

Screening for Prostate Cancer with the Prostate-Specific Antigen Test

Are Patients Making Informed Decisions?

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BACKGROUND. The benefits of early detection of prostate cancer are uncertain, and the American College of Physicians and the American Academy of Family Physicians recommend individual decision making in prostate cancer screening. This study reports the knowledge of male primary care patients about prostate cancer and prostate-specific antigen (PSA) testing and examines how that knowledge is related to PSA testing, preferences for testing in the future, and desire for involvement in physician-patient decision making.

METHODS. The sample included 160 men aged 45 to 70 years with no history of prostate cancer who presented for care at a university-based family medicine clinic. Before scheduled office visits, patients completed a questionnaire developed for this study that included a 10-question measure of prostate cancer knowledge, the Deber-Kraestchmer Problem-Solving Decision-Making Scale, sociodemographic indicators, and questions on PSA testing.

RESULTS. In general, patients who were college graduates were more knowledgeable about prostate cancer and early detection than those with a high school education or less. Aside from college graduates, most patients could not identify the principle advantages and disadvantages of PSA testing. Patients indicating previous or future plans for PSA testing demonstrated greater knowledge than other patients. Desire for involvement in decision making varied by patient education but was not related to past PSA testing.

CONCLUSIONS. Patients lack knowledge about prostate cancer and early detection. This knowledge deficit may impede the early detection of prostate cancer and is a barrier to making an informed decision about undergoing PSA testing.

KEY WORDS. Decision making; prostatic neoplasms; mass screening; primary health care. (*J Fam Pract* 1999; 48:682-688)

Prostate cancer is the most common noncutaneous cancer in men and the second leading cause of their cancer-related deaths.¹ Professional organizations, such as the American Cancer Society² and the American Urological Association,³ recommend annual screening with prostate-specific antigen (PSA) and digital rectal examinations, while the US Preventive Services Task Force⁴ recommends against PSA screening of asymptomatic men. More recently, the American College of Physicians⁵ and the American Academy of Family Physicians⁶ adopted guidelines for prostate cancer screening that call for patients to be educated about the potential harms and benefits of early detection. After receiving this information, a man should be better pre-

pared to decide which screening approach is appropriate for him.

Individualized approaches to decision making for prostate cancer screening highlight the need to educate patients and assess their knowledge about prostate cancer and early detection.⁷ Indeed, patients' understanding of the potential harms and benefits of prostate cancer screening with PSA has been questioned.⁸ These concerns are particularly important as mass screening efforts for prostate cancer have been undertaken in the United States in recent years, the most extensive being those related to Prostate Cancer Awareness Week.⁹

Advocacy of individualized decision making assumes that patients want to play a role in their health care, an assumption that complicates mass screening efforts. Deber's¹⁰ work on medical decision making suggests that patients want to be informed but not involved. This seems at odds with recent efforts, including those for prostate cancer, to encourage patient involvement in screening and treatment decision making. However, Deber and colleagues¹¹ have also demonstrated the importance of distinguishing *problem-solving* from *decision-making* aspects of patient involvement in clinical decisions. Problem solving involves assessment and diagnosis of the problem, determination of treatment, and estimation of

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the likelihood of treatment risks and benefits. Decision making involves an assessment of the acceptability of such risks and benefits and a determination of whose perspective is used in selecting among treatment options. Such a distinction is relevant to prostate cancer screening decision making.

Our study examined the following questions: (1) How knowledgeable are adult male family medicine patients about various potential harms and benefits of early detection of prostate cancer? (2) How is knowledge of prostate cancer related to screening behavior? and (3) How involved do these patients want to be in their health care decisions?

METHODS

SUBJECTS AND PROCEDURES

Subjects for this study were male primary care patients enrolled in a randomized controlled trial of shared decision making for prostate cancer screening.¹² Data were collected beginning in February of 1997 for a period of 5 months. We report data from baseline assessments of knowledge and past screening collected at entry before randomization.

Eligible subjects included men aged 45 to 70 years with no history of prostate cancer, who presented for any scheduled care at the University of Texas Medical Branch Family Medicine Center, a university-based family medicine clinic. Patients were selected from following-day clinic appointment lists, and their computerized records were reviewed for prostate cancer in the problem lists. Eligible patients were contacted by telephone before their visit and asked to participate in the study. Of 209 patients contacted, 24 refused to participate, and 25 were excluded for reasons of chronic disabling physical illness, incorrect patient records about history of prostate cancer, or cognitive impairment precluding participation. Thus, the final study sample size was reduced to 160.

Patients were asked to arrive 30 to 45 minutes before the appointment time to complete the study questionnaire. The questionnaire included sociodemographic indicators, questions about previous screening and intention to be screened in the future, a measure of knowledge about prostate cancer and early detection, and a measure of desire for involvement in medical decisions about health care (the Deber-Kraetchmer Problem-Solving Decision-Making [PSDM] scale). A Spanish translation of the questionnaire was prepared, and Spanish-speaking interviewers were used as needed. The Institutional Review Board approved this study for the use of human subjects, and each subject was given \$20 for participating.

MEASURES

PSA Testing. Participants were first asked if they had undergone a previous PSA test for prostate cancer, then preferences for PSA testing were measured by the question, "Given what you know about prostate cancer and

PSA testing, would you choose to have a PSA test?" Response options to both questions were "Yes," "No," and "I'm not sure."

Knowledge of Prostate Cancer. We developed a self-report measure of knowledge about prostate cancer for this study. The goal was to develop a brief, multiple-choice, self-administered questionnaire that reflected the content of various patient education materials (such as those available from the American Cancer Society) and a video on PSA testing distributed by the Foundation for Informed Medical Decision Making, Inc.¹³ Core domains of knowledge identified included prostate cancer epidemiology, PSA screening performance, treatment effectiveness, treatment-related complications, and general knowledge about advantages and disadvantages of PSA testing. A multiple-choice response format was adopted (with 3 initial options) following formats used in similar studies of patient education about prostate cancer screening. We then reviewed the PSA videotape and developed 16 items, written at a fifth grade reading level, for the test set. Items were reviewed by the project investigators and peer faculty for content validity, readability, and consistency in use of terminology. Item order was randomized, as was the order of the correct responses among the options. We administered the test set of questions to a pilot sample of 24 male family medicine patients. Redundant questions were eliminated, and a fourth response option was added for patients not willing to offer a guess when they did not have at least some idea of the correct response. The revised 10-item version of the test (*PC-Know*) was administered to a second pilot sample of 23 male family medicine patients. Response patterns proved acceptable in this revised version.*

Desire for Involvement in Decision Making. The PSDM scale has been previously studied and includes 6 questions framed as "Who should decide?" in response to various clinical vignettes.¹¹ We used 2 vignettes from the PSDM scale. The morbidity vignette read, "Suppose you often experience a burning sensation when you go to the bathroom." The mortality vignette read, "Suppose you had mild chest pain for 3 days and decided that you should visit your doctor about this."

The problem-solving questions were: Who should determine (diagnose) what the likely causes are of your symptoms? (diagnosis); Who should determine what the treatment options are? (treatment options); Who should determine what the risks and benefits for each treatment option are? (risks/benefits); and, Who should determine how likely each of these risks and benefits are to happen? (probability). The decision-making questions were: Given the risks and benefits of these possible treatments, who should decide how acceptable those risks and benefits are for you? (utility); and, given all the information about the

*This measure, the *PC-Know* questionnaire is available on the *Journal's* Web site at www.JFamPract.com.

risks and benefits of the possible treatments, who should decide which treatment option should be selected? (what is done). Response options consisted of "Doctor alone," "Mostly the doctor," "Doctor and you equally," "Mostly you," and "You alone." Only the decision-making questions were used in our analysis. Response options were collapsed into "defer" ("Doctor alone" and "Mostly the doctor"), "share" ("Doctor and you equally"), and "retain" ("Mostly you" and "You alone.") Internal consistency reliability (using coefficient α for the 2 vignettes) was .79 and .87.

DATA ANALYSIS

Characteristics of the sample were tabulated. The percentage of patients reporting previous PSA testing or plans to have a PSA test in the future was calculated. The total number of *PC-Know* questions answered correctly was also compared across patient education level by using 1-way analysis of variance (ANOVA) with post hoc comparisons and the nonparametric Kruskal-Wallis test 1-way, because the *PC-Know* distributions were not normal.¹⁴ The percentage of correct responses to each *PC-Know* question was calculated across patient education level. Chi-square served as the test statistic.

Responses to the *PC-Know* were compared across responses to the previous PSA testing and future testing questions and the decision-making style questions by using 1-way ANOVA with post hoc comparisons. Nonparametric tests (Kruskal-Wallis 1-way and Mann-Whitney) were used to confirm these analyses.¹⁴ Finally, we examined responses to the decision-making style questions by level of patient education and by the PSA testing questions and used chi-square as the test statistic.

RESULTS

SAMPLE CHARACTERISTICS

Sociodemographic characteristics of the sample are shown in Table 1. The sample characteristics reflected those of the practice and included patients from a range of socioeconomic and ethnic backgrounds. A family history of prostate cancer was noted for 24 (15%) of the subjects.

PREVIOUS PSA SCREENING AND PREFERENCES FOR FUTURE SCREENING

Patients' responses to the questions on PSA testing are given in Table 2. The percentages of patients who reported having or not having previous PSA tests were similar. Interestingly, 35 (21.9%) were not sure if they had undergone a previous PSA test. Only 6 (3.8%) patients indicated that they do not plan to have a PSA test in the future. Thus, the "I'm not sure" and "No" responses to this question were combined for further analyses.

PROSTATE CANCER KNOWLEDGE

Overall, the average number of *PC-Know* questions correctly answered (of 10 total) was 1.9 for patients with less

than a high school degree, 2.0 for high school graduates, 2.8 for patients with some college, and 4.1 for college graduates. Post hoc tests showed significant differences between the college graduates and the other groups ($P < .01$). Nonparametric analyses confirmed these findings.

Patients' responses to each question from the *PC-Know* questionnaire are shown in Table 3, stratified by education level. For 6 of the questions, statistically significant differences were seen in the percentage of correct responses across patient education. Fewer than 10% of patients with a high school education or less knew that most men with untreated early-stage prostate cancer would not die from it. Most patients knew that increasing age was a risk factor for prostate cancer, with 85.7% of college graduates answering this question correctly. As for PSA screening

TABLE 1

Characteristics of the Study Sample

	Frequency (%)*
Age, years	
Minimum - maximum	45 - 70
25th percentile	53
50th percentile	59
75th percentile	66
Race/ethnicity	
African American	31 (19.4)
White	98 (61.3)
Mexican American	25 (15.6)
Other	6 (3.8)
Education	
Not a high school graduate	36 (22.5)
High school graduate	32 (20.0)
Some college/vocational training	50 (31.3)
College graduate	25 (15.6)
Postgraduate degree	17 (10.6)
Employment status	
Full-time	58 (36.3)
Part-time	10 (6.3)
Retired	54 (33.8)
Disabled	28 (17.5)
Unemployed	10 (6.3)
Annual household income, dollars	
<\$10,000	32 (20.0)
\$10,000 - \$19,999	35 (21.9)
\$20,000 - \$39,999	37 (23.1)
\$40,000 - \$69,999	41 (25.6)
>\$70,000	15 (9.4)
Marital status	
Married	117 (73.1)
Single	12 (7.5)
Divorced	26 (16.3)
Widowed	5 (3.1)
Family history of prostate cancer	24 (15.0)

*Percentages do not total 100% because of rounding.

TABLE 2

Patients' Responses to Questions Regarding the Prostate-Specific Antigen (PSA) Test

Question/Responses	Frequency (%)*
Ever had a PSA test?	
Yes	66 (41.3)
No	59 (36.9)
I'm not sure	35 (21.9)
Plan to have a PSA test in the future?	
Yes	125 (78.1)
No	6 (3.8)
I'm not sure	29 (18.1)

*Percentages do not total 100% because of rounding.

performance, less than 20% of patients, regardless of education level, knew that an abnormal PSA level was usually a result of an enlarged prostate associated with aging. College graduates were more likely than other patients to know that PSA levels tend to increase with age. Very few patients recognized that most men with a high PSA level do not have prostate cancer.

In the areas of treatment effectiveness and treatment complications, only 22.2% of patients with less than a high

school education knew that prostate cancer when detected early was curable compared with more than 50% of patients with a college education who knew it. Less than 20% of the patients with a high school education or less knew the benefits of "nerve sparing" radical prostatectomy, while less than 25% of patients could identify loss of sexual function as a common complication of radiation therapy. Regarding patients' general knowledge of PSA testing for prostate cancer, from 27.8% (those with less than high school education) to 42.9% (college graduates) understood that reassurance following a negative PSA test result was a possible advantage of PSA testing. More than half of the college graduates knew that a positive PSA test result could cause anxiety and lead to unnecessary testing in men who do not have cancer.

PSA TESTING AND KNOWLEDGE OF PROSTATE CANCER

Table 4 shows the average number of *PC-Know* questions answered correctly related to their PSA testing status. Nonparametric analyses confirmed the findings as presented. Patients who reported having a previous PSA test answered approximately 3.5 of the 10 *PC-Know* questions correctly, while patients unsure of previous testing answered 1.9 questions correctly, on average ($P < .05$). Similarly, patients planning to have a PSA test in the future scored higher than other patients, answering 3.0 questions

TABLE 3

Percent of PC-Know Questions Answered Correctly, by Patient Education Level

Domain/Question Descriptor*	Education Level				P
	Not a High School Graduate	High School Graduate	Some College	College Graduate	
Prostate cancer epidemiology					
Mortality from untreated prostate cancer	5.6	9.4	24.0	38.1	.001
Age and prostate cancer risk	55.6	56.3	72.0	85.7	.011
PSA screening performance					
Meaning of an abnormal PSA level	13.9	12.5	4.0	16.7	.244
Abnormal PSA levels and age	16.7	3.1	14.0	35.7	.003
Predictive value of PSA	0.0	6.3	2.0	4.8	.428
Treatment effectiveness					
Early detection and cure	22.2	43.8	58.0	64.3	.001
Treatment complications					
Benefit of "nerve sparing" surgery	11.1	6.3	16.0	42.9	.000
Complications of radiation therapy	19.4	15.6	10.0	23.8	.344
General PSA knowledge					
Advantages of PSA	27.8	34.4	36.0	42.9	.583
Disadvantages of PSA	19.4	12.5	40.0	52.4	.001

*For the complete *PC-Know* questionnaire visit the *Journal's* Web site at www.JFamPract.com.

PSA denotes prostate-specific antigen test.

TABLE 4

PC-Know Questions Answered Correctly, by Prostate-Specific Antigen (PSA) Testing Status

Question/Responses	Mean* (95% CI)
Ever had a PSA test?	
Yes (n = 66)	3.45 (2.96 - 3.94)
No (n = 59)	2.49 (1.97 - 3.01)
Unsure (n = 35)	1.91 (1.29 - 2.53)
Plan to have a PSA test in the future?	
Yes (n = 125)	3.00 (2.64 - 3.36)
No or unsure (n = 35)	1.91 (1.31 - 2.52)

Note: For the previous PSA testing question, post hoc comparisons significant for "Unsure" compared with "Yes" and "No" at $P < .05$. The question about future PSA testing question is significant at $P < .005$.

*Mean number of questions answered correctly out of 10 total questions.

CI denotes confidence interval.

correctly, on average. Patients unsure of previous testing scored lowest (1.9) on the *PC-Know* ($P < .005$).

Analysis of the individual *PC-Know* questions showed that differences related to having a previous PSA test or preferring to be tested in the future were attributed to the following: greater recognition that prostate cancer when detected early can be cured, better understanding that "nerve sparing" surgery decreases the risk of impotence, and to a lesser degree, recognition that most men with prostate cancer will not die of it and that an abnormal PSA may lead to unnecessary diagnostic testing.

PATIENTS' DESIRE FOR INVOLVEMENT IN DECISION MAKING

Table 5 shows the average number of *PC-Know* questions answered correctly for patients from each of the decision-making styles determined by the PSDM scale. Responses to the morbidity and mortality vignette were similar, and thus only the morbidity vignette is reported. In general, patients who would defer to their physician decision making about the acceptability of treatment risks and benefits and selection of the treatment modality scored lowest on the *PC-Know* compared with patients who would want to share or retain decision-making control. Nonparametric analysis confirmed these findings.

Preferences for patient involvement in decision making varied by the education level of the patient (Figure). For the question of acceptability of risks and benefits, more than 40% of patients with high school degrees or less preferred to defer to their doctor, compared with 7.1% of college graduates. Similarly, more than 61.9% of college graduates indicated they would retain control, compared with approximately 30% of all other patients.

The findings for the question about who should

decide which treatment option should be selected followed a similar pattern by patient education. Overall, most patients with any education beyond high school preferred to share or retain control in decision making. Finally, decision-making styles were not related to previous PSA testing or intention to be tested in the future.

DISCUSSION

Several observations can be made from our findings. First, overall, men are not well informed about prostate cancer and the potential harms and benefits of early detection with the PSA test. Second, patients with more education tend to demonstrate modest but significantly greater knowledge of prostate cancer, although this was not consistent across all domains of the *PC-Know* questionnaire. Third, greater knowledge seems to be related to past PSA testing and a greater likelihood of testing in the future. (Most men do plan to have a PSA test in the future.) Finally, these patients' desire to be involved in decision making is related to their knowledge of prostate cancer and education level; patients with a high school education or less prefer to defer decision making to their physicians, while patients with more education want to share or retain control in making decisions. Patients who prefer to leave decision making to their physicians are least informed about prostate cancer. These decision-making preferences, though, are not related to past PSA testing or plans for testing in the future.

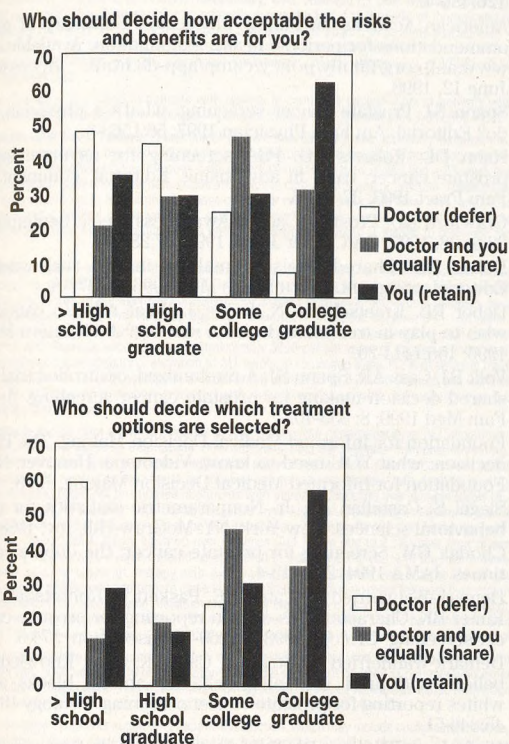
The general lack of knowledge of male primary care patients regarding prostate cancer screening is worrisome but not surprising. Although prostate cancer has become a high-profile disease,¹⁵ the function of the prostate gland, its location, and age-related changes are not well understood by many men. Studies of men reporting for prostate cancer screenings during Prostate Cancer Awareness Week have shown wide variability in knowledge of prostate cancer,^{16,17} and such sponsored screenings tend to attract men who are more educated, white, and often symptomatic.⁹

More disconcerting is the finding that only 1 in 5 patients who had not graduated from high school knew that prostate cancer was curable if detected early. Conventional wisdom about cancer in general reflects the importance of early detection and possible cure. The obvious concern is that less-educated men may not avail themselves of screening because they lack knowledge regarding prostate cancer.

The relationship between prostate cancer screening knowledge and patient education was not consistent across domains. Education level was related to knowledge of prostate cancer epidemiology and PSA screening performance as related to patient age. Most patients could not interpret the meaning of an abnormal PSA level or demonstrate lay knowledge of the predictive value of the test. With the exception of college graduates, most patients could not identify the principal advantages and disadvantages of PSA testing.

FIGURE

The patients' desire for involvement in decision making about their health care, related to education level.



Not surprisingly, those patients who reported having a PSA test or who were planning to have one were more knowledgeable about prostate cancer and screening than those patients who were unsure of previous testing. Previously screened patients probably had more opportunities for learning about prostate cancer and PSA testing from physicians or other health care personnel, family and friends, or the media.

The large proportion of men in this study who did not know whether they had a previous PSA test (21.9%) is also noteworthy. Perhaps patients confuse the PSA test with other blood tests (eg, cholesterol screening), assuming that blood tests are simply part of general physical examinations, and may not realize this particular test's purpose when the results are normal and not reviewed with the health care provider. Other studies have found that many patients do not realize they had a PSA test for prostate cancer shortly after the blood draw and do not understand that additional testing is required if the results are abnormal.¹⁸

Patients' preferences for involvement in treatment decision making showed marked variability in this study and were related to patient education but not to previous PSA testing. The general lack of knowledge about prostate

cancer and early detection may explain why so many less-educated patients prefer to leave decision making to their physicians. Improving the knowledge base of less-educated patients might increase their interest in being involved in decision making about screening. Deber and coworkers¹¹ also found a small but significant relationship between patients with at least some college education and their preference to be more involved in their health care decisions.

An individualized approach to prostate cancer screening decision making requires that patients are informed about the potential harms and benefits of early detection and treatment. Decision aids that emphasize patients' values and preferences are needed to facilitate patient education and shared decision making about many preventive services. Screening mammography for women younger than 50 years and at normal risk of breast cancer^{19,20} and colorectal cancer screening strategies⁴ are examples of preventive services for which optimal strategies are uncertain and patients' preference may be crucial in decision making.

LIMITATIONS

Our study is limited by the use of a single clinical site. Patient self-report was the sole source of information on PSA testing and the reliability of this information is

TABLE 5

PC-Know Questions Answered Correctly, by Patients' Desire for Involvement in Decision Making About Their Health Care

Decision-Making Questions	Mean* (95% CI)
Who should decide how acceptable the risks and benefits of treatment are for you?	
Doctor alone or mostly the doctor (defer) (n = 46)	1.83 (1.34 - 2.32)
Doctor and you equally (share) (n = 52)	2.90 (2.36 - 3.45)
You alone or mostly you (retain) (n = 62)	3.34 (2.79 - 3.88)
Who should decide which treatment option is selected?	
Doctor alone or mostly the doctor (defer) (n = 57)	1.89 (1.42 - 2.37)
Doctor and you equally (share) (n = 49)	2.90 (2.35 - 3.44)
You alone or mostly you (retain) (n = 54)	3.56 (2.99 - 4.12)

Note: Post hoc comparisons significant for "defer" compared with "share" and "retain" at P < .05.

* Mean number of questions answered correctly out of 10 total questions.

CI denotes confidence interval.

unknown. Also, although some differences in prostate cancer knowledge appear to be related to patient education, better test-taking skills might explain these effects. Because of the study focus and sample size, we were not able to look at the effects of education stratified by race or ethnicity. That type of research would have important implications for high-risk groups, such as African American men.

CONCLUSIONS

Knowledge about prostate cancer and early detection was lacking in this sample of male primary care patients, particularly for those with a high school education or less. This knowledge deficit is a barrier to making informed decisions about PSA testing and may also be a barrier to the early detection of prostate cancer. Physicians cannot assume that even those patients who ask for PSA tests are truly knowledgeable about them. Continued patient education about prostate cancer screening is clearly needed for informed patient decision making.

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