

Treatment decision making in prostate cancer: Patients' participation in complex decisions

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Abstract

Objective: (1) To explore to what degree prostate cancer (PC) patients felt they had participated in treatment decision making (TDM). (2) To determine whether perceived roles during TDM were associated with medical and sociodemographic variables. (3) To examine to what extent satisfaction with TDM was related to perceived role or medical and sociodemographic variables.

Methods: Patients ($n = 126$) were recruited in hospitals and from the Dutch PC patient organization. The relationship between patients' role and stage of disease, treatment modality, age, social status and education was determined, as well as patients' satisfaction with TDM.

Results: Most patients felt they had participated in TDM (autonomous 18%, collaborative 60%). Older patients and those with advanced disease more frequently reported not having been involved in decision making. Satisfaction with TDM was related to age and role in TDM but not to stage of disease or treatment modality. Younger men were least content when they had not been involved in decision making.

Conclusion: Patients' level of participation and satisfaction with TDM appears to be related to medical and sociodemographic variables. **Practice implications:** Satisfaction with TDM may be related to patients' age and assumed role. It is recommended to take this into account when planning treatment for prostate cancer patients.

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1. Introduction

Prostate cancer is the most common malignancy in Dutch men, with approximately 7000 new cases diagnosed every year [1]. The risk of developing the disease increases with age and is less common in men under 50. In the early stages of prostate cancer, few men will experience any physical symptoms. Therefore, early detection is often coincidental. The occurrence of physical symptoms (e.g. micturition problems and lower back pain) is associated with advanced stages of the disease.

In case of a localized tumor, several curative treatment options exist, such as surgery (radical prostatectomy) or

radiation therapy (by external beam or by radioactive seed implantation into the prostate). No curative treatment is currently available for patients with metastases. Treatment options for these patients consist of hormone therapy, which temporarily suppresses tumor growth, or chemotherapy [2]. Radiation or surgery can relieve pain caused by bone metastases. Because the disease often develops slowly, 'watchful waiting' is an often chosen strategy for older men with prostate cancer, even in advanced stages [3].

Deciding on medical treatment for PC is complex for two reasons. First of all, there is still no worldwide consensus among specialists about which treatment should be applied in which disease condition [4]. For instance, surgery and radiation therapy have comparable effects on survival. Secondly, with regard to quality of life, each treatment option has high risks of side effects. With surgery, for instance,

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there is a high risk of erectile dysfunction and incontinence. Radiation will cause fewer side effects in the short run, but the occurrence of incontinence and bladder problems increases with time after treatment [5,6]. Hormone treatment has a severe impact on libido, and therefore on the patient's sex life [7]. In older patients the costs of treatment on quality of life may even outweigh the expected benefits and lead to the decision not to initiate active treatment. The absence of one preferred treatment and the high risk of side effects make prostate cancer a disease suitable for shared decision making.

In TDM studies three types of decision making are usually distinguished [e.g., 8,9]: (a) active or autonomous decision making, indicating the patient is solely responsible for the decision; the physician's preferences are not prominent and his role is that of a counsellor; (b) collaborative or shared decision making, referring to the situation where both patient and physician share responsibility for the decision making; (c) a passive role of the patient implies that the patient is not involved in decision making. In this case the physician reviews the treatment options and makes the decision.

Recent research has shown that a large proportion of PC patients prefer to participate in TDM. [9–12] However, little is known about patients' actual participation in TDM. As it has been demonstrated that cancer patients' preferred and assumed roles in TDM match in approximately 35–65% of the cases [13–17], role preferences are not a reliable indication of patients' level of participation. One recent study found that 94% of men with PC were involved (actively or collaboratively) in decision making [18]. However, these men had taken part in a previous study designed to enhance their feeling of self-efficacy with regard to TDM.

Limited research also exists about PC patients' evaluation of the treatment planning consultation. A qualitative study showed that TDM consultations are often perceived as physician-led. Immediately after consultation patients were content with the paternalistic decision making style. However, acceptance of this one-sided decision making style decreased over time once patients were able to reflect on the complexity of their condition [19].

In order to shed new light on prostate cancer patients' participation in TDM, the aim of this study is three-fold. First, to determine to what degree prostate cancer patients in retrospect feel they have been involved in TDM. Second, to explore the relationship between patients' perceived roles in TDM and medical and sociodemographic characteristics. Finally, to determine to what degree satisfaction with TDM is related to perceived role, medical and sociodemographic variables.

2. Method

2.1. Procedure

This study was conducted as part of a longitudinal study on changes in quality of life and psychosocial problems

among men with PC. Over a period of 10 months, with intervals of 4 and 6 months, respondents were asked to fill out three questionnaires (T1–T3), which they received by mail. Within the longitudinal study, all men with prostate cancer were eligible, regardless of the stage of their disease and treatment. Exclusion criteria were: having or having had another type of cancer or serious illness, and inability to speak Dutch. Respondents were recruited in co-operation with the Dutch prostate cancer patients' organization (SCP), in five hospitals, and during four educational meetings on prostate cancer. These educational meetings were organized by hospitals and offered information about prostate cancer and existing treatment options. The meetings were open to all patients with PC and partners.

2.2. Questionnaire

The questionnaire covered sociodemographic, medical and psychosocial topics. Sociodemographic characteristics included age, current relational status ('Are you currently involved in an intimate relationship?') and education. Education was classified as lower (primary school or lower vocational training), medium (secondary school or intermediate vocational training), or higher (higher vocational training or university). Medical aspects that were used in this study were: time since diagnosis (years), stage of disease (localized or metastatic disease) and type of treatment.

Psychological measures included coping style, quality of life and psycho-social distress (POMS) [22]. From the shortened version of the UCL we used three coping scales: active coping, avoidant coping and social support seeking [20]. The European Organisation for Research and Treatment of Cancer quality of life questionnaire (EORTC QLQ-C30), measures several dimensions of quality of life. In the present study the 'global quality of life' subscale, consisting of two items was used [21]. The Profile of Mood State (POMS) questionnaire includes five subscales: depression, anger, tension, fatigue and vigor [22]. All five subscales have been used in the present analyses. All used questionnaires showed sufficient reliability (Cronbach's α UCL 0.70–0.87; POMS 0.90–0.92; ppmc EORTC 0.76).

With regard to TDM patients were first asked to indicate whether their doctor had discussed one or several treatment options, which may be an indication of physicians' effort to involve patients in decision making. Next, respondents were asked to what degree they felt they had had the opportunity to decide about their treatment. For their answer patients had three options: "I had no say in the decision, the doctor made the decision" (passive), or "I have decided together with my doctor about my treatment" (collaborative), or "The doctor left the decision up to me" (autonomous). Finally, satisfaction was determined by asking respondents to evaluate (on a 5-point Likert scale, ranging from "very dissatisfied" to "very satisfied") the manner in which a decision about their treatment was reached. Except for the sociodemographic characteristics, which were only

measured once (T1), all variables used in this study were obtained at T3.

2.3. Statistical analyses

Descriptive statistics were used to create an overview of respondents' sociodemographic and medical characteristics and role in TDM. Chi-square analyses were used to examine whether the patients' role in TDM was related to medical (stage of disease, treatment modality) and sociodemographic variables (age, education, relational status).

Non-parametric analyses of variance (Kruskal–Wallis) and post hoc contrast analyses with an overall significance level of 0.05 were used to test whether satisfaction scores varied with the role in TDM and the sociodemographic and medical variables mentioned above. Non-parametric analyses of variance were also used to determine whether patients with an active, collaborative or passive role during TDM differed in coping style. Pearson correlations were used to test the association between satisfaction with TDM and well being (quality of life and distress). An eventual relationship may reflect a general positive or negative attitude in life, which may act as a confounding factor in the relationship between perceived role and satisfaction with TDM.

3. Results

3.1. Subjects

The set of 3 questionnaires was completed by 187 of 261 (72%) respondents. Main reasons for drop out were worsening of medical condition and the wish not to be reminded of illness, or no longer motivated to complete questionnaires. In 33% of the cases patients gave no reason for dropping out. Time since diagnosis ranged from 0 to 11 years. To prevent a memory bias, patients who had been diagnosed longer than 3 years ago were further excluded from the analyses. Among the remaining 126 men, mean age was 67 years (range: 48–82) and on average PC diagnosis had occurred one and a half years ago (Table 1). Most respondents indicated they had a localized disease. Radical prostatectomy (RP) and hormone therapy (HT) were the most frequently reported treatment modalities, each reported by 29% of the respondents.

3.1.1. Patients' participation in TDM

Most respondents (78%, $n = 98$), indicated that their doctor had reviewed more than one treatment option with them before a decision was made. With regard to the role in the decision making process, 60% ($n = 75$) stated they had decided in collaboration with their physician. A minority (18%, $n = 22$) indicated they had decided autonomously. Twenty-two percent ($n = 28$) answered they had not been involved in TDM.

Table 1
Sociodemographic and medical characteristics ($n = 126$)

	N (%)	Mean (S.D.)
Age		67.0 (7.9)
Education		
Lower	37 (29)	
Medium	42 (33)	
Higher	47 (37)	
Time since diagnosis (years)		1.5 (1.1)
Stage of disease (metastases)		
No	75 (60)	
Yes	42 (33)	
Unknown to patients	8 (6)	
Treatment		
Radical prostatectomy (RP)	37 (29)	
Hormone therapy (HT)	37 (29)	
Radiation therapy (RT)	22 (18)	
Intentionally curative and HT	21 (17)	
RP and RT	3 (2)	
No treatment/'wait and see'	6 (5)	

Men who reported to have had a passive role in TDM were in most cases (68%) presented with only one treatment option. Most respondents who had decided alone or in accordance with their physician remembered two or more treatment options were reviewed in the treatment consultation (82% and 95%, respectively).

3.1.2. Medical and sociodemographic variables associated with patient participation in TDM

It was tested whether type of treatment was associated with patients' involvement in decision making. Chi square analysis was performed on the 96 patients who had received a single treatment (i.e. radical prostatectomy, radiotherapy or

Table 2
Patients' roles across treatment, disease stage and age at time of diagnosis

Role	Passive (%)	Collaborative (%)	Autonomous (%)
Treatment ^a			
Surgery ($n = 37$)	13	68	19
Radiotherapy ($n = 22$)	5	68	27
Hormone therapy ($n = 37$)	32	54	14
Stage of disease ^b			
Localized ($n = 75$)	18	59	23
Metastatic ($n = 42$)	33	59	7
Age at time of diagnosis ^c			
65 and younger ($n = 61$)	15	57	28
Older than 65 ($n = 65$)	31	61	8

^a $\chi^2 = 8.7, p = 0.07$.

^b $\chi^2 = 6.2, p < 0.05$ (patients who could not tell the stage of their disease were left out of this analysis).

^c $\chi^2 = 10.9, p < 0.01$.

Table 3
Patients' satisfaction with TDM across perceived role ($n = 125$)

Role	Quite dissatisfied (%)	Neither satisfied nor dissatisfied (%)	Quite satisfied (%)	Very satisfied (%)	Mean (median)
Passive (a) ($n = 28$)	14	29	21	36	3.8 (4.0)
Collaborative (b) ($n = 75$)	4	4	24	68	4.6 (5.0)
Autonomous (c) ($n = 22$)	5	–	59	36	4.3 (4.0)

Kruskal–Wallis $\chi^2 = 14.8$; $p < 0.001$. Post hoc comparison of satisfaction ($\alpha = 0.05$): $a < b$.

hormone therapy). Although not reaching significance, there was a tendency towards a higher frequency of passive decision making for patients treated with hormone therapy (Table 2).

Patients' participation showed a significant association with stage of disease ($\chi^2 = 6.2$, $p < 0.05$). Both patients with and without metastases had decided collaboratively in 59% of the cases. However, passive decision making was more frequent in patients with advanced disease (Table 2).

To test whether age at time of diagnosis had an influence patients' role, the group of respondents was divided into men younger or older than 65 years at time of diagnosis (65 years represented the median age, 52% versus 48%). The chi-square analysis revealed that role frequencies were not equal across age (Table 2). Younger respondents more often reported an autonomous role than older patients ($\chi^2 = 10.9$, $p < 0.01$). No relationship was found between patients' roles in TDM and education or marital status.

3.2. Satisfaction with TDM

Generally, satisfaction with the decision making process was very high. More than half (55%, $n = 69$) of the respondents were "very satisfied" and 29% ($n = 37$) were "quite satisfied". Nine percent ($n = 11$) were "neither dissatisfied nor satisfied" and only 6% ($n = 8$) were "quite dissatisfied".

Although the distribution of satisfaction scores was highly skewed, a relationship with patients' perceived role

during the process of decision making could be demonstrated (K–W $\chi^2 = 14.8$, $p < 0.01$). Subsequent multiple comparison analyses revealed that men who had gone through passive decision making reported lower satisfaction than those who had gone through collaborative decision making. Ratings from respondents who had decided autonomously did not differ significantly from those who had gone through collaborative or a passive decision making (Table 3).

Although hormone treatment and advanced stage of the disease were associated with rather high frequencies of passive decision making, satisfaction scores with TDM were not related to treatment modality (K–W $\chi^2 = 0.97$, $p > 0.1$) or stage of disease (M–W $U = 1483$, $p > 0.1$). However, there was an association between age at time of diagnosis and satisfaction with TDM. Compared to the younger patients, older patients appeared to be more satisfied (M–W $U = 1561$, $p < 0.05$).

Since both patients' perceived roles and their age at time of diagnosis appeared related to their satisfaction with TDM, a separate analysis for both age groups was conducted to detect a possible interaction effect between age and role on satisfaction scores. This analysis revealed that satisfaction scores of younger patients varied with the level of involvement in TDM (K–W $\chi^2 = 15.7$, $p < 0.001$). Multiple comparison analyses revealed that patients who felt they had not been heard in TDM were less satisfied than patients who remembered to have decided collaboratively or

Table 4
Patients' (aged ≤ 65) perceived role and satisfaction with TDM ($n = 61$)

Role	Quite dissatisfied (%)	Satisfied nor dissatisfied (%)	Quite satisfied (%)	Very satisfied (%)	Mean (median)
Passive (a) ($n = 9$)	33	33	33	–	3.0 (3.0)
Collaborative (b) ($n = 35$)	9	3	29	60	4.4 (5.0)
Autonomous (c) ($n = 17$)	–	–	65	35	4.4 (4.0)

Kruskal–Wallis $\chi^2 = 15.7$; $p < 0.001$. Post hoc comparison of satisfaction ($\alpha = 0.05$): $a < b, c$.

Table 5
Patients' (age > 65) perceived role and satisfaction with TDM ($n = 64$)

Role	Quite dissatisfied (%)	Satisfied nor dissatisfied (%)	Quite satisfied (%)	Very satisfied (%)	Mean (median)
Passive ($n = 19$)	5	26	15	53	4.2 (5.0)
Collaborative ($n = 40$)	–	5	20	75	4.7 (5.0)
Autonomous ($n = 5$)	20	–	40	40	4.0 (4.0)

Kruskal–Wallis $\chi^2 = 5.9$; $p = 0.054$. Post hoc comparison of satisfaction ($\alpha = 0.05$) ns.

autonomously (Table 4). For the older patient group satisfaction scores appeared to vary only slightly with their perceived role in TDM (K–W $\chi^2 = 5.9, p = 0.054$). Post hoc comparison tests in the older patient group did not reach significance (Table 5).

A classification of respondents on perceived role did not reveal any group differences in coping styles. Furthermore, all correlations between satisfaction and EORTC and POMS subscales were below $r = 0.20$. Satisfaction scores with TDM were therefore not likely to reflect a generally positive or negative attitude in life.

4. Discussion and conclusion

4.1. Discussion

Since is it still undecided whether there is one superior treatment option for each stage of prostate cancer and risks of side effects with each treatment are high, there is much room for patient participation in medical decision making. Indeed, this study shows the degree of patient participation in TDM is high. Nearly 80% of the patients indicated they had selected their treatment by themselves or in collaboration with their physician. This level of participation is comparable to findings from previous research [8,18]. The fact that participation in TDM was related to stage of disease (and treatment) may be explained by the fact that when metastases are discovered, few other options remain except for hormone treatment. As a result patients with advanced disease may be less often involved by physicians in the process of decision making. However, the fact that patients with advanced disease are not less satisfied with TDM may also be an indication of patients' preference not to participate in TDM once their disease has become incurable [23].

In general, patients were very satisfied with the process of decision making, especially those who indicated to have decided in close collaboration with their doctor. Patients in a passive role were least satisfied. Satisfaction with TDM was also related to the age at which patients were diagnosed. Patients diagnosed at older age were more satisfied with TDM than men who were younger at time of diagnosis.

Moreover, the age at which patients had been diagnosed and the perceived role showed an interaction effect on satisfaction with TDM. Younger patients turned out to be less satisfied with a passive role compared to patients who had decided autonomously or collaboratively. Whereas none of the younger patients who had gone through passive decision making were 'very satisfied' with TDM, more than half of the older patients with a passive role were 'very satisfied' with the decision making process. The association between patients' preference for participation in TDM and younger age has been found in several studies [24]. One possible explanation for this finding is a socio-cultural change in the patient–physician interaction. A physician-centered communication style (with the doctor being solely

responsible for the medical decisions) in cancer management has long been undisputed [e.g. 25]. Nowadays, patients tend to become more knowledgeable with medical information readily accessible. It has been demonstrated that patients who feel well informed show a greater preference for involvement in TDM [8].

Our empirical findings have some limitations and consequently leave questions to be answered in future research. First of all, our study sample is small and heterogeneous. Therefore one should be cautious in interpreting these findings. Second, we have limited insight in the factors that influence a decision making style during consultation. Our findings suggest that patients' coping style does not influence their assumed role during TDM. Patients with an active role are not characterized by a high problem-focused coping style, as one might expect. Future research needs to further focus on factors (patient and physician factors) that determine the role that patients attain during TDM. For example, a passive role in decision making may be a consequence of patients' low internal locus of control and a strong belief in the abilities of his physician [11]. On the other hand, it might also be a reflection of a physician's paternalistic communication style [19].

Third, patients' conceptual definition of 'deciding together with the doctor about medical treatment' needs to be established. Our results did show that most men with a collaborative or autonomous role had been presented with two or more treatment options. However, it is not clear to what degree patients' treatment preferences were discussed in collaborative decision making. After all, shared decision making involves more than the patient's approval once the doctor has presented a treatment proposal. In other words, what aspects in communication do patients consider a prerequisite for 'shared decision making'?

4.2. Conclusion

In sum, most Dutch PC patients feel they have been involved in the process of deciding about treatment. Older patients and patients with metastases more frequently feel they have had a passive role in TDM compared with younger patients and those without metastases. On the whole, a collaborative role is associated with higher patient satisfaction about TDM. This seems particularly true for younger patients.

4.3. Practice implications

Notwithstanding the limitations of our study, the high satisfaction with TDM of patients who had decided in collaboration with their doctor supports our plea for shared decision making in prostate cancer. Our data suggest that this may be particularly important for patients diagnosed at younger age. To date, the number of treatment options for patients with advanced disease is limited. However, it is important to note that this fact in itself does not restrict the possibility for patients to participate in TDM. Educating patients (and partners) about the benefits and drawbacks of

hormone treatment together with the patient and leaving room for negotiation about whether and when to initiate treatment (for instance dependent on patients' sexual activity), may enhance a sense of control and perception of participation in decision making.

One final word of caution may be in order. Patient-centeredness in medicine does not necessarily imply shared decision making. Medical decision making for PC is difficult. Sometimes for professionals, often for patients [12,26]. It is important to keep in mind that the individual patient may or may not feel comfortable with the responsibility of choosing between the available treatment options and too much encouragement towards active involvement in TDM may lead to unwanted control [27]. Where possible, we would like to encourage clinicians to assess the degree to which patients want to be involved in TDM. Enabling patients to take on their preferred role in TDM may reduce patients' anxiety [15] and increase satisfaction with the treatment choice [16].

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