Big Insurance: Men Not Worth Treating Like Women

Paul Beauchemin January 06, 2015

(Newswire.net -- January 14, 2015) -- New York, NY -- Cancer. It's one word that most people dread hearing. For men, it's prostate cancer that scares them more than any other type. For Raymond Fischer of Plainfield IL when he heard these words from his urologist he could barely breathe. His urologist told him he needed immediate surgery - what's called a radical prostatectomy - to "cure" him. At age 44 he knew his world was about to change forever.

Prostate cancer is more common than breast cancer and afflicts 1 in 7 men. About 233,000 men are diagnosed with prostate cancer each year and about 30,000 die annually from the disease. African-American men are 250% more likely to die from the disease than any other group. The chance of finding cancer in men is proportional to their age. For example, by age 60 there is a 60% chance cancer cells will be found in a biopsy.

Prostate cancer treatment, as currently practiced for organ confined cancer, involves either radical prostatectomy, where the prostate is surgically removed, or radiation treatments that provide similar results. Though the survival rate for both these procedures is pretty good, the side effects are life changing and often debilitating.

Most of the 233,000 men diagnosed don't need radical treatments, but none the less, they are subjected to them by urologists who seem to be motivated by greed, afraid of lawsuits or ignorant of alternatives.

A huge number of men still suffer for many years after surgery. A study by Andrew Vickers at Memorial Sloan Kettering Cancer Institute in New York showed that for radical prostatectomy 2 years after surgery:

- 20% of men have incontinence
- 81% of men have erectile dysfunction
- 12% of men have bowel dysfunction
- 100% of men have no ejaculation (obviously)

Radiation treatment can have similar results, though the side effects develop years later rather than immediately plus the risk of secondary cancer from the radiation increases.

After investigating treatment options Fischer realized that surgery could cost him his livelihood (he's a lineman for AT&T which often involves work outside in the worst conditions with no access to a bathroom). He was also told that taking too much time off would cause loss of the job and potential for earning a pension. In addition, prostate treatments negatively affect marriage and mental health for many men. Many men suffer depression and divorce after this life altering surgery. At his young age the thought of spending his life in diapers and loss of intimacy with his lover was too much to bear for Raymond and his family.
Raymond Fischer and family

With some internet research Mr. Fischer found an online community of men suffering from prostate cancer at the Inspire Us TOO Prostate Cancer forum. He was able to read many stories of men who had acquiesced to their surgeon and regretted having gotten a prostatectomy. Others had gotten radiation treatments and then gotten secondary cancers. But he also found something unexpected.

Inside that forum is a group of determined men who are willing to fight back against big insurance and big medicine by crowdsourcing their own research program. They believe that they have found a treatment that works nearly as well as surgery for many types of prostate cancers and avoids almost all of the side effects.

The treatment is called focal laser ablation (FLA). This is a treatment that ablates or destroys only the tumor and not the whole prostate gland. Women's breast cancer treatments have evolved from total removal of the breast (mastectomy) to removal of the small cancer nodules (lumpectomies). Nearly 80% of all breast cancer patients now receive the less radical

The FDA approved lasers for use in cancer treatment more than a decade ago. There is a large body of evidence that they are safe and effective. Just as a lumpectomy removes a small lesion inside the breast, laser ablation destroys just the tumor. So why are focal therapies not used to treat prostate cancer? Though prostate cancer is more common than breast cancer, Federal funding for prostate cancer is half of that for breast cancer.

There are some physicians that believe that prostate cancer can be effectively treated with focal laser treatment. They have been pursuing focal laser ablation and showing quite a bit of success. The development of more powerful MRI's and new ways to read images of the prostate allow the radiologist to see exactly where the cancerous tumors are. And with a laser that can be operated inside the MRI machine the physician can ablate the cancerous tumor in real time. MRI cannot see all the tiniest tumors but it has nearly 90% effectiveness at seeing the significant cancers.

Two such physicians are Dr. Dan Sperling of the Sperling Prostate Center in New York City and Dr. Eric Walser of University of Texas Medical Branch (UTMB) in Galveston TX. Both are working diligently to bring FLA to men with prostate cancer and both have had significant success with the treatment. And both are active contributors to the Inspire forum.

Dr. Sperling has performed over 400 procedures with the Medtronics Visualase Laser Ablation equipment. Medtronics claims over 1000 procedures have been performed at over 50 centers in the US (many for brain tumors). According to Dr. Sperling the procedure takes an hour and a half and patients are ready to go home 30 minutes later. He recommends a couple of weeks of rest but many of his patients resume their normal activities within a day, including sexual intercourse.

Sperling claims that none of his 400 patients has had serious side effects and it's the ideal treatment for many as long
as the tumor is within the prostate capsule and not too large in volume.

**Dr. Walser**, who moved to UTMB from the Mayo Clinic, has performed FLA on 85 men and has had very low levels of side effects (one with ED). Dr. Walser indicates that most cancers are now treated with focal therapies and there is no real reason that the prostate cannot be treated the same way. He also predicted that active surveillance treatments would move away from biopsies with advances in MRI. Walser said that many of the men he sees who have undergone multiple biopsies have prostates that look like hamburger.

Early evidence from focal patients seems to be very good. Nearly 90% recover urinary, erectile and ejaculatory functions within a month after treatment and are cancer free at their one year checkup according to Mark Emberton a professor of oncology, University College, London. Wayne (an Inspire forum member) who had focal treatment at the University of Colorado in 2009 is one of the early patients. Subsequent testing shows no recurrence of cancer and at age 66 he is living a fully healthy life with zero side effects and no cancer. Wayne is a major advocate of the treatment in the Inspire forums and an inspiration to many.

Though Fischer's cancer is more aggressive, his tumor seemed to be all within the capsule. So he borrowed some money and made an appointment with Dr. Walser at UTMB. Last August he had the procedure and within a couple of days he felt good and returned to his normal life.

But it seems that neither the medical community nor the insurers (including Medicare) want to look at the evidence and see that the same technologies effectively used to treat other cancers would be just as effective for prostate cancer. Nor do they want to look at the change of breast cancer treatments and transfer that to men. It's almost as if there is a bias against men and a deliberate attempt to restrict access to this important technology. They argue that prostate cancer is multi-focal (so is breast cancer). They argue that there is no long term benefit (though that didn't stop implementation of robotic surgery). In the end they seem mostly afraid of the change to their pocket book.

Insurers such as Aetna tell men who apply for reimbursement of focal treatments that such treatment is experimental. But no such requirement was made when robotic prostate surgery became available and Medicare covers proton beam therapy though only a fraction of men have been treated via that method compared to focal treatments. There were no 10 year studies to see the long term effects. In the opinion of many in this forum there is already sufficient evidence since focal treatments are done for many other cancers and failure to apply that principle across to different organs is a failure on the part of the insurers.

To the online community Aetna's position makes no sense. Surgery costs $55,000 plus treatment of side effects could cost nearly as much over a 10-15 year survival after surgery. So why is it that Aetna is refusing to pay for focal laser ablation (FLA)?

We asked Aetna about the issues raised here but they refused to answer our questions and hid behind their obtuse "experimental" position. Radiologists we spoke with indicated that it's mostly about money and loss of income to urologists.

Men at Inspire are quite cynical about the medical profession. The sentiment in many posts is that many urologists will recommend what is best for their wallet, not what is best for the patient. Frustrated by insurance denials for prostate cancer treatment that they believe is life saving and preserves quality of life, a men's online group takes on Big Insurance. They are paying thousands of out of pocket dollars to get the treatment they believe is best for them - focal laser treatment. They have been compiling their own data to help others rather than wait for some government funded study to say FLA is OK.

Focal treatments can cost anywhere from $20,000 to $35,000 and insurance typically does not cover it. In fact, the insurers do not even have a medical code for the treatment. So men like Raymond Fischer are forced to pay out of their pocket. Fisher's friends set up a fund raising benefit to help him with some of the medical costs, but most men are not that fortunate. Still it is a price that many are willing to pay.

So the men at Inspire are doing the record keeping of their own results and tabulating them with the goal of confronting the big insurers with some real life data. One man with the forum name MRFLYGUY is tabulating the results in a...
spreadsheet. John, whose forum name is JDAtlanta, is an insurance actuary expert and is documenting coverage by carrier and providing insight into how to file claims with carriers.

Women have been much more vocal about getting better treatment for breast cancer to the point of making football players wear pink shoes for a month. Men, most of whom are reluctant to even go to a doctor, are almost embarrassed to talk about prostate cancer. So there has been no push to get better treatment or to publicize their suffering from current treatments.

The advances in MRI technology have ushered in a new age of treatment options. First, with an MRI men no longer need to undergo a blind biopsy when their PSA reading is high. Blind biopsies have only a 35% chance of missing the cancer according to Dr. Laurence Klotz Chief of Urology Sunnybrook Health Science Center in Toronto, while more powerful MRI scans now allow radiologists to see significant tumors in the prostate with 93-97% negative predictive value.

Can you imagine a woman to allow a doctor to randomly insert needles into her breast without imaging? This happens every day with men's prostates biopsies.

There are many focal ablation treatments under development such as IRE, cryoablation and HIFU. What makes FLA unique is that the tumor can be ablated in real time while the radiologist is viewing the tumor inside the MRI. The radiologist can measure temperature and shoot laser bursts at the tumor while keeping the temperature under control to prevent damaging surrounding tissue. The tumor literally disappears in a matter of minutes.

So why is FLA not on a level playing field with other treatments that are more expensive and have worse side effects? Frankly, much of the problem is those who control men's health - the urologists - are trained as surgeons. Their self-interest is performing expensive surgeries. The potential loss of income and pressure on insurance carriers keeps this low risk option away from men.

The US Department of Health says it is concerned about overtreatment of prostate cancer. This is costing taxpayers enormous amounts of money and creates immeasurable suffering among men. Most prostate cancers are low to medium risk, yet urologists use radical treatments to serve their own self-interest and not the interests of their patients.

The US House of Representatives passed Resolution 353 in 2008 to try to bring attention to this, but it was just a half-hearted attempt to shed some light on the situation and not a real solution.

The solution will come when men en masse start to demand the treatments that will not only provide good survival rates, but not kill their quality of life. The men at Inspire know that only they control their destiny and vow to fight on until the tide turns.

If the length of the thread on the Inspire forum is any indication of how important these issues are (it's the largest inspire thread with over 2000 comments as of December 2014), this is a problem that men are desperate to find a solution to and willing to go the extra mile to solve.

But for now Fischer is waiting for results from his follow-up after his FLA. He is one of the higher risk patients. Because of his age there is likelihood that other treatments will be needed since prostate cancer just seems to increase with age. But future FLA treatments can be done with almost no risk of side effects and new technology could be developed before any radical procedures need to be done. For now though he is treasuring time with no side effects and the majority of his tumor obliterated.

Source: http://newswire.net/newsroom/pr/00086818-prostate-cancer-focal-laser-ablation.html