Developing Dementia-Capable Health Care Systems: A 12-Step Program

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KEYWORDS

• Dementia • Alzheimer disease • Primary care • Comprehensive management
• Care coordination • Partnership • Quality measurement • Annual wellness visit

KEY POINTS

- Increasing detection of dementia through routine cognitive assessment is the first step toward improving care at the population level.
- Key goals of population-based health care for dementia are to reduce excess morbidity, poor health outcomes, and preventable emergencies for both patients and their family caregivers.
- The main components of high-quality dementia care are known and can be implemented and measured in primary care settings.
- Delivering those components requires transforming the culture and processes of health care into a sustainable, dementia-capable structure.
- Dementia-capable health care systems are those that provide individualized, coordinated, and integrated medical and psychosocial care for patients and their care partners, delivered by cohesive teams of clinicians, staff, and health care administrators.
- Many steps toward dementia-capable systems can be implemented now, supported by new national policies favoring early detection, care planning, and coordination, support for caregivers, and measurement of care quality.

THE PROBLEM

Alzheimer disease (AD), the most common cause of dementia in later life, affects nearly 5 million people in the United States.[1] But for patients and families, finding clinicians prepared to navigate the diagnostic process, offer treatment, and provide

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knowledgeable and compassionate long-term management, remains a matter of luck. Physicians, other primary care providers (PCPs), and health care systems in the United States do not adhere to uniform expectations or evidence-based approaches to recognizing dementia, or to providing long-term health management and support for dementia patients and their caregivers. Compounding this problem are the limited access to dementia specialist consultations and the absence of quality monitoring to evaluate the care that patients receive, leaving little practical opportunity to achieve real-time improvement.

The mood in health care at the national level is one of energetic innovation, giving rise to a wealth of chronic disease management programs, a rapidly evolving science of implementation, and broad engagement of many stakeholders in improving chronic care. The health care and societal costs of dementia care are high (at least comparable with those of heart disease and cancer),[2] and many thoughtfully conducted clinical demonstrations and intervention trials have identified where gaps exist in health services and defined what works in dementia care. However, health care systems have been slow to translate the evidence into practice; barriers to change, such as entrenched attitudes and the costs inherent in innovation, are substantial. Our aim is to help bring solutions within reach by outlining steps to promote implementation of sustainable systems of dementia care. We term such health care systems "dementia-capable".

PCPs (who may be physicians, nurse practitioners, or physician assistants) play an essential role in implementation of dementia-capable health systems, but they vary broadly in knowledge, skill set, and system resources,[3] all of which affect their level of engagement in managing patients with dementia. It is useful to consider how professionals and health systems respond to heart failure, another similarly complex challenge in chronic disease care. Some PCPs diagnose heart failure themselves, obtain the necessary diagnostic tests, prescribe medical and lifestyle interventions, schedule regular follow-up, and make adjustments in the treatment plan as clinical changes warrant. Some PCPs may prefer that the patient be managed by a cardiologist from diagnosis onward. In the second scenario, the PCP mainly acts as a monitor: on observing a new symptom, the PCP encourages an earlier-than-planned visit to the cardiologist. If lack of PCP capability and heart failure prevalence overwhelm the supply of cardiologists within a health care system, an administrator can choose to hire more, and solve the problem of clinical capacity at the system level. Similarly, in dementia, some PCPs take on all aspects of diagnosis and management, whereas others would, if they could, refer even the most straightforward patients to a specialist (geriatrician, geriatric psychiatrist, or neurologist). However, the specialty-trained physician workforce is too small to care for the large and increasing numbers of patients with dementia, and it is decreasing (**Fig. 1**). Hiring more specialists to manage the need is not a viable health system response, nor is simply expecting PCPs to do more without structural changes in the delivery of care.

A recent modeling study[4] estimated that a typical PCP can manage between ~1300 and 2000 patients, varying with the level of task delegation that is built into the practice structure. If the age distribution of primary care patients reflects national demographics,[5] about 13% of a typical 2000-patient panel (260 patients) are older than 65 years. Of these patients, 5% to 10% (13–26 patients) have AD and perhaps 3 to 10 more have other dementias, but only half are recognized. However, the numbers of older adults with some cognitive disability are potentially larger, reflecting the wide spectrum of systemic and cerebral conditions that are associated with cognitive impairment. Moreover, the disproportionate use of health care by older patients means that a still larger percentage of clinical encounters involve individuals with cognitive impairment, but much of that impairment goes either unnoticed or