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## Redesigning Systems of Care for Older Adults with Alzheimer' Disease

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### Abstract

The basic principle of care for patients with Alzheimer's disease is support for a patient-caregiver dyad. Any model of care seeking to improve the quality, efficiency, or cost of care for persons with Alzheimer's disease must attend to this principle. Models of care seeking to support this dyad began with strategies focusing mainly on the family caregiver. These models have grown in complexity to encompass team-based care that seeks to coordinate care across settings and providers of care for a defined population of patients. Most Americans in most communities, however, do not have access to these best practices models. While the effectiveness of new models of care is evidence-based, there are multiple barriers to widespread adoption including workforce limitations and the cost of practice redesign. We review the origins and content of current models and describe early efforts to improve their implementation on a broader scale.

### Introduction

We all fear the diagnosis of Alzheimer's disease, we easily recall images of friends, family, and parents losing a sense of self, we shudder at the thought of losing our independence, and we despise the ugly picture of growing old so often associated with dementia. Late stages of the disease ravage older adults with immobility, incontinence, difficulty eating, and an inability to communicate with or even recognize family members. A cure for Alzheimer's disease continues to elude scientists as do strategies to prevent it.(1) For these reasons, the millions of people who already have Alzheimer's disease will be followed by millions more who are currently developing mild cognitive impairment and millions more who are approaching older age.(2) That the pathology for Alzheimer's disease has already begun in many of us(3) leaves us eating blueberries, running on treadmills, searching the internet for natural cures, and taking up crossword puzzles. We confide to family and friends that we would prefer death over dementia. If this presents a somewhat gloomy picture of dementia, we should also recognize that the single biggest risk factor for Alzheimer's disease is

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growing old-making it into your 70's and 80's means that you did not die of heart disease or cancer in your 50's and 60's. In addition, the symptomatic clinical course of Alzheimer's disease may play out over a decade but with interest in early diagnosis this clinical course could reach more than a decade.(4) Many people will die *with* Alzheimer's disease rather than *from* it. Finally, given proper care, older adults with Alzheimer's disease can live in their own homes for many years enjoying their family, friends, and hobbies. Indeed, it is often treatments that are burdensome and incongruent with goals of care that make the final years of Alzheimer's disease so feared.(5, 6)

Over the past few decades, researchers have designed and tested new models of care to address the unique needs of persons with dementia and their caregivers.(7) These models of care improve patient and caregiver outcomes; however, they are not generally available in the United States. The new models require a costly and often unwelcomed redesign of the physical and cultural practice environment. The models require a prepared workforce which exists only in a small number of specialized clinical sites.(8, 9) The models run counter to financial incentives in the current health care marketplace.(10) Finally, if not effectively applied, the models can add costs rather than make care more efficient. For this reason, the Centers for Medicare and Medicaid Services (CMS), among other payers, seeks to identify models of care that provide proper care at a lower cost for persons with dementia. In this manuscript, we briefly review the origins of our current models of care for dementia and describe the basic components of currently recommended best practice models. Next we summarize barriers to widespread implementation of these models and early efforts at taking these models to scale through the support of the CMS Innovation Center. In the text that follows, the terms Alzheimer's disease and dementia are used interchangeably recognizing that the term dementia encompasses other causes of progressive neurologic disease, including diagnoses such as Lewy Body dementia, frontotemporal dementia, and vascular dementia, among others. The terminology of dementia, its subtypes, and their diagnostic criteria continue to change, but many of the features of care models discussed here are relevant to other dementia subtypes.

## Origins of the current models of care

Current models of care draw from a half century of research and represent the confluence of research on caregiver support, dementia diagnosis and treatment, and the chronic care model which espouses an integrated model of care across the care continuum and across the patient's entire constellation of conditions.(11) Changes in models of care also reflect changing ideas about disease and changing federal policies regarding the financing of health care. For example, clinicians considered "senility" a consequence of normal aging until about 50 years ago and evolution in ideas about what conditions are reversible or irreversible result in major changes in the approach to care.(12) Older adults with senility, many of whom likely suffered from dementia, often received custodial care in asylums or almshouses until the 1950s. Older adults, often with confusing presentations of psychological and physical symptoms, accounted for an alarming percentage of hospital admissions.(13, 14) Thus, concern about the cost of institutional or hospital care for older adults with dementia is longstanding and federal policies regarding the financing of this care influence the structure and incentives for care.(15) As state mental institutions closed in the 1960s,

families found that nursing homes could not accept older adults with dementia and there were few alternatives for formal care. At that time, nursing homes were designed for well elders with limited economic means. Researchers began studying the group of older adults ineligible for nursing home care, many of whom had dementia, and began testing strategies to reduce the burden of care on family caregivers.(16) In the 1970s, professional opinion began to shift to the conclusion that senile dementia and Alzheimer's disease were due to the same process and the forecasted epidemic of Alzheimer's disease contributed to the formation of the Alzheimer's Association and the National Institute on Aging.(17, 18) Early caregiver interventions led to more intensive multi-site caregiver support and education programs such as the Medicare Alzheimer's Disease Demonstration Project (19) and the Resources for Enhancing Alzheimer's Caregiver Health projects, among others.(20, 21) Reviews of the caregiver support literature generally conclude that both patients and family caregivers benefit from these interventions but high rates of institutionalization and high cost of care persist.(22, 23) Unfortunately, caregiver-focused interventions generally operate outside the purview of medical care and medical care generally operates unaware of the effectiveness of caregiver support interventions.(24)

The National Institute on Aging developed a national infrastructure for medical research on Alzheimer's disease diagnosis and treatment through the Alzheimer's Disease Centers program.(25) This program was organized to facilitate research on the state-of-the-art in diagnosis and treatment but was never envisioned to provide clinical care for the large US population of older adults with dementia. Building from the initial caregiver support and education research and the growing infrastructure represented by the Alzheimer's Disease Centers, scientists conducted numerous randomized clinical trials testing various modalities and combinations of treatments to slow disability, reduce problem behaviors, or improve caregiver stress.(26–29). Many of these studies demonstrate statistically significant improvements in one or more symptoms or impairments among older adults with dementia or their caregivers. However, the clinical significance of these improvements remains controversial and evidence of cost-effectiveness is currently not available.(30)

In another vein of research, studies began testing the practical implementation of principles espoused in the Chronic Care Model and integrated lessons learned from the caregiver support and medical care literature for persons with dementia.(31–33) Our team conducted a clinical trial of older adults with Alzheimer disease and their caregivers who were randomized to receive collaborative care versus augmented usual care.(34) Termed Project PREVENT for Dementia, intervention patients received care management by an interdisciplinary team led by a nurse practitioner working with the patient's family caregiver. (35) Standardized protocols used by the nurse practitioner stressed non-pharmacologic management of problem behaviors. Caregivers and patients receiving the intervention reported fewer behavioral symptoms, lower caregiver stress, and improved caregiver depression.(34) Vickrey et al tested a guideline-based, comprehensive dementia care management intervention in a controlled clinical trial.(36) The multi-faceted intervention focused on connecting families with community resources and coordinating these services through a dementia care manager. The intervention resulted in large improvements in adherence to quality of care indicators and in improved patient self-reported health-related quality of life. Neither of these trials was designed to demonstrate cost-effectiveness, delay

in nursing home placement, or reduction in acute care use. Although the cost of nursing home care combined with hospital care is often cited as a target for cost containment, we have reported that not all patients with dementia follow these high-cost trajectories.(37) Because of this fact, we and others have concluded that well-targeted interventions embedded in new models of care could achieve substantial cost savings.

## Basic Components of Best Practice Models

The basic principle of care for patients with Alzheimer's disease is support for the care recipient-caregiver dyad.(38) This principle is relatively unchanged over the past century. (39) Any model of care seeking to improve the quality, efficiency, or cost of care for persons with dementia must attend to this fundamental principle. All medical, social, and community services for older adults with Alzheimer's disease build from the day-to-day, hands-on care provided by a family caregivers and direct care workers. The list of components in the text box is summarized from multiple guidelines published over the past 15 years and these components are reflected in the content of recently tested models of care; these key components are rather consistent across guidelines and these components have changed little over time.(40–43)

## Barriers to implementation

Currently, most older adults with Alzheimer's disease receive their medical care in primary care settings, yet most individual primary care physicians care for fewer than two dozen older adults with Alzheimer's disease.(44) It is also true that care for these patients is distributed across multiple care sites, including skilled nursing facilities and hospitals, and across multiple providers.(45) Older adults not only see multiple physicians but they may have multiple providers and agencies involved in home care and they receive hospital care across different health care systems.(46) Community services vary across communities and these services are often transient. Older adults with dementia also suffer from multimorbidity, including chronic conditions such as congestive heart failure and acute conditions such as pneumonia.(47) For a primary care practice to adhere to the key components of best practice care summarized in the table, providers would need to redesign their clinical practices to focus on team-based and population-based care and accept care for the patient's entire panoply of multimorbidity. Barriers to such redesign include financial, technical (e.g. information systems), cultural, and workforce constraints. Finally, there are many unmet care needs among older adults and quality improvement for dementia competes with other worthy quality improvement efforts targeting other high-cost conditions.

The United States has not implemented a best practices model of care for the majority of older adults with Alzheimer's disease. Many providers and payers view these models as impractical for the reasons outlined above. We would argue, on the other hand, that best practices models for Alzheimer's disease are no more impractical than hemodialysis, cardiac care units, or ambulatory surgery centers, for example. Aside from these problems of perception, we must find a way to efficiently train a new workforce and we must develop more efficient strategies to deploy the models at a lower cost. Cost is a critical consideration as demands on Medicare and Medicaid increase with the aging population. The Center for

Medicare and Medicaid Innovation ([www.innovation.cms.gov](http://www.innovation.cms.gov)) "supports the development and testing of innovative health care payment and service delivery models." Descriptions of projects from across the nation that are supported through the Innovations Center are described on the Center's website. We describe two ongoing implementation projects in Indiana that address issues of workforce and cost of care for persons with Alzheimer's disease.

## Implementation efforts

The first implementation project builds from the PREVENT clinical trial and an incremental dissemination project supported by Wishard/Eskenazi Health Services, the National Institute on Mental Health, and the National Institute on Aging. Wishard/Eskenazi Health Services is one of the largest safety net health systems in the US and provides care to a large population of dual-eligible older adults. The first transformation of the PREVENT model, termed the Aging Brain Care Model, adapted the intervention to address high rates of emergency department use and 30-day rehospitalizations among older adults with dementia, late life depression, and cardiovascular disease. To accomplish these goals, the partner organizations developed a population-based electronic medical record and expanded from expertise housed in a specialty memory care practice to care provided in patients' homes.(48–50) Based on this successful pilot, Indiana University and its community partners received a Health Innovation award to scale this project to reach 2,000 older adults with dementia or late life depression cared for in 11 Federally Qualified Health Centers affiliated with the safety net health care system. The project seeks to develop a new workforce of "care coordinator assistants," who have a minimum of a high-school diploma and experience working with older adults. This approach is consistent with recent calls for a broadening of the health care work force to include members of the lay community and peers.(8, 10) Members of this new front-line workforce, carefully chosen based on their humanistic qualities, provide care coordination to an enrolled population of Medicare beneficiaries across the continuum of care. It is the innovation of this lower-cost higher-touch workforce that offers the promise of delivering dementia care at a lower cost. The care coordinator assistants are supported by a nurse and social work team who are themselves supported by a geriatric medicine physician. This expanded team is supported by an electronic medical record specifically designed to support population and patient-level tracking, decision-support, and to monitor the patient's transitions across sites of care. In this manner, individual providers have accountability for a population of patients across a variety of patient and system-level outcomes. The team works with patients, families, primary care providers, and specialists to develop patient-specific care plans, deliver evidence-based protocols, and respond to real-time monitoring and feedback. Ultimately, the Aging Brain Care Model will be evaluated by CMS by its ability to deliver better health, improved care, and lower costs.

The second implementation project targets long-stay residents (many of whom suffer from dementia) in 19 central Indiana nursing facilities. The intervention combines lessons learned in collaborative care, care transitions, and palliative care to support nursing facilities in reducing potentially avoidable hospitalizations. The program invests in additional on-site direct care services and supports and delivers practical resources to help facilities manage cultural change and support ongoing education and training of staff. This support "in the

trenches" is accomplished through a registered nurse hired through the resources of the program and assigned to individual facilities. This project nurse is supported by advanced practice nurses who span several facilities but who are available to respond to urgent evaluation and care needs beyond the scope of practice of the registered nurse. This team is further assisted by geriatric medicine physicians with expertise in nursing facility medical care. Evidence-based interventions, which comprise the foundation of the project, have three major components: (a) improved medical care at the facility; (b) transitional care; and (c) palliative care with a strong focus on identifying goals of care. The innovative nature of the project stems from its integration of these components, the shift from reactive care to proactive care, and the goal to change the culture of the nursing home environment to a learning organization. The medical care component is adapted, in part, from the INTERACT model, and provides tools to allow facility staff to recognize and initiate early care for a change in resident status and to identify high risk residents.(51) Although the goal of the project is to reduce transitions, some transitions are appropriate. The interventions seeks to better manage these transitions through an enhanced exchange of information and building relationships between the facility and the emergency departments and hospitals where residents receive care, including nursing facility staff access to a regional health information exchange. The palliative care component is derived from the Physician Orders for Life Sustaining Treatment (POLST) program.(52) POLST overcomes the limitations of traditional living wills and code-status only orders by converting treatment preferences into immediately actionable medical orders that transfer across settings of care. The palliative care program also trains and engages nursing home staff in advanced care planning and supports education for both residents and their families in palliative and hospice care.(53)

Importantly, this program requires collaboration between multiple stakeholder groups including the academic project team (which draws from multiple institutions), a diverse network of nursing facilities representing national and regional chains as well as independent operators, community physicians who continue to provide primary care for this population, and State and Federal Government. The overall intervention, which invests in additional resources in the nursing facilities, must demonstrate that this investment not only results in better care but also reduces Medicare costs. Cost savings are to be achieved by reducing rates of inappropriate hospitalizations of long stay nursing home residents. Hospitalizations and program costs are being tracked internally by the project and by external CMS-contracted evaluators.

## Conclusions

As the population of older adults with dementia grows larger and because the prospect for a dramatic disease-modifying treatment remains elusive, the American health care system needs a more energized national effort to provide lower cost, humane, hands-on care. Academic researchers have produced an evidence-base that shows what works and what doesn't work to improve patient and caregiver outcomes. Although the impact of these interventions is modest, they do counter arguments that suggest that "nothing works". Academic researchers have not yet successfully partnered with health care systems, payers, and the American public to reach agreement on what cost we are willing to pay for this care or how we should assign value. Under most scenarios, the current models of care need to be

adjusted to provide better health at a lower cost and to encompass a greatly level of patient multimorbidity; these are new challenges to the field. Perhaps the major hurdle to the goal of better health at a lower cost is developing a new workforce that can be efficiently deployed in teams and on a scale commensurate with the magnitude of the patient need. Another hurdle is redesigning our communications infrastructure and ideas about professional roles to embrace teams serving populations of patients across the care continuum. Finally, a goal of better health and lower costs will require greater leadership from academia, industry, government, and advocacy groups to open debates about the proper goals of care among older adults nearing the end of life.

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**COMPONENTS OF BEST PRACTICE MODELS**

1. Make a formal diagnosis using a standardized instrument and with input from a family member;
2. Evaluate the patient for treatable causes of cognitive impairment or excess disability;
3. Consider referral to a specialty memory care practice;
4. Educate the patient and family about the diagnosis and care options;
5. Accept the caregiver-care recipient dyad as the target of care
6. Refer the patient to relevant community support services;
7. Regularly assess patient for problem behaviors and train the caregiver in identifying and managing these behaviors
8. Discuss goals of care
9. Discuss driving and home safety
10. Consider cognitive enhancing drugs
11. Regularly reassess the psychoactive side effects of prescription and non-prescription medications and alcohol and other substance abuse
12. Facilitate regular cognitive, physical, and social activity
13. Detect and treat vascular risk factors
14. Manage the patients comorbid conditions in the context of dementia
15. Track patient outcomes and adjust goals of care as appropriate