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Title
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Permalink
https://escholarship.org/uc/item/1j34f2kq

Journal
The American Journal of Managed Care, 28(12)

ISSN
1088-0224

Authors
Reuben, David B
Epstein-Lubow, Gary
Evertson, Leslie Chang
et al.

Publication Date
2022-12-01

DOI
10.37765/ajmc.2022.89258

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Chronic Disease Management: Why Dementia Care Is Different

David B. Reuben, MD; Gary Epstein-Lubow, MD; Leslie Chang Evertson, DNP, RN, GNP-BC; and Lee A. Jennings, MD, MSHS

ABSTRACT

With the rise in the population of older adults, the number of individuals living with chronic diseases that need management will increase dramatically. Successful programs have been developed for chronic conditions (eg, heart failure, diabetes, asthma, chronic obstructive pulmonary disease) that use principles of self-management, monitoring, and care coordination. However, because of the effects of dementia on the mind including behavioral complications, the progressive loss of capacity for affected individuals to participate in care or decision-making, the devastating effects on care partners, and the scope of disease management beyond medical issues, the management of dementia is different and demands different approaches. The success of dementia management will depend upon how well the care provided is able to maximize the function, independence, and dignity of the individual living with dementia while minimizing care partner strain and burnout.

Am J Manag Care. 2022;28(12):e452-e454. doi:10.37765/ajmc.2022.89258

As a result of better hygiene, sanitation, and nutrition, as well as advances in medicine and public health, over the past century, there has been a dramatic rise in the number of individuals living longer in the United States. Life expectancy from birth has risen from 60 years in men and 62 years in women in 1921[1] to 75 years in men and 80 years in women in 2020.[2] This success, however, comes at a price. For example, 60% of those 65 years and older live with 2 or more chronic diseases,[3] often for decades, posing challenges to organizing health care delivery systems to provide chronic disease management and paying for it.[4]

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Accordingly, approaches have been devised and implemented, with variable success, to manage diseases such as heart failure, diabetes, asthma, and chronic obstructive pulmonary disease. Once-lethal diseases, such as AIDS and many cancers, are now considered chronic conditions. Each of these chronic conditions has unique aspects and symptom clusters, but all share the absence of curative disease-modifying therapeutics. Hence, symptom management, prevention of complications, and attempts to achieve remission are the cornerstones of treatment. Because of its often slowly progressive nature, dementia is also included among chronic diseases. Yet, for many reasons, the management of dementia is different and demands different approaches (**Table**).

First, dementia is caused by diseases that affect the brain, and its most devastating effects are on the mind. Some of the most common symptoms of dementia manifest as behavioral and psychological problems (eg, agitation, delusions, wandering) that may be disruptive enough to lead to permanent placement in nursing homes or assisted living facilities, sometimes in secured units. Unfortunately, Alzheimer disease and related disorders and their resulting symptoms are recalcitrant to conventional treatment, including currently available medications and conventional disease management programs.

Second, sooner or later, individuals living with dementia lose capacity to engage in discussions about their care and living situations. They can no longer understand the details of their health situation and must rely on surrogates, usually family members who may or may not have elicited the patient's preferences about

decisions for potential future scenarios. Even if general values have been expressed (eg, "Dad was a fighter. He never wanted to give up"), these rarely fit the specific situation at hand. Although framing these in the context of the person (eg, "If your father could see himself in his current condition, what would he want to do?") is sometimes helpful, making decisions about others sometimes stretches the definition of self-determination and autonomy. Some proxies have difficulty separating their own preferences from what might be their loved one's preferences. Proxies' preferences may be guided by emotional factors, a sense of duty, or remembrances of the person in their prime.

Third, the effects on care partners are enormous (eg, up to 40% develop depression[5] and 30% report regularly feeling completely overwhelmed[6]). Care partners also require specialized education beyond the management of medical conditions (eg, adjusting diuretics for heart failure based on daily weights, promotion of health-related behaviors such as diet and exercise) that includes training to support daily functional tasks, provide a safe and supervised living environment, and manage behavioral and psychological symptoms such as verbal or physical aggression, which may be directed toward care partners.

Fourth, the scope of disease management is often broader than medical management of chronic diseases and includes social, legal, and financial issues. Not only do these issues extend beyond the bounds of the health system's expertise and capacity, but they are extremely complicated and do not fit well within protocols, which are the foundation of most disease management programs. Rather, each affected individual requires a solution that is uniquely tailored to meet their current situation and expected future course. Hence, effective dementia care programs must be designed to ensure the overall provision of comprehensive, person-centered care rather than primarily implementing protocolized, prespecified care processes. Although the National Academies of Science, Engineering, and Medicine published a framework for integrating social care into the delivery of health care in 2019,[7] very few health systems are currently engineered for such a shift.[8] Nor have insurance structures been devised to pay for needed nonmedical services. Hence, some effective programs (eg, those supporting caregivers[9]) are not widely available.[10]

These differences in traditional vs dementia-focused chronic care management are magnified by the extent of the dementia epidemic and costs during the last 5 years of life,[11] which far exceed those of individuals with heart disease and cancer. Most dementias are diseases of aging, and as baby boomers reach advanced age, the numbers of Americans affected will surge; an estimated 7.2 million Americans are projected to have Alzheimer disease by 2025.[12] Despite the recent publicity about disease-modifying drugs (eg, aducanumab), these drugs have high rates of adverse effects and have not been tested in individuals with more severe Alzheimer disease, who reflect the majority of individuals affected. These patients and their care partners require disease management that includes proactive, empowered health care professionals who can advocate for them; close monitoring; immediate access to care when crises occur; and coordination of care. However, dementia care management must be more comprehensive and address the

TAKEAWAY POINTS

As the population of older individuals increases, the number living with dementia will surge. Although dementia is considered a chronic disease, disease management programs developed for other chronic conditions will fall short of meeting the diverse needs of those living with dementia. The devastating effects on cognition, often with behavioral and psychological problems and loss of capacity of affected individuals to engage in their care; the burden on their care partners; and the scope of disease management, which includes social, legal, and financial issues, require different approaches for dementia care management, including the following:

- Frequent reliance on proxies for decision-making
- Training care partners to support daily functional tasks, provide a safe and supervised living environment, and manage behavioral and psychological symptoms
- Provision of comprehensive, person-centered care that includes social care and care partner support rather than primarily implementing protocolized, prespecified care processes.

TABLE. Differences Between Dementia Disease Management and Other Chronic Disease Management

Component	Management of other chronic diseases	Management of dementia
Drug treatment	• Effective drugs are available • Implementation and titration of evidence-based treatments	• Approved drugs are not very effective in decreasing symptoms • Empiric treatment of complications with medications that are used off label
Ability of patients affected to speak for themselves/decision-making capacity	Usually preserved if no comorbid dementia	Often lost, particularly in late disease
Self-management	Usually patient +/- care partner	Care partner after patient with dementia loses capacity
Caregiver/care partner training	Generally disease oriented	Person-oriented training to support daily functional tasks, provide a safe and supervised living environment, and manage neuropsychiatric symptoms
Community-based efforts	Improving social determinants of health	Providing direct services (eg, adult day care)

individual in the context of needs beyond health care. Accordingly, the success of dementia chronic care management cannot be measured solely in terms of clinical and health care utilization outcomes. Although some outcomes, particularly unnecessary health care utilization,[13,14] are likely to improve with comprehensive dementia care management, there are residual benefits that are not adequately captured by existing measures. Personalized outcomes that assess how well the journey of living with dementia is being managed may ultimately be most important to those affected and their loved ones.[15]

The challenge of providing good dementia care is already upon us and will increase as the number of Americans affected grows. Efforts to meet this challenge must recognize the complexities and differences that dementia imposes. Specific dementia-care programs will need to be implemented by health systems and supported financially by insurers. Medicare Advantage plans have the opportunity to make these changes now and potentially achieve overall cost savings.[13] For other payment systems (alternative payment models and fee-for-service Medicare), changes will be required to promote development or adoption of comprehensive dementia care programs. Additionally, other chronic disease management programs will need to be modified to accommodate the effects of dementia on the care of patients with those diseases. Because many older individuals have multiple chronic conditions and dementia affects the management of each of these, integration of dementia care into other disease management programs will be challenging. To date, the success of collaborative care management for patients with several chronic diseases (eg, heart failure and comorbid depression) has been limited.[16] Accordingly, at this time, patients living with dementia may be better served by programs that focus on dementia management and consider the larger context of the prognosis, therapeutic options, and realistic individual goals rather than optimize management of specific comorbid diseases. Ultimately, the success of management of this progressive and ultimately fatal disorder will depend upon how well the care provided is able to maximize the function, independence, and dignity of the individual living with dementia while minimizing care partner strain and burnout. ■

Author Affiliations: Multicampus Program in Geriatric Medicine and Gerontology, David Geffen School of Medicine, University of California, Los Angeles (DBR, LCE), Los Angeles, CA; Alpert Medical School of Brown University (GE-L), Providence, RI; University of Oklahoma Health Sciences Center (LAJ), Oklahoma City, OK.

Source of Funding: None.

Author Disclosures: Dr Epstein-Lubow reports receiving grants related to dementia and consultant work for the Gerontological Society of America. The remaining authors report no relationship or financial interest with any entity that would pose a conflict of interest with the subject matter of this article.

Authorship Information: Concept and design (DBR, GE-L, LCE, LAJ); acquisition of data (LCE); analysis and interpretation of data (LCE, LAJ); drafting of the manuscript (DBR, GE-L, LCE); and critical revision of the manuscript for important intellectual content (DBR, GE-L, LCE, LAJ).

Address Correspondence to: David B. Reuben, MD, David Geffen School of Medicine, University of California, Los Angeles, 10945 Le Conte Ave, Ste 2339, Los Angeles, CA 90095-1687. Email: dreuben@mednet.ucla.edu.

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