Cancer survivors’ psychosocial outcomes:
A population-based investigation of anxiety, depression and unmet needs at six to twelve months post-diagnosis

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DECLARATIONS

Statement of originality

The thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to this copy of my thesis, when deposited in the University Library**, being made available for loan and photocopying subject to the provisions of the Copyright Act 1968.

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I hereby certify that this thesis is in the form of a series of published papers of which I am a joint author. I have included as part of the thesis a written statement from each co-author, endorsed by the Faculty Assistant Dean (Research Training), attesting to my contribution to the joint publications.

_______________________  ______________
Allison Boyes  Date
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SYNOPSIS

The number of people living with a history of a cancer diagnosis (i.e. cancer survivors) is rapidly increasing. Understanding the nature and extent of the impact of cancer and its treatment on the lives of survivors is fundamental to informing care that optimises their health and wellbeing. The psychosocial issues faced by survivors when the active phase of treatment ends and frequent contact with the hospital-based cancer care team ceases, are relatively unexamined. The research program described in this thesis makes a significant and robust contribution to the evidence base concerning the psychosocial impact of cancer on survivors in this phase of care.

This thesis by publication comprises an introduction, five papers and a concluding discussion. The five papers focus on measuring the prevalence and risk factors of key psychosocial outcomes – anxiety, depression and unmet supportive care needs – among Australian cancer survivors six to twelve months post-diagnosis. All papers are based on data collected as part of the Cancer Survival Study, a large population-based cohort study tracking cancer survivors’ psychosocial and physical outcomes over time. The cancer registry-based study sample is diverse and includes survivors diagnosed with the top eight incident cancers in Australia (i.e. prostate, colorectal, female breast, lung, head and neck cancers, melanoma, non-Hodgkin’s lymphoma and leukaemia). The range of potential risk factors examined is extensive and spans survivors’ individual, medical, health behaviour, psychological and social characteristics. At the time of thesis submission, four papers have been published in peer-reviewed journals, and the fifth paper is under editorial review.
The Introduction describes the high burden of disease of cancer among the growing population of cancer survivors, with points of difference between the Australian and global context highlighted. The survivor population and the survivorship phase of care are defined. Using the biopsychosocial model of health as a framework, the psychological, physical, social and existential impact of cancer on survivors is described. The prevalence and correlates of anxiety, depression and unmet supportive care needs among cancer survivors six to twelve months post-diagnosis are summarised, and the challenges associated with the accurate assessment of these outcomes are described. It is argued that large and robust descriptive studies, which include a diversity of cancer survivors as subjects, as well as rigorous outcome measures, are needed to identify and inform subgroups of at-risk survivors about what they can expect to experience as a consequence of cancer and its treatment, identify gaps in care that may require development of interventions to prevent or minimise adverse psychosocial outcomes, and guide the development of social policies that recognise and address survivors’ limitations.

Paper 1 reports the results of a survey of 1323 cancer survivors. At six months post-diagnosis, the point prevalence of caseness for anxiety and/or depression, as assessed by the Hospital Anxiety and Depression Scale (HADS), was lower than expected. Twenty-four percent of subjects were identified as cases on anxiety (irrespective of depression), 15% as cases on depression (irrespective of anxiety) and 10% as cases on comorbid anxiety-depression. Survivors’ psychological characteristics (particularly a history of mental health treatment and maladaptive coping styles), health behaviours (particularly level of physical activity) and social characteristics were stronger
correlates of anxiety and/or depression than individual, disease or treatment characteristics. These findings provide insight into the profile of the small but important group of cancer survivors who may be at risk of psychological morbidity six months after diagnosis. Paper 1 has been published in the *Journal of Affective Disorders*.

Building on the findings of Paper 1, **Paper 2** describes the natural history of 1154 survivors’ psychological wellbeing from six months to one year after diagnosis. Contrary to expectation, the point prevalence of psychological morbidity did not decrease over time. However, tracking individual survivors’ psychological wellbeing revealed four trajectories of adjustment, with the majority of survivors demonstrating resilience (68%) or recovery (9%), with smaller groups experiencing chronic (14%) or late (9%) psychological morbidity. Consistent with Paper 1, survivors’ psychological characteristics, particularly levels of anxiety and depression at baseline, were the strongest factors associated with subsequent psychological morbidity. It is suggested that while the majority of survivors adjust well and require only low-intensity supportive care to manage psychological difficulties, those with a history of mental illness may benefit from being screened for psychological distress and targeted with early intervention. Paper 2 is currently under editorial review.

To support the targeted psychological distress screening of at-risk cancer survivors, as proposed in Paper 2, screening tools that are brief, easy to use and accurate are required. **Paper 3** reports the accuracy of the single-item Distress Thermometer (DT) to identify possible cases of anxiety and/or depression, using the HADS as the criterion...
measure. The findings, based on data from 1323 survivors, challenge the all-purpose use of the recommended DT threshold of 4 or more to identify possible cases of psychological distress among survivors at six months post-diagnosis. It is suggested that a DT cut-off score of 2 or more may be best for clinical use when it is desirable not to miss possible cases, a score of 4 or more best for research use when it is desirable not to over-inflate estimates of prevalence, and a score of 3 or more the best balance between sensitivity and specificity. With a high level of precision in correctly identifying non-cases, it is suggested that the DT may best serve initially to identify non-cases, as part of a two-stage screening process. Paper 3 has been published in *Supportive Care in Cancer*.

Supportive care needs encompass the informational, physical, emotional, social, practical and spiritual needs of individuals affected by cancer. Unmet supportive care needs are those needs where additional services or resources are required by an individual to achieve optimal wellbeing. The assessment of unmet supportive care needs is an alternative approach to psychological morbidity for examining the psychosocial impact of cancer. **Paper 4** reports the application of classical test theory to develop and validate a shortened version of the commonly used Supportive Care Needs Survey (SCNS) to enhance its clinical and research utility. Using the original *Supportive Care Review* dataset (n=888) and the *Cancer Survival Study* dataset (n=250), a 34-item short version of the SCNS (SCNS–SF34) was produced, with the five-factor structure (i.e. psychological, health system and information, physical and daily living, patient care and support, and sexuality needs) and strong psychometric properties of the original instrument maintained. Preliminary evidence of convergent validity of the
SCNS–SF34 with three other measures of psychosocial wellbeing was demonstrated. Paper 4 has been published in the *Journal of Evaluation in Clinical Practice*.

**Paper 5** utilises the SCNS-SF34 measure developed in Paper 4 to examine the prevalence and correlates of 1323 survivors’ supportive care needs six months after diagnosis. Thirty-seven percent of survivors reported moderate to high level unmet need, with most of these concerning psychological and physical aspects of daily living issues. A further 42% of survivors reported no need for help with any of the items assessed. Correlates of moderate to high level unmet need are consistent with those associated with anxiety and/or depression in Papers 1 and 2. It is suggested that while some survivors express unmet needs, current care appears to avert and/or adequately meet the needs of a large proportion of survivors. Paper 5 has been published in *BMC Cancer*.

**In conclusion**, this research program provided robust information about 1) the extent and type of psychological morbidity and unmet needs faced by cancer survivors six to twelve months post-diagnosis; 2) the potentially modifiable and non-modifiable characteristics of those at risk of poor outcomes; and 3) contributed to the refinement of screening and assessment tools to assist in the identification of psychosocial morbidity. Experimental studies testing the effectiveness of acceptable and feasible interventions to reduce psychosocial morbidity among at-risk cancer survivors are needed. The finding that most survivors recovered well should not be disregarded in the debate about the optimal allocation of scarce resources to post-treatment care, relative to the other phases of the cancer control continuum.
INTRODUCTION
Aetiology of cancer

Cancer is the uncontrolled division of abnormal cells that have the ability to invade nearby tissues and spread to other parts of the body through the bloodstream or lymphatic system. The following factors have been linked to the development of cancer: biomedical factors (e.g. increasing age, hereditary predisposition, hepatitis B and human papilloma virus infection); environmental factors (e.g. exposure to indoor air pollution, asbestos, and ultraviolet and ionising radiation); and lifestyle factors (e.g. tobacco and alcohol use, inadequate diet and physical inactivity).\(^1\) It is estimated that 30% of all cancer cases could be prevented by not smoking.\(^1\),\(^2\)

The site in the body where the disease begins is referred to as the ‘primary cancer’, while a cancer which is formed by the primary cancer spreading to another part of the body is referred to as a ‘secondary cancer’. Cancer can be diagnosed at an ‘early’ stage when it is small and contained within the tissue or area in which it originated (i.e. localised), or at an ‘advanced’ stage when it has already spread from the original site to distant organs (i.e. metastatic). Generally, the earlier a cancer is detected, the greater the likelihood of successful treatment. The major cancer treatments are surgery, radiotherapy, chemotherapy, hormone therapy and biological therapy, all of which are associated with a range of late and long-term physical and psychosocial effects.\(^3\) Many diagnosed individuals achieve ‘remission’ whereby cancer can no longer
Incidence of cancer

The incidence of cancer is increasing worldwide, including in Australia, mainly because of the growth and ageing of the population. The global number of new cases of cancer is expected to double from 12.4 million (6.7 million in males and 5.7 million in females) in 2008 to 27 million in 2030. The most common incident cancers globally are lung cancer in males and breast cancer in females. In Australia there were 112 304 (64 124 in males and 48 180 in females) new cases of cancer, excluding non-melanocytic skin cancer, diagnosed in 2008, and this number is projected to increase to 150 000 in 2020. Compared to other regions, Australia has the highest age-standardised incidence rate of cancer in the world.

The most commonly diagnosed new cancer cases in Australia are prostate cancer, followed by colon cancer, breast cancer, melanoma of the skin and lung cancer. Together, these five cancers accounted for 62% of all cases diagnosed in 2008. Australia has the world’s highest incidence rates of melanoma of the skin and prostate cancer and the third highest rate of breast cancer in females.

Similar to other chronic diseases such as cardiovascular disease, the likelihood of developing cancer increases with increasing age. In Australia in 2007, 74% of new cancer cases in males and 62% of new cancer cases in females occurred among those aged 60 years and older. The mean age of diagnosis was 67 years for males and 64
years for females. By the age of 85 years, 1 in 2 males and 1 in 3 females in Australia will have been diagnosed with cancer at some point in their lives.

**Mortality from cancer**

Cancer is one of the leading causes of death in the world, and is the second most common cause of death in Australia. An estimated 7.6 million people (4.3 million males and 3.3 million females) died from cancer in 2008, representing about 13% of all deaths worldwide. Lung cancer was the most common cause of cancer-related mortality in males, while breast cancer was the most common cause of cancer-related deaths in females. It is projected that by 2030 there will be 17 million cancer-related deaths a year. In Australia, there were 41,467 deaths from cancer in 2009, accounting for 29% of all deaths. The leading causes of cancer-related death were lung cancer, followed by bowel, prostate, breast and haematological cancers. Together, these five cancers accounted for 49% of all deaths from cancer. While the actual number of cancer-related deaths in Australia is increasing due to the ageing and growth of the population, overall mortality rates from cancer are decreasing, predominantly due to advances in detection and treatment. However, mortality rates vary across population groups, with Indigenous Australians, people living in remote areas and the most socioeconomically disadvantaged having significantly higher rates, compared to their non-Indigenous, city-dwelling and high socioeconomic status counterparts. The risk of dying from cancer in Australia by 85 years of age is 1 in 4 for males and 1 in 6 for females.
Relative survival from cancer

The prognosis for a person with cancer is affected by many factors, including characteristics of the individual (e.g. age, sex and comorbid health conditions), the cancer (e.g. cancer site, aggressiveness and extent of spread at diagnosis) and the health care system (e.g. availability of effective treatments).\(^1\) Survival from cancer is commonly reported in terms of ‘five-year relative survival’, which refers to the probability that a person with cancer will still be alive five years after diagnosis, relative to people in the general population of the same sex and age. Australia’s all-cancer survival rates have significantly increased over the past two decades\(^8\) and are among the highest in the world.\(^6\) For those diagnosed with cancer between 1998 and 2004, the five-year relative survival rate for all cancers combined was 61% (58% for males and 64% for females), compared to 47% (41% for males and 53% for females) for those diagnosed between 1982 and 1986.\(^8\) Cancers with the highest five-year relative survival in 1998-2004 were testicular cancer (97%), thyroid cancer (93%), melanoma of the skin (92%), breast cancer (88%) and prostate cancer (85%). In contrast, cancers with the lowest five-year relative survival were pancreatic cancer (5%), cancer of unknown primary site (9%), lung cancer (12%), brain cancer (19%) and stomach cancer (25%).\(^8\)

Prevalence of cancer

With both cancer incidence and cancer survival increasing, the population of people living with a history of cancer is growing. It is estimated that in 2008, there were 28 million people worldwide who had been diagnosed with cancer in the previous five
years and were still alive.1 In Australia, it is estimated that there were 654,977 people who had been diagnosed with cancer during the previous 23 years and were still alive at the end of 2004, accounting for 3% of the Australian population. The population of cancer survivors in Australia are mostly survivors of breast cancer (20%), melanoma of the skin (18%), prostate cancer (15%) and colorectal cancer (14%).8 For many cancer survivors, cancer is a chronic condition characterised by prolonged duration, functional impairment or disability, and incurability.9

Burden of disease due to cancer

Burden of disease encompasses the impact of premature death and prolonged illness or disability of a particular disease or injury on people or communities.10 Disease burden is usually measured in terms of ‘disability-adjusted life years’ (DALYs) with one DALY representing one year of healthy life lost due to premature death, prolonged illness and/or disability.10 Cancer is the leading cause of disease burden in Australia, accounting for almost one-fifth of total DALYs and responsible for more than 400,000 DALYs in 2003. It is estimated that four-fifths of the cancer burden is due to premature death. It is projected that the burden of cancer will increase, and that cancer will continue to be the leading cause of the burden of disease and injury in Australia.10 The World Health Organization has described cancer and other chronic diseases, including heart disease and stroke, as looming epidemics that will take the greatest toll in deaths and disability.11
Cost of cancer

The cost of cancer includes health system expenditure (e.g. hospital treatment, medical and allied health services and pharmaceuticals), productivity costs (e.g. lost wages, employment absenteeism and informal care), financial costs (e.g. transport, accommodation and educational materials), deadweight costs (e.g. forgone tax revenue, and welfare and disability payments) and the burden of disease. The total lifetime (i.e. from diagnosis to death) economic cost of cancer for people diagnosed in Australia in 2005 is expected to be approximately $94.6 billion, with the bulk of this accounted for by the value of burden of disease. If burden of disease is excluded, the total financial cost is about $11.2 billion, with most of this accounted for by productivity losses. Overall, lung cancer and colorectal cancer are the most costly cancers in Australia. The lifetime financial cost of cancer borne by diagnosed individuals and their households is substantial, averaging $47,200 per affected household, and predominantly represents productivity losses and out-of-pocket expenses.  

Public health priority of cancer

The ability of the health care system to provide effective treatment and ongoing care to the growing population of individuals diagnosed with and surviving cancer has been described as a public health crisis. In recognition of the urgent need to reduce the substantial burden imposed by the disease, in 1997 cancer was declared a National Health Priority Area in Australia. The prioritisation of cancer is reflected in the subsequent development of clinical practice guidelines for the management of common cancers; the release of seminal policy documents, such as Optimising
Cancer Care in Australia, the National Chronic Disease Strategy and the National Service Improvement Framework for Cancer, outlining wide-ranging strategies and recommendations for improving cancer control; and the establishment in 2006 of a dedicated government agency, Cancer Australia, to drive the national agenda to reduce the impact of cancer.

CANCER SURVIVORS AND SURVIVORSHIP

Defining cancer ‘survivors’

The term, cancer ‘survivor’, has many varied definitions among stakeholders. It has been used to describe individuals diagnosed with cancer who are in remission five years after diagnosis or treatment when the risk of recurrence is low, those who are not in remission but remain alive for more than five years, diagnosed individuals whose cause of death is something other than cancer, and diagnosed individuals who have completed initial cancer treatment. Key cancer agencies define a cancer ‘survivor’ as anyone diagnosed with cancer, from the time of diagnosis to the end of life. However, it should be noted that there is some contention among those diagnosed with cancer about the label, cancer ‘survivor’. Studies reveal that while identifying as a cancer ‘survivor’ is common, it is not universal, with many identifying as a person who has had cancer, a cancer patient or a cancer victim.
Defining cancer ‘survivorship’

Although its use is widespread, the term, cancer ‘survivorship’, is an ambiguous and poorly defined concept. The National Cancer Institute’s (NCI) cancer control continuum (See Figure 1.1) is an established concept used to depict the various phases in the cancer trajectory from cancer prevention to end of life. It classifies ‘survivorship’ as the phase of the continuum that follows cancer treatment and continues until recurrence, the diagnosis of a second cancer, or end of life. However, due to the nature of modern treatment regimens, it is increasingly difficult to establish when the treatment phase ends and the survivorship phase begins. For example, survivors of breast and prostate cancer may take hormone treatments for up to five years following active treatment, while survivors of haematological cancers typically receive intermittent chemotherapy or biological therapies for many years following diagnosis.

Figure 1.1: Simplified cancer control continuum (Source: Adapted from National Cancer Institute Cancer Control Continuum)
In contrast to the NCI cancer control continuum, the National Coalition for Cancer Survivorship (NCCS) uses an inclusive concept of cancer survivor to define ‘survivorship’ as the experience of living with, through and beyond a cancer diagnosis. Similarly, Mullan (1985) described cancer survivorship as a three-phase process: 1) acute survival, which encompasses diagnosis to the end of initial treatment and is often dominated by fear and anxiety; 2) extended survival, which starts at the completion of initial 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; and 3) permanent survival, which does not begin at a specific point in time but evolves from extended survival when the risk of recurrence is low and patterns of normal life may be re-established.

This thesis adopts the broad definition of a cancer survivor as any person who has been diagnosed with cancer. It focuses on survivors who are six to twelve months post-diagnosis. While acknowledging that each individual’s cancer trajectory is unique, survivors six to twelve months post-diagnosis have typically completed, or are nearing the completion of, primary active cancer treatments, including surgery, radiotherapy and chemotherapy. Thus, the time period of six to twelve months post-diagnosis straddles the treatment and survivorship phases of the NCI cancer control continuum, and is analogous with Mullan’s extended survival phase. It is suggested that optimal care during this phase involves 1) prevention and detection of new and recurrent cancers and other late effects; 2) surveillance for cancer spread, recurrence and second cancers, and assessment of physical and psychosocial late effects; 3) management of the effects of cancer and its treatment (e.g. physical symptoms,
psychological distress and socioeconomic concerns); and 4) coordination among specialists and primary care providers to ensure all of the survivors’ health needs (e.g. care of comorbidities) are met. Thus, it is posited that the optimal care of cancer survivors is consistent with a more circular cancer continuum, rather than the linear trajectory shown in Figure 1.1.

**Public health priority of cancer survivorship**

With the prevalence of cancer survivors rapidly increasing, survivorship has emerged in the past decade as a global public health priority. Consumer advocacy groups such as the National Coalition for Cancer Survivorship, and government reports such as *Living Beyond Cancer: Finding a New Balance*, have highlighted the limitations of the existing health care system in responding in a cohesive way to the comprehensive and complex care needs of this population. While guidelines exist for some aspects of survivorship care, such as nutrition and physical activity, currently there are no evidence-based clinical practice guidelines for the delivery of comprehensive survivorship care to survivors of adult cancers.

Various organisations worldwide have recognised the importance of addressing these issues as a priority. Governments have invested in the establishment of major research initiatives, such as the Office of Cancer Survivorship in the United States of America and the National Cancer Survivorship Initiative in the United Kingdom, to inform and accelerate improvements in survivorship care. Philanthropic funding has sponsored the establishment of organisations such as the Lance Armstrong Foundation and the Australian Cancer Survivorship Centre to develop and disseminate survivorship
resources, services and programs. Respected organisations have released high-profile reports championing issues in cancer survivorship,\textsuperscript{37} with the most influential of these being the Institute of Medicine’s seminal report, \textit{From Cancer Patient to Cancer Survivor: Lost in Transition},\textsuperscript{3} which delineated ten recommendations to improve cancer survivors’ care and quality of life.

\textbf{MULTIDIMENSIONAL IMPACT OF CANCER ON SURVIVORS IN EARLY SURVIVORSHIP}

Understanding the nature and extent of the impact of cancer and its treatment on the lives of survivors is a critical step for optimising their health and wellbeing during survivorship. Information about the problems, concerns and needs of survivors is necessary to inform survivors and health care providers about what survivors may expect to experience in the future as a consequence of cancer and its treatment. Knowledge of the onset, duration and frequency of the effects of cancer may guide the delivery of follow-up care, including the development of interventions to prevent or minimise adverse outcomes among survivors.

There are many complexities in understanding the impact of cancer on survivors, due to the heterogeneous nature of survivorship. First, there are a number of diverse survival trajectories that survivors may experience, including 1) living in complete remission with or without ongoing adjuvant therapy, 2) living in partial remission requiring intermittent or ongoing adjuvant treatment, 3) living with progressive disease and 4) living in remission initially but then being diagnosed with a recurrence, second cancer or metastases.\textsuperscript{38} Second, the survivorship phase is broad, encompassing
not only recent survivors who have completed active treatment recently, but also long-term survivors who have survived for many years after active treatment. Third, middle-aged and older survivors typically experience cancer survivorship concurrently with other age-related life events and health conditions, such as heart disease, arthritis and diabetes. It is likely that survivors’ experiences of survivorship will be influenced by their survival trajectories, phase of survivorship and coexisting medical conditions.

The focus of this thesis is on survivors who are six to twelve months post-diagnosis, a time period which, for most, corresponds with impending or recent completion of active treatment. It is typically a period of heightened vulnerability and coincides with survivors leaving the perceived ‘safety net’ of frequent monitoring and support from the hospital treatment team, facing the demands of resuming pre-cancer roles and patterns of daily life, adjusting to living with and managing the side-effects of treatment, and dealing with uncertainty about the future. Historically, cancer care and research have concentrated on the biomedical aspects of the acute survival or active treatment phase of the cancer trajectory. Consequently, despite all of the primary cancer treatments having a range of short-term, long-term and late effects, the wellbeing and psychosocial care needs of survivors transitioning from treatment to survivorship are poorly understood and largely undocumented.

**Conceptual framework**

The World Health Organization defines health as ‘a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’. While a number of different conceptual models have been used to underpin research directed
to better understanding the experience and consequences of cancer, the
biopsychosocial model of health\textsuperscript{48} and models of quality of life\textsuperscript{49, 50} dominate the field. Consistent with a holistic approach to health, these models posit that disease and illness have the potential to affect multiple aspects of an individual’s life, including physical, psychological, social and spiritual aspects. Coping has been identified as one of the factors moderating the extent to which cancer has a negative impact on survivors’ outcomes.\textsuperscript{51} It is argued that a host of factors influence an individual’s subjective appraisal of the threat associated with a potentially stressful event (e.g. cancer) and the physiological, cognitive, emotional and behavioural responses to the stressor.\textsuperscript{52} The research study, the \textit{Cancer Survival Study}, reported in this thesis draws upon the elements of these models and is conceptualised in Figure 1.2. With the emergence of survivorship as a recognised phase of care and as a discrete discipline in cancer research, survivorship-specific models have only recently begun to be developed. These include the Cancer Survivor Adaptation model,\textsuperscript{42} which takes into consideration the chronic nature of cancer.

Adjusting to cancer and its treatment is a complex and dynamic process that occurs over time.\textsuperscript{53} The existing body of research indicates that cancer has significant psychological, physical, social and existential impacts upon survivors, with both positive and negative sequelae reported.\textsuperscript{54} It is also known that some effects (e.g. hair loss) are short-term or transient, others (e.g. fear of recurrence) are long-term or permanent, and still others (e.g. lymphoedema) manifest some time after treatment completion.\textsuperscript{46} While quality of life and psychosocial wellbeing appear, for the vast majority of survivors, to return to normal by one to two years after diagnosis,\textsuperscript{55, 56}
problems continue to exist for some. Factors that contribute to individuals’ adjustment to cancer include individual (e.g. age), cancer-related (e.g. tumour type), health behaviour (e.g. physical activity), internal (e.g. self-efficacy) and external (e.g. social support) factors.\textsuperscript{57}

\textbf{Figure 1.2:} Conceptual framework for understanding the multidimensional impact of cancer on survivors
Psychological distress is a generic term that encompasses the spectrum of feelings from worry, vulnerability and sadness, to depression, anxiety and panic.\textsuperscript{58} It is a common and normal response to a stressor such as the transition from one point in the disease trajectory to another (e.g. completion of active treatment, and diagnosis of recurrence). In a recent study of survivors with mixed cancer diagnoses attending a large tertiary cancer care centre, Carlson et al\textsuperscript{59} found that 29\% reported clinically elevated levels of distress at one year post-diagnosis. In a novel approach to outcomes assessment, Henselmans et al\textsuperscript{60} linked assessments to key events in the first year since diagnosis and found that of the 171 breast cancer survivors tracked over time, 36\% experienced no distress, 33\% experienced distress only during active treatment, 15\% experienced distress during the transition to survivorship and 15\% experienced chronic distress. Psychological distress appears to be more prevalent among female survivors compared to male survivors, and among younger survivors (less than 50 years) compared to older survivors.\textsuperscript{61}

Studies consistently report fear of cancer recurrence and uncertainty about the future as the most common concerns among survivors in early survivorship.\textsuperscript{62, 63} When cancer does recur, it is often experienced as more traumatic than the first diagnosis.\textsuperscript{64} In a large multi-state study conducted with cancer survivors of mixed diagnoses, Baker et al\textsuperscript{65} found that at one year post-diagnosis, two-thirds were concerned about the cancer returning, 58\% were fearful about the future, 40\% had difficulties making long-term plans, 37\% felt vulnerable, and one-third felt helpless, angry and dependent. A recent qualitative study by Foster et al\textsuperscript{62} revealed that many survivors have low self-
confidence in their ability to self-manage treatment-related problems after active treatment finishes. For some survivors, feelings of relief and gratitude at having survived are mixed with sadness about the associated cost, such as limited functioning or inability to have biological children. Although rarely documented in the scientific literature, accounts from online blogs reveal that some survivors feel guilty for having survived cancer when others they knew have not.

**Physical**

Many cancer survivors live with a range of debilitating cancer-related physical side-effects. While there is limited information about the precise incidence and prevalence of many physical effects experienced during survivorship, fatigue, pain, sleep disturbance, cognitive dysfunction and sexual dysfunction appear to be among the most common. Carlson et al recently reported that 40% of survivors experienced clinically elevated levels of fatigue, and 20% experienced clinically elevated levels of pain at one year post-diagnosis. Similarly, Baker et al found that approximately two-thirds of survivors had problems with fatigue, almost half had sleep difficulties, 41% had problems with sexual function, and approximately one-third had problems with diminished ability to concentrate at one year post-diagnosis. Sexual dysfunction and fertility issues are most prevalent among survivors of breast and genitourinary cancers, while cognitive impairment is related to high-dose chemotherapy.
Due to the nature of cancer treatments, cancer survivors are at increased risk of a range of other medical conditions, such as a second cancer, cardiovascular disease and osteoporosis, requiring ongoing monitoring and adjustments in daily living. A recent review found that up to 30% of survivors experienced cancer-related cardiac or pulmonary impairment, and 16% of survivors developed a second cancer. In an analysis of the National Health Interview Survey, Hewitt et al found that 11% of survivors reported having one or more limitations in their ability to perform activities of daily living such as bathing, eating and using the bathroom, and 58% reported other functional disabilities, such as inability to walk a quarter of a mile and inability to stand or sit for two hours.

**Social**

After the completion of active treatment, support from families and friends typically declines sharply, and survivors are often faced with the unrealistic expectations of others to ‘get back to normal’. The perceived lack of understanding from family and friends about what the survivor has gone through leaves many survivors feeling unable to relate to and disconnected from their social networks. Baker et al found that one quarter of survivors at one year post-diagnosis had difficulties returning to their former roles and felt isolated. Feelings of social isolation after treatment lead some survivors to seek out other survivors with whom they can identify.
Although a high proportion of working survivors experience temporary changes in their employment, it is estimated that approximately 80% return to work within 12 to 18 months, with a minority of these working fewer hours or performing changed work tasks.\textsuperscript{74-77} A large population-based cohort study found that most breast cancer survivors resume their employment with minimal interference.\textsuperscript{78} A small proportion of survivors experience workplace discrimination\textsuperscript{79} and difficulties returning to physically demanding jobs due to cancer-related limitations.\textsuperscript{77, 80} A recent systematic review found that compared to non-cancer groups, cancer survivors had a significantly increased risk of unemployment and early retirement.\textsuperscript{81}

There is little information about the financial consequences of cancer during survivorship. Anecdotal evidence suggests that cancer survivors find it difficult to obtain new life, health, income protection and travel insurance policies, and yet there is little information about the extent to which this is a problem. A large population-based study of melanoma, colorectal and haematological cancer survivors found that 18% of those who tried to obtain life insurance and 9% of those who tried to obtain a mortgage experienced problems, including rejection or acceptance at a higher premium or mortgage payment.\textsuperscript{82}

**Existential**

For most survivors, cancer is a life-changing diagnosis, with many re-evaluating their values, priorities and outlook on life as a result of facing their own mortality. Early work by Little et al\textsuperscript{83} found that survivors typically engage in an ongoing process of constructing meaning from their experiences. Many survivors struggle to adjust to a
new ‘normal’, changes to their self-identity, and expectations of themselves as cancer survivors.\textsuperscript{42, 43, 84} Several studies have found that many survivors, particularly women and younger survivors, perceive benefits from their cancer experiences, including enhanced appreciation of life, fuller and more meaningful lives, closer relationships with others, increased faith, and engagement in positive health behaviour changes such as increased physical activity.\textsuperscript{43, 85-87}

**PSYCHOSOCIAL OUTCOMES OF CANCER SURVIVORS IN EARLY SURVIVORSHIP**

**Salience**

Biomedical endpoints such as tumour shrinkage, survival and length of remission were traditional measures of the impact of cancer and its treatment. However, with the increase in survival from cancer, the impact of cancer on the ‘quality’ of survivors’ survival has become important. Studies have found that psychosocial morbidity among cancer survivors is associated with poorer quality of life across multiple domains,\textsuperscript{88, 89} more intense physical symptoms, increased functional impairment and poor treatment adherence.\textsuperscript{90} Moreover, some evidence suggests there may be a relationship between psychological distress and cancer progression\textsuperscript{91} and reduced overall survival.\textsuperscript{92} However, this concept remains controversial. Importantly, however, psychosocial morbidity is potentially modifiable.\textsuperscript{90, 93-96} Accordingly, psychosocial wellbeing is now recognised as a clinically relevant outcome of cancer care, as demonstrated by key cancer policy documents such as *Cancer care for the whole patient: Meeting psychosocial health needs*\textsuperscript{37} and *Clinical practice guidelines for the psychosocial care of adults with cancer*,\textsuperscript{98} which specifically address this aspect of cancer care.
Measurement

A range of approaches have been used to measure the psychosocial outcomes of cancer survivors, including the assessment of quality of life, psychological distress and unmet supportive care needs. Quality of life has been the main focus of survivorship research conducted to date, and yielded much valuable information about survivors’ subjective appraisal of their health status across multiple dimensions of functioning. Although some studies have included comparisons with population norms, quality of life data have somewhat limited clinical utility because of a lack of criteria regarding the scores on quality of life tools that represent problems warranting intervention.

When considering psychological distress, research has predominantly focused on the indices of anxiety and depression. In contrast to quality of life, there are standardised criteria for measuring the presence and severity of clinical symptoms of anxiety and depression, and a corresponding range of evidence-based treatments. While most individuals with cancer do not meet the full diagnostic criteria for mental disorders, many experience a degree of psychological distress. Several clinical practice guidelines now recommend that all individuals diagnosed with cancer should be routinely screened for distress at periods of increased vulnerability during the cancer journey (e.g. at the end of treatment) to ensure those at risk are identified early and offered appropriate treatment or referral.
The assessment of unmet needs is a conceptually different approach to assessing either quality of life or psychological distress. Needs assessment allows survivors to self-report the issues of concern for which they perceive they require help, and the magnitude of their need for help.\(^{104}\) Thus, needs assessment is superior to quality of life methodology because it does not infer that if a survivor reports a deficit in functioning or an issue of concern, that he or she must want help with it. Needs assessment not only allows health care professionals to focus on the concerns survivors themselves have identified as the ones they most need help with, but also provides information necessary for deciding allocation of scarce resources to yield the greatest benefits for survivors.

This thesis focuses on the outcomes of anxiety, depression and unmet supportive care needs because of their clinical significance, relevance to clinical practice and potential amenability to intervention. The most accurate method for obtaining information about these outcomes is to ask survivors themselves,\(^{105, 106}\) and many self-report measures have been developed as an alternative to clinical interviews.\(^{107-109}\) The efficiency of a self-report measure will depend upon the extent to which it demonstrates adequate psychometric properties, including 1) acceptability to respondents in terms of length of time to complete and ease of understanding, 2) reliability of repeated measurement with minimum random error, 3) validity or fidelity in measuring what it purports to measure, and 4) sensitivity in discriminating between individuals and groups of different health states and in detecting changes over time.\(^{110}\)
Many generic and cancer-specific measures exist to assess anxiety, depression and unmet supportive care needs. For example, three recent systematic reviews found that approximately 30 different tools have been used to assess symptoms of anxiety, depression and/or general psychological distress among individuals diagnosed with cancer.\textsuperscript{108, 109, 111} These reviews concluded that of the short measures examined, the Hospital Anxiety and Depression Scale (HADS)\textsuperscript{112} and Center for Epidemiological Studies–Depression Scale (CES–D),\textsuperscript{113} demonstrated adequate psychometric properties.

In an effort to increase the implementation of routine psychosocial distress screening among cancer survivors in the clinical setting, ultra-short screening methods have been developed and tested. Of those available, the single-item Distress Thermometer\textsuperscript{51, 114} is the most commonly used ultra-short distress screening tool in the cancer care setting and is recommended by the National Comprehensive Cancer Network.\textsuperscript{58} Only two studies\textsuperscript{115, 116} have examined the screening performance of the DT among individuals in the survivorship phase of care, with both studies reporting poor detection of self-reported cases of anxiety and depression, relative to the criterion measure.

Similarly, two recent reviews identified approximately 15 different tools that had been used to assess the unmet needs of adults diagnosed with cancer.\textsuperscript{107, 117} Both reviews concluded that while many tools, such as the Cancer Rehabilitation Evaluation System (CARES)\textsuperscript{118} and the Supportive Care Needs Survey (SCNS)\textsuperscript{119} had merit, none demonstrated adequate psychometric properties. In particular, responsiveness to change and clinical utility were rarely examined.
Prevalence of anxiety and depression

Anxiety can be described as a state of constant worry or tension. It generally involves highly unpleasant feelings of apprehension or nervousness. The physical symptoms of anxiety include heart pounding, fatigue, sleep disturbances and difficulties concentrating. Depression is a sustained lowering of mood. It is characterised by feelings of sadness and helplessness, crying, decreased motivation and loss of interest in activities that were previously enjoyable. Physical symptoms of depression include loss of appetite, sleep disturbances and loss of energy.

The 2007 National Survey of Mental Health and Wellbeing assessed the mental health of approximately 8,800 individuals in Australia aged 16 to 85 years, using the World Mental Health Survey Initiative version of the World Health Organization’s Composite International Diagnostic Interview, version 3.0 (WMH–CIDI 3.0). The World Health Organization International Classification of Diseases, 10th Revision (ICD-10) was used to classify mental health problems. Anxiety disorders were the most common class of mental disorders reported. A total of 14.4% experienced anxiety disorders, and 6.2% experienced affective disorders in the 12 months prior to interview. Based on these data, it is estimated that 26% of Australians will experience an anxiety disorder and 15% will experience an affective disorder in their lifetimes. Rates of 12-month anxiety and affective disorders were higher among females, those aged less than 55 years, those who were single or never married, those from one-parent families with children, socioeconomically disadvantaged individuals (i.e. recipients of government allowance and those with histories of homelessness and/or incarceration), current smokers, users of illicit substances and/or abusers of prescribed...
medicines, and those with severe or profound limitations or restrictions to their activities of daily living.\textsuperscript{121}

Reviews of the literature suggest that, compared to the general population, the prevalence of anxiety and depression may be almost twice as common among cancer survivors, with up to 60% reported to experience anxiety\textsuperscript{123} and up to 23% reported to experience depression.\textsuperscript{124} While numerous studies have assessed the prevalence of anxiety and depression among those in the acute survival phase\textsuperscript{125-130} or long-term survivorship,\textsuperscript{131-133} relatively fewer studies have assessed these clinically important outcomes in the intervening period. An examination of studies published in the year 2000 onwards which were conducted with samples of at least 80 cancer survivors and used a valid and reliable approach to assess the symptoms of anxiety and/or depression in the period approximately six to twelve months post-diagnosis, found that the prevalence estimates ranged from 7% to 51% for anxiety and from 5% to 24% for depression.\textsuperscript{134-143}

The wide range of prevalence estimates reflects, in part, the variations across studies in the sampling framework and case-mix of the study populations, as well as the assessment techniques used to measure and define anxiety and depression. For example, Lynch et al\textsuperscript{137} recruited a sample of 1,822 colorectal cancer survivors from one state-based cancer registry. At six months post-diagnosis, 7% of survivors scored positive for anxiety and 8% scored positive for depression, as assessed by the Brief Symptom Inventory-18.\textsuperscript{144} At one year post-diagnosis, 7% of survivors scored positive for anxiety and depression respectively. Similar low rates of depression (5%) at one
year post-surgery were reported in a study by Uchitomi et al\textsuperscript{135} with a sample of 212 lung cancer survivors recruited from one treatment centre and assessed using the gold standard Structured Clinical Interview for DSM-III-R (SCID)\textsuperscript{145}.

In contrast, despite also using the SCID, the study by Kangas et al\textsuperscript{142} reported considerably higher prevalence of anxiety (32\% and 20\% at six and twelve months post-diagnosis respectively) and depression (22\% at both six and twelve months post-diagnosis) among a sample of 82 head, neck and lung cancer survivors recruited from one treatment centre. Similar levels of depression were reported in two other studies: Manne et al\textsuperscript{136} in a study of 113 gynaecological cancer survivors recruited from two treatment centres and assessed at twelve months post-diagnosis found that 23\% of survivors were depressed, as measured by the Beck Depression Inventory\textsuperscript{146} and Schlegel et al\textsuperscript{139} in a study of 225 breast cancer survivors recruited from nine treatment centres found that 23\% and 24\% of survivors respectively were depressed at six and thirteen months post-radiotherapy, as measured by the CES-D\textsuperscript{147}.

Nordin et al\textsuperscript{134} used a population-based sampling framework to recruit 415 survivors of breast, colorectal, gastric and prostate cancer from three hospitals in a single county. With a cut-off score of eight or more on the HADS, 16\% of survivors were categorised as cases on anxiety and 11\% as cases on depression at six months post-diagnosis\textsuperscript{134} in the studies by Schwarz et al\textsuperscript{138} with 367 breast and gynaecological cancer survivors from two treatment centres, and by Concalves et al\textsuperscript{141} with 85 ovarian cancer survivors from one treatment centre, the prevalence of anxiety and depression was at least
twice that reported by Nordin et al,\textsuperscript{134} despite the fact that the studies used the same assessment tool and criteria.

Of the studies that followed survivors longitudinally from six months to twelve months post-diagnosis, most found that the overall prevalence of anxiety and depression did not significantly decrease over time.\textsuperscript{137-139, 142, 143} However, studies that tracked individuals’ anxiety and/or depression levels over time revealed several clinically important trajectories of psychological adjustment. These studies consistently found that the majority of survivors demonstrated a trajectory of resilience characterised by no psychological morbidity, while smaller percentages experienced trajectories indicative of chronic or occasional psychological morbidity.\textsuperscript{53, 135, 140, 142} The findings from these studies support Bonanno’s assertion that resilience is the most common pattern of adjustment to traumatic life events.\textsuperscript{148}

Although several other relevant studies were identified, they reported prevalence of psychological distress, rather than anxiety and/or depression explicitly,\textsuperscript{59, 60, 149, 150} or they reported mean scores on anxiety and depression subscales, rather than the proportion of participants who were cases.\textsuperscript{151}

**Prevalence of unmet supportive care needs**

Unmet supportive care needs are the physical, emotional, social, psychological, informational, spiritual and practical issues with which individuals perceive they require additional services or care in order to achieve optimal wellbeing.\textsuperscript{152, 153} There has been a marked increase in the assessment of the unmet supportive care needs of
cancer survivors over the past decade. This can largely be traced to the publication of the Supportive Care Needs Survey (SCNS) and its large-scale application to a heterogeneous sample of 888 individuals with cancer who attended nine major cancer treatment centres in one Australian state. The SCNS is a cancer-specific tool for assessing cancer survivors’ perceived needs across the following five domains: psychological, health systems and information, physical aspects of daily living, patient care and support, and sexuality. A body of literature has begun to emerge, based on the administration of the SCNS, documenting the prevalence and correlates of the unmet supportive care needs of individuals diagnosed with cancer.

A recent systematic review of studies published between 1950 and 2006 found wide variation in the prevalence of unmet supportive care needs among people with cancer, ranging from 1% to 93% of individuals. Overall, the most frequently reported unmet needs were in the activities of daily living, psychological, information and physical domains. Consistent with these findings, the prevalence of unmet needs during the survivorship phase of care also varied widely within and between domains: information (6% to 83%); psychological (31% to 58%); patient care and support (24% to 53%); physical (26% to 52%); activities of daily living (41% to 47%); sexuality (33% to 34%); communication (30%); and economic (5% to 13%). This review illustrated several important points about the conduct of cancer-related needs assessments, including the wide variations among studies in the classification and reporting of unmet needs, the dearth of studies focused on individuals in the survivorship phase of the cancer continuum compared to studies focused on individuals in the treatment phase, and the lack of distinction between survivors in extended and permanent survival. These
methodological problems have contributed to difficulties in the ability to provide accurate estimations of the prevalence of unmet supportive care needs among cancer survivors at different stages of survivorship.

A search for studies published in the year 2000 onwards and which used a valid and reliable approach to assessing the multi-dimensional unmet supportive care needs of survivors in the period of approximately six to twelve months post-diagnosis, revealed a notable paucity of studies. Only two studies were identified that focused on survivors during this time period.

Smith et al found that of 978 survivors of prostate cancer recruited from a state-based cancer registry at approximately four months post-diagnosis, 74% reported unmet supportive care needs as assessed by the short-form SCNS. Unmet needs most commonly related to psychological (54%) and sexuality (47%) concerns. The specific concerns for which the highest proportion of men reported a moderate or high level of need for help were changes in sexual feelings (25%), changes in sexual relationships (22%), information about sexual relationships (21%) and uncertainty about the future (21%).

In a longitudinal study, Armes et al also used the short-form SCNS to assess the unmet needs of 1,152 survivors of breast, prostate, colorectal, gynaecological and haematological cancers recruited from 66 cancer centres and surveyed at the end of treatment and six months post-treatment. Moderate or high level unmet needs were reported by 60% of survivors at baseline and by 53% at follow-up. At both times, items...
from the psychological and physical domains, including fears about the cancer spreading (30% and 26% respectively), uncertainty about the future (26% and 20% respectively), lack of energy/tiredness (21% and 19% respectively), concerns about the worries of those closest to you (26% and 19% respectively) and worry that the results of treatment are beyond your control (22% and 17% respectively) were among the five most frequently endorsed moderate or high level unmet needs.

Other studies included survivors who were six months to one year post-diagnosis, but as part of larger heterogeneous samples of survivors at earlier or later stages of survivorship. Across these studies, between 43% and 58% of survivors reported moderate or high level unmet needs. While the most endorsed items of moderate or high level unmet need among these studies were consistent with those reported by Armes et al, there was greater variation in their associated prevalence: fears about the cancer spreading (17% to 40%); concerns about the worries of those closest to you (15% to 38%); lack of energy/tiredness (14% to 33%); and uncertainty about the future (14% to 32%). Although there are insufficient longitudinal data to describe the course of unmet supportive care needs over the cancer trajectory, it appears that psychological and physical concerns may continue to be the most commonly endorsed unmet needs, albeit at a lower prevalence than during earlier phases of the cancer trajectory.
Factors associated with anxiety, depression and unmet supportive care needs

Understanding the factors that influence survivors' likelihood of experiencing anxiety, depression and unmet supportive care needs is important because it can enable early identification, monitoring and intervention for those at greatest risk of these adverse outcomes. In addition, information about potentially modifiable risk factors is critical for informing the development of evidence-based interventions to prevent or ameliorate psychosocial morbidity. Reviews of the literature undertaken by Stanton et al\textsuperscript{57, 164} recounted that the extent to which cancer has a negative psychosocial impact varies from one survivor to another and is influenced by disease and treatment characteristics, attributes of the individual, interpersonal relationships, cognitive appraisals and coping processes. Their review of longitudinal studies concluded that survivors who experience poor psychological adjustment are characterised by socioeconomic disadvantage reflected in low educational attainment, membership of specific ethnic groups, being female, social isolation and use of avoidance-oriented coping involving strategies such as denial or damaging health behaviours. In addition, it was noted that research focused on the identification of factors contributing to the psychosocial wellbeing of survivors at treatment completion and the ensuing months is sparse and predominantly cross-sectional in nature.\textsuperscript{164}

Among those studies described previously that documented the prevalence of anxiety, depression and unmet supportive care needs, a number of consistent findings regarding factors associated with these outcomes were observed. Most studies examined the influence of multiple factors on anxiety, depression and unmet needs.
Having anxiety, depression and unmet needs at time 1 were the strongest predictors of anxiety, depression and unmet needs respectively at follow-up. Consistent with differences observed in the general population of Australia, the following characteristics were associated with poorer psychosocial outcomes among cancer survivors: being female; being of low socioeconomic status, reflected by low educational attainment or low income; being younger; and having poor social support.

Disease-related characteristics including advanced disease were associated with anxiety, depression and unmet needs while not being in remission and having received chemotherapy in the previous month were associated with multiple domains of unmet supportive care needs. However, it must be recognised that the collective findings of these studies are shaped by the suite of risk factors examined within each study. In some studies, when the range of explanatory factors examined encompassed individual, disease-related, psychological and social support characteristics, disease-related characteristics were less likely to be associated with anxiety, depression and unmet supportive care needs.

**Limitations of previous research**

While the studies conducted to date have undoubtedly provided valuable knowledge about the extent and correlates of anxiety, depression and unmet supportive care needs of cancer survivors in the late treatment to early survivorship phase of care, they are limited in several key ways. First, most information comes from cross-sectional studies which provide a snapshot of the wellbeing of survivors at a point in
time, with many studies mixing together survivors who are at different stages of survival. Cross-sectional studies are unable to provide information about how survivors’ outcomes change over time and do not allow conclusions to be drawn about the causes of outcomes. Second, most studies are based on survivors recruited from a small number of clinical settings. While potentially representative of the survivors at those settings, they are unlikely to be representative of all survivors, thereby limiting the inferences that can be made from the findings. Third, the majority of studies have concentrated on survivors of breast cancer. While breast cancer survivors are one of the largest groups of survivors of cancer, focusing on a single cancer type not only restricts the ability to compare outcomes among cancer types, but also contributes to gaps in knowledge about the problems faced by survivors of other cancers. Fourth, most studies have examined the relationship between a relatively narrow range of largely non-modifiable individual, disease and treatment characteristics with survivors’ psychosocial outcomes. Potentially modifiable factors such as health behaviours have only recently been taken into consideration. Finally, many studies use measures developed for patients in the acute cancer treatment period or for other populations, thereby raising doubts about the validity of the data in the survivorship context. These limitations compromise the robustness of the evidence guiding the development and delivery of high-quality survivorship care.
CANCER SURVIVAL STUDY

Rationale

As the population of cancer survivors continues to grow, attention has been directed to understanding the impact that cancer has on the wellbeing of survivors in the extended survival phase. The leading cancer survivorship policy document, *From Cancer Patient to Cancer Survivor: Lost in Transition*, and subsequent scoping reviews of the literature have called for the conduct of large-scale observational cohort studies, using valid and reliable measures, with diverse cancer populations and long-term follow-up. It is suggested that such studies would make a significant contribution to the literature and to guiding survivorship care. Recent reviews indicate that such research is well underway in North America. While these studies will undoubtedly make a valuable contribution to gaps in knowledge about the wellbeing of cancer survivors, global differences in the incidence and experience of cancer, as well as the structure and funding of health care services, necessitate that health services and policies are informed by local data. In Australia, 36% of those diagnosed with cancer live in regional and remote areas, and 27% of the resident population were born overseas, and cancer care is delivered in both the public and private health care systems, with responsibility shared between state and national governments. Although there are a number of large longitudinal studies underway in Australia to assess aspects of cancer survivors’ wellbeing, none includes a diversity of cancer survivors or examines the breadth of domains relevant to survivorship. The *Cancer Survival Study* was initiated to fill gaps in knowledge about the prevalence and
correlates of adult cancer survivors’ psychosocial wellbeing and health behaviours over the five years since diagnosis.

**Design**

Overcoming some of the limitations of previous studies, the *Cancer Survival Study* is a population-based, longitudinal survey of a cohort of 1453 adults who were diagnosed with their first primary cancers of one of the top eight incident cancer types in Australia (i.e. prostate, colorectal, female breast, lung, head and neck cancers, melanoma, non-Hodgkin’s lymphoma and leukaemia). Participants were recruited from the two largest state-based cancer registries in Australia, which together account for 60% of all new cancer cases diagnosed.\(^{168}\) Recruitment quotas were set for each registry (\(n_1=1006\) and \(n_2=654\)) due to differences in capacity to undertake case recruitment. The *Cancer Survival Study* is among one of the first large-scale surveys of cancer survivors conducted in Australia. It is unique in the diversity of the cancer survivors included, in terms of primary cancer type, extent of disease, treatments received, and rural/urban location. Notably, it includes under-studied cancer types such as colorectal, lung, head and neck cancers, and adult haematologic malignancies.\(^9\) Guided by the conceptual framework presented in Figure 2, aspects of survivors’ psychosocial wellbeing, health behaviours, disease and cancer care, and sociodemographic characteristics were assessed through a combination of self-administered surveys and linkage with the cancer registries (see Table 1.1) at six months, one year, two years and three and a half years post-diagnosis.
Table 1.1: Data collected in the *Cancer Survival Study* at Time 1 (6 months post-diagnosis) and Time 2 (1 year post-diagnosis)

<table>
<thead>
<tr>
<th>Timing</th>
<th>Psychosocial</th>
<th>Self-report questionnaire</th>
<th>Disease</th>
<th>Sociodemographic</th>
<th>Cancer Registry</th>
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<tbody>
<tr>
<td>Time 1: 6 months post-diagnosis</td>
<td>Hospital Anxiety and Depression Scale</td>
<td>Smoking</td>
<td>Spread of disease</td>
<td>Marital status</td>
<td>Sex</td>
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<td>Distress Thermometer</td>
<td>Alcohol consumption</td>
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<td>Travel for treatment</td>
<td>Employment</td>
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<td>Multidisciplinary care received</td>
<td>Health insurance</td>
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<td>Sun behaviour</td>
<td>Community support service use</td>
<td>Family income</td>
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<td>Complementary therapy use</td>
<td>Household size</td>
<td>Extent of disease</td>
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Time 2: 1 year post-diagnosis

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<th>As for Time 1</th>
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<td></td>
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<td>Alternative therapy use</td>
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<tr>
<td></td>
<td></td>
<td>Cancer screening tests</td>
<td>Cancer clinical trials</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sun behaviour</td>
<td>participation</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Diet</td>
<td>New cancer diagnosis</td>
<td></td>
</tr>
</tbody>
</table>
SCOPE OF RESEARCH

The program of research presented in this thesis is based on data collected from Cancer Survival Study participants at six months and 12 months post-diagnosis. This research seeks to make a significant and robust contribution to the evidence base on the impact of cancer and its treatment on survivors’ psychosocial wellbeing in the early stages of survivorship. This research focuses on the key psychosocial outcomes of anxiety, depression and unmet supportive care needs. Together, these outcomes provide an in-depth understanding of the psychosocial impact of cancer on survivors. Specifically, this thesis aims to:

1. Describe the prevalence and correlates of anxiety and/or depression among cancer survivors at six months post-diagnosis (Paper 1)
2. Describe the prevalence and natural history of anxiety and/or depression from six months to one year after diagnosis, and identify the predictors of chronic and late psychological morbidity (Paper 2)
3. Examine the accuracy and optimal cut-off score of the single-item Distress Thermometer, compared to the Hospital Anxiety and Depression Scale, to identify possible cases of anxiety and/or depression among survivors (Paper 3)
4. Develop a short-form version of the Supportive Care Needs Survey and determine its psychometric properties (Paper 4)
5. Describe the prevalence and correlates of cancer survivors’ supportive care needs at six months post-diagnosis (Paper 5).
STRUCTURE OF THESIS

Rather than a series of chapters, this thesis by publication comprises five inter-related papers, of which four (Papers 1, 3, 4 and 5) are published and one (Paper 2) is under review. As a result of executing this thesis by publication, there is some unavoidable duplication of information about the study methodology in the papers. In addition to copies of the published papers and their associated authorship contribution statements (Appendices 1 to 5) and additional publications relevant to but not included in the thesis (Appendix 6), the Appendices also include detailed information about the study procedures (Appendices 7 to 10) that underpin the empirical data presented in Papers 1 to 5.
REFERENCES


47. World Health Organization. Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19-22 June, 1946; signed on 22 July 1946 by the representatives of 61 States
(Official Records of the World Health Organization, no. 2, p. 100) and entered into force on 7 April 1948


75. Cooper AF, Hankins M, Rixon L, Eaton E, Grunfeld EA. Distinct work-related, clinical and psychological factors predict return to work following treatment in four different cancer types. Psychooncology. In press. DOI: 10.1002/pon.3049


Anxiety and depression are clinically important outcomes of cancer care because of their association with poorer quality of life, more intense physical symptoms, increased functional impairment and poor treatment adherence. Information about the extent of the psychological impact of cancer on survivors, and the characteristics of those most at risk of such psychological morbidity, is critical for informing the delivery of optimal care. This paper describes the prevalence and correlates of anxiety and depression among a population-based sample of adult cancer survivors six months following diagnosis.

This paper was published in the *Journal of Affective Disorders* [Appendix 1.1].

Flourishing or floundering? Prevalence and correlates of anxiety and depression among a population-based sample of adult cancer survivors 6 months after diagnosis

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ABSTRACT

Objective: To describe the prevalence of anxiety, depression and comorbid anxiety-depression among adult cancer survivors six months following diagnosis, and identify the individual, disease, health behaviour, psychological and social factors associated with psychological morbidity.

Methods: A population-based sample of adult cancer survivors was recruited from two state-based cancer registries in Australia. Data for 1323 survivors were obtained by self-report questionnaire and linkage with registry data. Anxiety and depression were assessed by the 14-item Hospital Anxiety and Depression Scale (HADS).

Results: The prevalence of psychological morbidity was 28% (95% CI: 23%–33%). Specifically, 24% (95% CI: 19%–29%) of survivors were identified as cases on anxiety (irrespective of depression), 14% (95% CI: 9%–19%) as cases on depression (irrespective of anxiety) and 10% (95% CI: 5%–15%) as cases on comorbid anxiety-depression. In addition to mental health history prior to cancer, modifiable health behaviours (physical activity, smoking status), psychological (helplessness-hopelessness, anxious preoccupation coping) and social (low positive social interaction) characteristics were stronger indicators of psychological morbidity than survivors’ individual or disease characteristics.

Limitations: Psychological morbidity was assessed by self-report screening instrument rather than clinical interview. The extent to which psychological morbidity is age-related versus cancer-related cannot be determined without a gender- and age-matched control group.
**Conclusions:** Although lower than previously reported, psychological morbidity is prevalent six months after a cancer diagnosis and emphasises the need for routine psychosocial assessment throughout the cancer trajectory to identify those at increased risk or in need of immediate intervention. Physical activity, smoking cessation and coping skills training interventions warrant further exploration.
INTRODUCTION

A cancer diagnosis is a life-changing experience that affects 1 in 5 men and 1 in 6 women before the age of 75 years. While cancer incidence is projected to almost double over the next two decades to 21.4 million new cases annually, the number of people living with a history of cancer (i.e. ‘survivors’) is expected to triple to 75 million worldwide by 2030. This increasing global cancer burden has been described as a public health crisis. Compared to the earlier phases of the cancer continuum, relatively little is known about the nature and extent of the impact of cancer on survivors, or how best to deliver care that optimises their health and wellbeing. With their need for care typically spanning many years, the growing population of cancer survivors has recently become the focus of researchers, clinicians and policy-makers.

The psychological effects of cancer range from common normal feelings of uncertainty about the future and fear of cancer recurrence to clinically significant anxiety and/or depression and post-traumatic stress disorder. Psychological morbidity among those affected by cancer is an important clinical issue because of its association with poorer quality of life across multiple domains, more intense physical symptoms, increased functional impairment and poor treatment adherence. Further, some evidence suggests that there may be a relationship between psychological distress and cancer progression, and reduced overall survival; however, this remains a contentious issue. Many approaches have been utilised to identify cancer survivors experiencing
psychological morbidity, and there is a range of effective pharmacological and psychological interventions to manage such morbidity.\textsuperscript{10, 13-16}

Estimates of the prevalence of anxiety and depression among cancer survivors vary widely,\textsuperscript{17} largely as a result of different measurement techniques, different criteria to define anxiety and depression, and different study populations, making it difficult to compare between studies. It is generally agreed that anxiety and depression are highest at the time of diagnosis and decrease over time, with levels of anxiety and depression typically returning to a level comparable to the general population around two years post-diagnosis.\textsuperscript{18, 19} The transition from patient to survivor is often experienced as stressful, as contact with the cancer care team deceases in frequency and the perceived safety of the hospital system is left behind.\textsuperscript{20} At six months post-diagnosis, estimates of the prevalence of depression range from 22\% to 28\%,\textsuperscript{7, 8, 21-24} while one-third of survivors are estimated to experience anxiety.\textsuperscript{7, 8, 21} However, psychological morbidity at this time has not been well-documented in the wider population of recent cancer survivors, and to our knowledge there are no published studies reporting the prevalence of comorbid anxiety-depression six months after a cancer diagnosis.

Information about the characteristics of survivors most at risk of experiencing psychological morbidity is critical for identifying those that should be targeted for screening, evaluation, and monitoring or intervention. There is an extensive literature on the individual (younger age, physical disability), disease and treatment (advanced disease, fatigue, pain), psychological (history of depression, adaptive coping styles),
social (socially isolated, socially disadvantaged) and lifestyle (insufficiently active, substance abuse) factors associated with psychological morbidity at various stages of the cancer continuum.\textsuperscript{10, 16, 17, 25, 26} Although some studies have examined various subsets of these characteristics as predictors of poor adjustment after cancer,\textsuperscript{27, 28} to date, no study has reported the relative contributions of a comprehensive range of individual, disease, psychological, social and lifestyle characteristics to the psychological morbidity experienced by cancer survivors in the late treatment to early survivorship phase of care.

There is an emerging body of high-quality evidence describing the magnitude and nature of the psychological impact of cancer on survivors, particularly for breast and prostate cancer survivors. However, more comprehensive studies with representative samples of survivors with different cancer types, survival probabilities, culturally and socially diverse backgrounds and geographic locations are needed in order to accurately assess the prevalence of the psychological effects of cancer among survivors and identify vulnerable subgroups. The landmark report, \textit{From Cancer Patient to Cancer Survivor: Lost in Transition},\textsuperscript{3} recommended that large-scale population-based studies with the diversity of cancer survivors be undertaken as a priority, in order to guide the development and delivery of effective survivorship care.

The aims of the current study were to:

1. Determine the prevalence of anxiety, depression and comorbid anxiety-depression at six months post-diagnosis overall and by cancer type.
2. Identify the factors (individual, disease, health behaviour, psychological, social) correlated with caseness for (a) anxiety, (b) depression and (c) comorbid anxiety-depression at six months post-diagnosis. It was hypothesised that psychological morbidity would be associated with (i) being aged less than 50 years, (ii) a history of mental health problems, (iii) insufficient physical activity, (iv) consuming more than two standard drinks a day, and (vi) perceived poor social support.

METHOD

This paper is based on the Cancer Survival Study, a population-based longitudinal study tracking the psychosocial wellbeing and lifestyle behaviours of 1453 cancer survivors in Australia over the first five years since diagnosis. Time 1 (T1) data reported here were collected from participants at approximately six months post-diagnosis.

Participants

Cancer survivors were prospectively recruited from new notifications to the two largest state-based cancer registries in Australia. Eligible participants were (1) diagnosed in the previous six months with their first primary cancer of one of the top eight incident cancer types in Australia (prostate, colorectal, female breast, lung, melanoma, non-Hodgkin’s lymphoma, leukaemia, head and neck); (2) aged between 18 and 80 years and living in the state of New South Wales (NSW) or Victoria (VIC) at the time of diagnosis; and (3) considered by their physicians to be aware of their diagnosis, as well as physically and mentally capable and proficient in English to complete a questionnaire.
**Procedure**

The registries attempted to contact by mail the physicians of survivors identified as potentially eligible to participate. Physicians in NSW were required to provide active consent for the nominated survivor to be contacted about the study; those physicians who did not respond within four weeks received one reminder telephone call. Passive physician consent was used in Victoria, whereby physicians were required to notify the cancer registry within four weeks of any contraindications to the nominated survivor being contacted about the study. Potential participants with physician approval to be approached were contacted by mail by the registries to seek permission to pass their names and contact details to the research team. Non-responders received one mailed reminder package three weeks later and one reminder telephone call after a further three weeks.

Using a modified Dillman approach, a study package was mailed to those survivors who agreed to be contacted about the study by the research team. Non-responders received one mailed reminder package three weeks later and one reminder telephone call after a further three weeks. Consent to participate was indicated by return of a completed survey. The Human Research Ethics Committees of the University of Newcastle, Cancer Institute NSW and Cancer Council Victoria approved the study.

**Measures**

Data were collected through a combination of self-administered scannable questionnaire and linkage with the cancer registries.
**Outcome measure**

Anxiety and depression were measured by the commonly used 14-item Hospital Anxiety and Depression Scale (HADS). Items assess two subscales: anxiety (HADS-A); and depression (HADS-D). Each item is rated on a four-point Likert scale and a score ranging from 0 to 21 calculated for each subscale, with a higher score indicating a higher level of anxiety or depression. A subscale score of 0–7 is considered normal (non-case), 8–11 considered borderline (doubtful case) and 12–21 considered clinically significant (probable case). Although there is debate about the optimal scoring method and cut-point to use, a review of the validity of the individual HADS subscales found that the best trade-off between sensitivity and specificity was achieved using a subscale cut-off point of 8 or above for identifying ‘cases’. To minimise the misclassification of survivors, we used the established subscale cut-off point ≥8 to identify ‘cases’ on HADS-A and ‘cases’ on HADS-D. In addition, those who were cases on both HADS-A and HADS-D were classified as ‘cases’ on comorbid anxiety-depression. The HADS measures aspects of depression that are not confounded by the physical symptoms of cancer or its treatment, such as fatigue, and was recommended as an instrument of choice for assessing cancer patients’ psychological morbidity in recent reviews of patient-reported outcome measures.

**Study factors**

*Individual:* Age at diagnosis and gender were obtained directly from the cancer registries. Current marital status, highest level of education completed, health insurance coverage, current employment situation, geographical location, size of
household, and presence of any physical comorbidities were obtained by standard self-report questionnaire items.

**Disease:** Primary cancer type and spread of disease at diagnosis were obtained directly from the cancer registries, and survivors’ cancers categorised as ‘early/less progressed’ (*in situ* or localised; grade 1 or 2; T1 or T2), ‘late/more progressed’ (invasion of adjacent organs, regional nodes or distant metastases; grade 3 or 4; not T1), or ‘not applicable’ (haematological cancers). Extent of disease at six months post-diagnosis and cancer treatments received in the last month were obtained by standard self-report questionnaire items.

**Health behaviours:** Smoking behaviour was assessed by two questions, and participants were classified as ‘current smoker’ (has smoked at least 100 cigarettes or the equivalent amount of tobacco in lifetime and currently smokes), ‘former smoker’ (has smoked at least 100 cigarettes or the equivalent amount of tobacco in lifetime but does not currently smoke) or ‘never smoker’ (never smoked more than 100 cigarettes or the equivalent amount of tobacco in lifetime).

Alcohol consumption was assessed by two questions adapted from the Australian National Drug Strategy Household Survey. Participants who consumed more than two standard drinks on any day were classified as being at increased lifetime risk of harm from alcohol-related injury or disease. Physical activity was assessed by three items adapted from the Active Australia survey, and participants were classified as ‘sufficiently active’ (at least 150 minutes of activity over one week), ‘insufficiently active’ (participating in some physical activity but not enough in total time) or ‘sedentary’ (no physical activity).

**Psychological:** Mental health history was obtained by two self-report questionnaire items assessing treatment for a mental health illness (e.g. depression, anxiety,
schizophrenia) before and since cancer diagnosis. Coping strategy was measured by the 21-item Mini Mental Adjustment to Cancer Scale (Mini-MAC). Items assess five cancer-specific coping strategies: helplessness-hopelessness, anxious preoccupation, fighting spirit, cognitive avoidance and fatalism. Items are rated on a four-point scale, and a score is calculated for each subscale, with a higher score indicating a stronger use of the coping strategy. Raw subscale scores were standardised from 0 to 100. As the distribution of scores was highly skewed, all coping subscales were dichotomised, with survivors who scored in the top 16% of each distribution classified as a ‘case’ on that specific coping strategy, in accordance with the user manual.

Social: Social support was measured by the 20-item MOS Social Support Survey (MOS–SSS). Items assess four subscales of functional support: emotional/informational, tangible, affectionate, and positive social interaction. Items are rated on a five-point scale, and a score calculated for each subscale, with a higher score indicating a higher level of support. Raw subscale scores were standardised from 0 to 100. As all subscale scores were highly skewed, all social support subscales were dichotomised, and survivors who scored in the bottom one-third of each distribution classified as ‘low’ on that particular type of social support (Sherbourne, personal communication, 19 May 2004).

**Statistical methods**

In accordance with recommended procedures for the HADS, in those instances where no more than one item was missing on a subscale, the mean of the remaining subscale items was imputed. If more than one item on a subscale was missing, then the subscale score was not calculated. Data from survivors of non-Hodgkin’s lymphoma or
leukaemia were combined to form a ‘haematological’ cancer type, due to small numbers. Scores were calculated for the HADS-A and HADS-D, and descriptive statistics computed. The prevalence of each of the three outcomes (case on anxiety, case on depression, and case on comorbid anxiety-depression) was estimated with 95% confidence intervals for each cancer type. The association between the individual, disease, health behaviour, psychological and social factors with each of the three outcomes was examined using chi-square analyses. Variables with a p-value of 0.2 or less were included in a backward stepwise logistic regression model for each outcome. Variables were removed from the model if they had a p-value of 0.05 or more on the likelihood ratio test. Odds ratio and 95% confidence intervals are reported for variables included in the final model.

RESULTS

Sample

A total of 3877 potential participants were assessed for study eligibility. Of the 3315 deemed eligible, 1691 consented to contact by the researchers, and a total of 1360 returned a T1 questionnaire (overall 41% response rate at T1; VIC=49% and NSW=33%). Thirty-seven participants returned their T1 questionnaire more than 9 months after diagnosis and were excluded. The 1323 survivors included in these analyses were surveyed at a median of 6 months after diagnosis (SD=1 month, range=4–9 months), and their median age was 63 years (SD=11 years, range=18–80). Table 2.1 shows that more than half (59%) were male, about half were diagnosed with early-stage disease (52%), the most common diagnosis was prostate cancer (26%), and
72% had not received any active treatment in the last month. The sample reflected the national profile for the top eight incident cancers diagnosed in 2005 in terms of gender and age; however, survivors of colorectal cancer were under-represented, and haematological and head and neck cancers were over-represented.

**Prevalence of anxiety and/or depression by cancer type**

Overall, cancer survivors reported low levels of anxiety (median score=4, range=0–20) and depression (median score=2, range=0–19). A total of 369 (28%; 95% CI: 23%–33%) cancer survivors reported clinical/borderline level anxiety and/or depression at six months post-diagnosis. As shown in Table 2.2, 24% of survivors were identified as cases on anxiety (irrespective of depression) and 14% (95% CI: 9%–19%) as cases on depression (irrespective of anxiety). A total of 10% (95% CI: 5%–15%) were identified as cases on comorbid anxiety-depression.

There was significant variation across cancer types in the percentage of survivors that reported psychological morbidity. Lung cancer survivors were more affected than survivors of other cancer types, with 40% (95% CI: 27%–53%) identified as cases on anxiety, 28% (95% CI: 14%–44%) as cases on depression and 24% (95% CI: 9%–39%) as cases on comorbid anxiety-depression. Compared to other cancer types, survivors of prostate cancer and melanoma reported the least psychological morbidity.
Table 2.1: Selected characteristics of study sample compared to national cancer incidence data

<table>
<thead>
<tr>
<th></th>
<th>Study sample&lt;sup&gt;a&lt;/sup&gt;</th>
<th>National&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>(%)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
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<tr>
<td>Male</td>
<td>781</td>
<td>(59)</td>
</tr>
<tr>
<td>Female</td>
<td>542</td>
<td>(41)</td>
</tr>
<tr>
<td><strong>Age at diagnosis (years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18–39</td>
<td>57</td>
<td>(4)</td>
</tr>
<tr>
<td>40–49</td>
<td>138</td>
<td>(10)</td>
</tr>
<tr>
<td>50–59</td>
<td>317</td>
<td>(24)</td>
</tr>
<tr>
<td>60–69</td>
<td>482</td>
<td>(36)</td>
</tr>
<tr>
<td>70 or more</td>
<td>329</td>
<td>(25)</td>
</tr>
<tr>
<td><strong>Primary cancer</strong></td>
<td></td>
<td></td>
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<tr>
<td>Prostate</td>
<td>343</td>
<td>(26)</td>
</tr>
<tr>
<td>Breast (female)</td>
<td>208</td>
<td>(16)</td>
</tr>
<tr>
<td>Melanoma</td>
<td>204</td>
<td>(15)</td>
</tr>
<tr>
<td>Haematological&lt;sup&gt;c&lt;/sup&gt;</td>
<td>183</td>
<td>(14)</td>
</tr>
<tr>
<td>Colorectal</td>
<td>157</td>
<td>(12)</td>
</tr>
<tr>
<td>Lung</td>
<td>133</td>
<td>(10)</td>
</tr>
<tr>
<td>Head and neck</td>
<td>95</td>
<td>(7)</td>
</tr>
<tr>
<td><strong>Stage of disease at diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early/less progressed</td>
<td>691</td>
<td>(52)</td>
</tr>
<tr>
<td>Late/more progressed</td>
<td>254</td>
<td>(19)</td>
</tr>
<tr>
<td>Not applicable</td>
<td>183</td>
<td>(14)</td>
</tr>
<tr>
<td>Unknown</td>
<td>195</td>
<td>(15)</td>
</tr>
<tr>
<td>Study sample</td>
<td>N</td>
<td>(%)</td>
</tr>
<tr>
<td>-------------</td>
<td>----</td>
<td>-----</td>
</tr>
<tr>
<td>Active (surgery, chemo, radio)</td>
<td>358</td>
<td>(28)</td>
</tr>
<tr>
<td>± passive treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Passive only (hormone, immunotherapy)</td>
<td>151</td>
<td>(12)</td>
</tr>
<tr>
<td>None</td>
<td>788</td>
<td>(61)</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>National</th>
<th>N</th>
<th>(%)</th>
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</thead>
<tbody>
<tr>
<td>Treatment in last month</td>
<td>1297</td>
<td></td>
</tr>
<tr>
<td>Active (surgery, chemo, radio)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>± passive treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Passive only (hormone, immunotherapy)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Treatment types in last month | 1297 | |
| Surgery | 58 | (5) |
| Chemotherapy | 198 | (16) |
| Radiotherapy | 131 | (10) |
| Hormone | 179 | (14) |
| Immunotherapy | 29 | (2) |

---

* Number of observations varies across characteristics due to missing data.

* 2005 data restricted to 8 most incident cancer and those aged 20–79 years; data not available for all characteristics.

* Includes non-Hodgkin’s lymphoma and leukaemia.

* Multiple responses allowed.
Table 2.2: Prevalence of anxiety and/or depression at 6 months post-diagnosis by cancer type

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>Total(^a)</th>
<th>Prostate</th>
<th>Breast</th>
<th>Melanoma</th>
<th>Blood(^b)</th>
<th>Colorectal</th>
<th>Lung</th>
<th>Head and neck</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Anxiety (irrespective of depression)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Case</td>
<td>310 (24)</td>
<td>48 (14)</td>
<td>63 (30)</td>
<td>44 (22)</td>
<td>48 (27)</td>
<td>32 (20)</td>
<td>53 (40)</td>
<td>22 (24)</td>
</tr>
<tr>
<td>Non-case</td>
<td>1004 (76)</td>
<td>294 (86)</td>
<td>144 (70)</td>
<td>157 (78)</td>
<td>133 (73)</td>
<td>125 (80)</td>
<td>80 (60)</td>
<td>71 (76)</td>
</tr>
<tr>
<td>(\chi^2)</td>
<td>=44.29; df=6; p&lt;0.001</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Depression (irrespective of anxiety)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Case</td>
<td>189 (14)</td>
<td>34 (10)</td>
<td>32 (15)</td>
<td>14 (7)</td>
<td>30 (17)</td>
<td>23 (15)</td>
<td>38 (29)</td>
<td>18 (19)</td>
</tr>
<tr>
<td>Non-case</td>
<td>1126 (86)</td>
<td>308 (90)</td>
<td>175 (85)</td>
<td>188 (93)</td>
<td>151 (83)</td>
<td>134 (85)</td>
<td>95 (71)</td>
<td>75 (81)</td>
</tr>
<tr>
<td>(\chi^2)</td>
<td>=39.13; df=6; p&lt;0.001</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comorbid anxiety-depression</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Case</td>
<td>130 (10)</td>
<td>22 (6)</td>
<td>26 (13)</td>
<td>7 (3)</td>
<td>20 (11)</td>
<td>14 (9)</td>
<td>32 (24)</td>
<td>9 (10)</td>
</tr>
<tr>
<td>Non-case</td>
<td>1184 (90)</td>
<td>320 (94)</td>
<td>181 (87)</td>
<td>194 (97)</td>
<td>161 (89)</td>
<td>143 (91)</td>
<td>101 (76)</td>
<td>84 (90)</td>
</tr>
<tr>
<td>(\chi^2)</td>
<td>=45.89; df=6; p&lt;0.001</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

\(^a\) Number of observations varies across outcomes due to missing data.

\(^b\) Includes non-Hodgkin’s lymphoma and leukaemia.
Factors associated with anxiety and/or depression

Individual characteristics

As shown in Table 2.3, the odds of caseness for anxiety increased with decreasing age, and were higher among survivors who lived alone (OR=1.8), compared to those who lived with another adult.

Disease characteristics

Cancer type, chemotherapy and hormone treatment were the only disease characteristics associated with psychological morbidity. Compared to survivors of prostate cancer, those diagnosed with lung cancer (OR=2.3) or melanoma (OR=2.1) had twice the odds of caseness for anxiety (Table 2.3). Those who received chemotherapy in the last month had almost twice the odds (OR=1.9) of caseness for depression, compared to those who did not receive this treatment, while survivors who received hormone treatment had lower odds (OR=0.46) of caseness for depression, compared to those who did not receive this treatment (Table 2.4).

Health behaviours

Physical activity, smoking status and alcohol consumption were associated with psychological morbidity (Tables 2.4 and 2.5). Compared to survivors who were sufficiently active, those who were sedentary or insufficiently active had two to four times the odds of caseness for depression (OR=3.5, 1.8) and comorbid anxiety-depression (OR=4.0, 2.4). Compared to survivors who had never smoked, current smokers had twice the odds of being a case on depression (OR=2.4) and comorbid anxiety-depression (OR=2.2). Survivors who consumed alcohol at a level that placed
them at increased risk of harm had lower odds (OR=0.45) of caseness for depression than those who drank alcohol at safe levels.

**Psychological**

A history of mental health treatment and coping strategy were significantly associated with all three outcomes (Tables 2.3–2.5). Compared to those without a history of mental health problems, survivors who had been treated for mental health problems before their cancer diagnosis had at least twice the odds of caseness for anxiety (OR=2.8), depression (OR=2.0) and comorbid anxiety-depression (OR=2.1), while those treated for mental health problems since their cancer diagnosis had higher odds of being a case on anxiety (OR=2.2). Survivors who engaged in the maladaptive coping strategies, helplessness-hopelessness or anxious preoccupation, had two to eight times the odds of being a case on anxiety (OR=2.7, 8.4), depression (OR=2.7, 4.6) and comorbid anxiety-depression (OR=3.5, 6.4), compared to survivors who did not use these strategies. In addition, survivors who used cognitive avoidance coping (OR=1.7) had greater odds of being a case on anxiety, while those who used fighting spirit had lower odds (OR=0.40) of being a case on depression.

**Social**

Positive social interaction was the only type of social support associated with psychological morbidity. Survivors who perceived that they had low levels of positive social interaction had about twice the odds of being a case on anxiety (OR=1.6), depression (OR=2.4) and comorbid anxiety-depression (OR=2.5), compared to survivors who perceived they had at least some positive social interaction.
Table 2.3: Factors significantly correlated with caseness for anxiety

<table>
<thead>
<tr>
<th></th>
<th>Adjusted OR (95% CI)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Individual</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age at diagnosis (years)</td>
<td></td>
<td>0.023</td>
</tr>
<tr>
<td>49 and younger</td>
<td>2.7 (1.4–5.3)</td>
<td></td>
</tr>
<tr>
<td>50–59</td>
<td>2.0 (1.1–3.6)</td>
<td></td>
</tr>
<tr>
<td>60–69</td>
<td>1.8 (1.1–3.2)</td>
<td></td>
</tr>
<tr>
<td>70 and older</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>Number of adults live with</td>
<td></td>
<td>0.04</td>
</tr>
<tr>
<td>Nil – live alone</td>
<td>1.8 (1.1–2.9)</td>
<td></td>
</tr>
<tr>
<td>More than 1</td>
<td>1.5 (0.94–2.3)</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td><strong>Disease and treatment</strong></td>
<td></td>
<td>0.027</td>
</tr>
<tr>
<td>Cancer type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>1.4 (0.76–2.5)</td>
<td></td>
</tr>
<tr>
<td>Colorectal</td>
<td>1.6 (0.85–3.2)</td>
<td></td>
</tr>
<tr>
<td>Haematological</td>
<td>1.1 (0.59–2.1)</td>
<td></td>
</tr>
<tr>
<td>Head and neck</td>
<td>0.75 (0.33–1.7)</td>
<td></td>
</tr>
<tr>
<td>Lung</td>
<td>2.3 (1.2–4.5)</td>
<td></td>
</tr>
<tr>
<td>Melanoma</td>
<td>2.1 (1.1–3.9)</td>
<td></td>
</tr>
<tr>
<td>Prostate</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td><strong>Psychological</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental health treatment before cancer</td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2.8 (1.7–4.5)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Adjusted OR (95% CI)</td>
<td>p</td>
</tr>
<tr>
<td>------------------------------</td>
<td>----------------------</td>
<td>------</td>
</tr>
<tr>
<td><strong>Mental health treatment since cancer diagnosis</strong></td>
<td></td>
<td>0.002</td>
</tr>
<tr>
<td>Yes</td>
<td>2.2 (1.1–4.3)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td><strong>Helplessness-hopelessness coping</strong></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Case</td>
<td>2.7 (1.8–4.0)</td>
<td></td>
</tr>
<tr>
<td>No case</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td><strong>Anxious preoccupation coping</strong></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Case</td>
<td>8.4 (5.6–12.6)</td>
<td></td>
</tr>
<tr>
<td>No case</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td><strong>Cognitive avoidance coping</strong></td>
<td></td>
<td>0.007</td>
</tr>
<tr>
<td>Case</td>
<td>1.7 (1.1–2.4)</td>
<td></td>
</tr>
<tr>
<td>No case</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td><strong>Social</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Positive social interaction</strong></td>
<td></td>
<td>0.021</td>
</tr>
<tr>
<td>Low</td>
<td>1.6 (1.1–2.3)</td>
<td></td>
</tr>
<tr>
<td>Some</td>
<td>1.00</td>
<td></td>
</tr>
</tbody>
</table>

OR = odds ratio; CI = confidence interval; p-value on the Wald chi-square analysis of effects test.
Table 2.4: Factors significantly correlated with caseness for depression

<table>
<thead>
<tr>
<th></th>
<th>Adjusted OR (95% CI)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Disease and treatment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>Chemotherapy last month</em></td>
<td></td>
<td>0.01</td>
</tr>
<tr>
<td>Yes</td>
<td>1.9 (1.2–3.1)</td>
<td></td>
</tr>
<tr>
<td>No/don’t know</td>
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<td></td>
</tr>
<tr>
<td><em>Hormone treatment last month</em></td>
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<td>0.037</td>
</tr>
<tr>
<td><em>Physical activity</em></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Sedentary</td>
<td>3.5 (2.0–6.2)</td>
<td></td>
</tr>
<tr>
<td>Insufficiently active</td>
<td>1.8 (1.1–3.1)</td>
<td></td>
</tr>
<tr>
<td>Sufficiently active</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td><em>Smoking status</em></td>
<td></td>
<td>0.044</td>
</tr>
<tr>
<td>Current</td>
<td>2.4 (1.2–4.8)</td>
<td></td>
</tr>
<tr>
<td>Former</td>
<td>1.0 (0.68–1.6)</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td><em>Alcohol consumption</em></td>
<td></td>
<td>0.002</td>
</tr>
<tr>
<td>Increased risk of harm</td>
<td>0.45 (0.27–0.74)</td>
<td></td>
</tr>
<tr>
<td>No increased risk of harm</td>
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<td></td>
</tr>
<tr>
<td><strong>Psychological</strong></td>
<td></td>
<td>0.005</td>
</tr>
<tr>
<td><em>Mental health treatment before cancer diagnosis</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2.00 (1.2–3.3)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>Coping Style</td>
<td>Adjusted OR (95% CI)</td>
<td>p</td>
</tr>
<tr>
<td>------------------------------------</td>
<td>----------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>Helplessness-hopelessness coping</td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Case</td>
<td>2.7 (1.7–4.3)</td>
<td></td>
</tr>
<tr>
<td>No case</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>Anxious preoccupation coping</td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Case</td>
<td>4.6 (2.9–7.3)</td>
<td></td>
</tr>
<tr>
<td>No case</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>Fighting spirit coping</td>
<td></td>
<td>0.005</td>
</tr>
<tr>
<td>Case</td>
<td>0.40 (0.21–0.75)</td>
<td></td>
</tr>
<tr>
<td>No case</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>Social</td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Positive social interaction</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>2.4 (1.6–3.7)</td>
<td></td>
</tr>
<tr>
<td>Some</td>
<td>1.00</td>
<td></td>
</tr>
</tbody>
</table>

OR = odds ratio; CI = confidence interval; p-value on the Wald chi-square analysis of effects test
Table 2.5: Factors significantly correlated with caseness for comorbid anxiety-depression

<table>
<thead>
<tr>
<th>Health behaviours</th>
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<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Physical activity</strong></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Sedentary</td>
<td>4.0 (2.1–7.7)</td>
<td></td>
</tr>
<tr>
<td>Insufficiently active</td>
<td>2.4 (1.3–4.4)</td>
<td></td>
</tr>
<tr>
<td>Sufficiently active</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td><strong>Smoking status</strong></td>
<td>0.046</td>
<td></td>
</tr>
<tr>
<td>Current</td>
<td>2.2 (1.0–4.5)</td>
<td></td>
</tr>
<tr>
<td>Former</td>
<td>0.87 (0.53–1.4)</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td><strong>Psychological</strong></td>
<td></td>
<td>0.008</td>
</tr>
<tr>
<td>Mental health treatment before cancer diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2.1 (1.2–3.6)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>Helplessness-hopelessness coping</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>Case</td>
<td>3.5 (2.1–5.8)</td>
<td></td>
</tr>
<tr>
<td>No case</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>Anxious preoccupation coping</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>Case</td>
<td>6.4 (3.9–10.6)</td>
<td></td>
</tr>
<tr>
<td>No case</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td><strong>Social</strong></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Positive social interaction</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>2.5 (1.6–4.1)</td>
<td></td>
</tr>
<tr>
<td>Some</td>
<td>1.00</td>
<td></td>
</tr>
</tbody>
</table>

OR = odds ratio; CI = confidence interval; p-value on the Wald chi-square analysis of effects test.
DISCUSSION

It is undisputed that a diagnosis of and treatment for cancer is a stressful life event, and therefore it is to be expected that some survivors will report psychological distress. In this population-based study, only 28% of cancer survivors at six months post-diagnosis reported clinical/borderline levels of anxiety and/or depression. A total of 24% of survivors were identified as cases on anxiety (irrespective of depression) and 14% as cases on depression (irrespective of anxiety). Overall, 10% were identified as cases for comorbid anxiety-depression. That is, about two-thirds (69%) of depressed survivors experienced anxiety at the same time, which is consistent with findings from a large heterogeneous sample of cancer patients receiving treatment at one clinic.\textsuperscript{44} Although comorbid anxiety-depression accounted for a relatively low proportion of survivors, these individuals are likely to be suffering greatly and should be actively identified and vigorously targeted for intervention.

The level of anxiety and depression identified in this study is lower than that reported by other studies of survivors at a similar timeframe post-diagnosis.\textsuperscript{8, 22-24} While this can be explained in part by the use of different measurement techniques or outcome measures, previous studies have tended to use convenience samples of survivors of a single cancer type recruited from one clinic, and are therefore prone to selection bias. One of the major strengths of this study is the use of the two largest state-based cancer registries in Australia as the sampling frame to recruit a population-based sample of survivors in the early stages of survivorship. As the study sample is generally
representative of its source population, we are confident that our findings are
generalisable.

Unlike previous studies which have included only one or two cancer types (mainly
breast), our large-scale study included a diversity of survivors, which enabled us to
directly compare psychological morbidity across seven common cancer types which
together account for 70% of all new cancer diagnoses in Australia. Univariate
analyses indicated that the prevalence of all three outcomes varied significantly across
cancer type, with the percentage of survivors who reported anxiety, depression and
comorbid anxiety-depression highest among lung cancer survivors. However,
multivariable analyses found that such variation across cancer type existed only for
anxiety, and is likely to reflect the challenges associated with poor prognosis and
deteriorating health that those diagnosed with lung cancer face.

A history of mental health treatment before cancer, greater use of anxious
preoccupation and helplessness-hopelessness coping strategies, and perceived low
levels of positive social interaction were strongly associated with caseness for anxiety,
depression and comorbid anxiety-depression. In addition to these, indicators of social
isolation (live alone, younger, mental health problems) and cancer type (lung,
melanoma) were uniquely and strongly associated with anxiety. Health behaviours
(lack of physical activity and current smoker) were strongly associated with both
depression and comorbid anxiety-depression.
The current study found that when considered together, health behaviours, psychological characteristics and social factors were more strongly associated (demonstrated by high odds ratios and highly significant p-values) with psychological morbidity than survivors’ individual and disease characteristics. While causality cannot be inferred from cross-sectional data, these findings are notable because health behaviours, coping strategies and social support are potentially modifiable and therefore have considerable promise for intervention efforts. For example, interventions targeting physical activity have been shown to reduce not only anxiety and depression, but also risk of cancer recurrence, other chronic illnesses and fatigue. Importantly, it has also been determined that it is generally safe and feasible for individuals affected by cancer to engage in physical activity during treatment and survivorship. Reviews of the evidence have recommended that coping skills training that maximises the use of adaptive coping and social skills training that emphasises reciprocal support should be integrated within interventions to impact upon psychological distress.

Contrary to our hypothesis, drinking alcohol at levels considered to be at increased risk of harm was associated with lower odds of depression. A possible explanation for this unexpected finding is that cancer survivors may use alcohol as a strategy to block or blunt feelings of sadness. Alternatively, having faced their own mortality and survived, survivors may simply be living each day to the fullest. It is also possible that this is a spurious finding resulting from methodological limitations. Although adapted from an existing questionnaire, the items assessing alcohol consumption were generally poorly completed, with many responses missing. Further, although we conformed to current
guidelines to classify survivors’ drinking levels, the criteria are crude and may have resulted in misclassification of drinking levels. Given the social stigma associated with excessive alcohol consumption, it is plausible that heavy drinkers under-reported their alcohol intake or avoided answering these questions. We recommend that future studies further explore the association between alcohol consumption and psychological morbidity among recent cancer survivors.

**Strengths and limitations**

To our knowledge, this is the first study to examine the prevalence of psychological morbidity among a large-scale population-based sample of diverse cancer survivors who at six months post-diagnosis are in the very early stages of cancer survivorship.

For logistical reasons related to patient recruitment via the cancer registries, the study sample was restricted to the eight most incident cancer types. Nonetheless, the sample included survivors of under-studied cancers (colorectal, head and neck, haematological and lung). The use of rapid case ascertainment procedures and registry policies prohibiting individuals being approached for more than one study meant the sampling frame from which the sample was recruited was incomplete. For example, young men (less than 55 years) diagnosed with prostate cancer and those diagnosed with early-stage colorectal cancer were unable to be approached by one registry for this study due to other studies targeting these patients. This contributed to differences between NSW and VIC participants in terms of gender, cancer type, stage of disease and treatments. Ideally, the sample recruited from each state would have been stratified by cancer type proportionate to its incidence in that state.
The T1 response rate of 41% (1360/3315 eligible individuals) may raise concerns about response bias. Due to privacy, confidentiality and adverse event concerns, the cancer registries used a multi-step recruitment process to identify potential participants on behalf of the research team; this process provided many opportunities for non-response and non-consent by clinicians and survivors prior to any contact from the researchers. The reported response rate almost certainly underestimates the true response rate because it assumes that all survivors of unknown eligibility (i.e. 764 survivors for whom the physician was uncontactable or refused, and 426 survivors who were uncontactable or non-responders) were eligible and therefore included in the denominator. While it exceeds the adjusted recruitment rate (34%) achieved by another study which used an equivalent method to recruit a similarly diverse sample of recent adult survivors via cancer registries, it is lower than other register-based studies which have recruited samples of recent survivors of a homogeneous cancer type. On the basis that the sample is generally representative of the cancer population, we propose that the impact of the response rate on the accuracy of the prevalence estimates reported is likely to be minimal.

Although Australia has one of the most multicultural populations worldwide, survivors who were not proficient in English were excluded due to prohibitive costs involved in translation of the questionnaire into other languages. This may have resulted in an underestimate of the prevalence of anxiety and depression, given that language barriers limit access to health care services and information. The range of static and modifiable individual, disease, health behaviour, psychological and social correlates examined in this study is considerably wider than that of previous studies.
Although cross-sectional in nature, it enabled us to identify the relationships between variables that should be further explored in longitudinal analysis.

The large-scale sample meant that it was not feasible to assess psychological morbidity by clinical interview; however, the HADS has good sensitivity and specificity in detecting cases of anxiety and depression, compared to clinical interview. Using the recommended HADS subscale cut-off score of ≥8 maximised the possibility of identifying all of the survivors with ‘caseness’ for anxiety and/or depression. However, it is possible that by using this lower threshold, some survivors may have been misclassified as ‘cases’, resulting in a small overestimate of psychological morbidity. Nevertheless, the rates of psychological morbidity found in this study are lower than those previously reported.

In balancing the questionnaire breadth and length, it was not possible to measure other potential correlates such as personality traits. While the lack of a gender- and age-matched non-cancer control group makes it difficult to determine if the psychological morbidity reported by survivors is age-related or cancer-related, the presence of other self-reported comorbid diseases (e.g. arthritis and hypertension) was assessed and found on multivariable analysis not to be associated with the outcomes examined. Furthermore, given that the rates of anxiety (24%) and depression (14%) were approximately double the rates of 12-month anxiety disorder (14%) and 12-month affective disorder (6%) found in the general population of Australia, it is likely that much of the psychological morbidity reported by survivors in this study is cancer-related.
CONCLUSIONS

About one quarter of cancer survivors in this study reported caseness for anxiety and/or depression at six months post-diagnosis, emphasising the importance of repeated assessment of psychological wellbeing during end of treatment and routine post-treatment follow-up care, and provision of appropriate interventions. In addition to mental health history, modifiable health behaviours (particularly physical activity and smoking behaviour), psychological characteristics (helplessness-hopelessness coping and anxious preoccupation coping) and social characteristics (low positive social interaction) were found to be stronger indicators of psychological morbidity than survivors’ individual and disease characteristics. Knowledge of the characteristics of survivors at increased risk of psychological morbidity may guide health care professionals in deciding which survivors to target for monitoring and early intervention. These findings suggest that focusing on healthy lifestyle behaviours, coping skills training and social skills training warrants further exploration and will likely require a multidisciplinary approach including psychosocial, medical, allied health, and community services.
REFERENCES


Prevalence and predictors of the short-term trajectory of anxiety and depression in the first year after a cancer diagnosis: A population-based longitudinal study

Understanding the course of anxiety and depression over time may enable early intervention with survivors at risk of persistent or delayed psychological morbidity. Building on the previous paper, this paper describes the prevalence and natural history of survivors’ anxiety and depression levels from six months to one year post-diagnosis, and the predictors of chronic or late anxiety and/or depression. This paper is currently under editorial review.
Prevalence and predictors of the short-term trajectory of anxiety and depression in the first year after a cancer diagnosis: A population-based longitudinal study

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4 Centre for Clinical Epidemiology and Biostatistics
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5 Hunter New England Population Health
Newcastle, Australia
ABSTRACT

Purpose: Few studies have examined psychological adjustment among cancer survivors in late treatment and early survivorship. This study investigated the prevalence and short-term trajectories of anxiety, depression and comorbid anxiety-depression among adult cancer survivors, and identified the individual, disease, health behaviour, psychological and social predictors of chronic and late psychological morbidity.

Method: A heterogeneous sample of adult cancer survivors was recruited from two state-based cancer registries. A total of 1154 survivors completed self-report questionnaires at six months (Time 1) and twelve months (Time 2) post-diagnosis. Anxiety and depression were assessed by the Hospital Anxiety and Depression Scale (HADS) with cases identified by a subscale cut-off score ≥ 8. Logistic regression analyses identified Time 1 characteristics associated with anxiety and/or depression at Time 2.

Results: The point prevalence of anxiety (Time 1: 22% and Time 2: 21%), depression (13% at both times) and comorbid anxiety-depression (9% at both times) was similar at six and twelve months post-diagnosis. Most survivors reported no psychological morbidity across the Time 1 to Time 2 trajectory (anxiety: 70%; depression: 82%; comorbid anxiety-depression: 87%). While psychological morbidity at Time 1 was the strongest predictor of psychological morbidity at Time 2, being diagnosed with lung cancer and health risk behaviours (i.e. smoking and insufficient physical activity) were also strong predictors.

Conclusions: Targeted psychological screening of vulnerable survivors and early intervention may prevent the onset and/or reduce the severity of psychological
morbidity in early survivorship among adult cancer survivors. Trials of risk reduction interventions targeting psychological functioning and health risk behaviours seem warranted.
INTRODUCTION

With the number of individuals living with a history of cancer expected to triple from 25 million in 2008 to 75 million in 2030,¹ attention has turned to how best to maximise the wellbeing of the growing population of cancer survivors. Mental health problems, including anxiety and depression, often co-occur with cancer and can impact on its management.²,³

Bonnano identified four patterns of adjustment to traumatic life events: resilience; recovery to normal after high levels of distress; persistent distress; and delayed distress.⁴ Henselmans’ study⁵ found that most breast cancer survivors within the first year post-diagnosis experienced no psychological distress (36%) or recovered to normal after completion of active treatment (33%). Small percentages of survivors became distressed soon after active treatment ended (15%) or experienced persistent distress (15%). Understanding the factors that influence trajectories of psychological adjustment may enable early intervention with survivors at risk of persistent or delayed psychological morbidity.

The few previous studies⁶-¹⁰ examining the course of psychological morbidity in early survivorship have mostly been conducted with breast cancer survivors, and relied on convenience samples drawn from a few treatment centres. To inform the care of the wider population of survivors, calls have been made for large-scale longitudinal studies with diverse samples.³,¹¹-¹⁴
Overcoming limitations of previous research, this study examined the short-term courses of anxiety and depression among a large population-based heterogeneous sample of survivors. The specific aims were to 1) identify the point prevalence of ‘caseness’ for anxiety, depression and comorbid anxiety-depression among adult cancer survivors at six and twelve months post-diagnosis; 2) examine the course of survivors’ anxiety, depression and comorbid anxiety-depression levels over the first year after diagnosis to identify the proportions who were non-cases, resolved cases, late cases and chronic cases; and 3) identify the factors at six months post-diagnosis that predicted ‘caseness’ for anxiety, depression and comorbid anxiety-depression at one year post-diagnosis.

METHODS

This paper is based on data collected at six months (Time 1) and twelve months (Time 2) post-diagnosis from survivors participating in the Cancer Survival Study.\textsuperscript{15-18}

Participants and procedures

The sample was recruited from the two largest state-based cancer registries in Australia.\textsuperscript{15} Sample quotas were set for each registry; one sampled cases proportional to cancer incidence rates, and the other sampled consecutive cases until the quota was achieved. Eligible survivors were those who were 1) diagnosed in the previous six months with their first primary cancer (localised or metastatic) of one of the top eight incident cancer types in Australia (prostate, colorectal, female breast, lung, head and neck cancers, melanoma, non-Hodgkin’s lymphoma and leukaemia); 2) aged between
18 and 80 years and living in the state of New South Wales or Victoria at diagnosis; 3) considered by their physicians to be aware of their diagnoses, physically and mentally capable of participating in the study, and sufficiently proficient in English to complete questionnaires; and 4) alive. The sample was restricted to the eight most incident cancers due to registry constraints in the number of cancer types for which rapid case ascertainment procedures could be implemented.

Eligible survivors who agreed to the registries passing on their contact details to the researchers were sent questionnaires to complete at approximately six and twelve months post-diagnosis. Participants were cross-checked against the National Death Index to avoid contacting those who had died between time points. Non-responders received one reminder questionnaire and one reminder telephone call three weeks apart. Return of a completed questionnaire indicated voluntary consent to participate. The study was approved by the relevant ethics committees.

**Measures**

Data were collected by self-administered questionnaires and cancer registry records.

**Outcome measures**

*Anxiety and depression* were measured by the 14-item Hospital Anxiety and Depression Scale (HADS) which includes two subscales: anxiety (HADS-A) and depression (HADS-D).\(^{19}\) A score from 0 to 21 is calculated for each subscale, with a higher score indicating a higher level of anxiety or depression. While acknowledging the current debate about the optimal scoring method and cut-point to use,\(^{20,21}\) the
established subscale cut-off score ≥8 was used to identify ‘cases’ on HADS-A and ‘cases’ on HADS-D.\textsuperscript{19,22} Cases on both HADS-A and HADS-D were also classified as ‘cases’ on comorbid anxiety-depression.

\textit{Predictor variables}

\textit{Individual:} Age at diagnosis and sex were obtained from the cancer registries. Marital status, highest level of education completed, employment, health insurance coverage, size of household, geographical location, use of complementary therapies for cancer-related purposes, and presence of physical comorbidities or significant life events (e.g. divorce) were obtained by questionnaire items at Time 1.

\textit{Disease and treatment:} Primary cancer type and spread of disease at diagnosis were obtained from the registries, with survivors’ cancer categorised as ‘early/less progressed’ (\textit{in situ} or localised; grade 1 or 2; tumour size T1 or T2), ‘late/more progressed’ (invasion of adjacent organs, regional nodes or distant metastases; grade 3 or 4; not tumour size T1) or ‘not applicable’ (haematological cancers). Current remission status, cancer treatments received in the last month, and having lived away from home to receive cancer treatment were obtained by questionnaire items at Time 1.

\textit{Health behaviours:} Seven items adapted from existing household surveys assessed health behaviours: three items assessed physical activity,\textsuperscript{23} with participants classified as ‘sufficiently active’ (at least 150 minutes of physical activity per week), ‘insufficiently active’ (participating in some activity but not enough in total time) or ‘sedentary’ (no physical activity);\textsuperscript{24} two items assessed smoking behaviour, with participants classified as ‘current’, ‘former’ or ‘never smoker’;\textsuperscript{25} and two items assessed alcohol...
consumption, with participants who consumed more than two standard drinks on any day classified as being at ‘increased lifetime risk of alcohol-related harm’. These measures of physical activity and smoking have demonstrated validity and reliability, compared to objective measures and longer self-report measures respectively.

**Psychological:** Two items at Time 1 assessed treatment for mental health illness before and since cancer diagnosis. Coping was assessed by the 21-item Mini Mental Adjustment to Cancer (mini-MAC) scale which measures five cancer-specific coping strategies: helplessness-hopelessness, anxious preoccupation, fighting spirit, cognitive avoidance and fatalism. Subscale scores were standardised from 0 to 100. Survivors who scored in the top 16% of each distribution were classified as ‘cases’ on that specific coping strategy, as recommended by the MAC scoring manual.

**Social:** Four items at Time 1 assessed the use of community-based information and peer support services since diagnosis. Perceived social support was assessed by the Medical Outcomes Study (MOS) Social Support Survey which measures functional support: emotional/informational, tangible, affectionate, and positive social interaction. Subscale scores were standardised from 0 to 100. For clinical usefulness, survivors who scored in the bottom one-third of each distribution were classified as having ‘low’ availability of that form of social support (C Sherbourne, personal communication, May 2004).

**Statistical methods**

If one item was missing on a HADS subscale, the mean of the remaining subscale items was imputed. Data from survivors with non-Hodgkin’s lymphoma and leukaemia were combined into the category, ‘haematological cancer’. Analysis was restricted to
survivors who returned both Time 1 and Time 2 questionnaires between 4 and 9 months post-diagnosis and 10 to 15 months post-diagnosis respectively.

Characteristics of Time 1 participants who did and did not complete the Time 2 questionnaire were compared using the chi-square test. The point prevalence of ‘caseness’ for anxiety, depression and comorbid anxiety-depression was calculated for each time with 95% confidence intervals (CIs). For each outcome, the proportions of survivors classified as ‘non-cases’ (non-case at Time 1 and Time 2), ‘resolved cases’ (case at Time 1 but not at Time 2), ‘late cases’ (non-case at Time 1 but case at Time 2) and ‘chronic cases’ (case at Time 1 and Time 2) were calculated with 95% CIs. Chi-square analyses examined the association between survivors’ individual, disease, health behaviour, psychological and social characteristics at Time 1 with ‘caseness’ for anxiety, depression and comorbid anxiety-depression at Time 2. Variables with a p-value ≤0.2 were included in multivariable backward stepwise logistic regression analyses for each outcome. After controlling for Time 1 anxiety and depression, variables were removed from the model if they had a p-value ≥0.1 on the likelihood ratio test. Variables with a p-value ≤0.05 were considered statistically significant.

Adjusted odds ratios, 95% confidence intervals and p-values are reported for variables included in the final multivariable model for each outcome. The estimated sample size of approximately 1320 would allow estimation of proportions with 95% CIs within ± 3% and provide 80% power, with a 5% significance level, to detect differences of 12% between categories of study factors predictive of anxiety and depression.
RESULTS

Sample

Of 3877 individuals assessed, 3315 were deemed eligible and 1691 consented to being contacted by the researchers. Overall, 1434 survivors (43% of those deemed eligible) completed at least one of the two questionnaires: 1360 at Time 1 and 1270 at Time 2. Between Time 1 and Time 2, 71 participants (5%) were lost to follow-up due to death (n=34) or withdrawal (n=37). Characteristics of the 1154 survivors who returned both questionnaires in the specified timeframe are shown in Table 3.1. While the study sample reflected the national profile for the top eight incident cancers in terms of gender and age, survivors of colorectal cancer appeared to be under-represented, and survivors of haematological and head and neck cancers appeared to be over-represented.

Relative to participants who completed Time 1 questionnaires only, those who completed both questionnaires were more likely at Time 1 to be older (25% vs 38% aged 60-69 years at diagnosis), diagnosed with prostate cancer (14% vs 28%) and less likely to have a lung cancer diagnosis (17% vs 9%), or have anxiety (32% vs 22%) or depression (27% vs 12%).
Table 3.1: Selected demographic and disease characteristics of the study sample compared to national cancer incidence data

<table>
<thead>
<tr>
<th></th>
<th>Study sample (N=1154)</th>
<th>National* (N=58,665)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>(%)</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>674</td>
<td>(58)</td>
</tr>
<tr>
<td>Female</td>
<td>480</td>
<td>(42)</td>
</tr>
<tr>
<td><strong>Age at diagnosis (years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-39</td>
<td>47</td>
<td>(4)</td>
</tr>
<tr>
<td>40-49</td>
<td>120</td>
<td>(10)</td>
</tr>
<tr>
<td>50-59</td>
<td>270</td>
<td>(23)</td>
</tr>
<tr>
<td>60-69</td>
<td>440</td>
<td>(38)</td>
</tr>
<tr>
<td>70 or more</td>
<td>277</td>
<td>(24)</td>
</tr>
<tr>
<td><strong>Primary cancer</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prostate</td>
<td>319</td>
<td>(28)</td>
</tr>
<tr>
<td>Breast (female)</td>
<td>184</td>
<td>(16)</td>
</tr>
<tr>
<td>Melanoma</td>
<td>168</td>
<td>(15)</td>
</tr>
<tr>
<td>Haematological*</td>
<td>157</td>
<td>(14)</td>
</tr>
<tr>
<td>Colorectal</td>
<td>140</td>
<td>(12)</td>
</tr>
<tr>
<td>Lung</td>
<td>104</td>
<td>(9)</td>
</tr>
<tr>
<td>Head and neck</td>
<td>82</td>
<td>(7)</td>
</tr>
<tr>
<td><strong>Stage of disease at diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Early/less progressed</td>
<td>600</td>
<td>(52)</td>
</tr>
<tr>
<td>Late/more progressed</td>
<td>228</td>
<td></td>
</tr>
<tr>
<td>Not applicable</td>
<td>157</td>
<td>(14)</td>
</tr>
<tr>
<td>Unknown</td>
<td>169</td>
<td>(15)</td>
</tr>
<tr>
<td><strong>Treatment received in first 12 months</strong>†</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery (n=1141)</td>
<td>841</td>
<td>(74)</td>
</tr>
<tr>
<td>Radiotherapy (n=1126)</td>
<td>422</td>
<td>(37)</td>
</tr>
<tr>
<td>Chemotherapy (n=1125)</td>
<td>386</td>
<td>(34)</td>
</tr>
<tr>
<td>Hormone therapy (n=1116)</td>
<td>250</td>
<td>(22)</td>
</tr>
</tbody>
</table>

* Includes non-Hodgkins lymphoma and leukaemia.
† Multiple responses allowed.
# 2005 data restricted to 8 most incident cancer types and those aged 20-79 years.
Prevalence of psychological morbidity at six and twelve months after diagnosis

Overall, the point prevalence of caseness for each outcome was low, and was similar for Time 1 and Time 2 (see Table 3.2). Of the three outcomes, anxiety was the most common, with a prevalence of 22% (95% CI: 20%–25%) at Time 1 and 21% (95% CI: 19%–24%) at Time 2. At both Time 1 and Time 2, 13% (95% CI: 11%–14%) of survivors were identified as cases on depression, and 9% (95% CI: 7%–10%) were identified as cases on comorbid anxiety-depression.

Table 3.2: Prevalence of ‘caseness’ for anxiety, depression and comorbid anxiety-depression at six months (Time 1) and one year (Time 2) post-diagnosis

<table>
<thead>
<tr>
<th></th>
<th>Time 1*</th>
<th></th>
<th>Time 2†</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>% (95% CI)</td>
<td>n</td>
</tr>
<tr>
<td>Anxiety (irrespective of depression)</td>
<td>257</td>
<td>22 (20–25)</td>
<td>241</td>
</tr>
<tr>
<td>Depression (irrespective of anxiety)</td>
<td>144</td>
<td>13 (11–14)</td>
<td>144</td>
</tr>
<tr>
<td>Comorbid anxiety-depression</td>
<td>98</td>
<td>9 (7–10)</td>
<td>97</td>
</tr>
</tbody>
</table>

* Number of observations across outcomes varies between 1148 and 1149 due to missing data.
† Number of observations across outcomes varies between 1131 and 1132 due to missing data.
Prevalence of course of psychological morbidity

Figure 2.1 shows for each outcome the proportion of survivors who were categorised to the four pathways: ‘non-case’, ‘chronic case’, ‘late case’ and ‘resolved case’. The most prevalent pathway was ‘non-case’ for anxiety (70%; 95% CI: 68%–73%), depression (82%; 95% CI: 79%–84%) and comorbid anxiety-depression (87%; 95% CI: 85%–89%). The prevalence of the ‘chronic case’ pathway was low, and more common for anxiety (14%; 95% CI: 12%–16%) than for depression (6%; 95% CI: 5%–8%) or comorbid anxiety-depression (4%; 95% CI: 3%–5%). The occurrence of the ‘late case’ pathway was also low for anxiety (7%; 95% CI: 6%–9%), depression (6%; 95% CI: 5%–8%), and comorbid anxiety-depression (5%; 95% CI: 3%–6%). A similarly small proportion of survivors who were cases of anxiety and/or depression at Time 1 recovered to non-case levels at Time 2.

Figure 2.1: Prevalence of anxiety, depression and comorbid anxiety-depression pathways in the first year after diagnosis
**Time 1 predictors of chronic or late psychological morbidity at Time 2**

The Time 1 characteristics that predicted caseness for anxiety, depression and comorbid anxiety-depression at Time 2 are shown in Tables 3.3 to 3.5 respectively.

**Individual**

Females (OR = 1.9) had almost twice the odds of being a case on anxiety than males (Table 3.3).

**Disease and treatment**

Compared to survivors of melanoma, those diagnosed with lung cancer (OR = 5.3) had higher odds of being a case on depression, as did survivors who were not in remission (OR = 1.8), compared to those who were in remission (Table 3.4).

**Health behaviour**

Survivors who were insufficiently active (OR = 2.1) had about twice the odds of being a case on depression than those who were sufficiently active (Table 3.4). Compared to survivors who had never smoked, those who were current (OR = 3.7) or former (OR = 2.4) smokers had at least twice the odds of being a case on comorbid anxiety-depression (Table 3.5).

**Psychological**

Caseness for anxiety and depression at Time 1 predicted all three outcomes (Tables 3.3 to 3.5). Survivors who were a case on anxiety at Time 1 had higher odds of caseness for anxiety (OR = 10.7), depression (OR = 1.6) and comorbid anxiety-depression (OR = 5.5)
at Time 2, compared to those who were non-cases at Time 1. Similarly, survivors who were cases on depression at Time 1 had higher odds of being cases on anxiety (OR = 1.9), depression (OR = 6.7) and comorbid anxiety-depression (OR = 6.3) at Time 2, compared to those who were non-cases on depression at Time 1. Survivors who used cognitive avoidance coping at Time 1 had greater odds of being cases on depression (OR = 1.7) and comorbid anxiety-depression (OR = 1.8) at Time 2, compared to those who did not use this strategy at Time 1. Those who used fighting spirit at Time 1 had higher odds (OR = 1.7) of being cases on anxiety at Time 2, compared to those who did not use this strategy at Time 1.
**Table 3.3:** Characteristics predicting ‘caseness’ for anxiety at one year post-diagnosis

<table>
<thead>
<tr>
<th>Predictor variable</th>
<th>Adjusted OR (95% CI)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Individual</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td>0.001</td>
</tr>
<tr>
<td>Female</td>
<td>1.9 (1.3–2.6)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td><strong>Psychological</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time 1 anxiety level</td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Case</td>
<td>10.7 (7.2–15.9)</td>
<td></td>
</tr>
<tr>
<td>Non-case</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Time 1 depression level</td>
<td></td>
<td>0.010</td>
</tr>
<tr>
<td>Case</td>
<td>1.9 (1.2–3.1)</td>
<td></td>
</tr>
<tr>
<td>Non-case</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Cognitive avoidance</td>
<td></td>
<td>0.054</td>
</tr>
<tr>
<td>Case</td>
<td>1.4 (0.99–2.1)</td>
<td></td>
</tr>
<tr>
<td>Non-case</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Anxious preoccupation</td>
<td></td>
<td>0.044</td>
</tr>
<tr>
<td>Case</td>
<td>1.6 (1.0–2.4)</td>
<td></td>
</tr>
<tr>
<td>Non-case</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Fighting spirit</td>
<td></td>
<td>0.023</td>
</tr>
<tr>
<td>Case</td>
<td>1.7 (1.1–2.8)</td>
<td></td>
</tr>
<tr>
<td>Non-case</td>
<td>1.0</td>
<td></td>
</tr>
</tbody>
</table>

OR = odds ratio; CI = confidence interval; p-value on the likelihood ratio test.
Table 3.4: Characteristics predicting ‘caseness’ for depression at one year post-diagnosis

<table>
<thead>
<tr>
<th>Predictor variable</th>
<th>Adjusted OR (95% CI)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Individual</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td>0.061</td>
</tr>
<tr>
<td>Married/de facto</td>
<td>0.59 (0.34–1.0)</td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td><strong>Disease</strong></td>
<td></td>
<td>0.003</td>
</tr>
<tr>
<td>Cancer type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bowel</td>
<td>2.4 (0.84–7.0)</td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>1.1 (0.39–3.4)</td>
<td></td>
</tr>
<tr>
<td>Haematological</td>
<td>1.6 (0.54–4.6)</td>
<td></td>
</tr>
<tr>
<td>Head and neck</td>
<td>0.99 (0.27–3.6)</td>
<td></td>
</tr>
<tr>
<td>Lung</td>
<td>5.3 (1.9–15.1)</td>
<td></td>
</tr>
<tr>
<td>Prostate</td>
<td>2.0 (0.73–5.6)</td>
<td></td>
</tr>
<tr>
<td>Melanoma</td>
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<td></td>
</tr>
<tr>
<td>Cancer status</td>
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<td>0.016</td>
</tr>
<tr>
<td>Not in remission</td>
<td>1.8 (1.1–2.9)</td>
<td></td>
</tr>
<tr>
<td>In remission</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td><strong>Health behaviour</strong></td>
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<td>0.035</td>
</tr>
<tr>
<td>Physical activity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sedentary</td>
<td>1.5 (0.75–2.9)</td>
<td></td>
</tr>
<tr>
<td>Insufficiently active</td>
<td>2.1 (1.2–3.6)</td>
<td></td>
</tr>
<tr>
<td>Sufficiently active</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td><strong>Psychological</strong></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Time 1 anxiety level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Case</td>
<td>1.6 (1.6–4.4)</td>
<td></td>
</tr>
<tr>
<td>Non-case</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Predictor variable</td>
<td>Adjusted OR (95% CI)</td>
<td>p-value</td>
</tr>
<tr>
<td>------------------------------------</td>
<td>----------------------</td>
<td>---------</td>
</tr>
<tr>
<td><strong>Time 1 depression level</strong></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Case</td>
<td>6.7 (4.0–12.2)</td>
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<tr>
<td>Non-case</td>
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<tr>
<td><strong>Cognitive avoidance</strong></td>
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<td>0.024</td>
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<tr>
<td>Case</td>
<td>1.7 (1.1–2.8)</td>
<td></td>
</tr>
<tr>
<td>Non-case</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td><strong>Social</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Emotional support</strong></td>
<td></td>
<td>0.068</td>
</tr>
<tr>
<td>Low</td>
<td>1.6 (0.97–2.6)</td>
<td></td>
</tr>
<tr>
<td>Some</td>
<td>1.0</td>
<td></td>
</tr>
</tbody>
</table>

OR = odds ratio; CI = confidence interval; p-value on the likelihood ratio test.
Table 3.5: Characteristics predicting ‘caseness’ for comorbid anxiety-depression at one year post-diagnosis

<table>
<thead>
<tr>
<th>Predictor variable</th>
<th>Adjusted OR (95% CI)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health behaviour</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical activity</td>
<td></td>
<td>0.043</td>
</tr>
<tr>
<td>Sedentary</td>
<td>0.75 (0.35–1.6)</td>
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</tr>
<tr>
<td>Insufficiently active</td>
<td>1.6 (0.93–2.9)</td>
<td></td>
</tr>
<tr>
<td>Sufficiently active</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Smoking status</td>
<td></td>
<td>0.001</td>
</tr>
<tr>
<td>Current</td>
<td>3.7 (1.6–8.3)</td>
<td></td>
</tr>
<tr>
<td>Former</td>
<td>2.4 (1.4–4.2)</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Psychological</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time 1 anxiety level</td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Case</td>
<td>5.5 (3.2–9.4)</td>
<td></td>
</tr>
<tr>
<td>Non-case</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Time 1 depression level</td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Case</td>
<td>6.3 (3.6–11.0)</td>
<td></td>
</tr>
<tr>
<td>Non-case</td>
<td>1.0</td>
<td></td>
</tr>
<tr>
<td>Cognitive avoidance</td>
<td></td>
<td>0.021</td>
</tr>
<tr>
<td>Case</td>
<td>1.8 (1.1–3.0)</td>
<td></td>
</tr>
<tr>
<td>Non-case</td>
<td>1.0</td>
<td></td>
</tr>
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</table>

OR = odds ratio; CI = confidence interval; p-value on the likelihood ratio test.
DISCUSSION

Prevalence and course of psychological morbidity

This large-scale longitudinal study found that the point prevalence of anxiety, depression and comorbid anxiety-depression among cancer survivors did not decrease over time. At both times, approximately 20% of survivors were cases on anxiety, 13% were cases on depression and 9% were cases on comorbid anxiety-depression. Analysis of the courses of anxiety and depression revealed a large group of survivors who demonstrated a pattern of psychological functioning consistent with resilience. Small groups of survivors experienced trajectories indicative of recovered, chronic and late psychological morbidity. Compared to simple point prevalence data for each time, these four clinically important patterns of adjustment provide a more complete picture of the psychological wellbeing of cancer survivors during early survivorship than previously known.

The finding that most survivors were not cases on anxiety and/or depression at either time point is consistent with previous studies conducted with survivors of breast, colorectal, lung, and head and neck cancer. Given that feelings of vulnerability are common when active treatment is completed, it may be reassuring to give survivors in late treatment the message that most will adjust well and require only low-intensity supportive care, including information and self-management support.
Predictors of chronic or late psychological morbidity

No other studies of the psychological outcomes of survivors in early survivorship have examined the relative contribution of the array of factors considered in this study. Potentially modifiable factors were the strongest and most consistent predictors of late or chronic anxiety and/or depression.

Potentially modifiable factors

Consistent with previous findings, caseness at Time 1 was the strongest predictor of caseness at Time 2. Smoking status (current or former) and physical activity (insufficiently active) at Time 1 uniquely predicted caseness for comorbid anxiety-depression and depression respectively at Time 2. This is consistent with evidence that physical activity may have beneficial effects on psychological wellbeing. Coping strategy at Time 1 also predicted caseness for psychological morbidity at Time 2, albeit to a lesser extent. Perceived social support did not predict psychological morbidity and may reflect the fact that 80% of the sample were married or living as married.

Non-modifiable factors

Cancer type uniquely predicted caseness for depression, with only survivors of lung cancer more likely to be cases at Time 2, possibly reflecting the poor prognosis associated with this cancer type. This is a unique contribution, as no other study has included a diversity of cancer types with sufficient numbers to conduct adequately powered subgroup analyses. While previous findings are mixed, this study found that being female predicted caseness for anxiety, and not being in remission predicted caseness for depression.
Implications

These findings may suggest that routine psychological screening of all cancer survivors during survivorship is not warranted. Rather, screening during survivorship may best be targeted at survivors at greatest risk of persistent or late psychological morbidity, i.e. those who screen as ‘cases’ on psychological morbidity at the end of active treatment, those who were diagnosed with lung cancer, former or current smokers, and those who were insufficiently active. While the detection of cases of psychological morbidity requires screening tools with a high degree of accuracy, information about cancer type and health risk behaviours is readily available in the clinical setting, making this group of vulnerable survivors relatively easy to identify. These findings suggest that trials of interventions targeting vulnerable survivors’ psychological functioning are merited.

Strengths and limitations

This is one of the first studies to examine the prevalence and predictors of the short-term courses of anxiety and/or depression among a diverse sample of cancer survivors in early survivorship. Although a population-based sampling frame was used, the 43% response rate may raise concerns about response bias. However, sample retention between Time 1 and Time 2 was high (95%). Analysis was restricted to survivors who returned both questionnaires, and as attrition from Time 1 to Time 2 was not completely random, the results may slightly underestimate psychological morbidity. While assessments were anchored to clearly defined time points post-diagnosis, there is much heterogeneity in the timing of transition from treatment to survivorship. Ideally, assessment points should be linked to key clinical events (e.g. end of hospital-
based treatment), in line with the approach used by Helselmans.\textsuperscript{5} The lack of assessment around the time of diagnosis was an unavoidable consequence of recruiting through the registries. In balancing the survey length and breadth, it was not possible to assess all potential risk factors (e.g. diet). As it was not feasible to assess psychological morbidity using a ‘gold standard’ structured clinical interview, given the large and dispersed sample, the HADS was used for this purpose. Although recent reviews have recommended the HADS as the tool of choice with oncology populations,\textsuperscript{39,40} screening tools are not diagnostic, have a tendency to overestimate cases and may not detect cancer-specific distress such as fear of recurrence. The use of case-based analyses, using the HADS cut-off score $\geq 8$ on each subscale to define caseness for anxiety and depression, can exaggerate small differences between scores that lie one point above or below the cut-point, and may be more clinically useful than subscale mean scores.

**CONCLUSIONS**

Between six and twelve months post-diagnosis, most cancer survivors demonstrated a trajectory of psychological adjustment indicative of resilience or recovery. Earlier psychological morbidity, lung cancer diagnosis, a history of smoking, and inadequate physical activity were the strongest predictors of subsequent psychological morbidity. The results suggest targeted psychological screening of these vulnerable subgroups of survivors during the survivorship phase of care to facilitate the early identification of and intervention for psychological morbidity. Intervention trials focusing on psychological functioning, coping style and health behaviours are warranted.
REFERENCES


PAPER 3

How does the Distress Thermometer compare to the Hospital Anxiety and Depression Scale for detecting possible cases of psychological morbidity among cancer survivors?

To support the targeted psychological distress screening of at-risk cancer survivors proposed in the previous paper, screening tools that are brief, easy to use and accurate are required. This paper examines the accuracy of the single-item Distress Thermometer (DT) to identify possible cases of anxiety and/or depression among adult cancer survivors, using the HADS as the criterion measure.

This paper was published in the journal Supportive Care in Cancer [Appendix 3.1].

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How does the Distress Thermometer compare to the Hospital Anxiety and Depression Scale for detecting possible cases of psychological morbidity among cancer survivors?

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ABSTRACT

Purpose: Use of the Distress Thermometer (DT) as a screening tool is increasing across the cancer trajectory. This study examined the accuracy and optimal cut-off score of the DT, compared to the Hospital Anxiety and Depression Scale (HADS), for detecting possible cases of psychological morbidity among adults in early survivorship.

Methods: This study is a cross-sectional survey of 1,323 adult cancer survivors recruited from two state-based cancer registries in Australia. Participants completed the DT and the HADS at 6 months post-diagnosis.

Results: Compared to the HADS subscale threshold ≥8, the DT performed well in discriminating between cases and non-cases of anxiety, depression and comorbid anxiety-depression, with an area under the curve of 0.85, 0.84 and 0.87, respectively. A DT cut-off score of ≥2 was best for clinical use (sensitivity 87%–95%; specificity 60%–68%), ≥4 was best for research use (sensitivity 67%–82%; specificity 81%–88%) and ≥3 was the best balance between sensitivity (77%–88%) and specificity (72%–79%) for detecting cases of anxiety, depression and comorbid anxiety-depression. The DT demonstrated a high level of precision in identifying non-cases of psychological morbidity at all possible thresholds (negative predictive value 77%–99%).

Conclusions: The recommended DT cut-off score of ≥4 was not supported for universal use among recent cancer survivors. The optimal DT threshold depends upon whether the tool is being used in the clinical or research setting. The DT may best serve to initially identify non-cases as part of a two-stage screening process. The performance of the DT against ‘gold standard’ clinical interview should be evaluated with cancer survivors.
INTRODUCTION

The diagnosis and treatment of cancer has wide-ranging physical, psychosocial and existential effects. \(^1\) Psychological distress is relatively common among oncology populations, with estimates of the prevalence ranging from 28% \(^2\) to 43%. \(^3\) Emotional stress has been linked to decreased social functioning, more physical and cognitive impairment, amplified somatic symptoms, \(^4\) non-adherence to treatments and health-promoting behaviours, \(^5\) and possibly cancer progression and recurrence. \(^6\) Despite the importance of detecting and treating psychological distress, health care providers often fail to accurately recognise distressed patients, \(^7\) and many cancer services report providing psychosocial care only to patients in crisis. \(^8\) Consequently, many people with cancer report unmet need for help with psychological issues. \(^9\) Guidelines recommend that all cancer patients should be routinely screened for distress at periods of increased vulnerability during the cancer journey. \(^10,11\) Screening itself is not diagnostic; rather, those who have a positive result from the screening test require further evaluation to confirm or discount the presence and severity of emotional distress. Routine distress screening is acceptable to people with cancer, feasible to implement \(^12,13\) and estimated to take one-quarter of the time and cost one-third as much as conducting clinical assessments. \(^14\)

It is widely accepted that a screening tool should be brief, easy to administer and interpret, reliable and able to accurately detect most of those with and without the condition of interest, based on a cut-off score. \(^15\) Various screening tools, such as the Hospital Anxiety and Depression Scale (HADS), \(^16\) Brief Symptom Inventory—18
(BSI–18)\textsuperscript{17} and Distress Thermometer (DT)\textsuperscript{18} have been developed to quickly identify individuals who may be psychologically distressed. The single-item DT is recommended by the National Comprehensive Cancer Network.\textsuperscript{11} Potential advantages of the DT over other screening tools are its brevity and ease of administration and scoring. While the accuracy of the DT to detect psychological distress has been demonstrated against longer criterion measures, including the HADS, BSI–18 and clinical interview, recent reviews have highlighted the DT’s lack of specificity to rule out false positive cases.\textsuperscript{19-21} Furthermore, study findings are mixed regarding the optimal DT cut-off score for case-finding, with some studies supporting a cut-off score of ≥4 and others supporting a cut-off score of ≥5.\textsuperscript{22}

Despite increased attention to the growing population of individuals transitioning to survivorship, to our knowledge only two studies have examined the screening performance of the DT among those in survivorship. Merport et al\textsuperscript{23} compared the DT to the BSI–18 in a heterogeneous sample of survivors at least 2 years post-diagnosis, while Craike et al\textsuperscript{24} compared the DT to the HADS in a sample of recent colorectal cancer survivors. In both studies, the DT demonstrated poor sensitivity relative to the criterion measure for identifying cancer survivors who self-reported symptoms of anxiety and/or depression. These findings highlight the importance of establishing the performance of a screening tool prior to using it with a different population or context to that in which it was validated.
This study aimed to (1) examine the sensitivity and specificity of the recommended DT cut-off score of ≥4 with the HADS for detecting possible cases of anxiety, depression and comorbid anxiety-depression among a heterogeneous sample of adult cancer survivors 6 months after diagnosis and (2) identify the optimal cut-off score on the DT for detecting possible cases of anxiety, depression and comorbid anxiety-depression among adult cancer survivors 6 months after diagnosis. The HADS was selected as the criterion measure because it is among the most widely used screening tools assessing symptoms of anxiety and depression in oncology populations\(^ {21, 22}\) and was recommended as the tool of choice in recent reviews.\(^ {25, 26}\)

**METHOD**

This paper is based on Time 1 (T1) data collected at 6 months post-diagnosis from survivors participating in the population-based longitudinal *Cancer Survival Study*. The study protocol and some of the findings have been reported elsewhere.\(^ {2, 27}\)

**Participants and procedures**

The sample was recruited from the two largest state-based cancer registries in Australia, which together account for 60% of all new cases of cancer diagnosed.\(^ {28}\) Eligible survivors were (1) diagnosed in the previous 6 months with their first primary cancer being one of the top eight incident cancer types in Australia (prostate, colorectal, female breast, lung, melanoma, non-Hodgkin’s lymphoma, leukaemia, head and neck), (2) aged between 18 and 80 years and living in the state of New South Wales or Victoria at diagnosis, (3) considered by their physicians to be aware of their
diagnosis, physically and mentally capable of participating in the study, and sufficiently proficient in English to complete a questionnaire, and (4) alive.

Eligible survivors who consented to the cancer registry passing on their contact details to the researchers were sent a self-administered questionnaire. Non-responders were sent one reminder questionnaire 3 weeks later and received one reminder telephone call after a further 3 weeks. Return of the questionnaire indicated voluntary consent to participate. Participants’ disease (primary cancer type, spread of disease at diagnosis) and demographic (age, sex) characteristics were obtained from the cancer registries. The study was approved by the appropriate ethics committees.

Measures

**Distress** was measured by the single-item DT. Responses self-reported their levels of emotional distress over the past week on a visual analogue scale from 0 (no distress) to 10 (extreme distress). Most studies have identified that a cut-off score ≥4 indicates clinically significant distress. However, a recent pooled analysis found that the DT yields high rates of false positives and appears to be better at ruling out possible cases of clinical distress, while a systematic review of the psychometric properties of screening instruments for emotional distress rated the DT as only fair.

**Anxiety and depression** were assessed by the HADS, a 14-item screening tool assessing self-reported symptoms of anxiety (HADS–A) and depression (HADS–D). Each item is rated on a Likert scale from 0 to 3, and a score from 0 to 21 is calculated for each subscale. Scores can be kept continuous, with higher scores indicating more anxiety or
depression, or categorised with scores from 0 to 7 classified as non-case, 8 to 11 as borderline case and 12 to 21 as probable case.\textsuperscript{16} While there is ongoing debate about the optimal HADS cut-off score,\textsuperscript{31} we used the established subscale cut-off score of $\geq 8$ to identify ‘cases’ on HADS–A and ‘cases’ on HADS–D.\textsuperscript{16, 32, 33} In addition, those who scored $\geq 8$ on both HADS-A and HADS-D were classified as ‘cases’ on comorbid anxiety-depression.

Analysis

The HADS was the criterion measure for defining caseness for anxiety, depression and comorbid anxiety-depression. If one item was missing from a HADS subscale, the mean of the remaining six items was imputed, in accordance with the recommendations for the measure.\textsuperscript{34} To examine the accuracy of the recommended DT cut-off score of $\geq 4$ to detect cases of psychological morbidity, participants were classified as ‘clinically distressed’ (DT score $\geq 4$) or ‘not clinically distressed’ (DT score $\leq 3$) and as ‘cases’ (HADS subscale score $\geq 8$) or ‘non-cases’ (HADS subscale score $< 8$) of anxiety, depression and comorbid anxiety-depression. The sensitivity, specificity, positive predictive value (PPV), negative predictive value (NPV) and proportion of correctly identified cases and non-cases (based on the HADS classification) were calculated for each outcome, with 95% confidence intervals (CI). In this context, sensitivity refers to the proportion of cases identified by the HADS that are correctly identified as cases by the DT, specificity refers to the proportion of non-cases identified by the HADS that are correctly identified as non-cases by the DT, PPV is the proportion of cases identified by the DT that are cases according to the HADS, and NPV is the proportion of non-cases identified by the DT that are non-cases according to the HADS.
To identify the optimal cut-point for the DT in detecting cases of anxiety, depression and comorbid anxiety-depression, the sensitivity, specificity, PPV, NPV and proportion of correctly identified ‘cases’ for each outcome were calculated, with 95% CI for all possible cut-off values for the DT. The optimal DT cut-off score was determined by finding the DT value which achieved the best balance between sensitivity and specificity. Receiver operating characteristic (ROC) curves were used to examine the ability of all possible cut-off values of the DT to detect ‘cases’ of anxiety, depression and comorbid anxiety-depression, as identified by the HADS subscale score ≥8. For each ROC curve, the area under the curve (AUC) estimate was used as an indicator of the overall accuracy of the DT to identify ‘cases’ of the outcome of interest.

RESULTS

Sample

A total of 3,877 potential participants were assessed for study eligibility. Of the 3,315 deemed eligible, 1,691 consented to contact by the researchers, and 1,360 returned a T1 questionnaire (41% response rate at T1). Of these, 37 questionnaires were returned more than 9 months after diagnosis and were excluded. The characteristics of the 1,323 participants included in these analyses have been reported previously.² In summary, participants were surveyed at a median of 6 months after diagnosis (SD=1 month, range=4–9 months) and their median age was 63 years (SD=11 years, range=18–80 years). More than half (59%) were male and diagnosed with early-stage disease (52%). The most common diagnosis was prostate cancer (26%), followed by breast cancer (16%) and melanoma (15%). Almost three-quarters of participants (72%)

had not received any active cancer treatment in the last month. The sample generally reflected the age and gender profile for the top eight incident cancers diagnosed in Australia in 2005.27

**Accuracy of the recommended DT cut-off score >4 for identifying cases of anxiety and depression**

**Anxiety**

A DT cut-off score of 4 correctly identified 67% of HADS cases of anxiety (sensitivity) and 88% of HADS non-cases (specificity). Of the anxiety cases identified by the DT, 62% (PPV) were cases according to the HADS and, of the non-cases identified by the DT, 90% (NPV) were defined as non-cases by the HADS. Overall, 83% of survivors were correctly classified as cases or non-cases of anxiety.

**Depression**

A DT cut-off score of 4 correctly identified 71% (sensitivity) of HADS cases of depression and 82% (specificity) of HADS non-cases. Of the depression cases identified by the DT, 40% (PPV) were cases according to the HADS, and of the non-cases identified by the DT, 95% (NPV) were defined as non-cases by the HADS. Overall, 81% of survivors were correctly classified as cases or non-cases of depression.

**Comorbid anxiety-depression**

A cut-off score of 4 correctly identified 82% (sensitivity) of HADS cases of comorbid anxiety-depression and 81% (specificity) of non-cases. Of the comorbid anxiety-depression cases identified by the DT, 32% (PPV) were defined as cases according to
the HADS, and of the non-cases identified by the DT, 98% (NPV) were defined as non-cases by the HADS. Overall, 81% of survivors were correctly classified as cases or non-cases of comorbid anxiety-depression.

**Optimal DT cut-off score for identifying cases of anxiety and depression**

The sensitivity, specificity, PPV, NPV and percentage correct for all possible DT cut-off values are presented in Table 4.1, and ROC curves are graphed in Figures 3.1 to 3.3.

**Anxiety**

The DT showed good overall accuracy relative to the HADS–A for discriminating between cases and non-cases of anxiety, with an AUC of 0.85 (95% CI: 0.82–0.88). The DT cut-off score for anxiety caseness which achieved the best balance between sensitivity and specificity was 3. A cut-off score of 3 detected 77% of survivors who were true cases and 79% of survivors who were non-cases of anxiety. In addition, half of all survivors who were identified by the DT as cases and 92% who were identified as non-cases of anxiety were classified as such according to the HADS. Raising the cut-off score to 4 decreased sensitivity to 67% but increased specificity to 88%. Lowering the DT threshold to 2 increased sensitivity to 87% but decreased specificity to 68%.
Depression

The DT showed good overall accuracy relative to the HADS–D for discriminating between cases and non-cases of depression, with an AUC of 0.84 (95% CI 0.81–0.87). The optimal DT cut-off score for depression caseness was 3. A cut-off score of 3 detected 78% of survivors who were true cases and 74% of survivors who were non-cases of anxiety. In addition, one-third of all survivors who were identified by the DT as cases and 95% who were identified as non-cases of anxiety were classified as such according to the HADS. Raising the DT threshold to 4 decreased sensitivity to 71% but increased specificity to 82%. Lowering the DT threshold to 2 increased sensitivity to 91% but decreased specificity to 63%.

Figure 3.1: Receiver operating characteristic curve of DT scores versus the HADS anxiety subscale (score ≥8)
Figure 3.2: Receiver operating characteristic curve of DT scores versus the HADS depression subscale (score ≥8)

**Comorbid anxiety-depression**

The DT showed good overall accuracy relative to the HADS for discriminating between cases and non-cases of comorbid anxiety-depression, with an AUC of 0.87 (95% CI 0.84–0.90). The optimal DT cut-off score for detecting cases of comorbid anxiety-depression was 4. A cut-off score of 4 detected at least 80% of survivors who were true cases and true non-cases of comorbid anxiety-depression. In addition, one-third of all survivors who were identified by the DT as cases and 98% who were identified as non-cases of comorbid anxiety-depression were classified as such according to the HADS. Raising the cut-off score to 5 lowered sensitivity to 74% but increased specificity to 86%. Lowering the DT cut-off score to 3 increased sensitivity to 88% but decreased specificity to 72%.
Figure 3.3: Receiver operating characteristic curve of DT scores *versus* the HADS (score ≥8 on both anxiety and depression subscales)
Table 4.1: Performance of DT scores compared to the HADS for identifying cases of anxiety, depression and comorbid anxiety-depression

<table>
<thead>
<tr>
<th>DT score</th>
<th>Sensitivity (95% CI)</th>
<th>Specificity (95% CI)</th>
<th>Positive predictive value (95% CI)</th>
<th>Negative predictive value (95% CI)</th>
<th>% correctly classified (95% CI)</th>
</tr>
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<td>Anxiety</td>
<td></td>
<td></td>
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<tr>
<td>0</td>
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<tr>
<td>≥8 on HADS–A</td>
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</tr>
<tr>
<td>1</td>
<td>93 (90–96)</td>
<td>49 (46–52)</td>
<td>35 (32–39)</td>
<td>96 (94–98)</td>
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</tr>
<tr>
<td>2</td>
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<td>68 (65–71)</td>
<td>45 (41–49)</td>
<td>95 (93–96)</td>
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</tr>
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<td>79 (77–81)</td>
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<tr>
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<td>84 (82–86)</td>
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<td>Specificity (95% CI)</td>
<td>Positive predictive value (95% CI)</td>
<td>Negative predictive value (95% CI)</td>
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<td>DT score</td>
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<td>Specificity (95% CI)</td>
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<tr>
<td>2</td>
<td>95 (91–99)</td>
<td>60 (58–63)</td>
<td>20 (17–24)</td>
<td>99 (98–100)</td>
<td>64 (61–67)</td>
</tr>
<tr>
<td>(≥8 on HADS–A and HADS–D)</td>
<td>3</td>
<td>88 (83–94)</td>
<td>72 (70–75)</td>
<td>25 (21–30)</td>
<td>98 (97–99)</td>
</tr>
<tr>
<td>4</td>
<td>82 (76–89)</td>
<td>81 (79–83)</td>
<td>32 (27–37)</td>
<td>98 (97–99)</td>
<td>81 (79–83)</td>
</tr>
<tr>
<td>5</td>
<td>74 (66–82)</td>
<td>86 (84–88)</td>
<td>36 (30–42)</td>
<td>97 (96–98)</td>
<td>84 (82–87)</td>
</tr>
<tr>
<td>6</td>
<td>53 (44–62)</td>
<td>91 (89–93)</td>
<td>38 (31–46)</td>
<td>95 (93–96)</td>
<td>87 (85–89)</td>
</tr>
<tr>
<td>7</td>
<td>42 (34–51)</td>
<td>94 (93–95)</td>
<td>43 (34–52)</td>
<td>94 (92–95)</td>
<td>89 (87–91)</td>
</tr>
<tr>
<td>8</td>
<td>33 (25–42)</td>
<td>97 (96–98)</td>
<td>57 (45–69)</td>
<td>93 (92–95)</td>
<td>91 (90–93)</td>
</tr>
<tr>
<td>9</td>
<td>12 (6–19)</td>
<td>99 (98–100)</td>
<td>56 (36–76)</td>
<td>91 (90–93)</td>
<td>91 (89–92)</td>
</tr>
<tr>
<td>10</td>
<td>6 (2–10)</td>
<td>99 (99–100)</td>
<td>50 (20–80)</td>
<td>91 (89–92)</td>
<td>90 (88–92)</td>
</tr>
</tbody>
</table>
DISCUSSION

The DT demonstrated good agreement relative to the HADS in discriminating between cases and non-cases of anxiety, depression, and comorbid anxiety-depression among cancer survivors 6 months after diagnosis. This is consistent with previous studies which have examined the performance of the DT against criterion measures such as the HADS, BSI–18 and clinical interview, to identify psychologically distressed cancer patients and survivors. However, at the suggested cut-off score of ≥4, the DT generated a high rate of false negative or ‘missed’ cases. For instance, the DT failed to identify 96 of 288 HADS cases of anxiety, 50 of 174 HADS cases of depression and 21 of 120 HADS cases of comorbid anxiety-depression. This low level of sensitivity suggests that the recommended DT cut-off score of ≥4 may not be ideal for detecting cases of anxiety and depression among survivors 6 months after diagnosis. These findings add to emerging evidence illustrating the DT’s lack of sensitivity among individuals in the survivorship phase of care, compared to those in the treatment phase.

The choice of optimal cut-point is a trade-off between sensitivity and specificity. While lowering the DT cut-off score increased sensitivity and reduced the number of cases that were ‘missed’, it resulted in a corresponding decrease in specificity and increased the number of false positive cases identified. Conversely, raising the DT cut-off score increased specificity and reduced sensitivity. Our study found that a DT cut-off score of ≥3 achieved the best balance between sensitivity and specificity. At this threshold, at least 75% of HADS cases and 72% of HADS non-cases of anxiety, depression and comorbid anxiety-depression were identified as such by the DT. While these rates of
sensitivity and specificity are at least as good as those reported in a recent pooled analysis of the DT, compared to the HADS, to detect self-reported symptoms of anxiety and depression in oncology populations, the optimal cut-point of the DT may depend upon the purpose of using the tool.

For clinical applications, it could be reasoned that optimising sensitivity is desirable in order not to miss possible cases of psychological morbidity that require further assessment and possible treatment. This would lead to over-detection of cases and unnecessary further evaluation, which in itself can be stressful. However, it could be argued that, in the survivorship context, over-detection is preferable to under-detection, given the intermittent nature of contact with health care professionals and thus fewer opportunities for psychological distress to be identified. While a DT threshold of ≥2 achieved at least 87% sensitivity for each outcome, the false positive rate was high, with 32% to 40% of HADS non-cases misclassified as cases by the DT. These findings suggest that if universal DT screening of cancer survivors in the early stages of survivorship was implemented, a two-stage sequential screening process would be necessary. Survivors who scored ≥2 on the DT in the initial screening would need to undergo a second stage of screening, such as completion of a longer and more sensitive screening tool or further discussion with a nurse or oncologist, to determine if referral to a mental health professional for more comprehensive assessment was warranted.

For research or policy applications, however, it could be argued that optimising specificity is desirable in order not to over-detect cases and thereby inflate prevalence.
rates of psychological morbidity. This is important because decisions about the allocation of limited health care resources are based, in part, on the magnitude of a given problem. In this context, our study found that a cut-off score of ≥4 on the DT resulted in a false positive rate of less than 20% for each outcome, and yet the false negative rate was high, with up to 33% of HADS cases misclassified as non-cases by the DT. Some clinical settings may choose to optimise specificity if there is limited capacity to follow up people identified as possible cases using a lower threshold.

Overall, the DT demonstrated a high level of precision in identifying non-cases of psychological morbidity, with NPV ranging from 77% to 99% for all possible DT thresholds. Using the balanced cut-off score of ≥3, at least 92% of survivors identified by the DT as non-cases of anxiety, depression or comorbid anxiety-depression were also identified as such by the HADS. These data corroborate evidence\(^\text{19}\) suggesting that a strength of the DT is its ability to rule out psychological morbidity. These findings, in conjunction with the brevity and ease of scoring the DT, support the conclusion reached by others\(^\text{19, 35}\) that the DT may be most useful as the first-stage screening instrument for identifying the large number of non-cases of psychological morbidity in a two-stage screening process.

Our study is one of the largest to investigate the sensitivity and specificity of the DT among a diverse population-based sample of survivors in the early stages of survivorship. While our findings provide support for the DT as a first-stage screening tool in this population, the accuracy of the tool is only one of several criteria that need to be fulfilled prior to implementing a screening program. One of the key principles
underpinning screening is evidence that the early detection and treatment of the condition leads to better outcomes than finding and treating it later when signs or symptoms present.\textsuperscript{15} Given the mixed evidence to date,\textsuperscript{36} well-designed studies of the effectiveness of distress screening programs among those diagnosed with cancer are urgently needed.

**Limitations**

The study response rate of 41\% may raise concerns about the generalisability of the findings. While the sample was representative of the population from which it was drawn in terms of age and gender, it is possible that the most distressed survivors may not have consented to participate. This may have contributed to the low PPV found in the current study, given that this value is directly proportional to the prevalence of the outcome of interest. The HADS was the only criterion measure of anxiety and depression used, with a subscale cut-off score of $\geq 8$ to identify cases. Although one of the most commonly used short screening measures, recent reviews\textsuperscript{21, 30, 33} have revealed a lack of consistency in HADS cut-off scores, compared to clinical assessments, to identify cases. If we had used the HADS subscale cut-off score of $\geq 11$ to identify cases, the sensitivity of the DT at each possible threshold would be higher, but the specificity would be lower. Although not possible in the current study, future research should examine the optimal DT threshold against a ‘gold standard’ clinical interview in this population. This would assist health care professionals in the selection of the most appropriate screening tool and the most appropriate threshold to use in their settings. For all participants, the DT was presented first and the HADS second, which may have had an effect on responses. Ideally, a cross-over design would be used.
to negate any order effect of survey administration; however, this was not possible in
the current study as the two instruments were included within a scannable booklet.

CONCLUSIONS

Compared to the HADS, the DT performed well in discriminating between cases and
non-cases of anxiety, depression and comorbid anxiety-depression among cancer
survivors in the late treatment to early survivorship phase of care. While appropriate
for detecting cases of comorbid anxiety-depression, our findings did not support the
recommended DT cut-off score of ≥4 to identify cases of anxiety and depression in this
population. Our results suggest that the optimal DT threshold varies according to the
use of the instrument, with a cut-off score of ≥2 best for clinical use, ≥4 best for
research use, and ≥3 the best balance between sensitivity and specificity. The high
level of precision in correctly identifying survivors who were non-cases indicates that
the DT may best serve to initially rule out the substantial number of survivors who are
not cases on anxiety, depression or comorbid anxiety-depression, as part of a two-
stage screening process. Future research should evaluate the performance of the DT
against ‘gold standard’ clinical interviews with cancer survivors.
REFERENCES


Brief assessment of adult cancer survivors’ perceived needs: Development and validation of the 34-item Supportive Care Needs Survey (SCNS–SF34)

The assessment of unmet supportive care needs is an alternative approach to psychological morbidity for examining the psychosocial impact of cancer. Unmet supportive care needs are those physical, emotional, social, psychological, informational, spiritual and practical issues with which individuals perceive they require additional services or care in order to achieve optimal wellbeing. This paper reports the application of classical test theory to develop and validate a shortened version of the commonly used Supportive Care Needs Survey (SCNS) to enhance its clinical and research utility.

Brief assessment of adult cancer patients’ perceived needs: Development and validation of the 34-item Supportive Care Needs Survey (SCNS–SF34)

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ABSTRACT

Objective: This study aimed to develop and validate a short version of the Supportive Care Needs Survey (SCNS) that would reduce respondent burden and could be used in routine cancer care, without compromising the psychometric properties of the original instrument.

Methods: Secondary analyses of the data from two studies (n=888 and n=250) were undertaken. All 59 items of the original SCNS were assessed using psychometric analyses and evaluated for clinical utility. The 34 items retained were examined for internal consistency, ceiling and floor effects, known-groups validity, convergent validity, sensitivity and readability.

Results: The 34-item instrument has five factors (psychological, health system and information, physical and daily living, patient care and support, and sexuality needs) identical to the original instrument, explaining 73% of the variance. Internal consistency was high, with Cronbach’s alpha coefficients for the five factors ranging from 0.86 to 0.96. Correlations of the 34-item short-form SCNS (SCNS–SF34) with three other measures of psychosocial wellbeing demonstrated convergent validity (r=0.48–0.56). Kappa coefficients of at least 0.83 for each domain indicated almost perfect agreement between the 34-item and 59-item surveys to identify patients needing help. The 34-item SCNS maintained the psychometric properties of the original instrument and could be readily comprehended by people with seventh to eighth grade education.

Conclusions: The SCNS–SF34 is a valid instrument for measuring cancer patients’ perceived needs across a range of domains, and could be utilised as part of routine cancer care.
INTRODUCTION

Morbidity in cancer patients has been estimated using a number of different strategies, including the assessment of quality of life and satisfaction with care and, more recently, needs assessment. In contrast to other approaches, needs assessment does not infer that a patient must want help if s/he experiences an issue at an elevated level. By directly measuring patients’ own perceptions of their need for help on given issues, as well as the magnitude of their desire for help in dealing with those needs, finite health care resources can be allocated to those issues patients themselves have identified as most needing help with.

The long-form Supportive Care Needs Survey (SCNS–LF59) is a 59-item self-administered instrument designed to measure the perceived needs of adults diagnosed with cancer. The SCNS–LF59 measures unmet needs within the defined period of the past month, across five factor-analytically-derived domains: psychological, health system and information, physical and daily living, patient care and support, and sexuality needs. It assesses whether issues of need have been experienced, which of the issues experienced remain unmet needs, and the magnitude of such needs, on a five-point response scale (1 = no need, not applicable; 2 = no need, satisfied; 3 = low need; 4 = moderate need; 5 = high need). A standardised Likert summated score with values ranging from 0 to 100 can be calculated for each domain, with a higher score reflecting a higher level of need.
Although the SCNS–LF59 has acceptable content validity, construct validity and internal reliability,\textsuperscript{2} its correlation with other external measures of a related concept and test-retest reliability have not been determined. The SCNS–LF59 takes approximately 20 minutes to complete and can be understood by people with a reading level of fifth grade. More details on the development and assessment of the survey’s psychometric properties can be found in a previous publication.\textsuperscript{2}

A guide to the administration, scoring and analysis of the Supportive Care Needs Survey (SCNS) has been produced to assist in the standardised analysis of SCNS data.\textsuperscript{3} The first in a series of reference values has also been produced to assist SCNS users in the interpretation of their data,\textsuperscript{4} although cut-points have not yet been established for categorising SCNS domain scores as high, moderate or low. A number of supplementary modules have been developed for use in conjunction with the core SCNS and provide detailed information about perceived needs specific to cancer type, stage of disease and type of treatment.

To date, the SCNS–LF59 has predominantly been used in descriptive research studies to identify cancer patients’ broad domains of need, as well as the specific issues faced by different groups of cancer patients.\textsuperscript{5-9} Although the high survey completion rates achieved in these studies suggest that cancer patients are willing to complete a survey of this magnitude, its length limits its utility in the clinical setting. As noted by Higginson and Carr,\textsuperscript{10} measures developed for research often cannot be easily used in clinical practice because they are not simple and quick to complete. A recent review of
needs assessment tools, including the SCNS–LF59, found that respondent burden was
generally considerable for those tools that reported on it.¹

Given patients’ reported preference for the SCNS over other health-related quality of
life questionnaires,¹¹ our aim was to develop and validate a short form of the SCNS
that would reduce respondent burden and be useful in routine clinical practice,
without compromising the psychometric strengths of the original instrument.

METHODS

A secondary analysis of the data from two studies was undertaken. The Supportive
Care Review was conducted in 1995 and assessed the supportive care needs of 888
adult cancer patients, using the SCNS–LF59.⁵ Given the large sample size, the data for
half the sample were randomly selected to perform the item reduction process
(n=444), and the other half was used to carry out the validation process (n=444). Table
5.1 presents the characteristics of the study populations. There were no significant
differences between these two subsamples in terms of gender (p=0.09), age (p=0.64)
and primary cancer type (p=0.98). Unpublished baseline data collected from the first
250 participants in the Cancer Survival Study was used to test the convergent validity
of the short-form SCNS against other validated instruments of psychosocial wellbeing.
The Cancer Survival Study is a population-based longitudinal study assessing the
psychosocial wellbeing of cancer patients diagnosed with the eight most incident
cancers in Australia, using the 34-item short-form SCNS (SCNS–SF34), Distress
Thermometer (DT),¹² Hospital Anxiety and Depression Scale (HADS)¹³ and Quality of
Life Questionnaire – Core 30 (QLQ-C30). Subjects provided informed consent to participate in the studies, as approved by the relevant Human Research Ethics Committees.

Table 5.1: Characteristics of patients involved in the item reduction and validation procedure

<table>
<thead>
<tr>
<th></th>
<th>Sample 1: Item reduction (N=444)</th>
<th>Sample 2: Validation (N=444)</th>
<th>Sample 3: Convergent validity (N=250)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>189 (43)</td>
<td>168 (38)</td>
<td>161 (64)</td>
</tr>
<tr>
<td>Female</td>
<td>228 (51)</td>
<td>256 (58)</td>
<td>89 (36)</td>
</tr>
<tr>
<td><strong>Age (years)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤50</td>
<td>109 (25)</td>
<td>99 (22)</td>
<td>31 (12)</td>
</tr>
<tr>
<td>51–60</td>
<td>94 (21)</td>
<td>94 (21)</td>
<td>56 (22)</td>
</tr>
<tr>
<td>61–70</td>
<td>110 (25)</td>
<td>126 (28)</td>
<td>104 (42)</td>
</tr>
<tr>
<td>≥70</td>
<td>131 (30)</td>
<td>125 (28)</td>
<td>59 (24)</td>
</tr>
<tr>
<td><strong>Primary cancer type</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast</td>
<td>137 (31)</td>
<td>139 (31)</td>
<td>14 (6)</td>
</tr>
<tr>
<td>Colorectal</td>
<td>74 (17)</td>
<td>70 (16)</td>
<td>21 (8)</td>
</tr>
<tr>
<td>Prostate</td>
<td>39 (9)</td>
<td>35 (8)</td>
<td>82 (33)</td>
</tr>
<tr>
<td>Lung</td>
<td>31 (7)</td>
<td>32 (7)</td>
<td>23 (9)</td>
</tr>
<tr>
<td>Other</td>
<td>137 (31)</td>
<td>142 (32)</td>
<td>110 (44)</td>
</tr>
</tbody>
</table>

**Item reduction**

The purpose of this process was to select the subset of items that most accurately measured cancer patients’ perceived needs and were the most useful in the clinical setting. The 59 items of the SCNS were subjected to an exploratory factor analysis,
resulting in five factors identical to the domains of need of the original SCNS. Items with a primary factor loading >0.70 and an item-to-total-score correlation within their domain coefficient ≥0.65 for two domains (daily living, sexuality) and ≥0.75 for three domains (psychological, health system and information, patient care and support) were identified. Although somewhat arbitrary, these cut-points were selected as a means of identifying the most consistent items within a domain. The frequency distribution of each item was also examined to avoid the selection of items where more than 50% of respondents chose either the highest (ceiling effect) or lowest (floor effect) response category. The three authors reviewed the results of the statistical analysis and selected 34 items based on a combination of clinical relevance and statistical evidence. A minimum of three items per domain were selected to ensure stability of the domain.\textsuperscript{15}

**Validation**

In order to test the construct validity of the 34 items selected for the short-form SCNS, a confirmatory factor analysis with five factors specified was conducted. Items were attributed to the factor with the highest loading, and the proportion of the variance explained by the factor structure calculated. The internal reliability of each factor was assessed using Cronbach’s alpha and item-to-total-score correlations. In keeping with recommended guidelines, a minimum alpha coefficient of 0.7 and correlation coefficient of 0.4 was required to demonstrate that the items in each domain measured a common attribute.\textsuperscript{16}
Known-groups validity was tested by comparing the standardised Likert summated mean scores for each SCNS domain between patients in remission and those not in remission. We expected patients not in remission to have higher mean scores on the psychological, health system and information, physical and daily living, and patient care and support domains than patients in remission. We did not expect any differences in mean scores on the sexuality domain between the two groups.

Convergent validity was assessed by correlating the short-form SCNS with other validated measures of psychosocial wellbeing. The correlations between the total number of moderate or high unmet needs and the score on the DT, the anxiety and depression subscales of the HADS, and the global health status scale of the QLQ–C30 were calculated. Moderate positive correlations between 0.30 and 0.70 would indicate convergent validity of the short-form SCNS with the DT and HADS, while moderate negative correlations between -0.30 and -0.70 would indicate convergent validity with the QLQ–C30.

As an indicator of sensitivity, the ability of the short-form survey to detect patients with moderate or high needs was compared to the long-form survey. For each SCNS domain, the proportion of patients identified in the short-form survey as having at least one item of moderate or high need in that domain was calculated and compared to the proportion of patients identified in the long-form survey as having at least one item of moderate or high need in that domain. To assess the levels of agreement between the two surveys, simple Kappa coefficients and the proportion of exact agreement were calculated for each domain. Kappa values of 0.41–0.6 would indicate
moderate agreement, 0.61–0.8 substantial agreement and 0.81–1.0 almost perfect agreement.\textsuperscript{17}

Readability was assessed using the Flesch–Kincaid Grade Level test, with the aim of achieving a reading grade score of 7–8.

**RESULTS**

**Item reduction**

The exploratory factor analysis procedure identified 20 items that achieved both a factor loading of at least 0.70 and an item-to-total correlation meeting the specified cut-points for their domains. Six additional items were selected on the basis that their item-to-total correlation within their domains exceeded the specified cut-points for their domains, and their factor loadings were relatively high (0.51–0.69). Four additional items were selected on the basis of their relatively high factor loadings (0.64–0.74) and their clinical importance. Four items were selected solely on the basis of their clinical importance. None of the selected 34 items showed ceiling or floor effects.

**Validation**

Confirmatory factor analysis identified five factors representing constructs identical to the original SCNS. These factors together accounted for 73% of the total variance. Ten items fell into the ‘psychological’ domain, 11 into the ‘health system and information’ domain, five into the ‘physical and daily living’ domain, five into the ‘patient care and
support’ domain and three into the ‘sexuality’ domain. The items and their primary factor loadings are displayed in Table 5.2.

**Table 5.2: Factor categories and item primary factor loadings**

<table>
<thead>
<tr>
<th>Factor</th>
<th>Item</th>
<th>Loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological</td>
<td>Anxiety</td>
<td>75</td>
</tr>
<tr>
<td></td>
<td>Feeling down or depressed</td>
<td>78</td>
</tr>
<tr>
<td></td>
<td>Feelings of sadness</td>
<td>80</td>
</tr>
<tr>
<td></td>
<td>Fears about the cancer spreading</td>
<td>77</td>
</tr>
<tr>
<td></td>
<td>Worry that the results of treatment are beyond your control</td>
<td>77</td>
</tr>
<tr>
<td></td>
<td>Uncertainty about the future</td>
<td>77</td>
</tr>
<tr>
<td></td>
<td>Learning to feel in control of your situation</td>
<td>74</td>
</tr>
<tr>
<td></td>
<td>Keeping a positive outlook</td>
<td>69</td>
</tr>
<tr>
<td></td>
<td>Feelings about death and dying</td>
<td>69</td>
</tr>
<tr>
<td></td>
<td>Concerns about the worries of those close to you</td>
<td>63</td>
</tr>
<tr>
<td>Health systems</td>
<td>Being given written information about the important aspects of your care</td>
<td>78</td>
</tr>
<tr>
<td>&amp; information</td>
<td>Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home</td>
<td>78</td>
</tr>
<tr>
<td></td>
<td>Being given explanations of those tests for which you would like explanations</td>
<td>85</td>
</tr>
<tr>
<td></td>
<td>Being adequately informed about the benefits and side-effects of treatments before you choose to have them</td>
<td>84</td>
</tr>
<tr>
<td></td>
<td>Being informed about your test results as soon as feasible</td>
<td>84</td>
</tr>
<tr>
<td></td>
<td>Being informed about cancer which is under control or diminishing (i.e. remission)</td>
<td>81</td>
</tr>
<tr>
<td></td>
<td>Being informed about things you can do to help yourself to get well</td>
<td>78</td>
</tr>
<tr>
<td></td>
<td>Having access to professional counselling (e.g. psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it</td>
<td>64</td>
</tr>
<tr>
<td></td>
<td>Being treated like a person not just another case</td>
<td>75</td>
</tr>
<tr>
<td></td>
<td>Being treated in a hospital or clinic that is as physically</td>
<td>79</td>
</tr>
<tr>
<td>Factor</td>
<td>Item</td>
<td>Loading</td>
</tr>
<tr>
<td>----------------------------</td>
<td>----------------------------------------------------------------------</td>
<td>---------</td>
</tr>
<tr>
<td></td>
<td>pleasant as possible</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Having one member of hospital staff with whom you can talk about all aspects of your condition, treatment and follow-up</td>
<td>76</td>
</tr>
<tr>
<td>Patient care and support</td>
<td>More choice about which cancer specialists you see</td>
<td>77</td>
</tr>
<tr>
<td></td>
<td>More choice about which hospital you attend</td>
<td>81</td>
</tr>
<tr>
<td></td>
<td>Reassurance by medical staff that the way you feel is normal</td>
<td>57</td>
</tr>
<tr>
<td></td>
<td>Hospital staff attending promptly to your physical needs</td>
<td>58</td>
</tr>
<tr>
<td></td>
<td>Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs</td>
<td>58</td>
</tr>
<tr>
<td>Physical and daily living</td>
<td>Pain</td>
<td>68</td>
</tr>
<tr>
<td></td>
<td>Lack of energy/tiredness</td>
<td>71</td>
</tr>
<tr>
<td></td>
<td>Feeling unwell a lot of the time</td>
<td>68</td>
</tr>
<tr>
<td></td>
<td>Work around the home</td>
<td>74</td>
</tr>
<tr>
<td></td>
<td>Not being able to do the things you used to do</td>
<td>73</td>
</tr>
<tr>
<td>Sexuality</td>
<td>Changes in sexual feelings</td>
<td>89</td>
</tr>
<tr>
<td></td>
<td>Changes in your sexual relationships</td>
<td>86</td>
</tr>
<tr>
<td></td>
<td>To be given information about sexual relationships</td>
<td>77</td>
</tr>
</tbody>
</table>

As shown in Table 5.3, the 34-item SCNS achieved high internal consistency, as demonstrated by Cronbach’s alpha coefficients for the five factors ranging from 0.86 to 0.96. Item-to-total-score correlation coefficients for all items exceeded 0.55. For each domain, less than 50% of respondents achieved either the highest (100) or lowest score (0).
Table 5.3: Cronbach alpha reliability coefficient and response distribution for each domain of the SCNS–SF34

<table>
<thead>
<tr>
<th>Domain</th>
<th>Alpha</th>
<th>Mean score (0–100)</th>
<th>Median</th>
<th>SD</th>
<th>% lowest score (floor)</th>
<th>% highest score (ceiling)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological</td>
<td>0.95</td>
<td>39.1</td>
<td>35.0</td>
<td>29.1</td>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td>(n=414)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health information</td>
<td>0.96</td>
<td>39.0</td>
<td>29.4</td>
<td>29.0</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>(n=404)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daily living</td>
<td>0.86</td>
<td>36.6</td>
<td>30.6</td>
<td>26.6</td>
<td>11</td>
<td>1</td>
</tr>
<tr>
<td>(n=410)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient care</td>
<td>0.90</td>
<td>25.3</td>
<td>25.0</td>
<td>24.0</td>
<td>22</td>
<td>2</td>
</tr>
<tr>
<td>(n=406)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sexuality</td>
<td>0.90</td>
<td>22.6</td>
<td>16.7</td>
<td>27.1</td>
<td>42</td>
<td>3</td>
</tr>
<tr>
<td>(n=397)</td>
<td></td>
<td></td>
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</tbody>
</table>

As shown in Table 5.4, cancer patients not in remission had significantly higher mean scores on the psychological, health system and information, physical and daily living, and patient care and support domains than patients in remission. Given that higher scores indicate higher levels of need, patients not in remission showed higher levels of perceived need than patients in remission, in the domains expected.
Table 5.4: Mean domain scores on the SCNS–SF34 for patients not in remission compared to those in remission

<table>
<thead>
<tr>
<th>Domain</th>
<th>Not in remission</th>
<th></th>
<th></th>
<th>In remission</th>
<th></th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>mean</td>
<td>SD</td>
<td>n</td>
<td>mean</td>
<td>SD</td>
</tr>
<tr>
<td>Psychological</td>
<td>256</td>
<td>45.2</td>
<td>29.2</td>
<td>145</td>
<td>30.2</td>
<td>26.3</td>
</tr>
<tr>
<td>Health information</td>
<td>243</td>
<td>43.8</td>
<td>29.4</td>
<td>145</td>
<td>32.3</td>
<td>27.4</td>
</tr>
<tr>
<td>Daily living</td>
<td>251</td>
<td>42.0</td>
<td>26.7</td>
<td>144</td>
<td>28.7</td>
<td>23.7</td>
</tr>
<tr>
<td>Patient care</td>
<td>250</td>
<td>28.3</td>
<td>25.4</td>
<td>142</td>
<td>20.6</td>
<td>20.8</td>
</tr>
<tr>
<td>Sexuality</td>
<td>244</td>
<td>23.8</td>
<td>28.4</td>
<td>139</td>
<td>20.9</td>
<td>24.9</td>
</tr>
</tbody>
</table>

Convergent validity was confirmed by significant correlations between the 34-item SCNS and the HADS subscales, DT and QLQ–C30 global health status subscale. As expected, the correlation coefficients between the SCNS and the anxiety \((r=0.48)\) and depression \((r=0.48)\) subscales of the HADS and the DT \((r=0.56)\) were moderate. The correlation coefficient for the QLQ–C30 global health status score was -0.51. All four correlations were statistically significant \((p<0.0001)\).

Table 5.5 shows for each domain the proportion of patients identified by the short-form and long-form SCNS as having some need for help, as well as the overall level of agreement between the two surveys in identifying people with at least one item of unmet need. For each domain, the kappa coefficients indicated almost perfect agreement in the proportion of patients identified as having some need for help according to the 34-item SCNS, compared to the long-form survey.
Table 5.5: Proportion of patients identified as having at least one moderate or high need for help by the SCNS–SF34 compared to the SCNS–LF59

<table>
<thead>
<tr>
<th>Domain</th>
<th>SCNS–SF34 (n=444)</th>
<th>SCNS–LF59 (n=444)</th>
<th>% exact agreement</th>
<th>Kappa coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological</td>
<td>53%</td>
<td>59%</td>
<td>94</td>
<td>0.88</td>
</tr>
<tr>
<td>Health information</td>
<td>43%</td>
<td>44%</td>
<td>99</td>
<td>0.98</td>
</tr>
<tr>
<td>Daily living</td>
<td>47%</td>
<td>51%</td>
<td>94</td>
<td>0.83</td>
</tr>
<tr>
<td>Patient care</td>
<td>22%</td>
<td>29%</td>
<td>96</td>
<td>0.92</td>
</tr>
<tr>
<td>Sexuality</td>
<td>15%</td>
<td>15%</td>
<td>100</td>
<td>1.00</td>
</tr>
</tbody>
</table>

A Flesch–Kincaid Grade Level of 7.2 indicated that the 34-item SCNS could be readily comprehended by people with seventh grade level of education, that is, approximately 8 years of schooling. The 34-item SCNS takes approximately 10 minutes to complete.

**DISCUSSION**

We developed a short form of the SCNS to use in routine clinical practice and undertook the first steps in validating it. The results of these preliminary analyses suggest that the SCNS–SF34 may be a valid tool for assessing the needs of people with cancer. The 34-item survey measures the same constructs as the original SCNS: psychological, health system and information, patient care and support, physical and daily living, and sexuality needs. The factor structure of the short-form survey explained more than 70% of the variance, thereby demonstrating good construct validity. The internal consistency of the short-form survey was comparable to its longer version, with Cronbach alpha coefficients exceeding 0.8 in all domains, and item-to-total-score correlation coefficients for all items exceeding 0.55. The results also
suggest that the short-form survey was able to distinguish between groups with known differences. A comparison of mean domain scores showed that patients not in remission had higher levels of psychological, health system and information, physical and daily living, and patient care and support needs than patients in remission. Furthermore, the instrument could be readily understood by people with an average level of education. Given the large sample size used for these analyses, we are confident that the 34 items will be useful in assessing needs for a wide spectrum of cancer patients in the clinical setting.

Results from preliminary analyses suggest that the short-form SCNS has good convergent validity with other validated instruments measuring similar constructs. The total number of unmet SCNS needs correlated moderately with three widely used valid and reliable measures of cancer-specific psychosocial wellbeing: the DT, HADS and QLQ–C30.

The cross-sectional nature of the Supportive Care Review data set did not allow us to test the ability of the SCNS–SF34 to detect changes in individual cancer patients’ needs. Furthermore, we have not yet determined what constitutes a meaningful change in level of need. When completed, our longitudinal Cancer Survival Study will be a useful data source for filling the gaps regarding further psychometric properties of the SCNS–SF34. Further testing of the instrument is required to examine other measurement properties, including test-retest reliability and the ability of the instrument to predict future health status or events such as survival time.
These results provide early evidence for the construct validity and criterion validity of the 34-item SCNS in assessing the perceived supportive care needs of people diagnosed with cancer. This short-form survey was primarily developed to facilitate the routine assessment of cancer patients’ needs in the clinical setting. Importantly, the 34-item SCNS showed almost perfect agreement in the proportion of patients identified as having some need for help, compared to the long-form survey. Providing brief and valid information about cancer patients’ needs could enable health care professionals to tailor their care to the specific needs identified by their patients.
REFERENCES


PAPER 5

Prevalence and correlates of cancer survivors’ supportive care needs
6 months after diagnosis: A population-based cross-sectional study

A key strength of needs assessment is that it enables resources to be focused on the issues that survivors have expressed they want help with in order to achieve optimal wellbeing. This paper utilizes the SCNS-SF34 measure developed in the previous paper to examine the prevalence and correlates of survivors’ supportive care needs six months after diagnosis.

This paper was published in the journal BMC Cancer [Appendix 5.1].

Prevalence and correlates of cancer survivors’ supportive care needs 6 months after diagnosis: A population-based cross-sectional study

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ABSTRACT

**Background:** An understanding of the nature and magnitude of the impact of cancer is critical to planning how best to deliver supportive care to the growing population of cancer survivors whose need for care may span many years. This study aimed to describe the prevalence of and factors associated with ‘moderate to high’ level unmet supportive care needs among adult cancer survivors six months after diagnosis.

**Methods:** A population-based sample of adult cancer survivors diagnosed with one of the eight most incident cancers in Australia was recruited from two state-based cancer registries. Data for 1323 survivors were obtained by self-report questionnaire and linkage with cancer registry data. Unmet needs were assessed by the 34-item Supportive Care Needs Survey (SCNS–SF34). The data were examined using chi-square and multiple logistic regression analyses.

**Results:** A total of 444 (37%) survivors reported at least one ‘moderate to high’ level unmet need, and 496 (42%) reported ‘no need’ for help. ‘Moderate to high’ level unmet needs were most commonly reported in the psychological (25%) and physical aspects of daily living (20%) domains. The five most frequently endorsed items of ‘moderate to high’ unmet need were concerns about the worries of those close to them (15%), fears about the cancer spreading (14%), not being able to do the things they used to do (13%), uncertainty about the future (13%) and lack of energy/tiredness (12%). Survivors’ psychological characteristics were the strongest indicators of unmet need, particularly caseness for anxious preoccupation coping which was associated (OR=2.2–5.9) with unmet need for help across all domains.
**Conclusions**: Unmet supportive care needs are prevalent among a subgroup of survivors transitioning from active treatment to survivorship, although lower than previously reported. In addition to coping support, valuable insight about how to prevent or address survivors’ unmet needs could be gained by examining the substantial proportion of survivors who report no unmet needs.
INTRODUCTION

Cancer is increasingly recognised as a chronic illness, with the number of people living with a history of the disease expected to triple to 75 million people worldwide in 2030.\textsuperscript{1} While most survivors adjust well over time,\textsuperscript{2} a minority are at risk of adverse physical,\textsuperscript{3, 4} psychological\textsuperscript{5, 6} and social\textsuperscript{7, 8} effects which may emerge soon after diagnosis and treatment, or in the ensuing years. Detailed knowledge about the issues faced by survivors, their care and support needs, and the extent to which these are met by current services is critical to guiding where to focus limited health care resources in order to deliver care that is responsive to the needs of the growing population of cancer survivors.

There are a number of different approaches for more fully understanding survivors’ cancer experiences and quantifying their outcomes, including assessment of quality of life, satisfaction with health care, and needs assessment.\textsuperscript{9, 10} Needs assessment not only identifies needs and their importance as perceived by the survivor, but also the extent to which they are met.\textsuperscript{10} The key strength of this approach is that it enables resources to be focused on the issues that survivors have expressed they want addressed in order to achieve optimal wellbeing.

Increasing interest in the application of needs assessment to cancer care has resulted in the development of a number of valid and reliable cancer-specific tools assessing a comprehensive range of needs,\textsuperscript{9, 11} and a growing literature describing their administration across a variety of settings, stages in the cancer journey, and
populations. A recent systematic review found that while the prevalence of unmet need among cancer survivors varied from 30% to 50% across studies, it is typically highest in the psychological, health information, and physical aspects of daily living domains.\textsuperscript{12} While evidence about the factors that influence survivors’ unmet needs is inconsistent, a number of studies have found that those who are not in remission,\textsuperscript{13-15} are psychologically distressed\textsuperscript{14, 16-18} and geographically isolated\textsuperscript{15, 19} are more likely to report unmet needs. However, the literature is plagued by a lack of consistency in the methods used to measure, classify and report unmet needs, making it difficult to compare studies and to generalise findings.\textsuperscript{12}

The seminal publication, \textit{From Cancer Patient to Cancer Survivor: Lost in Transition},\textsuperscript{20} focused the attention of the cancer control community on the survivorship stage of the cancer trajectory, with a series of recommendations to accelerate progress in this area, including the need for large-scale studies using valid and reliable measures with diverse cancer populations to be conducted as a priority. Furthermore, a recent review\textsuperscript{21} identified unmet supportive care needs as one of four main gaps in knowledge about the problems faced by adult cancer survivors. To guide care planning and help inform future health service delivery, the current study aimed to (1) describe the prevalence of adult cancer survivors’ supportive care needs, overall and by cancer type, at six months post-diagnosis, (2) identify the most prevalent items of ‘moderate to high’ level unmet need and (3) identify the individual, disease, health behaviour, psychological and social factors associated with survivors reporting ‘moderate to high’ level unmet psychological, health systems and information, physical and daily living, patient care and support, and sexuality needs.
METHODS

This paper is based on Time 1 (T1) data collected at six months post-diagnosis from survivors participating in the population-based longitudinal Cancer Survival Study. The study protocol and aspects of the study findings have been reported in detail elsewhere.\textsuperscript{22,23} While the term, cancer ‘survivor’, has varied definitions,\textsuperscript{24} this study considers ‘survivor’ to encompass anyone diagnosed with cancer, from the time of diagnosis to the end of life.\textsuperscript{25} This paper focuses on survivors in the late treatment to early survivorship phase of the cancer continuum.

Participants and procedures

The sample was recruited from new notifications to the two largest state-based cancer registries in Australia, which together account for 60\% of all new cancer cases diagnosed.\textsuperscript{26} Eligibility was restricted to those who were (1) diagnosed in the previous six months with their first primary cancer of one of the top eight incident cancer types in Australia (prostate, colorectal, female breast, lung, melanoma, non-Hodgkin’s lymphoma, leukaemia, head and neck), (2) aged between 18 and 80 years and living in the state of New South Wales (NSW) or Victoria (VIC) at diagnosis, (3) considered by their physicians to be aware of their diagnosis, physically and mentally capable of participating in the study, and sufficiently proficient in English to complete a questionnaire, and (4) alive.

The recruitment and survey methodology have been described in detail previously.\textsuperscript{22} Briefly, eligible potential participants whose physicians had given active (NSW) or
passive (VIC) consent for them to be contacted about the study received a mailed package from the registries. Eligible survivors who agreed to the registries passing on their contact details to the researchers were sent a self-administered questionnaire to complete. Non-responders were sent a reminder questionnaire three weeks later and received a reminder telephone call after a further three weeks. A three-week interval was used to allow adequate time for survivors to receive, respond to and return the mailed questionnaire prior to receiving a reminder. Return of the questionnaire to the research team indicated voluntary consent to participate. The Human Research Ethics Committees of the University of Newcastle (H-199-1101), Cancer Institute NSW and Cancer Council Victoria approved the study.

Measures

Data were collected by self-administered questionnaire, with additional clinical information obtained from the Cancer Registries for each participant.

Outcome measure

Supportive care needs were measured by the 34-item Supportive Care Needs Survey (SCNS–SF34) which assesses cancer-specific perceived needs across five factor-analytically-derived domains: psychological (10 items); health systems and information (11 items); patient care and support (5 items); physical and daily living (5 items); and sexuality (3 items). For each item, respondents indicate their level of need for help over the last month as a result of having cancer, on a five-point Likert scale with the following response options: 1 = no need, not applicable; 2 = no need, satisfied; 3 = low need; 4 = moderate need; and 5 = high need. For each domain, survivors were
categorised as having a ‘moderate to high’ level of need if they selected response options 4 or 5 for at least one item in the domain, and ‘no to low’ need if they selected response options 1, 2 or 3 to all items in the domain. The SCNS–SF34 has high internal consistency, with Cronbach’s alpha of at least 0.86 for each subscale, and is moderately correlated with the Hospital Anxiety and Depression Scale, Distress Thermometer and Quality of Life Questionnaire–Core 30 (QLQ–C30). Furthermore, cancer patients have reported a preference for the SCNS–SF34 over the QLQ–C30, Functional Assessment of Cancer Therapy–General and Kingston Needs Assessment–Cancer as a strategy for conveying their needs to health care providers.

**Study factors**

*Individual:* Age at diagnosis and sex were obtained from the cancer registries. Current marital status, highest level of education completed, health insurance coverage, current employment situation, geographical location, size of household, and presence of physical comorbidities were obtained by questionnaire.

*Disease and treatment:* Primary cancer type and spread of disease at diagnosis were obtained from the cancer registries, with survivors’ cancer categorised as ‘early/less progressed’ (*in situ* or localised; grade 1 or 2; T1 or T2), ‘late/more progressed’ (invasion of adjacent organs, regional nodes or distant metastases; grade 3 or 4; not T1) or ‘not applicable’ (haematological cancers).Extent of disease at six months post-diagnosis and cancer treatments received in the last month were obtained by questionnaire.

*Health behaviours:* Seven questionnaire items adapted from existing measures assessed health behaviours: two items assessed smoking behaviour, with participants
classified as ‘current’, ‘former’ or ‘never smoker’;\textsuperscript{30} two items assessed alcohol consumption,\textsuperscript{31} with participants who consumed more than two standard drinks on any day classified as being at ‘increased lifetime risk of harm’ from alcohol-related injury or disease,\textsuperscript{32} and three items assessed physical activity,\textsuperscript{33} with participants classified as ‘sufficiently active’ (at least 150 minutes of physical activity per week), ‘insufficiently active’ (participating in some activity but not enough in total time) or ‘sedentary’ (no physical activity).\textsuperscript{34}

\textit{Psychological:} Two questionnaire items assessed treatment for mental health illness (e.g. depression, anxiety, schizophrenia) before and since the cancer diagnosis. Coping was assessed by the 21-item Mini Mental Adjustment to Cancer Scale (Mini-MAC) which measures five cancer-specific coping strategies: helplessness-hopelessness, anxious preoccupation, fighting spirit, cognitive avoidance and fatalism.\textsuperscript{35} The Mini-MAC has demonstrated reliability, with Cronbach alpha coefficients for each subscale ranging from 0.62–0.88. Raw scores for each subscale were standardised from 0 to 100,\textsuperscript{35} and survivors who scored in the top 16% of each distribution were classified as a ‘case’ on that specific coping strategy.\textsuperscript{36}

\textit{Social:} Social support was assessed by the MOS Social Support Survey (MOS−SSS) which measures four domains of functional support: emotional/informational, tangible, affectionate, and positive social interaction.\textsuperscript{37} Raw subscale scores were standardised from 0 to 100, and survivors who scored in the bottom one-third of each distribution were classified as having ‘low’ availability of that particular type of social support (Sherbourne, personal communication). The survey has high internal consistency, with alpha coefficients exceeding 0.91 for each subscale, and demonstrated validity with the chronic illness population.\textsuperscript{37}
Statistical methods

Due to small numbers, data from survivors diagnosed with non-Hodgkin’s lymphoma or leukaemia were combined and categorised as ‘haematological’ cancer survivors. The proportions of survivors who reported either ‘no needs’ (i.e. selected response option 1 or 2 to all 34 items), ‘low needs’ (i.e. selected response option 3 to at least one item, but did not select response option 4 or 5 to any items) and ‘moderate to high needs’ (i.e. selected response option 4 or 5 to at least one item) were calculated overall and by cancer type, with 95% confidence intervals. The association between cancer type with reporting ‘no needs’, ‘low needs’ and ‘moderate to high needs’ was examined using chi-square analyses. For each domain, the proportion of survivors who reported ‘moderate to high needs’ versus ‘low or no needs’ was calculated with 95% confidence intervals. The proportion of survivors who endorsed each SCNS–SF34 item at either a ‘moderate’ or ‘high’ level was calculated with 95% confidence intervals, and the ten most prevalent items and their corresponding domains identified. Chi-square analyses examined the associations between survivors’ individual, disease, health behaviour, psychological and social characteristics, with ‘moderate to high’ needs versus ‘low or no’ needs for each domain. Multiple logistic regression analyses were then conducted to examine factors associated with ‘moderate to high’ needs, while adjusting for potential confounders. Variables with a p-value ≤0.2 on univariate analyses were included in a backward logistic regression model for each domain. Variables were removed from the model if they had a p-value <0.1 on the likelihood ratio test; those with a p-value ≤0.05 were considered statistically significant.
Sample size

The registries were required to recruit a quota of 1660 eligible survivors who consented to being contacted about the study. Based on previous experience,\(^6\) we estimated that 80% of survivors would return a completed survey, resulting in a sample size of approximately 1320 at T1. Assuming a prevalence of ‘moderate to high’ needs of 20%, a sample of this size would allow the proportion of survivors with unmet needs to be estimated with 95% confidence intervals within ± 3%, and provide 90% power to detect differences of 7% between categories of study factors associated with ‘moderate to high’ needs at the 5% significance level.

RESULTS

Sample

Of the 3877 potential participants assessed for study eligibility, 3315 were deemed eligible, and of these, 1691 (51%) consented to being contacted about the study by the researchers. A total of 1360 eligible survivors returned a T1 survey (41% response rate at T1). Thirty-seven participants who returned their T1 survey more than 9 months after diagnosis were excluded from analyses. The 1323 survivors included in these analyses were surveyed at a median of 6 months after diagnosis (SD=1 month; minimum 4 months, maximum 9 months), and their median age was 63 years (SD=11 years; minimum 18 years, maximum 80 years). More than half of the participants (59%) were male, about half (52%) were diagnosed with early-stage disease, the most common diagnosis was prostate cancer (26%), almost two-thirds (62%) were in remission at the time of survey completion, and 72% had not received any active
treatment in the last month. While the study sample reflected the national profile\textsuperscript{24} for the top eight incident cancers diagnosed in 2005 in terms of gender and age, survivors of colorectal cancer appeared to be under-represented and survivors of haematological and head and neck cancers over-represented. Participant characteristics have been reported in detail elsewhere.\textsuperscript{22}

**Prevalence of supportive care needs**

As shown in Table 6.1, 496 (42%, 95% CI: 39%–45%) survivors reported ‘no need’ for help with all of the 34 items assessed. A total of 444 (37%; 95% CI: 34%–40%) survivors reported having at least one ‘moderate to high’ level unmet supportive care need, and of these, 53% (n=237) had one to four ‘moderate to high’ needs and 47% (n=207) had five or more ‘moderate to high’ needs. There was significant variation across cancer types in the percentage of survivors who reported unmet needs ($\chi^2=91.39; df=12; p<0.001$). ‘Moderate to high’ level unmet needs were most common among survivors of lung cancer, with more than half (60%; 95% CI: 51%–69%) endorsing at least one item. Conversely, almost two-thirds (65%; 95% CI: 58%–72%) of melanoma survivors reported ‘no need’ for help with all items.
Table 6.1: Prevalence of supportive care needs at six months post-diagnosis by cancer type

<table>
<thead>
<tr>
<th></th>
<th>Total* (N=1187)</th>
<th>Prostate (n=309)</th>
<th>Melanoma (n=188)</th>
<th>Breast (n=186)</th>
<th>Blood (n=164)</th>
<th>Colorectal (n=145)</th>
<th>Lung (n=108)</th>
<th>Head &amp; neck (n=87)</th>
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<tbody>
<tr>
<td></td>
<td>n</td>
<td>% (95% CI)</td>
<td>n</td>
<td>% (95% CI)</td>
<td>n</td>
<td>% (95% CI)</td>
<td>n</td>
<td>n</td>
</tr>
<tr>
<td>No needs†</td>
<td>496</td>
<td>42 (39–45)</td>
<td>134</td>
<td>43 (37–49)</td>
<td>122</td>
<td>65 (58–72)</td>
<td>56</td>
<td>33 (26–40)</td>
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<tr>
<td>Low needs‡</td>
<td>247</td>
<td>21 (19–23)</td>
<td>58</td>
<td>19 (15–23)</td>
<td>33</td>
<td>17 (12–22)</td>
<td>47</td>
<td>17 (12–22)</td>
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</tr>
<tr>
<td>Moderate to high needs§</td>
<td>444</td>
<td>37 (34–40)</td>
<td>117</td>
<td>38 (33–43)</td>
<td>33</td>
<td>17 (12–22)</td>
<td>83</td>
<td>45 (38–52)</td>
</tr>
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</tbody>
</table>

* Includes those with no missing items across all domains.
† Selected ‘no’ need for help to all 34 items.
‡ Selected ‘low’ level need for help to at least one item, but did not select ‘moderate’ or ‘high’ need to any item.
§ Selected ‘moderate’ or ‘high’ level need for help to at least one item.
At the domain level, 318 (25%; 95% CI: 23%–27%) survivors reported unmet psychological needs, 251 (20%; 95% CI: 18%–22%) reported unmet physical aspects of daily living needs, and 232 (18%; 95% CI: 16%–20%) reported unmet health systems and information needs at a ‘moderate to high’ level. Only 167 (13%; 95% CI: 11%–15%) and 103 (8%; 95% CI: 7%–9%) survivors respectively reported ‘moderate to high’ level unmet needs for help with sexuality, and patient care and support domains.

**Most prevalent ‘moderate to high’ level unmet supportive care needs**

The 10 highest ranked items that survivors reported a ‘moderate to high’ level of need for help with are shown in Table 6.2. Overall, individual items were endorsed by relatively few (≤15%) survivors. The highest ranked items were concerns about the worries of those close to you (15%), fears about the cancer spreading (14%), not being able to do the things they used to do (13%), uncertainty about the future (13%), and lack of energy/tiredness (12%). Half of the top 10 needs items were from the psychological domain, three were from the physical aspects of daily living domain and the remaining two items were from the sexuality domain.
Table 6.2: Ten most prevalent ‘moderate’ or ‘high’ level unmet supportive care needs

<table>
<thead>
<tr>
<th>Rank</th>
<th>SCNS–SF34 item</th>
<th>Number (%) moderate or high needs</th>
<th>Domain</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Concerns about the worries of those close to you</td>
<td>192 (15)</td>
<td>Psychological</td>
</tr>
<tr>
<td>2</td>
<td>Fears about the cancer spreading</td>
<td>185 (14)</td>
<td>Psychological</td>
</tr>
<tr>
<td>3</td>
<td>Not being able to do the things you used to do</td>
<td>169 (13)</td>
<td>Physical/daily living</td>
</tr>
<tr>
<td>4</td>
<td>Uncertainty about the future</td>
<td>168 (13)</td>
<td>Psychological</td>
</tr>
<tr>
<td>5</td>
<td>Lack of energy/tiredness</td>
<td>157 (12)</td>
<td>Physical/daily living</td>
</tr>
<tr>
<td>6</td>
<td>Changes in your sexual relationships</td>
<td>140 (11)</td>
<td>Sexuality</td>
</tr>
<tr>
<td>7</td>
<td>Changes in sexual feelings</td>
<td>139 (11)</td>
<td>Sexuality</td>
</tr>
<tr>
<td>8</td>
<td>Work around the home</td>
<td>137 (11)</td>
<td>Physical/daily living</td>
</tr>
<tr>
<td>9</td>
<td>Worry that the results of treatment are beyond your control</td>
<td>128 (10)</td>
<td>Psychological</td>
</tr>
<tr>
<td>10</td>
<td>Feeling down or depressed</td>
<td>120 (9)</td>
<td>Psychological</td>
</tr>
</tbody>
</table>

Total number of observations for each item ranges from 1292 to 1302 due to missing values.

Factors associated with ‘moderate to high’ level unmet needs

The individual, health behaviour, disease, treatment, psychological and social characteristics associated with survivors reporting ‘moderate to high’ level unmet needs by domain are shown in Tables 6.3–6.5. Domains are displayed side-by-side for ease of comparison.
Table 6.3: Individual and health behaviour characteristics associated with ‘moderate to high’ level unmet needs by domain*

<table>
<thead>
<tr>
<th></th>
<th>Psychological</th>
<th>Physical and daily living</th>
<th>Sexuality</th>
<th>Health system and information</th>
<th>Patient care and support</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>p-value</td>
<td>p-value</td>
<td>p-value</td>
<td>p-value</td>
<td>p-value</td>
</tr>
<tr>
<td></td>
<td>Adjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
</tr>
<tr>
<td><strong>Individual</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>0.56 (0.29–1.1)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/de facto</td>
<td>3.0 (1.6–5.6)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single/widowed</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Age at diagnosis</strong></td>
<td>0.06</td>
<td>0.002</td>
<td>0.008</td>
<td></td>
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</tr>
<tr>
<td>49 and younger</td>
<td>1.7 (0.98–2.8)</td>
<td>4.4 (1.8–10.6)</td>
<td>2.9 (1.5–5.5)</td>
<td></td>
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</tr>
<tr>
<td>50-59</td>
<td>1.1 (0.67–1.8)</td>
<td>4.3 (2.0–9.1)</td>
<td>2.5 (1.3–4.6)</td>
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</tr>
<tr>
<td>60-69</td>
<td>0.88 (0.55–1.4)</td>
<td>2.7 (1.5–5.2)</td>
<td>2.2 (1.3–3.9)</td>
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<td></td>
</tr>
<tr>
<td>70 and older</td>
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<td>1.00</td>
<td>1.00</td>
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</tr>
<tr>
<td>Current employment</td>
<td>Psychological p-value</td>
<td>Physical and daily living p-value</td>
<td>Sexuality p-value</td>
<td>Health system and information p-value</td>
<td>Patient care and support p-value</td>
</tr>
<tr>
<td>-------------------------</td>
<td>-----------------------</td>
<td>----------------------------------</td>
<td>------------------</td>
<td>---------------------------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td></td>
<td>Adjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
</tr>
<tr>
<td>Paid work</td>
<td>0.78 (0.51–1.2)</td>
<td>0.92 (0.54–1.6)</td>
<td>&lt;0.001</td>
<td>0.005</td>
<td></td>
</tr>
<tr>
<td>Not working</td>
<td>1.8 (1.2–2.8)</td>
<td>2.0 (1.1–3.4)</td>
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<tr>
<td>Retired</td>
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**Health behaviour**

<table>
<thead>
<tr>
<th>Physical activity</th>
<th>Psychological p-value</th>
<th>Physical and daily living p-value</th>
<th>Sexuality p-value</th>
<th>Health system and information p-value</th>
<th>Patient care and support p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0.05</td>
<td>&lt;0.001</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Sedentary</td>
<td>1.7 (1.1–2.7)</td>
<td>2.5 (1.6–4.0)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Insufficient</td>
<td>1.5 (0.99–2.1)</td>
<td>1.8 (1.2–2.7)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sufficient</td>
<td>1.00</td>
<td>1.00</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

* Also adjusted for disease, treatment, psychological and social characteristics, as reported in Tables 5.4–5.5.

OR = odds ratio; CI = confidence interval; p-value on the Wald chi-square analysis of effects test.
Table 6.4: Disease and treatment characteristics associated with ‘moderate to high’ level unmet needs by domain*

<table>
<thead>
<tr>
<th>Disease</th>
<th>Psychological</th>
<th>Physical and daily living</th>
<th>Sexuality</th>
<th>Health system and information</th>
<th>Patient care and support</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>p-value</td>
<td>p-value</td>
<td>p-value</td>
<td>p-value</td>
<td>p-value</td>
</tr>
<tr>
<td>Cancer status</td>
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<td></td>
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</tr>
<tr>
<td>Not remission</td>
<td>&lt;0.001</td>
<td>2.0 (1.4–2.9)</td>
<td>2.2 (1.4–3.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Remission</td>
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<td>1.00</td>
<td>1.00</td>
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<tr>
<td>Cancer type</td>
<td></td>
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</tr>
<tr>
<td>Breast</td>
<td>0.003</td>
<td>2.3 (1.1–4.6)</td>
<td>9.0 (2.5–32.2)</td>
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<tr>
<td>Colorectal</td>
<td>&lt;0.001</td>
<td>2.1 (0.97–4.5)</td>
<td>6.4 (1.7–24.3)</td>
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<td></td>
</tr>
<tr>
<td>Blood</td>
<td></td>
<td>2.2 (1.1–4.5)</td>
<td>4.3 (1.2–15.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Head and neck</td>
<td></td>
<td>1.0 (0.41–2.5)</td>
<td>1.1 (0.21–6.1)</td>
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<tr>
<td>Lung</td>
<td></td>
<td>4.1 (2.0–8.7)</td>
<td>5.8 (1.6–21.8)</td>
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<tr>
<td>Prostate</td>
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<td>1.7 (0.86–3.4)</td>
<td>23.1 (6.7–80.4)</td>
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<tr>
<td>Melanoma</td>
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<td>1.00</td>
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<td></td>
</tr>
<tr>
<td>Treatment</td>
<td>Psychological</td>
<td>Physical and daily living</td>
<td>Sexuality</td>
<td>Health system and information</td>
<td>Patient care and support</td>
</tr>
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<td>---------------</td>
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</tr>
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<tr>
<td></td>
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<td>Adjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
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<tr>
<td>No/DK</td>
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<td></td>
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<tr>
<td>Chemotherapy</td>
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<td>0.023</td>
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<td></td>
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</tr>
<tr>
<td>Yes</td>
<td>1.8 (1.2–2.8)</td>
<td>1.6 (1.1–2.5)</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>No/DK</td>
<td>1.00</td>
<td>1.00</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>0.05</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1.6 (0.99–2.7)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>No/DK</td>
<td>1.00</td>
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<tr>
<td>Other</td>
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</tr>
<tr>
<td>No/DK</td>
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</tbody>
</table>

* Also adjusted for individual, health behaviour, psychological and social characteristics, as reported in Tables 5.3 and 5.5.

OR = odds ratio; CI = confidence interval; p-value on the Wald chi-square analysis of effects test; DK = don't know.
Table 6.5: Psychological and social characteristics associated with ‘moderate to high’ level unmet needs by domain*

<table>
<thead>
<tr>
<th>Psychological</th>
<th>Physical and daily living</th>
<th>Sexuality</th>
<th>Health system and information</th>
<th>Patient care and support</th>
</tr>
</thead>
<tbody>
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<td>p-value</td>
<td>p-value</td>
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<td>Adjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
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<tr>
<td><strong>Psychological</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Anxious</strong></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>preoccupation</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
<td>&lt;0.001</td>
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<tr>
<td>Case</td>
<td>5.9 (4.0–8.7)</td>
<td>2.2 (1.5–3.2)</td>
<td>3.4 (2.2–5.3)</td>
<td>3.3 (2.2–5.1)</td>
</tr>
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<td>1.00</td>
<td>1.00</td>
<td>1.00</td>
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<tr>
<td>Helplessness-</td>
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</tr>
<tr>
<td>hopelessness</td>
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<td></td>
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<tr>
<td>Case</td>
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<td>1.7 (1.1–2.7)</td>
<td>2.3 (1.3–3.8)</td>
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</tr>
<tr>
<td><strong>Cognitive</strong></td>
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</tr>
<tr>
<td>avoidance</td>
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</tr>
<tr>
<td>Case</td>
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<td>1.5 (1.0–2.3)</td>
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<td>Sexuality p-value</td>
<td>Health system and information p-value</td>
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<td>Adjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
<td>Adjusted OR (95% CI)</td>
</tr>
<tr>
<td><strong>Mental health help</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>before cancer</strong></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2.1 (1.4–3.2)</td>
<td>1.7 (1.0–2.8)</td>
<td></td>
<td>2.5 (1.5–4.2)</td>
</tr>
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<td>1.00</td>
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<td>1.00</td>
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<td><strong>Mental health help</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td><strong>since cancer</strong></td>
<td>&lt;0.001</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2.9 (1.6–5.2)</td>
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<tr>
<td>No</td>
<td>1.00</td>
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</tr>
<tr>
<td><strong>Social</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Affectionate support</strong></td>
<td>0.020</td>
<td>0.003</td>
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</tr>
<tr>
<td>Low</td>
<td>0.47 (0.25–0.89)</td>
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<td>2.1 (1.3–3.4)</td>
</tr>
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<td>1.00</td>
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<td>0.05</td>
<td>0.014</td>
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<td>Physical and daily living</td>
<td>Sexuality</td>
<td>Health system and information</td>
</tr>
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<td>------------------------</td>
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<tr>
<td><strong>Positive social interaction</strong></td>
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<td></td>
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<tr>
<td>Low</td>
<td>1.4 (0.99–2.0)</td>
<td>1.7 (1.1–2.5)</td>
<td>2.6 (1.4–4.8)</td>
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<tr>
<td>Some</td>
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<td>1.00</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td><strong>Emotional/informational</strong></td>
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<td>0.002</td>
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<td>Some</td>
<td>1.00</td>
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</tbody>
</table>

* Also adjusted for individual, health behaviour, disease and treatment characteristics, as reported in Tables 5.3–5.4.

OR = odds ratio; CI = confidence interval; p-value on the Wald chi-square analysis of effects test.
**Individual**

Age at diagnosis and current employment status were associated with multiple domains of unmet need (see Table 6.3). The odds of reporting sexuality, and health system and information needs increased with decreasing age. Compared with those who were retired, survivors who were currently not working (on leave, student, unemployed) or doing unpaid work (volunteer, household duties) had about twice the odds of reporting physical aspects of daily living and sexuality needs as those who were retired. Age was marginally non-significantly associated with psychological need. Survivors who were married or in de facto relationships had three times the odds of unmet sexuality needs, compared with those who were single or widowed.

**Health behaviour**

Physical activity was the only health behaviour associated with ‘moderate to high’ level unmet needs (see Table 6.3). The odds of reporting unmet psychological, and physical and daily living needs increased with decreasing levels of physical activity.

**Disease and treatment**

Cancer status, cancer type and having received chemotherapy in the last month were associated with multiple domains of unmet need (see Table 6.4). Compared with survivors in remission, those not in remission (stable, recurrent, metastatic disease) had about twice the odds of unmet health system and information, and patient care and support needs. Compared with survivors of melanoma, survivors of all other cancer types except head and neck had at least four times the odds of unmet sexuality needs, while lung, breast, and haematological cancer survivors had at least two times
the odds of unmet physical and daily living needs. Survivors who received chemotherapy in the last month had higher odds of unmet psychological, and physical and daily living needs than those who did not receive chemotherapy in the last month.

**Psychological**

Coping strategy and mental health treatment were associated with multiple domains of unmet need (see Table 6.5). Survivors who engaged in anxious preoccupation coping had two to six times higher odds of reporting unmet needs across all domains, compared with survivors who did not use this coping strategy. Survivors who used helplessness-hopelessness coping had about twice the odds of reporting unmet psychological, health system and information, and patient care and support needs, compared with those who did not use this strategy, while those who used cognitive avoidance coping had higher odds of reporting unmet psychological needs, compared with those who did not use this strategy. Compared with survivors without a history of mental health treatment, those who had been treated for such problems before their cancer diagnosis had about twice the odds of unmet physical and daily living, and patient care and support needs, while those who had been treated for such problems since their cancer diagnosis had almost three times higher odds of unmet psychological needs.

**Social**

Compared with those with some affectionate support, survivors who perceived they had low levels of affectionate support had lower odds of health system and information needs and higher odds of patient care and support needs. Compared with
survivors with some positive social interaction, survivors who perceived that they had low levels of positive social interaction had higher odds of unmet sexuality, and health system and information needs. Survivors who perceived low levels of emotional/informational support also had higher odds of unmet health system and information needs (see Table 6.5).

**DISCUSSION**

This study found that six months after a cancer diagnosis, about one-third (37%) of survivors reported one or more items of moderate or high level unmet need, while almost two-thirds (63%) reported either no or low level unmet needs. The most commonly reported ‘moderate to high’ level unmet needs were from the psychological, and physical and daily living domains. This is consistent with other recent needs assessments conducted with samples of cancer survivors at the end of treatment,\(^1^7\) in early phases of survivorship\(^1^5,1^8\) and in long-term survivorship.\(^1^4,1^6\) However, previous studies\(^1^3,1^5,1^7,1^8\) found between 43% and 60% of survivors reported at least one moderate or high level unmet need, compared to 37% of survivors in this study. Similarly, unlike earlier studies which found the most prevalent item of moderate or high unmet need occurred among 27%–40% of recent survivors,\(^1^3,1^7,1^8\) the most commonly reported item of unmet need in this study was endorsed by only 15% of survivors.

The prevalence of unmet need reported by survivors in this study is clearly lower than previously reported, despite using the same validated instrument and classification of
unmet need. This may be because earlier studies of cancer survivors diagnosed with a diversity of cancer sites did not use population-based samples and are therefore more susceptible to selection bias. In contrast, we used the two largest state-based cancer registries in Australia to assemble a population-based sample of survivors in the very early stages of cancer survivorship. Given that the study sample is generally representative of the source population, we are confident in our findings that most survivors’ supportive care needs, as measured by the SCNS–SF34, are relatively well met.

Due to the size and composition of the study sample, we were able to directly compare the prevalence of supportive care needs between seven common cancer types in Australia. This bivariable analysis revealed significant variation across cancer types, with particularly low levels of unmet need reported by survivors of melanoma, 65% of whom reported no items of unmet need. This fits with our anecdotal experience whereby participants who were survivors of melanoma often questioned the legitimacy of their contribution to the study as they perceived themselves to have suffered less than survivors of other cancer types, and therefore less deserving of attention. Australia has the world’s highest incidence rate of melanoma; it is typically identified at early stages when simple treatment such as surgery will achieve a good prognosis. It is possible that the omission of melanoma survivors from the sample composition of previous studies may have contributed to their higher prevalence of unmet need, compared with this study. In contrast, the highest levels of unmet need were reported by survivors of lung cancer, with 60% reporting at least one item of moderate or high level need. Given the high level of burden associated with lung
cancer in terms of poor prognosis, treatment side-effects and declining physical health, this finding is not surprising.

Subgroups of survivors with domain-specific and widespread unmet needs were identified. After adjusting for a comprehensive range of individual, disease, health behaviour, psychological and social factors, cancer type was found to be significantly associated with ‘moderate to high’ level unmet physical and daily living, and sexuality needs only. In particular, survivors of lung cancer had the highest odds of reporting unmet physical and daily living needs, while survivors of prostate cancer had extremely high odds of reporting unmet sexuality needs. These findings suggest that the type of unmet need experienced by survivors does not routinely differ among cancer types. Rather, the notion of cancer-site-specific unmet needs appears to apply to only a few explicit dimensions of unmet need.

Consistent with previous studies, not being in remission was associated with unmet health system and information needs and patient care and support needs; this is not surprising, given that this subgroup of survivors is likely to be receiving intermittent treatment and symptom management. While almost three-quarters of survivors reported not receiving any active treatment in the last month, we did not assess whether participants had completed all active treatments, given the changeable and uncertain nature of adjuvant treatment regimes. While each treatment was considered separately, having received chemotherapy in the last month was the only treatment associated with higher odds of reporting unmet needs. Interestingly, physical activity was the only health behaviour associated with unmet needs, with sedentary survivors
reporting higher odds of unmet psychological, and physical and daily living needs. Although 37% of the sample resided in regional or remote areas, our results did not support the findings from previous studies of an association between rural location and unmet needs. On account of the range of study factors examined in this study, a number of associations were established for the first time. Low levels of social support and maladaptive coping styles were associated with multiple domains of unmet need. Notably, survivors who were identified as cases on anxious preoccupation coping had more than twice the odds of reporting unmet needs across all five domains. While causation cannot be inferred, the new associations identified in this study are particularly valuable because social support and coping style are potentially amenable to intervention. In particular, attention could be directed towards exploring the contribution that targeted coping interventions, focusing on anxiety and helplessness, could make towards the prevention of or reduction in survivors’ unmet needs across a number of domains.

**Strengths and limitations**

While previous needs assessments have also included a diversity of recent cancer survivors, the population-based sampling method used in this study is a major strength as it increases the generalisability of the results. In Australia, the notification of cancer to cancer registries is a statutory requirement under the state and territory Public Health Acts. Indices of registry data quality demonstrate that the level of case ascertainment is high and the data collected are accurate. However, the overall response rate was 41% (1360/3315 eligible individuals) and may raise concerns about response bias. While this response rate seems low, it is higher than that achieved by
other studies which also used cancer registries to recruit diverse samples of recent survivors.\textsuperscript{40,41} Survivors who were not proficient in English were excluded due to the prohibitive cost of translating the questionnaire into other languages and this may have resulted in an underestimate of the prevalence of unmet needs, given that language barriers have been associated with poorer access to health care services. Our outcome measure, the SCNS–SF34, is a well-validated tool for assessing multiple dimensions of supportive care need and was developed with diverse samples of individuals diagnosed with cancer, in terms of cancer type and time since diagnosis.\textsuperscript{27} However, it is possible that the SCNS–SF34 may not fully capture the unique needs of cancer survivors in the late treatment to early survivorship phase of care, and therefore this study may underestimate the prevalence of unmet need reported by survivors at six months post-diagnosis. Since this study commenced, two cancer-survivor-specific needs assessment tools\textsuperscript{41,42} have been developed and should be considered for use in future studies.

\textbf{CONCLUSIONS}

About one-third of cancer survivors in the transition from late treatment to early survivorship had ‘moderate to high’ levels of unmet need, particularly in the psychological and daily living domains. Our findings directly inform health care professionals and organisations involved in the provision of survivorship care about the actions, resources and services most needed by subgroups of survivors. Our findings also suggest that coping support interventions may have the potential to contribute to the prevention or reduction of survivors’ unmet needs across all domains. However, it
is important not to overlook the finding that 63% of survivors in this study reported no
or low level unmet needs at six months post-diagnosis, suggesting that current care
appears to meet their needs adequately. On the basis that a valuable new perspective
on how to prevent or reduce cancer survivors’ unmet needs could be gained from
those with no unmet needs, future research should seek to identify and better
understand this subgroup of survivors.
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INTRODUCTION

This thesis comprises five papers exploring important issues concerning the psychosocial wellbeing of survivors in the late treatment to early survivorship phase of the cancer continuum. A population-based longitudinal survey of the psychosocial wellbeing of 1360 adult cancer survivors diagnosed with one of the eight most incident cancers in Australia was undertaken. The cohort was recruited from two state-based cancer registries, and surveyed at six and twelve months post-diagnosis. Outcome measures assessed survivors’ self-reported anxiety, depression and unmet supportive care needs. The individual, disease, treatment, health behaviour, psychological and social factors associated with these outcomes were assessed by self-report and linkage with registry records.

PREVALENCE OF CANCER SURVIVORS’ PSYCHOSOCIAL OUTCOMES

Information about the extent and natural history of the psychosocial issues faced by cancer survivors is critical to informing survivors about what they can expect to experience as a consequence of cancer and its treatment, identifying gaps in care that may require new programs to be developed or existing services to be modified, and guiding the development of social policies (e.g. regarding the workplace and superannuation) that recognise and support survivors’ limitations. Information about the psychosocial impact of cancer can be formally quantified using a number of different approaches, including assessment of psychological sequelae and unmet
needs. Anxiety and depression are among the most commonly examined indicators of psychological wellbeing.\textsuperscript{2, 3} Unmet needs are issues that have caused concern and for which individuals desire help.\textsuperscript{4} Together, these outcomes provide valuable insight into the psychosocial impact of cancer on survivors.

\textbf{Prevalence and natural history of anxiety, depression and comorbid anxiety-depression among cancer survivors}

Paper 1 examined the prevalence of anxiety, depression and comorbid anxiety-depression among cancer survivors six months after diagnosis. The proportion of survivors who reported psychological morbidity was lower than expected, with only 24\% identified as cases on anxiety (irrespective of depression), 15\% as cases on depression (irrespective of anxiety) and 10\% as cases on comorbid anxiety-depression.\textsuperscript{5} Paper 2 described the natural history of survivors’ psychological wellbeing from six months to one year after diagnosis. Contrary to expectation, the point prevalence of psychological morbidity did not decrease over time. However, by tracking individual survivors’ psychological wellbeing over time, four trajectories of psychological adjustment were identified. Overall, the majority of cancer survivors demonstrated a trajectory indicative of resilience (68\%) or recovery (9\%), while small groups experienced chronic (14\%) or late (9\%) psychological morbidity.

Collectively, the findings of Papers 1 and 2 indicate that while a small but important group of cancer survivors suffer psychological morbidity in the early stages of survivorship, the majority adjust well. These data refute the notion of cancer as a
disease of enduring psychological impairment, and suggest that for most survivors, their existing resources (e.g. coping strategies and social support) and/or current services (e.g. counselling) assist them to manage psychological difficulties before they escalate to clinically significant levels and/or become chronic. While psychological morbidity and unmet needs have been shown to be positively correlated, Papers 1 and 2 did not explore whether the survivors who reported chronic anxiety and/or depression also reported moderate to high levels of psychological needs at Time 1; this remains an area for future research. Nonetheless, these data suggest that survivors in late treatment should be given the message that most will adjust well and require only low-intensity supportive care, including information and self-management support.

There is considerable variation among studies in the estimate of the prevalence of psychological morbidity among oncology populations. The point prevalence of anxiety and/or depression identified in Papers 1 and 2 is lower than that reported by previous studies of cancer survivors at a similar timeframe post-diagnosis. While the prevalence of the four trajectories of psychological adjustment also varies among studies, the findings of Paper 2 that chronic and late cases of psychological morbidity are relatively uncommon is consistent with previous studies of survivors of single cancer types. One possible explanation for these disparities is the use of different measurement techniques. While the current study used the Hospital Anxiety and Depression Scale (HADS) to assess psychological morbidity, measures commonly used in other studies
include the Brief Symptom Inventory–18,18 the General Health Questionnaire,16,20 Centre for Epidemiological Studies–Depression15,19 and structured clinical interviews.12,17 While the trajectory analysis reported in Paper 2 was anchored to six months and one year post-diagnosis, some previous studies used similar but not identical assessment intervals,17,20 while others linked their assessment points to specific clinical events in the cancer trajectory (e.g. end of active treatment), rather than time since diagnosis.13,16,19

Another possible explanation is the differences in sampling frameworks among studies. While the findings of Papers 1 and 2 are derived from a population-based sample of the eight most incident cancer types, previous studies of psychological morbidity are predominantly based on convenience samples of breast cancer survivors,14,16,19,21 thus limiting the generalisability of the study findings to survivors of other cancer types.22,23 Furthermore, as many of the previous studies were conducted with samples of survivors drawn from the United States of America and the United Kingdom, it is possible that variation among countries in the structure and funding of health care services may have contributed to the differences observed. For example, cancer care in Australia is delivered in both the acute and primary care settings as well as the public and private health care systems, with responsibility shared between state and national governments.24

To build a global picture of the prevalence and trajectories of psychological morbidity experienced by cancer survivors in early survivorship and overcome some of the limitations to interpretation of previous research, international studies with uniform
sampling and measurement techniques would be needed. This would enable head-to-head comparisons among study findings to be made and differences in outcomes due to health care systems to be identified.

**Prevalence of unmet supportive care needs among cancer survivors**

Paper 5 examined the prevalence of supportive care needs six months after diagnosis. Surprisingly, almost half (42%) of survivors reported no need for help with any of the items assessed, with the majority indicating that these items were not applicable. Just over one-third (37%) reported at least one item for which they had a moderate to high level of unmet need for help, and yet individual items were endorsed by relatively few survivors.\(^\text{25}\) Moderate to high level unmet needs were most frequently reported in the psychological and physical aspects of daily living domains. These findings suggest that while some survivors express areas of unmet needs, current care appears to avert unmet needs and adequately meets the needs of a large proportion of survivors for the domains assessed.

While the domains of highest unmet need are consistent with other recent needs assessments, the prevalence of unmet need identified in Paper 5 is considerably lower than that reported in previous studies.\(^\text{26}\) This may be indicative of the changes in cancer care that have taken place in recent years in Australia, such as the wide-scale introduction of cancer care coordinators, establishment of psycho-oncology services, multidisciplinary approaches to care, and improved access to information and support through information technology advances. It is possible that these innovations may
have led to survivors either not experiencing as many issues of concern, or their needs being adequately met at the time. The finding that the supportive care needs of many survivors are adequately met raises questions about the investment of limited resources in survivor-specific clinics and services. That is, the resource allocation required to deliver such services may be disproportionate to the magnitude of survivors’ unmet supportive care needs.

The discrepancies among studies in the prevalence of unmet needs may also be explained by the variety of needs assessment tools that have been used, as well as differences in the classification of unmet needs. While the current study used the 34-item Supportive Care Needs Survey (SCNS–SF34) to assess unmet needs, other studies have used tools such as the 59-item Supportive Care Needs Survey (SCNS)\textsuperscript{27} and the Cancer Survivors’ Unmet Needs (CaSUN) Survey.\textsuperscript{28, 29} Although the response scales of these tools are identical to or highly analogous with the SCNS–SF34, some studies calculate and report the prevalence of unmet need based on the response options, ‘moderate’ and ‘high’ need,\textsuperscript{8, 25, 30, 31} while other studies also include ‘low’ need.\textsuperscript{28, 29} The inclusion of ‘low’ need obviously increases the prevalence of unmet need.

Nonetheless, the prevalence of unmet need identified in Paper 5 is considerably lower than other studies which have used the same instrument and classification of unmet need. While the assessment of survivors’ unmet needs was clearly anchored to six months post-diagnosis, other studies have a wide range in the length of time since participants were diagnosed or completed treatment.\textsuperscript{27} It is possible that the SCNS–SF34 does not fully capture the unique needs of survivors in early survivorship,
and consequently the prevalence of unmet need identified in Paper 5 is under-reported.

Consistent methods of calculating and reporting unmet needs would facilitate both comparisons among, and pooling of, study results. Furthermore, the development of criteria for identifying clinically significant levels of unmet need would assist in the interpretation and clinical application of unmet needs assessments. Research addressing these areas would make a significant contribution to and accelerate filling the gaps in knowledge about the problems that adult cancer survivors want addressed.

FACTORS ASSOCIATED WITH POOR PSYCHOSOCIAL OUTCOMES

Information about the factors associated with poor psychosocial outcomes is critical for identifying those survivors who are most at risk of poor outcomes, and guiding the development of interventions targeted to vulnerable survivors to prevent or minimise these outcomes. The current study examined the relationships among a broad range of factors (modifiable and non-modifiable) with caseness for anxiety and/or depression (Papers 1 and 2), and with moderate to high level unmet needs (Paper 5). Given that the suite of factors examined in relation to anxiety and/or depression (Papers 1 and 2) and moderate to high level unmet needs (Paper 5) were identical, and that many of the results were congruent, the findings in relation to these outcomes are discussed together.
The majority of studies with cancer survivors have assessed sociodemographic and medical correlates of psychosocial wellbeing.\textsuperscript{2,26} Comparatively fewer studies have examined health behaviour, psychological or social correlates. The factors examined in the current study span individual, disease and treatment, health behaviour, psychological and social characteristics. Factors that were potentially modifiable, such as health behaviours, coping style and social support, were of particular interest and intentionally included. For this reason, personality attributes were not included, despite being linked with psychosocial wellbeing in previous studies of oncology populations. Current concerns about the influence of the health care system on outcomes have mostly emerged since the current study commenced, and therefore were not included. While acknowledging that the findings are limited by the array of factors appraised, to our knowledge no other studies have examined the relative contributions of such a comprehensive range of factors to the psychosocial wellbeing of a heterogeneous sample of cancer survivors in the late treatment to early survivorship phase of care.

Potentially modifiable factors associated with poor psychosocial outcomes among cancer survivors

Multivariable analyses emphasised modifiable factors, including psychological, social and health behaviour characteristics, as the strongest and most consistent correlates of poor psychosocial outcomes among survivors. In both the cross-sectional (Papers 1 and 5) and longitudinal (Paper 2) analyses, psychological characteristics, many of which are potentially modifiable, were the strongest factors associated with poor psychosocial outcomes.\textsuperscript{5,25} More specifically, in the cross-sectional analyses, a history
of mental illness prior to cancer and the use of the maladaptive coping strategies, anxious preoccupation and helplessness-hopelessness, were the strongest correlates of psychological morbidity (Paper 1) and unmet needs (Paper 5). Of note, the longitudinal analyses revealed that earlier levels of anxiety and depression were the strongest factors associated with subsequent psychological morbidity. While these psychological variables are likely to be highly correlated, the findings suggest that earlier mental illness may act as a red flag for risk of subsequent caseness for anxiety and depression. In both of the cross-sectional analyses, a perceived low level of positive social interaction was linked to psychological morbidity and unmet needs. Across the three studies, inadequate levels of physical activity were linked to multiple domains of unmet need and depression in particular. The relationship between smoking and psychological morbidity was inconsistent between the cross-sectional and longitudinal approaches.

Non-modifiable factors associated with poor psychosocial outcomes among cancer survivors

Compared with the modifiable factors, the non-modifiable individual, disease and treatment factors were not as strongly or consistently associated with poor psychosocial outcomes. The cross-sectional approach linked age with multiple domains of unmet need and anxiety, with morbidity increasing with increasing age. In both the cross-sectional and longitudinal approaches, cancer type was linked with poor psychosocial outcomes, with those diagnosed with lung cancer the most likely to be affected. This is not surprising, as those diagnosed with lung cancer face a particularly poor prognosis, and there is stigma associated with a disease that is perceived by
others to be self-inflicted as a result of smoking.\textsuperscript{33} Nevertheless, this is a unique contribution as few other studies have included a similarly diverse range of cancer types with sufficient numbers to conduct adequately powered subgroup analyses. Unlike previous studies,\textsuperscript{34} level of education was not associated with poorer psychosocial outcomes, while being married, being female and having more advanced disease were associated with relatively few of the indicators of poor psychosocial outcomes.

**Profile of survivors at risk of poor psychosocial outcomes**

A clear picture emerged of the profile of the survivors who may be at greater risk of poorer psychosocial outcomes in the early phase of survivorship. Collectively, the findings from the current study suggest that survivors with anxiety and/or depression, a history of mental illness, a coping style consistent with anxious preoccupation or cognitive avoidance, perceived low levels of positive social interaction, low levels of physical activity, being diagnosed with cancer at less than 60 years of age and having lung cancer are likely to be at greater risk for psychosocial problems. Of course, these findings apply only to the population from which the sample was drawn. For example, these findings cannot be used to identify at-risk survivors diagnosed with cancers of the brain or kidney, as these cancer types were not included in the study sample.

The study design does not permit any conclusions to be drawn about what caused some survivors to experience poor psychosocial outcomes. An assertion of a causal relationship requires a higher level of evidence than that provided by the current
study. Nevertheless, the findings provide insight into and advance our knowledge of the variables that may influence the occurrence of anxiety, depression and unmet needs in the early stages of survivorship. Identifying non-modifiable individual and disease-related variables associated with psychosocial problems could facilitate health care providers to identify survivors who may be at risk and may benefit from monitoring and/or early intervention. The findings from the current study suggest that, in particular, individuals who are younger than 60 years of age when diagnosed with cancer, are diagnosed with lung cancer, or have a history of mental illness may benefit from screening for psychosocial problems and being targeted with early intervention. Identifying potentially modifiable health behaviour, psychological and social factors could also inform the development of interventions targeted to vulnerable survivors. The findings from the current study suggest that randomised controlled trials testing the effectiveness of interventions targeting psychological functioning, coping style, perceived social support and physical activity are merited. Such studies would provide a high level of evidence of a causal sequence between these variables and cancer survivors’ psychosocial outcomes.

REFINING PSYCHOSOCIAL OUTCOME MEASURES FOR CANCER SURVIVORS

Rigorous assessment is the first step towards providing the care, services and resources required by survivors to maximise their wellbeing. The extent to which data about survivors’ wellbeing and the inferences made from those data can be considered trustworthy is, in part, determined by the measurement tools used. There are
numerous options for assessing cancer survivors’ psychosocial outcomes and the key covariates associated with these outcomes. Available approaches include survivor report, proxy report by health care professionals or family members, and registry or medical record abstraction. Each of these options has strengths and limitations in terms of the cost, time and resources required, as well as the types and sources of bias.\textsuperscript{35, 36} Previous research suggests that compared with patient report, clinicians tend to underestimate the presence of anxiety and depression\textsuperscript{37, 38} and overestimate levels of unmet needs,\textsuperscript{39} while caregivers overestimate psychological morbidity.\textsuperscript{40} While registry records have a high degree of standardisation, completeness and accuracy, they record only a limited range of indicators, which do not currently include psychosocial morbidity status. Medical records contain more detailed information than registry records, and yet the recording of information such as psychosocial wellbeing is not standardised and often incomplete. Survivors are considered the optimal primary source of information about their emotional wellbeing. As it is not feasible to collect information from large numbers of survivors by clinical interview due to resource requirements, self-report measures are the most common method used. However, as there is no consensus about a standardised approach to assessment, copious different measures have been used over time, thereby limiting the ability to directly compare or combine study findings. Initiatives such as the Patient-Reported Outcomes Measurement Information System\textsuperscript{41} which produces standardised item banks for measurement of patient-reported outcomes may facilitate greater uniformity among studies in the future.
Screening for psychological distress among cancer survivors

In the absence of sufficient evidence of effects on patient-reported outcomes,\textsuperscript{42, 43} consensus-based guidelines recommend routine distress screening of survivors throughout the cancer trajectory.\textsuperscript{44, 45} The findings of Papers 1 and 2 support targeted screening of at-risk cancer survivors during the survivorship phase of care. However, this requires screening tools that are sensitive and specific, in order to ensure that those at risk are identified early and offered appropriate treatment or referral, and those not at risk are not subjected to unnecessary assessments. The single-item Distress Thermometer (DT) has been promoted as a suitable screening instrument, and its uptake has burgeoned in recent years,\textsuperscript{46} possibly reflecting changes to the licensing arrangements for the HADS which have made its widespread use as a screening instrument cost-prohibitive. However, there is scant evidence regarding the screening accuracy of the DT in the survivorship phase of care.

Paper 3 examined the sensitivity and specificity of the DT compared with the HADS threshold of 8 or more to identify cases of anxiety and/or depression among a large heterogeneous group of survivors in early survivorship. The HADS was selected as the criterion measure because it has traditionally been one of the most commonly used screening tools for psychological morbidity among cancer patients. Comparison with a more robust criterion such as a structured clinical interview would have been ideal. However, this was not feasible, given the large and dispersed sample, and prohibitive cost. The findings of Paper 3 challenge the all-purpose use of the recommended DT cut-off score of 4 or more to identify possible caseness of psychological distress among
this population. At the recommended DT cut-off score of 4 or more, for every 100 survivors screened, 10 would be subjected to unnecessary follow-up testing and possible treatment for anxiety (irrespective of depression), and 15 would be subjected to unnecessary follow-up testing and possible treatment for depression (irrespective of anxiety). However, at the recommended threshold, the DT demonstrated a high level of precision in correctly identifying non-cases.⁴⁷

Paper 3 raises the proposition that the optimal DT threshold for the late treatment to early survivorship phase of care may vary according to the purpose for which the instrument is being used; that is, whether sensitivity or specificity is more desirable in the given context. The findings indicate that a DT cut-off score of 2 or more may be best for clinical use when increased sensitivity is desirable in order not to miss possible cases, a score of 4 or more may be best for research use when specificity is desirable so as not to over-inflate estimates of prevalence, and 3 or more may be the best balance between sensitivity and specificity among survivors in early survivorship. Of course, these thresholds need to be corroborated by other studies using robust criterion measures of psychological distress before any firm conclusions could be drawn or recommendations made about the optimal DT cut-point for use with this population.

Nevertheless, given the limited psycho-oncology and mental health workforce, it is important to consider the clinical implications of a DT cut-off score of 2. The study findings suggest that while a high proportion of true cases of anxiety and/or depression would be identified using this threshold, a correspondingly high proportion
of false positive cases would also be identified and potentially referred unnecessarily to a specialist mental health professional. Therefore, if screening of cancer survivors in the early stages of survivorship was implemented using a DT cut-off score of ≥2, it is likely that those who scored above this threshold would need to undergo a second stage of screening (e.g. a longer and more sensitive tool or discussion with a nurse, oncologist or general practitioner) to determine if referral to a specialist mental health professional for assessment was warranted. Such a two-stage screening process is likely to maximise the appropriate referral of survivors to specialist psychosocial care.

**Assessing survivors’ unmet supportive care needs**

The key function of the assessment of unmet needs is to allow health care providers to focus on the issues that individuals themselves have expressed they want addressed in order to achieve optimal wellbeing. Interest in formal needs assessment tools for use with oncology populations has rapidly increased, with a range of measures now available. Reviews of the literature indicate that, compared with other needs assessment tools, the SCNS is one of the most commonly used, comprehensive and robust measures available. However, the response burden is high, with the 59 items taking approximately 20 minutes to complete, and its psychometric properties, including convergent validity with other external measures of a related concept, test-retest reliability and predictive validity, have not been established.

In Paper 4, classical test theory analyses were used to develop and validate a shortened version of the SCNS to enhance both its clinical and research utility. A secondary analysis of the original SCNS dataset and expert review produced the 34-
item SCNS (SCNS–SF34), with the factor structure and psychometric properties of the original instrument retained. Paper 4 also provided the first preliminary evidence of the convergent validity of the SCNS–SF34 against three other measures of psychosocial wellbeing. However, the absence of data about test-retest reliability and predictive validity is a limitation of the measure and remains an important area for future research, as does the impact of the SCNS–SF34 on the process of care and survivors’ outcomes. As one of the two datasets from which the SCNS–SF34 was developed and validated included individuals who were 3 months to more than 5 years post-diagnosis, the measure is generalisable across the cancer trajectory. Nevertheless, it is possible that items specific to the survivorship phase may have been omitted.

Measures should continue to be refined and evolve over time as new data come to hand and new priorities emerge. Anecdotal reports from researchers and health care professionals suggest that the SCNS–SF34 response scale may be problematic, resulting in the development of modified response scales published by other researchers. The SCNS–SF34 has been translated into Japanese, Chinese, German, French and Spanish by other researchers and clinicians. Some testing of the translated versions has been conducted using classical test theory analyses, thereby adding to the accumulating evidence of the psychometric properties of the measure. In the time since the SCNS–SF34 was developed, two survivorship-specific needs assessment tools, namely the Cancer Survivors’ Unmet Needs (CaSUN) survey and Survivors’ Unmet Needs Survey (SUNS), have been created. While the CaSUN was developed and validated in Australia with a relatively small sample (n=353) of breast, gynaecological and prostate cancer survivors, its relevance to the broader range of
survivors remains unknown. In contrast, the SUNS was developed and validated with a large (n=550) population-based sample of heterogeneous cancer survivors, but it has not been validated in the Australian setting. Nevertheless, preliminary psychometric evidence suggests that both of these measures are promising and warrant further study. Given that many survivors live with cancer as a chronic disease, a generic measure of the unmet needs of individuals living with chronic diseases may be useful. Such a measure would allow the unmet needs of survivors of cancer to be compared with the unmet needs of individuals with other chronic diseases.

The SCNS–SF34 may have potential for informing some of the content of Survivorship Care Plans which are tailored to individual survivors. The SCNS–SF34 could be used in the end-of-treatment evaluation to identify the unmet psychological, information, physical aspects of daily living, support and sexuality needs to be addressed in the individual’s Survivorship Care Plan. Other measures may also be required to assess aspects such as health behaviours. Specific recommendations about services and resources, based on best available evidence, for addressing the unmet needs identified could then be included in the Survivorship Care Plan. The utility of the SCNS–SF34 in care planning is an area for further study.
STRENGTHS AND WEAKNESSES OF THE STUDY DESIGN AND IMPLEMENTATION

Representativeness of the study sample

Most research assessing psychosocial outcomes for survivors of cancer is based upon convenience samples of individuals recruited from one or more cancer treatment centres.\textsuperscript{22, 23, 26} Although these samples may be representative of the survivors who attended particular treatment centres, they are not representative of all cancer survivors, and their results are generalisable only to the treatment centres and/or types of centres from which the samples were drawn. In contrast, a population-based sample of cancer survivors is one which is drawn from all known cases of cancer, thereby maximising the representativeness of the sample. Theoretically, data collected from population-based samples should enable accurate and precise inferences to be made about the entire population of individuals with cancer. In Australia, population-based samples of cancer survivors can be obtained via the state- and territory-based cancer registries which receive notifications of cancer under the relevant Public Health Act.

The papers comprising this thesis are based on a sample of cancer survivors drawn from the two largest state-based cancer registries in Australia, which together account for 60% of all cancers diagnosed in Australia. Although the sample is generally representative of its source population, several challenges were encountered which may compromise the validity of the study findings. The use of rapid case ascertainment procedures and registry policies prohibiting individuals being approached for more than one study meant that the sampling frame from which the sample was recruited
was incomplete. For example, young men (less than 55 years) diagnosed with prostate cancer and those diagnosed with early-stage colorectal cancer were not able to be approached by one of the registries due to other studies targeting these individuals. For one registry, the sample quota was stratified by cancer type proportionate to its incidence in that state, so that the sample reflected the natural distribution of the top eight cancer types in the state. Ideally, the sample recruited from both registries would have been stratified by cancer type proportionate to its incidence in that state.

Recruitment procedures varied between the two registries according to their individual policies. One registry required written consent from the primary treating clinician to approach potentially eligible survivors (active physician consent), while the other required the primary treating clinician to notify the registry of any reason why a potentially eligible survivor should not be approached (passive clinician consent); these variations contributed to different participant response rates being achieved between the two states (33% and 49% respectively). The overall response rate of 41% (1360/3315 eligible individuals) at Time 1 is low and raises concerns about response bias. This is partly a consequence of the multi-step recruitment process routinely used by cancer registries to identify potential study participants on behalf of the research team, due to privacy, confidentiality and adverse event concerns. While the response rate is much lower than desired, it must be noted that it is a conservative estimate because it assumes that all survivors of unknown eligibility (i.e. 764 survivors for whom the physician was uncontactable or refused, and 426 survivors who were uncontactable or non-responders) were eligible and therefore included in the denominator. Compared with other registry-based studies, it exceeds the adjusted
recruitment rate of 34% (i.e. after deducting a proportion of survivors with unknown eligibility from the calculation) achieved by the American Cancer Society’s Study of Cancer Survivors-1,\textsuperscript{56} which used an equivalent method to recruit a similarly diverse sample of adult survivors. However, it is lower than other studies that recruited samples of recent survivors of a single cancer type.

One of the advantages of using population-based registries to obtain the sample is the diversity of the cancer survivors included, in terms of primary cancer type, extent of disease, treatments received, and sociodemographic characteristics such as geographic location. The inclusion of the top eight incident cancer types in Australia, many of which are considered under-studied, enabled adequately powered comparison of outcomes among cancer types to be conducted. This is an important contribution to the field, as much of the research examining psychosocial aspects of cancer survivorship is based on women diagnosed with breast cancer. However, one of the limitations of population-based registries is the lack of detailed personal and clinical information available for linking with psychosocial outcome data. While sex, date of birth, cancer type, extent of disease and survival status are verified and coded by the registries in a standardised way, valuable information on the cancer notification about treatments received, Aboriginal and Torres Strait Islander status and country of birth is not coded and therefore not available for linkage.

**Longitudinal follow-up and sample retention**

Most information about the psychosocial impact of cancer on survivors comes from cross-sectional studies which provide a snapshot of the wellbeing of survivors at
specific points in time. Cross-sectional studies are unable to describe the natural history of cancer survivors’ psychosocial outcomes over time, or allow any conclusions to be drawn about the causes of outcomes. Nevertheless, they serve an important function in generating hypotheses to be tested in more rigorous study designs. In contrast, Paper 2 assessed the psychological outcomes and associated factors of the same survivors at six and twelve months post-diagnosis. This longitudinal approach enabled the natural history of the psychological impact of cancer on survivors in the early stages of survivorship to be delineated. By tracking the same individuals over time, four clinically important patterns of adjustment, impossible to identify by cross-sectional studies, were revealed. Furthermore, the effects of earlier factors (e.g. stage of disease at diagnosis) and ensuing factors (e.g. coping strategy) on later psychological functioning were able to be explored, thereby enabling risk factors for poor psychological outcomes to be identified. Although more expensive and time-consuming than cross-sectional studies, a key advantage of longitudinal research is that more convincing inferences about the causes of different outcomes can be made, thus enhancing the utility of the study findings. Nevertheless, the findings of longitudinal studies are influenced by the assessment time points. In Paper 2, assessments were conducted six months apart on the basis of clinical relevance and respondent burden. However, it is likely that this interval was too long, and some psychological morbidity which is not reflected in the findings may have occurred in the interim period. Furthermore, the registry-based recruitment method did not allow assessment of psychological morbidity at an earlier time point such as around the time of diagnosis. Assessments linked to clinical events may more accurately reflect the natural history of survivors’ psychological functioning.
Maximising the retention of study participants is an inherent challenge of conducting longitudinal research. From one assessment to the next, participants may die, change contact details, or actively withdraw from the study due to poor health or loss of interest. Attrition introduces response bias and diminishes the ability to draw robust conclusions about the study findings. A range of strategies based on the Australian Longitudinal Study of Women’s Health and a review of the literature were built into the Cancer Survival Study to maximise the retention of the sample from the outset. All study information packages (Appendix 7) included personalised letters signed in blue pen by the Project Manager, change of address forms, secondary contact forms, and reply-paid envelopes. Two reminders (one written and one telephone) were made to non-responders at three-weekly intervals to minimise overlap between incoming surveys and reminders, and standard procedures for conducting reminder calls were developed (Appendix 8.1). A study-specific freecall 1800 telephone number and dedicated email address were established to encourage participants to contact the research team with any questions or concerns they may have had, and standard responses to frequently asked questions were developed (Appendix 8.2). A range of contact details were requested, including mobile telephone number and email address, in addition to postal address and telephone number. At each wave of data collection, the contact details of a stable ‘secondary contact’ (i.e. someone who did not live with the participant but who would know how to get in contact with him or her) was requested to assist in re-establishing contact with ‘lost’ participants. Participants whose study packages were ‘returned to sender’ and were unable to be contacted using any of the contact details supplied by them or their secondary contact were tracked (Appendix 8.3) through the electronic White Pages or the electoral roll.
All requests for information or additional comments that participants noted on their surveys were responded to in writing to demonstrate that their time and effort in completing the surveys were valued. A newsletter informing participants about the study progress and results was distributed annually (Appendix 9). These strategies are likely to have contributed to the high level of sample retention achieved in this study (Appendix 10). Participants demonstrated strong commitment and adherence, with only 5% (71/1434) attrition between Time 1 and Time 2 due to death (n=34) and active withdrawal from the study (n=37). This is considerably lower than the 12% attrition between one and two years post-diagnosis (K. Stein, personal communication, April 2012) experienced by the American Cancer Society’s Study of Cancer Survivors–I.

**Appropriateness of the measures administered**

There are numerous self-report measures available for assessing the primary outcomes (anxiety, depression and unmet needs) and some of the study factors (coping and social support) examined. A total of 30 candidate measures were considered for selection. This included tools applicable to the general population (e.g. Beck Depression Inventory-II, Centre for Epidemiological Studies–Depression scale, Profile of Mood States, Social Support Questionnaire, and Ways of Coping–revised) as well as those specific to oncology populations (e.g. Brief Symptom Inventory, Cancer Rehabilitation Evaluation System, and Needs Evaluation Questionnaire). Candidate measures were assessed against the following criteria: 1) relevant dimensions represented; 2) adequate indices of reliability and validity in oncology or other chronic disease population or the general population; 3)
responsiveness or sensitivity to change; 4) self-report mode of administration; 5) response burden not exceeding 15 minutes; 6) scoring and interpretation guidelines; 7) nil or nominal administration fee; and 8) available in the English language. As no candidate measure met all of the criteria, a trade-off between the specified requirements was made. This resulted in the selection of the HADS, SCNS-LF59, Mini-Mental Adjustment to Cancer (Mini-MAC) scale and Medical Outcomes Study–Social Support Survey (MOS–SSS). The DT was also selected on an ad hoc basis, due to its growing profile and the unique opportunity to examine its performance among survivors in the early survivorship phase of care. The 59-item SCNS was shortened to 34-items to reduce its response burden.

The HADS, SCNS–SF34, Mini-MAC and MOS–SSS, as well as individual and disease-related items, were pilot-tested with 50 cancer survivors recruited from an advocacy group to examine: 1) rates of response and item completion; and 2) the acceptability of the battery of surveys to cancer survivors, with regard to survey format, length, clarity of instructions and items, and completeness of response options. An unprompted response rate of 56% was achieved, suggesting that the battery of measures were of interest to participants. While item completion rates varied among the individual measures, the primary outcome measures (HADS and SCNS–SF34) achieved excellent compliance, with rates ranging from 96% to 100%. Overall, 12 participants thought the survey was too long, 4 people needed help to complete it and only 2 felt worried after completing it. Almost everyone reported that the questions were easy to understand. As a result of the pilot-test, the response options of some individual and disease-related items were revised, the survey was reformatted to
reduce its length, and the instructions were expanded. The ensuing survey appeared to be relevant, acceptable and easy to understand.

Outcome measurement for longitudinal research has many challenges. The initial selection of outcome measures requires achieving a balance between longitudinal consistency and cross-sectional relevance. After measures have been selected and data collection commenced, researchers can be faced with the advent of new measures assessing the outcomes of interest, or new data casting doubt on the performance of the selected outcome measures. However, in order to maintain longitudinal consistency, the outcome measures initially selected need to be retained.

These issues were encountered in the course of this research. For example, the HADS was used as the outcome measure in Papers 1 and 2. The HADS is one of the most widely used tools for assessing psychological morbidity in oncology populations, and several reviews have concluded that it is among the best tools for assessing the psychological outcomes of this population. However, since the current study commenced, there has been considerable debate in the literature about the performance of the HADS. Some reviews have refuted its underlying factor structure and asserted that it is not dependable for differentiating between anxiety and depression. Other reviews contend that the validity of the recommended cut-point of 8 or more for defining caseness is poorly supported by validation studies using structured clinical interviews as the criterion measure. These findings raise some doubt about the accuracy of the estimates of the prevalence of anxiety and/or depression identified in Papers 1 and 2. It should be noted that none of the recent
reviews or commentaries which have argued against the HADS has recommended specific tools as alternatives, possibly suggesting that while it has shortcomings, it is still one of the better short, self-report options available for assessing both anxiety and depression.

**FUTURE DIRECTIONS INDICATED BY THE RESEARCH FINDINGS**

The research comprising this thesis makes an important contribution to better understanding of the extent and type of psychosocial issues faced by cancer survivors in the late treatment to early survivorship phase of care. This research found that while the majority of survivors had adjusted well, a small but important group experienced psychosocial morbidity. Importantly, this research identified the potentially modifiable and non-modifiable characteristics of survivors at risk of poor outcomes, and contributed to the refinement of tools to assist in the identification of psychosocial morbidity. While the study findings supported the biopsychosocial model of health as a useful framework for understanding the impact of cancer, future research should also consider the contribution of health care system factors (e.g. teaching hospital status of treatment centre) to survivors’ psychosocial outcomes.

This research did not address the critical issue of how best to prevent or diminish the adverse psychosocial impact of cancer among at-risk survivors. The next important step in the progression of survivorship research is to shift the focus from descriptive studies to intervention studies. That is, the knowledge now acquired about the issues that survivors face, the characteristics of those at risk of poor outcomes, and the
potentially modifiable risk factors, needs to be applied to the development of robust experimental studies testing the effectiveness of acceptable and feasible interventions to reduce psychosocial morbidity among cancer survivors in early survivorship.

The findings of Papers 1, 2 and 5 leave no question about the need to target intervention studies to those diagnosed with lung cancer. These findings suggest that to maximise the potential benefits that survivors stand to gain, interventions need to target multiple risk factors rather than individual risk factors. Multi-component interventions explicitly focused on enhancing psychological functioning, coping, social support, and health behaviours are required. These may include psycho-educational strategies such as the development and practice of new coping skills, relaxation and/or mindfulness meditation training, goal-setting and problem-solving. It may also include support strategies such as peer support which harnesses the altruistic goodwill of the growing population of cancer survivors who desire to ‘give back’. It has been suggested that the diagnosis and treatment of cancer offers a ‘teachable moment’ for smoking cessation and physical activity interventions. However, given the physical limitations and poor prognosis associated with lung cancer, modification of physical activity to the level required to achieve psychological benefits may be unrealistic, highlighting the need for flexibility to be built into intervention design. Evidence of the efficacy of many of these psychosocial and behavioural interventions is mostly based on trials conducted with breast or prostate cancer patients in active treatment.\textsuperscript{74, 75} Relatively few trials have been conducted with survivors transitioning to survivorship, although this is an area of increasing research attention.
In considering the development of intervention studies for lung cancer survivors, several design issues would need to be considered. The sample size required to identify clinically important changes in psychological wellbeing is large and would require multi-site collaboration. While interventions of at least 12 weeks are suggested to be more beneficial than those of a shorter duration,\textsuperscript{76} intervention length is a particular challenge for survivors of lung cancer, given that 50% have a life expectancy of less than 12 months after diagnosis. As physical limitations due to declining health make travel difficult for those with lung cancer, interventions that can be delivered remotely or at home may promote higher uptake and adherence. This may include delivery by telephone, internet or smart phones. Telephone-based service delivery is an important medium as it offers greater geographical reach, while information technology has increasingly become essential to daily life for many, with 72% of Australian households estimated to have home Internet access.\textsuperscript{77} As most survivors learn about psychosocial support themselves, a proactive approach to providing psychosocial care may be warranted. This may require the collaboration of primary health care providers and community-based organisations such as the Cancer Council. A crucial aspect of the design would be the choice of outcome measures and the timing of assessments. Clinically important changes in outcomes are likely to be a more meaningful indicator of effectiveness than statistical significance. A comprehensive battery of measures of adjustment, such as the Centre for Epidemiological Studies–Depression\textsuperscript{59} or Profile Of Mood States–37,\textsuperscript{60} may be required for adequate identification of changes in outcomes among groups.
CONCLUSIONS

In the aftermath of diagnosis and treatment, cancer survivors demonstrated an extraordinary ability to cope with and adjust to the psychosocial issues they were confronted with. Surprisingly few survivors reported psychosocial morbidity. Rather, survivors defied expectations and demonstrated considerable resilience in the face of adversity. Cancer survivorship is a rapidly growing field of research and service delivery. That the present circumstances enabled most survivors to recover well should not be underestimated or disregarded in the debate about the optimal allocation of scarce resources to survivorship care relative to the other phases of the cancer control continuum. The survivors who participated in this research generously documented their wellbeing and shared their cancer journeys. One of the challenges is to harness and make use of the goodwill of the growing population of cancer survivors to reduce the burden imposed by cancer.
REFERENCES


