

Illness perceptions in cancer survivors: what is the role of information provision?

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Abstract

Background: The aim of this study was to provide insight into the relationship between information provision and illness perceptions among cancer survivors.

Methods: All individuals diagnosed with lymphoma, multiple myeloma, endometrial or colorectal cancer between 1998 and 2008, as registered in the Eindhoven Cancer Registry, were eligible for participation. In total, 4446 survivors received a questionnaire including the EORTC-QLQ-INFO25 and the Brief Illness Perception Questionnaire; 69% responded ($n = 3080$).

Results: Lymphoma and multiple myeloma patients were most satisfied with the information they received, and they perceived to having received more information about their treatment and other services (after care) compared with colorectal and endometrial cancer survivors ($p < 0.05$). Multiple myeloma patients reported the highest scores (conceptualized their illness as very serious) on the illness perception scales.

The perceived receipt of more disease-specific information was associated with more personal and treatment control and a better understanding of the illness, whereas the perceived receipt of more information about other services was associated with more negative consequences of the illness on the patients' life, longer perceived duration of illness, less treatment control, more symptoms attributable to the illness, less understanding of, and stronger emotional reaction to the illness ($p < 0.05$). Satisfaction with the received information was associated with better illness perception on all subscales, except for personal control ($p < 0.05$).

Conclusion: Improving the patients' illness perceptions by tailoring the information provision to the needs of patients may help patients to get a more coherent understanding of their illness and will possibly lead to a better health-related quality of life.

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Introduction

Health-related quality of life (HRQoL) of cancer patients has been identified as an important endpoint in research and clinical practice. A major determinant of HRQoL, next to the illness itself, is the way patients' perceive and respond to their illness [1]. Research on these illness perceptions is guided by the self-regulation model [2]. This model is based on the assumption that patients respond to symptoms and signs of illness by forming cognitive and emotional representations of the illness, that lead to coping responses [3]. These representations can be divided into eight dimensions: (i) *consequences*, anticipated and experienced consequences of the illness on the patient's life; (ii) *timeline*, the perceived progress and duration of the illness; (iii) *personal control*, the perception of having self-control

and whether the illness is easy to cure; (iv) *treatment control*, how much treatment can help to control the illness; (v) *identity*, complaints or symptoms a patient attributes to his/her illness; (vi) *illness concern*, worries about illness; (vii) *coherence*, how well the patient feels (s)he understands the illness; and (viii) *emotional representation*, how much patients are emotionally affected by the illness [3]. Results of studies among different groups of cancer patients show that negative illness perceptions predicted worse HRQoL and depression after treatment [4–9].

Another important factor associated with HRQoL in cancer patients is adequate information provision [10]. The provision of information to patients is one of the most important factors of supportive cancer care across the whole cancer continuum. Appropriate information provision can result in informed decision making,

better treatment adherence, lower levels of distress (anxiety and depression), and higher levels of HRQoL, improved satisfaction with care and sense of control [11–16]. However, one of the most frequently reported unmet needs by cancer patients in all phases of the disease is information disclosure (6%–93%) [17], especially the information needs of cancer survivors (posttreatment) that are unrecognized [18]. There is a discrepancy between the actual information needs of cancer patients and the perception of health care providers about the needs of these patients [16,19]. A recent study showed that information needs of cancer patients vary as a function of adjustment to cancer [20]. The self-regulation model proposes that patients form beliefs about their illness on the basis of abstract and concrete sources of information available to them [7]. Information provision seems to play an important role in illness perception and HRQoL [10]. However, research into the relationship between information provision and illness perception is lacking.

Therefore, the aim of this study was to examine the association between illness perceptions and information provision. We hypothesized that patients who were satisfied with the received information would score better on each illness perception dimension.

Methods

Setting and participants

In this study, data from five large population-based cross-sectional surveys on survivors of Hodgkin lymphoma, non-Hodgkin lymphoma, myeloma, endometrial and colorectal cancer was used [21]. These surveys were set up between 2008 and 2009 by using data from the Eindhoven Cancer Registry (ECR) and were designed to evaluate different patient-reported outcomes (e.g., late effects, physical, and mental health status) among cancer survivors. The data collection procedure across those five surveys was comparable and is described in the succeeding paragraphs.

The ECR compiles data of all individuals newly diagnosed with cancer in the southern part of the Netherlands, an area with 10 hospitals serving 2.3 million inhabitants [22]. All individuals diagnosed with Hodgkin lymphoma, non-Hodgkin lymphoma, or multiple myeloma between 1999 and 2008, or with endometrial or colorectal cancer between 1998 and 2007, as registered in the ECR, were eligible for participation. Because of the large number of colorectal cancer survivors ($n = 5399$), a weighted random selection of 2219 patients based on tumor (colon/rectal), sex, and year of diagnosis was made [23,24]. The weights on tumor and sex were derived from the total distribution of colorectal cancer survivors in the ECR region. Patients with shorter years since diagnosis were oversampled for inclusion in future follow-up assessments.

After excluding those patients who had cognitive impairment (medical records and advice attending specialist), had unverifiable addresses, or had died prior

to study initiation (according to the ECR, hospital records, and the Central Bureau for Genealogy that collects information on all deceased Dutch citizens via the civil municipal registries), data collection started between 2008 and 2009. All surveys were approved by a local certified Medical Ethics Committee.

Data collection

Survivors were informed of the surveys via a letter from their (ex)-attending specialist. The letter explained that by completing and returning the enclosed questionnaire, patients consented to participate and agreed to the linkage of the questionnaire data with their disease history in the ECR. Patients were reassured that nonparticipation had no consequences on their follow-up care or treatment. Nonrespondents were sent a reminder letter and the questionnaire within 2 months.

Measures

Sociodemographic and clinical characteristics

Data on tumor and patient background characteristics were obtained from the ECR [25]. The questionnaire contained questions on sociodemographic data, including marital status, current occupation, educational level, and comorbidity. Socioeconomic status was determined by an indicator developed by Statistics Netherlands based on individual fiscal data from the year 2000 on the economic value of the home and household income, and provided as aggregate level for each postal code (average 17 households), which were then categorized into tertiles [26]. Disease progression (e.g., recurrence, metastasis, or new primary tumor) was determined through check of medical files.

Information provision

To evaluate the information received by cancer survivors, the EORTC QLQ-INFO25 questionnaire was used [27]. The EORTC QLQ-INFO25 consists of 25 items, grouped into four information provision subscales: perceived receipt of information about the disease (four items regarding diagnosis, spread of disease, cause(s) of disease, and whether the disease is under control), medical tests (three items regarding purpose, procedures, and results of tests), treatment (six items regarding medical treatment, benefits, side effects, effects on disease symptoms, social life, and sexual activity), and other care services (four items regarding additional help, rehabilitation options, managing illness at home, psychological support). The question format was as follows: 'During your current disease or treatment, how much information have you received on'. In addition, it contains eight single items on receiving written information or information on CDs or tape/video, receiving more or less information, and items on the satisfaction with amount and helpfulness of information. All responses were ranged according

to a four-point Likert scale, except for the first four single items that had a binary yes/no scale. All scales were linearly converted to a 0–100 scale, with higher scores indicating better perceived information provision. Internal consistency for all scales is good ($\alpha > 0.70$), as is test–retest reliability (intraclass correlations > 0.70) [27].

Illness perceptions

Illness perceptions were assessed using the Brief Illness Perception Questionnaire (B-IPQ), a nine-item instrument used to assess cognitive and emotional representations of the illness [28]. The English version of Brief Illness Perception Questionnaire (BIPQ) was translated into Dutch by forward-backward translation procedures and adapted for use among cancer patients. The B-IPQ uses a single-item scale approach to assess perceptions on a continuous linear 0–10 point scale. Five of the items assess cognitive illness representations: (i) How much does your illness affect your life (consequences); (ii) How long do you think your illness will continue (timeline); (iii) How much control do you feel you have over your illness (personal control); (iv) How much do you think your treatment can help your illness (treatment control); and (v) How much do you experience symptoms from your illness (identity). Two items assess emotional representations: (vi) How concerned are you about your illness (concern) and (vii) How much does your illness affect you emotionally (emotional representation). One item assesses illness comprehensibility: (viii) How well do you understand your illness (coherence). Answer scales of three items (personal control, treatment control, and coherence) were reversed for statistical analyses to get the same response direction as the other five items. A higher score means worse illness perception.

Statistical analyses

Routinely collected data from the ECR on patient and tumor characteristics enabled us to compare the group of respondents, nonrespondents, and patients with unverifiable addresses, by using analyses of variances (ANOVA's) for continuous variables and chi-square analyses for categorical variables.

Mean scores on the BIPQ and EORTC-QLQ-INFO25 for different subgroups were compared using ANOVA or chi-square analyses for dichotomous items of EORTC-QLQ-INFO25. Multivariate linear regression analyses were carried out to investigate the association between the four information provision subscales of the EORTC-QLQ-INFO25, with the BIPQ items controlled for demographics and tumor characteristics. Eight linear regression models, respective of the eight single items of the B-IPQ, were estimated with outcomes. Multicollinearity was checked for every analysis. We reran these linear regression analyses stratified by tumor group (endometrial, colorectal, Hodgkin lymphoma, non-Hodgkin lymphoma, and multiple myeloma), age group (younger than 65 years, older than 65 years),

gender, treatment modality (surgery, radiotherapy, chemotherapy), time since diagnosis (< 2 years, > 2 years), and comorbidity (none, 1, or > 1), on the basis of a priori assumptions that information provision or disease perception may be different among these strata. We tested for effect modification by including cross-product terms in the regression models, for variables where stratified analyses showed different results as the main regression models. All statistical tests were two-sided and considered significant if $p < 0.05$. All analyses were conducted using SPSS version 17.0 (Statistical Package for Social Sciences, Chicago, IL, USA).

Results

Patient characteristics

Three thousand and eighty (69.3%) patients returned a completed questionnaire. A comparison of respondents, nonrespondents, and patients with unverifiable addresses indicated that patients with unverifiable addresses were younger and with more years since diagnosis. They were less often treated with surgery and less often diagnosed with colorectal cancer. Nonrespondents were more often women and less often treated with radiotherapy or chemotherapy [21].

Sociodemographic and clinical characteristics of cancer survivors, according to type of tumor, are presented in Table 1. Hodgkin lymphoma patients were significantly younger, more likely to have a job, and reported less comorbid conditions than the other four patient groups. Multiple myeloma patients were more recently diagnosed compared with the other four tumor groups. Lymphoma and multiple myeloma patients did not receive surgery as a primary treatment but significantly more often received chemotherapy and radiotherapy compared with colorectal and endometrial cancer patients.

Information provision and satisfaction

Satisfied cancer patients perceived to have received more information (disease, medical tests, treatment, and other services) than dissatisfied patients ($p < 0.01$; Table 2). Hodgkin lymphoma cancer patients perceived to have received more information and were more satisfied compared with the other four tumor groups. Non-Hodgkin and multiple myeloma cancer patients perceived to have received more information about treatments than colorectal and endometrial cancer patients ($p < 0.01$). Endometrial cancer patients perceived to have received less information about other services (like options for after care) than the other four tumor groups ($p < 0.01$).

Patients with an advanced stage of the disease at diagnosis (III or IV) were more satisfied with and perceived to have received more information about treatment and other services ($p < 0.01$) than patients with earlier stage of the disease (I and II). Patients

Table 1. Demographic and clinical characteristics of respondents

	Endometrial cancer (n = 742)	Colorectal cancer (n = 1352)	Hodgkin lymphoma (n = 150)	Non-Hodgkin lymphoma (n = 716)	Multiple myeloma (n = 120)	p-value
Age at diagnosis	61.8 ± 8.3	65.0 ± 9.7	41.2 ± 15.4	58.9 ± 12.4	63.0 ± 9.9	<0.01
Age at time of survey	66.7 ± 8.5	69.4 ± 9.6	46.6 ± 15.3	63.7 ± 12.3	66.5 ± 9.4	<0.01
Years since diagnosis	4.9 ± 2.5	4.4 ± 2.5	5.3 ± 2.8	4.8 ± 2.5	3.5 ± 2.3	<0.01
Gender						
Male	-	765 (56.6%)	81 (54.0%)	439 (61.3%)	64 (53.3%)	<0.01
Female	742 (100%)	587 (43.4%)	69 (46.0%)	277 (38.7%)	56 (46.7%)	
Stage at diagnosis						
I	686 (92.5%)	381 (28.2%)	NA	NA	NA	<0.01
II	56 (7.5%)	519 (38.4%)				
III	-	383 (28.3%)				
IV	-	69 (5.1%)				
Treatment						
Surgery	742 (100%)	1341 (99.2%)	0 (0%)	0 (0%)	0 (0%)	<0.01
Chemotherapy	8 (1.1%)	364 (26.9%)	145 (96.7%)	436 (61.7%)	91 (75.8%)	<0.01
Radiotherapy	167 (22.5%)	342 (25.3%)	91 (60.7%)	168 (23.8%)	41 (34.2%)	<0.01
Comorbidity						
None	149 (20.1%)	324 (24.0%)	56 (37.3%)	201 (28.1%)	26 (21.7%)	<0.01
I	190 (25.6%)	361 (26.7%)	44 (29.3%)	193 (27.0%)	27 (22.5%)	
≥2	403 (54.3%)	667 (49.3%)	50 (33.3%)	322 (45.0%)	67 (55.8%)	
Marital status						
Married/living together	516 (71.8%)	984 (74.4%)	112 (75.2%)	564 (80.2%)	90 (75.6%)	<0.01
Divorced/widowed/ never married	203 (28.2%)	339 (25.6%)	37 (24.8%)	139 (19.8%)	29 (24.4%)	
Educational level						
University	71 (10%)	254 (19.4%)	13 (8.7%)	111 (15.9%)	23 (19.2%)	<0.01
Intermediate school	218 (30.6%)	456 (34.9%)	29 (19.5%)	169 (24.2%)	42 (35.0%)	
Secondary school	249 (34.9%)	322 (24.7%)	59 (39.6%)	253 (36.3%)	33 (27.5%)	
Primary school	175 (24.5%)	274 (21.0%)	48 (32.2%)	164 (23.5%)	22 (18.3%)	
Current occupation						
Employed	111 (15.5%)	195 (15.0%)	77 (56.6%)	164 (24.4%)	14 (12.1%)	<0.01
Not employed	605 (84.5%)	1106 (85.0%)	59 (43.4%)	508 (75.6%)	102 (87.9%)	
Socioeconomic status						
Low	164 (22.3%)	290 (22.1%)	29 (20.1%)	146 (20.9%)	25 (21.7%)	0.45
Intermediate	308 (41.9%)	522 (39.7%)	65 (45.1%)	272 (39.0%)	42 (36.5%)	
High	241 (32.8%)	470 (35.7%)	50 (34.7%)	279 (40.0%)	45 (39.1%)	

NA, not available.

who underwent radiotherapy perceived to have received more information about medical tests, treatment, and other services, whereas patients who underwent chemotherapy also perceived to have received more information about the disease and were more satisfied than their counterparts ($p < 0.01$). Patients without comorbidities received more information about the disease, medical tests, and treatment and were more satisfied than patients with one or more comorbidities ($p < 0.01$).

Men were more satisfied and wanted to receive more information than women ($p < 0.01$), whereas women more frequently reported to want less information ($p < 0.05$). Patients who are employed, under 65 years of age, with a partner, and with less than 2 years after diagnosis were more satisfied and scored better on most information provision subscales than their counterparts ($p < 0.01$). Higher educated patients perceived to have received more information about the disease and medical tests than lower educated patients ($p < 0.05$).

Illness perception

Endometrial cancer patients experienced less serious consequences and symptoms of their cancer, had

shorter timeline beliefs, and were less concerned and emotionally affected by their illness compared with the other four tumor groups (all had $p < 0.05$; Table 3). Endometrial and Hodgkin lymphoma cancer patients felt to have more personal control over their illness compared with the other three tumor groups, whereas Hodgkin lymphoma patients also felt that their treatment could control their illness more compared with the other groups. Multiple myeloma patients scored highest on all illness perception dimensions, indicating worse illness perceptions. No differences between the cancer types were seen on coherence (understanding) of their illness.

Patients who were not satisfied with the received information were less than 2 years after diagnosis, had a higher stage disease, had one or more comorbidities, received radiotherapy and/or chemotherapy, and scored worse on most illness perception scales than their counterparts.

Multivariate analyses

Receiving more disease-specific information was associated with more personal and treatment control over the

Table 2. Mean EORTC-INFO-25 subscale scores (\pm SD) according to demographic and clinical characteristics

	Information about disease	Information about medical tests	Information about treatment	Information about other services	Satisfaction with information	Usefulness of information	Want more information (%)	Want less information (%)
Satisfaction with information (item INFO25)								
Not satisfied	37.1(18.0)	47.1(21.6)	27.3(17.9)	10.6(13.3)	-	41.8(22.1)	444(39.4)	61(5.7)
Satisfied	59.0(18.2)**	71.8(19.7)**	50.1(22.9)**	23.7(23.5)**		72.3(20.0)**	190(11.3)**	32(1.9)**
Tumor								
Endometrial	51.3(22.7)	59.6(26.6)	38.4(24.9)	14.7(18.8)	56.3(26.8)	57.9(25.7)	103(15.3)	38(5.7)
Colorectal	47.7(20.7)	60.8(23.6)	36.9(23.3)	18.1(20.9)	53.4(25.6)	58.1(26.2)	299(23.8)	34(2.8)
Hodgkin lymphoma	56.7(16.2)	68.6(21.4)	56.8(19.0)	26.9(22.0)	66.0(24.7)	73.3(21.7)	42(28.4)	3(2.1)
Non-Hodgkin lymphoma	51.1(20.7)	63.4(22.3)	44.8(22.6)	19.7(22.4)	59.8(26.8)	63.3(24.3)	184(26.4)	21(3.1)
Myeloma	50.8(23.7)**	65.4(23.5)**	46.5(24.5)**	22.6(21.2)**	58.8(29.2)**	60.9(26.0)**	32(28.3)**	2(1.9)**
Age								
≤ 65 years	53.2 (20.5)	65.1 (22.2)	46.2 (22.9)	21.1 (21.9)	58.7 (25.9)	63.8 (24.2)	333 (26.3)	35 (2.8)
>65 years	47.3 (21.4)**	59.1 (25.0)**	36.0 (23.6)**	16.0 (20.1)**	54.7 (26.9)**	57.2 (26.6)**	326 (20.6)**	63 (4.0)
Time since diagnosis								
≤ 2 years	53.3(21.2)	65.3(22.9)	44.8(22.9)	22.1(22.3)	60.5(25.3)	63.9(24.3)	117(24.3)	17(3.6)
>2 years	49.3(21.2)**	61.1(24.1)**	39.8(24.0)**	17.6(20.7)**	55.7(26.7)**	59.4(25.9)**	542(22.5)	81(3.5)
Gender								
Male	49.9 (20.5)	62.7 (22.8)	42.0 (23.5)	19.3 (21.7)	57.9 (26.3)	60.7 (25.7)	346 (26.9)	34 (2.7)
Female	50.0 (21.8)	61.1 (24.9)	39.5 (24.1)	17.6 (20.5)*	55.4 (26.6)**	59.7 (25.7)	314 (19.6)**	64 (4.1)*
Stage at diagnosis								
I	49.9(22.7)	59.4(26.1)	36.3(24.8)	15.2(19.7)	55.6(26.9)	57.6(26.6)	170(17.4)	46 (4.8)
II	47.3(20.1)	60.1(23.6)	34.1(22.3)	15.9(19.2)	51.2(24.7)	56.2(25.8)	122(23.0)	16(3.1)
III	49.1(20.0)	62.7(22.0)	43.3(22.7)	22.2(21.9)	55.9(25.0)	60.9(24.7)	86(24.1)	9(2.6)
IV	49.5(21.6)	65.3(23.1)	47.2(19.0)**	19.6(21.9)**	55.2(29.3)**	62.6(25.8)*	24 (35.3)**	1(1.5)
Chemotherapy								
Yes	52.7(19.9)	65.4(22.0)	50.2(21.1)	23.9(22.7)	61.1(25.8)	65.6(25.5)	264(26.1)	28(2.8)
No	49.6(21.4)**	59.8(24.8)**	35.3(23.7)**	15.2(19.5)**	54.1(26.6)**	57.3(26.1)**	392(21.0)**	70(3.9)
Radiotherapy								
Yes	51.1(20.7)	63.7(22.9)	45.4(22.3)	20.1(21.8)	57.7(25.4)	62.9(25.5)	189(24.8)	21(2.8)
No	49.5(21.4)	61.1(24.3)*	38.9(24.2)**	17.7(20.8)**	56.1(26.7)	59.1(25.8)**	467(22.1)	77(3.8)
Comorbidity								
None	52.9(21.0)	64.5(24.5)	45.3(23.8)	18.6(20.5)	60.9(26.4)	63.1(25.8)	119(17.2)	29(4.3)
I	50.0(21.2)	61.8(23.7)	40.7(23.2)	18.4(21.4)	58.6(25.6)	61.5(24.8)	166(21.6)	17(2.3)
≥ 2	48.6(21.2)**	60.4(23.8)**	38.4(23.9)**	18.2(21.2)	53.2(26.7)**	57.9(25.9)**	375(26.3)**	52(3.8)
Marital status								
Married/living together	50.9(20.9)	62.5(23.3)	41.8(23.7)	18.2(21.1)	56.9(26.5)	61.2(25.6)	512(23.7)	65(3.1)
Divorced/widowed/never married	47.4(21.9)**	59.7(25.7)**	37.6(24.2)**	19.0(21.0)	55.3(26.3)	57.5(25.8)**	139(20.1)	28(4.2)
Educational level								
University	51.9(20.4)	65.5(22.1)	42.4(23.0)	17.8(20.5)	58.1(25.5)	62.4(25.6)	125(27.2)	13(2.9)
Intermediate school	50.8(20.4)	62.4(23.5)	40.8(22.2)	17.9(20.5)	56.8(25.8)	61.4(25.3)	200(23.0)	24(2.8)
Secondary school	49.4(21.8)	60.6(24.4)	40.7(25.0)	17.8(21.5)	55.7(26.8)	58.5(25.3)	199(22.8)	26(3.1)
Primary school	48.5(21.8)*	60.2(25.0)**	39.6(25.2)	20.0(21.7)	56.1(28.0)	59.8(26.6)*	122(19.4)*	29(4.8)
Current Occupation								
Employed	53.7(19.7)	66.2(21.5)	47.7(22.3)	20.8(21.6)	59.5(24.6)	64.4(23.0)	150(27.1)	13(2.4)
Not employed	49.0(21.6)**	60.6(24.5)**	38.7(23.8)**	17.4(20.8)**	55.6(27.0)**	59.0(26.2)**	486(21.8)**	78(3.6)
Socioeconomic status								
Low	50.0(22.6)	59.9(26.3)	40.0(25.2)	18.0(21.1)	54.2(27.6)	57.5(26.4)	136(22.7)	24(4.2)
Intermediate	49.5(20.7)	61.4(23.7)	40.5(23.6)	19.0(20.9)	56.6(26.6)	60.0(26.0)	255(22.3)	38(3.4)
High	50.7(20.8)	63.8(22.7)**	41.7(23.4)	17.7(20.9)	58.1(25.6)*	61.9(25.0)**	237(23.1)	32(3.2)

* $p < 0.05$.** $p < 0.01$.

illness and better understanding of the illness (Table 4). More receipt of information about other services was associated with worse consequences and symptoms of the illness, less treatment control, more concerns, and higher emotional impact. Satisfaction with received information was associated with better scores on all illness perception items, except for personal control.

The associations between information about the disease, treatment, other services, and illness perceptions were not found in the subanalyses among patients less than 2 years after diagnosis (data not shown). The relation between treatment information and emotional representation was not found for patients who underwent adjuvant chemotherapy and/or radiotherapy (data not shown). The

Table 3. Mean scores on items of BIPQ (\pm SD) according to demographic and clinical characteristics

	BIPQ1 Consequences	BIPQ2 Timeline	BIPQ3 Personal control	BIPQ4 Treatment control	BIPQ5 Identity	BIPQ6 Concern	BIPQ7 Coherence	BIPQ8 Emotional representation
Satisfaction with information								
Not satisfied	4.3(2.6)	5.1(3.5)	6.2(3.1)	4.1(2.8)	3.8(2.7)	4.4(2.8)	4.8(3.1)	4.0(2.7)
Satisfied	3.7(2.5)**	4.6(3.6)**	5.8(3.3)**	3.1(2.5)**	3.4(2.6)**	3.8(2.6)**	3.8(2.9)**	3.3(2.5)**
Age								
≤65 years	4.3(2.6)	4.9(3.6)	6.0(3.2)	3.3(2.5)	3.9(2.7)	4.3(2.6)	4.1(2.9)	4.0(2.6)
>65 years	3.7(2.6)**	4.7(3.6)	5.9(3.2)	3.7(2.9)**	3.3(2.6)**	3.8(2.7)**	4.3(3.1)	3.3(2.5)**
Time since diagnosis								
≤2 years	4.5(2.7)	5.5(3.5)	6.2(3.1)	3.4(2.5)	3.8(2.7)	4.7(2.7)	4.3(3.0)	4.0(2.6)
>2 years	3.9(2.6)**	4.7(3.6)**	5.9(3.2)	3.6(2.8)	3.5(2.6)*	3.9(2.7)	4.2(3.0)**	3.5(2.6)**
Gender								
Male	4.1(2.6)	5.3(3.6)	6.0(3.2)	3.5(2.6)	3.6(2.6)	4.0(2.7)	4.1(2.9)	3.5(2.5)
Female	3.9(2.6)	4.4(3.5)**	5.9(3.3)	3.5(2.8)	3.5(2.7)	4.1(2.7)	4.3(3.1)	3.7(2.6)
Tumor								
Endometrial	3.2(2.4)	3.1(2.8)	5.6(3.4)	3.4(2.9)	2.9(2.5)	3.6(2.7)	4.3(3.2)	3.3(2.6)
Colorectal	4.1(2.7)	4.5(3.4)	6.1(3.1)	3.8(2.7)	3.6(2.6)	4.2(2.7)	4.3(3.0)	3.6(2.6)
Hodgkin lymphoma	4.3(2.5)	4.0(3.1)	5.6(3.2)	2.3(1.7)	3.8(2.6)	3.9(2.7)	4.0(2.9)	3.9(2.6)
Non-Hodgkin lymphoma	4.1(2.5)	6.5(3.6)	6.1(3.3)	3.4(2.6)	3.7(2.6)	4.0(2.7)	4.2(3.0)	3.7(2.6)
Myeloma	5.5(2.5)**	8.6(2.2)**	6.2(2.9)**	4.1(2.5)**	5.4(2.6)**	5.5(2.7)**	3.9(2.7)	4.4(2.6)**
Stage at diagnosis								
I	3.4(2.5)	3.6(3.2)	5.7(3.3)	3.6(2.9)	3.1(2.6)	3.6(2.6)	4.3(3.2)	3.3(2.6)
II	3.6(2.5)	3.9(3.1)	6.0(3.2)	3.6(2.7)	3.2(2.4)	3.9(2.6)	4.3(3.0)	3.3(2.5)
III	4.7(2.6)	4.7(3.4)	6.1(3.0)	3.6(2.5)	4.0(2.7)	4.6(2.7)	4.3(2.8)	3.9(2.6)
IV	6.4(2.8)**	7.7(2.9)**	6.8(2.8)**	5.0(3.0)**	5.8(2.5)**	6.7(2.7)**	3.7(2.7)	5.5(2.6)**
Chemotherapy								
Yes	4.6(2.6)	5.4(3.5)	6.1(3.1)	3.1(2.3)	4.1(2.7)	4.4(2.7)	4.1(2.8)	4.0(2.6)
No	3.6(2.5)**	4.5(3.6)**	5.9(3.3)	3.8(2.9)**	3.3(2.6)**	3.8(2.7)**	4.3(3.1)	3.4(2.5)**
Radiotherapy								
Yes	4.3(2.6)	5.0(3.5)	5.9(3.1)	3.3(2.5)	4.1(2.7)	4.2(2.7)	4.3(3.0)	3.8(2.6)
No	3.8(2.6)**	4.7(3.6)	6.0(3.3)	3.6(2.8)**	3.4(2.6)**	4.0(2.7)*	4.2(3.0)	3.5(2.6)*
Comorbidity								
None	3.5(2.4)	4.4(3.6)	5.8(3.4)	3.1(2.7)	2.9(2.4)	3.6(2.5)	4.1(3.0)	3.2(2.4)
I	3.7(2.5)	4.6(3.6)	5.8(3.2)	3.3(2.6)	3.3(2.5)	3.9(2.7)	4.2(3.0)	3.4(2.5)
≥2	4.3(2.7)**	5.2(3.6)**	6.1(3.2)*	3.8(2.8)**	4.0(2.7)**	4.3(2.8)**	4.3(3.0)	3.9(2.7)*
Marital status								
Married/living together	4.0(2.5)	4.8(3.6)	6.0(3.2)	3.5(2.7)	3.6(2.6)	4.1(2.7)	4.2(3.0)	3.6(2.6)
Divorced/widowed/never married	3.9(2.7)	4.8(3.6)	5.8(3.2)	3.7(2.9)*	3.6(2.7)	3.9(2.7)	4.4(3.1)	3.5(2.6)
Educational level								
University	4.1(2.6)	5.2(3.5)	5.9(3.2)	3.5(2.6)	3.6(2.7)	4.0(2.6)	4.1(2.9)	3.5(2.6)
Intermediate school	4.0(2.6)	4.6(3.5)	5.9(3.2)	3.5(2.7)	3.6(2.6)	4.0(2.7)	4.2(3.0)	3.6(2.5)
Secondary school	4.0(2.6)	5.0(3.6)	5.7(3.3)	3.4(2.7)	3.7(2.7)	4.1(2.8)	4.3(3.0)	3.7(2.6)
Primary school	3.8(2.6)	4.7(3.6)**	6.3(3.2)**	3.7(2.9)	3.4(2.6)	4.0(2.8)	4.3(3.1)	3.6(2.6)
Current occupation								
Employed	4.1(2.5)	4.5(3.5)	5.9(3.2)	3.1(2.4)	3.5(2.5)	4.0(2.5)	4.1(2.8)	3.7(2.5)
Not employed	3.9(2.6)	4.9(3.6)*	6.0(3.2)	3.7(2.8)**	3.6(2.7)	4.0(2.8)	4.3(3.0)	3.6(2.6)
Socioeconomic status								
Low	4.2(2.7)	4.9(3.6)	5.9(3.2)	3.7(2.7)	3.7(2.7)	4.4(2.9)	4.5(3.1)	3.9(2.7)
Intermediate	4.0(2.6)	4.7(3.5)	6.0(3.2)	3.4(2.6)	3.6(2.7)	4.0(2.7)	4.3(3.0)	3.6(2.6)
High	3.8(2.5)**	4.8(3.6)	6.0(3.3)	3.5(2.8)	3.4(2.6)	3.9(2.6)**	4.0(2.9)**	3.4(2.5)**

BIPQ, Brief Illness Perception Questionnaire.

* $p < 0.05$.** $p < 0.01$.

formal tests for interactions between treatment and years since diagnosis with the information subscales only confirmed the effect modification for years since diagnosis (data not shown).

Discussion

In general, lymphoma and multiple myeloma patients were most satisfied with the received information and perceived to have received more information about

their treatment and other services compared with colorectal and endometrial cancer survivors. Multiple myeloma patients reported the worst scores on the illness perception scales, which is in accordance with their disease severity. The perceived receipt of more disease-specific information was associated with more control and understanding, whereas the perceived receipt of more information about other services was associated with worse illness perceptions. This last finding can be explained by the fact that patients who received more

Table 4. Standardized betas of multivariate linear regression analyses evaluating the association of independent variables with the BIPQ scales, all patients combined

	BIPQ 1 Consequences	BIPQ2 Timeline	BIPQ3 Personal control	BIPQ4 Treatment control	BIPQ5 Identity	BIPQ6 Concern	BIPQ7 Coherence	BIPQ8 Emotional representation
Information about disease	0.02	-0.04	-0.11**	-0.10**	0.05	-0.05	-0.12**	0.03
Information about medical tests	0.01	0.03	-0.01	-0.05	-0.02	0.04	-0.03	-0.04
Information about treatment	0.02	-0.01	-0.01	-0.03	-0.04	0.04	-0.04	0.06
Information about other services	0.13**	0.04	-0.04	0.06*	0.13**	0.08**	0.05	0.10**
Satisfaction with information	-0.23**	-0.10**	-0.05	-0.11**	-0.16**	-0.19**	-0.10**	-0.24**

BIPQ, Brief Illness Perception Questionnaire.

* $p < 0.05$.** $p < 0.01$; Corrected for gender, age, time since diagnosis, tumor type, treatment, comorbidity, educational level, marital status, and current occupation.

information about other services were the more severely affected patients and therefore had worse illness perceptions. Satisfaction with the received information was the strongest predictor of good illness perceptions.

Our findings are in agreement with the results of a study among head and neck cancer patients [7]. This study found that higher levels of satisfaction with information were related to stronger beliefs in the usefulness of treatment and the controllability of the illness, a better understanding of the illness, and a weaker illness identity, before treatment. However, this study only reported correlation coefficients and did not look deeper into the relationship. Another study among six illness groups (without cancer) showed that personal and treatment control and coherence were best in hospitalized myocardial infarction patients, who just received many disease-related information, whereas patients who did not receive a diagnosis reported the worst identity scores, lowest understanding, shortest timeline perceptions, lowest treatment control beliefs, and highest emotional response [28]. Both studies were not specifically focused on the relation between information provision and illness perceptions. In our study, we found that time after diagnosis was an effect modifier of the relation between information provision and illness perceptions. Patients diagnosed less than 2 years ago received more information and had worse illness perceptions; this might indicate that illness perceptions change over time. This finding could also be ascribed to information bias, as the majority of cancer patients receive most information immediately after diagnosis, and patients who are more recently diagnosed could therefore better remember the amount of information they received.

Negative illness perceptions were associated with a worse HRQoL, poor adjustment to cancer, depression, treatment adherence, and even the perceived benefit from surgery [6–8,29,30]. Besides the association of illness perceptions with HRQoL, adequate information provision and satisfaction with information also have a positive influence on HRQoL, anxiety, and depression levels of cancer survivors [10]. Our study showed that the illness perceptions were better for patients who were satisfied with the information they received. It is important to gain insight into patients' perceptions of

their illness in relation to their satisfaction with information prior to and during treatment [7], as patients compare the received information with their own ideas and theories of their illness (comparing own current health status with that of past and also health of others) and interpret their disease within this framework [31,32]. Inaccurate information provision, misunderstanding, or negative conceptualizations of the illness can all lead to maladaptive responses to the illness. Restructuring illness perceptions by providing appropriate information according to patients' needs may help patients to get a more coherent understanding of their illness and will help in a better (long-term) adjustment to cancer [1,8].

Patients differ in the kind and amount of information they require, and satisfaction is more related to the extent of information needs met than to having received all possible information available. The information needs of cancer patients vary by gender, age, cultural background, educational level, cancer type, stage of disease, and coping style [33,34]. For example, some patients (monitoring style) search for all kinds of information about their disease, whereas others (blunting style) distract themselves from information. Patients feel better when the information they receive is tailored to their own coping style [33]. Health care practitioners need to move from a 'one size fits all' method of information provision to a more patient-centered approach that considers the unique needs, skills, values, illness perceptions, and emotions of patients [35]. Research shows that information needs of cancer patients are broader than disease and treatment-related information, also encompassing issues of psychosocial well-being that are often not discussed [35,36]. The inclusion of a psychologist into the multidisciplinary oncology team could be helpful to identify maladaptive illness perceptions. Discussing psychosocial items more extensively could help patients interpret the information in the right way [1]. Maladaptive illness perceptions could be changed by giving information meeting patients' needs, when necessary, in combination with an individualized behavioral intervention. Empowerment of patients by teaching them adequate coping skills and self-management training will translate into illness perceptions reflecting greater sense of control [5]. More research into this area is needed.

The present study has limitations that should be mentioned. Although the response rate was high and information was present concerning demographic and clinical characteristics of the nonrespondents and patients with unverifiable addresses, whether nonrespondents declined to participate in the study because of poor health remains unknown. Second, the cross-sectional design of the study limits the determination of causal association between information provision and illness perception and the change in illness perceptions over time. Different studies found that illness perceptions predicted HRQoL; however, a randomized controlled trial showed that patients' illness perceptions before consultation (uncertainty and negatively emotionally involved) predicted patient satisfaction with the consultation [37]. Therefore, more research is needed to the direction of this relationship.

In conclusion, we have demonstrated that satisfaction with the received information was the most important factor associated with better illness perception. Improving the patients' illness perceptions by tailoring the information provision to the needs of patients can possibly lead to a better HRQoL.

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Conflict of interest

There is no conflict of interest.

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