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Better quality of life among 10–15 year survivors of Hodgkin's lymphoma compared to 5–9 year survivors: A population-based study

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ABSTRACT

This study describes the quality of life (QoL) of long-term Hodgkin's lymphoma survivors and compares it to an age-matched normative sample. The population-based Eindhoven Cancer Registry was used to select all patients diagnosed with Hodgkin's lymphoma from 1989 to 1998.

Eighty percent of survivors completed the SF-36 and the quality of life-cancer survivors questionnaire. QoL was better among patients diagnosed 10–15 years ago compared to patients diagnosed 5–9 years ago. The patients diagnosed 5–9 years ago experienced lower general health, social functioning, mental health and vitality compared to an age-matched normative sample, while the patients diagnosed 10–15 years earlier reported lower general health but better physical functioning. Most patients reported that their work situation did not change. Problems pertaining to the obtainment of health insurance, life insurance and mortgages were high. QoL among Hodgkin's lymphoma survivors is lower compared to an age-matched normative sample. Survivors furthermore experience some (financial) problems in the years after diagnosis.

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1. Introduction

Hodgkin's lymphoma is a relatively uncommon malignancy. In the Netherlands, the incidence is 1 in 50,000,¹ with approximately 350 new cases annually. The disease affects men more often than women. Onset occurs most frequently between the ages of 20 and 35 years. Between 35 and 50 years it occurs less often, especially in females, but from the age of 50 onward there is again a rise in incidence with age. Hodg-

kin's lymphoma is considered a curable disease although conditional 5-year survival is <90%.² The use of appropriate staging techniques and treatment methods has resulted in high long-term survival rates. In the south of the Netherlands, 5-year relative survival is 82% and 10-year relative survival is 77% depending on the stage.³ If a person is alive 5 years after initial diagnosis, he is considered a 'long-term survivor' according to the guidelines of the American Cancer Society.⁴ In 2000 there were about 4450 Hodgkin's lymphoma

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survivors in the Netherlands and this group is expected to increase to nearly 7000 survivors in 2010.¹ This illustrates the rapid increase in the numbers of individuals who are either cured of their cancer or are living with it as a chronic disease.⁵

Hodgkin's lymphoma survivors face very specific problems that have become more apparent as greater numbers of successfully treated patients have been followed for longer periods of time. They concern mainly chronic medical as well as psychosocial complications that can affect their quality of life (QoL). Patients can be treated with systemic therapy, radiotherapy or a combination of both. These interventions may result in severe infections and may cause thyroid, cardiovascular, pulmonary, digestive or gonadal dysfunction, hypothyroidism and secondary malignancy.^{6,7} To date, a number of studies have evaluated the long-term effects of Hodgkin's lymphoma and its treatment on QoL.^{8–17} These studies indicate that the survivors more often have a decreased, self-reported health status, increased levels of generalised distress, fear of recurrence and other worries about their disease, and problems in the realms of intimacy and sexuality. Furthermore, the survivors may experience fatigue and loss of energy and late effects on skin and mucous membrane. Practical problems may also occur, including employment and insurance discrimination and difficulties with financial loans.^{9–11,17–19} However, most of these studies were either based on a small number of survivors,^{9,11} were primarily investigating fatigue^{17,19} or included patients who were treated up to two decades ago.^{9,11,17}

The aim of the present, cross-sectional study was to obtain insight into the QoL of long-term Hodgkin's lymphoma survivors in a large population-based study. We compared the QoL of individuals who had survived the disease for 5–9 years with that of patients who had survived 10–15 years. We also studied the differences in QoL between Hodgkin's lymphoma survivors and an age-matched normative sample from the general Dutch population. Finally, we assessed changes in work situations, and problems with insurance and loans.

2. Materials and methods

2.1. Setting and participants

A population-based, cross-sectional survey was conducted at the Eindhoven Cancer Registry (ECR). The ECR records data on all patients newly diagnosed with cancer in the southern part of the Netherlands, an area with 2.3 million inhabitants, 18 hospital locations and two large radiotherapy institutes.³ The ECR was used to select all patients diagnosed with Hodgkin's lymphoma between 1989 and 1998. Participants older than 75 years at diagnosis were excluded, as it was expected that they would have difficulty in completing a self-report questionnaire without assistance. To exclude persons who had died before 1st November 2004, our database was linked with the database of the Central Bureau for Genealogy, which collects data on all deceased Dutch citizens via the civil municipal registries. Data collection started in November 2004. Approval for the study was obtained from a local, certified Medical Ethics Committee.

2.2. Data collection

Medical specialists sent their (former) patients a letter to inform them about the study and a copy of the questionnaire. The letter explained that by returning the completed questionnaire, the patient agreed to participate and consented with linkage of the outcome of the questionnaire with their disease history as registered in the ECR. The patients were reassured that non-participation would not have any consequence for their follow-up care or treatment. If the questionnaire was not returned within two months, a reminder letter with an additional copy of the questionnaire was sent.

2.3. Study measures

The ECR routinely collects sociodemographic and clinical data, including date of birth, gender, date of diagnosis, subsite, histology, stage (Tumour-Node-Metastasis clinical classification,²⁰) treatment and comorbidity at the time of diagnosis (a slightly adapted version of the Charlson comorbidity index²¹).

The Dutch version of the SF-36 questionnaire was used to assess generic QoL.²² According to standard scoring procedures, all scales were linearly converted to a 0–100 scale, with higher scores indicating better functioning. Differences of at least 5 points (the general health dimension),²³ 6.5 points (the physical dimensions) and 7.9 points (the mental health dimensions) were considered clinically meaningful.²⁴ The SF-36 has been demonstrated to be valid and reliable.^{25,26} The SF-36 scores of the patient sample were compared with those of an age-matched normative sample drawn from a large, random, nationwide normative sample of adults ($n = 1742$) taken from the general Dutch population.²⁶

Generic HRQL survival issues were assessed with the Dutch version of the quality of life-cancer survivors (QoL-CS) instrument,^{27,28} a 45-item visual analogue scale, each of which ranges from 0 (worst outcome) to 10 (best outcome). The questionnaire contains four multi-item subscales on well-being: physical, psychological, social and spiritual. It examines issues of particular concern to long-term cancer survivors such as fertility, employment, uncertainty about the future and the role of spirituality and religion.²⁹ The QoL-CS has been demonstrated to be a valid and reliable instrument.^{27,28,30,31}

The questionnaire also included questions on sociodemographic data, disease progression, current comorbidity and questions on insurance and loans.

2.4. Statistical analysis

All statistical analyses were performed using SAS (version 9.1 for Windows, SAS institute Inc., Cary NC). Routinely collected data from the ECR on patient and tumour characteristics enabled us to compare the group of respondents, non-respondents and patients with unverifiable addresses, using *t*-tests for continuous variables and χ^2 analyses for categorical variables. Survivors with recurrent disease or a new primary malignancy were excluded from further analysis. Because a number of subscales were skewed, non-parametric tests were used when appropriate. Linear regression analyses were

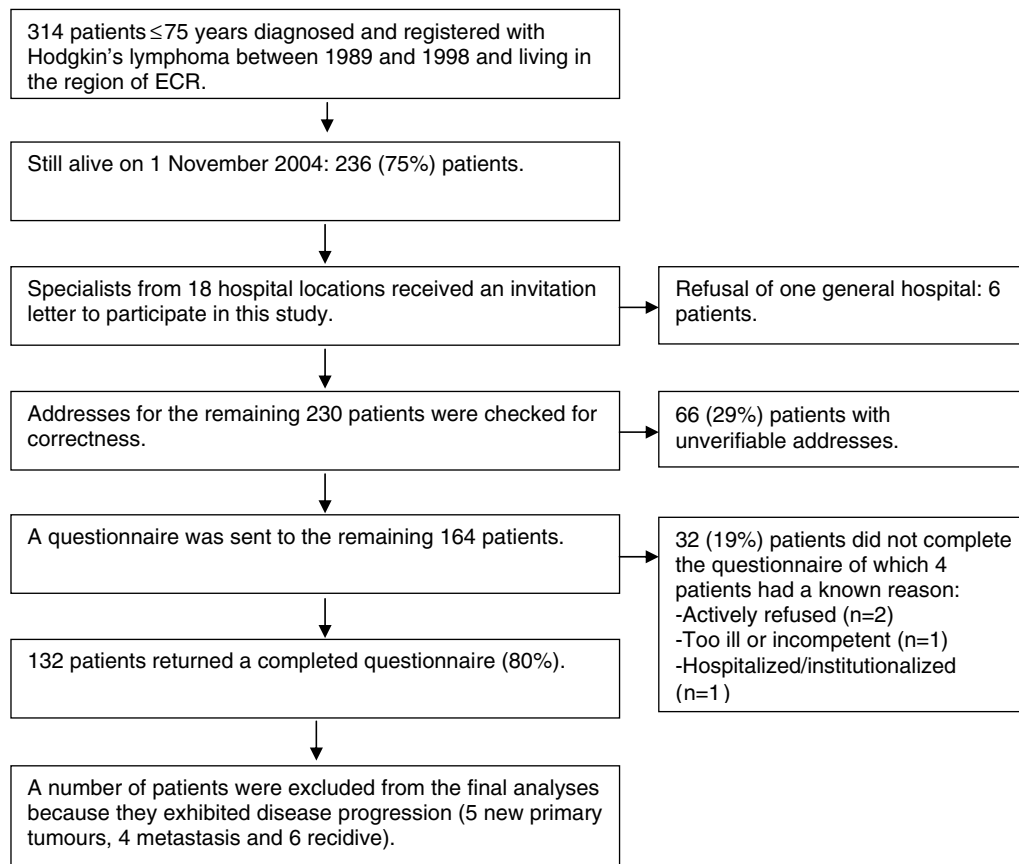


Fig. 1 – Flow-chart of the data collection process.

Table 1 – Socio-demographic and medical characteristics of questionnaire respondents, non-respondents and patients with unverifiable addresses

	Respondents, N = 132 N (%)	Non-respondents, N = 32 N (%)	Patients with unverifiable addresses, N = 66 N (%)	P-value
<i>Age at time of survey</i>				
20–34 years	36 (28)	10 (32)	29 (45)	0.20
35–49 years	47 (36)	11 (35)	21 (32)	
50+ years	46 (36)	10 (32)	15 (23)	
<i>Years since diagnosis</i>				
5–9 years	54 (41)	12 (38)	32 (48)	0.49
10–15 years	78 (59)	20 (63)	34 (52)	
<i>Stage at diagnosis</i>				
I	32 (24)	10 (31)	19 (29)	0.82
II	62 (47)	12 (38)	30 (45)	
III	28 (21)	6 (19)	9 (14)	
IV	6 (5)	3 (9)	6 (9)	
Unknown	4 (3)	1 (3)	2 (3)	
<i>Primary treatment</i>				
Systemic only	38 (29)	8 (25)	16 (24)	0.15
Radiotherapy only	25 (19)	6 (19)	18 (27)	
RT + ST ^a	66 (50)	16 (50)	29 (44)	
None/other/unknown	3 (2)	2 (6)	3 (5)	

a RT + ST: radiotherapy combined with systemic therapy.

carried out in order to investigate the association between patient characteristics (e.g. age, comorbidity) and tumour characteristics (e.g. stage, treatment, time since diagnosis) with the composite and subscale scores of the SF-36 and QoL-CS. On the basis of the univariate results, multivariate models were constructed to determine which patient and tumour characteristics were independently associated with QoL outcomes. We controlled for these variables in the analysis of covariance (ANCOVA), which was used to compare means of SF-36 and QoL-CS scores among different subgroups.

Mean scores on the SF-36 domain and summary scales were compared between our study sample and a Dutch general population normative sample, matched for age.

Percentages of patients experiencing changes in work situations and having problems with insurance and mortgages were calculated. We only analysed the changes in the work situation of patients who were younger than 60 years at diagnosis, because that is the age when most people in the Netherlands retire.

3. Results

Questionnaires were sent to 164 patients, 132 (80%) of whom returned completed forms (Fig. 1). No statistically significant differences in age at the time of survey, years since diagnosis, stage at diagnosis or initial treatment were found between respondents, non-respondents and patients with unverifiable addresses (Table 1). A number of patients were excluded from the final analyses because they exhibited disease progression (five new primary tumours, four metastasis and six recurrence), leaving 117 patients for the analysis.

Most patients were treated with a combination of radiotherapy and chemotherapy (Table 2). More than half of the patients reported one or more co-morbid conditions: arthrosis, thyroid disease and hypertension were the most common. Marital status, education level and current occupation were similar for the two groups.

Patients who had survived 10–15 years after diagnosis reported higher QoL scores for all subscales of the SF-36 and QoL-CS than patients who had survived 5–9 years (Table 3). This effect was statistically and clinically significant for the subscales vitality (64.8 versus 57.1, $P < 0.05$), social functioning (85.4 versus 73.1, $P < 0.01$) and role-emotional (85.7 versus 69.5, $P < 0.05$). It was also statistically significant for the mental component scale of SF-36 (52.1 versus 47.7, $P < 0.05$). Additional analyses, comparing QoL (SF-36 and QoL-CS) for different treatment methods, did not yield any significant differences (data not shown).

The SF-36 scores of the 5–9 year and 10–15 year survivors were compared with those of an age-matched norm population (Fig. 2). Patients diagnosed 5–9 years ago had lower mean scores for the subscales general health ($P < 0.01$), vitality ($P < 0.05$) and social functioning ($P < 0.05$) and for the mental component scale ($P < 0.05$) compared to the age-matched normative population, these differences were statistically and clinically relevant. Patients diagnosed 10–15 years ago scored lower for the general health scale ($P < 0.001$) compared to an age-matched norm population, but they had higher scores on the physical functioning subscale ($P < 0.01$), these differences were also statistically and clinically relevant.

Table 2 – Socio-demographic and clinical characteristics of long-term Hodgkin's lymphoma survivors without recurrent disease or new primary malignancies

	5–9 year survivors, N = 48 N (%)	10–15 year survivors, N = 68 N (%)	P-value
<i>Age at time of survey</i>			
20–34 years	13 (27)	19 (28)	0.85
35–49 years	17 (35)	24 (35)	
50+ years	16 (33)	24 (35)	
<i>Age at diagnosis</i>			
20–34 years	16 (33)	33 (49)	0.27
35–49 years	18 (38)	15 (22)	
50+ years	9 (19)	12 (18)	
<i>Stage at diagnosis</i>			
I	13 (27)	17 (25)	0.30
II	25 (52)	27 (40)	
III	7 (15)	19 (28)	
IV	3 (6)	3 (4)	
Unknown	0 (0)	2 (3)	
<i>Primary treatment</i>			
Systemic only	14 (29)	21 (31)	0.28
Radiotherapy only	5 (10)	14 (21)	
RT + ST ^a	29 (60)	33 (49)	
<i>Comorbidity</i>			
None	23 (48)	30 (44)	0.80
1	19 (40)	25 (37)	
2+	6 (13)	13 (19)	
<i>Most frequent co-morbid conditions</i>			
Arthrosis	7 (15)	15 (22)	0.31
Thyroid disease	5 (10)	13 (19)	0.20
Hypertension	6 (13)	7 (10)	0.71
<i>Marital status</i>			
Married	27 (56)	47 (69)	0.72
Not married/divorced	18 (38)	18 (26)	
Widowed	1 (2)	1 (1)	
Unknown	1 (4)	1 (3)	
<i>Education level</i>			
Low	12 (25)	13 (19)	0.25
Medium	17 (35)	37 (54)	
High	17 (35)	16 (24)	
Unknown	2 (4)	2 (3)	
<i>Current occupation</i>			
Employed	35 (73)	43 (63)	0.42
Unemployed	10 (21)	17 (25)	
Retired	1 (2)	6 (9)	
Unknown	2 (4)	2 (3)	

a RT + ST: radiotherapy combined with systemic therapy.

The QoL-CS contained the question: 'To what degree are you concerned about your fertility?'. The mean score was low and there were no significant differences observed as a function of treatment methods or time since diagnosis (data not shown). Among patients under the age of 40, 51% indicated that they did not worry at all, and only 13% indicated that they were very worried. Of the patients above 40 years of age, 77% indicated that they were not at all worried about fertility.

Table 3 – SF-36 and QoL-CS scores for long-term Hodgkin's lymphoma survivors according to years since diagnosis

	5–9 year survivors, N = 48 Mean (SD)	10–15 year survivors, N = 68 Mean (SD)	P-value ^a
SF-36 scales			
Physical functioning	78.7 (23.8)	85.1 (18.7)	0.11
Role-physical	64.4 (42.6)	76.2 (36.6)	0.12
Bodily pain	81.4 (24.1)	84.0 (22.3)	0.54
General health perception	56.6 (25.7)	59.8 (21.9)	0.45
Vitality	57.1 (23.5)	64.8 (17.4)	<0.05
Social functioning	73.1 (27.3)	85.4 (19.9)	<0.01
Role-emotional	69.5 (41.0)	85.7 (29.8)	<0.05
Mental health	72.3 (20.0)	77.8 (14.3)	0.09
Physical component scale	47.0 (11.4)	48.7 (10.7)	0.73
Mental Component scale	47.1 (12.5)	52.1 (8.3)	<0.05
QoL-CS Subscales			
Physical	7.7 (1.8)	8.0 (1.6)	0.28
Psychological	6.3 (1.6)	6.3 (1.4)	0.97
Social	6.5 (1.7)	6.8 (1.7)	0.36
Spiritual	4.5 (1.3)	4.5 (1.1)	0.82
Total	6.3 (1.3)	6.4 (1.1)	0.56

a P-value was adjusted for stage, age at diagnosis, treatment, years since diagnosis, education, marital status and comorbidity.

Table 4 – Changes in work situation and problems with insurance and mortgages

	5–9 year survivors, N (%)	10–15 year survivors, N (%)	P-value
<i>Changes in work situation</i>			
Nothing changed	N = 43 ^a 27 (63)	N = 64 ^a 48 (75)	0.20
Occupational re-settlement	5 (12)	2 (3)	0.11
Stopped working	0 (0)	1 (2)	1.00
Working more hours	0 (0)	2 (3)	0.51
Working less hours	8 (19)	5 (8)	0.13
Incapable of working	4 (9)	5 (8)	1.00
Fired	2 (5)	1 (2)	0.56
<i>Problems with</i>			
<i>Health insurance</i>			
Yes	3 (6)	10 (15)	0.06
No	13 (27)	30 (44)	
Did not try	31 (65)	26 (38)	
<i>Life insurance</i>			
Yes	3 (6)	12 (18)	0.14
No	10 (21)	17 (25)	
Did not try	34 (71)	36 (53)	
<i>Mortgage</i>			
Yes	15 (31)	24 (35)	0.11
No	3 (6)	11 (16)	
Did not try	29 (60)	29 (43)	

a Percentage of patients ≤60 years at time of diagnosis.

The impact of cancer on the work situation, health insurance, life insurance and home loans is shown in Table 4. No significant differences were found between 5–9 year survivors and 10–15 year survivors. The majority of patients (63% and 75%) stated that their work situation had not changed due to cancer. However, 7 patients followed occupational retrain-

ing due to cancer, 13 patients switched to part-time work and patient chose to stop working entirely following diagnosis and 1 treatment. In addition, 9 patients indicated that they were unable to work, and 3 patients said that they had been fired due to cancer.

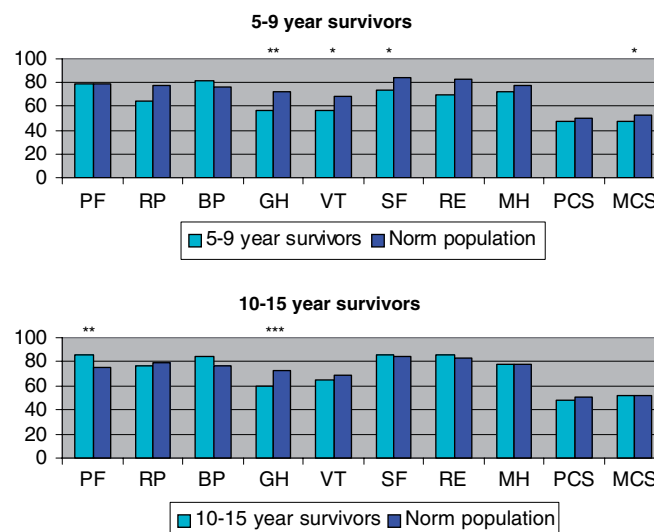


Fig. 2 – SF-36 subscale scores for Hodgkin's lymphoma survivors versus an age-matched norm population according to years since diagnosis. *P < 0.05; **P < 0.01; *P < 0.001 PF, physical functioning; RP, role limitations physical health; RE, role limitations emotional problems; VT, vitality; MH, mental health; SF, social functioning; BP, bodily pain, GH, general health; MCS, mental component scale; PCS, physical component scale. For a description of the norm population, see Section 2.3 of this article.**

Six percent of the 5–9 year survivors and 15% of the 10–15 year survivors who wanted new health insurance experienced problems in obtaining it in the years after their diagnosis. Six percent of the 5–9 year survivors and 18% of the 10–15 year survivors reported problems obtaining life insurance, and 31% of the 5–9 year survivors and 35% of the 10–15 year survivors experienced problems obtaining a mortgage due to cancer. These numbers represent problems in the total group of Hodgkin lymphoma patients. However, if we only look at patients who *actually* tried to get a new health insurance, life insurance or mortgage, the percentages of problems are much higher (25%; 38%; and 63%, respectively).

4. Discussion

The aim of the present study was to describe the QoL for long-term Hodgkin's lymphoma survivors 5–15 years after diagnosis, and to compare it to the general Dutch population. QoL was better among patients diagnosed 10–15 years ago compared to patients diagnosed 5–9 years ago. Patients diagnosed 5–9 years ago experienced lower general health, social functioning, mental health and vitality compared to an age-matched normative sample, while patients diagnosed 10–15 years earlier reported lower general health but better physical functioning. Most patients reported that their work situation did not change. Problems related to the obtaining of health insurance, life insurance and mortgages were high.

The statistically significant differences observed between 5–9 and 10–15 year survivors appeared to be clinically meaningful.^{23,24} It is important to note that these results were not confounded by differences in sociodemographic or clinical characteristics between the groups. The observed differences in QoL between 5–9 and 10–15 year survivors have not been reported previously in the literature. In a Norwegian study of 459 Hodgkin lymphoma survivors, time since diagnosis was not found to have a significant effect on QoL.⁸ Similarly, a Dutch study of 81 Hodgkin's lymphoma survivors found no significant association between time since treatment and SF-36 scores.¹¹ An Austrian study comparing patients treated 2–5 years earlier *versus* more than 5 years earlier also failed to detect time effects.¹⁵

Self-reported QoL was not found to be associated significantly with type of treatment received. This is largely in line with the existing literature on this topic.^{8,12} However, in an Austrian study, Hodgkin's lymphoma patients who received combined modality treatments were found to have a lower QoL in comparison to those treated with either radiotherapy or chemotherapy alone.¹⁵ The difference in findings between studies may be due to the fact that treatment methods have changed over time. Our study consisted of patients treated between 1989 and 1998, whereas the Austrian study included patients treated between 1969 and 1994 who were therefore more often treated with MOPP (nitrogen mustard, vincristine, procarbazine and prednisone). However, a study of patients treated between 1971 and 1991 did not find differences in QoL between treatment methods.⁸

Differences in QoL observed between the survivors and the normative sample have been noted earlier. In a Spanish study, patients ($n = 46$) reported lower physical functioning and worse social functioning compared with healthy controls

($n = 46$).¹² A Dutch study among long-term Hodgkin's lymphoma survivors found that, in comparison to healthy controls ($n = 114$), patients ($n = 81$) reported significantly worse physical functioning and role functioning and lower perceived overall health.¹¹ These effects were confirmed by a Norwegian study that also found significant differences in social functioning and vitality.⁸ A French study concluded that physical, role, cognitive and social functioning were significantly lower among survivors ($n = 93$) compared to controls ($n = 186$).⁹ Finally, a Swedish study reported that patients ($n = 121$) rated their physical health as worse than that of controls ($n = 236$).¹⁰ In all studies mentioned above, the survivors reported worse physical functioning compared to controls, also when they included patients who had survived more than 10 years after diagnosis. However, in our study, physical functioning of 5–9 year survivors was similar to that of controls, whereas surprisingly 10–15 year survivors reported an even better physical functioning than controls.

We expected to find somewhat more problems with fertility,⁶ especially for patients treated with a combination of drug regimens such as MOPP.³² In other studies, fertility was affected in 19–34% of cases.^{9,14,32,33} However, we assessed whether the survivors were *concerned* about their fertility, but we did not have any direct measure of actual problems with fertility. It is possible that fertility was affected in a number of our respondents but that it did not worry them.

The prevalence of thyroid disease was quite low in our study (10–19%) compared to other studies (57–65%).^{34–37} However, information on the presence of thyroid disease was not available from patients' medical records but was based on a self-reported questionnaire.

Fatigue is one of the most frequently reported symptoms among long-term Hodgkin's lymphoma survivors.³⁸ The prevalence of chronic fatigue ranges from 25% to 30%, compared to 12% of the general population.³⁹ It is common even many years after diagnosis.^{14,17,34} In our study, 5–9 year survivors reported significantly more fatigue in comparison with the norm population. This was not the case for those patients who had survived 10–15 years. Interventions may help to reduce fatigue, but this has only been investigated in a small group of Hodgkin's lymphoma patients with chronic fatigue who followed a home-based exercise intervention.⁴⁰ Further studies are therefore necessary.

Work situation changed in approximately one-third of the sample, which corroborates previous findings.^{7,9,14} The number of patients experiencing problems obtaining health insurance or life insurance was also in line with the literature.^{11,14,32} Problems related to the obtaining of a mortgage were slightly higher than in the existing literature, where problems were reported by 14% of survivors¹¹ in one study and by 28–33% of survivors in another.⁹ However, we should note that the majority of patients in our study had not attempted to obtain a mortgage after their diagnosis. We recommend that more attention should be paid and more information should be given to patients on the financial aspects of being a cancer survivor.

The present study had certain limitations that should be noted. Although only 20% of patients did not respond and 29% of patients were lost to follow-up, we do not know what their current health status is. However, non-respondents did

not differ significantly from the respondents or from patients whose addresses could be verified in terms of age, disease stage, treatment, or years since diagnosis. In addition, it is important to keep in mind that our results can only be generalised to a small percentage of the original group of 314 Hodgkin lymphoma patients while a large group of patients could not be included in our study (they died, there hospital declined to participate or their addresses could not be verified). Furthermore, it is more difficult to draw conclusions on QoL based on a cross-sectional study in comparison to a longitudinal study. Although baseline differences have not been found between patients treated 5–9 and 10–15 years ago, only randomised controlled trials can ensure comparable groups at baseline. However, only a selected group of patients will be eligible for randomised controlled trials. By controlling for stage, age at diagnosis, grade, years since diagnosis, education, marital status and comorbidity at diagnosis in our analysis, we attempted to minimize errors. Our results on problems in obtaining mortgages and life and health insurance have to be interpreted with caution because we have no reference data available from a healthy control group; furthermore, we do not know whether other factors (such as other diseases or age) might have played a role in this.

We can conclude that QoL in Hodgkin's lymphoma survivors is lower compared to an age-matched normative sample from the general population. Survivors furthermore experience some specific (financial) problems in the years after diagnosis.

Conflict of interest statement

None declared.

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