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Work, daily activities and leisure after cancer

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Abstract

Objective: Determine if cancer survivors have lower participation in paid work, more limitations in daily activities or more limitations in leisure compared with those without cancer, stratified by age (working age ≤65 years; retirement age >65 years). Secondary objectives are identifying sociodemographic or clinical factors associated with work, daily activities or leisure and analysis of the relationship between work, daily activities and leisure.

Methods: Secondary analyses, using logistic regression, were performed on three cohorts (lymphoma, prostate and thyroid cancer) from the Dutch Patient Reported Outcomes Following Initial treatment and Long-term Evaluation of Survivorship (PROFILES) registry and a nationally representative non-cancer sample.

Results: Working-age cancer survivors ($n = 926$) were significantly ($p < 0.001$) less likely to participate in paid work and more likely to report limitations in daily activities and leisure compared to the non-cancer cohort ($n = 1279$). Among retirement aged cancer survivors ($n = 1046$), paid work was significantly more likely ($p < 0.001$), as were limitations in leisure ($p < 0.05$), compared with the non-cancer controls ($n = 334$).

Conclusions: Cancer impacts daily activities and leisure, as well as paid work. These roles are important for cancer survivors' quality of life, suggesting support to return to these activities may be an important component of survivorship care.

KEYWORDS
cancer, daily activities, leisure, survivorship, unpaid work, work

1 | INTRODUCTION

It is well established that cancer and its treatment influences work status (Amir & Brocky, 2009; Feuerstein et al., 2010). The percentage of cancer survivors who return to work (usually measured after 12 months) has been estimated at 72% in recent meta-analyses (Tavan et al., 2019) but varies from 24% to 94% and depends on several factors such as health status, socio-demographics, work characteristics and the availability of support from others (Amir & Brocky, 2009; Arndt et al., 2019; Chow et al., 2014; Duijts et al., 2017; Feuerstein et al., 2010; Greidanus et al., 2018; Kiasuwa Mbengi et al., 2016; Mehnert, 2011; Mehnert & Koch, 2013; Silver et al., 2013; Soejima & Kamibeppu, 2016; Steiner et al., 2010; Stergiou-Kita et al., 2014; Tavan et al., 2019; van Muijen et al., 2013; Wells et al., 2013).

Unlike paid work, there has been little examination of cancer survivors' return to other primary activities (OECD, 2016), such as unpaid work (e.g., voluntary work, domestic work or caring for others), daily activities (e.g., personal care tasks) or leisure (such as exercise, cultural activities or socialising with friends). The available literature suggests

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nearly half (46.1%) of people with cancer in the outpatient setting experience disability with activities of daily living, including unpaid work tasks such as meal preparation and grocery shopping (Neo et al., 2017). Unpaid work and other daily activities have been found to be more difficult after cancer for men, and those with intensive treatments, limited support, limited financial security or a new perspective around what is important in their lives due to cancer (Ahn et al., 2009; Braybrooke et al., 2015; Lindahl-Jacobsen et al., 2015; Mackenzie, 2014). However, this evidence is limited to small sample sizes and primarily breast cancer survivors.

Changes in leisure activities following cancer have largely focussed on physical activity and exercise (Charlier et al., 2012; Kim et al., 2021; Miedema et al., 2008; Thomas et al., 2015; van Nieuwenhuizen et al., 2018; Wang et al., 2015). A single study in breast cancer found return to physical activity was dependent on treatment characteristics, psychological functioning, illness perceptions, social support and coping (Charlier et al., 2012). A systematic review identified only two studies on the effect of cancer on leisure among older cancer survivors, both confirming that leisure and social activities are reduced following diagnosis (Engels et al., 2021).

It is also unclear whether reduced levels of paid work after cancer are compensated with other activities such as unpaid work or leisure, or if all activities are equally impacted. Some cancer survivors attach less value to work after diagnosis (Chow et al., 2014; Kiasuwa Mbengi et al., 2016; Stergiou-Kita et al., 2014; Wells et al., 2013) and may reduce paid work to increase leisure activities such as spending time with family and friends (Chow et al., 2014). For other cancer survivors, the same factors that limit participation in paid work, such as physical side effects of treatment, also impact participation in activities such as unpaid work, other daily activities and leisure (Miedema et al., 2008; Thomas et al., 2015; van Nieuwenhuizen et al., 2018). A single study has previously examined how time is allocated between paid work, unpaid work, passive leisure and physical leisure among cancer survivors and found no significant long-term effect on time allocation; however, this study was limited to women with breast or skin cancer (Gao et al., 2020).

Participation and limitations in daily activities such as (un)paid work and leisure form significant parts of a person's identity and are therefore an important component of survivorship care (Chow et al., 2014; Kiasuwa Mbengi et al., 2016; Stergiou-Kita et al., 2014; Wells et al., 2013). However, the limited evidence in this area includes very few studies with larger samples or with a range of cancer types. Understanding the impact of cancer on unpaid work, daily activities and leisure may encourage clinicians and health services to take a more holistic view of cancer survivorship.

The primary objective of this study was to examine participation in paid work, limitations in daily activities and limitations in leisure activities in a large sample of cancer survivors diagnosed with lymphoma, prostate or thyroid cancer, compared with participation of a non-cancer control cohort. As participation in paid work, limitations in daily activities and limitations in leisure activities may be considerably different among those of working age and those of retirement age, we stratified the analysis into those of working age (up to 65 years) and those of retirement age (over 65 years). Secondary objectives were to (a) identify which sociodemographic or clinical factors are associated with cancer survivors' participation in work, limitations in daily activities and limitations in leisure and (b) explore the relationship between paid work, daily activities and leisure.

2 | METHODS

2.1 | Data

We used data from the Patient Reported Outcomes Following Initial treatment and Long-term Evaluation of Survivorship (PROFILES) registry (van de Poll-Franse et al., 2011). PROFILES is a population-based registry of short and long-term cancer survivors in the Netherlands (Profiles Registry, 2017), collected through a series of cohort studies conducted between 2004 and 2015 (de Rooij et al., 2018). Cancer survivors (defined as individuals with a history of cancer from the point of diagnosis onwards; Denlinger et al., 2014) are included in the PROFILES registry on the basis of the Netherlands Cancer Registry (van de Poll-Franse et al., 2011). The Netherlands Cancer Registry registers all newly diagnosed cancer patients within 6 months after diagnosis (van de Poll-Franse et al., 2011).

Patients are invited to participate in PROFILES studies via mail by their (former) treating physician (van de Poll-Franse et al., 2011). Recently, deceased patients and patients who are not eligible for a PROFILES study according to their physician are excluded (van de Poll-Franse et al., 2011). The PROFILES study questionnaires can be completed online or with paper-and-pencil, and non-responders receive a reminder letter and a paper-and-pencil version of the questionnaire within 2 months after the initial invitation (van de Poll-Franse et al., 2011).

For this secondary analysis, we combined a subset of three PROFILES study cohorts: lymphoma (multiple myeloma, non-Hodgkin and Hodgkin, collected 2009), prostate cancer (collected 2011–2012) and thyroid cancer (collected 2010), as the surveys administered to these cohorts contained similar questions about paid work, daily activities and leisure activities. This heterogenous sample improves generalisability of our results, as the chosen cohorts represent solid (prostate and thyroid cancer) and non-solid malignancies (lymphomas) and vary in terms of incidence by age (median age at diagnosis 39 years for Hodgkin's lymphoma to 69 years for multiple myeloma; International Agency for Research on Cancer, 2021), incidence by gender (prostate cancer is only in men, while thyroid cancer is up to three times more common among women; International Agency for Research on Cancer, 2020), survival (5 year survival rate ranges from 56% for multiple myeloma to 88% for prostate cancer; National Cancer Institute Surveillance, Epidemiology and End Results Program, n.d.) and treatment (including chemotherapy, radiotherapy, surgery and watchful waiting).

Eligible survey respondents were aged 18 years and older at time of cancer diagnosis, responded to the survey and answered at least one question about paid work, daily activities and leisure activities

and formed the 'cancer cohort' for this study. Pensionable age in the Netherlands at the time of data collection was 65 years (Sociale Verzekeringsbank, n.d.), and it is natural that participation in paid work, limitations in daily activities and limitations in leisure activities may be considerably different among those of working age (≤65) and those of retirement age (>65). Therefore, we divided the cancer cohort into respondents of working age (up to 65 years) and respondents of retirement age (over 65 years).

A nationally representative control group of people with no history of cancer is generated for PROFILES by Centerdata (Profiles Registry, 2017; van de Poll-Franse et al., 2011). This 'control group cohort' consists of approximately 2000 adult individuals from the general Dutch population. These individuals completed the same core questionnaire as the cancer cohort (Profiles Registry, 2017; van de Poll-Franse et al., 2011). The control group cohort from 2009 was used for this analysis and was divided into respondents of working age (up to 65 years) and respondents of retirement age (over 65 years). This control group cohort was not matched to the cancer cohort, but rather was used to represent the rates of participation in paid work, limitations in daily activities and limitations in leisure activities in the general population.

Each PROFILES cohort study was approved by the local certified medical ethics committee, and ethical approval for this secondary analysis was obtained from the University of Technology Sydney Human Research Ethics Committee (HREC REF NO. 2015000135).

2.2 | Measurements

2.2.1 | Participation in paid work, limitations in daily activities and limitations in leisure activities

In this study, we captured three categories of activities people can spend time on through self-report questions. *Participation in paid work* is defined through the question 'Do you have a paid job?' (response options yes [as an employee or as an entrepreneur] or no). While people may participate in work or other daily activities, they may feel limited in their ability to fully do so. To capture the limitations people may have in their daily activities, which may include paid work and unpaid roles such as home maintenance, volunteering, caring for relatives or children, the broader category of *limitations in daily activities* was defined through the question 'Were you limited in doing work or other daily activities during the past week?' (response options not at all, a little, quite a bit, very much). This variable was taken from the EORTC QLQ-C30, a validated cancer-specific quality of life instrument (EORTC, n.d.). Given small numbers (<5%) in some of the response options, this categorical variable was recoded to a binary variable for analysis—limited (if response a little, quite a bit or very much was selected) or not limited (if not at all was selected). *Limitations in leisure activities* were defined through the question 'Were you limited in pursuing your hobbies or other leisure time activities during the past week?' (response options not at all, a little, quite a bit, very much). This variable was also taken from the EORTC QLQ-C30 (EORTC, n.d.) and recoded to a binary variable for analysis due to small numbers in some response options—limited (if response a little, quite a bit or very much was selected) or not limited (if not at all was selected).

2.2.2 | Sociodemographic and clinical factors

Sociodemographic factors that previous literature has identified as possibly important to participation or limitations in paid work, unpaid work, daily activities or leisure activities after cancer, and which were collected via self-report in the selected PROFILES cancer cohort and control group cohort were: gender (male or female), age (standardised across studies to be in 10-year age groups), marital status (married or cohabiting, divorced, widowed or never married), education level (lower education, high school, vocational education or university education), comorbidities (0, 1 or ≥2 comorbidities, calculated from participant responses to the question 'Please indicate for each condition or disease whether you have it now or have had it in the past 12 months' followed by a list of 14 chronic conditions and diseases, including heart condition, stroke, diabetes, depression, arthritis etc.) and current receipt of follow-up care (yes or no). Information on the following relevant clinical factors were retrieved from the Netherlands Cancer Registry for the cancer cohort: time since diagnosis (<2, 2–5, 5–10, >10 years), cancer stage (I to IV) and cancer treatment received (categorised as hormone therapy, chemotherapy, radiotherapy, surgery, or wait and see).

2.3 | Analyses

The characteristics of the cancer cohort and the control group cohort for working age and retirement age participants were summarised in frequency tables in terms of sociodemographic and clinical factors. Participation in paid work, limitations in daily activities and limitations in leisure activities were summarised in frequency tables by age group and cancer type, with Pearson's chi-squared tests of independence conducted to compare differences between the total cancer group and the control group. These tests were not repeated for each cancer type to reduce the risk of erroneous inferences through multiple comparisons.

To investigate whether cancer survivors participate less in paid work, have more limitations in daily activities or have more limitations in leisure activities compared with the control group cohort, we compared the cancer cohort (grouped by cancer type) and control group cohort using multivariable logistic regression. For each age group (working age [≤65] and retirement age [>65]), a separate analysis was conducted for each category of activity (participation in paid work, limitations in daily activities and limitations in leisure), controlling for cancer type (Hodgkin, non-Hodgkin, Myeloma, thyroid, prostate or no cancer) and sociodemographic factors (gender, age, marital status, education level and comorbidities).

To examine which socio-demographic and clinical factors might be associated with cancer survivors' participation in work, limitations

in daily activities and limitations in leisure we conducted multivariable logistic regression analyses for each activity category separately. These models controlled for sociodemographic factors as well as clinical factors (cancer stage, time since diagnosis, treatment and receipt of follow-up care) and were run with the working age (≤65) and retirement age (>65) cancer cohorts.

Finally, to assess whether people who are not participating in paid work also report limitation in daily activities or limitations in leisure activities (while controlling for sociodemographic and clinical factors), we re-ran the multivariate regression analyses among cancer survivors of working age (≤65) and retirement age (>65), adding participation in paid work, limitations in daily activities and limitations in leisure activities as covariates. To test for multicollinearity between the three activity categories, we repeated the model as a linear regression and used the *R*-squared result to calculate the variance inflation factor (Chen et al., 2019). A rule of thumb suggests that a variance inflation factor of 10 or greater indicates a concerning level of collinearity (Chen et al., 2019).

All statistical analyses were performed in STATA version 15. A significance level of 5% or less was regarded as significant.

3 | RESULTS

The three cohort studies gave a total sample of 3560 cancer survivors invited to participate across five cancer types: Hodgkin's lymphoma ($n = 219$), non-Hodgkin's lymphoma ($n = 1062$), multiple myeloma ($n = 185$), thyroid cancer ($n = 445$) and prostate cancer ($n = 1649$). Cancer survivors who did not respond to the survey or who returned incomplete questionnaires were excluded from the sample. In total, 1972 eligible respondents (926 working age and 1046 retirement age) were included in the cancer cohort (Hodgkin's lymphoma $n = 146$,

TABLE 1a Sociodemographic characteristics of cancer cohort and control group cohort

	Cancer (age ≤65)		Cancer (age 66+)		Control (age ≤65)		Control (age 66+)	
	n	(%)	*n*	(%)	*n*	(%)	*n*	(%)
Gender								
Male	521	(56)	825	(79)	664	(52)	208	(62)
Female	405	(44)	221	(21)	615	(48)	126	(38)
Age at time of study								
18–25 years	17	(2)	-	-	80	(6)	-	-
26–35 years	60	(6)	-	-	199	(16)	-	-
36–45 years	141	(15)	-	-	277	(22)	-	-
46–55 years	236	(25)	-	-	337	(26)	-	-
56–65 years	472	(51)	-	-	386	(30)	-	-
66–75 years	-	-	605	(58)	-	-	226	(68)
76–85 years	-	-	339	(32)	-	-	103	(31)
86–95 years	-	-	14	(1)	-	-	5	(2)
Unknown	0	(0)	88	(8)	0	(0)	0	(0)
Marital status								
Married/cohabiting	772	(83)	802	(77)	1001	(78)	251	(75)
Divorced/separated	69	(7)	43	(4)	52	(4)	1	(0)
Widowed	32	(3)	151	(14)	0	(0)		
Never married/cohabiting	47	(5)	35	(3)	206	(16)	78	(23)
Unknown	6	(1)	15	(1)	20	(2)	4	(1)
Education								
Higher education	169	(18)	221	(21)	466	(36)	115	(34)
Medium education	572	(62)	601	(57)	747	(58)	191	(57)
Lower education	173	(19)	207	(20)	64	(5)	26	(8)
Unknown	12	(1)	17	(2)	2	(0)	2	(1)
Comorbidity								
None	342	(37)	278	(27)	640	(50)	79	(24)
One	293	(32)	291	(28)	349	(27)	92	(28)
Two or more	291	(31)	477	(46)	290	(23)	163	(49)

Abbreviation: *n*, number.

TABLE 1b Clinical characteristics and sociodemographic status of cancer cohort

	Cancer (≤65)		Cancer (66+)	
	n	(%)	*n*	(%)
Cancer				
Hodgkin lymphoma	130	(14)	16	(2)
Non-Hodgkin lymphoma	363	(39)	350	(33)
Multiple myeloma	56	(6)	63	(6)
Thyroid	222	(24)	81	(8)
Prostate	155	(17)	536	(51)
Cancer stage				
Stage I	365	(39)	351	(34)
Stage II	196	(21)	293	(28)
Stage III	146	(16)	172	(16)
Stage IV	118	(13)	106	(10)
Unknown stage	101	(11)	124	(12)
Age at diagnosis				
18–25 years	49	(5)	0	(0)
26–35 years	125	(14)	0	(0)
36–45 years	162	(17)	0	(0)
46–55 years	284	(31)	16	(2)
56–65 years	306	(33)	271	(26)
66–75 years	0	(0)	581	(56)
76–85 years	0	(0)	175	(17)
86–95 years	0	(0)	3	(<1)
Time since diagnosis				
<2 years	97	(10)	78	(7)
2–5 years	358	(39)	441	(42)
6–10 years	363	(39)	418	(40)
>10 years	105	(11)	50	(5)
Unknown time since diagnosis	3	(<1)	59	(6)
Treatment				
Wait and see	121	(13)	214	(20)
Hormonal therapy	4	(<1)	68	(7)
Surgery	293	(32)	236	(23)
Radiotherapy	90	(10)	244	(23)
Chemotherapy	402	(43)	264	(25)
Other(s)	6	(1)	11	(1)
Unknown treatment	10	(1)	9	(1)
Socioeconomic status[a] ($n = 1284$)				
Low	142	(15)	117	(11)
Medium	325	(35)	186	(18)
High	282	(30)	189	(18)
Living in a care institution	8	(1)	9	(1)
Unknown SES	169	(18)	545	(52)

Abbreviation: *n*, number; SES, socioeconomic status.
[a]Socioeconomic status was not available for participants in the prostate cancer cohort.

non-Hodgkin's lymphoma $n = 713$, multiple myeloma $n = 119$, thyroid cancer $n = 303$ and prostate cancer $n = 691$). For survey response rates of each individual malignancy, see Appendix A. The control group cohort had a total of 1613 respondents, 1279 working age and 334 retirement age. Tables 1a and 1b, respectively, present the sociodemographic and clinical factors of the cancer and control group cohorts.

3.1 | Descriptive results

Table 2 shows the self-reported rates of participation in paid work, limitations with daily activities and limitations with leisure among the cancer cohort and control group cohort. Among those of working age, 55% of those in the cancer cohort reported participating in paid work, 41% experienced limitations in daily activities and 41% reported limitations in leisure. This was significantly ($p < 0.01$) lower than in the working age non-cancer control group, where 66% reported participating in paid work, 22% reported limitations with daily activities and 20% reported limitations with leisure. Among those of retirement age, the non-cancer control group were significantly ($p < 0.01$) less likely to be participating in paid work (1%) but also less likely to have limitations in leisure (30%) than the cancer cohort (7% participation in paid work, 39% limited in leisure). There was no significant difference between the cancer survivors and non-cancer control group for limitations in daily activities among those of retirement age (40% and 36% respectively, $p = 0.26$).

Although not tested statistically, the descriptive results suggest the cancer types with the lowest participation in paid work among working age participants were multiple myeloma (27%) and prostate cancer (40%), and people with multiple myeloma were also most likely to have limitations in daily activities (75%) and leisure (68%). Those with Hodgkin lymphoma were most likely to participate in paid work (69%) and least likely to report limitations in daily activities (32%) and limitations in leisure (33%) although these rates were still higher than those reported by the control group cohort. Similarly, for participants of retirement age, multiple myeloma survivors were again most likely to experience limitations in daily activities and leisure. However, in the retirement age group, prostate cancer survivors were least likely to experience limitations in daily activities or leisure, although still at rates higher than the non-cancer control group.

3.2 | Participation in paid work, limitations in daily activities and limitations in leisure activities—cancer cohort compared to the control group cohort

Results of the multivariable logistic regression comparing the cancer cohort to the control group cohort with respect to participation in paid work, limitations in daily activities and limitations in leisure activities are shown in Table 3. Among those of working age, non-Hodgkin's lymphoma survivors were nearly two times less likely to

TABLE 2 Participation in paid work, limitations in daily activities and limitations in leisure among cancer types, cancer cohort, and control group cohort

	No paid job				Limitations in daily activities				Limitations in leisure activities			
	Age ≤65		Aged 66+		Age ≤65		Age 66+		Age ≤65		Age 66+	
	n	(%)	*n*	(%)	*n*	(%)	*n*	(%)	*n*	(%)	*n*	(%)
Hodgkin lymphoma ($n = 146$)	40	(31)	15	(94)	41	(32)	6	(38)	43	(33)	7	(44)
Non-Hodgkin lymphoma ($n = 713$)	176	(48)	332	(95)	161	(44)	151	(43)	163	(45)	125	(36)
Multiple myeloma ($n = 119$)	41	(73)	61	(97)	42	(75)	34	(54)	38	(68)	37	(59)
Thyroid ($n = 303$)	64	(29)	80	(99)	76	(34)	34	(42)	77	(35)	32	(40)
Prostate ($n = 691$)	93	(60)	480	(90)	56	(36)	190	(35)	59	(38)	202	(38)
Total cancer cohort ($n = 1972$)	**414**	**(45)**	**986**	**(94)**	**376**	**(41)**	**415**	**(40)**	**380**	**(41)**	**403**	**(39)**
Control group cohort ($n = 1613$)	**432**	**(34)**	**332**	**(99)**	**280**	**(22)**	**121**	**(36)**	**258**	**(20)**	**101**	**(30)**
Chi-squared test (*p* value)[a]	**27.1**	**(<0.001)**	**15.6**	**(<0.001)**	**90.0**	**(<0.001)**	**1.3**	**(0.260)**	**113.7**	**(<0.001)**	**7.5**	**(0.006)**

Abbreviation: *n*, number.

[a]Pearson's chi-squared test of independence, comparing the total cancer cohort with the control group cohort.

participate in paid work (OR 0.65 [CI 0.48–0.88], $p < 0.01$), and multiple myeloma cancer survivors were 1.3 times less likely to participate in paid work (OR 0.28 [CI 0.14–0.57], $p < 0.01$) compared with the control group cohort. In contrast, thyroid cancer survivors were more than twice as likely to participate in paid work (OR 2.02 [CI 1.39–2.94], $p < 0.01$). There were no significant differences between the control group cohort and those with Hodgkin's lymphoma. The model for those aged over 65 had very wide confidence intervals, likely because of the small proportion of cancer and control group participants participating in paid work after age 65 (6% [60 out of 1046] and 1% [2 out of 334], respectively). Given the risk of misinterpretation due to overfitting the model, we do not present the results here.

For limitations in daily activities among working age respondents, only thyroid cancer was not significantly different (Hodgkin's lymphoma $p < 0.05$, all others $p < 0.01$), and the largest difference was seen among Hodgkin's lymphoma survivors who are over 10 times more likely to have limitations in their daily activities (OR 0.56 [CI 0.36–0.87]). In the retirement age group (>65 years), only Non-Hodgkin's lymphoma and multiple myeloma survivors reported more limitations in daily activities than the non-cancer controls.

For leisure activities among the working age participants, thyroid cancer survivors were more than one third more likely to have limitations (OR 0.67 [CI 0.54–1.70], $p < 0.05$), and all other cancer types were at least twice as likely to have limitations as the control group cohort (e.g., multiple myeloma OR 0.13 [CI 0.07–0.25], all $p < 0.01$). The retirement age subgroup (>65 years) experienced greater limitations than the control group cohort in all cancer types, but the difference was not as large as seen in the younger age group (e.g., multiple myeloma OR 0.21 [CI 0.11–0.40], thyroid $p < 0.05$, all others $p < 0.01$).

3.3 | Sociodemographic and clinical factors associated with participation in paid work, limitations in daily activities and limitations in leisure among cancer survivors

Results of the multivariable logistic regression analyses examining participation in paid work, limitations in daily activities and limitations in leisure activities among the cancer cohort after controlling for sociodemographic and clinical factors are shown in Table 4. Among the working age group, being female ($p < 0.01$), older ($p < 0.05$) and having multiple comorbidities ($p < 0.05$) made it significantly less likely to participate in paid work. With respect to limitations in daily activities, people who were diagnosed with non-multiple myeloma ($p < 0.01$), never married ($p < 0.05$) or had multiple comorbidities ($p < 0.05$) were more likely to experience limitations. Among those of retirement age, being female ($p < 0.01$) and having multiple comorbidities made limitations in daily activities more likely. Limitations in leisure were more likely for people of working age who also received chemotherapy ($p < 0.01$) or hormonal therapy ($p < 0.05$), had lower education ($p < 0.05$) or had multiple comorbidities ($p < 0.01$). Among the retirement age group, having non-Hodgkin's lymphoma ($p < 0.01$) or prostate cancer ($p < 0.05$), being female ($p < 0.01$), receiving hormonal therapy ($p < 0.05$) or being never married ($p < 0.05$) made limitations in leisure more likely.

TABLE 3 Logistic regression analyses of participation in paid work, limitations in daily activities and limitations in leisure – cancer cohort and control group cohort, by age group

	PAID WORK[a] age ≤65		DAILY ACTIVITIES age ≤65		DAILY ACTIVITIES age 66+		LEISURE age ≤65		LEISURE age 66+	
	OR	OR	OR	(95% CI)	OR	(95% CI)	OR	(95% CI)	OR	(95% CI)
Cancer type (reference = no cancer)										
Hodgkin	0.93	(0.58–1.49)	0.56*	(0.36–0.87)	0.69	(0.22–2.13)	0.47**	(0.30–0.73)	0.42**	(0.14–1.30)
Non-Hodgkin	0.65**	(0.48–0.88)	0.35**	(0.26–0.48)	0.59**	(0.41–0.84)	0.31**	(0.23–0.42)	0.59**	(0.41–0.85)
Multiple myeloma	0.28**	(0.14–0.57)	0.10**	(0.05–0.20)	0.38**	(0.20–0.71)	0.13**	(0.07–0.25)	0.21**	(0.11–0.40)
Thyroid	2.02**	(1.39–2.94)	0.81	(0.57–1.15)	0.96	(0.54–1.70)	0.67*	(0.47–0.94)	0.62*	(0.35–1.09)
Prostate	0.52**	(0.35–0.77)	0.51**	(0.33–0.77)	0.77	(0.54–1.11)	0.43**	(0.29–0.66)	0.65**	(0.45–0.94)
Gender (reference = male)										
Female	0.39**	(0.31–0.49)	0.64**	(0.51–0.81)	0.71*	(0.52–0.98)	0.84	(0.67–1.05)	1.25	(0.90–1.73)
Age study (reference = 15–25 years)										
25–35 years	21.82**	(11.65–40.87)	0.61	(0.30–1.24)			0.92	(0.47–1.81)		
35–45 years	15.55**	(8.77–27.57)	0.74	(0.37–1.48)			0.94	(0.50–1.79)		
45–55 years	13.69**	(7.84–23.92)	0.58	(0.30–1.15)			0.75	(0.40–1.39)		
55–65 years	2.67**	(1.55–4.61)	0.58	(0.30–1.14)			0.97	(0.52–1.81)		
65–75 years	-	-	-	-	Base				Base	-
75–85 years	-	-	-	-	0.56**	(0.43–0.73)			0.67	(0.52–0.88)
85–95 years	-	-	-	-	0.36	(0.12–1.09)			0.37	(0.13–1.03)
Marital (reference = married/cohabiting)										
Divorced/separated	1.08	(0.70–1.69)	0.62*	(0.41–0.95)	0.92	(0.45–1.89)	0.63*	(0.41–0.95)	1.09*	(0.53–2.26)
Widowed	0.65	(0.27–1.57)	1.22	(0.52–2.89)	1.12	(0.74–1.69)	0.99	(0.43–2.29)	1.15	(0.76–1.73)
Never married or cohabited	1.25	(0.89–1.76)	0.90	(0.64–1.26)	0.63	(0.40–1.02)	1.11	(0.79–1.57)	0.75	(0.47–1.21)
Education (reference = higher)										
Medium	0.58**	(0.45–0.74)	0.65**	(0.50–0.83)	0.72*	(0.54–0.98)	0.70**	(0.54–0.90)	0.84**	(0.62–1.13)
Lower	0.46**	(0.31–0.69)	0.72	(0.48–1.08)	0.86	(0.58–1.30)	0.77	(0.52–1.14)	1.22	(0.80–1.84)
Comorbidity (reference = none)										
One	0.87	(0.68–1.12)	0.44**	(0.33–0.57)	0.78	(0.55–1.13)	0.41**	(0.32–0.54)	0.89**	(0.62–1.28)
Two or more	0.54**	(0.42–0.70)	0.15**	(0.11–0.19)	0.22**	(0.16–0.30)	0.15**	(0.12–0.20)	0.28**	(0.20–0.38)

Abbreviation: CI, confidence interval; OR, odds ratio.

[a]Results for paid work aged 66+ not shown due to potential for model overfitting.

*p value < 0.05. **p value < 0.01.

TABLE 4 Multivariable logistic regression analyses of factors influencing participation in paid work, limitations in daily activities and limitations in leisure activities – cancer cohort only, by age group and including other activity types as covariates

	PAID WORK[a] age ≤65		DAILY ACTIVITIES age ≤65		DAILY ACTIVITIES age 66+		LEISURE ACTIVITIES age ≤65		LEISURE ACTIVITIES age 66+	
	Odds ratio	(95% CI)	Odds ratio	(95% CI)	Odds ratio	(95% CI)	Odds ratio	(95% CI)	Odds ratio	(95% CI)
Work and daily activities (reference = limited)										
Not limited	2.51**	(1.33–4.76)	2.80**	(1.43–5.48)	0.67	(0.18–2.50)	1.13	(0.59–2.17)	2.48	(0.61–10.05)
Leisure activities (reference = limited)										
Not limited	1.18	(0.62–2.22)	140.94**	(70.81–280.51)	67.12**	(37.73–119.41)	135.77**	(68.99–267.19)	75.17**	(41.08–137.55)
Cancer type (reference = Hodgkin)										
Non-Hodgkin	0.80	(0.41–1.59)	0.42	(0.14–1.24)	0.15*	(0.02–0.89)	2.24	(0.77–6.55)	11.22**	(1.98–63.60)
Multiple myeloma	0.74	(0.22–2.51)	0.06**	(0.01–0.41)	0.29	(0.03–2.60)	2.17	(0.44–10.78)	2.46	(0.33–18.21)
Thyroid	5.04**	(1.50–16.95)	0.34	(0.05–2.41)	0.47	(0.04–5.19)	2.39	(0.35–16.41)	3.76	(0.38–37.54)
Prostate	0.90	(0.32–2.55)	0.39	(0.07–2.11)	0.18	(0.02–1.47)	3.17	(0.61–16.31)	10.05*	(1.34–75.37)
Stage (reference = I)										
II	0.95	(0.58–1.56)	0.84	(0.37–1.89)	1.02	(0.53–1.96)	0.87	(0.41–1.86)	0.96	(0.51–1.80)
III	0.80	(0.46–1.38)	1.04	(0.44–2.44)	0.62	(0.28–1.35)	1.03	(0.46–2.32)	2.34*	(1.09–5.03)
IV	0.97	(0.50–1.88)	0.84	(0.30–2.31)	0.55	(0.22–1.37)	0.56	(0.20–1.58)	1.11	(0.46–2.65)
Gender (reference = male)										
Female	0.43**	(0.27–0.70)	0.65	(0.31–1.36)	0.30**	(0.13–0.69)	1.50	(0.75–2.99)	3.21**	(1.46–7.05)
Time since diagnosis (reference = <2 years)										
2–5 years	0.79	(0.38–1.66)	1.61	(0.50–5.17)	1.58	(0.56–4.46)	0.94	(0.31–2.83)	0.83	(0.25–2.74)
5–10 years	0.70	(0.33–1.47)	1.59	(0.51–5.00)	1.38	(0.47–4.01)	1.45	(0.48–4.35)	0.88	(0.26–2.97)
≥10 years	0.81	(0.30–2.19)	1.29	(0.27–6.04)	1.77	(0.31–10.02)	1.87	(0.43–8.18)	1.59	(0.25–10.13)
Treatment (reference = wait and see)										
Hormonal therapy	1.72	(0.09–32.66)	1.00		1.08	(0.29–3.95)	18.16*	(1.12–294.16)	0.22*	(0.06–0.84)
Surgery	0.46	(0.19–1.12)	0.82	(0.19–3.47)	1.26	(0.45–3.52)	2.08	(0.47–9.18)	0.71	(0.26–1.92)
Radiotherapy	0.68	(0.31–1.47)	1.90	(0.55–6.54)	1.64	(0.68–3.95)	1.11	(0.33–3.73)	0.55	(0.23–1.31)
Chemotherapy	0.72	(0.34–1.52)	0.30*	(0.09–0.98)	1.89	(0.66–5.44)	5.78**	(1.80–18.56)	0.55	(0.19–1.56)
Other(s)	0.59	(0.05–7.20)	0.95	(0.05–19.64)	1.14	(0.12–10.80)	0.74	(0.02–31.83)	0.98	(0.10–10.01)
Age study (reference = 18–25 years)										
26–35 years	11.79**	(2.67–52.15)	0.07	(0.00–1.12)			3.02	(0.35–25.70)		
36–45 years	4.22*	(1.10–16.17)	0.05*	(0.00–0.66)			2.99	(0.41–21.93)		
46–55 years	4.93*	(1.29–18.86)	0.10	(0.01–1.27)			1.43	(0.20–10.20)		
56–65 years	0.78	(0.20–2.96)	0.05*	(0.00–0.63)			4.44	(0.62–31.92)		
66–75 years					Base				Base	
76–85 years					0.49*	(0.28–0.86)			1.31	(0.74–2.33)
86–95 years					0.23	(0.03–1.57)			2.58	(0.31–21.71)

TABLE 4 (Continued)

	PAID WORK[a] age ≤65		DAILY ACTIVITIES age ≤65		DAILY ACTIVITIES age 66+		LEISURE ACTIVITIES age ≤65		LEISURE ACTIVITIES age 66+	
	Odds ratio	(95% CI)	Odds ratio	(95% CI)	Odds ratio	(95% CI)	Odds ratio	(95% CI)	Odds ratio	(95% CI)
Marital (reference = married/cohabiting)										
Divorced/separated	1.27	(0.65–2.50)	1.10	(0.38–3.24)	0.49	(0.14–1.78)	0.47	(0.16–1.40)	2.44	(0.67–8.85)
Widowed	0.30	(0.09–1.04)	1.68	(0.32–8.92)	1.00	(0.47–2.15)	1.04	(0.20–5.32)	1.12	(0.52–2.38)
Never married/never cohabited	0.75	(0.31–1.83)	0.25*	(0.07–0.89)	0.34	(0.09–1.27)	3.45	(0.95–12.43)	4.48*	(1.04–19.35)
Education (reference = higher)										
Medium	0.98	(0.61–1.59)	1.24	(0.59–2.60)	1.06	(0.56–2.02)	0.46*	(0.21–0.98)	0.64	(0.34–1.18)
Lower	1.13	(0.60–2.15)	1.48	(0.54–4.10)	0.93	(0.39–2.22)	0.47	(0.17–1.29)	1.30	(0.55–3.08)
Comorbidity (reference = none)										
One	0.97	(0.61–1.53)	0.79	(0.38–1.64)	0.61	(0.29–1.25)	0.64	(0.32–1.29)	1.55	(0.78–3.08)
Two or more	0.59*	(0.36–0.95)	0.39*	(0.18–0.81)	0.26**	(0.14–0.50)	0.38**	(0.18–0.79)	0.90	(0.48–1.70)
Received follow-up care (reference = no)										
Yes	0.98	(0.67–1.45)	0.71	(0.39–1.30)	0.78	(0.45–1.36)	0.86	(0.48–1.56)	1.15	(0.66–1.99)

Abbreviation: CI, confidence interval.
*p value < 0.05. **p value < 0.01. [a]Results for paid work aged 66+ not shown due to potential for model overfitting.

3.3.1 | Limitations in daily activities and/or limitations in leisure activities when not participating in paid work

Among working age participants, those who did not have a paid job were two and a half times more likely to have limitations in daily activities (OR 2.51 [CI 1.33–4.76], $p < 0.01$), although there was no relationship with limitations in leisure activities (also shown in Table 4). An even stronger relationship was seen between daily activities and leisure activities, with working age and retirement age participants who reported limitations in daily activities 140 times (OR 140.94 [CI 70.81–280.51], $p < 0.01$) and 67 times (OR 67.12 [CI 37.73–119.41], $p < 0.01$) more likely to report limitations in leisure respectively. The variance inflation factor for the paid work model was 1.90, indicating a low probability of collinearity between the three activity types.

4 | DISCUSSION

Working age cancer survivors are less likely to have a paid job than the non-cancer control group, with the exception of Hodgkin's lymphoma and thyroid cancer. In addition, cancer survivors reported more limitations with daily activities and more limitations with leisure activities than the control group cohort, particularly among those who are of working age. The factors that limit participation in the paid workforce may also limit cancer survivors in their daily activities, but do not appear to limit their leisure activities. However, limitations in daily activities are strongly associated with limitations in leisure activities.

Our results are consistent with the existing literature in terms of the impact of different cancer types on participation in paid work. Previous research found that, of all haematological cancers, multiple myeloma had the lowest rates of return to work (Horsboel et al., 2013), likely due to the impact of the disease symptoms, extensive treatment and associated side effects, and the probability of relapse (Bennink et al., 2021). These same factors may also prevent survivors from participating in their broader daily activities. Similarly, non-Hodgkin's lymphoma has been found to result in some of the largest reductions in employment and earnings (Horsboel et al., 2013; Syse et al., 2008) perhaps because it more commonly occurs in those over 60 years of age and may require ongoing, recurrent treatment or result in long-term physical and psychological side effects (National Guideline Alliance UK, 2016). Conversely, thyroid cancer survivors tend to be younger at diagnosis and have less intensive treatment, perhaps explaining why they were more likely in our sample, and equally likely in previous studies (Amir & Brocky, 2009), to have a paid job when compared to people who had not had cancer.

Also consistent with the modest existing literature (Braybrooke et al., 2015; Lindahl-Jacobsen et al., 2015; Neo et al., 2017; Wang et al., 2015), our analyses suggest there is a relationship between cancer and limitations in daily activities or limitations in leisure activities. While previous research suggests some people reassess their life roles and choose to reduce their work to spend more time in unpaid daily

activities and leisure after cancer (Chow et al., 2014), in our sample those who are limited in paid work are also limited in their daily activities. This may simply reflect that many who do reassess their roles still rely on work for financial reasons and continue despite limitations in their physical or psychosocial abilities. It is also consistent with our finding that having more comorbidities was the only factor negatively associated with all three activity types—paid work, daily activities and leisure.

We found that female gender, older age and having more comorbidities are associated with reduced participation in paid work. It has been suggested that these subgroups might be more likely to retire or take on additional household commitments when they face the added difficulties associated with cancer (Chow et al., 2014; Kiasuwa Mbengi et al., 2016; Mehnert, 2011; van Muijen et al., 2013), although these studies were in samples that were closer to diagnosis and included different cancer types to our cohort.

In relation to limitations in daily activities and limitations in leisure activities, there is little comparative literature given the previous focus on breast cancer (Braybrooke et al., 2015; Charlier et al., 2012; Dontje et al., 2016; Johnsson et al., 2013; Kanker.nl, 2018; Kwon et al., 2012; Lindahl-Jacobsen et al., 2015; Mackenzie, 2015; MarketingFacts, 2019; Naik et al., 2016; van Nieuwenhuizen et al., 2018; Wang et al., 2015). Interestingly, we found fewer sociodemographic and clinical factors to be important in explaining limitations in daily activities and leisure among cancer survivors. It may be that those over retirement age typically already have limitations in their daily activities, but without a cancer diagnosis are able to continue with their leisure.

Comorbidities had a consistent negative impact on work, daily activities and leisure activities, but we found no significant relationship between treatment type and limitations in daily activities or leisure, despite some evidence that more intensive treatments are related to a reduction in unpaid work activities (Braybrooke et al., 2015; Kanker.nl, 2018). Reduced leisure participation among breast cancer survivors has previously been associated with higher cancer stage, shorter time since diagnosis, having had surgery and being older (Brajša-Žganec et al., 2011; Charlier et al., 2012; Johnsson et al., 2013; Kwon et al., 2012; Mackenzie, 2015; MarketingFacts, 2019; Naik et al., 2016; van Nieuwenhuizen et al., 2018; Wang et al., 2015), none of which were seen in our study. This may be because we measured limitations rather than participation, however these inconsistencies, along with the non-significant findings of our study in contrast with previous findings regarding gender, marital status, education and cancer type require further exploration.

Further research to examine how cancer survivors can best be supported to participate in unpaid work and leisure activities is required, given the previous focus of the cancer survivorship literature on return to paid work. Factors which have been shown to improve rates of return to paid work, such as support from family and friends (Chow et al., 2014), support of employers (Chow et al., 2014; Kiasuwa Mbengi et al., 2016) and participation in specific rehabilitation programs (Chow et al., 2014; Mehnert, 2011) may also apply to unpaid daily activities and leisure activities.

Our research had multiple strengths. Using the population-based PROFILES registry means the participants are broadly representative of the cancer survivorship population in the Netherlands. It is a relatively large sample with a variety of cancer types and thus extends the literature which has primarily focussed on breast cancer or had only small samples. The dataset also comes with some limitations, which should be considered when interpreting the results. Each questionnaire in the database was slightly different and none were specific to work and leisure impacts. This meant not all potentially important factors could be investigated. For example, the questionnaires did not collect information about pre-cancer work or leisure or ask about potential explanatory variables such as social supports available or other physical limitations. Similarly, additional questions addressing the types of activities reduced or how important these changes were to the participant would have allowed more qualitative analysis. In other cases, the information collected was not in the format we would have preferred (such as age as a categorical rather than continuous variable). Our results are limited to people with haematological, thyroid and prostate cancers as these were the only PROFILES cohort questionnaires that included consistent questions about work, daily activities and leisure. These cancers differ in terms of incidence by gender and age, treatment patterns and side effects as well as prognosis. While the small number of cancer sites is certainly a limitation, there is also an advantage in their variety, allowing us to examine the effect of various explanatory variables (such as gender and age) independent of cancer type.

One of the primary limitations of this study is that the outcome measure for limitations in daily activities is a question about 'work and daily activities', so could be confounded with our measure of participation in paid work. The lack of collinearity found in our models indicates this is unlikely to be the case, and suggests participants considered a broader range of activities and roles in 'work and daily activities' than in paid employment, and that limitations in a role may not prevent participation. However, our results do not allow us to look specifically at participation rates in unpaid work or leisure, to assess limitations in unpaid work independently of paid work, or to examine different aspects of daily activities such as voluntary work, domestic work or caring for others, and these remain a significant gap in the literature. In addition, while the questions on limitations in daily activities and leisure come from a validated instrument, the QLQ-C30 is validated as an assessment of quality of life, and future work would benefit from including instruments specifically validated for assessment of participation or limitations with paid work, daily activities, and leisure activities. Other limitations include the self-reported nature of the questionnaires, which can lead to recall bias, and that the treatments, employment practices, time use trends, and other social aspects may have changed both during the data collection period (2009–2012) and in the time since data collection, reducing generalisability of the rates and patterns seen. Similarly, the Netherlands has a unique health and social security system which includes up to 2 years of sickness benefits for those in paid work. While this could also limit generalisability to settings with less generous financial supports, the majority of respondents in this study were

more than 2 years after diagnosis, so were unlikely to be receiving sick leave at the time of their survey.

5 | CONCLUSION

We show that as well as reducing participation in paid work, cancer limits daily activities and leisure activities compared with people without cancer. Type of cancer and having multiple comorbidities may influence this, but the impact of other sociodemographic characteristics is less clear. While some people may reassess their priorities after cancer, for most people, the limitations which prevent them from returning to work appear to also limit them in their daily or leisure activities. Not doing these daily and leisure activities can impact on survivors' sense of identity and reduce their quality of life. Increasing awareness and support, and developing intervention programs, may increase participation in these important life roles.

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CONFLICT OF INTEREST

Marjon Faaij, Dounya Schoormans and Alison Pearce all declare they have no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available with permission from The PROFILES Registry at https://www.profilesregistry.nl/. Restrictions apply to the availability of these data, which were used under license for this study.

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APPENDIX A

PROFILES SURVEY COHORTS

Cohort	Survey title	Dates of diagnosis eligible	Date of data collection	Selected number of patients	Response rate
Prostate	Life after the diagnosis of prostate cancer	2006–2009	October 2011–October 2012	1050 (54 unverifiable addresses)	70% ($n = 695$)
Thyroid	Life after the diagnosis of thyroid cancer	1990–2008	November 2010	445 (90 unverifiable addresses)	86% ($n = 306$)
Lymphoma	Quality of life after Hodgkin lymphoma	1999–2008	May 2009 – August 2009	223 (38 unverifiable addresses)	81% ($n = 150$)
	Quality of life after multiple myeloma			185 (25 unverifiable addresses)	75% ($n = 120$)
	Quality of life after non-Hodgkin lymphoma			1062 (164 unverifiable address)	80% ($n = 715$)