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## Predicting Caregiver Burden from Daily Functional Abilities of Patients with Mild Dementia

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### Abstract

**OBJECTIVES**—To assess the relationship between performance- and informant-based measures of activities of daily living (ADLs) in patients with early dementia and burden or psychological distress experienced by the patients' caregivers.

**DESIGN**—Descriptive study.

**SETTING**—Ambulatory center.

**PARTICIPANTS**—Thirty-four patient-caregiver dyads in which the patient had mild dementia (Mini-Mental State Examination score  $\geq 17$ ).

**MEASUREMENTS**—A performance-based ADL measure (the Direct Assessment of Functional Status (DAFS)) was administered to patients with mild dementia. Caregivers completed an informant-based measure of patient functional status (instrumental activities of daily living). Caregivers also completed the Caregiver Burden Inventory (CBI) and the Brief Symptom Inventory (BSI).

**RESULTS**—Significant correlations were found between the informant-based ADL measure and caregiver burden (CBI) and psychological distress (BSI) (correlation coefficient ( $r$ ) =  $-0.34$  to  $-0.71$ , all  $P < .05$ ). Alternatively, fewer and weaker relationships were observed between the DAFS (performance-based) ADL measure and caregiver burden or distress ratings ( $r$  =  $-0.32$  to  $-0.43$ , all  $P < .05$ ). Of the seven tasks assessed using the DAFS, impairments in orientation, communication, financial, and transportation skills in patients were associated with greater time and developmental burden and greater hostility in caregivers. Impairment in financial skills in patients was the strongest

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predictor of time-dependence burden and hostility in caregivers, whereas impairment in patient transportation skills was the best predictor of developmental burden.

**CONCLUSIONS**—The ADL abilities of cognitively impaired patients can predict caregiver burden and psychological distress, with informant-based measures having the greatest association with patient impairment.

### Keywords

activities of daily living; observation-based ADLs; informant-based ADLs; functional assessment; caregiver burden; caregiver psychological distress; functional ability; dementia; cognitive impairment

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Most older individuals with dementia live in the community<sup>1</sup> and often survive an average of 8 years (range 3–25 years) postdiagnosis.<sup>2</sup> A number of factors, including age at diagnosis and the severity of other medical conditions, determine average survival time.<sup>3</sup> According to a study conducted in 1996 by the National Alliance for Caregiving and the Alzheimer's Association, more than 70% of caregivers are relatives who provide care at home. Furthermore, approximately 75% of caregivers are women between the ages of 35 and 64.

A growing body of literature on the caregivers of patients with dementia indicates that these individuals experience physical, psychological or emotional, social, and financial problems.<sup>4</sup> A study<sup>5</sup> using a brief screening measure to characterize cognitive impairment in patients with Alzheimer's disease found that patients' cognitive scores played a significant role in predicting the amount of time caregivers spent caring for the patient. A number of recent studies have found that caregivers of patients with dementia frequently report physical and emotional distress and that the most common complaints among caregivers include anger, depression, guilt, worry, feeling of isolation, and marital stress.<sup>6–13</sup> One study found that caregivers of patients with cognitive impairment who displayed high levels of anxiety and depression also showed high levels of care-giver burden.<sup>14</sup>

Less research has been conducted examining the relationship between patients' specific functional impairments and the burden and psychological distress experienced by caregivers. One study<sup>15</sup> revealed that scores of dementia patients on the Mini-Mental State Examination (MMSE) and behavioral inventories were related to the burden reported by caregivers. They also found significant associations between caregiver burden and a nonobservation-based activity of daily living (ADL) scale over a 2-year observation period. Similarly, another study<sup>16</sup> found that, when dementia severity surpassed a threshold of MMSE (< 20), the level of involvement with making medical decisions for the patient and burden increased for caregivers. A third study<sup>17</sup> found that burden ratings by caregivers of patients with mild dementia correlated more strongly with a caregiver-rated ADL measure than with a rater-observed ADL (patient functional) measure. This suggests that a caregiver's level of burden may affect his or her perception of the patient's ability or disability level.

The literature suggests that a large number of patients with cognitive impairment dwell in the community and are cared for by relatives who experience significant burden and that there may be a relationship between the patient's cognitive impairment and functional abilities and the level of caregiver burden.

The present study was designed to assess the performance-based and caregiver-rated ADLs of patients with relatively mild cognitive impairment and their relationship to the burden and psychological distress experienced by caregivers. An additional objective was to identify how well specific functional abilities of patients predict caregiver burden.

## METHODS

### Participants

Thirty-four patients with various forms of mild cognitive impairment and their caregivers (26 spouses, 4 children, and 4 other kin) participated. The dyads selected for this project were dementia patients participating in a larger research study comparing functional status of older people with and without dementia funded by the National Institutes of Health. As part of the larger study, patients completed approximately 2.5 hours of testing, including the ADL tasks and a neuropsychological test battery that involved tests of memory, abstract reasoning, language, and information processing domains. The cognitively impaired patients were recruited from four sites, including an Alzheimer's Association center, a hospital-based geriatric center, a Veterans Affairs healthcare center, and a university-based Alzheimer's disease center.

All patients were referred to the study with a predetermined diagnosis of dementia, based on a standard clinical evaluation by their primary physician or neurologist and neuropsychologist. Of the total 34 patients recruited, 23 were diagnosed with Alzheimer's disease, five with vascular dementia, and five with frontotemporal dementia, and one was given a *Diagnostic and Statistical Manual of Mental Disorders* diagnosis of dementia not otherwise specified. The demographic information for the patients and caregivers, including age, education level, and MMSE scores can be found in Table 1. As can be seen from this table, the patients and caregivers were on average nearing the end of their seventh decade of life and were relatively well educated. The patients were in the mild stages of dementia (as indicated by their MMSE scores) and resided at home with their caregivers.

All dyads were paid for their participation. Written informed consent was obtained from all patients and their caregivers. The institutional review boards at the California State University, Northridge, and the Veterans Affairs Greater Los Angeles Healthcare System approved the study.

### Measures

**The Direct Assessment of Functional Status**—This Direct Assessment of Functional Status (DAFS), a direct observation measure of ADLs, was administered to all patients. Seven functional abilities are assessed using the DAFS<sup>18</sup>.

- Time orientation: assesses the patient's orientation to person, place, and time
- Communication skills: demonstrates the patient's abilities such as dialing a telephone, mailing a letter, and writing a check
- Transportation skills: identifies the patient's knowledge of road signs and driving rules
- Financial skills: assesses the patient's ability to perform tasks such as balancing a checkbook or counting correct change
- Shopping skills: assesses the patient's ability to "shop" from a mock grocery store (by having patients recall shopping items they are provided to memorize and by providing a written shopping list)
- Grooming abilities: demonstrates the patient's ability to perform certain basic skills, including ability to comb hair or use a toothbrush
- Eating ability: demonstrates the patient's ability to perform tasks such as using utensils

Examiners presented the specific tasks to the patients and rated their ability based on observed performance. In the present sample, all participants obtained perfect scores on the grooming and eating subscales; therefore, the analyses focused on the total DAFS and the remaining five subscales: time orientation, communication, transportation, financial, and shopping skills.

**Instrumental Activities of Daily Living**—The instrumental activity of daily living (IADL)<sup>19</sup> scale is a modified version of the Lawton and Brody<sup>20</sup> ADL measure. It assesses intermediate abilities such financial management and ability to shop as well as basic functional ability (e.g., bathing, feeding, grooming). In the present study, caregivers rated the patient on each of the 13 functional areas on a 3-point Likert scale with a total possible score of 26. Higher scores indicate higher functioning.

Several aspects of caregiver burden were assessed using two different measures.

**Caregiver Burden Inventory**—The Caregiver Burden Inventory (CBI)<sup>21</sup> is a 24-item, self-rated questionnaire. Each question is rated on a 5-point Likert scale. This instrument has been shown to be valid and reliable and assesses multiple dimensions of caregiver burden. Research has also demonstrated that the items cluster into five factors that are designed to assess the following different aspects of caregiver burden:

- *Time-dependence* is the perceived burden due to restrictions on a caregiver's time imposed by the demands of caring for the patient.
- *Developmental burden* includes perceived feelings by the caregiver that they are “out of sync” with their peers or feelings of missing out on life.
- *Physical burden* describes chronic fatigue and damage to physical health of caregivers given the demands of caring for the patient.
- *Social burden* refers to conflicts with other family members about care decision, or feelings of isolation such as not having time to maintain social relationships.
- *Emotional burden* describes a caregiver's negative feelings toward the care receiver, compounded by the caregiver's subsequent feelings of guilt for having these socially unacceptable feelings.

Scores range from 0 to 96, with higher scores indicating greater feelings of burden.

**The Brief Symptom Inventory**—The Brief Symptom Inventory (BSI)<sup>22</sup> is a 53-item, multidimensional measure of psychiatric symptomatology that has been shown to assess caregiver distress in previous studies.<sup>23</sup> Participants are asked to rate how much in the previous week specific symptoms distressed them on a scale from not at all (0) to extremely (4). Nine subscale scores are obtained (high scores indicate elevated distress) from this measure. The outcome measures of interest for this study were three subscale scores: depression, anxiety, and hostility. Previous research has shown these three subscales of the BSI to be most important when assessing psychological distress in caregivers of patients with dementia, with the hostility and anxiety scales most specifically associated with caregiver burden.<sup>23</sup>

## Data Analysis

Bivariate correlations were conducted to assess the relationships between the patients' DAFS and IADL scores (as rated by the caregivers) and the caregivers' CBI, BSI, and various demographic variables. To determine the unique variability accounted for by the patients' functional abilities in caregiver distress, stepwise regression analyses using the caregiver burden and psychological indices as the independent variable and observational (DAFS) subscale measures as the dependent variables were performed.

## RESULTS

Table 1 shows the average burden and psychological distress experienced by caregivers. It appears that the caregivers reported moderate burden on the CBI and moderate levels of hostility, anxiety and depression on the BSI scale.

Table 2 reveals stronger correlations between the informant (caregiver)-rated functional abilities of the patient (i.e., the I-ADL) and specific domains of caregiving and psychological distress than between the performance-based ADL task (i.e., the DAFS) and specific domains of caregiving and psychological distress. Relatively strong correlations were found between the informant-rated ADL and the CBI total score, the CBI time dependence subscale, and the CBI developmental burden subscale. Moderate correlations were found between the informant-rated ADL and CBI emotional burden subscale, the BSI depression index, and the BSI hostility index. There were fewer and weaker correlations between the performance-based ADL measure (i.e., the DAFS) and the caregiver measures. It appears that the patients' DAFS communication, transportation, and financial skills correlated best with caregivers' CBI time dependence, whereas the patients' DAFS orientation and transportation correlated most closely with the caregivers' CBI developmental burden. The patients' DAFS scores correlated only with the BSI hostility subscale, not the BSI depression or anxiety ratings. Specifically, patients' DAFS orientation, communication, financial and to some degree shopping skills correlated with the caregivers' hostility ratings.

The final set of analyses was performed to determine the unique variability the observation-based (DAFS) daily functioning in patients accounted for in the specific domains of caregiver burden and psychological distress. Table 3 presents the results of the stepwise regression analyses using the DAFS subscales as the dependent variables and the CBI subscales and BSI domains as the independent variable. The results indicate that the patients' DAFS financial scores uniquely accounted for variability in the caregivers' CBI time dependence and hostility ratings (approximately 14% and 15% of the variability, respectively). Additionally, the patients' DAFS transportation scores uniquely accounted for approximately 9% of the variability in caregivers' CBI developmental scores.

## DISCUSSION

The purpose of the present study was to investigate the association between patients' functional abilities (as measured using a performance-based and a caregiver-rated instrument) and their caregivers' level of burden and psychological distress. A number of interesting findings were revealed.

It appears that there are greater numbers of significant correlations, with larger magnitude of relationship, between the caregiver-rated assessment of patient ADLs and the caregivers' own reported burden and psychological distress than between the performance-based measure of ADLs and caregiver burden and psychological distress. These correlations suggest that the caregivers who reported restrictions in their time, problems in their development relative to peers, greater physical problems, poorer emotional well-being, greater feelings of hostility, and greater depression tended also to rate functioning low in patients. These findings are not surprising and are consistent with previous reports. One study found that caregivers tend to rate patients' functional abilities in most domains lower than those measured through observation.<sup>17</sup> They posit that this is likely, because caregivers' own level of burden in caring for the patient influences their judgment ratings for what the patient is able to perform. Previous studies that have examined self- and informant reports of functional ability in healthy older adults have found that the informants who spend more time helping the subject tend to rate the subject as less capable than do the subjects themselves.<sup>24</sup> Similarly, other studies have

demonstrated that the closer the relationship is between the patient and the caregiver, the more likely the caregiver is to rate the patient's daily functional impairments as greater.<sup>25,26</sup> Given that the caregivers were relatives who resided with the patient and spent a great amount of time caring for the patient, it is not surprising that there is a strong association between caregivers' level of distress and their perceptions about the patients' functional ability. These findings, combined with those in the literature, would suggest that caregivers tend to align their perception of the patient's functional ability with their own level of burden and the psychological distress caused by caring for the patient. Thus, as the caregiver's stress and burden in caring for the patient increases, their judgment about what the patient is capable of performing tends to decrease. For this reason, caution is advised against using proxy (e.g., caregiver-rated) ADL estimates as the sole measure of patients' functional capacity.

The finding of fewer and weaker relationships between caregiver distress and patients' functional ability when assessed using a performance-based measure than when using an informant-based measure is interesting. Surprisingly, there was a relationship between only two areas of caregiver burden (time dependence and developmental burden) and the patients' overall functional ability as measured according to the observation test. This is also consistent with previous findings<sup>17</sup> and implies that there may be other factors, aside from the patients' actual abilities, that contribute to a caregiver's feelings of distress. Furthermore, the current results imply that patients' functional disabilities directly relate to time pressures and caregivers' feelings of being out of synchrony with their peers. Also, the lower the patient's functional ability, the greater the hostility reported by the caregiver. These findings can be useful when planning treatment for patients and their caregivers.

A third interesting outcome is that not all observed functional impairments create burden for caregivers. In the present study, transportation needs, disorientation, and lack of financial skills in the patient were associated with the greatest burden in terms of time demands and other restrictions in caregivers. Similarly, transportation needs and disorientation in patients were more strongly related to caregivers' sense of being out of sequence or "off time" in development relative to peers. Observed functional disability in patients did not appear to be related to other various aspects of caregiver burden such as physical, social, and emotional. In terms of the caregivers' psychological distress, areas of the patients' functional disability (with the exception of transportation dependence) tended to be related to caregivers' ratings of hostility but not anxiety or depression. The lack of relationship between caregiver depression and patient functioning has been reported,<sup>17,23</sup> although given the reported relationship between caregiver burden and anxiety,<sup>23</sup> a relationship between caregiver anxiety and patients' functional ability was expected. The current results would suggest that, as the functioning of the patient declines (in almost every domain), feelings of hostility rise in caregivers, which may be detrimental to the relationship between the patient and caregiver.

Finally, specific disabilities in patients predicted caregiver experience. Patients' ability to manage finances was the single most significant predictor of time dependence burden and hostility experienced in the caregiver. This implies that, of all of the functional impairments the patient displays, the need for the caregiver to take over the financial responsibilities of the household (e.g., write checks, balance the checkbook) creates the greatest time demand and leads to feelings of hostility. Similarly, transportation dependence in the patient was the single best predictor of developmental burden in the caregiver. These results also seem to fit within the context and demographic composition of the sample. The majority of the caregivers in the sample were female and spouses (77% and 76%, respectively) of the patient. It could be speculated that, before the dementing illness, the family had traditional roles, with the husband handling the financial and driving demands. The current role reversal, in addition to all of the other changes and demands on the caregiver, may be leading to greater hostility and resentment. Unfortunately, data were not available regarding how the household responsibilities were

distributed before the patient's illness. Obtaining such information in future studies would allow for more in-depth interpretation of the current results.

The findings from the current study provide some practical application for practitioners who treat patients with dementia and their families. Taken together, the results suggest that, when functional impairments are observed in patients, or even reported by the caregivers, healthcare providers can alert caregivers to the types of burden and psychological distress they are likely to experience. For example, the data would suggest that caregivers are likely to feel burdened emotionally and physically, in terms of their time and their feelings of being in synchrony with their peer groups. They are less likely to feel socially burdened by cognitive impairments displayed by the patient they care for. Additionally, healthcare providers should be alerted to the fact that functional disability in the patient may lead to hostility and anxiety in caregivers, more so than depression. This information can aid healthcare providers in assisting caregivers with finding appropriate support groups and, if necessary, respite care, given that, as functional impairments increase in patients, so does the aforementioned burden and psychological distress.

## CONCLUSIONS

The findings of the current study indicate that healthcare professionals can use level of functioning of patients with dementia to predict the type and degree of burden and psychological distress a caregiver is likely to experience. Informant- and observation-based ADL tests should be administered to patients with dementia whenever possible. Caregiver ratings of a patient's ADLs appear to predict burden and psychological distress in caregivers better than observation-based ADLs. This is most likely because caregivers' own feelings of burden affect their subjective ratings of the patient's abilities. For this reason, observation-based tasks most likely provide a more-accurate indication of the patients' true abilities but are not as likely to predict the caregiver's level of burden.

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Table 1

Patient and Caregiver Demographic Information

Demographic Information	N	Age	Education	Mini-Mental State Examination	Caregiver Burden Inventory	Hostility	Anxiety	Depression
		Mean ± Standard Deviation						
Participant								
Alzheimer's disease	23	73.2 ± 7.0	15.9 ± 3.3	23.1 ± 6.3	—	—	—	—
Frontotemporal dementia	5	61.5 ± 6.4	13.0 ± 1.3	21.3 ± 9.0	—	—	—	—
Vascular dementia	5	75.0 ± 7.0	13.2 ± 1.8	23.2 ± 4.2	—	—	—	—
Dementia not otherwise specified	1	65.0 ± 0.0	16.0 ± 0.0	24.0 ± 0.0	—	—	—	—
Caregivers	34	69.8 ± 10.6	14.4 ± 2.7	—	21.3 ± 17.6	2.2 ± 2.8	3.0 ± 3.1	2.8 ± 3.0

Correlations Between Patients' Functional Ability and Caregiver Burden or Distress

Table 2

Caregiver Burden	Tests and Subtests of Patient Functional Ability Tests							Informant-Rated Activities of Daily Living
	DAFS Total	DAFS Orientation	DAFS Communication	DAFS Transportation	DAFS Financial	DAFS Shopping		
Caregiver Burden Inventory								
Total score	-0.31**	-0.30	-0.23	-0.28	-0.20	-0.24	-0.55***	
Time dependence	-0.41**	-0.32 <sup>+</sup>	-0.34*	-0.37*	-0.41**	-0.28	-0.71***	
Developmental burden	-0.34*	-0.34*	-0.20	-0.35*	-0.25	-0.26	-0.60***	
Physical burden	-0.23	-0.21	-0.19	-0.27	-0.13	-0.15	-0.37*	
Social burden	-0.15	-0.23	-0.06	-0.12	-0.01	-0.15	-0.13	
Emotional burden	-0.05	-0.06	-0.10	-0.07	-0.11	-0.09	-0.34*	
Brief Symptom Inventory								
Depression	-0.11	-0.02	-0.13	-0.10	-0.11	0.01	-0.43*	
Anxiety	-0.28**	-0.22*	-0.29	-0.31	-0.29**	-0.01	-0.30*	
Hostility	-0.43***	-0.32*	-0.37	-0.12	-0.42	-0.31	-0.43*	

DAFS =Direct Assessment of Functional Status.

\*  $P < .05$ ,

\*\* .01,

\*\*\*.001.

**Table 3**  
 Results of Stepwise Regression Analyses with Caregiver Burden and Psychological Distress Measures Entered as the Independent Variable and Observational Subscale Measures Entered as the Dependent Variables

Caregiver Subscale Measure	Direct Assessment of Functional Status Variable Entered	Adjusted Coefficient of Determination	Standardized B	F-Value	P-Value
Caregiver Burden Inventory					
Time dependence	Financial	0.14	-0.41	6.47	.01
Development	Transportation	0.09	-0.35	4.40	.04
Physical	—	—	—	—	—
Social	—	—	—	—	—
Emotional	—	—	—	—	—
Brief Symptom Inventory					
Depression	—	—	—	—	—
Anxiety	—	—	—	—	—
Hostility	Financial	0.15	3 0.42	6.73	.01