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Health care utilization up to 11 years after diagnosis among patients with a hematologic malignancy and its association with socioeconomic position

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Abstract

Purpose To investigate health care utilization among patients with hematologic malignancies and its association with socioeconomic position (SEP) and compare health care utilization with a cancer-free population.

Methods Patients with aggressive lymphoma, indolent lymphoma, or multiple myeloma (MM), diagnosed between 1999–2010 and 2015–2019, participated in longitudinal patient-reported outcome research, up to 11 years post-diagnosis. Questionnaires assessed health care utilization at the general practitioner (GP), medical specialist, and additional health care. SEP was based on education and income, categorized as low, medium, or high. Sociodemographic and clinical data were obtained from the Netherlands Cancer Registry. Mixed models and logistic regression analyses were performed.

Results The study included 2319 patients (71% response rate), who completed on average five measurements. Patients with MM reported the highest health care utilization, both at the GP and medical specialist. Low SEP was associated with higher utilization at the GP (medium education $\beta = -0.72$, $p = 0.01$; high education $\beta = -1.15$, $p < 0.001$) and lower utilization of additional physical (OR = 1.7, $p = 0.01$) and psychosocial (OR = 1.5, $p < 0.05$) care, among all patients. For patients with MM, high SEP was also associated with higher utilization of health care at the medical specialist (high education $\beta = 2.56$, $p < 0.05$).

Conclusion Hematologic malignancy–related and SEP-related disparities in health care utilization were observed. To ensure equal access to health consumption, attention is needed for patients with a low SEP to provide better guidance in their cancer (survivorship) care.

Implications for Cancer Survivors Improving health literacy and involving informal caregivers and nurse-led patient navigation may help reduce disparities in access to (additional) health care.

Keywords Lymphoma · Socioeconomic position · Patient-reported outcome · Disparities · Health care utilization · Population-based registry

Introduction

The various subtypes of hematologic malignancies require different treatments and different utilization of health care [1, 2]. For aggressive subtypes, treatment often involves (multiple) courses of chemo-immunotherapy, whereas patients with indolent subtypes are more likely to be under active surveillance [3–5]. Survivors of all hematologic malignancies have ongoing follow-up and require surveillance to monitor for possible relapse and/or potential (long-term) complications [3–6]. One-third of patients with hematologic malignancies report significant physical and/or psychosocial symptoms such as neuropathy, fatigue, or functional impairment, who could benefit from additional health care [3, 5, 7–9].

To receive comprehensive cancer care, good access to health care for patients with hematologic malignancies is needed [10–12]. However, disparities in socioeconomic position (SEP), defined as the social and economic factors that influence a person's position in society (i.e., education and income) [13], may affect the ability to access health care

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Extended author information available on the last page of the article services [10, 14]. Studies have shown that patients with a low SEP, not limited to patients with cancer, report higher rates of primary care utilization (i.e., general practitioner (GP)), whereas those with a high SEP report higher rates of utilization of specialized care (i.e., medical specialist) and additional health care (i.e., rehabilitation programs or physiotherapy) [10–12, 15, 16]. Moreover, patients with cancer, as well as cancer-free people, with a low SEP have a considerably higher risk of impaired health-related quality of life (HRQoL) [17].

Many European countries, such as the Netherlands, have a national health insurance system, with a fundamental commitment to provide equal access to health care [18]. The Dutch health insurance covers utilization of health care at the GP and medical specialist. Coverage for additional health care depends on the individual's choice of supplementary insurance. In the Netherlands, people with a high SEP have higher rates of supplementary insurance [19, 20]. SEP-related disparities in relation to diagnosis, treatment, or survival of cancer have been reported previously [21–23]. However, so far, no studies investigated the association between SEP and health care utilization after diagnosis of hematologic malignancies in a country with national health insurance.

The aim of this study was to investigate (1) the frequency of health care utilization up to 11 years after diagnosis at the GP, medical specialist, and additional health care among patients with hematologic malignancies, comparing it to a cancer-free normative population, and (2) differences in health care utilization associated with SEP. We hypothesized that patients with a low SEP would report higher rates of health care utilization at the GP, whereas patients with a high SEP would report higher rates of health care utilization at the medical specialist and additional health care, irrespective of hematologic malignancy subtype.

Methods

Setting and population

Two longitudinal cohorts from the PROFILES (Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship) registry were used [24]. PROFILES is a registry for the study of the physical and psychosocial impacts of cancer and its treatment from a dynamic, growing population-based cohort of both short and long-term cancer survivors. PROFILES contains a large web-based component and is linked directly to clinical data from Netherlands Cancer Registry (NCR). Details of the data collection method have been previously described [24].

Both cohorts are embedded in the NCR, which was used to select patients, aged 18 years and older, diagnosed between 1999–2014 (cohort 1) and 2015–2019 (cohort 2), with lymphoma or multiple myeloma, as defined by the International Classification of Diseases for Oncology-3 codes (ICD-O-3) [25]. Patients who were deceased, transitioning to terminal care, or had severe cognitive impairment (i.e., dementia) were excluded.

Patients were enrolled at different time points. In the first cohort, patients were included between 2009 and 2014. In the second cohort, patients were included between 2015 and 2019. All patients received yearly follow-up questionnaires starting from the time of enrollment until the spring of 2019 (cohort 1) or the spring of 2021 (cohort 2).

Patients were divided into three groups: (1) aggressive lymphoma (Hodgkin lymphoma (HL), diffuse large B cell lymphoma (DLBCL), Mantle cell lymphoma, Burkitt lymphoma, B cell prolymphocytic leukemia, and lymphoma other/not otherwise specified), (2) indolent lymphoma (chronic lymphocytic leukemia (CLL), small lymphocytic lymphoma (SLL), follicular lymphoma (FL), Waldenstrom, hairy cell leukemia, and indolent other), and (3) multiple myeloma (MM).

Ethical approval was obtained from a certified Medical Ethics Committee (Maxima Medical Centre in Veldhoven, the Netherlands; 0734).

Normative population

The normative population was selected from a reference cohort of 2040 individuals from the general Dutch population (CentER panel) [26]. This cohort is considered representative for the Dutch-speaking population in the Netherlands. Norm participants were matched based on the frequency distribution by stratum (defined by age categories, sex, and comorbidity).

Study measures

Health care utilization

In each questionnaire, patients reported the number of visits to the GP and medical specialist during the last 12 months and if they had used additional health care (yes or no). If they answered yes, they could choose multiple additional health care services from a list. Additional health care was categorized into 3 groups: physical (rehabilitation program, physiotherapy, and dietetics), psychosocial (psychologist, social work, creative therapy, and oncology nurse), and informal care (peer support, family/friends, and other).

The normative population received a cross-sectional questionnaire in 2012, including frequency of health care utilization at the GP and medical specialist, without utilization of additional health care.

Socioeconomic position (SEP)

SEP was based on two proxy measures: educational level and median household income at street level. Educational level was assessed in the questionnaire and categorized as low (no/primary school), medium (lower general secondary/vocational), or high (pre-university/high vocational/university). Information about median household income at 6-digit postal code levels was used from 2016, covering an average of 17 households each, and divided into 9 categories based on income levels of the entire Dutch population. These data were provided by Statistics Netherlands and linked to the NCR [27]. Median household income at street level was categorized as low (first to third category), medium (fourth to sixth category), or high (seventh to ninth category).

Additional sociodemographic and clinical information

Primary treatment was retrieved from the NCR and classified into stem cell transplant (SCT), systemic therapy (chemotherapy, targeted therapy, immunotherapy, and hormone therapy), radiotherapy (mono), active surveillance, and other/unknown treatment. Comorbidity at the time of survey was measured using the adapted Self-administered Comorbidity Questionnaire (SCQ) [28] and categorized in having no, one, or ≥ 2 comorbidities. Age, sex, and marital status were also assessed in the questionnaire.

Statistical analyses

Statistical analyses were performed using IBM SPSS Statistics for Windows, version 29 (IBM Corp., Armonk, N.Y., USA). Sociodemographic and clinical differences between respondents and non-respondents, and between respondents who completed one versus more than one questionnaire, were analyzed by chi-squared or *t*-test, as appropriate. *p*-values < 0.05 were considered statistically significant.

Mixed-model analyses were conducted to assess health care utilization at the GP and medical specialist. The rate of change in the number of visits (β) was calculated per year of survival [29]. The Spearman rank correlation test was used to test for correlation between our variables of interest, being SEP (educational level and income level). Inclusion of both variables was based on a weak correlation (< 0.3) and improved model fit (based on a lower Akaike Information Criterion and Bayesian Information Criterion value). Additional main effects of a priori variables were also included in the models, being hematologic malignancy group, clinical characteristics (treatment and comorbidities), and sociodemographic characteristics (age, sex, and having a partner). To evaluate SEP-related differences in the utilization of additional health care (yes versus no), logistic regression analyses were performed, including the same a priori defined variables.

Results

Characteristics of the study population

The study included 2319 patients (71% response rate). Patients completed on average five measurements. A flowchart of the data collection is shown in the supplement (Supplement 1).

At inclusion, mean age was 63.2 years, 62% were male, and mean time since diagnosis was 3.1 years. Most patients had a medium educational level (57%) and a medium income level (52%). Patients with aggressive lymphoma and MM were mostly treated with systemic therapy (90% and 52%, respectively), while patients with indolent lymphoma were mostly under active surveillance (48%; Table 1).

The cancer-free normative population ($N = 357$) had a mean age of 63.1 years at inclusion, 62% were male. Most participants reported a medium educational level (54%) and a medium income level (53%).

Questionnaire non-respondents had a significantly lower income level than respondents (respectively 27% vs. 17% for low income; 51% vs. 52% for medium income; 22% vs. 31% for high income, $p < 0.001$). Questionnaire non-respondents also had a significantly shorter time since diagnosis (1.7 vs. 3.1 years, $p < 0.001$), were more often under active surveillance (32% vs. 23%, $p < 0.001$), and were more often female than respondents (45% vs. 38%, $p < 0.001$). Respondents who completed more than one questionnaire ($N = 1680$) were more likely to have higher education (29% vs. 19%, $p < 0.001$) and higher income (33% vs. 27%, $p = 0.003$) than respondents who completed only one questionnaire ($N = 640$). Furthermore, they had statistically significantly less comorbidities, a shorter time since diagnosis and more often a partner, than respondents who completed one questionnaire (data not shown).

Frequency of health care utilization among hematologic malignancies

Figure 1 shows the mean number of visits to the GP and medical specialist and the percentage of additional health care utilization per hematologic malignancy. During the first 2 years after diagnosis, the highest number of visits to the GP and medical specialist were reported by patients with MM, Mantle cell lymphoma, HL, or DLBCL. From 2 years after diagnosis, the highest number of visits to the GP and medical specialist were reported by patients with MM, Mantle cell lymphoma, CLL/SLL, or Waldenstrom. Compared to

Table 1 Characteristics of the study population at inclusion

Characteristic	Total lymphoma and MM patients	Aggressive lymphoma	Indolent lymphoma	Multiple myeloma	Normative population
	N = 2319	*N* = 1034	*N* = 941	*N* = 344	*N* = 357
	N (%)	*N* (%)	*N* (%)	*N* (%)	*N* (%)
Hematologic malignancy					n/a
DLBCL	622 (27)	622 (60)			
HL	265 (11)	265 (26)			
Mantle cell lymphoma	81 (4)	81 (8)			
Burkitt lymphoma	12 (1)	12 (1)			
B-PLL	3 (< 1)	3 (< 1)			
Lymphoma other/NOS	51 (2)	51 (5)			
CLL/SLL	364 (16)		364 (39)		
FL	298 (13)		298 (32)		
Waldenstrom	84 (4)		84 (9)		
Hairy cell leukemia	45 (2)		45 (5)		
Indolent other	150 (7)		150 (16)		
MM	344 (15)			344 (100)	
Sex					
Male	1430 (62)	631 (61)	585 (62)	214 (62)	220 (62)
Female	888 (38)	403 (39)	355 (38)	130 (38)	137 (38)
Missing data	1 (< 1)	0 (0)	1 (< 1)	0 (0)	0 (0)
Age: mean (SD)	63.6 (13.8)	60.3 (16.3)	65.8 (11.3)	67.3 (9.4)	63.1 (13.7)
Median	65.8	63.9	66.7	67.3	65.0
Range	18–91	18–91	22–90	36–89	24–90
Years since diagnosis: mean (SD)	3.1 (2.3)	3.2 (2.4)	3.2 (2.4)	2.5 (1.6)	n/a
Median	2.2	2.1	2.2	2.1	
Range	0.4–11.0	0.4–10.5	0.4–11.0	0.4–10.3	
< 2 years	1010 (44)	462 (45)	396 (42)	152 (44)	
2–5 years	878 (38)	359 (35)	352 (37)	167 (49)	
5–8 years	273 (12)	139 (13)	118 (13)	16 (5)	
8–11 years	157 (7)	74 (7)	74 (8)	9 (3)	
Missing data	1 (< 1)	0 (0)	1 (< 1)	0 (0)	
Stage					
Ann Arbor/Rai		Ann Arbor	Ann Arbor/Rai	n/a	n/a
I/0	464 (20)	234 (23)	137/65 (22)		
II/1	393 (17)	270 (26)	69/32 (11)		
III/2	304 (13)	194 (19)	93/13 (11)		
IV/3	507 (22)	236 (23)	200/6 (22)		
/4	24 (1)	n/a	/13 (1)		
Missing data	627 (27)	100 (10)	313 (33)		
Primary treatment					n/a
SCT	128 (6)	33 (3)	0 (0)	95 (28)	
Systemic therapy	1425 (61)	928 (90)	319 (34)	178 (52)	
Radiotherapy (mono)	149 (6)	20 (2)	113 (12)	16 (5)	
Active surveillance	539 (23)	35 (3)	449 (48)	55 (16)	
Other/unknown	78 (3)	18 (2)	60 (6)	0 (0)	
Educational level[a]					
Low	320 (14)	123 (12)	141 (15)	56 (16)	23 (6.4)
Medium	1325 (57)	585 (57)	535 (57)	205 (60)	194 (54.3)
High	606 (26)	293 (28)	239 (25)	74 (22)	140 (39.2)

Table 1 (continued)

Characteristic	Total lymphoma and MM patients	Aggressive lymphoma	Indolent lymphoma	Multiple myeloma	Normative population
	$N = 2319$	$N = 1034$	$N = 941$	$N = 344$	$N = 357$
	N (%)	N (%)	N (%)	N (%)	N (%)
Missing data	68 (3)	33 (3)	26 (3)	9 (3)	0 (0.0)
Income level[b]					
Low	390 (17)	153 (15)	164 (17)	73 (21)	55 (15)
Medium	1204 (52)	563 (54)	477 (51)	164 (48)	190 (53)
High	720 (30)	315 (31)	298 (32)	107 (31)	110 (31)
Missing data	5 (< 1)	3 (< 1)	2 (< 1)	0 (0)	2 (< 1)
Self-reported comorbidity:					
No comorbidity	724 (31)	373 (36)	269 (29)	82 (24)	131 (37)
1 comorbidity	701 (30)	305 (30)	294 (31)	102 (30)	105 (29)
≥ 2 comorbidities	750 (32)	290 (28)	331 (35)	129 (38)	118 (33)
Missing data	144 (6)	66 (6)	47 (5)	31 (9)	3 (1)
Most frequent comorbidities					
Arthrosis	514 (22)	199 (19)	225 (24)	90 (26)	85 (24)
High blood pressure	507 (22)	211 (20)	207 (22)	89 (26)	121 (34)
Heart diseases	402 (17)	175 (17)	166 (18)	61 (18)	63 (18)
Anemia	275 (12)	57 (6)	153 (16)	65 (19)	13 (4)
Lung diseases	230 (10)	94 (9)	104 (11)	32 (9)	36 (10)
Diabetes	204 (9)	75 (7)	97 (10)	32 (9)	38 (11)
Partner (yes)	1767 (76)	777 (75)	719 (76)	271 (79)	253 (71)

[a] Educational level categorized as low (no/primary school), medium (lower general secondary/vocational), or high (pre-university/high vocational/university). [b] Median household income at street level categorized as low (first to third category), medium (fourth to sixth category), or high (seventh to ninth category). *Abbreviations: *DLBCL*, diffuse large B cell lymphoma; *HL*, Hodgkin lymphoma; *B-PLL*, B cell prolymphocytic leukemia; *NOS*, not otherwise specified; *CLL*, chronic lymphocytic leukemia; *SLL*, small lymphocytic lymphoma; *FL*, follicular lymphoma; *MM*, multiple myeloma; *SCT*, stem cell transplant

the cancer-free normative population, patients with hematologic malignancies reported almost twice as many visits to the GP and three to four times as many visits to the medical specialist.

Of the total group of patients, 49% reported to have used some additional health care, most frequently being physical care during the first 2 years after diagnosis (58%). Patients with aggressive lymphoma reported the highest utilization of physical and psychosocial care. Compared to physical and psychosocial care, the utilization of informal care was relatively low in all groups. However, over time, the utilization of informal care remained at similar levels, while the utilization of physical and psychosocial care decreased.

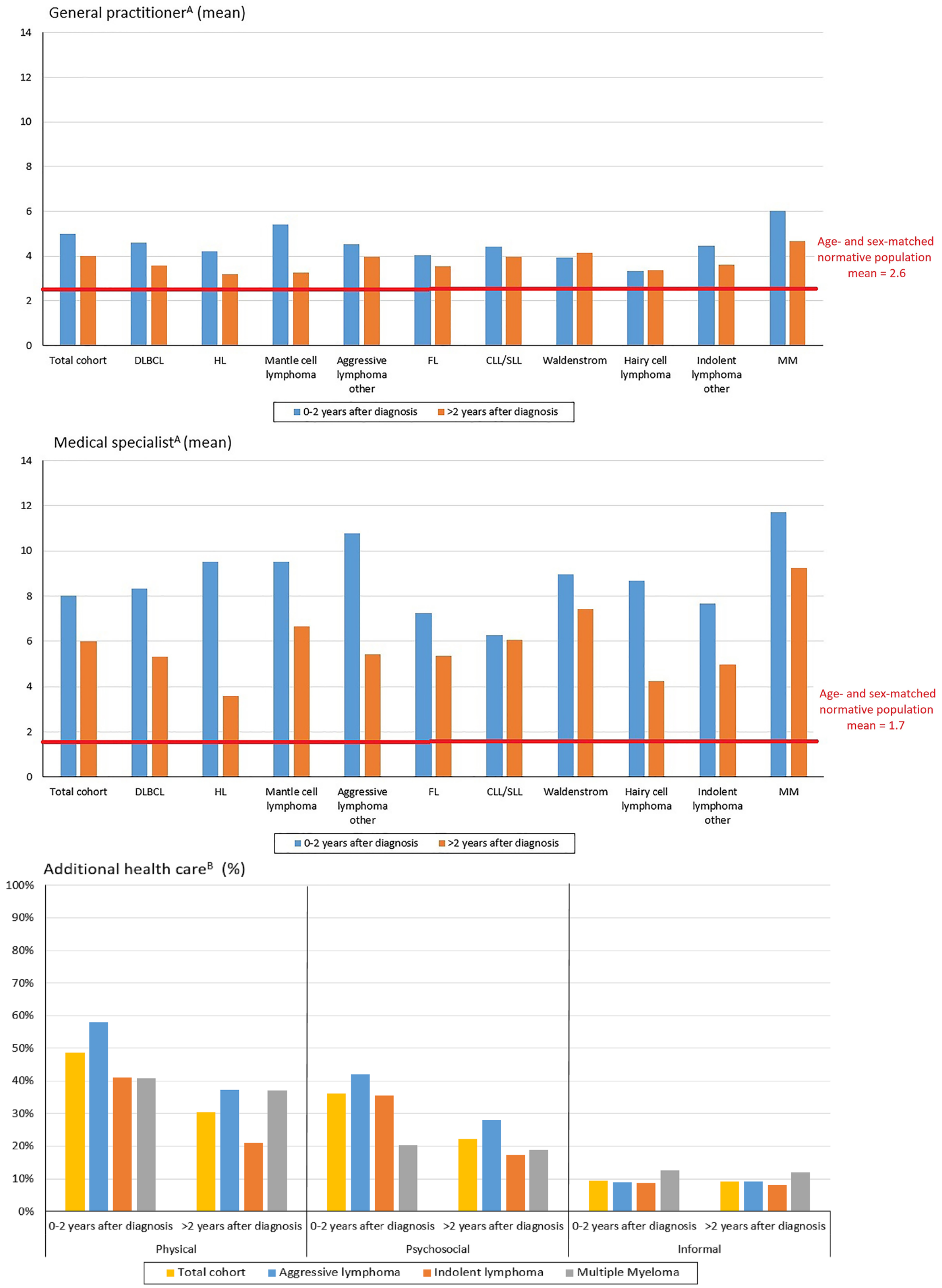
Over time, the frequency of visits to the GP remained relatively stable for all hematologic malignancy groups (Table 2 and Supplement 2; $\beta = -0.14$ per year since diagnosis, $p < 0.001$). The frequency of visits to the medical specialist decreased significantly ($\beta = -0.33$ up to -0.75 per year since diagnosis, $p < 0.001$).

Patients with MM reported significantly higher health care utilization than patients with lymphoma both at the GP ($\beta = 0.96$, SD 0.29, $p < 0.001$) and medical specialist ($\beta = 3.09$, SD 0.41, $p < 0.001$). Because patients with MM in our sample were on average 7 years older than patients with aggressive lymphoma, we tested for possible effect modification by adding an interaction term (hematologic malignancy group*age) to the models, which appeared statistically significant for utilization of care at the medical specialist ($p < 0.05$, data not shown). We therefore stratified the analyses for the utilization of health care at the medical specialist by hematologic malignancy group.

Associations between health care utilization and SEP

Health care utilization at the GP and medical specialist

Patients with a medium or high educational level reported significantly lower health care utilization at the GP compared to patients with a low educational level, also when controlled for sociodemographic and clinical characteristics (Fig. 2 and Table 2), although higher utilization at the GP was also associated with having 1 or more comorbidities. These disparities based on educational level persisted over



[A] Patients with Burkitt lymphoma and B-cell Prolymphocytic Leukemia were excluded for the frequency of health care utilization at the GP and medical specialist, based the small sample size for these malignancies (N < 25). [B] For additional health care utilization patients were divided into three groups, based on the small proportions of utilization per hematologic malignancy.

◂**Fig. 1 Frequency of health care utilization at the general practitioner and medical specialist and the percentage of utilization of additional health care per hematologic malignancy.** ^{A}Patients with Burkitt lymphoma and B cell prolymphocytic leukemia were excluded for the frequency of health care utilization at the GP and medical specialist, based on the small sample size for these malignancies ($N < 25$). ^{B}For additional health care utilization, patients were divided into three groups, based on the small proportions of utilization per hematologic malignancy

time. No disparities in the utilization of health care at the GP were observed for income level (Table 2 and Supplement 3).

Among patients with aggressive or indolent lymphoma, no disparities in health care utilization at the medical specialist were observed for SEP. In contrast, among patients with MM, a higher educational level was associated with significantly higher utilization of care at the medical specialist, compared to those with a low educational level (Fig. 2 and Table 2). Furthermore, visits to the medical specialist were significantly higher among patients with aggressive or indolent lymphoma who had 1 or more comorbidities and among patients with indolent lymphoma who received systemic therapy or other/unknown therapy as primary treatment, compared to patients who were under active surveillance. Finally, patients with aggressive lymphoma who were female, and male patients with MM, also reported higher utilization of care at the medical specialist.

Utilization of additional health care services

Patients with a high educational level reported statistically significantly higher use of additional physical ($\text{OR} = 1.7$, $p = 0.01$) and psychosocial ($\text{OR} = 1.5$, $p = 0.04$) care during the first 2 years after diagnosis, compared to patients with a low educational level (Fig. 3).

Patients with a high income level reported significantly lower utilization of informal care ($\text{OR} = 0.6$, $p = 0.02$) during the first 2 years and significantly higher utilization of psychosocial care ($\text{OR} = 1.5$, $p = 0.03$) from 2 years after diagnosis, compared to those with a low income level.

Furthermore, utilization of additional health care was significantly higher among patients who received more intensive treatment and patients who were younger and/or female (data not shown).

Discussion

In this large population-based study among patients with indolent NHL, aggressive NHL, and MM, the highest utilization of health care at the GP, medical specialist, and additional informal care was reported by patients with MM. Patients with aggressive lymphoma reported the highest utilization of additional physical and psychosocial care. In all hematologic subgroups, patients with a low SEP reported higher utilization of health care at the GP and lower utilization of additional physical and psychosocial care. Among patients with MM, a high SEP was also associated with higher utilization of health care at the medical specialist.

Higher health care utilization among patients with MM can be explained by the fact that MM is an aggressive and incurable hematologic malignancy [30], for which after first-line treatment with intensive (systemic) therapy, many treatment options are available [31, 32]. As shown in our analyses for additional health care, higher utilization of physical and psychosocial health care among patients with aggressive lymphoma is most likely because these patients receive more intensive treatment than patients with indolent lymphoma [4] and are relatively younger than patients with MM.

Observed SEP-related disparities may be partly explained by the association between SEP and health literacy [33–35]. Patients with a low SEP may have (more) difficulty understanding their diagnosis, treatment options, and self-care practices as a result of lower health literacy [11, 36]. They may therefore be unaware of available services, or struggle to navigate the health care system, resulting in (more) fragmented or inadequate care [10, 36], and possibly more GP visits. Patients with a high SEP may have a better understanding of the complexity of their disease and the many treatment options available, especially for MM. In addition, higher levels of health literacy may unconsciously create biases among GP's that affect their referral patterns, potentially leading to delayed referral of patients with a lower SEP because they are less likely to effectively advocate for their needs [37].

For patients with solid types of cancer, several studies have investigated strategies to integrate primary care (GP) into survivorship care [38, 39]. Although the GP already plays an important role in the continuous and comprehensive care of (cancer) patients, results have shown that their confidence and knowledge in providing cancer survivorship care vary and are limited in the management of physical effects and prevention/surveillance of recurrence [38, 39]. Studies about the role of the GP and medical specialist in cancer survivorship care are still limited. For patients with hematologic malignancies, it is not known if follow-up care at the GP may be appropriate or if patients are likely to be better served by follow-up care at the medical specialist. To optimize survivorship care, this should be evaluated in future research.

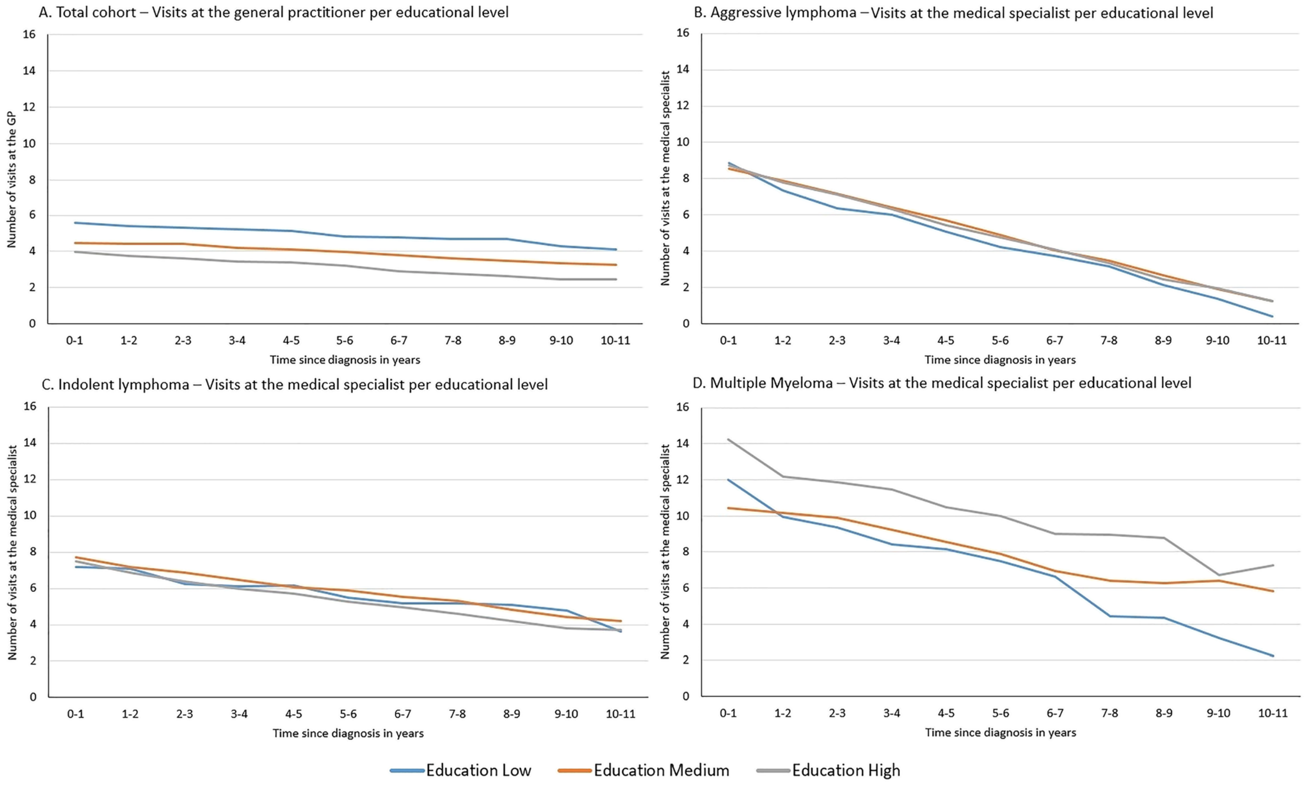
Another explanation for the observed disparities could be the individual choice of supplementary health insurance. Patients with a low SEP are expected to have fewer financial resources to choose supplemental health insurance and can/will therefore make less use of those. In addition, people with a low SEP are known to have lower insurance literacy (i.e., the knowledge, ability, and confidence to make

Table 2 Fixed effects of linear mixed models for health care utilization at the general practitioner and medical specialist

		General practitioner			Medical specialist								
		Total cohort			Aggressive lymphoma			Indolent lymphoma			Multiple Myeloma		
		$N=2319$			$N=1034$			$N=941$			$N=344$		
		Estimate	SE	*p*-value	Estimate	SE	*p*-value	Estimate	SE	*p*-value	Estimate	SE	*p*-value
Initial status[a]		**3.59**	**0.61**	**< 0.001**	**9.04**	**1.54**	**< 0.001**	**5.70**	**1.34**	**< 0.001**	**16.23**	**3.94**	**< 0.001**
Linear growth[b]: time since diagnosis in years		**− 0.14**	**0.03**	**< 0.001**	**− 0.75**	**0.07**	**< 0.001**	**− 0.33**	**0.07**	**< 0.001**	**− 0.61**	**0.19**	**< 0.01**
Socioeconomic position													
Educational level[c]	**Low**	**Ref**			**Ref**			**Ref**			**Ref**		
	Medium	**− 0.72**	**0.26**	**0.01**	0.46	0.59	0.43	0.22	0.53	0.67	0.17	1.03	0.87
	High	**− 1.15**	**0.30**	**< 0.001**	0.55	0.66	0.40	− 0.04	0.61	0.95	**2.56**	**1.25**	**0.04**
Income level[d]	Low	Ref			Ref			Ref			Ref		
	Medium	0.32	0.25	0.21	− 0.27	0.55	0.62	0.12	0.49	0.81	1.75	1.01	0.08
	High	0.16	0.28	0.57	0.17	0.61	0.78	− 0.36	0.55	0.52	1.39	1.10	0.21
Sociodemographic													
Age		0.01	0.01	0.12	**− 0.01**	**0.01**	**0.34**	< − 0.01	0.02	0.83	− 0.09	0.05	0.07
Sex (male = ref)		− 0.22	0.18	0.21	**0.76**	**0.37**	**0.04**	0.55	0.37	0.14	**− 2.55**	**0.79**	**< 0.01**
Partner (no = ref)		0.34	0.21	0.11	− 0.14	0.44	0.75	− 0.59	0.44	0.17	− 1.42	1.00	0.16
Clinical													
Hematologic malignancy group	Indolent lymphoma	Ref			n/a			n/a			n/a		
	Aggressive lymphoma	0.22	0.23	0.32									
	Multiple myeloma	**0.96**	**0.29**	**< 0.001**									
Primary treatment	Active surveillance	Ref			Ref			**Ref**			Ref		
	Radiotherapy (mono)	0.25	0.39	0.52	− 1.59	1.65	0.34	− 1.07	0.57	0.06	1.73	2.01	0.39
	Systemic therapy	− 0.09	0.25	0.74	− 1.38	1.02	0.18	**1.03**	**0.39**	**< 0.01**	1.50	1.08	0.16
	SCT	1.35	3.65	0.71	− 0.93	1.39	0.50	n/a			1.68	1.29	0.19
	Other/unknown	− 0.38	0.48	0.43	1.36	1.64	0.41	**2.01**	**0.69**	**< 0.01**	n/a		
Comorbidity	None	**Ref**			**Ref**			**Ref**			Ref		
	1	**0.49**	**0.18**	**0.01**	**1.65**	**0.41**	**< 0.001**	**1.28**	**0.39**	**< 0.001**	− 0.04	0.90	0.96
	≥ 2	**1.72**	**0.19**	**< 0.001**	**2.18**	**0.44**	**< 0.001**	**2.58**	**0.41**	**< 0.001**	1.12	0.91	0.22

[a] The number of visits to the GP or medical specialist when all the independent variables are 0. [b] The linear rate of change in the number of visits (β) was calculated per year of survival. [c] Educational level categorized as low (no/primary school), medium (lower general secondary/vocational), or high (pre-university/high vocational/university). [d] Median household income at street level categorized as low (first to third category), medium (fourth to sixth category), or high (seventh to ninth category)

Numbers in bold emphasis indicate statistical significance to make reading easier.



*Note. Fixed predicted mean values were corrected for: hematologic malignancy group, educational level, income level, age, sex, partner, primary treatment, comorbidity and time since diagnosis.

Fig. 2 Fixed predicted mean values for the course of health care utilization over time per educational level at the **A** general practitioner and **B**–**D** medical specialist per hematologic malignancy group. *Note. Fixed predicted mean values were corrected for hematologic malignancy group, educational level, income level, age, sex, partner, primary treatment, comorbidity, and time since diagnosis

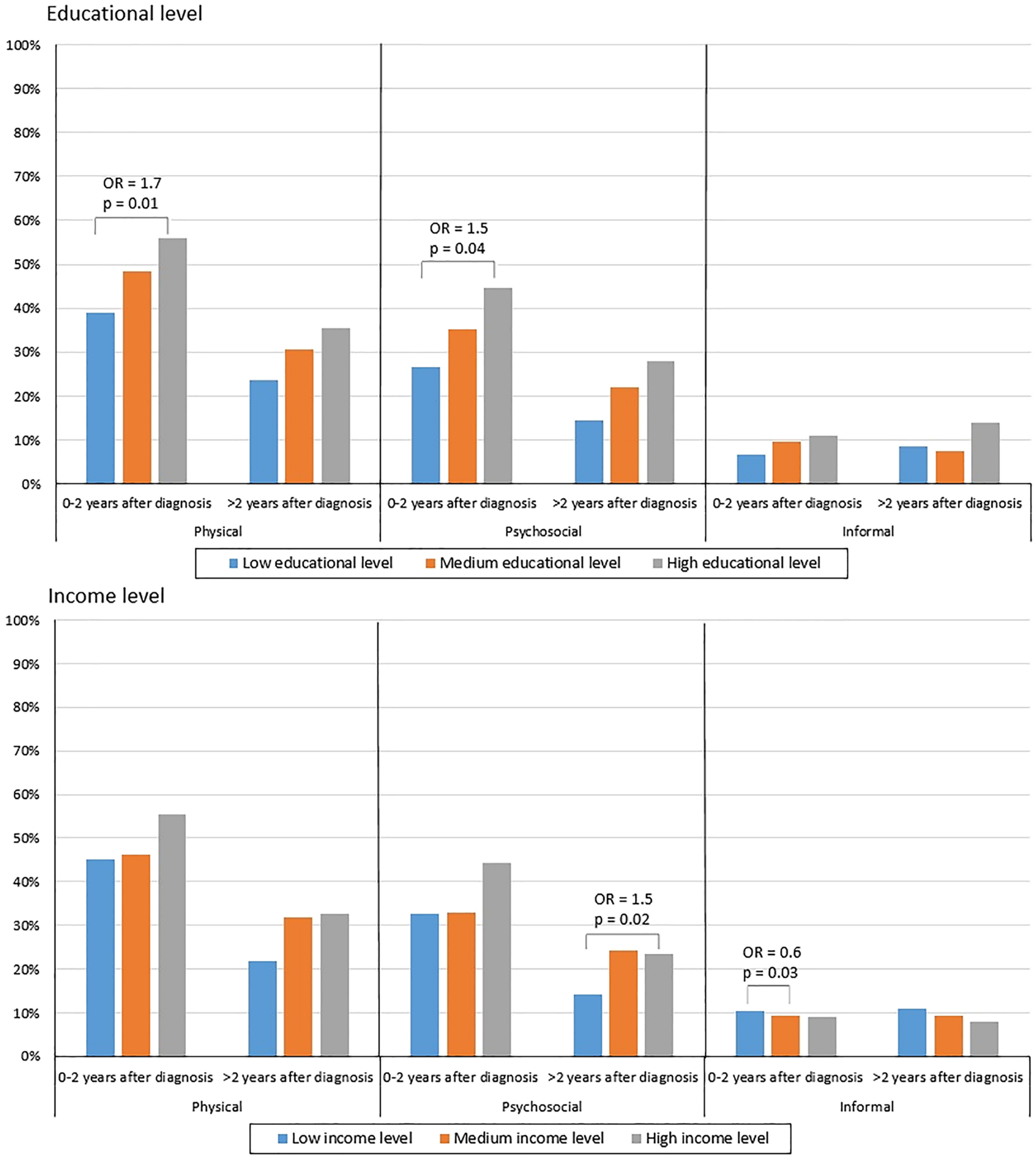
insurance choices and use the plan once enrolled) [40]. Patients with a low SEP may therefore be sub-optimally insured, face unexpected costs, or suffer from inadequate coverage for additional health care [40, 41]. The individual choice of insurance can lead to limited access to health care services and is also observed in other European countries (i.e., Belgium, Israel, or Germany) with similar national health insurance systems [42, 43].

Addressing SEP-related disparities in cancer care is critical, as patients with a low SEP report significantly higher symptom burden and impaired functioning after cancer diagnosis, with poor HRQoL [33, 44]. More equitable access to additional physical and psychosocial health care may therefore be particularly beneficial for patients with a low SEP. In addition, disparities in health care utilization itself may also affect HRQoL, which could exacerbate the effect of low SEP on impaired HRQoL [45].

Implementation of nurse-led patient navigation, with a direct patient care role that connects patients with clinical providers and their support systems [46], could offer patients with a low SEP more personalized, easy-to-understand information about their disease and care options [34, 35]. This might contribute to early screening and identification of patients in need and may help guide patients through the health care system [44, 47]. Active symptom monitoring with patient-reported outcomes could involve patients more actively in their own care process and increase awareness of their symptoms and needs [48, 49]. Involving informal caregivers, who can provide support related to health information, might be beneficial to empower patients and to help patients monitor symptoms and effectively advocate for their needs [50].

This study has several strengths including the long follow-up period and the large sample size, including patients with different and rare hematologic malignancies. Some limitations must be acknowledged; as study participation by itself was lower in patients with lower SEP, the results of this study will most likely underestimate disparities in health care utilization based on SEP. In addition, information on patients' insurance was not available, making it difficult to determine the exact role of individual insurance in the observed disparities in the utilization of additional health care.

In conclusion, despite national health insurance in the Netherlands, SEP-related disparities in health care utilization were observed among patients with hematologic



*Note. OR = Odds Ratio. Additional health care categories: physical (rehabilitation program, physiotherapy and dietetics), psychosocial (psychologist, social work, creative therapy, oncology nurse) and informal care (peer support, family/friends, other).

Fig. 3 Percentage of utilization of additional health care per educational level and income level, odds ratios and *p*-values for logistic regression analyses. *Note. OR, odds ratio. Additional health care categories: physical (rehabilitation program, physiotherapy, and dietetics), psychosocial (psychologist, social work, creative therapy, and oncology nurse), and informal care (peer support, family/friends, and other) malignancies. The gap seems the largest for the use of additional health care among patients with a low SEP, who also have a higher risk of poor HRQoL. Improving health literacy, involving informal caregivers, and implementing nurse-led patient navigation may help reduce disparities in access to (additional) health care, which could ultimately improve HRQoL outcomes and cancer care for patients with hematologic malignancies in the Netherlands, regardless of SEP.

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Author contribution Conception and design: AE, LP and SO. Inclusion of patients: DI, MO, RvdG, MH, AK, MN, LA, and EP. Data analysis and interpretation: AE, LP and SO. Manuscript writing and revision: all authors. Final approval of manuscript: all authors.

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Data availability Since 2011, PROFILES registry data is freely available according to the FAIR (Findable, Accessible, Interoperable, Reusable) data principles for non-commercial (international) scientific research, subject only to privacy and confidentiality restrictions. Data is made available through Questacy (DDI 3.x XML) and can be accessed by our website (www.profilesregistry.nl). In order to arrange optimal long-term data warehousing and dissemination, we follow the quality guidelines that are formulated in the 'Data Seal of Approval' (www.datasealofapproval.org) document, developed by Data Archiving and Networked Services (DANS).

Declarations

Ethics approval Ethical approval for the study was obtained from a certified Medical Ethics Committee (Maxima Medical Centre in Veldhoven, the Netherlands; 0734).

Conflict of interest The authors declare no competing interests.

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