

THE PATIENT'S VOICE

Prostate cancer on the cusp of change

Jeff Forster



I don't think of myself as a cancer patient, any more than my mother thought of herself as a heart patient after she had bypass surgery in her early 60s, the same age threshold I have now crossed myself. How can that be—I am now as old as my Mom was when I looked upon her—lovingly, to be sure—as an incipient senior citizen! Of course, she never looked upon herself in that way, not once in her 85 years. Old folks were those other people. And so I sometimes think of cancer patients as those other people. Not me. Yet my 39 radiation treatments would argue otherwise.

Diagnosed a year ago with early-stage prostate cancer, I have chosen my treatment, cast my lot, and now await the ambiguities of long-term follow-up. In my heart, I know how fortunate I am that this happened in 2009 and not 1989, and to be dealing with shades of gray rather than cold realities of black and white.

I remember with great fondness the legendary Frank A. Oski, MD, chair of pediatrics at Johns Hopkins, whose prostate cancer was diagnosed at a metastatic stage some 20 years ago, before prostate-specific antigen (PSA) testing had become the order of the day. During his treatment, he wrote an editorial urging his fellow males to submit to the indignities of the digital rectal examination (DRE), for it just might prove to be lifesaving. Dr. Oski was 64 years old when he died in 1996. I think of how much more the world of pediatrics would have been transformed and enlightened had he been granted the opportunity to live to a Spock-like 94.

Thanks largely to widespread PSA screening, 50% to 60% of men with newly diagnosed prostate

cancer have “favorable-risk” disease (based on Gleason score, PSA, and staging) with a presumably “long window of curability.”¹ The blessing of early diagnosis is accompanied by its own curse: What to do about a disease that, except for the happenstance of discovery, might have lurked but never leapt? Ah, the dilemma plaguing modern medicine is that our technological ability to discover clinical problems outpaces our practical understanding of what to do about them! Prostate cancer is the male poster child for this conundrum.

The man with early-stage, promisingly curable prostate cancer finds himself taking a multiple-choice pop quiz. Because the tendency in this country is to find it and fix it, sooner rather than later, the choices are typically to

- A. Take it out (radical prostatectomy, open or robotic)
- B. Nuke it (radiation, external beams or implanted radioactive seeds)
- C. Freeze it (cryotherapy); or
- D. Heat it (high-frequency focused ultrasound).

Another choice, now gaining currency, is (e) none of the above (simply bide some time and see what happens). Once called watchful waiting, it's now labeled active surveillance—monitoring the patient with rigorously scheduled PSAs, biopsies, and even good old-fashioned DREs, and intervening with active treatment when an incipient cancer appears to have shifted out of neutral and into overdrive. The National Comprehensive Cancer Network recently

THE PATIENT'S VOICE

embraced the concept of active surveillance for certain men with low-risk prostate cancer.

Active surveillance is based on the premise that many newly discovered prostate cancers are indolent and destined to remain so. The great unanswered question is, which cancers will march onward and which ones will lollygag? No surefire answers here, and thus much controversy. My Internet meanderings have led me to an imaginative characterization of prostate cancers as turtles (slow and basically stationary), rabbits (capable of hopping beyond the nest), or birds (likely to fly to distant metastatic sites).

An effort is under way to change our basic thinking about prostate cancer and, in fact, not to call some of it cancer at all. A recent commentary suggested the term IDLE (indolent lesions of epithelial origin) for minimal-risk lesions.² I can appreciate the thought and agree with the need to take a more measured approach to the management of prostate cancer. However, as one now walking around with this diagnosis, I suspect the benign terminology may lure us into a false complacency. An idle engine is still running. Maybe turtles can fly. Even some favorable-risk cancers “still progress to advanced, incurable prostate cancer and death.”¹

Yes, I have read the headlines declaring that prostate cancer is overdiagnosed and overtreated. Granted, the cancers harbored in some of those surgically extracted or radiated prostates might never have set sail. At the same time, I spend more than a few “idle” moments wondering whether my cancer may spawn occult metastases that will snicker at the efforts of the most skilled urologic surgeons or radiation oncologists. You tend to adopt a slightly less population-oriented point of view when it is literally your ass on the line.

Having a malignancy diagnosed at any age is a wake-up call. I can feel the frosty breath of mortality on my neck. Knowledgeable, caring nurses and doctors tell me that I shouldn't consider myself a sick person at this stage of the game. I am truly grateful for that perspective. At the same time, I am rejected as a blood donor and recognize that I've fallen off the life insurance salesman's list of top 10 prospects.

The epidemiologists cheerfully tell me I am much more likely to die of something other than prostate cancer in the time that lies ahead. They are quite likely right; my dad died of a heart attack a week before his 55th birthday. His dad didn't make it to 60 either. At 62, I feel like I'm playing with house money. I am blessed by the love and support of family and friends, whose therapeutic value is immeasurable.

After much contemplation and discussion, I have enrolled in a clinical trial comparing active surveillance with immediate intervention in men with favorable-risk prostate cancer.³ The hypothesis is that many men can be spared the possible downside of radical surgery or radiation—erectile dysfunction, persistent bladder and bowel problems—until documented disease progression sounds the bell for therapeutic intervention. Evidence to date suggests that only 1 in 3 men under active surveillance will show sufficient disease progression to warrant treatment.⁴

As it happens, I was randomized to the immediate treatment group and had to choose between surgery and radiation. I made what I consider to be a reasonable, well-informed choice. I was fortunate to be the recipient of wise counsel and excellent care from the top-notch physicians, oncology nurses, radiation specialists, and colleagues at Fox Chase Cancer Center in Philadelphia. Thank you all! The investigators will follow us for 15 years, trying to pinpoint the optimal time for active intervention. I hope this study, and others like it, will bring greater clarity to the diagnosis and treatment of prostate cancer in a way that supports evidence-based, cost-effective solutions to this ubiquitous male problem.

Continued on page 56



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THE PATIENT'S VOICE

My unsolicited advice to men in the same boat: Don't panic. Take some time to explore your options (I deliberated for several months). The pop quiz doesn't have to be handed in today—or even tomorrow. Collect points of view—not just from health professionals, but from men who have been through a similar experience. There are lots of us out there now, some of whom have emphatic post-prostatectomy regret. Listen carefully for voices that offer information and inspire trust.

For clinicians, my suggestion is to engage the newly diagnosed prostate cancer patient in truly shared decision making. Help us put everything in proper context—to understand levels of risk and explore all feasible options with care, underscoring the fact that every case has its own unique odyssey. As Sir William Osler, another Hopkins man, once noted, “It is much more important to know what sort of a patient has a disease than what sort of a disease a patient has.”

Examine us, treat us, but talk to us too. As more of us live (we can hope for many years) with cancer, our thoughts, feelings, and experiences will create a body of clinical lore—a rich oral history, if you will—worth capturing and comprehending.

Twenty years ago, the outlook was far too bleak for far too many men with prostate cancer. In another 20 years, we'll have much better answers. I hope we can look forward to the day when we can say that all cancers are appropriately diagnosed and appropriately treated. Better yet, prevented. ■

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REFERENCES

1. Klotz L. Point: active surveillance for favorable risk prostate cancer. *J Natl Compr Canc Netw*. 2007;5(7):693-698.
2. Esserman L, Shieh Y, Thompson I. Rethinking screening for breast cancer and prostate cancer. *JAMA*. 2009;302(15):1685-1692.
3. National Cancer Institute. Clinical Trials PDQ. Observation or radical treatment in patients with prostate cancer. <http://www.cancer.gov/clinicaltrials/CAN-NCIC-CTG-PR11>. Accessed August 4, 2010.
4. Klotz L, Zhang L, Lam A, et al. Clinical results of long-term follow-up of a large, active surveillance cohort with localized prostate cancer. *J Clin Oncol*. 2010;28(1):126-131.