

Evercare® Study of
**Family Caregivers – What They Spend,
What They Sacrifice**

The Personal Financial Toll of Caring for a Loved One



Report of Findings
November 2007



**Evercare® Study of
Family Caregivers – What They Spend, What They Sacrifice**

Findings from a National Survey

November 2007

**Evercare
in collaboration with
National Alliance for Caregiving**

Evercare

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National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of more than 40 national organizations that focus on issues of family caregiving across the life span. The Alliance was created to conduct research, do policy analysis, develop national programs and increase public awareness of family caregiving issues. They also work to strengthen state and local caregiving coalitions and work on international caregiving alliances. Recognizing that family caregivers make important societal and financial contributions toward maintaining the well-being of those for whom they care, the Alliance's mission is to be the objective national resource on family caregiving, with the goal of improving the quality of life for families and care recipients.

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Evercare and the National Alliance for Caregiving deeply appreciate the work of Linda Naiditch of Mathew Greenwald & Associates in heading the survey work for this study and of Donna L. Wagner, Ph.D., Director of Gerontology at Towson University, in heading the diarists' study and writing the report. Her research team included: Kelly Niles-Yokum, Ph.D., Caley Borglum, Mary DeFreest, Kate de Medeiros, Ph.D., and Nicole Sheehan.

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Section 1
Introduction

Background

The *Evercare Study of Family Caregivers — What They Spend, What They Sacrifice* was undertaken to explore the extent to which family caregivers are paying for goods and services on behalf of the person they are helping. Surveys of family caregivers have revealed that many are assisting the care recipient financially, in addition to helping them with their everyday activities. The NAC/AARP Survey of Caregiving in the U.S. (2004) found that about half of the caregivers who were helping an elder who was not their spouse were providing financial assistance — an average of \$200 a month.

This study was undertaken to explore the financial aspects of caregiving for all types of family caregivers, including spousal caregivers. The study included a national telephone survey to examine costs of caregiving and their correlates of 1,000 family caregivers. In addition to the survey, a sample of survey respondents was recruited to participate in a 30-day study of actual expenses by keeping a diary of these expenses, as well as the opportunity costs associated with their caregiving responsibilities. There were 41 family caregivers who participated in the 30-day expense study.

There are an estimated 34 million Americans involved in providing care for an older (50+) family member or friend and an additional 10.6 million helping someone between the ages of 18 and 49 (NAC/AARP, 2004). Surveys of these caregivers have found that many are involved in providing not only “hands on” care, but paying for the expenses of care recipients as well. This study of the out-of-pocket expenses of family caregivers of older adults was undertaken to provide the family caregiving research and practice community with a more in-depth understanding of expenses and opportunity costs associated with caregiving.

Methodology – Telephone Survey

This study was conducted as a mixed-method study that included a telephone survey (random digit dialed) of family caregivers that explored their expenses and the consequences and correlates of these expenses (n=1,000). A survey company conducted the survey, continuing to call until 1,000 screened respondents had been surveyed.

The four screening criteria for participation included:

- (1) Whether or not the respondent had spent time caring for a relative or friend over the age of 50 during the past month who had one or more chronic conditions making self-care difficult
- (2) Whether they helped that person on a regular basis either with activities of daily living (personal care — bathing, dressing, feeding, toileting, transferring) or instrumental activities of daily living such as grocery shopping, transportation, housekeeping, meal preparation, and managing finances
- (3) Whether they were paid to provide the care
- (4) How many hours per week they spent providing care

To be included in the study, the respondent must have provided unpaid help to someone age 50 and over during the past month and provided help with either the activities of daily living or the instrumental activities of daily living or both. If respondents reported they had provided help but did not report that they had provided either of the two types of assistance, they were not included in the respondent pool. In addition, they had to provide care for a minimum of 5 hours in a typical week.

The study was conducted during June and July 2007.

This study was undertaken to explore the financial aspects of caregiving for all types of family caregivers, including spousal caregivers.

Methodology — Diary Study

The study was also a tool for recruiting a pool of caregivers willing to keep a 30-day expense diary about their actual out-of-pocket expenses and the opportunity costs associated with caregiving. This report includes the expense totals for 41 diarists.

In addition to keeping track of their expenses, data was collected through personal phone calls with the diarists. Each diarist was assigned a researcher whose job it was to contact them on a regular basis to encourage them to keep up-to-date on their diary entries and to collect information about the care situation. Diarists who completed the 30-day diary were provided a \$100 honorarium.

The diary portion of the study spanned July, August, September and October 2007.

Both the survey instrument and the diary protocol provided special ways for caregiving expenses for those caregivers and care recipients living together to be separated from joint living expenses so that they could be included in the data collected. For the diarists, a separate format was created for those who live with the person for whom they are caring. All diarists were also instructed to determine whether or not an expense was a “caregiving expense” by asking this question: *Would you be incurring **this** expense if you were not caregiving?* Although each diarist was encouraged to submit expenses on a weekly basis, some preferred to submit on a less regular basis.

Of the 1,000 family caregivers in the survey, there were 200 who indicated a willingness to learn more about the diary-keeping. Some declined the

invitation to participate after hearing about the details of the diary-keeping or were not accessible through the phone number they provided. Finally, a pool of 110 potential diarists was identified. Diarists were offered the option of recording their expenses through an e-mail system or through the regular mail with paper forms. All diarists preferred to receive their material through the mail, and only two submitted partial diaries through e-mail. Potential diarists began to drop out within the first two weeks as a result of a worsening of the care recipient’s health condition, difficulties with their own work or personal health, travel and/or loss of interest. A majority of the dropouts were related to the health of the care recipients. Several diarists had their phones disconnected during the study period, and we could not ascertain why they didn’t participate.

Study Limitations

This telephone survey has limitations of other surveys conducted by phone. Those without telephones or those who monitor their phone calls would not be included in the survey. Since it is a survey, we are relying upon honest responses and good recall of the respondents. In terms of financial matters, faulty recall could affect the exact estimate of costs by category and total costs.

The 41 diarists we report on in this study are not necessarily representative of family caregivers; they are self-selected caregivers with an interest in telling their financial stories. However, their stories are illustrative of the diverse range of caregiving situations. We are grateful for their time and contributions to the study.



Section 2
Key Findings

The telephone survey and diary-keeping about out-of-pocket expenses of family caregivers suggest that there are significant implications associated with the financial aspect of caregiving.

The fact that the amount of out-of-pocket expenses was closely associated with reported stress, health and overall well-being of the caregiver for the survey respondents underscores the importance of dealing with financial worries as a part of caregiver interventions.

Higher out-of-pocket costs were also associated with work status and workplace accommodations for the survey respondents. And finally, the number of diarists who had left their jobs as a result of caregiving and those who reported they were “pushed out” of their jobs reinforces the concept of a complicated equation for balancing work and caring that requires additional study and analysis.

I hope this [diary] helps in highlighting the costs of caregiving — not only in terms of money, but in time and sacrifice.

Telephone Survey

- Survey respondents reported that they had an estimated annual out-of-pocket expense of \$5,531. This is more than 10% of the median income of the group, which was \$43,026.
- The most common expense categories of the survey respondents were household goods, food and meals (42% reporting), travel and transportation costs (40%), and medical care co-pays and pharmaceuticals (31%).
- For the survey respondents, the strategies most commonly used to manage the out-of-pocket expenses were cutting back on leisure activities (49%), vacations (47%), reducing or stopping saving for their own future (38%), and deferring major purchases or home improvement projects (34%).

- More than one-third of the respondents had used their savings (34%), cut back on basic home maintenance (32%), and cut back on spending for their own health or dental care (23%).
- Among the survey respondents, 37% reported that they had quit their job or reduced work hours as a result of caregiving responsibilities. Only 35% of the sample were working full time; 53% were not working.
- Long-distance caregivers had the highest annual expenses (\$8,728) compared to co-resident caregivers (\$5,885) and those who cared for someone nearby (\$4,570).
- Higher levels of out-of-pocket expenses were associated with reported emotional and physical effects of caregiving for survey respondents. For this sample, out-of-pocket expenses were higher among caregivers who reported health problems or emotional problems.

I had a [home-based] business until I couldn't do that and care for my husband both...I was also forced to take early retirement to supplement his income of Social Security and a small state pension which doesn't cover the cost of our insurance.

Diarists

- The 41 diarists included 22 who were co-resident with the person they were helping (15 spouses/companions, one adult son, six mom and/or dad), 16 who were living close to the care recipient and three who were long-distance caregivers. The age range of diarists was 27 to 93 years.
- There were 22 diarists who were not working and six of those had left paid work in order to provide care. Four diarists reported that they had been “forced out” of their jobs as a result of their caregiving.
- The average 30-day expenses reported by the 41 diarists were \$1,029.
- For the diarists, those living with the care recipient had the highest average annualized costs (\$14,832) compared with long-distance caregivers’ cost of \$14,064 and an annualized cost of those living nearby of \$8,496.
- Cost categories of the diarists were similar to those who participated in the survey, but a higher percentage of diarists than respondents reported costs in all of the categories. Almost 70% of the diarists were paying for groceries, 66% were paying for medical expenses, household expenses and transportation costs. Four diarists were paying for costs associated with pets; a cost not explored in the survey.
- Many diarists reported that, although they were paying for goods and services needed by their care recipient, the most important cost for them was the time they spent taking care of their family member or friend.

Additional work in exploring the relationship among well-being, costs of care and levels of care is likely to be an important contribution to effective future interventions for family caregivers.

I know I do not have a choice and must accept my role at this time...I am not able to be involved in church, which was a very important part of my life...and cannot take my morning bike ride with others in the neighborhood...I am a private pilot, and my plane sits in the hangar.

I think one of the hardest things for me is that I wish I could stay home more... I homeschool my children in order to spend time with them. Right now I'm away from home more often than home.

The diarists who worked with us and opened up their family lives to us in their writings and conversations demonstrate how interrelated dimensions of care, emotions, money and past relationships are. Themes that emerged from our diarists are illustrative of these interrelationships:

It's Not the Money, It's the Time

Diarists reported that, although many were experiencing a heavy financial burden, it was the time that was the most valuable contribution to the care recipient.

Time is the most expensive commodity I provide, but it has no price tag.

Caregiving Is a Life Deferred

Future plans, career advancement and leisure activities are just a few of the activities that caregivers put off while they see to the needs of the person they are helping.

I have postponed marriage as a result of caregiving.

Emotional Stress Trumps Time and Money

Many caregivers reported extreme emotional distress related to their caregiving responsibilities. This distress relates not only to the caregiving situation but also to the past relationship between the caregiver and the care recipient.

I can honestly say that my health is declining due to increased stress from the care of my mother in the last nine years...the stress it puts on my marriage, family life, and money...not to mention my work.

Some Caregivers Have Caregiving 'Careers'

Some of the diarists were not only caring for a family member as a "labor of love," but were paid direct care workers as well.

I am a nurse aide, and even though my husband, according to the doctor, needs 24-hour care, I can't give it to him because I must work and care for others.

Others had previous experience with caring for a parent or grandparent before their spouse needed care, and many were caring for children with disabilities and elders with disabilities simultaneously. For some diarists, the future only holds new caregiving responsibility.

I care for my [parent] and a morbidly obese, psychologically damaged child who is entirely dependent on me for her financial support and her emotional and medical support.

Caregiving Is a Labor of Love

Many diarists talked a great deal about how they were balancing the stress of caregiving with the benefits they derived as a result of a deeper relationship and satisfaction with their efforts.

I don't think I have given up anything to care for her, except perhaps my house isn't as clean as it could be.

One of the diarists who cares for a husband with dementia reminds us that a good set of neighbors goes a long way toward supporting the family caregiver.

Before you feel too sorry for me, I am the President of [an association] and we hold all the meetings in my home... it was a pre-requisite of my taking the position. I take my husband out...in the neighborhood and we visit with our neighbors who are out of doors as we pass their home. The neighbors know that it is becoming more difficult for me to take my husband to their home for dinner so they bring the food to our home.

It is about the money, but for family caregivers, it's also about the complexities of life, love and the future.

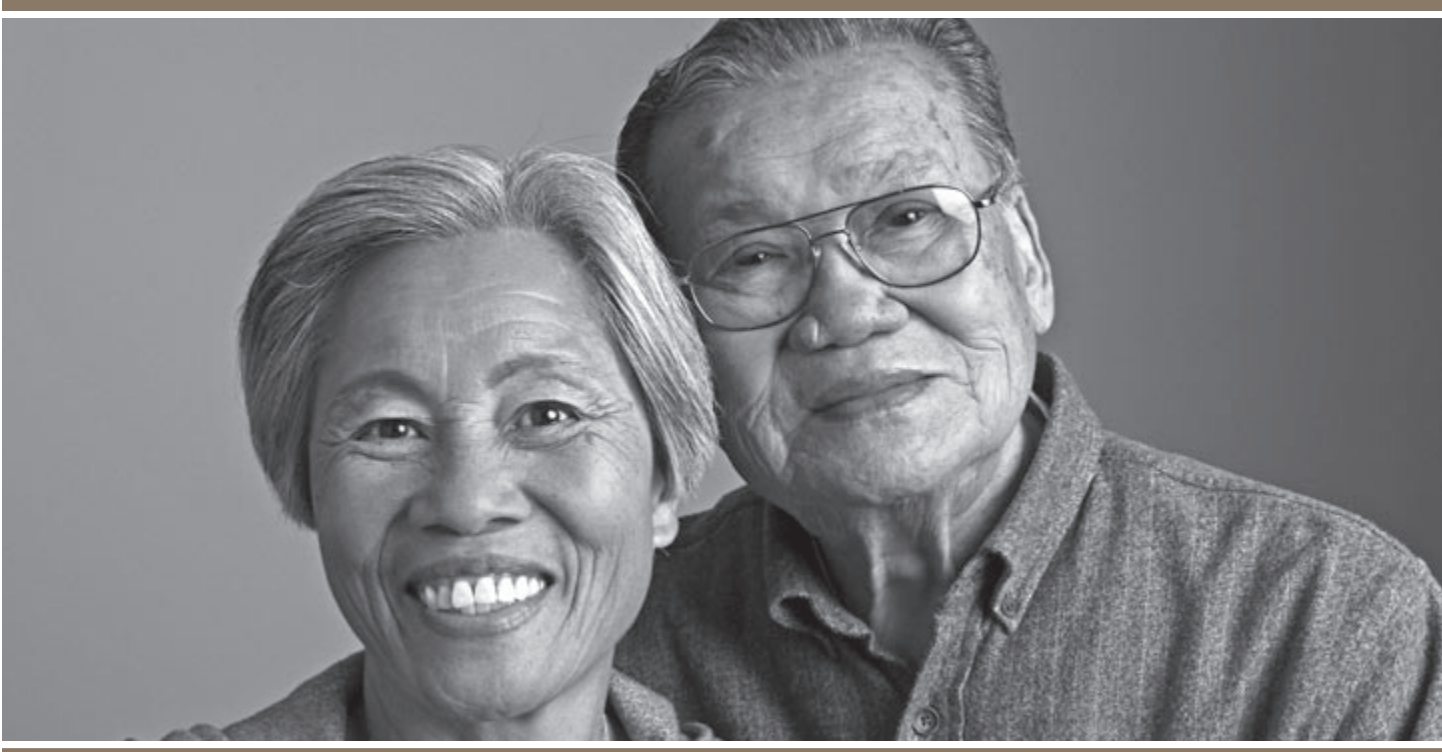
I don't give up anything I wanted to do because we just go together wherever we want — we get along great.

Policy Implications of the Study

Findings of this Study suggest that financial help should be taken seriously as a support for family caregivers. There have been several unsuccessful recent attempts in Congress to pass tax legislation giving caregivers some relief from long-term care expenses. Given the findings of this Study, especially on the financial burden for lower income families, such legislation should be given higher priority.

More research is needed about the out-of-pocket spending of family caregivers and its impact. Exploring the relationship between spending and other caregiving activities will provide additional insight into caregiver interventions that could effectively support caregivers. Many interventions for caregivers today are designed to alleviate emotional and psychological effects, reducing burden or strain. Would these interventions be more effective if they included financial support? Would financial support alone help other indicators of burden or strain?

- Family caregivers are spending at higher levels than previously reported. Caregiving tax credits or other stipends could assist these caregivers in what, for many, is a very real burden that is placed on top of their well-documented emotional and time costs.
- Nearly a third of the respondents reported that they had been employed before becoming a caregiver. Several diarists also reported that they were involuntarily out of work as a result of caregiving. Not only do we need a more in-depth understanding of how leaving work impacts caregivers, but employers interested in retaining workers should explore options that would allow caregivers to continue to work at some level regardless of how intense their caregiving situation is.
- Public policy interventions are needed to ensure that the unpaid long-term care services provided by family caregivers can be sustained over time. Paid leave, support services appropriate and accessible to caregivers of all incomes, as well as tax deductions, credits, and stipends for long-term care expenses are just a few important alternatives.



Section 3
Detailed Findings

The Caregivers in the Study

Most (57%) of the respondents were caring for a parent or parent-in-law, and 21% were providing care for a spouse. The remainder were helping siblings (4%), grandparents (5%) other relatives or friends (13%).

Two-thirds (67%) of the respondents reported they helped with ADLs, and 97% reported they helped with IADLs.

The average number of hours spent in helping the care recipient was 35.4 hours a week, with a median response of 20 hours. Half (52%) had been providing care for three or more years and 32% had been providing care for more than 5 years.

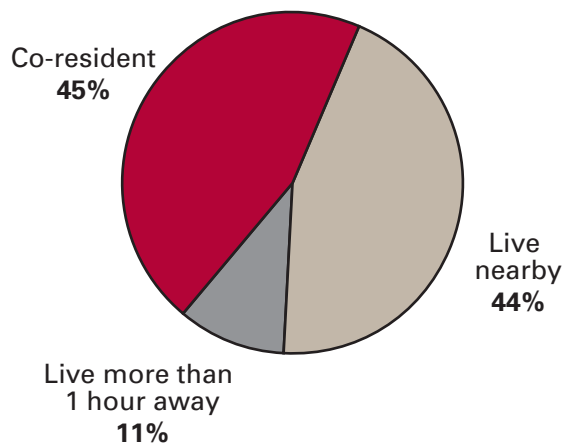
Nearly half of the respondents (45%) of this sample reported that the person they were helping lived with them and another 44% of the sample lived near the care recipient. One in ten caregivers (10%) reported that they lived more than an hour away from the person they were helping.

This sample represents family caregivers who, as a group, had high levels of care responsibilities and limited incomes.

Nearly a quarter of the respondents (22%) reported their household annual income was less than \$25,000. The median income for family households in the U.S. is \$59,894 compared to our sample's median income of \$43,026.

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

n=1,000



The Costs of Care

The average total annual costs of caregiving for the survey sample were \$5,531.

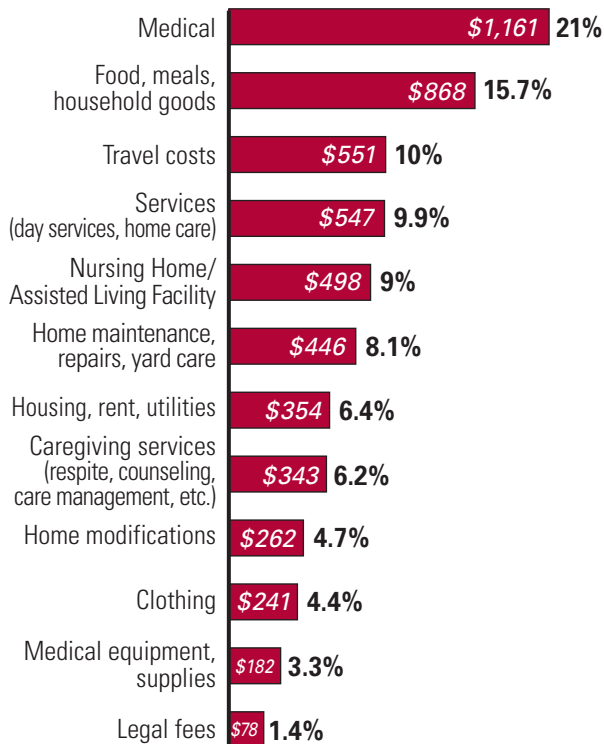
Extrapolating the costs of the diarists from their 30-day diaries was significantly higher than this — \$12,348 on an annual basis.

Annual cost of caregiving = \$5,531*
 Estimated average total annual cost of caregiving diarists = \$12,348

**All monthly expenses x 12 + annual expenses. For any given expense category, missing values were replaced with the mean.*

Across all caregivers, what are the average annual expenses?

n=1,000



Figures B and C display the percentage of the sample who reported each type of caregiving cost, and, among those who had such expenses, the average spending.

Figure B: Itemized means of cost category for survey sample – monthly

n=1,000

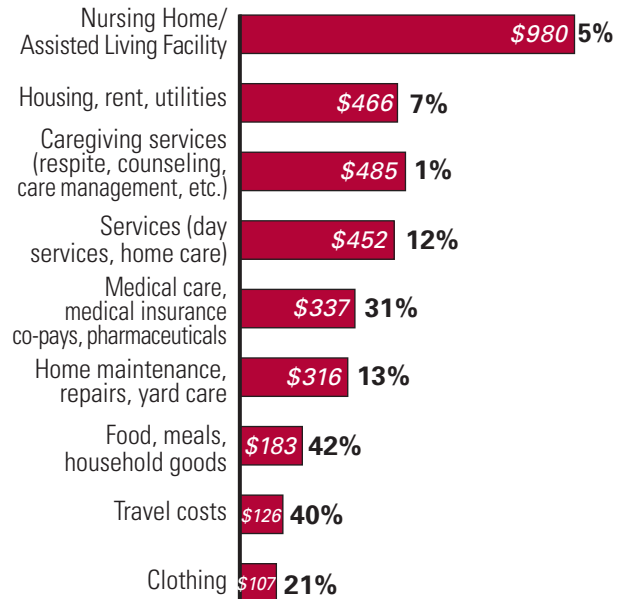
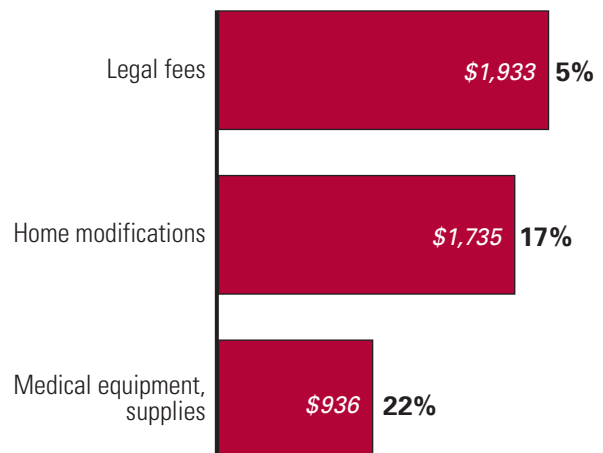


Figure C: Itemized means of cost category for survey sample – annually

n=1,000

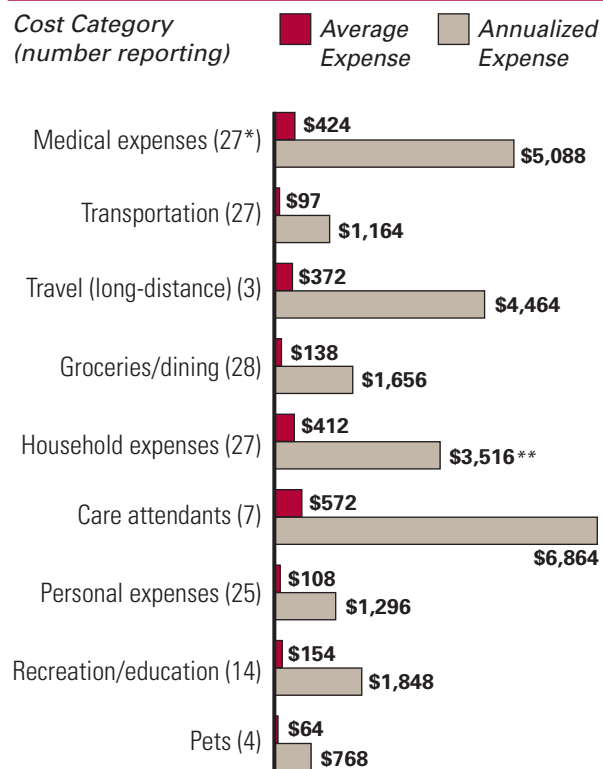


Figures B and C Note: Dollar figures are based only on the caregivers who reported having expenses in each category.

Diarist Cost Categories

The diarist cost categories were modified to reflect the actual costs reported. The categories, number reporting expenses in that category, and the average 30-day cost are found in Figure D.

Figure D: Diarist cost by category



* Does not include diarist who is spending \$3,360/30 days for skilled nursing facility.

** One-time remodeling expenses not included in annualized average.

Cost categories shown in Figure D reflect the actual expenses reported by the diarists. Medical expenses included prescription and over-the-counter drugs, co-pays, insurance and durable medical equipment. Household expenses were expenses related to supplies for the household, modifications made for accessibility, the costs of hired help for cleaning and yard maintenance as well as any costs for rent, mortgage payments or utilities for care recipients who were not living with the caregiver.

Personal expenses included items that the care recipient needed or wanted such as bath items, clothing, cigarettes/cigars/tobacco, incontinence supplies, etc.

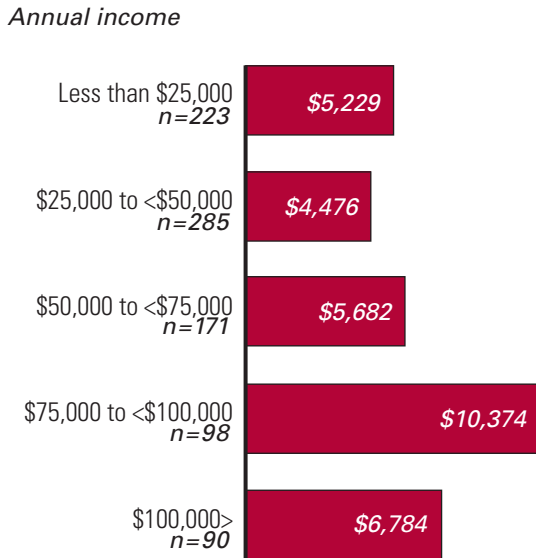
Recreation and education expenses were reported by those who took care recipients on an outing or paid for participation in senior centers, and, in one case, the cost of a caregiving class at the caregiver's church.

Interestingly, we first asked caregivers to keep separate records on the personal expenses of the care recipient and those expenses that caregivers spent on themselves such as respite care, counseling, alternative health services such as massage, etc. With the exception of the one caregiver who reported paying for the caregiver class, none of the diarists reported expenses in this category. The average out-of-pocket total expenses for diarists during the 30-day period were \$1,029.

There were some unexpected cost categories reported by the diarists. For example, one diarist reports that she must pay for a post office box so she can keep the mail from her husband who has dementia and stays home with a care attendant while she is at work. Several of the diarists reported that they were paying for cigarettes or chewing tobacco (for a parent with COPD and emphysema) and wine or whiskey. Nine diarists reported expenses for incontinence products. Five diarists reported pet-related expenses for the care recipient.

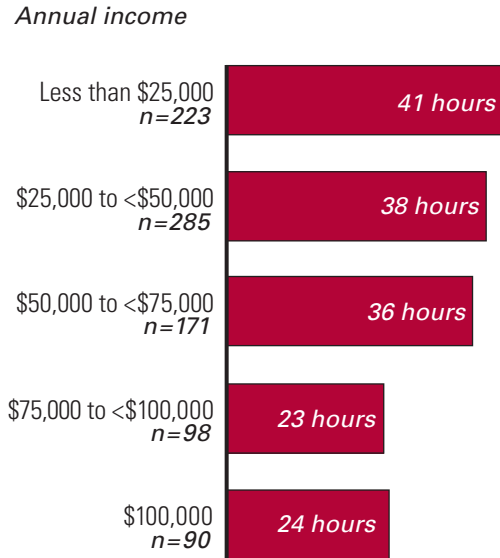
The costs of care were difficult for many survey respondents as well as diarists to manage. Figure E shows the average total annual costs for the survey respondents by their household income categories.

Figure E: Average annual cost of care by income category



There is an inverse relationship between income categories and the number of hours a week the respondent provides care as shown below in Figure F. The lower income caregivers are providing many more hours of care:

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



Note: 133 respondents refused to provide income information.

Lower Income, Higher Burden

In addition, the level of out-of-pocket spending remains high for those with extremely limited incomes. Those with the lowest income (less than \$25,000 per year) report an average annual expense of more than \$5,000 — more than 20% of their annual income. In all income categories, the percentage of annual costs represents significant cash outlays.

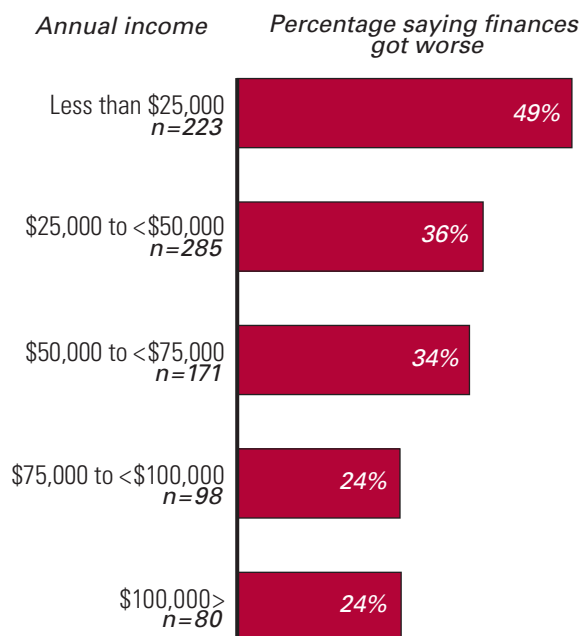
This level of burden on the lower income respondents is evident in their response to the question: *Since you began giving care would you say your finances have gotten better, stayed the same or gotten worse?*

For those respondents with less than \$25,000 per year incomes, nearly half (49%) reported that their finances had gotten worse. This compares with 36% in the \$25,000 to LT \$50,000 income range, 34% in the \$50,000 to LT \$75,000 income range, 24% in the \$75,000 to LT \$100,000 range and 24% in those making \$100,000 or more.

I have gotten so far behind in my bills that I had the phone turned off...and now they are going to turn off my cable service...It's very hard to say "no" to my [care recipient] so I just pay for things he wants...

The lowest income family caregivers have the highest burden of care in terms of both the number of hours they spend helping their family member and in their actual proportion of income spent on care.

Figure G: Since you began giving care would you say your finances have gotten better, stayed the same or gotten worse?

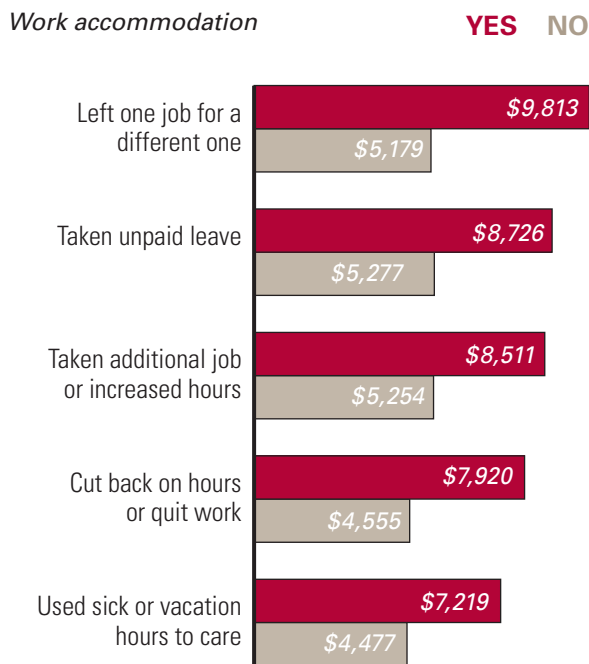


I am using all of my vacation and paid leave to provide care...If I wasn't caregiving, I would like to go on a vacation.

Those respondents reporting that they had to take an additional job or work extra hours also reported higher average annual expenses than those who did not. Figure K shows the average annual total expenses for those who have made work-related accommodations versus those who have not.

Figure K: Average annual total caregiving expenses by type of work accommodations of survey respondents

n=1,000



The average annual total expense for caregiving was higher for those working full-time than those who were working part-time — \$5,625 for full-time workers compared with \$4,358 for those working part-time. However, the average cost for caregivers who are not employed was \$5,723, comparable to the average expenses of full-time workers.

Figure L: Average annual total caregiving expenses by type of work schedules of survey respondents

n=1,000

Employed full-time	\$5,625
Employed part-time	\$4,358
Not employed	\$5,723

Employment status is also correlated with age of the respondents. The average age of respondents who are not employed is 61 years compared with full-time workers whose average is 49 years. Respondents who are employed part-time have an average age of 54 years.

Workplace accommodations were also more likely to be reported by younger respondents. The average age of respondents who changed jobs as a result of caregiving was 49 years compared with 52 years for those who did not change jobs. Working extra hours or taking an additional job was also related to younger aged respondents — 45 years for those who took on extra work compared to 53 years for those who did not.

Before I became the sole caregiver of my parents, an agency was paid \$75-\$85 per hour to coordinate and manage their care as I do now. [I can't] retain a full-time job due to home stress and trying to work around their need for doctor appointments, etc...I was 'let go.' This meant I could not work to full retirement age due to care needs of my mother.

Diarists who were continuing to work reported that they were missing hours of work each week and relying upon vacation days and personal days to provide care.

Other diarists reported that they were trying to balance the care needs of the care recipient with the needs of their job — they needed the job to pay the additional costs associated with caregiving and, for the younger spouses, keeping the health insurance was of critical importance.

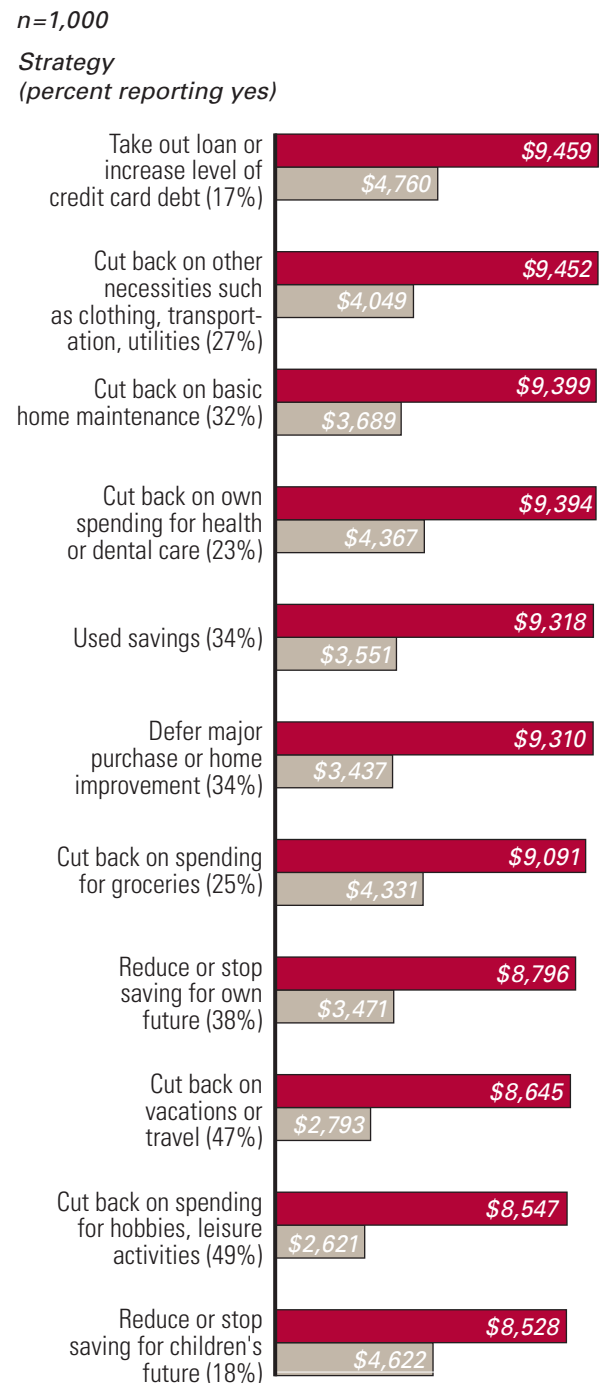
One diarist reports that her request to use a leave pool established by her employer was denied and, as a result, her health insurance was informed that she was on an unpaid leave. She did appeal the decision and was able to use the leave pool as payment for her time off, but it took a great deal of time to straighten out the health benefits.

Effects of Caregiving and Related Expenses

The survey sample was divided about the effect caregiving had on their overall financial situation with nearly half (43%) reporting that it had increased their financial worries and 53% reporting that there had been no change in their financial concerns as a result of caregiving. Figure H illustrates the strategies that surveyed caregivers have employed to manage the out-of-pocket expenses associated with caregiving and the average spending on caregiving expenses for those who have and those who have not used each strategy.

...I never have any extra money to do anything with...I get paid on Friday and I'm broke on Saturday.

Figure H: Annual expenses by strategies for compensating for caregiving expenses

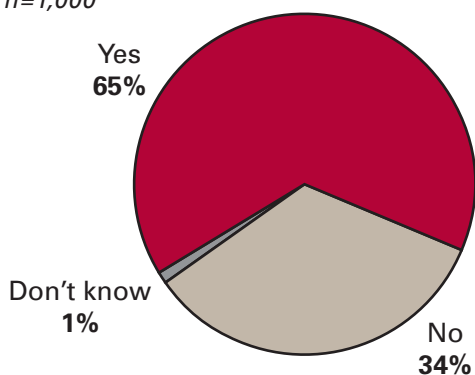


Survey respondents were also asked about personal and emotional effects of caregiving. Relatively high numbers of respondents reported difficulty managing the stress associated with caregiving.

Over two-thirds (65%) reported they had increased stress or anxiety as a result of their caregiving responsibilities, and 37% reported feeling depressed or hopeless as a result of their situation. Half (49%) reported difficulty sleeping and 42% reported they had gained or lost weight because of their caregiving. Two out of ten (23%) reported that they had to set aside their own personal medical or dental needs and a fourth (26%) reported that they had experienced new or worsening health problems as a result of caregiving. One in ten had started increasing bad habits such as smoking, misusing alcohol or, misusing prescription drugs to cope (10%).

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

n=1,000



Other diarists report that they feel resentful about the expenses they are incurring and would prefer that the care recipient would contribute to the household or overall costs of caregiving.

One diarist reports that she sold their home and has been living on the proceeds of that sale after buying a small, accessible condominium. She continues to be nervous about finances, however, since her husband had taken a lump sum payment for his retirement funds, and these funds have now been depleted. She had to take early retirement to manage the care of her husband and is looking forward to going back to work when he enters a nursing home.

[I] quit my job to move back [to my childhood home] to help with my father... [I made this decision] because I know my time with them is limited and the time I spend with them is quality time.

Expenses and Effects by Care Situations

The average costs per category or annualized totals can obscure the differences between smaller groups within the study. This section outlines some of the different effects experienced and reported by groups of caregivers according to their work status, the living situation of the care recipient, and the caregiver's income.

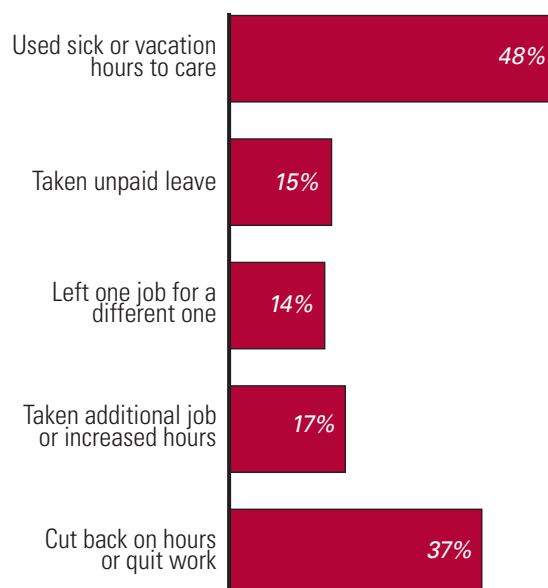
Work Status

Survey respondents were asked about the overall effects of care responsibilities on their work and work related issues. Not surprisingly, half (48%) of employed caregivers or those who had been working at some time while they were a caregiver reported that they had used their own vacation time or sick days to provide care. More than one-third (37%) cut back on work hours or quit work entirely.

A total of 15% of employed caregivers in the survey reported that they had taken an unpaid leave of absence and 14% reported they had left a job and taken another as a result of caregiving. One in six (17%) of the employed caregivers reported that they had taken an additional job or worked extra hours as a result of their care responsibilities.

Figure J: How has caregiving affected your work status?

n=1,000



CASE STUDY OF A WORKING CAREGIVER

An Older Woman's Look at Caregiving and Career

Jan is an 83-year-old woman who cares for her 87-year-old husband who has dementia, severe sleep apnea and other chronic conditions.

Although she is the primary caregiver for her husband and has responsibility for the cooking, cleaning, financial management, dressing and bathing, and transportation as well as accompanying him to his doctor appointments, she continues to work three days a week.

Jan reports that she started working when her husband took early retirement at 62 years of age. She has been working for 25 years and she “enjoys it greatly.” Work for her is not only an important source of income for her household and necessary because of the limitations in her husband’s pension and benefits, but because she loves her job and her role as worker. She is an up-beat and positive person with a distinctive “can-do” attitude that allows her to overlook her own health problems doing “what I’ve always done.”

She has arthritis which makes some of her caregiving tasks difficult and relies on a paid caregiver to stay with her husband while she is working.

She feels lucky that she saved her income over the years and is now able to pay the escalating medical expenses associated with her husband’s care. Her expenses for the 30-day period of time were \$2,560.

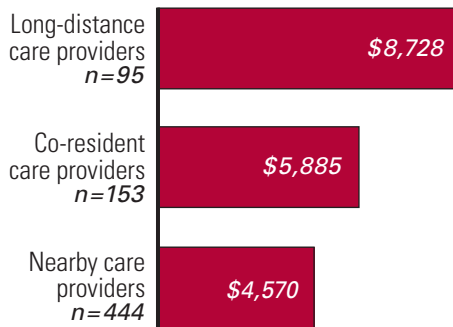
At age 83, she is the primary caregiver for her husband and continues to work three days a week.

Personal and Family Effects

For survey respondents, long-distance caregivers had higher average total expenses than caregivers who lived near and those who were co-resident.

Figure M compares the expenses of each of these three groups.

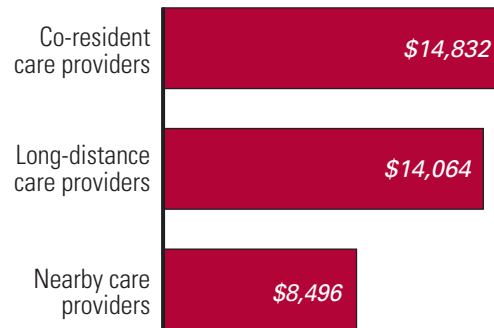
Figure M: Average total annual expense by type of care situation – survey respondents



For the diarists, co-residents had the highest reported average expenses during the 30-day period. The average for this group was \$1,236 with a range from \$90 to \$5,244. This average compares to the average for long-distance caregivers of \$1,172 and \$708 for those caring for someone who lived nearby. The annualized expenses for these three groups using the diarist's expenses are as in Figure N.

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

n=41



She never offers to pay for gas even though I take her everywhere... we even took her on vacation but we could not get away to be alone.

The co-resident diarists have a range of care situations and a range of responses to their new lifestyles. A couple who moved from the Midwest to the Southeast to live with her mother who refused to leave her friends are struggling with their decision and new life — financially and emotionally.

Co-residents were instructed not to list the household expenses that benefited all household members — only those that were directly related to the care recipient. In the case of the couple who relocated to care for the wife's mother, they reported that they not only pay all of the expenses of the mother, but the household as well.

Another co-resident reports he is caring for his wife who suffers from a variety of chronic diseases and requires 24-hour care. In his case, his biggest expense is the payment he makes to care attendants who stay with his wife when he leaves to go shopping, run other errands or his own leisure activities. For him, time is the most precious commodity.

I currently am very restricted in what I do. When I work in the yard, I have to stop every 30-45 minutes to check on [her]... watching TV is also difficult because she needs things... I also have to get up 4 to 6 times nightly to help her with the bathroom or to arrange her bedding."

For most of the co-resident diarists, caregiving was a 24-hour job.

A diarist who brought her mother into her home reports that at times she cannot attend church because both her husband and her daughter have to work and no one is available to stay with her mom. She pays a care attendant to stay with her mother while she works and relies upon her husband or other family members to lend a hand with her care. All of the family members — husband, son and daughter — arrange their personal schedules around the availability of care attendants. This diarist has her own business and is often required to defer work in order to stay home with her mom.

I hope this [diary] helps in highlighting the costs of caregiving — not only in terms of money, but in time and sacrifice.

CASE STUDY OF A SON LIVING WITH AND CAREGIVING FOR HIS MOTHER

A Life Deferred

Harry is a 47-year-old man who moved into his mother's home six years ago to help her when her health took a turn for the worse.

He is employed full-time in a demanding job and made the decision to move into his mother's home because he thought it would be easier to help her if they lived together.

Since moving into her home, he has had second thoughts about that decision. She needs a full-time caregiver when he is not home so he has hired a caregiver to be there when he is at work. He is managing her finances with the goal of making it last as long as possible. This means that he is hesitant to use a paid caregiver for his absences that are related to his social life.

In fact, he reports that he has no social life now. Although he is engaged to be married, he has postponed the marriage because both he and his fiancé are caring for aging parents. Together they have a complicated set of responsibilities that take up most of their time.

Harry has had stress-related health issues and has put his own life "on hold" in order to care for his mother. His personal expenses for the 30-day period are approximately \$400. He is paying the full-time caregiver out of his mother's funds.

Although he is engaged to be married, he has postponed the marriage because both he and his fiancé are caring for aging parents.

Emotional and Physical Effects of Caregiving

Out-of-pocket expenses are also associated with survey respondents' reported level of financial concerns.

Those reporting an increase in financial concerns had an average total annual expense of \$8,227 compared to those reporting no effects of \$3,445.

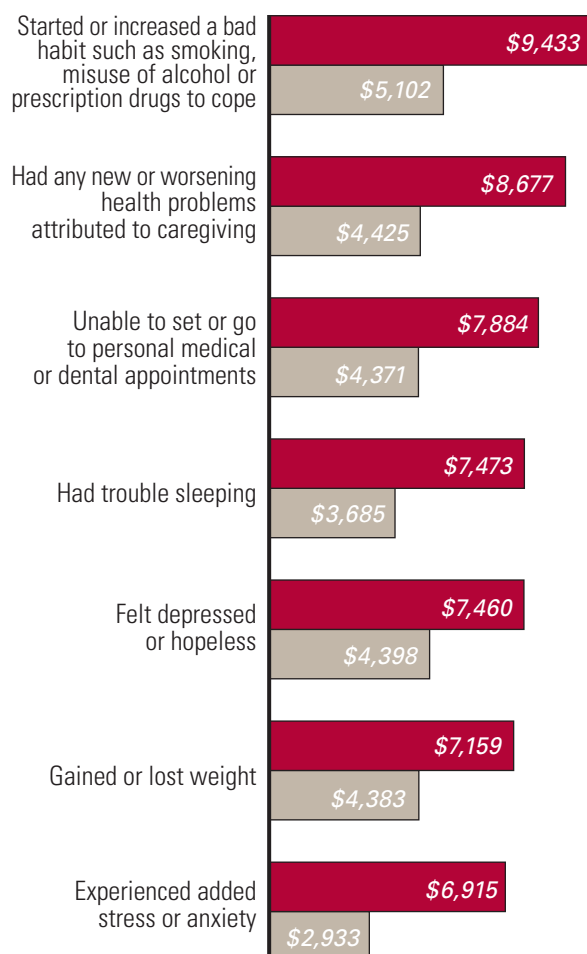
Levels of out-of-pocket expenses are also related to the extent to which surveyed caregivers report adverse emotional and physical effects of caregiving. Figure O shows the average annual expenses for caregivers who did experience these adverse affects versus those who did not.

Figure O: Average annual total expense by effects of caregiving for survey respondents

n=1,000

As a result of caregiving

YES NO



The diarists were not asked about these specific effects but many volunteered information about a range of physical and emotional effects of their caregiving responsibilities. Although most diarists (37 out of 41) told us they would rate their health “good” or “excellent,” details included in the diaries suggest many are having some health problems of their own.

One spousal caregiver reports that she has a hernia that was repaired by surgery but has returned as she struggles to lift her husband’s wheelchair and assist her husband in transferring. Another reports that she has diabetes and back problems that have emerged as a result of her helping her husband with his personal care needs. One diarist who is caring for her husband who has Parkinson’s Disease and dementia symptoms articulates the stress and emotional cost of caregiving.

Whenever someone takes care of someone, especially a loved one like me trying to help my husband as much as possible, there is so much stress involved. For the past three weeks my husband has been mixed up about half the time. Sometimes he doesn't know who I am or where we are or where everyone else is...There is no one else...Sometimes I have a really hard time trying to handle depression, stress plus my own medical problems. (She is disabled with osteoarthritis). The stress and depression is unreal at times for me. I know it is for him also.

Another diarist included in her personal costs the co-pay associated with a doctor visit for an anxiety attack.

The opportunity costs associated with caregiving for the diarists ranged from work-related effects to recreational and spiritual effects. Diarists reported that they were required to retire early as a result of caregiving and that this decision not only had an adverse effect on their financial well-being, but on their overall quality of life as well.

Many reported that they were unable to spend time with their children swimming or having a picnic because of caregiving responsibilities; others talked about the reduction in time available for their children, grandchildren or other family members.

Time for taking care of their own health was also mentioned as an opportunity cost by diarists. All of the employed diarists reporting taking time off — a particularly difficult issue for those who worked on an hourly pay basis and lost income.

CASE STUDY OF A CAREGIVER WHO CARES FOR HER PARENTS LIVING NEARBY

Caregiving is a Labor of Love

Annette is a 50-year-old woman who is providing care for both her parents. Annette's parents, both in their 80s, moved from Florida to be close to her when they began having serious health problems.

She originally planned to have them move into her home and was renovating the home for that purpose. In the meantime, however, they moved into an assisted living facility when they arrived. The renovations on Annette's home are now complete but both parents are experiencing worsening health problems and not likely to be able to leave the assisted living facility.

Annette has taken a lot of time off as a result of their health problems. She reports that one doctor appointment turned into an all-day affair that cost her a full day of work. In addition, her father was hospitalized in a psychiatric hospital for an acute episode. She not only was managing his care there and meeting with the physicians to develop a care plan, but spending time with her mother to allay her concerns about her missing husband. She reports that she had to cancel several days of work, her own health appointments and her volunteer work.

During the time she was keeping her diary she missed work every week and spent her evenings at the hospital or the assisted living facility.

Annette is looking forward to having the time to unpack her own boxes and move back into her renovated home and, with a little luck, return to her personal and professional life. Her expenses were nearly \$500 for the 30-day period of time.

She reports that she had to cancel several days of work, her own health appointments and her volunteer work.

Conclusion

The survey revealed that many family caregivers are involved in both “hands-on” care activities and in paying for needed goods and services.

The screening questions for participation in the survey sample did not include any financial questions. Nonetheless, we see that the average annual total cost estimate for the sample was more than \$5,000 — a relatively large burden for a sample in which the median household income was \$43,026.

Costs are obviously related to the level of care needed by the care recipient, most of whom are parents. It was interesting to see that those who are co-resident — no matter whether they are parents, spouses, or other friends and relations — have higher annual costs than those who live nearby, although long-distance caregivers had even higher costs. The co-resident costs were especially interesting since these caregivers were assumed to have no caregiving-related spending for housing payments, home maintenance, or travel to visit the person they care for and they obviously would not have nursing home expenses.

More specifically, the survey was designed to assess only caregiving expenses that were beyond normal household expenses that spousal or co-resident caregivers would have. This was an important design factor since 36% of the parents receiving care lived with the caregivers.

In addition to co-resident parents, there are co-resident households within the sample for all care recipient categories — adult child, sibling, other relatives, friends and grandparents — in addition to spousal caregivers for whom living together would be the norm. An interesting research question to explore is:

Why are the co-resident caregivers spending so much more than the others?

Another surprising finding of the study is how closely the level of out-of-pocket expenses corresponds with not only work status and work accommodations, but self-perceived personal effects of caregiving as well.

Not only were care costs related to the more obvious factors such as financial well-being and strategies to manage the costs, but they were related to perceived health effects, stress levels and other physical and emotional appraisals of well-being. There has been little work on this correlation in the caregiving field to date. Another good research area would be:

When researching caregiver burden and stress, how much of a role does lack of money play? And, would it be more cost-effective to give poorer caregivers money to help relieve their stress?



Section 4
Respondent Profile

Demographics

Telephone Survey Sample

The Evercare/NAC Survey asked respondents detailed questions about expenses related to caregiving, the care situation, employment and lifestyle of the caregiver. Respondents reported medical and personal care expenses, housing-related costs, medical equipment expenses and caregiver-specific costs such as travel, counseling, education, and respite and care management. The survey has a margin of error of plus or minus three percentage points at the 95% confidence level. (Sub-groups within this sample would have larger margins of error.)

The sample characteristics are displayed in Table A.

Table A: Profile of Survey Respondents

n=1,000

Gender					
	Female	75%		Care Recipient	
	Male	25%		Parent, parent-in-law	57%
				Spouse	21%
Average Age		56		Other (sibling, grandparent, relatives or friends)	22%
Ethnicity				Work Reduction	
	White	80%		Quit job and/or reduced work hours	37%
	African-American	10%		Caregiving Assistance	
	Hispanic	4%		ADL** (Activity of daily living)	67%
	Asian American	1%		IADL*** (Instrumental activities of daily living)	97%
	Other/refused	4%		Caregiving Time	
Marital Status				Average per week	35.4 hours
	Married/with Partner	72%		Median response	20 hours
	Widowed	6%		Caregiving Duration	
	Divorced	9%		< One year	20%
	Separated	2%		1-2 years	28%
	Single/never married	11%		3-4 years	19%
Children in the Household (under age 18)		19%		5+ years	32%
				Don't know/Refused	1%
Household Income				Caregiving Living Situation	
	Less than \$25,000	22%		Living with care recipient	45%
	\$25,000 to <\$50,000	29%		Living near care recipient (less than 1 hour away)	44%
	\$50,000 to <\$75,000	17%		Living more than 1 hour from care recipient	10%
	\$75,000 to <\$100,000	10%			
	\$100,000 or more	8%			
	Don't know	3%			
	Refused	12%			
Employment Status					
	Full-time*	35%			
	Part-time	10%			
	Not employed	53%			
	Don't know/refused	2%			

* This compares to the NAC/AARP sample of caregivers in which 60% of those caring for someone over the age of 50 is employed. Half of these caregivers make less than \$50,000 annually and the median income for the group is \$43,026. More than one in three respondents (37%) report that they had quit their job or reduced work hours as a result of caregiving responsibilities.

**ADLs are personal care such as bathing, feeding, dressing and toileting.

***IADLs are activities performed to manage one's daily life or maintain a household and independence such as preparing meals, grocery shopping, driving or using transportation system, doing light housework, taking medication, managing finances and paying bills.

Demographics

Diarist

The 41 caregivers who completed the 30-day expense diaries included three African-Americans and two Hispanics. Their ages ranged from 27 years to 93 years.

Table B contains the demographic information about this sample.

In addition to the parents and spouses who were receiving care, diarists were caring for grandparents, an aunt and a friend. The oldest diarist, a 93-year-old woman, is taking care of her husband who is 94 and recently was moved into a nursing facility. She is currently paying out-of-pocket for his care; “spending down” to Medicaid eligibility by paying \$3,360 for the 30-day period. Among the diarists, 11 were caring for someone with Alzheimer’s disease or a related dementia.

About half of the diarists were working either full-time or part-time. Of the diarists who were no longer working, six reported that they had been working before they began caregiving. One left the job to take early retirement and another chose to leave employment without taking early retirement. The other four described their departure from employment as a consequence of taking time off as a result of caregiving — being “forced out” of work.

The diarists were also encouraged to report the “opportunity costs” associated with caregiving on their diaries. Research team members talked on the phone often with the diarists to get detailed information about their opportunity costs, well-being and overall lifestyle issues associated with caregiving.

Table B: The Diarist Sample

n=41

Gender				Income Levels			
Female	10	76%		Less than \$25,000	8		
Male	31	24%		\$25,000 to <\$50,000	11		
Average Age		56		\$50,000 to <\$75,000	6		
Age Range		27 to 93 years		\$75,000 to <\$100,000	7		
Marital Status				\$100,000 or more	4		
Married	34	83%		Refused	5		
Single	4	10%		Employment Status			
Divorced	3	7%		Working	23	56%	
Children in the Household		2 5%		Not working	18	44%	
Ethnicity				Care Recipient			
White	35	85%		Parent(s)	20	49%	
African-American	4	10%		Spouse	16	39%	
Hispanic	2	5%		Other	5	12%	
				Care Situation			
				Co-resident	22	54%	
				Lives near	16	39%	
				Long distance	3	7%	

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Section 5

Appendix — Survey Questionnaire

Survey of Caregivers' Out-of-Pocket Expenses Questionnaire

I. Introduction and Screening Questions

Hello, my name is _____ and I am calling on behalf of the National Alliance for Caregiving with a very brief research study about caregiving. This is strictly for research purposes and I am not selling anything. All your answers will be kept confidential. **[AS NEEDED: This will take about 10 minutes.]**

S1. During the past month, have you or anyone in your household spent time caring for a relative or friend who is over the age of 50 and has one or more chronic conditions that make self-care difficult?

[AS NEEDED: Is that you, or another household member?]

- Yes, person on phone 1 **[SKIP TO S2]**
 Yes, someone else 2
 No 3 **[TERMINATE]**
 (Vol) Don't know 4 **[TERMINATE]**
 (Vol) Refused 5 **[TERMINATE]**

[IF RESPONDENT IS NOT CURRENTLY CAREGIVING, BUT HAS DONE SO IN THE PAST MONTH, SAY: Since you were a caregiver so recently, I'll ask you about it as if it were now.]

S1a. Could I speak to the person who is giving the care?

- Yes 1 **[CONTINUE]**
 Not available 2 **[MAKE APPT OR CALL BACK]**
 No 3 **[TERMINATE]**
 (Vol) Don't know 4 **[TERMINATE]**
 (Vol) Refused 5 **[TERMINATE]**

S1b. Hello, my name is _____ and I am calling on behalf of the National Alliance for Caregiving with a very brief research study about caregiving. This is strictly for research purposes and I am not selling anything. All your answers will be kept confidential. **[AS NEEDED: This will take about 10 minutes.]**

During the past month, have you spent time caring for a relative or friend who is over the age of 50 and has one or more chronic conditions that make self-care difficult?

- Yes 1
 No 2 **[TERMINATE]**
 (Vol) Don't know 3 **[TERMINATE]**
 (Vol) Refused 4 **[TERMINATE]**

[IF RESPONDENT IS NOT CURRENTLY CAREGIVING, BUT HAS DONE SO IN THE PAST MONTH, SAY: Since you were a caregiver so recently, I'll ask you about it as if it were now.]

S2. Do you help that relative or friend on a regular basis with any of the following tasks — bathing or grooming, toileting, feeding, transferring from bed to chair, or dealing with incontinence?

- Yes..... 1
- No 2
- (Vol) Don't know..... 3
- (Vol) Refused 4

S3. Do you help that relative or friend on a regular basis with any of the following — transportation, meal preparation, managing finances, grocery shopping, housework, medication management, or arranging for outside services to help him or her?

- Yes..... 1
- No 2
- (Vol) Don't know..... 3
- (Vol) Refused 4

[IF S2=1 OR S3=1, CONTINUE. OTHERWISE TERMINATE.]

S3b. Are you paid to help your relative or friend?

- Yes..... 1 **[TERMINATE]**
- No 2
- (Vol) Don't know..... 3 **[TERMINATE]**
- (Vol) Refused 4 **[TERMINATE]**

S4. In a typical week, how many hours in total do you spend helping your relative or friend in the ways that I listed for you? **[AS NEEDED: Your best estimate is fine.]**

[AS NEEDED: Bathing or grooming, toileting, feeding, transferring from bed to chair, dealing with incontinence, transportation, meal preparation, managing finances, grocery shopping, housework, medication management, or arranging outside services.]

[RECORD ACTUAL NUMBER OF HOURS]

_____ Hours

- (Vol) Don't know..... 98 **[TERMINATE]**
- (Vol) Refused 99 **[TERMINATE]**

[ALSO CODE HOURS]

- 1 to 4 hours 1 **[TERMINATE]**
- 5 to 7 hours 8
- 8 to 14 hours 2
- 15 to 20 hours 3
- 21 to 40 hours 4
- More than 40 hours 5
- (Vol) Don't know..... 6 **[TERMINATE]**
- (Vol) Refused 7 **[TERMINATE]**

S5. In what year were you born?

(Vol) Don't know/Refused99 [TERMINATE]

[RECORD INTO FOLLOWING CATEGORIES]

Less than 21 years of age1 [TERMINATE]

21 to 292

30 to 393

40 to 494

50 to 595

60 to 696

70 to 797

80 to 898

90 or older9

II. Background on Caregiving Situation

1. Thinking about the person you give care to, what is his or her relationship to you?

[RECORD WHO THE CARE RECIPIENT IS, NOT THE CAREGIVER]

[IF RESPONDENT GIVES CARE TO MORE THAN ONE PERSON: Please answer about the person over age 50 whom you spend the most time helping.]

Aunt or great aunt 1

Brother 2

Brother-in-law 3

Daughter..... 4

Daughter-in-law 5

Father 6

Father-in-law 7

Friend/neighbor 8

Grandfather or great grandfather..... 9

Grandmother or great grandmother.....10

Husband 11

Mother 12

Mother-in-law13

Sister 14

Sister-in-law15

Son 16

Son-in-law 17

Partner.....18

Uncle or great uncle19

Wife 20

Other (specify relationship)

_____21

(Vol) Don't know 22 [TERM]

(Vol) Refused 23 [TERM]

2. **[IF Q1=8 or 18 or 21] [CODE IF APPARENT FROM PRIOR ANSWER. OTHERWISE ASK.]**

Is that person male or female?

Male1

Female2

3. How old is your [Q1 RESPONSE]? [AS NEEDED, READ CATEGORIES OR SAY: Your best estimate is fine.]

- Less than 50 years of age 1 [TERMINATE]
- 50 to 59 2
- 60 to 69 3
- 70 to 79 4
- 80 to 89 5
- 90 or older 6
- (Vol) Don't know 7
- (Vol) Refused 8

4. For how long have you been giving care to your [Q1 RESPONSE]? [AS NEEDED: Your best estimate is fine.]

- 1 month 1
- 2 months 2
- 3 months 3
- 4 months 4
- 5 months 5
- 6 months 6
- 7 months 7
- 8 months 8
- 9 months 9
- 10 months 10
- 11 months 11
- 1 year to less than 2 years 12
- 2 years to less than 3 years 13
- 3 years to less than 4 years 14
- 4 years to less than 5 years 15
- 5 years or more 16
- (Vol) Don't know 17
- (Vol) Refused 18

5. Does your [Q1 RESPONSE] live with you, less than one hour away by car, or more than one hour away by car?

- With you 1
- Less than one hour away 2
- More than one hour away 3
- (Vol) Don't know 4
- (Vol) Refused 5

6. **[IF Q5 NE 1]** About how many miles away does he/she live?
 _____ Miles
 (Vol) More than 100 miles, but don't know exactly... 9997
 (Vol) Don't know.....9998
 (Vol) Refused 9999
7. Does your **[Q1 RESPONSE]** live in a home or apartment, an independent living retirement community, (or) an assisted living facility **[IF Q5=2 or 3]**, or a nursing home]?
 Home or apartment 1
 Independent living retirement community 2
 Assisted living facility 3
 Nursing home.....4
 (Vol) Other (specify).....5
 (Vol) Don't know.....6
 (Vol) Refused 7
8. **[SKIP IF (Q1=11 OR 20 OR Q1=18); CODE AS 1]** Is he/she married or living with a partner, widowed, divorced, separated, or single, never married?
 Married or living with a partner 1
 Widowed 2
 Divorced.....3
 Separated.....4
 Single, never married.....5
 (Vol) Don't know.....6
 (Vol) Refused 7

III. Financial Issues

I am now going to ask you about financial costs that you may have had as a result of the help and support you provide. Please tell me about expenses you pay for with your own money or with household money. I'll call these "out-of-pocket" expenses. Please do not count **[ADD PHRASE EXCEPT IF Q1 =11 OR 20:** expenses that your **[Q1 RESPONSE]** pays for and do not count] expenses that are covered by insurance or government programs.

9. In the past 12 months, have you had any out-of-pocket expenses for **[ASK a, THEN RANDOMIZE b-i]**?

10. **[IMMEDIATELY FOLLOWING A “YES” RESPONSE]** In a typical month, how much do you spend on that? **[AS NEEDED: An average is fine.]**
[COUNT ANY EXPENSE ONLY ONCE, WHEN FIRST MENTIONED.]

		Q9	Q10
a.	[IF Q7=3] Your [Q1 RESPONSE’s] assisted living fees? [IF Q7=4] Your [Q1 RESPONSE’s] nursing home care?	Yes..... 1 No..... 2 DK/Ref..... 3	\$_____ DK/Ref..... 9999
b.	Any services such as adult day care, home health care, physical or occupational therapy, or other such services for your [Q1 RESPONSE]	Yes..... 1 No..... 2 DK/Ref..... 3	\$_____ DK/Ref..... 9999
c.	[SKIP IF (Q1=11 or 20 OR Q1=18) and Q5=1] Your [Q1 RESPONSE’s] food, meals, household goods, or incidentals	Yes..... 1 No..... 2 DK/Ref..... 3	\$_____ DK/Ref..... 9999
d.	[SKIP IF Q5=1] Your [Q1 RESPONSE’s] Home maintenance, yard care, or repairs	Yes..... 1 No..... 2 DK/Ref..... 3	\$_____ DK/Ref..... 9999
e.	[SKIP IF Q5=1] Your [Q1 RESPONSE’s] housing payments, rent, or utilities [Q9a=1 and Q7=3: Separate from the assisted living fees you mentioned earlier / IF Q9a=1 and Q7=4: Separate from the nursing home fees you mentioned earlier] [AS NEEDED: Utilities include things such as electricity, water, and phone.]	Yes..... 1 No..... 2 DK/Ref..... 3	\$_____ DK/Ref..... 9999
f.	Your [Q1 RESPONSE’s] medical care, medical insurance, or prescriptions [IF Q9a=1 and Q7=3: Separate from the assisted living expenses you mentioned earlier / IF Q9a=1 and Q7=4: Separate from the nursing home expenses you mentioned earlier]	Yes..... 1 No..... 2 DK/Ref..... 3	\$_____ DK/Ref..... 9999
g.	[SKIP IF (Q1=11 or 20) OR (Q1=18 and Q5=1)] Your [Q1 RESPONSE’s] clothing	Yes..... 1 No..... 2 DK/Ref..... 3	\$_____ DK/Ref..... 9999
h.	Caregiver support services such as respite, family counseling, or a geriatric care manager	Yes..... 1 No..... 2 DK/Ref..... 3	\$_____ DK/Ref..... 9999
i.	[SKIP IF Q5=1] Travel to visit your [Q1 RESPONSE] ? That would include gas, parking, taxis, buses, trains, planes, hotels, or any other expenses related to the travel.	Yes..... 1 No..... 2 DK/Ref..... 3	\$_____ DK/Ref..... 9999

11. In the past 12 months, have you had out-of-pocket expenses for [RANDOMIZE a-c]?
12. [IMMEDIATELY FOLLOWING A “YES” RESPONSE] Altogether in the past 12 MONTHS, how much have you spent on that?

		Q11	Q12
a.	Medical equipment or supplies for your [Q1 RESPONSE] including a wheelchair, a walker, incontinence supplies, a special chair or bed, or any other medical supplies.	Yes..... 1 No..... 2 DK/Ref..... 3	\$_____ DK/Ref..... 9999
b.	Legal fees related to the caregiving situation	Yes..... 1 No..... 2 DK/Ref..... 3	\$_____ DK/Ref..... 9999
c.	Home modifications for your [Q1 RESPONSE] including ramps, grab bars, hand rails, bathroom modifications, and so on	Yes..... 1 No..... 2 DK/Ref..... 3	\$_____ DK/Ref..... 9999

13. Are you currently employed full-time, part-time, or are you not currently employed?

Full-time..... 1 [SKIP TO Q15]
 Part-time..... 2 [SKIP TO Q15]
 Not currently employed 3
 (Vol) On unpaid leave 4
 (Vol) Don't know..... 5
 (Vol) Refused 6

14. Since you began caregiving, have you ever had paid employment?

Yes..... 1
 No 2 [SKIP TO Q16]
 (Vol) Don't know..... 3
 (Vol) Refused 4

15. As a result of providing care to your [Q1 RESPONSE], have you made any of the following work-related changes?

Have you...[RANDOMIZE a TO d, THEN ASK e] as a result of your caregiving?

		Yes	No	DK/Ref
a.	Cut back on your work hours or quit work entirely	1	2	3
b.	Taken an unpaid leave or any leave under the Family Medical Leave Act?	1	2	3
c.	Left one job for a different one	1	2	3
d.	Used your own sick leave or vacation time	1	2	3
e.	Taken a job or worked additional hours to earn more money	1	2	3

16. Since you began giving care to your [Q1 RESPONSE], would you say your finances have [REVERSE 1-3/3-1] [READ RESPONSES]?

- Gotten better 1
- Stayed the same..... 2
- Gotten worse 3
- (Vol) Don't know..... 4
- (Vol) Refused 5

17. Would you say that being a caregiver...[READ AND ROTATE 1-2/2-1]

- Has had no effect on your financial worries?..... 1
- Has increased your level of financial worry?..... 2
- (Vol) Don't know..... 3
- (Vol) Refused 4
- (Vol) Has lessened worries 5

18. As a result of caregiving-related changes in your employment or expenses, have you had to... [RANDOMIZE a TO g, THEN READ h] [READ STEM QUESTION AT LEAST EVERY OTHER ITEM]

		Yes	No	DK/Ref
a.	Dip into your savings?	1	2	3
b.	Take out a loan or increase your level of credit card debt?	1	2	3
c.	Cut back on your own spending for vacations or travel?	1	2	3
d.	Cut back on your own spending for hobbies, going out to eat, movies, or other leisure activities?	1	2	3
e.	Cut back on your own spending for groceries?	1	2	3
f.	Cut back on your own spending for health care or dental care?	1	2	3
g.	Cut back on your own spending for basic home maintenance?	1	2	3
h.	Cut back on your own spending for necessities we have not already mentioned, such as clothing, transportation, or home utilities [AS NEEDED: Utilities include things such as electricity, water, and phone.]	1	2	3

19. Since you began giving care, have you had to...[RANDOMIZE a to c] [READ STEM QUESTION AT LEAST EVERY OTHER ITEM]

		Yes	No	DK/Ref	Not Appl
a.	Reduce or stop saving for your own future?	1	2	3	
b.	Reduce or stop saving for your children's future?	1	2	3	4
c.	Delay a major purchase such as buying a car, furniture, a home improvement, or some other major purchase?	1	2	3	

20. As a result of giving care, have you...[RANDOMIZE a to g] [READ STEM QUESTION AT LEAST EVERY OTHER ITEM]

		Yes	No	DK/Ref
a.	Experienced added stress or anxiety	1	2	3
b.	Felt depressed or hopeless	1	2	3
c.	Gained or lost weight	1	2	3
d.	Had trouble sleeping	1	2	3
e.	Started or increased a bad habit such as smoking, misusing alcohol, or misusing prescription drugs to cope	1	2	3
f.	Been unable to set or go to medical or dental appointments for yourself	1	2	3
g.	Had any new or worsening health problems that you or your doctor attribute to caregiving or the stress of it	1	2	3

21. [SKIP IF (Q1=11 OR 20 OR Q1=18); CODE AS 1] Now I have a few questions for classification purposes. Are you currently married or living with a partner, widowed, divorced, separated, or single, never married?

Married or living with a partner 1
 Widowed 2
 Divorced 3
 Separated 4
 Single, never married 5
 (Vol) Don't know 6
 (Vol) Refused 7

22. Do you have any children under the age of 18 living with you?

- Yes 1
- No 2
- (Vol) Don't know 3
- (Vol) Refused 4

23. What is your ethnic background? Do you consider yourself...**[READ LIST]**

- African-American or Black 1
- Hispanic or Latino 2
- Asian-American 3
- White, or 4
- Part of another group 5
- (Vol) Don't know/Refused 6

24. Finally, is your total annual household income...**[READ 1-5]**

- Less than \$25,000 1
- \$25,000 to less than \$50,000 2
- \$50,000 to less than \$75,000 3
- \$75,000 to less than \$100,000 4
- \$100,000 or more 5
- (Vol) Don't know 6
- (Vol) Refused 7

25. **[RECORD RESPONDENT GENDER]**

- Male 1
- Female 2

26. Thank you for participating in this important research. There is an opportunity to participate in a follow-up study about caregiver expenses. You would be paid \$100 if you complete it.

It will be conducted by researchers from Towson University in Maryland. All you would need to do is keep track of your expenses for one month, and they would provide a simple and easy-to-use diary method to help you do so. Your diary would be kept confidential, and your name would not be revealed. Most important, the findings from the study would be used to develop programs and policies that help other caregivers.

Is this something you would consider?

- Yes 1
- No 2 **[TERMINATE-2]**
- Not sure 3

TERMINATE-2: Thank you again so much for the time you gave me today.

27. **[IF PRIOR Q=1: Wonderful!]** What I would like to do then is to find out the best way to reach you and have the researchers give you a call. They will be able to explain further what you would be asked to do, and they could answer any questions you may have. I assure you they will not try to sell you anything.

28. First, what is your name?

Name: _____

(Vol) Refused99 **[TERMINATE 2]**

29. I reached you at **[INSERT PHONE NUMBER]**. What is your daytime phone number during the week?

Phone number: _____

Phone extension: _____

(Vol) Same number97

(Vol) Refused99

Thank you so much for your time and for your willingness to be involved in the study about caregiver expenses. The researchers will review your responses to today's questions and determine whether you qualify for that study. If so, they will call you within the next three weeks to invite you to participate. Thank you so much for your time today and your interest in the additional research.



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