





Comparing Perspectives of Canadian Men Diagnosed With Prostate Cancer and Health Care Professionals About Active Surveillance

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Abstract

Active surveillance (AS) has gained acceptance as a primary management approach for patients diagnosed with low-risk prostate cancer (PC). In this qualitative study, we compared perspectives between patients and health care professionals (HCP) to identify what may contribute to patient–provider discordance, influence patient decision-making, and interfere with the uptake of AS. We performed a systematic comparison of perspectives about AS reported from focus groups with men eligible for AS (7 groups, N = 52) and HCP (5 groups, N = 48) who engaged in conversations about AS with patient. We used conventional content analysis to scrutinize separately focus group transcripts and reached a consensus on similar or divergent viewpoints between them. Patients and clinicians agreed that AS was appropriate for low grade PC and understood the low-risk nature of the disease. They shared the perspective that disease status was a critical factor to pursue or discontinue AS. However, men expressed a greater emphasis on quality of life in their decisions related to AS. Patients and clinicians differed in their perspectives on the clarity, availability, and volume of information needed and offered; clinicians acknowledged variations between HCP when presenting AS, while patients were often compelled to seek additional information beyond what was provided by physicians and experienced difficulty in finding or interpreting information applicable to their situation. A greater understanding of discordant perspectives about AS between patients and HCP can help improve patient engagement and education, inform development of knowledge-based tools or aids for decision-making, and identify areas that require standardization across the clinical practice.

Keywords

prostate cancer, active surveillance, patient perspectives, health care professional perspectives

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Background

Active surveillance (AS) has emerged as a primary management strategy for clinically indolent, low-risk prostate cancer. Active surveillance aims to reduce the risk of overtreatment and its associated morbidity, opting for close monitoring of low-risk patients who undergo continued risk assessment over time before considering radical interventions. Very low- or low-risk clinically localized prostate cancer is defined by prostate-specific antigen (PSA) value (<10 ng/mL); Gleason score (≤ 6); tumor stage (T1c, PSA detected or T2a, small palpable nodule); and extent of disease in biopsy (<3 positive biopsy cores and $\leq 50\%$ cancer in any cores) (1); reviewed in the study by Bruinsma et al (2). Although the practice of AS for men with low-risk prostate cancer has been growing over the last decade, the approach is still largely underutilized (3). The decision to follow a regime of AS is multifaceted and thus dependent upon patient, clinical, and societal factors that influence an individual's decision.

Presently, the practice of informing men about AS is not yet standardized, and relatively little is understood about patient preferences or specific factors that contribute to patient's decision-making in selecting AS over curative interventions (4,5). Electing for a regime of AS runs counter to the general public's perceptions about cancer progression risks and the urgency of active treatment. Hence, asking men to consider AS may require a shift in their preconceived notions about the disease and the most appropriate course of action. In addition, men receiving a cancer diagnosis may experience significant distress, resulting in anxiety and uncertainty that can interfere with a clear understanding of their condition and making informed decisions (6–9).

Variation in managing patients eligible for AS has been largely attributed to physician and practice patterns (10). In particular, decision-making about AS is seen as largely dependent upon discussions between patients and physicians who can significantly influence the final decision (11,12). Physicians have reported challenges in having these discussions and convincing patients about the merits of AS (13).

Aims and Purpose

Previously, we undertook a qualitative investigation to deepen our knowledge about perspectives that influence men in their decision-making about AS and the nature of current practices for informing them about this course of action (14,15). We held focus groups in 4 Canadian provinces with men and doctors and gathered a rich understanding of participants' perspectives about AS. In the present study, we utilized this data resource for the purpose of completing a systematic comparison of perspectives about AS, expressed by men diagnosed with low grade prostate cancer and doctors managing this patient population. We anticipated obtaining a greater understanding of the influences and challenges involved in accepting a course of AS would inform

future clinical practices and provide guidance to improve patient education and support for patients.

Methods

Recruitment/Data Collection

Description of the data collection has been presented in detail previously (14,15). Briefly, focus groups were held in 2013 throughout 2015 in Montreal, Toronto, Thunder Bay, Winnipeg, and Vancouver. With 1 exception (Thunder Bay), all focus groups were held in metropolitan academic centers that served as regional referral sites where prostate cancer care was delivered within specialized clinical programs. Focus groups included men (7 groups, $N = 52$) who had been diagnosed with prostate cancer and were eligible for AS (14), and physicians (5 groups, $N = 48$) who managed low- and high-risk prostate cancer patients and engaged in conversations regarding AS (15). Eligible individuals were purposefully invited to participate by a research coordinator working in the local care center and formed a convenience sample. Research ethics approval was obtained from ethics boards at each site, and participants signed an informed consent (14,15).

The sessions were facilitated by a qualitative researcher fluent in the preferred language (French, English) of the individuals and lasted between 60 and 90 minutes. The focus group interviews were designed to guide the discussion about participants' understanding of AS, practices regarding conversations and information provided on AS, and factors influencing men's decisions to accept a regime of AS. Sessions were audiotaped and transcribed verbatim for analysis. Discussions proceeded in similar fashion in each setting covering the same topics despite the composition and geographical settings of the groups.

Analysis

We used conventional content analysis, as previously described (16), and examined the transcripts from the focus group with men and physicians, separately. Transcripts were reviewed independently by research team members (M.F., K.P., A-M. M., V.O.) who added marginal notes regarding topics covered in the sessions. Team members shared their perspectives, on all content identified, and designed a content-coding framework based on consensus. Two members (M.F. for the patients; K.P. for the health care professionals) used the defined content-coding framework to code all transcripts. Each coded category was reviewed in-depth, and the content summarized into key messages or themes. This analysis was presented to 3 other team members who assessed clarity and relevance of findings. Two team members had attended the group sessions and the other was a clinician highly involved in interactions with men considering AS.

Once the content analysis had been completed for the men and health care professional groups separately, a comparison

Table 1. Selected Demographic Characteristics—Men With Prostate Cancer.

Variables	N	Range (years)	Median (years)
Age	52	53-81	68
Time since diagnosis	52	1-16	3
Time on active surveillance	38	1-15	3

Table 2. Selected Demographic Characteristics—Physicians.^{a,b}

Variable	Number	Percent
Age (range)	22-78 years	
Gender		
Male		85%
Female		15%
Specialty		
Urologist and surgeon	23	48.9%
Radiation oncologist	8	17.1%
General practitioner	4	8.5%
Fellow	5	10.6%
Resident	6	12.8%

^an = 47.

^bOne participant did not state his role.

between the perspectives from the 2 groups was undertaken. The content in each content category from patients and physicians was reviewed (M.F.) to identify both similar and divergent viewpoints. For example, the coded content in the category “understanding of AS,” from both the men and the physicians, was read through with the aim of isolating points of agreement and of disagreement in the perspectives that had been shared. The results of the comparison were shared with the research team for validation and will be highlighted below (Supplementary data are available online.)

Results

Selected Demographics

Fifty-two Caucasian men with prostate cancer participated in the focus groups. Their age ranged from 53 to 81 years (mean = 67.8), and 70.8% had completed postsecondary education or above. Participants had been diagnosed between 1 and 16 years (median = 3). Table 1 presents the number of men who were on, or had been on, a regime of AS (range = 1-15 years; median = 3).

All 47 physicians who participated managed prostate cancer patients and held conversations about AS routinely. They ranged in age from 22 to 78 years (mean = 44.6 years), and the majority were males (85%). Urologists and surgeons (49%) and radiation oncologists (17%) formed the largest proportions of the group (Table 2).

Comparison of Perspectives Disclosed by Participants

Detailed analysis of transcripts from patients and clinicians has been reported elsewhere (14,15). Here, we describe shared and divergent perspectives on topics of understanding

AS, the decision to pursue a regime of AS, and exchange of AS information between patients and their physicians. Key themes are presented below. Illustrative quotes from participants are in Supplemental Table 1 for shared viewpoints and Supplemental Table 2 for differences in perspectives.

Shared/commonly held viewpoints by participants. The perspectives commonly held by men and physicians, as identified in this analysis, surround the definition of AS and understanding of its benefits. Disease status was seen as a critical indicator of the need for intervention.

Defining AS and its benefits. Patients and physicians shared similar perspectives regarding the definition of AS. They perceived it as appropriate for low grade or low-risk disease and involved activities to obtain blood PSA levels and biopsies for regular monitoring of disease status over time (Supplemental Table 1). They described benefits of the AS approach as postponing interventional treatment to avoid various side effects. Some acknowledged that a need for treatment intervention may not even occur if the disease did not progress. In addition, participants described how the regime of regular monitoring identified changes or progression of disease and facilitated treatment intervention whenever necessary.

Disease status is a key factor. Patients and physicians both described disease status as a key factor in deciding to pursue a regime of AS (Supplemental Table 1). Participants perceived understanding the nature of the disease, its slow growth rate, and small likelihood for impact on mortality as important considerations for decision-making. Most men had not known prostate cancer could be low risk and were unaware of AS. They were introduced to AS by their doctors at the time of diagnosis. All participants described the conversations surrounding diagnosis as important for developing a clear understanding of the disease and treatment options and to ensure informed decision-making about AS. This was particularly important for patients who understood that they had to make their own decision about what course of treatment to pursue.

Additionally, patients and clinicians talked about changes in disease status as the primary consideration in the decision to stop AS and pursue an interventional treatment. An indication that the disease was progressing (ie, change in test or biopsy results) was an incentive for conversations between the patients and their physicians about discontinuing the AS regime and considering another course of action regarding treatment.

Monitoring procedures provided reassurance. Participants in both groups agreed that patients could accept and be comfortable with AS, provided there was close monitoring of disease status and results of tests clearly indicated no change (Supplemental Table 1). The on-going observation or surveillance of the disease was perceived as an opportunity to know whether the disease was changing and offered an

opportunity for action. These realities provided a sense of comfort for all concerned.

Differences in viewpoints held by participants. The differences between perspectives expressed by men and physicians, identified in this analysis, emerged primarily in terms of the emphasis placed on certain topics, and the degree of detail members of each group perceived as necessary to include in conversations.

Emphasis on quality of life. Patients and clinicians presented different perspectives on quality of life as a factor in the decision to follow a regime of AS (Supplemental Table 2). Although physicians mentioned quality of life was important, patients described the consideration of this factor in much more detail and with greater emphasis compared to the physicians. Patients expressed a strong need to explore how different treatment options could potentially impact their daily personal lives before finalizing decisions. Balancing an increasing risk of disease (how their disease status might progress to death (given their age) with the impact of various interventional treatments on their quality of life (given their personal life context or situation) was clearly emphasized as an important aspect in making their decision. They needed to understand the reality of daily living with side effects (ie, impotence, incontinence, etc) and not just whether the side effects would likely occur. Men often did not receive this type of information from their physicians leading the patients to a search for additional information, beyond the clinical conversation and the materials provided by their doctor. Collectively, patients sought input from a wide range of information resources (eg, other health care professionals, family members, friends, peer support groups, written materials, the internet). Many patients found that it was difficult to search for, and find, relevant information and to apply what they found to their personal situation on their own.

Lack of consistency in tests and interpretations. Other differences in perspectives were evident when participants talked about topics concerning test procedures related to AS: criteria for eligibility, interpretation of blood test and biopsy results, and what constitutes a standard (best practice) approach (Supplemental Table 2).

Discussion within the physician group about eligibility criteria for AS and interpretation of test/biopsy results frequently focused on indications and the issues regarding the nature and strength of available evidence for guiding practice. Their discussion often circled around controversies surrounding the interpretation of evidence, the reliability of current procedures (eg, extent and grade of cancer in biopsy, blood PSA levels), and the adjustments they felt were required to fit each individual's clinical situation based on test results. They cited lack of commonly accepted standards for practice as a primary challenge for them in current clinical decision-making, especially for long-term follow-up.

In contrast, patients often spoke in absolute terms, referring to how they used definitive numbers for PSA and Gleason scores as their references. Some mentioned general controversies about test/biopsy procedures and results but reverted to describing the confidence they had in their own situation based on conversations with their physicians. Of note, the actual numbers that patients cited, which were considered in their decision about management approaches, and short and long-term protocols for AS, varied widely among patients attending focus groups.

Perspectives also differed between patients and physicians regarding the clarity and detail of information provided to patients and the time period required to make a decision. Patients described the need for a wide range of information before they felt they could decide on a course of therapy. Most wanted understandable and detailed information about the disease, treatment options, and outcomes; but they also wanted information about side effects and how those side effects would impact them personally each day, given their age and living circumstances. Many indicated they felt compelled to search for information on their own, beyond what was provided by their physicians, especially those living in more rural settings and receiving care in nonacademic centers. Most men described finding wide variations regarding whether information was readily available, understandable, and applicable to their individual situation. The challenge of having to search for meaningful information added to their anxiety and distress. They also needed time to reflect on what they were learning and how it applied to their own situation as much of the information was new to them and the decision was seen as a very important one. Decisions could not be rushed or made quickly and could ideally require several discussions. They found it helpful to have conversations that assisted them to apply or interpret information to their own situation, whether with physicians, nurses, or other health care practitioners.

For the clinicians, they acknowledged the importance of information, providing it primarily through conversations during clinical appointments and, in some cases, written documents. Practitioners acknowledged that their approaches were often based on their personal experiences in practice and were tailored to their own interpretation of the individual patient's needs for information. Evidence-based guidelines or standardized assessment of readiness to learn were not part of their approach. In particular, general practitioners saw their role as one of helping men with their decisions about AS but indicated a level of discomfort in discussing details about AS and felt they would benefit from educational sessions on the topic.

Discussion

This investigation was drawn from focus groups of men diagnosed with prostate cancer and clinicians who provide care to this population. Comparing and contrasting perspectives can assist in identifying gaps in practice and

opportunities for improvement. Differences in perspectives can be a source of tension and misunderstandings and can influence decision-making and satisfaction with care (4,5,17). Our findings add to the literature on understanding potential dissonance in perspectives between patients and physicians regarding AS and have implications for patient engagement and decision-making.

Some of the observed differences in perspectives may be a function of holding homogeneous groups. A different outcome may have emerged if focus groups had been a mix of patients and providers. Physicians were interacting with one another, utilizing their own language within their usual settings, and focusing on priorities in their practices. Patients were discussing a new experience for them and were challenged with learning new information and language. Most seemed surprised by the lack of consensus regarding prostate cancer treatment and were searching for definitive answers.

Variation in the emphasis placed on quality of life between patients and physicians suggests a function of personal priority. Treatment of cancer has more than a physical impact; men who have to live each day with consequences of their decision about treatment, expressed concerns in terms of functioning and coping with the resultant challenges. Clinicians are specialists primarily focusing on their responsibilities in the diagnosis of disease and determination of the most appropriate treatment approach. The presence of other health care professionals, such as nurses and social workers, may have initiated more detailed discussion about quality of life and impacts on daily living.

Nevertheless, patient preference is central in treatment-related decisions when there is limited evidence to support decisions, 2 or more suitable treatment options, or when treatment options are difficult to predict or may be adverse (18,19). In these preference-sensitive cases, such as making decisions about AS, quality of life should be an important consideration (20,21). Quality of life assessments, using standardized instruments, have been suggested as necessary at the time of diagnosis and incorporating them in conversations about treatment choices for prostate cancer (22). Incorporating other health care professionals such as advanced practice nurses, social workers, or psychologists could also be useful for helping men given detailed consideration to their questions about the future quality of their lives.

Incorporating decision aids has also been recommended as a strategy to assist patients in obtaining the information they desire and sort out the benefits and drawbacks of various therapies in accordance with their life situations (23). Patients vary in their preferences for acceptable levels of risk and differ in their information-seeking behaviors (24). The use of decision aids can help to clarify the implications of decisions ahead of time and reduce decisional conflict and regret (25,26). Decision aids, including the option of AS, showed that men became more active participants in decision-making by using the aid (25–27). Additionally, the use of value-based decision tools has shown an increase in treatment

decision concordance with the individuals' own preferences versus the recommendations of physicians (20,21).

Patient engagement strategies are expected to enhance person-centered decision-making and improve both satisfaction and experience, but interventions need to be directed at both patient and providers (4,5). To date, relatively little exploration has occurred about patient-provider concordance on patient preferences, experience with patient engagement and decision-making, or interventions to facilitate value-based communication on AS. Existing research reveals frequent discordance between patients' perspectives and those of physicians (22,28). Physicians can be poor at assessing patient preferences at baseline, which are subject to change once an individual is in full possession of all information relevant to his disease and health status. Future efforts could focus on training or new knowledge-based tools to physicians assist in their communication about AS with patients to ensure appropriate patient engagement and a person-centered approach to decision-making (4,5,20,21).

Finally, this work was based on gathering data with patients and practitioners from specialized prostate cancer programs across Canada with access to relevant evidence to inform best practice. Even so, there were variations in the processes involved in providing information, including availability of staff resources for personalized discussion and written documents about prostate cancer and treatment options. Active surveillance uptake and practice may benefit from developing guidelines for the provision of standardized information on AS as an optimal management option after adequate interpretation of test results. Future efforts could also be directed toward mobilizing a common source of reliable information (ie, web-based) to support interactive learning and decision-making and to ensure access to all patients. Several trials of a resource for AS have been launched and show an increase in knowledge about AS and greater intention to accept AS after completing standardized education modules (25,29,30).

Limitations

Limitations in this study include gathering data primarily from specialized cancer center programs in large urban areas. Perspectives may have differed in smaller centers and rural settings. Additionally, few general practitioners participated in the focus groups.

Conclusions

Understanding the perspectives of both patients and physicians is helpful to identify opportunities for improvements in clinical practice. Active surveillance is an emerging option that is a significant departure from the public expectation/perception on cancer treatments and requires patients to consider no interventional treatment for a potentially life-threatening disease at a time of uncertainty and emotional distress. Our findings support the notion that conversations

between men diagnosed with low-risk prostate cancer patients and their health care providers should include detailed information about the potential impact on personal quality of life and allow patients sufficient time to think about how treatment choices may influence their personal lives.

Authors' Note

FS, AMMM, SS, MF, and VO contributed to the conception and initial design. MF, KP, VO, SC, DED, AF, JBL, AS, ST, FS, and AMMM contributed to the acquisition. MF, KP, VO, FS, and AMMM contributed to the analysis and interpretation. MF, KP, VO, SC, DEC, AF, JBL, SS, AS, ST, FS, and AMMM contributed to the drafting and/or revision of the manuscript. Research ethics approval was obtained from each of the participating sites: the Centre de recherche du Centre hospitalier de l'Université de Montréal, the McGill University Health Centre, Cancer Care Manitoba, the University Health Network and the University of British Columbia. All participants signed an informed consent before participating in this study.

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Supplemental Material

Supplemental material for this article is available online.

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Kittie Pang, is the Primary Care Program Manager at the North Toronto Sub-Region located at Sunnybrook Health Sciences Centre. She was the research co-rordinator for the Nursing Research Program at the time the focus groups were held for this project.

Simone Chevalier, is a Professor at McGill University. Her research deals with establishing the clinical and functional significance of protein kinases implicated in the androgen-independent progression of human prostate cancer and the development of new therapeutic modalities for prostate cancer in animal models.

Darrel E. Drachenberg, is a urologic oncologist and surgeon as well as an Assistant Professor of Surgery at the University of Manitoba and Director of Research for the Manitoba Prostate Center and Section of Urology. Dr. Drachenberg's areas of research interests include Clinical Cancer Trials and the quality of survival outcomes, basic science of cancer and circulating tumor cells in GU malignancy. Area of expertise in Surgery includes GU Oncology, minimally invasive/laparoscopic surgery, Prostate brachytherapy and cryosurgery.

Antonio Finelli, is a urologic oncologist and surgeon investigator at the University Health Network (UHN) in Toronto and an Associate Professor at the University of Toronto. He is the Chief of Urology, GU Site Lead at the Princess Margaret Cancer Center and the inaugural GU Oncology Lead for the province of Ontario (Cancer Care Ontario). Dr. Finelli conducts health services research in urologic oncology with an interest in identifying gaps in care and designing knowledge translation strategies to overcome them. He is also actively involved in clinical trials.

Jean-Baptiste Lattouf, is a urologic oncologist and surgeon as well as an associate clinical professor in the Department of Surgery at the University of Montreal. He was a research fellow at the Quebec Health Research Fund (FRQS). He conducts basic research at the Centre de recherche du centre hospitalier de l'Université de Montréal on molecular biology of kidney cancer markers. Dr Lattouf is also highly involved in clinical research on prostate cancer kidney cancers.

Carmen Loiselle, is a professor at McGill University in the Ingram School of Nursing and the Department of Oncology. She is Program Director for psychosocial oncology and oncology nursing at

McGill University. Additionally, she holds the position of Co-director (academic) at the Segal Cancer Centre, as well as Senior Scientist in the Centre for Nursing Research and the Lady Davis Institute.

Alan So, is a urologic oncologist, surgeon and senior research scientist from the Vancouver Prostate Centre. Dr So is also an associate professor in the department of Urologic Sciences at the University of British Columbia. His current research focuses on discovery and development of novel agents to treat bladder and prostate cancer as well as development of the mechanisms of treatment resistance in renal cell carcinoma.

Simon Sutcliffe was a medical and radiation oncologist and is the past-President and CEO of the British Columbia Cancer Agency (BCCA), and of the Ontario Cancer Institute (OCI) and Princess Margaret Hospital. He has served on numerous scientific, academic and editorial boards, and has published extensively in the areas of radiation and medical oncology as applied to the treatment of lymphoma, leukemia and cellular immuno-deficiency and immunomodulation in cancer. Dr. Sutcliffe is the Vice Chair of the Canadian Partnership Against Cancer, which is an independent organization funded by the federal government to accelerate action on cancer control for all Canadians.

Simon Tanguay, is a urologic oncologist and surgeon from the McGill University Health Centre as well as a professor of the Department of Surgery at McGill University. Dr Tanguay is also

the head of the Division of urology in the department of Surgery. Dr Tanguay research interest are the natural history of prostate cancer progression as well as the outcome prediction for renal cell carcinoma.

Fred Saad, is a professor of surgery at the University of Montreal. He is currently chief of Urology and Director of Urologic Oncology at the University of Montreal Hospital Centre (Centre Hospitalier de l'Université de Montréal, CHUM). He holds the Raymond Garneau Chair in Prostate Cancer Research and is the director of clinical research and the molecular oncology research laboratory in prostate cancer. His research interests include novel therapeutics in prostate cancer, molecular prognostic markers, and mechanisms of progression.

Anne-Marie Mes-Masson, is a full professor in the Department of Medicine at the Université de Montréal, she is the associate director of the basic and translational research of the Centre de recherche du Centre hospitalier de l'Université de Montréal. She is the director of the Réseau de recherche sur cancer of the Fonds de la recherche du Québec Santé. She has developed some of the most comprehensive tissue banks (biobanks) and cell-based models in Canada. She has used molecular, and in particular high throughput genomic approaches, to probe the biology of ovarian and prostate cancers. Dr. Mes-Masson has also established a translational research program largely focused on personalized medicine for ovarian, breast and prostate cancer.