

Adult Patients' Perspectives on the Benefits and Harms of Overused Screening Tests: a Qualitative Study

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BACKGROUND: In recent years, there has been a growing interest in reducing the overuse of healthcare services. However, little is known about how patients conceptualize the benefits and harms of overused screening tests or how patients make decisions regarding these tests.

OBJECTIVE: To determine how patients think about the harms and benefits of overused screening tests and how they consider these and other factors when making decisions.

DESIGN: Semi-structured, qualitative interviews.

PARTICIPANTS: The study comprised 50 patients, ages 50–84, who had previously received or not received any of four overused screening services: 1) prostate cancer screening (men ages 50–69), 2) colon cancer screening (men and women ages 76–85), 3) osteoporosis screening (low-risk women ages 50–64), or 4) cardiovascular disease screening (low-risk men and women ages 50–85).

APPROACH: We conducted a thematic analysis, using a hybrid inductive-deductive approach. Two independent coders analyzed interview transcriptions to identify themes and exemplifying quotes.

KEY RESULTS: Many patients could not name a harm of screening. When they did name harms, patients often focused on only the harms of the screening test itself and rarely mentioned harms further along the screening cascade (e.g., from follow-up testing and treatment). In contrast, patients could easily name benefits of screening, although many seemed to misunderstand or overestimate the magnitude of the benefits. Furthermore, patients described many additional factors they considered when making screening decisions, including their clinicians' recommendations, their age, family or friends' experiences with disease, and insurance coverage.

CONCLUSIONS: This study highlights the need to help adults recognize and understand the benefits and harms of screening and make appropriate decisions about overused screening tests.

KEY WORDS: Screening; Qualitative research; Medical decision-making; Patient education; Preventive care.

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INTRODUCTION

In recent years, there has been a growing interest in reducing the overuse of healthcare services^{1–3}. Overuse, defined as “the use of healthcare services for which the harms outweigh the benefits,” extends across the spectrum of screening, diagnostic testing, and treatment, contributing at least \$158 billion of annual unnecessary healthcare costs^{1,3,4}, and resulting in physical, psychological, and financial harms to patients and missed opportunities to provide more beneficial care^{5,6}.

In response to these problems, professional societies and national experts are calling for action. As part of the Choosing Wisely Campaign, 62 organizations have created “Top 5” lists of tests and treatments that providers and patients should use less often^{7–9}, thus improving the quality and reducing the cost of care¹⁰. Additionally, the United States Preventive Services Task Force (USPSTF) has identified “avoiding the unintended harms of medical procedures and testing in older adults” as a priority in their annual report on evidence gaps in preventive services¹¹. Almost one-quarter of adult preventive services reviewed and graded by the USPSTF received a grade of D, indicating that the harms of these services outweigh the benefits¹². Others received a C grade, indicating little benefit on a population level, and raising concerns about overuse for at least some individuals¹².

Despite the growing interest in overuse, little is known about how to best reduce overuse of services¹³. Because patients are often unrealistically enthusiastic about screening¹⁴, a key component of any reduction strategy should be understanding patients' perspectives, needs, and concerns specifically about overused services. To date, however, few studies have explored whether and how patients generally think about the harms and benefits of overused screening tests, or how patients use other factors to come to a decision about whether to receive these tests¹⁵.

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Our study aimed to understand patients' perceptions of the harms and benefits of screening and the additional factors they consider when making decisions with regard to four overused screening tests.

METHODS

Study Design

We conducted semi-structured, one-on-one in-person interviews as part of a mixed-methods study that also included a randomized controlled trial (RCT) comparing the effectiveness of four communication strategies to reduce overuse of potentially harmful screening services. This paper describes only the qualitative interviews. The institutional review boards of the University of North Carolina, Chapel Hill, and Duke University Health System approved the study.

Participants

We recruited 50 patients from four Duke Primary Care Research Consortium (PCRC) practices (two internal medicine, two family medicine) in central North Carolina. Patients were 50 to 85 years of age and were eligible to receive information about at least one of four screening services based on their age and health factors (Table 1). Two screening services received D grades from the USPSTF, indicating net harm at the population level¹²: (1) prostate cancer screening in men ages 50–69, and 2) cardiovascular disease screening in low-risk men and women ages 50–85. Two others received C grades from the USPSTF, indicating little net benefit at the population level¹⁶: (3) colon cancer screening in men and women ages 76–85, and (4) osteoporosis screening in low-risk women ages 50–64. Of note, osteoporosis screening in women ages 50–64

Table 1 Study Inclusion Criteria for Patients

Eligible for Prostate cancer screening (prostate-specific antigen test)
Men
50-69 years old
No history of prostate cancer
Eligible for Osteoporosis screening (bone density test)
Women
50-64 years old
Body mass index of 18 or higher
No personal history of fracture
No family history of osteoporosis
No current use of prednisone (> 30 consecutive days)
Alcohol use < 3 drinks/day
No current smoking
Eligible for Colon cancer screening (colonoscopy, sigmoidoscopy, or fecal occult blood test)
Men or women
76-85 years old
No history of colorectal cancer
No history of adenomatous polyps, gastrointestinal bleeding, or symptoms prompting testing
Eligible for Heart disease screening (electrocardiogram or exercise tolerance test)
Men or women
50-85 years old
No history of cardiovascular disease
Low risk (≤ 5 %) for future coronary heart disease events according to Framingham calculator

received a C grade in 2002, but did not receive a grade when recommendations were revised in 2011^{17,18}.

We excluded patients with no phone number, who did not speak English, or who met any of the following criteria: psychosis, alcohol or substance abuse within the last two years, dementia or other severe cognitive dysfunction, metastatic cancer, cirrhosis, kidney failure requiring dialysis, chronic obstructive pulmonary disease (COPD) or congestive heart failure requiring oxygen, or any other illness for which life expectancy was less than two years. We purposely sampled to include patients in all four screening service groups and patients who were either previously screened with at least one of the four tests of interest or who were eligible but had not been screened. Our aim was to select information-rich cases that would provide a broad spectrum of experiences and perceptions.

Interview Content and Procedures

After identifying eligible patients through medical records, Duke PCRC staff mailed letters to eligible patients and followed up with up to three telephone calls. For patients who agreed to participate, we conducted interviews during a routine clinic visit or a unique visit for the purpose of this study. Patients provided written informed consent prior to participating in the interviews.

Two interviewers with extensive qualitative research experience (co-authors AS and MV) conducted interviews in private rooms at study practices. To ensure consistency, they reviewed the interview guide together prior to starting interviews. After three interviews, the two interviewers met with co-author SS to review the transcripts for interview consistency and to assess the need for additional probing questions.

During study visits and prior to any questioning, the interviewers reviewed with patients a handout that provided definitions of screening, benefits, and harms. Interviews assessed patients' experiences with screening and their general knowledge of the harms and benefits of screening (Appendix 1). Patients then read one-page evidence-based information sheets on the screening services pertinent to them. Information on these sheets was derived from USPSTF reports and best evidence by a panel of experts from UNC's Research Center for Excellence in Clinical Preventive Services¹⁷⁻⁴⁶. Each information sheet included a description of the pertinent condition (including its incidence and mortality rates), description of the screening test, and the quantitative benefits and harms of screening for that condition (Appendix 2). After reviewing the information sheet, patients answered additional questions about their intent to be screened for that particular condition and the factors they considered in deciding whether to be screened. The mean length of the interviews was 27 minutes (range, 15–55 minutes).

Data Analysis

Each interview was digitally recorded and transcribed verbatim for analysis. Analysis involved three steps: immersion

(reading and rereading transcripts to become immersed in the data), coding (assigning descriptive codes to appropriate segments of text), and thematic analysis (identification of salient themes related to patient perceptions of screening based on content and interpretative analysis)^{47,48}. We imported interview transcripts into ATLAS.ti (v.6.2), a qualitative data management program. Two independent coders (AS and MV) created a codebook with operational definitions using interview guide questions and the Harris et al. taxonomy of harms so that we could later triangulate our findings with their taxonomy⁵. The coders worked together to reach consensus on codes and operational definitions and to set a priori rules for coding. The two coders then independently read and coded all transcripts using both deductive and inductive coding techniques to assign codes to appropriate segments of text. They used a constant comparison technique such that new codes were iteratively added to the codebook, and codes that were not used upon completion of coding were removed⁴⁷. All transcripts were double-coded, with discrepancies resolved through discussion of coding decisions and referral to the codebook and a priori coding rules. Three members of the research team (AS, MV, and SS) then read through text associated with specific codes and met weekly to discuss, refine, and finalize emergent themes.

RESULTS

We contacted 185 patients who met inclusion criteria and were eligible for participation in interviews. Sixty-five patients agreed to participate. Of these patients, 14 did not show up for their scheduled study visits, and one was subsequently deemed ineligible. Thus, 50 patients were enrolled and completed interviews. Patients received information about screening for prostate cancer (n=13), cardiovascular disease (n=15), colon cancer (n=14), and osteoporosis (n=19). Eleven patients were eligible to read two of the screening information sheets. Patient mean age was 63 years (range 50–84 years; SD 10.82 years). Twenty-eight patients were women, 35 were white, 12 were black, one was Asian, one was American Indian, and one was multiple races (Table 2).

Perceived Harms

More than two-thirds of patients could not name a harm of screening when asked "what would you consider to be a harmful effect of screening?" Most patients reported having no personal experience with harms or hearing of harms experienced by others. Many patients stated that they could more readily name benefits. For example, one patient said:

"I can't really think of any harms. I tend to think of the benefits because I have friends that have had the screenings." (woman, age 64)

Table 2 Patient Characteristics

Characteristic	% (n)
Age, mean (range)	63 (50–84)
Sex	
Female	56 (28)
Race	
American Indian	2 (1)
Asian	2 (1)
Black	24 (12)
White	70 (35)
Multi-race	2 (1)
Education	
At least some college	92 (46)
Screening status	
Ever screened (for service of interest)	62 (31)
Self-reported health status	
Fair	8 (4)
Good	38 (19)
Very good	40 (20)
Excellent	14 (7)

When patients did name harms, many fit into the domains suggested in the Harris et al. taxonomy of harms⁵, including physical, psychological, and financial harms, and opportunities missed. Of note, however, patients mentioned psychological harms that extended beyond those originally conceptualized in the taxonomy (e.g., worry or anxiety), including fear, depression, nervousness, paranoia, and feeling out of control.

Patients also mentioned several harms from domains not enumerated in the original taxonomy. For instance, they discussed inconvenience or disruption of daily activities as harmful, particularly as related to colonoscopy preparation.

"And then just the prep to go into like a colonoscopy is... that's a pretty major undertaking...you can't eat and you take all this stuff and then, you know, you evacuate your system." (man, age 51)

Another harm of screening suggested by patients was the impact on health service use (i.e., either increase or decrease in use of other services).

"A harmful effect could be that it didn't really go well and the person would choose not to do it again...they would be frightened to think that something's going to happen or go wrong again." (woman, age 65).

Patients also suggested that screening may negatively affect an individual's family (e.g., hassle for family member or psychological harm to a family member) or society (e.g., financial cost to society).

When considering harms, patients typically focused only on the screening test and not on further actions that might be necessitated by a positive test result (e.g., follow-up tests, treatment).

"I mean [bone density testing is] a basic x-ray. It's an x-ray test, so there's no harm in that." (woman, age 53).

Additionally, many patients minimized the importance of harms.

“I don’t think that they’re actually harms because the statistical information is minimal suggesting that there are any harms.” (man, age 60).

“I don’t think there are negative things about screening. I think ...possible bad things may happen, but you don’t know if they would have happened anyway.” (man, age 61).

Perceived Benefits

Nearly all patients considered screening a necessity for good health and readily named benefits of screening. A majority mentioned that knowing is a benefit of screening, and explained several reasons for this. Some suggested that knowing “for the sake of knowing” was beneficial, while others suggested that a screening test might help “put a name on something.”

“Even if there’s nothing that can be done...just the knowledge...I’m very interested in my body, and why shouldn’t I be?” (woman, age 78).

“A lot of times it’s a lot easier to deal with stuff when you can put a name to it or you can know what is going on.” (woman, age 50).

Others explained that knowing would give them a sense of control or an opportunity to research options and make choices. Patients also suggested that knowing would give them an opportunity to prepare psychologically, financially, or interpersonally (e.g., make sure family is taken care of) for whatever comes next (e.g., treatment, ill health, or death).

Another perceived benefit that patients mentioned was the opportunity for intervention, either with treatment, monitoring the disease, or behavior change. Patients seemed to think that most diseases detected early by screening were treatable.

“Well, I’m sure if they found something, I would benefit by having them take care of it. I mean they’d know how to treat it.” (man, age 76).

If a treatment were not available, patients suggested that it would be beneficial to monitor the progression of the disease. Patients valued the opportunity or new motivation for behavior change, such as improving diet or physical activity. This benefit was often mentioned

in relation to osteoporosis or cardiovascular disease screening.

“This type of screening will help because, again, it kind of tells me or says, hey, if you keep on the same path that you’re on right now, this is the trouble that you’re heading for; but if you can turn it around and start doing X, Y, Z, then this is going to be a lot better.” (woman, age 50).

Other perceived benefits of screening included psychological benefits (e.g., relief or peace of mind), better prognosis, better quality of life, the possibility of detecting other health problems, reducing long-term healthcare costs, reducing the impact on others (e.g., family, future children), and reducing the impact on society (e.g., prevention decreases overall healthcare costs).

“If it’s found earlier, it’s going to be more easier to handle financially than if you get to a point that you have to go to [a hospital] to have heart surgery.” (man, age 62).

“It would help me get my affairs in order and, you know, see my children. I think that’s always good to know ahead of time for your family. It would be harder on me but it would be much better for my family to know ahead of time.” (woman, age 53).

Factors Affecting Patients’ Screening Decisions

After reading information sheets about specific screening tests, patients mentioned many factors, including benefits and harms, that would influence their decisions to get or avoid the specific screening tests. One of the most important factors to patients was their physicians’ recommendations. Patients not only suggested that their physician’s recommendation greatly influenced their decisions to get screened, but some patients also mentioned their physician’s recommendation as a motivator to avoid screening.

“If the doctor said I don’t think this [PSA test] is the right thing for you because of your medical history, I would trust that...by having looked at my medical history and understanding health problems, I would take the doctor’s opinion, because that’s what they do.” (man, age 62).

Patients reported that they assumed that their physicians considered their medical and family history and guidelines from professional organizations for specific tests when making recommendations. Many patients expressed a desire for a discussion with their physicians

regarding the benefits and harms of screening rather than receiving a simple recommendation. Some patients reported having had discussions with their doctors about screening, but said that harms were not often part of those discussions.

Patients mentioned many other factors as both reasons to get screened or to avoid screening: age, health status, quality of life, personal or family history of a disease, race, and past personal experience with screening or disease. For instance, patients indicated that being younger was a reason to get screened, and that they might be less likely to get screened as they got older. They also indicated that if their quality of life was good, they might choose to get screened, but might opt out of screening if their quality of life was poor. Similarly, patients indicated that they would be motivated to get screened if they had a personal or family history of disease, were black and perceived a greater risk for certain diseases, or had a positive personal experience with screening. They suggested that they might choose not to be screened if they had no family history of a disease, perceived themselves to be at low risk, or had a negative experience with screening.

Patients also incorporated the following interpersonal factors into decisions about screening: experience of a friend or family member with screening or disease, recommendation of a screening test by a friend or family member, and the impact of the test results on others (e.g., if the disease were hereditary).

Finally, patients considered many healthcare factors, such as the cost of the test, insurance coverage, reputation of the facility, and mistrust of the medical community. The type of screening test and disease being tested for also influenced patients' decisions about specific screening tests. For example, patients described the PSA test for prostate cancer as "just a blood test," and something they would be willing to do, but colonoscopy for colon cancer as inconvenient, time-consuming, and uncomfortable, and something they might delay.

Hypothetical Decisions about Screening

After reviewing evidence-based information sheets, the majority of patients said they would choose to get screened. In making hypothetical screening decisions, some patients said they would seek information and opinions and carefully weigh several factors.

"I seek a lot of information and then would think about it and...it would probably be something I would discuss with my wife or other kinds of close friends or family as well as my doctor. I'd really just go through an intellectual process, but I think some part of me still has this emotional thing of the big cancer word." (man, age 51).

Others said screening is "just something you are supposed to do" or depends on doctor recommendations.

Some preferred to take time before making decisions.

"I'll probably go home and what do you call it when you sit there and stuff goes through your mind and you work it out over and over. Probably a couple of nights of that would help me make a decision and maybe discuss it with my wife." (man, age 76).

Patients who had been screened previously and had not experienced harms often said they would want to get screened again without much discussion about benefits, harms, or other factors.

DISCUSSION

Our qualitative study of older adults in a primary care setting yielded several important findings. First, many patients could not name screening harms, and most who named harms focused solely on the harms of the screening test itself or minimized the harms. Many harms that patients mentioned aligned with the Harris et al. screening harms taxonomy (i.e., physical harms, psychological harms, financial harms, opportunities missed)⁵, but also included inconvenience and disruption of daily activities, increased or decreased health service use, and adverse effects on family and society. Second, patients could easily name benefits, and provided a diverse list of benefits they considered. However, these benefits were often overestimated or misunderstood. Third, patients described many other factors (individual, interpersonal, and healthcare) that they would consider when making decisions about screening, the most important of which was the recommendations of their doctor. Fourth, patients often said they would use heuristics (e.g., rules of thumb) about screening or suggested they would ultimately follow the recommendation of the doctor rather than considering the harms and benefits of screening.

Our study supports prior conclusions that patients are enthusiastic about screening^{14,15}, and consider it something to be done even when the medical community deems it to have net harm or marginal benefit^{17,19-21}. Further, our study builds on prior work about patients' perspectives on potentially harmful tests^{49,50}, demonstrating a misunderstanding of the benefits and incomplete knowledge of the harms of screening tests. For example, patients considered knowing about disease to be beneficial. However, patients who are diagnosed with a disease and are "labeled" often experience psychological harms such as distress, depression, and

anxiety^{5,51}. Furthermore, patients in the study considered knowing that they had a disease as an opportunity for action, even though some conditions are not treatable. They also considered the possibility of detecting other health problems as beneficial, although this may result in additional workup and harms for conditions that would never have caused any symptoms in a person's lifetime. Addressing misconceptions about such benefits will be important in reducing screening overuse.

Our study also shows that many patients had difficulty naming the harms of screening or that they considered only the harms of the screening test itself, even though harms can happen along the entire screening cascade, from screening through follow-up tests and treatment⁵. One reason for this difficulty could be that clinicians are not thoroughly discussing possible harms with their patients^{52,53}. This is supported by a nationally representative sample showing that providers discussed the benefits of screening in 90 % of patient-clinician encounters but discussed the harms in less than 30 %⁵². While clinicians may recall the harms of screening, including unnecessary follow-up tests and treatment (e.g., tests and treatment for prostate cancer in men with low-grade disease)⁵⁴, they do not seem to be sharing this information with patients. Greater discussion of the harms along the entire screening cascade will be important for reducing unnecessary testing, as evidence suggests that when patients consider the harms or costs of a healthcare decision as important, they are less likely to choose to receive the service⁵⁵. Assisting patients in weighing benefits and harms may help to ensure that their screening decisions appropriately take harms into account⁵⁶⁻⁵⁸.

Finally, our study suggests that patients do not always weigh the benefits and harms of screening, but instead sometimes use heuristics, such as "screening is what you are supposed to do", for screening decisions. Even after reading information about harms, the majority of patients wanted screening, and many said they would rely on heuristics to make these decisions. Given similar findings in other studies¹⁵, interventionists could consider evaluating new heuristics, such as "not all screening tests are the same" or "some screening tests can be harmful," that might prompt patients to appropriately consider each screening test on its own merit. Furthermore, patients may need assistance in identifying the best information for decision-making, given the often conflicting information from family, friends, or the media, which complicates efforts within the medical community to reduce overuse.

Overall, we believe that our findings suggest that overuse of specific screening services is a complex

problem that may require complex strategies to combat. Both clinicians and public health campaigns need to place more emphasis on clarifying the benefits and communicating the harms of screening to patients, as well as countering the unquestioned "gists" or general impressions that all screening is good. Our study further suggests appropriate information on harms for communication by clinicians and campaigns, supplementing that previously mentioned in the Harris et al. taxonomy⁵. Screening messages should include evidence-based information about the benefits of screening, and should clearly identify the individuals likely to experience those benefits. Screening messages should also include information about the full spectrum of harms, including possible harms along the entire screening cascade (from the initial screening test through diagnosis and treatment)⁵ and across multiple domains. Research is needed to determine the type and number of harms that patients consider important, and how this may affect their decision-making. Studies will also need to explore the best approaches for facilitating appropriate heuristics for screening decisions.

In considering these conclusions, we recognize the study's limitations. Study participants were asked to discuss their experiences with the benefits and harms of screening. However, because providers sometimes order tests without discussing them with patients⁵⁹, patients in our study did not always remember receiving screening tests, and thus it is not surprising that some had difficulty discussing their experiences with and perceptions of the benefits and harms of screening. Another limitation is that we asked only about factors affecting screening decisions in the context of four specific screening tests. Additional research is needed to determine whether patients consider these factors, and possibly others, with regard to other services. Finally, the generalizability of our sample remains to be established, as patients in our sample were mostly well-educated and white. The inclusion of more patients with lower education levels and minority status or who are over 85 years old would help us better understand how well our findings apply to these populations.

With the growing evidence that some screening tests may be more harmful than helpful, the medical and public health communities must determine strategies to reduce the use of these services. Our study found that patients were well aware of the benefits of screening, but may have overestimated those benefits and were not fully aware of the harms of screening. Additional research is needed to determine the prevalence of these beliefs, how to provide balanced communication to patients of screening benefits and harms, and how to motivate patients to choose against screening when rec-

ommendations suggest that the harms outweigh the benefits.

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APPENDIX 1

Table 3 Interview Guide Questions

Topic	Questions
Introduction	Tell me about a time when you've had screening for a health problem.
Potential benefits of screening	What kind of benefits, if any, have you experienced from screening? What would you consider to be a benefit of screening?
Potential harms of screening	What kind of harms, if any, have you experience from screening? What would you consider a harmful effect of screening? (If necessary, probe with screening cascade steps, such as "how about any negative effects from the screening test itself? Diagnosis? Treatment?")
Specific screening (after patient reads information sheet)	Looking at the information I've just given you [information sheet], do you want to get screened? What information, if any, makes you want to get screened? Avoid getting screened? How would you go about deciding whether or not to get screened? What information would you consider when deciding whether or not to get screened? Whose opinion, if any, would you seek in deciding about screening? How would you weigh the potential benefits against the potential harms of screening?

Appendix 2 Example Information Sheet



PROSTATE CANCER SCREENING (MEN AGES 65–69)

Here is some information about prostate cancer screening that you might find helpful in your next doctor's visit.

What is prostate cancer? Prostate cancer is an overgrowth of abnormal cells in the prostate, a gland that sits under the urinary bladder. It affects 80 of every 1,000 men your age. Most prostate cancers will never cause symptoms. Only a few will cause problems with urination and pain. Additionally, only 4 of every 1,000 men your age who have prostate cancer will die from prostate cancer.

How does prostate cancer screening work? The PSA test is a blood test that helps find prostate cancer. It finds all types of prostate cancer, whether they would ever cause problems or not.

What are the Benefits of Prostate Cancer Screening? Scientific studies are not completely sure about the benefits of screening. Experts' best guess is that finding and treating prostate cancer may lower prostate-related death in 1 of every 1,000 men screened and treated over 10 years (from 4 per 1000 to 3 per 1000).

What are the Harms of Prostate Cancer Screening? The harms of prostate cancer screening are not from the PSA test itself, but from the additional testing and treatment that follow a positive test.

First, if the PSA test level is high, the next step is a biopsy, which uses small needles to get samples of your prostate. Biopsies result in hospital stays for urine problems or infection in 50 out of every 1,000 people who have them over 10 years.

Second, if prostate cancer is found, the biopsy doesn't tell which cancers will cause problems. This leaves many men to wonder and worry. It also means that most men are treated for their prostate cancer.

Finally, treatment for prostate cancer can harm some men. This includes men with harmless cancers who wouldn't necessarily need treatment (if doctors knew who they were). Treatments for prostate cancer include burning with radiation or major surgery. About 260 out of every 1,000 men undergoing treatment have difficulty with sex because of the treatment and 180 of every 1,000 men have difficulty holding their urine. Surgery also increases the immediate chances of death in 5 of every 1,000 men treated and increases the chances of heart attacks and blood clots in the legs in 25 of every 1,000 men

The Decision. As you can see, there is a lot to consider before you get a PSA test. So think about what you've heard and decide what's right for you.
