he said. "We have to begin to make some degree of advance in this area, and that will be greatly facilitated by some degree of common parlance."

In their report, his group addressed questions about the diagnostic "boundary zones" between brain changes seen in LATE, Alzheimer disease, and FTLD. They argued that TDP-43 proteinopathy increases in old age while severe Alzheimer neuropathological changes decrease. And end-stage Alzheimer disease often doesn't present with TDP-43 proteinopathy.

Nelson called the idea that LATE could be a form of FTLD a "nonstarter." He pointed out that FTLD is usually associated with language and behavioral changes, not memory loss. Additionally, "whereas there appear to be important areas of overlap with FTLD, LATE is approximately 100 times more prevalent and affects persons at a later stage of the human aging spectrum," he said.

Whether or not they're all willing to call it "LATE," researchers on both sides of the debate agree that much more work is needed to increase understanding of TDP-43 pathology in dementia. Silverberg encouraged patients with cognitive impairment to participate in research that tracks clinical symptoms and collects biosamples over time. She said she also hopes more patients agree to be autopsied: "It's going to take years of looking at what the clinical symptoms are and then looking at people's brains when they pass to get a better understanding." ■

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The JAMA Forum

Federal Government Increases Focus on Price Transparency

Gail Wilensky, PhD

The Trump administration continues its focus on making information about medical costs more available as a strategy to help patients become more price- and cost-conscious in their choice of hospitals, physicians, and prescription drugs. The administration's current effort to increase price transparency for hospitals stems from the 2019 inpatient and long-term care hospital proposed payment final rule.

The rule, which went into effect in January of 2019, requires hospitals to post charges for all services and items for which they bill patients or their insurance companies, including all procedures, tests, drugs, and any other service charges that may be associated with the patient's care. The information has to be made available in a machine-readable format (a format easily processed by computers) on a hospital's website. Requiring the easy accessibility of charge information to patients is a dramatic change in the attitude of hospitals; as a 2017 article in the *New York Times* described, hospitals regarded the codes and master price list comprising their billing strategies as "trade secrets" to be used as part of their negotiations with private payers.

Executive Order

An executive order issued on June 24, 2019, broadened the price transparency effort by not only requiring the prices of hospital services negotiated with plans but also by mandating that physicians, their institutions, and insurers inform patients of their out-of-pocket costs before providing care to them. The challenge is determining what pricing information is meaningful and actionable for a patient or for the patient's physician to use on the patient's behalf.

Unlike pricing information for most other consumer goods, the gross price of health care is only the first step in providing relevant information to the patient. What is important to most patients is the price that the patient is likely to pay. That price depends on the patient's insurance, the extent to which the patient has already met his or her deductible, and whether the hospital or physician is in or out of the insurance plan's network.

Because patients may not know the exact services they will need during their hospital stay, hospital pricing that reflects the usual cost of care for a particulate episode of illness—such as a joint replacement or a heart valve replacement—may be more useful than prices for a list of individual services. Patients also are only in a position to comparison shop for care if the care is, as is most common, scheduled in advance rather than as care delivered in an emergency context. However, even for scheduled care, and even when they are facing a significant deductible, there is not much evidence that patients use price comparison tools that their employers or insurers make available to them.

Price differences can be significant, but it is hard to encourage patients to pay attention to them without also providing access to relevant information about any associated quality differences. The struggle most patients have to get relevant price and quality information for a planned medical procedure is in stark contrast to the information readily available to US consumers of other goods and services—even complex services. Consumers in the United States regularly consult information from Consumer Reports when purchasing consumer durable goods such as dishwashers or computers or the Kelley Blue Book for guidance for pricing and value of new and used cars.

Changing how patients think about purchasing health care services and—equally important—how health care professionals think about providing useful and relevant information to patients will require a sustained effort that has previously not occurred, despite the occasional lip-service that might suggest otherwise.

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There are some institutions that are attempting to provide relevant, individualized data to patients before they undergo procedures. The University of Colorado–affiliated UCHealth system offers individualized price estimates specific to a patient's insurance, as does the Indiana University School of Medicine–affiliated IU Health. St Luke's University Health Network in Pennsylvania created a "price lock" program in 2019, which is an all-inclusive, bundled, prepay cash price. They also offer an estimate of what the patient will pay out of pocket beyond the amount covered by his or her insurance.

According to the executive order issued by the Trump administration in June, a sample of cases analyzed by the Council of Economic Advisers found that 73% of the 100 highest-spending categories of medical cases requiring inpatient care were "shoppable"—meaning that patients would be able to schedule when they will receive care, compare and choose between multiple sources of care based on price and quality, and determine where they will receive services. The report also said that 90% of the 300 highest-spending categories for outpatient care were also shoppable. These findings suggest that the potential for changing patient behavior is greater than is sometimes believed. But whatever the amount of care that is shoppable, patients need better information on price and quality than has previously been made available.

Aggressive Timeline

The timeline outlined in the executive order is aggressive. It directs the secretary of the Department of Health and Human Services (HHS) to propose regulations for hospitals to publicly post standard charge information, including information based on negotiated rates, in an easy-to-understand, consumer-friendly, and machine-readable format within 60 days (by the end of August). By the end of September, the secretaries of the departments of HHS, Treasury, and Labor are to issue "an advance notice of proposed rulemaking, consistent with applicable law, soliciting comment on a proposal to require healthcare providers, health insurance issuers, and self-insured group health plans to provide or facilitate access to information about expected out-of-pocket costs for items or services to patients before they receive care."

The executive order also directs the HHS secretary to issue a report describing how price and quality transparency are being implemented and providing recommendations for eliminating impediments. In addition, the secretaries of the departments of HHS, Defense, and Veterans Affairs are to develop a health quality roadmap and increase access to claims data from taxpayer-funded programs for researchers, innovators, and entrepreneurs.

Whether the relevant parties will be able to produce the regulations and reports on this ambitious timeline remains to be seen. A more relevant question is whether there will be any discernible change in consumer, hospital, or physician behavior after more information about pricing of health care services become available. ■

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