

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 study⁴ 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

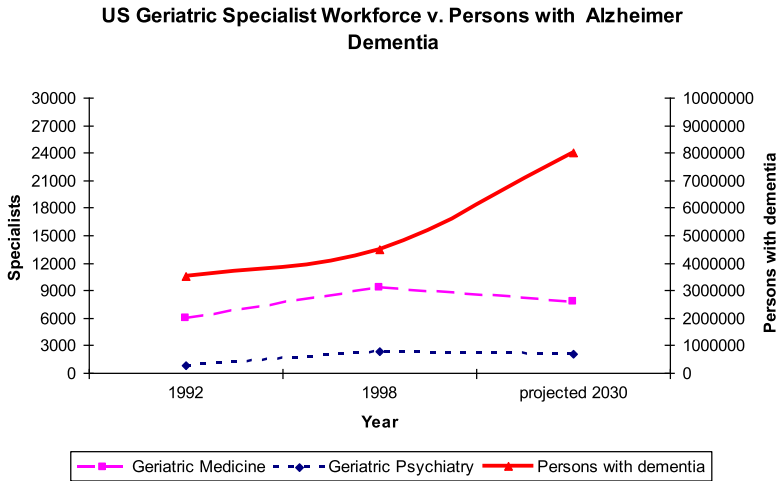


Fig. 1. Inadequate dementia specialist workforce. (Data from Brookmeyer R, Gray S, Kawas C. Projections of Alzheimer's disease in the United States and the public health impact of delaying disease onset. *Am J Public Health* 1998;88(9):1337–42; and Geriatric specialists. Available at: http://www.eldercareworkforce.org/research/issue-briefs/research:geriatrics-workforce-shortage-a-looming-crisis-for-our-families/#_edn10. Accessed May 29, 2014. Copyright S.M. DeMers and S. Borson.)

unremarked,⁶ never becoming a focus of clinical care. The combination of low frequency of frank dementia and low rates of provider recognition means that on-the-job experience by itself does not materially improve clinicians' ability to provide high-quality care for affected patients.

THE SOLUTION

In this article, we outline an incremental approach to health care redesign to achieve high-quality dementia management in health care systems. This approach includes what PCPs can accomplish now, the additional resources they require, how nonphysician staff can be used, retrained, or added to support PCP time and effort, and what clinical and institutional intelligence must be cultivated for sustainable improvements in care. Despite the shortage of providers with dementia expertise, smarter, dementia-capable health care systems can use their precious specialist resources more effectively by establishing coordinated systems that are supported by well-designed electronic health records (EHRs), tailored to assist in dementia care.⁷ Our goal is to show how redesign can be achieved in 12 steps linked to focused strategies that address each of the major deficiencies in health care for dementia and to show the ways that patients and their caregivers benefit through prevention or resolution of dementia-driven health care complications. Steps 1 to 3 deal with preparation for improving dementia management by increasing recognition, diagnosis, and clinician engagement; steps 4 to 7 address the 4 distinct domains that comprise high-quality clinical care; and steps 8 to 12 address health system changes needed to support this care and measure its quality (**Box 1**).

Step 1: Think Differently About Dementia

Many clinicians think of dementia as an abstract disease state caused by specific disorders^{8,9} and one that is mainly a problem for families and social workers. However,

Box 1**Twelve steps to dementia-capable health care systems**

Increase recognition and engagement

Step 1: think differently about dementia

Step 2: focus on detection in primary care settings

Step 3: engage care partners early

Organize comprehensive clinical care

Step 4: treat the disease process

Step 5: screen for and manage behavioral and psychological problems

Step 6: account for dementia in all clinical decisions

Step 7: make caregivers health care partners

Make necessary health system changes

Step 8: specify quality goals and organize care to meet them

Step 9: plan for complexity

Step 10: formalize care coordination

Step 11: make information accessible

Step 12: make job satisfaction a priority

2 other crucial aspects of dementia emerge from the vantage point of patient care: (1) it creates hidden vulnerability and (2) it acts as an organizing principle. As a hidden vulnerability, dementia (brain failure) can be invisible to clinicians until it is relatively advanced or unmasked by acute illness or another condition such as depression¹⁰ or adverse effects of medications.¹¹ As a condition that undermines autonomy, dementia becomes an organizing principle¹² in health care, changing the context, the participants, the methods, and the outcomes of clinical decision making. These important characteristics of dementia have had little or no influence on health care delivery systems.

Valid and reliable diagnostic standards exist for most causes of dementia (see the article by Hugo and Ganguli elsewhere in this issue), but physicians often do not diagnose it¹³ or document it when they do,¹⁴ and they find no clear pathways for organizing comprehensive patient care or support within their own clinical systems to encourage them to make, record, and use a diagnosis in planning care.¹⁵ This situation leaves health systems without accurate data on the prevalence and care of patients with dementia in their populations and unable to plan rationally for improvements in care. It also leaves many patients and families uncertain about what help they can or should expect from clinicians. Personal communications from physicians echo these themes:

"I'm not sure why I should diagnose dementia; I don't really know what to do after that." "I might see something (cognitive impairment), but I wait until the family brings it up or asks for a referral." "I don't have enough time to deal with it." "The pills we have...well, I just don't see them working that well." "What if I told the patient he had Alzheimer's and it wasn't that?" "I'm afraid she'd get depressed if I told her she had Alzheimer's." "It's just too complicated – not like most of the other problems I see in my older patients." "It's hard – it's emotional for me too."

Physicians can learn to diagnose and manage dementia comfortably when supported by well-prepared clinical and administrative health care teams. Peer-to-peer

physician education and federally supported workforce education can increase awareness and skills.^{16,17}

Focused strategy

Provide a variety of educational approaches (e.g., newsletter bulletins, text messages, email announcements, and formal programs) to teach physicians and other health care professionals about dementia diagnosis and its effects on clinical care.

Step 2: Increase Recognition of Dementia in Primary Care Settings

The first goal of dementia detection is to find patients whose cognitive deficits have gone unnoticed in routine clinical encounters but are severe enough to interfere with patient self-care and medical management. Dementia experts and specialty organizations universally recommend identification of dementia when it is present¹⁸ and agree that recognition can be substantially improved with simple assessments.^{6,19,20} Several brief tools are effective, practical, and easily incorporated into routine clinical visits as well as the Medicare annual wellness visit, which requires objective cognitive assessment,^{21,22} and some have been validated for administration by nonphysician staff^{23,24} as a cognitive vital sign.²⁵

Focused strategy

Train office staff to conduct short cognitive assessments such as the Mini-Cog. This can be performed when vital signs are checked and medications are reconciled. Incorporate cognitive assessments into EHR templates that populate encounter forms, triggered by preassigned patient age and other characteristics.

Step 3: Engage Family Members as Soon as Cognitive Impairment Is Suspected

A colleague tells this story: “A physician presents to the memory clinic with her spouse (also a physician). Notes from the referring provider document concerns about her memory. At her last visit, she told her PCP her memory was better, so he changed the diagnosis from possible dementia to mild cognitive impairment. At our first visit, she is so obviously impaired I attempt only a Mini-Cog, but she cannot register 3 words. I try a clock drawing test, drawing a circle to get her started. She draws several smaller circles in and around mine. I ask her husband what her doctors have previously told them; he says this is the first time he (or anyone else) has ever come with her to an appointment. There is no indication that the PCP ever tried to speak to a family member.”

—Courtesy of J.R. McCarten, MD

Detecting cognitive impairment in primary care does not automatically improve dementia diagnosis, disclosure, and treatment planning. The recent systematic evidence review conducted for the US Preventive Services Task Force concluded (as did the first such review published in 2003)²⁶ that detection alone has not been shown to improve decision making.¹⁹ A randomized trial of simple cognitive assessment by medical assistants in primary care²⁴ found a positive and specific impact on dementia-relevant physician actions, but in only about 20% of patients who screened positive. When cognitive impairment is suspected based on screening or other indicators, family members must be engaged to provide essential information about a patient’s everyday cognition and function to help direct further evaluation. Family engagement also sets the stage for development of an ongoing partnership, which, for patients with dementia, becomes the foundation of their health care into the future.

Mrs Murley, age 79 years, was anticoagulated with warfarin for atrial fibrillation. Her attentive children were aware that she needed regular INR monitoring but were uncomfortable “butting in”. When they reminded her about an upcoming appointment, she cheerfully responded, “I’ll have your father take me tomorrow.” When she died several months later of a cerebral hemorrhage with an INR 3.5 times the upper target limit, her dementia had not been formally diagnosed and no plan was in place to help her and her family safely manage and monitor her medication.

Focused strategy

Schedule a visit with the patient and a care partner when cognitive impairment is first suspected (or shown). Consider ordering a home visit if no care partner can be found. Insist on having a variable field added to the EHR that identifies and locates the patient’s key care partners.

Step 4: Diagnose and Manage Dementia as a Disease Process

For most patients, primary care clinicians can, with appropriate guidance, work up, diagnose, and disclose the presence of dementia to patients and family members. The guidance they need includes which tests to consider and which diagnoses to exclude; signs and symptoms that distinguish AD from rarer dementias; the role of cognition-enhancing medications in management; what initial steps to take to address problems in behavior and mood; and how to talk about the problem with caregivers.²⁷ Dementias with features unfamiliar to most generalist clinicians, such as early age of onset, rapid progression, or association with neurologic signs, are more difficult to diagnose without specialized assistance.

A previously healthy 42-year-old man brought shame to his prominent family when he was prosecuted for sexual abuse of a teenaged niece and fired from his job. Depressed, he had to move back in with his parents. A general psychiatrist treated him with a selective serotonin reuptake inhibitor and counseling without improvement. Within a few months, he had become aggressive and delusional, and his psychiatric diagnosis was changed to schizophrenia. Shortly thereafter, he lost the ability to speak. Eighteen months after his first behavioral symptom, he was diagnosed with frontotemporal dementia. He died 3 years later, strangulated in his bedclothes. Autopsy confirmed the diagnosis.

Earlier recognition of the real nature of this patient’s illness might have fostered easier acceptance by his family and community, fewer futile treatments, and a less traumatic death.

As part of characterizing dementia, staging is important in primary care because of its correlations with caregiver burden, mood and behavioral problems, need for supportive services or residential care, and long-term prognosis. Staging is based on the severity of cognitive and functional deficits caused by dementia and is most clearly defined for AD.²⁸ A clinical rule of thumb is that mild dementia impairs 1 or more independent activities of daily living, such as working, socializing, taking medications, managing money, and organizing activities and transportation. Loss of independence in 1 basic activity of daily living (e.g., bathing, dressing) signifies moderate stage, and dementia is severe when the patient can no longer function autonomously in any sphere of life (see the article by Merel and colleagues elsewhere in this issue for further discussion of how dementia stage influences clinical care). The most widely studied functional staging instruments are the Clinical Dementia Rating, which has not been

adapted for rapid administration in nonspecialist settings, and the Global Deterioration Scale/Functional Assessment Staging (GDS/FAST) procedures.²⁸ The 7 GDS/FAST stages are based on readily observed changes in cognition and function, from stage 1 (no impairment) to stage 7 (advanced, preterminal dementia). Staging can help clinicians and families to plan ahead for increases in everyday support, structure, and supervision and the possibility that important neuropsychiatric problems may arise and require treatment. The GDS/FAST system was based on clinical observations of patients with AD but may still provide broad guidance in other dementia types, and clinical support staff can use it. The following vignette shows the relevance of staging:

Mr Traylor, 69 years old when first diagnosed with mild cognitive impairment (GDS stage 3), improved to near-normal (stage 2) after burr hole evacuation of bilateral nontraumatic subdural hematomas discovered during a workup for cognitive symptoms. A year later, he showed unmistakable signs of AD dementia and brightened with treatment with a cholinesterase inhibitor (stage 4). Five years after his first symptoms, his wife was now managing all aspects of his everyday well-being, activities, and health care (moderate dementia, GDS stage 5), and he was finally willing to attend an adult day program, providing her with important time for herself. At 8 years, he could not talk about recent key events in the family's life, had become severely agitated and overactive (GDS stage 6, moderately severe dementia) and could no longer be cared for at home, because of his wife's exhaustion. His agitation was partially eased by judicious use of low-dose antipsychotic medication and a move to a small dementia care home. Ten years after first symptoms, he could not speak, walk, or recognize his wife of nearly 60 years, and frequently resisted personal care (very severe dementia, stage 7). He fell, broke a hip, and was transferred to a hospital, where he seemed comfortable if unaware of his circumstances. His wife, who had been prepared for this eventuality by a series of previous conversations with his physician and was now supported by the hospital palliative care team, was able to resist pressures to authorize a futile surgical procedure. He was transferred back to his care home, where he died without signs of distress, surrounded by his family.

Focused strategy

Provide primary care clinicians with straightforward guidelines for evaluating cognitive impairment and dementia, and train support staff to use simple staging tools in diagnosed patients.

Step 5: Screen for and Manage Mood and Behavioral Problems

Changes in personality, mood, and behavior are inherent in the dementia syndrome, and, when severe, take precedence in health care until improved or resolved. (See the article by Wang and colleagues elsewhere in this issue for a detailed discussion of pathogenesis and management.) Practical guidance for generalists in assessment and management of mood and behavior problems is available on websites (e.g., actonalz.org and alz.org) and in documents²⁷ that are easy to access at the point of care. Because dementia impairs self-reporting and self-management, caregivers become clinicians' primary source of information about patient mood and behavior problems, and the primary recipients of interventions to help manage them. All but the most severe problems are likely to improve with nonpharmacologic interventions,²⁷ such as activity planning, pleasant events scheduling, support and stress reduction for caregivers, and changes in routines and environmental stimulation matched to the patient's needs. Although PCPs can and should understand the

general principles and primary role of nonpharmacologic management, nonphysician clinicians (social workers and nurses who specialize in psychosocial assessment, intervention, and referral to community educational and support resources) can offer a more complete array of choices tailored to each family's needs.

Focused strategy

Train social workers or nurses already working in your health care system to help caregivers manage and monitor mood and behavior at home. The Alzheimer's Association is 1 source of such training.

Step 6: Account for Dementia in Clinical Decisions Regarding Evaluation and Treatment of Comorbid Conditions, Patient Safety, and Life Expectancy

Life expectancy

Survival after a diagnosis of AD is affected by many factors; key examples are shown in [Table 1](#).

Comparable mortality data are difficult to find for dementias less prevalent than AD, but in dementia with Lewy bodies, prominent autonomic dysfunction is associated with lower survival.³¹ Recognizing that dementia shortens life beyond expectations for common causes of death alone should help clinicians decide whether to recommend interventions with significant test or treatment burden, or long lag times to observed benefit.³²

Focused strategy

Use scripted statements to help manage the mutual discomfort of clinicians, patients, and family members when planning for health care that is influenced by life expectancy. For example, "No one can know for sure how long people will live. My predictions may well be wrong, but best estimates would tell me that your husband's dementia is likely to shorten his life; 5 years would not be an unreasonable estimate. We should think about what medical care is likely to be helpful. Some treatments take much longer than 5 years before there is any benefit."

Table 1
Factors influencing survival after a diagnosis of AD

Source	Variable	Survival (Mean [y]) (Standard Deviation)
MoVIES Study ²⁹	Age	
	<75 y	8.3 (4.6)
	≥85 y	3.8 (1.9)
ADPR/ACT Study ³⁰	Stage (MMSE)	
	Mild ^{25–30}	7
	Moderate ^{18–24}	5
	Severe (≤17)	<4
	Clinical features	
	Rapid cognitive decline (>5 MMSE points in first year after diagnosis)	
	Gait impairment, falls, incontinence	
	Wandering, getting lost	
	Frontal release signs	
	Comorbidities	
Ischemic heart disease, congestive heart failure, diabetes		

Abbreviations: ADPR/ACT, Alzheimer's Disease Patient Registry/Adult Changes in Thought; MMSE, Mini-Mental State Examination; MoVIES, Monongahela Valley Independent Elders Study; scored 0–30, with higher scores indicating better cognitive function.

Interactions of dementia with comorbid conditions

Brain dysfunction, comorbid conditions, and medical treatments may interact along unidirectional, bidirectional, or circular pathways. Although the principle applies to all chronic conditions, diabetes offers a clear example. Brain dysfunction is present in twice as many older diabetics as nondiabetics³³ and increases the risk of frequent hypoglycemic events.³⁴ Moreover, serious hypoglycemic events are associated with future dementia in nondemented individuals.^{35,36} Because hypoglycemia imposes a potentially preventable risk for onset or worsening of cognitive impairment, liberalization of diabetes treatment targets should be considered, as recommended in a recent consensus report from the American Diabetes Association and American Geriatrics Society.³⁷ Similarly, for hypertension in patients older than 60 years, new management guidelines recommend treating to a target of less than 150 mm Hg systolic and less than 90 mm Hg diastolic (lower only if well tolerated),³⁸ based on updated evidence relating blood pressure to risk of and time to vascular events; overtreatment increases risk for hypotension and potentially deleterious effects on the brain. Hypotension may go unrecognized as a cause of falls and injuries, ischemic cardiac, cerebral, or renal events (weak spells, confusional episodes, ministrokes, and worsening of preexisting renal insufficiency). Impaired central regulation of blood pressure, inadvertent overuse or overprescribing of medications (cardiac, antihypertensive, anticoagulant, or antidiabetic drugs), a noncompliant vascular system, physiologic increases in insensible fluid loss, low fluid intake because of impaired perception or fear of incontinence, and intentional underuse of medication because of poor understanding or side effects unrecognized by the physician: all may contribute to potentially preventable bad outcomes of chronic disease management in demented patients.

Mr Newhouse was an 83-year-old man with vascular dementia, congestive heart failure (CHF), and gait apraxia, who was started on twice-daily furosemide as part of his CHF therapy. He saw his cardiologist 2 months later who noted, in addition to dyspnea and marginal oxygen saturations, lower extremity edema and an 11.3-kg (25-pound) weight gain. A medication review showed that Mr Newhouse was taking furosemide once in the morning, at most. "Once a day is good enough." It was only after further discussion and personal engagement with the patient's daughter that the provider learned that Mr Newhouse does not like taking the medication, especially at night, because it causes nocturia: he struggles to get out of bed and get to the bathroom (gait apraxia). Sometimes, he does not make it in time and ends up urinating on the floor. Once, he slipped and fell, injuring his knee. Neither the patient nor his caregiver understood that the medication was necessary to maintain comfortable breathing. The provider had to adjust his original assumption that the patient simply did not like taking medications and "knew better than the doctor" (which, in some ways, of course, he did). Learning the reasons for the patient's behavior changed the care plan: a bedside commode, mobility aids, and more suitable medication schedule were patient-centered adjustments that increased the likelihood of success in his CHF care.

Focused strategy

Use checklists to monitor and update comorbid medical conditions, track treatments, and specify the added risks that they may pose in the presence of dementia. Spell out what caregivers need to do to manage the patient's health at home, and assess their understanding and ability to take on these tasks. You can start this as part of the health risk assessment in the annual wellness visit, which also calls for identifying all providers involved in the patient's care to promote collaboration and coordination. All of these elements can be incorporated into the EHR.

Everyday safety

Driving A recently updated American Academy of Neurology practice parameter³⁹ cited evidence that up to 75% of individuals with mild dementia can pass an on-road driving test, although some states mandate reporting of suspected unsafe driving or any dementia diagnosis. Tips for evaluating driving risk³⁹ are shown in **Box 2**.

Box 2
Factors associated with unsafe driving in dementia
More advanced dementia stage
History of citations or crashes
Family reports of unsafe driving
Self-reported driving restrictions
Impulsive or aggressive personality characteristics

Focused strategy
Ask about driving in any patient with cognitive impairment. Recommend behind-the-wheel testing and say, "I know that you have been an excellent driver but sometimes people with memory or other problems with thinking are not aware of limitations that put them at serious risk for a car accident. It would be good for you to know. I want you and your family to be safe."

Injuries Each year, more than half of individuals with AD sustain injuries requiring medical treatment⁴⁰ (about half because of falls), and in a series of 139 patients living alone,⁴¹ 31 potentially preventable emergencies occurred over a follow-up period of 18 months. Among these emergencies were serious medical illness caused by failure to obtain treatment of a mild problem; a house fire caused by an unattended stove; injuries caused by forgetting to use mobility assistive devices; dehydration; infection; and hip fractures.

Medication problems

Misadherence Problems with knowledge, reporting, management, and mechanics of using medications are commonplace in individuals with cognitive impairment.^{42–44}

Misprescribing The negative impact of anticholinergic medications in patients with dementia has been widely publicized, although discontinuing any but the most potent agents does not necessarily benefit patients. General guidance to help providers evaluate risks associated with specific drugs and drug classes in older adults is now widely disseminated.⁴⁵

Unusual but serious medication side effects The common side effects of cholinesterase inhibitors used to treat AD and some other dementias are well known, but other potential hazards are not; analysis of more than 80,000 patients with a dementia diagnosis showed that patients receiving a cholinesterase inhibitor had nearly twice the rate of hospital visits for syncope as untreated individuals, more visits for bradycardia, and more permanent pacemaker placements and hip fractures.⁴⁶

Mr Xavier was an 87-year-old with moderate AD who was started on a cholinesterase inhibitor for worsening memory impairment. He had periodic medical evaluations with his PCP since starting this medication. His physician had noted resting heart rates in the low 50s but no related symptoms. Three months later, after 2 falls and episodes of agitated behavior, Mr Xavier returned to the office,

at which time his resting heart rate was 38. The cholinesterase inhibitor was stopped, and there were no subsequent falls or agitated behavior over the next 6 months. His resting heart rate increased to 58 off medication.

Focused strategy

Train social workers or nurses to talk with family caregivers about injury risk and safety strategies. Ask patients to tell you what medications they take, and show you how they use them; if they cannot do this accurately, involve the caregiver. Use Web resources (such as actonalz.org) to find suitable safety checklists. Request EHR tools that list potentially harmful medications and flag any that appear in your patient's medication profile. Be alert to unusual side effects.

Potentially avoidable acute care

Patients with dementia have higher (in some cases, 5-fold) rates of potentially preventable hospitalizations for both medical and psychiatric diagnoses than other older adults.^{47–49} In a study that used epidemiologically sound ascertainment of incident cases,⁴⁸ stringent adjustment for multiple confounders, and a follow-up period of up to 8 years, rates of avoidable hospitalizations were still nearly 80% higher in dementia, yet reasons for admission, such as CHF and pneumonia, were similar to those for non-demented individuals. Some causes are more directly traceable to the effects of cognitive impairment,⁴⁷ including injuries linked to inattentiveness, poor motor control, or unnoticed environmental hazards, neurobehavioral problems and delirium, delayed recognition of an emerging acute medical problem, errors in medication management (too much or too little), and failures of homeostasis (e.g., dehydration). Similar effects are seen for emergency department visits.

Integrating awareness of dementia into medical care for comorbid diseases may reduce the need for acute care. In a recent study of patients hospitalized for CHF,⁵⁰ documentation of cognitive impairment by the clinician was associated with lower 6-month mortality and readmission rates. In another study of older adults,⁵¹ a standard index of comorbidity computed from prescription records underestimated disease burden relative to a comprehensive clinical assessment; dementia (even when mild) exaggerated the discrepancy, suggesting that common chronic conditions may be undertreated in cognitively impaired patients.

Focused strategy

Teach providers in the clinic, emergency department, and hospital about interactions between dementia and general medical conditions. Use brief clinically relevant checklists, integrated into the EHR, to track potential problems and identify patients who need complex care management.

Step 7: Make Caregivers Your Clinical Partners. Assess Their Information, Health, and Care Needs

Things change so much with (my husband with dementia), and with me...and the kids, too. I want to know my doctor will try to understand what's going on and answer my questions, help me know how to deal with things and what to expect. It's not just about the Alzheimer's – it's his heart problems too, and he gets upset by things so easily. He takes so many medications. How can I know if they're the right ones? He sees 5 different doctors. I'm never sure they talk to each other. And even if my doctor doesn't always know all the answers, I need to know s/he will guide me to someone who can help. But just being there for us makes a big difference. I guess I want a doctor who will "have my back" – one I can count on to be there for us all the way through.

Caregivers as people, proxies, and partners

Patients and family members seeking explanations for a cognitive problem want to know about the process and results of the diagnostic evaluation but feel overwhelmed when information is provided as a “crash course” at the end of a diagnostic process.⁵² For those fortunate to receive diagnostic and treatment information, many do not experience the process as patient-centered⁵³ or as leading toward clear definitions of the roles and responsibilities of family caregivers, clinicians, and other members of the care team, or to a cohesive plan of care. It is not surprising that a plan rarely follows a diagnosis, given that clinicians lack guidance on how best to manage dementia.

Focused strategy

Use talking points to increase provider comfort with difficult conversations and find ways to ask questions that create meaningful dialogue. Example: “Before we go over the results of our tests, it is helpful for me to hear your concerns and to know what you understand about all of this.” Do this first to ground the subsequent discussion in awareness of the patient’s and caregiver’s present knowledge and fears. “From what I understand about what has been happening this past year and the tests we have done, your/your wife’s thinking problems are likely due to a condition known as Alzheimer’s disease. This must be difficult to hear right now... but there is much to be done that can be very helpful to both of you. We’ll talk about that.”

Patient centeredness: application to dementia caregiving networks Patient-centered care focuses on negotiating between medical priorities and patient/family preferences and choice, and balancing the burdens of illness and treatments through effective relationships and communication between providers and patients. Three helpful constructs have recently been articulated,⁵⁴ each imposing a distinctive demand on the physician: (1) to understand the relevant biopsychosocial context in which the clinical problem is occurring; (2) to actively cultivate a shared understanding of the problem and the patient’s (and caregiver’s) experience of it; and (3) to be willing to share responsibility (and power) for what and how care is provided. In dementia, patients communicate with variable clarity about their experience, understanding of their condition, and wishes for care (relatively well in the early stages, but less well as dementia progresses). Clinicians, then, need to rely more on their skills in observing and interpreting nonverbal communication, and on working with caregivers and helping them function effectively as reporters, advocates, and mediators of patient centeredness in care. Clinicians’ readiness to share responsibility and power, without abrogating their professional responsibility to guide clinical care, is the foundation of collaboration: finding common ground, creating a therapeutic alliance, and accepting the affective and relational aspects of clinical care⁵⁵ as assets that facilitate, rather than impede, the achievement of therapeutic goals (**Box 3**).

Box 3

The main goals of dementia care

1. Intervening to improve patients’ and families’ ability to live with the day-to-day effects of dementia
2. Seeking to anticipate, prevent, or mitigate its medical and psychosocial complications

Patient centeredness is key to guiding effective clinical encounters, planning care, and creating an effective, enduring interactional structure for clinicians, patients, and families within a health care system.

Being a caregiver Effective communication in the interest of dementia care requires an understanding of the lived experience of caregiving. This experience, which includes becoming a caregiver (a person who provides for another what would normatively be done by the person for themselves) is a developmental process that is charted along a mostly slow, almost imperceptibly undulating path, punctuated by nodes (periods at which change comes rapidly or decisively, and reality seems altogether different). The point of formal medical diagnosis can be 1 such node, triggering a sense of a new reality, regardless of how much care might have been provided beforehand.⁵⁶ Caregivers who receive education and support soon after diagnosis experience substantial immediate benefits in self-confidence⁵⁷; the Alzheimer's Association provides such assistance through its early stage groups for patients and caregivers. Clinicians who recognize the dynamic course of dementia and the parallel trajectory of the caregiving career find it easier to provide excellent care to patients and families.

Turning points in the lives of caregivers occur predictably with progression of dementia to the next stage of functional dependency but also after catastrophic medical or behavioral events or changes in the caregiver's own health. Most often, gradual, subtle shifts of autonomous functions from the patient to the caregiver produce only incremental increases in the burden of care, resulting in a lag between what other family members (and perceptive clinicians) see and what the primary caregiver is able to acknowledge. Caregiver burden and stress have become a permanent part of the Alzheimer caregiving lexicon and a primary or secondary measure of the efficacy of many types of interventions. The Alzheimer's Association⁵⁸ reported that 60% of dementia caregivers experience moderate to severe stress, and, in elderly spouses, high, unmitigated caregiving stress can be lethal.⁵⁹ However, research on predictors, correlates, and interventions to manage stress and burden in dementia caregivers shows the complexity of these phenomena.

Managing the problems of caregiving The perceived burden of caregiving is associated with specific exposures (e.g., to the patient's unexpected outbursts of anger), caregiver vulnerabilities (personal health problems, anger, and anxiety), and specific caregiver resources (coping style, outlook on life, and social supports).⁶⁰ A recent twin study found that both genetic factors and early environment influence the relationship between later caregiving and anxiety, depression, and stress.⁶¹

Several experimental interventions have been shown in randomized trials to help caregivers manage specific behavioral and functional problems in patients and reduce their own feelings of stress and depression,⁶² but not all caregivers need the same kinds of help. In REACH II (Resources for Enhancing Alzheimer's Caregiver Health),⁶³ one of the few studies to examine variation in caregiver response to an intervention, only those with the highest depressive symptom scores improved; results were similar for self-rated stress. In general, the strongest overall evidence supporting the efficacy of caregiver interventions is for multicomponent approaches, which closely resemble the care provided in specialized, multidisciplinary dementia clinics or as part of collaborative care management paradigms. Key factors in their success are active engagement of patients (as appropriate), caregivers, and families; individual tailoring; and flexible long-term access to management support and assistance, which begins soon after diagnosis/disclosure and continues or resumes as needed.⁶⁴ Other interventions showing some efficacy combine information and individualized processing of problems in care, but peer support, referral to support groups, or self-help materials as the sole intervention are not effective.⁶⁴ (See the articles by Gaugler and colleagues, Merel and colleagues, and Wang and colleagues elsewhere in this issue for more discussion of caregiving.)

Focused strategy

Train social workers or nurses working within health care systems in dementia care management. The Alzheimer's Association and other organizations provide a variety of resources for such training. Provide opportunities to increase care management skills by participating in clinical case conferences with others from their discipline.

Caregivers as patients

Dementia caregivers are also, of course, patients with their own health concerns and needs. As patients, their health and health care utilization and costs are affected by caregiving stresses and burdens. A recent large study of caregivers enrolled in a Medicare Advantage plan found substantially higher odds of being treated for a wide range of symptoms and conditions (both medical and emotional) and greater use of outpatient, emergency, and home health care, relative to matched noncaregivers, resulting in an average of \$867 higher per-patient cost over 36 months.⁶⁵

The dementia caregiving network as the unit of health care

Most health care systems have no way to identify caregivers in either the patient's or the caregiver's EHR. However, the needs of patients and caregivers are widely acknowledged by dementia clinicians and researchers as intimately interlinked. A new instrument distills this principle into a simple tool to identify unmet needs. The Dementia Services Mini-Screen,⁶⁶ consisting of a single-item caregiver stress question and a short list of high-impact patient behavior problems, is a powerful predictor of medical and psychosocial needs for both patients and caregivers.

Focused strategy

Make the health and well-being of your patient's caregiver your priority. Spend time with the caregiver alone as part of the patient's visit to assess their level of stress and need for assistance. If you are not their PCP, request permission to share information with that provider. Refer to your health system social worker to provide additional support and assistance and follow up to be sure the connection is made.

Step 8. Set Specific Quality Goals for Care of Patients with Dementia, and Organize Clinical Information Gathering, Decision Making, and Care Tracking to Help Achieve Them

Understanding the interrelated components of health care for people with dementia, and knowing how to work with and help family members who care for patients at home, are skills that must become routine in clinical practice; they are an essential part of the culture of dementia-capable health care systems. The current physician-centric structure of most health care systems, the emphasis on episodic care delivered to 1 patient by 1 or a series of individual providers, and the sizable financial incentives favoring procedure-based over cognitive activities of providers⁶⁷ work poorly for chronic disease care in general and worse for dementia. In dementia, although we know what processes are needed, we have yet to structure our systems to provide them. Older⁶⁸ and newer⁶⁹ indicators of dementia care quality synthesize data on evidence-based care processes into a set of measures that can be tested with providers and used to assess the performance of health care systems. These measures can be easily incorporated into an organized, domain-based, dyadic approach to health care for patients with dementia (Fig. 2).

The previous sections provide the rationale for dividing dementia care into 4 core domains: dementia as a disease state; associated mood and behavioral problems; medical comorbidities and safety risks; and caregiver and family issues and concerns.

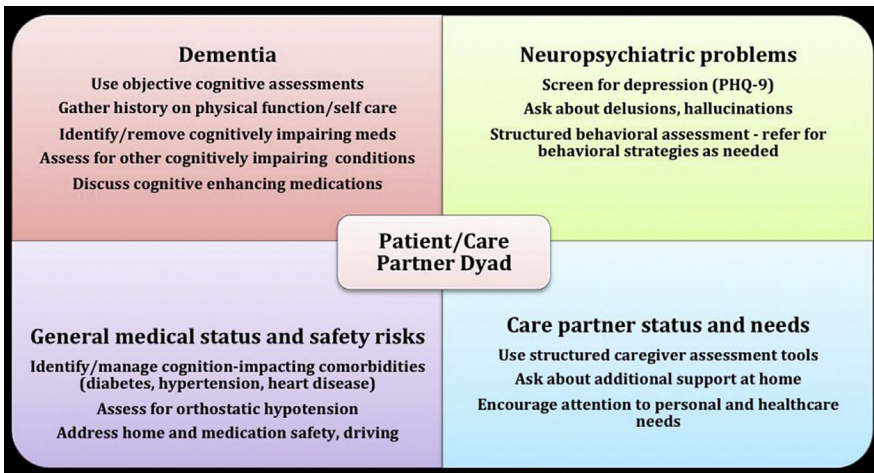


Fig. 2. Four-part model for dementia care assessment, tracking, and quality management. (Data from Lessig M, Farrell J, Madhavan E, et al. Cooperative dementia care clinics: a new model for managing cognitively impaired patients. *J Am Geriatr Soc* 2006;54:1937–42.)

Organizing clinical assessment around these 4 domains should start soon after the initial dementia diagnosis and disclosure, processes that set the stage for long-term partnership among patient, caregiver, and clinician. A domain-based assessment maintains a structured format and coherent framework for patient care, helps identify problems in caregiving and needs for caregiver education and assistance, and supports clinical improvement by tracking patient and caregiver responses to interventions. **Fig. 2** shows a simple assessment grid for primary care; the level of detail can be expanded for more specialized applications, and aggregated data from multiple providers can be used to identify system-level gaps and facilitate formation of more efficient team-based care.

Using the 4-part model is helpful in managing the complexity of dementia care. During the evaluation phase, a clinician can, if needed, conduct 4 visits: 1 for each of the 4 domains and each reimbursable by Medicare. Depending on findings, 1 or more of these domains of care may require active, focused follow-up, and the comprehensive assessment as a whole can be repeated as clinical change occurs. Documented assessment of each domain of care (and its associated processes and goals), at least once a year, can be used as a measure of health care quality in its own right. Repeated measurement is required by the predictably changing problems and needs of dementia dyads over time⁹⁹; annual reassessment is not sufficient for clinical management of most patients, and frequency must be dictated by active problem domains at any given point in time. A useful rule of thumb is every 6 months for mild dementia and every 4 months thereafter, with the expectation that interval problems are actively tracked and managed using communication tools made available by health care systems as part of their dementia care packages.

Focused strategy

Teach clinicians to use a 4-part approach to assessment and care of dementia patients. Develop EHR templates to simplify the assessment and documentation process. Use the annual wellness visit to help anchor clinical care, and make families aware of this copay-free Medicare benefit. Negotiate visit frequency according to the activity of clinical problems and caregivers' need for support.

Step 9. Plan for Complexity (and Measure It)

Managing complex care calls for systematic, planned actions that simplify goals and promote a sense of coherence for both patient/caregiver networks and clinicians. Three complementary approaches are especially promising: taking patient-centered care seriously; making care coordinators members of the clinical team^{70,71}; and developing quantitative methods to deal pragmatically with the joint effects of multimorbidity, demographic influences on health and health care, and features of health care organizations, to name a few of the sources of complexity. One new quantitative method, the Geriatric Complexity of Care Index (GXI),⁷² groups patients with dissimilar clinical problems by indexing the expected intensity of primary care management. In an initial study,⁷² the GXI was superior to conventional comorbidity measures in predicting ambulatory care visit numbers, exposure to polypharmacy, and total number of quality measures that would apply to each patient, but not other outcomes, and the conditions it measures are not all found in clinical or health systems data. However, the principles of measuring disease complexity are important for future development of guidelines for managing complexity in practice.^{73,74}

Patient-centered care aims to extend care beyond disease management to incorporate its lived reality and the goals, values, and priorities of patients and families. Organizational innovations such as patient-centered medical homes can improve patient experience and reduce clinician burnout.^{75,76} Medical home–like concepts specific for dementia care (specialty-led medical neighborhoods⁷⁷) have been described in both geriatric⁷⁸ and geropsychiatric outpatient⁷⁹ settings. Models like these bring specialist expertise to the diagnostic, neurobehavioral, medical, and family caregiving complexity inherent in much of dementia care and show how to operationalize the concept of dementia as an organizing principle for health care. They do not answer the undersupply of dementia specialists or the difficulties of translating multidomain care models into sustainable programs in health systems. This strategy requires solutions at higher levels of health care organization than the clinician-dyad encounter.

Focused strategy

Test the value of quantitative tools to identify groups of patients with varying needs for specialized care and meet those needs through patient-centered, coordinated, and actively managed care plans.

Step 10. Negotiate Defined Roles and Responsibilities for All Partners in Care, and Integrate Them by Care Coordination

The role of the PCP

In response to the global undersupply of specialists to care for patients with dementia, a panel of dementia specialists and PCPs in the European Union proposed modest but specific roles for the PCP in a 2009 position paper.⁸⁰ The panel assigned responsibility to the PCP for case finding, diagnosis, and management of uncomplicated dementia, including identification and monitoring of dementia-associated risks (e.g., falls, neuropsychiatric symptoms, and poor nutrition). Additional responsibilities within the scope of primary care practice are to provide up-to-date preventive and therapeutic interventions and basic counseling and education for family caregivers, with the goal of crisis prevention.

Families' needs for information, support, and referral for community-based services eventually go beyond those basic elements; many caregivers have several different unmet needs that require engagement of a mix of medical and psychosocial care

providers,⁶⁶ who may not communicate effectively or coordinate care without explicit connecting steps. The expertise required to assess dyadic needs, individualize psychosocial interventions, and monitor functional risks is most readily found in specially trained nonphysician providers. Randomized trials have reported successful care management by social workers,⁸¹ advanced practice nurses,⁸² and occupational therapists,⁸³ working flexibly as interventionists, dementia care managers, communication specialists, and early-warning systems for emerging problems.

If these models are successful in improving quality of care, why are they not more widely implemented? One reason is financial: none has focused on reducing high-cost care (e.g., preventable hospitalizations) as an outcome, and none has shown cost savings^{84,85} or cost neutrality. Care coordination models are covered inconsistently or not at all by health insurance. Medicare explicitly excludes payment for a clinician's work with family members on behalf of a patient unless the patient is present, yet much of what caregivers need in terms of information, explanation, and skills to manage a demented patient's health care is best provided in separate caregiver visits.

The role of community-based organizations

Some of the roles piloted by social workers in dementia care management trials, especially caregiver education, support, and referral for community services, can be effectively delivered through direct partnership between providers in a health care system and community-based organizations (CBOs), such as the Alzheimer's Association. Partnership is more successful when they share a common computerized record.⁸⁴ These collaborations bring value, but integration of CBO interventions and clinical care is not automatically robust.^{86,87} One Alzheimer's Association chapter has built, through intensive outreach to and between physicians, a growing network of providers and clinics who refer patients by word of mouth or via Direct Connect, a fax referral program from the physician's office or clinic to chapter staff. Sixty-one percent of Direct Connect referrals resulted in successful contact with patients and caregivers. Over 3 years, the Association increased the number of physician relationships from 113 to 498; **Fig. 3** shows results of this physician outreach effort created and led by staff at the Alzheimer's Association/Minnesota-North Dakota Chapter (with funding by the GHR Foundation).

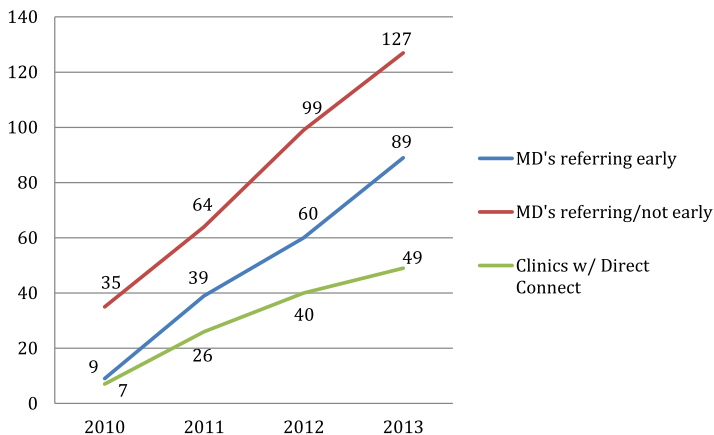


Fig. 3. Enhancing connectivity between physicians and the Alzheimer's Association. (Courtesy of Michelle Barclay, MA, Alyssa Aguirre, LCSW, and Maria Clarys, BA, Alzheimer's Association Minnesota/North Dakota Chapter.)

The dementia care manager within the health care system

The single most effective innovation to improve dementia care is the hiring and training of dedicated care managers who facilitate optimal use of community resources, coordinate care between CBOs and medical providers, and contribute management activities specific to their own discipline.⁸⁸ Models of dementia care with superior outcomes in randomized trials use either social workers or advanced practice nurses as care managers. Comparison of 6 randomized controlled trials using a structured case management evaluation tool⁸⁹ showed that higher intensity of care management and fuller integration of health and social care services (and in some instances, acute and long-term care settings) were common to the best-performing models.

Focused strategy

Recruit or retrain social workers or advanced practice nurses to provide dementia-specific care management and act as peer champions. This is an efficient way to rapidly increase dementia care capacity.

Step 11. Create Effective Communication Tools that Make Information Accessible to Providers, Family and Community Care Partners, and Care Managers

Health care systems face unprecedented challenges to supporting effective, sustained communication between providers and patients. How much time providers allocate (the length and focus of a visit, time spent talking vs doing) is increasingly defined and controlled by systems that use large provider panels, and by the payment arrangements they make with providers and insurers, although independent office practices struggle with the same issues. Short, single-problem visits, still driven by traditional views of the medical encounter as a 1-way transaction focused on bodily injuries and short-term ills, leave little room for complexity. Complexity (in age, functional status, comorbid disease, emotional and behavioral influences, and social-relational qualities that have much to do with chronic disease management) calls on clinicians to use excellent cognitive skills. These skills embody the ability and willingness to think through and integrate complex information into a coherent approach to the patient, preferably one that is contextual, social, and relational in addition to disease focused, to communicate clear and manageable goals and recommendations for care, and to acknowledge the potential burden of care and negotiate around it.

At the process level, dementia care exaggerates the divide between the improvements in organizational efficiency and factual accuracy expected from burgeoning communication and medical record technologies, and the homely virtues of learning about and attending to the patient's and family's needs, wants, and preferences over time, which are core tenets of high-quality care and care that is patient centered.⁹⁰ Nevertheless, high-quality communication is an indispensable feature of a dementia-capable health care system. Its content includes gathering accurate and meaningful information from patients and families; delivering health care information in understandable ways at the right time and to the right people; detecting communication barriers and correcting miscommunication; and having time to ensure sufficient opportunity and access to channels of communication. These elements build and strengthen relationships, and strong relationships between providers and dyads are the basis of effective long-term management. Responsibility for effective communication resides within the human interaction that occurs during the clinical encounter, but health care systems can facilitate or impede the process by the way they craft and deploy new communication tools.

Focused strategy

Use easy to understand patient/caregiver questionnaires, problem-based information sheets, and EHR-based patient portals for information transfer. Narrow the focus of the clinical visit to a specific dementia-related problem, and conclude with an action plan. Follow up on the plan. Make it easy to access the PCP's assistant by telephone, email, and fax. Consider individual patient information clearinghouses that exploit EHR capabilities to support multidirectional communication.

Step 12. Make PCP Job Satisfaction a Priority

Large health systems have many patients with dementia, but individual PCPs typically have few. Providers would understandably be reluctant to take on greater numbers, anticipating the higher intensity that can be associated with seeing and managing dementia differently, unless health systems embrace new tools to manage this intensity. Relatively simple changes at the level of the clinical encounter and the health care organization could speed improvements in care. At the encounter level, changes include: (1) focused revisit assessments delegated to other members of the primary care team (medical assistants, nurses); (2) brief assessment instruments that are relevant to the goals of care and patient/family needs and are easily accessible in the EHR; (3) communication protocols for managing between-visit questions and needs; (4) medical assistants as scribes (or more user-friendly EHR interfaces and templates) for medical record documentation during the office visit; and (5) brief EHR-accessible, problem-specific management “pearls” to reinforce on-the-spot education. Providers who are better informed find it easier to address dementia-related issues and can use their time more efficiently and effectively. Spending more time face to face with patients and families (and less time managing the administrative aspects of care) improves both physician and patient satisfaction and can even return joy to the physician's practice life.⁹¹ This situation results in more meaningful relationships between patients, families, and physicians, greater professional satisfaction and sense of accomplishment, and more sustainable care.

At the organizational level, planning for dementia care improvement relies on acquiring better data about the scope and nature of the need. Using the annual wellness visit as a practice standard to estimate the prevalence of cognitive impairment and associated medical complexity, identify actual or potential caregivers in the lives of affected patients, and evaluate urgent needs for dementia-specific care⁶⁶ would streamline estimation of how many, and where, staff need to be prepared to deliver it.

SUMMARY

Development of dementia-capable health systems requires simpler, yet broader, clinical paradigms than those used by dementia specialists in their own practices, and whose work has provided most of what we know about caring for patients with dementia. Methods and models can be friendly to primary care clinicians and to systems concerned about improving patient experience and quality of care without incurring large excess costs. Much of the work to improve care focuses first on highly symptomatic patients and burdened caregivers; this care can be well managed by social work or nursing disciplines, in close, team-based coordination with PCPs. Such collaborative models have shown improved care quality and psychosocial outcomes.^{81,88} Implementing proven models of care and improving general health outcomes and utilization profiles for patients and caregivers are the next thresholds.

Given the small numbers of patients with dementia seen by most PCPs, a dementia care management system that is shared among several PCPs is sensible and can be activated through enhanced communication systems for patient/caregiver dyads, physicians, and care managers that are supported by EHR packages. However, no care management system works without dementia-capable PCPs who manage patients' chronic diseases and who understand that the psychosocial care provided by care managers is integral to patients' health care. Nor does a care management system work without health systems that place high priority on relationships between providers and patient/caregiver dyads. With engaged PCPs and care managers, the clinical efforts of dementia specialists (in short supply) can then be selectively directed toward complicated diagnostic and management issues and to supporting and overseeing several dementia care management teams within the same primary care system.

The 12-step program we propose in this article is designed to support clinicians and health care systems in a phased process of becoming dementia capable. The steps are conceptually linked (each contributes a key component), but not all must be implemented at once. Some steps, such as timely recognition of cognitive impairment, can be quickly accomplished (and are already financially incentivized under Medicare) through implementation of the annual wellness visit within a practice or system. Others, such as modifications to the EHR to facilitate accurate dementia diagnosis, quality management, and communication, require more investment of time and resources. Care management training for a limited group of staff, social work, or nursing professionals requires an intermediate, but still small, level of organizational commitment.

Any proposal for health care redesign for a specific condition begs the question of how priorities are set. Is dementia care of high enough priority to justify the necessary investment? National initiatives argue 'yes': the National Alzheimer's Plan calls for substantive improvements in health care quality for patients with dementia and in support and assistance for family caregivers.⁹² New dementia care quality measures⁶⁹ have been authorized for physician incentive payments under the Physician Quality Reporting System. Do all patients with dementia and all caregivers require the full scope or intensity of services possible within the structure shown in Fig. 4? Clearly not,⁶⁶ or not all at the same time, but when they need it, all deserve access to the best that health care can provide: multicomponent services, flexibly combined, that can be quickly engaged when needed and stand ready until they are.

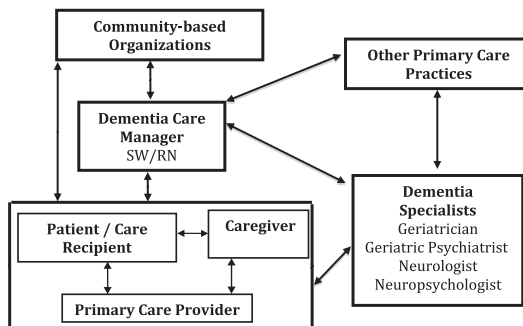


Fig. 4. Structuring the dementia-capable health care system.

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