



# Patient and Caregiver Benefit From a Comprehensive Dementia Care Program: 1-Year Results From the UCLA Alzheimer's and Dementia Care Program

David B. Reuben, MD, AGSF,\* Zaldy S. Tan, MD, MPH,\* Tahmineh Romero, MS,†  
Neil S. Wenger, MD, MPH,† Emmett Keeler, PhD,‡ and Lee A. Jennings, MD, MSHS<sup>§</sup>  

**BACKGROUND/OBJECTIVES:** Persons with Alzheimer disease and related dementias (ADRDs) require comprehensive care that spans health systems and community-based organizations. This study examined the clinical outcomes of a comprehensive dementia care program and identified subgroups who were more likely to benefit.

**DESIGN:** Observational, baseline and 1 year after intervention.

**SETTING:** Urban, academic medical center.

**PARTICIPANTS:** A total of 554 persons with dementia and their caregivers who had 1-year follow-up evaluations and data on clinical outcomes.

**INTERVENTION:** Health system-based comprehensive dementia care management program using nurse practitioner dementia care managers.

**MEASUREMENTS:** Patient measures included the Mini-Mental State Examination (MMSE), the Functional Activities Questionnaire, Basic and Instrumental Activities of Daily Living scales, the Cornell Scale for Depression in Dementia, and the Neuropsychiatric Inventory Questionnaire (NPI-Q) Severity. Caregiver measures included the Modified Caregiver Strain Index, the Patient Health Questionnaire-9, NPI-Q Distress, and the Dementia Burden

Scale-Caregiver). We used established minimal clinically important differences and lowest tertiles of baseline symptoms to define improving symptoms and maintaining low symptoms as clinical benefit for patients and caregivers.

**RESULTS:** At year 1, persons with ADRD improved on all scales, except MMSE and functional status measures; caregivers improved on all scales. Using validated instruments, 314/543 (58%) of patients, 282/447 (63%) of caregivers, and 376/501 (75%) of patients or caregivers demonstrated clinical benefit. In adjusted multivariate models, at year 1, more behavioral symptoms and fewer depression symptoms at baseline were associated with patient improvement; and fewer baseline depression symptoms were associated with maintaining low behavioral symptoms. Male caregiver sex, higher baseline caregiver burden, and caring for patients with fewer baseline depression symptoms were associated with caregiver improvement. Male caregiver sex and patients with fewer depression symptoms, fewer behavioral symptoms, and more functional impairment at baseline were associated with caregivers maintaining low burden at 1 year.

**CONCLUSIONS:** Health system-based comprehensive dementia care management is a promising approach to improving clinical outcomes, with benefits for both patients and caregivers. *J Am Geriatr Soc* 00:1-7, 2019.

**Key words:** Alzheimer disease; caregiver burden; collaborative care; comanagement; dementia

From the \*Multicampus Program in Geriatric Medicine and Gerontology, David Geffen School of Medicine, University of California, Los Angeles, Los Angeles, California; †Division of General Internal Medicine and Health Services Research, David Geffen School of Medicine, Los Angeles, California; ‡RAND Health, Santa Monica, California; and the §Reynolds Department of Geriatric Medicine, University of Oklahoma Health Sciences Center, Oklahoma City, Oklahoma.

Address correspondence to David B. Reuben, MD, Division of Geriatrics, David Geffen School of Medicine, University of California, Los Angeles, 10945 Le Conte Ave, Ste 2339, Los Angeles, CA 90095-1687. E-mail: dreuben@mednet.ucla.edu; Lee A. Jennings, MD, MSHS, Reynolds Department of Geriatric Medicine, University of Oklahoma Health Sciences Center, 1122 NE 13th St, ORB 1200, Oklahoma City, OK 73117. E-mail: lee-jennings@ouhsc.edu. Twitter: @LeeAJennings.

This research was presented at the 2019 Annual Meeting of the American Geriatrics Society on May 2, 2019, in Portland, OR.

DOI: 10.1111/jgs.16085

The clinical manifestations of Alzheimer disease and related dementias (ADRDs) are protean and devastating, including cognitive impairment, immobility and falls, swallowing disorders and aspiration pneumonia, and behavioral symptoms (eg, agitation, aggression, and hallucinations). These sequelae often lead to caregiver stress,

burnout, and medical illnesses. Thus, ADRDs can be considered the archetype for a disorder with complex needs that span both the patient and caregiver, include medical and social domains, and require health system and community-based interventions.

In response, several dementia care programs have been developed to comprehensively meet the needs of patients and their caregivers. Some have been based within healthcare systems and reach out to the communities,<sup>1-4</sup> whereas others have been based in the community and reach out to healthcare providers<sup>5</sup> or have used both community- and healthcare-based care managers.<sup>6,7</sup> The UCLA Alzheimer's and Dementia Care (ADC) Program, which adapted elements from an evidence-based collaborative ADRD care model,<sup>2,3</sup> was fully implemented in July 2012 and has cared for over 2600 patients and caregivers since that time. The UCLA ADC Program is a health system-based comanagement model of nurse practitioner (NP) dementia care managers (DCMs) working with primary care and specialty physicians.<sup>4</sup>

Increasingly, clinical programs are being evaluated on their ability to meet the triple aim of better care, better health, and lower costs.<sup>8</sup> We have previously reported the effect of the UCLA ADC Program on the quality of dementia care<sup>9</sup> and Medicare costs.<sup>10</sup> In this article, we report 1-year patient and caregiver clinical outcomes and predictors of clinical benefit of the program.

## METHODS

This study describes 1-year patient and caregiver outcomes for the first 1091 participants in the UCLA ADC Program; reports the percentages who demonstrated patient, caregiver, or either benefit; and identifies predictors of who benefits. The study was approved by the UCLA Institutional Review Board.

### Participants

Patients in the UCLA ADC Program were referred to the program by their primary care or specialist physicians, who agreed to comanage care with the DCMs. The only additional eligibility requirements were that they were UCLA patients and they did not live in a nursing home at the time of referral to the program.

### Description of the Program

The UCLA ADC Program utilizes an NP DCM supervised by a physician dementia specialist to tailor and facilitate dementia care delivery in collaboration with the primary care physician (comanagement). NPs can write orders, communicate directly through the electronic health record, and facilitate clinical care. Dementia care is based in the healthcare system, which partners with community-based organizations to provide comprehensive, coordinated, patient-centered care. Key components include:

- Structured needs assessments of patients and their caregivers.
- Creation and implementation of individualized dementia care plans.

- Ongoing dementia care management by a DCM supervised by a physician dementia specialist, including, as needed:
  - In-person sessions
  - Telephone follow-up to monitor implementation of dementia care plans
  - Teaching dementia management skills to caregivers
  - Consultation with neurology, geriatric psychiatry, psychology, or geriatrics
  - Caregiver support groups
  - Caregiver education through a community lecture series
  - Referral to community-based organizations for services (eg, adult day care, counseling) as well as caregiver training, including vouchers, if needed, for temporary services.
- Monitoring and revising care plans, as needed, including active monitoring (a minimum of a telephone call every 4 months) and support of caregivers.
- Access 24/7, 365 days a year for assistance and advice. Night, weekend, and holidays are covered by the UCLA geriatrician on call.

## Measures

*Mini-Mental State Examination (MMSE)* measures cognition with ranges from 0 to 30, with lower scores indicating greater cognitive impairment.<sup>11</sup>

*Functional Activities Questionnaire (FAQ)* measures functional status and ranges from 0 to 30, with higher scores indicating more functional dependence.<sup>12</sup>

*Cornell Scale for Depression in Dementia* is a 19-item validated tool used to assess depressive symptoms in patients with dementia. Scores range from 0 to 38, and a score of 11 or greater indicates probable depression.<sup>13</sup>

*Functional status* was measured using Basic Activities of Daily Living (ADLs)<sup>14</sup> and Instrumental ADLs (IADLs) scales,<sup>15</sup> which have been validated and are well established in research and clinical use. We also administered the FAQ, which measures functional status and ranges from 0 to 30, with higher scores indicating more functional dependence.<sup>12</sup>

*Neuropsychiatric Inventory Questionnaire (NPI-Q)*<sup>16</sup> is a validated survey that assesses the caregiver's perception of the severity of 12 dementia-related psychiatric and behavioral symptoms and the level of distress experienced by the caregiver as a result of these symptoms. NPI-Q Severity score ranges from 0 to 36, and NPI-Q Distress score ranges from 0 to 60, with higher scores indicating more severe symptoms and distress, respectively. In a nursing home population, the minimal clinically important difference was determined to be 2.8 to 3.2 points for severity and 3.1 to 4.0 points for distress.<sup>17</sup>

*Modified Caregiver Strain Index (MCSI)*<sup>18</sup> is a 13-item validated tool used to assess severity of caregiver strain. The index targets financial, physical, psychological, and social aspects of strain and is scored from 0 to 26, with higher scores indicating greater levels of strain.

*Patient Health Questionnaire-9 (PHQ-9)*<sup>19</sup> is a nine-item validated tool used to assess depressive symptoms in the caregiver using the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*, criteria for major

depression and is scored from 0 to 27, with scores greater than 10 indicating moderate symptoms and scores greater than 20 indicating severe depressive symptoms.

*Dementia Burden Scale-Caregiver (DBS-CG)*<sup>20</sup> is a composite of the NPI-Q Distress, MCSI, and PHQ-9 scales, with items transformed linearly to be on a 0 to 100 possible range and then averaged, with higher scores indicating higher caregiver burden. The minimal clinically important difference for the DBS-CG is five points.

### Definition of Clinical Benefit

We captured benefit in two ways: (1) for those in the two worst tertiles at the baseline, improvement by the minimal clinically important difference over 1 year (yes/no) or (2) for those who were in the lowest symptom tertile at the baseline, by maintaining low symptoms at baseline and 1 year (yes/no) (Table 1). We measured patient symptoms using the NPI-Q Severity scale (the only patient outcome measure anticipated to benefit from the program) and caregiver symptoms using the DBS-CG scale. Benefit on the NPI-Q severity scale was defined as improving by at least three points, the minimal clinically important difference,<sup>17</sup> or having baseline and 1-year scores of 6 or lower (the upper limit of the baseline tertile of fewest patient symptoms) (Supplementary Figure S1). DBS-CG benefit was defined as improving by at least five points, the minimal clinically important difference,<sup>20</sup> or having baseline and 1-year scores of 18.8 or lower (the upper limit of the baseline tertile of fewest caregiver symptoms) (Supplementary Figure S2). Defining benefit in this manner allowed us to capture both improvement (by the minimal clinically important difference or more) and maintenance of low symptoms (baseline and 1-year symptoms are low).

### Analyses

Baseline characteristics of the cohort who survived to 1 year, stratified by missing at year 1, were described using proportions for categorical variables and means with SDs or medians with interquartile ranges for continuous variables. Differences between missing/not missing were tested using the  $\chi^2$  test for categorical variables and the Student *t*-test or Wilcoxon test for continuous variables, depending on

whether mean or median was reported. We used item-level data from FAQ, MMSE, Cornell, and IADLs to impute full predictor scales for patients who had at least one item on the scale. For missing outcomes, we required at least one item in the NPI-Q Severity scale and at least one item in each of the three component scales (NPI-Q Distress, PHQ-9, and MCSI) to impute DBS-CG scores.

One-year changes in NPI-Q Severity and DBS-CG among patients and caregivers were used to measure the benefit from the program. To adjust for the bias that could arise from systematic differences between complete cases and patients with missing data, we used inverse probability weighting (IPW).<sup>21</sup> The estimated probability of being a complete case was calculated, performing a logistic regression modeling missing patient or caregiver outcomes at year 1 (yes/no), adjusting for patient's and caregiver's baseline demographic and clinical characteristics. The predictors of being a complete case include patient's age, sex, race, education, dementia type, and MMSE category and the tertiles of FAQ, Cornell, and NPI-Q Severity; and the caregiver's sex, relation to patient, and the tertiles of MCSI, PHQ-9, and NPI-Q Distress. The tertiles were modeled as continuous variables (test of trend). We examined the distribution of the estimated inverse probability of being a complete case, and there were no influential weights.

Continuous outcomes were modeled performing IPW linear regression. For binary outcomes, we used IPW univariable and multivariable logistic regressions to calculate unadjusted and adjusted odds ratios and their 95% confidence intervals, respectively. To model clinical benefit (improving [yes/no] by the minimal clinically important difference or maintaining low symptoms [yes/no]), for patients and caregivers, we included predictors that were significant in univariable logistic regressions plus the clinically relevant covariates. As a sensitivity analysis, all the models were redone without applying IPW.

All tests were two sided, and  $P < .05$  was considered statistically significant. Analyses were performed using SAS, version 9.4 (SAS Institute Inc).

## RESULTS

From July 1, 2012, to December 2014, 1091 patients and their caregivers entered the program; 991 patients survived for at least 1 year in the program, and 554 patients (56%) and 469 caregivers (47%) caregivers had completed outcome measures at year 1. Loss to follow-up at year 1 included 247 patient-caregiver dyads who were not actively involved in the program due to relocation, change in eligibility (eg, living in a nursing home or enrolled in hospice), or failing to respond to program outreach efforts as well as 190 patients and 275 caregivers who remained in the program but did not complete 1-year surveys. Baseline sociodemographic characteristics of patients and their caregivers with outcome data were similar to the sample missing outcomes but had slightly better baseline scores on the FAQ, Cornell Scale for Depression in Dementia, and both subscales of the NPI-Q that were statistically, although not clinically, significant (Table 2).

After 1 year in the program, patients' cognition (MMSE) and functional status (FAQ) worsened, but behavioral and psychological symptoms (NPI-Q Severity)

**Table 1. Definitions of Clinical Benefit**

Patient or caregiver	Symptom improvement	Maintenance of low symptoms
Patient	Improving by at least 3 points on the NPI-Q Severity (the minimal clinically important difference)	Lowest tertile of NPI-Q Severity ( $\leq 6$ ) at baseline and 1 year
Caregiver	Improving by at least 5 points on the DBS-CG (the minimal clinically important difference)	Lowest tertile of DBS-CG ( $\leq 18.8$ ) at baseline and 1 year

Abbreviations: DBS-CG, Dementia Burden Scale-Caregiver; NPI-Q, Neuropsychiatric Inventory Questionnaire.

and depressive symptoms (Cornell) improved (Figure 1A). At 1 year, all caregiver outcomes improved significantly (Figure 1B). In multivariable linear regression models (Table 3), the only predictor of patient change on NPI-Q Severity scale was baseline caregiver NPI-Q Distress score (worse baseline scores predicted better 1-year scores). Predictors of caregiver change scores on the NPI-Q Distress scale included baseline NPI-Q Severity and baseline MCSI (worse baseline scores predicted better 1-year scores). Predictors of change scores on MCSI were black race (predicted better 1-year score vs white race) and functional status measured by FAQ (worse baseline scores predicted better 1-year scores). Predictors of PHQ-9 improvement were child caregiver (predicted better 1-year score vs spouse) and baseline MCSI (worse baseline scores predicted better 1-year scores).

Using the above definitions of clinical benefit (Table 1), 314/543 (58%) of patients and 282/447 (63%) of caregivers demonstrated benefit at 1 year. When considering

benefit as for the patient, the caregiver, or both, 376/501 (75%) demonstrated benefit at 1 year. Among patients who derived benefit at 1 year, 188/314 (60%) was symptom improvement and 127/314 (40%) was maintaining low symptoms. Among caregivers who benefited at 1 year, 176/282 (62%) was by improving symptoms and 106/282 (38%) was maintaining low symptoms.

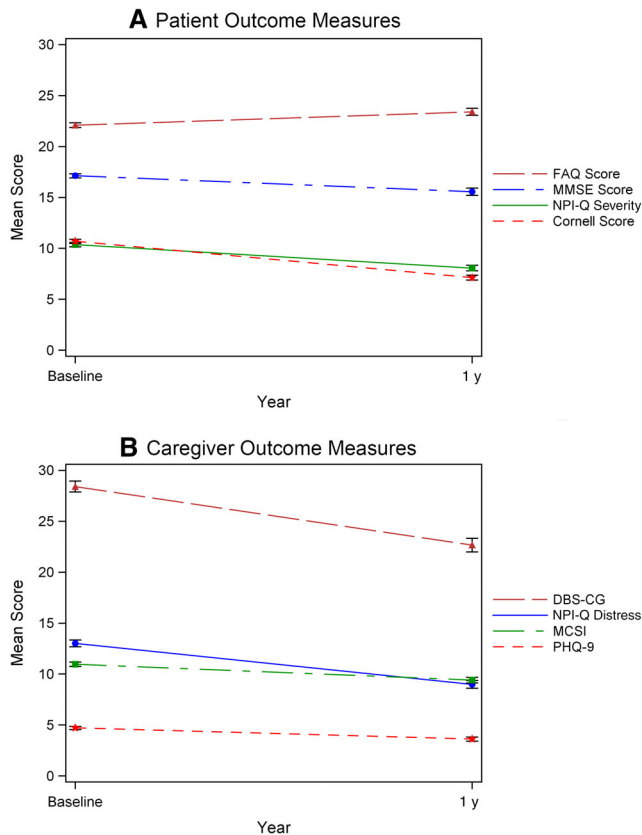
Unadjusted bivariate baseline predictors of 1-year clinical benefit are presented in Supplementary Table S1. In adjusted multivariable models (Table 4), at 1 year, patients who had more behavioral symptoms at baseline and fewer depression symptoms were more likely to improve and those with fewer baseline depression symptoms were more likely to maintain low behavioral symptoms. Being a male caregiver, caring for a patient with fewer depressive symptoms, and higher baseline caregiver burden were associated with caregiver improvement. Being a male caregiver and more baseline patient functional impairment, fewer patient depressive symptoms, and fewer

**Table 2. Patient and Caregiver Baseline Characteristics of Cohort, Those Completing 1-Year Outcomes, and Those Missing 1-Year Outcomes**

Characteristics	Entire cohort (N = 991)	Completed year 1 outcome	Missing year 1 outcome	P value <sup>a</sup>
<b>Patient Characteristics</b>		N = 554 (56%)	N = 437 (44%)	
Age, mean (SD), range, y	81.9 (8.8), 40-101	82.3 (8.6), 53-101	81.5 (9.1), 40-101	.148
Female, No. (%)	669 (68)	375 (68)	294 (67)	.891
Ethnicity, No. (%)				.440
• White, not Hispanic	627 (72)	354 (71)	273 (74)	
• Black, not Hispanic	69 (8)	46 (9)	23 (6)	
• Hispanic	112 (13)	65 (13)	47 (13)	
• Other, not Hispanic	64 (7)	36 (7)	28 (8)	
Primary language not English, No. (%)	169 (18)	86 (16)	83 (20)	.105
Those with college or higher education, No. (%)	421 (44)	249 (46)	172 (41)	.150
Medicare and Medicaid dually insured, No. (%)	115 (12)	57 (10)	58 (13)	.310
Alzheimer disease, mixed vascular and Alzheimer disease, or unspecified type of dementia, No. (%)	881 (90)	492 (89)	389 (90)	.681
Functional Activities Questionnaire, mean (SD)	20.8 (8.2)	20.3 (8.2)	21.5 (8.2)	.027
ADLs performed independently, median (IQR) (range = 0-65)	4 (1-6)	4 (1-6)	3 (1-5)	.440
IADLs performed independently, median (IQR) (range = 0-7)	0 (0-1)	0 (0-1)	0 (0-1)	.169
Mini-Mental State Examination, mean (SD) (range = 0-30)	17.5 (7.0)	17.8 (7.0)	17.2 (7.0)	.165
Neuropsychiatric Inventory Questionnaire Severity, mean (SD)	9.9 (6.9)	9.2 (6.4)	10.7 (7.4)	<.001
Cornell Scale for Depression in Dementia, mean (SD)	9.7 (6.1)	9.2 (5.4)	10.4 (6.2)	.005
<b>Caregiver Characteristics</b>		N = 469 (47%)	N = 522 (53%)	
Female, No. (%)	655 (67)	309 (65)	346 (68)	.402
Relationship				.004
• Child	491 (50)	265 (52)	226 (48)	
• Spouse	345 (35)	156 (30)	189 (40)	
• Other	150 (15)	90 (18)	60 (13)	
Neuropsychiatric Inventory Questionnaire Distress, mean (SD)	12.2 (10.1)	11.5 (9.4)	12.9 (10.6)	.045
Modified Caregiver Strain Index, mean (SD)	10.6 (6.7)	10.4 (6.3)	10.9 (6.9)	.302
Patient Health Questionnaire-9, mean (SD)	4.6 (4.8)	4.5 (4.8)	4.6 (4.8)	.654
DBS-CG (range 0-100)	27.6 (17.1)	26.8 (16.1)	28.4 (17.9)	.151

Abbreviations: ADL, activity of daily living; DBS-CG, Dementia Burden Scale-Caregiver; IADL, instrumental ADL; IQR, interquartile range.

<sup>a</sup>P values reported comparing baseline characteristics of patients and caregivers with and without the year 1 outcome:  $\chi^2$  test of association was performed for categorical outcomes, and Student *t*-test or Wilcoxon test was performed to compare means or medians, respectively.



**Figure 1.** Baseline and 1-year patient and caregiver outcomes measures. A, Patient outcome measures. B, Caregiver outcome measures. Cornell indicates Cornell Scale for Depression in Dementia; DBS-CG, Dementia Burden Scale-Caregiver; FAQ, Functional Activities Questionnaire; MCSI, Modified Caregiver Strain Index; MMSE, Mini-Mental State Examination; NPI-Q, Neuropsychiatric Inventory Questionnaire; PHQ-9 = Patient Health Questionnaire-9.

patient behavioral symptoms were associated with caregivers who were more likely to maintain low burden at 1 year.

In the sensitivity analyses using unweighted multivariable logistic models (Supplementary Table S2), the magnitude and direction of all the point estimates were similar to IPW models; however, a few of the predictors were no longer statistically significant, plausibly due to reduced power. Specifically, patient depressive symptoms were not statistically significant in predicting patient improvement; and in the model predicting caregiver maintaining low symptoms, caregiver sex, functional impairment, and patient behavioral symptoms were no longer statistically significant.

## DISCUSSION

Despite progression of cognitive and functional decline, most patients and caregivers participating in a health system-based comprehensive AD RD care program demonstrated clinical benefit at 1 year. Slightly more than half of patients and caregivers benefited by improvement of symptoms by at least the established minimal clinically important differences of the clinical symptom scales, and slightly less than half benefited by maintaining low symptoms. Thus, the program may

benefit patient-caregiver dyads by both improvement of symptoms and maintenance of low symptoms.

Persons with AD RD who had worse behavioral symptoms were more likely to improve, suggesting that the delivery of high-quality dementia care<sup>9</sup> and caregiver education and support<sup>22</sup> were beneficial in managing these symptoms. Caregivers who had more burden (a composite of distress, strain, and depression symptoms) benefited in a progressive manner (ie, those with the worst tertile of symptoms benefited more than those in the middle tertile), suggesting the importance of specific interventions aimed at caregivers. Unexpectedly, we found that male caregivers were also more likely to benefit. Although our data cannot provide an explanation for this finding, perhaps because of cultural norms (eg, caregiving provided more often by women), men may have had less experience in this role and benefitted more from teaching and support.

This research builds on and extends previous clinical trial data<sup>3</sup> conducted at Indiana University's affiliated urban health system, serving medically indigent patients, and a Veterans Affairs hospital. This study confirms that similar benefits on patient psychological and behavioral symptoms and caregiver distress can occur when implemented in a predominantly fee-for-service Medicare practice setting<sup>4,23</sup> in a competitive practice environment outside the context of a clinical trial. Moreover, we were able to use minimal clinically important differences, which were not available at the time of the Indiana trial, to classify individual patients as having clinical benefit. Finally, as a result of the larger sample size, we were able to identify predictors of benefit that can be used to prioritize patients when resources are limited.

These findings must be considered in light of the study's limitations. The UCLA ADC Program is a clinical program, and the evaluation did not follow a rigorous controlled trial research design. Rather, an observational design with assessments at the time of enrollment and 1 year later was employed. Accordingly, the maintenance of low symptoms or improvement of symptoms could have been a reflection of the natural history of AD RD in a subset of patients and unaffected by the program. However, randomized trial data have demonstrated that patients receiving usual care show deterioration on many of the same measures,<sup>3</sup> providing support that the improvements were a true effect. In addition, the decline in cognitive status on the MMSE in the program is consistent with published rates of decline.<sup>24</sup> The discordance between decline on a clinical measure that would not be expected to improve by the intervention (MMSE) and improvement on measures that would be expected to improve (NPI-Q Severity and Distress, MCSI, PHQ-9, and DBS-CG) also supports the validity of the findings. A second limitation was loss to follow-up was larger than would be expected in a clinical trial. Because of the clinical characteristics of AD RD and associated caregiver strain, follow-up rates tend to be lower. For example, only 67% of participants in the National Alzheimer's Coordinating Center Uniform Data Set had more than one visit.<sup>25</sup> Nevertheless, sociodemographic and clinical characteristics of those who had and who were missing 1-year outcomes were similar. We performed inverse proportional weighting to adjust for the high rates of loss to follow-up and conducted sensitivity analyses without applying weighting. The results of these sensitivity analyses were similar to models with weighting. Finally, the program was



**Table 3. Adjusted Predictors of 1-Year Change Scores for NPI-Q, Severity and Distress, MCSI, and PHQ-9**

Independent variables	Year 1 change, patient NPI-Q Severity	Year 1 change, caregiver		
		MCSI	PHQ-9	NPI-Q Distress
Age	0.01 (-0.06 to 0.08)	0.01 (-0.06 to 0.08)	0.02 (-0.03 to 0.08)	0.04 (-0.06 to 0.14)
Patient male	-0.44 (-1.83 to 0.96)	0.69 (-0.77 to 2.15)	-0.3 (-1.51 to 0.92)	-0.77 (-2.86 to 1.32)
Caregiver male	1.03 (-0.30 to 2.37)	0.74 (-0.66 to 2.15)	0.62 (-0.54 to 1.79)	1.75 (-0.26 to 3.76)
College graduate vs less than college	-0.04 (-1.28 to 1.21)	0.31 (-0.98 to 1.6)	-0.4 (-1.47 to 0.67)	-0.52 (-2.36 to 1.32)
Alzheimer disease, mixed, or unspecified dementia type	-0.76 (-2.62 to 1.11)	0.39 (-1.59 to 2.36)	0.16 (-1.49 to 1.82)	1.86 (-1.13 to 4.85)
Race				
Black vs white	-1.19 (-3.28 to 0.89)	-2.58 (-4.69 to -0.48)*	-0.44 (-2.19 to 1.3)	-1.93 (-4.94 to 1.08)
Hispanic vs white	-0.68 (-2.57 to 1.21)	0.23 (-1.75 to 2.21)	0.46 (-1.19 to 2.1)	1.11 (-1.72 to 3.94)
Other vs white	-0.64 (-3.00 to 1.73)	0.83 (-1.64 to 3.29)	1.8 (-0.26 to 3.86)	-0.16 (-3.69 to 3.38)
Caregiver relation				
Child vs spouse	0.98 (-0.48 to 2.44)	-0.86 (-2.37 to 0.65)	-1.42 (-2.68 to -0.16)*	-0.72 (-2.88 to 1.44)
Other vs spouse	0.00 (-1.91 to 1.91)	-0.12 (-2.14 to 1.9)	-0.34 (-2.01 to 1.33)	0.29 (-2.6 to 3.19)
MMSE category baseline	-0.03 (-1.03 to 0.98)	-0.05 (-1.08 to 0.99)	0.27 (-0.59 to 1.13)	0.22 (-1.25 to 1.69)
FAQ tertile baseline	-0.62 (-1.50 to 0.26)	-1.4 (-2.31 to -0.49)**	-0.6 (-1.38 to 0.17)	-0.19 (-1.51 to 1.13)
Cornell tertile baseline	0.95 (0.15 to 1.74)*	0.01 (-0.83 to 0.86)	-0.07 (-0.78 to 0.64)	1.07 (-0.15 to 2.28)
NPI-Q Severity tertile baseline		-1.12 (-2.47 to 0.23)	-0.14 (-1.27 to 0.98)	-5.19 (-6.48 to -3.89)***
Baseline MCSI tertile	-0.86 (-1.72 to -0.01)*		-0.89 (-1.64 to -0.14)*	-1.77 (-3.05 to -0.48)**
PHQ-9 baseline tertile	0.09 (-0.63 to 0.81)	-0.19 (-1.56 to 1.17)		0.24 (-0.84 to 1.31)
Baseline NPI-Q Distress tertile	-3.85 (-4.73 to -2.98)***	-0.29 (-1.03 to 0.44)	-0.13 (-1.28 to 1.03)	

Note: An increase in tertile (lowest to middle tertile or middle to highest tertile) is associated with the reported change.

Abbreviations: Cornell, Cornell Scale for Depression in Dementia; FAQ, Functional Activities Questionnaire; MCSI, Modified Caregiver Strain Index; MMSE, Mini-Mental State Examination; NPI-Q, Neuropsychiatric Inventory Questionnaire; PHQ-9, Patient Health Questionnaire-9.

\* $P < .05$ .

\*\* $P < .01$ .

\*\*\* $P < .001$ .

implemented at one site, and it is unknown whether replication sites would achieve the same findings. Yet, the implementation of the program was pragmatic and integrated into real-world clinical practice.

In summary, the UCLA ADC Program, a health system-based comprehensive dementia care program, was associated with improved scores on measures of patient and caregiver symptoms. Three-fourths of patient-caregiver

**Table 4. OR and 95% CI From Multivariable Adjusted Logistic Regressions for Patient and Caregiver Benefit at Year 1**

Variables	Patient benefit (NPI-Q Severity)		Variables	Caregiver benefit (DBS-CG)	
	Symptom improvement	Maintaining low symptoms		Symptom improvement	Maintaining low symptoms
Caregiver male	1.29 (0.861.93)	1.11 (0.622.01)	Caregiver male	3.01 (1.864.88)***	2.15 (1.114.16)*
MMSE tertile	1.23 (0.911.65)	0.79 (0.51.26)	MMSE tertile	0.87 (0.641.2)	1.02 (0.611.71)
FAQ tertile	1.18 (0.921.52)	0.81 (0.521.24)	FAQ tertile	1.2 (0.91.59)	1.64 (1.032.6)*
Cornell tertile	0.75 (0.580.95)*	0.49 (0.350.7)***	Cornell tertile	0.61 (0.460.81)***	0.53 (0.360.78)*
NPI-Q Severity tertile (13-36 vs 6-13)	4.32 (2.96.43)***		NPIQ Severity tertile	1.29 (0.971.7)	0.54 (0.320.92)*
DBS-CG tertile (27-100 vs 18.8-27)	1.19 (0.921.53)	0.97 (0.71.33)	DBS-CG tertile	3.26 (2.065.16)***	

Note: Data are given as OR (95% CI). An increase in tertile (lowest to middle tertile or middle to highest tertile) is associated with the reported OR.

Abbreviations: CI, confidence interval; Cornell, Cornell Scale for Depression in Dementia; DBS-CG, Dementia Burden Scale-Caregiver; FAQ, Functional Activities Questionnaire; NPI-Q, Neuropsychiatric Inventory Questionnaire; OR, odds ratio.

\* $P < .05$ .

\*\* $P < .01$ .

\*\*\* $P < .001$ .

dyads had patient and/or caregiver clinical benefit. Although clinical trial data are not yet available, ADRD comanagement by NPs may be a model for providing dementia care that meets the triple aim of quality care, lower-cost expenditures, and better clinical outcomes.

## ACKNOWLEDGMENTS

**Financial Disclosure:** Research reported in this publication was supported by the National Institute on Aging of the National Institutes of Health (NIH) under awards R21AG054681 and P30AG028748; the NIH/National Center for Advancing Translational Science UCLA Clinical and Translational Science Institute (CTSI) grant UL1TR000124; The Commonwealth Fund, a national, private foundation based in New York City that supports independent research on healthcare issues and makes grants to improve healthcare practice and policy; the Alzheimer's Association NIRG-15-364406, and the Centers for Medicare and Medicaid Services under contract HHSM 500-2011-000021 Task Order HHSM-500-T0009.

**Conflict of Interest:** None.

**Author Contributions:** DBR, NSW, LJ: concept and design, acquisition of subjects and/or data, analysis and interpretation of data, and preparation of manuscript. ZST: concept and design, acquisition of subjects and/or data, and preparation of manuscript. TR, EK: analysis and interpretation of data and preparation of manuscript.

**Sponsor's Role:** The views expressed in this article are the authors' and do not necessarily represent the views of the Centers of Medicare and Medicaid Services, the US Department of Health and Human Services, the National Institutes of Health, or The Commonwealth Fund, its directors, officers, or staff. The funders had no role in the in study design, data collection, analysis and interpretation of data, writing of the report, or the decision to submit the article for publication.

## REFERENCES

- Chodosh J, Colaiaco BA, Connor KI, et al. Dementia care management in an underserved community: the comparative effectiveness of two different approaches. *J Aging Health*. 2015;27(5):864-893. <https://doi.org/10.1177/0898264315569454>.
- Callahan CM, Boustani MA, Weiner M, et al. Implementing dementia care models in primary care settings: the aging brain care medical home. *Aging Ment Health*. 2011;15(1):5-12.
- Callahan CM, Boustani MA, Unverzagt FW, et al. Effectiveness of collaborative care for older adults with Alzheimer disease in primary care: a randomized controlled trial. *JAMA*. 2006;295(18):2148-2157.
- Reuben DB, Everson LC, Wenger NS, et al. The University of California at Los Angeles Alzheimer's and Dementia Care Program for comprehensive, coordinated, patient-centered care: preliminary data. *J Am Geriatr Soc*. 2013;61(12):2214-2218. <https://doi.org/10.1111/jgs.12562>.
- Vickrey BG, Mittman BS, Connor KI, et al. The effect of a disease management intervention on quality and outcomes of dementia care: a randomized, controlled trial. *Ann Intern Med*. 2006;145(10):713-726.
- Bass DM, Judge KS, Snow AL, et al. A controlled trial of partners in dementia care: veteran outcomes after six and twelve months. *Alzheimers Res Ther*. 2014;6(1):9. <https://doi.org/10.1186/alzrt242>.
- Bass DM, Judge KS, Snow AL, et al. Caregiver outcomes of partners in dementia care: effect of a care coordination program for veterans with dementia and their family members and friends. *J Am Geriatr Soc*. 2013;61(8):1377-1386. <https://doi.org/10.1111/jgs.12362>.
- Berwick DM, Nolan TW, Whittington J. The triple aim: care, health, and cost. *Health Aff*. 2008;27(3):759-769.

- Jennings LA, Tan Z, Wenger NS, et al. Quality of care provided by a comprehensive dementia care comanagement program. *J Am Geriatr Soc*. 2016; 64(8):1724-1730. <https://doi.org/10.1111/jgs.14251>.
- Jennings LA, Laffan AM, Schlissel AC, et al. Health care utilization and cost outcomes of a comprehensive dementia care program for Medicare beneficiaries. *JAMA Intern Med*. 2018;179:161-166. <https://doi.org/10.1001/jamainternmed.2018.5579>.
- Folstein MF, Folstein SE, McHugh PR. "Mini-mental state": a practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res*. 1975;12(3):189-198.
- Pfeffer RI, Kurosaki TT, Harrah CH Jr, Chance JM, Filos S. Measurement of functional activities in older adults in the community. *J Gerontol*. 1982;37(3):323-329.
- Alexopoulos GA, Abrams RC, Young RC, Shamoian CA. Cornell scale for depression in dementia. *Biol Psych*. 1988;23:271-284.
- Katz S, Downs TD, Cash HR, Grotz RC. Progress in development of the index of ADL. *Gerontologist*. 1970;10(1):20-30.
- Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. *Gerontologist*. 1969;9(3):179-186.
- Kaufer DI, Cummings JL, Ketchel P, et al. Validation of the NPI-Q, a brief clinical form of the neuropsychiatric inventory. *J Neuropsychiatry Clin Neurosci*. 2000;12(2):233-239.
- Mao HF, Kuo CA, Huang WN, Cummings JL, Hwang TJ. Values of the minimal clinically important difference for the neuropsychiatric inventory questionnaire in individuals with dementia. *J Am Geriatr Soc*. 2015;63(7): 1448-1452. <https://doi.org/10.1111/jgs.13473>.
- Thornton M, Travis SS. Analysis of the reliability of the modified caregiver strain index. *J Gerontol B Psychol Sci Soc Sci*. 2003;58(2):S127-S132.
- Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. *J Gen Intern Med*. 2001;16(9):606-613.
- Peipert JD, Jennings LA, Hays RD, Wenger NS, Keeler E, Reuben DB. A composite measure of caregiver burden in dementia: the dementia burden scale-caregiver. *J Am Geriatr Soc*. 2018;66(9):1785-1789. <https://doi.org/10.1111/jgs.15502>.
- Seaman SR, White IR. Review of inverse probability weighting for dealing with missing data. *Stat Methods Med Res*. 2013;22(3):278-295. <https://doi.org/10.1177/0962280210395740>.
- Warrick N, Prorok JC, Seitz D. Care of community-dwelling older adults with dementia and their caregivers. *CMAJ*. 2018;190(26):E794-E799. <https://doi.org/10.1503/cmaj.170920>.
- Tan ZS, Jennings L, Reuben DB. Coordinated care management for dementia in a large academic health system. *Health Aff (Millwood)*. 2014;33(4): 619-625. <https://doi.org/10.1377/hlthaff.2013.1294>.
- Clark CM, Sheppard L, Fillenbaum GG, et al. Variability in annual Mini-Mental State Examination score in patients with probable Alzheimer disease: a clinical perspective of data from the Consortium to Establish a Registry for Alzheimer's Disease. *Arch Neurol*. 1999;56(7):857-862. <https://doi.org/10.1001/archneur.56.7.857>.
- National Alzheimer's Coordinating Center. Uniform Data Set (UDS) - Follow-up. <https://www.alz.washington.edu/WEB/UDSFVonepage.pdf>. Accessed March 2, 2019.

## SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article.

**Supplementary Table S1:** Unadjusted baseline predictors of 1-year clinical benefit.

**Supplementary Table S2:** Unweighted multivariable models: sensitivity analyses

**Supplementary Figure S1:** Patient clinical benefit. Patients who benefitted are in blue shaded area, either because of improvement of at least the minimal clinically important difference (right of the diagonal) or maintenance of low symptoms at baseline and 1 year (below horizontal line).

**Supplementary Figure S2:** Caregiver clinical benefit. Caregivers who benefitted are in blue shaded area, either because of improvement of at least the minimal clinically important difference (right of the diagonal) or maintenance of low symptoms at baseline and 1 year (below horizontal line).