

Opportunities for Improving Managed Care for Individuals with Dementia:

Part 2—A Framework for Care

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Abstract

In this second part of a review of dementia, we argue that managed care organizations must develop strategies to identify and manage patients with dementia, whose numbers will increase dramatically in the near future. Improved coding and use of validated self-report instruments that include caregivers as information sources could assist in identifying patients with dementia who could benefit from disease management programs. These programs should include population-based screening efforts; the development of practice guidelines; the use of case managers; education of caregivers, case managers, and physicians in issues such as availability of community services, patient/caregiver self-management techniques, and the latest developments in efficacious treatment; and monitoring of care through quality assurance activities. Dementia is a highly prevalent, devastating, and costly chronic illness of the elderly, but it is also eminently manageable. Managed care has the potential to improve the quality of life and care for these patients, while managing the costs.

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The prevalence of Alzheimer's disease (AD) and of its related dementias (ADRD) is estimated to be 6% in individuals over age 65 and may approach 40% in those older than 85.¹⁻⁶ Annual direct and indirect healthcare costs for ADRD are currently estimated at \$100 billion in the United States.⁷ With greater numbers of elderly enrolling in Medicare managed care plans, the proportion of these costs being paid by managed care will increase as well.

As we described in part 1 of this article,⁸ to date most managed care organizations (MCOs) have failed to focus on the potential challenges of caring for large numbers of patients with dementia. They have not yet recognized the impact on their organizations of increased costs, significantly greater services usage, and poorer quality of life for both the patients and their caregivers that will result from the failure to develop a plan of care for patients with dementia.

In this article, we outline just such a plan. We argue that as a chronic illness, dementia has most of the characteristics that make it amenable to a disease management program such as is applied to patients with diabetes, asthma, and other chronic illnesses.

Improving Care of Patients with Dementia in Managed Care

There is no doubt that many patients with dementia are currently enrolled in MCOs even though their care may not be explicitly tracked by the organization⁹ and their numbers may be underestimated because of lack of recognition by physicians and undercoding for claims purposes. For example, dementia is rarely coded as the cause of a hospital admission, but it is the underlying cause of many admissions for infections in and injuries to the elderly.¹⁰ For this reason, analysis of the most frequent reasons for hospital admission in MCOs is

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unlikely to identify many patients with dementia. In addition, Medicare managed care programs can expect to see increasing numbers of individuals with dementia in their programs. The Balanced Budget Act of 1997 mandated the Health Care Financing Administration (HCFA) to develop and implement a risk-adjusted methodology for payment to health plans to replace the current method. The new payment system will likely encourage health plans to enroll and then actively manage care for the chronically ill elderly, including patients with dementia. Potentially, the new payment system could benefit health plans, their contracted providers who practice cost-effective medicine, and chronically ill members with dementia who may benefit from better managed care systems that meet their needs.

The recognition of the excess costs of care for patients with dementia creates incentives for MCOs to focus efforts on members with this chronic illness. Since dementia is a chronic, progressive disorder that requires a comprehensive multidisciplinary approach, managed care potentially offers a better way to care for patients with dementia than traditional fee-for-service (FFS) approaches. Traditional Medicare FFS payment systems tend to lead to fragmented care and lack of coordination of providers. In managed care, budgeted (capitated) care allows providers to dispense necessary care, either medical or nonmedical, and utilize all necessary sites of care to manage healthcare quality and costs. Budgets in the form of capitation give providers predictable and prospective revenue that can be used to better design service delivery beyond the usual limits of FFS practices. Capitation may promote efficient access to the full range of services required by patients with dementia if these services can be shown to be cost effective and promote quality of care. Furthermore, in Medicare managed care, many of the regulations that fragment care in Medicare FFS, such as the 3-day requirement for a hospital stay prior to nursing home admission, are waived so that direct admissions to skilled nursing care facilities from the home are possible. Thus, for the patient with dementia, managed care providers can employ budgeted funds for direct admissions to skilled nursing facilities for subacute medical problems, adult day care, respite for caregivers, and other targeted forms of long-term care. In principle, well-managed care can promote maintaining patients at their highest level of independence, preferably living in the community, and can prevent unnecessary hospitalizations.

In contrast to care under FFS arrangements, MCOs have the potential to employ systemwide case-finding strategies. Currently, Medicare MCOs commonly employ health-risk assessments to identify members requiring primary, secondary, or tertiary preventive health interventions. Identifying members at high risk enables Medicare managed care programs to effectively triage these members to proactive interventions such as geriatric care management.¹¹⁻¹⁵ Previous research has shown that elderly individuals at high risk for adverse health outcomes can be identified by self-reported health-risk assessments.^{14,16-20} However, health-risk assessments specifically designed for detecting dementia have not been previously developed or implemented on a widespread basis in MCOs.

An alternative approach to case finding for disease management depends on the use of administrative data. Although this approach has been successfully applied in diseases such as congestive heart failure,²¹ asthma, and diabetes, administrative data may not be useful for capturing data on individuals with dementia. Mild and even moderate AD/DR is grossly underrecognized resulting in undercoding, even when diagnosed. For example, one study showed that dementia was coded for in only 10% of patients who had already received the diagnosis.¹⁰ Thus, case finding and reporting must be improved in order to develop better medical management systems for dementia. Validated self-report instruments that include caregivers as information sources may offer useful alternatives for case finding. For administrative data to be useful for the detection of dementia, progress must occur at the level of physician recognition of AD/DR so that coding, particularly in the ambulatory care setting, reliably identifies disease episodes.

Capitated managed care also poses potential problems for the care of patients with dementia. In a fully capitated system, underutilization of medical services could occur. Health plans, as the organ of quality oversight, must be vigilant in monitoring capitated providers to ensure that profiteering through underutilization does not occur. Capitated physicians may be reluctant to see patients with dementia and their caregivers because of the longer time required for office visits. In addition, physician groups at risk for pharmacy costs may underutilize medications viewed as having marginal effectiveness, such as cognitive enhancers. To address potential problems with capitation and to promote quality care, MCOs could develop population-based disease management and quality improvement pro-

grams specific for patients with dementia that employ alternate providers and provide effective care management involving communication directly with members, their caregivers, or both. Through population-based approaches, MCOs can reduce variability and improve quality and access of care for patients with dementia.

The integration of acute and long-term care is an important issue facing managed care that particularly affects patients with dementia.²² Managed dementia care is and will be compromised (for the foreseeable future) by the fact that many individuals do not have access to comprehensive long-term care, because of problems with availability of local care, securing transportation to care, or paying for care. In addition, the lack of integration in our current government financing system for acute care (Medicare) and long-term care (Medicaid) promotes inefficiencies in the continuum of care for those individuals who are covered by both systems.

Some managed care systems are creating innovative programs for covering long-term care services, including home care, day care, and respite care. Such efforts are likely to increase substantially in the near future and will become an important component of dementia disease management programs.

Recommendations for Care and Disease Management for Patients with Dementia in MCOs

A Disease Management Approach. With more effective geriatric care management and dementia-specific disease management approaches, a population-based managed care approach could improve care of patients with dementia in MCOs. Table 1 gives an overview of medical management issues in ADRD. Table 2 shows our view of the state of current treatment and an optimal model of care for patients with dementia.

Does dementia fulfill criteria for a disease management approach? Disease management is a proactive, disease-specific way to deliver healthcare for chronic illness.²³ Diseases that are targeted by disease management programs are those in which natural history can be altered with available strategies. Disease management strategies integrate care across the continuum, enhance the traditional physician paradigm with efforts to reduce the frequency or severity of exacerbations of chronic diseases, and employ nonphysician practitioners specializing in the target disease. The most common disease management programs address congestive

heart failure, asthma, chronic obstructive lung disease, and diabetes.^{21,24,25} A number of criteria have been suggested that may be used to determine whether a disease management approach to an illness can be justified.²³ These are summarized in Table 3 as they apply to dementia. As noted in the table, dementia meets most criteria for the implementation of a structured disease management program.

Population-based screening of mental status by MCOs could increase rates of case finding in the community and of early detection of dementia. Existing standardized tests that screen for cognitive dysfunction such as the Mini-Mental State Examination²⁶⁻²⁸ have not had widespread applica-

Table 1. Issues in Effective Medical Management for Dementia Care

Recognition and diagnosis
Screening by health plan
Cognitive assessment as part of yearly examinations of elderly patients
Acknowledgment of caregiver concerns
Physician expertise in differential diagnosis
Development of practice guidelines for diagnosis
Drug treatments
Primary therapies: cholinesterase inhibitors and disease-modifying agents
Behavioral symptoms: agitation, depression, sleep disorders.
Nonpharmacological management of medical comorbidity
Functional impairment (homemaking, meal preparation, transportation)
Depression
Behavior disorders (agitation, wandering)
Sleep disorders
Immobility, falls, and other accidents
Feeding disorders and malnutrition
Urinary and fecal incontinence
Infections due to malnutrition, aspiration, immobility, and incontinence
Ethical dilemmas (loss of autonomy, care, and end-of-life decisions)
Care of the caregiver
Physical and mental health issues
Education and training
Guidance to community resources

Table 2. Care Issues in Dementia

Care Issues	Current Treatment	A Future Ideal?
Early diagnosis	Rare	Population screening
Diagnostic assessment	Variable	Follows practice guidelines
Role of primary care physician	Lack of knowledge; poor incentives for comprehensive management	Educated in diagnosis, and management; has incentives for complete management, including psychosocial and long-term care problems
Specialist referral when indicated	Variable	Follows practice guidelines
Antidementia drug use	Idiosyncratic	Follows practice guidelines; effective drugs promoted and appropriately utilized
Community service referrals	Physicians unaware and often fail to access	Improved access provides caregivers and physicians with multiple services
Care management	Few geriatric care management programs; none dementia specific; case manager knowledge generally poor	Well-developed, structured disease management programs
Measures of quality of care	None	Measures validated and employed by MCOs to improve outcomes of care
Educational resources	Available, but not widely disseminated	Widely available and used
Continuum of care utilization	Fragmented and inefficient	Efficient use of the entire continuum of care required by the patients with dementia; long-term care, adult day care, respite and end-of-life care available and appropriately utilized
Acute medical care	None dementia specific	Medical inpatients with dementia as a primary diagnosis or comorbidity recognized as having special needs
Inpatient behavioral care	Fragmented	Coordinated with outpatient or institutional care
Clinical research	Inaccessible	Participation facilitated through joint pharmaceutical, MCO, academic funding

MCO = managed care organization

tion in managed care. Brief telephone screening procedures could be developed that could overcome the potential barriers to the process in a managed care setting.

There are significant barriers, however, to screening for dementia in a managed care setting. Both cognitively intact and impaired members may refuse to answer questions from their health plan regarding their cognitive competency because of fears that revealing possible incompetence might lead to a loss of coverage or a denial of access to services. Furthermore, considerable problems exist with reliability in asking individuals about their mental status, either via the telephone or mail, methods that are commonly used by HMOs to perform risk screening. Brief screening instruments can be implemented in Medicare managed care programs as a component of a high-risk case-finding program. An area for future research is to determine how to best screen for dementia in the MCO setting.

Once diagnosis is made, the physician's role in a multidisciplinary approach can be focused on medical management but must also integrate care by nonphysician providers. Under various risk-sharing capitated arrangements currently in practice in many MCO models, primary care providers have the incentive to focus on preventing iatrogenesis, functional decline, and institutionalization.²⁹

Triage of high-risk patients can occur in specialized care management programs that have expertise and knowledge of dementia care. Geriatric care management programs can be situated in a health plan, an independent practice association network office, or the offices of large multispecialty group practices. Regardless of their site and the nature of the contractual relationship with the primary care provider, geriatric care management programs focused on dementia care can assist primary care providers within MCOs to practice multidisciplinary geriatric care by providing knowledge, additional personnel resources, and effective access to care.^{13,15,30,31}

Education as a Component of Care. In order to create a system for the comprehensive management of dementia, case

managers need education and training in the management of patients with dementia. Some services required by patients with dementia and their caregivers are in the traditional domains of case managers, such as linkage to community resources and social services. However, most case managers are not trained in the specific aspects of care related to dementia. Valuable resources are available for these purposes,³² as well as models for dementia case managers.³³

Case management for dementia care focuses on

- maintaining or improving functional health and quality of life for both affected individuals and their caregivers in addition to promoting better medical management of the continuum of care
- reducing unnecessary physician office visits, emergency room visits, and hospitalizations
- delaying nursing home placement

Prior attempts at these goals, such as the Medicare-Alzheimer Demonstration Project,³⁴ suggest that gains will be modest, but with more aggressive early diagnosis and better interventions, case management may have a more robust benefit.

A number of underutilized, nonpharmacologic care management interventions are available that can have a significant impact on quality of life and costs of care when implemented at the early stages of the symptomatic illness. Many of these interventions are psychosocial in nature and include education and counseling of caregivers in dementia care. The matter of driving points out the biopsychosocial nature of ADRD care. While there may be many instances in which patients with mild ADRD can still drive, most patients should not drive, or should drive only with restrictions. Family members may need the influence of the physician to take this difficult step. Another area that may benefit from interventional counseling and education is patient finances. Financial planning can prevent many future crises, especially when there is a spouse or substantial assets involved. Patients who have responsibility for checking accounts or other

Table 3. Application of Criteria for Successful Disease Management Programs to Dementia

Disease Management Criteria	Dementia
1. Does the illness generate high costs?	Yes, especially in moderate to late stages
2. Is the illness a high-volume one?	Yes, primarily among the rapidly growing population of people older than 75 years of age
3. Does the illness cause a high rate of preventable complications?	Yes
4. Is there a short time frame (1-3 years) for alternating natural history in early stages with drug therapy?	Probably
5. Is treatment outpatient focused, low technology, nonsurgical?	Yes
6. Are there coding boundaries for identifying disease episodes?	A problem because of a lack of coding by physicians and hospitals; requires education of providers
7. Is there a high rate of variability in treatment?	Yes
8. Is there a high rate of patient noncompliance, amenable to education for patients, caregivers, and/or physicians?	Yes
9. Is there a high rate of potentially unnecessary referrals for diagnosis and complications?	Yes
10. Is consensus achievable on quality care?	Yes
11. Can clinical practice guidelines be developed targeted to address areas of need?	Yes
12. Can dementia-specific outcome criteria be developed?	Yes
13. Are there opportunities for better coordination of community services, particularly those not generally covered by Medicare?	Yes
14. Can better case finding through administrative or self-reported (patient or caregiver) health surveys be developed?	Yes
15. Could better health-risk appraisals that predict utilization and costs be developed?	Yes
16. Are there opportunities for the application of information management technology for the disease?	Yes
17. Is there a need for better telephone demand management services, particularly for psychosocial needs of patients and caregivers?	Yes

financial affairs need to involve others to avoid catastrophic missteps. Planning for future medical care, advance directives, and living wills should be a routine aspect of dementia management and education. Patients should be given choices about future care. It is generally best to obtain advance directives and other necessary information from patients early in the disease when they are cognitively intact, or at least able to give assent regarding decisions.

In late-stage dementia, home care and caregiver education can prevent the costly comorbidities of dementia often associated with hospitalization, such as malnutrition, pressure sores, and infections including aspiration pneumonia, urinary tract infections, and wound infections; and to promote effective and humane end-of-life care.³⁵ One recent study³³ has shown that a concerted caregiver education program delayed nursing home placement by nearly 1 year.

The importance of education and support for the AD caregiver cannot be underestimated. As AD patients require more and more assistance in performing their activities of daily living, their caregivers will also require more support in handling the increased demands on their time, their possible financial problems, and their emotional strain.

Education of affected individuals in self-management is a general principle of effective chronic care.³⁶ In the case of dementia, the individual to be educated is the caregiver. Education of caregivers in self-management of dementia as a chronic illness is an important component of a disease management strategy that goes well beyond traditional medical management. Often, physicians are not able or willing to provide counseling because it is so time consuming. In addition, individual physicians may be unaware of how to access community agencies and other resources for assisting with and improving the care of patients with dementia.

In contrast to the typical strategy of teaching self-management to the individual affected by a chronic disease, a focus on teaching the caregiver the principles of management of dementia as a chronic illness poses novel challenges. Nevertheless, considerable educational resources exist already for these purposes through currently available organizations and texts. MCO promotion of caregiver education can utilize the information dissemination capabilities of the organization with little extra cost to the MCO itself. MCOs can disseminate educational information and facilitate access through physician offices, health plan hot lines, case managers, and member newsletters. MCOs also can facilitate care-

givers' self-referral to support care services such as support groups, day care facilities, respite care facilities, community agencies, county public health nursing services, private home care services, the Alzheimer Association, and others. Increasing the availability and access to these educational and support measures for caregivers would be a significant contribution of an MCO dementia care program.

Formal education of practicing physicians is occurring already in the form of various continuing medical education offerings from academic health centers and the pharmaceutical industry. However, the rates of diffusion of new knowledge and evolving practice standards are extremely slow and inefficient. In the case of dementia, the disappearance of terms like senility, hardening of the arteries, or organic brain syndrome suggests that progress is being made. Awareness about tacrine and donepezil show that dissemination of specific treatment information is occurring. However, with regard to accurate diagnosis, prognosis, care management, and the availability of community services, knowledge continues to be lacking among many practicing physicians. MCOs can offer education through sponsorship of educational seminars, reading materials, audiotapes, videotapes, and practice workshops. In addition, expert medical directors and geriatric case managers can often educate physicians through their involvement and assistance with care for specific patients with dementia.

Practice Guidelines and Quality Assurance Efforts. Practice guidelines for the diagnosis and management of dementia are an extension of educational interventions, but they have the potential for influencing behavior more directly if adherence to the guidelines can be tracked. Guidelines for diseases that have identifiable positive or adverse outcomes that arise as a result of adherence to or disregard for optimal practice (as embodied in the guidelines) are most likely to succeed. In dementia care, appropriate and timely nursing home placement is one such readily identifiable outcome that is a measurable indication of quality of care. As described in part 1 of this article,⁸ potentially preventable psychiatric and medical comorbidities that occur both in the early and late stages of the disease also can be identified and tracked. Monitoring adherence to clinical practice guidelines also may be useful in determining appropriateness of referrals to specialists for diagnosis and treatment and of the use of dementia-specific medications. Guidelines for dementia care have already been published.³⁷⁻³⁹

Finally, quality improvement activities are crucial to the continuous improvement and monitoring of care. The accreditation standards of the National Committee on Quality Assurance (NCQA) and the HCFA Quality Improvement System for Managed Care require that MCOs assess performance and prioritize areas for clinical improvement for care of patients with chronic diseases that are particularly relevant to the elderly. Quality outcomes are also important to MCOs for patient and provider satisfaction and member retention. Assessment and improvement of the care of the patient with dementia fulfills these standards. As NCQA moves to measurable outcomes improvement as an accreditation requirement, opportunities will increase for measuring the value of various programs to care for patients with dementia. Specific outcomes for dementia that could be tracked as measures of quality include rates of use of diagnostic tests, mental status examinations, and anti-ADRD drug treatments; and reductions in rates of medical comorbidities, nursing home placement, and hospitalization. Clinical outcomes such as improved functional health, better quality of life, and reductions in caregiver stress are also important in the evaluation of quality of care for patients with dementia and dementia disease management programs.

... CONCLUSION ...

In the near and long term, the number of individuals with dementia in managed care can only be expected to increase fairly dramatically. MCOs need to recognize that dementia is a highly prevalent, devastating, and costly chronic illness of the elderly that affects both members and their caregivers. Dementia is also an eminently manageable chronic illness. Population-based MCO programs have great potential to improve the quality and manage the costs of care for individuals with dementia in managed care systems.

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See part I of this article.

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