THE ELDER CARE STUDY: EVERYDAY REALITIES AND WISHES FOR CHANGE

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This Study Has Been Conducted in Memory of Leora Osgood May
It has been more than five years since my mother’s death. I have copies of one of the last photographs I ever took of her spread throughout our house. It is the photograph we used for her obituary. She is sitting in her favorite crewel chair, looking straight at me, and smiling.

I spent the last eight weeks of her life caring for her, as did my sister and my husband. It all began when a non-critical incident, a slight fall that occurred when she was getting up from her desk after balancing her checkbook, turned into a medical nightmare. She was taken to the emergency room, where it was discovered that she had a hairline fracture in a non-weight bearing part of her pelvis. While she was in the ER, I spoke to her by phone from my home, 550 miles away. She told me that she wasn’t in too much discomfort; nonetheless, she was given Morphine, a drug that had almost killed her eight years before in the same hospital system. Despite our calls to the hospital about her history with Morphine, she was given it again when she was moved upstairs to admitting. Then, the doctor on call gave her Ativan to counter the delirium caused by the Morphine, but that sent her into a worse drug-induced coma. And all of this happened in the few hours before we could travel to West Virginia.

Mother was almost 98 years old at the time, but she had been quite healthy for someone her age, as that glorious photograph of her that I so cherish reveals.

We brought Mother back to her own home, where she most wanted to be. From then on, every day seemed like a battle. My sister, my husband, my mother’s doctor and I had to fight to set up a good system of home-based care for her. We learned how to administer medical procedures we never thought we could do, how to fill out complex forms for insurance, and how to get the right medical equipment delivered to her home. We already had some great care to help her, but now we needed 24-hour care, as well as nurses on call when emergencies arose. We went through numerous caregivers and nurses before we found people who were “caregivers” in the true sense of that word—individuals who were caring, not just people who spent their time filling out paperwork. We found some remarkable people who stayed by her side, just as we did.

We won those battles, but we lost the big one. Mother fought with everything she had to live. She told us she wasn’t ready to die and she wanted our help to “make me better.” But, ultimately, her systems began to shut down.

When one has an experience like this, one can feel disheartened or embittered or one can try to use the experience to bring about change. In honor of the kind of person my mother always was, I have chosen the latter route.

First, we worked to bring changes in the hospital system where she had been cared for. Spearheaded by Mother’s beloved doctor, Kathleen Mimnagh, the hospital system now lists “adverse reactions” in addition to anaphylactic allergies on every patient’s computerized medical history; they have developed procedures to ensure that the emergency room and the admitting floors communicate about a patient’s drug reactions; they include treating patients’ families with respect as a “quality” measure the hospital is to be held accountable for; and they have made a commitment to reduce “unnecessary deaths.”
Second, I wanted to do something on a larger scale. As the president of a research organization that conducts ongoing studies of the U.S. workforce, I was in a remarkable position to create a study that shares the experiences of a nationally representative group of caregivers and asks them for their wishes to bring about change. So when people asked us about donations in Mother’s memory, we invited them to contribute to this study. From small donations of a couple of dollars to a large donation from IBM, we have created *The Elder Care Study*.

I deeply hope that the voices we share in this study add to the momentum created by so many pioneers in this field and to the brilliant efforts of Maria Shriver in bringing much-needed research and attention to caregiving.

Ellen Galinsky
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There have been so many people who have contributed to this study. I am grateful to all of them.

First, there are the people who served as advisors, helping me shape a study that would be a fitting tribute to my mother and would address major unanswered questions about elder care. As I spoke with all of them, they were inspirational as they shared their dreams for this study. In addition, many reviewed the questionnaire and provided invaluable feedback. Very special thanks to: Maria Ferris formerly of IBM and now of Maria S. Ferris, LLC; Daniel J. Conti of JPMorgan Chase; Nancy Lewin of Johnson & Johnson; Ann Bookman of Brandeis University; Marcie Pitt-Catsouphes and Melissa Brown of the Sloan Center on Aging & Work at Boston College; Kathleen Mimnagh, M.D.; Robert Arnold, M.D. of the University of Pittsburgh Palliative Care Program; Diane E. Meier, M.D. of the Hertzberg Palliative Care Institute, Mount Sinai School of Medicine; Shelley MacDermid Wadsworth of Purdue University; Jaya K. Rao, M.D. of the Centers for Disease Control and Prevention; Suzanne Mintz of the National Family Caregiver Association (NFCA); Gail Gibson Hunt of the National Alliance for Caregiving; Skip Schlenk of the Lupus Foundation of Colorado; Ellen Marram of the Barnegat Group LLC; Kathy Burnes of the Jewish Family & Children’s Services Boston; Risa Greendlinger of the National Center on Family Homelessness; Kathleen Christensen of the Alfred P. Sloan Foundation; Andrea Cohen of Houseworks; Ken Knapp of the International Longevity Center; and Kathleen M. Foley, M.D. of Memorial Sloan-Kettering Cancer Center. I especially want to thank Bob Arnold, a true champion for palliative care and good family communications for continuing to care about and push this study over the five years it took to turn it from an idea we discussed in a restaurant in Pittsburgh to a reality, as well as Ellen Marram, who, as a member of Families and Work Institute's Board, has also been an invaluable ongoing source of assistance, including reviewed drafts of the questionnaire and asking the questions that always improve what we do.

This study would not have taken place without its forward-thinking and deeply caring funders. Our most appreciative thanks to the Alfred P. Sloan Foundation and to Kathleen Christensen for funding data collection for the 2008 National Study of the Changing Workforce. For providing the funds for this report, our heartfelt thanks to Maria Ferris, formerly of IBM, Randy MacDonald, Senior Vice President of Human Resources of IBM, Ron Glover, Vice President, Diversity & Workforce Programs, Patricia L. Lewis, Vice President, Human Resources Diversity and Employee Experience, and Julie Baskin Brooks, Global Work Life Integration & FlexibilityTeam Leader.

Our research team at FWI has been without parallel. Thanks to Kerstin Aumann, Senior Research Associate, who took on the role of project director, lead author of the qualitative interview protocol and lead author of the report, finishing the draft just before giving birth to her first child, Alex. Thanks to James T. (Terry) Bond, Senior Research Advisor, as always, for being a mainstay—from taking the lead in writing the elder care research questions for the quantitative 2008 National Study of the Changing Workforce (NSCW) and for working with Harris Interactive to arrange for conducting interviews with family caregivers. We are deeply grateful to Kelly Sakai for her truly impressive skill in data analysis and for her fantastic can-do attitude. Thanks to Melissa Brown of the Sloan Center for Aging & Work for her insightful
work on the study design and interview protocol and to Marcie Pitt-Catsouphes of the Sloan Center for her thoughtful guidance—they have truly been integral parts of the FWI team.

And this study would also not have taken place without the interviewers who conducted the interviews for the study. Again, we are grateful to Kerstin Aumann of Families and Work Institute, Melissa Brown of the Sloan Center for Aging & Work at Boston College, and Toni Sciarra Poynter. Their insightful interviews are the strength upon which this study rests. Many thanks also to Toni Sciarra Poynter for her swift and meticulous editing of this report.

To ensure high-quality data, the Harris staff went above and beyond the call of duty and their contract terms in administering the 2008 NSCW. In particular, we want to acknowledge the efforts of David Krane, Vice President, Public Affairs and Policy Research; Kaylan Orkis, Senior Project Researcher; and Humphrey Taylor, Chair of The Harris Poll. We also thank the many U.S. employees who took part in the telephone interviews conducted for this quantitative and then qualitative study.

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INTRODUCTION

THE ELDER CARE STUDY: EVERYDAY REALITIES AND WISHES FOR CHANGE

For decades, there has been talk about the aging of the workforce. There are legions of books, articles, speeches and blogs on this subject. As America began graying, it was said that the 1990s would be the decade when we begin to take elder care seriously. But the 1990s came and went. Then it was said that the 2000s would be the decade when we begin to take elder care seriously—because elder care is a game changer. Now that decade is ending, too.

Perhaps we tend to look at the future as if through trick glasses that make nearby objects seem distant. Or perhaps we are in denial. Or perhaps more of us need first-hand experiences with elder care in order to make it real.

If ever there were an indication that this issue is not a future reality—that the future is now—it is a finding from the 2008 National Study of the Changing Workforce (NSCW). In that nationally representative study, we found that 42% of employed Americans (nearly 54.6 million employees) have provided elder care in the past five years. Forty-two percent! That’s almost one in two of us.

This is all the more striking because the NSCW uses a very strict definition of elder care. We ask: “Within the past five years, have you provided special attention or care for a relative or in-law 65 years old or older—helping with things that were difficult or impossible for them to do themselves?” Notice we limit this to relatives and in-laws who are 65 years old or older. And notice that we define elder care as helping people with things that “were difficult or impossible to do themselves.”

Now that almost half of us have experienced elder care, what have we learned? What are the everyday experiences that worker family caregivers have in providing this care with their other family members, with the medical system and with their employers? What are their wishes for change in each of these areas? And, most importantly, what are their wishes for themselves as they age? These are the questions addressed in The Elder Care Study.

A UNIQUE STUDY

Although there are many important studies of elder care conducted by a number of pioneers who have blazed the way, we see The Elder Care Study adding to this literature for two reasons.

First, this study is unique in its design. It is typical for research to have to make tradeoffs between breadth and depth. For example, if the study is a nationally representative study, it has breadth, but may lack depth because cost and time constraints limit the number of questions the researchers can ask or the number of times they can repeat the study. If the study is a qualitative study, it has depth, but may lack breadth because the people in the study may not be typical of caregivers.

This study has both breadth and depth. It is based on a nationally representative sample of employed caregivers, drawn from the Families and Work Institute’s ongoing National Study of the Changing Workforce (NSCW). The NSCW is a very comprehensive study with over 600 data points on employees’ lives on and off the job. Based on the 1977 Quality of Employment Survey conducted by the U.S. Department of Labor, the NSCW was first conducted by Families and Work Institute in 1992 and has been conducted every five to six years since then.
With its 54.6% response rate, it provides very rich quantitative information on working family caregivers of the elderly over the past 16 years.

From the 2008 NSCW, caregivers—both those who were currently providing care or who had provided care to someone who had died within the past five years—were invited to participate in an telephone interview, thus providing a great deal of depth. This is the qualitative part of our study. For more information on the overall study methodology, see Methodological Note on page 45.

The second reason that this study is unique is that we ask these family caregivers a series of “one wish” questions—one thing they would most like to see changed in the way workplaces, other family members and the health care system support them as caregivers. And we asked them about their wishes for themselves as they age.

HIGHLIGHTS OF FINDINGS

From the quantitative study, we find:

- Almost one in two individuals in the workforce (42% or nearly 54.6 million employees) have provided elder care over the past five years.

- Among those who have provided care in the past five years, almost half (44%) have cared for more than one person.

- 17% of workers in the workforce are currently providing elder care.

- Among the entire workforce, women (20%) and men (22%) are equally likely to have provided family care in the past five years and equally likely to provide care at the current time (9% versus 8%).

Although women and men provide care in roughly equal numbers, there are many differences in the way that these experiences play out in their lives.

- Women are more likely (44%) than men (38%) to provide family care on a regular basis rather than on an intermittent basis.

- In addition, women spend more time than men providing care on average. Women spend 9.1 hours a week providing care (an average of 6.4 hours providing in-person care and an average 2.7 hours providing indirect care), while men spend 5.7 hours as caregivers (an average 3.4 hours providing in-person care and an average 2.2 hours providing indirect care).

- Many of these caregivers are in the sandwich generation—46% of women who are caregivers and 40% of men also have children under the age of 18 at home.

- Just under half of the workforce (49%) expect to be providing elder care for a family member in the coming five years.

- Family caregivers work as many hours on average (45 hours) as those without caregiving responsibilities (44 hours).

- Although most working caregivers (55%) report that they would prefer to work fewer hours, only 23% have actually reduced their hours.
• Not surprisingly, many are experiencing a time famine: 71% report not having enough time for their children, 63% report not having enough time for their spouse/partner and 63% report not having enough time for themselves.

Interestingly, men who are providing care are now more likely than women caregivers to experience work-life conflict.

• 49% of men experience “some” or “a lot” of conflict compared with 42% of women.

**From the qualitative study, we find:**

Family caregivers’ top wishes for the way in which workplaces could better support them as caregivers include:

• greater flexibility, more options for managing time;

• time off for elder care, especially paid time off without having to use up vacation time; and

• more understanding of their situation from management.

As far as support for elder care from other family members is concerned, caregivers have only one wish—more active involvement and help from others in the family. Though many family caregivers say others do help them in providing care, the level of support from other family members often falls short of the caregiver’s needs and expectations. Since the selection of caregivers we interviewed was random, one can only imagine that the views of some other family members might also be similar, with others feeling that he or she has an unfair burden, too.

When it comes to health care, our findings suggest that family caregivers need to play a very active role in their elder’s medical care, serving as their elder’s advocate within the health care system. One of the most alarming findings in our survey is that 36% of former family caregivers whose elder has passed away report that medical mistakes were made by professionals. In some cases, caregivers believe that these medical mistakes were severe enough to contribute to their relative’s death.

Top wishes for the way in which doctors, nurses and others in the health care system could better support family caregivers include:

• more frequent and better quality two-way communication with doctors and other medical providers;

• less overworked, more compassionate staff at medical and nursing facilities with the skills to listen and learn from the caregivers and the elders; and

• a more user-friendly, easier-to-navigate and less costly health care system.

In terms of their own aging, the caregivers present a bleak picture. Having experienced the elders’ aging and ailments, family caregivers tend to be both more aware of the challenges of growing old and more discouraged about it. Many seem to find it too difficult, too depressing to imagine themselves as being in the care recipient’s shoes. Their wishes are more about what they do not want to happen to themselves, than what they do want. These are:

• not to be a “burden” to others, especially to their children;
• not to burden themselves or others with unaffordable expenses; and
• not to end up in a nursing home.

Among hopes for their own aging, family caregivers most often cite being able to live in their own homes, maintaining good health and remaining independent for as long as they can.

Yet, ultimately, far too many wish to escape from aging as it now plays out in America:

I don’t even want to think about it. I want to pass in my sleep of old age. It’s an ugly time of life—the last few years of suffering.

I would rather die in a car wreck than put anyone through what I had to go through taking care of my mother.

Although there are some inescapable difficulties that come with aging and illness, there is huge room for improvement. As our country grows older, we desperately need to use some of the more effective models of care for the elderly that already exist, and we need to develop and test new models.

We believe that this is not only possible, but doable. No one should have to wish “just shoot me.” Instead, we must be able to age and die with dignity. That is what Leora Osgood May had in her final years and days. In her memory, we hope to make that happen for more and more Americans.

Since this study is a tribute to Leora May, we make one concluding wish in her name: please use this study as a call to action and send us your positive ideas for better aging. We will share them as broadly as possible and help to turn them from wishes into realities. Please visit: http://familiesandwork.org/site/work/workforce/eldercare.html.

FINDINGS FROM THE QUANTITATIVE STUDY

About the quantitative study

The research findings presented below are drawn from the 2008 National Study of the Changing Workforce (NSCW) conducted by Families and Work Institute. In this report, we refer to the 2008 NSCW as the quantitative study. Its total sample (i.e., wage and salaried employees, self-employed individuals and small business owners) includes 1,589 individuals who reported providing special attention or care for a relative or in-law 65 years old or older. This sample is weighted to the Current Population Survey on various factors.¹

Finding: Almost one in two individuals in the workforce have provided elder care over the past five years

• 42% of employed people in the U.S. (or nearly 54.6 million employees) report that within the past five years, they have provided “special attention or care for a relative or in-law 65 years old or older—helping with things that were difficult or impossible for them to do themselves.”
Finding: Nearly half of workers who have provided elder care in the past five years have done this for more than one person

- 44% of workers who have provided elder care in the past five years have cared for more than one person in that time period.

Finding: Almost one in five are currently providing elder care

- 17% of people in the workforce are now working caregivers of the elderly.

Finding: Working men and women are equally likely to be family caregivers

There is a widely held assumption that those who care for elders are most likely to be women. While that is true in the general population, it is generally not the case among women and men who remain in the workforce while providing care.

- Among all individuals in the workforce, women (20%) and men (22%) are equally likely to have provided family care in the past five years.
- Women (13%) and men (14%) are also equally likely to have provided family care in the past year.
- Women (9%) and men (8%) are equally likely to be providing this care currently.

Finding: Over the past 16 years, the percentages of those in the workforce providing care among both women and men have continued to rise

Because our question changed over time, thus we share the exact question we asked and the results.

- In 1992, we asked: “Is there any friend or family member, living with you or not, to whom you provide special care or attention because of a handicap, illness, or old age?” We found that women (5.1%) were more likely to be providing care than men (4.5%).
- In 1997, we asked: “Do you CURRENTLY provide special attention or care for someone 65 years old or older?” We found that women (7%) were equally as likely to be providing elder care as men (7%).
• In 2002 and 2008, we asked working people who had provided elder care in the past five years: “Do you CURRENTLY provide special attention or care for a relative or in-law 65 years old or older—helping with things that are difficult or impossible for them to do themselves?” In 2002, we found that women (9%) and men (9%) were equally likely to be providing care. And as reported above, this is also true in 2008 (9% of women and 8% of men).

Finding: Despite the fact that both women and men provide care, women are more likely than men to be providing care on a regular basis

• Among those currently providing care, 44% of women provide family care on a regular basis rather than on an intermittent basis, compared with 38% of men.

Finding: Many family caregivers are in the sandwich generation—they care for both elders and children

• Among those who care for elders, 46% of women and 40% of men are also parents of children under 18 years of age who live with them.

Finding: Just under half of the workforce (49%) expect to be providing elder care in the coming five years

• 24% of women in the workforce and 25% of men expect to provide care for a relative or in-law in the coming five years.

Finding: Over the past decade, the number of workers expecting to provide family care for the elderly has been gradually increasing—there have been no differences between men and women in these expectations

Since 1997, we have asked the same question: “Do you expect to have some responsibility for the care of someone 65 years old or older in the next five years?”

• In 1997, we found that 43% of the workforce (23% of men and 20% of women) expected to provide elder care in the next five years.

• In 2002, we found that 48% of the workforce (26% of men and 22% of women) expected to provide elder care in the next five years.

Finding: On average, current working caregivers range in age, with the vast majority over 40 years old

• The median age of current working caregivers is 47 years old.
• Only 14% of current caregivers are under the age of 30.
• 16% of current caregivers are 30 to 39 years old.
• 28% are 40 to 49 years old.
• 42% are 50 years old or older.

Finding: As the workforce has aged, so too have caregivers—in 1992, the median age of working caregivers was 43 years old

• In 1997, the median age of caregivers was 44 years old.
• In 2002, the median age of caregivers was 46 years old.
Finding: Working caregivers spend long hours at work

We wondered how many hours per week caregivers work and how this compares to employees who are not caring for an elderly relative or in-law.

- On average, family caregivers work an average of 45 hours per week—similar to those in the workforce without elder care responsibilities (44 hours per week).
- Male family caregivers work an average of 50 hours per week, somewhat more than men who do not provide elder care (46 hours per week).
- Female family caregivers and non-caregivers both work an average of 41 hours per week.
- There is no difference in average number of hours worked per week between those who are caregivers of differing ages and those who are not, except among the youngest group of caregivers.

Figure 2: Hours worked per week by age and elder care responsibilities

![Bar chart showing hours worked per week by age and elder care responsibilities]

Source: The Elder Care Study, FWI, 2010.
N = 3,404

Finding: Although most working caregivers report that they would prefer to work fewer hours, few have actually reduced their hours

According to the 2008 NSCW, the majority of working family caregivers in general (55%) indicated that they would prefer to work fewer hours, but most do not follow through on this preference:

- Only about one in four (23%) report that he or she has cut back on work hours to allow more time for caregiving.
- An even smaller proportion (15%) of family caregivers report that they have taken a break from work in the past year to care for an elderly family member.
• Since the NSCW only surveys those currently in the workforce, we don’t know how many have left the workforce completely to provide family care.

Among those who did not take any time off for elder care in the past year:

• A large majority (80%) of working caregivers feel they did not need time off.

• Nearly one in five workers (17%) who didn’t take any time off say they could not afford to do so, and another 2% say they were not allowed to take time off.

Finding: Workers who took time off to care for an elderly family member generally found their employers helpful in doing so, but a large majority report losing income during their caregiving leaves

Findings from the 2008 NSCW indicate that among the 38% of family caregivers who took time off in the last year or worked fewer hours to care for an elderly family member, a majority say that their employers were helpful. It may be that employers are particularly sympathetic to elder care issues.

• 64% say their employers were very helpful.

• 25% report their employers were somewhat helpful.

Still, about one in ten (10%) of workers found their employers not at all or not very helpful in arranging for them to take time off to care for an elderly relative or in-law.

Further, it should be noted that nearly half of workers who took time off for elder care lost income during their caregiving leave (48%). Thus, caregiving leaves are likely to strain family resources—especially during these challenging economic times.

On the other hand, 70% of family caregivers report being able to take as much time away from work as needed without worrying about losing their jobs.

Finding: Given how much time working caregivers spend on their jobs and how few took time off, caregivers spend a considerable amount of time also providing care

We asked about how much time employed caregivers spend providing care in the 2008 National Study of the Changing Workforce. We find:

• Family caregivers report spending an average of five hours per week on direct, in-person types of caregiving such as meal preparation, household work, physical care, transportation to medical services and so forth. This kind of care needs to be more regular and is more time intensive.

• Family caregivers spend an average of 2.5 hours per week on indirect care, such as arranging for services and handling finances.

Finding: Although women and men are both likely to be family caregivers, women spend more time in providing care than men do

• On average, women spend 9.1 hours a week providing care (or an average of 6.4 hours providing in-person care and an average 2.7 hours providing indirect care).

• On the other hand, men spend an average total of 5.7 hours as caregivers (or an average 3.4 hours providing in-person care and an average 2.2 hours providing indirect care).
Finding: Working caregivers are experiencing a time famine

Not surprisingly, in light of full work schedules and a substantial number of hours per week spent on caregiving, working caregivers report feeling starved for time in other areas of their lives:

• 71% report not having enough time for their children.
• 63% report not having enough time for their spouse/partner.
• 63% report not having enough time for themselves.

These figures do not differ significantly from those who are not family caregivers of the elderly, except for feelings of not having enough time for self: 63% of family caregivers report this compared with 57% of those who do not provide elder care.

Finding: Over the past six years, men have experienced more work-life conflict than women

• Between 2002 and 2008, men who are caregivers continue to experience more work-life conflict than women who are caregivers do.
• In 2008, 49% of men experience “some or “a lot” of conflict compared with 42% of women. It is unclear why men experience more conflict, but perhaps the role of caregiving is newer to them than it is to women and thus the demands are experienced more intensely.

Figure 3: Percent of family caregivers who experience work-life conflict “a lot” or “somewhat” by gender

Source: The Elder Care Study, FWI, 2010.
N = 544 (2002); N= 548 (2008)

Finding: Family caregivers who are also parents experience significantly more work-life conflict than caregivers who are not parents, but this gap seems to be lessening over time
Figure 4: Family caregivers with and without child care responsibilities who experience work-life conflict “a lot” or “somewhat”

Source: The Elder Care Study, FWI, 2010.
N = 546 (2002); N=600 (2008)
* p < .05; *** p < .001

About the qualitative study

At the time they were interviewed for the 2008 NSCW, a subsample of 421 family caregivers with elder care responsibilities agreed to be contacted for a follow-up interview exploring their experiences caring for an elderly relative or in-law. Of these, 140 were successfully contacted and interviewed from October 2008 to August 2009. We refer to this as the qualitative study. For the purpose of this report, the samples are weighted to the Current Population Survey on various factors.ii

The qualitative study explores the experiences of family caregivers to the elderly both during and after the caregiving experience. To this end, two groups of caregivers were specifically interviewed—those currently providing elder care and those who have cared for a recently deceased elderly relative or in-law within the last five years.iii The interviews were conducted by telephone and lasted approximately 15 to 30 minutes.

We found no significant demographic differences between caregivers who are currently providing elder care and those whose elder recently passed away. That being the case, we consider these two groups together when we compare the people we interviewed with those in the quantitative study.

To assess the extent to which the sample for the qualitative study is representative of the workforce in general (the total sample of the 2008 NSCW) and to caregivers (elder care providers from the 2008 NSCW), we conducted demographic comparisons. These findings are summarized in Table 1.
### TABLE 1: Comparisons among the interviews from the qualitative study and the quantitative study 1) with elder care responsibilities and 2) the total workforce

<table>
<thead>
<tr>
<th>Variable</th>
<th>Qualitative Study Interviewees</th>
<th>Quantitative Study—those with Elder Care</th>
<th>Sig.</th>
<th>Quantitative Study—Total Workforce</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>36%</td>
<td>52%</td>
<td>**</td>
<td>53%</td>
<td>***</td>
</tr>
<tr>
<td>Female</td>
<td>64%</td>
<td>48%</td>
<td></td>
<td>47%</td>
<td></td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White (non-Hispanic)</td>
<td>89%</td>
<td>83%</td>
<td></td>
<td>80%</td>
<td></td>
</tr>
<tr>
<td>Black (non-Hispanic)</td>
<td>5%</td>
<td>7%</td>
<td></td>
<td>8%</td>
<td>n.s.</td>
</tr>
<tr>
<td>Hispanic</td>
<td>3%</td>
<td>5%</td>
<td></td>
<td>6%</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>3%</td>
<td>4%</td>
<td></td>
<td>5%</td>
<td></td>
</tr>
<tr>
<td>Age (mean)</td>
<td>52 years</td>
<td>48 years</td>
<td>***</td>
<td>46 years</td>
<td>***</td>
</tr>
<tr>
<td>Generation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gen Y</td>
<td>1%</td>
<td>8%</td>
<td>***</td>
<td>12%</td>
<td></td>
</tr>
<tr>
<td>Gen X</td>
<td>13%</td>
<td>23%</td>
<td>***</td>
<td>28%</td>
<td>***</td>
</tr>
<tr>
<td>Boomers</td>
<td>80%</td>
<td>61%</td>
<td></td>
<td>53%</td>
<td>***</td>
</tr>
<tr>
<td>Matures</td>
<td>6%</td>
<td>8%</td>
<td></td>
<td>8%</td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Legally married</td>
<td>74%</td>
<td>67%</td>
<td></td>
<td>64%</td>
<td></td>
</tr>
<tr>
<td>Living with partner</td>
<td>4%</td>
<td>6%</td>
<td></td>
<td>7%</td>
<td>n.s.</td>
</tr>
<tr>
<td>Single</td>
<td>22%</td>
<td>27%</td>
<td></td>
<td>29%</td>
<td></td>
</tr>
<tr>
<td>Children under 18 at home</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>34%</td>
<td>36%</td>
<td>n.s.</td>
<td>40%</td>
<td>n.s.</td>
</tr>
<tr>
<td>No</td>
<td>66%</td>
<td>64%</td>
<td></td>
<td>60%</td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HS/GED or less</td>
<td>27%</td>
<td>40%</td>
<td></td>
<td>40%</td>
<td></td>
</tr>
<tr>
<td>Some college</td>
<td>31%</td>
<td>28%</td>
<td>***</td>
<td>29%</td>
<td>**</td>
</tr>
<tr>
<td>4-year college degree or more</td>
<td>42%</td>
<td>32%</td>
<td></td>
<td>31%</td>
<td></td>
</tr>
<tr>
<td>Occupational level</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Manager/executive</td>
<td>17%</td>
<td>17%</td>
<td></td>
<td>16%</td>
<td></td>
</tr>
<tr>
<td>Professional</td>
<td>30%</td>
<td>20%</td>
<td>n.s.</td>
<td>19%</td>
<td>**</td>
</tr>
<tr>
<td>Other</td>
<td>53%</td>
<td>63%</td>
<td></td>
<td>65%</td>
<td></td>
</tr>
<tr>
<td>Full-time vs. part-time status</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full time</td>
<td>65%</td>
<td>80%</td>
<td>***</td>
<td>81%</td>
<td>***</td>
</tr>
<tr>
<td>Part time</td>
<td>35%</td>
<td>20%</td>
<td></td>
<td>19%</td>
<td></td>
</tr>
<tr>
<td>Average number of hours worked per week in all jobs</td>
<td>43</td>
<td>45</td>
<td>n.s.</td>
<td>44</td>
<td>n.s.</td>
</tr>
<tr>
<td>Years with current employer/in current line of work (average)</td>
<td>11 years</td>
<td>13 years</td>
<td>n.s.</td>
<td>12 years</td>
<td>n.s.</td>
</tr>
<tr>
<td>2008 family income (average)</td>
<td>$91,000</td>
<td>$95,000</td>
<td>n.s.</td>
<td>$89,000</td>
<td>n.s.</td>
</tr>
</tbody>
</table>

Source: The Elder Care Study, FWI, 2010.
Qualitative Study—EC interviewees N=114-122; Quantitative Study—EC workforce N=1,393-1,589; Quantitative Study—Total Workforce N=3,227-3,502

a Significant differences between EC interviewees in the qualitative study and workforce with elder care responsibilities in the quantitative study; *** p<.001, ** p<.01, * p<.05

b Significant differences between EC interviewees in the qualitative study and total workforce in the quantitative study; *** p<.001, ** p<.01, * p<.05
As Table 1 indicates, our sample of elder care interviewees in the qualitative study differs from the sample in the quantitative study with elder care responsibilities in some characteristics. Elder care interviewees in the qualitative study are more likely to be women, are somewhat older and better educated than workers with elder care responsibilities in general. It is likely that our elder care interviewees reflect the demographic characteristics of those most likely to be willing to take the time to cooperate in an interview study. It is also possible that women, who are more typically seen and see themselves as caregivers and nurturers, are simply more interested than men in contributing to a study on caregiving.

In comparison with the total workforce, our sample of elder care interviewees from the qualitative study is more likely to be employed in professional-level positions. It should also be noted that professional-level workers are generally more likely than others to report having elder care responsibilities. It is possible that there is a greater share of professionals among those providing elder care because professional positions are more likely than other types of jobs to offer the flexibility needed to manage work and caregiving activities, and that employees without this flexibility might have had to quit their jobs.

In sum, while our sample of elder care interviewees in the qualitative study represents the broader population of workers with elder care responsibilities and the general workforce in several important aspects, it differs in certain other characteristics. Thus, the findings presented in this report should be considered exploratory.

Our findings, however, do offer important insights into the experiences of family caregivers at work, in medical settings and at home. And since no other study asks caregivers about their wishes for change, this study breaks new ground.

**FAMILY CAREGIVING: BACKGROUND**

**Finding: Women are more likely to be the recipients of care than men among this group of working caregivers**

The quantitative study reveals that 42% (or nearly 54.6 million employed Americans) of the workforce have provided elder care in the past five years and 17% are currently providing care. Since our study restricted caregiving to relatives or in-laws, it is not surprising to find that most provide, or have recently provided, care to this group. What is surprising is how often the recipient of the care is a woman—mothers (48%) or mothers-in-law (20%), followed by fathers (12%) and fathers-in-law (5%). It is not clear why this is the case, but it may relate to women's longer life expectancy.

**Table 2: Elderly family members receiving care by family caregivers**

<table>
<thead>
<tr>
<th>Relationship to family caregiver</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother</td>
<td>48%</td>
</tr>
<tr>
<td>Mother-in-law</td>
<td>20%</td>
</tr>
<tr>
<td>Father</td>
<td>12%</td>
</tr>
<tr>
<td>Father-in-law</td>
<td>5%</td>
</tr>
<tr>
<td>Grandmother</td>
<td>3%</td>
</tr>
<tr>
<td>Grandfather</td>
<td>3%</td>
</tr>
<tr>
<td>Other</td>
<td>9%</td>
</tr>
</tbody>
</table>

Source: The Elder Care Study, FWI, 2010; N=121
If the working caregiver was caring for more than one person, he or she was asked to select one person to talk about. Interestingly, we find that they tended to talk about people who are generally quite elderly.

- Three quarters of the elderly relatives cared for by participants in the qualitative study were age 75 and older.
- In fact, half were between the ages 75 and 85, with an average age of 80 years.

**Finding: Providing elder care tends to be a long-term commitment**

- Elder care providers in the qualitative study have provided elder care, on average, for just over four years (4.1 years).
- One in four (25%) have provided care for five years or more.

**Finding: Few working caregivers have paid assistance**

Family caregivers tend to provide all of the personal day-to-day care their elderly relative needs without help from paid caregivers, such as home health aides, nursing assistants, hospice workers or other paid assistants:

- Only one in four family caregivers currently providing care report that a significant amount of personal day-to-day care is provided by paid caregivers.
- Thus, three quarters (76%) of family caregivers rely solely on themselves and their families to care for their elderly relative.

**Finding: Many current working family caregivers in this study live near their aging relatives or in-laws**

- Nearly one in four working caregivers live with their elderly relative or in-law, either in the caregiver’s home (18%) or in the elderly person’s home (6%).
- An additional 52% live 20 minutes or less from the person for whom they are proving care.
- One in four live more than 20 minutes away.

**Figure 5: Distance of elder relative/in-law**

Source: The Elder Care Study, FWI, 2010; N=119
Finding: Most elders in this study live in their own homes

- Two thirds of the caregivers report that their relative or in-law lives in her or his own home.

**Figure 6: Living arrangement of elderly relative/in-law (not living with caregiver)**

- In her/his own home: 67%
- Nursing home: 13%
- Assisted living facility: 8%
- Relative's home: 1%
- Other arrangement: 12%

Source: The Elder Care Study, FWI, 2010.; N=53

In addition, elderly family members who passed away often still lived in their own home at the end of their lives:

- 50% of caregivers reported their elderly relatives lived in their own home during the last three months of their life.
- One in five caregivers report that the elderly family member lived in the caregiver’s home for some time during the last three months of her or his life.
- Near the end of life, however, living arrangements often change to include hospitalization or nursing homes. (See Table 3.)

**Table 3: Living arrangements during last three months of elder’s life**

<table>
<thead>
<tr>
<th>Type of living arrangement</th>
<th>% of elderly family members who lived in this type of arrangement during the last three months of life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Her/his own home</td>
<td>50%</td>
</tr>
<tr>
<td>Hospital</td>
<td>42%</td>
</tr>
<tr>
<td>Nursing home</td>
<td>37%</td>
</tr>
<tr>
<td>Caregiver’s home</td>
<td>21%</td>
</tr>
<tr>
<td>Assisted living facility</td>
<td>7%</td>
</tr>
<tr>
<td>Hospice facility</td>
<td>3%</td>
</tr>
</tbody>
</table>

Source: The Elder Care Study, FWI, 2010; N=56; caregivers could cite more than one arrangement.

Finding: The most frequent health conditions for this group of elders of current and former family caregivers are cardiovascular and neurological disorders

Family caregivers provide care and attention for a variety of health conditions of their elderly family members. Table 4 summarizes those most frequently cited. Many caregivers reported more than one condition:
• 55% cited only one primary health condition in their elderly relative.
• 30% reported two conditions.
• 15% reported three or more conditions.

**Table 4: Types of conditions for which family caregivers provide care**

<table>
<thead>
<tr>
<th>Type of Condition</th>
<th>Percentage of caregivers who provide care for this condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiovascular disorders, including heart disease, high blood pressure, stroke</td>
<td>20%</td>
</tr>
<tr>
<td>Neurological disorders, including Alzheimer’s, Parkinson’s, dementia, seizures</td>
<td>19%</td>
</tr>
<tr>
<td>Cancer</td>
<td>16%</td>
</tr>
<tr>
<td>Musculoskeletal disorders, including arthritis, joint disease, bone fractures</td>
<td>14%</td>
</tr>
<tr>
<td>General old age issues, including mobility, vision, hearing problems</td>
<td>12%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>5%</td>
</tr>
<tr>
<td>Mental health problems, including depression, psychiatric conditions</td>
<td>2%</td>
</tr>
<tr>
<td>Other types of conditions (e.g., respiratory disorders, renal disease, liver disease)</td>
<td>29%</td>
</tr>
</tbody>
</table>

Source: The Elder Care Study, FWI, 2010; N=121; caregivers could cite multiple conditions.

**Finding: Medicare and other medical insurance provide most of the coverage for these recipients of care**

The cost of care for elderly family members is paid for by a variety of arrangements. (See Table 5.)

**Table 5: Sources covering the financial cost of care**

<table>
<thead>
<tr>
<th>Source of funding</th>
<th>% whose elder care is paid for by this source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicare</td>
<td>60%</td>
</tr>
<tr>
<td>Other medical insurance</td>
<td>44%</td>
</tr>
<tr>
<td>Elder pays part</td>
<td>34%</td>
</tr>
<tr>
<td>Medicaid</td>
<td>8%</td>
</tr>
<tr>
<td>Long-term care insurance</td>
<td>8%</td>
</tr>
<tr>
<td>Financial contributions from a relative</td>
<td>8%</td>
</tr>
<tr>
<td>Elder pays all</td>
<td>4%</td>
</tr>
</tbody>
</table>

Source: The Elder Care Study, FWI, 2010; N=62; caregivers could indicate multiple sources of funding.
Finding: Almost half of these working caregivers help to cover the cost of care

In addition to providing in-person and indirect personal day-to-day and social-emotional care, family caregivers often contribute financially to their elderly relative's care:

• 48% report that they and/or their spouse help cover the cost of care for their elder.

• The majority of family caregivers who contribute financially to their elder’s care do not perceive this as a financial burden (59%).

• 27% of caregivers, however, perceive their financial contributions as somewhat of a burden, and 14% perceive this as a great burden.

These findings possibly reflect the fact that this sample of working caregivers is somewhat more advantaged than the general population of working caregivers.

Finding: Virtually all caregivers interviewed provide both direct, in-person care (99%) and indirect care (96%) that does not require direct contact

• The most frequent forms of direct care are emotional and social care (92%) and transportation (76%).

• The most frequent forms of indirect care are shopping (88%) and arranging services (68%).

Table 6: Types of direct and indirect care provided by family caregivers

<table>
<thead>
<tr>
<th>Type of direct/in-person care</th>
<th>% who provide this type of care</th>
<th>Types of indirect care</th>
<th>% who provide this type of care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional/social care (e.g., visiting, doing activities or going out together)</td>
<td>92%</td>
<td>Shopping</td>
<td>88%</td>
</tr>
<tr>
<td>Transportation (e.g., to medical appointments)</td>
<td>76%</td>
<td>Arranging for services</td>
<td>68%</td>
</tr>
<tr>
<td>Household work</td>
<td>69%</td>
<td>Overseeing medical care</td>
<td>66%</td>
</tr>
<tr>
<td>Meal preparation</td>
<td>48%</td>
<td>Handling finances</td>
<td>57%</td>
</tr>
<tr>
<td>Medical care</td>
<td>25%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dressing</td>
<td>24%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeding</td>
<td>9%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Toileting</td>
<td>8%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bathing</td>
<td>7%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other types of direct/in-person care</td>
<td>7%</td>
<td>Other types of indirect care</td>
<td>7%</td>
</tr>
<tr>
<td>No direct/in-person care provided</td>
<td>1%</td>
<td>No indirect type of care</td>
<td>3%</td>
</tr>
</tbody>
</table>

Source: The Elder Care Study, FWI, 2010; N=65; caregivers could cite more than one type of care.
Finding: The majority (52%) of working caregivers in this study provide hands-on in-person care every day or several times a week

This is no small feat, given that many family caregivers interviewed for the qualitative study work full-time schedules (65%) for an average of five workdays with 42 hours worked per week on average.

Recall that when taking into account part-time versus full-time status in the quantitative study, family caregivers worked just as many hours per week on average as the total workforce.

Figure 7: Frequency of direct/in-person care by family caregivers

![Frequency of direct/in-person care by family caregivers](image)

Source: The Elder Care Study, FWI, 2010; N=62

Finding: One third of working caregivers in this study provide indirect care every day or several times a week

Direct, in-person care tends to be provided more frequently by family caregivers than indirect care—presumably because many of these tasks (e.g., transportation, household work, meal preparation, medical care) are required more frequently than indirect care (e.g., handling finances, arranging for services).

Figure 8: Frequency of indirect care by family caregivers

![Frequency of indirect care by family caregivers](image)

Source: The Elder Care Study, FWI, 2010; N=62
As described above, findings from our quantitative study reveal that working caregivers provide five hours a week on direct care and 2.5 hours a week on indirect care, on average.

**OVERALL QUALITY OF FAMILY CAREGIVERS’ EXPERIENCES**

Finding: The majority of family caregivers find it very or somewhat difficult (61%) to manage caregiving with other responsibilities (e.g., work, child care)

As discussed above in the quantitative findings, most working caregivers (63%) feel that they don’t have enough time for themselves. Among the 43% who have children, almost three quarters (71%) feel that they don’t have enough time with their children. And among the 70 percent who are married or living with a partner, almost two thirds (63%) feel they don’t have enough time for these relationships.

- 61% of the working caregivers interviewed in the qualitative study report that it is very or somewhat difficult to manage caregiving responsibilities with everything else they have to do.

*Figure 9: Managing caregiving with other responsibilities is . . .*

![Bar chart showing the percentage of caregivers finding caregiving easy or difficult](chart)

Source: The Elder Care Study, FWI, 2010; N=104

Finding: For almost one in two caregivers, providing care affects their own care, leaving them with less time and resources to take care of themselves—for example, getting enough sleep, having a good diet, exercising or going to doctor appointments

- 44% of current and former family caregivers report that caregiving has had a negative impact on the way they take care of themselves, with 18% reporting a strong negative impact and 26% reporting somewhat of a negative impact.

Obviously, this is one of the costs that society is paying for how we manage aging—in many cases, the health of the caregivers is being compromised.

- On the other hand, the majority of current and former caregivers—57%—feel that caregiving has had little or no impact on how they take care of themselves, with 26% reporting very little negative impact and 31% reporting no negative impact at all.

Finding: Although all caregivers interviewed for this study report facing major challenges in caregiving, most also report positive aspects of their caregiving experience

Family caregivers describe a broad range of challenges—ranging from practical and logistical to social and emotional issues. These challenges are often grounded in the specifics of the
individual’s or family’s situation and, therefore, reflect a diverse range of experiences, as depicted below in the working caregivers’ words:

When her mind kind of goes on her—when she says something that doesn’t make sense, you kind of lose your patience. That’s the hardest thing—to realize that she is not the same as she was, and it’s a fact.

Getting quality of medical care [is my biggest challenge]. To make sure that he can get to the proper doctors, and not just be seen by anybody. He is blind in one eye, which was basically a mistake by an eye doctor. The doctor did some laser surgery and ruined his eye. So we need good doctors to make sure no one is messing with his [good] eye and that they monitor him very closely because we don’t want him to lose vision in that eye, too.

[H]e gets calls or junk mail coming in asking for money for this or that—some financial scams. And there has been a situation where he has signed up three different times for an extended warranty on his car, which already has a warranty ... One time I was away on vacation and he signed up to another one to the tune of $2,500 and luckily I found the note that he had done this, and again I had to take care of it and get him out of it.

The biggest challenges were working and trying to take care of her at home, and that she couldn’t talk—that was frustrating. I would have rather spent more time caring for her than working. One thing about my mother is that she was always smiling, even though she didn’t talk. And you would be stressed, but seeing her smile would calm me down. I mean you don’t understand why they have to go through it but—I think it helped me—because when it seemed like she was happy, it made me feel better.

Finding: The top challenge for many family caregivers is managing their relationship with their elderly relative—striking a balance between dependence and independence, getting the elderly relative to accept help and embrace a positive or cooperative attitude

When asked about their major challenges in caregiving, about one third of family caregivers note that challenges that pertain to their relationship with the elder and her or his attitude toward caregiving and the aging process. These challenges mainly include:

- striking a balance between the elder’s desire for independence and their need to accept help from others;
- managing a reversal of parent-child roles, getting the elder to accept such role reversal; and
- overcoming resistance and “stubbornness” on part of the elder—for example, getting her or him to cooperate with caregivers, take medications, etc.

Here are some of the comments of the working caregivers we interviewed:

I think the hardest thing for me is drawing that line between the dependence and independence. Trying to make him do everything he can do for himself, but wanting to make sure that he gets everything he needs.

[My challenge is] wanting her to have as much independence as she can, but wanting her to be safe. It’s a real struggle. She wants to handle her own medical things, but she forgets appointments and gets confused. It’s a struggle.
I think she is very frustrated with not being able to do things, and I think she gets quite angry that she is not able to do them. Sometimes if she doesn’t want to wait for it to be done for her, she will try and take on projects by herself. I live in fear that she is going to try to go across the street and go shopping, and I don’t want her crossing the street, wandering around—in case she falls. You can’t be everywhere 100% of the time, so I don’t want her to do these things, and that produces a great deal of tension.

Oh, boy. He’s getting more difficult, stubborn to deal with, set in his ways and it has to be [his] way, right away!

Finding: Time management is a major challenge for many working caregivers—especially those with other family responsibilities; caregivers report feeling “guilty” when they are not available or able to spend as much time with their elder as needed or desired

Given that many working caregivers in this study have other family responsibilities, it comes as no surprise that time management ranks among the top challenges. Many note that it is a “struggle” or “juggle” to fit caregiving activities into busy work schedules and other family activities. When it is impossible to do so, some caregivers experience a sense of “guilt” for not spending enough time with their elder or for not being there when they are needed.

Guilt if I can’t be there [is a major challenge]. There are times when I want my life, and then I think she is going to judge me if it’s not a valid thing for me to be doing. There is a lot of fear that she is going to die and I am going to feel like I didn’t do enough.

I guess trying to make conversation, to visit with her while I am there, rather than just run in quickly and give her her medicine and run out. I feel guilty about that, but I am so busy with work and I have a child at home.

Well, I have a full-time job, so it makes it a little harder. I get very tired. And in the middle of this I’m trying to clean out her house so we can sell it. Just managing all I have to do [is my major challenge].

Finding: Many caregivers experience managing the various aspects of care as challenging

As noted before, family caregivers often provide a variety of care. These activities encompass a wide range of tasks and responsibilities, including hands-on, in-person care (e.g., feeding, bathing, performing housework, providing transportation to doctor appointments, etc.) and care that does not require direct care (e.g., arranging for doctor appointments and other services, managing finances, etc.).

Needless to say, managing and keeping track of various care activities and responsibilities is a challenge for many family caregivers. The need to “stay on top of things” related to elder care becomes particularly challenging when caregivers face responsibilities in other domains of their life that demand both their time, their attention and their energy.

Specific care activities that often present challenges to family caregivers include:

• coordinating and overseeing medical care;

• managing and/or overseeing day-to-day care, including diet, medication, hygiene, household chores;

• managing finances; and
• keeping their elder safe—e.g., from falling down, exceeding her or his capabilities, falling for scam artists, etc.

Specific obstacles to managing care activities include:

• distance, if the caregiver does not live nearby; it means increased travel time and expenses, which is especially problematic if the caregivers do not have access to a car or enough money for gas;

• strained relationships with, or lack of support from, other family members;

• difficult communication and decision-making processes with the elder and/or others involved in caregiving; and

• financial constraints (e.g., caregiver has difficulty paying expenses for care, high gas prices).

[We have] communication challenges—communication with him, communication with other family members not involved in the care, explaining things. [We also have] challenges with the care that he is receiving, and communication issues with the people involved in his care—trying to get as much accomplished with where he is so we don’t have to move him elsewhere. Basically all aspects of coordinating his care.

Just keeping track of everything [is a challenge]—the doctor visits, his eating, the nutrition, combined with the medicine and getting him to the doctor and following up with the doctor’s instructions.

Finding: Watching an elderly family member’s health decline throughout the caregiving process can be an emotionally challenging experience for caregivers.

Providing hands-on, in-person care means that the caregiver has a front row seat as their elderly relative’s physical or mental condition declines. Many working caregivers describe this as an emotionally wrenching experience—one that may confront them with difficult questions about their own aging process and mortality.

I think the hardest thing is watching her decline in health. My husband went to get our camera pictures on a CD, and I look at pictures of my mother from last year, and compared to how she looks today, it is such a change. In one year! It makes you start thinking about your own mortality. And sometimes you go through your day-to-day and you don’t realize how things are changing until you look at the points in time and see it.

The disease itself—the memory loss, the debilitation, the emotional detachment—that’s probably the most difficult. And the frightening awareness of that—this is what the end looks like for some people. It’s not a pleasant way to go, and, hopefully, they will find a cure down the road.

She is at the point where she doesn’t really talk—she sits and stares, which is also hard to see. She still knows who I am, but it will be so hard when she doesn’t. I think it is hard knowing how active she used to be and what she used to be like and seeing her so inactive now.

Finding: Among the positives of caregiving, by far the most frequently reported aspect is the opportunity to spend time with the elderly person and develop a closer relationship
In spite of the challenges and frustration that are often inherent in caregiving, many working caregivers report appreciating the opportunity to spend time with their elderly relatives, getting to know them better and establishing a closer relationship.

Many say it simply feels good knowing the help they are providing has a positive impact on the elderly person's life. They report deriving satisfaction from being able to help their elder—especially when it means they can avoid institutional care.

I get to see her and I know she is healthier and happier [because of this]. I know she is safe and that gives me peace of mind, and I can help her so that she can get older with dignity. It is hard because I have a full-time job and a child, but I can't imagine doing it differently.

Oh, I love her and it brings me joy when I cook the things that she likes and she enjoys it so much. I just love her, and want to do what I can for her.

We are a very close family, so just being with him and spending the time with him that I do. And us going as a family to breakfast and stuff, that's good for our whole family, not just good for him. To be there for each other and for him. Mainly we did it for him, but it is good for all of us.

Many working caregivers specifically point out that helping their family members stay in their own homes and avoiding a nursing home is an important positive aspect. The better quality of life elderly people enjoy in private homes represents a source of satisfaction and pride for their caregivers. The fact that this theme emerged again and again speaks volumes about people's perceptions of nursing homes and other institutionalized settings for the elderly. Avoiding these settings at all costs appears to be a major source of motivation for working caregivers.

Knowing that she is not in a nursing home, knowing that there is no one harming her, no one taking advantage of her. Because there is a lot of that when you turn over care. It is awful. I work in that industry, and the stories are horrifying, so knowing that she is safe in her own home—those are the comforts. And knowing that I can do everything I can for her.

Finding: The reversal of parent-child roles, which family caregivers often report to be challenging, also reflects a positive aspect of the caregiving experience

Interestingly, the reversal of traditional caregiving roles (e.g., parent-child) appears to be both challenging and satisfying at the same time. Many working caregivers report they derive satisfaction from fulfilling a sense of duty toward their elderly relative, repaying them, in a sense, for the things the elderly person had done for the caregiver earlier in life. This theme especially emerged in cases where care is provided to an elderly parent.

[Positive aspects include] just listening to his stories and hearing his experiences. He takes me back to a place where I can now appreciate all the things he did for me when I was a little girl, and didn’t think twice about them then. Now I see all the things he did.

There is a nice side to it—the opportunity to do some things for him. He took care of me for a long time. The opportunity to show a gentle love for him is satisfying.

Finding: Working caregivers also value the learning opportunities that come from their caregiving experiences
In addition to the intrinsic and emotional satisfaction family caregivers derive from spending time with their elder and improving their quality of life, many report that caregiving has allowed them to garner new insights on various aspects of the aging process. These include:

- the importance of planning ahead for the aging process—in other words, caregiving has spurred caregivers to think about how they themselves would like to age and be cared for down the road;
- gaining medical knowledge and experience with the health care system; and
- learning to be more patient and grow as a person.

"It has helped me in a lot of ways as a person, to understand people and be more empathetic and less judgmental."

"Positive aspects are understanding the process of aging and being more aware of planning for ourselves in the future."

"I’ve learned a lot about medical stuff, like what to look out for. We went for genetic testing, my sister and I, and neither of us carry the breast/ovarian cancer gene. I think I’ve learned don’t go by what the doctors say. You have to question on your own. I’ve learned a lot about preventative care and different medical things."

Finding: Witnessing the decline and suffering of a loved one at the end of life was particularly challenging for many former family caregivers; on the positive side, many report perceiving their relative’s passing ultimately as a “relief” from suffering and taking comfort in religious or spiritual perspectives on death.

Former family caregivers whose elderly relative has passed away recount many of the same challenges and positives feelings as those currently providing care to an elderly family member. There are some unique challenges and positives, however, around end-of-life caregiving and the elder’s death.

- The challenge of watching a loved one’s condition decline becomes more difficult near the end of the elder’s life.
- Many, however, perceive their relative’s death as a form of “relief”—ultimately, this often becomes a positive aspect of the end-of-life care experience.
- Spiritual or religious aspects of death are salient as positives in the end-of-life care experience.

"When she passed away, I was waiting for this overwhelming grief [but] I had experienced it about six months prior when she was having problems with her kidneys, and they were talking about pulling hospice in and it was so bad I spent the weekend in the hospital. I felt like I almost said goodbye to her then, and over the next six months, I felt like I slowly said goodbye to her, and my daughter felt the same way. It wasn’t like it was a shock, like when someone dies in an accident. She had been declining over that entire time and it was just ... it hurt, but we knew it was coming."

"The hardest part was to realize that she was never going to get back to her old self ... and it was ... I don’t want to say a relief, but ... the only positive thing I can say is that she had a full life. She wasn’t ready to die, I don’t want to say that, but she was as cheerful as she could be until the end. She was a fighter, so in that respect it
was positive. But it was also very depressing when you lose someone that you love, so I would say it’s both aspects of it. A mixed experience.

I would have to say it was more positive, though it was very difficult. It is very hard to see your parent hurt, to see your parent not be able to do the things she could do and yet it was encouraging because she didn’t complain and just did everything she could to maintain as much independence as she could. I am a Christian, and I know she is not hurting anymore. So that is very positive too, to know that you can get through the pain and there is better ahead.

My mother was a very positive person and had great faith in God, and never complained even though we could tell through her face that she maybe wasn’t feeling well. She was a great example for us and that was very positive to me and uplifting because it must have been very difficult for her to endure what she did without complaining. I’m sure I would be the biggest complainer around! So she encouraged us and was a great example for us, and it gave you a wonderful satisfaction that you were helping somebody else.

Finding: Compared with working caregivers who currently provide care to an elderly relative or in-law, working caregivers whose elderly relative has passed away have a different perspective on the quality of their relationship with that person—they are much more likely than those currently providing to say that the relationship had changed for the better as a result of caregiving

Family caregivers currently providing elder care are less likely to report any change in the relationship with their elderly relative than family caregivers whose elderly relative has passed away:

• 45% of current caregivers say there has been no change in the relationship compared with only 16% of former caregivers.

• Just over one in five current caregivers (22%), however, note a change in the nature of the relationship—a role reversal in the parent-child relationship, for example—rather than a change in the quality of the relationship per se.

• Relatively few current family caregivers note that their relationship with the person they care for has improved as a result of the caregiving experience (14%).

• The percentage of family caregivers who say caregiving has improved the relationship with their elderly relative, however, increases dramatically among caregivers whose elder has died—60% of former caregivers say caregiving improved their relationship with the elderly relative.

It appears that the death of the elder alters caregivers’ perspective on the caregiving experience and its impact on their relationship. It is possible that the demands and challenges of family caregiving may negatively impact the caregiver’s perception of the relationship with the elder during the caregiving experience. Quite possibly, caregivers do not have enough time or mental resources to reflect on the caregiving experience and the relationship with the care recipient until after the caregiving experience is over. The grieving process can thus be seen as a healing process.
Finding: Overall, a majority (58%) of working caregivers characterize their end-of-life care experience as positive

In spite of the many challenges they faced while caring for an elderly relative at the end of her or his life, most family caregivers at some point after the elder’s death feel the experience has been positive. This can be especially true if they have family support or caregiving support such as hospice. A substantial proportion of former family caregivers (12%), however, report less-than-positive experiences. (See Figure 11.)

**EXPERIENCES AT WORK**

Finding: The majority of family caregivers report that their caregiving interferes with their work responsibilities—and nearly a quarter report this interference has had a negative impact at work

As discussed above, in the quantitative study, we find that 42% of women and 49% of men experience some or a lot of work-life conflict.
In the qualitative study, we find that workers with current elder care responsibilities and those whose elder has passed away are equally likely to report that their caregiving responsibilities often or sometimes interfere or interfered with their work responsibilities:

- 54% of workers currently engaged in family caregiving and 59% of those whose caregiving experiences have ended report interference between caregiving and work.

- Further, both groups report experiencing negative impact at work as a result of this interference—one in five current family caregivers (22%) and one in four former family caregivers (27%) report so.

To summarize the data reported from the 2008 NSCW, we find that working caregivers work an average of 45 hours per week—similar to those interviewed a second time for the qualitative study (42 hours per week) and to those in the workforce without elder care responsibilities (44 hours per week). We also find that the majority of family caregivers in general (55%) indicated that they would prefer to work fewer hours. But only one in four (23%) actually reduced their work hours or took a break from work (15%) to care for their elder. The 2008 NSCW also reveals that most workers (64%) found their employer very helpful, while 10% found their employer not helpful. In addition, the 2008 NSCW reveals that 48% lost income for the time they took off for elder care responsibilities.

In the qualitative study, we are able to probe more deeply into their experiences.

**Finding: In most cases, family caregivers interviewed for this study report that their co-workers are aware and supportive of their caregiving responsibilities; workplace policies, rules and attitudes of managers, however, are less likely to be perceived as helpful**

The vast majority of workers interviewed for this study report that their co-workers are, or were, aware of their caregiving responsibilities—95% of current family caregivers and 87% of former family caregivers say so.

- Impressively, current and former family caregivers almost universally report that they got the support they needed from their co-workers during their caregiving experience—95% of current and 98% of former caregivers.

Both current and former family caregivers, however, are somewhat less likely to report that the policies, rules and attitudes of managers at work were helpful during the caregiving experience:

- Overall, 77% of workers with elder care responsibilities (82% of current and 69% of former caregivers) feel managers and organizational policies have been helpful.

- Nearly one in four (24% of current and former caregivers) say these workplace characteristics made it more difficult for them to manage their work and caregiving responsibilities.

Clearly, there is room for improvement when it comes to the ways in which workplaces support a substantial and growing proportion of workers with family caregiving responsibilities. Given that 51% of the workforce expect to take on new family caregiving responsibilities in the next five years, these are issues that should be addressed. In this study, we had a unique opportunity: to ask caregivers themselves for their “one wish” for change in how workplaces can better support them.
“ONE WISH”—CHANGES IN THE WAY WORKPLACES SUPPORT FAMILY CAREGIVERS

The top three changes working caregivers wish for at work are:

• greater schedule flexibility and options for managing time;
• time off, especially paid time off, without having to use up vacation time; and
• more understanding of their situation from management.

Finding: Working caregivers want greater flexibility to manage both work and caregiving responsibilities

Family caregivers most frequently wish for more flexibility at work—especially with respect to scheduling regular hours, making short-notice schedule changes, taking time off during the workday to attend to caregiving-related matters (e.g., phone calls), reduced schedules and compressed workweeks. Some family caregivers wish they could work from home to gain additional time for work and caregiving responsibilities by saving on commuting time.

I worked for a retail company at that time, and they didn’t like you taking off time for family. They didn’t care about family problems or family illness. You were there to do a job, and that was it. So I hope that workplaces would be more understanding. I wish that could change—that they would be more understanding that people have family things like they are where I [now] work.

They should allow people time to do some personal things and they will get a better worker.

You want to know if I would change one thing? For them to be more cooperative, that’s all. Sometimes I run into the freezer [at my workplace] or bathroom to answer [my cell] phone, which is ridiculous.

There’s a lot of lip service paid to “we understand people have families” … but the policies—when they come right down to it—aren’t there to support it.

Finding: Family caregivers want time off—especially paid time off without having to use up vacation or personal days—to help them care for their elderly family members

Many working caregivers report that it is difficult for them to take days off when needed to care for their elderly family member—they may either lose pay or have to use paid vacation days or personal time. Some expressed a desire to have opportunities to make up for lost income when they take unpaid time off for elder care responsibilities. Others regret that they have to use up their vacation days because this leaves them with little or no time available to actually take a vacation and recuperate from the demands of their work and caregiving responsibilities. Still others expressed a desire to have paid sick days specifically to care for ill family members.

Working caregivers also expressed a desire for less paperwork or bureaucratic hurdles when it comes to taking time off. Several caregivers noted that the need to take time off for elder care often arises at short notice or on an emergency basis—thus, they wished for the ability to take time off at short notice without negative repercussions, such as jeopardizing their job or losing pay. For others, the federal law that covers family and medical leave, the Family and Medical Leave Act (FMLA), didn’t help them much because 1) their organization did not meet the law’s eligibility standards—such as having 50 employees at their worksite or within a 75
mile radius—and was not required to comply; 2) their employer required them to use up their vacation time before using FMLA leave; or 3) the employee didn’t meet the law’s requirements (such as requiring that the elder has in-patient care in a hospital, hospice or residential care facility, or continuing treatment by a health care provider).

The one thing that I don’t like is that before I can use my Family and Medical Leave, I have got to use my earned vacation. I would change that. I earn two days a month of vacation, and if I have not used it, then I have to use them for Family and Medical Leave.

[I wish] that I could take FMLA to care for my grandfather. When I went to talk to [the HR manager] about my grandfather, she said, “Well, you know, grandparents aren’t covered under FMLA.”

Where I work you have to use whatever personal days or vacation days you have if you request time off, no matter what it is for. It is not like I would have an option to say I don’t want to use that time or to be paid for this time off—they just take it off of your vacation or personal time. So, maybe being able to take time off without using those days so you can actually take a vacation.

I’d like a vacation. I haven’t really had a vacation for a couple of years, actually, with the situation with my mother, and now I’m taking care of [my father too]. It would be nice to get away for a week and not have to worry about doing any work, or any cooking, cleaning, laundry. Sleep in bed til noon or whenever.

Finding: Family caregivers want more understanding for their situation from management

The third most wished-for change is more understanding for working caregivers’ situation—especially on the part of management. Several caregivers noted that managers and colleagues just can’t seem to understand or empathize with their caregiving experiences and the challenges they face at home.

Understanding that everybody is going to get old someday.

They should all be more lenient with some things. Like not being allowed to have our cell phones on us. I tell them I don’t care—I’m going to have it on me because I have to have it ... I’m going to answer my cell phone. [My boss] said, “Well, just don’t let the big boss see you.” But what am I going to do? They should all know that if you have a problem with a parent you have to be on the ready to go. Upper management needs to understand that.

Finding: In addition to greater flexibility, time off and understanding from management, family caregivers have a range of other wishes—including adult day care at work, extra assistance to cope with their workload and better insurance options for part-time workers

Some working caregivers note that it would be nice if companies had on-site adult day care facilities—similar to the concept of on-site child care—that would allow them to have their elderly family member nearby and cared for while they are at work.

Further, some caregivers wish they could reduce their workload or get extra assistance or more time to complete their tasks. For example, one teacher expressed a desire to have colleagues’ assistance to complete grading responsibilities, which are usually relegated to evenings and weekends when he needs to attend to his elderly relative.
Working caregivers also wish for better health insurance options for part-time workers. Recall that caregivers interviewed for this study are more likely to be employed part-time than the workforce in general. Part-time employment, unfortunately, often means workers are ineligible for insurance or have only limited coverage available to them.

EXPERIENCES WITHIN THE FAMILY

Finding: Caregiving is a family affair—most family caregivers have help from others in their families in caring for their elderly relative; the levels of help and support provided by other family members, however, may fall short of the primary caregiver’s needs and expectations.

Among family caregivers currently providing care, most have help from family members:

- 86% report having help from other family members.
- Only about one in ten (11%) report that their families do not help them with providing elder care.
- A small percentage (3%) do not have any other family members who could help with caregiving.

Help from other family members, however, may fall short of the caregiver’s expectations or needs:

- About half (49%) of current family caregivers say other family members who provide care do not help as much as they would like them to, and 7% say the level of help provided by others in the family varies.
- On the other hand, hindsight appears to shift these views: 76% of former family caregivers whose elder has passed away report that they received the help and support they needed from others in the family.

Finding: Women are more likely than men to be the ones taking the greatest responsibility for the care of their elderly relative

According to both women and men, women take the greatest responsibility in caring for their elderly relative including in-laws. We have found in other studies that people tend to define “responsibility” not just in terms of actually providing care, but also in terms of taking psychological responsibility—feeling that “I am in charge.” This finding is shown in Figure 12.
Gender roles influence family members’ expectations when it comes to providing care for an elderly relative—women are often expected to take on more responsibility than men.

- Uneven patterns of sharing care responsibilities within families—with women carrying more than their share—are often left unchallenged because they tend to conform to expected gender roles, with women cast as “nurturers” or the more “caring” ones.

- This inequitable distribution of caregiving responsibility within families can be a source of frustration for female caregivers who would like more help from their male relatives in caring for their elder.

  *I get frustrated with my brothers for not helping out more, but I guess it is the attitude that women are the nurturers.*

  *Sometimes I feel like [my brother] could help more, but I don’t know how to describe it. He’s a man I guess, and I’m the woman, so I think that women are more caring. The other thing I think is that he can help, to be honest, so sometimes I feel a bit overwhelmed with everything going on with my mom and he doesn’t help, and sometimes I wish he helped. But I don’t make an argument, I have to do what I have to do and that’s it.*

**Finding:** Working together or supporting each other in caring for an elderly relative can draw family members closer together, and a lack of help or support can undermine relationships; there appears to be little overall change, however, in the nature of family relationships—strained relationships remain strained, while good relationships remain good.

Caring for an elderly relative can be a real challenge for family relationships, testing good relationships and straining poor ones.

*It brought us together, but we had many arguments about the sale of her house, what she should do and what would be best for her—so there was a lot of stress involved. We all came to a meeting of the minds, but not without a lot of ... I can’t even give you the words ... a lot of anxiety involved and arguments. Not that we didn’t...*
love each other and everyone had their point of view. When you have a larger family, everyone has things to offer, and we were all struggling with what the right thing would be for my parents. I have two brothers and a sister, and we all tried to help my mother in the ways that we could. We are a close family and that helped tremendously, but it was hard. I was the only one that lived down south with my mother, so the burden really fell to me as far as being there for my mom. The rest lived out of state, but they did what they could.

Well, it was very negative after my mom died. I got angry at my sister—when my mother was on her deathbed the last day, my sister (the one who didn’t help out) went and took the jewelry my mom said she could have, before my mother died. I didn’t talk to her for quite a while after that. We’re finally now on talking terms.

Caregiving experiences may also potentially strengthen family relationships, drawing family members together around a common purpose. It appears, however, that this is more likely to occur when family relationships are generally strong or close before the caregiving experience.

It’s definitely brought us closer and shown everyone that we all support one another and will be there for one another. Having such a close-knit family makes it easier to do it all.

It brought us together. Everyone kind of knew what the situation was, so everyone worked together really well to make this process go as smoothly as possible despite the circumstances.

We all work real well together. We all help out as much as needed, and it’s brought us really close. We are all in different states raising our families, and the whole trauma of losing my mother and figuring out what to do with my dad and how to get everything taken care of, we’ve all—you hear about families fighting but we have done the opposite—[we all] have done a great job about caring for each other and making sure no one’s feelings are hurt. I know we see each other more than we did and we talk much more, especially my sister and I. And we have something in common that we cherish. We realize what we have with each other, I guess.

Understanding and empathy for other family members’ situations are important in preserving family relationships during a caregiving experience.

My sister-in-law, she did as much as she could. She had two young children, one with special needs, so it was challenging for her, but she stepped in as often as she could. My brother-in-law, not so much. They weren’t living nearby, so it didn’t work as well for them, but they tried when they could. We felt fairly supported, but it’s just hard. People have their lives, you know. I understand that.

Finding: Family caregivers’ relationships with their immediate family—spouses/partners and children—may suffer as a result of their caregiving

Not surprisingly, the time and energy involved in caring for an elderly relative implies that the caregiver has less time and energy available for other family activities. This can be a strain for the caregivers’ relationships with their immediate families, including their spouses and children.
Well, it’s just my wife and I managing it. And basically, it’s forced us to put our relationship on the back burner. Between work and caring for them and everything else, our relationship is last. It is the last thing on the list and it does affect the relationship, straining it a little; but logically, you know why it is happening and understand that it’s just something you have to deal with for now.

My husband has been really supportive, though sometimes it’s hard for my daughter if she wants to do something with me and I need to visit my mom. I try to remind her that Grandma won’t be around forever, and I need to spend time with her while I can.

Caring for my dad has brought me closer to my parents and my brother, but it has caused some strain within my immediate family here just because of the extra time and things caring for him that take away from things I may need to be doing for them.

“ONE WISH”—CHANGES IN THE WAY FAMILIES SUPPORT THEIR FAMILY CAREGIVERS

Finding: When it comes to support from other family members, caregivers have only one wish—more active involvement and help from others in the family in caring for their elderly relative.

Insights from our interviews suggest that caring for an elderly relative can be a difficult, complex and time-consuming responsibility—one that is not easily fulfilled by just one person. Caregiving should, thus, be viewed as a family responsibility. In reality, however, the lion’s share of caregiving tends to fall to one individual, and support from other family members falls short:

- 46% of current family caregivers report that they take on most of the responsibility.
- 44% of primary caregivers report that other family members who help with caregiving do not help as much as the main caregiver would like.

It’s not surprising, therefore, that many family caregivers express a desire for other family members to be more actively involved in caring for their elderly relatives—be it by simply visiting more, by communicating more frequently or by helping out with certain tasks.

- Some caregivers express a desire for a more structured approach to elder care within the family, for example, by rotating responsibilities and schedules of care activities.
- Sometimes, family caregivers wish that others in the family lived closer by, so that they could be more actively involved in providing care to their elderly relative.
- Caregivers also express a need for greater emotional support for themselves by other family members—this might include simply listening to the caregiver “whine” about or discuss the challenges of caregiving.
- In a similar vein, some caregivers say they wish other family members would stop criticizing them for the things they do to provide care and show some respect or appreciation for the caregiver.

It would be nice to have somebody to share the decision-making process over medical care and where he is going to be placed, or his finances, and that type of thing.
It’s nicer to have more than one person. It would have been nice if someone could have taken medical care, someone could have taken social activities and such, and someone could have taken finances, or his placement, rather than one person dealing with all of it. Splitting it up … would have been better for him because he would have [had] more interactions with people.

I think there were people that could have stepped up a little more. I was so busy and overwhelmed at the time I didn’t think about it—I didn’t think about that aspect until afterwards. I would have made a schedule and made sure that other people were there to help out, and that the burden wasn’t so much on me, because it was very wearing.

I guess [my wish] would be chip in if you can, and if you can’t, don’t criticize what I do. It’s very hurtful.

[I wished] that they would have helped me, to relieve me. I mean, it wasn’t stressful to take care of her, it was just stressful because of having to work and take care of her at the same time.

I would have liked some emotional support—a phone call now and again, a letter; a visit. They knew that she was difficult.

If I had my way and if it were possible that they lived closer, they could have spent more time with her. There were times when she didn’t recognize anyone, but that was OK. I think maybe she could have used visits from all her other children.

Obviously, sharing care for elders is a complex issue, just as it is with children, where people want help but then sometimes act as gatekeepers or have trouble if someone else handles an issue differently than the caregiver might. It is possible that if we had happened to interview other members of the same families, they might have told us a similar story: that others didn’t help out as much as they would have liked. Caveats aside, these sometimes wrenching experiences point to a difficult reality in caring for an elderly relative, and it is clear that elder care works best when families share the care and communicate well.

**EXPERIENCES WITH THE HEALTH CARE SYSTEM AND PROFESSIONAL PROVIDERS**

**Finding:** Overall, family caregivers’ satisfaction with the quality of health care for their elderly relative and the quality of communication with health care professionals is mixed

Figure 13 summarizes family caregivers’ perceptions about the overall quality of health care their elderly relative receives. Although about one third (36%) of family caregivers perceive their elder’s health care as excellent, these numbers do suggest that there is some room for improvement, with about half (53%) of caregivers reporting that their elder’s health care is “pretty good” and about one in ten (12%) reporting that their health care falls short.

One might expect a relationship between overall quality of health care received by the elder and the caregivers’ family income. Our data, however, do not indicate a significant relationship between these factors.
When it comes to communication with health care professionals involved in their elderly relative's care, most family caregivers report that they generally have good communication with these professionals. Yet, about one in five (21%) of caregivers have mixed feelings about the quality of communication with health care professionals, suggesting again some room for improvement. A relatively small percentage (6%) believes the quality of communication with health care professionals is poor.

One source of frustration for family caregivers in communicating with health care professionals involves the condescending attitudes with which health care professionals sometimes treat family caregivers. Family caregivers would like to be educated and informed about their loved one's medical care. As these working caregivers see it, health care professionals do not always make enough effort to talk with relatives and explain things—whether this is due to a lack of time, a lack of respect for the relatives’ capacity to understand medical information, or a lack of skill to have these conversations that can be difficult.

A slightly larger percentage of former family caregivers whose elderly relative died than current caregivers report dissatisfaction or mixed feelings about the level of support they
received from health care professionals. As depicted in Figure 15 below, about two thirds feel that they received adequate support from health care professionals—leaving one third feeling that communication could have been better.

**Figure 15:** Former family caregivers’ perceptions as to whether they received the support they needed from health care professionals in caring for their elder

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>Mixed</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent</td>
<td>66%</td>
<td>20%</td>
<td>14%</td>
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Source: The Elder Care Study, FWI, 2010; N=54

A common theme of problems reported by former family caregivers centers around the quality of care their elderly relatives received in nursing homes. These problems generally included:

- not enough staff;
- staff who is overworked, not sufficiently skilled, or perceived as uncaring; and
- insufficient physical therapy and other care.

*When she was in the nursing home, I stopped working because it is really bad, you just must—if you have anyone in the nursing home—you must be there and let them see you there.*

One of the most alarming findings in our survey is that a relatively high percentage—36%—of former family caregivers whose elder has passed away report that medical mistakes were made by professionals involved in caring for their loved ones. In some cases, family caregivers believe that these medical mistakes were severe enough to contribute to their relative’s death.

Medical mistakes reported by former family caregivers include:

- misdiagnoses, lack of effort to develop correct diagnosis;
- problems with treatment, e.g., wrong medication, too much radiation, surgical mistakes; and
- releases from hospitals that were too soon.

*I think she had been misdiagnosed on a lot of things. They had done several tests on her lungs to see if she had cancer. They even lost one test. It just seemed to me she wasn’t an important [person] here. She was more or less like the guinea pig they were just trying stuff on. They just didn’t really give us any answers. They would do tests and do tests—they’d say, “Well, we’d better do this test,” and “We’ve got to do that test,” and she was going through a lot. In my opinion, a lot of the doctors—I’m not trying to be mean or anything—but in my opinion, a lot of the doctors are out for*
how much money they can make and not for the patient. They don't take the time to find out exactly what's wrong with the person. And that ends up in the person suffering a lot and eventually dying or they just don't have any care at all.

Overall, stories shared by family caregivers throughout this survey suggest that the caregivers need to be actively involved in the health care of their elderly family member and become advocates on their behalf to ensure a high quality level of medical care.

I think the fact that there was always someone there made a difference, and my mother’s sister was a nurse. When you can’t use your own voice [as was the case with my mother], you need someone there.

On a number of occasions she was in the ER because she had collapsed and had to call an ambulance. At the ER, they just want to patch you up and send you home, and we kept telling them she needs more care than this—you need to get to the root of this problem. This has happened four times already this month. Something is wrong. I thought that was wrong—having the mind[set] that we just want to get [patients] through here. Get them out. Get them out. They should have admitted [her] and done tests once they realized it was a chronic condition, and that did not happen. And when they did realize after our urging—she was in the hospital for about a month. She was really ill. That’s when the doctor said, “Take her home and let her die.” That would have happened to her if she didn’t have kids that cared about her enough. We advocated and pushed for the surgery because we knew that is how she felt about it. But those last few months of her life would have been horrible. She would have been in agony, living on Morphine, and that didn’t happen because we pushed for the surgery.

I was walking past a room [in my friend’s nursing home] and the side rails were down and the patient fell out of bed. And of course, I can’t touch them, and there were aides walking by that didn’t stop. I turned around and said, “Do you hear her calling you? She is on the floor.” And then they ran back and got her. But I mean they walked by the room, totally ignoring the fact she was saying “Help me” on the floor and everything. With my friend, we had no problems, but I think that was because I visited her quite often.

“ONE WISH”—CHANGES IN THE WAY DOCTORS, NURSES AND OTHERS IN THE HEALTH CARE SYSTEM SUPPORT FAMILY CAREGIVERS

Family caregivers’ top wishes for ways in which health care professionals and staff could better support them in caring for their elderly relatives include:

• better two-way communication with doctors;

• less overworked, more compassionate caregiving staff with the skills to listen and learn from the caregivers and the elders; and

• a more user-friendly and easily navigable health care system, especially with respect to managing cost and insurance issues.

Finding: By far the most common wish among family caregivers is for better two-way communication with health care providers—that they take more time to explain things and listen to patients and their family caregivers.
Although almost three quarters (73%) of family caregivers interviewed for this study report having good communication with their elder’s health care providers, a wish for better communication with doctors and other health care professionals clearly emerged as a top priority—suggesting that communication between health care providers, their patients and caregivers remains a critical concern and an area in need of reform.

Specifically, working caregivers voice frustration that doctors often seem rushed, taking little time to explain things or to listen to patients and their caregivers. They feel as if doctors mainly focus on the elder as a collection of “organs” without considering them as whole people with emotions. Many caregivers attributed this to a general sense of overwork among doctors and health care providers—it seems that many simply do not have the time, or even perhaps the skills, to engage in meaningful and constructive conversations with patients and caregivers. Thus, family caregivers express a wish for less overworked, more engaged health care providers who do take the time and have the skills to explain and listen.

I would say physicians need to listen better to what the families and patients are saying. I think that doctors in general don’t spend as much time listening what the patient’s needs are. They will really focus more on the hypertension or leg ulcer or the liver function test and not so much the depression, anxiety or whatever is really part of the whole care, but sometimes is not as focused on because it takes more time, and unfortunately, the way the health care reimbursement is set up, they don’t have the time to spend with the people.

[My wish is] I guess to spend more time with the families. The medical care professionals are so busy, so rushed. I really noticed that. They had more people than they could give attention [to] ... Nobody has time to check on all the patients and check in with the families. It’s just the way we’ve created our medical system to be. It is overloaded.

In addition, family caregivers often complain that doctors seem simply unwilling to listen or respect their patients’ and caregivers’ intelligence. Many express a wish for more respectful treatment and less condescending attitudes on the part of some doctors.

I wish her primary care physician would have listened to her more honestly instead of just thinking, “Oh, it’s just an old woman—her time’s about up, anyway.” I just felt like she wasn’t taken seriously when she’d go to the doctor frequently with the same complaints over and over.

In terms of the logistics of communication, family caregivers express a wish for more expedient call-backs from doctors and for ways to communicate electronically (e.g., by e-mail) to have questions answered.

Finding: Family caregivers generally wish for less overworked and more compassionate staff, especially in institutional settings such as nursing homes

Family caregivers’ wishes with respect to staffing at caregiving institutions (e.g., nursing homes, assisted living facilities and hospitals) include:

• more staff to alleviate overwork;
• better trained, more skilled staff;
• better supervision and accountability; and
• more caring and compassionate attitude toward older people.
The hospital, they are understaffed. They are just understaffed. And [the staff] couldn’t tell their supervisor that they didn’t know what they were doing because they didn’t want their supervisor to know they didn’t know what they were doing.

I would [wish for] a little bit more understanding and consideration of a fellow human being. Because some of the aides are not concerned, they try to distance themselves because they don’t want to get attached. I understand, but, nevertheless, the person staying there—that is their home for as long as they are there. And if you are getting paid to take care of them, then people there need to actually put a smile on their face when they walk into a room. Their bedside manners have to be a little bit better. I mean they come in and sometimes look at you like, “I’m here just for the paycheck” not “I’m here just to take care of you.”

Finding: Family caregivers wish for a more user-friendly, easier-to-navigate health care system—especially with respect to managing costs, insurance issues and information sharing

The complexities of the health care system, especially when multiple health care providers, institutions and health problems are involved, leave many family caregivers frustrated. Specific wishes include:

- easy access to relevant and reliable information and resources about an elder’s condition and treatment options;
- access to information about legal rights of patients and caregivers, and about legal issues (e.g., power of attorney);
- guidance in navigating the insurance system and completing paperwork; and
- better communication and sharing of information between health care providers and institutions involved in the elder’s care.

If I have to go through this again with someone in my family, [I wish] to have a person who would take the time to sit down and explain to me exactly what’s going on with a member of my family, and what I can do to make it better for them and what I can do to get them better care.

I guess there [are] so many different aspects, but the biggest and most important is having a better system of sharing medical records, diagnoses and tests. And the health insurance—the way it is now is crazy. Especially with lab testing and things, she has supplemental health insurance and sometimes it goes around and round in circles between insurances and trying to find out what was paid when by who. I think they make it confusing on purpose because you can’t figure out who has gotten paid when. It is a waste of time and money.

The high cost of health care and the complexities of the insurance system are a particular area of concern for many working caregivers. Specific frustrations include:

- high cost of insurance, medical services, equipment and supplies (e.g., prescription drugs);
- extensive amounts of paperwork;
- delayed or denied payments; and
- insurance companies making decisions about treatment rather than the elder’s doctors.
The cost of insurance is way too high, and I’m saying that both as a provider and a consumer. It is just ridiculous. People cannot afford to have their health insurance costs escalating like this, and the end result is that people don’t have access.

[The problem is] not the doctors or nurses; it’s the insurance companies. They will drive you bonkers. They want to nickel and dime over everything. That shouldn’t be their decision, that should be the doctor[‘s], the oncologist’s decision, not about what it costs. So I’d change it so some person in the insurance industry isn’t making the decisions, but that it is up to the doctor.

OTHER SOURCES OF SUPPORT FOR FAMILY CAREGIVERS

This study explores family caregivers’ experiences at work, within the family and in the health care system. These settings often serve as the primary support systems for family caregivers. Needless to say, however, there are many other types of support individuals can draw on in providing care for an elderly relative.

We asked the working caregivers in this study which (if any) sources of support other than work, family and the health care system they found helpful during their caregiving experience. As depicted in Figure 16, we found some differences between family caregivers currently engaged in caring for an elderly relative and former caregivers whose elders had died:

- Current caregivers are more likely to say that their friends and community are an important source of support.
- They are also more likely than former caregivers to say that religious organizations played an important role as sources of support.
- Former caregivers are more likely to say they used formal support programs or groups (e.g., grief counseling or Hospice).
- Former caregivers are also more likely than current caregivers to rely on a combination of sources.
- Interestingly, about one quarter of current caregivers (24%) and one third of former caregivers (33%) do not report using any sources of support besides their families, the health care system and their workplaces.
Figure 16: Other sources of support for family caregivers

Source: The Elder Care Study, FWI, 2010; current caregivers N=63, former caregivers N=48
* p < 0.01

**IMPACT OF CAREGIVING EXPERIENCE ON CAREGIVERS’ WISHES FOR THEIR OWN AGING**

*When it’s my time, I hope I just fall dead.*

Taking care of someone who is aging usually makes us think about how we would like to age ourselves. We asked family caregivers to tell us how providing care for an elderly family member has affected their hopes for their own aging and how they would like to be cared for when they are older.

Family caregivers have witnessed first-hand some of the pain and suffering that old age and illness can bring. Their caregiving experiences have taught them what it can be like to be old. These insights have clearly left a profound mark on caregivers’ views of—and wishes for—their own aging.

**Finding:** Having learned from their loved ones’ aging and ailments, family caregivers tend to be both more aware of the challenges of growing old and more discouraged about it—many seem to find it too difficult, too depressing to imagine themselves in the care recipient’s shoes...
I don’t even want to think about it. I want to pass in my sleep of old age. It’s an ugly
time of life—the last few years of suffering.

(Laughs). I want to live until I can’t play golf anymore, and then goodbye. I don’t
want to get that old.

Caregivers interviewed for this study often seemed unwilling to talk about their own aging—
deny it or treating it as something that was not going to happen to them. Clearly, one of
the foremost hopes is that they would never be in a position where they would have to be
dependent on others who don’t care.

As much as they would like to avoid or deny their own aging, however, family caregivers are
also keenly aware that aging is inevitable and largely out of their control. As a result, many
responses to our question conveyed a genuine sense of discouragement, sadness and even
despair when it comes to the caregivers’ own aging.

Perhaps not surprisingly, even though our question was meant to elicit hopes for working
caregivers’ own aging and how they would like to be cared for, it actually seemed to elicit
fears. The top fears raised by family caregivers are:

• being a “burden” to others, especially to their children;
• not having anyone who will take care of them when they are old—a fear especially
  prevalent among caregivers without children;
• not being able to afford care that allows for an acceptable quality of life when they are old,
  especially without burdening children or other relatives; and
• ending up in a nursing home.

Oh, God. That is one of my biggest fears and sources of anxiety because I don’t have
children, and I tell my sister I’m going to get stuck in a nursing home in a wheelchair
with a dirty diaper with no one to visit me. I don’t have any kids. Who is going to take
care of me?

I don’t want to be a burden on anybody. I’m single and I don’t have any children, so
it’s a concern if I’m at a point where—if I’m bedridden or I’m in a nursing home—I
don’t want to hang on for years or something. I just remember I had a grandfather
that passed away and he had been in the nursing home for about five years and
didn’t really recognize anyone anymore. I don’t think I’d want to live like that. Being
bedridden or not knowing what is going on.

My biggest fear is being put in a nursing home. [I hope] to live on my own. I’ve seen
some of the things that happen in nursing homes: how impersonal [they are]. There
are just too many patients per person and people don’t get care the personal care
and affection and comfort they need, or just someone to talk to.

I definitely want to stay in my home. I will put something in my orange juice and
drink it before I have to go to a nursing home.

There’s part of me that pretends it’s never going to happen to me and there’s part of
me that would like to think, God, I really don’t want to have to turn to my daughter.
You know, I wonder about people who don’t have kids, or what if your daughter goes
and lives in a whole other state, you know, then who helps?
Finding: Among hopes for their own aging, family caregivers most often cite being able to live in their own homes, maintaining good health and a high degree of independence for as long as possible.

Many caregivers hope to be spared the fate of their elderly relatives’ health problems. In fact, many indicate they hope to “just die in my sleep” without ever getting sick or requiring any kind of special care. Caregivers also want to spend their final years living independently in their own homes.

I’d like to be like my mother. She has had a great aging. She is 91 and has had a very good life. She has never needed or wanted for anything. She is not dependent on assistance or anything. She’s done well. I would like that.

Unfortunately, however, as these family caregivers know all too well, this hope is not necessarily realistic—those who die happily in their sleep in their own homes, never having been sick a day in their independently lived lives, are the exception, rather than the norm.

I hope I just die in my sleep and I don’t have to go anywhere, to be honest.

I only have one daughter and I would hate that her dad and I would become a burden for her. I wouldn’t want to see that. You can just hope that you don’t end up with some long-term illness. I have a grandfather on my mother’s side that lived to be 102 and just went in his sleep one night and was relatively healthy his whole life. That is what I am hoping for. But you never know, our earth is not what it used to be and we are not eating the same quality food that they used to eat.

Finding: Family caregivers hope avoid needing care by maintaining their own health as much as possible.

Providing care to an ill relative appears to be a strong motivator for healthy lifestyles. Family caregivers hope that they can improve their odds for living independently in their old age by taking care of themselves now with diet, exercise and other health maintenance activities. If they do, one day, need care, they hope that their own family caregiving activities have set a good example to their children about elder care responsibilities.

Exercise, eating right, staying as healthy as I possibly can, physically and mentally. Do my part. And [pause] I’d rather die healthy than have to live like the way some of the elderly are living today.

Well, I’m trying to take better care of myself because my mother does worry about me when I get older. Who’s going to take care of me? I don’t have any children. So, I’m trying to take better care of myself—so that maybe I don’t have as many problems when I get older.

It makes me want to make sure I stay as healthy as I can and as sharp as I can be mentally, and I really don’t want to be a burden on my kids as far as if I was so unhealthy they couldn’t even live their lives.

We’ve already discussed this. I have a group of friends and we are all going to move into a house together and take care of each other. I mean some of us are single and don’t have the extended family or children, so we just said, we’ll all move in together and take care of each other.
I would hope that the way my kids are being brought up that they are givers and will always be there to help each other out. So I’m hoping that as I age ... my kids will be there to support me if I needed them. They have their core values. Bottom line is that it is my kids that will probably be responsible for me when I get older. But on the other hand, too, I am trying to make sure from a retirement perspective that we are covered in that regard because it is not only caregiving, but there is a financial component as well.

Finding: The prospect of growing old and needing some type of care by others—by family members or in institutional settings—seems to instill family caregivers with a sense of hopelessness to the point that they would rather give up than live that way.

An alarming theme that emerged from our interviews is that family caregivers overwhelmingly seem to view aging and receiving elder care as profoundly negative, depressing processes to be avoided if at all possible. People seem to dread the idea of aging and needing care so much they say they would rather be killed in some other way or even commit suicide.

(Crying). I would rather die in a car wreck than put anyone through what I had to go through taking care of my mother.

I’m not saying we should euthanize people, but to be honest with you, the cats and dogs I’ve owned have met their ends more gracefully through euthanasia than the way my father died. So I’d rather go quickly, not be a burden, and not suffer.

Nobody should have to suffer anything like Alzheimer’s. Her whole life was taken from her because you forget who you are. I can’t even imagine, and it scares me to think that it could happen to me. If I forgot something or can’t think of a word, I get scared. I have two sons and I’ve told them, if I get like that, shoot me. Just shoot me. I don’t want to live like that if I ever get that way. I want to be active and have a sharp mind. I have grandchildren from age 1-12 and I’d like to see them grow up and continue doing a lot of stuff with them. Sit on a porch where it is warm and be able to talk to my grandchildren [and] great-grandchildren and tell them stuff that went on. That’s something my mother couldn’t do.

I’m somebody who is looking for a Dr. Kevorkian. I do not have a family to burden because they have their own burdens. My sister-in-law is a cancer survivor, my sister has MS, so I have no one that would have the time to do that. As much as I hate to admit it, I’m not financially stable for any kind of long-term care, so should I be diagnosed with something that is life threatening, no treatment, there is just the end. Because I have seen what people have gone through.
CONCLUSION

If there ever were a call to action, the wishes from working caregivers about aging and their own future care should be that call. It is common knowledge that ours is an aging society, and yet this study finds far too many of us in denial or depressed about what this means in our country.

What can be done?

First, we can and should heed the suggestions made by the working caregivers to:

Improve the workplace by providing:

• greater flexibility, including more options for managing time;
• time off for elder care, especially paid time off without having to use up vacation time; and
• more understanding of their situation from management.

Improve the support we receive from family and friends.

Improve the health care system by providing:

• more frequent and better quality two-way communication with doctors and other medical providers;
• less overworked, more compassionate staff at medical and nursing facilities with the skills to listen and learn from the caregivers and the elders; and
• a more user-friendly, easier-to-navigate and less costly health care system.

Continue to focus on healthy living for all.

But, most of all, as our country grows older, we desperately need to use ensure that some of the best practices in caring for the aging become more widespread and we need to create new models of aging beyond the ones we have now. In this study, one family caregiver spoke of creating a group living arrangement where friends could care for each other. This could be a good solution for some. We need to continue to surface other such ideas and then experiment with them.

No one should have to wish “just shoot me.” Instead, we must be able to age with more dignity. That is what Leora May had in her final years and days. In her memory, we wish that for more and more Americans, and we ask you share your ideas with us on how to make this a reality. Please visit: http://familiesandwork.org/site/work/workforce/eldercare.html.

One doctor put it well. He was standing in a hospital next to an elderly person when he said:

*Look at that bed and imagine how many more people are going to be in beds just like this in the coming years. You and I will be in those beds someday! We have to make things better than they are now.*
METHODOLOGICAL NOTE

The 2008 NSCW gathered data from a nationally representative sample of employed people using a random digit dial procedure. Interviews were conducted by Harris Interactive, Inc. The total sample comprises 3,502 workers in United States: 2,769 wage and salaried employees, 478 independent self-employed workers who do not employ anyone else, and 249 small business owners who do employ others. The sample was adjusted to reflect (i.e., weighted to) 2007 U.S. Bureau of the Census statistics for the total U.S. population to adjust for any sampling bias that might have occurred. The response rate was calculated by applying the conservative method of calculation recommended by the American Association for Public Opinion Research. In 2008, the response rate was 54.6%. The completion rate was 99%. The estimated maximum sampling error for the total sample is approximately +/- 1%.

The March 2007 Current Population Survey (CPS) provided control totals for calculating the sample weights used for analyses in this report—that is, sample proportions were adjusted to CPS proportions. The weighting algorithm we used included the following demographic factors: number of eligibles in household, gender, education level completed and race/ethnicity. Various statistical tests for significance were used for this report: Pearson chi-square for comparing nominal scale variables, Mantel-Haenszel chi-square for comparing ordinal scale variables, t-tests for comparing differences between groups for interval scale variables, binary logistic regression for evaluating relationships between dichotomous and interval scale variables, and ordinary least squares regression for evaluating relationships between interval scale variables. Relative weights analyses were also used to determine the relative importance of effective workplace characteristics. Differences and relationships/correlations are only reported as statistically significant when they reach significance at $p < .05$ (less than 5 chances in 100 of being due to chance).
ENDNOTES

i The March 2007 Current Population Survey (CPS) provided control totals for calculating sample weights—that is, sample proportions were adjusted to CPS proportions. The weighting algorithm included the following demographics: number of eligible respondents in household, gender, highest education level completed and age.

ii Ibid

iii Two types of interview protocols were used: one for those currently providing elder care and one for those whose elder had passed away within the last five years. While both protocols shared a number of the same or similar questions, some questions were targeted specifically to each group. Of the weighted sample, 65 respondents were current family caregivers and 56 were former family caregivers (i.e., provided care within the last five years, elder has passed away).
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