

In The

Know

Confronting
Prostate
Cancer

MAY 2010



Evidence Concludes More Rapid Prostate Cancer Growth Rate And/Or Earlier Transformation From Latent To Aggressive Prostate Cancer In Black Men

by Virgil H. Simons

We have heard consistently that African-American men (AAM) bear a much greater prostate cancer (PCa) burden than white men (EAM). Between 1997 and 2001, age-adjusted incidence and mortality rates among Black men are, respectively, 62% and 144% higher than among white men.

There is concern that early screening and treatment for African-American men may be warranted; but there is disagreement on appropriate use of the PSA test and screening programs, especially for Blacks.

Significant research exists indicating that Blacks face greater barriers to health care than whites. These obstacles can be at least partially surmounted by educating Black men, insuring equality of access to health care providers, having successful outreach programs available to them and, establishing a network they will trust and use.

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THE FRIDAYS INITIATIVE



If you are an uninsured or under-insured patient who is seeking surgical treatment for localized prostate cancer, the Fridays Initiative was set up to help you.

Uninsured and under-insured patients who need surgery for prostate cancer may have difficulty finding high-quality treatment of their choice that is within their economic means.

Through the Fridays Initiative, pre-qualified, uninsured and under-insured patients can more easily overcome economic barriers and gain access to high-quality treatment.

The Fridays Initiative relies for surgical capabilities on a specialized prostate cancer surgeon associated with Mobile Surgery International. This surgeon introduced minimally invasive prostate cancer surgery (also known as laparoscopic radical prostatectomy) into the United States in 1999. In experienced hands, this kind of prostate surgery is associated with minimal bleeding, minimal pain, and rapid post-surgical recovery.

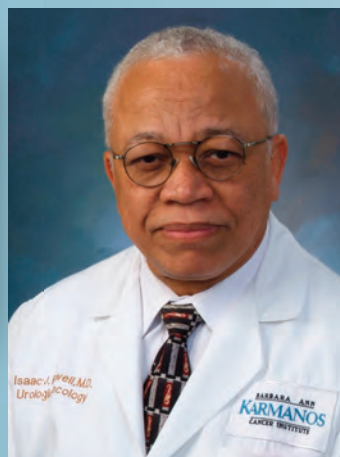
For more than 10 years this surgeon has focused only on minimally invasive prostate surgery, a service that he has provided to men from across the United States and from other countries. He has carried out more than 2,000 such procedures and is absolutely devoted to service and support at the highest level for all of his patients and their families.

All surgical procedures offered by Mobile Surgery International (MSI) are provided at "all-in package costs" for uncomplicated surgery for appropriately qualified patients, and include such things as hospital costs, the fees for the surgical team, immediate postoperative care, etc. They do not include the costs for travel, lodging, long-term follow-up, and medical complications.

For more information, contact Mobile Surgery International via email: help@emeseye.com or by phone: Hope or Ruth at 305.936.0474

Evidence Concludes More Rapid Prostate Cancer Growth...

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Dr. Isaac Powell

However, we now have scientific research that shows genetic proof supporting clinical differences between African-American men and whites. In an article published in *The Journal of Urology* (May 2010), Dr. Isaac Powell from the Karmanos Cancer Center in Detroit concluded "...that age at prostate cancer initiation and clinical characteristics did not differ by race in our autopsy series, prostate cancer volume after radical prostatectomy was greater in black than in white men and disease became distant disease at

a ratio of 4 black men to 1 white man in the Detroit Surveillance, Epidemiology and End Results (SEER) population."

The research team evaluated many externalities. The article continues, "Lack of access to care was suggested as responsible for disproportionate advanced disease and mortality in AAM compared to EAM. Data indicate that in recent years AAM are as likely to be tested for PCa by PSA as EAM. However, AAM continue to present with more advanced disease and a higher mortality rate. Financial barriers or the lack of insurance were also suggested as potential causes of the disparity. SEER insurance rates for AAM and EAM older than 50 years are 81% and 89%, respectively. That difference is statistically significant but in our opinion does not account for the entire disparity.

Socio-economic status (SES) was also reported as a factor contributing to PCa racial disparity but this issue is controversial. Studies that examined SES on multivariate analysis showed that SES does contribute to the racial outcome disparity. However, no difference in PCa recurrence after radical prostatectomy was identified in AAM when comparing lower vs. middle incomes. Nonfinancial barriers such as poor health seeking behavior were reported to delay PCa diagnosis in AAM. Fear of the PCa diagnosis and distrust of the health care system appear to be the most dominant factors. Evidence shows that PCa treatment differences contribute to the survival disparity. AAM are less likely to be treated for PCa than EAM for similar disease stages.

Dr. Powell's hypothesis is that a more rapid PCa growth rate and/or earlier transformation from latent to aggressive PCa in AAM than in EAM contribute significantly to the racial disparity of advanced disease at diagnosis and to the 2 to 3 times greater mortality rate in AAM than in EAM.

The methodology utilized by Dr. Powell's team evaluated prostates on deceased African-American and white men who died from non-prostate cancer related causes, which was compared with radical prostatectomy tissue of men with diagnosed prostate cancer. The study results found that age at prostate cancer initiation and clinical characteristics did not differ by race in our autopsy series, prostate cancer volume after radical

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Cabazitaxel: A New Weapon in the Fight against Advanced Prostate Cancer

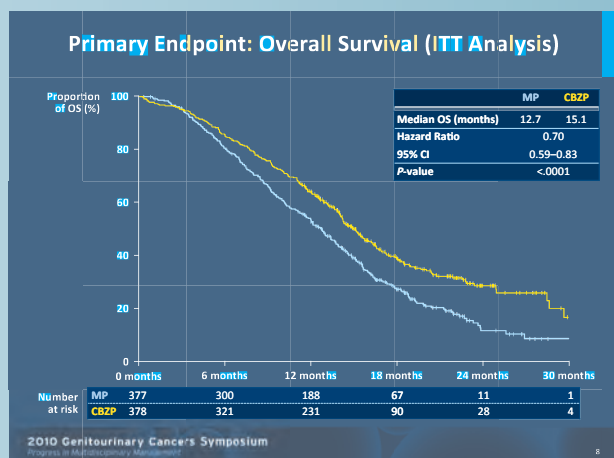
By Virgil H. Simons

The recent meeting of the American Society of Clinical Oncology Genitourinary Cancers Symposium (ASCO-GU) provided a forum for discussion of many new protocols that are emerging to manage advanced stage prostate cancer. One of the most significant reports was that which highlighted the results of the Phase III **TROPIC** Trial in the use of cabazitaxel + prednisone versus mitoxantrone + prednisone in the treatment of metastatic castration-resistant prostate cancer (mCRPC) after previous first-line chemotherapy.

Docetaxel (Taxotere) is the standard of care in treating first-line mCRPC; however, should the therapy fail and disease progression occurs, the patient is faced with:

- No currently approved standard second-line therapy
- Only treatment options: supportive care or investigational drugs
- Palliative care
- No protocols with Overall Survival (OS) benefit demonstrated

The data generated through the TROPIC trial, proven at 146 sites in 26 countries, points the way toward Cabazitaxel showing advantages over current taxane therapy in improving overall survival, progression free survival and safety. The graph shown below demonstrates the primary endpoint of OS.



In the words of Dr. Oliver Sartor, one of the trial's Principal Investigators: "Cabazitaxel is only the second chemotherapy agent to show a survival advantage in patients with advanced metastatic prostate cancer who have failed hormonal therapy. It is the first agent to show a survival advantage in patients who progressed after docetaxel chemotherapy."

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Alternatives to PSA

By editorial staff

The questions and contretemps over the use of the PSA test is focusing on the need for new bio-markers to detect the potential for and/or the progression of prostate cancer. The recent ASCO-GU Symposium highlighted several developments in this area.

Two key presentations based on new models focused firstly on the detection of TMPRSS2:ERG in urine for early detection of significant PCa; click [here](#) to view the abstract.

Another presentation, viewed [here](#), detailed the use of TMPRSS2:ERG to predict prostate biopsy outcomes using a mathematical model for greater diagnostic accuracy.



Dr. Nicholas Vogelzang

Building on data captured in the dutasteride REDUCE trial, the major presentation on the viability of the PCA3 molecular urine test generated significant interest in being able to predict repeat biopsy outcomes as well as providing a basis for increased diagnostic accuracy. The hypothesis is that PCA3 will be useful in identifying more aggressive PCa and detecting undiagnosed cancers. A summary of the presentation can be seen [here](#).

We had a brief conversation with Dr. Nicholas Vogelzang who commented on this new category of diagnostic tools. You can view the video of the interview by clicking [here](#).

PROVENGE® Approved

By editorial staff

The FDA has approved PROVENGE® (sipuleucel-T) as an autologous cellular immuno therapy for the treatment of men with asymptomatic or minimally symptomatic metastatic castrate resistant (hormone refractory) prostate cancer. PROVENGE is designed to stimulate a patient's immune system to target prostate cancer cells.

Pre-approval data was presented at ASCO-GU by Dr. Phil Kantoff and can be viewed by clicking [here](#).

For more information on PROVENGE, visit www.PROVENGE.com or contact Dendreon ON Call at 1.877.336.3736.

The Prostate Net



www.theprostatenet.org
Email: support@prostatenet.org
Phone: 1.888.477.6763

Please Ask, Please Tell: Ensuring Quality Cancer Care for All Men

By Diane Johnson

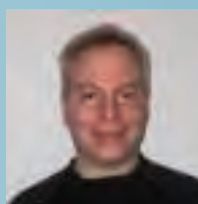
March, 2010

There are few things more intimate than being treated for prostate cancer. It affects your sexuality, your self-image, your relationship, your future relationships. What your treatment plan consists of, and whether you follow it, depends on clear and candid communication with your doctors. Imagine now that you have been diagnosed with prostate cancer and your doctor doesn't know that you're gay.

Although as many as 10% of our country's population identify themselves as gay or bisexual, it is still all too common for many of their clinicians to be unaware of that fact. As Thomas O. Blank from the University of Connecticut in Storrs stated in an article in the *Journal of Clinical Oncology* (Volume 23, Number 12), "...despite at least some attention to [cancer diversity] factors such as race, ethnicity, age, and socioeconomic status, one group remains almost totally invisible—the gay, bisexual, and transgender community." Fear of discrimination, misconceptions about cancer treatments and side effects, and a lifestyle and support system that differs markedly from that of straight men, keep many men from speaking up about their sexuality. But, just as often, clinicians haven't been trained, don't know how to ask, or automatically assume their patients are heterosexual. An estimated 218,890 men will be told they have localized prostate cancer this year, joining 1.9 million current survivors. Yet the role of sexual orientation in treatment and recovery is unknown; the experiences of gay men with prostate cancer have remained invisible.

There is an organization dedicated to bridging this gap. Since the late '90's, Malecare has been reaching out to educate and encourage gay and bisexual men. Darryl Mitteldorf, founder and Executive Director of Malecare, got involved after he learned that his father was diagnosed with prostate cancer. In search of a support group, he found none. "At that time, in 1997 or 1998, there actually weren't any [where I live]," Mr. Mitteldorf said, "...so I started one." As the group grew, he noticed that the majority of the members were "gay or bisexual guys who were just coming out both around their cancer and, for some of them, around their sexuality," he said. Eventually, as this gay men's cancer support group evolved, he decided to form a non-profit organization and Malecare was born.

Over the years the organization has grown organically—first to other cities in the U.S. and then internationally, with groups now in Australia, Italy, and England. The Malecare website, www.malecare.org, is one of the



Darryl Mitteldorf



largest prostate cancer sites on the web. Mr. Mitteldorf described Malecare's mission: "To provide support and access to healthcare to all gay and bisexual men and transgendered women around the world." Some of their many initiatives include:

- "A Gay Man's Guide to Prostate Cancer"—a collection of writings that discuss "the unique concerns gay men have with this life-altering disease"; includes a glossary of medical terms (available at amazon.com)
- Participation in the first LGBT (Lesbian, Gay, Bisexual, Transgender) Cancer Project, (www.lgbtcancer.org) designed to "give a voice to LGBT cancer survivors" through education, increased awareness, and partnerships with existing advocacy organizations.
- Satellite websites:

www.advancedprostatecancer.net — a website and forum for those struggling with advanced prostate cancer

www.outwithcancer.org — an online support group for gay, lesbian, and bisexual cancer survivors

www.fatherdad.com — website for African American men focusing on parenting skills for young fathers; includes education on men's healthcare issues

So, whether you are a prostate cancer survivor who happens to be gay, a physician or nurse who works with prostate cancer patients and their families, or a partner or friend of someone who has been diagnosed, Malecare is available and willing to advise, counsel, and educate.

The number of prostate cancer patients who are gay is irrelevant; what matters is that each and every cancer survivor receives the best and most appropriate care. Without knowing who that patient is—their sexual identity, their significant other, their support system—how can that happen? As Mr. Mitteldorf said, "From our point of view, not knowing whether a man is gay or straight when you're treating him for prostate cancer is as bad as not knowing what his Gleason score is." It is this writer's hope that these conversations will begin. Please ask, please tell.



Are You a Gay Prostate Cancer Survivor?

By editorial staff

Researchers at the Boston University School of Public Health are conducting a survey of gay men treated for prostate cancer to learn more about their health experiences and outcomes.

If you:

- Are an English-speaking gay man
- Are age 50+
- Were treated for prostate cancer at least 12 months ago

Then we would love to learn about your experiences!

The survey takes approximately 45-60 minutes to complete and is 100% confidential. The survey will be mailed to you and everyone who returns a completed survey will receive \$20. The results from this research study will be used to help educate prostate cancer patients and healthcare providers in the future. Your participation is voluntary and you can refuse to answer any question.

If you would like to participate or obtain more information about this research study, please contact Don Allensworth-Davies at 617-638-5816.

Medicare Interactive: Vital Information at your Fingertips

by Diane Johnson

Almost 45 million people are currently enrolled with Medicare. The Medicare Rights Center was created for them. This Center is "a national nonprofit consumer organization that works to ensure access to affordable health care for older adults and people with disabilities." Supported by a large volunteer network, community programs, hotlines and other services are available to all members across the country. Services offered include educational programs, counseling, and advocacy. But the Medicare system is large and complex, so even those who are part of the program are sometimes not aware of all the benefits that come with that coverage. For example, **men with Medicare are eligible for one PSA test and digital rectal exam each year.**

Medicare Interactive is a free online resource site created by the Medicare Rights Center. Medicare recipients, consumers, caregivers, and healthcare professionals can use this reference tool to find specifics about Medicare-covered services and prescription drug benefits, enrollment procedures, coverage options, and much more.

To access this valuable website, go to <http://www.medicareinteractive.org>.

Evidence Concludes More Rapid Prostate Cancer Growth...

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prostatectomy was greater in black than in white men and disease became distant disease at a ratio of 4 black men to 1 white man. These findings support the concept that PCa grows more rapidly in AAM than in EAM and/or earlier transformation from latent to aggressive PCa occurs in AAM than in EAM.

The full article is linked from above. For more information on this study and racial health disparity, Dr. Powell's contact information can be found at: <http://www.med.wayne.edu/urology/faculty/powellbio.html>

Focus on Research

By editorial staff

The significant news seen recently on emerging new drug protocols such as cabazitaxel, MDV-3100 and the recent approval of Provenge all for the treatment of advanced prostate cancer reinforce the reality that the cure for this disease will come through research.

Major developments in basic through translational research in prostate cancer were reported at the ASCO-GU Symposium (see summary highlights [here](#)), the Spring Meeting of the Southwest Oncology Group (SWOG) presentation summaries can be seen here; and at the American Association for Cancer Research's Annual Meeting (for program agenda, click [here](#)). It is imperative that as patients and advocates for our lives we stay informed as to the best standards of care that are current and emerging.

As survivors and advocates we should afford ourselves the opportunity to become more involved in the mission of scientific research by acquiring knowledge and representing the patient perspective in the research process.

The **Scientist Survivor Program** of the AACR's designed to build enduring partnerships among the leaders of the scientific and cancer survivor and patient advocacy communities worldwide." Details on the program can be found at: Survivors & Advocates.

The **SWOG Patient Advocate** program creates a process for advocate involvement with the overarching value of transparency in research. Their role is to bring the perspectives of those most affected by cancer to the work of the Group. At least one sits on each of the Group's disease committees. Two more cover the cancer control and prevention committees. Details on the Patient Advocates program and SWOG can be seen by clicking [here](#).

One of the most robust consumer/patient advocate programs is encompassed as part of the Department of Defense Congressionally Directed Medical Research Program (**CDMRP**) that places consumers in the forefront of the research process from peer review through to vision setting and funding strategies. Information on the range off Consumer Involvement can be viewed [here](#), including how to apply for the program.

Let's **listen** to Dr. Elisabeth Heath talk about the importance of research in overcoming the negative impact that prostate cancer has had on our society.



Dr. Elisabeth Heath

Cabazitaxel...

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An overview of the [presentation](#) made by Dr. Oliver Sartor of Tulane can be viewed from the ASCO-GU site, along with many others of interest.

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Dr. Oliver Sartor



Dr. Rob Dreicer

The significance of this drug development is reinforced by an interview we had with Dr. Rob Dreicer of The Cleveland Clinic. You can see the video with Dr. Dreicer by clicking [here](#)

The European Perspective on PSA

By editorial staff

A recent article from *European Urology* (September 1, 2009) highlighted the work of Dr. Fritz Schröder in developing strategies to reduce the number of unnecessary biopsies while still detecting those clinically significant cases of prostate cancer.

Dr. Schröder and his team concluded that utilization of certain diagnostic nomograms in conjunction with the PSA test and other pre-biopsy information can result in a considerable reduction in unnecessary biopsies and the identification of more important prostate cancers.



Dr. Fritz Schröder

For more information on the study, see:

http://www.eurekalert.org/pub_releases/2009-11/eaou-dpa110509.php

PSA and the PSA Test: What the Public Needs to Know

By James Mohler, MD

On March 22, **National Public Radio** ran a segment ("Prostate Test: Lifesaver or Big Mistake?") on its "Morning Edition" program on prostate-specific antigen (PSA) and the controversy regarding the PSA test as an effective screening tool for prostate cancer. Richard J. Ablin, PhD, a research professor of immunobiology and pathology at the University of Arizona College of Medicine, was interviewed for this segment.

On March 10, the **New York Times** ran an Op-Ed piece ("The Great Prostate Mistake") written by Dr. Ablin.

The take-home messages from these highly reputable news sources are that Dr. Ablin "discovered P.S.A. in 1970" and by virtue of that discovery, would obviously be the reigning authority on the use (and purported overuse) of the PSA test.

Prostate-specific antigen (PSA), a protein produced by the secretory epithelial cells of the prostate gland, is present in small quantities in the blood of normal men, and is often elevated in the presence of prostate cancer and in other prostate disorders. One should not confuse the current PSA with the "prostate-tissue-specific antigens" or proteins (the human prostate contains hundreds of proteins) that were discovered in the early 1970s.

While Dr. Ablin did discover a "prostate-specific antigen" that is confined to the normal prostate, he neither developed the PSA test nor discovered the PSA that the current test is based on. That credit goes to Roswell Park Cancer Institute researcher T. Ming Chu, PhD, DSc, who, with an extraordinary team of over 20 researchers, including urologists and pathologists, discovered what the American Association for Cancer Research would later call one of the "landmark scientific discoveries of the 20th century."

Working with human prostate tissue from cancer and benign prostatic hyperplasia, Dr. Chu and his colleagues identified and purified PSA and later developed the simple PSA blood test that is used today for the early detection and management of prostate cancer.

The team published their first major paper in 1979 in **Investigative Urology**, followed by a 1980 paper in **Cancer Research** that used the PSA test to demonstrate PSA in the blood of prostate cancer patients. A patent was issued in 1984 to the State of New York and Roswell Park Cancer Institute, and the technology was transferred to the biomedical industry for preparing testing kits. The PSA test received FDA approval in 1986 as a monitor for treatment response and disease recurrence, and in 1994, as a screening tool for diagnosis. Since then, an estimated one billion PSA tests have been given.



T. Ming Chu, PhD, DSc



In recognition of his many contributions to the field of urology, Dr. Chu received the Presidential Award from the American Urological Association in 1993 and was featured in the April 15, 1998 issue of **Cancer Research** for his seminal research on the use of tumor cell products in the diagnosis and treatment of cancer, and for his leadership role in the discovery of PSA and the development of the PSA test.

Is the effectiveness of the PSA test no better than a coin toss, as Dr. Ablin contends in his recent remarks to the media? Let's look at the facts. PSA has revolutionized our ability to detect prostate cancer in its early stages and monitor its course of treatment. Prior to the development of PSA, only 4% of men diagnosed with prostate cancer could be cured. Most were diagnosed with prostate cancer when it had spread to their bones and caused pain. The standard treatment was androgen deprivation therapy and the mean survival was three years. The development of the PSA test has completely changed the demographics of newly-diagnosed prostate cancer patients. Less than 10% of American men are diagnosed with incurable prostate cancer today, and the five-year survival after treatment is essentially 100%. In addition, one British study has shown that the prostate cancer mortality rate in the USA for the period 1994-2004 had a rate of decline greater than four times that of the United Kingdom, where the PSA test was not widely used.

As the pioneer of the PSA test, Roswell Park Cancer Institute has been in the frontlines of the recent national discussion on the challenges and value of mass prostate screening using the PSA test. Two Roswell Park faculty members, including myself as chair, serve on the National Comprehensive Cancer Network (NCCN) Guidelines Panel for Prostate Cancer, the group that develops the national/international "best practice" guidelines. On March 4, I was invited to give expert testimony at an important hearing ("Prostate Cancer: New Questions About Screening and Treatment") before the House Committee on Oversight and Government Reform. My testimony, I believe, provided some clarification as to why the PSA controversy continues to be waged.

For example, the incidence of prostate cancer if one autopsied the prostate is approximately the age of the man. In other words, 20% of 20 year olds already have cancer in their prostate and 80% of 80 year olds have prostate cancer. Prostate biopsies will find about 1/2 of these autopsy cancers. Thus, 40% of 80 year olds and 10% of 20 year olds will be found to have prostate cancer if their prostates are biopsied. Because PSA can be elevated for many reasons, many men who undergo prostate biopsy may have an autopsy-type prostate cancer diagnosed rather than one that poses a threat to their life expectancy.

There is legitimate concern that widespread use of the PSA test may over-diagnose prostate cancer and put men at risk for complications from unnecessary treatments such as surgery and radiation. But it's not the use of the PSA test that's at the root of the national debate — it's deciding what to do with the information it yields.

Indiscriminate use of PSA and aggressive diagnosis and treatment of prostate cancer is unlikely to impact significantly the survival of American men and may adversely affect the quality of life of American men. The NCCN has responded by changing the **2010 Guidelines** to focus on a more careful detection of aggressive prostate cancer in younger men while

urging a more conservative approach to early detection of prostate cancer in older men; NCCN recommends that attempts to find prostate cancer cease when a man's life expectancy falls to <10 years. The NCCN 2010 Guidelines also recommend active surveillance of men who were found to have low risk prostate cancer when life expectancy is <10 years. In addition, the NCCN has created a new prostate cancer risk category, very low risk prostate cancer; active surveillance is the only recommended treatment in this group of men when life expectancy is <20 years. These changes allow appropriate aggressive treatment of men who are at high risk of death from prostate cancer while avoiding overtreatment of men at low risk of prostate cancer death.

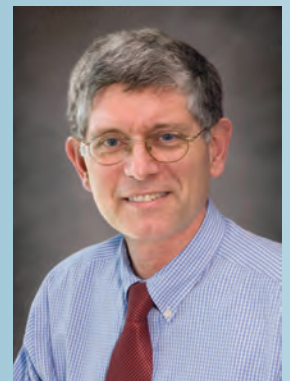
At Roswell Park, we continue to build on the milestone contributions of Dr. Chu and his colleagues. Our research is focused on developing a better PSA test, one that will distinguish aggressive, life-threatening prostate cancers from those that are slow-growing and not life-threatening so that appropriate treatment decisions can be made.

The need for a more precise early detection tool is both challenging and urgent. On this point, we are all in agreement.

How Do I Know If I'm A "High Risk"?

By editorial staff

Part of the controversy surrounding the issue of screening and use of the PSA test deals with whether or not a patient has a truly aggressive form of prostate cancer or merely an indolent form that doesn't pose a significant danger. An emerging tool stemming from the Prostate Cancer Prevention Trial (PCPT) is the "**Prostate Cancer Risk Calculator**", an online tool that will aid the patient in determining a basis of potential risk that can be discussed with his healthcare providers.



Dr. Ian Thompson

Dr. Ian Thompson, Chairman of the Department of Urology at the University of Texas Health Science Center in San Antonio, has been actively involved in the research of protocols impacting on early detection and effective disease management. You can view his comments on the subject of PSA on The Prostate Net's YouTube Channel by clicking [here](#)

You can access the calculator [here](#) in order to assess your personal risk profile.

Note though that all of the tools and data are meaningless if you don't become proactive about your health and act accordingly to get tested, monitor any PSA changes and stay educated about the disease and your risk from it.

Tell Me Where It Hurts: Stopping the Cycle of Prostate Cancer Pain

by Diane Johnson
May, 2010

Forgive me for stereotyping, but men don't like to talk about their pain—some see it as a sign of weakness. Besides, a diagnosis of cancer is hard enough; dealing with pain takes too much energy away from that fight. But it is critical to talk about: to describe when the pain happens and how bad it is. Untreated pain can hinder healing. The only way to treat pain effectively is to quantify it. As my guest, Dr. Saraiya, says, "There is no reason a patient should be suffering; there is always a solution."



Dr. Biren Saraiya is a medical oncologist at the Cancer Institute of New Jersey. He specializes in improving patient-physician communication and treating cancer symptoms, especially pain. He also teaches palliative care (treatment focused on disease symptoms to reduce patient suffering) to medical students and residents at the Robert Wood Johnson Medical School. I spoke with Dr. Saraiya about this vital issue:

DJ: Thank you for speaking with me, Dr. Saraiya. What prompted you to concentrate on this field?

BS: From the beginning of my training, I was very interested in patient suffering and alleviating it. As I was studying internal medicine, I realized there was a specialty called palliative medicine, so I decided to train in that in addition to oncology. There are a lot of questions and misconceptions about this area.

DJ: In general, do your patients bring up their concerns about pain or do you have to prompt them?

BS: For some patients, it is not acceptable to [talk about it], so I have to bring it up. For others, they assume if they have cancer, they will have pain. Those patients don't report the pain or its severity or the impact it has on them until someone really coaxes them. When I ask if they have pain, they don't want to complain, so they might say, "Oh, it's okay." I have to ask specifically, "Are you having no pain at all or is it manageable?" or "What do you like to do that you can't?"

DJ: In my experience, patients may not mention the pain because they think that means the cancer is getting worse.

BS: That's true. That is one fear and another is it might make the doctor not pay as much attention to the cancer. Patients very often minimize their symptoms. It's interesting when a family member who is with them says, "That's not what you said yesterday." There's still a mentality that they want

to be a "good patient" and not complain. I reassure the patient that my job is to take care of them, including their pain.

DJ: You mentioned other misconceptions when it comes to cancer and pain. What are some?

BS: One that is very common and very strong is the fear that the patient will become a pain medication addict. In my mind this leads to a lot of suffering. I find it best to approach it head on with a very direct question—"Are you afraid of this?"—so I can address it right away. Most people will be honest about it. Then I can tell them, "I have zero concerns about this for you." I do also treat patients who have a history of addiction and I tell them they are absolutely correct that this is a concern, but to me it is more important that I treat the pain so I can treat their cancer better.

Another misconception is when people hear the word "morphine" they may think they are dying. There's a lot of resistance to taking that medication. But morphine is a good pain medication.

And some fear they will be "loopy" or drugged from pain medication. This is where frequent reassessment helps. They may feel a lack of concentration or sleepy at first, but I tell them it usually gets better after 3 days. If it doesn't, then we can change the amount or the type of medicine.

DJ: What tools do you use to help quantify pain?

BS: I use the scale with 'zero' meaning 'no pain' and '10' meaning the 'worst pain.' But I also try to get a qualitative read—what does it mean for them? I find sometimes that's actually better than a number.

"What do you like to do?", "What is the pain not letting you do?", "What time of day or what are you doing when you get pain?" is a better way for me to understand the story of their pain in a typical day. If the pain is a '6', is it a '6' right now, when you do something, or is a '6' the best you can expect? I need to know what kind of impact the pain has on how they lead their lives. Then I can develop a plan to target that. For example, if they're planning to do something in a couple of hours, they can take the pain medication now.

DJ: So you're treating the pain cycle instead of having someone heavily medicated all day long.

BS: Yes, and the most important thing is frequent reassessment. If I make a change in their medications, I have them call me or come into the office 2 to 3 days later to see if it worked. I ask, "Did you get to do what you wanted to in the afternoon?" for example. If it worked, then fine. If not, what happened? My goal is to get the maximum benefit as fast as I can, especially when the pain is severe. I will continue to check in every 2 or 3 days until we get the right dose for them. With frequent reassessment you can make sure the patient is getting to the point they want to with their medications. Otherwise, if the side effects are bad, they may just stop taking it.

DJ: Aside from quality of life, does controlling pain have any effect on healing?

BS: I look at it from a slightly different perspective. With cancer, one important thing is how active you are. We know that treatment side effects are worse when the patient is more immobile or less active. That is one reason doctors frequently ask patients what they are doing during the day and



how much time they spend in bed. So one of the reasons we want to manage their pain is to increase how active they can be, and that is directly related to how effective treatment may be. Also there are some medications now, like Quadramet, that treat both the pain and the cancer.

DJ: At what point in prostate cancer are issues with pain likely to occur?

BS: There could be some pain with the primary treatment itself. With radiation therapy, some men develop proctitis or radiation burns. There are topical treatments for it, but, for the most part, time is the best way to heal this. Also inflammation, urinary symptoms, or rectal bleeding can occur. The doctor needs to determine where the bleeding is coming from. Impotence and urinary symptoms can occur with both surgery and radiation.

What gets the most attention is when the cancer spreads outside of the prostate. If it has spread to the bone, the patient might have compression of the nerves near the spinal cord. They usually complain of back pain. For that, radiation is a great tool because you can treat the cancer at the exact spot. If the cancer comes back in a different spot, they can treat that also, sometimes in many places. For some patients, the pain still doesn't go away. Then we can try oral medication in addition to the radiation, using short- and long-acting medications.

DJ: Could you tell us more about the short- and long-acting medications?

BS: Absolutely. There are two kinds of pain medication: one that prevents the pain (long-acting) and one that controls the pain when it happens (break-through pain). The problem is that some people say they only take the medicine when they have pain. If you're having pain 4 times a day, you're in pain most of the day because the medicine can take up to 45 minutes to work. Taking a long-acting medication once or twice a day, every day, can prevent most or all of that pain. Then, if needed, a shorter-acting medication can be used to treat additional pain when it happens. For example, oxycontin is a good long-acting medicine and Oxycodone can be used for break-through pain.

DJ: What other kinds of medications do you use?

BS: For minor pain, medicine like Tylenol and ibuprofen, like Motrin, can work; for more severe pain we use things like morphine, Dilaudid or oxycodone. I also prescribe patches, like Fentanyl. Some medications are or can be prepared by a pharmacy as a liquid, if there is trouble swallowing. Doctors, such as an anesthesiologist, can give pain or numbing injections right into where the pain is. This usually gives temporary relief, but can last up to 3 or 4 weeks. I also use medicines designed especially to treat pain from nerve damage, like gabapentin. One very effective medicine is Methadone, especially for those with severe pain who are taking a lot of medication throughout the day. It's a very strong opioid so they don't have to take as many pills. Many people have a misconception that this is a drug just used for those addicted to heroin, so I really need to clear that up from the beginning.

DJ: Many of the medicines you mentioned can cause side effects. What are the most common and how are those treated?

BS: Let me focus more on the categories of drugs to answer your question. The majority of pain medications for moderate to severe pain are opioids: morphine and Oxycodone, for example. The side effects for most of them are

the same. When the patient first starts they may have some nausea or vomiting. This is temporary. It gets better, usually within 24 to 48 hours. Other common side effects can be lack of concentration or feeling drowsy. Typically both of them also get better over time. Most of these side effects are reversible and patients get used to the drug. On the other hand, constipation is a side effect that doesn't go away as long as you take those medications. It is very important to let your doctor know if your bowel movements become irregular—don't wait. Either the patient or family should let the doctor know right away. This can be treated.

Neuropathic drugs or ones that affect the nerves: such as gabapentin, amitriptyline or Pregabalin. These can cause swelling, edema (fluid retention), problems with concentration or tremors. Some of these side effects can go away by themselves, the medication can be changed, or steroids might be used.

Steroids and anti-inflammatory drugs like naproxen or ibuprofen shouldn't be used for a long time because of the potential of developing bleeding in the stomach or ulcers. I usually recommend only 1 to 2 weeks at a time.

DJ: If someone is having pain, who should they talk to about it?

BS: I think the best person to consult first would be your oncologist. Radiation oncologists also have great treatments for pain. If the pain is still severe, then you can see a doctor who specializes in pain.

Most of the pain management I do involves prescriptions for oral medications or a patch. But a pain management specialist can prescribe a pain pump that puts medication directly into the spinal column.

Electrical or nerve stimulation can help especially if the pain is caused by nerve damage. Some of this care might have to be done in a hospital if, for example, IV medication is required.

DJ: Have there been any new developments in pain management?

BS: We are trying to find better formulations and treatments for pain, but the categories remain the same. There is a lot of research into pain that is caused by nerves, especially that caused by chemotherapy. That kind of pain can be debilitating. There are also clinical studies looking for other ways to administer pain medications, like intra-nasally or pills that dissolve.

DJ: Is there anything else you'd like our readers to know?

BS: Yes. There is absolutely no reason why a patient should be in pain and suffering. It is true that sometimes it is hard to balance pain treatment and side effects. But not taking pain medication should never be the case. I want every patient and every family member to know there is no reason for them to suffer. **There is always a solution.**

DJ: Thank you so much, Dr. Saraiya. As the NCI FactSheet says, it is important to note that "palliative care is different from hospice care. Although they share the same principles of comfort and support, palliative care begins at diagnosis and continues during cancer treatment and beyond."

(<http://www.cancer.gov/cancertopics/factsheet/support/palliative-care>.) In addition, a list of palliative care specialists by state (and city) can be found on the Center to Advance Palliative Care's website: <http://www.getpalliativecare.org/providers>.

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