Unmet Needs of Caregivers of Individuals Referred to a Dementia Care Program

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OBJECTIVES: To characterize caregiver strain, depressive symptoms, and self-efficacy for managing dementia-related problems and the relationship between these and referring provider type.

DESIGN: Cross-sectional observational cohort.

SETTING: Urban academic medical center.

PARTICIPANTS: Caregivers of community-dwelling adults with dementia referred to a dementia care management program.

MEASUREMENTS: Caregivers were surveyed and completed the Patient Health Questionnaire (PHQ-9) about themselves; the Modified Caregiver Strain Index; the Neuropsychiatric Inventory Questionnaire, which measures patient symptom severity and related caregiver distress; and a nine-item caregiver self-efficacy scale developed for the study.

RESULTS: Of 307 patient–caregiver dyads surveyed over a 1-year period, 32% of caregivers reported confidence in managing dementia-related problems, 19% knew how to access community services to help provide care, and 28% agreed that the individual's provider helped them work through dementia care problems. Thirty-eight percent reported high levels of caregiver strain, and 15% reported moderate to severe depressive symptoms. Caregivers of individuals referred by geriatricians more often reported having a healthcare professional to help work through dementia care problems than those referred by internists, family physicians, or other specialists, but self-efficacy did not differ. Low caregiver self-efficacy was associated with higher caregiver strain, more caregiver depressive symptoms, and caring for an individual with more-severe behavioral symptoms.

CONCLUSION: Most caregivers perceived inadequate support from the individual's provider in managing dementia-related problems, reported strain, and had low confidence in managing caregiving. New models of care are needed to address the complex care needs of individuals with dementia and their caregivers. **J Am Geriatr Soc 63:282–289, 2015.**

Key words: dementia; primary care; caregiver strain

In 2012, 5.2 million Americans were estimated to have Alzheimer's disease, and 15.4 million Americans provided an estimated 17.5 billion hours of unpaid care for people living with dementia.[1] Caring for a person with dementia poses several challenges. Caregivers must provide increasing supervision and personal care as the person with dementia becomes more functionally dependent. Caregivers must learn to manage behavioral disturbances, personality changes, and the loss of the ability to communicate effectively with their loved ones. As dementia progresses, caregivers experience increasing strain and burnout, depression, disruptions in employment, and depleted finances.[1]

High levels of caregiver strain are associated with worse outcomes for individuals with dementia, including higher rates of nursing home placement.[2–4] High levels of strain also result in greater risk of poor health outcomes for caregivers, including depression,[5] cardiovascular disease,[6,7] and perhaps mortality in caregivers with the highest levels of stress.[8,9] Low self-efficacy for dementia caregiving, specifically low perceived ability to manage behavioral symptoms or access community resources, has

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been associated with more depressive symptoms and lower health-related quality of life in family caregivers.[10–12]

Interventions developed to decrease the negative aspects of caregiving have focused on training caregivers on strategies to manage behavioral symptoms, enhancing caregiver social support, and providing respite. Multicomponent interventions that longitudinally engage multiple family members to provide ongoing assistance as the disease progresses have been most effective at reducing caregiver strain,[13–16] but busy physicians have neither the time nor, in some cases, the skills to adequately implement interventions to reduce caregiver strain and improve self-efficacy. In primary care settings, fewer than half of dementia caregivers receive counseling about managing behavioral symptoms or accessing caregiver support,[17–19] and caregiver mental health is often insufficiently addressed.[5] Specialists, including geriatricians, neurologists, and psychiatrists, also provide dementia care, and less is known about how caregiver strain, depressive symptoms, and self-efficacy may differ according to provider type. Community resources (e.g., the Alzheimer's Association) can improve the quality of dementia care by providing education and support for caregivers, but these organizations are underused.[19]

In response to these needs, in July 2012, the University of California at Los Angeles (UCLA) launched the Alzheimer's and Dementia Care Program (ADC), a dementia management program that provides comprehensive, coordinated, patient-centered care for individuals with dementia and their families. The program uses a co-management model, with a nurse practitioner dementia care manager partnering with primary care physicians and five local community-based organizations.[20]

To better understand the needs of caregivers upon entry into the program, a baseline evaluation was conducted of caregiver reports of their perceived ability to manage dementia-related problems, perceptions of dementia care, caregiver mental health and strain, and the relationship between these and the type of referring provider. This article describes the unmet caregiver needs for the first 307 individuals enrolled in the program.

METHODS

All participants were enrolled in the UCLA ADC, which required that enrollees be community dwelling, have a diagnosis of dementia of any type, and be referred by a UCLA provider. UCLA is an urban academic health system in west Los Angeles. Primary caregivers were surveyed as part of the clinical data collection of the UCLA ADC Program. The UCLA Office of the Human Research Protection Program determined that this quality improvement evaluation did not require institutional review board review.

The primary caregivers of the first 307 enrollees completed the nine-item Patient Health Questionnaire (PHQ-9)[21] and the 13-item Modified Caregiver Strain Index (MCSI)[22] about themselves and the 12-item self-administration version of the Neuropsychiatric Inventory Questionnaire (NPI-Q)[23] about the individual with dementia. Before the intake visit, 227 caregivers also completed a nine-item survey of self-efficacy for managing dementia-related problems and accessing help. This survey (developed for the UCLA ADC evaluation) was added to the previsit assessment 3 months after the start of the program, so only 254 caregivers were eligible for the survey.

The PHQ-9 is a validated tool used to assess depressive symptoms using *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*, criteria for major depression and is scored from 0 to 27, with scores >10 indicating moderate depressive symptoms and scores >20 indicating severe depressive symptoms.[21] The MCSI is a validated tool used to assess severity of caregiver strain. It targets financial, physical, psychological, and social aspects of strain and is scored from 0 to 26 with higher scores indicating greater levels of strain.[22] The NPI-Q 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 that the caregiver experiences in response to these symptoms. The NPI-Q severity score ranges from 0 to 36 and the NPI-Q distress score from 0 to 60, with higher scores indicating more-severe symptoms and distress.[23]

Cognitive status of the individual with dementia was measured using the Mini-Mental State Examination (MMSE),[24] which ranges from 0 to 30, with lower scores indicating greater impairment, and functional status was measured using the Functional Activities Questionnaire (FAQ),[25] which ranges from 0 to 30, with higher scores indicating greater functional dependence.

A nine-item previsit caregiver survey was developed to assess three domains: caregiver perception of the primary care provider's recognition of the individual's cognitive impairment and its effect on health conditions, whether the caregiver had received advice on dementia-related topics, and the caregiver's self-efficacy for caring for the individual with dementia and for accessing help, including community resources. Response options were on a 5-point rating scale (1 = strongly disagree, 5 = strongly agree). Six items were adapted from prior surveys (I. Zlateva, unpublished data),[10,26] including three items from the Fortinsky scale for dementia caregiving self-efficacy.[10] Cognitive interviews were conducted with 10 caregivers of individuals with dementia to evaluate the comprehensibility, clarity, and timing of the questions.

Statistical Analysis

Frequencies or means and standard deviations were used to examine demographic characteristics of individuals with dementia and their caregivers, including age, sex, race and ethnicity, insurance status, type of dementia, functional and cognitive status, whether the individual lived with the caregiver, the caregiver's relationship to the individual, and referring provider.

The Cronbach alpha was calculated for the responses to the four survey items addressing caregiver self-efficacy for managing dementia-related problems and accessing services (items 4–7 in Table 2). A self-efficacy score was calculated for each caregiver as the average of the responses to these four survey items within the self-efficacy domain. The self-efficacy score ranged from 1 to 5, with higher scores indicating greater self-efficacy. Responses to the previsit caregiver survey were then collapsed into three categories (strongly agree or agree, neutral, disagree or strongly disagree) for ease of presentation.

Caregiver self-efficacy survey responses were compared according to type of referring provider using chi-square tests. One-way analysis of variance or Kruskal-Wallis tests for variables with nonnormal distributions were used to compare self-efficacy score, MCSI, PHQ-9, and NPI-Q severity score according to type of referring provider.

Two-sample *t*-tests with equal variances or Wilcoxon–Mann–Whitney tests (for continuous variables) or chi-square tests or Fisher exact tests (for categorical variables) were used to compare characteristics of caregivers with high and low self-efficacy. Low self-efficacy was defined as a self-efficacy score of <3. Two-sample *t*-tests or chi-square tests were also used to compare characteristics of caregivers with high and low levels of strain (MCSI < 13). The midpoint of the MCSI was chosen as a cut point to define high and low levels of strain based on the definition of a positive screen for the original Caregiver Strain Index (CSI)[27] and use of the scale in prior studies.[28,29] All analyses were cross-sectional and were performed using Stata IC version 13 (Stata Corp., College Station, TX).

RESULTS

Over 12 months, 307 patient–caregiver dyads were evaluated as part of the baseline assessment of the dementia care program. The mean age of individuals with dementia in the study was 82, 63% were female, 25% were racial or ethnic minorities, and 10% were Medicare and Medicaid dually insured. Ninety percent had Alzheimer's disease, mixed vascular and Alzheimer's dementia, or an unspecified type of dementia. Mean MMSE score was 16.2, and mean FAQ score was 22 on a scale from 0 (complete functionality) to 30 (maximum functional dependence). Geriatricians referred 57% of individuals to the program, internists or family medicine physicians 23%, and neurologists 19% (Table 1).

Forty-nine percent of caregivers were children, 41% were spouses, 67% were female, and 65% lived with the patient. Mean caregiver PHQ-9 score was 4.7, reflecting mild depressive symptoms in caregivers on average; 44 (15%) had PHQ-9 scores of 10 or greater, consistent with moderate or severe depressive symptoms. Mean MCSI score was 11.5, reflecting moderate strain, with 115 caregivers (38%) reporting high levels of strain (>13; index midpoint) (Table 1).

On the NPI-Q, caregivers reported a mean symptom severity score for individuals with dementia of 11.1 on a scale of 0 to 36 and a mean distress score of 13.9 on a scale of 0 to 60. Agitation or aggression was the most commonly reported behavioral symptom, with 70% of caregivers reporting it as present in the last month. More than 60% of caregivers reported depression or dysphoria, anxiety, apathy or indifference, irritability or lability, or nighttime behaviors as present in the last month. Apathy (17%) and nighttime behaviors (22%) were the two behaviors that caregivers most commonly rated as severe, and agitation or aggression (18%) and nighttime behaviors (16%) were the behaviors most commonly reported as very or extremely distressing to caregivers, causing difficulty with coping or an inability to cope.

Table 1. Characteristics of Individuals with Dementia and Caregivers (N = 307)

Characteristic	Value
Individual with dementia	
Age, mean ± SD	81.8 ± 8.6
Female, n (%)	193 (63)
Race and ethnicity, n (%)	
White, non-Hispanic	230 (75)
Black, non-Hispanic	36 (12)
Hispanic	22 (7)
Asian or Pacific Islander	19 (6)
Medicare and Medicaid dually insured	31 (10)
Type of dementia	
Alzheimer's disease	138 (45)
Mixed or unspecified	138 (45)
Vascular	13 (4)
Lewy body	11 (4)
Frontotemporal	6 (2)
Parkinson's	1 (0.3)
Mini-Mental State Examination score, mean ± SD (range 0–30) (N = 297)	16.2 ± 7.7
Functional Assessment Questionnaire score, mean ± SD (range 0–30) (N = 305)	22.0 ± 7.5
Neuropsychiatric Inventory Questionnaire score, mean ± SD (N = 301)	
Symptom severity (range 0–36)	11.1 ± 7.1
Caregiver distress (range 0–60)	13.9 ± 10.1
Referring provider, n (%)	
Internal medicine or family practice	71 (23)
Geriatrics	174 (57)
Neurology	59 (19)
Psychiatry	3 (1)
Caregiver	
Female	206 (67)
Lives with individual with dementia	198 (65)
Caregiver relationship to individual with dementia	
Spouse or partner	125 (41)
Child or child-in-law	149 (49)
Other	33 (11)
Modified Caregiver Strain Index score (range 0–26) (N = 299)	
Mean ± SD	11.5 ± 7.0
>13, n (%)	115 (38)
Patient Health Questionnaire-9 score (range 0–27) (N = 298)	
Mean ± SD	4.7 ± 4.7
>9, n (%)	44 (15)
Self-efficacy score (range 0–5) (N = 227)	
Mean ± SD	2.8 ± 1.0
1.0–2.9, n (%)	115 (38)

SD = standard deviation.

Internal consistency in this sample, measured using Cronbach alpha, was high for all scales (PHQ-9, 0.87; MCSI, 0.90; NPI-Q severity scale, 0.80; NPI-Q distress scale, 0.82; FAQ, 0.72).

Caregiver Self-Efficacy and Perception of Dementia Care

Eighty-nine percent of caregivers (n = 227) completed the previsit caregiver survey. MCSI score, caregiver PHQ-9 score, NPI-Q severity and distress scores, MMSE score, and FAQ score did not differ between caregivers who completed the previsit survey and those who did not (n = 80). Thirtyfive percent indicated that they had received advice about problems to expect in the future related to dementia, 39% had received advice about managing dementia-related problems, and 25% were aware of services available to help them provide care. Concerning self-efficacy, 19% of caregiver respondents knew how to get community services to help them provide care; 32% felt confident handling problems such as memory loss, wandering, or behavioral problems related to dementia; and 35% felt confident dealing with the frustrations of caregiving. Although 79% of respondents felt that the regular doctor of the individual with dementia understood how memory or behavior problems complicate other health conditions, only 28% agreed that they had a healthcare professional who helped them work through dementia care problems (Table 2).

The internal consistency of the four survey questions assessing the caregiver's self-efficacy for managing dementia-related problems and accessing help (items 4–7 in Table 2) was high (Cronbach alpha = 0.84). The mean caregiver self-efficacy score was 2.8 (range 1–5, higher scores indicating greater self-efficacy). Low caregiver self-efficacy, defined as a self-efficacy score <3.0, was associated with higher caregiver strain, more caregiver depressive symptoms, and more-severe behavioral symptoms on the NPI-Q (Table 3).

Relationship Between Unmet Caregiver Needs and Referring Provider

There was no difference in MCSI score ($F = 0.40$, $P = .67$), caregiver PHQ-9 score (chi-square = 0.64, $P = .73$), caregiver self-efficacy score ($F = 2.51$, $P = .08$), or NPI-Q severity score ($F = 1.21$, $P = .30$) according to type of referring provider. Similarly, there were no differences in responses to the four survey items (items 4–7 in Table 4) addressing caregiver self-efficacy for managing dementia-related problems and accessing services according to specialty of referring provider, although caregivers were more likely to report that they had a healthcare professional who helped them work through dementia care problems if a geriatrician referred them to the program (42%) than an internist or family practitioner (14%) or a neurologist or psychiatrist (16%). Caregivers of individuals referred by neurologists or psychiatrists also less frequently agreed that the individual's regular doctor understood how dementia complicates other health conditions, that they had received advice about handling dementia-related problems or about what to expect in the future, and that they were aware of services to help provide care (Table 4).

Caregiver Strain and Its Correlates

Caregivers reporting higher levels of strain (>13 on the MCSI) were more likely to be female (77% vs 61%, $P = .004$), reported more depressive symptoms (PHQ-9 score 6.7 ± 5.1 vs 3.5 ± 4.0, $P < .001$), and cared for more functionally impaired individuals (FAQ score 25.0 ± 4.7 vs 20.1 ± 8.2, $P < .001$) with more behavioral symptoms (NPI-Q severity score 14.0 ± 6.8 vs 9.1 ± 6.3, $P < .001$) than those reporting lower levels of strain (Appendix 1).

Table 2. Caregiver Dementia Care and Self-Efficacy Survey Responses (N = 227)

Survey Item	Agree or Strongly Agree	Neutral	Disagree or Strongly Disagree
	n (%)		
Domain: Experience with advice on dementia-related topics			
1. I have received advice about what problems to expect in the future related to Alzheimer's or dementia.	79 (35)	50 (22)	96 (43)
2. I have received advice about handling problems like the patient's memory loss, wandering, or behavior problems.	87 (39)	52 (23)	83 (38)
3. I am aware of services available to me to help me provide care.	57 (25)	74 (33)	95 (42)
Domain: Self-efficacy for caring for individual with dementia and accessing help			
4. I know how to get community services that will help me provide care.	43 (19)	54 (24)	130 (57)
5. I feel confident that I can handle problems like the patient's memory loss, wandering, or behavior problems.[10]	73 (32)	68 (30)	86 (38)
6. I feel confident that I can deal with the frustrations of caregiving.[10]	78 (35)	60 (27)	88 (39)
7. I know where to turn to get answers to questions about problems like the patient's memory loss, wandering, or behavior problems.[10]	82 (36)	51 (23)	92 (41)
Domain: Perception of dementia care before program entry			
8. The patient's regular doctor understands how memory or behavior problems complicate other health conditions.[26]	178 (79)	36 (16)	12 (5)
9. I have a healthcare professional who helps me work through dementia care problems.	63 (28)	47 (21)	112 (51)

Table 3. Characteristics of Caregivers and Individuals with Dementia According to Level of Caregiver Self-Efficacy

Characteristic	Low Self-Efficacy (<3.0), n = 115	High Self-Efficacy (≥3.0), n = 112	*P*-Value
Caregiver			
Modified Caregiver Strain Index score, mean ± SD	13.9 ± 7.2	9.1 ± 6.1	<.001
Caregiver PHQ-9 score, mean ± SD	5.9 ± 5.2	3.5 ± 3.6	<.001
Neuropsychiatric Inventory Questionnaire score, mean ± SD			
Symptom severity	12.4 ± 7.2	10.2 ± 6.7	.02
Caregiver distress	16.5 ± 10.9	11.9 ± 8.8	<.001
Female, n (%)	84 (73)	72 (64)	.16
Lives with individual with dementia, n (%)	76 (66)	67 (60)	.33
Relationship with individual with dementia, n (%)			
Spouse	50 (43)	39 (35)	.29
Child	56 (49)	59 (53)	
Other	9 (8)	14 (12)	
Individual with dementia			
Age, mean ± SD	82.4 ± 7.4	80.6 ± 10.3	.14
Female, n (%)	67 (58)	78 (70)	.07
Racial or ethnic minority, n (%)	29 (25)	27 (24)	.85
Medicare and Medicaid dually insured, n (%)	13 (11)	11 (10)	.72
Mini-Mental State Examination score, mean ± SD	18.1 ± 7.0	15.1 ± 7.7	.002
FAQ score, mean ± SD	22.0 ± 7.5	21.3 ± 8.0	.66
Dementia type, n (%)			
Alzheimer's	52 (45)	60 (54)	.22
Mixed or unspecified	49 (43)	45 (40)	
Other	14 (12)	7 (6)	
Referring provider, n (%)			
Internal medicine or family practice	30 (26)	23 (21)	.06
Geriatrics	50 (44)	66 (59)	
Neurology or psychiatry	35 (30)	23 (21)	

Continuous variables were compared using two-sample t-tests or Wilcoxon-Mann-Whitney tests for variables with nonnormal distributions (Patient Health Questionnaire (PHQ-9) and Functional Assessment Questionnaire (FAQ)). Categorical variables were compared using chi-square tests or Fisher exact tests for variables with small sample size (any cell with n < 10).
SD = standard deviation.

DISCUSSION

Caregivers of individuals referred to a dementia care program experienced high levels of strain, had low confidence in their ability to manage caregiving and access help, and frequently felt that they did not have a healthcare professional to help them with dementia-related problems. One in seven caregivers had symptoms consistent with moderate to severe depression. Caregivers in this cohort who reported low self-efficacy for dementia caregiving also reported higher levels of strain and more depressive symptoms and cared for individuals with more-severe behavioral symptoms.

In prior cross-sectional studies of dementia caregivers, low self-efficacy for managing dementia-related behaviors was similarly associated with greater caregiver burden, more depressive symptoms, and poorer self-rated health.[10–12,30–33] Self-efficacy for dementia symptom management has also been shown to mediate the relationship between neuropsychiatric symptoms of the individual with dementia and caregiver burden and depression in those caring for individuals with greater cognitive impairment.[31] Assessment of self-efficacy for managing dementia-related symptoms and accessing help may be a good way to identify caregivers who are most vulnerable to strain and depression. Furthermore, if an intervention (e.g., dementia care program) can modify self-efficacy, it may have implications for caregiver strain and depression.

The CSI has been widely used to evaluate strain in people caring for individuals with a variety of chronic illnesses,[34–37] including dementia,[28,29,38,39] and high CSI scores have been linked to poor mental health outcomes for caregivers.[34–37] This is consistent with the strong correlation between MCSI and PHQ-9 scores in caregivers in this cohort.

The finding that most caregivers felt that they did not have a healthcare professional to help them with dementia-related problems underscores the need for additional caregiver support. This is particularly striking considering that more than half of referring providers were geriatricians, who are trained in the management of dementia and often have panels with large numbers of patients with dementia. Although caregivers of patients who geriatricians, internists, and family practitioners referred to the program were more likely to report that they had received advice on dementia-related topics than those that other subspecialists referred, the percentage of caregivers who had received advice was low overall, and there was no difference in self-efficacy for managing dementia-related problems or accessing help according to type of referring provider. Similarly, neither caregiver strain or depressive symptoms nor the severity of behavioral symptoms differed according to type of referring provider.

Table 4. Caregiver Dementia Care and Self-Efficacy Survey Response (Agree or Strongly Agree) According to Referring Provider

	All Caregivers, n = 227	Internal Medicine or Family Practice, n = 53	Geriatrics, n = 116	Neurology or Psychiatry, n = 58	
Survey Item	**N (%)**				***P*-Value**
Domain: Experience with advice on dementia-related topics					
1. I have received advice about what problems to expect in the future related to Alzheimer's or dementia.	79 (35)	20 (38)	49 (42)	10 (17)	.005
2. I have received advice about handling problems like the patient's memory loss, wandering, or behavior problems.	87 (39)	25 (47)	51 (44)	11 (19)	.002
3. I am aware of services available to me to help me provide care.	57 (25)	13 (25)	36 (31)	8 (14)	.043
Domain: Self-efficacy for caring for individual with dementia and accessing help					
4. I know how to get community services that will help me provide care.	43 (19)	8 (15)	27 (23)	8 (14)	.23
5. I feel confident that I can handle problems like the patient's memory loss, wandering or behavior problems.[10]	73 (32)	17 (32)	40 (34)	16 (28)	.72
6. I feel confident that I can deal with the frustrations of caregiving.[10]	78 (35)	18 (34)	41 (35)	19 (33)	.93
7. I know where to turn to get answers to questions about problems like the patient's memory loss, wandering, or behavior problems.[10]	82 (36)	20 (38)	47 (41)	15 (26)	.15
Domain: Perception of dementia care before program entry					
8. The patient's regular doctor understands how memory or behavior problems complicate other health conditions.[26]	178 (79)	46 (87)	99 (85)	33 (57)	<.001
9. I have a healthcare professional who helps me work through dementia care problems.	63 (28)	7 (13)	47 (41)	9 (16)	<.001

Pearson chi-square tests were used to compare groups.

These findings suggest less that the unmet need is due to deficits in physician knowledge or ability and more that the current model of primary care does not facilitate adequately addressing the complexities of dementia care. For example, busy primary care physicians often do not have the time or resources available to adequately counsel patients and families and may not be familiar with community organizations to which they can direct caregivers. Moreover, caregivers may not have access to the primary care physician after hours for advice to help manage dementia-related behaviors and avert crises.

A more-comprehensive model of dementia care is needed to improve health outcomes for individuals with dementia and their caregivers. This model should routinely provide individualized care plans that address all aspects of the disease; caregiver counseling and anticipatory guidance about the expected progression and complications of dementia; formal linkage to community organizations for respite care, caregiver training and education programs, and support groups; guidance on advance care planning; and around-the-clock access to a dementia care provider to manage problems in real time and prevent unnecessary emergency department visits and hospitalizations. An individual primary care provider cannot realistically provide these enhanced services alone, but they could be provided through other novel care delivery models, such as a co-management model with a nurse practitioner dementia care specialist[20,40,41] or an interdisciplinary team approach with collaboration among the primary care provider and other health professionals, including psychologists; pharmacists; social workers or nurse care managers; and occupational, recreational, and physical therapists.

There is also an increased national awareness of the current gaps in care for adults living with dementia and their caregivers, further supporting the implementation of new models of comprehensive dementia care. In January 2014, President Obama signed into law a $122 million increase for Alzheimer's research, education, outreach, and caregiver support to enable the continued implementation of the National Plan to Address Alzheimer's Disease.[42,43] The 2013 update to the National Alzheimer's Plan includes new provisions to improve the quality of dementia care that primary care practitioners provide, better address the needs of those in the late stages of the disease, and connect those living with dementia and their caregivers to available resources.[44]

This study has several limitations. The study cohort included the caregivers of the first 307 individuals referred to a new dementia care program. Individuals who were first referred to the program may have had more-severe behavioral symptoms or may have had caregivers who were more strained than the general population of caregivers of individuals with dementia. Also, the UCLA ADC program serves an insured population at a large, metropolitan academic medical center that may not be generalizable to other populations. Because this was a baseline evaluation of a quality improvement program, little sociodemographic information and no health status data were available for caregivers, and it is likely that these caregiver characteristics influence the health outcomes of individuals with dementia and their caregivers. Last, this is a cross-sectional observational study using data collected at the time of program enrollment, so causality among severity of dementia-related symptoms, caregiver strain, caregiver self-efficacy, and caregiver depressive symptoms cannot be determined.

Longitudinal studies will help better identify those groups with the highest strain and lowest self-efficacy and allow implementation of changes to the program to better meet caregiver needs. Future research should also focus on further validation of task-specific caregiver self-efficacy scales, including the one that the program used. A better understanding of the specific areas in which caregivers feel least confident may allow the development of more-customized interventions to improve self-efficacy and ultimately caregiver health outcomes.

In conclusion, the findings of this study illustrate the substantial gap between caregiver needs and the current care provided for dementia. These needs include low self-efficacy for dementia caregiving, caregiver strain, and in some cases, substantial depressive symptoms. These findings provide a strong rationale for implementing comprehensive care management approaches for individuals with Alzheimer's disease and other dementias.

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APPENDIX

Characteristics of Individuals with Dementia and Caregivers According to Level of Caregiver Strain

Characteristic	Lower Levels of Strain (MCSI ≤ 13), n = 184	Higher Levels of Strain (MCSI > 13), n = 115	*P*-Value
Individual with dementia			
Age, mean ± SD	80.7 ± 9.1	83.0 ± 7.4	.02
Female, n (%)	114 (62)	74 (64)	.68
Race and ethnicity, n (%)			
White, non-Hispanic	140 (76)	82 (71)	.33
Black, non-Hispanic	24 (13)	12 (10)	
Hispanic	11 (6)	11 (10)	
Asian or Pacific Islander	9 (5)	10 (9)	
Medicare and Medicaid dually insured, n (%)	16 (9)	14 (12)	.33
Type of dementia, n (%)			
Alzheimer's	86 (47)	48 (42)	.66
Mixed or unspecified	81 (44)	54 (47)	
Other	17 (9)	13 (11)	
Mini-Mental State Examination score, mean ± SD (range 0–30) (N = 289)	16.9 ± 7.8	15.2 ± 7.4	.06
Functional Assessment Questionnaire score, mean ± SD (range 0–30) (N = 298)	20.1 ± 8.2	25.0 ± 4.7	<.001
Neuropsychiatric Inventory Questionnaire symptom severity score, mean ± SD (range 0–36) (N = 292)	9.1 ± 6.3	14.0 ± 6.8	<.001
Referring provider, n (%)			
Internal medicine or family practice	36 (20)	32 (28)	.24
Geriatrics	108 (59)	62 (54)	
Neurology or psychiatry	40 (22)	21 (18)	
Caregiver			
Female, n (%)	113 (61)	89 (77)	.004
Lives with individual with dementia, n (%)	115 (63)	81 (70)	.16
Relationship with individual with dementia, n (%)			
Spouse or partner	80 (43)	44 (38)	.09
Child or child-in-law	80 (43)	63 (55)	
Other	24 (13)	8 (7)	
Caregiver Patient Health Questionnaire-9 score, mean ± SD (range 0–27) (N = 292)	3.5 ± 4.0	6.7 ± 5.1	<.001
Self-efficacy score, mean ± SD (range 0–5) (N = 224)	3.0 ± 0.93	2.5 ± 0.99	<.001

MCSI = Modified Caregiver Strain Index; SD = standard deviation.