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Cognitive and Affective Representations of Active Surveillance as a Treatment Option for Low-Risk Prostate Cancer

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Abstract

Benefits of early diagnosis and treatment remain debatable for men with low-risk prostate cancer. Active surveillance (AS) is an alternative to treatment. The goal of AS is to identify patients whose cancer is progressing rapidly while avoiding treatment in the majority of patients. The purpose of this study was to explore cognitive and affective representations of AS within a clinical environment that promotes AS a viable option for men with low-risk prostate cancer. Participants included patients for whom AS and active treatment were equally viable options, as well as practitioners who were involved in consultations for prostate cancer. Data were generated from semistructured interviews and audits of consultation notes and were analyzed using thematic analysis. Nineteen patients and 16 practitioners completed a semistructured interview. Patients generally viewed AS as a temporary strategy that was largely equated with inaction. There was variation in the degree to which inaction was viewed as warranted or favorable. Patient perceptions of AS were generally malleable and able to be influenced by information from trusted sources. Encouraging slow deliberation and multiple consultations may facilitate greater understanding and acceptance of AS as a viable treatment option for low-risk prostate cancer.

Keywords

prostatic neoplasm, choice behavior, active surveillance, decision making, qualitative research

Prostate cancer is the most frequently diagnosed nonskin cancer among men in the United States, with an estimated 220,800 new cases a year (Siegel, Miller, & Jemal, 2015). The increased use of prostate-specific antigen (PSA) testing has led to the increased detection of low-grade prostate tumors that will never progress to clinical significance. Indeed, nearly half of newly detected tumors are low grade, confined cancers, and are frequently referred to as "low-risk" prostate cancer (Cooperberg, Lubeck, Meng, Mehta, & Carroll, 2004).

The benefits of early diagnosis and treatment are debatable for men with low-risk prostate cancer. Regardless of treatment choice, the 5-year survival rate for low-risk prostate cancer is 100% and the 10-year survival rate is 98% (American Cancer Society, 2015). Available active treatment choices are surgery, radiation, or hormonal ablation which carry a significant side effect burden including urinary and bowel incontinence and erectile dysfunction (Cooperberg et al., 2004) that can reduce quality of life (Litwin, Pasta, Yu, Stoddard, & Flanders, 2000; Steineck et al., 2002). Recent studies suggest a growing number of men regret their treatment decisions over time as these side effects fail to ameliorate (Diefenbach & Mohamed, 2007).

Active surveillance (AS) is a viable alternative to active treatment for men with low-risk prostate cancer (National Comprehensive Cancer Network, 2016). AS uses a combination of serial PSA tests, digital rectal exams, imaging, and repeated prostate biopsy to monitor disease status. The goal of AS is to identify patients

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whose cancer is progressing rapidly while avoiding treatment in the majority of patients whose cancer is not an immediate health threat. A study following men on AS for 82 months reported that no men developed metastatic disease or died of prostate cancer (Roemeling et al., 2007). In another trial of AS with 450 patients followed for 6.8 years on average, overall survival was 78.6% and disease-specific survival rate was 97.2% (Klotz et al., 2010). Other studies have reported that psychosocial outcomes of men choosing AS do not seem to differ from those choosing active treatment; both groups report equivalent anxiety levels regarding recurrence or progression (Steineck et al., 2002; van den Bergh, Korfage, & Bangma, 2012). Yet only a small proportion (10.2%) of men with low-risk prostate cancer choose AS (Cooperberg, Broering, Kantoff, & Carroll, 2007). Studies suggest that knowledge deficits about the benefits and risks of AS, the fear of "doing nothing," the desire to cure cancer, and the lack of support from physicians and family, lead men to choose active treatment over AS (Xu, Dailey, Eggly, Neale, & Schwartz, 2011; Xu, Victoria Neale, Dailey, Eggly, & Schwartz, 2012).

Some academic institutions are developing protocols for identifying viable candidates for AS and executing standardized surveillance. Those protocols, clinical processes, and cultural environments through which AS is supported and encouraged have not been reported or studied. In order to assess the feasibility of disseminating and implementing those protocols in other settings, it is important to understand patient and provider perspectives and communication practices regarding AS in clinical environments where AS is supported as a first-line treatment for low-risk prostate cancer. This study used semistructured interviewing of patients and providers to explore the cognitive and affective processes that influence the decisions men make regarding low-risk prostate cancer treatment. This first analysis of those data explores the following question: What do men think and feel about AS as an option to manage their low-risk prostate cancer?

Method

Theoretical Background and Design

This study evaluated the cognitive and affective processing involved in making treatment decisions among men with low-risk prostate cancer within two academic medical centers where AS is promoted as a viable option for low-risk prostate cancer. The research question and the design were informed by self-regulation theory. Self-regulation theory asserts that people generate both cognitive and affective representations of illness when faced with a health threat (Leventhal, Diefenbach, & Leventhal, 1992; Leventhal & Leonard, 1970). Cognitive representations include knowledge or beliefs about the threat, its causation, consequence, duration, and treatability. Affective representations include emotional responses to the threat and the potential treatment options. Cognitive and affective representations are processed in parallel systems that appear to be interdependent and can influence each other (Epstein, 1994; Petty & Wegener, 1999; Zajonc, 1980). Both modes of processing are important and decision making is facilitated when affective and deliberative modes work in concert and decision makers think as well as feel their way through judgments and decisions (Damasio, 1994).

Population

The study team interviewed providers who were involved in consultations for prostate cancer at two academic institutions. The sampling frame included a pool of 18 providers, including urologists, radiation oncologists, nurse practitioners, and medical oncologists. While interviewing the provider sample, recruitment began among men diagnosed with prostate cancer for whom AS or active treatment were equally viable options. Each patient who received follow-up care (i.e., more than one consultation) at either institution was prospectively screened to determine if he met the following inclusion criteria:

a. Eighteen years or older and diagnosed with Stages T1 or T2 prostate cancer within the past year
b. Prostate-specific antigen value ≤10
c. Gleason score ≤6
d. Chose AS or Active Treatment
e. Competent to provide consent
f. Adequately fluent in English

For this study, watchful waiting and AS were defined as separate treatment choices. Although both observe patients for changes in disease status, these changes are identified differently. While AS rigorously monitors changes through PSA tests, digital rectal exams, and imaging at specific intervals, watchful waiting relies more on changes in the patients' symptoms when metastatic disease develops (Adolfsson, 2008; Klotz, 2005). In essence, AS can be seen as an option with curative intent where monitoring may lead to reclassification of the prostate cancer to a higher risk disease. Watchful waiting can be seen as an option with a palliative intent where monitoring only occurs when symptoms reach an initiation threshold (Filson, Marks, & Litwin, 2015). The scope of the project focused on potential candidates for whom AS and active treatment were equally viable options. Individuals following watchful waiting were not included in the sampling frame.

Data Collection

This research was reviewed and approved by the institutional review boards of Dartmouth College, University of Vermont, and SUNY Upstate Medical University. All participants engaged in informed consent that was documented by a written consent form. Three interviewers completed the interviews at the participants' convenience, either face-to-face or by telephone. One interviewer (KDL) was a doctorally prepared occupational therapist with expertise in qualitative methodology. The second interviewer (TM) was a graduate student doing a research internship while pursuing a psychology degree. The third interviewer was a project coordinator trained in standardized and semistructured interviewing. The first interviewer trained and supervised the other interviewers. Immediately after each of the first four interviews, the interviewers met to discuss modifications to the interview guide (i.e., addition and reordering of questions). Subsequently, the first and second interviewers met weekly to debrief regarding the interviews and the evolving data set.

Separate interview guides were used for the provider and the patient interviews. The providers were asked to recount the typical process of diagnosing low-risk prostate cancer (e.g., what type of information they convey, how they convey it, whether they use graphics or literature, and the degree to which they recommend a specific treatment). The providers were then asked to define their role in the treatment decision and what a "good" decision means. Finally, providers were asked to discuss the ways in which the clinical systems support or do not support "good decision making."

Patients were asked to tell the story of how and when they were diagnosed with prostate cancer. Patients were asked to identify the treatment options that were given to them, the advantages and disadvantages of each option, and the rationale for the option they picked. Then patients were asked to talk about where they learned about the treatment options, whether they knew people who had experienced a similar diagnosis, and what they were thinking and feeling when making the decision. Finally, patients were asked about how they typically made decisions in life and how this decision compared with other decisions they have made in their lifetime.

Data collection began by interviewing the providers. This allowed the interviewers to develop an understanding of how the various providers generally framed and communicated the decision-making process to their patients. Recruitment of patients began after a third of the providers were interviewed. Near the end of the recruitment period, the team tried to purposively recruit more patients who chose active treatment by asking providers to identify them from their past-year caseload (as opposed to prospectively waiting for a new patient for choose active treatment). This yielded only an additional two men who chose active treatment in the past year and two men who were following AS, but felt a decision for active treatment was imminent. The final sample included 16 providers and 19 patients. The first interviewer conducted 11 interviews (31%; 10 providers, 1 patient), the second interviewer conducted 23 interviews (66%; 6 providers, 17 patients), and the third interviewer conducted one interview (3%; 1 patient).

All interviews were digitally recorded, transcribed by a professional transcriptionist, and proofread by an interviewer for accuracy. Deidentified information (e.g., provider documentation of the decision-making process, education offered, etc.) from the consultation closest to the date of diagnosis was abstracted from the medical record. Corrected transcripts and deidentified consultation notes were loaded into Atlas.ti (software version 7) to enable data management and analysis.

Analysis

Patient data were not linked to a particular provider during any stage of the analysis (i.e., patients and providers were not analyzed as a dyad). A number of reasons led to this decision. First, many providers were interviewed before any of their patients enrolled in the study (and some providers had no patients fitting the inclusion criteria during the recruitment period). As such, there was not an opportunity to ask providers to discuss specific aspects of their clinical reasoning regarding the patients enrolled in this study. Additionally, most of the patients reported that more than one provider influenced their representations of AS (e.g., primary care physicians, other providers seen for first or second opinions).

Two interviewers (KDL and TM) developed a preliminary code list while reading and discussing the initial interviews. Subsequently, one interviewer (KDL) continued to develop the code list and coded all 35 interviews and 19 medical record notes. The codes were essentially descriptive labels that identified the topic of each fragment of text. Examples of descriptive codes include "age," "information from providers," and "people known with cancer."

After all data were coded, the first author consolidated and sorted the codes to create a visual framework of patient, provider, and system factors that participants' mentioned as contributing to treatment decisions. The preliminary framework, a selected data summary (i.e., answers to why each man chose a treatment option, grouped by age and treatment choice), and the evolving analysis were shared with the study team and two external reviewers skilled in qualitative analysis and decision-making research. To enhance reliability, two other team members read the transcripts to search for evidence to support or refute the evolving analysis. Findings were again presented to the team verbally and in writing to hone the interpretation.

Results

Participants

All five eligible practitioners at the Dartmouth site enrolled and only two practitioners from the University of Vermont site declined to participate due to scheduling constraints. Fourteen male (88%) and two female practitioners (12%) completed an interview. There were 10 urologists (63%), 3 radiation oncologists (19%), 1 medical oncologist (6%), and 2 nurse practitioners (12%). The practitioners had an average of 15.6 years working with men with prostate cancer (range: 1-37, *SD* = 9.2).

Nineteen patients enrolled in the study and completed an interview. While all men who were approached enrolled in the study, the patient sample primarily consisted of men below the age of 70 years (*n* = 14; 74%) who had chosen AS (*n* = 13; 68%). Patients had a mean age of 65 years (*SD* = 6.4) and were all White and non-Hispanic. The majority was married (*n* = 15; 79%) and had more than a high school education (*n* = 16; 84%). Only 1 (5%) of the 19 patients had ever been diagnosed with another form of cancer (that man was diagnosed with a hematological cancer years ago). Fourteen (74%) men reported having a blood relative who had any form of cancer and 11 (58%) men reported having a blood relative who had been diagnosed with prostate cancer. Characteristics of the patient sample are listed in Table 1.

Table 1. Characteristics of the Patient Sample (*N* = 19).

Characteristic	
Age, *M* (*SD*)	65 (6.4)
Race/ethnicity, *n* (%)	
White	19 (100)
Non-Hispanic	19 (100)
Marital status, *n* (%)	
Never married	3 (16)
Married	15 (79)
Divorced	1 (5)
Employment, *n* (%)	
Full time	9 (47)
Retired	9 (47)
Declined to answer	1 (6)
Annual income, *n* (%)	
Less than $40,000	5 (26)
$40,000 or more	11 (58)
Declined to answer	3 (16)
Education, *n* (%)	
High school graduate/GED	2 (10)
Some college/technical school	6 (32)
College graduate	7 (37)
Graduate degree	3 (16)
Declined to answer	1 (5)
Insurance, *n* (%)	
Private	8 (42.5)
Medicare	1 (5)
Medicaid	1 (5)
Military	1 (5)
Medicare + private	8 (42.5)
Decision, *n* (%)	
Active surveillance	13 (68)
Active treatment	4 (21)
Undecided	2 (11)

Note. GED = general educational development test.

Cognitive and Affective Representations of Active Surveillance

Three themes were apparent in the patient accounts of the advantages and disadvantages of AS. First, AS was generally seen as a temporary strategy, appropriate for certain moments in time. Second, AS was largely equated with inaction, with variation in the degree to which men viewed inaction as warranted or favorable. Finally, the cognitive and affective representations of AS were somewhat malleable and able to be influenced by information from trusted sources.

Active Surveillance as a Temporary Decision. The men generally saw AS as a temporary choice or state. Men who chose AS described it as what they were doing "for the time being, to see if anything changes" (Participant 5, chose AS). Several men felt that, eventually, disease progression would require them to make another decision regarding the treatment of their prostate cancer. Conversely, others believed that they might never need to treat their prostate cancer. "This prostate cancer is not . . . a life changing thing yet and it may never be . . . it doesn't require me to make a big decision yet" (Participant 4, chose AS).

Each surveillance visit provided information patients used to gauge whether they should continue to follow AS or if it was time to choose another option.

> The other two options [radiation or surgery] were somewhat-ya know- once it's done, it's done. And you live with the result. . . . This one here [AS], the very fact that every three or four months, this thing gets checked, and more than likely, you've got an option to go back and do one of the other two if something changes. (Participant 7, chose AS)

This cognitive representation of AS as a potentially temporary choice was accompanied by various affective representations. Many men who chose AS stated that they did not worry about the decision on a day-to-day basis; however, they experienced apprehension as the time drew closer for a surveillance visit. Most reported that the surveillance ultimately provided reassurance as to the indolent nature of their cancer. As one man said, "And nothing's changed, the last biopsy showed very little change, so I think I made the right decision" (Participant 5, chose AS).

Comments from practitioners corroborated these patient viewpoints. Several practitioners felt that patients grew more at ease with their decision to follow AS as they spent longer amounts of time on the surveillance plan.

> I find that some people might think that over time patients will get more and more anxious: "Oh my gosh! The cancer's in there! Is it growing, is it growing, is it growing?" I've seen the opposite, at least in my practice, where somebody's been on active surveillance: they've been on active surveillance for a year now. The longer they get into it they're kinda like, "Nothing bad's happening to me." And they're like, more and more comfortable with it almost. (Practitioner V03, urologist)

Many practitioners encouraged patients to take time to fully consider the options. One went so far as to say he used AS as the "default" decision for patients, even if it ended up being a temporary decision.

> I tell them they have plenty of time to decide what they want to do. And often, um, especially if they have low risk . . . and even if maybe they are thinking about therapy, I will say. . . . "Why don't we make a visit for you at three months' time, with a PSA, which would be an active surveillance visit, but, um, we can use that to see where you are on your decision process . . . and if you decide to do treatment sooner, you can let us know." . . . Almost always at the end of that initial conversation, I encourage people *not* to have decided. (Practitioner 02, urologist)

Active Surveillance as Informed Inaction. While the term *active surveillance* is meant to connote a series of steps and a state of vigilance, many men viewed it as "inaction." One patient framed AS as an option wherein "there's no action that you really have to take . . . it's just monitoring" (Participant 5, chose AS). The men could recount the series of tests and biopsies involved in AS, but they tended to characterize AS as "doing nothing" or watching the cancer. For many men, inaction was a logical choice because any other action would be premature.

> Why would I choose anything else? In other words, I'm at the stage where we can watch it . . . I don't see anything else to do . . . I don't see there is a choice really . . . there would be no reason to go in and take it out. It would be just getting, ah, you know, overly aggressive. (Participant 3, chose AS)

> I mean, if it's not absolutely necessary right away I'd rather not go through that and take a chance of having a lot of other problems that I really don't have to have. . . . He's [the physician] monitoring it very well and . . . I trust them and so I'm very comfortable with them monitoring everything and, you know, if it comes to a point where something has to be done then I'll probably have it taken out. (Participant 9, chose AS)

> I had thought that the radiation treatment would be like you go like a couple of times. And you don't. You go many times, almost every day for like a long time. And the possible side effects are pretty severe. You know, you can become incontinent and have sexual difficulties and everything. And I thought, wow, that just seemed like a dramatic overreaction for something that was just, at the very beginning, suggesting there may be an issue. So that was, to me, at the level that I was, it just didn't make any sense at all to have any extreme treatment. (Participant 15, chose AS)

While they may have described their choice as "doing nothing" about the cancer, all emphasized that the vigilant monitoring of AS would indicate when it was appropriate to "do something" about the cancer. They also expected that providers would offer clear and direct instructions on when action was needed. "I really would wait for the physician to say, 'you know, it's time to take it out, take the prostate out'" (Participant 6, chose AS).

> And unless I was in the situation where, you know, the doctor was looking me in the eye and saying, "Well, this is the point where you really need to have your prostate out or have radiation treatment," I'm just going to continue [with AS]. (Participant 15, chose AS)

Inaction had some benefits that were mentioned by a few men. One man was optimistic that surgical and radiation treatment options would improve over time: " . . . the field of treatment is changing so fast that by the time I have to make a decision the treatment choices might be quite different than they are today" (Participant 4, chose AS). Some men were aware that there was controversy regarding prostate cancer screening and treatment.

> I went with it [AS] for the simple reason that I kinda know my body . . . I said to myself, "Well, these PSAs are comin' back quite a bit lower. And I'm not havin' any more trouble than I ever had." And so I just went with the active surveillance. And I think it's payin' off. Because from everything I read, and even doctors say the same thing that ah, they're over-treating it sometimes. (Participant 2, chose AS)

The affective representations linked to inaction varied. As illustrated by the quotations above, most men who chose AS were comfortable with the decision, because of how they understood the disease process and trusted the recommendation of the physician. However, four men in the patient sample chose active treatment and felt that the inaction of AS was too risky for them to endorse. These men wanted an aggressive approach that would "take care of the cancer." One man who chose surgery said succinctly and repeatedly, "Cancer is cancer and I want it gone" (Participant 16, chose active treatment). That man did not have cognitive or affective representations of cancer that allowed for gradation of risk and tolerance of inaction. Similarly, the other three men stated as follows:

> And surgery seems much more "let's get that thing out of there." . . . We're talking life and death here . . . I think our bottom line or our priority was to take the most aggressive step possible against the cancer. And everything else was MUCH less important than that. (Participant 10, chose active treatment)

> And I chose the surgery because as far as I'm concerned that's the best way to go with the most, how do I put it? You improve your chances of ridding yourself of cancer the most by having surgery in my opinion . . . from my personal experience, the people I personally know, all the people who had surgery are alive, all the people that either waited too long or didn't have surgery are dead. So I figured that was pretty good thing to go by. (Participant 11, chose active treatment)

> It's still cancer . . . so it's something to be taken seriously . . . I mean, you have to do something. I think the active surveillance is non action or no decision. That's just procrastination. You either get the rods or you get the surgery. (Participant V02, chose active treatment)

Malleability of Representations of Active Surveillance. For some men, AS was easily accepted as a choice because of various predispositions to favor the philosophy behind AS. For example, one man articulated a preference for medication or medical intervention only as a last resort and another man stated AS "resonated" with him because he has a "PhD in procrastination." In contrast, there were other men who came to choose AS *after* assuming that active treatment would be the best or only option for them.

> I was prepared when I went to him [surgeon] to go through the surgical procedure as my brother-in-law had done because I simply did not want to run the risk of not intervening in time. . . . I said, "If you recommend the surgery, I'm ready for that." And he said, "No, I don't want to do surgery on you." . . . And that blew me over. I thought, "What is going on here?" I was surprised and a little bit confused. He was very, very confident that my situation just did not warrant surgical intervention. . . . He laid out the plan of . . . a surveillance process as long as four years. And that really took me aback. But this guy knows that he's doing and I have trust in him. So I'm going to follow what this man says. (Participant 13, chose AS)

It is notable that men were expected to synthesize a lot of information in making their decision. The information came from providers, but also from family members, friends, books, and the Internet. This information could be difficult to understand and synthesize and some messages were seen as confusing.

> They gave me a book to read, and I read it, and they gave me a bunch of stuff that was a little confusing. After I read the whole thing, I didn't know what the best scenario was . . . I was still a little puzzled about it, which way to go. (Participant 12, chose AS)

> I understand somewhat of it. Although I started reading stuff in a book, the wording is way beyond my comprehension . . . because a lot of it was medical terms. It meant nothing to me. I did understand enough about it so I knew I should probably do something. (Participant 14, chose active treatment)

Consistency of information helped the men formulate coherent cognitive and affective representations of their disease and the treatment choices. Confusing or contradictory information led to skepticism and some sought more information or a second opinion from another practitioner.

> When he said, "this is a tough one," I was thinking really, really bad. As we talked, he started saying it's not a bad one at all. He explained it all, biopsies that only showed up 2 percent on one biopsy. He was lucky to even catch it, you know. There's nothing to lose sleep over. You know, "this is a tough one" and then he started explaining it. "It's nothing to worry about." I couldn't connect that. I couldn't so that's when I asked for a second opinion because it's like to me that was, when you're the receiver of the information, it's like you know, it's all a big–and I just couldn't connect those dots. (Participant V1, chose AS)

Of note, the providers were sometimes skeptical regarding the malleability of cognitive or affective representations and, correspondingly, the power they had to shape them. "There are some people who definitely know what they want when they come in. And there are people that don't know" (Practitioner 1, nurse practitioner).

> Many people who come in have preconceived ideas and we try to get an understanding of what their depth of knowledge is of various forms of treatment and, ah, and then correct them where necessary, augment the discussion where necessary, and ultimately, ah, in my particular situation, I try to let the patient come to conclusions of their own . . . many

> people have already made a decision as to what treatment what they favor. Some people don't like thought of surgery. Some people don't like the thought of radiation. And these are based on long-time perceptions that are pretty difficult to change and pretty difficult to talk someone out of. One thing I've learned over the years is that, uh, you do not spend a big effort to trying to talk someone out of a preconceived perception that they've already drilled into their head. (Practitioner 3, urologist)

> And some patients can just become overwhelmed with all the data and, um they become fixated on . . . aspects that I would consider are probably, you know, largely irrelevant or unimportant. And they are unable to kind of see the big picture and figure out what's right for them. Um and . . . they perseverate about what to do and perseverate about, in various different aspects, that they consider very important but actually in reality, probably aren't very important. And it's difficult to—it's difficult to make people understand those things. (Practitioner 2, urologist)

The providers reported some discomfort with the way in which cognitive and affective representations of cancer can be influenced from various sources.

> We hear this a lot: "I had a friend who had trouble with x, or y, or z" where x is surgery, y is the seed implant, and z is external beam. So, some come in [with] predilections against or for one particular form of therapy. Very much anecdotal. . . . And even after they've done all this reading and heard all this advice from everybody, they're very influenced, quite often, just by the immediate experience of one or two people that they know well and also trusted. (Practitioner 4, radiation oncologist)

Patients and practitioner comments indicate that information is most salient and utilized when it comes from trusted sources. "He's monitoring it very well and . . . I trust them and so I'm very comfortable with them monitoring everything" (Participant 9, chose AS).

> I think a good relationship is where the doctor really tried to get to know the patient, get to know what their values and interests are. And so you get to know folks and then you try to given them good advice . . . in a very supportive way. And always honoring options . . . I will always make sure they understand these are *their* choices. (Practitioner 4, radiation oncologist)

Discussion

The purpose of this article was to explore cognitive and affective representations of AS within a clinical environment that promotes AS as a viable option for men with low-risk prostate cancer. The patient accounts revealed that AS is seen as a temporary, somewhat passive intervention and that the representations of AS are at least partially malleable. The results corroborate prior investigations that indicate patients perceive AS to be a passive and nonaggressive approach to a cancer diagnosis (Xu et al., 2012). However, these findings contrast with Xu's study of 21 men who had limited knowledge about AS, felt it was only appropriate for older men, and reported a notable lack of support for and endorsement of AS by providers. In light of such, AS appeared to be a highly unreasonable strategy to that sample of men. The current sample was recruited in clinical settings where AS is promoted as an option, and the men in this study were able to explain the rationale for AS and voiced varying levels of comfort with the strategy.

Self-regulation theory suggests that in order to decide how to treat their prostate cancer, men need to process their cognitive and affective representations of cancer, of their particular type and stage of cancer, of the treatment options, and how the treatment options might affect their daily lifestyle and overall survival. Essentially all of the men shared the cognitive representation of AS as "inaction." The men who chose AS, however, also had cognitive representations that suggested the immediate risk of harm from their cancer was relatively low. These cognitive representations allowed them to tolerate negative affective representations of worry and distress and encouraged positive affective representations such as feeling like they are avoiding potential harm that can come with treatment. Similar to the men in this study, other research has also reported that men on AS tolerate the "inaction" of the approach by emphasizing the avoidance of harm and potential to learn about other treatment options that may appear in the future (Oliffe, Davison, Pickles, & Mróz, 2009). Both the men in this study choosing AS and the men in the study cited before by Oliffe et al. (2009) reported experiencing increased negative affect prior to a surveillance visit, but generally did not feel distressed about their treatment choice on a daily basis.

Conversely, the few men in this study who chose active treatment had cognitive representations that suggested the risk of being harmed from their type of cancer was substantial. Because this study did not audiotape or observe the interaction between the provider and the patient and the interviewers did not ask each provider to specifically discuss the idiosyncrasies of each patient participant's care, it is uncertain whether the patients' cognitive representations reflect the information the provider was trying to convey. However, research suggests that powerful affective representations, such as fear or anxiety, can make it hard to cognitively process and synthesize information (Peters, Lipkus, & Diefenbach, 2006). That adds to the challenge providers face in helping patients synthesize complex and potentially confusing information.

It is important to note that information, both that garnered from providers and from anecdotal experiences of salient friends and family members, can affect both cognitive and affective representations of cancer and its treatment options. In fact, research in the field of medical sociology indicates that men facing cancer often fortify their cognitive defenses to the uncertainty of their disease and diagnosis through knowledge building, and that men value the guidance provided by both health care providers and social connections in this process (Wenger & Oliffe, 2014). There was evidence in these data to suggest that both cognitive and affective representations are at least partially malleable and potentially modifiable. There was also evidence in these data that both patients and providers are skeptical of the ability to modify any long-held belief or feeling about cancer or a particular treatment. This suggests that both interventions designed to facilitate acceptance of AS as a viable treatment option for low-risk prostate cancer need to target both patients and providers for maximum potency.

There is a temporal aspect that is important to consider in decision making. More than one practitioner felt that both practitioners and patients seem to become more comfortable with choosing and practicing AS over time. Affective representations are particularly powerful when a person feels the need to make a rapid decision (Peters, Diefenbach, Hess, & Västfjäll, 2008). As such, it may be wise, as some providers in the study advocated, to build clinical systems and procedures that encourage periods of deliberation so that men may be better able to appreciate or accept the philosophy behind AS. Understanding core themes in how patients contemplate AS may benefit providers who are new to counseling these patients, for example, to provide expectations of patient viewpoints and inform strategies to proactively address their concerns. The demonstration of malleability in patient perspectives reflects the importance of disabusing patients of misconceptions about risks of "cancer" that may lead to overtreatment.

Limitations

These interpretations are limited by the use of a single verbal interview with a convenience sample of men recruited from two academic institutions with protocols that guide eligibility for and execution of AS. The interviews were conducted by three females with no clinical experience in urology. It is possible that different interviewers (e.g., males, nurses, etc.) would have elicited different responses from the patients and providers. However, this "outsider" perspective was perhaps ultimately a strength of the design, because the skilled interviewers' lack of familiarity with the urology culture and setting encouraged them to ask for clarification when participants were using jargon or giving superficial answers. While the team did not engage in formal inter-rater reliability processes during data collection and analysis, the interviewers did discuss the evolving data set with the principal investigator (MTH) at least weekly to share their perceptions, given their unfamiliarity with the subject content.

Furthermore, the demographics of the sample are largely homogeneous and only five men were older than 70 years. There are age differences in the way information is cognitively and affectively processed (Peters et al., 2008) and this data set is unable to inform that distinction. Most important, the recruiters had a difficult time finding men with low-risk prostate cancer who had chosen to pursue active treatment and the views of men choosing active treatment are subsequently underrepresented here. As such, these results may not be generalizable to other, more diverse populations receiving care at other institutions.

Patients were only approached for participation in the study if they were diagnosed with prostate cancer within the past year. Participants who are farther out from the time of diagnosis might suffer from recall bias. Alternatively, the knowledge that they have now may be different from what they knew at the time of diagnosis. For example, some men had been under surveillance for a few months and may have been able to express more confidence in their decision than they had originally felt. While this variation helped illustrate the phenomenon, future research should focus on specific time points in the decision-making process. Additionally, future studies would benefit from the inclusion of spouses and naturalistic observation of interactions between patients and practitioners to fully understand how men come to understand and choose their approach to managing their prostate cancer.

Conclusion

To choose AS is to have a somewhat high tolerance for "inaction" in the face of a cancer diagnosis. While not all of the men in the study were comfortable with only monitoring their cancer, many men articulated several reasons why inaction may actually be preferable to action. They included such reasons as avoiding side effects and complications of treatment, the potential for treatment procedures to be refined and more effective in the future, and not overreacting to what might be an indolent problem. These findings suggest that for at least some men, the representations of cancer and cancer treatment options are malleable. While providers may confront patients with entrenched attitudes toward cancer and various forms of treatment, these data suggest that it is possible to reshape these views at times. Designing systems that encourage slow deliberation and multiple consultations may facilitate greater understanding and acceptance of AS as a viable treatment option for low-risk prostate cancer.

Authors' Note

This information or content and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, or the U.S. Government.

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