

Caring for Individuals with Dementia and Cognitive Impairment, Not Dementia: Findings from the Aging, Demographics, and Memory Study

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OBJECTIVES: To compare the characteristics and outcomes of caregivers of adults with dementia with those of caregivers of adults with cognitive impairment, not dementia (CIND).

DESIGN: Cross-sectional.

SETTING: In-home assessment for cognitive impairment and self-administered caregiving questionnaire.

PARTICIPANTS: One hundred sixty-nine primary family caregivers of participants in the Aging, Demographics, and Memory Study (ADAMS). ADAMS participants were aged 71 and older drawn from the nationally representative Health and Retirement Study.

MEASUREMENTS: Neuropsychological testing, neurological examination, clinical assessment, and medical history were used to assign a diagnosis of normal cognition, CIND, or dementia. Caregiving measures included caregiving time, functional limitations, depressive symptoms, physical and emotional strain, caregiving rewards, caregiver health, and demographic characteristics.

RESULTS: Dementia caregivers spent approximately 9 hours per day providing care, compared with 4 hours per day for CIND caregivers ($P = .001$). Forty-four percent of dementia caregivers exhibited depressive symptoms, compared with 26.5% of CIND caregivers ($P = .03$). Physical and emotional strains were similar in both groups of caregivers. Regardless of the strains, nearly all caregivers reported some benefits from providing care. Behavioral

problems ($P = .01$) and difficulty with instrumental activities of daily living ($P = .01$) in persons with CIND partially explained emotional strain experienced by CIND caregivers. For those with dementia, behavioral problems predicted caregiver emotional strain ($P < .001$) and depressive symptoms ($P = .01$).

CONCLUSION: Although support services are available to dementia caregivers, CIND caregivers also expend considerable time and experience strains. The real caregiver burden of cognitive impairment in the U.S. population may therefore be greatly underestimated if people who have reached the diagnostic threshold for dementia are focused on exclusively. *J Am Geriatr Soc* 59:488–494, 2011.

Key words: caregiving; mild cognitive impairment; dementia; aging

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Dementia affects a large and growing number of individuals and families in the United States.^{1,2} Informal caregivers spend significant time caring for those with dementia,³ which may allow those with dementia to remain at home longer and delay the need for nursing home care,⁴ but many dementia caregivers report higher levels of stress than caregivers of individuals without dementia,⁵ as well as higher levels of depression, higher demands on them as part of the caregiving experience, and stronger feelings of captivity in the caregiving role.^{6,7} These adverse outcomes associated with caregiving for patients with dementia may be due to feeling overloaded in the caregiving role, which in turn may compromise caregivers' own health and well-being. Feelings of overload have been shown to mediate the link between dementia and caregiver stress, as well as between dementia and caregiver health.⁸

Most of what is known about caregiving for cognitively impaired individuals pertains to individuals with dementia.⁹

The majority of such studies have compared dementia caregivers with caregivers of individuals without dementia. No studies have specifically examined characteristics of caregivers and caregiver outcomes for those providing care to individuals with the diagnostic classification of cognitive impairment, not dementia (CIND).

CIND is cognitive impairment that does not reach the diagnostic threshold for dementia. It is important to examine caregiving concerns related to those with CIND because CIND affects significantly more individuals in the United States than dementia;¹⁰ individuals with CIND may progress to dementia at a significantly higher rate (e.g., 10–15% per year vs 1–2.5% of those who are cognitively normal^{11–13}); and CIND may lead to neuropsychiatric symptoms, disability, and poorer quality of life.^{14,15}

CIND, particularly in community-based samples, is heterogeneous in clinical presentation and etiology. Although mild cognitive problems in people with CIND may lead to the need for some assistance or supervision in complex daily activities, by definition, individuals with CIND should not need a caregiver to assist with basic daily activities because of their cognitive impairment. However, physical and sensory limitations may add burden to cognitively impaired individuals such that they need more care than their cognitive status alone would suggest. In addition, physical and sensory limitation may lead directly to the need for assistance with more basic daily activities independent of cognitive impairment.^{7,16,17}

A study was conducted to assess caregiving in persons with CIND and dementia. The amount of time spent providing care was examined because it is an important indicator of burden. Although similar studies have typically focused on active help (e.g., assistance with activities of daily living (ADLs) or instrumental activities of daily living (IADLs)), general supervision was also included because this is an important role when caring for someone with cognitive impairment. Based on more-recent research suggesting that caregivers may also derive emotional and physical benefits from providing care, whether caregivers perceived any rewards from their caregiving experience was also examined.^{18,19}

METHODS

Data from the Aging, Demographics, and Memory Study (ADAMS) were used to study outcomes of CIND and dementia caregivers. ADAMS is a nationally representative community-based study of dementia in the United States that includes dementia and CIND caregivers.²⁰ The ADAMS sample was drawn from the larger Health and Retirement Study (HRS), an ongoing nationally representative cohort study of individuals born before 1954 that was designed to investigate the health, social, and economic implications of aging in the U.S. population.^{20,21} (The HRS is a cooperative agreement between the National Institute on Aging and the University of Michigan. The HRS began in 1992 and has interviewed more than 30,000 individuals.)

To accomplish the ADAMS goal of obtaining clinical assessments on 850 individuals across the full range of cognitive ability, a stratified random sample of 1,770 individuals was selected for participation in ADAMS based on a nationally representative sample of approximately 7,000

HRS respondents aged 70 and older who completed the 2000 or 2002 wave of the HRS. To achieve a sufficient number of ADAMS respondents across the full range of cognitive ability, the sample was stratified based on cognitive test scores in the HRS.^{20,22} Respondents were classified into one of five cognitive strata ranging from low to high cognition. For those who completed their own HRS interview, the HRS cognitive performance test scores were calculated using an abbreviated version of the modified Telephone Interview for Cognitive Status.^{23–26} Respondents for whom a proxy completed the HRS interview did not complete the cognitive performance tests; therefore, proxy respondent cognitive scores were classified using Informant Questionnaire on Cognitive Decline in the Elderly scores.^{26,27} The three highest cognitive strata were further stratified according to age (70–79 vs ≥ 80) and sex to ensure adequate numbers in each subgroup. Additional details of the ADAMS sample design are described elsewhere.^{20,22} Eight hundred fifty-six individuals, 56% of the nondeceased target sample, participated in all phases of the ADAMS dementia assessment.

Assessments

A nurse and a neuropsychology technician assessed all participants at their residence for cognitive impairment. Full details of the assessment and diagnostic procedures are described elsewhere.^{1,20} In brief, information on chronological history of cognitive symptoms, medical history, current medications, current neuropsychiatric symptoms, measures of severity of cognitive and functional impairment, and family history of memory problems was collected from a knowledgeable informant. The participant completed a battery of neuropsychological measures (including measures of verbal and visual immediate and delayed memory, language, attention, orientation, executive function, praxis, and reading ability), a depression measure, a standardized neurological examination, a blood pressure measurement, collection of buccal deoxyribonucleic acid samples for apolipoprotein E (APOE) genotyping, and a 7-minute videotaped segment covering portions of the cognitive status and neurological examinations. Medical record releases were also sought to obtain relevant neuroimaging and laboratory results from participants' physicians. All information collected during the in-home assessment was reviewed, and preliminary research diagnoses regarding cognitive status were assigned in case conferences at Duke University that the study investigators with expertise in dementia and the nurse and neuropsychology technician who conducted the assessment attended.

A consensus expert panel of neuropsychologists, neurologists, geropsychiatrists, and internists reviewed all information collected during the in-home assessment and assigned final diagnoses. The consensus panel reviewed each case and assigned a diagnosis in two stages, first without and then with medical records. Diagnoses were assigned within three general categories: normal cognitive function, CIND, and dementia. The consensus panel used clinical judgment to assign the final diagnosis, but the following criteria anchored the diagnoses. Dementia diagnosis was based on guidelines from the *Diagnostic and Statistical Manual of Mental Disorders (DSM), Third Edition,*

*Revised*²⁸ and the DSM-IV²⁹; diagnoses of Alzheimer's disease (AD) and other types of dementia were based on currently accepted criteria.^{30–33} The definition of CIND and its subtypes was based on the accumulated clinical experience of a group of researchers common to ADAMS and three other epidemiological studies of dementia.^{1,10,20,34–36} CIND was defined before ADAMS on the basis of analyses of neuropsychological data and assessment of daily function of participants with this diagnosis in other studies.^{35,36} Criteria for CIND are cognitively not normal but not demented, self- or informant report of problems with cognition of daily activities, or performance on neuropsychological measures that was below expectation and at least 1.5 standard deviations below published norms on any test.

Informants present at the assessment were asked to complete a questionnaire about their caregiving role. For 549 participants with CIND or dementia, 464 individuals completed the caregiving questionnaire, for a response rate of 85%. In the present study, caregiving data only from family members who indicated that they were the primary caregiver for those with CIND or dementia were examined. Primary caregivers endorsed a question asking whether they were the person most responsible for providing care to the care recipient, resulting in a sample of 169 caregivers (71% caregivers for those with dementia, 29% caregivers for individuals with CIND). The caregiving questionnaire included questions about difficulty with ADLs and IADLs and self-reported measures of depressive symptoms, physical strain, emotional strain, positive aspects of the caregiving experience, time spent providing active help (assistance with ADLs and IADLs), time spent providing supervision, and demographic characteristics.

The institutional review boards at Duke University Medical Center and the University of Michigan approved all study procedures, and informed consent was obtained from study participants or their surrogates.

Measures

Time Spent Providing Active Help and Supervision

Caregivers indicated the number of days during the preceding month that they had provided active help to their family member because of health or memory problem, as well as the number of hours per day that they usually helped. A similar set of questions was asked to ascertain the extent to which caregivers supervised family members to ensure safety, provide reassurance, or to make sure that nothing went wrong. Data are reported as number of hours per month.

ADLs and IADLs

Caregivers reported whether their family member had difficulty with six ADLs (getting across a room, dressing, bathing, eating, getting out of bed, and using the toilet) and five IADLs (preparing meals, grocery shopping, making telephone calls, taking medications, and managing money). Scale scores were calculated for ADLs ($\alpha = 0.83$) and IADLs ($\alpha = 0.76$) by summing yes responses to the items.

Depressive Symptoms

Respondents reported how they had felt during the past week based on five items (depressed, happy, lonely, enjoyed life, and sad) from the Center for Epidemiologic Studies

Depression Scale (CES-D). The responses were summed to create a scale score ($\alpha = 0.84$) ranging from 0 to 5; higher values indicate greater numbers of depressive symptoms.

Physical and Emotional Strain

Caregivers rated the extent to which they experienced physical strain (3 items, $\alpha = 0.86$) and emotional strain (3 items, $\alpha = 0.91$) as part of their caregiver role. These questions were taken from the Caregiver Health Effects Study.³⁷ Scale scores were calculated separately for physical and emotional strain by taking the mean of the three items; higher values indicate higher levels of strain.

Caregiving Rewards or Benefits

Caregivers answered five items developed for use in the ADAMS to indicate a variety of caregiving rewards, including feeling useful, feeling closer to the care recipient, feeling good about oneself, feeling able to handle most problems, and feeling that the care that they were providing prevented the care recipient from getting worse.^{38,39} Scale scores were calculated by summing the number of yes responses to the caregiving rewards/benefits items ($\alpha = 0.66$).

Caregiver Health

Caregiver health was assessed in terms of self-rated overall health using a 5-point Likert-type rating scale ranging from poor to excellent.

Behavior Problems

Behavioral problems were measured using the Neuropsychiatric Inventory (NPI), a widely used measure administered to informants to obtain information about the presence, frequency (4-point scale), and severity (3-point scale) of symptoms in 10 neuropsychiatric domains. The total number of domains with clinically significant problems defined as frequency times severity greater than 4 was calculated.^{40–42}

Cognitive Status

Cognitive assessment measures reported here are the Clinical Dementia Rating Scale (CDR),⁴³ the Dementia Severity Rating Scale (DSRS),⁴⁴ and the Mini-Mental State Examination (MMSE).⁴⁵ An informant completed the DSRS which assesses the presence and severity of impairment in 12 cognitive and functional domains. Scores range from 0 to 54, with higher scores reflecting greater impairment. The CDR scale assesses the severity of dementia; scores range from 0 to 5, with higher scores indicating greater impairment. The CDR score is based on information collected from both the informant and the respondent. In ADAMS, the final CDR score was assigned at the initial case conferences at Duke University (described above) after all assessment information was reviewed. The MMSE is a 22-item cognitive performance test; scores range from 0 to 30, with higher scores indicating better functioning.

Demographic Characteristics

Caregiver demographic characteristics (age, sex, race, education, and marital status) were obtained according to self-report as part of the caregiver survey. Care recipient demographic characteristics were obtained during the ADAMS assessment.

Statistical Analysis

Demographic characteristics, time spent caregiving, and outcomes of groups of dementia and CIND caregivers were compared using chi-square tests, *t*-tests, and analysis of variance. Secondary analyses were conducted to examine selection bias in individuals with and without caregivers using *t*-tests. Which ADLs and IADLs may be related to depressive symptoms and rewards in caregivers was examined using linear regression. The criterion for statistical significance for all analyses was $P < .05$. All analyses were conducted using SAS, version 9.2 (SAS Institute, Inc., Cary, NC).

RESULTS

Tables 1 and 2 show caregiver and care recipient characteristics, respectively. Caregivers were most often female family members of the care recipient and most likely to be the care recipient's child. Caregiver demographic characteristics were similar between CIND and dementia caregivers. Care recipients with dementia had higher levels of dementia severity based on the CDR ($t(167) = -7.42$, $P < .001$) and had significantly higher levels of cognitive impairment based on their MMSE scores ($t(157) = 10.16$, $P < .001$) than CIND care recipients. Care recipients with dementia had difficulty with more daily functions (ADLs, $t(167) = -3.09$, $P = .002$; IADLs, $t(167) = -6.72$, $P < .001$) than those with CIND, and this result held after adjusting for a previous history of heart disease, diabetes mellitus, stroke, and cancer ($F(5,159) = 3.25$, $P = .008$). Based on other information collected at the assessment, difficulty with ADLs for those with CIND was due to

physical or sensory problems, not cognitive problems. Some of the difficulties with IADLs were also attributed to physical problems, although care recipients with dementia were more likely to need help with all of the other activities, particularly with all of the IADLs. A high proportion of individuals with dementia had difficulty with these activities.

Table 3 shows caregiving outcomes. Approximately the same proportion of dementia and CIND caregivers performed active help for care recipients, but dementia caregivers reported spending more hours per month providing active help than CIND caregivers ($t(139) = -3.01$, $P = .003$). Dementia caregivers spent approximately 9 hours per day providing care, compared with 4 hours per day for CIND caregivers ($P = .001$). Dementia caregivers were more likely to report having depressive symptoms ($\chi^2(1) = 4.55$, $P = .03$) than CIND caregivers, although there were no statistically significant differences with regard to physical strain or positive caregiving perceptions. Table 4 presents results from multiple regression analyses performed to understand the extent to which care recipients' difficulty with ADLs and IADLs, cognitive status, and behavioral problems were related to caregivers' time spent caregiving, emotional strain, and depressive symptoms. For those with CIND, behavioral problems and IADL difficulties predicted emotional strain in their caregivers ($P = .01$ for both). For those with dementia, behavioral problems predicted caregiver emotional strain ($P < .001$) and depressive symptoms ($P = .01$).

Which ADLs and IADLs may be related to depressive symptoms and rewards in caregivers was also examined. Using linear regression models incorporating ADLs and IADLs as predictors of depressive symptoms and rewards, it was found that providing care for someone who needs help with toileting was associated with lower feelings of rewards ($\beta = -0.200$, $P = .02$) and higher levels of depressive symptoms ($\beta = 0.244$, $P = .02$). Caring for someone who needs help managing money was associated with higher levels of rewards ($\beta = 0.231$, $P = .02$), and caring for someone who needs help with taking medications was related to lower levels of depressive symptoms ($\beta = -0.243$, $P = .02$).

Whether there may be a selection bias was also examined by comparing those who indicated that they were caregivers with individuals who did not report that they were a caregiver or for whom no one completed the informant questionnaire using data from the HRS before the ADAMS assessment. Results indicated that, for individuals with dementia, there was no significant difference in ADLs or IADLs based on whether there was a caregiver. Individuals with CIND with a caregiver had more difficulty with IADLs than those who did not have a caregiver or for whom no one completed the informant questionnaire ($t(239) = -2.52$, $P = .01$).

Table 1. Family Caregiver Characteristics

Characteristic	Combined (n = 169)	Dementia (n = 120)	Cognitive Impairment, Not Dementia (n = 49)	P- Value
Age, mean \pm standard deviation	60.4 \pm 14.1	60.1 \pm 14.4	61.3 \pm 13.4	.62
Female, %	73.7	70.6	81.3	.16
Race, %				.65
Non-Hispanic white	67.1	65.6	70.8	
Non-Hispanic black	21.6	21.9	20.8	
Hispanic	10.2	11.8	6.3	
Education, years, %				.94
< 12	17.3	16.7	18.8	
12	36.9	37.5	35.4	
> 12	45.8	45.8	45.8	
Married, %	70.2	70.0	70.8	.92
Relationship to care recipient, %				.45
Spouse	26.0	23.3	32.7	
Child	53.3	55.0	49.0	
Other family member	20.7	21.7	18.4	
Live with care recipient, %	62.5	60.8	66.7	.48

DISCUSSION

The present study was conducted to compare caregiver characteristics and outcomes of family caregivers of individuals with CIND and dementia. The ADAMS data used for this study are unique because they permit the examination of caregiving for individuals with dementia, as well as for individuals without dementia who are cognitively

Table 2. Care Recipient Characteristics

Characteristic	Combined (n = 169)	Dementia (n = 120)	Cognitive Impairment, Not Dementia (n = 49)	P-Value
Age, mean \pm SD	83.7 \pm 4.5	84.5 \pm 3.7	83.0 \pm 6.0	.13
Female, %	73.1	71.4	74.7	.75
Race, %				.67
Non-Hispanic white	82.0	78.1	85.8	
Non-Hispanic black	11.7	14.1	9.4	
Hispanic	6.3	7.9	4.8	
Education, years, %				.32
< 12	49.1	54.4	43.9	
12	30.5	32.1	28.9	
> 12	20.5	13.5	27.2	
Married, %	29.3	29.9	28.6	.91
Dementia Severity Rating Scale score, mean \pm SD	16.0 \pm 8.5	22.9 \pm 7.9	9.3 \pm 4.8	< .001
Clinical Dementia Rating Scale score, mean \pm SD	1.2 \pm 0.8	1.8 \pm 0.8	0.5 \pm 0.2	< .001
Mini-Mental State Examination score, mean \pm SD	21.0 \pm 4.6	15.4 \pm 3.2	25.5 \pm 3.0	< .001
Number of functional limitations, mean \pm SD				
Activities of daily living	2.9 \pm 1.4	3.3 \pm 1.2	2.5 \pm 1.8	.01
Instrumental activities of daily living	3.1 \pm 1.1	3.9 \pm 0.9	2.4 \pm 1.3	< .001
≥ 1 clinically significant neuropsychiatric symptoms	34.0	30.3	37.5	.46

SD = standard deviation. Values are weighted using the ADAMS respondent-level sample weights.

impaired. A minority of the participants with CIND had someone meeting the definition of caregiver, but a fairly high proportion of these individuals had difficulty with some basic ADLs. Even though these difficulties were due to noncognitive problems, they contributed to the surprising finding that primary caregivers of individuals with CIND also spend considerable amounts of time caring for their family members. CIND caregivers experience many of the burdens of caregiving known to be challenges for dementia caregivers. Care recipients' behavioral and neuropsychiatric problems and difficulty with IADLs seems to explain why CIND and dementia caregivers experience emotional

strain. The finding that dementia caregivers were more likely to report depressive symptoms seems related to care recipients' behavioral and neuropsychiatric problems. People with CIND may seem more like their typical selves, whereas those with dementia may seem like different people. These findings are generally consistent with prior research on strains associated with caregiving.^{46,47}

In addition to examining caregiving burden, caregiving rewards were also assessed. Almost all caregivers for both groups reported some rewards from their caregiving experience, viewing themselves as more efficacious in a number of ways, such as feeling closer to the care recipient and

Table 3. Descriptive Statistics: Caregiving Types and Outcomes

Caregiving Type or Outcome	Combined (n = 169)	Dementia (n = 120)	Cognitive Impairment, Not Dementia (n = 49)	P-Value
Active help, %	90.5	89.2	93.9	.34
Active help, number of hours, mean \pm SD	236.5 \pm 267.2	278.7 \pm 285.3	133.7 \pm 181.9	.001
Supervision, %	82.3	85.8	73.5	.06
Supervision, number of hours, mean \pm SD	291.3 \pm 279.1	309.9 \pm 283.4	231.5 \pm 260.5	.20
Physical strain, % reporting	65.6	69.1	57.9	.23
Physical strain, mean \pm SD*	1.7 \pm 0.6	1.7 \pm 0.6	1.6 \pm 0.6	.32
Emotional strain, % reporting	70.8	73.6	64.1	.27
Emotional strain, mean \pm SD*	1.8 \pm 0.7	1.9 \pm 0.7	1.6 \pm 0.6	.06
Depressive symptoms, % reporting	39.1	44.2	26.5	.03
Depressive symptoms, mean \pm SD*	1.0 \pm 1.5	1.1 \pm 1.6	0.8 \pm 1.5	.21
Caregiving rewards, % reporting	98.8	98.3	100.0	.87
Caregiving rewards, mean \pm SD*	4.1 \pm 1.2	4.1 \pm 1.2	4.2 \pm 1.1	.67
Caregiver health, mean \pm SD*	3.2 \pm 1.1	3.3 \pm 1.1	3.1 \pm 1.2	.42

* See Methods for description of scale used.

SD = standard deviation.

Table 4. Multiple Linear Regression Analysis of Care Recipient’s Difficulty with Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs), Cognitive Status, and Behavioral Problems

Outcome	Predictor	Dementia			Cognitive Impairment, Not Dementia		
		Estimate	SE	P-value	Estimate	SE	P-value
Number of hours of active help	ADLs	−0.2	14.8	.98	1.8	16.6	.91
	IADLs	13.3	23.0	.56	38.5	21.9	.09
	CDR	59.0	27.1	.03	36.5	151.7	.81
	NPI	32.2	20.3	.11	8.2	35.3	.82
Emotional strain	ADLs	0.06	0.04	.09	0.0	0.05	.97
	IADLs	0.09	0.05	.09	0.2	0.06	.01
	CDR	−0.08	0.06	.17	−0.3	0.42	.43
	NPI	0.20	0.05	<.001	0.3	0.1	.01
Depressive symptoms	ADLs	0.06	0.07	.36	−0.09	0.13	.49
	IADLs	0.06	0.11	.56	0.12	0.17	.48
	CDR	−0.04	0.14	.75	−2.17	1.22	.08
	NPI	0.31	0.10	.01	0.51	0.28	.08

Scores are based on the total number of clinically significant behavioral problems or neuropsychiatric symptoms.

CDR = Clinical Dementia Rating; NPI = Neuropsychiatric Inventory; SE = standard error.

feeling in control over the recipient’s well-being. This extends prior research that has also shown that caregivers may experience benefits rather than just strains.^{38,39,48}

Implications

Caregivers for individuals with CIND who require assistance may be struggling with many challenges that are well known as problems for dementia caregivers, so appropriate resources should be recommended and made available to CIND caregivers. CIND caregivers provide a great deal of informal assistance to older family members and should be afforded services and supports available to dementia caregivers (if they are not already). Medicare and other paid help services may not be available without a dementia diagnosis. A more-comprehensive service system would be of benefit to people with dementia and CIND and their caregivers. For those with CIND that convert to dementia, there is a period of caregiving expense and strain before the diagnosis of dementia. Some individuals with CIND may have marked medical and physical problems that demand medical attention, and these other health conditions may overshadow the cognitive problems of individuals with CIND, but this subset of individuals with CIND may require additional assistance to manage their health conditions and to perform some daily activities due to physical and mild cognitive problems.

The real societal cost of cognitive impairment and dementia may be greatly underestimated if estimates of caregiver burden are limited to care recipients who have reached the diagnostic threshold for dementia. Supporting CIND caregivers may reduce burdens of caregiving, sustain their

ability to provide care, and prevent or postpone institutional placement of the impaired family member.

This study also has some limitations worth noting. The cross-sectional design warrants caution when interpreting cause-and-effect relationships. Another limitation is the small sample size of CIND caregivers. Not all participants with CIND needed assistance from a caregiver, so those with CIND in the present study may exhibit more cognitive or physical limitations. Inferences from these results should be directed not to all individuals with CIND but to those with CIND who require caregiving. Last, the time estimates that caregivers provided may reflect the caregiver’s feelings of distress and not the precise amount of time spent performing the task.

In sum, this study highlights important concerns that should be considered when treating people with CIND and referring family caregivers for resources. This study reveals high levels of caregiver burden associated with CIND, which is more common than dementia in the United States. It is therefore possible that the caregiver burden associated with cognitive impairment is far higher than previously assumed, and caregiver supports should not be limited to caregivers of those with a dementia diagnosis.

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