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**Anxiety and depression among long-term survivors of cancer in
Australia: results of a population-based survey**

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ABSTRACT

Objective: To assess the prevalence and predictors of anxiety and depression among a heterogeneous sample of long-term adult cancer survivors.

Design: A cross-sectional survey.

Participants: 863 adult cancer survivors randomly selected from the New South Wales Central Cancer Registry who were diagnosed with a new histologically confirmed cancer (local or metastatic) five to six years earlier, living in NSW, able to read and understand English adequately, physically and mentally capable of participating, and aware of their cancer diagnosis.

Main outcome measures: (a) Prevalence of anxiety and depression as assessed by the Hospital Anxiety and Depression Scale; and (b) factors (patient, disease, and treatment characteristics; coping style; and social support) predicting clinical/borderline levels of anxiety and depression.

Results: Levels of anxiety and depression were low; only 9% reported clinically important levels of anxiety and 4% reported depression. The strongest predictive factors of borderline/clinical anxiety were history of psychiatric illness, maladaptive coping styles (helplessness-hopelessness, anxious preoccupation) and poor social support. Borderline/clinical depression was most strongly predicted by history of psychiatric illness, being an invalid pensioner, maladaptive coping style (helplessness-hopelessness) and poor positive social interaction.

Conclusions: Five years after a cancer diagnosis, most survivors have adjusted well to their cancer experience with levels of psychological well-being similar to the general population. Nevertheless, a small and important group of long-term survivors continue to suffer adverse psychological effects and need assistance. Monitoring of psychological well-being as part of routine cancer survivorship care will increase the likelihood of early identification of this sub-group and appropriate referral.

INTRODUCTION

Cancer is a life-changing diagnosis that will affect one in two men and one in three women living in Australia by the age of 85 years.¹ The psychological morbidity associated with cancer is significant with evidence suggesting that 15% to 23% of cancer patients experience clinically significant anxiety and 20%-35% experience depression. The impact of these disorders can be considerable with major effects on relationships as well as social and occupational functioning.² With the overall rate of death from cancer declining, the number of people living with or beyond cancer is growing; it is estimated that there are approximately 340,000 cancer 'survivors' in Australia, representing about 2% of the population.³ For many, cancer becomes a chronic disease, yet relatively little is known about the psychological well-being of long-term (> 5 years) cancer survivors.

In contrast to the general public's perception of cancer as an insidious and relentless disease,⁴ there is an emerging body of recent evidence suggesting that long-term cancer survivors' psychosocial well-being is comparable to or only slightly lower than general population controls.⁵⁻⁷ However, as most of these studies were conducted in the United States and Europe with homogenous samples of cancer survivors. It is unknown if these findings are indicative of the psychological well-being of the diverse and growing population of long-term cancer survivors in Australia.

Understanding the extent to which cancer impacts upon long-term survivors, and identifying the characteristics of those most likely to benefit from targeted intervention, is essential for guiding the development and delivery of suitable services, and the optimal allocation of limited resources. Therefore, we undertook Australia's first large-scale, population-based study to assess the prevalence and predictors of anxiety and depression among a heterogeneous sample of long-term adult cancer survivors who were five to six years post-diagnosis.

METHOD

Participants

Long-term cancer survivors who were diagnosed with a new histologically confirmed cancer (local or metastatic) five to six years earlier, aged between 18 and 75 years at the time of diagnosis, currently alive, and living in New South Wales (NSW), were randomly selected from all cancer cases registered at the NSW Central Cancer Registry. The Registry confirmed with each survivor's GP or referring doctor that s/he could read and understand English adequately, was physically and mentally capable of participating, aware of the cancer diagnosis, and could be contacted about the study. The Registry contacted 1,374 eligible long-term cancer survivors and requested their permission to forward their contact details to the researchers.

Between April 2002 and December 2003, a total of 1,008 survivors who agreed to contact by the researchers were mailed a self-administered scannable survey consisting of a number of instruments. Non-responders were followed up with one reminder survey (+ 3 weeks) and one reminder telephone call (+ 6 weeks). Survivors' personal and clinical information was obtained from the cancer notification including date of birth, sex, date of diagnosis, primary cancer type and spread of disease at diagnosis. A total of 863 survivors indicated their consent to participate by returning a completed survey, providing an overall participation rate of 63%. There were no significant differences between those who did and didn't return a completed survey in terms of cancer type, spread of disease, age, gender, country of birth, and Aboriginal and Torres Strait Islander status. The Human Research Ethics Committees of the University of Newcastle and The Cancer Council NSW approved the study.

Measures

The findings reported in this paper are based on administration of the following instruments:

Hospital Anxiety and Depression Scale (HADS): A commonly used 14-item tool screening for anxiety and depression, each item is rated on a four-point scale with scores ranging from 0 to 21 for each sub-scale. Score cut-off points classify patients' anxiety and depression levels as within normal range, borderline or clinical.⁸ The HADS has demonstrated validity for detecting cases of anxiety and depression in cancer patients.^{9,10}

MOS Social Support Survey (MOS-SSS): A 19-item tool assessing perceived social support across four subscales: emotional/informational, tangible, affectionate and positive social interaction. Each item is rated on a 5 point scale ranging from “none of the time” to “all of the time” with a high subscale and/or overall score indicating a high level of social support. The tool has demonstrated validity with the chronic illness population.¹¹

The Mini-Mental Adjustment to Cancer Scale (mini-MAC): A 29-item tool assessing five cancer-specific coping strategies: helpless-hopelessness, anxious preoccupation, fighting spirit, cognitive avoidance, and fatalism. Each item is rated on a four-point scale ranging from “definitely does not apply to me” to “definitely applies to me” with a higher subscale score indicating stronger use of the coping strategy.¹²

Survivor, disease and treatment characteristics: Patient, disease and treatment characteristics were assessed by 26 questions about cancer treatments received, remission status, time since last hospital admission, marital status, education level, current employment status, health insurance status, gross household income, number of adults and children living with, and psychiatric history.

Analyses

Participants’ responses to the HADS were scored and categorised as normal (0-7), borderline (8-10) or clinical (11-21) levels of anxiety and depression.⁸ To explore whether any individual, disease, treatment, social support or coping characteristics predicted borderline/clinical levels of anxiety and depression, each potential predictor variable was tested for association using chi-square analyses. Variables with an association of 0.2 or less were included in the backward stepwise logistic regression model where the least significant variable was removed and the new model tested until all variables in the model were significant ($p \leq 0.05$).¹³

RESULTS

Study participants

Participants’ median age at the time of diagnosis was 63 years (range 26 to 76 years). A little more than half (55%) were female; most were diagnosed with breast (29%), prostate (15%), melanoma (15%) or colorectal cancer (13%); and 58% had localised disease at the time of diagnosis.

Compared to all cases of cancer diagnosed in NSW from February to November 1997 and still alive in 2002, the study sample was not representative in term of age ($\chi^2 = 11.97$; $p = 0.007$) and cancer type ($\chi^2 = 26.59$; $p < 0.001$). The study sample included significantly fewer survivors aged 18-39 years (9%) than expected (13%) and more breast cancer survivors (29%) than expected (23%).

Levels of anxiety and depression

Overall, long-term cancer survivors reported low levels of anxiety (median score = 3; range = 0-20) and depression (median = 2; range = 0-21). Only 9% ($n = 76$) of long-term survivors reported clinically important levels of anxiety and 12% ($n = 101$) reported borderline levels. Levels of depression were lower; only 4% ($n = 34$) met the cut-point for clinically important levels and 7% ($n = 61$) met borderline levels of depression. As shown in Figure 1, the proportion of long-term survivors reporting clinically important levels of anxiety and depression was comparable to the general population.^{14,15}

Figure 1 about here

As shown in Table 1, at least half of the survivors with clinical/borderline levels of anxiety or depression reported seeing their general practitioner in the previous 6 months, but less than 10% reported receiving specialist psychological care from a psychologist, psychiatrist, social worker or counsellor.

Table 1 about here

Predictors of clinical/borderline levels of anxiety and depression

Coping styles and a history of psychiatric illness were the variables that most widely predicted poor psychological well-being among long-term cancer survivors, and each of these independently predicted clinical/borderline levels of both anxiety and depression (Table 2).

Long-term survivors who engaged in the maladaptive coping styles 'anxious preoccupation' or 'helplessness-hopelessness' had at least twice the odds (OR range 2.24-8.87) of reporting clinical/borderline levels of anxiety or depression compared to survivors who did not use these strategies. In addition to these coping strategies, clinical/borderline levels of depression were also predicted by the use of cognitive avoidance coping.

As would be expected, survivors who were treated for a psychological or psychiatric illness in the past six months had at least six times the odds of reporting high levels of anxiety and depression compared to those who hadn't received treatment for a psychological illness. With regard to other patient characteristics, anxiety was also significantly more likely in younger survivors than those aged 70 years or older, and in those neither married nor in a de-facto relationship. Survivors who were invalid pensioners had greater odds of being depressed compared to those who were retired or pensioners, as did those who were not born in Australia compared to Australian-born survivors.

Survivors' perceived level of social support was also a strong predictor of well-being.

Clinical/borderline levels of anxiety were more likely amongst survivors who reported low levels of overall support while clinical/borderline levels of depression were more likely among those who reported low levels of positive social interaction.

Surprisingly, few disease and treatment characteristics significantly predicted levels of anxiety or depression. Survivors diagnosed with non-localised disease had greater odds of being anxious compared to those diagnosed with localised disease, while those whose current remission status was unknown had significantly greater odds of depression than survivors who reported being in remission.

Table 2 about here

DISCUSSION

Contrary to popularly held opinion,⁴ the results of this study suggest that life after cancer is not all doom and gloom. Five to six years after a cancer diagnosis, most survivors in Australia appear to have adjusted well to their cancer experience with levels of anxiety and depression generally comparable to that of the general Australian population.¹⁵ Although we did not have an age and gender matched population control group to compare our survivors' rates of anxiety and depression against, our findings are consistent with other previously published research conducted in the United States and Europe.⁵⁻⁷ On the basis of these findings, we are currently undertaking a longitudinal study to identify the critical time-point in the cancer trajectory where psychological well-being returns to population levels.

The large-scale, population-based approach and the diversity of cancer survivors included are major strengths of this study. The participation rate of 63% of all eligible survivors is comparable to or better than participation rates achieved by other Australian population-based studies.^{17,18} Given that our sample shows evidence of selection bias on only two (age, cancer type) of five key characteristics, we are confident that our results are by and large representative of and generalisable to long-term cancer survivors in NSW. It is known that younger age is associated with an increased risk of psychosocial problems,² therefore the under-representation of younger survivors aged 18-39 years in our sample is likely to result in a slight under-estimate of the true levels of anxiety and depression.

Nevertheless, our study suggests that there is a small and important group of long-term cancer survivors who continue to suffer adverse psychological effects and need assistance. The findings from this study suggest that long-term cancer survivors who have a history of psychiatric illness, maladaptive coping styles and poor social support should be routinely monitored given their increased risk of psychological problems. To date, most research seeking to identify risk factors for impaired psychosocial well-being has focused upon demographic, disease and treatment variables.¹⁶ Our study has extended this body of research by identifying modifiable risk factors that can be targeted for intervention or prevention.

That half of anxious or depressed survivors in our sample reported seeing their general practitioner suggests that primary care providers need to be equipped to identify and address the psychological issues facing long-term cancer survivors. However, less than 10% of the long-term survivors with clinically important levels of anxiety or depression also reported receiving specialised psychological care from a psychologist, social worker, counsellor or psychiatrist in the past six months. This suggests that monitoring of psychological well-being and offering referral as appropriate needs to be integrated within routine cancer survivorship care.

REFERENCES

1. Australian Institute of Health and Welfare & AACR Australasian Association of Cancer Registries. *Cancer in Australia: an overview, 2006*. Cancer series no. 37. Cat. no. CAN 32. Canberra: Australian Institute of Health and Welfare, 2007.
2. National Breast Cancer Centre & NCCI National Cancer Control Initiative. *Clinical practice guidelines for the psychosocial care of adults with cancer*. Camperdown: National Breast Cancer Centre, 2003.
3. Australian Bureau of Statistics. *National Health Survey: Summary of results Australia 2004-05*. Canberra: Australian Bureau of Statistics; 2006.
4. Murray M & McMillan CL. Gender differences in perceptions of cancer. *J Cancer Educ* 1993; 8(1): 53-62.
5. Helgeson VS & Tomich PL. Surviving cancer: A comparison of 5-year disease-free breast cancer survivors with healthy women. *Psycho-Oncology* 2005; 14: 307-317.
6. Wettergren L, Bjorkholm M, Axdorph U, et al. Determinants of health-related quality of life in long-term survivors of Hodgkin's lymphoma. *Qual Life Res* 2004; 13: 1369-1379.
7. Ganz PA, Rowland JH, Desmond K, et al. Life after breast cancer: Understanding women's health-related quality of life and sexual functioning. *J Clin Oncol* 1998; 16: 501-514.
8. Zigmond AS, Snaith RP. The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scand* 1983; 67: 361-370.
9. Bjelland I, Dahl A, Tangen Haug T, et al. The validity of the Hospital Anxiety and Depression Scale: an updated literature review. *J Psychosom Res* 2002; 52:6 9-77.
10. Hermann C. International experiences with the Hospital Anxiety and Depression Scale - a review of validation data and clinical results. *J Psychosom Res* 1997; 42: 17-41.
11. Sherbourne CD, Stewart AL. The MOS Social Support Survey. *Soc Sci Med* 1991; 32: 705-714.
12. Watson M, Law M, M dos Santos, Greer S, Baruch J, Bliss J. The mini-MAC : Further development of the mental adjustment to cancer scale. *J Psychosoc Oncol* 1994; 12: 33-46.
13. Hosmer D, Lemeshow S. *Applied logistic regression*. New York: Wiley, 1989.

14. Crawford JR, Henry JD, Crombie C, et al. Brief report - Normative data for the HADS from a large non-clinical sample. *Br J Clin Psychol* 2001;40:429-434.
15. Australian Bureau of Statistics. *Mental health and well-being: profile of adults, Australia*. Canberra: Australian Bureau of Statistics, 1998.
16. Ayanian J & Jacobsen P. Enhancing research on cancer survivors. *J Clin Oncol* 2006; 24: 5149-5153.
17. Smith DP, Supramaniam R, King M, et al. Age, health, and education determine supportive care needs of men younger than 70 years with prostate cancer. *J Clin Oncol* 2007; 25: 2560-2566.
18. Girgis A, Boyes A, Sanson-Fisher RW, et al. Perceived needs of women diagnosed with breast cancer: rural versus urban location. *Aust N Z J Public Health* 2000; 24: 166-173.

Figure 1: Prevalence of clinically important levels of anxiety and depression among long-term cancer survivors compared to the general population

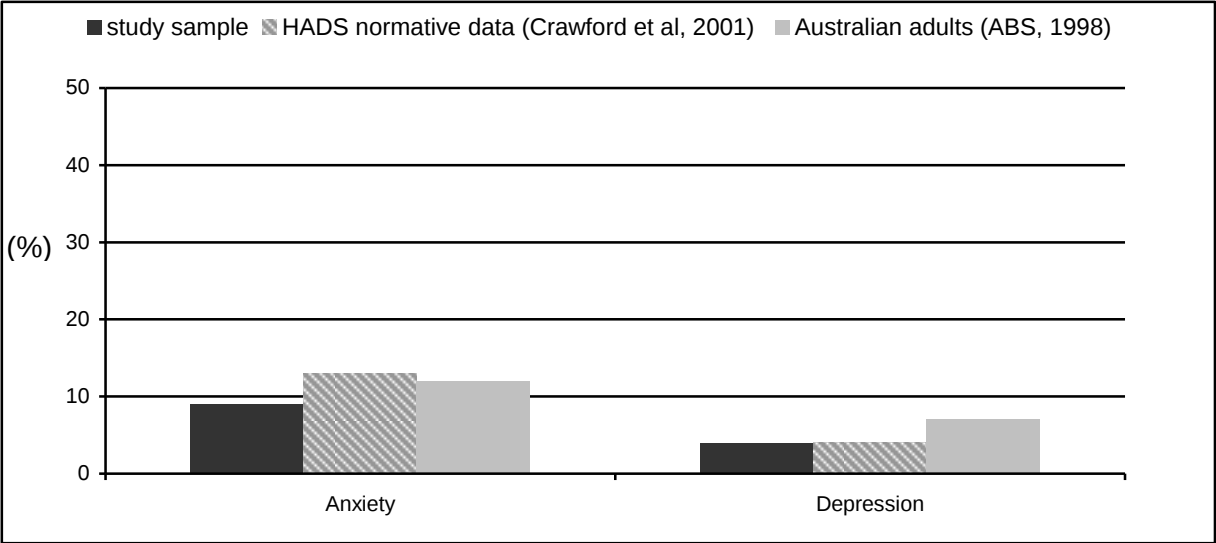


Table 2: Use of psychological support services in the previous 6-months by survivors with clinical/borderline levels of anxiety or depression

		General Practitioner	Support group	Psychologist/ social worker/ counsellor/ psychiatrist
Anxiety	Clinical (n=76)	64%	7%	7%
	Borderline (n=101)	63%	4%	3%
Depression	Clinical (n=34)	59%	3%	3%
	Borderline (n=61)	52%	7%	5%

Table 2: Significant predictors of reporting clinical/borderline anxiety or depression

Variable	Anxiety				Depression			
	n	%	Odds Ratio (95% CI)	p	n	%	Odds Ratio (95% CI)	p
PATIENT CHARACTERISTICS								
Psychological treatment								
last 6 months								
Yes	61	61	7.94 (3.98-15.84)	***	62	37	6.10 (2.91-12.82)	***
No	691	18			698	8		
Current age								
18-49 years	117	29	3.98 (1.87-8.46)	**				
50-59 years	207	29	2.88 (1.45-5.70)					
60-69 years	240	17	2.13 (1.07-4.22)					
70+ years	188	13						
Marital status								
Not married/defacto	188	34	2.13 (1.30-3.50)	**				
Married/defacto	564	17						
Current work status								
Invalid pensioner					48	44	6.27 (2.72-14.49)	***
Household duties					74	8	0.76 (0.25-2.27)	
Paid employment					287	7	0.71 (0.36-1.40)	
Other					22	14	1.38 (0.27-6.91)	
Retired/pensioner					329	9		
Country born								
Missing					84	17	2.80 (1.30-6.04)	**
Not Australian born					112	16	2.29 (1.11-4.72)	
Australian born					564	9		
DISEASE and TREATMENT CHARACTERISTICS								
Spread at diagnosis								
Not localised	149	29	1.56 (0.90-2.70)	*				

Unknown spread	162	19	0.61 (0.33-1.12)
Localised	441	19	

In remission

Don't know				61	26	2.66 (1.21-5.87)	*
No				139	10	0.80 (0.39-1.68)	
Yes				560	9		

COPING STYLE and PERCEIVED SOCIAL SUPPORT

Anxious preoccupation

Yes	151	62	8.87 (5.37-14.64)	***	148	29	2.24 (1.15-4.33)	*
No	601	11			612	6		

Helpless-hopeless

Yes	125	55	3.28 (1.89-5.71)	***	126	33	3.50 (1.84-6.67)	***
No	627	14			634	6		

Cognitive avoidance

Yes					192	19	2.24 (1.22-4.10)	**
No					568	8		

Overall social support

Low	241	34	2.45 (1.52-3.96)	***				
Some	511	15						

Positive interaction

Low					248	20	3.13 (1.75-5.60)	***
Some					512	6		

***p <0.001; **p<0.01; *p<0.05
 % shows for each variable, the proportion of survivors who reported clinical/borderline levels