

## **Assuring Quality Care for Persons Living with Alzheimer's Disease**

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### **Introduction**

Care can go terribly wrong for people with Alzheimer's disease. Imagine your elderly widowed mother at the age of 76 who appears to enjoy wonderful health. Maybe you've noticed some things, maybe an accident in the kitchen or in the car, maybe you noticed her repeating stories -but she seems happy and maintains a clean home. You keep your concerns to yourself. Then you get a call from the neighbor that your mom walked into the wrong home last night and was rude and disheveled. As you investigate further, you find that your mother's finances are a shambles. Her bank accounts have been drained by a heartless scammer. She has overdue utility bills. You take her to visit with her physician who admits he saw the signs but he didn't want to break her spirit when nothing can be done for this disease. He says she never mentioned she had children. Later that year, she falls and fractures her hip. She seems to ping-pong between the hospital and the nursing home for years with a dizzying array of medicines and doctors. You feel completely alone.

Stories like this will be played out multiple times per day over the coming years. Many families can tell a story much worse and more tragic. It doesn't have to be this way. Alzheimer's is a terrible disease- even without a cure, however, much can be done and we know how to do it. To make the journey of Alzheimer's disease less painful and costly, we all must do better. This includes patients, families, providers, communities, and policy-makers.

When we look at the key features of good care for failing brains, the very first thing we need is an early and accurate diagnosis. Many things can look like Alzheimer's disease and it is easy to dismiss early signs. A failing brain is not normal aging. Once a patient receives a diagnosis of Alzheimer's disease or a related dementia, a complex road lies ahead in terms of education, decision-making, treatments, and care planning. People need to know their new vulnerabilities and the services and supports available to them. But roadmaps exist. Research on models of care funded by the VA, NIH, AHRQ, the John A. Hartford Foundation, and CMMI show that we can decrease caregiver burden, improve patient outcomes, reduce burdensome care, and perhaps even decrease costs. These models integrate the health care team with community and social support services. The most ambitious of these models seeks to change the entire community response to Alzheimer's disease.[1]

Unfortunately, these new models fail to reach the millions of Americans who could benefit. None of these models is available to the typical American. Older adults living in rural America often find themselves hundreds of miles away from even basic services. This is true because these new models of care require significant effort to deploy.[2] Recently, the Center for Medicare and Medicaid Innovations (CMMI) funded programs to help primary care providers transform their practices to adopt such new models of care. Every person with Alzheimer's and every family caregiver will tell you that these efforts are welcomed, but they do not match the scale of the problem.

One difficulty in bringing these hopeful models of care to scale is an inadequate workforce. We've known for decades that the United States' production of physicians with special training in geriatric medicine and related fields lags far behind the need. For this reason, new models seek to expand the reach of this limited professional workforce. These strategies might include training nurses, social workers, or other professionals to provide the needed services or to serve as key members of team-based care. However, this workforce of medical professionals also falls short of the need as documented in several recent reports from the Institute of Medicine.[3, 4] In addition, our country needs a very large increase in the number of direct care workers who provide the hands-on care for older adults with Alzheimer's disease in the home and in nursing homes. In planning for the growing number of older adults with dementia, we need more physicians, nurses, social workers, direct care workers, and other paid professionals with special training in dementia care. However, if there is one reality that I could best highlight, it would be this: family caregivers are the hands, backbone, and hearts of the nation's workforce for Alzheimer's disease. This will not change in the coming 25 years as the number of Americans with dementia doubles. Family caregivers will sacrifice their sleep, their health, their finances, their careers, and their friends to provide care for their loved one in the home for as long as possible. They will provide this difficult care, but they shouldn't have to do it alone. So often, we hear family caregivers say at the end of their draining 10-year journey that they wish they knew then what they know now. If we hope to assure quality care for persons living with Alzheimer's, then we need to better support their family caregivers. New models of care show that this is possible.

### **A Better Way to Care for Persons Living with Alzheimer's Disease**

There are many examples of research studies that demonstrate improved care for persons living with Alzheimer's disease. Recent publications provide a more extensive review of the history, design, and components of these interventions.[5-7]. A summary of current clinical practice guidelines for Alzheimer disease suggests that comprehensive dementia care should include, for example:[2]

1. Case-find for cognitive impairment coupled with a second stage assessment to diagnose dementia
2. Evaluate for treatable conditions contributing to cognitive impairment
3. Evaluate for remediable causes of excess disability due to treatable impairments
4. Disclose the diagnosis, prognosis, and treatment options to the patient and family
5. Refer patient and caregiver to community support agencies, such as the local Alzheimer's Association
6. Encourage and facilitate patient's continued physical, social, and mental activity
7. Consider specialty referral for patients with unclear diagnosis
8. Assess and treat depression and other behavioral and psychological symptoms of dementia with an emphasis on non-pharmacologic approaches
9. Consider the risks and benefits of all medications, including anti-dementia drugs
10. Facilitate communication among the care providers both within the health care system and the community
11. Discuss home safety, driving, potential for financial abuse, and advanced care planning
12. Support the family caregiver as a key member of the health care team

Four exemplar studies, among many others, provide examples of how these guidelines might be put into practice.[2] One of the first such studies, the "Family Intervention to Delay Nursing Home Placement in Patients with Alzheimer's Study" focused on spouse-caregivers.[8, 9] The intervention sought to organize more support from other family members and across the entire journey of the disease. The program included tailored individual and family counseling,

participation in support groups, and telephone counseling. This support delayed nursing home placement by 1.5 years. In another study called “Resources for Enhancing Alzheimer’s Caregiver’s Health” (REACH), researchers were able to reduce the burden of caregiving and improve caregivers’ emotional health through education and support that also reduced the time burdens of caregiving.[10] REACH interventions have now been adapted and adopted in multiple different settings, including the VA.[11] In a third study, investigators used a population-based approach that emphasized linkages with community resources and multi-agency coordination, including coordination with primary care providers.[12] Patients were identified through their diagnosis in electronic records and provided an intervention that included a professional care manager, internet-based care protocols, and tools to collaborate with the family caregivers in developing care plans. The intervention improved the quality of care, improved patients’ and caregivers’ access to existing community services, and improved the quality of caregiving and social support. In a fourth study, a collaborative care model focused within the primary care setting sought to improve the outcomes of care for both the patient and the family caregiver.[13] A nurse practitioner led the care management team and focused on non-drug strategies to manage the behavioral symptoms of dementia. Aided by the medical care team and by web-based tracking of symptoms, the nurse practitioner and family caregiver were able to reduce the burden of behavioral symptoms for the patient and the caregiver.

Unfortunately, the typical American family living with dementia would not find these models of care available in their communities.[14] Providers and health care systems adjudge these programs difficult to implement in a typical clinical practice. The models require substantial redesign of the clinical practice including changing the roles and types of providers that comprise the team-based approach. As already noted, these team members are not widely available in the workforce.[3] These approaches also require a robust and high-tech communications infrastructure to coordinate care across health care providers, community service agencies, and family caregivers. This communications infrastructure is unavailable to most clinical practices. Finally, most primary care physicians provide care to fewer than 50 persons with dementia and they face competing priorities in providing care for many other complex chronic medical conditions.[15] Because these models of care and their requisite workforce are unavailable, persons living with dementia and their family caregivers face a fragmented health care system and a patchwork community services that seems to be hopelessly ineffective. Recent publications from the Institute of Medicine describe the burden of family caregiving and other workforce limitations.[3, 4, 16, 17] Caregivers suffer from extreme emotional and physical stressors as well as economic stressors.[17] Caregivers, who are most often women, sacrifice personal income to provide care in the home and spend more out of pocket than caregivers for other diseases.[18]

As researchers, providers and policy makers seek to plan for the future, three assumptions greatly limit the potential choices to assure care across the long arc of Alzheimer’s disease. First, the number of older adults with dementia will double in the next 20 years. Second, technology will not save us from needing to provide hands-on care for persons with Alzheimer’s disease. Third, family caregivers will provide the majority of hands-on care. Medicare beneficiaries with dementia live about 90% of their last five years of life at home, receiving care from family and paid (out of pocket) caregivers while consuming ambulatory health care services largely paid for by Medicare. However, 40% of health care payments by Medicare and Medicaid support the 10% of care days provided to persons with dementia in hospitals and nursing homes.[19] Among persons with dementia, research suggests that we are spending money on care that may be ineffective and unwanted.[20, 21] Recent projects supported through the Center for Medicare and Medicaid Innovation (CMMI) build from prior research (such as the four clinical trials described above) to explore whether care could be

improved for patients and their families by redesigning care and reallocating health care dollars away from high-cost settings. Three CMMI-supported projects are briefly described below.

#### The Indiana University Aging Brain Care Program

With support from CMMI, Indiana University implemented the Aging Brain Care (ABC) program.[22] The project included partners from the Regenstrief Institute, Inc, and Eskenazi Health in Indianapolis. The partner organizations developed a population-based electronic medical record (eMR-ABC) and designed the program to be primarily based on care in patients' homes.[23] The project also developed a new workforce of care coordinator assistants who had a minimum of a high-school diploma and were given special training to care for older adults with dementia.[24] The care coordinator assistants were supported by a nurse and social work team who are themselves supported by a geriatric medicine physician. This expanded team is supported by the eMR-ABC which was specifically designed to support population and patient-level tracking, decision-support, and to monitor the patient's transitions across sites of care. The team worked 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.[25]

Over 36 months, the program reached more than 3,000 patients with either dementia or late life depression receiving care from 8 primary care clinics in Indianapolis (Urban) and five primary care clinics in Lafayette (rural). Within the first 12 months, at least 90% of the informal caregivers of patients had no evidence of clinically relevant caregiver burden and at least 60% of the patients had no clinically relevant behavioral and psychological symptoms. Informal caregivers reported more stress relief and improved communication among patients, caregivers, and their providers. Patients and informal caregivers also developed better coping mechanisms. Although the official findings of the independent evaluator are still in progress, preliminary findings suggest no clear trends for cost of care. The ABC Program has been sustained beyond the evaluation period. It is a flagship program for Eskenazi Health's new Center for Brain Care Innovation in Indianapolis. Indiana University also licensed the ABC model and the eMR-ABC case management software to Preferred Population Health Management to better assure its wider distribution.

#### The UCLA Alzheimer's and Dementia Care Program

The UCLA Alzheimer's and Dementia Care (ADC) program supported by CMMI was launched in November 2011.[26] The program is based at an academic health care system and partners with community-based organizations to provide comprehensive, coordinated, patient-centered care for patients with Alzheimer's disease and other dementias. Unlike the Indiana project, the UCLA program focused exclusively on persons with dementia. The goals of the program are to maximize patient function, independence and dignity, minimize caregiver strain and burnout and reduce unnecessary costs through improved care. The UCLA ADC program was developed based on theory and evidence for enabling, empowering, and supporting caregivers,[27, 28] as well as providing disease management/care coordination to navigate the complicated health care system[12, 13] with the goal of achieving the 'triple aim' of improving the experience of care, improving the health of populations, and reducing health care costs.[29]

The program, which has now provided care to over 2000 patients and their family members, uses a co-management model (nurse practitioner Dementia Care Manager) and consists of five key components:

- patient recruitment
- structured needs assessments of patients and their caregivers

- creation and implementation of individualized dementia care plans based on needs assessments
- monitoring and revising care plans, as needed, and
- access 24/7, 365 days a year for assistance and advice

Because many of the services that patients with dementia and their caregivers need are provided by community-based organizations, the program created a menu of services provided by each of the 8 partnering community-based organizations that the DCMs can use to provide referrals for specific services and a voucher system so that community-based organizations will receive payment for services provided. Details about each of these components have been published in peer-reviewed journals and a book chapter.[26, 30, 31]

The program has addressed unmet needs. Prior to the program, caregivers were uninformed and fighting this battle alone. Only 38% knew where to turn to get answers about dementia problems and only 24% felt that they had a healthcare professional to help them work through dementia issues. At baseline, 13% of caregivers were depressed and 33% had high stress; those reporting higher levels of stress were more likely to be female, reported more depressive symptoms and cared for more functionally impaired patients with more behavioral symptoms.[32]

After entering the program, 94% of caregivers felt that their role was supported and 92% would recommend the program to others. At one year, they reported receiving significantly more advice about dementia care and had significantly higher self-efficacy about managing the disease. Their confidence in handling problems and complications of Alzheimer's disease and dementia improved by 79%. A sample quote from a grateful caregiver included: *"The program has turned my life around. I now have a grip on things. I do not feel totally overwhelmed. I have been given some counseling and adult day care... I can honestly say she has sort of saved me."*

As a result of this program, at one year, despite disease progression, patients' behavioral symptoms improved by 12% and depressive symptoms were reduced by 24%. In addition, at 1 year, caregiver depression scores, distress related to behavioral symptoms, and caregiver strain improved by 25%, 24%, and 11%, respectively. The program's external evaluator has not yet released the program's final results. However, preliminary findings are encouraging for overall reductions in preventable acute care use and total costs.

#### The Optimizing Patient Transfers, Impacting Medical Quality, and Improving Symptoms: Transforming Institutional Care (OPTIMISTIC) Program

A third project funded by CMMI and conducted in collaboration with the Medicare-Medicaid Coordination Office was also based at Indiana University and included multiple regional partner organizations seeking to improve care for older adults in nursing homes.[33] The project targeted long-stay residents, most of whom suffer from dementia, in 19 central Indiana nursing facilities. The intervention combined lessons learned in collaborative care, care transitions, and palliative care to support nursing facilities in reducing avoidable hospitalizations. Not all hospitalizations are avoidable; some older adults with dementia whether at home or in nursing homes require hospitalization. Potentially avoidable hospitalizations are those that could be avoided with improved care or care more in accordance with the patient and family goals of care. The program invested 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 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 care needs beyond the scope of practice of the registered nurse. This team is further assisted by geriatric medicine physicians. 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. 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.[34] Although the goal of the project is to reduce transitions, some transitions are appropriate. The intervention 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. Information exchange is vital for transitions of residents with dementia who often cannot articulate their needs. The palliative care component is derived from the Physician Orders for Life Sustaining Treatment (POLST) program.[35] 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.[36] Importantly, this program requires collaboration between multiple stakeholder groups including the academic project team, a diverse network of nursing facilities, community physicians, and State and Federal Government.

An independent evaluation of this project was recently published in *Health Affairs* in March 2017.[37] The independent evaluator reported that the Indiana intervention resulted in a reduction in all-cause hospitalizations and a reduction in potentially avoidable hospitalizations. These reductions in hospitalizations were associated with a reduction in Medicare costs. Thus, we have evidence that we can improve quality and outcome of care at an affordable cost.

## **Summary**

In 2017, it is not acceptable to suggest that nothing can be done to assure quality care and improve outcomes for persons living with dementia and their families. The studies described here represent only a small percentage of hundreds of studies conducted over five decades of research. It is also no longer acceptable to say that these studies are limited to impractical academic exercises. We now have evidence that these interventions can be practically implemented. These studies show we can do much better. In 2017, the question is not whether we have programs to assure quality care, the question is how we take these programs to scale so that they are available to all American families struggling with Alzheimer's disease. In the opening paragraph of this testimony, I asked that you imagine the frustrating care that so many American families currently endure. Imagine instead your own care as an older adult with a failing brain just 10-20 years from now- or maybe even next year. Imagine that you and your child, recognizing how much can be offered for a person with cognitive impairment, seek an early evaluation. Imagine that your provider's office is now fully resourced to provide team-based care, including access to collaborative care programs and community-based resources and home-based supports. Imagine your community has been redesigned to promote aging in place. Imagine that your goals of care are honored and that your spouse or child is duly recognized as part of your care team. Imagine that you are able to stay in your home until your last days with support services for you and your family. We know now that this future is possible. We are designing this future not only for our parents, but for ourselves and for our children.

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