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Unmet needs in community-living persons with dementia are common, often non-medical and related to patient and caregiver characteristics.

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Abstract

Objective: Understanding which characteristics of persons with dementia (PWD) and their caregivers are associated with unmet needs can inform strategies to address those needs. Our purpose was to determine the percentage of PWD having unmet needs and significant correlates of unmet needs in PWD.

Design: Cross-sectional data were analyzed using bivariate and hierarchical multiple linear regression analyses.

Setting: Participants lived in the greater Baltimore, Maryland and Washington DC suburban area.

Participants: A sample of 646 community-living PWD and their informal caregivers participated in an in-home assessment of dementia-related needs.

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Conflict of Interest
None

Description of Authors' Roles

Designing the study: Samus, Black, Johnston, Lyketsos

Supervising data collection: Samus, Black, Johnston, Reuland, Kelly, Amjad, Willink, Davis Formulating the research question(s):

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Measurements: Unmet needs were identified using the Johns Hopkins Dementia Care Needs Assessment. Correlates of unmet needs were determined using demographic, socioeconomic, clinical, functional and quality of life characteristics of the PWD and their caregivers.

Results: PWD had a mean of 10.6 (± 4.8) unmet needs out of 43 items (24.8%). Unmet needs were most common in Home/Personal Safety (97.4%), General Health Care (83.1%), and Daily Activities (73.2%) domains. Higher unmet needs were significantly related to non-white race, lower education, higher cognitive function, more neuropsychiatric symptoms, lower quality of life in PWD and having caregivers with lower education or who spent fewer hours/week with the PWD.

Conclusions: Unmet needs are common in community-living PWD and most are nonmedical. Home-based dementia care can identify and address PWD's unmet needs by focusing on care recipients and caregivers to enable PWD to remain safely at home.

Keywords

dementia; unmet needs; community-living; care recipients; caregivers

Introduction

Alzheimer disease and other types of dementia exact a heavy toll on the estimated 50 million people worldwide (Alzheimer Disease International, 2018) who have these disorders. In America, 5.7 million individuals with dementia receive informal care from 16.1 million unpaid family members and friends (Alzheimer's Association, 2018). At least 70% of these persons with dementia (PWD) reside in the community (Alzheimer's Association, 2018), usually requiring caregiver assistance and supportive services to avoid or delay long term care (LTC) placement. Care needs of PWD are multidimensional and vary by level of cognitive impairment, functional abilities, medical comorbidities and neuropsychiatric symptoms (Rabins et al., 2016; Black et al., 2013]. Individuals whose dementia-related care needs go unmet are at greater risk for adverse consequences (Beach et al., 2018), lower quality of life (Black et al, 2012), nursing home placement and death (Gaugler et al, 2005).

Identifying dementia-related needs requires attention to environmental, social, behavioral and health care issues. PWD receive care in many health care settings (e.g., outpatient clinics, inpatient hospitals, rehabilitation units), but most of their care occurs at home (Alzheimer's Association, 2018). Focusing on in-home care provides opportunities to identify and intervene on needs unique to dementia, such as wander-risk management, challenging behaviors, safe medication administration or adherence, nutrition and hydration, and other home safety concerns. These issues may not be uncovered easily during office-based health care visits but may drive higher health care utilization and lower quality of life.

Informal caregivers have a major role in identifying and addressing unmet needs of care recipients. Caregivers' demographic characteristics (e.g., age, education), other obligations (e.g., employment, caring for others) and wellbeing (e.g., physical and mental health) may influence whether they are able to recognize and/or adequately address the needs of PWD. For example, more unmet needs have been identified in PWD whose caregivers are younger,

have lower incomes, experience greater burden, report higher anxiety, express a desire to institutionalize the PWD or have lower quality of life (QOL) (Kerpershoek et al., 2017); MirandoCastillo et al., 2010; Gallagher et al., 2011; van der Roest et al., 2009).

This study extends our prior research (Johnston et al. 2011; Black et al., 2013) on this topic using data from two new samples of community residents and their caregivers to determine the percentage of PWD having unmet needs and the significant correlates of their unmet needs. We examine characteristics of both the care recipient and caregiver to identify correlates of unmet needs in PWD. By knowing which PWD and caregiver characteristics are associated with more unmet needs, home and community-based service providers will be better able to identify high risk individuals and develop targeted interventions for addressing those needs with the goal of avoiding high-cost outcomes such as emergency department (ED) visits, hospitalizations or LTC placement.

Methods

Study Design

Cross-sectional, baseline data from two intervention studies evaluating the impact of the Maximizing Independence at Home (MIND at Home) dementia care coordination program (Samus et al, 2014) were combined to determine the percentage of community-residing PWD who have dementia-related unmet needs and the correlates of their unmet needs. The MIND-HCIA is a Health Care Innovation Award (HCIA) Round Two demonstration project sponsored by the Centers for Medicare and Medicaid Services (1C1CMS331332, 09/01/2014-11/30/2017, NCT02395731) (n=342), and MIND-RCT is a randomized controlled trial (RCT) funded by the National Institute on Aging (NIA) (R01 AG046274, 08/15/2014-04/30/2019, NCT02396082) (n=304). See Table S1, published as supplementary material online attached to the electronic version of this paper, for a comparison of MIND-HCIA and MIND-RCT study designs and methods. Further protocol details are described elsewhere (Samus et al, 2017; Samus et al., 2018). Both studies were approved by the Johns Hopkins Medicine Institutional Review Board (IRB). Written consent was obtained from all participants and their study partners (i.e., a reliable family member or friend who knew the participant well) or informal caregiver. For participants who lacked consent capacity, proxy consent was obtained from a legally authorized representative using the Maryland Health Care Decisions Act as a guide, with assent obtained from the participant.

Study Procedures and Measures

Baseline data used in this report were collected prior to any randomization or initiation of MIND at Home interventions. In both studies, participants lived at home in the greater Baltimore, MD and Washington DC suburban area within a 40-mile radius of the Johns Hopkins Bayview Medical Center. Inclusion criteria for both studies included being English-speaking and meeting diagnostic criteria for all-cause dementia (McKhann et al., 2011). Participants in MIND-HCIA were either dually eligible for Medicare and Medicaid benefits or had Medicare only. Insurance status was not an enrollment criterion in MIND-RCT. PWD in MIND-HCIA participated with either a study partner as a proxy informant or caregiver (i.e., a person who provides unpaid assistance in one or more instrumental activities of daily

living (IADLs)), with 98% having a caregiver. MIND-RCT required all PWD to participate with a caregiver.

Enrollment in MIND-RCT occurred between February 2015 and April 2017; MIND-HCIA enrolled participants from March 2015 to October 2016. Participants in both studies were recruited using the same three approaches. First, community organizations, health and community service providers, local and state Medicaid waiver programs and health departments sent targeted mailings about these studies to individuals on their mailing lists. Second, existing Johns Hopkins research registries were used with IRB approval. Last, the study team conducted a broad outreach campaign using community-based events and local media publicity. Interested individuals responded to recruitment information by telephone or email.

A two-staged enrollment and assessment process was implemented for both studies to identify eligible individuals. First, a telephone screen was conducted by trained screeners who explained study procedures, determined whether demographic and insurance eligibility requirements were met, and screened for cognitive disorder using the 11-item Telephone Interview for Cognitive Status (TICS, score range 0-41) (Brandt et al., 1988) with the potential participant and the 16-item Informant Questionnaire for Cognitive Disorders in the Elderly (IQCODE, score range 16-80) (Jorm and Jacomb, 1989) with the study partner or caregiver. A positive screen was defined as a TICS score of <31 and an IQCODE score of >52 (Brandt et al., 1988; Jorm and Jacomb, 1989; Jorm et al., 1996). Second, eligible and willing participants received an in-home baseline visit by a clinician (i.e., geriatric psychiatrist or registered nurse) and a trained, non-clinical memory care coordinator (MCC) to conduct an assessment and confirm a dementia diagnosis using NIA all-cause dementia criteria (McKhann et al., 2011). The assessment 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. A second in-home visit was conducted by trained research assistants to collect data on health services use, QOL and caregiver health and wellbeing. Of the 2,049 individuals who responded to recruitment efforts, 1311 completed screening and 665 were ineligible for either study (e.g., not English-speaking, not community-residing, not meeting dementia criteria, planned on moving to residential care within six months), leaving 342 enrolled in MIND-HCIA and 304 enrolled in MIND-RCT, with a combined sample totaling 646 PWD.

Table S2, which is published as supplementary material online attached to the electronic version of this paper, lists the quantitative measures and their characteristics used in analyses for this report. For the PWD, these instruments include the General Medical Health Rating (GMHR) (Lyketsos et al., 1999) to assess general health, Lawton and Brody's (1969) Instrumental Activities of Daily Living (IADLs) and the Psychogeriatric Dependency Rating Scale (PGDRS) (Wilkinson and Graham-White (1980) to assess functional status, the Mini Mental State Examination (MMSE) (Folstein et al., 1975) to assess cognitive impairment, the Neuropsychiatric Inventory (NPI) (Cummings et al., 1994) to identify neuropsychiatric symptoms and the Quality of Life-Alzheimer Disease (QOL-AD) (Logsdon et al, 2002) to determine proxy-rated QOL. PWD demographic and socioeconomic data included age, sex, race, education, living arrangement (i.e., alone or with others), income and Medicaid status.

Quantitative measures for caregivers' include the GMHR as a measure of general health, the 12-Item Short Form (SF-12) (Ware et al., 1996) used to assess physical and mental wellbeing, the Patient Health Questionnaire 9 (PHQ-9) (Kroenke et al., 2001) used to identify symptoms of depression and the Zarit Burden Inventory (ZBI) (Zarit et al., 1980) as a subjective measure of caregiver burden. Caregivers' demographic and socioeconomic data included age, sex, race, education, relationship to the PWD, employment status, and whether they provided care to other adults or any children aged <18. Two objective caregiver burden indicators were hours per day spent caring for and hours per day spent with the PWD.

The Johns Hopkins Dementia Care Needs Assessment (JHDCNA, 2.0), a revised version of the original tool (JHDCNA, 1.0) (Black et al., 2013; Johnston et al. 2011), was used to identify dementia-related needs of PWD and their caregivers. A multidisciplinary group of clinical dementia care experts developed the JHDCNA, which is based on best practices in dementia care (Rabins et al., 2016; Committee AGSCP, 2003; Lyketsos, et al., 2006; Waldemar et al, 2007), suggesting content validity. Prior studies demonstrate concurrent validity with quality of life (Black et al., 2012) and caregiver burden measures (Hughes et al., 2014). For PWD, the JHDCNA is used by trained clinicians to document unmet needs in seven domains (Cognitive Symptom Management, Neuropsychiatric Symptom Management, General Health Care, Home/Personal Safety, Daily Activities, Legal Concerns/Advanced Care Planning, Health Care Financing) with a total of 43 items. Clinicians and MCCs complete the JHDCNA after an in-home assessment, interviews with the PWD and caregiver, a visual assessment of the PWD's home, and considering the individuals' perspectives on their needs. Each JHDCNA item is assessed as being needed or not and, if needed, whether the need is met or unmet.

Data Analyses

The percentage of PWD with unmet needs was based on identifying those with one or more total unmet needs and those with one or more unmet needs in each domain. Descriptive statistics (frequencies, means, standard deviations) were calculated for all variables. To identify correlates of unmet needs, participant characteristics were categorized as predisposing (e.g., demographic characteristics), enabling (e.g., social and economic characteristics) or need for care (e.g., clinical and functional characteristics) factors based on Andersen's Behavioral Model of Health Services Use (Andersen, 1995). Bivariate analyses (t-tests, Pearson correlations, analyses of variance) were used to determine relationships between participant characteristics and the dependent variable of total percentage of unmet needs, calculated as $(\text{number of unmet need items} / \text{number of need items assessed}) \times 100$. Hierarchical multiple linear regression models (Jeong and Jung, 2016) were estimated to identify which characteristics were the primary correlates of unmet needs in PWD. The first regression analysis identified the primary correlates of unmet need using only characteristics of the PWD. We hypothesized that need for care factors would account for more of the variance in unmet needs than either predisposing or enabling factors. For the model building process, independent variables with $P < .10$ based on bivariate analyses were included in three blocks representing predisposing, enabling and need factors. The second regression analysis, which used data from only cases with a caregiver, estimated whether any caregiver characteristics were also primary correlates of unmet needs in PWD. We hypothesized that

PWD characteristics would account for more of the variance in unmet needs than caregiver characteristics. Using independent variables with $P < .10$ based on bivariate analyses, PWD characteristics were first entered as one block and caregiver characteristics were entered as a second block. The data were checked to confirm that they met the assumptions for using linear regression analyses. Cohen's f^2 (Cohen, 1988) was calculated as an indicator of effect size for each final regression model. SPSS 24.0 (IBM Corporation, Armonk, NY) was used for data analyses; $P < .05$ was considered statistically significant.

Results

The sample of 646 PWD had a mean age of 80.0 (range 45-103); 69% were females; 56% were non-whites (89% of whom were African Americans); and had completed 12.3 years of education. Most PWD (79%) lived with others, 43% had annual incomes $< \$25,000$ and 36% received Medicaid benefits. Their mean MMSE score for cognitive impairment was 17.2, with 39% mildly impaired (MMSE > 20), 42% moderately impaired (MMSE 11-20) and 19% severely impaired (MMSE < 11) (Pernecky et al., 2006). Table 1 shows other PWD characteristics.

All PWD had at least one unmet need, with a mean of 10.6 (± 4.8) out of 43 JHDCNA items (30% had < 8 , 48% had 8-14, 22% had ≥ 15 unmet needs). Figure 1 shows that unmet needs in the Home/Personal Safety domain were most common (97%), such as the need for emergency planning (83%), fall risk management (73%) or help with medication use/adherence (42%). Other domains with high percentages of unmet needs were General Health Care (83%), Daily Activities (73%) and Neuropsychiatric Symptoms Management (66%).

Bivariate relationships between total percentage of unmet needs and PWD predisposing, enabling and need factors are also shown in Table 1. Individuals with significantly higher unmet needs were younger, non-white, had less education, lived alone, had annual incomes of $< \$25,000$, and were receiving Medicaid benefits. Other significant correlates of unmet needs in PWD were measures of general health (GMHR), IADL impairments, neuropsychiatric symptoms (NPI), QOL (AD-QOL) and cognitive function (MMSE). Those with severe cognitive impairment had significantly fewer unmet needs than those with either moderate or mild impairment, with no significant difference between those with mild and moderate impairment ($F = 10.049$, $p < .001$, $df = 2, 617$). The severely cognitively impaired were also less likely to be living alone ($X^2 = 11.683$, $p = .003$, $df = 2$).

Table 2 shows results of the hierarchical linear regression models in which PWD characteristics (predisposing, enabling, and need factors with $P < .10$ based on bivariate analyses) were included. The 12 variables in Model 3 accounted for 30% of variance in percentage of unmet needs (Cohen's $f^2 = .429$), with need factors accounting for more of the variance than either predisposing or enabling factors. Variables that remained significantly associated with unmet needs in Model 3 were age, race, education, income, cognitive function, neuropsychiatric symptoms, and QOL.

This sample included 637 informal caregivers, two of whom each served as caregiver for two participating PWD. Caregivers' mean age was 62.4 (range 23-92); 77% were females;

57% were non-whites; and they had completed 14.8 years of education. Thirty percent of caregivers were spouses to the PWD; 41% were employed; 17% provided care to other adults; and 16% cared for children. Table 3 shows other caregiver characteristics.

Bivariate relationships between caregiver characteristics and total percentage of unmet needs in PWD are also in Table 3. PWD with significantly higher unmet needs had caregivers who were younger, non-white, had lower education, were non-spouses, or were caring for another adult. Unmet needs were also significantly higher in PWD whose caregivers had lower general health (GMHR), worse physical and mental health based on the SF-12, more symptoms of depression (PHQ-9), or spent fewer hours per week with the PWD.

Table 4 shows results of the hierarchical linear regression analysis when both PWD and caregiver characteristics were considered. Model 1 included only PWD predisposing, enabling and need factors with $P < .10$ based on bivariate analyses. Model 2 added caregiver predisposing, enabling and need factors with $P < .10$ in bivariate analyses except for caregiver race, which was excluded because of its high correlation (Pearson .959, $p < .001$) with PWD's race. Model 2 shows that 33.9% of variance in percentage of unmet needs in PWD was accounted for by these variables (Cohen's $f^2 = .513$), with most due to PWD characteristics. In Model 2, PWD's income was no longer a significant factor, but two caregiver characteristics—education and hours spent per week with the PWD—remained significantly associated with unmet needs in PWD.

Discussion

This study demonstrates that community-living PWD often have high rates of unmet needs, and their unmet needs are associated with characteristics of both the care recipient and caregiver. While unmet needs in PWD are primarily associated with indicators of need for care (e.g., neuropsychiatric symptoms), they are also associated with demographic (e.g., race) and socioeconomic (e.g., income) characteristics and with caregiver demographic (e.g., age), socioeconomic (e.g., education) and need for care (e.g., objective burden) factors. Thus, service providers should consider aspects of both the patient and caregiver to identify individuals at high risk for unmet needs and use targeted, person-centered interventions to address those needs.

Most unmet needs in this sample involved non-medical concerns. Highest among these and in our prior study (Black et al., 2013) were in the Home/Personal Safety domain, such as needing a plan for dealing with emergencies (e.g., power outages), avoiding falls or managing medication use. This domain also includes driving safety, wander risk management, and the potential for fraud, abuse, neglect or exploitation. Safety has been identified as one of five critical areas of risk for PWD and their caregivers (Schulz and Martire, 2004). Fall-related injuries, for example, are primary contributors to hospitalizations and ED visits in PWD (Benner et al., 2018) and are often preventable. An in-home assessment can aid in identifying issues that pose a danger for PWD.

Unmet needs were also high in the General Health Care (83%) and Daily Activities (73%) domains. The General Health Care domain includes issues such as the need for dental care,

medical specialist care, incontinence care, management of multiple medications, attention to vision and hearing problems, and addressing poor nutrition or dehydration. PWD are more likely than those without dementia to have co-existing chronic health conditions (Alzheimer's Association, 2018) that need attention from primary or specialist care providers. Having multiple chronic medical conditions often means that the PWD is taking multiple medications that they may not have the cognitive capacity to manage safely. Unmet needs in the Daily Activities domain include needing IADL and ADL assistance, lacking meaningful activities or a daily structure, physical inactivity or being socially isolated. With caregiver education, in-home activities customized to the PWD's interests and capabilities can significantly increase their engagement, reduce behavioral symptoms, and reduce caregiver burden (Gitlin et al., 2009).

This sample had higher rates of unmet needs for Neuropsychiatric Symptom Management (66%) than reported in our prior study (16%) (Black et al., 2013). In further comparison, this sample had higher total unmet needs and other characteristics (e.g., lower education, lower income) that may have influenced whether their neuropsychiatric symptoms were identified and adequately addressed. Neuropsychiatric symptoms can include delusions, hallucinations, agitation, anxiety, depression, apathy or sleep disturbances. These symptoms are often under-recognized, are associated with adverse outcomes for PWD and caregivers, and can be challenging to treat (McClam et al, 2015; Lancot et al., 2017). Both pharmacologic and nonpharmacologic interventions can be effective for addressing neuropsychiatric symptoms (Lancot et al., 2017), but nonpharmacologic methods should be used first if possible to avoid adverse events (Dyer et al., 2018). In-home providers may be better positioned to help caregivers implement non-pharmacologic interventions than office-based providers.

Over half (58%) the PWD in this sample had unmet needs in the Legal Concerns/Advance Care Planning domain, compared with 48% in our prior study (Black et al., 2013). Education, race and income may be influencing factors in this difference since the current sample includes more PWD with lower education, lower income or non-white race. In another study involving PWD, those with higher education and white race were significantly more likely to have an advance directive (Porter, 2018). Higher income may also be an enabler for obtaining legal assistance. Estate planning, designating a health care agent and completing an advance directive, are important matters to address early when individuals have decisional capacity. An advance directive is an important tool for elucidating the individual's values and preferences for treatment, research participation and end-of-life care (Triplett et al., 2008).

Indicators of need for care—cognitive function, neuropsychiatric symptoms, quality of life—in PWD were primary correlates of unmet needs. Those with severe cognitive impairment had significantly fewer unmet needs and were less likely to be living alone. Their care needs may be more apparent to care providers than those with mild to moderate cognitive impairment. While PWD in this sample with more neuropsychiatric symptoms had significantly more unmet needs, findings in previous studies have been mixed (Black et al., 2013; Mirando-Castillo et al., 2010). These relationships warrant further study to determine whether specific types of neuropsychiatric symptoms (e.g., depression vs agitation vs sleep disturbances) are associated with unmet needs. For example, our prior study (Black et al.,

2013) found that depressive symptoms in PWD were associated with unmet needs. The significant relationship between unmet needs and lower QOL is consistent with prior research (Black et al., 2013; Black et al., 2012; Kerpershoek et al., 2017; Gitlin et al., 2014; Kerpershoek et al., 2017). Our cross-sectional data cannot establish a causal relationship between these factors, but some investigators suggest that there is overlap between the domains of unmet need and QOL (Mazurek et al., 2017).

Based on multivariate analysis, only one indicator of need in caregivers—spending fewer hours per week with the PWD—was associated with higher unmet needs in care recipients. Caregivers spending less time with PWD may be less likely to identify and/or address the patients' needs. This may be particularly true for caregivers who live elsewhere or also care for others. In these cases, PWD may benefit from having additional providers involved in daily care and supervision. Bivariate analyses showed, however, that other indicators of caregiver need (i.e., worse physical and mental health, more symptoms of depression) were associated with unmet needs in PWD. This suggests that interventions for addressing unmet needs in PWD should also assess and address caregivers' health and wellbeing.

Some predisposing and enabling PWD and caregiver characteristics were also independently associated with unmet needs in care recipients. Less education, less income and non-white race are factors that we and others (Black et al., 2013; Hinrichsen and Ramirez, 1992; Scholzel-Dorenbos et al., 2010; Zhor et al., 2018; Stein et al, 2017) have previously identified as significant correlates of unmet needs in PWD. Education and income may be enabling factors for obtaining information on and/or access to dementia-related services. The link between race and unmet needs warrants further study, perhaps using a mixed methods approach, to better understand why this relationship exists and what approaches are effective in reducing unmet needs in groups such as African Americans.

The variance accounted for in the two final regression models were .300 when considering only PWD factors and .339 when both PWD and caregiver characteristics were included in the model, with effect sizes (f^2) of .429 and .513 respectively. Cohen (1988) suggest as a crude guide that an f^2 value of at least .35 could be considered to be large.

Study limitations relate primarily to sampling, measurement and data analysis approaches. Participants were drawn from one area in the US (mid-Atlantic) and may not be representative of PWD from other areas. Individuals with higher unmet needs may have selectively volunteered since the two studies from which this sample derived provided interventions to either some (in MIND-RCT) or all (in MIND-HCIA) participants. Our cross-sectional data do not allow for causal relationships to be established between variables. Unmet needs in this sample were identified by clinicians using the JHDCNA who based their judgments on information derived from PWD and their caregiver or study partner. An alternative approach to needs assessment may have resulted in different findings. The variance accounted for by our theoretically driven independent variables suggests that other unidentified factors account for a substantial percentage of variance in unmet needs.

This study's results help to advance our understanding of the scope of dementia-related needs and the extent to which the needs of PWD who live in the community are being met.

In a scoping review of international literature that included 27 articles on this topic, Morrisby and colleagues (2018) concluded that the needs of PWD and their caregivers were diverse and not always effectively met by services designed to support them. Our findings are consistent with their conclusion for those with dementia and, additionally, identify characteristics of both the PWD and caregiver that are risk factors for having unmet needs. These risk factors may enable service providers to use more targeted interventions to address the needs of PWD according to their demographic, socioeconomic and health status characteristics.

Identifying and addressing unmet needs in PWD can help relieve some burdens that dementia imposes on them and their caregivers. Key characteristics (e.g., age, race, education, mental health symptoms) of both the PWD and caregivers can help health care and service providers identify individuals who may be at greater risk of having unmet needs. Person-centered, evidence-based dementia care coordination programs, such as the MIND at Home model, can help reduce unmet needs, enable PWD to live safely at home longer, and improve QOL for PWD (Samus et al., 2014). Prospective data derived from participants in this study will determine whether home-based dementia care coordination can reduce care costs while improving outcomes for both the care recipient and family caregiver.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1.

Percent of Persons with Dementia with One or More Unmet Needs (n=646)

Table 1.

Characteristics of Persons with Dementia and Bivariate Relationships to Having Unmet Needs

Characteristics (n=646)	Value	Unmet Needs, % Mean $\pm$ SD	Bivariate Relationship to Percentage of Unmet Needs
<i><u>Predisposing Factors</u></i>			
Age, mean $\pm$ SD	80.0 $\pm$ 9.6		$r = -.092$, $df = 640$, $P = .020$
Sex, %			
Female	69.0	24.9 $\pm$ 11.4	$t = -.116$, $df = 640$, $P = .908$
Male	31.0	24.8 $\pm$ 10.5	
Race, %			
White	44.0	22.2 $\pm$ 11.0	$t = 5.330$, $df = 641$, $P < .001$
Non-white	56.0	26.8 $\pm$ 10.8	
<i><u>Enabling Factors</u></i>			
Education years, mean $\pm$ SD	12.3 $\pm$ 3.9		$r = -.184$, $df = 631$, $P < .001$
Living arrangement, %			
Alone	20.8	27.0 $\pm$ 12.0	$t = 2.558$, $df = 639$, $P = .011$
With others	79.2	24.3 $\pm$ 10.8	
Income, %			
< \$25,000	42.9	28.0 $\pm$ 11.8	$t = 5.946$, $df = 465$, $P < .001$
\$25,000	57.1	22.3 $\pm$ 10.2	
Medicaid, any benefits, %			
Yes	36.4	27.7 $\pm$ 11.8	$t = -4.993$, $df = 641$, $P < .001$
No	63.9	23.2 $\pm$ 10.4	
<i><u>Need Factors</u></i>			
GMHR, mean $\pm$ SD	2.8 $\pm$ 0.8		$r = -.111$, $df = 641$, $P = .005$
IADLs, mean $\pm$ SD	23.6 $\pm$ 5.7		$r = -.143$, $df = 621$, $P < .001$
PGDRS, mean $\pm$ SD	10.6 $\pm$ 8.9		$r = -.051$, $df = 603$, $P = .206$
MMSE, mean $\pm$ SD	17.2 $\pm$ 7.7		$r = .173$, $df = 618$, $P < .001$
NPI Freq $\times$ Sev, mean $\pm$ SD	21.5 $\pm$ 18.4		$r = .267$, $df = 607$, $P < .001$
QOL-AD Proxy-Rated, mean $\pm$ SD	31.0 $\pm$ 6.4		$r = -.256$, $df = 617$, $P < .001$

Abbreviations: SD – standard deviation, df – degrees of freedom, GMHR – General Medical Health Rating, IADL – Instrumental Activities of Daily Living, PGDRS – Psychogeriatric Dependency Rating Scale, MMSE – Mini-Mental State Examination, NPI – Neuropsychiatric Inventory Frequency $\times$ Severity, QOL-AD – Quality of Life in Alzheimer Disease

Missing data: age (1), sex (1), education (10), living arrangement (2), income (91), medications (9), IADLs (20), PGDRS (38), MMSE (23), NPI (35), QOL-AD Proxy-Rated (24)

Table 2.

Hierarchical Linear Regression Models for Percentage of Unmet Needs in Persons with Dementia

Independent Variables*	Model 1			Model 2			Model 3		
	B	t	95% CI	B	t	95% CI	B	t	95% CI
<i>Predisposing Factors</i>									
Age	-.146	-2.738**	-.251, -.041	-.201	-3.741***	-.306, -.095	-.130	-2.525**	-.231, -.029
Race (white=1)	-5.750	-5.759***	-7.712, -3.788	-4.070	-4.013***	-6.062, -2.077	-4.500	-4.758***	-6.359, -2.641
		$R^2 = .076$							
		$F = 19.052$							
<i>Enabling Factors</i>									
Education years				-.467	-3.296***	-.746, -.189	-.405	3.057**	-.665, -.145
Living status (with others=1)				-.821	-.665	-3.248, 1.606	-.628	-.532	-2.951, 1.694
Income (\$25,000/yr=1)				-2.870	-2.611**	-5.030, -.710	-2.036	-2.006*	-4.030, -.042
Medicaid insurance				1.764	1.589	-.417, 3.945	1.770	1.698	-.278, 3.818
					$R^2 = .145$				
					$R^2 = .070$				
					$F = 9.376$				
<i>Need Factors</i>									
GMHR				-.101	-.171	-1.252, 1.051			
IADLs				-.160	-1.466	-.374, .054			
PGDRS				.094	1.332	-.044, .232			
MMSE				.361	5.035***	.220, .502			
NPI				.168	6.572***	.118, .218			
QOL-AD				-.254	-3.354***	-.403, -.105			
					$R^2 = .300$			$R^2 = .155$	
								$F = 16.826$	

* Included all variables significant at $P < .10$ based on individual bivariate analyses; predisposing, enabling and need variables entered together as blocks in each model

Abbreviations: CI – Confidence Intervals, GMHR – General Medical Health Rating, IADLs – Instrumental Activities of Daily Living, PGDRS – Psychogeriatric Dependency Rating Scale, MMSE – Mini-Mental State Examination, NPI – Neuropsychiatric Inventory, QOL-AD – Quality of Life Alzheimer Disease (proxy-rated)

* P-values: p .05;

Degrees of freedom =467

*** p < .001

*** p < .001

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Table 3.

Characteristics of Informal Caregivers and Bivariate Relationships to Unmet Needs in Persons with Dementia (PWD)

Characteristics (n=637)	Value	Bivariate Relationship to Percentage of Unmet Needs in PWD
<i><u>Predisposing Factors</u></i>		
Age, mean $\pm$ SD	62.4 $\pm$ 12.1	$r = -.125$, $df = 630$, $P = .002$
Sex, %		
Female	76.6	$t = -1.764$, $df = 632$, $P = .078$
Male	23.4	
Race, %		
White	42.9	$t = 5.350$, $df = 632$, $P < .001$
Non-white	57.1	
<i><u>Enabling Factors</u></i>		
Education years, mean $\pm$ SD	14.8 $\pm$ 3.2	$r = -.139$, $df = 628$, $P < .001$
Relationship to PWD		
Spouse	30.1	$t = 3.129$, $df = 632$, $P = .002$
Other	69.9	
Employed		
Yes	40.7	$t = -1.472$, $df = 611$, $P = .142$
No	59.3	
Cares for Other Adults		
Yes	16.6	$t = -2.721$, $df = 620$, $P = .007$
No	83.4	
Cares for Any Children < 18 years		
Yes	16.0	$t = -1.869$, $df = 621$, $P = .062$
No	84.0	
<i><u>Need Factors</u></i>		
GMHR, mean $\pm$ SD	3.3 $\pm$ 0.8	$r = -.096$, $df = 629$, $P = .016$
SF-Physical Health	47.4 $\pm$ 10.9	$r = -.111$, $df = 608$, $P = .006$
SF-Mental Health	49.2 $\pm$ 10.3	$r = -.131$, $df = 608$, $P = .001$
PHQ-9	4.9 $\pm$ 4.6	$r = .143$, $df = 598$, $P < .001$
Hours Per Week Helping PWD	34.7 $\pm$ 37.6	$r = -.005$, $df = 608$, $P = .896$
Hours Per Week Spent With PWD	89.7 $\pm$ 65.2	$r = -.179$, $df = 609$, $P < .001$
Zarit Burden Inventory	15.9 $\pm$ 9.4	$r = .022$, $df = 599$, $P = .590$

Abbreviations: PWD – Person with dementia, SD – standard deviation, df – degrees of freedom, GMHR – General Medical Health Rating, SF – Short Form, PHQ-9 – Patient Health Questionnaire 9 Missing data: age (2), education (4), employed (21), cares for other adults (12), cares for any children (11), medication (11), GMHR (3), SF-Physical Health (24), SF-Mental Health (24), PHQ-9 (34), Hours helping PWD (24), Hours with PWD (23), Zarit Burden Inventory (33)

Table 4.

Hierarchical Regression Models for Percentage of Unmet Needs in Persons with Dementia Including Person with Dementia (PWD) and Caregiver (CG) Characteristics

Independent Variables*	Model 1			Model 2		
	B	t	95% CI	B	t	95% CI
PWD Characteristics						
<i>Predisposing Factors</i>						
Age	-.162	-2.966**	-.270, -.055	-.131	-2.159*	-.250, -.012
Race (white=1)	-4.978	-5.098***	-6.898, -3.059	-5.616	-5.353***	-7.678, -3.553
<i>Enabling Factors</i>						
Education years	-.473	-3.483***	-.740, -.206	-.360	-2.434*	-.650, -.069
Living status (with others=1)	-.770	-.626	-3.188, 1.648	-.485	-.348	-3.226, 2.257
Income (\$25,000/yr=1)	-2.067	-1.971*	-4.129, .005	-1.369	-1.248	-3.525, .787
Medicaid insurance	1.298	1.188	-.851, 3.447	1.704	1.500	-.529, 3.937
<i>Need Factors</i>						
GMHR	-.335	-.557	-1.515, .846	-.307	-.470	-1.590, .977
IADLs	-.131	-1.130	-.360, .097	-.106	-.907	-.337, .124
PGDRS	.096	1.312	-.048, .239	.081	1.097	-.064, .227
MMSE	.403	5.384***	.256, .550	.383	5.027***	.233, .533
NPI	.172	6.447***	.119, .224	.165	5.807***	.109, .221
QOL-AD	-.225	-2.861**	-.380, -.071	-.181	-2.211*	-.342, -.020
		R ² = .318				
		F = 16.179***				
CG Characteristics						
<i>Predisposing Factors</i>						
Age				.016	.280	-.098, .131
Sex (female=1)				-.684	-.600	-2.928, 1.559
<i>Enabling Factors</i>						
Education years				-.387	-2.431*	-.701, -.074
Spouse				1.609	.962	-1.679, 4.898
Cares for other adults				1.019	.749	-1.656, 3.694
Cares for children				-.177	-.127	-2.923, 2.569
<i>Need Factors</i>						
GMHR				-.159	-.219	-1.590, 1.272
SF-Physical Health				-.009	-.158	-.114, .097
SF-Mental Health				-.068	-1.133	-.187, .050
PHQ9				-.035	-.261	-.300, .229
Hours spent with PWD				-.021	-2.256*	-.040, -.003
					R ² = .339	
					R ² = .021	

Independent Variables*	Model 1			Model 2		
	B	t	95% CI	B	t	95% CI
F = 1.183						

* Included variables significant at $P < .10$ based on individual bivariate analyses except for caregiver race which was excluded; all PWD characteristic variables and all caregiver characteristic variables entered as blocks in each model

Abbreviations: GMHR – General Medical Health Rating, IADLs – Instrumental Activities of Daily Living, PGDRS – Psychogeriatric Dependency Rating Scale, MMSE – Mini-Mental State Examination, NPI – Neuropsychiatric Inventory, QOL-AD – Quality of Life Alzheimer Disease (proxy-rated), SF – Short Form, PHQ9 – Patient Health Questionnaire 9, CI – Confidence Intervals

* P-values: $p < .05$;

** $p < .01$;

*** $p < .001$;

Degrees of freedom = 429