

# Is psychological distress in people living with cancer related to the fact of diagnosis, current treatment or level of disability?

## Findings from a large Australian study

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It is widely accepted that people living with a diagnosis of cancer experience higher levels of psychological distress than the general population.<sup>1,2</sup> However, cancer is a heterogeneous condition, and recent evidence suggests that although high levels of psychological distress are seen at the time of diagnosis and treatment<sup>3</sup> and with advanced disease,<sup>4</sup> long-term survivors may have similar rates of anxiety and depression to the general population.<sup>5</sup> There is a lack of reliable evidence on the joint contributions of the diagnosis of cancer, current treatment and functional impairment to psychological distress.

In this study, we aimed to investigate the separate and combined associations of cancer diagnosis, current treatment and functional impairment with psychological distress in a large cohort of Australian adults.

### METHODS

The 45 and Up Study is a large-scale study of healthy ageing of men and women from the general population of New South Wales, Australia. It is described in detail elsewhere.<sup>6</sup> Briefly, individuals aged 45 years and over were sampled from the Medicare Australia database, with oversampling of rural residents and older people. Participants joined the study by completing a postal questionnaire and providing written consent for follow-up. Recruitment began on 1 February 2006. These analyses relate to 89 574 participants who joined the study up to 30 April 2008 and had valid Kessler Psychological Distress Scale (K10) scores.<sup>7,8</sup>

All the variables we examined in this study were from self-reported data from the 45 and Up Study questionnaire (available at <http://www.45andUp.org.au>), apart from remoteness of residence, which was derived from the Accessibility Remoteness Index of Australia Plus (ARIA+)<sup>9</sup> score for each participant's postcode. Relevant variables were grouped according to the categories in Box 1 and Box 2.

### ABSTRACT

**Objective:** To investigate whether the observed elevated levels of psychological distress in cancer survivors relate specifically to aspects of cancer diagnosis, to treatment or to disability.

**Design, participants and setting:** Self-reported questionnaire data on demographic, health and lifestyle factors and mental health from 89 574 Australian men and women aged 45 years or older, sampled from the Medicare database for the 45 and Up Study from 1 February 2006 to 30 April 2008. Logistic regression was used to examine the risk of high levels of psychological distress in relation to cancer diagnosis and disability, adjusting for age, sex, income and education.

**Main outcome measure:** High psychological distress (Kessler Psychological Distress Scale score  $\geq 22$ ).

**Results:** Overall, 7.5% of participants had high levels of psychological distress. Among cancer survivors, the median time since diagnosis was 7.3 years. Compared with people without cancer, the odds ratios (95% CIs) for psychological distress were: 1.17 (1.09–1.26) in people reporting having had any cancer apart from non-melanoma skin cancer; 1.34 (1.08–1.67) in those with cancer diagnosed in the previous year; 1.53 (1.33–1.76) for those reporting treatment for cancer in the previous month and 1.11 (1.03–1.19) for those with cancer but without recent treatment. Using individuals with neither cancer nor disability as the reference group, the adjusted odds ratio (95% CI) for psychological distress was 6.51 (5.95–7.12) in those reporting significant disability but no cancer, 1.14 (1.04–1.24) in those without disability but with cancer and 5.81 (4.88–6.91) in those with both cancer and disability.

**Conclusion:** The risk of psychological distress in individuals with cancer relates much more strongly to their level of disability than it does to the cancer diagnosis itself.

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The outcome measure used in these analyses was symptoms of psychological distress over the previous 4 weeks,<sup>10</sup> as measured by the K10.<sup>7</sup> Scores on the K10 range from 10 (no distress) to 50 (severe distress), and scores of 22 and above were considered indicative of high levels of psychological distress.<sup>11</sup>

Individuals who reported needing assistance with daily tasks because of long-term illness or disability were considered to have a major disability. Functional capacity was measured using the physical functioning subscale of the Medical Outcomes Study Short Form 36-item Health Survey (MOS SF-36), which asks participants about whether they are limited in their ability to perform vigorous and moderate physical activities and tasks such as: lifting shopping; climbing stairs; walking; bending, kneeling or stooping; and bathing or dressing. Those with a score of 100 were considered to have

no functional limitations and those with scores of 90–99, 60–89, and 0–59 to have minor, moderate and severe limitations, respectively.

Participants who answered “yes” to the question “Has a doctor ever told you that you have melanoma, breast cancer (for women), prostate cancer (for men) or other cancer (please specify)?” were classified as having had cancer. Time since diagnosis was calculated using participants' reported age at diagnosis. Participants who answered “yes” to the question “In the last month have you been treated for cancer?” were classified as having had recent treatment for cancer. Non-melanoma skin cancer was not included in the overall diagnosis or treatment of cancer, but was investigated as a cancer subtype (see below). The coding of free-text data on “other” cancer types was incomplete at the time of writing, so further types of cancer could not be examined.

Ethics approval for the study was provided by the University of New South Wales Human Research Ethics Committee.

**Statistical analysis**

Odds ratios (ORs) and 95% CIs for high levels of psychological distress according to a range of personal characteristics were estimated using unconditional logistic regression, adjusting where appropriate for age, sex, income and education. The relationship between cancer and psychological distress, including recency of diagnosis and recent treatment, was then examined, using the same adjustments. How much of any observed relationship could be attributed to disability was evaluated by estimating the relationship between disability and psychological distress in different categories of cancer diagnosis (breast cancer, prostate cancer, melanoma, current treatment) and by adding the functional impairment level to the regression model. Separate models, stratified by recent treatment and disability, were used to examine the association of psychological distress with breast cancer (women), prostate cancer (men), melanoma and non-melanoma skin cancer.

Sensitivity analyses were conducted to investigate whether the relationship between cancer and psychological distress could be accounted for by other factors such as smoking, alcohol consumption, physical activity and language spoken at home, by adding these separately to the regression model. Where specified, statistical interaction was evaluated by the Wald  $\chi^2$  statistic from the Type III sums of squares table.

All analyses were carried out in SAS software, version 9.13 (SAS Institute Inc, Cary, NC, USA). All statistical tests were two-sided, with a significance level of  $P < 0.05$ . Owing to the large sample size, conclusions were based on both significance and the effect size.

**RESULTS**

Overall, 7.5% of participants had K10 scores indicating high levels of psychological distress. The prevalence of high psychological distress generally decreased with increasing age, was significantly higher in those reporting lower educational qualifications, lower income, a language other than English spoken at home (Box 1) and current smoking (Box 2), and varied significantly according to work status (Box 1). The risk of high psychological distress was six to eight times greater in people needing help with daily tasks and

**1 Psychological distress in relation to demographic factors for 89 574 participants in the 45 and Up Study**

Demographic factor	Total no.	No. (%)	High psychological distress	
			Odds ratio adjusted for age and sex	Odds ratio adjusted for age, sex, income and education (95% CI)
Male	43 394	2952 (6.8%)	1.00	1.00
Female	46 180	3808 (8.2%)	1.15	0.96 (0.91–1.01)
Age in years				
45–49	12 117	1263 (10.4%)	1.00	1.00
50–59	31 865	2860 (9.0%)	0.86	0.76 (0.71–0.82)
60–69	25 160	1536 (6.1%)	0.57	0.37 (0.34–0.40)
70–79	13 074	605 (4.6%)	0.43	0.23 (0.20–0.25)
80–89	6 864	437 (6.4%)	0.61	0.31 (0.27–0.35)
90 +	494	59 (11.9%)	1.19	0.57 (0.43–0.76)
Education				
School Certificate or less	28 425	2762 (9.7%)	2.22	1.45 (1.34–1.56)
Trade, certificate or diploma	29 211	2077 (7.1%)	1.48	1.12 (1.04–1.21)
Higher School Certificate or equivalent	8 714	636 (7.3%)	1.50	1.12 (1.01–1.24)
Tertiary	21 979	1161 (5.3%)	1.00	1.00
Annual income				
< \$20 000	16 436	2113 (12.9%)	5.55	4.86 (4.44–5.32)
\$20 000–\$49 999	23 059	1654 (7.2%)	2.37	2.16 (1.98–2.36)
\$50 000–\$69 999	9 945	592 (6.0%)	1.57	1.49 (1.33–1.66)
≥ \$70,000	21 649	931 (4.3%)	1.00	1.00
Place of residence				
Major city	38 891	2860 (7.4%)	1.00	1.00
Inner regional	32 422	2502 (7.7%)	1.05	0.93 (0.88–0.99)
Outer regional	16 359	1254 (7.7%)	1.05	0.86 (0.80–0.92)
Remote/very remote	1 791	136 (7.6%)	1.02	0.80 (0.67–0.96)
Work status				
Paid work	44 232	2761 (6.2%)	1.00	1.00
Home/family	3 407	316 (9.3%)	1.63	1.26 (1.11–1.43)
Retired	35 798	2231 (6.2%)	1.72	1.31 (1.21–1.42)
Unemployed	1 550	291 (18.8%)	3.79	2.41 (2.10–2.77)
Other	2 147	218 (10.2%)	2.16	1.61 (1.38–1.87)
Disabled/sick	2 440	943 (38.6%)	10.87	6.41 (5.79–7.08)
Language other than English spoken at home				
No	81 543	5734 (7.0%)	1.00	1.00
Yes	8 029	1026 (12.8%)	1.91	1.74 (1.62–1.88)

in those with functional impairment, than in those without such disabilities (Box 2).

A total of 14 380 participants (16.1%) reported having had cancer apart from non-melanoma skin cancer. People with cancer were more likely to have a significant disability; compared with those without cancer, the adjusted OR (95% CI) for requiring help with

daily tasks was 2.86 (2.45–3.18) for people with cancer treated in the past month and 1.27 (1.17–1.39) in people with cancer but not treated in the past month. The median time since diagnosis among cancer survivors was 7.3 years, with 1023 (1.1%) being diagnosed within about the previous year. Compared with people without cancer, the ORs

**2 Psychological distress in relation to lifestyle and disability factors for 89 574 participants in the 45 and Up Study**

Lifestyle or disability factor	Total no.	No. (%)	High psychological distress	
			Odds ratio adjusted for age and sex	Odds ratio adjusted for age, sex, income and education (95% CI)
<b>Smoking status</b>				
Never smoker	50 229	3134 (6.2%)	1.00	1.00
Past smoker	32 177	2417 (7.5%)	1.30	1.25 (1.18–1.33)
Current smoker	6 669	1157 (17.3%)	2.97	2.27 (2.11–2.46)
<b>Alcohol consumption</b>				
0–6 drinks per week	53 685	4513 (8.4%)	1.00	1.00
7–13 drinks per week	16 904	938 (5.5%)	0.65	0.75 (0.70–0.81)
14–20 drinks per week	10 247	580 (5.7%)	0.68	0.79 (0.72–0.86)
≥21 drinks per week	7 323	533 (7.3%)	0.90	0.94 (0.86–1.04)
<b>Physical activity</b>				
Sufficient	60 821	3722 (6.1%)	1.00	1.00
Insufficient	28 753	3038 (10.6%)	1.84	1.72 (1.63–1.81)
<b>Major disability</b>				
Do not need help with daily tasks	82 174	5134 (6.2%)	1.00	1.00
Need help with daily tasks	4 065	1237 (30.4%)	8.01	6.19 (5.72–6.70)
<b>Functional physical limitation</b>				
No functional limitation	27 820	1043 (3.7%)	1.00	1.00
Mild functional limitation	15 034	604 (4.0%)	1.25	1.25 (1.13–1.39)
Moderate functional limitation	27 112	1971 (7.3%)	2.77	2.51 (2.31–2.71)
Severe functional limitation	12 675	2532 (20.0%)	10.53	8.02 (7.38–8.71)

for psychological distress were 1.34 (1.08–1.67) in those with cancer diagnosed in the previous year, and 1.20 (0.97–1.49), 1.04 (0.90–1.22) and 1.13 (1.04–1.24) for those diagnosed 1–2, 3–4 and 5 or more years previously, respectively.

Compared with individuals without cancer, the adjusted OR for a high level of psychological distress was 1.17 (1.09–1.26) in individuals reporting having had cancer apart from non-melanoma skin cancer, 1.53 (1.33–1.76) for those reporting cancer treatment in the previous month and 1.11 (1.03–1.19) for those reporting cancer without treatment in the previous month (Box 3;  $P$ [heterogeneity] < 0.001 for recent treatment v not recent treatment, among cancer survivors). Additional adjustment for smoking status, alcohol consumption, physical activity and language other than English spoken at home did not change these ORs materially (ie, the OR changed by < 5%) so these factors were not included in the final model.

Using individuals with neither cancer nor disability as the reference group, the adjusted OR for psychological distress was 6.51 (5.95–7.12) in those reporting needing help with daily tasks but no cancer, 1.14 (1.04–1.24) in those with cancer but not needing help and 5.81 (4.88–6.91) in those with cancer and needing help with daily tasks (Box 3). A similar pattern of increasing psychological distress with increasing degree of functional limitation was seen, independent of the diagnosis of cancer (Box 3). There was no significant difference in the effect of functional limitation on psychological distress according to cancer survivor status ( $P$ [interaction] = 0.60), and, although the relationship between needing help with daily tasks and psychological distress was significantly attenuated in cancer survivors compared with cancer-free individuals ( $P$ [interaction] = 0.01), this difference did not appear to be clinically meaningful (Box 3). When the OR for psychological distress in people with cancer treated in the previous

month versus those without cancer was further adjusted for level of functional limitation, it decreased from 1.53 to 1.16 (1.00–1.34), confirming that functional limitation, was responsible for a substantial proportion of the overall effect.

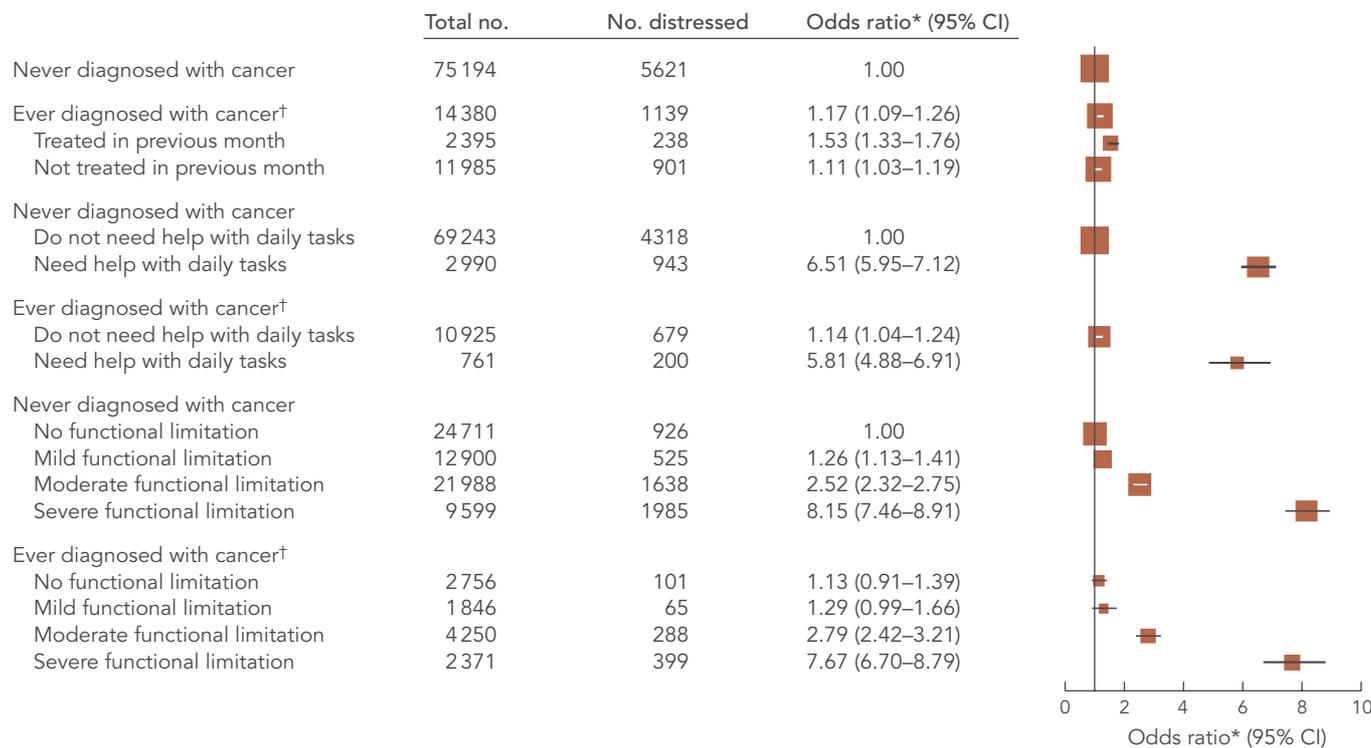
High psychological distress did not differ significantly between men without cancer and those reporting prostate cancer, regardless of treatment status (Box 4). Men reporting recent treatment for melanoma or for “other cancers” (ie, other than prostate cancer, melanoma and non-melanoma skin cancer) had significantly increased distress, but this was of borderline significance in those with melanoma (Box 4). For women, there was no significant difference in psychological distress between those without cancer and those reporting breast cancer or melanoma cancer, regardless of recent treatment status. There was a significantly increased risk of high psychological distress among those with “other” cancers, both with and without recent treatment and with or without disability. Men and women ever diagnosed with non-melanoma skin cancer had a small, marginally significant reduction in the risk of psychological distress (Box 4). The OR for psychological distress related much more strongly to disability than to site-specific cancer diagnosis (Box 4).

**DISCUSSION**

In this large population-based sample the risk of psychological distress was around six to eight times higher in those reporting significant disability compared with those without disability. In contrast, among those without disability, the level of psychological distress among those with cancer was around 14% higher than those without cancer. Hence, the excess risk of psychological distress attributable to disability is about 40 times greater on average than that attributable to cancer diagnosis, in the absence of disability, among long-term survivors.

A diagnosis of cancer is associated with increased psychological distress.<sup>2</sup> Other studies have shown that physical disability is one of the most consistent predictors of psychological distress, in the general population.<sup>2,12</sup> The interaction between mental health and disability is complex; depression predicts the onset and progression of both social and physical disability, and psychological distress can contribute to functional impairment.<sup>13</sup> The measure of disability that we used, relating to needing help with daily tasks, does not specify the cause of the disability and therefore

3 Odds ratios for high psychological distress according to cancer diagnosis, recent treatment and disability



Odds ratios in the graph are presented as squares with areas proportional to the amount of statistical information; horizontal black or white lines represent the 95% CI.

\* Adjusted for age, sex, income and education. † Excluding non-melanoma skin cancer.

includes disability resulting from mental health problems. The measure of functional capacity relates predominantly to physical disability. The few studies to investigate the association between disability and psychological distress among people with cancer have tended to focus on cancers at specific sites and, consistent with our findings, have observed functional impairment to be the most important predictor of psychological distress in patients with lung cancer<sup>14</sup> and ovarian cancer.<sup>15</sup> One study found increased depression and anxiety in cancer survivors who were recipients of disability-support pensions.<sup>5</sup> Other factors, such as pain and side effects of treatment, may also play a role. As with previous studies, our findings show recent cancer diagnosis and treatment to be associated with increased distress<sup>3,4,15</sup> and that some increase in distress may persist in the long term.<sup>16,17</sup>

The association between psychological distress and cancer may also vary according to other factors such as the cancer type, stage, grade and prognosis. In a previous study of patients with predominantly newly diagnosed cancer, psychological distress was highest for cancers associated with a poor

prognosis, such as those of the lung, pancreas, brain and liver.<sup>4</sup> Although we were able to present new insights showing minimal effects on psychological distress of a diagnosis of breast cancer, prostate cancer, melanoma and non-melanoma skin cancer, practical constraints prevented us from exploring this in depth for other cancer types. The increased risk of distress in those with “other” cancer types may reflect the proportion of tumours associated with a poor prognosis in this group; it would be of interest to explore this further, using linkage to cancer registrations among participants.

In this article, we address specific questions around the relationship between psychological distress, cancer diagnosis and disability. Many other factors are likely to contribute to distress in cancer survivors, including previous psychiatric disease, comorbidity, pain and symptom burden. Although we did not investigate these, it is important to note that individuals with multiple risk factors are likely to be at particularly high risk of psychological distress.

The large size, population-based nature and wide age range of the 45 and Up Study allowed us to examine both main effects and interactions between groups of interest. The

study uses a well established and validated measure of psychological distress,<sup>10</sup> incorporating both anxiety and depression. The K10 does not permit separate consideration of anxiety or depression, because the scores on individual items are highly correlated with each other and with the total score (overall alpha, 0.88). Nor are we able to determine whether the distress, or disability, is acute or chronic in nature. The 45 and Up Study questionnaire has two measures of general functional impairment, but does not allow direct attribution of disability to cancer. These analyses use cross-sectional data, so it is not possible to establish the temporal relationship between the diagnosis of cancer and the occurrence of psychological distress. However, our findings regarding recency of diagnosis and the role of disability are reassuring, as they suggest intuitively reasonable temporal and aetiological relationships that are consistent with the evidence to date.

The 45 and Up Study is a population-based cohort study, with a response rate of 18%,<sup>6</sup> which is in keeping with other cohort studies of this nature. It is important to note that both theoretical<sup>18</sup> and empirical<sup>19</sup> evidence shows that representativeness is not necessary for generating reliable estimates of

4 Psychological distress in relation to cancer type,\* recency of diagnosis and disability

	Men			Women		
	Total men	High psychological distress		Total women	High psychological distress	
		No. (%)	Odds ratio† (95% CI)		No. (%)	Odds ratio† (95% CI)
Never diagnosed with cancer	26 455	1897 (7.2%)	1.00	31 165	2664 (8.5%)	1.00
Ever diagnosed with cancer						
Prostate/breast cancer	1 274	73 (5.7%)	1.02 (0.80–1.31)	1 441	93 (6.5%)	0.82 (0.66–1.02)
Melanoma	1 291	106 (8.2%)	1.24 (1.01–1.53)	1 046	79 (7.6%)	0.88 (0.69–1.11)
Non-melanoma skin cancer	9 693	540 (5.6%)	0.89 (0.81–0.99)	8 419	565 (6.7%)	0.86 (0.78–0.95)
Other cancer	1 368	114 (8.3%)	1.30 (1.06–1.59)	1 850	205 (11.1%)	1.32 (1.13–1.54)
Treated for cancer in last month						
Prostate/breast cancer	241	16 (6.6%)	1.21 (0.72–2.03)	286	23 (8.0%)	0.89 (0.64–1.52)
Melanoma	28	5 (17.9%)	2.75 (1.01–7.52)	11	2 (18.2%)	2.01 (0.41–9.93)
Non-melanoma skin cancer	325	26 (8.0%)	1.37 (0.91–2.07)	134	9 (6.7%)	0.81 (0.41–1.61)
Other cancer	261	34 (13.0%)	1.91 (1.31–2.78)	183	29 (15.8%)	2.02 (1.35–3.04)
Not treated for cancer in last month						
Prostate/breast cancer	1 033	57 (5.5%)	0.98 (0.74–1.29)	1 155	70 (6.1%)	0.78 (0.61–1.00)
Melanoma	1 263	101 (8.0%)	1.21 (0.98–1.50)	1 035	77 (7.4%)	0.87 (0.68–1.10)
Non-melanoma skin cancer	9 368	514 (5.5%)	0.88 (0.79–0.98)	8 285	556 (6.7%)	0.86 (0.78–0.95)
Other cancer	1 107	80 (7.2%)	1.15 (0.90–1.46)	1 667	176 (10.6%)	1.25 (1.06–1.47)
Not needing help with daily tasks						
Never diagnosed with cancer	24 271	1419 (5.8%)	1.00	28 446	2052 (7.2%)	1.00
Prostate/breast cancer	1 145	49 (4.3%)	1.00 (0.75–1.35)	1 317	68 (5.2%)	0.80 (0.62–1.03)
Melanoma	1 198	81 (6.8%)	1.28 (1.01–1.62)	981	65 (6.6%)	0.93 (0.72–1.20)
Non-melanoma skin cancer	9 100	422 (4.6%)	0.92 (0.82–1.03)	7 900	454 (5.7%)	0.90 (0.81–1.00)
Other cancer	1 205	84 (7.0%)	1.40 (1.11–1.77)	1 632	151 (9.3%)	1.34 (1.12–1.59)
Needing help with daily tasks						
Never diagnosed with cancer	1 019	356 (34.9%)	7.13 (6.14–8.28)	1 285	413 (32.1%)	6.09 (5.32–6.97)
Prostate/breast cancer	84	22 (26.2%)	6.40 (3.85–10.63)	89	20 (22.5%)	4.05 (2.41–6.80)
Melanoma	58	22 (37.9%)	8.34 (4.74–14.67)	49	13 (26.5%)	5.78 (2.99–11.16)
Non-melanoma skin cancer	366	94 (25.7%)	6.03 (4.68–7.78)	362	94 (26.0%)	5.38 (4.18–6.92)
Other cancer	132	30 (22.7%)	4.62 (2.99–7.14)	175	51 (29.1%)	5.25 (3.72–7.40)

\* The cancer types listed here contain individuals with only that specific cancer type; individuals reporting multiple cancer types are not included in this table.  
 † Adjusted for age, sex, income and education.

relative risk based on internal comparisons from within such a cohort, including those relating to psychological distress. Cancer survivors included in the 45 and Up Study may not be representative of cancer survivors more broadly. There may have been an under-representation of those with aggressive disease, cancers with a poor prognosis or advanced disease, and those on current treatment, including rural residents attending urban-based treatment facilities; this potential bias would generally cause under-estimation of the association between cancer and psychological distress.

A number of additional factors have the potential to confound the relationship between cancer and psychological distress,

including alcohol consumption, smoking, physical activity, remoteness of residence and language. However, further adjustment for these factors did not have a material effect on the conclusions reached. Although our findings are consistent with a small increase in the risk of psychological distress in cancer survivors without significant disability, it is possible that this minor increase is due to residual confounding.

The cancers included in our study are based on self-report. Although this provides a good general indication of cancer status, especially for breast and prostate cancer, the validity of such data varies according to cancer site and other factors,<sup>20-23</sup> results on non-melanoma skin cancer in particular

should be regarded with caution. As the main issue with self-reported cancer relates to reduced sensitivity for some cancer sites, and as specificity is generally good, any resulting bias would tend to lead to more conservative estimates of effect in relation to psychological distress.

Many people with cancer have excellent long-term survival with minimal disability, but a significant number experience physical disability as a result of their cancer, its treatment, or some other comorbid condition. Although it is somewhat academic in this context to separate out the effect of cancer diagnosis from the effect of disability, these findings suggest that individuals are able to adapt to a previous diagnosis of

cancer where they have good functional capacity. Cancer survivors can be reassured that they should, in general, be able to re-establish their emotional equilibrium once they have been through the period of diagnosis and treatment, particularly if they remain able-bodied. The findings also suggest that, following the initial diagnosis and periods of treatment, psychological and other forms of support services for people with cancer may be particularly important for those with significant disability.

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## COMPETING INTERESTS

None identified.

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