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ORIGINAL ARTICLE

Long-term satisfaction with curative treatment and follow-up in prostate cancer survivors

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ABSTRACT

Purpose: In a cross-sectional observational study to explore long-term satisfaction with treatment among men who had undergone radical prostatectomy (RP) or definitive pelvic radiotherapy (RT) for prostate cancer (PCa).

Methods: After mean 7 years from therapy (range: 6–8), 431 PCa-survivors (RP: $n = 313$, RT: $n = 118$) completed a mailed questionnaire assessing persistent treatment-related adverse effects (AEs) (Expanded Prostate cancer Index Composite [EPIC-26]) and seven Quality indicators describing satisfaction with the health care service following a most often general practitioner (GP)-led follow-up plan. A logistic regression model evaluated the associations between long-term satisfaction and treatment modality, age, the seven satisfaction-related Quality indicators, and persistent AEs. The significance level was set at $p < .05$.

Results: Four of five (81%) PCa-survivors reported long-term satisfaction with their treatment. In a multivariable model, satisfaction was positively associated with sufficient information about treatment and AEs, patient-perceived sufficient cooperation between the hospital and the GP and sufficient follow-up of AEs (ref.: insufficient). Age ≥70 years (ref.: <70) and a rising summary score within the EPIC-26 sexual domain additionally increased long-term satisfaction. The treatment modality itself (RP *versus* RT) did not significantly impact on satisfaction.

Conclusions: The majority of curatively treated PCa-survivors are satisfied with their treatment more than 5 years after primary therapy. Sufficient information, improved cooperation between the hospital specialists and the responsible GP and optimized follow-up of AEs may further increase long-term satisfaction among prostatectomized and irradiated PCa-survivors.

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Introduction

Radical prostatectomy (RP) and definitive pelvic radiotherapy (RT) represent curative treatment modalities for prostate cancer (PCa) with similar oncological outcomes, but the types and levels of treatment-related adverse effects (AEs) may vary [1].

With an 8-year post-treatment overall survival rate of at least 75%, persisting AEs can affect the PCa-survivor's life for many years [2,3]. Thus many PCa-survivors will repeatedly have contact with health care professionals not only for disease control, but also for handling of bothersome AEs.

Many authors have documented AEs following RP or RT [4]. In the review of Ávila *et al.*, post-RP incontinence and post-RT bowel problems are documented as the most frequent AEs followed by sexual dysfunction after both treatment modalities.

In Scandinavia, follow-up of PCa-survivors is recommended as *shared care* between the hospital specialists and the general practitioner (GP) [5–7]. The GP is assumed to contact the *specialist* (urologist/oncologist) in case of suspicious signs of PCa-relapse or treatment-requiring AEs. However, only few studies have focused on satisfaction among PCa-survivors during long-term follow-up [8–11]. These studies have emphasized the impact of AEs, patient participation, and information as key factors associated with satisfaction. No studies are available concerning the Norwegian PCa-survivors, and none of the mentioned studies have focused on the GP's role, in spite of the increasing interest in a long-term GP-led follow-up plan in PCa-survivors.

With this background, this study deals with two questions: (1) What is the proportion of Norwegian men who more than 5 years after RP or RT are satisfied with their treatment in a GP-led follow-up strategy? (2) Which factors are associated with long-term satisfaction in these men?

Methods

Eligible patients were identified among PCa-survivors included in the Norwegian Urological Cancer Group (NUCG)-VII study, which from 2008 to 2010 included patients in whom RP or RT was planned. By three follow-up waves, this

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longitudinal questionnaire-based multicenter study aimed to document post-treatment AEs. At inclusion 914 men, planned for RP or RT, completed a pretreatment questionnaire. Of those, 902 finally underwent RP or RT. These men were again asked to complete a similar questionnaire 3 months, 1 year, and 3 years after their treatment. Selected findings related to the NUCG -VII study have been published elsewhere [12,13].

For the purpose of this study, patients who had responded to the 3-year questionnaire were in 2016 again asked to complete a *long-term questionnaire*. Finally, evaluable PCa-survivors fulfilled the two following criteria:

1) RP without post-RP radiotherapy or RT without salvage prostatectomy

AND

2) Completion of the long-term questionnaire with valid EPIC-26 domain summary scores.

The long-term questionnaire contained PCa-related questions (the Expanded Prostate cancer Index Composite [EPIC-26]) [14], sociodemographics and medical variables. Following published scoring instructions [15], EPIC-26 single items and DSSs were converted to the range between 0 (worst) and 100 (best). Each domain summary score (DSS) thus consisted of four 25-point categories (0 to <25, 25 to <50, 50 to <75, and 75–100), indicating gradual decrease of the assessed AE [9].

The long-term questionnaire also contained eight satisfaction-related questions, extracted from the Cancer Patient Experiences Questionnaire (CPEQ) [16,17]. This instrument assesses the patients' perspective on their cancer care and has acceptable psychometric properties. For the purpose of this study, we verbally modified selected questions, addressing PCa patients. The PCa patients rated their experiences related to the specified questions by a score varying from 1 (worst) to 5 (best) (Supplementary Table 1). The outcome variable was the question: '*Overall, how satisfied are you with your prostate cancer treatment*'? The responses to this question were dichotomized as '*satisfied*' or '*dissatisfied*'. Answers to the remaining seven satisfaction-related questions, *Quality indicators*, represented the independent variables, dichotomized as '*sufficient*' or '*insufficient*'. Emerging mean values across PCa-survivors significantly differed between satisfied and dissatisfied men (Supplementary Table 2). After combining the seven Quality indicators in each patient, the resulting scale showed good internal consistency (Cronbach's alpha = 0.79).

The respondents also reported if a specialist or their GP had been mainly responsible for the PCa follow-up during the past 2 years. They also reported *major comorbidity* present by at least one of the following conditions: coronary artery disease, cardiac failure, chronic lung disease, diabetes mellitus, stroke, and/or other cancer the past 5 years. Responses to how they evaluated their general health were dichotomized as '*poor*' or '*good/fair*', partner status as '*single*' or '*paired*' and level of education as '*low*' (high school or less) or '*high*' (university/college). The respondents also reported their most recent Prostate-Specific Antigen (PSA) level, and use of hormones.

The final research file also contained information provided by the Cancer Registry of Norway as type of treatment and tumor risk group in according to EAU guidelines [1].

'*PCa relapse*' was defined as an elevated level of PSA (RP: ≥0.2 ng/ml, RAD: ≥2.0 ng/ml), current use of hormone therapy and/or irradiation to distant metastases.

Statistics

Standard descriptive statistics were presented by means and standard deviations (SDs) for continuous variables and by absolute numbers and proportions for categorical variables. The Independent t-tests and chi-square tests analyzed intergroup differences. Clinically relevant differences on continuous variables were described by *Cohen's d* coefficient as small (0.2), medium (0.5) or large (0.8) [18]. A multivariable logistic regression model assessed associations between long-term satisfaction and selected covariates: Treatment modality, age, AEs, and the Quality indicators. The final model is graphically illustrated as a figure (Figure 1).

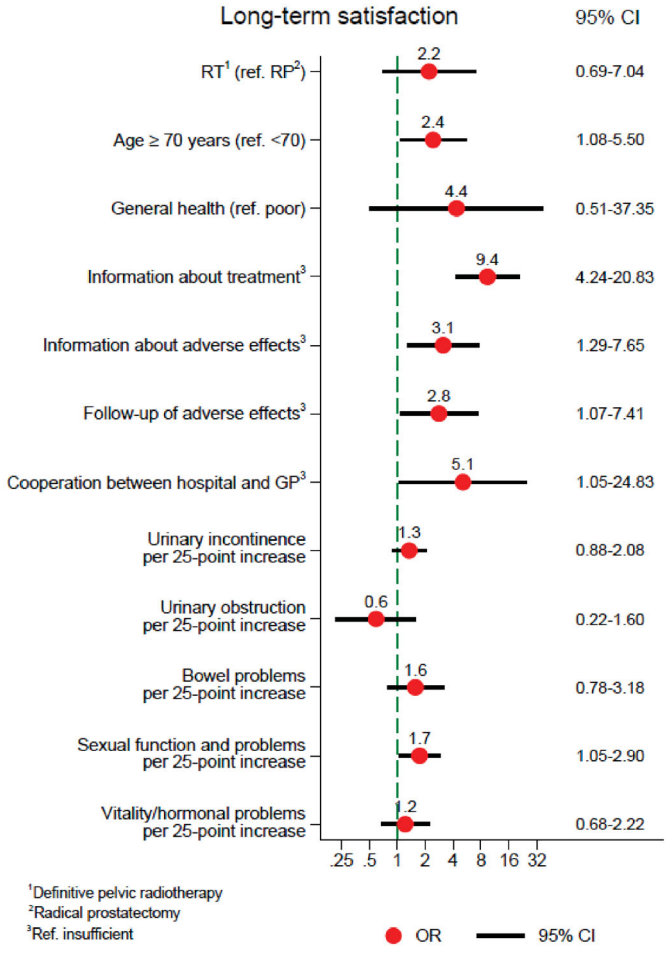

Figure 1. OR and confidence interval (95% CI) of the covariates in the final logistic regression model.

To arrive at the final simplified model, we first estimated a larger model with all independent variables deemed to be of potential statistical relevance. Insignificant covariates with the smallest effects or odds ratios (ORs) close to one were successively removed, comparing values of the Bayesian information criterion (BIC) before and after the removal of a covariate. If the BIC was lower after removal of a covariate the covariate was dropped from the regression model.

All analyzes were performed by SPSS for PC version 25 (SPSS Inc., Chicago, IL, USA) and STATA version 16.1 (StataCorp, College Station, TX, USA). All tests were two-sided, and the significance level was set at $p < 0.05$.

Checklist -STROBE

We used the STROBE cross-sectional checklist when writing our report [19].

Ethics

This study was approved by the Regional Ethical Committee of the South-Eastern Health Region in Norway (no. 2015/429). All patients gave written informed consent to participate.

Results

Of the 914 patients initially included in the NUCG-VII study, 715 PCa-survivors were in 2016 invited to participate in the long-term survey (Supplementary Figure 1). Finally, 431 respondents were evaluable (RP: $n = 313$; RT: $n = 118$) for this study. Low education and high-risk tumors were more frequently reported among non-evaluable patients (data not shown). There was no difference according to age between evaluable and non-evaluable men.

The mean time between RP or RT and completion of the long-term questionnaire was 7 years (Table 1). Compared to prostatectomized men, irradiated men were 4 years older and more often reported major comorbidity. The lowest EPIC-26 DSS was observed within the sexual domain, similar for both treatment modalities. A significant difference emerged for bowel function, favored prostatectomized men. Significantly more urinary incontinence appeared in the RP compared to the RT group. The majority in both groups (RP: 91%, RT: 62%) reported that their GP had mainly been responsible for PCa follow-up the past 2 years.

Satisfaction

Of the 431 evaluable PCa-survivors, 347 (81%) reported long-term satisfaction with their treatment (Table 2). Respondents aged 70 years or older expressed satisfaction more often than the younger ones. Major comorbidity and general health, but not the experience of PCa relapse, were significantly associated with satisfaction.

Irrespective of treatment, satisfied men had higher DSSs in all five EPIC-26 domains compared to dissatisfied men (Table 3). Cohen's coefficients indicated that these differences were relevant, most often of medium size. The largest coefficient (0.73) was observed within the sexual domain. The EPIC-26 single item scores principally confirmed the findings of the domains.

Table 4 shows frequencies and proportions of satisfied and dissatisfied PCa-survivors related to the seven Quality indicators. Overall, 273 men (65%) described sufficient

Table 1. Patient characteristics according to TREATMENT.

	RP[a] $n = 313$	RT[b] $n = 118$	p
Time since treatment (years), mean (±SD)	7.1 (±0.3)	6.7 (±0.4)	**<.01**
Age (years), mean (±SD)	70 (±5.3)	74 (±5.7)	**<.01**
<70, *n* (%)	138 (44%)	32 (27%)	**<.01**
≥70, *n* (%)	175 (56%)	86 (73%)	
Level of education, *n* (%)			
Low (high school or less)	144 (46%)	55 (47%)	.90
High (university/college)	167 (54%)	62 (53%)	
Mainly responsible of follow-up the past 2 years, *n* (%)			
GP	267 (91%)	69 (62%)	**<.01**
Specialist (urologist/oncologist)	27 (9%)	43 (38%)	
Major comorbidity[c], *n* (%)			
Yes	109 (35%)	63 (53%)	**<.01**
No	204 (65%)	55 (47%)	
General health, *n* (%)			
Poor	10 (3%)	5 (4%)	.74
Good/fair	302 (97%)	113 (96%)	
Prostate cancer relapse[c], n (%)			
Yes	37 (12%)	16 (14%)	.62
No	276 (88%)	102 (86%)	
EPIC-26 domain summary scores[c], mean (±SD)			
Urinary incontinence	74 (27.4)	86 (21.8)	**<.01**
Urinary irritative/obstructive	91 (11.9)	82 (16.9)	**<.01**
Bowel	92 (14.2)	86 (15.8)	**<.01**
Sexual	29 (26.6)	26 (21.4)	.14
Vitality/hormonal	89 (15.6)	83 (17.7)	**<.01**

[a]Radical prostatectomy.
[b]Definitive pelvic radiotherapy.
[c]Cfr. methods.
(*N* does not always add up to $N = 413$ due to missing data. Significant level: $p < .05$ (bold).).

Table 2. Patient characteristics according to SATISFACTION.

Covariates	All $N = 431$	**Satisfied**[a] $n = 347$ (81%)	**Dissatisfied**[a] $n = 84$ (19%)	p
Treatment, *n* (%)				
Radical prostatectomy	313	245 (78%)	68 (22%)	.06
Definitive pelvic radiotherapy	118	102 (86%)	16 (14%)	
Age (years), mean (±SD)		72 (±5.8)	71 (±5.1)	.31
<70, *n* (%)	170	132 (78%)	38 (22%)	.23
≥70, n (%)	261	215 (82%)	46 (18%)	
Level of education, *n* (%)				
Low (high school or less)	199	161 (81%)	38 (19%)	.80
High (university/college)	229	183 (80%)	46 (20%)	
Prostate cancer relapse[1], *n* (%)				
Yes	53	38 (72%)	15 (28%)	.08
No	378	309 (82%)	69 (18%)	
Major comorbidity[1], *n* (%)				
Yes	172	130 (76%)	42 (24%)	**.04**
No	259	217 (84%)	42 (16%)	
General health, *n* (%)				
Poor	15	8 (53%)	7 (47%)	**<.01**
Good/fair	415	339 (82%)	76 (18%)	
Responsible of follow-up the past 2 years, *n* (%)				
Regular general practitioner	336	275 (82%)	61 (18%)	.94
Specialist (urologist/oncologist)	70	57 (81%)	13 (19%)	

[a]Cfr. methods.
(*N* does not always add up to $N = 431$ due to missing data. Significant level: $p < .05$ (bold).).

Table 3. Means (±SD) of the EPIC-26 domain summary scores and their single-item scores in patients satisfied or dissatisfied with TREATMENT.

EPIC-26	All mean (±SD)	**S**atisfied[a] mean (±SD)	**D**issatisfied[a] mean (±SD)	p	Cohen's D
Urinary incontinence	**77 (±26.5)**	**80 (±24.7)**	**67 (±31.4)**	**<.01**	**0.46**
Leakage ≥ once a day		75 (±38.2)	60 (±46.7)	**<.01**	0.35
Control		78 (±21.5)	67 (±26.8)	**<.01**	0.45
Pad use		88 (±24.2)	77 (±33.5)	**<.01**	0.38
Dripping		78 (±27.3)	68 (±32.6)	**.01**	0.33
Urinary irritative/obstructive	**89 (±13.9)**	**89 (±13.8)**	**86 (±14.3)**	.06	**0.21**
Pain		98 (±9.4)	98 (±8.0)	.85	0.00
Blood in urine		99 (±7.2)	98 (±10.3)	.46	0.11
Weak stream		83 (±26.1)	77 (±28.2)	.09	0.22
Frequently urinate during the day		77 (±29.6)	70 (±31.1)	.06	0.23
Urinary function overall		81 (±25.3)	73 (±30.4)	**.02**	0.29
Bowel	**91 (±14.9)**	**92 (±13.9)**	**86 (±18.0)**	**.01**	**0.37**
Urgency		87 (±22.6)	82 (±28.5)	.11	0.19
Increased frequency		90 (±21.1)	83 (±25.5)	**.03**	0.30
Losing control		95 (±16.5)	93 (±16.5)	.39	0.12
Bloody stools		97 (±11.8)	96 (±14.8)	.35	0.07
Regional pain		93 (±16.4)	85 (±26.3)	**<.01**	0.37
Bowel habits overall		87 (±22.3)	80 (±29.4)	**.03**	0.27
Sexual	**28 (±25.3)**	**31 (±26.0)**	**15 (±16.8)**	**<.01**	**0.73**
Ability to have an erection		22 (±26.9)	9 (±15.5)	**<.01**	0.59
Ability to reach orgasm		33 (±29.2)	23 (±28.9)	**<.01**	0.34
Usual quality of erections		38 (±37.8)	21 (±29.4)	**<.01**	0.50
Frequency of erections		27 (±36.7)	8 (±21.1)	**<.01**	0.63
Ability to function sexually		21 (±26.8)	9 (±16.4)	**<.01**	0.54
Sexual function overall		47 (±34.1)	23 (±27.8)	**<.01**	0.77
Vitality/hormonal	**87 (±16.4)**	**89 (±14.6)**	**80 (±21.2)**	**<.01**	**0.49**
Hot flashes		93 (±18.7)	85 (±30.9)	**.04**	0.31
Breast tenderness/enlargement		98 (±10.1)	94 (±17.5)	.07	0.28
Feeling depressed		89 (±21.5)	82 (±28.1)	**.03**	0.28
Lack of energy		77 (±29.8)	65 (±34.7)	**<.01**	0.37
Change in body weight		89 (±22.4)	76 (±33.5)	**<.01**	0.46

[a]Cfr. methods.
(Significant level: $p < .05$ (bold).).

follow-up in general and 251 of them were satisfied with their treatment. Among the satisfied men, 288 (84%) reported sufficient information about their treatment and 264 (77%) sufficient information about treatment options. Only 140 participants (33%) described perceived cooperation between the hospital and the responsible GP as sufficient. The majority of dissatisfied men reported insufficiency to all of the seven Quality indicators.

In the multivariable logistic regression model, the highest significant odds became evident for the Quality indicators '*Information about treatment*' (OR 9.4) and '*Cooperation between hospital and GP*' (OR 5.1) (Figure 1). Age 70 years or older as well as sufficient information about and follow-up of AEs (ref.: insufficient) also remained significantly associated with satisfaction, together with a higher EPIC-26 score within the sexual domain. The treatment modality itself had no significant impact.

Table 4. Long-term satisfaction or dissatisfaction.

Quality indicators	Satisfied[a] *n* (%)	Dissatisfied[a] *n* (%)
Follow-up in general		
Insufficient	92 (27%)	58 (73%)
Sufficient	251 (73%)	22 (27%)
Information about treatment		
Insufficient	54 (16%)	56 (70%)
Sufficient	288 (84%)	24 (30%)
Information about treatment options		
Insufficient	81 (23%)	51 (61%)
Sufficient	264 (77%)	33 (39%)
Information about possible adverse effects		
Insufficient	142 (41%)	57 (67%)
Sufficient	204 (59%)	27 (32%)
Participation in treatment decisions		
Insufficient	120 (35%)	51 (61%)
Sufficient	225 (65%)	32 (39%)
Follow-up of adverse effects		
Insufficient	173 (51%)	70 (84%)
Sufficient	168 (49%)	13 (16%)
Cooperation between hospital and GP		
Insufficient	202 (60%)	76 (94%)
Sufficient	135 (40%)	5 (6%)

[a]Cfr. methods.
All differences were statistically significant, $p < .01$.
(*N* does not always add up to $N = 431$ due to missing data.).

Discussion

At mean 7 years from RP or RT, four of five (81%) PCa-survivors expressed satisfaction with their treatment, though only two-thirds reported sufficient follow-up in general. In the multivariable regression model, '*information about treatment*' remained the strongest factor associated with long-term satisfaction accompanied by the patient's perception of sufficient '*Cooperation between hospital and GP*'. Age 70 years or older, as well as information about and follow-up of AEs, also contributed significantly to long-term satisfaction. The treatment modality itself (RP or RT) was not associated with satisfaction.

In line with previous studies, the great majority of PCa-survivors reported long-term satisfaction [8–11]. Most of our respondents had during the past 2 years mainly been followed up by their GP as recommended in the Norwegian national guidelines [5]. With this background, our finding of a strong association between long-term satisfaction and patient-perceived cooperation between the hospital and their GP is of importance, as well as the finding that only one-third of the men described this aspect of shared care as sufficient. Importantly, we lacked any objective data on existing interactions between the GPs and the specialist health care system. Nevertheless, the low percentage of patient-perceived sufficient cooperation leaves room for improvement. The addition of a 'GP-dedicated'chapter in the current Norwegian national guidelines for PCa-management, is certainly a step in the right direction. Another possibility to improve this aspect is an individualized follow-up care plan provided to each patient at start of the follow-up period, accompanied by a copy to the GP. This will ensure a better, more uniform, and holistic communication between the actors: the patient, the GP and the specialist [20–22]. Development of appropriate information technology which facilitates easy and 'fast links' between the different health care professionals, is a challenge and an opportunity, and should be prioritized [20].

The importance of an individualized high-quality information, e.g., to facilitate an active patient participation in therapeutic decisions, has repeatedly been emphasized in the literature [8–10, 21,23]. Our study confirms that sufficient information through the entire PCa-pathway is essential. Use of decision aids, per internet or as flyers, in addition to consultations, may increase the patients' experience of high-quality information [24–27]. Further, use of specialized nurses may reduce the doctor's time spent with information provided to the patient [9,20,21,28]. According to Bergengren *et al*., access to a '*Nurse navigator*' was significantly associated with long-term overall satisfaction [9]. In Norway, such specialized nurse practitioners are available only in hospitals, and as far as we know, not in the primary health care service.

In the univariate analyses, the levels of EPIC-26 DSSs reflected published rates of AEs after RP or RT [4]. Most of our between-treatment differences (Cohen's coefficients) were moderate, possibly explaining why the treatment modality itself, in the multivariable analysis, did not impact significantly on long-term satisfaction. Published findings are inconsistent, but the review of Christie et al. documents that the levels of regret are generally higher after RP compared to RT [29]. In contrast to Bergengren et al.'s observations, persistent bowel and urinary AEs were in our study not associated with long-term satisfaction [9]. Different case mix may be an explanation: Bergengren et al. included patients with the strategy '*Active surveillance*' in their cohort in addition to prostatectomized and irradiated men. In line with Bergengren et al., an increasing DSS within the sexual domain was in our cohort positively associated with long-term satisfaction, pointing to the importance of sexuality also in elderly men.

Limitations and strengths

The fact that only one of every fourth evaluable patients had undergone RT is a limitation. Furthermore, the eight satisfaction-related questions have not been psychometrically tested only among PCa-survivors specifically. Our findings may only be relevant in health care systems with a similar follow-up strategy after RP or RT as in Scandinavia. Finally, our dichotomizations are debatable on the background of the 'uncertain' category and the resulting loss of information.

On the other hand, the major strength of this study is the nation-wide cohort focusing on long-term satisfaction in a GP-led shared care follow-up strategy. The use of EPIC-26, a validated questionnaire to assess treatment-related AEs after RP or RT, represents an additional strength.

Conclusion

At mean 7 years from RP or RT, the majority (81%) of curatively treated PCa-survivors, mainly followed up by their GP, reported satisfaction with their treatment. Sufficient information and improved cooperation between the hospital specialists and the responsible GP may, in addition to an optimized follow-up of AEs, further increase long-term satisfaction among prostatectomized or primary irradiated PCa-survivors.

Geolocation information

This is a nationwide study based on data delivered from patients treated at different hospitals throughout Norway.

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Disclosure statement

The authors report no conflict of interest.

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