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Prostate Cancer: What to Do When You Learn you Have It

More than a quarter of a million men in the United States are newly diagnosed with prostate cancer each year. They deserve the best and most appropriate treatment they can get. Instead, many rush to embrace treatment methods that may not be the best for them.

A recent AMA study showed that prostate cancer patients often opt for inappropriate or unnecessary treatment by practitioners touting their own specialties while disparaging or dismissing others. Furthermore, the psychological drive to get rid of the cancer as quickly as possible often leads patients to hasty decisions to embrace more drastic measures than their conditions warrant.

My own experience was typical.

For more than 20 years my annual physical exam has routinely included a PSA test and a digital examination of the prostate, a walnut-sized gland, essential to the reproductive process, lying deep inside the pelvic area. The test measures the level of an enzyme in the blood called Prostate Specific Antigen.

A rapidly rising PSA level may be a sign of potential cancer in the prostate. The test is not foolproof, and lately some specialists have felt the chances of false alarms and the fact that most prostate cancers grow slowly mean its use should be cut back.

But if the PSA levels rise significantly over time, doctors go to the next step - a biopsy: using a hollow needle device they take a series of threadlike samples from the prostate - as many as two dozen - which pathologists then examine to see if cancer cells are present.

A routine exam early in 2007 showed that while my PSA level was still fairly low, it had doubled in less than a year, so my urologist in Boston decided a biopsy was warranted. He performed it in April.

When he called to tell me that the biopsy was positive and I had cancer, I was devastated.

My first instinct was to get rid of the disease as quickly as possible, even if it would mean a lifetime of incontinence and impotence--the risks you run if you have surgery (the so-called "gold standard" for prostate cancer treatment), or most other common ways to try to cure the cancer.

But unlike most newly-diagnosed cancer patients, I had good reason not to jump for the first chance to "get rid of it." My wife Joy had been going through a series of abdominal operations. There had been complications, and both of us felt I should not be making hasty decisions about my own treatment options until we knew she was out of the woods. We decided to make no decision until after July 1, when her last set of stitches would be taken out.

So I had time to learn more about my own case, the different options available, and to seek advice from a variety of specialists. On the advice of a friend, I asked a medical oncologist to assemble a team of specialists (a surgeon and a radiation oncologist) to examine me.

The surgeon agreed with my urologist that my age (I would soon be 74) meant that surgery could impose unnecessary risks. But the radiation oncologist seemed to go out of his way to irritate me. He chastised me for wasting his time with questions about information I had found on the Internet. "You lay people can't expect to understand all these details," he said.

And he dismissed my concerns about side-effects, most prominently incontinence and impotence. He said he could get rid of my cancer--wasn't that what I wanted?- with external beam x-ray radiation. Besides, he said, "almost everyone gets side effects." But then he told me that long-term side effects from radiation only affect some 2 to 3% of patients.

I was not reassured. I had no interest in wearing a diaper and having no sex for the rest of my life. When he and the surgeon left, the medical oncologist astonished me by saying, "That 2-3% number is just bullshit. It's more like 40 per cent."

His caustic remark was recently confirmed by an article in the American Medical Association publication Archives of Internal Medicine (March 8, 2010), which concluded:

> *"Specialist visits relate strongly to prostate cancer treatment choices. . . [cancer] specialists prefer the modality they themselves deliver . . . . it is essential to ensure that men have access to balanced information before choosing a particular therapy for prostate cancer."*

This bias, combined with a psychological drive to "get rid of" the cancer the fastest way possible, leads many newly diagnosed patients to unwise treatment decisions, quite often surgery. And even though I had been told that at my age surgery was not a good option, part of me was still reluctant to rule it out.

Confused by conflicting advice from doctors, I went to a prostate cancer support group meeting. There I was urged to learn all I could about my own case so I could explore my options with a better understanding of their consequences.

I also contacted other patients who had undergone the most frequently used therapies: surgery - conventional, laparoscopic and robotic; radiation, both external beam radiation and brachytherapy (radioactive seed implants); and "watchful waiting" --and found that many of them had developed distressing side-effects and wished they had tried something else.

But the patients who had experienced proton radiation therapy were almost uniformly pleased

with the results. For many of them, the cancer was gone, and they often had no side-effects whatever. In their case, a 2-3% incidence rate seemed more plausible.

Most of them had received their treatment at the Loma Linda University Medical Center in Southern California.

I live near Boston, where there are many fine medical institutions that can treat prostate cancer. One of them, Massachusetts General Hospital, is equipped to perform proton therapy, but a senior radiation oncologist there told me that in more than 30 years they had only treated about 300 prostate patients.

At Loma Linda University Medical Center they had treated thirty times as many. The decision to have my cancer treated there with proton radiation was easy.

In a future article I will describe how proton radiation works, and how it left me cancer-free, with no side effects.