Considerations re: Prostate Cancer

Last Updated: 19-April-2024
Check for Updates: https://bit.ly/3eBjMjg

- **Good News:** Only 1-in-4 men with elevated PSA levels have prostate cancer!

  - PSA itself is not cancer. It is a protein made by the prostate. Higher values are sometimes (1:4) associated with prostate cancer. If cancer, it could be lethal or non-lethal. Additional tests are necessary. More on this matter, later.

  - Of the 1:4 men that complete treatment, 1:3 will have their prostate cancer return and require additional treatment.

- **Before Every Doctor Visit:** Write down your questions! Write down their answers!

- **TL;DR - The Trajectory of Diagnosis & Treatment:**

  - Limit activities that might spike your PSA test result.
  - PSA test.
  - Digital rectal exam.
  - Ultrasound.
  - Antibiotics to rule-out a prostate infection spiking the PSA test results.
  - PSA test to confirm the first test result.
  - Genetic biomarker test. Typically optional.
  - Multi-parametric MRI. Typically optional, but IMHO should not be optional.
  - Fusion/needle biopsy. The keyword here is “fusion”
  - Laxative. Opiate pain meds cause constipation. Do not strain. Brief mud butt is better than a hernia repair.
  - Pathology report is required before insurance companies will cover any treatment(s).
  - Insurance does not cover all of the available treatments. Contest denials.
  - PSMA-Pet scan to rule-out cancer spreading beyond the prostate. Typically optional.
  - Prehab: Kegel exercises & more are recommended before some treatments.
  - Choose a treatment(s) from among the 13+ alternatives.
  - Laxative. Opiate pain meds cause constipation. Do not strain. Brief mud butt is better than a hernia repair.
  - Discharge instructions, meds and imitations.
  - Rehab: Physical therapy.
  - Counseling: No shame whatsoever in having frank discussions with a PCa-trained therapist. Hint: They have heard it all before.

- **The Half-Life of a PCa Fact is ~Two Years:** The science and treatment of PCa is evolving swiftly. Whatever was “standard” two years ago may indeed have changed. If this document is two years olde, its value is should be considered “diminished.”

- **Support Groups:** There are good groups and bad groups. The two in my area both failed me. They were attended solely by men that perpetually kvetched about their bad experiences. No participants had treatment within the past two years. Both groups were essentially self-licking ice cream cones of anger.

Feedback: kdtsi8u3@duck.com

Considerations re: Prostate Cancer

Last Updated: 19-April-2024
Check for Updates: https://bit.ly/3eBjMjg

- **Early Detection & Intervention …** provides more treatment options, reduces side effects and increases the likelihood of a durable cure. A cure is considered durable when prostate cancer has not returned in five (5) years.

  - Watchful Waiting = **ACTIVE** Surveillance: A legitimate option for some cases, not all cases. It should only be considered after consulting with a urology oncologist. Second (and third) opinions are very important before choosing Watchful Waiting.

  - But Watchful Waiting has consequences. As we get older, the available treatment options decline and the risks of side effects and/or a bad outcome increase.

- **Advocacy - Do NOT be a Sheople!** If you cannot do it, find someone who can. In my case; from the biopsy and diagnosis to robotic surgery was a six (6) month march. I called the surgical schedulers 2x weekly and very politely inquired/reminded them that if there is a cancellation, I am available on very, very short notice. My advocacy reduced my wait by two months.

  It is not (only) who YOU know. Who do your friends know? I reached out to a few pilot/doctor/healthcare friends, asking if they would inquire about moving me forward on the schedule. I was #1 on-call list and received an after-hours call on Friday night asking if I would be available Monday morning. Put me In, Coach!

- **Collect & Manage Your Own Records:**

  - During EVERY visit, ask for hardcopy of everything the doc is reading from a screen. EVERYTHING. EVERY visit. Do not leave without your own hardcopy. Always. Paper, DVD, whatever.

  - Determine specifically who (name, address & tele) has physical possession of your pathology slides. Call the number provided to verify physical custody of your slides.

  - Hospitals do misplace/lose records. The morning of my surgery, the necessary pre-approval letter from my insurance company could not be found. I was able to instantly provide a copy of the missing letter and my surgery was not delayed or rescheduled.

Feedback: kdtsi8u3@duck.com

Considerations re: Prostate Cancer

Last Updated: 19-April-2024
Check for Updates: https://bit.ly/3eBjMjg

- **Second Opinions:** A second opinion is always appropriate. Be concerned if your doctor does not encourage you to seek a second or third opinion and offer to provide a list of alternative specialists.

  - The hospital I chose for my second opinion of my biopsy slides lamented that they could see me in three days, if only my records were not encumbered by the glacial one month bureaucracy of the first hospital. Thankfully, I had all my records and emailed them immediately. But I did not have my actual pathology slides. Getting my slides required five+ hours, driving, waiting and (ahem) reminding them: **HIPAA rules require** healthcare institutions to provide your PHI documents for a reasonable fee, whenever you request them:

    - Info: https://www.hhs.gov/sites/default/files/righttoaccessmemo.pdf
    - Fees: https://bit.ly/39iexQ7

  - **Ask for a Different Pathologist at a Different Institution (re)Grade Your Slides.** Why? Decrease the risk of a false negative report. An acquaintance in Ottawa shared:

    - The first pathology report (done locally) said, "you have cancer, but don't worry. It's not aggressive."

    - The second pathology report (Mayo Clinic) said, "you have a clinically significant cancer that will likely be fatal within two years." The local urologist said, "It's hard to argue with the Mayo Clinic."

    - Mayo Clinic: https://www.mayoclinic.org/medical-professionals/provider-relations/refer-patient
      800-533-1564 & 507-516-0443

    - Johns Hopkins: https://pathology.jhu.edu/patient-care/second-opinions
      410-955-2405 x4

- **Before Every PSA Test** … avoid the activities that can increase PSA results:

  - Sexual activity; yes, this includes masturbation
  - Bicycle/motorcycle/horseback riding
  - Groin injury
  - Digital rectal exam
  - Urinary catheterization or surgery
  - Biopsy
  - Supplements (diet, sports, etc.)
  - Medications (chat with your PCP and uro about Rx and non-Rx meds)
  - Recreational drugs have unknown effects on PSA levels
  - Prostate infection (Prostatitis)

- Other characteristics that increase PSA:

  - Age
  - Heredity
  - Environment
  - Enlarged prostate

Feedback: kdtsi8u3@duck.com

Considerations re: Prostate Cancer

Last Updated: 19-April-2024
Check for Updates: https://bit.ly/3eBjMjg

- **The Typical Trajectory** for investigating elevated PSA levels:

  - **Rule-out** the items above.

  - **Antibiotics;** to rule-out a prostate infection. Prostate infections are hard to kill.

  - **Ultrasound;** to determine if the prostate is enlarged and if there are suspicious lesions on the surface of the prostate. Not all enlarged prostates are malignant. Color Doppler Ultrasound offers a ~15% diagnostic improvement over classic grey-scale ultrasound.

  - **Option: Before agreeing to a biopsy**, consider buying better data. There are several advanced tests available. Urologists' opinions vary regarding the various tests. Nonetheless; they can useful for determining if an elevated PSA is due to a lethal or non-lethal cancer.

    My urologist did not suggest any of these tests. But when I inquired, he was exceptionally supportive and thrilled to have additional data. miR Scientific's Sentinel (urine) test offers significantly improved PPV and NPV with a false negative rate of just 1.7%.

    PPV (positive predictive value): The probability of a positive test result being correct.

    NPV (negative predictive value): The probability of a negative test result being correct.

    Other available tests:

    - Genetic biomarker tests (urine or blood)
    - % Free PSA
    - PSA density
    - 4Kscore
    - Prostate Health Index (PHI)

  - **Insurance:**

    Insurance may not cover some of the tests I have mentioned. Appeal any a denial of coverage. An acquaintance in LA could not find an in-network Medicare Advantage provider that would cover these; or even order these tests if he paid cash. He had to change to standard Medicare to gain coverage for a genetic biomarker test and mpMRI guided, fusion biopsy.

Feedback: kdtsi8u3@duck.com

Considerations re: Prostate Cancer

Last Updated: 19-April-2024
Check for Updates: https://bit.ly/3eBjMjg

- **Option: Before the biopsy**, consider a 3-Tesla mpMRI with ERC (better than a standard MRI) to locate suspicious areas that the biopsy can target. mpMRI results for prostate screening are also operator dependent. It is better to visit a facility that does a lot of prostate scans using 3-Tesla mpMRI equipment. If 3-Tesla mpMRI w/ERC is unavailable, perhaps consider Color Doppler Ultrasound. AKA: CDUS or CDI. Insure that you get your own CD/DVD of the images. My urologist loved having this additional information.

  - **Important:** MRI's are blind to small cancer lesions (< ~17 million malignant cells).

  - More: https://bit.ly/2voGBCu

  - **Mandatory: Before the biopsy** please insure that the following "life" documents are up to date and available to whoever you designate: https://www.nia.nih.gov/health/getting-your-affairs-order

  - **Biopsy:** Typically harvests 12 cores. A pathologist will assign a Gleason score or Group Grade score.

    - Info: https://wb.md/39Ys0MM
    - FAQ: https://wb.md/2TlCKyn
    - A biopsy may spill malignant cells into the body: https://bit.ly/2Tnlybr

Gleason Score	=	Group Grade
<= 6	=	1
3+4=7	=	2
4+3=7	=	3
8	=	4
9-10	=	5

- **Without a MRI or mpMRI,** a urologist does a TRUS biopsy: Imagine a blind man using a bar straw, poking a loaf of raisin bread, trying to find raisins. Maybe he finds the raisins. Maybe.

- **During a Fusion Biopsy**, the (static) mpMRI image is fused (overlaid) with the live ultrasound video to guide the needle to the lesions that were large enough to be imaged.

  - More: https://bit.ly/384kKO3

- **Prostate Infections suck** and are difficult to kill. ~15% of (classic) transrectal biopsies result in complications; and, 3-4% will require hospitalization within 30 days. Transperineal biopsies are an olde technique that Cleveland Clinic is again recommending as it reduces the risk of infection and improves the ability to more fully sample the prostate. More: https://cle.clinic/3MP7HEF

Feedback: kdtsi8u3@duck.com

Considerations re: Prostate Cancer

Last Updated: 19-April-2024
Check for Updates: https://bit.ly/3eBjMjg

- **Before Selecting a Treatment,** it is possible to determine if the cancer has spread elsewhere in the body, typically the lymph, bones or brain. Seven+ years of data from Australia determined that ~55% of the time, PSMA-PET will indeed change the initial treatment recommendation.

  Unlike Australia, USA urologists typically withhold PSMA-PET testing until cancer returns. Had it been available me, I would have gladly paid $3,000 to determine up-front, if the cancer had already spread elsewhere. Insurance coverage for this test varies regionally. Appeal any denial of coverage – appeals are yet more work for your Doc.

  - https://nycancer.com/news/psma-pet-ct-scan-improves-prostate-cancer
  - https://youtu.be/DNCHBVMjhtU
  - https://nyti.ms/3leve5F
  - https://bit.ly/3l8ViPy

- **There Is No Single "Best" Treatment:** Everyone has a different frame of reference. My best treatment; is **probably not,** your best treatment:

  - https://www.prostate-cancer.com/index.html
  - https://www.cancer.org/cancer/prostate-cancer.html

- **Whole-Prostate Treatment vs. Focal (Precision) Treatment:**

  - Focal (precision) treatments promise a lower risk of side effects. But focal treatments can only treat what the MRI can see. Cancer lesions that are below the MRI's detection threshold go untreated … and an increased risk of cancer returning.

  - Whole-prostate treatments may increase the risk of some side effects, but residual cancer is unlikely to escape treatment.

- **Treatments Not Mentioned on the Next Page:** Verify insurance coverage in-writing!

  - Focal Laser Ablation: https://bit.ly/2IdvLlG
  - Aqua Ablation: https://pubmed.ncbi.nlm.nih.gov/31481145/
  - TUSLA-PRO (ultrasound): https://bit.ly/3eyauof
  - Cyber Knife https://cyberknife.com
  - Pluvicto (177Lu-PSMA-617): https://bit.ly/39kLtgd (Expensive!)
  - Focal Cryo Ablation: https://bit.ly/3TxmeLG

- **What-If Cancer Returns?**

  - 1:3 men treated for prostate cancer will have their cancer recur. Typically it is residual cancer cells that the first treatment missed, which is why I am a fan of PSMA-PET testing before selecting the initial treatment - finding ALL the cancer before the choosing an initial treatment.

  - After the initial treatment; consider a Vitamin D3 supplements: https://bit.ly/41UrvPe

  - If your first treatment results in scar tissue, (salvage) surgery is seldom an option. If it is possible, it is considerably more complicated, the risk of side effects increase and the likelihood of a durable cure is diminished.

Feedback: kdtsi8u3@duck.com

Considerations re: Prostate Cancer

Last Updated: 19-April-2024
Check for Updates: https://bit.ly/3eBjMjg

■ Anatomy and Physiology:

- This video focuses on surgery, but the general anatomy and physiology aspects also apply to alternative treatments. E.g. SpaceOAR radiation block to protect the rectum: https://youtu.be/EjMvDN7q5Zs

■ Why Travel For Treatment?

- Not all treatments are available everywhere. Specialized alternatives include: Proton Beam, High-Frequency Ultrasound (HIFU), TUSLA-PRO (ultrasound), Focal Laser Ablation, Aqua Ablation, Focal Cryo Ablation and Pluvicto are only available at a few medical centers. Insurance coverage should be verified in-writing.

- An acquaintance traveled home by airline from Baltimore to Oklahoma City two days after robotic surgery, with the catheter in-place. He was very happy to be home, but it was not a great travel experience.

- Pro Tip: Use **TSA Cares** to minimize the possible public humiliation of security screening. I have used it. It was a terrific experience!
https://www.tsa.gov/travel/passenger-support

Feedback: kdtsi8u3@duck.com

Considerations re: Prostate Cancer

Last Updated: 19-April-2024
Check for Updates: https://bit.ly/3eBjMjg

■ **All Treatments Have Potential Side Effects**:

- **Minimizing Side Effects:** Experience matters. It matters a lot. Ask the urologists for their track records. Ask if they take everyone referred to them? Do they take the complicated/salvage cases? Dr. Ted Schaeffer (Northwestern University Hospital, Urology Dept. Chairman) says that any urologist claiming 0% or 100% is lying.

- **Two Big Elephants** in the room are incontinence (urine and fecal) and erectile dysfunction. Again; experience matters a lot. FWIW; I chose robotic surgery. My surgeon's stats over 2,770+ robotic surgeries:

  - 95% of patients dry within six (6) months.
  - 97% of patients dry within nine (9) months.
  - 98% of patients dry within twelve (12) months.
  - 95% of 60 YO patients have some sexual function is restored within twelve months.

  Let me be clear: I am not championing robotic surgery - but it was MY best option and even recommended by the Proton Beam radiologist. You must make your own decision.

  - Surgery has an increased risk of urine leakage, but it tends to improve over time.

  - Radiation treatment has an increased risk of fecal leakage and tends to get worse over time.

  - Does the treatment result in scar tissue? Should cancer return, scar tissue may significantly complicate future treatment alternatives and side effects.

  - See the treatments and side effects on Page 7.

  - Ask questions! Take notes!

- **Infection Control; ERAS = Enhanced Recovery After Surgery**: Numerous research reports document that ERAS practices result in fewer infections. ERAS starts at-home, before surgery and continues in the hospital and thru recovery at home. While ERAS is mainstream in Western Europe, few USA hospitals have (yet) adopted ERAS. I asked my urologist to write a medical order for ERAS-like care while I was hospitalized and he indulged my request:

  - https://bit.ly/2Pz3iem
  - https://bit.ly/2TgYhrO

Feedback: kdtsi8u3@duck.com

Considerations re: Prostate Cancer

Last Updated: 19-April-2024
Check for Updates: https://bit.ly/3eBjMjg

- **The Tenor Sings Tenor:** Surgeons, cut. Radiologists, radiate. Talk with multiple urologists, preferably with different institutions, to insure that you get perspective that is not biased by "that's how we always do it here." Otherwise …

  - If your PCP refers you to a surgeon, a single specific surgery will likely be offered. There are at least three surgery alternatives. Interview multiple surgeons and discuss the risks and alternatives in detail.

  - If your PCP refers you to a radiologist, a single specific radiation therapy will likely be offered. Each radiologist seems to have one favorite therapy from the many available alternatives (3D-CRT, IMRT, IGRT, VMAT, SBRT, Cyber Knife, Proton Beam, etc) that vary from 3 days to 90 days of treatment. Interview multiple radiologists.

  - Specialty (boutique?) treatments that are available at only several places worldwide. These can be quite expensive and insurance coverage is unlikely.

  - If your PCP sends you to a <Insert Specialty Here> … you get the idea, eh?

- **Do Not Be Bullied:** Beware of hyperbole and outright disparagement that is intended to manipulate:

  - One surgeon told me, "If you do not choose surgery, you are clinically insane."

  - A VA urologist told a friend that dared to ask for a 2nd opinion referral, "If you get a second opinion, don't come back."

  - A radiologist working at a facility offering (only) External Beam, ridiculed a friend considering Proton Beam, advising that those seeking Proton Beam are members of a science denying cult. A few years later the same radiologist was working at a Proton Beam center and ridiculing what he was previously recommending.

  - If you find it unpleasant or difficult to insist on getting complete and satisfactory answers to ALL of your questions:

    - Consider delegating to a Type-A personality that will advocate for you.

    - Consider a new doctor. Thoughtful, informative discussion is a reasonable expectation.

Feedback: kdtsi8u3@duck.com

Considerations re: Prostate Cancer

Last Updated: 19-April-2024
Check for Updates: https://bit.ly/3eBjMjg

- **Why I Chose a Teaching/Research Hospital:**

  - Residents are indeed "real" docs. They have completed med school. They will likely be in year four or five of their 5-year urology oncology residency.

  - Abdominal anatomy is surprisingly variable. Especially so, deep down in the abdomen where the prostate is located. I wanted a unified team with zero hierarchical barriers to effective communication. I found an experienced leader unafraid of peer review, and he included me in the group discussion where the big brains discussed: Me, What, When, How, Why and the What-If's: https://youtu.be/hW7LGxCLauo

- **My Frustrations:**

  - The first hospital could not satisfactorily communicate any plan or trajectory whatsoever. After completing a procedure, I would be told to expect a call sometime in the next week about a mystery next-step. Invariably; I would learn that each next-step was 2-5 weeks in the future. I asked for a plan/outline/trajectory and they could not provide one.

    The second hospital, during my first visit, provided a folder with a proposed schedule for my next 12 months: Appointment dates & times, 2nd opinions, names, buildings, rooms, maps and parking info.

  - Having to answer all the damn robo-calls because I did not want to risk missing a medical call. Pro Tip: www.1-voip.com has terrific features to defeat robo-callers.

- **Catheter:** An inconvenience, not the horror that I anticipated. Only a few brief moments of self-inflicted unpleasantness. For the first 3-4 days I moved very deliberately as I was figuring it out. I was told that it would stay in-place for ten (10) days, but it was removed on day seven. I was "dry" two days later – a spectacular outcome.

Feedback: kdtsi8u3@duck.com

Considerations re: Prostate Cancer

Last Updated: 19-April-2024
Check for Updates: https://bit.ly/3eBjMjg

■ Meds & Supplies:

- I was sent home with:
  - Antibiotics
  - Rx for narcotic pain meds (typically cause significant constipation).
  - Laxative; zero abdominal straining allowed. Better to endure mud butt that require a hernia or hemorrhoid repair
  - Catheter bags
  - Tape, gauze and dressings
  - Rx for Viagra; promotes blood flow and nerve recovery

- Meds & supplies you should buy:
  - Extra-Strength Tylenol; only used for a few days
  - Bacitracin ointment or Neosporin w/lidocaine; used several times each day
  - Urine pads for bed and chairs
  - Urine/bladder pads or adult diapers
  - Butt wipes
  - Very loose clothing – sweats, etc.
  - Bard Statlock Foley Stabilizers; Qty 2-3. Amazon: https://amzn.to/2VKpu8d
  - Fresh batteries for the TV remote
  - Long charging cord for the phone and tablet

■ Exercises:

- Pre-Surgery:
  - Kegels: https://wb.md/2I2U31X
  - Pelvic floor: https://www.wikihow.fitness/Do-Pelvic-Floor-Exercises
  - Walking @ target heart rate for 30+ minutes per day: https://mayocl.in/2Pmcr9T
  - Tip: Use your smartphone calendar/reminder app to insure that you do your exercises on-time, every day.

- Post-Surgery; after catheter removal:
  - Do not (re)start exercises until approved by your doctor
  - Kegels: https://wb.md/2I2U31X
  - Pelvic floor: https://www.wikihow.fitness/Do-Pelvic-Floor-Exercises
  - Walk at a comfortable pace without exertion
  - My lift limit was one gallon of milk. Do not strain.

Feedback: kdtsi8u3@duck.com

Considerations re: Prostate Cancer

Last Updated: 19-April-2024
Check for Updates: https://bit.ly/3eBjMjg

■ Other Resources:

Title: Guide to Surviving Prostate Cancer
4th Edition is current as of February 2020
Author: Patrick C. Walsh, MD
Amazon: https://amzn.to/3cjbLfw

Title: Five vital documents that you should have: https://bit.ly/2vmTcWY

Support Groups: This link anonymizes a Google search: https://bit.ly/396yBVj

■ General Thoughts & Reminders:

- Surgery traumatizes the urinary/genital systems once; the day of surgery. There is a reasonable expectation for a return urinary and sexual normalcy over time. Experience matters. It matters a lot … because abdominal anatomy can vary significantly and the prostate is deep in the abdomen among many vital organs.

- Radiation; whether X-ray, Proton or another alternative, creates cumulative trauma. Function may continue to decline for months before rebounding. There are very different mechanisms are at work. Rectal/fecal incontinence tends to get worse over time.

- If disease recurs after radiation or ablation therapy, salvage surgery is unlikely to be an option.

- Both the biopsy and surgery risk inadvertently spilling malignant cells into the body, allowing the cancer to spread elsewhere.

- Surgery was certainly a discomfort, but not painful. No regrets.

- Attitude: On every visit, I worked to be the best, on-time, friendliest, up-beat, disciplined and attentive patient. Don't be a Grump – if favors are being granted, Grumps don't get favors.

■ **Acknowledgements:** Thank you for your encouragement and sharing your experience.

- Artee
- David & David
- David & David
- George
- Jim, Jim & Jim
- John
- Luc
- Michael
- Phil
- Randy
- Ron
- Scott
- Walter
- Ward

Feedback: kdtsi8u3@duck.com