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

Allison W Boyes, Afaf Girgis, Alison C Zucca and Christophe Lecathelinais

ABSTRACT

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

Design and participants: Cross-sectional survey of 863 adults diagnosed with a new histologically confirmed cancer (local or metastatic) between 1 April and 30 November 1997 and still alive in 2002, living in NSW, able to read and understand English adequately, physically and mentally capable of participating, and aware of their cancer diagnosis, who were randomly selected from the New South Wales Central Cancer Registry.

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

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

Conclusions: By 5 years after diagnosis, most survivors had adjusted well to their cancer experience, with levels of anxiety and depression similar to those of the general population. Nevertheless, a small and important group of long-term survivors continue to experience adverse psychological effects and need assistance. Monitoring of psychological wellbeing and referring patients when appropriate need to be integrated into routine care for cancer survivors.

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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%–23% of cancer patients experience clinically significant anxiety and 20%–35% experience depression. The impact of these psychological disorders can be considerable, and can have 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 about 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 wellbeing of long-term cancer survivors (those surviving more than 5 years).

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

Understanding the extent to which cancer affects 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. 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 adult long-term cancer survivors at 5–6 years after diagnosis.

METHODS

Long-term cancer survivors who had been diagnosed with a new histologically confirmed cancer (local or metastatic) 5–6 years earlier, were aged between 18 and 75 years at the time of diagnosis, currently alive, and living in New South Wales, were randomly selected from potentially eligible patients with cancer who were diagnosed between 1 April and 30 November 1997, still alive in 2002, and registered at the NSW Central Cancer Registry. The Registry confirmed with survivors' general practitioners or referring doctors that they could read and understand English adequately, were physically and mentally capable of participating, aware of the cancer diagnosis, and could be contacted about the study. The Registry contacted eligible survivors, and asked for their permission to forward their contact details to the researchers.

Between 1 April 2002 and 20 October 2003, survivors who agreed to being contacted 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 later) and one reminder telephone call (6 weeks later). Survivors' personal and clinical information was obtained from the cancer notification held by the Registry, including date of birth, sex, date of diagnosis, primary cancer type and spread of disease at diagnosis.

The human research ethics committees of the University of Newcastle and the Cancer Council NSW approved the study.

Measures

Our findings are based on the following instruments:

- ***Hospital Anxiety and Depression Scale (HADS):*** a commonly used 14-item screening tool for anxiety and depression. Each item is rated on a four-point scale, with scores ranging from zero to 21 for each subscale. 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]

- ***Medical Outcomes Study 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 five-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 in chronically ill patients.[11]
- ***The Mini-Mental Adjustment to Cancer (mini-MAC) Scale:*** a 29-item tool assessing five cancer-specific coping strategies (helplessness–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; current remission status; time since last hospital admission; health professionals consulted in past 6 months; any treatment for psychiatric illness, anxiety or depression in past 6 months; marital status; education level; current employment status; health insurance status; gross household income; and number of adults and children living with the patient.

Statistical analysis

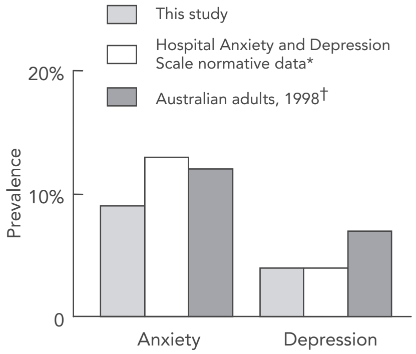
Missing data were imputed only for those measures (MOS-SSS and mini-MAC) that recommend this procedure for handling missing data. Participants' responses to the HADS were scored and categorised as normal (0–7), borderline (8–10) or clinical (11–21) levels of anxiety and depression.[8] To explore whether any individual, disease, treatment, social support or coping characteristics predicted borderline or clinical levels of anxiety and depression, each potential predictor variable was tested for association using χ^2 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 remaining variables in the model were significant ($P<0.05$).[13]

RESULTS

There were 6854 potentially eligible patients with cancer registered at the NSW Central Cancer Registry, of whom 2029 were randomly selected. Of these, 1374 were identified as eligible and were contacted by the Registry for permission to be contacted by us for our study. A total of 1008 survivors who agreed to be contacted were mailed the self-administered survey, and 863 survivors indicated their consent to participate by returning a completed survey; this gave an overall participation rate of 63% of eligible patients. There were no significant differences between those who did and did not return a completed survey in terms of cancer type, spread of disease, age, sex, country of birth, and Aboriginal and Torres Strait Islander status.

Participants were surveyed at a mean of 5.5 years after diagnosis (SD, 3 months), and their median age was 63 years (range, 26–76 years). A little more than half (55%) were female; most were diagnosed with breast (29%), prostate (15%), melanoma (15%) or colorectal (13%) cancer; and 58% had localised disease at the time of diagnosis. Many had had surgery (85%), radiotherapy (45%), chemotherapy (25%) and/or hormone therapy (24%). Compared with all 6854 patients with cancer diagnosed in NSW from 1 April to 30 November 1997 and still alive in 2002, the study sample was not representative in terms of age ($\chi^2 = 11.97$; df, 3; $P = 0.007$) and cancer type ($\chi^2 = 26.59$; df, 7; $P<0.001$). Our sample included significantly fewer survivors aged 18–39 years (9%) than expected (13%), and more breast cancer survivors (29%) than expected (23%).

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



* Hospital Anxiety and Depression Scale normative data.[14] † Australian Bureau of Statistics data.[15] ◆

Levels of anxiety and depression

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

As shown in Box 2, at least half of the survivors with clinical/borderline levels of

2 Use of psychological support services by long-term cancer survivors in the previous 6 months, by level of anxiety and depression

	Anxiety level ($n = 846$)			Depression level ($n = 847$)		
	Clinical	Borderline	Normal	Clinical	Borderline	Normal
Total patients	76	101	669	34	61	752
Use of services						
General practitioner	51 (67%)	65 (64%)	350 (52%)	23 (68%)	32 (52%)	411 (55%)
Support group	5 (7%)	4 (4%)	29 (4%)	1 (3%)	4 (7%)	33 (4%)
Psychologist/social worker/counsellor/psychiatrist	5 (7%)	3 (3%)	12 (2%)	1 (3%)	3 (5%)	16 (2%)

3 Significant predictors of reporting clinical or borderline anxiety or depression in long-term cancer survivors

	Anxiety			Depression		
Variable*	No. (*n* = 752)	Odds ratio (95% CI)	*P*	No. (*n* = 679)	Odds ratio (95% CI)	*P*
Patient characteristics						
Psychological treatment in past 6 months			< 0.001			< 0.001
Yes	61	7.94 (3.98–15.84)		54	6.58 (2.99–14.51)	
No	691			625		
Current age			0.003			
18–49 years	117	3.98 (1.87–8.46)				
50–59 years	207	2.88 (1.45–5.70)				
60–69 years	240	2.13 (1.07–4.22)				
⩾ 70 years	188					
Marital status			0.003			
Not married/de facto	188	2.13 (1.30–3.50)				
Married/de facto	564					
Current work status						< 0.001
Invalid pensioner				43	6.72 (2.81–16.07)	
Household duties				67	0.95 (0.32–2.82)	
Paid employment				254	0.69 (0.32–1.49)	
Other				21	1.61 (0.32–7.97)	
Retired/pensioner				294		
Country of birth						0.029
Not Australia				113	2.23 (1.09–4.56)	
Australia				566		
Disease and treatment characteristics						
Spread at diagnosis			0.033			
Regional/metastatic	149	1.56 (0.90–2.70)				
Unknown	162	0.61 (0.33–1.12)				
Localised	441					
In remission						0.049
Don't know				55	2.57 (1.11–5.95)	
No				119	0.76 (0.33–1.77)	
Yes				505		
Coping style and perceived social support						
Helpless–hopeless			< 0.001			< 0.001
Yes	125	3.28 (1.89–5.71)		112	4.51 (2.37–8.56)	
No	627			567		
Cognitive avoidance						0.004
Yes				169	2.56 (1.35–4.84)	
No				510		
Anxious preoccupation			< 0.001			
Yes	151	8.87 (5.37–14.64)				
No	601					
Overall social support			< 0.001			
Low	241	2.45 (1.52–3.96)				
Some	511					
Positive interaction						< 0.001
Low				222	3.10 (1.64–5.84)	
Some				457		

* Variables that remained in the final regression model for anxiety and the final regression model for depression.

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anxiety or depression reported seeing their GP in the previous 6 months, but less than 10% reported receiving specialist psychological care from a psychologist, psychiatrist, social worker or counsellor.

Predictors of clinical or borderline levels of anxiety and depression

Coping styles and a history of psychological or psychiatric illness were the variables that most widely predicted clinical or borderline levels of anxiety and depression among long-term cancer survivors (Box 3).

Long-term survivors who engaged in the maladaptive coping style of helplessness–hopelessness had at least three times the odds of reporting clinical or borderline levels of anxiety or depression compared with survivors who did not use this strategy. In addition, clinical or borderline levels of depression were also predicted by the use of the cognitive avoidance coping style, while clinical or borderline levels of anxiety were also predicted by anxious preoccupation.

As would be expected, survivors who were treated for anxiety, depression or psychiatric illness in the past 6 months had at least six times the odds of reporting high levels of anxiety and depression compared with those who hadn't received such treatment. With regard to other patient characteristics, anxiety was also significantly more likely in younger survivors than in 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 with those who were retired or non-invalid pensioners, as did those who were not born in Australia compared with Australian-born survivors.

Survivors' perceived level of social support was also a strong predictor of wellbeing. Clinical or borderline levels of anxiety were more likely among survivors who reported low levels of overall support, while clinical or 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 regional spread/metastatic disease had greater odds of being anxious compared with 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.

DISCUSSION

Contrary to popular opinion,[4] the results of this study suggest that life after cancer is not all doom and gloom. By 5–6 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 with those of the general Australian population.[15] Although we did not have an age- and sex-matched control group to compare our survivors' rates of anxiety and depression against, our findings are consistent with other previously published research conducted in the US 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 lives of cancer survivors when psychological wellbeing returns to population levels.

Our study's major strengths were its large-scale, population-based approach and the diversity of cancer survivors included. Our participation rate of 63% of all eligible survivors is comparable with or better than participation rates achieved by other Australian population-based studies.[16,17] Given that our sample shows evidence of selection bias on only two of five key characteristics (age and cancer type), we are confident that our results are, by and large, representative of and generalisable to long-term cancer survivors in NSW. As it is known that younger age is associated with an increased risk of psychosocial problems,[2] the under-representation of younger survivors (aged 18–39 years) in our sample is likely to have resulted in a slight underestimation 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 experience adverse psychological effects and need assistance. Our findings suggest that long-term cancer survivors with a history of psychological or psychiatric illness, maladaptive coping styles and poor social support should be routinely monitored as they have an increased risk of psychological problems. To date, most research seeking to identify risk factors for impaired psychosocial wellbeing has focused on demographic, disease and treatment variables.[18] Our study has extended this body of research by identifying modifiable risk factors that can be targeted for intervention or prevention.

That more than half of anxious or depressed survivors in our sample reported seeing their GP 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 6 months before being surveyed. This suggests that monitoring of psychological wellbeing and referring patients when appropriate need to be integrated into routine care for cancer survivors.

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COMPETING INTERESTS

None identified.

AUTHOR DETAILS

Allison W Boyes, BA(Psych), MPH, Behavioural Scientist
Afaf Girgis, BSc(Hons), PhD, Director
Alison C Zucca, BA(Psych)(Hons), Research Officer
Christophe Lecathelinais, DESS de Mathématiques Appliquées, Statistician
Centre for Health Research & Psycho-oncology, Cancer Council New South Wales, University of Newcastle and Hunter Medical Research Institute, Newcastle, NSW.
Correspondence:
allison.boyes@newcastle.edu.au

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