

# What Is a “Good” Treatment Decision? Decisional Control, Knowledge, Treatment Decision Making, and Quality of Life in Men with Clinically Localized Prostate Cancer

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**Objective.** We explored whether active patient involvement in decision making and greater patient knowledge are associated with better treatment decision-making experiences and better quality of life (QOL) among men with clinically localized prostate cancer. Localized prostate cancer treatment decision making is an advantageous model for studying patient treatment decision-making dynamics because there are multiple treatment options and a lack of empirical evidence to recommend one over the other; consequently, it is recommended that patients be fully involved in making the decision. **Methods.** Men with newly diagnosed clinically localized prostate cancer (N = 1529) completed measures of decisional control, prostate cancer knowledge, and decision-making experiences (decisional conflict and decision-making satisfaction and difficulty) shortly after they made their treatment decision. Prostate cancer-specific QOL was assessed at 6 months after treatment. **Results.** More active involvement in decision making and greater knowledge were associated with lower

decisional conflict and higher decision-making satisfaction but greater decision-making difficulty. An interaction between decisional control and knowledge revealed that greater knowledge was only associated with greater difficulty for men actively involved in making the decision (67% of sample). Greater knowledge, but not decisional control, predicted better QOL 6 months after treatment. **Conclusions.** Although men who are actively involved in decision making and more knowledgeable may make more informed decisions, they could benefit from decisional support (e.g., decision-making aids, emotional support from providers, strategies for reducing emotional distress) to make the process easier. Men who were more knowledgeable about prostate cancer and treatment side effects at the time that they made their treatment decision may have appraised their QOL as higher because they had realistic expectations about side effects. **Key words:** prostate cancer; detailed methodology: QOL in special populations; patient decision making; cohort studies. (*Med Decis Making* XXXX;XX:xx-xx)

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For most men diagnosed with clinically localized prostate cancer, there are multiple clinically appropriate intervention or management strategies, but they involve tradeoffs between side effects.<sup>1,2</sup> Consequently, there is consensus in the medical, academic, and policy communities that “good” treatment decisions for clinically localized prostate cancer are informed and consistent with patients' preferences and values.<sup>3–6</sup> Good treatment decisions can also be set apart by their outcomes: satisfaction

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with the decision and little or no regret about the choice<sup>6</sup> and, potentially, better psychological well-being in survivorship.<sup>7</sup> To increase the likelihood that treatment decisions are consistent with patient priorities and values, the current standard of care requires physicians, at the very least, to involve patients in collaborative decision making.<sup>8</sup> According to models of shared decision making,<sup>9–11</sup> patients and physicians should collaboratively identify the problem to be solved. Patients should be fully informed about treatment options, benefits and drawbacks, clinical indicators, and recommendations and have opportunities to clarify and communicate preferences to their physicians. There should also be periodic feedback to check understanding on the part of patients and follow up with respect to implementation of the decision.

Beyond the ethical argument for patient involvement in treatment decisions, some, although not all,<sup>12</sup> empirical evidence indicates that patient involvement fosters better treatment decisions.<sup>13</sup> Greater patient participation in treatment decisions has been associated with higher satisfaction with the decision, at least among younger patients with prostate cancer,<sup>14</sup> and higher quality of life (QOL) among survivors of breast cancer.<sup>13</sup> Lack of control over treatment decisions has been associated with more decisional conflict in patients with HIV/AIDS making medication decisions.<sup>15</sup>

The shared decision-making paradigm assumes that patients are knowledgeable about treatment options and potential risks and benefits.<sup>9,16</sup> However, to date, the idea that knowledge improves treatment decision making, especially when patients are actively involved in decision making, has largely been assumed. Kaplan and others<sup>17</sup> studied 70 men, most of whom had a low socioeconomic status, and found that lower knowledge was associated with higher decisional conflict; however, it is unknown whether this would be true of a larger sample that varies with respect to socioeconomic status. In a second sample that included, but was not limited to patients with prostate cancer, patients' knowledge about treatments was not associated with a measure of concordance between values/preferences and treatment choice (decisional dissonance).<sup>3</sup> Shared treatment decision making is becoming institutionalized through policy and practice, and resources are continuing to be allocated for developing decision aids,<sup>18,19</sup> a primary component of which is increasing men's knowledge.<sup>20</sup> A valuable addition to the science and practice of shared decision making would be improving our understanding of the extent to

which knowledge contributes to decision-making experiences and survivorship outcomes, especially among those actively involved in making a treatment decision.

The goal of the present study was to test whether men's control over the treatment decision and level of prostate cancer knowledge were associated with better treatment decision-making experiences and better well-being in survivorship. We hypothesized that patients who exert more control over the decision-making process and are more knowledgeable about prostate cancer and treatment side effects would experience less decisional conflict and be more satisfied with the decision-making process. However, given evidence that many men and their families experience prostate cancer treatment decision making as challenging,<sup>21–23</sup> we predicted that greater engagement in the process, indicated by higher decisional control and knowledge, would be associated with greater decision-making difficulty. It is possible that knowledge has a larger impact on treatment decision making to the extent that patients are actively involved in the treatment decision-making process. We therefore hypothesized that decisional control would moderate associations between knowledge and decisional outcomes and that knowledge would be more strongly associated with decisional outcomes for men who made the decision actively or collaboratively than for men who had little or no input in the decision.

QOL ratings are appraisals that could be influenced by a variety of patient beliefs. Patients with cancer who expect to experience a given side effect are indeed more likely to experience the side effect.<sup>24</sup> We reasoned that the degree to which men feel that they are responsible for their treatment decisions and outcomes might also influence their posttreatment appraisals of side effects. We know that when they make hypothetical treatment decisions, people justify their choices by inflating the probability of treatment success.<sup>25</sup> After they have been treated, people may engage in similarly biased information processing and appraisals to reduce cognitive dissonance between their choice and their actual outcomes (i.e., side effects). We expected that being more knowledgeable and participating to a greater extent in treatment decision making would reduce decisional conflict and increase decision-making satisfaction and that this, in turn, would be associated with higher ratings of QOL. Our reasoning was that the same men who were most satisfied with their decision would be motivated, even if they experienced side effects, to continue to believe that they

had made the best possible decision under the circumstances. Six months after treatment, in order to justify their decision, these men might minimize side effects and report higher QOL.

## METHODS

### Procedure

Study procedures were approved by an institutional review board. Data for the current study are from a multisite longitudinal observational study of men who were recruited shortly after being diagnosed with clinically localized prostate cancer. Participants were recruited from 5 clinical facilities (2 academic cancer centers and 3 community practices) between July 2010 and September 2014. They were typically recruited at the follow-up visit after having a positive biopsy result or when seeking a second opinion. Men would typically have received some type of decision counseling at these consultations, although many would also seek additional opinions after the consultation. For the present analyses, we used data (demographic and clinical) from a baseline questionnaire that was completed at, or shortly after consent, and prior to the start of treatment. We also used data (decisional control, knowledge, and decision-making outcomes) from a treatment questionnaire that was completed after participants made their treatment decision but before they started treatment. For some men, making the decision took some time. A mean of 26.5 days passed between the return of the baseline questionnaire and the treatment decision-making questionnaire. Prostate cancer-specific QOL was ascertained from a questionnaire that was administered 6 months after treatment.

### Participants

We approached 3337 participants, and of these, 74.2% ( $n = 2476$ ) were enrolled in the study. Participants were given the first survey after informed consent and completed it in the clinic (39.3%), at home and then returned it by mail (59.9%), or with a research staff member over the telephone (0.8%). The response rate for the first questionnaire was 81.1% ( $n = 2008$ ). Participants ( $n = 1654$ ) were only included if they also completed a second survey inquiring about their treatment decision-making experience. This survey was completed after they made their decision but prior to treatment. Decisional experiences were analyzed for 1529 participants who

had data on the variables included in the decisional conflict, decision-making satisfaction, and decision-making difficulty multivariable models. Of these participants, 1342 had 6-month follow-up data at the time that the data were analyzed.

### Measures

*Predictor variables.* Prostate cancer knowledge was assessed with a 17-item (range = 0–17) scale. Participants responded “true,” “false,” or “don’t know” to 13 items from a study by Deibert and others<sup>26</sup> that assess general prostate cancer knowledge (e.g., “a man can have prostate cancer without having any pain or symptoms”) and 4 author-created items added to assess knowledge of treatment side effects of radical prostatectomy and external beam radiation (e.g., “radiation treatment of prostate cancer can cause rectal pain or discomfort”). “Don’t know” responses were recoded as incorrect. The total number of correct responses was summed to generate scores. Internal reliability was not calculated because this scale does not assess a single underlying construct.

*Decisional control* was assessed with a question that asked participants to report how much control that they had over their treatment decision using response options adapted from Degner and Sloan’s<sup>27</sup> assessment of decision-making role preferences (1 = “My doctor(s) made the decision with little input from me,” 2 = “My doctor(s) made the decision but seriously considered my opinion,” 3 = “My doctor(s) and I made the decision together,” 4 = “I made the treatment decision after seriously considering the opinion of my doctor(s),” and 5 = “I made the treatment decision with little input from my doctor(s)”). Responses for the first 2 and the last 2 options were collapsed, yielding passive, collaborative, and active decision-making categories.

*Outcome variables.* *Decisional conflict* was assessed with the 16-item Decisional Conflict Scale.<sup>28</sup> Subscales assess the degree to which participants felt informed, supported, and uncertain about the decision, clear about which benefits and risks mattered most to them, and thought the decision was effective. Participants responded to 16 questions, such as “Are you clear about which benefits matter most to you?,” using a 5-point Likert-type response format. According to the author’s instructions, scale scores were computed by summing item values, dividing by 16, and multiplying by 25 to yield scores potentially ranging from 0 to 100,<sup>29</sup> with higher scores indicating

greater decisional conflict ( $\alpha = 0.89$ ). Reliability for the informed, values clarity, support, uncertainty, and effective decision subscales were  $\alpha = 0.82, 0.90, 0.66, 0.59,$  and  $0.80,$  respectively.

*Decision-making satisfaction* was assessed using a modified version of the Satisfaction with Decision Scale<sup>30</sup> that included 4 ( $\alpha = 0.87$ ) of the original 6 items. Participants responded to 4 statements using a 5-point Likert-type response format (1 = strongly disagree, 5 = strongly agree). Scores were averaged (range = 1–5), and higher scores indicate higher decision-making satisfaction.

*Decision-making difficulty* was assessed with 3 items ( $\alpha = 0.72$ ),<sup>23</sup> for which participants rated the extent to which they agreed (1 = strongly disagree, 5 = strongly agree) with the following statements: “Making the decision about the type of treatment to have was stressful,” “It was difficult to make the decision about what treatment to have,” and “Knowing the opinions of family members made it more difficult for me to decide what kind of treatment to have.” Scores were summed (range = 3–15), with higher scores indicating a more difficult decision-making process.

*QOL* was assessed with the Expanded Prostate Cancer Index Composite (EPIC), a 50-item prostate cancer health-related QOL scale ( $\alpha \geq 0.82$ ).<sup>31</sup> The EPIC assesses both function (how frequently one has been affected by a treatment-related side effect during the previous 4 weeks) and bother by urinary, bowel, sexual, and hormone-related side effects (“how big a problem” were these side effects?) during the same time period. We used outcome scores that combined both function and bother. The hormonal scale was not analyzed for this study because relatively few of our participants underwent androgen deprivation therapy. Scores for each domain can range from 0 to 100.

### Covariates

Research assistants recorded the site at which participants were recruited. Participants self-reported years of education completed (high school or less, some college, college, and beyond college), income (<\$25,000, \$25,000–\$49,999, \$50,000–\$74,999, \$75,000–\$99,999, and  $\geq$ \$100,000), marital status (married/cohabitating v. single/never married/divorced/widowed), employment status (full time, part time, unemployed, and retired), age at diagnosis, and race/ethnicity (non-Hispanic white, non-Hispanic black, Hispanic, and other). They completed the MacArthur perceived social status

assessment by rating their standing in their community on a ladder graphic representing social standing from low to high.<sup>32</sup> Each ladder rung corresponded to a response option ranging from 1 to 10. Treatment (active surveillance v. surgery v. external beam radiation, proton therapy, or brachytherapy) was ascertained via self-report and verified via chart abstraction in the majority of cases.

### Statistical Analyses

We conducted multivariable linear regression with robust standard errors to test for adjusted associations between decisional control and knowledge and the outcomes, including decisional conflict subscales. We estimated the association between decisional control and knowledge with the Pearson correlation coefficient and evaluated whether the two interacted to predict outcomes using multivariable linear regression with robust standard errors. Recruitment site, years of education, race/ethnicity, age at diagnosis, marital status, employment status, and perceived social status were also included as covariates in all multivariable models. Given that there were so few sites (2 comprehensive cancer centers and 3 community facilities), we did not attempt to make any comparisons on the basis of the type of facility or geographical location. Income was not included in the model due to a high percentage of missing data (14.4%). Furthermore, there were moderate to strong correlations between income and social status ( $r = 0.36, P < 0.001$ ) and between income and education ( $r = 0.44, P < 0.001$ ), which were included in the multivariable models. We tested whether level of prostate cancer knowledge at the time of the decision and decisional control predicted QOL at 6 months after treatment or the initiation of active surveillance. These tests were performed on a subset of participants because only 1342 participants had 6-month data at the time that the analyses were conducted and some participants had missing data on variables included in the models. As baseline QOL and type of treatment have significant influences on QOL after treatment, we controlled for these, along with the covariates included in the other multivariable models.

## RESULTS

### Participant Characteristics

Demographic and clinical characteristics of the sample are reported in Table 1, along with mean

knowledge scores as a function of participant characteristics. The majority of the sample was non-Hispanic white (81.6%) and married (84.0%), and more than half had a college degree or greater (57.4%). The mean ( $\pm$ standard deviation) age at diagnosis was  $63.1 \pm 7.9$  years. Most of the men reported that they had made the decision on their own or with their physicians' input (actively; 66.8%) or collaboratively with their physician(s) (26.4%). A minority reported that their physicians made their decisions with or without their input (passively; 6.5%). The mean knowledge score across the sample was  $11.72 \pm 3.26$  out of 17. The mean decisional conflict score was  $8.05 \pm 10.36$  out of 100, the mean decision-making satisfaction score was  $4.55 \pm 0.53$  out of 5, and the mean decision-making difficulty score was  $8.71 \pm 2.72$  out of 15. Among those with 6-month follow-up data and confirmed treatment type data, 22.3% ( $n = 294$ ) underwent active surveillance, 26.8% ( $n = 353$ ) underwent radiation, and 51.0% ( $n = 672$ ) underwent surgery. Mean urinary, sexual, and bowel QOL scores were  $83.9 \pm 14.6$ ,  $40.0 \pm 27.0$ , and  $93.3 \pm 9.2$  out of 100, respectively.

Differences in knowledge as a function of participant characteristics can also be found in Table 1. There were also a number of differences in decisional control as a function of participant characteristics. Men who were married were more likely to have made the decision collaboratively (relative risk [RR] = 2.28; 95% confidence interval [CI] = 1.35–3.84;  $P = 0.002$ ) and actively (RR = 2.04; 95% CI = 1.27–3.27;  $P = 0.003$ ) than passively compared to those who were unmarried. Those who were employed part time (RR = 0.44; 95% CI = 0.21–0.93;  $P = 0.03$ ) or retired (RR = 0.53; 95% CI = 0.34–0.83;  $P = 0.006$ ) were less likely to have made the decision actively than passively compared to those who were employed full time. Older age was associated with a lower likelihood of making the decision actively (RR = 0.96; 95% CI = 0.94–0.99;  $P = 0.005$ ) compared to passively. There were no differences in how men made the decision as a function of education, race/ethnicity, recruitment site, or perceived social status. Correlations between predictors and outcomes are shown in Table 2.

## Multivariable Analyses

*Decisional control and decision-making experiences.* Adjusted models of decision-making outcomes as a function of decisional control are found in Table 3. Participants who made the decision

collaboratively ( $b = -4.88$ ; 95% CI =  $-7.88$  to  $-1.88$ ;  $P = 0.001$ ) or actively ( $b = -6.62$ ; 95% CI =  $-9.47$  to  $-3.78$ ;  $P < 0.001$ ) reported less decisional conflict than those who were passive (model 1). For most decisional conflict subscales (informed, values clarity, support, effectiveness, and uncertainty), making the decision more actively compared to being passive was significantly associated with better (lower) decisional conflict subscale scores. Comparisons between collaborative and passive and between active and passive decision makers all yielded significant results ( $P \leq 0.05$ ), except 3 effects for uncertainty and effectiveness that only reached a trend level ( $P \leq 0.07$ ). Collaborative ( $b = 0.24$ ; 95% CI = 0.12–0.36;  $P < 0.001$ ) and active decision makers ( $b = 0.25$ ; 95% CI = 0.14–0.36;  $P < 0.001$ ) were more satisfied with the decision-making process than those who were passive (model 2). However, active ( $b = 0.72$ ; 95% CI = 0.22–1.22;  $P = 0.005$ ) but not collaborative decision makers reported more difficulty than those who were passive (model 3).

*Prostate cancer knowledge and decision-making experiences.* Adjusted models of the associations between knowledge and decision-making outcomes are found in Table 4. Being more knowledgeable about prostate cancer was associated with lower decisional conflict ( $b = -0.49$ ; 95% CI =  $-0.68$  to  $-0.29$ ;  $P < 0.001$ ) (model 4). Having more knowledge was associated with lower scores on all of the decisional conflict subscales except uncertainty ( $P \leq 0.02$ ). Having more knowledge was associated with higher decision-making satisfaction ( $b = 0.01$ ; 95% CI = 0.00–0.02;  $P = 0.03$ ) (model 5). Being more knowledgeable was associated with greater decision-making difficulty ( $b = 0.12$ ; 95% CI = 0.08–0.17;  $P < 0.001$ ) (model 6).

*Covariates and decision-making outcomes.* There were consistent patterns in relations between covariates and decision-making outcomes across models 1 to 6. Married men fared better with respect to all decision-making outcomes, and older age was associated with experiencing lower decision-making difficulty.

*Decisional control moderates associations between knowledge and decision-making outcomes.* There was a significant interaction between decisional control and knowledge, predicting decision-making difficulty ( $b = 0.28$ ; 95% CI = 0.13–0.43;  $P < 0.001$ ) but not predicting decisional conflict or decision-making satisfaction. The interaction predicting

**Table 1** Participant Characteristics and Mean Prostate Cancer Knowledge as a Function of Participant Characteristics ( $N = 1529$ )

Characteristic	<i>n</i>	% or Mean $\pm$ SD	Knowledge, Mean $\pm$ SD or <i>b</i> Value (95% CI)
Education			
≤High school	444	29.04	10.45 $\pm$ 3.37
Some college	207	13.54	11.20 $\pm$ 3.47 <sup>a</sup>
College degree	408	26.68	12.27 $\pm$ 2.99 <sup>b</sup>
Graduate degree	470	30.74	12.66 $\pm$ 2.83 <sup>b</sup>
Marital status			
Not married/cohabitating	245	16.02	11.05 $\pm$ 3.63
Married/cohabitating	1284	83.98	11.84 $\pm$ 3.16 <sup>b</sup>
Income, \$			
<25,000	86	6.57	9.14 $\pm$ 4.01
25,000–49,999	147	11.23	10.55 $\pm$ 3.08 <sup>a</sup>
50,000–74,999	196	14.97	11.68 $\pm$ 3.08 <sup>b</sup>
75,000–99,999	185	14.13	11.94 $\pm$ 2.87 <sup>b</sup>
≥100,000	695	53.09	12.46 $\pm$ 2.93 <sup>b</sup>
Race			
Non-Hispanic white	1248	81.62	11.95 $\pm$ 3.18
Non-Hispanic black	157	10.27	10.43 $\pm$ 3.28 <sup>b</sup>
Hispanic	102	6.67	10.71 $\pm$ 3.57 <sup>b</sup>
Other	22	1.44	12.36 $\pm$ 3.16
Employment status			
Full time	782	51.14	12.22 $\pm$ 3.03
Part time	112	7.33	11.63 $\pm$ 2.99
Unemployed	39	2.55	11.56 $\pm$ 2.94
Retired	596	38.98	11.08 $\pm$ 3.49 <sup>b</sup>
Age at diagnosis, y	1529	63.14 $\pm$ 7.90	–0.09 <sup>b</sup> (–0.11 to –0.07)
Perceived social status	1529	6.78 $\pm$ 1.67	0.23 <sup>b</sup> (0.13 to 0.33)
Treatment			
Active surveillance	294	22.29	11.80 $\pm$ 3.60 <sup>a</sup>
Radiation	353	26.76	11.00 $\pm$ 3.29
Surgery	672	50.95	12.31 $\pm$ 2.86 <sup>b</sup>
Quality of life			
Urinary	1340	83.92 $\pm$ 14.56	0.02 <sup>b</sup> (0.01 to 0.03)
Sexual	1318	39.98 $\pm$ 27.00	0.01 (0.00 to 0.02)
Bowel	1342	93.33 $\pm$ 9.17	0.06 <sup>b</sup> (0.04 to 0.07)

Notes: Percentages for a given variable do not sum to 100% if cases were missing data for the variable. Referent groups for comparisons of knowledge as a function of participant characteristics were ≤high school, not married, income <\$25,000, non-Hispanic white, being employed full time, and undergoing radiation. CI = confidence interval; SD = standard deviation.

a.  $P < 0.01$ .

b.  $P < 0.001$ .

decision-making difficulty was due to there being an association between having greater knowledge and decision-making difficulty in men who made the decision actively ( $b = 0.17$ ; 95% CI = 0.11 to 0.23;  $P < 0.001$ ) and an association between greater knowledge and less decision-making difficulty in men who were passive ( $b = -0.17$ ; 95% CI = –0.35 to 0.00;  $P = 0.05$ ). Of note, there was no relationship between prostate cancer knowledge and decision-making difficulty among men who made the decision

collaboratively ( $b = 0.05$ ; 95% CI = –0.04 to 0.14;  $P = 0.28$ ).

*Knowledge, decisional control, and QOL.* We modeled 6-month posttreatment QOL after controlling for treatment choice, baseline QOL, and demographic and clinical characteristics (results not shown in tables). Prostate cancer knowledge predicted sexual QOL at 6 months after treatment ( $b = 0.49$ ; 95% CI = 0.13–0.86;  $P = 0.008$ ),<sup>a</sup> whereas decisional control did not ( $P > 0.22$ ). Knowledge also

**Table 2** Correlations between Predictor and Outcome Variables

	Decisional Control	Knowledge	Decisional Conflict	Decision-Making Satisfaction	Decision-Making Difficulty	Sexual Quality of Life	Urinary Quality of Life	Bowel Quality of Life
Decisional control	1.00							
Knowledge	0.22 <sup>a</sup>	1.00						
Decisional conflict	-0.16 <sup>a</sup>	-0.16 <sup>a</sup>	1.00					
Decision-making satisfaction	0.10 <sup>a</sup>	0.10 <sup>a</sup>	-0.54 <sup>a</sup>	1.00				
Decision-making difficulty	0.10 <sup>a</sup>	0.15 <sup>a</sup>	0.28 <sup>a</sup>	-0.23 <sup>a</sup>	1.00			
Sexual quality of life	0.05	0.17 <sup>a</sup>	-0.07 <sup>b</sup>	0.08 <sup>c</sup>	-0.01	1.00		
Urinary quality of life	-0.03	0.05	-0.09 <sup>a</sup>	0.09 <sup>c</sup>	-0.06 <sup>b</sup>	0.43 <sup>a</sup>	1.00	
Bowel quality of life	0.07 <sup>b</sup>	0.16 <sup>a</sup>	-0.10 <sup>a</sup>	0.07 <sup>c</sup>	-0.06 <sup>b</sup>	0.27 <sup>a</sup>	0.35 <sup>a</sup>	1.00

a.  $P < 0.001$ .  
b.  $P < 0.05$ .  
c.  $P < 0.01$ .

**Table 3** Multivariable Analyses of Decisional Control and Decision-Making Outcomes

Predictors	Outcomes		
	Model 1, b Value (95% CI) (n = 1517) Decisional Conflict	Model 2, b Value (95% CI) (n = 1524) Decision-Making Satisfaction	Model 3, b Value (95% CI) (n = 1515) Decision-Making Difficulty
Decisional control			
Collaborative	-4.88 <sup>a</sup> (-7.88 to -1.88)	0.24 <sup>b</sup> (0.12 to 0.36)	0.25 (-0.28 to 0.79)
Active	-6.62 <sup>b</sup> (-9.47 to -3.78)	0.25 <sup>b</sup> (0.14 to 0.36)	0.72 <sup>a</sup> (0.22 to 1.22)
Education			
Some college	0.91 (-0.90 to 2.72)	0.04 (-0.05 to 0.12)	-0.12 (-0.56 to 0.32)
College degree	0.84 (-0.59 to 2.26)	0.04 (-0.04 to 0.11)	-0.06 (-0.43 to 0.31)
Graduate degree	0.26 (-1.15 to 1.68)	0.06 (-0.01 to 0.14)	-0.18 (-0.55 to 0.19)
Married/cohabitating	-2.81 <sup>a</sup> (-4.41 to -1.21)	0.11 <sup>c</sup> (0.03 to 0.19)	-0.69 <sup>b</sup> (-1.07 to -0.31)
Race			
Non-Hispanic black	1.20 (-0.77 to 3.15)	-0.06 (-0.15 to 0.03)	0.15 (-0.29 to 0.60)
Hispanic	0.82 (-1.51 to 3.14)	-0.06 (-0.17 to 0.06)	0.48 (-0.19 to 1.15)
Other	3.69 (-3.07 to 10.45)	-0.05 (-0.30 to 0.20)	0.94 (-0.21 to 2.09)
Employment status			
Part time	1.79 (-0.77 to 4.35)	-0.04 (-0.16 to 0.08)	0.32 (-0.26 to 0.88)
Unemployed	-1.77 (-5.70 to 2.17)	0.06 (-0.11 to 0.23)	0.56 (-0.20 to 1.32)
Retired	-1.05 (-2.42 to 0.32)	0.03 (-0.04 to 0.10)	0.25 (-0.10 to 0.60)
Age	0.06 (-0.03 to 0.16)	0.00 (-0.01 to 0.00)	-0.06 <sup>b</sup> (-0.08 to -0.04)
Perceived social status	-0.26 (-0.60 to 0.08)	0.01 (0.00 to 0.03)	-0.02 (-0.11 to 0.07)

Notes: Referent groups were passive decisional control,  $\leq$ high school, not married, non-Hispanic white, and full-time employment status. The facility at which participants were recruited was included in all of the models; however, output for this variable was not included as comparisons between sites are arbitrary. CI = confidence interval.

- a.  $P < 0.01$ .  
b.  $P < 0.001$ .  
c.  $P < 0.05$ .

predicted bowel QOL ( $b = 0.18$ ; 95% CI = 0.04–0.32;  $P = 0.01$ ), whereas decisional control did not ( $P > 0.21$ ). Neither knowledge nor decisional control predicted urinary QOL ( $P > 0.43$ ).

Controlling for treatment type, baseline QOL, and other covariates, the indirect effect of knowledge on bowel QOL through decision-making difficulty was small but reliable ( $-0.02$ ; 95% CI =  $-0.05$  to  $0.01$ ).

**Table 4** Multivariable Analyses of Knowledge and Decision-Making Outcomes

Predictors	Outcomes		
	Model 4, b Value (95% CI) (n = 1522) Decisional Conflict	Model 5, b Value (95% CI) (n = 1529) Decision-Making Satisfaction	Model 6, b Value (95% CI) (n = 1520) Decision-Making Difficulty
Knowledge	-0.49 <sup>a</sup> (-0.68 to -0.29)	0.01 <sup>b</sup> (0.00 to 0.02)	0.12 <sup>a</sup> (0.08 to 0.17)
Education			
Some college	1.19 (-0.60 to 2.98)	0.03 (-0.05 to 0.12)	-0.20 (-0.64 to 0.25)
College degree	1.04 (-0.39 to 2.47)	0.04 (-0.04 to 0.12)	-0.17 (-0.55 to 0.20)
Graduate degree	0.70 (-0.74 to 2.14)	0.06 (0.01 to 0.14)	-0.35 (-0.73 to 0.03)
Married/cohabitating	-2.76 <sup>c</sup> (-4.38 to -1.14)	0.11 <sup>c</sup> (0.03 to 0.19)	-0.73 <sup>a</sup> (-1.10 to -0.36)
Race			
Non-Hispanic black	0.69 (-1.30 to 2.68)	-0.05 (-0.14 to 0.04)	0.28 (-0.16 to 0.73)
Hispanic	0.65 (-1.66 to 2.96)	-0.06 (-0.17 to 0.06)	0.54 (-0.13 to 1.21)
Other	3.55 (-2.94 to 10.03)	-0.05 (-0.30 to 0.21)	0.97 (-0.19 to 2.13)
Employment status			
Part time	2.12 (-0.45 to 4.69)	-0.05 (-0.16 to 0.07)	0.27 (-0.30 to 0.84)
Unemployed	-1.33 (-5.48 to 2.82)	0.05 (-0.13 to 0.23)	0.48 (-0.28 to 1.24)
Retired	-0.94 (-2.32 to 0.43)	0.02 (-0.05 to 0.09)	0.24 (-0.10 to 0.59)
Age	0.04 (-0.05 to 0.13)	0.00 (-0.01 to 0.00)	-0.05 <sup>a</sup> (-0.08 to -0.03)
Perceived social status	-0.26 (-0.60 to 0.08)	0.01 (0.00 to 0.03)	-0.03 (-0.12 to 0.06)

Note: Referent groups were passive decisional control, ≤high school, not married, non-Hispanic white, and full-time employment status. CI = confidence interval.

a. *P* < 0.001.

b. *P* < 0.05.

c. *P* < 0.01.

0.00; *P* = 0.04), and the indirect effect of knowledge on bowel QOL through decisional conflict was not significant (0.02; 95% CI = 0.00 to 0.04; *P* = 0.07). The indirect effect of knowledge on sexual QOL through decisional conflict was not significant (0.00; 95% CI = -0.06 to 0.06; *P* = 0.94).<sup>b</sup> We did not test a mediation model for decision-making difficulty and sexual QOL because the two were not associated. Decision-making satisfaction did not predict sexual or bowel QOL (*P* > 0.11); therefore, we did not test if it mediated relationships between knowledge and QOL.

Of all covariates in the multivariable models, the type of treatment that men underwent had the largest impact on QOL. Adjusting for knowledge and covariates, compared to men who underwent active surveillance, men who underwent surgery had lower sexual (29 points lower), urinary (10 points lower), and bowel (1 point lower) QOL. Men who underwent radiation also had significantly lower sexual (16 points lower), bowel (4 points lower), and urinary (4 points lower) QOL than men who underwent active surveillance.

## DISCUSSION

The hypothesized main effects for decisional control/knowledge and decision-making outcomes were supported. For men deciding how to treat their prostate cancer, the more decisional control they had, the less decisional conflict they experienced and the more satisfied they were with the decision-making process. However, more actively involved men rated the decision as having been more difficult. We found a similar pattern of results for knowledge; men who were more informed about prostate cancer reported less decisional conflict and greater decision-making satisfaction but greater difficulty with the decision-making process.

Knowledge and decisional control interacted to predict decision-making difficulty; being more knowledgeable was only associated with experiencing more treatment decision-making difficulty for men who were most actively involved in making their treatment decision. However, this was the largest subgroup of men. They may have been more active in the decision-making process and consequently



sought prostate cancer information more widely and extensively and spent more effort and time comparing treatment options. While these patients may ultimately have low decisional conflict and may be satisfied with the decision-making process, they may also have found decision making difficult and stressful, given how effortful it was. Another interpretation of the results is that men's judgments of their decision-making satisfaction and conflict are motivated by a need to reduce cognitive dissonance or discrepancies between their attitudes and behavior. When people put more effort into a task, they often evaluate it more favorably<sup>33</sup>; in this case, if they put considerable effort into making the treatment decision, they may perceive their decision as better justified and are more satisfied with the decision-making process. Although we hope that the decision-making conflict and satisfaction measures are capturing truly well-justified decisions, future research could attempt to rule out the cognitive dissonance hypothesis by measuring both patient knowledge and decision-making effort and determining their independent effects on decisional conflict and decision-making satisfaction.

Across all multivariable models, being married was associated with greater decision-making satisfaction and lower decisional conflict and decision-making difficulty. Marital status was unrelated to QOL. Married men diagnosed with prostate cancer are more likely to choose aggressive treatment, in particular surgery, than unmarried men.<sup>34,35</sup> Their family roles and wives' social influence may lead them to prioritize choosing a treatment that they believe will maximize their chance of cure and longevity. In contrast, some unmarried men may place relatively greater value on sexual function, making potential erectile dysfunction more threatening to their identities and lifestyles. Consequently, married men may not be as conflicted about the treatment choice as single men who may weigh the costs of treatment more heavily and therefore have a more negative decision-making experience. Married men likely also have a more positive decision-making experience than unmarried men because of the social support afforded by marriage.

Survivors of breast cancer who played a more active role in decision making have been found to report higher physical and social QOL compared to those who were less active<sup>13</sup> as well as better psychological well-being after treatment.<sup>36</sup> Whether there is a relationship between decisional control and QOL has hitherto not been tested in men with prostate cancer. Decisional control was not associated with QOL

in our sample. A reason for the divergent findings may be that the women in Hack and others' study were reassessed 3 years after surgery, whereas we assessed QOL in our sample only 6 months after treatment.<sup>13</sup> Perhaps over time, as side effects emerge or fail to subside, prostate cancer patients' perceptions of their QOL might come to be more influenced by misgivings about treatment decision-making outcomes and processes. Being more knowledgeable about the disease and treatment side effects was associated with higher sexual and bowel QOL at 6 months after treatment; however, little or no part of these relationships were explained by decision-making experiences. Perhaps more knowledgeable men make more positive appraisals of QOL because they have more realistic expectations about the likelihood and time course of side effects. Consistent with this idea, educational interventions that improve prostate cancer knowledge have been shown to reduce bother by sexual problems<sup>37</sup> and side effects of radiation.<sup>38</sup>

The field has embraced shared decision making as the ideal for preference-sensitive treatment decision making,<sup>39-41</sup> and shared decision making is becoming institutionalized through health policy changes.<sup>18</sup> Patients too appear to have embraced shared or autonomous decision making; only 6.5% of our sample reported having been passive in their decision making, which is a smaller proportion than previously reported.<sup>14,42,43</sup> Consequently, it is important to continue to develop and invest in strategies that both increase patient knowledge and reduce the psychological burden of treatment decision making.<sup>44</sup> One important implication of our findings is that patient participation and knowledge are important for good prostate cancer treatment decisions, but they are not sufficient. The treatment decision may remain difficult for many men and their families. Treatment decision making can be difficult for a third or more of men diagnosed with the disease.<sup>22,23</sup> Also, when shared decision making involves family members, couple- or family-centered support may be beneficial<sup>45</sup> as family members and other supporters often have unmet informational needs.<sup>46,47</sup> Support at this point in the cancer care continuum could benefit many. In essence, interventions are needed to help patients and their families manage what may be the paradoxical nature of "good" prostate cancer treatment decisions. In order to make an informed choice between 2 or more treatment options, patients presumably need a high level of knowledge about treatment procedures and potential side effects. They, therefore, are likely to require support gathering, processing, and integrating the

information that they need in order to perceive that they have an adequate basis for choosing between treatment options. Psychosocial support from nurses, social workers, and psychologists may be valuable<sup>48</sup> as well as the increased use of decision aids.<sup>49,50</sup>

In light of a recent meta-analysis of 14 decision aid trials having revealed mixed effects of decision aids on outcomes such as decisional conflict and decision-making satisfaction,<sup>50</sup> supporting prostate cancer treatment decision making in patients and their families remains an area in need of innovation and rigorous evaluation. Decision aids may be helpful for reducing information-seeking strain, and some decision aids may help men integrate their values and preferences; however, other strategies might also be considered for reducing decision-making difficulty. Health care providers can provide valued emotional support that may reduce decision-making stress.<sup>51</sup> Decision-making self-efficacy is associated with lower decision-making difficulty<sup>23</sup> and can be successfully modified to improve outcomes for a range of challenging behaviors.<sup>52</sup> Brief cognitive behavioral therapy strategies are effective at reducing negative mood states<sup>53</sup> that might make information seeking and decision making more challenging. Finally, as an initial step, providers may consider inquiring about how their patients with prostate cancer are coping with the treatment decision as a routine part of clinical care.

### Limitations and Future Directions

As with all cross-sectional designs, a limitation of our study is that one cannot infer that men's decisional control and knowledge causally influenced their decision making. Men's decision-making experiences could have influenced the extent to which they were involved in making their decision. For example, the outcome measures may tap into men's experiences of dissatisfaction with their physicians. Men who are unhappy with their interactions with their physicians may consequently become more involved in the decision. However, this is inconsistent with the association between decisional control and satisfaction with support from others during decision making, which is assessed by the support subscale of the decisional conflict measure. Another possible issue is conceptual overlap between prostate cancer knowledge and items from the Decisional Conflict Scale that ask people to self-report their level of knowledge (e.g., "I feel I have made an informed choice" or "I know the risks and side effects of each

option"), which are part of the informed and effective decision subscales of the decisional conflict measure. This overlap may be inflating associations between the 2 constructs; however, knowledge was associated with decisional conflict subscales that did not include self-assessments of how informed men were (i.e., values clarity and support subscales).

There was also overlap between the decision-making difficulty scale and 1 item from the Decisional Conflict Scale, "Is this decision easy for you to make?," whereas all the other items on the Decisional Conflict Scale were positively related with knowledge and decisional control. This item was negatively related to these constructs, similarly to the decision-making difficulty scale.

Our sample was quite well educated; one would expect prostate cancer knowledge to be considerably lower in less educated patients with prostate cancer, as evident in the very low knowledge reported in studies with low-income, minority patients.<sup>26,54</sup> In samples including larger proportions of less educated men, greater variance in knowledge should result in greater variation in decision-making experiences.

Future work might consider the relationships between decision-making experiences, decisional regret, and QOL. Decisional regret, which has been found to be associated with whether one was able to play one's desired role in the decision-making process,<sup>55,56</sup> as well as decision-making satisfaction and decisional conflict,<sup>57</sup> may be an important mediator of the influence of decision-making experiences on QOL.

### NOTES

- a. The EPIC QOL assesses both function and bother dimensions for each domain. Knowledge significantly ( $P = 0.05$ ) predicted both function and bother; therefore, we only report results for the combined scales.
- b. When estimating indirect effects, we controlled for all covariates except recruitment site because the models did not converge when this variable was included.

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