

NOTHING LEFT UNSAID | Ending the stigma of prostate cancer

Sep 6, 2017

"I've never understood why men don't talk about it. A couple of men I know who had prostate cancer, as far as them coming together — nobody talks about it. There are times men are bragging, you know, on this subject, but now it's just total silence," says "Joe" (not his real name) of Oxnard, who was 65 at the time of his prostate cancer diagnosis.

Can a disease be healed if patients do not and will not talk about it?

A prostate cancer diagnosis can fuel shame in a tough-guy culture that won't talk about it. The prostate gland is a male organ that produces semen. It's about sex. That's why it's uncomfortable to discuss. And it's about severe problems urinating. Some men have died rather than talk about it.

"Because men often equate having prostate cancer with sexual dysfunction and urinary incontinence, they suffer needless shame and can be reluctant to seek support," says Pam Brady, who is senior manager of Community Development at the American Cancer Society's Ventura County office.

"Like breast cancer, which was unmentionable 100 years ago and is now completely in the open," she says, "we're making progress against the stigma of prostate cancer."

September is National Prostate Cancer Awareness Month. But for all 12 months a year, American Cancer Society's hotline takes calls around the clock, 24/7/365, by bilingual operators. "For many men, the unnecessary embarrassment of a prostate cancer diagnosis causes them to be secretive in their search for support," Brady says.

The prostate is a walnut-sized organ just below the bladder, and both urine and semen move through it on their way out of the body. Almost 3 million U.S. men whose prostate cancer was treated at an early stage are living normal lives. While it can be fatal, most men diagnosed do not die from it.

Joe had a robotic prostatectomy in March. His surgeon, Dr. Marc Beagler, a urologist and director of robotic surgery at Community Memorial Hospital in Ventura, surgically removed Joe's prostate. Now, six months later, according to his Fitbit watch, Joe registers 10,000 steps a day.

"It was a blessing I chose that surgery, because the biopsy showed it was a very aggressive form of cancer. Once it spreads outside the prostate, my chances of survival would have been very reduced."

Joe has a romantic partnership with his wife, which is not the same as they had before surgery, but about intimate love, he says, "There are so many different things you can do. Some men just stop trying. They just opt out.

"If they get a diagnosis, they just go into their garage or into their man cave, and decide they don't need anything."

Prostate cancer develops mainly in men over 55. The average age at time of diagnosis is 66. About 90 percent of men diagnosed in early stages do recover. Men can address it by talking to a doctor starting at age 55. If their genetic risk is high — if they have a brother or father who had it — they should talk at 40. There are other genetic factors too: African-American men are twice as likely to develop prostate cancer as those of other ethnicities.

"Don" was 65 years old when he was diagnosed, and the Thousand Oaks man is now 77. "There has been almost no change in my life since the treatment 13 years ago," he explains. He has some problems with sex, but he and his wife work it out. "This is a couples' disease. Just like when a woman has breast cancer. You need that support."

Don's chosen treatment was brachytherapy, which is radioactive seed implantation; seeds last only temporarily, but fight the cancer around them while they are functioning inside the prostate. Before treatment, Don sought advice from different doctors. "It's a do-it-yourself disease," he says. Don's experience is that urologists are trained surgeons, so they tend to suggest surgery first. But there are alternative treatments. "Gather opinions from lots of sources, get advice from more than just urologists," he says. "We're really lucky there are so many good radiologists and oncologists here in Ventura County."

That's why he tells men and their families, in support groups he leads, that they should seek many opinions. "Having cancer is

so damn scary. The men that come to our groups are scared to death. They don't know you can learn to live with it.”

Where to go, what to do



The Cancer Support Community in Westlake Village offers many free Open House events, and educational events open to the public.

The Cancer Support Community of Valley/Ventura/Santa Barbara, in Westlake Village, offers many free services for people who do not know where to turn for help.

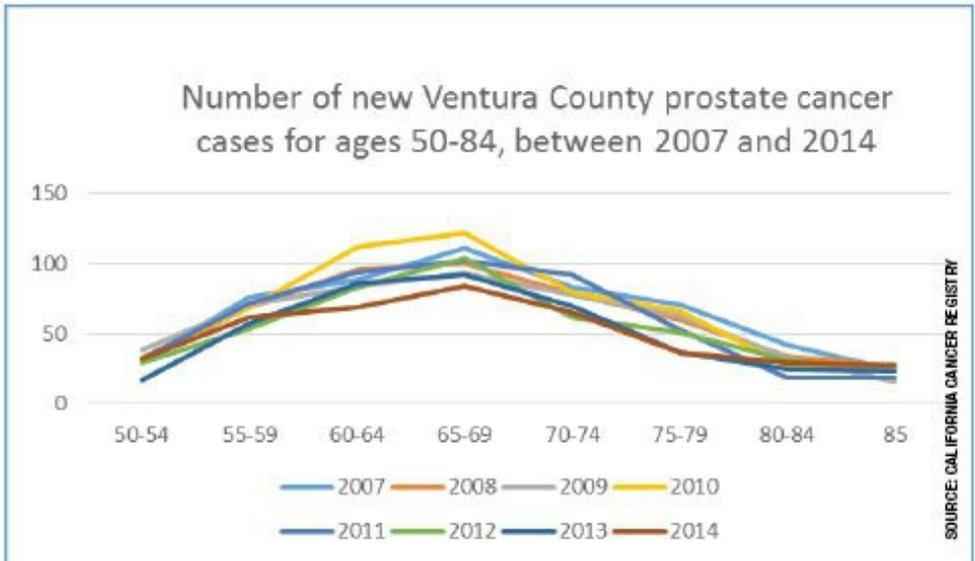
St. John's Regional Medical Center in Oxnard also offers free support services, including counseling and nutrition advice, as meal-planning is critical to recovery.

Patients from rural areas who travel long distances into county hospitals for treatment can utilize the American Cancer Society hotel program for reduced-rate lodging while in the area.

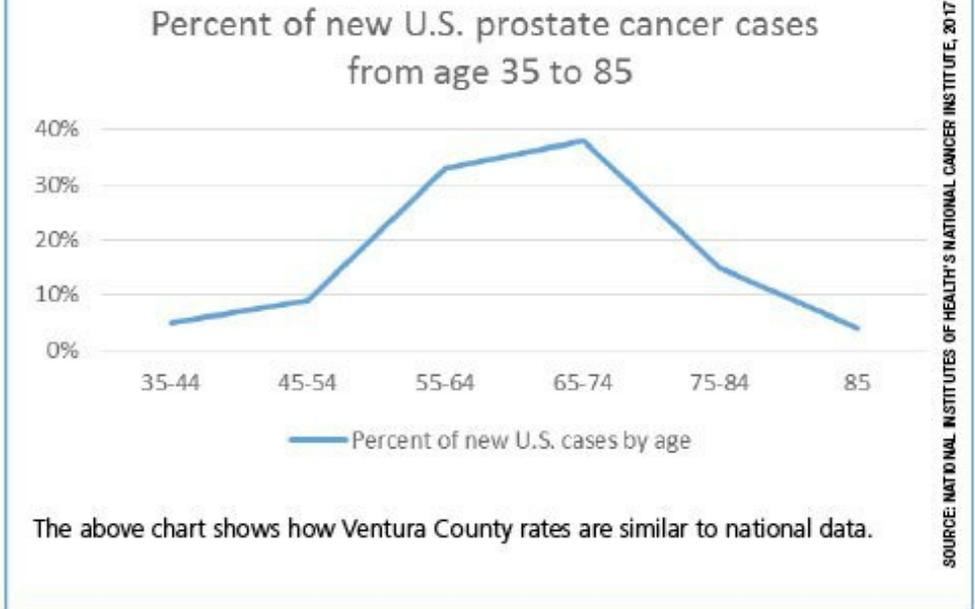
For 14 years, “Harry” (not his real name) of Ventura has enjoyed good health following his 2003 brachytherapy treatment. “I basically do everything I used to do,” the 87-year-old says. For many years he too facilitated support groups where men could feel safe about talking.

He invites men to bring their wives or partners or adult children — whoever they need for support. “There is still stigma, but it's better than it used to be, and they open up in my group. One does not have to sneak away for information,” Harry emphasizes.

Early detection is key



In the above chart, the "2014" line shows the downward trend in the number of new cases found in men age 60-70, compared to previous years.



The above chart shows how Ventura County rates are similar to national data.

Source: California Cancer Registry In the above chart, the "2014" line shows the downward trend in the number of new cases found in men age 60-70, compared to previous years. Source: National Institutes of Health's National Cancer Institute, 2017

Prostate cancer is the most frequently diagnosed cancer in men after skin cancer, and is the third leading cause of cancer death, after lung and colorectal cancer. Getting tested early offers the best chance of survival for all ages, all ethnic groups and all family histories.

About one in six men will be diagnosed with it during their lifetimes. An estimated 161,360 new cases will be diagnosed in the U.S. during 2017. About 16 percent of them will likely be fatal.

Census data show Ventura County's population is just above 850,000, and analysts consider about 207,000 male county residents to be "at-risk" due to age or ethnicity. Smoking increases the risk of fatal prostate cancer.

About 80 percent of newly diagnosed prostate cancers are localized, meaning they are discovered while still in the prostate gland. About 12 percent are regional, meaning they have spread to nearby tissue. About 5 percent are distant, having spread to

other parts of the body. For local and regional stages, the 10-year survival rate is about 98 percent, and the 15-year survival rate is 96 percent. The survival rate for metastasized cases is about 30 percent.

What's known, what's unknown

Many prostate tumors grow so slowly that they never need treatment because they never become dangerous. In such cases, doctors recommend continued observation, called “active surveillance.” In this way, men diagnosed with low-risk cancer get regular checkups, delay treatment and avoid side effects that might include impotence and incontinence.

Some autopsy studies demonstrate slow growth dramatically. They show that older men who died of other causes also had prostate cancer that never affected them during their lives. Neither they nor their doctors even knew they had it.

Two common screening tests are the digital rectal examination, called DRE, and the PSA blood test. Sometimes a doctor can feel a tumor, or enlargement of the prostate, during a manual DRE. The PSA test is a blood test that measures a man's level of prostate-specific antigens. An abnormally high PSA indicates that cancer might be growing.

Neither the DRE nor the PSA test alone is 100 percent accurate, so both are used together. If they both indicate cancer might be present, doctors do a biopsy. A biopsy is a surgery to remove a sample of the prostate to be tested in a laboratory.

A biopsy is currently the only way to know for certain if cancer is present.

“We're lucky to have the PSA test,” Don believes. “It's easy to be tested. I get a test every three months, which is fine unless you have a very aggressive type. It can be more dangerous if you have it in your family.” Medicaid and most insurance policies cover regular testing. Without insurance, tests cost about \$50-\$80, but many neighborhood clinics offer free or reduced-cost tests to men without insurance.

Some experts consider the PSA test to be too unreliable to use at all. PSA levels rise naturally as men age, and because of this, levels are always fluctuating, making them unpredictable. Like a car's tire pressure that is always decreasing — yet rises and falls with hot weather or cold weather — if it's not monitored regularly, there's big trouble.

Ongoing research to save lives



r. Marc Beaghler, a urologist and director of robotic surgery at Community Memorial Hospital in Ventura

Controversy surrounds the PSA test because in the past, if it suggested the cancer was present, some men would get treatment without first having a biopsy to confirm the cancer. These treatments caused problems with urinating so severe that they disrupted daily routine and inability to maintain an erection for sex. Some of the men learned later that they never actually had

cancer, because their PSA test was not accurate. Higher cancer rates were recorded in the 1990s because of this.

The debate continues because the U.S. Preventive Services Task Force earlier this year recommended not using the PSA test.

For many men, the only reason they have an annual physical at all is to get the PSA test. For that reason, CMH's Beagler is a vocal critic of the recent recommendation. He believes the decision to get the PSA test, or not, should be made by the patient and his doctor, and not some faraway task force.

"Unfortunately, I have a real issue with this task force," Beagler says. "They are doctors who are not specialists in prostate cancer care. They are not urologists. That may remove bias, which is a good thing, but they do not care for men with prostate cancer, they don't know what patients go through, and I don't believe they know what the issues are."

Beagler has treated his patients with radiation, chemotherapy, surgery or brachytherapy. There are more options as well.

Beagler sees a real impact. "Now we see patients coming in with later-stage prostate cancer because of these recommendations that were first put out by the task force back in 2012," he says. "Now we are seeing patients who would have come in earlier. And now they come in with higher PSA levels, and higher-grade prostate cancer."

"One of the biggest points that is overlooked is that men do not get annual physical exams reliably, like women do," Beagler says. "Women see a doctor every year. Men are unreliable about this. If men would see a doctor, just once a year, just for the PSA test, they would know about their prostate health."

"This same task force (the USPSTF) made a recommendation some time ago that mammograms for women be cut back," Beagler notes. "There was backlash from women, and it was later changed, so that insurance would cover more regular mammograms. Women fought back because they care about their health."

"After the task force's no-PSA-test recommendation, men did nothing."

The way forward



Dr. Jennifer Kujak, a diagnostic radiologist and director of oncology imaging for Rolling Oaks Radiology/Radnet

Dr. Jennifer Kujak, a diagnostic radiologist and director of oncology imaging for Rolling Oaks Radiology/Radnet, detects prostate cancer using imaging. "Exciting and revolutionary" is how she describes a new radiology testing product called Axumin. Right now, this test is only for recurrences, when prostate cancer grows again after treatment.

"We are on the edge of something that is really going to take off for cancer imaging and greatly benefit patients" Kujak says.

Tests for recurrence previously included CT scans and bone scans to detect where the prostate cancer had spread. This new scan uses PET — positron emission tomography — to detect spreading, with great accuracy.

A radioactive-labeled protein specific to prostate cancer, and not to other cancers, is injected into patients before the PET scan. This protein attaches to prostate cancer cells and then “lights” them up for detection by radiologists. This is like turning on a porch light in the dark, over a door not visible at night; once a light is turned on, the door is obvious. The protein “lights up” cancer cells so they can be seen easily.

In one case, prostate cancer was discovered in a patient’s brain, in another case it was found only in a man’s chest, and in another case was found only in the lung. Previously, these areas of prostate cancer spread would not have been detected or have been thought to be prostate cancer spread, because historically prostate cancer spreads near the prostate first, then to distant areas. These cases show that it can spread far away from the prostate, and “skip” the pelvis. This new innovative scanning method located these recurrences, making them treatable by doctors who then knew where the cancer was.

“This is the astonishing aspect of this innovation. Axumin is teaching us about how prostate cancer behaves,” Kujak says of the discovery that the tumor spread so far from the expected location in the body. In the past, a patient might have a recurrence that advanced to fatal levels before being detected.

“We don’t understand prostate cancer as well as we think we do. That’s why this test is so exciting,” Kujak says about the surprising location of the tumors.

“Axumin PET/CT imaging will change how we think of and manage prostate cancer,” Kujak says.

New science might change how doctors manage it. But only talking openly about stigma will change how ordinary people manage it.

FIND SUPPORT

Cancer Support Community (CSC) of Valley, Ventura, Santa Barbara

530 Hampshire Road, Westlake Village 91361

www.cancersupportvvsb.org

Hosts three free prostate cancer support groups each month: **805-379-4777**

St. John’s Regional Medical Center

Cancer Center: 1600 N. Rose Ave. Oxnard 93030

Many free services for prostate cancer patients, including critical nutrition counseling: **805-988-2641**

American Cancer Society’s Ventura County hotline

Answered 24 hours a day, seven days a week, 365 days a year: **800-227-2345**.

2186 Knoll Drive Ventura, 93003. Office number: 805-644-4237

FOR MORE INFORMATION:

http://ccrcal.org/Data_and_Statistics/index.shtml

cancer.org/research.

www.cancer-rates.info/ca/

<https://seer.cancer.gov/statfacts/html/prost.html>

www.health.harvard.edu/mens-health/2017-annual-report-on-prostate-diseases