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How Do We Make Comprehensive Dementia Care a Benefit?

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Given the evidence that comprehensive dementia care improves outcomes for persons living with dementia and their caregivers at a cost savings to Medicare, why isn't this care as widely available as magnetic resonance imaging or total knee arthroplasty or hemodialysis? Do we need more evidence, and if so, what kind of evidence would tip the balance? If clinical trial evidence is not sufficient, what other information do payers require to affirm the readiness of comprehensive dementia care as a healthcare benefit? What other information is necessary to facilitate widespread dissemination of this beneficial care model?

In this issue of the *Journal of the American Geriatrics Society*, Jennings et al. report additional evidence supporting the cost effectiveness of comprehensive dementia care.¹ The research team places their findings in the context of a literature that is now 30 years in development. Beginning with studies of caregiver interventions and eventually maturing toward integrated medical and social care models, these many studies report a wide range of positive outcomes.² In this literature, we find evidence of improved caregiver and patient outcomes as well as reduced healthcare utilization and costs. For example, in 2019 the University of California, Los Angeles (UCLA) Alzheimer's and Dementia Care (ADC) program reported delayed long-term nursing home admissions and reduced total cost of care for fee-for-service Medicare beneficiaries receiving comprehensive dementia care.³ To explore where those cost savings accrued, the UCLA team obtained Medicare claims data for participants in the ADC program and compared these claims with the claims data of UCLA patients diagnosed with dementia but not cared for in the ADC program.¹ Participants in the comprehensive dementia care program accrued lower total costs because they used the emergency department less, had shorter hospital stays, stayed in their own

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This editorial comments on the article by Epstein-Lubow et al. and the article by Jennings et al.

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homes longer, and chose hospice sooner. These are all outcomes that persons living with dementia and their families seek, and the ADC program achieved these outcomes without increasing the costs to Medicare.

Summarizing this study in the 100 words just written, we tend to overlook the millions of dollars in federal and philanthropic funding, the thousands of hours of hard work, the altruism of study participants, and the practical creativity needed to answer what our stakeholders may view as a simple question: Does comprehensive dementia care save money for the Medicare program, and if so, how? Before addressing this question, Jennings et al. first had to conduct a large pragmatic trial of comprehensive dementia care management that itself was built on the foundation of a previous research-intensive clinical program at UCLA that was based on decades of research testing new models of care for dementia. These generations of research studies address a series of questions beginning with “Does it work?” and continuing through “Does it work in the real world and at what cost?”

Scientists face myriad methodological hurdles in creating this evidence base. For example, obtaining Medicare claims data and merging it with existing electronic health record data may sound straightforward, but it is difficult, costly, and fraught with limitations in the data. Excellence in database research is only one of the tools our research teams need to conduct pragmatic clinical trials, and the United States has precious few research teams capable of engaging in this work. Pragmatic trials provide evidence to facilitate the widespread adoption of new models of care and other complex interventions. Embedded pragmatic trials move beyond “Does it work and at what cost?” to questions like “How do we implement this new model of care in our local healthcare system, how do we adapt it to the special goals and needs of our heterogeneous patients, and how do we pay for it?”

In 2019, the National Institute on Aging funded the IMbedded Pragmatic Alzheimer’s disease and AD Related Dementias Clinical Trials (IMPACT) Collaboratory to build the nation’s capacity to conduct pragmatic clinical trials of interventions embedded within healthcare systems for people living with dementia and their care partners.⁴ We need this new generation of research, research teams, and research infrastructure because answering “Does it work?” is only the first question in a long series of questions leading to a decision about providing a healthcare benefit and making the care available to everyone who needs it.

Notably, “saving money for Medicare” is not itself an end goal for persons living with dementia or their caregivers or their healthcare providers. Persons living with dementia and their caregivers demand care that matches their needs. They demand and deserve services and supports even though these supports may not fit our current concepts of healthcare benefits. People living with dementia demand that we reconceptualize how we think about and pay for health care. People living with dementia are our family, friends, and future selves. Notably, in comprehensive dementia care models, savings may accrue to Medicare, but the expenses accrue to a fluid and unstable network of local service providers, patients, and their families.

We are currently asking our healthcare systems, along with their affiliated provider groups, local social service agencies, collaborating community-based organizations, persons living

with dementia, and their families, to coordinate and provide services not reimbursed by third-party payers. The few programs able to sustain comprehensive dementia care for their patients over a period of decades typically accomplish this feat through funding from research, philanthropy, volunteers, and cost shifting within their healthcare system. This strategy will not lead to widespread adoption and is inherently inequitable. The quality of the dementia care you are able to obtain for your mother should not depend on being fortunate enough to live near one of the few dementia care centers.

Payment reform alone is not a panacea. Persons living with dementia face other obstacles in receiving care and improving their quality of life. For example, “comprehensive dementia care” is itself a paradox. For care of persons living with dementia to be comprehensive, it must encompass the entire spectrum of their care that for many people includes conditions other than dementia. As noted by Jennings et al., one area for further improvement in these programs that could also result in further cost savings is improved co-management for comorbid chronic conditions. Dementia care models need more study to embed these models into workflows with our actual workforce in the places where people currently receive their care. Payment reform, however, would fuel innovation in managing comorbidity as well as innovation in addressing other obstacles such as care fragmentation, home redesign, stigma, and emotional and physical barriers to participation in our communities.

Also in this issue of the journal, Haggerty and colleagues present the recommendations of a national conference to review promising strategies for payment reform and ways to accelerate their adoption within existing approaches to payment for healthcare services.⁵ The team first opens the black box of comprehensive dementia care to describe eight elements of the larger package of services. This dissection of key components is needed to promote replication and fidelity to the tested models and to provide payers with information to understand what activities new benefits would support. Notably, each of these individual elements comprise a complex series of activities that could present barriers to adoption for a typical primary care provider. In addition, providers must tailor each of these elements to the unique goals, resources, and needs of individual persons living with dementia and their caregivers and discover which services are available in their local community. Tailoring inevitably leads to a combination of services requiring ongoing coordination of care and, because the person living with dementia will have changing needs over time, the content of the care plan will continue to change. This tailoring justifiably leads to concerns from administrators and payers as they struggle to understand the definition of the benefit, the definition of the workforce and their key competencies, and the definition of quality.

In dissecting the components of comprehensive dementia care, we can begin to identify which elements map to a payment mechanism in the currently available menu of payment schemes, including how services available for the patient’s comorbid conditions might open opportunities for services equally valuable for the comorbid dementia. Here the authors point to opportunities for patching together at least some support for some services using existing benefits.⁵ Unfortunately, the design of all current payment schemes falls short with regard to support for comprehensive dementia care. Perhaps the most vexing limits are those services that Medicare has none or limited statutory authority to provide to beneficiaries. As noted by Haggerty and colleagues, comprehensive dementia care is built on the foundation

of caregiver education, support, and services, and all current payment schemes fail at this foundational level. The authors outline practical approaches that could create incentives to provide comprehensive dementia care and thus expand access to these proven models. In particular, they advocate for a value-based population health approach with tiered services based on risk stratification to provide tailored care to large groups of people with dementia and their caregivers. The Alzheimer's Association and the Alzheimer's Impact Movement, in collaboration with experts in dementia care models, recently published a framework for such an approach.⁶ The framework proposes a Medicare alternative payment mechanism that would allow a greater number of providers the resources needed to deliver comprehensive dementia care for persons living with dementia while also providing payers with eligibility, competency, and quality criteria.

The Centers for Medicare & Medicaid Services and the National Institutes of Health, philanthropy, and local health systems have supported research on comprehensive dementia care for decades. The National Plan to Address Alzheimer's Disease specifically seeks to enhance care quality and efficiency and to expand supports for persons living with dementia and their caregivers. Through this support, scientists have demonstrated impact on outcomes important to persons living with dementia and their caregivers including delaying nursing home placement, reducing days in the hospital, and increasing time at home. Policymakers responsible for the fiscal health of the Medicare program and other entities who assume risk for Medicare beneficiaries also care about these outcomes. Widespread access to high-quality comprehensive dementia care is a shared national goal. To make this possible, we do need a different kind of science to address different kinds of questions about how practically to implement and administer these models. We also need payment models to catch up with the science and with the needs of persons living with dementia and their caregivers.

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