Published in final edited form as:

Urology. 2018 May ; 115: 133–138. doi:10.1016/j.urology.2018.01.048.

Which patients report that their urologists advised them to forgo initial treatment for prostate cancer?

Archana Radhakrishnan, MD, MHS¹, David Grande, MD, MPA², Nandita Mitra, PhD³, and Craig Evan Pollack, MD, MHS^{4,5}

¹Division of General Medicine, University of Michigan, Ann Arbor, MI

²Division of General Internal Medicine, University of Pennsylvania, Philadelphia, PA

³Department of Biostatistics, Epidemiology and Informatics, University of Pennsylvania, Philadelphia, PA

⁴Division of General Internal Medicine, Johns Hopkins University, Baltimore, MD

⁵Johns Hopkins Bloomberg School of Public Health, Baltimore, MD

Abstract

Objective—To examine how frequently patients report that their urologist recommended they not have definitive treatment and assess the impact of these recommendations on treatment choice and perceived quality of cancer care.

Methods—We mailed surveys to men newly diagnosed with localized prostate cancer between 2014–2015 (adjusted response rate 51.3%). Men reported whether their urologist recommended forgoing definitive treatment. Using logistic regression models, we assessed patient-level predictors of receiving a recommendation to forgo definitive treatment and estimated associations of receiving this recommendation with receipt of definitive treatment and perceived quality of cancer care among men with low-risk tumors and limited life expectancies.

Results—Nearly two-thirds (62.2%) of men with low-risk tumors and 45.6% with limited life expectancies received recommendations from their urologists to forgo definitive treatment. Among men with limited life expectancies, those with low-risk tumors were more likely to receive this recommendation compared to men with high-risk tumors (Odds Ratio 3.43; 95% Confidence Interval 2.17–5.42). Men with low-risk tumors who were recommended to forgo definitive treatment were less likely to receive definitive treatment (OR 0.48; 95% CI 0.32–0.73) but did not report lower perceived quality of care (OR 0.97; 95% CI 0.63–1.48).

Conclusions—In this population-based study, a majority of men with low-risk prostate cancer report receiving recommendations from their urologists to forgo definitive treatment. Our results suggest that urologists have a strong influence on patient treatment choice and could increase

Corresponding author: Archana Radhakrishnan, MD, MHS, University of Michigan, Division of General Medicine, 2800 Plymouth Road, NCRC Bldg 16, 471C, Ann Arbor, MI 48109-2800.

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active surveillance uptake in men eligible for expectant management without patient's perceiving lower quality of cancer care.

Keywords

prostatic neoplasms; urologists; therapy; quality of care

INTRODUCTION

In the United States, an estimated 161,360 men will be newly diagnosed with prostate cancer in 2017.¹ Nearly eighty percent of prostate cancer is diagnosed at the localized stage for which treatment ranges from definitive therapy (surgery or radiation) to expectant management (active surveillance (AS) or watchful waiting). Men with favorable-risk disease and limited life expectancies may be particularly well suited for expectant management given their low risk of dying from their prostate cancer.^{2,3} Guidelines have evolved to recommending AS as the preferred treatment strategy for men with favorable-risk disease^{4,5} and the use of expectant management has increased over the past five years in men with low-risk prostate cancer to upwards of 40%.^{6,7} However, there remains room for improvement in increasing uptake of expectant management—in Swedish cohorts, nearly three-quarters of men with low-risk tumors are in AS⁸—and further research is needed to ascertain which patients are recommended for expectant management, and the subsequent impact of these recommendations on patient treatment choices and experiences in cancer care.

Patient enrollment in AS may, in large part, be driven by recommendations they receive from their cancer specialists. In a national survey of urologists and radiation oncologists, 72% believed that AS was effective for low-risk prostate cancer and 80% believed it to be underused. However, only 22% recommended AS to their patients with 71% believing that their patients were likely not interested in AS.⁹ This discordance may be due to specialists responding to patient expectations for treatment; some patients perceive definitive treatment as more efficacious¹⁰ and fear the consequences of delaying treatment.¹¹ Specialists' behaviors may further be reinforced by concern for patient satisfaction with care. As quality metrics are increasingly being utilized to rate physician performance, specialists may feel pressured to provide care concordant with patient preferences to ensure patient satisfaction.

In this study, we draw upon a large cohort of men with localized prostate cancer to assess the frequency of recommendations by urologists for forgoing definitive treatment, focusing on men with low-risk disease and men with limited life expectancies. We further evaluate whether a urologist's recommendation for forgoing definitive treatment is associated with patient treatment choice and lower perceived quality of care. We hypothesize that a urologist's recommendation to forgo definitive treatment is associated with a higher likelihood of patients choosing expectant management. We further hypothesize that patients who receive recommendations to forgo definitive treatment will not perceive lower quality of care, regardless of the treatment they ultimately receive. This hypothesis stands in contrast to physicians' expectations that their patients are not interested in expectant management but in line with prior studies reporting high decision satisfaction and minimal decisional regret for patients who elect AS.^{12,13}

MATERIALS AND METHODS

Data for this study were obtained from the Philadelphia Area Prostate Cancer Access Study (P² Access). This study was approved by the institutional review boards at Johns Hopkins University and University of Pennsylvania.

Study design and population

Using the Pennsylvania Cancer Registry (PCR), we identified white and black men with newly diagnosed localized prostate cancer between January 1, 2012 and December 31, 2014 (Hispanic and other race/ethnicity excluded, n=70). Men were residents of the Greater Philadelphia region (Berks, Chester, Delaware, Lancaster, Lehigh, Montgomery and Philadelphia counties) and were excluded if they had military insurance (n=8) or received chemotherapy (n=4).

Men were mailed surveys between June 2014 and August 2015. The first mailing included an unconditional \$2 incentive and all non-responders received up to two additional mailings. Responders received \$15 upon completion of the survey.

Urologists' recommendations

To assess whether urologists recommended forgoing definitive treatment, men were asked "Some people with prostate cancer decide NOT to use medicines, radiation, or surgery to treat their cancer unless the cancer shows signs of growing. Was this suggested to you by your urologist?" This question was formulated based on pilot testing with men with localized prostate cancer (n=10). Though we hoped that iterations which specifically asked about 'active surveillance' or 'watchful waiting' would lead to increased precision of the measure, multiple patients reported low comprehension of these terms. Our measure of forgoing definitive treatment, therefore, encompasses formal active surveillance to watchful waiting.

Receipt of definitive treatment

We used PCR data to determine whether men received definitive treatment, defined as radical prostatectomy or radiation therapy (external beam radiotherapy or seed brachytherapy).

Patient-reported quality of care

We adapted our question to assess patient-reported quality of care from items used in the Consumer Assessment of Healthcare Providers and Systems and from prior research on patients' experiences with health care.^{14,15} Men were asked to rate the quality of health care for their prostate cancer on a 1 (poor) to 5 (excellent) scale. Responses were dichotomized as excellent or less than excellent given the minimal variation in responses for less than excellent quality of care.

Patient characteristics

We used survey responses to obtain patient age, race/ethnicity, education, employment and insurance at the time of diagnosis, and marital status. Life expectancy was estimated using a

validated 10-year mortality index based on patient self-reported age, body mass index, medical comorbidities, and functional status.¹⁶

Tumor data were obtained from the cancer registry. We abstracted Gleason scores, prostate specific antigen results, and clinical tumor stage and created risk categories based on National Comprehensive Cancer Network (NCCN) criteria classified as low, intermediate and high risk.¹⁷

Statistical Analysis

We summarized responder sociodemographic and clinical characteristics. Given guidelines recommend AS as the primary treatment strategy for men with favorable-risk disease and limited life expectancies^{4,5}, we performed the remainder of our analyses on two subgroups of men: men with (1) NCCN low-risk tumors, and (2) limited life expectancies (10-year risk of mortality $\geq 50\%$). Analyses were conducted separately for each subgroup of men.

First, using chi-squared tests, we compared characteristics between patients whose urologists did and did not recommend forgoing definitive treatment. We used multivariable logistic regression models to identify the association of sociodemographic (age, race/ethnicity, education, employment, marital status, and insurance) and clinical (10-year risk of mortality, NCCN risk) characteristics with receiving a recommendation from a urologist to forgo definitive treatment.

Second, we examined the association between a urologist's recommendation to forgo definitive treatment and (1) receipt of definitive treatment and (2) perceived quality of prostate cancer care using multivariable logistic regression models. The outcome was receipt of definitive treatment or quality of care and the independent variable was a urologist's recommendation to forgo definitive treatment. We adjusted for sociodemographic and clinical characteristics in each of these models. Additionally, for models examining quality of care, we adjusted for receipt of definitive treatment.

We used multiple imputation to account for missing data using multiple chained equations based on all available patient sociodemographic and clinical characteristics, using twenty imputed datasets. All tests were two-sided with significance level set at 0.05. Analyses were conducted using STATA 13.0 (College Station, TX).

RESULTS

Our adjusted response rate was 51.3% (2386/4672). Compared to responders, non-responders were more likely to be black (30.2% vs. 16.4%) and to have not received definitive treatment (24.8% vs. 16.5%). On average, men in our cohort were 65 years old, 80.7% were white and 62.7% had some level of college education or higher. Slightly over a quarter of men (28.3%, N=651) had low-risk disease and nearly 35% of men had limited life expectancies (10-year risk of mortality $\geq 50\%$, N=781).

Urologists' recommendations

Nearly two-thirds of men with low-risk tumors (62.2%) and 45.6% of men with limited life expectancies received a recommendation from their urologist to forgo definitive treatment.

Among men with low-risk tumors, in unadjusted analyses, there was significant variation in receiving a recommendation from a urologist to forgo definitive treatment based on life expectancy though this association did not persist in adjusted models (Table 1).

Of the men with limited life expectancies, in unadjusted analyses, men with lower levels of education (53.0% high school graduates or less and 53.5% with some college) were more likely to receive recommendations from urologists to forgo definitive treatment compared to men with higher levels (40.7% for college graduates and 44.0% for those with more than college) (Table 2). Men with low-risk tumors (63.6%) were more likely to receive a recommendation from their urologist compared to men with high-risk tumors (38.7%). In adjusted analyses, significant variation remained based on tumor risk; men with low-risk tumors were more likely (OR 3.42; 95% Confidence Interval 2.17–5.42) to be recommended to forgo definitive treatment by their urologist compared to men with high-risk tumors.

Receipt of definitive treatment

For men with low-risk tumors, 71.3% of men had either surgery or radiation therapy to treat their prostate cancer. This included 82.3% of men who received a recommendation from their urologist to forgo definitive treatment and 67.7% of men who did not. In adjusted models, men who were recommended to forgo definitive treatment by a urologist were less likely to receive definitive treatment (OR 0.48; 95% CI 0.32–0.73). Over three-quarters (77.9%) of men with limited life expectancies had definitive treatment, however, in adjusted models, there were no significant differences in the odds to receive definitive treatment based on whether urologists recommended men to forgo definitive treatment or not (OR 0.81; 95% CI 0.54–1.20).

Patient-reported quality of care

The majority of men reported their quality of prostate cancer care to be excellent including 77.6% of men with low-risk tumors and 73.7% of men with limited life expectancies. Receiving recommendations from their urologists to forgo definitive treatment was not associated with lower quality of care, both among men with low-risk tumors (OR 0.97; 95% CI 0.63–1.48) and men with limited life expectancies (OR 0.93; 95% CI 0.66–1.32).

DISCUSSION

In the setting of a recent increase in the use of active surveillance in men with localized prostate cancer, we found that nearly two thirds of men with low-risk disease and nearly half with limited life expectancies report receiving a recommendation from their urologist to forgo definitive treatment. Among men with low-risk disease, receiving this recommendation was associated with lower rates of definitive treatment. Though many men ultimately opted for definitive treatment, receiving a recommendation to forgo treatment was not associated with men perceiving their quality of care to be lower. Our results reinforce the

importance of urologists' recommendations on patient treatment choice and the potential for urologists to increase AS uptake in men eligible for expectant management.

Urologists were more likely to recommend forgoing definitive treatment to men based on tumor risk rather than life expectancy. Urologists may perceive tumor biology to be more conclusive than patient-level characteristics to determine treatment, and therefore, may feel more comfortable recommending AS based on tumor risk. In a qualitative study which examined physician decision-making around active surveillance, reassuring data on long-term prostate cancer mortality outcomes for patients with favorable-risk disease was reported as key in physicians feeling comfortable recommending AS.¹⁸ On the other hand, urologists may find it challenging to make recommendations based on life expectancy. Similar to other clinical contexts, predicting life expectancy and long-term prognosis can be viewed with uncertainty and skepticism, and urologists may be uncomfortable applying it in their clinical practice.^{19,20} In fact, prior research shows that among patients with very limited life expectancies, physicians tend to be overly optimistic in their treatment discussions.²¹ Additionally, urologists may be concerned with patients' reactions, not wanting to seem as 'giving up' on the patient.^{20,22}

Men who had low-risk disease were more likely to follow their urologist's recommendation to forgo definitive treatment. However, in those men with limited life expectancy, urologists' recommendations did not lead to *not* receiving definitive treatment. There may be multiple possible explanations for this. First, guidelines recommend against routing PSA screening in men with limited life expectancies. It is possible that men in our study represent a selected group of activated patients who were not only more likely to undergo PSA screening and more likely to receive treatment. For some, it will be critical to look at 'upstream' factors influencing decisions around PSA screening and biopsies. Second, similar to urologists, patients may view characteristics of their disease as paramount in their decision-making. Third, it is unknown whether and to what extent urologists may have framed treatment discussions around life expectancy and thus whether and to what extent patients considered life expectancy and its components (age, comorbidity, and functional status) when deciding on treatment. Fourth, even if life expectancy were raised, patients may be reluctant to consider this information. Similar to physicians, patients may not believe that life expectancy can be accurately estimated. Older patients reported wanting to continue cancer screening even with limited life expectancy because of their doubt in physicians' life expectancy predictions.²³ Related to this, previous work has shown that many patients have an unrealistic sense of their mortality, tending to overestimate their survival which then influences their decision to choose active treatment.²⁴ Tools that help clinicians and patients accurately estimate and understand life expectancy are critical towards the appropriate application of life expectancy in treatment decision-making. Recognizing the difficulties in having discussions incorporating life expectancy, facilitating improved communication between patients and physicians about its potential importance are needed to promote shared treatment decision-making.²⁵

It is reassuring that men who were recommended to forgo definitive treatment in our cohort did not perceive lower quality of cancer care. Patient preferences and expectations drive in part urologists' recommendations for prostate cancer management.^{11,26,27} Patients report

fear and anxiety and desire to treat their cancer rapidly^{26,27} and urologists may be hesitant to recommend a treatment approach that contradicts this view. However, our results suggest that urologists should not be overly concerned with lower satisfaction when considering recommending active surveillance for these men.

Our study has several limitations. First, the majority of men underwent definitive treatment raising concerns that they may not recall discussions about forgoing treatment. However, the high recall rate of men with low-risk disease in our sample who were recommended to forgo treatment argues against this. Further, our rates are within the range of those reported by Davison¹² and Sidana.¹³ Second, we did not specifically ask our responders whether they received recommendations to enroll in ‘active surveillance’ or ‘watchful waiting’ programs, but rather if urologists recommended *forgoing treatment*. This was based on pilot testing designed to improve comprehension of this concept. However, we recognize that forgoing treatment can have a range of different monitoring strategies and approaches that we did not fully capture with our question. Further, our question focused on whether the urologist ‘recommended’ forgoing treatment rather than listing it as one of many management options offered to the patient. While this may lead to us underestimate scenarios where such an approach was discussed, it provides greater specificity towards understanding where the option was likely encouraged by urologists. This has, to our knowledge, not been previously evaluated, especially as active surveillance gains more widespread endorsement for favorable-risk cancer. Third, our measurement for quality of cancer care is based on a single question and may not capture all variables that impact patients’ experiences with their providers. Fourth, data were obtained from a single geographic region which may limit the generalizability of our findings. However, the region includes 5.3 million residents across urban and suburban settings and is racially and ethnically diverse (29% of the area’s population is non-White). Fifth, we do not have detailed enough cancer information to examine men with very low risk cancer, though this would be an important extension of the research. Sixth, we lack detailed information on the characteristics of the treating urologist such as practice setting and academic affiliation, factors which have previously been shown to impact urologists’ recommendations and would be an important next step to examine in this line of research.⁹ Lastly, though we used multiple evidence-based approaches to increase our response rates, our results may be impacted by non-response bias.²⁸ Non-response among black men was higher than white men, which may impact the observed association between race and receipt of recommendations to forgo definitive treatment. In addition, men who received definitive treatment were more likely to respond. With recommendations correlated with treatment men received, it is likely that our estimates of receipt of recommendations to forgo definite treatment reflect lower bounds.

CONCLUSION

When choosing their prostate cancer treatment, patients report high levels of trust in their physician and frequently rely on their physician to help guide their decision making.^{10,29} Our results underscore the importance of urologists’ recommendations, showing that a large proportion of men with low-risk disease received a recommendation to forgo definitive treatment and, consequently, were less likely to receive definitive treatment. However, overall rates of treatment were high among men with limited life expectancies with over

three quarters receiving definitive treatment. To continue and expand efforts to reduce overtreatment of prostate cancer, an important next step is to examine other groups of men who are unlikely to benefit from definitive treatment, such as men with limited life expectancies, and elucidate physician drivers for recommendations for treatment.

Acknowledgments

This work was supported by the National Institute on Minority Health and Health Disparities (P60 MD006900). Dr. Radhakrishnan's salary was supported by the National Heart, Lung, and Blood Institute (T32H1007180). Dr. Pollack's salary is supported by the National Cancer Institute (K07CA151910).

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Table 1

Bivariate and multivariable analyses of patient-level characteristics associated with urologists' recommendations to forgo definitive treatment among men with NCCN low-risk tumors

	Urologist recommended forgoing definitive treatment			
	No (N, %)	Yes (N, %)	P-value	Adjusted Odds Ratio (95% Confidence Interval)*
	207 (31.8%)	405 (62.2%)		
Age				
<60 years	82 (40.6)	120 (59.4)	0.06	Ref
60–64 years	41 (29.1)	100 (70.9)		1.56 (0.95–2.56)
65–69 years	37 (26.6)	102 (73.4)		1.26 (0.62–2.55)
70–74 years	29 (35.8)	52 (64.2)		0.85 (0.36–2.00)
75 years	17 (35.4)	31 (64.6)		1.00 (0.38–2.60)
10-year risk of mortality				
<25%	88 (39.1)	137 (60.9)	0.03	Ref
25–50%	56 (26.8)	153 (73.2)		1.49 (0.83–2.68)
51–75%	36 (21.9)	77 (68.1)		1.45 (0.71–2.96)
>75%	14 (42.4)	19 (57.6)		0.82 (0.32–2.13)
Race				
Non-Hispanic White	174 (33.7)	343 (66.3)	0.76	Ref
Non-Hispanic Black	29 (35.4)	53 (64.3)		1.01 (0.58–1.76)
Education				
High school or less	54 (32.3)	113 (67.7)	0.94	Ref
Some college	38 (30.4)	87 (69.6)		1.04 (0.63–1.70)
College graduate	34 (34.3)	65 (65.7)		0.79 (0.46–1.34)
More than college	56 (32.2)	118 (67.8)		0.85 (0.52–1.38)
Insurance				
Private	149 (36.1)	264 (63.9)	0.07	Ref
Medicare	48 (27.4)	127 (72.6)		1.56 (0.96–2.57)
Other	8 (47.1)	9 (52.9)		0.73 (0.25–2.06)
Employment				
Employed	97 (32.9)	198 (67.1)	0.81	Ref
Retired	60 (30.3)	138 (69.7)		0.85 (0.51–1.42)
Unemployed/ot her	23 (33.3)	46 (12.0)		0.75 (0.39–1.42)
Marital status				
Single	32 (31.4)	70 (68.6)	0.57	Ref
Married	173 (34.3)	331 (65.7)		0.89 (0.54–1.48)

* **Bold** signifies statistically significant associations at $p < 0.05$

Table 2

Bivariate and multivariable analyses of patient-level characteristics associated with urologists' recommendations to forgo definitive treatment among men with limited life expectancies

	Urologist treatment recommended forgoing definitive			
	No (N, %)	Yes (N, %)	P-value	Adjusted Odds Ratio (95% Confidence Interval)*
	350 (48.8%)	318 (44.3%)		
NCCN risk				
High	146 (61.3)	92 (38.7)	<0.001	Ref
Intermediate	190 (54.9)	156 (45.1)		1.37 (0.95–1.96)
Low	63 (35.4)	115 (64.6)		3.41 (2.17–5.37)
Race				
Non-Hispanic White	345 (52.1)	317 (47.9)	0.68	Ref
Non-Hispanic Black	83 (50.3)	82 (49.7)		0.96 (0.63–1.46)
Education				
High school or less	156 (47.0)	176 (53.0)	0.05	Ref
Some college	81 (46.6)	93 (53.5)		0.98 (0.65–1.48)
College graduate	54 (59.3)	37 (40.7)		0.67 (0.40–1.14)
More than college	107 (56.0)	84 (44.0)		0.68 (0.44–1.04)
Insurance				
Private	141 (50.9)	136 (49.1)	0.97	Ref
Medicare	266 (50.5)	261 (49.5)		1.27 (0.90–1.78)
Other	22 (52.4)	20 (47.6)		0.93 (0.45–1.93)
Employment				
Employed	69 (46.3)	80 (53.7)	0.18	Ref
Retired	267 (52.6)	241 (47.4)		0.69 (0.44–1.08)
Unemployed/ot her	57 (44.9)	70 (55.1)		0.75 (0.43–1.31)
Marital status				
Single	95 (46.6)	109 (53.4)	0.21	Ref
Married	331 (51.6)	311 (48.4)		0.89 (0.62–1.27)

* **Bold** signifies statistically significant associations at p<0.05

** Age excluded due to collinearity within the limited life expectancies cohort