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Cite this article as:

Zaldy S. Tan, Lee Jennings and David Reuben
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Health Affairs, 33, no.4 (2014):619-625

doi: 10.1377/hlthaff.2013.1294

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By Zaldy S. Tan, Lee Jennings, and David Reuben

Coordinated Care Management For Dementia In A Large Academic Health System

DOI: 10.1377/hlthaff.2013.1294
HEALTH AFFAIRS 33,
NO. 4 (2014): 619–625
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Foundation, Inc.

ABSTRACT Alzheimer's disease and other dementias are chronic, incurable diseases that require coordinated care that addresses the medical, behavioral, and social aspects of the disease. With funding from the Center for Medicare and Medicaid Innovation, we launched a dementia care program in which a nurse practitioner acting as a dementia care manager worked with primary care physicians to develop and implement a dementia care plan that offers training and support to caregivers, manages care transitions, and facilitates access to community-based services. Postvisit surveys showed high levels of caregiver satisfaction. As program enrollment grows, outcomes will be tracked based on the Triple Aim developed by the Institute for Healthcare Improvement and adopted by the Centers for Medicare and Medicaid Services: better care, better health, and lower cost and utilization. The program, if successful at achieving the Triple Aim, may serve as a national model for how dementia and other chronic diseases can be managed in partnership with primary care practices. It may also inform policy and reimbursement decisions for the recently released transitional care management codes and the complex chronic care management codes to be released by Medicare in 2015.

Zaldy S. Tan (ztan@mednet.ucla.edu) is an associate clinical professor of medicine at the David Geffen School of Medicine, at the University of California, Los Angeles (UCLA).

Lee Jennings is an assistant professor of medicine at the David Geffen School of Medicine, UCLA.

David Reuben is a professor of medicine and chief of geriatrics at the David Geffen School of Medicine, UCLA.

Dementia is a clinical syndrome characterized by persistent intellectual deterioration severe enough to interfere with social or occupational functioning in an alert person. It is a common and costly chronic condition, affecting 4.7 million people¹ in the United States with an annual cost of \$109 billion² in direct health expenditures. Recognizing dementia's large societal and financial burden, President Barack Obama signed into law the National Alzheimer's Project Act (NAPA) in January 2011. Its primary goal is to develop effective prevention and treatment for Alzheimer's disease and related dementias by 2025. However, in light of the sharply escalating societal and economic costs of dementia, an urgent need exists now for the US health care system to find

new models to deliver coordinated, patient-centered, and cost-effective care for people currently afflicted with dementia. The need to identify such new care models has parallels in some of NAPA's other goals, which include the enhancement of dementia care quality and efficiency and expansion of support for people with Alzheimer's disease and their families. To address these goals, the Center for Medicare and Medicaid Innovation is testing innovative service delivery models for people with Alzheimer's disease.

One such model is the University of California, Los Angeles (UCLA), Alzheimer's and Dementia Care (ADC) program. The UCLA health system is a large academic health system based in an urban, competitive, fee-for-service environment. The UCLA ADC program launched in Novem-

ber 2011 and began enrolling patients in July 2012 after being awarded an Innovation Center grant. It aims to improve the quality of dementia care and reduce unnecessary costs by minimizing caregiver strain and burnout, optimizing transitions between care sites, and facilitating access to community-based services.

Gaps In Dementia Care

Health care for people with Alzheimer's disease and other dementias has been characterized as inconsistent in quality³ and fraught with potentially preventable episodes of acute care.⁴ Proactive dementia care and care management have the potential to avert preventable health crises, thereby reducing avoidable emergency department visits and hospitalizations.⁵ *Care management* is the application of systems, science, incentives, and information to improve medical practice and help patients manage medical conditions more effectively.⁶ Dementia care management has been shown to result in significant improvement in the quality of care and in behavioral and psychological symptoms of dementia among primary care patients and their caregivers.⁷ It can lower health care spending by reducing emergency department visits, inpatient hospitalizations, and thirty-day readmissions.⁸ A systematic review and meta-analysis demonstrated that dementia care management reduced the risk of long-term care placement in older people with dementia.⁹

Care for patients with dementia is delivered in multiple sites, including home, outpatient clinics, emergency departments, hospitals, rehabilitation facilities, and nursing homes. Transitions in care represent periods of increased risk for medical errors and care inefficiencies,¹⁰ and patients with Alzheimer's and other forms of dementia are at particularly high risk. A study found that older people with dementia had more care transitions per year and more hospital, home health, and nursing home use as compared with those without the diagnosis.¹¹ Additionally, 45 percent of patients among 851 patients with dementia who had a rehospitalization within thirty days in this study had been discharged to a nursing facility.

The Alzheimer's And Dementia Care Program

Based in the urban area of West Los Angeles and operating in a primarily fee-for-service environment, UCLA has the resources for the comprehensive diagnosis and treatment of dementia: namely, a large primary care network, dementia-related specialty services (for instance, geriatric

medicine, behavioral neurology, geriatric psychiatry, and neuropsychology), and an Alzheimer's disease research center. UCLA also has dedicated geriatric medicine and geriatric psychiatry units for inpatient care of dementia-related conditions. Despite these resources, there had been little coordination of dementia care between specialty services and primary care, no formal linkages with community-based programs, and virtually no caregiver support.

The UCLA ADC¹² program seeks to improve dementia care by addressing three important gaps in dementia care: lack of support and training for caregivers, poor care transitions, and inconsistent access to community-based services. It began in November 2011 with support from philanthropic organizations and the UCLA health system. Patient enrollment began in July 2012 after the program was awarded an Innovation Center grant. The program was modeled after two successful dementia care management programs: a community-based program located in San Diego led by Barbara Vickery and colleagues, and the Indiana University/Eskenazi Health System Aging Brain Center Medical Home in Indianapolis. The similarities and differences between the UCLA ADC program and these two dementia care programs are summarized in online Appendix Exhibit A1.¹³ To be eligible for the program, a patient must have a diagnosis of dementia, receive medical care from a UCLA physician, and not reside in a nursing home. The key interventions of the UCLA ADC program are detailed below.

TRAINING AND SUPPORT FOR CAREGIVERS Informal caregivers are the spouses, adult children, grandchildren, other relatives, and friends of noninstitutionalized people with dementia who provide unpaid care at home. In 2012 more than fifteen million Americans provided an estimated 17.4 billion hours of unpaid care to people with Alzheimer's or other dementias, representing 80 percent of dementia care at home.¹⁴ When the cost of informal care is taken into account, dementia's estimated annual cost for the US population ages seventy and older is in the range of \$159–\$215 billion.² Taking care of a person with dementia exacts a physical and emotional toll on caregivers, who are sometimes subjected to the verbal and physical aggression that can appear during the moderate to severe stages of dementia. Caregiver stress can result in poor health, depression,¹⁵ and an increase in mortality risk.¹⁶ Despite this, fewer than half of dementia caregivers receive counseling or other support to help keep them safe and help them effectively manage conflicts.¹⁷

In the UCLA ADC program, each patient is assigned to a dementia care manager (DCM),

Taking care of a person with dementia exacts a physical and emotional toll on caregivers.

who is a geriatric nurse practitioner with expertise in dementia, specialized knowledge of managing dementia-related behaviors, and familiarity with community-based resources for cognitively impaired people and their caregivers. The patient and caregiver meet with their DCM for an initial ninety-minute visit, which includes a medication review, a neurological examination, a screening for caregiver depression and strain, and an inventory of the patient's and caregiver's needs and resources. During the initial visit, the DCM completes an assessment of the caregiver's needs and resources. Caregivers are provided with text-based, web-based, or in-person training, or some combination, on the basics of dementia treatment and prognosis, effective communication, and the prevention and management of behavioral problems. Caregivers are offered individualized behavioral interventions for patients who exhibit common problematic behaviors, such as wandering, care refusal, agitation, and repetitive behaviors. Caregivers are also given a referral to community-based organizations for services not offered within the UCLA health system, such as adult day care, legal services, and financial planning.

The dementia care manager queries the patient and caregiver about their communication preferences and considers the patient's decision-making capacity and severity of dementia in making the determination of whether to communicate with the caregiver alone or with both the patient and the caregiver. The patient and caregiver have access twenty-four hours per day to expert advice from a UCLA geriatrician on the management of dementia-related issues from their DCM and the UCLA Geriatrics On-Call system.

TRANSITIONS IN DEMENTIA CARE The UCLA ADC program addresses challenges in care transitions by facilitating communication with the patient, the caregiver, and the treatment team at each site of care. The DCM partners with the referring physician to craft a care plan that covers medical, behavioral, and psychosocial inter-

ventions that may prevent unnecessary emergency department visits and hospitalizations. Once the plan is approved by the referring physician, the DCM shares it with the patient and the caregiver. The DCM also initiates or adjusts medication as appropriate and refers patients—for instance, to geriatric, neurology, psychiatry, or physical therapy services—as needed. The patient's response to psychoactive medications is monitored. Patients and caregivers are instructed to contact their care manager when any of the following events occurs: new or worsening of behavioral problems; an emergency department visit or hospitalization outside the UCLA health system; caregiver stress or crisis; or a change in living situation, such as nursing home placement or hospice enrollment.

The DCM receives an alert from the UCLA electronic medical record system whenever an assigned patient has an emergency department encounter or is admitted to a UCLA health facility. Upon receiving such an alert, the DCM contacts the patient's caregiver and the treatment team to offer medical and psychosocial expertise and support. The DCM remains involved during posthospitalization home care or rehabilitation or nursing home stays by facilitating communication between home health nursing staff or nursing facility providers and the UCLA primary care physician.

All patients are seen at least annually by the DCM, and care plans are modified according to changes in the disease stage and the patient's medical, behavioral, and psychosocial status or goals of care. When appropriate, the DCM arranges hospice referral through the primary care physician's office. The relationship between caregiver and DCM continues for the entire course of the disease and extends to the bereavement period in case of death. Through these efforts, the UCLA ADC program expects to reduce disruptions during care transitions and thereby improve health outcomes for patients living with dementia.

ACCESS TO COMMUNITY-BASED SERVICES Community resources are services and programs outside the health care system that support a patient's health and wellness, such as adult day care centers, exercise programs, and support groups. Community-based organizations such as the Alzheimer's Association provide people with dementia and their caregivers with information about community resources and assistance with the various aspects of the disease. Community-based interventions that are directed to the patient, such as physical exercise, have been shown to have beneficial effects in improving physical functioning in people with dementia. Likewise, caregiver-focused interventions, such as respite

17.4

Billion hours

In 2012 more than 15 million Americans provided an estimated 17.4 billion hours of unpaid care to people with Alzheimer's.

care and individualized counseling, have been shown to alleviate the burden on caregivers and improve their psychological health.¹⁸ Adult day services, which are facilities that provide companionship, activities, and meals to older people with physical or cognitive impairment, or both, decrease caregivers' stress and anger, and improve caregivers' affect.¹⁹ There has traditionally been a paucity of coordination efforts between the medical services provided by health systems and the social and supportive services provided by community-based services such as respite care, adult day care, support groups, and financial and legal planning.

The UCLA ADC program care plan includes referrals to governmental and nongovernmental agencies and five community-based organization partners (Jewish Family Services, Leeza's Place, Optimistic People In a Caring Atmosphere [OPICA] Adult Day Care and Caregiver Support Center, WISE & Healthy Aging, and the California Southland Chapter of the Alzheimer's Association) for specific services that would benefit patients and caregivers. These services include respite care, counseling, in-home support services, benefits counseling, and financial planning and legal services. Formal partnerships with these community-based organizations were formed through memoranda of understanding and systematized referral and communication mechanisms.

DCMs match patients and their caregivers to appropriate community resources based on need, costs, and geography. A need-based voucher system allows the ADC program to partially

subsidize the cost of paid services (for example, adult day care) using federal funds from the Centers for Medicare and Medicaid Services (CMS) that are allocated for community services for patients who cannot afford such services. The DCMs and community-based organizations communicate electronically and by phone regarding patient referrals and adjust services as the patient's and caregiver's needs change.

Program Measures

PATIENT CHARACTERISTICS The sociodemographic and clinical characteristics of the UCLA ADC program's first 519 patients, seen between July 2012 and December 2013, are presented in Exhibit 1. UCLA ADC patients had a mean age of 81.7 (± 8.3) years and were primarily female, and most had moderate-to-severe dementia of the Alzheimer's type (mean Mini Mental State Examination²⁰ score 16.1 [± 7.8]). The primary caregivers were mostly adult children (49 percent) or spouses (38 percent).

HEALTH OUTCOMES The ADC program is being evaluated according to the Triple Aim developed by the Institute for Healthcare Improvement and adopted by CMS:²¹ better care, better health, and lower cost and utilization. First, better care is monitored based on adherence to the Assessing Care of Vulnerable Elders (ACOVE-3)²² and the Physician Consortium for Performance Improvement²³ quality indicators for dementia. Quality indicators measure whether patients receive appropriate care processes for the evaluation and management of dementia (see Appendix Exhibit A2).¹³ Information on referrals to community-based organizations and services used by caregivers is also being collected as part of the program's quality improvement effort. The program surveys patients, caregivers, and referring physicians after the initial intake visit regarding their satisfaction with the care provided by the program.

To measure success in achieving better population health, we are evaluating the program based on patient and caregiver health outcomes, including better management of neuropsychiatric complications and maintenance of functional status for patients and decreased caregiver strain and depressive symptoms, by using validated survey tools designed for the clinical setting.²⁴⁻²⁷ We are also surveying caregivers regarding their perceived self-efficacy for managing dementia-related problems and accessing help as well as their experiences with receiving advice on managing dementia-related problems. We will compare dementia process of care measures for patients enrolled in the program to literature benchmarks for similar populations of commu-

EXHIBIT 1

Sociodemographic And Clinical Characteristics Of The UCLA Alzheimer's And Dementia Care Program's Patients Seen Between July 2012 And December 2013

Characteristic	Mean or percent
Mean age, years (SD)	81.7 (8.3)
Percent male	34
Mean Mini Mental State Examination score (SD)	16.1 (7.8)
Percent dually insured	12%
TYPE OF DEMENTIA (%)	
Alzheimer's	44
Frontotemporal	2
Lewy body	3
Vascular	5
Parkinson's	1
Other, mixed, or unknown	45
IDENTITY OF CAREGIVER (%)	
Spouse	38
Child	49
Friend or other (other family, partner)	13

SOURCE Authors' analysis. **NOTES** N = 519. "Dually insured" means covered by both Medicare and Medicaid. SD is standard deviation.

nity-dwelling adults with dementia in primary care. For utilization and cost outcomes, we will use a quasi-experimental controlled before-and-after study design comparing program enrollees with a national dementia control group drawn from Medicare claims and also compare cost and usage to nationally published benchmarks. Utilization measures will include emergency department visits, hospital admissions and readmissions, hospice referrals, and long-term care nursing home placement. A driver diagram for the theory of action is presented in Appendix Exhibit A3.¹³

CAREGIVER SATISFACTION The results of the caregiver survey administered after the initial intake visit with the DCM to assess the caregiver's satisfaction with the visit are presented in Appendix Exhibit A4.¹³ With a response rate of 52 percent, the survey found that caregivers felt that the intake visit was time well spent (90 percent), the DCM listened to their concerns (94 percent), and decisions made during the visit were important to the patient (87 percent). Referral programs, for instance, to support groups were considered helpful by 59 percent. Caregivers said they felt supported in their role (96 percent) and would recommend the program to other caregivers (95 percent).

REFERRING PHYSICIAN SATISFACTION A survey was sent to referring physicians, and 37 percent responded. Physicians felt that the ADC program provided valuable behavioral (82 percent) and social (82 percent) recommendations; and 87 percent would recommend the program for other patients (see Appendix Exhibit A5).¹³

Discussion

To achieve the best care at lower cost, the Institute of Medicine urges health delivery organizations to ensure care continuity, forge community links, and promote patient-centered care.²⁸ Arguably, these recommendations are even more pertinent and pressing for patients with dementia, who experience more frequent care transitions, require an array of community-based services, and have changing goals of care because of disease progression. The UCLA Alzheimer's and Dementia Care program aims to deliver high-quality, cost-effective dementia care by providing caregiver training and support, easing care transitions, and facilitating access to community-based services guided by the patient's and caregiver's respective goals of care. Although we are still in the process of collecting quality and usage data for the ADC program, comprehensive dementia care has been shown to improve care quality⁶ and holds promise in reducing the cost of care for patients with Alz-

heimer's and other forms of dementia.⁷

ENSURING ADEQUATE PAYMENT Historically, care management services, including caregiver training and support, care transitions interventions, and coordination of community-based services, have not been covered by Medicare and other insurance plans. The recently introduced CMS transition care management codes (*Current Procedure Terminology* codes 99495 and 99496) allow for reimbursement of non-face-to-face communication between clinicians and patients or caregivers during transitions between acute care settings and the community. Additionally, CMS announced that beginning in 2015 it will provide reimbursement for complex chronic care management (CCCM) services for patients with two or more chronic conditions.²⁹ Although important details, including reimbursement rates and service requirements, are still being finalized, the CCCM services represent progress in supporting care management for dementia and other chronic diseases. Through analysis of patient, caregiver, and health system outcomes, the UCLA ADC program hopes to provide details needed for future policy and reimbursement decisions on dementia care management, including patient and caregiver characteristics, stage-specific social and behavioral challenges, nature and intensity of care management interventions, and specific community-based services that will have positive impacts on patient and provider satisfaction, quality of care, and health services use.

LESSONS LEARNED Seventeen months into full implementation of the program, we have learned a number of lessons through our self-monitoring and analysis. These lessons can be broadly divided into the following categories: patient recruitment, DCM training, and caregiver training.

► **PATIENT RECRUITMENT:** The best source of patients to date has been spontaneous physician and self-referral. During the first six to twelve months of the program, the demand was strong enough that this was the exclusive source of our patient recruitment. With the implementation of the Epic-based electronic health record, we have begun identifying patients in UCLA hospitals and outpatient practices with the diagnosis of dementia. We then contact their primary care physicians and invite referral of these patients into the program. We have given presentations to UCLA practices (on average, two presentations per month) to encourage referrals. Finally, we have enlisted the nurse practitioners and care coordinator on the inpatient geriatrics unit to identify patients for the program.

► **TRAINING CARE MANAGERS:** An important component of dementia care management is the formulation and implementation of care plans

by the DCM. To be effective in this task, the DCM needs to have knowledge of dementia treatment, familiarity with the local health system and community services, and good communication and coordination skills. We found that nurse practitioners with geriatrics experience have most of these skills, which facilitated their training for the DCM role. We have recruited and trained four DCMs, three of whom are still with the program.

► **TRAINING CAREGIVERS:** We have encountered barriers related to the caregivers' inability to attend training classes. To address this, we developed programs with our community-based partners to offer online and off-hours classes and in-home services to provide greater flexibility for caregiver training needs. We have also begun developing online educational materials, including video vignettes of problem behaviors and how to effectively manage them.

Conclusion

The UCLA Alzheimer's and Dementia Care program aims to fulfill the Triple Aim adopted by CMS of better care, better health, and lower cost and utilization. Our postvisit surveys of caregivers and referring physicians show a high level of satisfaction with the program. We are currently collecting data on quality of care and patient outcome measures. Improved outcomes, including better management of neuropsychiatric complications, reduced caregiver strain, and better advance care planning, have the potential to reduce unnecessary emergency department visits and hospitalizations, increase hospice use, and lower the overall cost of care for this vulnerable

If successful in achieving the Triple Aim, the UCLA ADC program could become a national model for improving dementia care.

population.

Finally, the UCLA ADC program operates in a competitive fee-for-service environment similar to most primary care settings in the United States, which makes findings from the evaluation of the program relevant to the broader population of patients and caregivers accessing the health system for dementia-related care and their physicians. If successful in achieving the Triple Aim, the UCLA ADC program could become a national model for improving dementia care as well as a model for effective co-management of other chronic diseases in partnership with primary care practices. Findings from the evaluation of the ADC program can also inform health policy by providing an evidence-based structure for reimbursement of chronic disease co-management services. ■

The project described was supported by Funding Opportunity CMS-1C1-12-0001 from the Center for Medicare and Medicaid Innovation (No. 1C1CMS330982-01-00); the UCLA Claude Pepper Older Americans Independence Center, funded by National Institute on Aging Grant

No. P30AG028748; and the National Institutes of Health (NIH)/National Center for Advancing Translational Science (NCATS) UCLA CTSI (Clinical and Translational Science Institute) Grant No. UL1TR000124. The contents of this article are solely the responsibility of the authors and do not

necessarily represent the official views of the Department of Health and Human Services or any of its agencies. The authors thank Katherine Serrano and Michelle Nguyen for their assistance in manuscript preparation.

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