



CAREGIVING OUT-OF-POCKET COSTS STUDY

June 2021






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EXECUTIVE SUMMARY

Executive Summary

According to the National Alliance for Caregiving and AARP's *Caregiving in the U.S. 2020* study, **there are approximately 48 million individuals in the United States providing unpaid care to an adult family member or friend.** This study showed an increase of about 8 million caregivers from 2015 to 2020 demonstrating a growing caregiver population.

Family caregivers experience physical, emotional, and financial challenges. Family caregivers not only spend time and energy caring for a loved one, but many also spend money of their own to help care for their loved one.

The purpose of this study is to **explore the out-of-pocket costs of caregiving and financial strain on family caregivers as well as personal sacrifices they may have to make** that can affect their own financial security. This study is a five-year follow-up to the landmark 2016 AARP out-of-pocket study*.

Three quarters of caregivers report regularly spending their own money on caregiving expenses.

- 78% of caregivers report having out-of-pocket expenses as a result of caregiving.
- The average annual amount caregivers spend on caregiving is \$7,242.
- A financial strain measure shows family caregivers are spending, on average, one-quarter (26%) of their income on caregiving activities.

Housing expenses account for more than half of caregiver out-of-pocket costs.

- Rent or mortgage payments on behalf of their care recipients accounted for 30% of household expenses. Home modification costs made up 21% of household expenses and assisted living made up seven percent.
- Medical costs account for about one-fifth (17%) of caregiver spending. The most common medical costs are direct payments to healthcare providers, hospitals, therapists, etc. This category also includes medical equipment and devices, in-home care, and adult day care.

**Several societal shifts occurred in the last 5 years related to income distribution, employment status, age of the population and household composition making direct comparisons problematic without considering the necessary context changes over the last 5 years and most abruptly over the last year due to the coronavirus pandemic.*

Executive Summary (cont.)

Gen X caregivers are incurring the most expenses.

- Gen X caregivers report the highest out-of-pocket costs compared to other generations of caregivers (\$8,502).
- Yet the youngest cohort of caregivers (Gen Z and Millennials) experience the most financial strain (spending, on average, \$7,462 per year). These caregivers have had less time in the workforce to build financial security.

Caregivers of color experience higher financial strain.

- Hispanic/Latino and African American caregivers experience higher financial strain than White and Asian American caregivers. Hispanic/Latino caregivers are spending, on average, \$7,167 per year, and African American caregivers are spending \$6,746.
- Gender disparities are large for Hispanic/Latino and Asian American caregivers. Hispanic/Latino and Asian American female caregivers experience much higher financial strain than their male counterparts.

Some caregiving situations lead to increased out-of-pocket spending.

- Caregivers caring for someone with dementia report spending approximately \$8,978 per year.
- Those caring for someone with a mental health issue are also spending a higher than average amount on caregiving (\$8,384).
- Caregivers spending more than ten hours per week providing care also incur higher than average out-of-pocket costs (\$8,603).
- Higher-intensity caregivers helping with activities of daily living (\$8,811) and medical/nursing tasks (\$8,430) also incur higher costs.
- Caregivers who report two or more work-related strains are spending, on average, \$10,525 per year on caregiving expenses. This is twice the amount that caregivers with no strain or even one work-related strain incur.

Executive Summary (cont.)

Work-related and personal strain as a result of caregiving may also impact long-term financial security.

- Neary half (47%) of caregivers have experienced at least one financial setback as a result of their caregiving. These setbacks include dipping into personal savings, cutting back on their own spending, and reducing how much caregivers save for their own retirement.
- More than half of working caregivers (53%) have experienced at least one work-related impact as a result of their caregiving. Taking time off (both paid and unpaid) and working different hours are the most common ways that caregiving affects work.

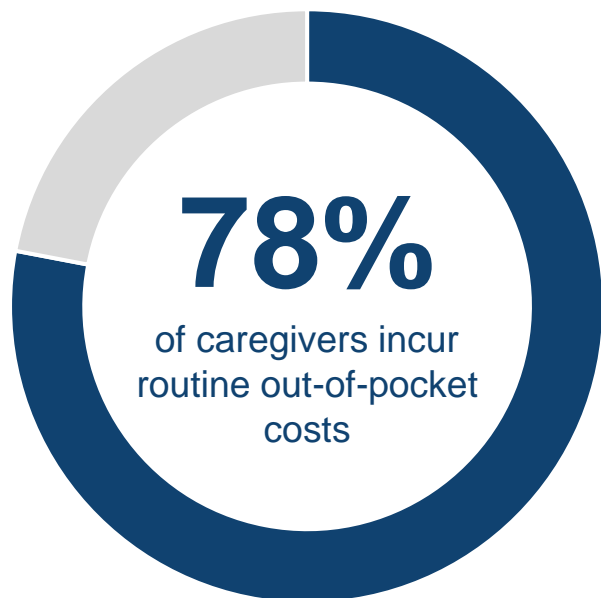
This study demonstrates the importance of supporting family caregivers with not only resources and education but financial assistance as well. The coronavirus pandemic has only heightened the need for caregivers and shone a light on both the emotional and financial sacrifices family caregivers make every day to help their family member or friend they care for. The recently introduced bipartisan *Credit for Caring Act* that would provide a tax credit of up to \$5,000 to eligible working caregivers would offer much needed financial support to eligible family caregivers, many of whom sacrificed their own careers and financial security.



OVERALL SPENDING

Most Family Caregivers Incur Out-of-Pocket Caregiving Costs.

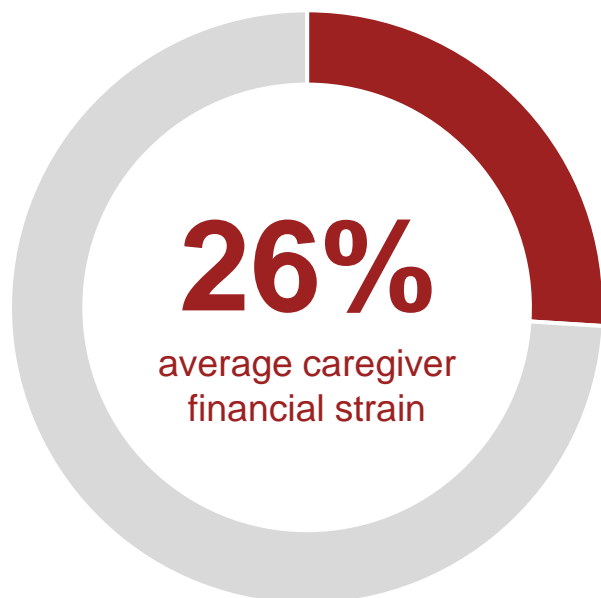
More than three-quarters of caregivers are spending their own money on a regular basis to help the person they care for. Virtually all caregivers (95%) had at least one caregiving expense over the course of the last year. Only 5% of caregivers reported no expenses (either ongoing or incidental) over the last 12 months.



Caregivers spent, on average,

\$7,242

Of their own money on caregiving expenses.



On average, caregivers spend a quarter of their annual income on caregiving expenses.*

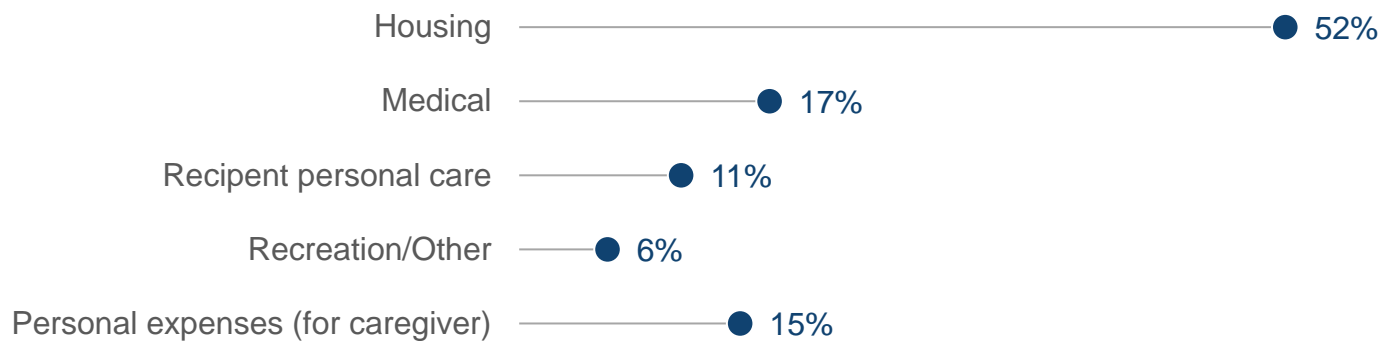
*Financial strain is defined as the ratio of annual caregiver expenses divided by the caregivers' annual income where 0 equals no caregiving expenses and 100 means caregiving expenses exceed a single year annual income and debt is then incurred (which would be paid off over multiple years' income). Multiplying 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. 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.

Housing Costs Drive Spending

Household expenses account for half of all caregiver spending. This includes expenses such as rent or mortgages, assisted living, home modifications, relocation, etc. This is followed by medical expenses accounting for about one-fifth of caregiver spending. Not surprisingly, spending on recreational and travel expenses was relatively low over the last year likely due to the coronavirus pandemic. Lower travel costs may have particularly reduced the cost burden among long-distance caregivers.

Caregivers are spending, on average, more than a quarter of their income on caregiving expenses. This expense indicates significant financial strain for many caregivers. Some caregivers may even be incurring debt because they are spending more on caregiving expenses than their income can support.

Percentage of total caregiver spending
By expense category



Actual spending & financial strain

	Average annual expense
Average annual caregiver expense	\$7,242
Household expenses	\$3,791
Medical expenses	\$1,225
Caregiver personal spending (respite, travel, etc.)	\$1,058
Personal care expenses (for recipient)	\$768
Recreation, education, legal and other expenses	\$400

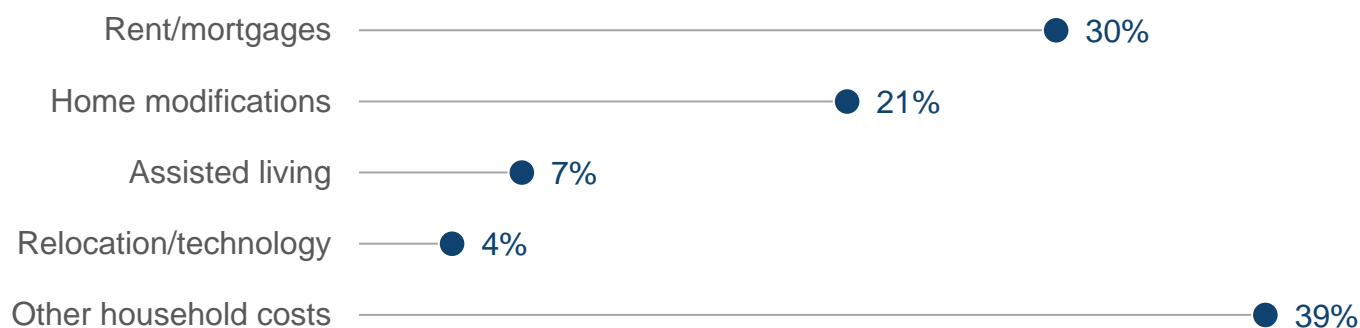
Note: Individual categories may not add up to total cost due to rounding.

Housing Costs and Payments to Providers Account for a Plurality of Household and Medical Costs

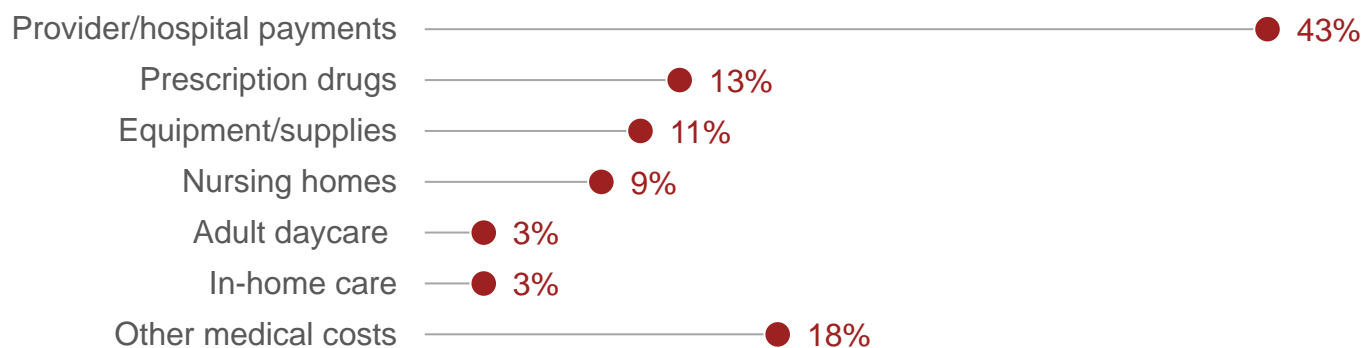
Contributing to a care recipient's rent or mortgage payments accounts for nearly a third of household-related expenses. In addition, home modifications garner about one-fifth of household costs.

Nearly half of all medical expenses (43%) are spent on direct payments to hospitals and health care providers, whether in the form of co-payments, co-insurance, or full cost. These payments go to various types of health care providers, such as hospitals, practitioners, physical or occupational therapists, etc.

Percentage of total household spending
By expense category



Percentage of total medical spending
By expense category





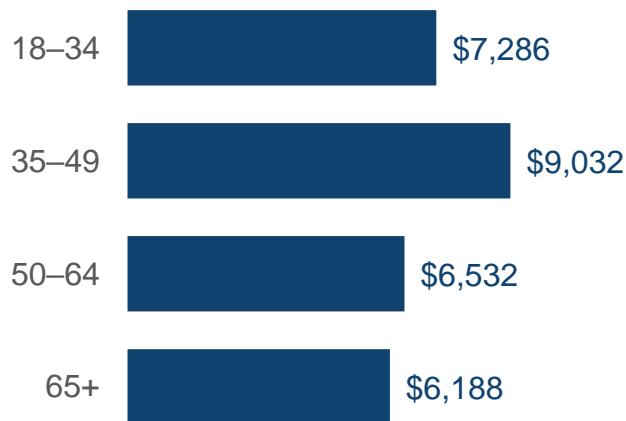
TYPES OF CAREGIVERS

Age of Caregiver

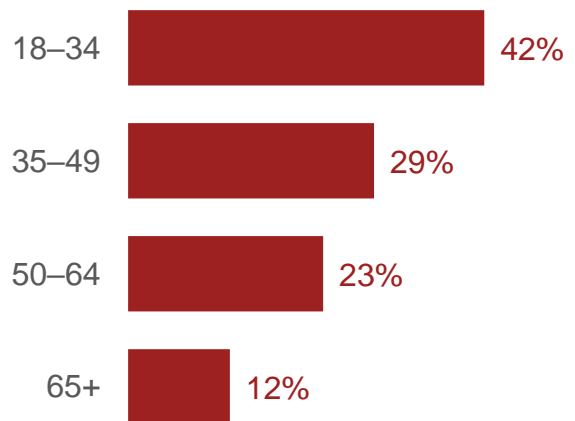
Caregivers under the age of 50 report the highest out-of-pocket costs related to caregiving. In particular, these caregivers are spending a disproportionate amount on household costs. While absolute spending is highest among caregivers ages 35-49, financial strain is highest among the youngest cohort of caregivers. This is not surprising as younger caregivers typically have had less time in the workforce to build financial security.

Older caregivers (Boomers and Silents*) are also spending more time per week caregiving which may suggest they are providing more in-kind services rather than purchasing them.

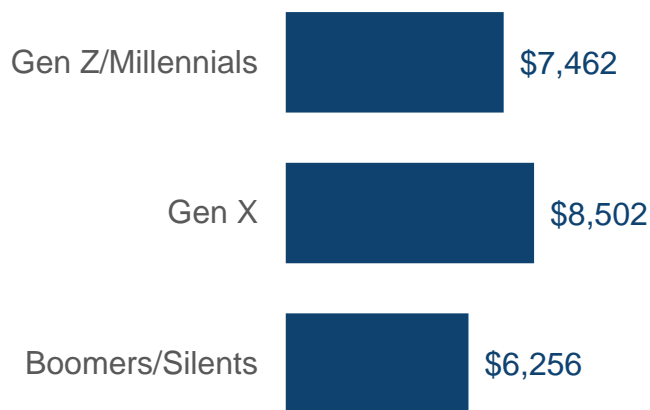
Average actual caregiving expenses
By age



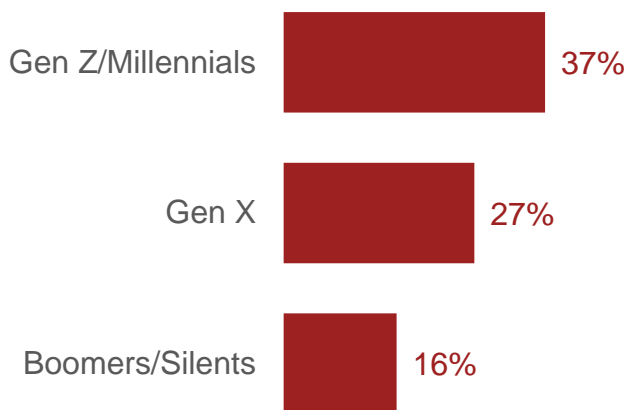
Average financial strain
By age



Average actual caregiving expenses
By generation



Average financial strain
By generation



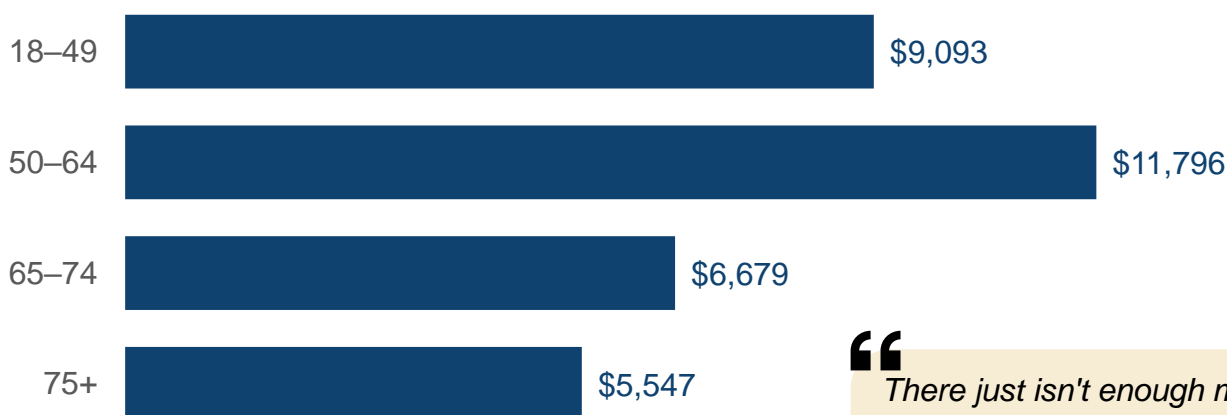
*Boomers and Silents were combined because there were not enough Silent generation caregivers in this study to report out separately.

Age of the Care Recipient

The median age of care recipients in this study was 75 years old. Caregivers caring for individuals under the age of 65 (particularly those ages 50–64) are spending the highest amount on caregiving and are experiencing the most financial strain.

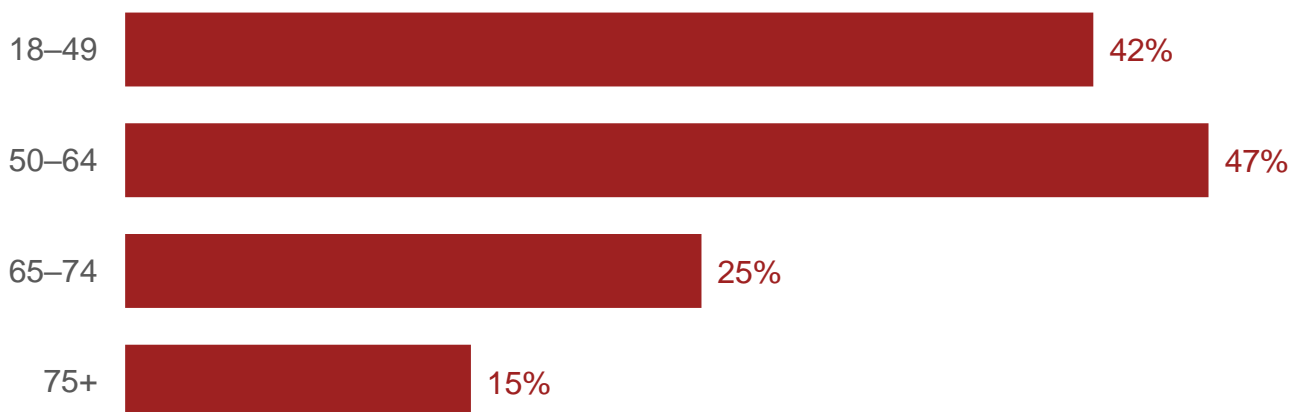
These caregivers are spending just slightly more money on household-related costs but significantly more on medical expenses. Those requiring care under the age of 65 may have relatively debilitating or long-term conditions that lead to extensive caregiving situations over a longer period of time.

Average actual caregiving expenses
By care recipient's age



“
There just isn't enough money to go around with both of us on social security disability.
White Male caregiver, age 58, caring for a spouse
”

Average annual financial strain
By care recipient's age

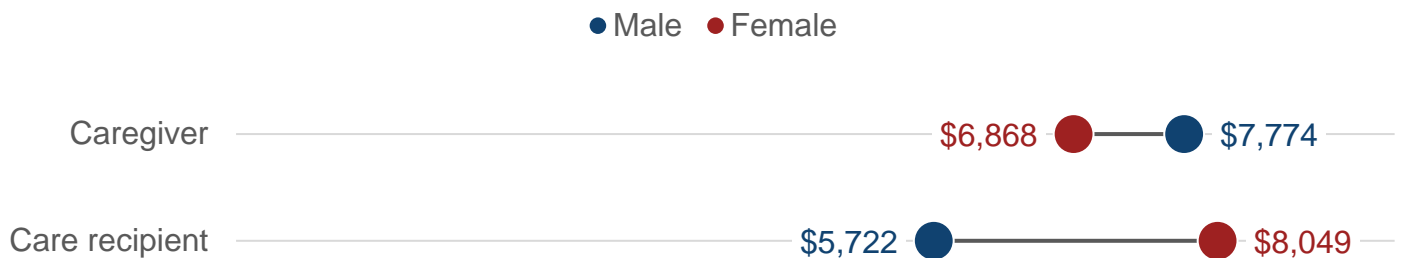


Gender Differences

Overall, caregivers are spending roughly \$7,000 on caregiving expenses with male caregivers spending a slightly higher amount than female caregivers; however, women experience higher financial strain owing to different annual incomes. Female caregivers are spending more than male caregivers on medical costs, particularly co-pays to providers. They also report higher out-of-pocket costs on home modifications. Male caregivers, on the other hand, report higher costs for both assisted living fees and rent or mortgage payments.

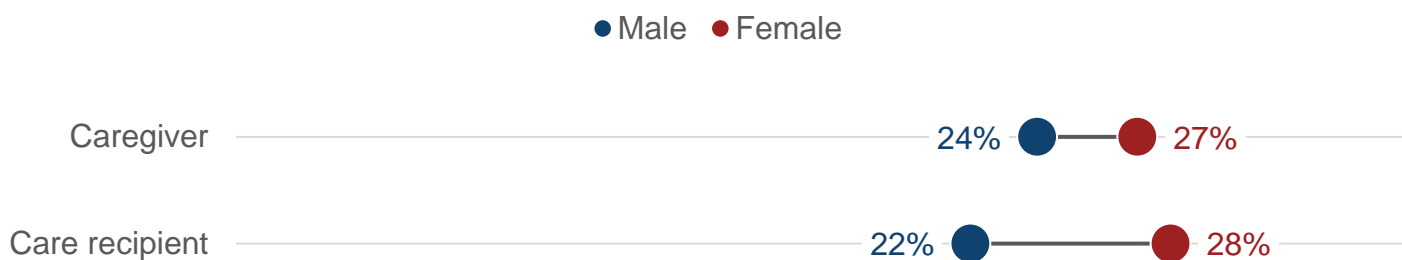
In addition, those caring for a female recipient are incurring both significantly higher costs as well as financial strain, on average, than those caring for men. The most common caregiving arrangement is a female caregiver caring for a female recipient. Women, on average, have lower incomes and the cost of caring for female recipients is higher, suggesting this type of caregiving relationship could lead to a significant financial strain. Female caregivers are also spending more hours per week caregiving.

Average actual caregiving expenses
By caregiver and care recipient gender



“
My fear is his expenses start to eat too much into my budget - particularly if he outlives his finances.
White male, age 47, caring for a parent
”

Average annual financial strain
By caregiver and care recipient gender



Race & Ethnicity Differences

Caregiving expenditures are fairly uniform across race and ethnic groups, with the exception of Asian American caregivers. Asian American caregivers report the highest out-of-pocket costs; however, their overall financial strain is lower due to a significantly higher average household income for the Asian American population as a whole.* Financial strain is greatest among Hispanic/Latino and African American caregivers.

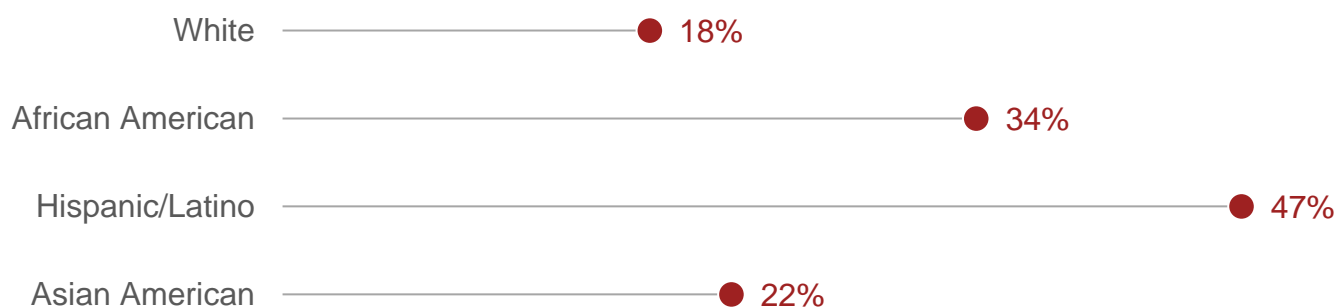
Asian American caregivers tend to incur higher costs medical costs, particularly co-pays and medical equipment and supplies as well as higher rent or mortgage payments. Hispanic/Latino caregivers report relatively high rent or mortgage payments, compared to White caregivers.

Average annual caregiving expenses
By race/ethnicity



“
I worry about not having sufficient funds to maintain the lifestyle they're accustomed to.
African American male, age 79, caring for a spouse
”

Average annual financial strain
By race/ethnicity



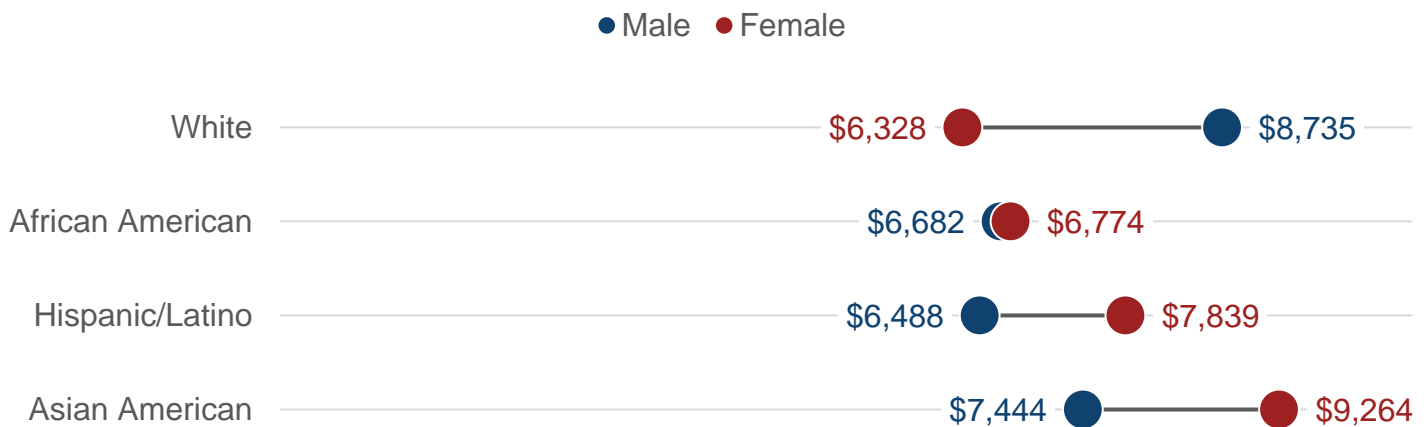
*Asian American caregivers in this study include all caregivers who self-identify as Asian American and Pacific Islander.

Race & Ethnicity, by Gender

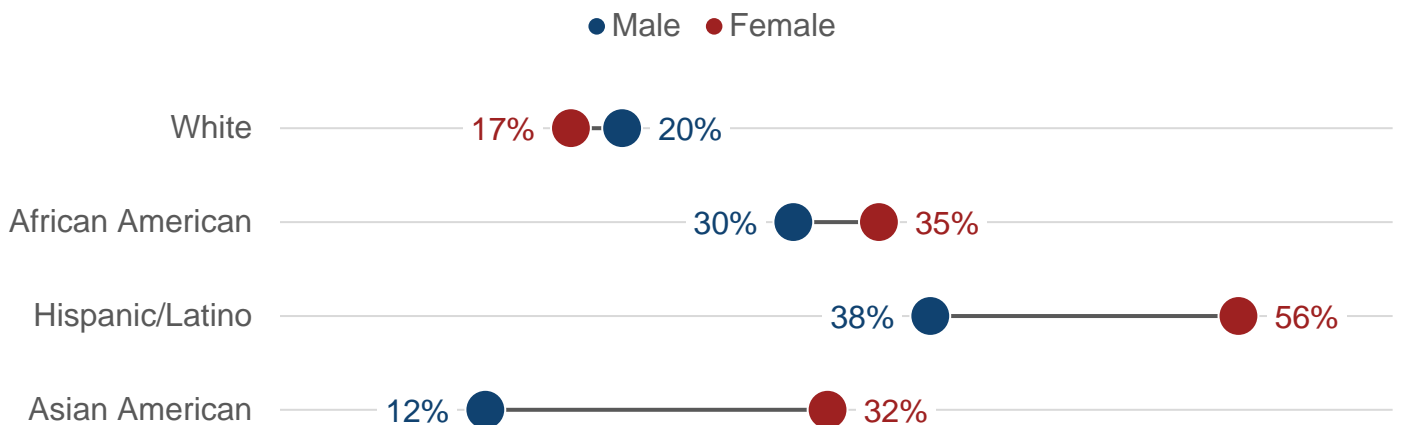
While White male and female caregivers experience similar financial strain, this is not the case for caregivers of color. Financial strain is most disparate between Asian male and female caregivers as well as Hispanic/Latino caregivers.

Asian female caregivers are more likely to be caring for someone with dementia and/or mental health issues and spending more time per week caregiving. These situational factors may result in higher out-of-pocket spending due to the health of the recipient. Hispanic female caregivers are also particularly strained (in a similar regard to female Asian caregivers) but they are also spending a greater share of their expenses on medical costs.

Average annual caregiving expenses
By caregiver race/ethnicity and gender



Average annual financial strain
By caregiver race/ethnicity and gender



Reasons for Caregiving

Caregivers caring for someone with Alzheimer's disease/dementia or mental health issues tend to spend more money than those caring for someone without those conditions. Those caring for someone with mental health issues experience higher financial strain than those caregivers whose recipient does not have a mental health condition. This may be due to both a younger than average caregiver and recipient.

While those caring for someone with dementia report lower out-of-pocket costs compared to 2016, their financial strain remains the same suggesting a lower income reflective either of full-time caregiving, retirement, or even employment uncertainty due to the pandemic. There is indications they are doing more direct care with fewer of these caregivers employing paid help this year than in 2016.

Average actual caregiving expenses

By presence of mental health issues or Alzheimer's disease/dementia

● No, does not have the condition ● Yes, has the condition

Mental health issue \$6,851 ● ● \$8,384

Alzheimer's disease/dementia \$6,663 ● ● \$8,978

Average annual financial strain

By presence of mental health issues or Alzheimer's disease/dementia

● No, does not have the condition ● Yes, had the condition

Mental health issue 19% ● ● 32%

Alzheimer's disease/dementia 25% ● ● 28%

There is a Linear Relationship Between Time and Money

The more hours per week caregivers spend providing care, the higher their the out-of-pocket expenses tend to be. Likewise, caregivers in higher-intensity situations assisting with activities of daily living (ADLs) and medical or nursing tasks report higher out-of-pocket costs and financial strain.

Average annual caregiving expenses

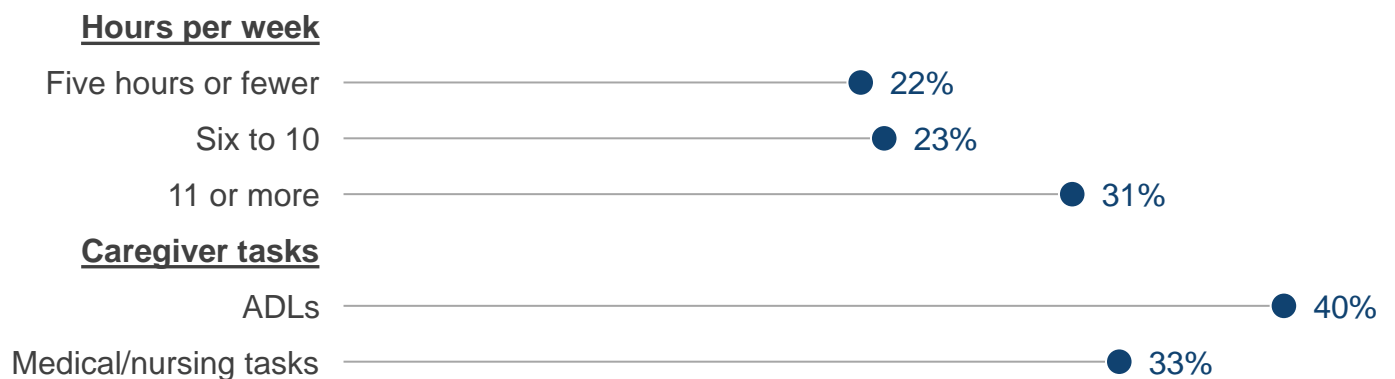
By hours of caregiving per week and caregiver tasks

For caregiver tasks: **Does the tasks** or **does not do the tasks**



Average annual financial strain

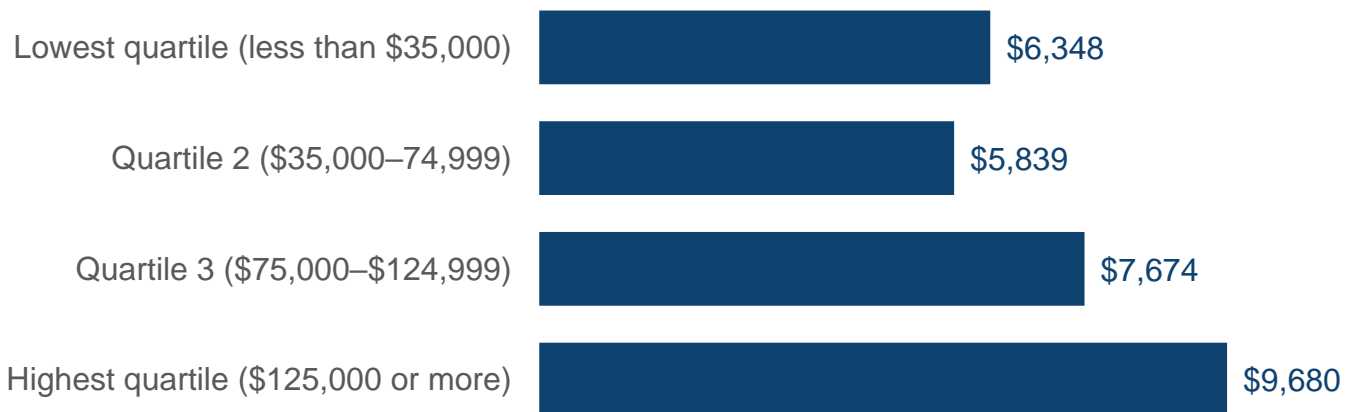
By hours of caregiving per week and caregiver tasks



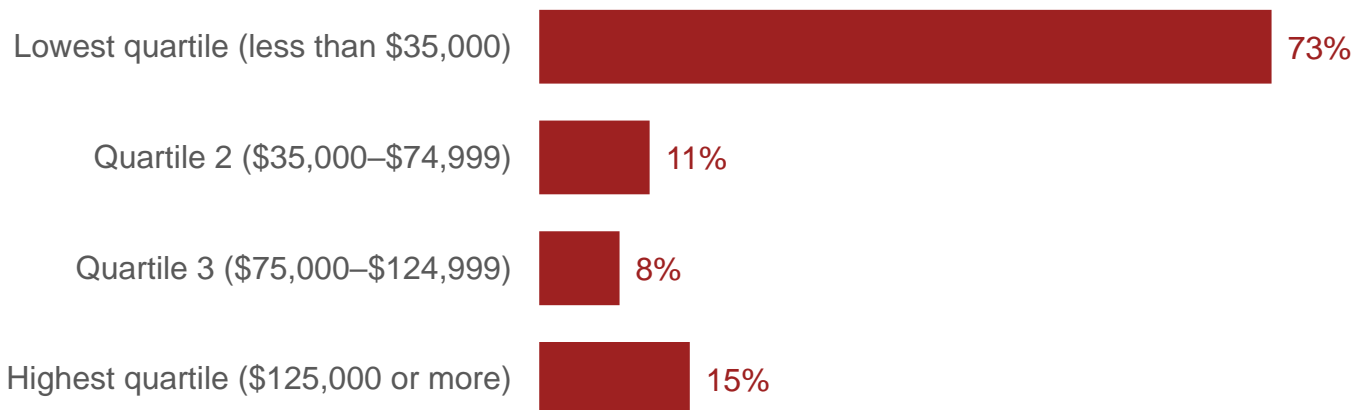
Caregiver Income

Those caregivers whose annual household income falls in the lowest income quartile for this study are the most financially strained, spending, on average, almost three-quarters of their income on caregiving. In some cases, these caregivers' out-of-pocket expenses exceed their income and therefore result in accumulation of additional debt.

Average actual caregiving expenses *By caregiver annual household income*



Average annual financial strain *By caregiver annual household income*



Who are the Most Financially Strained Caregivers?

Income levels will always be related to financial strain, but additional factors, such as those related to the caregiving context, can affect strain within income groups.*

- **Among the lowest income caregivers:** The most “highly financially-strained” caregivers (i.e., earning no more than \$34,999 annually) were non-White/non-Asian caregivers caring for someone who needs assistance with at least one activity of daily living (ADL). Within this income quartile, 41% of African American/Black and 59% of Hispanic/Latino caregivers were caring for someone who needed assistance with at least one ADL were highly financially-strained.
- **Among the middle-income caregivers:** The most highly financially-strained caregivers within the middle two quartiles (i.e., earning between \$35,000 and \$124,999) were those caring for a recipient younger than age 63 for at least 11 hours per week. Fifty-two 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 is in residential care (nursing home, assisted living, etc.) and/or has a mental health condition. Fifty-six percent of high income caregivers who are providing care under such an arrangement are highly financially strained.

* A basic statistical classification method (CHAID) was used to identify what determines being “the most highly strained” within each income quartile (note: income quartiles reflect U.S. Census national household income cut points and do not necessarily reflect the income of caregiver households). Highly financially-strained subgroups were determined by identifying the 25% of caregivers with the highest financial strain percentages in each quartile. The CHAID analysis then combined all of the demographic subgroups of caregivers and recipients to determine which combinations had the highest concentrations of caregivers in the top quartile of financial strain. These subgroups were considered “highly financially-strained” caregivers.

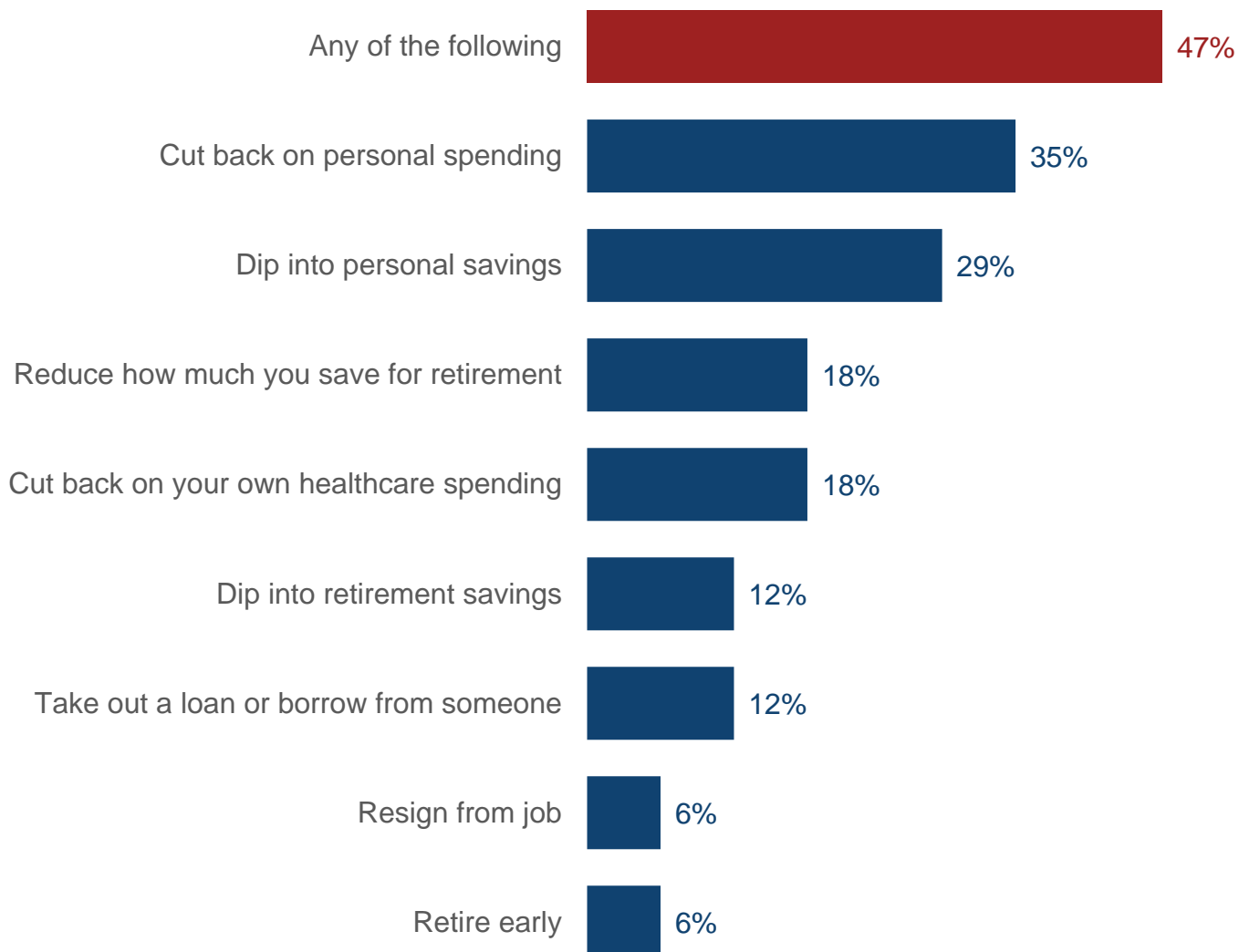


WORK, SAVINGS AND OTHER PERSONAL STRAIN

Caregivers' Overall Financial Security May Be at Risk

The financial implications of caregiving are evident in ways beyond out-of-pocket costs. Nearly half of caregivers (47%) have experienced at least one financial setback as a result of their caregiving. The most common effects are cutting back on personal spending or dipping into savings accounts. But nearly one in five have had to cut back on their own health care spending or reduce the amount they save for retirement (18% each).

Percent of caregivers doing the following
As a result of caregiving



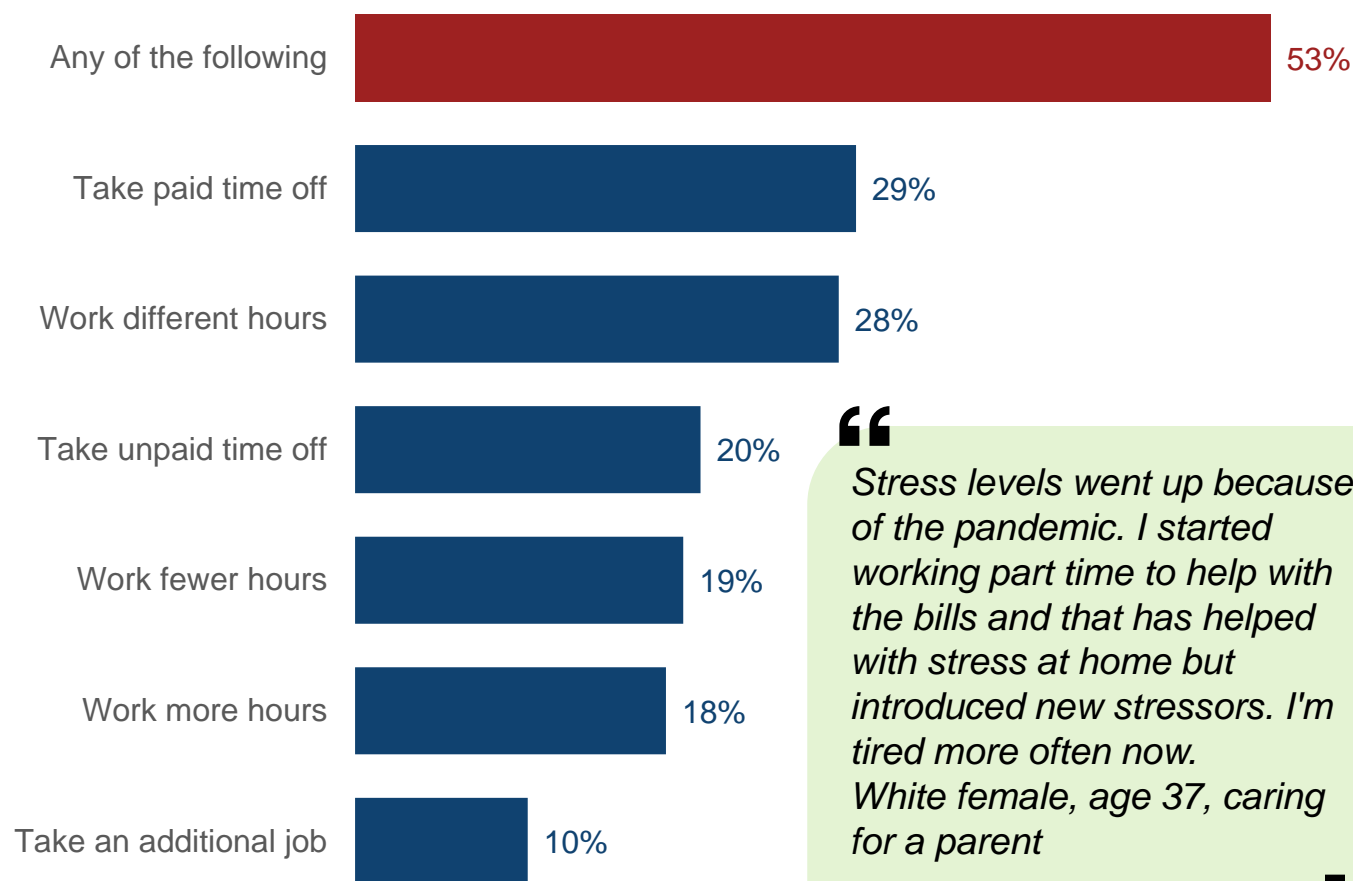
Q.A28. In the last 12 months, have you had to do any of the following as a result of caregiving?

Caregivers' Employment May Also be Jeopardized

Nearly six in 10 caregivers are currently working (59%) either full-time or part-time and more than half of them (53%) have experienced a work-related event in the last year. Many employed caregivers face strain in managing both caregiving and work responsibilities simultaneously. These consequences can lead to reduced job security, fewer employment opportunities, and ultimately, lower retirement savings.

Taking time off and working different hours are the most common ways that caregiving affects work.

Percent of working caregivers doing the following
As a result of caregiving



Q.A28. In the past year, have you had to do any of the following as a result of caregiving?
Base = (1, 415 working caregivers)

Caregivers With More Work Strain Report Higher Costs

More than half of employed family caregivers (53%) have experienced at least one work-related strain as a result of caregiving. In fact, one-third (34%) have experienced two or more strains. Caregivers who report two or more work-related strains are spending, on average, \$10,525 per year on caregiving expenses. This is twice the amount that caregivers with no work-related strain or even one work-related strain incur.

“

*Now that I work from home, I won't be able to go back to an office because she would not be able to take care of herself anymore.
White female, age 44, caring for a spouse*

”

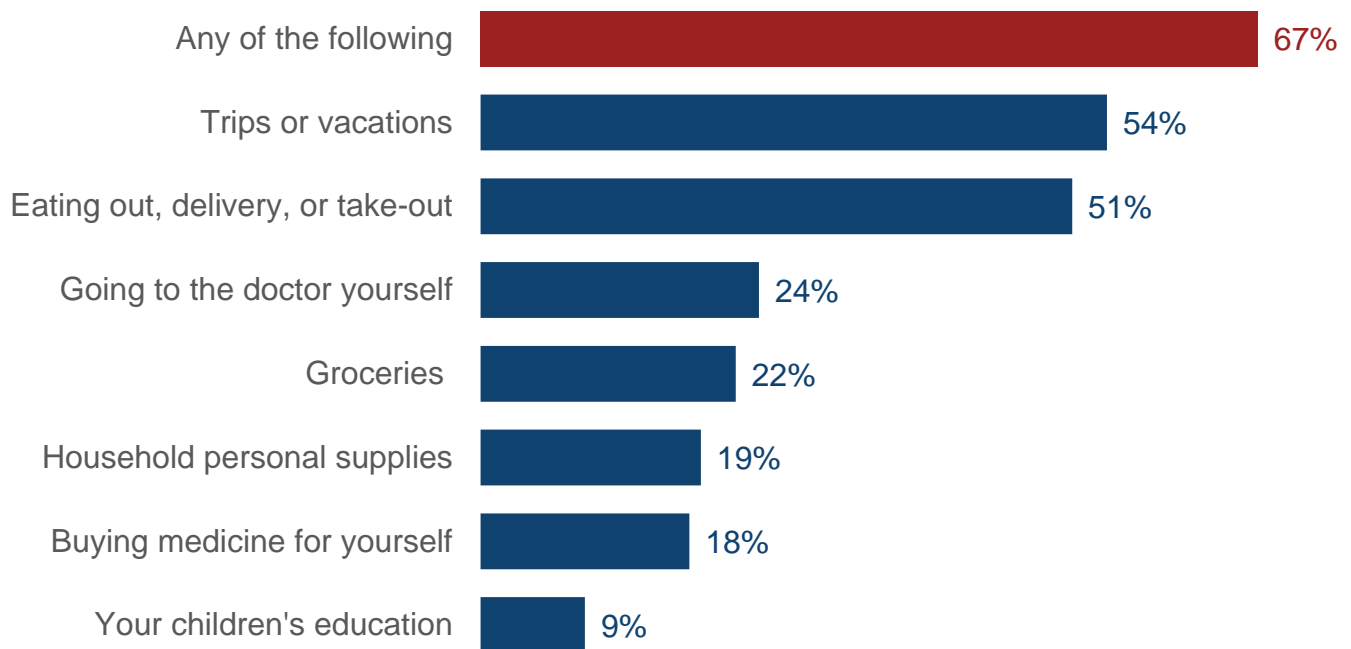
Average annual caregiving expenses
Among employed caregivers, by number of work strains



Significant Personal Sacrifices are Also Being Made

Almost seven in 10 caregivers (67%) have made at least one personal sacrifice due to the financial costs of caregiving. The most common sacrifices were cutting back on leisure activities such as dining out and vacations. Yet nearly one-quarter (24%) have had to cut back on their own health care.

Percent of caregivers who had to cut back on the following
Due to the costs of caregiving



“
It's stressful, of course, because I feel like I have no life of my own.
Male caregiver, age 64, caring for a parent
”

“
My greatest fear is that my one year old son will not struggle hitting milestones because I'm having to give more of my time to someone other than him.
Female caregiver, age 30, caring for a parent
”

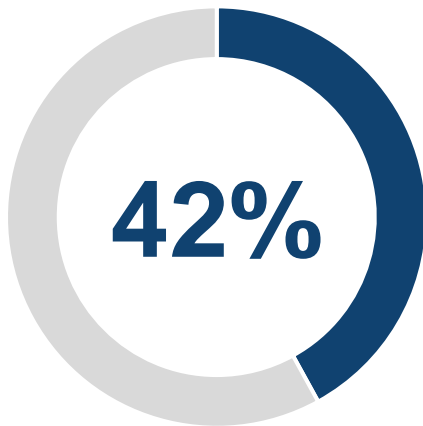
Q.C2. Below is a list of things that people might cut back spending on due to the costs of caregiving. Please indicate if any of these apply to you.



PANDEMIC-RELATED STRAIN

Caregivers Feel the Pandemic Strain

The pandemic has heightened caregiver strain. More than four in 10 caregivers report spending both more time per week and more money on caregiving as a result of the pandemic. In addition, almost three in 10 say the pandemic has impacted their caregiving-related financial strain.



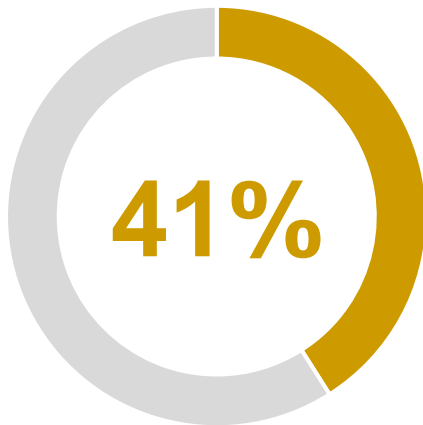
Report more time per week providing care due to the coronavirus pandemic.

“

I spent more on groceries, PPE, and on installing cameras to watch her because she is alone more.

Hispanic female, age 46, caring for a parent

”



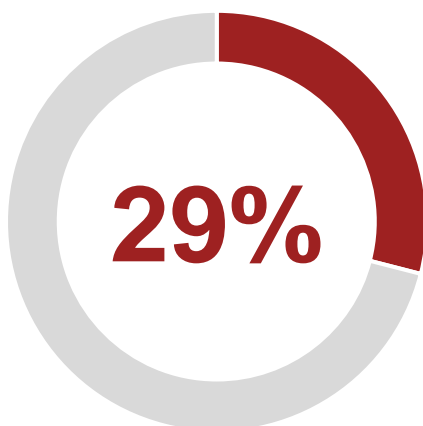
Say they are spending more money on caregiving as a result of the pandemic.

“

I'm spending more on food, electric, technology and less on gas and travel.

White female, age 47, caring for a parent

”



Say the pandemic has impacted their financial strain to at least *some extent*. An additional 22% say it has impacted their strain to a *little extent*.

Q.A11. How has the COVID-19 pandemic impacted the amount of time you have spent caring for your...?

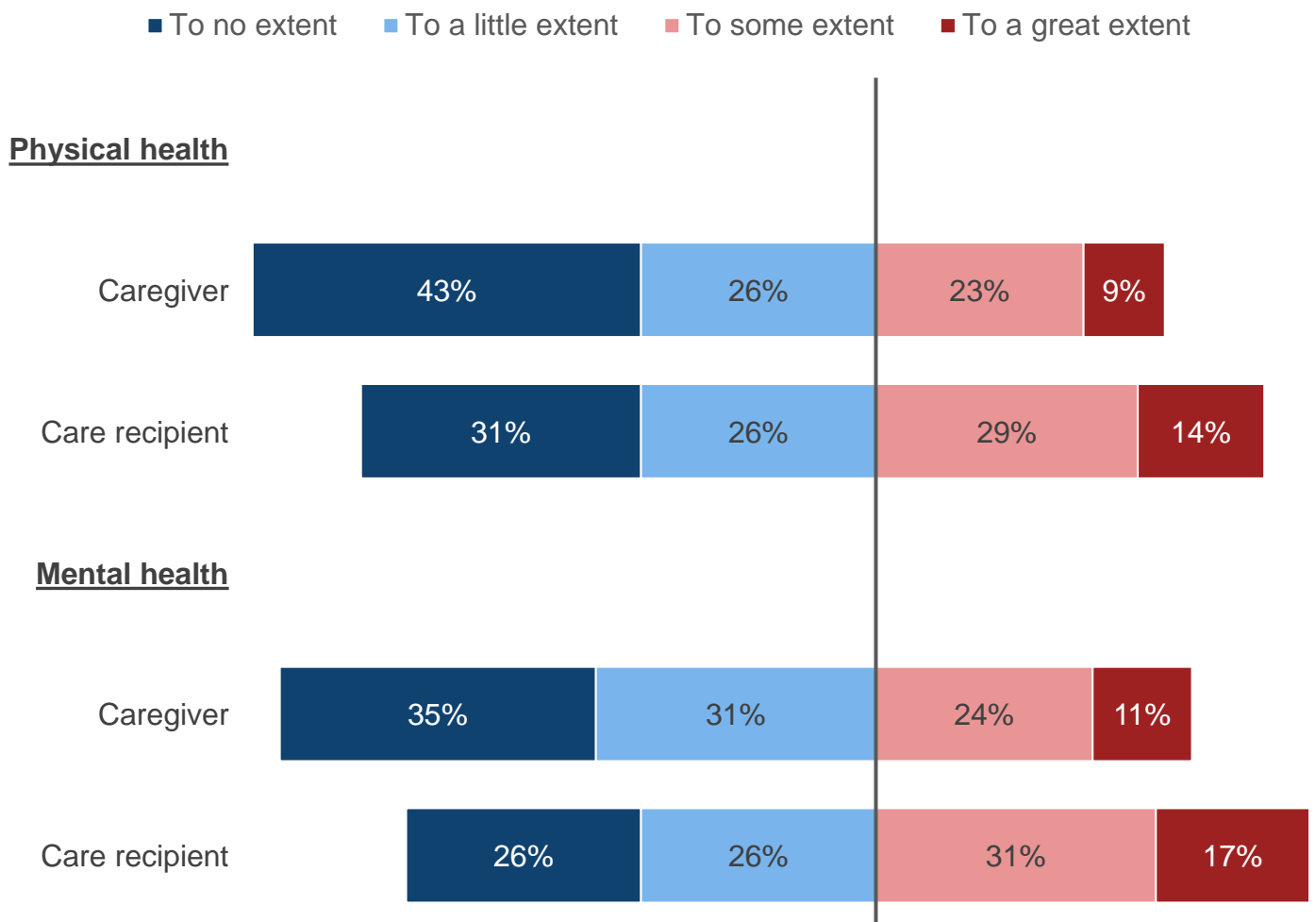
Q.A19. To what extent, if at all, has the COVID-19 pandemic had on your financial strain as a result of helping your...?

Q.A20. How has the COVID-19 pandemic impacted the amount of money you spend caring for your...?

The Pandemic Took a Toll on Both Caregiver & Recipient Health Status

At least three in 10 caregivers say the pandemic has worsened both their own and their care recipient's physical and mental health to at least *some extent*. The effect is particularly striking for care recipients. Nearly half of caregivers (48%) say the pandemic has worsened the mental health of the person they care for and 43% say it has worsened their care recipient's physical health to at least *some extent*.

Extent to which the pandemic worsened health
For caregivers and care recipients

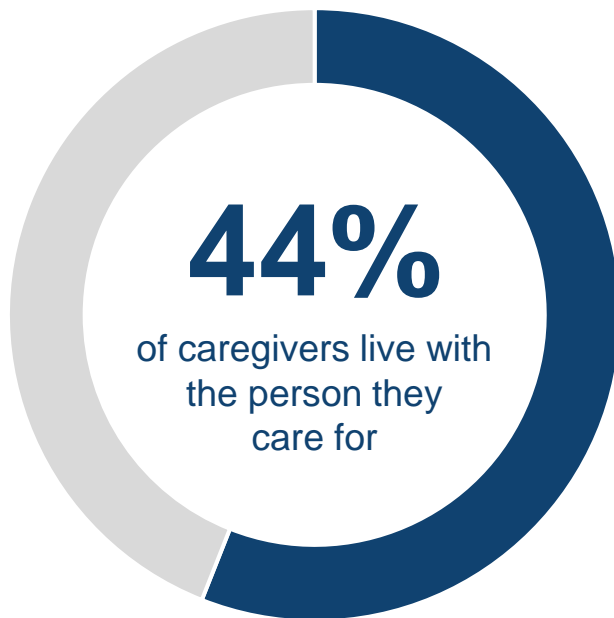


Q.A12. To what extent do you think the COVID-19 pandemic has worsened physical health problems or physical health status for...?

Q. A12A. To what extent do you think the COVID-19 pandemic has worsened mental health problems or mental health status for...?

And Altered Some Housing Situations

One in 10 caregivers who live with the person they care for say they moved in together due to the pandemic.



- 11% moved in together as a result of the pandemic.
- Most (62%) expect this move to be permanent.
- Among African American caregivers who co-reside, nearly one-quarter (23%) did so as a result of the pandemic.

“

My greatest fear is that my mom wants to move in with me so that I can take care of her daily. I love her but I would feel trapped. I feel guilty for not wanting to live with her.

White female, caring for a parent

”

Q.S02 Where does the person you care for live...

Q.S02A. Did he or she move into your home or you into theirs as a result of the pandemic?

Q.S02B. Do you expect to permanently live with this person or this a temporary move due to the pandemic?

A photograph of two men standing in a field of tall grass. The man on the left is older, with white hair and a beard, wearing glasses and a dark blue jacket. The man on the right is younger, with dark hair and a beard, wearing a brown leather jacket. They are both looking towards the right. The background is a soft-focus landscape with trees and a building.

METHODOLOGY

Methodology

This study was conducted using a mixed method approach that included both a survey and diary component. This study utilized Ipsos' national, probability-based, online KnowledgePanel®.

This study was conducted from March 15 to April 25, 2021 among 2,380 family caregivers. Quota samples were established for Hispanic, African American, Asian American caregivers, and long-distance caregivers; however, their at-random incidence resulted in only minor disproportionate representation.

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. Ipsos 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 completed a retrospective survey examining out-of-pocket expenses incurred in the last year across 30 categories of spending. A total of 4,220 caregivers qualified for the study and completed the survey. Caregivers were then asked to participate in the diary study and track their spending on caregiving costs over the course of one week. A total of 2,380 caregivers agreed to participate in the diary study. Diary study participants did not differ in any systematic way from the remainder of qualified caregivers.

The final annual estimate reported in this study comes mainly from expenses reported in the diary study. 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. These expenses were explored in the retroactive survey and used to project an annual estimate from a mix of reported monthly and one-time expenses.

Methodology, continued

Each caregiving expense was recorded as falling into one of five categories:

- **Medical Expenses**
 - Co-pays, co-insurance, or direct pays to hospitals or providers (medical, dental, etc.)
 - Prescription drugs
 - Medical equipment/devices, supplies, or over-the-counter medications
 - Nursing home care
 - Adult day care
 - In-home care
 - Other medical costs
- **Household Expenses**
 - Rent/mortgage payments
 - Assisted living fees
 - Home modifications
 - Relocation costs
 - Technology for video chat
 - Other housing-related costs
- **Personal Care Expenses**
 - Everyday personal care
 - Incontinence supplies
 - COVID-19 related items
- **Recreation/Education, Travel, and Other Expenses (Includes legal fees)**
 - Vans or retrofitting vehicle costs
 - Other recreation/education costs
- **Personal Expenses Related to Caregiving**
 - Paid help you hire to get a break (respite)
 - COVID-19 related items (for you to wear to protect the person you care for)
 - Other personal expenses related to caregiving

*For more detailed information on the methodology, please refer to the detailed methodology available at www.aarp.org/caregivercosts



APPENDIX

Appendix A: Categorical Breakdown, by Demographic Group

	Household	Medical	Personal Care	Recreation/ Other	Caregiver Personal	Total
Mean (TOTAL)	\$3,791	\$1,225	\$768	\$400	\$1,058	\$7,242
Male	\$4,544	\$838	\$588	\$338	\$1,466	\$7,774
Female	\$3,260	\$1,498	\$895	\$445	\$771	\$6,868
Age 18-34	\$3,524	\$1,174	\$735	\$673	\$1,180	\$7,286
Age 35-49	\$5,654	\$1,478	\$687	\$501	\$712	\$9,032
Age 50-64	\$3,856	\$1,108	\$781	\$181	\$606	\$6,532
Age 65+	\$1,552	\$1,160	\$881	\$401	\$2,194	\$6,188
GenZ/Millennials	\$3,827	\$1,257	\$753	\$641	\$984	\$7,462
GenX	\$5,526	\$1,339	\$544	\$315	\$778	\$8,502
Boomers and Silents	\$2,629	\$1,126	\$926	\$277	\$1,297	\$6,256
White, Non-Hispanic	\$3,695	\$1,248	\$598	\$436	\$1,323	\$7,300
African American	\$3,380	\$889	\$1,692	\$198	\$588	\$6,746
Asian American	\$5,240	\$1,786	\$600	\$212	\$530	\$8,368
Hispanic/Latino	\$3,920	\$1,185	\$726	\$545	\$792	\$7,167

Note: Individual categories may not add up to total cost due to rounding.

About AARP

AARP is the nation's largest nonprofit, nonpartisan organization dedicated to empowering Americans 50 and older to choose how they live as they age. With nearly 38 million members and offices in every state, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands, AARP works to strengthen communities and advocate for what matters most to families with a focus on health security, financial stability and personal fulfillment. AARP also works for individuals in the marketplace by sparking new solutions and allowing carefully chosen, high-quality products and services to carry the AARP name. As a trusted source for news and information, AARP produces the nation's largest circulation publications, AARP The Magazine and AARP Bulletin. To learn more, visit www.aarp.org or follow @AARP and @AARPadvocates on social media.



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