The Manitoba Prostate Cancer Support Group NEWSLETTER

Vol. 229 – July 2010

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Thought For Today

We know the speed of light but what is the speed of dark?

- Norm Oman

Medical Advisors to The Manitoba Prostate Cancer Support Group

=> Paul Daeninck M.D.
Pain Management

=> Darryl Drachenberg M.D. Urologist

=> Graham Glezerson M.D. Urologist

=> Ross MacMahon M.D. Urologist

=> John Milner M.D. Urologist

=> Jeff Sisler M.D.
Family Practitioner

=> Gary Schroeder M.D.
Radiation Oncologist

Thanks!

NEXT MEETING:

Thursday, July 15th, 2010 7 - 9 P.M.

"Sharing and Snacks"

Location: AUDITORIUM of the Seven Oaks General Hospital - Leila & McPhillips

SHARING IS CARING

The Manitoba Prostate Cancer Support Group encourages wives, loved ones, and friends to attend all meetings.

Feel free to ask basic or personal questions without fear of embarrassment. You need not give out your name or other personal information.

The Manitoba Prostate Cancer Support Group does not recommend treatment modalities, medications, or physicians. All information is however freely shared.

Special Thanks

Sanofi Aventis, manufacturer of Eligard and Taxotere, has recently given our Support Group a generous donation. We are grateful that they have chosen to assist our work. *Their kindness is much appreciated.*

sanofi aventis
Because health matters

Many thanks to Eli Lilly Canada Inc.

for their generous donation to our Prostate Cancer Support Group. Lilly manufactures Cialis - a drug used to treat erectile dysfunction. Their donation, along with those from individual members, makes the running of our Support Group possible. Their kindness is much appreciated.

Lilly

Newsletter Sponsorship

Many thanks to the Winnipeg Foundation for sponsoring this issue of our newsletter.

THE WINNIPEG FOUNDATION

The Foundation was formed in 1921 and has been supporting non-profit organizations in our city since that time.

We are grateful that they have chosen to assist us with our newsletter expenses.

Choosing— And Sticking With— Active Surveillance: A Patient's Story

****Please note that this is part three of a patient's prostate cancer journey – the final segment****

So if your PSA suddenly jumped to 10 ng/dl, would you opt for treatment? Or would you want to see changes in multiple factors before changing course?

Well, the first thing I would do is get another PSA test. PSA can change for reasons other than prostate cancer. But if my PSA moved from 5 to 10 ng/dl within one or two years, it would be a huge red flag that the cancer was advancing. I'd also look at recent biopsy results. Most importantly, did the Gleason score go up? Or has cancer been found in three or more cores? Is cancer in 50% or more of any core? Those would all be indications that the tumor is growing. If I move significantly out from under the umbrella of the generally accepted criteria for active surveillance, I will go ahead with treatment. [See "Guidelines for intervention," .]

(Continued on page 3)

WE REALLY APPRECIATE YOUR SUPPORT

The Manitoba Prostate Cancer Support Group operates on your donations

Have you used any of our services?

Newsletter - General Meetings - Hospital visits - One-on-one visits - Speakers

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Guidelines for intervention

The same Toronto researchers who established active surveillance criteria recommend suspending active surveillance if one of the following happens:

- **The patient's PSA doubles in less than three years (from 4 ng/dl to 8 ng/dl, for example).**
- **The patient's Gleason score rises to 7 (4 + 3) or more after a repeat biopsy.**

Some doctors suggest treatment if any component of the Gleason score is a 4 (for example, a 3 + 4) or if significant changes are noted during a DRE.

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Given all of the potential treatments, which one would you choose?

I haven't made that decision yet. I will cross that bridge when I have to.

Treatment definitely makes sense if you don't fit the active surveillance criteria, but the techniques and technologies are improving very, very fast. For example, surgeons are getting more experienced with the da Vinci robot, so robotic surgery may not have some of the disadvantages of traditional surgery. Radiation techniques are evolving very fast. One of the patients I consulted has undergone treatment with CyberKnife, which is a new technology. It's too early to tell, but this technology might have a lot of advantages over other types of radiation therapy. And improvements in imaging technology are making the placement of radioactive seeds more accurate.

Several centers are getting more experienced with high-intensity focused ultrasound [HIFU] and cryotherapy. These technologies are still experimental, but researchers are doing clinical trials in the hope that these technologies will gain FDA approval in a couple of years.

Right now, I'm just trying to buy time. Every year that I don't have to deal with the side effects of a treatment is a year that I've won. Perhaps if I'm lucky, by the time I have to choose a treatment, one will have proven to be clearly superior, and my choice will be easier.

How do you keep up to date on all of the technological advances? Do you still read everything you can find?

I've gotten over my obsession with reading dozens of scientific papers each month, because I now feel I have a strong knowledge base. I concentrate on just a few select things, such as understanding the improvements in HIFU and following what happens with CyberKnife and other radiation therapies. I'm also focusing on improvements in robotic surgery. One of the challenges there is to reduce side effects like urinary incontinence.

What advice would you give to readers in a situation like yours who don't have the time or resources to study prostate cancer to the extent you did?

I would strongly advise people not to make any decisions while they feel panicked or depressed because the decision is likely to be wrong. You want to make a decision after you have calmed down and accepted the fact that you have this disease and that you are not alone. If you are diagnosed with early-stage disease, you have time to make a decision.
Next, I would recommend consulting with at least three physicians: a urologist, an oncologist, and a radiation oncologist. If you are seriously considering surgery, talk with both a robotic surgeon and a traditional surgeon. Do not be afraid to get a referral to another specialist for a second opinion, even if the first opinion is from a top surgeon. Talk to someone from a different institution. When we're patients, we're all reluctant to ask for a second opinion. You just have to get over that. That's part of doing your due diligence.
I would also recommend reading a couple of the major books on the subject because they'll give you good background. But keep in mind that most of them have been written by prominent surgeons and are biased in favor of surgery. There are good Internet sites, too. I'd recommend the National Cancer Institute's site, www.cancer.gov. And, of course, you should immediately subscribe to Perspectives on Prostate Disease or another major publication aimed at patients.

If you could direct prostate cancer research, where you would place the most emphasis?

I think the biggest challenge is to find a way to differentiate indolent prostate cancer and aggressive prostate cancer. It's critical for patients; they need to make informed treatment decisions. It's also critical for the health care system in general. The cost of treating people who don't really need it has to be extremely high. In the long term, I think we need to better understand what causes prostate cancer. Ultimately, that might help us prevent it.

Any final comments?

I'm in good health. I'm very fit. I exercise two to three hours a day, and have done that all my life. My parents lived to be 94 and 100 years old. I thought that I was pretty much indestructible. So, this diagnosis changed my life. I became much more aware of my own mortality.

I slowed down after the diagnosis. I was already retired, but I disengaged from many commitments that involved lots of meetings or a great deal of time. I wanted to have more control of my own time. I started to eliminate the activities in my life that I didn't find fun or that were frustrating. I have a much higher appreciation of time as a resource — and that it's vanishing faster than I once thought. I feel fortunate that my condition isn't worse, and I'm reasonably optimistic that I can achieve a good outcome.

Date published: January, 2009 www.harvardprostateknowledge.org

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PROSTATE BIOPSY: PAIN OR NO PAIN

The following article is taken from a collection of essays by Henry Morgenstein. (essays.henryandjacqui.com)

Before you read my article, here is my conclusion: If you must undergo a Prostate biopsy, "There is no reason for pain in a modern, well equipped room."

You will not find this advice on the internet. What you will find are painful words describing the procedure: A little like being "sodomized with a knitting needle." "Sometimes the pain is so severe that the men jump off the table." "A dozen needles" are inserted where the sun don't shine" Those dozen needles pluck fifteen separate samples from your prostrate because five separate samples were found to be not enough to be sure.

One doctors answers the question "Does it hurt?" with the words, "It is painful…local anesthesia is useless…it hurts."

The title of another, lengthy article, seems to offer relief: "What causes Men Pain in Prostrate Biopsy and Best Method To Alleviate it." The articles lists three kinds of pain relief, One, injection between prostrate base & seminal… Two, Intrapostatic injection… Three, injection… Good grief: pain relief in the form of an injection which the article admits "caused more pain."

Relieve pain by causing more pain! And after all this pain & more pain, the writer of this article says "pain…may never be completely overcome by anesthetic."

I disagree strongly. When it comes to a Prostate biopsy, "There is no reason for pain in a modern well equipped room." Do not accept anything less than the kind of sedation all men receive during a colonoscopy - you are awake during the procedure but you will remember nothing. Ask for it. Demand it!

My story - which took place in America.

There was a clear need for a prostrate biopsy -- two separate readings, eight months apart, revealed a sharp rise in PSA levels. Coincidentally, it was time for a colonoscopy. Good. I asked them to do the two together. My last colonoscopy involved no pain, no memory, no nothing. I'm all for that.
No, we can't do it, they said to me, the two can't be done at the same time, they said to me. Lots of excuses: you need to be awake, we need to talk to you, you need to be moved….blah, blah, blah… Essentially, the answer was no way Jose, and you can do nothing about it because we make the rules.

(Much, much later I found out that it was a "scheduling" problem… the equipment is in two different rooms…. When each procedure can bring the hospital almost fifteen hundred dollars, what incentive does the hospital have to combine procedures? They will always choose to double their income - and double your fun.)

I hate pain. I am a devout coward, and I let every medical person I encountered (doctors, nurses…) know my feelings, my fears. Sorry, they all said silently. Pain is part of the procedure, they all let me know. "Take it like a man" was the unstated sub-text of all communication with me. (An article, by a doctor, in a medical journal, even said that doctors know the procedure is painful, but they believe we should "take it like a man.")

I voiced my fears so often that finally, over the phone, the nurse who phoned from the hospital to "take my details" suggested I ask my doctor for an "anti anxiety" pill. I did. He prescribed it, I took it, and showed up on a Monday morning at the appropriate room in the hospital, still out of my mind nervous.

I continued to let all & sundry know how afraid I was, how I wish I could be sedated, how I wish I were elsewhere.

After about five minutes into my by-now-well-rehearsed litany of fears, the nurse prepping me for the doctor who was about to perform the procedure said: "Well we could sedate you. It would be less painful. You would be more comfortable." I said, "You can sedate me?" She said, yes, but we would have to re-schedule your appointment. "That's okay with me" I almost yelled gleefully. Reschedule me, and why wasn't I offered the sedation option before?

She couldn't answer that. No one answered that. I wonder, still wonder, why I wasn't offered sedation by my doctor, or by one of the almost half dozen nurses who heard me voice my fears. The best I was offered was a prescription for anti anxiety pills.

Anti anxiety pills? That is nowhere near enough. I want to be unconscious, not there, not able to remember. I want to be in another universe - and when you are finished, invite back into this universe.

My Prostrate Biopsy was rescheduled. I was given the very same kind of intravenous feed I had received just three weeks earlier for my colonoscopy, but I was told it was a lower dosage.

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While I was in the recovery room, the nurse told my wife why the sedation option was suddenly being offered at this hospital. It seems that recently a Radiologist at the hospital had a Prostrate Biopsy. After the biopsy he said "Okay, that's it. No more. We will offer sedation. I know how painful this procedure is. We have solutions. If someone asks for it, we should offer sedation."

If someone asks for it! If someone asks for it!!

All men everywhere should demand sedation during a Prostate Biopsy. Accept no less. Demand sedation - unless you like knitting needles being inserted where the sun don't shine - and 15 samples (or more!) being extracted by a circle of eleven needles, from a place that does not usually have needles pricking it & poking it.

I think what makes me most furious is that in this day & age of instantaneous information available on the internet, the "sedation" option for a Prostrate biopsy is almost not there.

Almost not there? Far into one article the writer says, in a very vague way, "general anesthesia helps….but your insurance company might refuse to pay." Saying "general anesthesia helps" sounds like saying that an aspirin might help a headache. No, no, no. General anesthesia obliterates all pain at time of contact (later you will feel some soreness). General anesthesia doesn't just help, it annihilates all memory of the pain.

In Modern Times there should be an addition to the Doctor's Motto: "If at all possible, inflict no pain," should be added to "Above all do no harm."

I really am furious at the state of affairs. Everyone needs to know that in the case of a Prostate biopsy (a very-very common procedure for older men), "There is no reason for pain in a modern, well equipped room."

The situation, on the internet in England & Ireland, is even worse. I could not believe the words I read in almost the first article that popped up in Yahoo UK/Ireland: "By some accounts, a prostate biopsy hurts - but not as much as you might think." Liar. Complete liar. Many, many doctors (and others) have admitted it is painful, and recent research reveals that certain areas of the prostate are more sensitive to the extraction of a "pound of flesh" than other areas. "Some doctors will take as many as 45 samples." Oh my God. Forty five samples, and he has the gall to say, it hurts, but not as much as you might think.

The tone of this article makes me foam at the mouth: " A prostate biopsy is a simple procedure…takes about 15 minutes…does not require any anesthesia." It takes all my will power not to say, "Up yours 45 times with a knitting needle."

On the internet in England, I find no mention of the use of any sedation or anesthesia. They want you to keep a stiff upper lip.

Maybe there are benefits to living in America. Please sing this lovely song along with me: "There is no reason…"

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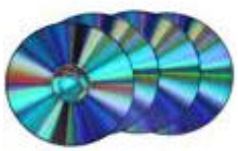

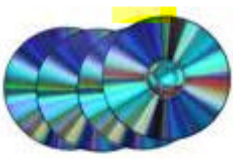

Prostate Biopsy and the Gleason Score: What You Should Know

By Peter Jaret WebMD Feature
Reviewed by Brunilda Nazario, MD

A biopsy is used to detect the presence of cancer cells in the prostate and to evaluate how aggressive cancer is likely to be. Thanks to an array of biopsy techniques and new tools to interpret the results, doctors are better able to predict when cancers are slow-growing and when they're likely to be aggressive. That information, in turn, can help you and your doctor choose the best course of treatment.

Before having a prostate biopsy performed, most men have undergone other tests for prostate cancer. PSA tests, for example, measure a substance called prostate-specific antigen in the bloodstream. Abnormally high levels may signal the presence of cancer. Because PSA levels are higher in men with larger prostate glands, doctors also use a test called PSA density, which relates PSA level to the size of the gland. A digital rectal exam, in which the doctor inserts a gloved lubricated finger into the rectum, is used to detect unusual bumps or hard areas on the prostate that might be cancer. If these tests raise concern, the next step is a prostate biopsy.

How a biopsy is performed

The goal of a biopsy is to remove small samples of prostate tissue so that it can be examined under a microscope for signs of cancer. In the most commonly performed procedure, a needle is inserted through the wall of the rectum into the prostate gland, where it removes a small cylinder of tissue.

The biopsy needle can also be inserted through the skin between the rectum and the scrotum, an area called the perineum. In order to sample tissue throughout the gland, 12 or more core samples are typically removed from different parts of the prostate. To guide the procedure, doctors view an ultrasound image of the gland on a video screen as they manipulate the needle.

Most biopsies are performed in an urologist's office. The procedure, which only takes about 15 minutes, may cause some discomfort but not serious pain. Your doctor may prescribe an antibiotic medicine to take one day before and a few days after the procedure. You may experience a little soreness afterward, and you may notice blood in your urine or semen for a few weeks.

Deciphering the Results

Biopsied tissue is sent to a laboratory, where a pathologist views the cells under a microscope. When healthy cells become cancerous, their appearance begins to change. The more altered the cells look, the more dangerous the cancer is likely to be.

The results from a prostate biopsy are usually given in the form of the Gleason score. On the simplest level, this scoring system assigns a number from 2 to 10 to describe how abnormal the cells appear under a microscope. A score of 2 to 4 means the cells still look very much like normal cells and pose little danger of spreading quickly. A score of 8 to 10 indicates that the cells have very few features of a normal cell and are likely to be aggressive. A score of 5 to 7 indicates intermediate risk.

A careful, detailed look at the biopsy results gives your doctor an even more precise picture of what's happening in your prostate, says Michael Morris, MD, an oncologist at Memorial Sloan-Kettering Cancer Center in New York. For each biopsy sample, pathologists examine the most common tumor pattern and the second most common pattern. Each is given a grade of 1 to 5. These grades are then combined to create the Gleason score. For example, if the most common tumor pattern is grade 2, and the next most common tumor pattern is grade 3, the Gleason score is 2 plus 3, or 5. Because the first number represents the majority of abnormal cells in the biopsy sample, a 3 + 4 is considered less aggressive than a 4 + 3. Combined scores of 8 or higher are the most aggressive cancers. Those under 6 have a better prognosis.

It's important to remember that the Gleason score is assigned by a pathologist viewing cells under a microscope. Although the grading system has been shown to be reliable, it is not perfect. It depends on the skill of the pathologist observing the cells. For that reason, doctors may sometimes order a follow-up biopsy if they have any doubts or questions about the results.

Understanding the Gleason Score

The Gleason score is only one piece of information that you and your doctor will use. Biopsy reports also typically include the number of biopsy core samples that contain cancer, the percentage of cancer in each of the cores, and whether the cancer occurs on one side or both sides of the prostate. The farther the cancer has spread, the more risk it poses. Researchers have developed a number of different tools that help doctors come up with the best prediction of the aggressiveness of the cancer they found.

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"Prostate cancer is really a spectrum of diseases," says Howard I. Scher, MD, chief of genitourinary oncology at Memorial Sloan-Kettering Cancer Center. "The type of tumor, the Gleason grade, and the extent of the disease varies widely among patients." Along with biopsy results, your doctor will weigh the results from your PSA test, a digital rectal exam, and perhaps images from ultrasound or CAT scans.

To make sense of so many variables, doctors use a staging system, based on how much cancer is present and how far it has spread. Stage I, also called T1, describes when tumor cells are found in less than 5% of prostate tissue and the cells are low-grade. Stage II (T2) describes more extensive or more aggressive cells that are confined to the prostate. In stage III, or T3, the tumor has grown through the capsule that contains the prostate. In Stage IV (T4), the cancer has spread beyond the prostate to other organs.

Follow-up Tests

Whatever treatment approach you ultimately choose -- whether surgery, radiation, or watchful waiting -- your doctor will recommend follow-up tests, including repeated PSA tests and biopsies. These are used to detect signs that the cancer has returned or progressed. The longer you go with no sign of a change, the less frequently you will need follow-up tests.

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Question: What advice can you give on using Viagra and similar type drugs for erectile dysfunction, after prostate cancer treatment?

Answer: Greg Harochaw is a Winnipeg pharmacist specializing in erectile dysfunction, pain and palliative care. He is contacted by many for his expertise in the area of compounding medicine. Mr. Harochaw has been a guest speaker at the Manitoba Prostate Cancer Support Group meetings in the past.

The topic of using PDE5 inhibitors (PDE5i) to recover sexual function after prostate cancer treatment is an important one. Within 6 months of surgery, 85% of men with a prostatectomy do not respond to PDE5i, due to nerve trauma. However, they have an excellent chance of becoming a responder after 18 – 24 months. Inversely, men who received radiation treatment usually can produce erections during the 1st year after treatment. They may start developing problems 2 – 4 years later and may find that PDE5i do not work very well, due to nerves being damaged by the radiation.

There are currently 3 PDE5i on the market; sildenafil (Viagra®), vardenafil (Levitra®) and tadalafil (Cialis®). Men should start with the maximum strength, as research shows that 44% of people use a sub-optimal dose, which leads to failure. Hellstrom et al. conducted a study in 2004 and determined that the maximum chance for using sildenafil 100mg is between 6-8 attempts, whereas vardenafil 10mg and tadalafil 20mg was between 3-8 attempts. Lastly, sometimes taking a PED5i on a once-a-day dosing may lead to a response in males, who were unresponsive when taking the same medication as a on-demand dose.

Taking PDE5i with or without food can play an important role. While tadalafil is unaffected by food, sildenafil and vardenafil need to be taken on an empty stomach. If these two medications are taken after a meal which has a high presence of fatty foods, this can reduce the dose anywhere from 20 -50%, thus resulting in a 32% chance of failure. Also, the fatty food content doubles the time that the medication takes to be absorbed, from 1 hour to 2 hours. In the case of people who are diabetics, stomach emptying time is even more delayed, so it is important to take sildenafil and vardenafil before meals.

Insufficient time of taking the PDE5i before sexual intercourse resulted in a 22% failure. Sildenafil and vardenafil should be taken at least 1 hour before sexual activity on an empty stomach. For 1st time users of tadalafil, it may be necessary to try this medication 4 hours prior to activity, as it may take 2 – 4 hours to take effect.

Men experiencing inadequate sexual stimulation accounted for 12% of the failures. It is important not to "rush" and allow for proper stimulation. Men with low testosterone levels have a 25 – 33% chance of failure and thus may also have to take a testosterone supplementation.

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All calls are kept confidential

2010 MEETINGS:

Jan. 21.....Dr. Anne Katz, Clinical Nurse Specialist
"Sexual Relationships Following Prostate Cancer"

Feb.18.....Dr. Aldrich Ong, Radiation Oncologist
" Radiation and Chemotherapy for Prostate Cancer"

Mar.18.....Dr. Piotr Czaykowski, Medical Oncologist
"New Developments in Drug Treatment"

April 15.....Dr. Graham Glezerson, Urologist
"Treating Erectile Dysfunction After Prostate Cancer - The Hard Facts"

May 20.....Dr. Spencer Gibson,
Provincial Director, Research, Cancercare MB.
"Research at Cancercare Tumour Bank"

June 17.....Nursing Staff from the Prostate Centre, Cancercare MB
"What Happens at the Manitoba Prostate Centre"

July 15.....TBA

Aug. 19.....Dr. Paul Daeninck,
Pain Management Specialist
"Insights into Pain Management"

Sept. 16.....Dr. Robert Wightman, Pathologist
"Understanding Your Biopsy Report"

Oct. 21.....Katherine Gottzmann, Psychosocial Oncology

Nov. 18.....Dr. Aziz Mhanni, Medical Geneticist.

Dec. 16.....Potluck Party Time

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