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The Role of Health Literacy in Perceived Information Provision, Satisfaction, and Health-related Quality of Life Among Rare and Common Cancer Patients: A Population-based Registry Study

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Abstract

Health literacy (HL) has been found to affect perceived information provision (PIP), satisfaction with information provision, and health-related quality of life (HRQoL) in patients with cancer. Patients with a rare cancer are confronted with challenges, such as a lack of information. The aim of this study was to explore the impact of HL on PIP, satisfaction with information provision, and on HRQoL in rare compared to common cancer patients. A population-based study was conducted using the PROFILES registry. Patients with rare ($n=385$) and common ($n=1,692$) cancer were included. Within group associations (low/medium HL, high HL, rare cancer, common cancer) were assessed. Regression analyses were used to assess associations between HL, PIP, satisfaction, and HRQoL, taking cancer group into account. Within the *low/medium* HL group, no statistically significant differences were found between rare and common cancer patients. Yet, within the *high* HL group, rare cancer patients scored significantly lower on all PIP-categories (except PIP-medical tests), satisfaction and HRQoL. Within the *rare* cancer group, patients with low/medium HL scored lower, compared to those with high HL, on PIP-medical tests and PIP-treatment, while within the *common* cancer group, patients with low/medium HL scored lower on all PIP-categories, satisfaction and HRQoL (all: $p<0.05$). Information needs might vary between patients with a different HL level and/or cancer group. Healthcare professionals should take individual needs into account, with a special focus on patients with a rare cancer and low/medium HL, in order to convey information in an understandable, patient-tailored way.

Keywords Health literacy · Health-related quality of life · Information provision · Oncology · Rare cancer · Satisfaction with information provision

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Background

Health literacy (HL) is of high importance for patients in order to navigate themselves through the health care system. According to Liu et al., the definition of HL is ‘the ability of an individual to obtain and translate knowledge and information in order to maintain and improve health in a way that is appropriate to the individual and system contexts’ [1]. HL is particularly important for cancer patients, since prevention, screening and treatment options are becoming more complex [2]. Low HL can lead to difficulties obtaining, understanding and retaining information about diagnosis, treatment and recovery. Previous research on HL among cancer patients has shown that low HL is associated with poor health outcomes, including an increased risk of hospitalization [3]. When cancer patients do not understand information, they might experience increased stress levels and dissatisfaction with care [4]. Patients might draw incorrect conclusions about their cancer diagnosis and treatment, which may even lead to unnecessary interventions or undertreatment [5]. It can also negatively impact health-related quality of life (HRQoL), as has been shown in a study by Nilsen et al., in which patients with inadequate HL had lower HRQoL scores than patients with adequate HL [6].

Several studies have shown the relation between HL and perceived information provision (PIP) and satisfaction [7, 8]. Information provision (IP) is needed during the entire disease process, but is particularly important in the diagnosis and treatment phase (Sim et al., 2015). Adequate IP is highly valued by cancer patients and has many advantages, i.e., good communication between provider and patient is associated with psychosocial outcomes, such as coping, satisfaction and commitment [9]. Research has shown that patient-centered communication and adequate IP can lead to a decreased anxious preoccupation and increased adherence to the treatment plan and satisfaction with the treatment plan [10]. Accurate and comprehensive information provision to cancer patients has been reported to improve HRQoL, daily functioning and pain management [11]. Unmet information needs, however, are associated with worse illness perception and lower satisfaction with received care [12]. Furthermore, research showed that cancer patients who are satisfied with the provided information have a better illness perception and HRQoL compared to cancer patients who are not satisfied [12].

Most studies regarding HL, PIP and satisfaction have been conducted among patients with a common cancer type, such as breast or colorectal cancer. However, patients with a rare cancer type, such as head and neck cancers or endocrine tumors, often have to deal with additional challenges regarding information about their diagnosis and

treatment [13]. According to the RARECARE definition of rare cancer (< 6 per 100,000 per year), there are annually more than 540,000 newly diagnosed cases in Europe [14]. Despite the low incidence of the individual rare cancer types, the total group of rare cancer patients is rather large [14], and collectively shares problems, such as late or incorrect diagnosis, difficulties in finding clinical expertise and receiving adequate treatment, a lack of research to develop new treatments and many insecurities in clinical decision making [15]. Patients with rare cancer have reported unmet needs in many domains, but most unmet needs were found in the healthcare system and information domain [16]. Since this vulnerable group of cancer patients is often confronted with a lack of information and experiences challenges regarding the health care system, rare cancer patients with a low HL, specifically, may face double exclusion and may be at an even greater risk for poor health outcomes and increased anxiety levels [3, 10]. No previous research has examined how HL influences PIP, satisfaction with IP, and HRQoL between and within rare and common cancer groups separately, making this exploratory analysis important for understanding subgroup-specific needs.

Therefore, the aim of this study was to explore the impact of HL on PIP, satisfaction with IP, and on HRQoL, in rare cancer patients compared to common cancer patients. While the amount of rare cancer types exceeds 200, in this study, a preliminary exploration has been performed based on only a few cancer types to gain some first insights into shared problems of these patients.

Methods

Design

A population-based study was conducted, using the PROFILES (Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship) registry. This registry contains patient reported outcomes of a large, dynamic cohort of more than 20,000 short- and long-term cancer patients, within a sampling frame of the Netherlands Cancer Registry (NCR) [17]. The NCR collects clinical data of all patients diagnosed with cancer in the Netherlands [18]. PROFILES is registered with the Dutch Data Protection Authority (registration code 1433221), which supervises the FAIR and lawful use and security of personal data collected in the Netherlands [17]. Three datasets from the PROFILES registry were used in the current study, all having Medical Ethical approval (METC NL33429.008.10; METC ETZ 2011.129; METC MMC 0822).

Study Sample and Data Collection

PROFILES studies that included data regarding HL, PIP, satisfaction, and HRQoL of cancer patients were combined. This resulted in a convenience sample, as inclusion was based on the availability of relevant data rather than systematic sampling. The final sample consisted of patients with a rare cancer type (mainly rare types of ovarian cancer) and patients with a common cancer type (mainly colorectal cancer) based on the RARECARENet Cancer List [19]. In order to collect the necessary patient reported outcomes (i.e., HL, PIP and satisfaction, and HRQoL), patients were sent a letter from their specialist with information, a questionnaire and an informed consent form, which they were asked to complete, sign, and return to the researchers in a pre-stamped envelope. If patients wanted to complete the questionnaire online, they were able to fill out the questionnaire on the PROFILES website after secured login. Patients were excluded if they were not able to complete a Dutch questionnaire, or if they died or emigrated before the study started.

Measures

Sociodemographics and Clinical Characteristics

Sociodemographics and clinical data were gathered via both the NCR and the PROFILES registry, and included age at time of diagnosis, age at time of survey, sex, Socio-Economic Status (SES), marital status, employment status, cancer type, time since diagnosis, stage at time of diagnosis, and primary treatment.

Health Literacy

A single item of the Dutch version of Chew's three-item Set of Brief Screening Questions (SBSQ) was used to assess the HL among patients [20], namely: 'How confident are you filling out medical forms by yourself?', with response options 'very', 'quite', 'somewhat', 'a little', and 'not at all'. This item was selected because it has demonstrated strong validity as a standalone screener for limited health literacy in large and diverse patient populations [21]. Low HL occurs when patients report they are somewhat, a little, or not at all confident when filling out medical paperwork on their own. Medium HL occurs when patients report they are quite confident when filling out medical paperwork on their own, and high HL occurs when patients report they are very confident when filling out medical paperwork [22]. To ensure sufficient group sizes and to reflect meaningful differences in support needs, patients with low and medium HL were combined into a single group, as both levels may

indicate challenges in understanding and applying health information in complex care contexts.

Perceived Information Provision and Satisfaction

The Dutch adaptation of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Information (EORTC QLQ-INFO25) was used to assess the perceived level of and satisfaction with IP [23]. Responses to the questionnaire are divided into four categories: perceived level of information about the *disease*; perceived level of information about *medical tests* performed in relation to the disease; perceived level of information about *treatment*; and other *care services* [7]. Scores range from 0 to 100, with higher scores meaning better PIP [24]. The questionnaire also includes a question regarding the patient's satisfaction with the information they received about their disease, with response options: '1 - not at all', '2 - a little', '3 - quite a bit', and '4 - very much'.

Quality of Life

The European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30; version 3.0) was used to assess HRQoL among cancer patients. This questionnaire consists of five functional scales (physical, role, cognitive, emotional, and social), three symptom scales (fatigue, pain, and nausea and vomiting), a global health status/QoL scale, several single items regarding further symptoms that are often reported by cancer patients (i.e., dyspnea, loss of appetite, insomnia, constipation and diarrhea) and perceived financial impact of the disease. In this study, the summary score was used to assess the HRQoL of cancer patients.

Statistical Analyses

Descriptive analyses were conducted to present sociodemographics and clinical characteristics of the patients included, sorted by cancer group. For continuous variables, the mean and standard deviation (SD) were calculated and compared, when relevant, using t-tests. For categorical variables, frequencies and percentages were calculated, and compared, when relevant, using chi-square tests. In order to analyze the PIP-variables, linear transformation was applied, which resulted in continuous variables with range 0–100. Data on PIP was available in two of the three datasets (i.e., ovarian and endometrial cancer).

Within the total group of patients with *low* HL, mean values of the PIP-categories (i.e., disease, medical tests, treatment, and other services) per cancer group (rare/common) were calculated and examined with t-tests. Furthermore,

the association between information satisfaction and cancer group (rare/common) was assessed with a Fisher's exact test. The mean values of HRQoL were compared between the two groups, using a t-test. Corresponding analyses were conducted within the total group of *high* HL patients in order to compare the results and identify differences within low and high HL patient groups.

Within cancer groups (*rare* and *common* cancer patients, separately), differences between low and high HL patients were assessed regarding perceived level of and satisfaction with IP, and regarding HRQoL, using t-tests and Fisher's Exact tests. Results were compared between groups as part of an exploratory analysis to identify potential differences.

Furthermore, multivariate regression analyses were performed to assess the association between: (1) HL with PIP, satisfaction and HRQoL, with cancer group (rare vs. common) added as effect modifier, and (2) HL and cancer group, satisfaction, and HRQoL, with HL (low/medium vs. high) added as effect modifier, and age, SES and marital status added to both models to adjust for confounding. For all analyses, a p -value < 0.05 was considered statistically significant. All analyses were performed using Stata/SE (version 17.0, Stator LP, College Station, TX).

Results

Sample Characteristics

In this study, data on 385 rare and 1,692 common cancer patients were analyzed. As only a few cancer types were included in the current study, almost all rare cancer patients (mostly ovarian) were (obviously) female (98.4%). Yet, about half of the common (mostly colorectal) cancer patients in this study were men (53.3%). Within both cancer groups (rare; common), most patients were married/cohabiting (70.0%; 77.9%), had a medium SES (40.4%; 40.9%), and were aged between 60 and 79 years (57.1%; 73.3%). Further, most patients within both cancer groups (rare; common) had a low/medium HL (54.3%; 58.3%) ($p=0.147$). Finally, rare cancer patients reported a lower HRQoL (summary score) than patients with a common cancer (84.97; 87.01) ($p=0.004$). In Table 1, an overview of all sample characteristics can be found.

Differences between HL Levels and Cancer Groups Regarding PIP, Satisfaction and HRQoL

Within the *low/medium* HL group, rare cancer patients scored lower than common cancer patients on PIP-disease ($p=0.010$), and comparable ('quite a bit'), yet statistically significant ($p=0.008$), on satisfaction with IP which can be

explained by differences in patient numbers per category. Within the *high* HL group, rare cancer patients scored lower than common cancer patients on PIP (all categories: $p<0.05$), and lower ('quite a bit' vs. 'very much') on satisfaction ($p<0.001$). Rare cancer patients scored lower on HRQoL compared to common cancer patients (85.88; 89.39, respectively) ($p<0.001$).

Within the *rare* cancer patient group, patients with low/medium HL scored lower on PIP compared to high HL patients, with PIP-disease ($p=0.009$), PIP-medical tests ($p<0.001$) and PIP-treatment ($p=0.003$) being significantly associated with HL. Within the *common* cancer patient group, patients with low/medium HL scored lower on PIP compared to patients with high HL (all categories: $p<0.05$). Further, HL was significantly related with satisfaction with IP ($p=0.010$), i.e., low/medium HL patients were significantly less satisfied with IP than high HL patients ('quite a bit' and 'very much', respectively). Common cancer patients with low/medium HL scored statistically significantly lower on HRQoL compared to patients with high HL (85.23; 89.39, respectively) ($p<0.001$) (Table 2).

Adjusted Associations between HL/cancer group, PIP, Satisfaction and HRQoL

Among patients with *low/medium* HL, cancer group was not significantly associated with PIP, satisfaction nor HRQoL after adjusting for confounding (i.e., age, SES, and marital status). Yet, rare cancer patients scored lower than common cancer patients on almost all categories, (except PIP-other services). Among patients with *high* HL, cancer group was negatively and significantly associated with all PIP-categories (except PIP-medical test), satisfaction and HRQoL, after adjusting for confounding (all categories: $p<0.05$). Specifically, rare cancer patients scored lower than common cancer patients on all categories.

Among *rare* cancer patients, HL was negatively and significantly associated with PIP-medical tests and PIP-treatment, after adjusting for confounding ($p=0.001$; $p=0.006$, respectively). Other categories were not significantly associated with HL level, but within this rare cancer group, patients with low/medium HL scored lower on all categories – including satisfaction, but excluding HRQoL – compared to high HL patients. Among *common* cancer patients, HL level was negatively and significantly associated with the PIP-categories, after adjusting for confounding (all categories: $p<0.05$). Low/medium HL patients scored lower than high HL patients on all PIP-categories. Furthermore, HL level was significantly associated with satisfaction and HRQoL ($p=0.001$; $p<0.001$, respectively), with low/medium HL patients scoring lower than high HL patients (Table 3).

Table 1 Sample characteristics

	Rare cancer <i>n</i> = 385; <i>n</i> (%)	Common cancer <i>n</i> = 1,692; <i>n</i> (%)	
<i>Sociodemographics</i>			
Sex	6 (1.6)	901 (53.3)	
Male	379 (98.4)	791 (46.8)	
Female			
Age at time of survey (yrs)	12 (3.1)	7 (0.4)	
<40	137 (35.6)	240 (14.2)	
40–59	220 (57.1)	1,240 (73.3)	
60–79	16 (4.2)	205 (12.1)	
80+			
Marital status	264 (70.0)	1,309 (77.9)	
Married/cohabiting	32 (8.5)	93 (5.5)	
Divorced/separated	56 (14.9)	224 (13.3)	
Widowed	25 (6.6)	54 (3.2)	
Never married/never cohabitated			
Socioeconomic status (SES)	83 (22.5)	322 (19.5)	
Low	149 (40.4)	674 (40.9)	
Medium	137 (37.1)	653 (39.6)	
High			
Employment status	103 (28.7)	244 (14.8)	
Paid employment contract	7 (2.0)	47 (2.8)	
Entrepreneur	248 (69.1)	1,362 (82.4)	
Unemployed			
<i>Disease-related characteristics</i>			
Cancer type †	351 (91.2)	0 (0.0)	
Ovarian	18 (4.7)	116 (6.9)	
Endometrial	3 (0.8)	1,575 (93.1)	
Colorectal	13 (3.4)	1 (0.1)	
Other			
Age at time of diagnosis (yrs)	25 (6.5)	27 (1.6)	
<40	174 (45.2)	484 (28.6)	
40–59	171 (44.4)	1,130 (66.6)	
60–79	6 (1.6)	51 (3.0)	
80+			
Time since diagnosis (yrs)	128 (33.3)	116 (6.9)	
0–<2	68 (17.7)	612 (36.2)	
2–<4	59 (15.3)	269 (15.9)	
4–6	121 (31.4)	695 (41.1)	
6+			
Treatment	174 (45.2)	798 (47.2)	
Surgery	4 (1.0)	4 (0.2)	
Chemotherapy	71 (18.4)	337 (19.9)	
Surgery + chemotherapy	9 (2.3)	412 (24.4)	
Surgery + radiotherapy	0 (0.0)	137 (8.1)	
Surgery + chemotherapy + radiotherapy	125 (32.5)	0 (0.0)	
Surgery + stem cell transplantation	2 (0.5)	4 (0.2)	
Other			
Tumor stage	152 (39.5)	580 (34.3)	
I	33 (8.6)	553 (32.7)	
II	83 (21.6)	467 (27.6)	
III	20 (5.2)	55 (3.3)	
IV	97 (25.2)	37 (2.2)	
Missing/unknown			
<i>Patient-reported outcomes</i>			
Health literacy	209 (54.3)	987 (58.3)	P-value 0.147
Low/medium	176 (45.7)	705 (41.7)	
High			

Table 1 (continued)

	Rare cancer <i>n</i> = 385; <i>n</i> (%)	Common cancer <i>n</i> = 1,692; <i>n</i> (%)	
Perceived information provision, mean (SD) ‡	56.02 (22.69)	65.57 (22.40)	<0.001
Disease	64.40 (26.06)	72.08 (23.38)	0.003
Medical tests	45.65 (25.23)	55.65 (27.07)	<0.001
Treatment	25.87 (25.10)	32.71 (28.34)	0.008
Other services			
Satisfaction with information provision	21 (5.7)	0 (0.0)	<0.001
Not at all	103 (28.1)	13 (11.6)	
A little	156 (42.6)	58 (51.8)	
Quite a bit	86 (23.5)	41 (36.6)	
Very much			
Summary score HRQoL, mean (SD)	84.97 (14.03)	87.01 (12.99)	0.004

SD, standard deviation. In case numbers do not add up to the total number of patients, missing values were present

† Classification based on RARECARENet cancer list [RARECARENet]

‡ Data from two out of three datasets (i.e., ovarian and endometrial cancer) were used

Table 2 Differences between low HL and high HL patients, and rare and common cancer patients regarding PIP, satisfaction and HRQoL

Outcomes	Low/medium HL†			High HL†		
	Rare cancer mean (SD)	Common cancer mean (SD)	p-value	Rare cancer mean (SD)	Common cancer mean (SD)	p-value
PIP – disease	53.52 (21.18)	60.84 (22.57)	0.010	59.11 (24.12)	71.80 (20.88)	<0.001
PIP – medical tests	60.26 (24.92)	64.96 (21.89)	0.091	69.51 (26.59)	80.56 (22.43)	0.004
PIP – treatment	42.36 (24.60)	46.87 (22.39)	0.103	49.73 (25.48)	65.79 (28.61)	<0.001
PIP – other services	24.24 (22.59)	23.80 (23.53)	0.552	27.88 (27.83)	43.19 (30.14)	<0.001
Satisfaction with IP ‡	3	3	0.008	3	4	<0.001
HRQoL	84.23 (13.76)	85.23 (13.76)	0.167	85.88 (13.52)	89.39 (11.48)	<0.001
	Rare cancer†			Common cancer†		
	Low/medium HL mean (SD)	High HL mean (SD)	p-value	Low/medium HL mean (SD)	High HL mean (SD)	p-value
PIP – disease	53.52 (21.18)	59.11 (24.12)	0.009	60.84 (22.57)	71.80 (20.88)	0.004
PIP – medical tests	60.26 (24.92)	69.51 (26.59)	<0.001	64.96 (21.89)	80.56 (22.43)	<0.001
PIP – treatment	42.36 (24.60)	49.73 (25.48)	0.003	46.87 (22.39)	65.79 (28.61)	<0.001
PIP – other care services	24.24 (22.59)	27.88 (27.83)	0.085	23.80 (23.53)	43.19 (30.14)	<0.001
Satisfaction with IP ‡	3	3	0.511	3	4	0.010
HRQoL	84.18 (14.45)	85.88 (13.52)	0.122	85.23 (13.76)	89.39 (11.48)	<0.001

Data from two out of three datasets (i.e., ovarian and endometrial cancer) was used for PIP-categories and satisfaction with IP

† N differs per group: $N_{\text{low/medium HL}}=262$ (201 rare cancer; 61 common cancer) and $N_{\text{high HL}}=216$ (165 rare cancer; 51 common cancer) for PIP-categories and satisfaction with IP; $N_{\text{low/medium HL}}=1,103$ (199 rare cancer; 904 common cancer) and $N_{\text{high HL}}=848$ (173 rare cancer; 675 common cancer) for HRQoL

$N_{\text{rare cancer}}=366$ (201 low/medium HL; 165 high HL) and $N_{\text{common cancer}}=112$ (61 low/medium HL; 51 high HL) for PIP-categories and satisfaction with IP; $N_{\text{rare cancer}}=372$ (199 low/medium HL; 173 high HL) and $N_{\text{common cancer}}=1,579$ (904 low/medium HL; 675 high HL) for HRQoL

‡ A Fisher's Exact test was used as satisfaction was a categorical variable

Discussion

Main Findings

In this study, the impact of HL on the perceived level of and satisfaction with IP, and on HRQoL, in rare cancer patients compared to common cancer patients has been explored. Regarding the adjusted findings, within the *low/medium* HL group, no statistically significant differences were found

between rare and common cancer patients, yet, within the *high* HL group, rare cancer patients scored significantly lower on all PIP-categories (except PIP-medical tests), satisfaction and HRQoL. Further, within the *rare* cancer group, patients with *low/medium* HL scored lower, compared to those with *high* HL, on PIP-medical tests and PIP-treatment, while within the *common* cancer group, patients with *low/medium* HL scored lower on all PIP-categories, satisfaction and HRQoL (all: $p < 0.05$).

Table 3 Adjusted associations between HL/cancer group, and PIP, satisfaction, and HRQoL

	Low/medium HL†			High HL†		
	β	95% CI	p-value	β	95% CI	p-value
PIP-disease	-5.419	[-11.904; 1.065]	0.101	-10.892	[-19.313; -2.471]	0.012
PIP-medical tests	-3.100	[-10.344; 4.143]	0.400	-7.956	[-19.614; 7.988]	0.407
PIP-treatment	-3.448	[-10.863; 3.967]	0.361	-13.721	[-23.201; -4.240]	0.005
PIP-other services	0.145	[-6.904; 7.193]	0.968	-13.387	[-23.489; -3.284]	0.010
Satisfaction	-0.478	[-1.032; 0.767]	0.091	-1.157	[-1.830; -0.484]	0.001
HRQoL	-0.465	[-2.695; 1.764]	0.682	-3.657	[-5.774; -1.540]	0.001
	Rare cancer†			Common cancer†		
	β	95% CI	p-value	β	95% CI	p-value
PIP-disease	-4.868	[-9.927; 0.191]	0.059	-12.559	[-21.726; -3.391]	0.008
PIP-medical tests	-9.789	[-15.506; -4.071]	0.001	-14.649	[-24.006; -5.292]	0.002
PIP-treatment	-8.017	[-13.720; -2.314]	0.006	-18.156	[-29.444; -6.868]	0.002
PIP-other services	-5.071	[-10.699; 0.557]	0.077	-19.799	[-31.858; -7.739]	0.002
Satisfaction	-0.342	[-0.758; 0.075]	0.108	-1.520	[-2.425; -0.615]	0.001
HRQoL	0.244	[-2.873; 3.361]	0.878	-4.110	[-5.433; -2.786;]	<0.001

Data from two out of three datasets (i.e., ovarian and endometrial cancer) was used for PIP-categories and satisfaction with IP. Reference categories were common cancer or high HL. Adjusted for confounding by age at diagnosis, marital status and SES

† N differs per group: $N_{\text{low/medium HL}}=249$ and $N_{\text{high HL}}=203$ or PIP-categories and satisfaction with IP; $N_{\text{low/medium HL}}=1,060$ and $N_{\text{high HL}}=817$ for HRQoL

$N_{\text{rare cancer}}=344$ and $N_{\text{common cancer}}=108$ for PIP-categories and satisfaction with IP; $N_{\text{rare cancer}}=348$ and $N_{\text{common cancer}}=1,529$ for HRQoL

Interpretation of Findings

Within low/medium HL patients, rare cancer patients scored lower (with the exception of PIP-other services) compared to common cancer patients, yet *not* statistically significantly, on PIP-categories, satisfaction and HRQoL, which is partly unexpected. Both Hyun et al. and de Heus et al. 2021 reported, for example, that patients with a rare cancer type experience many unmet information needs regarding their disease, but also regarding their treatment, and psychosocial concerns [16, 25]. Further, differences between rare and common cancer patients, within the low/medium HL group, were expected as there is a lack of guidance and support from medical professionals for rare cancer patients specifically, since information on rare cancer, or rare diseases in general, is relatively hard to find and/or understand [26]. Conversely, low HL was previously found to be associated with greater difficulties in understanding and processing cancer-related information, poorer quality of life and poorer experience of care in cancer patients in general [27]. Herewith, cancer group is not a pivotal factor for perceived level of and satisfaction with IP and HRQoL, when patients are already more vulnerable because of low/medium HL.

Within high HL patients, it was found that patients with a rare cancer type scored significantly lower, after adjustment, on all PIP-categories – except PIP-medical tests –, satisfaction, and HRQoL compared to patients with a common cancer type. Correspondingly, Ladd (2017) reported

that rare cancer patients frequently search for (online) information themselves, and are regularly confronted with the lack of information that is available on rare cancer types in comparison to common cancer types, resulting in worse PIP [28]. Specifically regarding treatment, those rare cancer patients with high HL might be more aware of the gaps in available information and knowledge about their treatment options, possibly leading to greater uncertainties. The difference in satisfaction might be explained by the lack of knowledge and education regarding rare diseases (e.g., rare cancer) among physicians, which subsequently may lead to dissatisfaction with IP among high HL patients suffering from a rare disease [29]. In addition, the difference in HRQoL might be explained by the emotional burden experienced by high HL patients with a rare cancer, due to awareness of the lack of information and support, the confrontation with ‘not knowing’, contributing to feelings of isolation, anxiety and uncertainty regarding their illness [30].

Within the rare cancer group, patients with a low/medium HL scored significantly lower on PIP-medical tests and PIP-treatment than patients with high HL. This is in line with previous studies, since in most studies, low HL patients reported to have worse PIP [8, 31]. An explanation of the reported PIP-scores in this study might be that low/medium HL patients rely more on information from healthcare professionals in comparison to high HL patients, due to which they might be less critical of information they receive from their healthcare professional

and have a better perception of and satisfaction with IP than high HL patients [32, 33].

Within the common cancer group, patients with a low/medium HL significantly scored lower on all PIP-categories, satisfaction, and HRQoL than patients with high HL, of which all remained significant after adjustment. This, again, complies with previous results, showing that patients with a low HL generally score lower on PIP and HRQoL [8], and are less satisfied with IP [7]. As found in earlier studies, the reported differences are likely to be due to the challenges faced by patients with lower HL in understanding and coping with their disease as well as difficulties in communicating with healthcare professionals [34, 35].

Study Limitations

To our knowledge, this is the first explorative study on differences in HL, PIP, satisfaction, and HRQoL among rare and common cancer patients. Still, a number of limitations must be addressed. First, regarding generalizability, the study sample included patients with mostly (rare types of) ovarian cancer and colorectal cancer, and rare cancer patients were, obviously, mostly female. Therefore, the results should be interpreted with caution as they are not representative for all cancer patients. As information needs are highly unmet in rare cancer patients, and patients with low HL are expected to be affected even more, it was determined that insights regarding a selected sample could function as a first exploration of this topic. Second, regarding recall bias, a notable group of patients who responded to the questionnaires were diagnosed over six years ago, while patients are most likely to receive information regarding their disease relatively soon after their diagnosis. This means that part of the IP assumably occurred over six years ago, which may have resulted in recall bias. Finally, data on PIP and satisfaction was only available in two of the three datasets used in this study. Therefore, these analyses were performed on less data (i.e., 368 rare and 114 common cancer patients), which means a loss of statistical power.

Clinical Implications

Future research on the impact of HL on PIP, satisfaction and HRQoL should include *both* rare and common cancer patients, for comparison, and patients with a variety of sociodemographic (i.e., sex, SES, marital status) and cancer-related characteristics (i.e., cancer type, time since diagnosis). Further, studies on a range of different cancer types need to be conducted, to gain more knowledge on

individual types. Additionally, longitudinal studies on the impact of HL on PIP and satisfaction should be conducted during a patient's disease trajectory. A study by Berkman et al. (2010), for example, reported that a patient's HL level can change over time based on gained experiences with health circumstances and encounters with the healthcare system [36]. Furthermore, a study by Fang et al. (2012) reported that information needs change over time, and that patients with an early-stage disease have higher information needs compared to patients with a further progressed disease [37].

The results of this study support the need for additional education for healthcare professionals, emphasizing the importance of HL among cancer patients. Training should address how different HL levels require tailored information provision and communication strategies (e.g., using clear, jargon-free language for patients with low HL) [38, 39]. For patients with high HL and a rare cancer type, professionals should be aware that the lack of available information may negatively impact HRQoL. In such cases, transparency about knowledge gaps is essential. Furthermore, cancer educators can help high HL patients develop critical appraisal skills and provide tools to assess the credibility of online sources, supporting them in managing the emotional impact of incomplete information. Patients with low HL should receive guided support to help them ask questions and understand what is known versus unknown. In rare cancer care, where information is often limited or fragmented, a key focus should be on building patients' skills to navigate uncertainty. Implementing such training for healthcare professionals and cancer educators may improve PIP, patient satisfaction, and potentially HRQoL.

Finally, it was shown that rare cancer patients and low/medium HL patients tend to have most unmet information needs. As unmet information needs were previously found to potentially affect anxiety and depression, support in applying coping strategies, or mind-body exercise, to deal with such anxiety and depression might be successful among these patients [40, 41].

Conclusions

HL level and cancer group may impact PIP, satisfaction with IP, and HRQoL. Further in-depth studies on a much broader group of rare and common cancer patients are necessary in order to generalize results. Healthcare professionals should take differences in information needs among patients with divergent HL levels and specific cancer types into account in order to convey information in an understandable, patient-tailored way.

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Declarations

Ethics Approval Three datasets from the PROFILES registry were used in the current study, all having Medical Ethical approval (METC NL33429.008.10; METC ETZ 2011.129; METC MMC 0822). All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed Consent was obtained from all individual participants included in the study.

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