Health of Spouse Caregivers of Dementia Patients: The Role of Personality and Social Support

Deborah J. Monahan and Karen Hooker

Providing care to a spouse with dementia is a challenging activity. Why one spouse caregiver copes effectively whereas another becomes demoralized, unable to cope, and at heightened risk for negative health outcomes is not well understood. There is increasing evidence that individual differences associated with effects of caregiving through the subjective appraisal of the stressor are related to health outcomes. In this study, measures of social support and personality were examined to determine their influence on health outcomes for 51 spouse caregivers of dementia patients. The finding of a relationship between health outcomes and personality and social support may help practitioners target and improve interventions with dementia patients and their families.

Key words: caregivers; dementia; health; social support; spouses

Providing care to a spouse with dementia is a challenging activity, even under the best of circumstances. Why one spouse caregiver copes effectively whereas another becomes demoralized and unable to cope is not well understood. There is an extensive literature on the stresses of caregiving (George & Gwyther, 1986; Haley, Levine, Brown, & Bartolucci, 1987; Horowitz, 1985; Pruchno & Resch, 1989) and evidence that the strains of caregiving can affect a caregiver’s physical and mental health (Kiecolt-Glaser et al., 1987; Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991; Moritz, Kasl, & Berkman, 1989; Vitaliano, Maiuro, Ochs, & Russo, 1989). Dementia-related caregiving is particularly demanding for spouses because the caregiver’s stress arises not only from the heavy and often relentless responsibilities but also may involve bearing witness to and being victimized by the inevitable intellectual and psychological deterioration of one with whom the caregiver has had close and longstanding social and emotional ties.

That individual differences are associated with the effects of caregiving through the subjective appraisal of the stressor is a recent line of inquiry in caregiving research (Hooker, Monahan, Shifren, & Hutchinson, 1992), as is the relationship between individual differences and the appraisal of social support resources (Sarason et al., 1991). In this article, we examine relationships among social support, personality, and health. We explore the extent to which social support, gender, and personality (specifically neuroticism) independently predict caregivers’ health. Whether personality plays a role in bolstering social support has important implications for understanding how...
spouses of dementia patients deal with the daily strains of caregiving and for reducing negative health outcomes for these caregivers.

**Literature Review**

**Social Support**

Social support, a multidimensional construct, encompases a multitude of relationships, behaviors, and consequences (Streeter & Franklin, 1991) and has been studied widely as a coping resource that might mitigate the adverse psychological effects of stress (Cohen & Syme, 1985). Although the nature, meaning, and measurement of social support are still being debated in the literature, investigators remain challenged by the need for more systematic and precise conceptualizations of the construct (Kessler, Price, & Wortman, 1985). Although the concept has been operationalized in diverse ways, there is evidence that an individual's perception of social support is most crucial in predicting the buffering effect of social support on stress (Sarason et al., 1991). For a person in a caregiving role, perceived amount and adequacy of social support seem to be important variables for understanding how that individual copes with stress.

Under some types of chronic stress, the buffering effects of social support are short lived, because the stressor eventually erodes the support (Lepore, Evans, & Schneider, 1991). Antecedents of support, such as environmental and genetic factors, seem to buffer the effect of stress on mood (Kessler, Kendler, Heath, Neale, & Evans, 1992). Another possible antecedent of social support that has not been examined in the context of caregiving is personality. Whether personality plays an autonomous role in the need for and development, maintenance, and mobilization of social support is a question that requires further exploration (Cohen & Wills, 1985). Sarason et al. (1991) concluded that the association between self-perceptions and perceived social support makes intuitive sense because individuals who do not feel good about themselves have little reason to believe that others will take an interest in them.

Dementia caregiving is an arena in which these questions can be explored, because the stress of such caregiving is usually long term, and caregivers need concrete as well as emotional assistance (Clipp & George, 1990). In the absence of the emotional support of a spouse, caregivers of dementia patients often face the adversity alone and are particularly vulnerable to the corrosive effects of caregiving responsibilities (Dean & Lin, 1977). Also, gains from social support can accrue when assistance is available to buttress a caregiver's social, psychological, and physical needs (Pilisuk & Parks, 1981), although such effects may be influenced and mediated by key personality characteristics.

**Gender**

Gender also has been found to play a significant role in caregiving. Men and women provide different patterns of assistance based on gender-based divisions of labor (Stoller, 1990). Gender differences reveal women's more frequent, intensive, and affective involvement in the caregiver role and the associated psychological costs (Parks & Pilisuk, 1991). In a study of instrumental and expressive support in caregiving relationships, 81 percent of the women and 47 percent of the men in the sample selected women as confidants, even when gender was controlled (Sherman, Ward, & LaGory, 1988).

The study of gender differences is gaining increasing recognition in the caregiving literature, leading some researchers to examine sample bias and measurement issues in the interpretation of results (Abel, 1990; Barer & Johnson, 1990; Matthews, 1989). Miller and Cafasso (1992), in a meta-analysis of 14 studies of gender differences in caregiving, found no significant differences in functional impairment of the care recipient, total care involvement, or money management tasks. However, their meta-analysis suggested that female caregivers were more likely to carry out personal care and household tasks and more likely to report greater burden.

**Personality**

Previous research has found that personality variables operate as "personal resources" during stressful periods (Johnson & Sarason, 1979). Self-
efficacy predicts a wide range of adaptive life behaviors, including coping skills, resignation in the face of failure, and achievement strivings (Bandura, 1982). A composite of personality factors (commitment, control, and challenge) termed “hardiness” has distinguished between highly stressed middle- and upper-level managers who became ill and those who did not (Kobasa, 1979; Kobasa, Maddi, & Kahn, 1982). Holahan and Moos (1985) reported that people who adapted to stress without experiencing physical or emotional strain were more easy going and tended not to use avoidance coping responses.

The relationship between personality and health has been studied widely (Carson, 1989; Rodin & Salovey, 1989). Although many theoretical and methodological issues remain to be resolved (Krantz & Hedges, 1987), there is emerging consensus that certain personality characteristics can put one at higher risk for disease (Barefoot, Dahlstrom, & Williams, 1983; Barefoot et al., 1987; Friedman & Booth-Kewley, 1987). Research on personality characteristics that make an individual more vulnerable to disease implicates negative emotional states such as hostility and anger (Taylor, 1990; Williams et al., 1988). Both hostility and anger have been linked to physical health outcomes (Friedman & Booth-Kewley, 1987). Investigations have consistently related anger to high blood pressure (Koin, 1989), and suppressed anger with elevated blood pressure has predicted the highest mortality risk (Dimsdale et al., 1986). Anxiety and hostility subscales of the Brief Symptom Inventory predicted elevated levels of burden among caregivers (Anthony-Bergstone, Zait, & Gatz, 1988). Anger-in and anger-out scores were found to be higher among caregivers than a comparison group of noncaregivers (Vitaliano et al., 1989). Indeed, anger was the most common negative feeling among caregivers of dementia patients in a study by Gallagher, Wrabetz, Lovett, Del Maestro, and Rose (1989). Expressed emotion and anger were related to burden in a model developed by Vitaliano, Russo, Young, Teri, and Maiuro (1991).

In terms of the traits that seem to adequately represent the major domains of personality, neuroticism comes the closest to embodying these negative affective states. For example, in a sample of Alzheimer's disease and cancer caregivers, neuroticism predicted negative affect two years later (Rabins, Fitting, Eastham, & Zabora, 1990).

**Methods**

**Procedures**

Participants in this study were 51 spouse caregivers (26 wives, 25 husbands) of people who had a confirmed diagnosis of Alzheimer's disease or a related dementia. Requirements for participation were that the caregiver and care recipient lived in the same household and that the caregiver had been in the caregiving role for a minimum of one year. Caregivers were recruited from three sources: (1) the Alzheimer's Disease Assistance Center associated with a medical center, (2) support groups associated with the local chapter of the Alzheimer's Disease and Related Disorders Association (ADRDA), and (3) advertising in a local newspaper targeted toward senior citizens.

If prospective participants were interested in learning more about the study, they either returned a prepaid stamped postcard or left a message at the project's office. A member of the research team then called the prospective participant and, after briefly describing the study, asked the following questions: Does your spouse have memory loss? Has a diagnosis been made? What is the diagnosis? How long have you been a caregiver? If the caregiver met the requirements and agreed to participate in the study, an interview was scheduled. Caregivers had the opportunity to be interviewed in their homes, at the university, or at some other public place. Interviewers were extensively trained research assistants (graduate students in social work and psychology and upper-division undergraduate psychology students). Interviews lasted one hour on average. Participants were paid $10 for their interviews, although many donated their checks to the local ADRDA chapter.

**Measures**

**Personality.** Neuroticism was operationalized by scores on factor N (neuroticism) of the NEO Five-Factor Index (NEO-FFI) (Costa & McCrae, 1989), a short version of the NEO Personality Inventory (NEO-PI). The short version was chosen over the longer version (60 items versus 181 items) because of caregivers' time constraints. Factor N on the NEO-PI contains the facets “anxiety,” “hostility,” “depression,” “self-consciousness,” “impulsiveness,” and “vulnerability.” Individuals scoring highly on factor N can be characterized as “worrying, nervous, emotional, insecure, inadequate, and
hypochondriacal,” whereas low scorers are “calm, relaxed, unemotional, hardy, secure, and self-satisfied.” Factor N on the NEO-FFI is a single index of 12 items that has been found to correlate highly with factor N from the NEO-PI (r = .89), and like the longer inventory, the NEO-FFI has been shown to have strong validity and high internal consistencies and to be free of response set biases. Cronbach’s alpha for factor N in this study was .82, indicating good internal consistency.

**Social Support.** We assessed the caregivers’ subjective appraisals of social support using the Social Support Appraisals (SS-A) Scale (Vaux et al., 1986). This 23-item scale assesses the degree to which one feels loved and respected and has shown good validity and high reliability across diverse samples, including older adults. Sample items contained in this scale include the extent to which “friends respect me,” “I am important to others,” “I can rely on my friends,” “members of my family rely on me,” “friends and I have done a lot for one another,” and so on. Other questions about social support determined whether the participant received paid help and hours of paid help received, whether the participant received help from other family members and hours of help received, closeness to spouse, availability of someone in a crisis, and whether caregiving responsibilities affected their health.

**Physical Health.** The physical health index was created from five items commonly used in health-related research and found to be predictive of morbidity and mortality (Idler & Kasl, 1991; Kaplan & Camacho, 1983): (1) “In general, would you say your health is excellent (= 4), good (= 3), fair (= 2), or poor (= 1)?” (2) “Of the past three months, how much pain have you had?” (1 = a great deal of pain, 2 = some pain, 3 = a little pain, 4 = no pain); (3) “During the past three months, how much has your health worried or concerned you?” (1 = a great deal, 2 = somewhat, 3 = a little, 4 = not at all); (4) “Do your health problems stand in the way of doing the things that you want?” (3 = not at all, 2 = a little, 1 = a great deal); and (5) “Would you say that your health is better (= 3), about the same (= 2), or not as good (= 1) as most people your age?” Responses on all five items were summed; Cronbach’s alpha for this index was .77.

Participants were also asked for the number of days they spent in a hospital during the past 12 months, and the number of times they visited a doctor during the past 12 months, and the number of days they spent in bed during the past 12 months. Participants were given a checklist to record the presence of typical medical conditions (for example, diabetes, high blood pressure, heart trouble, arthritis, glaucoma, cataracts, and cancer).

**Analysis**

To assess the independent effects of social support, personality, and gender on caregiver health, we used a multivariate regression approach to control for spurious effects arising from correlation among the independent variables.

**Results**

Study participants had a mean age of 68.7 years (SD = 8.75) and were married a mean of 43.5 years (SD = 10.33) (Table 1). Ninety-eight percent were white, and 86.3 percent had living children. The majority of the sample (54.9 percent) were retired, and only 9.8 percent were working full-time.

The Hollingshead (1975) Four-Factor Index was used to determine socioeconomic status, with a possible range of scores from a low of eight to a high of 66; participants had a mean score of 44 (SD = 13). The sample was well educated for a cohort of this age (M = 13.0 years, SD = 3.80). Spouses had been caregiving for a mean of 4.6 years (SD = 2.73) and were relatively healthy, based on self-reported data on the mean number of days during the past year spent in the hospital (1.41), the number of doctor visits (4.51), and the number of days spent in bed (0.62). Almost one-third (29.4 percent) reported having high blood pressure, 27.5 percent had cataracts, and 21.6 percent had heart trouble. Smaller proportions of the sample had cancer (11.8 percent) and diabetes (7.8 percent). Almost three-fifths reported having arthritis (58.8 percent).

Providing care to a spouse may involve sacrifices in other areas of one’s life. A large proportion (29.4 percent) retired earlier than they wished to provide care to their spouse. For a small proportion of the study respondents (11.7 percent), getting out of the house on a weekly basis was not possible.

Almost half of the respondents indicated that they had paid help, usually in the form of housekeeping or homemaker services (Table 2). Although men used more hours of paid help per week (M = 12.24 versus 8.54), the difference is not
Table 1
Demographic and Health Characteristics of Caregivers (N = 51)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n</th>
<th>%</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Husbands of care recipients</td>
<td>25</td>
<td>48.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wives of care recipients</td>
<td>26</td>
<td>50.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have children</td>
<td>44</td>
<td>86.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>28</td>
<td>54.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work full-time</td>
<td>5</td>
<td>9.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>50</td>
<td>98.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
<td>68.7</td>
<td>8.75</td>
</tr>
<tr>
<td>Married (years)</td>
<td></td>
<td></td>
<td>43.5</td>
<td>10.33</td>
</tr>
<tr>
<td>Education (years)</td>
<td></td>
<td></td>
<td>13.0</td>
<td>3.80</td>
</tr>
<tr>
<td>Caregiving (years)</td>
<td></td>
<td></td>
<td>4.6</td>
<td>2.73</td>
</tr>
<tr>
<td>Health</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Number during the past year of</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hospital days</td>
<td></td>
<td></td>
<td>1.41</td>
<td>3.32</td>
</tr>
<tr>
<td>Doctor visits</td>
<td></td>
<td></td>
<td>4.51</td>
<td>4.77</td>
</tr>
<tr>
<td>Days in bed</td>
<td></td>
<td></td>
<td>0.62</td>
<td>2.01</td>
</tr>
<tr>
<td>Health conditions reported</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arthritis</td>
<td>30</td>
<td>58.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High blood pressure</td>
<td>15</td>
<td>29.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cataracts</td>
<td>14</td>
<td>27.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart trouble</td>
<td>11</td>
<td>21.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>6</td>
<td>11.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>4</td>
<td>7.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Glaucoma</td>
<td>2</td>
<td>3.9</td>
<td></td>
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</tbody>
</table>

statistically significant. More men received help with caregiving responsibilities from other family members (68 percent versus 19 percent, p < .005). However, among those receiving help from family, the quantity of help received did not differ significantly between men and women. Most of the caregivers could call on someone to help in a crisis.

Although more women felt very close to their spouse than did men, the difference did not achieve statistical significance. Lack of spousal closeness, with the strains of caregiving, may put caregivers at greater risk for burden and possibly the institutionalization of their spouse (Colerick & George, 1986; Greene & Monahan, 1987). Blieszner and Shifflett (1990) studied the effects of dementia on close relationships between patients and caregivers and found a declining level of intimacy over an 18-month period. However, they concluded that over time the caregivers accepted

Table 2
Gender Differences in Social Support Resources

<table>
<thead>
<tr>
<th>Social Support</th>
<th>Men (n = 25)</th>
<th></th>
<th>Women (n = 26)</th>
<th></th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Receive paid help to provide care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hours per week</td>
<td></td>
<td>12.24</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Receive help from other family</td>
<td></td>
<td>4.48</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has someone available in a crisis</td>
<td></td>
<td>84</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is very close to spouse</td>
<td></td>
<td>40</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health is affected by caregiving</td>
<td></td>
<td>29</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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the medical diagnosis and reported more patience with their spouses and greater understanding of the changes in their relationship. The women in our sample felt that their health was affected by caregiving responsibilities more than the men (56 percent versus 29 percent, p < .05). This finding is consistent with results from other studies of caregiving (Parks & Pilisuk, 1991; Stoller, 1990).

Table 3 presents the multivariate linear regression analysis of the effects of perceived social support, personality, and gender on caregiver health. Overall, the regression explains 28 percent of the variance in the health measure and is highly significant [F(3, 46) = 7.60, p < .005]. Higher levels of perceived social support were significantly and independently associated with better health (b = .11, p < .05), whereas higher levels of neuroticism were significantly and independently associated with worse health (b = -.15, p < .005). Gender differences in health, controlling for personality and social support, were not statistically significant.

Discussion

The provision of care to dementia patients and their families has become a major service delivery and public policy issue in the United States and has important implications for the practice of social work. Recognition of the interdependence of family members (Brody, 1989; Hartman & Laird, 1983) is a fundamental theoretical perspective among social workers, who often provide services to families caring for a cognitively impaired elderly person.

In many cases, caregivers are the gatekeepers to the long-term care system in this country, influencing the amount of public resources allocated to the care of cognitively impaired older adults. The cost paid by the federal government to nursing homes for dementia patients was estimated to be $4.4 billion in 1986, and the states’ share was $4.1 billion (U.S. Congress, 1987). In view of these costs, increasing public policy attention has been given to enhancing the capacity of families to care for dementia patients in the community. Lieberman and Kramer (1991) found that the health status of the caregiver was one of the strongest predictors of institutionalization. By designing interventions to promote caregivers’ mental and physical health, social workers can assist in the reduction of unnecessary social costs and reduce the untimely institutionalization of dementia patients.

In our study an equal number of husbands and wives were providing care to a spouse with a dementia, had been providing care for an average of five years, and were of retirement age themselves. For this sample, gender was not a significant determinant of social support or negative health outcomes. Although we did not examine attributes of the marital relationship to account for the fortitude of male and female spouses, further research of this relationship should be considered as more women enter the paid labor market and face more difficult choices in work and caregiving roles (Parks & Pilisuk, 1991).

Although our study focused on spouse caregivers, it is important to distinguish between spouses and adult children in future studies of gender and caregiving. For example, Wright (1991) found that among spouses where one member was afflicted with Alzheimer’s disease, marital quality was lower than in a matched comparison group of non caregiving spouses. Important questions remain unanswered regarding how intimacy is sustained when illness is long term and cognition is severely impaired. Social work skills in helping spouses understand the unavoidable strains in the marital relationship will be important in future work with dementia patients and their families (Sherman et al., 1988) and is an area for continued research.

One goal of family work is to prevent excess disability in the dementia patient (Gwyther, 1990). Knowledge about what additional social support resources are needed should assist families in providing the necessary amount of care and may contribute to more effective treatment plans. For example, in direct practice with caregivers, it is important to recognize individual differences in perception of social support, and assessment questions should inquire about the adequacy of social support resources. Because the appraisal of
social support resources may be related to personality (Sarason et al., 1991), careful probing during assessment is essential, because caregivers who have low perceived social support may be at risk for health consequences associated with caregiving even though more objective indicators (for example, number of family members living nearby) do not suggest high risk.

The assessment should also identify whether additional resources are needed and encourage caregivers to think more positively about resources that may be readily available. Resources linking the caregiver and family members to community resources (case management) should be explored. Participation in respite programs such as adult day care that could expand a client’s social support network as well as in caregiver support groups should be encouraged. In addition to assessment, social workers can advocate for the expansion of existing community resources and the development of new resources to meet the needs of families struggling to provide care for dementia patients.

Although the empirical data on the relationship between perceived social support and personality are limited, researchers have found that subjects who perceived higher levels of available support are more accurate in their estimations than subjects who perceived only low levels of available support (Sarason et al., 1991). Perceived social support may describe an important organizing principle of self-attributes that moderate an individual’s ego distortions. If this is the case, perceived social support may emerge as an even more fundamental variable in client assessment than is currently recognized. Further empirical research on this topic is clearly needed.

Designing effective interventions for caregivers who have negative emotional states requires creative interdisciplinary collaboration among social workers, psychologists, social scientists, and mental health professionals. Interdisciplinary collaboration on assessment instruments and treatment regimens might lead to a more comprehensive evaluation of client problems. For example, clients at risk for negative health effects might benefit from interventions designed by an interdisciplinary team of practitioners to lessen the anger and guilt that are often associated with caregiving over protracted periods of time (Gallagher et al., 1989).

Examples of other interdisciplinary collaborations include the evaluation of respite services for dementia caregivers (Lawton, Brody, & Saperstein, 1989), the evaluation of caregiver well-being (George & Gwyther, 1986), the analysis of mental and physical health outcomes of dementia caregivers (Hooker et al., 1992), and the examination of excess disability in mentally impaired elderly people and its impact on treatment (Brody, Kleban, Lawton, & Silverman, 1971).

Conclusion

Physical and mental health consequences of long-term caregiving require further study. A question that deserves a direct assessment is whether the availability of mental health services decreases the morbidity of caregivers. What may have begun as a typical role associated with the bonds of marriage (caregiving) may put the caregiver’s health at risk. Whether caregivers realistically anticipate these consequences in the course of providing care to a spouse is also a question for further investigation. How actual social support is perceived and used and its relationship to individual differences among caregivers of patients with other chronic illnesses (for example, cardiovascular disease, cancer, and Parkinson’s disease) also merit further study. Knowledge gained from understanding the effects of social support and personality on the health of spouse caregivers should lead to more effective interventions with dementia patients and their families. Social workers have a pivotal role in understanding these relationships, implementing effective programs, and evaluating the efficacy of the interventions.

References


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