

Prostate cancer: 13. Whose prostate is it anyway?

The view from the other side of the examining table

Ross E. Gray, PhD; Al Philbrook, BA, BLA

Only in the last decade has it been acknowledged broadly that patients need to be involved in planning for and implementing their own health care. The inclusion in this series of a paper written from the patient's perspective is a welcome extension of this long-overdue trend toward meaningful patient participation.^{1,2}


In February 1997 a National Prostate Cancer Forum, with representation from the academic community, health care professionals, administrators and patients, made recommendations to both policy-makers and researchers. The inclusion of patients in this forum added to the richness of the discussions and increased the credibility of the recommendations. Some of our reflections on patient perspectives in this paper are based on experiences from the forum. Another source of information is a 1997 national survey of Canadian men with prostate cancer.³ We also draw on our personal and professional experience in interacting with men who have this disease.

Men with prostate cancer speak with many voices; therefore, it is impossible to present an overall patient perspective. In addition, the men who are more able or willing to voice their opinions or respond to surveys may not always be representative of the larger population of patients with prostate cancer. Finally, not all men are interested in participating in decisions about their own treatment or discussions about the health care system. Despite these issues, we still think there is general agreement among men with prostate cancer about a number of topics, and many of these points of agreement have implications for research.

Patience is a luxury of the well

Michael Milken, who himself has prostate cancer, has argued that the medical and scientific establishment in North America should approach cancer research with more urgency.⁴ A wealthy man, he has helped to establish funding for prostate cancer research in the US. Milken is typical of patients with prostate cancer. They want results. They don't want progress to be held up by inefficient bureaucracies or interdisciplinary politicking. Although they recognize the need for proper scientific investigation of new treatments, they do not want such investigations to drag on interminably when it is clear to all involved that clinical benefits are available.

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Dr. Gray is Co-director, Psychosocial and Behavioural Research Unit, Toronto-Sunnybrook Regional Cancer Centre, Toronto, Ont.

Mr. Philbrook, who has had prostate cancer, is Vice-Chair of the Man to Man Prostate Cancer Support Group, and is a drug and alcohol rehabilitation counsellor in Toronto, Ont.

The members of the Prostate Cancer Alliance of Canada, an umbrella group formed to carry out the recommendations of the 1997 National Prostate Cancer Forum, are pleased to support the intent to inform both health care professionals and lay people about the detection, diagnosis and treatment of prostate cancer through this 13-part series. The list of members of the Alliance appears at the end of this article.

Series editors: Dr. Neill A. Iscoe, Medical Oncologist, Toronto-Sunnybrook Regional Cancer Centre, and Dr. Michael Jewett, Professor and Chairman, Division of Urology, University of Toronto, Toronto, Ont.

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Canadian patients find it infuriating when promising new treatments are withheld in this country, are accessible only through clinical trials or are offered only at selected facilities. For example, over the past few years, many Canadian prostate cancer patients would have preferred the most recent radiotherapy techniques (e.g., 3-dimensional conformal radiotherapy) as their treatment of choice. However, they had to either travel to the US or choose another treatment that was covered by Canadian health insurance. Could these treatments have been made accessible more quickly? Even if it is impossible to make changes at the pace patients would like, why not try?

We recognize that scientists and health care professionals often share patients' frustration with the slow pace of change. For example, the paper in this series by Meyer and Fradet⁵ acknowledges the terrible scientific impasse we've reached regarding the usefulness of screening for prostate cancer with the prostate-specific antigen (PSA) test. Their recommendation to move forward on the basis of existing evidence, rather than waiting for evidence that may arrive late or not at all, is the kind of reasoning that resonates with patients. Similarly, Gallagher and Fleshner⁶ acknowledge that there is as yet no firm evidence to support wide-scale primary prevention trials related to prostate cancer. But they also argue that there *is* enough evidence about the likely benefit of a number of lifestyle interventions to warrant discussing them with patients. Most patients would rather be told that there is something they can do that *might* help prevent the disease or its recurrence than hear that there is insufficient evidence to support any action. Scientists may be able to wait for the final word. Patients can't afford to.

Men need to be educated about the benefits of PSA screening

With reference to screening, we acknowledge the differences in terminology referred to by Meyer and Fradet,⁵ and, like them, we assume that screening means "the examination of asymptomatic people in order to classify them as likely, or unlikely, to have the disease that is the object of screening."⁷

Although there are debates about the benefits of PSA screening within the larger health care system, there is little debate on this subject among men with prostate cancer. Many prostate cancer patients feel that their disease might have been cured or that they might have a longer life expectancy if testing had been done earlier. Most feel adamantly that PSA testing should be readily accessible to all men. A core issue is that men believe that they themselves, rather than physicians or health care bureaucrats, should be making decisions about their health care, such as the decision to undergo screening. This

sentiment is reflected in a broadly supported recommendation from the national forum, that Canadian men be made aware of the benefits and risks of PSA testing *so that they can make their own informed decisions*.⁸ Men with prostate cancer strongly encourage physicians to follow this recommendation.

Communicating information is critical

The importance of information and communication for men with prostate cancer was evident in the findings of the national survey.³ All types of information were rated as important, and disease and treatment-related information were rated as most important. Even though most of the respondents were satisfied overall with the information they had received and the way in which it had been communicated, there still appeared to be room for improvement. For example, in the domain of supportive care, men's satisfaction was relatively low, which raises questions about how they might better gain access to this type of information. Another important finding was the evidence that many men did not comprehend the information that had been conveyed to them. For example, most respondents said that they had been informed about the stage of their disease and that the staging classification system had been explained to them. Yet most were unable to specify disease stage, typically confusing many different aspects of the medical information that had been communicated to them.

Patients appreciate receiving information that is balanced and that acknowledges the potential benefits (and negative consequences) of all possible interventions. The papers in this series that discuss various interventions indicate how health care professionals can put forward the merits of a particular approach while respecting other approaches and the central value of patient choice.

Because of the considerable controversy surrounding prostate cancer screening, testing and treatment, it is especially critical that health care professionals adopt a comprehensive approach in communicating information about choices. Although not all men want such information, many of those who are reluctant to ask questions nevertheless do want to understand their medical situation. All evidence suggests that most cancer patients do not get as much information as they would like.^{9,10} Development of printed materials and decision-making aids is helping to address this issue for men with prostate cancer, but much more could be done.

In their paper on palliative care for men with prostate cancer, Iscoe and colleagues¹¹ discuss the importance of giving patients evidence-based evaluations of experimental and complementary or alternative therapies. We agree that physicians should be balanced in discussing any un-



proven therapy, whether it's a new chemotherapy drug or a herb from the Amazon. We also agree that it is helpful if they can provide detailed information about what is known about the effects of nonstandard treatments. In one recent study of cancer patients¹² many advocated better access to information about complementary or alternative approaches through their physicians.

Many patients are looking for more than just facts and figures when they raise the possibility of other treatment approaches. Indeed, we believe that most men who pursue complementary approaches know that there is little or no scientific evidence supporting the therapies and that positive benefit may be a long shot. However, they would like their physicians to take their interest in complementary approaches seriously, engage in discussion and be supportive of treatment choices that have little potential for harm. Values other than anticancer effect, such as the patient's religious and cultural beliefs and social and psychological needs, should be included when complementary options are considered. These factors can have every bit as much legitimacy as data from a clinical trial in terms of justifying a decision to try an unconventional approach.

Quality of life cannot be neglected

Around the time of diagnosis, considerations of survival are typically paramount for men with prostate cancer. For those who do well with treatment and have few long-term consequences, there may not be many quality-of-life concerns. Nevertheless, many men experience continuing consequences of illness and treatment, and in cases of recurrent or metastatic disease, quality-of-life concerns become primary.

One of us recently heard a prostate cancer patient tell about his humiliating experience in trying to arrange for a vacuum pump to help him continue an active sex life. He was initially discouraged from investigating this option by his primary care physician, who apparently assumed that sexuality should cease to be of concern after a certain age. Then, when he obtained the device, he had difficulty understanding how it worked and was embarrassed to ask for help. Later, the device broke and he had lengthy negotiations with the manufacturer about getting it fixed. This story reveals some of the struggles that men often face, yet is silent about other struggles that are inevitable for couples working out a new approach to lovemaking.

Half of the respondents in the national survey³ identified sexual function as a problem. In response to an open-ended question about the impact of the disease and treatment on their quality of life, many of the men described the distress they experienced. Of those who identified sexuality as a problem, only 20% reported having received adequate help. Although some of this inaction may have

been due to the patients' choosing not to investigate treatment options, systemic barriers probably contributed (e.g., the discomfort of health care professionals in discussing sexual dysfunction and the lack of time in busy clinical practices to deal with sensitive issues). With the promising new treatments now available for erectile dysfunction, as discussed by Hassouna and Heaton,¹³ it will become even more important for health care professionals to engage their patients in discussions of the options.

Another quality-of-life issue for some men with prostate cancer is urinary incontinence, a problem well elucidated by Hassouna and Heaton.¹³ In the national survey,³ a minority of men who reported incontinence felt that they had received adequate help. Interestingly, details like what types of pads work best are often learned from other patients in support and self-help groups. Encouragement from physicians to attend a prostate cancer support group will increase the likelihood of patients participating and, consequently, their access to helpful information.

We commend the focus in this series on the treatment of metastatic disease and the management of medical issues related to advanced disease and dying.^{11,14} There is a pressing need for additional research in this area.

Sensitive treatment and care must be a priority

In addition to the topics already covered in this series, a number of psychosocial dimensions of care need attention. There are no easy prescriptions for what constitutes a "sensitive" approach for physician-patient encounters in the context of prostate cancer. At a basic level, the physician should establish a welcoming physical environment, choose a receptionist who puts people at ease, provide relevant reading materials and include the spouse in discussions and deliberations.

One of the concerns we have heard most often is the feeling of being alone in navigating the steps of diagnosis, treatment and follow-up care. It is so easy for older men to get lost in the system, to miss making the necessary appointments, to get confused about what steps to take next, to feel that there is no single professional who has the time or the inclination to help chart his course. The phrase "falling through the cracks" has been used to describe the situation of many patients. In a recent study of cancer patients,¹⁵ a substantial number of respondents indicated a desire to have access to someone who might be able to spend more time with them than their cancer specialist, someone who could help explain the issues, answer their questions, and help them to navigate the system. For some, this role was already being played by their primary care physician or a nurse at a cancer treatment centre.

Another need commonly expressed by cancer patients



is continuity of care. Ensuring such continuity should perhaps be the role of the primary care physician, but this role has not always been adequately fulfilled. Too often, it has been left to specialists or the staff of cancer treatment centres to respond to patients' needs. In the national survey³ only 51% of respondents agreed that their primary care physician was part of their treatment team. Responses to open-ended questions pointed to men's desire for contact with primary care physicians who would be willing to help them negotiate the sometimes-daunting path of their illness. The need for extra time for discussion is especially critical after the initial diagnosis, when men have so many options to consider. Support groups may play a role by giving men opportunities to hear about others' experiences with various treatments. Men who live in rural areas may especially need support from their primary care physicians because of limited access to both cancer specialists and self-help groups.

Men need independence but also appreciate help

Most men express little interest in receiving psychological support or talking about problems.³ They want to be treated as competent adults, not as sick, vulnerable people. They are more concerned with proactive gathering of information than with expressing feelings. These preferences must be considered when interacting with men with prostate cancer. Yet a recent study of men in prostate cancer self-help groups reported that many benefited from and enjoyed the supportive components of the groups, despite the fact that they had initially attended just to obtain information.¹⁶ This suggests that both components need to be taken seriously by health care professionals. The desire to remain independent should be recognized and facilitated, but efforts should be made to accommodate the need for sharing, whether through support and self-help groups, family discussions or formal counselling.

Conclusion

Men with prostate cancer typically share a sense of urgency about their individual and collective health. They want their sons and grandsons to be able to avoid what has happened to them, and they want researchers to search for the necessary answers. Men also want to be treated well and with respect. They want health care professionals to spend time explaining complex options, and they want to know that there is at least one professional who can be counted on to help them pull all the threads together. They want help in sustaining the best possible quality for their lives.

Many men with prostate cancer are grateful for the assistance that primary care physicians have provided. But others would have liked more assistance, more time. On their behalf, we ask you to consider what is possible.

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Reprint requests to: Dr. Ross Gray, Toronto-Sunnybrook Regional Cancer Centre, 2075 Bayview Ave., Toronto ON M4N 3M5; fax 416 480-5144; Ross_Gray@cancercare.on.ca

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