



Published in final edited form as:

Clin Gerontol. 2014 ; 37(3): 235–252. doi:10.1080/07317115.2014.885920.

The Effects of Declining Functional Abilities in Dementia Patients and Increases Psychological Distress on Caregiver Burden Over a One-Year Period

Jill Razani, PhD¹, Roberto Corona², Jill Quilici, PhD¹, A. Adelina Matevosyan, BA³, Cynthia Funes, MA⁴, Andrea Larco, BA¹, Beyon Miloyan, BA⁵, Justina Avila, BA¹, Julia Chung, MD⁶, Hope Goldberg, PhD⁷, and Po Lu, PsyD⁸

¹California State University, Northridge ²University of California, Merced ³Allient University
⁴Georgia State University ⁵The University of Queensland ⁶Harbor-UCLA Medical Center ⁷Olive View-UCLA Medical Center ⁸University of California, Los Angeles

Abstract

The degree to which changes in caregiver burden over a one year period can be predicted by functioning of dementia patients and caregiver psychological stress was examined. The Direct Assessment of Functional Status (DAFS) was administered to 44 patients and the Caregiver Burden Inventory and the Brief Symptom Inventory were administered to their next-of-kin caregivers. All patients and caregivers were assessed at baseline and again in approximately one year with the same measures. Hierarchical regression revealed that baseline patient functioning predicted overall changes in caregiver burden, but that increases in psychological symptoms of caregivers such as depression, anxiety and hostility were the best predictors for specific types of increased caregiver burden, such as social, developmental, or physical burden. These results suggest that interventions should target reduction of particular psychological symptoms in order to reduce caregiver burden over time.

Keywords

caregiver burden; psychological distress; depression; anxiety; hostility; activities of daily living; dementia

INTRODUCTION

Declines in cognitive and daily functioning are the primary characteristics of dementia. The prevalence of dementia and cognitive impairment are likely to grow as the aging population increases. A diagnosis of dementia or cognitive impairment creates tremendous hardship for both patients and their families, particularly for next-of-kin caregivers (George and Gwyther, 1986; Gaugler et al., 2004). Studies of caregivers of patients with cognitive impairment have documented increased physical, emotional, social and financial burdens

Address correspondence to Jill Razani, PhD, Department of Psychology, California State University, Northridge, 18111 Nordhoff Street, Northridge, CA 91330. jill.razani@csun.edu.

(Anderson et al., 2007; Razani et al., 2007). Furthermore, caregivers of dementia patients are more likely to suffer from symptoms of depression and anxiety relative to caregivers of patients with other illnesses (Anderson et al., 2007; Burnes and Rabins, 2000; Gonzalez-Salvador et al., 1999; Leinonen et al., 2001). Understanding how psychological distress and patient functioning impact reported types and severity of caregiver burden of patients with dementia is imperative for the purpose of treatment planning.

Patients' functional abilities have been shown to be related to psychological distress (Razani et al., 2007; Berger et al., 2005; Hirschman et al., 2004) and reported caregiver burden (Razani et al., 2007; Epstein-Lubow et al., 2008). These associations are not only demonstrated at baseline, but persist over periods of several months to years (Berger et al., 2005; Mohamed et al., 2010). Given the progressive nature of dementia, it is not surprising to find that specific caregiver demands and psychological stressors change over time as patient disability increases (Perren et al., 2006). However, it is unclear to what degree the combination of change in patient functioning and caregiver psychological distress accounts for reported changes in caregiver burden over time.

Much attention has been focused on caregiver depression and anxiety (albeit to a lesser degree), but virtually no research has been conducted on caregiver hostility. In reviewing the literature, Cooper, Balamurali, Selwood, and Livingston (2007) reported that 10–34% of caregivers experience clinically significant levels of depression and approximately 10–35% report anxiety. Studies have demonstrated that specific aspects of care-giving (such as feelings of being trapped in a caregiver role and feeling out of sync with their peers) are related to feelings of depression (Alspaugh et al., 1999; Caserta et al., 1996). Other studies have demonstrated a strong relationship between caregiver anxiety and overall reported burden (Liu et al., 2012). In one of only a few studies that has focused on caregiver burden and hostility, we found that caregivers reported significant feelings of hostility (more so than depression and anxiety) and that these scores were much more significantly associated with patient daily functioning than caregivers' depression and anxiety (Razani et al., 2007). Similarly, Wright et al (2010) also found that while certain aspects of caregiver burden were related to depression and anxiety, social burden (i.e., negative social interactions as a result of care-giving) were most predictive of feelings of hostility. These findings suggest that hostility in caregivers is an important aspect of psychological wellbeing and factors that influence increases in this type of psychological distress over time are important to understand. To our knowledge, there are no studies on the longitudinal aspects of caregiver hostility and its contributions to increased caregiver burden.

Thus, the purpose of the present study was to examine whether changes in patient daily functional ability and caregiver psychological distress (specifically depression, anxiety and hostility) predict increases in specific aspects of caregiver burden over a one year period. We hypothesize that while initial (i.e., baseline) daily functional ability of dementia patients is a good predictor of baseline caregiver burden, continued psychological distress over a period of one year will be a better predictor of increases in caregiver burden. Along the same lines, it is predicted that hostility will be a particularly important predictor of circumscribed aspects of increased caregiver burden over the one year period.

METHODS

Participants

Forty-four patients with various forms of cognitive impairment and their caregivers (38 spouses, 4 children, and 2 other kin) participated. The dyads (patients-caregivers) selected for this project were part of a larger research study comparing functional status of older people with and without dementia. As part of that larger study, all patients were administered a neuropsychological test battery (in addition to the activities of daily living task). The broad goal of the large project was to better understand the relationship between patient neuropsychological performance, ability to carry out daily functions and caregiver burden. For the purposes of this study, all patients who had completed the functional task and who had next-of-kin caregivers who had completed all first and second year questionnaires were included.

The cognitively impaired patients were recruited from different teaching and research medical centers in the greater Los Angeles area. 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 44 patients recruited, 26 were diagnosed with Alzheimer's disease, 7 with vascular dementia, and 3 with frontotemporal dementia, 5 were diagnosed with mild cognitive impairment, and 7 were given a diagnosis of dementia not otherwise specified based on the Diagnostic and Statistical Manual of Mental Disorders criteria.

The demographic information for the patients and caregivers, including age, education level, and Mini Mental State Exam (MMSE; Folstein, Folstein, and McHugh, 1975) scores can be found in Table 1. As can be seen from this table, the patients and caregivers were on average nearing or at the end of their seventh decade of life and were relatively well educated. Overall, the patients were in the mild stages of dementia (as indicated by the groups' average MMSE score) and resided at home with their caregivers.

Measures

Mini Mental State Exam—The Mini-Mental State Examination (Folstein, et al, 1975), a widely used brief cognitive screening test, was administered to patients. A total score of 30 is possible on the MMSE based on questions regarding orientation to time, person, and place, memory, attention, visual-construction and language skills. The total score on this exam was obtained in order to better understand the relative stage of dementia, but was not used for further analyses.

Assessment of Functional Status—This Direct Assessment of Functional Status (DAFS; Loewenstein, Amigo, and Duara, 1999), a direct observation measure of ADLs, was administered to all patients. Seven functional abilities are assessed using the DAFS.

- 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 select shopping items that they were asked to memorize or by providing a written shopping list)

Examiners presented the specific tasks to the patients and rated their ability based on observed performance. This test also includes measures of grooming and eating skills, but given that all participants obtained nearly perfect scores on these two subscales, they were not included in the analysis. The total DAFS outcome scores were used in the analysis.

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

Caregiver Burden Inventory—The Caregiver Burden Inventory (CBI; Novak and Guest; 1989) 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; Derogates and Spencer, 1987) is a 53-item, multidimensional measure of psychiatric symptomatology that has been shown to assess caregiver distress in previous studies.¹⁶ 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 (Anthony-Begeston, Zarit, and Gatz, 1988).

Procedures

Participants were tested by trained undergraduate and graduate research assistants. Participants were given the choice of testing at CSU, Northridge or in their home. All of these participants chose to be tested in their home. The condition for testing in their home was that the patient would be tested without a caregiver in a quiet room with a table (so participant and examiner could sit across from each other). All materials for testing were portable and set up as instructed by the specific standardized test procedures.

All dyads (patient and caregiver) were tested at baseline and then retested with all of the same measures approximately 12 months later. They were paid for their participation in both testing years. Written informed consent was obtained from all patients and their caregivers. The institutional review board at the California State University, Northridge approved the study.

Data Analysis

Bivariate Pearson r correlation analyses were conducted between patients' DAFS scores, caregiver BSI (all 3 subscales) and CBI (all 5 subscales) in order to determine relationships between these variables during baseline (year 1) and the follow-up year (year 2).

Six individual hierarchical regression analyses were then performed using each of the follow-up data for the 6 caregiver scores (total CBI score and 5 CBI subscales) as the dependent variable; for each analysis, baseline data for the variables DAFS, CBI, BSI Hostility, BSI Depression, and BSI Anxiety were entered into Block 1, and follow-up data for the variables DAFS, BSI Hostility, BSI Depression, and BSI Anxiety were entered into Block 2. The purpose of these analyses was to determine to what degree patient functioning and the various caregiver psychological stressors at year 2 would account for changes in caregiver burden, once year 1 data were accounted for.

RESULTS

Correlation Analyses

The results of the Pearson r bivariate correlations are presented in Table 2. These findings reveal that baseline data for the patients' DAFS scores are not related to any of the baseline CBI subscales, and only related to the follow-up CBI Time-Dependence subscale. However, the relationship between caregiver burden and patient functioning is somewhat stronger at follow-up testing, as DAFS follow-up scores are strongly related to follow-up CBI Time-Dependence and Developmental Burden subscales. Baseline BSI Anxiety scores were significantly related to three out of the five CBI subscales (Developmental, Emotional, and Physical Burden), and, at follow-up, the BSI Anxiety scores were significantly related to all of the follow-up CBI scores. There were similar relationships between BSI Depression and

Hostility scores and most areas of the CBI subscales at baseline and follow-up. Taken together, these findings suggest that high levels of psychological distress are related to most aspects of caregiver burden and increases in psychological distress indicate increases in burden.

Regression Analyses

Table 3 displays the results of the six hierarchical regression analyses. For each analysis, unstandardized and standardized regression coefficients after entry of all independent variables are presented.

Prediction of Follow-up Total CBI Ratings

The results of the regression used found that baseline independent variables (IVs of Block 1) accounted for a significant proportion of the variability in total CBI scores, $R^2 = .46$, $F(5, 37) = 6.25$, $p < .001$. Of the IVs entered, caregiver BSI Anxiety and Hostility subscales were significant predictors for one year follow-up total caregiver burden scores. After the IVs for Block 2 were entered in the equation, an additional 25% of the follow-up caregiver scores were predicted, R^2 change = .25, $F(4, 33) = 7.04$, $p < .001$. Interestingly, in the presence of depression, the predictive direction of anxiety is negative, suggesting depression (the suppressor) actually enhances the relationship between anxiety and change in total caregiver burden ratings. Once the second block of IVs was entered, only the baseline patient DAFS scores and year 2 Hostility scores were the best predictors for follow-up caregiver burden scores (see Table 3). This suggests that initial patient functioning and increased hostility over the year predicts increases in overall caregiver burden.

Prediction of Follow-up Time Dependence CBI Ratings

Baseline IVs (i.e., Block 1) accounted for a significant proportion of the variability in the follow-up Time Dependence CBI subscale, $R^2 = .45$, $F(5, 37) = 6.01$, $p < .001$. Baseline BSI Depression was the best predictor of second year CBI Time Dependence subscale (see Table 3). No significant variability was accounted for by Block 2 IVs, R^2 change = .05, F change (4, 33) = .76, $p = .56$. These findings suggest that change in caregiver Time Dependence subscale is mostly predicted by their initial depression scores.

Prediction of Follow-up Developmental Burden Ratings

Baseline IVs (i.e., Block 1) accounted for a significant proportion of the variability in the follow-up CBI Developmental Burden subscale, $R^2 = .30$, $F(5, 37) = 3.15$, $p < .05$. Of the IVs entered in this first block, caregivers' initial depression scores (BSI Depression) was the single, best predictor for increased (i.e., follow-up) caregiver Developmental Burden (see Table 3). Additionally, another 30% of the variability was accounted when the second block of IVs were entered, R^2 change = .30, $F(4, 33) = 6.17$, $p < .01$. At this point, the second year BSI Depression subscale was the best predictor (see Table 3), suggesting that increases in caregiver depression (above and beyond the baseline depression ratings) leads to increases in CBI Developmental Burden.

Prediction of Follow-up Social Burden Ratings

For year 2 CBI Social Burden, baseline IVs (i.e., Block 1) did not account for a significant amount of the variability, $R^2 = .2$, $F(5, 37) = 1.87$, $p = .12$. This suggests that none of the baseline IVs alone were significant predictors of second year caregiver Social Burden ratings. However, a significant proportion of variability was accounted for by Block 2 IVs, R^2 change = $.27$, $F(4, 33) = 4.26$, $p < .01$. It appears that follow-up BSI Hostility was the single, best predictor of changes in Social Burden (see Table 3).

Prediction of Follow-up Emotional Burden Ratings

Baseline IVs accounted for a significant proportion of the variability in the follow-up CBI Emotional Burden subscale, $R^2 = .33$, $F(5, 37) = 3.68$, $p < .01$. Of the IVs entered in this first block, caregivers' initial depression scores (BSI Depression) was the single, best predictor for increased (i.e., follow-up) caregiver Emotional Burden (see Table 3).

Additionally, another 18% of the variability was accounted when the second block of IVs were entered, R^2 change = $.18$, $F(4, 33) = 3.10$, $p < .05$. At this point, the initial CBI total score and the follow-up BSI Anxiety subscale were the best predictors (see Table 3), suggesting that the initial reported burden of care and increases in caregiver anxiety leads to increases in CBI Developmental Burden.

Prediction of Follow-up Physical Burden Ratings

IVs entered into Block 1 accounted for a significant proportion of the variability in the follow-up Physical Burden CBI subscale, $R^2 = .33$, $F(5, 37) = 3.68$, $p < .01$. Of the IVs entered in this first block, caregivers' initial anxiety and depression scores were the best predictors for increased caregiver Physical Burden (see Table 3). Suppressor effects were present for anxiety, such that in the presence of depression, the predictive ability of anxiety actually increased (as indicated by the negative beta sign). Additionally, another 18% of the variability was accounted when the second block of IVs were entered, R^2 change = $.18$, $F(4, 33) = 3.10$, $p < .05$. At this point, follow-up patient DAFS scores and follow-up caregiver BSI Anxiety ratings were the best predictors of increased physical burden (see Table 3). These findings indicate that changes in patient functioning and caregiver depression scores are predictive of changes in CBI physical burden over a one year period.

DISCUSSION

Most often dementia is progressive and leads to increased cognitive impairment, decline in the ability to perform daily functioning, and increased psychological distress and ultimately, caregiver burden (Berger et al., 2005). As expected, a pattern of change in patient and caregiver characteristics was found to predict changes in various aspects of caregiver burden in the present longitudinal study.

Consistent with previous research, there were moderate relationships between patient functioning, as well as caregiver symptoms of depression and anxiety, and caregiver burden (Epstein-Lubow et al., 2008; Mohamed et al., 2010). In the present study, we extended our understanding of this relationship in two ways.

First, we demonstrated that in some cases baseline patient functioning and in many cases caregiver psychological distress are related to and predictive of changes (over a one year period) in specific aspects of caregiver burden. One of the main findings of this study is that the initial level of patient functioning is predictive of increases in total caregiver burden ratings, but not of any one specific sub-type of burden. These findings are consistent with previous reports that the lower the functioning of dementia patients, the higher the levels of reported burden in caregivers (Garand et al., 2005; Razani et al. 2007). However, it also appears that initial functional impairment in patients not only predicts the level of burden at baseline but *also* increased burden at follow-up assessment of caregivers. Interestingly, follow-up scores in patient activities of daily living did not predict change in caregiver burden. This suggests that changes to functioning over the year do not add any predictive value to caregiver burden. These findings add to the existing literature in highlighting the importance of providing caregiver support to those who are caring for loved ones needing daily assistance (Cooper et al., 2008). Additionally, these findings add unique contributions to the literature given that there are very few longitudinal studies available to examine the association between patient functioning and caregiver burden, and of those that are available, most use an ADL rating form which is completed by the caregiver rather than an observation-based functional task (Berger et al., 2005).

A second important finding is that we identified baseline and longitudinal changes in specific types of psychological distress (depression, anxiety, and/or hostility) can predict changes in circumscribed areas of caregiver burden. Depression ratings at baseline strongly predicted increases in caregiver perception of time restrictions, perceptions that they are “out of sync” with peers, and fatigue and poor physical health. However, while increases in caregiver depression ratings over the year did not improve prediction for caregiver’s perception of burden due to time restrictions, it did predict increased burden due to feeling out of sync with peers and perceived physical issues over the one year. These findings are consistent with previous reports (Wright et al. 2010; Gaugler et al., 2000) and highlight the importance of detecting and treating depression in caregivers. Similarly, baseline caregiver reports of anxiety were predictive of changes in physical burden, and increased anxiety over the one year period continued to significantly predict increases in physical burden. In line with previous studies that have found strong relationships with anxiety and caregiver burden (Wright et al., 2010; Garcia-Alberca, Lara, & Luis Berthier, 2010; Razani et al., 2007), these findings also extend our understanding of the longitudinal predictive ability of anxiety to predict change in physical burden experiences by caregivers.

There is currently sparse literature on the construct of hostility and its relationship to reported caregiver burden. As such, one of the most significant findings of the current study is that hostility predicts changes in caregiver burden. Specifically, we found that increases in overall caregiver burden (total CBI scores at follow-up testing) and social burden were best predicted by increases in hostility ratings. Wright et al. (2010) found similar relationships between anger/hostility and social burden. The social burden subscale of the CBI measures feelings of social isolation as well as conflicts with family members about care decisions. The BSI subscale of hostility taps into feelings of irritation and annoyance, as well as frequent outbursts and arguments (Derogates & Spencer, 1987). Thus, it appears that

increased feelings of hostility and anger towards their situation, care receiver and even other family members are indicative of greater feelings of social isolation and conflict. In the current study we did not examine the ramifications of high hostility levels in caregivers and what this means for their own welfare or the well being of those for whom they care. This is an area that warrants future investigation so that better support can be provided to caregivers in dealing with their hostile feeling. For example, a study by Perren, Schmid, and Wettstein (2006) found that interventions aimed to help caregivers solicit social support and respite care stabilized their state of well-being relative to those who were not provided such intervention. While these authors did not explicitly include hostility as a measure of well-being, such supportive types of intervention techniques may well apply to stabilizing feelings of hostility in caregivers.

Clinical Implications

The findings of the current study have some practical implications for healthcare professions. First, attention needs to be paid not only to caregiver symptoms of depression and anxiety, but also that of hostility. As these psychological distress symptoms increase, they tend to lead to greater caregiver burden. Research has started to focus on very specific types of caregiver burden treatments to reduce psychological stressors. Schulz et al. (2002) of intervention studies found most to be helpful in reducing depressive and anxiety symptoms, but to a lesser degree feelings of hostility. Copper et al.'s (2007) review of treatments for anxiety found that caregivers benefited significantly from relaxation training and to some degree from yoga exercises. Perhaps such techniques can be incorporated with the traditional caregiver support which education about care-receptient's disease, the caregiver role, and available resources typically given to caregivers. Shulz et al.'s (2002) review also emphasizes that one intervention, for example designed to target depression, may not reduce other psychological symptoms, such as anxiety and hostility. Taken together with the findings of our study, targeted interventions that effectively treat the various forms of psychological symptoms in caregivers of dementia patients are likely to reduce or minimize increases in various types of burden over time.

Limitations and Future Directions

One of the main limitations of this study was the relatively small sample size and for this reason findings should be considered preliminary. Second, the majority of the patients were males, while the majority of the caregivers were females (typically the spouses of the patients). Previous studies have demonstrated gender differences in the reported stress associated with caregiving (Anthony-Bergstone et al., 1988). It is unclear how these different perceptions or experienced psychological distress would impact predicted changes in care-giving. Thus, future studies need to be conducted with a more gender-balanced sample of patient and caregivers. Finally, on average the patients and their caregivers were from higher educated backgrounds. Higher education may also imply (although not directly assessed in this study) higher socioeconomic status, and thus, greater resources. Despite this limitation, increased burden and psychological distress in caregivers was found and strong relationships between these factors were demonstrated. Thus, the negative impact of burden and psychological distress on caregivers over time is undeniable. It is, however, important to replicate this study using a less educated sample.

Acknowledgments

This study was supported by NIGMS grant GM094051 to JR. Additional support for the project was provided by NIMH T34 MH20023 (Career Opportunities in Research), NIGMS grants GM008395 (MARC) and GM063787 (RISE-MBRS), and College of Social & Behavioral Sciences at CSUN.

REFERENCES

- Alspaugh MEL, Stephens MAP, Townsend A, Zarit SH, Green R. Longitudinal patterns of risk for depression in dementia caregivers: Objective and subjective primary stress predictors. *Psychology and Aging*. 1999; 14:34–43. [PubMed: 10224630]
- Anthony-Begeston CR, Zarit SH, Gatz M. Symptoms of psychological distress among caregivers of dementia patients. *Psychology and Aging*. 1988; 3:245–248. [PubMed: 3268265]
- Berger G, Bernhardt T, Weimer E, Peters J, Kratzsch T, Frolich L. Longitudinal study on the relationship between symptomatology of dementia and levels of subjective burden in depression among family caregivers in memory clinic patients. *Journal of Geriatric Psychiatry and Neurology*. 2005; 18:119–128. [PubMed: 16100100]
- Burns A, Rabins P. Carer burden in dementia. *International Journal of Geriatric Psychiatry*. 2000; 15(suppl 1):9–13.
- Cooper C, Balamurali T, Selwood A, Livingston G. A systematic review of the treatment of anxiety in caregivers of people with dementia. *International Journal of Geriatric Psychiatry*. 2007; 22:1818–188.
- Derogates, LR.; Spencer, PM. *The Brief Symptom Inventory (BSI): Administration and Procedures Manual-1*. Baltimore, MD: Johns Hopkins University School of Medicine, Clinical Psychometric Research Unit; 1987.
- Epstein-Lubow G, Davis JD, Miller IW, Tremont G. Persisting burden predicts depressive symptoms in dementia caregivers. *Journal of Geriatric Psychiatry and Neurology*. 2008; 21:198–203. [PubMed: 18838742]
- Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*. 1975; 12:189–198. [PubMed: 1202204]
- Garand L, Dew MA, Eazor LR, et al. Caregiver burden and psychiatric morbidity in spouses of persons with mild cognitive impairment. *International Journal of Geriatric Psychiatry*. 2005; 20:512–522. [PubMed: 15920711]
- Gaugler JE, Anderson KA, Leach MS, Smith CD, Schmitt FA, Mendiondo M. The emotional ramifications of unmet need in dementia caregiving. *American Journal of Alzheimers Disease and Other Dementias*. 2004; 19:369–378.
- George LK, Gwyther LP. Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *Gerontologist*. 1986; 26:253–259. [PubMed: 3721232]
- Gonzalez-Salvador MT, Arango C, Lyketsos CG, Barba AC. The stress and psychological morbidity of the Alzheimer patient caregiver. *International Journal of Geriatric Psychiatry*. 1999; 14:701–710. [PubMed: 10479740]
- Hirschman KB, Xie SX, Feudtner C, Karlawish JHT. How does an Alzheimer's disease patient's role in medical decision making change over time? *Journal of Geriatric Psychiatry and Neurology*. 2004; 17:55–60. [PubMed: 15157344]
- Leinonen E, Korpisammal L, Pulkkinen LM, Pukuri T. The comparison of burden between caregiving spouses of depressive and demented patients. I. *International Journal of Geriatric Psychiatry*. 2001; 16:387–393. [PubMed: 11333426]
- Loewenstein DA, Amigo E, Duara R. A new scale for assessment of functional status in Alzheimer's disease and related disorders. *Journal of Gerontology: Biological Sciences*. 1999; 44A:M114–M121.
- Mangone CA, Sanguinetti RM, Baumann PD, Gonzalez RC, Pereyra S, Bozzola FG, Gorelick PB, Sica RE. Influence of feelings of burden on the caregiver's perception of patient's functional status. *Dementia*. 1993; 4:287–93. [PubMed: 8261026]

- Mohamed S, Rosenbeck R, Lyketsos CG, Schneider LS. Caregiver burden in Alzheimer disease: Cross-sectional and longitudinal patient correlates. *American Journal of Geriatric Psychiatry*. 2010; 18:917–927. [PubMed: 20808108]
- Novak M, Guest C. Application of a multidimensional caregiver burden inventory. *Gerontologist*. 1989; 29:798–803. [PubMed: 2516000]
- Perren S, Schmid R, Wettstein A. Caregiver's adaptation to change: The impact of increasing impairment of persons suffering from dementia on their caregivers' subjective well-being. *Aging & Mental Health*. 2006; 10:539–548. [PubMed: 16938689]
- Rabins P, Mace NL, Lucas MJ. The impact of dementia on the family. *Journal of the American Medical Association*. 248:333–335. [PubMed: 7087127]
- Razani J, Kakos B, Orita-Barbalace C, Wong JT, Casas R, Lu P, Alessi C, Josephson K. Predicting caregiver burden from daily functional abilities of patients with mild dementia. *Journal of the American Geriatric Society*. 2007; 55:1415–1420.
- Schoenmakers B, Buntinx F, Delepeleire J. Factors determining the impact of care-giving on caregivers of elderly patients with dementia. A systematic literature review. *Maturitas*. 2010; 66:191–200. [PubMed: 20307942]
- Schulz R, O'Brien A, Czaja S, Ory M, Norris R, Martire LM, Belle SH, Burgio L, Gitlin L, Coon D, Burns R, Gallagher-Thompson D, Stevens A. Dementia caregiver intervention research: In search of clinical significance. *The Gerontologist*. 2002; 42:589–602. [PubMed: 12351794]
- Wright JM, Battista MA, Pate DS, Hierholzer R, Mogelof J, Howsepian AA. Domain-specific associations between burden and mood state in dementia caregivers. *Clinical Gerontologist*. 2010; 33:237–247.

Table 1

Demographic information, and baseline and year 2 means and standard deviations for patient and caregiver outcome scores.

Caregiver Variables	Baseline (Year 1)	Follow-up (Year 2)
Age	68.93 (± 10.90)	-
Education	14.36 (± 2.45)	-
Gender (M/F)	36/12	-
CBI Subscales		
Time-Dependence	8.48 (± 6.74)	7.39 (± 5.23)
Developmental Burden	4.73 (± 3.24)	6.18 (± 4.35)
Social Burden	1.59 (± 2.81)	1.70 (± 2.84)
Emotional Burden	1.73 (± 2.43)	2.25 (± 2.89)
Physical Burden	2.20 (± 2.84)	3.16 (± 3.47)
BSI Subscales		
Hostility	1.72 (± 2.04)	1.74 (± 1.95)
Anxiety	1.70 (± 2.32)	1.77 (± 1.88)
Depression	1.97 (± 2.32)	2.20 (± 2.18)
Patient Variables		
Age	74.00 (± 9.89)	-
Education	15.07 (± 3.45)	-
Gender (M/F)	38/10	-
MMSE	23.98 (± 5.02)	-
DAFS Total Score (performed by patient)	70.65 (± 14.15)	64.40 (± 19.77)

Table 2

Correlations Between Change Scores (Year 2-Year 1) of Patient Functional Ability, Caregiver Burden and Psychological Distress Measures

Variables	DAFS Total (Baseline)	BSI Anxiety (Baseline)	BSI Depression (Baseline)	BSI Hostility (Baseline)	DAFS Total (Follow-up)	BSI Anxiety (Follow-up)	BSI Depression (Follow-up)	BSI Hostility (Follow-up)
DAFS Total (Baseline)	--							
BSI Anxiety (Baseline)	.31*	--						
BSI Depression (Baseline)	.21	.76**	--					
BSI Hostility (Baseline)	.06	.52**	.64**	--				
DAFS Total (Follow-up)	.75***	.17	.60**	.06	--			
BSI Anxiety (Follow-up)	.24	.44**	.54*	.44**	.04	--		
BSI Depression (Follow-up)	.22	-.30*	.65**	-.09	-.06	.70**	--	
BSI Hostility (Follow-up)	.22	-.04	.23	-.12	.15	.59**	.59**	--
CBI (Baseline) Time-Dependence	-.25	-.09	.10	.16	-.17	-.06	-.04	-.09
CBI (Baseline) Developmental	-.17	.30*	.59**	.52**	-.24	.37*	.52**	.14
CBI (Baseline) Social Burden	.01	.24	.40**	.23	-.05	.57**	.35*	.14
CBI (Baseline) Emotional Burden	.02	.31*	.67**	.47**	-.08	.42**	.67**	.06
CBI (Baseline) Physical Burden	.13	.31*	.44**	.31*	-.06	.37*	.23	.14
CBI (Follow-up) Time-Dependence	-.44**	.02	.30*	.14	-.53**	.32*	.34*	.22
CBI (Follow-up) Developmental	-.15	.13	.41**	.24	-.30*	.59**	.73**	.53**

Variables	DAFS Total (Baseline)	BSI Anxiety (Baseline)	BSI Depression (Baseline)	BSI Hostility (Baseline)	DAFS Total (Follow-up)	BSI Anxiety (Follow-up)	BSI Depression (Follow-up)	BSI Hostility (Follow-up)
CBI (Follow-up) Social Burden	.02	.27	.44**	.35*	.01	.55***	.35*	.25
CBI (Follow-up) Emotional Burden	.17	.07	.43**	.33*	.11	.45***	.70**	.49**
CBI (Follow-up) Physical Burden	.06	.20	.30*	.25	-.10	.66***	.54**	.58**

* $p < .05$;

*** $p < .01$

Table 3

Results of hierarchical regression.

Model	CBI total Y2		CBI Time Dependence Y2		CBI Dev Burden Y2	
	B	StB	B	StB	B	StB
<i>Model 1 IVs</i>						
DAFS Total Score Y1	-0.14	-0.13	-0.16	-0.38	-0.06	-0.19
CBI total Y1	0.27	0.23	0.12	0.27	-0.01	-0.01
BSI Depression Y1	5.19*	0.77*	1.48*	0.58*	1.76*	0.82*
BSI Anxiety Y1	-2.59*	-0.43*	-0.66	-0.29	-0.41	-0.78
BSI Hostility Y1	-0.56	-0.07	-0.64	-0.25	-0.23	-0.09
<i>Model 2 IVs</i>						
DAFS Total Score Y1	-0.37*	-0.34*			-0.11	-0.33
CBI total Y1	0.35	0.30			0.03	0.08
BSI Depression Y1	1.79	0.26	N.S.		0.15	0.07
BSI Anxiety Y1	-0.62	-0.10			0.08	0.04
BSI Hostility Y1	-1.96	-0.24			-0.52	-0.20
DAFS score Y2	0.07	0.10			0.01	0.01
BSI Depression Y2	1.85	0.26			1.88*	0.53*
BSI Anxiety Y2	1.32	0.18			0.14	0.06
BSI Hostility Y2	2.36*	0.35*			0.64	0.30
Independent Variables						
	CBI Social Burden		CBI Emotional Burden		CBI Physical Burden	
	B	StB	B	StB	B	StB
<i>Model 1 IVs</i>						
DAFS Total Score Y1	0.06	0.23	-0.01	-0.05	0.03	0.13
CBI total Y1	0.09	0.34	0.11*	0.44*	-0.05	-0.19*
BSI Depression Y1	0.37	0.23	0.14	0.10	1.44*	1.00*
BSI Anxiety Y1	-0.27	-0.19	0.09	0.07	-0.98*	-0.77*
BSI Hostility Y1	-0.06	-0.03	0.09	0.05	0.28	0.16
<i>Model 2 IVs</i>						

Model	CBI total Y2		CBI Time Dependence Y2		CBI Dev Burden Y2	
	B	StB	B	StB	B	StB
DAFS Total Score Y1	0.01	0.04	-0.08	-0.35	-0.05	-0.21
CBI total Y1	0.11	0.39	0.10*	0.41*	-0.01	-0.05
BSI Depression Y1	-0.13	-0.07	0.13	0.09	0.34	0.24
BSI Anxiety Y1	-0.62	0.04	0.07	0.06	-0.37	-0.29
BSI Hostility Y1	0.06	-0.21	-0.19	-0.11	-0.07	-0.04
DAFS score Y2	-0.41	0.05	0.04	0.27	0.05*	0.35*
BSI Depression Y2	0.01	-0.01	-0.14	-0.09	1.16*	0.77*
BSI Anxiety Y2	0.30	0.29	0.64*	0.42*	-0.12	-0.08
BSI Hostility Y2	0.68*	0.43*	0.21	0.15	0.22	0.15

Y1= baseline; Y2= follow-up; N.S. = Block 2 was not statistically significant

* p<.05;

** p<.01