Burden Among Family Caregivers of Persons With Alzheimer’s Disease in Nursing Homes

Jane B. Tornatore, PhD, and Leslie A. Grant, PhD

Purpose: This article examines family caregiver burden after placement of a relative with Alzheimer’s disease or a related dementia in a nursing home. Design and Methods: A systems-oriented contextual approach was used to study burden in 276 family caregivers. Results: SAS PROC MIXED analysis showed burden to be associated with caregiver age, length of time involved in caregiving, custodial units, involvement in hands-on care, and expectations for care. Implications: The findings suggest that more services aimed at relieving caregiver burden after nursing home placement may be warranted, particularly so for caregivers who are older and for those who had a shorter length of involvement in direct caregiving before institutionalization.

Key Words: Dementia, Family caregiver, Stress, Nursing home, Special care unit

Because of the heavy burden associated with caregiving for persons with Alzheimer’s disease and related dementia, many families eventually institutionalize their relative (Pushkar Gold, Feldman Reis, Markiewicz, & Andres, 1995). Family caregiver burden usually does not end after institutional placement because most families continue their commitment to the caregiver role in the nursing home (Duncan & Morgan, 1994; Keefe & Fancey, 2000; Monahan, 1995; Murphy et al., 2000; Vinton & Mazza, 1994; Zarit & Whitlatch, 1992). This exploratory study applies systems and stress theoretical perspectives to identify factors associated with family caregiver burden after nursing home placement of a demented relative.

Different models of stress theory exist (e.g., Hill, 1958; Krause, 1990; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Pearlman, Mullan, Semple, & Skaff, 1990). Among these, Hill’s ABC-X model offers the clearest conceptualization of the influence of structural factors, extraromial resources, resource strains, and family caregiver perceptions on stress outcomes such as caregiver burden, which are the focus of this article. Under the rubric of general systems theory, the family stress ABC-X model provides a framework for examining factors that mediate an individual family member's ability to cope with a stress-producing event or situation (Biegel, Song, & Milligan, 1995; Boss, 1988; Hill, 1958; Vinton & Mazza, 1994). We expand on the ABC-X model of family stress to examine the relationship between burden and family caregiver characteristics, characteristics of the institutionalized relative, resource strains, organizational resources of the nursing home, and caregiver perceptions of nursing home care. Our expanded version of Hill’s model incorporates factors that have not been examined in previous research using the ABC-X model. In the original model (Hill, 1958), Factor A is the stressor; Factor B, the resources available to the family member; Factor C, the perceptions of the family member; and Factor X, the outcome or state of functioning after the stressful event. We take a systems-oriented contextual approach to look at A, characteristics of the caregivers and their institutionalized relative; B, resources in the form of extraromial systems, as well as resource strains; and C, family member perceptions. Figure 1 shows our overall conceptual framework. We view burden of caregiving not as a single event, but as a situational mixture of circumstances, experiences, responses, and resources, the combination of which affects burden after nursing home placement.

The stress-inducing situation examined here is that of being in the role of primary family caregiver of a relative with a dementing illness in a nursing home. This stressful situation was observed within the context of structural parameters (Factor A) defined by caregiver characteristics (family caregiver’s level of education, marital status, familial relationship to the institutionalized relative, work status, and age). Structural factors also encompassed characteristics of the institutionalized relative (stage of dementia and length of stay).

Resource strains and resources were represented by Factor B. Resource strains are aspects of the caregiver’s life with the potential to drain coping resources.
Resource strains diminish the positive effect of a coping resource on outcome. We included travel distance from home to nursing home, length of time involved in caregiving before institutionalization, and visitation frequency as potential resource strains in our model. Factor B also encompassed resources outside the family system that enable family members to cope with the stress of caregiving in the nursing home. Extrafamilial resources examined in our model were related to organizational attributes of the nursing home such as geographic location, ownership status, unit type, and unit designation.

Nursing facilities in the United States are evolving toward greater diversification in the range of services provided and types of residents served. Increasingly, facilities admit residents to different unit types (e.g., Alzheimer’s unit, rehabilitation unit, or subacute unit) on the basis of resident care needs. Unit type refers to the operational and environmental characteristics of the nursing unit where the relative with dementia is housed. An empirical typology of unit types serving persons with Alzheimer’s disease developed by Grant (1998) was used to classify units as custodial versus other type. We selected custodial units for this analysis because they provide the fewest dementia-oriented services of all unit types. Unit designation was based on self-report and referred to whether a unit was identified as a dementia special care unit (SCU) or a traditional (non-SCU) unit. We hypothesized that lack of organizational resources (represented by custodial units) and provision of dementia-oriented services (represented by SCU designation) would be related to levels of caregiver burden.

Factor C was defined as the primary family caregiver’s perceptions of the stressful situation. Family caregiver perceptions were operationalized in terms of how involved caregivers perceived themselves to be in the care of their relative and their overall expectations about the care their relative received in the nursing home.

Caregiver burden was Factor X, or the outcome, in our model. According to Stull, Kosloski, and Kercher (1994), burden taps a unique domain not represented by more objective indicators of caregiver stress. Burden is a sign that caregivers may need more support and/or professional assistance (Mangone et al., 1993).

**Methods**

**Sample**

Data for this study were collected as part of a larger study to evaluate the effectiveness of SCUs in Minnesota nursing homes (Grant, Kane, & Stark, 1995). The evaluation of family caregiver outcomes was not a primary goal of that study, so the analysis presented below is a secondary analysis of an existing data set. Resident and family caregiver data were collected from 100 units in 38 skilled nursing facilities in Minnesota. The size of nursing facilities in our sample ranged from 65 beds to 490 beds. Average facility size for the respondents in our sample was 180 beds. Unit size ranged from 16 beds to 79 beds. Average unit size for the respondents in our sample was 40 beds.

We used a two-stage sampling design. At the first stage, 334 nursing units in 123 Minnesota nursing homes were stratified to represent a sixfold typology of dementia units developed by Grant (1998). One hundred units were randomly drawn to represent the six unit types. At the second stage, we randomly selected dementia residents from these 100 units. Custodial units composed only 6.3% of our sample of 334 units and residents in these units composed 6.5% of our final sample. SCUs composed 17% of these units, and 30% of the residents in the final sample were in an SCU. Because our primary interest was in comparing dementia resident outcomes between SCUs...
and non-SCUs, we sampled a higher proportion of SCU residents. For each of 464 residents sampled, the most involved family member for that resident (corroborated by staff and facility records) was interviewed by phone using a closed-ended questionnaire that took on average one half hour to complete. Seventy-two residents had no living family member; only a friend, attorney, or other legal guardian could be identified. These 72 residents were deemed ineligible for this analysis as the legal guardians’ involvement in the nursing home and knowledge of residents were limited. Of the 392 dementia residents with living relatives, 31 family members could not be contacted, and 4 caregivers refused the interview. This further reduced the sample size to 357 family caregivers, or a response rate of 91%. Resident data and organizational data were gathered through nurse informant interviews, interviews with other nursing home staff, and a review of facility records. If data were missing at the organizational level or for the family member or their institutionalized relative, those observations (N = 81) had to be dropped (because there were too many missing items in a scale or discrete items were used that could not be prorated). This procedure resulted in a final sample size of 276 resident–caregiver pairs with complete data. Family members dropped from the analysis differed from those retained in the analysis in several ways. They were less likely to be daughters or older and more likely to be retired. Also, their institutionalized relative was more likely to be in an SCU and have a longer length of stay.

**Measures**

Our dependent measure was derived from the work of Montgomery (National Coordinating Center, 1991). Her scale is unique in that it focuses on burden among caregivers with demented relatives in nursing homes after institutionalization (Montgomery, 1994). The Burden scale assesses subjective feelings of how the caregiving situation has changed since the relative went into the nursing home. Ten Likert-type scale items with response choices ranging from “a lot less” to “a lot more” make up the scale (Cronbach’s coefficient α = .90). Questions include “Since your relative came to the nursing home do you find that you have: ‘time to do your own work and daily chores’ and ‘tension in your life.” Possible scores range from 10 to 50; high scores represent more burden.

Five demographic caregiver characteristics were included as independent variables: (a) type of relationship (three dummy variables representing spouse, son, or daughter vs other relative); (b) age (continuous); (c) education (6-point measure ranging from 1 = less than 8 years to 6 = postcollege); (d) marital status (1 = married, 0 = not married); and (e) employment status (1 = working full time, 2 = working part time, 3 = unemployed/retired/homemaker).

We examined two resident characteristics: (a) length of stay in the nursing home (days) and (b) the Functional Assessment Staging Technique (FAST; Reisberg, Sclan, Franssen, Kluger, & Ferris, 1994). FAST scores (Reisberg, 1988) were used to determine a resident’s stage of dementia. This measure is a 16-item hierarchical scale designed to measure progressive functional deterioration in Alzheimer’s disease (Auer, Sclan, Yaffe, & Reisberg, 1994). Reisberg and colleagues report high estimates of interrater reliability (r = .83) and construct validity (r = .99). Scores can range from 1 to 16; higher FAST scores represent more advanced stages of Alzheimer’s disease.

We used three variables to assess caregiver resource strains: (a) distance from caregiver residence to nursing home (5-point measure ranging from 1 = same city to 5 = different city 60 or more miles away), (b) frequency of visitation (8-point measure ranging from 1 = visit less than once a year to 8 = visit daily), and (c) length of time involved in giving direct care prior to nursing home placement (6 point measure ranging from 1 = never before involved to 6 = involved for over 5 years).

Four organizational variables were examined: ownership status (0 = nonprofit, 1 = for profit), geographic location (1 = rural, 0 = urban), SCU designation (1 = SCU, 0 = non-SCU), and custodial unit type (1 = custodial unit, 0 = noncustodial unit). SCU versus non-SCU designation was based on self-report. Custodial units are a unit type without dementia-oriented attributes. They are geared to the needs of high-functioning, cognitively intact residents. None of the custodial units had an SCU designation. The correlation between SCU designation and custodial units was low (r = −.18). Although most SCUs consisted of a single unit type, SCU designation does not connote a homogenous unit type as SCUs differ in the degree to which they are tailored to dementia (Grant, 1998; Grant & Ory, 2000). Furthermore, research has found that many non-SCUs provide quality of care comparable to SCUs (Chappell & Reid, 2000).

Variables describing family caregiver perceptions focused on two dimensions, caregiver involvement and expectations, and are based on instruments developed by Montgomery (National Coordinating Center, 1991). Involvement entailed two dimensions: involvement in the nursing home (Cronbach’s coefficient α = .76) and involvement with hands-on care (Cronbach’s coefficient α = .76). Each scale consists of four items with 5-point Likert-type responses of “never,” “rarely,” “sometimes,” “often,” and “frequently.” Questions for involvement in the nursing home include “How often in the past month have you engaged in participating in a care plan meeting with staff members?” and “How often in the past month have you engaged in attending a training session or seminar for families?” Involvement with hands-on care includes questions such as “How often in the past month have you engaged in directly providing care for your relative by assisting with feeding, clothing, toileting, or bathing?” Family caregiver Expectations is a 14-item scale using 5-point Likert-type responses (Cronbach’s coefficient α = .74). Expectations measures what family caregivers anticipated nursing home care would be like before they institutionalized
their relative. The scale includes questions such as “Did you believe or understand that the unit would be a soothing and calming place for your relative to be?” and “Did you believe or understand that this would be a place where your relative would be accepted regardless of his or her behavior?” On the Caregiver Burden, Involvement, and Expectations scales, up to 20% of missing items in each scale were prorated, using the mean score for that person.

Analysis

Zero-order correlation coefficients were examined by means of Pearson correlation coefficients. We tested our conceptual model in order to examine the effect of individual characteristics (caregiver and resident characteristics, resource strains, and perceptions), unit characteristics (SCU and custodial unit status), and facility characteristics (location and profit status) on caregiver burden. We used a three-level model to incorporate the effects of individuals, nested within units, which are nested within facilities. This approach is warranted because the individual is the unit of analysis within a nested sample (Diez-Roux, 1998, 2000). Single-level, fixed-effects analyses on individual outcomes, such as ordinary least squares regression, ignore group membership and look only at individual, or “between,” variation. This ignores the potential influence of group-level attributes on individual-level outcomes. If outcomes for individuals within groups are correlated, the assumption of independence of observations is violated, leading to underestimated standard errors. This results in an attribution of more variance to individual-level variables than is warranted. Multi-level analyses correctly estimate standard errors associated with regression coefficients because they take into account residual correlation of group-level variables that individuals within groups share, or “within variation,” and estimate larger standard errors to account for fewer independent observations than the sample size would suggest (Bryk & Raudenbush, 1992; Yow-Wu, 1995). We used SAS PROC MIXED (SAS Institute, Cary, NC) in this research to perform a multilevel analysis because it allows for the incorporation of group-level variables into a micro-level equation when individuals are the unit of analysis and correctly estimates standard errors (Diez-Roux, 2000; Littell, Milliken, Stroup & Wolfinger, 1996; Singer, 1998).

Four models were tested in the hierarchical analyses to determine which results indicated a better fit of the model to the data. In the first, facilities, and units within facilities, were treated as random effects, and the independent variables outlined above were treated as fixed effects. This analysis was performed to determine the variance in caregiver burden associated with facilities and units. The second model included the same fixed variables, but only facilities were treated as random effects. The third model included only the fixed variables, and random effects were not included. The fourth model examined only the significant fixed factors from the previous analyses, with facility and unit treated as random effects.

Results

Table 1 summarizes descriptive characteristics of the 276 family caregivers and residents in the final sample. The respondents were primarily Caucasian (99%). Most caregivers were either daughters (45%) or sons (29%). Only 9% of caregivers were spouses. The mean age of the caregivers was 59.6 years, and most respondents either worked full time (45%) or were not employed (38%). Approximately a third of the caregivers had a high school diploma (30%), and 63% received at least some postsecondary education. More than three quarters of the caregivers were married at the time of the interview (80%). Most respondents

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver age (years)</td>
<td>M = 59.6, SD = 11.3</td>
</tr>
<tr>
<td>Married</td>
<td>80</td>
</tr>
<tr>
<td>Full-time work</td>
<td>45</td>
</tr>
<tr>
<td>Part-time work</td>
<td>17</td>
</tr>
<tr>
<td>Unemployed/retired/homemaker</td>
<td>38</td>
</tr>
<tr>
<td>Relationship to Resident</td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>9</td>
</tr>
<tr>
<td>Daughter</td>
<td>45</td>
</tr>
<tr>
<td>Son</td>
<td>29</td>
</tr>
<tr>
<td>Other relative</td>
<td>16</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>Fewer than 8 years</td>
<td>2</td>
</tr>
<tr>
<td>Some high school</td>
<td>5</td>
</tr>
<tr>
<td>High school graduate</td>
<td>30</td>
</tr>
<tr>
<td>Some postsecondary</td>
<td>34</td>
</tr>
<tr>
<td>College graduate</td>
<td>22</td>
</tr>
<tr>
<td>Postcollege</td>
<td>7</td>
</tr>
<tr>
<td>Length of Time Involved in Caregiving Before</td>
<td></td>
</tr>
<tr>
<td>Institutionalization</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>33</td>
</tr>
<tr>
<td>0–6 months</td>
<td>13</td>
</tr>
<tr>
<td>6 months–1 year</td>
<td>11</td>
</tr>
<tr>
<td>1–2 years</td>
<td>13</td>
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<tr>
<td>2–5 years</td>
<td>15</td>
</tr>
<tr>
<td>Over 5 years</td>
<td>15</td>
</tr>
<tr>
<td>Visitation Frequency</td>
<td></td>
</tr>
<tr>
<td>Less than once a month</td>
<td>6</td>
</tr>
<tr>
<td>Once a month</td>
<td>7</td>
</tr>
<tr>
<td>Twice a month</td>
<td>11</td>
</tr>
<tr>
<td>Once a week</td>
<td>28</td>
</tr>
<tr>
<td>2–6 times a week</td>
<td>37</td>
</tr>
<tr>
<td>Daily</td>
<td>11</td>
</tr>
<tr>
<td>Distance from Nursing Home</td>
<td></td>
</tr>
<tr>
<td>Same city</td>
<td>42</td>
</tr>
<tr>
<td>Under 16 miles</td>
<td>38</td>
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<tr>
<td>16–60 miles</td>
<td>13</td>
</tr>
<tr>
<td>Over 60 miles</td>
<td>8</td>
</tr>
<tr>
<td>Resident Characteristics</td>
<td></td>
</tr>
<tr>
<td>Stage of dementia</td>
<td>M = 9.5, SD = 2.6</td>
</tr>
<tr>
<td>Length of stay (years)</td>
<td>M = 2.8, SD = 3.1</td>
</tr>
</tbody>
</table>

Note: Due to rounding, percentages may not equal 100.
were involved in caregiving before nursing home placement (67%), with many involved for more than 1 year (43%). The majority of caregivers (80%) lived less than 16 miles from the nursing home where their relative lived, and most caregivers (76%) visited their relative in the nursing home at least weekly. Resident scores on the FAST ranged from 2 (little impairment) to 16 (severe impairment). The mean score was 9.5 (SD = 2.6). The length of stay in the nursing home ranged from 1 month to 21 years. The mean length of stay was 2.8 years (SD = 3.1 years).

Table 2 shows zero-order correlation coefficients between burden and the independent variables (N = 276). Caregivers who felt more burden were older (p < .01), lived farther away from their relative (p < .05), had spent less time in the caregiving role before institutionalization (p < .001), had a relative who was not in a dementia SCU (p < .05), and had lower expectations for care provided by the nursing home (p < .05). Zero-order correlation coefficients among the independent variables were low to moderate (data not shown). Out of 171 possible pairwise comparisons among the independent variables, 62 coefficients were significantly correlated. Six of these correlation coefficients were greater than .40: spouse and age, .42; son and daughter, −.58; age and work status, .59; visitation frequency and distance from the nursing home, −.52; involvement with hands-on care and visitation frequency, .58; and involvement with hands-on care and involvement in the nursing home, .43.

The fit statistics for three of the four multivariate models tested were roughly equivalent. Examination of the model fit information in Table 3 shows the same fit for Model 1 (both facility and unit as random effects) and Model 2 (only facility as a random effect). The third model (no random effects) had a worse fit on the −2 Res log likelihood and a slightly better fit according to Akaike’s information criterion. The fourth model, which included only the five variables significant in Models 1 and 2, did not fit the data as well as the others. Theoretical considerations suggest that including units and facilities is appropriate; therefore, we chose to present Model 1.

Neither facility nor unit were significantly correlated with caregiver burden. Although facilities seemed to have a small correlation (estimate = 2.44) with caregiver burden, no variation was accounted for by units (estimate = 0). In other words, there was no significant correlation of burden scores among caregivers with relatives in the same unit or facility. (See Table 4.) The multivariate analysis with facility and unit as random effects indicated that all three elements of the expanded ABC-X model are associated with caregiver burden. Most of the variables included in our model, however, were not significantly associated with burden. Five variables significantly contributed to burden: higher caregiver age (Factor A—structural factor, p < .001), shorter length of time in caregiving prior to institutionalization (Factor B—resource strain, p < .001), custodial unit (Factor B—organizational resource, p < .05), more involvement with hands-on care (Factor C—caregiver perception, p < .05), and lower expectations (Factor C—caregiver perception, p < .01). (See Tables 5 and 6.)

Table 2. Pairwise Correlations of Independent Variables

| Varlable                          | Pearson Correlation | 2-tailed p | |
|----------------------------------|---------------------|------------|
| Caregiver Characteristics        |                     |            |
| Education                        | .066                | .273       |
| Marital status                   | .004                | .945       |
| Spouse                           | .016                | .785       |
| Daughter                         | −.013               | .835       |
| Son                              | .009                | .881       |
| Work status                      | .023                | .700       |
| Age                              | .185                | .002       |
| Resident Characteristics         |                     |            |
| More advanced stage of dementia  | .014                | .821       |
| Length of stay                   | .020                | .743       |
| Resource Strains                 |                     |            |
| Distance from nursing home       | .121                | .045       |
| Length of time involved in caregiving | −.313           | .000       |
| Visitation frequency             | .003                | .955       |
| Organizational Resources         |                     |            |
| Rural location                   | .100                | .097       |
| Special care unit                | −.119               | .048       |
| For profit ownership             | .040                | .510       |
| Custodial unit                   | .101                | .093       |
| Perception                       |                     |            |
| Involvement in the nursing home  | .089                | .140       |
| Involvement with hands-on care   | .078                | .199       |
| Expectations for care            | −.127               | .035       |

Table 3. Model Fit Statistics

<table>
<thead>
<tr>
<th>Description</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Facility and unit random; 19 fixed variables</td>
<td>1,856.4</td>
</tr>
<tr>
<td>Akaike’s information criterion</td>
<td>1,860.4</td>
</tr>
<tr>
<td>Facility random; 19 fixed variables</td>
<td>1,856.4</td>
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<tr>
<td>Akaike’s information criterion</td>
<td>1,860.4</td>
</tr>
<tr>
<td>19 fixed variables</td>
<td></td>
</tr>
<tr>
<td>−2 Res log likelihood</td>
<td>1,857.8</td>
</tr>
<tr>
<td>Akaike’s information criterion</td>
<td>1,859.8</td>
</tr>
<tr>
<td>Facility and unit random; 5 fixed variables</td>
<td>1,877.8</td>
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<tr>
<td>−2 Res log likelihood</td>
<td></td>
</tr>
<tr>
<td>Akaike’s information criterion</td>
<td>1,881.8</td>
</tr>
</tbody>
</table>

Table 4. PROC MIXED Analysis of Association of Independent Variables (Facility and Unit Random): Covariance Parameter Estimates (REML)

<table>
<thead>
<tr>
<th>Covariance Parameter Subject</th>
<th>Estimate</th>
<th>SE</th>
<th>Z</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept Facility</td>
<td>2.44</td>
<td>2.5</td>
<td>0.98</td>
<td>0.16</td>
</tr>
<tr>
<td>Intercept Unit (Facility)</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Residual</td>
<td>48.59</td>
<td>4.62</td>
<td>10.52</td>
<td>0.00</td>
</tr>
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</table>
Discussion

This study focused on caregivers of nursing home residents with a particular type of illness—Alzheimer’s disease or a related dementia. As this illness has a gradual downward trajectory, caregiving demands become greater over time, frequently leading to institutionalization. Although most prior studies have examined burden of caregiving before institutionalization, this study examined caregiver burden after nursing home placement. Family caregivers who were older and who cared for their relative for a shorter duration before placement were more burdened after institutionalization. Having a family member in a custodial unit (least geared toward dementia care) was associated with more burden. Caregivers who perceived themselves as more involved in hands-on care of their relative and whose expectations for nursing home care were low also experienced more burden.

Except for age, caregiver characteristics were not associated with burden. Our finding that older caregivers felt more burden supports those of other studies (Monahan, 1995; Vitaliano, Russo, Young, Teri, & Maiuro, 1991). Education, marital status, employment, and type of relationship were not related to burden. Previous research has indicated that caregiver burden is associated with having more education (Mangone et al., 1993; Monahan, 1995), being married (Monahan, 1995), and being employed (Barusch & Spaid, 1989; Morris, Woods, Davies, & Morris, 1991; Pearl et al., 1990; Scharlach & Boyd, 1989; Young & Kahana,
The literature is inconsistent regarding the question of who among immediate family members experiences the most burden in caregiving (Coen, Swanwick, O’Boyle, & Coakley, 1997; Grafstrom, Fratiglioni, Sandman, & Winblad, 1992; Grafstrom & Winblad, 1995; Ritchie & Ledesert, 1992; Young & Kahana, 1989). We found no association between type of relationship to the nursing home resident and burden.

An examination of zero-order correlations may help explain some of these negative findings. Caregiver age was significantly related to work status \( (r = .59) \) and familial relationship \( (\text{spouse}, r = .42; \text{daughter}, r = -.24; \text{son}, r = -.15) \). As these caregiver characteristics were correlated, the strong association of caregiver age to burden may hide the effects of other caregiver characteristics, such as work status, which shows a trend toward statistical significance \( (p = .058 \text{ in the SAS PROC MIXED analysis}) \). Nonetheless, most caregiver characteristics (education, marital status, family relationship, and work status) have low zero-order correlations with burden. Perhaps these caregiver characteristics have more salience as coping resources or potential stressors before placement than afterward.

Resident characteristics are not associated with burden in either zero-order or multivariate analyses. Research is contradictory regarding the effect of level of impairment on caregiver burden. There is growing evidence suggesting that level of impairment is not as important as other factors in caregiver outcomes (Hepburn, Tornatore, Center, & Ostwald, 2001; Fisher & Lieberman, 1999). Our research supports the findings of Coen and colleagues (1997), Fisher and Lieberman (1994), and Yates, Tennstedt, and Chang (1999). Length of stay is also not associated with caregiver burden as reported in another study (Drinka, Smith, & Drinka, 1987), but contrary to Monahan’s (1995) findings. Although these caregiver and care receiver structural factors may be associated with caregiver burden in community settings, they appear to be less salient after nursing home placement.

The length of time spent in the direct caregiving role before institutionalization is the single most powerful predictor of caregiver burden. Caregivers who spent less time taking care of their relative prior to nursing home placement had greater burden. The burden of caregiving after institutionalization could be greater because they are taking on a new role and may be taking on responsibilities they did not previously have. Keefe and Fancey (2000) suggested in their study of family caregivers of institutionalized relatives that for caregivers whose extent of caregiving in the community is low or nonexistent, any involvement (even in decision-making responsibilities) is perceived as a new stressor in their lives. Rather than seeing institutionalization as an alleviation of role strain, these novices in the caregiving role may perceive nursing home placement as a new source of stress.

Caregivers who have more experience in direct caregiving may be more likely than those without this experience to have developed effective coping strategies for the caregiving role. Those who have coped successfully with stress in the past might be better equipped to find effective strategies to handle new situations (Boss, 1992; Brubaker, 1990). Similarly, more experienced caregivers may have had more time to accept the decline of their relative as a result of Alzheimer’s disease. Because dementia is a progressive illness, caregivers who have more experience with the disease may be further along in grieving the loss of their relative. These caregivers may be more accepting of their relative’s cognitive and physical decline.

Another interpretation involves feelings of guilt. The societal misperception still exists that when families place their loved ones in a nursing home, they “dump” them there and cease to be involved in their lives, even though research has shown that most caregivers continue to be involved (Dellasega, 1991; Kaplan & Boss, 1999; Keefe & Fancey, 2000). It is common for caregivers who have recently placed a relative to feel guilty because they were unable to continue giving care (Nolan & Dellasega, 1999). Perhaps family members who have provided direct care over a longer duration feel they have fulfilled familial obligations and feel less guilty about putting their relative in a nursing home, compared with those without this experience.

Although it was significant in the bivariate analysis, longer distance from home to nursing home was not associated with burden in the multivariate analysis. This finding contradicts that reported by Stephens, Ogrocki, and Kinney (1991). We originally hypothesized that higher visitation frequency would be associated with more burden, but neither our multivariate nor our bivariate findings support this position. Because distance from home to nursing home and visitation frequency are correlated with involvement in hands-on care \( (rs = -.29 \text{ and } .58, \text{respectively}) \), their effects may be masked in the multivariate model by the effect of involvement in hands-on care, which is significantly associated with burden.

Organizational resources that reflect macro-level attributes at the facility level (e.g., for-profit ownership or rural location) are not associated with caregiver burden. In contrast, organizational resources that reflect micro-level attributes at the unit level (e.g., SCU designation or custodial unit) are associated
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tricities may be more relevant to caregiver adaptation
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stronger when other independent variables are intro-
possible that the effect of custodial unit becomes
result, it provides a more efficient estimate of the ef-
variables at individual, unit, and facility levels. As a
model, but not in the bivariate analysis. Facilities with
why custodial unit was significant in the multivariate
cause it did not connote a homogenous unit type, as
did the custodial unit, which is based on an empirical
typology of environmental, program, and staff at-
tributes (Grant, 1998). Custodial units provide few
dementia-oriented services, and a poor fit between the
needs of dementia residents and the operational and
environmental resources offered by custodial units
may increase caregiver burden. Organizational poli-
cies related to admissions criteria may help explain
why custodial unit was significant in the multivariate
model, but not in the bivariate analysis. Facilities with
more differentiated (i.e., more specialized and less ge-
eric) units tend to admit residents at early, moderate,
and late stages of dementia into different units within
the same facility (Grant, 1998). The variance among
the variables in our conceptual model may have been
influenced by such facility-level and unit-level poli-
cies. The multilevel model examines the effects among
variables at individual, unit, and facility levels. As a
result, it provides a more efficient estimate of the ef-
cost of custodial unit on caregiver burden. It is also
possible that the effect of custodial unit becomes
stronger when other independent variables are intro-
duced into the model. Overall, our findings support
Ritchie and Ledesert's (1992) assertion that it is im-
portant to study organizational characteristics of the
nursing home because institutional policies and prac-
tices may be more relevant to caregiver adaptation
than patient-related variables.
Our results are consistent with previous research
showing that caregiver perceptions are integral to the
process of adaptation (Boss, 1988, 1992; Deimling &
Bass, 1986). Caregiver perceptions of involvement
with hands-on care are associated with burden, which
supports the findings of Yates and colleagues (1999).
Friedemann, Montgomery, Maiberger, and Smith
(1997) found that some family members provide di-
crect care to their relative to compensate for perceived
inadequate care by nursing home staff. Involvement
with the nursing home is not significantly related to
burden, perhaps because involvement with the nurs-
ing home has a moderate zero-order correlation with
hands-on care ($r = .43$). In addition, care given be-
cause nursing home care is seen as deficient is likely to
be more stressful than care given because of a contin-
ued wish to be involved in family members’ lives. Nurs-
ing home staff need to provide opportunities for
family caregiver involvement in ways that facilitate
caregiver adaptation to the placement of their relative
and do not create ambiguity between what are tradi-
tionally considered nursing staff functions and family
caregiver responsibilities.

Low caregiver expectations are associated with
more burden. Low expectations can reflect a lack of
confidence or trust in the adequacy of services pro-
vided by a nursing home. Caregivers with low expec-
tations may adopt a “vigilance” role in the nursing
home to ensure that their relative’s care needs are being
met. Not trusting nursing home staff to provide ade-
quate care, or having to maintain vigilance over nurs-
ing home care, is likely to increase caregiver burden.

This study has a number of limitations. First, these
data were collected at one point in time. A longitudi-
nal research design is needed to explore causal rela-
relationships among variables, as well as to investi-
gate caregiver coping and burden over time. Second,
our sample of units is drawn exclusively from Minneso-
ta nursing homes, and the unit types described here may
not generalize to other states. Third, more research is
needed to further validate the measures used to test
our models. Fourth, a broader family systems per-
spective that includes more than just the primary
caregiver is warranted as interactions among family
members and their involvement with the resident and
nursing home staff can affect adaptation (Fisher &
Lieberman, 1999). Further research using a more
conceptually complex model such as Pearlin and col-
leagues’ (Aneshensel, Pearlin, Mullan, Zarit & Whit-
latch, 1995; Pearlin et al., 1990) model of the stress
process, which incorporates secondary stressors—
aspects of life not specific to caregiving—would be valu-
able. Aspects of the caregiver’s life such as intrapsy-
chic strains and informal and institutional role strains
could be incorporated into the model, thus giving a
more in-depth view of the caregiving process. Data
for this analysis were taken from a larger study to
evaluate the efficacy of dementia SCUs for nursing
home residents, so these secondary data did not allow
for such complex analyses. Fifth, the small number of
participants in this sample whose relatives were in a
custodial unit, as opposed to another unit type, may
mean the findings are not robust. Therefore, these
findings need to be replicated with a larger sample of
custodial units. Sixth, there are two sources of possible
bias in the data. There is a potential for systematic
bias in our results due to the number of cases dropped
from this analysis because of missing data. Also, resi-
dents and family members were not randomly as-
signed to facilities or type of unit. As a result, we were
unable to completely control for all possible selection
bias, such as differences in cognitive levels in SCUs,
non-SCUs, or custodial units, although we included
resident FAST scores in the analyses, which con-
trolled for bias to some extent.

We hope that exploratory study will direct re-
searchers, policymakers, clinicians, and consumer
groups toward further inquiry into how to more appropriately support family caregivers after placement of a cognitively impaired relative in a nursing home. Our results suggest that programs might benefit from approaches that identify progressive stages of family caregiving over time. Caregiver experiences, both before and after institutionalization, appear to affect adaptation. Although the decision to institutionalize a demented relative represents a major transition in the family caregiver's role, the caregiver's previous experiences are linked to how a caregiver adapts to this role after nursing home placement. Our findings suggest that more services aimed at relieving caregiver burden after nursing home placement may be warranted, particularly so for caregivers who are older and for those who had a shorter length of involvement in direct caregiving before placement. Specifically, greater attention needs to be focused on family caregivers who are new to the caregiving role at the point of nursing home placement, as they appear to be at a heightened risk for burden.

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**Appendix**

**Note**

1. Bravo and colleagues (1999) found residents with severe cognitive deficits received lower quality of care in for-profit facilities in bivariate analyses, but that effect did not remain significant when tested with other variables in the model.