



Employment situation among long-term Hodgkin lymphoma survivors in Europe: an analysis of patients from nine consecutive EORTC-LYSA trials

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Abstract

Purpose Little is known about the employment situation of long-term Hodgkin lymphoma (HL) survivors despite their young age at diagnosis and the favorable prognosis of the disease. In this cross-sectional study, we aim to describe the employment situation in a cohort of long-term HL survivors compared to the general population and investigate the associations with disease characteristics and treatment exposure.

Methods HL survivors > 25 years ($n = 1961$) were matched 1:25 to controls ($n = 49,025$) from the European Union Labour Force Survey. Individual treatment information was obtained from trial records. Employment and socio-demographic characteristics were collected using the Life Situation Questionnaire. Logistic regression models were used to estimate associations between disease and treatment characteristics with employment status and work-related attitudes.

Results At employment assessment, 69.7% of survivors (95% CI: 67.6–71.7%) were working; of these, 68.9% (95% CI: 66.3–71.3%) worked full-time, a figure comparable to that of controls (p value 0.17). The risk of not working was associated with increasing age at diagnosis, increasing age at survey, female sex, lower educational level, and relapse history. Of those who were at work during treatment, 16.8% (95% CI: 14.5–19.3%) stated their income had subsequently decreased, which was attributed to their HL by 65.4% (95% CI: 57.5–72.8). Among those not at work, 25.1% (95% CI: 20.7–29.8) survivors were disabled compared to only 14.5% (95% CI: 13.8–15.3%) of controls.

Conclusions In this cohort of HL survivors, employment status was comparable to that of the general population. However, increasing age at follow-up, female sex, lower educational level, and relapse history are risk factors for unemployment, a perceived decrease in income, and disability.

Implications for Cancer Survivors To further improve follow-up care, special attention should be paid to these vulnerable subgroups.

Keywords Hodgkin lymphoma · Survivorship · Rehabilitation · Employment · Work

Introduction

Due to improved efficiency in prevention, early detection, and especially improved treatment of malignant diseases, the number of long-term cancer survivors is increasing [1–3],

highlighting the need for knowledge about the social functioning, including employment situation, following a cancer diagnosis and treatment. Previous research has shown that long-term cancer survivors are typically part of the workforce [4, 5]; however, survivors of some cancers are characterized by lower employment rates [6–9], higher disability rates [7, 10], and earlier retirement [11, 12] compared to the general population.

In Hodgkin lymphoma (HL), the cure rate has steadily improved over the past four decades as a result of treatment advances, with a 5-year relative survival rate reaching 90%

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[13, 14]. Because of the high cure rate, the relatively young age at diagnosis, and the consequent long life-expectancy, many HL survivors will fall within the working age range.

Loss of work and reintegration into employment has often been studied in the context of cancer survivorship in general, but frequently without separate outcomes for HL survivors. However, findings for patients with other underlying cancers are not always generalizable to HL survivors due to wide variation in patient group characteristics, antineoplastic treatment-modalities, and prognosis (even patients with a recurrence are often successfully treated). Most previous studies on employment among HL survivors are based on small single institution samples or are studies concerning a vast spectrum of possible psycho-medical problems relegating employment to be less rigorously studied [3, 15–19]. A comprehensive analysis of the work situation among HL survivors has to date not been studied in a broad multicenter setting.

The European Organisation for Research and Treatment of Cancer (EORTC) database, which includes both clinician- and patient-reported outcome information, offers a unique opportunity to characterize the population of HL survivors. In this study, we describe the employment situation in a cohort of long-term HL survivors compared to the general population and investigate the associations with disease characteristics and treatment exposure.

Methods

Study design and patients

Between 1964 and 2004, 6658 patients from 13 European countries with newly diagnosed, histologically confirmed HL were included in nine consecutive randomized trials (referred to as the H1–H9 trials) by the EORTC Lymphoma Group and, from 1993, in collaboration with the Lymphoma Study Association (LYSA, previously named GELA). Data from the original case report forms are stored at the EORTC headquarter, Brussels, Belgium (periodically updated in accordance with the trial protocols). Most studies were conducted in stage I–II patients, and details of treatment and results of the individual trials have previously been published [20–29].

To study the socio-economic consequences of HL treatment, the EORTC Lymphoma Group developed the Life Situation Questionnaire (LSQ). The LSQ is a unique, wide-ranging patient-reported outcome questionnaire, consisting of both factual questions and validated questionnaires. It addresses issues such as career changes and influence of disease on work and education situation among other (topics not available in any other validated questionnaire). The LSQ is specially developed for HL survivors, and in previous

publications, fertility, parenthood, long-term fatigue, and cardiovascular disease have already been evaluated [30–35].

Between 2009–2011, the LSQ was distributed by mail (as part of a cross-sectional study) to all HL survivors from the H1–H9 trials with a registered address. The LSQ study was approved by local ethical committees in each participating country. The employment situation was addressed with several questions such as “are you currently working?—if yes, how much are you currently working?” If not, what situation describes your current situation best (homemaker, student/pupil, unemployed, disabled, retired, other)? Professional ambition changes were also evaluated using the following questions “Do you feel that the work you do corresponds with your level of education and experience?” and “Has your attitude towards your work/profession changed due to your Hodgkin’s disease” (for further details see supplement, Annex 1). Only HL survivors older than 25 years at the time of filling out the LSQ (and for whom LSQ forms regarding employment were available) were included in the analysis. For the whole cohort, information was extracted from the EORTC database about patient demographics, time since diagnosis, disease stage at diagnosis (according to the Ann Arbor classification), treatment exposure as well as information about relapse. Information about employment status and work-related attitudes of survivors were obtained from the LSQ. The European Union Labour Force Survey (LFS) was used as a source of general population controls [36], as it provides detailed information on topics including unemployment, part-time employment, and education (see supplement, Annex 2). The LFS is conducted by the national statistical institutes all over Europe and is centrally processed by Eurostat. Anonymized data were made available for this research project.

Statistical analysis

For all estimated parameters, point estimates and two-sided 95% confidence intervals are presented. All tests were performed at a two-sided significance level of 0.05. Confidence intervals for proportions were estimated using the exact method of Clopper and Pearson. Confidence intervals for differences in proportions were estimated using the Newcombe score method.

Each survivor was individually matched by age (using 5-year intervals), sex, education level, country, and year of survey (exact year) with 25 controls from the general population. Five-year intervals were used for age because only this data was available for controls. The number 25 was chosen because this number of controls was available for all but one HL survivor (who was excluded from the comparison of survivors to controls). In case more than 25 controls were available for a certain survivor, 25 controls were randomly selected. Survivors with missing information on the level of

education (43 out of 2026 LSQ participants, 25 years of age or older) were excluded from the comparison of survivors to controls because the level of education was a matching factor. Employment status, part-time employment among those working, and main labor status among those not working were compared between survivors and controls using the chi-square test. In addition, we investigated whether the effect on the employment situation of being a survivor varied by age, sex, country, or education level by testing the interaction terms using logistic regression (for employment status and part-time employment) and multinomial logistic regression (for main labor status among those not working). These regression models included only the indicator of being a survivor, the covariate of interest, and the interaction term as covariates.

Logistic regression was used to investigate the associations between age at LSQ, age at diagnosis, sex, time since diagnosis, level of education, country, disease stage, radiotherapy, chemotherapy, relapse, and the following outcomes: employment status, part-time employment, disability, perceived income decrease due to HL, perceived mismatch between qualifications and type of work done, and decrease in the professional ambitions due to HL. Estimates from fully adjusted models were provided. The inference was based on the Wald tests and confidence intervals. For categorical covariates with more than two categories, the inference was based on the global Wald test. Tukey–Kramer post hoc comparisons were used to estimate differences between specific categories. All patients with available information on the outcome and covariates were included in the regression models.

Results

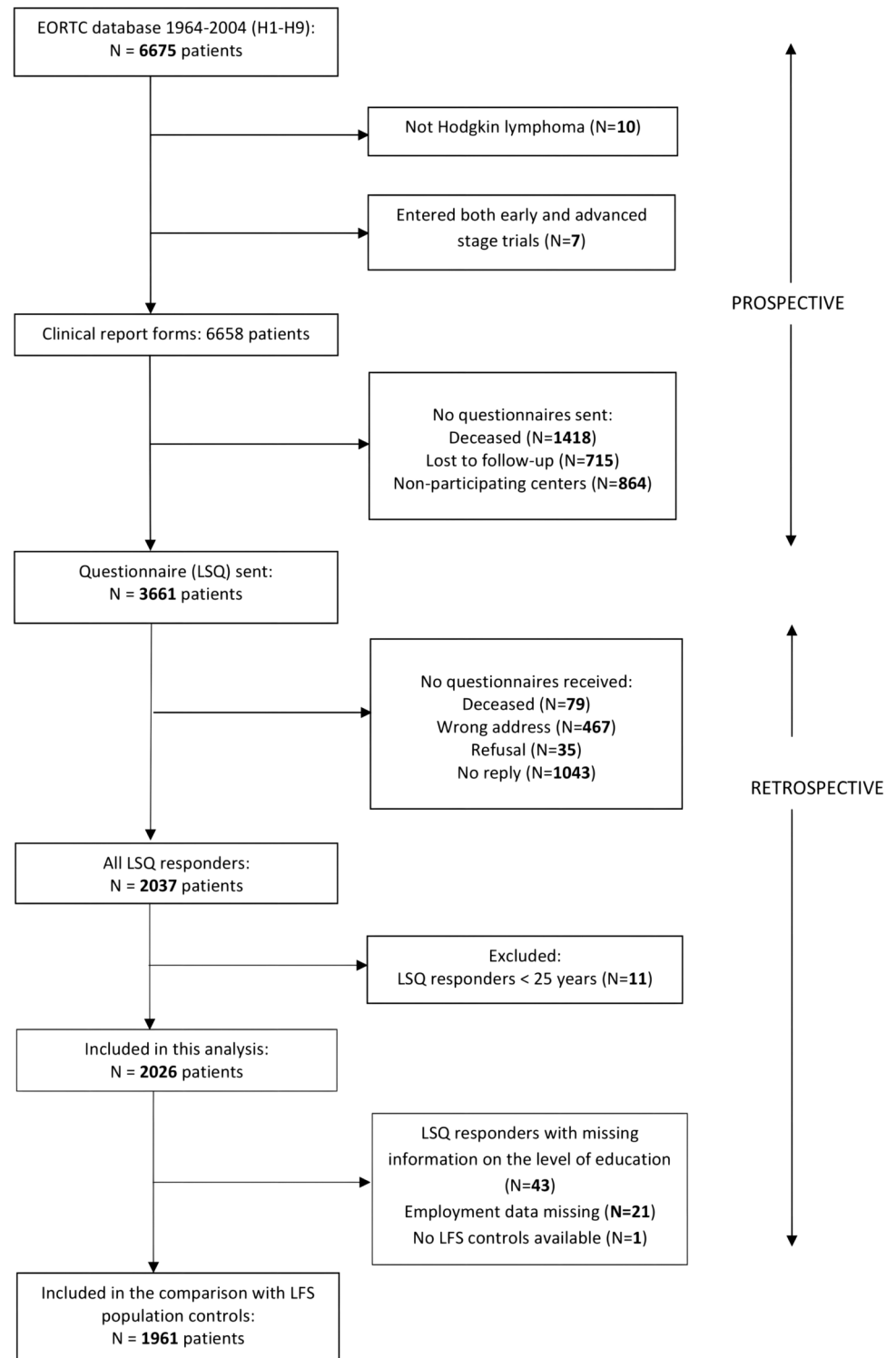
Among 6658 HL patients, the LSQ was sent to 3661 survivors of whom 2037 (56%) responded. A non-responder analysis has previously been performed indicating almost no differences in characteristics (including disease stage distribution) between those who returned the questionnaires compared to those who did not [30]. However, it must be mentioned that responders more often came from less recent trials and had to some extent been treated with non-alkylating chemotherapy and radiotherapy above the diaphragm less frequently [30]. In total, 1961 HL survivors had all matching factors available, had LFS controls available, and were included in the comparison with the general population (Fig. 1).

Characteristics of the study population are presented in Table 1. Among the HL survivors who responded to the LSQ, 49.3% were male, the median age at survey was 47 years (range: 25–84 years), the median age at diagnosis was 30 years (range: 7–69 years), and the median time since

HL diagnosis was 14 years (range: 5–45 years). Most of the responders were treated for stage I or II disease (24.6% and 61.8%, respectively), whereas only 13.5% for stage III or IV disease. The vast majority had been treated with radiotherapy (90.2%) and/or chemotherapy (81.8%) and 10.5% experienced a relapse. Most of the responders lived in the Netherlands (46.9%) or France (38.0%), followed by Belgium (7.5%) and Italy (4.5%). Educational level was evenly distributed with about one-third (29.8%) having no high school diploma, one-third (31.8%) having a high school diploma, and approximately one-third (36.3%) having a university degree.

At the time of the survey, most survivors (69.7%, 95% CI: 67.6–71.7%) were working; of these, 68.9% (95% CI: 66.3–71.3%) worked full-time, which was comparable to the general population (Table 2). Among the HL survivors who worked both at the time of diagnosis and at the time of the study, only 16.8% (95% CI: 14.5–19.3%) reported that their income had subsequently decreased and 65.4% (95% CI: 57.5–72.8%) attributed this to their HL. The risk of perceived income decrease due to HL was associated with higher age at diagnosis (p value = 0.016), female sex (p value = 0.003), country (p value < 0.001, with a lower risk in France as compared to the Netherlands and a similar risk in the Netherlands, Belgium, and Italy), and relapse (p value = 0.001) (Table 3). The majority had no change in professional ambitions following HL treatment (62.9%, 95% CI: 59.9–65.9%) and felt their job to match qualifications (85.9%, 95% CI: 83.9–87.7%). A job qualification mismatch was associated with female sex (p value 0.002), chemotherapy (p value 0.042), radiotherapy (p value 0.048), and age at survey (p value 0.024). Having a relapse was associated with a decrease in professional ambitions (p value 0.038) (Table 3). However, some (16.2%, 95% CI: 14.0–18.6%) were even more ambitious after their HL diagnosis (see supplement, Annex 6).

Status among those not at work showed that only 29.6% (95% CI: 25.0–34.6%) of the HL survivors were retired versus 38.8% (95% CI: 37.8–39.8%) of the general population (Table 2). This was found even though non-working survivors were older than the non-working general population controls (see supplement, Annex 7). Only 5.7% (95% CI: 3.5–8.5%) of HL survivors were unemployed versus 11.8% of the general population (95% CI: 11.2–12.5%) and there were as many survivors reported as homemakers as in the general population (~24%) (Table 2). Disability showed an overrepresentation of HL survivors (25.1%, 95% CI: 20.7–29.8%) compared to the general population (14.5%, 95% CI: 13.8–15.3%) (Table 2). The risk of being disabled was associated with increasing age at survey (p value 0.002), country (p value < 0.001), educational level (p value 0.044), and relapse (p value 0.003) (Table 3).

Fig. 1 Patient flowchart

Among the HL survivors, there was a higher proportion of females not working compared to males (34.0% vs. 26.5%), but the proportions were comparable to those of the general population (33.1% vs. 24.5%). The percentage of non-working survivors was 47.8% (95% CI: 43.7–51.9%) among those without a high school diploma, 27.8% (95% CI:

24.3–31.4%) among those with a high school diploma and 18.4% (95% CI: 15.6–21.4%) among those with a university degree, which was a comparable distribution to that found in the general population (see supplement, Annex 6).

Overall, the risk of not working was associated with increasing age at diagnosis (p value < 0.001), increasing age

Table 1 Characteristics of the study population

	N	(%)
Total no. of patients	2026	100
Sex		
Male	998	(49.3)
Female	1028	(50.7)
Age at diagnosis		
7–25	666	(32.9)
25–35	639	(31.5)
35–45	416	(20.5)
45–70	305	(15.1)
Time since diagnosis		
5–10	490	(24.2)
10–20	1091	(53.8)
20–45	445	(22.0)
Country		
The Netherlands	950	(46.9)
France	770	(38.0)
Belgium	151	(7.5)
Italy	91	(4.5)
Other*	64	(3.2)
Stage		
I	498	(24.6)
II	1253	(61.8)
III	159	(7.8)
IV	115	(5.7)
Missing	1	(0.0)
Chemotherapy		
No chemotherapy	369	(18.2)
Vinca alkaloids only	124	(6.1)
Containing anthracyclines	1533	(75.7)
Radiotherapy		
No	198	(9.8)
Yes	1828	(90.2)
Relapse		
No	1813	(89.5)
Yes	213	(10.5)
Age at survey		
25–35	317	(15.5)
35–45	573	(28.3)
45–55	569	(28.1)
55–65	383	(18.9)
65–85	184	(9.1)
Educational level		
No high school	604	(29.8)
High school diploma	644	(31.8)
University degree	735	(36.3)
Missing	43	(2.1)

*The category “other” includes the Slovak Republic, Slovenia, and Switzerland, which were merged due to a small number of study participants from these countries

at survey (p value < 0.001), female sex (p value < 0.001), lower education level (p value < 0.001), and relapse (p value < 0.001) (Table 3).

Part-time employment among HL survivors was more frequent among females than males (51.6% vs. 12.3%) but these proportions were comparable to those of the general population. The prevalence of part-time employment varied greatly among the participating European countries, where almost half of all Dutch participants were part-time employed against only approximately 20% of participants in the other participating countries. However, the same trend was observed in the general population (data not shown). In general, part-time employment was found to be associated with increasing age at survey (p value < 0.001) and female sex (p value < 0.001) (Table 3).

Discussion

As the improvement in survival rates has led to a constantly growing cohort of long-term HL survivors, the importance of work ability, (re-)employment, and social reintegration is a major concern.

To the best of our knowledge, this study is the first to describe the employment situation of long-term HL survivors in a large-scale international, multicenter cohort. Over a four-decade period, more than 1900 individuals were enrolled, making this study the largest to date. Our findings showed that even though HL is often diagnosed at an early age and will be a life-defining event to many, the employment status of HL survivors was comparable to that of the general population and most managed to maintain their work goals and ambitions. However, when disabled by HL and/or its treatment, survivors face nearly twice the risk of unemployment as controls.

In line with our results, a Swedish study including 121 HL survivors treated in Stockholm County during the period 1972–1991 found that 72% of survivors were employed, which did not differ significantly compared to the general population [17]. Also, a Boston study including 511 HL survivors (treated between 1969 and 1996) reported up to 85% of HL survivors being employed, comparable to that of siblings [16]. The study, however, was based on a group of patients predominantly from well-educated and higher income backgrounds and should be interpreted with caution. When investigating whether HL diagnosis and its treatment would influence the future professional ambition, we found that the majority felt their job to match qualifications and only a small proportion having less ambitions. This is supported by findings from a Stanford study [37] which included 403 HL survivors and found that 81% of the employed survivors had their work ambitions unchanged or greater than prior to treatment. A French population-based,

Table 2 Employment situation of Hodgkin lymphoma survivors versus population controls

Outcome	Survivors		Controls		Difference		p value
	N	%	(95% CI)	N	%	(95% CI)	
Employment status	1961			49,025			0.170
Working	1367	69.7	(67.6–71.7)	34,877	71.1	(70.7–71.5)	
Not working	594	30.3	(28.3–32.4)	14,148	28.9	(28.5–29.3)	
Status of those working	1355			34,877			0.961
Part-time	422	31.1	(28.7–33.7)	10,840	31.1	(30.6–31.6)	
Full-time	933	68.9	(66.3–71.3)	24,037	68.9	(68.4–69.4)	
Status of those not working*	371			8866			<0.001
Retired	110	29.6	(25.0–34.6)	3439	38.8	(37.8–39.8)	
Homemaker	89	24.0	(19.7–28.7)	2202	24.8	(23.9–25.7)	
Unemployed	21	5.7	(3.5–8.5)	1048	11.8	(11.2–12.5)	
Disabled	93	25.1	(20.7–29.8)	1287	14.5	(13.8–15.3)	
Other	58	15.6	(12.1–19.7)	890	10.0	(9.4–10.7)	

CI: confidence interval

*Excludes study participants from France due to the unavailability of information for controls from this country

case–control study looking into late psychosocial sequelae in 93 HL survivors [15] and a Norwegian study looking into the socio-medical situation of 459 HL survivors [19] also reported results in agreement with our findings. In general, HL survivors seem to fare well.

There is, however, a subgroup of HL survivors who suffer from impaired health because of their treatment and this impairment sometimes leads to a reduced capacity to work, to a perceived decrease in income or even disability [38].

Due to the treatment (both multiagent chemotherapy as well as radiotherapy) HL survivors are at risk of developing a variety of therapy-related long-term complications resulting in excess morbidity and mortality (cardiovascular disease, second malignancy, hormonal dysfunction, infections, and chronic fatigue being the most important) [14, 34, 35]. It is therefore not surprising that higher disability rates were found among HL survivors than in the general population.

Similar to our results unemployment and impaired work ability was found to be associated with type of treatment, health status, higher age, female sex, educational level, and physical workload in other studies [5, 38–40]. Especially relapse treatment may result in more fatigue, longer sick leave, heavier side effects, and/or late effects as well as treatment complications, which may be the major reason for the low employment rate and higher disability rate in this category of HL survivors. In general, prevalence of treatment-related symptoms has been found to independently predict how soon a cancer patient may be able to return to work [41, 42].

The effect of sex on future employment is not fully understood, but it has been observed in other studies as well [39, 43, 44]. However, the same pattern (risk for unemployment associated with female sex) appeared both among HL survivors and in the general population, which could indicate that it is merely a reflection of general tendencies in Europe. Our results also demonstrated an association between status as not working and a lower educational level. It has previously been suggested that people with a lower educational level are more likely to have physically demanding jobs, and since cancer and its treatment may reduce a person's physical capacity, it is expected that cancer patients with a lower level of education might be more likely to terminate their work career [10, 38, 45]. Consistent with this hypothesis, Taskila et al. reported that profession rather than education level affected subsequent employment rates [435].

Only a minor proportion reported a perceived decrease in income due to HL and its treatment. The same was observed in a study by Brierley et al. on treatment-related late effects among 362 early-stage HL patients, where only 14.6% reported being worse off financially due to HL [46]. Brierley et al. did not elaborate on this data; however, our results found that risk factors for a perceived decrease in income included sex and country. Of note, this may be explained

by societal issues such as differences in (full-time) employment rates between men and women [18] as well as differences in social welfare systems between countries. By extension, difficulty obtaining insurance due to past medical history (which again may be different among the participating countries) can contribute to retaining of a job (without the possibility of promotion) in order to maintain insurance coverage [47]. Reordering of life priorities after a cancer diagnosis may also be a reason for a job change or even giving up work entirely [48].

The exact prevalence of employment after HL diagnosis and its treatment has until now been difficult to quantify because earlier studies have been based on rather small sample sizes and often did not include any reference group. The main strength of our study is the unique dataset of thousands of HL survivors across Europe with a median follow-up of 14 years matched to general population controls. Also, we did not rely on a dichotomous measure of employment only, which allows for a more nuanced understanding of the employment situation. Additionally, by matching HL survivors to population controls by the level of education (which is a reliable indicator of the socioeconomic position) [49], the extent of any selection bias is expected to be reduced. There are, however, limitations to our findings, several of which are inherent to the retrospective design. First, our data depended on self-reported outcomes, which may have led to recall or nonresponse bias. However, questions that concern important life events (such as changes in professional situation) are generally well memorized, and recall bias should, therefore, be limited [15]. Also, a major source of nonresponse were entire centers not participating in the LSQ, which again reduces the risk of bias (as participation in the LSQ study is unlikely to be related to the employment status of cancer survivors previously treated in that facility). However, possible selection bias due to social inequality cannot be excluded. Second, the study design does not allow for causal inferences (only for associations) nor investigation of any temporal relations. The higher incidence of disability in this cohort of HL survivors has been associated to HL disease and/or its treatment, which (as a result of the above) must be interpreted with caution. Third, most HL survivors in our cohort had stage 1 or 2 disease at the time of diagnosis. Since a more advanced disease stage at time of diagnosis has been shown to be a barrier of re-employment after treatment in other cancers [4, 5, 12], this could have led to over-optimistic estimates of the employment situation. However, no association between disease stage at time at diagnosis and employment situation was found in this study. Also, both exposure and dose sizes have decreased in radio- and chemotherapy over time [34], which may have led to poorer employment outcomes than those that would be obtained with currently used treatment regimens. Finally, we did not have the opportunity to study any relation to the

Table 3 Associations between survivors' characteristics and their employment situation and work-related attitudes

Covariate	Not working (<i>n</i> = 1961)			Part-time employment among those working (<i>n</i> = 1354)			Disability (<i>n</i> = 1940)			Perceived decrease in income due to HL* (<i>n</i> = 945)			Decrease in professional ambitions* (<i>n</i> = 1094)			No match between qualifications and type of work^ (<i>n</i> = 1269)		
	OR	95% CI	<i>p</i> value	OR	95% CI	<i>p</i> value	OR	95% CI	<i>p</i> value	OR	95% CI	<i>p</i> value	OR	95% CI	<i>p</i> value	OR	95% CI	<i>p</i> value
Sex																		
Male	Ref		< 0.001	Ref		< 0.001	Ref		0.792	Ref		0.003	Ref		0.117	Ref		0.002
Female	2.17	(1.68–2.78)		14.07	(10.05–19.70)		1.05	(0.71–1.57)		1.99	(1.27–3.12)		1.29	(0.94–1.78)		1.70	(1.21–2.38)	
Age at diagnosis																		
7–25	Ref		< 0.001	Ref		0.960	Ref		0.174	Ref		0.016	Ref		0.068	Ref		0.905
25–35	0.88	(0.54–1.38)		1.03	(0.62–1.71)		0.66	(0.32–1.37)		1.54	(0.62–3.79)		1.84	(1.00–3.40)		1.18	(0.66–2.10)	
35–45	0.89	(0.49–1.62)		1.15	(0.55–2.37)		0.49	(0.19–1.25)		3.21	(1.02–10.09)		1.98	(0.87–4.50)		1.16	(0.47–2.90)	
45–70	2.29	(1.08–4.87)		1.18	(0.39–3.62)		0.38	(0.12–1.26)		5.71	(1.26–25.79)		2.39	(0.70–8.19)		1.09	(0.22–5.56)	
Country																		
The Netherlands	Ref		0.489	Ref		< 0.001	Ref		< 0.001	Ref		< 0.001	Ref		0.173	Ref		0.216
France	1.11	(0.76–1.63)		0.17	(0.10–0.27)		0.34	(0.17–0.65)		0.26	(0.12–0.58)		0.69	(0.42–1.13)		1.44	(0.85–2.44)	
Belgium	1.10	(0.57–2.14)		0.20	(0.09–0.46)		0.41	(0.12–1.38)		1.31	(0.45–3.88)		0.92	(0.38–2.24)		1.31	(0.54–3.15)	
Italy	0.83	(0.34–1.99)		0.22	(0.08–0.60)		0.81	(0.20–3.25)		1.07	(0.31–3.72)		0.60	(0.18–1.97)		0.93	(0.28–3.07)	
Other	1.72	(0.67–4.36)		0.14	(0.03–0.61)		0.26	(0.05–1.21)		0.43	(0.05–3.55)		0.41	(0.07–2.32)		0.50	(0.09–2.85)	
Stage																		
I	Ref		0.785	Ref		0.799	Ref		0.192	Ref		0.860	Ref		0.658	Ref		0.118
II	1.17	(0.79–1.72)		1.00	(0.62–1.62)		1.41	(0.75–2.65)		1.00	(0.48–2.06)		1.28	(0.76–2.18)		0.85	(0.50–1.46)	
III	1.09	(0.55–2.15)		0.75	(0.32–1.75)		0.65	(0.18–2.35)		1.38	(0.46–4.19)		1.26	(0.50–3.15)		1.83	(0.75–4.51)	
IV	1.14	(0.52–2.50)		0.88	(0.35–2.18)		0.81	(0.20–3.25)		1.06	(0.29–3.89)		1.07	(0.38–3.01)		0.95	(0.31–2.93)	
Chemotherapy																		
No	Ref		0.817	Ref		0.799	Ref		0.749	Ref		0.882	Ref		0.603	Ref		0.042
Vinorelbine only	1.13	(0.61–2.09)		1.22	(0.52–2.86)		0.92	(0.37–2.30)		1.26	(0.28–5.63)		1.05	(0.35–3.14)		1.39	(0.54–3.57)	
Radiotherapy																		
Containing anthracyclines	0.95	(0.63–1.45)		1.14	(0.69–1.89)		1.21	(0.61–2.40)		0.93	(0.42–2.07)		0.80	(0.46–1.41)		0.63	(0.36–1.10)	
No	Ref		0.443	Ref		0.526	Ref		0.977	Ref		0.553	Ref		0.323	Ref		0.048
Yes	1.19	(0.76–1.87)		0.85	(0.51–1.42)		0.99	(0.43–2.24)		1.26	(0.59–2.69)		1.34	(0.75–2.40)		1.93	(1.00–3.71)	
Relapse																		
No	Ref		< 0.001	Ref		0.534	Ref		0.003	Ref		0.001	Ref		0.038	Ref		0.592
Yes	1.93	(1.33–2.80)		1.18	(0.71–1.96)		2.17	(1.30–3.64)		2.68	(1.47–4.89)		1.66	(1.03–2.67)		0.84	(0.45–1.57)	
Age at survey																		
25–35	Ref		< 0.001	Ref		< 0.001	Ref		0.002	Ref		0.553	Ref		0.071	Ref		0.024
35–45	1.24	(0.67–2.33)		2.20	(1.20–4.04)		1.58	(0.52–4.75)		0.82	(0.24–2.81)		1.65	(0.70–3.90)		0.60	(0.32–1.13)	
45–55	1.81	(0.90–3.67)		2.69	(1.29–5.64)		3.39	(1.05–10.91)		0.60	(0.15–2.42)		1.01	(0.39–2.66)		0.38	(0.16–0.88)	
55–85	13.87	(6.15–31.30)		6.71	(2.50–18.02)		5.84	(1.53–22.29)		0.87	(0.17–4.38)		0.88	(0.26–2.93)		0.30	(0.08–1.05)	
Educational level																		
No high school	Ref		< 0.001	Ref		0.892	Ref		0.044	Ref		0.082	Ref		0.270	Ref		0.079
High school diploma	0.93	(0.65–1.33)		1.10	(0.68–1.78)		1.23	(0.70–2.18)		1.37	(0.70–2.66)		0.97	(0.58–1.61)		0.82	(0.47–1.43)	
University degree	0.46	(0.32–0.67)		1.07	(0.67–1.71)		0.65	(0.35–1.22)		0.75	(0.37–1.52)		1.28	(0.78–2.11)		0.61	(0.35–1.06)	

Table 3 (continued)

OR, odds ratio

CI, confidence interval

*Measured among survivors working both at the time of diagnosis and the time of the study

^Measured among survivors working at the time of the study

Estimates from fully adjusted logistic regression models are presented

For disability, the categories Italy and other were merged to avoid small cell count

presence of fatigue, anxiety, or depression, which could have influenced the results [44].

The ability to return to work and maintain occupational pursuits after a cancer diagnosis has previously been demonstrated to improve welfare, increase self-esteem, and reduce social isolation [3]. For this reason, it seems important to identify the HL survivors at risk of impaired work ability. Our data provide an identification of vulnerable subgroups for unemployment among HL survivors, thus, enabling identification of survivors with the highest risk of a reduced work ability and who are more likely to leave work life early. By identifying these people, it will be possible to provide extra support, e.g., by arranging work-related adjustments and individualized follow-up [38].

In conclusion, most HL survivors do not encounter major professional problems nor occupational discrimination. However, increasing age at follow-up, female sex, lower educational level, and relapse are risk factors for unemployment, a perceived decrease in income, and disability. To further improve follow-up care and to strengthen rehabilitation, future research should focus on effective adaptation, transition, and retention of these vulnerable subgroups in the workplace after treatment.

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Author contribution MVDK and MVM are study coordinators. MVDK, BMPA, HCKN, MHA, and PM designed the LSQ questionnaire. MVDK, BMPA, HCKN, MHA, JMMR, PM, MS, CF, OC, AS, MA, and FLB are responsible for acquisition of data and MK for statistical analysis. SJJ drafted the first manuscript with the collaboration of SR. All authors critically reviewed the paper. All authors commented, revised, and approved the final manuscript.

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Data availability Access to the data that support the findings of this study (request form) can be found at <https://www.eortc.org/data-sharing/>. All data sharing takes place in accordance with EORTC's data sharing policy.

Declarations

Ethics approval Protocols and informed consent for the H1-H9 trials as well as the LSQ study was approved by local ethical committees in each participating country. The studies were carried out in accordance with the Helsinki Declaration.

Consent to participate Participants receiving the Life Situation Questionnaire have all consented to their responses being analyzed.

Competing interests The authors declare no competing interests of relevance to this study.

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