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ABSTRACT

This is a nationally-representative mailed survey of 2000 urologists to (1) collect information about physician sociodemographics and clinical practice characteristics and (2) relate this information to treatment recommendations in three clinical vignettes. The vignettes allow for assessments of the independent effects of patient race, age, socioeconomic status, and tumor characteristics on urologist treatment recommendations in the setting of moderate grade, localized prostate carcinoma. To date, we have completed the survey and written three manuscripts. Two of these have been accepted for publication and a third is under review. A fourth is in preparation. The survey response rate was 66.1%, which is excellent. Key findings include the following. First, patient social vulnerability interacts with race to influence urologist treatment recommendations for radical prostatectomy. This is a novel finding with important implications for health disparities research more broadly. Second, the vast majority of urologists report performing fewer than 2.5 radical prostatectomies per month. Based on volume-outcome literature for radical prostatectomy, this raises significant concerns about surgical skill and outcomes. Third, a majority of urologists rate their own surgical outcomes as better than the national average, and a significant proportion provide erroneous information about comparative outcomes for major treatment modalities. Finally, for a hypothetical 77 year old patient who desires “cure,” 85% of urologists recommended aggressive therapy when the patient has few concerns about treatment side effects and 68% of urologists recommended aggressive therapy when the patient does have concerns about side effects. These results are concerning because aggressive therapy confers little survival benefit but a high likelihood of side effects that should be avoided even in patients who profess little concern about side effects. Informed by the above analyses as well as others by the PI, the PI is currently developing an R01 proposal to develop and evaluate a novel decision aid for African American patients newly-diagnosed with localized prostate carcinoma.

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Annual Report

Introduction

African American men with localized prostate cancer are about 25% to 30% less likely than non-Hispanic white men to be treated with radical prostatectomy (RP), even when adjustments are made for age, tumor characteristics, sociodemographic characteristics, and comorbid conditions [1-11]. Lower rates of prostatectomy among African Americans are intriguing because virtually all patients see urologists for confirmatory biopsies and for initial discussions about treatment, and because most urologists view prostatectomy as the best option for cure [12]. Although African Americans are more likely to fear surgery and distrust physicians than members of other racial/ethnic groups [13,18] – and may therefore refuse prostatectomy when offered - it is important to ascertain whether treatment disparities also emerge from systematic differences in clinician recommendations or, possibly, impaired opportunities for African American men to participate in therapeutic decision-making.

These possibilities are amply supported by evidence from other disease conditions showing that patient race and socioeconomic status can adversely influence physicians' advice and perceptions of patients [14, 15], that poor and minority patients are likely to receive lower quality health care [16], and that difficulties in doctor-patient communication are more apt to arise when the cultural and social background of physicians and patients diverge [17].

Body

Through a national survey of urologists, the goal of the proposed study is to assess whether differences in treatment recommendations and aspects of shared decision-making are associated with black-white disparities in recommendation for prostatectomy. The study will also provide valuable descriptive information related to aspects of urologic practice in general, urologists' beliefs and attitudes about prostate cancer patients, and will characterize the sociodemographic and practice characteristics of urologists who treat large numbers of African American patients. The study will inform the development of patient and urologist-focused interventions to improve the care of African American men.

Key research accomplishments

- We have developed, pilot-tested, and completed all survey mailings, collected responses, entered these into an Access database, and have carried out several analyses. A response rate of 66.1%, using Dillman survey methodology, is excellent. (See Appendix, page 9.)
- Manuscript forthcoming in *Medical Care* (44(6), 2006): The Influence of Patient Race and Social Vulnerability on Urologist Treatment Recommendations in Localized Prostate Carcinoma. (See Appendix, page 16.)
- Manuscript forthcoming in *British Journal of Urology*: Self-reported radical prostatectomy volume among U.S. urologists. (See Appendix, page 22.)

- Analysis of urologist treatment recommendations for an elderly patient with moderate grade, localized prostate cancer – assessing the independent and joint effects of patient preferences for cure and treatment side effects. Manuscript under preparation. (See Appendix, page 39.)
- Analysis of urologist perceptions of radical prostatectomy outcomes. Manuscript under preparation. (See Appendix, page 41.)
- Over the performance period for this DOD career development award, PI has published two additional manuscripts in the journal *Cancer* having to do with factors that influence patient decision-making in the setting of localized prostate carcinoma. (see Appendix, page 55 and 62.)

Reportable Outcomes

- Race interacts with social vulnerability to influence urologist recommendations for RP. Because PCa tends to be more lethal in blacks, urologists may view such patients as good candidates for RP. However, black race may amplify perceptions of social vulnerability, heightening urologists' concerns about poor surgical outcomes and follow-up. These findings affirm the importance of modeling interactions between race/ethnicity and other social variables in health disparities research. (See Appendix, page 16.)
- Among urologists who performed RP (89.1% of the sample), 37.3% performed ≤ 10 RPs/year, 46.9% performed 11-30 RPs/year, and 15.8% performed >30 RPs/year. Academic and urologic oncology fellowship-trained urologists were, respectively, 41% and 27% more likely than private-practice and non-fellowship-trained urologists to perform a high volume of procedures. Of all RPs performed yearly in the U.S., only an estimated 46.1% are performed by high volume urologists. A significant proportion of urologists report an RP volume that may be associated with higher rates of cardiac, respiratory, vascular, wound-healing, and genitourinary complications. (See Appendix, page 22.)
- A majority of urologists claim that RP has lower long-term rates of impotence and incontinence than is supported by evidence derived from larger community/multi-institutional series that use patient-reported measures. A majority claim that their own rates of urinary and sexual side effects are lower than what is supported by the evidence.. Forty percent of all urologists, and 55% of high-volume urologists, believe that rates of cure are better with RP than XRT, but the existing evidence does not support this. A sizable proportion (20%) of urologists believe incontinence outcomes are better w/ RP than ECBR — in fact, ECBR has significantly better incontinence outcomes. A significant proportion of urologists manifest unsupported optimism about RP side effects in general, about their *own* side effect outcomes, and about the side effects and potential for cure of RP in relation to XRT. We found many of these patterns to be more pronounced among urologists who perform greater numbers of RP's. (See Appendix, page 41.)
- In a vignette portraying a hypothetical, generally health 77 year-old patient with moderate risk (Gleason 3+3), localized prostate carcinoma, urologist recommendations for aggressive therapy were influenced to a similar degree by patient concerns about side effects and desire for cure. A high proportion of urologists recommend aggressive therapy despite the absence of a clear-cut

survival benefit and even though the likelihood of treatment side effects is large. (See Appendix, page 39.)

Conclusions

The PI has been very successful in carrying out the work described in the original grant proposal. Publications in first-rate journals have resulted and additional manuscripts are in preparation. The PI is now formulating an independent investigator research proposal to continue work related to treatment decision-making in localized prostate carcinoma, with an emphasis on reducing treatment and outcome disparities among African American men.

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APPENDIX

Sample survey

Medical Care manuscript

British Journal of Urology manuscript

Urologist treatment recommendations for elderly patient

Urologist perceptions of radical prostatectomy side effects

Cancer manuscript (1)

Cancer manuscript (2)

Appendix: Sample survey

University of Colorado Health Sciences Center

Localized Prostate Cancer Research Group

SURVEY

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Thomas D. Denberg, MD, PhD, Department of Medicine, University of Colorado
Fernando J. Kim, MD, Chair of Urology, Denver Health Medical Center, University of Colorado

SECTION 1:

Vignette 1: Please consider the following information and then offer a treatment recommendation:

Patient: 77 year-old white male

Social: Married, retired furniture salesman, lives close to a major medical center, no transportation barriers.

Insurance: Medicare

Diagnosis: Localized (organ-confined) prostate cancer (TRUS=DRE;
No nodule)

Gleason grade: 3+3

Biopsy: 2 out of 12 cores on the left each had 10% tumor

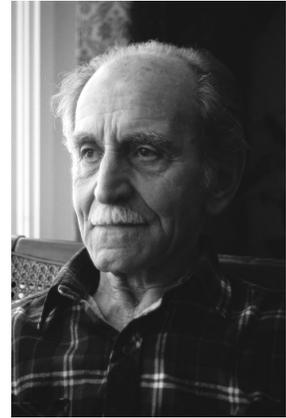
PSA: 5.4 (obtained by primary care provider)

CT scan: No evidence of regional lymph node involvement

Bone scan: Negative

Prostate size: 30 grams

Family history of prostate cancer: None



AUA symptom score: 7 (i.e. mild urinary symptoms)

Sexual function: Normal erections satisfactory for intercourse

Comorbidities: Gout, on allopurinol and a daily aspirin. Otherwise healthy and active.

Patient concerns: Patient understands the potential side effects of all treatment alternatives.

He says, “cure is not as important as enjoying life – everyone has to die sometime.”

He also says, “I would not be greatly bothered by urinary leakage and could wear pads if I had to. As far as sex is concerned, my wife and I enjoy it but could easily adjust to living without it.”

He is anxious to know your treatment advice and is willing to carry through with anything you recommend.

Given the following four options only, please indicate which one you are *more likely* to recommend (**mark only one answer**):

___ Radical prostatectomy with optional nerve sparing

___ A form of radiation: ___brachytherapy OR ___external beam

___ Observation (or “watchful waiting”)

___ Cryotherapy

In the year 2005, would you refer this patient to a medical oncologist to discuss or assist with treatment?

___ Almost certainly ___ Probably ___ Doubtful ___ Definitely not

Vignette 2: Please consider the following information and then offer a treatment recommendation:

Patient: 70 year-old African American male.

Social: Married, retired electrical engineer, lives close to a major medical center, wife is very concerned.

Insurance: Medicare

Diagnosis: Localized (organ-confined) prostate cancer (TRUS=DRE;
No nodule)

Gleason grade: 3+3

Biopsy: 2 out of 12 cores on the left each had 10% tumor

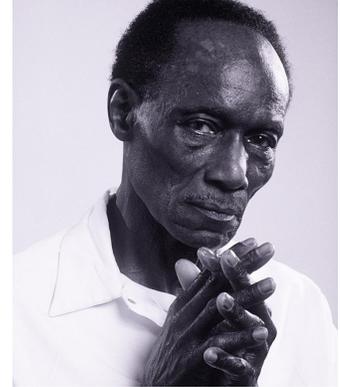
PSA: 3.2 (was 4.8 two years ago, by primary care provider)

CT scan: No evidence of regional lymph node involvement

Bone scan: Negative

Prostate size: 35 grams

Family history of prostate cancer: None



AUA symptom score: 6 (i.e. mild urinary symptoms)

Sexual function: Normal erections satisfactory for intercourse

Comorbidities: Essential hypertension on an ACE-inhibitor. Otherwise healthy and active.

Patient concerns: Patient understands the potential side effects of all treatment alternatives.

He says he wants a chance at cure more than anything but very much wants to avoid treatment that interferes with his sexual function.

He is anxious to know your treatment advice and is willing to carry through with anything you recommend.

Given the following four options only, please indicate which one you are *most likely* to recommend (**mark only one answer**):

___ Radical prostatectomy with optional nerve sparing

___ A form of radiation: ___brachytherapy OR ___external beam

___ Observation (“watchful waiting”)

___ Cryotherapy

If given the opportunity, would you recommend a form of hormonal therapy instead of, or as an adjunct to, your choice, above?

___ Hormonal therapy alone (i.e. instead of above choice)

___ Hormonal therapy as an adjunct to above choice

___ No hormonal therapy

Vignette 3: Please consider the following information and then offer a treatment recommendation:

Patient: 66 year-old white male

Social: Married real-estate agent, lives close to a major medical center, no transportation barriers.

Insurance: Medicare

Diagnosis: Localized (organ-confined) prostate cancer (TRUS=DRE;
No nodule)

Gleason grade: 3+3

Biopsy: 2 out of 12 cores on the left each had 10% tumor

PSA: 5.7 (obtained by primary care provider)

CT scan: No evidence of regional lymph node involvement

Bone scan: Negative

Prostate size: 45 grams

Family history of prostate cancer: None



AUA symptom score: 12 (i.e. moderate urinary symptoms)

Sexual function: Normal erections satisfactory for intercourse

Comorbidities: Takes a daily aspirin, a statin, and a multivitamin. Had a “small” myocardial infarction five years ago with a single stent of his right coronary artery. He has excellent exercise tolerance and no cardiac symptoms. He walks about one mile a day.

Patient concerns: This patient understands the potential side effects of all treatment alternatives.

He says, “My urinary leakage is not a big problem – if I had to, I could wear pads.”

He also says, “my wife and I enjoy occasional sex, but we could easily adjust to living without it.”

He is anxious to know your treatment advice and is willing to carry through with anything you recommend.

Given the following four options only, please indicate which one you are *most likely* to recommend (**mark only one answer**):

- Radical prostatectomy with optional nerve sparing
- A form of radiation: brachytherapy OR external beam
- Observation (“watchful waiting”)
- Cryotherapy

If given the opportunity, would you recommend a form of hormonal therapy instead of, or as an adjuvant/neoadjuvant to, your choice, above?

- a. No hormonal therapy
- b. Hormonal therapy alone (i.e. instead of above choice)
- c. Hormonal therapy as an adjunct to above choice

If (b) or (c) checked, above, please indicate preferred therapy (check more than one for combination therapy):

- orchiectomy
- LHRH analog (e.g. leuprolide, goserelin)
- anti-androgen (e.g. bicalutamide, flutamide)

SECTION 2:

Please circle your answers to the following questions:

1. For Gleason grade 8-10 localized prostate cancers, rates of cure are

- higher with prostatectomy than radiation (external beam or seeds)**
- roughly the same with prostatectomy and radiation (external beam or seeds)**
- higher with radiation (external beam or seeds) than with prostatectomy**

2. With nerve-sparing prostatectomy, national rates of *any* form of long-term incontinence are:

<25% **26-50%** **51-75** **>75%**

3. Different urologists treat different patient populations. Compared with the national average, your *own* surgical rate of long-term incontinence associated with nerve-sparing prostatectomy is:

lower **about the same** **higher**

4. With nerve-sparing prostatectomy and early oral phosphodiesterase-5 enzyme inhibitor treatment (e.g. Viagra), average national rates of long-term impotence (inability to sustain an erection for intercourse) are:

<25% **26-50%** **51-75** **>75%**

5. Different urologists treat different patient populations. Compared with the national average, your *own* surgical rate of long-term impotence associated with nerve-sparing prostatectomy is:

lower **about the same** **higher**

6. In general, external conformal beam radiation has better long-term urinary incontinence outcomes than prostatectomy:

True **False**

7. In general, external conformal beam radiation has better long-term sexual function outcomes than prostatectomy:

True **False**

8. In your practice, all else being equal, married men with localized prostate cancer are more likely than unmarried men to have prostatectomy as opposed to a form of radiation

True **False**

9. There is an ongoing adjuvant trial for high risk prostate cancer for patients following radical prostatectomy (SWOG 9921). All receive 2 years of hormone therapy and 50% receive 6 cycles of chemotherapy.

* Are you aware of this trial? yes_____ no_____

* Would you be willing to enroll qualifying patients (5 - very likely; 1 - unlikely): 5 4 3 2 1

* Would decreasing reimbursement for GnRH analogs have any effect on your willingness to collaborate with medical oncologists in order to enter patients into this trial?

No effect_____ Some effect_____ Large effect_____

SECTION 3: Please provide the following information about yourself and your clinical practice:

1. Your age: _____

2. Your race/ethnicity: **White, non-Latino / African American / Latino / Asian or Pacific Islander / Other**

3. How many years have you been practicing urology? _____

4. Did you complete a fellowship in urologic oncology?

Yes

No

5. In your clinical practice, the percentage of white, non-Latino patients is:

<10%

10-30%

31-60%

>60%

6. In your clinical practice, the percentage of African American patients is:

<10%

10-30%

31-60%

>60%

7. In your clinical practice, the percentage of Latino patients is:

<10%

10-30%

31-60%

>60%

8. Please circle the average number of *prostatectomies* that you perform per year:

None

1-10

11-30

>30

9. Please circle the average number of *brachytherapy procedures* that you perform/assist per year:

None

1-10

11-30

>30

10. What percentage of the time do you refer your localized prostate cancer patients to a radiation oncologist for discussion of radiation as possible primary therapy?

<10%

10-25%

26-50%

51-75%

>75%

11. What percentage of the time do you refer your *high risk* localized prostate cancer patients to a medical oncologist for a second opinion and possible adjuvant therapy?

<10%

10-25%

26-50%

51-75%

>75%

12. Which best describes your clinical practice:

Academic

Private-practice

13. What is the bed size of the largest hospital in which you usually practice:

<100

101-300

>300

Thank you for your participation!
Please feel free to provide any comments in the space below

The Influence of Patient Race and Social Vulnerability on Urologist Treatment Recommendations in Localized Prostate Carcinoma

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Background: In localized prostate carcinoma (PCa), many studies have found that black subjects receive radical prostatectomy (RP) less often than white subjects. Such disparities involve barriers to health care, comorbid illnesses, tumor characteristics, and patient preferences. It is unclear whether differences in urologist treatment recommendations also might play a role.

Methods: Using a randomized, 2 × 2 factorial design, we presented 2000 urologists with a clinical vignette and asked them to recommend treatment of a healthy 70-year-old patient with low-risk, clinically localized PCa. Options included either RP, external beam radiotherapy, brachytherapy, cryotherapy, observation, or hormonal therapy. There were 2 variables within 4 otherwise-identical versions of the vignette: 1) patient race (black vs. white) and 2) social vulnerability (middle-income and married vs. low-income and widowed). We used multivariable logistic regression to model the effects of patient race, social vulnerability, and their interaction on recommendations for RP versus radiotherapy.

Results: The response rate was 66.1% (n = 1313). Race and social vulnerability interacted (P = 0.05) such that the highly vulnerable black patient received an RP recommendation 14.4% less often than his less vulnerable counterpart; the difference between the 2 white patients was 4.2%.

Discussion: Race interacts with social vulnerability to influence urologist recommendations for RP. Because PCa tends to be more lethal in blacks, urologists may view such patients as good candidates for RP. However, black race may amplify perceptions of social vulnerability, heightening urologists' concerns about poor surgical outcomes and follow-up. These findings affirm the importance of modeling interactions between race/ethnicity and other social variables in health disparities research.

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Key Words: health disparities, localized prostate carcinoma, treatment, social support, socioeconomic status

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Racial and ethnic disparities in cancer treatment have been widely documented.¹ For localized prostate carcinoma, numerous studies during the past decade have reported that black patients receive radical prostatectomy significantly less often than white patients.^{2–13} Several studies also have found that black patients receive less curative therapy overall (prostatectomy or radiation).^{3,4,11,13–15} Differences in treatment are likely to involve structural barriers to health care, comorbid illnesses and tumor characteristics, and patient treatment preferences.¹⁶ Differences in physician treatment recommendations also may be implicated, but this is poorly understood. Because physicians do not generally furnish researchers with information about treatment recommendations for actual patients, we surveyed a national sample of urologists to evaluate how a patient's race and other social characteristics as represented in a clinical vignette would influence their recommendations for radical prostatectomy and aggressive therapy in general.

Methods

We selected physicians who listed their specialty as Urology from the American Medical Association (AMA) Master List of Physicians, excluding trainees, pediatric urologists, and urologists uninvolved in patient care. We further limited our sampling to urologists who were linked by unique identifiers to the National Drug Council (NDC) database as prescribers of hormonal therapies (the All Antineo Antimetabolites therapeutic class) to identify urologists directly involved in the treatment of prostate carcinoma. Out of a total of 6,104 urologists who met these criteria, we selected a random sample of 2000 to receive a mailed survey.

Following Dillman survey methodology,¹⁷ and modeled on a previous survey by Fowler et al,¹⁸ we mailed each urologist a pretested survey, \$10 cash incentive, and postage-paid return envelope. Nonrespondents received reminder letters and up to 2 additional mailings of the survey. We

explained that the purpose of the confidential survey was to better understand national patterns of care for early-stage prostate cancer. We did not mention our interest in assessing the potential influence of patient race on treatment recommendations. If urologists indicated they were retired, we removed them from the denominator. If a noncompleted survey was returned as undeliverable, we substituted randomly another urologist who practiced in the same town or city.

The survey collected information about urologist demographic and clinical practice characteristics, including age, gender, years in practice, type of practice (academic vs. private), fellowship training in urologic oncology, annual procedure volume for radical prostatectomy and brachytherapy, and black and Latino composition of patients seen in practice. The size of the metropolitan area of each urological practice was derived from cross-referencing each urologist zip code to its U.S. Census Core-Based Statistical Area. The survey included a clinical vignette that asked urologists to make a treatment recommendation for a 70-year-old, generally healthy and active patient who had moderate-grade, low-risk (Gleason 3+3, PSA 3.2), clinically localized prostate carcinoma. The vignette specified that the patient's erectile function was satisfactory for intercourse, his urinary symptoms were mild (AUA symptom score of 6), and he had Medicare coverage and lived close to a major medical center. The patient was interested primarily in cure but, to the extent possible, he also wanted to avoid treatment that would interfere with his sexual function. We asked urologists to recommend a single form of treatment that could include radical prostatectomy, external beam radiotherapy, brachytherapy, cryotherapy, or observation ("watchful waiting"). Hormonal therapy could be selected in addition to, or instead of, these other options.

Using a 2 × 2 factorial design, we produced 4 versions of the vignette. The patient's medical characteristics, insurance status, geographic proximity to treatment, and preferences for cure and side effects were identical in each, but 2 elements varied dichotomously: 1) the patient's race (black vs. white, incorporating an appropriate photograph) and 2) his level of social vulnerability. Social vulnerability influences susceptibilities, responses, and outcomes of illness, and is influenced by traits such as age, physical and mental disability, family structure, social networks, income and material resources, and housing.¹⁹⁻²¹ The patient in the vignette was either "widowed, unemployed, and living in low-income housing" (high vulnerability) or else he was "a retired electrical engineer with a very concerned wife" (low vulnerability). At random, each urologist received one version of the vignette.

We used multivariable logistic regression to model the effects of patient race, social vulnerability, and the interaction between these 2 variables on recommendations for: 1) radical prostatectomy versus radiotherapy (external beam or brachytherapy), and 2) aggressive therapy (radical prostatectomy, radiotherapy, or cryotherapy) versus watchful waiting. We displayed our results in terms of bivariate associations between patient race, social vulnerability, and race-social vulnerability interactions, on the one hand, and urologist treatment recommendations, on the other. We also computed relative risks and risk differences between each of the 2

possible main effects (race and social vulnerability) and for both races stratified by social vulnerability. All statistical analyses were conducted by use of SAS (SAS Institute, Inc., Cary, NC). This study was approved by the Colorado Multiple Institutional Review Board (COMIRB).

Results

The response rate was 66.1% (n = 1313), excluding 15 urologists who returned a postcard indicating they were retired. There were no differences between respondents and nonrespondents in terms of all measures available for both groups, including age, gender, metropolitan size of practice location, region of the country, or number of prescriptions generated quarterly for hormonal therapy. Table 1 summarizes the demographic and clinical practice characteristics of the respondents. The sample was overwhelmingly white (83.3%), male (97.9%), and had been in practice for an average of 19.5 years. Approximately 7% had completed a fellowship in urologic oncology, and 93% were in private practice. Majorities practiced in a metropolitan area with a population of at least 50,000 and had fewer than 10% black or Latino patients in their practices. The distribution of Table 1 variables and response rates were similar for recipients of each version of the vignette.

For all vignette versions combined, 6.4% of urologists recommended watchful waiting and 93.5% recommended some form of aggressive therapy: radical prostatectomy (29.3%), radiotherapy (62.3%), or cryotherapy (1.8%). Of those recommending radiotherapy, and without difference based on vignette version, brachytherapy was the overwhelming choice (85.1%). Adjunctive hormonal therapy was recommended by 11.9% of urologists.

Table 2 summarizes the impact of race and socioeconomic vulnerability on urologist treatment recommendations. Social vulnerability influenced recommendations for radical prostatectomy over radiotherapy such that the less-vulnerable black and white patients combined received a radical prostatectomy recommendation 9.3% more often than their highly vulnerable counterparts ($P = 0.0005$). There also was a race-social vulnerability interaction ($P = 0.05$). The less-vulnerable black patient received a radical prostatectomy recommendation 14.4% more often than the highly vulnerable black patient, whereas the difference was 4.2% for the 2 white patients.

Social vulnerability also had a significant, albeit small, overall effect on recommendations for watchful waiting ($P = 0.004$, Table 3). The highly vulnerable black and white patients combined received a watchful waiting recommendation 4.2% more often than their less vulnerable counterparts. The highly vulnerable white patient received a watchful waiting recommendation 6.9% more often than the less vulnerable white patient while the difference was 1.3% between the 2 black patients. There was, however, no significant race-social vulnerability interaction in this model.

Discussion

In a clinical vignette, we found that a patient's social vulnerability strongly influenced urologists' treatment recommendations for localized prostate carcinoma. The more vul-

TABLE 1. Sociodemographic and Clinical Practice Characteristics of Survey Respondents

Category	Percent
Respondents	1313 (66.1%)
Male	97.9
Mean age, yr (SD)	52.8 (10.3)
Mean yrs in practice (SD)	19.5 (10.2)
Race/ethnicity	
White	83.3
Black	2.0
Latino	2.1
Asian/Pacific Islander	10.5
Other	2.1
Completed fellowship	7.2
Type of practice	
Academic	7.0
Private	93.0
Average prostatectomies/year	
None	10.9
1–10	33.2
11–30	41.7
>30	14.1
Average brachytherapies/year	
None	32.0
1–10	25.9
11–30	31.9
>30	9.0
Size of metropolitan area (CBSA)	
<10,000	1.7
10,000 to 49,999	10.3
50,000 to 2.5 million	57.8
≥2.5 million	30.3
Hospital bed size of primary practice	
<100 beds	7.8
101–300 beds	64.7
>300	27.5
Race of patient population	
<10% Black	52.4
10–30% Black	36.6
>30% Black	11.0
Ethnicity of patient population	
<10% Latino	71.9
10–30% Latino	22.7
>30% Latino	5.4

CBSA indicates core-based statistical area.

nerable patients experienced lower rates of recommendation for aggressive therapy as well as radical prostatectomy, specifically. Race also interacted with social vulnerability to influence the selection of radical prostatectomy for black patients, specifically. These results offer further evidence that interactions between race and other social variables, often overlooked in health disparities research, may be important across a large number of health conditions.^{22–25}

This is the first study to describe, using methodology that minimizes the influence of unmeasured confounders,

how urologist treatment recommendations for prostate cancer are influenced by a patient's race and socioeconomic circumstances. To the extent that a hypothetical scenario illuminates clinical decision-making in the real world, this study is noteworthy because it elucidates the influence of these variables individually and in combination. The results also show that nonclinical factors, such as social vulnerability, exert a strong influence on physician recommendations. This is important because physician recommendation is often the principal determinant of treatment that patients receive.²⁶

In the vignette, a highly vulnerable black patient received the lowest overall rate of recommendation for radical prostatectomy whereas his less socially vulnerable counterpart received the highest. The difference, quite large, was 14.4% and compares with a 4.2% difference between the 2 white patients whose degree of social vulnerability was described in identical terms. Because prostate cancer has higher rates of biochemical recurrence²⁷ and tends to be more lethal in black than white subjects,⁴ urologists may feel that married, middle-class black patients with moderate-grade, low-PSA tumors are good candidates for prostatectomy, which urologists regard as the most definitive option for cure.¹⁸ In comparison, urologists may reason that socioeconomically disadvantaged patients are less appropriate for surgery. Such patients might be more likely to experience postoperative complications and require longer hospital stays. Analgesia, diet, fluid intake, bowel habits, physical activity, and Foley catheter hygiene require careful attention in the postoperative period. Patients who are less educated and socially isolated may have significant difficulties with these details. Second, socially vulnerable patients may have poorer adherence to follow-up, including regular PSA surveillance. Ultimately, urologists may assume that patients who are socially disadvantaged *and* black are especially susceptible to poor outcomes and follow-up. In other words, black race may amplify their perceptions of social vulnerability and its adverse consequences. It is unclear whether such perceptions would be shaped by reality-based probabilities, or whether they would instead reflect implicit biases or stereotypes,²⁸ but both possibilities have some merit.²⁹

A previous study in cardiovascular disease found that patients' socioeconomic status strongly influenced physician perceptions of patient intelligence and likelihood of having social supports and adhering to medical advice.²⁹ Another study found that physicians perceive socioeconomically disadvantaged patients as having higher rates of medical non-adherence, adversely influencing their referrals for kidney transplantation.³⁰ In prostate cancer, if urologists assume that patients will do poorly with, or are unlikely to accept prostatectomy if offered, they may not mention it or may downplay its suitability in comparison with other options.

Study Limitations

We did not study the actual relationship between social vulnerability and receipt of medical care. In addition, we were unable to assess how individual urologists interpreted the vignettes. Instead, our goal was to evaluate whether the presentation of a small number of variables implicated in the

TABLE 2. Urologist Treatment Recommendations: RP Versus XRT (n = 1205)

Patient Variables	RP % (n)	XRT % (n)	Risk Difference* (%)	Relative Risk [†]	P [‡]
Black	31.6 (194)	68.4 (419)	0.0	1.00	0.74
White	31.6 (187)	68.4 (405)	(-0.1 to 0.1)	(0.85-1.18)	
High vulnerability	26.8 (155)	73.2 (424)	9.3	0.74	0.0005
Low vulnerability	36.1 (226)	63.9 (400)	(4.1-14.5)	(0.63-0.88)	
Black, high vulnerability	23.9 (68)	76.1 (216)	14.4	0.63	0.05
Black, low vulnerability	38.3 (126)	61.7 (203)	(7.1-21.6)	(0.49-0.80)	
White, high vulnerability	29.5 (87)	70.5 (208)	4.2	0.88	
White, low vulnerability	33.7 (100)	66.3 (197)	(-3.3 to 11.7)	(0.69-1.11)	

*Risk difference: second minus first group receiving a recommendation for RP vs. XRT.

[†]Relative risk: first versus second group receiving a recommendation for RP vs. XRT.

[‡]Wald χ^2 level of significance based on full logistic regression model of patient race, social vulnerability, and race; social vulnerability based on interaction on radical prostatectomy versus radiotherapy.

RP indicates radical prostatectomy; XRT, radiotherapy (brachytherapy or external beam).

TABLE 3. Urologist Treatment Recommendations: Aggressive vs. WW* (n = 1313)

Patient Variables	Aggressive % (n)	WW % (n)	Risk Difference [†] (%)	Relative Risk [‡]	P [§]
Black	94.5 (623)	5.5 (36)	-1.9	1.02	0.41
White	92.7 (606)	7.3 (48)	(-4.5 to 0.1)	(1.00-1.05)	
High vulnerability	91.5 (590)	8.5 (55)	4.2	0.96	0.004
Low vulnerability	95.7 (639)	4.3 (29)	(1.5-6.8)	(0.93-0.98)	
Black, high vulnerability	93.8 (289)	6.2 (19)	1.3	0.99	0.10
Black, low vulnerability	95.2 (334)	4.8 (17)	(-3.3 to 11.7)	(0.95-1.02)	
White, high vulnerability	89.3 (301)	10.7 (36)	6.9	0.93	
White, low vulnerability	96.2 (305)	3.8 (12)	(3.0-10.8)	(0.89-0.97)	

*Aggressive therapy indicates radical prostatectomy, radiotherapy, or cryotherapy.

[†]Risk difference: second minus first group receiving a recommendation for curative therapy vs. WW.

[‡]Relative risk: first versus second group receiving a recommendation for curative therapy vs. WW.

[§]Wald χ^2 level of significance based on full logistic regression model of patient race, social vulnerability, and race. Social vulnerability interaction based on on curative therapy versus watchful waiting.

WW indicates watchful waiting.

broader concept of social vulnerability¹⁹⁻²¹ influenced treatment recommendation patterns among a nationally-representative sample of urologists. We recognize that our results may not be generalizable to actual patients. In addition, they would not be applicable to many patients whose clinical characteristics differ from those in the vignette. For example, if the patient we presented had been much younger or had had higher risk disease, this would likely have attenuated the differences we found in rates of recommendation for prostatectomy. It is possible that physical features of the photographed models (eg, facial expression, hairstyle, hand gestures), rather than skin color alone, influenced urologists' recommendations.³¹ Even if this were the case, however, it is nonetheless important that a patient's superficial characteristics would have had such an effect. There was also some potential for nonresponse bias. Finally, our results only indirectly support the idea that clinicians view black patients as more socially vulnerable than white patients. Despite these limitations, we believe the vignette offers a compelling illustration of how the race/ethnicity of patients might influence physician perceptions of social vulnerability to affect treatment recommendations. These, in turn, could help to explain overall differences in treatment actually received. Our findings are bolstered by a balanced, randomized design, a large,

nationally-representative sample of urologists who treat prostate carcinoma, and by the ability to study the effects of patient race and social vulnerability in the absence of common, unmeasured confounders.

Conclusion

Our results reaffirm the importance in health disparities research of modeling interactions between race/ethnicity and multiple variables that reflect diverse aspects of a patient's socioeconomic circumstances.

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AUTHOR QUERIES

AUTHOR PLEASE ANSWER ALL QUERIES

AQ1---What do bold values indicate in Tables 2 and 3? Significant difference?

SELF-REPORTED RADICAL PROSTATECTOMY VOLUME AMONG U.S. UROLOGISTS

July 26, 2006

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Abstract

BACKGROUND: Prior studies have demonstrated that individual surgeon volume for radical retropubic prostatectomy (RP) is associated with clinical outcomes. We evaluated the variability of RP volume among U.S. urologists and the physician characteristics that predict RP volume.

METHODS: In a nation-wide, representative survey of 2,000 urologists who treat prostate carcinoma we asked respondents to indicate a numerical range of RPs they perform each year (none, 1-10, 11-30, and >30, which we defined as “high volume”). We then identified provider and practice characteristics associated with performing a high volume of procedures. Supplementing survey results with other national data, we estimated the proportion of all RPs in the U.S. performed by high-volume urologists.

RESULTS: The survey response rate was 66.1% (n=1,313) without differences between respondents and non-respondents in terms of measured demographic variables. Among urologists who performed RP (89.1% of the sample), 37.3% performed ≤ 10 RPs/year, 46.9% performed 11-30 RPs/year, and 15.8% performed >30 RPs/year. Academic and urologic oncology fellowship-trained urologists were, respectively, 41% and 27% more likely than private-practice and non-fellowship-trained urologists to perform a high volume of procedures. Of all RPs performed yearly in the U.S., only an estimated 46.1% are performed by high volume urologists.

DISCUSSION: A significant proportion of urologists report an RP volume that may be associated with higher rates of cardiac, respiratory, vascular, wound-healing, and genitourinary complications. Further study is needed to characterize the possible relationships between RP volume and tumor recurrence, survival, and long-term erectile dysfunction and incontinence.

INTRODUCTION

Better surgical outcomes have been linked to greater surgeon and hospital volume for many procedures, including radical retropubic prostatectomy (RP).¹⁻⁸ Surgeons who perform greater numbers of RPs have been found to have, on average, lower rates of cardiopulmonary, vascular, wound-healing, and urinary complications^{5,8} and, possibly, fewer positive surgical margins.³ However, no minimal volume thresholds have been rigorously established for any RP outcomes. Little is known about the variability in RP volume among U.S. urologists, and about urologist characteristics that predict RP volume. We carried out a nation-wide representative survey of urologists who treat prostate carcinoma in order to identify provider and practice characteristics associated with high self-reported RP volume. Supplementing survey results with other national data, we also estimated the proportion of all RPs in the U.S. performed by urologists who reported high RP volumes

METHODS

We selected physicians who listed their specialty as Urology from the American Medical Association (AMA) Master List of Physicians, excluding trainees, pediatric urologists, and urologists uninvolved in patient care. We further limited our sampling to urologists who were linked by unique identifiers to the National Drug Council (NDC) database as prescribers of hormonal therapies in order to identify urologists directly involved in the treatment of prostate carcinoma. Out of 6,104 urologists who met these criteria, we selected a random sample of 2,000 to receive a mailed survey. The survey was administered between February and May, 2005 and was approved by the Colorado Multiple Institutional Review Board (COMIRB).

Following Dillman survey methodology,⁹ we mailed each urologist a pre-tested survey, \$10 cash incentive, and postage-paid return envelope. Non-respondents received reminder letters and up to two additional mailings of the survey. We explained that the purpose of the confidential survey was to better understand national patterns of care for early-stage prostate cancer. If urologists indicated they were retired, we removed them from the denominator. If a non-completed survey was returned as undeliverable, we substituted randomly another urologist who practiced in the same town or city.

The survey collected information about urologist demographic and clinical practice characteristics. The size of the metropolitan area of each urological practice was derived from cross-referencing each urologist zip code to its U.S. Census Core Based Statistical Area (CBSA). We also asked urologists to specify their yearly RP and brachytherapy volume. To ensure that results were statistically sound and clinically meaningful, and because providers are more likely to recall a range rather than an exact number of procedures, we assessed provider volume as a categorical, rather than continuous, variable. Response categories, based on a range of values gleaned from prior studies of RP volume^{5 8} and identical to those used by Nuttall *et al.*,¹⁰ included none, 1-10, 11-30, and >30 RPs/year.

We defined >30 RPs/year as high volume. By necessity, this was subjective because no minimal RP thresholds have been properly established. Nonetheless, at least 31 RPs/year falls between a cut-off of 16 associated with better outcomes as specified by Begg, *et al.*,⁸ and 40 RPs/year specified by Hu, *et al.*⁵ We determined significant associations ($p < 0.05$ using chi-square test for categorical variables) between individual urologist characteristics and three categories of RP volume for urologists who performed RP. We employed multivariable stepwise logistic regression to identify significant predictors of performing 1-30 RPs/year versus >30 RPs/year. We determined *a priori* that the independent variables in the logistic model would be those significantly associated with RP volume in bivariate analyses based on a p -value of ≤ 0.25 . Results of the logistic regression model are shown as risk ratios associated with each independent variable adjusted for the others. Risk ratios were computed as corrections of the adjusted odds ratios.¹¹

Using national data and survey results, we estimated the total number and proportion of U.S. urologists whose yearly RP volume was >30/year. First, using weighted frequencies of ICD-9-CM procedure code 60.5 (radical retropubic prostatectomy) in the National Hospital Discharge Survey dataset,¹² the total number of RPs performed in the U.S. in 2004 was 54,711 RPs. (While SEER can also be used to determine procedure rates, these data were unavailable for 2004.) We then estimated the number of urologists who perform RP as the proportion who performed RP in our nationally-representative survey multiplied by the total number of U.S. urologists who treat prostate carcinoma identified through the comprehensive AMA physician file. We determined the upper and lower bounds for the number of RPs performed by high volume urologists as follows. For the upper bound, we assumed that urologists in the lower volume categories performed the minimum number of procedures possible. Thus, we subtracted from the total number of year 2004 RPs the sum of: (1) the proportion of urologists who perform 1-10 RPs/year multiplied by the total number of urologists who perform RP multiplied by 1 RP/year and (2) the proportion of urologists who perform 11-30 RPs/year multiplied by the total number of urologists who perform RP multiplied by 11 RPs/year. We used an analogous approach to determine the lower bound by assuming that urologists in the >30 RP/year

category performed the minimum possible number of procedures, calculated as the proportion of urologists in this category multiplied by the total number of urologists who perform RP multiplied by 31 RPs/year. The mean of the upper and lower bounds served as our point estimate for the total number of RPs performed by high volume urologists, then used to calculate the overall proportion of all RPs performed by urologists in this group. As a sensitivity analysis, we recalculated the upper and lower bounds by varying the number of urologists who perform RP by ± 500 and by varying the proportion who perform more and less than 30 RPs by $\pm 5\%$. All statistical analyses were conducted by use of SAS (SAS Institute, Inc., Cary, NC).

RESULTS

The response rate was 66.1% (n=1,313), excluding 15 urologists who returned a postcard indicating they were retired. There were no differences between respondents and non-respondents in terms of age, gender, metropolitan size of practice location, region of the country, or number of prescriptions generated quarterly for hormonal therapy. The proportion of respondents who performed at least one RP per year was 89.1% (n=1,170).

Table 1 summarizes the demographic and clinical practice characteristics of these respondents. The sample was overwhelmingly white, male, and had been in practice for an average of 25.1 years. Fewer than 10% were in academic settings or had completed a urologic oncology fellowship. A substantial majority practiced in metropolitan areas with a population of $\geq 50,000$ people. Of respondents, 37.3% performed ≤ 10 RPs per year (i.e. less than an average of one per month), 84.2% performed ≤ 30 per year (i.e. less than 2.5 per month) and 15.8% performed >30 per year.

Table 2 shows significant predictors of RP volume. Urologists who worked in academic settings, were fellowship-trained in urologic oncology, practiced in hospitals with >300 beds and in metropolitan areas with $\geq 50,000$ residents, or were earlier in their careers were determined to perform significantly more RPs than their counterparts who worked in private practice, were not fellowship trained in urologic oncology, practiced in smaller hospitals and metropolitan areas, or were later in their careers. Table 3 displays the adjusted relative risks of performing >30 RPs/year versus fewer than this amount. Academic and urologic oncology fellowship-trained urologists were, respectively, 41% and 27% more likely than private-practice and non-fellowship-trained urologists to perform >30 RPs per year.

Finally, an estimated $46.1\% \pm 12.5\%$ of all RPs in the U.S. are performed by urologists whose volume is >30 RPs per year. The results of a sensitivity analysis (Figure 1) evidence little variation in these results on the basis of varying by ± 500 the number of urologists and by $\pm 5\%$ the proportion of urologists in each volume category.

DISCUSSION

Among urologists who perform RP, 37.3% reported performing ≤ 10 per year, while 84.2% reported performing ≤ 30 per year. Based on these and other national data, we estimated that fewer than half (46.1%) of all RPs in the U.S. are performed by high-volume urologists (i.e. those whose volume is >30 RPs/year). Academic practice and urologic oncology fellowship training were the most important predictors of performing >30 RPs/year.

These findings are important because RP is a technically complex operation in which lower hospital and surgeon volumes have each been associated with a variety of adverse outcomes, and because a significant proportion of U.S. urologists have RP volumes that fall within a “lower” range based on prior studies. For example, a recent study that adjusted for both clustering and case mix found that rates of cardiovascular, pulmonary, wound-healing, and urinary complications were significantly higher among urologists who performed <16 RPs per year.⁸ Another study incorporating case-mix adjustment found that urologists who performed <40 RPs/year in a Medicare population had significantly higher rates of cardiac, respiratory, vascular, wound-healing, and genitourinary complications than those who performed ≥ 40 RPs/year.⁵ Of note, if the authors of this second study had estimated total urologist RP volumes based on the assumption that 42% of all RPs are performed on patients ≥ 65 ,¹³ then their cutoff would be closer to 95 RPs per year, a volume that applied to only 7.8% of urologists in their study.

Although a strong volume-outcome relationship has been shown for perioperative complications, the relationship between surgeon volume and other important outcomes of RP has been less thoroughly assessed. Mortality rates are higher among patients of low-volume surgeons for a variety of complex surgical procedures, regardless of the volume of the hospitals in which they practice.² RP, however, is generally a low-mortality procedure without an evident relationship between surgeon volume and mortality.⁶ Meanwhile, although a case-mix adjusted study of 44 university-based urologists found that lower RP volume was associated with a higher rate of positive surgical margins,³ no

well-designed, population-based studies have evaluated the impact of surgical volume on recurrence or duration of survival. Similarly, little is known about long-term erectile dysfunction and incontinence outcomes. These last two are of particular concern to patients because they are very common and can have profound effects on quality of life.¹⁴ These outcomes could, at least in part, be associated with volume since nerve-sparing RP is a particularly complicated procedure that is highly sensitive to surgical technique which, in turn, is likely to be influenced by surgeon experience.¹⁵

Some caveats are in order. First, minimal volume thresholds (MVT's) have not been established for any RP outcomes. In prior RP volume studies, it is unclear how volume categories were derived or whether they were defined before or after analysis of data. Not establishing cutoff points ahead of time increases the chance of demonstrating a volume-outcome relationship that in reality does not exist.⁷ While a recent survey of 212 urologists in the United Kingdom revealed that 43% would set a minimal volume threshold at ≥ 10 cases/year for RP, this cutoff was entirely subjective and most likely influenced by the number of procedures that these urologists actually perform.¹⁰

While a volume threshold *may* be necessary for ensuring favorable RP outcomes, it is unclear whether total experience or yearly volume would be more important. In either case, volume alone is unlikely to be sufficient to determine outcomes. At least two studies have demonstrated that outcomes of RP vary significantly and are sensitive to small differences in performance even among high volume providers.^{1,3}

This study had several limitations. Most importantly, although our results were consistent with 1998 survey data in which urologists performed a mean of 18 RPs/year,¹⁶ RP volume in both cases was self-reported and therefore subject to bias. Urologists, however, are much more likely to *overestimate* rather than underestimate their RP volume. There is a widespread perception both among professionals and the public that volume is a surrogate for procedural skill and high-quality outcomes. Just as physicians commonly overestimate their level of adherence to clinical practice guidelines,¹⁷ urologists may be subject to a social desirability bias when reporting their yearly number of procedures. Stronger evidence in favor of overestimating RP volume comes from the

most detailed, objective description of RP volume, published by Begg *et al*,⁸ in which the estimated proportion of urologists who performed fewer than 10 RPs/year was actually more than twice what we found in our survey. Also, despite the absence of significant differences between respondents and non-respondents in measured variables, response bias was possible. For example, urologists who perform small numbers of RPs may have been less likely than others to respond to the survey. Ultimately, however, any overestimation or skewing towards greater RP volume in our study would only strengthen a potential concern that a large proportion of urologists perform an insufficient number of procedures to minimize perioperative complications.

For assessing surgeon volume, Medicare claims are often used. However, while this approach is useful for assessing relationships between provider volume and outcomes, aggregating patient claims to the provider level does not yield a nationally-representative picture of variation in procedure volume among individual surgeons. In addition, CMS data do not include men under 65 years and provider identifiers are absent in more than 10% of cases.^{18 19} While our volume categories were based on prior work, it would have been desirable to include a category reflecting >100 RPs/year since this is a threshold considered by many top surgeons to be a minimum standard for assuring the best results.²⁰ Finally, individual procedure volume varies by year and we did not assess cumulative experience, which may be a more important predictor of outcomes than yearly volume. Nonetheless, the ability to maintain surgical skill over time, even among very experienced surgeons, is likely to depend on performing a minimum number of procedures annually. We believe, therefore, that a one-year snapshot of self-reported volume is meaningful.

Despite limitations, this work does have significant strengths. The survey represents the largest and most recent nationally representative assessment of U.S. urologists. Unlike prior studies, it collected detailed information about the characteristics of individual urologists and related these to measures of RP volume. Finally, a response rate of 66.1% is excellent.

CONCLUSION

A large minority of urologists (37.3%) report performing ten or fewer RPs/year, while a majority (84.2%) report fewer than 30 RPs/year. In addition, more than half of all RPs in the U.S. are performed by urologists whose volume is <30 RPs/year. Although these results are based on self-report, they raise concerns that a large number of surgeons may be performing insufficient procedures to reduce adverse outcomes associated with RP. Our findings should stimulate further study based on more objective measures of volume. For example, in an effort to achieve the best possible outcomes, are minimal cumulative and yearly numbers of RPs required to attain and maintain technical proficiency, does fellowship training in urologic oncology hold advantages over residency training in high volume centers, and should RP be regionalized through surgical centers of excellence? Especially important are studies that explore the relationship between RP volume, on the one hand, and survival and long-term incontinence and erectile dysfunction, on the other. Because only observational studies are feasible, these should assess RP volume through medical record review or claims analyses and should link these with patient-reported quality of life outcomes.

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Table 1: Sociodemographic and clinical practice characteristics of survey respondents who perform radical prostatectomy (n=1,170)

<u>Category</u>	<u>Percent</u>	<u>Category</u>	<u>Percent</u>
Male	98.0	Average brachytherapies / yr	
		None	29.7
Mean age, yr (s.d.)	51.5 (10.0)	1-10	26.9
		11-30	33.7
Mean yrs in practice (s.d.)	25.1 (10.5)	>30	9.3
Race/ethnicity		Size of metropolitan area (CBSA)	
Caucasian	81.9	<50,000	11.4
African-American	1.8	50,000 to 2.5 million	58.2
Latino	2.0	≥2.5 million	30.4
Asian/ Pacific Islander	9.9		
Other/ Unknown	4.3	Hospital bed size of primary practice	
		<100 beds	7.4
Type of Practice		101-300 beds	65.3
Academic	7.0	>300	27.3
Private	93.0	Race of Patient Population	
Urologic oncology fellowship	7.3	<10% African-American	52.6
		10-30% African-American	36.5
		>30% African-American	10.0
Average RP's / yr		Ethnicity of Patient Population	
1-10	37.3	<10% Latino	71.0
11-30	46.8	10-30% Latino	23.6
>30	15.9	>30% Latino	4.4

Table 2: Bivariate predictors of radical prostatectomy (RP) volume

Variable	Volume (RP's/year) <i>n</i> =1,170			<i>p</i> *
	1-10	11-30	>30	
Practice type				
Private	38.7	47.4	13.8	
Academic	13.7	39.7	46.6	<0.0001
Urologic oncology fellowship				
No	38.2	47.7	14.1	
Yes	26.0	32.5	41.6	<0.0001
Hospital bed size				
<300	41.0	45.8	13.3	
≥300	27.3	48.8	23.9	<0.0001
Years in practice				
0-9	35.1	49.2	15.7	
10-19	29.3	50.9	19.8	
20-29	40.4	43.1	16.6	
≥30	48.9	41.8	9.3	<0.0001
Metropolitan area size				
<50,000 residents	41.7	50.0	8.3	
≥50,000 residents	36.7	46.2	17.2	0.045

* Chi-square test for categorical variables.

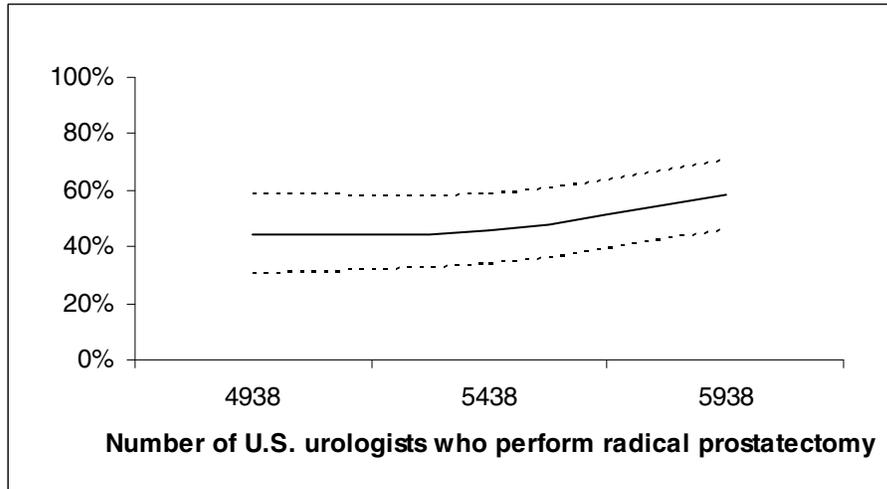
Table 3: Summary of logistic regression predicting > 30 RP's*/year among urologists who perform RP

Variable/Model	Overall RR (CI)
Total <i>n</i>	1,170
Academic vs. Private practice	1.41(1.18-1.80)*
Fellowship vs. No Fellowship	1.27(1.10-1.58)*
Years in practice	
0-9 (REF)	
10-19	1.09(1.01-1.14)*
20-29	1.04(0.96-1.10)
≥30	0.97(0.88-1.03)

Variables displayed are those that retained significance in stepwise logistic regression; original predictor variables included practice type, fellowship training in urologic oncology, years in practice, hospital bed size, metropolitan population > 50,000.

* RP = radical prostatectomy.

Figure 1: Percentage of all RPs performed by urologists whose radical prostatectomy volume is >30/year*



* The solid line represents the point estimate for the proportion of all RP's performed in 2004 by high volume urologists (i.e. >30 RPs/year); the dashed lines represent the upper and lower bounds as determined by the extreme values obtained in a sensitivity analysis (see Methods section).

1. How does patient preference for cure and treatment side effects influence urologist recommendations for watchful waiting versus aggressive therapy in an elderly patient (age 77) with moderate grade (Gleason 3+3) localized prostate carcinoma?

2.

Key:

Version 1 - SE-/Cure+

Version 2 - SE+/Cure+

Version 3 - SE-/Cure-

Version 4 - SE+/Cure-

Cure - : "Cure is not as important as enjoying life – everyone has to die sometime."

Cure + : "Cure is the most important thing – I want to see my five-year-old grandson graduate from high school."

SE - : "I would not be greatly bothered by urinary leakage and could wear pads if I had to. As far as sex is concerned, my wife and enjoy it but could easily adjust to living without it."

SE + : "I would be greatly bothered by urinary leakage of any sort. As far as sex is concerned, my wife and I continue to enjoy it and I do not want any impairment in my erectile function."

Tx	1 SE-/Cure+	2 SE+/Cure+	3 SE-/Cure-	4 SE+/Cure-	Total
WW	42 15.56	98 32.03	108 38.43	209 65.52	457 38.86
RP/XRT	228 84.44	110 67.97	173 61.57	208 34.48	719 61.14
Total	270 100.00	306 100.00	281 100.00	319 100.00	1176 100.00

Pearson chi2(3) = 163.1634 Pr = 0.000

Logit: predict WW using SE and Cure and SW*Cure

Tx (WW)	Odds Ratio	Std. Err.	z	P> z	[95% Conf. Interval]
SE+ (v SE-)	3.043519	.5175342	6.545	0.000	2.180889 4.247352
Cure - (v Cure+)	4.032653	.6854012	8.204	0.000	2.890136 5.626826
SE*Cure	.8403735	.2256876	-0.648	0.517	.4964515 1.422551

Interpretation:

1. Minimal patient concern about side effects seems to have a similar influence on urologist treatment recommendation for RP/XRT as patient desire for "cure"; together, the two are additive.
2. High proportion of urologist treatment recommendation for RP/XRT when patient desires cure (>68%) seems to overemphasize the actual benefit of "cure." In an elderly patient, there is little survival benefit of aggressive therapy but a high likelihood of side effects.
3. Urologists should be more cautious about making treatment recommendations for RP/XRT on the basis of elderly patient preference for "cure." Recognize that it is difficult to avoid action orientation ("do something"), especially when patient seems to imply this desire through use of the word "cure."

SECTION 1:

Vignette 1: Please consider the following information and then offer a treatment recommendation:

Patient: 77 year-old white male

Social: Married, retired furniture salesman, lives close to a major medical center, no transportation barriers.

Insurance: Medicare

Diagnosis: Localized (organ-confined) prostate cancer (TRUS=DRE)

Gleason grade: 3+3

Biopsy: 2 out of 12 cores on the left each had 10% tumor

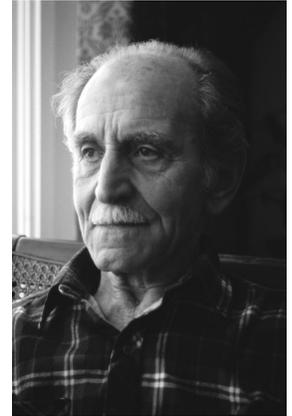
PSA: 5.4 (obtained by primary care provider)

CT scan: No evidence of regional lymph node involvement

Bone scan: Negative

Prostate size: 30 grams

Family history of prostate cancer: None



AUA symptom score: 7 (i.e. mild urinary symptoms)

Sexual function: Normal erections satisfactory for intercourse

Comorbidities: Gout, on allopurinol and a daily aspirin. Otherwise healthy and active.

Patient concerns: Patient understands the potential side effects of all treatment alternatives.

He says, “cure is not as important as enjoying life – everyone has to die sometime.”

He also says, “I would not be greatly bothered by urinary leakage and could wear pads if I had to. As far as sex is concerned, my wife and I enjoy it but could easily adjust to living without it.”

He is anxious to know your treatment advice and is willing to carry through with anything you recommend.

Given the following four options only, please indicate which one you are *more likely* to recommend (**mark only one answer**):

___ Radical prostatectomy with optional nerve sparing

___ A form of radiation: ___brachytherapy OR ___external beam

___ Observation (or “watchful waiting”)

___ Cryotherapy

TITLE: Side effects of radical prostatectomy: Urologist perceptions in a nationally-representative survey

Goals:

- (1) Characterize urologist beliefs about RP side effects in order to gain insight into how they might represent the procedure to patients.
- (2) Identify predictors of these beliefs based on urologist sociodemographic and clinical practice characteristics.
- (3) Compare urologist beliefs to published outcome data, including 2-year (conservative) and 5-year PCOS data and data from other studies.

Note that PCOS provides the most comprehensive, longitudinal, patient-reported perspective of outcomes of care received in community practice. Other, relatively recent studies have also employed larger sample sizes and patient-reported measures.

These more recent outcome studies are different from earlier ones. Earlier outcome data, especially Johns Hopkins data from Walsh, may be misleading because outcomes were generally assessed and interpreted by surgeons rather than patients, sample sizes were relatively small, patients were highly selected, community practices were under-represented, and assessment criteria were limited. Single center reports, especially from earlier series,¹⁻³ for example, quote impotence rates of 28-37%, markedly less than what has been reported in more recent, community-based or multi-institutional series and after the advent of medications such as sildenafil.

Problems with PCOS, especially at 5 years, include selection bias from loss to follow-up. There is also potential recall bias related to pre-treatment symptoms (although a sub-study has shown that recall is fairly accurate). Finally, PCOS was unable to determine the surgical volume or expertise of individual urologists. In reporting outcomes from the published literature, we will refer to a variety of studies but will give precedence to PCOS because it is the highest quality outcome study to date. We will include 2 year PCOS data for more conservative estimates of outcomes because non-responders at 2 years were considered to have good outcomes.

We assess urologist beliefs in three areas using seven survey items.

A. "National" RP impotence and incontinence rates.

1. With nerve-sparing prostatectomy, national rates of *any* form of long-term incontinence are...
 2. With nerve-sparing prostatectomy and oral phosphodiesterase-5 enzyme inhibitor treatment (e.g. Viagra), average national rates of long-term impotence (inability to sustain an erection for intercourse) are...
- $\leq 25\%$ 26-50% 51-74% $\geq 75\%$

B. Urologist's own perceived impotence and incontinence rates relative to a perceived "national" average.

3. Different urologists treat different patient populations. Compared with the national average, your *own* surgical rate of long-term incontinence associated with nerve-sparing prostatectomy is...
 4. Compared with the national average, your *own* surgical rate of long-term impotence associated with nerve-sparing prostatectomy is...
- lower about the same higher

C. Comparisons between RP and ECR in terms of cure, impotence, and incontinence outcomes.

5. For Gleason grade 8-10 localized prostate cancers, rates of cure are higher / the same / lower with prostatectomy compared with radiation (external beam or seeds)
 6. In general, prostatectomy has equal or better long-term urinary incontinence outcomes than external conformal beam radiation...
 7. In general, prostatectomy has equal or better long term impotence outcomes than external conformal beam radiation...
- true false

These domains are relevant because most urologists assign the greatest importance to addressing patient questions about major treatment morbidity and cure rates.⁴

Potential predictors of beliefs:

- a. # prostatectomies/year (surgical volume)
- b. completion of urologic oncology fellowship
- c. academic vs. private practice
- d. years practicing urology
- e. population of town/city in which practice is located
- f. urologist-affiliated hospital bed size
- g. >40% black/Latino patients in practice

Rationale for including:

a-d: surgical volume, clinical training, clinical setting, and years in practice influence beliefs about RP and about one's own skills.

e-f: population of town/city and hospital bed size are proxies for frequency of contact with other urologists and multidisciplinary specialists in PCa.

g: significant black/Latino patient population could influence urologist beliefs about impotence outcomes, in particular, because of cultural factors and preferences in these patient groups

These predictors were assessed in bivariate analyses and then multivariate logistic regression. All logistic regressions were run with variables that were significant in the bivariate analyses at $p=0.25$ or less, then backward stepwise regression was done.

Methods:

Physicians who listed their specialty as urology were selected from the American Medical Association Masterfile. Because not all urologists treat prostate cancer, we limited our sampling to urologists who were also listed in the National Drug Council (NDC) database as prescribers of hormonal therapies (the All Antineoplastic Antimetabolites therapeutic class). Based on AMA data fields, we also excluded trainees, pediatric urologists, and urologists not involved in patient care. A total of 6,104 urologists met the above criteria. Of these, a random sample of 2,000 urologists was selected to receive a mailed survey. These criteria were designed to produce a nationally representative sample of urologists directly involved in the treatment of prostate carcinoma.

An initial letter was mailed specifying that the survey would arrive in approximately one week. A week later, urologists received the survey, an explanatory letter, a \$10 incentive, and a postage-paid return envelope. A reminder letter was sent a week later. Urologists who failed to return the survey after a month received another copy of the survey with a reminder letter. Non-respondents at two months received by overnight post a third and final copy of the survey. Urologists were asked to indicate on a postage-paid return postcard whether they were retired or did not wish to participate in the study. In the former case, they were removed from the denominator; in the latter case, no further mailings were sent. In the event that a non-completed survey was returned by the post office with a bad address and a correct address could not be determined, the urologist was replaced by another urologist who practiced in the same town or city.

The survey collected information about sociodemographic and clinical practice characteristics of the responding urologist. In seven items, it also asked urologists to specify beliefs about potency and continence outcomes associated with radical prostatectomy and in relation to radiotherapy.

Table 1

Respondents	1,306 (out of 1,985 non-retired)
Response rate	65.8%
Male %	97.9
Mean age, yr (SD)	51.9 (10.3)
Mean yrs in practice (SD)	19.5 (10.2)
Race/ethnicity %	
Caucasian	83.3
African-American	1.9
Latino	2.1
Asian/ Pacific Islander	10.5
Other	2.1
Completed fellowship %	7.1
Type of Practice (%)	
Academic	7.0
Private	93.0
Average number prostatectomies % year	
None	10.9
1-10	33.1
11-30	41.8
>30	14.2
Average number brachytherapies % year	
None	32.1
1-10	26.4
11-30	32.3
>30	9.1
Hospital bed size of practice (%)	
<100 beds	7.8
101-300 beds	64.9
>300	27.2
City size of practice %	
1-9,999	10.6
10,000-99,999	53.4
100,000-499,999	23.2
500,000-999,999	4.6
>1,000,000	8.1
Race of Patient Population %	
<10% African-American	52.3
10-30% African-American	36.6
31-60% African-American	9.9
>60% African-American	1.2
Race of Patient Population %	
<10% Latino	72.1
10-30% Latino	22.7
31-60% Latino	4.3
>60% Latino	0.0

NO DIFFERENCES between respondents (n=1306) and non-respondents (n=679) in terms of all tested variables: gender, hormone-rx'ing decile, practice type, population of city of clinical practice, region of country, year of birth, years in practice. Only 20/1,306 respondents were in the lowest quintile of hormone prescribing and also indicated that they perform no prostatectomies or brachytherapies, meaning that 98.5% of the sample was meaningfully involved in the treatment of prostate carcinoma.

1. POPULATION-BASED IMPOTENCE RATES WITH RP

National rates of impotence (inability to sustain erection for intercourse) < 50% with nerve-sparing RP & Viagra:
endorsed by 68% of all urologists; no association w/ volume; no significant predictors in multivariable analysis. (60% of urologists said impotence rates are between 25% and 50%).

best available evidence:

PCOS⁵ (2005): (5 year) impotence = 71%; and of 81% potent at baseline, only 28% are potent 5 years out

PCOS⁶ (2000): (2-year) impotence = 60%; and of 73% potent at baseline, only 19% are potent at 2 years.

Either interpretation (absolute rates of long-term impotence versus impotence related directly to RP) would require a response that national long-term rates of impotence are > 50%. This is important because 46% of men call impotence a moderate to big problem at 5 years⁵ and 42% call it a moderate to big problem at 2 years.⁶

Three large community/multi-institutional outcome series within the last dozen years that used patient-centered measures report impotence rates between 73% and 89%, but there was heterogeneity with regard to when outcomes were assessed, use of erectile aids, and nerve-sparing.⁷⁻⁹

With regard to impotence after bilateral nerve-sparing, specifically, few studies and most – especially earlier series - have significant flaws:

Quinlan¹ (1991): Of 503 men with bilateral nerve-sparing, 24% are impotent (but single center, urologist rather than patient-centered assessment, and did not specify quality of erections – i.e. sufficient for intercourse)

Leandri¹⁰ (1992): Of 106 men with bilateral nerve-sparing, 29% are impotent (same shortcomings as above reference)

Catalona³ (1993): Of 236 men with bilateral nerve-sparing, 37% are impotent (same shortcomings as above)

Geary¹¹ (1995): Of 69 men with bilateral nerve-sparing, 69% are impotent (single center, but quality of erections was defined)

With regard to impotence with bilateral nerve sparing and with sildenafil, specifically, there have been few studies.

PCOS⁵ (2005): Of 192 men with bilateral nerve sparing and sildenafil, 51% are still impotent.

Schover¹² (2002): Of 240 men with bilateral nerve sparing and medical treatment (including but not limited to sildenafil) when needed, impotence was 67% at an average of 4.3 years post-tx.

Zippe¹³ (2000): Of 53 men with bilateral nerve sparing and sildenafil, impotence was only 28%. However, the mean age of these patients was only 61 years, they were from a single center of excellence, and the sample size was small.

Conclusion: On balance, a majority of urologists, the vast majority of whom are community-based, have overly optimistic attitudes about potency outcomes with RP, even with sildenafil. There is no association with surgical volume, academic practice, years in practice, or urologic oncology fellowship. These findings raise concerns that a significant proportion of urologists may not represent to patients an accurate or complete account of the potency outcomes associated with RP.

2. UROLOGIST PERCEIVED IMPOTENCE OUTCOMES IN ABSOLUTE AND RELATIVE TO AVERAGE

One's own rates of long-term impotence in absolute terms and in comparison with national average:

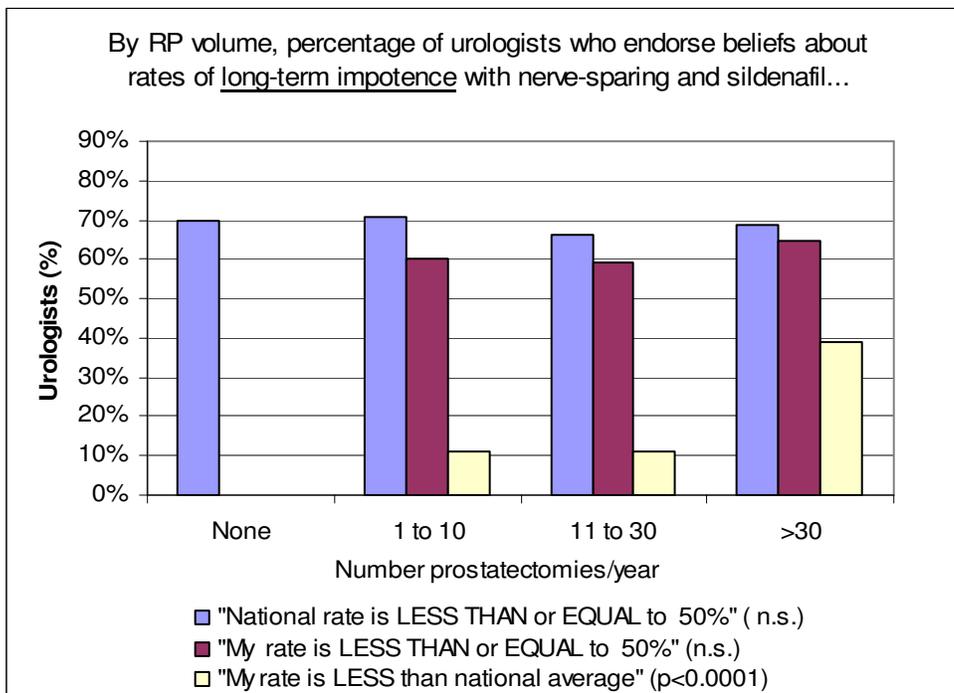
60% of urologists overall, without difference by surgical volume, reported that their own rates of long-term impotence were $\leq 50\%$.

In terms of comparisons with the perceived national average, about 11% of urologists who do < 30 RP's compared with 39% of those who do >30 RP's said that their own rates of impotence were lower. Higher volume surgeons are more likely to believe their outcomes are better than average; the lower volume surgeons are less likely to believe this.

Self-comparison with national average: Impotence outcome	OR (95% CI)
Number of Prostatectomies per year	
11-30 vs. 1-10	1.03 (0.69-1.55)
>30 vs. 1-10	5.25 (3.42-8.06)*

Conclusion: A majority of urologists in all surgical volume categories (60% overall) said their own rates of impotence were less than 50%, which does not correspond with the evidence and suggests that a majority of urologists may dramatically overrate their potency outcomes.

Among lower-volume urologists, only 11% claim their impotency outcomes are better than average compared with 39% of high-volume urologists. This volume – belief relationship is significant. **This particular “Lake-Wobegon” effect is relatively small compared with some of the other items and deserves interpretation/speculation.**



3. POPULATION-BASED INCONTINENCE RATES WITH RP

National rates of any form of long-term incontinence are <25% with nerve-sparing RP:

{Note: no evidence that nerve-sparing improves continence rates.}

endorsed by 70% of all urologists (no association by volume)

important issue: how do respondents interpret “any” long-term incontinence?

(1) “any” was emphasized in the question and was meant to imply any urinary leakage or use of pads. Best available evidence:

PCOS⁵: (5 year) incontinence (i.e. any dribbling) = 65% / (use of pad \geq 1/day) = 26%

PCOS⁶: (2 year) incontinence (i.e. any dribbling) = 49% / (use of pad \geq 1/day) = 22%

Also:

Kao⁹ (1069 pts.), community study: (min. 6 months post-RP) incontinence (i.e. any use of pad/diaper) = 33%

Sebesta¹⁴ (674 pts), community study: (min. 18 months post-RP, all <65 years) incontinence (i.e. any use of pad/diaper) = 32%

Fowler⁸ (739 pts in US sample, all >65), community study: incontinence (i.e. any use of pad/diaper) = 30%

Aristotelis¹⁵ (70 pts, 12 months post-RP), single center, incontinence (i.e. any use of pads) = 33%

Geary¹⁶ (481 pts, min 12 months post-RP), single center, two surgeons, incontinence (i.e. any use of pads) = 20%

But, “any” urinary leakage could have also been interpreted as:

(2) any “significantly bothersome” (to the patient) urinary dribbling

PCOS⁵: (5 year) incontinence (i.e. moderate to big problem) = 13%

PCOS⁶: (2 year) incontinence (i.e. moderate to big problem) = 9%

(3) anything more than occasional leakage (i.e. frequent or no control)

PCOS⁵: (5 year) incontinence (i.e. frequent leakage/no control) = 14%

PCOS⁶: (2 year) incontinence (i.e. frequent leakage/no control) = 9%

Hautmann¹⁷: (1 year) incontinence (i.e. more than occasional leakage) = 20%.

In sum: the response that long-term incontinence is < 25% would be justified only for interpretations (2) and (3). This ambiguity is a potential limitation of the survey item. Nonetheless, quoting rates < 25% might suggest that some urologists favor definitions (2) and (3). If so, this should be made clear to patients.

Initial variables: >60% NHW in practice, numprost, population, bedsize, years_prac, fellowship

	OR (95% CI)
Academic	0.59 (0.37-0.94)*
Number of years practicing urology	
10-19 yrs vs. 0-9 yrs	0.83 (0.59-1.17)
20-29 yrs vs. 0-9 yrs	1.03 (0.73-1.47)
30+ yrs vs. 0-9 yrs	1.63 (1.08-2.45)*

Conclusion: A large majority of urologists believe that rates of “any” urinary incontinence following surgery are <25% -- this response is valid for particular interpretations of “any incontinence” but is off the mark for the intended interpretation. These findings raise concerns that a significant proportion of urologists *may* represent to patients an inaccurate or incomplete account of the incontinence outcomes associated with RP.

Interestingly, there is no association between this belief and surgical volume or urologic oncology fellowship. Academic urologists are less likely to endorse this belief than private-practice urologists. Urologists who have been in practice for more than 30 years are significantly more likely than those in practice < 30 years to endorse this belief.

Interpretation...

4. UROLOGIST PERCEIVED INCONTINENCE OUTCOMES IN ABSOLUTE AND RELATIVE TO AVERAGE

One's own rates of long-term incontinence in absolute terms and in comparison with national average:

67% of all urologists, without relation to surgical volume, reported their own incontinence rates were $\leq 25\%$.

Beliefs that one's own incontinence rate were lower than the perceived national average were endorsed by 56% of all urologists; by 43% of urologists doing 1-10 RP's/year and 81% of urologists doing >30 RP's/year (\pm association w/ volume).

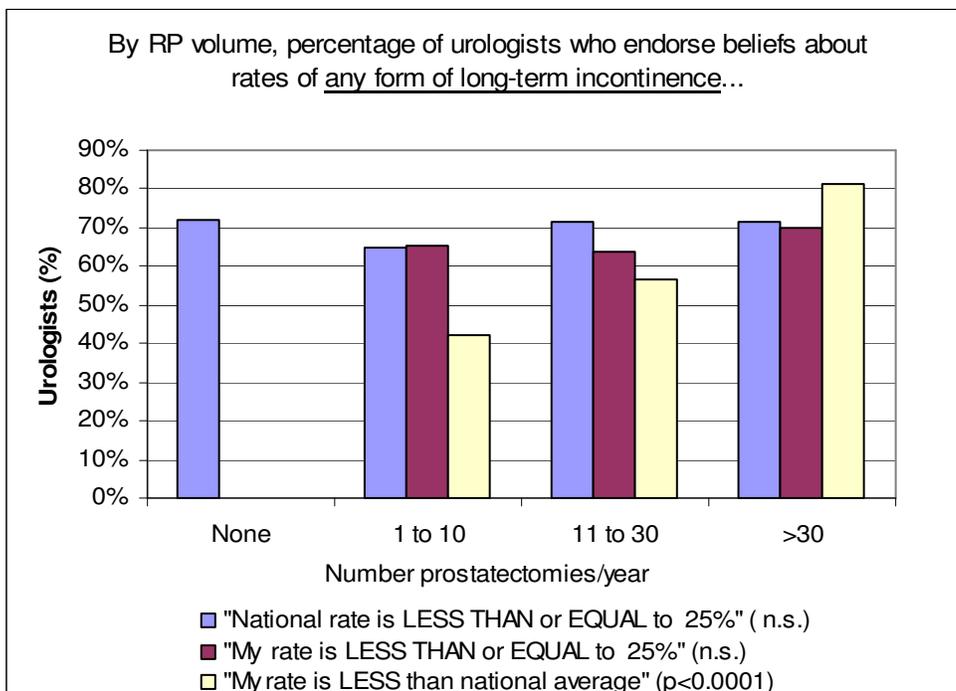
My own Incontinence Rates are Lower than National Average:

Initial variables: numprost, $>60\%$ NHW, region, fellowship

	OR (95% CI)
Number of Prostatectomies per year	
11-30 vs. 1-10	1.85 (1.42-2.42)*
>30 vs. 1-10	6.75 (4.36-10.46)*

Conclusion: A majority of urologists in all surgical volume categories (67% overall) said their own rates of incontinence were less than 25%, which does not correspond with the evidence applicable to interpretation (1) "any leakage or pads" although it is commensurate with interpretations (2) and (3).

Meanwhile, a large minority (43%) of low-volume urologists believe their incontinence outcomes are better than average compared with a large majority (81%) of high-volume urologists. These significant volume-related differences might be accurate if high-volume surgeons are more likely to treat younger patients. This is because potency and continence outcomes are superior in younger compared with older patients.¹⁸ While there is evidence from a large national cohort study that high-volume hospitals attract younger patients, this relationship is not confirmed for high-volume surgeons.¹⁹ The tendency for higher-volume surgeons to believe their continence and potency outcomes are better than average might be reasonable based on enhanced surgical skill and a vast literature related to other kinds of surgical volume-outcomes. Unfortunately, in relation to RP, specifically, there have been very few studies on this topic and none have shown that potency and continence outcomes are related to surgical volume. A very large RP volume-outcome study²⁰ found that major post-op and late urinary complications (e.g. strictures, fistulas, bladder neck obstructions) were both inversely related to surgeon and hospital procedure volume. This study did not demonstrate, however, that continence outcomes were better. Two separate studies^{21 22} also failed to detect relationships between surgeon volume, on the one hand, and sexual function and incontinence, on the other. The lower impotence and incontinence rates quoted from series derived from single centers of excellence seem to provide the best support for superior outcomes in these settings; however, no direct comparisons between institutions of varying surgical volume, employing identical definitions of outcomes and research methodologies, have demonstrated this relationship. Thus, beliefs among higher-volume surgeons about their ability to achieve superior (relative to their peers) outcomes is expected and may even be true but this has not, thus far, been demonstrated.



5. RP VS. ECBR IN TERMS OF CURE

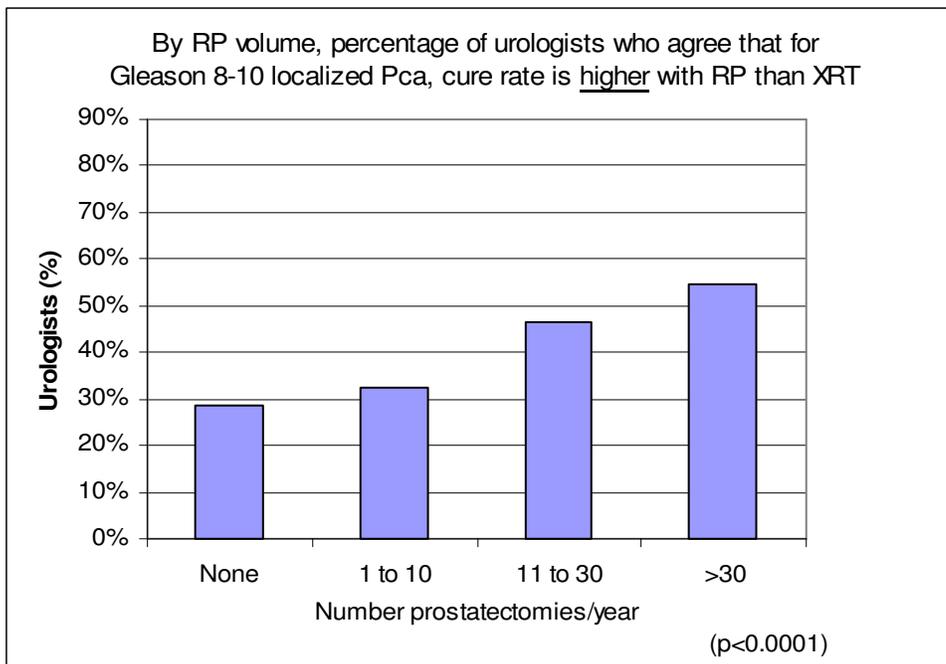
Cure rate higher with RP than XRT:

endorsed by 40% overall and by 55% of urologists doing >30 RP's/year (+ association w/ volume) best evidence, including PCOS, indicates that long-term survival is very similar between RP and XRT.^{23 24}

Initial variables: numprost, academic, region, fellowship

	OR (95% CI)
Number of Prostatectomies per year	
1-10 vs. None	1.19 (0.78-1.82)
11-30 vs. None	2.16 (1.44-3.26)*
>30 vs. None	3.03 (1.88-4.88)*

Conclusion: Cure is the most important outcome for most patients. A large minority (40%) of urologists endorse the idea that RP is better than XRT for cure, and a majority (55%) of urologists who perform greater than 30 RP's/year make this claim. The claim is not supported by the evidence.



6. RP VS. ECBR IN TERMS OF IMPOTENCE

RP has equal or better long-term impotence outcomes than ECBR:

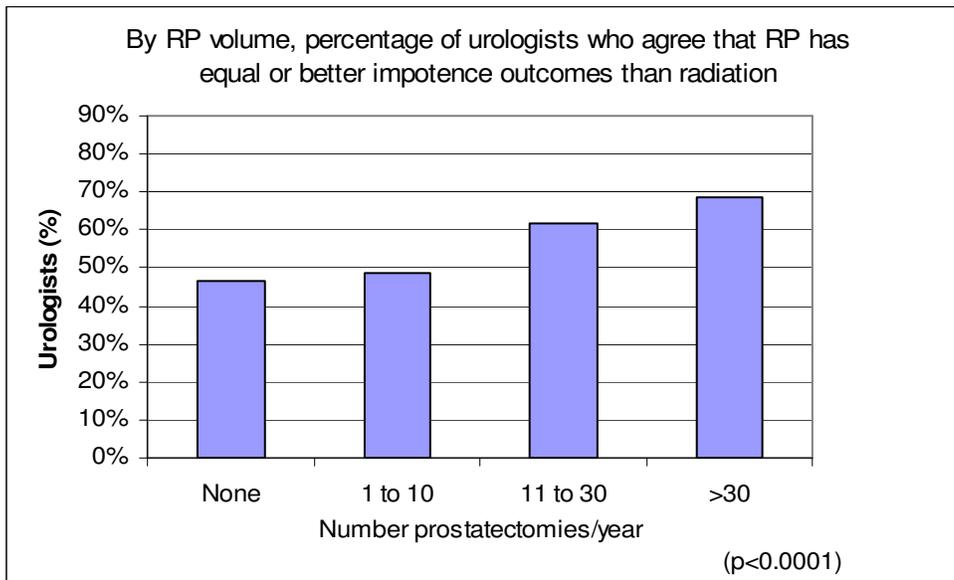
endorsed by 57% of urologists overall; by 48% of urologists doing <30 and 68% of urologists doing >30 RP's/year (+ association w/ volume)

*in fact, best available evidence indicates that long-term impotence outcomes are very similar or slightly higher with ECBR.²³⁻²⁵ Potosky (2004) 5-year PCOS data show impotence (no erection for intercourse, as in our survey item) worse for RP than ECBR (79.3% vs. 63.5%). **Note – need to reconcile/explain why RP impotence in this 5yr PCOS report are higher than in the Penson report.***

Initial variables: numprost, >60% NHW, academic, population, bedsize, years_prac, fellowship

	OR (95% CI)
Number of Prostatectomies per year	
1-10 vs. None	0.97 (0.65-1.45)
11-30 vs. None	1.59 (1.05-2.33)*
>30 vs. None	1.96 (1.22-3.23)*
Academic	1.72 (1.04-2.86)*
Number of years practicing urology	
10-19 yrs vs. 0-9 yrs	0.79 (0.56-1.11)
20-29 yrs vs. 0-9 yrs	0.64 (0.46-0.89)*
30+ yrs vs. 0-9 yrs	0.64 (0.44-0.93)*

Conclusion: Greater procedure volume, academic practice, and fewer years practicing urology were associated with more frequently favorable comparisons between RP and ECBR in terms of potency outcomes. **Interpretation...**



7. RP VS. ECBR IN TERMS OF INCONTINENCE

RP has equal or better long-term incontinence outcomes than ECBR:

endorsed by 20% overall (1 in 5 urologists); no association w/ surgical volume.

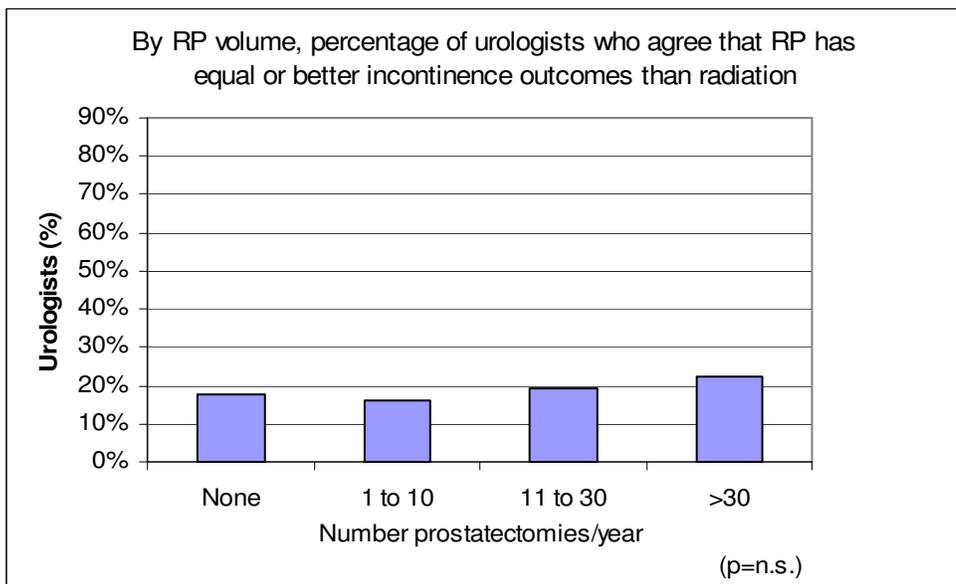
best available evidence indicates that incontinence outcomes tend to be much better on average w/ ECBR

PCOS²³: 5-year any pad = 29% (RP) vs. 4% (ECBR); and for other interpretations of incontinence, OR is 4.4 (2.2-8.6) for RP vs ECBR – “greater than occasional leakage”, and OR is 6.5 (2.7-15.6) “bothered by dripping/leaking urine”. Thus for any of the most conceivable interpretations of incontinence, ECBR clearly has better outcomes.

Initial variables: numprost, >60% NHW, academic, region

	OR (95% CI)
Number of Prostatectomies per year	
1-10 vs. None	0.88 (0.53-1.45)
11-30 vs. None	1.09 (0.67-1.75)
>30 vs. None	1.35 (0.77-2.33)

Conclusion: 20% of urologists believe incontinence outcomes are better w/ RP than ECBR —this may be a “problem” -- 20% is a sizable proportion and the differences in incontinence outcomes between RP and ECBR are quite large.



OVERALL CONCLUSIONS:

- A majority of urologists claim that RP has lower long-term rates of impotence and incontinence than is supported by evidence derived from larger community/multi-institutional series that use patient-reported measures. Caveat about interpretation of “any” incontinence.
- A majority of urologists, most of whom are in community practices and perform fewer than 2.5 RP’s/month, with over 40% of these performing fewer than 1/month, claim that their own rates of urinary and sexual side effects are lower than what is supported by the evidence. Caveat about interpretation of “any” incontinence.
- A sizable minority (39%) of high-volume urologists rate their potency outcomes better than what they perceive to be national averages – this claim may be reasonable but there is, thus far, no published evidence that clearly supports it.
- A large minority (44%) of low-volume urologists and a large majority (81%) of high-volume urologists rate their continence outcomes better than what they perceive to be a national average. Again, this Lake Wobegon effect is not (yet) supported by evidence.
- Cure is typically the most important outcome for patients. 40% of all urologists, and 55% of high-volume urologists, believe that rates of cure are better with RP than XRT, but the existing evidence does not support this.
- High volume urologists were significantly more likely than low volume urologists to compare RP favorably against ECRB in terms of potency outcomes.
- A sizable proportion (20%) of urologists believe incontinence outcomes are better w/ RP than ECRB — in fact, ECRB has significantly better incontinence outcomes.

→ A significant proportion of urologists manifest unsupported optimism about RP side effects in general, about their *own* side effect outcomes, and about the side effects and potential for cure of RP in relation to XRT. We found many of these patterns to be more pronounced among urologists who perform greater numbers of RP’s.

Discuss where academic and years in practice were predictors, and implications... Mention that academic and fellowship not predictors where one might have expected them to be... Lake Wobegon least pronounced in terms of perceptions of one’s own potency outcomes.

Important to clarify key issues:

- Urologists are not dishonest or disingenuous.
- These results should in no way be construed as an argument *against* RP, or *in favor* of a form of radiation. Rather, this is a study that compares urologist beliefs with the most recently published RP-associated outcomes. Knowledge of this evidence is important for patients in terms of decision-making -- they have to weigh treatment alternatives in light of personal preferences and values. It may be helpful for patients to know that a significant proportion of the time their physicians (in this case urologists) might quote side effect risks that are lower than what the evidence demonstrated from community studies with patient-reported measures. Patients should not assume that this will be true of any individual urologist, but these findings do highlight the importance of seeking information from more than one source.
- Urologists are no different than other types of specialists – they value and are biased towards the interventions they, themselves, provide.²⁶ If this survey had been given to radiation oncologists, the results would probably have been similar in terms of XRT.
- An important question is where urologists get their long-term outcome information. I would argue that older data and data from single-center series are a likely source. Because PCOS and other data are new, it is likely that many, if not most, urologists are unfamiliar with it.
- Although there may be controversy about PCOS it is hard to discount the idea that patient-reported outcomes in a comprehensive, longitudinal, community-based sample are more realistic than urologist-reported and -interpreted outcomes from earlier or single-center series.
- In terms of assessing one’s own outcomes, it is unusual for urologists to see a large fraction of their patients five years out from surgery. And, even if urologists do see patients five years out, patients may not be forthcoming about their symptoms. Both of these factors will limit urologists’ ability to accurately gauge their own long-term outcomes.

Three goals: (1) educate urologists about the latest outcome data so that they use it in discussions with patients (or at least tell patients that there is controversy, and then mention ranges of risk that include this data); community urologists, in particular, may have less justification for quoting results from single-center series; (2) reinforce to patients the importance of seeking information from more than one source; (3) carry out more studies of surgical volume relationships to impotence and incontinence outcomes; (4) be clear about definitions of “impotence” and “incontinence” (urinary and sexual function) in discussions with patients; be clear that each of these is a multi-dimensional construct.

Limitations: Although responders and non-responders very similar across all sociodemographic and clinical practice characteristics for which we had data, cannot exclude possibility of response bias, in which responders are more likely than non-responders to report favorable side effect outcomes. Ambiguity in item about incontinence. Does not directly ascertain the ways in which urologists actually present risk information to patients. **Details more...**

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Marriage and Ethnicity Predict Treatment in Localized Prostate Carcinoma

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This study used the linked SEER-Medicare database. The interpretation and reporting of these data are the sole responsibility of the authors.

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BACKGROUND. Primary treatment for early-stage prostate carcinoma includes expectant management or, for curative intent, radical prostatectomy or radiotherapy. Treatment recommendations are generally guided by clinical factors such as Gleason grade, prostate-specific antigen level, comorbid illnesses, and patient age. Sociocultural factors may also have influences on patient and urologist treatment choices.

METHODS. The authors used bivariate and multinomial logistic regression to identify medical and sociodemographic predictors of prostatectomy (compared with radiotherapy) and curative therapy (compared with expectant management) in a cohort of 27,920 non-Latino white, black, and Latino men without comorbidities in the latest linked Surveillance, Epidemiology and End Results–Medicare dataset (years 1995–1999). Predictors included tumor stage, patient age, marital status, race/ethnicity, and socioeconomic status.

RESULTS. Younger age and higher tumor grade were robust predictors of curative treatment compared with expectant management and of prostatectomy compared with radiotherapy. Sociodemographic factors had an additive role in treatment choice. Marriage predicted curative treatment compared with expectant management (adjusted risk ratio [RR] = 1.28 [1.25–1.30]) and prostatectomy compared with radiotherapy (adjusted RR = 1.24 [1.20–1.28]). Although blacks and Latinos were just as likely as whites to receive curative treatment, blacks were significantly less likely, whereas Latinos were more likely, to receive prostatectomy compared with radiotherapy (adjusted RRs = 0.77 [0.72–83]) and 1.24 [1.18–1.30], respectively).

CONCLUSIONS. Marriage was positively associated with curative treatment in general, and with prostatectomy specifically. Blacks received prostatectomy less often than whites, although they did not receive less curative treatment overall. Latinos received prostatectomy more often than whites. Clinicians should recognize the importance of cultural and social forces as well as biomedical factors in decisions regarding the treatment of patients with early-stage prostate carcinoma. *Cancer* 2005;103:1819–25. © 2005 American Cancer Society.

KEYWORDS: prostate carcinoma, localized disease, informed decision-making, treatment patterns, health disparities, marriage.

Prostate carcinoma is the leading cancer affecting men of all races in the U.S., and is the second most common cause of cancer death. After the introduction of the prostate-specific antigen (PSA) test in 1987, widespread screening led to a dramatic increase in the identification of patients with early-stage prostate carcinoma. With this diagnosis, many men face considerable challenges regarding treatment. In part, this is because of a lack of randomized trial evidence clearly favoring a mortality benefit for any of the main curative forms of treatment, including radical prostatectomy, exter-

nal-beam radiotherapy, and brachytherapy. In addition, each of these curative options carries a high risk of late side effects, such as incontinence, impotence, and bowel urgency.¹ Many men have difficulty deciding whether they can accept such risks. These difficulties are most acute among men healthy enough to have choices, whereas older and sicker men are less able to tolerate surgery, and therefore have fewer options. Indeed, because of a lack of clear-cut mortality benefit, there is also controversy regarding the merits of curative therapy versus expectant observation (sometimes known as "watchful waiting"). In summary, for men healthy enough to have treatment choices, the first decision is usually between prostatectomy and a form of radiotherapy. Another crucial choice, especially as men grow older, is between curative treatment and expectant management. In the face of such decisions, social and cultural factors may have an influence over and above purely biomedical considerations.

We hypothesized that sociocultural factors would add to the explanatory power of traditional clinical variables, such as tumor grade, PSA level, comorbid illnesses, and patient age, in predicting treatment choice in nonmetastatic prostate carcinoma. Previous studies²⁻⁶ have identified several such factors, including race/ethnicity, socioeconomic status (SES), and geographic region. Almost all studies have revealed significant regional variations in treatment patterns and substantially lower rates of prostatectomy among blacks compared with whites, possibly due to provider differences, patient preferences, or health care access barriers that constrain treatment choices. In the current study, we assess whether a number of clinical and sociodemographic variables predict treatment choice in a population of Medicare enrollees without documented comorbid illnesses. These healthier men have the greatest number of treatment options because the costs of their care are covered by Medicare. Our analysis employs the latest linked Surveillance, Epidemiology and End Results (SEER) cancer registry and Medicare inpatient records (1995-1999), and we include marital status and Latino ethnicity, variables that have not been assessed consistently in previous studies.

MATERIALS AND METHODS

Data Sources

We tested our hypotheses that particular clinical and sociodemographic characteristics predict receipt of 1) prostatectomy compared with some form of radiotherapy (external beam or brachytherapy) as well as 2) either form of curative therapy (prostatectomy or radiotherapy) compared with expectant management by

using data from the SEER cancer registries that have been linked with Medicare hospital-discharge records. We focused our analyses on a subset of men > 65 who do not have any documented comorbidities and are, therefore, likely to be among the healthiest in the database, with the greatest number of treatment options and opportunities to make treatment decisions that are informed by a consideration of risks and benefits. The SEER-Medicare dataset has been used in several other studies to assess patterns of care for newly diagnosed patients with cancer of several sites, and its strengths and limitations for this purpose were recently reviewed.⁷ Covering approximately 14% of the U.S. population, the SEER registries, sponsored by the National Cancer Institute (NCI), document all incident cases of cancer in 6 urban areas (San Francisco-Oakland, San Jose, Los Angeles county, Seattle, Atlanta, and Detroit) and in 5 states (Connecticut, Hawaii, Iowa, New Mexico, and Utah). In the linked dataset, SEER includes patient age and date of diagnosis; tumor location, grade, stage, and lymph node involvement; therapy received within 4 months of diagnosis; and sociodemographic characteristics including race/ethnicity, marital status, and a variety of census-based SES measures as proxies for individual-level data not collected by SEER.

The Medicare program provides health coverage for 97% of persons \geq 65 and collects claims for all program services. Hospitalization data, included in the Medicare Provider Analysis and Review (MEDPAR) files, contains information on all hospitalizations since 1984, including admission and discharge diagnoses and comorbid conditions.

The SEER and Medicare databases were linked to allow population-based studies of health outcomes. Data for 94% of persons \geq 65 in SEER have been linked successfully to Medicare records. Use of the combined dataset excluded approximately 22% of prostate carcinoma cases in SEER, primarily among men < 65 and those enrolled in Health Maintenance Organizations. The remaining, linked cases, however, allowed for adjustment by comorbid conditions and eliminated the confounding effects of insurance coverage. The research described here was approved by the Colorado multiple institutional review board.

Study Participants

Non-Latino white, black, and Latino men with localized prostate carcinoma were included if there were matching SEER and Medicare records and the diagnosis was not made at autopsy or on a death certificate. We included all cases between the years 1995 and 1999, the most recent data available in SEER-Medicare and not analyzed in previous studies. Subjects were

excluded if, at the time of diagnosis, they had one or more (nonprostate carcinoma) comorbidities or if data pertaining to patient age or tumor stage or grade were unavailable ($n = 25,311$). Based on these criteria, 27,290 patients were included in the current study.

Primary Treatment and Tumor Characteristics

Primary treatment was based on SEER data. In order of priority, primary treatment was defined as prostatectomy if any form of curative-intent prostatectomy was indicated by the site-directed surgery variable (transurethral resection of the prostate [TURP] procedures were excluded), as radiotherapy if indicated by any form of external-beam radiotherapy or brachytherapy, and as watchful waiting if neither of these was obtained. A variable indicating any form of curative treatment was assigned a true value if treatment included either surgery or radiotherapy.

Tumor stage was based on the SEER/American Joint Commission on Cancer extent of disease (EOD; 10 prostate pathology ext 1995+) variable corresponding to localized (T1 or T2) disease. Clinical as opposed to pathologic staging was utilized except that when the former was unavailable and prostatectomy was performed, staging was assumed to be localized because surgery is typically not indicated for clinically advanced disease. For patients who did not receive prostatectomy, staging was based only on biopsy results and radiologic criteria rather than on complete excision. In some cases, this underrepresented the true EOD but did reflect the clinical staging used to determine treatment. Tumor grade was trichotomized as low, moderate, and high (i.e., Grades 1, 2, and 3/4, respectively), corresponding to Gleason scores 2–4, 5–7, and 8–10. PSA scores were not included because these were unavailable in the SEER-Medicare database.

Demographic Characteristics and Coexisting Illnesses

Information on race and age at diagnosis was obtained from the SEER database. The SES of each patient was based on year 2000 census data. Zip code measures were utilized only if census-tract data were unavailable (21% of patients). SES measures included per capita income, percent of residents living below the poverty level (race and age specific), percent of persons ≥ 25 years with less than a high school education (race specific), and percent of persons ≥ 65 years not speaking English well. These variables were necessarily ecologic as opposed to individual-level measures. Because they were all highly correlated, we selected educational level to capture SES. Marital status was based on SEER (dichotomized as married vs. not married/unknown).

Comorbidity scores were derived from MEDPAR records, using the Deyo adaptation⁸ of the Charlson comorbidity index and calculated by means of a SAS macro (SAS Institute Inc., Cary, NC) available on the NCI SEER-Medicare website. All patients with scores > 0 were excluded from further analysis. If a patient received prostatectomy, we included all MEDPAR records through the date of this procedure. Otherwise, we included all MEDPAR records through the first hospitalization occurring within 6 months of the diagnosis. If there were no MEDPAR records before the diagnosis, the comorbidity score was assumed to be zero.

Statistical Analysis

Using bivariate analysis, we examined separately the association between 1) prostatectomy versus a form of radiotherapy, and 2) either form of curative therapy (prostatectomy or radiotherapy) versus expectant management and the following variables: patient age, tumor stage, tumor grade, race/ethnicity, marital status, per capita income, poverty level, educational attainment, and poor use of English. Descriptive analyses and multiple logistic regression models were conducted with SAS software. The outcome variables were dichotomous: 1) prostatectomy versus radiotherapy and 2) curative therapy (prostatectomy or radiotherapy) versus expectant management. We determined a priori that the independent variables in the logistic models would be those significantly associated with initial therapy in the bivariate analyses, using a statistical significance level of 0.05. We also examined statistical interactions of age and grade, race and grade, age and marriage, age and race, age and non-high school education, race and marriage, and race and non-high school education. Results of the logistic regression models are shown as percentages of patients by race/ethnicity receiving the treatment of interest and risk ratios (RRs) associated with each independent variable adjusted for the others. RRs were computed as corrections of the adjusted odds ratios.⁹

RESULTS

The sociodemographic and clinical characteristics of the study cohort (84.4% white, 9.9% black, 5.7% Latino) are shown in Table 1. Differences by race/ethnicity were evident. Blacks were much less likely than whites and Latinos to be married. Compared with whites, blacks and Latinos were increasingly likely to live in low SES areas, as reflected by the percentage of census-tract/zip code inhabitants who had not graduated from high school. Eighty-five percent of Latino men had tumors graded as moderately or poorly differentiated compared with 89% of white

TABLE 1
Sociodemographic and Clinical Characteristics of 27,290 Men with Early-Stage Prostate Carcinoma and No Comorbidities in SEER-Medicare, 1995-1999^a

Cohort	Married	SES			Tumor grade			Treatment		
		High	Mod	Low	Low	Mod	High	RP	XRT	WW
All ages										
All (n = 27,290)	75	48	31	21	11	70	20	37	30	32
White (n = 23,040)	77	55	33	12	11	70	19	38	30	32
Black (n = 2698)	58	13	25	62	8	71	21	30	35	35
Latino (n = 1552)	73	5	9	87	15	65	20	45	21	35
Age < 70 yrs										
All (n = 11,107)	77	47	31	22	9	73	18	61	23	16
White (n = 9011)	80	56	33	11	9	74	17	63	22	15
Black (n = 1375)	59	14	27	58	7	72	21	45	33	22
Latino (n = 721)	75	4	8	88	14	67	19	64	15	20
Age ≥ 70 yrs										
All (n = 16,183)	73	48	31	21	12	67	21	21	35	44
White (n = 14,029)	74	54	33	12	12	67	21	22	36	43
Black (n = 1323)	57	11	23	66	9	69	22	14	37	49
Latino (n = 831)	71	5	9	86	15	63	22	28	26	47

SEER: Surveillance, Epidemiology and End Results program; SES: socioeconomic status; Mod: moderate; RP: radical prostatectomy; XRT: external beam radiotherapy or brachytherapy; WW: conservative management ("watchful waiting").

^a All numbers are rounded percentages. Married refers to percentage of men currently married. SES (socioeconomic status) refers to the percentage of sample residing in census-tract/zip code areas where 0-10%, 11-20%, and ≥ 21% of inhabitants ≥ 25 years have less than a high school education. Grade corresponds to Gleason score (Low/well differentiated = 2-4; Med/moderately differentiated = 5-7; High/poor or undifferentiated = 8-10). Treatment refers to the percentage of men who received as primary treatment (mutually exclusive) radical prostatectomy (RP), any form of external beam radiotherapy or brachytherapy (XRT), or conservative management (WW).

TABLE 2
Receipt of Prostatectomy and Curative Therapy (Prostatectomy or Radiotherapy^a) by Race/Ethnicity and Marital Status

Race/ethnicity	White			Black			Latino		
	Unmarried	Married	P value ^b	Unmarried	Married	P value	Unmarried	Married	P value
Age < 70 n = 11,107									
Prostatectomy	49%	66%	< 0.001	37%	51%	< 0.001	49%	69%	< 0.001
Any curative therapy	76%	87%	< 0.001	74%	80%	0.007	71%	83%	0.008
Age ≥ 70 n = 16,183									
Prostatectomy	13%	24%	< 0.001	11%	16%	0.007	23%	29%	0.09
Any curative therapy	44%	62%	< 0.001	46%	55%	0.005	43%	57%	0.001

^a Radiotherapy refers to any external-beam radiotherapy or brachytherapy.

^b The P value was determined using the chi-square test.

men and 92% of black men. Black men were much less likely than white men to receive prostatectomy (30% vs. 38%), whereas Latino men were much more likely than white men to receive prostatectomy (45% vs. 38%). There was, however, little difference in receipt of either form of curative therapy (compared with expectant management) among whites, blacks, and Latinos (68%, 65%, and 66%, respectively).

Younger men (age < 70) received curative-intent therapy 84% of the time, with prostatectomy predominating for 73% of these men (i.e., 61% of the total). A higher percentage of married men compared with un-

married men received any form of curative therapy (86% vs. 75%) as well as prostatectomy, specifically (65% vs. 47%; data not shown). Blacks were less likely than whites to receive any form of curative therapy (78% vs. 85%) as well as prostatectomy, specifically (45% vs. 63%). whereas, among Latinos, there was greater parity with whites (79% vs. 85% and 64% vs. 63%, respectively). Table 2 depicts higher utilization of curative therapy in general, and of prostatectomy compared with radiotherapy among married men in all three racial/ethnic groups. The effect was most pronounced among younger, married Latinos, who

TABLE 3
Summary of Logistic Regression Predicting Prostatectomy versus Radiotherapy^a

Variable/model	Overall	White	Black	Latino
Total no. of patients	18,444	15,685	1743	1016
No. of patients (%) receiving prostatectomy	10,189 (55%)	8690 (55%)	806 (46%)	693 (68%)
Age (yrs) ≥ 70 vs. < 70	0.50 (0.48–0.52)	0.51 (0.48–0.53)	0.47 (0.40–0.54)	0.63 (0.55–0.72)
Tumor grade				
Moderate vs. low	1.21 (1.14–1.27)	1.18 (1.11–1.25)	1.68 (1.27–2.09)	1.26 (1.08–1.41)
High vs. low	1.29 (1.22–1.36)	1.26 (1.18–1.33)	1.81 (1.37–2.25)	1.31 (1.11–1.46)
			<i>P</i> = 0.003	<i>P</i> = 0.005
Married vs. unmarried	1.24 (1.20–1.28)	1.24 (1.20–1.29)	1.25 (1.12–1.38)	1.13 (1.01–1.23)
Percentage of persons with < 12 yrs of education				
11–20 vs. 0–10	0.95 (0.92–0.99)	0.96 (0.92–0.99)	0.86 (0.71–1.00)	NS
≥ 21 vs. 0–10	0.94 (0.91–1.00)	0.95 (0.90–1.00)	0.83 (0.69–0.96)	
	<i>P</i> = 0.008	<i>P</i> = 0.015	<i>P</i> = 0.04	
Race				
Black vs. white	0.77 (0.72–0.83)			
Latino vs. white	1.24 (1.18–1.30)	—	—	—

NS: not significant.

^a Radiotherapy includes external-beam radiotherapy or brachytherapy. Risk ratios—all variables are significant at *P* < 0.0001, except where noted.

TABLE 4
Summary of Logistic Regression Predicting any Form of Curative Therapy^a

Variable/model	Overall	White	Black	Latino
Total no. of patients	27,290	23,040	2698	1552
No. of patients (%) receiving curative treatment	18,444 (68%)	15,685 (68%)	1743 (65%)	1016 (65%)
Age (yrs) ≥ 70 vs. < 70	0.67 (0.65–0.69)	0.67 (0.65–0.69)	0.66 (0.60–0.71)	0.65 (0.58–0.73)
Tumor grade				
Moderate vs. low	1.60 (1.56–1.64)	1.60 (1.55–1.64)	1.49 (1.34–1.63)	1.76 (1.59–1.91)
High vs. low	1.56 (1.52–1.61)	1.58 (1.53–1.63)	1.33 (1.16–1.50)	1.73 (1.52–1.90)
Married vs. unmarried	1.28 (1.25–1.30)	1.30 (1.28–1.33)	1.13 (1.07–1.19)	1.27 (1.16–1.36)
Percentage of persons with < 12 yrs of education				
11–20 vs. 0–10	0.95 (0.93–0.97)	0.94 (0.92–0.97)		
≥ 21 vs. 0–10	0.91 (0.89–0.94)	0.92 (0.89–0.95)	NS	NS
Race				
Black vs. white	0.96 (0.93–0.99)			
Latino vs. white	1.00 (0.96–1.04)			
	<i>P</i> = 0.04			

NS: not significant.

^a Curative therapy includes prostatectomy or radiotherapy (external-beam radiotherapy or brachytherapy). Risk ratios—all variables are significant at *P* < 0.0001 unless otherwise noted.

had 20% more prostatectomies than their unmarried counterparts.

Among older men (age ≥ 70), 56% received a form of curative therapy, with radiotherapy predominating 63% of the time (i.e., 35% of the total). As in the younger cohort, a higher percentage of married compared with unmarried men in the older cohort received any form of curative therapy (61% vs. 44%) as well as prostatectomy, specifically (24% vs. 14%; data not shown). Blacks were less likely than whites to receive any form of curative therapy (51% vs. 58%) as well as prostatectomy, specifically (14% vs. 22%), whereas Latinos and whites were more similar (54%

vs. 58% and 28% vs. 22%, respectively; data not shown). A positive association between marriage and higher rates of prostatectomy and either form of curative therapy applied within all race/ethnic groups (Table 2). However, compared with the younger cohort, the association was less pronounced for prostatectomy, specifically, and somewhat more pronounced for any form of curative therapy.

In bivariate analyses, age, race/ethnicity, marriage, high school education, and tumor grade were predictive of prostatectomy and any form of curative therapy (*P* < 0.0001). However, none of the interaction terms was significant. The results of the multivariate

analyses are displayed in Tables 3 and 4, showing as relative risks the adjusted predictors of prostatectomy versus radiotherapy and curative therapy versus expectant management, respectively. As expected, younger age and higher tumor grade were strong predictors of prostatectomy compared with radiotherapy, and of curative treatment compared with expectant management. Marriage was also a strong predictor of prostatectomy and curative treatment (prostatectomy or radiotherapy) in all racial/ethnic groups. Black race was negatively associated, and Latino ethnicity was positively associated, with receipt of prostatectomy, although there were no racial/ethnic differences in receipt of curative treatment overall. Lower SES predicted lower rates of prostatectomy compared with radiotherapy among blacks. Finally, we performed a subgroup analysis in the four California and New Mexico registries because Latinos are concentrated in these areas and because we wanted to exclude regional variation in procedure utilization as a possible explanation for significant differences between Latinos and whites. The results were not significantly different from those in the overall sample.

DISCUSSION

The current study confirmed the hypothesis that sociocultural factors add significant explanatory power to traditional biomedical variables in understanding treatment patterns of early-stage prostate carcinoma. We analyzed a national sample of non-Latino white, black, and Latino Medicare beneficiaries who had no documented comorbid conditions between the years 1995 and 1999. This population is highly likely to face therapeutic options after diagnosis, including prostatectomy, external-beam radiotherapy, brachytherapy, and expectant management. We found, as anticipated, that younger age and higher tumor grade were very strong predictors of treatment. In addition to these biomedical influences, however, we also found that several sociocultural variables, such as marital status, high school education, and race/ethnicity, were also significant predictors of treatment.

That blacks were no less likely than whites to receive curative therapy, but were less likely to undergo prostatectomy compared with radiotherapy is intriguing for two reasons. First, almost all patients see urologists for confirmatory biopsies and, second, urologists in general are more likely to recommend prostatectomy rather than radiotherapy for curative intent.¹⁰ It is possible that physicians recommend surgery less often to their black compared with white patients because they perceive black men at higher risk for poor outcomes³ and also less likely to adhere to medical advice.¹¹ The beliefs and preferences of black patients must also be considered,

and could include distrust of physicians and fear of surgery,¹² more concerns about impotence,¹³ and more pessimism than other racial groups about the curability of prostate carcinoma.¹⁴ Finally, some urologists may downplay surgery as an option because of a priori assumptions that their black patients have these sorts of concerns.

Our finding of a higher rate of prostatectomy among Latinos compared with whites was somewhat surprising. Two previous studies, using cancer registry data through 1994, found either significantly lower⁵ or no difference⁶ in prostatectomy rates among Latinos. Neither of these studies adjusted for comorbidities or measures of SES, however, and both included a large proportion of men < 65. A third investigation,² based on 1994–1995 prostate cancer outcomes study data but also using a younger population than the one in the current study, derived results similar to our own. One possibility is that Latinos, many of whom live in rural areas or in Spanish-speaking enclaves, have less real or perceived access to radiotherapy oncology services. Alternatively, Latinos may have more favorable attitudes towards surgery (or more fear of radiotherapy) compared with whites and blacks, or perhaps they have a greater trust in the authority of physicians and, therefore, more willingness to accept prostatectomy when it is recommended.

A particularly noteworthy finding was that marital status appears to be at least as strong a predictor of prostatectomy as race/ethnicity, which has received the greatest attention in previous studies. The first study to identify higher utilization of prostatectomy among married men was conducted in 2000.⁵ Two subsequent studies^{2,3} showed that unmarried men received more conservative therapy. It is possible that married men (or their wives) advocate therapy that they perceive as likeliest to yield cure, whereas unmarried men are more likely to lack social supports that would encourage aggressive interventions. The influence of wives on the selection of curative therapy has some plausibility, based on a qualitative study of patients with early-stage prostate carcinoma in which wives were more interested in their husbands' cure whereas husbands tended to place greater emphasis on treatment side effects.¹⁵ Finally, perhaps clinicians recommend aggressive therapy more strongly to married than unmarried men.

Given the current emphasis on improving the quality of patient involvement in decision-making, the role of spouses deserves greater attention. Little is known, for example, about how often wives accompany their husbands to the clinic, and about how their presence influences consultations. Wives may enhance the quality of decision-making by gathering information, coaching the patient to ask questions, or advising about treatment.¹⁶

Conversely, even informed spouses have the potential to impair decision-making. One study found that in consultations that include the physician, patient, and spouse, patients frequently raise fewer topics, are less assertive, engage in less shared decision-making, and are frequently excluded from conversations.¹⁷

The current study has several limitations. Provider characteristics, referral patterns, and patient/spouse preferences could not be analyzed, and ecologic rather than individual measures of SES were utilized. If there was preferential underascertainment of comorbid conditions in more socially disadvantaged groups, this would have inflated the strength of association between treatment and marital status, SES, and race/ethnicity. Regional variation in practice patterns might also influence findings of racial/ethnic differences in treatment.⁴ However, our findings pertaining to black men are consistent with those of previous studies that controlled for registry, and a subgroup analysis performed for Latinos concentrated in California and New Mexico did not differ significantly from results obtained in the overall sample. In addition, although the sensitivity and specificity of a designation of Latino ethnicity is unknown in the SEER-Medicare database,¹⁸ we believe misclassification is unlikely to have been a major concern in our analysis. SEER race recode B is more exact than Medicare,¹⁸ whereas Medicare appears to misreport Latino ethnicity $\leq 10\%$ of the time.¹⁹ Finally, it should be noted that a strength of our study compared with previous research involved the inclusion of clinicopathologic staging information in the SEER-Medicare dataset beginning in 1995, thereby reducing the frequency of clinical upstaging based on surgical pathology.

As clinical uncertainty continues to surround the optimal treatment of early-stage disease, and as patient involvement in decision-making remains a key goal for ethical and quality-of-life considerations, the results of the current analysis suggest several important avenues of inquiry. How, for example, do spouses influence the nature and quality of decision-making and how might clinicians productively facilitate their involvement in this process? Do patients in certain racial/ethnic groups manifest particular beliefs and attitudes about cancer and medical therapies that complicate their ability to rationally weigh risks and benefits? Finally, which patient groups lack access to radiotherapy oncology? Assessing and ensuring the adequacy of shared decision-making in this very complex clinical scenario will depend on finding answers to these and related questions.

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Patient Treatment Preferences in Localized Prostate Carcinoma

The Influence of Emotion, Misconception, and Anecdote

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BACKGROUND. Multiple therapeutic options exist for localized prostate carcinoma, without conclusive evidence to guide the choice of treatment. Thus, treatment should reflect trade-offs between the probability of curing disease and the desire to avoid treatment-associated side effects. Factors that actually influence patient treatment preferences are poorly understood.

METHODS. We reviewed medical records and carried out in-depth, semistructured interviews of 20 men with newly-diagnosed, clinically-localized prostate carcinoma in a Veterans Affairs Hospital following their first consultations with urologists and before treatments were initiated. Six to eight months after treatment, we carried out follow-up interviews. Interviews explored beliefs and attitudes about prostate cancer and treatment options, emotional reactions to the diagnosis, treatment preferences, information sources, and perceptions of interactions with urologists.

RESULTS. Patient treatment preferences were not based on careful assessments of numerical risks for various clinical outcomes. Instead, feelings of fear and uncertainty contributed to a desire for rapid treatment, and specific preferences were profoundly influenced by misconceptions, especially about prostatectomy, and by anecdotes about the experiences of others with cancer. Few patients wanted to seek second opinions. Most patients received treatments that matched their initial preferences. Afterwards, they justified their choices in terms of the same misconceptions and anecdotal influences invoked during treatment deliberation.

CONCLUSIONS. For men with localized prostate carcinoma, the treatment decision-making process would benefit from interventions that moderate feelings of fear and a desire for rapid treatment, dispel common and powerful misconceptions about prostate cancer and its therapies, and help patients avoid over-reliance on anecdotes. *Cancer* 2006;107:620–30. © 2006 American Cancer Society.

KEYWORDS: localized prostate carcinoma, treatment, decision-making.

In localized prostate cancer, definitive therapy includes radical prostatectomy, external beam radiation, brachytherapy, and cryotherapy. Optimal treatment, however, is unknown because there is a lack of convincing evidence regarding which form of therapy offers the best long-term survival. Moreover, all forms of therapy have unique and potentially serious side effects. Indeed, despite at least one recent report,¹ questions remain about whether the morbidities associated with radical prostatectomy are worth the small potential benefits in overall survival when compared with watchful waiting, especially for low- and intermediate-grade disease.^{2,3} Ultimately, decisions about how to treat localized prostate cancer are highly

personal. Ideally, each patient would base his decision on accurate information, weighing all options in terms of the likelihood for tumor recurrence, personal preferences for avoiding specific treatment-related side effects, and pragmatic considerations such as cost, convenience, and requirements for follow-up care.

Little is known about how men diagnosed with localized prostate carcinoma choose their treatment. Studies using hypothetical patients, retrospective data, or non-U.S. populations have examined discrete influences on and correlates of decision-making, such as social supports, informational sources, demographic characteristics, and concerns about side effects and posttreatment quality of life.⁴⁻¹⁹ Some of these studies have utilized focus group and individual patient interviews to aid in the development of surveys and psychometric instruments but most have asserted conclusions without reporting the content of the actual interviews. There is also a small literature based on testimonials of predominately white, socially privileged men that recount odysseys of receiving a prostate cancer diagnosis, agonizing over what to do, and traversing perplexing health care systems.²⁰⁻²² Because the topic has not been adequately addressed in the prior literature this study aims to describe, from the perspective of working- and middle-class patients themselves, how they make treatment decisions in real time following the diagnosis of localized prostate carcinoma.

MATERIALS AND METHODS

Qualitative research methods are well-suited for studying the complex and dynamic experience of decision-making following a cancer diagnosis because they permit rich descriptions using the words and categories of participants themselves.²³ When phenomena are poorly understood, qualitative methods aid in the identification of key variables and can generate informed hypotheses for evaluation in subsequent, quantitative studies. Qualitative methods can also furnish novel ideas about how to target the improvements in health services delivery.

Participants

Patients were identified through the Denver Veterans Affairs Medical Center Urology Outpatient Practice. Clinic personnel confirmed patient eligibility for the study. Criteria included men (≤ 80 years, English-speaking), with clinically localized (i.e. T1 or T2) prostate cancer, who had been diagnosed within the previous six weeks and had not yet received treatment.

Description of Setting and Procedures

We carried out individual patient interviews within a week of, and typically on the same day as, a patient's first treatment discussion with a urology resident. Four urology residents beyond their second year of training rotated through the service during the interview period. Each urologic consultation, lasting an average of 35 min, included a description of prostate cancer and the patient's unique tumor characteristics, a review of all major treatment options and their associated side effects, and prognostic information based on the Partin table.²⁴ Available forms of treatment included radical prostatectomy, external beam radiotherapy, brachytherapy (an option that requires Veterans Affairs-paid travel to Seattle) and, as noncurative therapy, hormonal ablation and watchful waiting. Cryotherapy was also an option, usually referenced as 'experimental,' but was not available within the institution. All patients were given an informational brochure that summarized this basic information.²⁵ Although clinical characteristics (e.g. patient age, PSA level, sexual activity, and comorbidities) were expected to influence the ways in which clinicians presented treatment options to patients, we did not study this phenomenon nor did we focus on the treatment options that might have been medically preferred given a patient's clinical profile. Instead, our goal was to characterize patients' attitudes and beliefs about the choices they actually faced as well as the strategies they used to decide on one form of treatment over another.

With three patients, we pilot-tested and refined a semistructured, in-depth interview that lasted between 60 and 90 min. An open-ended protocol allowed respondents to express themselves completely, in their own words, without the imposition of researcher-defined categories. The interviews, carried out by a medical anthropologist and qualitative research assistant, focused on the emotional repercussions of the diagnosis, perceived treatment options, treatment preferences and their rationale, knowledge of treatment-associated side effects, perceived changes in attitudes toward treatment before and after the urologic consultation, current and anticipated sources of information and advice, and perceptions of the urologist's treatment recommendations and advice about decision-making. Interviews were audio-taped and transcribed verbatim using numerical codes to protect patient identities. Researchers made no effort to influence treatment choices or judge their appropriateness. At the end of their first interview, patients were given \$25 as compensation for their participation. The final sample size was dictated by thematic saturation, which refers to the point at which additional interviews replicate previously-identified themes and fail to reveal

TABLE 1
Medical and Demographic Characteristics of Participants

Patient no.	Age (years)	Married	Education	Race/ethnicity	Gleason score	Clinical stage	PSA	Initial Treatment preference	Treatment received
1	55	+	Some HS	NLW	7	T2b	39.3	RP	RP
2	58	-	Some college	AA	7	T2b	17.0	RP	RP
3	61	-	HS graduate	NLW	7	T2b	7.1	RP	RP
4	63	+	HS graduate	NLW	7	T1c	7.8	RP>EBT	RP
5	64	+	College graduate	NLW	6	T1c	5.5	RP	RP
6	67	+	College graduate	NLW	6	T1c	6.7	RP	RP
7	69	+	Some college	NLW	6	T1c	7.2	RP	brachy
8	74	+	College graduate	NLW	5	T1c	5.0	RP	RP
9	53	+	Some college	AA	6	T1c	12.0	brachy	wants brachy
10	57	-	Some college	NLW	6	T2b	4.6	brachy	EBT, HA
11	63	+	Some college	NLW	6	T1c	5.5	brachy	brachy
12	57	-	Some college	AA	6	T2b	5.3	brachy>EBT	EBT
13	54	-	Some college	AA	6	T1c	10.6	EBT>brachy	EBT
14	58	+	HS graduate	AA	7	T2b	16.2	EBT	EBT, HA
15	69	+	Some HS	Latino	6	T1c	20.7	EBT	HA
16	70	+	Some college	NLW	7	T2b	7.5	EBT	EBT, HA
17	77	+	Some college	NLW	6	T2b	5.3	EBT	EBT
18	80	+	College graduate	NLW	6	T2b	9.7	ww	wants cryo
19	74	+	College graduate	NLW	6	T1c	14.8	unsure; ww possible	ww
20	69	+	College graduate	NLW	7	T2b	5.5	alternative tx ("Protosel")	Alternative tx

AA indicates African American; NLW, Non-Latino White; RP, radical prostatectomy; brachy, brachytherapy; EBT, external beam radiotherapy; HA, hormonal ablation; cryo, cryotherapy; ww, watchful waiting; "wants", at the time of the follow-up interview, treatment has not yet been received and the patient's treatment preference is indicated.

new findings. Chart reviews provided supplementary information about patient sociodemographics, medical history, tumor characteristics, and urologist notations regarding their discussions with patients. Six to eight months after the initial interviews, we audio-taped and transcribed 10- to 15-min follow-up telephone interviews to reassess patients' reasons for choosing the form of treatment they ultimately received.

Data Analysis

Using grounded-theory methodology,²⁶ the initial stage of data coding and interpretation involved two experienced qualitative researchers who carried out independent, methodical reviews of individual transcriptions in order to prepare summary documents of key thematic elements. Jointly, the investigators then reviewed these summaries along with the original transcriptions in order to produce consensus documents for each patient. This process involved comparing findings, discussing divergent coding, and resolving differences of interpretation when necessary. Finally, on the basis of the summary and consensus statements, the investigators used an iterative process to develop synopses of recurrent themes applicable to the entire sample.

This study was approved by the Colorado Multi-Institutional Review Board (COMIRB). In this study, informed Consent was obtained from All participants.

RESULTS

Participants

Thematic saturation was achieved with 20 participants. Table 1 summarizes their sociodemographic and medical characteristics, as well as treatment preferences and treatment received. Age of patients ranged from 54 to 80, with a mean of 65 years. Fifteen percent or 75% of patients were currently married; the remainder were widowed, divorced, never married, or had a noncohabiting partner. The majority of the sample (75%) was white; five (25%) were African-American. Educational attainment ranged from non-high-school to college graduates. All patients had intermediate grade, clinically localized prostate cancer. PSA scores ranged from 4.6 to 39.3, with a median score of 7.4. Common to most Veterans Administration populations, about half the patients had significant comorbidities. Nonetheless, all patients were eligible for at least two forms of potentially curative therapy meaning they had choices and faced treatment deci-

Fear and uncertainty (with denial)

It's cancer man! ...I try to sleep and get bad dreams... I don't know how much longer it's going to be for me, you know.

I think it's a time bomb and you don't know if your time is going to be short or time is going to be long... my worry is that it will spread into your lungs. Once cancer hits your lungs I think you are fodder, I think it's bye-bye baby...

I'm a little in shock because I had a couple of days of anxiety attacks. I don't know how much cancer I have. ...I should just try to retire as soon as I can before I just die off. ...But it's a slow-moving cancer so stop freaking yourself out. It's just not serious. All systems go. I'm kind of happy.

It upset me a little bit, but not a real lot. I've read there are quite a few different options as to how you can cure it and most of them are real successful. ...It's a real deadly thing. I know some people who have died from it.

Desire for rapid treatment (despite intellectual knowledge)

I'm worried... I don't want to wait. ...Even though I'm low-low I'd like to get it out of the way...We'll probably make a decision by today.

I always had it in my mind that I wanted the surgery before I even went to talk to {the doctor}. ...You don't wait once you know you got cancer – if you can get rid of it. ...They wanted to give me two weeks to think about it, but I didn't want to do that.

Thankfully, prostate cancer is not fast-moving. But...I think at times, there is that process, where the prostate cancer all of a sudden where it just blossoms. Does it always go slowly or can it go slowly and then all of a sudden explode?

People minimize the danger of having this cancer because they are told it is easily treated. Or that it is slow growing and all of these things. Yeah, a train doesn't look dangerous when it's going 5 mph but if it runs you over you'll be just as dead.

FIGURE 1. Patient quotes illustrating fear, uncertainty, and a desire for rapid treatment.

sions. Below, we describe their initial treatment preferences and the factors that influenced these.

Fear, Uncertainty, and a Desire for Rapid Treatment

For most patients, decision-making occurred within a very charged emotional context characterized by fear, uncertainty, and a desire for rapid treatment. After hearing news of the diagnosis, about two-thirds of patients acknowledged marked and persistent fear and uncertainty about the future. Patients younger than 70 were particularly likely to acknowledge fear (this applied to 13/16 such patients). Typically, expressions of fear were complemented at other times by its denial, seeming to reflect an internal dialogue aimed at convincing oneself that everything would be fine. Illustrative patient quotes are presented in Figure 1.

Almost all patients noted that prostate cancer tends to be slow-growing. Some patients mentioned that their own tumor characteristics, such as low histological grade, low PSA level, and negative bone and CT scans, were encouraging. Nonetheless, more than half the patients (12/20) advocated treatment as quickly as possible. Intellectual knowledge did little to attenuate feelings of fear and the desire for rapid treatment; at the most it seemed to offer only transient reassurance.

Attitudes and Misconceptions About Prostatectomy

Patients expressed their most unambiguous opinions about prostatectomy, specifically. For and against, these opinions were very polarized (Fig. 2). On the

basis of such impressions, patients *then* evaluated other, much less familiar alternatives, including external beam radiotherapy, brachytherapy, and cryotherapy.

“Surgery is Best”

One group of patients (8/20, or 40%) felt surgery was the best option because it was the most certain, the most expeditious, and the most concrete and tangible. These patients believed that “getting the tumor out” was the most definitive thing one could do, that it offered the greatest sense of finality, and that it was the standard against which all other treatment options should be judged. For these patients, physically removing a cancerous tumor was simple common sense.

The ability of surgery to provide prompt *knowledge* about the tumor was also of paramount importance, because this could help alleviate uncertainty. Prostatectomy would yield the greatest amount of information about the nature and extent of the cancer itself, such as whether it had spread outside of prostate, possibly to involve the lymph nodes. Patients believed (erroneously) that if the excised tumor was wholly confined to the prostate, treatment success would be known and cure guaranteed, alleviating considerable doubt about the future. If, on the other hand, surgery were to reveal that tumor had escaped the prostate, this information would also be invaluable because, as one patient put it, “at least I will know what I’m dealing with.”

Advantages

I think it's better for me to have surgery right away. I want to see if we can't nip it in the bud right now. I wouldn't want to go through the radiation and then find out that didn't work. Then it just takes too long to do that.

...if it's confined to the prostate, and they take [the prostate] out, it's gone. And you're not going to get prostate cancer again, because it's gone.

...with radiation, you are not seeing... you are going by the PSA score afterwards – basically that would have been tough and I think surgery is just such a positive way to approach it.

If you get the surgery, then they will examine the prostate when it is out and they will know where the cancer was and that there was zero chance of it metastasizing or there was some or, but you'll have some more data.

If you have surgery you're in and out. You'll know pretty soon how you are. ...With radiation you don't know whether or not the cancer cell has jumped the boundary.

Disadvantages

I just don't trust the knife, man. I've got too many different things to worry about if I go under the knife. I mean not coming out from under the anesthesia right, or them making a mistake, or the tumor spreads... I don't want to deal with that.

...the actual surgery... they open you up and go in and cut away the prostate and the testicle or whatever and hopefully they get it all and put you back together. They actually set your guts out on the table as I understand it. ...You can get screwed up pretty bad with any surgery where you go under a general anesthetic.

...when they said surgery, I thought about going in and just doing a hack job and hacking it off. ...Well, I still envision myself having some sex life. A penile implant doesn't sound very appetizing. ...Then you go Viagra and you have to work every hour of your life to afford Viagra.

He did say you could leak [with surgery], but could you imagine wearing Depends for the rest of your life? ...I mean give me a break. I see people who have been drinking too much who wet their pants. It's not that I go around looking down at men's pants, but when you see a guy... with a big wet spot on him, then you know something's wrong.

FIGURE 2. Participant quotes regarding the advantages and disadvantages of prostatectomy.

Without exception, patients who desired surgery did not regard external beam radiotherapy, brachytherapy, and cryotherapy as attractive alternatives. An underlying theme was that these forms of therapy act upon a cancerous organ that remains hidden and unseen within the body. Furthermore, external beam radiotherapy, in particular, requires a protracted course of administration and the success and side effects of this option, as well as brachytherapy, only become evident at some indeterminate point in the future. In other words, compared with surgery, these other forms of treatment are less immediate, less visible, and more mysterious and indefinite (Fig. 2).

“Surgery is Dreadful”

In contrast to those who desired surgery, a similar-sized group of patients (11/20, or 55%) had equally strong but *negative* feelings about this option. These feelings were based on the idea that surgery (or anesthesia) is intrinsically “frightening,” “drastic,” and “extreme”; that death on the operating table is a real possibility; and that it is undesirable to cede complete control over one's unconscious body to physicians who may not be completely trustworthy or competent. Some patients suggested that surgery is messy or haphazard, or even rife with carnage. Some mentioned that surgery can cause a tumor to spread, or that the removal of a body part is simply

a bad idea. Some imagined, often in graphic terms, the worse possible outcomes associated with surgery (Fig. 2).

Patients who rejected prostatectomy were more likely to seriously consider alternatives. Among those who were in a position to choose, brachytherapy may have been somewhat more popular than external beam radiotherapy. Meanwhile, among patients who were ineligible for brachytherapy (e.g. because of a prior transurethral resection of the prostate or prostatic hypertrophy) external beam radiotherapy was accepted as a default option but without evident enthusiasm. No patients expressed an initial preference for cryotherapy. As primary disadvantages of external beam radiotherapy, patients cited its daily administration over six weeks and its perceived side effects. By contrast, the primary advantages of brachytherapy included convenience and minimal side effects (e.g. “it's like a prostate biopsy – a piece of cake, and you're good to go”). Two patients also mentioned that brachytherapy is “direct,” a term apparently gleaned from the notion that radioactive seeds are deposited “directly” into the prostate. “Directness” was associated with greater certainty of cure, in contrast to the uncertainty of external beam radiotherapy (e.g. “let's aim at this and hope we get it”).

Table 2 summarizes common knowledge deficits and mistaken ideas (misconceptions) about the risks and benefits of prostatectomy. These were prevalent

TABLE 2
Common and Influential Misconceptions About the Risks and Benefits of Prostatectomy

Misconceptions	Facts
<i>Proponents of prostatectomy:</i>	
Physically removing a cancerous tumor is the best way to guarantee cure.	Compared with prostatectomy, radiotherapy has similar, and occasionally slightly better, five-year progression free probabilities. ²⁷
Rapid surgery is most advisable to avoid the possibility that the tumor will 'spread' or suddenly metastasize ('blossom' or 'explode').	Although external beam radiotherapy may be time-consuming, the likelihood of transformation to rapidly progressive disease is remote and does not justify immediate prostatectomy. ²⁸
Surgery abolishes uncertainty if the postsurgical evaluation shows that the cancer is confined to the prostate.	Possible micrometastases and local recurrence necessitate prolonged postprostatectomy PSA surveillance. ²⁹
If the tumor has spread beyond the prostate, this information also minimizes uncertainty.	Postsurgical evidence of capsular penetration or lymph-node involvement raises uncertainty about giving radiation immediately for prevention or later as salvage therapy. ³⁰
<i>Detractors of prostatectomy:</i>	
Surgery/anesthesia is very dangerous and can lead to death. Surgery is butchery.	In eligible patients, prostatectomy/anesthesia is routine, highly structured, sterile, and very safe. ³¹
Surgery is painful and involves a prolonged recovery period.	Postoperative recovery of usual daily functioning is fairly rapid, and there are effective ways of managing postoperative pain. ³¹
Unlike other options, surgery causes impotence.	Long-term potency outcomes are similar with external beam radiotherapy. ³²
Surgery (or opening the tumor to air) can cause cancer to spread.	Exposing prostate cancer to air does not cause it to spread. ³³

among a majority of proponents and detractors of prostatectomy. It was noteworthy that, following news of the diagnosis but before their first urologic consultation, about half the patients (9/20) sought information about prostate cancer on the internet. These individuals, a majority of whom were college graduates, were just as likely as other patients to manifest misunderstandings and knowledge deficits about prostatectomy.

Failure to Weigh the Numerical Risks of Death and Treatment Side Effects

All urologists reviewed with patients the Partin table probabilities for organ-confined disease, extra-capsular extension, seminal vesicle and lymph node involvement, and lack of 5-year disease progression. Only one of the interviewed patients, however, explicitly compared surgery with its alternatives by referring to these numbers. Meanwhile, none of the patients explicitly compared treatments in terms of their relative likelihood of causing side effects. Although urologists did review the major side effects associated with each form of treatment, patients recalled this information poorly and inaccurately, even among those who had previously consulted the internet.

Several patients confused radiotherapy with chemotherapy, erroneously suggesting that the most common side effect of conformal beam radiotherapy is hair loss. Some patients, apparently having difficulty keeping track of the specific side effects associated with any one form of treatment, associated

major side effects with every form of treatment without regard to their probability of occurrence. Finally, almost half the patients (9/20) minimized concerns about side effects altogether, deeming these entirely irrelevant to the decision-making process.

[Side effects] are not important compared to dying. So you know, the rest of it is immaterial. If I have to wear Depends the rest of my life, then so be it.

The Influence of Anecdote

Nineteen patients had observed or been told about the cancer experiences of others and then had used this information to make sense of their own situation. For example, one patient with localized, potentially curable disease compared his circumstances with that of a cousin whose disease was regionally advanced and hormone-refractory. These kinds of anecdotes exerted strong sway over patients' feelings about their own prostate cancer, treatment preferences, and perceived ability to tolerate particular side effects, primarily because patients viewed prostate cancer as a uniform entity, unaware of differences in prognosis based on tumor stage and grade. In the end, patients paid much more attention to anecdotes than to population-based risk information. The following patient, for example, invoked anecdote to justify his desire for prostatectomy:

Well, see what happened to my dad [who had prostate cancer], it didn't do him no good... He had the radiation and it went through his body anyway... But my brother

just had his prostate removed last year and he is reading 0/0 on his count now and that was over a year now. So I like the results he got, so I feel that's what I'll do.

Avoiding Second Opinions

In 16/20 cases, interviewed patients said they did *not* intend to seek an independent second opinion or discuss treatment with another physician. The reasons generally reflected misconceptions about the purpose of second opinions, expressions of trust or faith in the urologist, and a desire to avoid additional delay, information overload, and prolonged uncertainty. A common misconception (5/20 patients) is that second opinions are only intended to confirm the diagnosis. A majority (6/8) of patients who desired prostatectomy made clear that a second opinion was unnecessary because they simply "trusted," "had confidence in," or "felt comfortable with" the urologist. Invariably, these patients referred to their perceptions of a urologist's personal qualities, such as directness and honesty, rather than a urologist's level of skill and experience or the pros and cons of different forms of treatment. Finally, 10/20 patients felt that second opinions would increase fear and anxiety, delay therapy, or add uncertainty to an already difficult situation.

Information Seeking and Processing

Two approaches seemed to predominate when it came to managing information about prostate cancer. About half of the patients (12/22) said that they wanted doctors or significant others to tell them what they needed to know, while the remainder (10/22) said that they were actively trying to collect and digest as many facts as possible. Among the patients who were reticent to gather information some seemed dissuaded by the unpleasantness of the topic.

I don't probe people to tell me all the details... I don't think no books or nothing like that would help me as far as reading about it because... it'd probably make me feel a little bit more insecure about it.

Another patient who was motivated initially to learn about his disease became discouraged by what he perceived to be confusing and contradictory advice.

Then I talked to these other people who have prostate surgery and they said that was the way to go. I talked to a couple of other people and they told me to take some kind of herbs and stuff, but I'm not listening to that. Someone else told me to go somewhere for some kind of treatment you know. When you listen to a lot of different people it's not good. It's not good.

Meanwhile, those for whom information seeking was important often observed that the process of assimilating it was uncertain, haphazard, and confusing.

I have a stack of papers over an inch thick probably, and I got some more today. Well, they all have differing opinions so you have to kind of read through that and you kind of try to sort it out the best way you can. I get my information mostly from doctors, hospitals, family and my own reading. ...The pamphlets and stuff I've been given, or reading newspaper articles about other people, this and that. That's what I'm talking about – resources. Just hopping around.

In summary, contending with a large quantity of sometimes contradictory information and advice was a major concern of almost every patient.

Treatment Received and Posttreatment Interviews

In only 4/20 cases did a patient subsequently request or receive treatment that did not match his initial preference (see Table 1). We were able to reach 16/20 patients for follow-up interviews 6-8 months after treatment. Fourteen of these who received treatments consistent with their initial preferences invoked exactly the same justifications that they had used prior to treatment.

DISCUSSION

We carried out detailed interviews of 20 patients with localized prostate cancer while they were still contemplating treatment but before they had initiated it. We recorded salient aspects of their decision-making experiences in real time, thereby avoiding recall bias. To our knowledge, no previously-published studies have used this methodology. On the basis of thematic analysis, we elucidated three factors that exerted particularly strong influences on initial treatment preferences. The first was profound fear and uncertainty, often corresponding with a desire to receive treatment as quickly as possible. In fact, a majority of patients were uninterested in obtaining a second opinion, typically because of concerns that this would delay treatment and increase uncertainty. Also, several patients erroneously declared that the only purpose of a second opinion is to confirm a diagnosis. Second, most patients had influential misconceptions about treatment, especially prostatectomy. Their beliefs were highly polarized: one group of patients avowed that prostatectomy is the best way of guaranteeing cure while another group asserted that it is very drastic or dangerous. Finally, almost all patients relied on anecdotes—stories about other people's cancer

experiences—to make sense of their own diagnosis and treatment choices. For the most part, these stories did not accurately match patients' own clinical circumstances.

Chart reviews and follow-up interviews revealed that most patients received treatments that matched their initial preferences. In addition, at the time of their follow-up interviews most patients invoked the same flawed ideas about prostate cancer and the same rationale for treatment that they had articulated during their initial interviews 6-8 months earlier. Although we were unable to directly determine the factors that actually influenced their final treatment choices, the persistence of these ideas bolsters our concern that many patients made early and quick decisions on the basis of erroneous and incomplete information, and then never changed their minds about treatment or altered the reasons for their choices. Altogether, these findings raise doubts about the quality of the decision-making process. Although the quality of an actual treatment *decision* in localized prostate carcinoma cannot, in general, be assessed in relation to an optimal form of treatment, the quality of the decision-making *process* is compromised when decisions are precipitous, and when they are based on significant misunderstandings and a lack of relevant knowledge.

Many of the patients we interviewed seemed as interested (and sometimes more so) in eliminating fear and minimizing uncertainty over the short term as they were in realizing cure over the longer-term. Even though most patients volunteered that prostate cancer is "slow growing," this abstract knowledge did little to dispel the vividly frightening, yet unlikely prospect of prostate cancer suddenly "exploding." Patients remained anxious and wanted to proceed with treatment as quickly as possible. Fear of death was much more prominent than fear of treatment side effects—to such an extent, in fact, that almost half the patients discounted concerns about treatment side effects altogether. In comparison with the possibility of death (which was greatly exaggerated), side effects were simply irrelevant. Another source of fear, again among nearly half the patients, was lack of definitive knowledge about the nature of the tumor. These patients believed—erroneously—that surgery furnishes the greatest amount of clinically useful knowledge and allows one to know quickly and with certainty whether cure has been achieved. Among a separate group of patients, on the other hand, prostatectomy induced fear because its dangers were magnified out of proportion to its real risks. In summary, although fear is to be expected and may be necessary for motivating serious delib-

eration and action, it overpowered reason in ways that were not rectified through the simple provision of accurate health information.

In the decision science literature, an early, primitive reaction to almost any personally relevant object or event is a dichotomous good-bad evaluative assessment. Such a reaction may help to winnow down large choice sets into smaller numbers of options that are more easily contemplated.³⁴ Polarized attitudes for and against surgery may exemplify this phenomenon. Patients' first and most important step in weighing treatment alternatives seemed to depend on their beliefs about the intrinsic merits and disadvantages of prostatectomy, specifically. Assessments of prostatectomy, however, were often based on powerful misconceptions (see Table 2). Misconceptions about cancer are common and often go unrecognized even though they may exert a profound effect on patient behavior.^{35,36} Although urologists (as in this study) typically present patients with factual information that, in principle, might correct their misconceptions, it is likely that patients often fail to recognize that such information is inconsistent with their preexisting beliefs. In this way, their misconceptions persist. Alternatively, they may simply choose to discount such information.³⁷

When making treatment recommendations, physicians often rely on personal opinion and anecdote more than on high-quality evidence.³⁸ It is unsurprising that patients also rely frequently on anecdotal reasoning rather than statistical information.^{39,40} In this study, the vast majority of patients reported the influence of anecdote when forming treatment preferences. In adversity, patients seek advice from other people who are known or trusted and who have lived through seemingly similar situations. This is the basis of support groups and is a key way of garnering emotional and practical assistance from others. Anecdotal information is especially important when it provides appropriate reassurance about particular forms of treatment (e.g. that most patients, in fact, do well with prostatectomy). Conversely, anecdotal information impairs decision-making quality when it leads patients to ignore treatment alternatives or make decisions based on inaccurate appraisals of their own clinical circumstances.⁴¹

In recent years, the literature on patient-centered decision-making has emphasized the importance of *informed decision-making* (IDM) and, to a somewhat lesser degree, *shared decision-making* (SDM).⁴²⁻⁴⁵ IDM in prostate cancer occurs when a patient understands the nature of the disease, the risks and benefits of various treatment alternatives, and makes a decision consistent with his values and

outcome preferences. SDM is an extension of IDM in which the clinician assumes an active role in helping the patient to clarify and express his values and preferences, proposes a form of treatment that seems to be most consistent with the patient's values and preferences, and collaborates with the patient to arrive at a mutually satisfactory treatment decision. Both IDM and SDM emphasize the centrality of communicating medical information to patients and encouraging patients to clarify their values and preferences in ways that can be represented as declarative facts. Also, IDM and SDM tend to emphasize the presentation and framing of numerical risk information in ways that patients can easily and correctly interpret.^{46,47}

This study illustrates that although attention to health information, outcome preferences, and the framing of numerical risk is necessary, it is hardly sufficient for achieving quality in patient-centered decision-making. In particular, traditional models of IDM and SDM often give short shrift to the three powerful influences on decision-making that we identified here. First, emotions such as fear and anxiety engender a profound desire for rapid treatment that is not alleviated by intellectual knowledge that prostate cancer, for example, is "slow growing." Second, influential misconceptions about cancer and treatment are commonplace and are not easily redressed by simply imparting accurate health information. Finally, there is a natural propensity to base personal decisions on anecdotal information, even when anecdotes are not germane to patients' own circumstances. In emphasizing the importance of rational decision-making, IDM and SDM approaches implicitly stress how patients "should" behave while often overlooking how they, in fact, do behave.

To address these challenges, clinicians should strive to meet patients closer to where they actually begin the decision-making process. Explicitly describing common misconceptions may allow patients to consciously recognize and correct them. Sources of patient fear can be elucidated and, where possible, reassurance can be offered. Patients can be asked to recount stories about other people that influence their attitudes and perceptions about prostate cancer, or can be connected to other individuals who have faced similar decisions in the face of comparable risk. Then, they can be helped to understand key differences between these stories and their own circumstances. Finally, the potential value of obtaining second opinions can be made clearer.

In future work, we plan to incorporate these recommendations into treatment decision-aids. Because we found that patients tended to be either passive information recipients or active information see-

kers,⁴⁸ we plan to tailor decision-aid content not only to a patient's clinical characteristics but to his preferences for handling and processing information. In comparison with usual care, we expect that such a decision-aid will lead to less precipitous and more personally satisfactory decisions, fewer treatment alternatives excluded on the basis of erroneous information, greater mutability in treatment preferences over time, and an enhanced ability to critically assess the relevance of other people's experiences with prostate cancer.

Limitations

This was a cross-sectional study of a small number of patients in a single Veterans Affairs Medical Center where, compared with the general population, patients tend to have poorer health and fewer socioeconomic resources.⁴⁹ In addition, patients in this study consulted with resident rather than attending urologists. Conversely, we included an age- and educationally diverse patient sample (including college graduates) and, for the first time, carried out comprehensive interviews during the actual decision-making period as well as 6 to 8 months following the treatment. Ultimately, we believe that the decision-making themes we have identified are likely to have universal applicability.

CONCLUSIONS

Promoting patient participation in treatment decisions requires more than the provision of medical information and the elicitation and weighing of outcome preferences. The process requires greater sensitivity to the factors that, for most patients, actually influence treatment preferences. These include fear, uncertainty, misconceptions, and anecdote.

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