Early Detection, Early Intervention: Penile Rehabilitation

by Diane Johnson

The shock of a prostate cancer diagnosis is quickly followed by an array of treatment options to consider. In addition, each treatment has a range of possible side effects, from weight gain to incontinence. One of the most dreaded side effects is “failure of the penis” or erectile dysfunction. In the past, patients were told it could take as much as two years to restore normal erections after a radical prostatectomy, even when the popular nerve-sparing technique is used. No interventions were offered—it was a “wait and see” strategy...or lack of strategy.

With the advent of earlier cancer detection and, therefore, earlier treatment, men have been demanding a more proactive approach. In response, a new field of research has emerged: penile rehabilitation. This is a primary area of concentration for Dr. David Shin, Chief of the Center for Sexual Health and Fertility at the Hackensack University Medical Center in Hackensack, New Jersey. I had an opportunity recently to speak with him about this vital issue:

DJ: Thank you for speaking with us, Dr. Shin. What are the most common side effects related to the different kinds of prostate cancer treatments: surgery (radical and laparoscopic procedures), radiation (immediate and delayed effects), and hormonal therapy?
When The Prostate Net® inaugurated the “In The Know Awards” in 2005, we envisioned the fight against health disparities in high-risk, minority and medically underserved communities. However, changes in the spectrum of health care in America have caused us to begin to re-think the impact of disparity on a broader spectrum of our population.

The U.S. spent last year over $1.6 trillion on healthcare, roughly 15% of our total Gross Domestic Product, yet we have over 47 million Americans without insurance coverage. We spend 40% more per capita than other developed nations, yet we are the only one that doesn’t offer a basic health benefits package to its citizens. We spent 1/7 of our nation’s productivity and we see corporations reducing retiree health benefits, increasing the active employee’s share of health care costs, yet we still are non-competitive in the global marketplace due to the cost of domestic healthcare. Despite the amount being spent on healthcare, the World Health Organization ranks the U.S. at 37th place in health system performance versus France and Italy who ranked #1 and #2 respectively.

Government “protectionism” has given oversight, if not exacerbation, to the demise of jobs and industries through programs such as NAFTA and the elimination of Fair Trade Agreements. We stand at a point wherein our health insurance system creates a level of non-competitiveness in global markets. We stand at a point where specialization in healthcare delivery is causing a decline in primary care physicians when many of the major disease conditions facing our society need to be addressed at a prevention level best served by that primary care doctor. We have a healthcare compensation structure that rewards performance in clinical management of illness versus prevention of disease onset.

The future doesn’t hold a great deal of promise either because our “Baby Boom” generation is moving into the age range wherein most critical and chronic diseases are diagnosed. Exacerbating this situation is the fact that we are projecting a continuing shortage of nurses all the while we’re moving into the time frame when health care costs are their highest and nurse practitioners could be utilized to provide a degree of primary care and preventive services. The W.H.O. again projects that by 2020 we will still be 10% lower than the global average per 100,000 for health care professional.

Today we spend more than $37 Billion annually to provide healthcare to the uninsured through governmental and private indigent care programs - a safety net that is rapidly evaporating with medical establishment guidelines based on pay-for-performance. The reality of life in America is that our healthcare costs will rise as we age; but that fact is further impacted based on the anticipated increase in the number of years we will have to work - by 2014 more than 20% of our labor force will be actively employed past the age of 55.

Since 1944 our Presidents have promised a reform in healthcare, the promise of an unbridled future for our children, the right to adequate medical care and the opportunity to achieve and enjoy good health. The Status Quo is not working for the masses of consumers, nor is it economically sustainable even if it were. It is imperative that multi-tangential approaches be used to change the system to insure equitable access to care and economic stability within our society. It is the best of times and the worst of times, but, for our present and our future, it must become changing times.

Virgil’s Blog
Virgil H. Simons
Founder & President
The Prostate Net, Inc.

In general, men may experience sexual dysfunction or voiding dysfunction after undergoing prostate cancer treatment. Prior to the advent of a penile rehabilitation program, 50-80% of men reported having erectile dysfunction (the inability to achieve and maintain an erection for satisfactory intercourse) after surgery with recovery not seen until 2 years after surgery. Total urinary incontinence, the inability to hold urine inside the bladder voluntarily to prevent leakage, is seldom seen after surgery. However, stress urinary incontinence (leakage of urine during abdominal straining) may be observed in 5% of patients. Currently, urinary continence and potency rates are similar for radical and laparoscopic procedures.

Patients who undergo radiation therapy often experience irritative voiding symptoms such as frequency, urgency, dysuria (painful urination), or nocturia (need to urinate in the night) within the first few weeks of treatment. Usually, these symptoms resolve within one year. Erectile dysfunction is not commonly seen in the immediate time period after radiation. However, recent data suggest that erectile function worsens with increasing duration after radiation therapy.

Hot flashes, erectile dysfunction and decreased libido are the most common side effects associated with hormonal therapy. Continence is not affected by hormonal treatment.

DJ: How is a man’s sexual function evaluated before treatment?

When a man comes to me for evaluation of his sexual function, I first obtain a detailed history regarding his erectile and orgasmic function. I ask whether or not he has tried pills such as Viagra, Levitra or Cialis. I perform a comprehensive physical exam specifically focusing on the genito-urinary exam. In addition, men answer a detailed questionnaire known as the International Index of Erectile Function (IIEF) to objectively determine their erectile function before treatment. After the initial evaluation has been completed, additional testing such as bloodwork or penile Doppler ultrasound (to measure blood flow into the penis) may be obtained to further help with the assessment of erectile function. Most urologists are capable of performing an initial evaluation for sexual dysfunction. However, specific tests such as a penile Doppler ultrasound may only be performed by a specialist.

DJ: How common is erectile dysfunction and is it ever permanent?

Some degree of erectile dysfunction will be present after open radical or laparoscopic prostatectomy. Improvements in sexual potency may not be seen until 10-14 months after surgery and may take up to 2 years before
The Prostate Net® Leads The Way: Informed To Fight Medical Education Symposium for Patients and Healthcare Professionals Successful.

Hackensack, NJ; Thursday, October 14, 2009: Virgil H. Simons, Founder and President of The Prostate Net®, a national prostate cancer advocacy group, announced the organization’s latest major initiative in the fight against prostate cancer successfully met its goal of delivering contemporary and emerging information on the care and treatment of patients with prostate cancer. A day-long, dual-track educational symposium targeting patients, caregivers and medical professionals took place on Tuesday, October 6, 2009 at New York University, Kimmel Center for University Life in New York City.

Donald Coffey, PhD, from Johns Hopkins University School of Medicine, was featured as the event’s Key Note speaker. Dr. Coffey, in his unique and entertaining style, delivered an inspirational presentation on the state of cancer treatment and development. Dr. Coffey was also joined by a world-class faculty of prostate cancer specialists who presented and discussed contemporary information and issues confronting the disease.

“We believe our goal of offering a specific awareness and educational effort, targeted to both patients and professionals, within an unique dual-track environment was very successful in providing symposium participants access to those world-class health professionals, whose work form disease management policy and best standard of care,” said Simons. “We are very pleased that this initiative provided access to information for both patients and professionals, not normally readily available, as to the best standards of care based on leading edge research and clinical practice.”

A series of interactive Audience Response System (ARS) questions were built into presentations, allowing symposium participants the opportunity to provide feedback on key issues raised during the event. ARS questions

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Prostate Cancer And African Americans: Looking For Answers

August, 2009

Editor’s note: If you are an African American man who has had surgery for localized prostate cancer within the past two years, you should read this article:

The following is an overview of the Prostate Cancer Recovery Enhancement Study (PROCARE) that is accruing participants now. Dr. Lisa Campbell, a health psychologist and Associate Director of the Center for Health Disparities Research at East Carolina University is leading a team that includes researchers from ECU and Duke University Medical Center, with support from several community partners including the Minority Prostate Cancer Awareness Action Team and the Triangle East Chapter of 100 Black Men. The PROCARE study is a randomized clinical trial that is funded by the National Cancer Institute.

by Lisa Campbell, Ph.D.

Background

African American men have the highest prostate cancer incidence and mortality rates in the U.S. and ethnic group disparities are particularly pronounced in North Carolina. According to the state’s Office of Minority Health and the Center for Health Statistics, African American men in North Carolina are almost three times as likely to die from prostate cancer as white males. In addition, these statistics show that the highest prostate cancer incidence and mortality rates appear to be trending toward the eastern region of the state. From 2003 to 2006, eastern North Carolina counties have been increasingly among the top ten for both cases of prostate cancer and deaths, with mortality rates among the highest in the world.

The PROCARE study was designed to address the psychological and support needs of African American prostate cancer survivors and their partners. Advances in surgical techniques that treat prostate cancer today result in improved quality of life for many men. However, sexual and urinary dysfunction and other treatment side-effects often continue well after surgery. Studies have found that African American prostate cancer survivors may experience slower improvements in overall

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FDA Patient Representative: 
A New Advocacy Opportunity

By Diane Johnson
December, 2009

I am a Prostate Cancer Patient Advocate. Before my husband, Jim, died from prostate cancer in 1998 at the age of 45, I couldn’t have told you what that meant. And, even though I’ve been doing it now for almost 10 years, I’m finding that I still have a lot to learn about what it means to be an advocate.

Stuck in an abyss of grief after Jim died, I would have been satisfied to never hear the term “prostate cancer” again. As the years passed and life began to return to something like normal, my anger remained: anger about his ungodly suffering, anger about the lack of solutions to save him, anger about the unfairness of his death, anger about his son left behind just when he really needed his dad. But eventually the day came when I was ready to channel my anger. Just as I began to look for ways to do that, I received an email from someone who had counseled us during Jim’s illness, Virgil Simons. Virgil, a prostate cancer survivor, had started an educational and support network for other survivors and their families—The Prostate Net®. With impeccable timing, he asked me if I would help him. I accepted and became, although I didn’t know the title at the time, a Patient Advocate.

For the last several years, my advocacy has taken many forms. I write for The Prostate Net website and newsletter: interviews with survivors, clinicians, and researchers; synopses in lay language of scientific findings and papers; updates on the latest science and future trends. I participate in local support groups and fundraisers, statewide planning meetings, and national oncology and medical conferences. To me, being an advocate means I represent those who are, against their will, caught up in the maze of prostate cancer. I gather and share information, provide whatever support I can, and speak up loudly and often about what needs to change in prostate cancer communications and care.

Now I’ve been given a new advocacy opportunity. I’ve been appointed to be a Patient Representative for the FDA. I will participate in meetings of the Oncologic Drug Review Committee when they consider new products and therapies for prostate cancer. I consider this position an honor and a great responsibility. As part of that responsibility, I want to share what I learn about how the FDA review process works.

This will be the first in a series of articles on my experiences as an FDA Patient Representative. I hope you will find them informative and helpful. Like you, I know first-hand how it feels to sit in the dark in front of the computer screen at 3 a.m. searching for any shred of information that might lead to an answer. It’s all about hope—finding it, keeping it, sharing it. So, let me begin……

Knowledge of Cancer, Its Treatments and Their Side Effects

We are studying people’s knowledge about reproductive-related cancers, their treatment options, and side effects. We are focusing on various communities affected by these diseases. Our study addresses testicular and prostate cancers in males, and breast, uterine, cervical and ovarian cancers in females. We are interested in what patients with any of these cancers know about the other cancers. We are also interested in how some of the language about treatments is understood.

You do not need to be an expert to help out. The questionnaire is for people who are themselves, or have a family member, affected by any of these diseases. The questionnaire takes about 15 minutes to complete. If you are interested in helping out please click here...

Link to the survey:
http://www.surveymonkey.com/s.aspx?sm=ijGPehBGVv980wI7bi5YHh_3d_3d

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erectile function returns. If erectile function does not return with or without the use of oral medications, then more invasive therapies such as injections or surgery may be warranted to reverse the erectile dysfunction.

DJ: Urinary incontinence is also relatively common after treatment, either immediately or delayed. How do you address this problem?

In order to treat postprostatectomy incontinence, it is important to first determine the severity and type of incontinence. A description of precipitating events, pattern and nature of incontinence episodes is needed to help with the characterization of the type of incontinence a man may be experiencing. Additional diagnostic testing such as cystoscopy (scope into the bladder) and videourodynamics (bladder function testing) may be warranted in this evaluation.

DJ: How soon after treatment can men begin to address these conditions?

Men can begin to address both continence and erectile function immediately after treatment for prostate cancer. After prostatectomy, men are advised to perform Kegel exercises to strengthen the pelvic floor muscles involved with voiding. Penile rehabilitation programs are often initiated either prior to or immediately after surgery to promote early recovery of erectile function.

DJ: What treatment options are available now and which shows the most promise for each type of problem?

For urinary continence, non-invasive treatment options include Kegel exercises, biofeedback and medication therapy (depending on the type of incontinence). Surgical treatment options include collagen injections, male urethral sling surgery and artificial urinary sphincter. The male urethral sling is the newest, minimally invasive surgical treatment for male stress incontinence with a cure rate of 85-90%. This outpatient procedure is typically offered to men with mild stress incontinence who use 1-2 pads per day. For men who experience total incontinence (3-5 pads per day), they may benefit from artificial urinary sphincter surgery which is more invasive, but considered the gold standard for treatment for this type of incontinence.

For treatment of erectile dysfunction after prostatectomy, men should be enrolled in a penile rehabilitation program which incorporates the use of phosphodiesterase-5 inhibitors (Viagra, Levitra, Cialis), alprostadil intraurethral suppositories (MUSE), vacuum erection devices or intracorporeal injections (alprostadil, papaverine, phentolamine). Success has been reported in 50-60% of patients using either one or a combination of these therapies. Penile rehabilitation programs have been primarily focused on men who have undergone surgery. However, a similar treatment regimen could be applicable for those patients who have received radiation therapy.

DJ: Are the treatments you mentioned widely available?

Treatments for both incontinence and erectile dysfunction are widely available, but academic care referral centers, who specialize in these specific areas of treatments, may offer longer experience with better clinical outcomes for these therapies.

DJ: How do you deal with the psychological effects of erectile dysfunction? Is the patient’s spouse/partner involved in the process?

The psychological effects of erectile dysfunction can be very difficult for the patient and his partner. Because return of erectile function may not be seen immediately after cancer therapy, men may become discouraged when no beneficial effects are seen from penile rehabilitation. Proper counseling and discussion of the goals of penile rehabilitation after prostate cancer treatment can help men to have realistic expectations of the timing of erectile function recovery. I believe it is very important to have the spouse/partner be involved with the recovery process prior to the initiation of therapy. In addition, counseling and support groups are available at most hospitals for men who need the extra support.

DJ: What treatments are being researched? Are there any clinical trials currently available?

Hackensack University Medical Center is one of 29 nationally designated sites to conduct a Phase 3 clinical trial examining the effectiveness of avanafil (oral medication) for the treatment of erectile dysfunction after bilateral nerve-sparing radical prostatectomy. More information can be found at: http://clinicaltrials.gov/ct2/show/NCT00895011.

DJ: Thank you again, Dr. Shin. Is there anything you would like to add?

Men undergoing open radical or laparoscopic prostatectomy should not be discouraged if erectile dysfunction or incontinence occurs after the surgery. As previously mentioned, there are minimally invasive treatment options available to treat both conditions which can tremendously improve quality of life after curative prostate cancer treatment has been performed. The following websites can be useful to learn more about incontinence and erectile dysfunction:

http://www.webmd.com/erectile-dysfunction/default.htm

DJ: Where can patients get more information on the program at your center?

Please visit our Hackensack University Medical Center Department of Urology website www.humc.com/urologynew. In addition, men are invited to set up an office consultation to further discuss their continence and sexual health issues. Our address is 360 Essex St., Suite 403, Hackensack, NJ 07601. Office phone number is 201-336-8090.

View Dr. Shin’s comments on You Tube at:
http://www.youtube.com/vhsimons
covered topics such as PSA Testing, Quality of Life, Emerging Treatments, Prevention Strategies, Effective Use of The Internet, Becoming Your own Advocate and much more. The Prostate Net plans on incorporating these and future ARS questions into an unique format that will be housed on their website: www.theprostatenet.org. This offering will be used not only to provide valuable information to patients, but to also gather specific feedback on a series of “key” issues confronting prostate cancer patients while also providing a forum for patients to interact and communicate with each other as a way of empowering and securing support as they fight the fight against their disease. Data will be captured and form the basis of providing pertinent topics for future educational sessions.

“We will provide a package of the 10/6 event program information to prostate cancer support group leaders, health service professionals and any other educational resource for consumers and patients to enable them to enhance the quality of their educational efforts” commented Virgil Simons. “This material, in conjunction with the online resources to be provided, will serve to improve the process of informed decision-making by communities, patients, survivors and their families and caregivers.” AstraZeneca was the event’s principal sponsor. Also supporting the event: Abbott, Amgen, GTX, Sanofi Aventis, Purdue, and Genentech.

Following the October 6th model, The Prostate Net plans on convening a series of regional prostate cancer educational initiatives starting in 2010. For future dates and locations, please access www.theprostatenet.org.

About The Prostate Net®

Virgil H. Simons founded The Prostate Net in 1996 as a result of his own encounter with prostate cancer. When he was diagnosed, there was little to no readily accessible information to help prostate cancer patients and their families make informed treatment decisions.

Today, men diagnosed with prostate cancer can readily access The Prostate Net’s website to find information empowering them to make treatment decisions that ensure a desirable quality of life. Recognizing that people absorb information differently, The Prostate Net also features PodCasts, Web Casts and an opt-in cell cast network as well as a Toll-Free “Hotline” for those seeking one-to-one support. The website also is an educational vehicle for the public to learn about prostate cancer in general. The Prostate Net’s newsletter, “In The Know,” may be viewed on the website, but is available through free subscription as well as also distributed in conjunction with our other public education initiatives.

The job of raising public awareness about prostate cancer risks is far from complete. The Prostate Net seeks to expand its current initiatives through effective partnerships in disease education, community intervention and population research studies. This site has been designed to provide you with some of those tools and guidance that can be employed on a local basis to address particular issues for your community or organization. For more information on The Prostate Net, please go to: www.theprostatenet.org or call toll-free: 1.888.477.6763

For More Information Click http://theprostatenet.org/Symposium.html
physical functioning, bowel functioning and symptom distress after treatment. Interventions that address these and other challenges are important to help men and their intimate partners cope with symptoms that can affect their physical, emotional, and social well-being.

Process

The research team will administer questionnaires privately over the telephone to collect data about symptom distress and relationship functioning. A total of six educational sessions will also be conducted by telephone, so couples can participate in the privacy of their own homes. Using the telephone avoids the burden of transportation usually required for those who participate in studies, and eliminates the stigma often associated with seeking psychological or supportive care. Intimate partners of survivors will also participate in the study because they are a primary source of support for survivors. Partners will take part in each session. They will be encouraged to take an active role in the discussion of educational topics and help survivors use the information provided in ongoing efforts to manage symptoms.

While prostate cancer survivors can certainly benefit from medical information about symptom management, the PROCARE team believes survivors also need help in maintaining physical and emotional intimacy in spite of any on-going sexual, urinary, or bowel symptoms. Therefore, the study will evaluate which of two educational approaches is better for reducing symptom distress and improving relationships. One educational approach focuses on symptoms and medical options for symptom management. The second educational approach focuses on teaching specific coping skills to reduce symptom interference, enhance communication, and manage moods like sadness or anxiety.

Goal

Ultimately, the team hopes the findings from the PROCARE study will increase understanding of the psychosocial needs of African American prostate cancer survivors and help clinicians develop new ways to help survivors and their partners after treatment.

If you are interested in participating: The PROCARE study is still open. African American men who have had surgery for localized prostate cancer within the past two years, and their identified intimate partners, may be eligible to participate. Although the study focuses on North Carolina, those living out of state may also be eligible. Couples will participate in a six-week educational program over the telephone in the privacy of their own homes. Speaker phones will be provided. For more information, call 1-888-442-8202 or email PROCARE@ecu.edu. The study’s website is www.ecu.edu/procare.