

# The University of California at Los Angeles Alzheimer's and Dementia Care Program for Comprehensive, Coordinated, Patient-Centered Care: Preliminary Data

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Dementia is a chronic disease that requires medical and social services to provide high-quality care and prevent complications. As a result of time constraints in practice, lack of systems-based approaches, and poor integration of community-based organizations (CBOs), the quality of care for dementia is poorer than that for other diseases that affect older persons. The University of California at Los Angeles (UCLA) Alzheimer's and Dementia Care (UCLA ADC) program partners with CBOs to provide comprehensive, coordinated, patient-centered care for individuals with Alzheimer's disease and other dementias. The goals of the program are to maximize function, independence, and dignity; minimize caregiver strain and burnout; and reduce unnecessary costs. The UCLA ADC program consists of five core components: recruitment and a dementia registry, structured needs assessments of individuals in the registry and their caregivers, creation and implementation of individualized dementia care plans based on needs assessments and input from the primary care physicians, monitoring and revising care plans as needed, and around-the-clock access for assistance and advice. The program uses a comanagement model with a nurse practitioner Dementia Care Manager working with primary care physicians and CBOs. Based on the first 150 individuals served, the most common recommendations in the initial care plans were referrals to support groups (73%) and Alzheimer's Association Safe Return (73%), caregiver training (45%), and medication adjustment (41%). The program

will be evaluated on its ability to achieve the triple aim of better care for individuals, better health for populations, and lower costs. *J Am Geriatr Soc* 61:2214–2218, 2013.

**Key words:** Alzheimer's disease; dementia; care coordination; caregiver support

In the United States, an estimated 5.4 million persons have Alzheimer's disease.<sup>1</sup> The total burden of dementia is even higher because Alzheimer's disease accounts for only 60% to 80% of dementia cases. In many respects, dementia is a prototypic chronic disease that requires medical and social services to provide high-quality care and prevent complications, including hospitalizations (most notably for ambulatory care-sensitive conditions such as heart failure, exacerbation of chronic obstructive pulmonary disease, urinary tract infection)<sup>2</sup> and other costly care, estimated at \$130 billion in 2011.<sup>1</sup>

Busy physicians, including geriatricians, have neither the time nor, in some cases, the skills to adequately manage many aspects of dementia, including coordinating social and medical care, instructing caregivers, and counseling families. As a result, the quality of care for dementia is poorer than for other diseases that affect older persons.<sup>3–5</sup> Community resources (e.g., Alzheimer's Association) can help improve the quality of care, especially by providing education and support for caregivers,<sup>6</sup> but these organizations are underused and are poorly integrated into the healthcare system.

In response, several dementia care programs have been developed to more comprehensively meet the needs of individuals and their families. A community-based program in San Diego that used care managers, primarily social workers, working with a Web-based care management software system for dementia care planning and

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coordination demonstrated better adherence to dementia practice guidelines and better health-related quality of life, overall quality of care, caregiving quality, and social support and a lower level of unmet caregiving assistance needs than in a usual-care group.<sup>7</sup> The Indiana University Wishard Health System Aging Brain Center uses a dementia care manager to customize and facilitate delivery of non-pharmacological and pharmacological care process components to individuals in collaboration with their primary care physicians. This program has demonstrated effectiveness in terms of quality measures and outcomes (reduced behavioral symptoms and caregiver stress by half at 12 months).<sup>8,9</sup> Moreover, there is some evidence that the Indiana program may be cost saving as a result of almost halving emergency department visits, inpatient hospitalizations, and 30-day readmission.<sup>10</sup>

Although these programs have succeeded in improving dementia care, they have not been disseminated widely, partly because they have depended on grant support without sustained commitment by health systems or have served special populations (e.g., low income) that have relied on funding sources outside of traditional fee-for-service Medicare payments. In November 2011, with support from philanthropists and the University of California at Los Angeles (UCLA) Health System, the UCLA Alzheimer's and Dementia Care (ADC) program was launched. In July 2012, with additional support, including a Centers for Medicare and Medicaid Services Innovations Challenge Award, the UCLA ADC program was fully implemented.

The UCLA ADC program, which primarily serves a fee-for-service Medicare population, with primary care physicians providing care in a highly competitive market, is based at an academic healthcare system and partners with community-based organizations (CBOs) to provide comprehensive, coordinated, patient-centered care for individuals with Alzheimer's disease and other dementias. The goals of the program are to maximize function, independence, and dignity; minimize caregiver strain and burnout; and reduce unnecessary costs through improved care. This report describes the clinical aspects of the program's operation and its experience with the first 150 individuals.

## METHODS

### Description of the Program

The UCLA ADC program consists of five core components: recruitment and a dementia registry, structured needs assessments of individuals in the registry and their caregivers, creation and implementation of individualized dementia care plans based on needs assessments and input from the primary care physicians, monitoring and revising care plans as needed, and around-the-clock access for assistance and advice.

### *Recruitment to the Program and UCLA Dementia Registry*

Individuals are recruited into the program through two methods: referrals from the UCLA primary care and geriatrics practices, the psychiatry and neurology memory and dementia clinics, or direct inquiries from individuals

or families and identification of potential participants by billing codes (*International Classification of Diseases, Ninth Revision*, diagnosis codes 290.0, 290.1, 290.2, 290.3, 290.4, and 331.0). The UCLA electronic billing system is queried, and a list of individuals who have one of these diagnostic billing codes is generated and sorted according to primary care physician. These lists, along with information about the program, are presented to physicians at their practice group meetings, and the physicians are asked to verify the dementia diagnosis and whether they would like to refer individuals.

To enroll in the program, a physician who will be the point of contact for communication about recommendations from the program must refer the individual. If they have no UCLA physician, individuals are referred to geriatricians to establish care and make the referral.

### *Structured Caregiver and Care-Recipient Needs Assessments of Individuals in the Registry*

The UCLA ADC begins with an in-person visit with a dementia care manager (DCM) and the individual and at least one family member or caregiver. To prepare for the visit and make it most efficient, individuals (if early stage) and family or caregivers are asked to complete a structured previsit instrument (available at <http://dementia.uclahealth.org/workfiles/patientforms/B1-ADC-Pre-Visit-Questionnaire.pdf>) that includes information about the individual and caregivers.

The assessment (Appendix 1) is scheduled as a 90-minute in-person session during which additional information is obtained using a structured interview and examination. In this manner, the DCM assesses the individual's and family's needs and their resources.

### *Individualized Dementia Care Plans Based on Needs Assessments*

Based on these initial assessments, the DCM (with input from a physician dementia specialist (ZST)) works with the individuals and family to draft a personal care plan, which is sent to the referring physician for approval or modification. This interaction with the physician is aimed at ensuring continuity of care in addition to providing education about the care of the individual with dementia. To be efficient and succinct, this secure e-mail-delivered information is divided into medical recommendations that the primary care physician is asked to address (and respond back by e-mail) and social and behavioral recommendations that the DCM implements independently. When the DCM has received a response from the referring physician, the assessment note is finalized and uploaded to the electronic health record. The individual and family then receive a telephone call from their DCM to discuss the final recommendations.

All individuals and their families receive dementia care management from a nurse practitioner supervised by a physician dementia specialist that may include in-person sessions at which individual's and family members' specific questions about problems, resources, and implementing care plans are answered; telephone follow-up to monitor implementation of dementia care plans; facilitation of appointments with consultants when the treatment plan

needs to be reassessed (e.g., managing new behavioral complications); teaching dementia management skills to caregivers through individual counseling including information on legal and financial planning with referral to community services, behavioral techniques to avoid and manage behavioral problems, and coping strategies for caregivers.

Because individuals enrolled in the UCLA ADC program vary in terms of stages of evaluation, severity of dementia, and nature and extent of needs, the other components of the care plan are customized to the individual and can include the following components.

- Consultation with neurology, geriatric psychiatry, psychology, or geriatrics for additional diagnostic evaluation (e.g., if there are unusual symptoms) or management of refractory complications.
- Advance care planning intervention with a clinical ethics expert if there are particularly complex questions related to feeding modalities and burdensome interventions.
- Hospitalization, when needed, on the Santa Monica–UCLA Geriatrics Special Care Unit or Geriatric Psychiatry Unit at the Neuropsychiatric Hospital. The Santa Monica–UCLA Geriatrics Special Care Unit is multidisciplinary and patient-centered, with services aimed at frail elderly adults, including those with dementia. Individuals with dementia with severe behavioral problems (e.g., aggression and psychosis or profound mood disorders) are referred for admission to the Geriatric Psychiatry Unit at the Neuropsychiatric Hospital, which is multidisciplinary and focuses on a therapeutic milieu.
- Referral to the Mary S. Easton Alzheimer's Disease Research Center (ADRC) at UCLA for appropriate clinical trials. Through its ADRC, UCLA has access to investigational treatments that are commercially unavailable. Individuals who have expressed interest in participating in clinical trials are identified, and the UCLA ADRC program facilitates referrals to these clinical trials.

The care plan can also include the following caregiver components.

- Support groups at UCLA hospitals, the Patti Davis "Beyond Alzheimer's" support program. These are held twice weekly and co-led by former President Reagan's daughter and a psychologist.
- Caregiver education through a community lecture series. These are held monthly, initially in person and now as webinars, which are archived on the program's website (<http://dementia.uclahealth.org>).
- Referral, when appropriate, to the California Southland chapter of the Alzheimer's Association or other CBOs (Jewish Family Services, Leeza's Place, Optimistic People In a Caring Atmosphere Adult Day Care & Caregiver Support Center, Wise & Healthy Aging, and other CBOs) for services such as support groups with or without respite care, caregiver referrals, delivered meals, adult day care, care and case management, counseling, and transportation assistance. An important function of the CBOs is to provide caregiver training through evidence-based programs such as The Savvy Caregiver<sup>11</sup> and Partnering With Your Doctor.<sup>12</sup> As part of the

program, these CBOs have established formal relationships with UCLA. Referrals are made at the time of the assessment or at any time they are needed. The CBOs are notified that the referral has been made by e-mail or telephone. If the individual or family has signed a Health Insurance Portability and Accountability Act release, a copy of the care plan is often e-mailed to the contacts at the CBOs.

- Monitoring and revising care plans, including active monitoring and support of the caregiver's emotional and physical health. Calls or e-mails from caregivers indicating that the plan is not working have triggered early revisions of the care plan. Adjustments to the care plan, including referral to hospice, are made as the DCM deems appropriate and communicated to the referring physician. All individuals, even those in the earliest stages of dementia, are reevaluated for disease progression and adequacy of resources at no >1-year intervals.
- Around-the-clock access for assistance and advice. The DCM handles daytime calls, and the UCLA geriatrician on-call manages night and weekend calls.

### Organizational Aspects, Support, and Sustainability

The program plans to initially serve 1,000 individuals enrolled over 2 years and their families. These individuals will be drawn from primary care practices within the UCLA Health System and from subspecialists, particularly neurology and psychiatry. To meet this need, the program will employ four full-time DCMs, a medical director initially at a 0.25 full-time equivalent (FTE) and then at a 0.5 FTE, a program manager initially at a 0.5 FTE and then at a 1.0 FTE. While building their practices, approximately 50% of their time is spent evaluating new individuals and 50% in follow-up, but as their practices grow, more time is spent in follow-up. All of the clinical support services (e.g., scheduling, encountering, billing) are built into the overhead of the Department of Medicine Practice Group. The Division of Geriatrics has agreed to add the program to the responsibilities of the geriatrician on call, so there have been no additional costs for this component. The Health System has provided support for media and marketing services, a part-time development officer, and funding for one of the support group leaders.

The current financial model to support the program relies on three sources of income. First, the DCM generates clinical income from in-person visits, including initial assessments. All other components of the program are provided free of charge. Second, a CMS Innovations Challenge grant has supported expansion of the program to the intended 1,000 individuals within 2 years. Third, the program has been successful in obtaining philanthropic support. Individuals' families have recognized the gaps in current care for dementia and have been generous in making contributions ranging from \$10 to more than \$1 million.

Without grant support and philanthropy, the program would not be sustainable under fee-for-service Medicare funding. Under managed care reimbursement, the program could be directly supported as a member benefit. If the return on investment is high (e.g., cost savings based on reduced hospitalization and emergency department use),

the program could potentially be supported through a startup case management fee, which could be paid to accountable care organizations with continuation of payment dependent on shared savings to Medicare that offsets the payment or through a redesign of the Medicare benefit.

## RESULTS

### Progress to Date and Results

The UCLA ADC program began to see individuals in July 2012. Approximately eight to 10 new individuals per week have been enrolled and assessed by the first DCM; nine individuals have refused during the first 7 months. Sociodemographic and clinical characteristics and initial services provided for the first 150 individuals (through February 7, 2013) are listed in Table 1.

### Challenges

Despite its success, the UCLA ADC has had challenges that other institutions would need to face in implementing similar programs. First, identification of individuals with dementia has not been straightforward. Although it was

expected that the billing system would capture the vast majority of individuals with dementia, only a minority of individuals enrolled (26%) to date have been identified through billing diagnoses. Physicians may be reluctant to assign a diagnosis of dementia for financial (lower reimbursement for psychiatric diagnostic codes) and social reasons, including individual or family preference. Second, dementia evaluations and medical and psychological histories recorded in the medical record have been highly variable, reflecting clinical practice rather than a research setting and the limitations of medical record documentation. Thus, it has taken substantial time for the DCM to distill the needed clinical information. Third, delineating the role of the DCM with respect to medical conditions that may affect or be affected by cognition (e.g., managing falls) has required some negotiation of clinical boundaries with referring physicians. Some have felt comfortable allowing the DCM to manage any related condition, whereas others have restricted the program's management to care directly related to dementia. Fourth, the data collection, documentation, and communication burden have been large. No commercially available software product serves the spectrum of needs, and the program has had to use several systems while new custom software is developed.

**Table 1. Sociodemographic and Clinical Characteristics and Initial Services Provided**

| Characteristic                                     | Value          |
|--|----------------|
| Age, mean $\pm$ SD                                 | 82.7 $\pm$ 7.4 |
| Male, %  | 42             |
| Ethnicity, %                                       |                |
| Caucasian  | 76             |
| African American                                   | 11             |
| Hispanic   | 8              |
| Asian  | 5              |
| Type of dementia, %                                |                |
| Alzheimer's disease                                | 42             |
| Frontotemporal                                     | 1              |
| Lewy body  | 5              |
| Vascular   | 4              |
| Parkinson's  | 1              |
| Other, mixed, or unknown                           | 47             |
| Mini-Mental State Examination score, mean $\pm$ SD | 15.8 $\pm$ 8.0 |
| Referred by primary care physician, %              | 93             |
| Dually insured, %                                  | 7              |
| Caregiver, %                                       |                |
| Spouse   | 37             |
| Child  | 48             |
| Friend or other                                    | 15             |
| Initial services provided, %                       |                |
| Medication adjustment                              | 41             |
| Recommendation for additional evaluation           | 21             |
| Caregiver education                                | 14             |
| Referral to support group                          | 73             |
| Referral to community-based organization           | 55             |
| Caregiver training                                 | 45             |
| Referral to legal services                         | 5              |
| Alzheimer's Association Safe Return                | 73             |
| Physician Orders for Life-Sustaining Treatment     | 5              |
| Caregiver agency list                              | 20             |
| Life Alert information                             | 5              |
| Veterans' benefits                                 | 10             |

SD = standard deviation.

## DISCUSSION

Despite advances in the diagnosis and treatment of dementia, many of the needs of individuals and families go unmet. The most successful efforts to improve dementia care have relied on comanagement models that typically engage a nurse practitioner focused on dementia and, in some programs, other geriatric conditions.<sup>6-9,13</sup> The UCLA ADC program has built on these previous successes at other institutions and has adapted them to a university-based healthcare system that provides primary and specialty care for a large population, most of which fee-for-service Medicare covers. To determine whether this model will achieve the triple aim of better care for individuals, better health for populations, and lower costs, the program will need to be evaluated on each of these components and on how well it achieves person-centered goals. Although the results of these evaluations are several years away, individuals, caregivers, and referring physicians have received the program well. If it succeeds in its goal of providing better quality of care and better health for individuals and caregivers, the program has the potential to become a national model for comprehensive dementia care.

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- ## APPENDIX 1 INITIAL 90-MINUTE ASSESSMENT BY DEMENTIA CARE MANAGER WITH APPROXIMATE TIMES IN PARENTHESES
- Introduction, including DCM's role, program description, description of the initial visit interview (5 minutes)
    - Review of pre-visit questionnaire, modified caregiver strain index,<sup>14</sup> functional assessment questionnaire<sup>15</sup> and Neuropsychiatric Inventory Questionnaire (NPI-Q)<sup>16</sup> (15 minutes).
    - Check for completeness.
  - Clarify answers, ask for supporting information.
  - Ask the caregiver(s) to step out of the room to complete a Patient Health Questionnaire,<sup>17</sup> Cornell Scale for Depression in Dementia,<sup>18</sup> Health Insurance Portability and Accountability Act release form, and to expand upon the behaviors indicated on the NPI-Q.
  - While the caregiver is completing the forms mentioned above, the DCM completes cognitive testing with the patient (15 minutes).
    - Mini-Mental State Examination (MMSE).<sup>19</sup>
    - If the patient scores 20 or better on the MMSE, complete the Montreal Cognitive Assessment.<sup>20</sup>
  - DCM reviews the Cornell Scale for Depression in Dementia with the caregiver and patient (5 minutes).
  - DCM discusses advance care planning with patient (if capable) and family (15 minutes).
    - What is the plan if the primary caregiver is no longer able to care for the patient with dementia?
    - How would anyone know if something happened to the primary caregiver?
    - Durable power of attorney for health care, Physician Orders for Life-Sustaining Treatment.
  - DCM discusses financial resources such as Social Security income, retirement income, assets (10 minutes).
    - If applicable, long term care insurance benefits are reviewed.
    - If applicable Medi-Cal and related programs.
  - Physical examination (5 minutes)
    - Vital signs.
    - Neurological exam.
    - Gait and balance assessment.
  - Discuss issues/concerns that the patient and or family may have (15 minutes).
  - Review services/programs that the caregiver is interested in receiving as indicated on the previously completed questionnaire.
  - Start to discuss potential programs that are applicable to the patient and caregiver.
  - Review the UCLA ADC resource folder that is provided and partially filled out. The DCM explains when the caregiver will receive a follow-up phone call to discuss their personalized care plan that has been approved by the primary care physician (5 minutes). The DCM later mails the approved care plan, supporting reference material and referrals for the caregiver to review and file in the binder.