Predicting Caregiver Burden and Depression in Alzheimer’s Disease

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Objectives. The purpose of this study was to investigate the predictors of caregiver burden and depression, including objective stressors and mediating forces influencing caregiving outcomes.

Methods. This investigation is based on the 1994 Canadian Study of Health and Aging (CSHA) database. Participants were 613 individuals with dementia, living in either the community or an institution, and their informal caregivers. Participants for the CSHA were identified by screening a large random sample of elderly persons across Canada. Structural equation models representing four alternative pathways from caregiving stressors (e.g., functional limitations, disturbing behaviors, patient residence, assistance given to caregiver) to caregiver burden and depression were compared.

Results. The data provided the best fit to a model whereby the effects on the caregiver’s well-being are mediated by appraisals of burden. A higher frequency of disturbing behavior, caring for a community-dwelling patient, and low informal support were related to higher burden, which in turn led to more depressive symptomatology. Caregivers of patients exhibiting more disturbing behaviors and functional limitations received less help from family and friends, whereas those whose care recipients resided in an institution received more informal support.

Discussion. Our findings add to the preexisting literature because we tested alternative models of caregiver burden using an unusually large sample size of participants and after overcoming methodological limitations of past research. Results highlight the importance of the effective management of disturbing behaviors, the provision of formal services for caregivers with highly impaired patients and no informal support, and the improvement of coping skills in burdened caregivers.

One in 13 Canadians over the age of 65 has been diagnosed with Alzheimer’s disease (AD) or a related dementia (Canadian Study of Health and Aging Working Group, 1994a). The majority of these individuals are cared for in the community, typically by spouses who are elderly themselves (Canadian Study of Health and Aging Working Group, 1994b). Informal caregivers of individuals with AD play a major role in supporting impaired elders throughout the course of the illness and are one of our health care system’s greatest resources. Their task is not an easy one and is fraught with emotional strain, distress, and physical exhaustion (Cohen et al., 1990; Grafstrom, Fratiglioni, Sandman, & Winblad, 1992; Vitaliano, Russo, Young, Teri, & Mauaro, 1991). Others have referred to this special group of people as the “hidden victims” of Alzheimer’s disease (Zarit, Orr, & Zarit, 1985).

A substantial body of literature documents the negative psychological, physical, and social consequences associated with providing care to a relative with AD. Informal caregivers are more likely to report that their health is in fair or poor condition than are noncaregivers (Baumgarten et al., 1992; Haley, Levine, Brown, Berry, & Hughes, 1987b; Schulz, O’Brien, Bookwala, & Fleissner, 1995). They are also more likely to use psychotropic drugs (Baumgarten et al., 1992; Grafstrom et al., 1992; Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991), engage in fewer health-promoting behaviors and self-care over the course of caregiving (Fuller-Jonap & Haley, 1995; Gallant & Connell, 1997; Kiecolt-Glaser et al., 1991), and report frequent utilization of medical care (Draper, Poulos, Cole, Poulos, & Ehrlich, 1992; Kiecolt-Glaser et al., 1991).

The burden and depressive symptoms sustained by caregivers of AD patients have been the two most widely studied caregiving outcomes. The association between feelings of burden and the overall caregiver role is well documented (Deimling, Bass, Townsend, & Noelker, 1989; George & Gwyther, 1986; Pratt, Wright, & Schmoll, 1987; Zarit, Todd, & Zarit, 1986). Several studies suggest that caregivers of dementia patients are significantly more likely to be depressed than are noncaregiver controls (Dura, Stukenberg, & Kiecolt-Glaser, 1991; Haley et al., 1987b; Kiecolt-Glaser et al., 1991; Russo, Vitaliano, Brewer, Katon, & Becker, 1995). At least two reports indicate that depression symptoms are twice as common among caregivers than noncaregivers (Baumgarten et al., 1992; Canadian Study of Health and Aging Working Group, 1994b).

In addition, findings of several studies suggest that many caregivers are at risk of experiencing clinical depression (Cattanach & Tebes, 1991; Gallant & Connell, 1997; Schulz & Williamson, 1991; Song, Biegel, & Milligan, 1997; Williamson & Schulz, 1993). Nearly half of the caregivers in some studies were reported to meet diagnostic criteria for depression when structured clinical interviews were used (Cohen & Eis dorfer, 1988; Drinka, Smith, & Drinka, 1987; Gallagher, Rose, Rivera, Lovett, & Thompson, 1989). There is also some evidence to
suggest that a diagnosis of depression can be directly related to the caregiving situation. Nearly one quarter of caregivers in one study (Dura et al., 1991) met the criteria for depression while caregiving, although they had never been diagnosed with depression prior to their assumption of the caregiver role. The societal implications of this are underscored by reports indicating that the stressed caregiver is more likely to institutionalize the care recipient (Cohen et al., 1993; Colerick & George, 1986; Haupt & Kurz, 1993).

Successful management of caregiver and patient symptoms requires a solid understanding of the factors influencing the caregiver experience. This analysis must include consideration of the role of objective demands of the caregiving context in contributing to caregiving outcomes, as well as the caregiver’s subjective reactions to providing care. The present study uses structural modeling techniques to investigate the predictors of caregiver depression and burden. We tested a large random sample of informal caregivers to AD patients who participated in the 1994 Canadian Study of Health and Aging. Four models were tested in order to assess the complex relationships existing between the characteristics of the caregiving situation and the burden and depression of the caregiver.

Predictors of Caregiver Burden and Depression

Patient characteristics.—There is overwhelming support for the claim that a higher frequency of behavior problems presented by the patient is associated with an elevated level of caregiver depression (Cook, Pearson, & Ahrens, 1997; Lévesque, Cossette, & Laurin, 1995; Strauening et al., 1995) and burden (Béard et al., 1991; Molloy, Pedlar, Lever, & Stones, 1997; Chappell & Penning, 1996; Stuckey, Neundorfer, & Smyth, 1996). The frequency with which behavior disturbances are manifested by the patient has been identified as the strongest predictor of caregiver distress (Coen, Swanwick, O’Boyle, & Coakley, 1997; Song et al., 1997) and plays a significant role in the caregiver’s decision to institutionalize the patient (Cohen et al., 1993; O’Donnell et al., 1992).

The literature consistently demonstrates that the frequency of behavior problems is a more reliable predictor of caregiver burden and depression than are the functional and cognitive impairments of the individual (Béard et al., 1991; Coen et al., 1997; Pruchno & Resch, 1989a; Williamson & Schulz, 1993). The research generally shows no relationship between cognitive impairment and caregiver burden/depression (e.g., Dura et al., 1991; Pruchno & Resch, 1989b; Russo et al., 1995; Williamson & Schulz, 1993). Findings regarding the relationship of functional impairment and negative caregiver outcomes have been inconclusive. Some studies document a weak association of objective measures of patient functional status and caregiver burden/depression (Béard et al., 1997; Coen et al., 1997; Kiecolt-Glaser et al., 1991; Russo et al., 1995), whereas others report a stronger relationship (Baumgarten et al., 1992; Chappell & Penning, 1996; Gallant & Connell, 1997).

Caregiver characteristics.—The evidence from cross-sectional studies repeatedly indicates that females are more likely to experience depression or burden than are male caregivers (Chappell & Penning, 1996; Pruchno & Resch, 1989b; Song et al., 1997; Stuckey et al., 1996). Caregiver health has also been identified as a significant predictor of caregiver depression (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Zanetti et al., 1997). This association with depression suggests that caregivers with lower levels of physical health are more vulnerable to the psychological consequences of caregiving.

The caregiving context.—A third category of predictors involves characteristics of the caregiving context, including the caregiver’s relationship to the care recipient, living arrangements, and the amount of assistance provided to the caregiver. The literature provides substantial evidence that the caregiving experience is most difficult for spousal caregivers (Pruchno & Resch, 1989a; Rankin, Haut, & Keefover, 1992). Spousal caregivers experience more depressive symptoms (Baumgarten et al., 1992; Cohen et al., 1990) and are more likely than nonspousal caregivers to experience poor health and limited social activities (Barber & Pasley, 1995; Cohen et al., 1990).

Findings concerning the relationship between patient residence and caregiver outcome are inconsistent. Several studies have indicated that caregivers who live with their patient have higher burden or depression scores than those who do not reside with the care recipient (Grafstrom et al., 1992; Zanetti et al., 1997; Zarit & Whitlatch, 1992). Others, however, have found no significant association between living arrangements and caregiver distress (Dura et al., 1991; Russo et al., 1995; Song et al., 1997). These conflicting findings suggest that the difficulties of caregiving do not end when the patient is institutionalized. Relatives often continue to provide care even when they are not residing with the patient (Max, Webber, & Fox, 1997; Zarit et al., 1995). Thus, they may merely experience different types of burden than those who are living with the patient (Pratt et al., 1987).

Social support has profound effects on caregiver outcomes. Despite inconsistent measurement approaches to assess social support, reports invariably indicate that more social support corresponds to less depressive symptomatology (Baumgarten et al., 1992; Schulz & Williamson, 1991; Song et al., 1997) and lower perceived burden (Coen et al., 1997; Gallant & Connell, 1997; Pushkar Gold, Reis, Markiewicz, & Andres, 1995).

In summary, behavior problems are a powerful predictor of caregiver distress. Other patient characteristics appear to be less important. The evidence regarding the role of functional impairments in predicting caregiver outcomes is inconclusive. Female spouses appear to be particularly prone to the ill effects of caregiving. The predictive value of patient residence is less decisive, with the stresses of caregiving continuing after institutionalization. The findings also suggest the importance of social support as it relates to lower burden and depression in the caregiver.

Assessing Caregiver Outcomes

It has been well established that depression and burden are fairly common consequences among caregivers of AD patients (Dura et al., 1991; Russo et al., 1995). It has also been concluded that there is a wide range of factors related to these outcomes, including patient, caregiver, and contextual variables. Although both caregiver burden and depression are recognized as outcomes of caregiving, it is unclear as to how they relate to one another.

Correlational data suggest that there is at least some definitional and conceptual overlap between measures of caregiver
burden and depression (Gallant & Connell, 1997; Pearson, Teri, Wagner, Truax, & Logsdon, 1993; Song et al., 1997; Stommel, Given, & Given, 1990). The correlations between burden and depression, however, indicate that in some instances some of the variance between them is not shared (Pearson et al., 1993; Stuckey et al., 1996). In addition, although burden and depression are related to similar variables, respective correlations differ in magnitude (Pruchno & Resch, 1989a). Thus, the findings seem to indicate that the two variables reflect overlapping constructs, but are not identical.

Our understanding of the individualized and unique reactions to the caregiving experience could be improved through a more methodologically rigorous assessment of how the predictors of caregiving relate directly and indirectly to each other and to caregiver outcomes. There is great variability in the ways that caregivers respond to their situation, even when the circumstances appear to be similar. Certainly, the consequences of caregiving cannot be explained solely by objective demands. There are mediation forces that likely influence the impact of these demands. That is, the mediators affect subsequent outcomes by filtering the effects of the antecedents. To best understand the varied reactions to the caregiver role, it is important to understand the mediation influences at work within the caregiving experience. There is a lack of clarity associated with the role that depression and burden play as predictors and outcomes, as well as substantial evidence that behavioral disturbance has profound effects on caregiver depression, burden, the likelihood of institutionalization, and support received (Coen et al., 1997; Cohen et al., 1993; Song et al., 1997). Thus, consideration should be given to these variables.

The Chappell and Penning (1996) Study

Chappell and Penning (1996) provided some clarification on these issues. Using data from the Canadian Study of Health and Aging, these authors examined relationships of behavioral disturbance with the burden and depression of informal caregivers. To do so, they factor-analyzed the items of the Dementia Behavior Disturbance Scale (DBD; Baumgarten, Becker, & Gauthier, 1990) and identified eight factors. In four separate multiple regressions, they included either total DBD scores or DBD factor scores as predictors of burden or depression. Their findings were as follows: (a) the total score on behavioral disturbance explained more variance than any other indicator, with total explained variances of $R^2 = .45$ for burden and $R^2 = .28$ for depression; (b) replacement of the total behavioral disturbance index by the DBD factor scores failed to increase the explained variance in burden or depression; (c) the DBD factors that predicted burden and depression were generally the same (i.e., five factors had significant regression coefficients on both dependent variables, one factor only predicted depression, and two factors had nonsignificant coefficients); and (d) burden and depression were significantly correlated. Although these findings demonstrate the importance of disturbing behavior as a powerful indicator of caregiver distress and suggest that burden and depression are overlapping constructs, the results reported by Chappell and Penning (1996) leave three issues tantalizingly unresolved.

The first issue concerns the decomposition of the DBD. Chappell and Penning (1996) used principal components analysis with orthogonal rotation. Retained factors had eigenvalues greater than one. Although the procedure used to retain factors (known as Kaiser’s K1 rule) is commonly used, it severely overestimates the number of components: “Explicit endorsement by textbook authors and implicit endorsement by computer packages, contrasted with empirical findings that the procedure is very likely to provide a grossly wrong answer, seems to guarantee that a large number of incorrect findings will continue to be reported” (Zwick & Velicer, 1986, p. 439). Other reasoning similarly casts doubt on the usefulness of the factor scores. First, correlations between factor scores for orthogonal factors should be zero, but the values reported by Chappell and Penning (1996) show a non-zero range. Second, the reliability of the factors was not reported but may have been low. Because the DBD contains 28 items with an internal consistency of approximately 0.85, the mean interitem correlation can be computed as $r_{xx} < .17$. However, a mean estimate approximately three times higher is required for adequate reliability in components containing three or four highly weighted items (i.e., a mean $r_{xx} > .5$ provides for a $r_{xx}$ with $28/8 = 3.5$ items per factor). Such an expectation is probably unrealistic given the diversity of item content in the DBD. Third, the factor scores failed to explain more variance in either burden or depression than the composite DBD index. Consequently, the usefulness of decomposing the DBD is at best equivocal, with the predictive power not enhanced by factorial decomposition.

The second issue related to Chappell and Penning’s study concerns the absence of analysis of data from informal caregivers of institutionalized dementia patients. Although previous reports indicate lower distress for caregivers of institutionalized dementia patients than for caregivers of dementia patients residing in the community (e.g., Harper & Lund, 1990; Zanetti et al., 1997), some degree of burden remains present (Pratt et al., 1987). Because relevant data are available from the Canadian Study of Health and Aging, patient residence can be included within the predictor array.

The third issue concerns relationships of the predictor variables to both burden and depression. Chappell and Penning (1996) used separate regression analyses to assess the relationships of the predictors to each variable, precluding an evaluation of mediating forces occurring among depression and burden. Structural equation modeling would permit a more comprehensive analysis of these relationships.

The present study advances the findings of Chappell and Penning (1996) by addressing these issues. Because their findings suggested that burden and depression are affected by the total amount of disturbance, irrespective of how that total disturbance score is composed, the total score on the DBD is applied. The present study also includes an assessment of the informal caregivers to dementia patients residing in an institution. Finally, this study allows for a comprehensive evaluation of the mediating influences acting on the consequences of caregiving by comparing four alternative models of mediation representing the process whereby the particular stressors of caregiving (e.g., disturbing behavior, assistance provided, functional impairments) led to negative caregiving outcomes. The conceptual basis of these models is grounded in previous research on caregiver depression and burden both as outcomes and predictors. Figure 1 shows the prototypical pathways that define possible relationships of predictor variables to caregiver distress.
The Models

**Model 1.**—Model 1 (*depression mediates burden*) tests the assumption that the predictor variables directly influence depression, which in turn influences burden. The impact of the stressors on burden is filtered by their effects on depression. Feelings of depression may influence appraisals of burden. For example, the findings reported by O'Rourke, Haverkamp, Tuokko, Hayden, and Beattie (1996) suggest that negative thought processes (e.g., hopelessness, globality, stability) by the caregiver contributed significantly to levels of burden. These appraisals were not linked explicitly to the demands of caregiv-
ing, but to the caregiver’s overall distorted perceptions. The authors suggested that burden may be the result of hopelessness by the caregivers. O’Rourke and colleagues conjectured that burden may be the single best predictor of burden, explaining up to 33% of its variance. The authors argued that depression acts as a mediating variable influencing the caregiver’s overall appraisal of the situation and the burden it creates. Perceptions of burden depend, to a large degree, on the attitudes and mental health attributes of the caregiver. Similarly, Harper and Lund (1990) reported that the degree of burden associated with caregiver demands (e.g., patient aggression) was compounded by low life satisfaction in the caregiver.

Further support for this model is provided by the findings of Stommel and coworkers (1990), who found depression to be the single best predictor of burden, explaining up to 33% of its variance. The authors argued that depression acts as a mediating variable influencing the caregiver’s overall appraisal of the situation and the burden it creates. Perceptions of burden depend, to a large degree, on the attitudes and mental health attributes of the caregiver. Similarly, Harper and Lund (1990) reported that the degree of burden associated with caregiver demands (e.g., patient aggression) was compounded by low life satisfaction in the caregiver.

Model 2.—This model (burden mediates depression) represents the opposite premise of Model 1 and proposes that the effects on depression are mediated by the subjective burden associated with the caregiving stressors. The conceptual basis of this model is rooted in work by Lazarus and colleagues (e.g., Lazarus, 1991; Lazarus & Folkman, 1984). Their model of the stress process helps provide some insight into the great variability that exists in the way that caregivers adapt to similar caregiving situations and challenges. Lazarus and colleagues assert that an individual’s appraisal of stressors depends on his or her personal resources and characteristics. Mediating variables (e.g., stress appraisal, coping, social support) play a key role in determining the outcome of stress. Once a demand is interpreted as stressful, other negative outcomes may result, including depression. Lazarus and Folkman (1984) argued that an individual’s health and well-being are not affected by the stressors themselves, but by how the individual appraises them (i.e., subjective burden). Objective stressors of the caregiving situation act as antecedents to the appraisal of burden, which in turn acts as an antecedent of depression. Their explanation of the stress process has been applied in a host of caregiving studies. Haley, Levine, Brown, and Bartolucci (1987a), for example, investigated the predictors of caregiver outcomes (e.g., depression, life satisfaction, self-rated health) and the effects that mediating influences such as social support, coping, and appraisal have on caregiving outcomes. Appraisals of caregiver demands (e.g., behavioral problems, patient disability) as highly stressful were significantly related to elevated levels of caregiver depression.

The findings of Pruchno and Resch (1989a) also suggest the possibility that burden may act as a mediator of depressive symptomatology. These authors reported that, although there was a significant relationship between forgetful/disoriented behaviors and burden, these behaviors were not significantly related to depression. The authors concluded that although these patient behaviors were bothersome and stressful to the caregivers, they did not affect the caregivers’ mental health.

Further support for the burden-mediates-depression theory may also be indicated by the results of a study by Pearson et al. (1993). Only 6% of their sample of spousal caregivers was categorized as having high burden but low depression. The authors concluded that caregivers may rarely be depressed when they are not significantly burdened, with elevated rates of burden leading to increased feelings of depression. Pearson and colleagues also suggested that these findings could partly be attributed to the stronger direct link from behavioral problems to burden than to depression.

Song and coworkers (1997) reported similar findings regarding the relationship between burden, depression, and disturbing behaviors. They reported that burden explained 16% of the variance in depressive symptomatology, with most of the variance jointly contributed by caregiver burden, patient behavioral problems, and support provided to the caregiver. These variables had a significant impact on caregiver depression through their association with burden.

Model 3.—The latent variable mediation model theorizes that a latent variable subsumes both burden and depression, with the predictor variables influencing the latent variable. Therefore, the predictor variables explain common variance shared by both burden and depression. The premise of this model is in accordance with the view expressed by George and Gwyther (1986), that measures of burden are synonymous to measures of well-being.

Model 4.—The no mediation model asserts that there are no mediating forces at play with burden and depression; all links to burden and depression are direct.

The purpose of this study was to differentiate among these four models using structural equation modeling. The data are from patient–caregiver dyads participating in the Canadian Study of Health and Aging, with the patients sampled from both community residences and institutions. The predictor array includes assessments of functional status, behavior problems, assistance given to caregiver, and patient residence (i.e., community vs institution).

METHODS

Sample

Because the sampling of caregivers for the Canadian Study of Health and Aging is described extensively elsewhere (Canadian Study of Health and Aging Working Group, 1994a; Chappell & Penning, 1996), only a summary of procedures is presented here. The primary sampling was of 9,008 and 1,255 elderly persons residing in the community and institutions, respectively. The community sample was obtained using computerized records of provincial health insurance plans, with the exception of the province of Ontario, where the Enumerated Composite Record was used. Random samples were drawn from the 65–74, 75–84, and 85+ age strata. Institutional sampling included a stratified random sample of institutions by region (e.g., nursing homes, chronic care facilities), with random sampling of residents from the selected institutions.

The cognitive status of all community residents was assessed in two stages. First, participants were screened using the Modified Mini-Mental State Exam (3MS; Teng & Chui, 1987).
Second, participants screened as impaired were referred for a comprehensive clinical examination (i.e., neurological test battery, cognitive and family history, etc.). Participants in the institutional sample were not screened but participated in the comprehensive clinical examination.

The data reported in this article were obtained from two sources. The first source involved all participants from the Canadian Study of Health and Aging who were classified as having dementia. The second source involved the primary caregiver of each dementia patient. The primary caregiver was defined as the person considered by the patient or family to be ordinarily responsible for daily decision making and care provision. This could be either a paid professional or an unpaid family member or friend. The primary caregivers were interviewed by a trained researcher. The overall refusal rate for participation by caregivers was 3.4%.

Participants were 349 caregivers to dementia patients living in the community (i.e., 93.7% informal caregivers) and 699 caregivers to dementia patients living in institutions (i.e., 76% informal caregivers). Ninety-four percent of the dementia patients living in the community were cared for by unpaid caregivers, typically family members; 78% of the institutionalized patients were cared for by informal caregivers. Of those persons caring for a community-dwelling patient, 37% were married to the patient and 29% were daughters of the patient. Spouses were less likely to be the primary caregivers of institutionalized patients (13.3%), with daughters (44.6%) and sons (19.3%) being more likely to take on this role (Canadian Study of Health and Aging Working Group, 1994b). Although the subsample of caregivers analyzed by Chappell and Penning (1996) was limited to 327 informal caregivers of community-dwelling dementia patients, the present study also included informal caregivers of institutionalized dementia patients. Consequently, the exclusion criteria for the present study were as follows: The study excluded paid caregivers; caregivers with relatives not classified as cognitively impaired; and caregivers with incomplete data on the measures that follow. Complete data on the measures were available for 613 informal caregivers and dementia patients, with the latter residing in either the community or an institution.

**Predictor Variables**

The measures were collected as part of the Canadian Study of Health and Aging. These measures include established scales with adequate reliability and validity, and indices of caregiver assistance based on temporal (rather than qualitative) parameters. Cognitive disturbance in the care recipient was not included in the predictor array, but failed to predict either burden or depression in the previous investigation (Chappell & Penning, 1996).

**Disturbing behavior.**—The disturbing behavior manifested by persons with dementia was measured by the DBD, which has a reported internal consistency of 0.83 and a stability of 0.71 (Baumgarten et al., 1990). The caregivers were asked to rate the frequency of each of the problem behaviors on a scale that ranged from (0) never to (4) all the time. Examples of the behaviors include making unwarranted accusations, engaging in verbal abuse, and making physical attacks.

**Activities of Daily Living (ADLs).**—The Activities of Daily Living Scale (Fillenbaum, 1988) was used to assess the functional limitations of the patient. Examples of ADLs include eating, dressing, and bathing. Caregivers rated the care recipient on 14 activities according to three categories: (1) performance without any help; (2) with some help; or (3) completely unable to perform. The score was a weighted summary scale indicating the amount of assistance required.

**Total assistance.**—The amount of outside help that the caregiver received in caring for the dementia patient was assessed by calculating the total number of minutes of help provided per week by both formal and informal helpers (i.e., neighbors and friends).

**Help received from informal sources.***—The amount of assistance provided by the caregiver’s social network of family and friends was assessed by calculating the total number of minutes/week that help was given.

**Help received from formal services.**—The amount of help the caregiver received from formal service providers was assessed by calculating the total number of minutes/week that help was given. Because this variable had a nearly perfect correlation with whether or not the care recipient was institutionalized (i.e., \( r = .97 \)), it was not used in data analysis.

**Institutionalization.**—This variable simply indicates whether or not a person with dementia was institutionalized at the time of assessment.

**Outcome Variables**

**Assessment.**—The Burden Interview (Zarit, Anthony, & Boutselis, 1987) was used to assess caregiver burden. This scale consists of 22 items on the perceptions of caregiving, with the responses to each item coded on a scale ranging from 0 (never) to 4 (nearly always). Scale scores range from a low of 0 to a high of 88. Examples of scale items include “Do you feel strained when you are around [care receiver]?” and “Do you feel that [——] asks for more help than needed?”

**Depression.**—The Center for Epidemiologic Studies Depression scale (CES-D; Radloff, 1977) was used to assess caregiver depression. This scale has been noted as the most widely used measure of caregiver depression (Schulz et al., 1995). Respondents are asked to rate how often during the past week they have experienced 20 different feelings, such as fear, being disliked by others, or a poor appetite. Responses range from rarely or none of the time (0) to most or all of the time (3). A score of 16 or above indicates a risk of clinical depression (alpha = 0.88 in CSHA, 1994b).

**Statistical Methodology**

The independent and dependent variables were analyzed by LISREL VII. Figure 1 shows the models that were tested. The predictor variables are shown in Figure 2. Although Chappell and Penning (1996) decomposed the disturbing behavior scale into orthogonal components, we did not attempt such decomposition for reasons outlined earlier.
The models in Figure 1 were tested as follows: Free linkages in Model 4 (no mediation) included those from all the independent variables to both the dependent variables, with the linkage between the latter fixed at zero to provide one degree of freedom for assessment of fit. Model 1 (depression mediates burden) included free linkages from all the independent variables to depression, and from depression to burden, with linkages from the independent variables to burden fixed at zero. For Model 2 (burden mediates depression), the pattern of free and fixed linkages was reversed (i.e., free linkages from all the independent variables to burden, and from burden to depression, with linkages from the independent variables to depression fixed at zero). Model 3, latent variable mediation, included free linkages from all the independent variables to the latent variable, with depression free on the latter and burden fixed at unity.
RESULTS

Preliminary Analyses

The caregivers had a mean age of 58.8 (±13.5) years, and 71% were female. Fifty percent were caregivers of dementia patients living in the community, and 50% cared for someone living in an institution. Compared to caregivers of community residents, caregivers of institutional residents received less informal help (t(628) = 8.768, p < .001) and experienced lower burden (t(628) = 2.013, p < .05) but not lower depression (t < 1). Institutionalized care recipients showed higher disturbing behavior (t(628) = 6.476, p < .001) and activity limitations (t(628) = 16.952, p < .001) than those living in the community. Distributional statistics for the scales used in data analysis are shown in Table 1, and their correlations with objective indices are shown in Table 2. The demographic indices were not used in subsequent analyses because they failed to correlate significantly with the other measures.

Tests of Models 1, 2, 3, and 4

Figure 2 shows a schematic representation of the path models, depicting free linkages for the models and maximum likelihood ratios as parameter estimates. So as to avoid clutter, both error variables (i.e., random disturbance terms) and linkages associated with nonsignificant maximum likelihood ratios are omitted from the display.

Model 4 (no mediation) shows poor fit as evidenced by a high χ² and a low adjusted goodness-of-fit index (χ²[1] = 115.19, p < .0001; GFI = .947; AGFI < 0). The parameters show caregiver burden to be higher with a high level of disturbing behavior, low informal help, and patient residence in the community rather than an institution. Caregiver depression relates to high disturbing behavior, a high level of activity limitation, and community residence of the person receiving care. Activity limitation relates nonsignificantly to burden, and informal care relates nonsignificantly to depression. The poor fit for the model suggests that the covariation between the dependent variables cannot be explained by the predictor variables. The model can be modified only by freeing the fixed linkage between the error terms for the dependent variables. Such modification produces bivariate regression, but because bivariate regression is just identified at zero degrees of freedom, the modified model cannot be tested for goodness-of-fit.

Model 1 (depression mediates burden) shows a poor fit to the data (χ²[4] = 170.49, p < .0001; GFI = .927; AGFI = .615). Caregiver depression shows significant linkages from disturbing behavior, activity limitation, and community residence for the person receiving care, and caregiver depression shows a significant linkage from caregiver burden. However, the poor fit of the model provides no convincing evidence that caregiver depression mediates the effects of the independent variables on caregiver burden.

Model 2 (burden mediates depression) provides a good fit to the data (χ²[4] = 4.86, p = .301; GFI = .997; AGFI = .987). The significant parameters show linkages to burden from high disturbing behavior, community residence of the person receiving care, and low informal help, as well as from caregiver burden to caregiver depression. The total coefficient of determination for the structural equations was .304, which is only moderate.

Model 3 (latent variable mediation) also provides a good fit to the data (χ²[3] = 3.77, p = .288; GFI = .998; AGFI = .986). Significant linkages to the latent variable indicated that disturbing behavior and community residence of the person receiving care, and low informal help, all contributed to caregiver distress. The latent variable had a free positive linkage to caregiver depression, and a fixed positive linkage to caregiver depression. The total coefficient of determination for the structural equations was only moderate (.338).

A comparison of the two models that provide good fit to the data, Models 2 and 3, suggests that neither provides a better fit than the other (i.e., the quantitative difference in fit was nonsignificant, with χ²[1] = 1.09). The respective total coefficients of determination are also comparable at .304 and .338, respectively. Consequently, the rule of parsimony suggests that if two models provide comparable fit, the simpler and more stringent model may be preferable. Use of this rule favors Model 2 over Model 3 because the former contains fewer free parameters (i.e., 4 vs 3 degrees of freedom). Model 2 also has the advantage of being conceptually simpler in that all the variables are observable, which is not true of Model 3.

Refinement of the Model

The measures within the predictor array fall within two categories. First, disturbing behavior, activities of daily living, and resident are all indices that describe the patient (i.e.,
patient variables). Second, informal help measures the support provided to the caregiver by the social network of family and friends. It is reasonable to anticipate that levels of informal help vary with the condition and situation of the patient with dementia (e.g., friends may be reluctant to help primary caregivers look after community-dwelling patients with severe behavioral or physical problems, but they may relieve the caregivers by visiting such patients in institutional settings). In this example, patient variables influence informal help, and both of these variables in turn influence caregiver distress.

Refined models were tested and included disturbing behavior, activities of daily living, and patient residence as independent variables. Dependent variables were informal help, burden, and depression. Figure 3 shows a refined model based on Model 2 (burden mediates depression), previously tested. This model has free linkages from the independent variables to informal help and burden (i.e., with the exception of a fixed linkage from activities of daily living to burden, which was nonsignificant in the earlier analysis), from informal help to burden, and from burden to depression. All the other linkages were fixed at zero. Refined models based on Models 1, 3, and 4 were also tested, but none provided better fit than the model illustrated (i.e., fit was poor for the no mediation and depression mediates burden models).

The refined model in Figure 3 provides good fit to the data ($\chi^2[5] = 6.64, p = .249; \text{GFI} = .997; \text{AGFI} = .986$), with a fairly high total coefficient of determination for the structural equations of .622. Comparison of the total coefficients of determination from before to after refinement of the model indicates a considerable gain in the explained variance (i.e., .338 vs .622). The parameter estimates show disturbing behavior and activity limitation to be negative influences on informal help, whereas institutional residence of the patient was positively related. Disturbing behavior, low informal help, and community residence related to higher burden, with the latter influencing levels of depression.

**DISCUSSION**

Our findings differ from those of previous studies because we tested four alternative models of caregiver burden using an unusually large sample of participants and after overcoming methodological limitations of past research (e.g., Chappell & Penning, 1996). Unlike any previous research, we tested four possible models of mediation using a methodologically rigorous approach. Most studies have not directly assessed mediation influences and have relied exclusively on regression and correlational analyses to assess the relationships between depression, burden, and caregiving stressors (e.g., Chappell & Penning, 1996; Pearson et al., 1993; Pruchno & Resell, 1989a).

The Canadian Study of Health and Aging has possibly the largest sample size in the world of any study about the patterns of caring for persons with dementia. Because the sample was randomly drawn from the broader community, it is free from the biases associated with convenience samples common to the caregiving literature (e.g., Dura et al., 1991; Haley et al., 1987a; Hooker, Monahan, Shifren, & Hutchinson, 1992; Lawton et al., 1991; Pratt et al., 1987; Song et al., 1997). Previous research indicates a bias toward more distressed caregivers when they are drawn from support groups, community agencies, and other programs where the individual is seeking help (Gallagher et al., 1989).

We compared four models of burden and depression and their relationship with several characteristics of the caregiving situation using data from the Canadian Study of Health and Aging. The findings demonstrated an equivalent fit to Model 2 (whereby the depression of the caregiver is mediated by the relationship between the stressors and caregiver burden) and Model 3 (in which burden and depression are mediated by a common latent variable). As Model 2 (burden mediates depression) is technically more stringent and conceptually closer to the measures than Model 3, where the latent variable is a statistical abstraction derived from the measures, it was considered advantageous. We identified significant linkages to burden from disturbing behavior, patient residence, and informal assistance.
Frequency of disturbing behaviors, community residence of the patient, and little help from family and friends were related to higher caregiver burden, which in turn led to greater feelings of depression in the caregiver. These findings are consistent with previous research showing that the psychological well-being of the caregiver is affected largely through the caregiver’s appraisal of burden (Haley et al., 1987a; Pearson et al., 1993; Pruchno & Resch, 1989a; Song et al., 1997). Two studies also have pointed out that disturbing behaviors have a stronger link with burden than they do with depression (Pearson et al., 1993; Song et al., 1997). Our findings are consistent with previous reports (e.g., Coen et al., 1997; Harper & Lund, 1990) that caring for a patient living in the community and low levels of social support are related to caregiver burden.

A further refinement of this model indicated that patient variables, including activity limitations and disturbing behavior, influenced the amount of help the caregiver received from family and friends. This finding is consistent with recent research showing that individuals caring for family members who presented with more behavior problems were less likely to receive adequate levels of overall social support (Song et al., 1997). Caregivers receiving more informal support were more likely to be caring for patients residing in an institution, indicating that family and friends may be more likely to spend time with patients within an institutional environment than in the community. This finding may be attributed to fewer feelings of apprehension or burden when knowing that professional caregivers are readily available for assistance if it is needed.

These results highlight several important intervention and research strategies for the future. First, there is the need for educational intervention to help caregivers effectively manage problem behaviors. Given that some of the stress induced by behavior problems can be attributed to their unpredictability (Haley, Brown, & Levine, 1987; Teri et al., 1992), there must be additional investigation into the situations that trigger behavioral outbursts, as well as techniques on how to manage and cope with disturbing behaviors when they occur (e.g., Stones et al., 1997). The lack of informal help among those who need it most underscores the importance of ensuring that community caregivers receive the assistance they need from formal services. In addition, the finding that the outcome of caregiving is related to the individual’s appraisal of the situation highlights the importance of interventions aimed at improving the coping skills and stress management techniques of the caregiver. Finally, there is a need for longitudinal data on the effects of caregiving and how changes in the caregiving situation (e.g., changes in behavior problems, functional status, support received) relate to changes in the caregiver’s reactions. There is some evidence that caregivers gain a better tolerance for behavior problems over the course of caregiving (Zarit et al., 1986). There is also some indication that there is improvement in subjective burden and mental health of caregivers over time (Townsend, Noeker, Deimling, & Bass, 1989). However, others have reported that although female caregivers had stable levels of depression throughout the duration of caregiving, male caregivers had significantly more depressive symptoms over time (Schulz & Williamson, 1991). Longitudinal data could resolve these issues.

Although the relationships depicted by the models tested here suggest temporal causation, longitudinal analyses are required to ascertain causality and time-order effects (Campbell & Alwin, 1996). We cannot conclude with certainty, for example, that burden preceded depression, or that disturbing behaviors preceded burden (i.e., it is possible that more stressed caregivers are less tolerable of behavior problems). Nonetheless, our analyses permit inferences about probabilistic relationships among observed and/or latent variables, and enable the models tested to be compared quantitatively using available resources.

It must be noted that the measurement approach used to assess the formal, informal, and total assistance provided to the caregivers represents a fairly crude measure of the support provided to the caregiver and gives no account of how satisfied the caregiver is with the assistance received. Previous research has shown that satisfaction with support does not correlate highly with objective measures of support, including network size and the number of people providing assistance (Given, Collins, & Given, 1988; Haley et al., 1987b). There have also been indications that caregiver outcomes correlate more strongly with satisfaction with support than they do with the size of the caregiver’s network (Fiore, Coppell, Becker, & Cox, 1986). Future tests of caregiver burden models could incorporate measures of caregiver satisfaction with support.

It must be noted that the Burden Interview (Zarit et al., 1987) used in the Canadian Study of Health and Aging is a unidimensional assessment that provides a summary score of overall burden, precluding an analysis of different types of burden. There has been some suggestion that different dimensions of burden (e.g., financial, social, physical) are variably affected by the caregiver role (George & Gwyther, 1986). Thus, summary burden scores may mean that some sources of burden may be overlooked. The use of a more multidimensional measure of burden, such as the Caregiver Burden Inventory by Novak and Guest (1989), may have given a more informative assessment of burden.

Overall, the results of this study provide support for a model whereby the effects on the caregiver’s well-being depend on how the demands of caregiving affect his or her appraisal of burden. This model highlights the role of disturbing behavior in caregiver distress, as well as the importance of improving informal help to caregivers. Informal help is most important for caregivers who care for persons who exhibit serious behavior problems and functional limitations. Finally, this study reinforces the value of establishing ways to improve the coping skills of the caregiver, as well as of developing interventions to help the caregiver manage the patient’s disturbing behaviors and functional limitations. As the number of Alzheimer’s patients continues to rise, questions relating to the alleviation of caregiver burden must remain at the forefront of aging research.

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