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Physical disability and psychological distress before and after a diagnosis of cancer: evidence on multiple cancer types from a large Australian cohort study, compared to people without a cancer diagnosis

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Abstract

Background Although most people with cancer now survive long-term, evidence on long-term person-centred outcomes in survivors is limited, particularly relative to people without cancer. We quantified changes in physical and psychological outcomes among adults aged ≥ 45 years from pre- to post-cancer-diagnosis, for multiple cancer types and compared to changes in people without cancer.

Methods Questionnaire data from the Australian population-based 45 and Up Study were linked to cancer registrations, hospitalisations and deaths; those without cancer at baseline (2006–2009) and participating in a follow-up survey (by 2015) were included (n = 142,682). Generalised linear models quantified changes in physical functioning (MOS-PF score, range = 0–100) and psychological distress (Kessler-10 score, range = 10–50) between surveys in people diagnosed and not diagnosed with cancer between surveys, adjusting for confounding factors.

Results Overall, 9313 individuals had incident cancer (12.2/1000 person-years; median follow-up=5.2 years). Among those without cancer, 30.0% had moderate or severe physical functioning limitations at baseline, increasing to 40.6% at follow-up; corresponding figures were 35.2% and 52.3%, respectively, in participants with incident cancer. Around 80% of those with and without incident cancer had low psychological distress at baseline and follow-up. Compared to those without cancer, cancer survivors had greater average physical functioning declines (mean-score: 77.5 versus 82.9 at follow-up; mean-change: -8.31 versus -4.71; adjusted-difference -2.55 (95%CI = -2.97-2.13)) and slightly greater increases in psychological distress (mean-score: 13.6 versus 13.5 at follow-up; mean-change: 0.24 versus -0.04; adjusted-difference 0.21 (95%CI = 0.12-0.31)). Physical outcomes varied by cancer type with greater deterioration with multiple myeloma, lung cancer and leukaemia and lesser declines with breast, colorectal and prostate cancers. Greater deterioration in physical and psychological outcomes were observed in cancer survivors with more advanced

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disease at diagnosis and recent cancer treatment at follow-up; psychological outcomes in those not receiving recent treatment did not differ from cancer-free participants.

Conclusions On average, cancer survivors experienced greater declines in physical wellbeing than people without cancer and minimal differences in psychological distress. Those not receiving recent cancer treatment and those with many common cancer types had physical and psychological outcomes comparable to people without cancer. Additional targeted support may particularly benefit those receiving treatment, with specific cancer types, and advanced disease.

Keywords Cancer, Physical functioning, Psychological distress, Survivorship, Change in outcomes, Cohort

Background

There were an estimated 20 million new cases of cancer and 9.7 million cancer deaths in 2022 worldwide [1]. Overall survival among people with cancer has increased, largely due to improvements in early detection and disease management [2]. In Australia, the 5-year relative survival rate for all cancers combined increased from 50.2% in 1989–1993 to 70.6% in 2015–2019 [3]. In 2021, over one million people in Australia were estimated to have been diagnosed with cancer at some stage in their lives. This number is expected to grow as cancer incidence and survival continue to increase [4], highlighting the importance of understanding and promoting the long-term health of cancer survivors [5].

Person-centred outcomes, including physical and psychological wellbeing, are recognised as important for quality of life. Research to date indicates that while cancer survivors are on average more likely to experience physical disability and slightly higher psychological distress than those without cancer, there is marked variation according to cancer stage and type [6].

To provide robust evidence to inform policy, practice and the community, it is important to understand the extent to which person-centred outcomes change from before to after a cancer diagnosis, above and beyond background changes occurring over time, in the absence of such a diagnosis [7]. Given the heterogeneity of cancer, it is also important that data relate to a range of cancer types. However, reliable evidence is lacking, since virtually all studies to date have not had measures of personcentred outcomes before and after cancer diagnosis in the same individuals. Furthermore, most studies have been limited to single cancer types [8–10] and short-term outcomes [8–12] and have lacked controls without cancer [13–17].

This study aims to provide large-scale evidence of the change in physical functioning and psychological wellbeing, from pre- to post-diagnosis of a registry-notified cancer in comparison with changes among participants without such a diagnosis, over a comparable period. Changes in outcomes were quantified, accounting for potential confounding and mediating factors—for any type of cancer as well as separately for a range of specific cancer types, and according to time since diagnosis, stage of cancer at diagnosis and cancer treatment in the past month at follow-up.

Methods

Data sources

The Sax Institute's 45 and Up Study is a cohort study of 267,357 men and women aged 45 years and over, randomly sampled from the general population of New South Wales (NSW), Australia, using the Services Australia Medicare enrolment database. Regional and remote areas and those aged 80 years and over were over-sampled. Individuals joined the study by completing postal baseline questionnaires distributed from 2005 to 2009 and consenting to long-term follow-up through repeated surveys and linkage of their data to other population health databases. The response rate was 19%, and participants included ~11% of the NSW population aged 45 years and over.

Participants' follow-up data used in this analysis was obtained through the Social, Economic, and Environmental Factor (SEEF) Study survey in 2010 (100,000 questionnaires sent, n = 60,404 participants completed the questionnaire) and the Wave 2 survey from 2012 to 2015 (n = 142,548, 57.9% response rate). Details of the 45 and Up Study are described elsewhere [18]. Question items in the baseline and follow-up questionnaires can be viewed at http://www.45andup.org.au [19].

To ascertain cancer status, questionnaire data from study participants were linked probabilistically to administrative datasets, including data from the NSW Central Cancer Registry (CCR, 1 January 1994 to 31 December 2015) and NSW Admitted Patient Data Collection (APDC, 1 July 2001 to 31 December 2015). This probabilistic matching was conducted by the NSW Centre for Health Record Linkage (CHeReL) and is known to be highly accurate with false-positive and false-negative rates <0.5% [20]. Secure data access was provided through the Sax Institute's Secure Unified Research Environment. The NSW CCR dataset comprises records of all diagnosed primary cancers, including the date of diagnosis and International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM)-coded cancer types and sites, except C44 codes that indicate a basal cell carcinoma or a squamous cell carcinoma (which are not notifiable diseases; thus not reported to cancer registries). The APDC data is a complete census of all public and private hospital admissions in NSW and contains admissions details, including the primary reason for admissions using ICD-10-AM and up to 50 additional clinical diagnoses.

Study population

Following the exclusion of participants who withdrew from the study, invalid recruitment dates or invalid age, the original baseline survey data from the Sax Institute consisted of 266,720 participants. We excluded participants with invalid baseline questionnaire dates (n = 175, 0.07%), data linkage errors (n = 267, 0.1%), baseline age under 45 (n = 7, <0.1%) and a cancer history at baseline (n = 28,297, 10.59%). Finally, we excluded participants who did not respond to follow-up questionnaires (either SEEF or Wave 2 study) by December 2015 (n = 95,292, 35.67%). The analyses in this paper consisted of 142,682 individuals without a history of cancer at baseline, who participated in a follow-up survey.

A diagnosis of a cancer history at baseline was defined as a record of cancer in the CCR in the 12 years prior to baseline or a hospital admission for cancer, chemotherapy or radiotherapy in any of the 51 diagnosis code fields of the APDC in 5 years prior to baseline (Additional file 1: Table S1.1). The look-back periods were based on the availability of linked data, and they ensured a uniform probability of identification of previous cancer diagnoses for all participants.

Exposure

Following exclusion of all participants with cancer at baseline, the main exposure was an incident cancer diagnosis between the baseline and follow-up surveys (Additional file 1: Table S1.2). The follow-up survey date was defined as the date of completing either the SEEF or Wave 2 questionnaire, whichever was the latest. Participants were defined as having a cancer diagnosis if they had a record of cancer in the CCR database or hospitalisation for cancer in the primary diagnosis code field in APDC.

The cancer type and date of diagnosis were ascertained from either the CCR database or APDC. The 12 cancer types with the highest age-standardised incidence in Australia [4], as well as those with known adverse impacts on wellbeing (oesophageal cancer and multiple myeloma), were investigated separately; cancer of the pancreas was excluded due to the small number of cases in the 45 and Up Study. Cancer types were classified as breast (ICD-10-AM diagnosis code C50, women only), prostate (C61, men only), lung (C33–C34), melanoma (C43), colorectal (C18–C20), non-Hodgkin's lymphoma (NHL, C82–C86), kidney (C64), oesophagus (C15), uterus (C54–C55, women only), bladder (C67), thyroid (C73), leukaemia (C91–C95) and multiple myeloma (C90.0). All remaining cancers with a small number of patients were included in the "other cancer" category (Additional file 1: Table S1.3).

Time since diagnosis was calculated as the number of years from the date of incident cancer diagnosis to the last day of follow-up. The diagnosis closest to the baseline survey date was used if a participant had multiple cancers. Time since diagnosis was classified as less than 1 year, 1 to <2 years, 2 to <4 years and 4 or more years. Stage of cancer was ascertained from the CCR database. Extent of disease at diagnosis (shown as cancer stage) was classified as (1) localised to the tissue of origin, (2) regional spread to adjacent organs or regional lymph nodes and distant metastases and (3) unknown stage or missing (only solid cancers (ICD-10-AM diagnosis codes C00.0-C43.9 or C45.0-C80) were staged). Recent treatment was classified as yes or no based on the response to the question item in the follow-up survey: "In the last month, have you been treated for cancer?".

Outcomes

The main outcomes were changes in physical functioning limitation and psychological distress from the baseline survey date to the follow-up survey date (Additional file 1: Table S1.4). Physical functioning limitations were assessed using the Medical Outcomes Study Physical Functioning (MOS-PF) score [21], eliciting self-reported data on limitations in the ability to perform vigorous and moderate physical activities and tasks such as lifting or carrying shopping; climbing stairs; walking; bending, kneeling or stooping; and bathing or dressing. The MOS-PF is a valid and reliable measure of physical functioning [22]. MOS-PF scores range from 0 to 100, where higher scores represent fewer limitations [23], and were categorised as no limitation (MOS-PF = 100), minor limitations $(90 \leq MOS-PF < 100)$, moderate limitations $(60 \leq MOS-$ PF < 90) and severe limitations ($0 \leq MOS-PF < 60$). Psychological distress was assessed using the Kessler-10 (K10), a validated measure of non-specific symptoms of psychological distress [24]. Respondents indicated the frequency of symptoms experienced in the past 4 weeks, from 1 "none of the time" to 5 "all of the time". K10 scores range from 10 (no distress) to 50 (severe distress) [25] and were categorised as low distress ($10 \leq K10 < 16$), moderate distress (16 \leq K10 < 22) and high distress (22 \leq K10

 \leq 50). After logical imputation and backfilling for the 10 question items of the MOS-PF and K10 scores, participants with missing outcome data (n = 20,347, 14.3% for physical functioning limitation; n = 16,908, 11.9% for psychological distress) were excluded from the corresponding analyses.

Changes in the outcomes of physical functioning limitations and psychological distress were measured as the changes in scores of MOS-PF and K10, respectively. The score changes were calculated by subtracting a score on the baseline survey from a score on the follow-up survey.

Other variables

Sociodemographic and health characteristics included age, sex, education (no school certificate, certificate/ diploma/trade, university degree), region of residence, country of birth (Australian born, not Australian born), body mass index (BMI (kg/m^2) 15 to <18.5, 18.5 to <25, 25 to < 30 and 30-50), physical activity (tertiles of physical activity sessions per week weighted for intensity), smoking status (never/past/current smoker) and number of alcoholic drinks per week (0, 1–14, \geq 15 drinks per week) (Additional file 1: Table S1.5). Age at followup survey was categorised as 45-64 years, 65-79 years and \geq 80 years. The region of residence derived from the address was categorised as major city, inner regional, outer regional and remote/very remote. Other health conditions at follow-up were based on responses to questions of "has a doctor ever told you that you have...". Selfrated health and quality of life at follow-up were based on the question, "In general, how would you rate your overall health/quality of life?", followed by response options of "excellent", "very good", "good", "fair" and "poor".

Statistical analysis

The sociodemographic characteristics of the study population, as well as the clinical characteristics of cancer among those with incident cancer, were summarised using descriptive statistics. Categories of physical functioning limitations and psychological distress at followup according to those at baseline were used to summarise patterns of change in outcomes. Next, we summarised the change in outcomes, considered as continuous variables, from baseline to follow-up. We summarised the mean (standard deviation) scores at baseline and followup and further calculated the mean changes in scores from baseline to follow-up. Generalised linear models (GLMs) with Gaussian distribution and an identity link function estimated changes in physical functioning limitation or psychological distress in relation to incident cancer, adjusting for age at follow-up as a continuous variable, sex (male, female), education (no school certificate, certificate/diploma/trade, university degree), region of residence (major cities, inner regional, outer regional, remote/very remote areas), country of birth (Australia, not Australia), months of follow-up as a continuous variable and baseline level of outcome as a continuous variable. GLMs allow for direct estimation of change in physical and psychological outcomes while adjusting for relevant covariates. The coefficient of the cancer diagnosis variables indicated the difference in changes between those with incident cancer and non-cancer participants. We examined variations in this relationship according to cancer types, time since diagnosis, cancer stage at diagnosis and recent treatment (in the past month at follow-up).

Results

Overall

Of the 142,682 participants included in the study, 9313 were diagnosed with incident cancer over a median follow-up of 5.2 years, and 133,369 did not develop cancer. Compared to participants without cancer, a higher proportion of those diagnosed with incident cancer were male, had a history of smoking and had doctor-diagnosed cardiovascular disease at follow-up. The distribution of education level, urban/rural residence, country of birth, BMI, level of physical activity, alcohol intake, diabetes, Parkinson's disease, asthma, self-rated health and selfrated quality of life was similar between those with and without cancer at follow-up (Table 1).

Of the cancers diagnosed, the most common were prostate (29%), breast (15%) and melanoma (15%). Clinical characteristics, including time since cancer diagnosis, cancer stage and recent treatment, varied according to cancer type. The median time between cancer diagnosis and end of follow-up was 2.5 years, and 26.9% of those with incident cancer were followed up for more than 4 years. Those with incident lung and oesophageal cancer were more likely to have been diagnosed within the previous year than those with other cancers. The spread of cancer varied, with localised disease being most common in those with melanoma (80.4%) and least common in those with bladder cancer (26.8%). Most participants with incident cancer had not received cancer treatment in the past month, except for those with multiple myeloma (46.4%) (Additional file 2: Table S2.1).

Physical functioning

At baseline, 31.2% of participants who developed cancer during follow-up reported no limitations in physical functioning, 33.7% reported minor limitations, 25.6% reported moderate limitations and 9.6% reported severe limitations. For those without cancer, 38.4% reported no limitation, 31.5% reported minor limitations, 21.8%

Incident cancer during follow-up (n People without cancer (n =Total (n = 142.682)= 9313) 133,369) Age at follow-up 45-64 years 30% (2838) 52% (68,956) 71,794 65–79 years 52% (4870) 38% (50,342) 55,212 ≥80 years 17% (1605) 11% (14,071) 15,676 Sex 59% (5484) 44% (58,095) 63,579 Male Female 41% (3829) 56% (75,274) 79,103 Education No school certificate 10% (890) 8% (11.253) 12.143 Certificate/diploma/trade 64% (5928) 62% (83,284) 89,212 University degree 39,754 25% (2362) 28% (37,392) Region of residence Major city 50% (67,302) 72,040 51% (4738) Inner regional 36% (3362) 36% (48,214) 51,576 Outer regional 10% (975) 10% (13,961) 14,936 Remote/very remote 1% (1237) 1310 1% (73) Country of birth Australia 77% (102,979) 110.339 79% (7360) Not Australia 20% (1894) 31,481 22% (29,587) BMI, kg/m² 1479 Underweight (15-<18.5) 1% (69) 1% (1410) Normal weight (18.5-<25) 32% (2944) 35% (47,225) 50,169 Overweight (25-<30) 40% (3748) 37% (49,556) 53,304 Obese (30-50) 22% (2048) 21% (27,608) 29,656 Physical activity First tertile 27% (2538) 27% (36,384) 38,922 Second tertile 34% (3194) 35% (46,074) 49,268 Third tertile 36% (3329) 36% (47,936) 51,265 Smoking status Current smoker 5% (500) 6% (7985) 8485 Past smoker 40% (3751) 35% (46.287) 50.038 Never smoker 59% (78,757) 54% (5035) 83,792 Alcohol intake (drinks per week) 0 27% (2476) 30% (39,383) 41,859 1 - 1454% (4997) 55% (72,925) 77,922 ≥15 18% (1708) 14% (19,255) 20,963 Cardiovascular disease No 82% (7595) 86% (114,595) 122,190 Yes 18% (1718) 14% (18,774) 20,492 Diabetes 91% (8480) 93% (123,995) 132,475 No Yes 9% (833) 7% (9374) 10,207 Parkinson's disease 99.6% (132,851) No 99.6% (9273) 142,124 Yes 0.4% (40) 0.4% (518) 558 Asthma No 69% (6429) 75% (99,972) 106,401 Yes 9% (871) 10% (13,561) 14,432

Table 1 Characteristics of the study population according to cancer status at follow-up

	Incident cancer during follow-up (<i>n</i> = 9313)	People without cancer (<i>n</i> = 133,369)	Total (<i>n</i> = 142,682)
Self-rated health	· · · · · · · · · · · · · · · · · · ·		
Excellent	15% (1394)	18% (24,401)	25,795
Very good	40% (3726)	40% (53,049)	56,775
Good	32% (3011)	30% (40,300)	43,311
Fair	9% (837)	8% (10,819)	11,656
Poor	1% (98)	1% (1421)	1519
Self-rated quality of life			
Excellent	25% (2349)	27% (36,579)	38,928
Very good	39% (3635)	38% (51,266)	54,901
Good	25% (2309)	24% (31,526)	33,835
Fair	6% (563)	6% (7733)	8296
Poor	1% (83)	1% (1184)	1267

Table 1 (continued)

Variable definitions are included in Additional file 1: Table S1.5

Proportions of missing data were 1% (n = 1573) for education, 2% (n = 2820) for region of residence, 1% (n = 862) for country of birth, 5% (n = 6835) for BMI, 2% (n = 3227) for physical activity, <1% (n = 367) for smoking status, 1% (n = 1938) for alcohol consumption, 15% (n = 21,849) for asthma, 3% (n = 3626) for self-rated health and 2% (n = 2455) for self-rated quality of life. There was no missing data for age or sex or health conditions including cardiovascular disease, diabetes and Parkinson's disease

BMI Body mass index

reported moderate limitations and 8.2% reported severe limitations (Table 2).

Deterioration in physical functioning over time was more common in those with incident cancer than those without cancer, with 40.6% of those without cancer and 52.3% of those with incident cancer having moderate or severe physical functioning limitations at follow-up (Table 2). Among participants with no physical functioning limitation at baseline, a greater proportion of those with incident cancer had severe limitations at follow-up (4.9%) than people without cancer (1.9%). Among participants with minor limitations in physical functioning at baseline, the proportions of those with severe limitations at follow-up were 8.1% in those with incident cancer and 4.1% in those without cancer (Table 2).

On average, participants—including those with and without cancer—experienced a decline in physical functioning over time (shown as a negative value in the change), accompanying increasing age. Those with incident cancer of any type experienced a crude decrease of 8.3 points on the 100-point MOS-PF score from before to after cancer diagnosis compared to a 4.7-point decrease among those without cancer during a similar period, indicating a decline in physical functioning in both groups. The magnitude of the decline in physical functioning varied according to cancer type. Those with prostate cancer experienced a 6.7-point decrease and those with breast or colorectal cancer experienced an 8.8-point decrease. Those with multiple myeloma experienced an almost 25-point decrease, and those with lung cancer experienced an almost 20-point decrease in MOS-PF score (Fig. 1).

After adjusting for sociodemographic factors, follow-up time and baseline level of physical functioning, overall, those with incident cancer experienced 2.55/100-point greater decline in physical functioning from before to after diagnosis compared to those without cancer during a similar period. Declines in physical functioning among those with bladder, oesophagus, thyroid and kidney cancer and melanoma did not differ significantly from those without cancer, after adjustment (Fig. 1). Compared to people without cancer, those with leukaemia, NHL, uterus, breast, colorectal, prostate and cancers other than those listed separately experienced greater declines in physical functioning that were less than 10/100 points in magnitude, after adjustment. Those with multiple myeloma or lung cancer experienced a 15–20/100-point greater decline than those without cancer, after adjustment.

The degree of worsening physical functioning relative to non-cancer participants was greater among those with cancer diagnosed in the past year, more advanced stage at diagnosis and recent treatment in the past month at follow-up (Fig. 2). Compared to those without cancer, those with cancer diagnosed less than a year ago experienced a 4.10 (3.09–5.11) point greater decline, while those diagnosed at least 4 years ago experienced a 1.55 (0.78–2.32) point greater decline. Compared to those without cancer, people with localised cancer had a slight decrease in physical functioning (relative decline of 0.95 (0.41–1.5) **Table 2** Levels of physical functioning limitations (PFL) at baseline and follow-up, by baseline levels of physical functioning limitations and cancer diagnosis

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PFL at baseline	PFL at follow-up						
	No limitations (n=1,362, 17.4%)	Minor limitations (n=2,380, 30.4%)	Moderate limitations (n=2,646, 33.8%)	Severe limitations (n=1,449, 18.5%)			
No limitations (n=2,445, 31.2%)	41.1%	36.5%	17.4%	4.9%			
Minor limitations (n=2,640, 33.7%)	11.1%	43.8%	37.0%	8.1%			
Moderate limitations (n=2,003, 25.6%)	2.8%	14.9%	54.5%	27.8%			
Severe limitations (n=749, 9.6%)	0.9%	4.3%	20.6%	74.2%			

People with incident cancer during follow-up (n=7,837)

Peopl	e wit	hout c	ancer (n=114,498)

PFL at baseline	PFL at follow-up						
	No limitations (n=29,835, 26.1%)	Minor limitations (n=38,208, 33.4%)	Moderate limitations (n=32,052, 28.0%)	Severe limitations (n=14,403, 12.6%)			
No limitations (n=43,986, 38.4%)	52.0%	34.7%	11.4%	1.9%			
Minor limitations (n=36,107, 31.5%)	16.0%	49.6%	30.3%	4.1%			
Moderate limitations (n=24,990, 21.8%)	4.2%	18.8%	55.6%	21.4%			
Severe limitations (n=9,415, 8.2%)	1.5%	3.5%	23.3%	71.7%			

Physical functioning limitations are based on Medical Outcomes Study Physical Functioning (MOS-PF) scores, categorised as no limitation (MOS-PF = 100), minor limitations ($90 \le MOS$ -PF < 100), moderate limitations ($60 \le MOS$ -PF < 90) and severe limitations ($0 \le MOS$ -PF < 60)

PFL Physical functioning limitations

points) while those with non-localised disease experienced a 5.34 (4.37–6.32) point larger decrease in physical functioning. Cancer survivors who had not received treatment in the last month had slight declines in physical functioning compared to those without cancer (relative decline 0.90 (0.47–1.34) points), while those reporting cancer treatment in the past month experienced an 8.36 (7.30–9.42) point larger decline (Fig. 2). Change in physical functioning limitations in relation to clinical characteristics of cancer for different cancer types are presented in Additional file 2 (Figs. S2.1a–S2.1c).

Psychological distress

At baseline, 81.0% of participants who developed cancer during follow-up had low distress, 13.6% had moderate distress and 5.4% had high distress. Of those without cancer, 78.9% had low distress, 15.0% had moderate distress and 6.1% had high distress (Table 3). At follow-up, 79.7% of participants with cancer and 79.8% without cancer had low distress.

Among participants with low distress at baseline, the majority reported low distress at follow-up (around 89% regardless of cancer diagnosis), while 2% reported high distress at follow-up. Among those with moderate distress at baseline, 47.4% of those with incident cancer and 51.9% of those with no cancer had low distress at follow-up; 37.4% of those with incident cancer and 35.1% of those with no cancer remained at moderate distress at follow-up; and 15.2% of those with incident cancer and 13.0% of those with no cancer experienced high distress at follow-up. Among those with high distress at baseline, around one in four (regardless of cancer diagnosis) experienced low distress at followup (score of $\geq 10 - \langle 16 \rangle$, 31.0% (regardless of cancer diagnosis) experienced moderate distress at follow-up (score of $\geq 16-$ <22), and 42.1% of those with incident cancer and 44.3% of those with no cancer stayed at high distress at follow-up (score of $\geq 22 - \leq 50$) (Table 3).

K10 scores at baseline and follow-up were similar regardless of cancer status. Therefore, average changes in psychological distress from baseline to follow-up were slight (Fig. 3). After adjusting for sociodemographic factors, follow-up duration and baseline level of psychological distress, overall, those with incident cancer experienced 0.2-point greater increase in K10 scores

Type of cancer	n	Mean (SD)	Mean (SD)	Mean		Adjusted difference [^]
		at baseline	at follow-up	change*		cancer vs no cancer
Multiple myeloma	71	85.1 (20.1)	60.2 (28.5)	-24.83	\	-19.56 (-25.66, -13.47)
Lung	148	77.6 (24.6)	58.0 (30.1)	-19.59	\	-15.10 (-19.40, -10.80)
Leukaemia	135	83.2 (23.4)	69.7 (27.0)	-13.54	\ _	-8.23 (-11.51, -4.96)
NHL	276	86.0 (18.0)	75.4 (24.6)	-10.67	_ _	-4.44 (-6.77, -2.10)
Other cancer	1,135	83.5 (21.4)	73.4 (26.6)	-10.15	-	-4.67 (-5.84, -3.50)
Uterus (female only)	144	79.7 (24.3)	70.8 (27.0)	-8.95	\	-4.21 (-7.37, -1.04)
Breast (female only)	1,205	85.9 (19.5)	77.1 (23.3)	-8.79	-	-3.22 (-4.25, -2.19)
Colorectal	789	84.1 (20.7)	75.3 (25.4)	-8.74	-	-2.27 (-3.54, -1.00)
Bladder	174	80.6 (21.7)	72.7 (24.3)	-7.89		-2.03 (-4.88, 0.81)
Oesophagus	31	82.3 (23.9)	74.7 (25.7)	-7.58	+	-1.97 (-7.16, 3.23)
Thyroid	122	86.0 (18.2)	79.1 (21.2)	-6.89	+	-1.59 (-4.76, 1.58)
Prostate (male only)	2,308	88.5 (16.5)	81.8 (21.8)	-6.7	•	-0.88 (-1.58, -0.17)
Kidney	139	84.5 (21.1)	78.6 (22.0)	-5.93	+	-1.14 (-4.46, 2.18)
Melanoma	1,156	86.8 (18.6)	81.1 (22.4)	-5.72		• 0.38 (-0.51, 1.27)
Any cancer	7,837	85.8 (19.4)	77.5 (24.3)	-8.31	•	-2.55 (-2.97, -2.13)
No cancer	114,498	87.6 (18.7)	82.9 (21.8)	-4.71	•	• 0
						÷
				-30	-20 -10	0 10

Fig. 1 Change in physical functioning between surveys among cancer survivors (before to after cancer diagnosis) by type of cancer diagnosed, compared to change among people without cancer

NHL non-Hodgkin's lymphoma, SD standard deviation. Physical functioning limitations are based on Medical Outcomes Study Physical Functioning (MOS-PF) scores. Scores range from 0 to 100, where higher scores represent fewer limitations; a score of 60 to 89 represents moderate limitations and a score below 60 represents severe limitations. *Crude means of within participant changes in physical functioning (MOS-PF score at follow-up minus MOS-PF score at baseline). ^Difference between those diagnosed with cancer and those without cancer in change in scores, adjusted for age at follow-up, sex, education, residence, country of birth, months of follow-up and baseline physical functioning limitation score. Diagnosis codes grouped under "other cancer" and the corresponding numbers of participants are included in Additional file 1: Table S1.3. The number of participants with breast cancer includes eight males. They were excluded from subsequent analyses

		Chai	nge in physical	functional limita	tions, measured by	MOS-PF
Clinical characteristics	n	Mean (SD)	Mean (SD)	Mean		Adjusted difference^
		at baseline	at follow-up	change*		cancer vs no cancer
No cancer	114498	87.6 (18.7)	82.9 (21.8)	-4.71	•	0
Any cancer	7837	85.8 (19.4)	77.5 (24.3)	-8.31	+	-2.55 (-2.97, -2.13)
Time since diagnosis						
<1 year	1575	85.6 (19.6)	76.2 (25.3)	-9.37	-	-4.10 (-5.11, -3.09)
1-<2 years	1566	85.7 (19.6)	77.8 (24.1)	-7.94		-2.57 (-3.46, -1.68)
2-<4 years	2591	85.5 (19.7)	77.5 (24.1)	-8.02	—	-2.39 (-3.09, -1.69)
≥4 years	2105	86.4 (18.8)	78.2 (23.9)	-8.15	-	-1.55 (-2.32, -0.78)
Stage						
Localised to tissue	3812	86.3 (19.1)	79.6 (23.1)	-6.67	+	-0.95 (-1.50, -0.41)
Regional spread / distant metastases	1718	86.1 (19.1)	75.1 (25.4)	-11.01	-	-5.34 (-6.32, -4.37)
Unknown/missing	1360	84.8 (20.2)	77.3 (24.2)	-7.45		-1.51 (-2.48, -0.54)
Recent treatment for cancer						
No treatment	6017	86.3 (18.9)	79.5 (23.2)	-6.84	+	-0.90 (-1.34, -0.47)
Recent treatment	1750	84.0 (20.9)	70.5 (26.9)	-13.54 –	←	-8.36 (-9.42, -7.30)
				· · · ·	1	
				-15 -10	-5 0	5

Fig. 2 Change in physical functioning between surveys among cancer survivors (before to after cancer diagnosis) by clinical characteristics of cancer diagnosed, compared to change among people without cancer

SD standard deviation. Physical functioning limitations are based on MOS-PF scores. Scores range from 0 to 100, where higher scores represent fewer limitations; a score of 60 to 89 represents moderate limitations and a score below 60 represents severe limitations. *Crude means of within participant changes in physical functioning (MOS-PF score at follow-up minus MOS-PF score at baseline). ^Difference between those diagnosed with cancer and those without cancer in change in scores, adjusted for age at follow-up, sex, education, residence, country of birth, months of follow-up and baseline physical functioning limitation score

(40-point scale) than those without cancer (Fig. 3). This indicated that those with incident cancer experienced a slightly greater deterioration in psychological distress

from before to after their diagnosis than those without cancer during a similar period. Those with lung cancer, NHL, colorectal cancer and other cancers experienced

Table 3	Levels of psychological distress at baseline and follow-up, i	, by baseline levels of psychological distress and cancer diagnosis
People	e with incident cancer during follow-up (n=7,837)	

PD at baseline		PD at follow-up	
	Low distress (n=6,328, 79.7%)	Moderate distress (n=1,110, 14.0%)	High distress (n=500, 6.3%)
Low distress (n=6,430, 81.0%)	88.7%	8.9%	2.4%
Moderate distress (n=1,078, 13.6%)	47.4%	37.4%	15.2%
High distress (n=430, 5.4%)	26.3%	31.6%	42.1%

People without cancer (n=114,498)

PD at baseline		PD at follow-up	
	Low distress (n=94,073, 79.8%)	Moderate distress (n=16,383, 13.9%)	High distress (n=7,380, 6.3%)
Low distress (n=92,979, 78.9%)	89.4%	8.6%	2.1%
Moderate distress (n=17,707, 15.0%)	51.9%	35.1%	13.0%
High distress (n=7,150, 6.1%)	24.7%	31.0%	44.3%

Psychological distress was assessed using Kessler-10 (K10) and categorised as low distress ($10 \le K10 < 16$), moderate distress ($16 \le K10 < 22$) and high distress ($22 \le K10 \le 50$)

PD Psychological distress

Type of cancer	n	Mean (SD) at	Mean (SD) at	Mean					Adjust	ted difference^
		baseline	follow-up	change*					cance	r vs no cancer
Multiple myeloma	73	13.2 (4.2)	15.2 (4.5)	2.00	1		•	_	1.9	91 (1.08, 2.75)
Oesophagus	29	13.4 (3.8)	14.6 (5.7)	1.16		•			1.2	2 (-0.63, 3.06)
Lung	155	14.2 (5.6)	14.8 (5.5)	0.54	—	•	-		0.8	34 (0.18, 1.51)
Leukaemia	136	14.1 (5.6)	14.8 (6.1)	0.69		•	_		0.7	0 (-0.25, 1.65)
NHL	273	13.1 (4.5)	13.7 (5.1)	0.54		←			0.5	51 (0.01, 1.01)
Kidney	138	13.7 (4.5)	13.9 (5.6)	0.23		—			0.4	6 (-0.32, 1.23)
Uterus (female only)	148	13.9 (4.9)	14.2 (4.7)	0.27					0.3	8 (-0.18, 0.93)
Other cancer	1,143	13.4 (4.5)	13.7 (4.6)	0.33	-	-			0.3	32 (0.09, 0.55)
Colorectal	800	13.3 (4.3)	13.6 (4.7)	0.37	-	-			0.3	30 (0.01, 0.59)
Thyroid	135	15.0 (6.1)	14.8 (6.3)	-0.22					0.2	8 (-0.41, 0.96)
Breast (female only)	1,240	13.8 (4.8)	13.9 (5.1)	0.18	-	-			0.2	26 (0.00, 0.51)
Bladder	156	13.2 (4.6)	13.4 (4.3)	0.22		_			0.2	0 (-0.33, 0.73)
Prostate (male only)	2,329	12.9 (4.1)	13.1 (4.4)	0.20	-				0.0	9 (-0.07, 0.25)
Melanoma	1,178	13.1 (3.9)	13.1 (4.4)	-0.01					-0.1	3 (-0.34, 0.09)
Any cancer	7,938	13.3 (4.4)	13.6 (4.7)	0.24	+				0.2	21 (0.12, 0.31)
No cancer	117,836	13.6 (4.7)	13.5 (4.8)	-0.04	•					0
						4	1			
				-1	0	1	2	3	4	

Fig. 3 Change in psychological distress between surveys among cancer survivors (before to after cancer diagnosis) by type of cancer diagnosed, compared to change among people without cancer

NHL non-Hodgkin's lymphoma, SD standard deviation. Psychological distress was assessed using Kessler-10 (K10), which ranges from 10 (no distress) to 50 (severe distress); a score < 16 indicates low distress. *Crude means of within participant changes in psychological distress (K10 score at follow-up minus K10 score at baseline). ^Difference between those diagnosed with cancer and those without cancer in change in K10 scores, adjusted for age at follow-up, sex, education, residence, country of birth, months of follow-up and baseline K10 score. Diagnosis codes grouped under "other cancer" and the corresponding numbers of participants are included in Additional file 1: Table S1.3. The number of participants with breast cancer includes eight males. They were excluded from subsequent analyses

small but significantly greater average increases in psychological distress than those without cancer, with a magnitude of difference of less than 1/40 points. Those

with multiple myeloma experienced an almost 2/40 point greater increase in K10 than those without cancer (Fig. 3).

Clinical characteristics	n	Mean (SD)	Mean (SD)	Mean		Adjusted difference^
		at baseline	at follow-up	change*		cancer vs no cancer
No cancer	117836	13.6 (4.7)	13.5 (4.8)	-0.04	•	0
Any cancer	7938	13.3 (4.4)	13.6 (4.7)	0.24		0.21 (0.12, 0.31)
Time since diagnosis						
<1 year	1628	13.5 (4.5)	13.7 (4.6)	0.16		0.15 (-0.06, 0.37)
1-<2 years	1598	13.3 (4.4)	13.6 (4.8)	0.29	•	0.23 (0.00, 0.45)
2-<4 years	2615	13.3 (4.5)	13.6 (4.8)	0.24	•	0.18 (-0.01, 0.37)
≥4 years	2097	13.1 (4.3)	13.4 (4.7)	0.28		0.26 (0.05, 0.46)
Stage						
Localised to tissue	3887	13.3 (4.3)	13.4 (4.7)	0.14	—• —	0.11 (-0.03, 0.25)
Regional spread / distant metastases	1747	13.4 (4.5)	13.8 (4.7)	0.42	_	0.43 (0.19, 0.67)
Unknown/missing	1349	13.3 (4.7)	13.4 (4.6)	0.13		0.08 (-0.18, 0.35)
Recent treatment for cancer						
No treatment	6056	13.1 (4.2)	13.3 (4.6)	0.15		0.09 (-0.02, 0.21)
Recent treatment	1814	13.9 (5.1)	14.4 (5.0)	0.54		0.55 (0.32, 0.79)
				-0.5	0 0.5	1

Fig. 4 Change in psychological distress between surveys among cancer survivors (before to after cancer diagnosis) by clinical characteristics of cancer diagnosed, compared to change among people without cancer

SD standard deviation. Psychological distress was assessed using Kessler-10 (K10), which ranges from 10 (no distress) to 50 (severe distress); a score < 16 indicates low distress. *Crude means of within participant changes in psychological distress (K10 score at follow-up minus K10 score at baseline). ^Difference between those diagnosed with cancer and those without cancer in change in K10 scores, adjusted for age at follow-up, sex, education, residence, country of birth, months of follow-up and baseline K10 score

Although also small, the worsening psychological distress relative to non-cancer participants was greater for those with more advanced disease and with recent treatment for cancer in the past month (Fig. 4). Compared to people without cancer, changes in K10 scores were similar among those with localised cancer and those with cancer who had not received cancer treatment within the last month. Those with regional spread or distant metastases stages and those with recent cancer treatment experienced 0.43 (0.19-0.67) and 0.55 (0.32-0.69) points greater increase in K10 scores, respectively, than those without cancer. Psychological distress did not differ statistically for those diagnosed with cancer within 4 years prior to follow-up compared to those without cancer. Those diagnosed four or more years ago experienced a 0.26 (0.05-0.46) point increase in K10 score indicating worsening psychological distress compared to people without cancer (Fig. 4). The change in psychological distress among those with incident cancer in relation to detailed clinical characteristics is presented in Additional file 2 (Figs. S2.2a–S2.2c).

Discussion

Overall, in this large population-based study, participants who developed cancer experienced greater average declines in physical functioning and minimal differences in psychological wellbeing compared to participants with no cancer, over the same time period. Those who had not received cancer treatment in the month prior to followup and those diagnosed with many common cancer types with high survival rates had physical and psychological outcomes comparable to people without cancer.

The overall average difference in declines in physical functioning between those with and without cancer was 2.55 points on a 100-point scale. However, its magnitude varied substantially according to cancer type, stage of cancer at diagnosis and time since diagnosis. Compared to people without cancer, those diagnosed with certain cancers such as multiple myeloma, lung cancer and leukaemia had the greatest deterioration in physical outcomes, while those diagnosed with melanoma or prostate cancer reported similar levels of deterioration. People with more recent diagnosis and treatment and those with more advanced disease had substantially greater declines in physical functioning.

Around 80% of those with and without cancer reported low psychological distress (K10 score $\geq 10- <16$) at baseline and follow-up. Psychological distress increased to a slightly greater extent in those diagnosed with cancer compared to those without cancer, but the difference in this average increase was marginal—0.21-point difference, across a 40-point scale—meaning it may not represent a clinically significant difference. However, this is an average and there were variations by cancer type and clinical characteristics; the greatest difference was observed among those diagnosed with multiple myeloma (1.91 point) followed by cancer of lung (0.84), while those diagnosed with localised cancer and no recent cancer treatment had no significant difference. Qualitative studies show high variability in psychological distress, even among survivors of individual cancer types. While the majority of lung [26] and colorectal cancer [27] survivors report low distress, an important minority of survivors experience ongoing (sometimes debilitating) symptoms of depression, anxiety, fear of recurrence/progression and existential distress. It is crucial that cancer survivors who are experiencing distress are appropriately identified and treated. Routine screening for psychological distress and provision of stepped care, where the type and intensity of psychological support is tailored to the level of need, form an important part of best-practice cancer survivorship care [28].

Evidence pertaining to cancer survivorship prior to our study was limited. We identified a total of seven studies worldwide that examined physical functioning and psychological distress before and after a diagnosis of cancer compared to background changes in people without cancer, over the same period [8-12, 29, 30]. These studies, reflected in five publications relating to Surveillance, Epidemiology, and End Results-Medicare Health Outcomes Survey (SEER-MHOS) data, one publication from the Women's Health Initiative study on physical functioning and one from the Wisconsin Longitudinal study on psychological distress, were generally smaller than ours and were all from the USA. Direct comparison with our findings is difficult, due to differences in outcome measures used, duration of follow-up since cancer diagnosis, availability of clinical data and geographic setting. Further, most were based on single cancer types: breast cancer (number of cancer cases = 542 [10], n = 1636 [30]), prostate cancer (n = 445 [12]) and colorectal cancer (n = 346 [8]), while one included common cancer types excluding advanced disease (n = 921 [9]) and two others included multiple cancer types (n = 1432 [11] and n = 448 [29]). Their findings were, in general, consistent with ours, showing greater average deterioration in physical outcomes in cancer survivors compared to people without cancer, and adverse psychological outcomes with recently diagnosed cancer and advanced disease at diagnosis, but with large variations by cancer type—including limited long-term impacts with some cancers.

The SEER-MHOS studies found that patients diagnosed less than 2 years previously with any cancer type and with breast, prostate, lung and colorectal cancer reported greater average declines in physical health than control participants; outcomes were worse for those with lung cancer [9] and did not differ significantly from controls for melanoma or endometrial cancer [11]. Where time since diagnosis data were available, people with a recent diagnosis of colorectal [8], breast [10] and prostate cancer [12] had reduced physical functioning compared to controls, but had similar functioning 12 months postdiagnosis. However, data from the Women's Health Initiative study found that women with breast cancer experienced a greater decline in physical functioning from before to after diagnosis than women without breast cancer over a comparable time period, with differences continuing up to 12 years post-diagnosis for invasive disease [30].

With respect to psychological distress, evidence from the SEER-MHOS studies indicated that, compared to people without cancer, changes in mental health scores (based on mental health elements of the SF (short form)-36) were similar for people diagnosed with melanoma, NHL and cancers of the endometrium, breast and kidney and were significantly worse for people with cancers of the lung, colorectum and prostate [11]. Subsequent more detailed analyses indicated: (i) greater risk ratings for major depressive disorder in prostate cancer survivors, but no significant difference in overall mental health scores >19 months post-diagnosis, compared to controls [12]; (ii) no significant difference between control and colorectal cancer survivor overall mental health scores for early stage disease (stages I and II), but reduced scores in more advanced disease (stages III and IV) [8]; and reduced mental health scores in breast cancer survivors within 6 months of diagnosis compared to women without breast cancer, and no significant difference seven or more months after diagnosis [10]. A study comparing 448 participants with different cancer types and 4714 participants without cancer found that within the first 5 years following diagnosis, cancer survivors were more likely than controls to experience worsening depressive symptoms, but had no significant difference five or more years post-diagnosis. Compared to people without cancer, cancer survivors experienced similar trajectories for anxiety within the first 5 years following diagnosis and worsening anxiety symptoms five or more years after diagnosis [29]. However, no significant difference in overall psychological wellbeing was observed between participants with or without cancer, including according to time since diagnosis [29].

People with cancer can experience physical disability and psychological distress as a consequence of the cancer and its treatment, as well as experiencing disability and distress relating to non-cancer conditions. There is strong evidence of a high prevalence of emotional difficulties among cancer patients, low levels of reporting of these concerns by patients to their healthcare providers and low detection rates by health professionals [31]. Cancer type and stage are closely related, with cancers such as those of the lung, oesophagus and ovary having a poorer prognosis and greater morbidity; their tendency to be diagnosed at a more advanced stage is an important contributor to this. Cancers that have symptoms enabling early detection and those that can be diagnosed as part of screening—such as those of the breast, prostate and colorectum—have a greater proportion diagnosed with localised disease. Certain cancers, including multiple myeloma, can cause considerable pain and other symptoms, which contribute to physical disability and psychological distress [32].

Strengths and limitations

This study has several key strengths, including its large sample size, use of multiple linked datasets for comprehensive information on cancer diagnoses and validated measures for physical and psychological outcomes. This is the largest and most comprehensive study to our knowledge to evaluate change in physical and psychological outcomes from before to after cancer diagnosis, and in comparison to those without cancer for a range of cancer types—overall and according to different clinical characteristics of cancer. Our study captured measures before the onset of cancer, which enabled us to understand the likely impact of a new cancer diagnosis on physical and psychological wellbeing among older Australian adults. People with cancer in the study are embedded within a population-based cohort study, with cancer diagnosis identified from multiple independent linked datasets, including cancer registry and hospital admissions data. The large sample size of the 45 and Up Study permitted examination of the change in outcomes separately for 13 specific cancer types, and according to time since diagnosis, stage of cancer at diagnosis and cancer treatment in the past month at follow-up. Additionally, the available data allowed adjustments for a wide range of factors associated with incidence of cancer and physical/psychological outcomes, including age, sex, education (an indicator for socioeconomic status), region of residence (capturing access to health care) and country of birth (as an indicator for cultural differences). As the outcome measures were changes over time within individuals, we also included baseline level of outcome and the period over which the change was observed (followup time) in the model. Validated measures of physical functioning limitations and psychological distress further strengthened the reliability of our findings.

The study has several limitations. The study includes participants from the 45 and Up Study who completed a follow-up questionnaire, including those who did and did not develop cancer between surveys. Hence, estimates from this study are conditional on survival and participation in the follow-up study. Individuals diagnosed with cancers that have relatively lower survival rates (e.g. lung cancer) are inherently less likely to survive long enough than those with other cancers to participate in the follow-up survey. Those unable to complete a followup questionnaire due to death or illness could not take part—irrespective of a cancer diagnosis. Incident cancer cases with relatively high survival rates are more likely to be represented.

The 45 and Up Study had a 19% response rate to the baseline questionnaire and an overall 60% response rate to the follow-up questionnaires, with those experiencing disadvantage, ill-health and health risk more likely to be lost to follow-up [33]. In general, this pattern of differential attrition tends to lead to cohort studies often being an increasingly healthy and wealthy subpopulation [34]. However, estimates from internal comparisons within the cohort are likely to remain internally valid [35-38]. As the estimates are conditional on survival at follow-up, bias from loss to follow-up is unlikely to be a major issue as selection into the sample is not specifically related to the exposure (cancer diagnosis) [39, 40]; other conditions cause reductions in survival, physical functioning and/ or psychological health, and potentially reduce participation in a follow-up survey. While they are an important group to study and support, it is beyond the scope and methods of this study to do this. Further, the 45 and Up Study recruited community-dwelling individuals. Those in care facilities, including hospitals and hospices, are not included.

The main analyses are based on averages and it should be noted that individual experiences will vary from this central tendency. At a population level, there are marked inequities in cancer detection and treatment, as well as background levels of morbidity from other causes [41]. Moreover, each person's cancer experience should be considered separately and these results used to inform general policies and expectations, acknowledging variation. This study is quantitative in nature. Qualitative studies within our broader program of work provide greater depth on individual experience [42, 43]. Also, the results are based on brief questionnaire-based measures and may not be as sensitive as other more detailed measures, including additional clinical measures. While the K10 is a validated and widely used tool to measure psychological distress, it is more sensitive to serious psychological distress and may not capture subtle changes over time; further, it may not be sensitive to the certain more specific mental health concerns of those undergoing cancer treatment or those in remission. Further, this study includes Australians aged 45 years and over; experiences of psychological distress and physical functioning may be different among younger cancer survivors [44].

Our models adjust for potential confounding factors, including key demographic factors, time periods of follow-up and baseline outcome levels, but some residual confounding may remain. This could arise from unmeasured factors such as prior mental health history or coping strategies, which were not available in our dataset. However, our study's within-person design minimises the impact of confounding by focusing on changes over time within individuals rather than between-group differences.

Multimorbidity is common among older adults, including among those with and without cancer, and causes adverse physical and psychological outcomes [45, 46]. In this study, we did not specifically consider the role of conditions other than cancer in the relationship of cancer to changes in physical and psychological outcomes. However, regression models included age as a continuous variable, enabling fine adjustment for age. Research on the role of comorbidity in the relationship of cancer and changes in physical and psychological outcomes is planned as a topic of future research.

Since 2015, the use of, and indications for, immune and targeted therapy has increased. These have improved survival expectations and impacted on the quality of life for many cancers, especially lung cancer and melanoma. However, for the study period of this paper, it was not possible to capture the impacts of immuno- and targeted therapies.

Conclusions

This study is an order of magnitude larger than previous studies and extends what is known, including by estimating the magnitude of change in physical and psychological outcomes before and after diagnosis overall and for 13 distinct cancer types and an additional category for "other cancers"-to determine their relation to cancer diagnosis, compared to other middle-aged and elderly community-dwelling people without cancer. On average, the changes are small-particularly for psychological distress-and there is a lack of clarity on what constitutes clinically relevant change. However, changes for certain cancer types like lung cancer and haematological cancers appear substantial for physical functioning, with similar but attenuated patterns in point estimates observed for psychological distress. Average levels of physical functioning decreased with increasing age, regardless of a cancer diagnosis. However, those with incident cancer of many types experienced a somewhat greater decline in physical functioning following their diagnosis than those without cancer. This emphasises the importance of including an assessment of physical functioning in cancer survivorship care, especially for those with non-localised cancer stages and those who have been treated recently. In addition, those with localised disease and many common cancer types can be reassured that once they have completed treatment their outcomes are, on average, likely to be similar to those for people without cancer.

The large majority of this cohort with and without cancer were not experiencing psychological distress. For most cancer types-except for multiple myeloma and cancer of the lung-the average change in psychological distress among those with incident cancer following their diagnosis was small, and there was little difference compared to those without cancer. Acknowledging lower prevalence of high psychological distress in this cohort than that observed in the Australian population (~ 6% versus 15%) [47], and variations in individual experiences even within cancer type, findings indicate positive long-term psychological outcomes for the majority of those aged 45 years and over diagnosed with cancer, especially among those diagnosed at an early stage and who have been through the period of treatment.

People diagnosed with cancer, and those supporting them, fear physical and psychological suffering. These findings are likely to be informative for those affected by cancer, including expectations regarding outcomes, as well as policy and practice. Findings from this study highlight the variation in cancer outcomes, including positive findings for many, and cancer types with greater vulnerability and in greater need of support, such as multiple myeloma, and those with advanced disease and having recently received treatment. As cancer detection and treatment evolve, population outcomes are also likely to change, so ongoing monitoring will be of value.

Abbreviations

NHL	Non-Hodgkin's lymphoma
BMI	Body mass index
NSW	New South Wales
SEER-MHOS	Surveillance, Epidemiology, and End Results—Medicare Health
	Outcomes Survey
ICD-10-AM	International Statistical Classification of Diseases and Related
	Health Problems, Tenth Revision, Australian Modification
CCR	NSW Central Cancer Registry
APDC	NSW Admitted Patient Data Collection
MOS-PF	Medical Outcomes Study Physical Functioning
K10	Kessler-10
PFL	Physical functioning limitation
CHeReL	NSW Centre for Health Record Linkage
SEEF	Social, Economic, and Environmental Factor Study

Supplementary Information

The online version contains supplementary material available at https://doi. org/10.1186/s12916-025-04111-0.

Additional file 1: Supplementary methods. Table S1.1 Definitions used for history of diseases. Table S1.2 Exposure definitions. Table S1.3 List of cancer types grouped together as "other cancer". Table S1.4 Outcome definitions. Table S1.5 Other variables of interest.

Additional file 2: Supplementary results. Table S2.1 Clinical characteristics of those with incident cancer during follow-up, by cancer type. Fig. S2.1a Changes in physical functioning stratified by time since diagnosis of cancer and type of cancer diagnosed. Fig. S2.1b Changes in physical functioning stratified by stage of cancer and type of cancer diagnosed. Fig. S2.1c Changes in physical functioning stratified by recent treatment of cancer and type of cancer diagnosed. Fig. S2.2c Changes in psychological distress stratified by time since diagnosed. Fig. S2.2b Changes in psychological distress stratified by time since diagnosed. Fig. S2.2b Changes in psychological distress stratified by recent treatment of cancer and type of cancer diagnosed. Fig. S2.2c Changes in psychological distress stratified by recent treatment of cancer and type of cancer diagnosed. Fig. S2.2c Changes in psychological distress stratified by recent treatment of cancer and type of cancer diagnosed. Fig. S2.2c Changes in psychological distress stratified by recent treatment of cancer and type of cancer diagnosed. Fig. S2.2c Changes in psychological distress stratified by recent treatment of cancer and type of cancer diagnosed.

Acknowledgements

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Authors' contributions

EB, GJ, BK and RL-P, along with collaborators, acquired funding for the project, and conceived the idea for this study. JT and KS conducted the statistical analyses. YZ conducted the literature search. YZ and JT drafted the initial version of the manuscript. MW and CL contributed to critical review of the manuscript. All authors read and approved the final manuscript.

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Data availability

This research was completed using data collected through the 45 and Up Study (www.saxinstitute.org.au). Data supporting the findings from this study are available from the Sax Institute, the NSW Department of Health, and the Australian Bureau of Statistics, with data linkage conducted by the NSW Centre for Health Record Linkage. Restrictions apply to the availability of these data, which were used under license for the current study, and so are not publicly available. Data are available from the authors upon reasonable request and with permission of the Sax Institute and the NSW Department of Health.

Declarations

Ethics approval and consent to participate

Ethical approval for the conduct of the 45 and Up Study was provided by the University of New South Wales Human Research Ethics Committee. All participants joined the study providing written informed consent for followup through repeated data collection and linkage of their data to population health databases. Ethical approval for this research project was provided by the NSW Population & Health Services Research Ethics Committee (12/ CIPHS/31) and the Australian National University Human Research Ethics Committee (2012/504).

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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