



# What We Do (and Don't) Know about Dementia

By JOHN MORRISSEY

**D**ementia is anathema to health care and its mission of curing, healing or at least preventing maladies from worsening. By the time symptoms surface, the irreversible damage is done. Diagnosed patients can live as long as 20 years; the human and financial cost is open-ended. Nearly 4 million people in the United States have dementia, and a recent study calculates that number will exceed 9 million by 2040.<sup>1</sup>

Much of the caregiving will be provided outside the hospital or physician office, at least in the milder early stages. But deteriorating health and behavior eventually call for skilled nursing or hospitalization, and experts say the care systems in place are fraught with excess cost, conflicting reimbursement incentives and poor understanding of cognitive impairment.

Complicated by chronic diseases, dementia can confound care plans. “The combination of having problems with thinking, remembering, organizing tasks and, say, for example, chronic diabetes, makes you likely to be a really expensive Medicare beneficiary,” said Michael Splaine, a consultant on dementia care approaches, “because a lot of our care is uncoordinated and built around a self-management model. These people are incapable of it.” Emerging disease management and patient engagement models are little help for dementia, he said, because “almost none of that factors in the brain.”

On any given day, according to one

study,<sup>2</sup> 40 to 45 percent of Medicare beneficiaries in an acute-care hospital have some form of cognitive impairment. But inpatient norms don't consider the patient holistically. “The broken hip with the broken brain is still just the broken hip,” said Splaine, who also runs a company focused on hospital care and dementia. “We can demonstrate that a big part of readmissions, long length of stay, disastrous hospital stays, can be attributed to the fact that people aren't thinking about *thinking* in the acute-care environment.”

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But as costly as a hospital can be, “medical care for a patient with dementia is, in fact, a small fraction of the cost of caring for people with dementia,” said David Knopman, MD, a Mayo Clinic neurologist and expert on dementia. “The nursing home bed is really the expense of dementia, not the medical care.”

A disconnect between Medicare and Medicaid in care of the elderly makes it worth a hospital's while to discharge a dementia patient to skilled nursing forthwith, said Knopman. “The perverse and cynical perspective is that a care system that provides hospitalization, clinical care, doesn't actually care whether someone enters a nursing home and, in fact, might even like it, because [the patient's] needs from the point of view of the health system will go down. Somebody else is picking up the tab for long-term care.”

That somebody is likely the taxpayer via Medicaid, but only after the dementia patient's elderly spouse or adult children have coped with years of increasingly difficult caregiving, then “spent down” the patient's assets until he or she is impoverished enough to qualify for government coverage, said Knopman. The financial and physical burden puts caregivers at health risk themselves. One of the most common reasons for nursing home placement is

when a caregiver gives out.

In fact, a less visible but proliferating consequence of dementia that directly affects accountable health systems is “the medical health and the mental health and status of the caregiver,” he said. “Caregiving is stressful, and it’s hard on the health, especially for an older person.”

#### DIAGNOSIS FACTORS

The first challenge for health care organizations, before most care decisions and associated costs, is to detect whether someone has dementia and, if so, what variety. Dementia is not neatly a dis-

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ease; instead, it is a syndrome, or a group of illnesses, said David Carr, MD, clinical director for the division of geriatrics and nutritional science at Washington University School of Medicine, St. Louis. Think of arthritis, he said, which can present symptoms similar to those of gout, lupus, osteoarthritis or rheumatoid arthritis.

Carr describes four main types of dementia:

1. Alzheimer’s disease, the most prevalent and best-known, with gradual onset and declining cognition. Typically it affects short-term memory at first, then progresses to other cognitive areas.

2. Lewy bodies, the second most common cause, with visual hallucinations, delusions and suspicions, fluctuation in mental status and risk of falls.

3. Vascular, from small strokes. By itself, it is not associated with progressive cognitive impairment, but often it coexists with Alzheimer’s.

4. Frontal temporal, often with problems both receiving and expressing language. Loss of social filter and inhibitions can cause disruptive personality and behavior changes.

Up until a few years ago, the only sure way to diagnose Alzheimer’s disease was an autopsy. But new test methods, such as PET scans and spinal taps looking for biomarkers, now can detect the

abnormal buildup of proteins and brain changes responsible for Alzheimer’s, said Carr. Additionally, though, there has to be impaired occupational, social or functional abilities to a level that interferes with daily function, he said. Classically the big tipoff was memory loss, but “we’ve come to understand, with the different types of dementia, that language may be the predominant problem, or spatial skills or attention; or personality, behavior, may be the first thing to change,” he said.

Diagnosis still isn’t timely, generally speaking. The time between onset of symptoms and diagnosis is between one and three years, said Knopman.

The time between diagnosis and when people need skilled nursing is generally three to seven years, and “the time that people spend in nursing homes and need skilled care is an average of three years.” Much variability exists from person to person, but those are good approximations on a population basis, he said. “The point of dividing it that way is that it reflects care needs and costs dramatically,” he said.

Alzheimer’s increasingly complicates the already high burden of aging and its growing frailty. The prevalence of Alzheimer’s doubles every five years past age 65. “Where it really is an issue, in terms of numbers, is the over-75, over-80 groups,” Knopman noted. “And it so happens in the U.S. that that’s the fastest-growing segment of the American demographic.”

#### CONCENTRATING EFFORT

To advance the art and science of dementia detection and develop care plans accordingly, pockets of expertise such as the Mayo Clinic, Washington University medical school and Montefiore Medical Center, Bronx, N.Y., have dedicated efforts to diagnosis, research and crucial attention to families of patients.

Carr, the Washington University clinical director, has had an outpatient dementia practice for 20 years in conjunction with the Memory Diagnostic Center on the medical school campus, affiliated with Barnes-Jewish Hospital. He sees advanced dementia patients as medical director of Parc Provence, a state-of-the-art dementia care facility in suburban St. Louis.

The Albert Einstein College of Medicine and Montefiore jointly launched the Center for the Aging Brain in Yonkers, N.Y., in mid-2014, intent on a multidisciplinary approach to people with “a



spectrum of cognitive impairments,” said Joseph Verghese, MD, center director. Its mission covers the range from “older adults who are worried that their memory is not as good as it used to be,” to mild cognitive impairment to dementia. His 15 years’ experience as a neurologist in a Bronx dementia clinic convinced him of the need for geriatricians and neuropsychologists to work closely with neurologists. Patients see all three in one appointment at the new center, Verghese said.

Health care systems currently ramping up efforts to integrate their facilities and harness both financial and intellectual capital around population health management would do well to consider how to organize care of chronically ill older adults, with or without dementia, as their numbers proliferate, experts say. St. Louis-based Ascension Health is doing just that, uniting the majority of its senior-focused programs into one national organization called Ascension Health Senior Care. Mark Frey, president and CEO of Alexian Brothers Health System, which is part of Ascension Health, is doubling as the program’s ministry leader. Organizing around some “very, very good nuclei” in Illinois and Kansas, Ascension aims to “capitalize on the intellectual capital we already have” and begin to spread best practices in senior care across the system, he said.

For care of dementia patients, except when chronic illness is a factor, best practices would include staving off runs to the hospital. “As a general rule, in managing this type of progressive illness — where it’s got a known natural history and known natural course — you know where these patients are going to go over time,” said Frey. With a good understanding of that course and a strong team of professionals, “most of the issues that arise and the crises that develop should be managed outside of a hospital setting, and certainly outside of the [emergency department].”

#### ACUTELY VARIABLE

When hospitalization is required, the extra implications of cognitive impairment can create a range of responses to the patient, from a quick once-over to heroic but senseless lifesaving measures.

“It is the case that, rightly or wrongly — I think it’s more rightly — the patient who has obvious dementia is probably not going to get the more expensive interventions, because the family sees it as futile, and the care system sees it as futile,”

said Knopman. “A dementia patient who comes into the hospital with pneumonia is going to be treated and sent out as quickly as possible. And if that person, say, also has severe congestive heart failure, that person is likely to get more in the way of palliative care rather than really aggressive cardiac interventions.”

When family members aren’t there to set limits, however, the opposite response is likely. Providers who don’t know what the family wants end up doing the gamut of interventions, “engaging in care that’s expensive and sometimes unnecessary, and against the wishes of the patient and the family,” said Verghese.

One persistent intervention, said Splaine, is the continuing use of feeding tubes in the end stages of dementia, despite all scholarly conclusions to the contrary. “As far back as seven years ago, every review said there isn’t a shred of evidence to support the practice,” he said. “In fact, it’s contraindicated. Further, the end stages of people with dementia are recognizable.”

The issue of family wishes sprang to the fore within a few months of the Montefiore-Einstein center’s opening, said Verghese. The center mobi-

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lized to meet a demand for advance care planning services, including how to establish a health care proxy to make decisions worked out beforehand, once a dementia patient needs hospitalization. “Having advance care planning is very important, not only to respect their wishes but just from an economics perspective,” he said.

Health care organizations have to create an ethos around letting such patients die, a decision that remains hard to make for medical professionals, said Splaine. Anecdotally, from personal experience and that of his contemporaries, end-stage dementia has whipped up “a literal battle with health care providers to let their people go in peace.” To prevent such confrontations, doctors need to assess a patient’s status with families every few years and have a frank discussion, he said.

Of course, the last time that approach was sanctioned, through the lobbying efforts of advocates for the elderly to insert a measure into the Affordable Care Act, it morphed into the disastrous political “death panels” debate. “So that’s poisoned the air, big time, but it’s something that we’ve got to come back to,” Splaine said.

### CAREGIVER CRUSH

Decisions at the end of a loved one’s life are but the last part of an ordeal lasting years for families. Often caregivers are frail themselves and saddled with responsibilities a spouse handled before he or she developed dementia. Caregivers of patients with Alzheimer’s are reported to have higher rates of depression, and some experts have sug-

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gested that such caregiving puts them at higher risk of dementia themselves, said Verghese.

Included in all intake procedures for patients referred to the Center for the Aging Brain is a caregiver questionnaire to measure stress. A high-stress score triggers a referral to a social worker, who sets up sessions with the caregiver to determine reasons for the stress and how to reduce it, said Verghese. “That’s one of the major areas that our social worker covers.”

The plight of caregivers also is a priority for Ascension Health’s senior care initiative. “It isn’t good enough just to bring them together in a support group and say, ‘Gee, this is tough,’” said Frey. “We have to do the things with those family members that meet their specific needs, too, and not forget that going through this is just as difficult for them.”

It includes education on the reality of dementia and setting expectations, encouraging family to remain active participants in care “when they may look at their mother or father and realize their parents no longer remember who they are,” he said. “What about the impact that has on an adult child in terms of just how they begin to think about themselves and their relationship?”

Keeping caregivers well cared for increases the odds of a dementia patient’s remaining at home as long as possible, said Frey. “But you might start to

think about day treatment if the adult children are in work situations where they can’t be home with Mom or Dad — but they don’t want Mom or Dad institutionalized. So creating a day care option is certainly important.”

Ultimately, though, the length of time between diagnosis and institution “largely depends on the progression of the disease” rather than caregiver efforts, said Knopman. Timely diagnosis still is important so that families can understand and deal with it, but it doesn’t buy much in the way of delaying skilled care.

“At this point, medical science has not found an effective way to slow down the biology of Alzheimer’s disease or any of the other causes of dementia. Period,” said Knopman. “And contrary to conventional wisdom that early diagnosis is good, the reality is that early diagnosis by itself doesn’t have much population benefit.”

### PINPOINTING RISK EARLY

Researchers still are testing medicines aimed at removing or decreasing abnormal production of the amyloid and tau proteins in the brain that lead to much of dementia, said Carr. The focus of that work has traveled to use of the protein-clearing drugs in the earliest stages of mild cognitive impairment or even pre-clinical dementia.

But “by the time you have symptoms, it just may be too late — there’s just so much protein and so much widespread damage that we can’t reverse things,” he said. Because of limited benefit for people showing dementia, “a lot of the focus of Alzheimer’s research is looking at delaying the onset of the disease.”

One line of defense against dementia is identifying the risk ahead of the damage, said Verghese, including new tests detecting risk far earlier than any outright evidence of the syndrome. Other changes to be vigilant for include a deteriorating sense of smell or personality change. Research at Einstein also has found a connection between walking slowly and cognitive impairment, both common complaints among the elderly but significant if occurring together, he said. If detected, it elevates someone from the run-of-the-mill aging population into a high-risk group “that we have to pay extra attention to.”

The gait factor joins elements of a memory impairment screen developed by Einstein research that originally was a word-based test but now also has a picture version for patients who





were not well-educated and for whom the language-oriented test was not working well, Verghese explained.

Citing the expense of brain-imaging tests as a diagnosis tool, Verghese emphasized that non-clinicians could ask the right questions and isolate people for further testing instead. It's not practical, he said, to order a scan on everyone over 65: "You would find things about the brain, but then we all probably would go bankrupt in the process."

Proactive simple tests for patients at risk could find, say, vitamin or thyroid deficiencies that could be reversed; if no underlying obvious causes were found, people at high risk of dementia could be prodded to follow a healthy lifestyle. For example, health benefits of regular exercise are many, including lowering risk of dementia, Verghese said.

As health care organizations develop longer-term horizons for activities designed to improve future health outcomes, existing campaigns around reducing big-ticket costs of heart disease and diabetes should be expanded to include dementia prevention, said Splaine. The simple slogan to remember: "What's good for your heart is good for your brain." Instituting a focus on brain health could lower both population risk and make a difference in individual lives.

For instance, another reason to stop smoking is to reduce dementia risk, he said. A recent World Health Organization issue brief on smoking and dementia attributed 14 percent of the global population's risk of dementia to smoking.<sup>3</sup> By adding smoking cessation to activity, control of hypertension and cholesterol reduction regimens, heart and brain benefit equally. "Forty percent of our blood supply goes up to our brain every time our heart pumps," Splaine said. Toxins otherwise horrible for health "are also swirling around in your brain."

### RAISING HOPE, FUNDS

National and state efforts to turn around the current dim prospects for dementia care are showing signs of life. A commitment of \$156 million in federal funding in 2012 jump-started a national plan to address Alzheimer's disease, an initiative required by the National Alzheimer's Project Act enacted in early 2011. The plan sets five broad goals: prevent and effectively treat Alzheimer's disease by 2025; enhance care quality and efficiency; expand support for families of people with the disease; enhance public awareness and engagement; and improve data to track progress.

In addition, more than 40 states have launched

their own comprehensive programs, including how to better organize their social and health infrastructures to address dementia and to evaluate how money is spent on care, research and other aspects. Among other impacts, these plans have helped foster an understanding that people with Alzheimer's have other diseases, and that a separate effort around improving care and controlling costs won't work, said Splaine, who has been deeply involved in these state efforts since 2007.

A focus on guiding clinical efforts also is gaining momentum, he said. "No less an authoritative document than the Healthy People 2020 plan — which is the every-decade public health plan for the nation — in its 2010 version identified two new objectives around dementia care. One was around improving detection and diagnosis, and the second was about seeing what could be done about reducing preventable hospitalizations of people with dementia."

Four years later, the measures for that are ready to be published, he said.

An important factor becoming more apparent is that people with dementia should not be left to themselves, and that isn't just because of safety factors, said Carr. They still have social needs like anyone else and can actually improve for a period of time when they enter assisted living.

"I've seen people who have been very delusional, also suspicious and paranoid, because they're living alone," he said. "And then they get admitted into a social, group environment, and all those delusions and suspicions, they just go away. It's amazing."

**JOHN MORRISSEY** is a freelance writer specializing in health care delivery policy and performance measurement. He lives in Mount Prospect, Ill.

### NOTES

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