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

Allison Wendy Boyes BA (Psych), MPH

Submitted for the Degree of Doctor of Philosophy
November 2012

School of Medicine and Public Health, University of Newcastle, Australia
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.

**Unless an Embargo has been approved for a determined period.

Statement of authorship

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
ACKNOWLEDGEMENTS

I acknowledge the guidance provided by my panel of supervisors (in alphabetical order) Dr Mariko Carey, Professor Cate D’Este, Professor Afaf Girgis and Laureate Professor Rob Sanson-Fisher. In particular, I am immensely grateful to Rob and Mariko who generously stepped in at the eleventh hour to fill the void created by extraordinary circumstances – their wisdom has undoubtedly made this thesis and its contribution to the field immeasurably better.

The Cancer Survival Study, upon which this thesis is based, was supported by funding received from the National Health and Medical Research Council, the Cancer Council NSW, the Hunter Medical Research Institute, the Honda Foundation and the University of Newcastle. This research would not have been possible without the cooperation of the numerous cancer survivors who generously gave their time to complete questionnaires and share their cancer journeys. I am also grateful for the excellent research assistance provided by Alison Zucca and Alix Hall.

I am fortunate to have been surrounded by supportive and understanding friends and family members who have cheered me on towards the finish line, with an honourable mention to Helen, Erica and Cath. I am indebted to my husband Matt who has endured two research higher degrees, and to whom I promise that this one is definitely the last one. As articulated by a study participant, “It’s been a journey, I am a survivor”.

LIST OF PAPERS INCLUDED AS PART OF THE THESIS

Paper 1

Paper 2

Paper 3

Paper 4

Paper 5
LIST OF ADDITIONAL PUBLICATIONS RELEVANT TO BUT NOT INCLUDED IN THE THESIS

Peer-reviewed paper


Book chapter

Introduction ............................................................................................................. 1
Epidemiology and burden of cancer ............................................................................. 2
Cancer survivors and survivorship ............................................................................. 8
Multidimensional impact of cancer on survivors in early survivorship ...................... 12
Psychosocial outcomes of cancer survivors in early survivorship ................................ 20
Cancer Survival Study ............................................................................................ 34
Scope of research .................................................................................................... 37
Structure of thesis .................................................................................................... 38
References .............................................................................................................. 39

Paper 1: Flourishing or floundering: Prevalence and correlates of anxiety and depression among a population-based sample of adult cancer survivors 6 months after diagnosis ................................................................. 58
Abstract .................................................................................................................. 60
Introduction ............................................................................................................. 62
Method ...................................................................................................................... 65
Results ..................................................................................................................... 70
Discussion ............................................................................................................... 82
Conclusions .......................................................................................................... 88
References ............................................................................................................. 89
Paper 5: Prevalence and correlates of cancer survivors’ supportive care needs 6 months after diagnosis: A population-based cross-sectional study .......... 171

Abstract ................................................................. 173

Introduction ............................................................. 175

Methods ................................................................. 177

Results ................................................................. 182

Discussion ............................................................. 196

Conclusions ............................................................ 200

References ............................................................... 202

Discussion ................................................................. 208

Introduction ............................................................. 209

Prevalence of cancer survivors’ psychosocial outcomes ................................. 209

Factors associated with poor psychosocial outcomes ...................................... 215

Refining psychosocial outcome measures for cancer survivors ....................... 219

Strengths and weaknesses of the study design and implementation ................ 226

Future directions indicated by the research findings ........................................ 234

Conclusions ............................................................ 237

References ............................................................... 238
LIST OF TABLES

Introduction
Table 1.1: Data collected in the Cancer Survival Study at Time 1 (6 months post-diagnosis) and Time 2 (1 year post-diagnosis) ...........................................36

Paper 1
Table 2.1: Selected characteristics of study sample compared to national cancer incidence data .................................................................72
Table 2.2: Prevalence of anxiety and/or depression at 6 months post-diagnosis by cancer type .................................................................74
Table 2.3: Factors significantly correlated with caseness for anxiety ...........................................77
Table 2.4: Factors significantly correlated with caseness for depression. ................................79
Table 2.5: Factors significantly correlated with caseness for comorbid anxiety-depression .................................................................81

Paper 2
Table 3.1: Selected demographic and disease characteristics of the study sample compared to national cancer incidence data ..................107
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 .........................................................................................108
Table 3.3: Characteristics predicting ‘caseness’ for anxiety at one year post-diagnosis .....................................................................................112
Table 3.4: Characteristics predicting ‘caseness’ for depression at one year post-diagnosis .....................................................................................113
Table 3.5: Characteristics predicting ‘caseness’ for comorbid anxiety-depression at one year post-diagnosis .......................................................115
Paper 3
Table 4.1: Performance of DT scores compared to the HADS for identifying cases of anxiety, depression and comorbid anxiety-depression ..........139

Paper 4
Table 5.1: Characteristics of patients involved in the item reduction and validation procedure ................................................................................158
Table 5.2: Factor categories and item primary factor loadings ...............................162
Table 5.3: Cronbach alpha reliability coefficient and response distribution for each domain of the SCNS–SF34 .................................................................164
Table 5.4: Mean domain scores on the SCNS–SF34 for patients not in remission compared to those in remission .................................................................165
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 .........166

Paper 5
Table 6.1: Prevalence of supportive care needs at six months post-diagnosis by cancer type ...........................................................................................................184
Table 6.2: Ten most prevalent ‘moderate’ or ‘high’ level unmet supportive care needs ................................................................................................................186
Table 6.3: Individual and health behaviour characteristics associated with ‘moderate to high’ level unmet needs by domain ........................................187
Table 6.4: Disease and treatment characteristics associated with ‘moderate to high’ level unmet needs by domain .........................................................189
Table 6.5: Psychological and social characteristics associated with ‘moderate to high’ level unmet needs by domain .........................................................191
LIST OF FIGURES

Introduction

Figure 1.1: Simplified cancer control continuum .................................................................9
Figure 1.2: Conceptual framework for understanding the multidimensional impact of cancer on survivors .................................................................15

Paper 2

Figure 2.1: Prevalence of anxiety, depression and comorbid anxiety-depression pathways in the first year after diagnosis .................................................109

Paper 3

Figure 3.1: Receiver operating characteristic curve of DT scores versus the HADS anxiety subscale (score ≥8) .................................................................................136
Figure 3.2: Receiver operating characteristic curve of DT scores versus the HADS depression subscale (score ≥8) .................................................................137
Figure 3.3: Receiver operating characteristic curve of DT scores versus the HADS (score ≥8 on both anxiety and depression subscales) ..............................138
LIST OF APPENDICES

Appendix 1: Paper 1
Appendix 1.1: Published paper ................................................................. A2
Appendix 1.2: Statements of contribution from co-authors ......................... A11

Appendix 2: Paper 2
Appendix 2.1: Statements of contribution from co-authors ......................... A15

Appendix 3: Paper 3
Appendix 3.1: Published paper ................................................................. A21
Appendix 3.2: Statements of contribution from co-authors ........................ A30

Appendix 4: Paper 4
Appendix 4.1: Published paper ................................................................. A35
Appendix 4.2: Statements of contribution from co-authors ........................ A40

Appendix 5: Paper 5
Appendix 5.1: Published paper ................................................................. A43
Appendix 5.2: Statements of contribution from co-authors ........................ A53

Appendix 6: Additional publications relevant to but not included in the thesis
Appendix 6.1: Published paper ................................................................. A57
Appendix 6.2: Published book chapter ....................................................... A61

Appendix 7: Study information packages
Appendix 7.1: Certificates of ethics approvals ......................................... A79
Appendix 7.2: Survivor information statement (baseline) ............................ A83
Appendix 7.3: Reminder letter (baseline) .................................................. A85
Appendix 7.4: Cancer Survival Study leaflet .............................................. A87
Appendix 7.5: Cancer Survival Study survey 1 .......................................... A89
Appendix 7.6: Change of address form ....................................................... A113
Appendix 7.7: Secondary contact form ......................................................... A114
Appendix 7.8: Future studies form ................................................................. A115
Appendix 7.9: Survivor information statement (follow-up) ......................... A116
Appendix 7.10: Reminder letter (follow-up) .................................................. A117
Appendix 7.11: Cancer Survival Study survey 2 .......................................... A118

Appendix 8: Standardised study procedures
Appendix 8.1: Protocol for reminder telephone calls ................................... A143
Appendix 8.2: Frequently asked questions .................................................... A145
Appendix 8.3: Protocol for tracking .............................................................. A158
Appendix 8.4: Protocol for complaints and adverse events ........................ A163

Appendix 9: Participant newsletters
Appendix 9.1: Cancer Survival Study newsletter 1 ...................................... A165
Appendix 9.2: Cancer Survival Study newsletter 2 ...................................... A169

Appendix 10: Study flowchart
Appendix 10.1: Study flowchart ................................................................... A174
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 well-being. 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.