Empowering Patients as Decision Makers in the Context of Early Stage Prostate Cancer

by

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Date: April 6, 2017

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Dissertation submitted in partial fulfillment of
the requirements for the degree of Doctor
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ABSTRACT

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Abstract

Patients with early stage prostate cancer face a difficult preference-sensitive decision. There are multiple treatment options, each of which is associated with a unique set of benefits and risks. For example, surgery may cure the cancer but also come with the risk of serious side effects, such as impotence and incontinence. Alternatively, active surveillance avoids those side effects but requires patients to live with an untreated cancer inside their body. The optimal treatment for each patient will thus depend not only on his medical characteristics but also on how he personally values those risks and benefits. Ideally, patients and their physicians would partner together in a process of shared decision making (SDM) to ensure that patients receive treatments that reflect their personal preferences (i.e., preference-concordant treatments). In this dissertation, I use both qualitative and quantitative methods to examine patients' decision-making processes in the context of early stage prostate cancer, focusing on if and how patients and physicians work together in the decision-making process to incorporate patients' preferences into their treatment choices.

Essay 1 examines patients' decision making processes within the context of a larger trial that was designed to assess the impact of a novel patient-centered (vs. standard) decision aid (DA) on patients' decision making processes. The patient-centered DA increased patients' desire to participate in the decision-making process and

interest in active surveillance (Fagerlin et al., unpublished). However, regardless of which DA patients received, their treatment choices were primarily driven by physicians' recommendation which, in turn, were driven by patients' medical characteristics (e.g., cancer severity) and not their personal preferences (e.g., interest in sexual activity). Qualitative analyses of clinical appointments revealed relatively passive patients regardless of condition, suggesting that patients may not have known *how* to participate in clinical appointments and would benefit from pre-appointment communication skills training.

Essay 2 examines the effect of a novel patient communication skills intervention plus a patient-centered DA (vs. a patient-centered DA only) on several measures of patient empowerment using a randomized controlled trial. The intervention was a video (DVD) that modeled specific communication skills patients could use to participate in their upcoming appointments. The intervention increased patients' intentions to use four process skills (e.g., taking notes) and sense of self-efficacy regarding their ability to ask for referrals and express personal concerns during their upcoming clinical appointments. It did not increase patients' sense of self-efficacy regarding their ability to seek information or make assertive utterances.

Essay 3 examines focuses on a specific moment in clinical appointments: patients' requests for treatment recommendations (data from Essay 1). Patient requests for recommendations are a pivotal and powerful moment in clinical appointments, yet no existing studies have examined how patients actually request recommendations nor what patient characteristics are associated with requests for recommendations. Patients or their companions requested recommendations in approximately 20% of appointments. Patients who requested recommendations had higher prostate cancer anxiety, placed increased importance on sex in their lives, preferred shared (vs. patient-led) decision making, and were more likely to prefer active treatment prior to appointments. When requesting recommendations, patients discussed physicians' expertise and the role of their recommendations, asked physicians to engage in self-disclosure (e.g., "What would you do?") and repeated their requests.

Truly empowering patients as decision makers in the context of early stage prostate cancer is difficult, and both patients and physicians may be uncertain how to behave in this new paradigm of patient empowerment. Patient communication skills interventions show promise, but continued research is needed to truly transform clinical medicine into a domain in which patients are empowered to fully participate in the medical decision-making process.

Dedication

This work is dedicated to my family: Mark, Mom, Dad, Heather, John, and Erin.

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1. Introduction: Patient empowerment

1.1 The patient empowerment movement

Over the past several decades, the health care sector has undergone a rapid shift, changing from a world in which "doctor knows best" to one in which patients actively partner with their physicians in the decision making process and, in some cases, even lead the process (National Research Council, 2001). Some of this shift is driven by advances in medical care. Years ago, there were no effective treatments for many medical conditions, and physicians' primary job was often to comfort patients. As such, physicians sometimes even hid diagnoses from patients in order to avoid upsetting them. However, as medical advances have led to increasingly effective treatments, the physician's role has shifted from comforter to administer of treatments. Currently, hiding a diagnosis from a patient would be considered unethical and now rarely occurs. Physicians are now legally obligated to include patients in the decision-making process. The Canterbury Case of 1972 formalized the patient's role in the decision-making process, and emphasized the importance of a "patient-oriented standard of informed consent in which the physician has a 'duty' to provide appropriate medical facts to empower the patients to use his or her values to determine what interventions should be implemented." Implementing this patient-oriented standard of informed consent, however, has been quite difficult.

The patient empowerment movement has worked to achieve this patient-oriented standard of informed consent and also move beyond the informed consent process to a broader, more inclusive view of patient empowerment within all aspects of medical care. The concept of empowerment is based in the "'social action' ideology of the 1960s and the 'self-help' perspectives of the 1970s" (Aujoulat, d'Hoore, & Deccache, 2007). These original empower movements focused on historically oppressed groups (e.g., African Americans and women) and focused on increasing individuals' sense of power and control (Aujoulat et al., 2007). But what does "empowerment" mean in the health care domain? In the healthcare domain, there is a lack of consensus regarding the term and researchers, policymakers, and clinicians have used the term "empowerment" in various ways (Aujoulat et al., 2007; Tengland, 2008; Bravo et al., 2015). Tengland (2008) provides a comprehensive conceptual definition of empowerment as both a process and a goal:

> "We achieve empowerment (in a combined sense) when a person (or group) A acts towards (in relation to) another person (or group) B in order to support B (by creating the opportunity and environment, and giving 'expertise' support) in gaining better control over (some of) the determinants (those relevant for the situation or profession) of her (quality of) life through (necessarily) an increase in B's knowledge (self-knowledge, consciousness raising, skills development, or competence), or

> health (e.g., autonomy, self-confidence, self-efficacy, or self-esteem) or freedom (positive and negative), and this acting of A towards B involves minimizing A's own 'power' (or influence) over B with regard to goal/problem formulation, decision-making and acting, and B seizes (at least) some control over this situation or process (goal/problem formulation, decision-making and acting). "

There are two dimensions to the process of patient empowerment: an inter-personal dimension and an intra-personal dimension (Aujoulat et al., 2007). In this research, we focus on the inter-personal dimension of empowerment with the decision-making process; namely, patient empowerment within the interaction between patients and clinicians when discussing and choosing treatment options.

1.2 Transformation of the patient-physician relationship

The patient-physician relationship has been transformed by patients' increased patient participation during clinical appointments as part of the patient empowerment movement. The changes in the patient-physician relationship were formalized in a seminal work by Emanuel and Emanuel (1992), in which they outline four broad models of the patient-physician relationship as it relates to decision making. First is the paternalistic model, in which "the physician acts as the patient's guardian, articulating and implementing what is best for the patient." Second is the informative model, also known as the consumer model, in which the physician "provides the patient with all relevant information and the patient selects the medical interventions they want." Third is the interpretive model, in which the physician "helps the patient to elucidate and articulate his values (which may be unknown to the patient) and then helps him select the available medical interventions that realize these values." Finally, fourth is the deliberative model, in which the physician acts as a "teacher or friend, engaging the patient in dialogue on what course of action would be best," and then, based on that conversation, informs the patient what they should do while also promoting certain health-related values (e.g., "safe sex" practices). Emanuel and Emanuel (1992) acknowledge that different approaches may be appropriate for different medical situations, but argue that the deliberative or interpretive models are ideal in most situations, particularly in the context of preference-sensitive decisions. These approaches have been refined and incorporated into the paradigm of shared decision making, which many experts would argue is the optimal approach to preference-sensitive decision making.

1.3 Shared decision making as a key to patient empowerment

This shift in the role of patients and physicians during the decision making process is particularly relevant when patients face "preference-sensitive" decisions, which are medical decisions in which patients' personal values and medical characteristics jointly determine the optimal treatment alternative. Although there are certainly medical situations in which a single treatment is clearly superior (e.g., a heart attack), there are many medical situations in which there are multiple medically-appropriate treatment options.

To help patients navigate preference-sensitive decision making, patients and physicians can engage in a process called "shared decision making" (SDM). SDM is a process by which the patient and physician work together to choose the best treatment for the patient, and it is considered by many to be the "pinnacle of patient-centered care" (Barry & Edgman-Levitan, 2012). SDM is endorsed by many prominent medical societies, including the American Urology Association, the Institute of Medicine, and the National Cancer Institute (Thompson et al.. 2007). SDM is "characterized by intentional and cooperative communication between patient and clinician in which knowledge, values, and preferences are shared and a process of common deliberation leads to a treatment decision" (Thompson et al., 2007). Karni (2009) describes the process of shared decision making during clinical appointments as follows:

> "The decision making problem is interactive, involving the integration of the private information of the two parties. The physician's input includes the diagnosis, the identification of the alternative treatments, and the determination of the probabilities of the outcomes associated with the alternative courses of action. The patient's input consists of his personal characteristics and preferences, including his valuation of the health

outcomes, his outcome-dependent risk attitudes, and his valuation of the nonfinancial aspect of the cost associated with the alternative treatments."

One of the key aspects of patient empowerment within clinical appointments is "patient participation" in the visit. Patient participation can be defined as the "extent to which patients produce verbal responses that have the potential to significantly influence the content and structure of the interaction as well as the health care provider's beliefs and behaviors" (Street & Millay, 2001). Patient participation has numerous positive consequences; patients who participate more in clinical appointments report increased satisfaction with their care, feel more in control of their health, and may achieve better health outcomes (Anderson & Sharpe, 1991; Griffin et al., 2004). Patient participation is particularly important when patients face preference-sensitive decisions.

1.4 Early stage prostate cancer as a preference-sensitive decision

Early stage prostate cancer is a paradigmatic example of a preference-sensitive decision. Patients with early stage prostate cancer must choose whether to receive surgery, radiation, or active surveillance, each of which is associated with a unique profile of risks and benefits. Although there may be cases where a treatment is medically inappropriate (e.g., surgery may be contraindicated for morbidly obese patients), many patients could reasonably choose from more than one treatment option. Because each treatment option within the choice set is associated with a different profile of risks and benefits, the "right" choice for each patient will depend on how he personally values the pros and cons of the options (Thompson et al., 2007). For example, surgery offers the chance of cure but may also lead to impotence and incontinence, and, not surprisingly, men who received surgery reported significantly greater distress from these symptoms than men on active surveillance (Johansson et al., 2011). Thus, surgery and radiation may be a worse choice for patients who feel that penetrative sex is an important part of their life. Alternatively, active surveillance allows men to avoid these side effects but requires regular follow-ups and leaves cancer in their bodies, which some men may find anxiety provoking as it requires them to accept the (low) risk that the cancer may spread between follow-ups. In fact, men with higher levels of neuroticism reported relatively high levels of distress after choosing active surveillance (van den Bergh et al., 2010). Thus, active surveillance may be a worse choice for patients who are more neurotic or have higher levels of anxiety about their prostate cancer.

1.5 Low baseline levels of patient empowerment in early stage prostate cancer

Unfortunately, baseline levels of patient empowerment and shared decision making in early stage prostate cancer are relatively low, and physicians frequently do not incorporate patients' values into their recommendations. For example, clinicians in one study offered a treatment choice to only 40% of patients with early stage prostate cancer despite the fact that a choice of treatments is nearly always appropriate for men with early stage prostate cancer (Pieterse et al., 2011). Another study found that physicians spent relatively minimal time addressing patients' psychosocial concerns, which included discussion of their preferences and values (Hack et al., 2012). During these appointments, 86% of physicians' utterances were about biomedical content, 9% were about administrative issues, and only 5% of their utterances were about psychosocial issues. Non-qualitative studies also suggest that patients with early stage prostate cancer do not receive treatments that are informed by their personal values. For example, rates of active surveillance have been shown to vary dramatically depending on which physician a patient sees, which suggests that physicians' recommendations may reflect their personal biases rather than patients' preferences (Hoffman et al., 2014). One reason for these low rates of shared decision making may be the information asymmetry between patients and physicians, such that patients do not feel qualified to participate during clinical appointments (Joseph-Williams, 2014).

1.6 Decision aids to empower patients

Although there will always be some information asymmetry between patients and physicians, decision aids (DAs) can decrease the asymmetry by educating patients about their medical condition and treatment options. Decision aids can be classified conceptually as (1) traditionally medical; (2) technology assessment; or (3) patient centered (Holmes-Rovner 2005). DAs developed using a traditionally medical approach present medical information, with an emphasis on the disease and take a relatively paternalistic approach in terms of treatment choice. DAs developed using a technology assessment approach often use the Ottowa Decision Support Framework (Légaré et al., 2006); they incorporate information regarding the quality of evidence and make sure to present the risks and benefits in a balanced manner. However, DAs based on both traditionally medical and technology assessment approaches often use relatively complicated language and may not place the patients' needs at the center of the intervention. Patient-centered decision aids attempt to address these issues by using lower literacy levels, information presentation strategies to increase comprehension, and considering the patients' needs when designing the interventions.

Across all medical decisions, DAs create more realistic expectations of outcomes and increase the likelihood that patients' decisions are based on personal values (Stacey et al., 2014). However, there are many instances in which DAs fail to translate into meaningful clinical outcomes, including early stage prostate cancer (Violette et al., 2015). This may be because many prostate cancer treatment DAs require patients to have relatively high literacy and numeracy to understand the information and do not incorporate principles of information presentation. However, even with a patient-centered DA that incorporated best practices for information presentation and included a values-clarification exercise, patients' treatment choices still did not reflect their preferences (Scherr et al., 2017a). This suggests that more complicated medical settings may require more than just increasing patients' declarative ("what") about their medical conditions and treatment options. In these settings, patients may also need procedural knowledge ("how") knowledge regarding how to participate in the decision-making process with their physicians (Anderson, 1990).

1.7 Patient communication skills training interventions to empower patients

Patient communication skills training may be an effective way to teach patients this procedural knowledge and truly empower them to participate in their health care decisions. Communication skills training has been used successfully to improve physicians' communication skills (Cegala & Lenzmeier Broz, 2002) and shows promise for helping "the other half of the whole" (i.e., patients) improve their communication skills (Post, Cegala, & & Miser, 2002).

There are several reasons to believe that patient communication skills training may be helpful and even necessary to truly empower patients. The Medical Communication Alignment Theory (Cegala, 2006) posits that the rules of interpersonal society mean that physicians will, by and large, adjust their conversation in response to patients' communication, even though the conversation is among relative "unequals" (Goffman, 1967). Indeed, physicians' communication styles are affected by patients (Street & Millay, 2001), and physicians interacting with patients who are more participatory display a more patient-centered style of communication (Cegala & Post, 2009). This suggests that patient communication skills training interventions that increase patients' procedural knowledge of how to interact with physicians during clinical appointments (essentially creating "high participation" patients) may be an effective method to increase SDM during clinical appointments. In addition, SDM "takes two to tango" (Charles, Gafni, & Whelan, 1997). Physicians cannot fully engage in SDM without patients who are also prepared to engage with them. For example, patients often "miss" that physicians offer treatment options (Keating et al., 2003) and may ask indirect questions or provide subtle verbal cues that make it difficult for physicians to understand their underlying needs (Butow et al., 2002). Patient communication skills interventions can address these issues by teaching patients specific ways to more effectively communicate with their physicians. However, despite their promise, there have been relatively few studies on patient communication skills training interventions (Cegala & Eisenberg, 2010), and continued research is needed to fully optimize these interventions.

1.8 Permissions

Essay 1 is drawn from the following published article, which is reprinted with permission from Sage Publishing: K.A. Scherr, A. Fagerlin, T. Hofer, L.D. Scherer, M. Holmes-Rovner, L.D. Williamson, V.C. Kahn, J.S. Montgomery, K.L. Greene, B. Zhang, P.A. Ubel, Physician Recommendations Trump Patient Preferences in Prostate Cancer Treatment Decisions, Med. Decis. Making. (2016). doi:10.1177/0272989X16662841.

2. Essay 1: Physician recommendations trump patient preferences in prostate cancer treatment decisions despite patient-centered decision aid

2.1 Introduction

For some diagnoses, like early stage prostate cancer, the right treatment choice for any patient depends not only on medical factors, but also on patient preferences (Keirns & Goold, 2009). Patients with early stage prostate cancer choose between surgery, radiation, and active surveillance, a choice understood to be preference-sensitive because the alternatives involve difficult trade-offs (Sidana et al., 2012). 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 (Johansson et al., 2011).

In recognition of the preference-sensitive nature of this decision, 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" (Thompson et al., 2007). This recommendation is consistent with the practice of shared decision making (Barry & Edgman-Levitan, 2012), by which clinicians are urged to discuss patient values so they can help patients determine which treatment alternative best fits their preferences (Mulley, Trimble, & Elwyn, 2012). 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?

In this study, we examine the factors that influence patients' treatment choices using data from a larger study that tested the effectiveness of a patient-centered (vs. standard) decision aid (NLM identifier: NCT00432601). The patient-centered decision aid increased patients' desire to participate in the decision making process and interest in active surveillance (Fagerlin et al., unpublished). However, it is unknown if and how the patient-centered decision aid influenced patients' treatment choices. Of note, 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 (e.g., Berry et al., 2003; Davison & Breckon, 2012; Diefenbach et al., 2002; Gwede et al., 2005; Hall, Boyd, Lippert, & Theodorescu, 2003; Song et al., 2013). However, most 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 strongly 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 patients' preferences and urologists' recommendations on patients' treatment choices.

2.2 Methods

2.2.1 Study design

Recruitment. Patients were recruited 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.

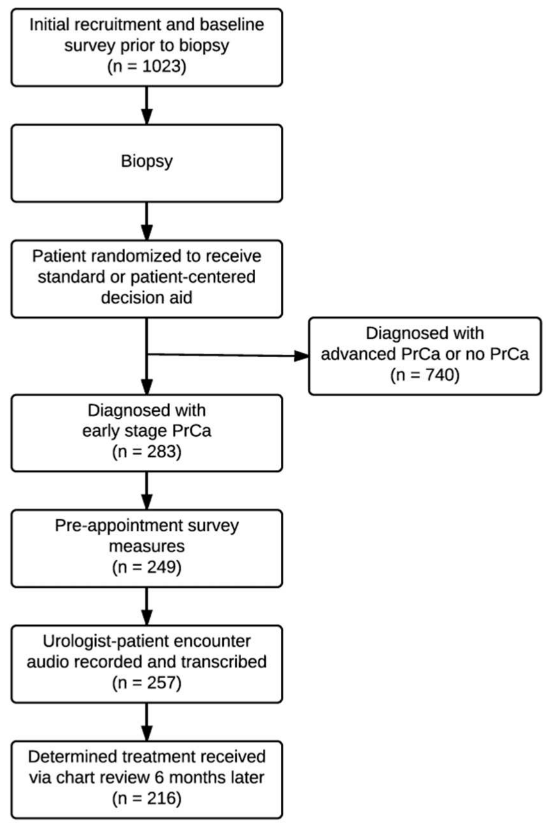

Figure 1. Basic study flow. PrCa = prostate cancer

2.2.2 Decision aids

The standard DA was produced by the National Comprehensive Cancer Network (NCCN) and the American Cancer Society, and it was chosen because of its high quality information and credibility. The DA, entitled, "Prostate Cancer: Treatment Guidelines for Patients," was designed by the NCCN to provide treatment guidelines for patients with either early or later stage prostate cancer. The information in the DA was based on the NCCN's Clinical Practice Guidelines. It included common side effect rates in percentages, and used decision trees to present treatment options.

The patient-centered DA was produced by the Michigan Cancer Consortium (MCC). The DA, entitled, "Making the Choice: Deciding What to Do About Early Stage Prostate Cancer," was designed for patients making treatment decisions about clinically localized prostate cancer and did not include information about advanced or metastatic prostate cancer (Holmes-Rovner et al., 2005). The DA incorporated text and document layout features that supported readers in understanding basic health information needed to make health decisions. Patient testimonials and language throughout the DA conveyed the message that each man should make the decision that was right for him. The DA described the number of people out of 100 who are likely to experience specific risks and benefits. Treatment options were described in text, with comparisons of side effects presented in a table.

Content within each of the two decision aids was similar, although there were several important differences. The patient-centered DA differed from the standard DA in three key ways: 1) it was written at a lower reading level (7^{th}-8^{th} grade vs. graduate level); 2) it contained quantitative expression of the risks/benefits of each treatment options; and 3) it contained patient testimonials and information about the patient decision making experience, including education that their treatment choice should be influenced by medical factors and their personal values. In addition, the standard DA included information about the treatment of advanced cancer (not relevant for patients recruited for this study).

Notably, the type of DA did not affect our key outcomes. Thus, type of DA was treated as a covariate in all analyses and results are collapsed across intervention groups.

2.2.3 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 after they received and reviewed the DA, prior to their urology appointments in which they received their diagnoses and discussed treatment options. 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 prior to appointments 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, that this does mean these preferences were measured prior to patients learning their diagnoses 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 surveillance but not 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 (Roth et al., 2003). 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).[1] See Appendix A for all questions.

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

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[1] 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.

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 (Scherr et al., 2017b). 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 (Hseih & Shannon, 2005). to assess whether urologists and patients discussed three sex-related topics during clinical appointments. Two coders read each transcript and determined whether the urologist: 1) assessed patient baseline sexual function and/or activity; 2) assessed how important sex was to the patient; and 3) discussed the relationship between interest in sex and treatment choice. 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.

2.2.4 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).

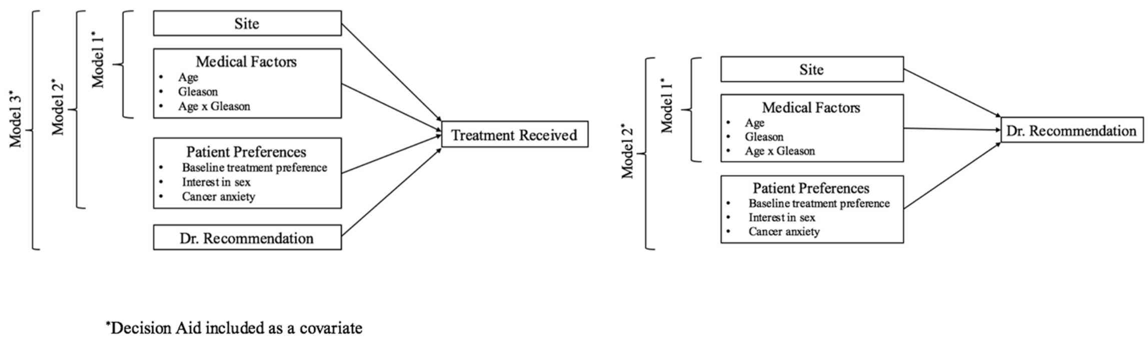

Figure 2. Heirarchical logistic regressions predicting treatment received (left) and doctor recommendation (right). Dr = Doctor

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 x 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 (Williams, 2000).

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 x 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 (Williams, 2000).

Coefficients from multinomial models are notoriously difficult to interpret; they represent conditional odds ratios, which are conditioned on a comparison to the base outcome from a dependent variable with more than two outcomes (Long 2014). Therefore, for ease of interpretation, 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 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 (StataCorp, 2013).

2.2.5 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.

2.2.6 Funding

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

2.3 Results

2.3.1 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.

2.3.2 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.

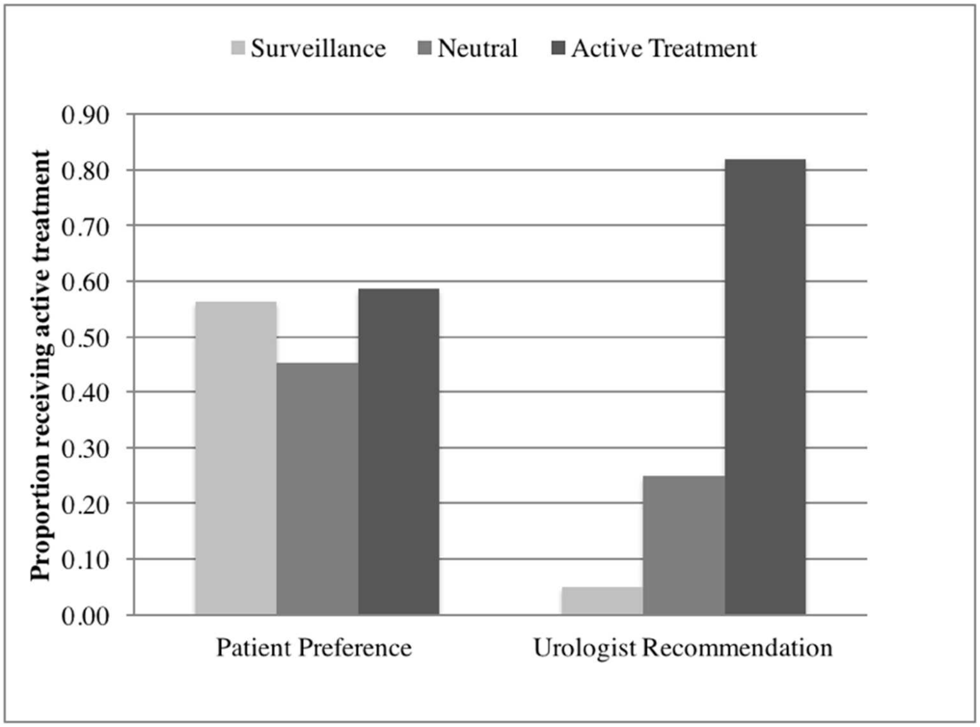

Figure 3. Proportion of patients who received active treatment as a function of patient initial treatment preference and urologist recommendation

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' recommendations and treatment received ($\chi^2(2) = 91.78$, $p < .001$). When urologists recommended active treatment, 82% of patients (97/118) received 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 1 shows the results of our hierarchical logistic regression. Accounting for patient preferences (Model 2) did not improve the fit of the model ($\Delta\chi^2$ (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 ($\Delta\chi^2(2)$ = 32.81 p < .001), indicating that urologists' recommendations did predict treatment choice above and beyond the other factors in the model.

Table 1. Adjusted Odds Ratios for factors predicting whether patient received active treatment

Predictor	Model 1	Model 2	Model 3
Site [a]			
Site 2	1.41	1.41	1.56
	[0.64,3.10]	[0.64,3.10]	[0.70,3.48]
Site 3	0.53	0.41	0.36*
	[0.19,1.52]	[0.15,1.16]	[0.15,0.89]
Site 4	0.46	0.55	0.67
	[0.19,1.12]	[0.20,1.49]	[0.23,1.91]
Decision aid [b]	1.16	1.08	1.30
	[0.51,2.63]	[0.45,2.56]	[0.49,3.44]
Gleason [c]	23.41***	25.25***	9.03***
	[11.82,46.37]	[12.18,52.37]	[3.74,21.79]
Age	0.93	0.95	0.96
	[0.86,1.01]	[0.87,1.03]	[0.88,1.05]
Gleason x Age	0.85*	0.82*	0.84
	[0.72,1.00]	[0.69,0.98]	[0.70,1.01]
Interest in sex [d]		0.83	0.85
		[0.57,1.21]	[0.54,1.32]
Cancer anxiety [d]		1.37	1.41
		[0.95,1.97]	[0.89,2.21]
Pt tx preference [e]			
Active surveillance		0.82	0.53
		[0.24,2.82]	[0.14,2.03]
Active treatment		1.54	1.06
		[0.66,3.59]	[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. [b] Reference group = standard decision aid. [c] Reference group = Gleason 6. [d] Measures are standardized. [e] Reference group = neutral
*p < .05. **p < .01. ***p < .001.

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.

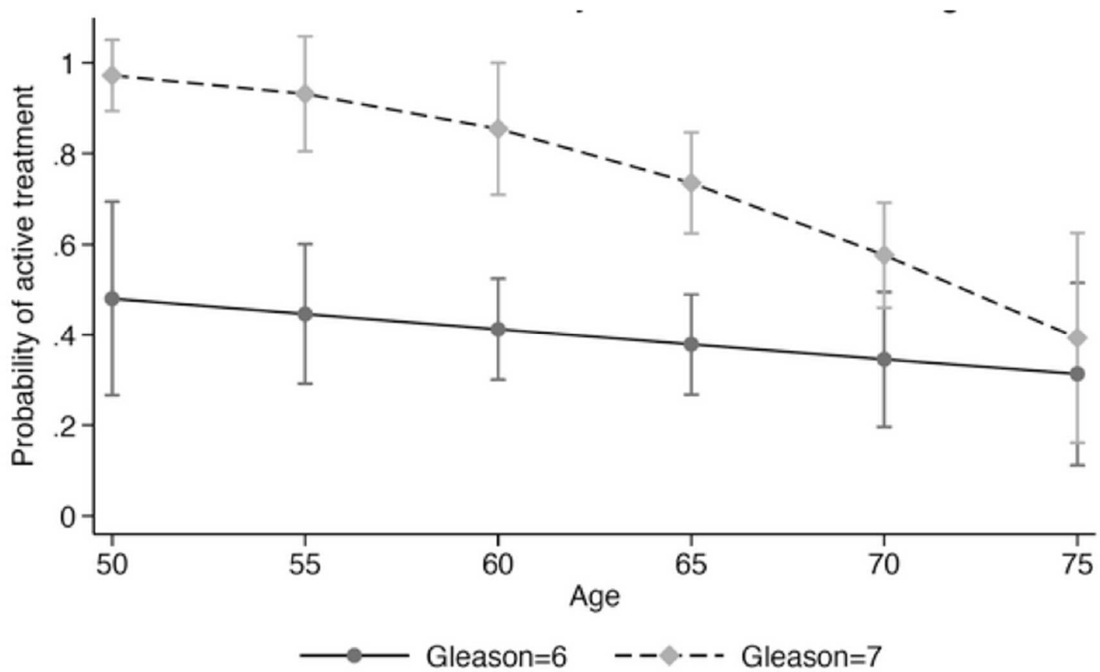

Figure 4. Modeled predicted probability that patients received active treatment as a function of age and Gleason score. Estimates averaged across all other factors in model.

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.

2.3.3 Predicting urologists’ recommendations

First, we examined the simple relationship between urologists’ recommendations and patients’ initial treatment preferences as well as their Gleason scores (Table 2). 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.

Table 2. Urologists' recommendations compared to patients' initial treatment preferences and 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.

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.

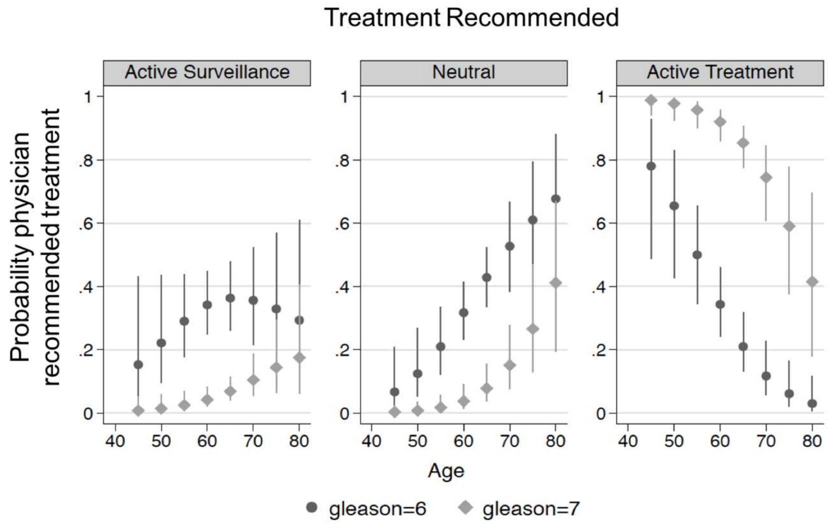

Figure 5. Marginal predicted probability for each type of urologist recommendation as a function patient age and Gleason score. Estimates averaged across all other factors in model. Error bars represent 95% Confidence Intervals.

Recommendations for active surveillance did not vary by patient age. For patients with Gleason 6 tumors, urologists recommended surveillance 20-40% of the time whereas for patients with Gleason 7 tumors, urologists almost never 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 ($\Delta\chi^2 (6) = 0$, $p = 1$). Figure 6 shows the marginal predicted probability that the urologist recommended each option (active surveillance, neutral, and active treatment) as a function of patients' initial treatment preference, separated by Gleason score. There was little consistent effect of patients' initial treatment preferences on urologists' recommendations.

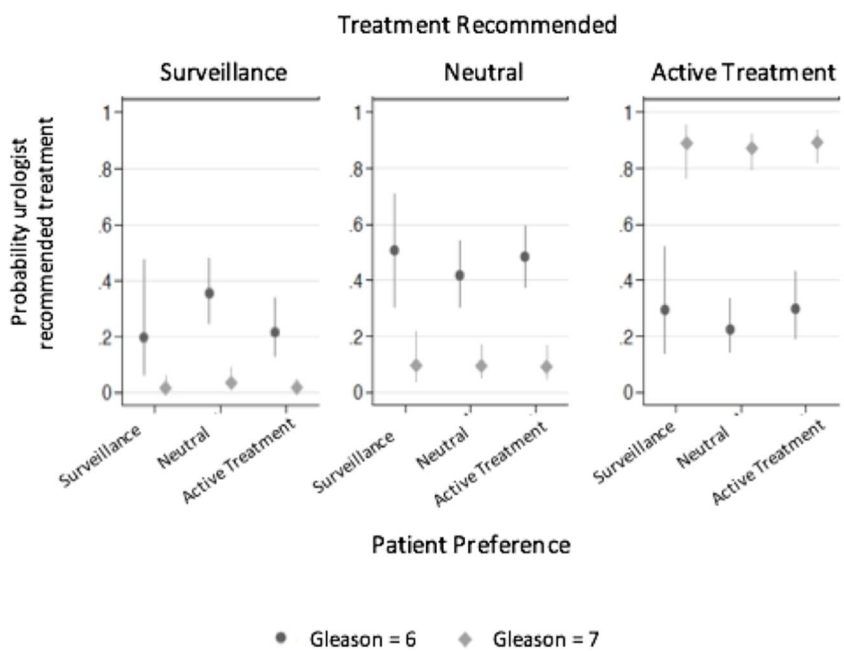

Figure 6. Marginal predicted probability of each type of urologist recommendation as a function of patient initial treatment and Gleason Score. Estimates averaged across all other factors in model. Error bars represent 95% Confidence Intervals.

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.

2.3.4 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 3). 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.

Table 3. Urologists' discussion of sex during appointments

Topic	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

2.3.5 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.

2.4 Discussion and Conclusion

2.4.1 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 (Ubel, 2012). 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 (Pierorazio, Walsh, Partin, & Epstein, 2013). 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 (Sommers et al., 2007). In fact, some experts have even questioned whether physician recommendations are compatible with shared decision making (Frongillo, Feigelmann, Belkora, Lee, & Sepucha, 2013). Physicians have been shown to recommend different treatments to patients than they would choose for themselves (Ubel, Angott, & Zikmund-Fisher, 2011), and rates of active surveillance have been shown to vary dramatically depending on which physician a patient sees (Hoffman et al., 2014), raising questions about whether such recommendations incorporate hidden value judgments (Ubel, 2012). 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 medically-based 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 (Holmes-Rovner, 2015). 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 (NCCN, 2012). 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 (Bill-Axelson et al., 2014). 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 PSA testing, the reason many of the patients in our study received prostate biopsies (Wilt et al., 2012). 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.

2.4.2 Limitations

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 (Oliver, 2007). 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 in the study were fellows or residents. We cannot determine whether more senior urologists would have communicated differently about these treatment decisions, although residents' behaviors may be influenced by their attending physicians

(Feldman, Skeel-Williams, Knox, Coates, 2012). In addition, the majority of urologists were male; given the differences in communication styles between male and female physicians (Roter & Hall, 2004), we cannot determine whether our results would have been different with a higher percentage of female urologists.

2.4.3 Conclusion

In conclusion, patients' treatment choices in our study were determined largely by clinical factors and 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.

3. Essay 2: A randomized controlled trial of a patient communication skills training intervention in the context of early stage prostate cancer

3.1 Introduction

In Essay 1, we found that although a novel patient-centered (vs. standard) decision aid (DA) improved several aspects of patient empowerment (e.g., desire to participate in the decision; Fagerlin et al., unpublished), patients' preferences had no impact on their treatment choices regardless of which DA they received, suggesting patients were not yet fully empowered to participate in the decision-making process. Patients' passivity during clinical appointments may have contributed to this lack of empowerment. We agree with Berry et al. (2003) that "patient education about medical therapies and the patients' own medical factors is not enough. A clinic visit dialogue that brings personal factors to the conversation along with medical factors can guide a man to making his "best choice" for localized prostate cancer." In other words, true patient empowerment requires patients to actively participate in clinical appointments, which may not be accomplished with traditional decision aids. In particular, we hypothesized that patients need procedural knowledge regarding how to participate in clinical appointments to become truly empowered decision makers.

Patient communication skills training may be an effective way to teach patients this procedural knowledge and empower them to participate in their health care decisions (Post, Cegala, & Miser, 2002). However, despite the promise of patient communication skills training interventions, there has been relatively little research in this area. As of 2010, there were only 30 studies that had tested interventions with "at least minimal attention to one of more communication skills" in primary care (Cegala & Eisenberg, 2010; Cegala, 2003; Wilkes et al., 2003). In primary care settings, patient who received communication skills training were more active during appointments (Cegala, Post, & McClure, 2001; Cegala, McClure, Marinelli, & Post, 2000) and experienced positive downstream consequences, such as increased rates of colorectal screening among low-income minority patients (Katz, Fisher, Fleming, & Paskett, 2012). As of 2010, there were even fewer studies of communication skills interventions in the context of cancer, which presents its own unique challenges and thus requires specialized attention (Cegala & Eisenberg, 2010). The results within a cancer context have been less promising, although several limitations across studies limit the interpretation of the studies' null results (Cegala & Eisenberg, 2010). More specifically, many patient communication skills training interventions suffer from three broad limitations: 1) lack of conceptual or theoretical framework; 2) outcome measures that do not match their interventions; and 3) an exclusive focus on question-asking, which is only one form of patient participation (Parker, Davison, Tishelman, & Brundage, 2005).

In this study, we develop and assess the effectiveness of a patient communication skills training intervention on patient empowerment using a randomized controlled trial. In doing so, we are one of the first studies to use a large-scale randomized controlled trial to assess the effect of a patient communication skills intervention in the context of early stage prostate cancer (see Mishel, 2009 for an exception). We address several limitations noted in previous communication skills interventions (Cegala & Eisenberg, 2010; Parker et al., 2005). First, we use theoretical models from multiple disciplines guide the development of the intervention. Specifically, we use Bandura's (1977) model of self-efficacy from the psychology literature and the Comskill model of physician communication skills training from the medical literature (Brown & Bylund, 2010). In addition, we use established barriers to and facilitators of SDM to guide our development of the intervention (Joseph-Williams, Elwyn, & Edwards, 2014). Second, we directly match our primary outcome measures to our intervention (self-efficacy regarding communication skills). Finally, we expand our intervention beyond question asking and aim to also improve patients' expressions of concern and provision of preferences and values.

3.2 Methods

3.2.1 Study design

Patients were recruited at two clinics within a private university-affiliated hospital in the Midwestern United States before receiving prostate biopsies to test for prostate cancer (primarily due to elevated PSA levels on screening tests). Patients completed an initial survey and then were randomized to either the control group (patient-centered DA only) or the intervention group (patient communication skills training video in addition to the patient-centered DA). Randomization at biopsy ensured that men had the opportunity to review the intervention materials before they received their diagnosis and discussed their treatment options with their physicians (which typically occurred 1-2 weeks after the biopsy). Only men diagnosed with low or intermediate risk prostate cancers (Gleason scores of 6 or 7 and PSA < 20) were eligible to continue in the study. Prior to their clinical appointments and learning their diagnoses, patients completed a second survey. Figure 7 shows the basic study flow.

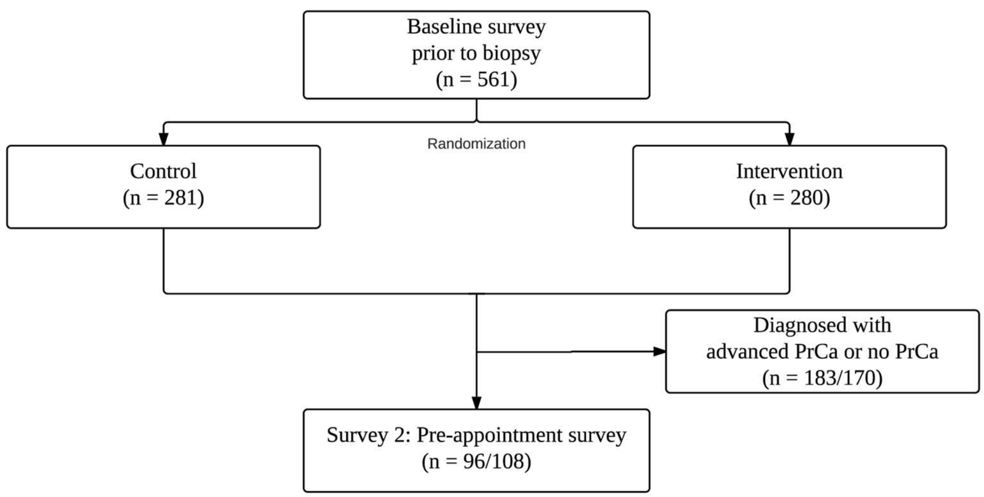

Figure 7. Basic study flow. PrCa = prostate cancer

3.2.2 Materials

3.2.2.1 Patient-centered decision aid

The patient-centered decision aid (DA) was based on our existing booklet "Making the Choice: Deciding What to Do About Early Stage Prostate Cancer," designed to empower men with early stage prostate cancer (Holmes-Rovner et al., 2005). The DA uses plain language and research on information presentation to be accessible to men with lower numeracy and literacy levels. We made modifications based on medical updates and feedback we elicited since the original publication. The modified decision aid was completed in Fall of 2009.

Of note, the DAs differed slightly for the control versus intervention groups. Patients in the intervention group received an "enhanced" DA which differed in three ways from the control DA: 1) there was a summary page of the communication skills and process tasks emphasized in the video with pictures of a patient modeling the behavior (matched on race); 2) the "questions you may wish to ask your doctor" page listed more questions about preferences and the decision-making process rather than purely about knowledge; and 3) there was more space for "notes." Otherwise, the DAs were identical.

3.2.2.2 Patient communication skills training intervention

3.2.2.2.1 Theoretical basis

As noted above, we used Bandura's (1977) model of self-efficacy, the Comskill model of physician communication skills training (Brown & Bylund, 2010), and previously established barriers to and facilitators of SDM (Joseph-Williams et al., 2014) to guide the development of our intervention. Bandura (1977) posits that people's behavior depends, to a large extent, on their efficacy expectations, which are the "convictions that one can successfully execute the behavior required to produce the outcomes." These expectations will influence both the initiation and persistence of a particular behavior. Self-efficacy expectations can be acquired through four principal sources: 1) performance accomplishments; 2) vicarious experience; 3) verbal persuasion; and 4) physiological states. Our communication skills training intervention focuses primarily on increasing patients' efficacy expectations through vicarious experience via modeling of communication skills and verbal persuasion via verbal suggestion and encouragement. To a more limited extent, we also aim increase efficacy through performance accomplishments via encouraged visualization and physiological states by normalizing potential negative emotional reactions that patients may have during their upcoming appointments such that patients do not misattribute their negative emotions to a lack of communication skills, which can undermine efficacy expectations.

The Comskill model of communication was developed in the context of physician communication but we adapted it to patients. The model is based on two theories: goals, plans, and action (GPA) theory and sociolinguistic theory. The Comskill model describes five components of communication for physicians: (1) goals: desired outcome of the consultation or portion of the consultation; (2) strategies: a priori plans that direct communication behavior toward the successful realization of a communication goal; (3) skills: discrete mode (or unit of speech) to achieve fulfillment of a strategy, which are verbal, concrete, teachable, and observable; (4) process tasks: sets of dialogues or non-verbal behaviors that create an environment for effective communication; and (5) Cognitive appraisals: observation and internal processing of the communication partner's verbal and non-verbal behavior (Brown & Bylund, 2010). The communication skills intervention we developed addressed each of these components.

3.2.2.2.2 Development of the intervention

We assembled a team of clinicians and health communication experts to develop the patient activation intervention using the above theoretical models as a foundation. The team reviewed previously-recorded clinical appointments from another study (Scherr et al., 2017a) in which patients learned about their prostate cancer diagnoses and discussed treatment options with their physicians. The team first identified the typical appointment flow as follows: introduction, discussion of biopsy results, discussion of treatment options, and making a decision (Henry et al., 2015). Then, using an iterative process, we identified categories of "communication problems" that often occurred within each of these sections of the appointment. In consultation with communication experts, the team identified strategies that patients could use to overcome each of these communication problems based on the theoretical models outlined above (Table 4).

Table 4. Communication problems and solutions

TYPICAL FLOW	PROBLEM	SOLUTION
Introduction		
Diagnosis delivery/risk classification		
	No time to process bad news	It's hard to give bad news and doctors may be trying to "get past" hard part of job. Ask for time to process the bad news.
	Information given too quickly with extensive use of numbers.	It's hard to take it all in – ask doctors to slow down. Numbers can be confusing – ask doctors to clarify or explain percentages
Discussion of treatment options		
Active Surveillance	Doctors may quickly reject active surveillance	Clarify why surveillance is inappropriate
Active Treatments	Doctors are biased towards their own treatment option	Realize that doctors understand their own treatment best and are biased
	Doctors spend most of their time talking about their treatment and may only able to provide specific statistics for that treatment.	Make sure to get a referral to other specialist (radiation oncologist or urologist). Consider talking to your primary care doctor before making a decision
Recommendations	Doctors may not know the "full story" and may make recommendations that do not incorporate patients' preferences	Let your doctor know your preferences.
Making a decision	Doctors may pressure patient to make decision that day. Doctors offer to schedule surgery with the option of "cancelling" if patients decide they do not want surgery.	Tell your doctor that you want to take time to think about your options before making a decision.
Wrap-up	Doctors often ask "Any final questions?" without really pausing or allowing time for questions	Make sure you get all of your questions answered before you leave.
	Ending may be rushed and patients may be unsure of next steps	Clarify the "next steps" with your doctor.

We decided to use a video to demonstrate these communication problems and model these solutions and visual modeling has been shown to be an effective way to increase self-efficacy regarding new behaviors, second only to actual practice (Bandura, 1977).

An initial video script was created using the identified problems and solutions as a template. The video portrayed a series of hypothetical clinical interactions between patients and physicians (played by professional actors) to demonstrate communication problems and model solutions. After the actors portrayed a communication problem, the narrator would describe the communication problem and describe specific skills for how patients can overcome that particular communication issue. The clinical interaction was then replayed with the patient incorporating the narrator's suggestions and modeling the suggested communication strategy. In all cases, the physician then responded appropriately, potentially increasing patients' outcome expectations, another important aspect of behavior change (Bandura, 1977). Finally, the narrator asked patients to think about which of these strategies would work best for them, getting them to visualize using the new skill, which is a particularly effective way to increase self-efficacy regarding new skills (Bandura, 1977; Anderson & Sharpe, 1991).

We revised the video script according to feedback from communication experts, patients, and their families. First, we revised the script based on critical feedback from our collaborators, which included experts in the field of decision making and health care related decisions, decision aids and patient empowerment, and physicians with expertise in prostate cancer decision making. Second, we elicited feedback from the intended audience - men preparing to undergo prostate biopsies and those with a history of prostate cancer. We conducted individual interviews with four men preparing to undergo prostate biopsies at a urology clinic within the same health system as our study. Next, we elicited feedback from those with a prior history of prostate cancer by conducting: 1) a small focus group comprised of three members (2 men with a history of prostate cancer and the spouse of one of the men); and 2) individual interviews with men with a prior history of prostate cancer (n = 2).

During the interviews and focus group, the video script was offered in a reader's theater format. Men read the video script and listened to an audio recording with readers portraying the patient, doctor, and narrator, and gave their reactions to it. The focus group and interviews were conducted by an experienced interviewer and facilitator who was not one of the readers. The focus group and interviews were conducted in a semi-structured format to identify specific content that was useful, confusing, helpful, upsetting, and/or valuable, and to elicit suggestions for improvements. We completed the focus group and interviews in Fall of 2009 and made revisions to the script based on feedback from the focus group, interviews, and our experts, prior to filming. Filming and editing were completed in March 2010.

Two patient actors were featured in every video, 1 White and 1 Black; there were 2 different versions of the video, one in which the white patient was predominantly featured and one in which the black patient was predominantly featured. Black patients received the video in which the black patient was predominantly featured and non-Black patients received the video in which the white patient was predominantly featured.

See Appendix B for a copy of the final video script.

3.2.3 Measures

Demographics. Patients self-reported their age, ethnicity, and education at the time of recruitment. For the purposes of analyses, race was collapsed into white versus non-white and education was collapsed into associate's degree or less versus bachelor's degree or greater. We recorded each patient's PSA and Gleason score from their medical charts.

Evaluation of the intervention materials. As part of the pre-appointment survey, patients answered several questions regarding their use of the materials they received, whether they would recommend the materials, and the trustworthiness of the materials. Participants also evaluated the quantity and balance of the information. See Appendix C for a list of all questions.

Knowledge. As part of the baseline and pre-appointment surveys, we assessed patients' knowledge of prostate cancer and their treatment options using fourteen questions primarily adapted from previous studies (Lee et al., 2010; Lee et al., 2012; Sepucha, n.d.). For example, patients answered the following question: "For most men with early stage prostate cancer, how much would waiting 4 weeks to make a treatment decision affect their chances of survival?" *(1 = A lot, 2 = Somewhat, 3 = A little or not at all, 4 = I am not sure*). We calculated the proportion of questions participants answered correctly. See Appendix C for a list of all questions.

Patient empowerment regarding the decision-making process. As part of the baseline and pre-appointment surveys, patients were asked eight questions about their decision-making process, all of which were designed to capture some aspect of patient empowerment based on previously-identified barriers to SDM (Joseph-Williams et al., 2014). Specifically, we assessed patients': 1) sense of urgency in making a treatment decision; 2) their perception of the importance of medical factors versus personal preferences in the decision-making process; and 3) their preferred decision-making role (patient-led vs. shared vs. physician-led) using the Control Preferences Scale (Degner & Sloan, 1992). Additionally, as part of the pre-appointment survey we assessed whether participants planned to seek out second opinions (primary care, radiation oncologist, and additional urologist). See Appendix C for a list of all questions.

Patient empowerment regarding clinical appointments. As part of the baseline and pre-appointment surveys, patients answered four questions designed to assess their intentions to use four process tasks during their upcoming clinical appointments. Recall that process tasks are "sets of non-verbal behaviors that create an environment for effective communication" (Brown & Bylund, 2010). Questions were based on process tasks that were emphasized in the communication skills intervention (although they were also mentioned in the DA). Specifically, patients were asked how likely they were to do the following process tasks (*1 = not at all likely, 5 = very likely*): (1) Take notes when talking with your doctor; (2) Bring a tape recorder when talking with your doctor; (3) Bring in a list of questions for your doctor; and (4) Bring someone to the doctor's visit with you.

Patients also answered 10 questions designed to assess their sense of self-efficacy regarding whether they could utilize specific communication skills during their upcoming clinical appointments. Recall that communication skills are verbal, concrete, teachable, and observable "discrete units of speech [that] achieve fulfillment of a strategy" (Brown & Bylund, 2010). Some questions were drawn from the "communication with physician" subscale of the Chronic Disease Self-Efficacy Scale (Lorig, 1996). Additional questions were created by our research team to specifically assess self-efficacy regarding skills taught in the communication skills training. For example, patients were asked, "How confident are you that you could tell your doctor that you did not understand something he or she said?" (*1 = not at all confident, 3 = somewhat confident, 5 = extremely confident*). Because self-efficacy is relatively specific rather than general (Bandura, 1977) and patients may feel self-efficacy regarding one type of skill but not another, we conducted a factor analysis to reveal whether there were underlying latent structures. Factor analysis revealed three sub-domains of self-efficacy, which were consistent with previous literature (Street & Millay, 2001; Cegala, Thoesen Coleman, & Warisse, 1998) and the structure of the communication skills intervention: (1) asking for referrals; (2) expressions of concern; and (3) information seeking/assertive statements. See Appendix C for a list of all questions and detailed results of factor analysis.

3.2.4 Statistical analyses

To test the impact of the video, we used one-way ANOVAs for continuous variables and chi-squared tests for categorical variables. When Levene's test of homogeneity of variance was violated, we used a Brown-Forsythe correction. Although we report the results of parametric tests, when variables were not normally distributed, we used non-parametric tests to ensure results were substantively unchanged. In all analyses for which we had data from both the baseline and pre-appointment surveys, we controlled for patients' baseline values when testing the effects of the intervention at time 2 (after ensuring that were no differences in the baseline measure as a function of condition). Note that we had pre-appointment survey measures but were missing baseline survey measures for 5 patients ($n_{control} = 3$, $n_{intervention} = 2$). We did not include these 5 patients in analyses which included baseline survey measures as covariates.

3.3 Results

3.3.1 Patient demographics

204 patients who were recruited into the study were ultimately diagnosed with early stage prostate cancer and remained in the study past the baseline survey. On average, patients were 61.59 years old (SD = 7.69, range = 43-84). The sample was relatively well-educated (64% had at least a bachelor's degree) and primarily non-Hispanic White (85%). Basic demographics did not differ across condition (Table 5). Note: physician demographics were unavailable at the time of this publication.

Table 5. Patient demographics as a function of condition

Characteristic	control (n = 96)	intervention (n = 108)	Overall (n = 204)	p
Age (*M*, SD)	61.18 (.80)	61.93 (7.52)	61.57 (7.76)	.49
Clinic A (%)[a]	82.3	73.1	77.5	.12
Education (% ≥ bachelors)	61.5	66.7	64.2	.44
Race/Ethnicity (% white, non-Hispanic)[b]	15.6	14.8	15.2	.87
Married or domestic partnership (%)	80.0[c]	86.1	83.3	.25
Gleason 6 (%)[c,d]	47.4	40.7	43.8	.34

[a] All other patients were at Clinic B
[b] Non-white, non-Hispanic (n = 31) included primarily Black (48%) and Asian (16%) patients. The remaining patients were White Hispanic, Black Hispanic, Hispanic, White Middle-Eastern, and White Native American
[c] Data missing for 1 patient
[d] All other patients had Gleason 7 tumors by study design

3.3.2 Evaluation of the intervention materials

Evaluation of the communication skills intervention. The patient communication skills training intervention was highly utilized; 90.7% of patients reported that they watched the entire video and only 6.5% of patients reported that they did not watch it at all. In general, it was highly rated, whereby 92.8% of patients would probably or definitely recommend the video to other men making decisions about prostate cancer treatment.

Evaluation of the DA. The DA was relatively highly utilized, with 76% of patients spending 30 minutes or more reading the DA. The amount of time spent reading the DA did not differ across condition ($F(1,198) = .15$, $p = .70$). The DA was also highly rated, whereby 92.3% of patients would probably or definitely recommend the DA to other men making decisions about prostate cancer treatment. Recommendation scores did not differ across condition ($F(1,198) = 2.73$, $p = .10$).

Evaluation of all intervention materials. Overall, patients felt that the amount of information they received was appropriate in quantity, whereby their mean rating was not different from the mid-point of the response scale ($t(199) = .59$, $p = .56$). Patients' perception of the quantity of information in the materials did not differ as a function of condition ($F(1,198) = 1.14$, $p = .29$). Patients also felt that the information was balanced, with 94.5% of patients agreeing or strongly agreeing that the information was balanced. Again, evaluation did not differ across condition ($F(1,198) = 1.47$, $p = .23$). Finally, patients believed that the information was trustworthy, with a mean trustworthiness score of 9.36 (SD = 1.65), where 0 indicated completely untrustworthy and 11 indicated completely trustworthy. Patients who received the video rated the materials as more trustworthy ($F(1,195) = 6.39$, $p = .012$), although average trustworthiness ratings were high in both conditions ($M_{control} = 9.04$, SD = 1.74 vs. $M_{intervention} = 9.63$, SD = 1.53).

3.3.3 Pre-appointment measures of patient empowerment

Knowledge. Across both conditions, knowledge increased from baseline, from 45.6% of question correct at baseline to 68.4% of questions correct prior to appointments (after reviewing the intervention). As expected, pre-appointment knowledge did not differ across conditions ($F(1,192) = .44$, $p = .51$).

Patient activation regarding the decision-making process. Patients wo received the communication skills training intervention were more empowered on all measures of decision-making process empowerment (Table 6).

Table 6. Patient empowerment regarding the decision-making process

Outcome	control (n = 96)[a]	intervention (n = 108)[b]	p-value
Decision urgency (*M*, SD)	3.30 (1.26)	2.80 (1.21)	.02
Decision role (*M*, SD)	3.39 (.58)	3.65 (.52)	.01
Medical factors vs. preferences (*M*, SD)	2.72 (.75)	2.90 (1.01)	.11
Plan to seek second opinion (% yes)			
Radiation oncologist	51	73	.001
Second urologist	42	46	.48
Primary care physician	81	72	.33

[a] data missing for 3 patients
[b] data missing for 1 patient

Patients who received the intervention reported less decision urgency and believed that it was less important to make a decision quickly ($F(1,192) = 6.00$, $p = .015$; $M_{control} = 3.30$, SD = 1.26 vs. $M_{intervention} = 2.80$, SD = 1.21). In addition, patients who received the intervention wanted to take a more active role in the decision-making process ($F(1,190) = 8.66$, $p = .004$; $M_{control} = 3.39$, SD = .58 vs. $M_{intervention} = 3.65$, SD = .52). Notably, however, patients in both groups were significantly above the mid-point of the scale, indicating a preference for patient-led decision making (for control group: $t(92) = 6.53$, $p < .001$; for intervention group: $t(106) = 12.86$, $p < .001$). Patients who received the intervention expressed a marginal increase in their belief that personal preferences (vs.

medical factors) were more important when deciding how to treat early stage prostate cancer ($F(1,191) = 2.56$, $p = .11$; $M_{control} = 2.72$, $SD = .75$ vs. $M_{intervention} = 2.90$, $SD = 1.01$). Patients who received the intervention believed that the two factors were equivalent ($t(106) = 1.16$, $p = .25$) whereas patients in the control condition believed that medical factors were more important than personal preferences ($t(91) = 3.81$, $p < .001$). Finally, patients who received the intervention were more likely to report that they planned to talk with a radiation oncologist before making their treatment decision ($\chi^2(2) = 11.24$, $p = .004$). They did not differ in whether they planned to talk to a primary care physician or consult a second urologist (ps > .3).

Patient empowerment regarding the clinical appointment. Patients who received the intervention had increased intentions to record their visits ($F(1,190) = 7.30$, $p = .008$; $M_{control} = 1.42$, $SD = .95$ vs. $M_{intervention} = 1.79$, $SD = 1.20$) and increased intentions to take notes ($F(1,190) = 8.33$, $p = .004$; $M_{control} = 2.86$, $SD = 1.43$ vs. $M_{intervention} = 3.23$, $SD = 1.39$). They did not differ in their intentions to bring a list of questions ($F(1,190) = 1.47$, $p = .23$; $M_{total} = 3.88$, $SD = 1.09$) or bring someone with them to their appointments ($F(1,190) = 1.39$, $p = .24$; $M_{total} = 3.77$, $SD = 1.46$). Patients who received the intervention had higher self-efficacy regarding their ability to ask for referrals ($F(1,190) = 9.64$, $p = .002$) and marginally higher self-efficacy regarding their ability to share personal concerns ($F(1,190) = 3.65$, $p = .058$). The intervention did not affect patients' sense of self-efficacy regarding their ability to engage in information seeking/assertive utterances ($F(1,190) = 2.51$, $p = .12$).

3.4 Discussion and Conclusion

3.4.1 Discussion

In this study, we developed a novel theory-based patient communication skills training intervention in the context of early stage prostate cancer and tested its effects on patient empowerment using a randomized controlled trial. The intervention was well-received and highly utilized by patients. Patients who received the intervention improved on several measures of empowerment prior to appointments; they had increased intentions to use two process skills (record their appointments and take notes), a higher sense of self-efficacy regarding asking for referrals and expressing personal concerns during their upcoming clinical appointments, and had more empowered beliefs regarding several aspects of the decision-making process.

Patients face various barriers to empowerment, only one of which is knowledge about their medical condition and treatment options. As Joseph-Williams et al. (2014) noted, knowledge is not power; it is necessary but not sufficient for true empowerment. In our study, we attempted to address this issue by increasing patients' procedural knowledge of how to participate in clinical appointments. Because declarative knowledge is necessary for empowerment, we provided all patients with a patient-centered DA, which increased knowledge equivalently across groups. This suggests that our positive results were, in fact, the result of increases in procedural knowledge rather than increases in declarative knowledge that translated into increases in self-efficacy.

Our results suggest that video videos modeling specific communication skills may be a cost-effective method to distribute communication skills training interventions. Previously, the most effective patient communication skills training interventions have been “high intensity” and included a one-to-one coaching session between the patient and someone like a health coach (Cegala & Eisenberg, 2010); unfortunately, the utility of these interventions is limited by their resource-intensiveness. Our results suggest that communication skills training videos may be a viable, cost-effective alternative to these resource-intensive coaching interventions.

3.4.2 Limitations

There are several limitations to our study. First, it is not clear whether these increases in self-efficacy and intentions will translate into increases in empowerment during clinical appointments. Self-efficacy expectations are a significant determinant of behavior (Bandura, 1977), but clinical appointments are complicated and there may be other factors that affect whether or not patients participate in clinical appointments. Future analyses that examine actual participation in appointments will help elucidate whether the statistically significant increase in self-efficacy associated with the intervention translated into a practically significant difference in patient empowerment during clinical appointments. Second, our sample of men was relatively well-educated (64% had at least a bachelor's degree) and had unexpectedly high levels of self-efficacy prior to our interventions. Thus, our ability to find effects of the intervention may have been limited by a ceiling effect. In fact, this may have been why we failed to find an effect of the intervention on patients' self-efficacy related to information seeking and providing assertive utterances. Alternatively, it may be that communication skills training interventions are not as effective at increasing these skills; future research is needed to better understand these findings. Because self-efficacy interventions require room for improvement (Bandura, 1977), the effect of the communication skills training intervention may be more evident for patients with lower initial self-efficacy. Unfortunately, we are underpowered to reliably test for interactions between demographics and the effectiveness of the intervention within our dataset, but future research should be attuned to this possibility. Finally, all our patients were older males (due to the nature of the disease); we cannot know whether the intervention would work similarly in other patient populations or clinical settings.

3.4.3 Conclusion

Patient communication skills training interventions show significant promise for empowering patients and increasing their participation during clinical appointments, but past studies have suffered from significant limitations. We addressed those limitations and developed a novel, theory-based patient communication skills training video. The intervention addressed several established barriers to shared decision making (Joesph-Williams et al., 2014); it increased patients' intentions to use two process skills (record their appointments and take notes), increased their sense of self-efficacy regarding several communication skills, and improved several common misconceptions about the decision-making process that are often barriers to shared decision making. Our novel patient communication skills training video may be a cost-effective way to empower patients with early stage prostate cancer to more fully participate in the decision-making process.

4. Essay 3: "Doc, what should I do?": Patients' requests for recommendations during clinical appointments

4.1 Introduction

Essays 1 and 2 examined patient decision-making and patient-physician communication at a relatively high level, focusing on appointments as a whole and overall communication. Essay 3 takes a closer look at one specific moment in clinical encounters with particular importance for shared decision making and patient empowerment: patients' requests for recommendations.

When faced with difficult medical decisions, patients may ask their physicians for recommendations. Physician recommendations are an important part of many patients' decision-making processes (e.g., O'Malley et al., 2001; Kinney, Richards, Vernon, & Vogel, 1998; Diefenbach et al., 2002; Ahmed, Bryant, Tizro, & Shickle, 2012). As such, patients' direct requests for recommendations are pivotal moments in clinical appointments. However, despite the importance of patient requests for recommendations, there has been little empirical research on the subject. Furthermore, the limited research that does exist has focused exclusively on the clinician side of these interactions, using simulated appointments to assess how physicians respond to standardized patients' requests for recommendations (Boss, Donohue, Roter, Larson, & Arnold, 2012; Meyer, Lamiani, Foer, & Truog, 2012; Tucker Edmonds, 2015; Corke, Stow, Green, Agar & Henry, 2004). These simulations were designed to assess physicians' responses to patients' requests for recommendations. Thus, they do not provide evidence of how, and how often, patients request recommendations. One study did analyze actual appointments, but also focused exclusively on providers' responses (White, Malvar, Karr, Lo, & Curtis, 2010), once again leaving us with few insights regarding the context in which patients request recommendations.

Currently, we do not know *who* requests recommendations; in other words, we do not know what factors influence whether patients request recommendations. Rather, studies have focused more broadly on patients' desire for physician advice in general (Ahmed, Bryant, Tizro, & Shickle, 2012) and their preferred (e.g., Gwede et al., 2005; Berry et al., 2003) or perceived (e.g., Song et al., 2013) decision-making role. However, no studies have connected patient characteristics to requests for recommendations. For example, we do not know what type of preferred decision-making role is most frequently associated with requests for recommendations. On the one hand, perhaps patients who prefer a physician-led decision-making role are more likely to request recommendations as patients may perceive requests for recommendations as equivalent to handing over responsibility for the decision to their physicians. Alternatively, perhaps patients who prefer a patient-led decision-making are more likely to request recommendations, as patients may perceive requests for recommendations as equivalent to gathering information in order to make the best decision possible. Finally, perhaps patient who prefer a shared decision making approach are more likely to request recommendations, as patients may perceive requests for recommendations as invitations to work together to decide on the optimal treatment choice. A better understanding of the preferred decision making style of patients who request recommendations may help to inform debates regarding the compatibility of physician recommendations and shared decision making (e.g, Gurmankin, Baron, Hershey, & Ubel, 2002; Ubel, 2002).

In addition, we do not know *how* patients request recommendations. We do not know if patients ask their physicians to disclose their personal preferences (e.g., “What would you do?”) or instead ask their physicians for advice in general (e.g., “What should I do?”). The majority of simulated studies instruct standardized patients to phrase their requests for recommendations as requests for self-disclosure (e.g., “What would you do?” or “What would you do if this was your child?”). However, this focus on requests for recommendations phrased as requests for self-disclosure is not based on an empirical examination of patients’ requests for recommendations, but instead by clinicians’ recollections of patients’ requests for recommendations. The content of patients’ requests is important because different ways of requesting advice may raise unique concerns regarding either the appropriateness of self-disclosure or concerns about differences in self-other decision making (Garcia-Retamero & Galesic, 2012; Zikmund-Fisher et al., 2006). Thus, it is important to know if and how patients ask physicians to engage in self-disclosure.

Several authors have written guidelines regarding how to respond to patients’ requests for recommendations, yet these guidelines are not informed by an understanding of the patient side of these requests. The guidelines vary widely in terms of how they advise physicians to respond to patients' requests (Truog, 1999; Truog, 2002; Halpern, 2003, Kon, 2006; Ross, 2003). For example, Halpern (2003) posits that when patients request advice, they are often asking for something else, such as emotional support; he encourages physicians to clarify the "need" behind patients' requests and provide recommendations relatively sparingly. Alternatively, Kon (2006) argues that recommendations are often appropriate and may, in fact, be exactly what patients need. A better understanding of the types of patients who request recommendations and how they make those may provide guidance as we continue to develop these guidelines.

In this paper, we examine patients' requests for treatment recommendations using recorded appointments in the context of early stage prostate cancer, a preference-sensitive decision in which patients choose between active surveillance, surgery, and radiation (Thompson et al., 2007). We also use survey data to examine the characteristics of patients who request recommendations. Thus, using both qualitative and quantitative methods, we examine: 1) how often patients request recommendations; 2) who requests recommendations; and 3) how they request recommendations.

4.2 Methods

4.2.1 Overview of study design

Data was obtained from the same study in Essay 1. The type of decision aid did not influence our main outcome (i.e., whether patients requested recommendations;

$\chi^2(1) = .02$, $p = .90$); therefore, type of decision aid is not included in our analyses (although we consider the implications of this in the discussion).

4.2.2 Qualitative analyses

We uploaded all transcribed appointments into Dedoose, a mixed methods data analysis software program. A team of coders (5 undergraduates and 2 professional research assistants) identified appointments in which patients or their companions (hereafter referred to as "patients" for ease of readability) requested recommendations. After coders were trained, we double-coded 50 randomly-selected transcripts to ensure reliability; there was only one instance in which one coder missed a request for a recommendation that should have been coded. Coders single-coded the remaining 207 transcripts, noting whether patients requested recommendations.

After identifying all transcripts in which patients requested recommendations (n = 47), two coders re-read these transcripts and created excerpts that contained all text from the moment in which patients requested recommendations until the topic changed. Multiple requests for recommendations within a single transcript were allowed. We then used a directed content analysis to identify themes within patients' requests for treatment recommendations (Hsieh & Shannon, 2005). The first author developed initial categories of behaviors (e.g., requests for personal disclosure) based on previous literature. Three coders (KS, NA, and MB) read a subset of excerpts individually, applied the initial codes, and noted other emerging themes. We then met as a research team and developed a preliminary codebook. We engaged in an iterative process to refine the codebook through repeated individual application and team discussions, adjusting the codebook to reflect new observations. Once the codebook was finalized, all excerpts were triple-coded in NVivo. Discrepancies were resolved through team discussion. See Appendix D for codebook.

4.2.3 Measures

Timing of initial requests. We determined "when" in the conversation patients initially requested recommendations by dividing the character count of the first letter of the first request by the total character count of the transcript.

Patient characteristics. At the time of recruitment, patients reported basic demographic variables, including age. We obtained patients' Gleason scores via medical chart review.

Prostate cancer knowledge. Prior to appointments, but after receiving the DAs, patients answered fourteen questions about prostate cancer and their treatment options (Lee et al., 2010, Lee et. al, 2012; Sepucha, n.d.). For example, "For most men with early stage prostate cancer, how much would waiting 4 weeks to make a treatment decision affect their chances of survival?" *(1 = A lot, 2 = Somewhat, 3 = A little or not at all, 4 = I am not sure*). We calculated the proportion of questions participants answered correctly. See Appendix E for list of all questions.

Trust in the Veterans Affairs health care system. Seven to 10 days after appointments,[2] we measured patients' trust in the Veterans Affairs (VA) health care system using a modified version of the 10-question Health Care System Distrust Scale (Rose, Peter, Shea, & Armstrong, 2004). For example, "The VA health care system puts my medical needs above all other considerations when treating my medical problems." (*1 = strongly disagree, 5 = strongly agree*). We averaged patients' responses (alpha = .82). See Appendix E for list of all questions.

Prostate cancer anxiety. Prior to appointments, we measured patients' prostate cancer-related anxiety using the thirteen-question MAX-PC scale (Roth et al., 2003). For example, "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 (alpha = .91). See Appendix A for list of all questions.

Importance of sex. Prior to appointments, we assessed the importance patients placed on sex by asking, "Overall, how important would you say sex is in your life?" (*1 = not at all important, 4= extremely important*).

Preferred decision-making style. Prior to appointments, we assessed patients' preferred decision-making style using the Control Preferences Scale (Degner & Sloan, 1992): "How you would make this decision if you were to end up having prostate

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[2] Unfortunately, we did not collect this measure prior to appointments. However, given that this scale measures a belief system, it should be relatively unchanged by appointments, and thus should still reflect a patient characteristic that may have influenced whether they requested recommendations.

cancer?" (*1 = My doctor(s) will make the decision with little input from me, 2 = My doctor(s) will make the decision but will seriously consider my opinion, 3 = My doctor(s) and I will make the decision together, 4 = I will make the decision after seriously considering my doctor(s) opinion, 5 = I will make the decision with little input from my doctor(s)*). Scores of 3 (the midpoint of the scale) indicate a preference for shared decision making; scores less than 3 indicate a preference for physician-led decision making; and scores greater than 3 indicate a preference for patient-led decision making.

Baseline treatment preference. Prior to appointments, we assessed patients' baseline treatment preferences by asking, "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?" We classified patients as: 1) *preferring active surveillance;* 2) *having no preference* (interested in both active treatment and surveillance or stating no preference); or 3) *preferring active treatment*.

4.2.4 Statistical Analyses

We used chi-squared tests (categorical DVs) and one-way ANOVAs (continuous DVs) to determine the characteristics associated with whether patients requested recommendations. To further quantify the predictive effect of patient characteristics on whether they requested recommendations, we conducted several logistic regressions. We did not conduct an overall multivariate logistic regression because we did not have sufficient power; in addition, we were not interested in examining the predictive power of each characteristic controlling for all other characteristics. Rather, we were interested in the bivariate association between each patient characteristic and requests for recommendations.

4.3. Results

4.3.1 How often patients requested recommendations

Patients or their companions requested recommendations in 18% of appointments (47/257) with a total of 68 discrete requests (range: 1-5 requests per appointment).[3] In 11 appointments, only the patient's companion (and not the patient) made the request(s). For our quantitative analyses of "who" requests recommendations, we exclude appointments in which only the patient's companion requested a recommendation because the influence of patient characteristics on companions' decisions to request recommendations is unclear.[4] For our qualitative analyses, we include all recommendation requests, regardless of speaker. For ease of reading, we often use the term "patients" to refer to both patients and their companions in the main text, although we note the speaker when providing specific quotes.

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[3] In one case, the transcript cut-off immediately after the patient's request. Thus, this transcript is only included in analyses of "who" requests recommendations but not "how" patients request recommendations.
[4] Results remain substantively unchanged if we include those appointments and classify them as ones in which patients did not request recommendations.

4.3.2 Who requested recommendations

Patients who requested recommendations differed from patients who did not request recommendations in four ways (Table 7).

Table 7. Who" requested recommendations: Patient characteristics as a function of whether they requested recommendations

Characteristic	Did patient request a recommendation? Yes (n = 36)[a]	No (n = 210)[b]	p-value
Gleason 6 (%)	55.6	49.5	.50
Age (*M*, SD)	62.64 (6.82)	63.24 (5.95)	.59
Knowledge (*M*, SD)	.45 (.22)	.51 (.24)	.16
Trust in the VA (*M*, SD)	3.98 (.59)	3.92 (.57)	.63
Cancer anxiety (*M*, SD)	1.39 (.74)	.96 (.69)	< .01
Importance of sex (*M*, SD)	2.97 (.74)	2.69 (.87)	.07
Preferred decision-making style (*M*, SD)	3.14 (.72)	3.49 (.61)	< .01
Baseline treatment preference (%)			.10
Active surveillance	8.3	17.3	
Neutral	30.6	40.4	
Active treatment	61.1	42.3	

Note: We excluded data from appointments in which only the patient's companion requested a recommendation.
[a] Anxiety missing for 1 patient. Trust in the VA missing for 7 patients.
[b] All data except age missing for 2 patients. Importance of sex missing for 1 additional patient. Trust in VA missing for additional 40 patients.

First, patients who requested recommendations reported higher anxiety about prostate cancer ($F(1,241)=11.02$, $p=.001$, $d=.60$); for each unit increase in cancer anxiety, patients had 2.21 times the odds of requesting a recommendation (Wald (1) = 9.97, $p = .001$, 95% CI [1.35, 3.62]). Second, patients who requested recommendations felt sex was marginally more important in their lives ($F(1,241)=3.40$, $p = .07$, $d=.35$); for each unit increase in the importance of sex, patients had 1.50 times the odds of requesting a recommendation (Wald(1) = 3.30, $p = .07$, 90% CI [1.04, 2.17]). Third, patients who requested recommendations differed in their preferred decision-making style ($F(1,242)=9.53$, $p=.002$, $d=.52$). Patients who requested recommendations preferred a shared decision-making style (their mean score did not differ from the scale mid-point ($t(36)=1.15$, $p=.26$) whereas patients who did not request recommendations preferred a more patient-led decision-making style (their mean score was significantly higher than the scale mid-point ($t(207)=11.52$, $p<.001$)). For every unit increase in the Control Preferences Scale, patients had .45 times the odds of requesting a recommendation (Wald (1) = 8.59, $p = .003$, 95% CI [.26, .77]. Fourth, patients who requested recommendations had marginally different treatment preferences prior to their appointments ($\chi^2(2)=4.72$, $p=.10$, Cramer's $V=.15$), which was driven by differences in preferences for active treatment versus active surveillance ($\chi^2(1)=3.92$, $p=.05$, Cramer's $V=.12$). Patients who preferred active treatment prior to their appointments had 2.14 times the odds of requesting recommendations (Wald(1) = 4.25, $p = .04$, 95% CI [1.04, 4.42]).

Patients who requested recommendations did not differ in terms of Gleason score, age, knowledge, or trust in the VA health care system (ps > .15).

4.3.3 How patients requested recommendations.

4.3.3.1 Timing and context of initial requests

Patients' initial requests for recommendations generally occurred after their physicians provided them with at least some information regarding their diagnosis and treatment options. In 75% of appointments, the first request occurred after 50% of the appointment had passed. Patients' initial requests occurred after four types of physician behaviors: 1) provision of information (44%); 2) elicitation of questions (22%); 3) discussion of the "next steps" of the decision-making process (22%); and 4) elicitation of treatment preferences (9%). See Table 8 for exemplars of each of behaviors.

Table 8. Context of requests: Types of physician behaviors prior to patients' initial requests

Physician behavior prior to request	Exemplar	Frequency (%)
Providing information	So radiation is very much localized directly to the prostate, other than the side effects that I mentioned with the bowel and bladder, you're not going to lose your hair with radiation. Most people are able to function at their normal level, even while they're getting their radiation treatments. So it's not like a systemic big type thing, it's directed specifically to the prostate.	48
Eliciting questions	Do you have any questions based on what I said?	22
Discussing "next steps" for decision	So that's the way I kind of see it. You don't have to make any decisions today, this is just a counseling session, you can just kind of come back and say, "Ok Doc thanks for talking to me about it, I will look into it." I can give you some pamphlets if you want to read about it. You can come back and see us in 2 weeks or something.	22
Eliciting treatment preferences	Um, what are your thoughts on those [treatment options]?	9

4.3.3.2 Role of physicians' recommendations and physicians as experts

As part of their requests, some patients discussed the role of physicians' recommendations in their decision-making process. Several patients (n = 3) indicated that they intended to follow their physicians' recommendations:

> "The decision as to which way I go is gonna be based on what you tell me as far as, you know, the direction I should go. You know, what's best…what needs to be done, you know?"

Other patients and companions (n = 3) acknowledged their own (the patient's) role as the "final decision maker" while requesting a recommendation. For example, one companion acknowledged her husband's ultimate authority in making the choice while requesting a recommendation:

> "Just throw it out there, you know, because if he says there's two options for his age, you being a smart man, a doctor, what would you suggest? I mean it's your [the patient's] decision, but - "

Finally, some patients (n = 3) questioned whether their physicians could actually provide recommendations. For example, one patient asked his physician, "What would you recommend?" but then immediately appended his request with "Or, don't you do that?", questioning whether his physician could provide recommendations.

Patients referenced physicians' expertise when requesting recommendations in 15% of appointments (7/46). This ranged from simply acknowledging that the physician had extensive experience ("You've done a lot of these.") to specifically calling the physician an "expert" and noting this expertise as the reason for their request:

> "You're the surgeon, you're the expert…Because you're the surgeon, you know more about that. If this was your father, what would you do?"

4.3.3.3 Repeating requests

Twenty-six percent of patients (12/46) requested recommendations more than once during their appointments. Patients repeated their requests in two ways: (1) within a single discrete exchange (n = 7); and (2) across multiple exchanges, each of which began with a recommendation request (n = 5). In all cases, patients' second requests occurred after their physicians did not provide recommendations in response to their initial requests. For example, one patient's companion repeated her request after the physician hesitated to provide a recommendation in response to her initial request:

> Companion: So what is your recommendation?
>
> Physician: It's a really tough call. Uh (trails off).
>
> Companion: But I, I need for you to be matter-of-fact, point to a—I mean matter-of-fact, to a point.
>
> Physician: I mean and I'm not even beating around the bush cause I'm trying to be polite or something, and even if you were -
>
> Companion: We ain't gotta be polite! Go on.
>
> Physician: Yeah, but even if, even if you were my dad or relative, I mean I can't sit here and say definitely "Oh, there definitely this is what you need to have done." I just really can't.
>
> Companion: Well, your recommendation then is?

In one case, the patient repeated his request for a recommendation a third and fourth time even though the physician provided a recommendation in response to his second request.

4.3.3.4 Requests for personal disclosure

Patients asked physicians to disclose their personal preferences using some form of "What would you do?" (WWYD) in 40% (17/46) of the appointments in which they requested recommendations. Some patients simply asked, "If it was you what would you do?" while others specifically asked their physicians to take their personal situation into consideration:

> "I'm curious - if you were seventy six and had the same situation I've got, do you have any idea what you would do?".

Some patients asked their physicians to engage in personal disclosure in anticipation of (or in response to) their physicians' refusal to provide them with recommendations. For example, one patient stated, "I know you can't give me an absolute answer here, so I'm going to ask you what you would do if you were sitting here in this chair." In addition, 42% of patients who repeated their requests (5/12) changed the form of their request to WWYD after their physicians did not provide recommendations in response to their initial request. This shift to WWYD occurs in the following exchange:

> Patient: Okay, so what would you recommend?

Physician: (sigh) It's hard to say.

Patient: No, I, I'm not saying what I'm thinkin. I'm saying what would you do?

4.4. Discussion and Conclusion

4.4.1 Discussion

In the context of early stage prostate cancer, patients and/or their companions directly asked physicians for recommendations in approximately 20% of appointments. Patients who requested recommendations had increased anxiety about prostate cancer, placed more importance on sex, preferred shared (vs. patient-led) decision making, and were more frequently interested in active treatment prior to appointments. Patients' requests typically occurred in the latter half of appointments and most commonly occurred while physicians were providing patients with information about their prostate cancer or treatment options. When requesting recommendations, patients discussed physicians' expertise and the role of their recommendations, repeated their requests, and asked physicians to self-disclose.

Our discovery of "who" requests recommendations offers insights into the potential needs of patients who request recommendations and may help to inform debates regarding how physicians should respond to requests for recommendations. For example, the fact that patients who requested recommendations had higher anxiety about prostate cancer suggests that some patients requesting recommendations may be benefit from emotional reassurance. Alternatively, it is possible that patients with higher levels of prostate cancer anxiety are experiencing more decision conflict, given that the "classic" decision trade-off is between living with an untreated cancer in one's body (which can be anxiety-provoking) versus dealing with treatment side effects such as impotence and incontinence. Patients with increased anxiety or interest in sex may be struggling more to balance these side effects, and thus may benefit from physicians who help them connect their values with the treatment options. Finally, patients who requested recommendations were more likely to prefer active treatment (versus active surveillance or no preference). Because patients were meeting with surgeons (urologists), who are likely to recommend surgery (a form of active treatment; Kim et al., 2014), perhaps patients were more likely to request recommendations when they anticipated that their physicians' recommendations would match their baseline preferences based on their physicians' attitudes towards the treatment options prior to their requests. This suggests that some patients may be looking for reassurance of their current leanings when requesting recommendations.

Our findings also offer insight into how patients perceive the role of physicians' recommendations in their decision-making process. In general, patients who requested recommendations preferred a shared decision-making approach, suggesting that patients consider asking for advice to be part of a shared decision-making process rather than as equivalent to giving physicians control of the decisions. Notably, there were a few exceptions to this, whereby patients specifically informed their physicians that they intended to follow their advice. However, patients usually appeared to request recommendations so that they could incorporate them into their decision-making process, rather than ceding control of the decision-making process to their physicians. Interestingly, some patients actually questioned whether their physicians could provide recommendations, suggesting that patients (like physicians) may also be uncertain about the role of physician recommendations in the context of preference-sensitive decisions (Boss et al., 2012).

The characteristics of patients that did not differ as a function of whether they requested recommendations also provides insights into the reasons patients request recommendations. Specifically, patients' prostate cancer knowledge was not associated with requests for recommendations, suggesting that patients who requested recommendations were not doing so because of a relative lack of knowledge. Patients who request recommendations may not be doing so simply because they do not understand their options, and thus may not be looking for physicians to respond with more information. In addition, patients' cancer severity (Gleason scores) did not differ as a function of whether they requested recommendations, suggesting that patients' decisions to request recommendations were driven more by personality factors than medical characteristics.

Notably, we failed to find several predicted associations between patient characteristics and requests for recommendations. First, we did not find any difference in age, which is surprising given that past studies consistently find that patient age influences their preferred decision-making style (e.g., Song et al., 2013). It is possible that we did not have enough variation in our sample to find a difference, given that most men in our sample would have been considered "older" in previous studies (90% of patients were between 55 and 71 years old). In addition, these past studies have examined patients' preferred decision-making role, not their requests for recommendations; patients' decisions to request recommendations are influenced by a variety of factors, only one of which is preferred decision-making role. Second, there was no difference in trust in the Veterans Affairs health system. It is possible that patients' trust in their individual physician (rather than in the overall VA health system) may have been associated with whether patients requested recommendations, but we did not collect those data. Of note, trust in the VA was measured after appointments. However, given that this scale measures a belief system, it should be relatively unchanged by appointments and thus should still reflect a patient characteristic that may have influenced whether they requested recommendations.

Our results raise a number of interesting avenues for future research, particularly regarding patients' requests for physicians to engage in self-disclosure. We found initial evidence that patients may strategically use requests for personal disclosure when they experience (or expect to experience) resistance to receiving recommendations. Future research could examine whether physicians are more likely to provide recommendations when patients asked them to disclose their personal preferences. This would be particularly important given differences in self vs. other decision-making, whereby physicians may choose different treatments for themselves than they recommend for their patients (Garcia-Retamero & Galesic, 2012). Notably, we found that less than half of patients requested their physicians disclose their personal preferences, which suggests that research on patient requests for recommendations should broaden from its near-exclusive focus on requests phrased as "What would you do?". Interestingly, the current focus on WWYD seems to be based at least partially on physicians' recollections of being asked this question. Future research could examine whether physicians overestimate the frequency with which they are asked WWYD. Perhaps physicians feel more emotional burden when patients ask them to engage in personal disclosure and thus remember these requests more than other types of requests due to the tendency to more strongly remember emotional events (Cahill & McGaugh, 1995).

4.4.2 Limitations

Our study has several limitations. Our results may be limited in terms of generalizability for several reasons. First, our patients were male and in the VA system. Given differences in communication styles between males and females (Hall & Roter, 1995; Street, 2002), it is unclear if our findings would hold for female patients. In addition, patients in the VA are sicker, poorer, and less educated than non-VA patients (Oliver, 2007), and their history of military service may influence their willingness to accept the traditional hierarchy between patients and physicians. (Thomas, 2011). Second, the majority of our physicians were male and residents. Although we focused on patients' behaviors, it is important to consider that patients may behave differently when meeting with different types of physicians. Third, our results may not generalize outside early stage prostate cancer, particularly in medical contexts with differing disease severities. Fourth, all patients in our study were provided with Decision Aids (DAs), which is not representative of standard practice. Patients who do not receive DAs may differ in their requests for recommendations.

In addition to concerns about generalizability, our study is limited in that we did not analyze entire appointments; thus, it is possible that other non-examined factors may have influenced whether patients requested recommendations. For example, some patients who did not request recommendations may have received unsolicited recommendations, and thus they did not need to request recommendations from their physicians. However, given that physicians were more likely to provide strong recommendations to patients with Gleason 7 tumors (Scherr et al., 2017a), if differences in unprompted recommendations were driving our results, we would expect fewer individuals with Gleason 7 tumors to request recommendations, which we did not observe.

4.4.3 Conclusion

In the context of early stage prostate cancer, patients and/or their companions asked their physicians for treatment recommendations in approximately 20% of appointments. Patients who requested recommendations were unique in several ways: they had higher cancer anxiety, felt sex was more important, preferred shared (vs. patient-led) decision making, and were more likely to prefer active treatment prior to their appointments. Patients engaged in several behaviors while requesting recommendations: (1) discussing physicians' expertise and the role of their recommendations; (2) asking physicians to engage in personal disclosure; and (3) repeating their requests. Exploratory analyses suggest that some patients may have strategically used these behaviors to encourage their physicians to provide them with recommendations.

4.4.4 Practice Implications

Physicians should be prepared for some patients to request recommendations, including requests for them to disclose their personal preferences (although this may not be as common as previous literature suggests). Patients who request recommendations may differ from patients who do not request recommendations in terms of their personalities and values (e.g., increased anxiety), and they may have unique needs that physicians could address when responding to requests. In general, patients do not appear to consider physician recommendations to be at odds with patient autonomy.

Rather, patients may consider physician recommendations to be a part of a shared decision-making process, although a small minority of patients may request recommendations with the intention of delegating decision-making power to their physicians.

5. Conclusion

In this dissertation, I explored how men with early stage prostate cancer make treatment decisions. Essays 1 and 2 examined the effects of two different interventions designed to increase patient involvement in the prostate cancer decision making process. Essay 3 looked more closely at patients' requests for recommendations, a clinical moment with particular importance in patients' decision-making process.

In Essay 1, we found that although a patient-centered (vs. standard) DA increased patients' desire to participate in clinical appointments (Fagelin et al., unpublished), it did not increase the likelihood that patients received preference-concordant treatments. Rather, regardless of the type of DA patients received, their treatment choices were driven by physicians' recommendations which, in turn, were driven entirely by medical factors and not patient preferences. This failure of the intervention to truly empower patients seemed to be due (at least in part) to patient passivity during clinical appointments.

Thus, in Essay 2, we developed and tested a patient communication skills training intervention that was designed to teach patients specific ways to interact with their physicians during their upcoming clinical appointments. The intervention was positively received by patients and increased several measures of empowerment prior to clinical appointments. Communication skills training interventions in the form of videos reviewed prior to appointments may be a cost-effective way to empower patients in complicated medical settings.

Finally, in Essay 3 we examined a particularly important moment in clinical appointments: patients' requests for recommendations. Our analysis of "who" requested recommendations and "how" they requested those recommendations provides new insights that may be incorporated into "best practice" guidelines regarding how physicians should respond to patient requests for recommendations. For example, our findings suggest that most patients who requested recommendations perceived it to be part of a shared decision making process rather than as equivalent to ceding responsibility for the decision to their physicians.

Empowering patients as decision makers is a complex, difficult process with many barriers. Consistent with previous research, we posit that for many medical decisions knowledge alone is not power (Joseph-Williams et al., 2014), and both patients and physicians may be uncertain how to behave in this new paradigm of patient empowerment. Continued research is needed to truly transform clinical medicine into a domain in which patients are empowered to fully participate in the medical decision-making process.

Appendix A: Survey measures for Essay 1

<u>Prostate Cancer Anxiety</u>

Please tell me how frequently these comments were true for you during the past week…

(0 = not at all, 1 = rarely, 2 = sometimes, 3 = often)

1. Any reference to prostate cancer brought up strong feelings in me.
1. Even though it's a good idea, I found that getting a PSA test scared me.
2. Whenever I heard about a friend or public figure with prostate cancer, I got more anxious about prostate cancer.
3. When I thought about having a PSA test, I got more anxious about my having prostate cancer.
4. Other things kept making me think about prostate cancer.
5. I felt kind of numb when I thought about prostate cancer.
6. I thought about prostate cancer even though I didn't mean to.
7. I had a lot of feelings about prostate cancer, but I didn't want to deal with them.
8. I had more trouble falling asleep because I couldn't get thoughts of prostate cancer out of my mind.
9. I am afraid that the results from my PSA test will show that I have prostate cancer.
10. Just hearing the words "prostate cancer" scared me.

In thinking about the past week, please tell me how much you disagree or agree with each statement. (0 = strongly disagree, 1 = disagree, 2 = agree, 3 = strongly agree)

11. Because cancer is unpredictable, I feel I cannot plan for the future.

12. My fear of having cancer gets in the way of my enjoying life.

Appendix B: Script for patient communication skills training video

I. TALKING WITH YOUR DOCTOR ABOUT EARLY STAGE PROSTATE CANCER

Doctor: That's the one good thing about early stage prostate cancer… it's really slow growing and you can take time to decide. You don't have to decide right now. You can take a couple of months weigh your options, talk to people… and then make what you think is the best decision for you.

Narrator: If you're watching this video then possibly you or someone you care for may soon be finding out whether they have prostate cancer. It is never easy to find out you have cancer. If you find out you have prostate cancer, you'll have a decision to make. This video, along with the booklet ""Making the Choicer"" will help you make that decision. The booklet will give you information to understand prostate cancer - what it is, how its treated, and what the side effects are of treatment. The video will give you what you need to be actively involved in this decision. We'll show you where conversations with a doctor and a patient can go wrong. We'll also show you examples of what patients can do to get more involved - what you can do to get your opinions and preferences across to your doctor. This decision about how to treat prostate cancer isn't just a medical decision. It isn't just about what the doctor thinks. The treatments can also have a big effect on your life afterward.

Doctor 2: The treatments have side effects. The side effects can make you unable to have sex… or need to wear a diaper.

FORMER Patient (interview): When I first found out, I didn't realize how much my decision would matter. Depending on the choice I made, I might need to buy diapers. I might not be able to make love to my wife. At first, I thought the doctor should just decide. He's the expert, right? But now, I see how it's really my decision because it affects my life.

Doctor: But there's also a treatment where you can just leave the cancer alone and watch it carefully.... but then you're living with cancer in your body.

Narrator: If these things matter to you, then getting involved in this decision is very important. Your doctor may not know what's important to you, but you can let him or her know. But we're going to help you with all of this. We'll go through a typical doctor visit and give you tips to help you with each step... From getting your biopsy results to talking about treatments and side effects, and finally to making a decision. In this video, we'll try to make it easier for you to ask the questions that matter most. We'll talk about getting a second opinion. And we'll talk about taking the time you need - even months - to make this decision. Let's get started. Next, we're going to show you a visit where a patient finds out that his biopsy shows he has cancer. The scenes you'll see are based on actual visits with doctors. Try not to worry about exactly what the doctor says about the cancer. Instead, pay attention to how overwhelmed the patient is by the information...

II. GETTING BIOPSY RESULTS

Doctor: So it sounds like you're recovering ok from the biopsy itself.

Patient: Yeah, everything is back to normal now.

Doctor: Ok, great. Well, your biopsy results are back from pathology. And you know, we take 12 cores. The bad news is that of those 12, 5 of them did show some cancer in them. [patient speaks, but doctor doesn't really acknowledge it]

Patient: [shrinking, dismayed] Oh.

Doctor: [continuing without a pause] Of those 12, five are positive … so we did find some cancer. [fading out] And so now, what I want to talk to you about…

Narrator: It's never easy to find out that you have cancer. But doctors try to do their best to deliver the news in a compassionate manner. But as you can see from this scene, the news is overwhelming. Imagine how this man feels, having just learned he has cancer.

Patient (interview): After the doctor told me I had cancer, the next few minutes felt like a blur. The doctor was doing his best to explain where I had cancer, and how much cancer I had, but all I could hear was the word "cancer."

Narrator: Now imagine how the doctor probably feels at this time. It's not easy to give patients bad news. We think that may explain why some doctors move very quickly from breaking the bad news right into the long and technical discussions of a patient's diagnosis…Now, you'll see the doctor go over the patient's Gleason score. Again, you don't need to remember what the doctor is saying, but notice how many details he gives in a short time.

Doctor: [talking fairly quickly]: The way we typically split it up is into thirds: low risk, intermediate risk, and high risk. Low risk is Gleason 6, intermediate risk is usually sevens, your three plus four or four plus three, depending on how it looks under the microscope, and then 8, 9 and 10 are all high risk. So yours was an intermediate risk. So it's in the middle. It was three plus three and three plus four, so just enough of the atypical cells of the grade for to make it three plus four which means you're intermediate risk. [fades out]

Patient: [pretends to understand]

Narrator: All the numbers and information can be confusing and overwhelming… especially when people have just learned they have cancer. Is there anything patients can do to slow down the doctors? How can people get more time to understand this important information? Let's go back to that last encounter, and see what the patient could have done to help the doctor communicate more effectively.

Doctor: [fade in; doctor talking fairly quickly] ... intermediate risk is usually sevens, your three plus four or four plus three, depending on how it looks under the microscope, and then 8, 9 and 10 are all high risk.

Patient: [looking confused]

Doctor: I see I am going too fast. Let me try this again…

Narrator: The first time we showed this patient, he tried to ""act nice"" by nodding his head, as if he understood what the doctor was saying. The second time, he showed his confusion on his face so the doctor knew he needed to slow down. Don't be afraid to show the doctor when things are confusing to you. Sometimes facial expressions work, but other times it's not enough. Watch how the patient jumps in when the doctor didn't see or respond to the confused look on his face.

Doctor: [fade in] … depending on how it looks under the microscope, and then 8, 9 and 10 are all high risk.

Patient: [looking confused; gesturing to stop the doctor]

Doctor:[doc didn't see patient's face - looking at chart] So yours was an intermediate risk. So it's in the middle. It was three plus three and three plus four, so just enough of the atypical cells…

Patient: I'm sorry, doctor. Could you say that again? I don't really understand what a Gleason score is. And what this all means…

Doctor: Oh, sure… no problem… The Gleason score tells you how fast …

Doctor (interview): I try to explain things in a way my patients understand, but this is complicated stuff. I never know how much they already know about it… or whether I'm going too fast. So I really have to rely on the patient to let me know when they're confused.

Narrator: Think about what style would work best for you, if you found yourself in this situation. Think of what you might say, to slow the doctor down so you have time to absorb this new information. Here are a few more ideas to consider. If it feels more comfortable for you, tell the doctor you need to explain it to your wife - so you really need to make sure you understand it."

Doctor: It was three plus three and three plus four, so just enough of the atypical cells…

Patient (gently interrupting): My wife will want me to explain this to her later, so I have to be sure I get it right. Can you say that again please?

Narrator: Ask the doctor to slow down so you can take good notes.

Doctor:It was three plus three and three plus four, so just enough of the atypical cells…

Patient: (gently interrupting) I'm trying to write this down, but it's a little fast. Could you go over that again?

Patient (interview): "I didn't want the doctor to think I was stupid. So I just found myself nodding my head, like I understood what he was saying. I knew it was important to remember, but I was having a hard time understanding. So, I told my doctor I was confused, and then he described it in a way I could understand. "

Narrator: Even if your doctor does do a great job of explaining, it's still a lot to remember. Here are some more ideas that might help you remember the details of your visit.

Patient (interview): I was nervous about the results and knew I'd have a hard time remembering. One of my friends told me to bring a tape recorder. I was glad to have it so I didn't have to write stuff down and could pay attention to what the doctor was saying. Plus, I figure I can listen to it again or even have my other doctor listen if I ask him for a second opinion.

Narrator: A lot of patients also find it helpful to bring a loved one with them to their appointments. They can help take notes, ask questions the patient might not think of, and help remember some of the details.

Patient (interview): When I got this video, I also got a booklet. I read the whole thing, and it turned out to be really helpful. It had a lot of the same information in it that the doctor talked about… so in my appointment, I didn't feel like it was the first time I was learning some of it.

Narrator: Also included with this video is a booklet called "Making a Choice: Deciding What to Do About Early Stage Prostate Cancer." It's a great place to write questions for your doctor and to keep track of your scores and test results. There's a place to write them down near the back. We've just shown you how a typical visit begins. We've also given you some examples of how to make sure you understand and remember the information your doctor tells you. You might think of others that would work better for you. Let's go back to the visit. This is when doctors often start talking about treatment options.

III. LEARNING ABOUT TREATMENT

A. Active Surveillance

Doctor: Early stage prostate cancer is typically slow growing, so you can take some time and kind of think through things before you decide what kind of treatment you want. But let's talk about your treatment options…

Narrator: For people with early prostate cancer, they have three main options. The first is watchful waiting, which is also called active surveillance. This is where doctors keep a close eye on your cancer at regular checkups. With watchful waiting, you don't do anything to get rid of the cancer unless it grows or causes problems. If you choose watchful waiting now, you could still choose to start another treatment later, if you want. One thing we notice in conversations like these, is that doctors sometimes talk patients out of this option... even though for many men with prostate cancer, it's their best option. Let's watch what happens while the doctor describes Watchful Waiting to the patient. This is based on a real interaction between a patient and a doctor. In this scene, notice how quickly the doctor dismisses watchful waiting for this patient.

Doctor: There’s three standard options we offer to people with early prostate cancer. The first is called active surveillance or watchful waiting. So really it’s more of watching than it is actual treatment. Prostate cancer grows really slowly, so sometimes we just say 'let’s just watch it real closely, let’s see what see happens.' That is a good option if your life expectancy is less than 10 years or if you have a low risk prostate cancer. For you, 62 is young in prostate cancer terms. We anticipate you've got another 20 or so years to live and you have an intermediate risk prostate cancer. So watchful waiting is an option you can choose but it’s not one that we would recommend. [fading out] The other two options, surgery and radiation...

Narrator: The doctor talks about active surveillance or watchful waiting as an option. But soon says he doesn't recommend it. The patient didn’t get much time to ask questions about watchful waiting or really give it much thought.

Patient (interview): When I walked in the room, I wasn't sure what I wanted to do. I'd rather not have to deal with the side effects. But, I don't know if I could get used to LIVING with cancer, either. The biggest thing was that it was hard to tell why my doctor took watchful waiting off the table so quickly. Was it because I SHOULDN'T choose watchful waiting for some medical reason? Or, was he just guessing about which things are important in my life?"

Doctor: No matter what options people choose for treatment (surgery, radiation, or watchful waiting), the chances of surviving for 5 years are about the same. It's really the patient's choice.

Narrator: What's your preference? Would you rather get the cancer out. Do you want to avoid the risk of side effects? So what could the patient have done differently in this situation? Let's look at the conversation again. This time, the patient interrupts the doctor to talk in a little more detail about watchful waiting.

Doctor: [fading in]… Watchful waiting is an option for you, but we wouldn't recommend it. As I said, you're an otherwise healthy guy, so we'd recommend treatment for you.

Patient: Ok. So you wouldn't recommend watchful waiting for me? But I could go that route - is that what you're saying?

Doctor: Yes, watchful waiting is an option… but most people your age don't like the thought of living with cancer.

Patient: Well, for me… I just don't want to deal with the side effects.

Narrator: This may be the first time you meet with the urologist. He may not know you as well as your regular doctor… so he won't know what you want most out of this decision. This is part of why it's so important that you ask questions and make your wishes known. In some cases, though, the doctor may have more medical reasons he or she doesn't recommend watchful waiting.

Patient: Ok. So you wouldn't recommend watchful waiting for me? But I could go that route - is that what you're saying?

Doctor: It's a choice you could make, but I don't recommend it. Your cancer is more worrisome than others, even with the same Gleason score. Let me explain… [fades out]

Narrator: For most patients with early prostate cancer, watchful waiting is an option.

Doctor: Sometimes, we don't recommend watchful waiting for certain patients. Sometimes, doctors might assume what the patient wants - but they may not always be right. Other times, these reasons are medical. There might be something about the patient's specific cancer or health that makes the doctor think it's not a good option.

Narrator: It's important to know what your doctor's reasons are. Are they guessing about what matters in your life? Or are they making a recommendation for medical reasons? The only way to find out is to ask questions. Also, let your doctor know what is important to you. Some people really want to just get rid of the cancer. Other people really don't want to deal with the side effects, like leaking urine or sexual problems. It's a trade-off only you can make, and it's important to tell your doctor how important each of these issues is to you. Also, let your doctor know what your other health problems are. Sometimes, they don't know your full health history and that may affect which treatment option makes the most sense for you. To learn as much as you can about the side effects and each different treatment, look over the booklet included with this video. Next, let's look at how this doctor presented the two other treatment options: surgery and radiation. We don't want you to pay attention to all the details of radiation and surgery. We want you to notice how this doctor, a surgeon, discusses radiation only briefly and moves right into what he knows best - surgery. "

B. Surgery and Radiation

Doctor: So the first option is radiation. Radiation is done by the Radiation Oncology Department here. Usually, you'd come in every day, five days a week, for somewhere between 6 and 8 weeks. They shoot focused radiation right at your prostate. Initially there aren't a ton of side effects but then over time, over a period of years, people do start to develop side effects from the radiation and those can range from leaking urine, to not being able to get an erection, to irritation of your bladder or your rectum because those are the things that are right by where your prostate is. You can get blood in your urine, blood in your stool, chronic pain when you have a bowel movement, chronic pain when you urinate, things like that. So that's radiation and then the other option is surgery and that's what we do as the surgeons..."

Narrator: The doctor gave some information about radiation, and didn't pause for questions. Remember, it's ok to ask the doctor to slow down. It's ok to ask questions. Maybe the doctor isn't leaving time for questions because he doesn't know the answers. Remember surgeons are not experts in radiation treatment. At the same time, radiation oncologists are not experts in surgery. So if you want to get a complete picture of your treatment options, think about seeing both a surgeon and a radiation oncologist. Early stage prostate cancer is usually very slow growing. You have time to get a second opinion, if you want. This is a very important decision, and it's important to understand the choices. Now listen to the doctor talking about surgery. Again, we don't expect you to remember what he's saying… but notice how much he says about surgery.

Doctor: So that’s radiation and then the other option is surgery and that’s what we do as the surgeons. So that’s kind of where my bias lies... but with surgery, you'd be in the hospital for about 2 days. You end up with an incision that’s made down right in the middle of your abdomen, below your belly button, it’s about this long [gesturing 4 inches in length]. We take the prostate out and the lymph nodes next to it. Then they send all that to the lab, look at it under the microscope and figure out exactly what kind of cancer it was, and how extensive it was. After a day or two in the hospital, you're typically up walking around, eating a regular diet, and you feel well enough to go home. Then, you have a week or so where you're a little sore and not really having a lot of energy. Over the next couple of weeks, you tend to feel better. You go home with a catheter in - it’s a rubber tube that comes out of your bladder - to help everything heal and then that comes out about 10 days after the surgery.

Narrator: At this point, the doctor has said about as much about surgery as he did about radiation. But he has even more to say about surgery - because it's his specialty and he's more familiar with surgery.

Doctor: "So the benefits of surgery are typically we're able to get all of the cancer completely out. Every once in a while the lab says it looks like there might've been some cancer that was left behind but usually we're able to get all the cancer out. We're also able to take out the lymph nodes so then you know for sure whether or not there's cancer that's spread there. Now remember: I'm a surgeon - so I know more about surgery than I know about radiation... and I tend to think that most patients do better with surgery than with any other treatments. The thing with surgery is that the side effects get better over time rather than worse. So after the surgery, everybody across the board, no matter who you are, everybody leaks urine and then over a time, that tends to get better. At one year out from the surgery, 95% of guys are happy enough with their ability not to leak, and they don't want anything else done. Five percent of guys are so bothered, they consider having another surgery to fix the problem. And then the other big one is that everybody has erectile dysfunction. Everybody's impotent after the surgery and then over time, some of that ability to get an erection comes back. It can come back for up to the next two years and it will probably never be the same as it is before surgery but some guys get to the point where with like Viagra, Levitra or something like that, they're able to get an erection and still have intercourse, okay? So those are the two big things after surgery but again those and all the, and any recovery, those things tend to get better with time. So for surgery, we tend to tell people that you know, if you're younger and you're going to have longer to live, longer to heal, if you're healthy, that those are the type of people that make good surgical candidates. Any questions that I can answer for you?

Narrator: Doctors are most familiar with the kind of treatment they usually perform. Surgeons are more familiar with surgery. Radiation oncologists are more familiar with radiation. This is very important to keep in mind as you make your decision. If you see a surgeon, you'll get a lot of good, detailed information about surgery. But you may not get as much detail about radiation. It's a good idea to get a second opinion from a radiation oncologist."

Doctor: Remember: The number of people who are still alive 5 years after watchful waiting, surgery, or radiation are similar. In other words - this decision really isn't about which treatment is most effective. It's about which treatment best fits your life.

Narrator: Are you ok with the idea that you can live with cancer inside of you? Would you like to just get it out and deal with whatever side effects happen from treatment? You have the time - usually months - to make this decision. Prostate cancer usually grows very slowly, so it's a good idea to get more information and make a decision you can live with. In this doctor's description of surgery and radiation, he did not directly compare each side effect for surgery versus radiation. For each treatment, the number of people who have each side effect is different. It's important to know these numbers before you make your decision.

Doctor 2: The differences in the side effects of surgery and radiation are very important. For example, sometimes people have trouble holding their urine after surgery. This is less common with radiation, but with radiation, people can sometimes have more frequent bowel movements.

Narrator: The point is, some side effects may be more important to you than others. To make the decision that's best for you, you'll need to get the full story on both types of treatments. Also, ask your doctor for more details about side effects... especially about the ones you care most about.

Patient: So with the side effects… you gave me some numbers for surgery, but not for radiation. How can I know which side effects happen with surgery versus radiation? And, I'm most worried about leaking… you know, incontinence.

Doctor: Ok, great question. With surgery, about 20% of men say… (fade out)

Narrator: Asking your doctor to clarify is a great way to get more information. The booklet included with this video can also be helpful. On the side effects page, we describe each side effect and how common it is for each treatment. We also recommend you see a radiation oncologist as you make this decision. Some places schedule appointments w/ radiation oncology automatically. At other places, you have to ask for an appointment. However your hospital works - know you have a right - and the time - to see a radiation oncologist to learn as much as you can about both treatments.

Patient (interview): I knew that if I decided to treat my cancer, I had to think really hard about the side effects. After talking with the surgeon, I felt like I knew what surgery would be like, but not radiation. I knew the side effects could have a huge impact on my life… so I wanted to make sure I learned as much as I could. Learning all the new words, numbers, and keeping all the information straight was a challenge. But the doctors were patient with me and helped me really understand what both treatments would be like."

IV. Making a Decision

Doctor: Ok, so you've got a lot to think about. Typically what we do is we ask people to come back and see us again. That way, we can further discuss the options and see what you're thinking. In the meantime, if you want us to set up an appointment to see the radiation oncologist, we can do that. And then, you can weigh your options You just have to keep in mind that they're as biased for radiation as we are towards surgery.

Patient: Ok, that sounds good. I do have a lot to think about. Thank you doctor.

[shaking hands]

Patient (interview): I was nervous about asking for a referral. I mean, I didn't want to offend him. But, he was very understanding about it and acted like it was a routine thing.

Narrator: Asking for a referral to see someone about radiation is routine, and a smart idea in this situation. Try to think of ways you would feel comfortable asking your doctor for a referral.

Doctor (interview): I was glad he asked questions. I never know when people are confused or if they get it. I was also glad he asked for a referral… it's important, and I feel better knowing people are getting as much information as they can to help them decide.

Narrator: As we've said before: you usually have time to make this decision. You don't have to make your choice in this first meeting. Let the news sink in. See a radiation oncologist. Talk to your primary care doctor. Getting more information will help you make a decision that's best for your life. We gave you a lot of ideas in this video. Let's do a quick review of some of the main points.

Narrator: Hearing biopsy results usually means lots of medical terms and numbers that can be overwhelming and confusing.

Patient (interview): Let the doctor know when you're confused. Ask him to slow down or explain things differently.

Doctor (interview): Bring with you anything that you think might help you remember: a loved one, a tape recorder, the booklet, "Making the Choice, that was included with this video, or a list of questions.

Narrator: Learning about treatment options can be scary. The choice you make is extremely important, and sometimes the amount of information is overwhelming.

Doctor: Remember, watchful waiting is an option for most men with early prostate cancer. Some doctors might dismiss it quickly, but it is something you could choose. Let your doctor know if you are seriously considering watchful waiting.

Doctor 2: Doctors know their own treatments best. There is time to make a decision, so feel free to get a second opinion. You can ask for a referral to see a radiation oncologist or your primary care doctor to help you decide which treatment is best for you.

Narrator: All of the treatment options have advantages and disadvantages. Some of these may matter more to you than others. Think carefully about which side effects matter most to your life.

Doctor (interview): Finally, make sure you get all your questions answered. It's ok to ask for time to run down your list and make sure the doctor answered all of them. You can also ask for a follow-up visit in case you have new questions that come up later. Or, schedule a visit with your primary care doctor to go over your options.

Narrator: Remember that you have time. It's ok to take time to think about things, gather more information... and talk to other doctors. Waiting to get test results is a very stressful and scary time. If you do find out that you have cancer, we hope this video helps you. You're the expert on what matters most in your life. And we hope you feel more comfortable making this decision with your doctor - the best possible decision for you and your family."

Appendix C: Survey measures for Essay 2

Evaluation of intervention materials

Evaluation of the video: answered only by participants in the intervention condition

1. Did you watch the video?" (all, some, I did not get a chance to watch it)
2. Would you recommend this video to other men who are making decisions about prostate cancer treatment? (1 = probably not, 2 = unsure, 3 = probably, 4 = definitely).

Evaluation of the DA: answered by all participants.

3. About how much time did you spend looking at or reading the decision aid Booklet? (1 = less than 30 minutes, 2 = 30-60 minutes, 3 = 1-2 hours, 4 = more than 2 hours, 5 = I did not get a change to look at it)
4. Would you recommend this decision aid Booklet to other men who are making decisions about prostate cancer treatment? (1 = probably not, 2 = unsure, 3 = probably, 4 = definitely).

Evaluation of all materials received: answered by all participants. For participants in the control condition, the questions used the word "booklet." For participants in the intervention condition, the questions used the word "materials."

5. I felt that the amount of information in the decision aid (booklet or materials) was ___ (1 = too little, 5 = too much)

6. I felt that the information in decision aid (booklet or materials) was balanced and not slanted towards any one treatment. (1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, 5 = strongly agree)
7. How trustworthy was the decision aid (booklet or materials)? (0 = not at all trustworthy, 11 = completely trustworthy).

<u>Prostate Cancer Knowledge</u>

Note: Correct answers are bolded.

1. With treatment, about how many men diagnosed with early stage prostate cancer will eventually die of prostate cancer?

(1) Most will die of prostate cancer

(2) About half will die of prostate cancer

(3) Most will die of something else

(4) I am not sure

2. Without treatment, about how many men diagnosed with early stage prostate cancer will eventually die of prostate cancer?

(1) Most will die of prostate cancer

(2) About half will die of prostate cancer

(3) Most will die of something else

(4) I am not sure

3. For most men with early stage prostate cancer, how much would waiting 4 weeks to make a treatment decision affect their chances of survival?

(1) A lot

(2) Somewhat

(3) A little or not at all

(4) I am not sure

4. What is the best plan for managing early stage prostate cancer?

(1) Surgery

(2) Radiation

(3) No active treatment right away, but continued monitoring of the cancer

(4) Any of the above, based on what the person wants

(5) I am not sure

5. There is good evidence that which of the following treatments for early stage prostate cancer can help men live a bit longer?

(1) Surgery

(2) Radiation

(3) Both surgery and radiation

(4) There is no good evidence for either surgery or radiation

(5) I am not sure

6. Do any of the following treatments for early stage prostate cancer cause sexual problems, such as problems with erections?

a. Surgery	**(1) Yes**	(0) No	(2) Don't know
b. Radiation	**(1) Yes**	(0) No	(2) Don't know
c. No active treatment right away	(1) Yes	**(0) No**	(2) Don't know

7. Do any of the following treatments for early stage prostate cancer cause problems with dripping or leaking urine?

a. Surgery **(1) Yes** (0) No (2) Don't know

b. No active treatment right away (1) Yes **(0) No** (2) Don't know

8. Which of the following possible side effects from treatment for early stage prostate cancer is more common five years after surgery than five years after radiation?

(1) Sexual problems

(2) Dripping or leaking urine

(3) Both sexual problems and dripping or leaking urine

(4) I am not sure

9. If a man diagnosed with early stage prostate cancer visits a surgeon to talk about his options for managing his cancer, what will the surgeon most likely recommend?

(1) Surgery

(2) Radiation

(3) No active treatment right away, but continued monitoring of the cancer

(4) I am not sure

10. If a man diagnosed with early stage prostate cancer visits a radiation oncologist to talk about his options for managing his cancer, what will the radiation oncologist most likely recommend?

(1) Surgery

(2) Radiation

(3) No active treatment right away, but continued monitoring of the cancer

(4) I am not sure

11. Which of the following are good reasons for a man with early stage prostate cancer to consider not having active treatment right away?

(1) To avoid or delay the possible side effects of active treatment

(2) To make sure active treatment is really needed

(3) Both to avoid or delay the possible side effects of active treatment and to make sure active treatment is really needed

(4) I am not sure

Note:

The following question was asked but not included in analyses because of confusion regarding the correct answer based on the wording of the question and answer choices compared to information in the decision aids:

Does radiation treatment for early stage prostate cancer cause problems with dripping or leaking urine? (Yes, No, Don't know)

Patient empowerment regarding the decision making process

Decision urgency:

1. If you find out you have early stage prostate cancer, how important would it be to make a decision quickly? (1 = not at all important, 5 = extremely important)
2. It is important to make a decision in the first week after a diagnosis of early stage prostate cancer. (1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, 5 = strongly agree)
3. If you find out you have early stage prostate cancer, how quickly would you want to decide on a treatment? (1 = within a day, 4 = within a month, 7 = several months or longer)

Medical factors versus personal preferences

4. What is most important when deciding on how to treat early stage prostate cancer? (1 = medical factors are most important, 3 = they are both equally important, 5 = personal preferences are most important)

Preferred decision role (control preferences scale)

5. How would you make the treatment decision if you find out that you have early stage prostate cancer? (1 = My doctor(s) will make the decision with little input from me, 2 = My doctor(s) will make the decision but will seriously consider my opinion, 3 = My doctor(s) and I will make the decision together, 4 = I will make

the decision after seriously considering my doctor(s) opinion, 5 = I will make the decision with little input from my doctor(s))

Plan to seek second opinion/referral

6. If you find out you have early stage prostate cancer, will you plan to talk to your primary care doctor? (no, yes, not sure)
7. If you find out you have early stage prostate cancer, will you plan to talk to a radiation oncologist? (no, yes, not sure)
8. If you find out you have early stage prostate cancer, will you plan to talk to more than one urologist (surgeon)? (no, yes, not sure)

<u>Self-efficacy regarding communication skills</u>

For each question, patients were asked: "How confident are you that you can __?" (*1 = not at all confident, 3 = somewhat confident, 5 = extremely confident*)

1. Ask your doctor things about your treatment that concern you
2. Discuss openly with your doctor any personal problems that may relate to your illness
3. Work out any differences with your doctor
4. Participate in the decision about what treatment to have
5. Ask for a second opinion to see another urologist (surgeon)
6. Ask for a referral to see a radiation oncologist
7. Tell your doctor that you do not understand something he or she said
8. Tell your doctor that you disagree with something that he or she is saying
9. Ask your doctor to slow down if he or she explains things too fast
10. Tell your doctor what is important to you when making a treatment decision

Factor analysis:

We used exploratory factor analysis (principal axis factoring) with non-orthogonal rotation (direct oblimin) to reveal the underlying latent constructs captured by these questions. There were initially two factors extracted; however, there were 28% of residuals greater than .05, which is higher than suggested. Looking at the residuals, the extracted factors seemed to be doing a poor job reproducing the correlations for two questions about asking patients' how confident they were that they could ask for a referral during the appointment (items 5 and 6). Those two questions accounted for more than 50% of residuals with absolute values greater than .05. Therefore, we averaged these two items into a composite measure of self-efficacy regarding asking for a referral (alpha = .71 and re-ran the factor analysis without these two items. There were then only 17% of residuals with absolute values greater than 5, which is better than the 28% previously. Additionally, the factors seemed to make more sense conceptually.

The first factor reflects patients' sense of self-efficacy regarding expressions of concern during their appointments and was calculated by averaging questions 1 and 2 (alpha = .85). The second factor reflects patients' sense of self-efficacy regarding information-seeking behavior and assertive statements and was calculated by averaging questions 3, 7, 8, 9, and 10. (alpha = .72). Two items loaded relatively equally across both factors: question 3 (work out any differences with your physician) and question 4 (participate in the decision about what treatment to have). We did not include either of these items in our final factors since we wanted to be able to assess the effect of the intervention on each specific type of communication behavior.

Appendix D: Codebook for patients' requests for recommendations

Note: For all codes, mark if the speech was by the patient's companion.

Key: P = patient, PC = patient's companion, Dr = doctor.

13. How does the patient request the recommendation? Note: Each time the patient requests a recommendation it will receive (at least) one of these codes.
    a. General request (e.g., what do you recommend, which is best)
        i. *So what is best to do right now with it?*
        ii. *What would you recommend in my stage?*
    b. Requests physician engage in personal disclosure
        i. For doctor: ("What would you do?")
            1. *I'm curious, if you were seventy-six and had the same situation I've got do you have any idea what you would do?*
            2. *If it was you, what would you do?*
        ii. For father/relative: ("What would you tell your father/relative to do?")
            1. *I bet you get this question asked all the time. Your father comes to you, tell you what to do, what would you do? In most cases*
            2. *If this was your father what would you do?*

2. Patient behaviors as part of the request for recommendation. Note: These may or may not occur. Mark each discrete occurrence.
    a. References to physician expertise

i. *Just throw it out there, you know, because if he says there's two options for his age, you being a smart man, a doctor, what would you suggest?*

ii. *What do you think, I mean, you've done a lot of these… and I what what's ah your suggestion?*

b. Role of recommendations

i. Intention to follow physician recommendation

1. *You're the doctor, I don't know anything about this. I will go by your recommendation.*

ii. Expresses uncertainty about ability of physician to give recommendation

1. *I'd ask you for your personal opinion but you, you know, you probably can't give it but*

2. *What would you recommend? Or, don't you do that?*

iii. Patient as final decision maker

1. *I mean, it's up to me to decide what to do, but…*

3. Repeat Request: Any recommendation request that occurs after one has already happened. Note: Each of these requests will receive at least one code from section (1) and may or may not receive codes from section (2).

1. Patient repeats request in the same discrete exchange as the previous request

a. [PC]: *What would be your recommendation for him?*

[Dr]: *I mean if you're leaning…in your situation it's always tough for me to provide a recommendation, like between surgery and—*

[PC]: *Okay never, if it was you what would you do?*

2. Patient repeats request for recommendation later in appointment, with intervening, non-related conversation between the previous request and the repeated request.

a. [P]: *I bet you get this question asked all the time. Your father comes to you, tell you what to do, what would you do? In most cases.*

[…conversation continues, topic changes…]

[P]: *Well, what would you do if it was your father or your relative, if you had the same input there that I've got?*

[…conversation continues, topic changes…]

[P]: *Well, what would you do sir?*

Example of how codes would be applied in an excerpt.

Text	Codes applied
PC: What would be your recommendation for him?	• general request • speaker: patient's companion
Dr: I mean, if you're leaning…in your situation, it's always tough for me to provide a recommendation. Like between surgery and -	
PC: Okay, never, if it was you, what would you do?	• repeat request - same discrete exchange • request to engage in personal disclosure - dr • speaker: patient's companion

Appendix E: Survey measures for Essay 3

Trust in the VA System

All questions answered on a 5-point likert scale: (1=strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, 5 = strongly agree). “rev” indicates item was reverse coded.

1. Medical experiments can be done on me without my knowing about it. (rev)
2. My VA medical records are kept private.
3. People die every day because of mistakes by the VA health care system. (rev)
4. When they take my blood, they do tests they don't tell me about. (rev)
5. If a mistake were made in my health care, the VA health care system would try to hide it from me. (rev)
6. People can get access to my medical records without my approval. (rev)
7. The VA health care system cares more about holding costs down than it does about doing what is needed for my health. (rev)
8. I receive high-quality medical care from the VA health care system.
9. The VA health care system puts my medical needs above all other considerations when treating my medical problems.
10. Some medicines have things in them that they don't tell you about. (rev)

<u>**Preferred decision-making style**</u>

The decision about what type of prostate cancer treatment to undergo can be made in many different ways. We would like to learn more about how you would make this decision if you were to end up having prostate cancer. Please choose the ONE statement that best applies.

(1) My doctor(s) will make the decision with little input from me.

(2) My doctor(s) will make the decision but will seriously consider my opinion.

(3) My doctor(s) and I will make the decision together.

(4) I will make the decision after seriously considering my doctor(s) opinion.

(5) I will make the decision with little input from my doctor(s).

Baseline treatment preference

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? (0 = no, 1 = yes)

a. Surgery (radical prostatectomy)

b. External beam radiation

c. Brachytherapy (radiation delivered from metal seeds put inside the prostate)

d. Adjuvant hormone therapy

e. No active treatment

f. Experimental therapies such as HIFU, cryotherapy, and radiofrequency ablation

g. Other (write in):____________________

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Biography

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