

MILES AWAY:
THE METLIFE STUDY OF
LONG-DISTANCE CAREGIVING

*Findings from a
National Study by the
National Alliance for Caregiving
with
Zogby International
July 2004*



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Executive Summary

Family care from a distance is a fact of life for millions of Americans. Living at a distance from an aging parent or grandparent can make care provision a complex and difficult challenge. And, for many of those who are caring at a distance, these challenges affect not only the personal activities of the care providers, but their work and career as well. In 2004, the MetLife Mature Market Institute and the National Alliance for Caregiving undertook a survey of long-distance caregivers to examine these challenges. A sample of 1,130 long-distance care providers participated in an on-line survey conducted by Zogby International, an international polling and market research firm.

KEY FINDINGS

The Caregiving Situation

- Despite an average distance of 450 miles and 7.23 hours of travel time one-way, long-distance caregivers reported substantial regular personal contact with the person they were helping; 51% reported visiting at least a few times a month.
- Nearly one-fourth (23%) of the long-distance caregivers reported they were the only or primary care provider.
- Nearly three-quarters of the respondents were helping their loved one with instrumental activities like transportation, shopping, managing finances or cooking and were spending 22 hours a month on this help.
- Almost half reported that they were managing needed services and spending the equivalent of nearly one full day a week doing so.
- Long-distance caregivers most often depend upon a sibling who lives near the care recipient.
- Nearly 80% of these care providers were working either full or part-time.

Effect on Work

- More than four in ten had to rearrange their work schedules in order to take care of their caregiving responsibilities, more than a third (36%) reported missing days of work, and 12% took a leave of absence.
- Both men and women were equally likely to have rearranged their work schedules, left early or came in late to work, taken an unpaid leave, or to have considered changing employers.
- Women were more likely than men to report that they missed days of work and/or moved from full-time work to part-time work.

Financial Contribution

- Long-distance caregivers spend an average of \$392 per month on travel and total out-of-pocket expenses.
- Distance is a factor in the total out-of-pocket expenses reported by respondents. Those who live between 1 and 3 hours away from the care recipient spent an average of \$386 per month on travel and direct expenses for items needed by the care recipient; those who live more than 3 hours away spent an average of \$674 per month.
- For the relatively small group of respondents (nearly 10%) who also paid for services the care recipient needed, women reported spending on average \$751 a month compared to men who spend an average of \$490 a month.



Introduction

There are millions of Americans providing care to older family members—34 million, in fact. According to the 2004 National Caregiver Survey by the National Alliance for Caregiving in collaboration with AARP, 15% of those caregivers are living an hour or more away from their relative.¹ Caring for someone at a distance adds additional complexities and responsibilities. This study, undertaken in 2004 by the MetLife Mature Market Institute and the National Alliance for Caregiving, was designed to identify some of the special challenges of long-distance caregiving to those 55 and older.

An on-line survey was administered to a sampling of respondents who had agreed to participate in on-line surveys with Zogby International. A total of 1,130 individuals met the criteria for long-distance caregiving (more than one-hour travel time from the care recipient) and participated in the full survey.

What We Know About Long-Distance Caregiving

Large geographic distances—and even the time it takes to travel across a big city with congestion and snarled traffic—can add unique and complicated challenges to what is already an often emotion-laden and stressful job: helping a family member whose health and well-being are deteriorating. Long-distance caregivers are often required to miss work to see to their relative's care, may need to manage and supervise paid care providers from a distance, and often feel left out of decisions made by health care professionals and other family members who are on-site.

A study of long-distance caregivers conducted in 1997 included caregiver focus groups to determine

an operational definition of “long-distance”; as a result, “living one hour or more away” from the care recipient was adopted as the definition. In that study, the average distance was more than 300 miles (Wagner, 1997).² In a more recent survey, long-distance caregivers were defined as living 100 miles or more away from the care recipient. The current study chose to use the one-hour definition because we felt that the physical distance itself was not as big an issue in caregivers' lives as the amount of time it takes to reach the care recipient in an emergency or to help with everyday tasks.

Previous research has shown that distance plays an important role in family decision-making about who will do caregiving. Stern's 1996 research³ suggested that the nearest sibling takes on the major responsibility regardless of whether he or she works and more recent work by Stern and Neuharth (2002) found distance to be a key factor in determining care responsibilities.⁴ In Wagner's 1997 long-distance caregiver survey, 91% of the respondents reported that they received help from family, friends and neighbors, with the majority of the help coming from family members. Whether the long-distance caregiver played the role of primary decision-maker or a helper to others, support from family members and friends was key to managing the long-distance situation. Only half the respondents reported that their family member had ever received paid help.

This current research offers important insight into the issues faced by family caregivers struggling with distance in addition to the normal challenges and rewards of family caregiving. The main purpose was to draw a portrait of the long-distance caregiver. In particular, we looked at the following research questions:

- What is the relationship between distance and whether the caregiver is the only, the primary or one of several caregivers?



- What effect does distance have on the caregiver’s work and workplace accommodations?
- How does distance affect out-of-pocket expenses?
- Has caregiving affected the caregiver’s health?

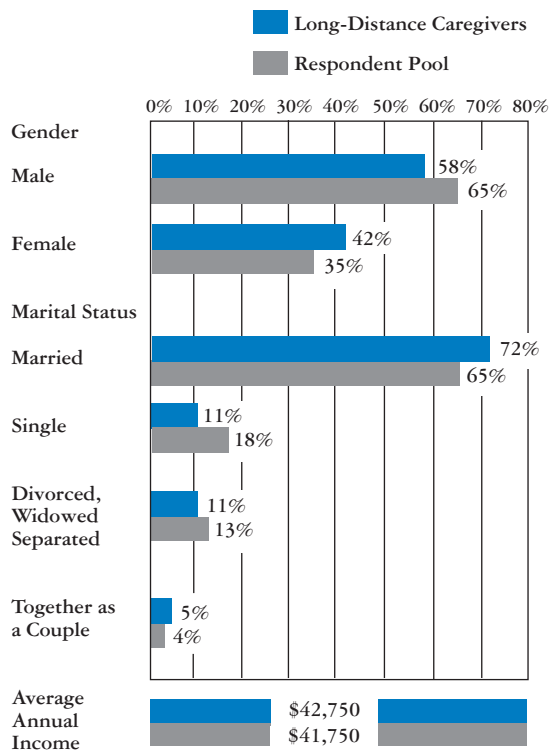
Study Methodology

Zogby International, a polling and market research firm, issued email invitations to 79,851 individuals who had agreed to participate in on-line surveys. This pool was configured to be representative of the larger US population with a margin of error of +/- 2.8%. There were 8,438 responses to the invitation to participate in a survey on family life, with 1,130 (13%) of the respondents meeting the criteria of helping someone 55+ during the past year, who has “chronic physical, cognitive or mental health problems” and who lives an hour or more away.

As Table 1 shows, the long-distance caregiver sub-sample was more likely to be married and to report a higher income as a group than the larger group from whom they were sampled. The relatively large number of male long-distance caregivers is most likely an artifact of the respondent pool, two-thirds of whom are men.

The Zogby International on-line survey panel was determined to be representative of the US population within +/- 2.8% margin of error; sub-samples of this panel have higher margins of error. An on-line methodology is not necessarily generalizable to the universe of long-distance caregivers in the US.

Table 1. Comparison of Long-Distance Caregivers With National Respondent Pool



The distance makes it very difficult to keep up to date on how my aunt is doing. It makes it very difficult to see her physically in order to make an evaluation of her medical and mental stability.

The most difficult part of caring for someone at a distance is taking time away from my own home and things that need to be done. I’m exhausted after returning home from giving assistance.



Profile of a Long-Distance Caregiver

The following profile reflects the characteristics of many of the long-distance caregivers who responded to this survey.

Howard, a 53-year-old attorney, has been struggling for the past few years to deal with his caregiving situation with his father. Howard lives in Boston where he is a partner in a small law firm; his 81-year-old widowed father lives in a small town in North Carolina, about an hour's drive from Charlotte.

Until several years ago, Howard's fiercely independent father had enjoyed good health and thrived on his own surrounded by his many friends and neighbors from church and the community. His older sister lived down the street and the two siblings looked after each other. Howard's own younger sister lived in Charlotte and visited their father several times a week. Howard visited his father three or four times a year, for holidays and family vacations.

About three years ago, things started to change. Howard's sister and her husband and children had to move to Florida to take over a family business, his father's sister died, and his father was diagnosed with congestive heart failure, macular degeneration, and diabetes. Since then, Howard has been flying from Boston to Charlotte and driving to visit his father at least once or twice a month. And he is progressively unhappy with the situation.

On those weekends when he visits to do grocery shopping and help around the house, Howard usually takes Friday or Monday off from work so that he'll have time to meet with his dad's doctors or other healthcare professional. He tries, not always successfully, to arrange his father's doctor appointments for those days to accompany him. One of Howard's major concerns is that he feels helpless at such a distance trying to sort through his father's medical issues. He isn't sure that he is getting all the information he needs to help make the best healthcare decisions for his father. Several times his father has called him in Boston with what seemed like a medical emergency; Howard flew down to see his father right away, only to find that there was no emergency. On the other hand, at several other times his father has concealed troubling diabetic symptoms from Howard, saying everything was fine when there were true emergencies.

Howard would like to bring his father to live with him in Boston, but his father refuses to move to the colder climate. Howard wishes he could visit even more often, especially as his father's health worsens. In talking about his caregiving situation, Howard says, "It's not the expense of the trips and the time it all takes, it's the uncertainty about when he's really in danger and knowing I can't get to him right away if I need to."



Demographics of Long-Distance Caregivers

Long-distance caregivers in this study included both those currently providing help to relatives (62%) and those who have been caregiving over the past year (38%). More than half of those no longer providing assistance had done so up until the death of their loved one. One out of five former caregivers reported that someone else had taken over the caregiving responsibilities, and one in eight said that the care recipient's condition had improved and they no longer needed care.

The long-distance caregivers in this sample included more men (58%) than women (42%). The average age was 51, with 27% reporting a child under age 17 living at home. Almost three-quarters were married, and 95.5% were white. The remainder of the sample included 2% Hispanics, 2% African Americans, 1/2% Asians.

They were also a highly educated group with 70% reporting a college degree or graduate school. They were quite affluent: 50% reported an income of \$75,000 or higher. Eighty-five percent owned their own home. The majority were working: 62% full-time and 18% part-time.

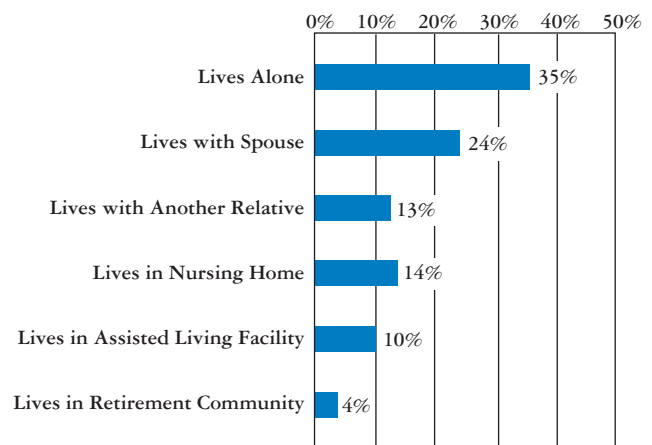
These characteristics are comparable to Wagner's 1997 long-distance phone survey and reinforce the image of a caregiver sub-group who are educated, affluent, and married.

The Caregiving Situation

The majority (76%) of long-distance caregivers in this study were providing help to a parent, step-parent or parent-in-law. In the 1997 study, only 56% were caring for a parent or parent-in-law.

Not surprisingly, the care recipient was more likely to be a woman (68%). As shown in Table 2, the care recipient—average age 89—most often lived alone or with a spouse.

Table 2. Living Arrangement of Care Recipient

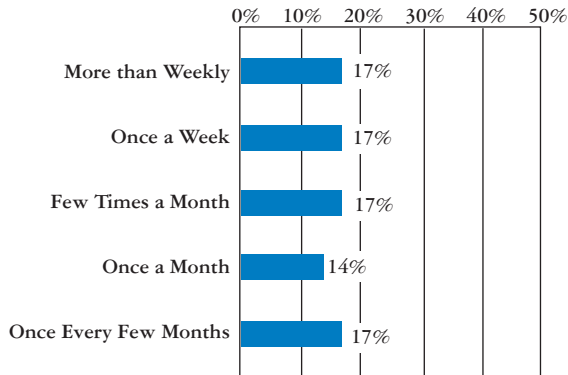


The long-distance caregivers lived an average of 450 miles from the person they were helping, and it took them an average of 7.23 hours to reach the care recipient when they visited. Table 3 illustrates the frequency of visits for the sample.

It is very hard to have a loved one at a distance who needs care. You worry because they may not eat, or have anyone to look out for them in an emergency.



Table 3. Frequency of Personal Visits



A third of these long-distance caregivers are visiting their relatives at least once a week—a striking display of commitment. Almost half reported that they were spending the equivalent of nearly one full work day per week managing needed services.

One-third of respondents reported that the health of the person they were caring for was poor; another 45% reported it was only fair. If they were living with a spouse, half of the care recipients' spouses were also in fair or poor health themselves.

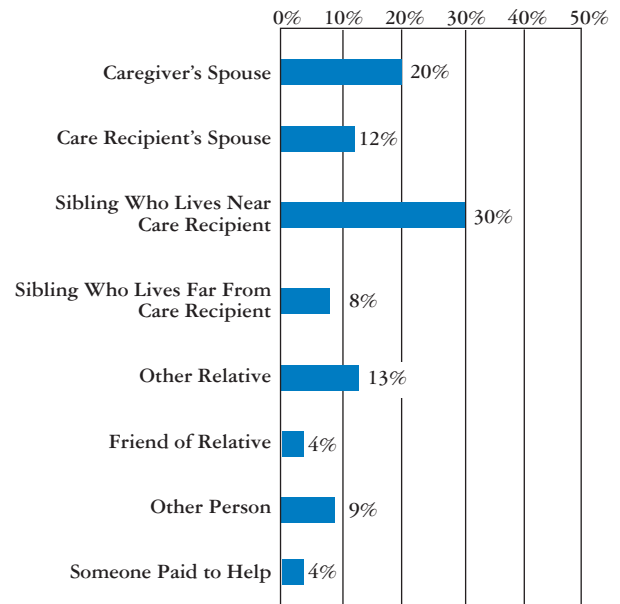
Nearly one-third of long-distance caregivers reported that they were helping someone with Alzheimer's disease or other form of dementia. This is substantially more than the 20% who reported Alzheimer's caregiving in the 1997 study.

Nearly one fourth (23%) of the long-distance caregivers reported that they were the only or primary caregiver.

I am not able to be there as much or as often as I would like. I wish to see more of my Mother and I would like to lessen the burden of oversight for my sister.

Whether the caregiver plays a primary or secondary helper role is important in any caregiving situation. For long-distance caregivers, it makes sense that half of long-distance caregivers reported that they provided care as a helper to others. The other respondents were either the only helper (5%), the main helper (18%), or they shared the responsibility equally with someone else (23%). Nearly one-third reported that they were helped by a sibling who lived near the care recipient, while another 13% reported that a relative other than a sibling was helping with most of the care. Table 4 shows the categories of helpers involved in supporting the care recipient.

Table 4. Person Who Helps the Long-Distance Caregiver the Most



91% of the long-distance caregivers reported that they were somewhat or very satisfied with the support they were receiving from others.



One interesting finding is that paid helpers were most important to those long-distance caregivers who reported that they were the only ones doing the caregiving. This small percentage of respondents (5%) were more likely to report using paid help than from any other category. For this group, if a family member was involved in helping them, it was most likely their own spouse rather than a sibling or relative who lived near the care recipient.

Nearly half (46%) of the respondents reported spending time arranging for needed services for the care recipient and/or monitoring or checking on the care being received (49%). On average, they spent 3.4 hours per week arranging services and another 4 hours per week checking on the person or monitoring care. Nearly three-quarters (72%) reported that they provide help with Instrumental Activities of Daily Living—such as transportation, grocery shopping, cooking, housework, managing finances, or managing medications—for an average of 22 hours per month. Nearly 40% also reported that they provide some help with the more intense personal care activities—bathing, dressing, feeding, toileting—for an average of 12 hours per month.

The most difficult part of caring for someone is making time to go see them and spend quality time with them. Expense is not just a plane ticket, it's also lost work time.

Financial Contribution of Long-Distance Caregivers

Long-distance caregivers have substantial financial costs associated with their care. These caregivers say they spend an average of \$193 per month on out-of-pocket purchases and services for the care recipient. In addition, they report spending another \$199 per month in traveling and long-distance phone expenses associated with their distance from their relative, for a total of \$392 per month.

The total out-of-pocket expenses associated with caregiving (both travel and direct expenses) varies by distance. Those caregivers who live between 1 and 3 hours from the care recipient report spending an average of \$386 per month; those who live more than 3 hours away report a monthly expenditure of \$674.

For the relatively small group of respondents (nearly 10%) who also paid for services the care recipient needed, women reported spending on average \$751 a month compared to men who spend an average of \$490 a month, meaning most family members take on the burden themselves.

Table 5 illustrates the cost categories for out-of-pocket purchases for the care recipient and the average amount spent each month.

Table 5. Specific Types of Monthly Expenses by Percent of Caregivers Providing Them

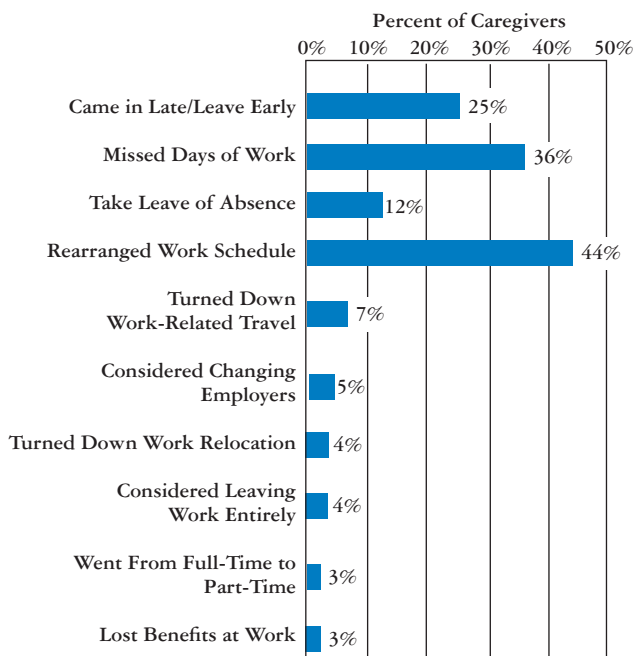
	% of Caregivers Providing	Average Monthly Amount
Medical Supplies	14%	\$97
Meals	31%	\$63
Pharmaceuticals	13%	\$175
Home Maintenance/Upkeep	20%	\$145
Cash to Pay their Bills	17%	\$455



Effect of Long-Distance Caregiving on Work

As described earlier, the majority of respondents in this study were working either full or part-time (80%), although the percent working part-time increased substantially since the 1997 study (from 8% to 18%). Other research has shown that employed caregivers often are required to make significant adjustments to their work in order to accommodate their caregiving responsibilities. These long-distance caregivers were no exception. Overall, half of the respondents reported having to make some workplace accommodation. The major adjustments they made were in coming in late or leaving early, missing days of work, rearranging their work schedule and taking unpaid leave. They missed an average of 20 hours of work per month. Table 6 shows the workplace effects of caregiving.

Table 6. Work Effects of Long-Distance Caregiving



In general, the percentage of long-distance caregivers who said that they missed days of work or came in late and left early has increased since the 1997 study.

Distance makes a difference in the work accommodations made by the caregiver. Those caregivers who live closer to the care recipient are most likely to report that they have come in late or left work early. Those who live farther away are more likely to report that they have missed workdays as a result of caregiving.

The small group of long-distance caregivers (5%) who are the only care provider were more likely than those who helped others or shared in the care to report that they had to rearrange their work schedule, turn down work-related travel, and to report they had lost benefits at work as a result of their caregiving responsibilities.

Regarding their health, the majority of respondents said that caregiving had no effect on their health. However, 18% reported that their health had changed for the worse. And 18% of the respondents reported that their health was only fair or poor (versus 9% of the general US population).

The combined stress of caring for someone and the stress of the potential of losing my job is becoming overwhelming.

Distance and Caregiving

Family caregivers who live at a distance have that additional factor to weigh and manage when compared to those family caregivers who live nearby the person they are helping. Time, a scarce resource for most family caregivers, now becomes even more of a problem due to travel. Distance also may require family caregivers to have high out-of-pocket costs for both travel and purchases of needed goods and services to supplement family care. Distance may also complicate the caregiver's ability to manage work and family. And, finally and most importantly to many family caregivers,



distance constrains their contact with an ill family member and limits the caregiver's ability to interact with this person regularly.

As mentioned before, some previous research suggests that distance is a key, if not the primary, factor in determining the role of the family member in the caregiving situation. Our sample illustrates the confounding role distance plays in caregiving. With the exception of the long-distance caregivers who report that they are the only care providers, distance is related to the intensity of the caregiver's role. Table 8 below shows that the respondents who describe themselves as the main helper live closer than those who say they are sharing the care equally. Similarly, those who report they are sharing equally are closer than the respondents who report they are primarily helping another person.

Table 7. Distance and the Role of the Long-Distance Caregiver

Role of Respondent	Average Miles from Care Recipient
Only Helper	424.37 Miles
Main Helper	242.17 Miles
Shared Equally with Other(s)	378.63 Miles
Others Have Been Main Helper with Some Help From Respondent	554.64 Miles

Distance between respondents and care recipients did not differ by gender or age. Men and women reported similar distances and, with the exception of those who were older than 65, the different age groups reported similar distance patterns. Table 8 displays average distances by age group.

Table 8. Distance and Age of Caregiver

Age Category of Caregiver	Average Miles from Care Recipient
18-29	425.17 Miles
30-49	456.17 Miles
50-64	469.90 Miles
65+	327.73 Miles
All Ages	450 Miles

Table 9. Distance and Frequency of Visiting

Frequency of Visits	Average Miles from Care Recipient
Few Times a Week	45 Miles
Once a Week	66 Miles
A Few Times a Month	186 Miles
Once a Month	334 Miles
Once Every Few Months	751 Miles
A Few Times a Year	1231 Miles

There are no significant distance differences related to the number of hours respondents report spending on arranging needed services, supervising or monitoring these services or helping with personal care needs. However, those who live between 1 and 3 hours from the care recipient report fewer hours (20 hours a month) helping around the home of the care recipient than those who live more than 3 hours away (25 hours a month).

Looking at the relationship between distance and workplace accommodations, we see a more complicated picture. Those who report that they have had to come in late or leave early from work live nearer to the person they are helping than those who didn't have to come in late or leave early. Those who reported that they had to miss days of work as a result of their care responsibilities lived, on average, farther from the person they helped than those who did have to miss work days. And, for those respondents who had to take an unpaid leave, turn down a promotion or work travel or who lost benefits at work, distance seemed to play a role in these work-related decisions. Table 10 illustrates the average distance between the caregiver and the care recipient for those groups of respondents who reported specific work effects and those who did not.



Table 10. Average Distance for Respondent Groups Reporting Work Effects

Work Adjustment	(No./Average Miles) for Caregiver Who Experienced Adjustment	(No./Average Miles) for Caregiver Who Had Not
Came in Late/Left Early	328 Miles	490 Miles
Took Unpaid Leave	743 Miles	410 Miles
Turned Down a Promotion	621 Miles	447 Miles
Turned Down Work Travel	607 Miles	438 Miles
Lost Benefits at Work	670 Miles	444 Miles
Missed Days of Work	548 Miles	393 Miles
Considered Leaving Work	492 Miles	448 Miles
Moved From Full-Time to Part-Time	473 Miles	449 Miles
Considered Changing Employers	493 Miles	447 Miles
Turned Down a Relocation	404 Miles	451 Miles
Rearranged Work Schedule	476 Miles	429 Miles

For those who had to rearrange their work schedule, the average distance was no different than for those who did not. Similarly, those who reported they turned down relocation were similar to those who did not in terms of distance from the care recipient.

Gender and Long-Distance Caregiving

In our sample of long-distance caregivers we had more men than women completing the survey. This is likely an artifact of the larger sample characteristics. Nonetheless, previous research on long-distance caregiving suggests that men may be more likely than women to identify themselves as long-distance caregivers. We were interested in looking at the extent gender played a role in the overall care activities as well as care effects. We did find some interesting patterns.

There was no real difference between men and women in terms of the distance they lived from the person they were helping (males lived an average of 452 miles from the person they were helping; females, an average of 446 miles.) There were, however, differences in the care situation and selected work-related factors.

Women reported missing more hours of work per month as a result of caregiving (24 hours) than men (17 hours). Women also reported spending more time helping the care recipient around their home and with personal care. Women reported an average of 23.5 hours a month helping around the home compared to men who reported 21 hours a month in this activity. Women reported 14.5 hours a month helping with personal care and men reported 11 hours. And, on average, women spent more money each month on services needed by the care recipient (\$751) than men (\$490). And, finally, women were more likely than men to report that they were the only helper or the main helper in the care situation.



Both men and women were equally likely to report that they had rearranged their work schedules, left early or came in late, taken an unpaid leave, turned down a promotion, relocation or work-related travel, considered changing employers or missed days of work. Women, however, were more likely than men to report that they had moved from full-time work to part-time work and to say they were considering leaving work altogether.

Long-Distance Caregiving and Family Support

Long-distance caregivers, as a group, are managing their care situations with the help of others, primarily relatives. The only group of long-distance caregivers who are most likely to rely on paid caregivers are the 5% who report they are the only person providing care. This group is unique from the other long-distance caregivers not only in the use of paid care providers but also in the extent to which distance was correlated to their role. Those who were the only person providing care reported a higher average distance than those who reported they were the main care provider.

A sibling who lives nearby the care recipient was the most commonly mentioned support for these long-distance caregivers, with spouses the second most common. Relatives comprised 83% of the help being provided in the care situation. Other relatives who helped were siblings who also lived at a distance (8%), the care recipient's spouse (12%), or another relative. For those who reported that a spouse was present in the care recipient's home, 53% of these spouses were reported to be in either poor or only fair health (most likely because they too are elderly).

For the relatively small group of respondents (nearly 10%) who also paid for services the care recipient needed, women reported spending on average \$751 a month compared to men who spent an average of \$490 a month.

Fewer than 4% of the respondents reported that they were being helped most by a paid provider.

Implications for Employers

This study of long-distance caregiving contains several important implications for employers. A long-distance caregiving situation may be one factor complicating job and career decisions for employees and, for some, may be the impetus for deciding to change work schedules or even change jobs or leave the workplace entirely.

For employers who have high rates of long-distance caregivers and who want to reduce attrition rates and minimize productivity impacts due to work/family conflicts, attending to the special needs of long-distance caregivers is a sensible strategy. Our study, for example, found that distance was related to how much time the caregiver took off from work. Rather than coming in late and leaving early and making personal calls during the work-day—which many employed caregivers do—long-distance caregivers are often required to miss whole days of work. A policy of personal days off may support these caregivers more than flex-time, based upon hours worked during the day.



Other important findings for employers:

- A relatively small group of long-distance caregivers in our sample reported that they were the only care provider. For them, access to and information about formal services is essential to manage their caregiving situation. These caregivers do not have what most long-distance caregivers have: a relative living nearby the older adult. This group might be most effectively supported at work by access to a geriatric care manager who could arrange and monitor services “on the ground”.
- While the majority of long-distance caregivers are not dependent upon paid service providers, they are involved on a regular basis with arranging services with their relatives who live nearby and reported spending approximately one day a month doing so. Allowing the relatives who lived near the older person to use an existing workplace resource and referral service available to the long-distance caregiving employee might be a good strategy that would save the employee time and complications in communicating with these other relatives.
- Long-distance caregivers have financial burdens as well as time conflicts. The farther away the caregiver lives, the more he or she is likely to spend on travel and long-distance phone calls. And, in some cases, the long-distance caregiver is actually paying directly for the cost of services needed by the elder. Eldercare programs that offer help with these financial costs would be an important benefit. For example, voluntary pooling of frequent flyer miles for employees who need to travel on family emergencies is one idea, as is the monitored use of company long-distance phone accounts to call the care recipient.

- Our study found that women were more likely than men to report that they had reduced their work hours as a result of their care responsibilities. Women were also more likely than men to report that they were considering leaving work altogether. For many of these employees, as well as the men who may have difficult long-distance care situations, job-sharing and access to temporary short-term part-time work schedules could provide short-term relief and an alternative to leaving work entirely.

Long-distance care providers have complicated situations that pit their career choices directly with their family obligations. Emotional issues are difficult for many of these care providers as they face feelings of guilt because they are far from their loved one. A supportive workplace and recognition of the difficult situation by friends and co-workers can provide some respite for these caregivers. In particular, sensitizing line supervisors about workplace eldercare turns out to be one of the most valuable corporate responses for these employees.

As more people become involved in long-distance caregiving, new approaches and strategies of programming may be developed to help them. In the meantime, learning about the special situations facing this group of family caregivers is an important beginning to their effective support.

Endnotes

- ¹ Caregiving in the U.S. (2004). National Alliance for Caregiving and AARP, funded by the MetLife Foundation.
- ² Wagner, D.L. (1997). “Caring Across the Miles: Findings of a Survey of Long-Distance Caregivers,” Final Report for The National Council on the Aging: Washington, DC.
- ³ Stern, S. (1996). “Measuring Child Work and Residence Adjustments to Parents’ Long-Term Care Needs”. *The Gerontologist*, Vol. 36, No. 1, p. 76-87.
- ⁴ Neuharth, T.J. & Stern, S. (2002). “Shared Caregiving Responsibilities of Adult Siblings with Elderly Parents”. *Journal of Human Resources*, Vol. 37, No. 3.



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