American Journal of Alzheimer's
Disease & Other Dementias®
26(2) 110-114
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DOI: 10.1177/1533317510394649
http://aja.sagepub.com
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Dependence and Caregiver Burden in Alzheimer's Disease and Mild Cognitive Impairment

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Abstract

The dependence scale has been designed to be sensitive to the overall care needs of the patient and is considered distinct from standard measures of functional ability in this regard. Little is known regarding the relationship between patient dependence and caregiver burden. We recruited 100 patients with Alzheimer's disease or mild cognitive impairment and their caregivers through a memory clinic. Patient function, dependence, hours of care, cognition, neuropsychiatric symptoms, and caregiver burden were assessed. Dependence was significantly correlated with caregiver burden. Functional decline and dependence were most predictive of caregiver burden in patients with mild impairment while behavioral symptoms were most predictive in patients with moderate to severe disease. The dependence scale demonstrated good utility as a predictor of caregiver burden. Interventions to reduce caregiver burden should address patient dependence, functional decline, and behavioral symptoms while successful management of the latter becomes more critical with disease progression.

Keywords

Alzheimer's disease, dependence, caregiver burden

Introduction

The global prevalence of dementia is rising and Alzheimer's disease (AD), which accounts for 50% to 60% of all cases of dementia, represents an increasing challenge for older adults, families, and health care systems worldwide.[1] One of the recurring themes in caregiver research is the diversity of response to care-giving demands, and while some caregivers are overwhelmed by care responsibilities relatively early in their career, others report stability or even decreases in key care-giving outcomes over time.[2] This variability in caregiver outcomes has often been explained in terms of the caregiver burden model whereby burden is a subjective measure of the physical, economic, and psychosocial strain of care-giving and is considered the product of a dynamic interaction between caregiver resources, vulnerabilities, and care demands.[3] Informal caregivers report higher levels of depression and anxiety,[4] use psychotropic medication more frequently,[5] engage in fewer protective health behaviors, and are at increased risk of medical illness[6] and mortality.[7] High caregiver burden is also a predictor of early institutionalization of the patient.[8] Reviews of caregiver interventions have reported small but significant effects upon caregiver burden and have underlined the need for increased understanding of the dynamics of care-giving toward the development of more targeted and effective interventions.[9]

Patient variables that have been associated with increased caregiver burden include cognitive impairment, functional decline, and neuropsychiatric symptoms. Behavioral symptoms have been most consistently associated with increased caregiver burden,[10,11] while, surprisingly, patient cognitive status has not been consistently found to be a predictor.[12] Equally functional deficits have not been found to strongly predict caregiver burden with negative findings in a number of studies.[10,13] One reason for this may be that current measures of functional status do not adequately capture the overall time spent by carers

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supervising and overseeing patient activities of daily living, which they can otherwise complete correctly.

The dependence scale is a scale that has been designed to be sensitive to the overall care needs of the patient and asks questions regarding tasks for which the caregiver must both provide direct assistance and supervision.[14] It has been shown to tap into dependency needs both early and late in the disease process and to measure distinct but related components of disability in AD compared to measures such as the Blessed Dementia Rating Scale (BDRS).[15] It has also been used in economic analyses of Alzheimer's Disease and has been shown to track indirect costs of care more closely than functional capacity as assessed by the BDRS.[16] Little is known regarding the relationship between dependence and caregiver burden. One study reported a significant association which remained independent of number of functional impairments suggesting that dependence may more accurately predict caregiver burden than functional assessment alone.[17] This finding has not been replicated or examined in the context of a more comprehensive assessment of functional status along with other patient variables. The objectives of this study therefore are to determine how patient dependence impacts, if at all, upon caregiver burden, to describe the relationship between dependence and other patient variables such as function, cognitive status, and neuropsychiatric symptoms, and to determine the value of patient dependence as a predictor of caregiver burden in this context.

Methods

Sample

Participants were recruited in the course of the Enhancing Care in Alzheimer's Disease (ECAD) study, which was conducted in 2009, and identified participants from referrals to the memory clinic of a university teaching hospital in Dublin. Inclusion criteria required patients to have received a diagnosis of probable or possible AD or mild cognitive impairment (MCI) and to be aged >50 years. Only community dwelling patients were included. Patients were excluded if they had comorbid illness, which was a significant independent cause of disability (eg, Parkinson's disease or dense hemiplegia), if they lived distant from the hospital or if they did not have a caregiver who was willing and able to complete the required assessments. Local ethics approval was obtained for the study.

Measures

Assessments were completed by a trained nurse and doctor in the patient's home or hospital according to the circumstances. Sociodemographic and medical details were collected as part of a structured questionnaire. A diagnosis of dementia was made according to the *Diagnostic and Statistical Manual of Mental Disorders* (Fourth Edition; *DSM-R IV*).[18] Probable or possible AD was diagnosed according to the NINCDS-ADRDA criteria.[19] Mild cognitive impairment was diagnosed according to international consensus criteria.[20] Diagnoses were made by team consensus (neuropsychologist and consultant geriatrician or psychiatrist) in the memory clinic following neuropsychological assessment together with relevant hematological and neuroimaging investigations. Diagnoses were reviewed and Mini Mental State Examination (MMSE)[21] conducted at the time of recruitment to the study.

Caregiver Burden

Caregiver burden was measured with the Zarit Burden inventory, which is a 22-item self-report instrument where caregivers rate the frequency with which they experience certain stressful aspects of caregiving on a scale from 0 (never) to 4 (nearly always). Responses to the individual items are summed with higher scores indicating a higher degree of burden to give a possible maximum score of 88.[22]

Neuropsychiatric Symptoms

Neuropsychiatric symptoms were assessed with the Neuropsychiatric Inventory (NPI).[23] This is a structured interview completed with the caregiver during which the caregiver is questioned regarding the occurrence of neuropsychiatric symptoms including delusions, hallucinations, agitation, depression, anxiety, euphoria/elation, apathy, disinhibition, irritability/lability, aberrant motor behavior, night time behavior, and appetite change. The frequency and severity of each symptom is recorded and may be multiplied to give a possible maximum score of 12 per symptom or 144 for all symptoms combined.

Patient Function

Patient function was assessed with the Disability Assessment for Dementia (DAD) scale.[24] The DAD is a well-validated, multi-item instrument that assesses 10 activities of daily living and includes 6 instrumental activities of daily living (IADLs; telephoning, performing housework/leisure activities, preparing meals, taking medications, going on an outing, and managing finance/correspondence) and 4 basic activities of daily living (BADLs; dressing, eating, hygiene, and continence). The DAD is based on an interview with the caregiver whereby the caregiver is asked to rate the patient's actual performance on observed activities of daily living over the preceding 2 weeks. Higher scores reflect greater ability to give a potential maximum score of 40 points (23 for IADLs and 17 for BADLs).

Patient Dependence

The Dependence scale[14] is a 13-item measure which is administered to a knowledgeable caregiver and asks questions regarding varying levels of dependence from mild (eg, "does the patient need frequent help finding misplaced objects?") to moderate (eg, "does the patient need to be watched when awake?") and severe (eg, "does the patient have to be fed?"). A dependence score may be derived by summing the 13 items to give a possible maximum score of 15 with greater scores indicating more dependence. In addition, a 6-level ranking of

Table 1. Summary Data Regarding Patient Clinical Characteristics (n = 100)

	Mean	SD (Range)
Cognitive function (MMSE)	20.5	6.4 (1-29)
Neuropsychiatric symptoms (NPI)	24.6	26.5 (0-132)
Activities of daily living (total DAD)	27.2	11.6 (0-40)
IADL subscore	13.1	7.5 (0-23)
BADL subscore	14.0	4.9 (0-17)
Dependence (sum score)	6.4	3.0 (0-14)
Dependence (level)	2.8	1.0 (0-5)
Hours of care (total/month)	121.1	148 (0-525)

Abbreviations: DAD, Disability Assessment for Dementia; MMSE, Mini Mental State Examination; IADL, activities of daily living; BADL, basic activities of daily living; NPI, neuropsychiatric Inventory.

dependence may be determined from level 0 to 5 with level 5 indicating the greatest level of dependence.

Caregiver Time

Total number of hours spent by the primary caregiver supervising the patient and assisting with activities of daily living over the previous month was assessed with the Resource Utilisation in Dementia instrument (RUD-Lite).[25]

Analysis

Statistical analysis was performed with SPSS 16 for Mac. Student's *t* test was used for continuous data and Pearson's chi-square test for dichomotous data as appropriate. The Spearman correlation coefficient was used to investigate the individual relationships between patient variables and caregiver burden. A nominal significance level of $\alpha = .05$ was used. Stepwise backward multivariate regression analyses were conducted to determine which patient variables best predicted caregiver burden.

Results

A total of 100 patients and their caregivers were recruited. The patient sample was 61% female and 68% of patients had spousal caregivers. The mean patient age was 74.5 (SD 8.1) with a mean MMSE of 20.5 (SD 6.4). Eighty-three participants had a diagnosis of AD while the remainder had a diagnosis of mild cognitive impairment (15 amnestic subtypes, 2 nonamnestic). Summary data regarding patient clinical characteristics are outlined in Table 1. The mean caregiver burden score (Zarit burden inventory) was 31.5 (SD 16.8). Caregiver burden was not significantly associated with patient age ($P = .78$), gender ($P = .8$), or relationship to the caregiver ($P = .11$). Patient cognitive status (MMSE) correlated significantly with caregiver burden (rho $= -0/.38$, $P < .001$) as did patient function (DAD, rho $= -.58$, $P < .001$), dependence (sum dependence score, rho $= .52$, $P < .001$), hours of care (total caregiver hours, rho $= 0.33$, $P < .001$), and neuropsychiatric symptoms (NPI, rho $= .52$ $P < .001$). Patient dependence displayed a strong negative correlation with patient function (rho $= -.88$ $P < .001$) and was more closely associated with reported deficits in IADLs (rho $= -.85$ $P < .001$) than BADLs (rho $= -.78$ $P < .001$). Dependence (rho $= .69$ $P < .001$) and total DAD correlated significantly with total caregiver hours (rho $= -.68$ $P < .001$). Cognition demonstrated a larger correlation with functional status (rho $= .5$, $P < .001$) and dependence (rho $= -.4$, $P < .001$) than with neuropsychiatric symptoms (total NPI, rho $= -.25$, $P = .02$) although neuropsychiatric symptoms also displayed a moderately strong correlation with functional impairment (total DAD, rho $= -.65$, $P < .001$) and dependence (rho $= .66$, $P < .001$).

Table 2. Final Stage Backward Stepwise Multiple Regression Models of Caregiver Burden (Including Function) in the Total Sample and Patients with Mild and Moderate-to-Severe Cognitive Impairment Respectively

	Variables Retained	Beta	*P*	R^2
Model 1:	DAD (total score)	−.393	.0001	
(Total sample)	NPI (total score)	.295	.006	.385
Model 2: (MMSE >20)	DAD (total score)	−.569	.0001	.324
Model 3: (MMSE ≤20)	NPI (total score)	.575	.0001	.330

Abbreviations: DAD, Disability Assessment for Dementia; MMSE, Mini Mental State Examination; NPI, neuropsychiatric Inventory.

To determine which patient variables best predicted caregiver burden: cognition (MMSE), neuropsychiatric symptoms (NPI), functional status (DAD), and total caregiver hours were entered into a backward stepwise regression model with the Zarit burden inventory score as the dependent variable. Total DAD score and total NPI score were retained in the optimal model which explained 38.5% of the variance in observed burden (Table 2). The sample was then split into patients with milder impairment (MMSE >20, n = 58) and moderate-to-severe disease (MMSE ≤20, n = 42) to determine whether the relationships changed according to disease severity. The same backward stepwise regression analyses were conducted in both groups. Functional impairment (DAD) was found to be the only significant predictor retained in patients with mild impairment while neuropsychiatric symptoms (NPI) was the only significant predictor in patients with moderate-to-severe disease (Table 2). To determine the predictive ability of the dependence scale as an alternative to the DAD, the predictor variables of cognition, total dependence score, neuropsychiatric symptoms, and hours of care were entered into a backward stepwise regression model which excluded the DAD (given collinearity between the DAD and dependence). The variables of neuropsychiatric symptoms and dependence were retained in the optimal model which explained 35.6% of the variance in observed burden. In patients with mild impairment, dependence and cognition were retained as the optimal predictors, with the larger weight of prediction for dependence, while in patients with moderate-to-severe impairment, neuropsychiatric symptoms remained the most important predictor (Table 3).

Discussion

In this sample, we found that patient dependence displayed good concurrent validity when compared with another

Table 3. Final Stage Backward Stepwise Multiple Regression Models (Including Dependence) of Caregiver Burden in the Total Sample and Patients with Mild and Moderate to Severe Cognitive Impairment Respectively

	Variables Retained	Beta	*P*	R^2
Model 1:	Dependence (total score)	0.318	.003	
(Total sample)	NPI (total score)	.351	.001	.356
Model 2:	Dependence (total score)	.491	.0001	.317
(MMSE >20)	Cognition (MMSE)	−.229	.046	
Model 3:	NPI (total score)	.575	.0001	.330
(MMSE ≤20)				

Abbreviations: DAD, Disability Assessment for Dementia; MMSE, Mini Mental State Examination; NPI, neuropsychiatric Inventory.

well-established measure of functional decline and that this relationship was greater for deficits in IADLs than other activities. In addition, patient dependence correlated closely with total hours of care by the primary caregiver. This is consistent with the proposition that the dependence scale taps into the instrumental assistance and supervision needs of the patient in early AD.

The 3 domains of patient cognitive status, function, and behavioral symptoms all correlated significantly with caregiver burden in this sample of patients with mostly mild-to-moderate impairment. In multivariate analysis, patient dependence and neuropsychiatric symptoms combined to explain 35.6% of the observed variance in caregiver burden. Neuropsychiatric symptoms and functional decline were retained in a marginally superior model which explained 38.5% of the variance in observed burden. Functional decline and patient dependence were most predictive of caregiver burden in patients with mild impairment, while neuropsychiatric symptoms were most predictive in patients with moderate-to-severe impairment. Neuropsychiatric symptoms have been one of the most consistently reported patient predictors of caregiver burden with variable findings or no association reported for measures of cognition and function.[10,11] In this sample, we found that markers of declining function and increasing dependence were more burdensome in the early stages of the disease while behavioral symptoms became more important as the disease progressed. Neuropsychiatric symptoms displayed a significant linear relationship with advancing cognitive decline which is consistent with previous findings in both AD and MCI.[26, 27] It is therefore not surprising that in the initial stages of the disease, time spent assisting and supervising the patient with instrumental activities of daily living may be more burdensome while neuropsychiatric symptoms impose increasing demands with disease progression. Of course, neuropsychiatric symptoms are significantly correlated with both functional decline and increasing patient dependence and it is likely that commonly occurring behavioral symptoms such as depression and anxiety undermine functional ability and increase dependence needs thereby presenting a therapeutic opportunity in a proportion of patients.

The observed correlation between patient cognitive status and function was greater than that observed between cognitive status and neuropsychiatric symptoms. This is consistent with findings that have linked neuropsychiatric symptoms such as apathy and delusions with degeneration of specific frontostriatal and frontoparietal neural networks.[28] The MMSE provides limited assessment of executive function and executive deficits have previously been independently associated with neuropsychiatric symptoms.[29]

This study has a number of strengths and limitations. Strengths include the use of a structured assessment procedure with well-described and validated instruments. In addition, patients underwent standardized diagnostic assessments as part of a memory clinic assessment. Limitations include the fact that findings from this population of patients with mostly mild-to-moderate AD may not be readily extrapolated to patients with more severe impairment. In addition, the cross-sectional nature of the study precludes conclusions regarding causality. We do, however, describe the nature of the relationship between dependence and caregiver burden according to severity of cognitive impairment which has not previously been reported. We also examine the value of patient dependence as an independent predictor of caregiver burden in the context of other relevant patient predictors. The dependence scale, which is a brief and easily administered scale, demonstrated similar if marginally less predictive utility to a more extensive measure of patient function. It is noteworthy that the patient variables included in this analysis accounted for less than half of the observed variance in caregiver burden indicating the importance of additional caregiver and context-related variables which should be addressed as part of a multimodal approach to reduce caregiver burden.

Conclusion

In conclusion, we found that the dependence scale demonstrated good utility as predictor of caregiver burden and correlated well with measures of patient function and hours of care. In this sample, we found that markers of functional decline and increasing dependence were most burdensome in the early stages of the disease while behavioral symptoms were more burdensome in patients with moderate-to-severe disease. Interventions that seek to reduce caregiver burden should address patient dependence, functional decline, and neuropsychiatric symptoms while successful management of the latter will become more critical with disease progression. The dependence scale is a brief and easily administered scale which may be usefully considered in this context.

Declaration of Conflicting Interests

The authors declared no conflicts of interest with respect to the authorship and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research and/or authorship of this article: Elan Pharmaceuticals

(Janssen acquired the Alzheimer Immunotherapy Program from Elan in September, 2009) and Wyeth (which was acquired by Pfizer in October, 2009).

References

1. Ferri CP, Prince M, Brayne C, et al. Global prevalence of dementia: a Delphi consensus study. *Lancet*. 2005;366(9503):2112-2117.
2. Gaugler JE, Davey A, Pearlin LI, Zarit SH. Modeling caregiver adaptation over time: the longitudinal impact of behavior problems. *Psychol Aging*. 2000;15(3):437-450.
3. Vitaliano PP. A model of burden in caregivers of DAT patients. In: E Light, BD Lebowitz, eds. *Alzheimer's Disease Treatment and Family Stress*. New York: Hemisphere Publishing Corporation; 1990:267-291.
4. Schulz R, O'Brien AT, Bookwala J, Fleissner K. Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. *Gerontologist*. 1995;35(6):771-791.
5. Clipp EC, George LK. Psychotropic drug use among caregivers of patients with dementia. *J Am Geriatr Soc*. 1990;38(3): 227-235.
6. Vitaliano PP, Zhang J, Scanlan JM. Is caregiving hazardous to one's physical health? A meta-analysis. *Psychol Bull*. 2003;129(6):946-972.
7. Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *Jama*. 1999;282(23):2215-2219.
8. Luppa M, Luck T, Brahler E, Konig HH, Riedel-Heller SG. Prediction of institutionalisation in dementia. A systematic review. *Dement Geriatr Cogn Disord*. 2008;26(1):65-78.
9. Pinquart M, Sorensen S. Helping caregivers of persons with dementia: which interventions work and how large are their effects? *Int Psychogeriatr*. 2006;18(4):577-595.
10. Coen RF, Swanwick GR, O'Boyle CA, Coakley D. Behaviour disturbance and other predictors of carer burden in Alzheimer's disease. *Int J Geriatr Psychiatry*. 1997;12(3):331-336.
11. Black W, Almeida OP. A systematic review of the association between the behavioral and psychological symptoms of dementia and burden of care. *Int Psychogeriatr*. 2004;16(3):295-315.
12. Etters L, Goodall D, Harrison BE. Caregiver burden among dementia patient caregivers: a review of the literature. *J Am Acad Nurse Pract*. 2008;20(8):423-428.
13. Campbell P, Wright J, Oyebode J, et al. Determinants of burden in those who care for someone with dementia. *Int J Geriatr Psychiatry*. 2008;23(10):1078-1085.
14. Stern Y, Albert SM, Sano M, et al. Assessing patient dependence in Alzheimer's disease. *J Gerontol*. 1994;49(5):M216-M222.
15. Brickman AM, Riba A, Bell K, et al. Longitudinal assessment of patient dependence in Alzheimer disease. *Arch Neurol*. 2002;59(8): 1304-1308.
16. Zhu CW, Leibman C, McLaughlin T, et al. The Effects of Patient Function and Dependence on Costs of Care in Alzheimer's Disease. *J Am Geriatr Soc*. 2008;56(8):1497-1503.
17. Lacey L, McLaughlin T, Mucha L, Grundman M, Black R. Relationship between patient dependence on others and caregiver burden in Alzheimer's disease. *Alzheimer's Dement*. 2009;5(4): 229-230.
18. APA. *Diagnostic and Statistical Manual of Mental Disorders.* Revised 4 ed. Washington DC: American Psychiatric Press; 1994.
19. McKhann G, Drachman D, Folstein M, Katzman R, Price D, Stadlan EM. Clinical diagnosis of Alzheimer's disease: report of the NINCDS-ADRDA Work Group nder the auspices of Department of Health and Human Services Task Force on Alzheimer's Disease. *Neurology*. 1984;34(7):939-944.
20. Winblad B, Palmer K, Kivipelto M, et al. Mild cognitive impairment–beyond controversies, towards a consensus: report of the International Working Group on Mild Cognitive Impairment. *J Intern Med*. 2004;256(3):240-246.
21. Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res*. 1975;12(3):189-198.
22. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist*. 1980;20(6):649-655.
23. Cummings JL, Mega M, Gray K, Rosenberg-Thompson S, Carusi DA, Gornbein J. The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia. *Neurology*. 1994;44(12):2308-2314.
24. Gelinas I, Gauthier L, McIntyre M, Gauthier S. Development of a functional measure for persons with Alzheimer's disease: the disability assessment for dementia. *Am J Occup Ther*. 1999;53(5): 471-481.
25. Wimo AW, B. Resource utilization in dementia: RUD Lite. *Brain Aging*. 2003;3(1):48-59.
26. Steinberg M, Shao H, Zandi P, et al. Point and 5-year period prevalence of neuropsychiatric symptoms in dementia: the Cache County Study. *Int J Geriatr Psychiatry*. 2008;23(2): 170-177.
27. Gallagher D, Coen RF, Kilroy D, et al. Anxiety and behavioural disturbance as markers of prodromal Alzheimer's disease in patients with mild cognitive impairment. *Int J Geriatr Psychiatry.* 2010 (IN PRESS).
28. Bruen PD, McGeown WJ, Shanks MF, Venneri A. Neuroanatomical correlates of neuropsychiatric symptoms in Alzheimer's disease. *Brain*. 2008;131(Pt 9):2455-2463.
29. Chen ST, Sultzer DL, Hinkin CH, Mahler ME, Cummings JL. Executive dysfunction in Alzheimer's disease: association with neuropsychiatric symptoms and functional impairment. *J Neuropsychiatry Clin Neurosci*. 1998;10(4):426-432.