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## “It's Not Like You Just Had a Heart Attack”: Decision-Making about Active Surveillance by Men with Localized Prostate Cancer

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### Abstract

**Background**—Growing recognition that active surveillance (AS) is a reasonable management option for many men diagnosed with localized prostate cancer led us to describe patients' conceptualizations of AS and reasons for their treatment decisions.

**Methods**—Men were patients of a multidisciplinary prostate cancer clinic at a large tertiary cancer center where patients are routinely briefed on treatment options, including AS. We conducted a thematic analysis of interviews with 15 men who had chosen AS and 15 men who received radiation or surgery.

**Results**—Men who chose AS described it as an organized process with a rigorous and reassuring protocol of periodic testing, with potential for subsequent and timely decision making about treatment. AS was seen as prolonging their current good health and function with treatment still possible later. Rationales for choosing AS included trusting their physician's monitoring, “buying time” without experiencing adverse effects of treatment, waiting for better treatments, and seeing their cancer as very low risk. Men recognized the need to justify their choice to others because it

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seemed contrary to the impulse to immediately treat cancer. Descriptions of AS by men who chose surgery or radiation were less specific about the testing regimen. Getting rid of the cancer and having a cure were paramount for them.

**Conclusions**—Men fully informed of their treatment options for localized prostate cancer have a comprehensive understanding of the purpose of AS. Slowing the decision-making process may enhance the acceptability of AS.

### Keywords

Cancer; Oncology; Prostate Neoplasms; Decision Making; Qualitative Research

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### Introduction

For men diagnosed with localized prostate cancer (PCa), observation may be a viable management option [1-6]. Clinical guidelines from the National Comprehensive Cancer Network [5] and the American Urological Association [6] include the option of observation for men with localized PCa that is deemed low risk on the basis of the tumor's characteristics and the patient's life expectancy. Yet among men with low-risk disease, less than a fifth select it over immediate treatment [7, 8].

Observation has been described as “active surveillance” (AS), “watchful waiting,” or “expectant management,” but historically these terms have often been used without specific definitions [3]. This lack of clarity complicates evaluation of the scientific literature on observation [9]. Recently, the National Institutes of Health issued a consensus statement defining AS “as a disease management strategy that delays curative treatment until it is warranted based on defined indicators of disease progression” (p. 4) [3]. In contrast, with watchful waiting, curative treatment is not the goal and treatment is initiated when the patient becomes symptomatic.

Not a great deal is known about the choice of AS among men with PCa. Only a few surveys and qualitative studies have been used to collect patients' views on AS and their reasons for choosing it over treatment. A qualitative study of 25 Canadian men who had selected AS found that they perceived that their cancer was not an immediate threat to their health or life and wanted to avoid the side effects of treatment [10]. The physician's recommendation for observation was also an important influence. The importance of support from physicians, as well as from family members, as a factor in selecting AS has been noted by other researchers as well [11].

With the current study, we sought a richer understanding of the views on AS of patients diagnosed with localized PCa. This project used qualitative methods to explore patients' conceptualizations of AS and treatment decision making. The results will be used to inform the development of patient education and decision support tools to assist men and their health care providers who may find these value-based decisions difficult.

## Method

### Setting and Participants

Subjects for this study were recruited from the Multidisciplinary Prostate Cancer Clinic (MPCC) at The University of Texas MD Anderson Cancer Center. On the basis of a thorough assessment of a patient's tumor characteristics, potential longevity, and other medical and psychosocial concerns, the MPCC educates the patient about his cancer and management choices. Patients are seen by a urologist and radiation oncologist in the same clinic, one then the other usually just a few minutes apart. The team then confers and makes a joint recommendation about treatment options, including AS. Patients who select AS are referred to a protocol for monitoring.

Eligible patients were men diagnosed with prostate cancer defined as cancer that had not spread beyond the prostate gland at the time of diagnosis. Men who were re-staged higher at the time of treatment were not eligible to participate. All respondents were English speaking.

Two groups of patients were targeted for recruitment. First, the AS patients must have chosen AS and be 6 to 18 months from the decision to enter the AS protocol. This time frame was selected to allow patients to have had several months of experience with this protocol, including returning to the MPCC for surveillance, but few would have already transitioned to active treatment because of disease progression. These men were further selected to ensure a mix of patients younger than and older than 65 years of age.

The second group were men with localized disease who chose to be treated surgically or with radiation. Surgery and radiation patients were selected to be 6 to 18 months following treatment (the date of surgery or completion of the course of radiation). In this time window, the acute recovery period would have passed and most patients would have achieved continence. Because surgery patients tend to be younger than radiation therapy patients, we sampled to produce a mix of men under and over 60 years of age for surgery and under and over 70 years of age for radiation therapy.

The eligibility of each patient who agreed to participate was confirmed via medical record review. Of the 36 men who were contacted, 30 agreed to participate (15 AS patients and 15 treated patients). The study was described to them as involving a telephone-based interview about their treatment decisions in order to help with the development of educational materials for men facing similar decisions. The project was reviewed and approved for use of human subjects by the Institutional Review Board of the MD Anderson Cancer Center and the Committee for the Protection of Human Subjects, The University of Texas Health Science Center at Houston.

### Interview Procedures

Audiorecorded telephone interviews were conducted by male interviewers between May and August 2011. The interview was structured around the following topics: treatment options discussed and considered, a description of AS using the patient's own words, how the treatment decision was made, recommendations made by the health care team, and the role of others (e.g., a partner) in decision making. Specific questions were asked about the

importance of treatment-related side effects (e.g., impotence, urinary and bowel incontinence) in the treatment decision. A payment of \$50 was made to participants at the end of the interview.

## Data Analysis

The purpose of our analysis was to identify themes across all 30 interviews and within the two patient cohorts. In identifying the themes, we began with the topic areas in the interviews (e.g., involvement of a partner in the decision) and augmented them with themes emerging from the respondents' interviews (e.g., the physician's evaluation as a factor in the decision process).

Once the audiotapes were transcribed, we performed the initial coding of the transcripts, familiarized ourselves with the interviews, and then identified more detailed themes. We worked with two general-purpose computer programs to code the original transcripts and to generate reports of retrieved coded sections. That is, we abstracted chunks of text from the numbered transcript files prepared in Microsoft Word and copied them to Microsoft Access, a general database program for assignment of descriptors (e.g., AS vs. T [for immediate treatment]) and thematic codes. This approach provided the functionality of code searching and retrieval found in specialized qualitative data analysis software but without the expense or effort of using a special-purpose computer program.

Transcripts were assigned to individual coders who were members of the research team and experienced in qualitative methods for the initial selection of chunks of text into the database. We then worked from major chunks to identify subthemes. In our analysis meetings, two persons presented their coding results, accepted additional input from other analysts, and reconciled coding disagreements. Quotes provided below are identified by the patient group (AS vs. T) and a patient number.

## Results

### Patient Characteristics

Men in the AS group were on average  $62.6 \pm 7.6$  years old (range, 49–72 years), and men in the treatment group were on average  $58.6 \pm 6.9$  years old (range, 45–70 years). Most men had at least some college education, all but two classified themselves as white, and three quarters were married (Table 1). More than twice as many men who had been treated than men in the AS group reported having a relative who had had PCa (47% versus 20%).

### Definition of AS

All respondents were asked about their understanding of AS. We also read a definition to the treated men and asked about circumstances where they think a man with localized prostate cancer should select AS.

**Theme 1: AS Is an Organized, Supportive Process**—AS men gave a consistent description of AS: meet with their physician twice a year, have prostate-specific antigen (PSA) tests, undergo an annual biopsy, and at least yearly discuss with their physician the

decision to be on AS. This set of activities accurately covers what is involved in AS for PCa within this treatment environment.

Among AS men, monitoring was viewed as an organized process that is supportive should a change occur: “I really like the fact that [the hospital] was kind of putting me in a program.” (AS10) There was satisfaction with regular monitoring, which was seen as a system to check whether the tumor was getting out of hand. One man summarized that he was:

“...comfortable with the idea that they were going to watch me closely enough and with enough skill that if this began to be more aggressive or turn into something [else], that they would recognize it and then it would be time to get involved in [active treatment].” (AS5)

The results of tests and biopsies provide information that allows the medical team and patient to determine when implementing curative treatment would be appropriate. AS is not a matter of going it alone; the patient is part of a team. The men described their trust in their treatment teams.

This group compared AS with watchful waiting. For example,

“Active surveillance is essentially waiting on having surgery or other types of treatments for prostate cancer. It's a watchful program, where you wait and see whether the cancer is growing or how much it is growing.... The thing I like about the active surveillance is... it's not active waiting. The active part is the emphasis.” (AS14)

In contrast, the treated men described AS in its general contours and as a less active process: “Basically you sit back and watch and wait and periodically do testing to see the progression of the disease.” (T27) Treated men were less specific about time intervals and the tests involved, did not distinguish between watchful waiting and AS, did not see AS as involving an organized program or being part of an ongoing relationship with the treatment team.

Treated men described the principal goal of treatment as cure (“taking care of it” or “getting rid of it”). They valued the fact that they had made a definitive choice to deal with the cancer. For them, the key issue was getting rid of the cancer.

Finally, some treated men erroneously associated AS with any sort of monitoring such as post-treatment monitoring with PSA tests to assess for recurrence: “Let's get rid of it and do the watchful waiting afterwards.” (T27) Others applied the term AS for some other disease altogether. For example, a man who had had melanoma referred to his regular skin checks as AS.

**Theme 2: AS Prolongs Current Good Health**—The decision for AS was seen by men not as a final decision but likely the first of a sequence of decisions. AS provides an interval in which to continue enjoying current health and function without undergoing treatment or risking the side effects of treatment. One man described AS as fitting with his 5-year plan: the program would evaluate him each year, but he had slated himself a major time of

reflection after 5 years. The idea behind AS is to “buy some time from having to make a difficult decision that involved potential risk.” (AS11)

### Factors Associated with Treatment Decision

One advantage of this study is that both treated and AS men had undergone a similar multistage process to reach an initial treatment decision. In several cases, men described being diagnosed by a community-based urologist, but they may also have had consultations with other urologists, radiation oncologists, or other specialists before being seen at the cancer center. Some had been dissatisfied with the treatment options they had been offered and skeptical about the motivations of the diagnosing clinician. At MD Anderson, patients had undergone another biopsy and participated in multiple consultations at the MPCC. Here, we organized the analysis of factors in men's treatment decisions around three topics: a) how men described their condition, b) pros and cons of the treatment option, and c) physician support.

**Theme 3: Viewing Their Cancer as Low Risk and Having Time to Decide About Treatment**—Men in the AS cohort described the tumor as being small and could give a detailed account of biopsy results. For example, one man recalled,

“My particular diagnosis appeared to be a very small cancer risk.... Of the cores that were taken in my initial biopsy, only one core returned with a cancer sample and it was less than 1 mm. The other cores were negative. And my second biopsy, all the cores were negative.” (AS12)

These men also referred to the slow growing nature of their cancer, but there was greater emphasis on how it was only “a little” cancer.

AS men believed they still had time to make a decision about active treatment. In light of the slow growth of their cancer and small tumor size, they concluded that immediate treatment was unnecessary. One man summarized the situation as, “It's not like you just had a heart attack.” (AS17)

The disadvantage of AS is that the cancer could, despite its small size, be aggressive. AS men said this concern was less important because regular monitoring would be sufficient to detect any changes and that effective treatment could be introduced then. Several men in the AS group thought that postponing treatment might allow sufficient time for technological advances when they were ready to receive treatment.

Thirteen of the 15 treated men did not characterize the size or nature of their condition. Their descriptions of biopsy results were general rather than detailed: “Once you have a biopsy, deal with it.” (T20) Treated men did not refer to slow-growing tumors.

**Theme 4: Avoidance of Side Effects of Treatment**—The principal reason for selecting AS was to avoid the side effects of treatment, particularly those affecting sexual function. This is one participant's interpretation:

“I believe that the risk of those side effects right now is greater than the risk of my dying of prostate cancer. And implied in that statement is the idea that suffering

those side effects is equivalent to dying. That's not a bad description of the way I feel about it.” (AS5)

**Theme 5: Importance of Physician Recommendation about AS**—AS men had conducted substantial independent research regarding the decision for AS or immediate treatment but valued physician input as well. According to one patient, “I asked [the physician] what he would do [in my situation]. And he said active surveillance.” (AS3) AS men also described their confidence in the doctors running the AS program.

### Other Themes

**Theme 6: Justifying the Decision to Others**—AS men recognized that their decision was counter to expected norms for people with cancer, and at times they felt the need to justify their decision to other people. They commented that the decision was often more difficult for their spouses than for themselves. One AS man reported that once he convinced his children that he was not suicidal, they generally agreed with his decision. Another man mentioned that not only was he not worried about having PCa, but he would almost forget he had PCa and needed to remind himself to mention it on medical history forms.

**Theme 7: Desire for Immediate Cure**—Among treated men, the principal reason for selecting active treatment for PCa (i.e., surgery or radiotherapy) was described variously as protecting one's life, wanting a cure, or wanting to remove the cancer from the body. Treated patients had understood the risk of adverse consequences of treatment before they had decided to follow their “gut reaction” to “cut it out.”

Treated men reported that their physicians communicated about the level of risk for side effects. However, treated patients placed a higher priority on actively treating the disease. One participant stated: “I was overwhelmingly wanting to get rid of the cancer, so that was really driving me. Not necessarily being able to still perform sexually was not going to outweigh getting rid of the cancer out of my body.” (T22)

Treated men discussed their choice of treatment in relation to other possible active treatments and rarely in relation to AS. Some men expressed preferences for specific treatment features, mentioning that the outcome with one type of radiation was as good as that with surgery or that there are fewer sexual side effects with radiation than with surgery. A patient who had selected brachytherapy described the radiation seeds as going “right where they are needed,” (T2) a claim for precision. Patients also mentioned drawbacks or advantages in relation to the treatment delivery and recovery time: one man rejected surgery because he thought the recovery time would be too long. Some of the radiation options would have required treatment far from home for a lengthy period, which was highly undesirable for some men. Finally, men talked about advantages of particular physicians or forms of treatment.

### Discussion

In this qualitative study, men with localized PCa who had chosen AS over immediate treatment gave highly quantified and detailed descriptions of their condition. Telling their

stories in this way may reinforce the decision to be monitored and show that they made a sensible choice. These data are also a crucial part of surveillance, so they are relevant until a decision to receive treatment is made. In contrast, treated men did not give such detailed descriptions; they might have had these facts at their fingertips at the time of the decision to undergo treatment and then forgotten the details, as they were no longer pertinent.

Adapting a broader model [12], Penson [13] developed a systematic-heuristic model of decision making around the acceptance of and adherence to AS for localized PCa. The systematic process involves gathering information, analyzing thoughts and feelings about the information, and integrating the information to form preferences and make a decision; it is a deliberative, time-consuming, and cognitively difficult process. In contrast, heuristic processing is far less taxing and requires less information; decisions are based on preconceived expectations, schemas, stereotypes, and commonsense “rules of thumb” learned and modified through interactions with others. A heuristic strategy relies on only a subset of information and short-cut rules to make decisions quickly [12]. According to the model, using heuristic short cuts to selectively interpret information can lead to bias in systematic processing. Penson argues that factors related to the initial acceptance of and long-term adherence to AS can be explained by this model [13].

Penson's model provides an organizing framework for the themes we identified. In our study, AS men demonstrated systematic processing both in their conceptualization of AS and their decision-making about PCa management, and they revealed in-depth understanding of the periodic testing required by the AS protocol. They also found that this structured monitoring provided reassurance. Patients who chose immediate treatment offered far less detail in their conceptualizations of AS, seeing it as indistinguishable from watchful waiting.

The concept of time was important both for information seeking and making the management decision. For AS, slowing the decision making process allowed men to gather more information about their options and consider the opinions of others. They were able to counter the prevailing heuristics that cancer must be treated immediately and aggressively and that delaying treatment means risking disease progression and death [14]. AS men demonstrated understanding that their current health status could be prolonged, their cancer would be carefully monitored, and they could decide on curative treatment later if the cancer progressed. For men who chose immediate treatment, extending the decision-making time was seen as a threat to longevity.

Understanding the level of risk associated with localized PCa was a key factor in men's decisions to select AS. Other studies have observed that AS patients often believe in the indolent nature of their cancer and that immediate treatment is unnecessary [13, 15-17]. These observations have clear implications for the design of interventions that educate men about a spectrum of risks and include messages that not all cases of localized PCa are the same.

A strength of this study is that the AS cohort and the treated cohort were drawn from the same clinical population, with each person having gone through a multistage process of



consultation and information seeking. In addition, the qualitative analysis of perceptions and treatment decisions permitted the study participants to discuss factors of concern to them rather than being limited to closed-ended questions.

There are limitations to this study. This study was largely limited to white, non-Hispanic men treated at a large cancer center. Views of active surveillance may be very different for men treated in the community, including those from disadvantaged groups [18]. While there may be an increase in the use of multidisciplinary models for PCa treatment in the United States, current PCa programs may be difficult to replicate in community settings. The MPCCC gives men the opportunity to consider alternatives, but the aggressiveness of the cancer, the presence of comorbidities, and other considerations can restrict options. Some of the treated men reported that AS was not recommended to them.

Slowing the decision making process may be conducive to more systematic decision-making by men with localized PCa. Most men learn their diagnosis from the urologist who conducted the biopsy [19]. Studies vary in the extent to which men report seeing other specialists after diagnosis [19]. How can the consideration of AS be made more compatible with current medical practice? Patient decision aids may play an important role in slowing the decision-making process, giving men and others involved in the decision time to deliberate about the options, and encouraging men to question the options they are offered [20]. Patient decision aids educate patients about their options and allow them to compare attributes, and potential harms and benefits, deliberate about tradeoffs, begin to construct their preferences for the options, and make an informed, values-based decision with their health care provider [21]. The findings from this study will inform the messages to be communicated in the design of such interventions.

In addition to providing patients with high quality evidence, patient decision aids can encourage patients to actively pursue treatment options appropriate to their situation and cancer, provide them with the language with which to have meaningful conversations with their health care providers about treatment and observation, and encourage adherence to AS protocols for patients who decide on observation.

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**Table 1**

## Sociodemographic Characteristics of Men with Localized Prostate Cancer

Characteristic	<u>Active surveillance (n=15)</u>		<u>Immediate treatment * (n=15)</u>	
	No.	%	No.	%
Education				
High school graduate or less	0	0.0	4	26.7
Some college or college graduate	8	53.3	6	40.0
Postgraduate	7	46.7	4	26.7
Not stated	0	0.0	1	6.7
White, non-Hispanic	15	100.0	13	86.7
Annual income				
Under \$50,000	1	6.7	1	6.7
\$50,000–\$99,999	5	29.4	9	60.0
\$100,000 and above	7	46.7	4	26.7
Not stated	2	13.3	1	6.7
Currently married	11	73.3	11	73.3
Family member with prostate cancer	3	20.0	7	46.7

\* Brachytherapy (n = 6 men), proton therapy (n = 1), robotic prostatectomy (n = 5), or open prostatectomy (n = 3).

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