



Original article

Prostate cancer survivors with a passive role preference in treatment decision-making are less satisfied with information received: Results from the PROFILES registry

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Abstract

Objective: To investigate decision-making role preferences and their association with the evaluation of information received in a sample of low-risk and intermediate-risk prostate cancer (Pca) survivors.

Methods: Cross-sectional study involved 562 men diagnosed with low-risk or intermediate-risk Pca (median time since diagnosis, 48 mo), measuring preferred decision-making role (Control Preference Scale) and the evaluation of information received (EORTC QLQ-INFO25). Analyses were performed using analysis of variance, chi-square tests, and multivariable linear regression models.

Results: Men who preferred a passive role were older and less educated than other preference groups and more often selected a noninvasive treatment option (all with $P < 0.001$). The passive role preference group reported having received less information, judged the received information as less helpful, and indicated lower overall satisfaction with information received (all with $P < 0.05$). Role preference groups did not differ in their desire to receive more information.

Conclusion: Compared with nonpassive preference groups, the preference for a passive role in Pca treatment decision-making is associated with less satisfaction with the information received.

Practice implications: Assessment of role preferences and tailored information provision could improve satisfaction with information received and perhaps may ultimately lead to improved patient participation in treatment decision-making. © 2016 Elsevier Inc. All rights reserved.

Keywords: Prostate cancer; Patient participation; Shared decision-making; Decision-making roles; Preferences; Information provision

1. Introduction

Shared decision-making (SDM) is widely recognized as best practice in preference-sensitive treatment decision-making [1–3]. Following the principles of SDM, a clinician shares the best available evidence on the treatment

alternatives and the patient receives support in sharing his personal values and preferences [4]. Across several medical conditions, it has been found that a large majority of patients (75%) prefers this collaborative or even a more active role, though leaving a substantial proportion of patients (25%) preferring a passive role in treatment decision-making [5]. Some studies with SDM interventions such as decision support tools show improved patient involvement, whereas other studies show little variability

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over time, indicating that role preferences could represent an intrinsic personality trait that is consistent over time and situations [1,6]. Although patients prefer different roles for involvement in treatment decision-making, information provision practices are often standardized for all patients. Whereas the variation in decision-making role preferences has been studied before, its relation with the evaluation of information received has so far remained untested [3,5,7,8].

The present study aims to investigate the association between decision-making role preferences and the evaluation of information received in a sample of low-risk and intermediate-risk (stage cT1 and cT2) patients with prostate cancer (Pca). Incidence of low-risk and intermediate-risk Pca is growing because of an aging population and because of the increased use of prostate-specific antigen screening [9–11]. Available treatments for low-risk and intermediate-risk Pca offer oncologically equivalent outcomes, but they come with different treatment side effects that could have a significant influence on quality of life, emphasizing the need for proper information provision and careful determination of patients' preferences and characteristics [12,13]. However, it was found that 1 in 3 patients with Pca is dissatisfied with information received [14]. Our hypothesis is that patients with a passive role preference require less information than patients with a preference for an active decision-making role. However, for satisfaction with information received, we hypothesize that patients with a passive role preference are equally satisfied with information received as they prefer to delegate the final decision in a larger extent to the clinician involved and may have a lower need for information.

2. Methods

2.1. Participants and data collection

A total of 7 hospitals in the southern area of the Netherlands Cancer Registry (NCR) participated in this study. Per hospital, a random selection was made of 150 patients with Pca who were diagnosed between 2006 and 2009 (stage cT1–cT3). Patients with a cT3-stage tumor were later excluded from this sample as their treatment alternatives and medical conditions are less comparable to the cT1 and cT2 stages. Data were collected in October 2011 within Patient Reported Outcomes Following Initial Treatment and Long-Term Evaluation of Survivorship (PROFILES). PROFILES is a registry for the study of the physical and psychosocial influence of cancer and its treatment from a dynamic, growing population-based cohort of both short-term and long-term cancer survivors. PROFILES registry contains a large web-based component and is linked directly to clinical data from the NCR [15]. Urologists sent their (former) patients a letter to inform them about the study and to invite them to complete an online questionnaire. On request, patients received a paper questionnaire that could be returned in a prestamped

envelope. Patients consented on linking questionnaire data to their clinical data from the NCR. Earlier studies on related topics have been carried out within the same sample [14,16]. Our study protocol was reviewed and centrally approved for all participating hospitals by the medical ethics committee of one of the participating hospitals.

2.2. Measures

2.2.1. Sociodemographic and clinical characteristics

Clinical and patient information were obtained from the NCR (i.e., date of birth, date of diagnosis, disease stage, and initial treatment). The questionnaire included questions on sociodemographic variables (i.e., marital status, employment status, and educational level).

2.2.2. Preferred decision-making role

The Control Preferences Scale was used to assess the role a patient prefers in treatment decision-making [17]. Responses to this single-item question range on a unidimensional scale from passive (“I prefer to leave all decisions regarding treatment to my doctor”) to active (“I prefer to make the decision about which treatment I will receive”). The 5 answer categories are condensed into 3 categories, with the first 2 roles combined as passive, the middle role as shared decision-making (collaborative), and the last 2 roles as a preference for an active role. The Control Preferences Scale has been used to measure role preferences worldwide for multiple medical conditions and has proven to be a valid and reliable measure [18–20].

2.2.3. Evaluation of information received

The evaluation of information received was assessed with the EORTC QLQ-INFO25 questionnaire [21]. The EORTC QLQ-INFO25 consists of 4 subscales that assess the perceived receipt of information about (1) the disease, (2) medical tests, (3) treatment, and (4) other care services. Additionally, 8 single items assess the receipt of information in different formats (e.g., written information and information on CDs or tape/video), evaluation of the amount of information and satisfaction with the amount and helpfulness of information. All responses were given on a 4-point Likert scale (1—not at all, 2—a little, 3—quite a bit, and 4—very much), except for 4 single items that have a binary yes/no scale. Subscales were converted to a 0 to 100 outcome. Reliability of the full scale ($\alpha > 0.91$) was excellent, subscale reliability (range between $\alpha = 0.74$ and $\alpha = 0.89$) was acceptable to be good.

2.2.4. Health-related quality of life

We used a general measure for health-related quality of life (HRQoL) in patients with cancer (EORTC QLQ-C30) and supplemented this with a Pca-specific module (EORTC QLQ-PR25) [22,23]. Both the scales were used to assess functional outcomes and symptom burden, as a previous study reported a negative correlation between HRQoL and

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