PSA testing: are patients aware of what lies ahead?

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ABSTRACT

INTRODUCTION Screening for prostate cancer with serum prostate specific antigen (PSA) remains a controversial topic. The UK NHS Executive has issued extensive guidance stressing the importance of adequate counselling prior to performing this test. This study aims to assess men's knowledge of the PSA test at the time of their referral and their attitude towards screening.

PATIENTS AND METHODS A total of 219 men referred to urology via the 'fast track' prostate cancer service were recruited into the study. Of these, 191 were referred from primary care and 28 from secondary care. All men completed a questionnaire regarding their knowledge and expectation of the test.

RESULTS The response rate for completed questionnaires was 100%. Overall, 91 (41.5%) men were aware that their PSA had been performed prior to referral and only 79 (36%) men understood why the test was being done. Patients referred from secondary care appeared to be better informed. Despite these figures, 175 (80%) men said they would recommend PSA testing to a friend or colleague, and 196 (89%) men said the test should be broadly publicised.

CONCLUSIONS Nearly two-thirds of the men referred to urology with an elevated PSA were unaware that they had even had their PSA done. Information about the limitations of PSA testing and the consequence of a positive test result had been deficient. Informed counselling for the PSA test should form part of the consultation of any physician intending to undertake this test whether for lower urinary tract symptoms or for prostate cancer screening.

KEYWORDS

Prostate cancer – Screening – Prostate specific antigen (PSA) – Consent

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Prostate cancer makes up 20% of all newly diagnosed cancers and is the second commonest cause of cancer death (12%) amongst men in the UK with the incidence rising sharply in men over the age of 50 years.¹ In view of these statistics, it may seem advantageous both to clinicians and patients to offer men over 50 years of age a PSA test to aid screening them for prostate cancer. However, the benefits of routine PSA for prostate cancer screening have yet to be proven and have remained a matter of controversy in the UK and overseas. Currently in the UK, there is no screening programme for prostate cancer in asymptomatic men. The UK National Screening Committee has adjudged that PSA screening does not fulfil the requirements of such a programme.² Indeed, concerns have been raised regarding the inadequate information given to men prior to having a test.³ Consequently, a Prostate Cancer Risk Management programme was initiated, which aims to advise clinicians and patients on key points a man should understand before having a PSA test.⁴ The British Association of Urological Surgeons (BAUS) and The Royal Colleges of Radiologists and Clinical Oncology also issued guidelines for primary

care clinicians regarding PSA testing advising against testing asymptomatic men unless the patient requests the test.⁵ This paper addresses the issue of the present practice of patients' informed consent prior to PSA testing in the UK to see just how informed the patients attending the fast track prostate cancer service really are.

Patients and Methods

Patients were recruited between January and December 2003. Questionnaires were filled out by all new patients referred through the urology department's 'Fast Track Cancer Service' by their general practitioner (GP) or a secondary care physician with a raised PSA and the suspicion of an underlying prostate malignancy. Men were excluded from the study if they had a prior diagnosis of prostate cancer. The questions related to age, symptoms, origin and instigator of the PSA test, and knowledge and attitudes towards PSA testing (Fig. 1). The resultant questionnaires were collected by medical students prior to the patient's consultation with a urologist. Any questionnaire discrepancies were reviewed with the patient

1. To which of the following age groups do you belong (tick appropriate)?	
Younger than 45	☐
45 – 55	☐
56 – 65	☐
66 – 75	☐
76 – 85	☐
Older than 85	☐
2. Why initially did you visit the doctor who referred you to the urology clinic (tick all that apply)?	
Increased frequency of urination	☐
Needing to urinate excessively at night	☐
Poor flow of urine	☐
Sense of urgency to urinate	☐
Difficulty getting urine flow started	☐
Prolonged dripping following urination	☐
Family history of prostate problems	☐
Other (please provide details in the space below)	☐
3. Did you have a PSA blood test prior to attending urology clinic?	
Yes	☐
No	☐
Don't know	☐
If yes, how many times?	
Go straight to Question 12	
4. Were you aware that a PSA test was being carried out, at the time?	
Yes	☐
No	☐
5. Who suggested that the test be carried out?	
Yourself	☐
GP	☐
Hospital consultant	☐
Don't know	☐
If yourself, why?.....	
6. Did the doctor who referred you to the urology clinic examine your prostate before your first PSA test?	
Yes	☐
No	☐
Don't know	☐
7. How did the doctor describe the results of your most recent PSA blood test?	
High	☐
Within normal range	☐
Results were not explained	☐
Can't remember	☐
Results not yet received	☐
8. Do you feel that you understand why a PSA test is carried out?	
Yes	☐
No	☐
9. Did you understand this before attending clinic for the first time?	
Yes	☐
No	☐
10. Would you recommend others to have their blood PSA tested (please provide a reason)?	
Yes	☐
No	☐
Reason:	☐
11. Do you think that the availability of PSA testing should be more widely publicised?	
Yes	☐
No	☐
No opinion	☐
12. Other than problems with your prostate, do you suffer from any other major health complaints?	
Yes	☐
No	☐
If your answer was 'yes', please list in the space below	

Figure 1 A questionnaire completed by men attending the 'fast track' prostate cancer service questioned their understanding both for the reason for referral and regarding the subject of PSA and prostate cancer.

Figure 2 The age range of men referred to the prostate cancer fast track service due to a raised PSA.

to ensure all forms were completed to a suitable standard for analysis. Data analysis was performed using Microsoft Excel and Access.

Results

We assessed 219 men referred with an elevated PSA via the new cancer referral service. The age range of the respondents was from 45–85 years old with the majority between 56–85 years (93%) as shown in Figure 2. Most men had presented to the referring physician with the lower urinary tract symptoms (LUTS) of frequency (30%), nocturia (25%) and poor flow (20%). A family history of prostate cancer prompted the test in 10% of the men. Self-referral for PSA screening in asymptomatic men comprised 3% of the men studied.

Figure 3 Patient awareness reason for referral to the 'Fast Track Cancer Service' and had they been adequately examined before referral.

Patients were asked who propagated the test and which was corroborated with the medical notes. The major referral source was primary care accounting for 191 (87%) with 175 (79%) of these requested by the patient's GP and 18 (8%) at the patient's request. Referrals from secondary care made up 13% of all patients questioned.

The number of men who recalled having had the test in primary care was 67/191 (35%) compared to 24/28 (86%) of men tested in secondary care. Men's insight into the reason why the referring physician had requested a PSA was lacking in both primary and secondary care settings by 134/191 (70%) and 6/28 (22%), respectively. In total, 125/218 (57%) of men (both primary and secondary care) stated that they did not understand what the indications for the PSA test were as depicted in Figure 3.

Once men had been given information on PSA testing and prostate cancer, they were asked if they would recommend the test to a friend or colleague. PSA testing was recommended by 80% of the men questioned while 10% felt it was inappropriate with a further 10% uncertain of whether they would or not. Furthermore, 90% of men felt that the test should be more widely publicised, 5% did not think it should be due to previously stated uncertainties regarding screening issues and 5% remained uncertain.

Discussion

The natural history of prostate cancer is varied with autopsy studies suggesting that the majority of elderly men have a focus of prostate cancer by the time they die.⁶ Consequently, accurate prediction of progression for screen-detected prostate cancer remains uncertain. Most men with low-grade tumours will incur no loss of life expectancy, no symptoms and are likely to die from another cause.^{7,8} The ultimate aim of screening will be to detect the localised aggressive cancers which can be cured by radical treatment if detected in time.⁹ The converse to this is men with clinically insignificant tumours which do not require treatment will be detected through PSA testing and exposed to the associated morbidity of radical therapy or the anxiety of active surveillance.¹⁰ Consequently, treatment is detrimental to such a low-risk population, leading us to await the outcome of on-going assessments of risk stratification to balance the benefits and harm of screening.^{11,12} The American Urological Association (AUA) recommended screening to be offered to all men over 50 years of age with a life expectancy of greater than 10 years. Yet the US Preventive Services Task Force states that there is insufficient evidence for the benefits to outweigh the risks thus illustrating the lack of consensus regarding the subject.¹⁵ To confound patients and clinicians further, the optimal management of prostate cancer to reduce disease-related mortality, maintain quality of life and improve life expectancy has not been confirmed.¹⁴

It is evident that most men in our study who had their PSA tested had initially presented to their GP with LUTS and only a minority (3%) actively sought to find out their own PSA. Two-thirds of men failed to recall having had a PSA test; furthermore, a similar figure (64%) stated that their level of understanding was not as one would expect prior to making such a potentially important decision. Similar studies in the US showed varied results in primary care of male awareness of prior PSA testing. One study of university-affiliated veterans and a further one during 'National Prostate Cancer Awareness Week' showed 19–33% of men younger than 80 years could not recall having had their PSA tested.^{15,16} In these studies, the time from testing to completing the questionnaire after testing was longer than in our study. In a small study in Oxford ($n = 52$), almost all patients analysed remembered having had a PSA test, but stated that they had received little information at the time of the test.¹⁷

More men in our study reported a lack of awareness in the general practice referred group compared to those men tested in secondary care. In the primary care setting when patients present with LUTS or to request PSA testing, there is often insufficient time to have a lengthy discussion to cover all of the ramifications of PSA testing unless the patient books an appointment specifically for prostate cancer screening. With the issues over introduction of a screening programme and lack of knowledge regarding the optimal treatment of prostate cancer, some clinicians may be unclear how to inform their patients proficiently.

Following consultation, some men may forget or may not have understood the information that they had been given by the physician.¹⁸ Our analysis did not take into consideration education level amongst the men questioned. Other studies have shown evidence that lack of understanding of the PSA test was more prevalent in men with poorer school education.^{19,20} It is also possible that they were never informed of having the test or given information on prostate cancer when consulting with the attending physician at the time of their PSA being tested.

Our study and data from other studies highlight the importance of counselling these men to help make an informed choice on testing. The question needs to be asked how improvements can be made to increase men's knowledge about PSA before having the test. This is not an easy question to answer because aforementioned factors need to be taken into consideration. The use of shared decision videos have shown to significantly improve men's knowledge of detecting prostate cancer and the possible treatments in the decision to have the test.²¹ By increasing knowledge surrounding the limitations of PSA testing and controversies over prostate cancer treatment through videos, internet and fact sheets, more men are likely to decline the test.^{18,22} In our sample who were given verbal information on PSA testing, 10% of men were unsure or felt

that the test should not be used widely as a screening tool given its limitations. This suggests that better aids are required to help men seeking advice from a physician on PSA testing to help in their understanding and decisions.

Conclusions

There is disparity between the number of patients recruited from the community and hospital referral groups so no firm conclusions can be drawn regarding either groups' consenting practice. This paper is not intended for vilification but instead is intended to increase the awareness of clinicians who deal with this group of patients. There is a requirement for informed consent prior to testing a man's PSA and our study shows this to be lacking in present clinical practice.

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