

Patient Factors That Influence How Physicians Discuss Active Surveillance With Low-Risk Prostate Cancer Patients: A Qualitative Study

American Journal of Men's Health
2018, Vol. 12(5) 1719–1727
© The Author(s) 2018
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/1557988318785741
journals.sagepub.com/home/jmh


Joanna Veazey Brooks, MBE, PhD¹, Shellie D. Ellis, PhD¹, Emily Morrow, MA², Kim S. Kimminau, PhD^{1,3}, and J. Brantley Thrasher, MD⁴

Abstract

For men diagnosed with prostate cancer, making treatment decisions can be overwhelming. Navigating treatment options, along with potential treatment side effects, can be difficult, and patients often rely heavily on the advice of their physicians. This study was aimed at understanding more about the way urologists talk with their patients about one treatment option: active surveillance (AS), a recognized management strategy for men with low-risk prostate cancer that includes close observation and monitoring of the cancer. This study reports, through 22 interviews with urologists, that urologists believe patients are hesitant about AS for a number of reasons, including misperceptions about cancer severity, anxiety, aversion to repeated biopsies that accompany AS, or family member preferences. Because urologists play an influential role in educating patients about treatment options, the discussion around AS can be impacted by barriers that physicians believe matter for their patients. Improving awareness among urologists about what factors impact their patient education about low-risk prostate cancer is important. Identifying tools to improve shared decision making in this area could result in treatment decisions that are increasingly concordant with patients' values, concerns, and goals.

Keywords

active surveillance, low-risk prostate cancer, physician–patient communication, prostate cancer treatment

Received March 12, 2018; revised May 15, 2018; accepted 28 May 2018

For men diagnosed with low-risk prostate cancer, deciding the best treatment option can be challenging and can even cause distress (Dall'Era, 2015; Hedden et al., 2017). Active Surveillance (AS) is increasingly recognized as a management strategy for men with low-risk prostate cancer and as an important alternative to overtreatment (Cooperberg, Carroll, & Klotz, 2011; Miller, Gruber, Hollenbeck, Montie, & Wei, 2006). Unlike other curative and more aggressive treatments which can result in serious side-effects for patients, AS involves close observation and repeated biopsies to monitor the progression of the disease (Cooperberg et al., 2011; O'Callaghan et al., 2014). Active surveillance has been recommended for the last 15 years (Bahnon et al., 2000) and became the preferred treatment for low risk disease in 2016 when the American Society for Clinical Oncology released new guidelines (Chen et al., 2016).

Evidence is mounting about the safety of active surveillance (Yamamoto et al., 2016), and while adoption of this management strategy is increasing, the change is slow and uneven (Cooperberg & Carroll, 2015). Choosing between AS and curative options are complex and difficult decisions

¹Department of Health Policy and Management, University of Kansas Medical Center, Kansas City, KS, USA

²Department of Sociology, University of Kansas, Lawrence, KS, USA

³Department of Family Medicine, University of Kansas Medical Center, Kansas City, KS, USA

⁴Department of Urology, University of Kansas Medical Center, Kansas City, KS, USA

Corresponding Author:

Joanna Veazey Brooks, MBE, PhD, Department of Health Policy and Management, University of Kansas Medical Center, 3901 Rainbow Blvd, Mail Stop 3044, Kansas City, KS 66106, USA.
Email: jbrooks6@kumc.edu



for patients (Dall'Era, 2015), and while patients want to be actively involved in treatment decisions (Feldman-Stewart et al., 2011), they also routinely elicit and rely on recommendations from their physician (Adsul, Wray, Boyd, Weaver, & Siddiqui, 2016). Research identifies that the physician continues to have a moderate (Berry et al., 2003) to strong level of influence (Dall'Era, 2015; Davison & Breckon, 2012; Davison & Goldenberg, 2011) on the treatment decisions of patients with low-risk prostate cancer. A recent 2017 study reported that men who rely primarily on their physicians or other patients for treatment information had less decisional regret about their treatment decisions compared to patients who primarily relied on information from the internet (Shaverdian et al., 2017), reiterating the importance of patient education about treatment options during the physician encounter (Loeb, 2017).

One of the main reasons patients do not choose AS is because it is not presented to them as an option by their provider. One study reported that more than one third of low-risk prostate cancer patients were not presented with active surveillance as an option, and patient preferences were used in only 30% of encounters to guide treatment choice (Holmes-Rovner et al., 2015). While Berger, Yeh, Carter, and Pollack (2014) identified that patients' own personal criteria can drive decisions to leave active surveillance programs, other researchers reported that some urologists ask patients about preferences whereas others made "assumptions" about their patients' preferences (Adsul et al., 2016). The presentation of information by the provider as well as the education given during the clinic visit are centrally important factors in men's decisions about treatment (Chapple et al., 2002; Davison & Breckon, 2012; Davison, Oliffe, Pickles, & Mroz, 2009; Holmes-Rovner et al., 2015). This qualitative interview study sought to understand what patient factors (in addition to clinical test results) urologists consider important as they tailor their communication to men diagnosed with low-risk prostate cancer.

Methods

Study Design

This study was approved by (the University of Kansas Medical Center) Institutional Review Board, Study#00001837. Urologists were recruited at a national urology meeting in 2015 (American Urological Association) as well as through personal networks (of the senior author), using snowball methodology (Trochim, 2001). This multimodal recruitment strategy (Ellis et al., 2007) led to both in-person and phone interviews using the same semistructured questions. To encourage participation and acknowledge the time required to complete the interview, each participant received a \$300 gift card

upon completion of the interview. The authors recruited both academic-based and community-based urologists based on the hypothesis that practice and environmental factors, as well as patient panels, may vary between the two groups.

Data collection and analysis. The interview guide was originally based on ethnographic interview methods (Spradley, 2016), and was pilot-tested with four residents. After pilot-testing, questions were refined and five essential questions were identified as priorities among the 13-item interview guide (see Appendix A for the full interview guide). Prompts and follow-up questions were adapted to the respondents' answers. This allowed flexibility to address topics and issues raised by respondents. Interviews were audio-recorded and later transcribed. Verbal consent was obtained from each participant prior to the interview. Consent was recorded at scheduling. Both phone and in-person participants had to agree to the time and place, so consent was signified by appearing for the interview, as per the study protocol. Analysis included comparing and contrasting perceived barriers by the setting in which the urologist practices because it was hypothesized that urologists practicing in community settings may have different patient panels, and therefore might be responding to different patient factors.

A codebook of themes was developed that was derived from a larger model of treatment decision making: Andersen and Aday's *Behavioral Model of Health Service Use* which identifies external macro and micro level factors that affect processes of care (Aday & Andersen, 1974; Andersen, 1995). The authors adjusted this model to focus on the medical decision making influences from the health-care provider's perspective, while still retaining the presence of factors at the patient, provider, practice, and environmental levels that impact medical decisions. Two team members then coded interviews in ATLAS.ti (Scientific Software Development GmbH, 2011), meeting regularly to resolve any coding differences. Grounded coding also was conducted for themes that were present in the interview data and emerged but were not captured in the model. This article describes all the types of physician-perceived patient barriers to recommending AS for their patients that respondents identified during interviews.

Findings

We conducted semistructured interviews with 22 community-based practice ($n = 11$) and academic institution-based practice ($n = 11$) urologists between May and October 2015 about their beliefs and practices regarding prostate cancer treatment decisions, specifically about the use of AS for men with low-risk prostate cancer. Interviews

lasted an average of 30 min; see Appendix B for additional demographic details of respondents.

Patient Factors Perceived by Urologists

Urologists reported they considered a variety of factors about their patients when tailoring their patient education and treatment recommendations. When asked about how they discuss management options with patients who have a diagnosis of low-risk prostate cancer, a number of patient-related factors emerged. Physicians shared that they perceive or respond to preferences based on (a) patient understanding of the severity of the cancer diagnosis; (b) patient anxiety; (c) patient discomfort with biopsies; and (d) patient and/or family preference for curative therapy, all common themes that emerged across interviews. Each factor is discussed in more detail below, and then how urologists reported responding to these factors is described, and how it impacted how they counseled patients about treatment options.

Misperceptions about diagnosis severity. More than half of the urologists interviewed perceived some patients to misunderstand the severity of disease. One community-practicing urologist described a patient who he felt was “just not understanding [his disease] as a low risk disease, no matter what I said.” Another academic urologist described what he saw as exaggerated fears of a cancer diagnosis:

When people hear the word cancer, they really freak out. Getting them to accept that this can be kind of a chronic issue like hypertension or diabetes—that’s the biggest barrier that I can see with these patients getting on AS.

As this physician reports, it can be difficult for patients to consider their low-risk prostate cancer as a more “chronic issue” that can be managed over time. The word cancer alone may keep patients from wanting to pursue less aggressive management strategies.

Patient anxiety. When deciding what treatment options to suggest to men with low-risk prostate cancer, many urologists were concerned about recommending AS for patients they perceived as anxious because they believed adherence would be less likely among these patients. Physicians reported that anxious patients can be more challenging to counsel, and arriving at a treatment decision can be circuitous and difficult. Furthermore, if a decision to proceed with AS is made, urologists anticipated that anxious patients may change their minds or want to reinstate treatment decision making after additional information gathering and consideration. Some respondents explained how anxiety was a more common factor in specific populations of patients:

We’re at the VA so we’ve got a lot of patients that have stress disorders, anxiety problems, and depression. So going into a procedure for them may be a little bit more high stress than just the average person. (academic urologist)

Anxiety was also reported to play a role in switching from active surveillance protocol to treatment for patients. Active surveillance requires a series of follow-ups, and the “anxiety of waiting time,” as one urologist put it, can be difficult for patients. As one urologist elaborated:

A drawback of the active surveillance is the frequency of visits and blood checks and there’s anxiety associated with that, so every time you get a PSA checked, that patient comes in – “What is it, Doc? What is it, Doc?”

Discomfort with biopsies. When a man chooses active surveillance as a management strategy for his low-risk prostate cancer, repeated biopsies are a standard part of the treatment. While biopsies are less invasive than more aggressive treatment options, a third of respondents mentioned that perceived patient discomfort with repeated biopsies was another factor that impacted treatment discussions around AS:

The thing about the biopsy is a real problem. People are bothered by the biopsy. Not everybody, but there’s a subset of people who really have a hard time with the invasiveness of the biopsy and that’s, unfortunately, that’s the best thing we have. (academic urologist)

In addition to a general dislike for biopsies, some patients had previous negative experiences with biopsies, which could serve as a barrier to their full consideration of AS as a management option:

There are some people that have had some very bad experiences through the years and trying to get them to do another biopsy when it’s really needed is like pulling teeth. (community urologist)

Patient or family preference for curative treatment. Almost half of the urologists reported that some of their patients prefer curative treatment, often surgery. As one community urologist explained, there is something about the word *cancer* that encourages a patient to react with: “No, Doc, take it out,” even if AS might be the clinically indicated option. As one respondent explained,

Some patients just don’t feel comfortable knowing that they were diagnosed with cancer and saying, “okay. We’re just going to watch it.” I mean, that’s a big thing that a lot of the patients have a hard time struggling with is saying, “well I was just diagnosed with cancer. Aren’t we going to do anything about it?” Getting them to accept that we’re actively monitoring it, that’s a big change in thinking. (academic urologist)

A number of urologists noted that preference for curative therapy among patients' families is also strong. One community urologist explained that "I feel that the wives don't like AS." Another urologist recalled the influential preference of a spouse for one of his patients:

His wife was intent on him getting treatment, and there was a little bit of a conflict. He was essentially open to going by whatever we recommended. She was intent on him getting treatment... (academic urologist)

Physicians also described how a patient's friend or family member's experience with cancer could exert a strong influence on a patient's decision:

If a patient has talked to all his friends that have had prostate cancer and he's really impressed about radiation therapy, then we're not going to steer him against what he wants. Our job is to give him an unbiased opinion in terms of the treatment options that are out there and help him come to a decision on which way to address the prostate cancer. (academic urologist)

Community Practice Factors

Community urologists described two patient factors that academic urologists did not: out-of-pocket costs of active surveillance (i.e., copays and coinsurance may be required at each follow-up visit and spread over multiple deductible periods) and distrust of physicians. While the urologist was not aware of it being a problem yet, he described the concern about potential out-of-pocket costs:

I think it certainly may in the future with increasing out-of-pocket deductible costs and knowing that they're going to need a PSA three to four times a year depending...And they're probably going to have to pay probably out-of-pocket of their whole biopsy cost...

Another urologist explained feeling like an occasional patient did not trust him when he recommended active surveillance instead of surgery:

I can think of one of two times...where people just look at you in a very distrustful way and...and it's almost a litigious way. It's the vibe you get at the end of the meeting that says you're just [suggesting active surveillance] because you don't think I'm worth the treatment and then...I know the patient is going to walk out of my office and go—because we're in a large metropolitan area, they're going to find somebody to...take their prostate out."

These two factors were only mentioned once.

Physicians Responses to Perceived Patient Barriers

The physicians interviewed described factors that they perceive matter for their patients, and these perceptions and preferences in turn affect how they educate, counsel, and present options to their patients diagnosed with low-risk prostate cancer. In this section, the variety of strategies and common practices that urologists reported using to address these patient factors and preferences are outlined.

Responding to discomfort with biopsies. Urologists reported a variety of responses to their patients' discomfort with biopsies, which are a standard component of AS. In some practices, patients are given medications to help them relax and deal with the pain of the procedure:

I usually give them some Percocet and Xanax to make sure they're really comfortable, do Lidocaine injections and most of them are like "gosh, that's not near as bad as I thought it was going to be" or "that's nowhere near what somebody told me it was going to be like" and so if they have a good experience with it the first time, they're much more likely to do another biopsy. (community urologist)

Another urologist explained that he sometimes spreads the biopsies out and adapts the protocol if a patient is dreading them.

So, if they say, "...that was a horrible experience," then you say, "Okay, well," you can discuss with them that maybe we can push it further out than we normally would. So, we might be a little less aggressive with that. [...] you kind of work it out with them. (academic urologist)

Responding to understanding of severity and preferences for curative treatment. As outlined above, urologists perceive the presence of several attitudinal and emotional factors for their patients that can create obstacles to considering AS as an option. Urologists report that patients and family alike often indicate a preference for curative treatment, largely driven by their reaction to a cancer diagnosis. One way that physicians respond to this factor is by setting a common practice of meeting with patients and family members simultaneously in order to share information and talk about treatment options. Some urologists specifically request that family members be present at the counseling session, in an effort to be more patient-centered and avoid misconceptions or misinformation.

I encourage them to bring their family members with them so that way ultimately the decision is the patient's but when they have their whole family understanding what decision they make, it really helps support the patient instead of one

family member saying you need to do this and another family saying you should have done this and so I try to get as much of the family together and then say okay, let's go over all this stuff again, here's your treatment options from do nothing to surgery to everything else in between. (community urologist)

Urologists also highlighted the importance of including family members in particular for patients considering AS:

[There are] some cases where the patient is actually comfortable with active surveillance themselves but the family is not and really wants them to get treated because they're worried about that person's longevity. And so making sure that the family is actually comfortable with the approach is, I think, also important for uptake. (academic urologist)

The strategy of intentional inclusion of family members at clinical appointments means that physicians must actively respond to the emotions and fear of these additional stakeholders, in addition to responding to their patient's emotions.

Understandably, they tend to be nervous and amped up. Either the husband, or if there is a significant other, one of the two is usually amped up. Sometimes it's the one, sometimes it's the other, but if they're both there one of them is usually nervous, which is understandable. (academic urologist)

One urologist described how he makes a special effort to assure the patient's spouse and establish an open communication pathway:

I usually make sure when I give them my card at the end with the number, I look at the wife and say, "You can call me any time as well and talk about it." (academic urologist)

When treating a man with low-risk prostate cancer, these are some of the ways urologists reported adapting their discussion of treatment options with patients and their families.

Discussion

Urologists in this study consistently reported several factors that they believe impact their patients' ability to consider all treatment options when diagnosed with low-risk prostate cancer. These include patients' understanding of disease severity, anxiety, and preferences for curative treatment. These findings also describe how these physicians adjust patient education and counseling in response to these factors. The hypothesis that urologists practicing in academic settings might report different patient factors than community urologists was not strongly supported by findings. However, more systematic exploration of the two

factors we did identify is warranted. For example, academic physicians may be shielded from patients' financial concerns by health system factors.

The findings identified a patient and family preference for curative treatment that is documented elsewhere (Davis et al., 2017; Showalter, Mishra, & Bridges, 2015; Srirangam et al., 2003). Clinicians recognize the role family members play in influencing patients' decisions about AS, and this research confirms the need to explore the best ways to achieve guideline-concordant care for patients amidst various relational and emotional pressures (Showalter et al., 2015). Research is needed to better understand how third parties alter the decision process and urologists may need different tools to counsel patients and their family members to determine the preferred treatment option (Hagerman et al., 2017). In particular, they may need training on how to manage the emotional responses that typically arise from both patients and their families when a diagnosis of prostate cancer is made (Adsul et al., 2016). Finally, there may be special populations of men who have experienced trauma (e.g., Veterans), who may not be good candidates for the biopsy-intensive AS protocol and/or may benefit from adapted protocols.

Despite the emphasis on shared decision making and guideline-concordant care, patients still rely heavily on their physicians for advice and unbiased information when making decisions in the face of a cancer diagnosis (Adsul et al., 2016). Therefore, the opinions and perceptions of urologists and the way clinicians present information and treatment options to their patients considering AS carries with it a great deal of influence (Berry et al., 2003; Chapple et al., 2002; Davison & Breckon, 2012; Davison & Goldenberg, 2011; Davison et al., 2009; Pickles et al., 2007). Urologists interacting with patients about cancer treatment options occupy different positions on the decision-making continuum—with strict paternalism at one end and shared decision making on the other. The urologists interviewed in this study were shaping treatment decisions on perceived patient preferences, although these assessments were based on previous patient behavior or indications as often as being based on preferences that the patient (or family members) voiced. While these urologists undoubtedly value their patients' perspectives, few described consistently eliciting the values and preferences of patients—a behavior essential for shared decision making.

This study has several limitations. Urologists who agreed to be interviewed could differ from those uninterested in discussing their AS perceptions and practice. Additionally, while urologists in this sample did vary by practice type/location and reported similar perceived obstacles to AS across practice type, the sample is not

representative of all U.S. urologists. Finally, this study relies on urologists' reports of their own behavior and may not align with behavior in practice. Direct observation is required to know what truly happened. Feeding back structured information about decision-making behaviors may help align behavior with reality. In the meantime, educational tools that negotiate current misalignments are needed.

Findings indicate that physicians actively consider patient factors and preferences, although they may sometimes rely on their own perceptions of these preferences and factors instead of asking the patient directly. Data suggest that the doctor–patient interactions around these decisions is complicated and the movement toward improved shared decision making requires increased understanding of the alignment or lack of alignment between the factors that matter for patients and those that their physician perceives matter. Many of the perceived patient factors reported by respondents are consistent with patient self-reported factors, like patient anxiety, fear of cancer, and preference for curative treatment (Berger et al., 2014; Pickles et al., 2007). It could be that physician perceptions of salient patient factors are well aligned with reality. Other research has documented a substantial gap between what physicians report they communicate and what patients hear during these encounters (Ramsey et al., 2011). Whether accurate or not, findings indicate that these factors matter because physicians adapt their recommendations accordingly. As Adsul and colleagues reported, urologists consider themselves “guides” and “pilots” for their patients; thus, their perceptions about patient factors that need responses can and do have very real effects (Adsul et al., 2016). The findings in this study can also be helpful for patients to better understand what their urologist may be considering during treatment discussions, and how to communicate their preferences with their urologists. Further study of the factors that are salient for both providers and patients diagnosed with low-risk prostate cancer are essential for increased awareness and improved quality of care and decisions that align with patient goals and values.

Appendix A. Interview Guide

Low-risk Prostate Cancer Treatment Decision Making

Marked questions are priority

I appreciate your participation. We're trying to identify best practices in offering active surveillance to men with low-risk prostate cancer and we are asking leaders in the field how your practice presents treatment options and what types of things help or get in the way of the delivering it to patients who might be eligible for it.

I. Prostate Cancer Treatment Context

How is your clinic organized for reaching a treatment decision for patients with confirmed diagnosis of prostate cancer?

Probe: Multidisciplinary? Resident involvement? Nurse or staff involvement?

What treatments do you offer for prostate cancer?

Probe: How does that change for patients with low-risk disease?

What kinds of situations or circumstances occur when a patient with low-risk cancer isn't offered those options?

Probes: Something about the tumor? About the patient? Medical Staff? Certain practice environments?

Across your practice, about what proportion of patients get each treatment option?

II. Active Surveillance Offer

Can you describe how the decision to undergo active surveillance came about for the **most recent patient** for whom you recommended it?

Probes: What was different about this patient, his circumstances, or care team? What made similar patients in similar circumstances not candidates for active surveillance?

Tell me about patients who are good candidates for active surveillance.

Probes: How do you identify the good candidates? Does this change after you meet them?

Tell me about patients who are poor candidates for active surveillance.

Probes: How do you identify the poor candidates? Does this change after you meet them?

III. Active Surveillance Context

How do you think your colleagues in the local area perceive active surveillance?

Probes: Do you get feedback from referring physicians about treatment decisions? Do area physicians discuss treatment strategies? Are you competing with other providers for cases? Are there local networks of physicians who have developed treatment styles or routines?

To what extent do you feel active surveillance is used appropriately in your area?

Probes: underused? Overused? Inappropriately used?

Has your practice adopted any resources to facilitate offering active surveillance or to help patients accept active surveillance?

Probe: Tools, prompts or pathways to identify candidates?
Decision aids or materials to describe the treatment option?

What barriers do you face in offering active surveillance to your patients?

How does recommending active surveillance affect your practice?

Probes: Volume of patients? Mix of patients? Ease of reimbursement? Practice revenues?

What concerns do you have about active surveillance?

Probes: Biopsy complications? What is your experience with biopsy complications? Patient anxiety? Loss to follow-up?

IV. Offer to Treatment Gap

Think of the last time when you identified a patient as a great candidate for active surveillance and they didn't undergo active surveillance. Can you describe that situation and what got in the way of that treatment option happening?

Probes: Patient factors? Social factors? Practice environment? Reimbursement/insurance? Other doctors in your practice? Other specialists in your practice? Practice management staff directives? Technology available in your practice?

Think of a time when you identified a patient as a great candidate for active surveillance and they did undergo active surveillance. What helped facilitate that treatment option happening?

Probes: Patient factors? Social factors? Practice environment? Reimbursement/insurance? Other doctors in your practice? Practice management staff directives? Technology available in your practice?

V. Follow-up

We will eventually be engaging non-academic urologists in our research. Can you think of one or two influential

community urologists in your community who might be willing to participate and help us ensure our findings are relevant to non-academic physicians?

May I follow up with you after the meeting with some information you can forward to them?

Appendix B: Demographic Characteristics of Urologist Respondents

Table 1. Demographic Characteristics of Urologist Respondents.

	Study sample (N = 22)	No. (%)
Gender	Male	21 (95%)
Observed race/ Ethnicity	Caucasian	18 (82%)
Trainee	Yes	3 (14%)
Region	West	2 (9%)
	Midwest	11 (50%)
	South	8 (36%)
	Northeast	1 (5%)
Practice site	Academic	11 (50%)
	Community	11 (50%)

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by an American Cancer Society grant (IRG-09-062-06); a National Institutes of Health Clinical and Translational Science Award grant (UL1 TR000001, formerly UL1RR033179), awarded to the University of Kansas Medical Center; and, an endowed gift provided by an anonymous donor.

References

- Aday, L. A., & Andersen, R. (1974). A framework for the study of access to medical care. *Health Services Research, 9*(3), 208–220.
- Adsul, P., Wray, R., Boyd, D., Weaver, N., & Siddiqui, S. (2016). Perceptions of urologists about the conversational elements leading to treatment decision-making among newly diagnosed prostate cancer patients. *Journal of Cancer Education, 32*(3), 580–588. doi:https://dx.doi.org/10.1007/s13187-016-1025-2
- Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: Does it matter? *Journal of Health and Social Behavior, 36*(1), 1–10.

- Bahnson, R. R., Hanks, G. E., Huben, R. P., Kantoff, P., Kozlowski, J. M., & Kuettel, M. ... National Comprehensive Cancer Network. (2000). NCCN practice guidelines for prostate cancer. *Oncology (Williston Park, N.Y.)*, *14*(11A), 111–119.
- Berger, Z. D., Yeh, J. C., Carter, H. B., & Pollack, C. E. (2014). Characteristics and experiences of patients with localized prostate cancer who left an active surveillance program. *The Patient*, *7*(4), 427–436. doi:https://dx.doi.org/10.1007/s40271-014-0066-z
- Berry, D. L., Ellis, W. J., Woods, N. F., Schwen, C., Mullen, K. H., & Yang, C. (2003). Treatment decision-making by men with localized prostate cancer: The influence of personal factors. *Urologic Oncology*, *21*(2), 93–100.
- Chapple, A., Ziebland, S., Herxheimer, A., McPherson, A., Shepperd, S., & Miller, R. (2002). Is “watchful waiting” a real choice for men with prostate cancer? A qualitative study. *BJU International*, *90*(3), 257–264.
- Chen, R. C., Rumble, R. B., Loblaw, D. A., Finelli, A., Ehdaie, B., Cooperberg, M. R., & ... Jain, S. (2016). Active surveillance for the management of localized prostate cancer (Cancer Care Ontario Guideline): American society of clinical oncology clinical practice guideline endorsement. *Journal of Clinical Oncology*, *JCO657759*, *34*(18), 2182–2190. doi:https://dx.doi.org/10.1200/JCO.2015.65.7759
- Cooperberg, M. R., & Carroll, P. R. (2015). Trends in management for patients with localized prostate cancer, 1990–2013. *JAMA*, *314*(1), 80–82. doi:https://dx.doi.org/10.1001/jama.2015.6036
- Cooperberg, M. R., Carroll, P. R., & Klotz, L. (2011). Active surveillance for prostate cancer: Progress and promise. *Journal of Clinical Oncology*, *29*(27), 3669–3676. doi:https://dx.doi.org/10.1200/JCO.2011.34.9738
- Dall'Era, M. A. (2015). Patient and disease factors affecting the choice and adherence to active surveillance. *Current Opinion in Urology*, *25*(3), 272–276. doi:https://dx.doi.org/10.1097/MOU.0000000000000154
- Davis, K., Bellini, P., Hagerman, C., Zinar, R., Leigh, D., Hoffman, R., ... Taylor, K. (2017). Physicians' perceptions of factors influencing the treatment decision-making process for men with low-risk prostate cancer. *Urology*, *107*, 86–95. doi:https://dx.doi.org/10.1016/j.urol.2017.02.056
- Davison, B. J., & Breckon, E. (2012). Factors influencing treatment decision making and information preferences of prostate cancer patients on active surveillance. *Patient Education and Counseling*, *87*(3), 369–374. doi:https://dx.doi.org/10.1016/j.pec.2011.11.009
- Davison, B. J., & Goldenberg, S. L. (2011). Patient acceptance of active surveillance as a treatment option for low-risk prostate cancer. *BJU International*, *108*(11), 1787–1793. doi:https://dx.doi.org/10.1111/j.1464-410X.2011.10200.x
- Davison, B. J., Oliffe, J. L., Pickles, T., & Mroz, L. (2009). Factors influencing men undertaking active surveillance for the management of low-risk prostate cancer. *Oncology Nursing Forum*, *36*(1), 89–96. doi:https://dx.doi.org/10.1188/09.ONF.89-96
- Ellis, S. D., Bertoni, A. G., Bonds, D. E., Clinch, C. R., Balasubramanyam, A., Blackwell, C., ... Goff, D. C. (2007). Value of recruitment strategies used in a primary care practice-based trial. *Contemporary Clinical Trials*, *28*(3), 258–267. doi:https://dx.doi.org/10.1016/j.cct.2006.08.009
- Feldman-Stewart, D., Capirci, C., Brennenstuhl, S., Tong, C., Abacioglu, U., Gawkowska-Suwinska, M., & ... Wördehoff, H. (2011). Information for decision making by patients with early-stage prostate cancer: A comparison across 9 countries. *Medical Decision Making: An International Journal of the Society for Medical Decision Making*, *31*(5), 754–766. doi:https://dx.doi.org/10.1177/0272989X10395029
- Hagerman, C. J., Bellini, P. G., Davis, K. M., Hoffman, R. M., Aaronson, D. S., Leigh, D. Y., ... Taylor, K. L. (2017). Physicians' perspectives on the informational needs of low-risk prostate cancer patients. *Health Education Research*, *32*(2), 134–152. doi:https://dx.doi.org/10.1093/her/cyx035
- Hedden, L., Wassersug, R., Mahovlich, S., Pollock, P., Sundar, M., Bell, R. H., & ... Higano, C. S. (2017). Evaluating an educational intervention to alleviate distress amongst men with newly diagnosed prostate cancer and their partners. *BJU International*, *120*(5B), E21–E29. doi:https://dx.doi.org/10.1111/bju.13885
- Holmes-Rovner, M., Montgomery, J. S., Rovner, D. R., Scherer, L. D., Whitfield, J., Kahn, V. C., ... Fagerlin, A. (2015). Informed decision making: Assessment of the quality of physician communication about prostate cancer diagnosis and treatment. *Medical Decision Making: An International Journal of the Society for Medical Decision Making*, *35*(8), 999–1009. doi:https://dx.doi.org/10.1177/0272989X15597226
- Loeb, S. (2017). Educational intervention in prostate cancer. *BJU International*, *120*(5B), E3–E3. doi:https://dx.doi.org/10.1111/bju.13958
- Miller, D. C., Gruber, S. B., Hollenbeck, B. K., Montie, J. E., & Wei, J. T. (2006). Incidence of initial local therapy among men with lower-risk prostate cancer in the United States. *Journal of the National Cancer Institute*, *98*(16), 1134–1141. doi:https://dx.doi.org/10.1093/jnci/djj308
- O'Callaghan, C., Dryden, T., Hyatt, A., Brooker, J., Burney, S., Wootten, A. C., ... Schofield, P. (2014). “What is this active surveillance thing?” Men's and partners' reactions to treatment decision making for prostate cancer when active surveillance is the recommended treatment option. *Psycho-Oncology*, *23*(12), 1391–1398. doi:https://dx.doi.org/10.1002/pon.3576
- Pickles, T., Ruether, J. D., Weir, L., Carlson, L., & Jakulj, F. SCRIN Communication Team. (2007). Psychosocial barriers to active surveillance for the management of early prostate cancer and a strategy for increased acceptance. *BJU International*, *100*(3), 544–551. doi:https://dx.doi.org/10.1111/j.1464-410X.2007.06981.x
- Ramsey, S. D., Zeliadt, S. B., Fedorenko, C. R., Blough, D. K., Moynour, C. M., Hall, I. J., & ... Penson, D. F. (2011). Patient preferences and urologist recommendations among local-stage prostate cancer patients who present for initial consultation and second opinions. *World Journal of Urology*, *29*(1), 3–9. doi:https://dx.doi.org/10.1007/s00345-010-0602-y

- Scientific Software Development GmbH. (2011). *ATLAS.ti: The knowledge workbench*. Berlin: Scientific Software Development GmbH.
- Shaverdian, N., Kishan, A. U., Veruttipong, D., Demanes, D. J., Kupelian, P., McCloskey, S., ... King, C. R. (2017). Impact of the primary information source used for decision making on treatment perceptions and regret in prostate cancer. *American Journal of Clinical Oncology*. doi:<https://dx.doi.org/10.1097/COC.0000000000000387>
- Showalter, T. N., Mishra, M. V., & Bridges, J. F. (2015). Factors that influence patient preferences for prostate cancer management options: A systematic review. *Patient Preference and Adherence*, 9, 899–911. doi:<https://dx.doi.org/10.2147/PPA.S83333>
- Spradley, J. P. (2016). *The ethnographic interview*. Long Grove, IL: Waveland Press.
- Srirangam, S. J., Pearson, E., Grose, C., Brown, S. C. W., Collins, G. N., & O'Reilly, P. H. (2003). Partner's influence on patient preference for treatment in early prostate cancer. *BJU International*, 92(4), 365–369.
- Trochim, W. (2001). *The research methods knowledge base* (2nd ed.). Retrieved from <http://www.anatomyfacts.com/research/researchmethodsknowledgebase.pdf>
- Yamamoto, T., Musunuru, B., Vesprini, D., Zhang, L., Ghanem, G., Loblaw, A., & Klotz, L. (2016). Metastatic prostate cancer in men initially treated with active surveillance. *The Journal of Urology*, 195(5), 1409–1414. doi:<https://dx.doi.org/10.1016/j.juro.2015.11.075>