

'It's a maybe test': men's experiences of prostate specific antigen testing in primary care

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ABSTRACT

Background

Prostate specific antigen (PSA) testing in primary care is an important and contentious issue. Due to concerns about the test and the value of early detection, countries such as the UK advocate 'informed choice' instead of population screening. It is not known whether this policy is actually adhered to in primary care. Furthermore, little is known of the experiences of men who face this decision.

Aim

To explore the experiences, understanding, and views of men who considered or undertook PSA testing in UK primary care.

Design of study

Qualitative interview-based study.

Setting

Primary care, Wales, UK.

Method

Semi-structured one-to-one interviews were conducted with 28 men, representing a range of clinical outcomes. Transcripts were coded and subjected to thematic analysis.

Results

Three themes were identified: the decision-making context, the locus of decision making, and uncertainty related to the PSA test.

Conclusion

The decision to undertake PSA testing was affected by both social and media factors and it did not appear to be a patient-led decision. The decision created considerable uncertainty for men and this uncertainty persisted after the test, even if the result was normal. Raised PSA led to further investigations and this exacerbated the uncertainty. Anxiety and regret were consequences of this uncertainty.

Keywords

primary care; prostate; prostate-specific antigen; uncertainty.

INTRODUCTION

Men considering prostate specific antigen (PSA) tests face a difficult decision. On the one hand there is increasing awareness of the extent of the problem of prostate cancer: 27 000 men were diagnosed with it in 2002 with almost 10 000 deaths.¹ On the other hand, the only test currently available is, in many respects, unsatisfactory, as up to two-thirds of men with an abnormal PSA will not have prostate cancer² and almost one-fifth of men with prostate cancer will have a 'normal' test.³ Furthermore, at present, there is no evidence that early detection of prostate cancer improves prognosis and reduces mortality. There is a strong argument that PSA testing can cause harm, due to the physical and psychological side-effects of prostatic biopsies and prostate cancer treatments. It is hoped that the ongoing ProtecT trial will improve understanding of the relative effectiveness of these different treatments.⁴

Given these concerns about PSA testing, some commentators have taken a highly critical position.⁵ In the UK, as in other countries, prostate cancer screening using the PSA test is not currently

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How this fits in

Little is known about the views of men regarding PSA testing in primary care. This study demonstrates that men experience significant uncertainty relating to the process of the test itself, the result, and any further interventions. The men also have difficulties in understanding this uncertainty and the whole experience can cause considerable anxiety. The decision to have a PSA test is affected by both social and media factors, and there is little evidence of it being a patient-led decision.

advocated. Instead, the UK National Screening Committee has introduced the 'Prostate Cancer Risk Management Programme' (PCRMP), a strategy enabling men to make informed choices about PSA testing.⁶ Little is known about the understanding and experiences of men who consider the PSA test. Chapple *et al*, found that men with suspected or diagnosed prostate cancer had scant memories of receiving any information prior to the test; however, the men were keen advocates of increasing PSA testing for men in the UK and very supportive of a national screening programme.⁷ More broadly, it is known that a range of factors influence men's decisions to seek advice regarding urological problems. Wolters *et al*, in a questionnaire survey, found that social factors such as the advice of others and the media were influential in men's decisions to see a doctor regarding lower urinary tract symptoms.⁸

Table 1. Clinical sampling framework for including men in the study.

Group	Clinical outcome	PSA test	Urological symptoms (n)	Total (n)	Study identifier
1	Declined PSA	Declined	1	1	1
2	Normal PSA result	Undertaken test	8	11	2–12
3	PSA raised; no biopsy	Undertaken test	2	3	13–15
4	PSA raised; prostate cancer not diagnosed on biopsy	Undertaken test	4	5	16–20
5	PSA raised; prostate cancer diagnosed on biopsy	Undertaken test	2	4	21–24
6a	—	Uncertain of undertaking test	1	1	25
6b	—	Uncertain of the result	2	3	26–28
Total			20	28	

PSA = prostate specific antigen.

What is not known is how men react to the institutional uncertainty created by a national strategy such as the PCRMP, where men are allowed access to a test such as PSA, the value of which is highly questionable at a population level, though possibly beneficial on an individual level. This is a significant research gap for primary care, and this study aimed to redress this deficit by exploring the understanding, views, and experiences of men who have considered or undertaken PSA testing in primary care. By casting some light on the natural event of PSA testing in UK primary care, it is hoped that clinicians and policy-makers will be better informed about the current situation.

METHOD

A qualitative study design was employed, using semi-structured interviews. Men between the ages of 40 and 75 years were recruited — this was the age range identified for the PCRMP. The men were identified from six Welsh general practices: one urban, one suburban, one rural town, one coastal village, and one post-industrial valleys town. GPs in these practices were asked to identify men who had undertaken PSA testing, principally using computer searches. No requirement was made for the GPs to restrict recruitment to men who had recently undergone PSA testing. GPs were also asked to identify men who had discussed but subsequently declined PSA testing.

A sampling framework was developed to include men in the study from five different groups, defined in terms of clinical outcome (Table 1). These groups represented the range of possible PSA test experiences, from men who had considered and declined the test to those who had subsequently undergone treatment for prostate cancer. Recruitment continued until these five groups had been represented and thematic saturation had been attained for the sample as a whole. An additional group of six men had to be constructed for those who were uncertain of having undertaken the PSA test or uncertain of the result (Table 1).

Invitation letters, information sheets, and consent forms were sent to the men by their GPs. Consent forms were returned to the GPs who transferred affirmative ones to the research team. The men were contacted and interviews arranged in their homes. The scope of the interview included pre-existing knowledge, discussions with the GP about the PSA test, the actual decision, responses to the result and any subsequent investigations or treatments. From this information the clinical group in which the men belonged was identified (Table 1). Transcribed interviews were coded independently with qualitative software, Atlas-ti (version 4.1), using the constant

comparison technique.⁹ Coded transcripts were then subjected to thematic analysis using the network analysis functionality of the software to construct hierarchies, or 'trees' of themes.¹⁰ This is a systematic approach which seeks to minimise bias in the analysis. These hierarchies were developed in the context of two thematic networks: before and after the PSA test.

RESULTS

Twenty-eight men were interviewed between September 2003 and March 2004. One or more men in each of the six recruitment groups. For data protection reasons, GPs only provided names of those men who were willing to participate. Four response sheets were received from men declining to take part; however, the details of those men who were invited to participate and either declined or did not return their consent sheets were not known.

There was an imbalance in the number of men in each of the six clinical groups, with group 2 (normal PSA result) disproportionately represented by 11 of the 28 men. This was because the researcher was unaware of the clinical characteristics of the men prior to interview. A significant number of men with normal PSA results were interviewed before those with different clinical characteristics were identified. The other imbalance lay in group 1 (men who declined the PSA test) as difficulties were encountered in recruiting for this particular group. However, thematic saturation was attained for the sample as a whole. The majority of the men interviewed (21/28) had urinary symptoms when they initially presented to their GPs. Numerous medical issues, many unconnected with PSA and/or prostate problems, were raised during the interviews. This may have been due to the interviewer being a GP, but it may also be a reflection of the complexity of the PSA question. No medical advice was imparted during the interviews and, if concerns or questions arose, the men were advised to contact their own GP.

Analysis of themes

From the two thematic networks (before and after the PSA test), three themes were identified: the decision-making context; the locus of decision making; and uncertainty related to the PSA test.

At the end of each quotation, the interviewed man's corresponding clinical group and identifier number is shown. The presence of urological symptoms at presentation is indicated by the letter 'U'.

Theme 1. The decision-making context

Outside the formal healthcare setting, two important contextual factors influenced the men's awareness of PSA issues: their social networks and the media.

Men's social networks. The men's social networks, specifically their family and friends, were found to have a strong influence on PSA testing decisions:

'So my brother, who's 3 years older than myself, and I'm 74 in a week's time, had this prostate trouble, back about 10 years ago from now. He kept onto me to get a test and I said, "What do I need a test for? I've got no problems". He said that it could be hidden and you don't know it's there. So he badgered me for quite a long time. At the end of the day I said: "Ok, I'll go and have a blood test".' (Group 5, man 23)

Direct advice from individuals within the networks was important, as in this example, where the daughter's status, as a healthcare professional, added to the legitimacy of her opinions:

'Because I was noticing that I was going to the toilet quite a lot in the night, and because my daughter is a state registered nurse, and if I've got any problems regarding my health, I always ask her. And she advised me to go to the doctor immediately. So he sent me for the PSA test.' (Group 2, man 7, U)

Change in the men's social networks could have a significant effect, for example, the arrival of a new neighbour:

'We had a neighbour move in just below us, and he told us that he'd actually had prostate cancer, and that he'd had an operation which apparently cured it; and since, has had no more problems. He said that it showed up by having what's known as a PSA test, which I knew nothing about, so I asked the local doctor and he said, yes it was possible to have the test.' (Group 2, man 9)

Another influential factor on testing was the potential effect of the men's decisions on their social networks:

'I know I am elderly, and I can't expect to live many years longer, but I don't want to leave my wife on her own, so I'm going to hang on to life for as long as I can.' (Group 5, man 21, U)

Media influences. It was clear that some of the men had been exposed to significant media coverage of PSA/prostate issues:

'There was a lot of stuff in the press at the time about how easy it was to detect early prostate problems, through a PSA test.' (Group 4, man 18)

Of the different media, the newspapers seemed to be particularly important:

'Well, quite a few articles appear in the press from time to time. The two main newspapers I read are the Telegraph and the Times — sometimes I read the two, sometimes just the one. Also I got a couple of textbooks, books on prostate problems.' (Group 5, man 24)

There was only one example of using the internet as a source of information, and this had been accessed by the man's son:

'I had got all the information to read from what my son had taken from the internet.' (Group 5, man 22, U)

There no example in the interviews of the media directly influencing men to have a PSA test. There was, however, evidence of an effect on the men's knowledge, as in the case of one man who subscribed to a general periodical:

'I knew quite a bit about the prostate. I'd subscribed to Reader's Digest for a long time, and it covered the matter completely.' (Group 4, man 19, U)

And from his reading, the man had gleaned an understanding of some of the uncertainties of the PSA test:

'I'd read various articles concerning prostate cancer and the anonymity of it really. The PSA test is the only way of catching it and even that is not infallible, as you know.' (Group 5, man 24)

Finally there was the effect of media celebrities, as exemplified by one man relating his raised PSA to the experience of a popular singer/comedian, who was born in his city:

'I was worried to put it lightly. Hearing about people like Sir Harry Secombe — he died because of prostate cancer — and that sort of thing goes through your mind.' (Group 4, man 20, U)

It is difficult to differentiate the effect of information relating to prostate cancer from that relating to PSA testing. This is particularly so as half of these quotations in this section on media influences are from men with prostate cancer:

Theme 2. The locus of decision making

There was little evidence that the decision-making

process relating to the PSA test was patient-centred. The following example illustrates doctor-centric decision making:

'I know my doctor very well. He's been treating me now since I left the army. He suggested a blood test, and I said fine. He didn't have to go into the details.' (Group 2, man 3, U)

The acceptance of this passive role seemed to be reliant on a high level of trust, as illustrated by the same man's use of a religious metaphor:

'Well I suppose it's like going into a church. You put your umbrella in the corner and let the priest get on with it quite frankly. I've never really been one for criticising doctors. We seem to live in this world of litigation where they can hardly get on with their job as it is. So I tend to leave the expert to do their job. I explain what's wrong with me, and I hope and trust that if they're well qualified, that I'm going to get the right treatment.' (Group 2, man 3, U)

Only one man in this study declined the PSA test. Nevertheless, his decision could not be described as being an active, patient-centred one:

'She gave me a leaflet to read about the PSA test that we are talking about now. I just haven't been back to the doctors since. No, no reason whatsoever really on why I haven't been back. I've not thought of any real reason to have the test.' (Group 1, man 1, U)

In contrast, the following quote is from a man who was unusual in firmly leading the decision-making process, partly as he was clearly influenced by a significant event within his social network:

'I went and asked for it. Because a friend of mine had died, through prostate cancer, and I being roughly the same age, I thought I would go and have a check up myself.' (Group 4, man 16, U)

Theme 3. Uncertainties of the PSA test

The uncertainties that related to the PSA testing process are described in terms of three sub-themes: 'pre-test' uncertainty; 'post-test' uncertainty; and the effects of these uncertainties.

Pre-test uncertainty. The uncertainty of the PSA test, both in terms of its validity and the broad range of subsequent outcomes, was an issue faced by a number of the men before the test:

'He did explain that although the test would find

out whether I had prostate cancer, it wasn't the be all and end all as far as the test was concerned. In other words if I came up as clear, there still may be some signs there, which I thought was a little strange at the time.' (Group 2, man 9)

Furthermore, the men differed in their understanding of these uncertainties. In general, understanding was poor:

'I didn't even know, until now, that it was called the PSA. All I understood was that it was a blood test, which should confirm whether there was cancer in the prostate or not.' (Group 2, man 2, U)

Other men, however, did demonstrate a level of understanding, albeit with hindsight in the interview:

'It's a "maybe" test. Maybe you have, maybe you haven't.' (Group 4, man 19, U)

Moreover, this man was able to recollect a metaphor that is used to explain to patients how individual prostate cancers differ from each other in their aggressiveness:

'I then read about the pussy cat and the tiger type of cancers: you've got the pussy cat type where it's better left alone, and the tiger type then of course, needing strong action immediately, or at least an eye kept on it.' (Group 6b, man 27,U)

One of the main challenges for the men was to understand the PSA test's poor specificity for both benign and cancerous prostate conditions. This man demonstrated some understanding:

'I don't think one blood test alone would be sufficient to determine whether I have got prostate cancer, or a prostate problem. I think there'd have to be something else to balance it up.' (Group 2, man 3, U)

In contrast, the man who made the following comment clearly experienced difficulties, and seemed to attribute this shortcoming to a lack of information:

'I think my principal ignorance was that I actually thought that most of the problems that were detected were to do with having an enlarged prostate in some benign fashion. I really didn't think it was all about having prostate cancer. I hadn't realised that at all, I have to say. So maybe I didn't get myself properly briefed, but nobody told me that either.' (Group 4, man 18)

Men's different desires for information, particularly from their doctors, seemed to contribute to their varied understanding of uncertainties prior to the PSA test. On the one hand some clearly wanted information, as in this case, where the man's healthcare background may also have been a contributory factor:

'I asked the doctor different things, and as I worked in a hospital anyway, I found out as much as I could about it.' (Group 4, man 20, U)

On the other hand, the following man seemed to prefer a relative degree of ignorance:

'I don't want to know to be quite honest with you. All they do is take the blood, and they tell me a number — four or five, and I say "is that alright?" and they say "yes" and I'm quite happy about that.' (Group 3, man 13, U)

While it is difficult in many cases to assess, from the men's recollections, what information was imparted by the GPs, it is probably true to say that if information was given, it varied in its detail. Some patients received very little information, as in this case:

'I received no information, other than what I knew and read about myself.' (Group 6a, man 25)

In contrast, the following man's GP attempted to explain the uncertainties relating to PSA testing, albeit with some difficulty:

'Well they apparently see if you've got cancer. I don't know really. He tried to put me in the picture the best he could.' (Group 2, man 7, U)

Post-test uncertainty. The PSA test result did not always resolve the uncertainty, even if it was 'normal':

'Nobody suggested that there should be a test every 12 months or 2 years. I thought that maybe I should go back every 12 months, but I don't know what the time scale should be.' (Group 2, man 9)

Repeated PSA testing could occur, particularly if the initial result was raised:

'There were more than one test, because the first one was marginally high, and the second one was slightly higher. So there were two tests, maybe three. I can't remember. It went on for a fair while, being a bit high.' (Group 4, man 18)

A raised PSA opened the possibility of cancer. It

also revealed different approaches, by doctors, to managing the uncertainty. In this case, the GP gave a fairly balanced view and a clear recommendation on the best course of action:

'The doctor said that although the level was raised, I didn't necessarily have cancer, but that it was best to find out whether or not.' (Group 4, man 20, U)

In contrast, the doctor of the following man took a far more reassuring, although arguably more risk-laden approach:

'The doctor decided that it was fairly high, but nothing to worry about.' (Group 5, man 23)

One consequence of this diagnostic uncertainty was the need for further investigations, specifically prostate biopsies. Even then, the situation could remain unclear:

'He arranged for a biopsy to be done and that was clear. So it was further monitored and up it went again, so back I went for another biopsy, and that was also clear. Monitored again and up it went again and I said to him, look, do you think I could have a third biopsy?' (Group 5, man 24)

And, in the event of a diagnosis of prostate cancer, further uncertainty was generated, in terms of outlook, as described by this man:

'The urologist explained that I did have cancer; suggested that I have hormone treatment and he explained that at my age the onset of cancer was likely to be slow, but that it may suddenly shoot out. He wasn't certain where I came on the curve, and that would appear on the tests that he would give me from time to time.' (Group 5, man 21, U)

Effect of uncertainty. The uncertainties of the PSA testing process could generate considerable disaffection among the men:

'What I don't like is the delay. The process of the system. During the 6 month period, could I develop cancer? If I could, something should have been done earlier.' (Group 2, man 8, U)

After the test a raised PSA could generate further anxiety, as in this case, where the man made an immediate diagnostic assumption of prostate cancer and turned his thoughts to the issue of life expectancy:

'Extremely worried. In fact I was shaken rigid, as I never thought that I'd have cancer there. I'd had

some exposure to sunlight and that sort of thing, and had cancerous things on my ear and there were other things removed from my body, but certainly never dreamt that I would have cancer of the prostate. I may have been told something, but to be quite honest when I knew what it was I was just horrified, and I walked out thinking, "How long?", because, with it being so high and I had seen things on the internet that a PSA of around 20 was not good. To think I got double this. I was very worried.' (Group 5, man 22, U)

Regret was this man's reaction to the testing process, and he clearly laid out a message for other men:

'I think in retrospect, I wish I hadn't. I would say, get very well briefed on what happens if the result of the test is borderline or potentially problematic. Be sure you know what you are letting yourself in for.' (Group 4, man 18)

DISCUSSION

Summary of main findings

Uncertainty was a theme that ran through the experiences of the men interviewed. It related not only to the test itself but also to further investigations and treatments, causing significant anxiety and sometimes regret. Men's opinions about the PSA test, and their subsequent experiences, were found to be influenced by their social networks and by the media. From the evidence available, the decision-making process did not, in general, seem to be patient-centred, apart from a small group of men whose decisions could be described as patient-led.

Strengths and limitations of the study

The methodology used in this study (semi-structured interviews) was appropriate to generate hypotheses from a low evidence base. Verbatim transcriptions were undertaken and selected quotations were not edited. There was independent analysis of the data and concordance in the identification of themes. The choice of setting, South and Mid Wales, allowed men to be recruited from GP practices whose patients represent a range of socioeconomic groups. Furthermore, the men formed a representative sample in terms of the clinical outcomes related to PSA testing in primary care. The men were made aware at the beginning of the interviews that the interviewer was both a researcher and a GP. While this knowledge may have been helpful in allowing the men to feel comfortable in a traditional patient-GP setting, thereby facilitating discussions about health-related matters, this knowledge may have had an impact on the data. Specifically, the men may have felt obliged to

align their views with what they perceived to be the established medical standpoint, for instance offering a more positive opinion on PSA testing than they would have done otherwise.

The transcripts from the interviews represent men's accounts of the events surrounding their healthcare experience. These accounts are subject to men's recollections and their interpretations of those recollections, both of which may have been particularly affected by the time gap between the PSA test and the interview. The transcripts may not have been entirely faithful to the spoken word: for instance, an interpretation may have been made of sentencing and words such as 'um' and pauses may have been removed.

The imbalance in the number of men in each clinical group means that thematic saturation cannot be claimed for each individual group. The challenges involved in attaining such a sample would have been considerable. The study GPs, who were not compensated for their involvement, were asked to identify men who had either undergone PSA testing or considered and declined PSA testing. Their information systems did not allow a more sophisticated sampling strategy to be undertaken easily. For instance, it was not possible to specify, for those who underwent PSA testing, how long ago they had the test. Furthermore, it was not possible to ensure that the men represented a desired broad range of socioeconomic groups. The researcher, therefore, was unaware of the men's clinical details until the commencement of the interview. Arguably, the men could have been asked about some of these details by the researcher when they were phoned to arrange the interview. However, entering into such a discussion may not only have prejudiced the subsequent interview but also caused anxiety for the men, particularly those who were uncertain about their PSA result.

A large number of men with normal PSA results were interviewed before the experiences of those with other clinical outcomes were captured (see Table 1). The recruitment, or sampling strategy, was therefore prospective rather than purposive, and it would have been preferable to interview more men who declined the test and men from ethnic minorities, as all of the interviewed men were 'White British'. This is notable in the context of prostate cancer as the prevalence of the disease is relatively high in men of African and African-Caribbean extraction. Finally, it would have been preferable to interview more men who did not have urological symptoms on initial presentation and whose concerns centred on prostate cancer. Nonetheless, as is evident in the transcripts, it is to be noted that men can present to their GP with both problems.

Comparison with existing literature

Two other qualitative studies have looked at PSA testing. Chapple *et al*, looked at a group of 52 men with suspected or confirmed prostate cancer and found that while they remembered having their PSA test, they remembered far less about receiving any information before testing.⁷ In contrast, this study recruited a group of men with a range of clinical outcomes, many without prostate cancer, and exclusively from primary care. In the other qualitative study,⁴ part of the larger ProtecT study, men were invited to a nurse-led clinic in general practice where they were given information about the PSA test and prostate cancer and asked to provide consent for the blood test; those with abnormal results were then invited for further investigations. The authors found that changes to the way treatment options were presented improved recruitment to the study.⁴ However, this tells us relatively little about the natural event of PSA testing, particularly in primary care.

This study's findings on the decision-making context is in agreement with other work on urological symptoms in primary care, albeit in the context of lower urinary tract symptoms and not specifically PSA testing. Wolters *et al*, found that men with lower urinary tract symptoms who consulted a GP were more likely to have received advice from both their social networks and the media than those who did not seek advice. Moreover, men were more likely to see their GPs if they believed that he or she could address their symptoms.⁸ Uncertainty has been described by other commentators as a key element of clinical situations. A paper by Edwards *et al*, described a three-level model of uncertainty in clinical encounters: first, collective (professional) uncertainty; second, individual (clinician) uncertainty; and third, stochastic uncertainty — the irreducible chance elements for all conditions.¹¹ The relevance of this model — certainly the first two levels of the model — to the PSA context is supported by this study, specifically by the inconclusiveness of the process and also by further components, as described in the current analysis, that relate to understanding of the uncertainty and the effect of the uncertainty.

Implications for clinical practice and future research

The finding that PSA testing is surrounded by issues of uncertainty imposes new obligations on clinicians. This involves embracing more patient-centred consultation styles in addition to the specific techniques drawn from the frameworks of shared-decision making, risk communication, and evidence-based patient choice.^{12,13} Moreover, comprehensive communication is crucial for men to make 'informed

choices', as envisioned in the PCRMP, currently being implemented throughout the UK.⁶ The challenge, is considerable, as is evident in other aspects of general practice, in particular the ordering of 'tests', where the implementation of shared decision making has been found to be difficult.¹⁴

Information designed for men needs to explain the multitude of uncertainties, both before and after the PSA test, and these uncertainties need to be discussed. Furthermore, recognition is needed that men's decision-making contexts are both rich and varied. Men do not rely solely on their doctors' opinions, important as they often are as reported here. They are also influenced, often strongly, by their extended social networks and by the media. Policymakers must therefore respond accordingly and recognise that PSA information does not start and finish in the doctor's consulting room. Paper decision aids, for instance, could be made available in a range of public places such as community centres and libraries. The greatest possibilities, however, are afforded by the internet. Notwithstanding the real

issue of equity of internet access, web-based PSA information could facilitate the decision-making process for men, with or without the help of their doctors.¹⁵

At present, the range of experiences encountered by men who consider PSA tests in primary care is not fully understood. While this sample may well reflect existing primary care practice in the UK, more research is needed on the experiences of men with raised PSA tests, those who decline the test, and men from ethnic minorities. Improved use of specific computer codes in primary care will help in this respect. This would also allow the development of PSA information that was both balanced and culturally sensitive.

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