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Memories Past and Future

This is the 11th of a 12-part series: This year we're focusing on the phenomenal progress that the medical community has made in the 30 years of Federal Practitioner's existence. Each month we'll feature an editorial written by one of our Editorial Advisory Association members, reminding us how much has changed in their particular medical field over the past 30 years. This month's focus is dementia care.

—James V. Felicetta, MD

Thirty years ago, I was a predoctoral intern in clinical psychology. A major puzzle was dementia—what goes wrong in the brain to cause a profound, progressive decline in memory, thinking, and self-care? Can it be treated? Can it be prevented? What's the best way to manage it? We've come a long way toward answering some of the questions, but the puzzle of dementia is not yet solved.

Remember when dementia (*senility*) was considered a normal and inevitable part of aging? Now we understand that dementia represents abnormal brain functioning and not everyone develops it (dementia occurs in about 5% of those aged 71-79 years, 24% of those aged 80-89 years, and 37% of those aged 90 years and older).¹ Remember when the vague term *organic brain syndrome* was common? Now we know there are multiple types of dementia, and we use more precise terms, most often

Alzheimer type, but also vascular dementia, dementia with Lewy bodies, dementia associated with Parkinson disease, and many others. There is now a growing understanding of distinct pathologies of different types of dementia as well as increased recognition of areas of overlap and association with other diseases, such as heart disease and diabetes.

Then, as now, a brain autopsy is the gold standard in diagnosing dementia. However, advances in imaging have contributed to more precise clinical diagnosis. In the early 1980s, structural brain imaging techniques were just coming into use, allowing an unprecedented look inside the brain. Now we have a veritable alphabet soup of imaging techniques (CT, MRI, PET, SPECT) that allow an ever more sophisticated examination of the structure and function of the brain in different types of dementia. Diagnostic techniques have also been aided by development of brief cognitive measures that provide objective quantification of memory complaints. Of course, the diagnostic tools are not yet perfect, and there is controversy over when and with whom they should be used (eg, screening asymptomatic individuals or waiting for signs and symptoms to emerge). Without clear research evidence, some diagnostic decisions remain personal choices between individuals and their providers.

Multiple specialists, such as neurologists, geriatricians, psychiatrists, and neuropsychologists, are trained in the diagnosis of dementia. As the need for such specialists has greatly outgrown the supply, there has been

increasing emphasis on the role of primary care providers in the recognition of warning signs, diagnosis of dementia in collaboration with specialists, and ongoing management of care.

In the 1980s, there were no drugs to treat the most common type of dementia, Alzheimer disease (AD). The first drug that came on the market in 1993 is rarely prescribed today due to safety concerns. Now there are 4 additional drugs approved by the U.S. Food and Drug Administration for AD and many more in the pipeline. Clinical effectiveness of these drugs has been limited, temporarily easing symptoms without affecting the underlying disease. There is no cure. Prevention is an idea that remains on the horizon. In a 2010 conference, "Preventing Alzheimer's Disease and Cognitive Decline," the National Institutes of Health (NIH) reported formidable challenges in conducting prevention research and stated that no firm conclusions can be drawn about the association of any modifiable risk factor with cognitive decline or AD.² For now, experts generally advise that what's good for the heart (eg, healthy diet, exercise) is good for the brain.

When I joined VA headquarters in 1991, the VA already had a long history in the development of geriatrics and dementia care. They correctly anticipated there would be a dramatic increase in the number of older veterans due to a very large World War II cohort, and planning had begun for it in the mid-1970s. A centerpiece of VA's strategy was the creation of centers of excellence called Geriatric

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Research Education and Clinical Centers (GRECCs). When the GRECCs opened in 1975, only a few focused on AD and other types of dementias. Today, all 19 GRECCs devote some attention to dementia.

Various dementia care models have also been investigated. In the 1980s and 1990s, the focus was on nursing home care and dementia special care units (DSCUs). When NIH-funded collaborative studies on DSCUs in the 1990s demonstrated mixed results and no clear support of segregated units as the best way to provide dementia care, the priority shifted to training all staff in all settings to be *dementia-capable*. Within the nursing home arena, a culture transformation is now underway, with a focus on small “households”; continuous meaningful activities for all residents, including those with dementia; and staff training in environmental, behavioral, and communication techniques to help prevent and manage challenging behaviors associated with dementia. Recently, attention has turned to helping individuals with dementia remain at home with appropriate supports. Development of effective care coordination models has also become a major issue. For the majority of people who do not receive care in an integrated health care system such as VA, fragmentation of services and providers is especially challenging.

Another major development has been the recognition of the critical role played by family and other informal caregivers in maintaining the health and safety of persons with dementia, as well as the heavy toll that caregiving takes on the caregiver. Following publication of the NIH-funded Resources for Enhancing Alzheimer's Caregiver Health (REACH) trial in 2006, VA began the first national clinical translation of this multicomponent caregiver support intervention. Today, VA promotes an adapted ver-

sion called REACH-VA within the VA health care system.

November is National Alzheimer's Disease Awareness month, making the timing of this editorial opportune. In November 1982, President Ronald Reagan proclaimed the first National Alzheimer's Awareness Week. In 1994, President Reagan revealed to the nation that he himself had been diagnosed with AD, and in 2004 he died after a lengthy course of the illness. Since then, public awareness has increased exponentially.

Alzheimer disease and related dementias are now recognized as a major public health issue, affecting an estimated 5 million Americans, with a total monetary cost between \$157 billion and \$215 billion in 2010, which represents a financial burden similar to that of heart disease and cancer.³ Due to an aging baby boomer generation, the number of people with dementia is expected to increase dramatically in the next 2 decades.

In 2011, President Barack Obama signed into law the National Alzheimer's Project Act, which established the public-private Advisory Council on Alzheimer's Research, Care, and Services under leadership of the U.S. Department of Health and Human Services. In 2012, the first U.S. National Plan to Address Alzheimer's Disease was unveiled with the following 5 goals: (1) prevent and effectively treat AD by 2025; (2) enhance care quality and efficiency; (3) expand supports for people with AD and their families; (4) enhance public awareness and engagement; and (5) improve data to track progress. The National Alzheimer's Plan is a collaborative effort to leverage resources. In essence, it “will take a village” of scientists, public policy makers, health and social service providers, advocates, and individuals to develop creative solutions to the pressing challenges faced

by people with dementia and their families.

Thirty years from now, what will we remember about dementia? Will we have met our audacious goals and conquered dementia, so that its physical, emotional, and financial burdens are only a distant memory? Or will we be grappling with the same or even greater magnitude of the problem? How much closer will we be to our ideal vision of long-term services and supports for individuals with dementia and their caregivers? After seeing how far we've come and how much new-found drive there is, I'm looking forward to discovering those future memories. ●

Author disclosure

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