

The Hidden Toll of Cancer Testing

Research Shows That Even Benign Results Have Emotional and Financial Consequences

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Cancer researchers are learning that a problem once considered minor in the fight against cancer -- false-positive test results -- in fact have long-term psychological and economic consequences.

And researchers say these costs need to be considered before a patient undergoes screening.

It has long been recognized that cancer screening sometimes finds abnormalities that later turn out to be benign. So-called false positives naturally create a great deal of anxiety until a biopsy or other testing reveals that a patient is cancer-free. The assumption has been that as long as a person eventually finds out the first test was wrong, any distress is transitory and minor -- and that the cost of additional testing is worthwhile for the peace of mind it brings.

Instead, several new studies reveal that the impact of false positives can be serious and persist far longer than expected. One recent study showed that significant numbers of men who had a false positive on a prostate-cancer screening test still experienced anxiety several weeks after learning they were cancer-free. And the medical costs of unnecessary additional testing can be considerable. In a study published this month, researchers found that men and women who had false-positive screening results averaged more than \$1,000 each in follow-up care in the year following the test.

The emerging research will likely fuel the debate over who should get screened, especially for those who are at only average risk of getting cancer. As screening increasingly moves to easier, noninvasive methods, such as blood, urine or saliva tests, the number of people getting tested is increasing, and so is the number of false positives. Many of these newer tests use technologies that are extremely sensitive and are more likely to pick up small abnormalities that actually aren't cancerous.

Some tests, such as the prostate specific antigen, or PSA, test for prostate cancer and the spiral CT scan for lung cancer, already are widely used in the general population despite a lack of conclusive clinical-trial data showing that they save lives. Researchers are cautioning that patients are ill-prepared for the consequences of the many false positives these screens can generate.

There are no guarantees in screening. Cancers still can be missed, and the results of follow-up testing are frequently inconclusive. Add in the psychological and financial impact of false positives, and the results of cancer screening can wind up being the opposite of what patients seek: Rather than peace of mind, they can come away with more questions, distress and financial expense than they bargained for.

Timothy J. Wilt, a professor of medicine at the Minneapolis VA Center for Chronic Diseases Outcomes Research, says doctors often don't discuss these issues with patients. Even when they do, he says, "it is one small component going against a sea of basic promotion" of screening.

Roo Harris, 58, of Littleriver, Calif., says doctors underestimate the distress a false positive can cause and don't adequately prepare people. A few months ago, his annual PSA test showed elevated levels. "It sounded like it could be cancer," he said. He had a biopsy, and all 10 tissue samples were negative. But the benign biopsy didn't mean he was cancer-free, his doctor explained, just that no cancer had been found on that test. Follow-up PSA tests were inconclusive, and he continued to worry.

"I lived in fear, and wasn't enjoying living," Mr. Harris says. When his doctors suggested a second, more extensive biopsy, Mr. Harris balked. Instead, he preferred to continue to monitor his PSA levels. His decision to take more control, he says, gave him a sense of relief he hadn't felt for months.

A study published in November in the American Journal of Medicine found that a significant proportion of men who had an elevated PSA test followed by a benign biopsy result still felt negative psychological effects from the experience six weeks later. Researchers studied 400 men from three Boston-area hospitals who all had PSA tests in the same period. One group had suspicious PSA results followed by a benign biopsy. The other group had a normal PSA test result.

Even six weeks after the biopsy results, 49% of the men in the group with the suspicious screening test said they still thought "a lot" about cancer, compared with only 18% in the control group. These men viewed their chances of getting prostate cancer as being above average in higher numbers than the other men, despite the fact that there was no evidence supporting this idea.

Mary McNaughton-Collins, an assistant professor of medicine at Harvard Medical School and the lead author on the study, says the study results made her realize "we are creating this new group of men who are in limbo about cancer." These men are never completely sure that they don't have cancer, she says.

The health impact of this anxiety is still being worked out. Research on stress in general suggests that people who have chronic stress may be more susceptible to colds and other infections. Stress also can irritate the digestive system, cause diarrhea and often is related to weight gain and tension headaches, and in exacerbating some skin conditions such as hives and eczema.

Dr. McNaughton-Collins says she was struck by the fact that, among the men who were in the group that had a benign biopsy, 25% of them said they had additional biopsies because their doctors wanted to make sure that the first one truly was benign, adding to the medical costs associated with false positives.

The potential cost associated with such additional testing is staggering, given the prevalence of false positives. In two of the most widely used cancer-screening tests -- the PSA for prostate cancer and mammography for breast cancer -- some studies have estimated that more than half the men and women screened annually will receive at least one false positive test result in the course of their lifetimes. In a study of 1,087 people in Detroit who received tests for prostate, ovarian, colorectal and lung cancer as part of a wider national screening trial, 43% of the participants had at least one false positive, according to Jennifer Elston Lafata, director of the Center for Health Services Research at the Henry Ford Health System in Detroit.

In a study published this month in the journal *Cancer Epidemiology, Biomarkers & Prevention*, Dr. Lafata measured the economic cost of the false positives in that national screening trial. The study found that in the year following the false positive, follow-up medical care cost \$1,024 more for women and \$1,171 more for men than for those who had negative screens. The additional testing prompted by the false positives included blood tests, biopsies, colonoscopies, ultrasounds and X-rays. Moreover, when the researchers looked at a smaller group of people who had false-positive chest X-rays for lung cancer, they found that the participants lost on average 1.5 hours of their time pursuing follow-up care. "At a population level, 1.5 hours add up quickly to a substantial time investment," the researchers wrote.

Dr. Wilt at the Minneapolis center and Melissa R. Partin, associate director of the center, are studying ways to reduce the potential anxiety associated with cancer screening. Their research suggests that doing the test where there is a short time between the test and the notification of results can help reduce anxiety. Some centers that do mammograms give women results on the spot. Someone who feels anxious about certain tests should discuss this with a family doctor, who can assess based on family history and personal health which tests are likely to be beneficial. Consumers also should do their own research to weigh the likelihood of a false positive against what is known about a test's ability to lower a person's risk of dying from cancer.

Janine E. Guglielmino says she understands the costs of false positives. Off and on for the past 10 years, the 33-year-old spokeswoman for an Ardmore, Pa., nonprofit has had irregular Pap smears that turn out to be false positives. "I feel relief when the Pap smear comes back negative, but the feeling of anxiety never completely goes away," Ms. Guglielmino says.

At one point, she considered stopping screening and accepting the risk that any cancer might be caught late. In the end she decided to continue the screening, but she switched to a specialist in cervical cancer rather than a regular gynecologist, which made it easier to live with the tension. "I feel calmer now knowing that if I do get cancer," she says, "it will be caught early."

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