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Unmet Needs of Community-Residing Persons with Dementia and Their Informal Caregivers: Findings from the MIND at Home Study

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Abstract

OBJECTIVES—To determine the prevalence and correlates of unmet needs in a sample of community-residing persons with dementia (PWD) and their informal caregivers.

DESIGN—Analysis of cross-sectional, baseline participant characteristics prior to randomization in a care coordination intervention trial.

SETTING—Baltimore, MD.

PARTICIPANTS—Community-residing PWD (n=254) and their informal caregivers (n=246).

MEASUREMENTS—In-home assessments of dementia-related needs based on the Johns Hopkins Dementia Care Needs Assessment. Bivariate and multivariate regression analyses were

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Dr. Black's role included substantial contributions to the conception and design of this research, analysis and interpretation of the data, drafting and revising this article for important intellectual content, and final approval of the version for publication.

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conducted to identify demographic, socioeconomic, clinical, functional and quality of life correlates of unmet needs.

RESULTS—The mean number of unmet needs in PWD was 7.7 (SD=4.8) and 4.6 (SD=2.3) in caregivers, with almost all PWD (99%) and caregivers (97%) having one or more unmet needs. Unmet needs in PWD were significantly greater among those with higher cognitive function. Ninety percent of PWD had unmet safety needs, over half had unmet needs for meaningful activities, and almost one-third had not received a prior evaluation or diagnosis. Higher unmet needs in PWD were associated significantly with non-white race, lower incomes, less impairment in activities of daily living and more symptoms of depression. For caregivers, more than 85% had unmet needs for resource referrals and caregiver education. Higher unmet caregiver needs were associated significantly with non-white race, less education, and more symptoms of depression.

CONCLUSION—Many community-residing PWD and their caregivers have unmet dementia-related needs for care, services and support. Providers should be aware that unmet needs may be higher among minority and low-income community residents, caregivers with lower education, and individuals with early-stage dementia. Identifying and treating symptoms of depression in PWD and caregivers may enable them to address their other unmet needs.

Keywords

dementia; community-residing; informal caregivers; unmet needs

INTRODUCTION

Seventy percent of the estimated 5.4 million people in the United States (US) who have Alzheimer disease and other types of dementia are cared for in the community by family members and friends.¹ While most of these individuals have mild to moderate dementia, some with severe dementia are cared for at home rather than in nursing homes where most people with advanced dementia reside prior to death.²

Dementia-related needs of community-residing individuals are multidimensional and based on the types and severity of their cognitive impairments, functional dependencies, neuropsychiatric symptoms (e.g., behavioral problems, depression), and medical comorbidities.³ In addition to needing a dementia evaluation and advance care planning early in the illness, persons with dementia (PWD) need increasing assistance with instrumental and basic activities of daily living (ADLs), meaningful activities suited to their interests and capabilities, treatment and management of dementia-related symptoms, and care for co-existing physical illnesses. Most importantly, they need knowledgeable caregivers to ensure a safe and supportive environment where the individual's dignity is protected and quality of life is maximized.

Caregiving responsibilities for community-dwelling PWD are often assumed gradually as the PWD's needs increase and change with disease progression. In addition, many US caregivers face a daunting task of navigating a loose network of long-term care supports that increases the complexity of their role. The burdens and stress of these caregivers are often higher than for caregivers of individuals with other illnesses,^{4,5} and depression is common.⁶

Caregiver tasks include assisting with ADLs, managing the individual's safety and behavioral symptoms, identifying and coordinating supportive services, facilitating health care visits, advocating for the PWD, and making proxy financial and health care decisions. All this work occurs within a context of loss—losses for the PWD and losses for the caregiver.

Unmet dementia-related needs for care, services and support are known to increase the risk of undesirable health outcomes. For example, a study of over 5,800 PWD and their caregivers found that greater unmet need for ADL assistance was predictive of nursing home placement and death.⁷ Caregiver stress is also predictive of nursing home admission for PWD,⁸ and unmet needs are associated with lower quality of life (QOL).⁹

Prior efforts to define¹⁰ and describe unmet needs in PWD and their caregivers,^{11,12,13} have included the use of multi-item needs assessment instruments.^{13,14,15} No one measure is widely used in community settings, and assessment tools differ in what need domains are considered, the extent to which caregiver needs are assessed, and the methods used to identify unmet needs.

This study examined unmet needs in a community-residing sample of PWD and their caregivers using a comprehensive, multidimensional needs assessment tool.⁹ The study's purpose was to address two questions: (1) what is the prevalence of unmet dementia-related needs in community-residing individuals, and (2) what are the primary correlates of their unmet needs? Using Andersen's Behavioral Model of Health Services Use¹⁶ as a framework, we examined the relationships between unmet needs and factors hypothesized to predispose individuals to use services (e.g., demographics), that enable or impede service use (e.g., social and economic characteristics), and that reflect need for care (e.g., clinical and functional characteristics). Identifying primary correlates of unmet needs may help dementia care and service providers develop strategies for reducing unmet needs in this population.

METHODS

This study examines cross-sectional, baseline data on PWD and their caregivers prior to randomization into a single-blind controlled trial evaluating a dementia care coordination intervention (i.e., the MIND at Home study). The Johns Hopkins Medicine Institutional Review Board approved this research. Oral consent was obtained for telephone screening interviews, and written consent was obtained for all participants at the in-home assessment. For those who lacked consent capacity, proxy consent was obtained from their legally authorized representatives as defined by Maryland's Health Care Decisions Act, and assent was obtained from the cognitively impaired individuals.

Study Procedures and Measures

Participants lived in a geographically defined area of 28 postal codes in Baltimore, Maryland. Inclusion criteria for the primary participants were that they be community-residing, English-speaking, age 70 or older with a cognitive disorder (i.e., mild cognitive impairment (MCI) or dementia), and have a study partner. Recruitment methods included

obtaining referrals from community service organizations, sending letters to clients of community aging services, and promotions at local community events and through news media.

A two-staged assessment process was used to identify eligible individuals from among those referred. First, telephone screening identified persons with probable cognitive disorder using the 11-item Telephone Interview for Cognitive Status (TICS)¹⁷ (score range 0–41) and the 16-item Informant Questionnaire for Cognitive Disorders in the Elderly (IQCODE)¹⁸ (score range 16–80). A positive screen was defined as a TICS score of <31 and an IQCODE score of >52.^{17,19} Second, clinicians (i.e., geriatric psychiatrist, clinical nurse specialist) conducted in-home assessments of those who screened positive to identify individuals with a cognitive disorder. Assessments included reviews of medical and mental health histories, medications, physical health problems, mental status and neurological examinations, measures of cognition and function, and use of health and social services. Clinicians reviewed the assessment data to determine whether individuals met DSM-IV-TR²⁰ criteria for dementia or cognitive disorder NOS, referred to here as MCI. Individuals who met DSM-IV-TR criteria then received a baseline study visit to administer quantitative assessments of ADLs, neuropsychiatric symptoms, depression and QOL. Table 1 provides a description of the study's quantitative measures. Dementia severity was based on Mini-Mental State Examination (MMSE)²³ score ranges of >20 for mild, 11–20 for moderate, and <11 for severe.³² Primary participants' demographic and socioeconomic data included age, gender, race, education, living arrangement, and income.

Of the 1,275 individuals referred to the study, 664 were eligible for and agreed to the telephone screen, and 371 screened positive. Of these, 360 completed an in-home clinician's assessment, and 303 were eligible for participation in the MIND at Home study (265 [85%] with dementia, 38 [13%] with MCI). These analyses include only those with dementia who had an informal caregiver (n=254).

An informal caregiver was defined as a person in contact with the primary participant (1) at least once a week, and (2) is relied on by the participant for assistance. During the baseline study visit, quantitative measures were used to determine the caregiver's health and wellbeing. A single item was used to measure caregiver self-rated health as excellent, very good, good, fair, or poor.³³ Other measures, described in Table 1, assessed caregiver burden, symptoms of depression, QOL and time spent per day caring for the primary participant. Caregivers' demographic and socioeconomic data included age, gender, race, education, employment status, and relationship to the primary participant.

The Johns Hopkins Dementia Care Needs Assessment (JHDCNA) was used to identify participants' and caregivers' dementia-related needs.^{34,35} It was developed by a multidisciplinary group of clinical dementia care experts and is based on best practices in dementia care,³ suggesting content validity. While its psychometric properties have not been formally tested, a prior study demonstrates concurrent validity with QOL measures.⁹ The JHDCNA includes 15 care recipient need domains (77 items) and 4 caregiver need domains (12 items), with standardized descriptions and definitions for each item [See Figure 1]. Clinicians completed the JHDCNA following each in-home assessment and based their

judgments on interviews with the PWD and caregiver, a visual assessment of the PWD's home, and considered the individuals' perspectives on their needs. Each item on the JHDCNA is assessed as being needed or not and, if needed, whether the need is met or unmet. A "met" need is one that is being addressed and potential benefits of available interventions have been achieved to the extent possible for the individual. A need is considered "unmet" if (1) it has not been addressed and potentially beneficial interventions are available, or (2) it has been or is being addressed but potential benefits of available interventions have not yet been achieved.

Data Analyses

Prevalence of unmet needs was based on the percent of participants with one or more unmet need items in each domain. Descriptive statistics (i.e., frequencies, means, standard deviations) were calculated for all variables. To identify correlates of unmet needs, participant characteristics were categorized as predisposing (e.g., demographics), enabling (e.g., social and economic characteristics), and need for care factors (e.g., clinical and functional characteristics). Bivariate analyses (i.e., *t* tests, Pearson correlations, ANOVA) were used to determine relationships between total percent of unmet needs, calculated as (# unmet need items/# need items assessed) × 100 (i.e., the primary outcome measure) and participants' other characteristics. Multiple linear regression analyses were conducted to identify which characteristics were the primary correlates of unmet needs in PWD and caregivers. For each regression analysis, the model-building process began by including independent variables with *P* values <.10 based on bivariate analyses, and the forward stepwise method was used to identify the most parsimonious model that would explain the greatest amount of variance associated with unmet needs. SPSS 19.0 (IBM Corporation, Armonk, NY) was used for all analyses; *P* values of <.05 were considered statistically significant.

RESULTS

Persons with Dementia (PWD)

The mean age of PWD who had a caregiver was 83.6 (±5.9), and the majority were female (65%), white (68%) and lived with others (81%). Their mean MMSE score was 17.7 (±7.6), with 44% having mild, 38% moderate and 18% severe dementia. Other sample characteristics are shown in Table 2.

Based on the JHDCNA, nearly all (99%) of PWD had one or more unmet needs, with an average of 7.7 (±4.8) unmet needs. Forty-two percent of PWD had 8 or more unmet needs. Figure 1 shows that unmet needs were most common for PWD in the domain of safety (90.6%), such as unmet needs for fall risk management (74.8%), home safety evaluation (44.5%) and wander risk management (33.9%). Unmet needs were also common in the domains of general health/medical care (62.6%), meaningful activities (53.1%), legal issues/advance care planning (48.0%), and evaluation/diagnosis of dementia, with almost one-third (31.5%) having no prior dementia assessment.

Bivariate relationships between total percent of unmet needs and PWD's predisposing, enabling and need factors are shown in Table 2. Individuals with significantly higher unmet needs were non-whites (95% were African Americans), had less education, lower incomes, and lived alone. Other significant correlates of unmet needs included total medications, limitations in IADLs, and scores on the MMSE, CSDD, and QOL-AD as rated by the PWD and caregiver. Those with mild dementia had significantly higher total unmet needs than those with severe dementia; unmet needs of those in the moderate stage did not differ significantly from those with either mild or severe dementia.

Table 3 shows that four variables remained statistically significant in the multiple regression analysis, including CSDD scores, race, PGDRS scores, and income. These accounted for 17.7% of variance in total percent of unmet needs. When the same series of bivariate and multivariate analyses were conducted using data that also included the 10 PWD *without* a caregiver, the regression analysis ($F=10.303$, $df=2$, $p<.001$) showed that three factors—CSDD scores ($p<.001$), race ($p=.001$) and living alone ($p=.019$)—were associated with unmet needs (adjusted $R^2=.164$).

Caregivers of PWD

The study included 246 informal caregivers, 8 of whom served as caregiver for two PWD. The majority of caregivers were female (75%), white (69%), non-spouses (59%) and not employed (51%); their mean age was 66.1 (± 13.3). Caregivers spent an average of 6.7 (± 6.2) hours per day providing care to the PWD, and 22% rated their health as fair or poor. Other caregiver characteristics are shown in Table 4.

Based on the JHDCNA, 97% of caregivers had one or more unmet needs, with an average of 4.6 (± 2.3) unmet needs. A third (33%) had more than 5 unmet needs. Caregiver's most common unmet needs (see Figure 1) were for resource referrals (88.6%), followed by caregiver dementia education (85.4%), mental health care (45.1%), and general health/medical care (22.0%). On average, 24.1% of all need items assessed on the JHDCNA for caregivers were unmet.

Bivariate relationships between percent of unmet need and caregivers' predisposing, enabling and need factors are shown in Table 4. Caregivers with significantly higher unmet needs were non-whites (95% where African Americans), had less education, fair or poor self-rated health, more symptoms of depression, and lower QOL based on SF-12 scores. Caregiver burden approached statistical significance. In multiple regression analysis (see Table 3), symptoms of depression, race, and years of education remained statistically significant, accounting for 12.7% of variance in caregivers' total percent of unmet needs.

DISCUSSION

This study demonstrates that dementia-related needs for care, services and support of community-residing PWD and their caregivers are often unmet. Unmet needs in PWD were most common in domains of personal and home safety, general health/medical care, meaningful activities, legal issues/advance care planning, and evaluation/diagnosis of dementia. Caregivers' unmet needs were most common in domains of resource referrals,

caregiver education, and mental health care. The primary correlates of unmet needs in PWD and their caregivers included predisposing, enabling and need factors. Being non-white or having more symptoms of depression were associated significantly with more unmet needs for both caregivers and PWD. In addition, unmet needs were significantly higher for PWD with lower incomes or fewer ADL impairments and for caregivers with less education.

Ninety percent of PWD had unmet safety needs, particularly for fall risk and wander risk management and home safety evaluations. This domain also includes needs related to driving safety and safe management of guns and tools at home. Lack of attention to safety can lead to injury or death of PWD or others and to costly and distressing emergency department visits or hospitalizations. Schulz and Martire⁴ identified safety as one of five key areas of risk for PWD and their caregivers and suggested interventions that included home assessment and alterations, use of patient monitoring devices, and eliminating access to items that pose a danger.

Over 60% of PWD had unmet needs for medical care, including the need to see their primary care provider, a medical sub-specialist, or a dental, vision or hearing specialist. PWD are more likely than those without dementia to have other chronic medical conditions and to be hospitalized for those conditions.¹ This high rate of unmet medical need raises the possibility that earlier recognition could prevent hospitalizations for co-morbid conditions that could be recognized sooner and addressed in primary care settings.³⁶ Since worse general medical health is associated with poorer outcomes in PWD,³⁷ earlier recognition might improve QOL and lower the costs of care.

Over half of the PWD had unmet needs for meaningful activities, which includes needs for adult day care, attending senior centers and in-home activities. Prior studies have also found high unmet needs for daytime activities and company for PWD.^{12,38} Gitlin and colleagues demonstrated that in-home activities tailored to the interests and capabilities of PWD can significantly increase their engagement, reduce behavioral symptoms, and reduce caregiver burden.³⁹

Nearly half of PWD (48%) had unmet needs in the area of legal issues/advance care planning. This domain includes designating someone to have general and health care power of attorney (POA) for the PWD, and documenting wishes for end of life care and distribution of personal property after death. These issues must be addressed early on when individuals have decisional capacity. This domain may also have relevance for caregivers. For example, several PWD in this study were designated years earlier to have POA for a spouse who is now the caregiver, and no changes were made after dementia onset, leaving caregivers who are vulnerable to their own health emergencies without a capable proxy decision maker.

Almost one-third of PWD had not received a prior dementia evaluation or diagnosis. The prevalence of undiagnosed dementia in primary care settings is unknown but thought to be substantial.⁴⁰ Bradford and colleagues identified a range of provider, patient, caregiver and health system factors that hinder early detection of dementia, many of which are amenable

to interventions.⁴⁰ Early diagnosis provides opportunities to initiate treatments for dementia symptoms and for patients and families to plan for future care.

Over 85% of caregivers had unmet needs for both referrals to community resources (e.g., the Alzheimer's Association) and caregiver education on topics such as how dementia affects individuals and their loved ones, availability of community-based services, and caregiver skills. Other studies have attributed high unmet needs for information or service use to caregivers' lack of awareness, lack of perceived need, or belief that services would not be helpful.^{38,41} While caregivers' unmet needs for services have been associated with greater stress⁴² and higher burden,³⁸ caregiver burden fell just short of statistical significance in this study. However, 45% of caregivers had unmet needs in the mental health domain, most of whom needed emotional support or respite care.

Symptoms of depression were correlated with more unmet needs in both caregivers and care recipients. Depression is a frequent complication of dementia^{6,43} and is associated with caregiver depression and burden.⁴⁴ Bejjani and colleagues⁴⁵ also found that depressed caregivers had higher unmet needs than those without depression. Our cross-sectional data cannot determine whether there is a causal relationship between depressive symptoms and unmet needs. However, it is plausible that identifying and treating depression in PWD and their caregivers may enable them to better address their other unmet needs.

The finding that PWD with milder cognitive and functional impairment had more unmet needs may seem counterintuitive. We speculate that these individuals are more likely to live alone and less likely to be recognized or assessed for their memory disorder, or for other potential unmet needs.⁴⁶ In fact, when data on PWD without a caregiver were included in our analyses, living alone was significantly correlated with unmet needs. Few studies have examined relationships between dementia severity and unmet needs, and their findings are inconsistent.^{11,38} However, studies using different assessment methods have found that PWD living alone have significantly higher unmet needs.^{11,47} Further analyses are needed to determine whether specific domains of unmet need vary by dementia severity.

Demographic (predisposing) and socioeconomic (enabling) factors that are likely unrelated to dementia status (e.g., type or severity of dementia) were independently associated with unmet needs. It is not surprising that unmet needs were related to lower income in PWD and lower education in caregivers, since income and education can be enabling factors for obtaining information on and access to dementia-related services. In addition, non-white participants (mostly African Americans) had higher caregiver and care recipient unmet needs. Hinrichsen and Ramirez⁴⁸ also found that blacks were more likely than whites to report unmet needs and had less desire to admit the PWD to a nursing home (NH). Other studies suggest that African Americans with dementia live in the community longer than whites prior to NH admission—perhaps due to greater psychosocial support of family members—but with substantial unmet needs.^{49,50} To identify persons with unmet dementia-related needs, providers should be aware of demographic and socioeconomic factors that may influence knowledge of, access to and attitudes toward use of health care and social services.

This study has a number of limitations. First, participants were not randomly selected and were recruited from one urban geographic area, thus limiting its generalizability. Second, this report is based on cross-sectional data that do not allow for establishing causal relationships between variables. Third, participants' unmet needs were based on the JHDCNA, which relies on clinicians' judgments that consider participants' perspectives, and may differ from findings derived from other needs assessment approaches. Factor analysis is warranted to determine whether the JHDCNA could include fewer items or domains for practical use in clinical settings. Fourth, the sample is not representative of people with a specific type of dementia. This study did not focus on identifying or describing the causes of dementia, primarily because the needs assessed on the JHDCNA are potentially relevant to all forms of dementia, regardless of etiology. Fifth, a sampling bias could exist if people with higher unmet needs volunteered selectively for this study. Finally, while we identified several significant theoretically-driven correlates of unmet needs, we were not able to account for a substantial proportion of the variance in percent of unmet needs. This implies that other factors, perhaps psychosocial or personal preferences not assessed here, play important roles in unmet dementia-related needs.

For all individuals with dementia to live safely and comfortably in the community for as long as possible, it is imperative that their needs for care, services and support and those of their caregivers are met. This study suggests that dementia-related needs are often unmet and some groups in particular, including African Americans, people with lower incomes and caregivers with lower education, are at higher risk for unmet needs. Since symptoms of depression are associated with higher unmet needs in both PWD and caregivers, screening for and treating depression may be a key factor in the process of helping to reduce unmet dementia-related needs. The MIND at Home study will determine whether a care coordination intervention can reduce unmet needs in PWD and their caregivers and enable those with dementia to live at home longer without compromising their QOL.

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Conflicts of Interest:

Elements of Financial/Personal Conflicts	Black		Johnston		Morrison		Rabins		Lyketsos		Samus	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Employment or Affiliation		X		X		X		X		X		X
Grants/Funds	X		X		X		X		X		X	
Honoraria		X		X		X		X	X			X

Elements of Financial/Personal Conflicts	Black		Johnston		Morrison		Rabins		Lyketsos		Samus	
	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No	Yes	No
Speaker Forum		X		X		X		X		X		X
Consultant		X		X		X		X	X			X
Stocks		X		X		X		X		X		X
Royalties	X			X		X	X			X		X
Expert Testimony		X		X		X		X		X		X
Board Member		X		X		X		X		X		X
Patents		X		X		X		X		X		X
Personal Relationship		X		X		X		X		X		X

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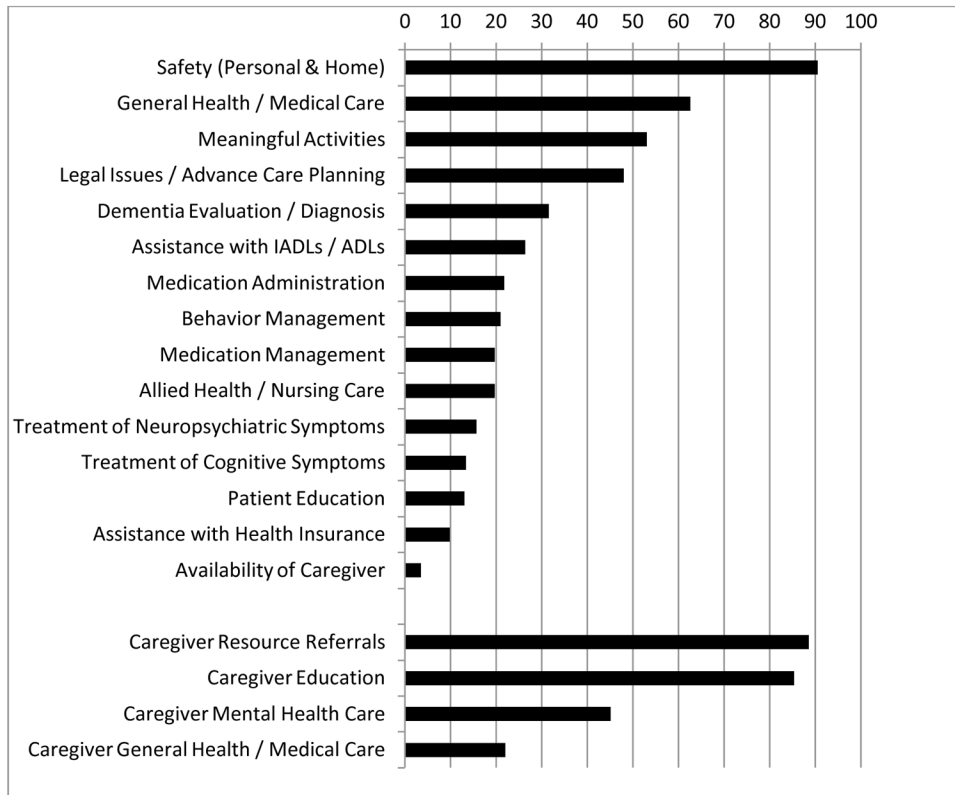


Figure 1. Percent of PWD (n=254) and Caregivers (n=245) with Any Unmet Needs by JHDCNA Domains^a

^a Johns Hopkins Dementia Care Needs Assessment domains

PWD – persons with dementia

IADLs – instrumental activities of daily living

ADLs – basic activities of daily living

Table 1

Structured Measurement Instruments

Measures	Administered To	Items	Score Range (Other)	Score Direction	Internal Reliability for This Study ^a
Measures for PWD					
Lawton and Brody Instrumental ADLs (IADLs) ²¹	CG	8	8 – 31	Higher = Worse	0.88
Psychogeriatric Dependency Rating Scale for basic ADLs (PGDRS) ²²	CG	16	0 – 39	Higher = Worse	0.89
Mint-Mental State Examination (MMSE) ²³	PWD	30	0 – 30	Higher = Better	NA
Neuropsychiatric Inventory-Questionnaire (NPI-Q) ²⁴					
NPI-Q Severity	CG	12	0 – 36	Higher = Worse	0.77
NPI-Q Distress	CG	12	0 – 60	Higher = Worse	0.78
Cornell Scale for Depression in Dementia (CSDD) ²⁵	PWD & CG	19	0 – 38	Higher = Worse	0.76
Quality of Life-Alzheimer Disease ²⁶					
Self-rated (QOL-AD_SR)	PWD	13	13 – 52	Higher = Better	0.89
Caregiver-rated (QOL-AD_CR)	CG	13	13 – 52	Higher = Better	0.82
Alzheimer Disease Related Quality of Life (ADRQL) ²⁷	CG	40	0 – 100	Higher = Better	0.84
Measures for Caregivers					
Zarit Burden Inventory (ZBI) ²⁸	CG	12	0 – 48	Higher = Worse	0.87
Geriatric Depression Scale (GDS) ²⁹	CG	15	0 – 15	Higher = Worse	NA
Caregiver Activity Survey (CAS) ^{b, 30}	CG	5	(Time)	--	--
Short Form 12 (SF-12) ^{c, 31}	CG	12	0 – 100	Higher = Better	NA

^aInternal reliability – Cronbach’s alpha.

^bCAS items 1–5 were included in the analyses; item 6 was excluded.

^cSF-12 is a measure of quality of life.

CG – caregivers

PWD – person with dementia

NA – not available

Table 2

Characteristics of PWD and Bivariate Relationships to Their Unmet Needs

Characteristics	PWD (n=254)	Bivariate Relationship to Percent of Unmet Needs ^a
PREDISPOSING FACTORS		
Age, years – Mean (SD)	83.6 (±5.9)	r = -.044, df=1, p=.489
Gender – %		t = -0.52, df=252, p=.606
Female	65.0	10.34 (6.2)
Male	35.0	9.91 (6.5)
Race – %		t = 3.56, df=252, p=.001
White	68.1	9.15 (5.5)
Non-white	31.9	12.42 (7.4)
ENABLING FACTORS		
Education, years ^b – Mean (SD)	13.0 (±3.7)	r = -.163, df=1, p=.010
Living Arrangement – %		t = -2.27, df=252, p=.024
Lives alone	18.9	12.04 (7.4)
Lives with others	81.1	9.76 (6.0)
Income ^b – %		t = 2.587, df=175, p=.011
< \$25,000	27.1	11.96 (7.0)
\$25,000	72.9	9.26 (5.8)
NEED FACTORS		
Total Medications – Mean (SD)	6.4 (±3.1)	r = -.124, df=1, p=.049
Total Health Problem Categories ^c – Mean (SD)	3.0 (±1.4)	r = .090, df=1, p=.154
IADL Score ^b – Mean (SD)	23.0 (±5.7)	r = -.186, df=1, p=.003
PGDRS Score ^b – Mean (SD)	10.4 (±8.2)	r = -.112, df=1, p=.075
MMSE Score ^b – Mean (SD)	17.8 (±7.6)	r = .157, df=1, p=.013
Dementia Severity		
MMSE >20 (mild)	11.5 (±6.8)	F = 4.749, df=2, p=.009
MMSE 11–20 (moderate)	9.8 (±6.2)	
MMSE <11 (severe)	8.2 (±4.6)	
NPI-Q Scores		
Severity ^b – Mean (SD)	7.7 (±6.1)	r = .061, df=1, p=.334
Distress ^b – Mean (SD)	9.6 (±8.5)	r = .085, df=1, p=.183
CSDD Score ^b – Mean (SD)	6.1 (±4.5)	r = .217, df=1, p=.001
QOL-AD_SR ^b – Mean (SD)	37.7 (±6.8)	r = -.313, df=1, p<.001
QOL-AD_CR ^b – Mean (SD)	31.2 (±6.0)	r = -.225, df=1, p<.001
ADRQL – Mean (SD)	83.1 (±13.2)	r = -.047, df=1, p=.452

^aStatistical tests – Pearson’s product-moment correlations (r), Student’s t-tests (t)

^bMissing data –Education=3, Income=77, IADLs=2, PGDRS=1, MMSE=2, NPI-Q Severity=3, NPI-Q Distress=5, CSDD=20, QOL-AD Self-rated=34, QOL-AD CG-rated=11.

^cTotal health problem categories – A nosology of current health problems classified each condition according to the following general (organ system) disease group categories: cardiovascular/hypertension, pulmonary, central nervous system/sensory, endocrine, rheumatology/orthopedics, gastrointestinal, hematology/oncology, renal/urological; the total number of health problem categories was used as a health status indicator.

PWD – persons with dementia

IADL – instrumental activities of daily living; score range 8–31

PGDRS – Psychogeriatric Dependency Rating Scale for basic ADLs; score range 0–39

MMSE – Mini-Mental State Examination; score range 0–30

NPI-Q – Neuropsychiatric Inventory-Questionnaire; Severity score range 0–36, Distress score range 0–60

CSDD – Cornell Scale for Depression; score range 0–38

QOL-AD_SR – Quality of Life-Alzheimer Disease – Self Rated; score range 13–52

QOL-AD_CR – Quality of Life-Alzheimer Disease – Caregiver Rated; score range 13–52

ADRQL – Alzheimer Disease Related Quality of Life; score range 0–100

Table 3

Multiple Regression Models for Percent of Unmet Needs in PWD and Caregivers

Variables in Final Regression Models In Order of Entry ^a	Beta	t	P-value	95% CI
MODEL FOR PWD ^b (Constant)		8.202	.000	10.062 – 16.462
CSDD	.288	3.584	.000	.189 – .657
White race	-.270	-3.260	.001	-6.048 – -1.479
PGDRS (ADLs)	-.177	-2.145	.034	-.295 – -.012
Low income (<\$25K)	-.169	-2.116	.036	-4.512 – -.151
MODEL FOR CAREGIVERS ^c (Constant)		8.260	.000	24.467 – 39.793
GDS	.292	4.786	.000	.693 – 1.662
White race	-.166	-2.683	.008	-7.422 – -1.137
Education years	-.139	-2.240	.026	-1.037 – -.066

^aIncluded all variables significant at $p < .10$ based on individual bivariate analyses; method – Forward stepwise

^b $F=8.004$, $df=4$, $p < .001$; Adjusted $R^2 = .177$

^c $F=12.480$, $df=3$, $p < .001$; Adjusted $R^2 = .127$

PWD – persons with dementia

CSDD – Cornell Scale for Depression; score range 0–38

PGDRS – Psychogeriatric Dependency Rating Scale for basic ADLs; score range 0–39

GDS – Geriatric Depression Scale; score range 0–15

Table 4

Characteristics of Caregivers and Bivariate Relationships to Their Unmet Needs

Characteristics	Caregivers ^a (n=246)	Bivariate Relationships to Percent of Unmet Needs ^b
PREDISPOSING FACTORS		
Age, years – Mean (SD) ^c	66.1 (±13.3)	r = -.029, df=1, p=.656
Sex – %		t = -.227, df=242, p=.821
Female	74.8	24.1 (12.1)
Male	25.2	23.7 (11.8)
Race – %		t = 3.025, df=242, p=.003
White	68.7	22.5 (11.5)
Non-white	31.3	27.4 (12.3)
ENABLING FACTORS		
Education, years – Mean (SD) ^c	15.4 (±3.0)	r = -.179, df=1, p=.005
Employed – % ^c		t = .272, df=240, p=.786
No	50.8	24.2 (12.7)
Yes	48.4	23.8 (11.3)
Relationship to Care Recipient – % ^d		t = -.278, df=242, p=.781
Spouse	41.5	24.3 (12.3)
Other	58.5	23.8 (11.8)
NEED FACTORS		
Self-Rated Health – % ^c		t = 3.733, df=240, p<.001
Excellent/Very Good/Good	77.6	22.5 (11.5)
Fair/Poor	21.5	29.4 (12.4)
Zarit Burden Inventory – Mean (SD) ^c	15.0 (±8.6)	r = .126, df=1, p=.051
Geriatric Depression Scale – Mean (SD) ^c	2.8 (±3.0)	r = .285, df=1, p<.001
Caregiver Activity Survey, Hours/Day – Mean (SD) ^{c,d}	6.7 (±6.2)	r = .083, df=1, p=.193
SF-12 Physical Health – Mean (SD) ^c	48.3 (±11.0)	r = -.208, df=1, p=.001
SF-12 Mental Health – Mean (SD) ^c	48.1 (±10.1)	r = -.185, df=1, p=.004

^a Nine caregivers provided care to each of two care recipients who had dementia.

^b Statistics tests – Pearson's product-moment correlations (r), Student's t-tests (t)

^c Missing Data – Age=3, Education=3, Employed=2, Self-rated Health=2, Zarit Burden Inventory=1, Geriatric Depression Scale=2, Caregiver Activity Survey=4, SF-12=1.

^d Included all caregivers for persons with dementia (n=254).

Zarit Burden Inventory – score range 0–48

Geriatric Depression Scale – score range 0–15

SF-12 – Short Form 12; score range 0–100