Evercare/NAC Study of Family Caregivers: What They Spend, What They Sacrifice

November 27, 2007
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Purpose and Design of the Study

- To examine the spending and opportunity costs of family caregivers

- Design of the study included two phases:
  - Telephone survey of 1,000 unpaid family caregivers who were helping with either/or ADLs or IADLs and spending 5 hours or more a week for a person over 50 years of age;
  - Cost diaries kept for 30 days by 41 caregivers
The Survey Sample (n=1,000)

- 57% caring for parents, 21% caring for spouse, 5% grandparents, 4% siblings, 13% other relatives or friends.
- 67% helping with ADLs, 97% with IADLs
- Average weekly hours: 35.4 hours
- Female – 75%
- Average Age - 56
Where They Lived

Figure A: Proximity of caregivers to the person they are helping

n=1,000

- Co-resident: 45%
- Live nearby: 44%
- Live more than 1 hour away: 11%
Monthly Out-of-Pocket Costs for Survey Respondents

- Medical – (31%) $337
- Food, meals, household goods (42%) $183
- Travel costs (40%) $126
- Services (12%) $452
- Nursing home/assisted living (5%) $980
Annual Cost Expenses

- Medical equipment and supplies
  - 22% $936
- Home Modifications
  - 17% $1,735
- Legal Fees
  - 5% $1,933
The Diarists (n=41)

- Female – 76%
- Average Age – 56
- Employed – 56%
- Care Situation:
  - Co-resident 54%
  - Lives near 39%
  - Long-Distance 7%
Annualized Costs for Diarists

- Medical Expenses (27) $5,088
- Transportation (27) $1,164
- Groceries/dining (28) $1,656
- Household Expenses (27) $3,516
- Personal Expenses (25) $1,296
- Total Average Annual Expenses $12,348
Costs of Care Falls Most Heavily on Those Who Can Afford it Least

**Figure E: Average annual cost of care by income category**

<table>
<thead>
<tr>
<th>Annual income</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than $25,000</td>
<td>$5,229</td>
</tr>
<tr>
<td>$25,000 to &lt;$50,000</td>
<td>$4,476</td>
</tr>
<tr>
<td>$50,000 to &lt;$75,000</td>
<td>$5,682</td>
</tr>
<tr>
<td>$75,000 to &lt;$100,000</td>
<td>$10,374</td>
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<tr>
<td>&gt;$100,000</td>
<td>$6,784</td>
</tr>
</tbody>
</table>

Note: 133 respondents refused to provide income information.

**Figure F: Average hours of care per week by income category**

<table>
<thead>
<tr>
<th>Annual income</th>
<th>Hours</th>
</tr>
</thead>
<tbody>
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<td>Less than $25,000</td>
<td>41</td>
</tr>
<tr>
<td>$25,000 to &lt;$50,000</td>
<td>38</td>
</tr>
<tr>
<td>$50,000 to &lt;$75,000</td>
<td>36</td>
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<tr>
<td>$75,000 to &lt;$100,000</td>
<td>23</td>
</tr>
<tr>
<td>&gt;$100,000</td>
<td>24</td>
</tr>
</tbody>
</table>
What strategies are being employed by caregivers to manage their costs?

- Cutting back on spending for hobbies, leisure time (49%)
- Cutting back on vacations or travel (47%)
- Reduce or stop saving for future (38%)
- Defer major purchase or home improvement (34%)
- Using savings (34%)
The Stress of Caring and Spending

Figure 1: Have you had stress or anxiety associated with caregiving?

- Yes: 65%
- No: 34%
- Don’t know: 1%

n=1,000
Effects on Employment

Figure J: How has caregiving affected your work status?

n=1,000

- Used sick or vacation hours to care: 48%
- Taken unpaid leave: 15%
- Left one job for a different one: 14%
- Taken additional job or increased hours: 17%
- Cut back on hours or quit work: 37%
The Diarists and Work

- Several mentioned giving up work as key opportunity cost of caregiving
- Four reported they had been forced out of work as a result of caregiving
- Spousal caregivers report having to take early retirement
- Caring as work and caring after work
Type of Care Situation Affects Expenses

Figure M: Average total annual expense by type of care situation – survey respondents

- Long-distance care providers: $8,728 (n=95)
- Co-resident care providers: $5,885 (n=153)
- Nearby care providers: $4,570 (n=444)

Figure N: Average total annual expense by the type of care situation – diarists

- Co-resident care providers: $14,832 (n=41)
- Long-distance care providers: $14,064
- Nearby care providers: $8,496
Correlates of Expenses

- Bad habits
- New/worsening health problems
- Deferring medical/dental appointments
- Trouble sleeping
- Feelings of depression or hopelessness
- Workplace accommodations: unpaid leave, changing jobs, additional job, cut back hours or leaving work, using sick or vacation days
Themes Identified for the Diarists

- It’s not the money, it’s the time
- Caregiving is a life deferred
- Emotional stress trumps time and money
- Caregiving careers
- Caregiving is a labor of love
Key Findings for Policy

- Correlations between adverse caregiving effects and amount of expenses suggests money may play a larger role in perceived burden.
- Lowest income families have the highest burden.
- Spending is more common than previously thought and at higher levels.
Policy and Practice Implications

- Health insurance for those not yet eligible for Medicare is of vital importance for many caregiving families.
- Tax credits or subsidies for caregivers
- Long term care system improvements including family caregiver assessment and support.
- Take financial burden into account when assessing needs and capacity