

# Patients are dissatisfied with information provision: perceived information provision and quality of life in prostate cancer patients

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## Abstract

**Objective:** To determine the satisfaction with information received by prostate cancer survivors and associations with health-related quality of life (HRQoL) and illness perception.

**Methods:** A cross-sectional study was performed among 999 patients diagnosed between 2006 and 2009. All patients received a questionnaire on HRQoL (EORTC QLQ-C30), illness perception (B-IPQ) and satisfaction with information provision (EORTC QLQ-INFO-25). Multivariate regression analyses were performed to assess the association between satisfaction with information provision and HRQoL as well as illness perception.

**Results:** Response rate was 70% ( $N=697$ ), 34% ( $N=222$ ) indicated to be dissatisfied with the information received. Multivariate linear regression analyses showed a significant positive association between satisfaction with information provision and global health ( $P<0.001$ ), emotional functioning ( $P=0.004$ ), social functioning ( $P=0.027$ ), physical functioning ( $P=0.002$ ) and role functioning ( $P=0.001$ ). Satisfaction was negatively associated with illness perception subscales on *consequences* ( $P=0.020$ ), *timeline* ( $P=0.031$ ), *personal control* ( $P=0.013$ ), *treatment control* ( $P<0.001$ ), *illness concern* ( $P<0.001$ ), *coherence* ( $P=0.001$ ) and *emotional representation* ( $P=0.004$ ). Hence, more satisfied patients reported fewer consequences of disease, illness concern and emotional representation, but higher personal and treatment control and coherence.

**Conclusions:** A third of all prostate cancer survivors reported to be dissatisfied with the information received and scored worse on HRQoL and illness perception. A prospective randomized study is needed to study the effect of an intervention that improves information provision on HRQoL and illness perception outcomes.

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## Background

After introduction of PSA testing, prostate cancer (PC) has become a disease with an increased number of long-term survivors related to stage shift and generally favourable outcomes [1,2]. Proper information provision after diagnosis helps patients understand their illness, prepares them for treatment, promotes recovery and assists them to cope with the disease [3,4]. Unfortunately, many prostate cancer patients have unmet information needs or are dissatisfied with information provision after being diagnosed with PC [5,6]. Worse, in some European countries around a third of prostate cancer patients do not receive information about their condition at diagnosis [5,6]. This is an unwanted situation, considering the fact that over 80% of the patients indicate that they want to

know all possible information, both good and bad news [4,7]. Previous studies have described the importance of information provision considering the association with illness perception and health-related quality of life (HRQoL) [3,8]. In Dutch patients diagnosed with lymphoma, multiple myeloma, endometrial or colorectal cancer it has been described that satisfaction with the information received is associated with better illness perception and higher overall HRQoL [3,9,10]. However, despite the growing number of PC survivors the association between information provision and illness perception and HRQoL in prostate cancer survivors is indistinct [11]. Hence, better insight in this relation is needed to investigate if improvement of satisfaction with information provision may possibly improve illness perception and HRQoL in the near future. This study aims to assess satisfaction with information received

and the relationship with illness perception and HRQoL in PC patients. We hypothesized that dissatisfied prostate cancer patients would indicate worse scores on illness perception and HRQoL scales.

## Methods

### Settings and participants

In 2011, a cross-sectional study was performed among 999 patients, diagnosed with prostate cancer between 2006 and 2009, as registered in the Eindhoven Cancer Registry (ECR) of the Comprehensive Cancer Centre the Netherlands (CCCN). The ECR is part of the nationwide Netherlands Cancer Registry and collects data of all new cancer patients in the southern part of the Netherlands. This geographic area covers 2.4 million inhabitants [12].

The ECR registry comprises 10 general public hospitals and 2 public radiotherapy departments. Patients in 10 hospitals were selected using the ECR. We made a random selection of approximately 150 patients for each hospital. Seven hospitals were willing to participate, leaving 1053 patients eligible for study participation. In 54 cases the address was unverifiable; as a result 999 participants were approached for participation. A total of 697 patients responded to the invitation and 302 patients did not respond (70% response rate). Similar PROFILES studies reported response rates between 69% and 86% [9,13].

### Data collection

All prostate cancer patients (tumour stage T1–T4) were eligible for participation.

Participation implied that a patient filled in a web-based or, on request, a paper-based questionnaire. Patients were asked for participation through their (ex-)urologist by a letter explaining the study and questionnaire. After obtaining informed consent the questionnaire form was returned to the CCCN. Patients also consented to link to their clinical disease history as registered in the ECR. When the questionnaire was not received after informed consent the patients were reminded within 2 months by sending a new information letter. Medical characteristics had been prospectively collected between 2006 and 2009 within the ECR. In 2011 data were collected within the PROFILES (Patient Reported Outcomes Following Initial treatment and Long Term Evaluation of Survivorship) registry. PROFILES is a registry for the study of the physical and psychosocial impact of cancer and its treatment from a dynamic, growing population-based cohort of both short- and long-term cancer survivors. It contains a large web-based component and is linked directly to clinical data from the ECR. Detailed information on the PROFILES registry has been described earlier [14]. The study was approved by the Medical Ethics Committee of the Maxima Medical Centre Eindhoven.

### Disease and patient characteristics

We collected socio-demographic data (i.e. marital status, employment status and level of education) using questionnaires. The ECR data was used to obtain clinical characteristics and further patient information, for example date of birth, treatment characteristics, date of diagnosis, Gleason score and Tumour-Node-Metastasis (TNM) stage at diagnosis [15]. To assess co-morbidity we used the Self-administered Co-morbidity Questionnaire (SCQ) whereby patients were asked to identify the presence of co-morbidities in the previous 12 months [16].

### Questionnaires

#### Information provision

For the evaluation of perceived level of and satisfaction with information provision the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-INFO-25) questionnaire was used. This is a 25-item questionnaire to evaluate the provided information received by cancer patients [17]. The response format is a 4-point Likert scale ('not at all'–'a little'–'quite a bit'–'very much'), except four items that have a dichotomous yes/no response. For the current analyses the 4-point Likert scale of the 'satisfaction with information provision' item was dichotomized in dissatisfied ('not at all'–'a little') and satisfied ('quite a bit'–'very much') to ease clinical interpretation. The questionnaire is divided in four subscales: information about the disease, medical tests, treatment, other services and eight additional single items (among others: satisfaction with the amount of received information and helpfulness of the information disclosed). All scales (except for satisfaction with information provision) were linearly converted to a 0–100 scale where higher scores implicate higher level of information received or higher information wishes [18]. Previous studies reported good internal consistency for all scales ( $\alpha > 0.7$ ) as for test–retest reliability (intraclass correlations  $> 0.70$ ) [18]. Internal consistency based on the current data was good ( $\alpha = 0.74–0.89$ ).

#### Health-related quality of life

We used the EORTC QLQ-Core 30 (EORTC QLQ-C30) and prostate module (EORTC QLQ-PR25) to assess HRQoL in prostate cancer survivors [19,20]. The EORTC QLQ-C30 questionnaire includes 30 items, divided in several scales: five functional scales (physical, role, emotional, social and cognitive functioning), three symptom scales (fatigue, pain and nausea/vomiting) and several single items considering global health and quality of life, financial impacts and symptoms. Side effects of cancer treatment, bowel- and urinary symptoms, sexual activity and sexual functioning were assessed using the 25-item EORTC QLQ-PR25. The answer format of both scales is

a 4-point Likert scale ('not at all'–'a little'–'quite a bit'–'very much'). In line with the prescribed scoring instructions of the EORTC all scales were linearly converted to a 0–100 scale. Higher scores are unfavourable for the symptom items whereas for the functional items higher scores indicate favourable outcomes. For urinary symptoms and sexual function scales internal consistency is good ( $\alpha=0.70$ – $0.86$ ) [21]. The use of these questionnaires to assess the HRQoL in prostate cancer patients is internationally validated and well accepted in Europe as well in the Netherlands [22–25]. Internal consistency based on the current data was good for EORTC QLQ-C30 ( $\alpha=0.65$ – $0.92$ ).

### Illness perception

Illness perception was evaluated using the Brief Illness Perception Questionnaire (B-IPQ), a nine item scale which assesses cognitive and emotional representations of the illness [26]. The questionnaire is divided in cognitive and emotional domains concerning *consequences* (How much does your illness affect your life?), *timeline* (How long do you think your illness will continue?), *personal control* (How much control do you feel you have over your illness?), *treatment control* (How much do you feel your treatment can help your illness?), *identity* (How much do you experience symptoms from your illness?), *concern* (How concerned are you about your illness?), *emotional representation* (How much does your illness affect you emotionally?) *coherence* (How well do you understand your illness?). The response format is a single item scale approach to assess perceptions on a linear 1–10 point scale [9]. A good test–re-test reliability and concurrent validity is described [26]. Higher scores indicate a more threatening view of patients' illness, except for *personal control*, *treatment control* and *coherence* where higher scores indicate a more positive view of their illness. Therefore these reversed answer scales on *personal control*, *treatment control* and *coherence* are converted. Based on the current data internal consistency was good ( $\alpha=0.71$ ).

### Statistical analyses

We conducted a one-way ANOVA to estimate differences in age between responders, non-responders and patients with unverifiable addresses. Chi-square test was used to examine group differences for discrete variables. Means on different subscales were compared between satisfied and dissatisfied patients using independent samples T-tests. The association between the dichotomized outcome satisfaction with information and HRQoL was assessed using a multiple linear regression analysis. We adjusted for age at the time of questionnaire, T-stage, partnership, co-morbidity, time since diagnosis and education. Covariates were determined a priori as has been done in

similar previous studies and as earlier has been described as a solid method [10,27].

For further analyses of the EORTC QLQ-PR25 we excluded *bowel function* and *side effects of hormonal treatment* subscales because of poor internal consistency in these subscales ( $\alpha<0.7$ ) [21]. Bivariate correlation analyses (Pearson's) were performed to investigate correlations between prostate cancer specific symptoms and global health. Clinically relevant differences were determined with 'Norman's rule of thumb'. This implicates that a difference of approximately half a standard deviation (SD) indicates a clinically relevant threshold of discrimination for changes [28].

All analyses were performed using SPSS version 19.0 (Statistical Package for Social Sciences, Chicago, IL, USA). A  $P$ -value  $<0.05$  was considered statistically significant.

## Results

### Patient and tumour characteristics

Six hundred and ninety seven patients completed and returned the questionnaire which resulted in a response rate of 70%. Patients with unverifiable addresses were younger compared with non-respondents (mean 73, 76, respectively,  $P<0.001$ ). There were no group differences in tumour stage ( $P=0.198$ ) between respondents, non-respondents and patients with unverifiable addresses. Baseline demographics and clinical characteristics are represented in Table 1.

### Perceived information provision

Of the PC patients, 34% ( $N=222$ ) indicated to be dissatisfied with information provision. Mean age did not significantly differ between patients satisfied with information provision and dissatisfied patients ( $P=0.107$ , Table 1). Over a quarter (27%,  $N=177$ ) of the patients indicated that they had wanted to receive more information about PC whereas 4% ( $N=25$ ) wanted to have received less information about their PC. The information actually received was found to be helpful by 72% ( $N=469$ ). Satisfaction with information provision was 66% for radical prostatectomy, 78% for brachytherapy, 63% for EBRTx, 66% for EBRTx+hormones, 66% for expectant management and 63% for hormonal treatment (Table 1). No significant differences in satisfaction between initial treatment options were found ( $P=0.243$ , Table 1).

Multivariate linear regression analyses, adjusted for covariates, showed a statistically significant positive association of the EORTC INFO-25 subscale 'information about disease' with global health (Beta 0.161,  $P<0.001$ ), and emotional functioning (Beta 0.087,  $P=0.034$ ).

**Table 1.** Baseline demographics and clinical characteristics of respondents  $N = 697^a$ 

<b>Demographic characteristics</b>				
	<b>Total</b>	<b>Dissatisfied patients</b>	<b>Satisfied patients</b>	<b>P-value</b>
Age at time of survey in years, mean (SD)	71.3 (7.2)	71.8 (7.3)	70.8 (7.1)	0.107
Years since diagnosis, mean (SD)	4.0 (1.2)	4.0 (1.1)	4.0 (1.2)	0.679
	<b>Total N (% column)</b>	<b>Dissatisfied patients N (% row)</b>	<b>Satisfied patients N (% row)</b>	<b>P-value</b>
<b>Demographic characteristics</b>				
Education*				
Low	105 (16)	42 (40)	63 (60)	
Medium	386 (59)	141 (37)	245 (63)	
High	161 (25)	36 (22)	125 (78)	0.002
Current occupation				
Employed	87 (14)	26 (30)	61 (70)	
Not employed	546 (86)	181 (33)	365 (67)	0.539
Partnership				
Partner	554 (85)	181 (33)	372 (67)	
No partner	100 (15)	39 (39)	61 (61)	0.218
<b>Clinical characteristics</b>				
	<b>Total N (% column)</b>	<b>Dissatisfied patients N (% row)</b>	<b>Satisfied patients N (% row)</b>	<b>P-value</b>
<b>Clinical stage</b>				
T1	306 (47)	94 (31)	212 (69)	
T2	226 (35)	81 (36)	145 (64)	
T3	107 (16)	40 (37)	67 (63)	
T4	13 (2)	2 (15)	11 (85)	0.222
<b>Gleason score</b>				
2–6	347 (54)	112 (32)	235 (68)	
7	193 (30)	67 (35)	125 (65)	
8–10	103 (16)	37 (36)	66 (64)	0.730
<b>Initial treatment**</b>				
Prostatectomy	174 (26)	60 (34)	114 (66)	
Brachytherapy	87 (13)	19 (22)	68 (78)	
EBRT***	52 (8)	19 (37)	33 (63)	
EBRT + hormones	106 (16)	36 (34)	70 (66)	
Managed expectantly	121 (18)	41 (34)	80 (66)	
Hormonal treatment	75 (11)	28 (37)	47 (63)	
Other combinations/treatments	44 (7)	19 (43)	25 (57)	0.243
<b>Co-morbidity (self report)</b>				
none	155 (24)	56 (36)	99 (64)	
1	208 (33)	50 (24)	158 (76)	
≥2	275 (43)	105 (38)	170 (62)	0.003

<sup>a</sup>Because of missing values number do not always add up to count 697.

\*Education: low (no or primary school), medium (lower general secondary education or vocational training) and high (pre-university education, high vocational training and university).

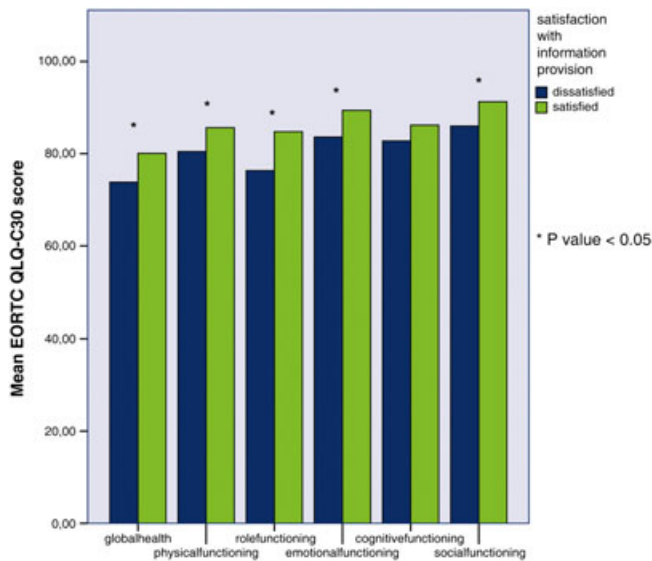
\*\*Treatment received in the first 6 months after diagnosis.

\*\*\*External beam radiotherapy.

### Health-related quality of life

In total 688 patients completed the EORTC QLQ-C30. Mean global health score for all prostate cancer survivors was 77.8 (SD 18.1). Dissatisfied patients scored significantly lower ( $P \leq 0.001$ ) compared with satisfied survivors on global health (mean 74 vs. 80), physical

functioning (mean 80 vs. 85), role functioning (mean 76 vs. 84), emotional functioning (mean 84 vs. 89) and social functioning scale (mean 86 vs. 91). Only for cognitive functioning (mean 83 vs. 85, respectively) this was not statistically significant ( $P = 0.163$ ), see Figure 1. Mean scores on symptom scales fatigue (23 vs. 19,  $P = 0.02$ )



**Figure 1.** HRQoL and satisfaction with information provision. Mean EORTC QLQ-C30 scores (range 0–100) on different HRQoL subscales in satisfied and dissatisfied patients (univariate)

and pain (19 vs. 14,  $P=0.029$ ) were statistically significantly higher for dissatisfied patients; nausea/vomiting (3 vs. 2,  $P=0.4$ ) was not different.

Multivariate linear regression analysis, including confounding variables, showed a statistically significant positive association between satisfaction with information provision and global health ( $P < 0.001$ ), emotional functioning ( $P=0.004$ ), social functioning ( $P=0.027$ ), physical functioning ( $P=0.002$ ) and role functioning ( $P=0.001$ ) (Table 2).

**Table 2.** Multivariate linear regression analysis evaluating the association of dissatisfaction/satisfaction with information provision with HRQoL functioning scales

	Global health N = 573 Beta	Cognitive functioning N = 569 Beta	Emotional functioning N = 564 Beta	Social functioning N = 571 Beta	Physical functioning N = 560 Beta	Role functioning N = 560 Beta
Satisfaction						
Satisfied vs. dissatisfied	.143**	.046	.116**	.092*	.123**	.14**
Partner						
Yes vs. no	.024	.062	.026	-.009	-.020	-.033
Co morbidity						
I vs. 0	-.060	-.077	-.016	.026	-.082	-.029
>I vs. 0	-.307**	-.280**	-.319**	-.202**	-.353**	-.303**
T-stage						
T2 vs. T1	-.036	-.011	.000	-.081	-.033	-.003
T3 vs. T1	-.056	-.032	-.110*	-.102*	-.079	-.032
T4 vs. T1	-.120*	-.065	-.041	-.114**	-.152**	-.109**
Education						
Medium vs. low	-.016	-.003	.017	.094	.020	-.041
High vs. low	-.007	-.025	.060	.116	.083	.020
Age at time of questionnaire	.005	-.024	.099*	.076	-.199**	-.035
Years since diagnosis	.025	-.044	-.063	-.086	-.041	-.037

\* $P < 0.05$ .  
\*\* $P < 0.01$ .

Prostate cancer specific quality of life

The EORTC QLQ-PR25 was completed by 639 patients (urinary function  $N=639$ , incontinence  $N=208$ , sexual activity  $N=641$  and sexual functioning  $N=312$ ). Higher scores indicate better functioning or increased symptoms. Dissatisfied patients had lower mean scores on sexual activity and sexual functioning (24 vs. 25,  $P=0.531$  and 50 vs. 56,  $P=0.028$ , respectively). Furthermore, dissatisfied patients reported statistically significantly higher mean scores on urinary symptoms and incontinence (23 vs. 17,  $P < 0.001$  and 24 vs. 12 (clinically relevant difference),  $P=0.004$ , respectively). We also found statistically significant correlations between global health scores and sexual activity ( $r=0.15$ ,  $P < 0.001$ ), sexual functioning ( $r=0.23$ ,  $P < 0.001$ ), urinary symptoms ( $r=-0.24$ ,  $P < 0.001$ ) and incontinence ( $r=-0.22$ ,  $P < 0.002$ ). Higher global health scores were reported in patients with higher sexual activity and sexual functioning. Negative correlations were found between global health and prostate cancer treatment symptoms indicating lower global health scores when urinary symptoms and incontinence increase. Data not shown.

Illness perception

In total 677 patients completed the B-IPQ questionnaire. Dissatisfied patients scored significantly higher on all illness perception subscales in comparison with satisfied patients: *consequences* (mean 4.4 vs. 3.4,  $P < 0.001$ ), *timeline* (mean 6.4 vs. 5.6,  $P=0.008$ ), *personal control* (6.2 vs. 5.4,  $P=0.005$ ), *treatment control* (mean 4.4 vs. 3.1,  $P < 0.001$ ), *identity* (3.9 vs. 3.5,  $P=0.039$ ), *illness concern* (4.6 vs. 3.4  $P=0.001$ ), *coherence* (4.4 vs. 3.3

$P < 0.001$ ) and *emotional representation* (mean 3.8 vs. 3.15  $P = 0.001$ , respectively). In multivariate regression analyses, satisfaction was negatively associated with subscales on consequences ( $P = 0.020$ ), timeline ( $P = 0.031$ ), personal control ( $P = 0.013$ ), treatment control ( $P < 0.001$ ), illness concern ( $P < 0.001$ ), coherence ( $P = 0.001$ ) and emotional representation ( $P = 0.004$ ), indicating better illness perception in satisfied patients (Table 3).

### Post-hoc analyses

The above mentioned results describe the relationship between prostate specific symptoms, global health and satisfaction with information provision. With regard to possible confounders we therefore performed additional analyses to eliminate the effect of prostate cancer specific symptoms on HRQoL and satisfaction with information provision. Multiple linear regression analyses including the previous described confounding variables with the additional covariates 'urinary symptoms' and 'incontinence' still showed a statistically significant positive association between satisfaction with information provision and global health (Beta 0.112,  $P = 0.008$  and 0.187, ( $P = 0.018$ )). For the additional covariate sexual functioning Beta was 0.061 ( $P = 0.315$ ) (data not shown).

### Discussion

The present study shows that more than a third of all prostate cancer patients is dissatisfied with the received information provision.

Patients who were dissatisfied with information provision reported clinically relevantly lower scores on all subscales

of provided information provision compared to satisfied patients. Similar results were earlier described in patients with lymphoma, multiple myeloma, endometrial cancer, colorectal cancer and thyroid cancer [9,29]. Furthermore, over a quarter of the respondents indicated they had wanted to receive more information. These are undesirable results taking into account that information provision plays an important role in understanding the illness, preparing for treatment and treatment choice and coping with the disease [3,4].

When comparing satisfaction with information provision between different treatment groups we found no statistically significant differences.

In our study we revealed that patients dissatisfied with information provision scored statistically significantly lower on HRQoL subscales global health, emotional functioning, social functioning, physical functioning and role functioning. Concerning the information provision subscales we found a significant association between the EORTC INFO-25 subscale 'information about disease' and global health indicating higher global health scores in patients who received a larger amount of information about disease. This is in line with our previously described results that patients dissatisfied with information provision scored significantly lower on the HRQoL subscale global health. Similar effect sizes between these scales are found in lymphoma patients; however the direction of these associations (positive/negative) was different which may be a result of a different malignancy, longer time since diagnosis and/or lower age in the lymphoma study [10]. Husson and colleagues investigated the relationship between satisfaction with information provision and illness perception among patients with lymphoma, multiple

**Table 3.** Multivariate linear regression analysis evaluating the association of satisfaction with information provision with illness perception (B-IPQ) subscales

	Consequences N = 571 Beta	Timeline N = 557 Beta	Personal control N = 555 Beta	Treatment control N = 558 Beta	Identity N = 565 Beta	Illness concern N = 572 Beta	Coherence N = 562 Beta	Emotional representation N = 568 Beta
Satisfaction								
Satisfied vs. dissatisfied	-.149**	-.093*	-.110*	-.207**	-.081	-.192**	-.150**	-.120**
Partner								
Yes vs. no	.061	.080	.047	.023	.041	.053	-.082	.058
Comorbidity								
1 vs. 0	.075	-.030	-.030	-.109*	.054	-.031	-.071	.008
>1 vs. 0	.209	-.072	-.010	-.057	.148**	.163**	-.014	.190**
T-stage								
T2 vs. T1	.117**	.081	.136**	-.025	.048	.064	.020	.057
T3 vs. T1	.261**	.127	.014	.007	.129**	.215**	-.032	.209**
T4 vs. T1	.131**	.086*	.029	.002	.072	.093*	.017	.048
Education								
Medium vs. low	-.111	-.001	-.004	-.010	.013	-.021	.052	-.077
High vs. low	-.035	.103	.067	.058	.022	-.023	-.015	-.112
Age at time of questionnaire	-.145**	.126**	.013	.044	-.100*	-.058	.077	-.182**
Years since diagnosis	-.016	-.041	.032	-.009	.060	-.052	-.006	-.007

\* $P < 0.05$ .

\*\* $P < 0.01$ .

Answer scales on 'personal control', 'treatment control' and 'coherence' are converted because of reversed answer scales.

myeloma, endometrial and colorectal cancer. They found significant associations between satisfaction and better illness perception in all subscales, except for personal control [9]. In our current analyses we found statistically significant correlations between all subscales except for identity. Apparently the effect of satisfaction with received information provision is, just like in other malignancies, highly associated with illness perception in prostate cancer patients.

The negative impact of prostate cancer and treatment-related symptoms as urinary symptoms, bowel symptoms and sexual dysfunction on HRQoL is well described [23,30,31]. In our study, we found a significant but weak correlation between global health and sexual activity, sexual functioning, urinary symptoms and incontinence ( $r = -0.22$ ,  $P < 0.002$ ), confirming the earlier described findings.

Also in accordance with our hypothesis we showed that patients dissatisfied with information provision scored significantly lower on sexual activity and sexual functioning and higher on urinary symptoms and incontinence compared to satisfied patients. However, this study does not provide information on the direction or origin of these associations. We hypothesize that more symptoms will lead to dissatisfaction in retrospect and lower HRQoL scores (and vice versa). Therefore we performed post-hoc analyses to adjust for the association between prostate cancer specific symptoms and HRQoL. Addition of the covariate 'sexual functioning' eliminated the statistical significance of this association. However, after addition of the covariates 'urinary symptoms' and 'incontinence', a positive significant association between satisfaction with information provision and global health remained.

These results may imply that there is a possible relationship of the perceived information provision on HRQoL so that improving information provision may lead to higher HRQoL scores, regardless accompanying symptoms. The observed association between perceived information provision and HRQoL suggests that improving information provision may lead to higher HRQoL scores. However, as our findings are based on a cross-sectional data collection with retrospective questions, strong conclusions

about causal associations between information provision, HRQoL and illness perception cannot be drawn.

Another limitation is that patients with unverifiable addresses were younger compared with non-respondents which could lead to selection bias in our study population. Furthermore, the mean time since diagnosis was 4 years which could influence results because of disturbed recall. It is for example possible that non-respondents are more negative, depressed or have overall lower HRQoL compared to respondents. As well for dissatisfied patients compared to the satisfied patients. On the other hand, the satisfied patients can be more optimistic, or have a better overall HRQoL compared to dissatisfied patients. Or patients with higher HRQoL scores indicate better received information provision when asked retrospectively and vice versa. These HRQoL issues will be addressed in a prospective RCT (The Dutch National Trial Register NTR4554), where satisfaction with information provision and HRQoL is measured directly after actual information provision (but before treatment) and 6 and 12 months after treatment. We will also investigate whether or not the use of a decision aid will improve satisfaction with information provision. This can then answer the question if higher satisfaction with information provision will improve HRQoL. Strengths of our population-based study are the high response rate of 70%, large sample size and the use of widely validated questionnaires.

In conclusion, after they had been treated, one in three of all prostate cancer survivors reported to be dissatisfied with the information received from the moment of diagnosis and these men scored worse on HRQoL outcomes and illness perceptions. A prospective randomized study is needed to study the effect of an intervention that improves information provision at diagnosis on HRQoL outcomes.

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