

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

November 29, 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



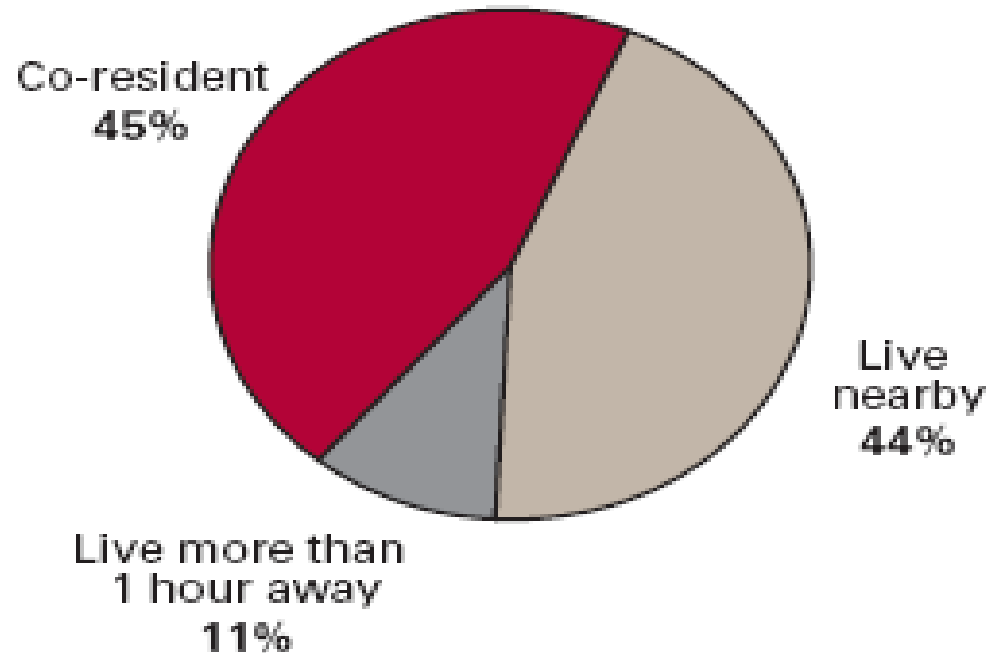
The Survey Sample (n=1,000)

- 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





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

Annual income

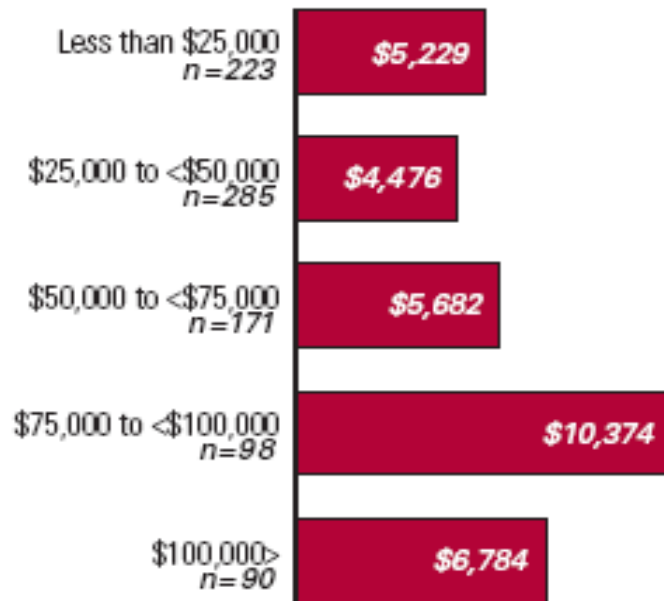
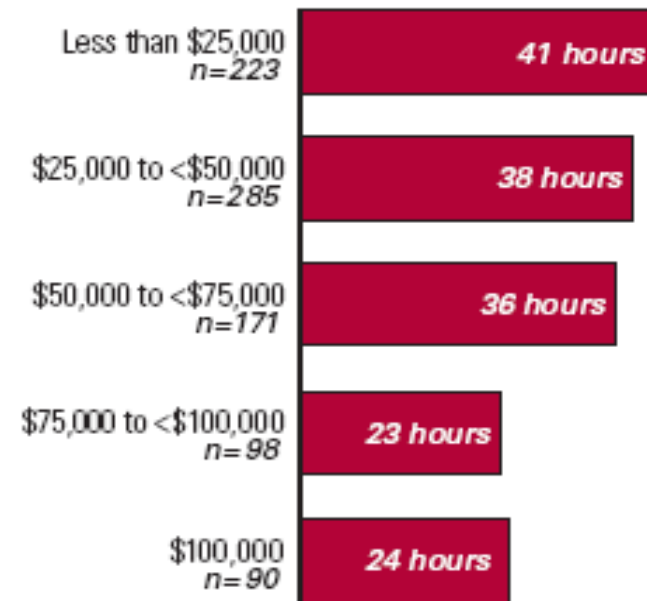


Figure F: Average hours of care per week by income category

Annual income



Note: 133 respondents refused to provide income information.

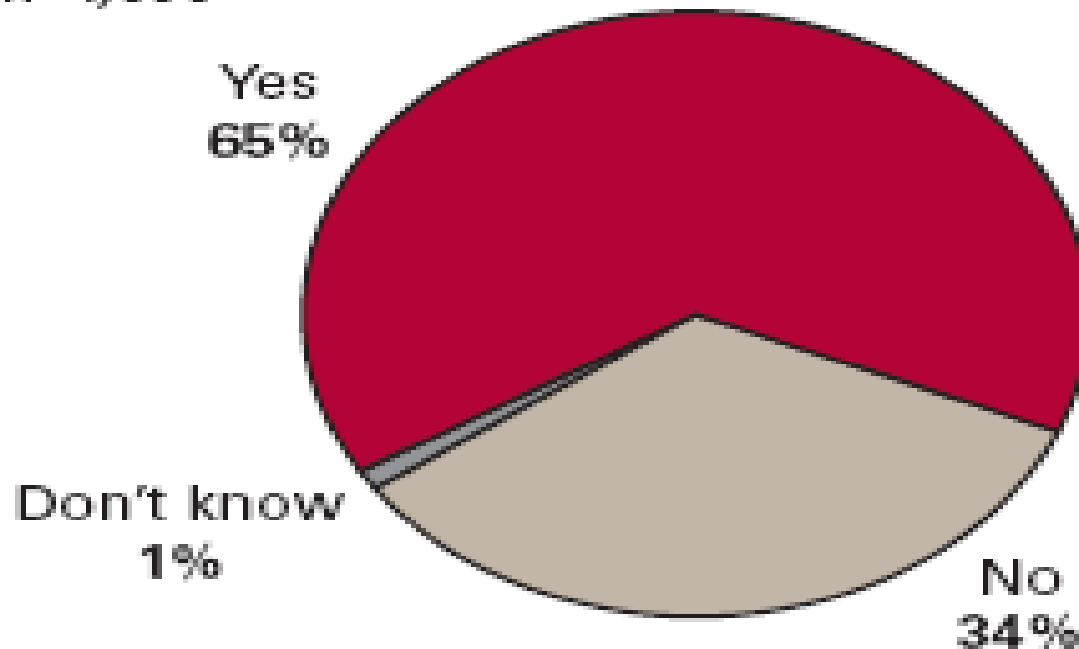
What strategies are being employed by caregivers to manage their costs?

- ❑ 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?

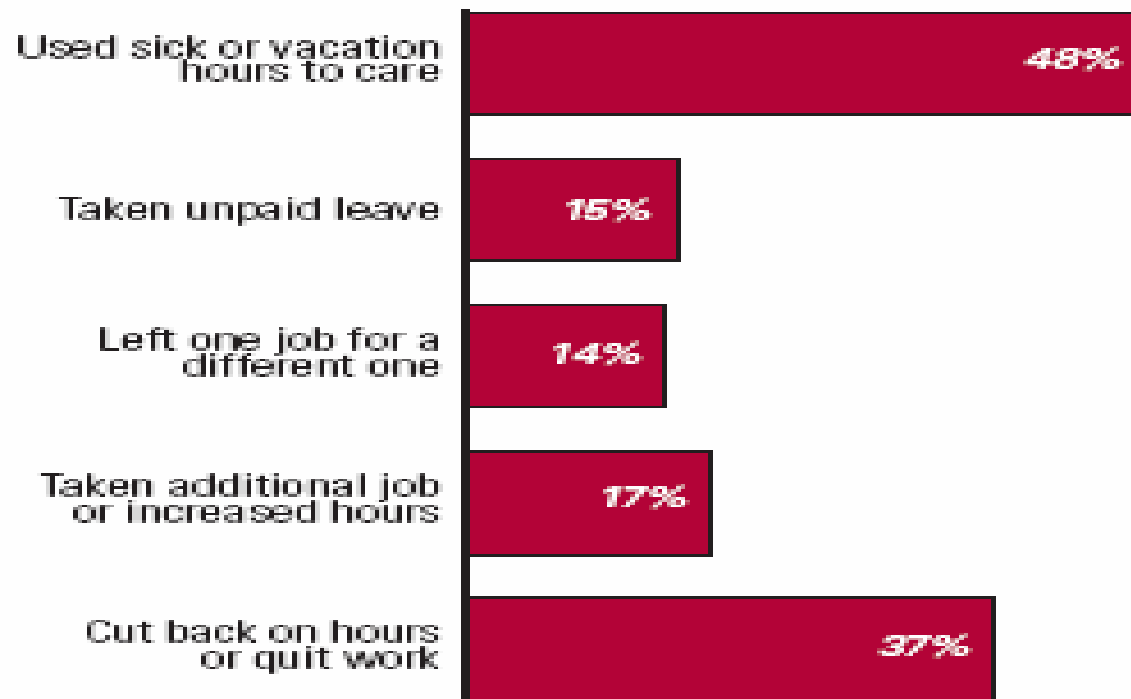
n = 1,000



Effects on Employment

Figure J: How has caregiving affected your work status?

n = 1,000





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

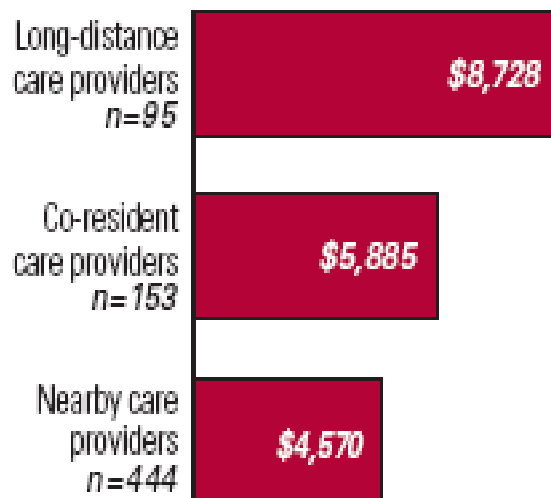
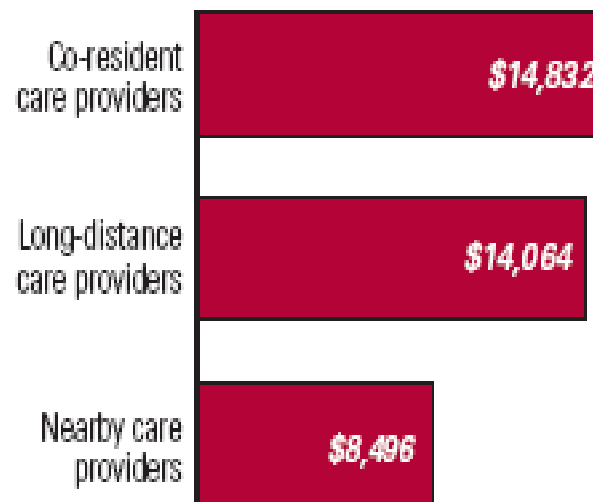


Figure N: Average total annual expense by the type of care situation – diarists

n=41





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