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The UCLA Alzheimer's and Dementia Care Program for Comprehensive, Coordinated, Patient-centered Care: Preliminary Data

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Abstract

Dementia is a chronic disease that requires both medical and social services to provide high quality of 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 poor compared to other diseases that affect older persons.

The UCLA Alzheimer's and Dementia Care (UCLA ADC) program partners with CBOs to provide comprehensive, coordinated, patient-centered care for patients with Alzheimer's disease and other dementias. The goals of the program are to maximize patient function, independence and dignity, minimize caregiver strain and burnout and reduce unnecessary costs. The UCLA ADC program consists of five key components: patient recruitment and a dementia registry,

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Author Contributions

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structured needs assessments of patients 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 access 24/7, 365 days a year for assistance and advice. The program uses a co-management model with a nurse practitioner Dementia Care Manager working with primary care physicians and CBOs.

Based on the first 150 patients served, the most common recommendations in the initial care plans were referrals to support groups (73%), 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.

INTRODUCTION

In the United States, an estimated 5.4 million persons are affected by Alzheimer's disease.[1] Moreover, the total burden of dementia is even higher as Alzheimer's disease accounts for only 60–80% of cases of dementia. In many respects, dementia is a prototypic chronic disease that requires both medical and social services to provide high quality of care and prevent complications, including hospitalizations (most notably for ambulatory care-sensitive conditions such as heart failure or COPD exacerbation, UTI)[2] and other costly care, estimated at $130 billion in 2011.[1]

Busy physicians, including geriatricians, have neither the time nor, in some cases, the skills to adequately manage many aspects of dementia, including coordinating social as well as medical care, instructing caregivers, and counseling families. As a result, the quality of care for dementia is poor compared to other diseases that affect older persons.[3, 4, 5] Community resources (e.g., the Alzheimer's Association), can help improve the quality of care, especially by providing patient education and support for caregivers.[6] However, these organizations are underutilized and are poorly integrated with the health care system.

In response, several dementia care programs have been developed to more comprehensively meet the needs of patients and their families. A community-based program in San Diego used care managers, primarily social workers, working with a web-based care management software system for dementia care planning and coordination demonstrated better adherence to dementia practice guidelines and improved patient health-related quality of life, overall quality of patient care, caregiving quality, social support, and level of unmet caregiving assistance needs.[7] The Indiana University Wishard Health System Aging Brain Center uses a dementia care manager to tailor and facilitate delivery of nonpharmacological and pharmacological care process components to individual patients in collaboration with the primary care physician. This program has demonstrated effectiveness on quality measures and patient outcomes (reduced behavioral symptoms and caregiver stress by half at 12 months).[8, 9] Moreover, there is some evidence that the Indiana program may be cost-saving as a result of reducing ED visits, inpatient hospitalizations, and 30-day readmission by almost half.[10]

Although these programs have succeeded in improving dementia care, they have not been disseminated widely, partly because they have been dependent 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 payment. In November 2011, with support from philanthropists and the UCLA Health

System, the UCLA Alzheimer's and Dementia Care (ADC) program was launched. In July 2012, with additional support, including a Center 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 where care is provided by primary care physicians in a highly competitive market, is based at an academic health care system and partners with CBOs to provide comprehensive, coordinated, patient-centered care for patients with Alzheimer's disease and other dementias. 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. In this report, we describe the clinical aspects of the program's operation as well as its experience with the first 150 patients.

METHODS

Description of the Program

The UCLA Alzheimer's and Dementia Care program consists of five key components:

- patient recruitment and a dementia registry

- structured needs assessments of patients 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

- access 24/7, 365 days a year for assistance and advice.

Recruitment of patients to the program and UCLA dementia registry—Patients are recruited into the program through two methods: 1) referrals from the UCLA primary care and geriatrics practices, the psychiatry and neurology memory and dementia clinics, or direct inquiries from patients or families and 2) identification of potential participants by billing codes (ICD-9 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 patients who have one of these diagnostic billing codes is generated and sorted by primary care physician. These patient 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 individual patients. To enroll in the program, the patient must be referred by a physician who will be the point of contact for communication about recommendations from the program. If they have no UCLA physician, patients are referred to geriatricians to establish care and make the referral.

Structured caregiver/care-recipient needs assessments of patients in the registry—The UCLA ADC begins with an in-person visit with a Dementia Care Manager (DCM) including the patient and at least one family member or caregiver. To prepare for the visit and make it most efficient, patients (if early stage) and/or family/caregivers are asked to complete a structured pre-visit instrument (available at www.geronet.ucla.edu) that includes information about the patient and caregivers.

The assessment (Table 1) is scheduled as a 90-minute in-person session during which additional information is obtained by structured interview and examination. In this manner, the DCM assesses the patient and family's needs as well as 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 patient 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 patient with dementia. To be efficient and succinct, this secure email-delivered information is divided into medical recommendations that the primary care physician is asked to address (and respond back by email) 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 patient/family then receives a telephone call from their DCM to discuss the final recommendations.

All patients and their families receive Dementia Care Management by a nurse practitioner supervised by a physician dementia specialist, which may include:

- In-person sessions at which patient 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/manage behavioral problems, and coping strategies for caregivers.

Because patients 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 tailored to the individual and can include the following patient 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 issues relating 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 the frail elderly, including those with dementia. Patients 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. Patients 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 program's website, http://dementia.uclahealth.org.

- *Referral, when appropriate, to the California Southland chapter of the Alzheimer's Association or other community-based organizations* (Jewish Family Services, Leeza's Place, Optimistic People In a Caring Atmosphere [OPICA] Adult Day Care & Caregiver Support Center, Wise & Healthy Aging, and other community-based organizations) for services such as support groups with or without respite care, caregiver referrals, delivered meals, adult day care, care/case management, counseling, and transportation assistance. A key function of the CBOs is to provide caregiver training through evidence-based programs such as The Savvy Caregiver,[11] and Partnering With Your Doctor[12]. 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 patient/family has signed a HIPPA release, a copy of the care plan is often emailed to the contacts at the CBOs.

Monitoring and revising care plans including active monitoring and support of the caregiver's emotional and physical health. Early revisions of the care plan have been triggered by calls or emails from caregivers indicating that the plan is not working. Adjustments to the care plan, including referral to hospice, are made as deemed appropriate by the DCM and communicated to the referring physician. All patients, even those in the earliest stages of dementia, are reevaluated for disease progression and adequacy of resources at no greater than 1-year intervals.

Access 24/7, 365 days a year for assistance and advice—Daytime calls are handled by the DCM, and nights and weekend calls are managed by the UCLA geriatrician on-call.

Organizational Aspects, Support, and Sustainability

The Program plans to initially serve 1000 patients enrolled over two years and their families. These patients will be drawn from primary care practices within the UCLA Health System as well as subspecialists, particularly neurology and psychiatry. To meet this need, the program will employ 4 full-time DCMs, a medical director initially at 0.25 and then at 0.5 FTE, a program manager initially at 0.5 and then at 1.0 FTE. While building their practices, approximately 50% of their time is spent evaluating new patients and 50% in follow-up but as their practices grow larger, more time is spent with follow-up work. All of the clinical support services (e.g., scheduling, encountering, and 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 cost 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 1000 patients within two years. Third, the program has been successful in obtaining philanthropic support.

Patients' families have recognized the gaps in current care for dementia and have been generous in making contributions ranging from $10 to over $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 Alzheimer's and Dementia Care program began to see patients in July 2012. Approximately, 8 to 10 new patients per week have been enrolled and assessed by the first DCM; 9 patients have refused during the first 7 months. Sociodemographic and clinical characteristics, and initial services provided for the first 150 patients (through February 7, 2013) are listed in Table 2.

Challenges

Despite its success, the UCLA ADC has had challenges that other institutions would need to face in implementing similar programs. First, identification of patients with dementia has not been straightforward. Although we expected that the billing system would capture the vast majority of patients with dementia, only a minority of patients 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 patient or family preference. Second, dementia evaluations and medical/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 in 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 needed to use several systems while new custom software is developed.

DISCUSSION

Despite advances in the diagnosis and treatment of dementia, many of the needs of patients and families go unmet. The most successful efforts to improve dementia care have relied on co-management models that typically engage a nurse practitioner focused on dementia, and, in some programs, other geriatric conditons.[6–9,13] The UCLA Alzheimer's and Dementia Care program has built on these previous successes at other institutions and has adapted them to a university-based health care system that provides primary and specialty care for a large population, most of which is covered by fee-for-service Medicare. To adequately 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, the program has been well-received by patients/ caregivers and referring physicians. If it succeeds in its goal of providing improved quality of care and better health for patients and caregivers, the program has the potential to become a national model for comprehensive dementia care.

Acknowledgments

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Table 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,[14] functional assessment questionnaire[15] and NPI – Q[16] (15 minutes)
  - Check for completeness
- Clarify answers, ask for supporting information
- Ask the caregiver(s) to step out of the room to complete a PHQ-9 [17], Cornell scale for depression in dementia [18], HIPAA 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)
  - MMSE [19]
  - If the patient scores 20 or better on the MMSE, complete a MOCA[20]
- 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?
  - DPOA for Health Care, POLST
- 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 exam (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/caregiver
- Review the UCLA ADC resource folder that is provided and partially filled. 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 PCP (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.

Table 2

Sociodemographic and Clinical Characteristics and Initial Services Provided

Age (Mean, SD)	Mean – 82.7 SD – 7.4
Gender (% male)	42% male
Ethnicity	
• Caucasian	76%
• African-American	11%
• Hispanic/Latino	8%
• Asian	5%
Type of dementia	
• Alzheimers (%)	42%
• Frontotemoral (%)	1%
• Lewy Body (%)	5%
• Vascular (%)	4%
• Parkinson's (%)	1%
• Other, mixed, or unknown (%)	47%
MMSE (Mean, SD)	Mean – 15.8 SD – 8.0
Referred by primary care physician	140 (93%)
Dually insured (%)	7%
Caregiver	
• Spouse (%)	37%
• Child (%)	48%
• Friend or Other (other family, CG, partner) (%)	15%
Initial services provided	
• Medication adjustment (%)	41%
• Recommendation for additional evaluation (%)	21%
• Caregiver education (%)	14%
• Referral to support group (%)	73%
• Referral to CBO (%)	55%
• Caregiver training (%)	45%
• Referral to legal services (%)	5%
• Alzheimer's Association Safe Return	73%
• POLST	5%
• Caregiver Agency List	20%
• Life Alert Info	5%
• Veterans Benefits	10%