

Confronting Prostate Cancer: A Personal Reflection

Senator David W. Hoyle

Editorial Note: Because prostate cancer, its early detection and treatment, raise so many issues of personal concern, we considered it important to include a discussion of some of these matters from a personal perspective. We are fortunate that one of our state's leading public policy makers, Senator David Hoyle of Gaston County, was willing to share his own experience with all phases of the process from detection and diagnosis to surgical intervention and post-operative care. We hope that this narrative will help bring clear focus to many of the issues raised by the authors in this issue of the Journal and encourage men who are not regularly screened at appropriate ages to raise these issues with their personal physicians.

No one likes the sound of the word “cancer,” especially when it applies to you. In this respect, I was just like everyone else.

But, I had heard from many that “most of us [men] have this condition, whether we know it or not, and that we may all die from this disease if we live long enough. Although most of us die from something else long before symptoms of prostate cancer appear.” The fact that the disease is slow-growing (in most) and more prevalent in older men makes many feel less concerned at younger ages. I was one of those, although I had been having prostate-related problems for many years, since my mid-40s. Off and on, I had experienced problems with discomfort, inflammation, and something my doctors referred to as prostatitis. My PSA levels had been slowly rising (from around 2, then 3, then 4, and eventually to 6; the so-called “velocity” of change was notable, but still failed to raise the concern of my physician).

Finally, my primary care physician, who had been taking care of me for years, after a usual digital rectal examination as part of a normal physical, noted a lump or hard spot on my prostate. My doctor thought it would be good for me to see a urologist for a consultation visit.

This preliminary unusual finding from a regular primary care visit began a long and convoluted series of events that caused no small amount of anxiety for me and my family.

Importance of Follow-Up to Preliminary Findings

Right away, my physician helped me get an appointment at the University of North Carolina Hospital (UNC) in Chapel Hill. A biopsy was performed and laboratory results came back with the unwelcome news that I did have cancer of the prostate, with a Gleason score of “6.” My urologist at UNC explained several (surgical and non-surgical) options, but recommended that I consider surgery to remove the prostate.

I consulted a number of friends, including friends in the field of surgery and urology, about my situation and asked several of them: “If you had this condition, where would you go to have the surgery performed.” A physician friend, with whom I had often played golf, recommended a surgeon at Johns Hopkins University in Baltimore. On his recommendation, I contacted that surgeon and arranged an appointment to be seen in his clinic. He recommended surgery within two weeks of that appointment.

The “Ups and Downs” of Good and Not-So-Good News

Then, a startling thing happened. A week later, after I returned to my regular work at the North Carolina General Assembly, I was summoned from a committee meeting by my secretary who said the surgeon from Baltimore was trying to reach me rather urgently. I rushed from the room and spent a nervous 20 minutes or so trying to page the surgeon. I had all sorts of images racing through my mind. Were the results of my laboratory tests found to be even more serious than they first appeared to be? Was it necessary for surgery to take place even sooner for some reason? What could it be?

When my surgeon and I managed to speak, he explained that when the pathologists at Johns Hopkins looked at the slides I brought with me from North Carolina, they concluded that I did not have prostate cancer after all! My surgeon was

Senator David W. Hoyle represents the 25th Senatorial District in the North Carolina General Assembly, which includes portions of Cleveland, Gaston, and Lincoln counties. He lives in Gastonia and can be reached at davidh@ncleg.net or 300-A Legislative Office Building, Raleigh, NC 27603-5925. Telephone: 919-733-5734.

calling to tell me that he had cancelled my scheduled surgery for the next week.

Even though there was a certain sense of “relief” in this news, my surgeon followed his announcement of these results with the request that I try to have an immediate second biopsy done here in North Carolina. He felt that was necessary to confirm the Hopkins pathologist’s opinion that no disease existed, and then we would re-evaluate further options.

So, a few days later, I was scheduled for a second biopsy. This time, different from my first experience, the procedure was less painful and more extensive. Instead of six “punches,” they did 12. But this time, I was more psychologically prepared and knew what to expect.

Two days later, the results were disappointing in that they confirmed the initial diagnosis: I did have prostate cancer. Surgery was scheduled for a second time, just before Christmas, after my prostate had time to heal from the extensive biopsy procedure. I got out of the hospital after surgery two days before Christmas and checked into a Baltimore hotel to rest for a few days before traveling home. The Hopkins surgeons wanted to make certain that I had no post-operative complications.

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After the surgery, I had a catheter to assist with bladder issues, which I kept in place for 20 days when it was removed by my own physician in Gastonia. I also wore paper diapers to make certain that I did not have a problem with incontinence. Thankfully, these were necessary for only a few days. I had no problems with urination or anything else after that.

I was relieved to learn that the surgical margins of my disease were contained (localized) within the prostate, and the disease had not spread to other parts of my body. Therefore, I had no post-surgical radiation. I am now followed on a regular basis (every six months) by a urologist in Charlotte, and my PSA has dropped to “zero.” Several other tests have been done, such as a bone scan in Chapel Hill, to make certain that the disease was not transmitted to other parts of the body. In every respect, this has been a complete success, and I am pleased to have been disease-free for the seven-to-eight years since the surgery was performed.

Lessons Learned

This experience provides a number of “lessons” that I would pass along to others who may yet have to confront this same set of circumstances. First, it is important to have a regular primary care physician who knows you and your health situation well.

It was important that my physician who had been seeing me off and on for many years was able to note the appearance of a “hard spot” on my prostate during a routine examination. Were it not for that finding, one might have concluded that an elevated PSA level alone, which had remained high for many years, was simply benign prostatic hypertrophy (BPH) and no cause for concern. I have a family history of prostate cancer, so I knew that this was something that might likely develop in my case.

Second, once I followed-up this initial finding with a more thorough urological examination and biopsy, and once I had a definitive diagnosis, I asked lots of questions of my doctors and my friends who had gone through this before. I read everything I could get my hands on about this condition, so I would know what courses of action were available to me, and what the likely (or possible) outcomes might be of any given course of action. One of my friends, who had considered the option of the implantation of radiological “seeds” instead of surgery, had worried (before taking that route) about problems with both incontinence and impotence. Neither of these problems resulted in his case. But, I learned that once radiation is chosen as an option, surgery is no longer an option.

Third, it is important to realize that medicine is not “perfect.” Mistakes do happen, and test results are often inaccurate. It is important, especially with diseases like cancer, to double check test results and, if possible, with a different laboratory or clinical setting. I was fortunate that my Hopkins physicians recommended that I have another biopsy performed here in North Carolina.

That second set of biopsy results confirmed the findings of the first biopsy—I did, in fact, have cancer and needed surgery. I’ve tried many times to figure out how the Hopkins pathologists could have been so certain that I didn’t have cancer. My only explanation is that somehow the slides I brought with me from Chapel Hill were either the wrong slides, or they got mixed up in some way in the lab at Hopkins. In any event, a second set of biopsy results were necessary to actually detect the disease.

Finally, the combination of early diagnosis and immediate follow-through with a detailed diagnostic workup and consultation can lead to better treatment outcomes. Also, although there are risks of post-operative complications, for large numbers of men who undergo these procedures, results are similar to mine. In this day and age, there is really no reason for men to die from prostate cancer if they follow these recommended procedures for clinical examination and testing.

I am one of those grateful patients who has been well-served by many healthcare professionals here in North Carolina and elsewhere, as my family and I have confronted what, for some, is a very unnerving diagnosis. **NCMedJ**