

Why aren't under-65's diagnosed with cancer until the disease is advanced?

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With cancer, the earlier you are diagnosed, the great your chances for

survival. It is easier, and more effective, to treat a cancer that is in its early stages and hasn't spread to other parts of the body. And that's why health care providers stress the importance of regular cancer screening.

But late-stage diagnosis is still a major problem, especially for breast and [colorectal cancer](#). And rates of late-stage diagnosis are higher for younger populations than older populations.

As a professor of [health economics](#), I wanted to understand why so many adults under 65 with [cancer](#) weren't getting diagnosed as early as they could be.

The most obvious reason may be the lack of good [health insurance](#) and regular guidance by health professionals for people who are middle-aged and younger. But that is not the whole story. Based on what we found, it looks like where you live, and what regulations that state has for health insurers, may have a major impact on whether you are diagnosed early or not.

Under-65's at greater risk of late diagnosis

The chances of developing cancer increase with age. For colorectal cancer, about 42% of cases are in individuals under 65, and for breast cancer, this is about 62%. Both diseases can affect people as young as 20.

My colleague and I compared and contrasted data across all individuals diagnosed with breast or colorectal cancer from 2004-2009 (before the Affordable Care Act was passed in 2010) in 40 states, using the United States Cancer Statistics database.

We [found](#) that, across individual states in the US, from 54% to 60% of colorectal cancer cases were diagnosed at a late stage, while 24% to 36%

of breast cancers were diagnosed late. The most startling fact is that people under age 65 were at much greater risk than older people were of having their cancers diagnosed late.

People under 65 had more limited access to health insurance before 2010

Perhaps an important reason for this disparity is that individuals under age 65 had much worse options in terms of health insurance than the older group during this period.

Most Americans 65 and older are covered by Medicare. In contrast, before the passage of the ACA in 2010, many middle-aged and younger Americans could not afford health insurance and did not see doctors regularly.

If one does not have health insurance, or has the type that requires high out-of-pocket costs, one is less likely to seek cancer screening tests. And the best colorectal cancer tests – colonoscopies – are expensive and were not always covered by insurers before the ACA, which led to high out-of-pocket costs. Poorer individuals were unable to afford colonoscopies, even when they had health insurance. The Affordable Care Act has removed these out-of-pocket costs for cancer screening tests, so these tests are now more affordable.

The data we examined didn't specify whether a person had insurance or not at the time of their diagnosis. But it did include data measuring the percentage of people under 65 without health insurance in the cancer patient's county of residence. We found that living in a county with a higher percentage of uninsured adults was associated with a higher percentage of cancer patients being diagnosed at a late stage.

State regulations play a role

We also examined three specific regulations governing the insurance industry to see if that could predict higher or lower chances of being diagnosed late.

The first was a law requiring insurers to allow people to make an appointment with a specialist, without needing a referral from their regular doctor. Having to seek permission could result in additional delays, red tape or extra payments, all of which could discourage someone with "troubling" or unexplained new health symptoms from seeing a specialist. So having laws to help remove obstacles to see specialists may be especially beneficial to younger people.

The second regulation is one prohibiting insurance companies from rewarding doctors for prescribing cheaper services, which might include self-breast exam for breast cancer or a fecal smear test for colorectal cancer, which are much cheaper – but less effective – alternatives to mammograms and colonoscopies. These cheaper tests aren't good at detecting cancer in its early stages. Mammograms and colonoscopies can detect the early stages of cancer or precancerous changes that are likely to evolve into cancer. That means they are effective at preventing, as well as detecting, cancer.

The third regulation we examined was one that would allow nurse practitioners to open and operate health clinics without having doctors on staff. Some states have passed this kind of law to improve access to health care, especially in areas where physicians are in short supply.

In states without this regulation, insurance companies are not required to reimburse the nurse practitioners for services they offer outside of physician offices. We expected this regulation to be important because in areas with health care shortages, providers do not have adequate

resources to talk to patients, discuss their symptoms and urge them to seek cancer screening. The lack of access to health professionals is even greater for uninsured people.

We found that younger people (under age 65) living in states that have adopted any of these patient-friendly regulations are less likely to be diagnosed at a late stage of their cancer than other people like them living in areas without any of these three insurance regulations.

But, this doesn't "prove" that living in states with these regulations causes young people to be diagnosed sooner for their cancers. It just means that these states had fewer obstacles to seeing specialists, getting the most effective diagnostic tests or access to care overall.

Will we find different results because of the ACA?

Keep in mind that this study examines the time period before the Affordable Care Act was passed in 2010. So we are now conducting a follow-on study using data from 2010-2015, when insurance markets were vastly improved by provisions in the Affordable Care Act. More people, especially younger adults, have insurance, and it is easier for people who are sick to get insurance as well.

And the ACA has removed some of the obstacles to getting a timely cancer diagnosis. For instance, the ACA requires private insurance companies that developed new insurance packages since 2010 to cover mammograms and colonoscopies with no out-of-pocket costs to patients who meet cancer screening guidelines' age requirements. These guidelines state that women 40 and over should be screened for breast cancer using mammograms, and adults 50 and over should be screened for colorectal cancer using colonoscopy.

Also, [cancer screening](#) guidelines have expanded to recommend that

individuals with documented above-average risk be screened at younger ages than the normal guidelines, as recommended by their personal physician.

With better insurance coverage available under the ACA, we expect that the fear of knowing about one's disease will be replaced by empowerment to do something about it. Once we have completed the update to this study, we will know if and how much the situation may have improved for younger adults in the US.

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