



# Family Caregiving and Out-of-Pocket Costs: 2016 Report

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## Executive Summary

The purpose of this study was to explore the out-of-pocket costs of caregiving and the financial strain on the family caregiver. This report estimates the *monetary costs* of caring for an adult with care needs by quantifying the out-of-pocket costs family caregivers are incurring. In addition to out-of-pocket costs, this study also explores other financial and personal strains. For example, family caregivers may need to cut back on spending in other areas (e.g., personal spending, basic living expenses, retirement savings, etc.) due to the costs of assisting their care recipient. Furthermore, employed caregivers may experience work-related strain if they need to leave the workforce, take unpaid leave, or cut back on hours because of family caregiving responsibilities.

This study was conducted using a mixed method approach that included both a survey and diary component in order to calculate an annual figure of out-of-pocket spending for each family caregiver. This study utilized GfK's national, probability-based online KnowledgePanel®. This study was conducted from July 18, 2016 to August 28, 2016 among 1,864 family caregivers.

## Key Findings

- More than three in four family caregivers (78%) are incurring out-of-pocket costs as a result of caregiving. This report estimates that family caregivers, on average, are spending roughly \$7,000 per year (\$6,954) on out-of-pocket costs related to caregiving in 2016.
- A financial strain measure (average annual family caregiver expense divided by the caregivers' annual incomes) shows family caregivers are spending, on average, nearly 20% of their income on caregiving activities.
- Household expenses garner the largest share of family caregivers' out-of-pocket spending with 41% of total spending. This includes rent/mortgage payments, home modifications, as well as other household expenses. Medical expenses account for the second largest share of caregivers' spending (25%) which includes in-facility care, insurance costs, and other medical expenses.
- When looking across race/ethnicity, out-of-pocket spending is highest among Hispanic/Latino caregivers (\$9,022 per year; on average, 44% of their income)<sup>1</sup>. While African American caregivers spend similar amounts as White caregivers, their financial strain is higher (on average, 34% of their income vs. 14% of income for Whites).
- Long-distance caregivers (defined as family caregivers living more than one hour from the care recipient) are incurring high out-of-pocket costs (\$11,923); however caregivers living with their care recipient also incurred high costs (\$8,616).

<sup>1</sup> Note: Occasionally, multiplying the average annual expense and the average annual financial strain, for reasons related to underlying distributions, will not lead to accurate average annual income estimates. For example for Hispanic/Latino caregivers, \$9,022 per year is not multiplicatively related to 44% of their income as a way to obtain the annual income of all Hispanic/Latino caregivers. One example of a problem related to underlying distributions is that for some caregivers, average out-of-pocket expenses exceed 100% of their annual income. This suggests that tapped savings or loans for some caregivers are being applied to out-of-pocket caregiving costs.

- Caring for an adult over the age of 50 results in slightly higher out-of-pocket costs than caring for an adult younger than 50 years old (\$7,064 vs. \$5,721).
- Those caring for an adult with dementia reported nearly twice the out-of-pocket costs than those caring for someone who does not have dementia (\$10,697 vs. \$5,758).
- Family caregivers in the lowest income quartile (up to \$32,499 annually) report spending, on average, 44% of their annual income on caregiving (\$5,114) (see footnote 1).
- The individuals most “highly financially-strained” tend to be lower income, non-White/non-Asian family caregivers, and caring for a relative or close friend who needs assistance with at least one Activity of Daily Living (ADL). There are, however, subgroups in every income group that are “highly financially-strained”. For example, among those in the middle income groups, those caring for someone who needs assistance with at least one ADL are also disproportionately “highly financially-strained”.
- More than half of employed caregivers (56%) experience at least one work-related strain. This may take the form of working different hours, fewer/more hours, and taking time off (whether paid or unpaid).
- Many family caregivers also need to cut back on other spending which can undermine the family caregiver’s future financial security. Three in ten (30%) have dipped into their personal savings, one in six (16%) have reduced contributions to their retirement savings, and roughly half have cut back on leisure spending (e.g., 45% cut back on eating out or vacations as a result of caregiving expenses).

## Conclusions

This study demonstrates that family caregivers not only spend time and energy caring for an adult with care needs but also spend a significant amount of money of their own. Family caregivers are spending roughly \$7,000 (\$6,954) in 2016 on caregiving expenses which amounts to, on average, 20% of their total income.

Certain groups or types of caregivers are disproportionately spending more than others; however, the overwhelming majority of caregivers (78%) are incurring out-of-pocket costs as a result of caregiving. Higher than average out-of-pocket costs are seen for several groups of caregivers including Hispanic/Latino caregivers, those caring for someone with dementia (also those engaged in many ADLs) and those caring for a loved one from a distance.

In addition to out-of-pocket costs, many caregivers are experiencing work strain and personal strain. More than half of caregivers in this study reported at least one work-related strain (e.g., a change in work hours, taking paid or unpaid time off, etc.). Many family caregivers are also dipping into their savings and cutting back on their own personal spending to accommodate for caregiving costs. For example, roughly half are cutting back on leisure spending and one in six has cut back

on retirement savings. This finding raises the importance for not only education and assistance for family caregivers but also financial assistance such as a family caregiver tax credit that would help address the financial challenges of caregiving.

## Detailed Findings

### Background

Family caregivers are at the core of the U.S. health and long-term services and supports system (LTSS). The bulk of LTSS services are provided by unpaid family caregivers. *Valuing the Invaluable: 2015 Update* has shown that there are approximately 40 million family caregivers providing care to an adult care recipient (age 18 and older)<sup>2</sup>. The term “family caregiver” is used broadly and refers to any relative, partner, close friend, or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic, disabling or serious health condition. Family caregivers also provide care to children under 18 because of medical, behavioral, or other conditions or disability. However, this study focuses more specifically on family caregivers of adults age 18 and older.

Family caregivers often take on a wide range of activities from managing finances, transportation and housework to medication management, bathing/dressing, and feeding. Family caregivers also help the care recipient to locate, arrange, and coordinate health care and supportive services and to hire and supervise direct care workers when the family can afford to hire paid help<sup>3</sup>. Today’s family caregivers also perform complex medical/nursing tasks with little or no preparation or training.<sup>4</sup>

Family caregivers experience emotional, physical, and financial challenges and the demands of caregiving can take a toll on family members who take on caregiving responsibilities. Family caregivers not only spend time and energy caring for an adult relative or close friend with care needs, but many also spend money of their own to help care for the care recipient.

The purpose of this study was to explore the out-of-pocket costs of caregiving and the financial strain on the family caregiver. This report estimates the *monetary costs* of caring for an adult with care needs by quantifying the out-of-pocket costs family caregivers are incurring. As the United States population becomes more diverse, it is very important to look at various demographic groups of caregivers. This study aims to do so by examining out-of-pocket spending across various subgroups of caregivers.

In addition to out-of-pocket costs, this study also explores other financial and personal strains. For example, family caregivers may need to cut back on spending in other areas (e.g., personal spending, basic living expenses, retirement savings, etc.) due to the costs of assisting the care recipient. Furthermore, employed caregivers may experience work-related strain if they need to

<sup>2</sup>AARP. *Valuing the Invaluable: 2015 Update*. July 2015.

<sup>3</sup>Ibid.

<sup>4</sup>AARP. *Home Alone: Family Caregivers Providing Complex Chronic Care*. October 2012.



leave the workforce, take unpaid leave, or cut back on hours because of family caregiving responsibilities.

Between family caregivers, recipients, and other family members, large and varied groups throughout America are engaged in, or are affected by, a primarily unrecompensed caregiving system.

## Methodology

This study was conducted using a mixed method approach that included both a survey and diary component in order to calculate an annual figure of out-of-pocket spending for each family caregiver. This study utilized GfK's national, probability-based online KnowledgePanel®. This study was conducted from July 18, 2016 to August 28, 2016 among 1,864 family caregivers. The sample was stratified to assure a sufficient number of Hispanic/Latino, African American and Asian caregivers to support analysis; however, their at-random incidence resulted in only minor disproportionate representation.

Family caregivers were recruited over a four week period so that data collection could take place over a 30-day period. Panelists were recruited on a rolling basis in cohorts of roughly 500 qualified caregivers. GfK screened for and recruited caregivers to participate in this study using the following criteria:

- Currently providing unpaid care to a relative or friend 18 years or older to help them take care of themselves. This may include helping with personal needs or medication management, household chores, or transportation. It might be managing a person's finances, arranging for outside services, preparing meals or grocery shopping, helping with bathing or dressing, or even visiting regularly to see how they are doing.

Each qualified respondent first completed a retrospective survey examining out-of-pocket expenses incurred in the last year. Three thousand two hundred and seventy seven respondents qualified for the study and completed the retrospective survey.

Caregivers were then asked to participate in the diary study and track their spending on caregiving costs over the course of one week. Eighteen hundred and sixty four caregivers agreed to participate in the diary study. Diary study participants did not differ in any systematic way from the remainder of qualified caregivers. For the qualified caregivers in the diary study, each of their caregiving expenses were recorded as falling into one of five categories (see Appendix C for full descriptions of diary expenses captured into each expense categories) :

1. Medical/Dental/Vision expenses (for the person you are helping)
2. Household expenses (for the person you are helping)
3. Personal care item expenses (for the person you are helping)
4. Educational, legal, travel, and other expenses (for the person you are helping)
5. Caregiver personal expenses/Respite (Aides, adult day services, self-care, other paid help, and other expenses)

The final annual estimate reported in this study comes mainly from expenses reported in the diary study as diary studies and retrospective surveys have differing strengths. The diary study is better at capturing routine, often small costs within the study period as well as major expenses that occur within the study period. However, diary studies, even if annualized, fail to account for large, rare expenses not captured outside of the diary collection period.

To account for this, diarists responded to a retrospective survey in which 19 caregiving expense types were listed (each of these 19 expense categories naturally fell into one of the five diary study expense categories; see Table A2 in Appendix B for their distribution). These expense types exclude small, routine expenses so are non-exhaustive (i.e. they do not aggregate to an annual caregiver expense figure). However, the retroactive expenses were explored for evidence of large, seasonal expenditures as it is the only way to capture large expenses that are not likely to have been observed during a diary study period (but should be included in annual estimates). Expenditures deemed non-redundant with the annualized expenses in the diary study, were deemed “retrospective survey additions”. The computation of these additions, which required a few assumptions, is described in Appendix B. The chief assumption was that greater expense variability among the larger caregiver sample (N=3,277) was evidence of relatively infrequent, but costly caregiver expenses that failed to be observed within the diary study population (N=1,864).

Weights were applied to weekly figures to produce a 28-day caregiving expense estimate and to address survey stratification. This 28-day estimate was used to produce an annualized diary expense figure (note: this was done using a multiplier equal to  $365/28 = 13.03$ ).

For more detailed information on the methodology, please refer to Appendix B.

## Costs of Care

Overall, the average annual out-of-pocket cost for family caregivers was \$6,954. This figure varies considerably among several subgroups of caregivers that will be discussed in this report. A financial strain measure is also included that includes the annual caregiver expense divided by the caregivers’ annual income. On average, nearly twenty percent of caregivers’ income is devoted to caregiving expenses.

To examine this spending in more granular detail, categories of spending were explored. Table 1 shows the percent of total spending represented by each of the five diary categories as well as financial strain. The results show that household expenses garner the largest share of family caregivers’ spending with 41% of total caregiving expenses. This was followed by medical expenses which represents one-quarter of caregivers’ spending.

Table 1

	<b>Average annual expense</b>	<b>% of overall annual expense amount</b>	<b>Percent of caregiver's total income</b>
<b><i>Average annual caregiver expense*</i></b>	<b>\$6,954</b>	<b>100%</b>	<b>20%</b>
Household expenses	\$2,854	41%	7%
Medical expenses	\$1,722	25%	4%
Personal care item expenses	\$961	14%	3%
Travel, education, legal, and other expenses	\$830	12%	2%
Caregiver personal expenses/Respite (Aides, adult day services, self-care, other paid help, and other expenses)	\$587	8%	3%

\*Appendix B includes companion tables and discussions of measures to explain how these figures were estimated. The broad categories shown here are those used in the diary study component but expense estimates are based on two sources- reported expenses in the diary study and qualified expenses in the retroactive survey.

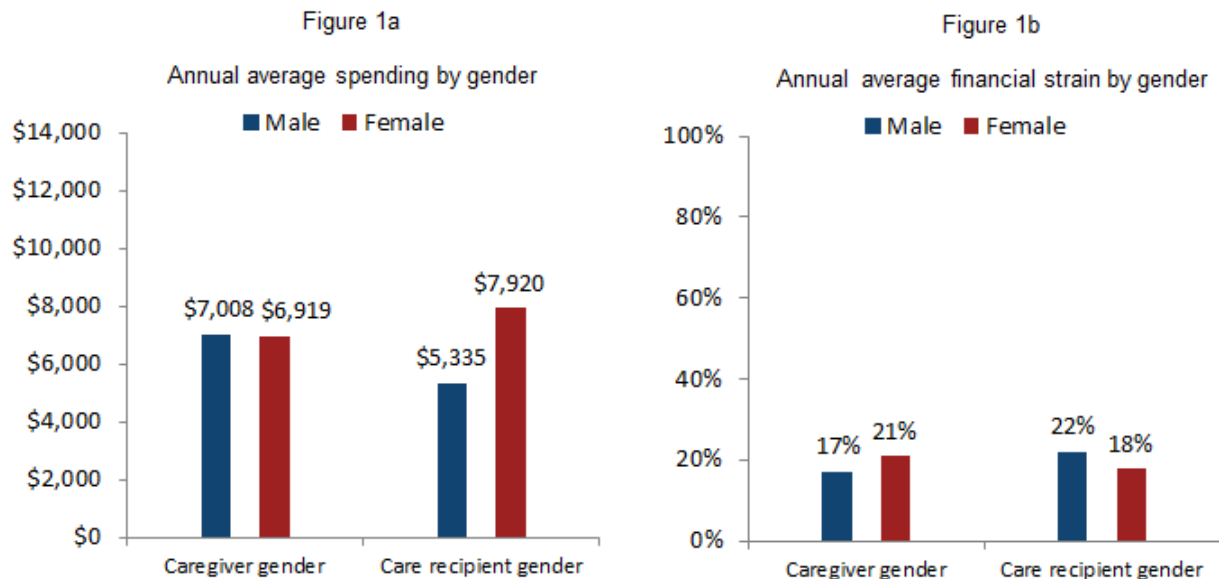
## Costs of Care: Gender Differences

Overall, female and male caregivers are spending similar amounts on caregiving each year (roughly \$7,000 annually) but owing to different annual incomes, females are spending a higher percentage of their average annual income on caregiving expenses. This results in greater financial strain for female caregivers (on average, 21% of income vs. 17% of income for males). In addition, more female caregivers in this study (68%) compared to male caregivers (60%) report being the sole caregiver. Females also spend more hours per week caregiving.

Most family caregivers are female and caring for a female care recipient. Annual out-of-pocket spending is higher for caregivers caring for a female care recipient; however the financial strain is higher for those caring for a male recipient. This is likely due to the fact that about two-thirds (64%) of male recipients are being cared for by female caregivers who report lower household incomes. Most family caregivers do not split their duties with another family member in the household. In addition, female caregivers are relatively less apt to pay for help<sup>5</sup> (29% reporting that they do compared to 32% of male caregivers).

<sup>5</sup> Note: Paid help includes aides, housekeepers, or other people paid to help the recipient.

Figures 1a and 1b present annual spending and financial strain, by gender of both the caregiver and care recipient.



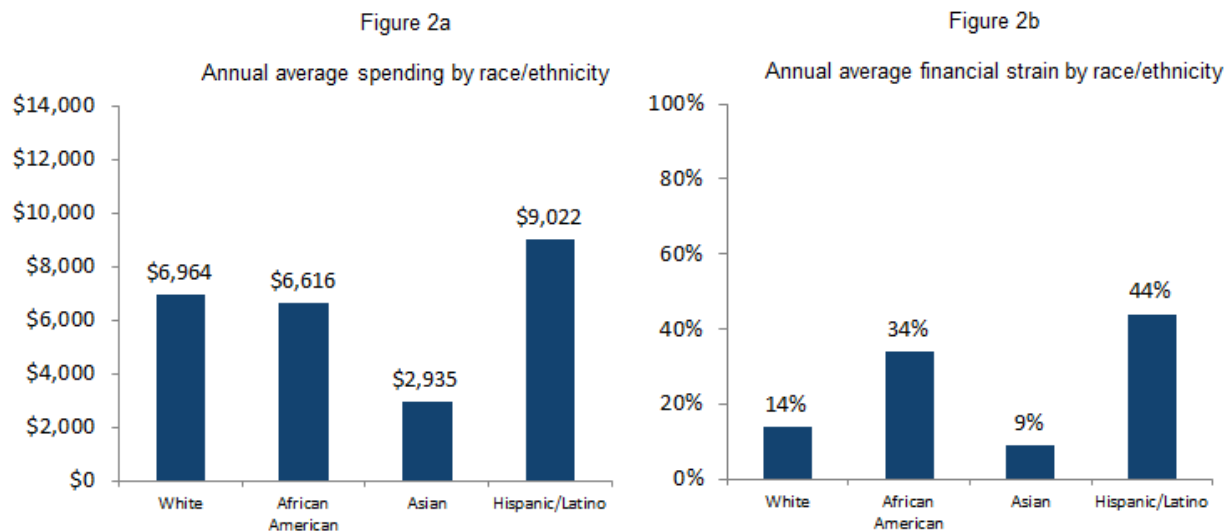
Note: Figures in the main body of the report are generally limited to costs and income measures. Descriptives related to other characteristics of the caregiver and recipient population (i.e. frequency distributions or group sizes) appear in the “Caregiver Profile” section of the Appendix.

### Costs of Care: Race/Ethnicity Differences

There are variations in caregiving expenditures related to the race/ethnicity of the caregiver (see Figures 2a and 2b). Out-of-pocket spending is highest among Hispanic/Latino caregivers (\$9,022 annually; on average, 44% of their income; see footnote 1). African American caregivers report fairly similar costs compared to White caregivers, however, they report a much higher financial strain (on average, 34% of their annual income vs. 14% of income for White caregivers).

The relatively low expenditures for Asians may be due to the observation that they had relatively low levels of employing help (15% reporting doing so compared to 33% for Whites) and relatively high levels of dividing caregiving responsibilities among other (unpaid) co-caregivers, presumably family members or friends. There are also a few indicators that Asian caregivers are caring for relatively healthy recipients. They are the least likely to be caring for a recipient with dementia, are relatively likely to be caring for a recipient who does not need assistance with ADLs, and the least likely to have been caring for a recipient for five years or more.

The relatively high expenditures for Hispanic/Latinos suggest nearly the opposite dynamic as Asian caregivers. Hispanics are the most likely to have been caring for a recipient for five or more years (39% percent doing so, compared to 34% among the general caregiver population). Also unlike Asians, a quarter of Hispanics are caring for recipients with dementia (compared to 15% of Asians) and relatively few Hispanic/Latino caregivers divide their caregiving work up among other unpaid caregivers.



As shown in Table 2, Hispanic/Latino caregivers are spending a disproportionately large amount of money on caregiving because they are the most likely group of caregivers to be coordinating long-distance care. Further analyses showed that this subgroup had a higher frequency of relocation expenses and multiple housing payments than other groups.

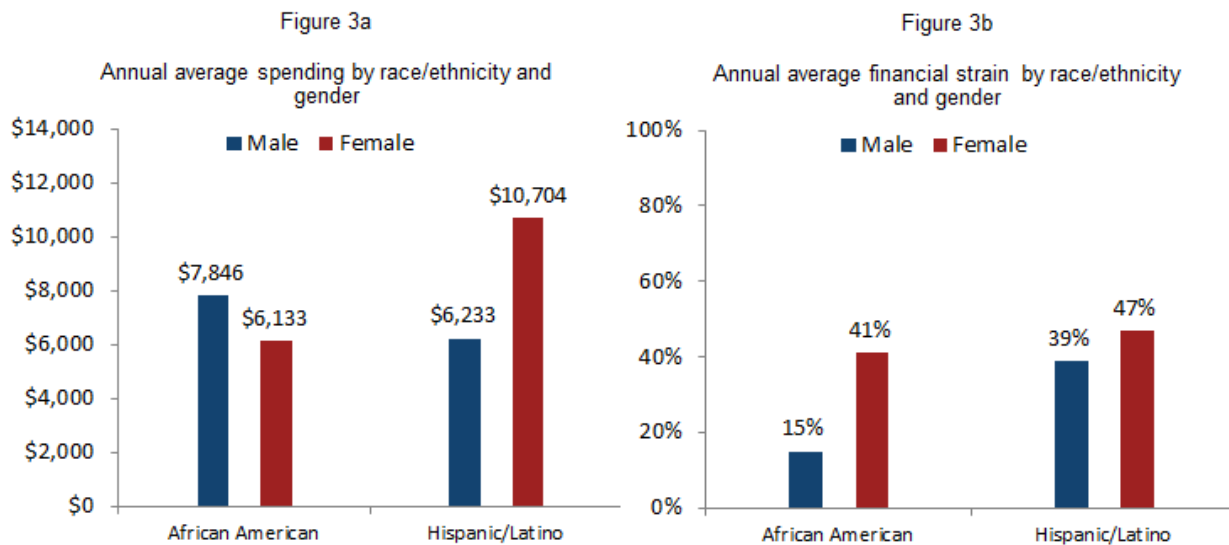
**Table 2**  
Caregiving expense category figures by race/ethnicity

Expense Category	All Caregivers	White	African American	Hispanic/Latino	Asian
<b>Sum of all expenses</b>	<b>\$6,954</b>	<b>\$6,964</b>	<b>\$6,616</b>	<b>\$9,022</b>	<b>\$2,935</b>
Medical Expenses	\$1,722	\$2,072	\$1,041	\$1,093	\$650
Household Expenses	\$2,854	\$2,894	\$2,097	\$3,846	\$908
Personal Care Item Expenses	\$961	\$967	\$495	\$1,547	\$262
Education, legal/travel expenses	\$830	\$541	\$1,828	\$1,753	\$769
Caregiver personal expenses/Respite (Aides, adult day services, self-care, other paid help, and other expenses)	\$587	\$490	\$1,156	\$783	\$346
<b>Sum of expenses as a percentage of annual income</b>	<b>20%</b>	<b>14%</b>	<b>34%</b>	<b>44%</b>	<b>9%</b>

Note: disproportionate spending would be a percentage exceeding that of the “Sum” column for each expense category.



Gender differences also emerge within multicultural populations. Hispanic females are devoting, on average, nearly half (47%) of their annual income to caregiving and African American women are, on average, devoting more than 40% of their annual incomes. Among Hispanic/Latino caregivers, females are spending more than males yet among African-American caregivers, males are spending more than females (see Figures 3a and 3b). Though the precise dynamic is not known, housing-related costs appear to drive the difference in expenditures between Hispanic male and female caregivers. For African American caregivers, one likely explanation is related to paid help. African American male caregivers are significantly more likely than African American female caregivers to pay for help (40% versus 28%) as are Hispanic/Latino male caregivers compared to Hispanic/Latino female caregivers (24% versus 16%).



Note: Figures for Asian caregivers could not be broken down by gender due to sample size.

*“There are some months that I can't afford all his prescriptions.” (47-year old, low-income female caregiver)*

*“We have used everything - retirement, mutual funds, savings, etc. to care for him. There is nothing left. We will not have the option of retirement.” (59-year old, female caregiver for her spouse)*

As noted previously, household expenses drive the Hispanic/Latino figures, but notably this appears to be only the case for Hispanic/Latino women. Hispanic/Latino women were more likely to incur higher travel costs and home repair expenses. A greater percentage of Hispanic/Latino women had also tapped into retirement savings, reduced retirement contributions, and reported having had to take additional jobs.

Table 3  
Caregiving expense category figures, by gender and race/ethnicity

Expense Category	All Caregivers	Male	Female	African American Male	African American Female	Hispanic/Latino Male	Hispanic/Latino Female
Sum of all expenses	<b>\$6,954</b>	\$7,008	\$6,919	\$7,846	\$6,133	\$6,233	\$10,704
Medical expenses	\$1,722	\$2,501	\$1,204	\$646	\$1,196	\$935	\$1,187
Household expenses	\$2,854	\$2,480	\$3,102	\$3,776	\$1,436	\$2,425	\$4,703
Personal Care Item expenses	\$961	\$738	\$1,109	\$243	\$595	\$1,869	\$1,353
Education\Legal\Travel expenses	\$830	\$585	\$994	\$708	\$2,268	\$175	\$2,705
Caregiver personal expenses/Respite (Aides, adult day services, self-care, other paid help, and other expenses)	\$587	\$704	\$509	\$2,473	\$638	\$829	\$755
<b>Sum of expenses as a percentage of annual income</b>	<b>20%</b>	17%	21%	15%	41%	39%	47%

Note: disproportionate spending would be a percentage exceeding that of the “Sum” column for each expense category. Figures for Asian caregivers could not be broken down by gender due to sample size.

*“I worry that I will not be there when she needs me, because I live out of town. I also worry that she will outlive her money.” (67-year old long-distance caregiver)*

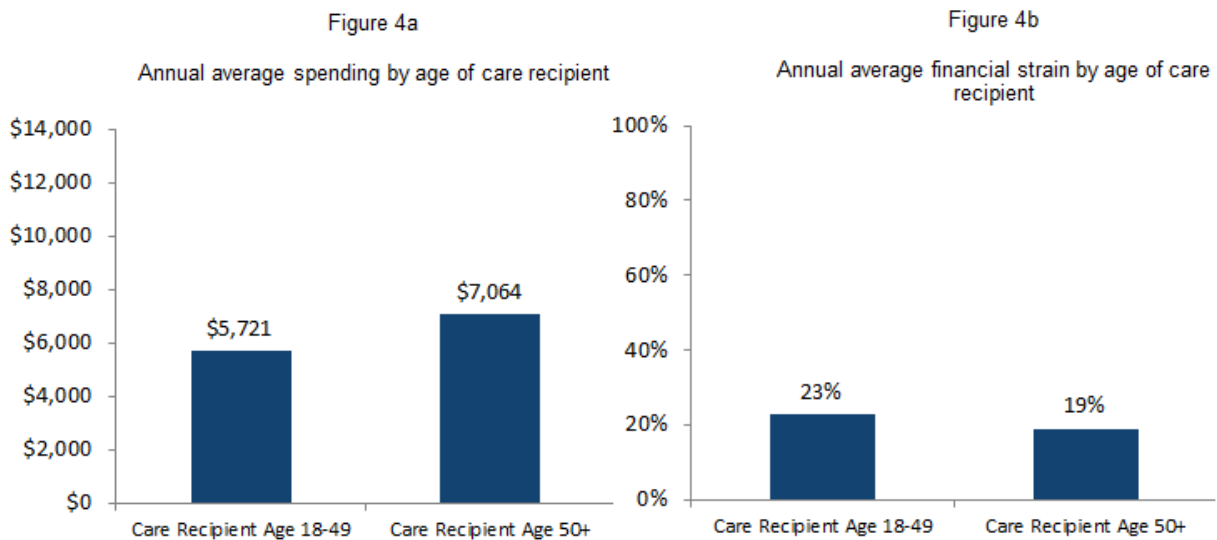
## Costs of Care: Age of, and Distance to, Care Recipient

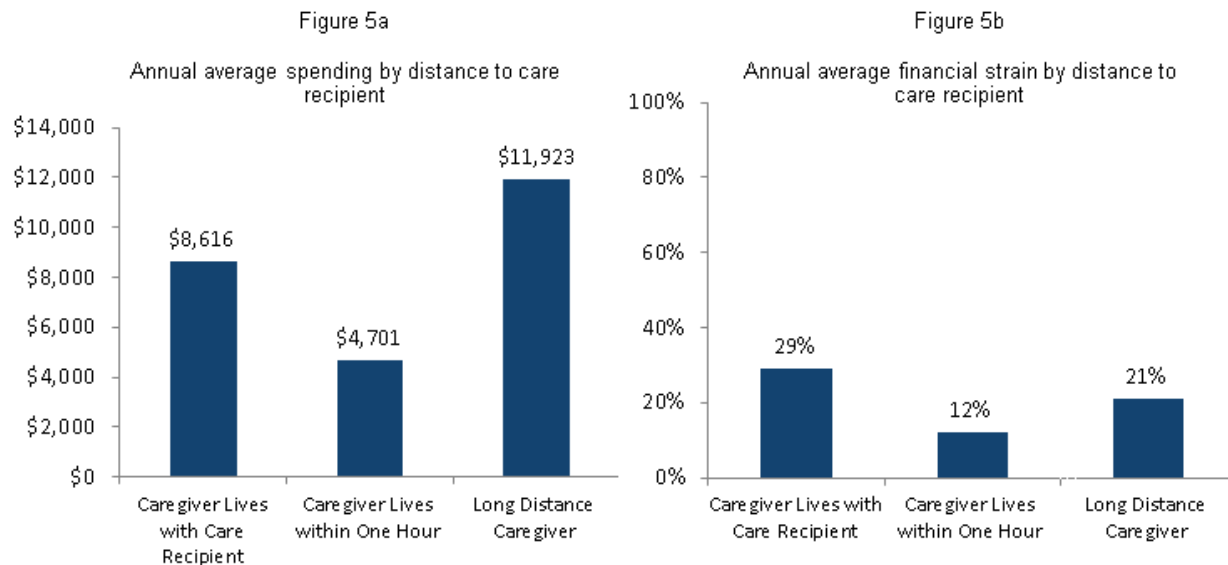
Family caregivers caring for someone over the age of 50 reported higher out-of-pocket costs than caregivers caring for an individual 18-49 years old. Several indicators suggest the health of older recipients drive expenditures. Two such factors are a higher percentage of 50+ recipients having dementia than recipients age 18-49 (28% versus 8%). A second factor is that 32% of those caring for recipients 50 or older had some form of paid help compared to only 19% of those caring for younger recipients.

It was speculated that long-distance caregivers (defined as living more than one hour away from the care recipient) would necessarily devote more out-of-pocket resources to caregiving in that monetary contributions were in lieu of direct care. Long-distance caregivers did indeed report higher out-of-pocket costs than caregivers living with or nearby their care recipient.

Yet family caregivers living in the same household as their care recipient also had high expenditures. However, these caregivers were a less wealthy group which resulted in a slightly higher financial strain measure. For both caregivers living with their care recipient and long-distance caregivers, housing and travel costs are relatively high. For long-distance caregivers, specifically, paying for help drives expenditures.

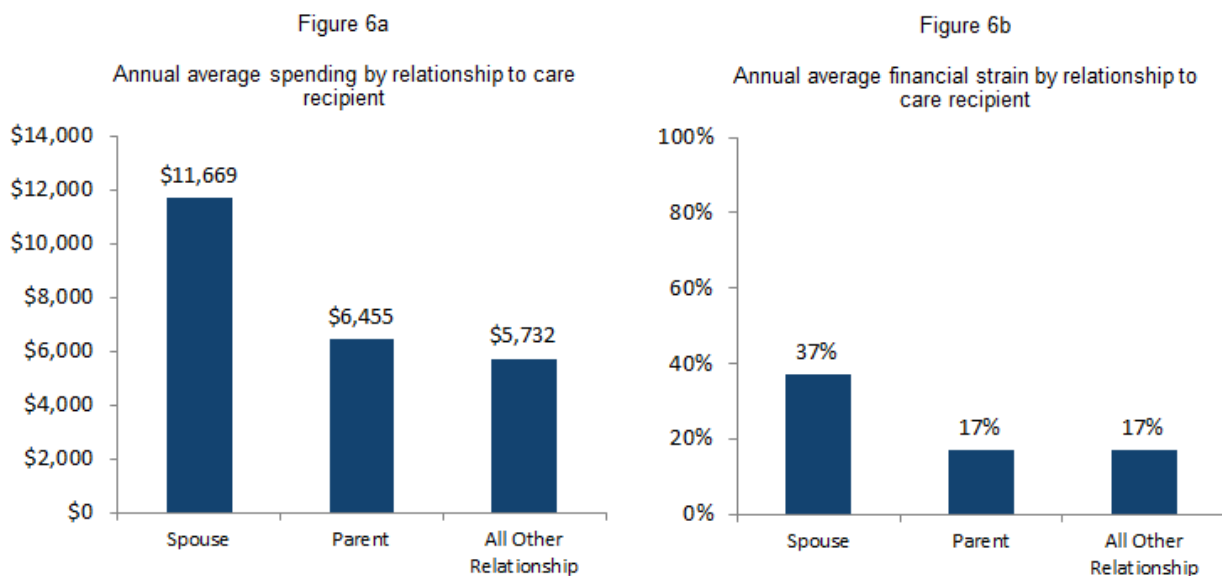
Figures 4a and 4b and Figures 5a and 5b show out-of-pocket costs and financial strain broken down by age of the care recipient and distance to him or her.





### Costs of Care: Relationship to Care Recipient

Caregiving costs also vary depending on who the caregiver is caring for. This study shows that caring for a spouse results in more out-of-pocket expenses than caring for a parent or other relative/friend. Caregivers caring for a spouse reported spending roughly \$12,000 per year (\$11,669) and, on average, 37% of their annual income on caregiving (see Figures 6a and 6b). These caregivers had notably disproportionate spending on the medical and household expense categories. Caring for a spouse makes splitting caregiving duties more of a challenge. Fully 99% of those caring for a spouse report that they are doing it on their own. They are, paradoxically, also slightly less likely than other caregivers to pay for help (25% versus 30% each for those caring for a parent or another relation).



## Costs of Care: Generational Differences

Out-of-pocket costs also vary by caregiver age or generation. Silent generation (age 71-91) family caregivers are incurring the highest out-of-pocket costs (\$13,875) as they are more likely to be caring for a recipient with dementia (31% caring for a recipient with dementia) and with at least one ADL (53%). Although Silents, on average, spend more raw dollars than other generations on caregiving, Millennials (age 18-34) are spending the greatest share of their annual income (on average, 27%) on caregiving. Millennials, who are often caring for their parents and other older relatives, account for 19% of caregivers, suggesting a sizable population of Americans balancing (or choosing between) family formation and/or caregiving. Figures 7a and 7b present caregiving expenses by generation/age-group in more detail.

*“I’m worried I will have to choose between my father (and my fiancée) and children.”* (26 year-old mother caring for two toddlers and a father with multiple ADLs)

*“My biggest fear is that I’ll never be able to save money for myself.”* (29 year-old Asian female caregiving for her parents in-house)

*“I worry that what I do is not enough but I can’t afford to have her cared for someplace else.”* (Hispanic female millennial caregiver looking after her mother)



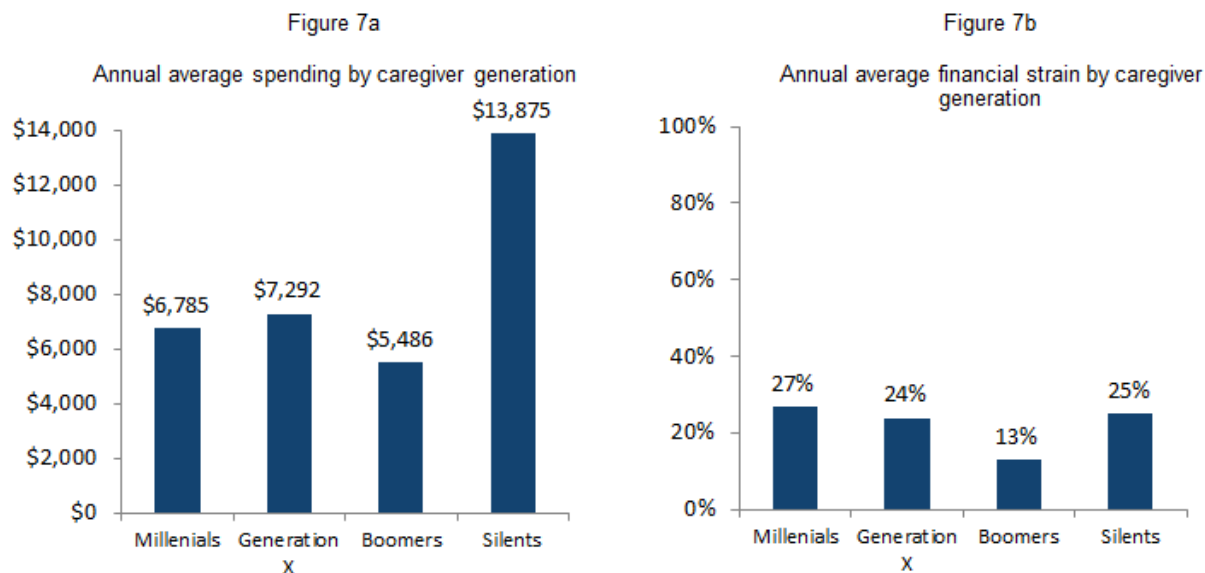


Table 4 shows Silent generation caregivers incurring much higher medical costs than other generations as most are caring for older recipients often with higher medical expenses. These caregivers spend significantly more on nursing homes or long-term care facilities, possibly due to the higher incidence of dementia among their care recipients. It appears household expenses are driving Millennials out-of-pocket costs.

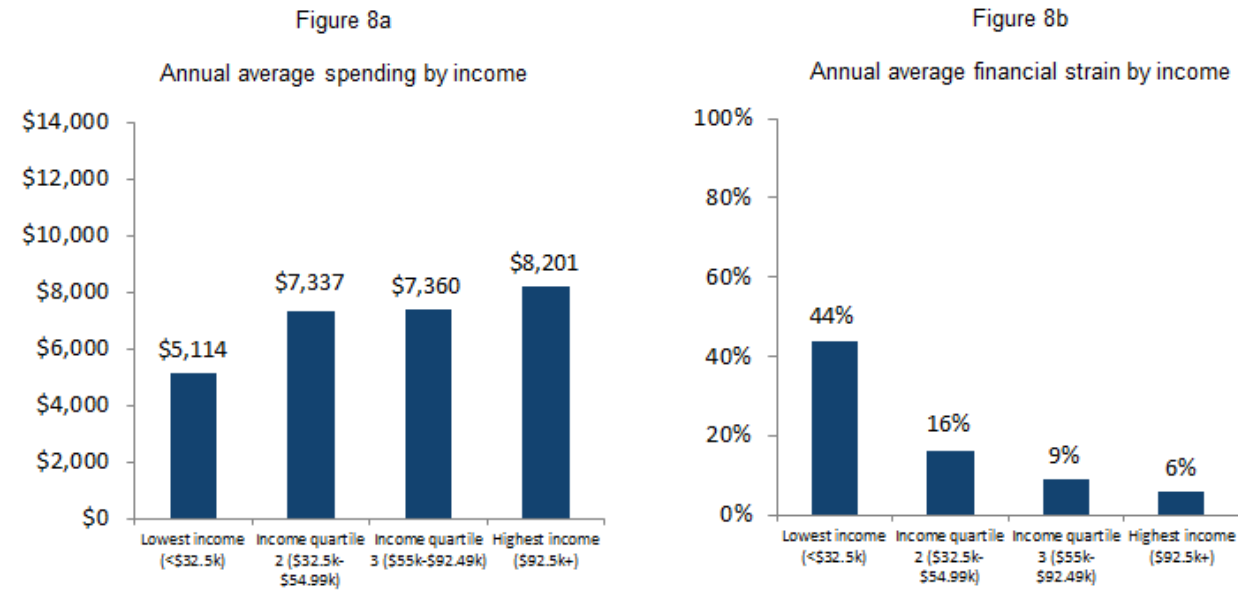
Table 4  
Caregiving expense category figures, by generation

Expense Category	All Caregivers	Millennials (18-34)	Generation X (35-50)	Baby Boomers (51-70)	Silents (71-91)
Sum of all expenses	<b>\$6,954</b>	\$6,785	\$7,292	\$5,486	\$13,875
Medical expenses	\$1,722	\$886	\$987	\$1,185	\$8,283
Household expenses	\$2,854	\$3,326	\$2,600	\$2,849	\$2,599
Personal Care Item expenses	\$961	\$778	\$1,760	\$539	\$1,268
Education\Legal\Travel expenses	\$830	\$1,292	\$1,116	\$519	\$652
Caregiver personal expenses/Respite (Aides, adult day services, self-care, other paid help, and other expenses)	\$587	\$502	\$829	\$394	\$1,074
<b>Sum of expenses as a percentage of annual income</b>	<b>20%</b>	27%	24%	13%	25%

Note: disproportionate spending would be a percentage exceeding that of the "Sum" column for each expense category.

## Costs of Care: Income Differences

In order to determine if spending varied by income, we examined out-of-pocket spending by income quartiles. Not surprisingly, family caregivers in the lowest income quartile (up to \$32,499 annually) appear to be the most financially strained. This group reports spending, on average, 44% of their annual income on caregiving (see Figures 8a and 8b).



*“I am draining my savings. Making two house payments, two light bills, gas and water bills and cost of gas running him to and from his appointments. We are retired, so we are on a fixed budget.”*

(62 year old male, caring for a son in his 30’s, requiring more than 21 hours of care per week).

*“What will happen if my husband dies before me and I don’t have his income anymore? Where will the money for all these expenses come from?” (61- year old, multiracial female)*

Table 5 shows spending within expense categories by income quartile. What is interesting to note is that about one half of the lowest income quartile's costs are driven by household expenses, as is the case with the highest income quartile's costs.

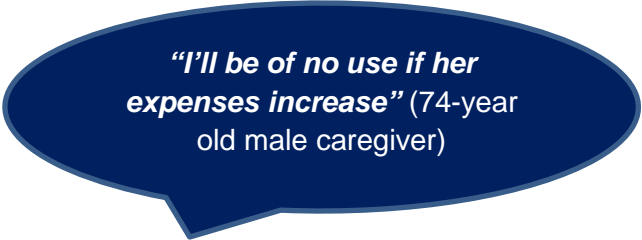
Table 5  
Caregiving expense category figures, by income quartile

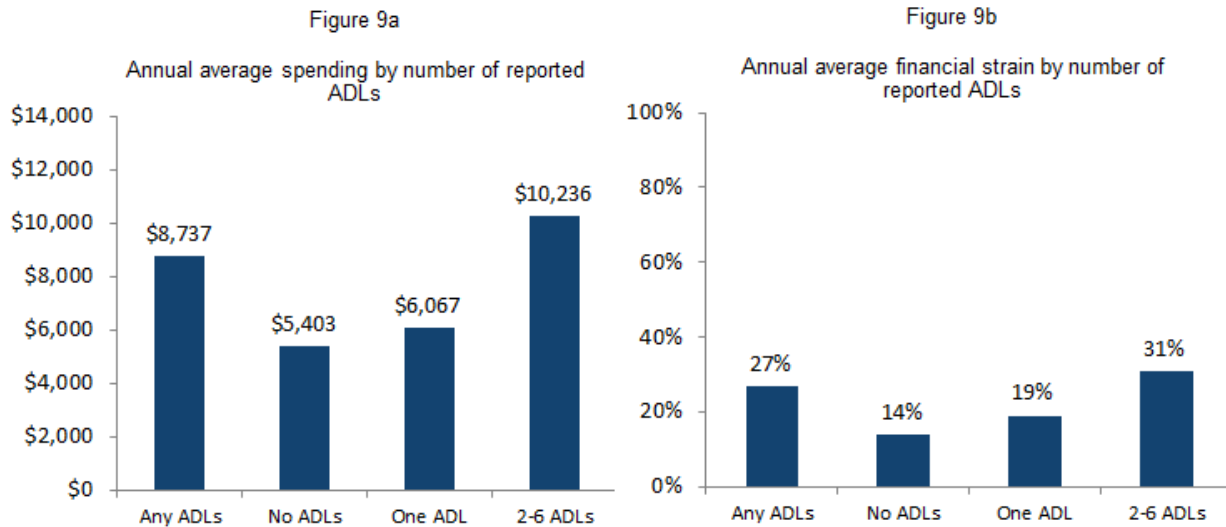
Expense Category	All Caregivers	Lowest Income (up to \$32,499)	Income Quartile 2 (\$32,500-\$54,999)	Income Quartile 3 (\$55,000-\$92,499)	Highest Income (\$92,500 or more)
Sum of all expenses	<b>\$6,954</b>	\$5,114	\$7,373	\$7,360	\$8,201
Medical expenses	\$1,722	\$998	\$3,322	\$1,232	\$1,535
Household expenses	\$2,854	\$2,432	\$1,840	\$2,233	\$4,657
Personal Care Item expenses	\$961	\$684	\$576	\$2,230	\$540
Education\Legal\Travel expenses	\$830	\$437	\$1,286	\$977	\$741
Caregiver personal expenses/Respite (Aides, adult day services, self-care, other paid help, and other expenses)	\$587	\$563	\$350	\$688	\$729
<b>Sum of expenses as a percentage of annual income</b>	<b>20%</b>	44%	16%	9%	7%

Note: disproportionate spending would be a percentage exceeding that of the "Sum" column for each expense category.

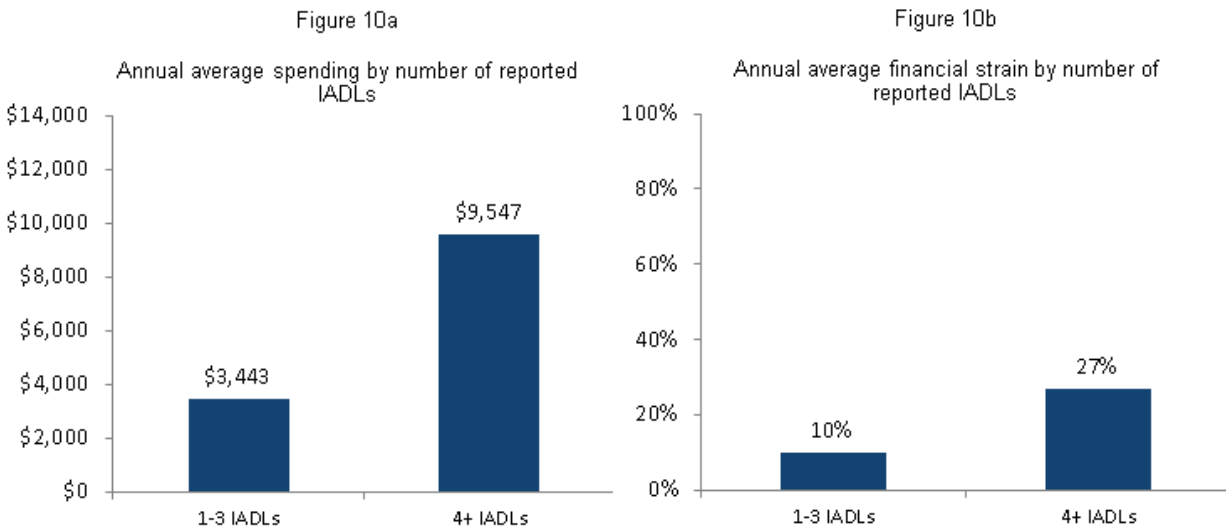
### Costs of Care: Activities of Daily Living (ADL) and Hours of Care per Week

Caregivers indicated which ADLs (Activities of Daily Living) they helped their care recipients with. These included: a) getting in and out of beds and chairs, b) getting dressed, c) getting to and from the toilet, d) bathing/showering, e) dealing with incontinence, and f) feeding. Caregiving expenditures increase in somewhat of a linear fashion with annual caregiving expenditures for those with 2 to 6 ADLs being about double the amount spent by those caregiving for a recipient with no ADLs (\$10,236 and \$5,403 , respectively) (shown in Figures 9a and 9b).

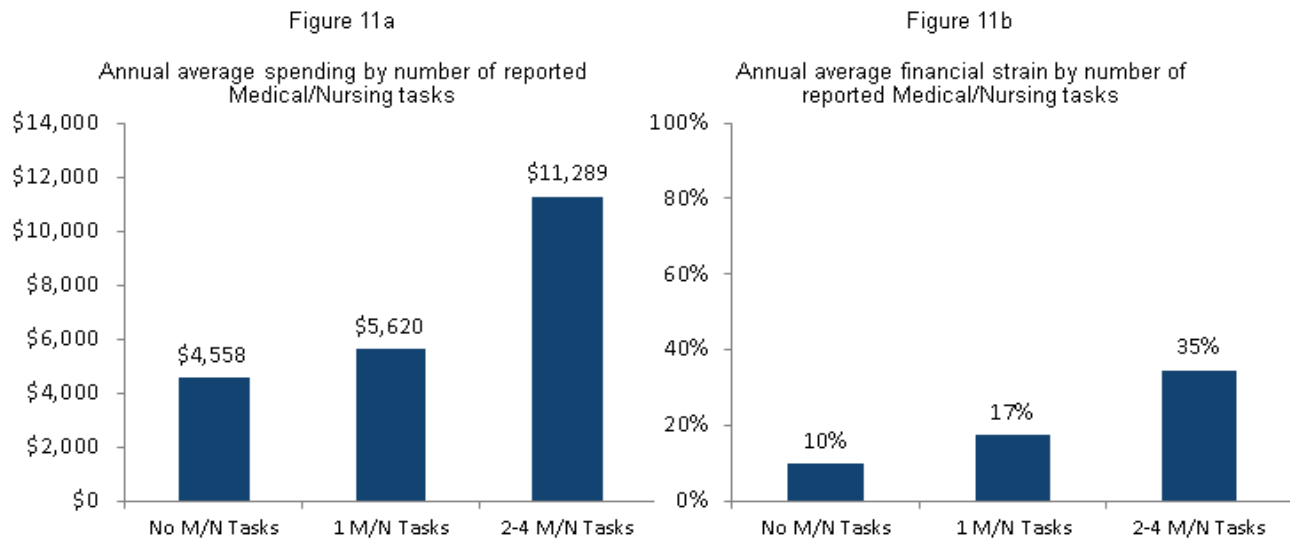




A similar linear pattern is noted for IADLs (instrumental activities of daily living). These include (a) grocery and other shopping, (b) housework/cleaning, (c) providing transportation, (d) managing finances, (e) meal preparation, and (f) arranging for outside care services. Those caring for recipients requiring assistance with 4 or more IADLs spend nearly three times more than those with recipients requiring assistance with 1 to 3 IADLs (\$9,546 versus \$3,443) (shown in Figures 10a and 10b).



Some family caregivers also provide assistance with medical/nursing tasks. These include: medication management, wound care, operating medical equipment, and monitoring blood pressure/blood sugar. For medical/nursing tasks (shown in Figures 11a and 11b), annual caregiving expenditures for those performing 2 to 4 tasks are more than double the amount spent by those caregivers performing no medical nursing tasks (\$11,289 and \$4,558, respectively).



### Costs of Care: Dementia and Mental Health Issues

Caregivers caring for a family member or close friend diagnosed with dementia reported nearly twice the out-of-pocket costs than caregivers whose care recipient does not have dementia (\$10,697 compared to \$5,785). Similarly, caregivers with recipients who had been diagnosed with mental health issues reported higher spending (see Figures 12a and 12b). It is noteworthy that those caring for a recipient with dementia are twice as likely as those caring for a recipient with mental health issues to pay for assistance (45% versus 22%).



Figure 12a

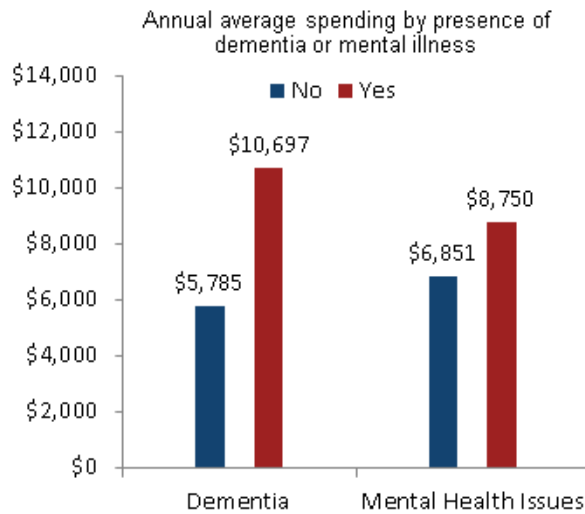
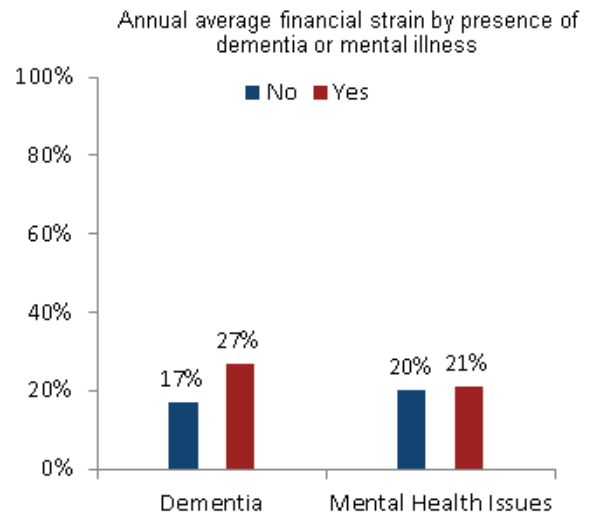


Figure 12b



### Costs of Care: Hours spent on Caregiving

Numerous factors affect the number of hours spent on caregiving. Those devoting more than 21 hours per week are spending nearly triple the amount than those spending five hours or fewer per week (\$11,251 versus \$4,081 respectively) (see Figures 13a and 13b). Among the factors associated with spending six or more hours on care include recipient’s dementia status, long-distance care, caring for a spouse, whether the caregiver can enlist unpaid help or not, whether the recipient is male, and other factors.

Figure 13a

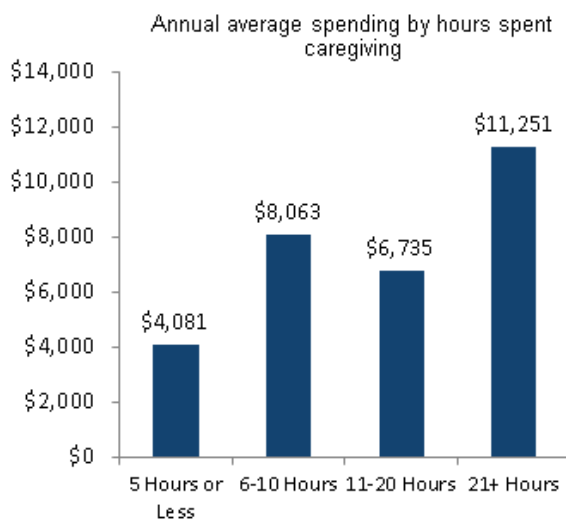
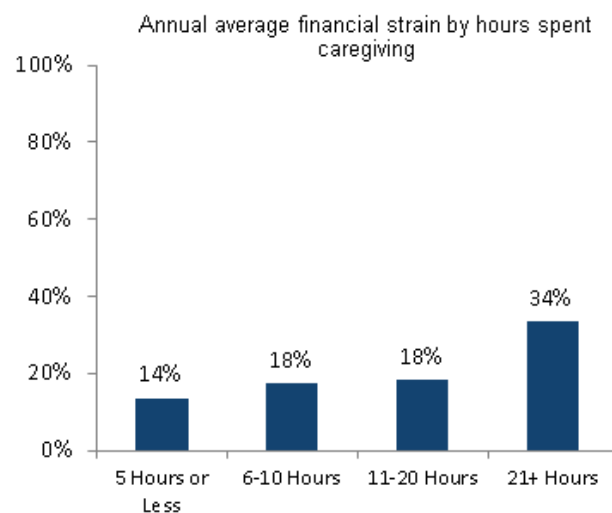


Figure 13b



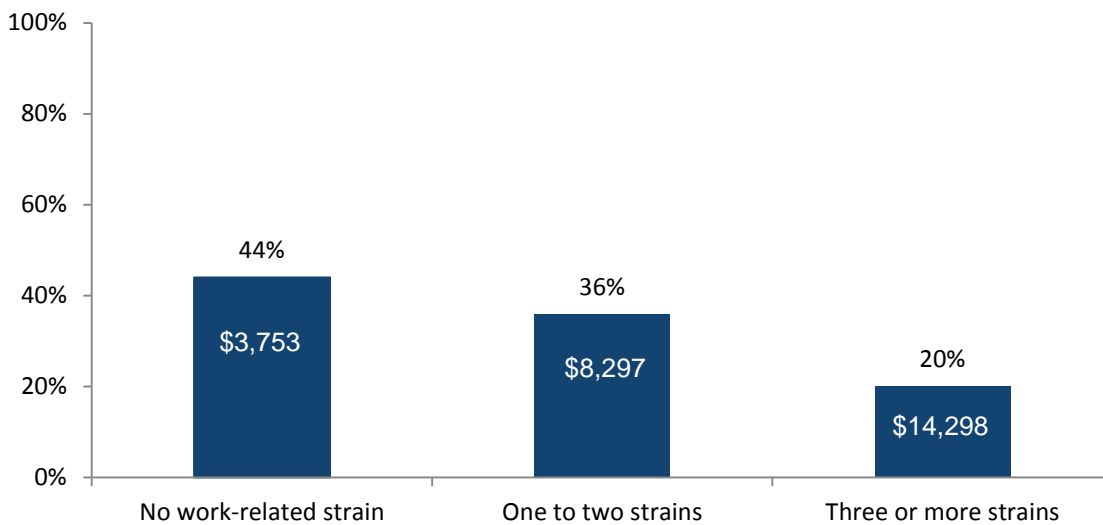
## Work-related Effects

In addition to out-of-pocket spending, many employed caregivers also face work-related strain. This may be in the form of taking additional time off (whether paid or unpaid), reducing their work hours, or leaving the work force altogether to accommodate for the caregiving responsibilities. This can often result in reduced job security, employment benefits and retirement savings.

This study shows that more than half of employed family caregivers (56%) experience at least one work-related strain (see Figure 14) and that two in ten (20%) experience three or more strains. Caregivers who report three or more work-related strains are spending \$14,298 per year on caregiving. This is more than three times the amount of caregivers with no work-related strain (see Figure 14).

Figure 14

Percent of employed family caregivers who report work-related strain

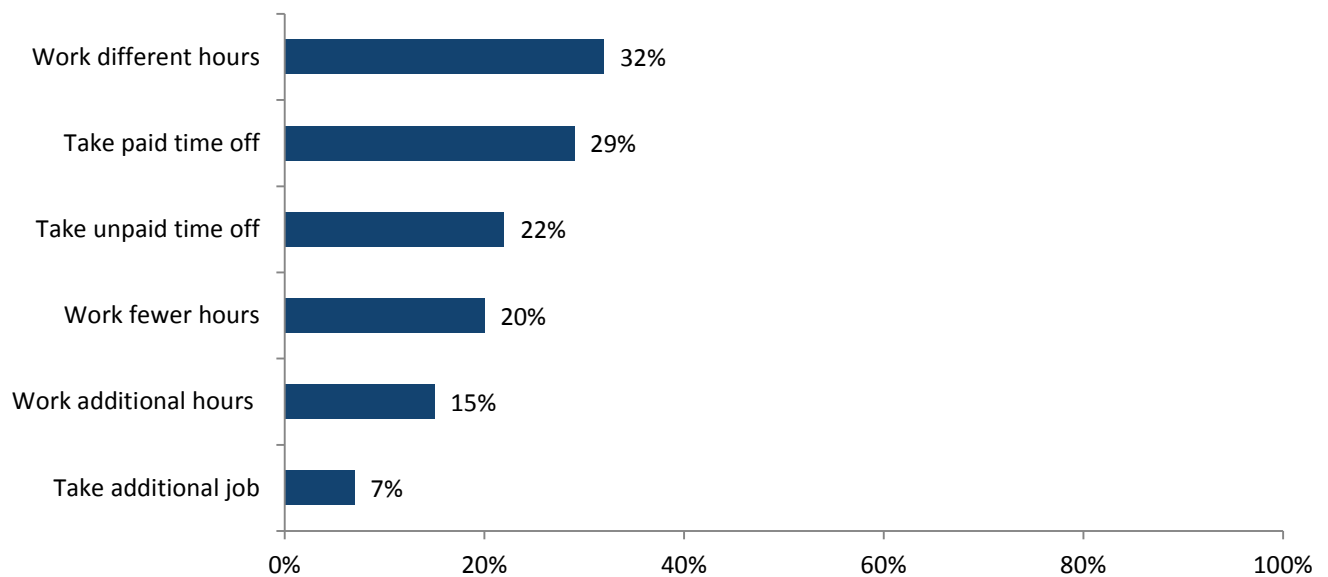


**“My biggest fear is that I will lose my job due to excessive time off”** (51-year old with 2 kids at home, caring for her mother)

The most common type of work-related strain was working different hours (32%). This likely reflects caregivers' need for flexibility-- having to respond when the caregiving role demands it. Relatedly, large percentages of family caregivers also take time off (whether paid or unpaid) and curtail their work hours. (See Figure 15).

Figure 15

Percent of employed family caregivers experiencing the following work-related strains



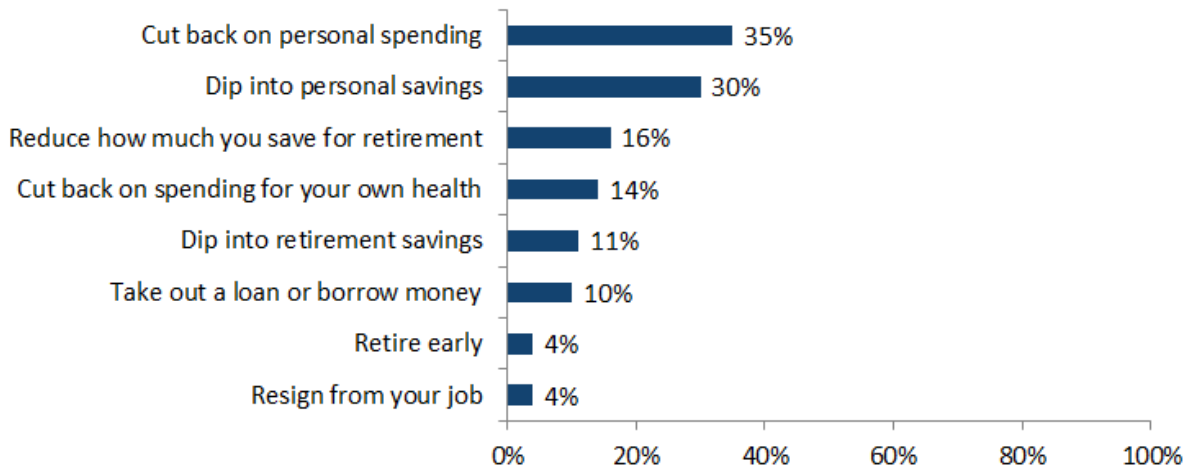
## Personal Sacrifices

Whether or not a caregiver is employed, they have savings goals, expenses and professional goals of their own. Figure 16 suggests how caregiving expenses pose challenges in these areas. More than a third of caregivers (35%) report cutting back on their personal spending due to caregiving expenses and 30% have dipped into personal savings. For both retiring early or resigning from their job, four percent report doing so as a result of caregiving. This suggests a challenging balance, for some, between family caregiving and outside employment.

*“My biggest fear is that their expenses will become more substantial and that I am neglecting myself in caring for them.”* (49-year old African-American male caregiver to a friend)

Figure 16

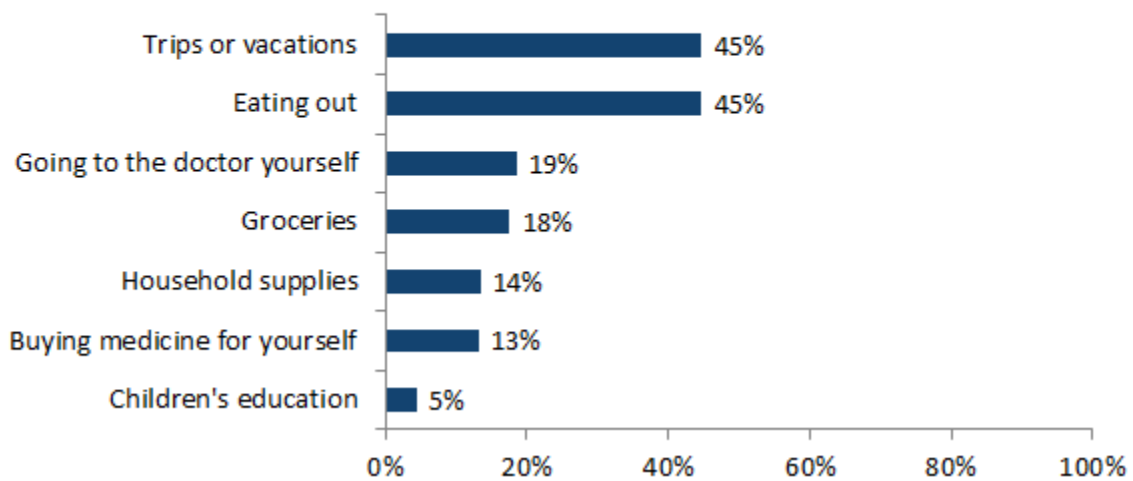
Percent of family caregivers reporting changes in personal spending/savings practices and career



Previously substantial percentages of family caregivers indicated they cut back on certain types of spending to compensate for their caregiving expenses. Asking specifically on what they cut back on, over four in 10 (45%) caregivers said they cut back on eating out and trips or vacations. While these two items may be considered luxury items, family caregivers also cut back on necessities such as their own doctor visits (19%) and groceries for themselves (18%). Figure 17 shows all of the areas where caregivers reduced spending as a result of their caregiving costs.

Figure 17

Percent who say they cut back on certain items due to the cost of caregiving



## Who are the most financially-strained caregivers?

Throughout this report it is noted that several demographic groups of caregivers had greater financial strain. Within these demographic groups it was hypothesized that there are several subgroups that are disproportionately financially-strained. A basic statistical classification method (CHAID) was used to identify these highly financially-strained subgroups.

Highly financially-strained subgroups were determined by identifying the 25% of caregivers with the highest financial strain percentages. The CHAID analysis then combined all of the demographic subgroups of caregivers and recipients searching to find which combinations had the highest concentrations of caregivers in the top quartile of financial strain. These subgroups were considered “highly financially-strained” caregivers.

As had been previously noted, financial strain was closely related to the caregiver’s income quartile. This analysis also finds income a chief, but not sole determinant of being a “highly financially-strained” caregiver. The presence of needing assistance with any ADL was a factor associated with financial strain for all caregivers, despite income. Additionally, race/ethnicity was a factor among the lowest income quartile. Among the two highest-earning quartiles, care for a recipient either living in the same household as the caregiver or long-distance was associated with high financial strain.

- **Among the lowest income caregivers:** The most “highly financially-strained” caregivers were those non-White/non-Asian caregivers caring for someone who needs assistance with at least one ADL. Fully 61% of this subgrouping which were highly financially-strained making them the most strained group.
- **Among the middle income caregivers:** The most “highly financially-strained” caregivers were those caring for a recipient who needs assistance with at least one ADL. Thirty-four percent of this subgroup was highly financially-strained.
- **Among the higher income caregivers:** The most “highly financially-strained” caregivers are those caring for someone who lives with them or more than one hour away and needs assistance with at least one ADL. Forty percent of this higher income subgroup of caregivers is, nonetheless, highly financially strained.

*“My greatest fear is that I will run out of money and that the bottom will fall out. I also wonder what will happen to my son after I am gone....*

*” (54-year old low-income mother caring for her son)*

## Conclusions

This study demonstrates that family caregivers not only spend time and energy caring for an adult with care needs but also spend a significant amount of money of their own. Family caregivers are spending roughly \$7,000 (\$6,954) in 2016 on caregiving expenses which amounts to, on average, 20% of their total income.

Certain groups or types of caregivers are disproportionately spending more than others; however, the overwhelming majority of caregivers (78%) are incurring out-of-pocket costs as a result of caregiving. Higher than average out-of-pocket costs are seen for several groups of caregivers including Hispanic/Latino caregivers, those caring for someone with dementia (also those engaged in many ADL's) and those caring for a loved one from a distance.

In addition to out-of-pocket costs, many caregivers are experiencing work strain and personal strain. More than half of caregivers in this study reported at least one work-related strain (e.g., a change in work hours, taking paid or unpaid time off, etc.). Many family caregivers are also cutting back on their own personal spending and dipping into their savings to accommodate for caregiving costs. For example, roughly half are cutting back on leisure spending and one in six has cut back on retirement savings. This finding raises the importance for not only education and assistance for family caregivers but financial assistance as well such as a family caregiver tax credit that would help address the financial challenges of caregiving.

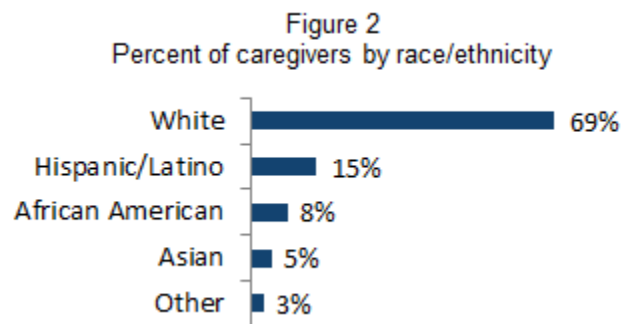
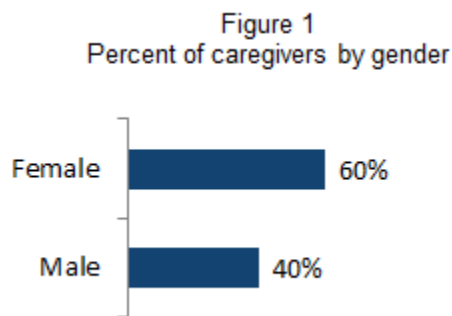
## Appendix A: Profile of Family Caregivers in this Study

A national estimate of caregivers was determined by asking a screening question to find caregivers qualified for the current study. The resulting incidence was 16.2% which represents an estimated 37.5 million U.S. adults currently caring for an adult. These family caregivers are a subset of all family caregivers as the qualified caregiver in the U.S. group is confined to:

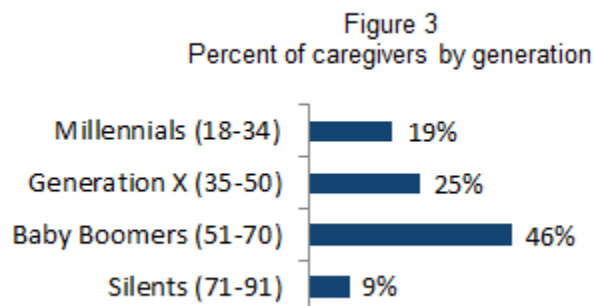
- a) those age 18 or older, *and*
- b) those *currently* serving as a caregiver, *and*
- c) those providing unpaid care, *and*
- d) those caring for an adult recipient.

### Caregivers

Six in 10 caregivers are women and the majority (69%) is white. Fewer than one in 10 (8%) caregivers are African American and 15 percent are Hispanic/Latino (see Figures 1 and 2).



The largest percentage (46%) of caregivers is from the Baby Boomer generation followed by Generation X that comprises one-quarter (25%). The Silent generation represents less than one in 10 (9%) caregivers (see Figure 3).



Due to categorical cutpoints, the lowest income quartile makes up greater than 25% of family caregivers (28%). Additionally, a nearly equal percentage of caregivers fall within the highest income group (27%) (see Figure 4).



Figure 4  
Percent of caregivers by income quartile

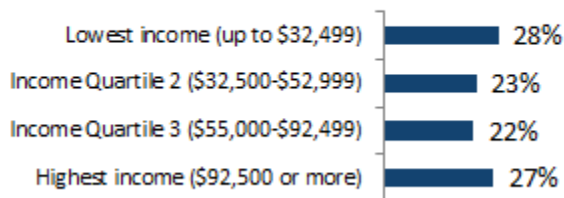


Figure 5 shows the number of ADLs that the family caregiver helps the care recipient with and nearly half (47%) provide assistance with at least one ADL. Figure 6 shows the specific help that caregivers provide and three in 10 caregivers provide help getting in and out of chairs and beds.

Figure 5  
Number of ADLs the caregiver helps with

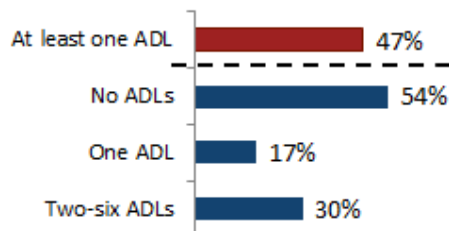


Figure 6  
The ADLs the caregiver helps with

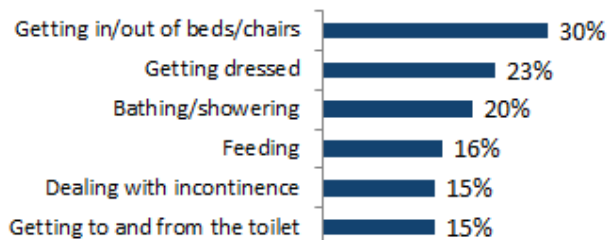


Figure 7 shows the number of IADLs that the caregiver helps the care recipient with and nearly all care recipients require help with at least one IADL. Figure 8 show the individual IADLs where assistance is provided by the caregiver. More than half of caregivers provide assistance with meal preparation, financial management, housework, transportation, and shopping.

Figure 7  
Number of IADLs the caregiver helps with

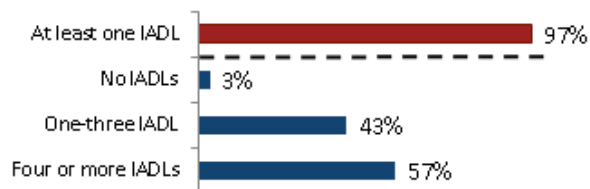
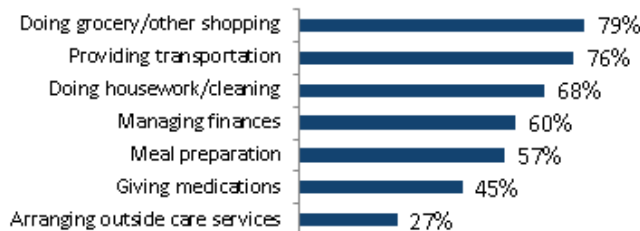
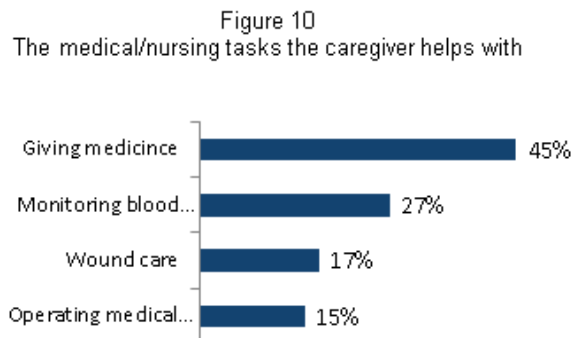
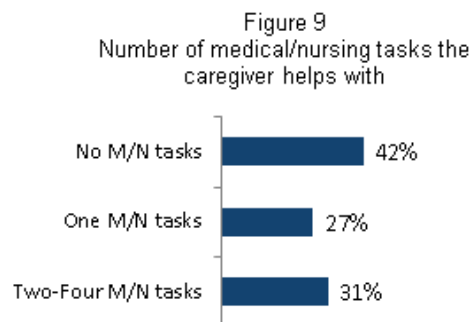


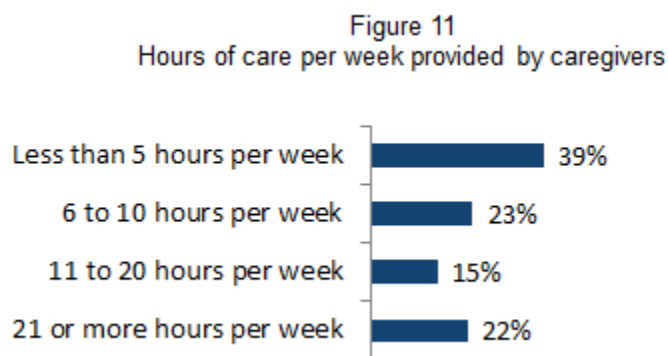
Figure 8  
The IADLs the caregiver helps with



For nearly six in 10 (58%) of those requiring care, caregivers are helping with at least one medical/nursing task (see Figure 9). When it comes to the specific medical/nursing tasks that are being provided, more than two in five (45%) give medicine to their care recipient and over one-quarter (27%) provide blood sugar or blood pressure monitoring (see Figure 10).



Caregiving often requires a large time commitment from the family caregiver. Over one in five (22%) caregivers provides 21 or more hours of assistance per week to their care recipient (see Figure 11).



## Care recipients

Over six in 10 (63%) care recipients are women and over half (52%) are the caregiver's parent. One third (34%) of care recipients is a grandparent, aunt, uncle, or friend of the caregiver (see Figures 12 and 13). Unsurprisingly, most (85%) care recipients are 50 or older (see Figure 14).

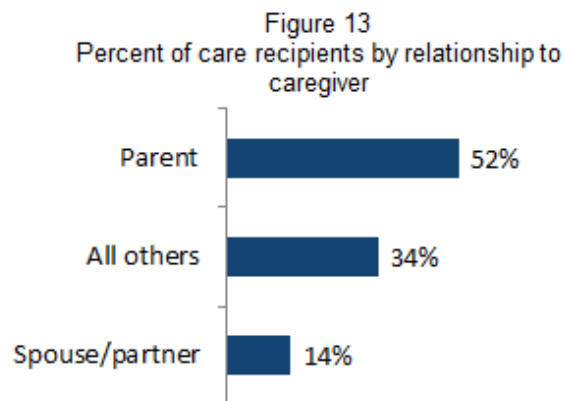
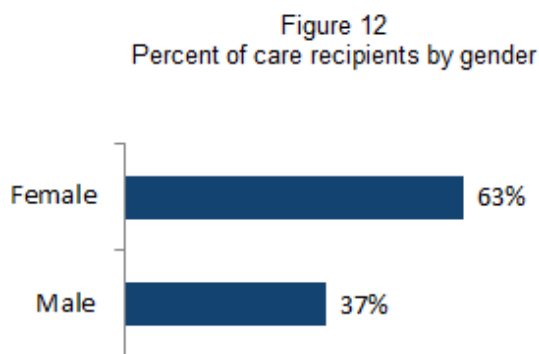
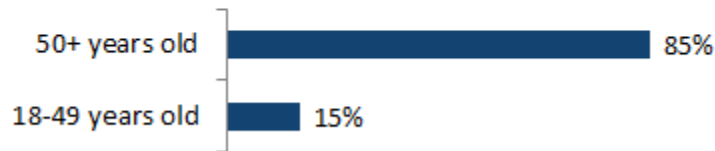


Figure 14  
Percent of care recipients by age



One-quarter of care recipients in this study have been diagnosed with dementia (see Figure 15). About one in 20 (6%) have mental health issues (see Figures 16).

Figure 15  
Percent of care recipients with dementia

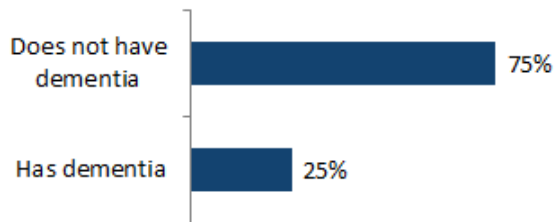
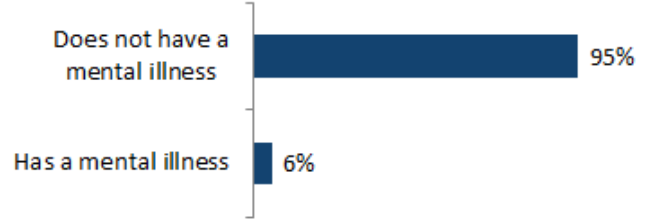


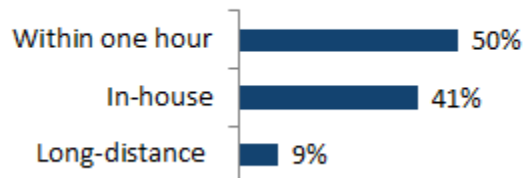
Figure 16  
Percent of care recipients with mental illness



## Location of Family Caregiver

Half of caregivers live within one hour of their care recipient. Four in 10 (41%) care recipients live with their caregivers and relatively few (9%) adults are long-distance caregivers defined as living over an hour away from their care recipient (see Figure 17).

Figure 17  
Percent of caregivers by location of care



## Appendix B: Detailed Methodology

The sample consisted of qualified caregivers defined as those U.S. adults age 18 or older responding “Yes” to the following screener:

“Are you currently providing unpaid care to a relative or friend 18 years or older to help them take care of themselves?”

This may include helping with personal needs or medication management, household chores, or transportation. It might be managing a person's finances, arranging for outside services, preparing meals or grocery shopping, helping with bathing or dressing, or even visiting regularly to see how they are doing. This adult need not live with you.”

Among this sample, research was conducted using two related data sources (with all data being collected on-line between July 18-August 28, 2016 using GfK’s on-line probability-based panel):

The primary data source was a month-long diary study of 1,864 qualified caregivers. Quota samples were established for Hispanic, African American and Asian American caregivers but their at-random incidence resulted in only minor disproportionate representation. Each of the diary study caregivers recorded expenses for one week. Recruitment for the diary study was from 3,277 qualified caregivers identified through an initial screener. Diary study participants did not differ in any systematic way from the remainder of qualified caregivers. The caregivers in the diary study coded each of their recorded caregiving expenses as falling into one of five differing caregiving expense categories (e.g. medical expenses, household expenses, etc. [see Table A1]). Weights were applied to weekly figures to produce a 28-day caregiving expense estimate and to address survey stratification. This 28-day estimate was used to produce an annualized diary expense figure (note: this was done using a multiplier equal to  $365/28 = 13.03$ ).

**Table A1. Dollar amounts and percentages represented by each of the five diary study expense categories (Diary study figures)**

1. Medical expenses	\$1,330.59	28.04%
2. Household expenses	\$1,609.84	33.92%
3. Personal Care Item expenses	\$935.02	19.70%
4. Education\Legal\Travel expenses	\$356.22	7.51%
5. Caregiver personal expenses/Respite	\$513.92	10.83%

\*For tables, category descriptors are necessarily abbreviated. See Diary Study form for the expenses included in each expense category.

The secondary data source was a retrospective survey asking about caregiving outlays over the previous year for each of 19 (non-exhaustive) expense categories (see Table A2). The retrospective survey and the diary study have differing strengths. The diary study is better at capturing routine, often small costs within the study period as well as major expense that occur

within the study period. The retrospective survey is not as good as the diary method at estimating the sum of small, routine costs, but is the only method for capturing large expenses that are not likely to have been observed during a diary study period (but that should be included in annual estimates).

### **Blending raw diary study estimates and retrospective survey expenses**

The intent of the retrospective survey is to detect expensive, “atypical” caregiving expenditures. Some of these atypical expenses *may* occur within the 28-day diary study period but many will occur multiple times throughout the year or otherwise not be wholly captured in the diary study. To estimate the average annual caregiving expenditure for our sample, figures from the 1,864 caregivers providing both diary and retrospective survey data needed to be combined and then averaged. Below is a description of the approach adopted:

1) When blending diary expenses with retrospective survey expenses, there was a desire to maintain the error structure of the annualized diary study expenses (mainly by ending up with an overall expense figure with a similar standard deviation and distribution skew). The 19 individual retrospective survey categories feed into the five general expense categories of the diary study (see Table A2). This enables qualified expenses from each of the 19 retrospective survey expense categories to be included in the overall caregiver expense figure.

2) Retrospective survey results were available for 3,277 qualified caregivers allowing for an outlier analysis among the larger qualified caregiver group (3,277). A similar analysis was done for the subset of qualified caregivers who completed the diary study (1,864). As expected, for most of the 19 expense categories in the retrospective survey, maximum values and the percentages of cases in the right tail of the distribution (“outliers”) were greater among the 3,277 caregivers than among the 1,864 diarists.

3) The approach leading to a conservative inclusion of “atypical” or “outlier” expenses was to review expenses in each of the 19 retrospective survey expense categories entered by diary study participants to find the retrospective survey values that diarists recorded that were three or more standard deviations from the means of each of the retrospective survey expense categories. In essence, this allows for the addition of only a few major expenditures reported by the 1,864 caregivers on the retrospective survey. This low volume of qualified expenses, though often representing high dollar amounts, were added to the diarists’ annualized diary expenditures to arrive at an overall caregiving expense total. This approach preserved the error structure of the diary survey expenses and, by including figures from the 19 component categories, allowed for a summary of expenses by general expense categories (i.e. the 5 expenses categories used in the diary study [e.g. “medical”]).

Table A2 presents the distribution of retroactive survey expenses across the 19 caregiver expense types. Although the percentages sum to 100%, the non-exhaustive nature of the category renders these percentages as merely illustrative and, possibly, not accurate reflections of the share of caregivers’ expenses linked to each of the 19 categories. That said, high percentages for housing and medical-related categories are consistent with what was found in the diary study (and its related 5-category expense designation). Table A2 also presents the average *non-redundant retrospective survey expenses*). These expenses are “non-redundant” as they are expenditures not

believed to have been captured in the diary study (per the methods described above). The figure in the right column of Table A2 reflects the mean dollar amounts that were added to the annualized diary study expenses to come up with an overall annual caregiving expense figure.

**Table A2. Measures related to 19 caregiving expense categories in the retrospective survey**

	Related Diary Study expense category	Distribution of retrospective survey expenses	Non-redundant retrospective survey expenses
<b>Retrospective survey figures</b>		100.00%	\$2,208.80
1. Home modifications related to mobility/safety issues (e.g., installing ramps, bathroom modifications, etc.)	Household	11.54%	\$332.25
2. Remote health and/or safety monitoring devices	Household	0.48%	\$9.57
3. Nursing home or long-term care facility fees	Medical	3.98%	\$145.49
4. Assisted living or other residential setting fees	Household/Medical	9.64%	\$188.23
5. Independent living/retirement community fees	Household	0.97%	\$30.24
6. Travel (includes airfare, trains, etc. as well as hotels, parking, gas, etc.)	Education\Travel\Legal	10.53%	\$210.07
7. Legal fees related to the caregiving situation	Education\Travel\Legal	0.93%	\$26.45
8. Relocation costs for you or the person you are caring for	Education\Travel\Legal	5.88%	\$197.13
9. Major medical equipment such as a wheel chair, motorized scooter, special bed, etc.	Medical	1.13%	\$30.35
10. Services such as home care aides, adult day services	Caregiver personal expenses\Respite	1.79%	\$62.96
11. Medical, dental, or vision insurance premiums	Medical	7.34%	\$131.25
12. Long-term care insurance premiums	Medical	1.57%	\$51.68
13. Caregiver support services such as geriatric care managers or counseling	Caregiver personal expenses\Respite	0.38%	\$10.04
14. Services such as household care (e.g. cleaning, lawn, home maintenance)	Housing	4.76%	\$79.07
15. Clothing for the person you care for	Personal care items	2.20%	\$26.02
16. Other housing payments such as rent, utilities, phone/computer service	Household	24.42%	\$449.72
17. Home repairs	Household	9.68%	\$154.96
18. Retrofitting vans or vehicles to accommodate wheel chairs	Education\Travel\Legal	1.38%	\$40.61
19. Assistive technologies and devices (e.g., hearing aids, cognitive assistance devices, etc.)	Medical	1.41%	\$32.71

The 19 expenditure categories were referred to (among other expenses) in the diary study instrument as belonging to 1 (and only 1) of the five expense categories, for instance, “medical,

dental or vision insurance premiums” are described in the diary studies as expenses to be coded as “medical expenses”. Accordingly, the 19 separate non-redundant dollar amounts (in Table A2.) can be “rolled into” their corresponding diary study expense category (in short, all 19 retrospective survey expense types “belong” to one of the five diary study categories). Table A3 presents the final overall caregiver expense and its component expense elements.

**Table A3: Constituent elements of the overall average annual caregiving expense figure**

	Diary study expenses	Retrospective survey expenses	Total	Percent of total expenses
Average annual caregiver expense	\$4,745.59	\$2,208.81	<b>\$6,954.40</b>	100.00%
1. Medical expenses	\$1,330.59	\$391.48	\$1,722.07	24.76%
2. Household expenses	\$1,609.84	\$1,244.05	\$2,853.89	41.04%
3. Personal Care Item expenses	\$935.02	\$26.02	\$961.04	13.82%
4. Education\Legal\Travel expenses	\$356.22	\$474.26	\$830.48	11.94%
5. Caregiver personal expenses/Respite	\$513.92	\$73.00	\$586.92	8.44%

By way of summary, the final caregiving expense figures are comprised as shown in Table A4.

**Table A4: Composition of the average annual caregiver expense figure, by data source**

	Average annual expense	Percent of total expenses (by study component)
<b>Total expenses</b>	<b>\$6,954.40</b>	100%
Diary study expenses	\$4,745.49	68%
Retrospective survey expenses	\$2,208.81	32%

### Measure of financial strain and other costs

The **raw dollar amounts** devoted to caregiving do not account for the fact that the same caregiving expenses for a caregiver with a low annual income will prove more of a financial strain than the same caregiving expense would for a higher-income caregiver. For this reason, the following analysis will present caregiving expenses as raw dollar amounts and also as a **percentage of a caregiver’s annual income** (given by: average annual caregiving expense divided by annual household income). In terms of regarding the percentage measure as an indicator of financial strain, it should be noted that the higher the percentage of one’s income devoted to caregiving, the less one has of their remaining income to devote to other expenses.

Throughout this report additional measures, when significant differences are noted, will be included as indicators of caregiver costs (although these measures are not truly *expenses*). Examples of



these measures include hours devoted to caregiving, whether one is the sole caregiver or has some assistance, and, for the subset of caregivers who are employed, the number of work-related strains (e.g. unpaid time off, reduced hours, etc.) are considered. These are included to provide context for the observed expense figures, given that these costs may be substitutes or complements for caregiving expenditures.

**Incidence** The present study was designed chiefly to estimate caregiver expenses for a specific group of caregivers—unpaid, adult caregivers currently providing care to another adult. The current study also had a stratified sample design that differs from most other caregiving studies in that it only includes current caregivers and three target populations (African American, Hispanic/Latino, and Asian). National caregiver incidences can be estimated from the current study but it is not a profile that should necessarily comport with previous studies, given the unmatched definitions of caregiving and differing methods.

An incidence of 16.2% of Americans was observed. That is, an estimated 37.5 million U.S. adults are currently providing unpaid care to an adult recipient. There are some differences in caregiving incidences by race/ethnicity group. The general pattern is that non-White adults are disproportionately likely to currently be providing unpaid care to an adult recipient.

Race/ethnicity	Caregiving incidence
White, non-Hispanic	15.3%
African American, non-Hispanic	21.6%
Asian American, non-Hispanic	16.8%
Hispanic, Any	18.2%
Multiple Races, Other	20.5%

## Appendix C: Annotated Questionnaire

### 2016 Caregiving Costs Study 18+ Caregivers (n=3,277\*)

(\*Note: this includes the larger sample of caregivers who participated in the retrospective study; the percentages may vary slightly between the annotated questionnaire and the main document)

<b>S03 Where does the person you care for live?</b>	<b>Total</b>
In your household	40.8%
Within twenty minutes of your home	36.7%
Between twenty minutes and an hour from your home	12.7%
One to two hours from your home	3.5%
More than two hours away	6.2%
Refused	0.1%

<b>S04 [Lives in Different Household] Where does the person you care for live?</b>	<b>Total</b>
In their own home	67.3%
In someone else's home	6.2%
In an independent living or retirement community	6.5%
In an assisted living facility or other residential setting where some care is provided	10.4%
In an nursing care or long-term care facility	6.8%
Somewhere else	2.9%

<b>A01 Is the person you are caring for...?</b>	<b>Total</b>
Male	37.2%
Female	62.8%

<b>A02 Who are you caring for?</b>	<b>Total</b>
Aunt or great aunt	2.3%
Brother	2.3%
Brother-in-law	0.6%
Daughter	2.6%
Daughter-in-law	0.1%
Father	9.9%
Father-in-law	2.6%
Companion/partner	3.2%
Friend/neighbor	7.7%
Grandfather or great grandfather	0.7%
Grandfather-in-law or great grandfather-in-law	0.1%
Grandmother or great grandmother	2.6%
Grandmother-in-law or great grandmother-in-law	0.2%
Adult grandson or adult great grandson	0.3%
Adult granddaughter or adult great granddaughter	0.1%

## 2016 Caregiving Costs Study

### 18+ Caregivers (n=3,277\*)

(\*Note: this includes the larger sample of caregivers who participated in the retrospective study; the percentages may vary slightly between the annotated questionnaire and the main document)

Husband	9.6%
Mother	31.6%
Mother-in-law	5.2%
Sister	2.8%
Nephew	0.3%
Niece	0.2%
Sister-in-law	0.6%
Son	4.3%
Son-in-law	0.1%
Stepmother	0.1%
Stepfather	0.2%
Step brother	0.0%
Step sister	0.0%
Uncle or great uncle	0.7%
Wife	6.1%
Other	3.1%

Which of these activities do you help your care recipient with...?

#### **A05\_1 Getting in and out of beds and chairs** **Total**

Yes	29.2%
No	70.3%
Refused	0.5%

#### **A05\_2 Getting dressed** **Total**

Yes	27.2%
No	72.3%
Refused	0.5%

#### **A05\_3 Getting to and from the toilet** **Total**

Yes	15.3%
No	84.1%
Refused	0.6%

#### **A05\_4 Bathing or showering** **Total**

Yes	23.0%
No	76.4%
Refused	0.6%

#### **A05\_5 Dealing with incontinence or diapers** **Total**

Yes	18.5%
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## 2016 Caregiving Costs Study

### 18+ Caregivers (n=3,277\*)

(\*Note: this includes the larger sample of caregivers who participated in the retrospective study; the percentages may vary slightly between the annotated questionnaire and the main document)

No	80.9%
Refused	0.6%

<b>A05_6 Feeding him or her</b>	<b><u>Total</u></b>
Yes	17.4%
No	82.0%
Refused	0.7%

<b>A05_7 Preparing food for special diets or tube feedings</b>	<b><u>Total</u></b>
Yes	23.3%
No	76.1%
Refused	0.5%

<b>A05_8 Giving medicines, like pills, eye drops, or injections for his/her condition</b>	<b><u>Total</u></b>
Yes	47.5%
No	52.2%
Refused	0.3%

<b>A05_9 Monitoring blood pressure or blood sugar</b>	<b><u>Total</u></b>
Yes	26.8%
No	72.5%
Refused	0.6%

<b>A05_10 [Operating equipment like hospital beds, wheel chairs, oxygen tanks, nebulizers, or suctioning tubes</b>	<b><u>Total</u></b>
Yes	16.6%
No	82.8%
Refused	0.6%

<b>A05_11 Doing wound care</b>	<b><u>Total</u></b>
Yes	18.2%
No	81.2%
Refused	0.6%

Do you provide help to your care recipient with...?

<b>A06_1 Managing finances, such as paying bills or filling out insurance claims</b>	<b><u>Total</u></b>
Yes	65.9%
No	33.9%
Refused	0.2%

<b>A06_2 Grocery or other shopping</b>	<b><u>Total</u></b>
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## 2016 Caregiving Costs Study

### 18+ Caregivers (n=3,277\*)

(\*Note: this includes the larger sample of caregivers who participated in the retrospective study; the percentages may vary slightly between the annotated questionnaire and the main document)

Yes	79.6%
No	20.3%
Refused	0.1%
<b>A06_3 Housework, such as doing dishes, laundry, or straightening up</b>	
	<b><u>Total</u></b>
Yes	68.7%
No	31.1%
Refused	0.2%
<b>A06_4 Preparing meals</b>	
	<b><u>Total</u></b>
Yes	58.8%
No	41.0%
Refused	0.2%
<b>A06_5 Transportation, either by driving him/her, or helping him/her get transportation</b>	
	<b><u>Total</u></b>
Yes	80.3%
No	19.6%
Refused	0.1%
<b>A06_6 Arranging outside services, such as nurses, home care aides, or meals-on wheels</b>	
	<b><u>Total</u></b>
Yes	30.3%
No	69.4%
Refused	0.3%
<b>A06_7 Advocating for him/her with health care providers, community services, or government agencies</b>	
	<b><u>Total</u></b>
Yes	62.3%
No	37.4%
Refused	0.3%
<b>A06_8 Monitoring the severity of his/her condition so that you can adjust care</b>	
	<b><u>Total</u></b>
Yes	57.6%
No	42.1%
Refused	0.3%
<b>A06_9 Communicating with health care providers like doctors, nurses, or social workers about his/her care</b>	
	<b><u>Total</u></b>
Yes	71.6%
No	28.2%
Refused	0.2%

## 2016 Caregiving Costs Study

### 18+ Caregivers (n=3,277\*)

(\*Note: this includes the larger sample of caregivers who participated in the retrospective study; the percentages may vary slightly between the annotated questionnaire and the main document)

#### **A07 What is the main problem or illness your care recipient has, for which he/she needs your care? Total**

Alzheimer's, confusion, dementia, forgetfulness	12.6%
Arthritis	2.7%
Back problems	4.0%
Blood pressure, hypertension	1.4%
Brain damage or injury	1.3%
Broken bones	1.4%
Cancer	5.0%
Developmental or intellectual disability, mental retardation, Down syndrome	2.5%
Diabetes	3.8%
Feeble, unsteady, falling	3.4%
Hearing loss, deafness	0.6%
Heart disease, heart attack	3.3%
Lung disease, emphysema, COPD	2.5%
Mental illness, emotional illness, depression	4.9%
Mobility problem, can't get around	6.1%
Old age, Aging	19.3%
Parkinson's	2.4%
Stroke	3.8%
Substance, drug, alcohol abuse	0.6%
Surgery, wounds	2.1%
Vision loss, blindness, can't see well	3.7%
Other (specify)	10.4%
Not sure	2.0%
Refused	0.1%

#### **A08 Does the person you are caring for have Alzheimer's Disease, dementia, or another form of cognitive impairment? Total**

Yes	28.7%
No	71.2%
Refused	0.1%

#### **A09 Approximately how many hours per week do you spend providing care to your care recipient? Total**

5 hours or fewer	38.3%
6-10 hours	22.4%
11-20 hours	15.4%
21-30 hours	7.2%
More than 30 hours	16.6%
Refused	0.1%

## 2016 Caregiving Costs Study

### 18+ Caregivers (n=3,277\*)

(\*Note: this includes the larger sample of caregivers who participated in the retrospective study; the percentages may vary slightly between the annotated questionnaire and the main document)

<b>A10 How long have you been providing care to your care recipient?</b>	<b>Total</b>
Less than six months	10.7%
Six months to less than one year	9.6%
One year to less than three years	26.3%
Three years to less than five years	19.3%
Five years or more	34.1%

<b>A11 Has anyone else provided unpaid help to your care recipient during the last 12 months?</b>	<b>Total</b>
Yes	52.4%
No	47.6%
Refused	0.1%

<b>A12 Who would you consider to be the person who provides most of the unpaid care for your care recipient?</b>	<b>Total</b>
You (yourself)	67.6%
Someone else	20.6%
We split it evenly	11.8%

<b>A13 During the last 12 months, did your care recipient receive paid help from any aides, housekeepers, or other people who were paid to help him/her?</b>	<b>Total</b>
Yes	34.4%
No	65.5%
Refused	0.1%

<b>A14 Approximately how many hours per week did your [A02 RESPONSE] receive paid help?</b>	<b>Total</b>
10 hours or fewer	54.5%
11-20 hours	12.1%
21-30 hours	8.6%
31-40 hours	5.5%
More than 40 hours	19.4%

<b>A15 How much of a financial strain would you say that caring for your care recipient is for you?</b>	<b>Total</b>
Not a strain at all	40.8%
2	23.1%
3	20.1%
4	8.8%
Very much a strain	7.3%
Refused	0.0%



## 2016 Caregiving Costs Study

### 18+ Caregivers (n=3,277\*)

(\*Note: this includes the larger sample of caregivers who participated in the retrospective study; the percentages may vary slightly between the annotated questionnaire and the main document)

In the past 12 months, have you had any out-of-pocket expenses for:

<b>A16_1 Home modifications related to mobility/safety issues</b>	<b><u>Total</u></b>
Yes	18.6%
No	81.2%
Refused	0.1%
<b>16_2 Remote health and/or safety monitoring devices</b>	<b><u>Total</u></b>
Yes	8.2%
No	91.7%
Refused	0.1%
<b>A16_3 Nursing home or long-term care facility fees</b>	<b><u>Total</u></b>
Yes	3.0%
No	96.8%
Refused	0.2%
<b>A16_4 Assisted living or other residential setting fees</b>	<b><u>Total</u></b>
Yes	3.7%
No	96.2%
Refused	0.1%
<b>A16_5 Independent living/retirement community fees</b>	<b><u>Total</u></b>
Yes	2.3%
No	97.5%
Refused	0.2%
<b>A16_6 Travel to visit your care recipient</b>	<b><u>Total</u></b>
Yes	58.7%
No	41.2%
Refused	0.0%
<b>A16_7 Legal fees related to the caregiving situation</b>	<b><u>Total</u></b>
Yes	5.8%
No	94.1%
Refused	0.2%
<b>A16_8 Relocation costs for you or the person you are caring for</b>	<b><u>Total</u></b>
Yes	6.9%
No	93.0%
Refused	0.2%

## 2016 Caregiving Costs Study

### 18+ Caregivers (n=3,277\*)

(\*Note: this includes the larger sample of caregivers who participated in the retrospective study; the percentages may vary slightly between the annotated questionnaire and the main document)

#### **A16\_9 Major medical equipment such as a wheel chair, motorized scooter, special bed, etc.** **Total**

Yes	9.8%
No	90.1%
Refused	0.2%

#### **A16\_10 Services such as home care aides, adult day services** **Total**

Yes	6.2%
No	93.7%
Refused	0.1%

#### **A16\_11 Medical, dental, or vision insurance premiums** **Total**

Yes	20.3%
No	79.6%
Refused	0.2%

#### **A16\_12 Long-term care insurance premiums** **Total**

Yes	5.6%
No	94.2%
Refused	0.2%

#### **A16\_13 Caregiver support services such as geriatric care managers or individual or family counseling** **Total**

Yes	3.9%
No	95.9%
Refused	0.2%

#### **A16\_14 Services such as household care** **Total**

Yes	28.9%
No	71.0%
Refused	0.1%

#### **A16\_15 Clothing for the person you care for** **Total**

Yes	35.9%
No	64.0%
Refused	0.2%

#### **A16\_16 Other housing payments such as rent, utilities, phone/computer service** **Total**

Yes	33.3%
No	66.5%
Refused	0.1%

## 2016 Caregiving Costs Study

### 18+ Caregivers (n=3,277\*)

(\*Note: this includes the larger sample of caregivers who participated in the retrospective study; the percentages may vary slightly between the annotated questionnaire and the main document)

<b>A16_17 Home repairs</b>	<b>Total</b>
Yes	31.1%
No	68.7%
Refused	0.2%

<b>A16_18 Retrofitting vans or vehicles to accommodate wheel chairs</b>	<b>Total</b>
Yes	2.2%
No	97.6%
Refused	0.2%

<b>A16_19 Assistive technologies and devices</b>	<b>Total</b>
Yes	10.1%
No	89.7%
Refused	0.2%

Have you had to do any of the following as a result of caregiving?

<b>A20_1 Work more hours at your job</b>	<b>Total</b>
Yes	14.7%
No	85.0%
Refused	0.3%

<b>A20_2 Work fewer hours at your job</b>	<b>Total</b>
Yes	22.4%
No	77.3%
Refused	0.3%

<b>A20_3 Work different hours at your job</b>	<b>Total</b>
Yes	32.3%
No	67.4%
Refused	0.3%

<b>A20_4 Take an additional job</b>	<b>Total</b>
Yes	6.6%
No	93.1%
Refused	0.3%

<b>A20_5 Take paid time off work</b>	<b>Total</b>
Yes	30.5%
No	69.2%

## 2016 Caregiving Costs Study

### 18+ Caregivers (n=3,277\*)

(\*Note: this includes the larger sample of caregivers who participated in the retrospective study; the percentages may vary slightly between the annotated questionnaire and the main document)

Refused	0.3%
<b>A20_6 Take unpaid time off work</b>	<b>Total</b>
Yes	20.8%
No	78.9%
Refused	0.3%
<b>A20_7 Resign from your job</b>	<b>Total</b>
Yes	4.8%
No	95.0%
Refused	0.2%
<b>A20_8 Retire early</b>	<b>Total</b>
Yes	6.5%
No	93.4%
Refused	0.2%
<b>A20_9 Dip into your personal savings to cover expenses</b>	<b>Total</b>
Yes	32.3%
No	67.6%
Refused	0.1%
<b>A20_10 Dip into your retirement savings to cover expenses</b>	<b>Total</b>
Yes	13.1%
No	86.8%
Refused	0.1%
<b>A20_11 Reduce how much you save for retirement</b>	<b>Total</b>
Yes	18.6%
No	81.2%
Refused	0.2%
<b>A20_12 Take out a loan, borrow from a friend or family member or assume other debts to cover expenses</b>	<b>Total</b>
Yes	10.6%
No	89.2%
Refused	0.2%
<b>A20_13 Cut back on personal spending to cover expenses</b>	<b>Total</b>
Yes	37.7%
No	62.2%
Refused	0.1%

## 2016 Caregiving Costs Study

### 18+ Caregivers (n=3,277\*)

(\*Note: this includes the larger sample of caregivers who participated in the retrospective study; the percentages may vary slightly between the annotated questionnaire and the main document)

<b>A20_14 Cut back on spending for your own health care</b>	<b>Total</b>
Yes	14.0%
No	85.9%
Refused	0.1%

<b>A22 Would you say the financial impact of having to take unpaid leave has...</b>	<b>Total</b>
Not been a burden at all	21.4%
Been a minor burden	62.2%
Been a major burden	16.3%

People might cut back on spending due to the costs of caregiving. Please indicate if any of these apply to you. Did you cut back on...?

<b>C02_1 Groceries like bread, fruit, vegetables, and meat</b>	<b>Total</b>
Yes	16.0%
No	80.5%
Refused	3.5%

<b>C02_2 Eating out, delivery or take-out</b>	<b>Total</b>
Yes	42.2%
No	55.2%
Refused	2.6%

<b>C02_3 [Household supplies like shampoo, detergent, or toilet paper]</b>	<b>Total</b>
Yes	11.5%
No	85.0%
Refused	3.4%

<b>C02_4 Trips or vacations</b>	<b>Total</b>
Yes	44.0%
No	53.3%
Refused	2.7%

<b>C02_5 Your children's education</b>	<b>Total</b>
Yes	3.9%
No	91.7%
Refused	4.3%

<b>C02_6 Going to the doctor yourself</b>	<b>Total</b>
Yes	15.9%
No	80.7%

## 2016 Caregiving Costs Study

### 18+ Caregivers (n=3,277\*)

(\*Note: this includes the larger sample of caregivers who participated in the retrospective study; the percentages may vary slightly between the annotated questionnaire and the main document)

Refused	3.4%
<b>C02_7 Buying medicine for yourself</b>	<b>Total</b>
Yes	10.1%
No	86.2%
Refused	3.7%
<b>C02_8 Other</b>	<b>Total</b>
Yes	6.9%
No	53.8%
Refused	39.3%
<b>DEMOGRAPHICS</b>	
<b>Gender</b>	<b>Total</b>
Male	38.9%
Female	61.1%
<b>Reside Status</b>	<b>Total</b>
Caregiver resides with care recipient	40.8%
Caregiver resides separately from care recipient	59.2%
<b>Race</b>	<b>Total</b>
White	87.2%
Black or African American	7.4%
American Indian or Alaska Native	0.5%
Asian	2.1%
Native Hawaiian/Pacific Islander	0.1%
Other	2.7%
<b>Hispanic Descent</b>	<b>Total</b>
No, I am not	87.7%
Yes, Mexican, Mexican American, Chicano	6.2%
Yes, Puerto Rican	1.3%
Yes, Cuban, Cuban American	0.9%
Yes, Other	3.9%
<b>Student Status</b>	<b>Total</b>
Full-time student	2.9%
Part-time student	2.5%
Not enrolled in school	94.6%

## 2016 Caregiving Costs Study

### 18+ Caregivers (n=3,277\*)

(\*Note: this includes the larger sample of caregivers who participated in the retrospective study; the percentages may vary slightly between the annotated questionnaire and the main document)

Refused 0.1%

<b>Age</b>	<b>Total</b>
18-24	2.1%
25-34	10.5%
35-44	11.1%
45-54	16.4%
55-64	25.8%
65-74	23.9%
75+	10.2%

<b>Education</b>	<b>Total</b>
Less than high school	3.2%
High school	15.6%
Some college	34.2%
Bachelor's degree or higher	46.9%

<b>Household Head</b>	<b>Total</b>
Yes	87.9%
No	12.1%

<b>Household Size</b>	<b>Total</b>
1	24.3%
2	42.7%
3	14.3%
4	10.8%
5	4.7%
6	2.1%
7+	1.3%

<b>Children (younger than 18) in the Household</b>	<b>Total</b>
Yes	26.7%
No	73.3%

<b>Household Type</b>	<b>Total</b>
One-family house detached from any other house	71.8%
One-family house attached to one or more houses	8.4%
Building with 2 or more apartments	16.4%
Mobile home	3.2%
Boat, RV, van, etc.	0.2%

<b>Household Size</b>	<b>Total</b>
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## 2016 Caregiving Costs Study

### 18+ Caregivers (n=3,277\*)

(\*Note: this includes the larger sample of caregivers who participated in the retrospective study; the percentages may vary slightly between the annotated questionnaire and the main document)

Less than \$5,000	2.7%
\$5,000 to \$7,499	1.3%
\$7,500 to \$9,999	1.6%
\$10,000 to \$12,499	2.2%
\$12,500 to \$14,999	2.2%
\$15,000 to \$19,999	3.2%
\$20,000 to \$24,999	4.7%
\$25,000 to \$29,999	4.8%
\$30,000 to \$34,999	5.2%
\$35,000 to \$39,999	5.7%
\$40,000 to \$49,999	9.5%
\$50,000 to \$59,999	9.0%
\$60,000 to \$74,999	11.4%
\$75,000 to \$84,999	7.7%
\$85,000 to \$99,999	8.3%
\$100,000 to \$124,999	8.9%
\$125,000 to \$149,999	4.5%
\$150,000 to \$174,999	2.8%
\$175,000 or more	4.4%
<b>Marital Status</b>	<b>Total</b>
Married	57.2%
Widowed	7.3%
Divorced	14.4%
Separated	1.7%
Never married	15.8%
Living with partner	3.5%
<b>Metropolitan Area</b>	<b>Total</b>
Non-metro	12.5%
Metro	87.5%
<b>Region</b>	<b>Total</b>
Northeast	17.4%
Midwest	24.9%
South	33.2%
West	24.5%
<b>Ownership of Living Quarters</b>	<b>Total</b>
Own	77.0%
Rented	21.0%
Occupied without payment of cash rent	2.0%

## 2016 Caregiving Costs Study

### 18+ Caregivers (n=3,277\*)

(\*Note: this includes the larger sample of caregivers who participated in the retrospective study; the percentages may vary slightly between the annotated questionnaire and the main document)

<b>Employment Status</b>	<b>Total</b>
Working - as a paid employee	43.5%
Working - self-employed	7.6%
Not working - on temporary layoff from a job	0.5%
Not working - looking for work	3.7%
Retired	31.8%
Disabled	5.7%
Not working - other	7.1%

\*\*

### Diary Form Expense Categories

If Caregiver Lives with Recipient:

#### **Medical/Dental/Vision Expenses (for the person you are helping)**

This includes co-payments when the person you are helping visits a physician or other health care provider, hospital co-pays, any prescription co-payments, or any costs of non-prescription drugs as well as insurance premiums paid by you for the person you are helping. Other medical expenses might be equipment such as wheel chairs, motorized scooters, walkers, bandages, oxygen supplies, or assistive technologies (e.g., hearing aids, cognitive assistance devices, computer software or hardware to help with mobility or sensory impairments, etc.). It also includes the costs of getting someone to the doctor, dentist, or clinic. Home care services and adult day care is also included. The cost of other professionals such as Physical Therapists or Occupational Therapists or Care Managers is also included in this category.

#### **Household Expenses (for the person you are helping)**

This includes co-payments when the person you are helping visits a physician or other health care provider, hospital co-pays, any prescription co-payments, or any costs of non-prescription drugs as well as insurance premiums paid by you for the person you are helping. Other medical expenses might be equipment such as wheel chairs, motorized scooters, walkers, bandages, oxygen supplies, or assistive technologies (e.g., hearing aids, cognitive assistance devices, computer software or hardware to help with mobility or sensory impairments, etc.). It also includes the costs of getting someone to the doctor, dentist, or clinic. Home care services and adult day care is also included. The cost of other professionals such as Physical Therapists or Occupational Therapists or Care Managers is also included in this category.

#### **Personal care item expenses (for the person you are helping)**

This includes products such as shampoo, soap, cosmetics as well as paid professionals such as hair dressers or nail care. The costs of incontinence supplies are included. It also includes the purchase of clothing for the person you are caring for. This category also includes pet care or pet supplies.

#### **Educational, legal, travel and other expenses (for the person you are helping)**

## 2016 Caregiving Costs Study

### 18+ Caregivers (n=3,277\*)

(\*Note: this includes the larger sample of caregivers who participated in the retrospective study; the percentages may vary slightly between the annotated questionnaire and the main document)

This includes club memberships, travel, special educational expenses, tutors or private lessons, books and music as well as paid companions. This also includes costs associated with vans or retrofitting vehicles to accommodate wheel chairs. Any legal fees related to your caregiving situation would also fall under this category.

#### **Caregiver personal expenses/Respite (Aides, adult day services, self-care, other paid help, and other expenses)**

This includes travel costs, babysitters for your dependents, house or pet sitters you need to hire to spend time with the person you are caring for. This also includes paid help you may hire to give yourself a break, educational materials, training, or support groups to help with your caregiving situation as well as counseling services you have incurred as a result of the physical and emotional demands of caregiving.

If Caregiver Does Not Live With Recipient:

#### **Medical/Dental/Vision Expenses (for the person you are helping)**

This includes co-payments when the person you are helping visits a physician or other health care provider, hospital co-pays, any prescription co-payments, or any costs of non-prescription drugs as well as insurance premiums paid by you for the person you are helping. Other medical expenses might be equipment such as wheel chairs, motorized scooters, walkers, bandages, oxygen supplies, or other assistive technologies (e.g., hearing aids, cognitive assistance devices, computer software or hardware to help with mobility or sensory impairments, etc.). It also includes the costs of getting someone to the doctor, dentist, or clinic. Home care services and adult day care is also included. The cost of nursing homes, assisted living or other residential settings, as well as other professionals such as Physical Therapists or Occupational Therapists or Care Managers is also included in this category.

#### **Household Expenses (for the person you are helping)**

This includes any rent or mortgage payments or property taxes you pay on their behalf. The costs of assisted living or retirement communities are included. It also includes home repairs, house cleaning professionals or cleaning supplies, yard maintenance, food purchases or delivery of meals, utilities, transportation costs to shop for and/or with person, remote health and safety monitoring devices, as well as other safety devices. This category also includes any modifications (e.g., installation of ramps, shower bars, stair lift, or other safety/mobility devices) that you make to the home or furnishings such as special beds. This category also includes relocation costs you may incur in order to provide care (e.g., moving closer to the person you are helping or moving them closer to you).

#### **Personal care item expenses (for the person you are helping)**

This includes products such as shampoo, soap, cosmetics as well as paid professionals such as hair dressers or nail care. This also includes incontinence supplies. The purchase of clothing for the person you are caring for also falls under this category. This category also includes pet care or pet supplies.

#### **Educational, legal, travel and other expenses (for the person you are helping)**

## 2016 Caregiving Costs Study

### 18+ Caregivers (n=3,277\*)

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#### **Caregiver personal expenses/Respite (Aides, adult day services, self-care, other paid help, and other expenses)**

This includes travel costs (airfare or other transportation, hotels, gas, parking, etc.), as well as babysitters for your dependents, house, or pet sitters you need to hire to spend time with the person you are caring for. This also includes paid help you may hire to get a break, educational materials, training, or support groups to help with your caregiving situation as well as counseling services you have incurred as a result of the physical and emotional demands of caregiving.

**AARP Research** | For more information about this survey,  
please contact Chuck Rainville at:  
202.434.6295 or e-mail [grainville@aarp.org](mailto:grainville@aarp.org)

