beck Depression Inventory.<sup>13</sup> An advantage of the top-down approach is that the use of a gold standard criterion provides a common language.<sup>14</sup> This allows for a person to be defined as depressed or anxious in a standardised way across settings. However, such external definitions do not take into account patient views about their wellbeing or their willingness to accept interventions.

## Bottom-up – an alternative approach

This framework acknowledges the need to involve patients in decision making about their own healthcare and wellbeing.<sup>15</sup> The cancer survivor is accorded 'expert' status alongside the healthcare professional. This approach owes much to the growth in the consumer movement and the acknowledgment that patients have the right to be involved in their care and decision making.<sup>16</sup> An essential element of this approach is not only that the patient indicates that they have a problem, but also their choice about whether they wish to seek assistance for that problem. These two complementary components of the patient perspective: i) expert status and ii) determining whether help is required, differentiate the bottom-up approach from the more usual top-down framework.

While value placed on the patient view in the bottom-up approach is in line with principles of patient-centred care, the approach does have disadvantages. For example, a diagnosis of depression may reduce one's ability to self-identify as depressed and seek help. Additionally, some patients may be unaware of the availability of effective interventions.

## A hybrid approach

There is a potential role for both approaches when attempting to improve cancer patients' psychosocial wellbeing. The need for monitoring and, when necessary, intervening in an effort to assist patients with depression or anxiety is seen as an integral part of cancer care.<sup>17</sup>

A two step process involving a screening tool as an initial mechanism to detect those at risk, followed by a clinical assessment, is often advocated.<sup>18</sup>

However, the need to elicit cancer patients' perceptions regarding what problems they want addressed is increasingly accepted. This acknowledges the respondent's right to make decisions about what is appropriate for them, irrespective of the views of healthcare providers. It also acknowledges that in many domains the patient is arguably the best judge of their need for help. Patient's views about their unmet needs have therefore become increasingly important.

### Some examples of existing unmet need questionnaires

Unmet need scales can be broadly classified in terms of stages of the cancer 'journey'. Some scales estimate treatment related unmet needs, some focus on issues for cancer survivors and others focus on unmet needs relating to advanced or terminal stage issues. Given the differing demands of these phases of the disease trajectory, it is unlikely that measures designed for patients in one of the groups will accurately reflect concerns relevant to the other group. The following is a brief and non-exhaustive overview of some of the more commonly used scales designed to identify patient concerns over a range of domains of need.

#### **Cancer patients undergoing treatment**

Among the scales developed to assess cancer patients' needs during the treatment phase is the Supportive Care Needs Survey.<sup>19</sup> This is a 52 item scale which uses a five point response scale. The questionnaire covers unmet needs relating to health information, psychological wellbeing, sexuality, patient care and support, and physical and daily living needs. Test-retest reliability, face and construct validity have been established.<sup>19</sup> The Patient Information Needs Questionnaire is a self administered, 17 item questionnaire which allows the patient to indicate the need for information about the disease and treatment, as well as issues surrounding access to help and solving practical problems.<sup>20</sup> The Creating Better Health Outcomes by Improving Communication about Patients Experiences questionnaire was designed as an assessment tool for cancer specific symptoms and associated functional problems.<sup>15,21</sup> It can be administered via touch pad computer tablet and has questions and answers tailored to individual responses to problem areas from a potential list of 16 categories. It asks patients to indicate their agreement or views regarding the severity of their symptoms and needs and rate the importance of their problems.

#### **Cancer survivors**

There are two general types of response scales used in the measurement of cancer survivors' needs: i) defining the extent of the perceived problem and ii) exploring patients' desire for help.

The Cancer Rehabilitation Evaluation System is a generic measure of health-related quality of life items which is argued to be specific to cancer.<sup>22</sup> The 139 items can

be completed via computer. The global score is said to indicate overall quality of life and five summary tables reflect important domains - physical, psychosocial, medical interaction, marital and sexual. The scale is presented as being suitable for outpatients with a variety of different cancer types.<sup>22</sup> The Quality of Life Cancer Survivors was developed to measure the specific concerns of long-term cancer survivors.<sup>23</sup> This instrument consists of 41 items representing four domains of quality of life, including physical, psychological, social and spiritual wellbeing, as well as unique areas of concerns for cancer survivors. This scale demonstrated high reliability, reproducibility and validity. The Quality of Life in Adult Cancer Survivors asks cancer survivors to rate their satisfaction on a seven category frequency scale (ranging from never to always).<sup>24</sup> It consists of 47 items tapping into 12 domains, seven generic and five cancer specific. This multidimensional scale enables comparisons to be made between cancer and non-cancer populations. Its domain and summary scores showed good test-retest reliability, internal consistency and convergent validity with other measures designed to assess generic HRQoL measure.<sup>25</sup>

The Survivor Unmet Needs Survey asks survivors to rate 83 items on a scale from zero (having no unmet need) to four (having a very high unmet need).<sup>26</sup> The scale assesses unmet needs in relation to five factors - emotional and mental health, medical care, relationship, jobs and finance, and concerns about the future. It was specifically constructed to be psychometrically rigorous while assessing a range of unmet needs of cancer survivors.<sup>26</sup> The Cancer Survivors' Unmet Needs Measure was designed to assess and identify needs in the general population of cancer survivors.<sup>27</sup> It includes 35 need items covering existential survivorship, comprehensive care, information, quality of life and relationships, and six positive change items. The scale demonstrated good acceptability, internal consistency and validity, although test retest reliability was low.

The findings of studies using these scales suggest survivors do have a range of unmet needs well beyond the treatment phase. For example, it was found that in breast cancer survivors, the highest unmet need was associated with existential survivorship, which addresses concerns with making decisions in the context of uncertainty and existing issues.<sup>28</sup> In long-term survivors, the most frequently reported problems were sexual problems, family related concerns and relationship problems.<sup>24</sup> Concerns about cancer recurrences were high in this population, highlighting the unique needs of cancer survivors.<sup>24,28</sup>

#### **Advanced stage or terminally ill cancer patients**

Limited work has been undertaken to develop unmet need questionnaires for patients with advanced cancer and those who are terminally ill. Among these is the scale developed by Rainbird and colleagues.<sup>29,30</sup> The Needs Assessment for Advanced Cancer Patients was developed, based on a review of available literature and professional opinion. Principal components analysis revealed seven domains assessing patients'

psychological/emotional, medical information/communication, social, symptom, daily living, spiritual and financial needs. The test-retest reliability estimates were within accepted levels, as were all but one of the internal consistency scores.<sup>28</sup> The scale was highly acceptable for this patient group.

### **Cancer survivors' significant others**

There is growing recognition of the impact of cancer on those close to a patient. Significant others may be partners, relatives or friends. Only recently has there been an attempt to identify the unmet needs of this group. The Support Persons' Unmet Needs Survey is a 76 item self report scale to measure the unmet needs of the primary support person of a cancer survivor.<sup>31</sup> As with the Survivor Unmet Needs Survey, iterative consultations occurred with consumers, clinical providers, allied health workers and psychosocial professionals, which led to the initial development of a draft questionnaire for support persons. Six factors were established via principal components analysis: informational needs; personal and family concerns; emotional and mental health issues; medical care needs; concerns about the future; and work issues. The Cancer Survivors' Partners Unmet Needs measure is a 35 item scale with items relating to five factors: relationships, information, partner issues, comprehensive care and emotional support.<sup>32</sup> The scale has high internal consistency, good convergent validity, but moderate test-retest reliability.

### **How well are unmet needs measured?**

There has been a notable expansion in the use of unmet need questionnaires. While there are patient benefits associated with this movement, caution about widespread adoption of the approach and its associated measurement scales must be considered. An overriding concern is whether the existing scales are psychometrically robust, accurate and sensitive measures of unmet needs. A review of needs scales for cancer survivors indicated that few met basic psychometric criteria.<sup>2</sup> Among the problems associated with the scales was the tendency to focus on the internal consistency of the scale as the principal indicator of its reliability.<sup>33</sup> Test-retest reliability of a measure's total score, sub-scale scores, or items, for example, are not often examined.<sup>2</sup> Item test-retest reliability may be particularly informative.<sup>34</sup> It is possible that similar scores at time one and two can be obtained for the sub-scales and overall scores, however the patients have endorsed different items. Item reliability is therefore important but infrequently examined.

It is common for scales to have demonstrable face, content and construct validity.<sup>32</sup> Higher levels of unmet needs are cross-sectionally associated with higher psychological distress, greater complementary and alternative medicine use and poorer quality of life.<sup>24,28,35</sup> While some more recent scales that are applicable to cancer survivors (eg, Survivor Unmet Needs Survey) have been subjected to more rigorous psychometric testing, yet to be considered and tested is whether high unmet need scores predict future outcomes. For example, do high scores on unmet

need measures predict that patients will have depression, consult more frequently with alternative or traditional medicine or visit emergency departments? We know of no studies which have undertaken this difficult task of predicting what a high or low score on unmet need questionnaires might mean for other important outcomes.

### **Issues for the future**

A driving impetus behind the assessment of unmet need is the goal of intervening and reducing needs. There have been several randomised control trials which have attempted to address unmet needs of cancer patients. One found a limited effect for a face-to-face session and follow-up phone call from a breast care nurse in reducing the unmet needs of women with advanced breast cancer.<sup>36</sup> Needs were reduced only on the psychological subscale of the Supportive Care Needs Survey and only for those participants who reported high levels of need at baseline.<sup>37</sup> A recent randomised trial undertaken by White and colleagues (presented at the 8th Biennial Cancer Control Conference, but not yet published) examined the use of well-trained volunteers who attempted to address unmet needs identified by bowel cancer survivors who were within three months of diagnosis, in order to reduce depression, anxiety and unmet needs.<sup>38</sup> The study was one of the largest of its type involving over 300 participants in each group. No intervention effect was demonstrated on the Supportive Care Needs Survey. This finding echoes other research by Boyes et al and a large randomised control trial undertaken by McLachlan and colleagues.<sup>18,39</sup> However, the latter studies were conducted with cancer patients currently undergoing treatment.

In these studies it is unclear whether failure to produce a treatment effect is the result of ineffective treatment strategies, lack of specificity in the unmet needs measure, or unmet needs being a reflection of the endemic uncertainty associated with a diagnosis of cancer. The likelihood that unmet needs naturally decrease during the survivorship phase suggests that at this stage, it is impossible to determine which of these alternatives is accurate. However, the field should continue to attempt to refine the psychometric qualities of unmet needs questionnaires and then use these modified questionnaires to test the effectiveness of intervention strategies with methodologically stringent research designs.

Statistically significant change in an outcome is often the yardstick by which the success of an intervention is measured. However, this criterion fails to take into account whether the intervention has a meaningful impact on patients' wellbeing.<sup>40</sup> Methods for establishing the clinical significance of changes in unmet needs scores have not been well developed. For quality of life measures, methods for assessing clinical significance have included assessment of survivors' views about what constitutes a meaningful change or anchor-based methods.<sup>41</sup> Establishing how clinical significance can be defined for unmet needs could be an important focus of future work.

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## FUEL, BEDS, MEALS AND MEDS: OUT-OF-POCKET EXPENSES FOR PATIENTS WITH CANCER IN RURAL QUEENSLAND

Louisa G Gordon,<sup>1</sup> Megan Ferguson,<sup>2</sup> Suzanne K Chambers<sup>2,3</sup> and Jeff Dunn<sup>2,4,5</sup>

1. Queensland Institute of Medical Research, Cancer and Population Health Studies, Queensland.

2. Viertel Centre for Research in Cancer Control, Cancer Council Queensland.

3. School of Psychology, Griffith University, Queensland.

4. School of Social Science, University of Queensland.

5. School of Public Health, Tropical Medicine and Rehabilitation Sciences, James Cook University, Queensland.

Email: Louisa.Gordon@qimr.edu.au

### Abstract

**Objective:** Cancer patients who travel long distances to access medical services face considerable disruption and personal financial cost. This study quantified the financial cost of receiving cancer treatment for individuals residing in regional, rural and remote locations.

**Method:** Adults diagnosed or treated for cancer at the Townsville Hospital Cancer Centre within the last 30 months who most recently presented to the cancer centre within the previous six months were recruited to this cross-sectional study (n=439). Direct out-of-pocket expenses relating to travel, accommodation and other expenses were estimated together with financial support received. Bootstrapping statistics assessed significant subgroup differences in costs with 95% confidence intervals.

**Results:** Over an average period of 16 months since diagnosis, net out-of-pocket expenses of \$1.8 million were reported for 410 regional men and women relating to their cancer treatment (mean \$4311, median \$2263, inter quartile range \$563-\$6231). Personal costs were significantly higher for participants who lived more than 100km from Townsville Hospital (\$7752) and for those treated with radiation (\$5135).

**Conclusion:** Financial costs for rural cancer sufferers vary widely and may be extensive. Consideration of adequate financial support from governments and other organisations is essential if rural Australians are to continue accessing standard cancer treatment.

Each year in Australia doctors tell more than 100,000 people that they have cancer (excluding squamous and basal cell skin cancers).<sup>1</sup> Thirty-six per cent of new cancers are diagnosed among people living in regional, rural and remote areas,<sup>2</sup> while the proportion of the Australian population living in regional, rural and remote areas is 32%.<sup>3</sup> As new cancer diagnoses are over-represented in rural Australians, this has important implications for cancer stage at diagnosis, treatment processes, and impact on families, as well as additional personal expenses associated with treatment and follow-up care. Despite improvements in screening and treatment that have extended the five-year survival rates during the last two decades for many common cancers,<sup>2</sup> rural cancer patients have not shared these survival benefits equally with their city counterparts.<sup>4-6</sup>

Access to effective healthcare is particularly difficult for patients living in rural and remote areas when the

majority of medical specialists are located in urban centres. Individuals with cancer who require radiation treatment, normally given daily for six weeks, have substantial relocation needs and role disruption. These treatment demands and the associated financial pressure for many patients and families, already struggling to cope with a life-threatening condition, can be very stressful and especially concerning for low-income patients or those already experiencing economic hardship.<sup>7</sup> Although medical concerns are of primary importance to doctors and patients, financial distress contributes to the context in which patients make decisions about treatment and recovery.<sup>8</sup> Therefore, high perceived out-of-pocket costs may potentially cause treatment delays or non-compliance for those living in areas remote from treatment centres.<sup>8,9</sup> Furthermore, financial concerns may also lead patients to entirely opt out of recommended treatments, potentially



contributing to and partially explaining the poorer survival outcomes for rural cancer patients.<sup>2</sup>

In an attempt to contain costs, hospital systems are shifting the management of many diseases on to patients and families. Early discharge programs and outpatient care are successful only if individuals are adequately supported in their physical, psychosocial and financial needs.<sup>10</sup> In the future, the need for financial and other assistance for patients with cancer is likely to increase substantially due to: an ageing population and the associated increased numbers of cancers expected; increases in complex health needs due to multidisciplinary cancer care and promotion of national screening services; advances in oncology pharmaceuticals and the potential for prolonged treatment regimes caused by multiple courses of chemotherapy; highly specialised and expensive equipment being limited to hospitals/specialist centres, requiring patients to travel for treatment; possible rationalisation and centralisation of health services by state and territory governments; and increased needs accompanying ongoing surveillance for detection of tumour recurrences and follow-up visits by doctors as a result of improvements in survival rates.<sup>11,12</sup>

To improve patient access to medical treatment in Australia, all states and territories have established Patient Assisted Travel Schemes (PATS) that provide limited travel and accommodation subsidies to eligible patients. Other forms of financial assistance and practical support may come from private health insurers, the government Home and Community Care program and numerous not-for-profit organisations (eg. state and territory Cancer Councils, the Leukaemia Foundation etc). However, some patients with cancer and their clinicians are not aware of these available support systems.<sup>13</sup> While clearer information on patient costs may encourage health professionals to identify patients who may benefit from referral to appropriate support agencies, it may also help those diagnosed with cancer to plan for anticipated costs. The purpose of this study was to quantify the actual out-of-pocket costs and identify factors for high-costs incurred by non-urban cancer consumers accessing their nearest tertiary cancer treatment centre.

## Methods

Patients presenting consecutively to Townsville Hospital Cancer Centre, Queensland, were recruited through their treating oncologist or clinic staff (n=439). Adult patients were eligible if they had been diagnosed or treated for cancer at the centre within the previous 30 months and had most recently visited the centre within the six months prior to study commencement. Patients with prostate cancer were excluded due to a pre-existing study.<sup>14</sup> Ethical clearance was obtained from the Townsville Health Service District Human Research Ethics Committee.

Data collection occurred from August 2006 to February 2007, and consenting participants were assessed through a computer-assisted telephone interview. Questions covered items on: demographic characteristics; medical treatment; symptoms; use of psychosocial care services; and travelling and other expenses. No standardised or validated instrument was available to assess self-

reported out-of-pocket cost information, so the authors developed these items. Economic questions included: mode of travel; number of visits to the centre; postcode of residence; accommodation needs (prompts for known donors); health service expenditure specifically attributable to cancer using prompts (eg. GPs, other health professionals, medical tests or exams, medications, support services, other such as private nursing, child care, home assistance); financial support received for travel/accommodation and other expenses and associated donor(s); and other out-of-pocket expenses (eg. for wigs, prosthetics, lymphoedema sleeve, bills, food vouchers, etc). The questionnaire was pre-tested with a sample of 10 cancer patients, supporting the face and content validity of the economic questions. Similar questions have been previously used in a published study.<sup>15</sup>

The analysis was intended to be descriptive and exploratory rather than inferential. Cost items were quantified directly from survey responses and may or may not have been abstracted from other sources (eg. receipts, insurance/tax records). Travel costs were calculated by identifying the road distance (kms) from the patient's home suburb to Townsville Hospital using internet mapping services and valued using Australian Taxation Office vehicle running cost estimates (\$0.70 per km for a medium-size car).<sup>16</sup> Descriptive statistics showing cost distributions (ie. means, standard deviations, medians, interquartile range) and sums are presented by major cost types. Proportions of each cost type to total cost were used to gauge the relative magnitude of each cost component. To handle the skewed nature of the cost data (with many participants having zero or minimal values in some categories and a small proportion of participants having very high values), mean costs per participant were obtained using bootstrapping statistics. This was achieved by drawing 1000 re-samples from the original skewed distribution, with replacement and using the bias-corrected approach. The Wald test assessed statistically significant subgroup differences.<sup>17,18</sup> Subgroups of interest included: distance from home to treatment centre ( $\leq 100$ kms v  $> 100$ kms); private health insurance (nil v some); age ( $\leq 50$  years v  $> 50$  years); time since diagnosis ( $\leq 6$  months, 6-12 months, 13-18 months, 19-24 months,  $> 24$  months); type of cancer grouping, with breast cancer being the referent; and type of adjuvant treatment received (radiation, chemotherapy, hormone therapy, other). Spearman's rank correlation coefficient assessed the correlation between net cost and living distance from the Townsville Hospital. Tests were two-sided and results were considered statistically significant when  $p < 0.05$ . Costs were brought forward to 2008 Australian dollars using the Consumer Price Index. Data were analysed using STATA/SE V9.<sup>19</sup>

## Results

A total of 439 participants were recruited to the study representing a 61% response rate. Compared to participants, non-participants were more likely to be male (48 v 41%,  $p=0.08$ ), aged over 75 years (21 v 6%,  $p < 0.001$ ), have respiratory/thoracic cancer (12 v 7%), head and neck cancer (14 v 9%) and less likely to have breast cancer (24 v 33%,  $p=0.06$ ). There were no differences

between participants and non-participants with regard to postcode at diagnosis. A total of 29 participants (7%) were excluded from the cost-analyses; six had missing data, 10 had very extreme responses on at least one cost item (considered invalid), three had unusually large support payments with no corresponding match in expenses and 10 had not started treatment. Compared to the remaining participants (n=410), the excluded participants were more likely to be male (66%, p=0.01) and less likely to have breast cancer (14%, p=0.02). Response rates for the individual economic survey questions were >97% owing to the telephone method used.

On average, participants were aged 57 years at the time of interview. Most were partnered (70%), 42% were retired and 55% had household incomes of <\$40,000 (table 1). Only 15% of participants lived alone, while 57% lived with one other person and 27% lived with two or more persons. Forty per cent of participants were diagnosed with cancer within one year of the interview, 39% between 1-2 years and 20% >2 years. Overall, 46% of participants lived greater than 100km from Townsville Hospital and of these, 92% required accommodation, with 33% staying with family or friends and 19% staying at Cancer Council Queensland's Gluyas Lodge. Twelve (3%) participants lived greater than 600km from Townsville Hospital in locations such as Mt Isa and Weipa. Overall, 75% of participants started treatment within six weeks of diagnosis and there was no evidence of delays in starting treatment for participants living remotely from Townsville Hospital.

As a percentage of total costs, travel expenses represented the highest share (71%) followed by medical appointments (10%) and co-payments for medications (9%). Some type of financial support was received by 44% of participants, mainly for travel and accommodation expenses, with all support payments received totalling \$211,427 (median \$53, interquartile range \$0-470) or 11% of total costs. Over an average time of 16 months since diagnosis, a net total of \$1,767,357 was spent on out-of-pocket expenses relating to cancer for 410 regional men and women (mean \$4311, median \$2263, interquartile range \$563-\$6231) (table 2).

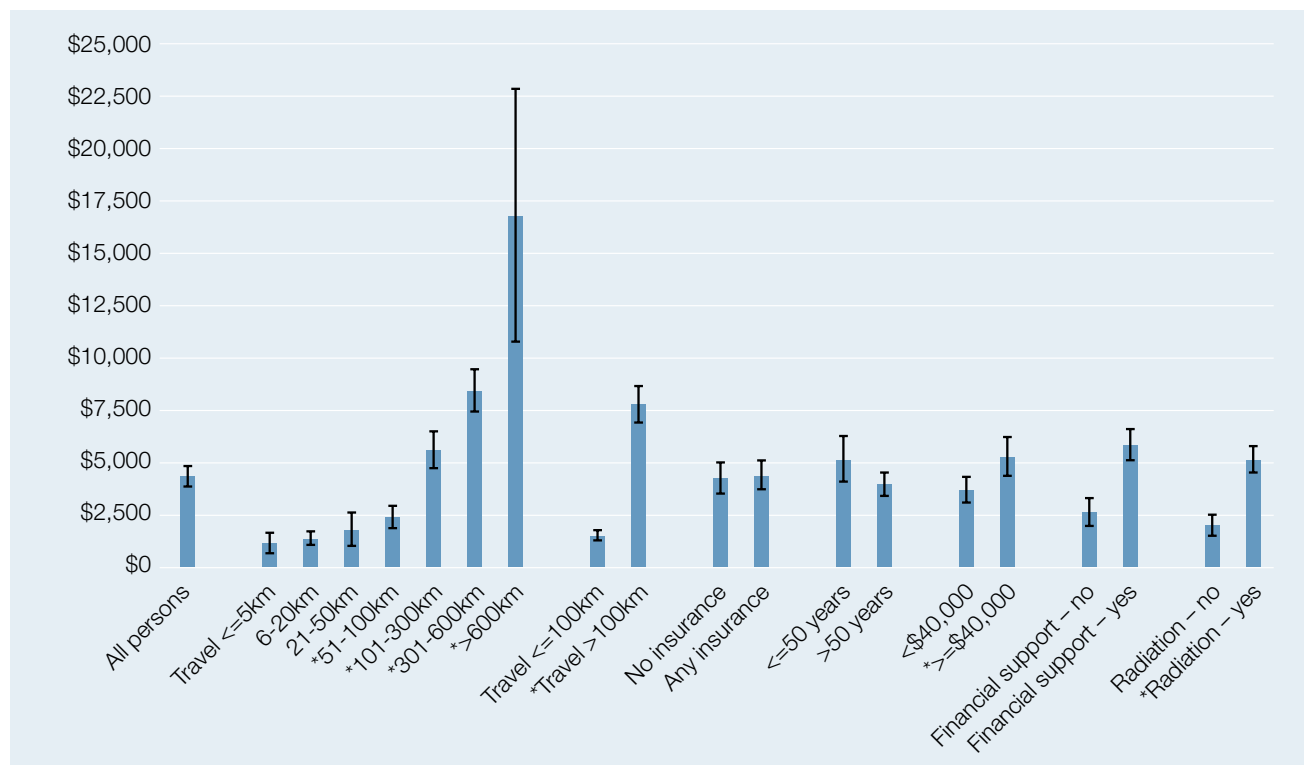
**Table 1.** Demographic and clinical profile of participants (n=410)

Characteristic	N	%
Age at interview – mean (sd)	57.4 (12)	–
Gender – female	249	61
Education level		
Primary	78	19
Secondary	185	45
Trade/certificate/diploma	71	17
Bachelor degree	65	16
Marital status		
Never married	30	7
Married/living together	287	70
Separated/divorced/widowed	93	23
Work status		
Employed full-time	86	21
Employed part-time/casual	65	16
Home duties/student/unemployed	50	12
Retired	186	42
Permanently ill/disabled	35	9
Other	5	1
Household income		
< \$40,000	226	55
≥ \$40,000	153	37
Unknown	31	8
Private health insurance		
None	220	54
Hospital plus extra	138	34
Hospital only	34	8
Some	78	4
Cancer type		
Breast	139	34
Hematology/blood	60	15
Digestive	58	14
Skin	38	9
Head/neck	36	9
Respiratory	27	7
Genitourinary	29	7
Other	23	6
Completed cancer treatment		
Yes	323	79
No	87	21
Cancer treatment (not mutually exclusive)		
Surgery	314	77
Radiation therapy	303	74
Chemotherapy	265	65
Hormone therapy	88	21
Other treatment	43	11
Time since treatment started (months) mean (sd), range	16 (10)	range 1-55

**Table 2.** Summary of out-of-pocket costs over an average 16 month period post-diagnosis by type of cost (n=410) (AUD 2008)

Cost category	Persons affected N (%)	Mean \$	SD \$	Median \$	Interquartile range \$	Total \$	% Net Total
Travel	408 (99%)	3430	4889	956	180-5013	1,399,540	0.71
Accommodation	179 (44%)	255	704	0	0-222	45,688	0.02
GP visits	83 (20%)	243	324	161	41-228	20,159	0.01
Health professional visits	135 (33%)	1408	1746	751	285-2048	190,035	0.10
Medical tests	99 (24%)	869	875	555	222-1138	86,075	0.04
Medications	208 (51%)	823	2904	261	111-798	171,123	0.09
Support services	19 (5%)	1275	1474	833	222-1707	24,216	0.01
Other services/aids	35 (9%)	1199	1645	433	213-1593	41,979	0.02
<b>Total costs</b>	<b>410</b>	<b>4826</b>	<b>5852</b>	<b>2661</b>	<b>699-6660</b>	<b>1,978,814</b>	<b>100.00</b>
Financial support received							
Travel & accommodation	182 (44%)	671	969	400	100-850	122,182	-0.06
Additional items	4 (1%)	13,500	15,695	6000	5000-22,000	54,000	-0.03
Other	66 (16%)	534	697	365	300-500	35,245	-0.02
<b>Total support received</b>	<b>410</b>	<b>516</b>	<b>2045</b>	<b>53</b>	<b>0-470</b>	<b>211,427</b>	<b>-0.11</b>
<b>Net Total</b>	<b>410</b>	<b>\$4311</b>	<b>\$5257</b>	<b>\$2263</b>	<b>\$563-\$6231</b>	<b>\$1,767,357</b>	

**Figure 1.** Bootstrapped mean net costs by sub-groups (95% confidence intervals) (\*indicates statistical significance)



Net out-of-pocket costs were five times higher, on average, for individuals living more than 100km from Townsville Hospital compared to those within 100km (\$7752 v \$1481,  $\chi^2=187.5$ ,  $p<0.001$ ) (figure 1). In addition, the positive relationship between net costs and living distance from Townsville Hospital was significant (Spearman's rho 0.714,  $p<0.001$ ). Net costs were also higher among patients with incomes  $\geq$ \$40,000 v  $<$ \$40,000 (\$5252 v \$3693,  $\chi^2=7.9$ ,  $p=0.01$ ), those who received radiation therapy compared to those who did not (\$5135 v \$1976,  $\chi^2=55.1$ ,  $p<0.001$ ) and those who received hormone therapy (\$5537 v \$3979,  $\chi^2=5.2$ ,  $p=0.02$ ) (table 3, figure 1). Costs were similar for patients regardless of their health insurance status (figure 1). While costs appeared to be higher for women with breast cancer compared with hematology/blood, digestive or genitourinary cancers, no differences were shown when compared to skin, head/neck, respiratory or 'other' cancer types (table 3). Most out-of-pocket costs appear to accumulate during the first 18 months from the start of treatment, with a mean \$6510 (95% CI \$5232-\$7789) in those first treated 13-18 months prior to being interviewed.

## Discussion

This research highlights the financial costs associated with having cancer incurred by individuals living in regional Queensland. With the exception of patients with prostate cancer, for a group of mostly typical cancer patients, many of whom were retired and/or on low incomes, patient costs associated with cancer treatment were dominated by travel expenses. Overall, patient out-of-pocket costs varied widely and were commonly between \$563 and \$6231. However, 25% of individuals in our sample incurred costs higher than this. Costs were especially high if the person lived further away from treatment, required

radiation therapy (74% of participants in our sample), or had higher incomes regardless of whether they had private health insurance.

Although accommodation costs were expected to be higher than shown here, over half the participants were able to stay with family or friends in Townsville, whereas others were able to avail the low cost or free supportive care lodgings of the non-government organisations located in Townsville. These costs would have been significantly higher for regional patients with cancer relocating to Brisbane and forced to use rental or motel accommodation near the major hospitals. The lack of self-catering facilities further increases living away costs.<sup>7</sup> In addition, our cohort was relatively young and financially disadvantaged, with 57% living with another person and 27% living with two or more people. Therefore, it is likely that our participants had dependent spouses or others and the potential implications and consequences for these families may have been considerable if the participant travelled long distances, stayed away from home and incurred significant costs for receiving cancer treatment.

Our results complement two previous studies on the economic impact of breast cancer to individuals and families in urban Australia.<sup>20,21</sup> International studies on out-of-pocket costs from cancer have limited application because they reflect different health care systems, are dated and may not reflect current treatment regimens and have small convenience samples.<sup>8,22-25</sup> However, similar to our findings, identified factors that are associated with higher individual out-of-pocket costs include advanced disease and associated medications, hormone therapy, insurance gap payments and greater travelling distances to the hospital.

**Table 3:** Bootstrapped mean net costs by subgroups (95% CIs)

	Mean \$	95% CIs \$	Chi <sup>2</sup>	P-value†
<i>Overall cost</i>	4,311	(3818, 4803)	-	-
<i>Distance to treatment</i>				
<=5km	1133	(707, 1559)	ref	
6-20 km	1371	(1037, 1706)	0.70	0.40
21-50 km	1782	(1004, 2561)	2.10	0.15
51-100 km	2369	(1834, 2905)	11.99	**
101-300 km	5575	(4716, 6,434)	82.49	**
301-600 km	8418	(7423, 9413)	175.00	**
>600 km	16771	(10,724, 22,817)	25.66	**
>100 km	7752	(6887, 8617)	187.48	**
<=100km	1481	(1245, 1718)		
<i>Private health insurance</i>				
nil	4249	(3505, 4994)	0.07	0.80
any	4382	(3711, 5052)		
<i>Age</i>				
<=50 years	5140	(4062, 6219)	3.65	0.06
>50 years	3947	(3387, 4507)		
<i>Household income</i>				
<\$40,000	3693	(3085, 4300)	7.93	*
>=\$40,000	5262	(4338, 6186)		
<i>Cancer type</i>				
breast	5469	(4541, 6397)	ref	
hem/blood	3240	(2323, 4157)	10.99	**
digestive/gas	3259	(2223, 4295)	9.45	*
skin	4257	(2466, 6048)	1.38	0.24
head/neck	4471	(2858, 6085)	1.13	0.29
respiratory/t	5552	(2377, 8728)	0.00	0.96
genitourinary	2168	(924, 3413)	17.64	**
other	3834	(1913, 5755)	2.36	0.12
<i>Treatment received</i>				
Radiation therapy - no	1976	(1455, 2497)	55.14	**
Radiation therapy - yes	5135	(4492, 5779)		
Chemotherapy - no	4228	(3363, 5094)	0.06	0.81
Chemotherapy - yes	4356	(3744, 4968)		
Hormone therapy - no	3976	(3431, 4520)	5.22	*
Hormone therapy - yes	5537	(4299, 6775)		
Other - no	4351	(3810, 4892)	0.11	0.74
Other - yes	4056	(2413, 5700)		
<i>Financial support received</i>				
No	2610	(1965, 3254)	44.53	**
Yes	5823	(5096, 6551)		
<i>Time from start of treatment to interview</i>				
≤ 6 mths	2857	(1806, 3907)	ref	
7-12 mths	4120	(3284, 4955)	3.46	0.06
13-18 mths	6510	(5232, 7789)	18.99	**
19-24 mths	4187	(2860, 5514)	2.40	0.12
>24 mths	2574	(1934, 3214)	0.20	0.65

†\* &lt; 0.05, \*\* &lt; 0.001

Like previous research in this area,<sup>15</sup> the analysis relied on self-reported survey data with the associated potential for recall bias, although telephone interview techniques helped maximise survey completion. Unfortunately, these economic data are unavailable from more objective sources, which necessitate survey methods. The demographic and clinical profiles of the participants may not be widely generalised as our sample had a higher proportion of women due to men with prostate cancer being excluded from the study. The study was observational, reflecting real life practice and included a wide mix of patients and cancer types in regional Queensland. On the other hand, the costs here are likely to be underestimated because any lost income arising

from cancer treatment or symptoms was omitted. In our study, 37% of the sample was working at the time of being told they had cancer. Productivity losses due to disease is an area of emerging research.<sup>26</sup> In addition, participants may have had more than one cancer concurrently and our questions asked respondents to concentrate on one 'main' cancer only.

For the Australian health system, the average cost per cancer case in 2001 was \$21,900<sup>27</sup> (or \$27,200 in 2008 dollars). Our findings show that individuals are contributing, on average, between 2-19% of the total cost burden of their cancer. The role of Australian governments in providing adequate transport assistance is widely regarded as having failed, while many non-

government organisations play a critical role in addressing the accommodation needs of families with cancer. Since 2000, several inquiries into cancer treatment and services have occurred.<sup>28-30</sup> In 2007, an inquiry into the special concerns for rural patients was undertaken<sup>11</sup> and, as a result, urgent calls were made to the Council of Australian Governments to: increase funding levels (unchanged since 1987) to better reflect the real costs of travel and accommodation; improve the equity and standardisation of benefits to achieve equality in health outcomes such as cross-border flexibility; allow carers of patients to receive funding; and streamline the current inefficient administrative and difficult application processes.

Beyond government, some research has suggested that clinical trial research groups, private health insurers and community groups could also have a more active role in providing travel and out-of-pocket funding to promote equity in the delivery of health services among regional Australia in the course of their respective core business.<sup>31</sup> While a number of community groups already play a role in the provision of access to health services for regional and remote Australians, more detailed investigation is required to understand the capacity of the non-government health sector and how they can most effectively articulate with the broader health system to respond to these needs. It has been argued that by not providing good transport assistance schemes, it creates a false economy because there will be additional health system costs to both federal and state governments, due to late diagnosis or treatment of conditions and increased costs to the community associated with more severe illness.<sup>11</sup> Our findings showed no differences in the time elapsed to starting treatment among those living within or beyond 100km from the Townsville Hospital. However, we did not compare directly with cancer patients living in Brisbane. Nor does it obscure the fact that cancer survival outcomes are reduced for country living Queenslanders compared to those in the city.<sup>5</sup> Our research design selected participants attending a clinical centre and therefore we have missed individuals who may have opted out of treatment completely due to their inability to access health services. Anecdotally, this appears to be occurring for some patients however, further research is required to confirm these claims.<sup>11</sup> Unfortunately, due to privacy restrictions, we were unable to provide clinical treatment information on the 39% of patients who chose not to participate in the study and therefore, we cannot rule out the possibility that treatment experiences, including delays starting or receiving treatment, were different for non-participants. There were no differences between participants and non-participants by postcode at diagnosis, which may suggest that out-of-pocket travel and accommodation expenses were similar across groups.

In conclusion, this research adds an important dimension for understanding the impact of cancer; the findings may be used to help improve supportive care services for people and families confronted by cancer. Formal travel and accommodation assistance is lacking for participants travelling more than 100km for cancer treatment. Out-of-pocket expenses necessary to access a comprehensive treatment centre for cancer are likely to be causing

financial hardship for a significant proportion of individuals living in regional, rural and remote areas in Queensland.

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## CANCER COUNCIL AUSTRALIA'S STUDENT ESSAY COMPETITION

Cancer Council Australia's annual essay competition is open to Australian residents enrolled in a medical course in an Australian university. Students are required to submit an essay on an issue related to cancer control. In 2009, the topic was *Multidisciplinary teams in cancer care: pros and cons*. The essays are judged by members of Cancer Council Australia's Oncology Education Committee.

This article is the winning essay by Monica Tang. As the winner, Monica attended the World Health Organisation's Collaborating Centre for Cancer Education's 12th International Summer School 'Oncology for Medical Students' in Vienna (8-17 July 2009).

## MULTIDISCIPLINARY TEAMS IN CANCER CARE: PROS AND CONS

**Monica Tang** ■ 6th Year Medical Student, University of New South Wales.  
Email: [monica.tang@gmail.com](mailto:monica.tang@gmail.com)



Cancer is the leading cause of burden of disease in Australia, accounting for 19% of our overall disease burden.<sup>1</sup> Based on current trends, one in three Australians will be diagnosed with cancer before the age of 75.<sup>2</sup> The incidence of cancer is rising as Australia's population ages, with a 30% increase projected over 2002-2010.<sup>3</sup> Therefore, early

detection and effective treatment are needed to control morbidity and mortality due to cancer.

Far from being the exclusive domain of surgeons and medical oncologists, cancer management today involves input from many disciplines. Due to the ever-growing complexity of cancer diagnosis and treatment, it is now impossible for a single doctor to oversee every aspect of a patient's care. Multidisciplinary teams are thus becoming increasingly important in the management of this major disease entity in Australia.

This essay will examine the relevance and delivery of multidisciplinary cancer care, advantages and

disadvantages of a team approach, as well as challenges and facilitators of multidisciplinary teamwork in Australia.

### The need for multidisciplinary care

In traditional models of multimodal cancer care, patients undergo a process of sequential referral, where they are shuttled from clinician to clinician at different stages of diagnosis and treatment.<sup>4</sup> A patient with breast cancer may initially consult a GP, who refers her to a radiologist for mammography, which is followed by a series of encounters with surgeons, radiation oncologists, medical oncologists and so on. This disintegrated approach can result in an overwhelming, confusing experience for the patient.<sup>5,6</sup> Other areas for improvement in traditional cancer care include:

- uncoordinated and fragmented care
- disjointed referral systems and long waiting times
- low patient satisfaction with services
- non-uniform access to specialist care
- large variations in frequency of individual treatments used, caseloads for particular doctors, and patient survival rates.<sup>6,7</sup>

Poor care co-ordination and access to specialist services are especially problematic in regional Australia due to geographical factors. This inequity is reflected in cancer statistics. Although the cancer incidence is 10% lower in remote areas compared to metropolitan centres, mortality is 10% higher, indicating significantly poorer cancer survival in remote regions.<sup>2</sup>

## Multidisciplinary care in Australia

Multidisciplinary care is described as “an integrated team approach to healthcare in which medical and allied healthcare professionals consider all relevant treatment options and develop collaboratively an individual treatment plan for each patient”.<sup>8</sup> While cancer care today is necessarily nearly always multidisciplinary, the presence of a multidisciplinary team signifies formal commitment to principles such as communication and co-operation that underpin effective multimodal care. Multidisciplinary cancer care teams include representatives from core specialties (eg. surgery, medical oncology, radiation oncology, pathology, radiology and general practice), who are supported by non-core team members as needed (eg. genetic counselling, physiotherapy, nuclear medicine, palliative care, social work).<sup>9</sup> Multidisciplinary meetings form the lynchpin of care by providing a forum for interdisciplinary communication, decision-making and co-ordination of care.

Multidisciplinary cancer care can be delivered in a number of ways. In centralised multidisciplinary clinics that act as a ‘one-stop shop’, patients can see all relevant specialists in one visit.<sup>10</sup> Despite the attractions of this model, its utility is limited to clinics with high patient volumes, which are only achievable in large metropolitan centres in Australia. Alternatively, care may revolve around meetings where different disciplines meet for case discussion and treatment planning.<sup>4</sup> Physical team meetings are often impossible in rural and remote Australia, but multidisciplinary care can be facilitated by collaborations with metropolitan sites and the use of telemedicine technology.<sup>11</sup>

Given Australia’s relatively small population, demographic and geographic diversity, and mixed public and private health systems, no single fixed model is suitable for the delivery of all multidisciplinary cancer care.<sup>10</sup> For this reason, five principles were developed by the National Breast Cancer Centre (NBCC)\* as a flexible framework for implementing multidisciplinary care strategies tailored to local services and needs:<sup>4-8</sup>

- a team approach to care
- communication among team members
- access to full therapeutic range
- provision of care in accord with nationally agreed standards
- patient involvement in decision-making.

## Advantages of multidisciplinary teams

### Benefits to patients

Multidisciplinary teams can lower mortality, improve quality of life and reduce the cost of cancer care.<sup>12-14</sup> Multidisciplinary involvement from the early stages of

management ensures that a full therapeutic range of options are considered, so patients receive appropriate and timely treatment.<sup>9</sup> Providing information about all treatment options has been shown to improve the mental health and wellbeing of adults with cancer.<sup>15</sup> There is evidence that decisions resulting from multidisciplinary discussions are more likely to align with evidence-based standards than those made by individual clinicians.<sup>4,7,16</sup> Furthermore, there is greater adherence to treatment plans when management decisions are made at multidisciplinary meetings and understood by all care providers.<sup>12</sup>

Multidisciplinary teams not only enhance decision-making but also coordination of services, leading to more efficient health processes. Multidisciplinary teamwork facilitates treatment planning, streamlines referral processes and prevents unnecessary duplication of investigations, saving time and resources.<sup>7,9,14,16</sup> Resultant improvements in treatment access, waiting times and continuity of care lead to better quality of life and greater patient satisfaction.<sup>6,17</sup>

A recent Australian study found that lung cancer patients seen in a multidisciplinary clinic were processed more rapidly and were more likely to receive active treatment than those managed through conventional services. Patients diagnosed with late stage lung cancer are often under-referred for assessment and treatment due to nihilistic attitudes towards prognosis and poor knowledge about current multimodal therapy.<sup>18</sup> Therefore a multidisciplinary team approach can improve the management and survival of the most common cause of cancer death in Australia.<sup>2</sup>

A drawback of traditional cancer care is the conflicting information provided to patients by different health professionals. Multidisciplinary teams, on the other hand, can provide more consistent information to patients after reaching a group consensus.<sup>7</sup> Patients’ emotional needs are identified more readily by multidisciplinary teams, paving the way for appropriate provision of psychosocial support.<sup>6,19</sup> In a multicultural society like Australia, the cultural backgrounds of team members are likely to be as diverse as those of patients. The assorted perspectives within multidisciplinary teams can provide valuable insight into pertinent social and cultural considerations, enabling culturally appropriate, holistic cancer care.

### Benefits to healthcare professionals

Patients are not the sole beneficiaries of multidisciplinary teamwork; healthcare professionals also profit in terms of support, communication and education. Multidisciplinary meetings provide reassurance and professional support for decision making.<sup>7</sup> Inter-specialty relationships are enhanced by opportunities for clinical discussion and collaboration.<sup>16</sup> Encouragingly, studies show that a multidisciplinary approach results in greater job satisfaction and psychological wellbeing in team members.<sup>20</sup>

Health professionals working together in multidisciplinary teams learn from each other informally as well as formally, via cross-discipline education and training practices. Through active discussion and retrospective review of cases in meetings, specialists acquire valuable experience of how treatments can be combined to optimise patient outcomes.<sup>6</sup> Not only do multidisciplinary meetings

\* Now called the National Breast and Ovarian Cancer Centre (NBOCC).

facilitate continuing education of specialist clinicians, they offer valuable opportunities for the education of medical students, junior doctors and trainees.<sup>16,21</sup> By becoming involved in multidisciplinary meetings and clinics, students can experience teamwork in clinical medicine and develop a working understanding of the ethical dilemmas and psychosocial considerations in cancer care.<sup>22</sup>

## **Benefits to health systems**

From a broader perspective, a multidisciplinary approach to cancer care helps to improve health services and standards of care. Open discussion at multidisciplinary meetings promotes peer review, in accordance with principles of clinical governance.<sup>7</sup> Streamlined care co-ordination benefits health systems by minimising inefficient communication and avoiding unnecessary duplication of investigations.<sup>6</sup> Multidisciplinary teams also support the shift of cancer care delivery from hospitals to ambulatory settings. This decentralisation will improve the sustainability of cancer care as the Australian health system faces a number of challenges, such as increasing cost of cancer treatment and the ageing health service workforce.<sup>12</sup>

By pooling resources and data across disciplines, multidisciplinary teams provide a fertile ground for collaborative research and innovation. Multidisciplinary care also promotes greater participation in clinical trials, which helps to improve evidence-based cancer care.<sup>7,14</sup>

## **Disadvantages of multidisciplinary teams**

Notwithstanding the advantages elucidated above, multidisciplinary teams are time and resource intensive and riddled with potential pitfalls.<sup>7,21</sup> A poorly designed team with ill-defined individual roles will complicate management by creating redundancies and discrepancies in patient care and communication.<sup>6</sup> Practical concerns such as organising meetings can create significant incursions on the time of team members if there is inadequate administrative support.<sup>7</sup>

In multidisciplinary teams, where decisions are based on group consensus, there is the danger of 'treatment by committee' without an individual clinician taking responsibility for patient care.<sup>21</sup> This not only has potential implications for quality of care and patient-clinician relationships, but also medico-legal ramifications. In Australia, all professionals who attend team meetings have a legal duty of care and liability for decisions, regardless of whether they have personal contact with the patient.<sup>23</sup> This could have dire consequences should medico-legal actions be brought against decisions made by multidisciplinary teams.

The benefits of wide-ranging professional input at multidisciplinary meetings should not come at the expense of patient involvement, since patients themselves are seldom present at meetings. Lack of patient participation in the decision-making process violates a key principle of multidisciplinary care and compromises the notion of patient-centred care.<sup>8</sup> If a patient's co-morbidities, preferences, and social circumstances are not taken into account, team decisions may be inappropriate and not

implemented, negating any amount of multidisciplinary discussion.<sup>15,22-23</sup> However, patient attendance at meetings is usually precluded by the patient's limited understanding of medical terminology and disadvantages such as restriction of the free flow of information and inefficient throughput of patients.<sup>23</sup>

While a culture of debate is central to effective multidisciplinary discussions, collective decision making can be hindered by strongly conflicting opinions. Even when a consensus is reached, if there are no reliable documentation and communication processes in place, patients may still be provided with inconsistent and incomplete information.<sup>6</sup> Therefore, precautions must be taken to ensure that the advantages of multidisciplinary care do not become disadvantages.

## **Barriers to multidisciplinary teamwork**

Although the advantages of multidisciplinary care are well established, a number of barriers prevent the full realisation of these benefits. Support for the principles of multidisciplinary care does not necessarily translate into clinical practice. Although over 95% of Australian clinicians believe that it is essential to communicate about the care of cancer patients, less than 30% of hospitals have regular treatment planning meetings.<sup>8</sup> Rural teams and small volume hospitals are especially unlikely to have communication frameworks in place.<sup>10</sup> In Australia, the greatest impediments to effective teamwork are perceived to be health system barriers, namely time pressures, insufficient facilities and administrative support, and lack of reimbursement for time spent in meetings.<sup>24,25</sup> Poor interpersonal and inter-professional relationships can also hamper teamwork.<sup>14</sup> Individuals, departments and units may resist the idea of shared responsibility out of fear that it will undermine professional autonomy.<sup>6</sup>

Australia's geography represents a particular challenge in the implementation of multidisciplinary care.<sup>26</sup> The tyranny of distance across Australia restricts access to many diagnostic, supportive and therapeutic services. For example, for patients in Darwin, the closest specialist radiation oncology service is located in Adelaide, over 3000 kilometres away.<sup>10</sup> Providing a full range of therapeutic options is problematic when trying to co-ordinate specialist and allied health services over large distances.<sup>24</sup> However, it is these less accessible parts of Australia that would benefit most from formal multidisciplinary teams and cancer service networks.

The challenge of multidisciplinary cancer care is further compounded by Australia's mix of private and public service provision, leading to inconsistencies in multidisciplinary practice.<sup>26</sup> Private practice teams tend to discuss cases less frequently and informally, on an ad-hoc basis. Multidisciplinary care is probably more challenging for private clinicians due to physical isolation from colleagues, less readily available technology and resources and the personal expense of managing teams.<sup>10,11</sup> Coordinating care across the public-private interface is also difficult, especially when complicated by privacy issues when sharing patient information.<sup>24</sup> These disparities and



difficulties in utilisation of multidisciplinary teams highlight the potential for inequitable cancer care in Australia.

### Strategies to facilitate multidisciplinary teamwork

Leaders with good communication and management skills can monitor team goals and processes, foster positive team dynamics and resolve interpersonal and interdisciplinary barriers to effective teamwork.<sup>7,16</sup> The success of multidisciplinary teams is highly dependent upon the efforts and leadership of a few committed individuals, or 'local champions'.<sup>8,24</sup> Dedicated support staff relieve the administrative workload on health professionals, allowing them to maximise their specialist contributions to the team.<sup>7,14</sup> Administrative tasks may include collating patient information in preparation for meetings and providing clear written explanations of decisions to all stakeholders (including patients and GPs) to ensure effective communication within and without the team.<sup>21</sup>

Without adequate technological, administrative and financial support, multidisciplinary teams can become burdensome, ineffective incursions on time poor health professionals. Teleconferencing facilities for multidisciplinary case conferencing can overcome communication difficulties over large geographical areas. The costs associated with implementing multidisciplinary teams are not insubstantial, and include the increased workload associated with preparing for and attending meetings.<sup>8</sup> In recognition of this, new Medical Benefit Schedule items were introduced in 2006 to provide rebates for medical practitioners participating in multidisciplinary cancer meetings.<sup>27</sup>

In coming years, multidisciplinary teams are likely to become widespread as a care delivery model in oncology, as well as in the management of other chronic conditions. Future doctors will be involved in multidisciplinary cancer care teams not only as surgeons and medical oncologists, but also as radiation oncologists, general practitioners, palliative care specialists, pathologists, radiologists and psychiatrists. As such, it is important for medical students to become familiar with the principles and practice of multidisciplinary teams from the beginning of their medical careers. Early immersion in a multidisciplinary paradigm will break down and prevent interdisciplinary prejudices that may thwart effective teamwork.

Active participation in multidisciplinary processes will provide medical students with first-hand experience of the advantages, disadvantages, challenges and skills of multidisciplinary teams. The following strategies are suggested as activities to complement existing objectives and clinical experiences in the recommended oncology curriculum for Australian medical students:<sup>28,29</sup>

1. Students should interview a cancer patient and analyse the effects of their interactions with multiple health professionals, to gain insight into patient experiences of multidisciplinary cancer care.
2. Students should attend and participate as much as practically possible in multidisciplinary team meetings

(eg. by presenting summaries of patient histories for case discussion), to prepare for future practice as multidisciplinary team members.

3. Students should critically evaluate the structure, processes and outcomes of a specific multidisciplinary team, comparing their findings with clinical guidelines. By performing a simple clinical audit, students can contribute to ongoing quality improvement and familiarise themselves with best practice standards for multidisciplinary cancer care.

### Conclusion

In the setting of Australia's rising cancer incidence and the growing complexity of cancer care, multidisciplinary teams have the potential to improve the quality of life and survival of cancer patients. This potential is currently tempered by a number of geographical, practical and financial challenges. However, ongoing commitment, training and support will ensure that multidisciplinary teams are harnessed as a powerful vehicle for delivering efficient, effective cancer care.

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## AUSTRALIA BEHAVIOURAL RESEARCH IN CANCER

### **Centre for Behavioural Research in Cancer (CBRC), Victoria**

#### ***Models of peer support for people living with colorectal cancer***

Disease-specific peer support services for people diagnosed with colorectal cancer are lacking. This research project aimed to examine the acceptability of peer support for people with colorectal cancer in metropolitan and regional areas of Victoria via three studies. First, a search of the literature on support models for people living with cancer was undertaken. Five models of peer support for people with cancer were identified from the 58 papers included in the review. Given the limited level 1 evidence for the effectiveness of any model, a formative study was then undertaken. This study explored the peer support needs of people with colorectal cancer recruited from outpatient clinics and their preferences for the various peer support formats, via quantitative (N=52) and qualitative (N=29) methods. The formative study led to the development of two peer support programs - a one-to-one telephone and face-to-face group program. The acceptability of these models was tested in a pilot study that adopted a pre-post intervention with patients and peers as support providers. Thirty-four patients were recruited, with half electing to participate in the telephone program and half in the group program. Twelve peers provided support in the telephone program. Two group programs were established (metro and regional), each co-facilitated by a peer and a health professional. The two peer support models were received favourably and findings suggest these models cater to different peer support needs. Clinician promotion and timing of referral (improved if closer to diagnosis) contributed to participation and retention. The project emphasised the value of peer support in cancer care for colorectal cancer patients.

#### ***Performance of anti-smoking television advertisements in low and middle-income countries using a standard pre-testing protocol***

Low and middle income countries may benefit from adapting previously successful anti-smoking television advertisements from other regions, reducing the substantial production costs of mass media campaigns. This study aimed to test the comprehensiveness, acceptability and potential effectiveness of existing anti-smoking ads in low and middle income countries. Within each country, 24 groups of male and female smokers aged 18-34 years were shown 10 anti-smoking advertisements. After viewing each advert participants completed a 10-item scale, rating each advert in terms of message acceptance

and emotional and cognitive impact. All adverts and advert rating materials were presented in participants' local language. Data has so far been collected in seven countries - China, Russia, India, Indonesia, Mexico, Vietnam and the Philippines. Initial results have shown that within each country, adverts that described the negative health effects of smoking using visceral imagery had the strongest performance overall. Adverts communicating interpersonal loss as a result of smoking, using personal testimony, tended to have variable performance across countries, highlighting the importance of cultural suitability and relevance of advert choice. Adverts that provided a secondhand smoke message (without visceral imagery) showed moderate performance relative to other ad types. These findings suggest that careful adaptation and translation of existing strong graphic advertisements can be considered as a lower cost mass media tobacco control strategy for low and middle income countries.

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

#### ***Effectiveness of smoking cessation drugs in real-life settings***

Clinical trials consistently demonstrate that smoking cessation pharmaceutical aids ( $R_x$ ) approximately double a smoker's chances of successfully quitting. However, despite their widespread availability, successful quitting rates within the general population do not seem to have improved. We aimed to determine if, and why, cessation  $R_x$  are less efficacious in real life settings compared to clinical trials. We have just concluded a longitudinal study with 1226 Western Australian smokers interviewed by telephone every three months for two years (2007–2009). Participants were asked in structured, open-ended manner about any quit attempts since their previous interview, antecedents to such attempts, attempt duration, and cessation aids used. Participants' mean age was 41.8 years (range 18–78), 45% were male and 55% female, and had an average consumption of 17.5 cigarettes a day (range 1–70). The retention rate after two years was 76.8%. Preliminary analyses suggest 88.4% participants made at least one quit attempt, 14.2% had remained abstinent for 6+ months and 8.8% for 12+ months. Cessation  $R_x$  were used by 33.8% of participants and predicted significantly greater rates of abstinence amongst those who used them at six months (20.8 v 12.7%;  $\chi^2=12.673$   $p<.001$ ) but not at 12 months (11.4 v 8.7%;  $\chi^2=2.060$   $p=.151$ ). Analysis is currently underway to determine whether  $R_x$  type, treatment compliance and adjuvant assistance are predictors of successful

abstinence. Our preliminary results complement previous research suggesting cessation Rx provide superior short-term but not long-term smoking abstinence. Through ongoing analysis we hope to determine the reasons why this is the case.

## ***Dissecting graphic health warnings: assessing what makes for the greatest impact***

Smoking cessation advertisements with gruesome health warning imagery are consistently demonstrated to maximise emotional arousal in viewers, increase their risk perceptions, and be more recalled by smokers. However, not all gruesome imagery has proven equally effective. One hypothesis suggests gruesome imagery with a clear ground/figure execution (eg. organ on a surgical tray v within the body) may aid recall memory. Another hypothesis suggests gruesome imagery incorporating physical violence enhances recall. We are currently testing these hypotheses by asking participants to view an online experiment depicting a randomised series of 36 four-second video clips of damaged body organs. Half the clips depict an aggressive condition, where the organ is subject to physical harm, such as being cut, dissected or punctured, resulting in oozing slurry. The other half depict a passive condition, where only the damaged organ and leaking fluids are depicted. The organs were filmed on a green screen so that backgrounds could be superimposed in both clear and merged fashion. Viewers are asked to rate how 'confronting' they consider the footage and one week later they are asked to view a second series of 72 videos, including the 36 previously viewed, plus an additional 36 similar videos not seen before, and to nominate if they have previously viewed each exact video. Preliminary analyses suggest a strong effect size for the physical violence hypothesis, but only a weak effect size for the clear figure/ground hypothesis.

## **Centre for Health Research and Psycho-oncology (CHeRP), NSW**

### ***Delivering smoking care to disadvantaged groups: a qualitative study of potential in community welfare organisations***

Despite falling rates of smoking in the general Australian population, smoking rates remain markedly higher among severely socially disadvantaged groups including Aboriginal and Torres Strait Islander people, the homeless and people on low incomes. Community service organisations provide a potentially ideal setting for accessing and delivering smoking care to disadvantaged smokers, however little is known about their current provision of smoking care, or the acceptability and feasibility of providing care in this setting. In-depth interviews and focus groups were conducted with eight managers, 35 staff and 32 clients of community service organisations between December 2008 and March 2009. Results suggest that providing and receiving cessation support in the community service setting is highly desirable. Staff reported that smoking was a significant issue for their clients, and perceived the provision of smoking care to be compatible with their role as care providers. However, they identified several barriers to providing care, including competing

priorities, insufficient resources and inadequate staff training. Managers and staff preferred brief intervention approaches. Many clients reported a desire to quit smoking, and thought that personalised support from the community service organisation would help. These results suggest that the community service setting represents a promising access point for targeting disadvantaged smokers that is acceptable and desired by managers, staff and clients. Further research examining the effectiveness of support offered in this setting is clearly warranted.

## ***Psychosocial needs of survivors***

Peer support programs provide one avenue for meeting the significant psychosocial needs of cancer survivors. Such programs are based on the premise that shared cancer experience is a valuable resource, which assists in adjusting to, and coping more effectively with, the disease. Cancer Council NSW has been operating a one-to-one matched peer support program, Cancer Council Connect, since 2000. CHeRP was commissioned to undertake an evaluation of the program to determine if the service satisfactorily met the needs of clients and volunteers. A total of 86 clients and 65 volunteers of the program completed a computer assisted telephone interview. Ten clients, who during the interview, expressed dissatisfaction with their involvement in the program, were invited to complete an in-depth semi-structured telephone interview about their experiences. Clients were highly satisfied with their interaction with the Cancer Council Connect consultants and their allocated volunteer, who was perceived to provide a high degree of practical and emotional support, with 'coping and reassurance' being most frequently sought by clients. The most disliked aspect related to insufficient or irregular volunteer contact. More than half reported all or most of their needs met, and almost all would recommend the program to others diagnosed with cancer. Cancer Council Connect volunteers reported a high degree of satisfaction with their volunteer role, feeling well supported by program staff. The most disliked aspect related to the emotional burden associated with client contact. Almost half felt under-utilised. Based on the findings, recommendations were made outlining potential areas for improvement.

## **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 in Queensland and NSW. It will assess the efficacy and cost-effectiveness of psychological interventions offered through Cancer Council Queensland - self-managed care with nurse counsellor support v five individualised sessions with a therapist. Outcomes for health services planning will include recommendations

about: the efficacy of self-managed support versus tele-based psychologist intervention to facilitate better psychosocial adjustment and mental health; an evidence-based, practical and applied approach to psychosocial care that can be rapidly translated into community and acute settings; and information on the potential economic value of interventions to help achieve efficient health service delivery.

### ***Amazon Heart Thunder: achieving personal growth through a Harley Davidson***

Amazon Heart is an organisation that coordinates adventure events aimed at providing a unique and inspiring peer support opportunity for breast cancer survivors. Amazon Heart Thunder is one such event, which recently comprised a Harley Davidson motorcycle ride from Brisbane to Sydney over 10 days. This research aims to identify the mechanisms for which positive life change occurs in the context of a motorcycle ride with other breast cancer survivors. Interviews and surveys completed by the motorcycle riders will explore elements of this peer support adventure-based activity that may contribute to personal growth, such as risk-taking behaviour, social identity and group cohesion. An important outcome will be identifying factors that contribute to the success of the adventures, allowing us to create further peer support activities for breast cancer survivors that promote personal transformation.

### ***Melanoma survivor study***

Melanoma is one of the most common cancers in Queensland, however surprisingly little is known about the psychosocial outcomes patients and their families experience following a melanoma diagnosis, particularly for long-term survivors. Patients and their carers may experience issues such as continued fear of recurrence, changes to appearance and self image and changes to social support structures to name a few. The Melanoma Survivors Study is investigating levels of psychological distress, physical and emotional well being, quality of life, and health behaviours for over 2500 long-term melanoma survivors. Using self-administered questionnaires, the study is collecting information on: levels of emotional, physical, functional and social well being; levels of distress

and anxiety; adjustment; and current health behaviours (such as sun exposure, sun protection practices, skin self-examination). Information regarding routine surveillance practices including: follow-up visits; consultation procedures (type of skin examination, other clinical procedures, education about sun protection and early detection); frequency of recurrence; and development of additional primary melanoma(s) is being collected through the questionnaires and the patient's physician.

### **Behavioural Research and Evaluation Unit (BREU), South Australia**

#### ***Influence of family on food choices***

Overweight and obesity are increasingly recognised as significant risk factors for chronic diseases including cancer. Some food behaviours and dietary preferences may be learnt in the family context. In the current study, focus groups were conducted with two or three generations of members of seven families to explore the roles of various family members in the development and maintenance of food choices, eating behaviours and meal practices. Three different cultural groups were included to explore the potential social influence processes on food choice in families from different cultural backgrounds. Participants included families who identified themselves as Anglo-Australian, Italian-Australian and Congolese-Australian families. This pilot study identified a bi-directional influence between parents and their children on food consumption across different cultural groups. For Australian families, the nuclear household was the key environment in which food was discussed and meals were prepared and eaten, without strong links to family or cultural food traditions. The influence of grandparents on the family food environment was unique to Italian-Australian families, with grandparents being very integrated in the preparation and sharing of food, and having strong views about food that were taken seriously by the families. The food environments of the Congolese-Australian families were also influenced by third generation family, although they did not reside in Australia, through the retention of cooking styles passed on from mothers to their children.

## Cancer Council, COSA applaud 'unprecedented' investment in rural cancer care

The gap in cancer care outcomes between rural and metropolitan Australia should begin to close significantly thanks to \$560 million in the 2009-10 Budget to build a network of regional cancer centres.

Described by Cancer Council Australia and the Clinical Oncological Society of Australia (COSA) as "an unprecedented move by a Commonwealth Government", the initiative is a highlight of the Rudd Government's \$2 billion cancer plan.

Cancer Council Australia Chief Executive Officer, Professor Ian Olver, and COSA President, Professor Bruce Mann, said their organisations had for a number of years sought a whole-of-government solution to the inequities in rural cancer care, which until the 2009-10 Budget announcement had been seen as a state issue.

"For the Government to make such a substantial investment in capital grants to build regional cancer centres shows they are serious about reducing inequities in cancer care outcomes and in working with other jurisdictions to put services where they are desperately needed," Professor Olver said.

"It is an unprecedented move by a Commonwealth Government to show such a strong commitment to a national problem that has been well-documented, but until now has been seen largely as a state and territory issue."

Professor Mann said Australians in rural and remote areas had poorer cancer survival rates than those in city areas, with outcomes worsening the further from a large population centre a patient lived.

"The best way to reduce the geographical disparity in cancer outcomes is to build capacity on the ground in regional areas – and this groundbreaking commitment from the Australian Government is set to do that," Professor Mann said.

## World No Tobacco Day should sound graphic warning to government

On World No Tobacco Day (May 31), Cancer Council Australia called for the Australian Government to increase the size of graphic warnings on tobacco products.

Chair of Cancer Council Australia's Tobacco Issues Committee, Kylie Lindorff, said Australia lagged behind world's best practice in key policy areas such as tobacco excise and graphic health warnings – the theme of this year's World No Tobacco Day.

"With the Preventative Health Taskforce report expected to call for important measures such as an increase in tobacco excise and the use of larger graphic health warnings, World No Tobacco Day should prompt the Government to adopt these evidence-based recommendations."

Ms Lindorff said the World Health Organisation observed World No Tobacco Day each year to highlight the enormous death and disease burden attributed to smoking – which remained by far the largest cause of premature death and disability internationally and in Australia.

"More than five million people worldwide die each year from tobacco-related disease, including more than 15,000 Australians," she said.

"Australia has fallen behind many other countries, with warnings here occupying only 30 per cent of the front of the pack, compared with 50 per cent in many jurisdictions requiring graphic health images.

"With lung cancer now claiming the lives of more Australian women than breast cancer and an increasingly disproportionate tobacco disease burden falling on socially disadvantaged Australians, the Government should respond to the WHO's World No Tobacco Day theme and adopt its own independent experts' recommendations to review graphic warnings."

## New data highlights urgency in bowel cancer screening

New data on bowel cancer screening released in June highlighted the urgent need to fully implement screening for all Australians over 50, according to Cancer Council Australia.

An analysis of bowel cancers by Biogrid Australia shows the current screening program, limited to three age groups, has found double the number of bowel cancers at the most curable stage, compared with cancers found after reporting of symptoms.

"This data shows how effective a national screening program can be, yet the program is currently only available to 50, 55 and 65 year-olds," said Professor Olver. "Five million Australians are missing out on a test that could help save their lives."

According to the data, 41 per cent of cancers found through the program were at the most curable stage (stage A), compared with just 18 per cent found through testing people reporting symptoms.

Launching a new Cancer Council campaign – Get Behind Bowel Screening ([www.getbehindbowelscreening.com.au](http://www.getbehindbowelscreening.com.au)) – which calls on the Government to extend screening to all Australians aged 50 and over, Professor Olver said the Biogrid data showed that bowel cancer screening found the majority of bowel cancers early, when treatment had the best chance of success. “Not only are five million Australians currently missing out, current participants are only offered one-off screening. This is contrary to national health guidelines, which recommend screening at least every two years from the age of 50.”

Professor Olver said that according to conservative estimates, the Government could save the lives of more than 30 Australians each week by expanding the program to include all Australians 50 and over.

Cancer Council is calling on all Australians to log on to [www.getbehindbowelscreening.com.au](http://www.getbehindbowelscreening.com.au) and send an email to pressure the Government to fully implement the National Bowel Cancer Screening Program.

## Opposition support for ‘alcopops’ bill can prevent cancer deaths

The Federal Opposition should be commended for supporting the increased excise on ready-to-drink spirit mixes because the tax could help prevent cancer deaths, Professor Olver said in June.

“While a comprehensive approach to alcohol control is required, sales data showed that the ‘alcopops’ tax was driving down net alcohol consumption, which on a population basis equates to reduced risk of alcohol-related cancers,” Professor Olver said.

“Around 1400 Australians die from alcohol-related cancers each year. This number could decrease significantly if the reductions in consumption that coincided with the ‘alcopops’ tax continue and are supported by other measures.”

“As well as links between alcohol and breast cancer, there is convincing evidence that alcohol consumption can lead to cancers of the mouth, pharynx, larynx, oesophagus and liver,” Professor Olver said.

“With evidence showing that people who binge drink when young are at higher risk of becoming chronic consumers of alcohol, the ‘alcopops’ excise is an important step towards a long-term culture change.”

## Gene patents threat to cancer research

Patenting genetic sequences may stifle groundbreaking research in cancer treatment as well as restrict access to life-saving diagnostic procedures, a Senate hearing in Sydney was told in August.

Professor Olver, and President of the Clinical Oncological Society of Australia (COSA), Professor Bruce Mann, stressed to a Senate inquiry that the current patent system allows human genetic material to be monopolised

by commercial interests, posing a serious threat to cancer research and care.

Professor Olver, a medical oncologist and researcher, said genes and genetic products were the keys to a new field of cancer treatment that would target an individual patient’s cancer, maximising benefits and minimising side effects.

“Medical science will soon be able to tailor cancer treatments according to prognoses made from genetic analyses and with treatments that target genetic products,” he said.

“But our potential to profoundly improve patient outcomes may not be realised, if an outdated patent system continues to let commercial interests monopolise matter that naturally exists in our bodies.

“The Senate must put the public interest first and recommend that non-commercial use of genetic sequences is exempted from patent enforcement, as a first step towards changing the law to invalidate future gene patent claims.”

Professor Mann, a breast cancer surgeon representing more than 1200 cancer care professionals nationwide, said an Australian company’s now withdrawn claim to enforce its patent licence over the genetic tests for breast and ovarian cancer risk set an alarming precedent.

“Genetic Technologies Ltd’s demand for public laboratories to cease testing for genetic risk of breast and ovarian cancers was only a hint of how the fundamental flaws in gene patent law could undermine public health,” Professor Mann said.

## Sally Birch Fellowship recipient announced for 2009-2011

Cancer Council Australia’s Sally Birch Fellowship in Cancer Control (2009-11) has been awarded to Associate Professor Gordon Howarth, of the University of Adelaide.

Associate Professor Howarth is researching innovative approaches towards managing the problem of chemotherapy-induced intestinal mucositis, and inflammatory bowel disease.

Professor Olver, welcomed the announcement and flagged the importance of the research. “Supporting patients on therapy by reducing the side-effects of treatment is important,” he said. It reduces the burden of treatment and can improve treatment outcomes.”

The Sally Birch Fellowship commenced in 2006 and is aimed at addressing current gaps in cancer control. The fellowship encompasses any intervention that will reduce the impact of cancer on the community, from primary cancer prevention to screening, diagnosis, treatment, support and palliative care. It is valued at \$100,000 per annum for a period of three years.

## Promoting a nationally consistent approach to clinical breast cancer data collection

The National Breast and Ovarian Cancer Centre has launched the *Breast cancer specific data items for clinical cancer registration*, aimed at improving the quality of data collected.

The National Health Data Dictionary recommends a core set of generic data items for clinical cancer registration however these often lack the detail required by groups interested in specific tumours.

In response, NBOCC has developed breast cancer specific data items for clinical cancer registration to facilitate comparative analysis, and where appropriate, data pooling.

The data items and data definitions were developed through a multidisciplinary working group, in consultation with key stakeholders. Where possible, these items and data definitions have been aligned with those already in use across Australia.

An NBOCC spokesperson said the organisation was committed to working in collaboration with key stakeholders to promote the adoption of the clinical minimum dataset for breast cancer, to help ensure a nationally consistent approach to data collection and reporting of breast cancer data.

*Breast cancer specific data items for clinical cancer registration* is available to download at [www.nbocc.org.au/resources](http://www.nbocc.org.au/resources). Hard copies can be ordered by phoning 1800 624 973.

For more information contact Tenna Rowe at [tenna.rowe@nbocc.org.au](mailto:tenna.rowe@nbocc.org.au) or phone 02 9357 9439.

## National External Breast Protheses Reimbursement Program

The Australian Government has committed \$31 million over five years to provide reimbursement for both new and replacement external breast protheses to Australian women who have had a mastectomy as a result of breast cancer.

The National External Breast Protheses Reimbursement Program commenced on 24 November 2008 and is administered by Medicare Australia. Breast protheses purchased from 1 July 2008 are eligible for reimbursement. The program provides a reimbursement of up to \$400 for each new and replacement external breast prothesis.

All women who are permanent residents of Australia, have a current Medicare entitlement and who have had a mastectomy as a result of breast cancer (may be recent or in the past) are eligible to claim the reimbursement. Department of Veterans' Affairs card holders should continue to claim their entitlements through the department.

Claims for the reimbursement can be lodged by post or at any Medicare office, with reimbursement processed by electronic funds transfer to the claimant's bank account.

Information about the program, including a fact sheet and claim form, are available on the Medicare Australia website [www.medicareaustralia.gov.au/public/services/breast-protheses.jsp](http://www.medicareaustralia.gov.au/public/services/breast-protheses.jsp), or by phoning Medicare Australia on 132 011 (call charges may apply), or visiting a Medicare Australia office.

## Events news

As 2009 comes to a close, Cancer Council is celebrating yet another successful year of fundraising events.

From launching new national events, Daredallion and Call to Arms, to hosting our mainstays of Australia's Biggest Morning Tea, Daffodil Day, Pink Ribbon Day, Girls Night In and Relay for Life, our supporters have gone above and beyond the call of duty, raising millions of dollars even as the world was worried about the Global Financial Crisis.

We would like to thank everyone who has been involved, whether you hosted an event, purchased merchandise or made a donation to the cause. Money raised plays a huge role in helping Cancer Council to continue to play our role in working to beat cancer.

We look forward to seeing you in 2010!





## A Guide to Cancer Genetics in Clinical Practice

**Sue Clark**

Tfm publishing (2009)  
ISBN: 9781903378540  
238 pages  
RRP: \$90.00

There is something wonderfully reassuring about a book where the title of the first chapter states cheerfully, "Genetics is not complicated".

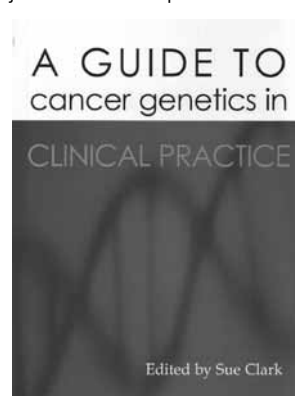
*A Guide to Cancer Genetics in Clinical Practice* aims to appeal to a reader who seeks simple, concise, practical advice and it delivers just that. The slim volume of just over 200 pages takes the reader through the introduction to basic concepts in genetics and cancer genetics, main genetics syndromes and tumour types where genetics input is required. It delivers information in a well structured, orderly format, with key points summarised at the end of each chapter. Chapters are written from the perspective of a practicing clinician, mostly by practicing oncologists rather than geneticists alone.

While the authorship is international, reaching as far as New Zealand (no Australian contributions), the majority of authors are from the United Kingdom and there are many references in the book to the clinical recommendations based on the National Institute for Health and Clinical Excellence guidelines, which are often applicable to the Australian setting. Each chapter contains a paragraph on "the future", which offers a commentary on emerging issues and future developments. The book is easy to navigate, clearly laid out with clinical recommendations summarised in tables, and theoretical concepts illustrated with clinical cases.

The text takes a rather medical approach to cancer genetics and any multidisciplinary aspects of this field are well hidden in the last chapter, 'The future structure of care: cancer genetics'. As such, it is likely to appeal most to clinicians requiring quick, point of care information, just before a patient consultation (although I found the

shortness of the paragraphs rather inviting for a more leisurely read for the sake of reading).

*A guide to Cancer Genetics in Clinical Practice* is likely to be too brief for those who already practice in the field of cancer genetics. However, for those of us who might have slept through the genetics lectures in medical



schools, or more likely, learned genetics in the days of mating drosophila flies and garden peas, this book may serve as a useful and very accessible resource.

*Bogda Koczwara, Department of Medical Oncology, Flinders Medical Centre, Bedford Park, South Australia.*

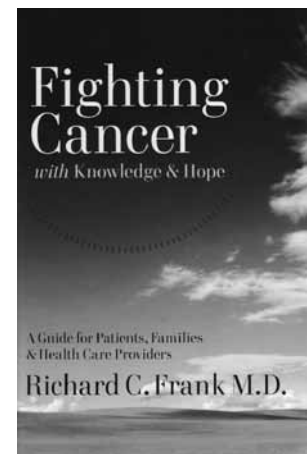
## Fighting Cancer with Knowledge & Hope – A Guide for Patients, Families and Health Care Providers

**Richard C. Frank**

Black Inc. (2009)  
ISBN: 9781863954341  
268 pages  
\$29.95  
RRP: \$29.95

In writing this review, I first must declare a potential conflict of interest. After an ASCO "Cancer in the News" email alerted me to an article the author had penned for the Wall Street Journal, I was prompted on a whim to communicate directly with him. His short article (<http://tinyurl.com/mp7brz>) discussed the fact that despite the majority of cancers being diagnosed in older patients, the elderly are poorly represented in clinical trials. The subsequent lack of trial data then hinders appropriate treatment. As I am on the Board of International Society of Geriatric Oncology (SIOG), I could not miss an opportunity to recruit a like-minded clinician and researcher. I emailed Dr Frank to inform him of the work SIOG was doing to address this problem. He replied that he would join our organisation if I bought his book. I agreed and I am pleased to say we have both fulfilled our promises and I look forward to working with him in the future.

*Fighting Cancer with Knowledge & Hope* is a book written for patients, carers and health professionals. It works on many levels as a guide, a reference written in plain English and an affirmation of the holistic approach to management of the patient with cancer. Richard Frank is an oncologist in general haematology and oncology practice, who clearly has a broad understanding of the disease and who clearly also understands his patients. His writing style serves to simplify and explain the complex concepts that patients with cancer need to understand to make decisions and



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that I, as an oncologist, need to explain to my patients on a daily basis. I felt myself nodding in agreement with the author as I read. Although principally aimed at patients and carers, this book gives answers to all the common questions our patients have when they are faced with meeting an oncologist for the first time.

This book is divided into two sections:

1. Exposing Cancer – an explanation of what cancer is, how it develops and how we make the diagnosis and then stage the disease.
2. Attacking Cancer – how cancer is treated, how the treatments work, an explanation of adjuvant therapy, why treatments sometimes don't work and finally a chapter on survivorship.

A striking feature of this work is that it is up-to-date. Throughout the book there are references to many of the newer agents now being used in cancer treatment. New drugs are mentioned in their appropriate context with both the generic and proprietary names used in most cases. Links to websites are included throughout the text.

The writer of the foreword states that with this work Dr Frank strives to "truly demystify cancer". There is no doubt that cancer is a complex illness and that most patients struggle with the concepts we oncologists take for granted. The author manages to simplify complex problems in a number of ways. The use of appropriate patient stories and clinical cases works to set the scene and provides a basis for further explanation. Simple illustrations and highlighted, boxed statements contribute to the readability of the text.

This book is probably most useful to the patient at first diagnosis. It stresses the need for accurate diagnosis and staging and the difficulties oncologists have predicting prognosis. The reasons for choosing the order of therapies are explained along with reasons why cancer therapies work. The chapter on survivorship issues provides practical advice, while at the same time giving hope for patients at the commencement of their "cancer journey". Despite the fact the author practices in the US, I would have no hesitation recommending this book to my patients. If anything, this book serves to remind us that the problems our patients face are the same the world over.

*Christopher Steer, Border Medical Oncology, Wodonga, Victoria*

## FNA Cytology in the Diagnosis of Lymphoma

**Lambert Skoog and Edneia Tani**

Karger (2009)  
ISBN 978-3-8055-8626-9  
78 pages  
RRP: \$US132.00

This is volume 18 in the *Monographs in Clinical Cytology* series. The book covers the changing role of cytology and fine needle aspiration in the management of lymphoma.

Cytological developments, particularly in immunohistochemistry and flow cytometry, have revolutionised the diagnosis and classification of lymphoma. As cytopathological techniques have become more sophisticated there is less emphasis on the archetypal features of lymphoma. This has important implications for those involved in diagnosis of lymphoma, particularly in relation to lymph node biopsy.

The book comprises 77 pages and is divided into three sections. The first two chapters deal with the technical and methodological issues, the next seven focus on cytological features of sub-types of lymphoma and the final chapter deals with lymphoma 'look alike' lesions such as Merkel cell carcinoma, desmoplastic round cell tumour and childhood tumours.

Each of the chapters is concise and beautifully illustrated with colour plates. The chapters are well written and provide good clinical correlation, cytological features and differential diagnoses.

While clearly aimed at (cyto)pathologists, this book is also a good reference for any clinician involved in the management of patients with lymphoma.

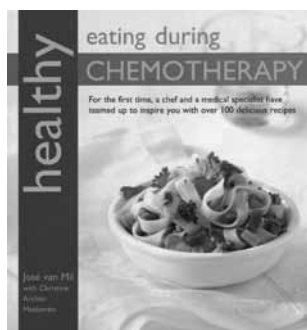
*Susan Neuhaus, Royal Adelaide Hospital, South Australia.*

## Healthy eating during chemotherapy

**Jose van Mil with Christine Archer-Mackenzie**

Kyle Cathie Limited (2008)  
ISBN 978-1-85626-816-5  
176 pages  
RRP: \$29.95

'*Healthy eating during chemotherapy*' is a recipe book with meals purposely designed for people with cancer undergoing chemotherapy and radiotherapy. The author, Jose van Mil, is a cordon bleu trained chef who currently works as a food writer, stylist and culinary consultant. She was motivated to write the book following her experience of caring for her husband through his cancer treatment. She sought the advice and input from a scientist whose research has focused on cancer, its treatments and associated side-effects, particularly eating difficulties. The scientific advisor has also had an experience of caring for her husband through his cancer treatment.



The introduction to the book contains a personal reflection by the author on her experience following her husband's cancer diagnosis. She discusses her observations of watching not only her husband's dissociation with food as a consequence of treatment, but also the difficulties other patients were experiencing maintaining adequate nutrition. With the help of an oncology dietitian, the author devised some menu plans which she believes helped her husband to maintain his weight throughout chemotherapy,

radiotherapy and stem cell transplantation. Her hope for the book is that it will inspire patients undergoing cancer treatment to keep eating, which she believes will aid their overall recovery.

The book is divided into two parts. The first part discusses the potential eating difficulties experienced by people undergoing cancer treatment. It also provides a clear and concise layperson description of the definition of cancer, the usual treatments and the most common side-effects. This section contains information on what food types to avoid during treatment (the sort of foods most people are recommended to avoid, processed and refined).

Part two contains over 100 recipes, divided into six chapters according to the texture of the food. There is a section of liquid dishes, moving through to dishes with a smooth texture, building up to recipes with a crisp and finally, firm consistency. Within the chapters, the meals are divided according to temperature, flavour and portion size. Before production of the book the recipes were tested and approved by patients undergoing cancer treatment.

I think the concept of the book is excellent and among the first of its kind. I also believe it provides helpful food creation ideas for carers and friends of people undergoing cancer treatment. However, some of the recipes might require an acquired taste. Take, for example, 'whipped tuna with orange juice', a concoction of tinned tuna, orange juice, mayonnaise, soya yogurt and soya cream whipped together and served as a mousse! There are however, many useful recipes, including some simple soup and dessert recipes which should have wide appeal.

Apart from some unique food combinations in the recipe section of the book, my main concern relates to some unsubstantiated health claims made in part one. Described as being backed by evidence, the author advocates for the inclusion of certain foods in the diet which are believed to 'stop or slow tumour growth'. Cognisant of this, the section is small and at no time does the author suggest that food or supplements should replace cancer treatment.

The book is targeted at patients undergoing cancer treatment and their carers. It is positively presented and may provide inspiration for patients or those preparing meals for people experiencing treatment related eating difficulties. It is inexpensive and may prove useful to have a copy handy in treatment areas to provide patients with some alternative recipe ideas.

*Mary Ryan, Gynaecological Cancer Centre, Royal Hospital for Women, Randwick, NSW.*

## Physicians' Cancer Chemotherapy Drug Manual 2008

**E Chu and VT DeVita**

Jones and Bartlett Publishers (2007)

ISBN: 9780763755621

551 pages

RRP: \$104.00

This is an easy to use book which covers topics including: principles of cancer chemotherapy: chemotherapeutic

and biologic drugs; guidelines for chemotherapy and dosing modifications; common chemotherapy regimes in clinical practice; and antiemetic agents for the treatment of chemotherapy induced nausea and vomiting. There is also a CD-ROM which allows for the information to be loaded on to work station computers.

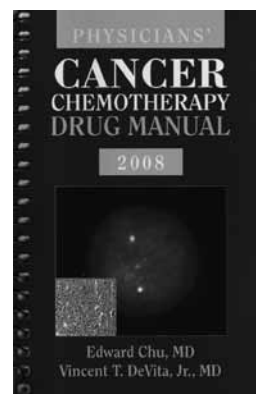
The book is well written and set out, so that it is easy to find the information you are searching for. The language is simple, allowing for ease of use by novice practitioners as well as the more experienced.

Drugs and protocols are listed alphabetically, allowing for easy use. Information on each drug includes: mechanism of action; mechanism of resistance; absorption; distribution; metabolism; indications; dosage range; drug interactions; special considerations; and toxicities in order of severity. All protocols are set out in an easy to read fashion and are referenced at the end of the chapter.

Our unit has found this book to be an excellent resource and guide to our clinical practice, with nurses, pharmacists and medical staff who have used it giving positive feedback. We have found it to be very useful for our novice practitioners to check against, prior to administration of any chemotherapeutic drug. Medical and pharmacy staff find it extremely useful for drug interactions and expected toxicities.

I would recommend this book to all nursing, medical and pharmacy staff involved in the prescribing and administration of chemotherapeutic agents.

*Sue Perrot, Townsville Cancer Centre, Townsville, Queensland.*



## Progress in Experimental Tumour Research: The Prevention of Second Primary Cancers

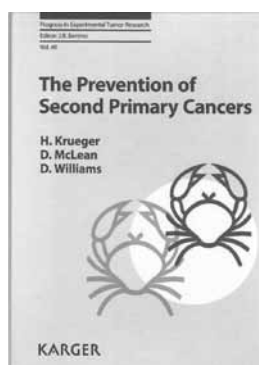
**H Krueger, D McLean and D Williams**

Karger (2008)

ISBN: 9783805584975

147 pages

RRP: \$US218.00



It was with some surprise, and not a little alarm to read that as a group, Second Primary Cancers (SPC) comprise approximately one sixth of all malignancies. This startling statistic, and the title itself, hooks one into thinking that what is contained within these pages is going to be of vital relevance. It is therefore a disappointment that the book

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does not live up to these expectations. The authors have delivered a good summary of the issues, including important clarity around definitions of SPC and provide a fairly straightforward way of looking up which SPCs are most common for specific types of primary cancers.

The incidence of SPC is related in part to the great successes achieved through the use of chemotherapy and radiotherapy in the treatment of many malignancies. This is so both because people have sufficient longevity for an SPC to arise and ironically because some of the treatments are clearly indicated as causative of SPCs themselves. The definition of an SPC is not as straightforward as one might think and this monograph does provide a useful discourse on the various issues that have arisen. Management may depend on whether the cancer is regarded as a recurrence or a new primary.

The importance of accurately describing and defining SPC is made in chapter 3, which makes the argument that we can't prevent them if we don't have a clear idea what they are. The contributing factors to SPCs are identified as: genetic predisposition that led to the first primary; treatments that may themselves cause new cancers through DNA damage and; behaviours of people such as smoking or exposure to sunlight that provide a sustained increase to risk of a second cancer. In all three cases strategies could be put in place to reduce the burden of SPC and could make a significant impact on cancer incidence as a whole. It is therefore a shame that the brevity of the book does not allow greater discourse on this topic and prevention strategies are dealt with in a cursory and not particularly useful manner.

It would also have been very useful to have had a more clear discourse around the concerns that adjuvant therapies aimed at reducing risk of recurrence may in fact cause a large number of SPCs, and in particular how the risks may be presented to patients considering such treatments. But perhaps that will require a separate monograph itself.

In conclusion, this book does not really live up to its title and as a result will not find a place in the busy schedule of the majority of clinicians, basic researchers or allied health professionals. This is a great shame as the prevention of SPC is indeed an issue of major importance.

*Nikolajs Zeps, St John of God Pathology, Bendat Family Comprehensive Cancer Centre, Subiaco, Western Australia.*

## Dx/Rx: Colorectal Cancer

**KD Holen & KY Chung**

Jones and Bartlett Publishers (2008)

ISBN-13: 9780763747442

81 pages

RRP: \$60.00

This book is aimed at a wide audience and would be useful for any clinician working with colorectal patients such as generalist nurses, stomal therapy nurses and junior medical staff. It provides up-to-date information about the diagnosis and treatment of colorectal cancer.

The format provides a comprehensive, yet succinct overview of the diagnosis and management of colon and rectal cancers. The use of bullet points allows for quick access to fundamental and practical management issues for patient treatment.

Throughout the book, tables and figures summarise important clinical data and current professional society recommendations. References at the end of each chapter provide a source of additional information.

One of the limitations of this book is that there is no mention of a multidisciplinary approach to care. However, the highlight is that it is a handy, pocket-sized reference manual that would be useful in ward or clinic, providing instant access to current information.

*Jan Stiberc, WA Cancer and Palliative Care Network, Perth, Western Australia.*

## Dx/Rx: Lymphoma

**DO Persky**

Jones and Bartlett Publishers (2008)

ISBN-13: 9780763750244

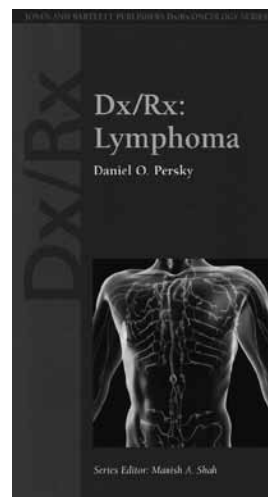
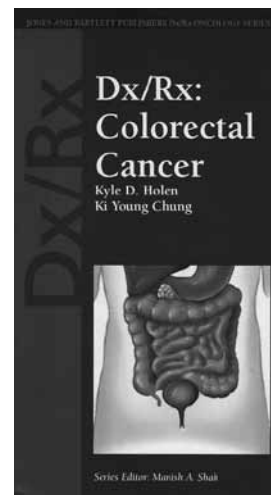
207 pages

RRP: \$49.95

This text is from a series of five Dx/Rx oncology books. Other titles include: *Upper Gastrointestinal Malignancies; Cancers of the Stomach and Oesophagus; Leukaemia; Lung Cancer; Palliative Cancer Care; and Breast Cancer*, with *Colorectal Cancer* coming soon.

This book is compact pocket-size with precise up-to-date information. Divided into eight chapters, each discusses the diagnosis and treatment of the most common lymphoma sub-types. These include diffuse large B-cell lymphoma, follicular lymphoma, marginal zone lymphoma, mantle cell lymphoma, Hodgkin's lymphoma as well as the less common cutaneous T-cell lymphomas; mycosis fungoides and sezary syndrome. Each chapter is further divided into sub-sections – epidemiology, presentation, pathology, prognosis, variants and treatment (early and advanced stage disease). Additionally, there is also a handy section at the back detailing common chemotherapy regimes used in the management of lymphoma.

The author aims to provide enough information to understand the diagnosis,



staging and initial evaluation of a lymphoma patient and how to manage the treatment phase. As the title states, this book looks at the diagnosis and treatment of lymphoma. Consequently, it focuses heavily on the pathology, classification, prognosis and treatment of the disease, and as such is aimed at medical professionals. The complexity involved in the classification of lymphoma is reflected in the latest and most comprehensive classification system by WHO, which notes 30 subtypes of this disease. This classification is determined by cell origin (B, T or NK) and by cell maturity (precursor/mature). Further to this system, there are sub-types based on the clinical behaviour of the disease (indolent, aggressive, and highly aggressive). This book has many tables and graphs that summarise clinical data.

I found the section on chemotherapy regimes very interesting, especially in regard to the use of rituximab both with induction phase treatment, as well as post-transplant maintenance schedules. The notes section following each treatment regime is a very handy reference in regard to why variances occur, prophylaxis medications needed with specific regimes and their dosing schedules. Overall this book provides a good reference to the oncology professional.

*Jacqueline Boe, Haematology Oncology Clinics of Australasia, North Brisbane, Queensland, Australia.*

## Ovarian Cancer – State of the Art and Future Directions in Translational Research

**Edited by George Coukos, Andrew Berchuck and Robert Ozols**

Springer (2008)  
ISBN 978-0-387-68966-1  
307 pages  
RRP: \$123.00

This book is divided into two parts, the first being about ovarian cancer detection and pathogenesis and the second ovarian cancer therapeutics. The editors and authors are all stars in the ovarian cancer firmament and the articles are mostly up-to-date and highly relevant.

Highlights include an excellent overview of the potential limitations in achieving an early diagnosis of ovarian cancer, particularly through screening tests, an update on both the genomics and proteomics of ovarian cancer and information on the International Ovarian Cancer Association Consortium, which is examining the role of genetic polymorphisms in ovarian cancer susceptibility.

Recent information on micro RNAs in human cancer was welcome and the role of oncogenes such as p53 and the retinoblastoma gene were well covered. The therapeutic section of the book offered little new information, however did have some interesting information about chemo resistance and the potential role of immunotherapy in this disease.

Unfortunately, the editing of the book was not up to the standard of the content. In particular some of the chapters had incomplete referencing.

This book will be of interest to gynaecologic oncologists in academic departments and medical oncologists with a special interest in ovarian malignancy.

*Michael Quinn, Frances Perry House Consulting Suites, Parkville, Victoria.*

## Prognosis in Advanced Cancer

**Edited by Paul Glare and Nicholas A. Christakis**

Oxford University Press (2008)  
ISBN: 978-0-19-853022-0  
439 pages

Despite advances in medicine and health care technologies, we know that people still die from cancer and that the majority of people with cancer report a preference for information about their disease and prognosis. Answering the question: "How long do I have?", is certainly no easy task. Glare and Christakis have enlisted contributors from palliative care and oncology to provide information on the complex and multifaceted task of forecasting prognosis, reminding the reader that it is a dynamic process that will need review in response to treatments and other factors.

The stated aim of this book is to improve health care practitioners' skills at prognostication for the person with advanced cancer, thereby improving clinical decision making about therapeutics and enhancing the opportunity for people to live well and achieve personal goals in the last months of their lives.

The book is presented in three parts. Part one is the science of prognostication and comprises eight chapters. Initial chapters discuss the value of prognostication and describe the challenges for health care professionals in formulating a prognosis. Communicating prognosis to people with cancer is also discussed, with recommended steps for patient discussion given to assist the medical practitioner in these interviews. Final chapters in this section discuss methods that may enhance the prediction of the person's outcome.

Part two is prognostication in specific cancers and comprises 15 chapters. This section reviews 15 cancer types, with each chapter providing the reader with a review of the disease, its natural history, treatments and other factors affecting prognosis.

Part three is prognosis in palliative care and comprises 14 chapters. This section discusses 13 clinical conditions that may affect the person with advanced cancer. Chapters include common metastases such as bone and lung secondaries, and clinical conditions and symptoms in advancing disease such as hypercalcaemia, delirium, pain and breathlessness. These chapters describe the particular topic, highlight frequency related to primary disease, provide advice on diagnosis and treatment and then discuss prognosis. The final chapter discusses the key skill of diagnosing dying, presents signs that suggest imminent death, identifies goals of care in the dying phase and provides direction regarding communication with the person and their family.

# BOOK REVIEWS

This book is very readable, well referenced and structured so that the reader can visit separate chapters to review a specific topic of interest. Tables, figures and photographs support the text and help clarify the subject for the reader. The planned format, used in many of the chapters in parts two and three, assists the reader to access information about diseases and clinical conditions. A concise table presenting the prognoses for metastatic cancer by major primary disease sites, including adverse prognostic factors, is provided inside the book's front cover.

I would recommend this text for cancer and palliative care settings and hospital libraries.

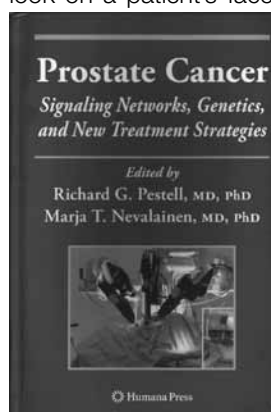
*Linda Barrett, Metro South Palliative Care Service, Brisbane, Queensland.*

## Prostate Cancer: Signalling Networks, Genetics and New Treatment Strategies

**Richard Pestell and Marja Nevalainen**

Humana Press (2008)  
ISBN: 9781588297419  
455 pages  
RRP: \$US139.00

For an organ that is (usually) quite small, and without which at least half of the world's population can live quite comfortably, the prostate seems to be associated with an inordinate amount of confusion and ignorance. The look on a patient's face when he realises a digital rectal examination has nothing to do with a computer is only one example. Even those of us who are supposed to know something about the prostate are frequently fazed by whole new areas of biology we knew little about, often in the context of a new treatment being promoted in the media.



With that in mind, it was refreshing, if somewhat intimidating, to read this book.

It has succeeded admirably in bringing together areas that the clinician usually skims over. The chapters move logically through mechanisms of carcinogenesis with a strong emphasis on the genetic and epigenetic factors involved. This is followed by a series of chapters describing the signalling pathways shown to be of relevance, many of which are non-canonical and overlap in unexpected ways. An example of this is a comprehensive description of androgen receptor biology and some of the clever ways by which prostate cancers evade androgen deprivation. Many of these still involve the androgen receptor, but through ligand-independent mechanisms. The roles of other steroids such as estrogen and the critical biology of estrogen receptor sub-types in normal and malignant prostate physiology are described very well, raising important questions about novel approaches to hormonal therapy. The book concludes with chapters outlining recent advances in surgical, radiation and systemic treatments of prostate cancer.

As with most textbooks, this one suffers from its timing; it is already out of date in some key areas, such as abiraterone and MDV-3100 (where the companies but not the drugs are mentioned only in passing), cancer stem cell biology and signalling pathways (still very controversial but not addressed at all), familial prostate cancer (where there has been a veritable explosion in candidate genes and SNPs) and cancer immunology (reflecting my personal prejudice). There is some overlap in content between chapters, but this is probably unavoidable since similar issues have been approached by different chapter authors from different perspectives. The chapters covering surgery, radiation and systemic therapies are obviously a little out of date, however are excellent summaries of the key pivotal trials up to that point.

In the current era it is always possible to put together a more up-to-date snapshot of the literature, however this would require some serious Pubmed bashing and would still be a picture without perspective. For that alone, this book will be a useful addition to my collection and I will refer to it often.

*Ian Davis, Ludwig Institute for Cancer Research, Austin Health, Heidelberg, Victoria.*

# CALENDAR OF MEETINGS



## AUSTRALIA AND NEW ZEALAND

Date	Name of Meeting	Place	Secretariat
<b>2009</b>			
<b>November</b>			
12 – 13	Australasian Leukaemia and Lymphoma Group Annual Scientific Meeting	Melbourne VIC	Australasian Leukaemia and Lymphoma Group Web: <a href="http://www1.peternac.org/allg/NewSite/">www1.peternac.org/allg/NewSite/</a>
17 – 19	Clinical Oncological Society of Australia Annual Scientific Meeting	Gold Coast QLD	Clinical Oncological Society of Australia Web: <a href="http://www.cosa.org.au">www.cosa.org.au</a>
20 – 21	Oncology Social Work Australia (OSWA) Progressing Social Work Practice: More Tools for the Tool Box	Brisbane QLD	Oncology Social Work Australia (OSWA) PO Box 47 Kotara NSW 2289 Web: <a href="http://www.oswa.net.au">www.oswa.net.au</a>
<b>December</b>			
10	kNOw Cancer in the Workplace	Canberra ACT	Cancer Council WA Conference Coordinator 46 Ventnor Ave, West Perth 6005 Tel: +61 8 9212 4363 Web: <a href="http://www.cancer.org.au/workplaceforum">www.cancer.org.au/workplaceforum</a>
<b>2010</b>			
<b>February</b>			
12 – 14	22nd Lorne Cancer Conference	Lorne VIC	ASN Events PO Box 200, Balnarring VIC 3926 Tel: +61 3 9329 6600 Web: <a href="http://www.lornecancer.org/index.php">www.lornecancer.org/index.php</a>
<b>May</b>			
4 – 7	Royal Australasian College of Surgeons Annual Scientific Congress 2010	Perth WA	Royal Australasian College of Surgeons College of Surgeons' Gardens 250 - 290 Spring Street East Melbourne VIC 3002 Tel: +61 3 9249 1200 Email: <a href="mailto:college.sec@surgeons.org">college.sec@surgeons.org</a> Web: <a href="http://www.surgeons.org">www.surgeons.org</a>
<b>September</b>			
12 – 18	Australia & Asia Pacific Clinical Oncology Research Development (ACORD) Workshop 2010	Sunshine Coast QLD	Australia & Asia Pacific Clinical Oncology Research Development (ACORD) Web: <a href="http://www.acordworkshop.org.au/">www.acordworkshop.org.au/</a>
15 – 17	Australia & New Zealand Society of Palliative Medicine	Adelaide SA	Australia & New Zealand Society of Palliative Medicine PO Box 238, Braidwood NSW 2622 Web: <a href="http://www.anzspm.org.au/">www.anzspm.org.au/</a>
<b>October</b>			
TBC	3rd Biannual Australian Lung Cancer Conference	TBC	Australian Lung Foundation PO Box 847, Lutwyche QLD 4030 Email: <a href="mailto:enquiries@lungfoundation.com.au">enquiries@lungfoundation.com.au</a> Web: <a href="http://www.lungfoundation.com.au">www.lungfoundation.com.au</a>
<b>November</b>			
10 – 12	Clinical Oncological Society of Australia Annual Scientific Meeting	Melbourne VIC	Clinical Oncological Society of Australia Web: <a href="http://www.cosa.org.au">www.cosa.org.au</a>

# CALENDAR OF MEETINGS

## INTERNATIONAL

Date	Name of Meeting	Place	Secretariat
<b>2009</b>			
<b>November</b>			
5 – 6	2009 AICR Research Conference on Food, Nutrition, Physical Activity	Washington DC United States	American Institute for Cancer research Research Department 1759 R Street, NWWashington, D.C. 20009 20009 Washington, D.C., United States Tel: 202-328-7744 Fax: 202-328-7226 Email: research@aicr.org Web: www.aicr.org/conference
5 – 6	Advances in Thoracic Surgery	London United Kingdom	Royal Brompton and Harefield NHS Trust Eric Lim Royal Brompton Hospital Sydney Street SW3 6NP London, United Kingdom Tel: +44 207 351 8591 Fax: +44 207 351 8560 Email: ats09@rbht.nhs.uk Web: www.thoracics.co.uk
5 – 7	5th International Congress on Myeloproliferative Disorders and Myelodysplastic Syndromes	New York United States	Imedex Heather Drew 4325 Alexander Drive 30022 Alpharetta, United States Tel: +1 770 751 7332 Email: meetings@imedex.com Web: www.imedex.com/calendars/oncology.asp
5 – 7	8th Middle East Oncology Congress	Beirut Lebanon	Lebanese Cancer Society Dr. Michel Daher Saint George Hospital- Achrafieh N/A Beirut, Lebanon Tel: +961 1 581714 Fax: +961 1 582560 Email: mndaher@inco.com.lb Web: www.cancer.org.lb
8 – 11	3rd International Cancer Control Congress	Lake Como Italy	3rd International Cancer Control Congress c/o International Conference Services Suite 2101 – 1177 West Hastings Street V6E 2K3 Vancouver, Canada Tel: +1 604 681 2153 Fax: +1 604 681 1049 Email: iccc2009@meet-ics.com Web: www.cancercontrol2009.com
10 – 14	27th Chemotherapy Foundation symposium on innovative cancer therapy	New York United States	The Chemotherapy Foundation Jaclyn Silverman Conference Management DirectorThe Mount Sinai Medical CenterOne Gustave L. Levy PlaceBox 1193 10029 New York, United States Tel: +1 212 866 2813 Fax: +1 646 215 7589 Email: jaclyn.silverman@mssm.edu Web: www.chemotherapyfoundation.com
11 – 14	Cancer in Africa. 7th AORTIC International Cancer Conference	Dar Es Salaam Tanzania	African Organisation for Research and Training in cancer P O Box 186 7701 Rondebosch, South Africa Tel: +27 21 689 5359 Fax: +27 21 689-5350 Email: info@aortic2009.org Web: www.aortic.org
12 – 13	6th SIO Annual Conference	Manhattan United States	Society for Integrative Oncology Dr. S. Sagar, President P.O. Box 63015 L9H 4H0 Dundas, Canada Email: sio@cogeco.ca Web: www.integrativeonc.org
12 – 14	20th Asian Pacific Cancer Congress	Tsukuba Japan	Asian Pacific Federation of Organizations for Cancer Control Hideyuki Akaza Department of UrologyTsukuba University1-1-1 Tennodai 305-8575 Tsukuba, Japan Tel: +82 298 53 3210 Fax: +82 298 53 3196 Email: akazah@md.tsukuba.ac.jp



# CALENDAR OF MEETINGS

Date	Name of Meeting	Place	Secretariat
13 – 15	10th Oncology Nursing Society Institutes of Learning	Tampa United States	Oncology Nursing Society Paula Rieger, RN, MSN, AOCN, FAAN 125 Enterprise Drive 15275 Pittsburgh, United States Tel: +1 412 859 6246 Fax: +1 412 859 6164 Email: jkent@ons.org Web: www.ons.org
14 – 15	Current Concepts in Head and Neck Cancer	New York United States	Memorial Sloan-Kettering Cancer Center Ammara Chowdhry 1275 York Avenue 10065 New York, United States Tel: +1 212 639 6857 Fax: +1 212 717 3302 Email: chowdhra@mskcc.org Web: www.mskcc.org/headandneckcme
25 – 27	1st EORTC symposium in quality of life, Brussels symptom research and patient reported Belgium outcomes in cancer clinical trials		EORTC Headquarters Av. E mounier 83/11 1200 brussels, Belgium Tel: +32 2 774 1057 Fax: +32.2.779.45.68 Email: irina.ghislain@eortc.be Web: www.eortc.be/seminar/qol_probe_2009/proberegistrationform.aspx
26 – 29	AROICON 2009 31st Annual conference of the Association of Radiation Oncologists of India	Hyderabad India	Association of Radiation Oncologists of India Apollo Cancer Institute, Apollo Health City Campus, Jubilee Hills 500033 Hyderabad, India Tel: +91 40 2355 6357 Fax: +91 40 2360 7530 Email: vijayapreddy@hotmail.com Web: www.aroicon2009.com
27 – 29	2nd multidisciplinary meeting on urological cancers	Barcelona Spain	European Association of Urology (EAU) European Society for Medical Oncology (ESMO) and European Society for Therapeutic Radiology and Oncology c/o Congress Consultants, Ms. Monique Oosterwijk PO Box 30016, 6803 AA ARNHEM, Netherlands Tel: +31 26 389 1751 Fax: +31 26 389 1752 Email: emuc-meeting2009@congressconsultants.com Web: www.emucbarcelona2009.org
29 Nov – 4 Dec	95th 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 Web: www.rsna.org/
<b>December</b>			
5 – 8	2009 American Society of Haematology Annual Meeting	New Orleans United States	American Society of Hematology (ASH) 1900 M Street, NW, Suite 200 20036 Washington, United States Tel: +1 202 776 0544 Fax: +1 202 776 0545 Email: ash@hematology.org Web: www.hematology.org/calendar.cfm
10 – 13	32nd 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 78229 San Antonio, United States Tel: +1 210 450 5912 Fax: +1 210 450-5009 Email: Rmarkow@ctrc.net Web: www.sabcs.org
26 – 30	CEAPP09	Bokakhat Town India	Assam Cancer Society & Rural Based Preventive Oncology Research Centre P.O. Bokakhat-785 612, Assam, India Tel: +91 3776 268377 Fax: +91 3776 268100 Email: surjya_bokakhat@rediffmail.com Web: www.karmayog.org/ngo/ACS
<b>2010</b>			
<b>February</b>			
2 – 5	ICACT : 21st International Congress on Anti-Cancer Treatment	Paris France	ICACT : 21st International Congress on Anti-Cancer Treatment International Medical Events (IME) 124 Bd Exelmans 75016 Paris, France Tel: +33 1 47 43 22 28 Fax: +33 1 47 43 22 26 Email: infos@im-events.com Web: www.icact.com

# CALENDAR OF MEETINGS

Date	Name of Meeting	Place	Secretariat
6 – 7	2nd Asian Breast Cancer Congress	Bangalore India	ABCC 2010 Secretariat c/o HealthCare Global Enterprises Ltd. HCG Towers #8 P, Kalingaroo Road SR Nagar, 560 027 Bangalore, India Tel: +91 98 80914343 Email: abcc2010@gmail.com Web: www.abcc2010.com
18 – 21	7th American Psychosocial Oncology Society Annual Conference	New Orleans United States	American Psychosocial Oncology Society Allison Ball 2365 Hunters Way, 22911 Charlottesville, United States Tel: +1 434 293 5350 Email: info@apos-society.org Web: www.apos-society.org
<b>March</b>			
7 – 11	16th International Conference on Cancer Nursing	Atlanta United States	International Society of Nurses in Cancer Care Sarah McCarthy 375 West 5th Avenue Suite 201 V5Y 1J6 Vancouver, Canada Tel: +1 604 630 5516 Fax: +1 604 874 4378 Email: info@isncc.org Web: www.isncc.org/conference
15 – 18	5th Latin American Congress for Palliative Care	Buenos Aires Argentina	Latin American Association for Palliative Care Carolina Monti Belgrano 141 2900 San Nicolás, Argentina Tel: +54 3461 433351 Fax: +54 3461 433351 Email: alcp.cmonti@gmail.com Web: vcongresoalcp.org/pagina-de-inicio
18 – 20	6th International Conference Clinical Cancer Prevention	St. Gallen Switzerland	St. Gallen Oncology Conferences c/o ZeTuP Rorschacherstrasse 150 9006 St. Gallen, Switzerland Tel: +41 71 243 0032 Fax: +41 71 245 6805 Email: info@oncoconferences.ch Web: www.oncoconferences.ch
23 – 27	7th European Breast Cancer Conference	Barcelona Spain	ECCO Michel Ballieu 83 av Mounier 1200 Brussels, Belgium Email: nicola@ecco-org.eu Web: www.ecco-org.eu/Conferences-and-Events/EBCC-7/ page.aspx/840
<b>April</b>			
3 – 7	5th International APOCP Conference	Istanbul Turkey	Asian Pacific Organization for Cancer Prevention Prof. A. Murat Tuncer (President) Tahran Cad. 40 / 1 Kavaklidere 06700 Ankara, Turkey Tel: +90 312 437 89 00 Fax: +90 312 437 84 66 Email: info@apocp.net Web: www.apocp2010.net/
15 – 17	7th EONS Spring Convention	The Hague Netherlands	ECCO Michel Ballieu 83 av Mounier, 1200 Brussels, Belgium Email: nicola@ecco-org.eu Web: www.ecco-org.eu/Conferences-and-Events/EONS-7/ page.aspx/645
29 Apr – 3 May	34th ONS Annual Congress	San Antonio United States	Oncology Nursing Society Gynisha M. Peeks 125 Enterprise Drive 15275-1214 Pittsburgh, United States Tel: +1 412 859 6301 Fax: +1 412 859 6167 Email: gpeeks@ons.org Web: www.ons.org
<b>May</b>			
6 – 9	1st Southeast European Conference of Chemotherapy and Infection	Varna Bulgaria	1st Southeast European Conference of Chemotherapy and Infection Prof. Dr Krasimir Metodiev 55, Marin Drinov str. 9002 Varna, Bulgaria Tel: +359 52 634 107 Fax: +359 52 634 107 Email: seeech2010@abv.bg

# CALENDAR OF MEETINGS

Date	Name of Meeting	Place	Secretariat
14 – 15	5th Baltic Congress of Oncology	Riga Latvia	Latvian Oncology Association Viesturs Kruminis, president 4 Hipokrate str. LV-1079 Riga, Latvia Tel: +371 29 485649 Fax: +371 6 539160 Email: aivars.stengrevics@aslimnica.lv Web: www.5BCO-2010-Riga.info
20 – 23	6th Chinese Conference on Oncology (CCO)	Shanghai China	Chinese Anti-Cancer Association Xi-Shan Hao No.47, Binshui Road, Hexi District, Tianjin, China 300060 Tianjin, China Tel: +86 22 23359958 Fax: +86 22 23526512 Email: bgs@caca.sina.net Web: www.caca.rog.cn
25 – 29	12th International Psycho-Oncology Society World Congress of Psycho-Oncology	Quebec City Canada	International Psycho-Oncology Society 2365 Hunters Way 22911 Charlottesville, United States Tel: +1 434.293.5350 Fax: +1 434.977.1856 Email: info@ipos-society.org Web: www.ipos-society.org
<b>June</b>			
5 – 9	57th Society of Nuclear Medicine Annual Meeting	Salt Lake City United States	Society of Nuclear Medicine 1850 Samuel Morse Drive 20190 Reston, United States Tel: +1 703 708 9000 ext. 1229 Fax: +1 703 708 9274 Email: MeetingInfo@snm.org Web: www.snm.org
15 – 19	4th World Congress of International Federation of Head & Neck Oncologic Societies	Seoul South Korea	IFHNOS 2010 Secretariat Meci International Convention Services, Inc. Rm. 1906, 19th floor Daerung Post Tower #1 212-8 Guro-dong, Guro-gu 152-05 Seoul, South Korea Tel: +82 2 2082 2300 Fax: +82 2 2082 2314 Email: ifhnos2010@meci.co.kr Web: www.ifhnos2010.org
26 – 30	21st Meeting of the European Association for Cancer Research	Oslo Norway	ECCO Michel Ballieu 83 av Mounier 1200 Brussels, Belgium Email: nicola@ecco-org.eu Web: www.ecco-org.eu/Conferences-and-Events/EACR-21/page.aspx/1105
30 Jun – 3 Jul	12th World Congress on Gastrointestinal Cancer	Barcelona Spain	Imedex Imedex Customer Service 4325 Alexander Dr. 30022 Alpharetta, United States Tel: +1 678-242-0906 Fax: +1 678-2420920 Email: meetings@imedex.com Web: www.imedex.com
<b>July</b>			
19 – 23	International Conference on Modern Cancer Management	Abuja Nigeria	Society of Oncology and Cancer Research of Nigeria Mrs Adebola Oyewole 102 Bashorun Road, Ashi Bodija Sectariat P.O Box 29822, 20000 Ibadan, Nigeria Tel: +234 802 343 1487 Fax: +234 2 241 0995 Email: info@socron.net Web: www.socron.net
<b>August</b>			
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 Web: 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 Web: www.iasp-pain.org/AM/Template.cfm?Section=Home

# CALENDAR OF MEETINGS

Date	Name of Meeting	Place	Secretariat
<b>September</b>			
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 Web: www.ecco-org.eu/Conferences-and-Events/ESSO-2010/page.aspx/1135
<b>October</b>			
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 Web: www.ifhnosworldtour2010.org
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 Web: 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 Web: 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 Web: 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 Web: 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 Web: www.ifhnosworldtour2010.org
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 Web: 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 Web: www.ifhnosworldtour2010.org

# CALENDAR OF MEETINGS

Date	Name of Meeting	Place	Secretariat
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 Tel: +1 502 891 4575 Fax: +1 502 891 4576 Email: adminoffice@igcs.org Web: www.kenes.com/igcs
25 – 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 Web: www.ifhnosworldtour2010.org
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 Web: www.ifhnosworldtour2010.org
<b>November</b>			
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 Web: 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 Web: 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 Web: www.rsna.org/

## 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.



### MEMBERS

Cancer Council ACT  
Cancer Council New South Wales  
Cancer Council Northern Territory  
Cancer Council Queensland  
Cancer Council South Australia  
Cancer Council Tasmania  
Cancer Council Victoria  
Cancer Council Western Australia

### AFFILIATED ORGANISATIONS

Clinical Oncological Society of Australia Inc

### CEO

Professor I Olver MBBS, MD, PhD, CMin, FRACP, FACHPM, MRACMA

### COUNCIL

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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.



Clinical  
Oncological  
Society of  
Australia

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

### EXECUTIVE COMMITTEE

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Dr J Turner

### MEMBERSHIP

Further information about COSA and membership applications are available from:

[www.cosa.org.au](http://www.cosa.org.au) or [cosa@cancer.org.au](mailto:cosa@cancer.org.au)

Membership fees for 2009

Ordinary Members: \$160

Associate Members: \$100  
(includes GST)

### INTEREST GROUPS

ANZ Children's Haematology and Oncology

Breast Oncology

Cancer Nurses Society of Australia

Cancer Pharmacists

Cancer Research

Clinical Research Professionals

Epidemiology

Familial Cancer

Gastrointestinal Oncology

Gynaecological Oncology

Lung Oncology

Medical Oncology

Melanoma and Skin

Neuro-oncology

Nutrition

Palliative Care

Psycho-Oncology

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](mailto: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](http://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](mailto:info@cancerforum.org.au)



GPO Box 4708, Sydney NSW 2001

Telephone: 02 8063 4100

Facsimile: 02 8063 4101

Website: [www.cancer.org.au](http://www.cancer.org.au)