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Coordinated Care Management For Dementia In A Large, Academic Health System

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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 (the Innovation Center), 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. Post-visit 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. The program 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.

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 people (1) in the United States with an annual cost of \$109 billion (2) 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 exponentially 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 that

include the enhancement of dementia care quality and efficiency, and expanding support for people with Alzheimer's disease and their families. To address these goals, the Center for Medicare and Medicaid Innovation (the Innovation Center) 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 November 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 quality (3) 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) and can lower health care costs 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 are periods of increased risk for medical errors and care inefficiencies, (10) and patients with Alzheimer's disease and other forms of dementia are at particularly high risk. A study found that older persons 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 re-hospitalization within thirty days in this study had been discharged to a nursing facility.

The UCLA 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 ADC (12) 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 Dr. Barbara Vickery et al. and the Indiana University/Eskanazi 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 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 non-institutionalized 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 persons 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 over age 70 is between \$159 billion to \$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 caregiver 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 Alzheimer's and Dementia Care program, each patient is assigned to a dementia care manager (DCM), 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 that 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 on the basics of dementia treatment and prognosis, effective communication, and 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 DCM 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 both the patient and 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 interventions that may prevent unnecessary emergency department visits and hospitalizations. Once approved by the referring physician, the DCM shares the plan 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--as needed. The patient's response to psychoactive medications is monitored. Patients and caregivers are instructed to contact their DCM 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 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 post-hospitalization 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 persons with dementia. Likewise, caregiver-focused interventions, such as respite care and individualized counseling, have been shown to alleviate caregiver burden and improve their psychological health. (18) Adult day services, which are facilities that provide companionship, activities, and meals to older people with physical and/or cognitive impairment, decrease caregiver stress and anger, and improve caregiver 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 non-governmental 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, were primarily female, and most had moderate to severe dementia of the Alzheimer's type (mean Mini Mental State Examination (20) 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 use. First, better care is monitored based on adherence to the Assessing Care of Vulnerable Elders (ACOVE-3) (22) and the Physician Consortium for Performance Improvement (23) 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 quality improvement effort of the program. 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 community-dwelling adults with dementia in primary care. For use 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 re-admissions, 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, 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. While 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 quality (6) and holds promise in reducing the cost of care for patients with Alzheimer's and other forms of dementia. (7) 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 (CPT 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) While important details, including reimbursement rates and service requirements are still being finalized, the CCCM services represents 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.

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. First, for 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.

The second lesson pertains to DCM recruitment and training. 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.

The third lesson has been the rate of training caregivers, where 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 on-line 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 these.

Conclusion

The UCLA Alzheimer's and Dementia Care program aims to fulfill the triple aim adopted by CMS of better care, better health, and more efficient health care use. Our post-visit 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 overall cost of care for this vulnerable population. Finally, the UCLA ADC program operates in a competitive fee-for-service environment similar to most primary care settings in the United States, making 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 CMS 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.

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Appendix A1. Comparison between three dementia care management programs

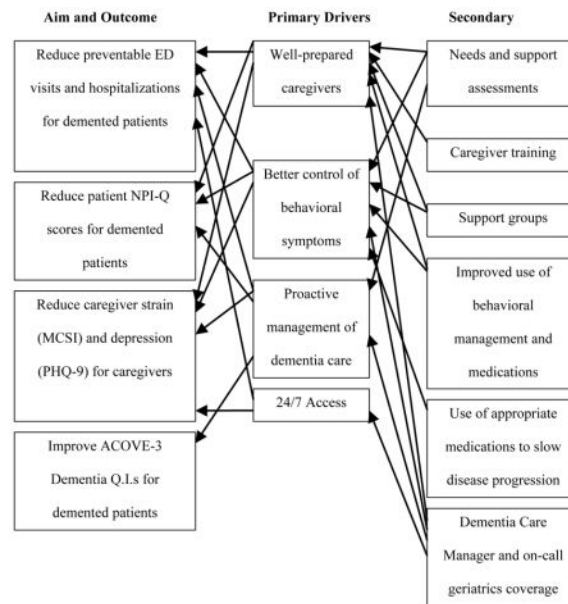
	UCLA ADC Program	San Diego Program	Indiana/Wishard ABC Medical Home
Location and Patient population	Urban, Medicare Fee-for-service	Urban, Medicare Managed care	Urban, Safety net health system
Target Disease	Dementia	Dementia	Dementia or Depression
Dementia Care Manager	Geriatric nurse practitioner	Social worker	Advanced practice nurse
Caregiver Training	Text-based, online and/or in-person training	Interactive seminars	Self-management tools
Transitions in care intervention	Outpatient, inpatient, post-acute care sites	Outpatient care sites	Outpatient care sites
Community services referrals	Yes	Yes	Yes

Appendix A2: Selected Quality Indicators for Dementia Care Processes

Assessment of cognitive status
Assessment of functional status
Staging of dementia
Laboratory testing for other causes of mental status change
Medication review for those that may worsen mental status
Stroke prophylaxis for vascular or mixed dementia
Screening for depression
Screening for behavioral symptoms of dementia
Discussion of behavioral interventions for dementia-related problems
Discussion of pharmacological treatments for dementia
Discussion of risks and benefits of anti-psychotic medications
Caregiver counseling regarding: <ul style="list-style-type: none"> • dementia diagnosis and prognosis • safety concerns • management of behavioral symptoms • available community resources

Assessment of driving
Discussion of advance care planning, including <ul style="list-style-type: none"> designating a surrogate decision maker life-sustaining care preferences, including artificial nutrition

Appendix A3: Driver Diagram for Theory of Action



ED=Emergency Department; NPI-Q=Neuropsychiatric Inventory Questionnaire; MCSI=Modified Caregiver Strain Index; PHQ=Patient Health Questionnaire; ACOVE=Acute Care of the Vulnerable Elderly; QI=Quality Improvement.

Appendix A4: Caregiver Survey After Initial Intake Visit

POST-CG Survey Questions	Agree	Neutral	Disagree	Not Applicable
1. The Dementia program intake visit was time well spent.	90%	5%	5%	0%
2. My concerns were listened to and addressed.	94%	3%	3%	0%
3. Decisions during the visit considered what is important to the patient.	87%	4%	1%	8%
4. Decisions during the visit considered what is important to me.	88%	4%	2%	6%
5. Referral programs (e.g., support groups) given to me were helpful.	59%	10%	9%	22%
6. Educational and printed materials were helpful.	76%	12%	6%	6%
7. It is easy to reach someone from the program if I need to.	73%	7%	8%	12%
8. I received information about sources of support for care that I was not aware of before.	75%	10%	12%	3%

POST-CG Survey Questions	Agree	Neutral	Disagree	Not Applicable
9. I was given suggestions for approaches to care that I was not aware of before.	67%	17%	13%	3%
10. I feel that my caregiver role was supported.	96%	2%	2%	0%
11. I would recommend the program to other caregivers	95%	3%	2%	0%

Appendix A5: Referring Physician Survey after Initial Intake Visit

PHYSICIAN SURVEY	Harmful	Neutral	Valuable
1. Did the Dementia program provide medical recommendations (e.g., starting or stopping a medication, referral) that were valuable?	2%	41%	57 %
2. Did the Dementia program provide behavioral recommendations (e.g., caregiver approaches to behavior problems) that were valuable?	0%	18%	82%
3. Did the Dementia program provide social recommendations (e.g., adult day program) that were valuable?	0%	18%	82%
	Wasteful	Neutral	Valuable
4. Did the Dementia program provide useful resources to the patient/caregiver?	0%	18%	82%
	Harmed	Neutral	Enhanced
5. Did the Dementia program enhance or diminish your relationship with the patient?	0%	34%	66%
	Too Autonomous	Neutral	Collaborative
6. Did you find the Dementia program to be collaborative or was it too autonomous?	2%	22%	76%
	Increased Time	Neutral	Saved Time
7. Did the Dementia program save you time or increase the amount of time you needed to spend caring for the patient's dementia?	2%	39%	59%
	Covered old	Neutral	New Issues
8. Did the Dementia program explore issues that had not been clinically addressed or just cover old territory?	13%	27%	60%
	Disrespectful	Neutral	Respectful
9. Was the Dementia program feedback to you respectful or disrespectful as a clinician?	0%	15%	85%
	Inappropriate	Neutral	Appropriate
10. Was the method of feedback (e-mail) an appropriate way to communicate with you?	0%	15%	85%
	Would Not Recommend	Neutral	Would Recommend
11. Would you recommend other patients with dementia to the program?	0%	13%	87%

Exhibit 1**Sociodemographic And Clinical Characteristics Of The UCLA Alzheimer's And Dementia Care Program's Patients Seen Between July 2012 And December 2013**

Mean age (years)	81.7 ^a
Sex (% male)	34
Mean Mini Mental State Examination	16.1 ^b
Dually insured	12%
Type of dementia (%)	
Alzheimer's	44
Frontotemoral	2
Lewy body	3
Vascular	5
Parkinson's	1
Other, mixed, or unknown	45
Caregiver (%)	
Spouse	38
Child	49
Friend or other (other family, partner)	13

SOURCE Authors' analysis. NOTES $N = 519$.

^aStandard deviation is 8.3.

^bStandard deviation is 7.8.