Factors Influencing Men Undertaking Active Surveillance for the Management of Low-Risk Prostate Cancer

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n North America, the widespread use of the prostate-specific antigen (PSA) prostate cancer screening test has resulted in approximately one of six men being diagnosed with prostate cancer. Although the overall mortality rate from prostate cancer has declined, this may reflect improved treatment or increased diagnosis of indolent disease that was not life threatening (Klotz, 2002, 2006). About 80%–90% of men diagnosed with asymptomatic, low-risk prostate cancer receive some form of active treatment (Harlan et al., 2003). In North America, radical prostatectomy, external beam radiation therapy, and brachytherapy continue to be the most common definitive treatments for early-stage prostate cancer, but newer treatments such as cryotherapy, thermo-ablation, and high-intensity focused ultrasound also are available at some larger centers. Despite the advances in the definitive treatment of prostate cancer, all forms of treatment affect quality of life, mainly in the areas of erectile dysfunction in more than half of patients, incontinence, and urinary irritation (Litwin et al., 1999, 2007; Litwin, Sadetsky, Pasta, & Lubeck, 2004). Therefore, active surveillance is considered by some men as a viable alternative to the aforementioned treatments. However, fewer than 10% of men in North America choose that approach (Barocas, Cowan, Smith, & Carrol, 2008; Harlan et al.). The literature is confusing with regard to the specific definitions of the terms active surveillance, expectant treatment and management, conservative management, and watchful waiting. Parker (2004) offered an explanation of the differences among the approaches. Watchful waiting (conservative management) is a palliative approach, typically used for older or physically unfit men with limited life expectancy. The approach follows patients until the cancer progresses to an incurable state, at which time treatment is palliative (Parker). Active surveillance (expectant treatment and management), on the other hand, is a proactive management approach with curative intent, where active treatment is delayed until

Purpose/Objectives: To identify and describe decisionmaking influences on men who decide to manage their low-risk prostate cancer with active surveillance.

Research Approach: Qualitative, semistructured interview.

Setting: The Prostate Centre at Vancouver General Hospital in Canada.

Participants: 25 patients diagnosed with low-risk prostate cancer and on active surveillance.

Methodologic Approach: An interpretative, descriptive, qualitative design.

Main Research Variables: Factors that influenced men's decisions to take up active surveillance.

Findings: The specialists' description of the prostate cancer was the most influential factor on men choosing active surveillance. Patients did not consider their prostate cancer to be life threatening and, in general, were relieved that no treatment was required. Avoiding treatment-related suffering and physical dysfunction and side effects such as impotence and incontinence was cited as the major reason to delay treatment. Few men actively sought treatment or healthpromotion information following their treatment decision. Female partners played a supportive role in the decision. The need for active treatment if the cancer progressed was acknowledged. Patients were hopeful that new treatments would be available when and if they needed them. Being older and having comorbidities did not preclude the desire for future active treatment. Patients carried on with their lives as usual and did not report having any major distress related to being on active surveillance.

Conclusions: The study findings indicate that men are strongly influenced by the treating specialist in taking up active surveillance and planning future active treatments. As such, most men relied on their specialists' recommendation and did not perceive the need for any adjunct therapy or support until the cancer required active treatment.

Interpretation: Oncology nurses should work collaboratively with specialists to ensure that men receive the information they need to make informed treatment decisions.

the cancer shows signs of significant growth (Carter et al., 2007; Cooperberg, Lubeck, Meng, Mehta, & Carroll, 2004; Parker). Patients on active surveillance are

monitored closely with PSA tests and transrectal ultrasound biopsies at predetermined times based on clinic protocol. The expectation of active surveillance is that most men will require curative treatment within 5–10 years. The potential benefit of active surveillance is that side effects of treatment can be postponed, with little to no effect on future cure rates (Parker). The current challenge is to differentiate between patients who will require definitive treatment early enough to cure them and those who can safely put off treatment to avoid or delay potential side effects.

How men choose to manage their prostate cancer with active surveillance and factors influencing their treatment decisions are poorly understood. The purpose of the current study was to identify and describe how men arrived at their decision to go on active surveillance as a preliminary step to identifying what types of resources and supports might be of future benefit to them.

Methods

Approach

An empirical phenomenologic research approach was used for the current study. Phenomenology describes the meanings of experiences from an individual's perspective (Oiler, 1982). The approach was chosen because little is known about how men arrive at their decision to be on active surveillance and the factors influencing such decisions. The researchers also wanted to describe the experiences of men during follow-up and their desire for future definitive treatment.

Participants

The purposive sample was recruited from the Prostate Centre at Vancouver General Hospital and the British Columbia Cancer Agency in Vancouver, both in Canada. The clinics are large, urban, tertiary care referral centers for the province of British Columbia. The sample included English-speaking men with low-risk prostate cancer (as confirmed by their physicians) currently on active surveillance. Physicians identified eligible patients. Low-risk prostate cancer was defined by the following parameters: a PSA of 10 or less, a Gleason score of 6 or lower, and clinical stage of T1C, T2a, or T2b.

Procedure

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Ethical approval was obtained from the appropriate academic and clinical institutions prior to data collection. Prostate cancer specialists at both sites mailed letters of invitation to men in their practices who met the study criteria. Patients contacted the study coordinator if they wished to learn more about participation in the study. The study coordinator also was responsible for arranging interviews with patients who agreed to participate in the study. A research assistant trained in qualitative health interviewing conducted all participant interviews in a private patient library. Open-ended interviews were conducted with each participant and digitally recorded. The goal of each interview was to get a rich description of how each participant made his decision to be on active surveillance and the factors influencing his decision. See Figure 1 for the interview guide. Participants were encouraged to continue talking until they believed their experiences had been fully described. As data collection progressed, the interview questions were refined to address themes that emerged from the preliminary data analyses (Glaser, 1978). The interviews lasted 45–60 minutes. The research assistant also made and documented observations during the interviews, following each interview. Personal and medical treatment information also was collected from patients and their clinic charts.

Analysis

The recorded interviews were transcribed verbatim and checked for accuracy by the research assistant. Data were uploaded to NVivo[™], a computer software program for organizing and grouping data into sets. Data collected from each participant were labeled with a unique alphanumeric identifier. Interviews were read and coded with open and then focused coding techniques to identify, label, and organize key concepts. This enabled the researchers to retrieve, code, and analyze the data from each participant. Reading the interview data identified key concepts and preliminary themes along with illustrative examples from the data. Broad categories were used to organize and inductively code the raw data. The

- 1. How long have you been on active surveillance?
- 2. Why did you choose to do active surveillance?
- 3. How did your approach to deciding to be on active surveillance compare with other important decisions you have made in your life?
- 4. How influential was your physician in your decision to begin active surveillance?
- 5. Was your physician supportive in your decision?
- 6. How influential was your family in your decision to begin active surveillance?
- 7. What previous health and illness experiences and beliefs influenced your decision to begin active surveillance?
- 8. In what ways was it a difficult decision or relief to go on active surveillance?
- 9. What are your plans in terms of continuing with active surveillance?
- 10. How important are the prostate-specific antigen and Gleason markers to you while on active surveillance? Has that changed over time?
- 11. What events would make you seek active treatment?
- 12. Would you continue active surveillance regardless of the cancer marker results?
- 13. What types of information, strategies, or tools would assist you to continue being on active surveillance?

Figure 1. Interview Guide

investigative team independently coded transcripts and met on four occasions to discuss, compare, and develop descriptive notes related to emergent themes.

Results

Forty-five men were invited to participate in the study and 25 agreed. Three men telephoned the research coordinator to inform her that they were ineligible because their most recent biopsies were negative and that they no longer had prostate cancer. The remaining men believed they did not have the time or just did not want to participate in research. The mean age of men in the study was 66 years (SD = 7.3, range = 48–77). Most of the men had a postsecondary education, were married, and were retired. Approximately half of the men were within one year of diagnosis (see Table 1).

Participants described many factors that influenced their decision to be on active surveillance. Representative quotations drawn from the participant interview data support the conclusions. Factors identified were not mutually exclusive; most participants related, at least in part, to all of the factors presented. Figure 2 summarizes the main themes identified in the analysis.

Patients' Perceptions of Their Prostate Cancer

Most men had never heard the term active surveillance until they received a letter from their doctors inviting them to participate in this study. They found the term intriguing and wondered whether it was different from watchful waiting. "Checking it often" was the terminology frequently used by physicians to define what the treatment plan was. Men considered prostate cancer a common disease in males and often inflated the potential incidence. One 65-year-old man said about 50% of men have prostate cancer so "it's not that bad" and "if you live long enough, you'll get cancer." Other men referred to having a "tumor or lump, a very small growth," because this was how their physicians had referred to the prostate cancer. Most men on active surveillance knew they might eventually require treatment, but for now the prostate cancer was in a "grey zone." The most vivid description a patient remembered was that his specialist called his type of prostate cancer a "slow-moving turtle." In the meantime, because everything was fine, it was better to "keep it that way" or "why rock the boat?" One 73-year-old man said that a specialist told him he had "indications of cancer in the prostate and that you have a free ticket right now, it's a low-risk cancer, and let's wait and see."

Physician Recommendation

The way in which physicians described the prostate cancer to patients influenced their perceptions of the

Table 1. Demographic and Medical Characteristicsof Participants

Characteristic	n	%
Age (years)		
< 50	2	8
51-60	2	8
61–70	17	68
71-80	4	16
Educational attainment		
High school or less	7	28
College degree	4	16
Undergraduate university degree	9	36
Graduate degree	5	20
Marital status		
Married or cohabitating	19	76
Single (no partner)	6	24
Employment		
Full-time	7	28
Part-time	6	24
Retired	12	48
Ethnicity		
Caucasian	23	92
South Asian	2	8
Years since diagnosis		
< 1	13	52
1–2	9	36
> 2	3	12
N = 25		

seriousness of the condition and set the tone for the ensuing treatment consultations. Most men experienced a sense of relief when informed their cancer was a lowrisk, slow-growing cancer that did not need immediate treatment. The most reassuring information was when specialists recommended to "just watch it for now" or "keep an eye on it." One 63-year-old patient said he would wait until he really had cancer before he considered treatment.

Men reported that urologists informed them about available treatment options and often suggested they seek second opinions from other urologists or radiation oncologists. The active surveillance decision was validated when other specialists concurred with the urologists' recommendation. The more renowned and published the specialists, the easier it was for the men to follow the advice. Specialists' professionalism, expertise, and research profiles provided a sense of security, trust, and confidence in their treatment recommendation.

Decision Control—Who Made the Decision?

A recurrent theme emerged that men chose active surveillance because their specialists considered it the best approach. A few men preferred to go with their specialists' advice. As one 73-year-old man said, "I was more or less directed to [active surveillance], which was fine with me, you know." However, most men believed they had taken ownership of the treatment decision

- · Patient's perception of his prostate cancer
- Physician recommendation
- Decision control; who made the decision?
- · Avoiding side effects of treatment
- Seeking information to make a treatment decision
- Advice from family and friends
- Preexisting medical conditions
- Age
- Coping on active surveillance

Figure 2. Theme Categories for Factors Influencing Decision to Go on Active Surveillance

after careful consideration of their specialists' opinion. One 69-year-old man wanted to take charge and make a treatment decision based on his research activities and assured his specialist that he had the means to pay for any new treatment that might be available elsewhere. That man stated,

The doctors here have to stay within the medical system, and if they don't know your financial circumstances, they don't realize that you can go and do this. [The doctor] is going by the rule book, and so unless you bring these things up and become proactive, you don't have the opportunity to look at these other alternatives.

Avoiding Side Effects of Treatment

The two main reasons for avoiding treatment were the potential for impotency and incontinence. However, several men stated that they already were experiencing erectile difficulties. Two quotations from men in their mid-60s illustrate how the prospect of surgery influenced their decision.

Well, are you kidding? I mean, there's potential nerve damage. . . . You can become incontinent. . . . You could, you know, your sex life might be over forever. . . . I'm not a young guy, but I'm a single guy and in a new relationship, and this would be pretty hard to take so . . . yeah . . . no, it's frightening.

Well, it influenced my decision because I still sort of enjoy trying to have sex, and having a prostatectomy, well, that would be the end of that one for all intents and purposes. I supposed that would definitely be a factor in shaking me toward active surveillance.

Seeking Information to Make a Treatment Decision

Men trusted their specialists to recommend the best treatment option for them because "doctors have your best interests at heart." The vast majority of men did not actively seek information because their specialists told them their prostate cancer was low risk and did not require treatment. Those men did not know what their Gleason scores were or the exact number of biopsies that were positive at the time of diagnosis. Some men still did not know what PSA was measuring other than being one of the tests used to diagnose prostate cancer. In most instances, seeking information on available treatments ended once the active surveillance decision was made. Of the 25 men interviewed, only 2 mentioned that they had talked to several specialists in other cities and countries to research other forms of treatment. One 70-year-old man who had been on active surveillance for five years was an information seeker, constantly researching new treatment options discussed in medical journals. Written information and the Internet were the most commonly used sources of information by men in this study. The chances of developing side effects quoted on Internet sites influenced some men's decision to avoid active treatment.

Two of the youngest patients, in their late 40s, consulted a naturopath and herbalist about going on active surveillance. One of the patients used information from a presentation given by a naturopath at a local support group to help make a treatment decision. The presenter mentioned that "the body can heal itself," and because all treatments are equal in survival rate, the patient assumed there was no point to being treated. That younger patient went on to invest in supplements, believing that they would boost his immune system, and changed his diet based on the naturopath's advice and a book his sister had given him about eating foods to fight cancer.

Approximately one-third of men and their spouses reported expressing a need for information at the time of treatment consultation. Those patients were referred to an education center to learn more about their prostate cancer and the available treatment options. The couples received written and oral information based on their individual disease characteristics from a specially trained nurse. The information they received was considered extremely helpful to the treatment decision-making process.

Advice From Family and Friends

Spouses usually accompanied their husbands to all treatment discussions with the specialists and assumed a supportive role in the treatment decision-making process. In a few instances, wives sought information and discussed it with the men. In the case of younger men, wives were vocal regarding wanting their husbands to have surgery. Adult children knew about the cancer diagnosis, but the decision was their fathers'. The amount of discussion with children was dependent on the closeness of the relationship prior to the prostate cancer diagnosis. Advice from friends varied depending on whether the friends had had any experience with prostate cancer. Friends who had been diagnosed with prostate cancer focused their information on the treatment-specific side effects they were experiencing and what treatments to avoid. Most friends treated for prostate cancer suggested active treatment before the cancer spread. The men listened to their friends but felt lucky that they had the option of delaying treatment. Nearly one-third of the men made a conscious decision to keep the prostate cancer diagnosis a secret. As one 69-year-old man stated,

I don't want [prostate cancer] brought up in discussions with friends. I don't want to be asked, "How is your prostate today?" so I'd rather not discuss it, so I don't. Outside of one or two people that my wife blurted it out to initially, no, I don't discuss it, not even with my family; my kids know nothing about it.

Preexisting Medical Conditions

Several men in the study had preexisting medical problems such as cardiovascular disease, diabetes, or cancer. Specialists who diagnosed the other medical conditions often were responsible for ordering a PSA test and noticing an abnormality in the digital rectal examination. Previous medical conditions did not influence how men perceived the seriousness of their prostate cancer or their ability to undergo active treatment. Overall, they had strong perceptions that treatment of low-risk prostate cancer was more controversial than other previously diagnosed medical conditions.

Older patients (in their 70s) with preexisting medical conditions hoped to be treated if the prostate cancer progressed but expressed concern that active treatment and frequency of follow-up were based on the seriousness of preexisting medical conditions. The fear of spread was real despite regular follow-ups and reassurances that they probably would die of something else before the prostate cancer affected them. One 61-year-old patient with premorbid disease who wanted to go off active surveillance asked, "If it is cancer, why can't it be treated?"

Age

Men in their 70s reflected on the loss of many of their friends to cancer during the prior decade. Some of the friends had had extensive cancer treatments (with subsequent side effects) and suffered in the late stages of their illnesses. Most men wanted to avoid treatment altogether and took solace in the fact that cancer in older men may be slow growing. However, others reported being anxious that the prostate cancer would kill them and that they would suffer a painful death. One 74-year-old man said, "If you're going to live another, who knows, five or six years, and this thing is going to get progressively worse, I don't want to die of that kind of cancer after seeing it happen to other people, you know."

Coping on Active Surveillance

Most men tried not to "think about" or "dwell on" having prostate cancer between PSA tests and visits to their specialists. Although most men were retired, travel plans and leisure activities such as golfing took their minds off having prostate cancer, and "life went on." Some men did not know or care about PSA test results. Most carried on as usual or tried to minimize their cancer status. As one 73-year-old man said, "At times, not daily, at times, you know, there's things you kind of have to put on the shelf, and, as they say in the movies, I'll think about it tomorrow."

Talking about having prostate cancer was uncomfortable. Most men talked to their wives around the time of follow-up appointments and PSA testing; otherwise, prostate cancer was a "private matter" or "no big deal." Men who still were checking out new treatment options described themselves as having higher anxiety or stress levels. Media reports about new treatments and stories about people who died from cancer of the prostate also raised men's awareness of having prostate cancer. At such times of "awareness," they worried about whether their cancer had grown or metastasized and the accuracy of PSA and biopsy results. Reliance on and confidence in their doctors' expertise and ability to monitor their cancer were evident. That provided the men with relief from thinking about their condition between clinic visits and follow-up tests. However, men were compliant with follow-up tests ordered by their specialists to monitor the progress of their prostate cancer. Biopsies were described as a painful necessity of the treatment plan but "better than having surgery." However, one 56-year-old man expressed concerns over the repeated biopsies spreading the cancer and would have preferred a computed tomography scan instead. Some men who had subsequent negative biopsies questioned whether they actually had prostate cancer and considered themselves lucky to be on active surveillance.

Discussion

This qualitative study has described several key elements that men with early prostate cancer identified as influencing their decision to be on active surveillance. The researchers gained some insight into how the men made their decision to be on active surveillance, factors that influenced their decision, information they accessed to make the decision, and how they were coping with being on active surveillance. Physician recommendation was identified as having the most influence on the decision for men to be on active surveillance. The finding is similar to other studies in which most patients with prostate cancer also reported physicians as most influential to their final treatment decisions (Demark-Wahnefried et al., 1998; Hall, Boyd, Lippert, & Theodorescu, 2003; Miles, Giesler, & Kattan, 1999). In addition, patients in the current study used the reputations and publication records of their specialists as indicators of their expertise in the treatment of prostate cancer. They had an expectation that the specialists would assume responsibility for actively monitoring the cancer and notifying them when indications of disease progression occurred.

Physicians were more likely to recommend active treatment at the time of diagnosis for younger patients, especially with radical prostatectomy, perhaps because the best prognosis after a prostate cancer diagnosis is among men aged 50-69 years (National Cancer Institute of Canada, 2007). Similarly, Bill-Axelson et al. (2005) reported that when comparing watchful waiting to radical prostatectomy, the 10-year absolute differences in diseasespecific and overall mortality were statistically significant in favor of radical prostatectomy. A recent analysis of the database for the Cancer of the Prostate Strategic Urologic Research Endeavor (also known as CaPSURE) reported that of the 16% (N = 310) of men who were diagnosed with low-risk prostate cancer from 1999–2004, only 9% of that group chose active surveillance (Barocas et al., 2008). Although the men with low-risk disease tended to be younger, Caucasian, and more highly educated, with a higher income and private insurance, being older was found to be predictive of going on active surveillance. Men in the current sample included 2 in their 40s and 2 in their 50s, with the remaining 21 in their 60s or 70s. Results suggest that even physicians who support the concept of active surveillance are more apt to delay treatment in older men with preexisting comorbid conditions. Further research is required to study the effect of patient age on patients' and specialists' comfort levels with active surveillance. Additionally, healthcare professionals should ensure that patients understand the differences between watchful waiting and active surveillance.

Most men newly diagnosed with prostate cancer prefer to play active or collaborative roles in medical treatment decision making (Davison & Degner, 1997; Davison et al., 2002; Davison, Goldenberg, Wiens, & Gleave, 2007). Similarly, men in the current study reported deciding to go on active surveillance after seriously considering their physicians' opinion or recommendation. According to previous work conducted by Davison and colleagues (Davison & Degner; Davison et al., 2002, 2007), men in the current study considered themselves to be active participants in the treatment decision-making process. Patients reported that their partners assumed a supportive role in the decision to go on active surveillance, regardless of how they really felt about the decision. The role spouses play in the final treatment selection varies in the literature. Some investigators have reported that, despite the fact that spouses want to have input in final treatment choices, they tend to leave the final decisions to their husbands (Davison et al., 2002; Davison, Goldenberg, Gleave, & Degner, 2003; Srirangam et al., 2003). Conversely, other investigators have reported that patients feel considerable pressure from their spouses and family members to seek active treatment (Chapple et al., 2002; Holmboe & Concato, 2000).

Patients' perceptions of potential toxicities associated with various treatment options can affect treatment choices (Denberg, Melhado, & Steiner, 2006). Patients in the current study also were concerned about future quality-of-life issues, especially those related to the two most common side effects, sexual dysfunction and incontinence. Litwin et al. (2007) described the general and disease-specific differences in quality of life after treatment of localized prostate cancer with brachytherapy, external beam radiation, and radical prostatectomy, but few, if any, studies have prospectively compared standard treatments to active surveillance. Patients on watchful waiting report minimal decreases in healthrelated quality of life (Arredondo et al., 2004) when compared to those who have received active treatment (Altwein et al., 1997). Because the terms watchful waiting and active surveillance appear interchangeably in the literature, future quality-of-life studies should distinguish between the two treatment modalities.

Psychological distress of men in the current study was evident because they were concerned about cancer progressing between follow-up testing with PSA tests and biopsies. Although the death of close friends or relatives from cancer-related illness seemed to exacerbate such feelings, most men tried not to think about their prostate cancer and to carry on with their lives and usual activities. Such bracketing or separating of an illness from regular life has been described previously for men on watchful waiting as a way of helping them to cope with the uncertainty of having untreated cancer (Bailey, Wallace, & Mishel, 2007). The interviews were not able to reveal the extent to which men in the current study were experiencing anxiety and feelings of isolation, but the researchers did not get the sense that the men were overly concerned once the decision to go on active surveillance was made. That observation could be explained by the work of Zakowski et al. (2003), who reported that men prefer not to express their emotions at the time of cancer diagnosis because they see it as a sign of weakness. However, the men in the current study appeared comfortable and relieved not to have the cancer removed or treated in the near future. The extent emotions play in the support men seek at the time of diagnosis and while on active surveillance requires further study.

The support needs of men on active surveillance remain an emerging area of research. However, few patients in the current study reported a need for access to additional information and supportive resources while on active surveillance. Nutrition resources for "prostate-friendly" dietary changes were not considered a priority because most men defined their current diets as healthful or had previously changed their diets as a result of preexisting medical conditions such as cardiovascular disease and diabetes. Patient support groups also were not identified as a resource required for psychological support while on active surveillance, even if anonymous contact could be offered through the Internet. The latter finding is similar to the first author's clinical practice observations that men do not use support groups in numbers proportionate to the incidence of cancer occurrence. One explanation is that the men did not yet consider themselves as needing to make active treatment decisions or as survivors. Still another reason may be that attendance at such meetings would disrupt the bracketing that many men relied on to minimize their anxiety.

Information seeking is one of the most common forms of coping with an uncertain life event such as prostate cancer (Lazarus & Folkman, 1984). Results from the current study can be useful in informing current clinical practice by shaping information interventions to fill the gaps in patients' knowledge of available treatments that the current research identified. This research also shows that, although specialists informed their patients about available treatment options, few men sought second opinions from radiation oncologists. In addition, one-third of the men in the current study were referred for patient education and counseling to learn more about available treatment options. Thus, most men in the current study reported having access to information at the time of diagnosis. Patients also were aware that they would have access to additional information resources in the event that their cancer progressed. However, most men did not know that active surveillance was an actual management option. Men continued to say that they were "watching it" or "doing nothing." Similarly, McGregor (2003a, 2003b) reported that men often lacked understanding of specifics related to physician-generated treatment recommendations. Because patients' readiness and need for information vary, further exploration is required into the type and amount of information men and their partners need to access at the time of diagnosis, while on active surveillance, and in the event of disease progression.

Limitations

This study had three major limitations that preclude the authors from making claims about the generalizability of the findings to other patients on active surveillance. Although the sample was small, the transcripts were remarkably similar to the themes (see Figure 2) that emerged. The second limitation is that patient recruitment was from two large, urban, tertiary care referral centers that support the uptake of active surveillance for low-risk prostate cancer. Because most community physicians and specialists throughout North America are hesitant about active surveillance, the authors cannot estimate how many patients in other outpatient clinics are aware of the active surveillance option. The third limitation is that no randomized clinical trials have been conducted to compare active surveillance with active treatment; therefore, whether active surveillance is a viable disease-management choice is unknown.

Nursing Implications

Nurses can play a key role in providing men diagnosed with low-risk prostate cancer with information about their available treatment options and the associated side effects of each treatment. Nurses should be knowledgeable about the differences between active surveillance and watchful waiting and be able to ensure that patients are knowledgeable about the differences between the two management strategies. Administrators of outpatient oncology clinics also have an obligation to ensure that nurses receive continuing education so that they are able to provide men with accurate information and emotional support during the follow-up phase and when decisions are required regarding active treatment.

Conclusions

This is a relatively new area of research, and the current study is one of the first to be conducted with patients on active surveillance. Several areas require further study. For example, what are the long-term effects of active surveillance on psychological distress? What role does coping style play in a patient's decision to be on active surveillance versus active treatment? What factors influence patients to agree to be in a study that will randomize them to either active surveillance or active treatment? Nurses can play a key role in conducting multidisciplinary research to answer those important clinical research questions.

The authors' next step is to use the results from this qualitative study to develop a survey questionnaire for a larger group of patients to determine whether the results are reflective of factors influencing men's decisions to consider active surveillance. Results from the larger study will guide the development of an intervention that will support men's treatment decision-making efforts.

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References

- Altwein, J., Ekman, P., Barry, M., Biermann, C., Carlsson, P., Fossa, S., et al. (1997). How is quality of life in prostate cancer patients influenced by modern treatment? The Wallenberg Symposium. *Urology*, 49(4A, Suppl.), 66–76.
- Arredondo, S.A., Downs, T.M., Lubeck, D.P., Pasta, D.J., Silva, S.J., Wallace, K.L., et al. (2004). Watchful waiting and health related quality of life for patients with localized prostate cancer: Data from CaPSURE. *Journal of Urology*, 172(5, Pt. 1), 1830–1834.
- Bailey, D.E., Jr., Wallace, M., & Mishel, M.H. (2007). Watching, waiting and uncertainty in prostate cancer. *Journal of Clinical Nursing*, 16(4), 734–741.
- Barocas, D.A., Cowan, J.E., Smith, J.A., & Carrol, P.R. (2008). What percentage of patients with newly-diagnosed carcinoma of the prostate are candidates for surveillance? An analysis of the CaPSURE database. *Journal of Urology*, *180*(4), 1330–1335.
- Bill-Axelson, A., Holmberg, L., Ruutu, M., Haggman, M., Andersson, S.O., Bratell, S., et al. (2005). Radical prostatectomy versus watchful waiting in early prostate cancer. *New England Journal of Medicine*, 352(19), 1977–1984.
- Carter, H.B., Kettermann, A., Warlick, C., Metter, E.J., Landis, P., Walsh, P.C., et al. (2007). Expectant management of prostate cancer with curative intent: An update of the Johns Hopkins experience. *Journal* of Urology, 178(6), 2359–2364.
- 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.
- Cooperberg, M.R., Lubeck, D.P., Meng, M.V., Mehta, S.S., & Carroll, P.R. (2004). The changing face of low-risk prostate cancer: Trends in clinical presentation and primary management. *Journal of Clinical Oncology*, 22(11), 2141–2149.
- Davison, B.J., & Degner, L F. (1997). Empowerment of men newly diagnosed with prostate cancer. *Cancer Nursing*, 20(3), 187–196.
- Davison, B.J., Goldenberg, S.L., Wiens, K.P., & Gleave, M.E. (2007). Comparing a generic and individualized information decision support intervention for men newly diagnosed with localized prostate cancer. *Cancer Nursing*, 30, 1-9.
- Davison, B.J., Gleave, M.E., Goldenberg, S.L., Degner, L.F., Hoffart, D., & Berkowitz, J. (2002). Assessing information and decision preferences of men with prostate cancer and their partners. *Cancer Nursing*, 25(1), 42–49.
- Davison, B.J., Goldenberg, S.L., Gleave, M.E., & Degner, L.F. (2003). Provision of individualized information to men and their partners to facilitate treatment decision making in prostate cancer. *Oncology Nursing Forum*, 30(1), 107–114.
- Demark-Wahnefried, W., Schildkraut, J.M., Iselin, C.E., Conlisk, E., Kavee, A., Aldrich, T.E., et al. (1998). Treatment options, selection, and satisfaction among African American and white men with prostate carcinoma in North Carolina. *Cancer*, *83*(2), 320–330.
- Denberg, T.D., Melhado, T.V., & Steiner, J.F. (2006). Patient treatment preferences in localized prostate carcinoma: The influence of emotion, misconception, and anecdote. *Cancer*, 107(3), 620–630.
- Glaser, B.G. (1978). Theoretical sensitivity: Advances in the methodology of grounded theory. Mill Valley, CA: Sociology Press.

- Hall, J.D., Boyd, J.C., Lippert, M.C., & Theodorescu, D. (2003). Why patients choose prostatectomy or brachytherapy for localized prostate cancer: Results of a descriptive survey. *Urology*, 61(2), 402–407.
- Harlan, S.R., Cooperberg, M.R., Elkin, E.P., Lubeck, D.P., Meng, M.V., Mehta, S.S., et al. (2003). Time trends and characteristics of men choosing watchful waiting for initial treatment of localized prostate cancer: Results from CaPSURE. *Journal of Urology*, 170(5), 1804–1807.
- Holmboe, E.S., & Concato, J. (2000). Treatment decisions for localized prostate cancer: Asking men what's important. *Journal of General Internal Medicine*, 15(10), 694–701.
- Klotz, L. (2002). Expectant management with selective delayed intervention for favorable risk prostate cancer. *Urologic Oncology*, 7(5), 175–179.
- Klotz, L. (2006). Active surveillance with selective delayed intervention for favorable risk prostate cancer. *Urologic Oncology*, 24(1), 46–50.
- Lazarus, R.S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Litwin, M.S., Flanders, S.C., Pasta, D.J., Stoddard, M.L., Lubeck, D.P., & Henning, J.M. (1999). Sexual function and bother after radical prostatectomy or radiation for prostate cancer: Multivariate qualityof-life analysis from CaPSURE. Cancer of the Prostate Strategic Urologic Research Endeavor. Urology, 54(3), 503–508.
- Litwin, M.S., Gore, J.L., Kwan, L., Brandeis, J.M., Lee, S.P., Withers, H.R., et al. (2007). Quality of life after surgery, external beam irradiation, or brachytherapy for early-stage prostate cancer. *Cancer*, 109(11), 2239–2247.
- Litwin, M.S., Sadetsky, N., Pasta, D.J., & Lubeck, D.P. (2004). Bowel function and bother after treatment for early stage prostate cancer: A longitudinal quality of life analysis from CaPSURE. *Journal of Urology*, 172(2), 515–519.
- McGregor, S. (2003a). Information on video format can help patients with localised prostate cancer to be partners in decision making. *Patient Education and Counseling*, 49(3), 279–283.
- McGregor, S. (2003b). What information patients with localised prostate cancer hear and understand. *Patient Education and Counseling*, 49(3), 273–278.
- Miles, B.J., Giesler, B., & Kattan, M.W. (1999). Recall and attitudes in patients with prostate cancer. *Urology*, *53*(1), 169–174.
- National Cancer Institute of Canada. (2007). *Canadian cancer statistics* 2007. Toronto, Canada: Canadian Cancer Society.
- Oiler, C. (1982). The phenomenological approach in nursing research. *Nursing Research*, 31(3), 178–181.
- Parker, C. (2004). Active surveillance of early prostate cancer: Rationale, initial results and future developments. *Prostate Cancer and Prostatic Diseases*, 7(3), 184–187.
- Srirangam, S.J., Pearson, E., Grose, C., Brown, S.C., 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.
- Zakowski, S.G., Harris, C., Krueger, N., Laubmeier, K.K., Garrett, S., Flanigan, R., et al. (2003). Social barriers to emotional expression and their relations to distress in male and female cancer patients. *British Journal of Health Psychology*, 8(Pt. 3), 271–286.