

Recommended Changes to Standards of Care for Prostate Cancer

The topics covered here include:

- 1) The push back from the medical community to stop getting prostate screening.
- 2) 4.0 PSA as a universal (age independent) “Red-line” Standard
- 3) Using an MRI as a primary screening tool vs prostate biopsy for initial diagnosis
- 4) PSMA PET CT/CAT scans vs previous imaging technology

1) The push back from the medical community to stop getting prostate screening

Although ignorance may be bliss, I find this trend to be troubling, since sticking your head in the sand will not save you from an oncoming bus. While I certainly understand that there is difficulty in distinguishing between aggressive and less-aggressive cancer based on biopsy analysis, and that aggressive treatment of prostate cancer that has not spread, and might never spread, can lead to very undesirable side effects (primarily incontinence and impotence). While that is unfortunate, I certainly don't feel that eliminating the screening procedures that could otherwise detect cancer that might well be aggressive should be discontinued. Obviously care needs to be taken to try to understand the results, and the potential risks associated with any given persons condition based on their age, family history of prostate cancer, and the screening results. But to stop doing the screening will eliminate the mode that might find an aggressive strain of cancer before it spreads too far.

In my case, I was not entirely aware of the risk level of finding a lump on the prostate during a DRE exam, nor was I overly confident of my or any doctors ability to accurately detect a lump during a prostate exam with a gloved finger up my rectum. I should have asked more questions about that, because a well defined lump is generally a sign of an advanced and potentially aggressive cancer growth in the prostate.

As to PSA testing, again there is a range of values that can be considered safe, and there is no certainly that surpassing a “safe level” by a marginal amount will mean that you will get cancer, BUT if your PSA jumps to a high level (like mine did when it went from under for to over 50), then you know for sure you are un trouble and need to take action. I had no idea that PSA could even go that high, but I have since found out that it can go to over 1000. I've met people in the patient room at U of M (the room that patients sit in as they are waiting for their radiation therapy) in which the first time they found out they had cancer it had already spread around their entire body, with a PSA level of well over 100. For that to occur seems to make it clear that such a person was not getting regular testing, since had they, the cancer could have been detected at an earlier state making the treatment much more likely to extend life significantly. To give up on an annual test that might well have caught the cancer when the PSA had hit a level of (for example) 20, and before it had spread to more than locally, which usually does occur first, well it's sad and in my opinion darn well irresponsible to forgo such screening. Get the data, then decide what to do, but don't eliminate the ability to detect a fire that if not treated may otherwise soon be burning out of control.

2) 4.0 PSA as a universal (age independent) “Red-line” Standard

In particular the use of a blanket standard for the “safe PSA threshold” of 4.0 I object to. The American Cancer Society espouses this (although they at least acknowledge that others used a more refined strategy), and the 4.0 standard was used by IHA, the health care provider that my physician worked for. I never knew there was a debate or consideration for an age differentiated guideline, which is sad, because as I now know, it is widely known that prostate size generally increases with age, and PSA goes up along with it, so I find any metric that does not account for that to be outdated and fundamentally lacking. Given that there has been a lot of push back on the value of PSA testing in general, possibly the use of a simplistic single point standard is based on that, and a feeling that if the test is somewhat unreliable, making it more refined for different ages or ethnicities is not helpful.

But what I do know very well is that in my case, the standard of 4.0 failed me in a spectacular fashion. My PSA rose to 3.6 – 3.8 and stayed there for a number of years, at which time (in hindsight) I obviously had prostate cancer. I got lulled into a false sense of security thinking I had not acceded the “4.0 red-line” yet. Had a standard of 3.5 been used, as I advocate and is used by the University of Michigan (where I am getting my care), I would have crossed the red-line a few years earlier and very likely would have caught the cancer before it spread. The Prostate Cancer Foundation, who’s work I generally respect, does use a graduated standard, but for men in the 50-60 year old group, they jump from 2.5 to 4.0, not the 3.5 level that I strongly recommend. I imagine they have a good reason for that, but I have one very good reason why that level isn’t valid – ME! (PSF – I sure hope you consider a change.)

3) Using an MRI as a primary screening tool vs prostate biopsy for initial diagnosis

This issue screams at me for common sense change. For reasons unclear, England appears to be leading the way in changing their system to switch from using a prostate biopsy as the first confirmation test if there is probably cause based on screening, to an MRI. The common sense benefits of this are so obvious that if they don’t smack you in the face, you are (in my opinion) suffering from denial. A biopsy is highly invasive, very uncomfortable, takes weeks to recover from and does have some degree of risk of infection. I understand that risk is fairly small when good use of antibiotics is properly used – but it’s still a risk that would not be subjected to if the procedure isn’t performed. An MRI is totally non-invasive, and doesn’t leave you urinating blood for days and with bloody ejaculation for weeks. (It’s disgusting - I know from personal experience.) I also know that I didn’t want to have the procedure done based on a marginal risk assessment. (In my case that was my doctors assessment that I had a nodule, but at the same time I had a PSA that was in the safe zone.

By golly, although I did see a urologist, I deferred on getting a biopsy at the time and decided to wait to get a biopsy and the urologist agreed with that. I didn’t even know that an MRI using contrast dye could even be considered for detecting prostate cancer – well by golly it sure can be. Had I been offered the chance to get an MRI vs having a porcupine suck up my ass, I’m pretty well sure I would have agreed to getting the MRI. Had that shown a result that indicated a high probability of cancer, that would almost

certainly convinced me to go ahead and get a biopsy to confirm the MRI finding. Had that test progression been suggested, my cancer would have been caught well before it became stage 4 and spread to my hip bone. What that may mean for my eventual life span I can't say at this point, but my likelihood of a long life and one that is enjoyable with a normal and healthy sex life sure is a lot more uncertain at the moment. Why did that have to be? Damned if I know, and if I sound a bit angry, well, it's because I am.

MRIs are safe and easy, biopsies are painful, risky and humiliating to endure and require weeks of recovery. The American medical community needs to pull its collective head out of its rear and start recommending MRIs as a primary means of testing with the biopsy done second. To whom ever is listening - PLEASE update the standard of care to go in this direction. If the data from the UK isn't convincing enough, know that I would have greatly benefited personally from that recommendation, and many others that don't want to have their colon perforated like a pin cushion when they aren't sure they have cancer will also definitely benefit. This one is a no-brainer in my mind. If someone could explain to me why the biopsy first is the current standard of care other than, that's the way it's always been, I'll give them a gold star and a chocolate chip cookie – but my guess is that I will get to keep all of my cookies to myself! (And I do like a good chocolate chip cookie – who doesn't?)

4) PSMA PET CT/CAT scans

Everyone with any experience with has heard of PSA. (PSA = Prostate Specific Androgen) Most have probably not heard of PSMA. (PSMA = Prostate Specific Membrane Antigen) This is a different antigen to look for in a blood test to get a gauge the level of normal, or abnormal prostate activity. As relatively modern research as discovered, PSMA can be used in conjunction with advanced imaging technology to find localized instances of metastatic prostate cancer at MUCH smaller levels than other types of detection technology, such as a standard bone scan or dye aided MRI. For patients with the metastatic form of this cancer – this can be a life-saving game changer. In fact, the first time I heard of this was when I was talking to a fellow patient in the radiation waiting room. He told me that his doctor planned to use it with him and that it was very likely the difference between life and death for him based on his situation. That got my attention in a hurry.

As of publishing this in 2021, PSMA PET CT/CAT scans are generally still not covered by insurance, or may be just starting to be. (CT = Computerized Tomography; CAT = Computerized Axial Tomography; PET = Positron Emission Tomography) Per the NIH website, a PET scan is a procedure in which a small amount of radioactive glucose (sugar) is injected into a vein, and a scanner is used to make detailed, computerized pictures of areas inside the body where the glucose is taken up. Because cancer cells often take up more glucose than normal cells, the pictures can be used to find cancer cells in the body. Also called positron emission tomography scan.

A bone scan is somewhat similar to a PET scan, in that it uses a radioactive dye that is injected. Per Cancer.com's website: A bone scan is a nuclear medicine test. This means that the procedure uses a very small amount of a radioactive substance, called a tracer.

The tracer is injected into a vein. The tracer is absorbed in different amounts and those areas are highlighted on the scan. When cells and tissues are changing, they absorb more of the tracer. This may indicate the presence of cancer.

To put it in layman's terms, what I was told was that a standard non-PSMA scan might be able to find a tumor the size of a pea, whereas a PSMA PET scan could find a growth the size of the head of a pin, allowing it to be found much sooner, and treated with very specifically targeted radiation (or possibly surgical extraction) and eliminate it before it has a chance to grow and continue to spread. Again, according to the guy I met in at U of M's Rogel Cancer Center's radiation treatment waiting room, for him it was potentially a life saving game changer. So if you are someone that might benefit from this, please read up on this technology and consider requesting it even if it isn't offered, and hopefully more insurance policies will cover the cost of it. (As of 2022, it may be they already are – my info on that was a year or so old based on another friend of mine that has prostate cancer that requested it in mid 2021 and was told it was not yet covered, so this is something that might change soon.)

Conclusion

I hope you have found some value in both my info flyer and with this paper. I've spent a lot of time on it and had a lot of people with their own experience with prostate cancer read it over and provide me with valuable input and editorial commentary. I certainly hope I live long enough to see the standard on MRI vs biopsy change, (that one I find to be particularly egregious) and also a change to an age graduated PSA scale. Hopefully I will, but I do know that medical standards do not change quickly, even at times when it seems like they clearly should – especially something seemingly as simple using MRIs to screen for cancer before scheduling a biopsy. (That one kinda makes me mad (for very personal reasons) as you may have noticed!) Please feel free to contact me via e-mail with questions or comments. I will make every effort to reply to any serious questions.

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(PSMA info added on 1-13-2022)