Subjective appraisal of Alzheimer's disease caregiving: The role of self-efficacy and depressive symptoms in the experience of burden

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Abstract

Most studies investigating correlates of Alzheimer's disease (AD) caregiver burden have focused on the role of objective factors as opposed to subjective factors. Although objective variables (e.g., caregiver age, patient dementia severity, functional status) have been shown to be significantly associated with burden, the correlations generally are modest and explain relatively little of the variability in caregiver outcomes. Moreover, many of these objective variables are not modifiable and are of limited use in the development of caregiver interventions. Thus, there continues to be a need to identify powerful and modifiable determinants of caregiver burden. This study examined the role of two subjective factors—self-efficacy and depressive symptoms—as predictors of AD caregiver burden. Based on a sample of 80 AD caregivers, hierarchical regression analyses revealed that self-efficacy and depressive symptoms each had a significant independent effect on the experience of burden even after accounting for objective factors. These findings suggest that caregiver interventions aimed to reduce burden may benefit from the incorporation of specific strategies to increase self-efficacy and decrease depressive symptoms.

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Introduction

Most of the 4.5 million Americans with Alzheimer's disease (AD) live at home and rely on family caregivers for assistance with daily living and self-care tasks, and the social, emotional, and financial burdens experienced by caregivers are well established. Family caregivers often are challenged to manage the symptoms of AD without adequate understanding of the disease course and its impact on cognition and behavior. Compared to their noncaregiver counterparts, AD caregivers are at increased risk for medical and psychiatric morbidities, including depression and anxiety,[1,2] and are more frequent users of healthcare services. Over one-half of the 100 billion dollars spent annually on AD-related services are attributable to the treatment of caregivers, as opposed to patients. Moreover, these costs are expected to rise dramatically as the number of individuals with AD increases from 4.5 million to an estimated 16 million over the next 40 years.[3]

Within the field of gerontology, the construct of caregiver burden has been broadly defined and incorporates the physical, psychological, social, and financial aspects of caregiving. Burden is thought to be the outcome of the chronic stress associated with caregiving. Although it is widely recognized that caregiving can also result in negative psychological responses such as depressive symptoms,[2] it is important to consider that such negative affective responses themselves may contribute directly to burden, and that burden can be differentiated from

negative psychological states such as depression.[4,5] Thus, although there is some degree of conceptual overlap between burden and affective states such as depression, research suggests that not all of the variance between these constructs is shared, indicating that they are different but related constructs.[5]

Recognition of the public health consequences of caregiver burden has prompted interest in interventions that effectively reduce the burden experienced by AD caregivers. However, most interventions to date have yielded, at best, only modest reductions in caregiver burden.[2,6,7] One potential explanation for their limited success is a lack of detailed knowledge regarding the subjective aspects of the caregiving experience. That is, most studies investigating the correlates of caregiver burden have examined the role of objective factors, as opposed to subjective factors. Whereas objective factors including caregiver demographic variables (e.g., gender, age, race, and relationship to the patient)[2,8,9] and patient variables (e.g., dementia severity, functional status, and neuropsychiatric symptoms)[10-12] have been shown to be significantly associated with burden, the correlations between objective factors and burden generally are small to moderate and explain relatively little of the variability in caregiver outcomes.[2] Moreover, many of the objective variables studied are not modifiable and, therefore, are of limited use in the development of caregiver interventions. Thus, there is an emergent need to identify powerful and modifiable determinants of caregiver burden.

Subjective aspects of the caregiving experience are understudied yet important and potentially modifiable determinants of caregiver burden. Subjective aspects include caregivers' appraisals of their own psychological state and resources, and it has been postulated that subjective factors, such as sense of self-efficacy and depression, may in fact be the primary determinants of burden.[13] Self-efficacy, described as the basis for "human motivation, well-being, and personal accomplishment,"[14] is thought to be a fluid psychological attribute that affects motivation and behavioral persistence for specific tasks.[14-16] As self-efficacy refers to an individual's perceived ability to successfully manage the demands of a particular situation, it follows that caregivers with high self-efficacy may view the caregiving situation as more manageable and, therefore, less burdensome.[17,18] Depressive symptoms also may influence perceptions of burden because they are related to caregivers' appraisals of their capacity to cope with the demands of the caregiving situation.[19]

Although relatively few studies have examined the role of subjective factors among AD caregivers, preliminary findings suggest that low self-efficacy is associated with increased burden, negative health behavior changes, and poor response to interventions among caregivers of cognitively impaired individuals.[18] Research findings also support an association between depressive symptoms and burden among dementia caregivers; depressive symptoms emerged as the single best predictor of caregiver burden in at least one study.[4] Importantly, however, depressive symptoms have not been studied specifically in conjunction with self-efficacy among AD caregivers.

The purpose of this study was to examine the extent to which self-efficacy and depressive symptoms contribute to burden among AD caregivers. Through the study's focus on the subjective aspects of caregiving, we sought to expand our understanding of how caregivers' psychological state and resources may influence the degree of burden experienced to facilitate the development of more effective AD caregiver interventions. Specific hypotheses were as follows:

1. In bivariate analyses, self-efficacy and depressive symptoms will be more strongly correlated with burden than previously studied objective variables (e.g., caregiver age, patient dementia severity, functional status).

2. In multivariate analyses, self-efficacy and depressive symptoms combined will explain a significant proportion of the variance in caregiver burden, even after accounting for objective variables.

3. In multivariate analyses, self-efficacy will independently explain a significant proportion of the variance in caregiver burden, even after accounting for objective variables and depressive symptoms.

Exploratory analyses also were conducted to examine the extent to which these subjective variables could discriminate between caregivers with varying degrees of burden.

Methods

Participants

Participants were 80 AD caregiver-patient dyads enrolled in a caregiver-based, behavioral intervention study designed to reduce neuropsychiatric symptoms among AD patients and to decrease caregiver burden. The data reported in this study were collected at the baseline assessment (pre-intervention), before participant randomization. Participants were recruited from the

Table 1. Mean scores for the assessment measures		
Measure	**Mean (SD)**	**Range**
Patient variables		
Dementia severity	16.9 (5.9)	10 to 29
Neuropsychiatric symptoms	22.0 (13.4)	2 to 58
Functional status	11.0 (7.2)	2 to 25
Caregiver variables		
Depressive symptoms	6.8 (6.4)	0 to 24
Symptom management self-efficacy	31.9 (9.1)	11 to 50
Social support self-efficacy	30.0 (7.3)	12 to 40
Burden	17.8 (8.0)	1 to 37
SD, standard deviation.		

greater Boston, Massachusetts metropolitan area via newspaper advertisements, flyers, community-based lectures, and referrals from elder day programs. Criteria for study inclusion were as follows:

1. the caregiver provides a weekly minimum of four hours of in-home caregiving;

2. the care recipient carries a physician-confirmed diagnosis of AD;

3. the patient's dementia severity falls in the mild-moderate range, as determined by a Mini-Mental State Examination (MMSE)[20] score of 10 or higher; and

4. the care recipient has at least one neuropsychiatric symptom at the time of enrollment.

The sample of caregivers included 56 spouses or partners and 24 adult children of AD patients. The majority of caregivers were female (64 percent) and white (94 percent). The average age of the caregivers was 64.8 years [standard deviation (SD), 3.7 years]. The vast majority of caregivers (90 percent) lived with the individual with dementia, and the average length of caregiving was 3.4 years (SD, 2.5 years).

Measures

Caregiver burden: Burden was measured using an abridged version of the Zarit Burden Interview.[21] This 12-item interview assesses those aspects of caregiving

most frequently described as burdensome, including patient needs, patient/caregiver interactions, caregiver well-being, and social functioning. Individual items are rated on a 5-point scale ranging from "never" (score = 0) to "nearly always" (score = 4), with higher scores reflecting greater burden.

Caregiver depressive symptoms: Caregiver depressive symptoms were assessed using the Modified Hamilton Rating Scale for Depression (modified Ham-D).[22] This 17-item, clinician-administered interview assesses depressive symptoms including dysphoria, insomnia, helplessness, and hopelessness. Individual items are rated as present or absent and are scored for symptom severity, with higher scores reflecting more depressive symptoms.

Caregiver self-efficacy: Self-efficacy was measured using the Fortinsky Self-Efficacy Questionnaire.[15] This 10-item, clinician-administered scale measures two domains: dementia symptom management and use of support services. Caregivers are asked to rate their level of certainty regarding their ability to perform various caregiving activities (e.g., deal with frustrations of caring for a loved one, handle problems a loved one has like memory loss, wandering, or behavior) using a 10-point scale, with 1 being "not at all certain" and 10 being "very certain." Individual item scores are summed to provide a total score for each scale, with higher scores indicating greater self-efficacy.

Patient dementia severity: Severity was measured using the MMSE,[20] a brief cognitive screening instrument. Total scores range from 0 to 30, with higher scores reflecting more intact cognition.

Patient neuropsychiatric symptoms: Neuropsychiatric

Table 2. Bivariate correlations between predictor variables and burden	
Predictor variables	**Correlation (r) with caregiver burden**
Dementia severity	–0.04
Neuropsychiatric symptoms	0.24*
Functional status	–0.19
Caregiver variables	
Depressive symptoms	–0.44**
Symptom management self-efficacy	–0.48**
Social support self-efficacy	–0.25*
* p < 0.05; ** p < 0.001.	

symptoms were assessed using the Neuropsychiatric Inventory (NPI).[23] This clinician-administered interview assesses the frequency and severity of patient neuropsychiatric disturbances. Ten neuropsychiatric symptoms are assessed, including delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability/lability, and aberrant motor behavior. Symptom frequency is rated on a scale of 1 to 4, with 1 being "occasionally, less than once per week" and 4 being "very frequently, once or more per day." Scores are then summed to provide a total symptom frequency rating. Symptom severity is rated on a scale of 1 to 3, with 1 being "mild" and 3 being "marked." Frequency and severity scores are then multiplied to provide a total score, with higher scores reflecting greater neuropsychiatric impairment.

Patients' functional abilities: Functional abilities were measured using the Lawton & Brody Activities of Daily Living Questionnaire.[24] This scale consists of eight questions pertaining to instrumental activities of daily living (e.g., ability to handle finances, perform housekeeping tasks, manage medications, cook) and six pertaining to basic activities of daily living. An item score of 0 reflects complete independence in performing the task, 1 reflects the need for some assistance, and 2 reflects complete dependence on others for task performance. Higher total scores indicate poorer functional performance.

Statistical methods

First, descriptive statistics and bivariate associations between variables were examined. Next, two multiple regression analyses were estimated hierarchically by entering the predictor variables in accordance with the hypotheses. The two-tailed p-value of < 0.05 was used as the cutoff for statistical significance. Finally, a discriminant function analysis was performed to further explore the predictive power of the two subjective factors, self-efficacy and depression.

Results

Mean scores on the assessment measures are presented in Table 1. The caregivers, on average, indicated a relatively mild degree of depressive symptoms, a moderate sense of self-efficacy, and a moderate level of caregiver burden. Mean scores on the patient measures indicated moderate degrees of dementia and functional impairment, and a mild to moderate degree of neuropsychiatric symptoms.

Bivariate Pearson correlations between the predictor variables and caregiver burden are presented in Table 2. As hypothesized, depressive symptoms and self-efficacy were more strongly associated with burden than previously studied objective caregiver demographic and patient variables. Intercorrelations between predictor variables consistently fell below 0.4 and therefore are not believed to reflect colinearity.

A multiple regression analysis was used to examine the contributions made by depressive symptoms and self-efficacy to caregiver burden. Because we were interested in the contribution of these subjective variables after accounting for the objective variables, the predictors were entered in the following order: caregiver age and patients' MMSE scores at step 1, and Ham-D and self-efficacy scores at step 2. As shown in Table 3, the model was significant and explained a total of 54 percent of the

Table 3. Results of primary multiple regression predicting caregiver burden: Model 1		
	B	β
Step 1		
Caregiver age	−0.27*	−0.45
Patient dementia severity	−0.05	−0.04
R^2 *at Step 1*	*0.21**	
Step 2		
Caregiver depressive symptoms	0.56*	0.44
Symptom management self-efficacy	−0.29*	−0.33
Social support self-efficacy	0.10	0.09
R^2 *at Step 2*	*0.54**	
* p < 0.001.		

variance in caregiver burden (p < 0.001). As predicted, self-efficacy and depressive symptoms explained a significant proportion of the variance in burden (p = 0.001), above and beyond other variables. Depressive symptoms were the most significant predictor of burden, followed by self-efficacy and caregiver age.

A second hierarchical regression analysis was run to examine the independent contribution made by self-efficacy to caregiver burden, and the results of this analysis are presented in Table 4. Because we were interested in the contribution of self-efficacy above and beyond depression and objective variables, predictors were entered in the following order: caregiver age and patients' MMSE scores at step 1, Ham-D scores at step 2, and self-efficacy scores at step 3. The model was significant and explained a total of 55 percent of the variance in caregiver burden. As predicted, self-efficacy explained a significant proportion of the variance in burden, above and beyond all other variables (p = 0.027).

Given that patients' neuropsychiatric symptoms were significantly associated with caregiver burden in the bivariate analyses, an additional regression equation was undertaken to determine the potential influence of patients' neuropsychiatric symptoms on the previously mentioned findings. For this analysis, caregiver age and MMSE were entered at step 1, NPI scores were entered at step 2, Ham-D scores were entered at step 3, and self-efficacy scores were entered at step 4. The model was significant, with a total of 55 percent of the total variance in burden explained; notably, the NPI alone accounted

for only 6 percent of the variance in burden (p = 0.87) and did not significantly increase the percentage of variance explained by the model.

Finally, a discriminant function analysis was used to further examine the association between caregiver depressive symptoms, self-efficacy, and burden. This analysis examined the extent to which Ham-D and self-efficacy scores predicted "high" versus "low" scores on the Zarit Burden Interview (high/low was determined using a median split of the data). Together, depressive symptoms and self-efficacy alone accurately classified 68.5 percent of the overall sample (76 percent of low, 63 percent of high; canonical correlation = 0.48; Chi Square = 21.1; p < 0.001).

Discussion

The results of this study demonstrate that self-efficacy and depressive symptoms are strongly related to the burden experienced by caregivers of individuals with AD and suggest that subjective variables may be more powerful determinants than objective variables. Together, self-efficacy and depressive symptoms explained 24 percent of the total variance in caregiver burden, even after accounting for the objective variables most commonly studied. Self-efficacy also emerged as an important independent predictor of burden, above and beyond depressive symptoms.

This study is the first that we are aware of to demonstrate a significant predictive association between self-efficacy and burden among AD caregivers. Importantly,

Table 4. Results of multiple regression predicting caregiver burden: Model 2		
	B	β
Step 1		
Caregiver age	−0.27*	−0.46
Patient dementia severity	−0.05	−0.04
R^2 at Step 1	*0.21**	
Step 2		
Caregiver depressive symptoms	0.64*	0.51
R^2 at Step 2	*0.46**	
Step 3		
Symptom management self-efficacy	−0.30*	−0.33
Social support self-efficacy	0.10	0.09
R^2 at Step 3	*0.55**	
* $p < 0.001$.		

of the two aspects of self-efficacy examined (symptom management and social support), only self-efficacy related to symptom management was significantly associated with burden in bivariate analyses. Self-efficacy refers to perceptions of one's ability to perform successfully in a specific situation,[17] and it is possible that caregivers may have low self-efficacy in one area, but high self-efficacy in another. One potential hypothesis for the lack of a significant association between social support and burden is that our sample consisted primarily of caregivers who were already actively pursuing social support and, therefore, may not have perceived this as a critical component of their burden. Moreover, self-efficacy for symptom management may be most critical for AD caregivers because it encompasses a greater array of activities and abilities (e.g., self-efficacy for managing problem behaviors, cognitive symptoms, and functional loss). Other areas of self-efficacy that have been explored in relation to caregiving include the ability to meet the needs of the patient and the ability to maintain one's own health. Further exploration of those aspects of self-efficacy most relevant to caregiving will help provide a more comprehensive understanding of the caregiving experience and a better understanding of the role of self-efficacy as a predictor of burden.

The finding that self-efficacy, a modifiable psychological attribute, is associated with caregiver burden has important implications for the development of effective interventions for caregivers. Previous research indicates that high self-efficacy is associated with positive psychological effects in a variety of contexts, including psychiatric and medical settings and weight loss and smoking cessation programs.[14] Coon and colleagues recently demonstrated that increases in self-efficacy positively impacted the outcome of an intervention designed to teach anger and depression management skills to caregivers of dementia patients, above the effects of skill training alone.[25] Bandura identified four methods which can be used to enhance self-efficacy, including mastery experience, vicarious experience/modeling, social persuasions, and altering emotional/somatic states.[26] Future interventions for AD caregivers may benefit from the incorporation of self-efficacy enhancing strategies, such as practicing specific symptom management techniques, learning/modeling behavior management skills from professionals, and learning emotion regulation techniques such as relaxation to decrease negative affect.

Our results also provide additional evidence of the important influence of depressive symptoms on caregiver burden. Several previous reports have indicated that depressive symptoms are associated with medical problems and isolation among caregivers of AD patients,[27,28] and our results suggest that depressive symptoms in and

of themselves are determinants of caregiver burden. Depressive symptoms may impair caregivers' ability to manage new challenges, thereby adding to negative life events and outcomes.[29] Caregivers therefore may benefit greatly from depression screenings and the treatment of depressive symptoms, and caregiver interventions also should include specific methods for reducing depressive symptoms. Existing research suggests that depressive symptoms can be treated successfully with pharmacologic and psychosocial interventions, and it is our belief that such treatments may be best applied before or in conjunction with self-efficacy—enhancing strategies to improve caregiver outcomes.

Our finding that caregiver age and patients' neuropsychiatric symptoms were significantly associated with burden is consistent with previous reports.[19,30] Patients' dementia severity and functional status were not significantly associated with burden in the present study, and related previous findings have been conflicting.[19] Some have suggested that the lack of an association between dementia severity, functional status, and burden can be explained by the predictable, linear pattern of decline in these areas as opposed to other dementia symptoms (e.g., neuropsychiatric symptoms) that are more variable; thus, dementia severity and functional status may become less important determinants of burden as the disease progresses.[1]

Several study limitations warrant discussion. First, the caregivers who enrolled in this study were motivated help-seekers, which limits the generalizability of our findings. The literature suggests that up to 70 percent of AD caregivers do not access support services or actively seek help.[31] Isolated caregivers may experience the greatest burden, yet the determinants of burden remain unclear in that understudied population. Second, although the present study used a measure designed to apply self-efficacy theory to domains thought to be important to dementia caregivers (i.e., symptom management and support use), self-efficacy is multifaceted, task specific, and situation dependent, and there is some debate regarding the most appropriate aspects of self-efficacy in this population.[17] For example, Bandura's conceptualization of self-efficacy includes the importance of effectively managing emotional responses to events.[14] Although this may be an important aspect of self-efficacy for AD caregivers, it was not assessed by the measure used in the current study.

Future research should continue to investigate the relationship between subjective aspects of the caregiving experience and negative caregiver outcomes, particularly burden. A more complete understanding of those aspects of self-efficacy that are most important among AD caregivers may lead to the development of effective interventions to reduce burden and improve quality of life for caregivers and patients alike.

Acknowledgment

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