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## Fatigue Among Elders in Caregiving and Noncaregiving Roles

Cynthia S. Teel

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*Fatigue is a complex symptom prevalent in informal caregiving. When role demands exceed caregiver resources, fatigue ensues and caregiving can be compromised. The purpose of this study was to compare perceptions of fatigue among older adults (N = 92) caring for spouses with Alzheimer's disease, Parkinson's disease, or cancer with a control group of older adults (N = 33) whose spouses required no extra care. Caregiving elders reported more fatigue, less energy, and more sleep difficulty than did control participants. All caregiving groups reported similar levels of fatigue, energy, sleep, and self-reported health even though there were marked differences regarding spousal status. Health care providers can support older caregivers in monitoring their own health and in recognizing the need for services that support the caregiving role.*

Fatigue is a ubiquitous symptom and is a part of many acute and chronic health conditions. This complex symptom is so pervasive in contemporary society that it motivates a large percentage of the health care-seeking behavior among adults (Libbus, Baker, Osgood, Phillips, & Valentine, 1995). More than 20% of primary care office visits are related to complaints of fatigue (Goroll, 1995). Fatigue is also part of many stressful life circumstances that are not directly related to health problems, such as with an informal caregiving role.

A number of potential etiologies for fatigue have been identified, including infection and other immune dysfunction, medication side effects, overexertion, sleep disturbance, and chronic stress. In an effort to categorize these etiologies, Carpenito (1995) suggested that fatigue could be caused by pathophysiologic, situational, maturational, or treatment-related factors. The etiology for fatigue can be multifactorial, which further complicates diagnosis and treatment (McPhee & Schroeder, 1997). A clear understanding of the relationship between etiology and the symptom of fatigue is not

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always evident. For example, persistent fatigue has been associated with depression, but whether fatigue is causal or consequential to depression is unclear (see, e.g., Milligan, Lenz, Parks, Pugh, & Kitzman, 1996).

Regardless of etiology, persistent fatigue interferes with quality of life and functional capacity, which limits the ability to meet role expectations. Ream and Richardson (1996) noted the importance of impaired functional capacity in their definition of *fatigue* as a “subjective, unpleasant symptom which incorporates total body feelings, ranging from tiredness to exhaustion, creating an unrelenting overall condition that interferes with individuals’ ability to function to their normal capacity” (p. 527). When role expectations include caregiving responsibilities, the presence of caregiver fatigue can have serious implications for both the caregiver and care recipient. The ability to maintain caregiving commitments may be compromised and the likelihood of caregiver distress or care recipient institutionalization, or both, is increased.

The present study was conducted as a component study of the Exploratory Center for Biobehavioral Studies of Fatigue Management at the University of Kansas School of Nursing (Aaronson et al., 1999).<sup>1</sup> The center adopted a self-monitoring/self-regulation framework to understand the fatigue experience. An assumption of the framework is that fatigue is a consequence of demand that exceeds available energy or resources. Resources include biological, psychological, and social factors. If energy demands persist and there is inadequate ability to monitor, regulate, or restore energy, fatigue can be expected to ensue. The subjective nature of fatigue requires an awareness of the symptom. Awareness of a decreased capacity for activity and an imbalance in resources necessary to support the activity are key features of fatigue (Aaronson et al., 1999). The concepts of perceived fatigue, energy, demands, and resource availability, use, and restoration of the self-monitoring framework provided guidance for variable selection in the present study.

### FATIGUE IN CAREGIVING

There are an estimated 30 million people older than age 65 in the United States, and 68% of these persons continue to live in the community either with friends or family members (American Association of Retired Persons, 1997; Stevens, Walsh, & Baldwin, 1993). According to 1990 U.S. Department of Health and Human Services National Health Survey data, most (72.3%) noninstitutionalized elders rate their health as either excellent, very

good, or good (cited in Wicclair, 1993). On the other hand, more than 7 million elders who continue to live in the community would rate their health as fair or poor with many requiring care and assistance from others.

Approximately 80% of care supporting impaired elders in the community is provided by family and friends (Wallhagen, 1992; Wilson & Trost, 1987). Spouse caregivers older than age 65 who participated in the 1982 National Long-Term Care Survey and Informal Caregivers Survey comprised 37% of all caregivers for frail elders. Most live with their disabled spouses and provide care without either informal or formal help from others (Barusch, 1988). Only half of this group rated their health as good or excellent (Stone, Cafferata, & Sangl, 1987) compared with similar ratings by almost three fourths of noninstitutionalized elders in general, which suggests that giving informal care extracts a significant health cost.

Despite a number of caregiver outcomes that have been examined (Baumgarten, 1989), the element of fatigue has received only indirect attention. Rabins, Mace, and Lucas (1982) noted that 87% of family members of persons with dementia reported chronic fatigue, anger, and depression. Nygaard (1988) found that 75% of dementia patient caregivers complained of chronic fatigue. In a study of caregivers of relatives with dementia, caregivers reported physical and emotional exhaustion in the final caregiving stages, which the investigators suggest may place the caregiver at risk for physical or emotional dysfunction (Collins, Liken, King, & Kokinakis, 1993). For caregivers of persons with either physical or cognitive impairment, 52% said the care responsibilities left little time or energy for other activities (Barusch, 1988). Upon investigation of fatigue among caregivers of persons with cancer, Jensen and Given (1991) found a wide variability in reported levels of fatigue with 28% complaining of severe fatigue. Fatigue was not associated with caregiver age, duration of caregiving, or hours of daily caregiving (Jensen & Given, 1991). Among caregivers of persons with stroke, constant fatigue and low energy were reported by 48% and sleep pattern disturbances were reported by 66% of the caregivers (Williams, 1993).

The implications of caregiver fatigue extend beyond the symptoms experienced by an individual. Caregiver fatigue can also affect the care recipient and the caregiving relationship. For example, depletion of caregiver resources has been noted as a reason behind the decision to institutionalize an impaired elder (Chenoweth & Spencer, 1986; Rabins et al., 1982). Bergman-Evans (1994) found that, in addition to increasing care recipient dependency, caregiver health problems and sleep disturbances were the main predictors of institutionalization. Wilson (1989) maintains that many family caregivers view turning over care as a negative choice and will

continue in the caregiving role beyond their own tolerances, until they are overwhelmed. Although the decision for institutionalization may relieve 24-hour physical care requirements, social costs are incurred with the decision. Family units are disrupted; former caregivers must relinquish the actions of providing care at home and adopt new positions in the care of their loved ones. New strains associated with caring for an institutionalized loved one are encountered, including a new focus on care management in the nursing home setting (Collins, Stommel, Wang, & Given, 1994; Lindgren, 1993).

Caregiving tasks are complex and potentially include physical care, vigilance, and altered spousal, extended family, and community roles. Summarizing the caregiving literature, Schulz, Visintainer, and Williamson (1990) stated that the tasks of caregiving often lead to self-neglect, which in turn results in caregiver fatigue. The existence of fatigue among caregivers is evident, yet there is little information available about differential levels of fatigue among caregivers in various caregiving situations or the extent to which fatigue varies between elders who are and who are not in caregiving roles.

### **PURPOSE AND HYPOTHESES**

Interest in the presence of fatigue among older adult caregivers inspired the current study, in which indicators of fatigue among spouse caregivers were described, and similarities and differences in fatigue reported by caregiving and noncaregiving men and women were examined. Fatigue was assessed among elders in three caregiving situations as well as among older persons who provided routine care to healthy spouses. We hypothesized first that older adults in caregiving roles compared with older adults who did not have caregiving responsibilities would report greater levels of fatigue, less energy, and more difficulty with sleep. We also hypothesized that there would be no differences in fatigue, energy, and sleep disturbance among diverse caregiving groups.

### **METHODS**

#### **Design and Procedure**

An ex post facto research design was used in this study to compare fatigue in adults in caregiving and noncaregiving roles. To avoid confounding the

relationship between age and reported fatigue, and because more than one third of informal caregiving for frail elders is provided by spouses, older married persons comprised the study population. Multiple groups of caregiving adults were used to maximize variance in caregiving conditions. The conditions (Alzheimer's disease, Parkinson's disease, and cancer) were selected to include a range of cognitive and functional impairments encompassing a variety of caregiving tasks that probably influence fatigue. For example, the vigilance to monitor safety that is required in caring for a spouse with Alzheimer's disease differs from the intense therapy visits required for the spouse with cancer. Both differ from the functional assistance that can be required by the person with Parkinson's disease.

Participants were recruited from two sources: a neurology research clinic at a mid-western medical center and a cancer center clinic at a mid-western medical center. The neurology clinic was conducting an ongoing study of persons with Alzheimer's disease, persons with Parkinson's disease, and control participants who did not have either disease. Following detailed neuropsychological and functional assessment, persons in the neurology clinic study were grouped according to the presence of cognitive deficit (dementia), functional deficit (Parkinsonian syndrome without dementia), or nonimpaired (control). For the study reported here, potential participants in each of these three groups (Alzheimer's, Parkinson's, control) were randomly selected from a subset of clients who met the study criteria. Letters of invitation were sent to the spouses of patients who were in the Alzheimer's or Parkinson's group. Letters of invitation also were sent to clients categorized by the neurology clinic as nonimpaired. The latter group of individuals comprised the control group for the present study. All letters included information regarding the study purpose and participation criteria, along with assurance of the freedom to decline participation without prejudice. Approximately 1 week after mailing the introductory letter, telephone contact was initiated with potential participants. For interested individuals, interviews were arranged either in the participants' homes or in a conference room at the medical center. Questionnaires were completed during the arranged meeting or were returned to the investigator by mail using pre-addressed and stamped envelopes.

Spouse caregivers of individuals with cancer were recruited from an outpatient treatment clinic. The cancer clinic provided treatment to cancer patients with varied functional impairments. Many of these patients were accompanied to treatment sessions by spouse caregivers. From daily treatment listings, potential participants who met the study criteria and who

accompanied their spouses to the clinic for outpatient treatment were identified. Each potential participant who was in the clinic during times scheduled for data collection was invited by a research assistant to participate in the study. Questionnaire packets were left with interested participants. Packets were returned to the investigator using postage-paid envelopes. A small monetary stipend was mailed to each study participant within 4 weeks of participation.

### Sample

Individuals who cared for spouses with Alzheimer's disease ( $N = 30$ ), Parkinson's disease ( $N = 29$ ), or cancer ( $N = 33$ ) comprised the caregiving groups. Individuals whose spouses did not require exceptional care comprised the control group ( $N = 33$ ). Table 1 presents a description of the sample characteristics and a comparison of characteristics among the three caregiving groups and between the three caregiving groups on one hand, and the control group on the other.

Participants in each group were in their early 70s, on average, and had almost equal representation by males and females. All participants were currently living with their spouses and had been married an average of 45 years. Participants were predominantly White in all groups and predominantly Protestant. Noncaregivers compared with caregivers were both more educated and had significantly greater household income.

The time since learning about the spouse's illness varied significantly across the caregiving groups with the Parkinson's disease group reporting the longest interval of more than 10 years. A post hoc test using the Tukey *B* procedure showed that this caregiver group differed significantly from the other two, both of which reported less than 5 years on average. The number of years that the spouse, because of difficulties produced by the condition, had required extra care also varied significantly across the groups. Again, the Parkinson's disease group members reported the longest period of time that they had been providing extra care to their spouses whereas the cancer group members reported slightly more than 1 year that extra care had been required. The mean for each group differed significantly from the other two by Tukey *B* procedure. The number of hours of daily care given to the spouse also varied in the predicted manner among the groups with the Alzheimer's group providing the most care per day and the cancer group the least. These two groups differed significantly from each other by Tukey *B* procedure.

50 **TABLE 1: Sample Characteristics and Statistical Comparisons for Caregiving and Control Group Participants**

Caregiving Group	Alzheimer's Disease (N = 30)	Parkinson's Disease (N = 29)	Cancer (N = 33)	Noncaregivers (N = 33)	Comparison of Three Caregiving Groups	Comparison of Caregivers Versus Controls
Age (in years)	72	73	70	74	$F(2,88) = 2.12$	$F(1,122) = 2.75$
Gender (percentage male)	46.7	48.3	48.5	48.5	$\chi^2(2) = 0.02$	$\chi^2(1) = 0.004$
Years married (mean)	46.0	47.2	43.2	44.1	$F(2,89) = 1.36$	$F(1,123) = 0.41$
Ethnicity (percentage White)	100	97	94	100	$\chi^2(2) = 1.83$	ns (Fishers Exact Test)
Religion (percentage Protestant)	80	66	64	85	$\chi^2(2) = 2.32$	$\chi^2(1) = 2.92$
Highest level of education (percentage $\leq 12$ years)	37	38	46	15	$\chi^2(2) = 0.60$	$\chi^2(1) = 6.84^{**}$
Household income (mean)	\$25,400	\$32,100	\$38,600	\$40,600	$F(2,82) = 1.18$	$F(1,116) = 10.86^{***}$
Years since illness diagnosis (mean)	4.8	10.5	3.0	n/a	$F(2,82) = 25.98^{***}$	
Years extra care required (mean)	3.0	5.1	1.2	n/a	$F(2,70) = 11.65^{***}$	
Hours daily care provided (mean)	12.1	10.1	6.2	1.8	$F(2,80) = 3.41^*$	

\*  $p < .05$ . \*\*  $p < .01$ . \*\*\*  $p < .001$ .

## MEASURES

Demographic characteristics such as age and time in the relationship both with and without caregiving responsibilities were determined with numeric and categorical variables included in the demographics portion of the self-report instrument. Self-report data about assessment of fatigue-related distress and quantification of fatigue, presence of other symptoms, characteristics, and mood disturbance also were obtained.

The Visual Analog Scale for Fatigue (VAS-F) is an 18-item, 2-dimension scale that requires subjective quantification of fatigue and energy levels experienced at the time of scale completion (Lee, Hicks, & Nino-Murcia, 1991). A 10-point scale is used to rate responses to each pair of words with higher scores on each subscale indicative of more fatigue and more energy. In the present study, coefficient alpha was .95 for the fatigue subscale and .90 for the energy subscale.

The Verran and Snyder-Halpern Sleep Scale (VSH) is a 15-item scale that measures the previous night's sleep disturbance, effectiveness, and supplementation (Snyder-Halpern & Verran, 1987). The VSH was adapted from its original visual analogue format to a 10-point numeric rating scale for this study. Theta coefficients have been reported as .82 to .86 for the disturbance subscale, .72 to .81 for the effectiveness subscale, and .45 (healthy participants) and .68 to .84 (ill participants) for the supplementation subscale (Verran & Snyder-Halpern, 1988). In the current study, coefficient alpha was .85 for the disturbance subscale, .73 for the effectiveness subscale, and .56 for the supplementation subscale. Because the supplementation subscale reliability was less than .70, it was eliminated from further analysis.

The Symptom Distress Scale (SDS) is a 13-item scale that provides a subjective assessment of distress with several symptoms (McCorkle, 1987). Nausea, loss of appetite, disturbed sleep, pain, fatigue, and breathing difficulties are among the symptoms included in the scale. Each is rated relative to the participant's experience with the symptom during the preceding week and is scored on a 5-point scale from low to high distress. Cronbach's alpha has been reported between .79 and .89 (McCorkle, 1987). In the current study, only the single item related to fatigue (i.e., usually not tired) was included in the analysis.

The Profile of Mood States-Short Form (POMS-SF) is a 30-item measure of mood disturbance (McNair, Lorr, & Droppleman, 1992). The POMS-SF has several subscales, two of which address fatigue and vigor. The remaining subscales tap dimensions of tension, anger, confusion, and depression.

Items are scored on a 5-point scale between *not at all* (0) to *extremely* (4). Internal consistencies for the fatigue and vigor subscales have been reported at .86 to .95 and .87 to .93, respectively (McNair et al., 1992). In the present study, coefficient alpha was .92 for the fatigue subscale and .89 for the vigor subscale.

Three items from the Older Americans Resources and Services (OARS) scale were used to assess the physical health of the respondent: self-rating of overall health at the present time, comparison of current health with health 5 years ago, and whether health troubles interfere with activities (Duke University, 1978). Each item is scored between 0 and 3. Higher scores correspond with the assessment of better health.

Spouse caregivers are effective proxies for information about the caregiving situation (Clipp & George, 1992; Reifler, Cox, & Hanley, 1981), so participants were asked to provide an assessment of their loved ones' capabilities relative to specified tasks. Participants rated 14 items related to their spouses' activities of daily living (ADL) using the ADL section of the Multidimensional Functional Assessment, OARS (Duke University, 1978). Scores on the rating determined functional status of care recipients. The 7 instrumental ADL items are scored between *completely unable to do* (0) and *can do without help* (2). Item content reflects assistance required for using the telephone, meal preparation, handling money, and so forth. The 7 physical ADL items also are scored from 0 to 2. Item content reflects assistance required for eating, dressing, walking, bathing, and so on. Higher scores indicate a higher level of functioning. Scores can range from 0 to 28. A score of less than 21 is considered indicative of functional impairment (Cattanach & Tebes, 1991).

The Problematic Behaviors Scale is a 14-item summated rating scale to assess problem behaviors of the care recipient (Pearlin, Mullan, Semple, & Skaff, 1990). This measure defines problem behaviors as a unidimensional concept. Using a 4-point scale, problem behaviors the caregiver has dealt with in the previous week are rated in frequency from *5 or more days* (4) to *no days* (1). Higher scores indicate more frequently encountered problem behaviors. Coefficient alpha was reported by Pearlin at .79 and was .88 in the current study.

The Cognitive Status Scale was used to assess care recipient cognitive impairment by spousal report of cognitive functioning. The 8-item scale is scored on a 5-point scale from *can't do at all* (4) to *not at all difficult* (0), with higher scores indicative of more severe impairment (Pearlin et al., 1990). Pearlin reported coefficient alpha as .86. In the present study, coefficient alpha was .96.

The Expressive Social Support Scale was developed as a measure of the perceived availability of social support (Pearlin et al., 1990). The 8 items are scored on a 4-point *strongly agree/strongly disagree* scale. Scores can range from 8 to 32 and higher scores indicate higher perceived social support. Pearlin and colleagues reported coefficient alpha at .87. Coefficient alpha was .87 in the present study.

### DATA ANALYSES

The overall analysis compared and contrasted the three caregiver groups with the control group. Variables included in these comparisons were caregiver self-reports on measures of fatigue, energy, and sleep; self-reported measures of health; the cognitive, physical, and psychological limitations of care recipients; and a self-report measure on caregiver's perception of social support. For the caregiver groups, two orthogonal comparisons were made. First, the three caregiver groups as a whole were compared with the control group. Then, an independent comparison was made of the three caregiver groups among themselves. Multivariate analyses of variance were performed for each of the four classes of dependent variables outlined above, followed by univariate analyses when appropriate. Post hoc tests were conducted when needed by Tukey *B* procedure.

### FINDINGS

As expected, the multivariate analysis of variance found statistically significant differences on the fatigue measures between the caregiver groups and the control group (Wilks's lambda = 0.78,  $df = 9, 111$ ,  $p = 0.001$ ). Supporting expectations, subsequent univariate analyses showed that the caregiver groups reported significantly greater fatigue and sleep difficulty on all measures (see Table 2, Section A). As expected, the second comparison of the three caregiver groups themselves showed no differences on these fatigue measures (Wilks's lambda = 0.88,  $df = 18, 154$ ,  $p = 0.92$ ), nor were any of the univariate analyses statistically significant. Differences in fatigue and sleep behaviors among the caregivers in the three groups were, on average, quite similar.

The overall test comparing differences among the caregiver and control groups on the three health measures was not statistically significant (Wilks's lambda = 0.96,  $df = 3, 117$ ,  $p = 0.15$ ). Further analysis using univariate tests

on two of the three measures (assessment of health in general and health now compared with 5 years ago) were statistically significant (see Table 2, Section B). As would be expected, control group participants rated their health more positively than did caregiving participants. An overall comparison of the three caregiver groups as well as the univariate tests showed no differences (Wilks's lambda = 0.92,  $df = 6,164$ ,  $p = 0.32$ ) in the self-reports of health.

The differences between the caregiver groups and the control group on the patient measures of physical and mental functioning were statistically significant (Wilks's lambda = 0.73,  $df = 3,113$ ,  $p < 0.001$ ; see Table 2, Section C). Univariate analyses showed, as expected, significant differences on all three measures. Of more interest is the comparison of the three caregiver groups. The multivariate analysis showed a highly significant overall effect (Wilks's lambda = 0.27,  $df = 6,156$ ,  $p < 0.0001$ ). There were differences among the three groups on the OARS functional assessment,  $F(2,80) = 14.14$ ,  $p < .001$ . Both Alzheimer's and Parkinson's group means were less than 21, which indicates functional impairment. Patients with Alzheimer's had the lowest level of functioning, followed by those with Parkinson's disease, with the patients with cancer least affected. Differences among all three groups were significant by Tukey *B*. An analogous post hoc procedure using the analysis that included all four groups showed that the patients with cancer did not differ from the spouses of the control group on level of functioning.

Differences on the problematic behavior measure were also statistically significant,  $F(2,80) = 20.34$ ,  $p < .001$ . Patients with cancer showed the lowest degree of problematic behaviors, followed by those patients with Parkinson's disease. Patients with Alzheimer's showed the highest level of problematic behaviors; all three groups differed reliably from each other by Tukey *B* procedure. As would be expected, an analogous post hoc procedure using the analysis that included all four groups showed that the patients with cancer did not differ from the spouses of the control group on degree of problematic behaviors. There were also differences on the Cognitive Status Scale,  $F(2,80) = 86.68$ ,  $p < .001$ . Post hoc tests by Tukey *B* showed that the mean score of the patients with Alzheimer's was reliably higher (indicating lower performance) than the other two groups. An analogous post hoc procedure using the analysis that included all four groups showed that the patients with cancer did not differ from the spouses of the control group on this measure.

There were no differences on perceived social support between the caregiver and control groups,  $F(1,117) = 0.004$ , *n.s.*, or among the three caregiver

**TABLE 2: Mean Scores for Caregiving and Control Group Participants**

	Alzheimer's Caregiver Group	Parkinson's Caregiver Group	Cancer Caregiver Group	F-Values for Caregiver Groups (error df 80-86)	All Caregivers	Control Group	F-Values for Caregivers Versus Control Groups (error df 114-121)
<b>Section A</b>							
VAS-F fatigue subscale	3.38	3.72	3.32	0.47	3.50	2.11	16.96***
VAS-F energy subscale	6.26	5.38	5.45	2.37	5.51	7.27	21.48***
VSH disturbance subscale	4.48	3.88	3.88	0.97	3.95	3.02	7.77**
VSH effectiveness subscale	6.92	6.68	6.88	0.11	6.83	8.02	9.10**
SDS scale item							
"not tired-exhausted"	2.47	2.83	2.48	2.03	2.59	1.82	26.09***
POMS fatigue subscale	1.37	1.54	1.30	0.60	1.41	0.67	18.28***
POMS vigor subscale	1.90	1.58	1.64	1.12	1.64	2.32	12.12***
<b>Section B</b>							
OARS, self-rating of overall health	1.94	1.83	1.71	0.87	1.83	2.09	4.28*
OARS, comparison of current health	1.33	1.35	1.64	0.96	1.44	1.82	3.96*
OARS, health troubles interfere	2.24	2.07	2.09	0.26	2.13	2.42	2.72
<b>Section C</b>							
OARS, functional assessment	14.26	19.31	23.60	14.14***	19.06	27.81	39.59***
Problem behavior	27.44	20.52	16.81	20.34***	21.59	15.06	21.94***
Cognitive status	18.22	3.72	0.97	86.68***	7.64	0.58	18.41***
Expressive support	24.28	23.03	23.00	0.86	23.44	23.54	.004

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

groups on the Expressive Social Support Scale,  $F(2,87) = 0.86$ , *n.s.*. All groups reported the perception of a relatively high level of available social support.

## DISCUSSION

The principal objective of this study was to examine how fatigue might differ among older spouse caregivers of persons with different disabilities and to examine the similarities and differences in fatigue reported by caregiving and noncaregiving elders. The consequences of fatigue are important for both the caregiver and care recipient. Therefore, health care professionals should know how levels of fatigue reported by elders who have extra care responsibilities because of a spouse's illness compare with fatigue levels reported by elders who do not have extra spousal care responsibilities. Health care professionals should be aware of differences as a function of the type of caregiver condition if such differences exist.

In our samples of caregiving elders, the men and women who provided care for a spouse with Parkinson's disease had been in active caregiving roles for the longest period of time, averaging 5 years since the onset of extra care requirements for their spouses. Spouse caregivers for persons with Alzheimer's disease reported providing care for the greatest number of hours each day, whereas cancer caregivers reported the fewest hours and the shortest time in the caregiving role among the caregiving groups. In contrast, the control group participants estimated they spent less than 2 hours each day in care-related activities such as cooking, washing, and running errands. The caregiving groups were all engaged in daily care activities that far exceeded the maintenance activities of the control group and, furthermore, they had been providing the extra care for an extended period of time. Given these additional role requirements, caregivers could be expected to report more fatigue.

On each of the fatigue, energy, and sleep-related measures, as predicted, the caregiving groups were significantly different from the noncaregiving group. All caregiving groups reported more fatigue, less energy, and more difficulty with sleep than control group elders whose spouses were not ill. There were no differences among the caregiving groups on these fatigue and sleep variables even though there were significant differences in the caregiving situation regarding spouses' functional ability, cognitive status, and problematic behaviors.

For caregivers of spouses with cancer, the ill spouses did not differ from control group spouses in functional ability, cognitive status, or problematic behavior. Yet, even though the physical and mental functioning of the spouses with cancer and the control group spouses were similar, cancer caregiving participants reported significantly more fatigue, less energy, and more sleep difficulty than the control group participants. The typical characteristics that have been used to explain caregiving fatigue, such as providing more assistance with ADLs and IADLs, and managing impaired cognition and problem behaviors, did not predict fatigue in this sample; the differences between groups were not in patient/spouse level of function. Furthermore, between-group differences could not be attributed to caregiver age or time in the marital relationship because these had been kept constant between groups. Rather, differences in fatigue and energy that were reported by cancer and control group participants might be attributed to environmental differences between the groups, in other words, the requirements of the caregiving role. These role requirements are further intensified for the Alzheimer's and Parkinson's caregivers, who reported significant impairment with regard to their spouses' functional ability, problematic behavior, and cognitive status compared with the cancer group caregivers.

Stone and colleagues (1987) reported that fewer elders providing informal care for a disabled spouse characterize their own health as good or excellent when compared with noninstitutionalized elders in general. Significant differences in characterizations of health also were found in the current study. Those in caregiving roles were similar to each other in health assessment, with all caregiving groups reporting a less positive assessment of their health than their noncaregiving counterparts. This finding is supportive of the concern that providing informal home care extracts a significant health cost among older adults.

Elders in both caregiving and noncaregiving roles perceived relatively high levels of social support. Because the noncaregivers also reported high levels, no differences were found among the groups on this measure. Mean scores for all groups ranged between 23.00 and 24.28 out of a maximum of 32. In general, elders reported the sense that confidants were available, as were people with whom to share feelings of caring and understanding.

Of particular interest to note in this study was the similarity among the caregiving groups. Even though there were differences in care conditions, length of time in caregiving roles, and time of care provided each day, the groups reported similar responses to these disparate circumstances. All caregiving groups were more fatigued, less energetic, and had more sleep difficulties than the control group participants and they did not differ from

each other. All caregiving groups rated their health more negatively than the control group participants, and the negative assessment did not differ among the caregivers. These differences were evident in spite of the fact that all participants were of similar age and were living at home with their spouses.

Because the health and well-being of the caregiver is such an important factor in maintaining the caregiving role, health care providers must be sensitive to what is likely to be reported by older persons in this role. Just because the caregiver is older does not mean he or she should be expected to complain of fatigue and diminished energy. Control group participants did not complain about fatigue. Yet, the three groups of older caregivers did report fatigue, which accentuates the need for careful assessment. Williams (1993) suggested that control of caregiver fatigue might buffer the sense of burden and distress of caregiving. To promote health and to prevent illness in this population, older persons in caregiving roles must be supported in monitoring their own health and in recognizing the need for services to support the role.

Fatigue associated with situational stressors, such as those encountered in caregiving situations, is likely amenable to self-monitoring and self-regulation. Becoming aware of one's internal and external stressors that contribute to the symptom of fatigue is critical to self-monitoring. Identifying behaviors and mechanisms that can alter the stressful environmental stimuli is essential to self-regulation. Also, similar to the point made above, elderly caregivers should be reminded that fatigue is not normal for their age, but may well be associated with their caregiving role. Future research should incorporate longitudinal designs to examine how the process of caregiving over time interacts with the experience of fatigue. In addition, studies are needed to examine the effectiveness of interventions to assist in the identification and management of older spouse caregiver fatigue. Investigating the relationship between fatigue and caregiving activities, resources, and attitudes within a self-monitoring/self-regulation framework will ultimately allow for the introduction, consideration, and testing of health care interventions that will assist older caregivers to more effectively identify and manage the symptom of fatigue.

#### NOTE

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## Commentary

### Commentary by Lindgren

This study addressed an important issue in caregiving, namely fatigue, a somewhat neglected component of family's long-term care experience. The strength of the study is the measurement of fatigue across three caregiving population samples and comparison with a control of noncaregivers. Another strength is the use of multiple measures of the fatigue concept, thereby providing greater confidence in the findings. The results of the study are interesting in that cancer caregivers have the least fatigue, with Parkinson's

caregivers having more and Alzheimer's caregivers the most, but these differences are not significant. The caregiver groups do differ from the noncaregiving control. The question then becomes, what does that mean?

A limitation of the article is the lack of a conceptualization of fatigue that would incorporate all of the variables measured in the study. One has to assume that sleep disturbance, nature of the dependency of the care recipient, health of the caregiver, and social support have some link to the fatigue. The study findings determined how each of these variables differed across groups but not how the variables are related to one another within groups.

The nature of the dependency of the care recipient differed across the caregiving groups but fatigue level did not significantly differ across the caregiving groups as stated above. The measures of cognitive status and problematic behaviors of the care recipient were understandably highest for the Alzheimer group. It cannot be assumed from these findings that fatigue is not related to differing levels of the cognitive status and the problematic behaviors. Within group analysis of relationships among cognitive status, problematic behaviors and fatigue levels are necessary to determine how fatigue, cognitive status, and problematic behaviors are related. It is not known from the findings presented in this article if the variance in the variables within groups was great enough to allow for such testing.

If part of fatigue is emotional exhaustion, then the vigilance requirements for care of the Alzheimer's patient make sense as being fatiguing. The Alzheimer's caregivers had significantly more hours of care among the caregivers, which could contribute to a sense of fatigue or overload. Emotional exhaustion seems similar in definition to overload and depression measured in studies of burden in Alzheimer's caregivers. Other research studies of Alzheimer's caregivers support that problematic behaviors, such as combativeness and argumentation, have greater negative impact on caregivers' sense of overload and depression (Wright, Clipp, & George, 1993; Yates, Tennstedt, & Chang, 1999). Further investigation into the nature of fatigue as it pertains to managing difficult behaviors is needed to explore this relationship.

The study presented here provides evidence that caregiving contributes to fatigue. The study raises questions as to what activities, emotional states, and situational factors play a role in the development of that fatigue. Such factors need to be explored within a conceptual framework that is explanatory of the nature of fatigue and the contributing factors to its buildup.

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## Commentary

### Commentary by Nichols

In economics there is a concept called *free good*, that is, a good or service so universal or abundant that it does not have value in a market economy. In other words, people are not willing to pay for that service. In many cases, free goods are taken for granted and used carelessly. It is also true that the identification of a *good* as a free good may differ from market to market (Lipsey, Courant, Purvis, & Steiner, 1993). Examples of free goods are such things as air and water (in some places), and perhaps, provision of care by family members. Families are advantaged, obviously, if the use of free goods frees resources for other uses. This study makes it clear, however, that provision of care by family members may not be a free good. Providing care has a cost to the individual and family. Perhaps not a direct monetary cost, but definitely a resource cost.

This study suggests that caregiving is a drain on the physical resources of the elderly caregiving individual, no matter what the circumstances of the caregiving. It might be hypothesized that such variables as hope, expected duration, available social support, and opportunity for meaningful interpersonal interaction with the recipient of care would mitigate the burden of caregiving. From data presented here, it would appear that these factors do not mitigate fatigue. Perhaps for this sample, the physical demands of the caregiving and the psychological demands of uncertainty inherent in each of these diagnostic categories outweigh the effect of these potentially mitigating factors.

In this era of cost-conscious health care and increased expectations that the home and family will be the primary context for caregiving, there is a need for renewed focus on measures that support not only the identified patient but the recipient of care. There is a significant amount of literature on

burden and caregiving and the potential impact of care giving on the health of the caregiver as well as the impact on such resources as social support on burden (Bull, Maruyaman, & Luo, 1997; Holicky, 1996; Vrabec, 1996). It may be, as noted in other research, that elderly caregivers often do not use the support systems available to them, and so shoulder the majority of the burden themselves (Wallhagen, 1992). It seems that caregiving is physically tiring. Availability of resources, unless used, is not sufficient to reduce fatigue.

Whether the benefits to society (i.e., decreased overall monetary costs of health care provision) of elderly spouses providing care outweigh the costs to the care provider (fatigue, potential decrease in quality of life, and increased health vulnerability), is a policy question, not a research question, yet it is a significant one. The full impact of these costs has not been well articulated. Development and testing of nursing measures that can mitigate caregiving outcomes such as provider fatigue are needed, as are broader studies that provide data to address the broader policy questions about resource allocation.

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## Authors' Response

We are intrigued by the parallel drawn between the economic concept of *free good* and care that is provided by family members to support a loved one at home. This conceptualization is in keeping with using a self-monitoring and self-regulation framework to understand the fatigue experience in caregiving. Individuals have a number of biological, psychological, and social resources that are used to meet energy demands. Energy demands include basic activities of daily living and other activities deemed important to an individual beyond these basic necessities. For caregivers, the demands are varied and can include meeting personal needs, providing physical care for a loved one, and maintaining vigilance for another's safety and well-being. Each of these activities requires use of resources. Caregivers tap their physical, psychological, and social resources to maintain the caregiving environment. Resources are continually used and replenished to support these activities. When varied demands exceed available energy or resources and the person cannot adequately monitor, regulate, or restore energy, fatigue is an expected outcome (Aronson et al., 1999). Informal caregiving clearly is not a free good.

An important element of the self-monitoring and self-regulation framework is that an individual must have awareness of the phenomenon to successfully reallocate internal and external resources to ameliorate fatigue. If the person is unaware of the symptom, he or she is unlikely to monitor, regulate, or restore the energy necessary to forestall further fatigue. Having an awareness of the stressors that can contribute to fatigue is the essence of self-monitoring. Similarly, being able to identify behaviors that can alter environmental stimuli to more efficiently use and restore energy stores is essential to self-regulation.

It is precisely this conceptualization of fatigue that supports the inclusion of variables in this study. We used the self-monitoring and self-regulating framework as a guide to understanding the relationships among demands, resources, and fatigue. In this framework, demand that exceeds available energy or resources is a precursor to fatigue. System imbalance because of disturbances in energy-restoration mechanisms can also cause fatigue. Excess demand and/or disturbance in restoration of resources can produce fatigue. With awareness of an actual or potential imbalance, it may be possible to redistribute resources or modify energy expenditure to avoid or lessen fatigue. Testing this hypothesis is essential for future caregiving studies.

For the purposes of this study, caregiving demand was measured by an assessment of the care recipient's functional status, problematic behaviors, and cognitive status. Assessment of perceived energy, self-health, adequacy of sleep, and social support provided measures of energy and resources. Fatigue was measured by quantification of the symptom and its associated distress.

In this study, older spouse caregivers faced a variety of demands. There were differences between caregiving groups, on average, with regard to functional status and problematic behaviors of the care recipients. On the other hand, perceived energy and resources were remarkably consistent across the caregiving groups with all groups reporting, on average, similar levels of energy, sleep disturbance and effectiveness, and perceived social support. The quantification of fatigue and the distress associated with the symptom also was similar across the caregiving groups. These three samples of caregivers reported similar levels of energy and resources and similar perceptions of fatigue, yet different demands. The caregiving groups differed from the control group with respect to demands, perceived energy and self-health, and perceived fatigue. There were no differences, on average, with regard to the resource of social support.

Although it would be expected that within each caregiving group fatigue (and vigor) would covary with the other cognitive and psychosocial measures studied, the number of respondents per group was not deemed adequate for a within-group analysis. With differences likely as a function of gender as well as type of caregiving, 12 to 16 male and female caregivers per group is not sufficient to explore such relationships. Assessing these relationships as well as their implications for the delivery of effective interventions in substantially larger caregiving populations is recommended for future studies.

The self-monitoring and self-regulation framework provided a valuable guide for variable selection and for interpretation of findings in this study. For the caregiving groups, regardless of differences in the demands of caregiving, all reported similar energy, resources, and fatigue, on average. This finding suggests a more general interpretation for understanding the demands of caregiving. A broader conceptualization of these demands might illuminate interventions that would be effective in relieving the distress commonly experienced by those who take on the role of informal care provider in the home environment. By assisting caregivers to recognize the stressors that can contribute to fatigue, they can be supported in self-monitoring their energy. By assisting caregivers to identify behaviors that can alter environmental stimuli to regulate or restore energy stores, they can

be supported in the self-regulation of their energy. Both strategies are essential to management of caregiver resources and the reduction of caregiver fatigue.

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