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Alzheimer's Disease in Physicians — Assessing Professional Competence and Tempering Stigma

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r. Redd, a 76-year-old practicing physician, sought help for memory loss at an Alzheimer's disease research center. After being diagnosed with Alzheimer's, she became distressed

when she was instructed to stop working immediately. Abrupt retirement would leave patients in her highly subspecialized practice without care.

She obtained a second opinion through the New York state Committee for Physician Health, an advocacy group. Her diagnosis was confirmed. However, cognitive testing revealed that Dr. Redd's overall ability was at the 99th percentile for her age, with memory subscores ranging from the 16th to the 84th percentile. Given these findings, the committee recommended that she continue working while receiving ongoing medical care, stipulating that her patient charts be monitored by an independent auditor.

Dr. Redd worked for 4 more uneventful years, with annual testing showing mild declines. She retired at 80 as planned, assured that all her patients were well placed.

Alzheimer's is often wrongly regarded as a monolithic disease marked by an inexorable decline into incompetence. This misconception unduly stigmatizes patients. In fact, Alzheimer's is a heterogeneous spectrum disorder with varying pathologic subtypes and clinical courses.¹ Awareness of this heterogeneity can foster improved patient care and policy implementation and can mitigate prejudice.

Data on working health professionals with Alzheimer's, like Dr. Redd, are unavailable. Extrapolation from prevalence rates of 4.9% for Alzheimer's and 6.8% for all dementias among Americans 70 years of age or older yields estimates that 4600 of the nearly 95,000 actively licensed physicians in this age group have Alzheimer's and 6460 have any type of dementia.² Another estimated 11,000 have amnestic mild cognitive impairment (MCI), a precursor to Alzheimer's disease, and about 9400 have nonamnestic MCI, a precursor to other dementias marked by deficits in cognitive domains other than memory. On average, 7 of the 99 physicians who are enrolled in New York's physician health program each year are referred for cognitive problems, primarily by their hospitals. Most are permitted to continue working with restrictions and oversight. Among Ontario's 25,000 active physicians, 13 of 45 referred over 2 years because of concerns about competency were

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found to have significant cognitive impairment.³

In 23 years of subspecialization in memory disorders, I have seen about 3000 patients with cognitive loss. Standardized neurologic and cognitive evaluations indicate that approximately 60% of them are on the Alzheimer's spectrum. More than half are selfreferred, active professionals. Each year I see 6 to 10 health professionals, primarily physicians. About three quarters of them continue working. Some ultimately retire because of disease progression, whereas others remain stable or retire for the usual reasons.

Determining diagnosis and prognosis is particularly difficult with high-functioning professionals. There is clinical variability based on pathology. People with aggressive forms of Alzheimer's disease have annual declines of about five points on the Mini-Mental State Examination (MMSE); those with indolent versions have declines of about one point.1 Despite the addition of biomarkers to the decision tree, physicians who diagnose MCI or Alzheimer's disease rely primarily on clinical factors. Variables affecting diagnosis include the provider's training, the patient's education and socioeconomic status, the cognitive tests used, and the clinical determination of functional impairment.⁴ Because professionals routinely ace MMSE-type screening tests, standardized, extended cognitive testing is best.

Evolving diagnostic criteria add to the clinical ambiguity. New definitions resulted in 92.7% of mild Alzheimer's cases and 99.8% of very mild Alzheimer's cases diagnosed at Alzheimer's disease centers being retroactively reclassified as MCI.⁴ When Alzheimer's subtypes are clumped together, or when misclassifications occur, recommendations may not be appropriate for particular patients.

Finally, because Alzheimer's involves the brain - the most versatile and personal organ variability is common. What a person brings to the disease, both in terms of physical brain reserve (a measure of healthy nerve cells) and functional cognitive reserve (an index of the brain's networking strengths), affects symptom onset and alters disease trajectory independently of pathology.5 Coexisting conditions further obfuscate the relationship between pathology and performance, even within Alzheimer's subtypes. Patients with preclinical Alzheimer's - whose brains may be riddled with plaques and tangles - may live into their 90s without discernible symptoms.

But most people are unaware of these complexities, and widespread stereotyping holds severe cases to be representative of the spectrum. Such misrepresentation leads to fear, shame, and diagnosis avoidance. Many people with memory loss delay evaluations, particularly early in the illness, when intervention would be more effective. A colleague running a university-based memory-disorders center schedules clandestine faculty visits after hours, "because they don't want to be seen seeing me." After I'd repeatedly observed consternation among patients who encountered acquaintances in the waiting room, I myself removed the word "memory" from my practice's name.

Examples of stereotyping

abound. A university professor, confident in her consistently great reviews from students and peers, shared her Alzheimer's diagnosis with her department chair. At a hastily convened faculty meeting, she was asked to leave on disability. Another patient with Alzheimer's stabilized and improved over 4 years of treatment. Because his course was discordant with the expected narrative, his internist obtained a second opinion — but rejected the diagnostic confirmation. The patient was "doing too well" to have Alzheimer's.

Patient distress and stigma are two reasons why physicians avoid diagnosing Alzheimer's disease.⁴ Other likely explanations include therapeutic nihilism and the legal issues raised by permitting people with Alzheimer's to continue working. These dilemmas are less commonly encountered in relation to other disorders that affect cognition but are accepted as heterogeneous, such as brain tumors.

How do we move forward, protecting public and professional interests, as we live and work longer? The American Medical Association suggests that, after 70 years of age, physicians undergo periodic cognitive evaluations, which some institutions already conduct. I believe measuring cognitive baselines even earlier, at 60 years of age, would be reasonable. Periodic professional and maintenance-of-certification exams ensure that physicians' knowledge is up to date and evaluate specialty-specific skills; regular cognitive evaluations could be added to such testing.

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There is precedent for regulating evaluation of cognition and professional competence on the basis of age. State court judges must retire at 65 or 70, with limited extensions contingent on their passing biennial cognitive evaluations. The Supreme Court upheld

An audio interview with Dr. Devi is available at NEJM.org

peal, noting that judges occupy "policymaking" posi-

this decree on ap-

tions and "mental capacity sometimes diminish[es] with age." Supreme Court and federal justices have no mandatory retirement age, however. Consequently, several federal Circuit Appeals Courts have established wellness programs for judges featuring seminars on cognition as well as judicial-competence advice hotlines.

To circumvent ageism and institutional politics, impaired health professionals can be referred to independent groups, such as physician health programs. Providers can also refer their patients to such programs when public safety is a concern. Referred patients see specialists who report back to the programs. These programs act as final arbiters, overseeing work restrictions and medical care parameters. Such protocols balance the wisdom and contributions of older professionals with the realities of cognitive decline.

I believe these programs should be widely publicized, as we emphasize supporting, not penalizing, impaired professionals. Such an approach would encourage professionals to seek help early in the course of disease and promote reporting of problems by concerned colleagues, who often worry about reprisals for the professional. People who refuse help might yield if ongoing employment were dependent on receiving treatment.

Protecting professionals from public censure and stigma is crucial to the success of these programs. California's physician health program closed after lobbying by consumer-rights groups resulted in practice restrictions being made public. Like Nathaniel Hawthorne's Hester Prynne, forced to wear a scarlet "A" marking her as an adulterer, physicians with a publicly known Alzheimer's diagnosis risk ostracism and professional ruin. Similar programs may be considered for other professionals whose work affects public safety and policy, from engineers to elected officials.

Appreciating the nuances of Alzheimer's allows physicians to destigmatize the disease and educate patients and the public. Policies are needed to aid the increasing numbers of working health professionals with Alzheimer's while safeguarding their communities. The tandem approach taken by independent physician health programs helps people continue working as long as possible, permitting dedicated physicians like Dr. Redd to bring their careers to a fitting end.

The patient's name has been changed to protect her privacy.

Disclosure forms provided by the author are available at NEJM.org.

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1. Ferreira D, Verhagen C, Hernández-Cabrera JA, et al. Distinct subtypes of Alzheimer's disease based on patterns of brain atrophy: longitudinal trajectories and clinical applications. Sci Rep 2017;7:46263.

2. Katz MJ, Lipton RB, Hall CB, et al. Agespecific and sex-specific prevalence and incidence of mild cognitive impairment, dementia, and Alzheimer dementia in blacks and whites: a report from the Einstein Aging Study. Alzheimer Dis Assoc Disord 2012;26:335-43.

3. Turnbull J, Cunnington J, Unsal A, Norman G, Ferguson B. Competence and cognitive difficulty in physicians: a follow-up study. Acad Med 2006;81:915-8.

4. Morris JC. Revised criteria for mild cognitive impairment may compromise the diagnosis of Alzheimer disease dementia. Arch Neurol 2012;69:700-8.

5. Stern Y. Cognitive reserve in ageing and Alzheimer's disease. Lancet Neurol 2012;11: 1006-12.

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