Title	Shared Decision-Making in Prostate Cancer Care: Encouraging every patient to be actively involved in decision-making, or ensuring patients' preferred level of involvement?
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Key words	Prostatic Neoplasms; Decision Making; Patient Participation; Patient Reported Outcome Measures; Quality Of Life

ABSTRACT

PURPOSE

The aims of this study were: (1) to describe preferred and experienced roles in treatment decision-making among patients with localized prostate cancer (PC); (2) to identify how often patients' experienced roles matched their preferred roles; and (3) to determine whether active involvement in decision-making regardless of role preferences, or concordance between preferred and experienced role is the strongest predictor of more favourable patient-reported outcomes.

MATERIAL AND METHODS

In this prospective, multicenter, observational study we obtained serial questionnaire data from newly-diagnosed localized PC patients (cT1-cT2 or Gleason≤7, PSA≤20) (N=454). Questionnaires were completed prior to treatment, and at three, six, and twelve months post-treatment follow-up. Clinical data were obtained from patients' medical records. Active involvement and role concordance were operationalized using the Control Preferences Scale. Analysis of variance and effect sizes (Cohen's d; 0.2=small, 0.5=medium) were used to compare patients' knowledge of prostate cancer, decisional conflict, decision regret, and overall health-related quality of life (HRQoL).

RESULTS

Most patients (87%, n=393) reported having been actively involved in treatment decision-making. However, 17% (n=78) indicated having had either less or more involvement than preferred. Active involvement was significantly associated with more PC knowledge (*d*=0.30), less decisional conflict (*d*=0.52), and less decision regret (*d*=0.34). Role concordance was also, but less strongly, associated with less decisional conflict (*d*=0.41).

CONCLUSIONS

Our findings support a policy of encouraging all localized PC patients, regardless of their stated role preferences, to be actively involved in the decision about their treatment.

INTRODUCTION

Prostate cancer (PC) guidelines recommend shared decision-making (SDM) for patients with localized PC.[1–4] SDM is a process whereby the patient and the health care professional participate actively in selecting the treatment option that best fits the individual's needs and preferences.[5] Active involvement of patients in decision-making has been found to be associated positively with a number of relevant patient-reported outcomes, including perceived quality of care, decisional satisfaction, and health-related quality of life (HRQoL).[6–9]

However, patients vary in the extent to which they wish to be actively involved in treatment decision-making. Although a majority of cancer patients (61-86%) have a preference for active involvement, a minority (14-39%) prefers to defer the decision to the professional.[10–12] Several studies suggest that patients who prefer either more or less involvement in decision-making than they actually experience have worse decision- and health-related outcomes than those for whom their preferred and experienced role match (e.g., higher decision regret and psychological distress, and lower HRQoL).[11,13,14]

This creates a dilemma for health professionals in assisting patients in treatment decision-making.[15] Should they encourage all patients to be actively involved in decision-making, regardless of their role preferences?[7] Or should they make efforts to ensure that the role that patients play in decision-making reflects their preferred level of involvement?[11] To the best of our knowledge, only two studies have addressed this question in patients with a range of cancer diagnoses.[16,17] They both found that active involvement, regardless of preferred role, is a stronger predictor of positive health care experiences (e.g., perceived quality of care, patient anxiety, and satisfaction with care) than a match between patients' preferred and experienced role. However, these studies did not report on how patients looked back on the decision-making process some time

after the treatment had been received. And they did not include other relevant, long-term patient-reported outcomes such as decision regret and HRQoL.[7,15–18] It is also unclear as to whether the results of the previous studies can be generalized to patients with localized PC.

The aims of our study were: (1) to describe preferred and experienced roles in treatment decision-making among patients with localized prostate cancer (PC); (2) to identify how often patients' experienced roles matched their preferred roles; and (3) to evaluate which strategy results in the most favourable patient-reported outcomes, encouraging every patient to be actively involved in decision-making, or ensuring that the patients' experienced role is congruent with their preferred role?

METHOD

Study design and participants

Between 2014 and 2016, we recruited newly-diagnosed patients with clinically localized PC (cT1-cT2 or Gleason≤7, PSA≤20 ng/ml) from 13 Dutch clinical facilities (one academic centre, one dedicated cancer centre, and 11 community hospitals). Patients were recruited by the local urologist or clinical nurse specialist after information was provided about the treatment option(s), including active surveillance (AS), radical prostatectomy (RP), external beam radiotherapy (EBRT), and brachytherapy (BT).

Patients completed questionnaires at baseline (pre-treatment, preferably before treatment decision-making), and 3, 6 and 12 months after treatment or after the start of active surveillance. For external beam radiotherapy, the last day of treatment was set as the anchor date. Clinical data were obtained from the patients' medical records. The study was approved by the Medical Ethical Review Committee of the University Medical Centre Utrecht (reference number WAG/om/14/017805).

Outcome variables

Table 1 presents the patient-reported outcomes assessed in this study that are relevant to treatment decision-making, including their threshold values for clinical relevance.[7,18,19] These included Prostate Cancer Knowledge (3 months post treatment; Decision Quality Instrument for treating prostate cancer)[20]; Decisional Conflict (3 months post treatment; Decisional Conflict Scale; Table S3)[21]; Decision Regret (12 months post treatment; Decision Regret Scale; Table S4)[22]; and overall HRQoL (12 months post treatment; the European Organisation for Research and Treatment of Cancer QLQ-C30 questionnaire; Table S4).[23]

Independent variables

Decisional Roles

We assessed patients' *preferred* (before treatment) and *experienced* (three months post treatment) level of involvement in making the final treatment decision using the five-item Control Preferences Scale (CPS; Table S1).[24] The response categories of this scale include: 1. By the patient alone; 2. By the patient with physician input; 3. By the patient and physician together; 4. By the physician with patient input; or 5. By the physician alone. Response categories 1 to 3 were combined to indicate *a preference for* or *having experienced* 'active involvement in decision-making'. Response categories 4 or 5 were combined to reflect a *preference for* or *having experienced* 'passive decision-making' (i.e., physician-driven).[25]

Role Concordance

We compared patients' *preferred* and *experienced* role, and categorized these as: 1. "Patient preferred **less** involvement than experienced"; 2. "A **match** between preferred and experienced role"; or 3. "Patient preferred **more** involvement than experienced" (Table 3).[11] For example, if a patient reported at baseline that he preferred active involvement in decision-making, but reported after treatment that he had experienced passive involvement, he was categorized as 'preferring more involvement than experienced'.

Patient Clinical and Sociodemographic Characteristics

We obtained information about patients' cT-status, Gleason-score, and prostate specific antigen (PSA) levels from their medical records. Other clinical, socio- demographic, and psychosocial characteristics were assessed in the baseline or follow-up questionnaires (Table 2).

Statistical Analysis

We used Analysis of Variance (ANOVA) to evaluate the association between both *Experienced Role* and *Role Concordance,* and the study outcomes (Figure 1).[26] If, for any given outcome, both *experienced role* and *role concordance* were associated significantly with one or more outcomes, we included both factors in a two-way ANOVA to determine the strongest predictor of that outcome.[26]

We used SPSS version 20 to verify statistical test assumptions and to perform all analyses. We considered $p \leq 0.05$ as indicative of statistical significance. Where appropriate, we report 95% confidence intervals (95%CI), and effect sizes (Cohen's *d*: 0.2=small difference, 0.5=medium difference, and 0.8=large difference).[27]

To test the robustness of the results and to place our findings in a wider context, we performed several sensitivity analyses (details are included in Table S5). We

assessed: 1. The representativeness of the sample; 2. Differences between patients included and not included in the analyses; 3. The influence of missing values; 4. Verification of statistical test assumptions; 5. Differences between patients who completed the baseline questionnaire prior to and post treatment decision-making; 6. Changes in decision regret and HRQOL over time; and 7. Other factors associated with the outcomes.[26]

RESULTS

Of the 546 men invited to participate in the study, 474 (87%) agreed and completed the baseline questionnaire. The follow-up response rates were: 96% (3 months), 94% (6 months), and 92% (12 months). Among enrolled men, 20 did not reported both their preferred and experienced role. Therefore, this analysis included a final sample of 454 men. Clinical, sociodemographic, and selected psychosocial characteristics of these men are presented in Table 2.

Preferred and Experienced Role

Preferred and *experienced* level of involvement in decision-making and the concordance between these are presented in Table 3. The large majority of patients (89%) *preferred* active involvement in decision-making, with the remaining 11% indicating a preference for passive involvement. A similar distribution was observed for the *experienced* role in decision-making (active involvement=87%; versus 13% passive involvement).

Univariate correlates of active involvement are presented in Table 2. Multivariate correlates included: higher education (p=0.005), consulting more than one health professional (p=0.012), and RP as primary treatment (p<0.001). In the subgroup of

patients who started AS, those patients who reported active involvement in decision-making more often continued AS during the first year (p=0.036).

Role concordance

Most patients (n=376) experienced a role in decision-making that matched their preferred role. However, more than half (67%) of the patients who *preferred* passive involvement reported having *experienced* active involvement (n=34; Table 3). Conversely, of those who *preferred* active involvement, 11% (n=44) *experienced* passive involvement.

Univariate correlates of role concordance are presented in Table 2. Multivariate correlates included higher education (p=0.024), and RP as primary treatment (p<0.001).

Effects of involving every patient in decision-making versus matching patients' role with his preferences

PC knowledge

On average, patients correctly answered 55% of the PC knowledge questions (95%CI: 52%-57%). The average level of PC knowledge was significantly higher (p=0.03; Cohen's d=0.30; Table 4) in actively involved patients (mean=56%, 95%CI 53-59%) compared to those who experienced passive involvement in treatment decision-making (mean=47%; 95%CI 39-54%). We observed no significant association between Role Concordance and PC Knowledge (p=0.37, Table 4).

Decisional Conflict

On average, patients scored 22.4 on the Decisional Conflict Scale (DCS) (95%CI=21.0-23.8), with 14% of the patients reporting high levels of uncertainty about the treatment

decision.[21] Decisional conflict was significantly higher (p<0.01; Cohen's d=0.52, Table 4) in patients who experienced passive involvement in decision-making (mean=29.1; 95%CI 25.2-33.0) compared to those who experienced active involvement (mean=21.5; 95%CI 20.0-23.0).

Decisional conflict was also significantly higher (p=0.04; Cohen's d=0.41) in patients who 'preferred *more* involvement than experienced' (mean=27.8; 95%CI 23.2-32.3) compared to those whose 'preferred role *matched* their experienced role' (mean=21.7; 95%CI 20.2-23.3). We did not observe a significant difference between patients who 'preferred *less* involvement than experienced' (mean=23.1; 95%CI 18.1-28.1) and patients whose 'preferred role *matched* their experienced role' (p=0.99).

Only *active involvement* remained significantly associated with less decisional conflict (p=0.004) in the model including both independent variables.

Decision regret

On average, patients scored 19.3 (95%CI: 17.9-20.6) on the Decision Regret Scale, with 23% of the patients reporting high levels of regret about the treatment decision.[22]

Decision regret was significantly higher (p=0.03; Cohen's d=0.34; Table 4) in patients who experienced passive involvement in decision-making (mean=23.8; 95%CI 19.7-28.0) compared to patients who experienced active involvement (mean=18.3; 95%CI 16.8-19.9). Role Concordance was not associated significantly with decision regret (p=0.26, Table 4).

Overall HRQoL

On average, patients scored 92.6 on the overall HRQoL scale assessed 12 months after treatment (95%CI: 91.6-93.5). Patients who experienced active involvement reported significantly better overall HRQoL (mean=93.0; 95%CI 92.0-94.0) compared to patients

who experienced passive involvement in decision-making (mean=89.8; 95%CI 8.27-92.4; *p*=0.03; Cohen's *d*=0.49; Table 4). However, when adjusting for baseline HRQoL the association no longer was statistically significant (*p*=0.20).

Overall HRQoL was significantly better in patients whose 'preferred role matched their experienced role' (mean=93.1; 95%CI 92.1-94.2), compared to patients who 'preferred *more* involvement than experienced' (mean=89.1; 95%CI 86.1-92.2; *p*=0.04; Cohen's *d*=0.40). However, in analyses adjusting for baseline HRQoL, this association no longer remained statistically significant (*p*=0.31).

Sensitivity analyses

Details about the sensitivity analyses are presented in Table S5. The study participants were generally similar to the larger population of Dutch patients diagnosed with localized PC (Table S6). However, the study participants were somewhat younger (66 vs 68, *p*=<0.01), and more likely to have undergone RP (40% vs 30%; *p*<0.01) than the large population of patients.

Patients included and excluded in the analyses did not differ significantly in age, localized PC-risk group, or educational level (subgroup differences *p*>0.05). There was also no evidence of data clustering within the hospitals. The preferred level of involvement in decision-making did not differ significantly between patients who had (n=219, 48%) or had not yet (n=235, 52%) decided about their treatment before our baseline assessment (*p*=0.07). In addition, we did not observe any significant change over time in decision regret (*p*=0.27) or overall HRQoL (*p*=0.22) (Table S4).

Our results indicate that active involvement remained significantly associated with (less) decisional conflict in the multivariate model (*p*=0.03). However, for the remaining outcomes (PC knowledge, HRQoL, and decision regret) other factors such as the number of comorbid conditions, having consulted a clinical nurse specialist, choice of

treatment, educational level, and the use of active coping strategies were more strongly associated with the outcomes than were either active involvement of patients or role concordance (Table S2). In the multivariate models, indicators of PC severity (e.g. cT-status, Gleason-score or PC risk-group) were not associated significantly with any of the outcomes.

DISCUSSION

In this large, prospective multicentre study, we observed that patients with localized prostate cancer who indicated that they had been actively involved in treatment decision-making were better informed about their cancer and its treatment, and experienced less decisional conflict and less decision regret than patients who reported having experienced passive involvement. These results are in line with previous studies within other patient populations.[6–8]

Our results provide less support for previous studies that reported that a match between decision-making preferences and experienced role results in more favourable outcomes.[11,13,14] This suggests the need for caution in assuming that one should "fit" the decision-making process to the initial role preference of the patient.[16,17] A diagnosis of cancer is stressful, and many patients' first reaction may be the desire for a clear treatment plan determined by the clinician. However, especially in the context of localized prostate cancer, where no "best" treatment exists, it can be important for clinicians to gradually provide patients with information and to create an open communication climate that fosters patients' active involvement in decision-making.[12] This recommendation is further underpinned by our finding that levels of decisional conflict were similar between those patients who reported more involvement than initially preferred and those with a level of involvement that matched their initial preferences in

this regard. In contrast, patients who experienced less involvement than preferred experienced higher levels of decisional conflict.

Can we then conclude that patients benefit from active involvement in decision-making about their primary treatment for localized prostate cancer? While our findings indicate that patients who were actively involved in decision-making reported significantly more favourable patient-reported outcomes than those who were more passive in the decision-making process, these associations are not causal in nature.[16,17] Future studies, preferably with a prospective experimental design, are needed to unravel the mechanisms behind the association between active involvement and more favourable outcomes, and if confirmed, to evaluate interventions that could optimize the decision-making process.[9,28]

Our findings should be interpreted in light of several limitations. First, patients were asked about their 'preferred role' prior to treatment, and their 'experienced role' three months after treatment. Although this prospective longitudinal design actually is one of the strengths of the study,[11] recall bias might have influenced our assessment of the experienced role, as this was assessed some months after the decision had been taken and after the treatment had been completed. Second, to minimize respondent burden, we employed an abbreviated version of the Decisional Conflict Scale (DCS), omitting items with factor loadings below 0.65 in a Dutch sample of cancer patients (Table S3).[29] However, we empirically validated this abbreviated version in a dataset of men with localized prostate cancer who completed the full version of the DCS.[30]

Strengths of our study include the large, multiregional and multicentre patient cohort, the use of a prospective study design, and very high response rates and study retention rates.

CONCLUSIONS

In summary, while it may seem desirable to tailor the patients' role in decision-making to their initial preference, and particularly to a preference for deferring to the advice of the clinician, this does not result in less decisional conflict or regret. Rather, in patients with localized prostate cancer, our results support a strategy of shared decision-making to increase patients' knowledge about their disease and its treatment, their sense of certainty about the treatment decision, and their satisfaction with the chosen treatment.

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Shared Decision-Making in Prostate Cancer Care:

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TABLE 1

Table 1. Description of key study measures

	Outcome variable	Instrument	Timing of assessment	Number of items	Scoring	Interpretation	Threshold for clinical relevance
1.	Prostate Cancer Knowledge[20]	Short version Decision Quality Instrument (DQI) for treating prostate cancer	3 months after treatment	5 (α=.58)	0 to 100	A higher score indicates **more knowledge** about PC and its treatment options. The response, "I am not sure" was considered incorrect.	Not applicable
2.	Decisional conflict[21]	Nine items of the Decisional Conflict Scale (DCS)	3 months after treatment	9 (α=.87)	0 to 100	A higher score indicates **more uncertainty** about the PC treatment decision.	>37.5 = a high level of uncertainty about the treatment decision
3.	Decision regret[22]	Decision Regret Scale (DRS)	12 months after treatment	5 (α=.73)	0 to 100	A higher score indicates **more distress** or remorse about the PC treatment decision.	>25 = a high level of regret about the treatment decision
4.	Overall health related quality of life[23]	Quality of Life Questionnaire Core 30 (QLQ-C30) of the European Organisation for Research and Treatment of Cancer (EORTC)	12 months after treatment	30 (α=.88)	0 to 100	A higher score indicates a **better overall health** based on the overall summary score described by Giesinger et al.[19]	Not applicable

Abbreviations: α=Cronbach's alpha in sample; PC = Prostate cancer

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TABLE 2

Table 2. Patient characteristics and their association with the independent variables

				Experienced role			Role concordance			
				Passive	*Active*		*Pref. less*	*Conc.*	*Pref. more*	
	Patient characteristics	***N***	*% / M (SD)*	*%/M (SD)*	*%/M (SD)*	*p*	*%/M (SD)*	*%/M (SD)*	*%/M (SD)*	*p*
1.	**cT-status**			--	--	.41	--	--	--	.47
	cT1	238	53%	--	--	--	--	--	--	--
	cT2	195	43%	--	--	--	--	--	--	--
2.	**Gleason**			--	--	.17	--	--	--	.30
	Gleason 6	269	60%	--	--	--	--	--	--	--
	Gleason 7	161	36%	--	--	--	--	--	--	--
3.	**PSA**			--	--	.49	--	--	--	.14
	0-4	50	11%	--	--	--	--	--	--	--
	5-9	255	56%	--	--	--	--	--	--	--
	>9	149	33%	--	--	--	--	--	--	--
4.	**LPC Risk group**			--	--	.45	--	--	--	.99
	Low	183	40%	--	--	--	--	--	--	--
	Intermediate	205	45%	--	--	--	--	--	--	--
	High	66	15%	--	--	--	--	--	--	--
5.	**Nr. of comorbidities**			--	--	.96	--	--	--	.68
	0	249	55%	--	--	--	--	--	--	--
	1	112	25%	--	--	--	--	--	--	--
	>1	92	20%	--	--	--	--	--	--	--
6.	**Nr. of consulted HP's** (range: 1-4)	421	1.5 (0.6)	1.3 (0.5)	1.5 (0.6)	**.01**	--	--	--	.40
7.	**Received info from NS**			--	--	.09	--	--	--	.53
	Yes	209	47%	--	--	--	--	--	--	--
	No	212	46%	--	--	--	--	--	--	--
8.	**Received info from RT**			--	--	.27	--	--	--	.47
	Yes	31	7%	--	--	--	--	--	--	--
	No	390	93%	--	--	--	--	--	--	--
9.	**Primary treatment**			--	--	**<.01**	--	--	--	**<.01**
	Active surveillance	141	31%	50%	29%	<.01	54%	30%	24%	<.01
	Radical prostatectomy	199	44%	19%	49%	RC	17%	48%	41%	RC
	External beam radiotherapy	58	13%	29%	11%	<.01	27%	11%	15%	.01
	Brachytherapy	47	10%	2%	12%	.35	2%	11%	21%	.15
10.	**AS: stopped AS <1yr**[a]			--	--	**.04**	--	--	--	.19
	Yes	26	19%	33%	16%	--	--	--	--	--
	No	110	81%	67%	84%	--	--	--	--	--
11.	**RP: surgical margins**[b]			--	--	.95	--	--	--	.67
	Positive	21	15%	--	--	--	--	--	--	--
	Negative	118	85%	--	--	--	--	--	--	--
12.	**Baseline HRQoL** (range 0-100)	454	92.8 (8.4)	--	--	.08	90 (8.9)	93 (8.1)	91 (11)	**.05**
13.	**Age at diagnosis** (range 48-87)	454	66.5 (6.1)	68.3 (5.6)	66.2 (6.1)	**.01**	--	--	--	.10
14.	**Education**			--	--	**<.01**	--	--	--	**.01**
	< High school	22	5%	8%	4%	.04	9%	4%	9%	.04
	High school	142	31%	51%	28%	<.01	47%	29%	38%	<.01
	(Some) HE	289	64%	41%	67%	RC	43%	67%	53%	RC
15.	**Marital status**			--	--	.13	--	--	--	.38
	Has partner	407	90%	--	--	--	--	--	--	--
	No partner	47	10%	--	--	--	--	--	--	--
16.	**Ethnicity**			--	--	.07	--	--	--	.39
	Non-Dutch	23	5%	--	--	--	--	--	--	--
	Dutch	431	95%	--	--	--	--	--	--	--
17.	**Use of active coping** (range 0-100)	453	55.6 (18.5)	--	--	.13	--	--	--	.17
18.	**History of depression**			--	--	.62	--	--	--	.76
	No	412	91%	--	--	--	--	--	--	--
	Yes/Not sure	29	6%	--	--	--	--	--	--	--

Notes: Percentages for a given variable do not sum up to 100% if the variable contained missing data. Descriptive information per category only reported when the association between the variables was statistically significant ($p \leq 0.05$). Bolded and underlined *p*-values indicate multivariate correlates.
Abbreviations: Pref. less= Patient preferred less involvement than experienced; Conc.= Concordance between preferred and experienced role; Pref. more=Patient preferred more involvement than experienced; M=mean; SD=standard deviation; cT=clinical T-status; PSA=prostate specific antigen; LPC Risk group= Localized prostate cancer risk groups according to the EAU guidelines; Nr. of consulted HP's= total number of consulted health care professionals; NP=Clinical nurse practitioner; RT=radiotherapist; PC=Prostate Cancer; HRQoL=Health Related Quality of Life; RC= Reference Category; -- = Not applicable.
[a]Proportion of AS patients who changed to an active treatment within one year. Not included in multivariate analyses. [b]Proportion of RP patients with positive surgical margins.

Shared Decision-Making in Prostate Cancer Care:

Encouraging every patient to be actively involved in decision-making, or ensuring patients' preferred level of involvement?

TABLE 3

Table 3. Patients' preferred and experienced role in treatment decision-making

Preferred Role *(before treatment)*	**Experienced Role** *(3 months after treatment)* **Passive involvement**	**Active involvement**	Total
Passive involvement n (% of total)	A **match** between preferred and experienced role 17 (33%)	Patient preferred **less** involvement than experienced 34 (67%)	51 (11%)
Active involvement n (% of total)	Patient preferred **more** involvement than experienced 44 (11%)	A **match** between preferred and experienced role 359 (89%)	403 (89%)
	61 (13%)	393 (87%)	454

Shared Decision-Making in Prostate Cancer Care:

Encouraging every patient to be actively involved in decision-making, or ensuring patients' preferred level of involvement?

TABLE 4

Table 4. The association between post-treatment patient-reported outcomes and role in treatment decision-making

		PC Knowledge				Decisional conflict				Decision regret				Overall HRQoL			
Independent variables	*n*	*M*	*95%CI*	*d*	*p*	*M*	*95%CI*	*d*	*p*	*M*	*95%CI*	*d*	*p*	*M*	*95%CI*	*d*	*p*
Experienced role					**.03**				**<.01**				**.03**				**.03**
Passive involvement	61	47	39-54	.30		29	25-33	.52		24	19-28	.34		89	87-92	.49	
Active involvement	393	56	53-59	RC		21	19-23	RC		18	17-20	RC		93	92-94	RC	
Role Concordance					**.37**				**.05**				**.26**				**.03**
Preferred **more** involvement than experienced	44	49	40-58	.21	.60	28	23-32	.41	.04	23	18-28	.25	.46	89	86-92	.40	.04
A **match** between preferred and experienced role	376	55	52-58	RC	RC	22	20-23	RC	RC	18	17-20	RC	RC	93	92-94	RC	RC
Preferred **less** involvement than experienced	34	52	42-61	.12	.99	23	18-28	.10	.99	21	16-26	.18	.99	90	87-94	.24	.62

Abbreviations: PC=Prostate Cancer; HRQoL=Health Related Quality of Life; M=mean; 95%CI= 95% Confidence Interval; *d*=Cohens' d; RC=Reference Category.

Shared Decision-Making in Prostate Cancer Care:

Encouraging every patient to be actively involved in decision-making, or ensuring patients' preferred level of involvement?

ELECTRONIC SUPPLEMENT

Table S1. Preferred and experienced decisional roles measured with the Control Preferences Scale

	Scoring	N	%
Baseline questionnaire T0			
Preferred role			
Please choose one of the following statements that best describes how you would like the treatment decision to be made:			
a. I prefer to make the final treatment decision.	0	15	3
b. I prefer to make the final treatment decision after considering my doctor's opinion.	0	147	33
c. I prefer that my doctor and I share responsibility for deciding which treatment is best.	0	241	53
d. I prefer that my doctor makes the final treatment decision, but considers my opinion.	1	45	10
e. I prefer to leave all treatment decisions to my doctor.	1	6	1
Follow-up questionnaire T1			
Experienced role			
Please choose one of the following statements that best describes how the treatment decision was made:			
a. I made the final treatment decision.	0	77	17
b. I made the final treatment decision after considering my doctor's opinion.	0	176	39
c. My doctor and I shared the responsibility in deciding which treatment is best.	0	140	31
d. My doctor made the final treatment decision, but considered my opinion.	1	40	9
e. My doctor made the final treatment decision	1	21	5

Abbreviations: T0=Baseline questionnaire, assessed after treatment information was provided but before start of treatment; T1=follow-up questionnaire 3 months after treatment.

Table S2. Patient characteristics and their association with the dependent variables

				PC Knowledge		Decisional conflict		Decision regret		Overall HRQoL	
	Patient characteristics	***N***	*% /M (SD)*	*M/ß*	*p*	*M/ß*	*p*	*M/ß*	*P*	*M/ß*	*P*
1.	**cT-status**			--	.19	--	.34	--	.20	--	.75
	cT1	238	53%	--	--	--	--	--	--	--	--
	cT2	195	43%	--	--	--	--	--	--	--	--
2.	**Gleason**			--	.98	--	.80	--	.81	--	.60
	Gleason 6	269	60%	--	--	--	--	--	--	--	--
	Gleason 7	161	36%	--	--	--	--	--	--	--	--
3.	**PSA**			--	.35	--	.43	--	.19	--	**.02**
	0-4	50	11%	--	--	--	--	--	--	90	RC
	5-9	255	56%	--	--	--	--	--	--	93	.12
	>9	149	33%	--	--	--	--	--	--	91	.99
4.	**LPC Risk group**			--	.50	--	.39	--	.82	--	.79
	Low	183	40%	--	--	--	--	--	--	--	--
	Intermediate	205	45%	--	--	--	--	--	--	--	--
	High	66	15%	--	--	--	--	--	--	--	--
5.	**Nr. of comorbidities**			--	**<.01**	--	.18	--	**<.01**	--	**<.01**
	0	249	55%	57	RC	--	--	19	.06	94	<.01
	1	112	25%	57	.99	--	--	16	<.01	93	<.01
	>1	92	20%	44	<.01	--	--	23	RC	85	RC
6.	**Nr. of consulted HP's** (range: 1-4)	421	1.5 (0.6)	7.4	**<.01**	--	.65	--	.41	--	.16
7.	**Received information from Nurse Specialist**			--	**<.01**	--	.06	--	.28	--	.06
	Yes	209	47%	60	--	--	--	--	--	--	--
	No	212	46%	49	--	--	--	--	--	--	--
8.	**Received information from Radiotherapist**			--	.01	--	.90	--	.32	--	.30
	Yes	31	7%	67	--	--	--	--	--	--	--
	No	390	93%	54	--	--	--	--	--	--	--
9.	**Primary treatment**			--	.13	--	**<.01**	--	.06	--	**.03**
	AS	141	31%	--	--	25	RC	--	--	93	.22
	RP	199	44%	--	--	19	<.01	--	--	94	.02
	EBRT	58	13%	--	--	25	0.9	--	--	89	RC
	BT	47	10%	--	--	19	0.5	--	--	92	.99
10.	**AS: stopped AS <1yr**[a]			--	.11	--	.99	--	.92	--	.57
	Yes	26	19%	--	--	--	--	--	--	--	--
	No	110	81%	--	--	--	--	--	--	--	--
11.	**RP: surgical margins**[b]			--	.81	--	**.01**	--	.09	--	**<.01**
	Positive	21	15%	--	--	25	--	--	--	90	--
	Negative	118	85%	--	--	17	--	--	--	95	--
12.	**Baseline HRQoL** (range 0-100)	454	92.8 (8.4)	0.5	**<.01**	-0.3	**<.01**	-0.3	**<.01**	0.8	**<.01**
13.	**Age at diagnosis** (range 48-87)	454	66.5 (6.1)	-1.4	**<.01**	--	.11	--	.50	--	.28
14.	**Education**			--	**<.01**	--	.75	--	**.01**	--	.08
	< High school	22	5%	25	RC	--	--	19	.99	--	--
	High school	142	31%	45	<.01	--	--	22	<.01	--	--
	(Some) HE	289	64%	62	<.01	--	--	17	RC	--	--
15.	**Marital status**			--	.07	--	.08	--	.98	--	.31
	Has partner	407	90%	--	--	--	--	--	--	--	--
	No partner	47	10%	--	--	--	--	--	--	--	--
16.	**Ethnicity**			--	.80	--	**.02**	--	.77	--	**.02**
	Non-Dutch	23	5%	--	--	30	--	--	--	88	--
	Dutch	431	95%	--	--	22	--	--	--	93	--
17.	**Use of active coping strategies** (range 0-100)	453	55.6 (18.5)	0.4	**<.01**	-0.1	**<.01**	-0.1	**.01**	--	.51
18.	**History of depression**			--	.68	--	.47	--	.10	--	**<.01**
	No	412	91%	--	--	--	--	--	--	93	--
	Yes/Not sure	29	6%	--	--	--	--	--	--	85	--
19.	**Experienced role**[c]	454	--	--	**.03**	--	**<.01**	--	**.03**	--	**.03**
20.	**Role concordance**[c]	454	--	--	.37	--	**.05**	--	.26	--	**.03**
			Full model R^2		**24%**		**10%**		**7%**		**50%**

Notes: Percentages for a given variable do not sum up to 100% if the variable contained missing data. Descriptive information per category only reported when the association between the variables was statistically significant ($p \leq 0.05$). Bolded and underlined *p*-values indicate a significant association in the multi-factor ANCOVA including all significant univariate associates of our dependent variables.

Abbreviations: PC=Prostate Cancer; HRQoL=Health Related Quality of Life; M=mean; SD=standard deviation; *β*=Beta; RC= Reference Category; cT=clinical T-status; -- = Not applicable; PSA=prostate specific antigen; Nr. of consulted HP's= total number of consulted health care professionals (urologist, radiotherapist, clinical nurse specialist; and/or general practitioner); AS=Active surveillance; RP= radical prostatectomy; EBRT=external beam radiotherapy; BT=brachytherapy; LPC Risk group= Localized prostate cancer risk groups according to the EAU guidelines: a Low = PSA<10 and Gleason<7 and cT1-2a; Intermediate = PSA 10-20 or Gleason 7 or cT2b; High= PSA > 20 or Gleason > 7 or cT2c.

[a] Proportion of AS patients who changed to an active treatment within one year. Not included in multivariate analyses. [b] Proportion of RP patients with positive surgical margins. Not included in multivariate analyses. [c]Details are presented in Table 4.

Table S3. Uncertainty about the treatment decision measured with the Decisional Conflict Scale at T1

Considering the option you prefer, please answer the following questions:	Strongly disagree *n*	Disagree *n*	Neither agree or disagree *n*	Agree *n*	Stronly agree *n*	M (SD)
1. I was clear about the best choice for me	2	16	23	192	212	4.3 (0.7)
2. I felt sure about what to choose.	6	21	44	184	189	4.2 (0.9)
3. This decision was difficult for me to make.	112	111	58	128	34	2.7 (1.3)
4. I knew the benefits and risks of each option.	6	15	44	256	122	4.1 (0.7)
5. I was clear about which benefits matter most to me.	3	16	42	258	123	4.1 (0.8)
6. I was clear about which risks and side effects matter most.	2	16	38	250	134	4.1 (0.7)
7. I feel I have made an informed decision.	4	9	35	223	172	4.2 (0.8)
8. My decision shows what is important to me.	2	6	42	247	145	4.2 (0.7)
9. I am satisfied with my decision.	2	6	28	199	209	4.4 (0.7)

Notes. To decrease the burden on participants who were completing many other questions at the same time, we abbreviated the full version (16 items) omitting items with factor loadings below 0.65 in a Dutch sample of cancer patients [29]. The abbreviated version was empirically validated by assessing the correlation (Pearson R=0.95; 95% CI 0.91:0.96) between the 'full version total score' and 'abbreviated version total score' in a dataset of men with localized prostate cancer who completed the full version of the DCS [30].

Abbreviations: T1=follow-up questionnaire 3 months after treatment.

Table S4. Repeated measures analysis of overall HRQoL and decision regret

	Overall HRQoL									Decision regret						
	3 mo		6 mo		12 mo		time	IV	IV* Time	6 mo		12 mo		time	IV	IV* Time
Independent variables	*M*	*SD*	*M*	*SD*	*M*	*SD*	*p*	*p*	*p*	*M*	*SD*	*M*	*SD*	*p*	*p*	*p*
Experienced role							.15	.03	.57					.45	.01	.96
Passive involvement	89.2	11.7	89.1	11.9	89.8	11.6				24.8	16.0	23.8	14.4			
Active involvement	91.4	9.7	92.3	9.8	92.9	9.7				19.2	16.7	18.4	15.6			
Role Concordance							.27	.05	.25					.28	.06	.79
Preferred **more** involvement than experienced	88.5	12.2	88.2	12.8	89.1	11.6				25.4	16.7	22.8	14.3			
A **match** between preferred and experienced role	91.3	9.8	92.1	9.9	93.1	9.4				19.1	16.6	18.5	15.2			
Preferred **less** involvement than experienced	91.4	9.7	93.8	8.6	90.8	13.2				22.1	17.1	21.0	20.2			

Abbreviations: mo=months after treatment; -- = Not Applicable; M=Mean; SD=Standard Deviation. **Note**. In the HRQoL analyses we adjusted for baseline overall HRQoL.

Table S5. Purpose, method and results of sensitivity analyses.

	Purpose	Method	Result
1.	To assess how representative the sample was in relation to the population of Dutch men diagnosed with localized PC between 2014-2016	We used a mixed modelling approach (Generalized Estimating Equations) to compare the tumour-characteristics, choice of treatment, and age of patients included in the analysis with data available for the whole population obtained from the Netherlands Cancer Registry (NCR), which is managed by the Netherlands Comprehensive Cancer Organisation (IKNL).	As presented in Table S5, we observed no significant differences in tumour-characteristics (cT-status, Gleason, and PSA) between patient in the sample and the whole population. However, compared to the population, patients in the sample were significantly younger (mean age of 66 vs 68; $p<0.01$), more often received surgery (40% vs 30% $p<0.01$), and less often received external beam radiotherapy (12% vs 18%; $p<0.01$).
2.	To assess whether patients included in the analyses were comparable to patients not included in the analyses.	We used F- and X^2-tests to compare the PC-risk group and age of patients included and not-included (i.e. patients not willing to participate, T0 non-respondents, and patients with missing information about preferred or perceived role) in the analyses.	Age (F=2.9, df1=1, df2=551, p=0.09) and tumour aggressiveness (PC-risk group; X^2=4.2, df=2, p=0.11) of patients included (n=454) and not-included (n=100) did not differ significantly.
3.	To provide insight in the extent to which missing values influenced our results.	For those outcomes (PC Knowledge, Decisional Conflict, Decision regret, And Overall HRQoL) with more than 5% missing values, we used F- and X^2-tests to compare whether patients who had a missing value on that outcome differed significantly from the other patients in PC-risk group, age, and educational level.	Most of the four outcome variables had less than 5% missing values (range $n^{missing}$=1-35; $proportion^{missing}$=0.2-7.7%). The only outcome with more than 5% missing values was Decision regret ($n^{missing}$=35, $proportion^{missing}$=7.7%). Patients with missing values for this outcome did not differ significantly in PC-risk group (F=0.01, df^1=1, df^2=434, p=0.92), age at diagnosis (F=1.8, df^1=1, df^2=434, p=0.18), or educational level (X^2=4.8, df=2, p=0.90).
4.	To verify the assumption of independence of subjects	Mixed modelling procedure with hospital site as random effect.	For each of the outcomes we did not find evidence for clustering of data within the hospitals (intraclass correlations < 0.028).
5.	To assess whether recall-bias influenced the role preference measurement.	F-test to compare the preferred role of patients (Control Preference Scale) who already had made their treatment decision at T0 with those who had not yet made the decision at T0.	Patients who indicated that their treatment decision was already made at T0 did not differ significantly (F=3.2, df^1=1, df^2=452, p=0.07) in the level of preferred involvement in decision-making (mean = 2.80, SD=0.80; n=219, 48%) compared to patients for whom the treatment decision had not yet been made (mean = 2.67, SD=0.66; n=235, 52%).
6.	To describe the change in decision regret and HRQOL over time, and to assess whether the association between these variables and the independent variables was significantly different at 3, 6 or 12 months after treatment.	Repeated measures ANOVA with two (Decision regret, T2, and T3) or three (HRQoL, T1, T2, and T3) follow-up assessments. We assessed the direct effect of time (linear or quadratic time changes over time) and the interaction effect of time with the independent variable of interest (experienced role or role congruence) [IV*Time]. Results are presented in Table S3.	As presented in Table S3, decision regret did not differ significantly between 6 and 12 months after treatment (p>0.20). The association between decision regret and experienced role, and decision regret and role concordance did not differ significantly between 6 and 12 months after treatment (respectively p=0.96 and p=0.79 for interaction effects). Overall, we observed no significant linear or quadratic time trend in HRQoL after treatment (p>0.10). The association between HRQoL and experienced role, and HRQoL and role concordance was comparable at 3, 6 and 12 months after treatment (respectively p=0.57, and p=0.25 for the interaction effects).
7.	To provide insight into other factors associated with the dependent variables (knowledge, decisional conflict, decision regret; and overall HRQoL).	ANOVA and X^2-tests were used to investigate univariate associations between our dependent variables and clinical, sociodemographic, and psychosocial patient characteristics (Table 2). An ANCOVA, including all significant univariate associates, was used to identify those variables most strongly associated with the dependent variables.	As presented in Table 2, significant multivariate correlates of PC knowledge included: the number of comorbidities, age, educational level and the use of active coping strategies (adjusted proportion of explained variance by all the predictors in the model is 23%). Significant multivariate correlates of decisional conflict included: experienced level of involvement in decision-making, primary treatment, baseline HRQoL, ethnicity, and the use of active coping strategies (adjusted proportion of explained variance by all the predictors in the model = 10%). The only significant multivariate correlate of decision regret was baseline HRQoL (adjusted explained variance by all the predictors in the model is 7%). Significant multivariate correlates of overall HRQoL were baseline HRQoL and ethnicity (adjusted proportion of explained variance by all the predictors in the model is 50%).

Abbreviations: PC=Prostate Cancer; HRQoL=Health Related Quality of Life.

Table S6. Characteristics of participating men (sample) and all men diagnosed with localized PC during our recruitment period (population)

	Sample N=454		**Population N=9563**		
Patient characteristics	***N***	*% / M (SD)*	***N***	*% / M (SD)*	*p (d)*
1. **cT-status**					0.311
cT1	195	49%	4964	52%	
cT2	200	51%	4608	48%	
2. **Gleason**					0.515
Gleason 6	192	64%	3800	66%	
Gleason 7	106	36%	1943	34%	
3. **PSA** (range 0-70)					0.167
0-4	59	18%	1041	16%	
5-9	142	44%	2692	41%	
>9	123	38%	2801	43%	
4. **Active Surveillance**	163	36%	3659	38%	0.362
5. **Radical Prostatectomy**	186	40%	2904	30%	<0.01
6. **External Beam Radiotherapy**	56	12%	1713	18%	<0.01
7. **Brachytherapy**	49	11%	803	8%	0.050
8. **Age at diagnosis** (range 48-90)	454	66.26 (6.05)	9555	68.27 (7.27)	<0.01 (0.28)

Abbreviations: Sample=all patients included in the analysis; Population= all patients diagnosed with localized PC between 09-2014 and 02-2016 in The Netherlands; M=mean; SD=standard deviation; %=Valid percent; cT=clinical T-status; PSA=prostate specific antigen. **Notes.** The number of patients within the subgroups do not sum up to Total N if the variable contained missing or non-valid data.

Table S7. Post-treatment patient-reported outcomes stratified by preferred and experienced role in treatment decision making.

preferred role	**experienced role**	n	**Prostate cancer knowledge 3mo** M (SD)	p	**Decisional conflict 3mo** M (SD)	p	**Health Related Quality of Life 12mo** M (SD)	p	**Decisional Regret 12mo** M (SD)	p
active	active	359	56.1 (28.5)	RC	21.3 (14.1)	RC	93.2 (9.3)	RC	18.1 (15.0)	RC
active	passive	44	49.3 (31.6)	.15	27.8 (17.0)	<.01*	89.1 (11.6)	.01*	22.9 (14.1)	.07
passive	passive	17	40.3 (29.9)	.04	32.9 (22.1)	<.01*	91.7 (12.0)	.58	26.4 (14.9)	.05*
passive	active	34	51.8 (33.1)	.41	23.1 (14.7)	.49	90.8 (13.2)	.19	21.0 (20.2)	.32

Abbreviations. Mo = months after treatment; M = Mean; SD= Standard deviation; *p<0.05.