

HHS Public Access

Author manuscript *Med Decis Making*. Author manuscript; available in PMC 2018 January 01.

Published in final edited form as:

Med Decis Making. 2017 January ; 37(1): 56-69. doi:10.1177/0272989X16662841.

Physician Recommendations Trump Patient Preferences in Prostate Cancer Treatment Decisions

Karen A. Scherr, B.S.,

Fuqua School of Business and School of Medicine, Duke University

Angela Fagerlin, Ph.D.,

Department of Internal Medicine and Psychology, Center for Bioethics and Sciences in Medicine, University of Michigan Ann Arbor, The Ann Arbor VA Center for Clinical Management Research, Ann Arbor, Michigan

Timothy Hofer, Ph.D.,

Division of Internal Medicine, University of Michigan Ann Arbor, The Ann Arbor VA HSR&D Center for Practice Management and Outcomes Research, Ann Arbor, Michigan

Laura D. Scherer, Ph.D.,

Department of Psychological Sciences, University of Missouri

Margaret Holmes-Rovner, Ph.D.,

Department of Medicine and Center for Ethics and Humanities in the Life Sciences, Michigan State University

Lillie D. Williamson, B.S.,

Fuqua School of Business, Duke University

Valerie C. Kahn, M.P.H.,

Division of General Medicine, Department of Internal Medicine, Center for Bioethics and Social Sciences in Medicine, University of Michigan Ann Arbor

Jeffrey S. Montgomery, M.D.,

Department of Urology, University of Michigan Ann Arbor, Department of Surgery, Ann Arbor VA, Ann Arbor, Michigan

Kirsten L. Greene, M.D.,

Department of Urology, University of California San Francisco, Department of Urology, San Francisco VA, San Francisco, California

Biqi Zhang, B.S., and Duke University

Peter A. Ubel, M.D.

Conflict of Interest Disclosures

Correspondence concerning this article should be addressed to Peter A. Ubel, 100 Fuqua Dr., Fuqua School of Business, Duke University, Durham, NC 27708. peter.ubel@duke.edu.

Angela Fagerlin is now at the Department of Population Health Sciences, School of Medicine, University of Utah. Lillie D. Williamson is now at the Department of Communication, University of Illinois at Urbana-Champaign. Biqi Zhang is now at Harvard Medical School, Harvard University.

Peter A. Ubel is a consultant for Humana. The principal investigator and all other co-authors have no conflicts of interest.

Fuqua School of Business, School of Medicine and Sanford School of Public Policy, Duke University

Abstract

Objective—To assess the influence of patient preferences and urologist recommendations in treatment decisions for clinically localized prostate cancer.

Methods—We enrolled 257 men with clinically localized prostate cancer (PSA < 20; Gleason 6 or 7) seen by urologists (primarily residents and fellows) in 4 Veterans Affairs Medical Centers. We measured patients' baseline preferences prior to their urology appointments, including initial treatment preference, cancer-related anxiety, and interest in sex. In longitudinal follow-up, we determined which treatment patients received. We used hierarchical logistic regression to determine the factors that predicted treatment received (active treatment vs. active surveillance) and urologist recommendations. We also conducted a directed content analysis of recorded clinical encounters to determine if urologists discussed patients' interest in sex.

Results—Patients' initial treatment preferences did not predict receipt of active treatment versus surveillance (χ^2 (4) = 3.67, p = .45). Instead, receipt of active treatment was predicted primarily by urologists' recommendations (χ^2 (2) = 32.81 p < .001). Urologists' recommendations, in turn, were influenced heavily by medical factors (age and Gleason score) but unrelated to patient preferences (χ^2 (6) = 0, p = 1). Urologists rarely discussed patients' interest in sex (< 15% of appointments).

Conclusions—Patients' treatment decisions were based largely upon urologists' recommendations, which, in turn, were based on medical factors (age and Gleason score) and not on patients' personal views of the relative pros and cons of treatment alternatives.

For some diagnoses, the right treatment choice for any patient depends not only on medical factors, but also on patient preferences.¹ According to some experts, clinically localized prostate cancer is a classic example of such a preference-sensitive diagnosis. The diagnosis involves a choice between surgery, radiation, and active surveillance,² a choice understood to be preference-sensitive because the alternatives involve difficult trade-offs. Active treatments like surgery and radiation can cause patients to experience erectile dysfunction and urinary symptoms, while active surveillance requires follow-up testing and may cause anxiety among men who are uncomfortable living with an untreated cancer.³

In recognition of the preference-sensitive nature of these decisions, the American Urological Association (AUA) recommends that "patient preferences and functional status, with a specific focus on functional outcomes, including urinary, sexual, and bowel function, should be considered in decision making."⁴ This recommendation is consistent with the practice of shared decision making,⁵ by which clinicians are urged to discuss patient values so they can help patients determine which treatment alternative best fits their preferences.⁶

But how well do urologists partner with patients in making preference-sensitive decisions? What role do patients' preferences play in determining what treatment they receive? There has been a fair amount of research examining patients' decision-making processes in the context of early stage prostate cancer, reflecting the importance of this topic.⁷⁸⁹¹⁰¹¹¹²¹³

However, most studies studies rely on retrospective, cross-sectional self-report measures to examine the decision-making process, which are subject to issues such as recall bias. In addition, although we know that physician recommendations influence patient decisions, we know relatively little about how physicians make these recommendations during actual clinical appointments. The present study addresses these gaps, using longitudinal, prospective survey data and recordings of clinical interactions to assess the role of patient preferences and urologists' recommendations on patients' treatment choices.

Methods

Overview and Recruitment

Data were collected as part of a larger study designed to compare the impact of two decision aids on patient decision-making in early stage prostate cancer.¹⁴ (All analyses included the type of decision aid as a covariate. Results remained virtually identical regardless of whether or not decision aid was included as a covariate.) We recruited patients from four Veterans Affairs (VA) Medical Centers (Ann Arbor, Durham, Pittsburgh, and San Francisco) before or shortly after they received biopsies for elevated prostate specific antigen (PSA) tests. Recruitment occurred between September 2008 and May 2012. Only those men diagnosed with low or intermediate risk prostate cancers (Gleason scores of 6 or 7 and a PSA < 20) were eligible to continue in the study, as those are the cancers for which the AUA guidelines considered both active treatment and surveillance to be viable alternatives. Figure 1 shows the basic study flow.

Measures

Clinical variables—In addition to demographic measures, we recorded each patient's PSA and Gleason score.

Treatment received—We determined what treatment each patient received through chart review. Arguably, the most important choice patients face is whether to opt for active surveillance or active treatment (surgery or radiation). Therefore, we dichotomized treatment received into these two categories for our primary analyses. We knew which treatment patients received in 216 cases. (Among patients for whom we had all other data in our model, patients with missing data in terms of treatment received were more likely to have Gleason 7 tumors ($\chi^2(1) = 4.80$, p = .03); no other variables differed.) We excluded patients who received treatments other than active surveillance, surgery, or radiation (n = 5). Thus, for analyses which included treatment received, n = 211.

Initial treatment preference—We assessed patients' initial treatment preference prior to their urology appointments but after they received and reviewed the decision aid. Specifically, we asked, "Although you may not have cancer, we would like to know what treatment you think you might have if you were to have prostate cancer?". Research assistants read a list of treatments out loud and patients answered yes or no to each treatment. Preferences for multiple treatments were allowed – e.g., a patient could express interest in both active surveillance and surgery. We measured treatment preferences at baseline because this measure would be uninfluenced by the clinical interaction but occurred

after patients received information about early stage prostate cancer via the decision aid. Note, however, this does mean that these preferences were measured prior to patients learning their diagnosis or talking to their health care providers, and we therefore refer to them as "initial" preferences. We re-coded these initial preferences as a single categorical variable. Patients were categorized as one of the following: 1) *preferring active treatment*—interested in surgery and/or radiation but not surveillance; 2) *neutral*—interested in both active treatment and surveillance or stating no preference; or 3) *preferring active surveillance*—interested in surgery or radiation.

Interest in sex—Prior to urology appointments, we measured patients' interest in sex, a factor potentially relevant to the choice of active treatment, which may cause problems with sexual function. To assess patients' interest in sex, we asked patients four Likert-scale questions: 1) Overall, how important would you say sex is in your life? (1 = not at all *important*, 4 = extremely important); 2) Compared to other people of your age and gender, how would you rate the strength of your general sexual desire? (1 = much less desire, 9 = much more desire); 3) Which of the following best describes how often you typically engage in sexual activity? (1 = less than once a month, 2 = about once a month, 3 = a few times a month, 4 = once a week, 5 = more than once a week); and 4) If you were to need to have prostate cancer treatment, which of the following best describes how often you think you would engage in sexual activity after treatment? (*same responses as previous question*). We converted all questions to z scores and then averaged the items into a single "interest in sex" measure (alpha = .85).

Cancer-related anxiety—Prior to urology appointments, we measured patients' prostate cancer-related anxiety, a factor potentially relevant to the choice of surveillance, which requires patients to live with an untreated cancer. We used the 13-question MAX-PC scale.¹⁵ As an example, patients indicated to what extent the following statement described their experience: "I had more trouble falling asleep because I couldn't get thoughts of prostate cancer out of my mind" (0 = not at all, 1 = rarely, 2 = sometimes, 3 = often). We averaged patients' responses to calculate a single "cancer anxiety" score and then standardized the measure (alpha = .91). (We reassessed patients' cancer anxiety 7–10 days after learning about their cancer diagnosis and scores were highly correlated (r = .74). Results remain substantively equivalent if we conduct our analyses with the post-diagnosis anxiety measure.)

Preliminary qualitative analysis of clinical appointments—Prior to developing a coding scheme to analyze clinical appointments, we conducted an exploratory qualitative analysis to identify emergent themes of communication behaviors potentially relevant to treatment decision making. A team of five coders read approximately 25 interactions, evaluating how urologists and patients arrived at treatment decisions. In those analyses, we noticed that urologists' recommendations were common and potentially influential. To test this qualitative impression, we developed a coding scheme to quantify urologists' recommendations.

Urologists' treatment recommendations—Urologists' recommendations for or against each treatment alternative were scored according to the Physician Recommendation Coding System (PhyReCS), described in detail elsewhere.¹⁶ We recoded the PhyReCS scores into a single categorical recommendation variable: 1) *active treatment* – the strongest recommendation was for active treatment; 2) *neutral* – equally strong recommendations for active treatment and active surveillance; or 3) *active surveillance* – the strongest recommendation was for active surveillance.

Discussions of sex during appointments—As another way of examining whether urologists' recommendations were influenced by patient preferences, we performed a directed content analysis to assess whether urologists and patients discussed three sex-related topics during clinical appointments.¹⁷ Two coders read each transcript and determined whether the urologist: 1) assessed patient baseline erectile function and/or activity; 2) assessed how important sexual activity was to the patient; and 3) discussed the relationship between interest in sex and treatment choice. See Table 1 for examples within each of these categories. Discrepancies were resolved through team discussion.

Decision-making rationale for patients who received medically-atypical

treatments—We conducted an in-depth analysis to look for cases that might provide insight into the decision-making process by which patients received treatments that were potentially driven more by patient preferences than by medical factors. We identified two groups of patients who received treatments atypical for their age and Gleason score. The first group included young men (65 years old) with intermediate risk prostate cancers (Gleason 7 tumors or PSA 10ng/mL) who received active surveillance. The second group included older men (> 65 years old) with low risk prostate cancers (Gleason 6 tumors and PSA < 10ng/mL) who received active treatment. Two researchers created narrative summaries of each appointment, focusing on content that was part of the decision-making process, and a third researcher reviewed the transcripts and summaries. The coding team used a deductive, iterative process to determine the underlying rationale that explained patients' treatment choices. These rationales were condensed into two categories (medical factors vs. patient preference), and two coders identified which rationale was applicable in each appointment. There were no discrepancies.

Statistical Analyses

Predicting treatment received—First, we used two chi-squared tests to examine the relationship between: 1) treatment received and urologist recommendation; and 2) treatment received and patient initial treatment preference (excluding patients with initially neutral treatment preferences). We then used a hierarchical logistic regression to determine the factors that predicted which treatment patients received (Figure 2). In Model 1, we included type of decision aid as a covariate, a "site" fixed effect to account for heterogeneity in treatment received across our four study sites, and medical factors known to influence treatment received (age, Gleason, age \times Gleason). In Model 2, we added information about patient preferences (initial treatment preference, interest in sex, and cancer anxiety). Finally, in Model 3, we added urologists' recommendations. Of note, although some urologists were recorded in more than one appointment, a multilevel model to account for the clustering of

patients within urologists did not improve fit (based on likelihood ratio test, p = 1); therefore, we used a single level model without urologist-specific random effects. We acknowledge, however, that the likelihood ratio test may have limited power with relatively small sample sizes; thus, our final model uses a generalized Huber/White sandwich estimator to account for the effect of any clustering of observations by urologist and to conservatively calculate predicted probabilities and confidence intervals.¹⁸

To further examine the relationship between treatment received and these factors, we also computed the probability that patients received active treatment as a function of: 1) age and Gleason score (averaged across all other factors in the final model); and 2) urologist recommendation (averaged across all other factors in the final model).

Predicting urologists' recommendations—Given the strength of the association between urologists' recommendations and treatment received, we then developed a separate model to determine the factors that predicted urologists' recommendations (active surveillance vs. neutral vs. active treatment). For these analyses, n = 252. First, we examined the simple relationship between urologists' recommendations and patients' initial treatment preferences as well as their Gleason scores. We then used a hierarchical multinomial logistic regression to more formally determine the factors that predicted urologists' recommendations (Figure 2). In Model 1, we again included type of decision aid as a covariate, a "site" fixed effect to account for heterogeneity in urologists' recommendations across our four study sites, and medical factors known to influence treatment received (age, Gleason, age × Gleason). In Model 2, we added patient preferences (initial treatment preference, interest in sex, and cancer anxiety). Similarly to above, a multilevel model to account for the clustering of patients within urologists did not improve fit (based on likelihood ratio test, p = 1); however, we again use a generalized Huber/White sandwich estimator to conservatively calculate predicted probabilities and confidence intervals.¹⁸

Because coefficients from multinomial models are notoriously difficult to interpret (representing conditional odds ratios, conditioned on a comparison to the base outcome from a dependent variable with more than two outcomes),¹⁹ we present results from the final model by displaying the marginal predicted probability that the urologist recommended active surveillance, was neutral, or recommended active treatment as a function of 1) age and Gleason score (averaged across all other factors in the final model); and 2) initial treatment preference and Gleason score (averaged across all other factors all other factors in the final model).

Models were estimated using Stata 13.1, with random effects multinomial regression models estimated using the generalized structural equation modeling procedures.²⁰

Human Subjects Approval

This study was approved by the Institutional Review Boards at each of the participating sites; written informed consent was obtained from all patients and urologists.

Funding

All funding agreements ensured the authors' independence in designing the study, interpreting the data, writing, and publishing the report.

Results

Patient and urologist characteristics

The mean age of the patients who were recorded was 63.2 years (s = 6.02); 74% were white; 30% had a high school education or less. Forty-seven urologists were recorded in our study. The mean age of the urologists was 32.2 (s = 5.6); 20% were female; 68% were white. On average, each urologist was recorded in 5.31 clinical appointments (s = 3.77). Importantly, the majority of urologists were residents or fellows. Of note, attending urologists joined the resident for the end of the consultation in some appointments; for purposes of the qualitative analyses, we did not distinguish between conversations with residents versus fellows versus attending physicians.

Predicting treatment received

Forty-six percent of patients (98/211) received active surveillance and 54% of patients (113/211) received active treatment. Prior to urology appointments, 32 of these patients preferred active surveillance, 75 had no preference, and 104 preferred active treatment. During appointments, 37 urologists recommended active surveillance, 56 were neutral in their recommendations, and 118 recommended active treatment. Figure 3 shows the proportion of patients who received active treatment as a function of their initial treatment preference as well as their urologists' recommendations. There was no relationship between patients' initial treatment preference and treatment received ($\chi^2(1) = .06$, p = .80). By contrast, there was a statistically significant relationship between urologists' recommended active treatment; however, when urologists recommended active surveillance, only 5% of patients (2/37) received active treatment. This provides initial evidence that urologists' recommendations strongly influenced patients' treatment decisions while their preferences did not.

Table 2 shows the results of our hierarchical logistic regression. Accounting for patient preferences (Model 2) did not improve the fit of the model (χ^2 (4) = 3.67, p = .453), indicating that patient preferences did not predict patient treatment choice above and beyond medical factors and site. Accounting for urologists' recommendations (Model 3) did improve the fit of the model ($\chi^2(2) = 32.81 \text{ p} < .001$), indicating that urologists' recommendations did predict treatment choice above and beyond the other factors in the model. Figure 4 illustrates the importance of medical factors in patients' treatment decisions, displaying the predicted probability that patients received active treatment as a function of age and Gleason score (averaged across all other factors in the final model). As above, these results suggest that patients' treatment decisions were based on medical factors and not on their preferences.

However, this analysis could violate regression assumptions, if there are variables we did not account for that predict both urologists' recommendations and, by a different pathway, the treatment received. To ensure our results are robust to this assumption, we analyzed the factors that predict urologists' recommendations, which occur before the treatment choice.

Predicting urologists' recommendations

First, we examined the simple relationship between urologists' recommendations and patients' initial treatment preferences as well as their Gleason scores (Table 3). Notably, only 4.9% of the patients (2/41) who initially preferred active surveillance received recommendations for that treatment whereas 27.2% of the patients (34/125) with Gleason 6 tumors received recommendations for active surveillance. Examined another way, of the 38 patients who received recommendations for active surveillance, only 5.3% of them initially preferred that treatment whereas 89.5% of them had Gleason 6 tumors. This suggests that urologists' recommendations were strongly driven by medical factors and not patients' initial treatment preferences, but we examine the predictors of urologists' recommendations more formally below using hierarchical logistic regression.

Urologists' recommendations were strongly predicted by patient age and Gleason score, with a significant interaction between age and Gleason score. Figure 5 shows the marginal predicted probability that urologists recommended each option (active surveillance, neutral, and active treatment) as a function of patient age and Gleason score. Recommendations for active surveillance did not vary by patient age. For patients with Gleason 6 tumors, urologists recommended surveillance. Alternatively, recommendations for active treatment did vary by patient age. For patients with Gleason 7 tumors, urologists recommended active treatment almost 100% of the time for younger patients, dropping to about 50% of the time for older patients, with most of the recommendations shifting to neutral (rather than active surveillance). For patients with Gleason 6 tumors, urologists recommended active treatment 75% of the time for younger patients, dropping rapidly with age, with recommendations shifting to both neutral and active surveillance.

By contrast, urologist recommendations were not predicted by patients' initial treatment preferences (χ^2 (6) = 0, p = 1). Figure 6 shows the marginal predicted probability that urologists recommended each option (active surveillance, neutral, and active treatment) as a function of patients' initial treatment preferences, separated by Gleason score. There was little consistent effect of patients' initial treatment preferences on urologists' recommendations.

In sum, we find evidence that urologists' recommendations were strongly influenced by medical factors but not patient preferences. However, we acknowledge that patients' treatment preferences may have been aligned with their medical factors, and therefore perhaps our analysis is underestimating the impact of patient preferences on urologists' recommendations.

Discussions of sex during appointments

To account for this possibility, and to further characterize the extent to which urologists' recommendations may have reflected patients' preferences, we analyzed discussions of sex during appointments (Table 1). Physicians assessed patients' baseline erectile function and/or sexual activity in 67% of appointments (172/257). Physicians rarely assessed the

importance of sex to the patient (12% of appointments) or discussed the relationship between interest in sex and treatment choice (13% of appointments). Again, this points to the dominance of medical factors over patients' preferences in urologists' recommendations, as urologists' recommendations cannot reflect patients' preferences if they do not discuss them during appointments.

Decision-making rationale for patients who received medically-atypical treatments

Only 5% of patients (11/211) received treatments that were atypical given their age and Gleason score. In four of these cases, treatment decisions were driven by medical factors, whereby urologists recommended the atypical treatment for medical reasons not captured by age or Gleason score. For example, an older patient with low risk cancer had a high percentage of biopsy cores positive for cancer, making his cancer worse than the typical low risk cancer and the urologist thus recommended that he receive active treatment. The remaining eight patients received atypical treatments due to their preferences. For example, in one case, a younger man with intermediate risk cancer chose to receive active surveillance because he could "not afford to miss work right now" even though his urologist recommended against surveillance. In summary, even with our approach designed to capture preference-driven treatment choices, we found that patients rarely received atypical treatments due to personal preferences, again, suggesting that it was rare for patient preferences to "trump" medical factors.

Discussion

In our study of low and intermediate risk prostate cancer, patients' preferences did not discernibly influence the treatments they received. Patients' anxiety about cancer, which might influence them to actively treat their cancers, did not predict receipt of active treatment. Patients' interest in remaining sexually active, which might influence them to choose surveillance, did not predict receipt of this treatment. Instead, patients' treatment decisions were primarily determined by their urologists' recommendations, which, in turn, were driven by clinical factors (i.e., age and Gleason score) and not patients' preferences.

Are such recommendations justified? Answering this question requires us to determine whether such recommendations rely solely upon medical facts – whereby no reasonable patient would go against the recommendation – or sometimes reflect value judgments about how to weigh treatment tradeoffs.²¹ The pattern of recommendations observed in this study demonstrates that urologists' recommendations were neither haphazard nor arbitrary, but instead often reflect urologists' careful efforts to weigh patients' prognoses. Research has shown that age and Gleason score strongly predict biochemical recurrence-free survival.²² This is consistent with the very different recommendations urologists made based on patient age and Gleason score. This pattern of recommendations reveals urologists' efforts to guide patients toward the best alternative, given their medical situation.

But do patient age and Gleason score, alone, necessarily point towards the "best" choice for all men? Or could it be reasonable for a man with a 15-year life expectancy and a Gleason 7 tumor to pursue a strategy of active surveillance rather than proceed immediately to an active treatment like surgery or radiation? Shared decision making experts have argued that

treatment for patients like this should be influenced by patient preferences.²³ In fact, some experts have even questioned whether physician recommendations are compatible with shared decision making.²⁴ Physicians have been shown to recommend different treatments to patients than they would choose for themselves,²⁵ and rates of active surveillance have been shown to vary dramatically depending on which physician a patient sees, raising questions about whether such recommendations incorporate hidden value judgments.^{26,27} Because recommendations are potentially so influential, shared decision making experts have argued that in the context of preference-sensitive decisions, such recommendations should incorporate, or at least be informed by, patient values – by the specific attitudes patients have towards treatment-relevant outcomes.

Unfortunately, there was little evidence that discussion of such values informed urologists' recommendations in this study. Specifically, patients' initial treatment preferences – which admittedly were uninformed by their cancer diagnoses – did not predict which treatment patients received. In addition, urologists' rarely discussed patients' preferences regarding sexual function, which suggests that urologists' recommendations did not reflect important patient preferences. Furthermore, qualitative analyses of the clinical interactions – both our initial analyses and our in-depth analyses of patients receiving atypical treatments – revealed little evidence of urologists eliciting patient preferences before making treatment recommendations.

Our findings highlight the tension physicians may experience between making medicallybased treatment recommendations versus participating in shared decision making. In shared decision making, physicians make efforts to inform patients about the pros and cons of their healthcare alternatives. As we have published previously, most urologists in this study did a very thorough job of informing patients about all three treatment alternatives.²⁸ However, in shared decision making, physicians also must partner with patients to determine which healthcare interventions best promote patients' specific goals and preferences. Such shared decision making is compatible with physicians giving patients treatment recommendations. But these recommendations should be informed by explicit discussion of patient preferences. When physicians provide treatment recommendations without eliciting patient preferences, they are not fully engaging in shared decision making.

A second tension reflects the fundamental nature of professional guidelines in this evolving field. The AUA Guidelines endorse shared decision making, but guidelines released by National Comprehensive Cancer Network (NCCN) in 2012 suggest that urologists' recommendations should largely rely upon medical judgments.²⁹ In fact, the 2012 NCCN guidelines do not list active surveillance as a viable treatment alternative for men with Gleason 7 cancers who have a life expectancy of greater than ten years, very close to the recommendation patterns found in our study. This guideline presumably reflects the belief that over a long period of time, such tumors will progress and early treatment will thereby increase survival. Indeed, this belief was recently supported by the results of a large randomized trial comparing radical prostatectomy and watchful waiting in early prostate cancer.³⁰ The study revealed an 11% absolute reduction in mortality among men receiving prostatectomy, a treatment effect that was largest in younger men with intermediate risk cancers, the group most likely to receive recommendations for active treatment in our study.

However, several factors raise questions about the relevance of this trial for the patients in our study. First, the trial had not yet been published at the time we conducted the study. Second, the trial compared watchful waiting to prostatectomy. It is still not known whether active treatment would decrease mortality compared to active surveillance, the treatment patients received in our study. In addition, another randomized trial (the PIVOT study), published at the end of our data collection period, did not reveal a survival benefit for active treatment in a population of patients whose cancers were mainly diagnosed through routine PSA screening, the reason many of the patients in our study received prostate biopsies.³¹ In short, the survival benefits of active treatment are still controversial, particularly during the time of our study, potentially creating even more justification for engaging in shared decision making among these patients.

Our study has several limitations in terms of interpreting our results. First, and perhaps most importantly, we acknowledge that our operationalization of "patient preferences" has limitations and is only one way in which to study this important problem. Although we examine the relationship between patient preferences and treatment decisions using multiple methods, increasing the likelihood that our results represent "true" findings, future research using different conceptualizations of patient preferences is needed to better understand this important clinical situation. Second, due to data and feasibility constraints, we did not include all possible preference-related categories (e.g., concern about urinary incontinence), and therefore we may not have captured the inclusion of these preferences into urologists' recommendations. Of note, however, our initial exploratory qualitative analysis revealed very few (if any) discussions of these other preference-related topics during conversations. In addition, our analytic approach would not have captured urologists' incorporation of patients' preferences for radiation versus surgery (e.g., effect of treatment on ability to work). Third, we also did not collect data on other meaningful clinical variables that could inform urologist recommendations, such as prostatic volume. However, including this information would likely strengthen (rather than undermine) our primary conclusion.

Fourth, we dichotomized treatments into active surveillance and active treatment, even though active treatment includes both surgical and radiation therapies. We dichotomized the treatments because such dichotomization reflects the main decision-related tradeoffs, between living with untreated cancer or experiencing treatment-related side effects. That said, we repeated our analyses after breaking down initial treatment preference and treatment received into active surveillance, surgery, and radiation, and all our major findings held. Fifth, as stated previously, patients with Gleason 7 (vs. 6) tumors were more likely to be missing treatment received data. Although important to note, we believe that knowing the treatment received for more patients with Gleason 7 tumors would likely strengthen, rather than undermine, our results given that urologists often were more forceful in their recommendations for men with Gleason 7 tumors. Sixth, it is possible that some patients received surgery or radiation at a site outside of the VA and thus were inadvertently classified as receiving active surveillance. However, patient treatment decisions in our study are comparable to other studies of initial treatment decisions. Seventh, we did not assess urologists' views of the role of shared decision making in early stage prostate cancer; thus, our results may have reflected urologists' belief that their primary job was to make

recommendations consistent with current medical best practice as they understood it. Future studies are needed to examine urologists' beliefs about the shared decision-making process.

Our study also had limitations in terms of generalizability of results. First, it took place in four geographically diverse Veterans Affairs Medical Centers; it did not include a representative sample of either patients or urologists. Additional studies are needed to examine whether our results would generalize across other populations, particularly because patients in the VA are, on average, older, sicker, and poorer than the general population.³² Second, our study provided all patients with decision aids, which is not routine practice. Nevertheless, the use of decision aids in our study makes our results even more notable, given that such decision aids are designed to maximize the role of patient preferences in healthcare decisions. Third, the majority of urologists would have communicated differently about these treatment decisions, although residents are, in general, influenced by their attending physicians.³³ In addition, the majority of urologists were male; given the differences in communication styles between male and female physicians,³⁴ we cannot determine whether our results would have been different with a higher percentage of female urologists.

In conclusion, patients' treatment choices in our study were determined largely by urologists' recommendations, which, in turn, were influenced by medical factors and not patient preferences. It appears that the urologists in our study made medical assessments of whether patients were good candidates for active treatment versus surveillance, rather than assessments based both upon the medical evidence and patient preferences.

Acknowledgments

The authors thank the following individuals for their help with coding: Natalie Atyeo, Haley Miller, Margaret Oliver, Elizabeth Reiser, and Margot Zarin-Pass. The authors thank Michael Barry and several anonymous reviewers for comments on an earlier version of this paper.

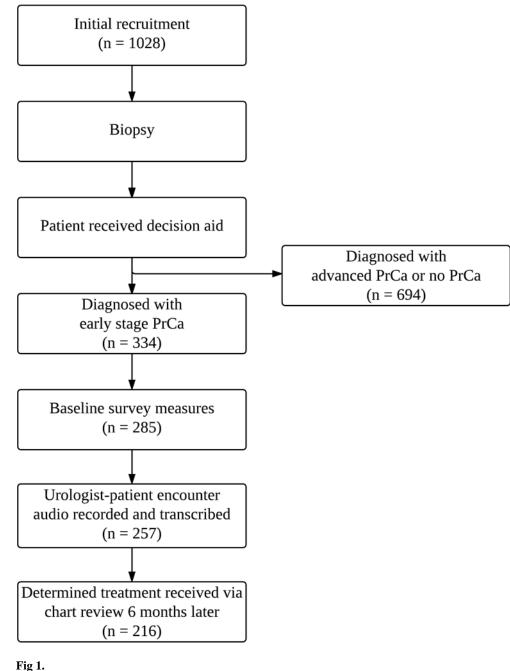
Financial support for this study was provided in part by the following institutions: an IIR Merit Award from U.S. Department of Veterans Affairs (IIR 05-283) to Angela Fagerlin, a grant to Margaret Holmes-Rovner from the Agency for Healthcare Research and Quality (R03 HS021764), a Health Policy Investigator Award from the Robert Wood Johnson foundation to Peter A. Ubel, and Federal Grant T32 GM007171 to Karen A. Scherr as part of the Medical Scientist Training Program. The decision aids used in the study were provided free of charge by the producers of the tools (Michigan Cancer Consortium provided the plain language decision aid and the American Cancer Society provided the higher literacy decision aid). However, neither organization nor the VA had any input in the design or implementation of the study. All funding agreements ensured the authors' independence in designing the study, interpreting the data, and publishing the results.

References

- 1. Keirns C, Goold SD. Patient-Centered Care and Preference-Sensitive Decision Making. The Journal of the American Medical Association. 2009; 302(16)
- Sidana A, Hernandez D, Feng Z, Partin A, Trock B, Saha S, Epsteing J. Treatment decision-making for localized prostate cancer: What younger men choose and why. The Prostate. 2012; 72(1):58–64. [PubMed: 21520163]
- Johansson E, Steineck G, Holmberg L, Johansson JE, Nyberg T, Ruutu M, Bill-Axelson A. Longterm quality-of-life outcomes after radical prostatectomy or watchful waiting: the Scandinavian Prostate Cancer Group-4 randomised trial. The Lancet Oncology. 2011; 12(9):891–899. [PubMed: 21821474]

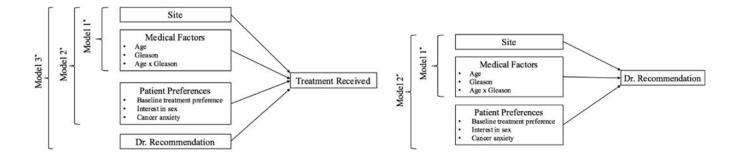
- 4. Thompson, I., Thrasher, J., Aus, G., Burnett, A., Canby-Hagino, E., Cookson, M., D'Amico, A., Dmochowski, R., Eton, D., Forman, J., et al. Guideline for the Management of Clinically Localized Prostate Cancer. American Urological Association; 2007.
- 5. Barry M, Edgman-Levitan P. Shared Decision Making The Pinnacle of Patient-Centered Care. The New England Journal of Medicine. 2012; 366:780–781. [PubMed: 22375967]
- 6. Mulley A, Trimble C, Elwyn G. Stop the silent misdiagnosis: patients' preferences matter. BMJ. 2012; 345:1–6.
- Davison B, Breckon E. Factors influencing treatment decision making and information preferences of prostate cancer patients on active surveillance. Patient Educ Couns. 2012; 3:369–374.
- Gwede C, Pow-Sang J, Seigne J, Heysek R, Helal M, Shade K, Cantor A, Jacobsen PB. Treatment decision-making strategies and influences in patients with localized prostate carcinoma. Cancer. 2005; 104(7):1381–90. [PubMed: 16080181]
- Hall J, Boyd J, Lippert M, Theodorescu D. Why patients choose prostatectomy or brachytherapy for localized prostate cancer: results of a descriptive survey. Urology. 2003; 61(2):402–407. [PubMed: 12597956]
- Steginga S, Occhipinti S, Gardiner R, Yaxley J, Heathcote P. Prospective study of men's psychological and decision-related adjustment after treatment for localized prostate cancer. Urology. 2004; 63:751–756. [PubMed: 15072894]
- Song L, Chen R, Bensen J, Knafl GJ, Nielsen ME, Farnan L, Wallen EM, Mishel M, Pruthi RS, Mohler JL, et al. Who makes the decision regarding the treatment of clinically localized prostate cancer-the patient or physician? Cancer. 2013; 119(2):421–8. [PubMed: 22786794]
- Diefenbach M, Dorsey J, Uzzo R, Hanks G, Greenberg R, Horwitz E, Newton F, Engstrom P. Decision-making strategies for patients with localized prostate cancer. Semin Urol Oncol. 2002; 20:55–62. [PubMed: 11828358]
- Berry D, Ellis W, Woods N, Schwien C, Mullen K, Yang C. Treatment decision-making by men with localized prostate cancer: the influence of personal factors. Urol Oncol. 2003; 21:93–100. [PubMed: 12856636]
- Veterans Affairs Office of Research and Development. ClinicalTrials.gov [Internet]. Bethesda (MD): National Library of Medicine (US); 2000. [cited 2016 Jun 16]. Available from: http:// clinicaltrials.gov/show/NCT00432601 NLM Identifier: NCT00432601
- Roth AJ, Rosenfeld B, Kornblith AB, Gibson C, Scher HI, Curley-Smart T, Holland JC, Breitbart W. The memorial anxiety scale for prostate cancer: Validation of a new scale to measure anxiety in men with with prostate cancer. Cancer. 2003; 97(11):2910–2918. [PubMed: 12767107]
- 16. Scherr KA, Fagerlin A, Williamson LD, Davis JK, Fridman I, Atyeo N, Ubel PA. The Physician Recommendation Coding System (PhyReCS): A Reliable and Valid Method to Quantify the Strength of Physician Recommendations During Clinical Encounters. Medical Decision Making. 2016 Forthcoming.
- Hsieh H, Shannon S. Three approaches to qualitative content analysis. Qual Health Res. 2005; 15(9):1277–1288. [PubMed: 16204405]
- Williams RL. A note on robust variance estimation for cluster-correlated data. Biometrics. 2000; 56:645–646. [PubMed: 10877330]
- Long, JS. Regression models for categorical dependent variables using Stata. College Station TX: Stata Press; 2014.
- StataCorp. Structural Equation Modeling Reference Manual. College Station TX: Stata Press; 2013.
- Ubel PA. Medical Facts versus Value Judgments Toward Preference-Sensitive Guidelines. N Engl J Med. 2015; 372(26)
- Pierorazio P, Walsh P, Partin A, Epstein J. Prognostic Gleason grade grouping: data based on the modified Gleason schoring system. BJU International. 2013; 111(5):753–760. [PubMed: 23464824]
- Sommers B, Beard C, D'Amico A, Dahl D, Kaplan I, Richie J, Zeckhauser R. Decision analysis using individual patient preferences to determine optimal treatment for localized prostate cancer. Cancer. 2007; 110(10):2210–2217. [PubMed: 17893907]

- 24. Frongillo M, Feibelmann S, Belkora J, Lee C, Sepucha K. Is there shared decision making when the provider makes a recommendation? Patient Education and Counseling. 2013; 90(1):69–73. [PubMed: 22999786]
- Ubel PA, Angott AM, Zikmund-Fisher BJ. Physicians Recommend Different Treatments for Patients Than They Would Choose for Themselves. Arch Intern Med. 2011; 171(7):630–634. [PubMed: 21482835]
- 26. Ubel, PA. Critical Decisions. New York: Harper Collins; 2012.
- Hoffman KE, N J, Shen Y, Jiang J, Davis JW, Kim J, Kuban DA, Perkins GH, Shah JB, Smith GL, Volk RJ, Buchholz TA, Giordano SH, Smith BD. Physician Variation in Management of Low-Risk Prostate Cancer. JAMA Internal Medicine. 2014; 174(9):1450–59. [PubMed: 25023650]
- Holmes-Rovner M, Montgomery J, Rovner D, Scherer L, Whitfield J, Kahn V, Merkle E, Ubel P, Fagerlin A. Informed Decision Making: Assessment of the Quality of Physician Communication about Prostate Cancer Diagnosis and Treatment. Medical Decision Making. 2015; 35(8):999– 1009. [PubMed: 26304063]
- 29. National Comprehensive Cancer Network and American Cancer Society. Prostate Cancer: Treatment Guidelines for Patients. 2007
- 30. Bill-Axelson A, Holmberg L, Garmo H, Rider J, Taari K, Busch C, Nordling S, Haggman M, Andersson SO, Spangberg A, et al. Radical Prostatectomy or Watchful Waiting in Early Prostate Cancer. The New England Journal of Medicine. 2014; 370:932–942. [PubMed: 24597866]
- Wilt T, Brawer M, Jones K, Barry M, Aronson W, Fox S, Gingrich J, Wei J, Gilhooly P, Grob M, et al. Radical Prostatectomy versus Observation for Localized Prostate Cancer. The New England Journal of Medicine. 2012; 367:203–213. [PubMed: 22808955]
- Oliver A. The Veterans Health Administration: an American success story? Milbank Q. 2007; 85(1):5–35. [PubMed: 17319805]
- Feldman L, Skeel-Williams K, Knox M, Coates J. Influencing controlled substance prescribing: Attending and resident physician use of a state prescription monitoring program. Pain Medicine. 2012; 13:908–914. [PubMed: 22681237]
- Roter D, Hall J. Physician gender and patient-centered communication: a critical review of empirical research. Annu Rev Public Health. 2004; 25:497–519. [PubMed: 15015932]



Study Flow. PrCa = prostate cancer.

Scherr et al.



*Decision Aid included as a covariate

Fig 2.

Hierarchical logistic regressions predicting treatment received (left) and doctor recommendation (right). Dr. = Doctor.

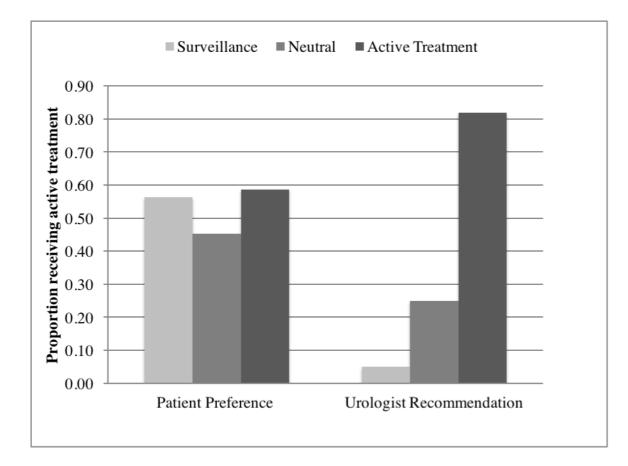


Fig 3.

Proportion of patients who received active treatment (vs. surveillance) as a function of patient initial treatment preference (surveillance vs. neutral vs. active treatment) and urologist recommendation (surveillance vs. neutral vs. active treatment). Recall that patients' initial treatment preferences were assessed before they received their cancer diagnosis and met with their urologists.

Scherr et al.

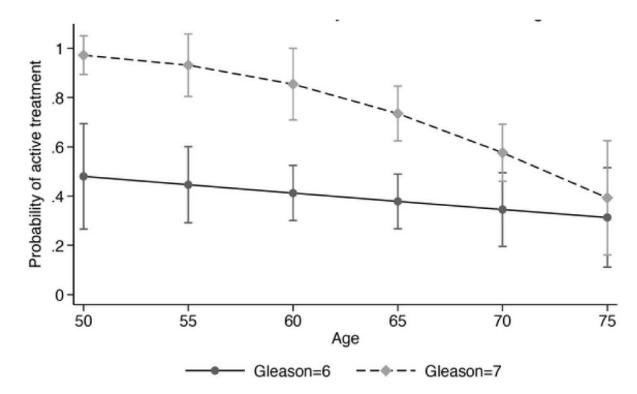


Fig. 4.

Modeled predicted probability that patients received active treatment as a function of age and Gleason score. Estimates averaged across all other factors in Model (site, decision aid, initial treatment preference, interest in sex, cancer anxiety, and urologist recommendation). Error bars indicate 95% Confidence Intervals.

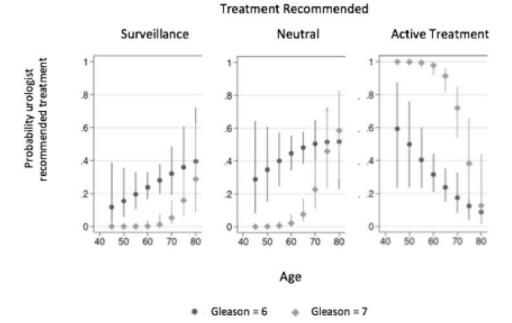
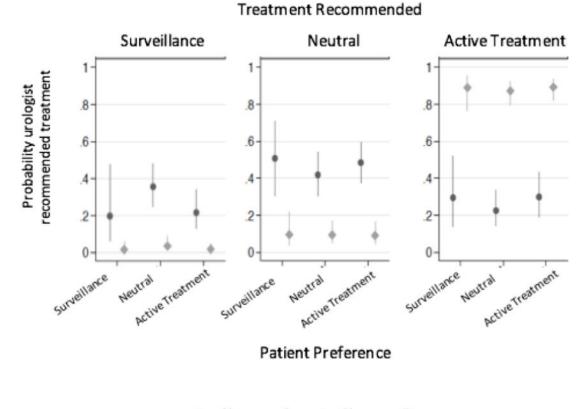


Fig 5.

Marginal predicted probability urologist recommended each treatment (Surveillance, Neutral, and Active Treatment) as a function patient age and Gleason score (6 vs. 7). Estimates averaged across all other factors in Model (site, decision aid, initial treatment preference, interest in sex, and cancer anxiety). Error bars represent 95% confidence intervals.



Gleason = 6 Gleason = 7

Fig 6.

Marginal predicted probability urologist recommended each treatment (Surveillance, Neutral, and Active Treatment) as a function of patient initial treatment preference (Surveillance vs. Neutral vs. Active Treatment) and Gleason Score (6 vs. 7). Recall that patients' initial treatment preferences were assessed before they received their cancer diagnosis and met with their urologists. Estimates averaged over site, decision aid, age, cancer anxiety, and interest in sex. Error bars represent 95% confidence intervals.

Table 1

Urologists' discussion of sex during appointments

Торіс	Frequency (% of appointments)	Exemplar
Assessment of baseline erectile function and sexual activity	67	Dr: How are your erections right now? Pt: Hmm, that's not, so-so Dr: Are you sexually active? Pt: A little bit I don't know
Assessment of importance of sex to patient	12	Dr: So it seems like right now your biggest concern is your erectile function. Is that? Pt: I mean, I mean, yeah!
Discussed relationship between interest in sex and treatment choice	13	Dr: So your erections, when we do either treatment are going to take a hit, they're going to be worse than they are now. Whether or not that is a bother for you, is something that only you can decide.

Note. N = 257. Dr. = urologist. Pt = patient

_

_

Table 2

Adjusted Odds Ratios for factors predicting whether patient received active treatment (vs. active surveillance).

Predictor	Model 1	Model 2	Model 3
Site ^a			
Site 2	1.41 [0.64,3.10]	1.41 [0.64,3.10]	1.56 [0.70,3.48]
Site 3	0.53 [0.19,1.52]	0.41 [0.15,1.16]	0.36 [*] [0.15,0.89]
Site 4	0.46 [0.19,1.12]	0.55 [0.20,1.49]	0.67 [0.23,1.91]
Decision aid ^b	1.16 [0.51,2.63]	1.08 [0.45,2.56]	1.30 [0.49,3.44]
Gleason ^C	23.41 *** [11.82,46.37]	25.25 *** [12.18,52.37]	9.03 ^{***} [3.74,21.79]
Age	0.93 [0.86,1.01]	0.95 [0.87,1.03]	0.96 [0.88,1.05]
$Gleason \times Age$	0.85 [*] [0.72,1.00]	0.82 [*] [0.69,0.98]	0.84 [0.70,1.01]
Interest in sex^d		0.83 [0.57,1.21]	0.85 [0.54,1.32]
Cancer anxiety d		1.37 [0.95,1.97]	1.41 [0.89,2.21]
Pt tx preference ^{e}			
Active surveillance		0.82 [0.24,2.82]	0.53 [0.14,2.03]
Active treatment		1.54 [0.66,3.59]	1.06 [0.39,2.91]
Dr recommendation ^e			
Active surveillance			0.23 [*] [0.05,0.98]
Active treatment			6.28 ^{**} [2.09,18.92]

Note. Adjusted odds ratios indicate the change in odds that a patient received active treatment (vs. active surveillance) with a one unit change in the predictor, controlling for all other predictors in the model. 95% Confidence Intervals are in parentheses.

Pt = patient. Tx = treatment. Dr = urologist.

^{*a*}Reference group = site 1.

bReference group = standard decision aid.

^{*C*}Reference group = Gleason 6.

^dMeasures are standardized.

^eReference group = neutral

* p < .05.

** * p < .01.

*** p < .001.

Table 3

Urologists' recommendations compared to patients' initial treatment preferences and their Gleason scores.

	Urologist Recommendation			
	Active Surveillance	Neutral	Active Treatment	
Initial treatment preference				
Active Surveillance	2	11	28	
Neutral	22	24	44	
Active Treatment	14	35	72	
Gleason score				
6	34	57	34	
7	4	13	110	

Note. Recall that patients' initial treatment preferences were assessed before they received their cancer diagnoses and met with their urologists.