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Satisfaction with Care Among Men with Localised Prostate Cancer: A Nationwide Population-based Study

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Article info

Abstract

Background: Information about how men with prostate cancer (PC) experience their medical care and factors associated with their overall satisfaction with care (OSC) is limited.

Objective: To investigate OSC and factors associated with OSC among men with low-risk PC.

Design, setting, and participants: Men registered in the National Prostate Cancer Register of Sweden as diagnosed in 2008 with low-risk PC at the age of ≤70 yr who had undergone radical prostatectomy (RP), radiotherapy (RT), or started on active surveillance (AS) were invited in 2015 to participate in this nationwide population-based survey (n = 1720).

Outcome measurements and statistical analysis: OSC data were analysed using ordinal logistic regression. Odds ratios (ORs) were calculated for comparisons between the highest and lowest possible response categories.

Results and limitations: A total of 1288 men (74.9%) responded. High OSC was reported by 958 (74.4%). Factors associated with high OSC were high participation in decision-making (OR 4.18, 95% confidence interval [CI] 2.61–6.69), receiving more information (OR 11.1, 95% CI 7.97–15.6), high-quality information (OR 7.85, 95% CI 5.46–11.3), access to a nurse navigator (OR 1.80, 95% CI 1.44–2.26), and better functional outcomes (defined as 25 points higher on the EPIC-26 questionnaire; OR 1.34, 95% CI 1.21–1.48). OSC was not affected by whether a doctor or specialist nurse conducted follow-up (OR 0.84, 95% CI 0.66–1.07). These findings were similar across treatment groups. Men who had undergone RP or RT reported high OSC more often than men on AS (78.2% vs 84.0% vs 72.6%), high participation in decision-making (70.5% vs 64.5% vs 49.2%), and having received more information (40.5% vs 45.8% vs 28.6%), and were less likely to believe they would die from PC (3.8% vs 3.9% vs 8.0%). Limitations include the nonrandomised retrospective design and potential recall bias.

Conclusions: Information and participation in decision-making, as well as access to a nurse navigator, are key factors for OSC, regardless of treatment. Men on AS need more information about their treatment and need to participate more in decision-making. OSC was as high among men who had nurse-led follow-up as among men who had doctor-led follow-up.

Patient summary: Information about how men with low-risk prostate cancer experience their medical care is limited. In this nationwide population-based study we found that information and participation in decision-making as well as access to a nurse navigator are key factors for satisfaction regardless of treatment. Men who are being closely watched for prostate cancer without immediate curative treatment need more information than they now receive and need to participate more in decision-making than they currently do.

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1. Introduction

Earlier detection and advances in cancer treatment have dramatically prolonged the lifespan of cancer patients, resulting in longer relations with caregivers. Overall satisfaction with health care (OSC) is considered an important indicator of the quality of care [1,2], and information and support given by health care professionals during the course of an illness are believed to play a key role in patient well-being [3,4]. As a consequence, evaluation of patients' health care experiences is gaining interest from researchers and health care providers. Patient-reported experience measures are used to improve the quality of care, while patient-reported outcome measures investigate the functional outcomes of treatments and quality of life [5].

Men with localised prostate cancer (PC) usually have several treatment options, including radical prostatectomy (RP), radiotherapy (RT), and active surveillance (AS). AS is the recommended management for men with low-risk PC in Sweden [6] and is gaining acceptance in other countries [7,8]. Little is known about how OSC differs between men who have had different treatments and whether there are any specific areas that need attention to improve OSC. We could not find any previous studies assessing OSC in men on AS for localised PC.

We used the National Prostate Cancer Register of Sweden (NPCR) to investigate OSC among men with low-risk PC who have undergone RP or RT or started on AS, and explored potential explanatory factors for their satisfaction.

2. Patients and methods

2.1. Study design and participants

In February 2015 we identified all men registered in the NPCR diagnosed in 2008 with low-risk PC at the age of ≤70 yr who had undergone RP or RT or started on AS and were still alive in 2015. The NPCR has a capture rate of >96% [9]. Low-risk disease was defined as Gleason score ≤6, prostate-specific antigen (PSA) <10 ng/ml, and clinical stage T1 or T2. In all, 1720 men were invited to participate in the study via a letter, in which we presented the study and its purpose. The letter included a questionnaire that combined study-specific questions, the Expanded Prostate Cancer Index Composite 26-item short-form version (EPIC-26), and an addressed and stamped envelope. The participants could also fill out the questionnaire online by using an individual code. Men who failed to return the questionnaire were contacted by a research assistant via telephone and were sent a second questionnaire.

The Regional Ethical Review Board at Uppsala University approved the study.

2.2. Questionnaire design

The questionnaire consisted of EPIC-26 and 49 study-specific questions. EPIC-26 is an instrument designed to assess pelvic organ function and bother after PC treatment. Results are presented for each domain as a median score on a scale from 0 to 100, where 100 is the most favourable outcome [10]. The study-specific questions were developed after interviews with men living with PC, and were tested for face validity with one investigator accompanying the men while they completed the questionnaire. Questions not fully understood as intended were changed to achieve clarity. The questionnaire was further validated in an unpublished pilot study. Our technique for developing a study-specific questionnaire is based on a one-concept–one-question method producing self-reported outcomes and has been previously described [11–13]. The questionnaire explored mental symptoms (anxiety, depressed mood, sense of well-being), quality of life, and OSC on a seven-point visual digital scale, with seven representing the best possible quality of life, the best possible health care, and being depressed all the time, respectively (Supplementary material). OSC was assessed using the following question: "How satisfied are you as a prostate cancer patient with your health care". The study-specific questionnaire also assessed experiences at the time of diagnosis and at follow-up, sociodemographics, smoking, alcohol consumption, physical activity, treatments, concurrent diseases (which were converted into a Charlson comorbidity index score [14]), and psychiatric comorbidity, which was obtained by asking the men if they suffered from depression and/or any other mental illness.

2.3. Data collection, analysis, and statistics

To assess long-term outcomes, data were collected 7 yr after PC diagnosis, between February and October 2015. The response rate is shown in Figure 1. The answers to the questionnaires and cancer characteristics data from the NPCR were assembled in a database. Potential differences between responders and nonresponders were analysed. The responders were grouped by their initial treatment: RP, RT, or AS. Variables affecting OSC were divided into perceived quantitative variables (no, little, moderate, or much information) and more qualitative variables that were influenced by the participants' personal preference (experience of insufficient or sufficient time). Statements such as "substantial information" or "high quality information" were defined as the highest possible response to that specific question. Missing data were handled using multiple imputations based on the method of chained equations [15]. Five imputation data sets were created. The analysis of factors potentially associated with OSC was carried out using ordinal logistic regression adjusted for age, marital status, fatherhood, profession, education, Charlson comorbidity index, and psychiatric comorbidity. Odds ratios (ORs) with 95% confidence interval (CI) show the probability of advancing one step on the seven-point visual digital scale for OSC when comparing the highest versus the lowest possible response.

3. Results

3.1. Patient characteristics

In all, 1288 of the 1720 men invited (74.9%) responded. Of these, 682 (53.0%) had undergone RP, 155 (12.0%) had received RT, and 451 (35.0%) had started on AS (Table 1). The mean age at diagnosis was 63 yr (range 40–70), with small differences between the groups. The proportion of men who were retired was 72.9% in the RP group, 83.2% in the RT group, and 83.6% in the AS group. The corresponding proportion of men who had university-level education was 33.6%, 23.2%, and 28.4% in these groups. A Charlson comorbidity index of ≥2 was reported for 12.4% in the RP group, 20.1% in the RT group, and 21.1% in the AS group.

A dropout analysis showed some differences between responders and nonresponders. Compared to responders, the nonresponders were on average 1 yr younger, had lower T stage and lower PSA, were more likely to be diagnosed after PSA testing, and were more likely to be initially managed with AS (Supplementary Table 1).