VIEWPOINT

The Other Dementia Breakthrough—Comprehensive Dementia Care

David B. Reuben, MD
Multicampus Program in Geriatric Medicine and Gerontology, David Geffen School of Medicine, University of California, Los Angeles, Los Angeles.

Gary Epstein-Lubow, MD
Education Development Center, Warren Alpert Medical School of Brown University, Providence, Rhode Island.

Nora Super, MPA
Long-Term Quality Alliance, Washington, DC.

These are momentous times for Alzheimer disease (AD) and Alzheimer disease and related dementias (ADRDs). For the first time, the US Food and Drug Administration has approved disease-modifying drugs that bring some hope for long-term clinical benefit for persons affected by mild cognitive impairment or early to mild dementia. Unfortunately, most persons living with AD and those with other causes of dementia will not be eligible to receive these new drugs. Nevertheless, they may benefit substantially from comprehensive dementia care that includes caregiver support, continuous monitoring and assessment, ongoing care plans, psychosocial interventions, self-management, medication management, treatment of related conditions, coordination of care, and advance care planning.[1,2]

Growing evidence suggests that comprehensive dementia care is beneficial for quality of care; clinical outcomes for people living with dementia (eg, reduced behavioral symptoms) and their caregivers (eg, distress, strain, and depression)[3]; and cost savings in a variety of settings,[2] including low-income safety-net health systems, the home setting, remotely by telephone, and dementia-specific comanagement and primary care clinics. Many of these models have been fostered and evaluated through the US Centers for Medicare & Medicaid Innovation (CMMI) using randomized and quasiexperimental designs, with each showing benefit on some important outcomes.

In 2012, the first National Plan to Address Alzheimer Disease was released and included the goal of preventing and effectively treating AD and ADRDs by 2025 via enhanced care quality and efficiency; the 2022 update specifically called attention to new models of care supported by CMMI.[4] A 2021 National Academies of Science, Engineering, and Medicine report concluded that collaborative dementia care models had enough evidence to justify broad dissemination.[5] Better dementia care would not only help persons living with dementia and their caregivers, but also benefit most sectors of the economy, including housing, transportation, and finance, that also bear the cost of suboptimal care of dementia.

Despite the supporting evidence and strong endorsement of effective models, barriers to the dissemination of comprehensive care persist, including the lack of an adequately trained workforce, attitudes of some health care professionals and administrators toward caring for persons living with dementia, competing priorities to develop cutting-edge clinical programs, and financial viability. These barriers require different approaches, such as the Health Resources & Services Administration's Geriatrics Workforce Enhancement Program,[6] for training health care professionals and payment reform to address the financial viability of new dementia care services delivery models. When dementia care programs are launched, medical groups typically incur the costs while the savings accrue to other components of the health care system such as hospitals (when length of stay is reduced) or insurers (when overall costs of care or long-term nursing home placements are reduced). Thus, the viability of these models depends on whether the costs of providing care can be recovered by insurance payment for services provided (in most health systems, they cannot) or whether they need to be considered as up-front costs to achieve downstream savings (eg, by reduced hospitalization). Managed care, with its integrated financing and health care delivery focus, could provide a solution, but uptake of comprehensive dementia care by health plans has been slow. Another promising option is an alternative payment model specific for comprehensive dementia care that would not rely on future cost savings to the local health care system to pay for delivery of clinical dementia services.

Recently, Medicare, through CMMI, has expressed renewed interest in exploring a comprehensive dementia care benefit. To this end, The John A. Hartford Foundation has sponsored 2 conferences, in 2019[2] and 2022,[7] to explore what such a benefit would look like, who would be eligible, and how it would be paid. Recommendations from the most recent conference included the need for any payment model to provide comprehensive dementia care that meets quality measures; address both beneficiary and caregiver needs; be restricted to persons who have a diagnosis of dementia; be widely available, including to those in rural and underserved communities; and be paid for by capitation with amounts based on severity of symptoms and available resources.[7] The Alzheimer's Association has proposed 3 pathways for differential payment, which, if implemented widely, could save Medicare and the federal share of Medicaid up to $20.9 billion and the states, through their share of Medicaid, another $10 billion over 10 years.[8]

These cost savings estimates are generated from studies of health systems with dementia services workforce structure and training sufficient to implement comprehensive dementia care. Needed workforce enhancements include a dementia-competent work force that includes basic dementia care competencies for all health care professionals; increased numbers of dementia specialists, including advance practice practitioners; and health system linkages to community-based organizations.

Just as disease-modifying drugs signal hope for persons with preclinical and early-stage AD, Medicare's interest in payment for effective models of dementia care offers hope for those whose disease has progressed

Corresponding Author: David B. Reuben, MD, David Geffen School of Medicine at UCLA, 10945 Le Conte Ave, Ste 2339, Los Angeles, CA 90095-1687 (dreuben@mednet.ucla.edu).

further and those who have other types of dementia. These complementary breakthroughs are strong evidence of progress on the National Plan to Address Alzheimer Disease toward preventing and comprehensively treating AD and ADRDs by 2025.

ARTICLE INFORMATION

Published Online: May 22, 2023. doi:10.1001/jamaneurol.2023.1252

Conflict of Interest Disclosures: Dr Reuben reported receiving grants from the Patient-Centered Outcomes and Research Institute (PCORI), the National Institute on Aging, the John A. Hartford Foundation, and the Archstone Foundation. Dr Epstein-Lubow received grants from the National Institute on Aging, the Centers for Disease Control and Prevention, PCORI, and The John A. Hartford Foundation. Ms Super reported receiving personal fees from The John A. Hartford Foundation during the conduct of the study and grants from The John A. Hartford Foundation, The SCAN Foundation, and The Gary and Mary West Foundation. No other disclosures were reported.

Additional Contributions: We thank Jane Carmody, DNP, MBA, RN, and Rani Snyder, MPA, The John A. Hartford Foundation, for reviewing an early draft of the manuscript. They received no compensation for their contributions.

REFERENCES

1. Boustani M, Alder CA, Solid CA, Reuben D. An alternative payment model to support widespread use of collaborative dementia care models. *Health Aff (Millwood)*. 2019;38(1):54-59. doi:10.1377/hlthaff.2018.05154

2. Lees Haggerty K, Epstein-Lubow G, Spragens LH, et al. Recommendations to improve payment policies for comprehensive dementia care. *J Am Geriatr Soc*. 2020;68(11):2478-2485. doi:10.1111/jgs.16807

3. Reuben DB, Tan ZS, Romero T, Wenger NS, Keeler E, Jennings LA. Patient and caregiver benefit from a comprehensive dementia care program: 1-year results from the UCLA Alzheimer's and Dementia Care Program. *J Am Geriatr Soc*. 2019;67(11):2267-2273. doi:10.1111/jgs.16085

4. Office of the Assistant Secretary for Planning and Evaluation. National plan to address Alzheimer's disease. Accessed January 29, 2023. https://aspe.hhs.gov/collaborations-committees-advisory-groups/napa/napa-documents/napa-national-plan

5. Larson EB, Stroud C. Meeting the challenge of caring for persons living with dementia and their care partners and caregivers: a report from the National Academies of Sciences, Engineering, and Medicine. *JAMA*. 2021;325(18):1831-1832. doi:10.1001/jama.2021.4928

6. Flaherty E, Busby-Whitehead J, Potter J, Lundebjerg N, Trucil DE. The Geriatric Workforce Enhancement Program: Review of the Coordinating Center and Examples of the GWEP in Practice. *Am J Geriatr Psychiatry*. 2019;27(7):675-686. doi:10.1016/j.jagp.2019.04.010

7. Super N, Epstein-Lubow G, Reuben DB, Snyder RE, Carmody J, Maglich A. Payment for comprehensive dementia care: five key recommendations. Health Affairs Forefront. February 7, 2023. Accessed March 12, 2023. https://www.healthaffairs.org/content/forefront/payment-comprehensive-dementia-care-five-key-recommendations

8. Baumgart M. An alternative payment model could deliver better care to people with dementia—and save Medicare money. Alzheimer's Impact Movement. July 4, 2020. Accessed January 29, 2023. https://alzimpact.org/blog/post/id/182