ANALYSIS HEALTH SYSTEMS

Uncertainty Around New Health-Care Law Could Affect Those at Risk for Breast Cancer

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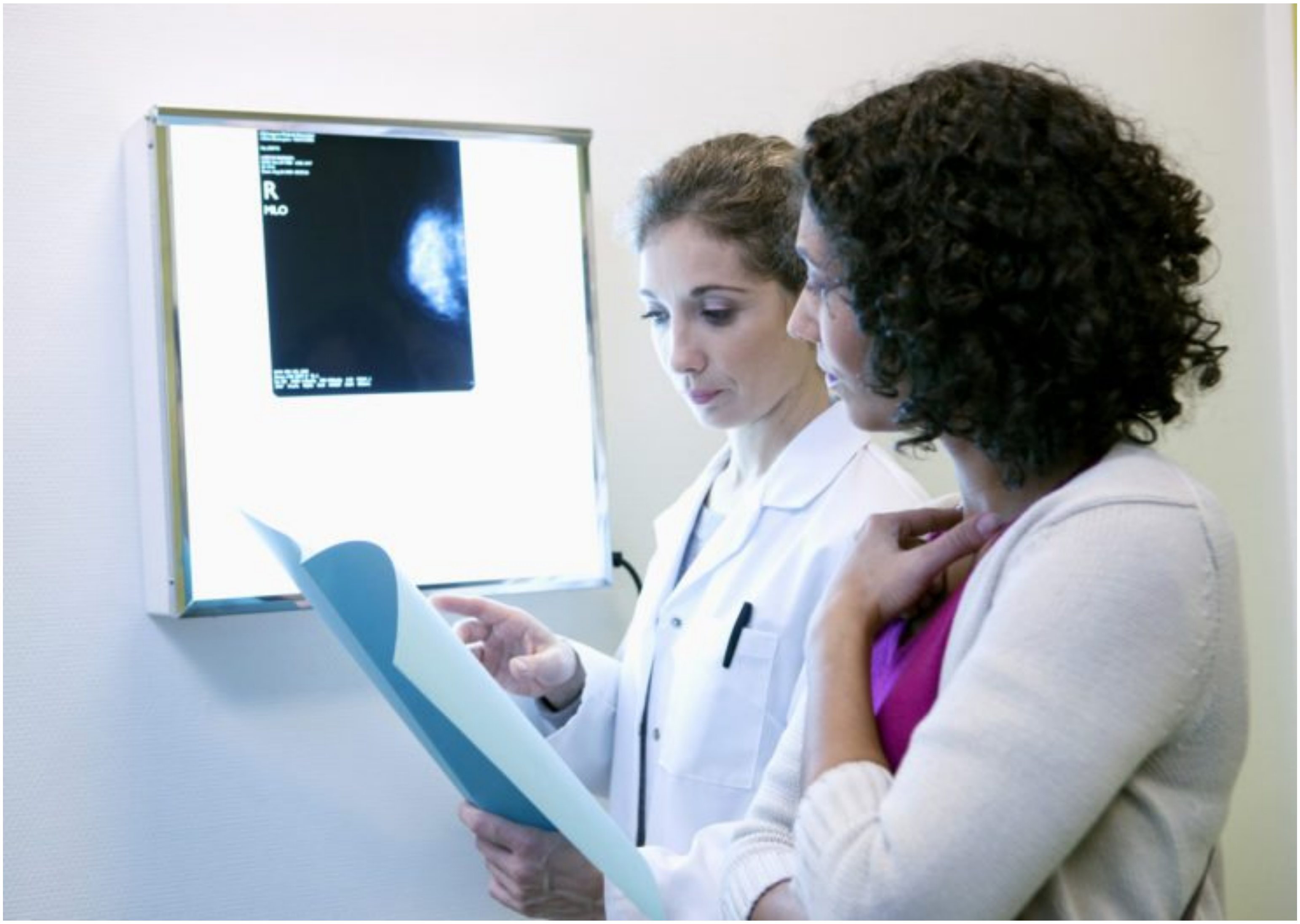
Knowledge that you have the BRCA1 or BRCA2 mutation can literally be a matter of life or death. But the ability to access, protect, or act on that knowledge may now be at risk.



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In December 2014, I found myself staring through tears at a letter that read "positive for a deleterious mutation." It is no exaggeration to say it changed the course of my future. Armed with the confirmation of my genetic connection to hereditary breast and ovarian cancer syndrome, I was able to consult with doctors, weigh risks, and make informed decisions. I didn't have to wait until the breast cancer cells that had invaded my aunt, great-aunt, and great-grandmother's bodies found me; instead, with the help of my health insurance, I could take control.

Mutations like I have in the BRCA1 or BRCA2 genes give women up to an 85 percent chance of developing breast cancer by age 70. The chances of having ovarian cancer are also greatly increased—

between 40 to 60 percent with a BRCA1 mutation and 16 to 27 percent for BRCA2. Approximately one in 300 to 500 women have this mutation.

Knowledge that you have this mutation can literally be a matter of life or death. Now, with the future uncertain as to what will replace the Affordable Care Act (ACA), the ability to access, protect, or act on that knowledge may be at risk.

The ACA designated BRCA testing as preventive care in 2013, making it possible for individuals who have marketplace or most employer health plans, and whose family history qualifies them as "high-risk," to have genetic testing and counseling for a BRCA mutation covered with no cost-sharing. Before this change, out-of-pocket costs for BRCA testing could run up to $4,000. According to Lisa Schlager, vice president of community affairs for Facing Our Risk of Cancer Empowered (FORCE), this has led to an increase in women being tested.

Preemptively finding out one has a BRCA mutation affords patients options like participating in intensive screenings, taking preventive medication, or opting for risk-reducing surgeries like prophylactic mastectomies to avoid related cancers. Surgical ovarian and fallopian tube removal, for example, reduces the risk of stealthy and highly fatal ovarian cancer by 80 to 90 percent; it can also reduce breast cancer risk by up to 50 percent. For those who learn about their mutation after a cancer diagnosis, this information can also play a valuable role in treatment plans, like using targeted therapies or close monitoring for a recurrence.

Judging by the current incarnation of the proposed plan to replace the ACA, the American Health Care Act (AHCA), Schlager and other experts believe that the consequences of a new health-care law will be varied for "previvors" (those with a genetic predisposition to cancer who haven't had the disease) and cancer survivors.

Risks for “Previvors”

Preventive care—which, again, currently includes yearly mammograms starting at age 40, in addition to genetic counseling and BRCA testing for those determined to be at risk—still appears to be covered under the AHCA. However, whether that will continue remains to be seen.

As Schlager noted in an interview with me, the level of discussion around the plan has not gone into the “nitty-gritty.”

“There’s still a lot of negotiation that needs to take place,” she says. “We’re hopeful that [cutting preventive services] won’t be the case—that they’ll see value in prevention—but nothing is set in stone yet.”

Even so, Professor Mark A. Rothstein, the founding director of the Institute for Bioethics, Health Policy and Law at the University of Louisville School of Medicine, anticipates that genetic testing, due to its high costs, may be one of the first services to go.

If that is the case, direct-to-consumer testing may be an option for those who can afford it; Schlager also hypothesizes that many traditional labs will offer financial assistance to make testing more affordable. Still, the costs of BRCA testing skew higher for those who do not already have an identified mutation in their family as they undergo comprehensive, rather than specific, mutation panels. Already, as previously noted, women must pre-qualify to be covered under insurance.

And costs do not end with testing alone. As Schlager describes, there are known disparities in care seeking—not only in genetic testing but also when a woman goes to the doctor for follow-up treatment—that are largely contingent upon insurance coverage. She noted that “the financial aspect of prevention and early detection and treatment” has a more severe effect on women of color and low-income women.

While coverage for preventive surgery was not mandated under the ACA, with its repeal, Rothstein expects co-pays to rise for a wide range of services, thus increasing out-of-pocket costs. However, neither Schlager nor Rothstein expect that existing insurer coverage of preventive surgery, outside of co-pays, will be profoundly affected. This is largely, they say, because most insurers follow National

Comprehensive Cancer Network guidelines, which support risk-reducing surgeries for those with mutations.

Schlager said that under the ACA, so-called previvors have seen high deductibles around the costs of screening MRIs, as they were not included as preventive services.

“But on the flip side, we saw important prevention services available at no cost which was a huge plus for the entire U.S. female population,” she said. Furthermore, those deductible prices may not decrease.

In addition, the AHCA’s proposed defunding of Planned Parenthood could be problematic for high-risk women who rely on the organization for care. According to Planned Parenthood’s 2014-2015 annual report, the organization performed more than 350,000 breast exams in that time period. Schlager also noted Planned Parenthood’s affordable care when it comes to providing oral contraceptives, which can reduce the risk of ovarian cancer.

“So that’s critical for a high-risk woman to have access,” she said.

What Happens to GINA?

In the midst of all this murkiness, some protections guaranteed under the Genetic Information Nondiscrimination Act of 2008 (GINA) may also be in danger. Under GINA, Rothstein explained, federal law “prohibits discrimination on the basis of genetic information in two areas: employment and health insurance.” This only applies to people who have not yet developed the disease or condition they are predisposed to manifest.

HR 1313, the Preserving Employee Wellness Programs Act currently in committee, could effectively circumvent GINA in some respects. A letter to the U.S. House Committee on Education and the Workforce that FORCE co-signed opposes the bill and describes it as giving employers the ability to “inquire about employees’ private genetic information or medical information unrelated to their ability to do their jobs.” The letter also noted that HR 1313 would allow penalties up to many thousands of dollars per year if employees do not disclose information from genetic tests that they, their spouses, their children or their other family members have had, or if they do not reveal their families' medical histories. "Allowing penalties of this magnitude would clearly allow employers to coerce employees into revealing their private genetic information," it concluded.

"Ultimately it's just another way for the businesses to pass additional health-care costs onto their employees, because these 'incentives'—they're not incentives. They're penalties for not participating because you're fearful of revealing personal information," said Schlager in an interview.

If passed, HR 1313 (which might be included in the ACA replacement bill) would also affect women who have opted for direct-to-consumer rather than doctor-ordered testing.

Dr. Robert Green, who directs the Genomes2People Research Program in the Division of Genetics at Brigham and Women's Hospital and Harvard Medical School, explained to me, "As sequencing costs come down, there are companies providing … genetic testing for anyone who wants to order it. There are going to be a lot more people finding out that they are carrying one of these mutations, and they're going to have to decide at what point do they bring it into the medical system."

Should HR 1313 pass, Green said, there is "potential for this to have a chilling effect on people wanting to learn about and use genomic information."

Currently, the American Health Care Act keeps the ACA's prohibitions on insurance companies from banning individuals based on pre-existing conditions. While unlikely, until its final version is passed, this could change.

The uncertainty of it all could lead people to selectively edit their medical histories.

"This is an odd situation developing because you're going to have people sort of trying to gauge when they tell their doctors about this genetic information that they know because they might be switching insurance plans and things like that, if indeed we lose some of these protections," Green said.

Rothstein believes that people are already withholding genetic information. "It's a concern for doctors because how can you treat someone effectively when you only have a percentage of the information you need?" he says.

On behalf of the hereditary cancer community, FORCE representatives told me it intends to ″fight any efforts to weaken genetic protections now and in the future.″

Current Cancer Survivors

Right now, as reported by the *Washington Post*, the AHCA provides for states to receive $100 billion over 10 years via a new Patient and State Stability Fund “for safety-net needs and possible ‘high-risk pools’ for consumers with expensive medical conditions”—such as cancer.

“If there are high-risk pools … those patients are going to see the worst in the way of financial burden under a new health system,” Schlager said. Prior to the ACA, 35 states and Washington, D.C., had high-risk pools, as the Pew Charitable Trusts’ Stateline blog noted, “for uninsurable people with serious and chronic health problems.”

However, these pools “charged premiums up to 250 percent of the prevailing rate, and some of them had long waiting lists. Most of them denied coverage for pre-existing conditions—their reason for being—for up to a year after enrollment.”

What these high-risk pools could look like is not yet clear.

Furthermore, while lifetime caps are currently not on the table, Schlager describes a disturbing scenario, should that change: “Whereas before cancer patients might have to declare bankruptcy because they’ve hit their [lifetime] cap with their insurance, that went away under ACA. A person who has cancer, especially someone who has ovarian cancer, where they might have to go through four, five, six regimens of treatment … or a metastatic patient who has to come in and out of treatment, they could ultimately reach that cap.”

Hopefully whatever replaces the ACA, whether it’s the American Health Care Act or another iteration, will afford enough protections that women feel comfortable sharing their results with their doctors and seeking follow-up care. However, as Schlager describes, “there are multiple potential replacement plans out there.”

“Most of them have gaps and many of them don’t even address some of the issues that we’re concerned about here in the high-risk community," she said. "That's why we're hoping 'replace' is more like 'revise.'"

In the meantime, many highly anticipated changes are striking fear in the hearts of BRCA mutation carriers. Breast cancer survivor Jennifer Elliott, in her 40s, recently switched from an employer health insurance plan to an ACA one after a period on COBRA.

She is currently healthy, and has taken preventive measures to try and stay that way, including chemoprevention and a salpingo-oophorectomy, but is greatly concerned that she will be left with no coverage post repeal.

She told me, "While I am free of cancer now, all the preventive measures are simply risk reducers, and not a guarantee against future cancers."

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