

Why men with prostate cancer want wider access to prostate specific antigen testing: qualitative study

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Abstract

Objectives To explore the attitudes of men with confirmed or suspected prostate cancer to testing for prostate specific antigen.

Design Qualitative interview study with a purposive sample.

Setting Great Britain.

Participants 52 men with suspected or confirmed prostate cancer, recruited through general practitioners, urologists, patient support groups, and charities.

Results Almost all men remembered their prostate specific antigen test but recalled being given little information beforehand. Arguments in favour of increased access to testing included the belief that early diagnosis would reduce mortality, improve quality of life, and save the NHS money. Men also thought that a national screening programme should be available because symptoms can be ambiguous, screening for cancer is responsible health behaviour, and screening would encourage men to be tested. Four men who opposed a screening programme had gathered information alerting them to uncertainty about the benefits of treatment, and two regretted that they had been tested. Others thought that access to testing is restricted in the United Kingdom because of a lack of government backing, concerns about the accuracy of the test, and a lack of resources.

Conclusions The few men in this study who subscribed to the argument that evidence of the benefits of treatment is a prerequisite for a screening programme did not want to see screening introduced. Men who proposed an alternative set of principles for testing gave reasons that did not all relate to overoptimism about the benefits of early diagnosis. People who plan services and people who respond to requests for testing need to understand men's perspectives and concerns.

Introduction

Screening for prostate cancer cannot be justified while uncertainty remains about whether early detection and treatment saves lives.¹⁻³ However, support groups and much of the media do not question the benefit of screening and rarely mention the lack of evidence sup-

porting open access to testing for prostate specific antigen (PSA).^{4,5}

Concern has been expressed that men receive little or no information before having a PSA test.⁶ Although men who have received reliable information on screening are less inclined to request the test, many men continue to request it.⁷ Men with prostate cancer clearly do not represent all men who might seek a PSA test, but as "cancer survivors" their views command attention and have influence through the media. Their perspective is therefore important in helping to define what information men need when considering a PSA test.

Method

Sample—We invited men with suspected or confirmed prostate cancer to be interviewed for DIPEX (database of individual patients' experience of illness).⁸ We interviewed 52 men from throughout Great Britain between September 2000 and January 2001. Purposive sampling included men who had PSA tests because of their symptoms, men who received a diagnosis after routine private health checks, and participants in UK trials that included testing. Interviewing continued until the sample included men at different stages of diagnosis with experience of a wide range of treatments and until no new themes emerged from the data.

Interviews—The interviewer asked the men to tell their story, from when they first noticed their symptoms or had a test, with prompts about specific issues. All interviews were audiotaped and lasted one to three hours.

Analysis—Respondents reviewed full transcripts. Subsequent data analysis involved examining sections of the interviews thematically across the whole dataset as well as in the context of each man's interview.⁹ See bmj.com for characteristics of the sample and fuller description of methods.

Results

Lack of information about the implications of the test

More than three quarters of men had consulted their general practitioner because of urinary symptoms, and almost all remembered having had a PSA test.

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Box 1: Reasons for recommending a prostate specific antigen screening programme: a better chance of being cured and a right to information

"If you are over 50 you should have a PSA test every year to make sure you don't have this problem, and if you do the quicker you get onto it the better your chances of being cured." (Routine PSA check, support group member)

"The five year survival rate in this country is about 42%; in America it's between 85% and 90%, and this is very largely due to far more people being scanned for prostate cancer by PSA and DRE [digital rectal examination] and it being caught at an early stage when it is still treatable." (Support group member, had searched the internet)

"In America the mortality rate has come down quite significantly because more PSA tests are carried out there than in this country, but we feel that that's because in America you pay your doctor for a consultation." (Support group member, had searched the internet)

"I believe that in the States, many of the American states, PSA is obligatory or on offer for everyone over 50 ... In view of the fact that it [cancer] is relatively easy to get rid of if it's caught in time, a PSA test ought to be a requisite for every man over 50. And I'm delighted that many of my friends have gone off and had the PSA test." (Had searched the internet)

"We require more money to be spent on prostate cancer, and the earlier it is diagnosed the better, and I feel that if it was diagnosed earlier this would also save the health service money, which is in short supply." (Support group member)

"I would say have regular PSA tests. I think men have a right to know even if it's difficult to interpret the results, and I think you should know, and if the government is not going to do it for you, which they're probably not, then you should do it for yourself."

Whether or not men had presented with symptoms, they recalled being given little information at the time of the test (see bmj.com).

Reasons for recommending testing

All but four men who discussed routine PSA testing were keen to see others, including their own friends and sons, have a PSA test. Their reasons included the following.

Beliefs about the benefits of early diagnosis—Many men believed that early diagnosis is important for cure of cancer or to prevent it spreading (box 1). Because prostate cancer can be present without symptoms, men reasoned that only a routine national screening programme would suffice. One man noted that when the change in the PSA concentration is important for diagnosis, regular repeat tests are needed.

Responsibility—Men regarded participation in screening as responsible behaviour, and several made comparisons with women's cancer screening programmes. Two men suggested that early diagnosis through PSA testing would save the NHS money.

Avoiding regrets—For some men the "avoidance of regrets" was important. One man knew of others who regretted not having an earlier test and so advised other men to go for early diagnosis. Newspaper articles and popular medical books with patients' stories also highlight this issue.^{5 10}

A right to information and improved access—Some men asserted that it should be a right to have a PSA test and that if the government is not going to introduce screening then men should seek the test. Others suggested that because men are reluctant users of health services they needed a screening programme to encourage them to have the test without embarrassment.

Equitability—Many men discussed rights and parity with other healthcare spending, particularly screening

programmes for women (box 2). It was also suggested that if prostate cancer had a higher profile more would be spent on research and treatment, thus leading to improved detection and cure.

Views about why prostate specific antigen screening is not yet available

Some of the men who favoured screening thought a programme had not been implemented in the United Kingdom because the government had taken bad advice, was reluctant to fund screening, and lacked resources to treat the men who would be identified with prostate cancer. Concerns about the accuracy of the test were mentioned but not considered a convincing deterrent: "I believe that the PSA test, for all its weaknesses, and I understand those, men should have [them]. It's outrageous to suggest to men that they shouldn't have one ... I think the government is completely wrong, and I'm afraid to say that a lot of it is to do with trying to save resources." (Retired economist)

Men who are not in favour of a screening programme

Four men said that they were against national screening for prostate cancer. Two had had a PSA test as part of a health check, and the others had been tested after developing symptoms.

One man who saw an American educational video about PSA testing, which demonstrates uncertainty about the treatment options for men with prostate cancer, concluded that "To go to total screening would terrify so many people that you would cause a lot more harm than good ... It shouldn't be done until you've got a guaranteed test and an assured treatment." (Tested during investigation of symptoms, had prostatectomy)

Another, who had been influenced by a doctor in his family, thought that only men at high risk should be

Box 2: Reasons for recommending a PSA screening programme: equitability and the belief that screening would save the NHS money

"Women get screening tests for breast cancer, which has helped an awful lot of people, and I think men, when they get to 50, they should get these PSA tests as a national thing ... so that they can catch things early and stop the cancer spreading to the bones." (Support group member)

"I believe that PSA screening after a certain age, say 50 or 55, should be exactly the same as breast cancer screening, because I believe in the long run it will save the NHS money, and I believe it would save lives."

"But I would think anybody who were in their 50s now and have some sort of problem with their waterworks should ask if they can have a prostate test. But until they put more funds into research into prostate cancer and government backing on people being tested over 50 years of age, it is going to be a slow process."

"I really believe PSA testing and screening should be done. There's so many cases where they jump up and down and say 'Why worry someone to death when we don't have an effective treatment for it?' Well why don't we have an effective treatment for it? Basically because we haven't spent the money on getting it; it's out there and available in America ... But the criminal thing, in 1999, the actual funds for breast screening were £3.8 million and the funds for prostate were £47 000."

tested: "I think to screen the whole of the male population, and then simply say to them 'Well, actually we are not quite sure what to do about it,' is probably not terribly helpful to people, and for a lot of people might be quite destabilising." (Tested during investigation of symptoms, chose watchful waiting)

The remaining two men had been found to have raised PSA readings, and both regretted having had a routine test. One, who was 74 years old, had had a pre-nuptial test in the United States. He decided, after asking medical friends and getting a second opinion, that treatment was too invasive and decided on watchful waiting: "I had read up on things, and I was terrified of either incontinence or lack of sex. Basically I wish I hadn't known. I would have happily lived on in ignorance."

The other man was 61 years old and had had a routine test when living in the United States. Although his PSA concentration was raised, cancer was not diagnosed. He became intensely anxious and expected to die. After searching the internet he concluded that surgery was akin to "butchery" and said he would prefer a shorter good quality life to living with probable incontinence and impotence: "I wish I had never had the very first PSA test... I think my principal point is really that it requires very informed consent in the same way that patients have to give informed consent to an HIV test. People should be taken through the worst case scenarios and see how they would cope with that."

Notably, whereas men who recommended screening compared the PSA test to screening for breast and cervical cancer in women, the two men who regretted their routine tests emphasised that men seeking a PSA test should have pretest counselling, as used for HIV testing.

Discussion

This study looks at PSA testing from the unique viewpoint of men with suspected or confirmed prostate cancer. Although we did identify misunderstandings, including optimism about the benefits of early diagnosis, men with prostate cancer who advocate screening are not simply uninformed. We suggest that many are following a different set of principles from those intended to guide screening programmes,¹¹ and men who advocated screening did not dwell on the lack of a clear treatment choice. The four men who opposed screening knew that there was no treatment proved to be effective, and crucially they accepted that this was a deterrent to screening. Epidemiological data indicate that screening for prostate cancer has serious disadvantages, including inaccurate testing, lack of evidence that treatment reduces mortality, and serious adverse effects of treatment.¹²

It is no surprise that men believe that PSA testing offers health benefits. Several men, particularly members of support groups and users of the internet, cited the "positive" effects of screening programmes in the United States and Austria. However, they may not have been aware of the serious limitations of these data, such as the problem of lead time bias.¹³ Many men with prostate cancer suspect that official reluctance to encourage a national programme is prompted by cost concerns and a misunderstanding of the evidence. The fact that PSA testing is offered routinely to men with

What is already known on this topic

The media report enthusiasm for both testing and screening among men with prostate cancer, but relatively little is known about their experiences of prostate specific antigen testing

What this study adds

The study helps to explain why most men with prostate cancer strongly advocate prostate specific antigen testing and screening

It also shows that many men are ill prepared for test results and for the possible iatrogenic effects of treatment

private health insurance in the United Kingdom may promote the notion that it is valuable.

General practitioners in the United Kingdom have been advised to ensure that men who have a PSA test are making an informed choice.¹⁴ A key component of this information should be the uncertainty about the benefits and risks of treatment. However, arguments based on principles such as the "right to information" about one's health, equality, and the "imperative to avoid regret" will persuade some men to have the test, even if they understand that no treatment is known to prolong life. An additional argument for screening, which may persuade even those who know that the research evidence is inadequate, is that a screening programme will raise the profile of the condition and thus enhance the probability of developing effective treatments. Doctors, policy makers, and politicians need to understand why people want wider access to PSA testing, so that they can find better ways of communicating information about risk.

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