

Nearly Everyone With Mild Cognitive Impairment Goes Undiagnosed

Millions of older adults likely have minor memory issues that can later become dementia. But only a fraction of them are diagnosed early enough for new treatments to stand a chance.

CT scans showing brain atrophy associated with Alzheimer's disease. PHOTOGRAPH: CALLISTA IMAGES/GETTY IMAGES



Millions of people over the age of 65 likely have mild cognitive impairment, or MCI—minor problems with memory or decisionmaking that can, over time, turn into dementia. But a pair of recent studies both concluded that 92 percent of people experiencing MCI in the United States are not getting diagnosed at an early stage, preventing them from accessing new Alzheimer's treatments that may be able to slow cognitive decline if it's caught soon enough.

"We knew it was bad. But we didn't know it was *that* bad," says Ying Liu, a statistician at the University of Southern California Dornsife's Center for Economic and Social Research and a researcher on both studies.

In the first, published this summer in [*Alzheimer's Research & Therapy*](#), Liu's team aimed to figure out how often MCI is being diagnosed—and how often it's overlooked. Using data from the [*Health and Retirement Study*](#), a longitudinal survey of some 20,000 people in the US about a wide range of age-related factors, Liu built a model predicting the number of expected MCI diagnoses for the over-65 population overall: about 8 million. Then, Liu's team pulled data from all Medicare beneficiaries aged 65 and up who were enrolled from 2015 to 2019, to see how many were actually diagnosed with the condition. They found that only 8 percent of the people whom their model predicted would be candidates for MCI, based on their health demographics, actually received a diagnosis. This number was even lower for Black and Hispanic beneficiaries and among lower-income people. (The team used eligibility for Medicaid, health coverage that supplements Medicare, as a marker of income status.)

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A second study, published in October by Liu's team, looked at Medicare claims submitted by 226,756 primary care physicians and compared their MCI detection rates with those predicted by their model. Again, they found that only about 8 percent of predicted cases were actually diagnosed, and only 0.1 percent of clinicians diagnosed the condition as often as the team calculated that they should.

Autopsies reveal that most people who die in old age have some kind of brain pathology that impairs cognition, from traces of stroke to the amyloid plaques that characterize Alzheimer's. Not everyone who has these anatomical markers of neurodegeneration experiences memory problems, but "the more of these things you have in your brain, the more likely you are to manifest dementia," says Bryan James, an epidemiologist at the Rush Alzheimer's Disease Center, who was not involved in this research. If someone does experience problems like forgetting who family members are, or getting lost while walking familiar paths, a combination of cognitive tests, brain scans, blood work, or a spinal tap can pinpoint the cause of their dementia.

Diagnosing mild cognitive impairment is much trickier. People might notice that something is off, but they're still able to function independently. Most are seen by primary care physicians, not researchers in specialized memory care clinics. Because these doctors don't see many dementia patients, their confidence in giving someone a potentially life-shattering diagnosis can be low. "They don't want to make a mistake," says Sarah Kremen, a neurologist at the Jona Goldrich Center for Alzheimer's and Memory Disorders, who was not involved in this research.

"We are still struggling, as a healthcare profession, with how to best identify mild cognitive impairment," adds primary care physician Barak Gaster, who is also a professor of medicine at the University of Washington. Many doctors in Gaster's field know they lack the training to handle cognitive concerns, and they are eager to learn. However, annual Medicare wellness visits are time-constrained—often just 60 minutes—and cover a lot of ground. Cognitive assessments are too cursory to detect the subtleties of MCI. "It's really challenging to ask a community health provider to do another thing, because they're already doing *everything*," says Nancy Berlinger, a senior research scholar at the Hastings Center, an independent bioethics research institute

in New York. Plus, people generally don't want to be told they have memory problems. "Because of the stigma surrounding dementia, primary care providers may just avoid the topic," says Berlinger.

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"We're failing a lot of people," says Sarah Banks, a neuropsychologist at the University of California, San Diego, and director of the neuropsychology program of their Memory Disorders Clinic. "I'm not surprised that it's being underdiagnosed, but I was surprised by how much."

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Even if both the doctor and the patient notice something is off, Gaster adds, "the elephant in the room is that, if a cognitive concern comes up, most primary care providers still aren't sure what to do." Until very recently, an MCI diagnosis didn't come with any actionable treatment options—just the knowledge that a patient may develop dementia someday. The same question has plagued efforts to develop [blood tests for Alzheimer's risk](#): Will they unnecessarily stress a person who can do little to change their outcome?

But this summer, [the US Food and Drug Administration approved](#) the new Alzheimer's medication lecanemab-irmb, or [Leqembi](#), which clears amyloid plaques from the brain and slows the progression of cognitive decline. Liu calls it "a big game changer." [Donanemab](#), another potential treatment developed by pharmaceutical company Eli Lilly, also reduced amyloid levels and slowed cognitive decline in

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Phase 3 clinical trials of people with early-stage Alzheimer's disease.

While these new medications are a big deal, "they're not a panacea," Kremen cautions. In Phase 3 clinical trials, lecanemab slowed cognitive decline by 27 percent over the 18-month study, a relatively modest improvement. And it's not an easy treatment—patients need infusions at a clinic every two weeks. The drug can have potentially life-threatening side effects like brain swelling and seizures. As a consequence, "I think a lot of us in the field are a little skeptical about how helpful they'll be," Banks says. James adds, "There's a risk-benefit balance that I don't think we've worked out yet."

Drug treatment also depends on early detection. Amyloid plaques kill brain cells, which can't grow back. If you don't try to get rid of the plaques until they've already killed a bunch of cells, James says, "You're trying to put out a fire after the house burned down."

More clinical testing will be necessary to determine exactly how effective these drugs will be for people who start taking them as early as possible. "Dementia is not a problem that we can quickly solve through a pill," Berlinger says, but "we may be in an era of promising interventions in early stages, which rely on the ability to detect early symptoms."

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Still, James predicts that in five years, as these treatments become more effective and accessible, the diagnostic rate for MCI will skyrocket. "Diagnostic practices are driven by

the availability of treatment,” he says. “People don’t just diagnose in a vacuum. They diagnose for a purpose.”

Even if these treatments work, the US healthcare system is not currently equipped to handle the demand for them. Lecanemab currently costs \$26,500 per year, and Medicare covers 80 percent of the cost. If all of the people whom Liu’s studies estimate are experiencing mild cognitive impairment are diagnosed and seek treatment, James says, “it would bankrupt Medicare.” Memory clinics will also struggle to handle the onslaught of referrals. (Rush Memory Clinic, where James works, already has a yearlong waitlist.)

These studies were limited to demographic basics like age, sex, race, and Medicaid eligibility. Age is one of the greatest risk factors for developing MCI—the older you are, the more likely you are to have it. Autopsy studies also show that women seem to develop neuropathology linked to dementia more than men, but in Liu’s studies, detection rates were not dramatically different across sexes or age groups.

Race, however, was one of the strongest predictors of whether or not MCI is accurately diagnosed, with Black people getting diagnosed at half the rate of white people. It’s unclear whether the stark racial divide in detection rates Liu’s team observed is due to differences in MCI prevalence itself, or to differences in healthcare access. Cognitive screening measures were largely developed by white people, for white people, Banks says, likely reducing their sensitivity in other populations. Factors like lower-quality childhood education, the chronic stress of systemic racism, and lack of access to healthy food can all contribute to dementia risk, James adds. Liu’s team is currently building predictive models that account for more of these factors.

Even if a person’s MCI never escalates into full-blown dementia, doctors say there is value in screening for it, because it can let them help alleviate symptoms or weed out other possible confounding causes. For example, doctors can review medications with patients to make sure nothing they are taking lists brain fog as a side effect. Hearing loss is a major contributor to dementia risk, and doctors can help people access hearing aids. Basic lifestyle changes like eating well, exercising, getting good sleep, and nurturing social connections address both brain health and overall well-being.

Doctors need to normalize talking about brain health with patients of all ages, says Elizabeth Head, a program manager at the Georgia Department of Public Health, who led their campaign for early detection of dementia. “We don’t have to ‘break the ice’ to talk about heart disease, cancer, or other chronic conditions,” she says. “It should be talked about like any other type of disease.”