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Michael H. Farrell

Yale University School of Medicine

Margaret Ann Murphy

University of Michigan

Carl E. Schneider

University of Michigan Law School

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ORIGINAL ARTICLE

MICHAEL H. FARRELL, MD

*Departments of Internal Medicine
and Pediatrics
Yale University School of Medicine
New Haven, Conn*

MARGARET ANN MURPHY, MA

*Departments of Sociology and
Family Medicine
University of Michigan*

CARL E. SCHNEIDER, JD

*School of Law and Department of
Internal Medicine
University of Michigan Health
System*

Ann Arbor, Mich

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How Underlying Patient Beliefs Can Affect Physician–Patient Communication about Prostate-Specific Antigen Testing

CONTEXT. Routine cancer screening with prostate-specific antigen (PSA) is controversial, and practice guidelines recommend that men be counseled about its risks and benefits.

OBJECTIVE. To evaluate the process of decision making as men react to and use information after PSA counseling.

DESIGN. Written surveys and semistructured qualitative interviews before and after a neutral PSA counseling intervention.

PARTICIPANTS. Men 40 to 65 years of age in southeastern Michigan were recruited until thematic saturation—that is, the point at which no new themes emerged in interviews ($n = 40$).

RESULTS. In a paper survey, 37 of 40 participants (93%) said that they interpreted the counseled information as unfavorable toward PSA. However, 30 participants (75%) said after the intervention that they intended to be tested in the future, including 29 of 30 men (97%) with prior PSA testing. In the interview, many participants cited underlying beliefs as a reason to dismiss the counseled information. Qualitative analysis found the seven most common beliefs cited were fear of cancer, relevance of salient anecdotes and analogies, distrust of statistics, enthusiasm for “prevention,” protection from “bad luck,” faith in science, and valuing PSA as knowledge for its own sake. Although some beliefs could be interpreted as judgment errors, most were credible on a personal level.

CONCLUSIONS. Most men who underwent PSA counseling cited underlying beliefs rather than the content of counseled information as the basis for their decisions regarding future PSA screening. If widespread, such beliefs may render clinician counseling and decision support methods less effective. Eliciting patient beliefs prior to counseling may improve the shared decision-making process.

Prostate-specific antigen (PSA) screening guidelines recommend that men be counseled about risks and benefits before the test is offered.^{1–7} These recommendations are consistent with ethical standards about autonomy and self-determination,^{8,9} but they exist chiefly because there is no consensus for or against routine screening.^{10–14} Many believe that PSA screening will reduce prostate cancer mortality; however, this has not been clearly demonstrated in a randomized, controlled trial. Others are concerned that, because most cases of cancer identified by PSA screening

*Edited by Brenda E. Sirovich,
MD, MS*

will never become clinically apparent during their lifetime, many men are unnecessarily exposed to the risks of treatment.^{1, 10–12} This ongoing debate has divided the medical community over whether PSA screening is more likely to lead to net benefit or harm.

The complexity of information needed to make an educated decision about PSA screening has led to quality improvement methods⁷ and educational interventions^{15–24} to enhance PSA counseling. PSA educational interventions are reported to improve postintervention knowledge, but do not have a consistent effect on intention to be screened, even in men who have never been tested.^{15–19, 22–24} In fact, despite increasing literature on the outcomes of counseling interventions, it is not clear how patients use the information given in counseling.^{25, 26} Patients may not understand detailed risk information to the extent implied by practice guidelines,^{25, 27, 28} and their perception of risk can be affected by the perceived severity of the cancer,²⁹ individual values,^{16, 30} or the counselor's framing of the communicated information.³¹ A better understanding of how patients process screening information presented by their physicians is fundamental to improving decision making.

The purpose of this study was to examine the process of decision making after PSA counseling. Because a fixed-answer instrument might overlook attitudes that we had not anticipated,^{32, 33} we developed an open-ended interview of how men use information about PSA screening.

Methods

This study used open-ended interviews and qualitative methods to examine PSA decision making. Design and analysis of the study are outlined in **Figure 1**. The University of Michigan Institutional Review Board approved all methods and materials.

Participants

Participants were recruited by two complementary methods: newspaper advertisements and direct mail to primary care patients. The newspaper advertisements solicited men 40 to 65 years of age to participate in a study about “patient decision making” without mentioning PSA testing. Advertising respondents were enrolled on a first-called, first-enrolled basis. For primary care patients, a letter was sent to 200 men randomly selected from an administrative database search of men 40 to 65 years of age with a recent health maintenance visit to an internist or family physician. Men who voluntarily responded to the letter were enrolled. Telephone calls were made to a random sample of nonresponders, with oversampling for African Americans to ensure sufficient representation.

Men with cancer, patients of the interviewer, physicians, and allied health care professionals were excluded from both pools. Recruitment continued from both pools until no new themes arose within the most recent interviews—that is, the point of thematic “saturation.”³³ Participants were compensated at \$10 per hour.

Interview

Each participant was interviewed by a single facilitator in a 60- to 120-minute, in-person session using written materials and a structured script of open-ended questions. Interviews were divided into three segments: the precounseling assessment, the counseling intervention, and the postcounseling assessment (**Figure 1**). Recordings of all three segments of each interview were transcribed for subsequent analysis.

The precounseling segment, approximately 5 to 10 minutes in duration, consisted of a written survey that included demographics and history of screening for prostate cancer and a one-on-one discussion about the participant's experience with prostate cancer screening, his general preferences for relationships with his physician, and his approach to medical decision making.

The counseling session was designed to be similar to the best-case experience envisioned in guidelines, including an interactive format, ability to use either numerical or nonnumerical language, and extended time for the participant's questions. The content of counseling (**Table 1**) centered around two main messages. The first message was that medical science as a whole (as reflected in consensus guidelines) is uncertain about whether routine PSA screening is effective and that individual physicians are divided about the value of screening. The second message was that estimating the likelihood of net benefit versus harm to an individual undergoing PSA screening requires weighing and valuing the risk for death or disability from prostate cancer (a risk that may be greater among unscreened men) and the risk for incontinence, impotence, or infection after treatment for cancer that, if left untreated, may or may not have proved to be aggressive (a risk that will be greater among screened men). This latter concept was conveyed to participants by hand drawing a simplified decision tree with estimated probabilities of the various good or bad outcomes. In addition, the counseling intervention included information about prostate cancer epidemiology, natural history (including prevalence in autopsy studies), and the estimated probabilities of true-positive, false-positive, and false-negative results of PSA testing.

Counseling continued until the participant voiced his understanding, which was usually between 2 to 10 minutes but occasionally was longer. All information and risk information was derived from published guide-

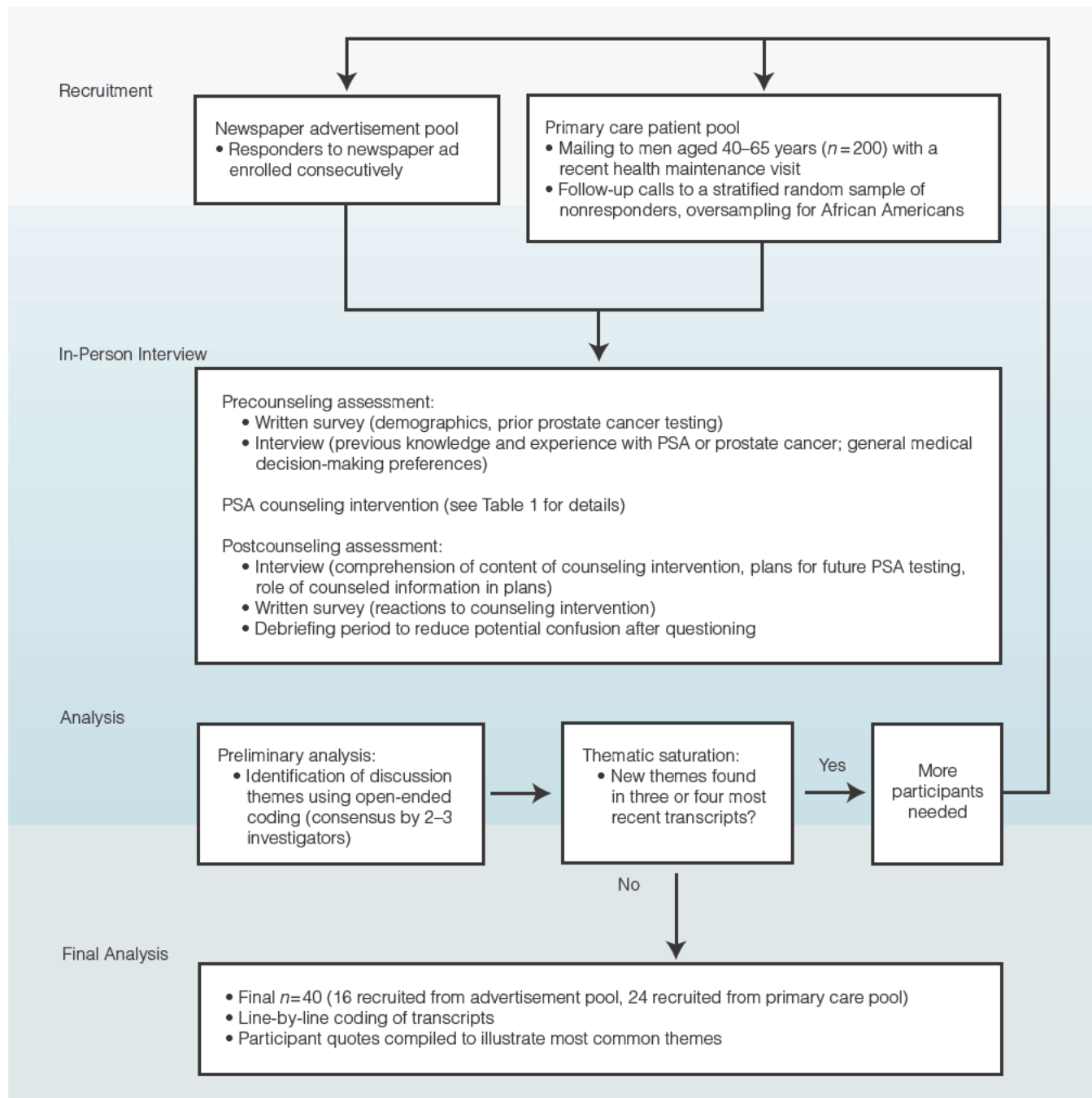


FIGURE 1. Study design. On the basis of medical records or questions during a telephone call, men with a history of cancer, patients of the interviewer, and physicians were excluded.

lines¹⁻⁷ and was similar to the neutral materials described by Wolf,¹⁵ Chan and Sulmasy,³⁴ and Burack and Wood.³⁵ To ensure that the counseling script was free from bias and consistent with the current scientific evidence, the interviewer practiced during its development with several internists, family physicians, and urologists who represented a spectrum of opinions about routine PSA screening.

In the postcounseling segment of the interview, the facilitator asked participants to reason aloud as they

formed an intention regarding PSA screening in the future. If the participant was vague or brief during this process, the interviewer used probe questions until he understood what the participant meant. A debriefing period was used to reduce potential confusion that might have been caused by the interviewer's probe questions. Last, a second written survey after the debriefing session assessed reactions to counseling and intention to be tested in the future. The postcounseling and debriefing segments typically lasted 30 minutes but occasional-

TABLE 1

Key Components of the PSA Counseling Intervention*

COUNSELING INTERVENTION COMPONENT	KEY MESSAGE
What is prostate cancer?	<p>Description of terms: prostate, prostate cancer, BPH.</p> <p>Prostate cancer is common.</p> <p>Some cancers are very aggressive; most are indolent (don't cause problems).</p> <p>No tests can distinguish between aggressive and indolent cancer until after aggressive cancer has spread.</p>
Prostate cancer screening	
Pros	<p>Screening can identify prostate cancer in an early stage, when treatment may be less difficult.</p> <p>Early detection may save lives.</p>
Cons	<p>False-positive screening results can occur.</p> <p>Prostate biopsy has risks (e.g., infection).</p> <p>Detection may result in unnecessary treatment of cancers that would not have caused symptoms in patient's lifetime.</p> <p>Substantial harms of early prostate cancer treatment (e.g., impotence, incontinence) can occur.</p>
Bottom line	<p>At present, it is unclear if screening men for prostate cancer will lead to benefit or harm for individuals tested.</p> <p>Results of large trials may help but are years away from a definitive conclusion about the utility of PSA.</p> <p>Medical experts recommend that men considering testing be counseled about risks and benefits before deciding.</p>

*BPH = benign prostatic hypertrophy.

ly lasted more than an hour for the more enthusiastic and talkative participants.

Analysis

Over 1200 pages of interview transcripts were analyzed using accepted methods from grounded theory³⁶ and content analysis.³⁷ All three authors read a subset of

transcripts to find common themes that occurred across several interviews. The authors discussed their findings and used three-way consensus to derive themes directly from participant quotes. These themes were used to develop a systematic structure of “codes,” which was applied by two authors. The coding process used Atlas software (Scholari Software, Thousand Oaks, CA) to assist in a line-by-line reading of the transcripts to identify quotes that either supported or contradicted the identified themes.

We followed several steps to ensure trustworthiness, which is a concept in qualitative research roughly analogous to validity and reliability in quantitative research.³⁸ The interviewers used restatement to verify that the participant agreed with the interviewers' interpretations. The authors reviewed the transcripts independently. The analysis and resulting themes were reviewed by experts in the fields of decision making, ethics, internal medicine, family medicine, and urology. Participants recall of previous PSA screening was verified with a review of electronic laboratory records from the laboratory systems of two local hospitals.

Results

The complementary recruiting method reached thematic saturation by the 16th advertising participant and the 24th mail respondent, for a total of 40 participants. Table 2 describes baseline characteristics of the study participants. Thirty participants (75%) either reported prior PSA screening or were found to have had a PSA test according to electronic records of one of three local hospital systems. After counseling, 37 participants (93%) said the intervention contained information that they interpreted as being unfavorable for PSA screening. However, 29 of 30 men (97%) who had had PSA screening favored testing in the future (Figure 2), although only 2 of 10 men (20%) without prior screening intended to be tested in the future.

Transcript analysis focused on how participants used the risk–benefit information to decide whether to be tested. Many men considered PSA screening in the context of benefits or harms from treatment of a hypothetical case of cancer in the future, as envisioned by guidelines,^{1–7} instead of considering only the consequences of the blood test itself. However, we were surprised to find that many men who said they interpreted the counseled information as unfavorable subsequently discounted the validity or applicability of the new information. Most of the dismissive beliefs fell into one of the seven thematic categories shown in Tables 3 and 4. Some beliefs (four of the seven) were cited by men regardless of their later-stated intention for or against PSA screen-

TABLE 2
Baseline Characteristics of Participants*

VARIABLE	PARTICIPANTS (n = 40)
Age (mean), yr	52.5
Ethnicity	
Caucasian	80%
African American	13%
Other	7%
Education	
College	65%
High school	30%
Didn't finish high school	5%
Income	
> \$80,000/yr	25%
\$30–\$80,000/yr	55%
< \$30,000/yr	20%
Previous PSA	
Yes	75%

*Information about previous PSA gathered from participant recall, confirmed by electronic chart review for patients with records in two major local hospital systems.

ing (Table 3), while others were cited exclusively to support PSA screening (Table 4).

For clinicians, one of the least surprising beliefs held by patients is the general alarm about cancer (“Fear of ‘The Big C’”) and willingness to do anything to reduce the risk. Some men who intended to have PSA screening in the future reported that a profound fear of cancer outweighed the value of new information unfavorable toward screening. However, this fear was also cited by men who said that they would not want an advance warning of cancer that might never cause them harm.

More than half of the men relayed a personal story to illustrate why they wished or did not wish to be tested (“Salient anecdotes and analogies”). In many of these quotes, men related how the counseled information was not as important to their decision making as anecdotes about the decisions of friends, family, or media celebrities or about how these individuals had fared with testing. Some men focused on avoiding side effects. Other men were interested in experiences or endorsement of respected public figures with prostate cancer, ranging from Bob Dole to Stokely Carmichael. Although the

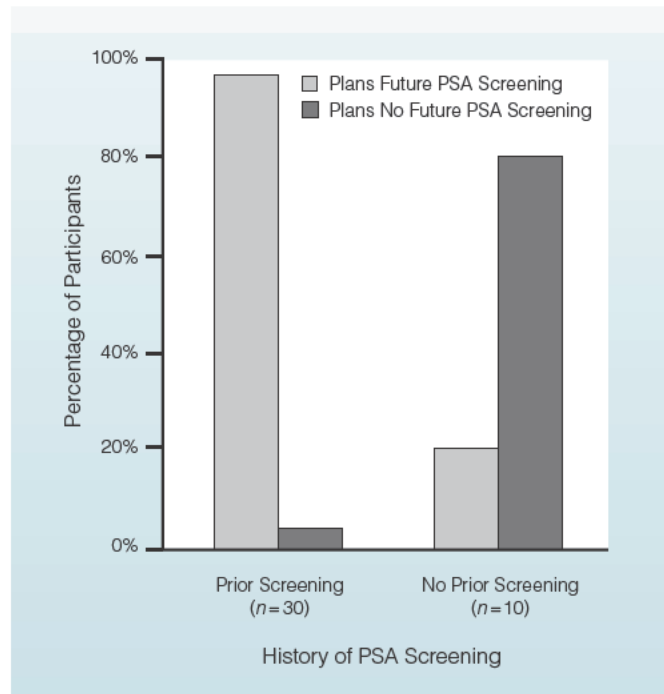


FIGURE 2. Percentage of participants who did and did not plan to obtain PSA screening in the future according to PSA screening history. Information was obtained after counseling intervention.

three quotes cited in Table 3 are relevant to PSA and prostate cancer, many narratives had little to do with PSA screening or cancer, as in the cases of several men who cited stories of how relatives had developed complications or otherwise fared poorly after treatment for other chronic illnesses.

Many participants dismissed the statistics and risk information in the intervention as inherently untrustworthy, on the grounds that numbers are “just statistics” (“Distrust of statistics”). Several participants echoed a cliché, such as one man who said, “You know what they say about statistics...you can make them say whatever you want.” Other quotes suggested a deeper suspicion for how numbers might be used; for example, one man grumbled that physicians who used statistics to criticize PSA screening for a whole population were still likely to get tested themselves. Other men reported a belief in the inevitable progress of science and technology and in future advances that would eliminate the present risks of either PSA testing or delays in prostate cancer diagnosis related to lack of testing (“Faith in science”).

In contrast to the previous four themes (Table 3), some themes were seen only in men intending to get PSA screening (Table 4). Some of the most enthusiastic quotes were from men who categorized PSA testing as “good prevention.” Prevention is a vital goal, they assumed,

TABLE 3

Underlying Beliefs Cited by Men Regardless of Plan for Future PSA Screening*

DESCRIPTION OF BELIEFS	PLANNING FUTURE PSA SCREENING	
	YES (n = 30)	NO (n = 10)
<p>Fear of “The Big C” (cancer) , n (%)</p> <p>“Most people would be too influenced by fear [of cancer] to decide.”</p> <p>“I’d be too afraid of cancer . . . I could never look at the numbers and decide like I do at work.”</p> <p>“I understand about [the low risk for morbidity and mortality with a positive PSA], but there is still a chance. I wouldn’t be able to sleep, think or even take a dump without worrying about that cancer. It would HAVE to come out! . . . My wife would make me take it out.”</p>	6 (20%)	3 (30%)
<p>Salient anecdotes and analogies, n (%)</p> <p>“Hey! That’s a sensitive area! I don’t want to end up impotent like [a friend].”</p> <p>“I have had friends that have had the prostate operation, and [became] incontinent!”</p> <p>“I think my impression initially was that [my physician] didn’t want to do the test, and I insisted that we do it . . . I think about Bo Schembechler, he had a prostate operation, and [a co-worker] . . . and somebody else, too, a pretty renowned citizen—oh! General Schwarzkopf.”</p>	15 (50%)	6 (60%)
<p>Distrust of statistics, n (%)</p> <p>“All that doesn’t matter. The real issue is whether you want to have cancer. If you do, by all means listen to statistics. If you don’t, get the test!”</p> <p>“It would be interfering with a sacred relationship between a man and his doc . . . I want to know that my doctor is thinking about me, not some other 100,000 guys.”</p>	14 (47%)	4 (40%)
<p>Faith in science, n (%)</p> <p>“There will be another test that the medical community will come up with in the future that will work better than the PSA . . . If I don’t get the PSA, then I won’t know to get that [other] test, I won’t be able to benefit from the advance . . . There was a time when the PSA didn’t exist men were subject to cancer without warning. Now, the PSA is here, and something else will be discovered soon.”</p> <p>“[PSA] is a tool, right now there isn’t anything else . . . unless the testing is there for them to see, what can come of it? These screenings and testings are going to lead to results down the road, possibly new treatments, possibly a new test.”</p>	8 (27%)	2 (20%)

*Totals do not equal the number in each group because participants may have multiple or no officially tallied beliefs.

therefore the benefits of PSA must outweigh the risks (“Enthusiasm for PSA as ‘good prevention’”). A few men who favored PSA testing complained about a history of bad luck and claimed they needed a PSA test specifically to protect against their tendency for misfortune (“PSA is protection against ‘bad luck’”). Many men were simply committed to “more information” or “knowing,” even if its usefulness might be obscure (“Valuing PSA as knowledge for its own sake”).

Discussion

Because most published guidelines advocate patient counseling before consideration of PSA screening, we sought to describe men’s reactions to and use of information provided during an “ideal” counseling session. Much of the prior work regarding patient decision making and PSA screening has focused on evaluating the outcomes, in terms of men’s knowledge and screening

TABLE 4

Underlying Beliefs Cited Only by Men Planning Future PSA Screening*

DESCRIPTION OF BELIEF	PLANNING FUTURE PSA SCREENING
	(n = 30)
<p>Enthusiasm for PSA as “good prevention”, n (%)</p> <p>“I honestly believe the knowing, and having the option of prevention, outweighs all the other risks . . . risk doesn’t matter, you gotta do the proper things for health anyway.”</p> <p>“Now, if they don’t get a PSA, and then they get [cancer], I have no sympathy for ‘em. That’s just stupid on their part, they could have prevented it, but didn’t . . . Why should we pay for their unnecessary medical care? It’s their doctor’s fault, too—a doctor is supposed to prevent things, not ignore them!”</p> <p>“I’ve been blessed with good health, for the most part, and I just did not want to run the risk. I didn’t want to do something stupid . . . if there’s a test, or an exam or something, I’m going to take it . . . I just want to be preventive, instead of regretting after the fact. My body’s like a [car], if the oil’s low, I’ll go ahead and change it. It’s by taking preventive measures like this I’ve been able to maintain a reasonable amount of good health . . . God knows I try to live right, do right . . . I try within reason to do the things that I know I should.”</p>	9 (30%)
<p>PSA is protection against “bad luck”, n (%)</p> <p>“I don’t think MOST people should have a PSA . . . I still want it because bad things happen to me. I am always the guy with bad luck, the one percent . . . I’ll get cancer because I get everything else.”</p> <p>“I’m not impressed with the numbers . . . I’m always in the slowest supermarket line. I’m always in the slowest expressway lane. I’m always in the minority anyways, so you’re telling me 80% of people will get better if you follow this procedure, it doesn’t tell me what is going to happen for me.”</p>	6 (20%)
<p>Valuing PSA as knowledge for its own sake, n (%)</p> <p>“I still like the idea of doing the blood test, only because I’m curious about these things.”</p> <p>“Well, I still find [PSA] interesting—I like to do the analysis thing, like I used to do with [work] . . . so I like to see results. But if I get a positive result, I’m not sure I’ll do anything.”</p> <p>“I can’t explain why. I just like to see tests.”</p>	17 (57%)

*Total does not equal the number in the group because participants may have multiple or no officially tallied beliefs.

behavior, of a specific decision aid administered to a sample of men.^{16–24} In contrast, the goal of this study was to investigate the processes and reasoning involved in patient decision making. The interview provided a best-case scenario for the informed decision making envisioned in guidelines. We found that men’s underlying beliefs and prior testing appeared to influence intentions toward future screening more than a weighing of communicated risks and benefits.

Interpretations

Most men who had been tested intended to be tested again. Some men may have felt a general confidence in the soundness of their previous decisions or that the new information did not differ sufficiently from what they remembered to justify a new appraisal. It may be that

because such underlying beliefs are formed over a period of months or years, a single intervention or doctor visit is insufficient to impact the participant’s intention. Although we have assumed that the underlying beliefs were similar to the “prior beliefs” reported to interfere in other studies of communication,^{39,40} another explanation is that they could have formed anew in reaction to unexpected negative information.

An alternative is that the influence of beliefs is somewhat similar to heuristic thinking,⁴¹ where early impressions interfere with appraisal of new information. A traditional approach to many of these influences might be to intensify or repeat counseling to minimize “errors” in appraisal of scientific evidence. This approach may be misplaced, because many beliefs are not necessarily judgment errors to be eradicated. For example, participant

reliance on “salient anecdotes” does not invalidate the importance of listening to others’ experiences in making decisions. It also seems unlikely that any educational intervention will change a basic belief in “bad luck.” Finally, some beliefs are the direct result of widely disseminated media messages for cancer screening; for example, some men quoted the slogan, “get the test,” or used the misapplied term *prevention*. Despite their origin or prevalence, underlying beliefs have the potential to limit consideration of the risk–benefit information that clinicians are asked to present to patients.

Comparison with Other Studies

Many published studies of pamphlets and videotaped decision aids^{15–23} report an improvement in knowledge about prostate cancer screening but also report variable effects on the rate of subsequent PSA testing. Many of these studies took place in a relatively controlled, supervised setting and, therefore, may not be generalizable to typical community practice settings. In contrast, a single effectiveness study²⁴ conducted in a variety of practice settings enrolled a group of men nearly half of whom had previous PSA testing; the study failed to show a significant effect on either knowledge or subsequent PSA screening.

Given the variety of these studies, it is difficult to make sweeping generalizations about the value of PSA decision aids, especially for a diverse patient population with a range of education, socioeconomic status, or desire for shared decision making. As a result, physicians are left with the traditional responsibility of appraising and communicating individual risk, one patient at a time. The chief value of the current qualitative study is to point out how even this type of individualized approach could be rendered less effective by the patient’s experience with PSA screening.

Limitations

Qualitative methods are associated with small sample sizes that do not allow for confidence in the ability to generalize conclusions, although the data are possibly richer than those of a larger survey. In our study, the use of a single interviewer was helpful to maintain consistency in counseling content but may have affected response diversity. Selection bias is often a problem with studies involving volunteer participants,⁴² but our study reduced such bias by using two complementary recruiting strategies that avoided mention of PSA screening.

The underlying beliefs that we uncovered may be more common in some populations than in others. Although this study included men with a wide range of income and education, the relatively high mean income and education level differ from other reported work on

decisions and PSA screening.¹⁵ The frequent discussions of PSA screening in the media could have resulted in a “contamination” effect. The results may not generalize well to patients who have never heard of PSA screening or who have never been tested, such as men in Wolf’s 1996 study.¹⁵ On the other hand, men who have never heard of PSA may be increasingly rare in an era dominated by the Internet and widespread advertising for PSA testing.⁴³ Some commentators may argue that highly educated or informed men may be more facile with decision making and interpreting medical evidence, but such a disparity in shared decision making argues more for a need for communication methods than against the existence of underlying beliefs.

Remaining Questions

Differences in intention toward future PSA screening between men with and without prior testing could argue for counseling before men learn about PSA screening from other sources, such as the Internet, advertisements in the mass media, or friends and family. On the other hand, counseling efforts are unlikely to compete well with messages promoting screening by the media and local hospitals, which have the advantage of marketing experience and solid funding. Given the currently low rates of counseling^{25, 26} and limitations in patient understanding of counseled information,^{25–29, 31} efforts to better understand patient experiences with counseling might be more advisable than further promoting noninteractive decision aids^{17–20, 23, 24} or encouraging documentation of counseling in patient records.⁷ Because shared decision making involves at least two participants sharing information and building consensus,⁴⁴ further study of persuasive communication should determine at what point clinician counselor efforts to clarify “misunderstandings” become persuasion or even coercive trespassing on patient rights.

This study is not meant to be a call for paternalism or against counseling. Rather, we suggest that consensus panels understand the limits of office communication before advising deferral of uncertain decisions to individual patients. It seems unlikely that simply giving more information to the patient will solve problems inherent to informed consent.⁴⁵ Regardless of origin or prevalence, prior or other underlying beliefs can limit consideration of the risk–benefit information that clinicians are asked to present to patients. Perhaps decision aids and other efforts to optimize counseling^{15–24} may not contribute as meaningfully as some evaluations suggest, especially in an uncontrolled setting, or when men have been previously tested or have previous knowledge about PSA. Clinicians who wish to have full patient participation in uncertain decisions should elicit prior expe-

periences before counseling. Further investigation of the ability of physicians or decision aids to briefly assess and discuss the prior or underlying beliefs of individual patients will be valuable to current policy about PSA testing and future policy about other upcoming tests.

Take-Home Points

- Routine screening for PSA is controversial, but recommendations for pretest counseling are not backed by evidence about the processes of communication and decision making, especially in men with precounseling knowledge of PSA.
- This qualitative study examines the reasoning of men in their own words, before and after a “best-case scenario” counseling intervention.
- Many men cited underlying beliefs to discount the risk–benefit information presented to patients, including a fear of cancer, salient anecdotes and analogies, distrust of statistics, enthusiasm for “prevention,” protection from “bad luck,” faith in science, and valuing PSA as knowledge for its own sake.
- The effect of underlying beliefs on counseling suggests that consensus groups should consider counseling limitations when forming recommendations.
- Clinicians who want full participation in shared decision making should attempt to ascertain the patient’s prior or underlying beliefs during counseling.

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Correspondence

Michael H. Farrell, MD, Yale University School of Medicine, Departments of Internal Medicine and Pediatrics, 333 Cedar Street, Room 87 LMP, New Haven, CT 06520-8033; telephone: 203-370-4950; fax: 203-578-4927; e-mail: Michael.Farrell@Yale.edu.