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Anxiety and health-related quality of life (HRQL) in patients undergoing active surveillance of prostate cancer in an Australian centre

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Objective

To assess anxiety, health-related quality of life (HRQL) and understanding of active surveillance (AS) in a cohort of patients enrolled in AS of prostate cancer in an Australian setting.

Patients and Methods

Survey of 61 men currently enrolled in AS for prostate cancer, which included validated measures of sexual function using the International Index of Erectile Function (IIEF-5), voiding using the International Prostate Symptom Severity Score (IPSS) and the Memorial Anxiety Scale for Prostate Cancer (MAX-PC), a measure of prostate cancer specific anxiety.

Three novel questions to assess patients' Understanding of AS (UAS).

IIEF-5 and IPSS scores obtained through the present survey were compared with patients' scores at initiation of AS.

Results

In all, 47 of 61 (77%) patients responded to the survey.

There was no significant difference in patients' IIEF-5 and IPSS scores at commencement of AS compared with the survey results.

Our patients' on AS MAX-PC scores were consistent with other published cohorts and did not suggest high rates of clinically significant anxiety amongst this cohort.

Most (89%) of the patients' responses to the UAS indicated a correct understanding of AS.

Conclusion

Our patients on AS maintained their HRQL with low levels of anxiety, which did not differ from those reported in other groups of men with prostate cancer and most had an appropriate understanding of AS.

This study represents one of the first Australasian investigations on HRQL and anxiety in men on AS of prostate cancer.

Keywords

prostate cancer, active surveillance, quality of life, anxiety

Introduction

The widespread adoption of prostate cancer screening and increased tissue sampling has resulted in an increased incidence of prostate cancer [1]. Many of these tumours will have little or no clinical significance for the men affected and little effect on mortality. As such, health-related quality of life (HRQL) considerations are often paramount in men's decisions about prostate cancer management [1–4]. Active surveillance (AS) has gradually increased in popularity since it was first described in 2002, as it provides a clinical path for men with low-risk prostate cancer by which they can avoid or delay radical treatment, with its attendant detriment to HRQL, while preserving the option of curative treatment in the event of disease progression or initial misclassification [5–7].

Studies thus far have not shown any significant oncological detriment associated with AS with delayed treatment and progression in low-risk prostate cancer [6,8,9]. However, there are fewer studies addressing HRQL issues, including both functional outcomes and measures of anxiety among patients on AS. Furthermore, studies of AS have indicated that a variable proportion of men abandon AS in favour of treatment without evidence of progression [5,10], some of whom are motivated by anxiety about their cancer diagnosis.

We present one of the first investigations into HRQL and anxiety in Australian men on AS for prostate cancer with validated questionnaires to evaluate their sexual function, continence and anxiety relating to their cancer. We have used additional questions to assess the patients' understanding of their management with AS.

Patients and Methods

From a single surgeon database, 61 men currently enrolled in an AS programme for management of their low-risk prostate

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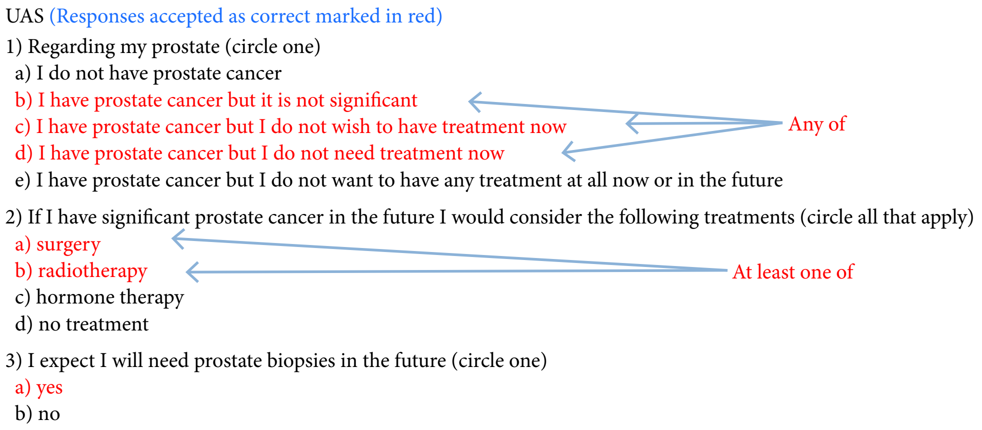
Fig. 1 Questions and accepted responses in UAS.



UAS (Responses accepted as correct marked in red)

1) Regarding my prostate (circle one)
a) I do not have prostate cancer
b) I have prostate cancer but it is not significant
c) I have prostate cancer but I do not wish to have treatment now
d) I have prostate cancer but I do not need treatment now
e) I have prostate cancer but I do not want to have any treatment at all now or in the future

Any of

2) If I have significant prostate cancer in the future I would consider the following treatments (circle all that apply)
a) surgery
b) radiotherapy
c) hormone therapy
d) no treatment

At least one of

3) I expect I will need prostate biopsies in the future (circle one)
a) yes
b) no

cancer as of May 2013 were contacted by mail with a letter explaining the study process, objectives and a copy of our survey. Ethics approval was obtained through Northern Sydney Coast EC0012 (NSC) Human Research Ethics Committee (HREC) 1206 212M for this part of the study.

The survey comprised the IPSS, the five-item version of the International Index of Erectile Function (IIEF-5) and the Memorial Anxiety Scale for Prostate Cancer (MAX-PC). We also included three novel questions designed to assess patients' Understanding of AS (UAS) (Fig. 1).

Patients were directed to return surveys anonymously by post in envelopes provided with the survey and a reminder sent at 8 weeks for those that had not responded. Data were extracted 'blindly' from the surveys and recorded in a secure database. Survey data from the IPSS and IIEF-5 were compared with patients' results at their initial pre-biopsy consultation before commencement of AS, information which is routinely collected. Data from the initial and survey IPSS and IIEF-5 were compared. Descriptive statistics was used for analysis of the MAX-PC and UAS data.

Results

In all, 61 patients were sent the survey and 47 (77%) responded. The group of eligible patients (61 patients) had a mean (95% CI) age of 62 (60–63) years, IPSS score of 9.7 (7.5–11.8) and IIEF-5 of 20.6 (18.5–22.7). The respondents (47 patients) had mean (95% CI) scores on IPSS of 9.4 (7.5–11.3) and IIEF-5 of 18.3 (16.1–20.4). The mean (95% CI) overall MAX-PC among the respondents was 15.5 (13.4–17.6) with subscale results of 7.4/33 for general anxiety (95% CI 5.5–9.3), 0.8/9 for PSA specific anxiety (95% CI 0.3–1.3) and 7.3/12 for fear of recurrence (95% CI 6.5–8.2) (Fig. 2). There was no significant difference in the commencement and survey IPSS and IIEF-5 scores (Figs 3,4). For patients' understanding of AS, five patients (11%) submitted responses that did not fulfil our criteria for correct understanding.

Discussion

The present study considered a population of men in a regional area undergoing AS, with a view to assessing their HRQL through measurements of sexual function, continence and anxiety about their disease. The published data on AS has shown no adverse oncological outcomes with delayed definitive treatment for progression [6]. Several studies have emerged reporting reassuring HRQL and functional outcomes among men on AS [11,12]. The present results are consistent with current published data, with no significant difference in urinary or erectile function while on AS.

The MAX-PC is an instrument designed to measure anxiety relating specifically to prostate cancer, fear of recurrence and anxiety associated with PSA testing. However, its utility is subject to certain limitations. The literature relating to the development of the MAX-PC has not established precise threshold scores for clinically significant anxiety levels in men with prostate cancer [13–15]. An initial study used a score of 27/54 to delineate significant anxiety with 10.6% of patients meeting this criterion [16]. A further study used this threshold with relevant scores in only 2.3% of participants. Dale et al. [17], considering progression to androgen-deprivation therapy rather than AS, equated scores of >16 with elevated levels of anxiety, which applied to 22% of patients. Burnet et al. [18], using another instrument, the Hospital Anxiety and Depression Scale, reported 16% of patients in their cohort on AS meeting criteria for anxiety. The present results are consistent with the published literature. The average score for this instrument among our respondents was 15.5, below both proposed thresholds for increased or clinically significant levels of anxiety. Five patients (11%) had scores of >27 and sixteen (34%) had scores >16.

Fig. 2 MAX-PC scores with mean and 95% CI.

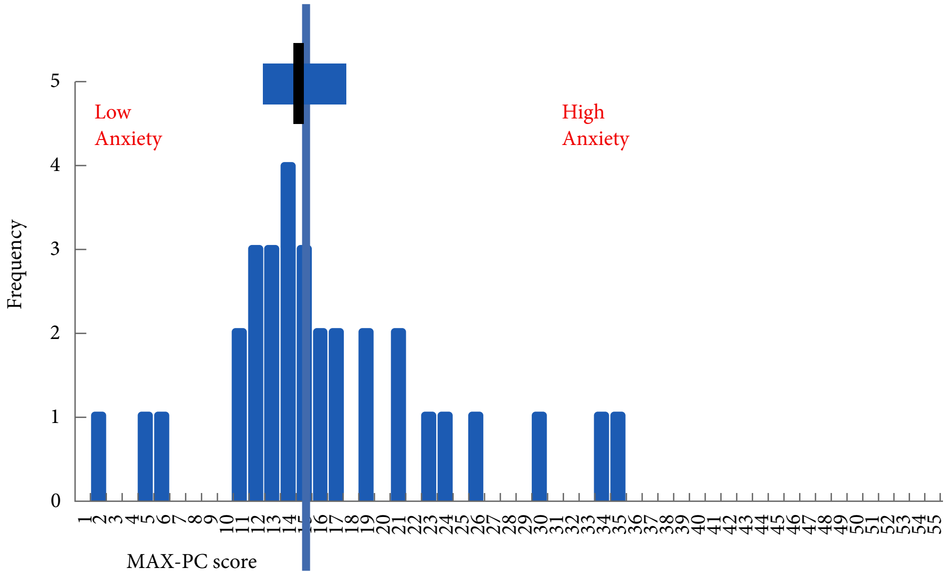


Fig. 3 IPSS scores before and after commencement of AS with mean and 95% CI.

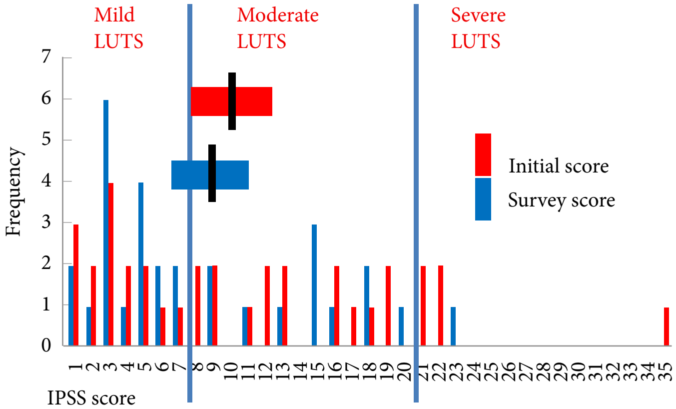
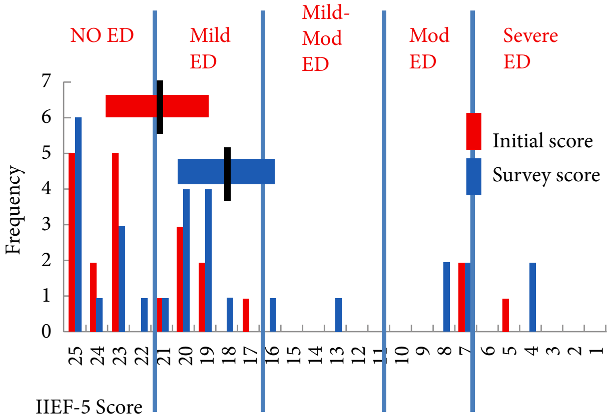


Fig. 4 IIEF-5 scores before and after commencement of AS with mean and 95% CI.



Patient anxiety is an important consideration in prostate cancer management and one of the reservations relating to AS has been its potential psychological impact [7]. This has been attributed to the experience of living with ‘untreated’ cancer [18] and also the requirement for repeated biopsy and PSA testing, as there is evidence to suggest that anxiety levels increase significantly around the time of investigations [19,20]. However, although men on AS are subject to regular biochemical, clinical and biopsy monitoring, the published data on anxiety and AS, and the results of the present study, do not support this hypothesis [11,21,22].

In addition, it has been shown that patient anxiety and distress are triggers for the pursuit of active treatment for prostate cancer [17,23]. Dale et al. [17] found that prostate cancer-specific anxiety (as indicated by a MAX-PC score of >16) was reliably associated with early initiation of androgen-deprivation therapy. Latini et al. [23] reported a similar trend among men on AS with increasing anxiety being an independent predictor of treatment. In addition, van den Bergh et al. [16] found that there was a strong correlation between patients’ MAX-PC scores at initiation of AS and at review 9 months later, suggesting a possible opportunity for intervention where patients are identified as higher levels of anxiety to either improve psychosocial functioning or to consider alternative treatment strategies.

Indeed, it is noteworthy that three of the five patients who had an incorrect understanding of AS in their responses to our questionnaire also had high MAX-PC scores (>16). This further suggests a need for thorough counselling of patients at enrolment into AS and throughout the monitoring process to avoid misplaced anxiety about their diagnosis or the likely course of their disease and treatment. There is an observed relationship between increased patient anxiety and distress and the role of the physician in the treatment decision [16,24]. Those with poor understanding of AS are perhaps more likely to defer to physician decisions, and therefore more likely to experience increased levels of anxiety. Counselling that encourages patient involvement and autonomy may improve the experience of AS for these patients [7]. In settings where treatment has been randomised rather than selected by the patient, patients have had increased anxiety and distress and decreased HRQLwhen compared with controls [4]. In the literature and in the present study, patients have elected to pursue AS, which may correlate with lower baseline levels of disease-specific anxiety [19] or may indeed result in decreased levels of anxiety or increased satisfaction with treatment outcome due to increased autonomy [16,21].

The present study assessed a small number of patients and relies on a single surgeon experience. In the present cohort, all patients were counselled individually about their treatment by the same consultant surgeon without involvement of junior medical staff, a practice nurse, psychologist or other input from allied health or medical personnel. The present results might not be reproduced in a setting where trainees with varying levels of knowledge and experience participate in or primarily conduct the consultations with patients. Furthermore, results may be altered, potentially improved, in a setting where there is access to multidisciplinary psycho-oncological input. However, we consider the characteristics of the present study to be reflective of practice in regional areas and encouraging of AS as a favourable management strategy in this patient setting.

To our knowledge, this is one of the first Australasian studies assessing anxiety and HRQL among patients on AS. Frydenberg et al. [25] also presented their data on psychological stress with AS at the USANZ Annual Scientific Meeting in Melbourne 2013 with similar conclusions. The present cohort, although smaller, had a high response rate. Smith et al. [3] studied the HRQL of a large cohort of Australian men with localised prostate cancer, including those on AS or watchful waiting, but did not assess anxiety levels.

These initial results indicate that Australian men on AS, despite concerns relating to psychological and functional morbidity, have comparable levels of anxiety to previously reported cohorts and consistent levels of sexual and voiding function. This adds weight to the argument for AS from a psychological perspective for the management of low-risk prostate cancer in the Australian context and confirms that it is a viable treatment option for patients outside major centres.

In conclusion, patients in our Australian AS programme for prostate cancer maintained their HRQL measured by IIEF-5 and IPSS, had low levels of anxiety measured by MAX-PC and most have a clear understanding of AS for prostate cancer. The present study results are consonant with international data, showing comparable anxiety levels among a cohort of Australian men on AS for prostate cancer.

Conflict of Interest

None declared.

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Abbreviations: HRQL, health-related quality of life; IIEF-5, five-item version of the International Index of Erectile Function; MAX-PC, Memorial Anxiety Scale for Prostate Cancer; (U)AS, (Understanding of) Active Surveillance.