Behavioral Change in Persons With Dementia: Relationships With Mental and Physical Health of Caregivers

Karen Hooker,¹ Sally R. Bowman,¹ Deborah Padgett Coehlo,¹ Shana Rae Lim,¹ Jeffrey Kaye,²,³ Robin Guariglia,² and Fuzhong Li⁴

¹Department of Human Development and Family Sciences, Oregon State University, Corvallis.
²Oregon Aging and Alzheimer’s Disease Center, Oregon Health Sciences University, Portland.
³Portland Veterans Affairs Medical Center, Oregon.
⁴Oregon Research Institute, Eugene.

The purpose of this study was to examine the effects that changes in behavioral and psychological symptoms of dementia of persons with Alzheimer’s disease have on their caregivers’ mental health and physical health. The research design was a prospective, longitudinal follow-up study conducted in a major medical center and in participants’ homes. Longitudinal analysis linking change in behavior to caregiver outcomes was based on 64 cases. Care recipients were assessed at the time of diagnosis with the Mini-Mental State Examination (MMSE). To provide information on the care recipient’s behaviors, caregivers participated in an interview with the Modified Neuropsychiatric Inventory at diagnosis and at follow-up. Caregivers also completed a battery of established instruments to measure stress appraisal, mental health, and perceptions of their physical health at follow-up. Results showed that increases in problem behaviors among persons living with dementia, along with residence status, were significant predictors of caregivers’ mental health and also their physical health. However, these relationships were mediated through stress appraisal. Variables such as MMSE score of the person with dementia, number of years caregiving, relationship status, and education level were not significant predictors of caregivers’ health when behavior change was in the model.

It has become a gerontological maxim that caregiving places one at higher risk for mental and physical health problems (e.g., Schulz, Visintainer, & Williamson, 1990; Vitaliano, Schulz, Kiecolt-Glaser, & Grant, 1997), and mental or emotional strain among caregivers has been shown to be even an independent risk factor for mortality (Schulz & Beach, 1999). Dementia caregiving (as opposed to caring for someone with primarily physical impairments) is particularly likely to have negative effects on the caregiver’s mental health (e.g., Hooker, Monahan, Bowman, Frazier, & Shifren, 1998; Schulz, O’Brien, Bookwala, & Fleissner, 1995).

Behavioral and psychological symptoms of dementia (BPSD), defined as “symptoms of disturbed perception, thought content, mood, or behavior that frequently occur in patients with dementia” (Finkel, Silva, Cohen, Miller, & Sartorius, 1998, p. 98), are among the core symptoms of dementia. Despite the long-acknowledged importance of behavioral problems and measures to assess them (e.g., Teri et al., 1992), study of these symptoms has not received the same level of research attention as cognitive deficits. Studies of persons with dementia have traditionally focused on memory and cognitive changes, but more recent studies have examined behavioral and personality changes as well (e.g., Bedard, Molloy, Pedlar, Lever, & Stones, 1997; Bolger, Carpenter, & Strauss, 1994; Gaugler, Davey, Pearlin, & Zarit, 2000; McCarty et al., 2000; Wild, Kaye, & Oken, 1994). Behavioral and personality changes are acknowledged as some of the earliest changes among persons with dementia (Jost & Grossberg, 1996; Petry, Cummings, Hill, & Shapira, 1988; Rubin, Morris, & Berg, 1987). A typical description of the most common of these BPSD changes includes increases in: (a) passivity, (b) depressive affect, (c) anxiety, (d) self-centeredness, (e) wandering, (f) agitation, and (g) paranoia along with diminished initiative (Bozzola, Gorelick, & Freels, 1992; Petry et al., 1988; Rubin et al., 1987). Conclusions from a consensus conference (Finkel et al., 1998) were that BPSD can result in lower quality of life for persons with dementia, their family members, and caregivers.

Why might BPSD be so damaging to caregivers’ well-being? It is becoming clear that BPSD, unlike cognitive symptoms, do not show a linear pattern of decline (McCarty et al., 2000). Indeed, it is thought that the unpredictability of the course of BPSD may be why these behaviors cause high levels of stress among caregivers. Research indicates that there is no direct relationship between level of cognitive or functional impairment in the care recipient and the caregiver’s reported stress (George & Gwyther, 1986; Zarit, Reever, & Bach-Peterson, 1980). In fact, research indicates that mental health of caregivers to persons with dementia is affected more heavily by BPSD than cognitive impairments (e.g., Schulz & Williamson, 1991; Victoroff, Mack, & Nielson, 1998). Similarly, the decision to institutionalize the person is more strongly associated with BPSD than cognition and memory problems (Cohen et al., 1993; Mittelman et al., 1993). Thus, the investigation of BPSD and their links to consequences for caregivers has implications for disease management and
social policy (Cohen et al., 1993; Colerick & George, 1986). Any information that can clarify relationships between BPSD and caregivers’ well-being could lead to the development of improved interventions for caregivers.

Existing studies are limited because most are not prospective, so it is unclear whether severity of BPMD or changes in these behaviors is more troublesome for caregivers. A study of people referred to a geriatric clinic for memory problems (Bedard et al., 1997) showed that decreases in dysfunctional behaviors over a 1- to 12-month follow-up period was the strongest predictor of reductions in caregiver burden among their spouses. A recent study showed that rate of change in behavior problems was a significant predictor of role overload among dementia caregivers (Gaugler et al., 2000). What remains to be clarified is the relationship between BPMD changes, caregiver stress, and mental and physical health outcomes. Thus an important gap to address in the existing caregiving literature is how BPMD changes in persons with dementia affect their caregivers.

The model guiding our work as well as others’ work is the stress and coping framework (e.g., Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Gatz, Bengtson, & Blum, 1990) originally formulated by Lazarus and Folkman (1984). According to this model, the effects of potential stressors on caregivers’ well-being can only be understood through the mechanism of cognitive appraisal. Thus, stress appraisal is considered to be an important mediating construct for understanding caregiver health outcomes.

This study was conceptualized as exploratory since relatively little is known about BPMD changes and their effects on caregivers. We were interested in understanding whether or not BPMD changes had direct effects on caregivers’ self-reported mental and physical health, or whether these were mediated through stress appraisal. Consistent with the stress and coping model, we expected stress appraisal to play a key role in that it mediates the effect of BPMD on mental and physical health outcomes. On the basis of prior caregiving literature, we also examined in our model aspects of the caregiving situation found to be of potential importance such as residence, relationship of caregiver to the person with dementia, cognitive status of the person with dementia, number of years caregiving, and education level. Our primary aim, however, was to examine the extent to which changes in BPMD among persons with dementia were related to caregivers’ mental and physical well-being.

**Methods**

**Participants**

The sampling frame consisted of persons diagnosed with possible or probable dementia according to National Institute of Neurological and Cognitive Disorders and Stroke–Alzheimer’s Disease and Related Disorders Association Work Group Guidelines (McKhann et al., 1984) and evaluated at the Oregon Alzheimer’s Disease Center (OADC) at Oregon Health Sciences University in Portland, Oregon, between 1992 and 1997. Initial criteria for being included in the sampling frame were that the person with dementia: (a) had to have a primary caregiver and (b) had to have visited the OADC and had a behavioral measurement scale (see third paragraph in this section) on record.

We sent invitational letters to the primary caregivers of 173 persons with dementia that we had determined to be potentially eligible for the study (although contact information was not always current). We included with these letters Caregiver Questionnaire booklets and self-addressed stamped mailers in which to return the questionnaires and consent forms. After our first mailing, 98 caregivers returned completed questionnaires. An item on the questionnaire assessed whether the caregiver would be willing to participate in a phone interview about current behaviors of the person with dementia, and 87 caregivers agreed to this request. We sent a second mailing (approximately 5 months later) to those who had not previously responded; this mailing produced four additional Caregiver Questionnaires, out of which three caregivers agreed to the phone interview. Thus, we had a total of 102 Caregiver Questionnaires returned and a total of 90 caregivers who provided behavioral information about the patient via a phone interview.

The OADC investigators had changed measuring instruments for the behavior assessments during the time period included in the sampling frame. They originally used the Consortium to Establish a Registry for Alzheimer’s Disease (CERAD) Behavior Rating Scale for Dementia (BRSD; Tarrot, Mack, Patterson, et al., & CERAD Behavioral Pathology Committee, 1995) but, over time, found the interview too cumbersome for caregivers to finish in many cases. Thus, they substituted it with the Modified Neuropsychiatric Inventory (NPI; Cummings, 1997; see description in Measures section) beginning in 1995. Although we had originally planned to use information from either behavioral scale, preliminary analyses showed that the BRSD and NPI could not be considered equivalent. This led us to limit our final sample to those who had been assessed with the NPI at both times of measurement leaving a total of 64 care recipient–caregiver dyads as the final sample used in analyses. In any research, especially longitudinal clinical research with a sample of dementia care recipients and caregivers, decisions are made about trade-offs in the research protocol. In this case, we chose to maximize the validity of the constructs we were measuring. Although this reduced sample size, it seemed cleaner to use the identical measure of BPMD (i.e., the NPI) at both time points to increase the likelihood that changes seen would be because of true change and not measurement error.

**Care recipients.**—Of the 64 persons with dementia, 55 had a diagnosis of probable Alzheimer’s disease (AD). Of these, 18 were uncomplicated, 32 showed extrapyramidal signs (Parkinsonism, Lewy Body variant), and 3 were identified as Myoclonus. The remaining 9 cases were diagnosed as possible AD with 5 listed as having isolated memory impairment, 1 listed as having isolated memory impairment with aphasia, 1 listed as having a benign subtype (no progression), and 2 listed as having vascular disease risk factors.

**Caregivers.**—We defined the caregivers in this study as any adult caring for a person with dementia at the time of diagnosis. There were 43 female caregivers and 21 male caregivers in the sample. Two thirds of the sample were spouse
caregivers; there were 26 wives caring for their husbands (40.6%) and 17 husbands caring for their wives (26.6%). Fifteen adult children (11 daughters; 4 sons) were caring for their mother or mother-in-law; only 1 adult child (a daughter) cared for a father in our sample. The remaining 5 female caregivers included 1 caring for a sibling and 4 caring for friends.

The average age of the caregivers was 64.1 years ($SD = 14.6$), and the sample was almost completely Caucasian with the exception of 2 American or Alaskan natives and 2 who chose not to report their racial/ethnic status. Most caregivers (85.7%) were married, and the average number of years as a caregiver was 4.2 ($SD = 7.8$ years). The majority of the sample was retired (60.9%), although some were employed full time (18.8%) or part time (9.4%) or reported their occupation as homemaker (4.7%). Education level was reported by participants in categories as follows: completed 8th grade (3.1%), high school graduate (18.8%), partial college (40.6%), college graduate (4-year degree; 9.4%), and graduate or professional degree (26.6%).

**Measures**

The OADC investigators assessed the cognitive impairment of the care recipient at diagnosis with the Mini-Mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975). The mean score was 19.74 ($SD = 6.1$). Scores on the MMSE can range from 0 to 30. The investigators used the NPI (Cummings, 1997; Cummings et al., 1994) to assess neuropsychiatric disturbances among persons with dementia. The 12 behavioral domains assessed include: irritability and/or liability, agitation and/or aggression, anxiety, depression and/or dysphoria, elation and/or euphoria, disinhibition, apathy and/or indifference, aberrant motor behavior, delusions, hallucinations, sleep, and appetite and eating disorders. For each domain investigators obtained a frequency and severity score via a structured interview with the caregiver and calculated a frequency by severity subscore. Additionally, investigators created a global NPI score by summing subscores across all domains, and this general indicator of behavioral disturbances was the score used in the analyses reported here. Scores could range from 0 to 144. The mean score for NPI at Time 1 was 15.83 ($SD = 17.26$) and for NPI at Time 2 was 28.25 ($SD = 22.27$).

Several studies have documented the reliability and validity of the NPI with dementia patients (Binetti et al., 1998; Cummings, 1997; Cummings et al., 1994). Cummings (1997) showed that the reliability of telephone interviews did not differ from those conducted in the clinic.

**Caregivers’ Physical Health**

*Health Perceptions Questionnaire (HPQ).*—This 9-item measure is the Current Health subscale of the Health Perceptions Questionnaire used in the Rand Health Insurance Experiment (Davies & Ware, 1981). The scale has good reliability and validity and was designed to provide discrimination at the less dysfunctional end of the illness continuum. Cronbach’s alpha for this scale in our study was .79, indicating adequate internal consistency reliability. We scored items so that high scores indicated poorer health. Scores could range from 9 to 45.

**Self-reported health.**—As an indicator of health, we used the item, “In general, would you say your health is excellent, good, fair, or poor?” These types of self-rated health questions have been found to predict morbidity and mortality even more strongly than physicians’ ratings (Idler & Kasl, 1991). Scores could range from 1 to 4.

**Chronic conditions.**—The chronic conditions checklist is a subindex of the Multi-Level Assessment Index that was designed for use with older adults and has good psychometric properties (Lawton, Moss, Fulcomer, & Kleban, 1982). The chronic conditions measure is a checklist of 20 health conditions (e.g., diabetes, heart trouble, arthritis, etc.). Caregivers were to circle yes or no as to whether they experienced each condition within the past year. A sum of conditions checked yes gives the chronic conditions score, with higher scores indicating worse health. Scores could range from 0 to 21.

**Caregivers’ Mental Health**

**Center for Epidemiologic Studies–Depression Scale (CES-D).**—The CES-D is a 20-item scale used to assess the overall level of depression experienced in the past week (Radloff, 1977). Psychometric properties have been shown to be strong in many studies, including studies of caregivers (Hooker et al., 1998; Pruchno & Resch, 1989). Cronbach’s alpha for the CES-D in this study was .91. Higher scores reflect higher levels of depressive symptomatology. Scores could range from 0 to 60.

**Bradburn Affect Balance Scale (ABS).**—The 10-item Bradburn Affect Balance Scale includes two subscales (5 items each)—one assessing positive affect (ABSPOS; Cronbach’s $\alpha = .70$) and the other assessing negative affect (ABSNEG; Cronbach’s $\alpha = .60$) (Bradburn, 1969). Following Bradburn, negative affect is typically subtracted from positive affect scores and a constant of 5 is added so that there are no negative scores. However, in this study we scored all measures so that a high score meant worse mental or physical health. Thus, we subtracted positive affect scores from negative affect scores and added a constant of 5—so higher scores reflect lower levels of psychological well-being. Scores could range from 0 to 10.

**Life Orientation Test (LOT).**—We used the LOT to measure dispositional optimism among caregivers (Scheier & Carver, 1985). This eight-item scale includes questions such as “In uncertain times, I usually expect the best” that tap one’s underlying propensity toward viewing life and the future optimistically. A 5-point scale is rated for each item, so scores can range from 0 to 40. Previous research has reported good psychometric characteristics of the scale (Hooker et al., 1998; Scheier, Carver, & Bridges, 1994). Cronbach’s alpha in this study was .81. Items were scored so that a higher score meant less optimism (i.e., a more pessimistic outlook on life).

**Stress Appraisal**

**Perceived Stress Scale (PSS).**—We chose a stress appraisal instrument that was not specifically linked to care-
giving per se, as recommended by George and Gwyther (1986). Our measure of stress appraisal was the PSS, a reliable and valid measure designed to assess the degree to which situations are appraised as stressful (Cohen, Karmarck, & Mermelstein, 1983). It has been used successfully with diverse samples and has an abbreviated four-item version that is also psychometrically sound (Cohen & Williamson, 1988). We used the short form of the PSS in an attempt to keep the questionnaire less burdensome and redundant. Scores could range from 0 to 16. Cronbach’s alpha for the PSS in our study was .75.

Caregiver experiences.—In addition to a nonspecific measure of stress appraisal (the PSS), we also assessed thoughts and experiences typically found to be common sources of stress for caregivers. The Caregiver Experiences Questionnaire (CGEXP) is a 25-item measure (Zarit, Stephens, Townsend, & Greene, 1998) with each item rated on a 4-point scale so scores could range from 25 to 100. It was designed specifically for dementia caregivers and has been found to have good psychometric properties. The subscales of role captivity, role competence, overload, worry, emotional control, and strength can be derived. We used the overall scale score. Cronbach’s alpha in our study was .70.

Procedure
We recruited potential participants as described above. OADC investigators evaluated each person with dementia in person at the time of diagnosis. Data used in this study from that initial evaluation are MMSE scores and NPI scores. A different OADC staff member interviewed caregivers simultaneously (and apart from the care recipient) to get the information relevant for scoring the NPI for the persons with dementia.

Time 2 data on the NPI were from the phone interview data collected by our research team. Depending on initial entry into the OADC, this phone assessment took place from 5 months to almost 2 years after the initial diagnosis. The average time between Time 1 and Time 2 assessments was 1.2 years (SD = 0.4 years).

We sent the caregiver questionnaires to all potential participants. When these were returned to the investigators, a research assistant called the caregiver to schedule a time for the NPI phone interview. We asked caregivers to allow up to 1 hour for the interview. Once we scheduled an interview we sent a cue card as a visual reminder of the NPI response alternatives. Two well-trained research assistants conducted the interviews. NPI phone interviews lasted approximately 35 minutes, although interview times ranged from 15 minutes to 90 minutes. The research assistants marked responses on the interview booklet as they conducted the interview. We calculated subscores for the 12 behavioral domains and an overall NPI score after the interview. We thanked the caregivers for their willingness to participate in the study and verified their address so we could send them a $10.00 check as a small remuneration for their time.

Analytic Strategies
We developed and tested competing conceptual models in which changes in BPSD were hypothesized to relate to caregivers’ mental and physical health either directly (DIRECT EFFECTS model) or indirectly, through stress appraisal (MEDIATION model). We used structural equation modeling procedures for model testing because of the ability to use multiple measures of latent constructs to examine relationships disattenuated from measurement error. Although we acknowledge the small sample size used in this study, we evaluated the stability of model solutions based on the size of factor loadings, along with the total sample size and the number of indicators per latent factor.

Results
Table 1 shows descriptive statistics and intercorrelations for all of the measures used in the following analyses. All analyses involved the method of latent variable structural equations modeling using the statistical software Mplus, version 2.0 (Muthen & Muthen, 1998). This program uses the raw score maximum-likelihood (ML) estimation procedure to treat the missing data (Little & Rubin, 1987). The raw data

Table 1. Means, Standard Deviations, and Correlations for Variables in Final Model

<table>
<thead>
<tr>
<th>Variable</th>
<th>NPI Δ</th>
<th>Residence</th>
<th>PSS</th>
<th>CGEXP</th>
<th>HPQ</th>
<th>EGFP</th>
<th>COND</th>
<th>CES-D</th>
<th>ABS</th>
<th>LOT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>15.51</td>
<td>9.88</td>
<td>57.04</td>
<td>24.00</td>
<td>2.22</td>
<td>2.52</td>
<td>16.38</td>
<td>5.33</td>
<td>17.10</td>
<td></td>
</tr>
<tr>
<td>SD</td>
<td>18.67</td>
<td>3.20</td>
<td>9.08</td>
<td>6.99</td>
<td>0.77</td>
<td>1.79</td>
<td>11.11</td>
<td>1.69</td>
<td>6.18</td>
<td></td>
</tr>
</tbody>
</table>

Notes: NPI Δ = difference in score on Modified Neuropsychiatric Inventory from time 1 to time 2; Residence = living at home (0) or living in long-term care (1); PSS = score on Perceived Stress Scale; CGEXP = score on Caregiver Experiences Questionnaire; HPQ = score on Health Perceptions Questionnaire; EGFP = self-health; COND = number of chronic conditions; CES-D = score on Center for Epidemiologic Studies–Depression scale; ABS = score on Bradburn Affect Balance Scale; LOT = score on Life Orientation Test. ns for correlations ranged from 44 to 63.

*p ≤ .05 (two-tailed); **p ≤ .01 (two-tailed).
ML method is designed to maximize the log likelihood for each observation (casewise). Specifically, the method generates full information raw data ML estimates by maximizing the log likelihood of parameter estimates containing the population mean vector and covariance matrix parameters of the observed variables, thus using the available data on all 64 participants.

Measurement Model for Stress and Mental and Physical Health Constructs

Before we could determine whether the structural model we developed fit the data, we examined the measurement properties of the three latent variables. Thus, we tested a measurement model empirically. We used total scale scores for the PSS and CGEXP as indicators in defining the latent variable of stress. We used total scale scores for the HPQ, the Chronic Conditions Checklist, and a global self-rated health perception question as indicators in defining the latent construct of physical health. We used scale scores for the CES-D, ABS, and LOT as indicators for operationalizing the latent construct of mental health. All indicators were significantly loaded on their corresponding latent constructs ($p < .05$). The standardized loadings for the measurement model are presented in Figure 1 and indicate that, despite the small sample size, the factor solution was stable due to the reliability of the observed variables.

Structural Model

We developed a structural model (see Figure 1) in which we tested the NPI score at diagnosis, the NPI score at Time 2, and the calculated NPI change score, which indicates changes in BPSD symptoms over that time period. We used the NPI change scores to predict caregivers’ stress and their mental and physical health. We included residence of care recipient (scored as a dichotomous variable where $0 =$ living at home and $1 =$ living in a long-term care setting) in the model, as well as MMSE score at time of diagnosis, relationship to caregiver (spouse vs. other), number of years the caregiver had been in the caregiving role, and caregiver’s education level. This initial model, which involved all controlled antecedent variables in predicting both the mediator and outcome variables, indicated that, of the six variables, four (MMSE, length of time caregiving, relationship of caregiver to care recipient, and education level) were nonsignificant predictors of the mediator of stress and outcomes of physical and mental well-being. Given that these variables failed to contribute significantly to the model, we eliminated them in the final model for the sake of parsimony. The results from this latter model were consistent with those in which we included all the controlled variables, and there were no changes in the direction or significance of the coefficients. This reduced model (without the four nonsignificant control variables) formed the basis for our final model testing.

We tested the hypotheses by using a competing model analysis such that two substantive models were estimated and compared. The first model, referred to as the DIRECT EFFECTS model, involved estimating the effects of the antecedent variables (NPI change score and residence) on the mental and physical health outcomes. The second model, the MEDIATION model, represents the posited hypotheses and involved estimating the effects of (a) antecedent variables on stress, (b) antecedent variables on mental and physical health outcomes, and (c) stress on mental and physical health outcomes. The hypothesized mediating effect of stress

![Figure 1. Model of relationships between changes in Modified Neuropsychiatric Inventory (NPI) scores, residence status ($0 =$ living at home; $1 =$ long term care residence), stress appraisal, and caregivers’ mental and physical health. Solid paths are statistically significant at the $p < .05$ level (two-tailed) in the structural equation model; broken paths are nonsignificant. Values shown are standardized path coefficients. All are significant. PSS = Perceived Stress Scale; CGEXP = Caregiver Experiences Questionnaire; HPQ = Health Perceptions Questionnaire; COND = Chronic Conditions Checklist; CES-D = Center for Epidemiologic Studies–Depression scale; ABS = Bradburn Affect Balance Scale; LOT = Life Orientation Test.]
is supported if, compared with the DIRECT EFFECTS model, the MEDIATION model yields: (a) higher explained variances (i.e., $R^2$), (b) a significant relationship between antecedent variables on stress, (c) substantially diminished or insignificant effects of antecedent variables on the mental and physical health outcome variables, and (d) significant effects for stress on the mental and physical health outcome variables.

Next, we tested our hypothesized competing models. The results indicated that the MEDIATION model, $\chi^2(27, N = 63) = 18.498, p = .89$, fit significantly better than the DIRECT EFFECTS model, $\chi^2(29, N = 63) = 35.268, p = .19, \chi^2_{\text{diff}}(2, N = 63) = 16.77, p = .001$. Compared to the DIRECT EFFECTS model, the MEDIATION model represents an improvement in $R^2$ for caregivers’ physical health (.447 vs. .370) and mental health (.922 vs. .800). Also, the MEDIATION model shows evidence of a discernible mediating effect. Specifically, the effects of both the NPI change score and residence on stress are statistically significant ($t = 3.912, p < .05$; $t = 1.960, p < .05$, respectively) as are the effects of stress on physical ($t = 2.057, p < .05$) and mental ($t = 2.88, p < .05$) health outcomes. Finally, compared with the DIRECT EFFECTS model, the MEDIATION model partially attenuates the effects of antecedent variables on physical health and mental health. Specifically, the residence variable was a significant predictor of mental health in the DIRECT EFFECTS model but became a nonsignificant predictor in the MEDIATION model.

Results from the MEDIATION model are presented in Figure 1. Table 2 shows the unstandardized and standardized parameter estimates. The correlation between NPI and residence was .179 ($p = .18$, two-tailed). Fit indices for the model are as follows: Comparative Fit Index = 1.00; Tucker Lewis Index = 1.04; root mean square error of approximation = .00 (confidence limits = .00, .05) indicating a good fit of the data to the overall model. The partial, unmediated effects of residence and NPI change variables on caregivers’ physical and mental health, after controlling for stress, also appear in Figure 1 (see the dashed lines). Note that none of the direct paths emanating from the two antecedent variables are significant. This offers support for our mediation hypothesis. Interestingly, however, it should be noted that NPI change scores come close to significantly predicting mental and physical health of caregivers, as shown in Table 2.

Coefficients from the MEDIATION model indicate that both amount of behavior change in the care recipient and being a caregiver for someone residing in a long-term care setting are positively associated with caregivers’ stress. In turn, stress is associated with substantively significant effects on caregivers’ physical and mental health such that, with increasing stress levels, participants experience lower levels of physical and psychological well-being.

### DISCUSSION

The primary findings of this study are that two conditions are strongly associated with worse mental and physical health for the caregiver: (a) the amount of increase in problematic behaviors among persons with dementia and (b) caregiving for someone who is in a long-term care setting. Although previous research has found that the extent to which the person with AD exhibits behavioral problems has been predictive of caregiver depression (e.g., Schulz et al., 1995), the link has not previously been made with physical health of the caregiver. These effects appear to be mediated through stress appraisal, although direct effects of behavioral change came close to significantly predicting caregiver outcomes and should be examined in future studies.

Aneshensel and colleagues (1995) found that increases in problem behaviors were associated with caregiver stress over a 3-year period, whereas increases in activity of daily living dependencies were not. On the basis of our findings, we would expect the increased stress to carry negative implications for caregivers’ mental and physical health. Likewise, caregivers with poorer mental and physical health may have more trouble coping with caregiving, which in turn, could affect behaviors of the care recipient.

To devise effective intervention strategies, researchers need to understand the mechanisms underlying the pathway from behaviors to caregivers’ appraisal of stress. Several researchers have hypothesized that caregivers’ increased stress is due to the capricious nature of these behaviors (Gaugler et al., 2000; McCarty et al., 2000). Additionally, we suspect that BPSD too often go unrecognized as caused by the underlying disease process whereas memory problems have traditionally been recognized as such. Thus, BPSD may be more damaging to the caregiver–care recipient relationship, which, over time, would create stress.

BPSD are core to dementia and, unlike the progression of cognitive decline, there are multiple strategies for minimizing BPSD. An important point is that the very symptoms for

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**Table 2. Parameter Estimates for the Mediation Model**

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Estimate (Unstandardized)</th>
<th>Standard Errors of Estimates</th>
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<tr>
<td><strong>Structural Coefficients</strong></td>
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<td>NPI $\rightarrow$ Physical Health</td>
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<td>NPI $\rightarrow$ Mental Health</td>
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<td>1.00</td>
<td>.00a</td>
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*Note: NPI = Difference in score on Modified Neuropsychiatric Inventory from time 1 to time 2; Residence = living at home (0) or living in long term care (1); PSS = score on Perceived Stress Scale; CGEXP = score on Caregiver Experiences Questionnaire; HPQ = score on Health Perceptions Questionnaire; COND = number of chronic conditions; CES-D = score on Center for Epidemiologic Studies–Depression scale; ABS = score on Bradburn Affect Balance Scale; LOT = score on Life Orientation Test.

*aFixed for identification purposes.*
which effective interventions are available are those that are most distressing for caregivers. Many problematic behavioral symptoms, such as depressed mood and disruptive behaviors, can be improved with appropriate treatment (e.g., antidepressant medication) or behavioral modification techniques (e.g., Cummings & Miller, 1990; Teri, Logsdon, Uomoto, & McCurry, 1997).

Simply being able to do something helpful for the care recipient may provide psychological benefits. In a large nationally representative study of spouse caregivers, increased helping was associated with fewer symptoms of anxiety and depression over a 1-year period (Beach, Schulz, Yee, & Jackson, 2000). Although this study was not limited to dementia caregivers (most were caregiving for a spouse with a physical disability), the results suggest that perceptions of being supportive may offset some negative effects of caregiving.

The finding that residence in a long-term care setting would be associated more highly with stress is an unexpected result, as previous studies have reported that placement results in higher well-being for dementia caregivers (Aneshensel et al., 1995; Gold, Reis, Markiewicz, & Andres, 1995). However, of the 21 persons residing in a long-term care setting, 16 were placed since entry into the study. Thus, the increased stress for caregivers may be due to the recency of the transition as placement decisions are difficult for families, and research does indicate that feelings of guilt intensify upon institutionalization (Aneshensel et al., 1995). Alternatively, those with high levels of stress may be more likely to place their care recipient, and symptoms of stress may not abate upon placement.

Study Limitations

Because our findings show that behavior change is crucially associated with caregiver mental and physical health, more research into the dynamics of that change trajectory is necessary. Although two observations collected over time allows for estimation of the amount of change, it is not possible to study the shape of the developmental trajectory or the rate of change in the individual. Longitudinal growth curve analyses of repeated measures would be the optimal analytic strategy for understanding intraindividual changes and, therefore, we advocate for multiple waves (at least three) of data collection for persons with dementia and their caregivers.

Future research should also be targeted toward a more narrowly focused understanding of the psychopathological behavioral domains and the trajectories of change therein. In this study, we used overall NPI scores to get a global measure of behavioral problems. Sample size precluded analyses of change in each of the 12 domains of the NPI separately, although this would enhance our knowledge about which changes caregivers find most problematic.

Implications and Future Directions

A person losing his or her ability to function independently understandably experiences a wide range of negative emotions such as anxiety, fear, frustration, and depression. The social psychological process by which a person becomes stigmatized, ostracized, and dehumanized once labeled AD deserves research attention. An unknown proportion of problem behaviors is likely related to the excess disability created by others’ negative stereotypical expectations (including even well-meaning caregivers) in the dementia person’s social context (Sabat, 2001). Levy, Hausdorff, Hencke, and Wei (2000) have experimentally demonstrated the role that stereotypes play in affecting mental and even physical health in a sample of cognitively intact older adults. Surely these effects could be even more powerful in the context of relentless negative portrayals of dementia in our society. As person-centered care protocols, such as the “Best Friends” approach (Bell & Troxel, 1997) become increasingly widely established, less excess disability should be shown. Understanding the meaning underlying aberrant behaviors and responding to what the person intended rather than labeling the incident as another bizarre expression of AD is likely to lead to fewer problem behaviors in the future.

From a practical standpoint, we advocate for the incorporation of standard repeated behavioral measures (such as the NPI) into the protocol testing for persons with dementia so that rate of change in behaviors can be assessed over time. Since change in problematic behaviors is associated with caregiver outcomes, sharp increases could serve as red flags for health care providers to be alert to high levels of caregiver stress, depression, and the necessity for possible interventions. Behavioral treatments, as well as medications, for the care recipient for purposes of increasing quality of life of caregivers (as well as the person with dementia) have been found to be effective (Teri et al., 1997). New interventions at the family level should be developed and tested, as caregivers that find their role satisfying and are themselves relatively healthy are less likely to seek institutionalization for their care recipients (Cohen et al., 1993). AD may be unique in that this disease offers opportunities to study family transitions and their ripple effects among individuals in the context of medical and family systems.

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