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Long-term Psychological and Quality-of-life Effects of Active Surveillance and Watchful Waiting After Diagnosis of Low-risk Localised Prostate Cancer

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Abstract

Background: Long-term psychological well-being and quality-of-life are important considerations when deciding whether to undergo active treatment for low-risk localised prostate cancer.
Objective: To assess the long-term effects of active surveillance (AS) and/or watchful waiting (WW) on psychological and quality-of-life outcomes for low-risk localised prostate cancer patients.
Design, setting, and participants: The Prostate Cancer Care and Outcome Study is a population-based prospective cohort study in New South Wales, Australia. Participants for these analyses were low-risk localised prostate cancer patients aged <70 yr at diagnosis and participated in the 10-yr follow-up.
Outcome measurements and statistical analysis: Validated instruments assessed outcomes relating to six health-related quality-of-life and nine psychological domains relevant to prostate cancer patients. Adjusted mean differences (AMDs) in outcome scores between prostate cancer treatment groups were estimated using linear regression.
Results and limitations: At 9–11 yr after diagnosis, patients who started AS/WW initially had (1) higher levels of distress and hyperarousal than initial radiation/high-dose-rate brachytherapy patients (AMD = 5.9; 95% confidence interval or CI [0.5, 11.3] and AMD = 5.4; 95% CI [0.2, 10.5], respectively), (2) higher levels of distress and avoidance than initial low-dose-rate brachytherapy patients (AMD = 5.3; 95% CI [0.2, 10.3] and AMD = 7.0; 95% CI [0.5, 13.5], respectively), (3) better urinary incontinence scores than initial radical prostatectomy patients (AMD = –9.1; 95% CI [–16.3, –2.0]), and (4) less bowel bother than initial radiation/high-dose-rate brachytherapy patients (AMD = –16.8; 95% CI [–27.6, –6.0]). No other significant differences were found. Limitations include participant attrition, inability to assess urinary voiding and storage symptoms, and nonrandom treatment allocation.
Conclusions: Notwithstanding some long-term differences between AS/WW and various active treatment groups in terms of distress, hyperarousal, avoidance, urinary incontinence, and bowel bother, most long-term outcomes were similar between these groups.
Patient summary: This study assessed the long-term psychological and quality-of-life impacts of initially monitoring rather than actively treating low-risk prostate cancer. The results suggest that initial monitoring rather than active treatment has only a minor impact on subsequent long-term psychological and quality-of-life outcomes.

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1. Introduction

The decision to undergo active treatment such as radical prostatectomy (RP) or radiotherapy for localised prostate cancer is complex for two reasons. First, active treatment can have serious negative impacts on quality of life including sexual dysfunction, urinary leakage, and compromised bowel function [1–7]. Second, even in the absence of active treatment, many localised cancers will never become life threatening [8,9]. Notwithstanding these limitations, most men with recently diagnosed localised prostate cancer in Europe, Australia, and the USA choose to receive active treatment [10,11].

An alternative to active treatment is active surveillance (AS). AS is a conservative management strategy for men with low-risk localised prostate cancer, which aims to avoid the overtreatment of clinically insignificant disease or delay the harsh side effects of active treatment without compromising long-term survival. It involves clinical examinations, imaging, prostate-specific antigen (PSA) tests, and prostate biopsies, with the option of transitioning to active treatment if disease progression is found. Prior to the emergence of AS almost 20 yr ago, watchful waiting (WW) was available to men seeking to conservatively manage their prostate cancer. WW differs from AS in that the former requires fewer medical tests and patients can generally be managed in the primary care setting. Currently, WW remains an option for patients with limited life expectancy and thus unlikely to benefit from the additional monitoring of AS.

Although AS and WW patients can avoid or delay the negative physical consequences of active treatment, there has long been the concern that these patients may suffer psychologically [12,13]. Despite this, there has only been one previous study with long-term follow-up of 10 yr or more comparing the psychological well-being of AS or WW patients with an active treatment group [14], and that study was limited to a single type of active treatment (RP) and to an assessment of only four psychological domains. Therefore, the first aim of the current study was to provide more long-term detail on psychological outcomes by assessing a greater variety of domains and active treatment types. A second aim was to assess the long-term effects of AS/WW on selected physical aspects of quality of life.

2. Patients and methods

2.1. Study sample

The Prostate Cancer Care and Outcome Study (PCOS) is a population-wide longitudinal cohort study conducted in New South Wales (NSW), Australia, with a primary objective of assessing the effects of various treatments on quality of life after the diagnosis of prostate cancer. A total of 3195 men, aged <70 yr, with histopathologically confirmed T1–4 prostate cancer diagnosed between October 2000 and October 2002 were identified through the NSW Cancer Registry and invited to participate in PCOS once consent had been given by their doctor (Fig. 1). "Baseline" interviews were completed by all participants as soon as practicable after diagnosis and recruitment, and, in the majority of cases, the interviews occurred after primary therapy had begun (mean = 3 mo after diagnosis; range 1–12 mo). Among participants who completed the baseline interview and had adequate clinical records, 1874 were recruited to PCOS and, if available, interviewed at baseline and at 1, 2, 3, and 5 yr after diagnosis. Men were eligible for the current component of the PCOS study if they had completed a baseline and 10-yr follow-up survey (mean = 10 yr after diagnosis; range 9–11 yr) and had "low-risk" localised disease at diagnosis (defined on the D'Amico risk scale [15] as PSA $\leq$ 10, Gleason score $\leq$6, and clinical stage = T1–2a; n = 341). The current analyses were restricted to men with low-risk disease because conservative management is less likely to be suitable for patients with higher-risk disease. PCOS was approved by the human research ethics committees of the Cancer Council NSW, the Cancer Institute NSW, and the NSW Department of Health. The 10-yr survey was approved by the Cancer Council NSW Human Research Ethics Committee (approval number: 2010#244).

2.2. Data collection

2.2.1. Clinical and sociodemographic data

Clinical data were collected for each participant by either a trained field worker or the treating doctor using a data collection form and protocol. These data were collected between 12 and 24 mo after the histological diagnosis of prostate cancer, and included PSA level at diagnosis, Gleason score and clinical stage at diagnosis, and treatment received within 6 mo of diagnosis. Place and socioeconomic status of patient's area of residence at diagnosis were based on the Accessibility/Remoteness Index of Australia [16] and the Socio-Economic Indexes for Areas [17], respectively. Highest level of education completed was self-reported in the baseline PCOS survey.

Information on prostate cancer treatments received was obtained from the treating doctor's records (from diagnosis to 12 mo) and from linked administrative records (from diagnosis to 10-yr follow-up). For each man who consented, treatment data were obtained from Medicare Australia and NSW Health's Admitted Patient Data Collection [18]. Active treatments included RP, external beam radiation therapy (RT), androgen deprivation therapy, high-dose-rate brachytherapy (HDR), and low-dose-rate brachytherapy (LDR). For conservatively managed patients, we were unable to ascertain whether they were managed through AS or WW (but they were probably more likely to be managed through WW at baseline because AS formally emerged only around the time that PCOS began recruitment). Hence, for the current analyses, conservatively managed patients were grouped together as AS/WW.

Active treatments were grouped according to patient's initial active treatment (RP, RT and/or HDR, LDR). Patients who received AS/WW at baseline were analysed as a single arm in the primary analysis but were divided into the following two groups in planned exploratory subgroup analysis: (1) those who subsequently received an active treatment ("AS/WW then active treatment") and (2) those who remained on AS or WW throughout the follow-up period ("AS/WW only").

2.2.2. Measures of psychological and health-related quality-of-life outcomes

A number of previously validated psychological instruments were included in the 10-yr survey: Kornblith's five-item Cancer Fear of Progression Scale [19]; the six-item course of cancer subscale from the Cancer Locus of Control Scale measuring each individual's perceived control of the course of their cancer [20]; the 22-item Impact of Event Scale-Revised measuring distress, hyperarousal, intrusive thinking, and cognitive avoidance associated with having prostate cancer [21]; and the 14-item Hospital Anxiety and Depression Scale measuring anxiety and depression [22].

The 10-yr survey also included questions from the 26-item Expanded Prostate Cancer Index Composite Short Form (EPIC-26) [23], while the baseline PCOS survey included questions from the University of California—Los Angeles Prostate Cancer Index (UCLA-PCI) [24]. From a subset of questions common to both UCLA-PCI and EPIC-26, baseline and

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