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Patient and Physician Factors Associated with Undisclosed Prostate Cancer Screening in a Sample of Predominantly Immigrant Black Men

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Abstract

Medical guidelines do not recommend prostate cancer screening, particularly without informed and shared decision making. This study investigates undisclosed opportunistic screening using prostate specific antigen (PSA) testing in black immigrant and African American men. Participants ($N = 142$) were insured urban men, 45-to 70-years old. Patients' reports of testing were compared with medical claims to assess undisclosed PSA testing. Most (94.4 %) men preferred to share in screening decisions, but few (46.5 %) were aware PSA testing was performed. Four factors predicted being unaware of testing: low formal education, low knowledge about prostate cancer, no intention to screen, and no physician recommendation (all p's <.05). Undisclosed PSA testing was common. Both patient and provider factors increased risk of being uninformed about prostate cancer screening. Interventions combining patient education and physician engagement in shared decision making may better align practice with current prostate cancer screening guidelines.

Keywords

Prostate cancer screening; Shared decision making; Minority health; Informed decision making; Patient preferences

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Compliance with ethical standards
Conflict of interest The authors have no conflict of interest to report.
Ethical Approval All procedures involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.
Research Involving Human Participants and/or Animals This article does not contain any studies with animals performed by any of the authors.
Informed Consent Informed consent was obtained from all individual participants included in the study.

Introduction

Prostate cancer accounts for about 26 % of new cancer cases and is the second most common cause of cancer deaths in American men [1]. Globally, black men of African descent are more likely to be diagnosed with prostate cancer and have higher mortality rates than other racial/ethnic groups [2]. The majority of prostate cancers are detected via screening of asymptomatic men, using digital rectal examination, prostate specific antigen (PSA) blood test, or both [3, 4]. PSA-based screening, including opportunistic screening, is widespread in Western countries and has been cited as a driver of the rise in prostate cancer incidence in recent decades [5–9]. PSA-based screening is especially controversial when performed without a patient's knowledge and consent, as it can lead to further and potentially unnecessary or harmful diagnostic evaluations and treatments for which the patient is unprepared [10]. This study investigates the extent to which a sample of PSA-screened black men was aware of being screened, had discussed screening with their physician prior to testing, preferred shared versus unilateral decision making related to PSA testing, and intended to test for prostate cancer. We also investigated characteristics of men who are at risk for being uninformed about their prostate cancer screening status.

The study sample consisted of black men from the greater New York City metropolitan area, with a large proportion of Caribbean immigrants. As noted in a recent review [11], Caribbean natives represent one of the largest subgroups of black immigrants in the US, and Caribbean men of African descent often have a higher incidence of prostate cancer and tend to screen less than African American men. Thus, the sample provides a unique opportunity to examine individual and physician factors related to prostate cancer testing in this high-risk group.

PSA screening for prostate cancer has been debated for years because of the uncertainty surrounding its benefits, risks and the optimal screening strategy [12]. As a result, its use may be abating in some segments of the population [13]. The latest United States Preventive Task Force (USPTF) report concludes that the benefits of PSA-based prostate cancer screening do not outweigh the harms and recommends against screening [14]. The USPTF also recommends that PSA testing be preceded with education and shared decision making that enables patients to make informed decisions. Similarly, the American Urological Association [15] recommends that physicians engage in shared decision making with patients about PSA screening, and the American College of Physicians emphasizes that patients be informed about the benefits and harms of screening for prostate cancer [16]. The American Society of Clinical Oncology recommends that physicians use informed consent, in which they discuss the pros and cons of PSA testing with patients before screening them [17]. Finally, the American Cancer Society guidelines state that men should have an opportunity to decide after being informed by their physician about testing pros and cons [18]. While recommendations about whether to screen or who to screen have varied among medical societies over the 15 years, there has been consistent consensus that men being tested for prostate cancer should be properly informed and that shared decision making be practiced [19–22].

Shared decision making honors a patient's right to be informed of potential harms and benefits of a medical procedure so that they understand the implications of their decision and maintain personal autonomy [23]. With respect to prostate cancer screening, the process also would take into account a patient's personal preferences and a discussion of what the outcome of the screening test could mean for the patient's health [10, 24]. Despite consensus among professional medical societies that prostate cancer screening be applied judiciously and in the context of shared decision-making, discrepancies exist between recommended clinical guidelines and practice. Men often make decisions about controversial procedures such as prostate cancer screening without a complete understanding of their options or the aid of decisional support materials [25]. In a national study of men 50- to 74-years-old, approximately 39 % of those undergoing annual PSA screening reported no shared decision making with their physicians [10]. An investigation of physicians found that one-third reported ordering PSA testing without discussion, especially when patients had lower education and health literacy [26]. When discussions do occur, they often are unbalanced. In a national survey, men over the age of 50 who underwent prostate cancer screening reported that physicians were more likely to discuss pros (51 %) than cons (7 %) of testing [25]. In a study of predominantly African American men with relatively low literacy, nearly half (48.4 %) recalled having a discussion regarding PSA testing during a routine medical visit and 88.5 % of those men recalled the physician saying it was important to get tested [27].

Opportunistic prostate cancer screening with a PSA test during routine medical visits is the most common method of detection of prostate cancer [28]. Screening can occur without men's knowledge, a discussion of the pros and cons of testing, or a consideration of their preferences [10, 26, 29]. One study of Australian men aged 50–70 years found that about 55 % of the men felt that undisclosed PSA testing was inappropriate and should not be included within an array of pathology tests without disclosure to the patients [30]. Men want to engage in shared decision making with their health care providers and agree on the decision whether or not to undergo prostate cancer screening. Opportunistic screening undermines patient autonomy and challenges national recommendations for prostate cancer shared decision making.

Our study examined aspects of shared decision making about prostate cancer screening in a high-risk population of predominantly immigrant black men. Specifically, we investigated the extent of undisclosed opportunistic PSA testing in the sample and the characteristics of men and their physicians that increased men's risk for undisclosed testing. This information can inform future interventions to improve doctor-patient communication and shared decision-making practices in clinical setting where PSA tests are being ordered for high-risk minority men.

Methods

Overview

Data for this observational study were drawn from a two-group (experimental vs. attention control group) randomized trial of 431 men on the efficacy of a decision support intervention about prostate cancer testing (for details, see [31]). Men in the intervention arm received print education material and tailored telephone education by a health educator focused on prostate cancer testing. The aim of the intervention was to provide accurate, balanced information that would help men to make an informed decision about prostate cancer testing that was consistent with their values. Men in the control arm received print material and tailored telephone education by a health educator focused on national recommendations for men's fruit and vegetable consumption. Trained telephone interviewers collected self-report data before (T1) and 8 months after (T2) randomization. Importantly, medical claims for PSA testing and physician visits were tracked throughout the study and we have complete claims data on 100 % of participants. Participants provided informed consent and an Institutional Review Board approved the study. The intervention was unrelated to the major variables included in this study, including claims-verified PSA testing and self-reported awareness of PSA testing, knowledge about prostate cancer and PSA testing intentions, efficacy to discuss prostate cancer with physician, preference for decision making about PSA testing, and physician recommendation to get a PSA test.

Participants

The sampling frame was constructed from a list of health insurance beneficiaries of a large healthcare workers' union in greater New York City (for details on the sampling frame and selection, see [31]). The list included men who met minimal study eligibility criteria that could be determined from the beneficiary database (e.g., age 45–70 years, male sex, no prostate cancer history). A random subset of men was recruited from this list. All men had a primary care physician and health insurance that covered PSA testing. The database did not include race, so we used a telephone eligibility assessment screen to identify race. A total of 1777 men were assessed for eligibility, which included being a black man of African descent between the ages of 45- to 70-years old with no history of prostate cancer. Many men were excluded during screening (N = 1287) due to ineligibility (N = 1153; 89.6 %) and some refusals (N = 137; 10.6 %). Of those screened eligible (N = 624), the majority (N = 490; 78.5 %) agreed to randomization. New York City has a very high concentration of black persons from the Caribbean, and this was reflected in the sample. This study included only the data from trial participants who completed the follow-up interview (N = 431). Analyses focused on participants who had a medical claim for a PSA test (N = 142).

Measures

Demographic and Health Characteristics—At T1, participants reported their age, education, immigrant and marital status. Standard instruments were used to assess comorbid illness [32] and genitourinary symptoms related to prostate cancer [33]. These variables were categorically coded (0 = no symptoms/illness; 1 = any symptoms/illness).

Knowledge About Prostate Cancer and Prostate Cancer Testing Intentions—At T1, participants reported whether they planned to get tested in the future (no/yes). Knowledge at T1 was measured with a 14-item index comprising items related to testing, risk factors and treatment [31]. A median split was used to classify participants' knowledge as lower (≤50 % correct) or higher (>50 % correct).

Patient Efficacy to Discuss Prostate Cancer Testing with Physician—A measure of communication efficacy was created using three items from T1. Participants reported whether they were confident (0 = no, 1 = a little, 2 = very) that: "you know enough about prostate cancer testing to talk about it with your doctor"; "you know enough about the possible risks of prostate cancer testing to talk about them with your doctor"; and "you know enough about the possible benefits of prostate cancer testing to talk about them with your doctor." A median split was used to categorize participants as low (0–3) or high (4–6).

Preference for Decision Making about PSA Testing—Using the approach of Degner [34], participants reported preference for active, passive or collaborative decision making at T1: "In thinking about the decision to get tested for prostate cancer, who would you prefer to make that decision? Would you say: (a) You? (b) Your doctor? or (c) You and your doctor together?"

PSA Testing, Awareness of Testing and Physician Recommendation—At the T2 assessment, participants reported if they had visited their physician since the T1 assessment. Visits were verified through medical claims (100 %). Participants reported whether their physician recommended a PSA test during a visit and whether they received a "PSA or blood test" for prostate cancer. Self-reports of having received a PSA or blood test for prostate cancer were compared with medical claims (present/absent) for a PSA test. Participants who both had a medical claim for a PSA test during the study period and reported not receiving a PSA or blood test for prostate cancer were classified as being unaware of PSA test. Digital rectal examination (DRE) also was self-reported. However, we do not discuss these results here because DRE is used for reasons other than cancer screening and could not be verified with medical claims.

Analysis

Data were analyzed using SPSS Version 23.0 (IBM Corporation, Armonk, NY). We used Chi Square tests to examine the associations between all of the provider and patient predictor factors shown in Table 1 and men's awareness (aware/unaware) of having had a PSA test. Factors for which p values in these bivariate analyses were <.10 were retained in a multiple logistic regression model predicting men's PSA test awareness. In the logistic regression, all predictor variables were entered simultaneously into the model. The multivariate analyses were repeated with and without an adjustment for experimental intervention condition. Condition did not influence outcomes, so the final report excluded experimental condition as a covariate. Odds ratios (ORs) and 95 % confidence intervals (CIs) were used, and all tests were 2-sided with a significance level of .05.

Results

In the 8-months between T1 and T2, 142 (32.9 %) of the T2 respondents had a PSA test medical claim. Of these 142 tested men, 76 (53.5 %) were unaware that they had been tested. Most men were immigrant and married, but had considerable variability in education and age (Table 1). At T2, most men reported some comorbid illness, but few reported genitourinary problems. A little over half had planned to get tested for prostate cancer in the future. Average knowledge about prostate cancer and testing was low. Efficacy to discuss prostate cancer testing with a physician also was low. Over 75 % of the men reported that their physician did not recommend a PSA test between T1 and T2. Most men reported that they preferred collaborative or shared decision-making about testing, with fewer than 6 % preferring that their physician make the decision.

Table 1 also compares those men who were versus were not aware that a PSA test was conducted. Being unaware of PSA testing was associated with less formal education, having no intention to get tested for prostate cancer, having little knowledge about prostate cancer and testing, having low efficacy to talk with one's physician about testing, and being unlikely to receive a recommendation for a PSA test during a visit with a physician who ordered such a test.

Table 2 shows results of the multivariate logistic regression of men's awareness of having had a PSA screening test. Four of the model predictors were independently associated with unawareness: education ≤high school (OR 4.347, CI 1.723–10.970); not planning to get tested (OR 3.356, CI 1.361–8.272); low prostate cancer knowledge (OR 2.378, CI 1.040–5.434); and no physician recommendation (OR 24.574, CI 5.904–102.289).

Discussion

Within a sample of insured and predominantly immigrant black men, most were unaware that they had been tested for prostate cancer by a PSA blood test. These findings suggest that the health care providers missed an opportunity to foster the patient-provider relationship, promote patient autonomy, improve patient knowledge, and create realistic patient expectations regarding the prostate cancer screening outcome. Moreover, testing in largely asymptomatic men, some of whom had little knowledge about testing and no intention to get tested, disregards national guidelines that recommend against routine screening and favor disclosure, patient education and shared decision making.

For most men in the sample, undisclosed PSA testing conflicted with their preferences for shared decision making. Fewer than 6 % of the men preferred that their physician make a unilateral decision about prostate cancer screening. This is consistent with prior research on shared decision making about prostate cancer testing among African American men [35], suggesting a strong preference for input to such decisions in this population. Prior research suggests that while most white men also prefer to be involved in the decision to test for prostate cancer, a fifth or more may prefer a more passive role [30, 36]. Williams et al. [35] have suggested that distrust in the medical profession may increase interest in shared decision making in the black population.

Our findings indicated that undisclosed testing also conflicted with some men's screening intentions. Fewer than half of the tested men intended to get tested for prostate cancer during the baseline interview. Not intending to get tested proved to be an independent risk factor for being uninformed about being tested at follow-up. Patients indicating an intention to get tested for prostate cancer in the future have been shown to have greater knowledge about prostate cancer testing and to be likely to participate in a discussion with their physician [37].

Both patient and provider factors were independently associated with being unaware that a PSA test had been conducted. Four factors increased men’s odds of being tested without their knowledge: no college education, no intention to get tested, lower levels of knowledge about prostate cancer and screening tests, and not receiving a physician’s recommendation to get tested. Similar factors have been found in research using self reported screening. For example, compared with men who did not have a PSA test, men reporting receipt of a PSA test tended to have a higher level of education and knowledge about PSA testing [38]. Provider factors that may impede doctor-patient communication about prostate cancer screening include time constraints and language barriers [39], and the perception among some providers that patients with less formal education will not understand complex medical issues [26].

Use of decision aids, particularly multimedia and entertainment-education interventions, may help address barriers related to education and literacy level [40]. Such aids can be administered in a waiting room using tablets and mobile phones. The men in our sample had low levels of self-efficacy to talk to their physicians about prostate cancer screening. Decisions aids have been shown to increase patients’ involvement in decision making about prostate cancer screening with their physician [24].

Technology also may promote greater physician adherence to best practice guidelines related to shared decision making about prostate cancer screening. For example, electronic reminder systems could be used to automatically prompt clinicians to inform patients and engage in shared decision-making whenever they attempt to order a PSA test. Of course, physicians also have to be motivated to improve communication by engaging in shared decision making [41]. Thus, interventions designed to improve physicians’ engagement in shared decision making should address attitudes in addition to knowledge, skills and opportunities [42].

One limitation of this study is that we had scant data on provider and clinic factors. It is possible that patient factors such as level of education covary with qualities of clinics and healthcare providers. For example, men with less than a college level of education may be more likely to use understaffed medical facilities, which could reduce the feasibility of implementing shared decision making. Alternatively, men with less formal education may also be at risk for more illnesses that were the topic of discussion during the clinic encounter, leaving no time to discuss PSA screening. Another limitation is that we had a relatively small sample of black men from the metropolitan New York area. Thus, we do not know if the results would generalize to a more representative sample of black men. Finally, it is possible that some of the discrepancy between patient reports and claims data relates to faulty memory of patients, particularly those with lower education. All patient reports of having had a medical visit were verified by claims data, but it is still possible for patients to have forgotten some details of the visit. Despite these limitations, this study has a number of strengths including verified PSA testing, physician visit outcomes, long-term follow-up, and a large community sample of black men with diverse educational and cultural backgrounds.

New Contribution to the Literature

In a sample of insured and predominantly immigrant black men in the greater New York City area, it was more common for men to be uninformed than informed about having been tested for prostate cancer by a PSA blood test. At highest risk were patients with no college education, low knowledge about prostate cancer and screening tests, no intention of getting tested, and no recommendation from a physician to get tested. Despite the large majority of men reporting a preference to share in the decision to get tested for prostate cancer, few had this opportunity because tests were ordered by their physician without the benefit of discussion. Bivariate analyses suggested that less informed men may have lower confidence, or efficacy, to talk about prostate cancer and screening tests with their physician, so the onus is on the physician to open up this dialog when tests are being ordered.

On the basis of these findings, we recommend that future interventions to promote informed and shared decision making about prostate cancer testing address both modifiable patient and physician factors. Patient-focused interventions promoting informed decision making among black men in the U.S. have been effective at increasing knowledge about prostate cancer testing, increasing communication between patients and physicians, and reducing decision conflict related to testing [31, 43–45]. However, such interventions do not prevent physicians from engaging in undisclosed opportunistic testing. Improvements in clinic systems and operations, possibly with the use of decision aids and electronic reminders and prompts, may further promote shared decision making in this context. Of course, implementation of such systems should be done carefully and with respect for the autonomy and many competing demands of the clinician, so that the tool does not contribute to excess demands [46]. A common barrier to shared decision making is the lack of time for discussion. This might be mitigated somewhat by increasing patients' knowledge about screening with decision aids before a physician encounter, so that the physician could effectively tailor and focus discussion.

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Table 1

Comparisons of men who were aware versus unaware of PSA screening status (N = 142)

	Total sample (%)	**Unaware (n = 76) (%)**	**Aware (n = 66) (%)**	***p* value**[a]
Immigrant				
No	17.6	17.1	18.2	.867
Yes	82.4	82.9	81.8	
Highest education achieved				
Post-secondary	37.3	25.0	51.5	.001
≤High school	62.7	75.0	48.5	
Age group in years				
45–49	23.9	28.9	18.2	.373
50–54	23.9	19.7	28.8	
55–59	28.2	28.9	27.3	
60–70	23.9	22.4	25.8	
Married				
No	14.8	14.5	15.2	.910
Yes	85.2	85.5	84.8	
Comorbid conditions				
None	19.7	22.4	16.7	.394
≥1	80.3	77.6	83.3	
Genitourinary symptoms				
Asymptomatic	64.1	59.2	69.7	.194
Symptomatic	35.9	40.8	30.3	
Plan to get tested for prostate cancer				
Yes	55.6	47.4	65.2	.033
No	44.4	52.6	34.8	
Prostate cancer knowledge				
>50 % correct	48.6	35.5	63.6	.001
≤50 % correct	51.4	64.5	36.4	
Efficacy to discuss prostate cancer testing with physician				
High	46.5	38.2	56.1	.033
Low	53.5	61.8	43.9	
Physician recommended PSA test (T2)				
Yes	21.1	3.9	40.9	.001
No	78.9	96.1	59.1	
PSA decision making preferences (T2)				
Patient decision	16.2	21.1	10.6	.188
Physician decision	5.6	6.6	5.6	
Physician-patient shared decision	78.2	72.4	84.8	

[a] Two-sided *p* values. Associations between awareness of PSA test being performed (no/yes) and categorical variables were calculated using Chi square analyses. Unless otherwise noted, variables measured at Time 1. T2 = Time 2

Table 2

Multiple logistic regression model of factors predicting men being unaware (no/yes) of PSA screening status (N = 142)

	Adjusted odds ratio (95 % CI)	***p* value**[a]
Highest education achieved		
Any college/post-secondary	Reference	
≤High school	4.347 (1.723–10.970)	0.002
Plan to get tested for prostate cancer		
Yes	Reference	
No	3.356 (1.361–8.272)	0.009
Prostate cancer knowledge		
>50 % correct	Reference	
≤50 % correct	2.378 (1.040–5.434)	0.040
Efficacy to discuss prostate cancer testing with physician		
High	Reference	
Low	1.309 (0.572–2.994)	0.524
Physician recommended PSA test (T2)		
Yes	Reference	
No	24.574 (5.904–102.289)	0.000

R^2 = .29 (Hosmer & Lemeshow), .33 (Cox & Snell), .44 (Nagelkerke). Model Chi Square (df = 5) = 56.15, p<.001

[a] Two-sided *p* values. Unless otherwise noted, variables measured at Time 1. T2 = Time 2