



Case Report

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Prostate Cancer; Living with it for Eighteen Years and Counting: a Case Study

Philip H Hutchens*

Independent Scientist, La Mesa, CA, USA

*Corresponding author: Philip H Hutchens, Independent Scientist, La Mesa, CA, USA.

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Abstract

In this article, the author shares his own story of living with prostate cancer. He shares maxims about living with prostate cancer and how there is some truth to these maxims and how the maxims can at times be misleading. He reviews decisions he had to make regarding his own treatment, and he visits the facts and statistics he used in making his treatment decisions. He ends with a “lessons learned” section on alternatives to surgery and radiation. The author strongly believes that clinical medicine is advanced for both the patient and physician by hearing personal stories, and that is why he is willing to share his personal story.

Introduction

According to the American Cancer Society, cancer cases in the U. S. among both men and women will rise significantly over the next 26 years. For example, in 2022, 1.9M new cases of cancer were reported. That figure rose to over 2M in 2023. Prostate cancer is included in the projected increase of cancer cases, and more cancer is being diagnosed among younger patients, including prostate cancer. In the face of this forecast, I want to share my personal medical journey, because from my own experience, when clinicians have a greater understanding of how a patient deals with a disease like prostate cancer, they are better able to treat their patients. It’s helpful to know how a patient feels as opposed to looking at cancer as just a bunch of numbers from a study. As a cancer patient, it helped me make informed decisions about my treatment by talking to (and reading about) other cancer patients and sharing our personal cancer stories. Hopefully, my story will enable others to ask more informed questions of their physicians. Also, it helped my decision-making process to get input from physicians with varying cancer specialties.

I have been living with prostate issues for the past 40 years; living with prostate cancer for the past 18 years; and living with metastatic prostate cancer for the past 10 years. When I told my Cardiologist that I had prostate cancer, he said, “Oh, that’s the dis-

ease you die with and not from.” There may be some truth to this maxim. However, treating prostate cancer is difficult. Easily, it can be undertreated or overtreated to the detriment of the patient.

Another maxim is that when it comes to prostate cancer, all men are different. There is some truth to this maxim, and that is part of the reason prostate conditions are so difficult to treat. However, there are many similarities regarding men’s experiences with prostate health, and the more we share our experiences, exchange information across medical disciplines and collaborate, the faster we create more effective treatments leading to remission and greater longevity.

Prostate Cancer Facts

There are an estimated 36 trillion cells in the average male human body [1]. These cells are regularly dying and being replaced in a process scientists call replication [2]. Cells from different parts of the body die and are replaced at different rates of speed. Often times during the replication process, the DNA in a new cell does not match exactly the DNA of the cell it is replicating. These cells are considered damaged. All humans have damaged cells in their body at any given time. Usually, cells with damaged DNA either fix themselves or die naturally [3]. For reasons not fully known to science, damaged cells can replicate themselves and form tumors that may



be benign or cancerous. However, the human body has an immune system including T cells and B cells whose function is to destroy the damaged cells. Sometimes the tumor cells are not destroyed, and they can grow and if cancerous can spread throughout our bodies and lead to death.

“Prostate cancer is the most common cancer in men in the US, other than skin cancer. It’s also the second leading cause of cancer death (after lung cancer). About 1 in 8 men will get prostate cancer in their lifetimes” [4]. The majority of them will be over the age of 65. In 2024, an estimated 299,000 men in the United States will be diagnosed with prostate cancer, and a little over 34,000 of those will die from it.

My Personal Story with Prostate Cancer

In my case, I started having some discomfort during urination when I was 46 years old. I was referred by my Internist to a Urologist specializing in prostate cancer for an examination. He performed a Digital Rectal Examination (DRE) and told me I had some thickening on one side of the prostate but no tumor. He referred me for a blood draw to measure my Prostate Specific Antigen (PSA). In a follow-up visit, he told me my PSA was 0.6 – nothing out of the ordinary. He advised me to return for a follow-up examination in one year, which I did. Unfortunately, after only one follow-up examination, my Urologist died from of all things, prostate cancer. After his death, I continued with my Internist, and he obtained a PSA measurement every year for the next several years.

When I was 62 years old, my Internist retired, and I was referred to a General Practitioner (GP) for prostate care. At this point, my PSA had been slowly creeping up and was now measuring 1.5. I was having some difficulty emptying my bladder and some burning during urination on occasion (not every time). My new GP prescribed a drug called Flomax (Tamsulosin). I was on Flomax for the next 10 years. It worked as advertised until it did not work – with one upsetting exception. When I first started the drug, I passed out at a major league baseball game between the Orioles and the Yankees and was taken by ambulance to the nearest hospital. I was not told that Flomax was time-released and could cause a drop in blood pressure. The greatest drop in blood pressure usually was about seven hours after taking it orally. After that incident, I took the drug before bed, and I never had an incident with it again where I passed out or felt faint.

When I was 63 years old, I moved from my home on the East Coast back to the West Coast where I had grown up. Promptly after the move, I became a patient of a new Urologist. This Urologist followed me for several years during which my PSA was taken annually and continued to rise slowly. When I was 68 years old, my PSA had risen to 2.6, and my Urologist ordered a UPM3 (urine test) that was positive for cancer. He then performed a biopsy on my prostate and that was negative for cancer. We continued a program of Active Surveillance.

Shortly after I turned 72 years of age, I had complete urinary blockage. The very day that I was unable to relieve myself, by chance I had an appointment with my Urologist. He inserted a Foley

catheter and got about a liter of urine out of my bladder. That same day, he sent me to the lab for tests on my kidneys to make sure they were not damaged by the stoppage of urine flow. They were not damaged. Months went by, and I was shown how to self-catheter. I ordered all the needed self-catheter supplies from a medical supply house as the Urologist considered what should be done for my blockage. About seven months later, he referred me to a specialist at a major university in my area. At this point, my PSA had risen to 4.5.

The university Urologist ran a number of tests and determined I was a good candidate for a “Transurethral Resection of the Prostate” (TURP). He did not perform a biopsy and told me he presumed I was cancer-free since I had a negative biopsy four years earlier. The TURP procedure is sometimes referred to as a “roto-rooter.” In my case, a laser instrument was inserted through the urinary tract to the point where the urethra passes through the prostate and where the blockage was occurring. The Urologist later told me he cut out about 40 percent of my prostate with the laser. While the laser is an effective tool for performing a TURP, a downside is that it burns away or cauterizes the prostate tissue, and no tissue is available from the procedure to check for cancer. A benefit of using a laser to perform the TURP is that it minimizes bleeding, and bleeding can be a problem with other methods of performing a TURP. I healed quickly from the TURP. I had no problem relieving myself, and that remains the case to this day. I was told to come back in one year.

At my examination one year later, my PSA had risen from 4.5 to 10.5. This was not a good sign. Sort of a rule of thumb is that if the PSA doubles in about nine months or less, it is cause for further examination. A biopsy was performed, and it was determined I had prostate cancer with a Gleason score of 4,5=9. The Gleason score is derived from two scores, where the first reflects the amount of cancer in the likely tumor area, and the second score reflects the amount of cancer in other areas of the prostate. Therefore, a 4,5=9 is a worse score than a 5,4=9. The highest Gleason score is a 10. My Gleason score suggested that my cancer had likely spread outside of the prostate. That is, I likely had metastatic prostate cancer. A follow-on CAT Scan showed probable cancer in the lymph nodes near the prostate.

In my situation, it made sense to get a biopsy of my prostate as recommended by my physicians. However, for some, getting a biopsy can be a difficult decision. If you wait too long to treat a troublesome prostate issue, the issue can become cancerous. However, if you treat a benign prostate issue too aggressively, you may cause unnecessary suffering to the patient [5]. For example, it has been theorized (not proven) that having a biopsy may release cancerous cells into the blood system, and that even a decision to have a biopsy of the prostate should not be made lightly.

My university Urologist referred me to both a surgeon and a radiologist specializing in cancer treatments. It was determined I was not a good candidate for surgery since the cancer had already spread outside of the prostate. The Radiologist determined that the prostate and surrounding lymph nodes should be radiated. Before the radiation procedure, however, I was put on Androgen Deprivation Therapy (ADT) for four months, and I continued on ADT for a

total time of 18 months. Statistics show that being on ADT along with radiation of the prostate greatly improves the outcome.

After four months of ADT, I underwent 45 radiation treatments over a 10-week period. At the end of the radiation, my PSA had dropped from nearly 11 to 0.1. This is a score, I was told, that was commensurate with a cure since I still had a prostate. Physicians don't like to use the word "cure" regarding prostate cancer treatments. Even if one cancerous cell survives inside or outside the prostate, there is a danger the cancer will re-emerge. That is why physicians prefer to say the cancer is in remission as opposed to the patient being cured.

When I was 75 years old, I had a reduced urine flow, and a Urologist performed a dilation of my urethra. That procedure re-established a normal urine flow for my age. When I was 76 years old, I took a "blood thinning" drug prescribed by my Cardiologist. That drug caused me to hemorrhage large stringy blood clots in my urine and make a Saturday night run to the emergency room. I had my bladder flushed out, and the emergency room physician told me to stop the drug and have a conversation with my Cardiologist. He said, "As long as you keep taking the drug, you will continue to have blood in your urine." My Cardiologist concurred. I stopped the "blood thinning" drug and have not had a single occurrence of blood in the urine since.

When I was 78 years old, I was referred to a university hospital in my area for additional radiation treatment of the prostate. During that treatment, things went terribly wrong. An artery in my abdomen burst, and I was bleeding internally. I was "code blue" and rushed to a lab for repair of the artery. They were able to stop the bleeding and repair the artery non-surgically, and I received 12 units of blood and plasma. In a few days I was sent home to recover. However, I did not get better.

After a few days of getting progressively worse, I visited the emergency room of my local hospital. On the second day of being hospitalized, a colonoscopy revealed that not only had the university physician sealed off my ruptured abdominal artery, but he sealed off arteries to 13 inches of my large intestine that was now dead. Emergency laparoscopic surgery removed the necrotized 13 inches of my colon, but the surgeon found it necessary to perform a procedure called an ileostomy, where a hole (stoma) is left in my abdomen going out into an external bag to collect waste. The ileostomy was reversed six months later, but I was unable to pass urine immediately following that surgery, and a procedure was performed called a Suprapubic Bladder Catheterization – where a needle catheter is pushed through the abdomen into the bladder to allow urine to leave the bladder. The catheter stayed in place for another couple of months before the Urologist felt it was safe to remove it. At that point, I was urinating normally.

Over the next few years, my PSA continued to rise. My Oncologist sent me for a PET/CT Pylarify scan that revealed metastatic prostate cancer. The scan showed no cancer in my prostate or in the pelvic floor below the prostate. However, there was cancer in two lymph nodes near the prostate and in my leg, hip, ribs, back and

collar bones. The cancerous spots subsequently were treated with radiation. I had another six scans over the following years, and each scan revealed that additional spots of cancer had spread to other bones and to lymph nodes. Also, those areas were radiated following each scan. The last scan showed five new spots of cancer in the bones and lymph nodes, and it was decided to try me on a medicine called Xtandi. I now get a Lupron injection every three months and take two Xtandi capsules daily. My PSA score was 8.5 when I started the Xtandi, but it has dropped down to 2.59. I will continue this regimen as long as it continues to work. I am now 83 years old.

Takeaways from my Experience

There are four key takeaways from my experience with prostate cancer.

Will the Treatment Result in a Cure?

One prostate cancer maxim is that if we diagnose the cancer soon enough, then we can cure the cancer. There is enough truth in this maxim to make it problematic. However, to me, as a patient, this involves a moving goal post. If the cancer is not cured, the answer is always, we did not get it soon enough. This presents a problem for treatment. It is possible to treat the cancer too aggressively and cause more harm than good for the patient. If you wait too long, we did not get it soon enough is the reason for a lack of cancer cure.

There is another maxim involved in treating prostate cancer that has some truth to it. That is, if you see a surgeon, they want to operate on your prostate. If you see a radiation oncologist, they want to radiate the prostate. If you see a medical oncologist, they want to use drugs to fight the cancer. I know from personal experience there is some truth to this maxim as I visited all three prior to my radiation and drug treatments. This makes the decision difficult for a patient who has prostate cancer and sometimes is told by three different physicians three different ways to "best" treat the cancer.

Two of the most common approaches to treating prostate cancer are surgery (prostatectomy), or radiation coupled with Androgen Deprivation Therapy (ADT). Unfortunately, with either approach, about 25 percent to 30 percent of the patients are not cured according to the Prostate Cancer Foundation [5]. In these cases, the cancer has already metastasized and sooner or later following treatment it shows up again in blood tests and on scans.

There are some tests that are helpful in trying to decide how to successfully treat prostate problems. Most tests are aimed at determining if cancer is present in the prostate, and if present, how best to treat it. One of the first tests is a urine test, and if appropriate, it is often followed with a PSA test. If the PSA test is >3, it may be followed up with a 4-Kallikrein panel [6]. Both the PSA and 4-Kallikrein tests are done with a simple blood draw. So, these tests are noninvasive. They can be performed if a patient is having symptoms. Should they be performed routinely without symptoms? A recent study suggests that it will not make much difference over a 15-year period in middle-aged men if the tests are performed routinely in the absence of symptoms [7]. The issue is that most

prostate cancer is slow growing, and detecting cancer can lead to overtreatment such as a biopsy, and the harm to the patient may be greater with treatment than with Active Surveillance or no routine testing. Another study suggests that routine testing without symptoms is not advised [8].

If appropriate, these tests may be followed with a biopsy. The Gleason score from a biopsy is helpful. For example, if the score is a 7 or higher it may be clinically significant (which means that it is possible that the cancer has already spread outside of the prostate, statistically speaking). A score of <7 may not be clinically significant and suggests we found it early enough [9]. However, the Gleason score by itself does not provide enough information for treatment. If appropriate, the patient may then get an MRI designed to show the amount of cancer in the prostate or whether the cancer has spread to other parts of the body. The scan is basically noninvasive and some physicians prefer the scan to precede the biopsy because PET scans are highly accurate in showing even small amounts of cancer and cancer locations.

So, two of the most widely used procedures for treating prostate cancer do not guarantee a cure. Although if either one of the procedures is done early enough, the odds are highly favorable for a cure or remission. Sometimes, physicians working together will recommend surgery followed by radiation. In my case, the surgeon advised against surgery and recommended radiation treatment. As described above, I received radiation treatment, but my cancer continued to spread following that treatment.

How Likely is the Treatment Apt to Cause Incontinence?

There are two valves that control urine flow – one above the prostate and one below the prostate. The valves are controlled by nerves so that both valves are open for urination. During a climax, nerves cause the upper valve to close so that seminal fluid (from the prostate) mixed with sperm will enter into the urethra through ducts in the prostate wall. That fluid mix then passes through the lower valve (that nerves have caused to be open) while the top valve remains closed. In that manner, urine does not mix with the ejaculate. Disturbance of these valves and nerves during prostate cancer treatment becomes problematic for incontinence.

To me, becoming incontinent was a major consideration in determining which of the two common cures for cancer that I would select. Unfortunately, (and depending upon the definition of incontinence), about 30 percent of surgery patients have immediate or soon-to-appear incontinence issues [10]. Incontinence issues following a prostatectomy are likely to grow to nearly 50 percent at six months, but usually improve over the years following the surgery [11].

When radiation, combined with ADT are used to treat prostate cancer, the chance of incontinence is low [12]. This is a possible reason to consider radiation over surgery, although it is not the only consideration. If the cancer has already escaped the prostate or metastasized, it calls into question the value of an attempt to treat the cancer with surgery or radiation. That is an issue you would need to discuss with your physicians, because sometimes the treatment

will include both surgery and radiation. However, if the cancer has metastasized, neither surgery nor radiation of the prostate alone is apt to cure it.

There is a maxim when it comes to treating prostate cancer that if you radiate you will not be able to later treat with surgery. However, if you undergo surgery first, you can later treat the prostate with radiation if the surgery is unsuccessful. This maxim is sometimes used as a reason in favor of treating prostate cancer with surgery. There is some truth to this maxim. It's not that you can't operate on a prostate that has been extensively radiated; the issue is that the outcome is likely to cause incontinence according to my physician. I was lucky in this regard, I have had no issues with incontinence following my radiation treatments.

Is the Procedure Likely to Cause Sexual Dysfunction (Including Infertility)

Many men are reluctant to talk about their virility. Many of the men I have talked with prefer to express themselves as real studs. In reality, the studies we do have suggest that most men suffer a significant drop in sexual capacity in their late 70s. This is not true for everyone, I know, but it is an average statistic. In other words, studies where men report their sexual activity are apt to be somewhat unreliable from the get-go. However, we can get some idea about aspects of sexual function from studies not involving cancer.

Apart from reasons of treating cancer, many men do undergo vasectomies and do not report any significant change in sexual pleasure following the vasectomy. What reports we do have from patients who have had their prostates surgically removed or radiated is that sexual function is similar to men following a vasectomy. Over time, however, patients who stay on ADT will see their libido drop off. After all, ADT is basically chemical castration, no matter any attempts to sugar coat its use, it is chemical castration. If the cancer is cured, loss of sexual function may be addressed later with testosterone supplements, if necessary. Sometimes following the cessation of ADT, testosterone may rebuild on its own accord. The older the patient, however, the less likely testosterone will rebuild without supplementation. However, physicians are reluctant to prescribe testosterone to a cancer patient because prostate cancer lives on testosterone. No one wants to feed cancer cells.

Additional Considerations

There are a number of additional considerations that might be considered before having extensive testing and scans or undergoing the knife or having traditional radiation treatments for prostate cancer.

Active Surveillance

The first is called Active Surveillance (AS). Using testing procedures such as PSA, urine testing, DREs, etc., allows you to watch prostate activity before making a decision to have further testing or treatment. This approach is based on the idea that prostate cancer is slow growing in most men and further testing or treatment may be unnecessary. I was on AS for a number of years when I first noticed some prostate problems starting in my mid-40s. I went many years with just a slow but steady rise in my PSA levels.

In other words, AS seeks to avoid overtreatment of the cancer, and to prevent undertreatment. One important study found that in men diagnosed with “favorable-risk” prostate cancer, roughly half required treatment over the next 10-year period. Therefore, AS can be an effective strategy, and waiting two years after diagnoses before treating (in those requiring treatment) did not seem to make much difference in outcome as measured by metastasis or death after 10 years. In fact, less than 1 percent of patients had died from prostate cancer 10 years after diagnoses, whether they were treated or not [13].

I have come to believe that physicians are cautious about treating newly diagnosed cases of prostate cancer aggressively after the patient is around 75 years of age. I believe this to be the case because there is fear of doing more harm than good, and that men in their mid to late 70s just might be more likely to die with prostate cancer than from prostate cancer. Therefore, diagnoses of prostate cancer after age 75 might involve a stronger case for considering AS than would be the case in younger men. Again, however, treatment through AS could be influenced by non-invasive tests for cancer as mentioned above.

Cryotherapy

If aggressive treatment is warranted, cryotherapy is a possible option. In this procedure, all or parts of the prostate are frozen to kill the cancer. It works best in early-stage cancer. I had heard about cryotherapy many years before it was offered to me when I was 78 years old. One physician recommended it to me, and a second physician did not favor it. I decided not to be treated with cryotherapy.

Tulsa-PRO

A newer treatment approach is called TULSA-Pro and uses ultra-sound heat to kill the cancer cells. Of course, it is only effective if the cancer is still confined to the prostate. However, it is highly effective and has fewer side effects than surgery or radiation treatments. It works best in early-stage cancer. I first learned of this treatment from an AARP publication and decided to read more about it. It could be promising for many patients.

Diagnostic Genetic Testing

Through the use of a lab blood draw, our genes can be tested for pathogenic variants known to cause diseases such as prostate cancer. If it turns out that someone has a predisposition to prostate cancer based on their genes, a physician may be able to make some adjustments in their treatment during any stage of cancer or even before cancer has been diagnosed. For example, if someone tests positive for a cancer-causing genetic disorder, they may very well want to notify their sons or brothers so they can be tested as well. I had genetic testing and was found not to have genes associated with prostate cancer.

The Foods We Eat and Our Environment

I’m often asked if the foods we eat can cause prostate cancer. From what I’ve read and learned, the answer is a resounding yes. Most health food practitioners recommend a Mediterranean diet or similar diet. The emphasis in this diet is on eating grains and vegetables along with fish as the primary meat source. Foods that

are recommended to avoid as a regular part of our diets include processed meats; red meat; dairy, etc. [14] (I would encourage anyone concerned about their health to read more about the Mediterranean diet.) Health practitioners universally recommend against smoking cigarettes and recommend against alcohol use or suggest use of alcohol in moderation as a means for both preventing prostate cancer or as a part of prostate cancer treatment. I have tried all my life to eat and live healthy. I never smoked cigarettes and was a very moderate drinker. Yet, I have metastatic prostate cancer. Presently, there is no guarantee that any of us males will not get prostate cancer. That is why we need to be vigilant in watching for it as we age by testing noninvasively, following our physicians’ advice, studying prostate cancer issues for ourselves, and together with our physicians determining how to best maintain good prostate health.

Theranostics

A theranostics center for treating cancer opened at UCLA Health in February, 2004, on an outpatient basis. The first patient treated was a prostate cancer patient whose PSA dropped to undetectable after treatment. With theranostics, the patient receives up to six rounds of a radioactive drug called Pluvicto that binds to prostate cancer cells and kills the cells. The treatment has a response rate of 40 to 50 percent with metastatic prostate cancer [15]. It is most effective with prostate cancer that has not yet spread to the bones. I’m on the UCLA mailing list and read about this procedure in one of their publications. The treatment looks promising.

Immunotherapy

This therapy involves trying to ramp up our T cells to find and kill the prostate cancer cells. To date, it has not been highly effective in treating prostate cancer. However, a drug called pembrolizumab is showing promise in the treatment of prostate cancer. Usually, this drug is taken intravenously every three weeks [16]. I have not been treated myself with this procedure, but it may have promise for the future for some prostate cancer patients.

Urine Tests to Detect Prostate Cancer

Urine tests for prostate cancer are highly accurate and can help the patient avoid unnecessary biopsies that are invasive [17]. If the urine test is negative, there may be no reason to perform a biopsy. If the urine test is positive, your physician may recommend going ahead with a biopsy. As a patient, we have to listen to all our physician tells us about recommending or not recommending a biopsy, and then make our decision. There are newer urine tests on the market for prostate cancer. “My Prostate Score (MPS)” looks for two genes found in the urine of men with prostate cancer. “PCA3” looks for a gene that is overexpressed in prostate cancer cells. This test is accurate about 80 per cent of the time. “My Prostate Score 2.0 (MPS2)” looks for 18 genes associated with high-grade cancer. It is effective about 90 percent of the time. These tests are an important tool in testing for prostate cancer and possibly avoiding any unnecessary biopsy. I was given a urine test for prostate when I was 65 years old, and I tested positive for prostate cancer at that time. It is possible I had cancer even prior to that test.

Concluding Thoughts

There is a maxim regarding prostate cancer that any male who lives long enough will eventually get prostate cancer. The maxim is true enough in that we know for certain that prostates tend to be problematic as we age. The maxim gives me comfort in believing I did not do anything careless or stupid in my life to cause cancer. I believe my physicians treating me all did the best they could at the time (and continue to do their best), given the tools for treatment at their disposal. I have lived for over 18 years with prostate cancer and believe my future will be productive. I have lived beyond the average age for death for men in this country, and I have no complaints about my length or quality of life. I have written this article to show that prostate cancer is not an early death sentence for most men. In fact, most men who have prostate cancer die with it and not from it.

I appreciate all the help I have gotten and continue to get from the medical community. I continue to monitor my condition carefully, and I continue to hope that new and better treatments are on the horizon.

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Conflict of Interest

None.

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