



# The Many Faces of Caregivers: A Close-Up Look at Caregiving and Its Impacts

*Transamerica Institute's Inaugural Study of Caregivers*

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# About the Authors

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With two decades of retirement services experience, Catherine has become a nationally recognized voice on retirement trends for the industry. She has testified before Congress on matters related to employer-sponsored retirement plans among small business, which featured the need to raise awareness of the [Saver's Credit](#) among those who would benefit most from the important tax credit. Catherine serves on the Advisory Board of the [Milken Institute's Center for the Future of Aging](#). In 2016, she was honored with a [Hero Award](#) from the [Women's Institute for a Secure Retirement \(WISER\)](#) for her tireless efforts in helping improve retirement security among women.

[Hector De La Torre](#) is the executive director of the [Transamerica Center for Health Studies](#)<sup>®</sup>, which is focused on empowering consumers and employers to achieve the best value and protection from their health coverage, as well as the best outcomes in their personal health and wellness. Hector served as a State Assemblymember for California's 50th District from 2004-2010. Among his accomplishments as an elected official were expanding access to doctors in underserved communities, consumer protections against retroactive cancellation of health insurance, and supporting facilities improvements at Children's Hospitals. Prior to that, he was Mayor and Councilmember in his hometown of South Gate.

Hector serves on the board of L.A. Care, the largest public health plan in the United States, a member of the Board of Trustees at Occidental College (his alma mater) in Los Angeles, and is a member of the California Air Resources Board (CARB) as a gubernatorial appointee.

# About Transamerica Institute

- Transamerica Institute® (TI) is a nonprofit, private foundation dedicated to identifying, researching and educating the public about retirement, health coverage, and other relevant financial issues facing Americans today. It is comprised of two research centers: [Transamerica Center for Retirement Studies®](#) (TCRS) and [Transamerica Center for Health Studies®](#) (TCHS). Its mission is to help educate and empower people to make informed decisions about important matters that can improve their health and wealth.
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# About the Inaugural Caregivers Survey

- The Many Faces of Caregivers is a comprehensive examination of the state of unpaid caregiving in America. Unpaid caregivers face a host of financial and health-related challenges – both for themselves and those they care for.
- A large proportion of the population is entering the age range where the need for them to become caregivers becomes more likely. At the same time, many find themselves financially unprepared for retirement and need to stay in the workforce longer. These factors, coupled with a healthcare system that is often difficult to navigate, result in an environment that is challenging for all concerned.
- The analysis contained in this report, *The Many Faces of Caregivers: A Close-Up Look at Caregiving and Its Impacts*, was prepared internally by the research team at Transamerica Institute.
- The survey uncovers the various challenges caregivers are facing as well as insight into their health, both physical and financial, and the support they desire.

# Methodology

- The national online survey was conducted by Harris Poll between March 13 - April 21, 2017 among 3,074 non-professional caregivers.
- A comprehensive demographic profile of the target population of interest of all U.S. non-professional caregivers is not available. Therefore, in order to ensure that this sample is properly representative, U.S. adults age 18+ who were *not* caregivers were also screened and asked certain demographic questions. However, the full survey was only administered to non-professional caregivers.
- The *combined* data for non-professional U.S. caregivers plus all other age 18+ respondents were weighted to make them representative of the general U.S. age 18+ population.
  - Data were weighted by race/ethnic groups [Hispanic, Black/African American (not Hispanic), Asian (not Hispanic), All Other (not Hispanic)] to each group's U.S. Census Bureau population distributions of U.S. adults age 18+ for gender, education, household income, household size, marital status, and employment status.
  - The weighting also adjusts for attitudinal and behavioral differences between those who are online versus those who are not, those who join online panels versus those who do not, and those who responded to this survey versus those who did not.
- The caregiver respondents were then analyzed as a representative subgroup of the general population age 18+.
- Caregivers for this survey met the following criteria:
  - U.S. residents, age 18 or older
  - Non-professional caregivers (who may or may not receive compensation for caregiver role)
  - Provided care for a relative or friend with an episodic, permanent, or temporary condition who needs help taking care of themselves at any time in the preceding 12 months. The care recipient could be an adult or a child.
- The average survey length was 32 minutes. Respondents were given the option to complete the survey in Spanish, and 199 respondents did so, including 79 percent Hispanics and 21 percent non-Hispanics.
- Percentages are rounded to the nearest whole percent. Differences in the sums of combined categories/answers are due to rounding.
- Main sub-sample:
  - Primary caregivers = 2,137
  - Non-Primary caregivers = 829

# Methodology (continued)

## Sample Sizes for Demographic Breakouts

Caregiver Status	N =
Primary Caregivers	2,137
Non-Primary Caregivers	829
Not Sure	105

Voluntary Status	N =
Volunteered	2,590
Did Not Volunteer	331
Not Sure	166

Gender	N =
Women	1,779
Men	1,278
Transgender	9
Decline To Answer	9
Neither	3

Generation	N =
Millennials	1,071
Generation X	688
Baby Boomers	1,113
Matures	202

Total Household Income	N =
Less than \$25,000	629
\$25,000 to \$49,999	584
\$50,000 to \$99,999	993
\$100,000 or more	655
Decline To Answer	132

Employment Status	N =
Full-time	1,183
Part-time	391
Self-Employed	227
Not Employed	1,265
None	12

Race/Ethnicity	N =
White	2,129
Hispanic	466
African-American	300
Asian/Pacific Islander	132
Other	8
Decline To Answer	29
Mix	4

Note: Subsample sizes do not add to full sample size due to other, non-responses, don't knows, and declined to answer.

# Terminology

*This report uses the following terminology:*

**Care Recipient:** *person for whom the caregiver provides care*

## Caregiver and Voluntary Status

- **Caregiver:** *18+ year old living in the U.S. who has provided care for a relative or friend at any time in the past 12 months*
- **Primary Caregivers:** *caregivers who self-identify as the primary caregiver*
- **Non-Primary Caregivers:** *caregivers who do not self-identify as the primary caregiver*
- **Voluntary:** *caregivers who self-identify as voluntarily becoming a caregiver*
- **Non-Voluntary:** *caregivers who do not self-identify as voluntarily becoming a caregiver*

## Employment Status

- **Employed full-time**
- **Employed part-time**
- **Self-employed** *including full-time and part-time self-employed*
- **Not employed** *including retired, stay-at-home spouse or partner, student, not employed but looking for work, not employed and not looking for work, not employed due to the caregiver's own disability or illness, and on leave of absence from employer*

## Generation

- **Millennial:** *born 1979 – 2000*
- **Generation X:** *born 1965 – 1978*
- **Baby Boomer:** *born 1946 – 1964*
- **Mature:** *born prior to 1946*

# ***The Many Faces of Family Caregivers: A Close-Up Look at Caregiving and Its Implications***

## **➤ Executive Summary**

### **A Portrait of Today's Caregivers**

- Key Highlights
- A Portrait of Today's Caregivers
- Insights About Care Recipients and Their Needs
- The Diverse Duties, Daily Lives, and Dedication of Caregivers
- The Employment Situation of Caregivers
- The Personal Financial Implications of Being a Caregiver
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- Ways to Help Caregivers with Their Responsibilities

### **Demographic Perspectives**

### **Appendix: Caregiver and Care Recipient Demographics**

### **Acknowledgements**



# Executive Summary

Caregiving for a loved one often transcends fulfilling the tasks and duties laid out daily. Nine out of 10 non-professional family caregivers feel that it's important to provide a good quality of life for the person they care for, like helping, and enjoy spending time with the care recipient. However, many caregivers are providing care at their own risk. Fifty-five percent say that their own health is taking a back seat to the health of their care recipient. Sixty-nine percent gave little or no consideration to their own financial situation when deciding to become a caregiver. These findings are part of *The Many Faces of Caregivers: A Close-Up Look at Caregiving and Its Impacts*, a report by nonprofit [Transamerica Institute](#) (TI), a collaboration between its [Center for Retirement Studies](#) (TCRS) and [Center for Health Studies](#) (TCHS).

“Millions of Americans are serving as unpaid caregivers for relatives or friends who need help taking care of themselves. With people living longer, the high cost of long-term care, and the aging of the Baby Boomer generation, the number of unpaid caregivers is likely to increase,” said Catherine Collinson, CEO and president of TI and TCRS. “It’s time to raise awareness of the challenges faced by caregivers so that they can simultaneously care for their loved ones and protect their own long-term health and financial well-being.”

Transamerica Institute’s national survey of 3,000+ non-professional caregivers examines their duties and the impact caregiving has on their personal health and well-being, employment, finances and retirement preparations. It offers an in-depth analysis and demographic portraits of caregivers by employment status, gender, generation, household income, race/ethnicity, and whether they are the primary caregiver and became a caregiver voluntarily or not. The report also offers detailed findings about care recipients, including their health status and financial situation.

## ***A Portrait of Today’s Caregivers***

“Caregivers are a highly diverse population that includes men and women of all ages, ethnicities, income levels and employment status. Amidst this diversity, caregivers share much in common in terms of their motivations for being a caregiver and the types of duties they perform,” said Hector De La Torre, executive director of TCHS. To illustrate the diversity of the caregiver population, the survey finds:

- Fifty-three percent are women and 47 percent are men;
- Thirty-four percent are Millennials (born 1979-2000), 22 percent are Generation X (born 1965-1978), 37 percent are Baby Boomers (born 1946-1964), and 7 percent are Matures (born before 1946);
- Thirty-nine percent are employed full-time, 13 percent are employed part-time, 8 percent are self-employed, and 40 percent are not employed; and
- Eighteen percent had a household income (HHI) of less than \$25k in 2016, 17 percent had an HHI between \$25k and \$49k, 30 percent had an HHI between \$50k and \$99k, 28 percent had an HHI of \$100k or more, and 7 percent declined to answer.

# Executive Summary

Notably, most caregivers provide care out of love for their care recipient. When asked how they became a caregiver, the most frequently cited reasons include a desire to care for their loved one (63 percent) and having a close relationship with the care recipient (58 percent). Some caregivers indicate they have the time and capacity to do so (43 percent) and live in close proximity to the care recipient (36 percent).

While the vast majority of caregivers (87 percent) are caring for a family member, the family relationship varies by generation:

- Generation X (42 percent) and Baby Boomers (42 percent) are more likely to be caring for a parent, compared to Millennials (24 percent) and Matures (8 percent);
- Matures (57 percent) are more likely than Baby Boomers (24 percent), Millennials (12 percent) and Generation X (11 percent) to be caring for a spouse or partner;
- Millennials (14 percent) and Generation X (12 percent) are more likely than Matures (8 percent) and Baby Boomers (7 percent) to be caring for a child; and
- Millennials (21 percent) are more likely to be caring for a grandparent compared to Generation X (9 percent), Baby Boomers (1 percent) and Matures (none).

Care recipients suffer from a wide range of conditions. Just over half suffer from a permanent condition (55 percent), while 21 percent of care recipients have a temporary condition, and 16 percent have a reoccurring condition. The 10 most common health conditions of care recipients (cited by caregivers) are: arthritis (26 percent), dementia/Alzheimer's disease (net 25 percent), high blood pressure (22 percent), diabetes (18 percent), depression (16 percent), anxiety (14 percent), heart disease (14 percent), cancer (12 percent), immobility (11 percent), and incontinence (11 percent).

## *The Daily Lives and Duties of Caregivers*

"Caregiving responsibilities involve commitments of time and energy to perform a wide variety of tasks, ranging from personal care to household management to administering medications and treatments. These responsibilities can be fulfilling, but also exhausting," said Hector De La Torre, executive director of TCHS. Seventy-four percent of caregivers have been providing care for one or more years and 27 percent have been providing care for five or more years.

# Executive Summary

Caregiving is a full-time job for many – 36 percent of caregivers spend 100 or more hours per month providing care, with a median of 50 hours spent per month, across all caregivers. Looking across various demographic segments, caregivers who are spending the most time per month:

- Have an HHI of less than \$25k at 112 hours (median) with 53 percent spending more than 100 hours per month;
- Are not employed at 86 hours (median) with 47 percent spending more than 100 hours;
- Are Hispanic at 80 hours (median) with 47 percent spending more than 100 hours;
- Are women at 60 hours (median) with 38 percent spending more than 100 hours; and
- Are Generation X at 60 hours (median) with 37 percent spending more than 100 hours.

Many caregivers are involved in a wide range of duties including household-related (89 percent), social/communication (72 percent), health-related (69 percent), personal care (62 percent), medical-related (49 percent), and paying bills/managing finances (43 percent). The four most time-intensive duties are providing companionship (33 hours median), meal preparation (20 hours median), and personal care and feeding (both 12 hours).

Among caregivers who perform medical/nursing-related tasks, only about half (54 percent) say they learned these tasks from hospital or doctor's office personnel. These findings are consistent across demographic segments.

“Many caregivers are in need of formal training to perform their caregiving duties, especially those involved in medical or nursing-related tasks. Without adequate training, they are putting both the care recipient and themselves in harm's way,” said De La Torre.

## ***The Precarious Employment Situation of Caregivers***

Many caregivers are holding down jobs in addition to their caregiving duties, which requires a daily balancing act. More than half of caregivers (52 percent) are employed either full-time (39 percent) or part-time (13 percent). Among those currently employed or who have been employed during their time as a caregiver, three in four (76 percent) have made some type of adjustment to their employment as a result of their caregiving duties, ranging from using vacation and sick days (30 percent), to taking on fewer hours or responsibilities (26 percent), to quitting their jobs or retiring (14 percent).

While most employed caregivers feel their employers are at least somewhat supportive (71 percent), two in five feel that being a caregiver has strained their relationship with their employer.

# Executive Summary

A harsh reality for caregivers is that their caregiving duties may conflict with job responsibilities which, in turn, may impact their performance and put a strain on their relationship with their supervisor or employer. Twenty-eight percent of caregivers who are employed or have been employed during their time as a caregiver have experienced adverse actions taken by their employers as a result of their caregiving responsibilities. Looking across demographic segments, the most likely to say that an adverse action was taken by their employer against them include: Millennial (44 percent), Men (33 percent), Hispanic (31 percent) and White (29 percent) caregivers, and those with an HHI of less than \$25k (27 percent).

## *The Potential Negative Financial Implications of Being a Caregiver*

“Caregiving responsibilities can impact a caregiver’s finances, ranging from lost income due to time off the job to incurring out-of-pocket expenses on behalf of the care recipient. Over time, it can negatively impact the caregiver’s own future retirement,” said Collinson.

Caregivers spend \$150 per month (median) out-of-pocket to cover expenses for their care recipient, a finding which increases with a caregiver’s household income. For example, caregivers with an HHI of less than \$25k spend \$100 (median) per month compared to those with an HHI of \$100k or more who spend \$300 (median) per month. Across all caregivers, 75 percent receive no financial assistance or payment for their work. Paradoxically, caregivers with an HHI of \$100k or more (32 percent) are more likely to receive some financial assistance for their caregiving duties, compared to only 20 percent of those with an HHI of less than \$25k.

Only 56 percent of caregivers self-describe their financial well-being as excellent or good, a survey finding which varies dramatically by a caregiver’s HHI. Specifically, caregivers with an HHI of less than \$25k (16 percent) are far less likely to describe their financial well-being as excellent or good, compared to those with an HHI between \$25k and \$49k (32 percent), between \$50k and \$99k (67 percent), or \$100k+ (86 percent). Forty-four percent of caregivers with an HHI of less than \$25k describe their financial well-being as poor – and 32 percent say that their financial situation has worsened since becoming a caregiver.

# Executive Summary

Perhaps one of the greatest measures of a caregiver's long-term financial security is their total household retirement savings. Many caregivers from all demographic backgrounds are at risk of not achieving a financially secure retirement. However, the survey findings reveal four demographic groups who are at an even greater risk based on their current levels of household retirement savings. Fifty-two percent of caregivers with an HHI of less than \$25k say that they have no retirement savings. Black/African American caregivers have saved just \$4,000 (estimated median) in total household retirement accounts; Hispanics have saved \$12,000 (estimated median); Women have saved \$19,000 (estimated median); and Generation X, which is now entering its fifties, has saved \$31,000 (estimated median). Almost one if five caregivers (18 percent) say that they have taken a loan, hardship withdrawal and/or early withdrawal from their retirement accounts as a result of becoming a caregiver.

## *The Health Effects of Being a Caregiver*

“Given the demands of being a caregiver, especially when juggling a job and other responsibilities, caregivers may be susceptible to health impacts,” said De La Torre. Fifty-five percent of caregivers say their caregiving duties leave them physically and emotionally exhausted. Forty-four percent say their duties leave them feeling completely overwhelmed.

Three out of four caregivers say they are in excellent or good health (74 percent), but approximately one in six caregivers (17 percent) indicate their general health has gotten worse/declined since becoming a caregiver. Caregivers with an HHI of less than \$25k are least likely to say they are in good or excellent health (52 percent) – and most likely to say their health has declined since becoming a caregiver (31 percent).

Ninety percent of caregivers have health insurance, a survey finding that is relatively consistent across demographic segments with two notable exceptions: lower rates of coverage among Hispanic caregivers (75 percent) and caregivers with an HHI of less than \$25k (77 percent).

## *Primary Caregivers Are More Likely to Be Negatively Impacted by Their Caregiving*

Some caregivers play a greater role in providing care than others. In order to better understand the nature, time commitment, and personal impact of their duties, the survey examines the similarities and differences between the 68 percent of caregivers who consider themselves to be the *Primary* caregiver of the care recipient and the 29 percent who do not consider themselves to be, or *Non-Primary* caregivers. (The remaining 3 percent were “not sure.”)



# Executive Summary

The survey finds that Primary caregivers are far more involved than Non-Primary caregivers and they are more likely to be negatively impacted in terms of their employment, financial situation, and health as a result of their caregiving duties. For example:

- Thirty-two percent of Primary caregivers have been providing care for five or more years compared to 17 percent of Non-Primary caregivers;
- Primary caregivers spend more time per month caregiving (80 hours median) compared to Non-Primary caregivers (22 hours median). Forty-five percent of Primary caregivers spend 100 or more hours per month caregiving compared to 15 percent of Non-Primary caregivers;
- Among caregivers who are currently employed or have been employed during their time as a caregiver, Primary caregivers (82 percent) are far more likely than Non-Primary (62 percent) to have made some form of adjustment to their employment. Primary caregivers (32 percent) are also more likely than Non-Primary caregivers (17 percent) to have experienced some form of adverse actions taken by their employers;
- Sixty-one percent of Primary caregivers indicate their own health takes a backseat to that of their care recipient, compared to only 41 percent of Non-Primary caregivers. And 21 percent of Primary caregivers say their health has declined since becoming a caregiver, a finding that is double that of Non-Primary caregivers (10 percent); and
- Twenty-two percent of Primary caregivers say their financial situation has worsened since becoming a caregiver, compared to 10 percent of Non-Primary caregivers.

“Caregiving can be a shared responsibility among family members. All too often, one family member takes on a disproportionate amount of the caregiving work without realizing the risks involved. This situation can be avoided by family members pitching in as best they can, either in terms of providing care or financial assistance,” said Collinson.

# Executive Summary

## *How to Help Caregivers with Their Responsibilities*

Caregivers want and need help with their caregiving duties, ranging from a desire for more information to financial assistance, including:

- Eighty-eight percent of caregivers would like more information on one or more topics related to caregiving.
- One-third of caregivers would like more information about free support services offered by nonprofits and the government. Caregivers would also like more information about financial assistance from nonprofits/the government, as well as long-term care and legal documents.
- In order to help them personally with their caregiving responsibilities, more than one-third of caregivers would like information about stress management (38 percent), tips for coping with challenges (37 percent), and government benefits available for caregivers (37 percent).
- In order to ease the demands of their caregiving role, caregivers often wish they could have more help and the ability to make adjustments to their personal lives and routines. Nineteen percent of caregivers wish for increased financial support (e.g., more money, less debt, or payment for their services) and additional help/support for their caregiver role.

Caregivers play a vital role in our society providing support for family, friends and loved ones. It is a labor of love that comes without a paycheck. In being caregivers, many are putting their own health and long-term financial security at risk. From a societal perspective, it is imperative that we raise awareness of the issues and risks faced by caregivers and offer meaningful solutions that can help them to better manage their caregiving duties to assist their care recipients and themselves,” said Collinson.

# ***The Many Faces of Family Caregivers: A Close-Up Look at Caregiving and Its Implications***

## **Executive Summary**

### **A Portrait of Today's Caregivers**

#### **➤ *Key Highlights***

- A Portrait of Today's Caregivers
- Insights About Care Recipients and Their Needs
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### **Demographic Perspectives**

### **Appendix: Caregiver and Care Recipient Demographics**

### **Acknowledgements**

# Key Highlights

## Introduction

Millions of Americans are serving as unpaid caregivers for a relative or friend with a temporary, episodic, or permanent condition who needs help taking care of themselves. With people living longer, the high cost of long-term care and the aging of the Baby Boomer generation, the number of unpaid caregivers is likely to increase.

[Transamerica Institute](#)®, including its [Center for Retirement Studies](#) and [Center for Health Studies](#), has undertaken a large-scale survey of 3,000+ caregivers to gain a better understanding of their duties and the impact of caregiving on their own health and well-being, employment, finances and retirement preparations. The survey provides an in-depth analysis by primary versus non-primary caregivers and demographic portraits by those who volunteered to become a caregiver compared to those who didn't volunteer, gender, generation, household income, employment status, and race/ethnicity. The survey also offers detailed findings about the care recipients, including their health status and financial situation.

## A Portrait of Today's Caregivers

Caregivers and their care recipients represent two highly diverse populations. Some caregivers play a greater role than others in providing care. In order to better understand the nature, time commitment, and personal impact of their duties, the survey examined the similarities and differences between the 68 percent caregivers who consider themselves to be the *Primary* caregiver of the care recipient and the 29 percent who do not consider themselves to be such or *Non-Primary* caregivers. (The remaining 3 percent were “not sure.”)

- **A Portrait of Caregivers.** Among all caregivers, the population is split almost evenly with slightly more women (53 percent) than men (47 percent). Millennials (34 percent) and Baby Boomers (37 percent) are more likely to be caregivers than Generation X (22 percent). Fifty-one percent are employed either full-time or part-time. Household income is \$57,000 (estimated median). These findings are relatively consistent between Primary and Non-Primary caregivers.
- **The Majority of Caregivers Are Caring for a Family Member.** Eighty-seven percent of all caregivers are caring for a family member, a finding which is higher among Primary (91 percent) compared to Non-Primary (79 percent) caregivers. Parents are the most frequently cited recipients of care among both Primary (34 percent) and Non-Primary (35 percent) caregivers. Primary caregivers are more likely than Non-Primary caregivers to be caring for a spouse/partner (27 percent vs. 2 percent, respectively) or a child (13 percent vs. 6 percent, respectively).

# Key Highlights

- **Three in Four Caregivers Provide Care for One Person.** Seventy-five percent of all caregivers provide care for only one person. Twenty-five percent care for two or more individuals. These findings are consistent among Primary and Non-Primary caregivers.
- **Most Caregivers Do So Out of Love.** People become caregivers for a variety of reasons, including: a desire to care for their loved one (63 percent), having a close relationship to the care recipient (58 percent), having the time and capacity to do so (43 percent), and living in close proximity to the care recipient (36 percent). These reasons are commonly shared among Primary and Non-Primary caregivers with a higher percentage of Primary caregivers citing these responses. However, the survey found two major differences between Primary and Non-Primary caregivers. Primary caregivers are more likely than Non-Primary caregivers to indicate that nobody else was available (25 percent vs. 16 percent, respectively) or that nobody else was willing to do so (20 percent vs. 9 percent respectively).
- **Four Out of Five Caregivers Came to it Voluntarily.** Eighty-four percent of all caregivers became a caregiver voluntarily, a finding which is slightly higher among Primary (85 percent) versus Non-Primary (82 percent) caregivers. Eleven percent of all caregivers say they did not become a caregiver voluntarily and the other 5 percent are “not sure.”
- **Most Caregivers Have Provided Care for Years.** Among all caregivers, the providing of care has been two years (median). Primary caregivers have been providing care for three years (median) while Non-Primary caregivers have been providing care for two years (median). Seventy-four percent of all caregivers have been providing care for one or more years. Primary caregivers (80 percent) are more likely to have been providing care for one or more years compared to Non-Primary caregivers (63 percent). Twenty-seven percent of all caregivers have been providing care for five or more years, a finding which is higher among Primary (32 percent) than Non-Primary (17 percent) caregivers.
- **Family Members Often Work Together to Provide Care.** Seventy-six percent of all caregivers indicate that other people (excluding medical professionals and care facility staff) are involved in providing care for the care recipient, a finding which is higher among Non-Primary (92 percent) than Primary (68 percent) caregivers. Family members (65 percent) are the most frequently cited type of individual involved in caregiving, a finding which is also higher among Non-Primary (82 percent) than Primary (58 percent) caregivers.



# Key Highlights

- **Almost Half of Caregivers Live with Their Care Recipient.** Almost half of caregivers (47 percent) live with their care recipient, a finding which is significantly higher among Primary caregivers (59 percent) than Non-Primary caregivers (19 percent). Primary caregivers (43 percent) are more than three times more likely than Non-Primary caregivers (12 percent) to have the care recipient living in their home. Similarly, Primary caregivers (16 percent) are also more likely than Non-Primary caregivers (7 percent) to live in the care recipient's home.
- **Caregivers Tend to Live in Close Proximity to the Care Recipient.** Among those who do not live with the care recipient, approximately half of all caregivers (49 percent) live within 10 miles of the care recipient, a finding which is relatively consistent between Primary (52 percent) and Non-Primary (45 percent) caregivers.

## *Insights About Care Recipients and Their Needs*

Caregivers are serving care recipients who are diverse in terms of their conditions and level of activity. Some more than other care recipients have discussed and/or documented their medical and financial wishes.

- **Care Recipients Have a Range of Conditions.** Caregivers provide care for a range of different ailments and health conditions. The three most common conditions are arthritis (26 percent), dementia/Alzheimer's disease (Net, 25 percent), and high blood pressure (22 percent).
- **Most Care Recipients Are at Least Somewhat Active.** Sixty-four percent of caregivers indicate their care recipient is somewhat active, a finding which is more frequently cited among Primary (66 percent) than Non-Primary (59 percent) caregivers. Among all caregivers, one in five (20 percent) indicate the care recipient is completely inactive, a finding which is more frequently cited among Non-Primary (25 percent) than Primary (18 percent) caregivers. Sixteen percent of all caregivers, including Primary and Non-Primary, say their care recipient is fully active.
- **Approximately Half of Care Recipients Have a Permanent Condition.** Fifty-four percent of all caregivers indicate that their care recipient has a permanent health condition while 21 percent indicate that their care recipient has a temporary primary condition and 16 percent have a reoccurring condition. These findings are consistent between Primary and Non-Primary caregivers.

# Key Highlights

- **Most Say Care Recipients Have Discussed Their Wishes.** The majority of caregivers indicate that their care recipients have discussed health directives with them or another close friend/relative, and almost half have written documentation for health information (HIPPA) waiver, and wills or trusts in place. While 74 percent of care recipients have discussed allowing a designated individual to make medical decisions (power of attorney), only 50 percent have documented the arrangement.
  - *Primary Caregivers' Discussions with Care Recipients.* Most Primary caregivers indicate their care recipients have discussed various matters related to their care with them or another close relative or friend, including medical power of attorney (78 percent), health information (HIPPA) waivers (77 percent), advance directives (72 percent), guardianship (63 percent), funeral and burial arrangements (71 percent), and wills or trusts (72 percent).
  - *Non-Primary Caregivers Are Having Discussions About Health Directives.* Most Non-Primary caregivers indicate their care recipients have discussed various matters related to their care with them or another close relative or friend, including medical power of attorney (68 percent), health information (HIPPA) waivers (67 percent), advance directives (59 percent), guardianship (51 percent), funeral and burial arrangements (58 percent), and wills or trusts (57 percent).

## *The Diverse Duties, Daily Lives, and Dedication of Caregivers*

Caregiving responsibilities involve commitments of time and energy performing a wide variety of tasks, ranging from personal care to household management and administering medications and treatments. These tasks can be fulfilling but may also be exhausting. Primary caregivers spend much more time providing care than Non-Primary caregivers and, in many ways, are more personally impacted.

- **Caregiving Is a Full-Time Job for Many.** Caregivers spend 50 hours (median) per month caring for the care recipient, a finding which varies dramatically between Primary (80 hours median) and Non-Primary caregivers (22 hours median). Thirty-six percent of all caregivers spend 100 or more hours per month caregiving, including more Primary (45 percent) than Non-Primary (15 percent) caregivers.

# Key Highlights

- **Caregiving Is a Multi-Dimensional Job.** Caregiving encompasses a broad range of duties, such as household, social/communication, health, personal care, medical-related and paying bills/managing finances. Primary caregivers are more likely to engage in these activities than Non-Primary caregivers.
  - Of particular note, 78 percent of Primary caregivers perform health-related duties for the care recipient, compared to only 47 percent of Non-Primary caregivers.
  - Similarly, Primary caregivers (59 percent) are twice as likely to perform medical-related duties as Non-Primary caregivers (28 percent).
  - More than half of Primary caregivers (53 percent) pay bills/manage finances for the care recipient compared to only 23 percent of Non-Primary caregivers.
- **Caregivers Devote Significant Time to Caregiving Duties.** Caregivers spend a significant amount of time each month on a wide range of caregiving duties, with Primary caregivers dedicating more time to these duties than Non-Primary caregivers.
  - Among all caregivers, providing companionship requires the most time (33 hours median). Primary caregivers (50 hours median) spend more than three times the amount of time on this role than Non-Primary caregivers (16 hours median).
  - Meal preparation is the second-most time consuming activity among all caregivers (20 hours median), a finding which is higher among Primary (21 hours median) compared to Non-Primary (9 hours median) caregivers.
- **Caregivers Rely on a Variety of Sources of Information.** Caregivers most frequently rely on friends and family (45 percent) or medical professionals (45 percent) as sources of information to assist in their caregiving duties.
  - Primary caregivers (49 percent) are more likely than Non-Primary caregivers (35 percent) to rely on medical professionals, while Non-Primary caregivers (55 percent) are more likely than Primary caregivers (40 percent) to rely on family and friends.
  - Primary caregivers are generally more likely than Non-Primary caregivers to rely on electronic sources of caregiving information (i.e. medical or caregiving websites), books or printed materials, and caregiving guides.

# Key Highlights

- **About Half Learn Medical/Nursing Tasks from Professionals.** Among caregivers who perform medical/nursing-related tasks, 54 percent say they learned these tasks from hospital or doctor's office personnel, including 56 percent of Primary caregivers and 45 percent of Non-Primary caregivers. Family and friends (36 percent) are the second most frequently cited source of training among caregivers, including 35 percent of Primary caregivers and 42 percent of Non-Primary caregivers.
- **Caregivers' Sentiments About Their Caregiving Duties.** The vast majority of all caregivers cite positive aspects of caregiving, including that they like helping and enjoy spending time with their care recipient (both 91 percent). However, more than half of all caregivers agree that their caregiving duties leave them feeling emotionally or physically exhausted (both 55 percent). Primary caregivers (61 percent) are far more likely than Non-Primary caregivers (41 percent) to indicate their own health is taking a backseat to the health of their care recipients.

## *The Employment Situation of Caregivers*

Many caregivers are also holding down jobs, in addition to their caregiving duties, which requires a delicate balancing act. The survey examined how these caregiving duties may be negatively impacting their employment situation.

- **More Than Half of Caregivers Are Employed.** The majority of all caregivers are currently employed full- or part-time (52 percent), including 53 percent of Primary caregivers and 47 percent of Non-Primary caregivers. Of the 40 percent of caregivers who are not currently employed, most (65 percent) were never employed during their time as a caregiver.
- **Caregiving Duties Negatively Impact Employment.** As a result of their caregiving duties, 76 percent of employed caregivers have made some type of adjustment to their employment, ranging from using vacation and sick days to quitting their jobs. Primary (82 percent) are more likely than Non-Primary caregivers (62 percent) to have done so.
  - Twenty-six percent of employed caregivers have reduced their hours or job responsibilities, including 30 percent of Primary and 16 percent of Non-Primary caregivers.
  - Eighteen percent of employed caregivers have taken a leave of absence. Primary (22 percent) are more likely to have done so than Non-Primary caregivers (9 percent).
  - Fourteen percent of employed caregivers have retired early or quit their job. Primary caregivers (16 percent) are somewhat more likely to have done so than Non-Primary (12 percent) caregivers.

# Key Highlights

- **Most Have Told Someone at Work That They Are a Caregiver.** Approximately three in four employed caregivers (77 percent) have told someone at work that they are a caregiver. Primary (82 percent) are more likely than Non-Primary caregivers (64 percent) to have told someone. More than half of all employed caregivers (57 percent) have told their immediate supervisor about their caregiving duties, including 63 percent of Primary and 42 percent of Non-Primary caregivers.
- **Most Caregivers Feel Their Employers Are Supportive.** A substantial majority (71 percent) of all employed caregivers feel their employer is at least somewhat supportive of their caregiving responsibilities. Primary caregivers (44 percent) are more likely than Non-Primary caregivers (34 percent) to indicate that they feel very supported by their employer.
- **Most Feel Employers Are Understanding.** Seventy-six percent of all employed caregivers either strongly or somewhat agree that their employer understands the difficulties they face as a caregiver, including 78 percent of Primary and 71 percent of Non-Primary caregivers.
- **Two in Five Caregivers Feel Strain with Their Employers.** Forty percent of all employed caregivers feel that their being a caregiver has strained their relationship with their employer, a finding which is more frequently reported among Primary (46 percent) than Non-Primary (28 percent) caregivers.
- **Some Have Experienced Adverse Actions Taken by Employers.** Twenty-eight percent of caregivers who are employed or have been employed during their time as a caregiver have experienced adverse action(s) taken by their employer(s) as a result of their caregiving responsibilities, a finding which is much higher among Primary caregivers (32 percent) than Non-Primary caregivers (17 percent). Types of adverse actions include been given less attractive assignments (10 percent), been written up or admonished (8 percent), passed over for a promotion (8 percent), fired (8 percent), forcibility had hours or duties reduced (8 percent), or been discriminated against (7 percent).
- **Caregivers Cite Few Programs Offered by Employers.** Caregivers who are currently employed full-time or part-time indicate that their employers offer few programs to assist with their caregiving responsibilities. The most commonly cited programs include flexible work schedules (57 percent), unpaid leave covered by FMLA (56 percent), unpaid leave of absence not covered by FMLA (49 percent), flexible working arrangements (46 percent), and an employee assistance program (46 percent). Eleven percent say that their employers do not offer any such programs. Primary caregivers are more likely to indicate such programs are offered and Non-Primary are more likely to be “not sure.”



# Key Highlights

- **Few Are Very Familiar with FMLA.** The Family Medical Leave Act (FMLA) is a federal law that requires covered employers to provide their employees with protected, unpaid leave for qualified medical and family reasons. Fifty-seven percent of all caregivers are “somewhat” or “very familiar” with FMLA. However, only 22 percent of all caregivers are “very familiar” with it. Primary (25 percent) are more likely than Non-Primary caregivers (17 percent) to be “very familiar.” An alarming 24 percent of all caregivers are “not at all familiar” with FMLA, a finding that is consistent among Primary (23 percent) and Non-Primary (25 percent) caregivers.

## *The Personal Financial Implications of Being a Caregiver*

Caregiving responsibilities can impact a caregiver’s finances, ranging from lost income from time off the job to incurring out of pocket expenses for the care recipient. Over time, it can even negatively impact the caregiver’s own future retirement. The survey explored these personal financial implications and their personal financial situation.

- **Caregivers’ Financial Well-Being.** More than half of all caregivers (56 percent) self-describe their financial well-being as excellent or good, a finding that is relatively consistent among Primary (57 percent) and Non-Primary caregivers (54 percent). A noteworthy 15 percent of all caregivers, including Primary and Non-Primary caregivers, say their financial well-being is poor.
- **Many Didn’t Consider Finances When Becoming a Caregiver.** Sixty-nine percent of all caregivers say they gave little or no thought into their own financial situation when deciding to become a caregiver, a finding which differs between Primary (66 percent) and Non-Primary (76 percent) caregivers. Primary caregivers (34 percent) are more likely than Non-Primary caregivers (24 percent) to have given some or a lot of thought to their financial situation when deciding to become a caregiver.
- **Most Caregivers’ Financial Situation Has Stayed the Same.** The majority of caregivers (65 percent) say their financial situation has not changed much as a result of becoming a caregiver, including Primary caregivers (61 percent) and Non-Primary caregivers (76 percent). However, Primary caregivers (22 percent) are more likely than Non-Primary caregivers (10 percent) to say their financial situation has worsened since becoming a caregiver.
- **Most Caregivers Spend Their Own Money to Cover Cost of Care.** Caregivers spend \$150 per month (median) out-of-pocket to cover expenses for their care recipient, with 9 percent of caregivers spending \$1,000 or more per month. Primary caregivers (\$250 median) spend five times as much per month on caregiving as Non-Primary caregivers (\$50 median). Primary caregivers (12 percent) are also four times as likely as Non-Primary caregivers (3 percent) to spend \$1,000 or more per month on caregiving-related expenses.

# Key Highlights

- **Most Caregivers Do Not Receive Any Financial Assistance.** Only 25 percent of all caregivers receive any sort of financial assistance for their caregiving duties, a finding which is higher among Primary (27 percent) than Non-Primary (21 percent) caregivers. With regards to possible sources of financial assistance, caregivers' most frequently cited source of funds are from the care recipient (10 percent), a finding which is relatively consistent between Primary (11 percent) and Non-Primary (8 percent) caregivers.
- **Almost Half of Caregivers Are Paying Off Debt.** Caregivers' most frequently cited financial priorities include just getting by – covering basic living expenses (43 percent) and saving for retirement (37 percent). A noteworthy and alarming 49 percent of caregivers cite paying off some form of debt as a financial priority including 32 percent who mentioned paying off credit card or consumer debt. These financial priorities are directionally similar among Primary and Non-Primary caregivers. However, Primary caregivers (34 percent) are more likely than Non-Primary caregivers (25 percent) to mention paying healthcare expenses. Primary caregivers are also more likely than Non-Primary caregivers to mention supporting children and supporting parents.
- **Household Income Among Caregivers Spans a Wide Spectrum.** The household income of caregivers is \$57,000 per year (estimated median). Twenty-eight percent of caregivers report a household income of \$100,000 or more per year, including 29 percent of Primary caregivers and 25 percent of Non-Primary caregivers. Thirty-five percent of caregivers report a household income of less than \$50,000 per year.
- **Most Are Confident About Retiring Comfortably.** Sixty percent of caregivers are “somewhat” or “very confident” that they will be able to fully retire with a comfortable lifestyle, including 24 percent who are “very confident” and 36 percent who are “somewhat confident.” However, one in five caregivers (21 percent) are “not at all confident.” These findings are consistent between Primary and Non-Primary caregivers.
- **Six in 10 Caregivers Are Saving for Retirement.** Most caregivers (61 percent) are saving for retirement in some way. The two most frequently cited savings vehicles that caregivers are using to save are employer-sponsored 401(k)s or similar programs (34 percent) and IRAs (29 percent). These findings are consistent between Primary and Non-Primary caregivers.
- **Are Caregivers Saving Enough For Retirement?** Caregivers have saved \$68,000 (estimated median) in all household retirement accounts, a finding which is relatively consistent among Primary and Non-Primary caregivers. Sixteen percent of all caregivers have saved \$500k or more in all retirement accounts, a finding which is slightly higher among Primary caregivers (17 percent) than Non-Primary caregivers (14 percent). Fifteen percent of all caregivers have no savings in retirement accounts.

# Key Highlights

- **Some Caregivers Have Dipped Into Their Retirement Accounts.** Eighteen percent of caregivers have taken some sort of loan or withdrawal from their retirement accounts as a result of their caregiving responsibilities. Primary caregivers (21 percent) are almost twice as likely as Non-Primary caregivers (12 percent) to have taken a loan, early withdrawal and/or hardship withdrawal from their 401(k), IRA, or similar plan.
- **One-Third of Caregivers Have a Financial Advisor.** Thirty-six percent of caregivers have a financial advisor, including 37 percent of Primary and 32 percent of Non-Primary caregivers.

## *The Health Effects of Being a Caregiver*

Given the demands of being a caregiver, especially if juggling a job and other responsibilities, caregivers may be susceptible to health issues.

- **Most Caregivers Consider Themselves to Be in Excellent/Good Health.** Three out of four caregivers say they are in excellent or good health (74 percent). Twenty-three percent of caregivers consider themselves to be in fair health. Only 3 percent consider themselves to be in poor health.
- **One in Six Experienced a Decline in Their Own Health.** Approximately one in six caregivers (17 percent) indicate their general health has gotten worse/declined since becoming a caregiver, a finding which is much higher among Primary caregivers (21 percent) than Non-Primary caregivers (10 percent). The majority of caregivers (65 percent) indicate that their general health has stayed the same. Primary caregivers (61 percent) are less likely than Non-Primary caregivers (74 percent) to say their health status has not changed.
- **Nine in 10 Caregivers Have Health Insurance,** a finding that is consistent between Primary (91 percent) and Non-Primary caregivers (90 percent). Employer benefits are the most frequently cited source of health insurance among all caregivers (39 percent), including Primary (39 percent) and Non-Primary (40 percent) caregivers. Other frequently cited sources of health insurance coverage among all caregivers include Medicare (19 percent) and Medicaid (10 percent). Of note, 10 percent of caregivers are currently uninsured.

# Key Highlights

## *Ways to Help Caregivers with Their Responsibilities*

Caregivers want and need help with their caregiving duties, ranging from a desire for more information to financial assistance.

- **Caregivers Want More Information to Help with Their Duties.** In order to help with their caregiving responsibilities, 88 percent of caregivers would like more information on one or more topics. One-third of caregivers would like more information about free support services offered by nonprofits and the government. Caregivers would also like more information about financial assistance from nonprofits/the government, long-term care, and legal documents.
- **Caregivers Would Like More Information to Help Them Personally.** In order to help them personally with their caregiving responsibilities, 71 percent of caregivers would like more information on one or more topics, including 76 percent of Primary and 60 percent of Non-Primary caregivers. More than one-third of caregivers would like information about stress management (38 percent), tips for coping with challenges (37 percent), and government benefits available for caregivers (37 percent). Primary caregivers are more likely than Non-Primary caregivers to want this information.
- **Caregivers Wish for More Help and Monetary Support.** In order to ease the demands of their caregiving role, caregivers often wish they could have more help and make adjustments to their personal lives and routines. Nineteen percent caregivers wish for increased financial support (i.e. more money, less debt, or payment) and additional help/support for their caregiver role.

Caregivers play a vital role in our society providing care for family, friends and loved ones. It is truly a labor of love that comes without a paycheck. In being caregivers, many are putting their own health and long-term financial security at risk. Many indicate their own health takes a backseat to that of their care recipients. Some are reporting a decline in their own health status since becoming a caregiver. All too often, whether employed or not employed, caregiving responsibilities conflict with a caregiver's own livelihood and ability to earn income. This can lead to lower retirement savings and benefits when they retire – and may need care themselves.

One of the most striking findings is that caregivers who self-identify as being the primary caregiver are at far greater risk than those who are not the primary caregiver. This leads to the imperative to raise awareness and make caregiving a shared responsibility among family members. This first step can help avoid a common scenario in which one family member bears a disproportionate amount of the caregiving duties their own health and financial detriment.

Public policy can also play a role in helping caregivers, ranging from earning Social Security benefits for time spent as a caregiver and a tax credit to help offset out-of-pocket expenses paid by caregivers for routine expenses of the care recipient.

Catherine Collinson, CEO and President, Transamerica Institute and Transamerica Center for Retirement Studies  
Hector De La Torre, Executive Director, Transamerica Center for Health Studies

# ***The Many Faces of Family Caregivers: A Close-Up Look at Caregiving and Its Implications***

## **Executive Summary**

### **A Portrait of Today's Caregivers**

- Key Highlights

#### **➤ *A Portrait of Today's Caregivers***

- Insights About Care Recipients and Their Needs
- The Diverse Duties, Daily Lives, and Dedication of Caregivers
- The Employment Situation of Caregivers
- The Personal Financial Implications of Being a Caregiver
- The Health Effects of Being a Caregiver
- Ways to Help Caregivers with Their Responsibilities

## **Demographic Perspectives**

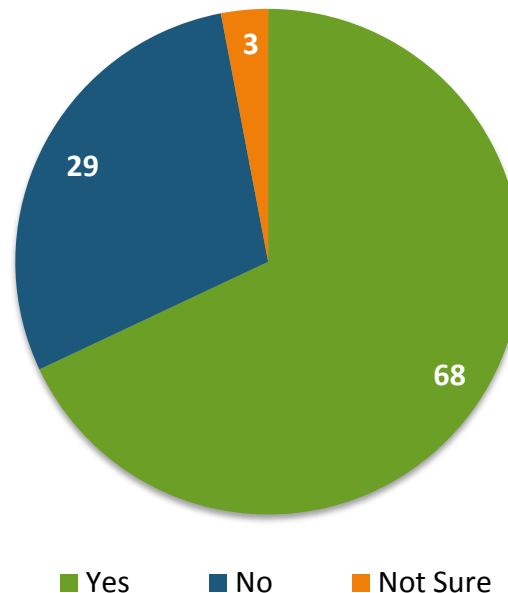
### **Appendix: Caregiver and Care Recipient Demographics**

## **Acknowledgements**

# Over Two-Thirds Consider Themselves to Be a Primary Caregiver

Sixty-eight percent of caregivers consider themselves to be the *Primary* caregiver of the care recipient. Twenty-nine percent do not consider themselves to be such, hence, the report refers to them as *Non-Primary* caregivers. The remaining 3 percent of caregivers are “not sure.”

“Would you consider yourself to be the Primary caregiver?” (%)



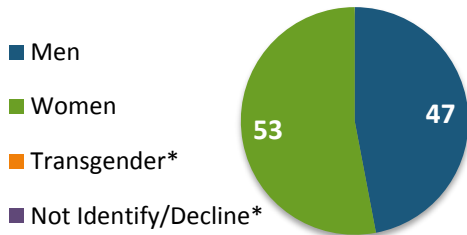
■ Yes    ■ No    ■ Not Sure

# A Portrait of Caregivers

Among all caregivers, the population is split almost evenly with slightly more women (53 percent) than men (47 percent). Millennials (34 percent) and Baby Boomers (37 percent) are more likely to be caregivers than Generation X (22 percent). Fifty-one percent are employed either full-time or part-time. Caregivers' household income is \$57,000 (estimated median).



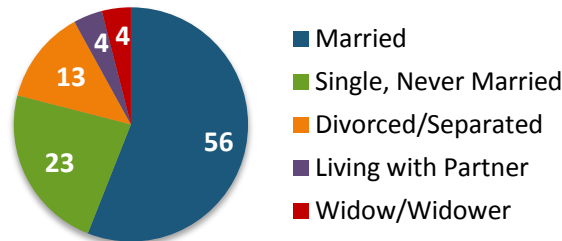
## GENDER



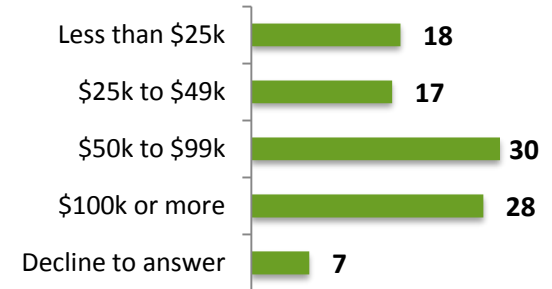
\*Note: Sample size for Transgender and Not Identify/Decline too small to report



## MARITAL STATUS



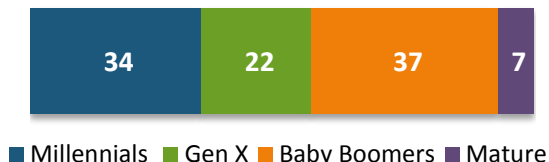
## HOUSEHOLD INCOME



Estimated Median: \$ 57,000



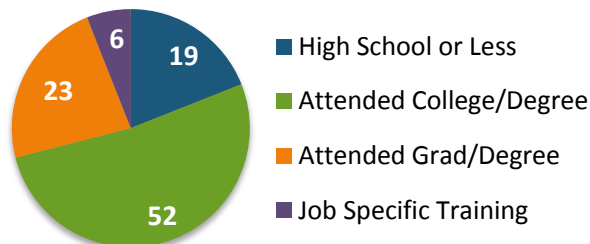
## GENERATION



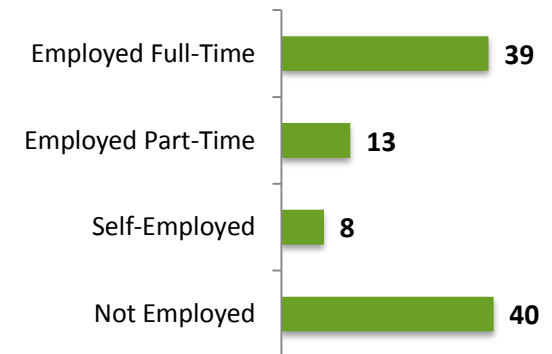
Median Age: 48



## EDUCATION



## EMPLOYMENT



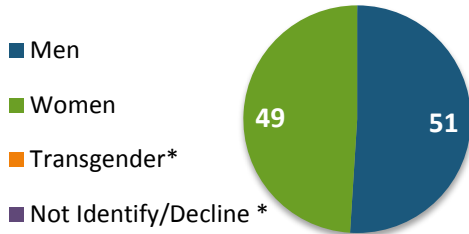
# A Portrait of Primary Caregivers

Among Primary caregivers, the population is evenly split between women (49 percent) and men (51 percent). Millennials (34 percent) and Baby Boomers (36 percent) are more likely to be Primary caregivers than Generation X (22 percent). Fifty-four percent are employed either full-time or part-time. Household income is \$58,000 (estimated median).

## Demographics of Primary Caregivers (%)



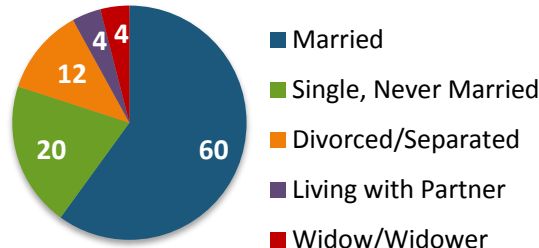
### GENDER



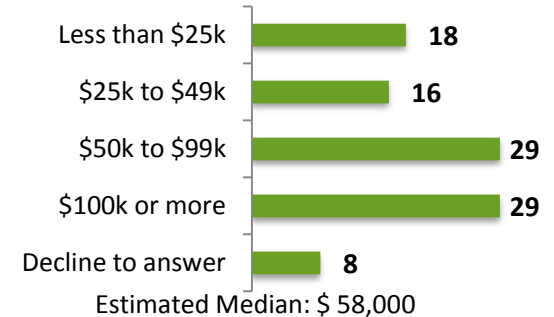
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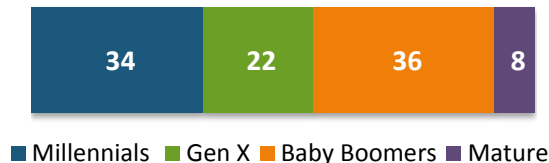
### MARITAL STATUS



### HOUSEHOLD INCOME



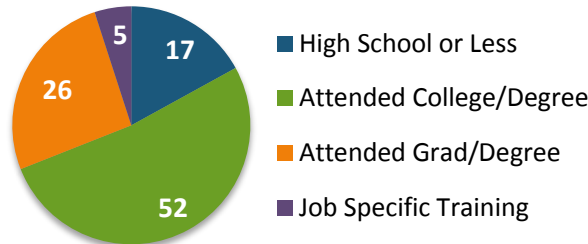
### GENERATION



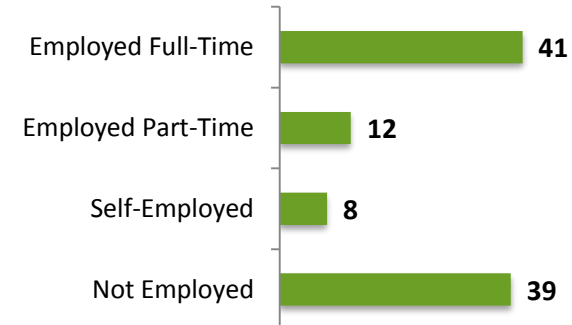
**Median Age: 47**



### EDUCATION



### EMPLOYMENT





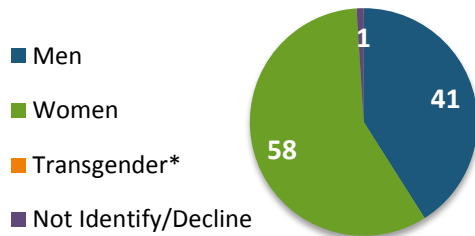
# A Portrait of Non-Primary Caregivers

Among Non-Primary caregivers, the population includes a higher percentage of women (58 percent) than men (41 percent). Millennials (33 percent) and Baby Boomers (39 percent) are more likely to be Non-Primary caregivers than Generation X (23 percent). Forty-seven percent are employed full-time or part-time. Household income is \$56,000 (estimated median).

## Demographics of Non-Primary Caregivers (%)



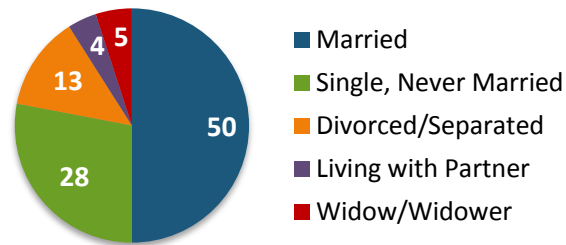
### GENDER



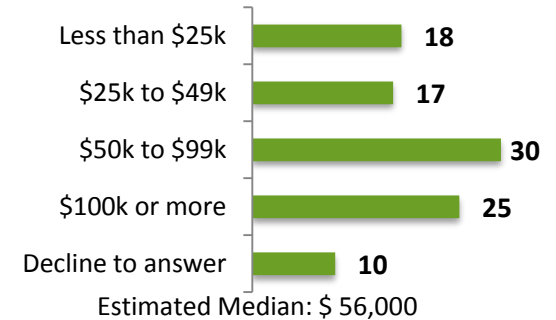
\*Note: Sample size for Transgender too small to report



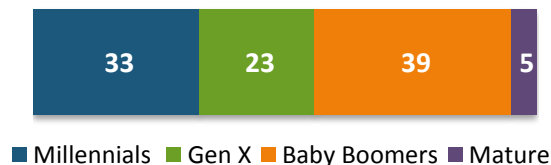
### MARITAL STATUS



### HOUSEHOLD INCOME



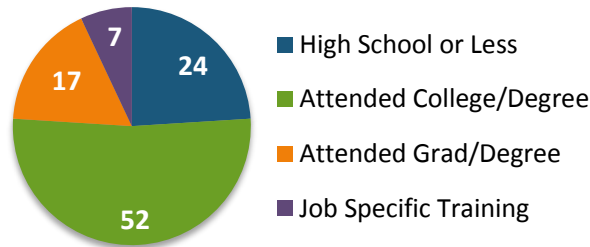
### GENERATION



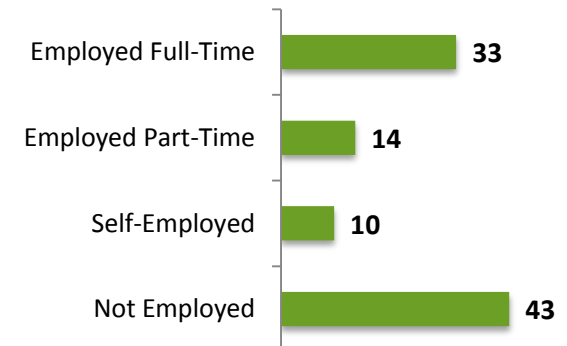
Median Age: 49



### EDUCATION

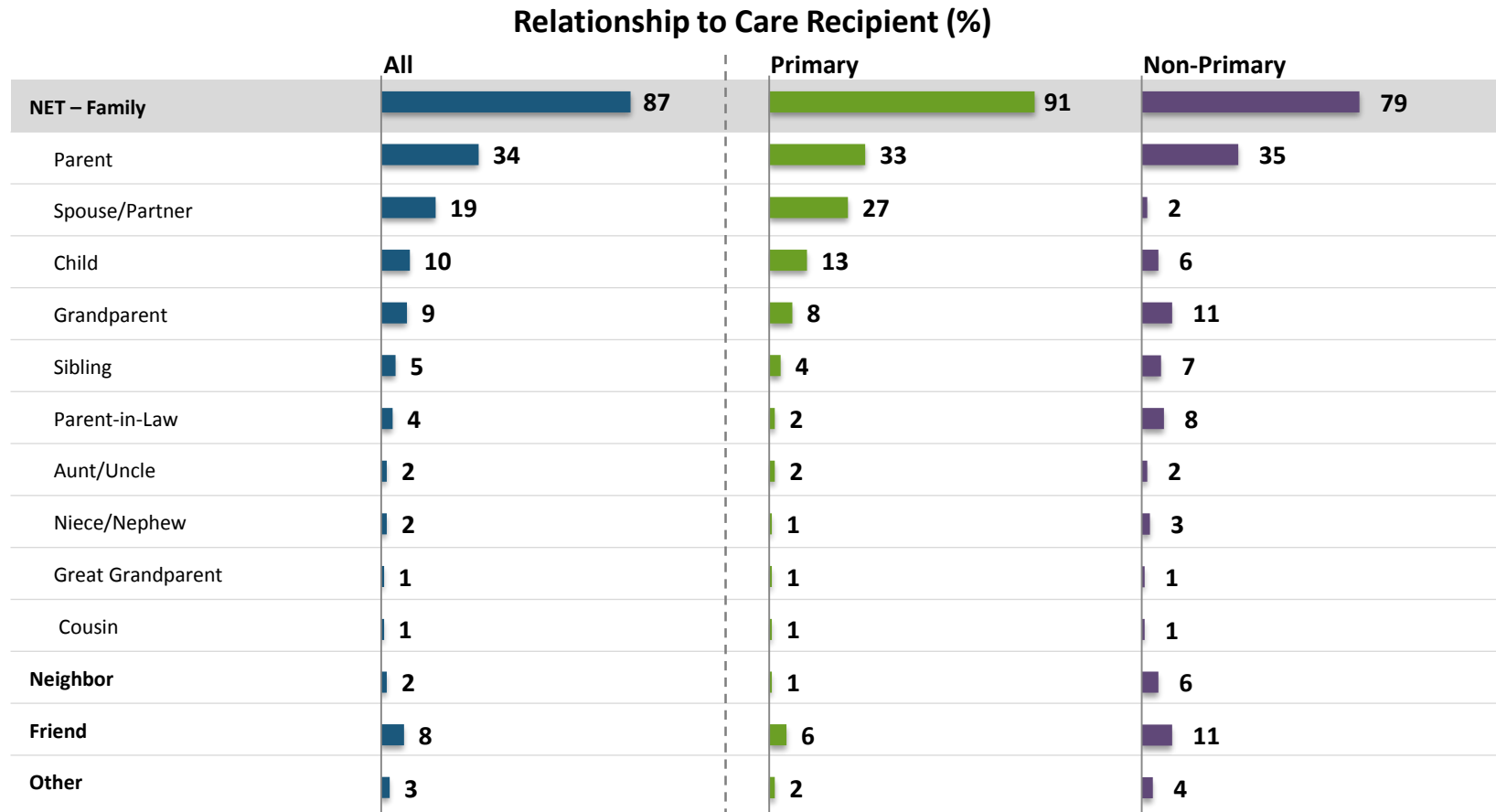


### EMPLOYMENT



# The Majority of Caregivers Are Caring for a Family Member

Eighty-seven percent of all caregivers are caring for a family member, a finding which is higher among Primary (91 percent) compared to Non-Primary (79 percent) caregivers. Parents are the most frequently cited recipients of care among both Primary (34 percent) and Non-Primary (35 percent) caregivers. Primary caregivers are more likely than Non-Primary caregivers to be caring for a spouse/partner (27 percent vs. 2 percent, respectively) or a child (13 percent vs. 6 percent, respectively) or a child (13 percent vs. 6 percent, respectively).



BASE: ALL QUALIFIED RESPONDENTS

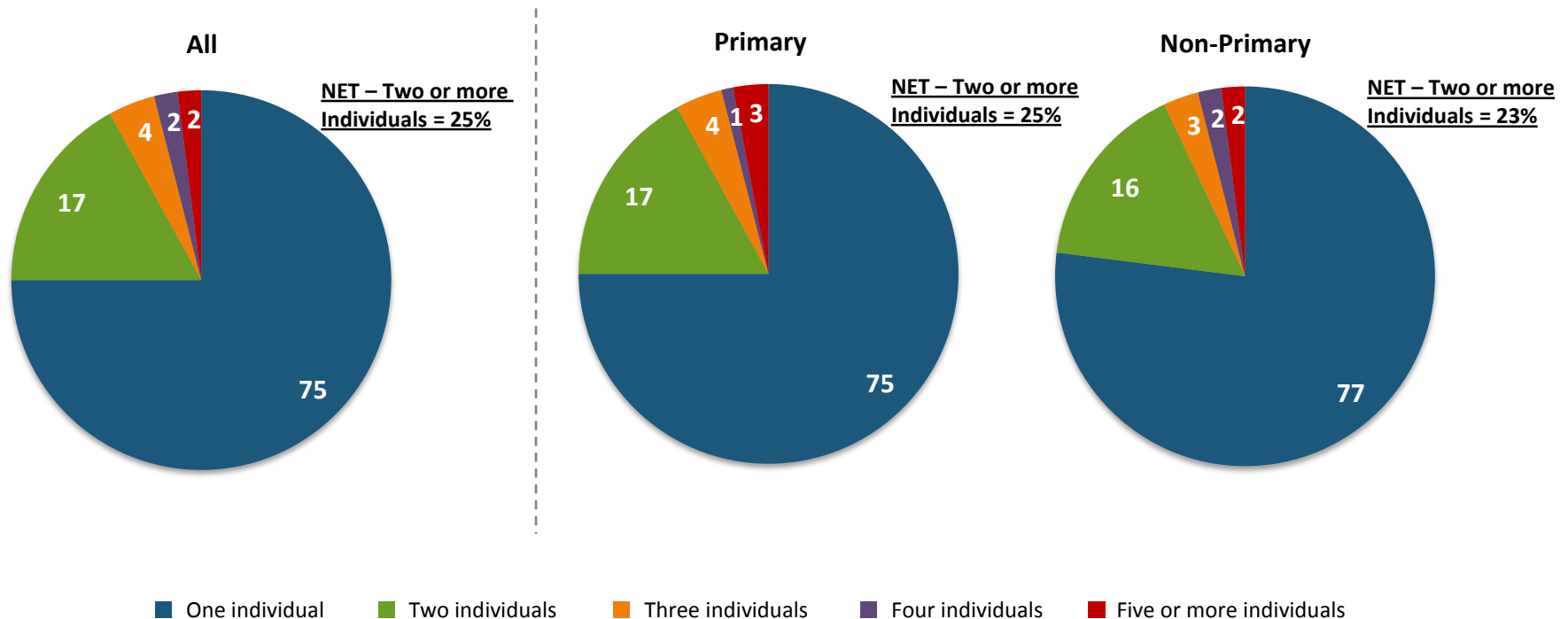
Q700. You mentioned providing care for [INSERT ANSWER FROM Q610] individual(s).

Please let us know your relationship to the person, their age, and their gender.

# Three in Four Caregivers Provide Care for One Person

Seventy-five percent of all caregivers provide care for only one person. Twenty-five percent care for two or more individuals. These findings are consistent among Primary and Non-Primary caregivers.

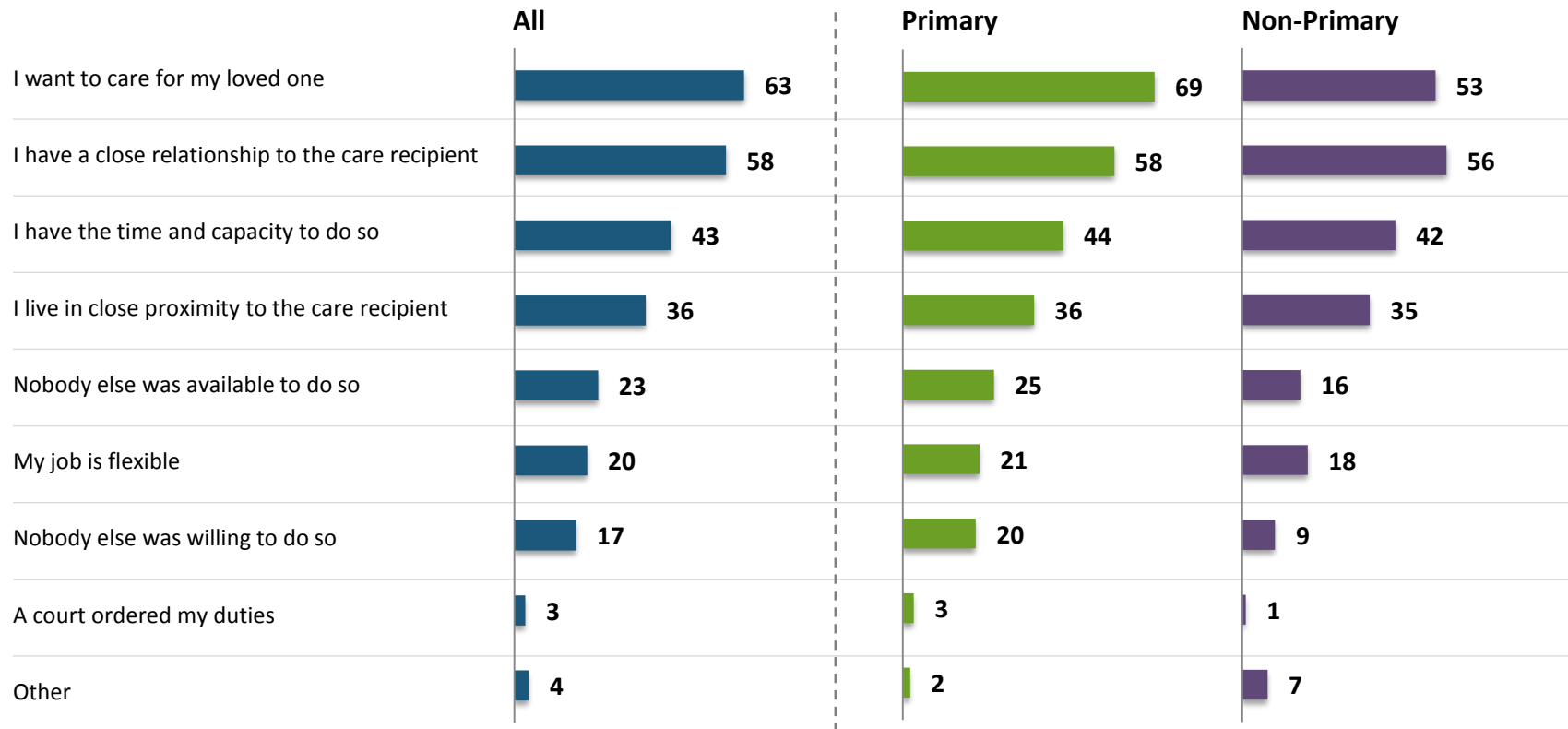
Number of Individuals Cared for in the Past 12 Months (%)



# Most Caregivers Do So Out of Love

People become caregivers for a variety of reasons, including: a desire to care for their loved one (63 percent), having a close relationship to the care recipient (58 percent), having the time and capacity to do so (43 percent), and living in close proximity to the care recipient (36 percent). These reasons are commonly shared among Primary and Non-Primary caregivers with a higher percentage of Primary caregivers citing these responses. However, the survey found two major differences between Primary and Non-Primary caregivers. Primary caregivers are more likely than Non-Primary caregivers to indicate that nobody else was available (25 percent vs. 16 percent) or that nobody else was willing to do so (20 percent vs. 9 percent respectively).

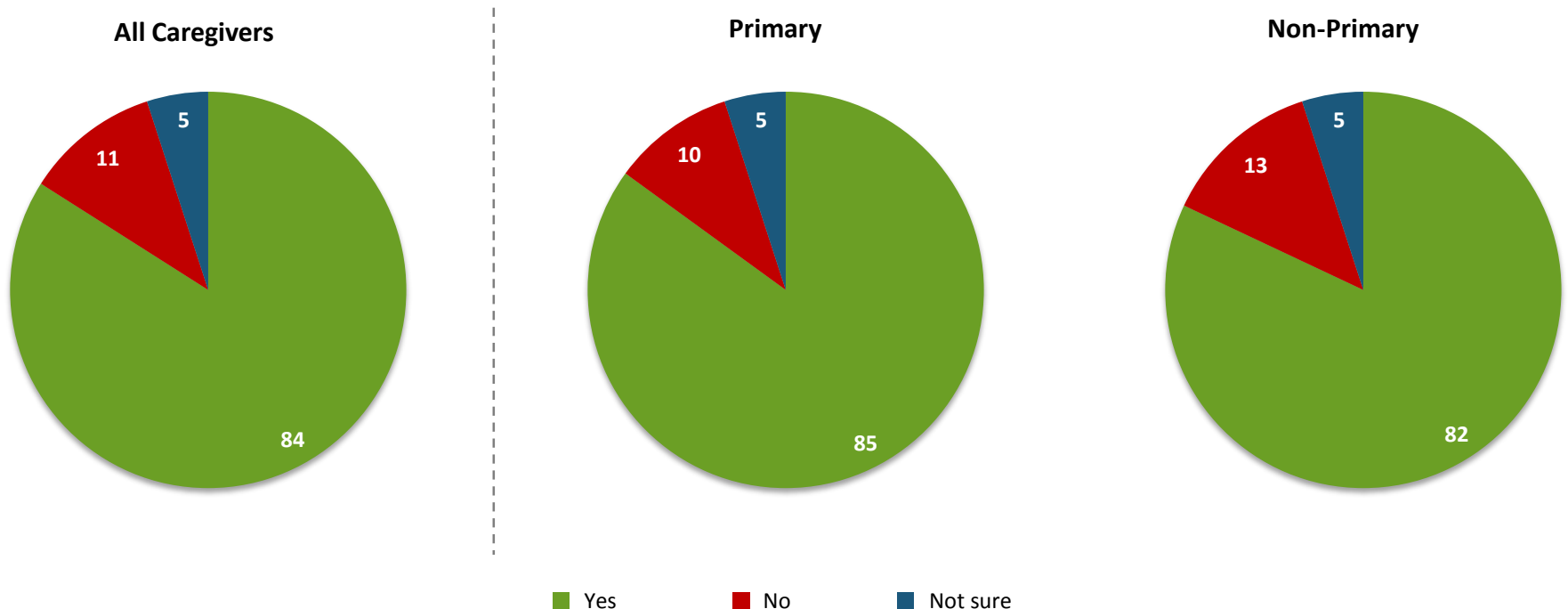
**Reasons for Becoming a Caregiver (%)**



# Four Out of Five Caregivers Came to it Voluntarily

Eighty-four percent of all caregivers became a caregiver voluntarily, a finding which is slightly higher among Primary (85 percent) versus Non-Primary (82 percent) caregivers. Eleven percent of all caregivers say they did not become a caregiver voluntarily and the other 5 percent are “not sure.”

“Do you feel that you became a caregiver voluntarily?” (%)

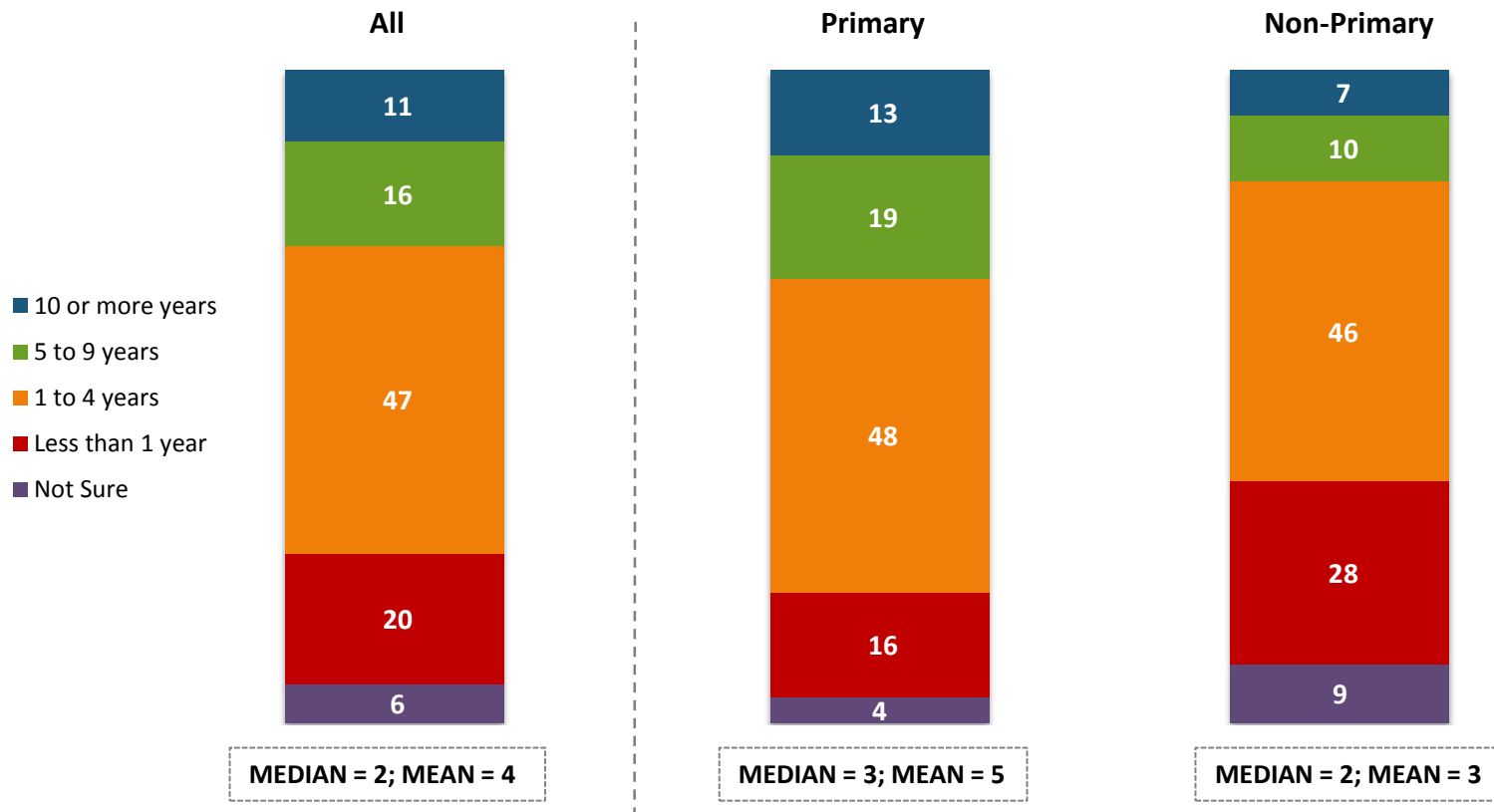


■ Yes ■ No ■ Not sure

# Most Caregivers Have Provided Care for Years

Among all caregivers, the providing of care has been two years (median). Primary caregivers have been providing care for three years (median) while Non-Primary caregivers have been providing care for two years (median). Seventy-four percent of all caregivers have been providing care for one or more years. Primary caregivers (80 percent) are more likely to have been providing care for one or more years compared to Non-Primary caregivers (63 percent). Twenty-seven percent of all caregivers have been providing care for five or more years, a finding which is higher among Primary (32 percent) than Non-Primary (17 percent) caregivers.

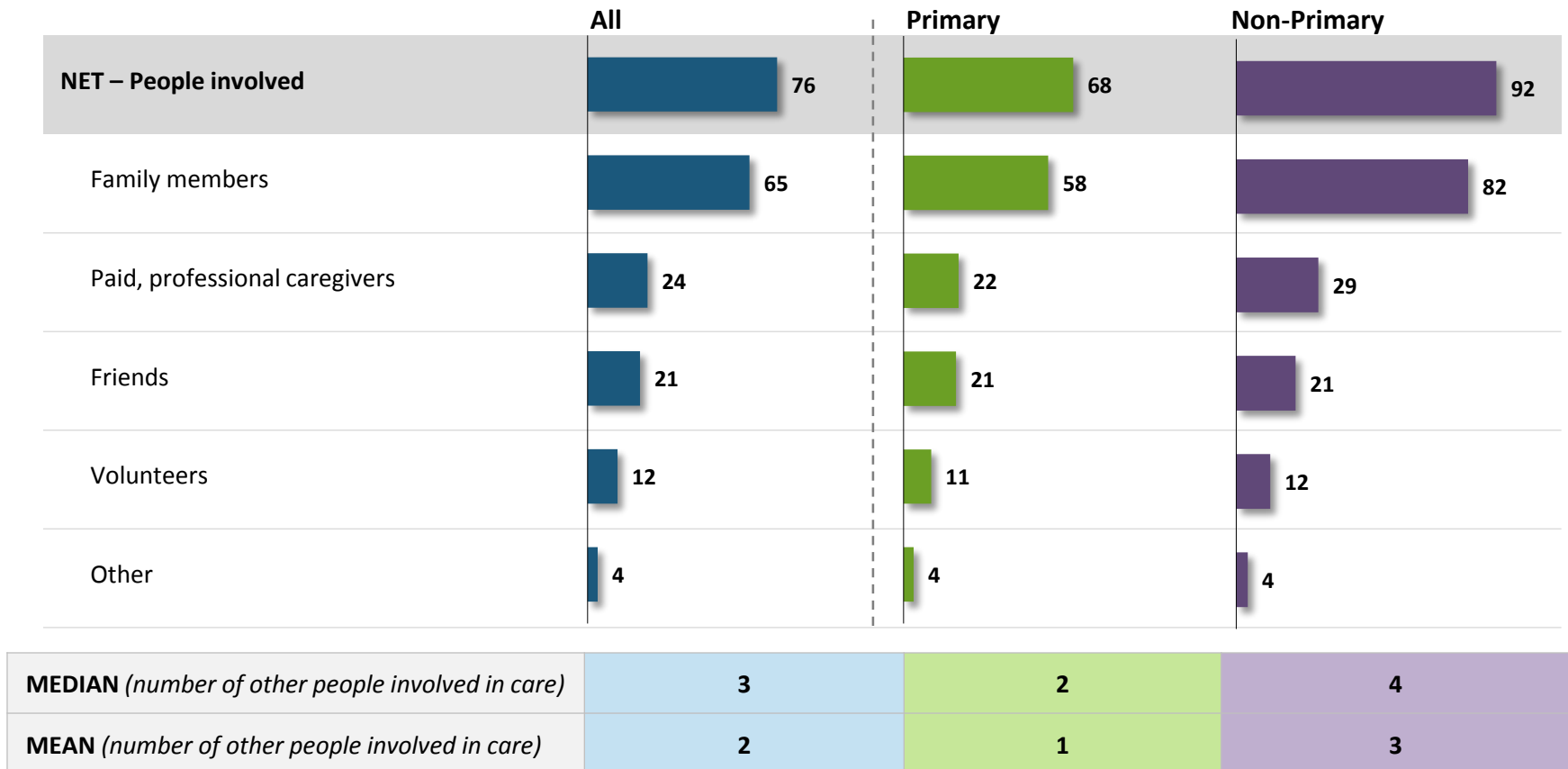
Duration of Time as a Caregiver (%)



# Family Members Often Work Together to Provide Care

Seventy-six percent of all caregivers indicate that other people (excluding medical professionals and care facility staff) are involved in providing care for the care recipient, a finding which is higher among Non-Primary (92 percent) than Primary (68 percent) caregivers. Family members (65 percent) are the most frequently cited type of individual involved in caregiving, a finding which is also higher among Non-Primary (82 percent) than Primary (58 percent) caregivers.

**Types of People Involved in Providing Care for the Care Recipient, Excluding Caregiver (%)**



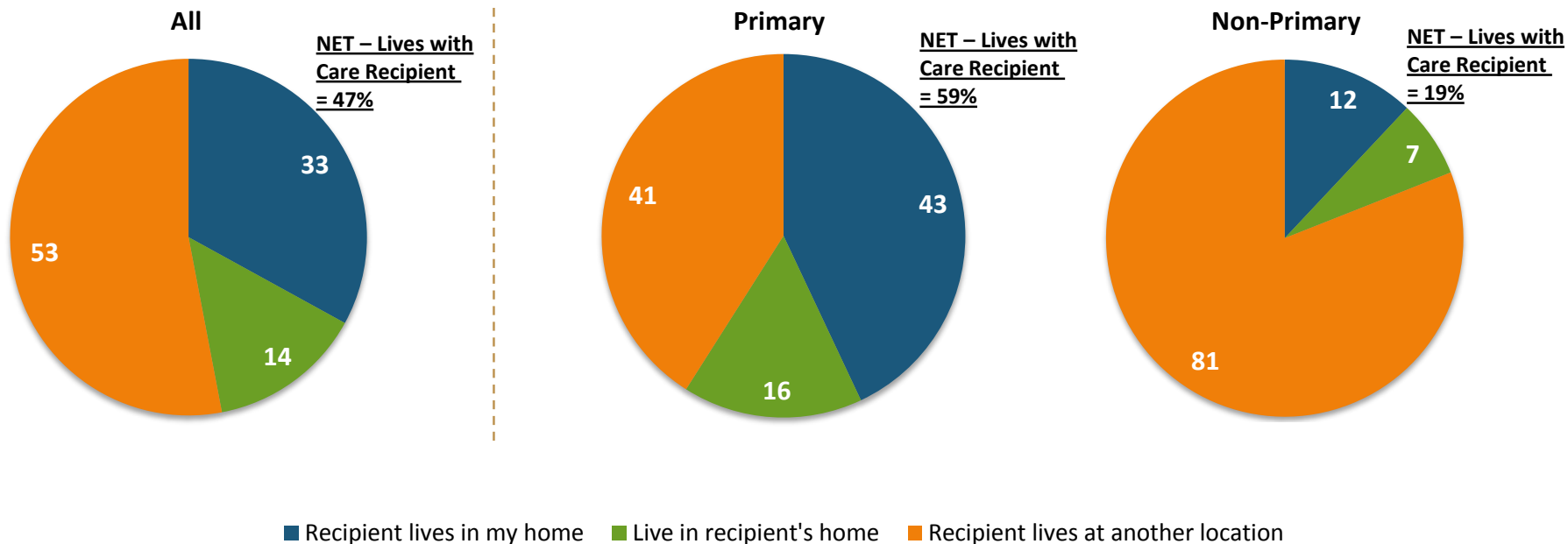
BASE: ALL QUALIFIED RESPONDENTS

Q805. Excluding yourself, how many other people are involved in providing care for the care recipient? Please exclude medical professionals and care facility staff, if applicable. Enter 0 in all of the boxes below if no one else is also providing care. Select all.

# Almost Half of Caregivers Live with Their Care Recipient

Almost half of caregivers (47 percent) live with their care recipient, a finding which is significantly higher among Primary caregivers (59 percent) than Non-Primary caregivers (19 percent). Primary caregivers (43 percent) are more than three times more likely than Non-Primary caregivers (12 percent) to have the care recipient living in their home. Similarly, Primary caregivers (16 percent) are also more likely than Non-Primary caregivers (7 percent) to live in the care recipient's home.

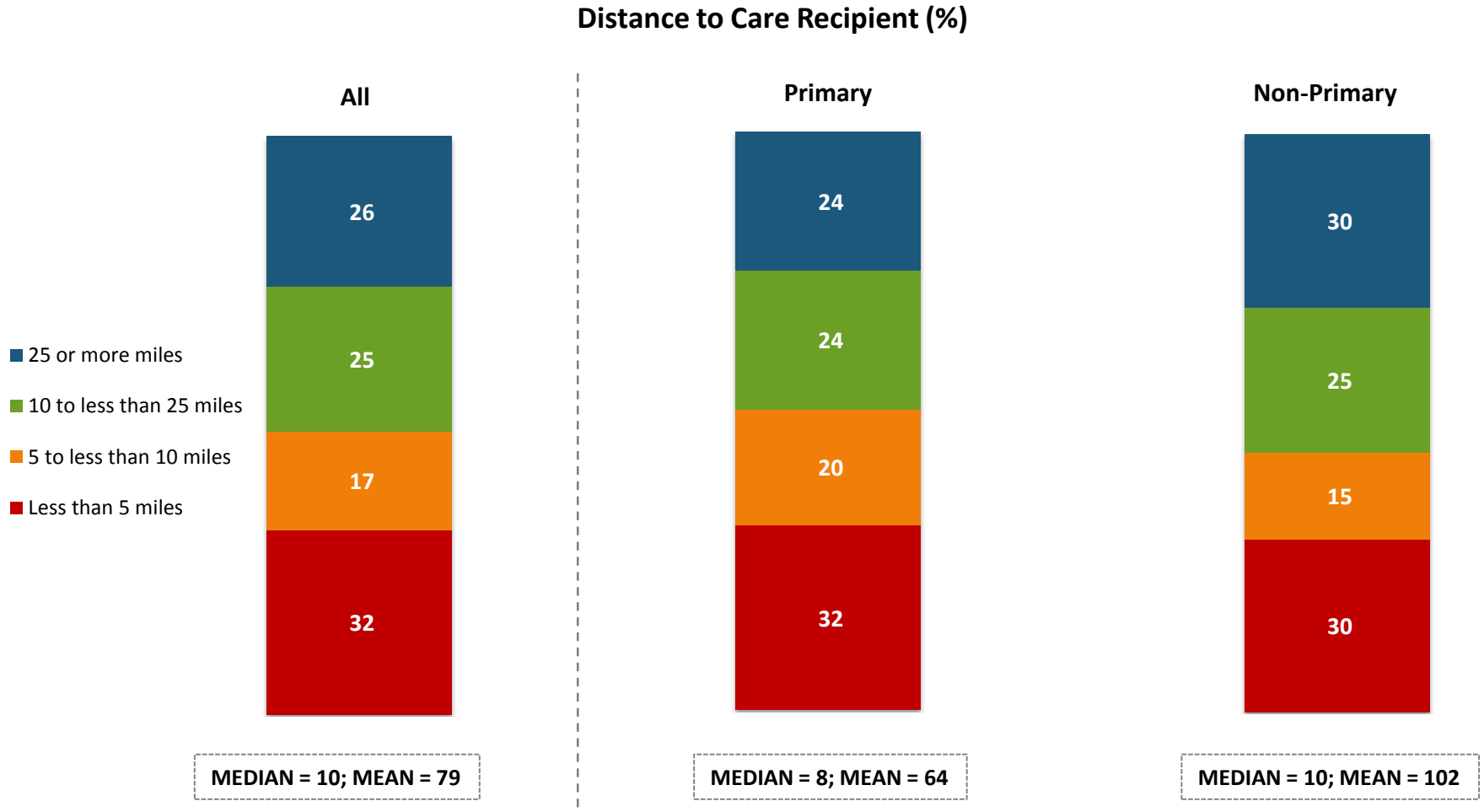
Where Care Recipients Live (%)





# Caregivers Tend to Live in Close Proximity to the Care Recipient

Among those who do not live with the care recipient, approximately half of all caregivers (49 percent) live within 10 miles of the care recipient, a finding which is relatively consistent between Primary (52 percent) and Non-Primary (45 percent) caregivers.



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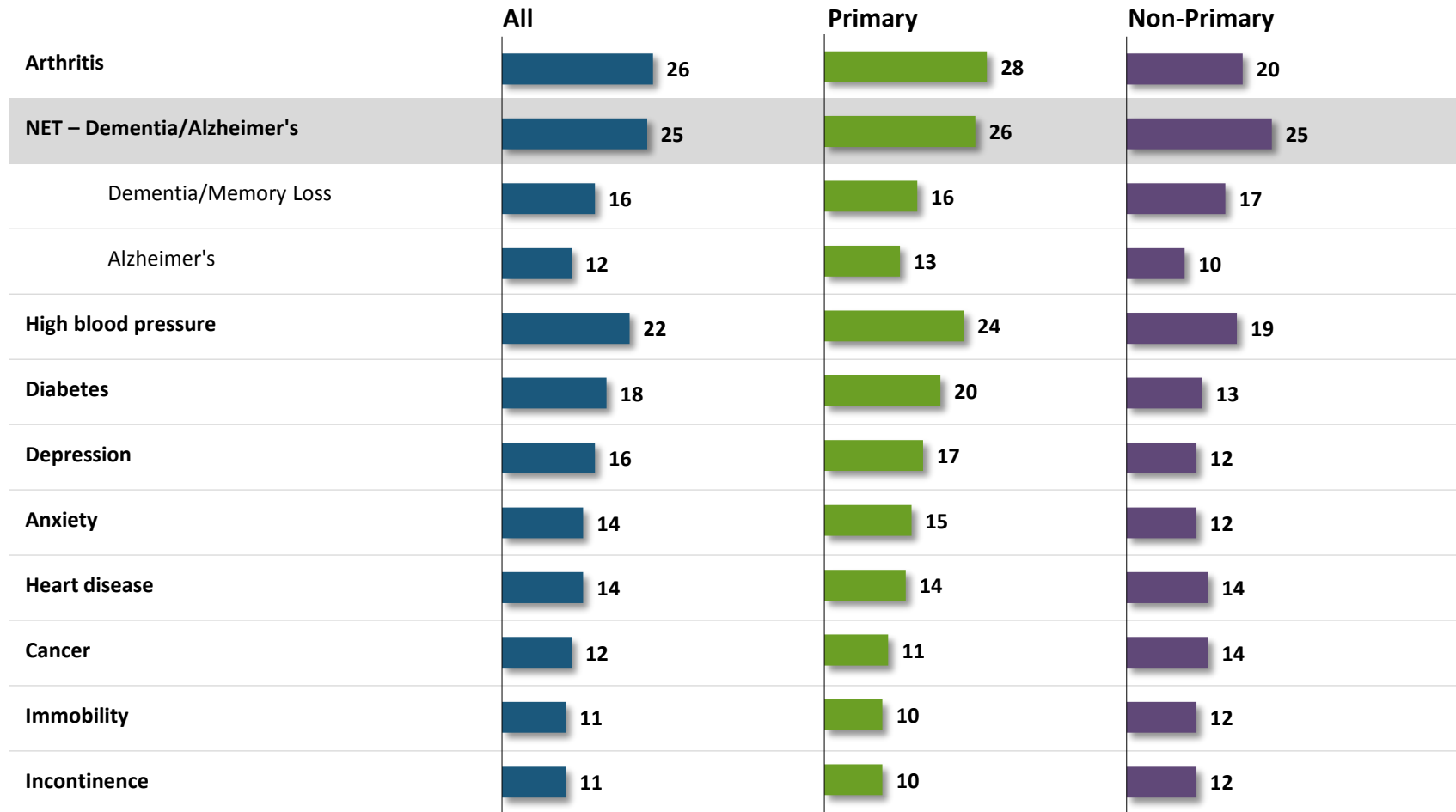
### **Appendix: Caregiver and Care Recipient Demographics**

### **Acknowledgements**

# Care Recipients Have a Range of Conditions

Caregivers provide care for a range of different ailments and health conditions. The three most common conditions are arthritis (26 percent), dementia/Alzheimer's disease (Net, 25 percent), and high blood pressure (22 percent). Refer to the Appendix for the full list of conditions.

**Top 10 Most Frequently Cited Conditions of Care Recipient (%)**



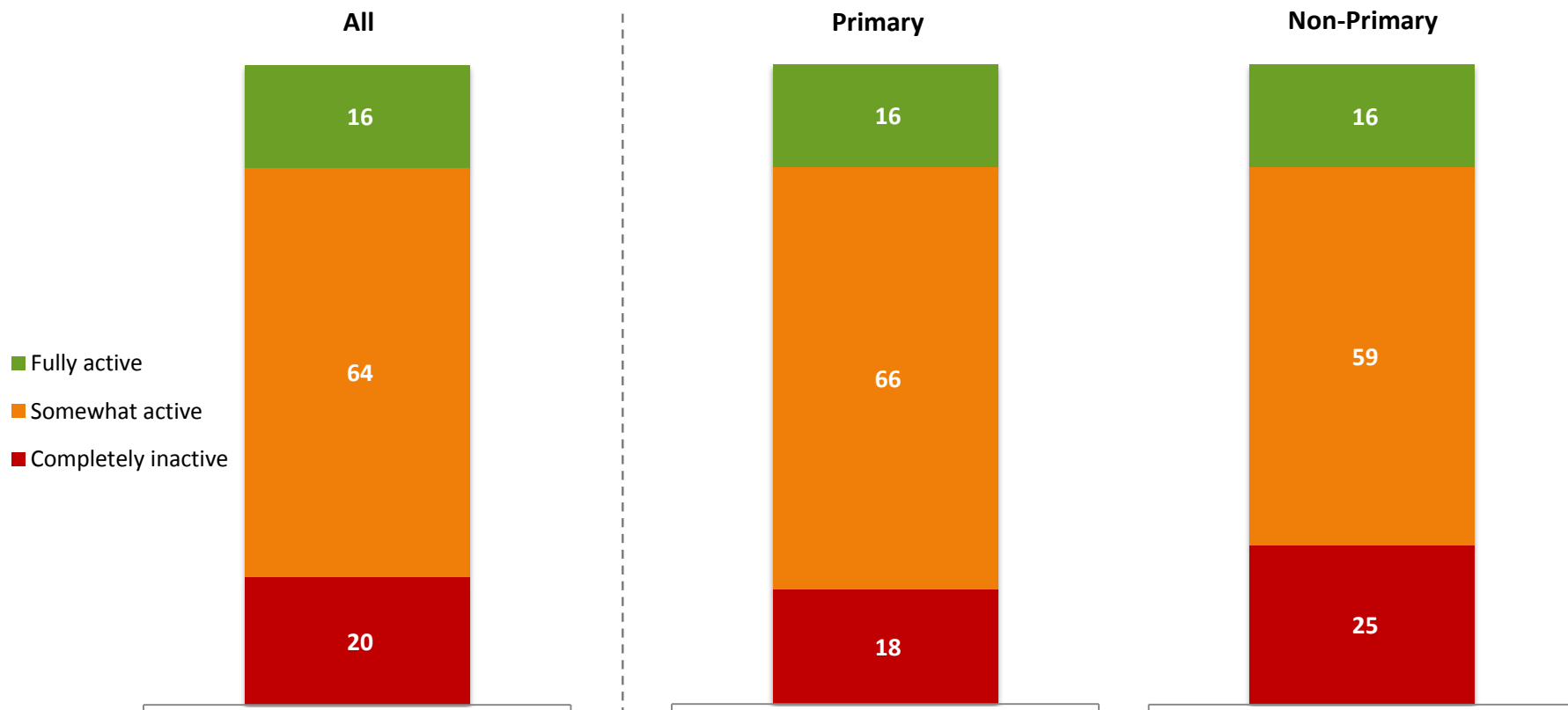
BASE: ALL QUALIFIED RESPONDENTS

Q725. Which of the following condition(s) apply to the care recipient? Please select all that apply.

# Most Care Recipients Are at Least Somewhat Active

Sixty-four percent of caregivers indicate their care recipient is somewhat active, a finding which is more frequently cited among Primary (66 percent) than Non-Primary (59 percent) caregivers. Among all caregivers, one in five (20 percent) indicate the care recipient is completely inactive, a finding which is more frequently cited among Non-Primary (25 percent) than Primary (18 percent) caregivers. Sixteen percent of all caregivers, including Primary and Non-Primary, say their care recipient is fully active.

**Current Activity Level of Care Recipient (%)**

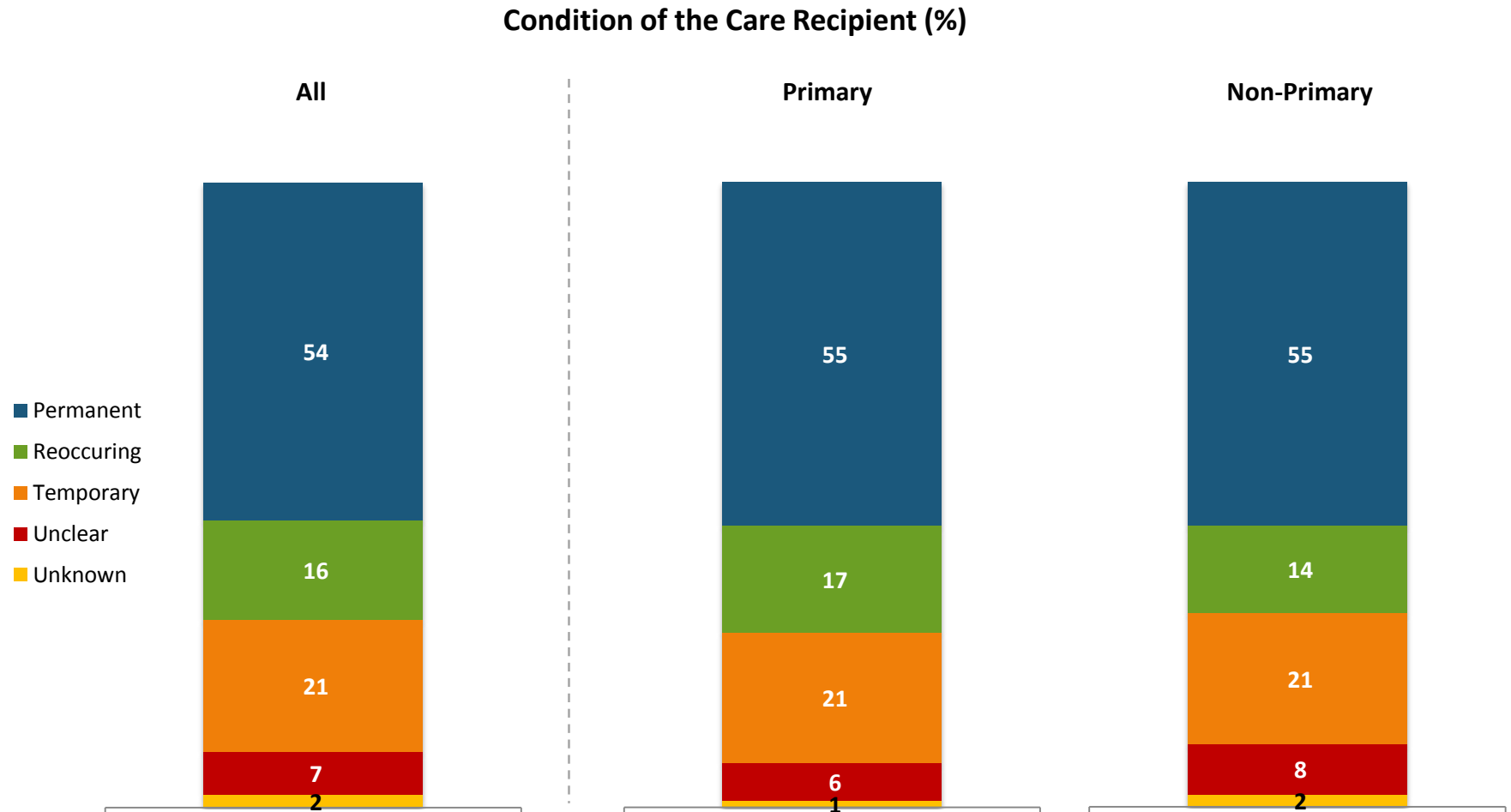


BASE: ALL QUALIFIED RESPONDENTS

Q720. Which of the following best describes the current activity level of the care recipient?

# Approximately Half of Care Recipients Have a Permanent Condition

Fifty-four percent of all caregivers indicate that their care recipient has a permanent health condition while 21 percent indicate that their care recipient has a temporary primary condition and 16 percent have a reoccurring condition. These findings are consistent between Primary and Non-Primary caregivers.



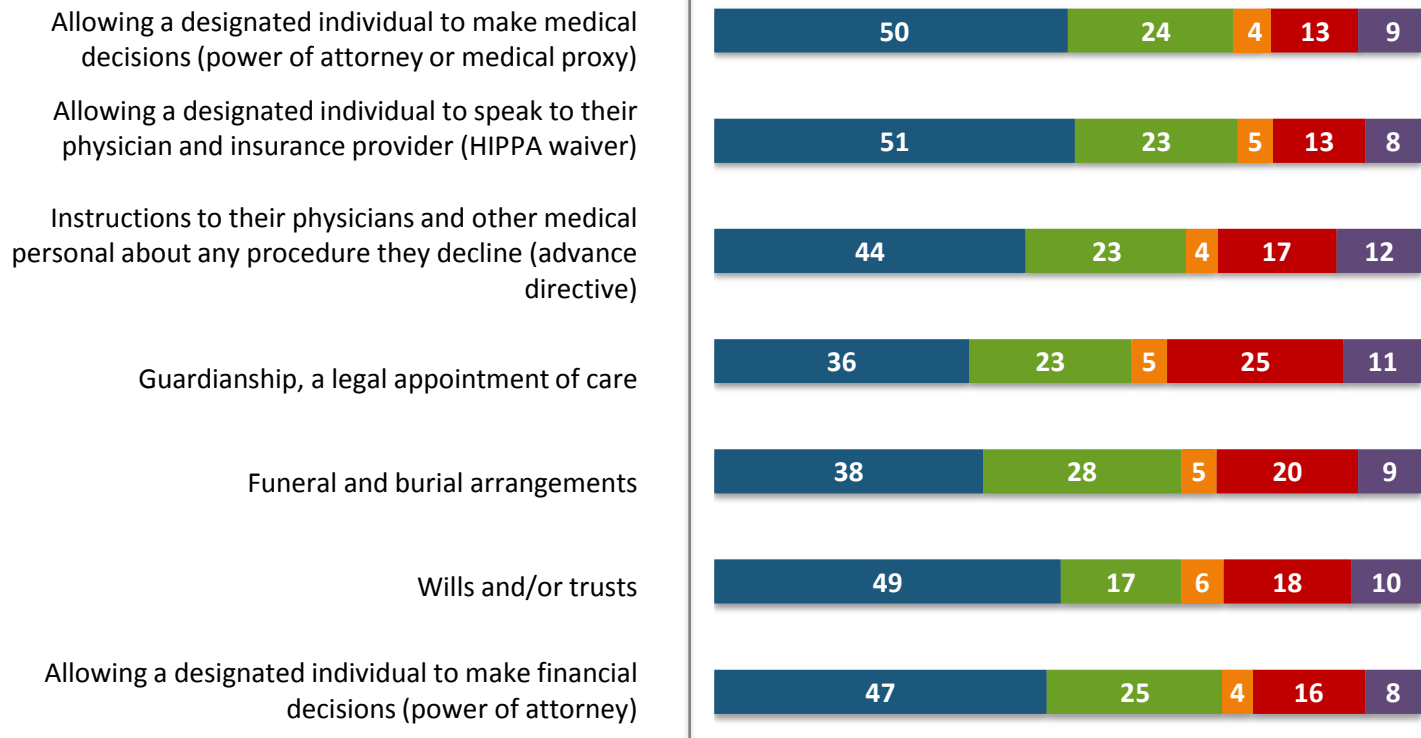
BASE: ALL QUALIFIED RESPONDENTS

Q715. Focusing on the individual you provide the most care for, is the primary condition of the care recipient permanent, episodic or temporary?

# Most Say Care Recipients Have Discussed Their Wishes

The majority of caregivers indicate that their care recipients have discussed health directives with them or another close friend/relative, and almost half have written documentation for health information (HIPPA) waiver, and wills or trusts in place. While 74 percent of care recipients have discussed allowing a designated individual to make medical decisions (power of attorney), only 50 percent have documented the arrangement.

## Discussions and Legal Documentation - All Caregivers (%)

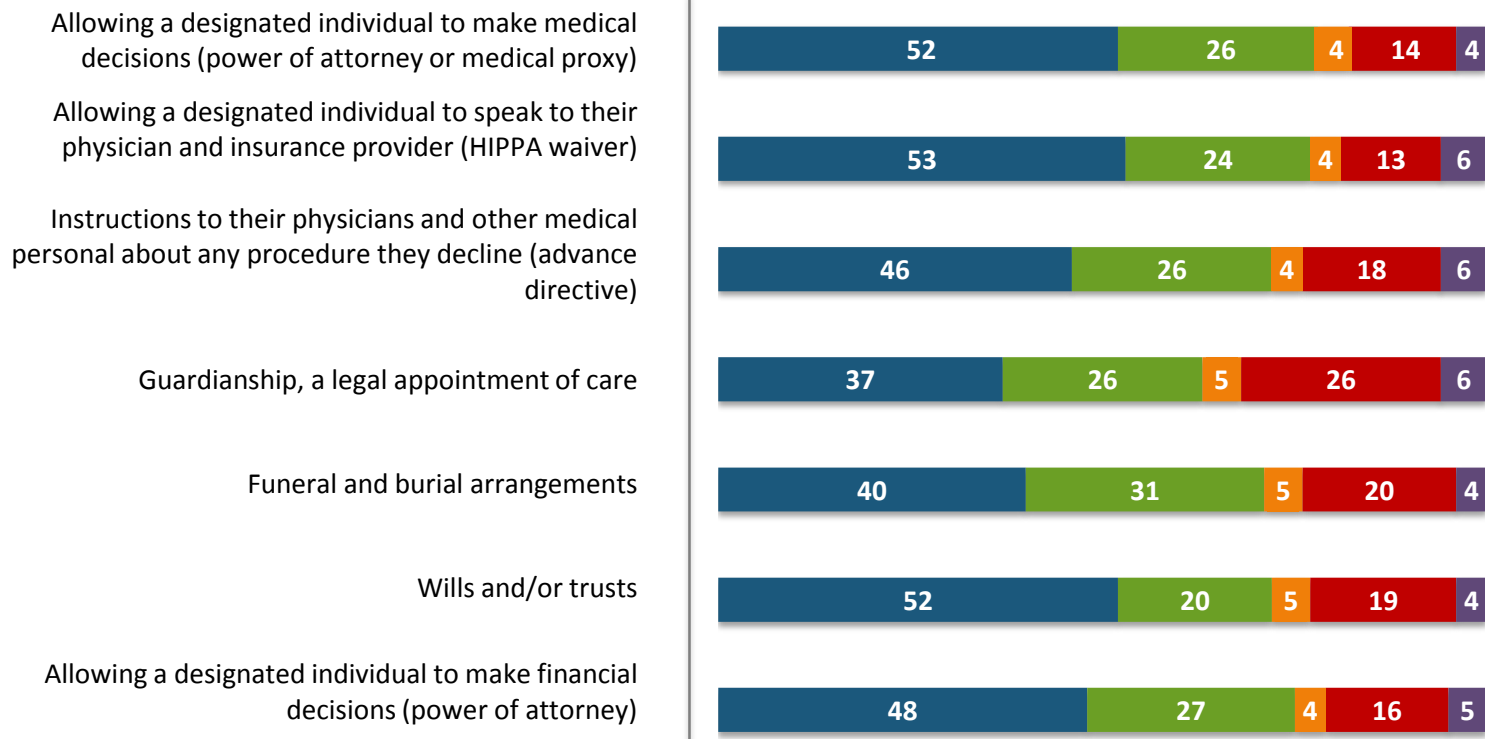


■ Discussed and written ■ Discussed but not written ■ Not discussed, but written ■ Not discussed and not written ■ Don't Know

# Primary Caregivers' Discussions with Care Recipients

Most Primary caregivers indicate their care recipients have discussed various matters related to their care with them or another close relative or friend, including medical power of attorney (78 percent), health information (HIPPA) waivers (77 percent), advance directives (72 percent), guardianship (63 percent), funeral and burial arrangements (71 percent), and wills or trusts (72 percent).

## Discussions and Legal Documentation – Primary Caregivers (%)



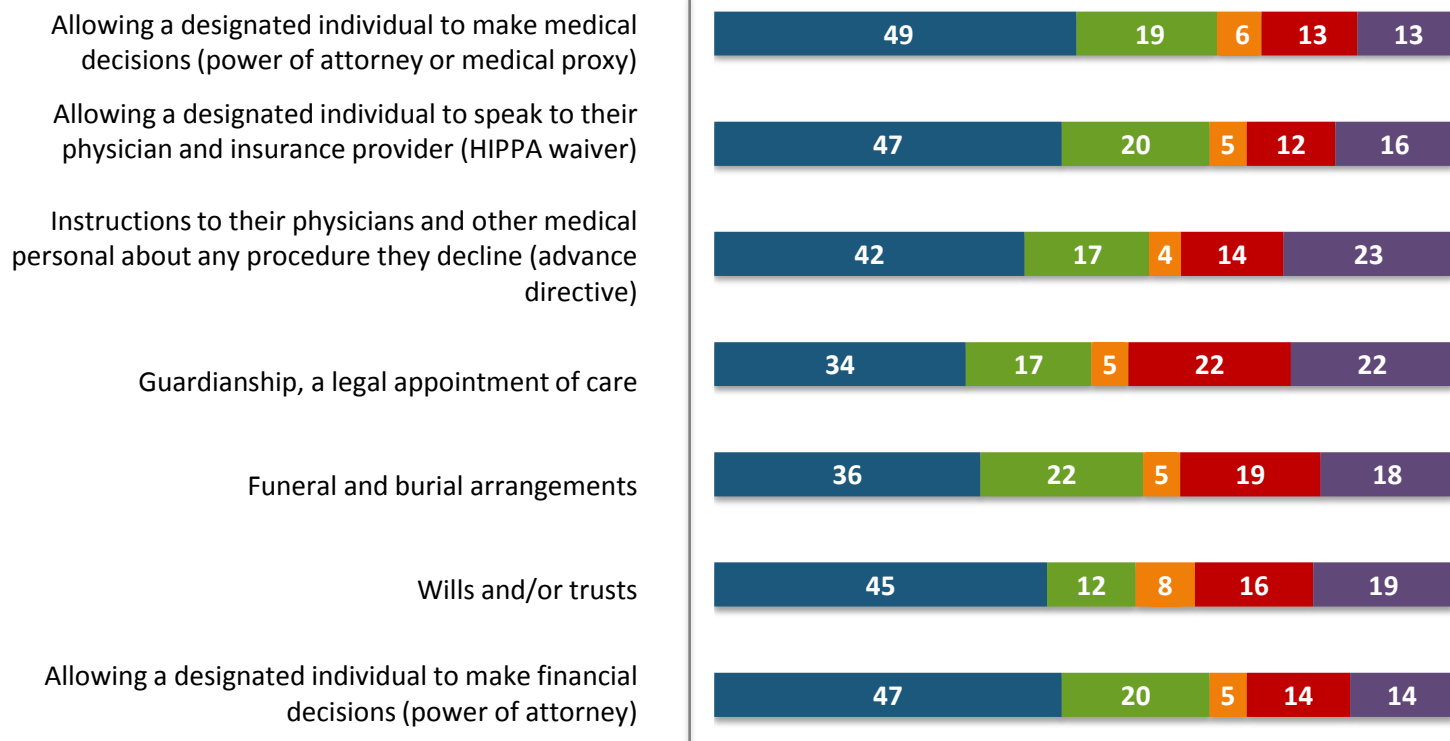
■ Discussed and written ■ Discussed but not written ■ Not discussed, but written ■ Not discussed and not written ■ Don't Know



# Non-Primary Caregivers Are Having Discussions About Health Directives

Most Non-Primary caregivers indicate their care recipients have discussed various matters related to their care with them or another close relative or friend, including medical power of attorney (68 percent), health information (HIPPA) waivers (67 percent), advance directives (59 percent), guardianship (51 percent), funeral and burial arrangements (58 percent), and wills or trusts (57 percent).

## Discussions and Legal Documentation – Non-Primary Caregivers (%)



■ Discussed and written ■ Discussed but not written ■ Not discussed, but written ■ Not discussed and not written ■ Don't know

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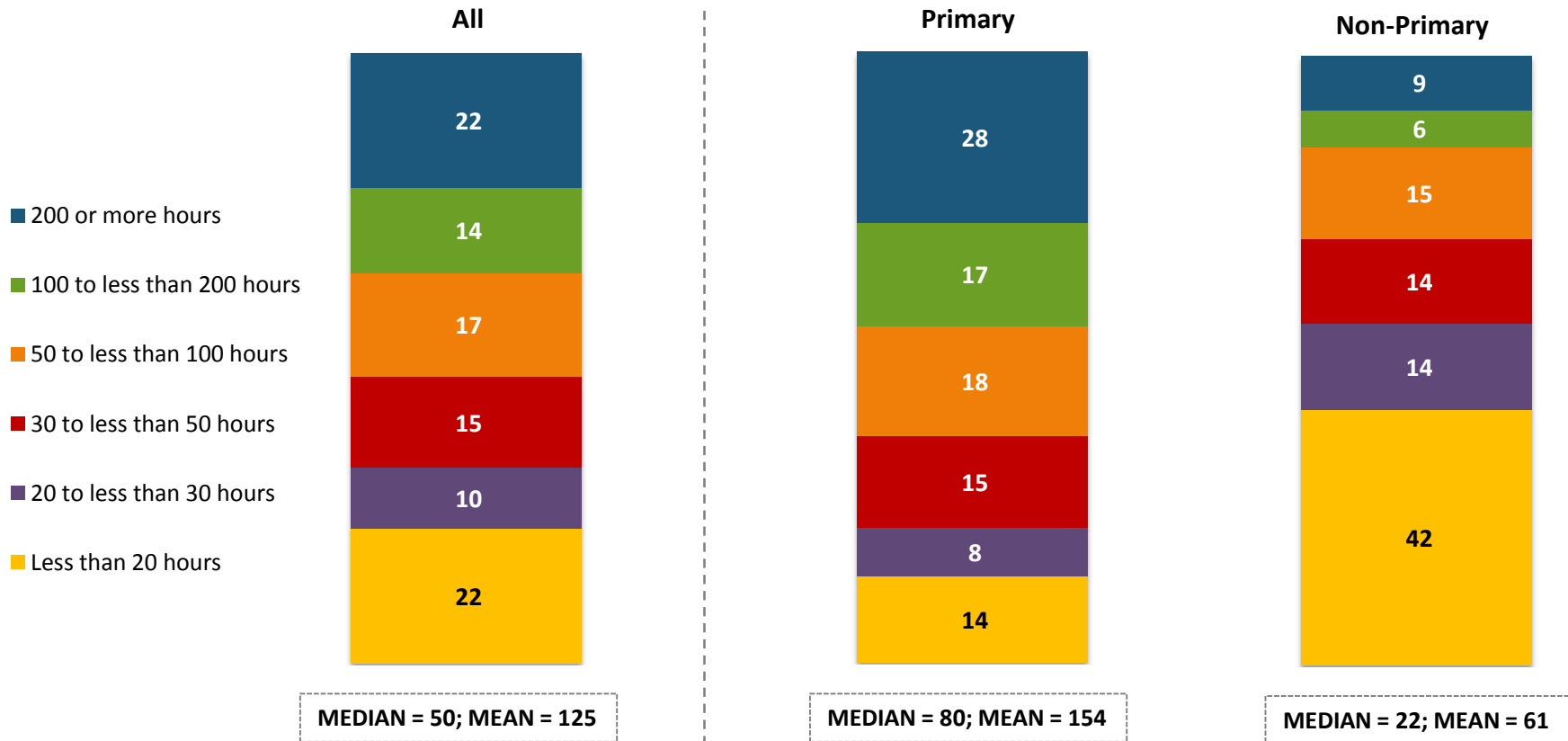
### **Appendix: Caregiver and Care Recipient Demographics**

### **Acknowledgements**

# Caregiving Is a Full-Time Job for Many

Caregivers spend 50 hours (median) per month caring for the care recipient, a finding which varies dramatically between Primary (80 hours median) and Non-Primary caregivers (22 hours median). Thirty-six percent of all caregivers spend 100 or more hours per month caregiving, including more Primary (45 percent) than Non-Primary (15 percent) caregivers.

**Total Hours Spent Caregiving Each Month (%)**



*Note: The median is the midpoint of the range of each response category. The mean is the average of all responses.*

**BASE: ALL QUALIFIED RESPONDENTS**

**Q832. In total, approximately how many hours per month do you spend caring for the care recipient?**

# Caregiving Is a Multi-Dimensional Job

Caregiving encompasses a broad range of duties, such as household, social/communication, health, personal care, medical-related and paying bills/managing finances. Primary caregivers are more likely to engage in these activities than Non-Primary caregivers.

Of particular note, 78 percent of Primary caregivers perform health-related duties for the care recipient, compared to only 47 percent of Non-Primary caregivers.

Similarly, Primary caregivers (59 percent) are twice as likely to perform medical-related duties as Non-Primary caregivers (28 percent).

More than half of Primary caregivers (53 percent) pay bills/manage finances for the care recipient compared to only 23 percent of Non-Primary caregivers.

Types of Caregiving Duties Performed	All	Primary	Non-Primary
<b>NET – Household</b>	<b>89%</b>	<b>92%</b>	<b>83%</b>
Running errands	68%	71%	62%
Housework	60%	66%	47%
Meal preparation	58%	65%	46%
Home repairs	30%	35%	20%
Home modifications	19%	24%	10%
<b>NET – Social/Communication</b>	<b>72%</b>	<b>74%</b>	<b>69%</b>
Companionship	61%	62%	61%
Basic communications	31%	32%	27%
Language translation	7%	8%	5%
<b>NET – Health-Related</b>	<b>69%</b>	<b>78%</b>	<b>47%</b>
Accompanying to medical appointments	61%	69%	42%
Healthcare coordination	44%	55%	19%
Health insurance coordination	30%	38%	11%
<b>NET – Personal Care</b>	<b>62%</b>	<b>67%</b>	<b>54%</b>
Mobility	39%	41%	34%
Personal care	35%	39%	28%
Feeding	27%	29%	24%
Incontinence care	15%	17%	11%
<b>NET – Medical-Related</b>	<b>49%</b>	<b>59%</b>	<b>28%</b>
Medication management	45%	54%	26%
Medical treatment administration	16%	20%	7%
<b>Paying bills/Managing finances</b>	<b>43%</b>	<b>53%</b>	<b>23%</b>
<b>Other</b>	<b>4%</b>	<b>3%</b>	<b>7%</b>

# Caregivers Devote Significant Time to Caregiving Duties

Caregivers spend a significant amount of time each month on a wide range of caregiving duties, with Primary caregivers dedicating more time to these duties than Non-Primary caregivers.

Among all caregivers, providing companionship requires the most time (33 hours median). Primary caregivers (50 hours median) spend more than three times the amount of time on this role than Non-Primary caregivers (16 hours median).

Meal preparation is the second-most time consuming activity among all caregivers (20 hours median), a finding which is higher among Primary (21 hours median) compared to Non-Primary (9 hours median) caregivers.

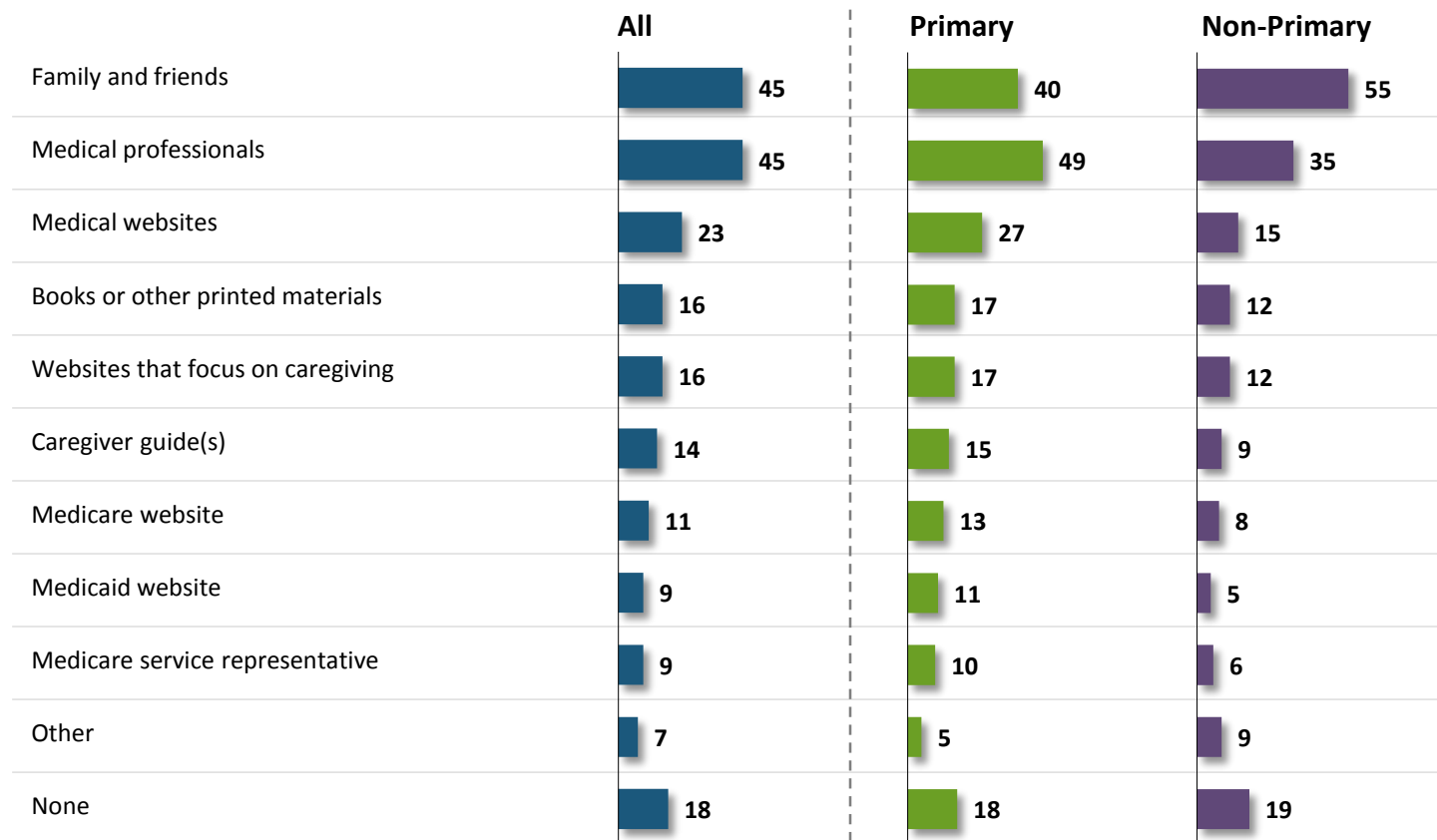
*Note: The median is the midpoint of the range of each response category. The mean is the average of all responses.*

Time Spent On Caregiving Duties Each Month (hours per month)	All		Primary		Non-Primary	
	Median	Mean	Median	Mean	Median	Mean
<b>Household</b>						
Running errands	8	18	10	19	4	14
Housework (e.g., cleaning, laundry)	10	28	12	31	6	17
Meal preparation	20	32	21	35	9	18
Home repairs	3	9	3	10	2	6
Home modifications	2	8	2	8	3	9
<b>Social/Communication</b>						
Companionship	33	92	50	114	16	42
Basic communications	10	46	12	52	6	23
Language translation	5	15	5	14	4	17
<b>Health-Related</b>						
Accompanying to medical appointments	4	11	5	11	4	7
Healthcare coordination	3	9	3	10	3	4
Health insurance coordination	2	9	2	9	2	3
<b>Personal Care</b>						
Mobility	10	23	10	26	6	13
Personal care	12	26	15	29	8	14
Feeding	12	34	15	38	10	23
Incontinence care	6	22	8	24	4	9
<b>Medical-Related</b>						
Medication management	5	16	5	17	4	10
Medical treatment administration	5	18	5	18	3	11
<b>Paying bills/Managing finances</b>	3	9	4	10	2	4
<b>Other</b>	5	63	8	50	5	83

# Caregivers Rely on a Variety of Sources of Information

Caregivers most frequently rely on friends and family (45 percent) or medical professionals (45 percent) as sources of information to assist in their caregiving duties. Primary caregivers (49 percent) are more likely than Non-Primary caregivers (35 percent) to rely on medical professionals, while Non-Primary caregivers (55 percent) are more likely than Primary caregivers (40 percent) to rely on family and friends. Primary caregivers are generally more likely than Non-Primary caregivers to rely on electronic sources of caregiving information (i.e. medical or caregiving websites), books or printed materials, and caregiving guides.

**Sources of Information to Assist in Caregiving Duties (%)**



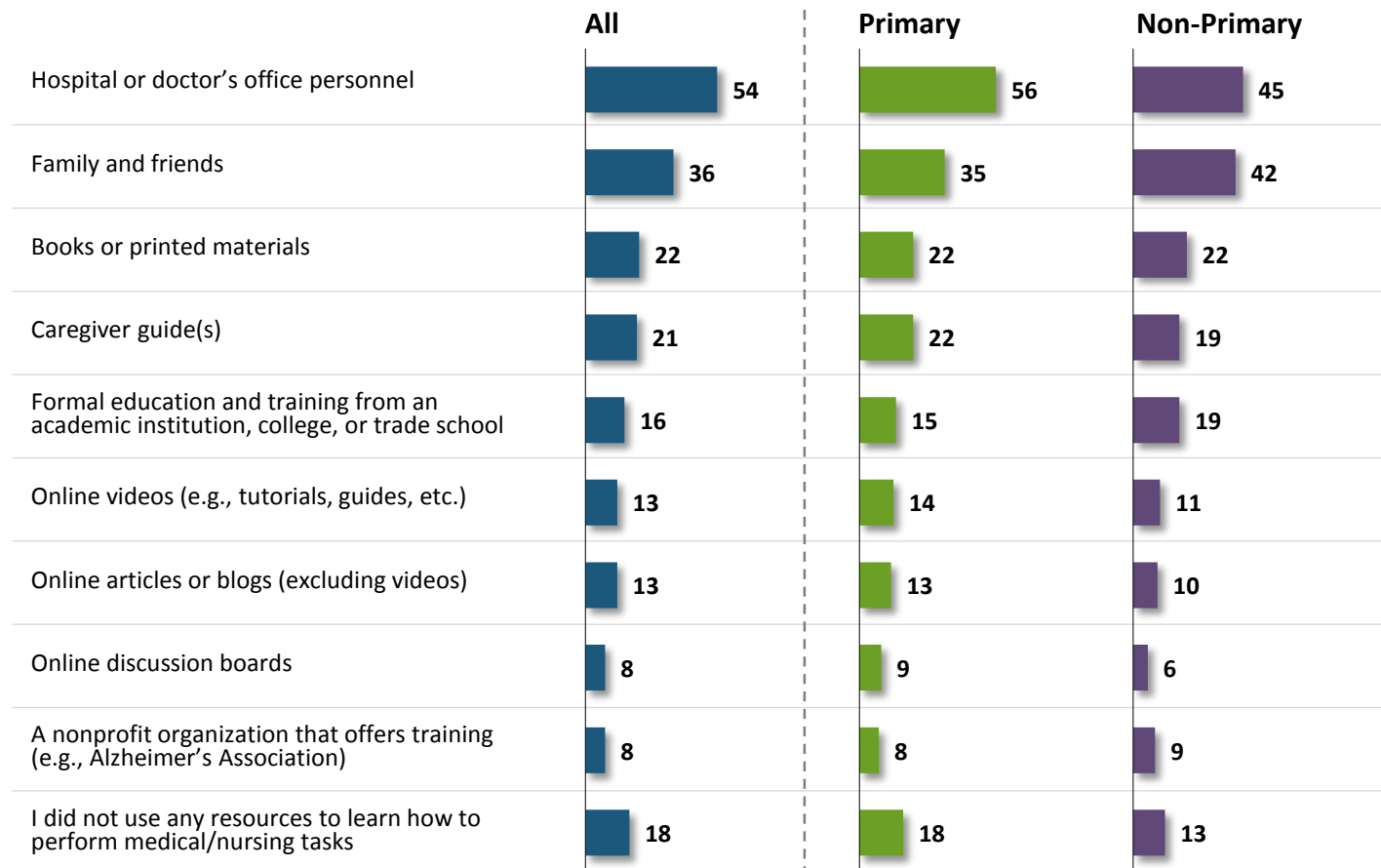
BASE: ALL QUALIFIED RESPONDENTS

Q840. Which of the following do you rely on as sources of information to assist in your caregiving duties? Please select all that apply.

# About Half Learn Medical/Nursing Tasks from Professionals

Among caregivers who perform medical/nursing-related tasks, 54 percent say they learned these tasks from hospital or doctor's office personnel, including 56 percent of Primary caregivers and 45 percent of Non-Primary caregivers. Family and friends (36 percent) are the second most frequently cited source of training among caregivers, including 35 percent of Primary caregivers and 42 percent of Non-Primary caregivers.

**Sources for Learning Medical/Nursing Tasks Related to Being a Caregiver (%)**



BASE: RESPONDENTS ADMINISTERING MEDICATIONS AND MEDICAL TREATMENTS

Q835. You mentioned you perform medication management or medical treatment administration for the care recipient. Where did you learn how to perform medical/nursing tasks related to being a caregiver? *Select all that apply.*



# Caregivers' Sentiments About Their Caregiving Duties

The vast majority of all caregivers cite positive aspects of caregiving, including that they like helping and enjoy spending time with their care recipient (both 91 percent). However, more than half of all caregivers agree that their caregiving duties leave them feeling emotionally or physically exhausted (both 55 percent). Primary caregivers (61 percent) are far more likely than Non-Primary caregivers (41 percent) to indicate their own health is taking a backseat to the health of their care recipients.

Caregivers’ Sentiments About Their Caregiving Duties	All	Primary	Non-Primary
	Strongly/Somewhat Agree (NET)		
Positive			
It’s important for me to provide a good quality of life for the care recipient	94%	96%	93%
I like helping the care recipient	91%	92%	89%
I enjoy spending time with the care recipient	91%	91%	89%
Being a caregiver gives me a strong sense of purpose	83%	85%	78%
Being a caregiver has led me to take better care of my own health	70%	72%	65%
Being a caregiver has inspired me to document my own health and legal wishes	66%	68%	63%
Negative			
My own health takes a backseat to the health of my care recipient	55%	61%	41%
My caregiving duties leave me feeling physically exhausted	55%	59%	44%
My caregiving duties leave me feeling emotionally exhausted	55%	58%	46%
I need more help with my caregiving duties	47%	52%	38%
With all of my caregiving duties, I barely have time for anything else	45%	52%	32%
My caregiving duties leave me feeling completely overwhelmed	44%	50%	30%

BASE: ALL QUALIFIED RESPONDENTS

Q855. How much do you agree or disagree with the following statements about performing your duties as a caregiver?

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# More Than Half of Caregivers Are Employed

The majority of all caregivers are currently employed full- or part-time (52 percent), including 53 percent of Primary caregivers and 47 percent of Non-Primary caregivers. Of the 40 percent of caregivers who are not currently employed, most (65 percent) were never employed during their time as a caregiver.

**Current Employment Status (%)**

	All	Primary	Non-Primary
<b>NET – Employed</b>	52	53	47
Employed full-time	39	41	33
Employed part-time	13	12	14
<b>NET – Self-employed</b>	8	8	10
Self-employed full-time	5	5	6
Self-employed part-time	3	3	4
<b>NET – Not employed</b>	40	39	43
Not employed, but looking for work	4	3	5
Not employed and not looking for work	2	3	1
Not employed, unable to work due to my own disability or illness	5	4	6
On leave of absence from my employer	0	0	0
Retired	19	19	18
Student	3	2	6
Stay-at-home spouse or partner	7	6	7
None of the above	0	2	0

**Employment Status During Time as a Caregiver (%)**

*Among those not currently employed*

	All	Primary	Non-Primary
<b>NET – Employed</b>	30	28	36
Full-time employed	18	18	16
Part-time employed	15	12	23
<b>Self-employed</b>	7	9	5
<b>Never employed</b>	65	65	61

Note: Multiple responses accepted; sums do not total 100%.



BASE: ALL QUALIFIED RESPONDENTS

Q1000. (Q410) Which one of the following best describes your employment status?

BASE: NOT CURRENTLY EMPLOYED

Q1015. Have you ever been employed during your time as a caregiver? Please select all the types of employment that apply.

# Caregiving Duties Negatively Impact Employment

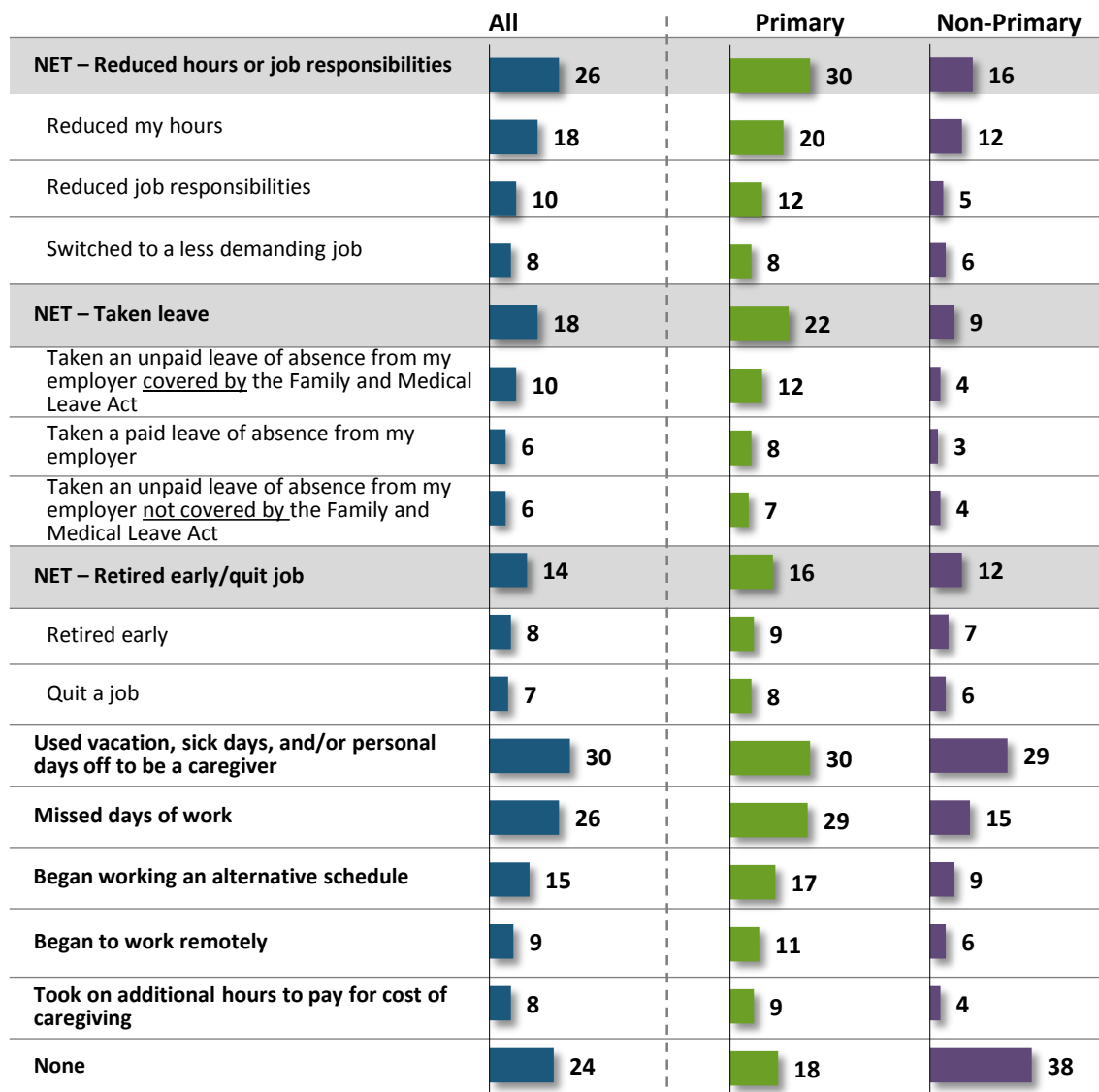
As a result of their caregiving duties, 76 percent of employed caregivers have made some type of adjustment to their employment, ranging from using vacation and sick days to quitting their jobs. Primary (82 percent) are more likely than Non-Primary caregivers (62 percent) to have done so.

Twenty-six percent of employed caregivers have reduced their hours or job responsibilities, including 30 percent of Primary and 16 percent of Non-Primary caregivers.

Eighteen percent of employed caregivers have taken a leave of absence. Primary (22 percent) are more likely to have done so than Non-Primary caregivers (9 percent).

Fourteen percent of employed caregivers have retired early or quit their job. Primary caregivers (16 percent) are somewhat more likely to have done so than Non-Primary (12 percent) caregivers.

**Employment-Related Adjustments Made as a Result of Becoming a Caregiver (%)**



NOTE: Thirteen most commonly selected sources shown.

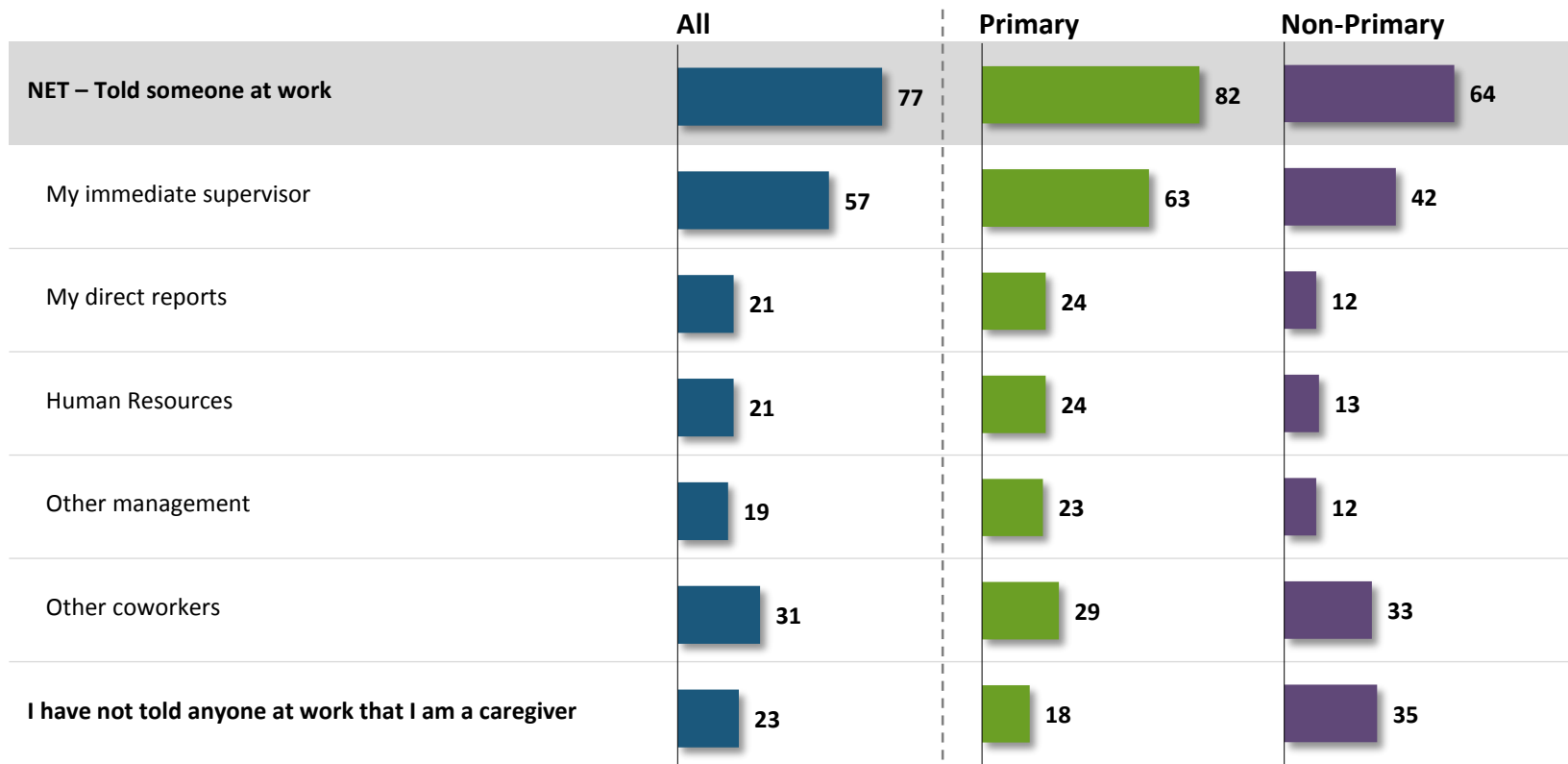
BASE: ALL EMPLOYED OR HAVE BEEN EMPLOYED DURING THEIR TIME AS A CAREGIVER

Q1025. Which of the following have you done as a result of becoming a caregiver? Select all that apply.

# Most Have Told Someone at Work That They Are a Caregiver

Approximately three in four employed caregivers (77 percent) have told someone at work that they are a caregiver. Primary (82 percent) are more likely than Non-Primary caregivers (64 percent) to have told someone. More than half of all employed caregivers (57 percent) have told their immediate supervisor about their caregiving duties, including 63 percent of Primary and 42 percent of Non-Primary caregivers.

**“Which of the following people at work have you told that you are a caregiver?” (%)**



NOTE: Self-employed and not employed were excluded from this question.

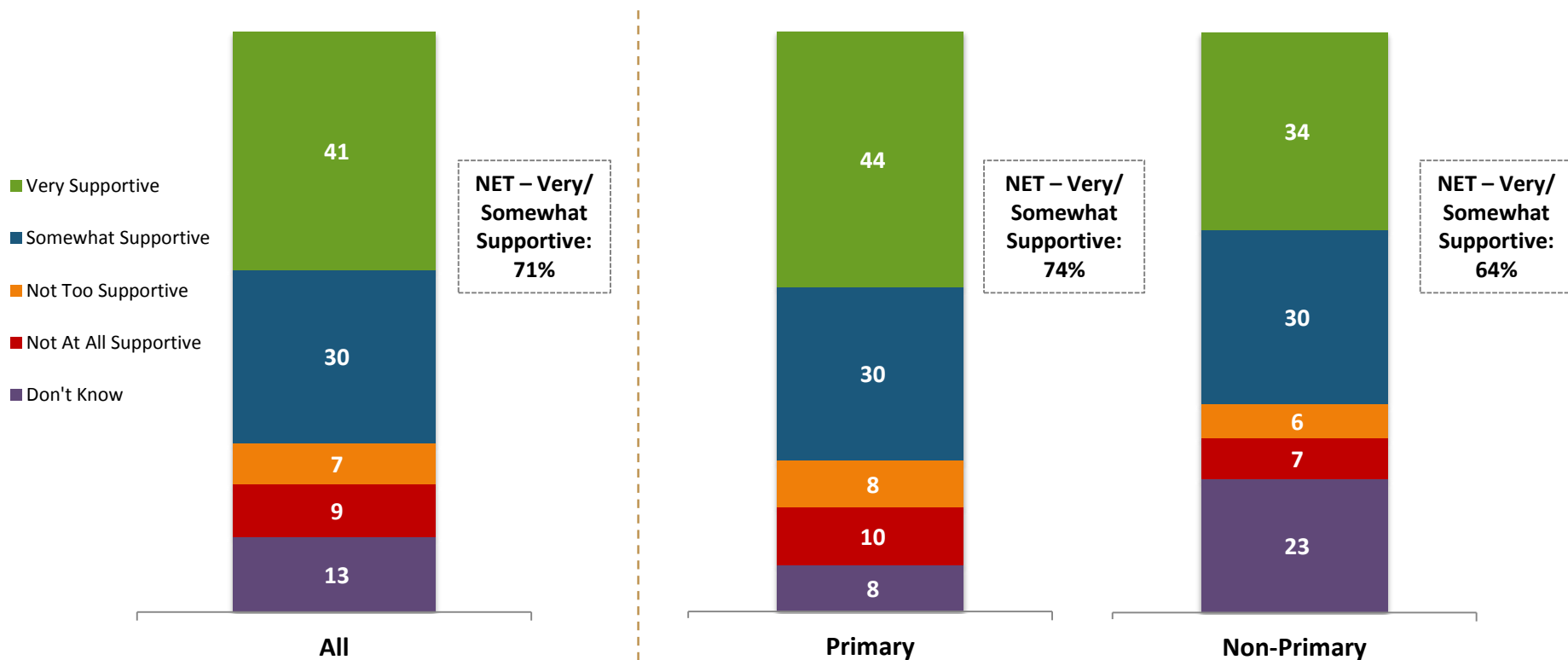
BASE: EMPLOYED FULL-TIME OR PART-TIME

Q1035. Which of the following people at work have you told that you are a caregiver? Please select all that apply.

# Most Caregivers Feel Their Employers Are Supportive

A substantial majority (71 percent) of all employed caregivers feel their employer is at least somewhat supportive of their caregiving responsibilities. Primary caregivers (44 percent) are more likely than Non-Primary caregivers (34 percent) to indicate that they feel very supported by their employer.

Employer Support of Caregiver Responsibilities (%)



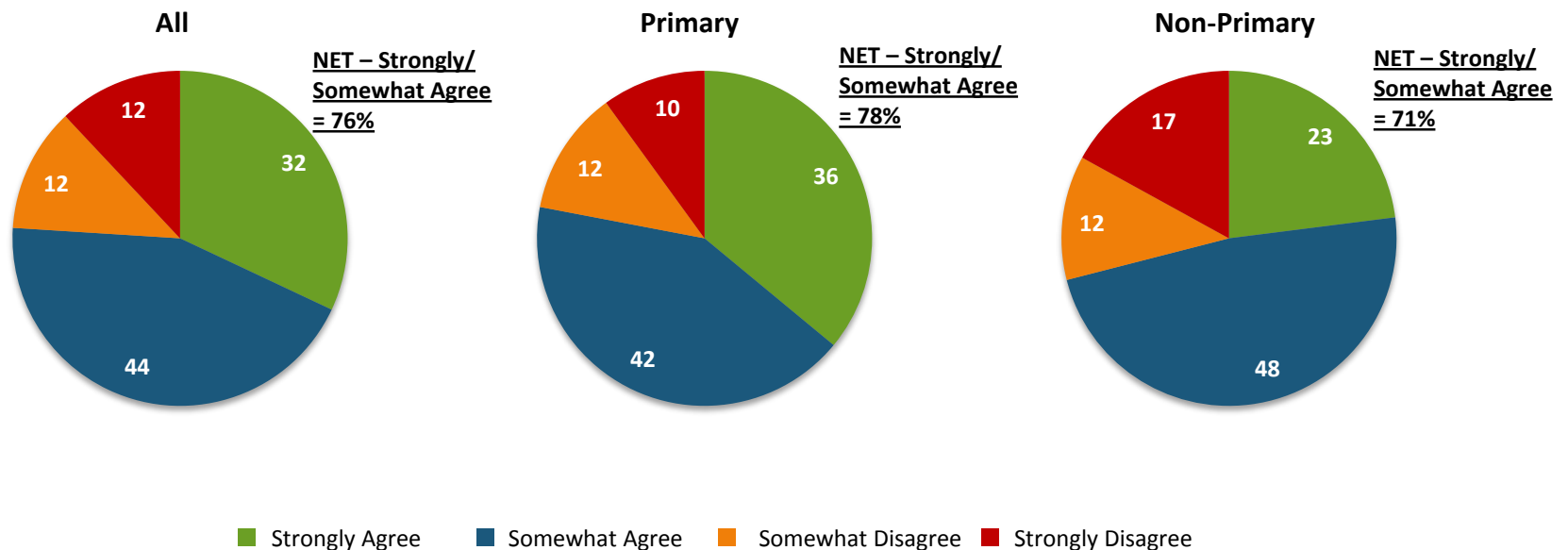
NOTE: Self-employed and not employed were excluded from this question.

BASE: CURRENTLY EMPLOYED FULL-TIME OR PART-TIME  
Q1045. How supportive is your employer of your caregiving responsibilities?

# Most Feel Employers Are Understanding

Seventy-six percent of all employed caregivers either strongly or somewhat agree that their employer understands the difficulties they face as a caregiver, including 78 percent of Primary and 71 percent of Non-Primary caregivers.

**“My employer understands the difficulties I face as a caregiver” (%)**



NOTE: Self-employed and not employed were excluded from this question.

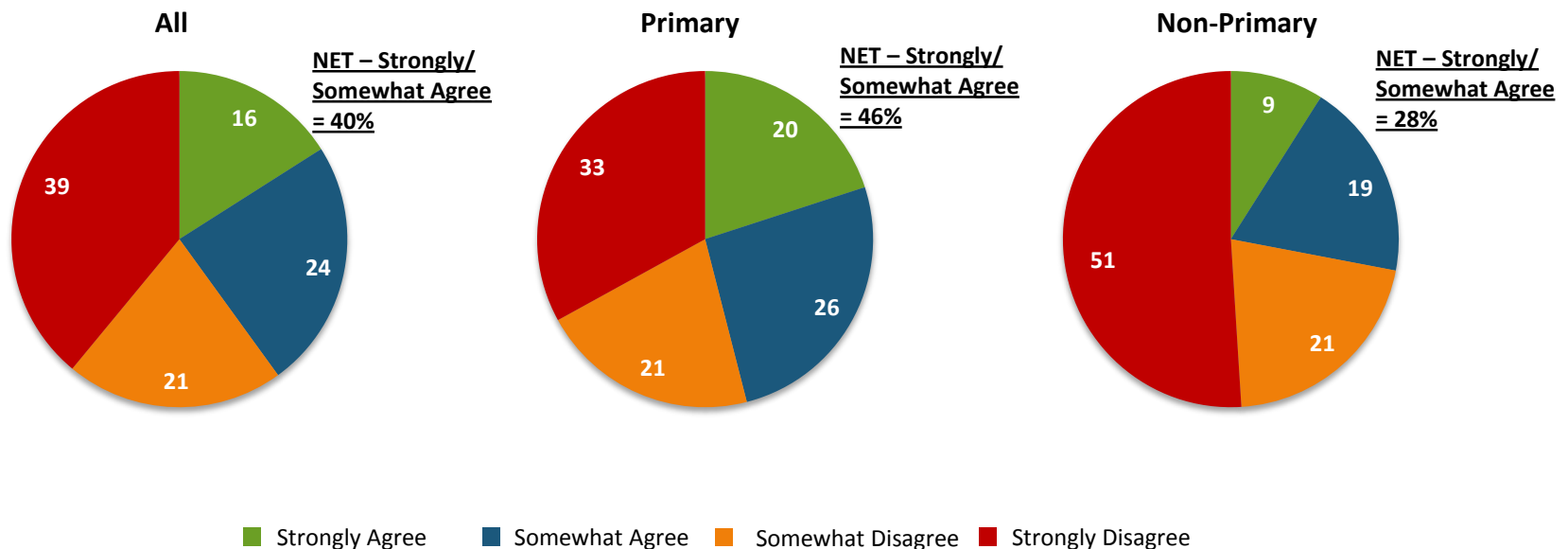
BASE: CURRENTLY EMPLOYED FULL-TIME OR PART-TIME

Q1050. How much do you agree or disagree with the following statements about working and being a caregiver?

# Two in Five Feel Strain with Their Employers

Forty percent of all employed caregivers feel that their being a caregiver has strained their relationship with their employer, a finding which is more frequently reported among Primary (46 percent) than Non-Primary (28 percent) caregivers.

**“Being a caregiver has strained my relationship with my employer” (%)**



NOTE: Self-employed and not employed were excluded from this question.

BASE: CURRENTLY EMPLOYED FULL-TIME OR PART-TIME

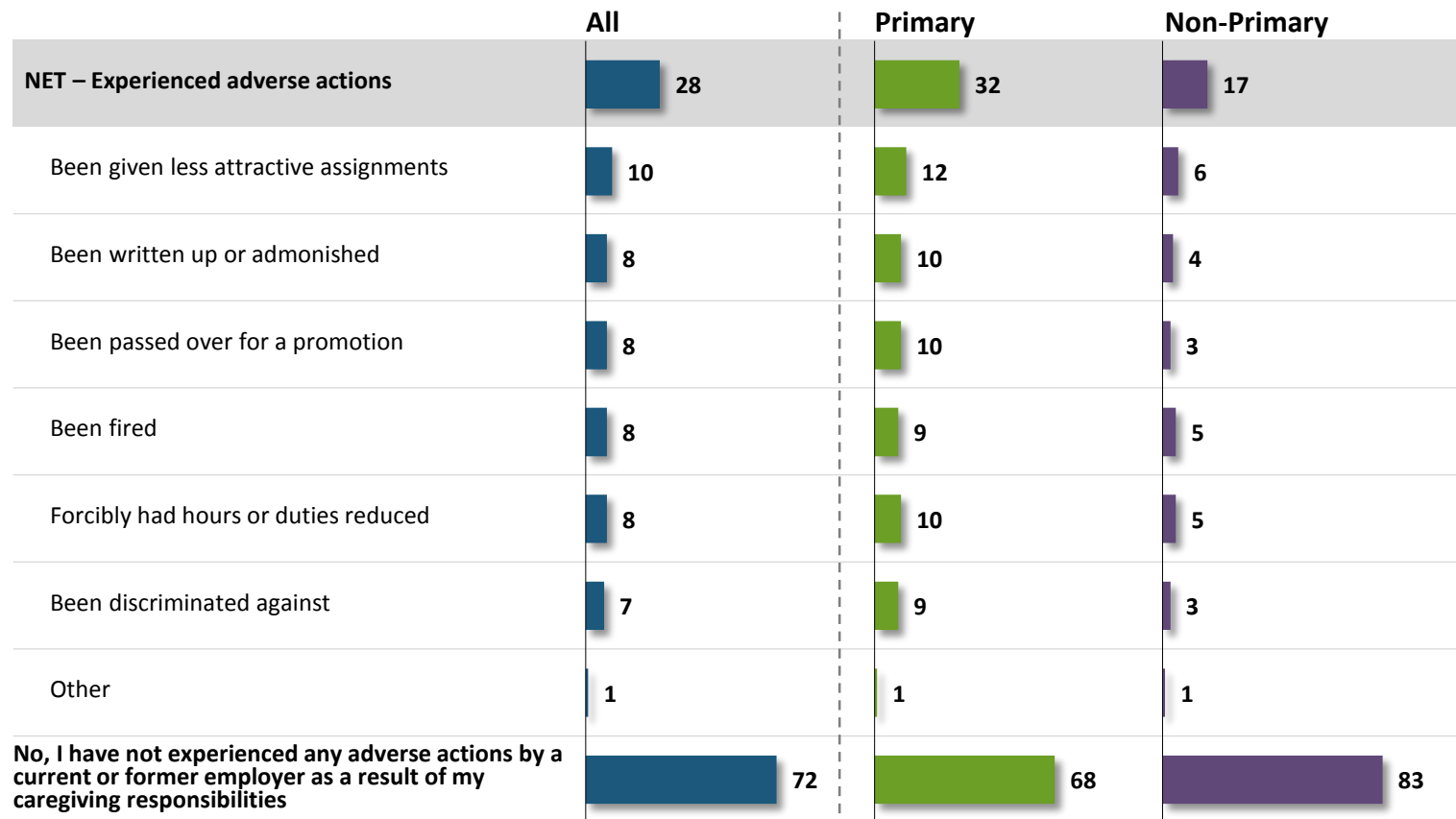
Q1050. How much do you agree or disagree with the following statements about working and being a caregiver?



# Some Have Experienced Adverse Actions Taken by Employers

Twenty-eight percent of caregivers who are employed or have been employed during their time as a caregiver have experienced adverse action(s) taken by their employer(s) as a result of their caregiving responsibilities, a finding which is much higher among Primary caregivers (32 percent) than Non-Primary caregivers (17 percent). Types of adverse actions include been given less attractive assignments (10 percent), been written up or admonished (8 percent), passed over for a promotion (8 percent), fired (8 percent), forcibly had hours or duties reduced (8 percent), or been discriminated against (7 percent).

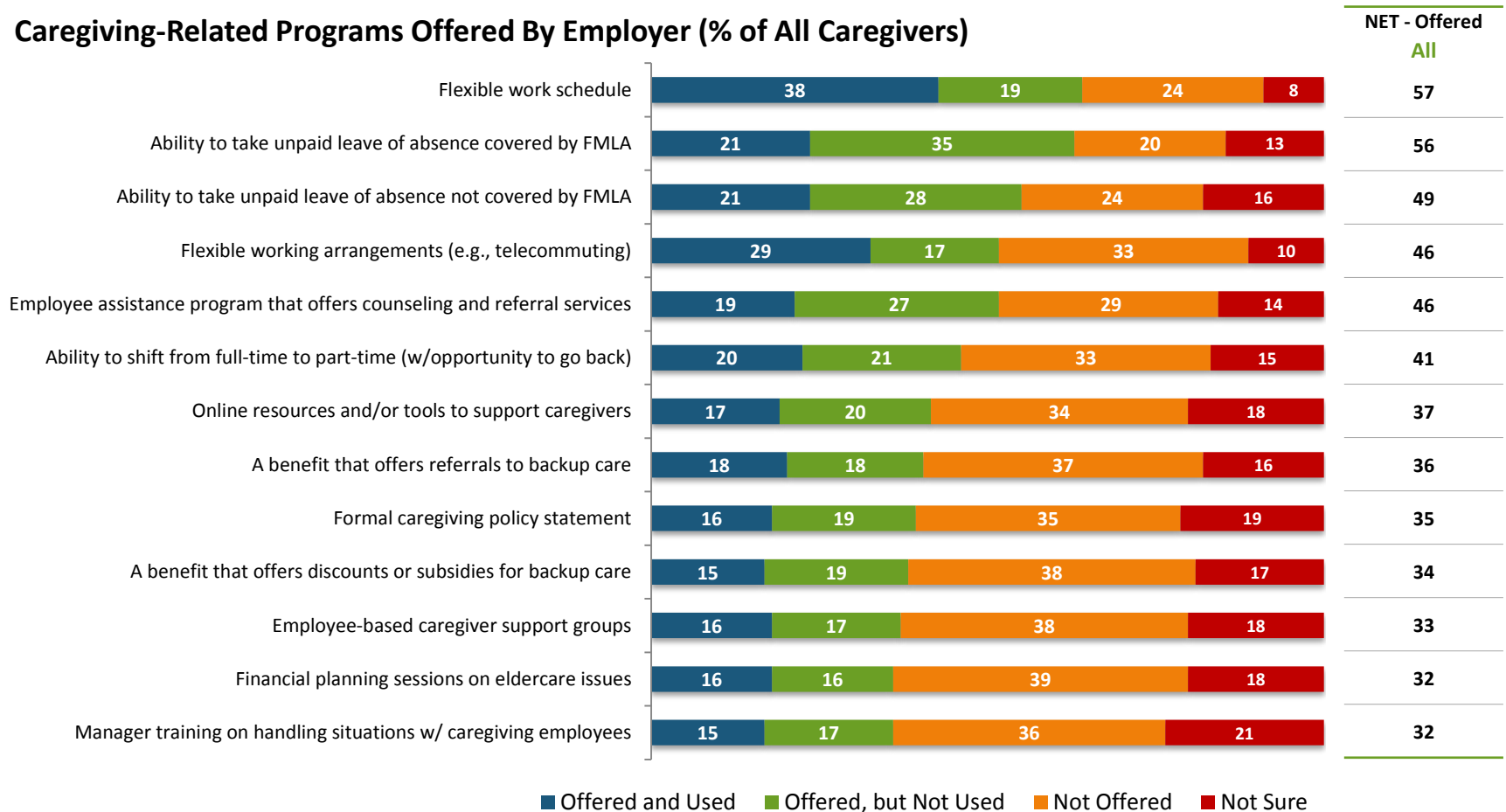
**Adverse Employment Actions Experienced As a Result of Caregiving Duties (%)**



# Caregivers Cite Few Programs Offered by Employers

Caregivers who are currently employed full-time or part-time indicate that their employers offer few programs to assist with their caregiving responsibilities. The most commonly cited programs include flexible work schedules (57 percent), unpaid leave covered by FMLA (56 percent), unpaid leave of absence not covered by FMLA (49 percent), flexible working arrangements (46 percent), and an employee assistance program (46 percent). Eleven percent say that their employers do not offer any such programs.

**Caregiving-Related Programs Offered By Employer (% of All Caregivers)**



NOTE: Self-employed and not employed were excluded from this question.

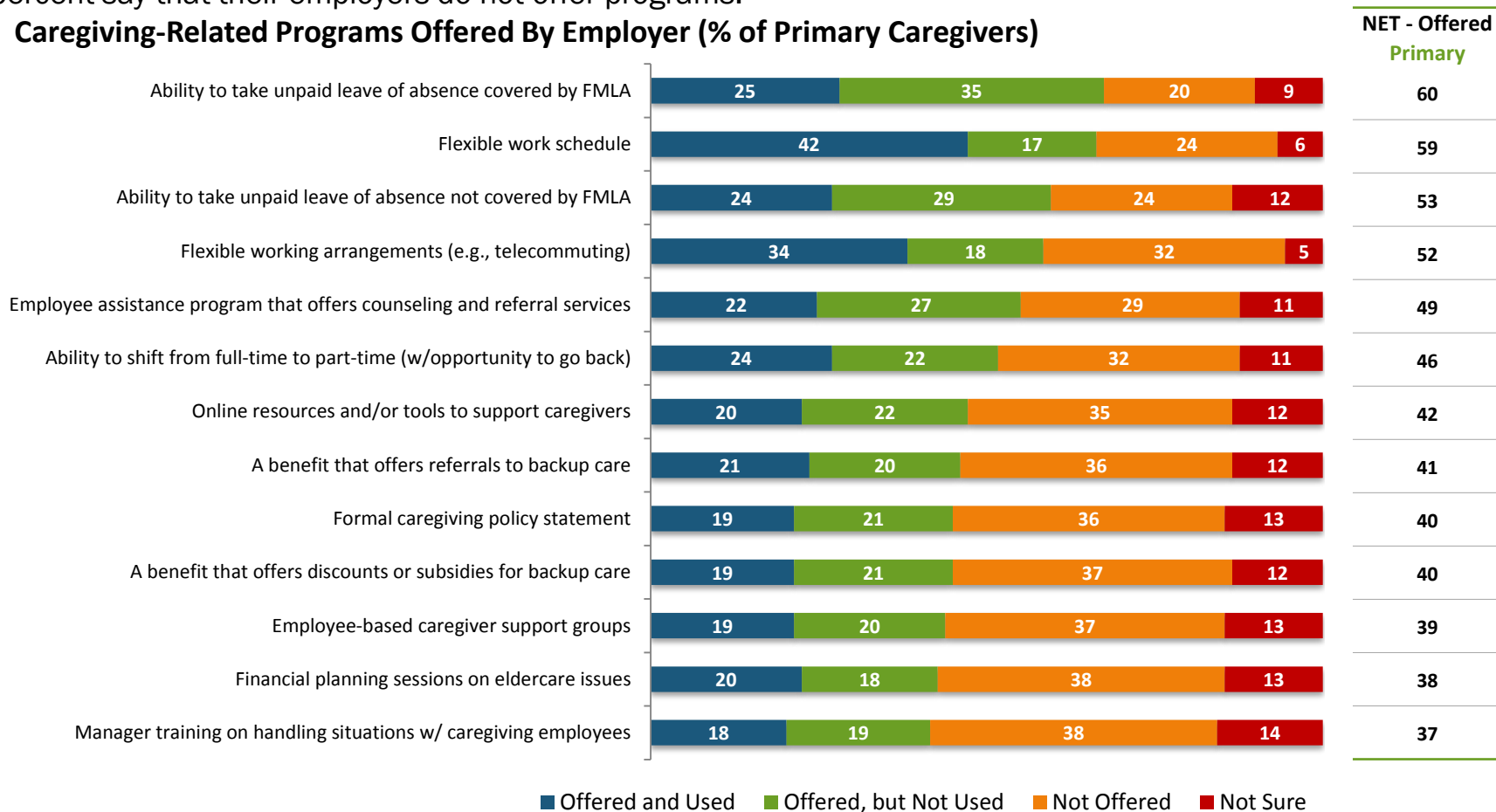
BASE: EMPLOYED FULL-TIME OR PART-TIME

Q1040. Which of the following programs, if any, does your employer offer to help its employees balance their caregiving obligations and are you using any that are offered?

# Primary Caregivers Cite Few Programs Offered by Employers

Primary caregivers who are employed full-time or part-time indicate their employers offer few programs to assist with their caregiving duties. The most commonly cited programs offered include unpaid leave covered by FMLA (60 percent), flexible work schedules (59 percent), unpaid leave of absence not covered by FMLA (53 percent), flexible working arrangements (52 percent), and an employee assistance program (49 percent). Only 37 percent mentioned their employers offer manager training on handling situations with caregiving employees. Eleven percent say that their employers do not offer programs.

## Caregiving-Related Programs Offered By Employer (% of Primary Caregivers)



NOTE: Self-employed and not employed were excluded from this question.

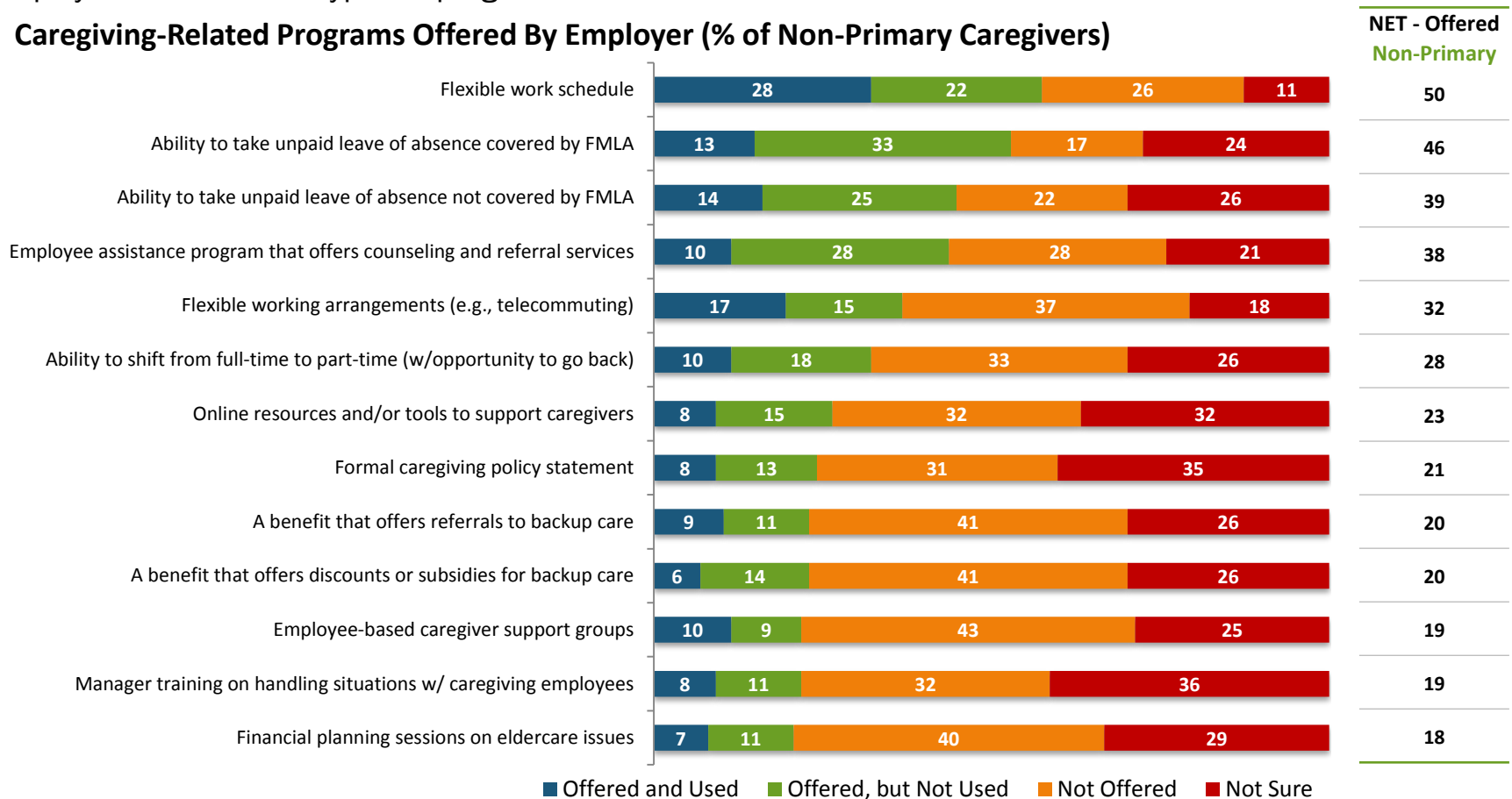
BASE: EMPLOYED FULL-TIME OR PART-TIME

Q1040. Which of the following programs, if any, does your employer offer to help its employees balance their caregiving obligations and are you using any that are offered?

# Non-Primary Caregivers Cite Few Programs Offered by Employers

Non-Primary caregivers who are employed full-time or part-time indicate that their employers offer relatively few programs to assist with their caregiving duties. The most commonly cited programs offered include flexible work schedules (50 percent), unpaid leave covered by FMLA (46 percent), unpaid leave of absence not covered by FMLA (39 percent), an employee assistance program (38 percent), and flexible working arrangements (32 percent). Non-Primary caregivers are much more likely than Primary caregivers to be “not sure” whether their employers offer various types of programs.

## Caregiving-Related Programs Offered By Employer (% of Non-Primary Caregivers)



NOTE: Self-employed and not employed were excluded from this question.

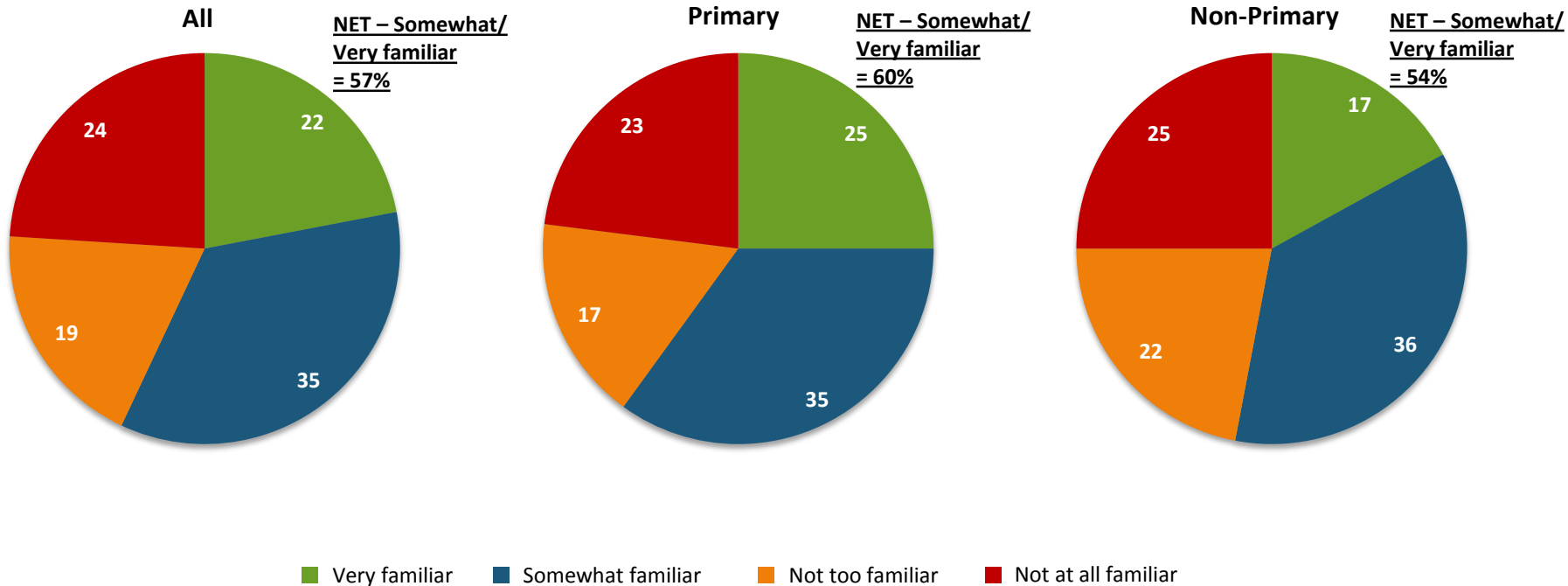
BASE: EMPLOYED FULL-TIME OR PART-TIME

Q1040. Which of the following programs, if any, does your employer offer to help its employees balance their caregiving obligations and are you using any that are offered?

# Few Are Very Familiar with FMLA

The Family Medical Leave Act (FMLA) is a federal law that requires covered employers to provide their employees with protected, unpaid leave for qualified medical and family reasons. Fifty-seven percent of all caregivers are “somewhat” or “very familiar” with FMLA. However, only 22 percent of all caregivers are “very familiar” with it. Primary (25 percent) are more likely than Non-Primary caregivers (17 percent) to be “very familiar.” An alarming 24 percent of all caregivers are “not at all familiar” with FMLA, a finding that is consistent among Primary (23 percent) and Non-Primary (25 percent) caregivers.

**Caregiver Familiarity with the Family and Medical Leave Act (%)**



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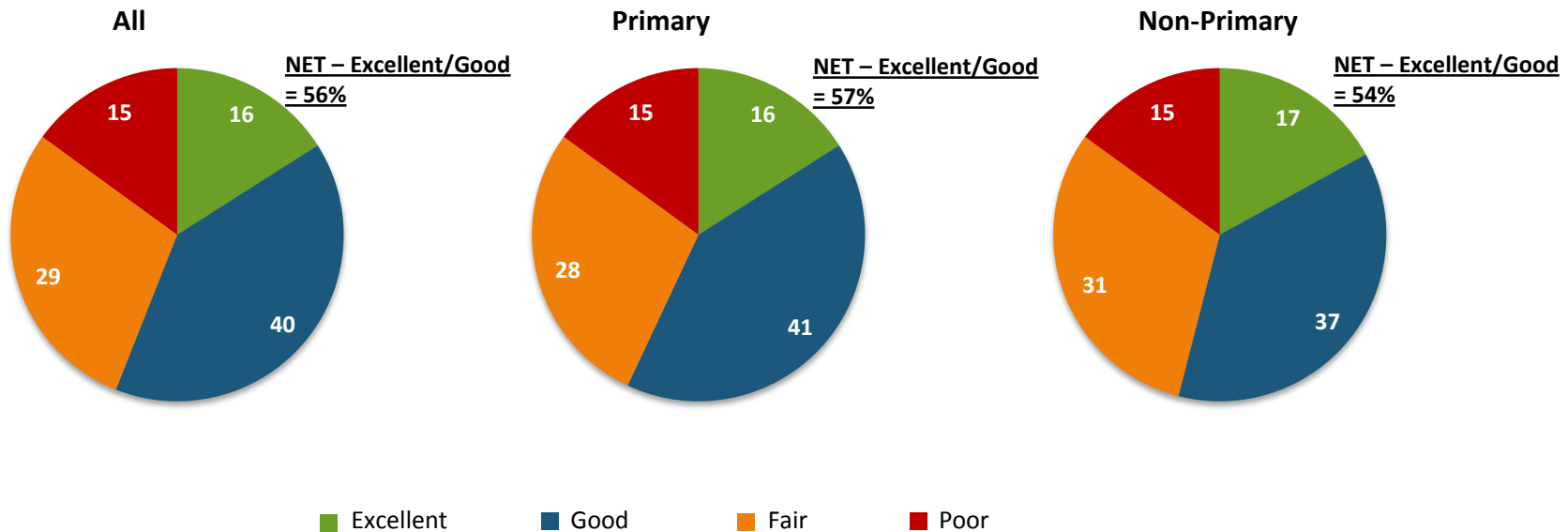
### **Appendix: Caregiver and Care Recipient Demographics**

## **Acknowledgements**

# Caregivers' Financial Well-Being

More than half of all caregivers (56 percent) self-describe their financial well-being as excellent or good, a finding that is relatively consistent among Primary (57 percent) and Non-Primary caregivers (54 percent). A noteworthy 15 percent of all caregivers, including Primary and Non-Primary caregivers, say their financial well-being is poor.

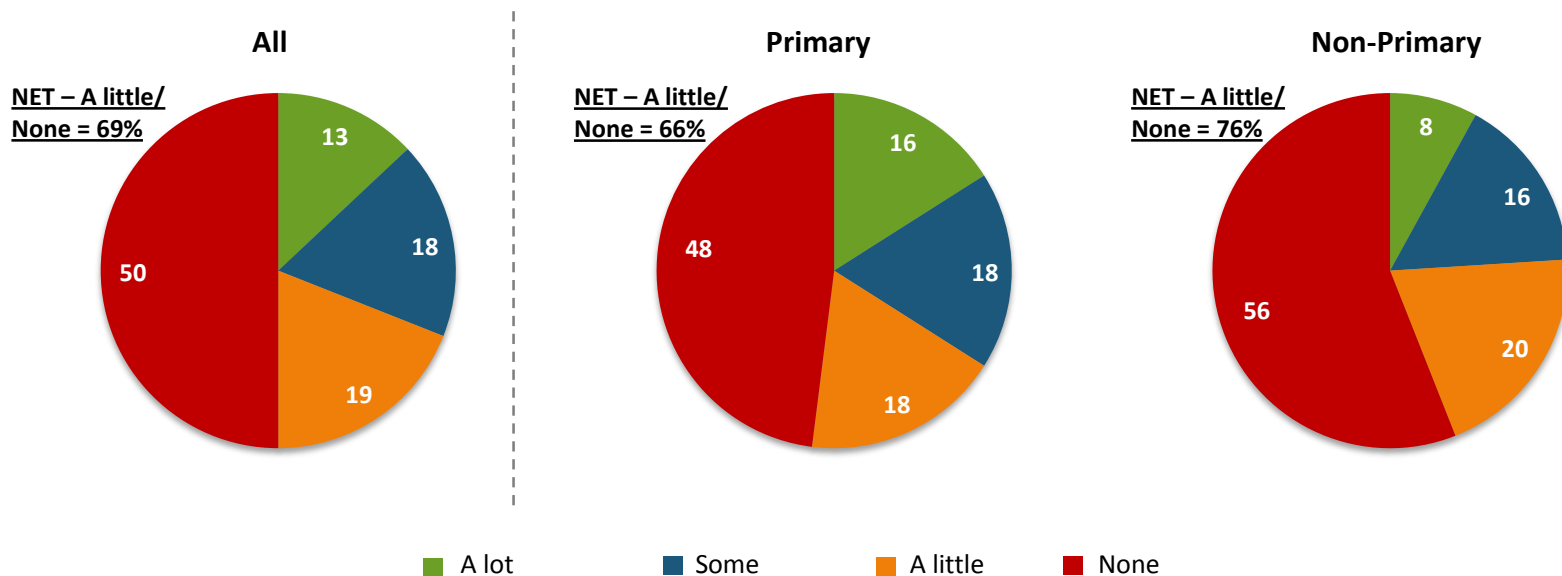
**“How would you describe your own financial well-being?” (%)**



# Many Didn't Consider Finances When Becoming a Caregiver

Sixty-nine percent of all caregivers say they gave little or no thought into their own financial situation when deciding to become a caregiver, a finding which differs between Primary (66 percent) and Non-Primary (76 percent) caregivers. Primary caregivers (34 percent) are more likely than Non-Primary caregivers (24 percent) to have given some or a lot of thought to their financial situation when deciding to become a caregiver.

**“To what extent did you consider your own financial situation when deciding to become a caregiver?” (%)**

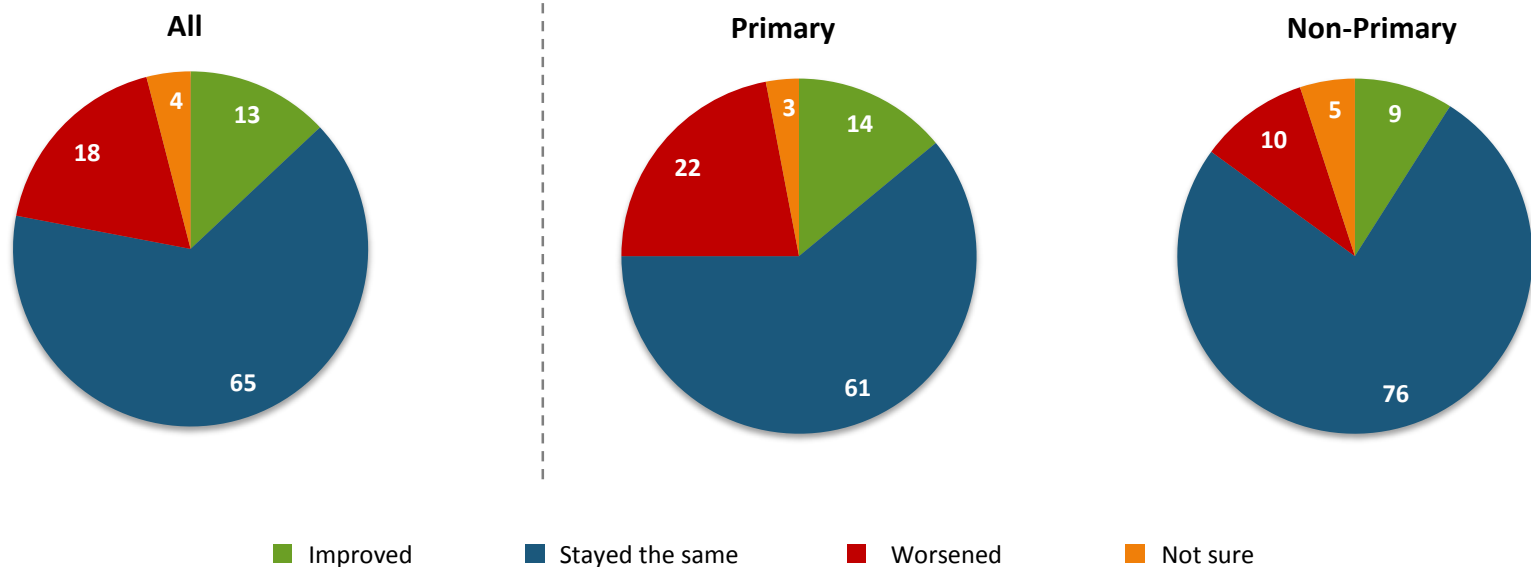




# Most Caregivers' Financial Situation Has Stayed the Same

The majority of caregivers (65 percent) say their financial situation has not changed as a result of becoming a caregiver, including Primary caregivers (61 percent) and Non-Primary caregivers (76 percent). However, Primary caregivers (22 percent) are more likely than Non-Primary caregivers (10 percent) to say their financial situation has worsened since becoming a caregiver.

**“How has your financial situation changed as a result of becoming a caregiver?” (%)**

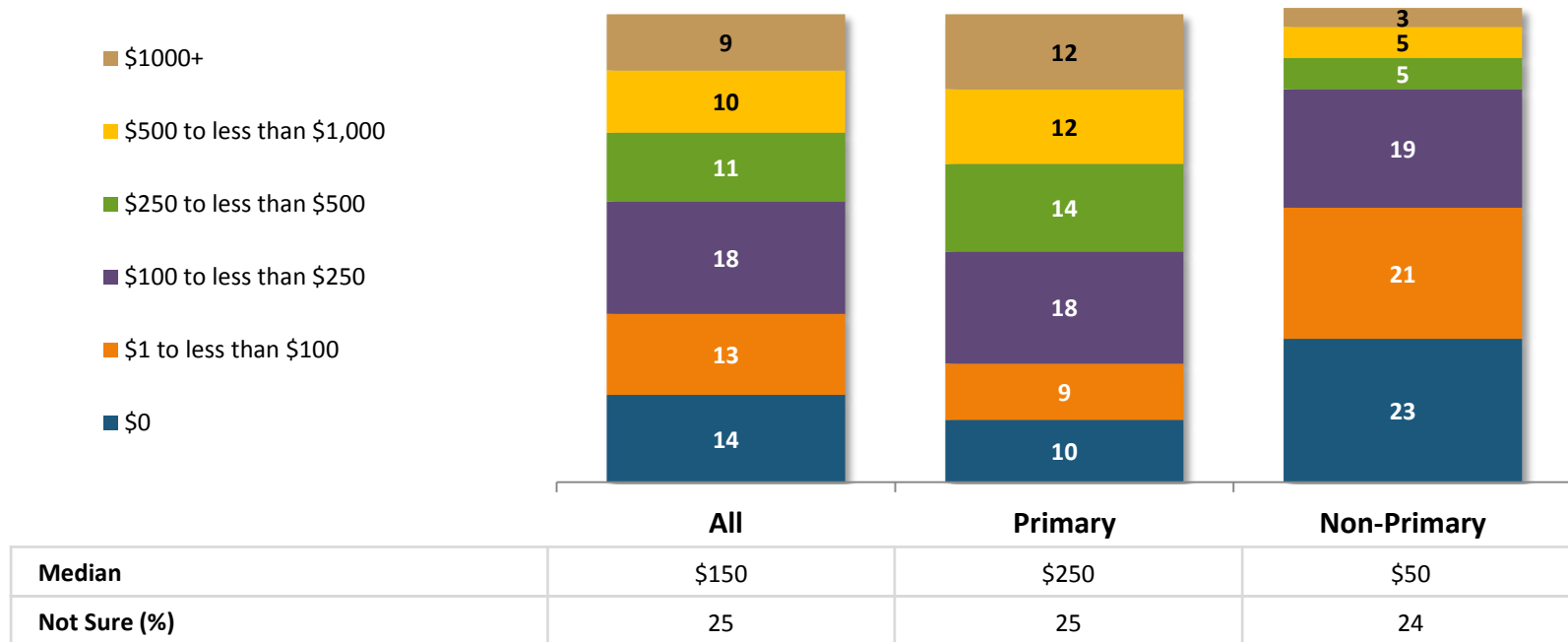


■ Improved   ■ Stayed the same   ■ Worsened   ■ Not sure

# Most Caregivers Spend Their Own Money to Cover Cost of Care

Caregivers spend \$150 per month (median) out-of-pocket to cover expenses for their care recipient, with 9 percent of caregivers spending \$1,000 or more per month. Primary caregivers (\$250 median) spend five times as much per month on caregiving as Non-Primary caregivers (\$50 median). Primary caregivers (12 percent) are also four times as likely as Non-Primary caregivers (3 percent) to spend \$1,000 or more per month on caregiving-related expenses.

**Monthly Personal Expenditures to Cover Expenses for Care Recipient (%)**



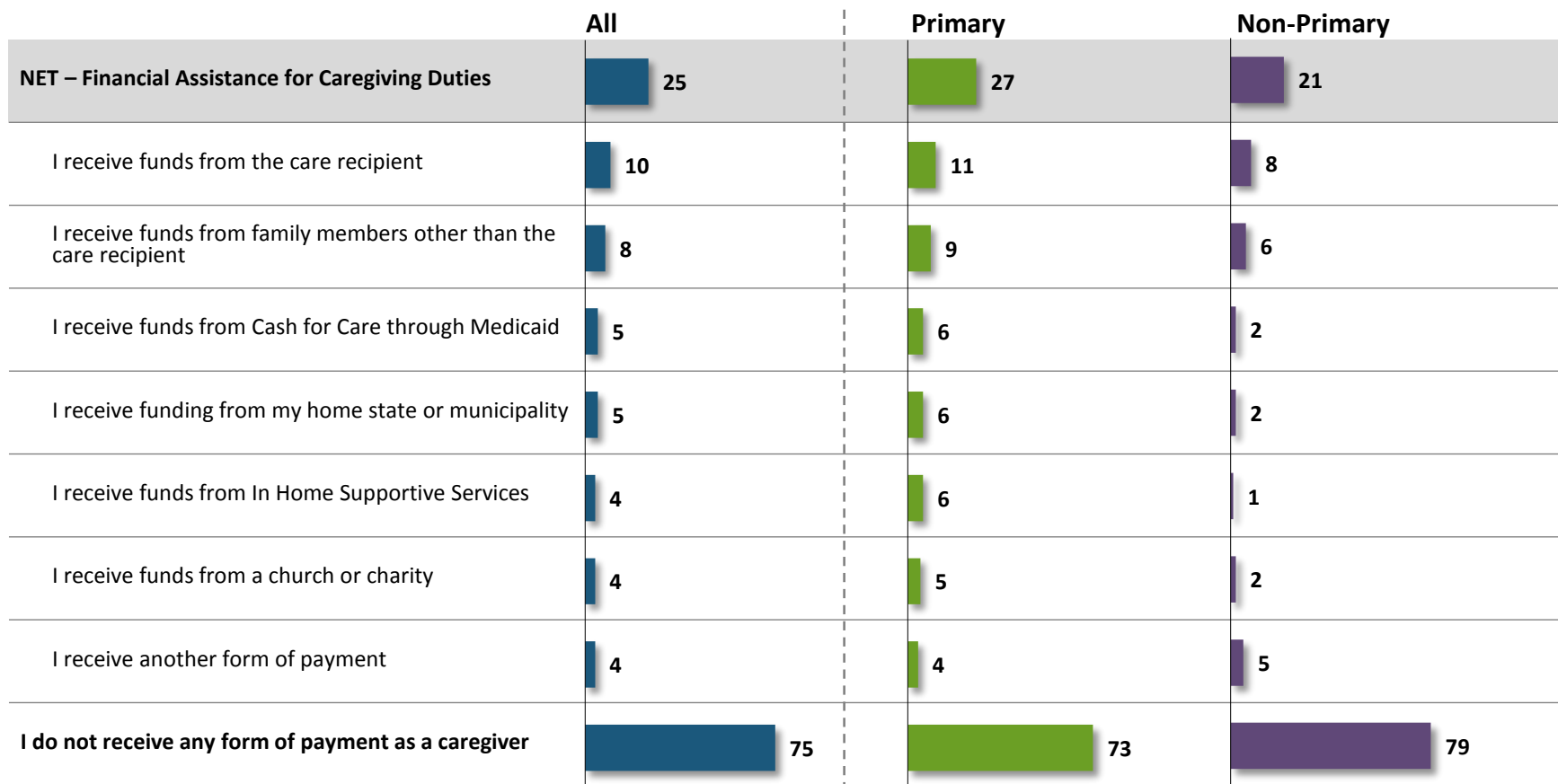
BASE: ALL QUALIFIED RESPONDENTS

Q1120. On average, approximately how much money do you spend each month paying out-of-pocket to cover expenses for the care recipient (e.g., for groceries, over-the-counter medications, gas, parking)?

# Most Caregivers Do Not Receive Any Financial Assistance

Only 25 percent of all caregivers receive any sort of financial assistance for their caregiving duties, a finding which is higher among Primary (27 percent) than Non-Primary (21 percent) caregivers. With regards to possible sources of financial assistance, caregivers' most frequently cited source of funds are from the care recipient (10 percent), a finding which is relatively consistent between Primary (11 percent) and Non-Primary (8 percent) caregivers.

**Sources of Financial Assistance Received for Caregiving Duties, If Any (%)**



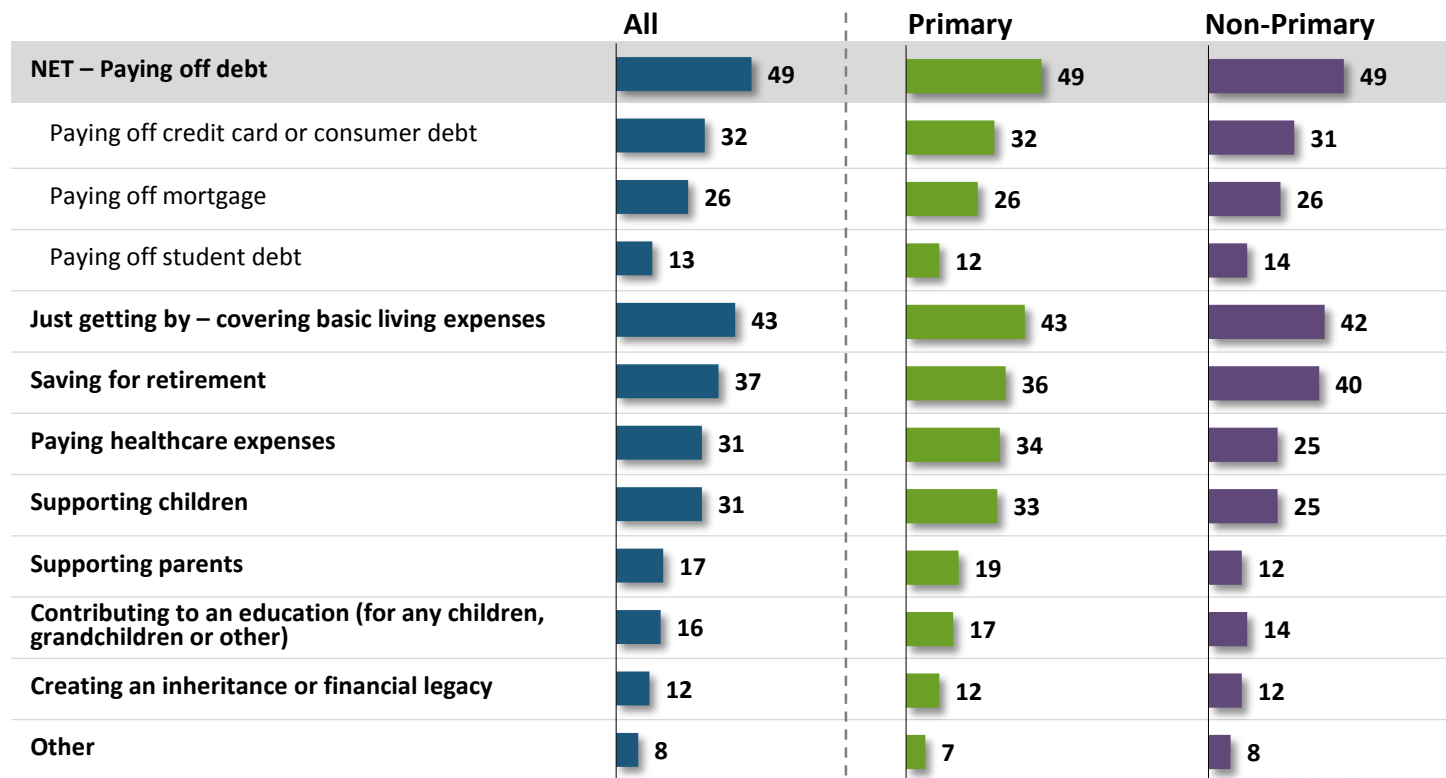
BASE: ALL QUALIFIED RESPONDENTS

Q1260. Which of the following do you receive for your caregiving duties? Please select all that apply.

# Almost Half of Caregivers Are Paying Off Debt

Caregivers' most frequently cited financial priorities include just getting by – covering basic living expenses (43 percent) and saving for retirement (37 percent). A noteworthy and alarming 49 percent of caregivers cite paying off some form of debt as a financial priority including 32 percent who mentioned paying off credit card or consumer debt. These financial priorities are directionally similar among Primary and Non-Primary caregivers. However, Primary caregivers (34 percent) are more likely than Non-Primary caregivers (25 percent) to mention paying healthcare expenses. Primary caregivers are also more likely than Non-Primary caregivers to mention supporting children and supporting parents.

## “Which of the following are your financial priorities right now?” (%)



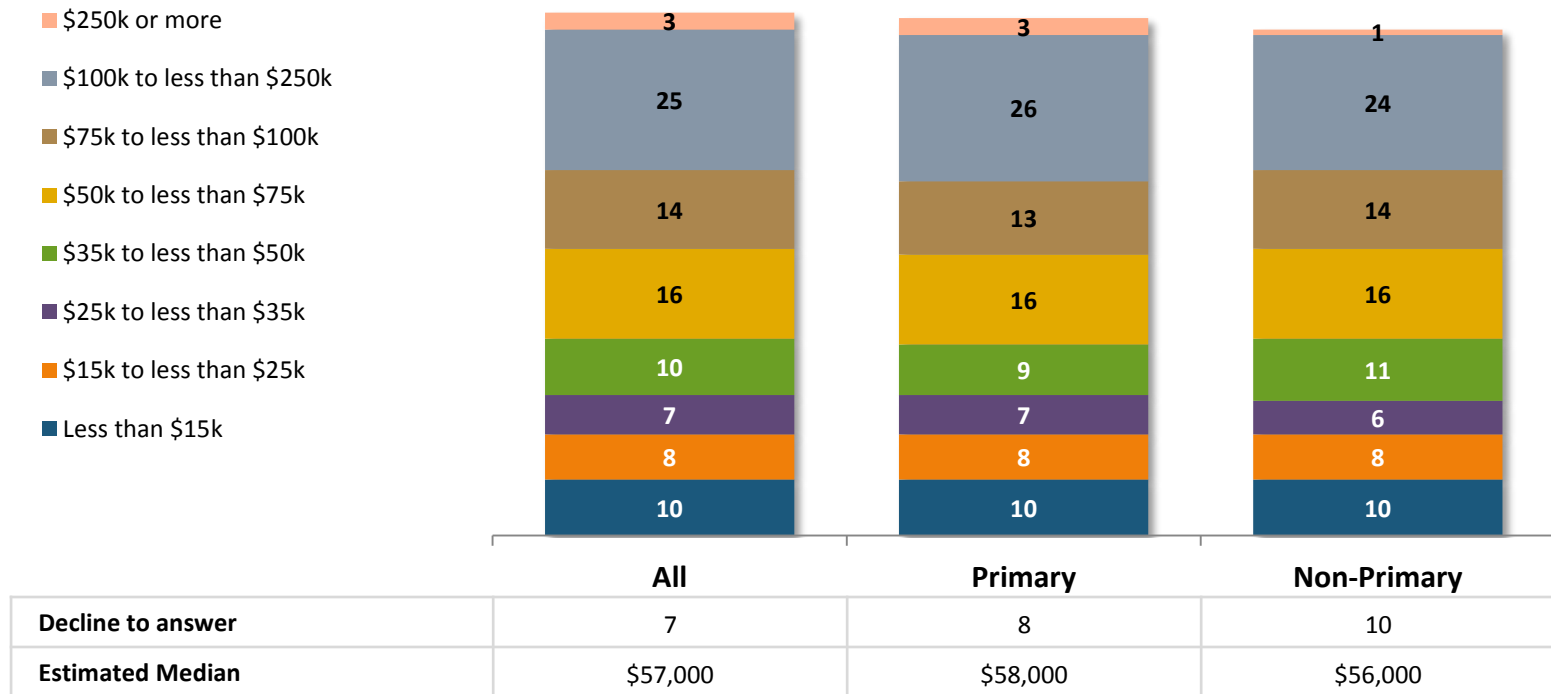
BASE: ALL QUALIFIED RESPONDENTS

Q1105. Which of the following are your financial priorities right now? Please select all that apply.

# Household Income Among Caregivers Spans a Wide Spectrum

The household income of caregivers is \$57,000 per year (estimated median). Twenty-eight percent of caregivers report a household income of \$100,000 or more per year, including 29 percent of Primary caregivers and 25 percent of Non-Primary caregivers. Thirty-five percent of caregivers report a household income of less than \$50,000 per year.

**Total Household Income in 2016 (%)**



Note: The median is estimated based on the approximate midpoint of the range of each response category. Non-responses are excluded from the estimate

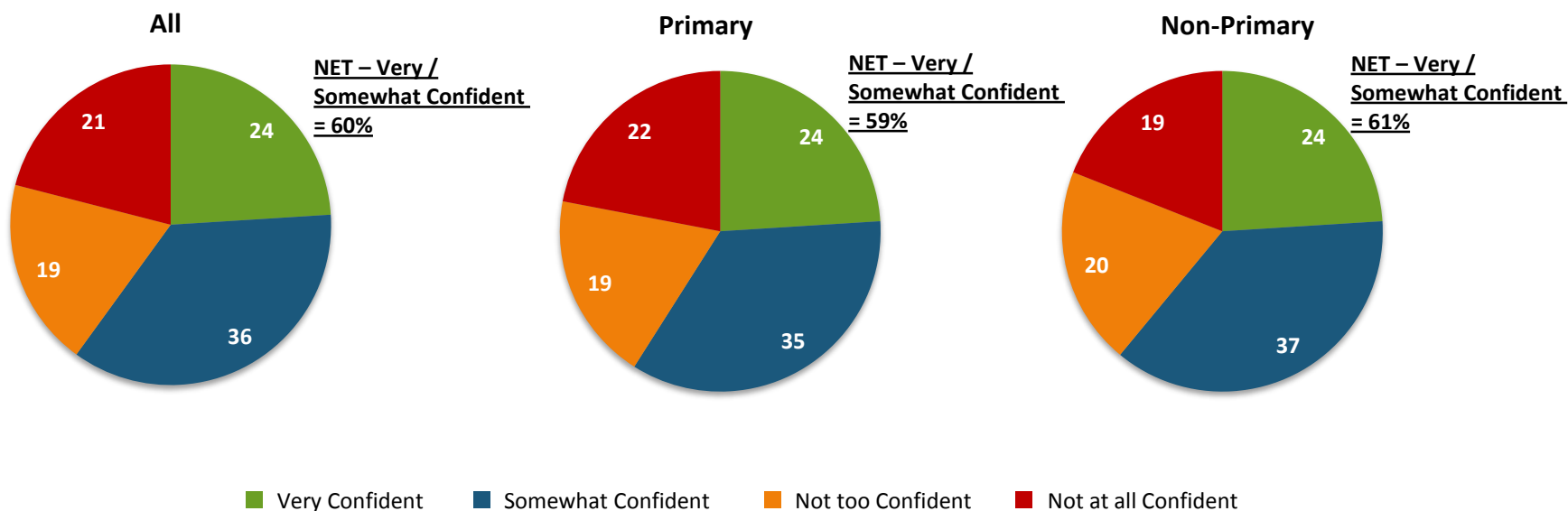
BASE: ALL QUALIFIED RESPONDENTS

Q1265. Which of the following income categories best describes your total household income in 2016?

# Most Are Confident About Retiring Comfortably

Sixty percent of caregivers are “somewhat” or “very confident” that they will be able to fully retire with a comfortable lifestyle, including 24 percent who are “very confident” and 36 percent who are “somewhat confident.” However, one in five caregivers (21 percent) are “not at all confident.” These findings are consistent between Primary and Non-Primary caregivers.

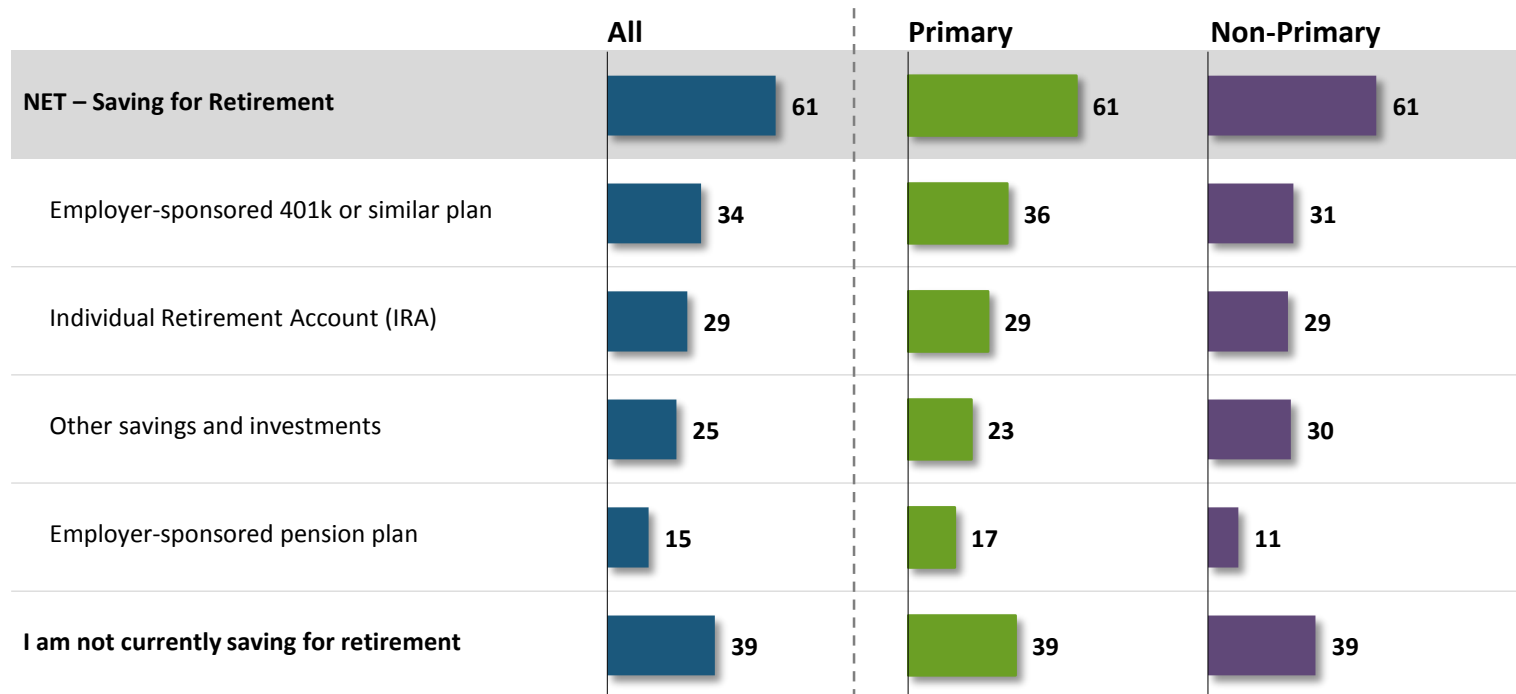
**“How confident are you that you will be able to fully retire with a lifestyle you consider comfortable?” (%)**



# Six in 10 Caregivers Are Saving for Retirement

Most caregivers (61 percent) are saving for retirement in some way. The two most frequently cited savings vehicles that caregivers are using to save are employer-sponsored 401(k)s or similar programs (34 percent) and IRAs (29 percent). These findings are consistent between Primary and Non-Primary caregivers.

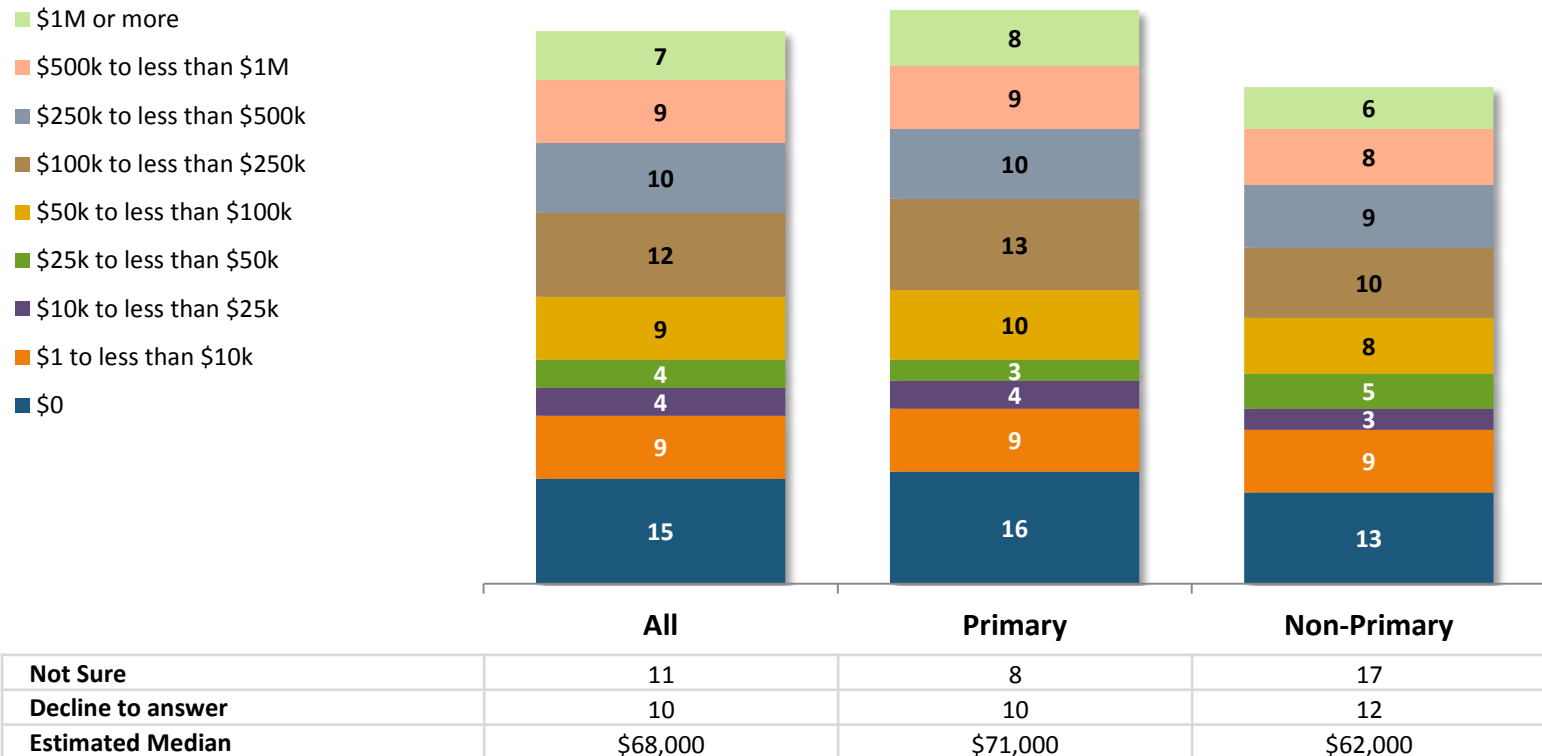
**Saving For Retirement (%)**



# Are Caregivers Saving Enough For Retirement?

Caregivers have saved \$68,000 (estimated median) in all household retirement accounts, a finding which is relatively consistent among Primary and Non-Primary caregivers. Sixteen percent of all caregivers have saved \$500k or more in all retirement accounts, a finding which is slightly higher among Primary caregivers (17 percent) than Non-Primary caregivers (14 percent). Fifteen percent of all caregivers have no savings in retirement accounts.

**Total Household Retirement Savings (%)**



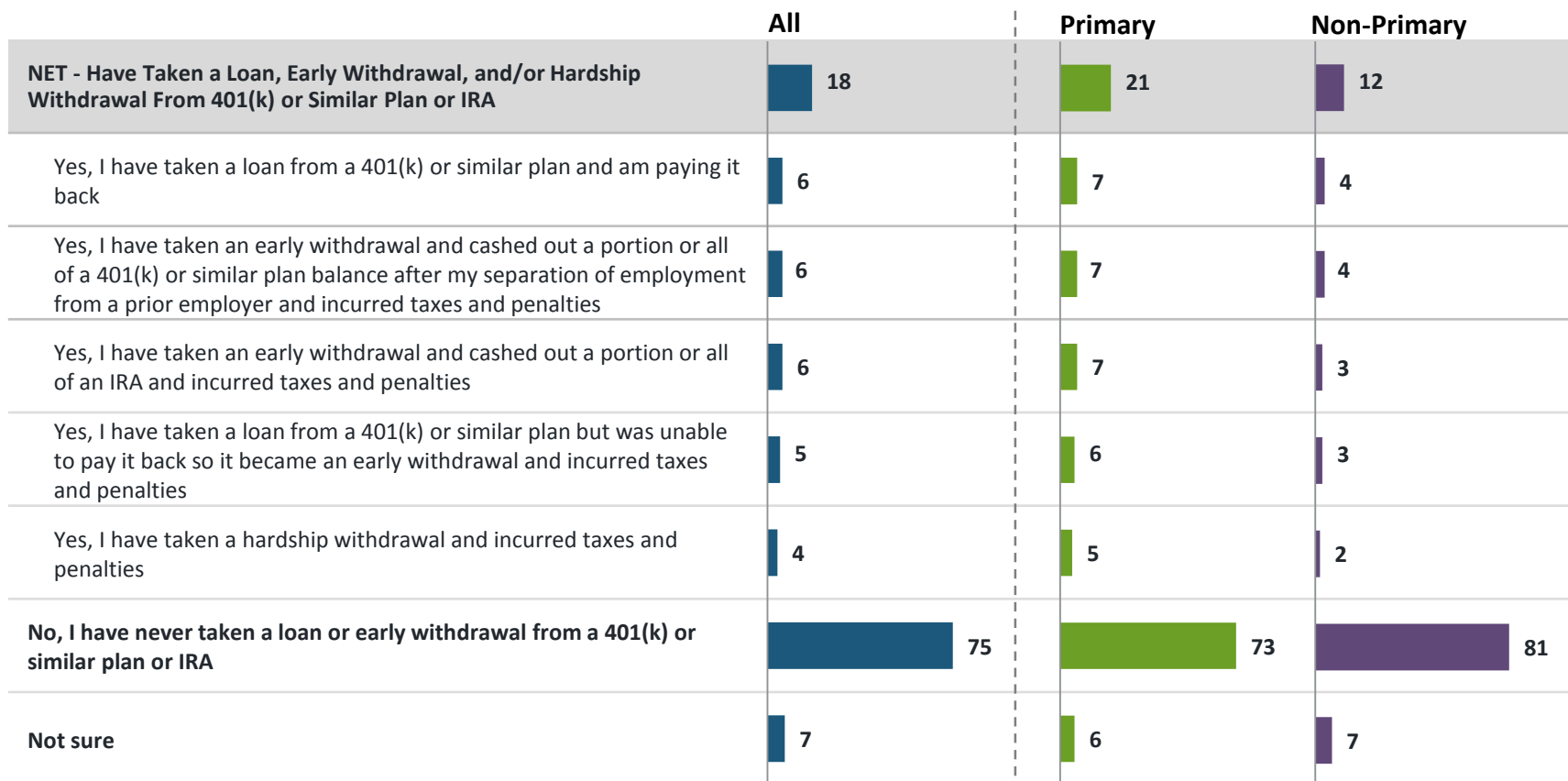
Note: The median is estimated based on the approximate midpoint of the range of each response category. Non-responses are excluded from the estimate.



# Some Caregivers Have Dipped Into Their Retirement Accounts

Eighteen percent of caregivers have taken some sort of loan or withdrawal from their retirement accounts as a result of their caregiving responsibilities. Primary caregivers (21 percent) are almost twice as likely as Non-Primary caregivers (12 percent) to have taken a loan, early withdrawal and/or hardship withdrawal from their 401(k), IRA, or similar plan.

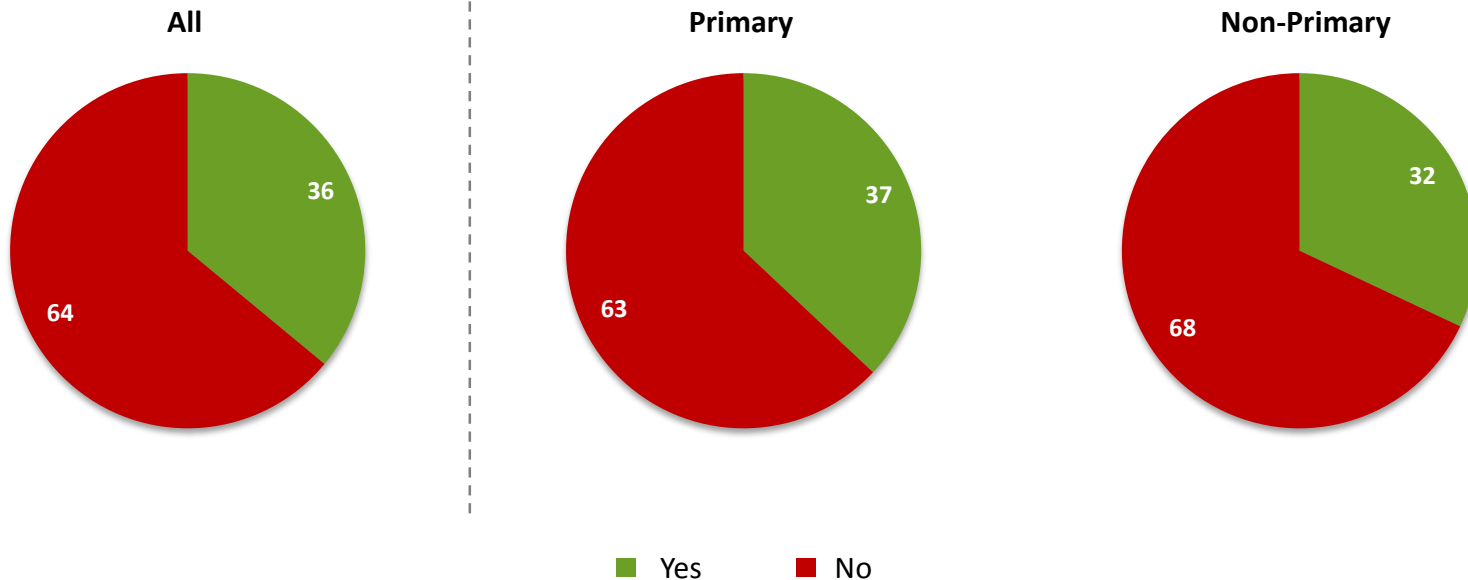
## Loans, Hardship Withdrawals, and/or Early Withdrawals From Retirement Accounts Taken as a Result of Caregiving Duties (%)



# One-Third of Caregivers Have a Financial Advisor

Thirty-six percent of caregivers have a financial advisor, including 37 percent of Primary and 32 percent of Non-Primary caregivers.

“Do you have a financial advisor?” (%)



# ***The Many Faces of Family Caregivers: A Close-Up Look at Caregiving and Its Implications***

## **Executive Summary**

### **A Portrait of Today's Caregivers**

- Key Highlights
- A Portrait of Today's Caregivers
- Insights About Care Recipients and Their Needs
- The Diverse Duties, Daily Lives, and Dedication of Caregivers
- The Employment Situation of Caregivers
- The Personal Financial Implications of Being a Caregiver

### **➤ *The Health Effects of Being a Caregiver***

- Ways to Help Caregivers with Their Responsibilities

## **Demographic Perspectives**

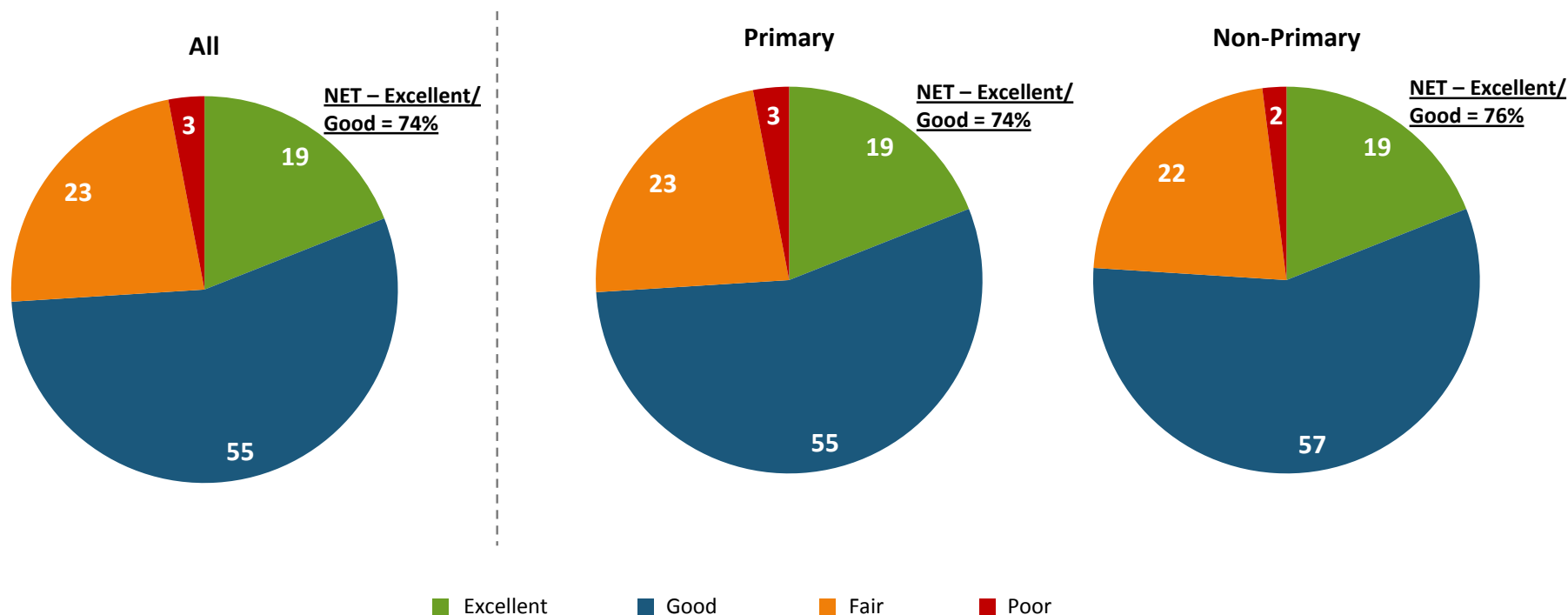
### **Appendix: Caregiver and Care Recipient Demographics**

## **Acknowledgements**

# Most Caregivers Consider Themselves to Be in Excellent/Good Health

Three out of four caregivers say they are in excellent or good health (74 percent). Twenty-three percent of caregivers consider themselves to be in fair health. Only 3 percent consider themselves to be in poor health.

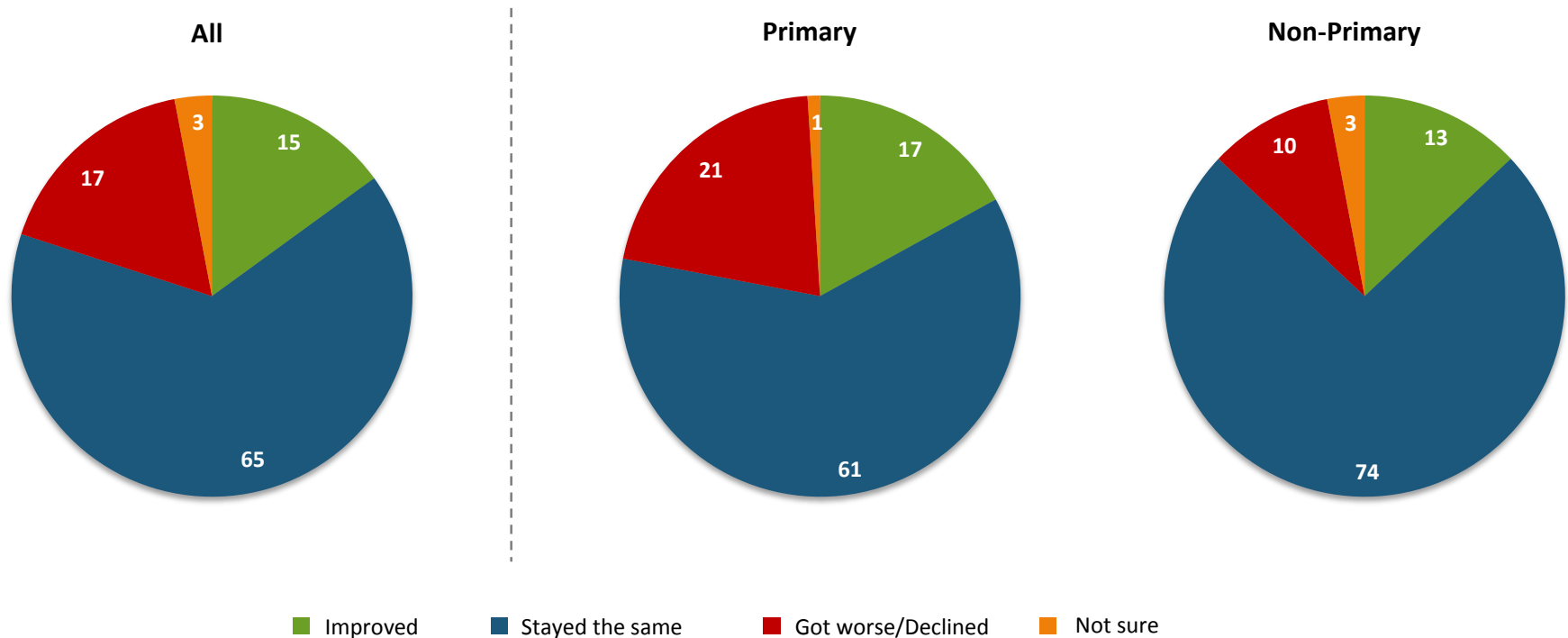
Caregivers' Self-Described Health Status of Their Own Health (%)



# One in Six Experienced a Decline in Their Own Health

Approximately one in six caregivers (17 percent) indicate their general health has gotten worse/declined since becoming a caregiver, a finding which is much higher among Primary caregivers (21 percent) than Non-Primary caregivers (10 percent). The majority of caregivers (65 percent) indicate that their general health has stayed the same. Primary caregivers (61 percent) are less likely than Non-Primary caregivers (74 percent) to say their health status has not changed.

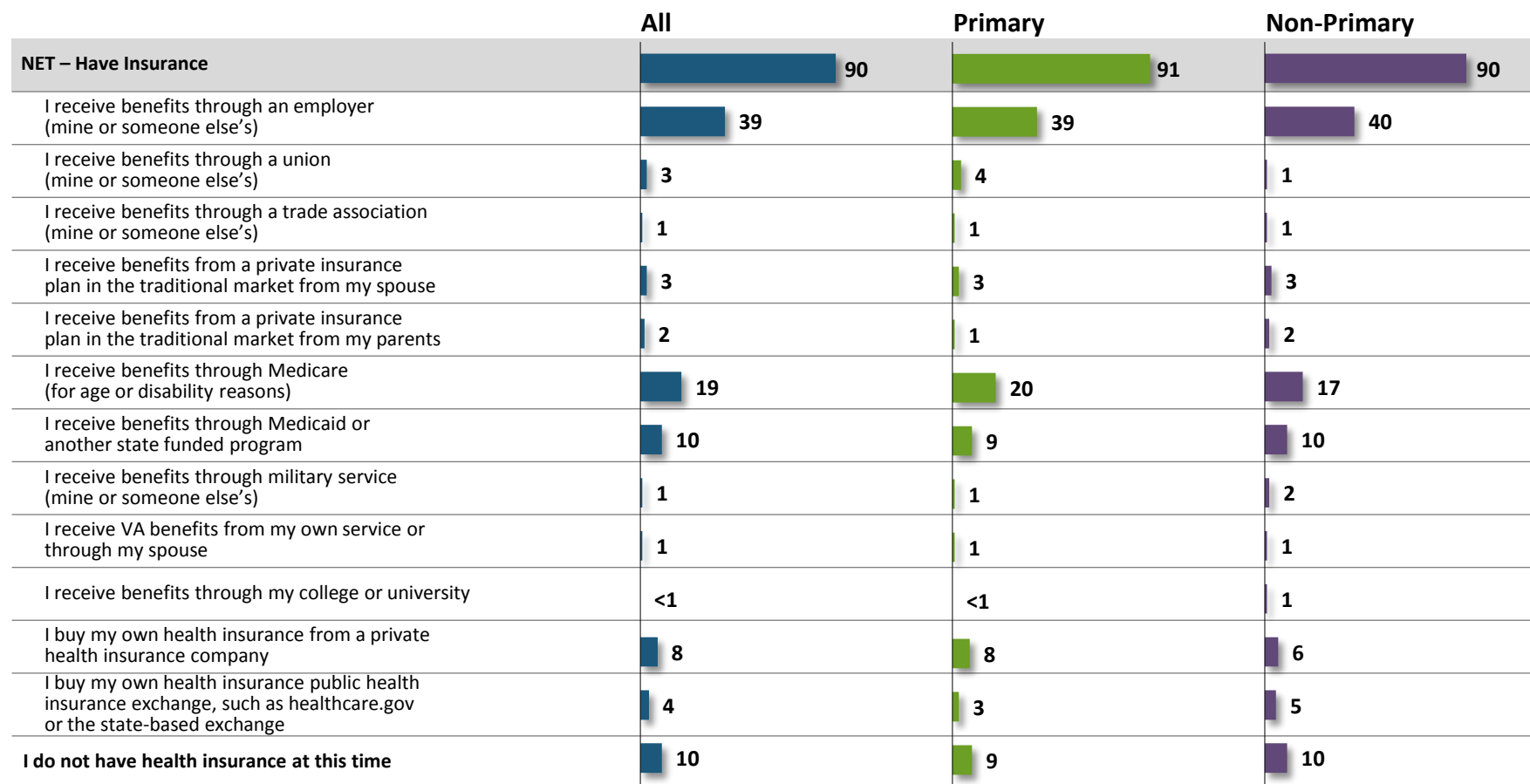
Changes in General Health Since Becoming a Caregiver (%)



# Nine in 10 Caregivers Have Health Insurance

Nine out of 10 caregivers currently have health insurance, a finding that is consistent between Primary (91 percent) and Non-Primary caregivers (90 percent). Employer benefits are the most frequently cited source of health insurance among all caregivers (39 percent), including Primary (39 percent) and Non-Primary (40 percent) caregivers. Other frequently cited sources of health insurance coverage among all caregivers include Medicare (19 percent) and Medicaid (10 percent). Of note, 10 percent of caregivers are currently uninsured.

**“Which of the following best describes how you primarily receive health insurance?” (%)**



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- The Health Effects of Being a Caregiver

### **➤ *Ways to Help Caregivers with Their Responsibilities***

## **Demographic Perspectives**

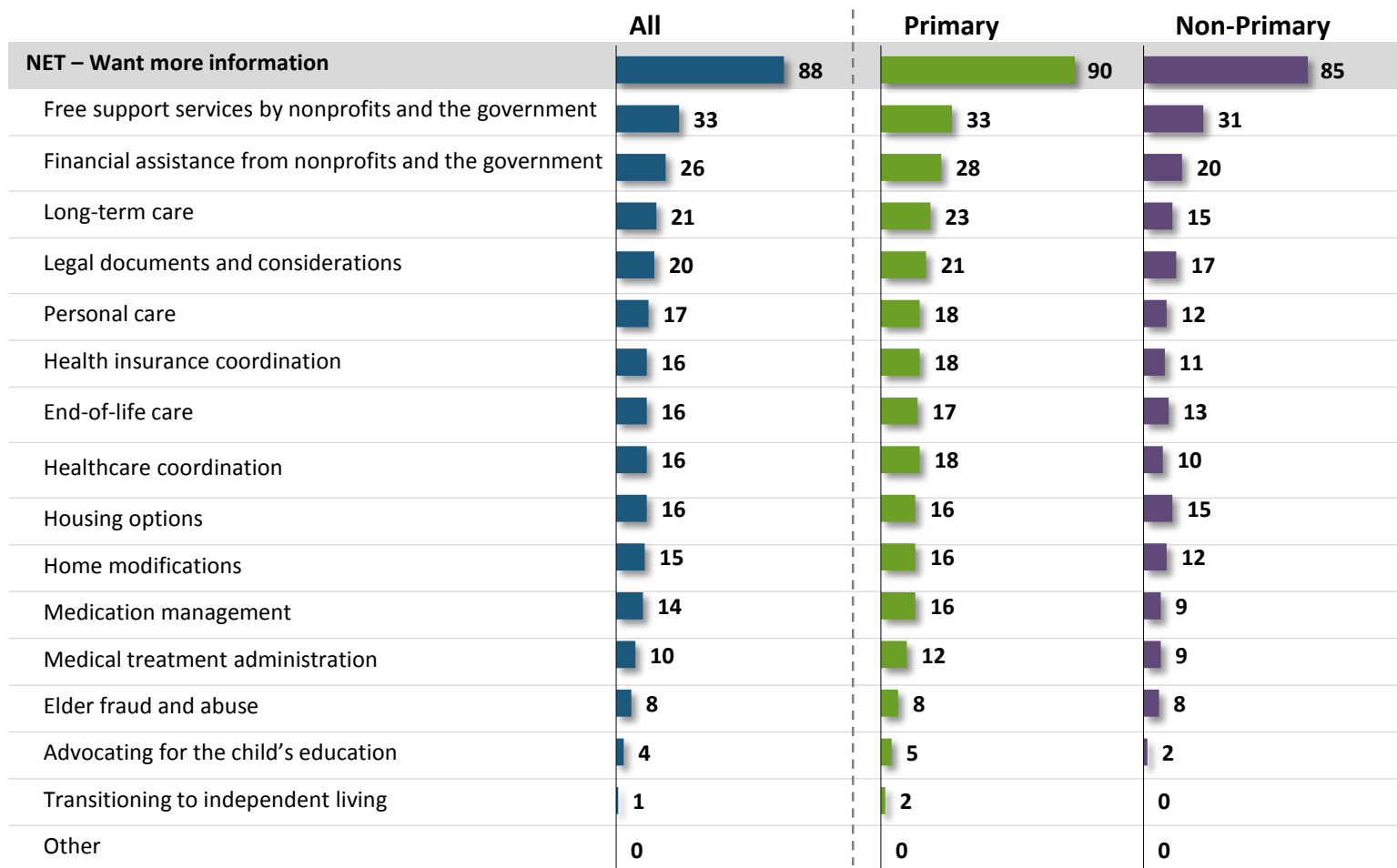
## **Appendix: Caregiver and Care Recipient Demographics**

## **Acknowledgements**

# Caregivers Want More Information to Help with Their Duties

In order to help with their caregiving responsibilities, 88 percent of caregivers would like more information on one or more topics. One-third of caregivers (33 percent) would like more information about free support services offered by nonprofits and the government. Caregivers would also like more information about financial assistance from nonprofits/the government, long-term care, and legal documents.

**Desired Information to Help with Caregiving Responsibilities (%)**



Only responses selected by 1% or more shown

BASE: ALL QUALIFIED RESPONDENTS

Q845. Which of the following topics would you like more information about to help you with your caregiving responsibilities? I would like more information about...

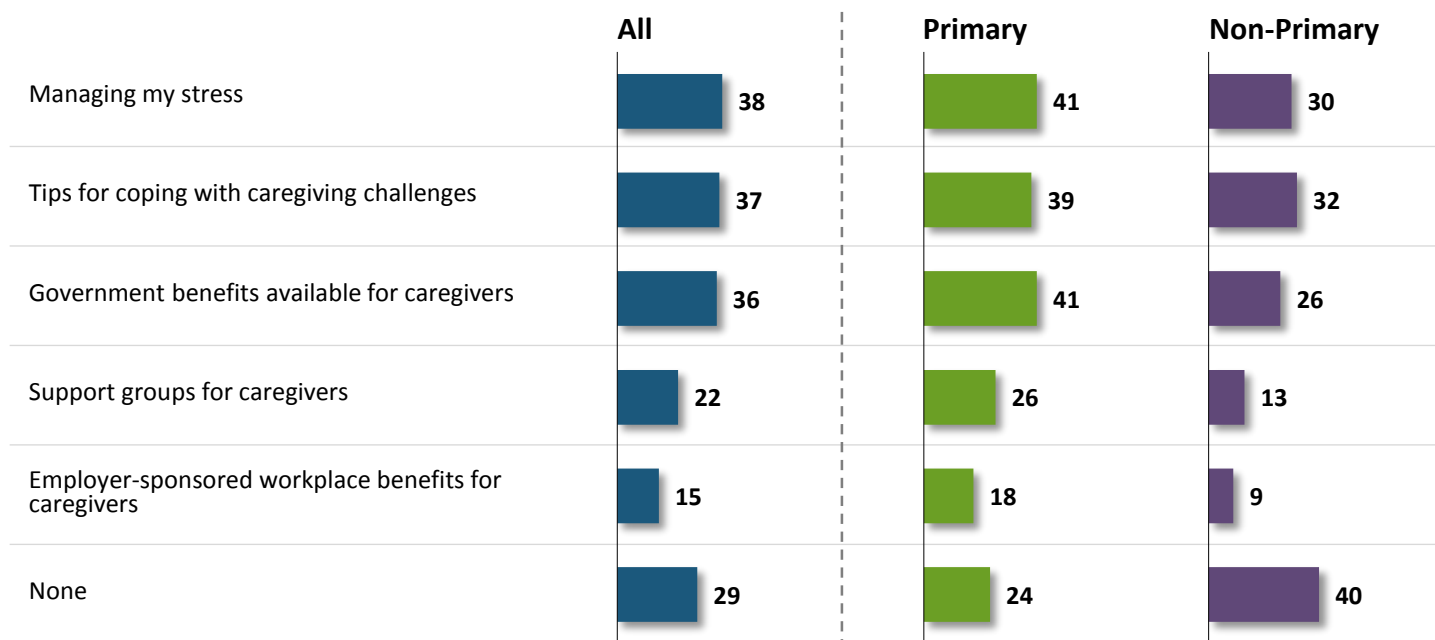
Please select all that apply.



# Caregivers Would Like More Information to Help Them Personally

In order to help them personally with their caregiving responsibilities, 71 percent of caregivers would like more information on one or more topics, including 76 percent of Primary and 60 percent of Non-Primary caregivers. More than one-third of caregivers would like information about stress management (38 percent), tips for coping with challenges (37 percent), and government benefits available for caregivers (37 percent). Primary caregivers are more likely than Non-Primary caregivers to want this information.

## Desired Topics of Information to Help Caregivers Personally with Their Caregiving Responsibilities (%)



NOTE: Five most commonly selected sources shown.

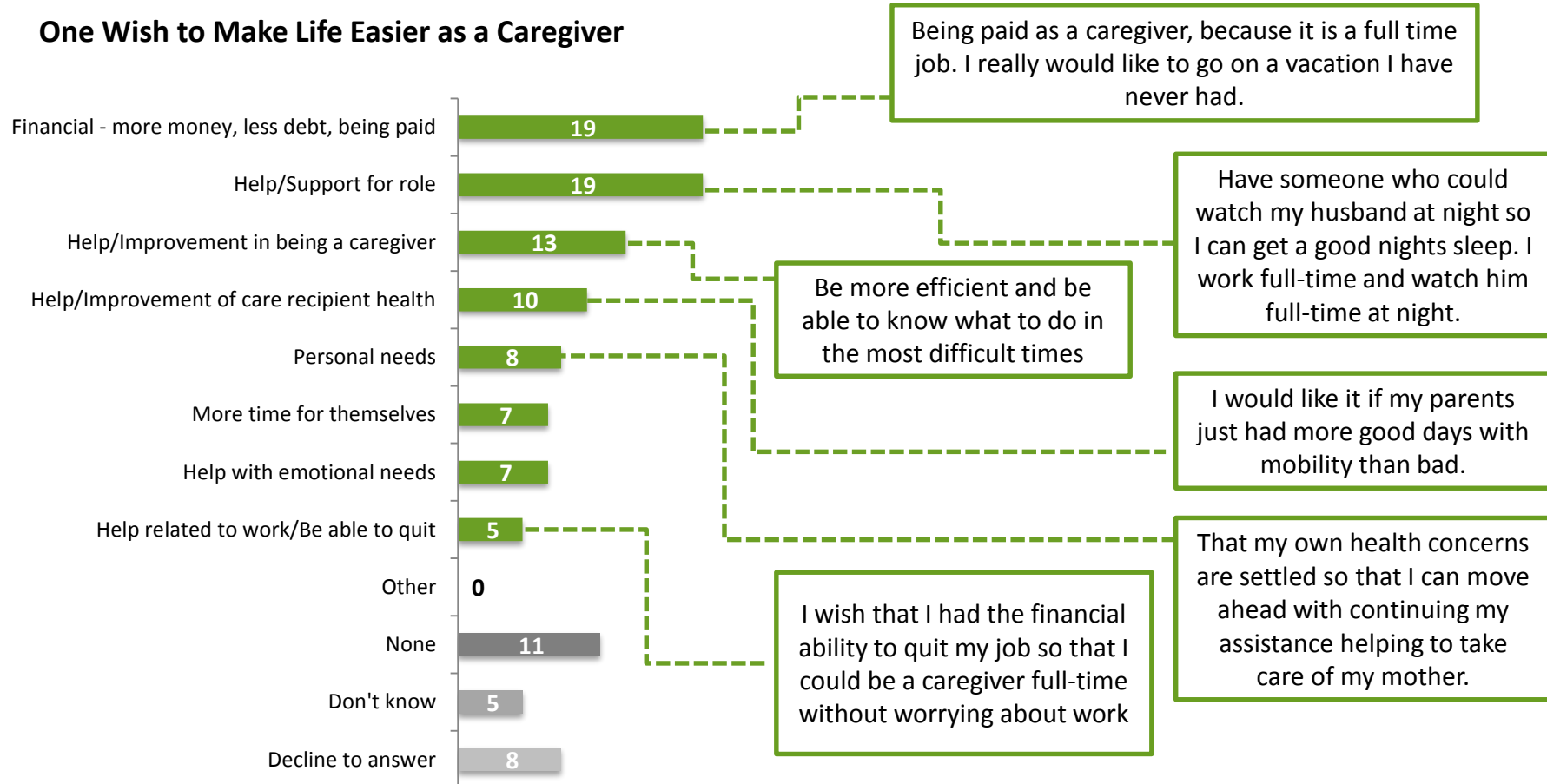
BASE: ALL QUALIFIED RESPONDENTS

Q850. Which of the following topics would you like more information to help you personally with your caregiving responsibilities? I would like more information about...

Please select all that apply

# Caregivers Wish for More Help and Monetary Support

In order to ease the demands of their caregiving role, caregivers often wish they could have more help and make adjustments to their personal lives and routines. Nineteen percent caregivers wish for increased financial support (i.e. more money, less debt, or payment) and additional help/support for their caregiver role.



# ***The Many Faces of Family Caregivers: A Close-Up Look at Caregiving and Its Implications***

## **A Portrait of Today's Caregivers**

### **➤ *Demographic Perspectives***

- Voluntary Status
- Employment Status
- Generations
- Gender
- Household Income
- Race/Ethnicity

## **Appendix: Caregiver and Care Recipient Demographics**

## **Acknowledgements**



## Demographic Perspectives by Voluntary Status

# ***The Many Faces of Family Caregivers: A Close-Up Look at Caregiving and Its Implications***

## **A Portrait of Today's Caregivers**

- Demographic Perspectives

### **➤ *Voluntary Status***

- Employment Status
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## **Acknowledgements**

# Demographic Perspectives of Caregivers By Voluntary Status

Most caregivers (84 percent) became so voluntarily, according to the survey's findings. However, 11 percent say they did not and 5 percent are "not sure." This chapter of the survey report compares the impact of caregiving responsibilities on caregivers based on whether they volunteered or not.

While caregiving is demanding for all caregivers, the survey finds that those who did not volunteer, in many regards, are having a more difficult time in coping with their caregiving responsibilities than those who volunteered. For example, caregivers who did not volunteer are more likely to indicate they are feeling overwhelmed by their caregiving duties and that their financial and general health has worsened as a result of becoming a caregiver. Among those who are employed, caregivers who did not volunteer are more likely to have experienced some form of adverse action taken by their employer.

## *Twenty-Six Facts About Caregivers Who Volunteered Compared to Those Who Did Not Volunteer*

- **Most Consider Themselves to Be the Primary Caregivers.** Sixty-nine percent of caregivers who volunteered to take on a caregiving role consider themselves to be the Primary caregiver of their care recipient. In contrast, only 63 percent of caregivers who did not volunteer identify themselves as the Primary caregiver.
- **The Majority of Caregivers Are Caring for a Family Member.** Approximately nine out of 10 of both caregivers who volunteered (88 percent) and caregivers who did not volunteer (88 percent) are caring for family members. Caregivers who volunteered (33 percent) and those who did not volunteer (34 percent) most frequently cite a parent as being the care recipient. More caregivers who volunteered (20 percent) are caring for a spouse/partner than those who did not volunteer (17 percent). More caregivers who did not volunteer (15 percent) are caring for a child than those who did volunteer (10 percent).
- **Reasons for Becoming a Caregiver.** Wanting to care for their loved one is the most frequently cited reason for becoming a caregiver for both those who volunteered (65 percent) those who didn't volunteer (53 percent). Having a close relationship with to the care recipient is the second most frequently cited reason among caregivers who volunteered (59 percent) and those who did not volunteer (49 percent). Of note, caregivers who volunteered are much more likely to say they did so because they have the time and capacity to do so (47 percent) compared to those who did not volunteer (25 percent).



# Demographic Perspectives of Caregivers By Voluntary Status

- **Total Caregiving Hours per Month.** Caregivers who volunteered spend much more time on caregiving at 60 hours per month (median) compared to caregivers who did not volunteer, at 45 hours per month (median). More caregivers who volunteered (36 percent) spend over 100 hours on caregiving per month, compared to caregivers who did not volunteer (32 percent).
- **Caregiver Duties Performed.** Caregiving encompasses a broad range of duties including household, social/communication, health-related, personal care, medical-related, and paying bills and managing finances. Caregivers who volunteered are generally more likely to perform all types of caregiving duties compared to those who did not volunteer.
  - For example, 70 percent of caregivers who volunteered conduct health-related duties, compared to 64 percent of caregivers who did not volunteer.
  - Similarly, more caregivers who volunteered (50 percent) engage in medical-related duties with the care recipient, compared to only 44 percent of caregivers who did not volunteer.
  - Caregivers who volunteered (63 percent) are more likely than those who did not volunteer (59 percent) to perform personal care duties.
- **Hours Spent Caregiving by Types of Duties.** Caregivers who volunteered and caregivers who did not volunteer spend comparable amounts of time on the various types of caregiving duties each month. Caregivers dedicate the most time per month providing companionship, including 32 hours by caregivers who volunteered (median) and 36 hours by caregivers who did not volunteer (median). Both caregivers who volunteered and caregivers who did not volunteer (each 20 hours median) spend the second most amount of time on meal preparation.
- **Sources of Information Relied on to Assist in Caregiving Duties.** Both caregivers who volunteered (46 percent) and caregivers who did not volunteer (39 percent) most frequently rely on family and friends as sources of information to assist in their caregiving duties. Medical professionals are the second most frequently cited source of information for caregivers who volunteered (45 percent) and those who did not volunteer (40 percent).
- **Sources for Learning About Medical/Nursing Tasks.** Among those currently performing medical-related tasks, more than half of caregivers who volunteered (55 percent) and caregivers who did not volunteer (52 percent) learned how to perform medical/nursing tasks from hospital or doctor's office personnel. Caregivers who volunteered (37 percent) are more likely to learn from family and friends, compared to caregivers who did not volunteer (25 percent).

# Demographic Perspectives of Caregivers By Voluntary Status

- **Caregivers' Sentiments About Their Caregiving Duties.** Caregivers who volunteered are more likely than those who did not volunteer to cite positive sentiments about their caregiving duties. For example, 93 percent of caregivers who volunteered agree that they like helping their care recipient compared to only 76 percent of caregivers who did not volunteer. On the other hand, caregivers who did not volunteer are more likely to cite negative effects of caregiving. For example, 72 percent of caregivers who did not volunteer feel that their caregiving duties leave them feeling physically exhausted, compared to 51 percent of volunteers.
- **Employment Status of Caregivers.** Caregivers who volunteered (51 percent) and those who did not volunteer (55 percent) are similarly likely to be employed either full-time or part-time. Forty percent of both caregivers who volunteered and those who did not volunteer are not employed. Nine percent of caregivers who volunteered and 5 percent who did not volunteer indicate they are self-employed.
- **Disruptions to Employment as a Result of Caregiving.** Caregiving responsibilities can be disruptive to a caregiver's employment situation. Among caregivers who are employed or who have been employed during their time as caregivers, some have had to reduce their hours or job responsibilities, take leave from their position, or retire early in order to accommodate their caregiving duties.
  - For example, approximately one-quarter of both caregivers who volunteered (29 percent) and caregivers who did not volunteer (30 percent) have used vacation, sick days, and/or personal days off to be a caregiver.
  - Twenty-one percent of caregivers who did not volunteer have either retired early or quit their job, compared to 14 percent of caregivers who volunteered.
- **Informing Coworkers About Their Caregiving Duties.** Among currently employed caregivers, caregivers who volunteered are more likely to tell people at work (i.e. their direct reports, management, and other coworkers) that they are a caregiver. For example, more caregivers who volunteered (58 percent) than caregivers who did not volunteer (50 percent) say that they informed their immediate supervisors about their caregiving role. On the other hand, 32 percent of caregivers who did not volunteer have not to have told anyone at work that they are a caregiver, compared to only 21 percent of caregivers who volunteered.
- **Employer Support of Caregiving Duties.** Among those who are employed, the majority of caregivers who volunteered (70 percent) and caregivers who did not volunteer (68 percent) believe that their employers are very or somewhat supportive of their caregiving responsibilities. In contrast, only 14 percent of caregivers who volunteered and 16 percent of caregivers who did not volunteer feel that their employers are either not too supportive or not supportive at all of their caregiving responsibilities.



# Demographic Perspectives of Caregivers By Voluntary Status

- **Adverse Actions Taken by Employers.** Caregiving duties may conflict with job responsibilities which, in turn, may lead to adverse actions taken by an employer. Among caregivers who are currently employed or who have been employed during their time as caregivers, caregivers who did not volunteer (37 percent) are more likely than those who volunteered (27 percent) to have experienced an adverse employment action such as being fired, written up or admonished, given less attractive assignments, passed over for a promotion, discriminated against, having hours or duties reduced, or other.
- **Caregivers' Financial Well-Being.** More than half of caregivers who volunteered (57 percent) and about half of caregivers who did not volunteer (48 percent) describe their financial well-being as excellent or good. Twenty-two percent of caregivers who did not volunteer say their financial well-being is poor compared to only 15 percent of caregivers who volunteered.
- **Financial Considerations Before Becoming Caregivers.** The majority of caregivers who volunteered (69 percent) and caregivers who did not volunteer (67 percent) gave little or no consideration to their own financial situation when deciding to become a caregiver.
- **Change in Financial Situation as a Result of Caregiving.** The majority of both caregivers who volunteered (67 percent) and caregivers who did not volunteer (55 percent) have not experienced any change in their financial situation as a result of becoming a caregiver. However, roughly one third of caregivers who did not volunteer (31 percent) say their financial situation has worsened, a finding which is significantly higher than the 17 percent of caregivers who volunteered.
- **Monthly Personal Expenditures for Caregiving.** Caregivers often find themselves paying out-of-pocket expenses for their care recipient (e.g., groceries, over-the-counter medications, gas, parking). Caregivers who volunteered (\$160 median) and caregivers who did not volunteer (\$150 median) report similar amounts of monthly out-of-pocket spending on expenditures for their care recipients.
- **Financial Assistance for Caregiving Duties.** While a large majority of all caregivers don't receive compensation for their caregiving duties, caregivers who did not volunteer (18 percent) are less likely to receive any form of compensation for their caregiving duties than caregivers who volunteered (27 percent).
- **Financial Priorities Among Caregivers.** Caregivers who volunteered (48 percent) and caregivers who did not volunteer (52 percent) most frequently cite paying off some form of debt (i.e. credit card, consumer, student, or mortgage debt) as a financial priority. Other frequently cited financial priorities include saving for retirement, paying for healthcare expenses, and supporting children. Alarming, more than two-fifths of caregivers who volunteered (42 percent) and half of those that did not volunteer (50 percent) identify "just getting by" as a current financial priority.

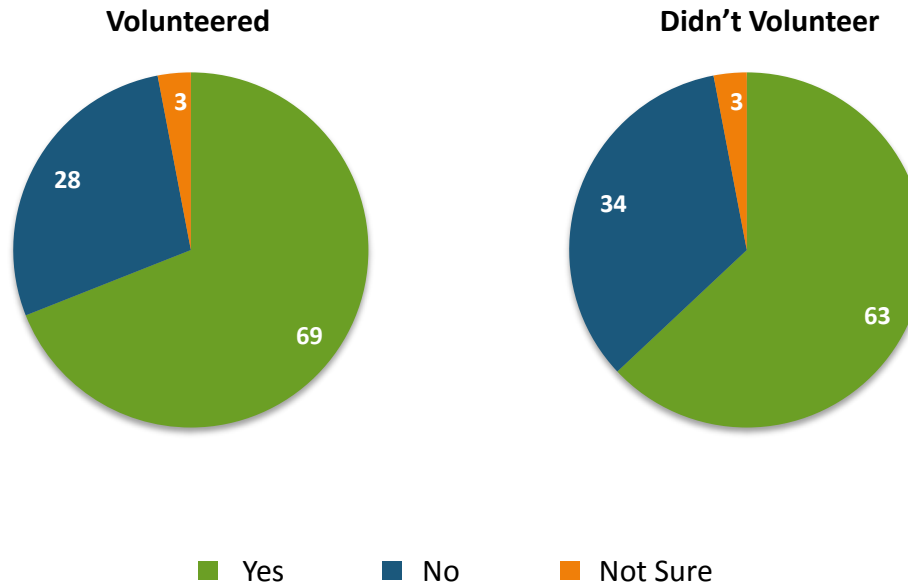
# Demographic Perspectives of Caregivers By Voluntary Status

- **Total Household Income Among Caregivers.** Both caregivers who volunteered and caregivers who did not volunteer report similar levels of annual household income. The estimated median HHI for caregivers who volunteered is \$58,000 and those who did not volunteer is \$54,000.
- **Total Household Retirement Savings Among Caregivers.** Caregivers who volunteered (\$75,000 estimated median) have more total household retirement savings compared to caregivers who did not volunteer (\$47,000 estimated median). More caregivers who volunteered report having \$100,000 or more in retirement savings (40 percent), compared to those who did not volunteer (31 percent). One in five caregivers who did not volunteer report having nothing in retirement savings, compared to 15 percent of those who did volunteer.
- **Caregivers' Self-Described General Health.** The majority of both caregivers who volunteered (76 percent) and caregivers who did not volunteer (70 percent) self-describe their general health as excellent or good. However, caregivers who volunteered are more likely to describe their general health as excellent (20 percent), compared to those who did not volunteer (12 percent).
- **Changes in General Health Since Becoming a Caregiver.** The majority of both caregivers who volunteered (66 percent) and caregivers who did not volunteer (57 percent) do not cite any change in their general health since taking on their role as a caregiver. However, caregivers who did not volunteer (30 percent) are more likely to indicate their health has declined since becoming a caregiver compared to caregivers who did volunteer (15 percent).
- **Caregivers' Health Insurance.** The vast majority of caregivers currently have health insurance, including 91 percent of caregivers who volunteered and 87 percent of those who did not volunteer. Both caregivers who volunteered (39 percent) and caregivers who did not volunteer (41 percent) most commonly receive health insurance through an employer. Of note, more caregivers who did not volunteer (13 percent) do not have health insurance, compared to caregivers who volunteered (9 percent).
- **Caregivers Would Like More Information to Help Them Personally.** Information on managing stress is the most frequently cited topic that caregivers would like more information about in order to help them personally with their caregiving duties. Caregivers who did not volunteer (46 percent) are more likely to want information about managing stress than caregivers who volunteered (36 percent). Other desired topics of information among both caregivers who volunteered and those who did not include tips on coping with caregiving challenges and government benefits available for caregivers. Some would like information about support groups for caregivers and employer-sponsored workplace benefits for caregivers.

# Most Consider Themselves to Be the Primary Caregivers

Sixty-nine percent of caregivers who volunteered to take on a caregiving role consider themselves to be the Primary caregiver of their care recipient. In contrast, only 63 percent of caregivers who did not volunteer identify themselves as the Primary caregiver.

**“Would you consider yourself to be the Primary caregiver?” (%)**

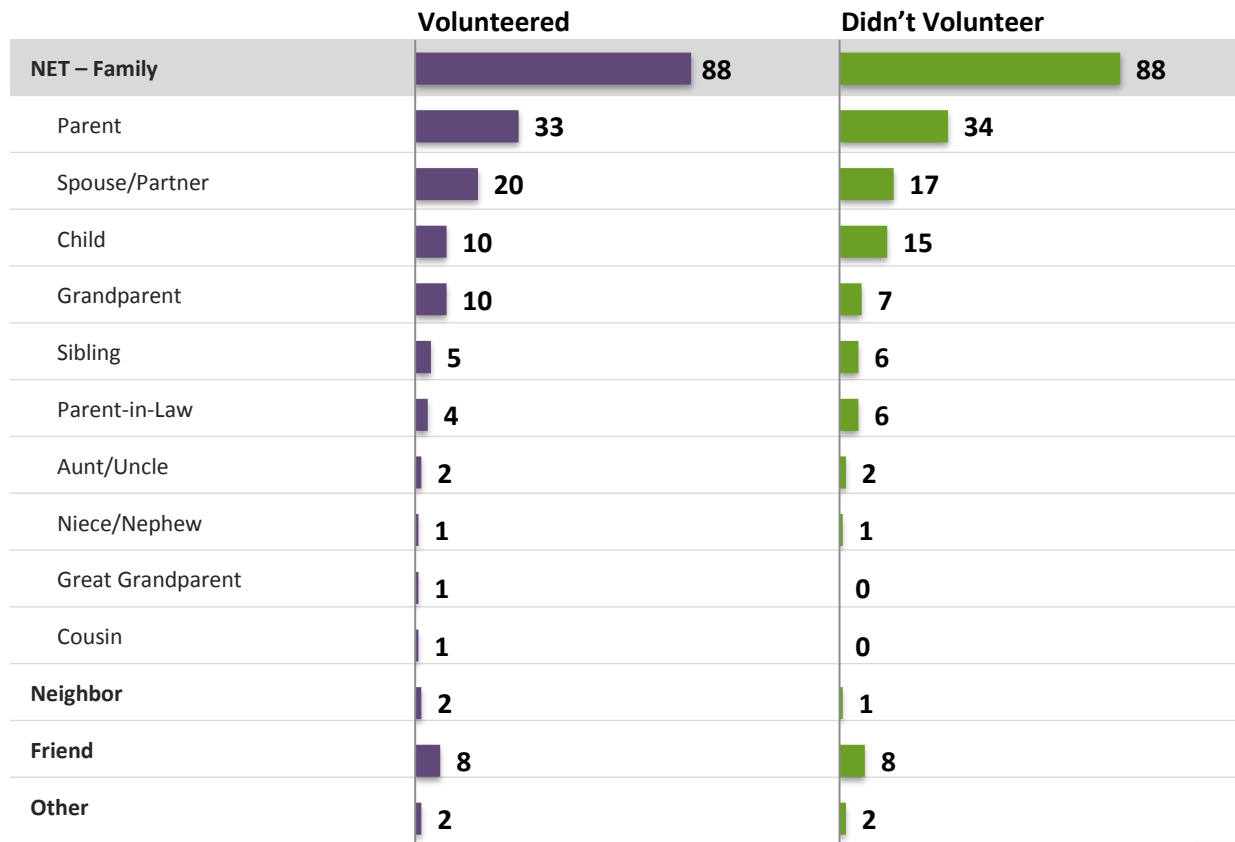


■ Yes    ■ No    ■ Not Sure

# The Majority of Caregivers Are Caring for a Family Member

Approximately nine out of 10 of both caregivers who volunteered (88 percent) and caregivers who did not volunteer (88 percent) are caring for family members. Caregivers who volunteered (33 percent) and those who did not volunteer (34 percent) most frequently cite a parent as being the care recipient. More caregivers who volunteered (20 percent) are caring for a spouse/partner than those who did not volunteer (17 percent). More caregivers who did not volunteer (15 percent) are caring for a child than those who did volunteer (10 percent).

**Relationship to Care Recipient (%)**



BASE: ALL QUALIFIED RESPONDENTS

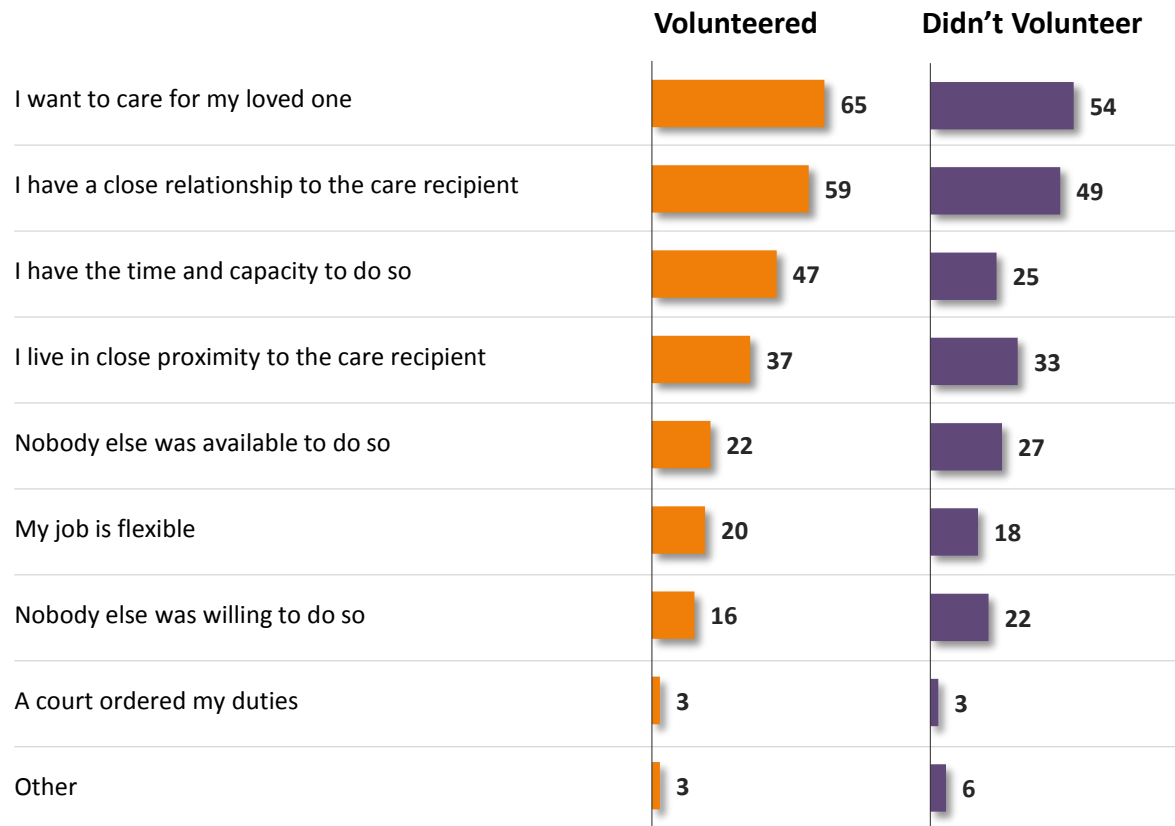
Q700. You mentioned providing care for [INSERT ANSWER FROM Q610] individual(s).

Please let us know your relationship to the person, their age, and their gender.

# Reasons for Becoming a Caregiver

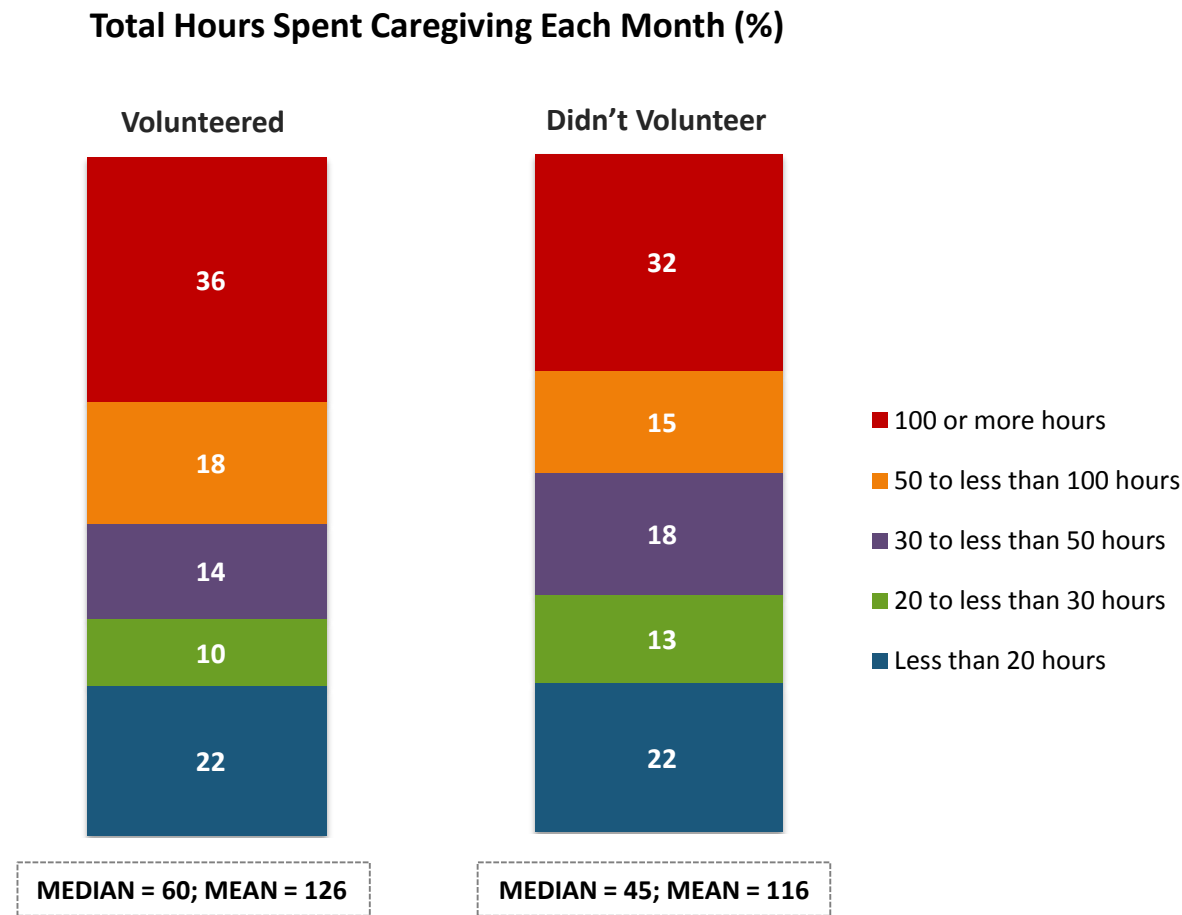
Wanting to care for their loved one is the most frequently cited reason for becoming a caregiver for both those who volunteered (65 percent) those who didn't volunteer (53 percent). Having a close relationship to the care recipient is the second most frequently cited reason among caregivers who volunteered (59 percent) and those who did not volunteer (49 percent). Of note, caregivers who volunteered are much more likely to say they did so because they have the time and capacity to do so (47 percent) compared to those who did not volunteer (25 percent).

**Reasons for Becoming a Caregiver (%)**



# Total Caregiving Hours per Month

Caregivers who volunteered spend much more time on caregiving at 60 hours per month (median) compared to caregivers who did not volunteer, at 45 hours per month (median). More caregivers who volunteered (36 percent) spend over 100 hours on caregiving per month, compared to caregivers who did not volunteer (32 percent).



*Note: The median is the midpoint of the range of each response category. The mean is the average of all responses.*

BASE: ALL QUALIFIED RESPONDENTS

Q832. In total, approximately how many hours per month do you spend caring for the care recipient?

# Caregiver Duties Performed

Caregiving encompasses a broad range of duties including household, social/communication, health-related, personal care, medical-related, and paying bills and managing finances.

Caregivers who volunteered are generally more likely to perform all types of caregiving duties compared to those who did not volunteer.

For example, 70 percent of caregivers who volunteered conduct health-related duties, compared to 64 percent of caregivers who did not volunteer.

Similarly, more caregivers who volunteered (50 percent) engage in medical-related duties with the care recipient, compared to only 44 percent of caregivers who did not volunteer.

Caregivers who volunteered (63 percent) are more likely than those who did not volunteer (59 percent) to perform personal care duties.

Types of Caregiving Duties Performed	Volunteered	Didn't Volunteer
<b>NET – Household</b>	<b>89%</b>	<b>88%</b>
Running errands	68%	68%
Housework	61%	54%
Meal preparation	59%	57%
Home repairs	30%	30%
Home modifications	19%	20%
<b>NET – Social/Communication</b>	<b>72%</b>	<b>71%</b>
Companionship	61%	59%
Basic communications	31%	29%
Language translation	7%	9%
<b>NET – Health-Related</b>	<b>70%</b>	<b>64%</b>
Accompanying to medical appointments	62%	56%
Healthcare coordination	43%	50%
Health insurance coordination	29%	31%
<b>NET – Personal Care</b>	<b>63%</b>	<b>59%</b>
Mobility	39%	39%
Personal care	36%	32%
Feeding	28%	22%
Incontinence care	15%	18%
<b>NET – Medical-Related</b>	<b>50%</b>	<b>44%</b>
Medication management	46%	40%
Medical treatment administration	16%	15%
<b>Paying bills/Managing finances</b>	<b>42%</b>	<b>47%</b>
<b>Other</b>	<b>4%</b>	<b>6%</b>

# Hours Spent Caregiving by Types of Duties

Caregivers who volunteered and caregivers who did not volunteer spend comparable amounts of time on the various types of caregiving duties each month.

Caregivers dedicate the most time per month providing companionship, including 32 hours by caregivers who volunteered (median) and 36 hours by caregivers who did not volunteer (median).

Both caregivers who volunteered and caregivers who did not volunteer (each 20 hours median) spend the second most amount of time on meal preparation.

*Note: The median is the midpoint of the range of each response category. The mean is the average of all responses.*

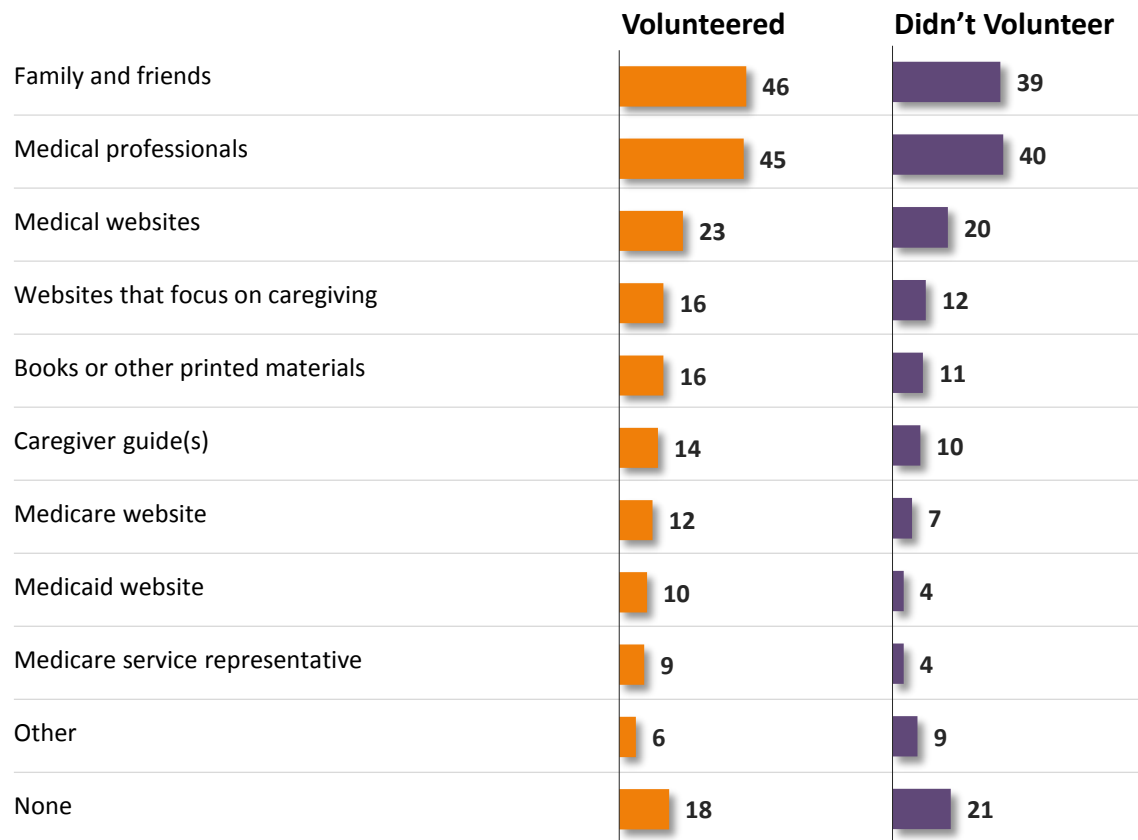
Time Spent On Caregiving Duties Each Month (hours per month)	Volunteered		Didn't Volunteer	
	Median	Mean	Median	Mean
<b>Household</b>				
Running errands	8	18	8	21
Housework (e.g., cleaning, laundry)	10	28	10	27
Meal preparation	20	32	20	30
Home repairs	3	10	4	8
Home modifications	2	8	3	11
<b>Social/Communication</b>				
Companionship	32	90	36	94
Basic communications	10	45	10	51
Language translation	5	16	5	7
<b>Health-Related</b>				
Accompanying to medical appointments	5	11	4	11
Healthcare coordination	3	10	2	7
Health insurance coordination	2	9	2	8
<b>Personal Care</b>				
Mobility	10	24	10	24
Personal care	12	26	12	20
Feeding	12	34	15	25
Incontinence care	6	23	8	18
<b>Medical Related</b>				
Medication management	5	17	5	20
Medical treatment administration	5	18	4	18
<b>Paying bills/Managing finances</b>	<b>3</b>	<b>9</b>	<b>4</b>	<b>12</b>
<b>Other</b>	<b>6</b>	<b>71</b>	<b>5</b>	<b>31</b>



# Sources of Information Relied on to Assist in Caregiving Duties

Both caregivers who volunteered (46 percent) and caregivers who did not volunteer (39 percent) most frequently rely on family and friends as sources of information to assist in their caregiving duties. Medical professionals are the second most frequently cited source of information for caregivers who volunteered (45 percent) and those who did not volunteer (40 percent).

**Sources of Information to Assist in Caregiving Duties (%)**



NOTE: Nine most commonly selected sources shown.

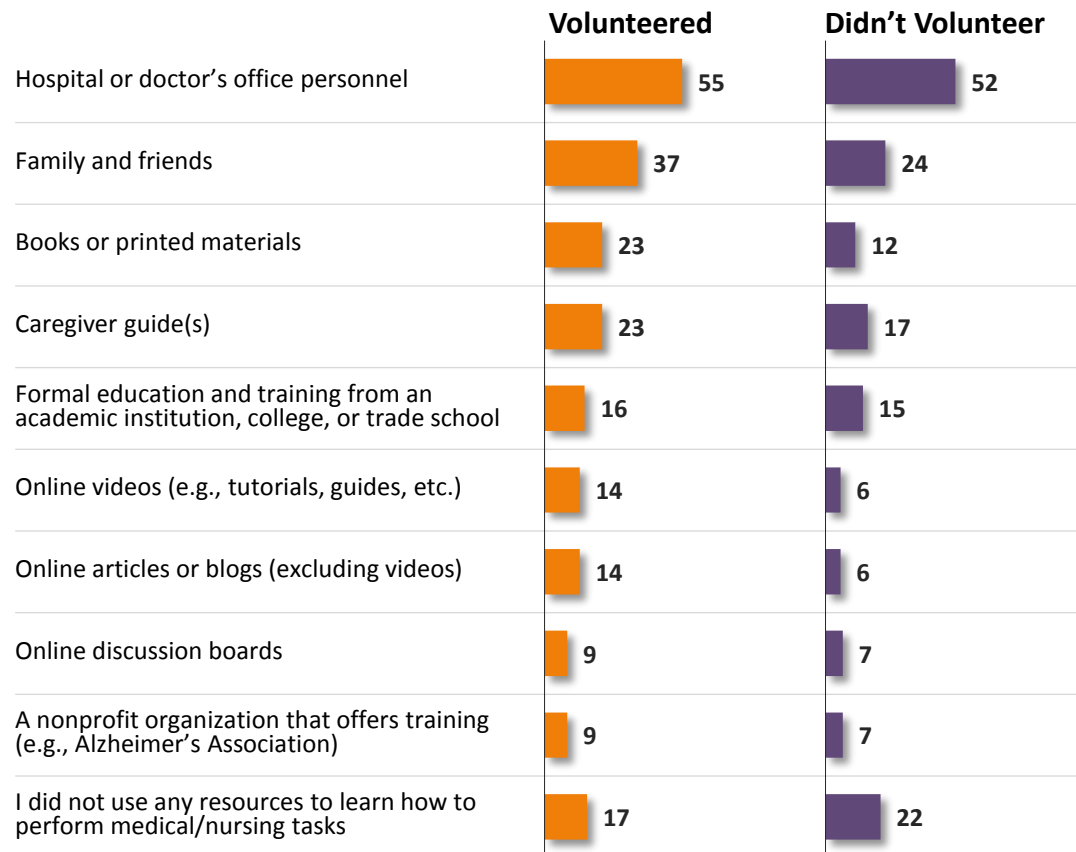
BASE: ALL QUALIFIED RESPONDENTS

Q840. Which of the following do you rely on as sources of information to assist in your caregiving duties? Select all.

# Sources for Learning About Medical/Nursing Tasks

Among those currently performing medical-related tasks, more than half of caregivers who volunteered (55 percent) and caregivers who did not volunteer (52 percent) learned how to perform medical/nursing tasks from hospital or doctor's office personnel. Caregivers who volunteered (37 percent) are more likely to learn from family and friends, compared to caregivers who did not volunteer (25 percent).

**Sources for Learning Medical/Nursing Tasks Related to Being a Caregiver (%)**



*NOTE: Nine most commonly selected sources shown.*  
**BASE: IF ADMINISTERING MEDICATIONS AND MEDICAL TREATMENTS**

Q835. You mentioned you perform medication management or medical treatment administration for the care recipient. Where did you learn how to perform medical/nursing tasks related to being a caregiver? Select all.

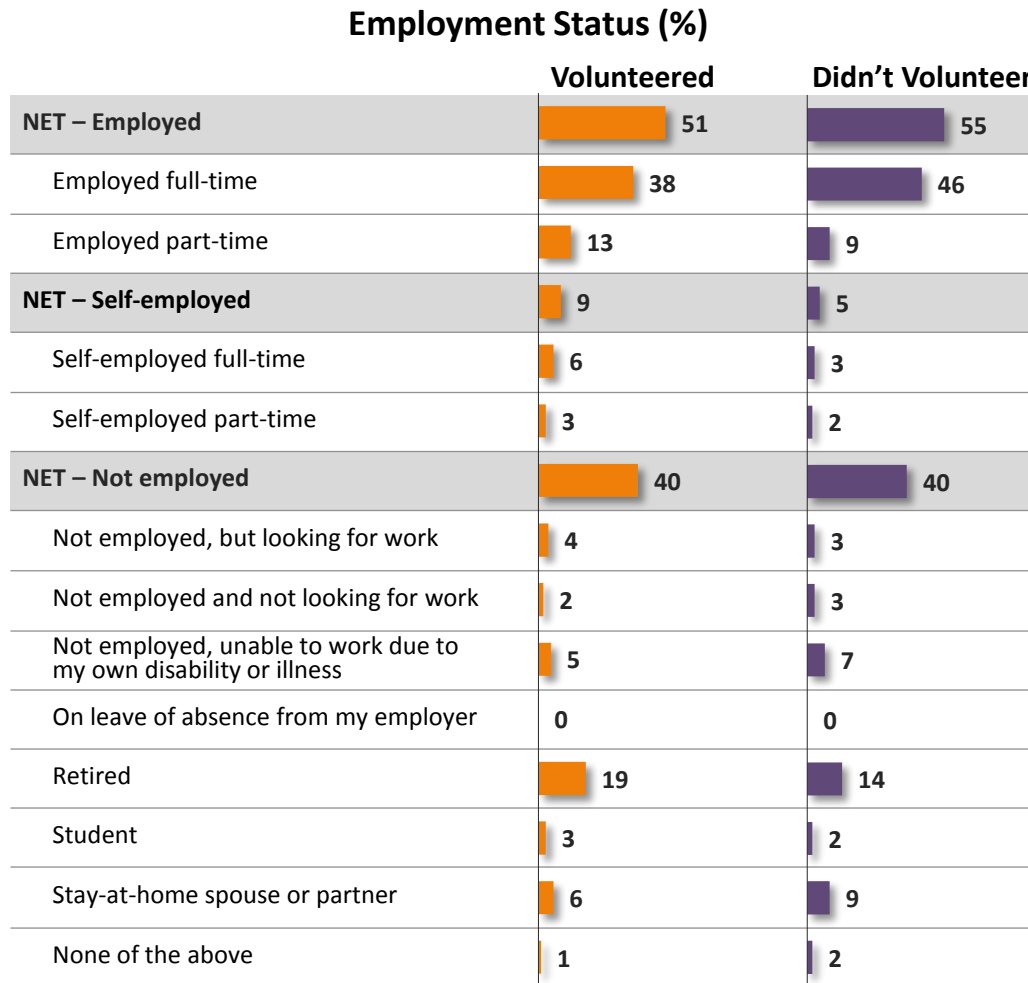
# Caregivers' Sentiments About Their Caregiving Duties

Caregivers who volunteered are more likely than those who did not volunteer to cite positive sentiments about their caregiving duties. For example, 93 percent of caregivers who volunteered agree that they like helping their care recipient compared to only 76 percent of caregivers who did not volunteer. On the other hand, caregivers who did not volunteer are more likely to cite negative effects of caregiving. For example, 72 percent of caregivers who did not volunteer feel that their caregiving duties leave them feeling physically exhausted, compared to 51 percent of volunteers.

Caregivers’ Sentiments About Their Caregiving Duties	Volunteered	Didn’t Volunteer
	Strongly/Somewhat Agree (NET)	
Positive		
It’s important for me to provide a good quality of life for the care recipient	95%	90%
I like helping the care recipient	93%	76%
I enjoy spending time with the care recipient	93%	75%
Being a caregiver gives me a strong sense of purpose	86%	63%
Being a caregiver has led me to take better care of my own health	73%	55%
Being a caregiver has inspired me to document my own health and legal wishes	68%	61%
Negative		
My own health takes a backseat to the health of my care recipient	53%	66%
My caregiving duties leave me feeling physically exhausted	52%	72%
My caregiving duties leave me feeling emotionally exhausted	51%	70%
I need more help with my caregiving duties	46%	61%
With all of my caregiving duties, I barely have time for anything else	43%	64%
My caregiving duties leave me feeling completely overwhelmed	40%	64%

# Employment Status of Caregivers

Caregivers who volunteered (51 percent) and those who did not volunteer (55 percent) are similarly likely to be employed either full-time or part-time. Forty percent of both caregivers who volunteered and those who did not volunteer are not employed. Nine percent of caregivers who volunteered and 5 percent who did not volunteer indicate they are self-employed.



# Disruptions to Employment as a Result of Caregiving

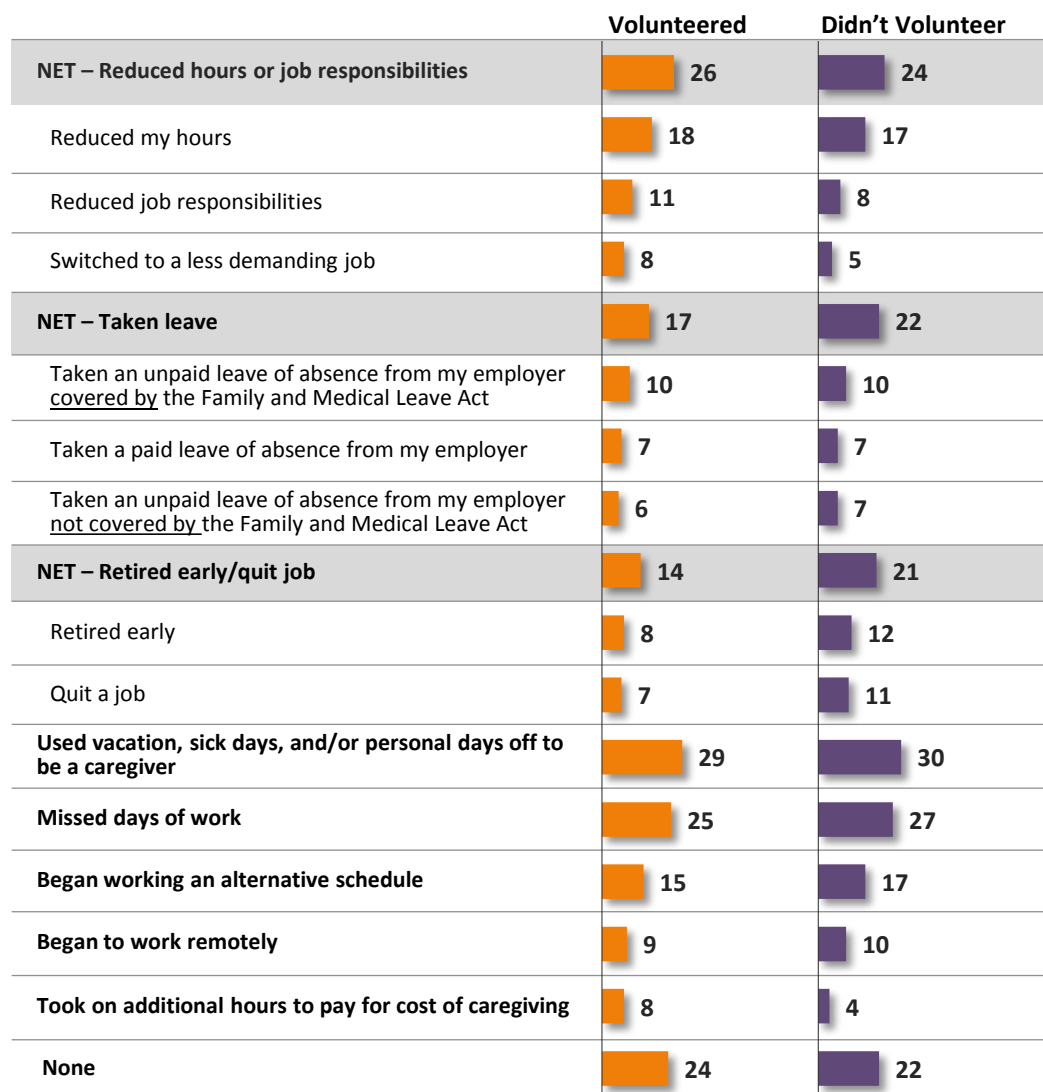
Caregiving responsibilities can be disruptive to a caregiver's employment situation.

Among caregivers who are employed or who have been employed during their time as caregivers, some have had to reduce their hours or job responsibilities, take leave from their position, or retire early in order to accommodate their caregiving duties.

For example, approximately one-quarter of both caregivers who volunteered (29 percent) and caregivers who did not volunteer (30 percent) have used vacation, sick days, and/or personal days off to be a caregiver.

Twenty-one percent of caregivers who did not volunteer have either retired early or quit their job, compared to 14 percent of caregivers who volunteered.

**“Which of the following have you done as a result of becoming a caregiver?” (%)**



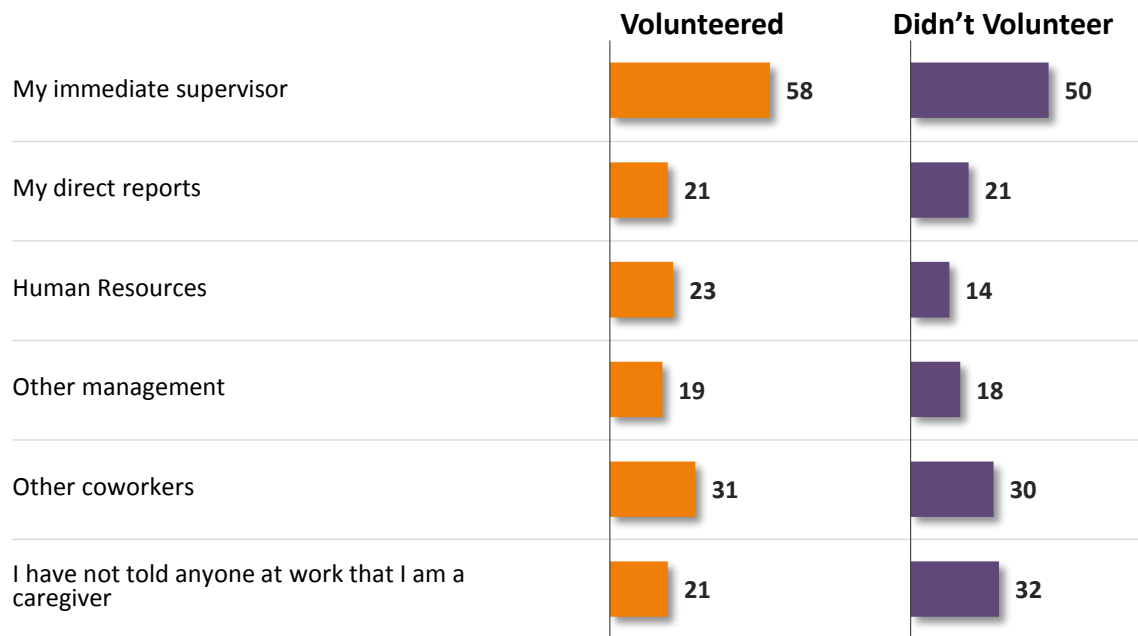
NOTE: Thirteen most commonly selected sources shown.

BASE: ALL EMPLOYED OR HAVE BEEN EMPLOYED DURING THEIR TIME AS A CAREGIVER  
Q1025. Which of the following have you done as a result of becoming a caregiver? Select all.

# Informing Coworkers About Their Caregiving Duties

Among currently employed caregivers, caregivers who volunteered are more likely to tell people at work (i.e. their direct reports, management, and other coworkers) that they are a caregiver. For example, more caregivers who volunteered (58 percent) than caregivers who did not volunteer (50 percent) say that they informed their immediate supervisors about their caregiving role. On the other hand, 32 percent of caregivers who did not volunteer have not told anyone at work that they are a caregiver, compared to only 21 percent of caregivers who volunteered.

## “Which of the following people at work have you told that you are a caregiver?” (%)



NOTE: Self-employed and not employed were excluded from this question.

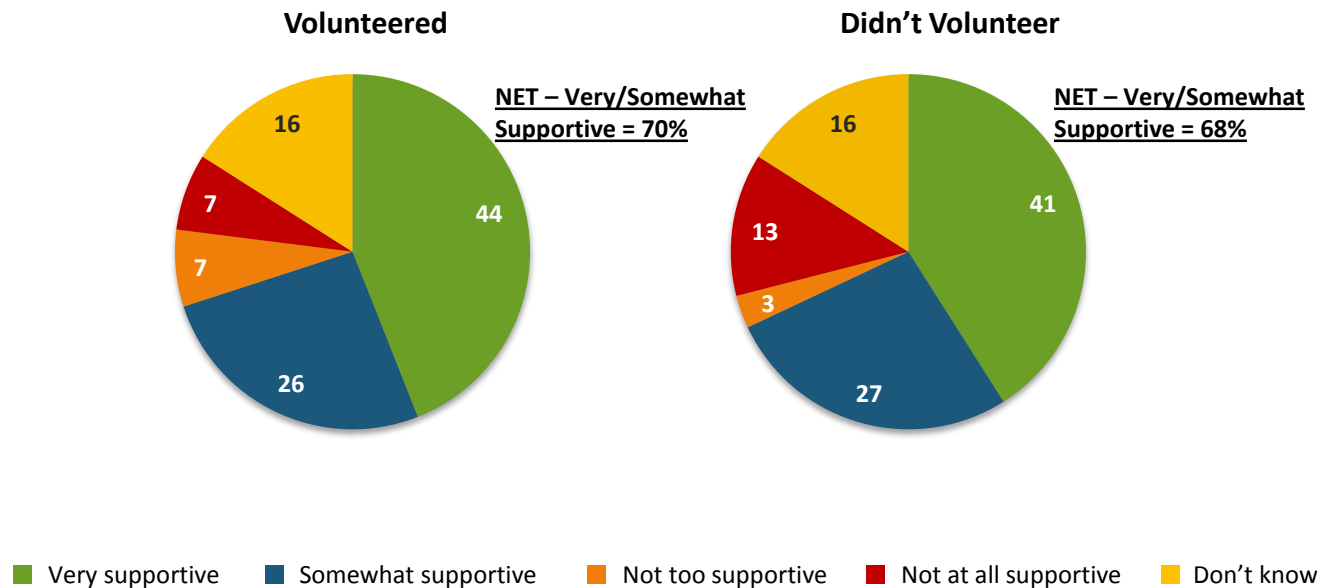
BASE: EMPLOYED FULL-TIME OR PART-TIME

Q1035. Which of the following people at work have you told that you are a caregiver? Select all.

# Employer Support of Caregiving Duties

Among those who are employed, the majority of caregivers who volunteered (70 percent) and caregivers who did not volunteer (68 percent) believe that their employers are very or somewhat supportive of their caregiving responsibilities. In contrast, only 14 percent of caregivers who volunteered and 16 percent of caregivers who did not volunteer feel that their employers are either not too supportive or not supportive at all of their caregiving responsibilities.

**“How supportive is your employer of your caregiving responsibilities?” (%)**



NOTE: Self-employed and not employed were excluded from this question.

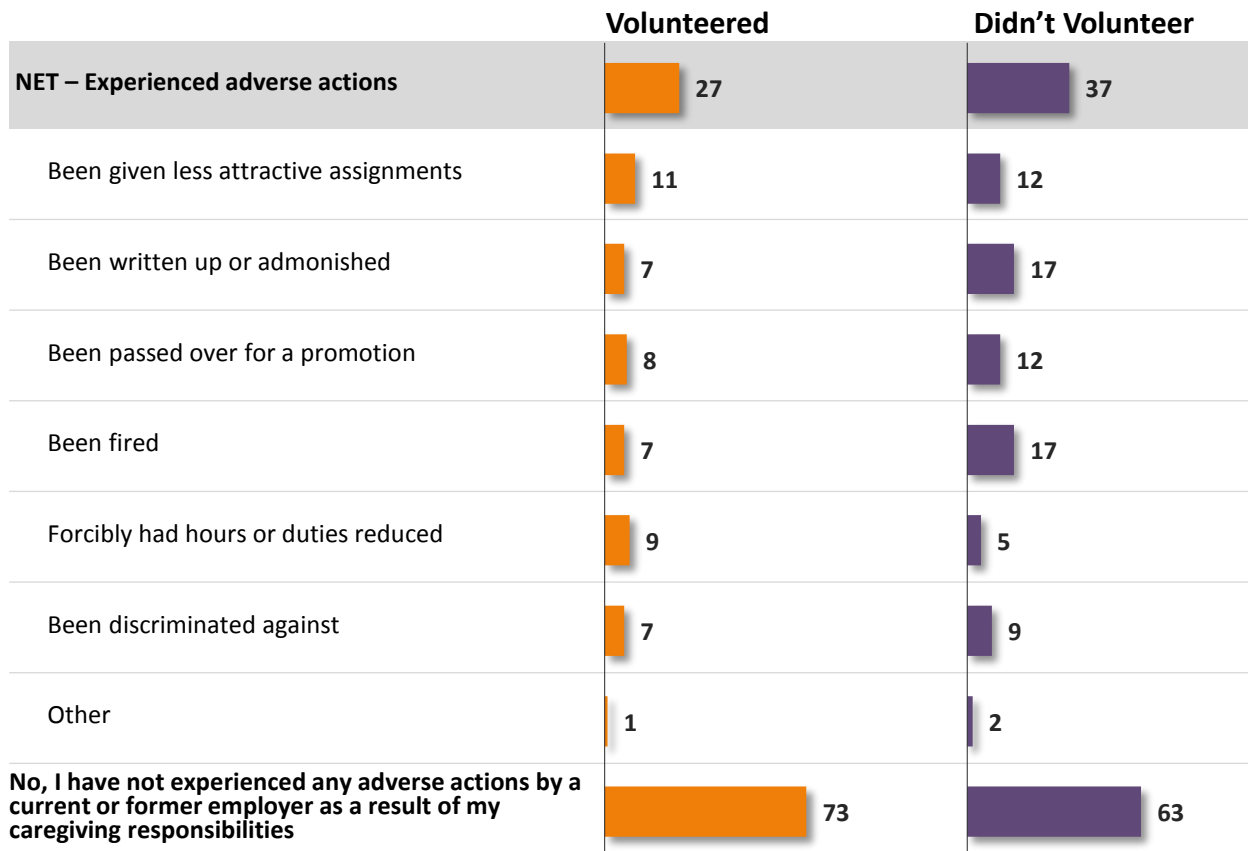
BASE: EMPLOYED FULL-TIME OR PART-TIME

Q1045. How supportive is your employer of your caregiving responsibilities?

# Adverse Actions Taken by Employers

Caregiving duties may conflict with job responsibilities which, in turn, may lead to adverse actions taken by an employer. Among caregivers who are currently employed or who have been employed during their time as caregivers, caregivers who did not volunteer (37 percent) are more likely than those who volunteered (27 percent) to have experienced an adverse employment action such as being fired, written up or admonished, given less attractive assignments, passed over for a promotion, discriminated against, having hours or duties reduced, or other.

## Adverse Employment Actions Experienced as a Result of Caregiving Duties (%)

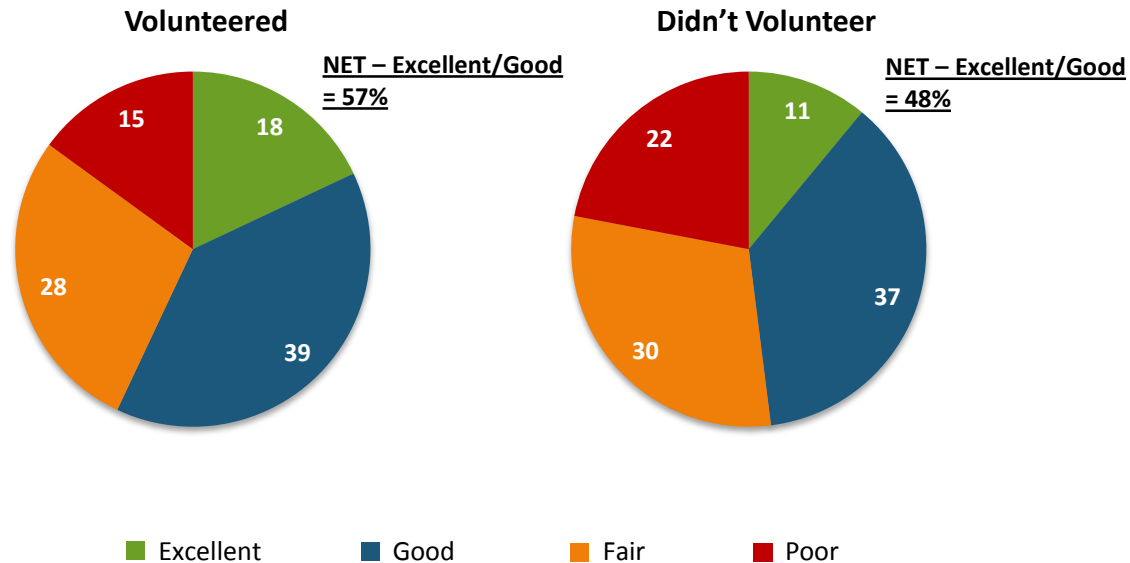




# Caregivers' Financial Well-Being

More than half of caregivers who volunteered (57 percent) and about half of caregivers who did not volunteer (48 percent) describe their financial well-being as excellent or good. Twenty-two percent of caregivers who did not volunteer say their financial well-being is poor compared to only 15 percent of caregivers who volunteered.

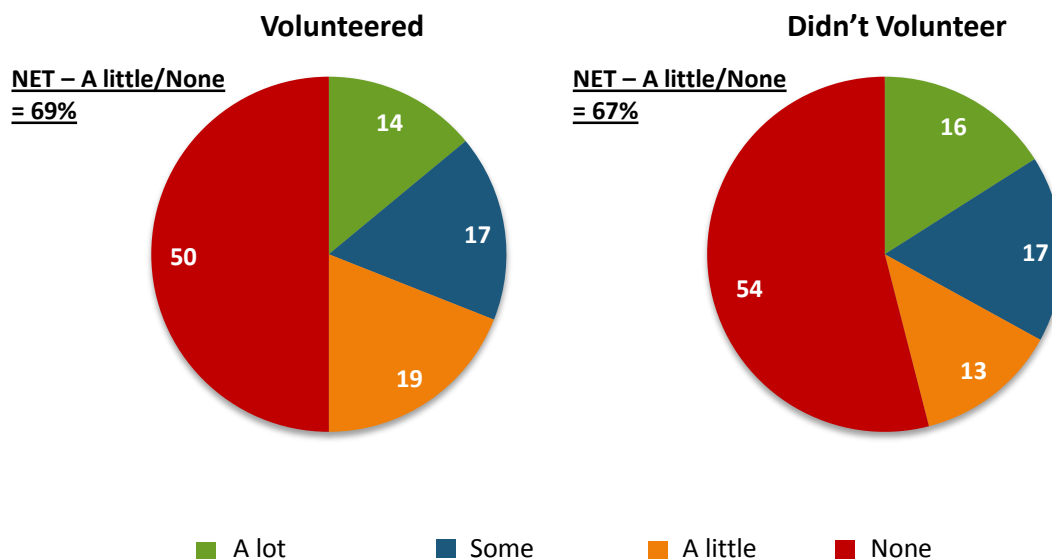
**“How would you describe your own financial well-being?” (%)**



# Financial Considerations Before Becoming Caregivers

The majority of caregivers who volunteered (69 percent) and caregivers who did not volunteer (67 percent) gave little or no consideration to their own financial situation when deciding to become a caregiver.

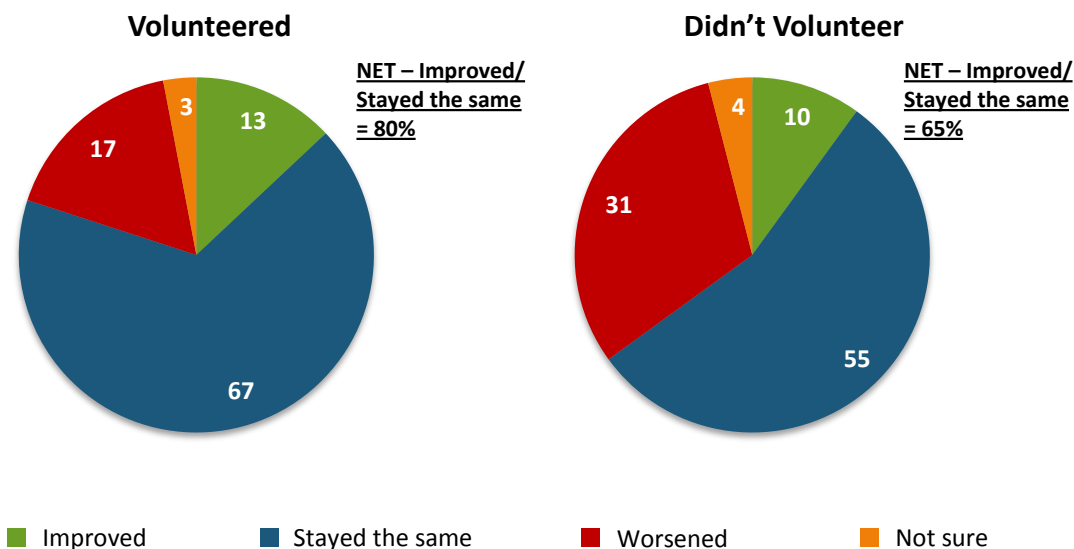
**“To what extent did you consider your own financial situation when deciding to become a caregiver?” (%)**



# Change in Financial Situation as a Result of Caregiving

The majority of both caregivers who volunteered (67 percent) and caregivers who did not volunteer (55 percent) have not experienced any change in their financial situation as a result of becoming a caregiver. However, roughly one third of caregivers who did not volunteer (31 percent) say their financial situation has worsened, a finding which is significantly higher than the 17 percent of caregivers who volunteered.

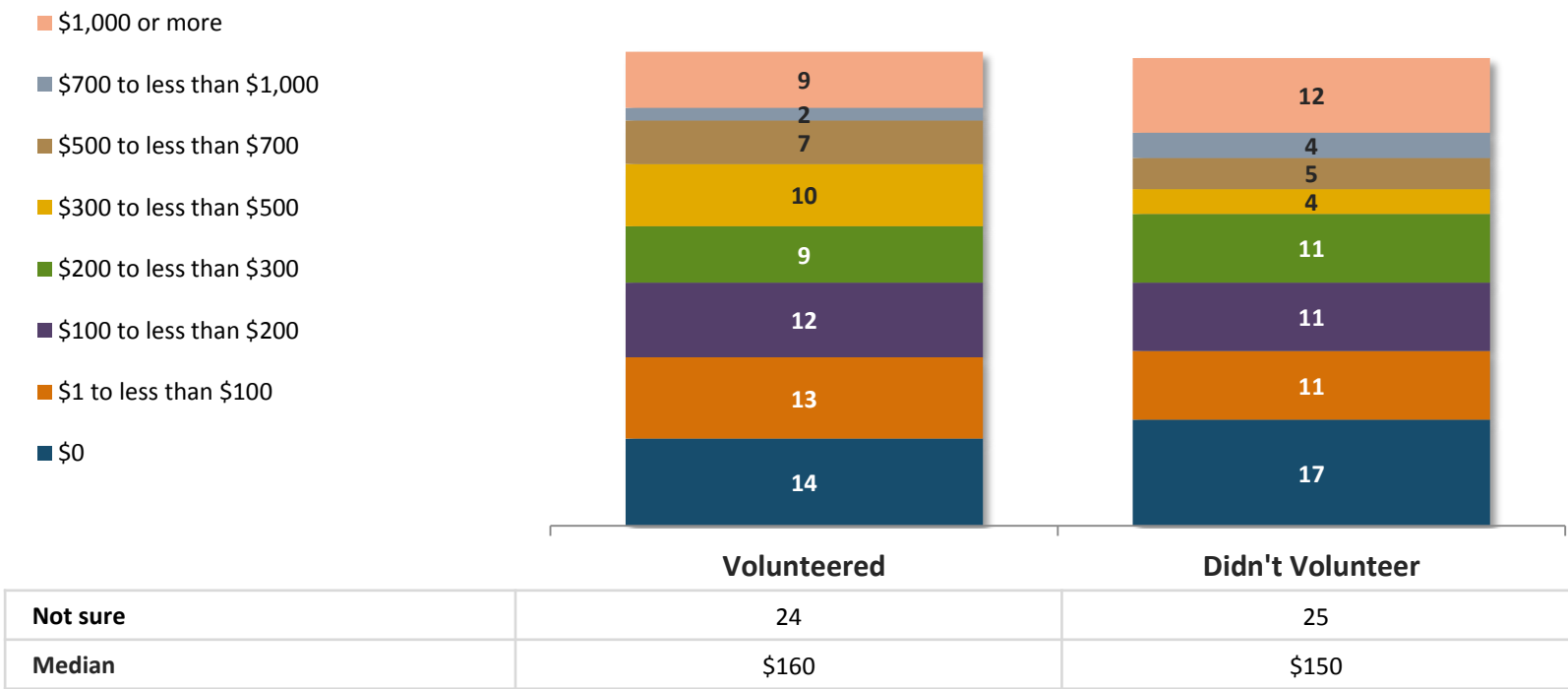
**“How has your financial situation changed as a result of becoming a caregiver?”**



# Monthly Personal Expenditures for Caregiving

Caregivers often find themselves paying out-of-pocket expenses for their care recipient (e.g., groceries, over-the-counter medications, gas, parking). Caregivers who volunteered (\$160 median) and caregivers who did not volunteer (\$150 median) report similar amounts of monthly out-of-pocket spending on expenditures for their care recipients.

Monthly Personal Expenditures to Cover Expenses for Care Recipient (%)



Note: The median is the midpoint of the range of each response category. Non-responses are excluded from the estimate.

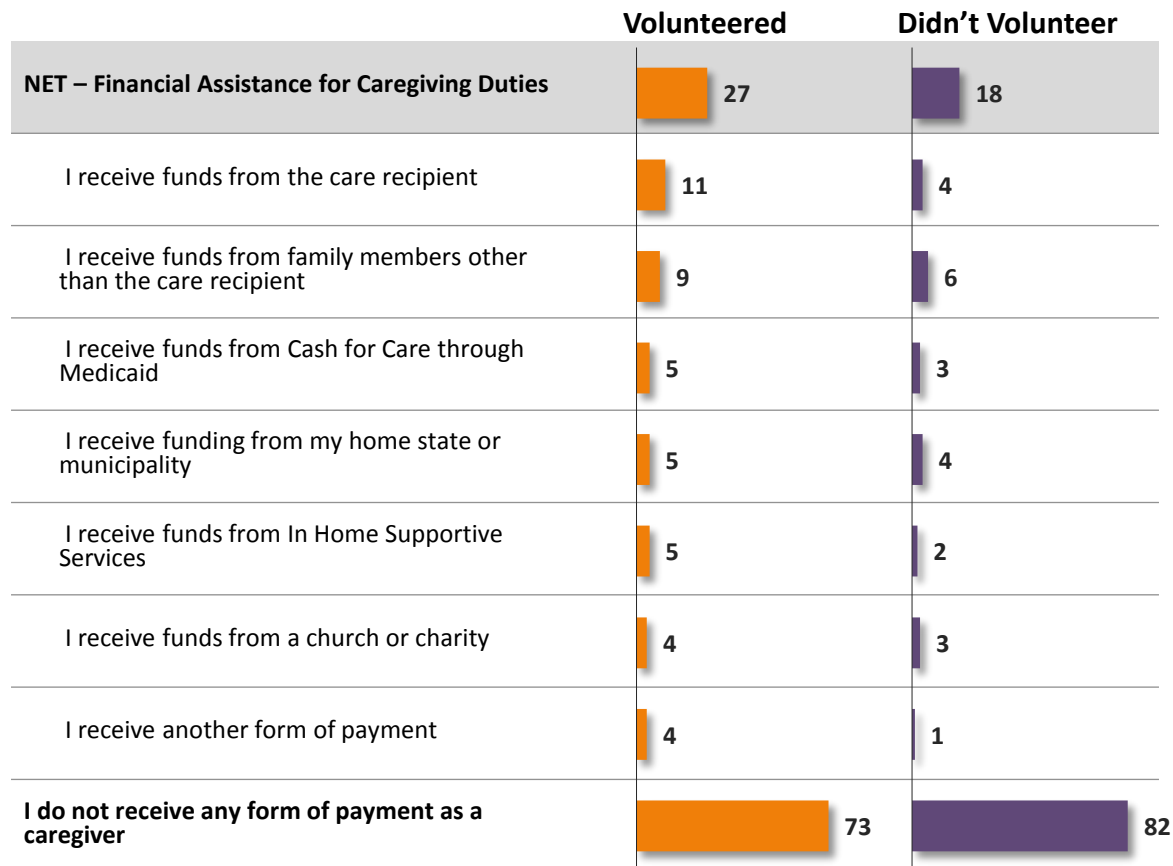
BASE: ALL QUALIFIED RESPONDENTS

Q1120. On average, approximately how much money do you spend each month paying out-of-pocket to cover expenses for the care recipient (e.g. for groceries, over-the-counter medications, gas, parking)?

# Financial Assistance for Caregiving Duties

While a large majority of all caregivers don't receive compensation for their caregiving duties, caregivers who did not volunteer (18 percent) are less likely to receive any form of compensation for their caregiving duties than caregivers who volunteered (27 percent).

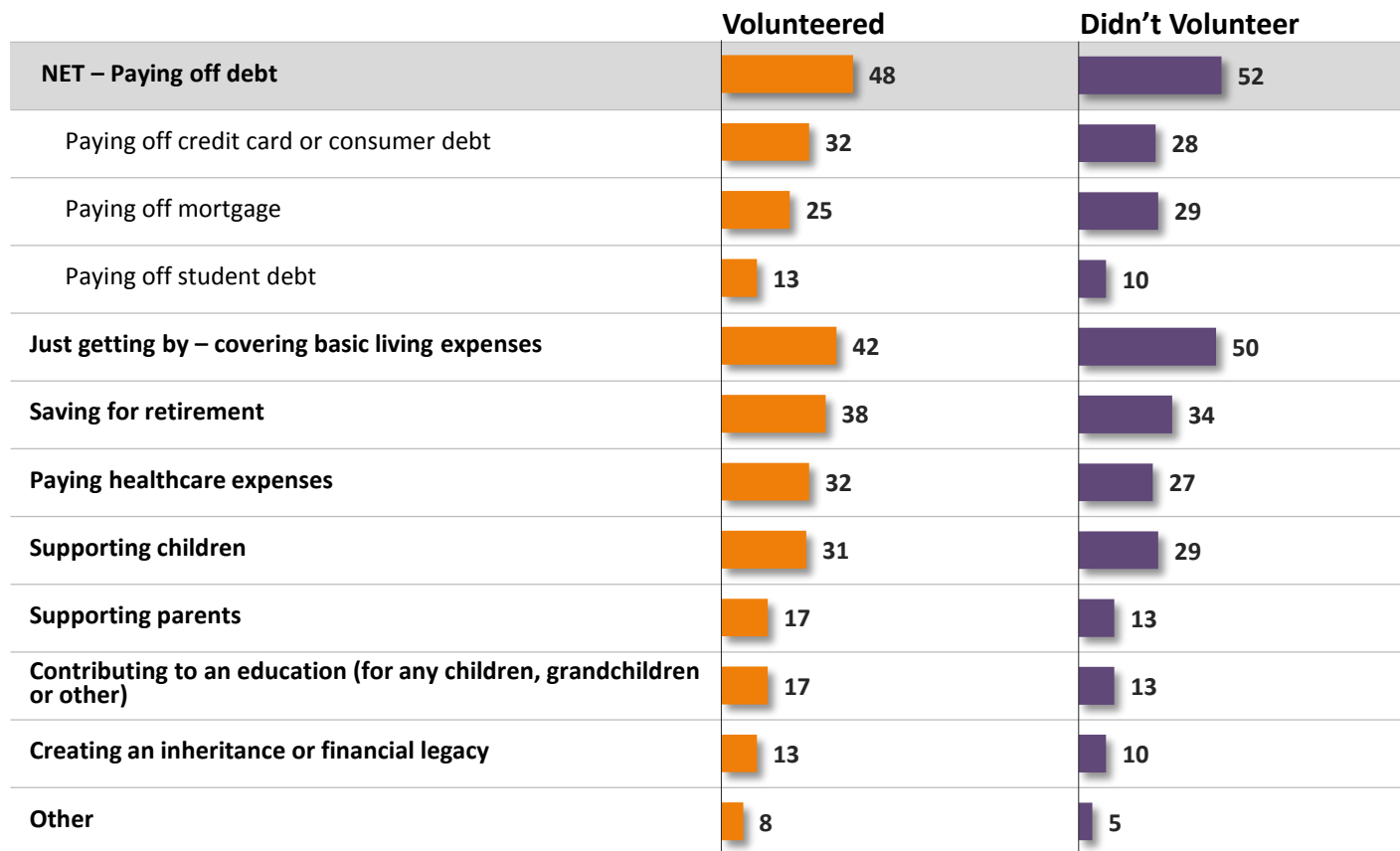
**Sources of Financial Assistance Received for Caregiving Duties, If Any (%)**



# Financial Priorities Among Caregivers

Caregivers who volunteered (48 percent) and caregivers who did not volunteer (52 percent) most frequently cite paying off some form of debt (i.e. credit card, consumer, student, or mortgage debt) as a financial priority. Other frequently cited financial priorities include saving for retirement, paying for healthcare expenses, and supporting children. Alarming, more than two-fifths of caregivers who volunteered (42 percent) and half of those that did not volunteer (50 percent) identify “just getting by” as a current financial priority.

**“Which of the following are your financial priorities right now?” (%)**



# Total Household Income Among Caregivers

Both caregivers who volunteered and caregivers who did not volunteer report similar levels of annual household income. The estimated median HHI for caregivers who volunteered is \$58,000 and those who did not volunteer is \$54,000.

**Total Household Income in 2016 (%)**

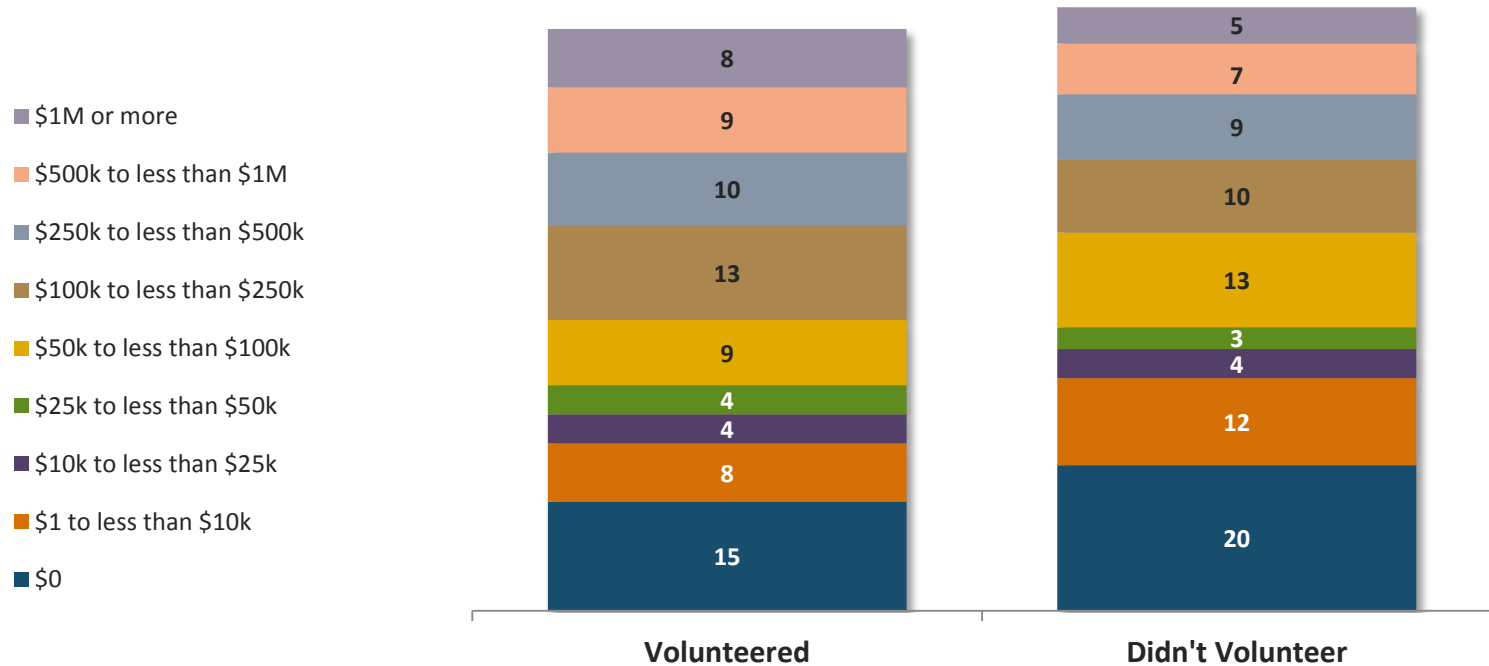


*Note: The median is estimated based on the approximate midpoint of the range of each response category. Non-responses are excluded from the estimate.*

# Total Household Retirement Savings Among Caregivers

Caregivers who volunteered (\$75,000 estimated median) have more total household retirement savings compared to caregivers who did not volunteer (\$47,000 estimated median). More caregivers who volunteered report having \$100,000 or more in retirement savings (40 percent), compared to those who did not volunteer (31 percent). One in five caregivers who did not volunteer report having nothing in retirement savings, compared to 15 percent of those who did volunteer.

**Total Household Retirement Savings in All Accounts (%)**



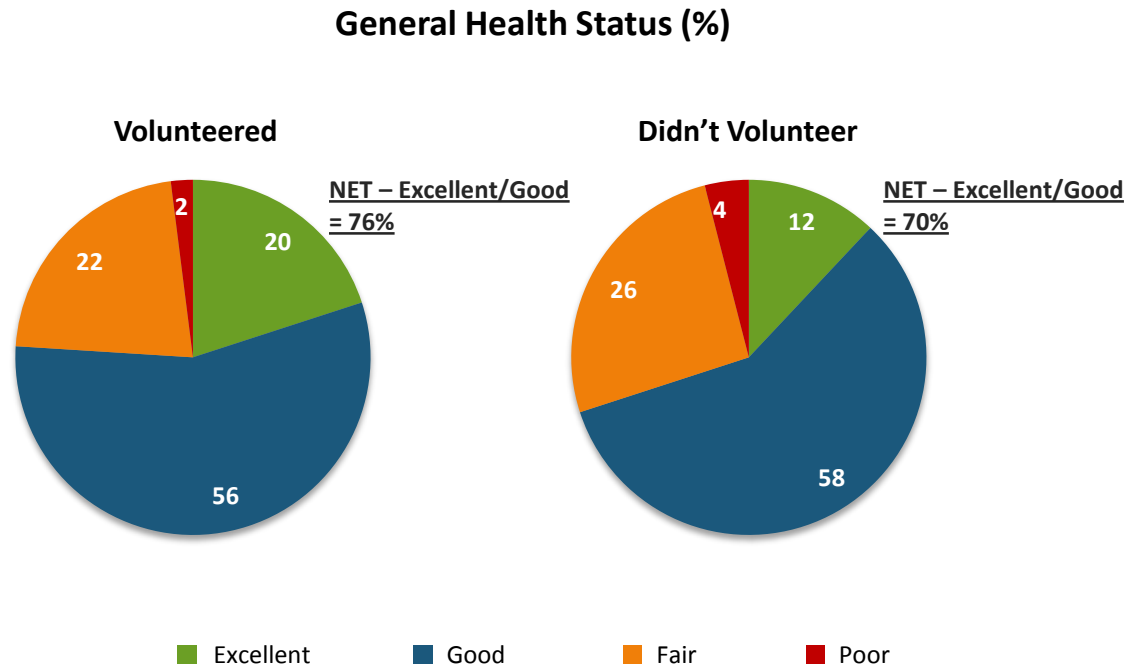
Not sure	10	10
Decline to answer	10	7
Estimated Median	\$75,000	\$47,000

*Note: The median is estimated based on the approximate midpoint of the range of each response category. Non-responses are excluded from the estimate.*



# Caregivers' Self-Described General Health

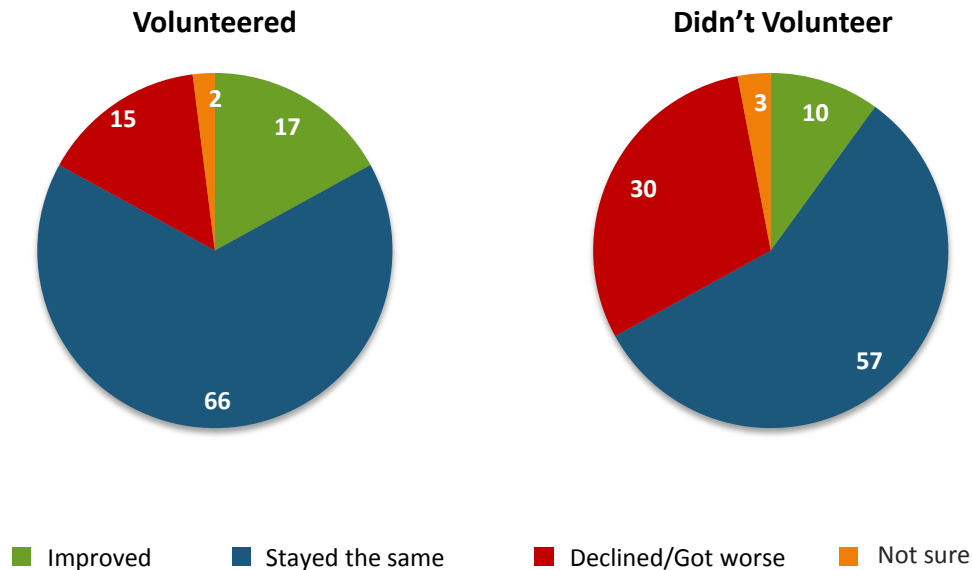
The majority of both caregivers who volunteered (76 percent) and caregivers who did not volunteer (70 percent) self-describe their general health as excellent or good. However, caregivers who volunteered are more likely to describe their general health as excellent (20 percent), compared to those who did not volunteer (12 percent).



# Changes in General Health Since Becoming a Caregiver

The majority of both caregivers who volunteered (66 percent) and caregivers who did not volunteer (57 percent) do not cite any change in their general health since taking on their role as a caregiver. However, caregivers who did not volunteer (30 percent) are more likely to indicate their health has declined since becoming a caregiver compared to caregivers who did volunteer (15 percent).

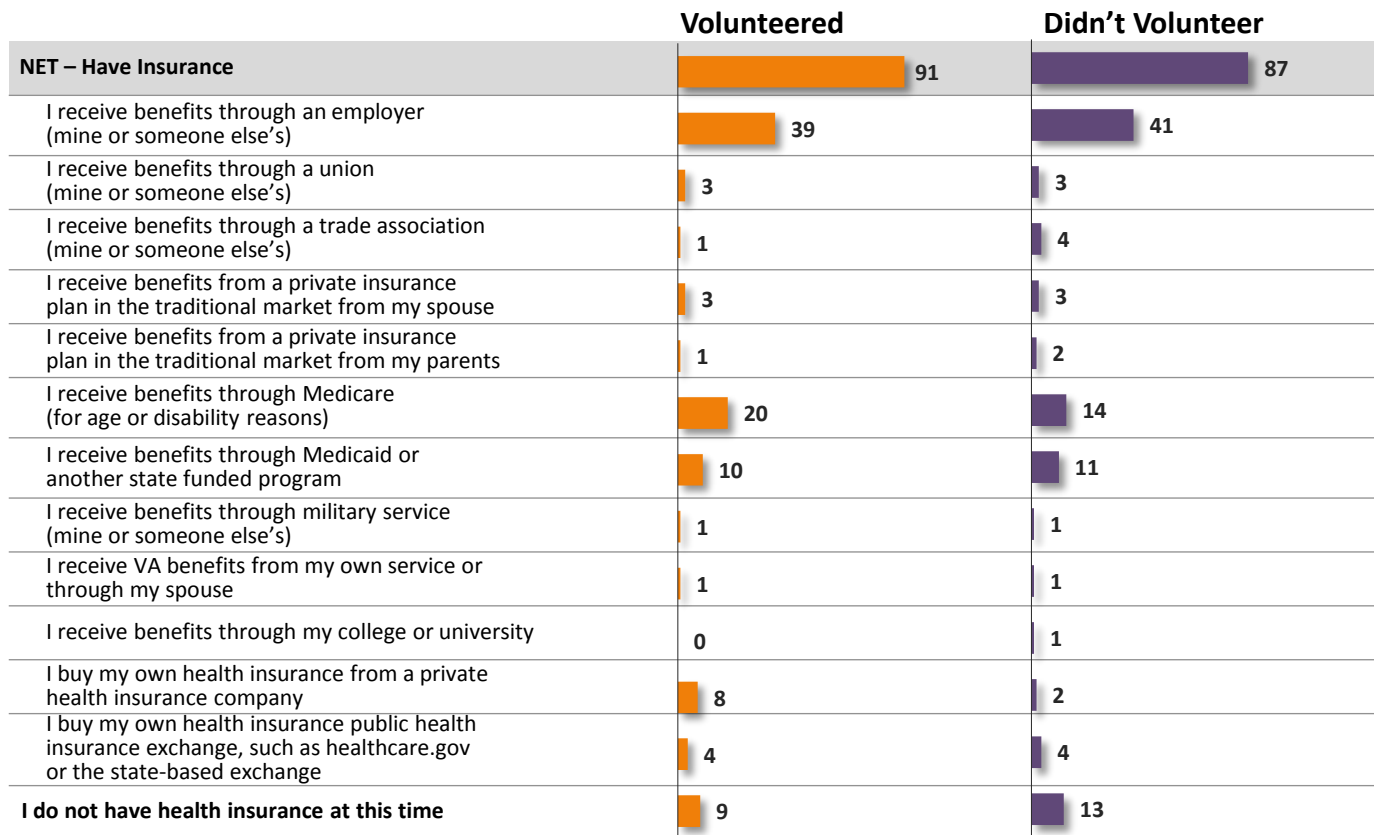
**Changes in General Health Since Becoming a Caregiver (%)**



# Caregivers' Health Insurance

The vast majority of caregivers currently have health insurance, including 91 percent of caregivers who volunteered and 87 percent of those who did not volunteer. Both caregivers who volunteered (39 percent) and caregivers who did not volunteer (41 percent) most commonly receive health insurance through an employer. Of note, more caregivers who did not volunteer (13 percent) do not have health insurance, compared to caregivers who volunteered (9 percent).

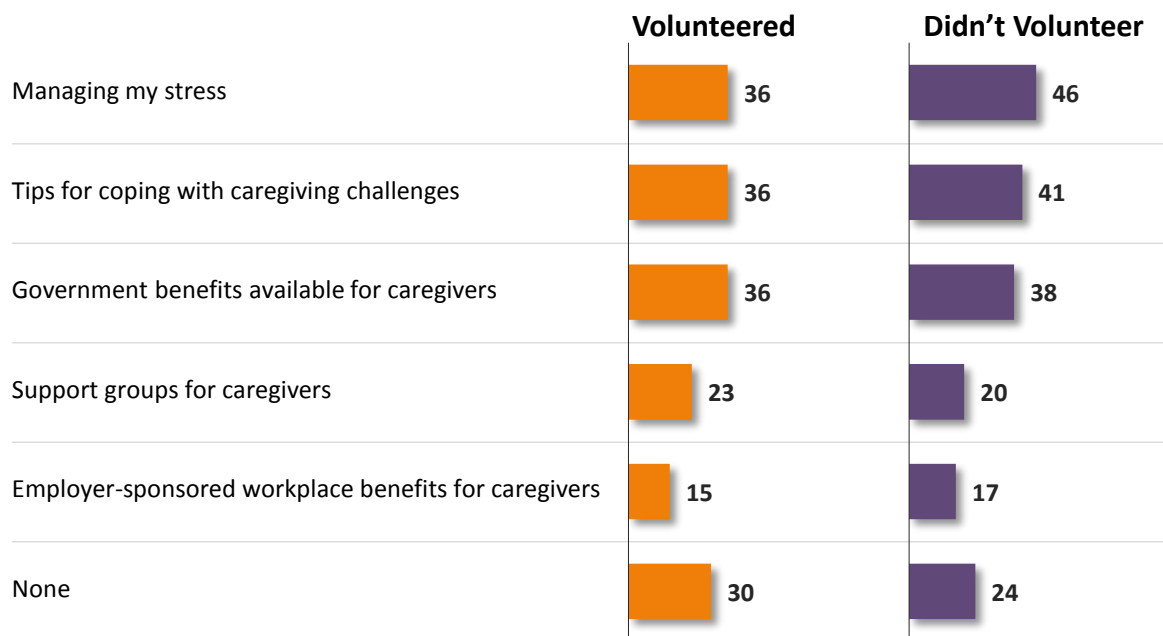
## “Which of the following best describes how you primarily receive health insurance?” (%)



# Caregivers Would Like More Information to Help Them Personally

Information on managing stress is the most frequently cited topic that caregivers would like more information about in order to help them personally with their caregiving duties. Caregivers who did not volunteer (46 percent) are more likely to want information about managing stress than caregivers who volunteered (36 percent). Other desired topics of information among both caregivers who volunteered and those who did not include tips on coping with caregiving challenges and government benefits available for caregivers. Some would like information about support groups for caregivers and employer-sponsored workplace benefits for caregivers.

**“Which of the following topics would you like more information to help you personally with your caregiving responsibilities?” (%)**



NOTE: Five most commonly selected sources shown.

BASE: ALL QUALIFIED RESPONDENTS

Q850. Which of the following topics would you like more information to help you personally with your caregiving responsibilities? I would like more information about... Select all.



## Demographic Perspectives By Employment Status

# ***The Many Faces of Family Caregivers: A Close-Up Look at Caregiving and Its Implications***

## **A Portrait of Today's Caregivers**

- Demographic Perspectives
- Voluntary Status

### **➤ *Employment Status***

- Generations
- Gender
- Household Income
- Race/Ethnicity

## **Appendix: Caregiver and Care Recipient Demographics**

## **Acknowledgements**

# Demographic Perspectives of Caregivers By Employment Status

Caregiving is a demanding job unto itself and many caregivers are juggling other responsibilities. More than half of caregivers (52 percent) are employed either full-time (39 percent) or part-time (13 percent). Eight percent are self-employed. Forty percent are not employed, including 19 percent who are retired and 7 percent who are a stay-at-home spouse or partner. In this chapter, the survey explores the impact of caregiving responsibilities based on caregivers' employment status.

While caregiving is demanding for all caregivers, the survey finds that caregivers who are employed tend to be better off financially than those who are not employed. However, they also have a more difficult time in balancing the demands their caregiving responsibilities with their jobs. Approximately one in three caregivers who are employed have experienced some form of adverse employment action as a result of their caregiving duties. In contrast, caregivers who are not employed spend more time caregiving each month. They are also more likely than caregivers who are employed to be in fair or poor health and indicate a decline in their health since becoming a caregiver.

## *Twenty-Five Facts About Caregivers By Employment Status*

- **Most Consider Themselves to Be the Primary Caregivers.** The majority of caregivers consider themselves to be the Primary caregiver of their care recipient. This finding that is relatively consistent among caregivers who are employed full-time (73 percent), employed part-time (66 percent), self-employed (62 percent), and not employed (65 percent).
- **The Majority of Caregivers Are Caring for a Family Member.** Most caregivers are caring for a family member, including caregivers who are employed full-time (90 percent), employed part-time (84 percent), self-employed (80 percent) and not employed (86 percent). Parents are the most frequently cited recipients of care among caregivers, including those who are employed full-time (36 percent), employed part-time (37 percent), self-employed (38 percent) and not employed (29 percent). Of note, caregivers who are not employed (25 percent) are more likely to be caring for a spouse/partner, compared to those who are employed full-time (16 percent), employed part-time (11 percent) or self-employed (20 percent).
- **Reasons for Becoming a Caregiver.** Caregivers most frequently cite wanting to care for a loved one as a reason for becoming a caregiver, including caregivers who are employed full-time and part-time (both 60 percent), self-employed (64 percent), or not employed (67 percent).
  - Of note, caregivers who are not employed (55 percent) are more likely to have become a caregiver because they had the time and capacity to do so, compared to caregivers who work full-time (30 percent).
  - Caregivers who work part-time (38 percent) are more likely to cite job flexibility as a reason for becoming a caregiver, compared to those who work full-time (25 percent).

# Demographic Perspectives of Caregivers By Employment Status

- **Total Caregiving Hours per Month.** Caregivers who are not employed spend the most time caring for their care recipient per month at 86 hours (median), followed by those who are self-employed (60 hours) and employed full-time or part-time (both 40 hours). Caregivers who are not employed (47 percent) are twice as likely as those who are employed full-time (25 percent) to spend 100 or more hours on caregiving each month.
- **Caregiver Duties Performed.** Caregiving encompasses a broad range of duties including household, social/communication, health-related, personal care, medical-related, and paying bills and managing finances. While many caregivers are involved in these duties, regardless of their employment status, caregivers who are not employed are often more likely to be involved than those who are employed or self-employed. For example, 75 percent of caregivers who are not employed are involved in health-related duties (i.e., accompanying to medical appointments, healthcare coordination, health insurance coordination) compared to approximately two-thirds of caregivers who are employed or self-employed.
- **Hours Spent Caregiving by Types of Duties.** Caregivers dedicate the most time to engaging in companionship with the care recipient, meal preparation, feeding, and personal care.
  - Caregivers who are not employed typically spend more time on these activities compared to those who are employed or self-employed.
  - For example, caregivers who are not employed spend 60 hours (median) per month engaging in companionship, a finding that is much higher than for those who are self-employed (40 hours median) or employed full-time or part-time (both 20 hours median).
- **Sources of Information Relied on to Assist in Caregiving Duties.** Caregivers most frequently rely on family and friends and medical professionals as sources of information to assist in their caregiving duties, a finding which ranges between 43 and 49 percent depending on employment status. Of note, caregivers who are employed full-time or part-time are typically more likely to rely on online resources (i.e. websites) compared to those who are self-employed or not employed. A noteworthy 25 percent of caregivers who are not employed say that they do not rely on any information sources of information.
- **Sources for Learning About Medical/Nursing Tasks.** Among caregivers currently performing medical-related tasks, approximately half learned how to perform their medical/nursing tasks from a hospital or doctor's office personnel, a finding which is relatively consistent among caregivers who are employed full-time (56 percent), employed part-time or self-employed (both 60 percent), and not employed (49 percent). A noteworthy 26 percent caregivers who are not employed say that they did not use any resources to learn how to perform medical/nursing tasks.



# Demographic Perspectives of Caregivers By Employment Status

- **Caregivers' Sentiments About Their Caregiving Duties.** Approximately nine out of 10 caregivers, across employment status, say that they like helping and enjoy spending time with the care recipient. However, caregivers employed full-time (62 percent) or part-time (56 percent) are more likely to say that their own health takes a backseat to the health of the care recipient, compared to those who are self-employed (43 percent) or not employed (50 percent). Caregivers who are employed are also more likely to indicate that they need more help and that their caregiving duties leave them feeling completely overwhelmed.
- **Disruptions to Employment as a Result of Caregiving.** Caregiving responsibilities can be disruptive to a caregiver's employment situation. Among caregivers who are employed or who have been employed during their time as caregivers, some have had to reduce their hours or job responsibilities, take leave from their position, or quit their job or retire early in order to accommodate their caregiving duties.
  - 36 percent who are currently not employed indicate they retired early or quit their job;
  - 37 percent who currently work part-time and 31 percent who are self-employed indicate they reduced their hours or job responsibilities; and,
  - 23 percent who are currently employed full-time have taken a leave of absence.
- **Informing Coworkers About Their Caregiving Duties.** Among caregivers currently employed, 59 percent who are employed full-time and 48 percent employed part-time have told their immediate supervisor that they are a caregiver. Caregivers who are employed full-time are more likely than those employed part-time to have told their direct reports (24 percent, 12 percent respectively). Caregivers who are employed full-time are also slightly more likely than those employed part-time to have told Human Resources (22 percent, 16 percent respectively). In contrast, caregivers who are employed part-time are more likely than those employed full-time to have not told anyone at work that they are a caregiver (30 percent, 20 percent respectively).
- **Employer Support of Caregiving Duties.** Most caregivers who are employed full-time (72 percent) or part-time (64 percent) feel that their employers are very or somewhat supportive of their caregiving duties. Sixteen percent of caregivers who are employed full-time or part-time feel that their employers are not too supportive or not at all supportive. Twenty percent of caregivers who are employed part-time "don't know" whether their employers are supportive, compared to only 12 percent of those employed full-time.

# Demographic Perspectives of Caregivers By Employment Status

- **Adverse Actions Taken by Employers.** Caregiving duties may conflict with job responsibilities which, in turn, may lead to adverse actions taken by an employer. Among caregivers who are either currently employed or who have been employed during their time as caregivers, 32 percent who are now employed full-time or part-time have experienced an adverse employment action(s) such as being fired, written up or admonished, given less attractive assignments, passed over for a promotion, discriminated against, having hours or duties reduced, or other. Twenty percent who are not currently employed and 13 percent who are now self-employed indicate they experienced an adverse employment action(s).
- **Caregivers' Financial Well-Being.** The self-described financial well-being of caregivers varies with employment status. Caregivers who are employed full-time (71 percent) are much more likely than caregivers who are not currently employed (43 percent) to say that their financial status is either excellent or good. Caregivers who work part-time and those who are self-employed (both 55 percent) similarly report their financial well-being as excellent or good.
- **Financial Considerations Before Becoming Caregivers.** Most caregivers gave little or no consideration to their own financial situation when deciding to become a caregiver, including caregivers who are employed full-time (61 percent), employed part-time (65 percent), self-employed (71 percent), and not employed (78 percent). Caregivers who are employed full-time (17 percent) are slightly more likely to have given their own financial situation a lot of consideration.
- **Change in Financial Situation as a Result of Caregiving.** Most caregivers believe that their financial situation has not changed as a result of becoming a caregiver, a finding that is relatively consistent among caregivers who are not employed (70 percent), self-employed (68 percent), employed full-time (63 percent), and employed part-time (59 percent). Approximately one in five caregivers across employment status indicate their financial situation has worsened since becoming a caregiver.
- **Monthly Personal Expenditures for Caregiving.** Caregivers who are employed full-time or part-time (both \$200 median) spend more money out-of-pocket per month to cover expenses for their care recipient than caregivers who are self-employed or not currently employed (both \$100 median).
- **Financial Assistance for Caregiving Duties.** While the majority of all caregivers do not receive compensation for their caregiving duties, caregivers who are employed full-time (32 percent) or part-time (42 percent) are somewhat more likely than those who are self-employed (23 percent) or not employed (14 percent) to receive any form of payment. Among those receiving payment, funds from the care recipient and family members are the most frequently cited sources.

# Demographic Perspectives of Caregivers By Employment Status

- **Financial Priorities Among Caregivers.** The most frequently cited financial priority among caregivers varies with caregiver employment status. Among caregivers who work full-time (56 percent), those who work part-time (51 percent), and self-employed (78 percent), paying off some form of debt (Net) is the most frequently cited financial priority. For caregivers who are not employed (52 percent), just getting by – covering basic living expenses is the most frequently cited financial priority.
- **Total Household Income Among Caregivers.** Caregivers who are employed full-time report the highest total household income in 2016 at \$79,000 (estimated median), followed by those who are employed part-time (\$53,000), self-employed (\$52,000), and not employed (\$36,000).
- **Total Household Retirement Savings Among Caregivers.** Caregivers who are employed full-time report the most total household retirement savings in all accounts at \$117,000 (estimated median), followed those who are self-employed (\$72,000), employed part-time (\$68,000), and not employed (\$8,000). A noteworthy 24 percent of caregivers who are not employed and 17 percent of those who are employed part-time indicate they have no savings in retirement accounts.
- **Caregivers' Self-Described General Health.** Most caregivers describe their general health as being excellent or good, a finding which is much higher among those who are employed full-time (85 percent), part-time (80 percent), or self-employed (81 percent), compared to those who are not employed (62 percent). A noteworthy 38 percent of caregivers who are not employed indicate their health is fair (33 percent) or poor (5 percent).
- **Changes in General Health Since Becoming a Caregiver.** Most caregivers indicate their general health has stayed the same since becoming a caregiver, a finding which is relatively consistent among caregivers who are employed full-time (64 percent), employed part-time (62 percent), self-employed (70 percent), or not employed (67 percent). An alarming 24 percent of caregivers who are not employed say their general health has gotten worse / declined since becoming a caregiver, a finding that is much higher than that of caregivers who are employed full-time (12 percent), employed part-time (14 percent), and self-employed (14 percent). A noteworthy 23 percent of caregivers who are employed either full-time or part-time indicate their health has improved since becoming a caregiver.
- **Caregivers' Health Insurance.** Most caregivers have health insurance, a finding which is relatively consistent among caregivers who are employed full-time (95 percent), employed part-time (86 percent), self-employed (86 percent), and not employed (89 percent). Caregivers who are employed full-time (67 percent) and part-time (34 percent) most frequently obtain health insurance through an employer, while caregivers who are not employed (37 percent) do so through Medicare and those who are self-employed (20 percent) do so from a private health insurance company.

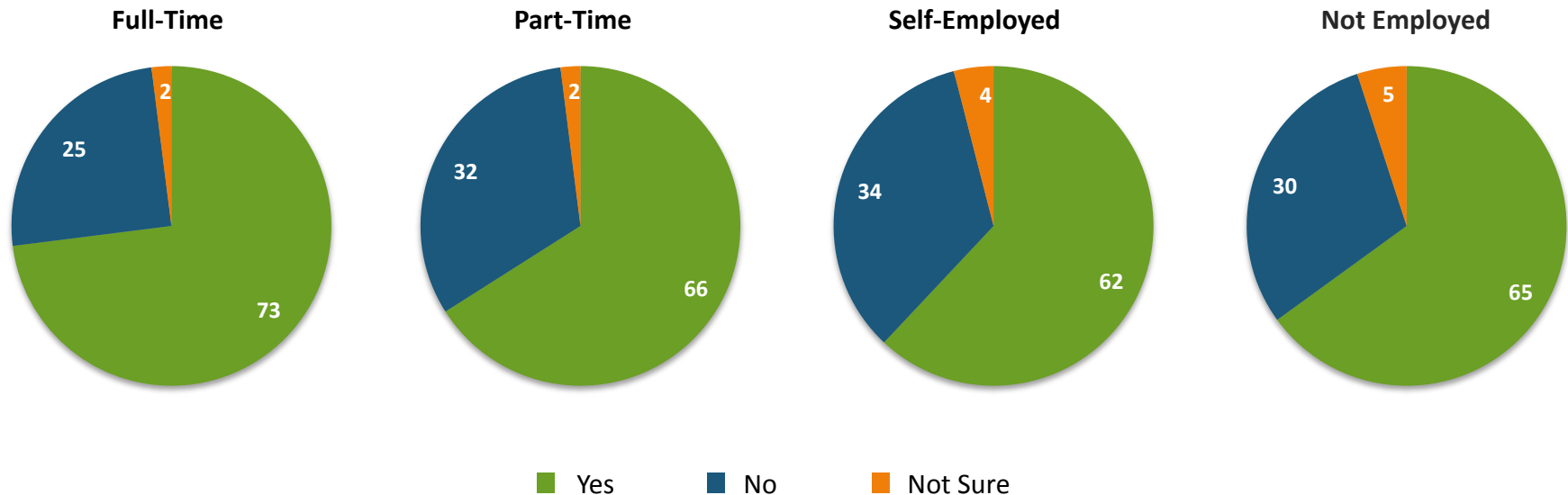
# Demographic Perspectives of Caregivers By Employment Status

- **Caregivers Would Like More Information to Help Them Personally.** When asked what information they would like to help them personally with their caregiving responsibilities, caregivers most frequently cite topics such as stress management, tips for coping with caregiving challenges, and government benefits available for caregivers. These findings are directionally consistent by employment status. Of note, caregivers who are employed are somewhat more likely to cite managing stress compared to those who are self-employed or not employed. Conversely, those who are self-employed or not employed are more likely to say “none.”

# Most Consider Themselves to Be the Primary Caregivers

The majority of caregivers consider themselves to be the Primary caregiver of their care recipient. This finding that is relatively consistent among caregivers who are employed full-time (73 percent), employed part-time (66 percent), self-employed (62 percent), and not employed (65 percent).

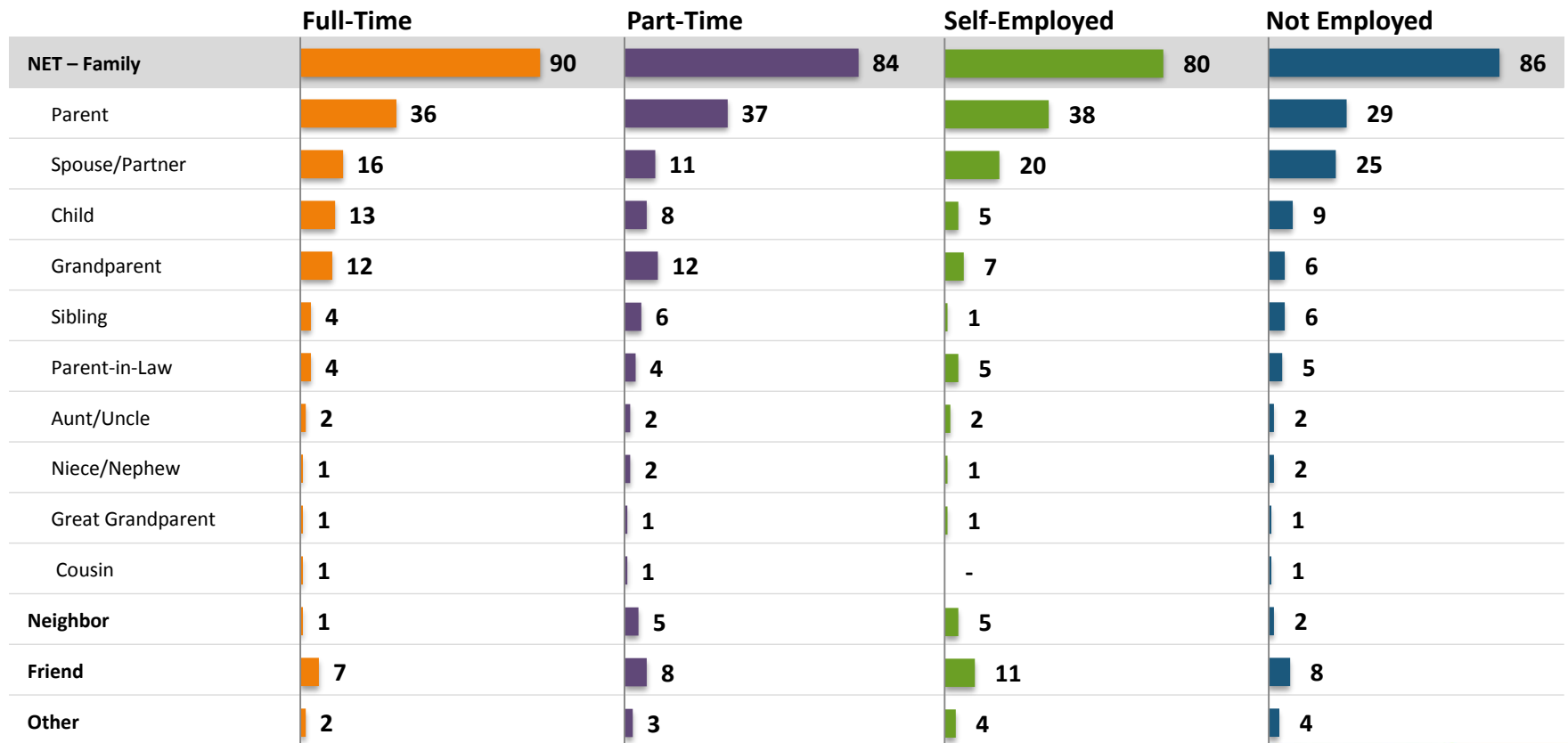
**“Would you consider yourself to be the Primary caregiver?” (%)**



# The Majority of Caregivers Are Caring for a Family Member

Most caregivers are caring for a family member, including caregivers who are employed full-time (90 percent), employed part-time (84 percent), self-employed (80 percent) and not employed (86 percent). Parents are the most frequently cited recipients of care among caregivers, including those who are employed full-time (36 percent), employed part-time (37 percent), self-employed (38 percent) and not employed (29 percent). Of note, caregivers who are not employed (25 percent) are more likely to be caring for a spouse/partner, compared to those who are employed full-time (16 percent), employed part-time (11 percent) or self-employed (20 percent).

**Relationship to Care Recipient (%)**



BASE: ALL QUALIFIED RESPONDENTS

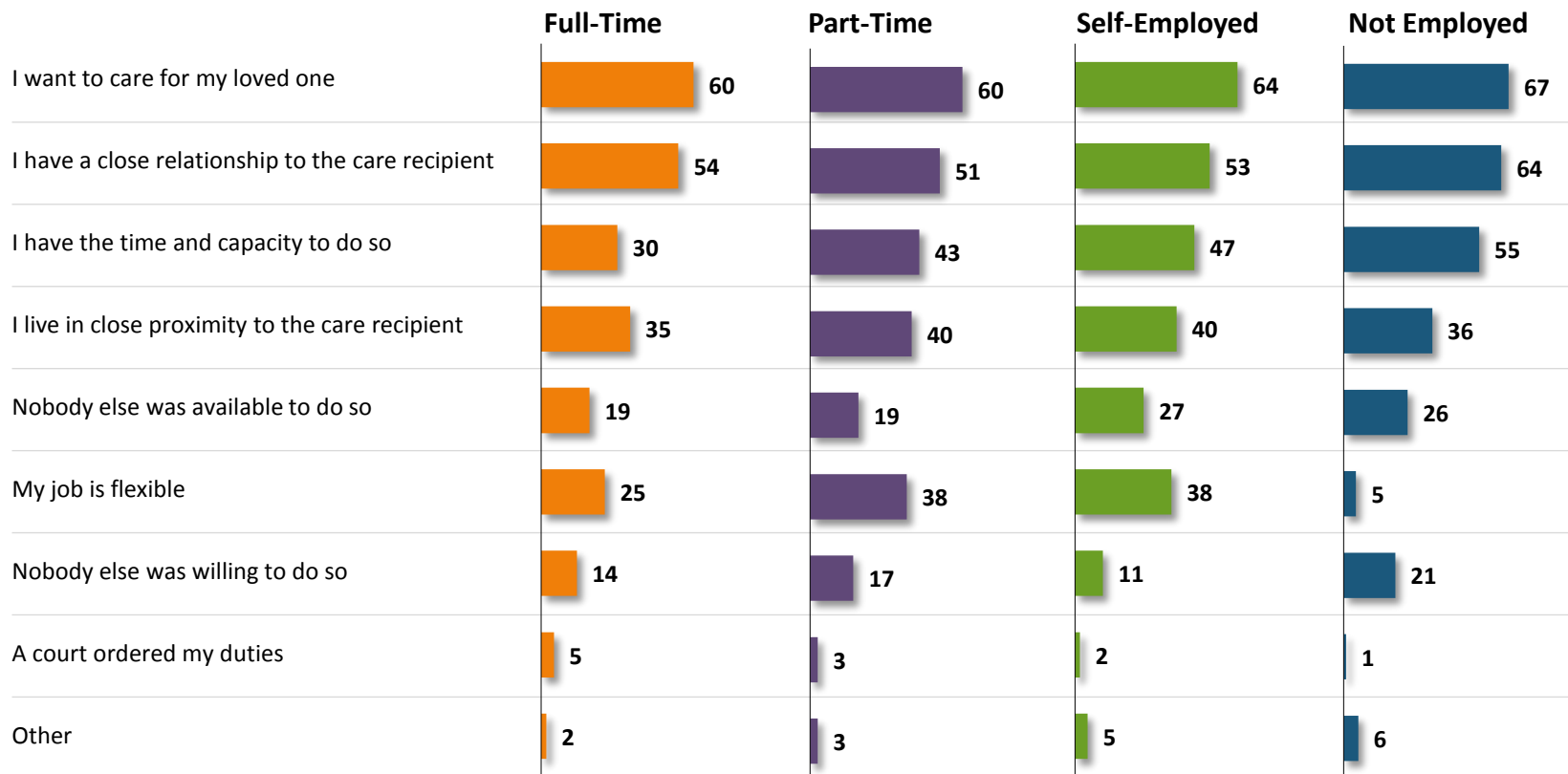
Q700. You mentioned providing care for [INSERT ANSWER FROM Q610] individual(s).

Please let us know your relationship to the person, their age, and their gender.

# Reasons for Becoming a Caregiver

Caregivers most frequently cite wanting to care for a loved one as a reason for becoming a caregiver, including caregivers who are employed full-time and part-time (both 60 percent), self-employed (64 percent), or not employed (67 percent). Of note, caregivers who are not employed (55 percent) are more likely to have become a caregiver because they had the time and capacity to do so, compared to caregivers who work full-time (30 percent). Caregivers who work part-time (38 percent) are more likely to cite job flexibility as a reason for becoming a caregiver, compared to those who work full-time (25 percent).

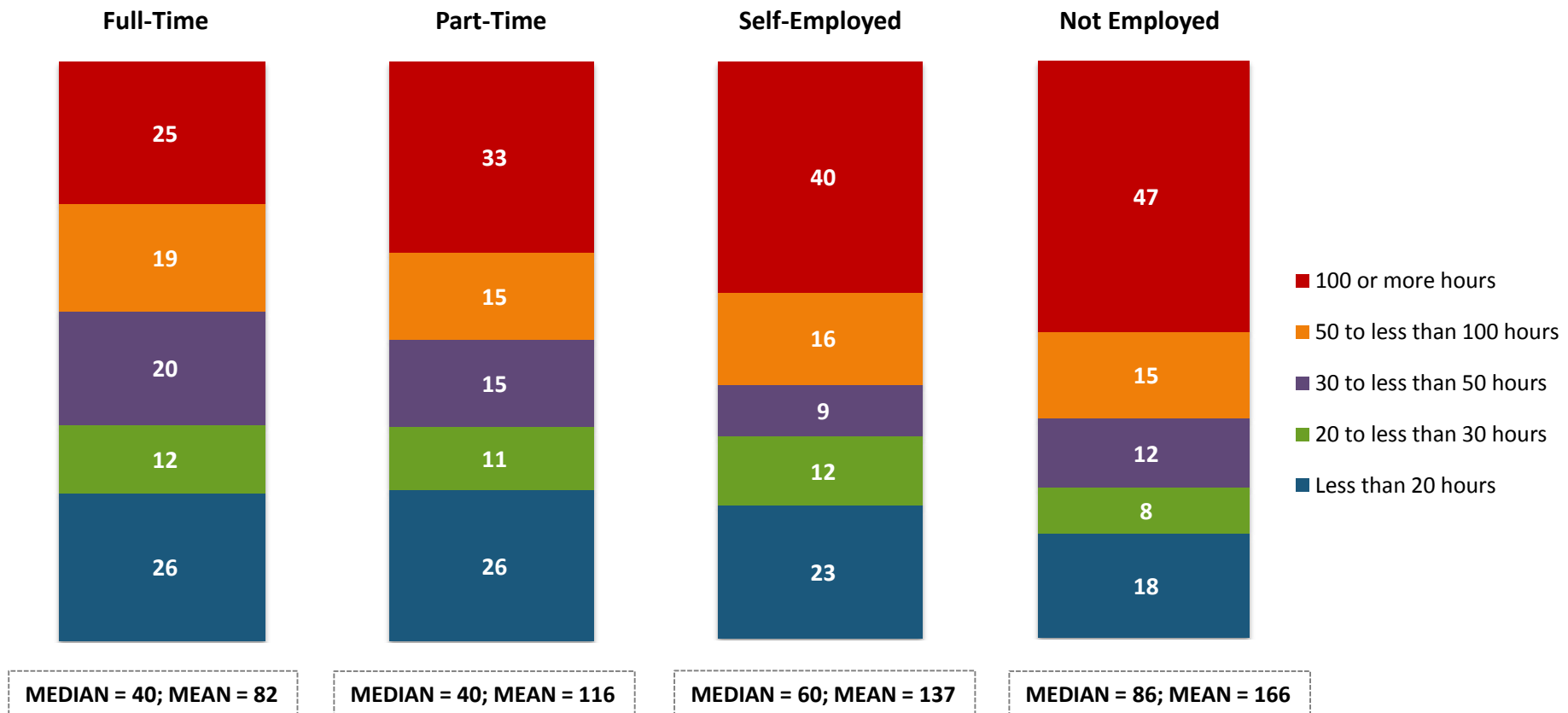
**Reasons for Becoming a Caregiver (%)**



# Total Caregiving Hours per Month

Caregivers who are not employed spend the most time caring for their care recipient per month at 86 hours (median), followed by those who are self-employed (60 hours) and employed full-time or part-time (both 40 hours). Caregivers who are not employed (47 percent) are twice as likely as those who are employed full-time (25 percent) to spend 100 or more hours on caregiving each month.

## Total Hours Spent Caregiving Each Month (%)



Note: The median is the midpoint of the range of each response category. The mean is the average of all responses.

BASE: ALL QUALIFIED RESPONDENTS

Q832. In total, approximately how many hours per month do you spend caring for the care recipient?



# Caregiver Duties Performed

Caregiving encompasses a broad range of duties including household, social/communication, health-related, personal care, medical-related, and paying bills and managing finances.

While many caregivers are involved in these duties, regardless of their employment status, caregivers who are not employed are often more likely to be involved than those who are employed or self-employed.

For example, 75 percent of caregivers who are not employed are involved in health-related duties (i.e., accompanying to medical appointments, healthcare coordination, health insurance coordination) compared to approximately two-thirds of caregivers who are employed or self-employed.

Caregiving Duties	Full-Time	Part-Time	Self-Employed	Not Employed
<b>NET – Household</b>	<b>87%</b>	<b>87%</b>	<b>89%</b>	<b>92%</b>
Running errands	63%	60%	69%	75%
Housework	51%	59%	60%	68%
Meal preparation	52%	57%	63%	65%
Home repairs	31%	23%	37%	29%
Home modifications	21%	14%	20%	19%
<b>NET – Social/Communication</b>	<b>65%</b>	<b>70%</b>	<b>74%</b>	<b>79%</b>
Companionship	50%	53%	68%	74%
Basic communications	25%	30%	35%	35%
Language translation	9%	8%	5%	6%
<b>NET – Health-Related</b>	<b>64%</b>	<b>66%</b>	<b>65%</b>	<b>75%</b>
Accompanying to medical appointments	53%	57%	57%	70%
Healthcare coordination	39%	42%	41%	50%
Health insurance coordination	30%	22%	30%	32%
<b>NET – Personal</b>	<b>62%</b>	<b>68%</b>	<b>58%</b>	<b>61%</b>
Mobility	38%	36%	41%	40%
Personal care	32%	43%	28%	37%
Feeding	26%	42%	22%	24%
Incontinence care	13%	17%	11%	17%
<b>NET – Medical-Related</b>	<b>44%</b>	<b>54%</b>	<b>48%</b>	<b>52%</b>
Medication management	39%	46%	46%	50%
Medical treatment administration	16%	24%	15%	14%
<b>Paying bills/Managing finances</b>	<b>42%</b>	<b>40%</b>	<b>50%</b>	<b>44%</b>
<b>Other</b>	<b>3%</b>	<b>3%</b>	<b>4%</b>	<b>5%</b>

# Hours Spent Caregiving by Types of Duties

Caregivers dedicate the most time to engaging in companionship with the care recipient, meal preparation, feeding, and personal care.

Caregivers who are not employed typically spend more time on these activities compared to those who are employed or self-employed.

For example, caregivers who are not employed spend 60 hours (median) per month engaging in companionship, a finding that is much higher than for those who are self-employed (40 hours median) or employed full-time or part-time (both 20 hours median).

*Note: The median is the midpoint of the range of each response category. The mean is the average of all responses.*

Time Spent On Caregiving Duties (hours per month)	Full-Time		Part-Time		Self-Employed		Not Employed	
	Median	Mean	Median	Mean	Median	Mean	Median	Mean
<b>Household</b>								
Running errands	6	15	6	15.9	8	13.3	10	22.3
Housework (e.g., cleaning, laundry)	10	17.9	8	22.2	10	20.0	15	37.5
Meal preparation	12	23.6	12	21.6	20	24.1	30	42.2
Home repairs	4	6.6	3	9.3	4	7.5	2	12.7
Home modifications	4	7.7	2	8.6	1	3.2	2	9.2
<b>Social Communication</b>								
Companionship	20	54.8	20	61.3	40	89.7	60	124.5
Basic communications	9	27.0	8	29.7	10	23.3	20	67.8
Language translation	5	11.5	2	16.2	5	10.1	5	19.5
<b>Health-Related</b>								
Accompanying to medical appointments	4	9.0	4	12.4	5	7.2	4	12.3
Healthcare coordination	3	8.7	4	9.6	2	5.5	3	10.1
Health insurance coordination	3	6.4	3	10.8	2	5.2	2	10.8
<b>Personal Care</b>								
Mobility	8	17.7	10	26.5	10	26.7	10	27.3
Personal care	10	22.6	15	27.1	15	20.5	12	28.2
Feeding	10	25.5	12	24.3	12	23.3	24	49.6
Incontinence care	5	22.7	6	21.1	10	16.3	7	22.3
<b>Medical-Related</b>								
Medication management	5	13.4	6	17.6	4	8.6	4	19.8
Medical treatment administration	6	20.6	5	19.8	10	16.7	4	14.9
<b>Paying bills/Managing finances</b>	3	7.5	4	10.4	3	5.9	3	10.4
<b>Other</b>	4	18.0	20	49.3	10	8.9	4	99.4

# Sources of Information Relied on to Assist in Caregiving Duties

Caregivers most frequently rely on family and friends and medical professionals as sources of information to assist in their caregiving duties, a finding which ranges between 43 and 49 percent depending on employment status. Of note, caregivers who are employed full-time or part-time are typically more likely to rely on online resources (i.e. websites) compared to those who are self-employed or not employed. A noteworthy 25 percent of caregivers who are not employed say that they do not rely on any information sources of information.

**Sources of Information to Assist in Caregiving Duties**



NOTE: Nine most commonly selected sources shown.

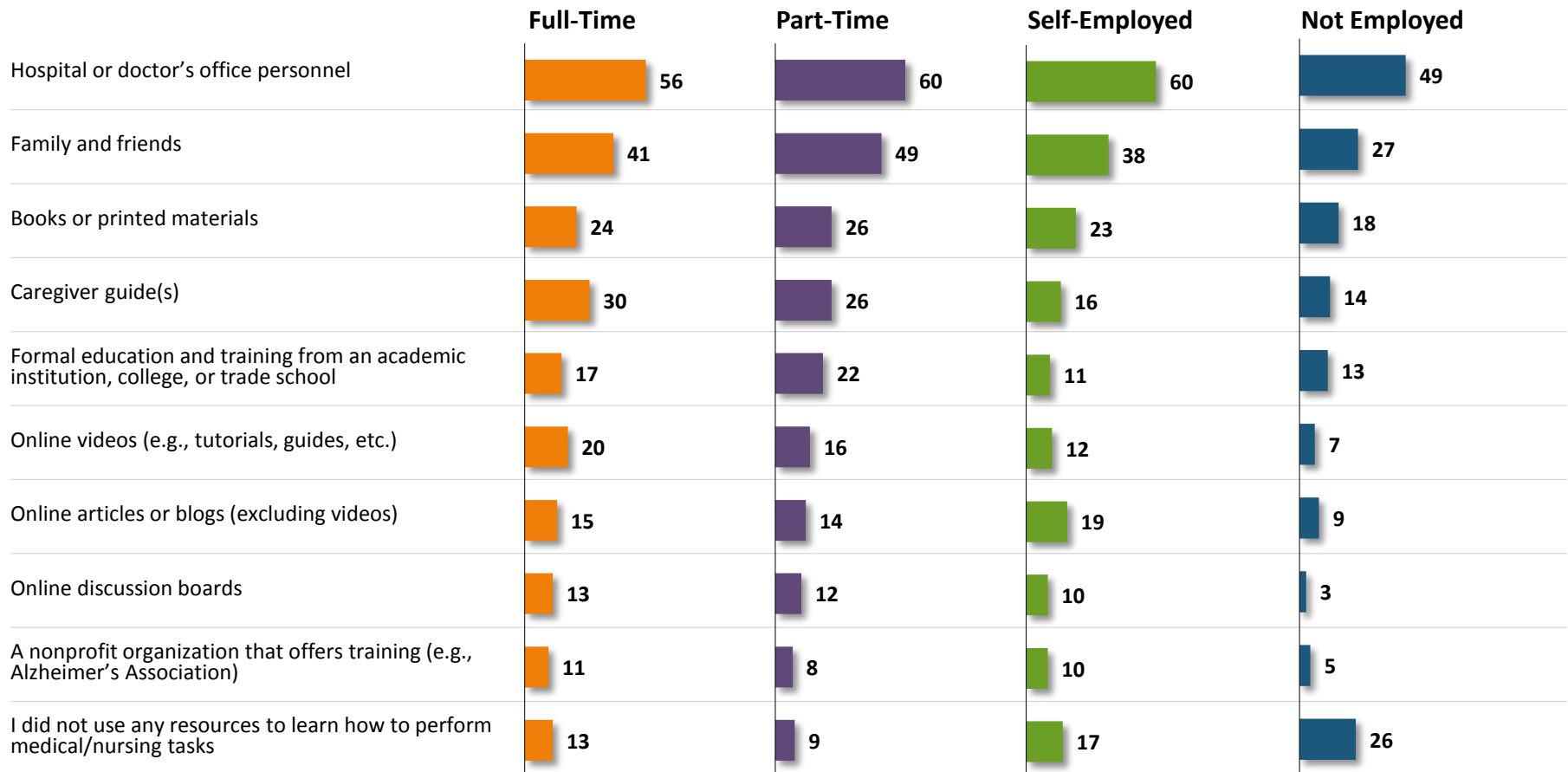
BASE: ALL QUALIFIED RESPONDENTS

Q840. Which of the following do you rely on as sources of information to assist in your caregiving duties? Select all.

# Sources for Learning About Medical/Nursing Tasks

Among caregivers currently performing medical-related tasks, approximately half learned how to perform their medical/nursing tasks from a hospital or doctor's office personnel, a finding which is relatively consistent among caregivers who are employed full-time (56 percent), employed part-time or self-employed (both 60 percent), and not employed (49 percent). A noteworthy 26 percent caregivers who are not employed say that they did not use any resources to learn how to perform medical/nursing tasks.

**Sources for Learning Medical/Nursing Tasks Related to Being a Caregiver (%)**



NOTE: Nine most commonly selected sources shown

BASE: IF ADMINISTERING MEDICATIONS AND MEDICAL TREATMENTS

Q835. You mentioned you perform medication management or medical treatment administration for the care recipient. Where did you learn how to perform medical/nursing tasks related to being a caregiver? Select all.

# Caregivers' Sentiments About Their Caregiving Duties

Approximately nine out of 10 caregivers, across employment status, say that they like helping and enjoy spending time with the care recipient. However, caregivers employed full-time (62 percent) or part-time (56 percent) are more likely to say that their own health takes a backseat to the health of the care recipient, compared to those who are self-employed (43 percent) or not employed (50 percent). Caregivers who are employed are also more likely to indicate that they need more help and that their caregiving duties leave them feeling completely overwhelmed.

Caregivers’ Sentiments About Their Caregiving Duties	Full-Time	Part-Time	Self-Employed	Not Employed
	Strongly/Somewhat Agree (NET)			
Positive				
It’s important for me to provide a good quality of life for the care recipient	94%	92%	95%	96%
I like helping the care recipient	92%	88%	92%	91%
I enjoy spending time with the care recipient	91%	89%	88%	91%
Being a caregiver gives me a strong sense of purpose	83%	84%	82%	82%
Being a caregiver has led me to take better care of my own health	74%	72%	67%	66%
Being a caregiver has inspired me to document my own health and legal wishes	71%	73%	65%	59%
Negative				
My own health takes a backseat to the health of my care recipient	62%	56%	43%	50%
My caregiving duties leave me feeling physically exhausted	60%	57%	37%	52%
My caregiving duties leave me feeling emotionally exhausted	60%	55%	41%	52%
I need more help with my caregiving duties	58%	49%	33%	39%
With all of my caregiving duties, I barely have time for anything else	55%	47%	35%	38%
My caregiving duties leave me feeling completely overwhelmed	52%	47%	37%	36%

BASE: ALL QUALIFIED RESPONDENTS

Q855. How much do you agree or disagree with the following statements about performing your duties as a caregiver?

# Disruptions to Employment as a Result of Caregiving

Caregiving responsibilities can be disruptive to a caregiver's employment situation.

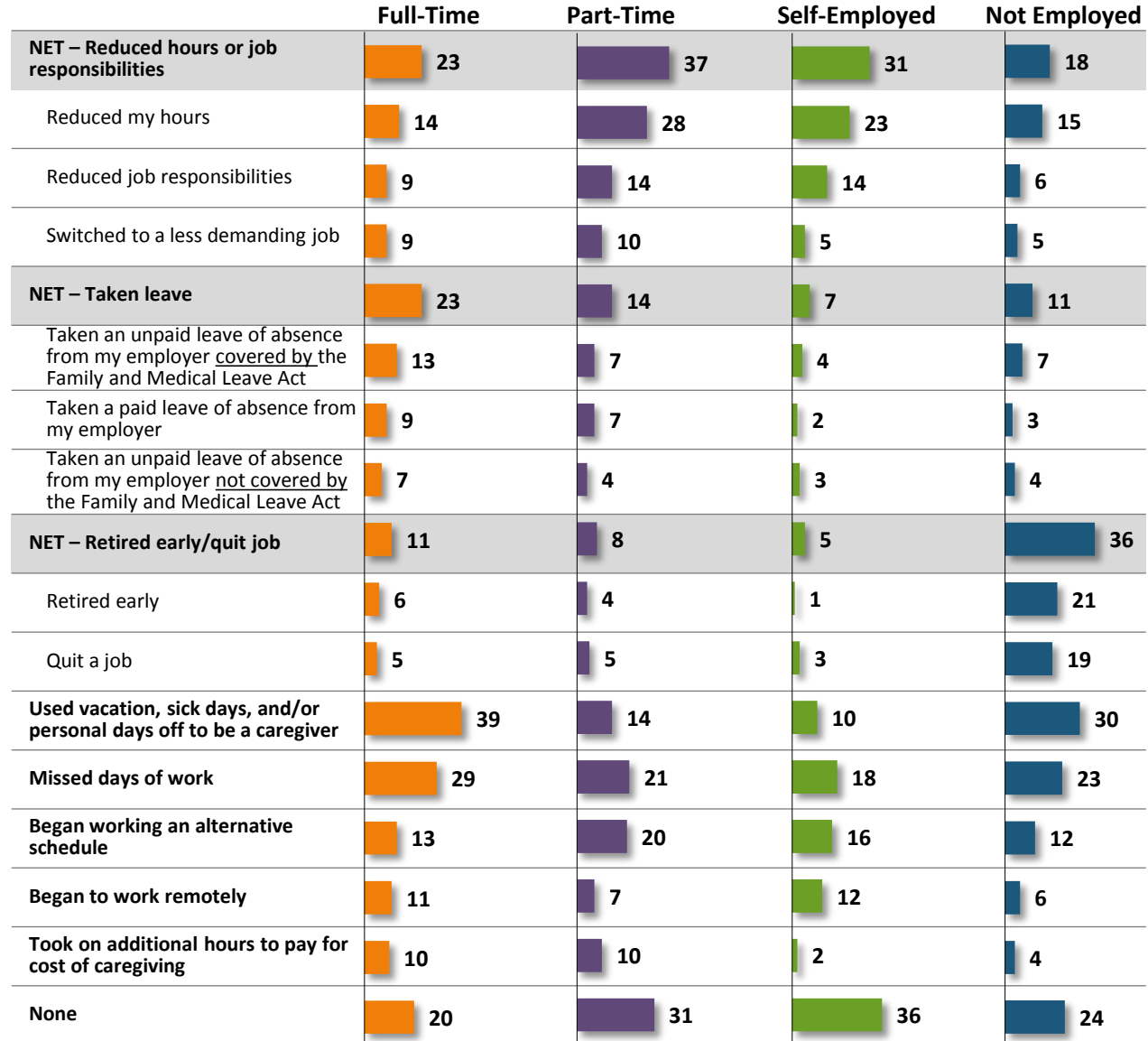
Among caregivers who are employed or who have been employed during their time as caregivers, some have had to reduce their hours or job responsibilities, take leave from their position, or quit their job or retire early in order to accommodate their caregiving duties.

For example, 36 percent who are currently not employed indicate they retired early or quit their job.

Thirty-seven percent who currently work part-time and 31 percent who are self-employed indicate they reduced their hours or job responsibilities.

Twenty-three percent who are currently employed full-time have taken a leave of absence.

"Which of the following have you done as a result of becoming a caregiver?" (%)



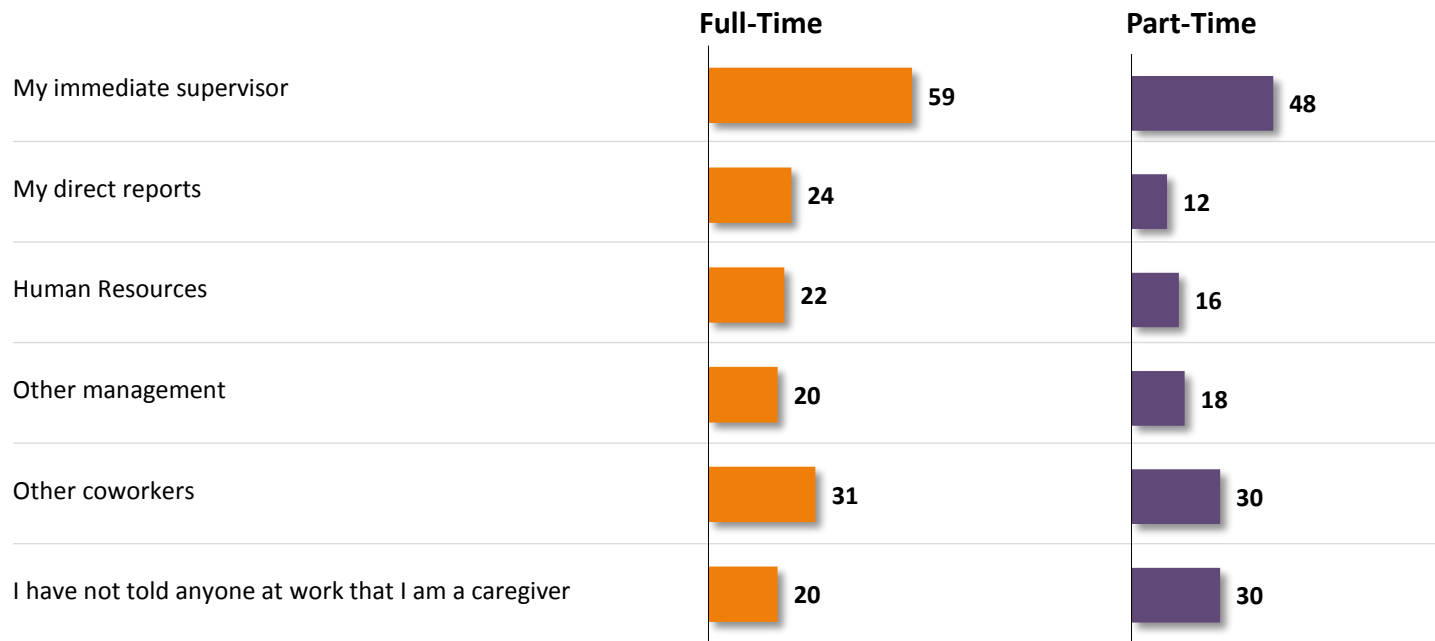
NOTE: Thirteen most commonly selected sources shown.

BASE: ALL EMPLOYED OR HAVE BEEN EMPLOYED DURING THEIR TIME AS A CAREGIVER  
Q1025. Which of the following have you done as a result of becoming a caregiver? Select all.

# Informing Coworkers About Their Caregiving Duties

Among caregivers currently employed, 59 percent who are employed full-time and 48 percent employed part-time have told their immediate supervisor that they are a caregiver. Caregivers who are employed full-time are more likely than those employed part-time to have told their direct reports (24 percent, 12 percent respectively). Caregivers who are employed full-time are also slightly more likely than those employed part-time to have told Human Resources (22 percent, 16 percent respectively). In contrast, caregivers who are employed part-time are more likely than those employed full-time to have not told anyone at work that they are a caregiver (30 percent, 20 percent respectively).

**“Which of the following people at work have you told that you are a caregiver?” (%)**



NOTE: Self-employed and not employed were excluded from this question.

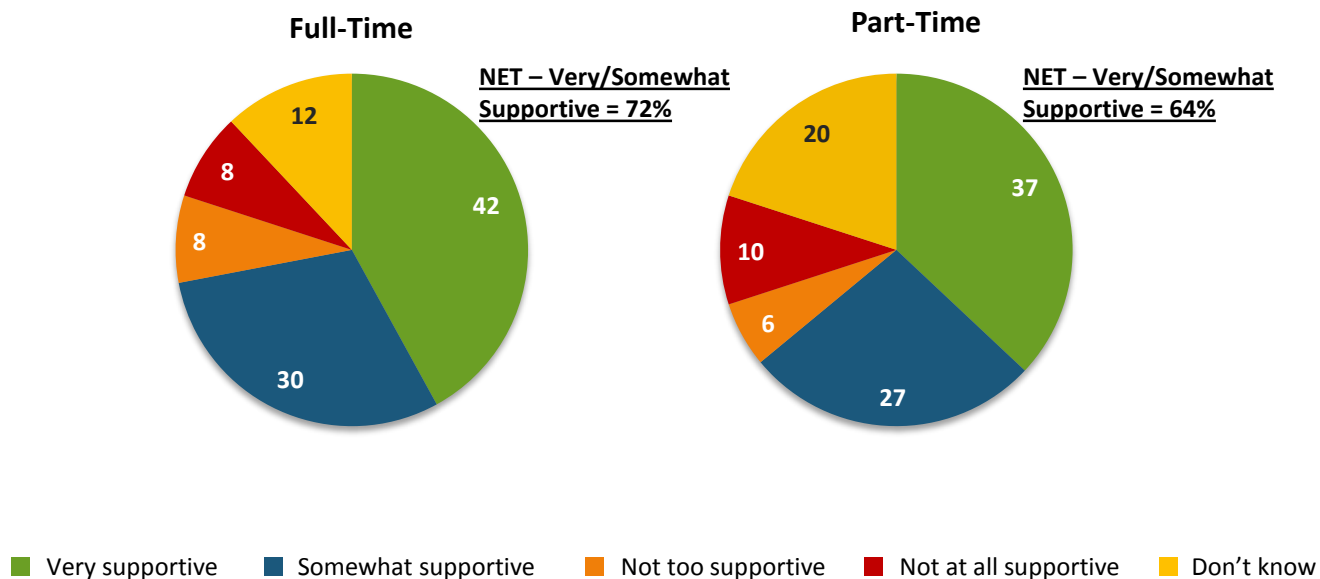
BASE: EMPLOYED FULL-TIME OR PART TIME

Q1035. Which of the following people at work have you told that you are a caregiver? Select all.

# Employer Support of Caregiving Duties

Most caregivers who are employed full-time (72 percent) or part-time (64 percent) feel that their employers are very or somewhat supportive of their caregiving duties. Sixteen percent of caregivers who are employed full-time or part-time feel that their employers are not too supportive or not at all supportive. Twenty percent of caregivers who are employed part-time “don’t know” whether their employers are supportive, compared to only 12 percent of those employed full-time.

**“How supportive is your employer of your caregiving responsibilities?” (%)**



NOTE: Self-employed and not employed were excluded from this question.

BASE: EMPLOYED FULL-TIME OR PART-TIME

Q1045. How supportive is your employer of your caregiving responsibilities?



# Adverse Actions Taken by Employers

Caregiving duties may conflict with job responsibilities which, in turn, may lead to adverse actions taken by an employer. Among caregivers who are either currently employed or who have been employed during their time as caregivers, 32 percent who are now employed full-time or part-time have experienced an adverse employment action(s) such as being fired, written up or admonished, given less attractive assignments, passed over for a promotion, discriminated against, having hours or duties reduced, or other. Twenty percent who are not currently employed and 13 percent who are now self-employed indicate they experienced an adverse employment action(s).

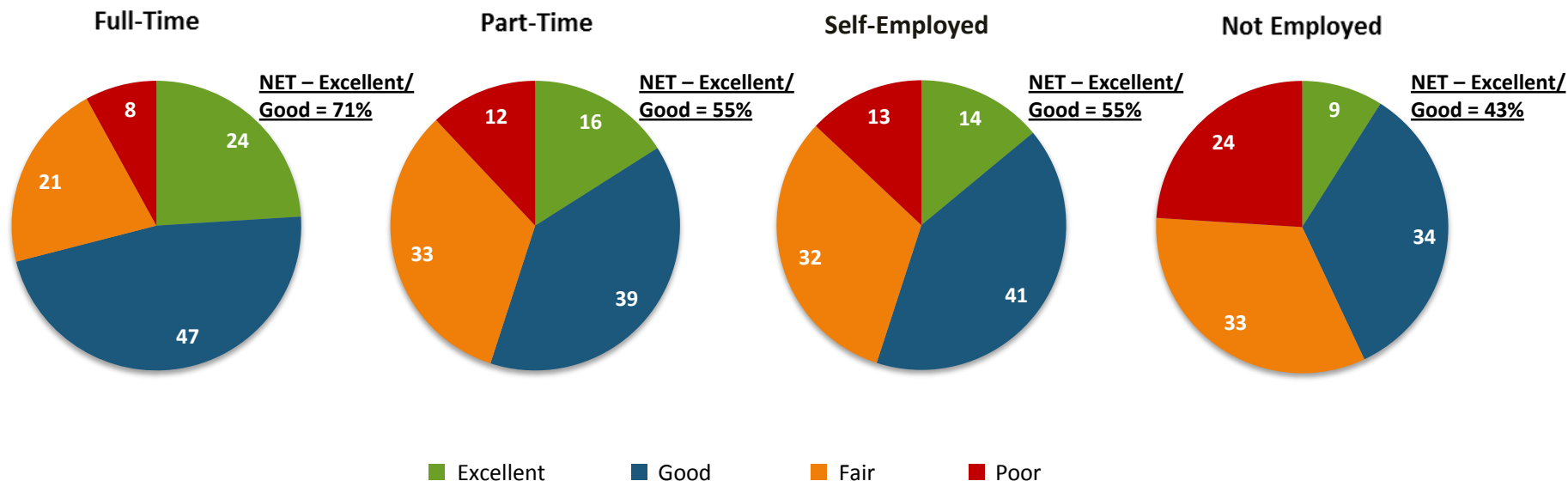
**Adverse Employment Actions Experienced as a Result of Caregiving Duties (%)**



# Caregivers' Financial Well-Being

The self-described financial well-being of caregivers varies with employment status. Caregivers who are employed full-time (71 percent) are much more likely than caregivers who are not currently employed (43 percent) to say that their financial status is either excellent or good. Caregivers who work part-time and those who are self-employed (both 55 percent) similarly report their financial well-being as excellent or good.

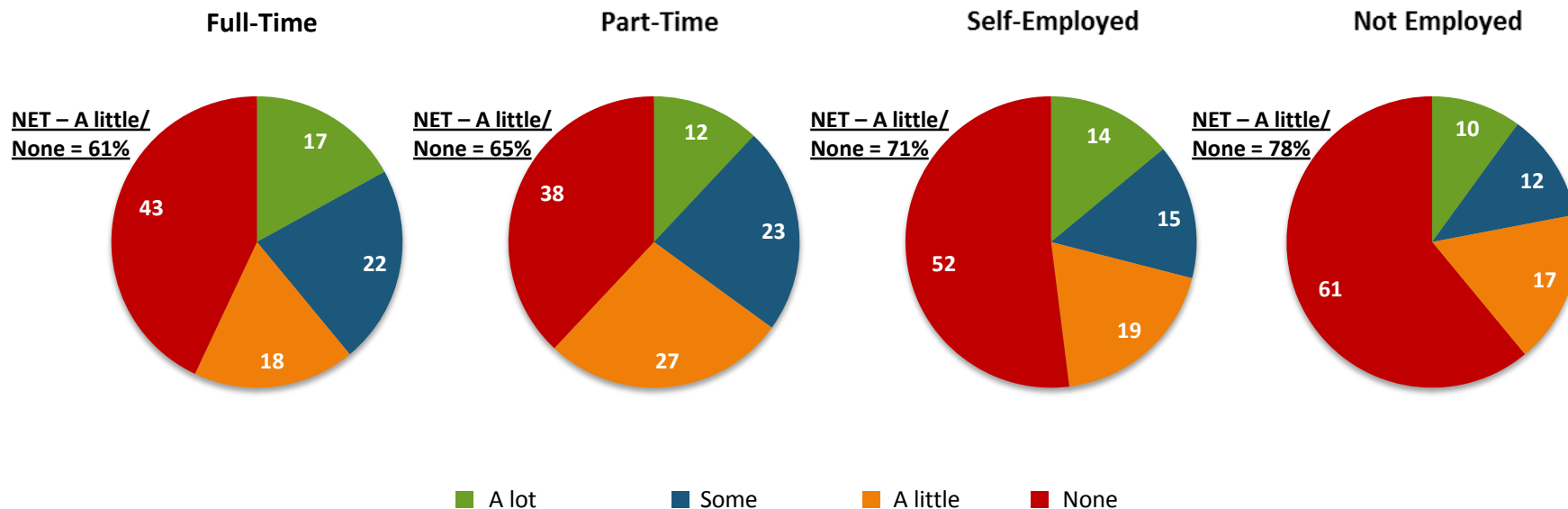
**“How would you describe your own financial well-being?” (%)**



# Financial Considerations Before Becoming Caregivers

Most caregivers gave little or no consideration to their own financial situation when deciding to become a caregiver, including caregivers who are employed full-time (61 percent), employed part-time (65 percent), self-employed (71 percent), and not employed (78 percent). Caregivers who are employed full-time (17 percent) are slightly more likely to have given their own financial situation a lot of consideration.

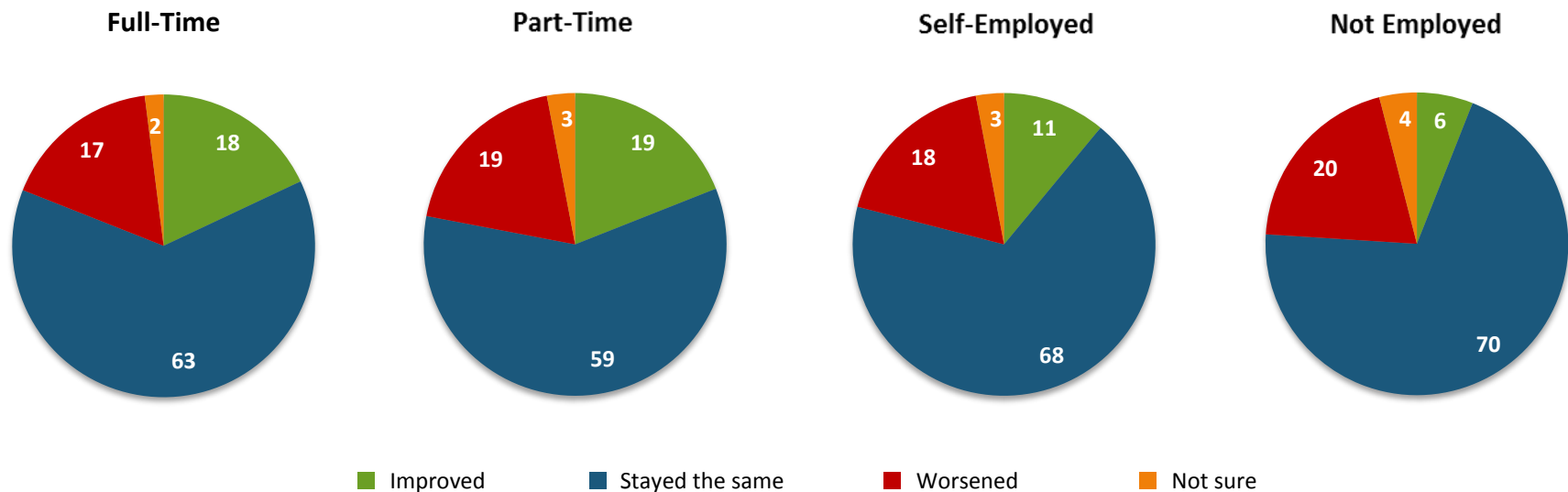
**“To what extent did you consider your own financial situation when deciding to become a caregiver?” (%)**



# Change in Financial Situation as a Result of Caregiving

Most caregivers believe that their financial situation has not changed as a result of becoming a caregiver, a finding that is relatively consistent among caregivers who are not employed (70 percent), self-employed (68 percent), employed part-time (59 percent), and employed full-time (63 percent). Approximately one in five caregivers across employment status indicate their financial situation has worsened since becoming a caregiver.

**“How has your financial situation changed as a result of becoming a caregiver?”**



Improved

Stayed the same

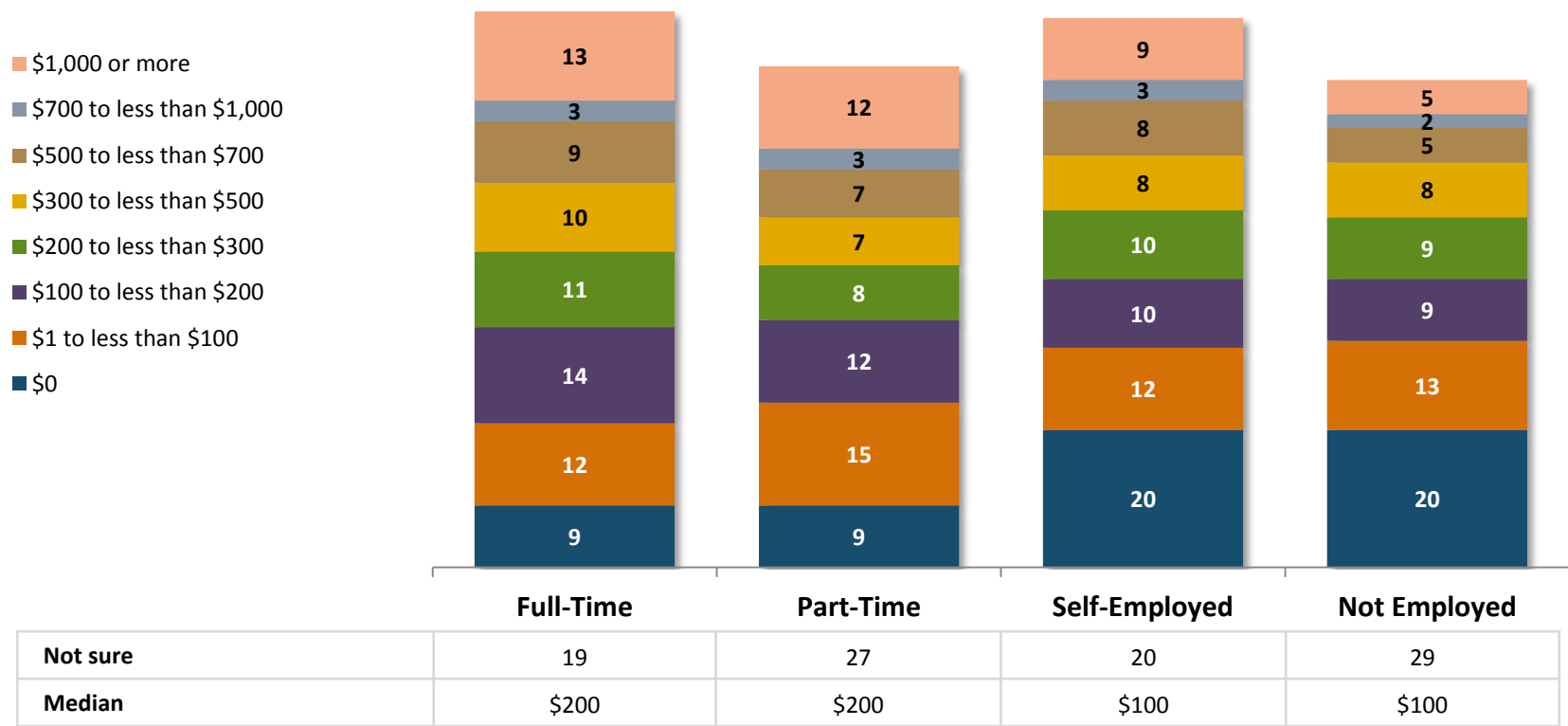
Worsened

Not sure

# Monthly Personal Expenditures for Caregiving

Caregivers who are employed full-time or part-time (both \$200 median) spend more money out-of-pocket per month to cover expenses for their care recipient than caregivers who are self-employed or not currently employed (both \$100 median).

Monthly Personal Expenditures to Cover Expenses for Care Recipient (%)



Note: The median is estimated based on the approximate midpoint of the range of each response category. Non-responses are excluded from the estimate.

# Financial Assistance for Caregiving Duties

While the majority of all caregivers do not receive compensation for their caregiving duties, caregivers who are employed full-time (32 percent) or part-time (42 percent) are somewhat more likely than those who are self-employed (23 percent) or not employed (14 percent) to receive any form of payment. Among those receiving payment, funds from the care recipient and family members are the most frequently cited sources.

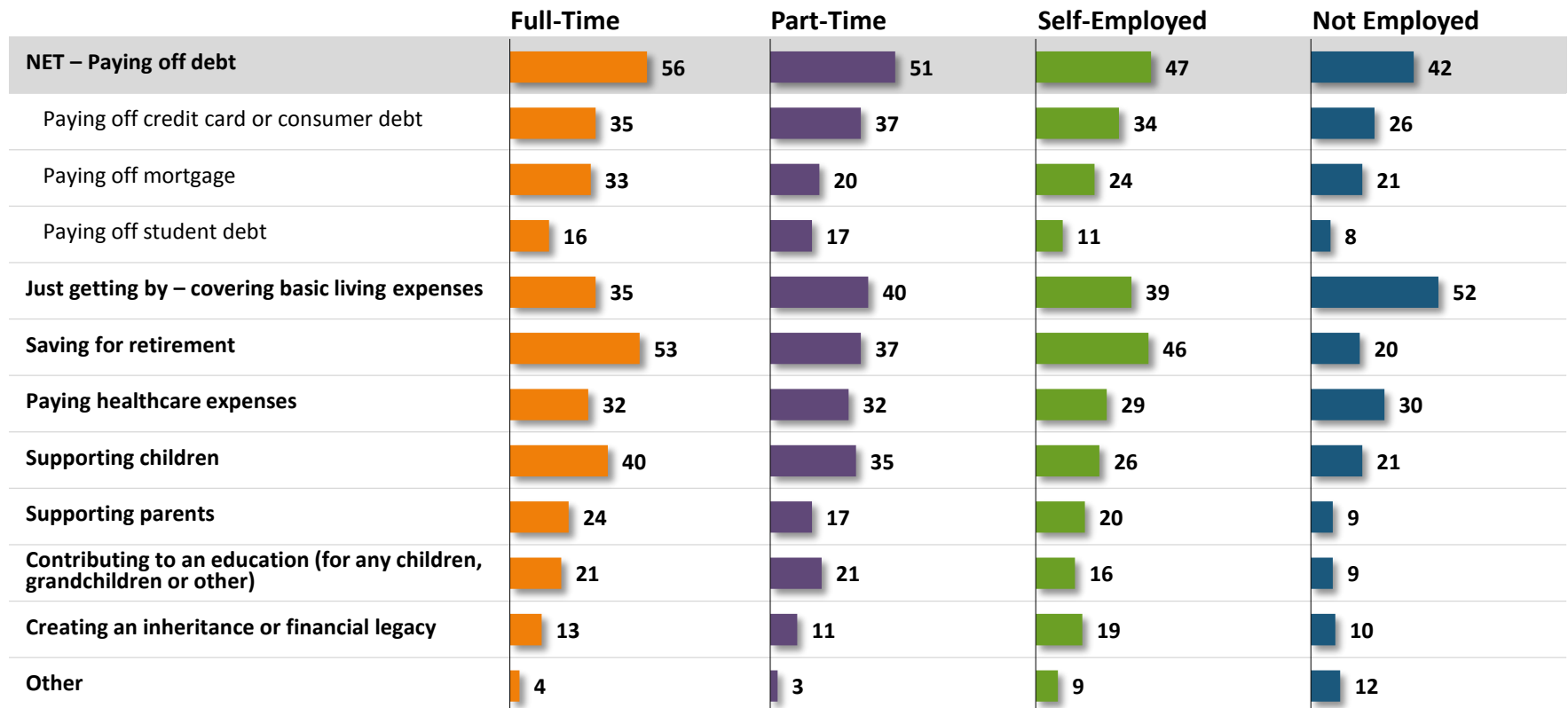
**Sources of Financial Assistance Received for Caregiving Duties, If Any (%)**



# Financial Priorities Among Caregivers

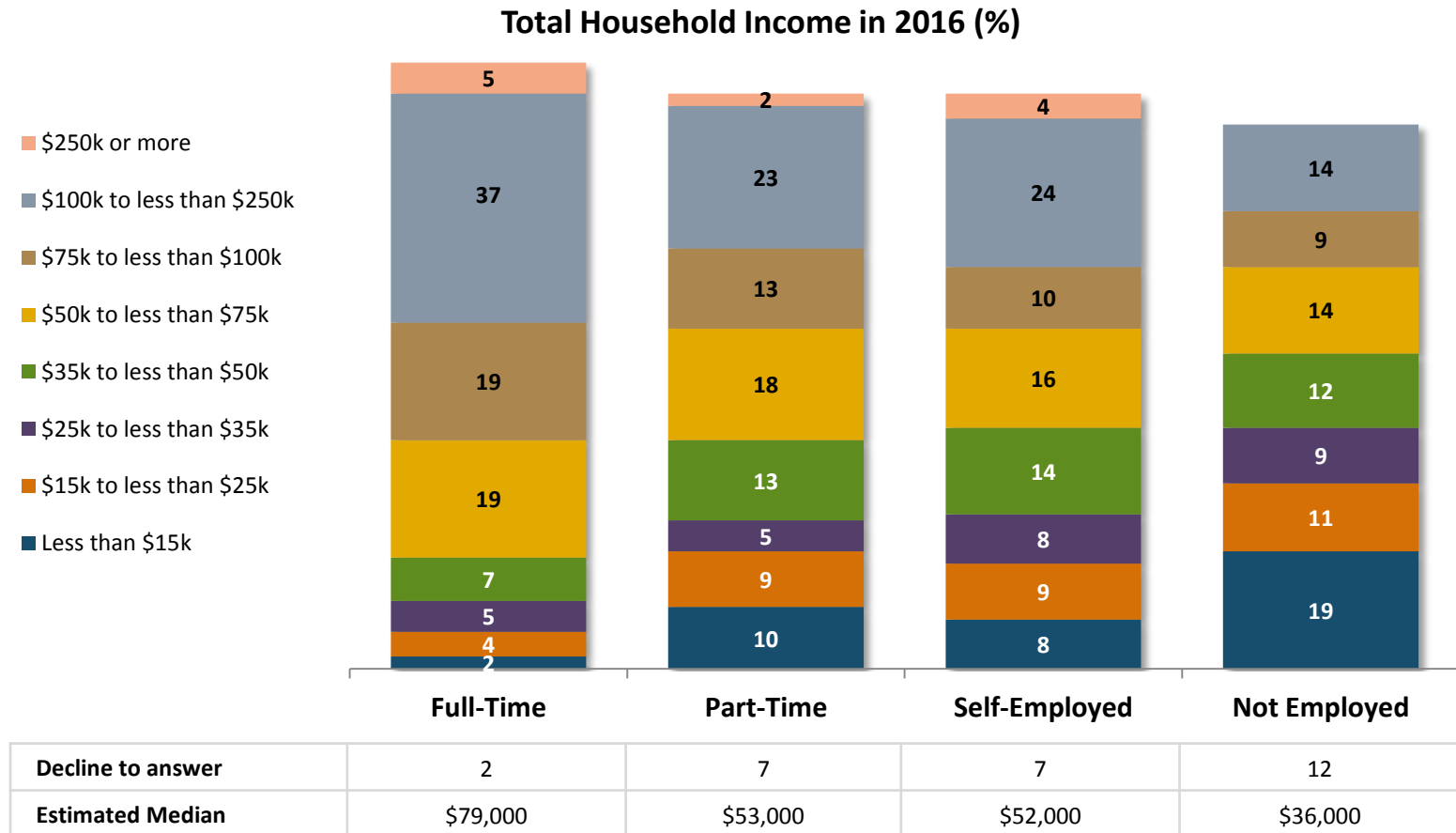
The most frequently cited financial priority among caregivers varies with caregiver employment status. Among caregivers who are employed full-time (56 percent), employed part-time (51 percent), and self-employed (47 percent), paying off some form of debt (Net) is the most frequently cited financial priority. For caregivers who are not employed (52 percent), just getting by – covering basic living expenses is the most frequently cited financial priority.

**“Which of the following are your financial priorities right now?” (%)**



# Total Household Income Among Caregivers

Caregivers who are employed full-time report the highest total household income in 2016 at \$79,000 (estimated median), followed by those who are employed part-time (\$53,000), self-employed (\$52,000), and not employed (\$36,000).



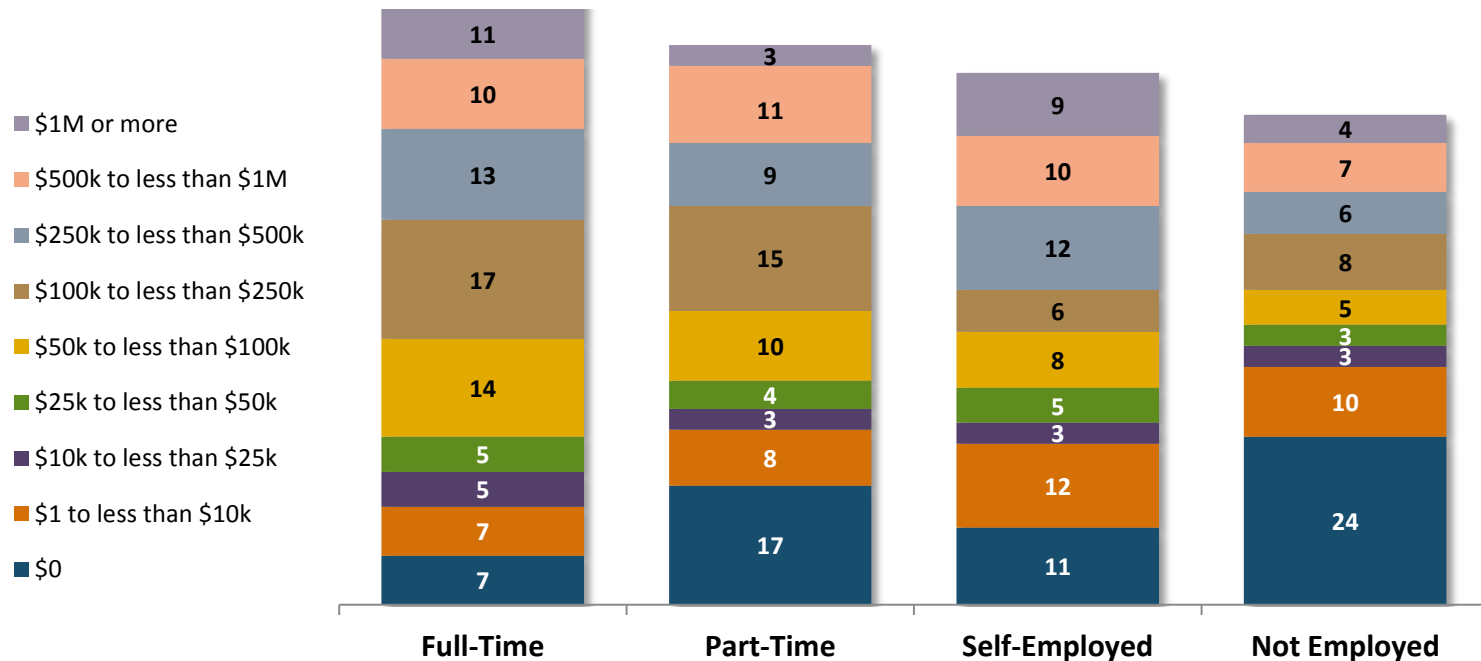
*Note: The median is estimated based on the approximate midpoint of the range of each response category. Non-responses are excluded from the estimate.*



# Total Household Retirement Savings Among Caregivers

Caregivers who are employed full-time report the most total household retirement savings in all accounts at \$117,000 (estimated median), followed those who are self-employed (\$72,000), employed part-time (\$68,000), and not employed (\$8,000). A noteworthy 24 percent of caregivers who are not employed and 17 percent of those who are employed part-time indicate they have no savings in retirement accounts.

**Total Household Retirement Savings in All Accounts (%)**



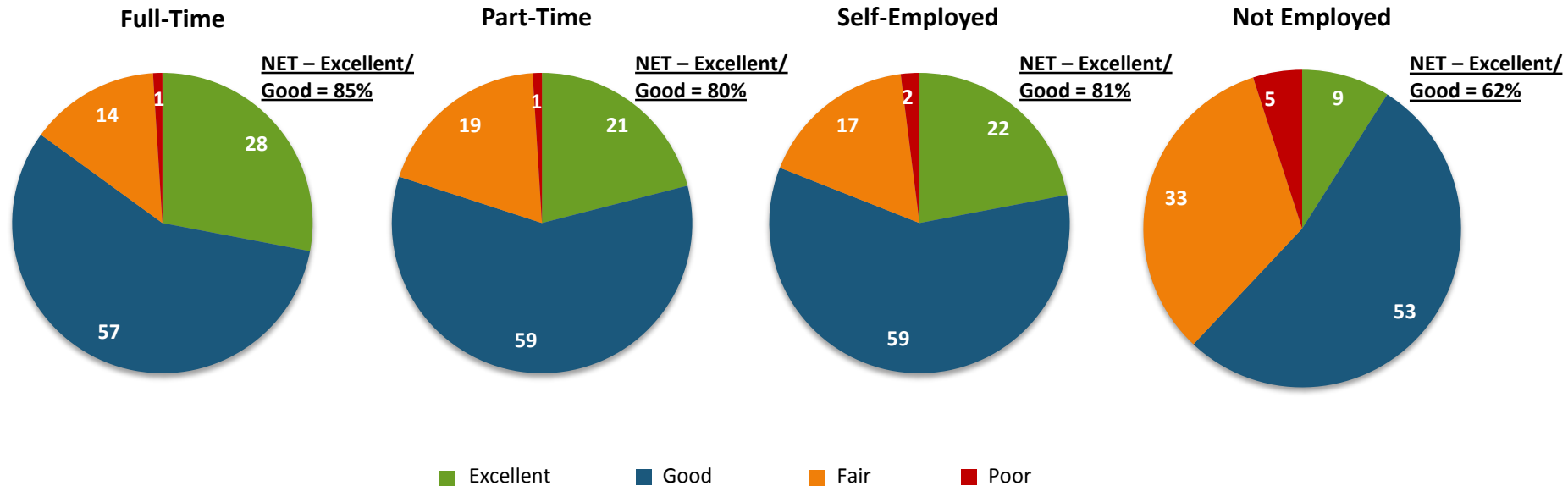
Not sure	6	7	14	17
Decline to answer	5	13	10	13
Estimated Median	\$117,000	\$68,000	\$72,000	\$8,000

*Note: The median is estimated based on the approximate midpoint of the range of each response category. Non-responses are excluded from the estimate.*

# Caregivers' Self-Described General Health

Most caregivers describe their general health as being excellent or good, a finding which is much higher among those who are employed full-time (85 percent), part-time (80 percent), or self-employed (81 percent), compared to those who are not employed (62 percent). A noteworthy 38 percent of caregivers who are not employed indicate their health is fair (33 percent) or poor (5 percent).

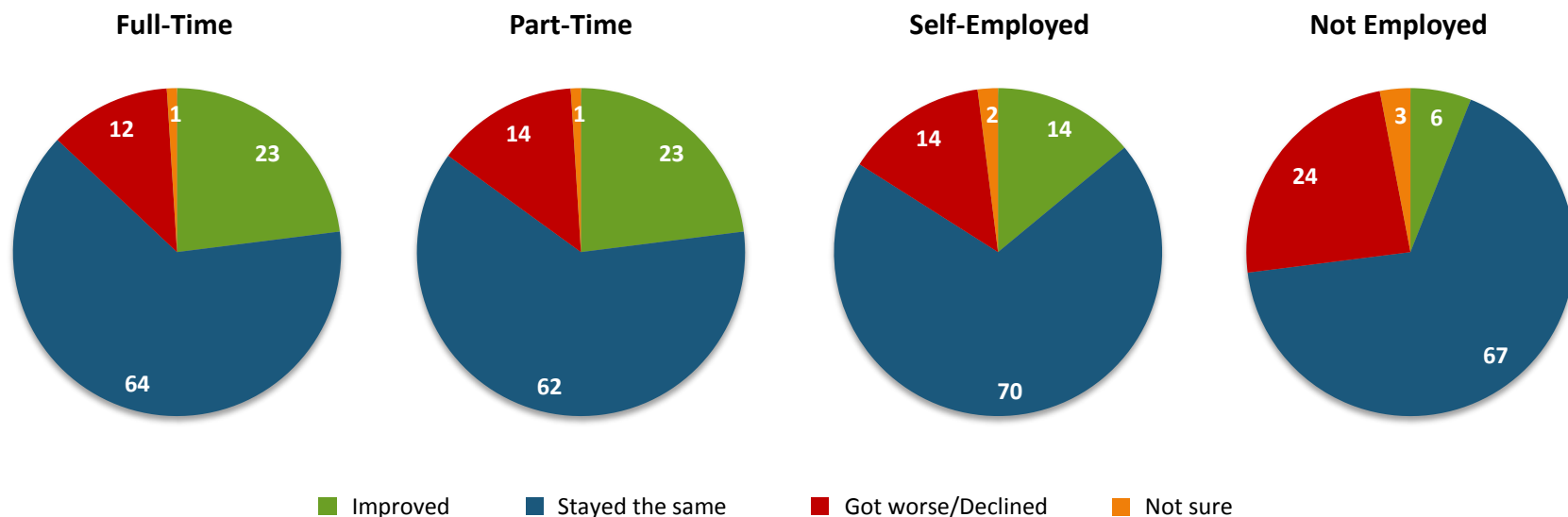
General Health Status (%)



# Changes in General Health Since Becoming a Caregiver

Most caregivers indicate their general health has stayed the same since becoming a caregiver, a finding which is relatively consistent among caregivers who are employed full-time (64 percent), employed part-time (62 percent), self-employed (70 percent), or not employed (67 percent). An alarming 24 percent of caregivers who are not employed say their general health has gotten worse / declined since becoming a caregiver, a finding that is much higher than that of caregivers who are employed full-time (12 percent), employed part-time (14 percent), and self-employed (14 percent). A noteworthy 23 percent of caregivers who are employed either full-time or part-time indicate their health has improved since becoming a caregiver.

**Changes in General Health Since Becoming a Caregiver (%)**



# Caregivers' Health Insurance

Most caregivers have health insurance, a finding which is relatively consistent among caregivers who are employed full-time (95 percent), employed part-time (86 percent), self-employed (86 percent), and not employed (89 percent). Caregivers who are employed full-time (67 percent) and part-time (34 percent) most frequently obtain health insurance through an employer, while caregivers who are not employed (37 percent) do so through Medicare and those who are self-employed (20 percent) do so from a private health insurance company.

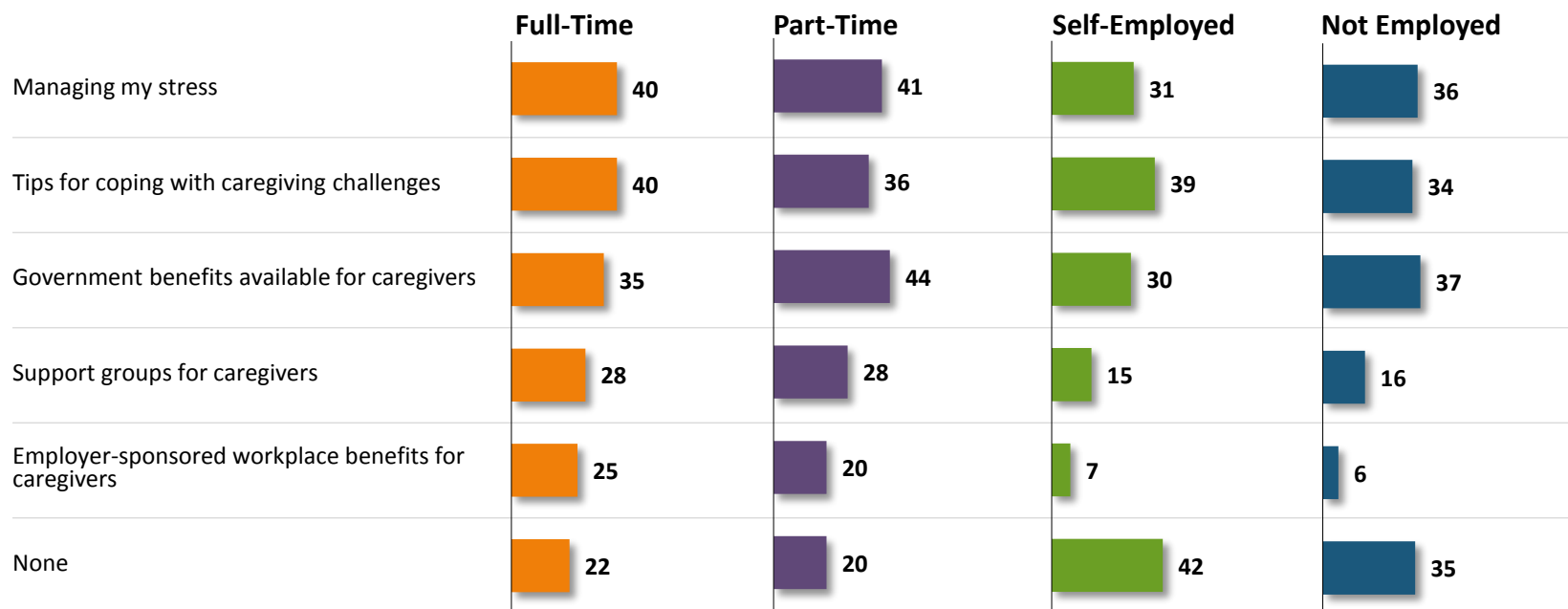
**“Which of the following best describes how you primarily receive health insurance?” (%)**

	Full-Time	Part-Time	Self-Employed	Not Employed
<b>NET – Have Insurance</b>	<b>95</b>	<b>86</b>	<b>86</b>	<b>89</b>
I receive benefits through an employer (mine or someone else's)	67	34	14	18
I receive benefits through a union (mine or someone else's)	4	4	2	1
I receive benefits through a trade association (mine or someone else's)	3	2	0	0
I receive benefits from a private insurance plan in the traditional market from my spouse	3	4	5	2
I receive benefits from a private insurance plan in the traditional market from my parents	2	1	0	2
I receive benefits through Medicare (for age or disability reasons)	3	12	17	37
I receive benefits through Medicaid or another state funded program	3	9	12	16
I receive benefits through military service (mine or someone else's)	0	2	1	2
I receive VA benefits from my own service or through my spouse	1	2	1	2
I receive benefits through my college or university	0	1	1	0
I buy my own health insurance from a private health insurance company	8	10	20	4
I buy my own health insurance public health insurance exchange, such as healthcare.gov or the state-based exchange	2	5	12	4
<b>I do not have health insurance at this time</b>	<b>5</b>	<b>14</b>	<b>14</b>	<b>11</b>

# Caregivers Would Like More Information to Help Them Personally

When asked what information they would like to help them personally with their caregiving responsibilities, caregivers most frequently cite topics such as stress management, tips for coping with caregiving challenges, and government benefits available for caregivers. These findings are directly consistent by employment status. Of note, caregivers who are employed are somewhat more likely to cite managing stress compared to those who are self-employed or not employed. Conversely, those who are self-employed or not employed are more likely to say “none.”

**“Which of the following topics would you like more information to help you personally with your caregiving responsibilities?” (%)**



NOTE: Five most commonly selected sources shown.

BASE: ALL QUALIFIED RESPONDENTS

Q850. Which of the following topics would you like more information to help you personally with your caregiving responsibilities? I would like more information about... Select all.



## Demographic Perspectives by Generation



# ***The Many Faces of Family Caregivers: A Close-Up Look at Caregiving and Its Implications***

## **A Portrait of Today's Caregivers**

- Demographic Perspectives
- Voluntary Status
- Employment Status

### **➤ Generations**

- Gender
- Household Income
- Race/Ethnicity

## **Appendix: Caregiver and Care Recipient Demographics**

## **Acknowledgements**

# Demographic Perspectives by Generation

Caregivers are well-represented across generations. Thirty-four percent are Millennials (born 1979 - 2000), 22 percent are Generation X (born 1965 - 1978), 37 percent are Baby Boomers (born 1946 – 1964), and 7 percent are Matures (born before 1946).

In this chapter, the survey explores the impact of caregiving responsibilities based on the caregiver's generation and finds some striking similarities and differences. Across generations, almost all caregivers feel that it is important to offer a high quality of life for the care recipient and approximately nine out of 10 indicate they like helping and enjoy spending time with the care recipient. To a greater or lesser extent, they perform the same types of caregiving duties.

Millennial and Generation X caregivers are more likely to be employed than Baby Boomer and Mature caregivers – and Matures and Baby Boomers are more likely to be retired. However, among caregivers who are employed, Millennials are more likely to have experienced some form of adverse action taken by their employers as a result of their caregiving.

Millennial caregivers tend to be better off financially and in better health than Generation X, Baby Boomer and Mature caregivers, who all are similarly likely to be in excellent or good health. However, Baby Boomer caregivers are the most likely across the four generations to indicate their health has declined since becoming a caregiver.

Of the four generations, Generation X caregivers are facing financial-related challenges and have saved the least for retirement. Mature caregivers are most often caring for a spouse or partner, have the most saved for retirement and spend the most time caregiving each month, compared to the three younger generations.

## *Twenty-Six Facts About Caregivers by Generation*

- **Most Consider Themselves to Be the Primary Caregivers.** At least two-thirds of caregivers across generations consider themselves to be the Primary caregiver for their care recipient, a finding that is higher among Matures (76 percent) compared to Millennials (68 percent), Generation X (67 percent), and Baby Boomers (67 percent).
- **The Majority of Caregivers Are Caring for a Family Member.** More than four in five caregivers are caring for a family member; however, the nature of family relationship varies by generation. Matures (57 percent) are by far most likely to be caring for a spouse or partner, compared to Baby Boomers (24 percent), Generation X (11 percent) and Millennials (12 percent). Generation X and Baby Boomers (both 42 percent) are more likely to be caring for a parent, compared to Millennials (24 percent) and Matures (8 percent). Millennials (14 percent) and Generation X (12 percent) are more likely to be caring for a child than Matures (8 percent) and Baby Boomers (7 percent). Millennials (21 percent) are more likely to be caring for a grandparent compared to older generations.



# Demographic Perspectives by Generation

- **Reasons for Becoming a Caregiver.** Across generations, a frequently cited reason for becoming a caregiver is the desire to care for their loved one, albeit a more prevalent reason among Baby Boomers (70 percent) and Matures (69 percent) compared to Generation X (59 percent) and Millennials (58 percent). Other frequently cited reasons are having a close relationship to the care recipient, having the time and capacity to do so, and living in close proximity to the care recipient. Approximately one in five caregivers said that nobody else was willing to do so, a finding which is higher among Millennials (16 percent), Generation X (20 percent), and Baby Boomers (18 percent) compared to Matures (9 percent).
- **Total Caregiving Hours per Month.** Mature caregivers spend the most time caregiving per month by far at 112 hours (median), followed by Generation X caregivers (60 hours), Baby Boomers (54 hours), and Millennials (40 hours). Fifty-seven percent of Mature caregivers and 37 percent of both Generation X and Baby Boomer caregivers spend 100 hours or more per month on caregiving each month, compared to 31 percent of Millennial caregivers.
- **Caregiver Duties Performed.** Caregiving encompasses a broad range of duties including household, social/communication, health-related, personal care, medical-related, and paying bills and managing finances. While many caregivers are involved in these diverse duties, across generations, Matures and Baby Boomers are typically more likely to be involved than Generation X and Millennials. For example, 80 percent of Matures and 79 percent of Baby Boomers are involved in health-related duties (i.e., accompanying to medical appointments, healthcare coordination, health insurance coordination) compared to 70 percent of Generation X and 56 percent of Millennials. However, one noteworthy exception, is that Millennials (72 percent) are more likely than Generation X (61 percent), Baby Boomers (56 percent) and Matures (54 percent) to perform personal-related care duties.
- **Hours Spent Caregiving by Types of Duties.** Caregivers spend the most time engaging in companionship with the care recipient, meal preparation, feeding, and personal care. Matures, Baby Boomers and Generation X typically spend more time than Millennials on these activities each month.
  - Matures (90 hours median), Generation X (40 hours) and Baby Boomers (35 hours) spend more time per month than Millennials (20 hours) on companionship.
  - Matures spend 30 hours (median) per month on meal preparation while both Generation X and Baby Boomers spend 20 hours and Millennials spend 15 hours per month doing so.

# Demographic Perspectives by Generation

- **Sources of Information Relied on to Assist in Caregiving Duties.** Family and friends and medical professionals are the most frequently relied upon sources of information to assist in caregiving duties. Millennials (48 percent) most frequently rely on family and friends, while Matures (64 percent) and Baby Boomers (50 percent) most frequently rely on medical professionals, and Generation X caregivers rely on each nearly equally (47 and 46 percent, respectively). Millennials are typically more likely to rely on online resources (e.g., websites). A noteworthy 24 percent of Matures and 23 percent of Baby Boomers do not rely on any information sources.
- **Sources for Learning About Medical/Nursing Tasks.** Among caregivers performing medical/nursing-related tasks, most learned how to perform these tasks from hospital or doctor's office personnel, a finding which is consistent among Millennials (54 percent), Generation X and Baby Boomers (both 56 percent), but lower among Matures (41 percent). Millennials (53 percent) are more likely to have learned from family and friends compared to Generation X (33 percent), Baby Boomers (26 percent), and Matures (22 percent). Millennials are also more likely than older generations to have learned from caregiver guides, formal education, and online resources, whereas 36 percent of Matures did not use any resources.
- **Caregivers' Sentiments About Their Caregiving Duties.** Almost all caregivers agree that it is important to provide a good quality of life for their care recipient – including 93 percent of Millennials, 92 percent of Generation X and 97 percent of both Baby Boomers and Matures. Across generations, approximately nine out of 10 Millennials, Generation X, Baby Boomers, and Matures indicate they like helping and enjoy spending time with the care recipient. Generation X (61 percent) and Millennials (59 percent) are more likely than Baby Boomers (49 percent) and Matures (44 percent) to say their own health takes a back seat to the health of their care recipients.
- **Employment Status of Caregivers.** The majority of Millennial (68 percent) and Generation X (62 percent) caregivers are employed, while fewer Baby Boomers (37 percent) and Matures (8 percent) are. Fifty-four percent of Baby Boomers are not employed, including 35 percent who are retired. The majority of Matures are retired (78 percent). Twenty-six percent of Millennials and Generation X are not employed. Twelve percent of Generation X, 10 percent of Matures, and 9 percent of Baby Boomers are self-employed, findings that are slightly higher than for Millennials (6 percent).

# Demographic Perspectives by Generation

- **Disruptions to Employment as a Result of Caregiving.** Caregiving responsibilities can be disruptive to a caregiver's employment situation. Among caregivers who are employed or who have been employed during their time as caregivers, some have had to reduce their hours or job responsibilities, take leave from their position, or quit their job or retire early in order to accommodate their caregiving duties.
  - 33 percent of Millennials have reduced their hours or job responsibilities.
  - 24 percent of Millennials and 17 percent of Generation X have taken a leave of absence.
  - 17 percent of Baby Boomers have retired early/quit their job.
- **Informing Coworkers About Their Caregiving Duties.** Among caregivers who are employed full-time or part-time, most have told their immediate supervisor that they are a caregiver, including Baby Boomers (63 percent), followed by Millennials (56 percent) and Generation X (53 percent). Millennials (27 percent) are more likely to have told Human Resources compared to Generation X (18 percent) and Baby Boomers (14 percent). A higher percentage of Baby Boomers (47 percentage) have told their other coworkers, compared to Generation X (34 percent) and Millennials (19 percent). Generation X (29 percent) and Baby Boomers (24 percent) are somewhat more likely than Millennials (18 percent) to not tell anyone at work that they are a caregiver.
- **Employer Support of Caregiving Duties.** Most caregivers who work full-time or part-time feel that their employers are supportive of their caregiving duties. Millennials (77 percent) are most likely to indicate their employers are very or somewhat supportive, followed by Generation X (70 percent) and Baby Boomers (63 percent). Fewer than one in five caregivers indicate their employers are not too supportive or not at all supportive, a finding that is consistent among Millennials (16 percent), Generation X (17 percent), and Baby Boomers (18 percent).
- **Adverse Actions Taken by Employers.** Caregiving duties may conflict with job responsibilities which may lead to adverse actions taken by an employer. Among caregivers who are currently employed or who have been employed during their time as caregivers, Millennials (44 percent) are more likely than Generation X (24 percent) and Baby Boomers (12 percent) to have experienced an adverse employment action such as being fired, written up or admonished, given less attractive assignments, passed over for a promotion, discriminated against, forcibly had hours or duties reduced and/or some other action.
- **Caregivers' Financial Well-Being.** Mature (73 percent) and Millennial caregivers (63 percent) are more likely to say that their financial well-being is excellent or good compared to about one-half of Generation X (48 percent) and Baby Boomers (51 percent). Generation X (19 percent) are slightly more likely than Millennials (14 percent) and Baby Boomers (16 percent) to describe their financial well-being as poor. Only four percent of Matures describe their financial well-being as poor.

# Demographic Perspectives by Generation

- **Financial Considerations Before Becoming Caregivers.** The majority of Mature (79 percent), Baby Boomer (78 percent), Generation X (69 percent), and Millennial (56 percent) caregivers gave little or no consideration to their own financial situation when deciding to become a caregiver. Although Millennials are more likely to have given at least some consideration to their financial situation, only 20 percent say that they gave it a lot of consideration.
- **Change in Financial Situation as a Result of Caregiving.** Most caregivers say that their financial situation has stayed the same as a result of becoming a caregiver, a finding which is higher among Matures (83 percent) compared to Baby Boomers (70 percent), Generation X (61 percent) and Millennials (60 percent). Twenty-two percent of both Generation X and Baby Boomer caregivers say that their financial situation has worsened, compared to only 13 percent of Millennials and 11 percent of Matures. Of note, Millennials (22 percent) are more likely than Generation X (12 percent) and Baby Boomers and Matures (both 5 percent) to say that their financial situation has improved.
- **Monthly Personal Expenditures for Caregiving.** Mature (\$275 median) and Millennial (\$220 median) caregivers are spending more money out-of-pocket per month to cover expenses for their care recipient than Generation X and Baby Boomers (\$100 median each). Fifteen percent of Millennials spend \$1,000 or more dollars per month for their care recipient, compared to 10 percent of Matures, 6 percent of Generation X and 5 percent of Baby Boomers. Nearly two out of five (39 percent) Matures aren't sure how much they're spending.
- **Financial Assistance for Caregiving Duties.** Most caregivers do not receive any form of payment for their caregiving duties, including the vast majority of Matures (94 percent), Baby Boomers (89 percent), and Generation X (76 percent) – and notably fewer Millennials (55 percent). Among those receiving payment, funds from the care recipient and family members are the most frequently cited sources. Millennials (11 percent) are more likely than older generations to be receiving funds from government subsidies.
- **Financial Priorities Among Caregivers.** Paying off some form of debt (i.e., credit card, consumer, mortgage, and/or student debt) is the most frequently cited current financial priority among Millennials (50 percent), Generation X (55 percent), and Baby Boomers (47 percent). Paying healthcare expenses is the most frequently cited priority among Matures (37 percent). More than 40 percent of Generation X, Baby Boomer, and Millennial caregivers cite “just getting by” as a priority, compared to only 25 percent of Mature caregivers. Generation X caregivers (46 percent) are more likely to cite “saving for retirement,” compared to 36 percent of Millennials and 39 percent of Baby Boomers. Twenty-one percent of Mature caregivers cite creating an inheritance or financial legacy as a priority.

# Demographic Perspectives by Generation

- **Total Household Income Among Caregivers.** Across generations, Millennial caregivers report having the highest total household income of \$69,000 (estimated median), compared to Generation X (\$56,000 estimated median), Matures (\$51,000 estimated median) and Baby Boomers (\$48,000 estimated median). Thirty-five percent of Millennial caregivers have total household incomes of \$100,000 or more annually, while only 25 percent of Generation X, 23 percent of Baby Boomer, and 21 percent of Mature caregivers report the same level of income.
- **Total Household Retirement Savings Among Caregivers.** Total household retirement savings vary among caregivers across generations. Generation X caregivers have saved \$31,000 (estimated median), an amount that is less than Baby Boomers (\$75,000 estimated median), Millennials (\$84,000 estimated median), and Matures (\$128,000 estimated median). More Generation X caregivers (41 percent) have saved less than \$50,000 than any of the other generations. Of concern, 19 percent of Generation X caregivers report having nothing in retirement savings, followed by 15 percent of both Millennial and Baby Boomers, and 7 percent of Matures.
- **Caregivers' Self-Described General Health.** Most caregivers self-describe their general health as being excellent or good – including 83 percent of Millennials, 73 percent of Matures, 71 percent of Baby Boomers, and 69 percent of Generation X. Across generations, Generation X (31 percent), Baby Boomers (29 percent), and Matures (27 percent) are more likely than Millennials (17 percent) to say they are in fair or poor health.
- **Changes in General Health Since Becoming a Caregiver.** Most caregivers say that their general health has stayed the same since becoming a caregiver, including 73 percent of Matures, 68 percent of Baby Boomers, 66 percent of Generation X, and 60 percent of Millennials. However, nearly one in four Baby Boomers (23 percent) indicate their health has declined, a finding that is slightly higher than for Matures (19 percent), Generation X (18 percent), and Millennials (10 percent). On the other hand, Millennials (28 percent) are more likely to report that their general health has actually improved since becoming a caregiver, compared to Generation X (14 percent), Baby Boomers (7 percent), and Matures (5 percent).
- **Caregivers' Health Insurance.** Nine out of 10 Millennial, Generation X (both 88 percent); and Baby Boomer (93 percent) caregivers have health insurance, while fully 100 percent of Matures have health insurance. Eighty percent of Matures receive benefits through Medicare. Employer benefits are the most common source of health insurance for Millennials (44 percent), Generation X (49 percent), and Baby Boomers (38 percent). Twelve percent of Millennials and Generation X do not have health insurance, compared to 7 percent of Baby Boomers and no Matures.

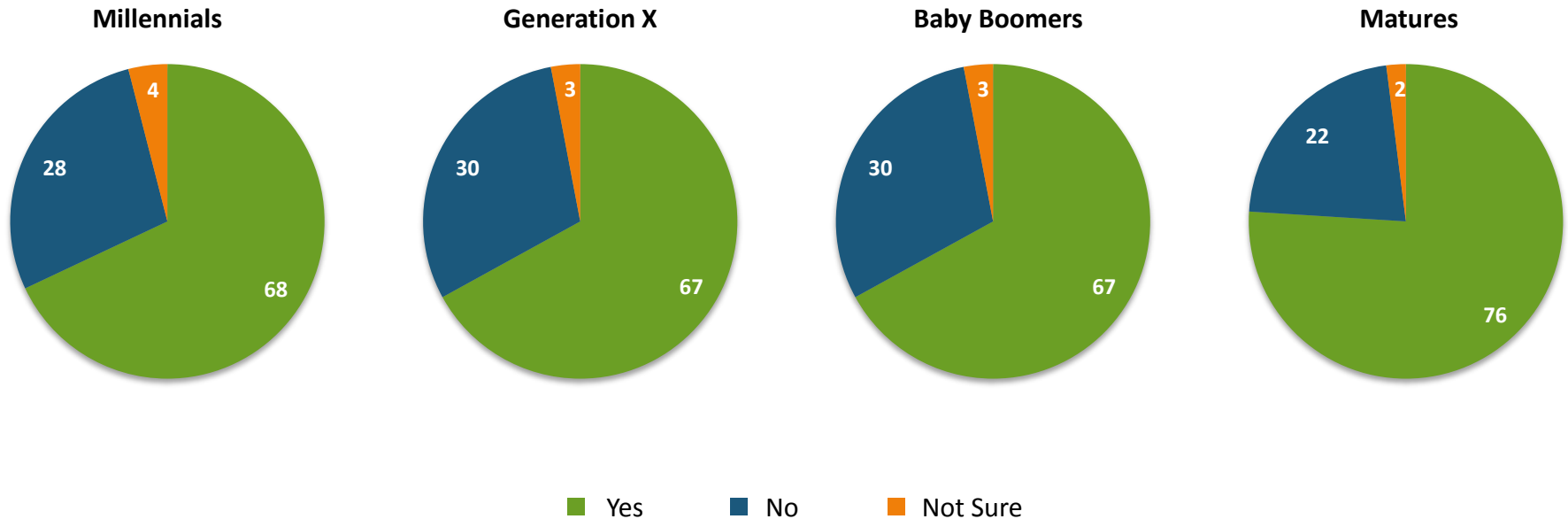
# Demographic Perspectives by Generation

- **Caregivers Would Like More Information to Help Them Personally.** Millennial, Generation X and Baby Boomer caregivers share a similar desire to receive more information to help them personally with their caregiving responsibilities to manage stress, get tips for coping with caregiving challenges, and learn about government benefits available to them. Mature caregivers are somewhat less likely to express an interest in various topics. Managing stress is the most frequently cited topic among Millennials (44 percent) and Generation X (42 percent), while information about government benefits is most frequently cited by Baby Boomers (38 percent) and Matures (35 percent). Millennials are more likely to want information about support groups (32 percent) and employer-sponsored workplace benefits for caregivers (25 percent) compared to older caregivers. A noteworthy 39 percent of Baby Boomers and Matures do not want any additional information.

# Most Consider Themselves to Be the Primary Caregivers

At least two-thirds of caregivers across generations consider themselves to be the Primary caregiver for their care recipient, a finding that is higher among Matures (76 percent) compared to Millennials (68 percent), Generation X (67 percent), and Baby Boomers (67 percent).

“Would you consider yourself to be the Primary caregiver?” (%)

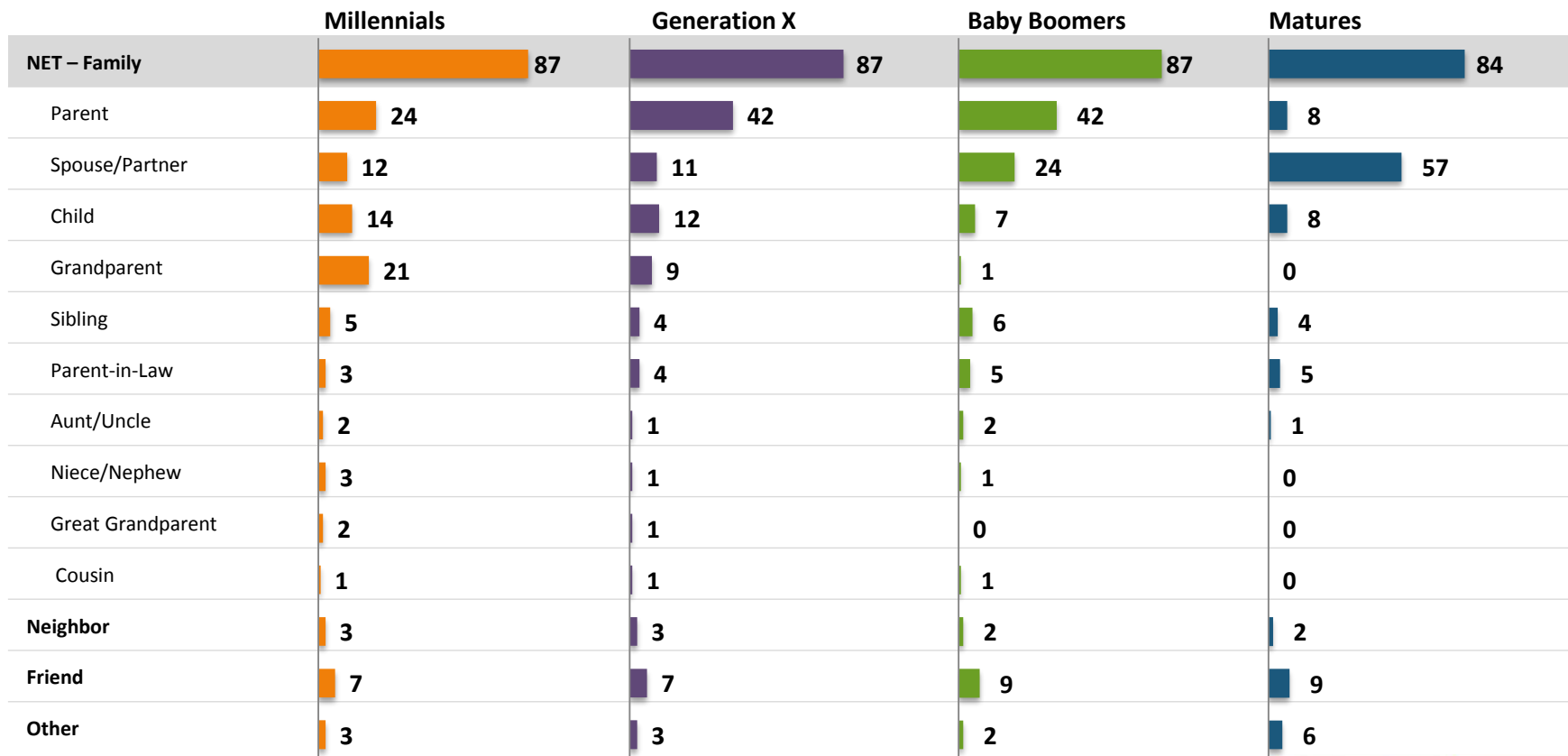


■ Yes ■ No ■ Not Sure

# The Majority of Caregivers Are Caring for a Family Member

More than four in five caregivers are caring for a family member; however, the nature of family relationship varies by generation. Matures (57 percent) are by far most likely to be caring for a spouse or partner, compared to Baby Boomers (24 percent), Generation X (11 percent) and Millennials (12 percent). Generation X and Baby Boomers (both 42 percent) are more likely to be caring for a parent, compared to Millennials (24 percent) and Matures (8 percent). Millennials (14 percent) and Generation X (12 percent) are more likely to be caring for a child than Matures (8 percent) and Baby Boomers (7 percent). Millennials (21 percent) are more likely to be caring for a grandparent compared to older generations.

**Relationship to Care Recipient (%)**



BASE: ALL QUALIFIED RESPONDENTS

Q700. You mentioned providing care for [INSERT ANSWER FROM Q610] individual(s).

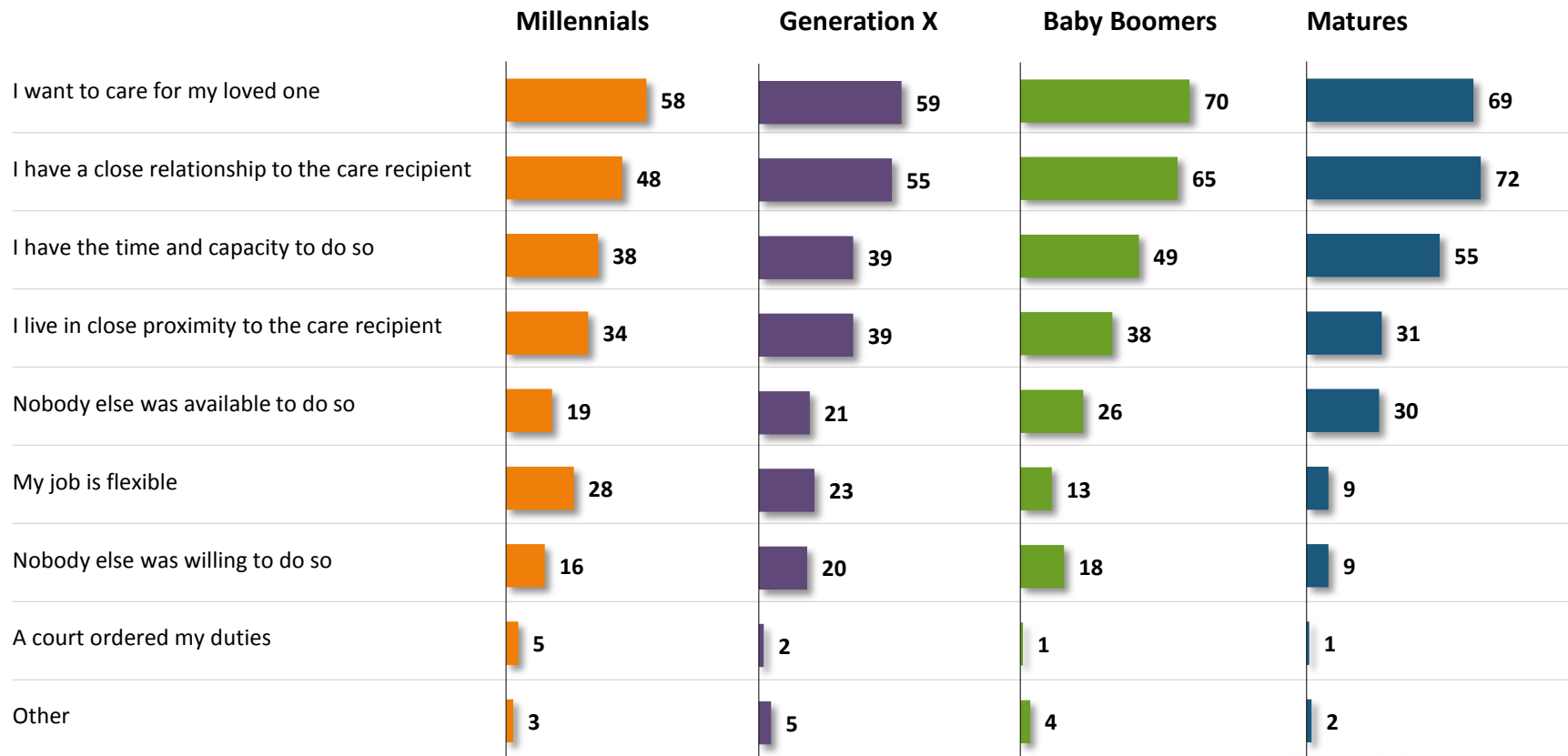
Please let us know your relationship to the person, their age, and their gender.



# Reasons for Becoming a Caregiver

Across generations, a frequently cited reason for becoming a caregiver is the desire to care for their loved one, albeit a more prevalent reason among Baby Boomers (70 percent) and Matures (69 percent) compared to Generation X (59 percent) and Millennials (58 percent). Other frequently cited reasons are having a close relationship to the care recipient, having the time and capacity to do so, and living in close proximity to the care recipient. Approximately one in five caregivers said that nobody else was willing to do so, a finding which is higher among Millennials (16 percent), Generation X (20 percent), and Baby Boomers (18 percent) compared to Matures (9 percent).

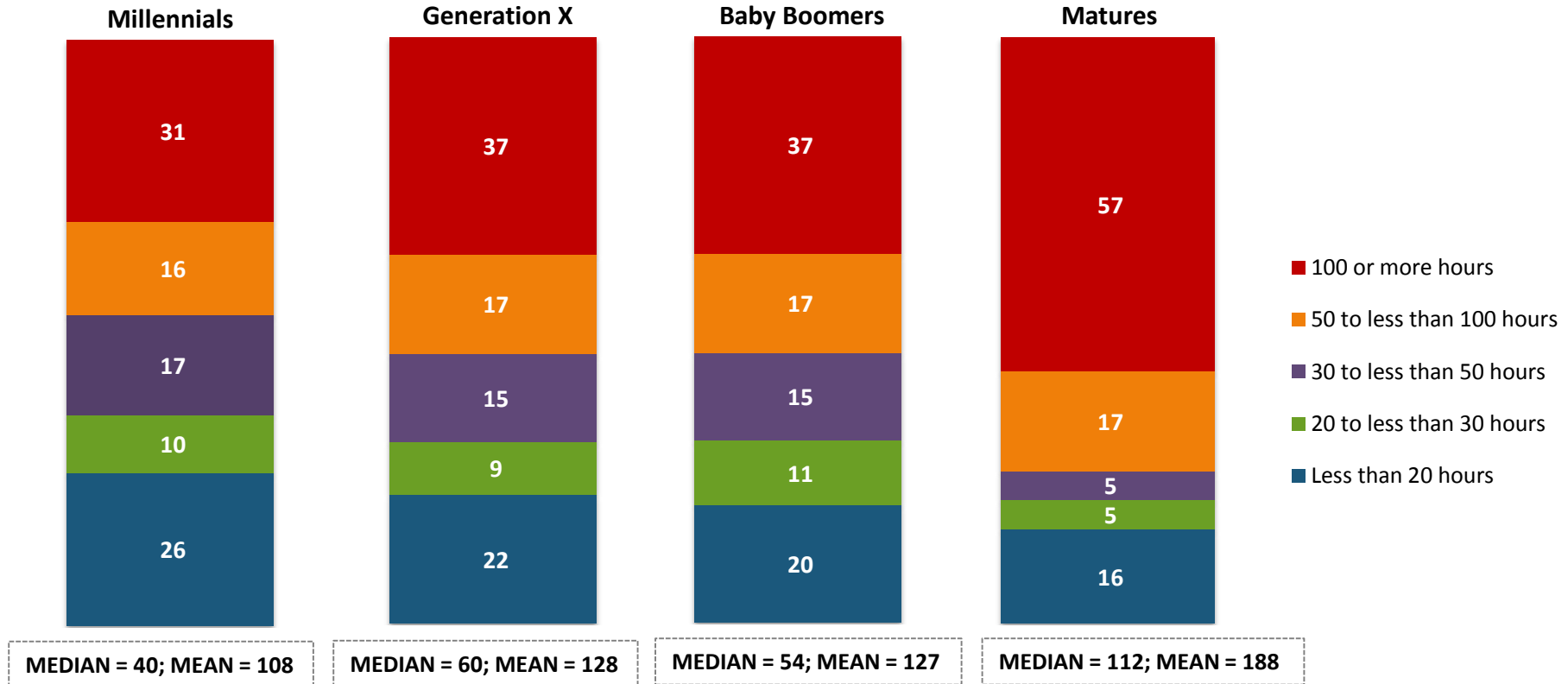
**Reasons for Becoming a Caregiver (%)**



# Total Caregiving Hours per Month

Mature caregivers spend the most time caregiving per month by far at 112 hours (median), followed by Generation X caregivers (60 hours), Baby Boomers (54 hours), and Millennials (40 hours). Fifty-seven percent of Mature caregivers and 37 percent of both Generation X and Baby Boomer caregivers spend 100 hours or more per month on caregiving each month, compared to 31 percent of Millennial caregivers.

**Total Hours Spent Caregiving Each Month (%)**



*Note: The median is the midpoint of the range of each response category. The mean is the average of all responses.*

BASE: ALL QUALIFIED RESPONDENTS

Q832. In total, approximately how many hours per month do you spend caring for the care recipient?

# Caregiver Duties Performed

Caregiving encompasses a broad range of duties including household, social/communication, health-related, personal care, medical-related, and paying bills and managing finances.

While many caregivers are involved in these diverse duties, across generations, Matures and Baby Boomers are typically more likely to be involved than Generation X and Millennials.

For example, 80 percent of Matures and 79 percent of Baby Boomers are involved in health-related duties (i.e., accompanying to medical appointments, healthcare coordination, health insurance coordination) compared to 70 percent of Generation X and 56 percent of Millennials.

However, one noteworthy exception, is that Millennials (72 percent) are more likely than Generation X (61 percent), Baby Boomers (56 percent) and Matures (54 percent) to perform personal-related care duties.

Types of Caregiving Duties Performed	Millennials	Generation X	Baby Boomers	Matures
<b>NET – Household</b>	<b>84%</b>	<b>90%</b>	<b>94%</b>	<b>88%</b>
Running errands	54%	71%	78%	73%
Housework	51%	64%	66%	64%
Meal preparation	53%	60%	62%	63%
Home repairs	22%	32%	36%	33%
Home modifications	16%	21%	21%	21%
<b>NET – Social/Communication</b>	<b>63%</b>	<b>74%</b>	<b>77%</b>	<b>84%</b>
Companionship	47%	62%	71%	80%
Basic communications	32%	30%	29%	38%
Language translation	10%	8%	5%	2%
<b>NET – Health-Related</b>	<b>56%</b>	<b>70%</b>	<b>79%</b>	<b>80%</b>
Accompanying to medical appointments	45%	62%	73%	75%
Healthcare coordination	30%	47%	53%	59%
Health insurance	20%	30%	36%	42%
<b>NET – Personal Care</b>	<b>72%</b>	<b>61%</b>	<b>56%</b>	<b>54%</b>
Mobility	35%	41%	40%	46%
Personal care	40%	36%	31%	30%
Feeding	39%	29%	17%	13%
Incontinence care	14%	14%	16%	18%
<b>NET – Medical-Related</b>	<b>46%</b>	<b>50%</b>	<b>52%</b>	<b>50%</b>
Medication management	39%	47%	49%	49%
Medical treatment administration	19%	16%	14%	15%
<b>Paying bills/Managing finances</b>	<b>31%</b>	<b>42%</b>	<b>52%</b>	<b>63%</b>
<b>Other</b>	<b>3%</b>	<b>3%</b>	<b>4%</b>	<b>11%</b>

# Hours Spent Caregiving by Types of Duties

Caregivers spend the most time engaging in companionship with the care recipient, meal preparation, feeding, and personal care.

Matures, Baby Boomers and Generation X typically spend more time than Millennials on these activities each month.

For example, Matures (90 hours median), Generation X (40 hours) and Baby Boomers (35 hours) spend more time per month than Millennials (20 hours) on companionship.

Matures spend 30 hours (median) per month on meal preparation while both Generation X and Baby Boomers spend 20 hours and Millennials spend 15 hours per month doing so.

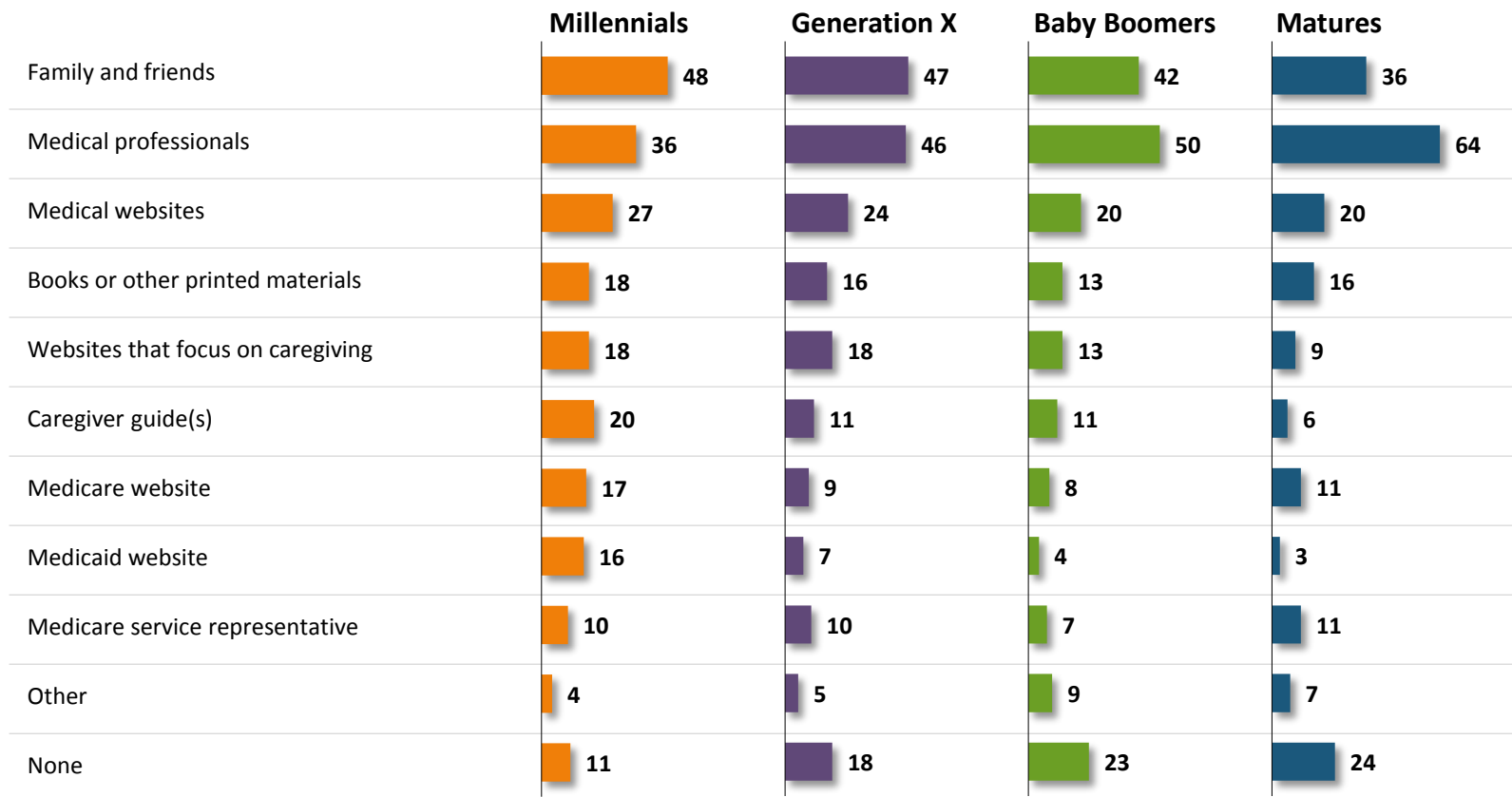
*Note: The median is the midpoint of the range of each response category. The mean is the average of all responses.*

Time Spent On Caregiving Duties Each Month (hours per month)	Millennials		Generation X		Baby Boomers		Matures	
	Median	Mean	Median	Mean	Median	Mean	Median	Mean
<b>Household</b>								
Running errands	8	21	8	21	8	14	10	23
Housework (e.g., cleaning, laundry)	12	35	12	26	10	22	10	32
Meal preparation	15	32	20	29	20	31	30	42
Home repairs	5	15	3	8	2	5	2	24
Home modifications	5	10	4	10	1	4	2	17
<b>Social/Communication</b>								
Companionship	20	84	40	81	35	92	90	145
Basic communications	10	49	10	43	8	36	20	72
Language translation	5	12	5	16	5	17	3	24
<b>Health-Related</b>								
Accompanying to medical appointments	5	15	4	8	4	9	5	16
Healthcare coordination	4	16	3	7	2	6	3	11
Health insurance coordination	4	16	2	6	2	5	2	14
<b>Personal Care</b>								
Mobility	10	26	10	26	8	17	10	39
Personal care	12	31	16	23	12	21	12	24
Feeding	10	34	15	31	15	28	30	72
Incontinence care	8	23	7	17	5	23	7	24
<b>Medical-Related</b>								
Medication management	7	24	5	12	4	12	4	22
Medical treatment administration	6	22	6	18	4	11	4	25
Paying bills/Managing finances	4	11	4	6	3	8	3	17
Other	3	41	20	25	4	32	8	190

# Sources of Information Relied on to Assist in Caregiving Duties

Family and friends and medical professionals are the most frequently relied upon sources of information to assist in caregiving duties. Millennials (48 percent) most frequently rely on family and friends, while Matures (64 percent) and Baby Boomers (50 percent) most frequently rely on medical professionals, and Generation X caregivers rely on each nearly equally (47 and 46 percent, respectively). Millennials are typically more likely to rely on online resources (e.g., websites). A noteworthy 24 percent of Matures and 23 percent of Baby Boomers do not rely on any information sources.

**Sources of Information to Assist in Caregiving Duties (%)**



NOTE: Nine most commonly selected sources shown.

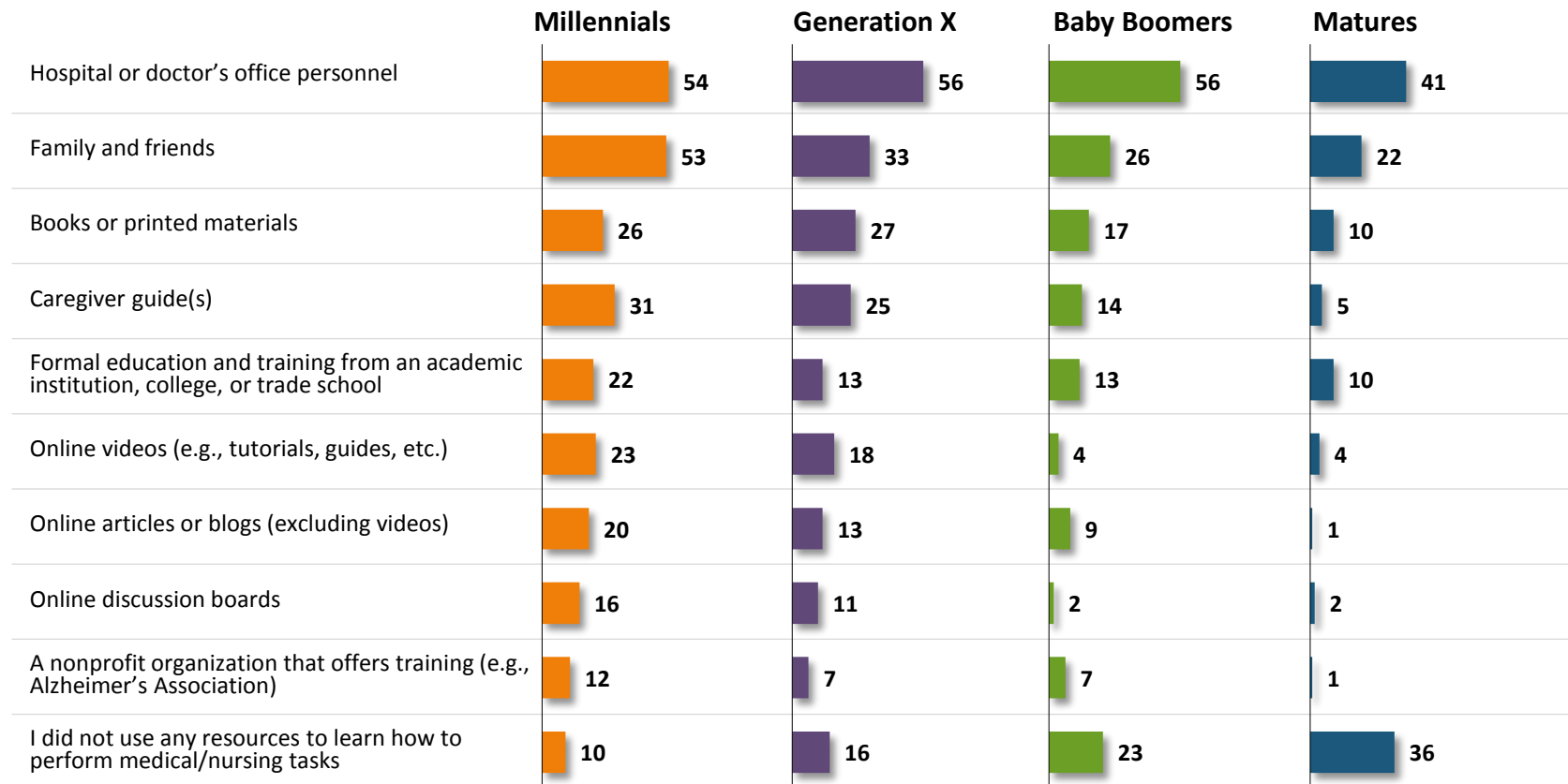
BASE: ALL QUALIFIED RESPONDENTS

Q840. Which of the following do you rely on as sources of information to assist in your caregiving duties? Select all.

# Sources for Learning About Medical/Nursing Tasks

Among caregivers performing medical/nursing-related tasks, most learned how to perform these tasks from hospital or doctor's office personnel, a finding which is consistent among Millennials (54 percent), Generation X and Baby Boomers (both 56 percent), but lower among Matures (41 percent). Millennials (53 percent) are more likely to have learned from family and friends compared to Generation X (33 percent), Baby Boomers (26 percent), and Matures (22 percent). Millennials are also more likely than older generations to have learned from caregiver guides, formal education, and online resources, whereas 36 percent of Matures did not use any resources.

**Sources for Learning Medical/Nursing Tasks Related to Being a Caregiver (%)**



NOTE: Nine most commonly selected sources shown.

BASE: IF ADMINISTERING MEDICATIONS AND MEDICAL TREATMENTS

Q835. You mentioned you perform medication management or medical treatment administration for the care recipient. Where did you learn how to perform medical/nursing tasks related to being a caregiver? Select all.

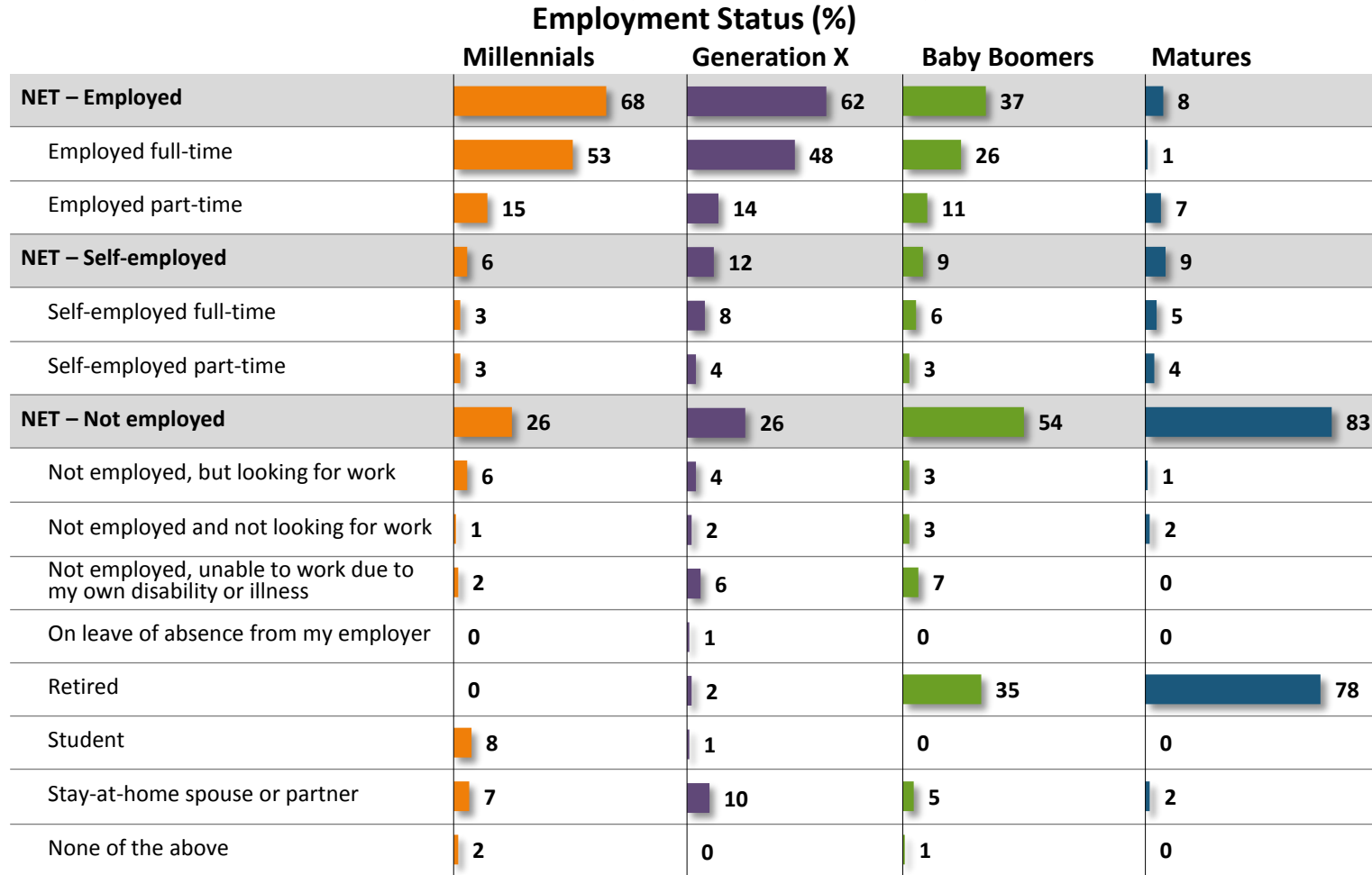
# Caregivers' Sentiments About Their Caregiving Duties

Almost all caregivers agree that it is important to provide a good quality of life for their care recipient – including 93 percent of Millennials, 92 percent of Generation X and 97 percent of both Baby Boomers and Matures. Across generations, approximately nine out of 10 Millennials, Generation X, Baby Boomers, and Matures indicate they like helping and enjoy spending time with the care recipient. Generation X (61 percent) and Millennials (59 percent) are more likely than Baby Boomers (49 percent) and Matures (44 percent) to say their own health takes a back seat to the health of their care recipients.

Caregivers' Sentiments About Their Caregiving Duties	Millennials	Generation X	Baby Boomers	Matures
	% Strongly/Somewhat Agree (NET)			
Positive				
It's important for me to provide a good quality of life for the care recipient	93%	92%	97%	97%
I like helping the care recipient	92%	89%	90%	94%
I enjoy spending time with the care recipient	91%	90%	90%	93%
Being a caregiver gives me a strong sense of purpose	86%	83%	79%	87%
Being a caregiver has led me to take better care of my own health	78%	66%	63%	79%
Being a caregiver has inspired me to document my own health and legal wishes	73%	65%	62%	57%
Negative				
My own health takes a backseat to the health of my care recipient	59%	61%	49%	44%
My caregiving duties leave me feeling physically exhausted	62%	56%	49%	37%
My caregiving duties leave me feeling emotionally exhausted	59%	59%	51%	40%
I need more help with my caregiving duties	60%	49%	37%	36%
With all of my caregiving duties, I barely have time for anything else	56%	50%	37%	25%
My caregiving duties leave me feeling completely overwhelmed	54%	48%	36%	18%

# Employment Status of Caregivers

The majority of Millennial (68 percent) and Generation X (62 percent) caregivers are employed, while fewer Baby Boomers (37 percent) and Matures (8 percent) are. Fifty-four percent of Baby Boomers are not employed, including 35 percent who are retired. The majority of Matures are retired (78 percent). Twenty-six percent of Millennials and Generation X are not employed. Twelve percent of Generation X, 10 percent of Matures, and 9 percent of Baby Boomers are self-employed, findings that are slightly higher than for Millennials (6 percent).





# Disruptions to Employment as a Result of Caregiving

Caregiving responsibilities can be disruptive to a caregiver's employment situation.

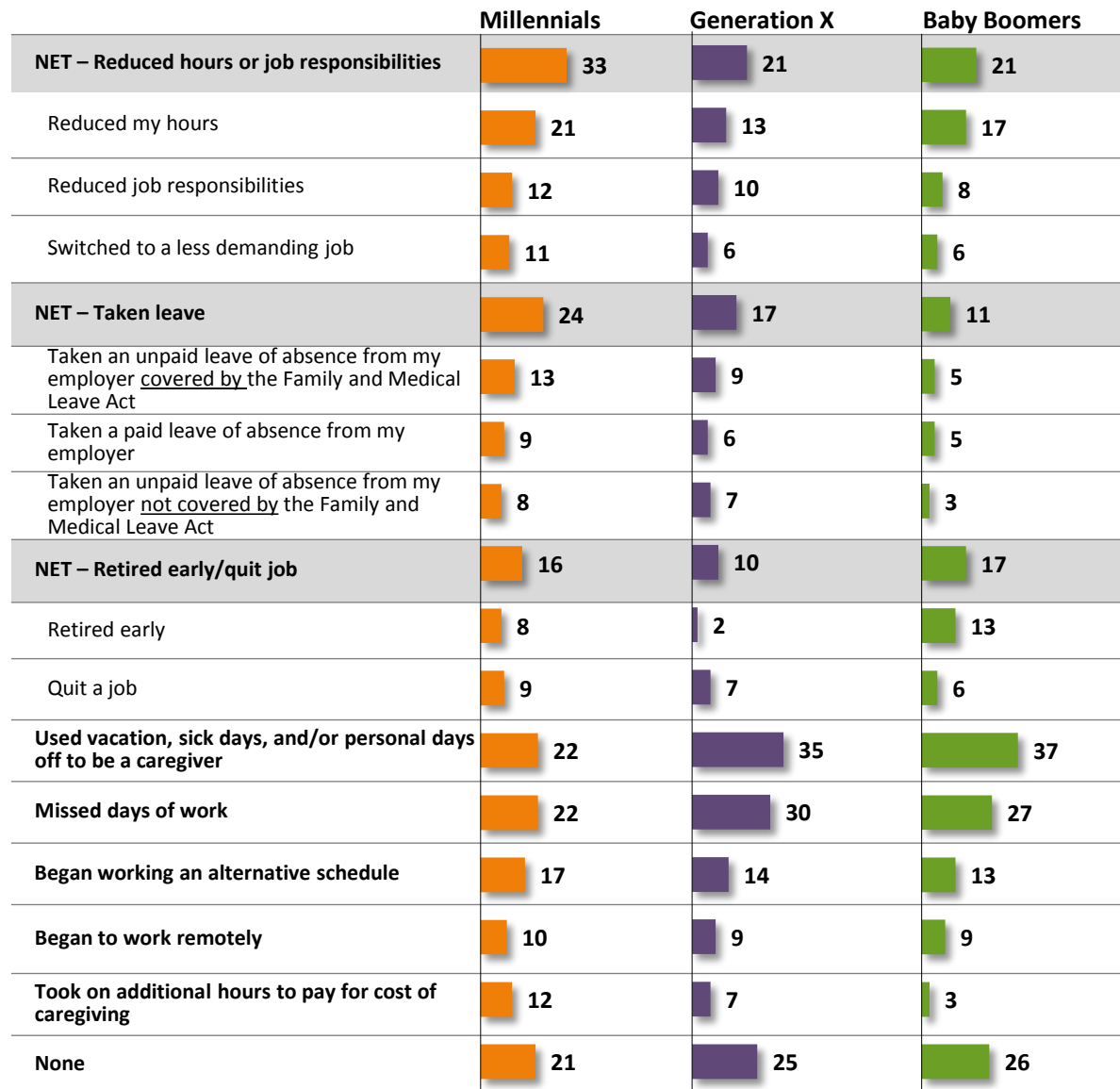
Among caregivers who are employed or who have been employed during their time as caregivers, some have had to reduce their hours or job responsibilities, take leave from their position, or quit their job or retire early in order to accommodate their caregiving duties.

For example, 33 percent of Millennials have reduced their hours or job responsibilities.

Twenty-four percent of Millennials and 17 percent of Generation X have taken a leave of absence.

Seventeen percent of Baby Boomers have retired early/quit their job.

"Which of the following have you done as a result of becoming a caregiver?" (%)



NOTE: Thirteen most commonly selected sources shown.

\*Matures are excluded from analysis due to small sample of employed Mature caregivers.

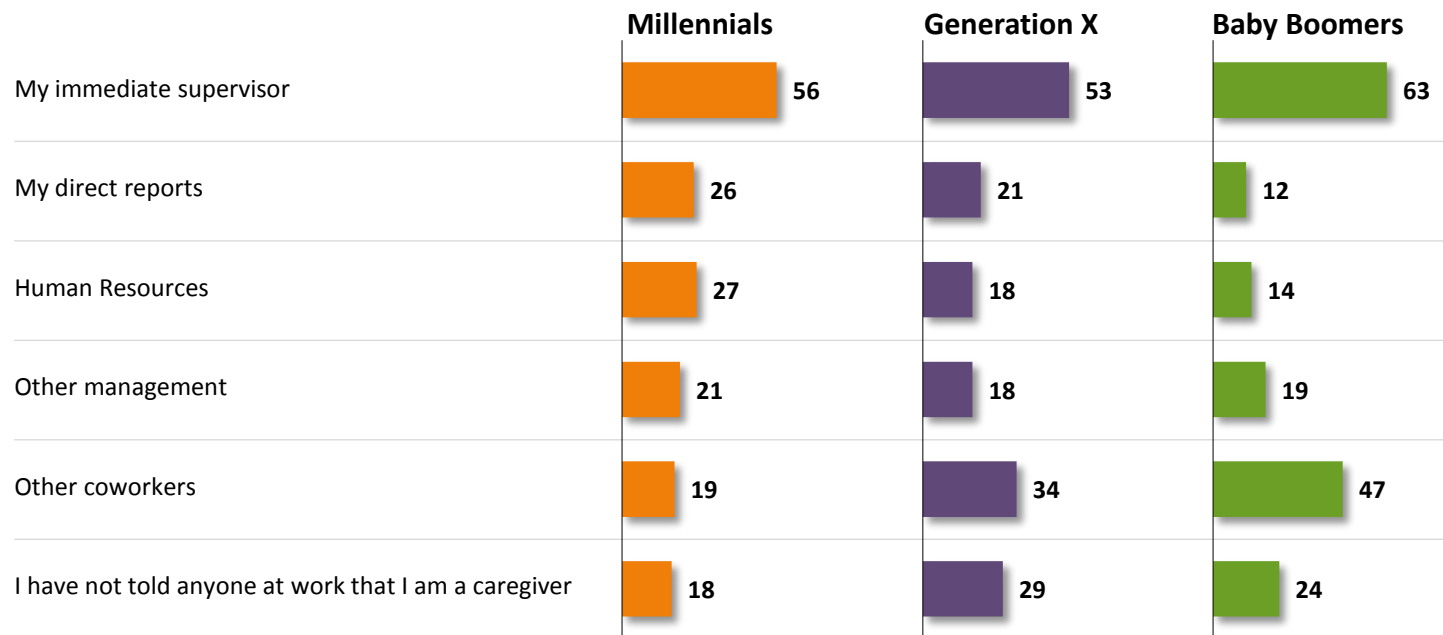
BASE: ALL EMPLOYED OR HAVE BEEN EMPLOYED DURING THEIR TIME AS A CAREGIVER

Q1025. Which of the following have you done as a result of becoming a caregiver? Select all.

# Informing Coworkers About Their Caregiving Duties

Among caregivers who are employed full-time or part-time, most have told their immediate supervisor that they are a caregiver, including Baby Boomers (63 percent), followed by Millennials (56 percent) and Generation X (53 percent). Millennials (27 percent) are more likely to have told Human Resources compared to Generation X (18 percent) and Baby Boomers (14 percent). A higher percentage of Baby Boomers (47 percent) have told their other coworkers, compared to Generation X (34 percent) and Millennials (19 percent). Generation X (29 percent) and Baby Boomers (24 percent) are somewhat more likely than Millennials (18 percent) to not tell anyone at work that they are a caregiver.

**“Which of the following people at work have you told that you are a caregiver?” (%)**



NOTES: Self-employed and not employed were excluded from this question. Matures are excluded from analysis due to small sample of employed Mature caregivers.

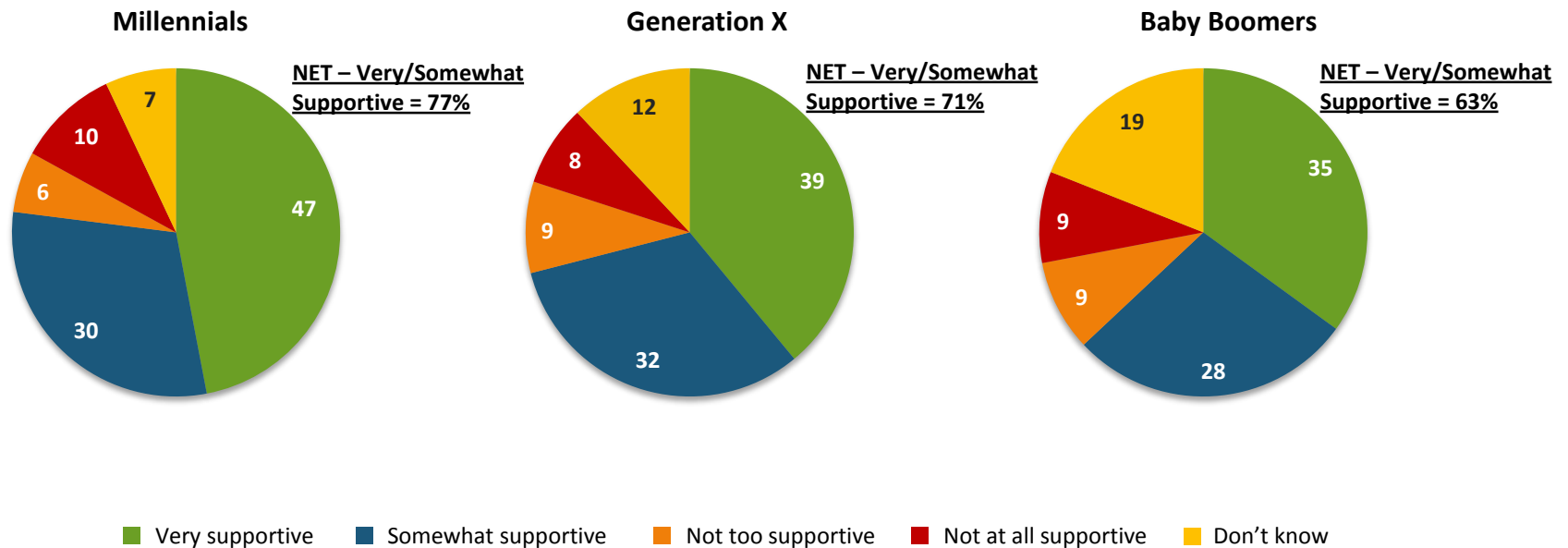
BASE: EMPLOYED FULL-TIME OR PART-TIME

Q1035. Which of the following people at work have you told that you are a caregiver? Select all.

# Employer Support of Caregiving Duties

Most caregivers who work full-time or part-time feel that their employers are supportive of their caregiving duties. Millennials (77 percent) are most likely to indicate their employers are very or somewhat supportive, followed by Generation X (70 percent) and Baby Boomers (63 percent). Fewer than one in five caregivers indicate their employers are not too supportive or not at all supportive, a finding that is consistent among Millennials (16 percent), Generation X (17 percent), and Baby Boomers (18 percent).

**“How supportive is your employer of your caregiving responsibilities?” (%)**



NOTES: Self-employed and not employed were excluded from this question. Matures are excluded from analysis due to small sample of employed Mature caregivers.

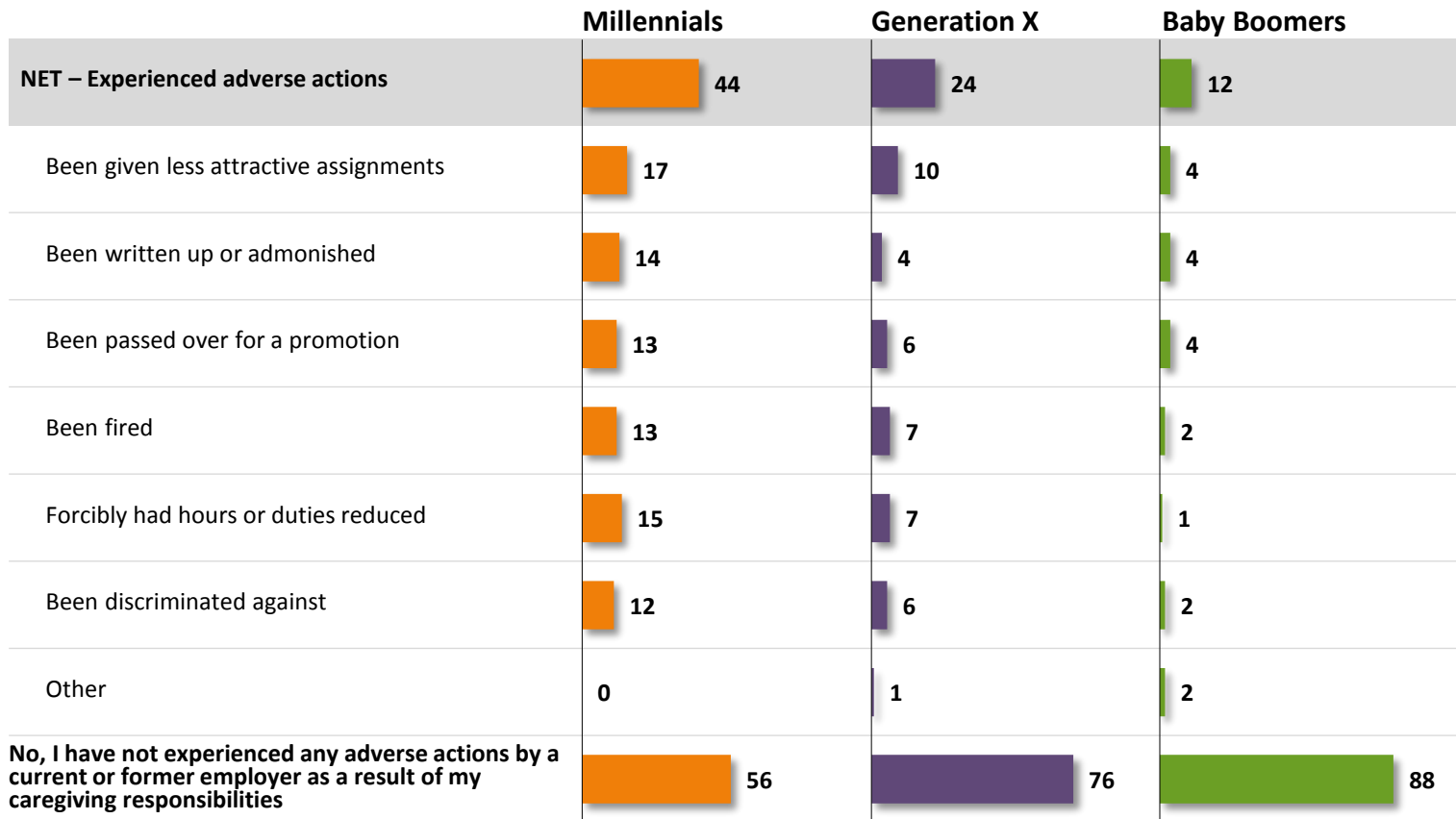
BASE: EMPLOYED FULL-TIME OR PART-TIME

Q1045. How supportive is your employer of your caregiving responsibilities?

# Adverse Actions Taken by Employers

Caregiving duties may conflict with job responsibilities which may lead to adverse actions taken by an employer. Among caregivers who are currently employed or who have been employed during their time as caregivers, Millennials (44 percent) are more likely than Generation X (24 percent) and Baby Boomers (12 percent) to have experienced an adverse employment action such as being fired, written up or admonished, given less attractive assignments, passed over for a promotion, discriminated against, forcibly had hours or duties reduced and/or some other action.

## Adverse Employment Actions Experienced as a Result of Caregiving Duties (%)



NOTE: Matures are excluded from analysis due to small sample of employed Mature caregivers.

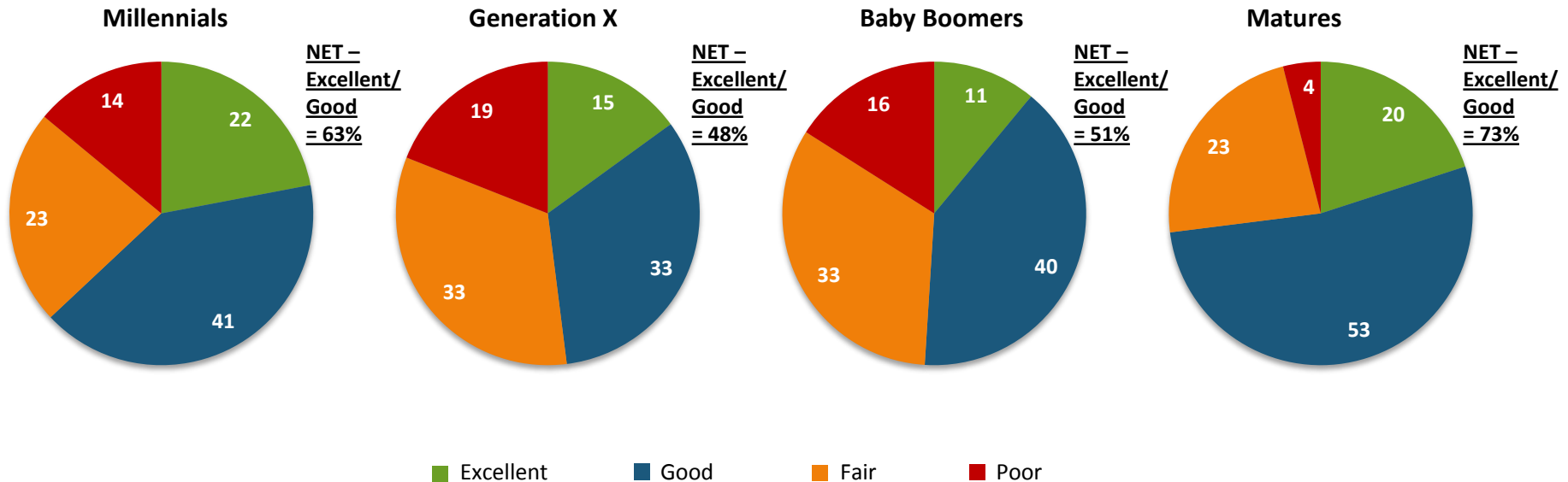
BASE: ALL EMPLOYED OR HAVE BEEN EMPLOYED DURING THEIR TIME AS A CAREGIVER

Q1030. Have you ever experienced any adverse actions by a current or former employer as a result of your caregiving responsibilities? Select all.

# Caregivers' Financial Well-Being

Mature (73 percent) and Millennial caregivers (63 percent) are more likely to say that their financial well-being is excellent or good compared to about one-half of Generation X (48 percent) and Baby Boomers (51 percent). Generation X (19 percent) are slightly more likely than Millennials (14 percent) and Baby Boomers (16 percent) to describe their financial well-being as poor. Only four percent of Matures describe their financial well-being as poor.

**“How would you describe your own financial well-being?” (%)**



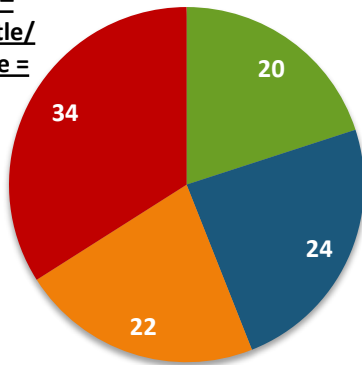
# Financial Considerations Before Becoming Caregivers

The majority of Mature (79 percent), Baby Boomer (78 percent), Generation X (69 percent), and Millennial (56 percent) caregivers gave little or no consideration to their own financial situation when deciding to become a caregiver. Although Millennials are more likely to have given at least some consideration to their financial situation, only 20 percent say that they gave it a lot of consideration.

**“To what extent did you consider your own financial situation when deciding to become a caregiver?” (%)**

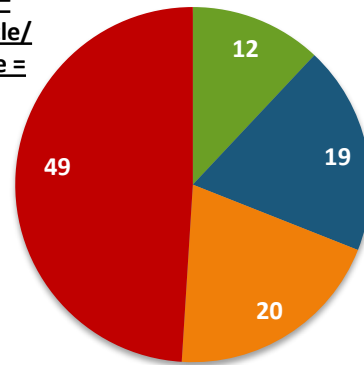
Millennials

NET –  
A little/  
None =  
56%



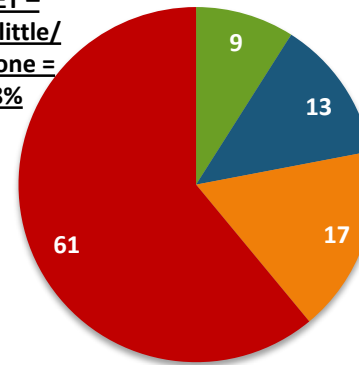
Generation X

NET –  
A little/  
None =  
69%



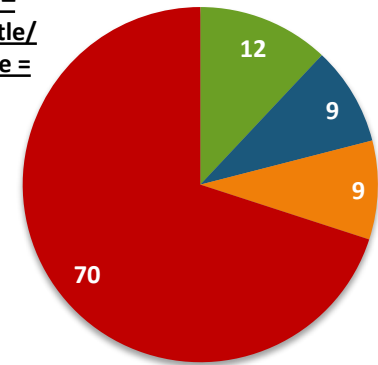
Baby Boomers

NET –  
A little/  
None =  
78%



Matures

NET –  
A little/  
None =  
79%



A lot

Some

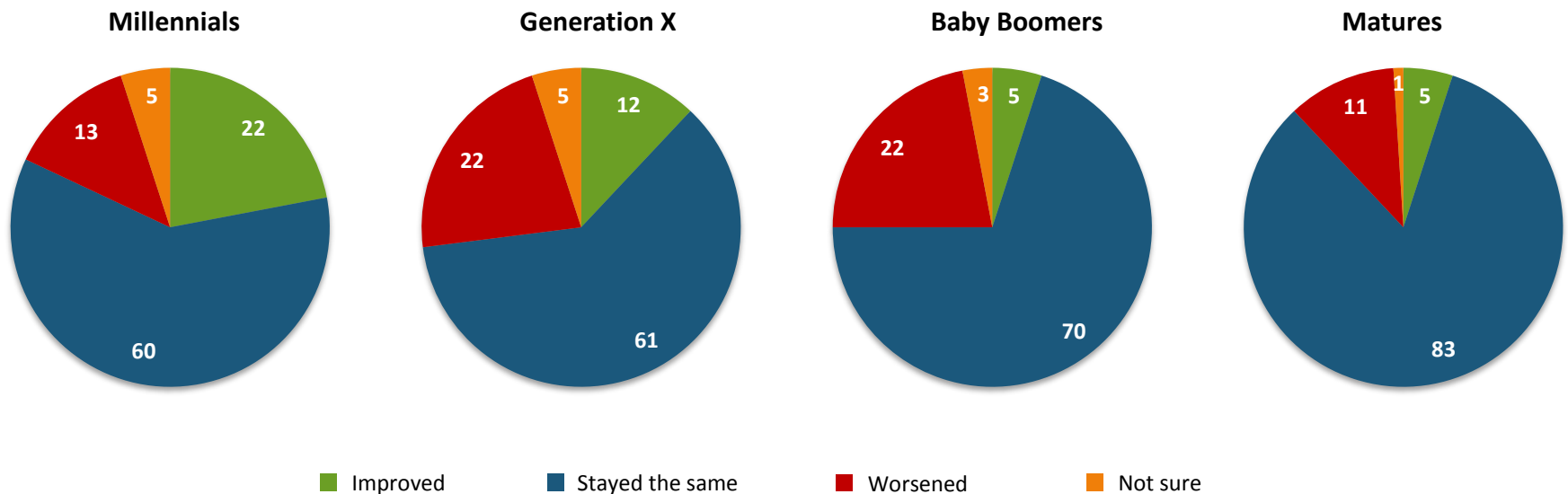
A little

None

# Change in Financial Situation as a Result of Caregiving

Most caregivers say that their financial situation has stayed the same as a result of becoming a caregiver, a finding which is higher among Matures (83 percent) compared to Baby Boomers (70 percent), Generation X (61 percent) and Millennials (60 percent). Twenty-two percent of both Generation X and Baby Boomer caregivers say that their financial situation has worsened, compared to only 13 percent of Millennials and 11 percent of Matures. Of note, Millennials (22 percent) are more likely than Generation X (12 percent) and Baby Boomers and Matures (both 5 percent) to say that their financial situation has improved.

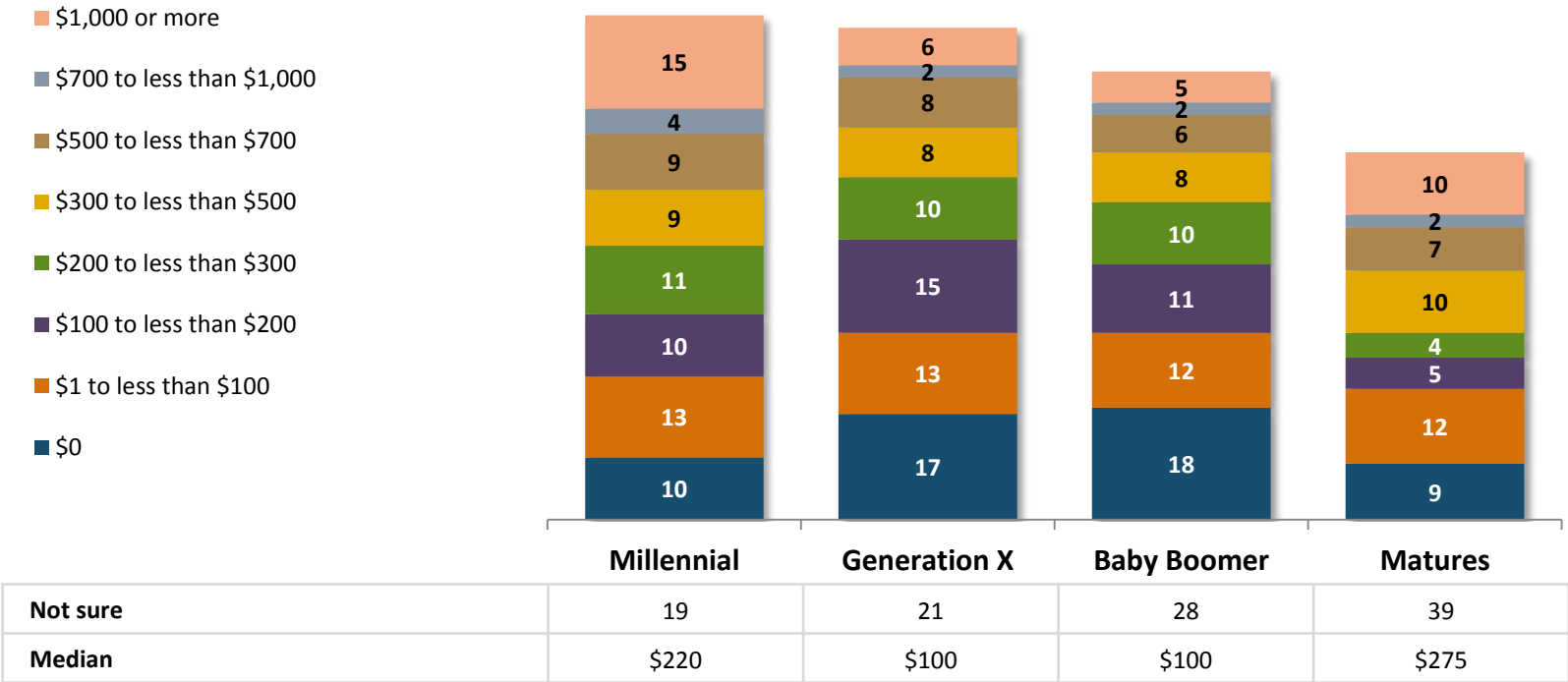
**“How has your financial situation changed as a result of becoming a caregiver?”**



# Monthly Personal Expenditures for Caregiving

Mature (\$275 median) and Millennial (\$220 median) caregivers are spending more money out-of-pocket per month to cover expenses for their care recipient than Generation X and Baby Boomers (\$100 median each). Fifteen percent of Millennials spend \$1,000 or more dollars per month for their care recipient, compared to 10 percent of Matures, 6 percent of Generation X and 5 percent of Baby Boomers. Nearly two out of five (39 percent) Matures aren't sure how much they're spending.

Monthly Personal Expenditures to Cover Expenses for Care Recipient (%)



Note: The median is the midpoint of the range of each response category. Non-responses are excluded from the estimate.

BASE: ALL QUALIFIED RESPONDENTS

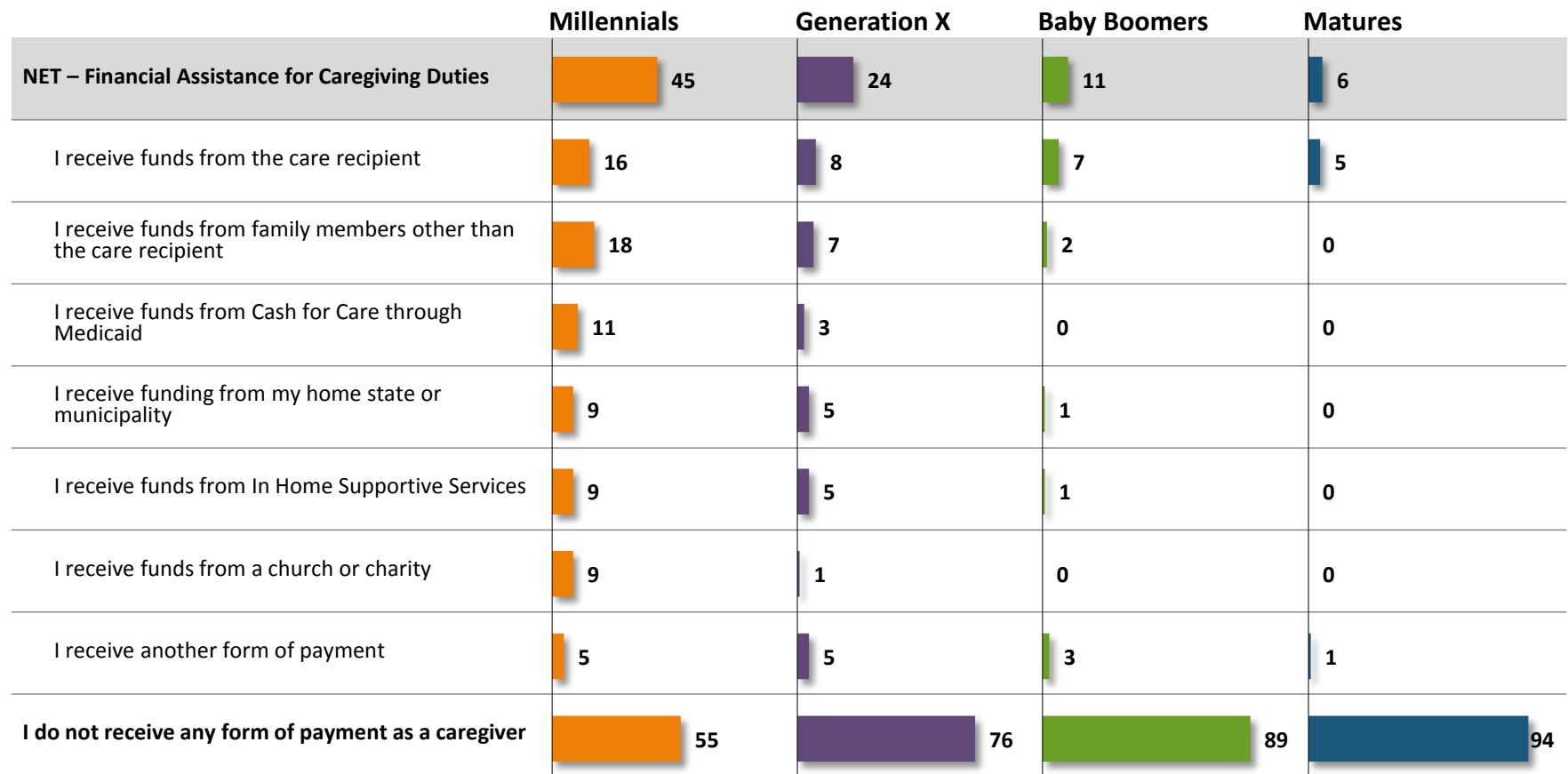
Q1120. On average, approximately how much money do you spend each month paying out-of-pocket to cover expenses for the care recipient (e.g. for groceries, over-the-counter medications, gas, parking)?



# Financial Assistance for Caregiving Duties

Most caregivers do not receive any form of payment for their caregiving duties, including the vast majority of Matures (94 percent), Baby Boomers (89 percent), and Generation X (76 percent) – and notably fewer Millennials (55 percent). Among those receiving payment, funds from the care recipient and family members are the most frequently cited sources. Millennials (11 percent) are more likely than older generations to be receiving funds from government subsidies.

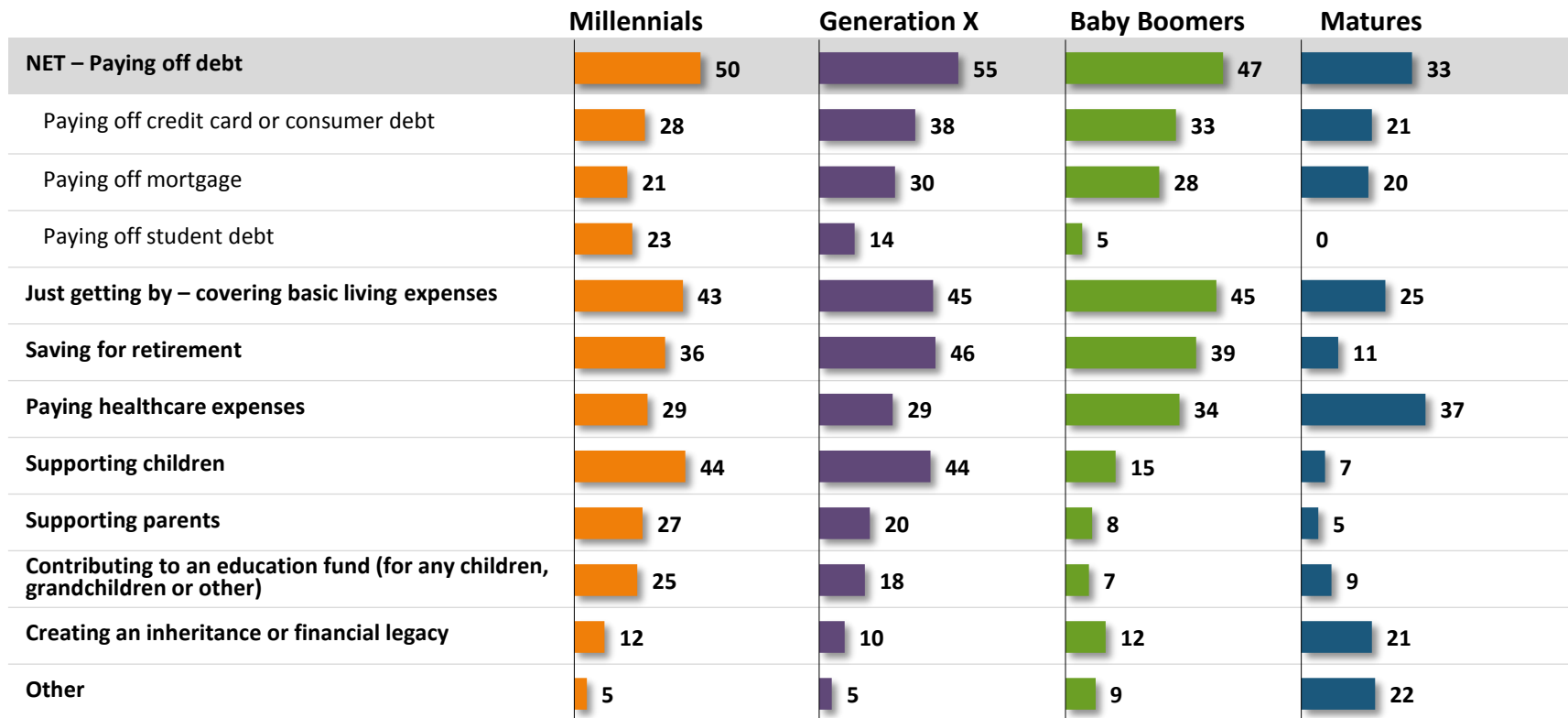
**Sources of Financial Assistance Received for Caregiving Duties, If Any (%)**



# Financial Priorities Among Caregivers

Paying off some form of debt (i.e., credit card, consumer, mortgage, and/or student debt) is the most frequently cited current financial priority among Millennials (50 percent), Generation X (55 percent), and Baby Boomers (47 percent). Paying healthcare expenses is the most frequently cited priority among Matures (37 percent). More than 40 percent of Generation X, Baby Boomer, and Millennial caregivers cite “just getting by” as a priority, compared to only 25 percent of Mature caregivers. Generation X caregivers (46 percent) are more likely to cite “saving for retirement,” compared to 36 percent of Millennials and 39 percent of Baby Boomers. Twenty-one percent of Mature caregivers cite creating an inheritance or financial legacy as a priority.

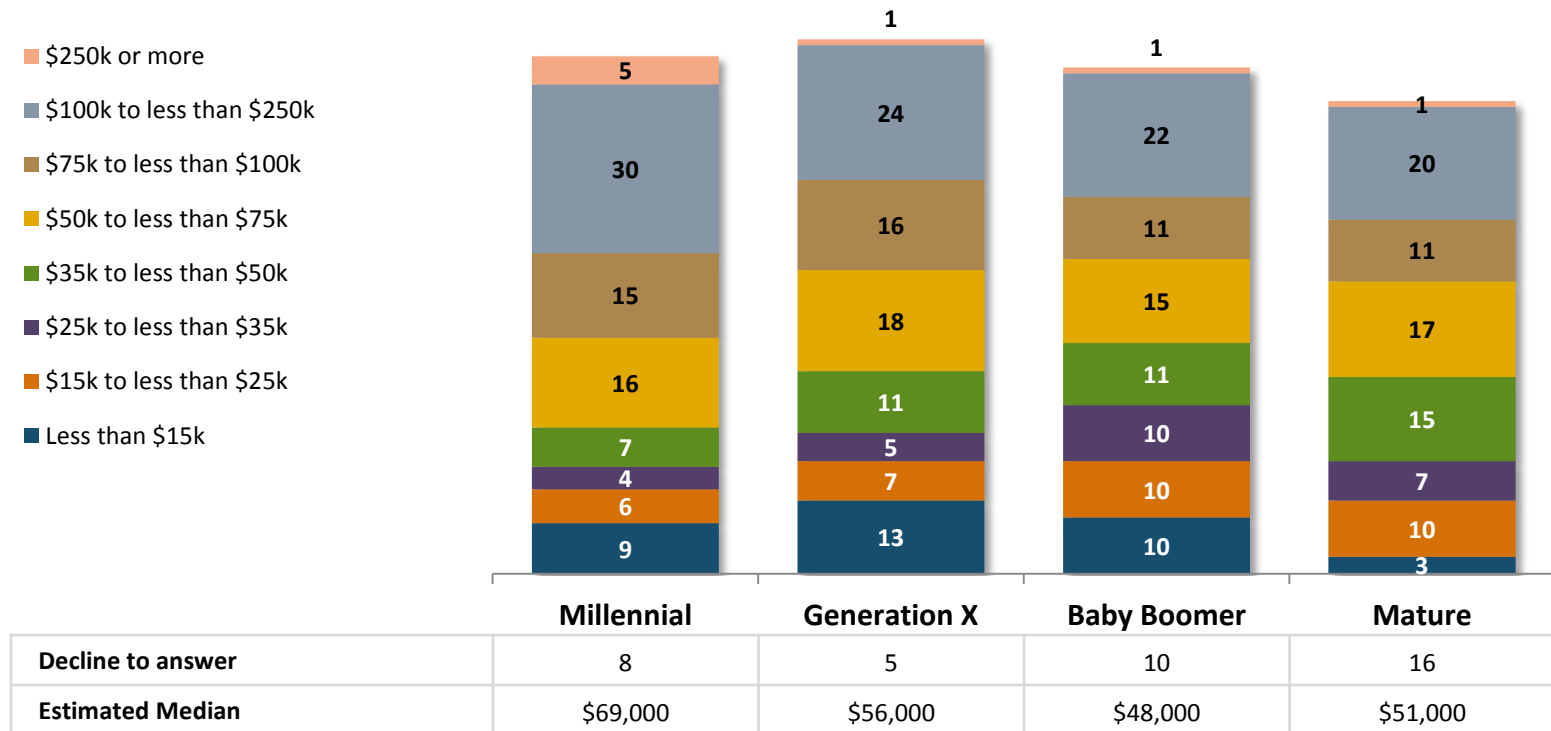
## “Which of the following are your financial priorities right now?” (%)



# Total Household Income Among Caregivers

Across generations, Millennial caregivers report having the highest total household income of \$69,000 (estimated median), compared to Generation X (\$56,000 estimated median), Matures (\$51,000 estimated median) and Baby Boomers (\$48,000 estimated median). Thirty-five percent of Millennial caregivers have total household incomes of \$100,000 or more annually, while only 25 percent of Generation X, 23 percent of Baby Boomer, and 21 percent of Mature caregivers report the same level of income.

**Total Household Income in 2016 (%)**

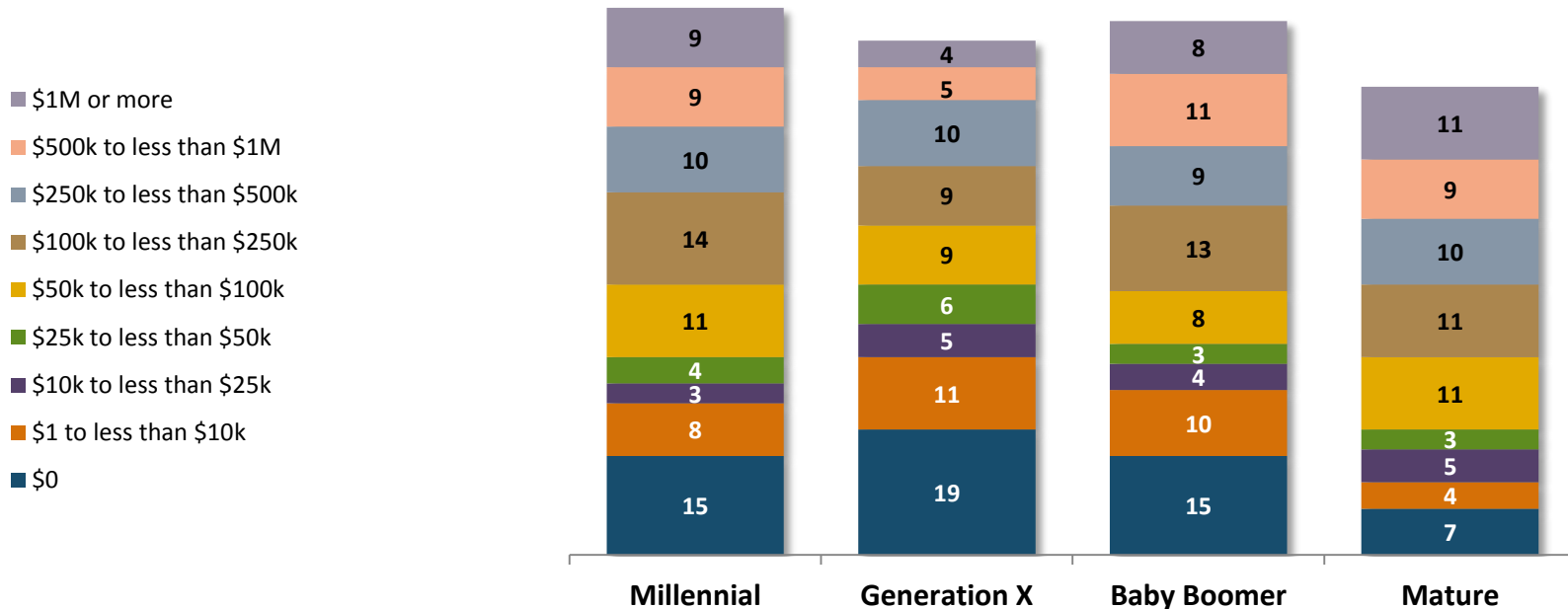


*Note: The median is estimated based on the approximate midpoint of the range of each response category. Non-responses are excluded from the estimate.*

# Total Household Retirement Savings Among Caregivers

Total household retirement savings vary among caregivers across generations. Generation X caregivers have saved \$31,000 (estimated median), an amount that is less than Baby Boomers (\$75,000 estimated median), Millennials (\$84,000 estimated median), and Matures (\$128,000 estimated median). More Generation X caregivers (41 percent) have saved less than \$50,000 than any of the other generations. Of concern, 19 percent of Generation X caregivers report having nothing in retirement savings, followed by 15 percent of both Millennial and Baby Boomers, and 7 percent of Matures.

**Total Household Retirement Savings in All Accounts (%)**



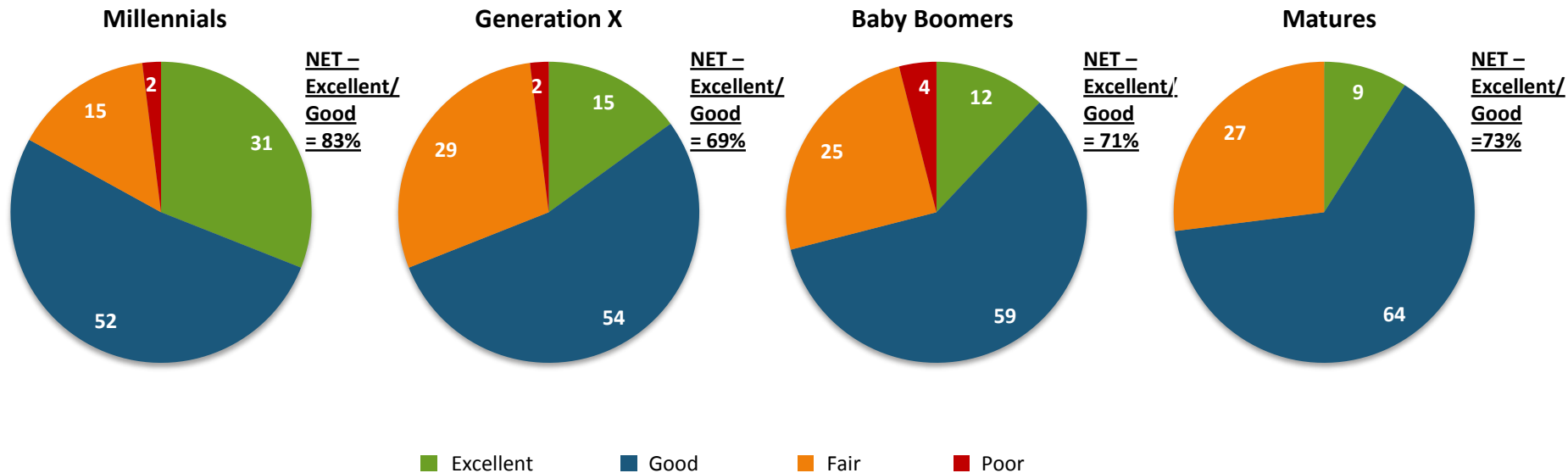
	Millennial	Generation X	Baby Boomer	Mature
Not sure	12	13	9	9
Decline to answer	5	9	13	19
Estimated Median	\$84,000	\$31,000	\$75,000	\$128,000

Note: The median is estimated based on the approximate midpoint of the range of each response category. Non-responses are excluded from the estimate.

# Caregivers' Self-Described General Health

Most caregivers self-describe their general health as being excellent or good – including 83 percent of Millennials, 73 percent of Matures, 71 percent of Baby Boomers, and 69 percent of Generation X. Across generations, Generation X (31 percent), Baby Boomers (29 percent), and Matures (27 percent) are more likely than Millennials (17 percent) to say they are in fair or poor health.

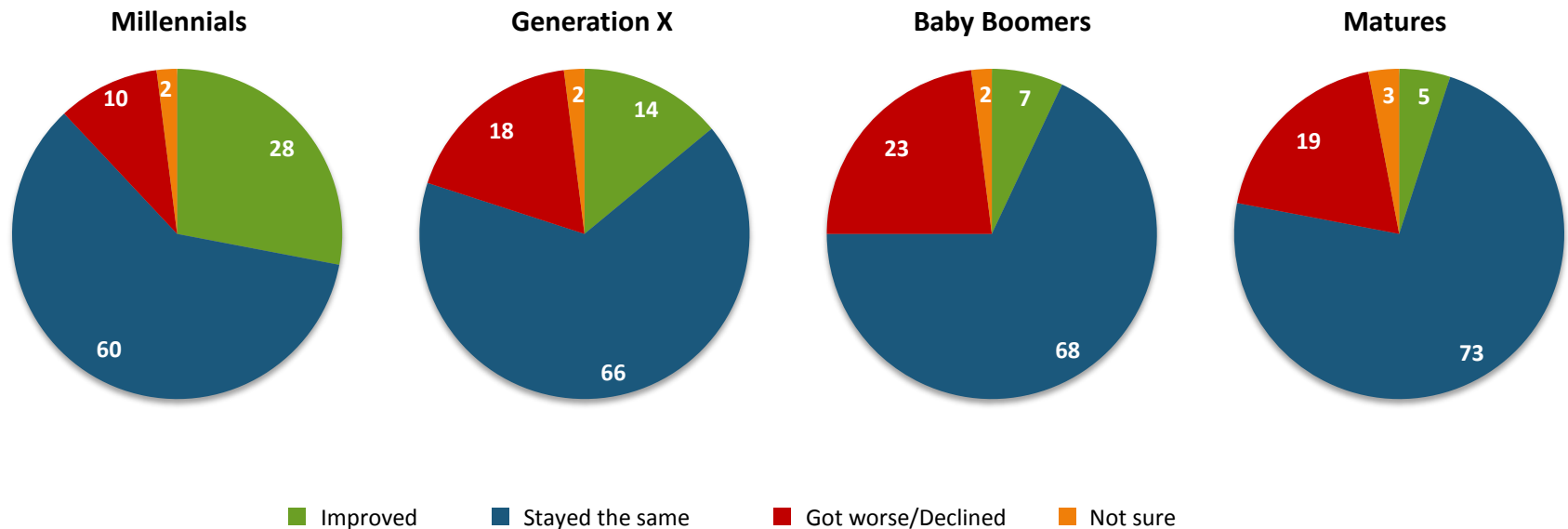
General Health Status (%)



# Changes in General Health Since Becoming a Caregiver

Most caregivers say that their general health has stayed the same since becoming a caregiver, including 73 percent of Matures, 68 percent of Baby Boomers, 66 percent of Generation X, and 60 percent of Millennials. However, nearly one in four Baby Boomers (23 percent) indicate their health has declined, a finding that is slightly higher than for Matures (19 percent), Generation X (18 percent), and Millennials (10 percent). On the other hand, Millennials (28 percent) are more likely to report that their general health has actually improved since becoming a caregiver, compared to Generation X (14 percent), Baby Boomers (7 percent), and Matures (5 percent).

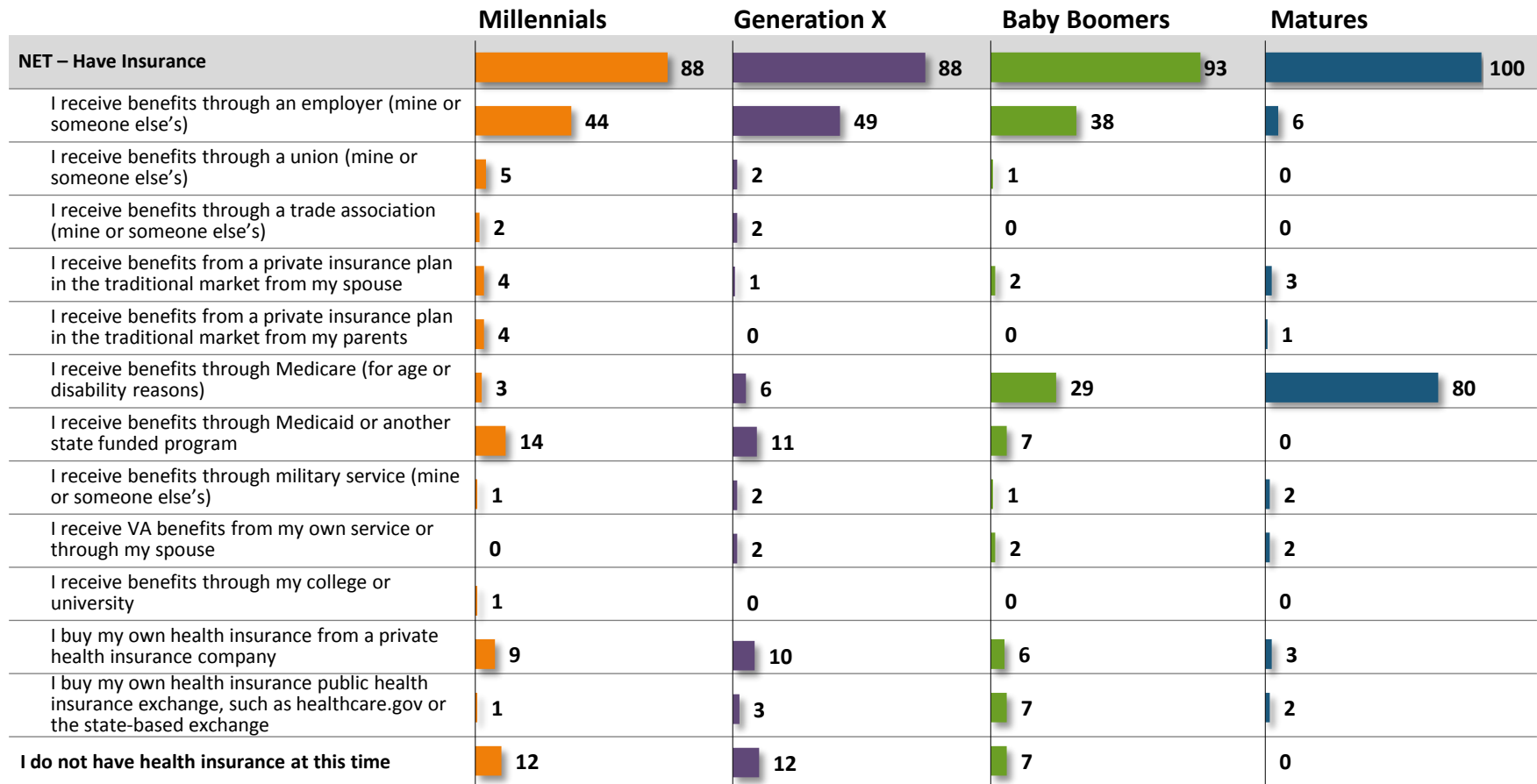
Changes in Health Status Since Becoming a Caregiver (%)



# Caregivers' Health Insurance

Nine out of 10 Millennial, Generation X (both 88 percent); and Baby Boomer (93 percent) caregivers have health insurance, while fully 100 percent of Matures have health insurance. Eighty percent of Matures receive benefits through Medicare. Employer benefits are the most common source of health insurance for Millennials (44 percent), Generation X (49 percent), and Baby Boomers (38 percent). Twelve percent of Millennials and Generation X do not have health insurance, compared to 7 percent of Baby Boomers and no Matures.

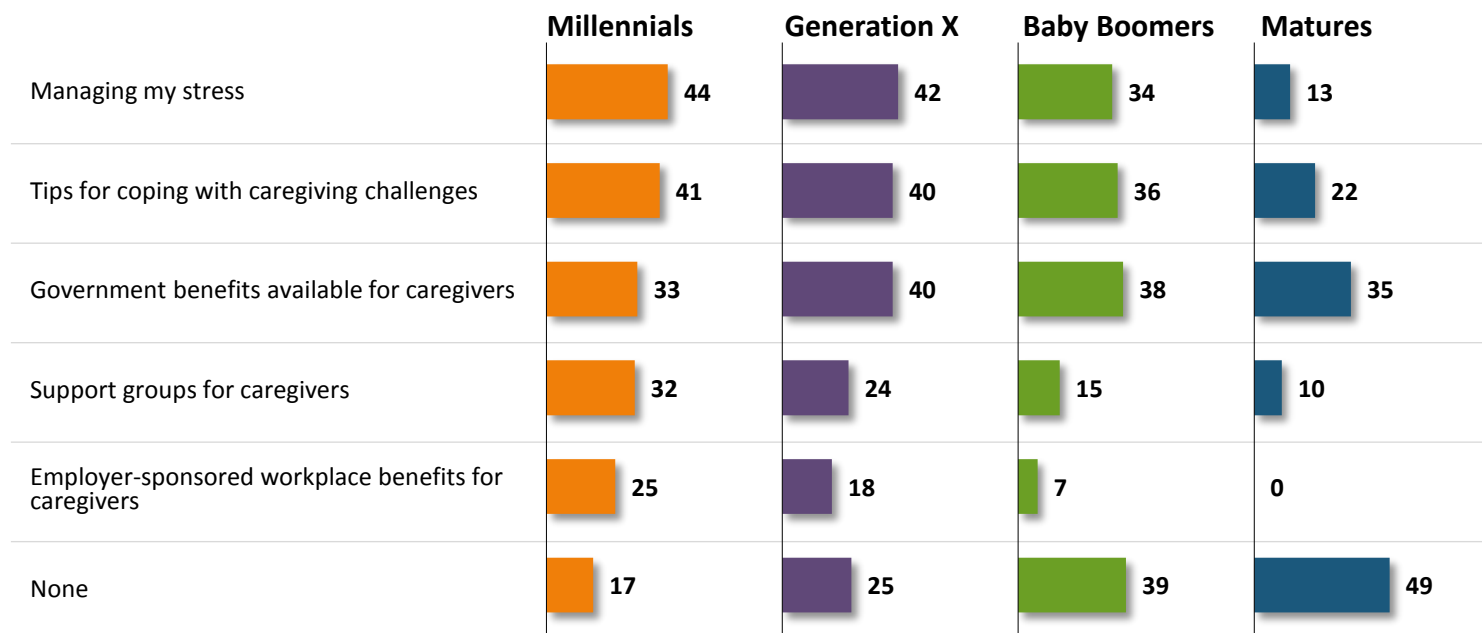
## "Which of the following best describes how you primarily receive health insurance?" (%)



# Caregivers Would Like More Information to Help Them Personally

Millennial, Generation X and Baby Boomer caregivers share a similar desire to receive more information to help them personally with their caregiving responsibilities to manage stress, get tips for coping with caregiving challenges, and learn about government benefits available to them. Mature caregivers are somewhat less likely to express an interest in various topics. Managing stress is the most frequently cited topic among Millennials (44 percent) and Generation X (42 percent), while information about government benefits is most frequently cited by Baby Boomers (38 percent) and Matures (35 percent). Millennials are more likely to want information about support groups (32 percent) and employer-sponsored workplace benefits for caregivers (25 percent) compared to older caregivers. A noteworthy 39 percent of Baby Boomers and Matures do not want any additional information.

**“Which of the following topics would you like more information to help you personally with your caregiving responsibilities?” (%)**



NOTE: Five most commonly selected sources shown.

BASE: ALL QUALIFIED RESPONDENTS

Q850. Which of the following topics would you like more information to help you personally with your caregiving responsibilities? I would like more information about... Select all.





## Demographic Perspectives By Gender

# ***The Many Faces of Family Caregivers: A Close-Up Look at Caregiving and Its Implications***

## **A Portrait of Today's Caregivers**

- Demographic Perspectives
- Voluntary Status
- Employment Status
- Generations

### **➤ Gender**

- Household Income
- Race/Ethnicity

## **Appendix: Caregiver and Care Recipient Demographics**

## **Acknowledgements**

# Demographic Perspectives by Gender

Women and men are similarly likely to be caregivers. Among all caregivers, the survey finds that 53 percent are women and 47 percent are men.

In this chapter, the survey explores who the similarities and differences among women and men in terms of their caregiving responsibilities and impact on their own well-being.

Both women and men caregivers cite similar reasons for becoming a caregiver including a desire to care for their loved one – and they are equally committed to being caregivers. However, women caregivers spend more time per month caregiving and they are far worse off than men in terms of their own financial situations with regards to their income and retirement savings.

Men are more likely than women to be employed which contributes to their having a better financial situation. Among caregivers who are employed, however, men are more likely than women to have experienced some form of adverse action taken by their employers.

## *Twenty-Six Facts About Caregivers by Gender*

- **Most Consider Themselves to Be the Primary Caregivers.** The majority of men and women caregivers consider themselves to be the Primary caregiver of their care recipient. However, men (72 percent) are more likely than women (64 percent) to identify themselves as the Primary caregiver.
- **The Majority of Caregivers Are Caring for a Family Member.** The vast majority of caregivers are caring for a family member, including 88 percent of women caregivers and 87 percent of men caregivers. Parents are the most frequently cited recipients of care among both women (36 percent) and men (31 percent). The second most frequently cited care recipients are spouses/partners with men (22 percent) being slightly more likely to care for a spouse or partner than women (17 percent). Ten percent of both women and men are caring for a child. Nine percent of women and 10 percent of men are caring for a grandparent.
- **Reasons for Becoming a Caregiver.** When asked how they came to be a caregiver, women (66 percent) and men (61 percent) most frequently cite a desire to care for their loved one as their reason for taking on the role. Other frequently cited reasons include a close relationship with their loved one (60 percent of women, 56 percent of men) and that they have the time and capacity to do so (42 percent of women, 45 percent of men).

# Demographic Perspectives by Gender

- **Total Caregiving Hours per Month.** Women caregivers dedicate 60 hours (median) per month to caregiving while men spend 47 hours (median) per month. Women (38 percent) are more likely than men (32 percent) to spend 100 or more hours per month caregiving.
- **Caregiver Duties Performed.** Caregiving entails a broad range of duties. The most frequently cited type of caregiving duty performed for the care recipient is household-related for both women (90 percent) and men (88 percent). Women are more likely to run errands (72 percent), do housework (66 percent) and prepare meals (64 percent) than men. In comparison, men more frequently perform home repairs (40 percent) and home modifications (24 percent) for their care recipient. Women also more frequently engage in social/communication (78 percent) and health-related (72 percent) caregiving duties compared to men (65 percent for both duties, respectively).
- **Hours Spent Caregiving by Types of Duties.** Both men and women caregivers spend the most time per month providing companionship to the care recipient, including 35 hours by men caregivers (median) and 30 hours by women caregivers (median). This is followed by meal preparation (median 22 hours for women, 15 hours for men) and personal care (median 14 hours for women, 12 hours for men). Women (20 hours median) spend twice as many hours per month feeding their care recipient, compared to men (10 hours median). In general, time spent on other caregiving duties (e.g., health-related, medical-related, household, and social/communication duties) is relatively consistent between genders.
- **Sources of Information Relied on to Assist in Caregiving Duties.** Both men and women caregivers most frequently rely on family and friends (46 percent of women, 44 percent of men) and medical professionals (45 percent of women, 44 percent of men) for information to assist with their caregiver duties. Men are slightly more likely than women to rely on online sources, such as medical, Medicare, and Medicaid websites, in order to assist in their caregiving roles. In contrast, women caregivers are more likely to use no outside sources of information, compared to men.
- **Sources for Learning About Medical/Nursing Tasks.** Among caregivers currently performing medical/nursing-related tasks, more than half of men (55 percent) and women (53 percent) most frequently report using hospital or doctor's office personnel to learn how to perform medical/nursing tasks. Of note, men (28 percent) are more likely than women (17 percent) to have learned from caregiver guides. Across potential information sources, men are somewhat more likely than women have used online videos and blogs.

# Demographic Perspectives by Gender

- **Caregivers' Sentiments About Their Caregiving Duties.** Both women and men caregivers generally have positive sentiments about their caregiving duties. Almost all women and men caregivers agree that it is important to provide a good quality of life for the care recipient (95 percent of women, 94 percent of men) – and indicate that they like helping and enjoy spending time with the care recipient. Men (58 percent) are more likely than women (52 percent) to say their own health takes a backseat to the health of their care recipient.
- **Employment Status of Caregivers.** Men caregivers (61 percent) are more likely to be employed than women caregivers (42 percent). Fifty-one percent of women describe themselves as not employed, compared to only 28 percent of men. Nineteen percent of both women and men are retired. Thirteen percent of women caregivers are stay-at-home spouses or partners compared to no men.
- **Disruptions to Employment as a Result of Caregiving.** Caregiving responsibilities can be disruptive to a caregiver's employment situation. Among caregivers who are employed or who have been employed during their time as a caregiver, 30 percent of men and 21 percent of women have reduced their hours, reduced job responsibilities, and/or switched to a less demanding job. Additionally, 15 percent of women and 14 percent of men have either retired early and/or quit their job.
- **Informing Coworkers About Their Caregiving Duties.** Among employed caregivers, the majority have told their immediate supervisor that they are a caregiver, including 55 percent of women and 59 percent of men. Men (27 percent) are more likely than women (13 percent) to have told their direct reports. Men (25 percent) are also more likely than women (16 percent) to have told Human Resources about their caregiving role. On the other hand, women (41 percent) are much more likely than men (23 percent) to have shared that they are a caregiver with their coworkers. Some have not shared with anyone at work about being their caregiver, including 27 percent of women and 19 percent of men.
- **Employer Support of Caregiving Duties.** Among employed caregivers, most say that their employers are either very or somewhat supportive of their caregiving responsibilities, including 75 percent of men and 66 percent of women. Men (17 percent) and women (16 percent) are similarly likely to say that their employer is not too supportive or not at all supportive. Women (18 percent) are more likely than men (8 percent) to say they don't know whether their employers are supportive.



# Demographic Perspectives by Gender

- **Adverse Actions Taken by Employers.** Caregiving duties may conflict with job responsibilities which, in turn, may lead to adverse actions taken by employers. Adverse actions may include being given less attractive assignments, being discriminated against, or being passed over for a promotion, among countless others. Among caregivers who are employed or who have been employed during their time as caregivers, more men (33 percent) compared to women (22 percent) say they have experienced adverse employment actions by a current or former employer as a result of their caregiving responsibilities.
- **Caregivers' Financial Well-Being.** Men caregivers (66 percent) are more likely than women caregivers (47 percent) to describe their financial well-being as excellent or good. In contrast, one-third of women (34 percent) self-report their financial status as fair, compared to only 23 percent of men. Nineteen percent of women caregivers describe their financial well-being as poor, compared to just 11 percent of men.
- **Financial Considerations Before Becoming Caregivers.** Most women (74 percent) and men caregivers (63 percent) say that they gave little or no consideration to their own financial situation when deciding to become a caregiver. Men (17 percent) are more likely than women (10 percent) to indicate they gave it a lot of consideration.
- **Change in Financial Situation as a Result of Caregiving.** Most caregivers say that their financial situation has stayed the same as a result of becoming a caregiver, including 68 percent of women and 62 percent of men. However, one in five women caregivers (20 percent) say their financial situation has worsened as a result of becoming a caregiver, a finding that is slightly higher than that of men caregivers (17 percent). Surprisingly, 18 percent of men caregivers report that their financial situation has actually improved due to their caregiver role, compared to only 8 percent of women.
- **Monthly Personal Expenditures for Caregiving.** Caregivers often find themselves paying out-of-pocket expenses for the care recipient (e.g., groceries, over-the-counter medications, gas, parking). Men caregivers spend \$250 per month (median), a finding that is more than twice the amount spent by women caregivers (\$100 median). Men (14 percent) are nearly three times more likely to spend \$1,000 or more per month on their care recipient than women (5 percent). In contrast, women (18 percent) are more likely to not spend any out-of-pocket money on their care recipient each month, in comparison to men (11 percent).

# Demographic Perspectives by Gender

- **Financial Assistance for Caregiving Duties.** Most women caregivers (80 percent) and men caregivers (69 percent) do not receive any form of compensation for their caregiving duties. However, men (31 percent) are more likely than women (20 percent) to receive some financial assistance. Both men and women most frequently received funding from the care recipient (12 percent of men, 8 percent of women) or from family members other than the care recipient (12 percent of men, 5 percent of women).
- **Financial Priorities Among Caregivers.** Men and women caregivers (both 49 percent) most frequently reference paying off some form of debt (i.e., credit card, consumer, student, or mortgage debt) as a current financial priority. Alarming, approximately one-half of women (48 percent) identify “just getting by” as a current financial priority, compared to 37 percent of men. Other frequently cited financial priorities include saving for retirement, paying for healthcare expenses, and supporting children.
- **Total Household Income Among Caregivers.** Men caregivers (\$70,000) have a higher total household income (HHI) than women caregivers (\$46,000 estimated medians). Thirty-eight percent of men caregivers were found to have an HHI of \$100,000 or more, whereas only 19 percent of women have the same HHI. Forty-one percent of women caregivers report an HHI of less than \$50,000 compared to 25 percent of men.
- **Total Household Retirement Savings Among Caregivers.** Men caregivers have seven times more money saved in total household retirement savings accounts than women caregivers. Men report having saved an estimated median of \$130,000 compared to just \$19,000 among women. An alarming one in five women (21 percent) have no household retirement savings, compared to only 9 percent of men. Twelve percent of men have saved \$1 million or more in total household retirement accounts compared to only 3 percent of women.
- **Caregivers’ Self-Described General Health.** Most women and men caregivers self-describe their general health as excellent or good, including 71 percent of women and 79 percent of men. However, men (24 percent) are more likely than women (15 percent) to report having excellent health. In contrast, women (29 percent) are more likely than men (21 percent) to say they are in fair or poor health.
- **Changes in General Health Since Becoming a Caregiver.** Sixty-five percent of women and men caregivers say their general health has stayed the same since taking on their role as a caregiver. However, one in five women (20 percent) indicate their general health has declined since becoming a caregiver, compared to only 14 percent of men. Conversely, men caregivers (20 percent) are nearly twice as likely as women (12 percent) to say that their general health has improved since becoming a caregiver.

# Demographic Perspectives by Gender

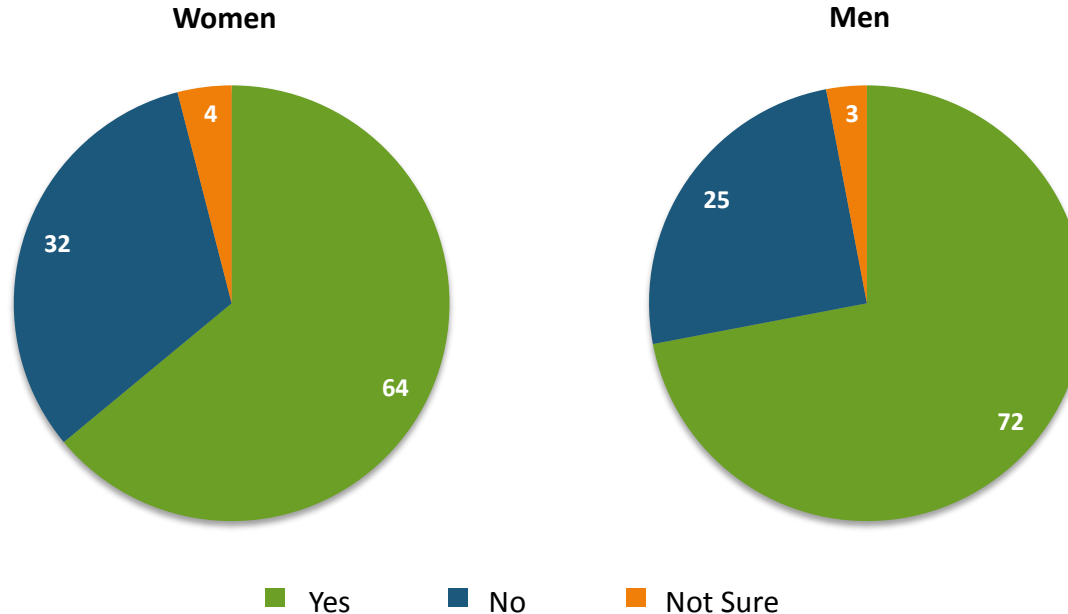
- **Caregivers' Health Insurance.** Most caregivers currently have health insurance, including 88 percent of women and 93 percent of men. Both men (42 percent) and women (36 percent) most commonly receive health insurance through an employer, with Medicare being the second most frequently cited provider of health insurance benefits (18 percent of men, 20 percent of women).
- **Caregivers Would Like More Information to Help Them Personally.** The three most frequently requested topics among women and men caregivers to help them personally with their caregiving responsibilities are: managing stress (39 percent women, 37 percent men), tips for coping with caregiving challenges (38 percent women, 37 percent men), and government benefits available for caregivers (36 percent women, 37 percent men). Men are slightly more likely than women to desire additional information about support groups for caregivers (25 percent of men, 20 percent of women) and employer-sponsored workplace benefits for caregivers (18 percent of men, 13 percent of women).



# Most Consider Themselves to Be the Primary Caregivers

The majority of men and women caregivers consider themselves to be the Primary caregiver of their care recipient. However, men (72 percent) are more likely than women (64 percent) to identify themselves as the Primary caregiver.

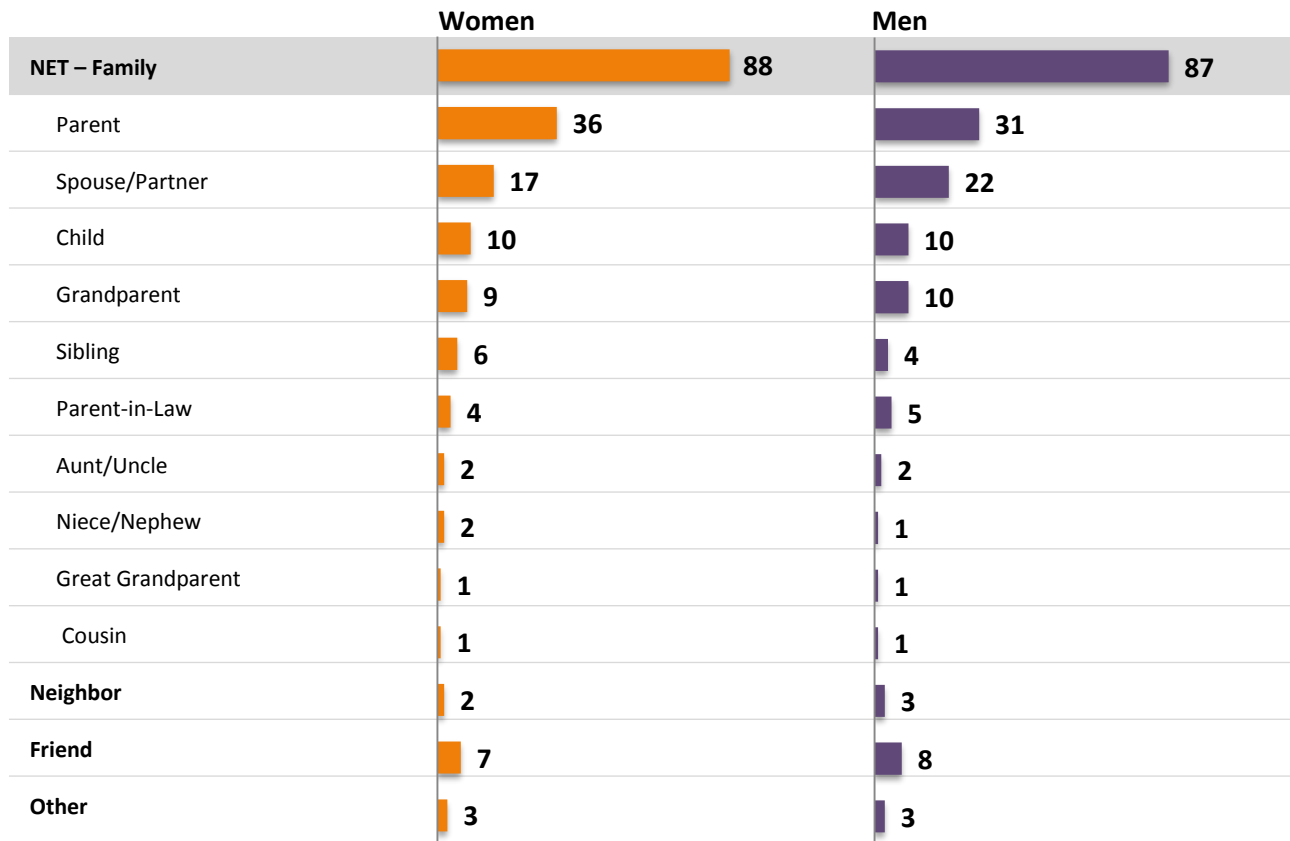
“Would you consider yourself to be the Primary caregiver?” (%)



# The Majority of Caregivers Are Caring for a Family Member

The vast majority of caregivers are caring for a family member, including 88 percent of women caregivers and 87 percent of men caregivers. Parents are the most frequently cited recipients of care among both women (36 percent) and men (31 percent). The second most frequently cited care recipients are spouses/partners with men (22 percent) being slightly more likely to care for a spouse or partner than women (17 percent). Ten percent of both women and men are caring for a child. Nine percent of women and 10 percent of men are caring for a grandparent. Ten percent of both women and men are caring for a child. Nine percent of women and 10 percent of men are caring for a grandparent.

**Relationship to Care Recipient (%)**



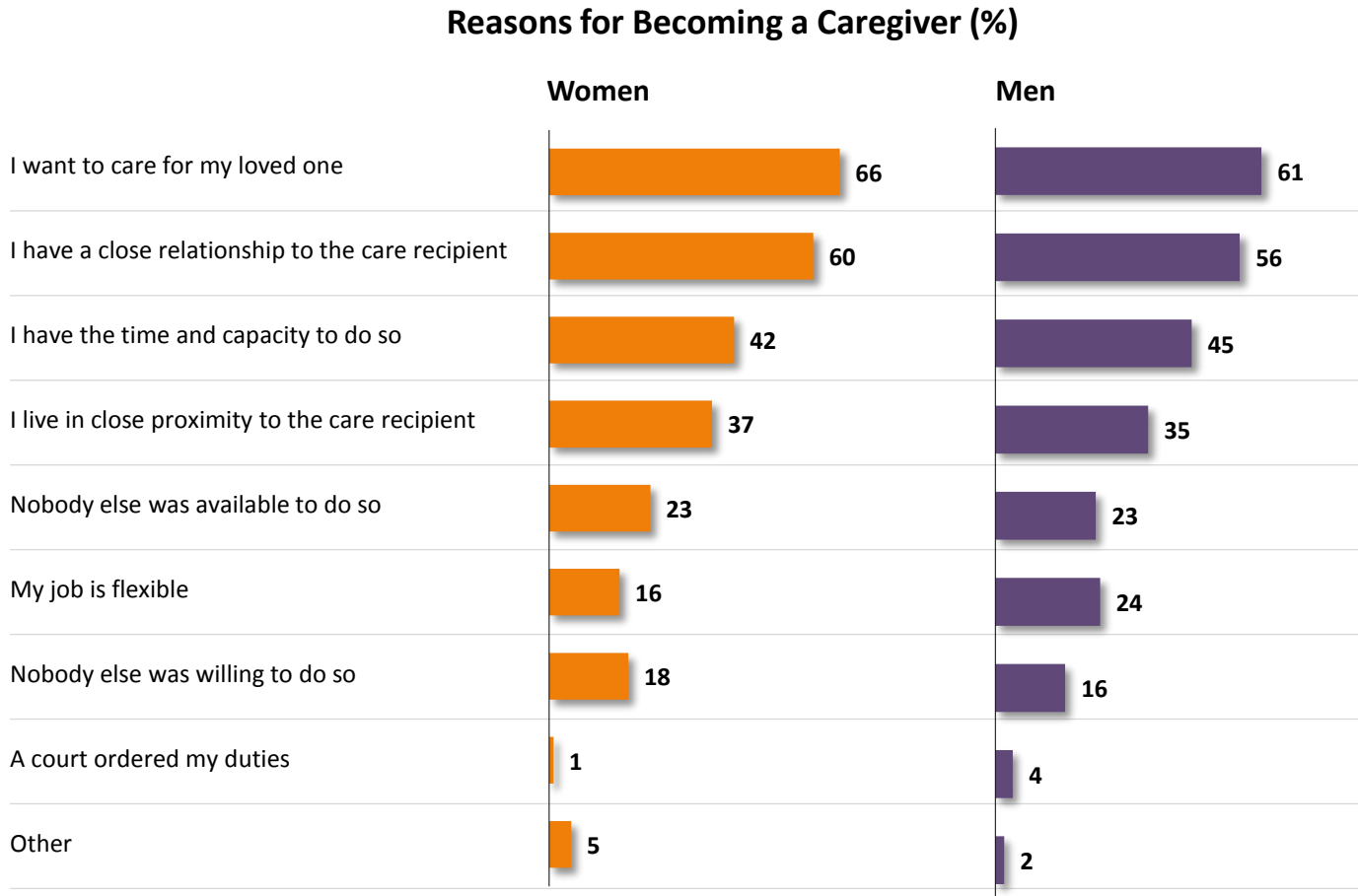
BASE: ALL QUALIFIED RESPONDENTS

Q700. You mentioned providing care for [INSERT ANSWER FROM Q610] individual(s).

Please let us know your relationship to the person, their age, and their gender.

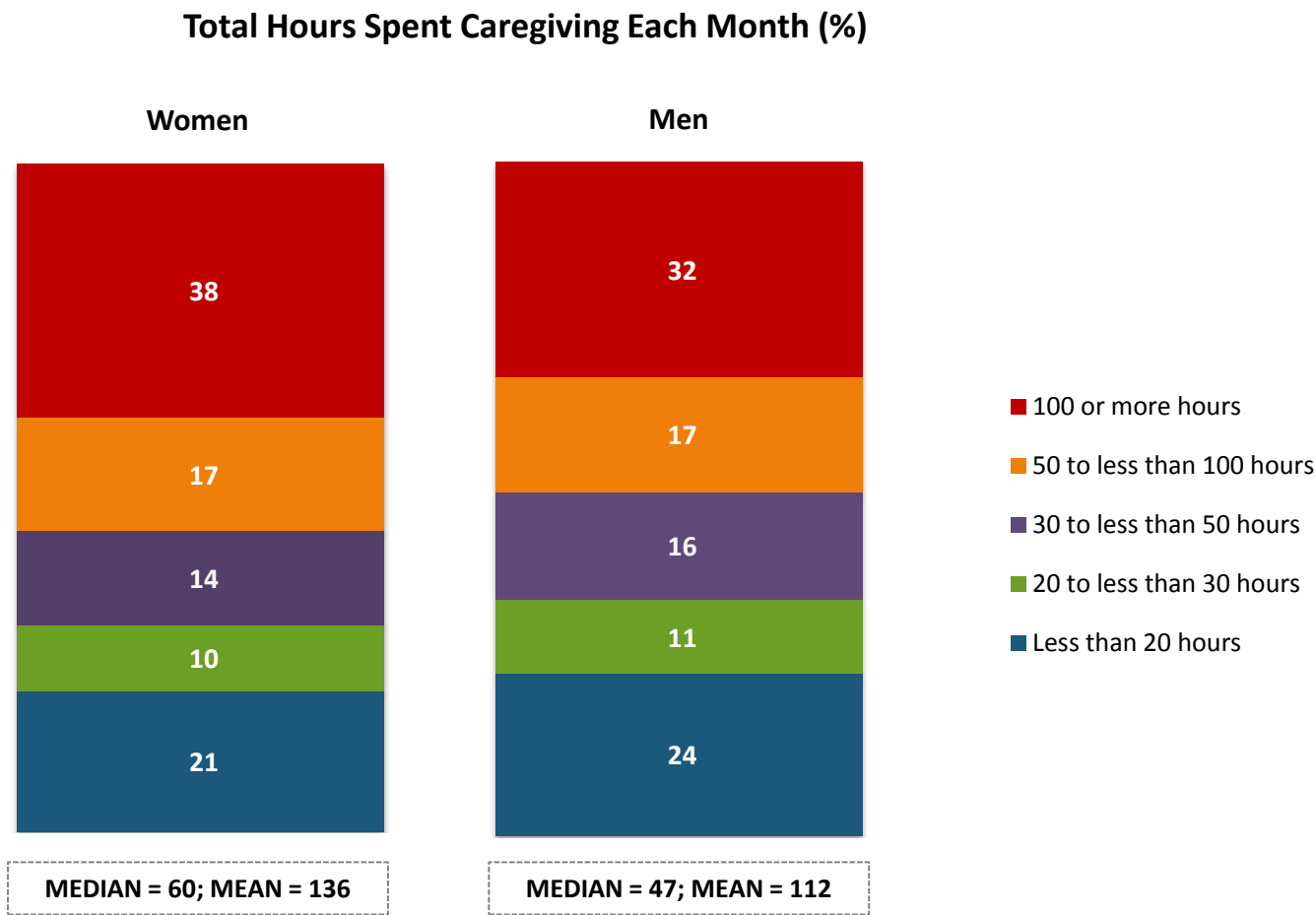
# Reasons for Becoming a Caregiver

When asked how they came to be a caregiver, women (66 percent) and men (61 percent) most frequently cite a desire to care for their loved one as their reason for taking on the role. Other frequently cited reasons include a close relationship to the care recipient (60 percent of women, 56 percent of men) and that they have the time and capacity to do so (42 percent of women, 45 percent of men).



# Total Caregiving Hours per Month

Women caregivers dedicate 60 hours (median) per month to caregiving while men spend 47 hours (median) per month. Women (38 percent) are more likely than men (32 percent) to spend 100 or more hours per month caregiving.



*Note: The median is the midpoint of the range of each response category. The mean is the average of all responses.*

BASE: ALL QUALIFIED RESPONDENTS

Q832. In total, approximately how many hours per month do you spend caring for the care recipient?

# Caregiver Duties Performed

Caregiving entails a broad range of duties.

The most frequently cited type of caregiving duty performed for the care recipient is household-related for both women (90 percent) and men (88 percent).

Women are more likely to run errands (72 percent), do housework (66 percent) and prepare meals (64 percent) than men. In comparison, men more frequently perform home repairs (40 percent) and home modifications (24 percent) for their care recipient.

Women also more frequently engage in social/communication (78 percent) and health-related (72 percent) caregiving duties compared to men (65 percent for both duties, respectively).

Types of Caregiving Duties Performed	Women	Men
<b>NET – Household</b>	<b>90%</b>	<b>88%</b>
Running errands	72%	63%
Housework	66%	53%
Meal preparation	64%	53%
Home repairs	21%	40%
Home modifications	15%	24%
<b>NET – Social/Communication</b>	<b>78%</b>	<b>65%</b>
Companionship	69%	53%
Basic communications	33%	28%
Language translation	7%	8%
<b>NET – Health-Related</b>	<b>72%</b>	<b>65%</b>
Accompanying to medical appointments	65%	57%
Healthcare coordination	50%	38%
Health insurance coordination	29%	30%
<b>NET – Personal Care</b>	<b>62%</b>	<b>62%</b>
Mobility	38%	39%
Personal care	39%	30%
Feeding	27%	27%
Incontinence care	17%	13%
<b>NET – Medical-Related</b>	<b>54%</b>	<b>44%</b>
Medication management	50%	39%
Medical treatment administration	16%	16%
<b>Paying bills/Managing finances</b>	<b>42%</b>	<b>45%</b>
<b>Other</b>	<b>4%</b>	<b>4%</b>

# Hours Spent Caregiving by Types of Duties

Both men and women caregivers spend the most time per month providing companionship to the care recipient, including 35 hours by men caregivers (median) and 30 hours by women caregivers (median). This is followed by meal preparation (median 22 hours for women, 15 hours for men) and personal care (median 14 hours for women, 12 hours for men).

Women (20 hours median) spend twice as many hours per month feeding their care recipient, compared to men (10 hours median).

In general, time spent on other caregiving duties (e.g., health-related, medical-related, household, and social/communication duties) is relatively consistent between genders.

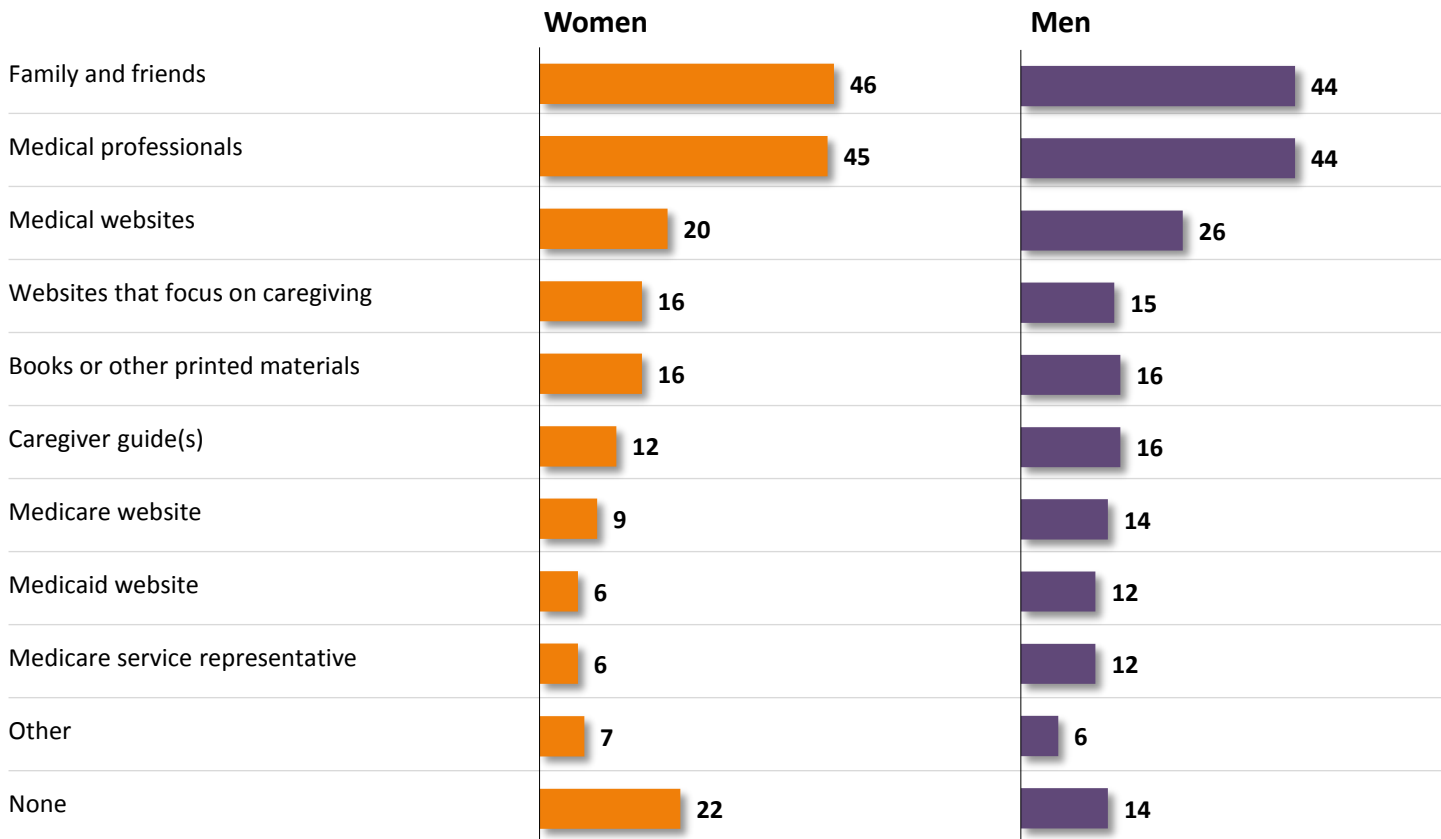
*Note: The median is the midpoint of the range of each response category. The mean is the average of all responses.*

Time Spent On Caregiving Duties Each Month (hours per month)	Women		Men	
	Median	Mean	Median	Mean
<b>Household</b>				
Running errands	8	21	8	15
Housework (e.g., cleaning, laundry)	15	33	10	20
Meal preparation	22	37	15	24
Home repairs	2	11	4	9
Home modifications	2	9	3	7
<b>Social/Communication</b>				
Companionship	30	94	35	88
Basic communications	12	55	8	33
Language translation	4	13	5	17
<b>Health-Related</b>				
Accompanying to medical appointments	4	12	5	9
Healthcare coordination	3	11	3	7
Health insurance coordination	2	11	2	6
<b>Personal Care</b>				
Mobility	10	28	8	19
Personal care	14	29	12	20
Feeding	20	41	10	25
Incontinence care	7	26	5	16
<b>Medical-Related</b>				
Medication management	4	19	5	13
Medical treatment administration	5	22	5	13
<b>Paying bills/Managing finances</b>	3	10	3	8
<b>Other</b>	6	103	4	23

# Sources of Information Relied on to Assist in Caregiving Duties

Both men and women caregivers most frequently rely on family and friends (46 percent of women, 44 percent of men) and medical professionals (45 percent of women, 44 percent of men) for information to assist with their caregiver duties. Men are slightly more likely than women to rely on online sources, such as medical, Medicare, and Medicaid websites, in order to assist in their caregiving roles. In contrast, women caregivers (22 percent) are more likely to use no outside sources of information, compared to men (14 percent).

**Sources of Information to Assist in Caregiving Duties (%)**



NOTE: Nine most commonly selected sources shown.

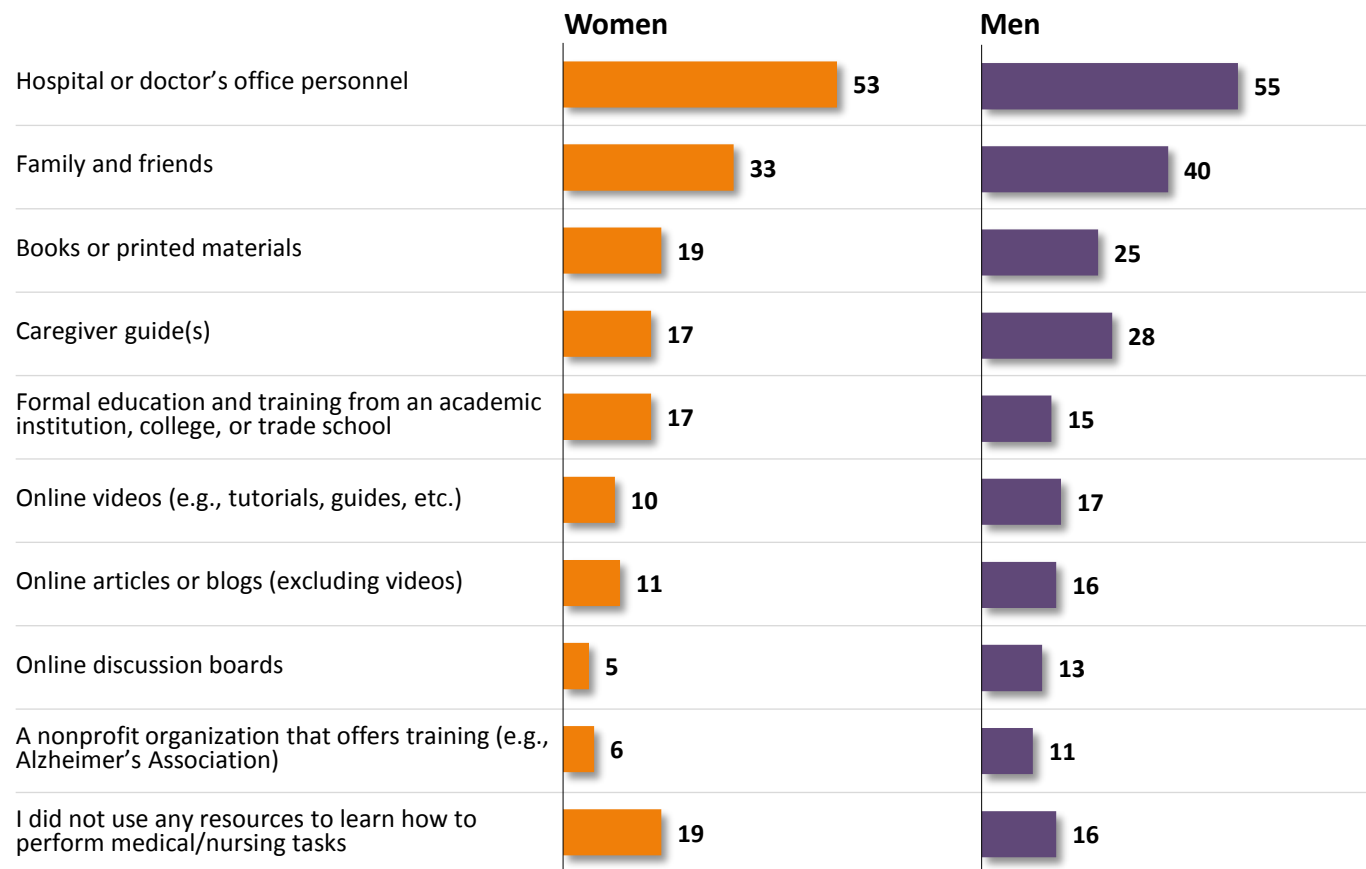
BASE: ALL QUALIFIED RESPONDENTS

Q840. Which of the following do you rely on as sources of information to assist in your caregiving duties? Select all.

# Sources for Learning About Medical/Nursing Tasks

Among caregivers currently performing medical/nursing-related tasks, more than half of men (55 percent) and women (53 percent) most frequently report using hospital or doctor's office personnel to learn how to perform medical/nursing tasks. Of note, men (28 percent) are more likely than women (17 percent) to have learned from caregiver guides. Across potential information sources, men are somewhat more likely than women have used online videos and blogs.

**Sources for Learning Medical/Nursing Tasks Related to Being a Caregiver (%)**



NOTE: Nine most commonly selected sources shown.

BASE: IF ADMINISTERING MEDICATIONS AND MEDICAL TREATMENTS

Q835. You mentioned you perform medication management or medical treatment administration for the care recipient. Where did you learn how to perform medical/nursing tasks related to being a caregiver? Select all.



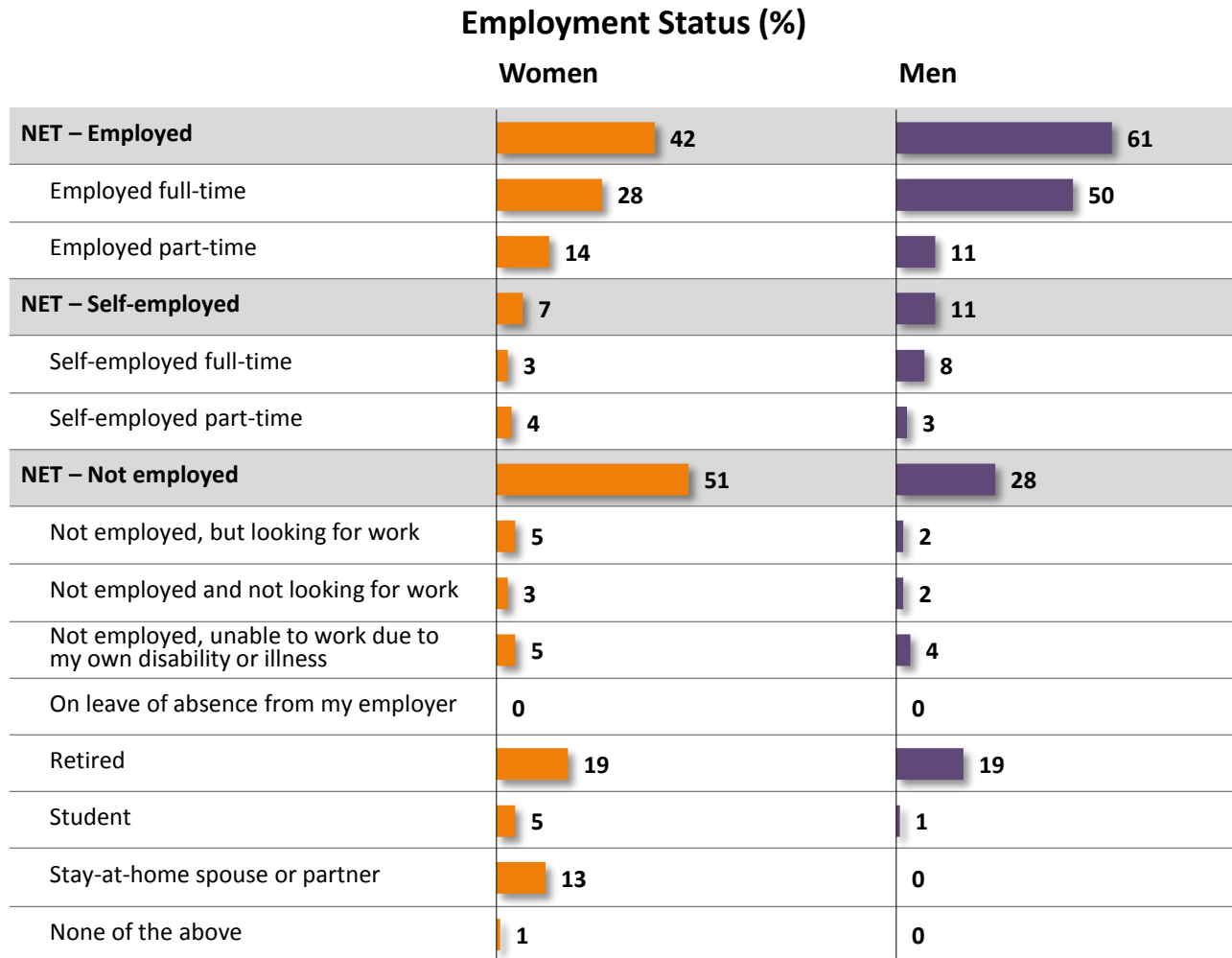
# Caregivers' Sentiments About Their Caregiving Duties

Both women and men caregivers generally have positive sentiments about their caregiving duties. Almost all women and men caregivers agree that it is important to provide a good quality of life for the care recipient (95 percent of women, 94 percent of men) – and indicate that they like helping and enjoy spending time with the care recipient. Men (58 percent) are more likely than women (52 percent) to say their own health takes a backseat to the health of their care recipient.

Caregivers' Sentiments About Their Caregiving Duties	Women	Men
	Strongly/Somewhat Agree (NET)	
Positive		
It's important for me to provide a good quality of life for the care recipient	95%	94%
I like helping the care recipient	92%	90%
I enjoy spending time with the care recipient	91%	90%
Being a caregiver gives me a strong sense of purpose	82%	84%
Being a caregiver has led me to take better care of my own health	68%	72%
Being a caregiver has inspired me to document my own health and legal wishes	65%	68%
Negative		
My own health takes a backseat to the health of my care recipient	52%	58%
My caregiving duties leave me feeling physically exhausted	54%	55%
My caregiving duties leave me feeling emotionally exhausted	55%	54%
I need more help with my caregiving duties	42%	54%
With all of my caregiving duties, I barely have time for anything else	43%	48%
My caregiving duties leave me feeling completely overwhelmed	43%	44%

# Employment Status of Caregivers

Men caregivers (61 percent) are more likely to be employed than women caregivers (42 percent). Fifty-one percent of women describe themselves as not employed, compared to only 28 percent of men. Nineteen percent of both women and men are retired. Thirteen percent of women caregivers are stay-at-home spouses or partners compared to no men.



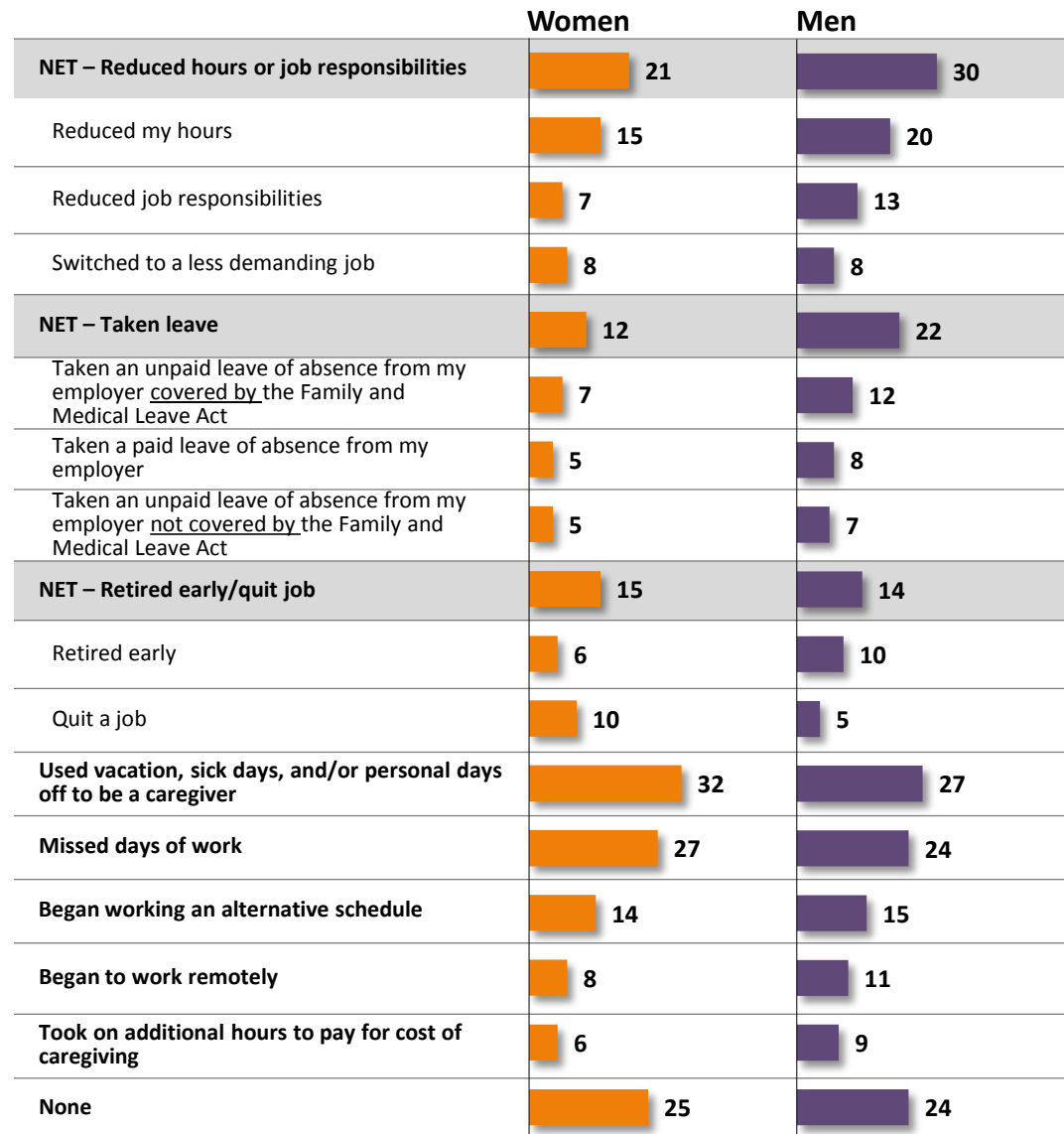
# Disruptions to Employment as a Result of Caregiving

Caregiving responsibilities can be disruptive to a caregiver's employment situation.

Among caregivers who are employed or who have been employed during their time as a caregiver, 30 percent of men and 21 percent of women have reduced their hours, reduced job responsibilities, and/or switched to a less demanding job.

Additionally, 15 percent of women and 14 percent of men have either retired early and/or quit their job.

**"Which of the following have you done as a result of becoming a caregiver?" (%)**



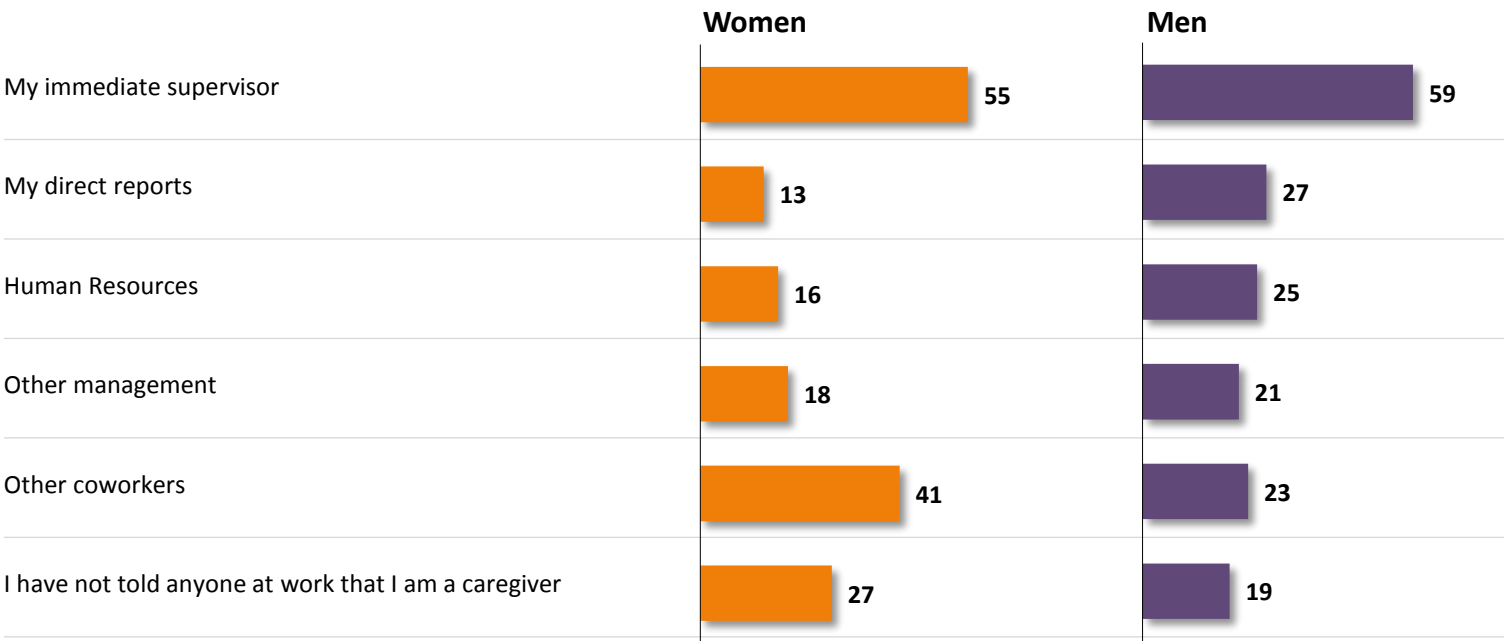
NOTE: Thirteen most commonly selected sources shown.

BASE: ALL EMPLOYED OR HAVE BEEN EMPLOYED DURING THEIR TIME AS A CAREGIVER  
Q1025. Which of the following have you done as a result of becoming a caregiver? Select all.

# Informing Coworkers About Their Caregiving Duties

Among employed caregivers, the majority have told their immediate supervisor that they are a caregiver, including 55 percent of women and 59 percent of men. Men (27 percent) are more likely than women (13 percent) to have told their direct reports. Men (25 percent) are also more likely than women (16 percent) to have told Human Resources about their caregiving role. On the other hand, women (41 percent) are much more likely than men (23 percent) to have shared that they are a caregiver with their coworkers. Some have not shared with anyone at work about being their caregiver, including 27 percent of women and 19 percent of men.

“Which of the following people at work have you told that you are a caregiver?” (%)



NOTE: Self-employed and not employed were excluded from this question.

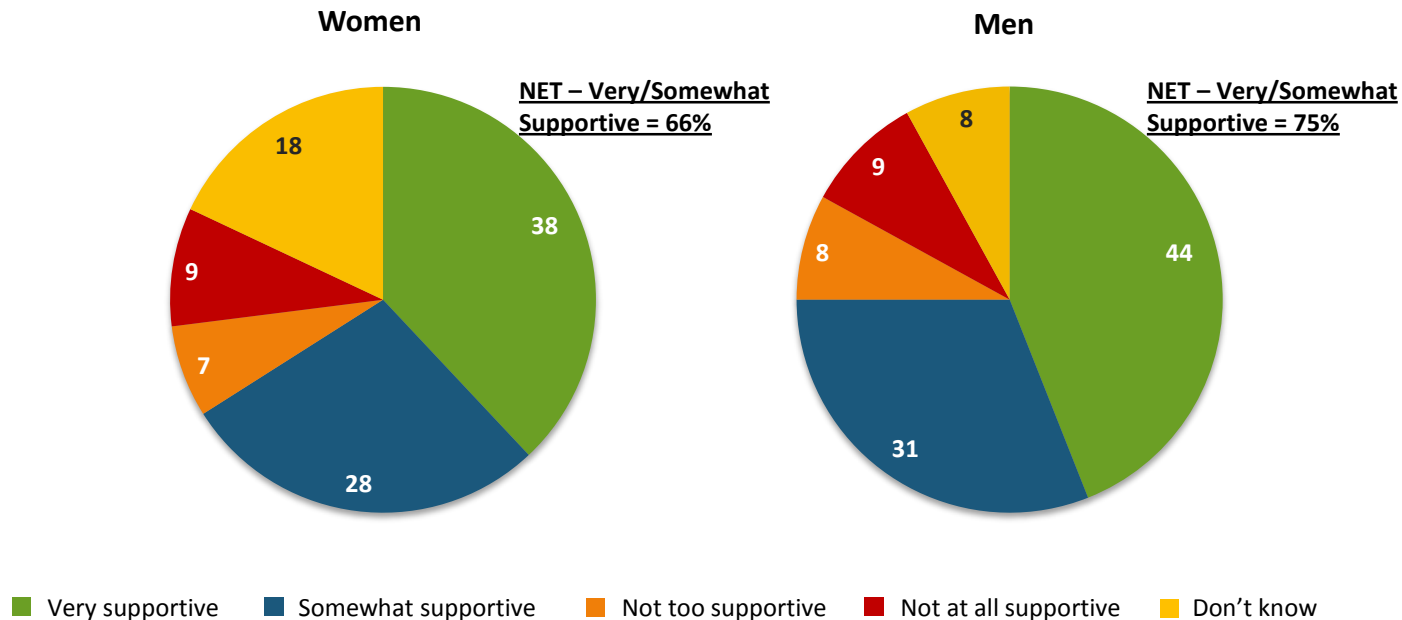
BASE: EMPLOYED FULL-TIME OR PART-TIME

Q1035. Which of the following people at work have you told that you are a caregiver? Select all.

# Employer Support of Caregiving Duties

Among employed caregivers, most say that their employers are either very or somewhat supportive of their caregiving responsibilities, including 75 percent of men and 66 percent of women. Men (17 percent) and women (16 percent) are similarly likely to say that their employer is not too supportive or not at all supportive. Women (18 percent) are more likely than men (8 percent) to say they don't know whether their employers are supportive.

**“How supportive is your employer of your caregiving responsibilities?” (%)**



NOTE: Self-employed and not employed were excluded from this question.

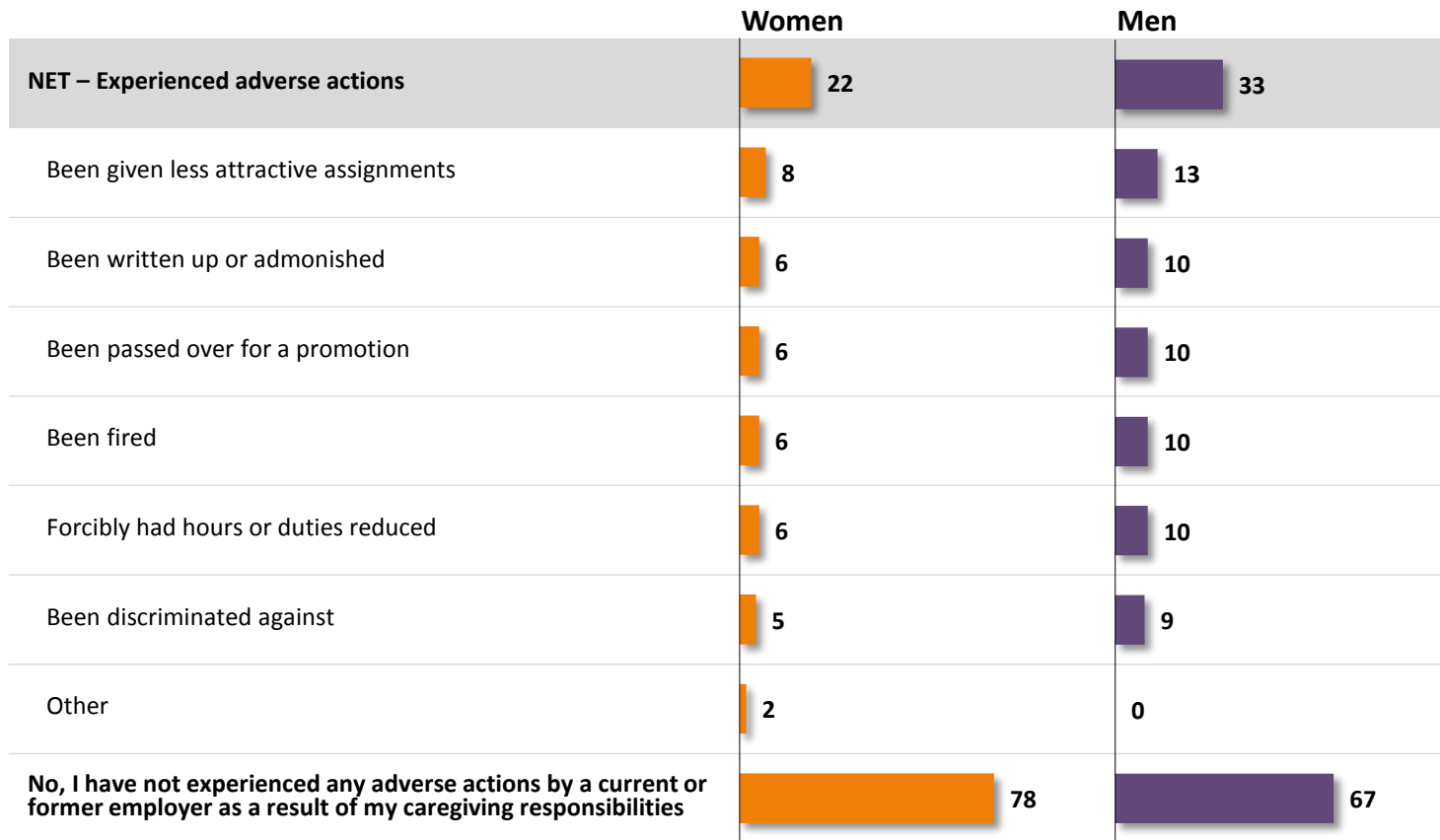
BASE: EMPLOYED FULL-TIME OR PART-TIME

Q1045. How supportive is your employer of your caregiving responsibilities?

# Adverse Actions Taken by Employers

Caregiving duties may conflict with job responsibilities which, in turn, may lead to adverse actions taken by employers. Adverse actions may include being given less attractive assignments, being discriminated against, or being passed over for a promotion, among countless others. Among caregivers who are employed or who have been employed during their time as caregivers, more men (33 percent) compared to women (22 percent) say they have experienced adverse employment actions by a current or former employer as a result of their caregiving responsibilities.

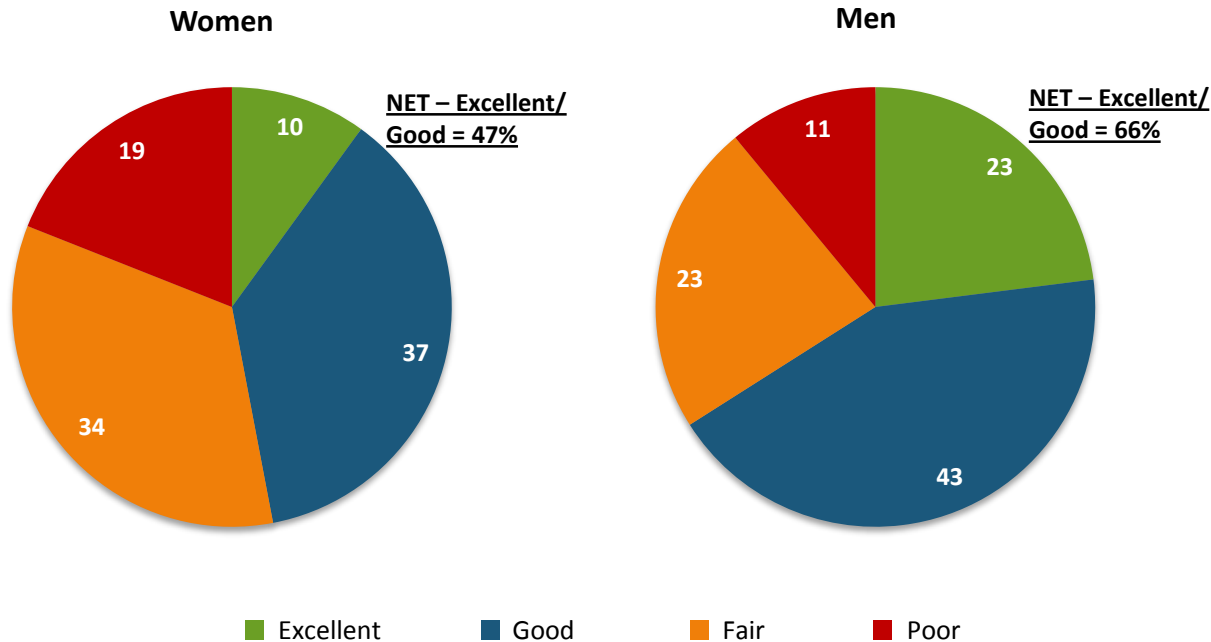
## Adverse Employment Actions Experienced as a Result of Caregiving Duties (%)



# Caregivers' Financial Well-Being

Men caregivers (66 percent) are more likely than women caregivers (47 percent) to describe their financial well-being as excellent or good. In contrast, one-third of women (34 percent) self-report their financial status as fair, compared to only 23 percent of men. Nineteen percent of women caregivers describe their financial well-being as poor, compared to just 11 percent of men.

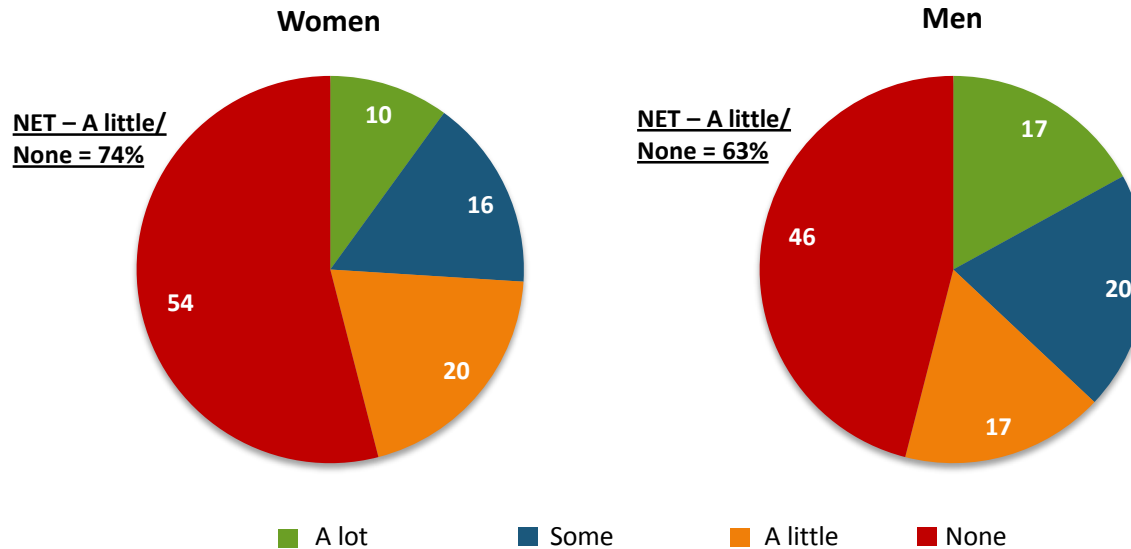
**“How would you describe your own financial well-being?” (%)**



# Financial Considerations Before Becoming Caregivers

Most women (74 percent) and men caregivers (63 percent) say that they gave little or no consideration to their own financial situation when deciding to become a caregiver. Men (17 percent) are more likely than women (10 percent) to indicate they gave it a lot of consideration.

**“To what extent did you consider your own financial situation when deciding to become a caregiver?” (%)**

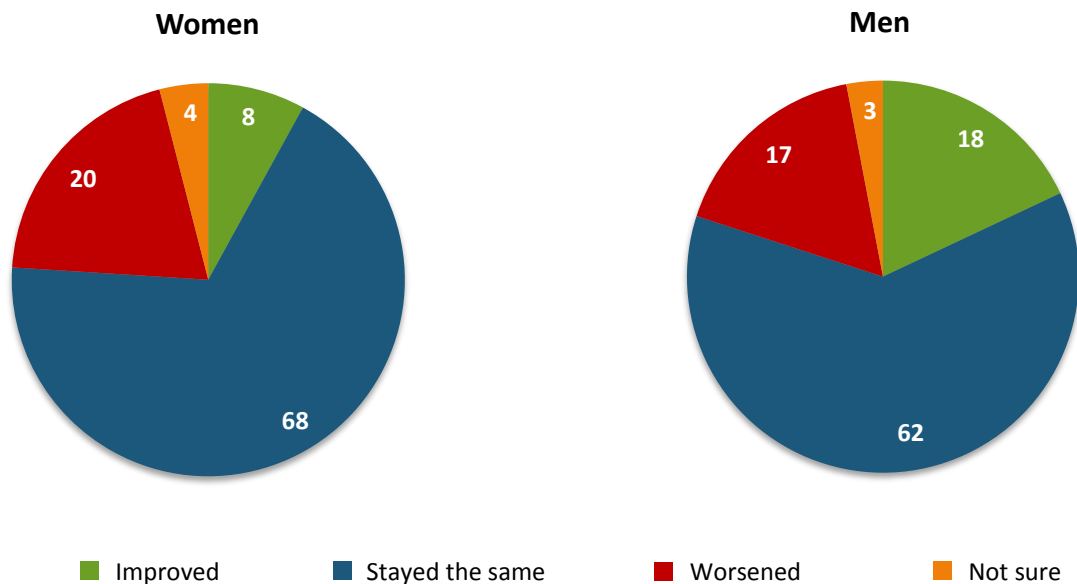




# Change in Financial Situation as a Result of Caregiving

Most caregivers say that their financial situation has stayed the same as a result of becoming a caregiver, including 68 percent of women and 62 percent of men. However, one in five women caregivers (20 percent) say their financial situation has worsened as a result of becoming a caregiver, a finding that is slightly higher than that of men caregivers (17 percent). Surprisingly, 18 percent of men caregivers report that their financial situation has actually improved due to their caregiver role, compared to only 8 percent of women.

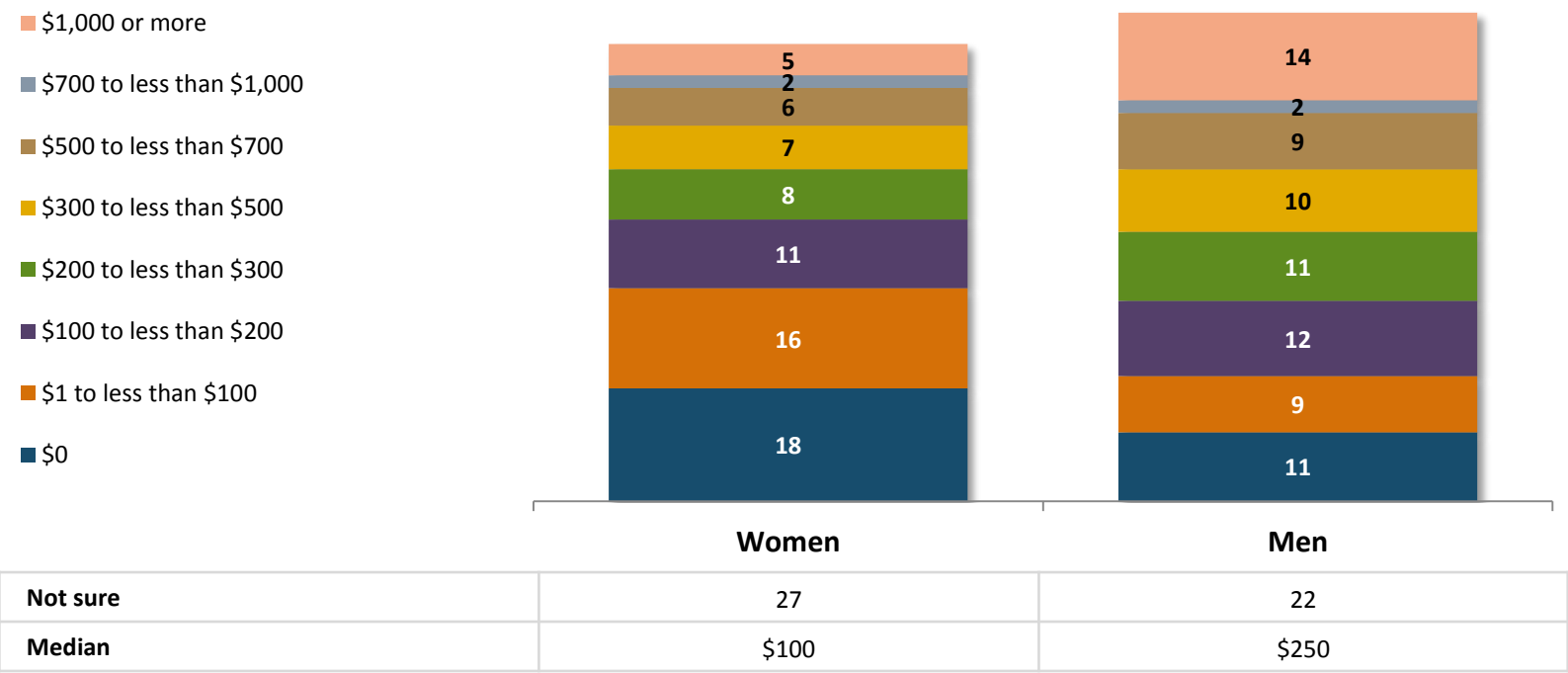
**“How has your financial situation changed as a result of becoming a caregiver?”**



# Monthly Personal Expenditures for Caregiving

Caregivers often find themselves paying out-of-pocket expenses for the care recipient (e.g., groceries, over-the-counter medications, gas, parking). Men caregivers spend \$250 per month (median), a finding that is more than twice the amount spent by women caregivers (\$100 median). Men (14 percent) are nearly three times more likely to spend \$1,000 or more per month on their care recipient than women (5 percent). In contrast, women (18 percent) are more likely to not spend any out-of-pocket money on their care recipient each month, in comparison to men (11 percent).

Monthly Personal Expenditures to Cover Expenses for Care Recipient (%)



Note: The median is the midpoint of the range of each response category. Non-responses are excluded from the estimate.

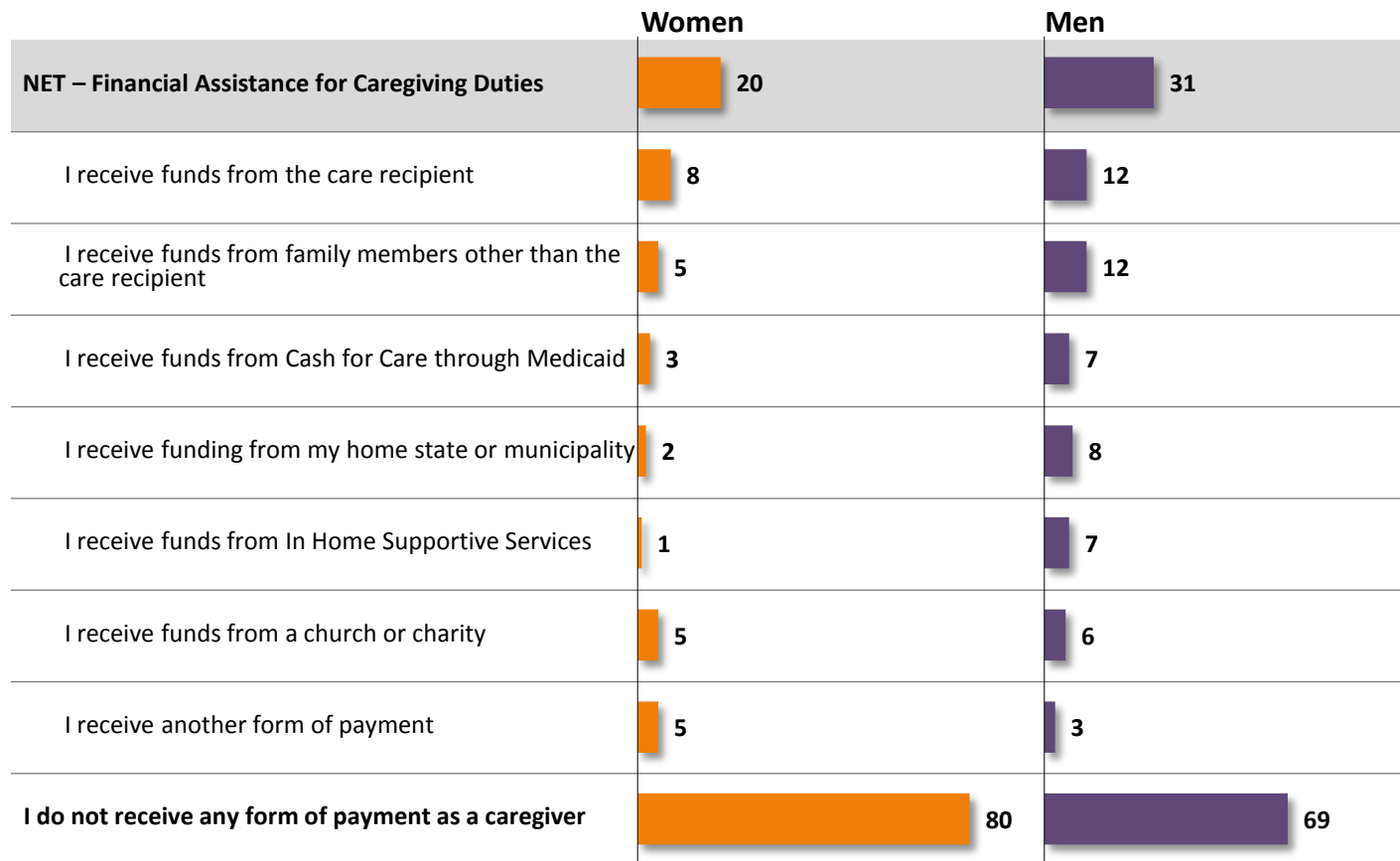
BASE: ALL QUALIFIED RESPONDENTS

Q1120. On average, approximately how much money do you spend each month paying out-of-pocket to cover expenses for the care recipient (e.g. for groceries, over-the-counter medications, gas, parking)?

# Financial Assistance for Caregiving Duties

Most women caregivers (80 percent) and men caregivers (69 percent) do not receive any form of compensation for their caregiving duties. However, men (31 percent) are more likely than women (20 percent) to receive some financial assistance. Both men and women most frequently received funding from the care recipient (12 percent of men, 8 percent of women) or from family members other than the care recipient (12 percent of men, 5 percent of women).

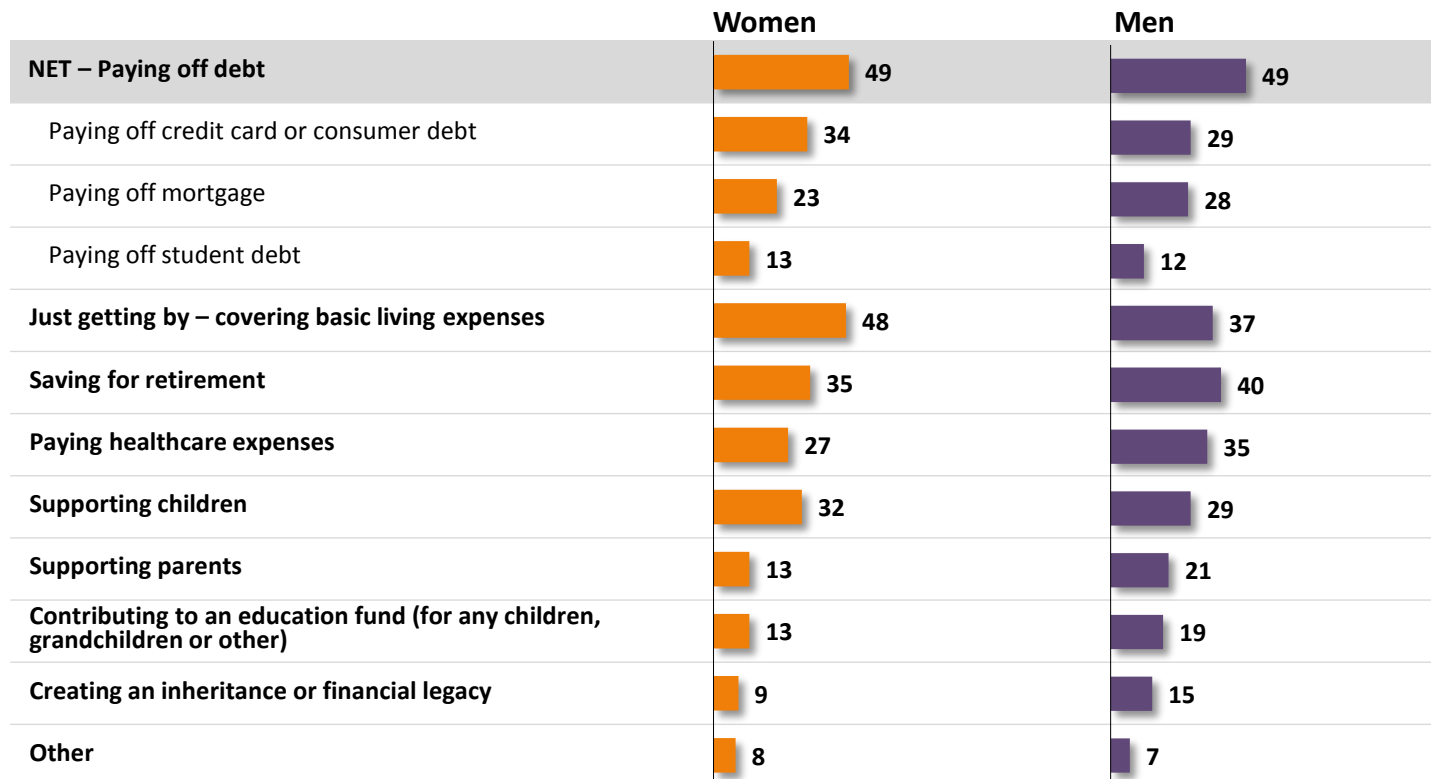
**Sources of Financial Assistance Received for Caregiving Duties, If Any (%)**



# Financial Priorities Among Caregivers

Men and women caregivers (both 49 percent) most frequently reference paying off some form of debt (i.e., credit card, consumer, student, or mortgage debt) as a current financial priority. Alarming, approximately one-half of women (48 percent) identify “just getting by” as a current financial priority, compared to 37 percent of men. Other frequently cited financial priorities include saving for retirement, paying for healthcare expenses, and supporting children.

**“Which of the following are your financial priorities right now?” (%)**



# Total Household Income Among Caregivers

Men caregivers had a higher total household income (HHI) in 2016 at \$71,000 (estimated median) compared to just \$46,000 (estimated median) among women caregivers. Thirty-eight percent of men were found to have an HHI of \$100,000 or more, compared to only 19 percent of women. Forty-one percent of women report an HHI of less than \$50,000 compared to 25 percent of men.

**Total Household Income in 2016 (%)**

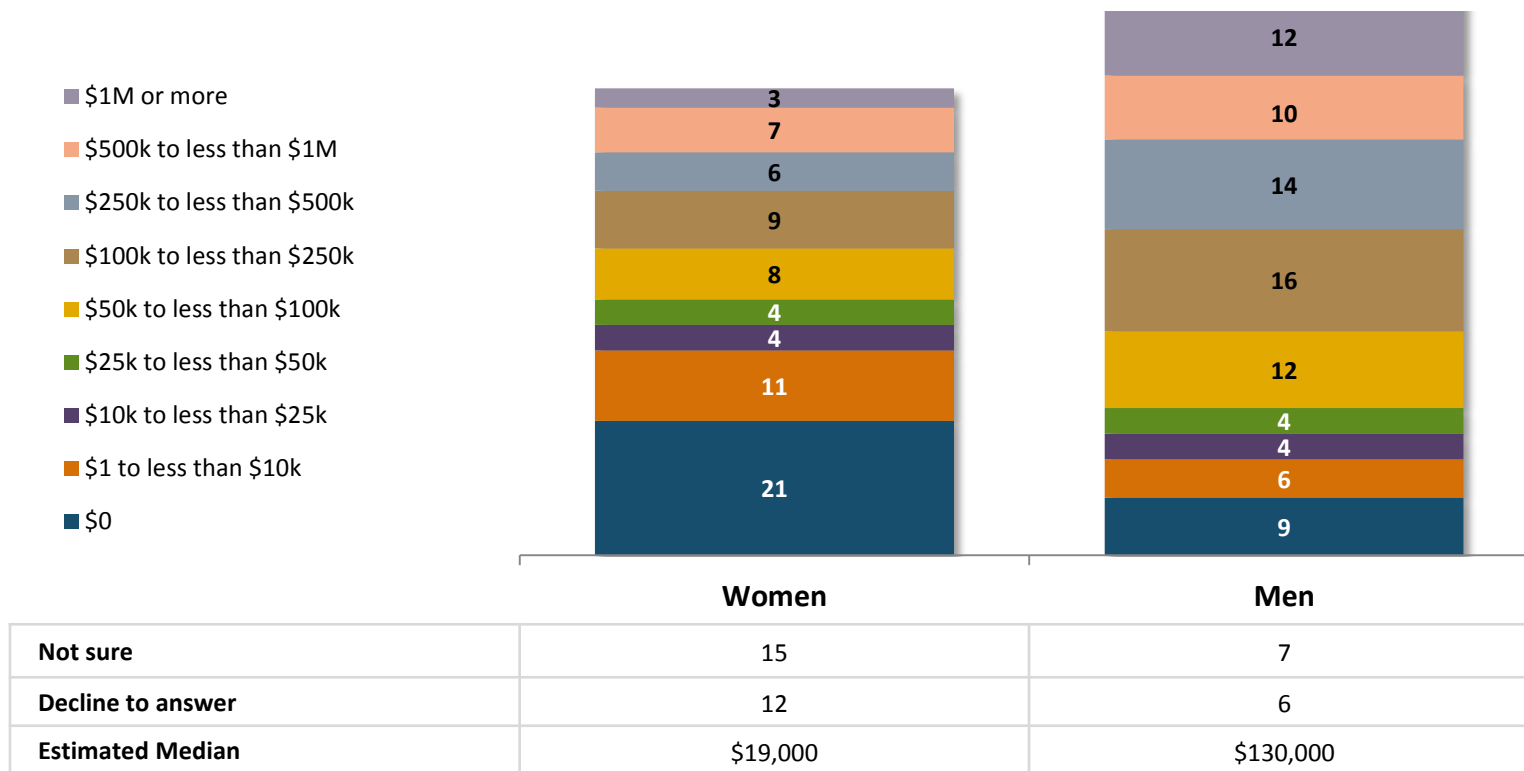


*Note: The median is estimated based on the approximate midpoint of the range of each response category. Non-responses are excluded from the estimate.*

# Total Household Retirement Savings Among Caregivers

Men caregivers have seven times more money saved in total household retirement savings accounts than women caregivers. Men report having saved an estimated median of \$130,000 compared to just \$19,000 among women. An alarming one in five women (21 percent) have no household retirement savings, compared to only 9 percent of men. Twelve percent of men have saved \$1 million or more in total household retirement accounts compared to only 3 percent of women.

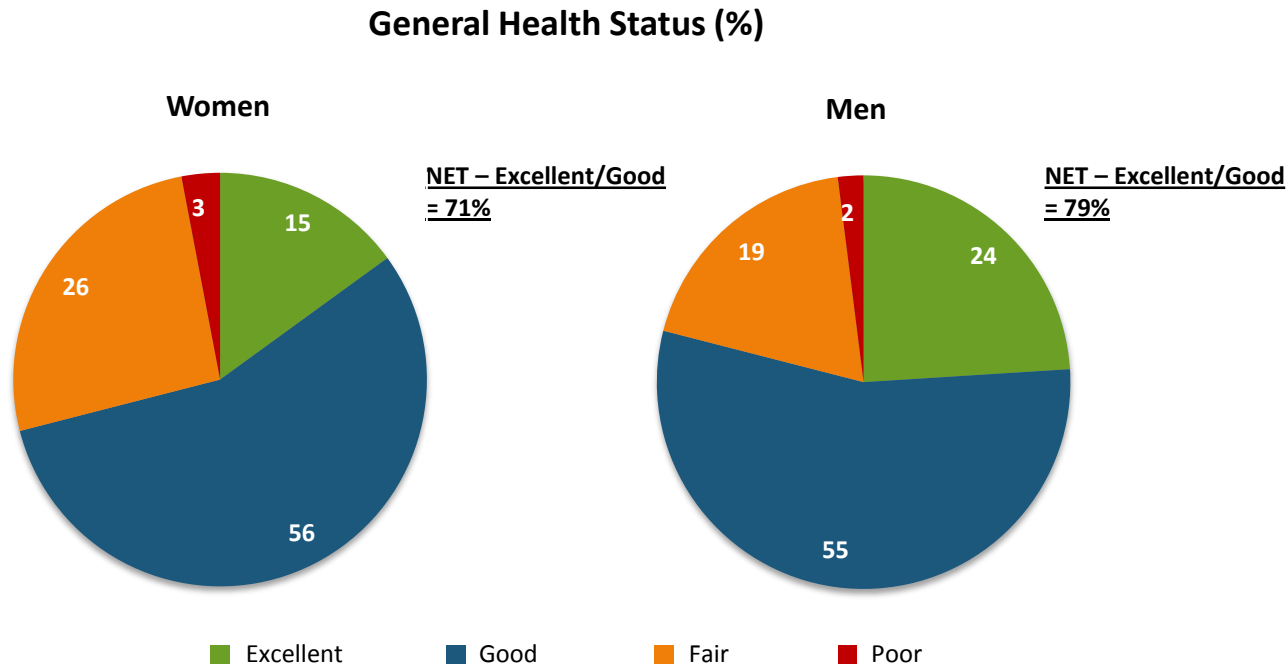
**Total Household Retirement Savings in All Accounts (%)**



*Note: The median is estimated based on the approximate midpoint of the range of each response category. Non-responses are excluded from the estimate.*

# Caregivers' Self-Described General Health

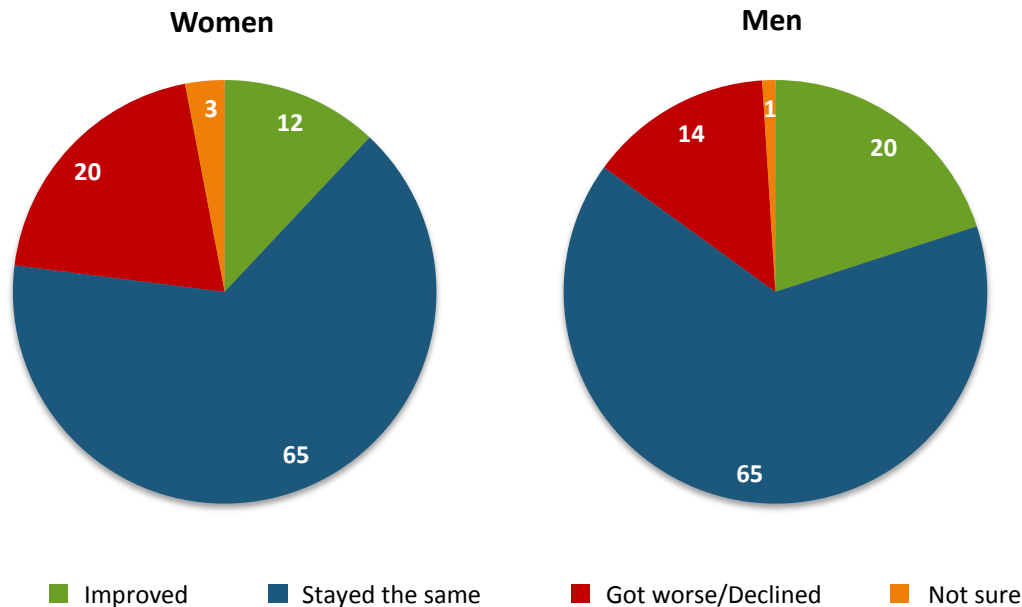
Most women and men caregivers self-describe their general health as excellent or good, including 71 percent of women and 79 percent of men. However, men (24 percent) are more likely than women (15 percent) to report having excellent health. In contrast, women (29 percent) and more likely than men (21 percent) to say they are in fair or poor health.



# Changes in General Health Since Becoming a Caregiver

Sixty-five percent of women and men caregivers say their general health has stayed the same since taking on their role as a caregiver. However, one in five women (20 percent) indicate their general health has declined since becoming a caregiver, compared to only 14 percent of men. Conversely, men caregivers (20 percent) are nearly twice as likely as women (12 percent) to say that their general health has improved since becoming a caregiver.

**Changes in General Health Since Becoming a Caregiver (%)**



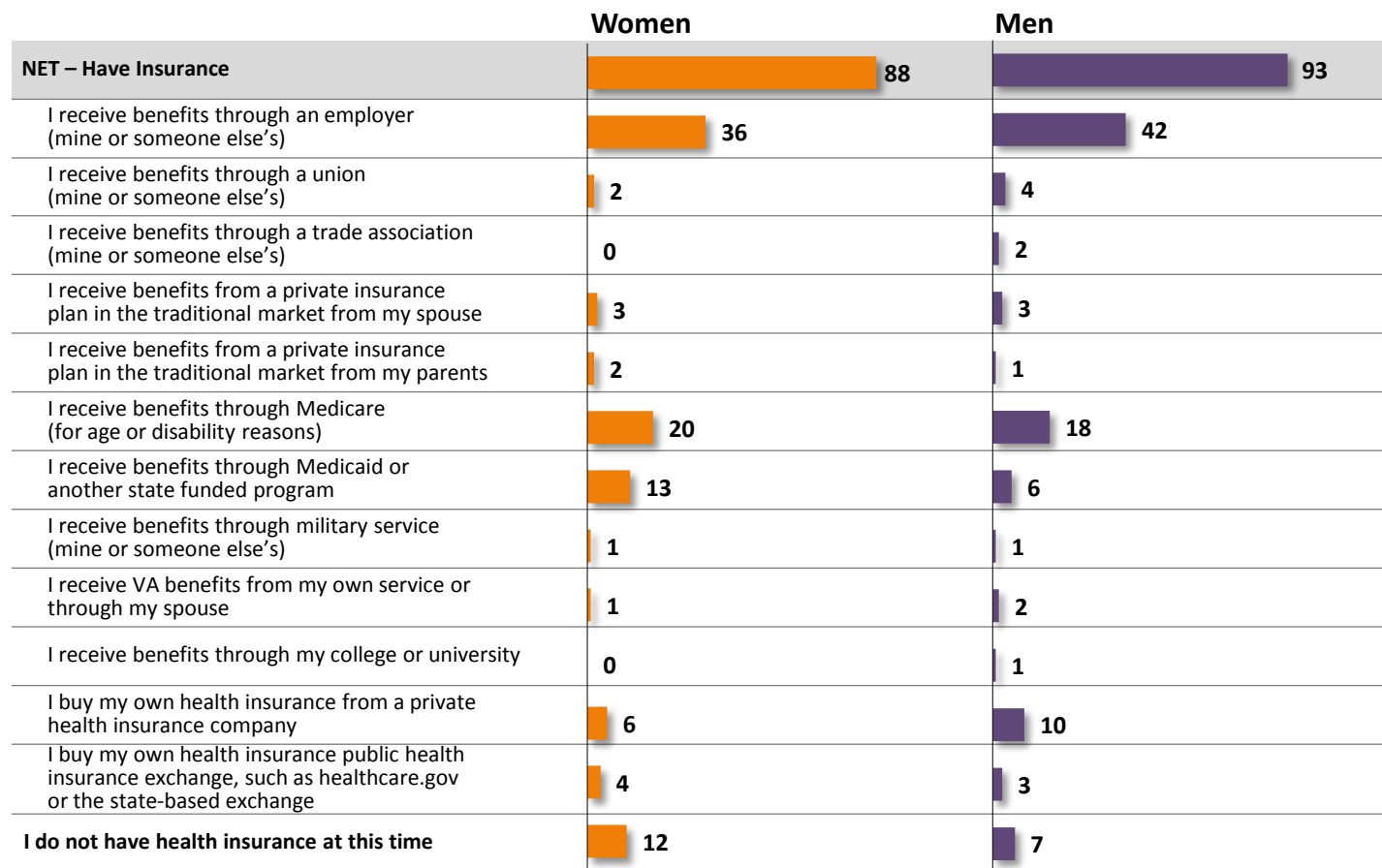
■ Improved ■ Stayed the same ■ Got worse/Declined ■ Not sure



# Caregivers' Health Insurance

Most caregivers currently have health insurance, including 88 percent of women and 93 percent of men. Both men (42 percent) and women (36 percent) most commonly receive health insurance through an employer, with Medicare being the second most frequently cited provider of health insurance benefits (18 percent of men, 20 percent of women).

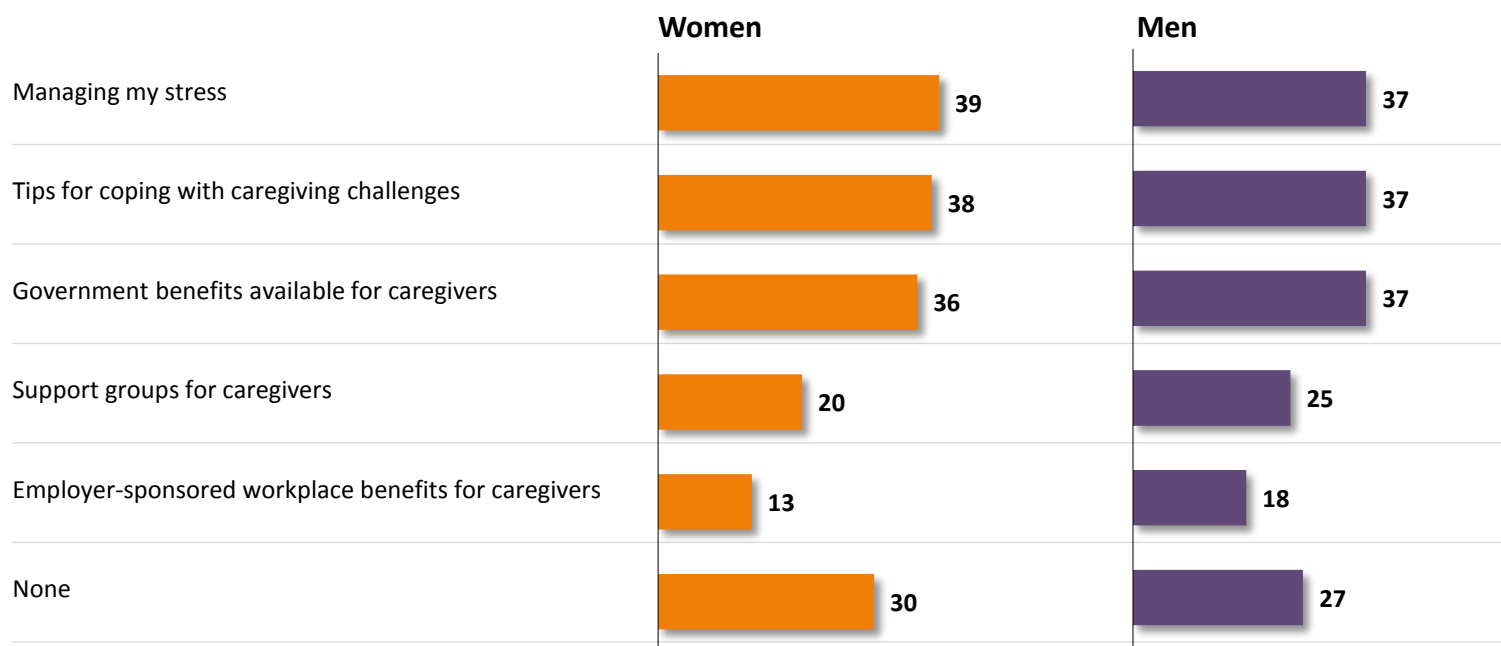
## “Which of the following best describes how you primarily receive health insurance?” (%)



# Caregivers Would Like More Information to Help Them Personally

The three most frequently requested topics among women and men caregivers to help them personally with their caregiving responsibilities are: managing stress (39 percent women, 37 percent men), tips for coping with caregiving challenges (38 percent women, 37 percent men), and government benefits available for caregivers (36 percent women, 37 percent men). Men are slightly more likely than women to desire additional information about support groups for caregivers (25 percent of men, 20 percent of women) and employer-sponsored workplace benefits for caregivers (18 percent of men, 13 percent of women).

**“Which of the following topics would you like more information to help you personally with your caregiving responsibilities?” (%)**



NOTE: Five most commonly selected sources shown.

BASE: ALL QUALIFIED RESPONDENTS

Q850. Which of the following topics would you like more information to help you personally with your caregiving responsibilities? I would like more information about... Select all.



## Demographic Perspectives by Household Income

# ***The Many Faces of Family Caregivers: A Close-Up Look at Caregiving and Its Implications***

## **A Portrait of Today's Caregivers**

- Demographic Perspectives
- Voluntary Status
- Employment Status
- Generations
- Gender

### **➤ *Household Income***

- Race/Ethnicity

## **Appendix: Caregiver and Care Recipient Demographics**

## **Acknowledgements**

# Demographic Perspectives by Household Income

Caregivers are well-represented across economic backgrounds. The survey finds that 18 percent had a household income (HHI) in 2016 of less than \$25,000, 17 percent of \$25,000 to \$49,999, 30 percent of \$50,000 to \$99,999, 28 percent of \$100,000 or more, and seven percent declined to answer.

In this chapter, the survey explores the similarities and differences of caregiving responsibilities and the impact on caregivers by HHI. Across levels of HHI, caregivers share common reasons for becoming a caregiver including the desire to care for their loved one. However, their economic circumstances translate to very different situations.

Employment status varies dramatically among caregivers by HHI. Caregivers with higher levels of HHI are far more likely to be employed than those of lower HHIs. They are better off financially, more likely to be in excellent or good health, and are less likely to indicate their own health has declined since becoming a caregiver.

In contrast, caregivers with lower levels of HHI spend more time per month caregiving. They are more likely to report a decline in their own health since becoming a caregiver. They most frequently cite “just getting by” as a financial priority and many have saved little or nothing for retirement.

## *Twenty-Five Facts About Caregivers by Household Income*

- **Most Consider Themselves to Be the Primary Caregivers.** Two-thirds of all caregivers consider themselves to be the Primary caregiver of their care recipient, a finding which is relatively consistent across all levels of HHI.
- **The Majority of Caregivers Are Caring for a Family Member.** Most caregivers are caring for a family member, a finding which is higher among caregivers with an HHI of \$50k to \$99k (89 percent) and those with an HHI of \$100k+ (90 percent) than those with an HHI of \$25k to \$49k (86 percent) and with an HHI of less than \$25k (81 percent). Approximately one in three caregivers across all levels of HHI are caring for a parent and approximately one in ten are caring for a child. Caregivers with an HHI of \$50k to \$99k (10 percent) and HHI of \$100k+ (14 percent) are slightly more likely to be caring for a grandparent, compared to those of an HHI of less than \$25k (7 percent) and HHI of \$25k to \$49k (5 percent).
- **Reasons for Becoming a Caregiver.** Approximately three in five caregivers cite a desire to care for a loved one and having a close relationship to the care recipient as motivations for becoming a caregiver, a finding which is consistent across levels of HHI. About four in ten caregivers across all levels of HHI indicate they have the time and capacity to do so as a motivation, while roughly one in three indicate they live in close proximity to the care recipient. Caregivers with an HHI under \$25k (27 percent) and those with an HHI of \$25k to \$49k (29 percent) are more likely to indicate that nobody else was available to do so, a finding that is slightly higher than those with an HHI of \$50k to \$99k (23 percent) and an HHI of \$100k+ (17 percent).

# Demographic Perspectives by Household Income

- **Total Caregiving Hours per Month.** The amount of time caregivers spend caregiving each month varies by HHI. Caregivers with lower HHIs spend significantly more time caregiving each month compared to those with higher HHIs. The time spent by caregivers with an HHI less than \$25k is 112 hours per month (median), a finding that is more than double those with HHIs of \$25k to \$49k (60 hours median), \$50k to \$99k and \$100k+ (both 40 hours median). Fifty-three percent of caregivers with an HHI less than \$25k spend 100 hours or more per month caregiving, compared to 40 percent of those with an HHI of \$25k to \$49k, 30 percent of those with an HHI of \$50k to \$99k, and 29 percent of those with an HHI of \$100k+.
- **Caregiver Duties Performed.** Caregiving encompasses a broad range of duties that vary across all levels of household income (HHI).
  - Approximately nine in 10 caregivers across levels of HHI are involved in doing some form of household duties for the care recipient (e.g., running errands, housework, meal preparation, home repairs, home modifications).
  - Caregivers with an HHI of less than \$25k (78 percent) and HHI of \$25k to \$49k (79 percent) are more likely to be involved in some form of social/communications-related activities with the care recipient, compared to caregivers with an HHI of \$50k to \$99k (70 percent) and those with an HHI of \$100k+ (65 percent).
  - Approximately seven in 10 caregivers across levels of HHI are involved in health-related tasks for the care recipient (e.g., accompanying to medical appointments, healthcare coordination, health insurance coordination). And approximately six in 10 provide assistance in various personal-related activities.
- **Hours Spent Caregiving by Types of Duties.** In terms of their caregiving duties, caregivers across all levels HHI dedicate the most time per month providing companionship to the care recipient. However, the time spent on companionship decreases with HHI.
  - Caregivers with an HHI of less than \$25k spend the most time providing companionship (60 hours median), compared to those with an HHIs of \$25k to \$49k (40 hours), \$50k to \$99k (30 hours) and \$100k+ (25 hours).
  - Across all levels of HHI, caregivers dedicate the next most amount of time per month on meal preparation and feeding-related activities. For these activities, the amount of time spent also decreases with the caregivers' HHI.
- **Sources of Information Relied on to Assist in Caregiving Duties.** Caregivers most frequently cite family and friends and medical professionals as sources of information that they rely on to assist with their caregiving duties, a finding which is relatively consistent across levels of HHI (ranging from between 40 and 50 percent). Caregivers with an HHI of \$100k+ are generally more likely to use online resources compared to the other levels of HHI. A noteworthy 26 percent of caregivers with an HHI of less than \$25k indicate that they do not use any sources of information.



# Demographic Perspectives by Household Income

- **Sources for Learning About Medical/Nursing Tasks.** Among caregivers currently performing medical-related tasks, hospital or doctor's office personnel are the most frequently used sources for learning such tasks, a finding which is consistent across levels of HHI (ranging from 51 to 56 percent). Approximately one in three caregivers across levels of HHI learned from family and friends. Of note, caregivers with an HHI of \$100k+ are somewhat more likely to have learned from online resources. Across levels of HHI, slightly more than one in five did not use any resources to learn how to perform medical/nursing tasks.
- **Caregivers' Sentiments About Their Caregiving Duties.** Across levels HHI, almost all caregivers feel that it is important to provide a good quality of life for their care recipient. Approximately nine in 10 caregivers across levels of HHI indicate that they like helping and enjoy spending time with the care recipient. However, roughly half of caregivers across levels of HHI say their own health takes a backseat to the health of the care recipient and that they need help with their caregiving duties.
- **Employment Status of Caregivers.** Employment status of caregivers varies dramatically by their levels of HHI. The percentage of caregivers who are employed increases with HHI: those with HHI of less than \$25k (26 percent), HHI of \$25k to \$49k (41 percent), HHI of \$50k to \$99k (62 percent), and HHI of \$100k+ (70 percent). Conversely, the percentages of caregivers who are not employed decreases with HHI. Of note, approximately one in ten caregivers are self-employed, a finding which is relatively consistent across levels of HHI.
- **Disruptions to Employment as a Result of Caregiving.** Caregiving responsibilities can be disruptive to a caregiver's employment situation. Among caregivers who are employed or who have been employed during their time as a caregiver:
  - Approximately one in four across levels of HHI have reduced their hours and/or changed their job responsibilities.
  - Across levels of HHI, caregivers are similarly likely to have taken a leave of absence (ranging from 13 to 22 percent).
  - Caregivers with an HHI of less than \$25k (21 percent) are more than twice as likely to have quit their job compared to those with HHIs of more than \$25k (fewer than 10 percent).
- **Informing Coworkers About Their Caregiving Duties.** Among caregivers who are employed, many have told their immediate supervisor that they are a caregiver, including those with an HHI under \$25k (49 percent), an HHI between \$25k and \$49k (53 percent), an HHI between \$50k and \$99k (56 percent), and those with an HHI of \$100k+ (60 percent). To a lesser extent, employed caregivers have told their coworkers about their caregiving responsibilities, including 40 percent of caregivers with an HHI under \$25k, 37 percent of those with an HHI between \$25k and \$49k, 20 percent of those with an HHI of \$50k to \$99k, and 19 percent of those with an HHI of \$100k+.

# Demographic Perspectives by Household Income

- **Employer Support of Caregiving Duties.** Across levels of HHI, fewer caregivers with an HHI of less than \$25k (64 percent) and caregivers with an HHI between \$25k and \$49k (54 percent) feel that their employers are supportive of their caregiving responsibilities, compared to caregivers with an HHI between \$50k and \$99k (74 percent) and caregivers with an HHI of \$100k+ (76 percent).
- **Adverse Actions Taken by Employers.** Caregiving duties may conflict with job responsibilities, which can lead to adverse actions taken by employers. Among caregivers who are currently employed or who have been employed during their time as a caregiver, some have experienced adverse actions by a current or former employer, including 27 percent of caregivers with an HHI less than \$25k, 19 percent of caregivers with an HHI between \$25k and \$49k, and 31 percent of caregivers with an HHIs of \$50k to \$99k and \$100k+.
- **Caregivers' Financial Well-Being.** Caregivers' sense of financial well-being increases with HHI. Caregivers with an HHI of less than \$25k (16 percent) are far less likely to describe their financial well-being as excellent or good, compared to those with an HHI between \$25k and \$49k (32 percent), between \$50k and \$99k (67 percent), or \$100k+ (86 percent). An alarming 44 percent of caregivers with an HHI of less than \$25k describe their financial well-being as poor.
- **Financial Considerations Before Becoming Caregivers.** Most caregivers gave little or no consideration to their financial situation when deciding to become a caregiver, including those with HHIs of less than \$25k (76 percent), \$25k to \$49k (77 percent), \$50k to \$99k (67 percent), and \$100k+ (61 percent). Moreover, caregivers with an HHI of less than \$25k (58 percent) and caregivers with an HHI between \$25k and \$49k (53 percent) did not consider their financial situation at all, compared to caregivers with an HHI between \$50k and \$99k (47 percent) and caregivers with an HHI of \$100k+ (45 percent).
- **Change in Financial Situation as a Result of Caregiving.** The majority of caregivers across all levels of HHI say that their financial situation has remained the same as a result of becoming a caregiver. However, the size of the majority increases with levels of HHI, ranging from HHIs of \$25k (63 percent), \$25k to \$29k (70 percent), \$50k to \$99k (82 percent), to \$100k+ (82 percent). It is alarming and noteworthy that caregivers with lower HHIs are more likely to say their financial situation worsened due to their caregiving responsibilities. Specifically, 32 percent of those with an HHI of less than \$25k say their financial situation worsened, compared to only 10 percent of those with an HHI of \$100k+.



# Demographic Perspectives by Household Income

- **Monthly Personal Expenditures for Caregiving.** Caregivers across levels of HHI find themselves paying out-of-pocket expenses for their care recipient. Caregivers with an HHI of less than \$25k spend roughly \$100 (median) on monthly expenditures for the care recipient, while those with HHIs of \$25k to \$49k and \$50k to \$99k both spend \$150 per month (median), and an HHI of \$100k+ spend \$300 (median) per month.
- **Financial Assistance for Caregiving Duties.** Most caregivers do not receive compensation for their caregiving duties across all levels of HHI, including caregivers with an HHI of less than \$25k (80 percent), an HHI between \$25k and \$49k (81 percent), an HHI between \$50k and \$99k (72 percent), and an HHI of \$100k+ (68 percent). Among those receiving some form of payment, the most frequently cited sources are funds from the care recipient and family members.
- **Financial Priorities Among Caregivers.** Caregivers' financial priorities vary across levels of HHI. Caregivers with an HHI less than \$25k (76 percent) and those with an HHI between \$25k and \$49k (57 percent) most frequently cite "just getting by" as a financial priority. In contrast, caregivers with HHIs of \$50k to \$99k (57 percent) most frequently cite paying off some form of debt (net) as a financial priority. Caregivers with an HHI of \$100k+ (50 percent) most frequently cite saving for retirement as a financial priority.
- **Total Household Retirement Savings Among Caregivers.** Caregivers' retirement savings increase with their level of HHI. Fifty-two percent of caregivers with an HHI of less than \$25k say that they have no retirement savings. Caregivers with an HHI between \$25k and \$49k have saved \$11,000 (estimated median), while those with an HHI between \$50k and \$100k have saved \$74,000 (estimated median) and those with an HHI of \$100k+ have saved \$347,000 (estimated median).
- **Caregivers' Self-Described General Health.** Caregivers' self-described general health varies dramatically across levels of HHI. Only 52 percent of caregivers with an HHI under \$25k describe their general health as excellent or good, compared to 65 percent of caregivers with an HHI of \$25k to \$49k, 82 percent of those with an HHI of \$50k to \$99k, and 90 percent of those with an HHI of \$100k+. Furthermore, fewer than 10 percent of caregivers with an HHI of less than \$50k report their general health as being excellent, compared to 20 percent of those with an HHI of \$50k to \$99k and 34 percent of those with an HHI of \$100k+.
- **Changes in General Health Since Becoming a Caregiver.** Most caregivers say that their general health has stayed the same since becoming a caregiver, including those with HHIs of less than \$25k (55 percent), \$25k to \$49k (74 percent), \$50k to \$99k (67 percent), and \$100k+ (64 percent). However, an alarming 31 percent of caregivers with an HHI of less than \$25k say that their health has declined since becoming a caregiver. This compares to just 18 percent of caregivers with an HHI of \$25k to \$49k, 15 percent of caregivers with an HHI of \$50k to \$99k, and 10 percent of caregivers with an HHI of \$100k+.

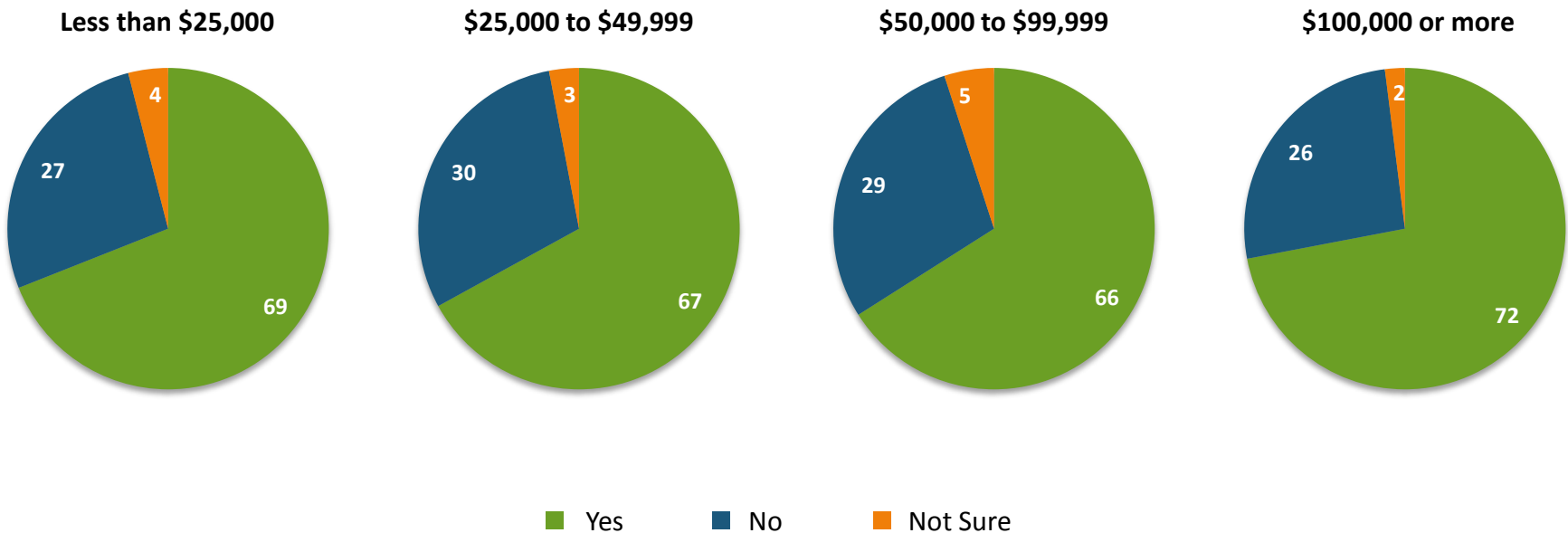
# Demographic Perspectives by Household Income

- **Caregivers' Health Insurance.** Most caregivers across all levels of household income (HHI) indicate that they have health insurance. However, caregivers with an HHI of \$25k or less (77 percent) are less likely to have health insurance, compared to those with an HHI \$25k and \$49k (92 percent), an HHI \$50k and \$99k (92 percent), and an HHI \$100k+ (97 percent). Caregivers of higher income households are more likely to receive their health insurance through an employer while those of lower income households are more likely to receive benefits from Medicare or Medicaid.
- **Caregivers Would Like More Information to Help Them Personally.** Across all levels of HHI, approximately four in 10 caregivers would like more information on managing stress, coping with caregiving challenges, and government benefits available for caregivers. Caregivers with an HHI of \$50k to \$99k (25 percent) and those with an HHI of \$100k+ (30 percent) would like more information about support groups for caregivers, more so than those with an HHI of \$25k to \$49k (16 percent) and those with an HHI of less than \$25k (15 percent).

# Most Consider Themselves to Be the Primary Caregivers

Two-thirds of all caregivers consider themselves to be the Primary caregiver of their care recipient, a finding which is relatively consistent across all levels of household income (HHI).

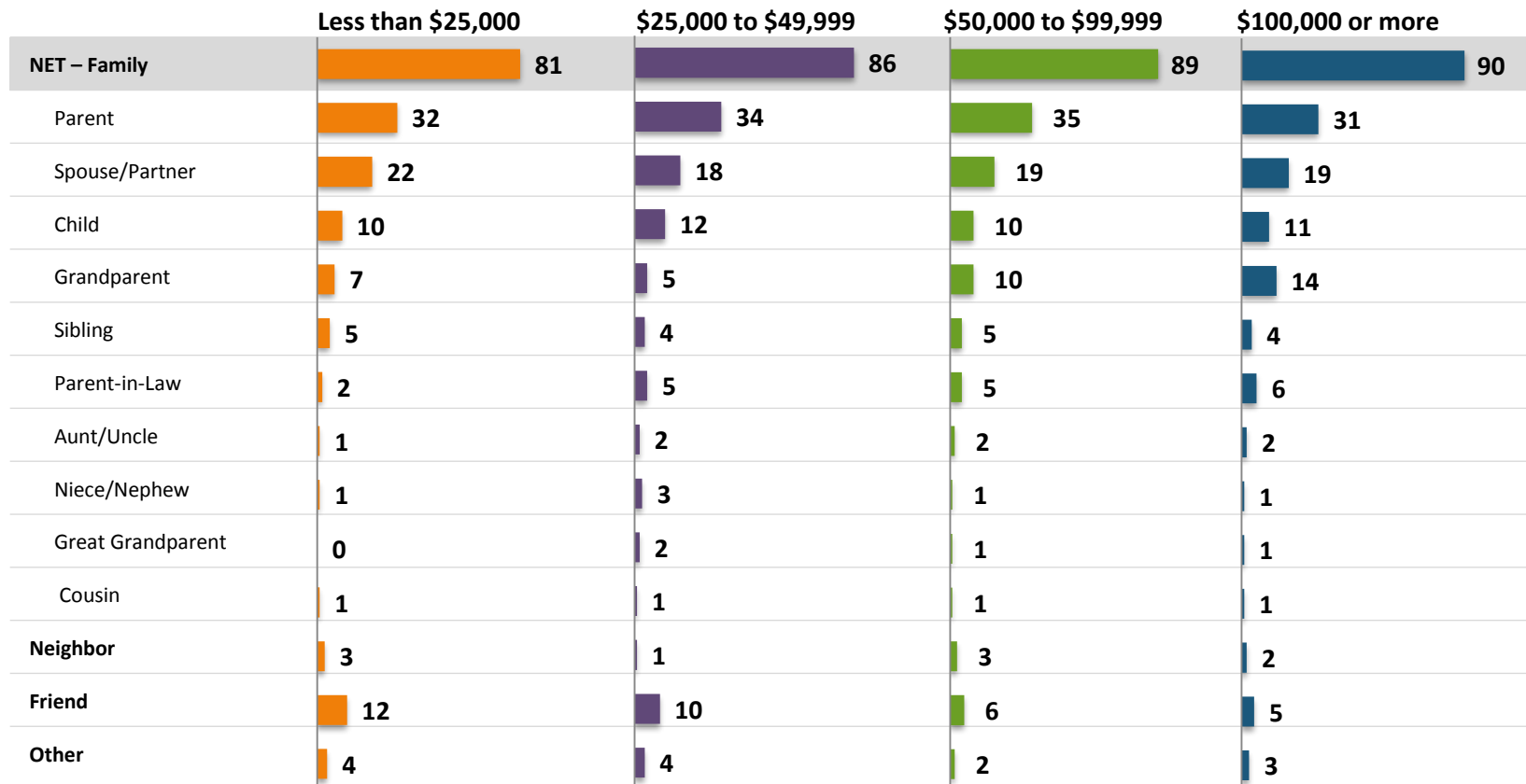
“Would you consider yourself to be the Primary caregiver?” (%)



# The Majority of Caregivers Are Caring for a Family Member

Most caregivers are caring for a family member, a finding which is higher among caregivers with an household income (HHI) of \$50k to \$99k (89 percent) and those with an HHI of \$100k+ (90 percent) than those with an HHI of \$25k to \$49k (86 percent) and with an HHI of less than \$25k (81 percent). Approximately one in three caregivers across all levels of HHI are caring for a parent and approximately one in ten are caring for a child. Caregivers with an HHI of \$50k to \$99k (10 percent) and HHI of \$100k+ (14 percent) are slightly more likely to be caring for a grandparent, compared to those of an HHI of less than \$25k (7 percent) and HHI of \$25k to \$49k (5 percent).

**Relationship to Care Recipient (%)**



BASE: ALL QUALIFIED RESPONDENTS

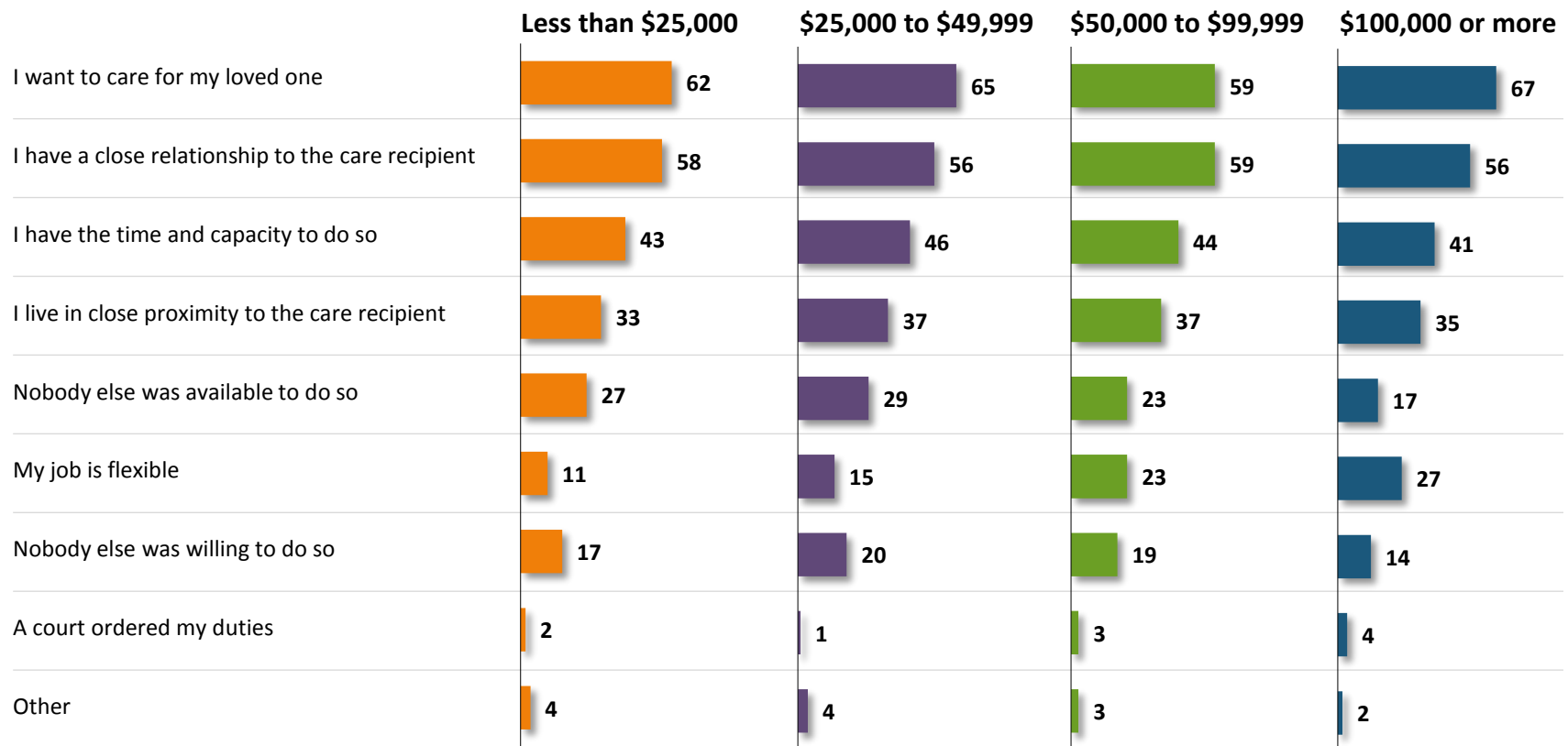
Q700. You mentioned providing care for [INSERT ANSWER FROM Q610] individual(s).

Please let us know your relationship to the person, their age, and their gender.

# Reasons for Becoming a Caregiver

Approximately three in five caregivers cite a desire to care for a loved one and having a close relationship to the care recipient as motivations for becoming a caregiver, a finding which is consistent across levels of HHI. About four in ten caregivers across all levels of HHI indicate they have the time and capacity to do so as a motivation, while roughly one in three indicate they live in close proximity to the care recipient. Caregivers with an HHI under \$25k (27 percent) and those with an HHI of \$25k to \$49k (29 percent) are more likely to indicate that nobody else was available to do so, a finding that is slightly higher than those with an HHI of \$50k to \$99k (23 percent) and an HHI of \$100k+ (17 percent).

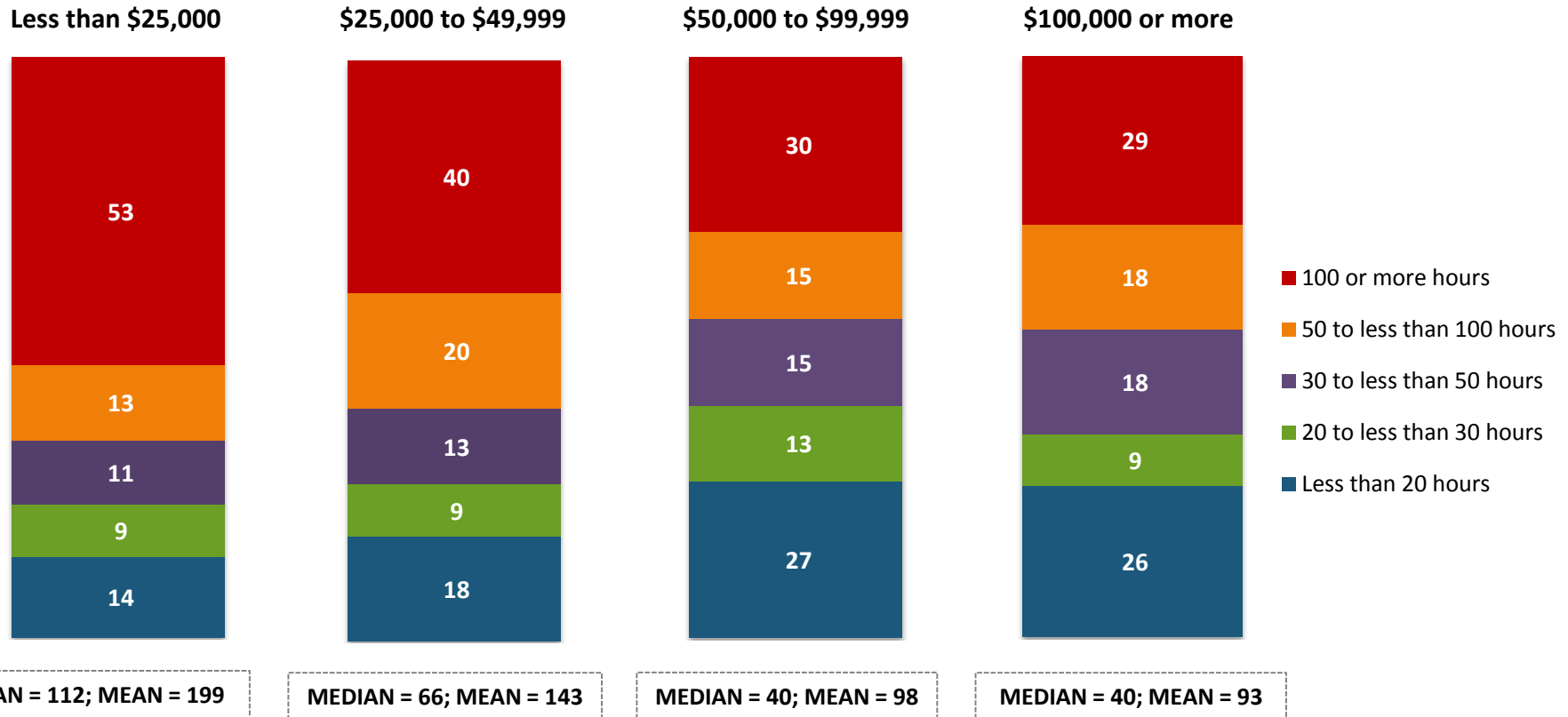
**Reasons for Becoming a Caregiver (%)**



# Total Caregiving Hours per Month

The amount of time caregivers spend caregiving each month varies by HHI. Caregivers with lower HHIs spend significantly more time caregiving each month compared to those with higher HHIs. The time spent by caregivers with an HHI less than \$25k is 112 hours per month (median), a finding that is more than double those with HHIs of \$25k to \$49k (60 hours median), \$50k to \$99k and \$100k+ (both 40 hours median). Fifty-three percent of caregivers with an HHI less than \$25k spend 100 hours or more per month caregiving, compared to 40 percent of those with an HHI of \$25k to \$49k, 30 percent of those with an HHI of \$50k to \$99k, and 29 percent of those with an HHI of \$100k+.

**Total Hours Spent Caregiving Each Month (%)**



Note: The median is the midpoint of the range of each response category. The mean is the average of all responses.

BASE: ALL QUALIFIED RESPONDENTS

Q832. In total, approximately how many hours per month do you spend caring for the care recipient?

# Caregiver Duties Performed

Caregiving encompasses a broad range of duties that vary across all levels of household income (HHI).

Approximately nine in 10 caregivers across levels of HHI are involved in doing some form of household duties for the care recipient (e.g., running errands, housework, meal preparation, home repairs, home modifications).

Caregivers with an HHI of less than \$25k (78 percent) and HHI of \$25k to \$49k (79 percent) are more likely to be involved in some form of social/communications-related activities with the care recipient, compared to caregivers with an HHI of \$50k to \$99k (70 percent) and those with an HHI of \$100k+ (65 percent).

Approximately seven in 10 caregivers across levels of HHI are involved in health-related tasks for the care recipient (e.g., accompanying to medical appointments, healthcare coordination, health insurance coordination). And approximately six in 10 provide assistance in various personal-related activities.

Types of Caregiving Duties Performed	Less than \$25,000	\$25,000 to \$49,999	\$50,000 to \$99,999	\$100,000 or more
<b>NET – Household</b>	<b>91%</b>	<b>91%</b>	<b>88%</b>	<b>86%</b>
Running errands	72%	73%	66%	61%
Housework	74%	67%	55%	50%
Meal preparation	68%	68%	54%	52%
Home repairs	29%	31%	31%	32%
Home modifications	17%	17%	22%	20%
<b>NET – Social/Communication</b>	<b>78%</b>	<b>79%</b>	<b>70%</b>	<b>65%</b>
Companionship	69%	72%	59%	50%
Basic communications	33%	35%	29%	29%
Language translation	10%	6%	6%	8%
<b>NET – Health-Related</b>	<b>72%</b>	<b>72%</b>	<b>65%</b>	<b>69%</b>
Accompanying to medical appointments	66%	65%	57%	59%
Healthcare coordination	50%	47%	42%	41%
Health insurance coordination	27%	31%	31%	32%
<b>NET – Personal</b>	<b>66%</b>	<b>58%</b>	<b>63%</b>	<b>65%</b>
Mobility	40%	36%	39%	40%
Personal care	42%	32%	32%	35%
Feeding	31%	23%	27%	27%
Incontinence care	15%	16%	16%	15%
<b>NET – Medical-Related</b>	<b>54%</b>	<b>48%</b>	<b>49%</b>	<b>47%</b>
Medication management	51%	47%	42%	42%
Medical treatment administration	16%	14%	17%	17%
<b>Paying bills/Managing finances</b>	<b>43%</b>	<b>47%</b>	<b>42%</b>	<b>46%</b>
<b>Other</b>	<b>7%</b>	<b>3%</b>	<b>3%</b>	<b>3%</b>

# Hours Spent Caregiving by Types of Duties

In terms of their caregiving duties, caregivers across all levels HHI dedicate the most time per month providing companionship to the care recipient. However, the time spent on companionship decreases with HHI.

Caregivers with an HHI of less than \$25k spend the most time providing companionship (60 hours median), compared to those with an HHIs of \$25k to \$49k (40 hours), \$50k to \$99k (30 hours) and \$100k+ (25 hours).

Across all levels of HHI, caregivers dedicate the next most amount of time per month on meal preparation and feeding-related activities. For these activities, the amount of time spent also decreases with the caregivers' HHI.

*Note: The median is the midpoint of the range of each response category. The mean is the average of all responses.*

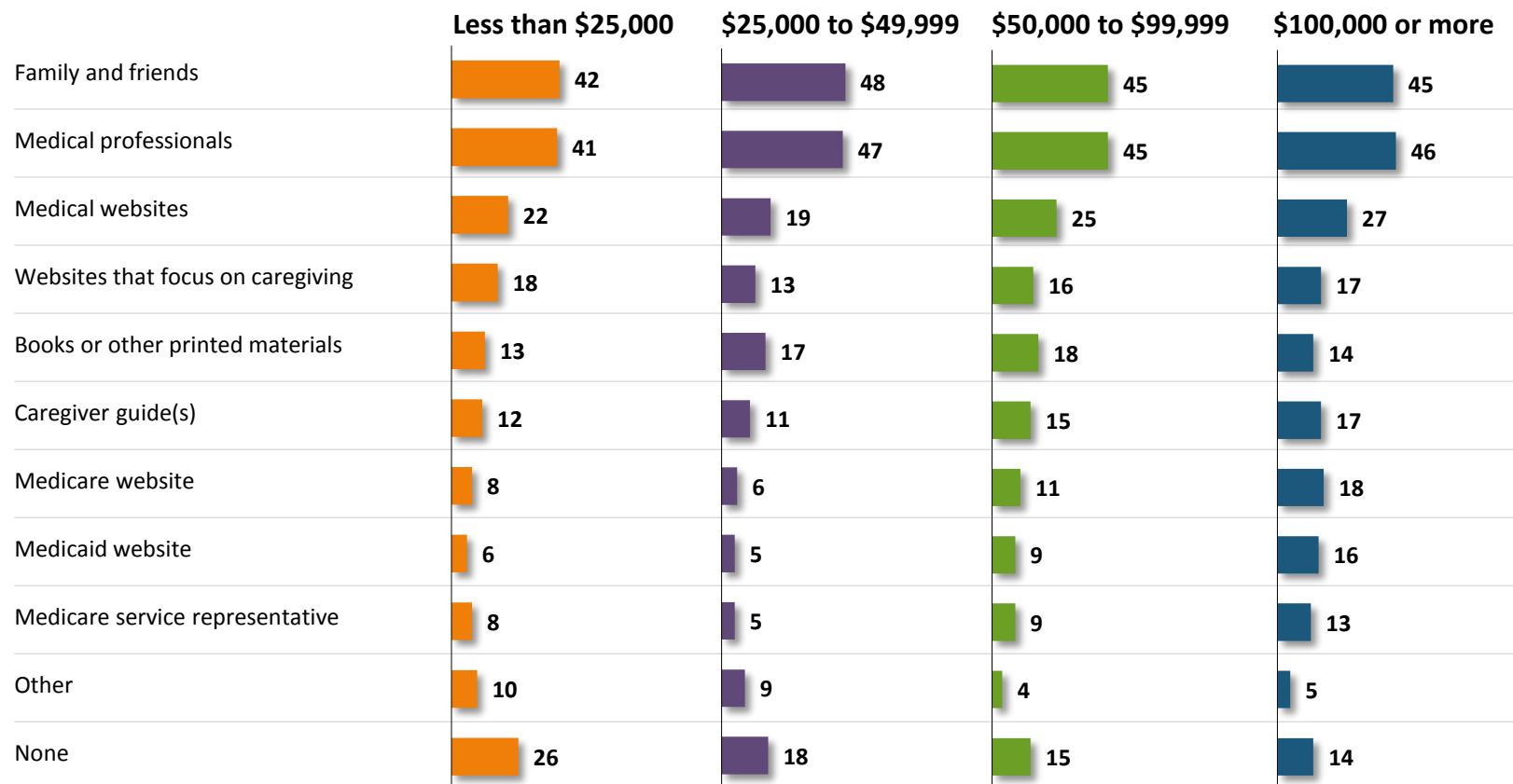
Time Spent On Caregiving Duties Each Month (hours per month)	Less than \$25,000		\$25,00 to \$49,999		\$50,000 to \$99,999		\$100,000 or more	
	Median	Mean	Median	Mean	Median	Mean	Median	Mean
<b>Household</b>								
Running errands	10	35.3	8	17.5	6	11.7	8	12.3
Housework (e.g., cleaning, laundry)	20	42.5	10	30.1	10	22.8	8	17.1
Meal preparation	30	48	20	32.6	16	26.5	11	22.3
Home repairs	5	17.6	4	9	3	6.2	2	5.6
Home modifications	7	20.8	2	9.9	2	4.5	3	5.0
<b>Social/Communication</b>								
Companionship	60	136.7	40	108.2	30	70.9	25	61.4
Basic communications	20	84.3	12	40.3	9	30.8	8	32.8
Language translation	5	20.7	4	13.5	4	9.8	5	14.6
<b>Health-Related</b>								
Accompanying to medical appointments	5	14.5	5	14.2	4	7.4	4	8.8
Healthcare coordination	3	14.3	2	9.7	3	6.0	3	7.7
Health insurance coordination	2	24.1	2	10.2	2	4.2	2	4.8
<b>Personal Care</b>								
Mobility	12	41.8	6	24.3	6	18.7	10	16.5
Personal care	20	42.3	10	22.6	10	18	10	22.8
Feeding	30	62.1	12	29.6	10	24.6	10	25.9
Incontinence care	8	33.9	7	15.2	6	20.5	6	21.9
<b>Medical-Related</b>								
Medication management	5	29.8	4	15.1	4	8.6	5	13.6
Medical treatment administration	4	27	5	22.9	5	12.3	6	18.1
<b>Paying bills/Managing finances</b>	4	17.1	3	9.3	3	6.8	3	4.9
<b>Other</b>	4	161.3	8	14.8	25	44.6	2	8.0



# Sources of Information Relied on to Assist in Caregiving Duties

Caregivers most frequently cite family and friends and medical professionals as sources of information that they rely on to assist with their caregiving duties, a finding which is relatively consistent across levels of HHI (ranging from between 40 and 50 percent). Caregivers with an HHI of \$100k+ are generally more likely to use online resources compared to the other levels of HHI. A noteworthy 26 percent of caregivers with an HHI of less than \$25k indicate that they do not use any sources of information.

**Sources of Information to Assist in Caregiving Duties (%)**



NOTE: Nine most commonly selected sources shown.

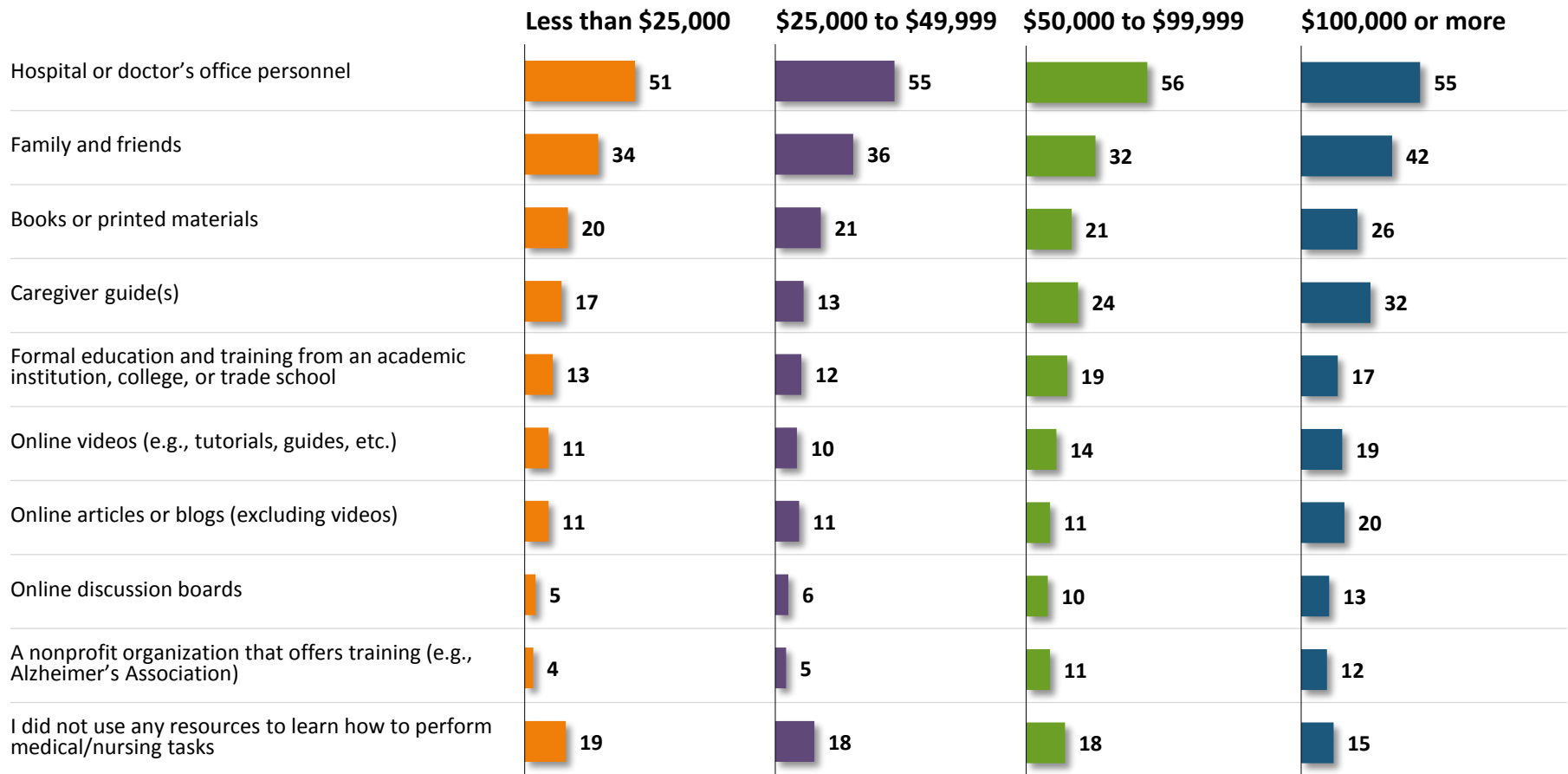
BASE: ALL QUALIFIED RESPONDENTS

Q840. Which of the following do you rely on as sources of information to assist in your caregiving duties? Select all.

# Sources for Learning About Medical/Nursing Tasks

Among caregivers currently performing medical-related tasks, hospital or doctor's office personnel are the most frequently used sources for learning such tasks, a finding which is consistent across levels of HHI (ranging from 51 to 56 percent). Approximately one in three caregivers across levels of HHI learned from family and friends. Of note, caregivers with an HHI of \$100k+ are somewhat more likely to have learned from online resources. Across levels of HHI, slightly more than one in five did not use any resources to learn how to perform medical/nursing tasks.

**Sources for Learning Medical/Nursing Tasks Related to Being a Caregiver (%)**



NOTE: Nine most commonly selected sources shown.

BASE: IF ADMINISTERING MEDICATIONS AND MEDICAL TREATMENTS

Q835. You mentioned you perform medication management or medical treatment administration for the care recipient. Where did you learn how to perform medical/nursing tasks related to being a caregiver? Select all.

# Caregivers' Sentiments About Their Caregiving Duties

Across levels HHI, almost all caregivers feel that it is important to provide a good quality of life for their care recipient. Approximately nine in 10 caregivers across levels of HHI indicate that they like helping and enjoy spending time with the care recipient. However, roughly half of caregivers across levels of HHI say their own health takes a backseat to the health of the care recipient and that they need help with their caregiving duties.

Caregivers' Sentiments About Their Caregiving Duties	Less than \$25,000	\$25,000 to \$49,999	\$50,000 to \$99,999	\$100,000 or more
	% Strongly/Somewhat Agree (NET)			
Positive				
It's important for me to provide a good quality of life for the care recipient	93%	95%	95%	94%
I like helping the care recipient	89%	92%	92%	91%
I enjoy spending time with the care recipient	89%	93%	91%	90%
Being a caregiver gives me a strong sense of purpose	84%	84%	81%	83%
Being a caregiver has led me to take better care of my own health	62%	69%	71%	75%
Being a caregiver has inspired me to document my own health and legal wishes	60%	64%	69%	71%
Negative				
My own health takes a backseat to the health of my care recipient	60%	51%	54%	56%
My caregiving duties leave me feeling physically exhausted	57%	48%	58%	53%
My caregiving duties leave me feeling emotionally exhausted	57%	51%	58%	53%
I need more help with my caregiving duties	46%	40%	52%	53%
With all of my caregiving duties, I barely have time for anything else	47%	42%	49%	46%
My caregiving duties leave me feeling completely overwhelmed	44%	37%	48%	44%

# Employment Status of Caregivers

Employment status of caregivers varies dramatically by their levels of HHI. The percentage of caregivers who are employed increases with HHI: those with HHI of less than \$25k (26 percent), HHI of \$25k to \$49k (41 percent), HHI of \$50k to \$99k (62 percent), and HHI of \$100k+ (70 percent). Conversely, the percentages of caregivers who are not employed decreases with HHI. Of note, approximately one in ten caregivers are self-employed, a finding which is relatively consistent across levels of HHI.

Employment Status (%)	Less than \$25,000	\$25,000 to \$49,999	\$50,000 to \$99,999	\$100,000 or more
<b>NET – Employed</b>	26	41	62	70
Employed full time	13	27	49	59
Employed part time	13	14	13	11
<b>NET – Self-employed</b>	8	11	8	8
Self-employed full time	4	7	5	6
Self-employed part time	4	4	3	2
<b>NET – Not employed</b>	66	48	30	22
Not employed, but looking for work	10	6	2	0
Not employed and not looking for work	7	2	1	0
Not employed, unable to work due to my own disability or illness	14	6	2	0
On leave of absence from my employer	0	0	0	1
Retired	19	26	16	14
Student	4	1	3	2
Stay-at-home spouse or partner	12	7	6	4
None of the above	0	0	0	1

# Disruptions to Employment as a Result of Caregiving

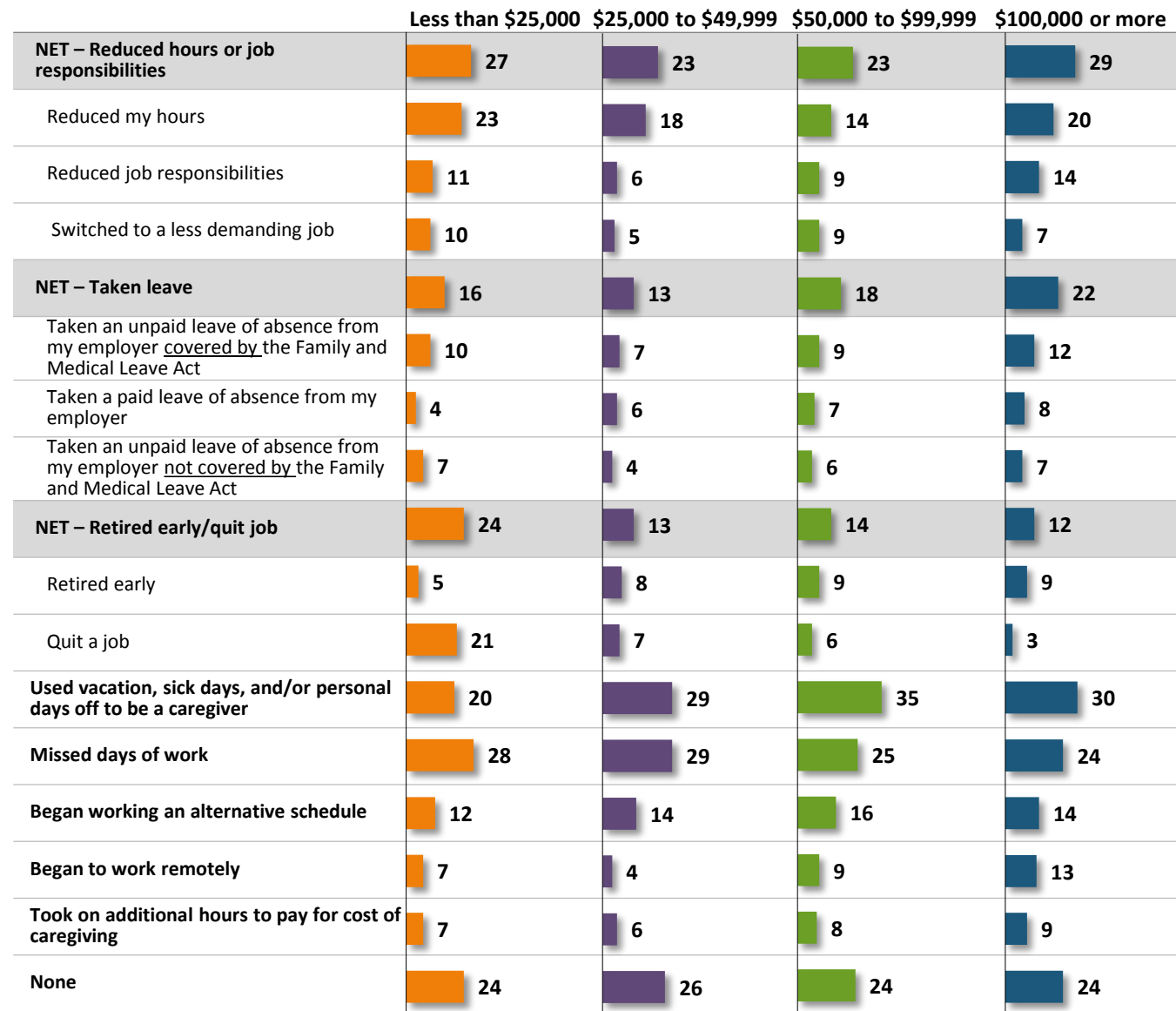
Caregiving responsibilities can be disruptive to a caregiver's employment situation.

Among caregivers who are employed or who have been employed during their time as a caregiver, across levels of HHI, approximately one in four have reduced their hours and/or changed their job responsibilities.

Further, across levels of HHI, caregivers are similarly likely to have taken a leave of absence (ranging from 13 to 22 percent).

Caregivers with an HHI of less than \$25k (21 percent) are more than twice as likely to have quit their job compared to those with HHIs of more than \$25k (fewer than 10 percent).

"Which of the following have you done as a result of becoming a caregiver?" (%)



NOTE: Thirteen most commonly selected sources shown.

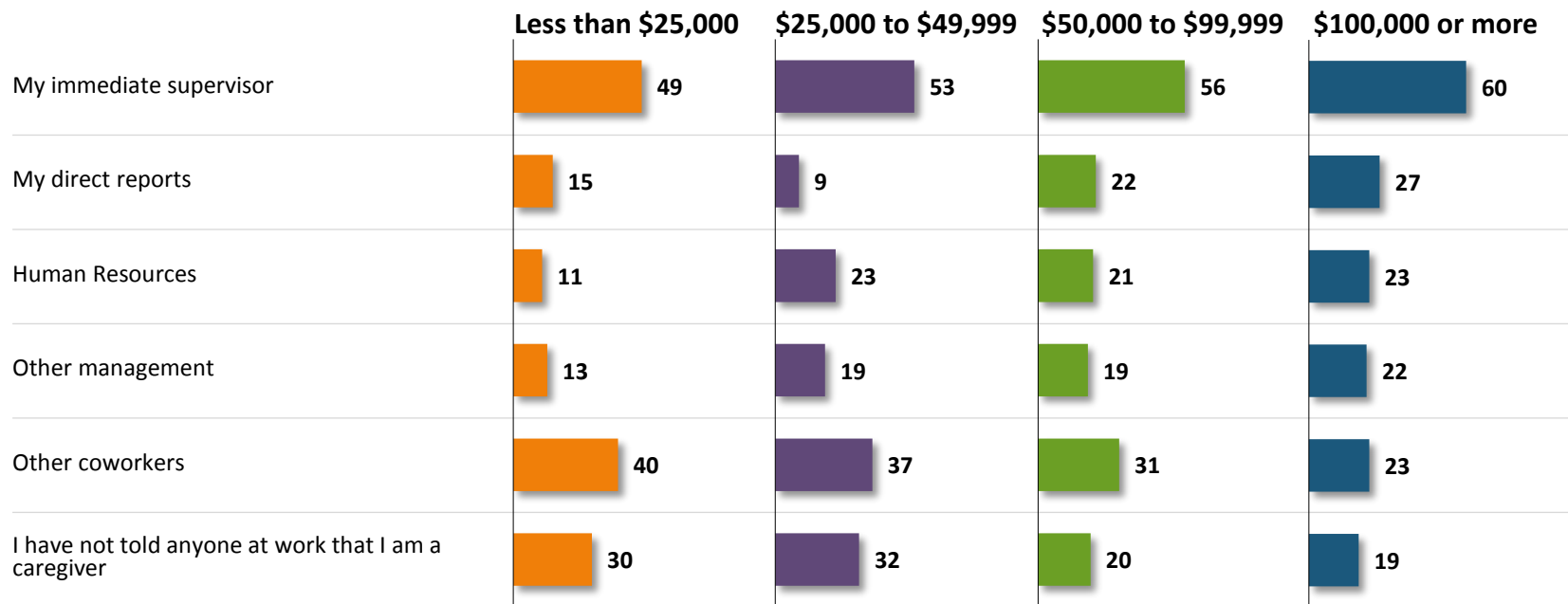
BASE: ALL EMPLOYED OR HAVE BEEN EMPLOYED DURING THEIR TIME AS A CAREGIVER

Q1025. Which of the following have you done as a result of becoming a caregiver? Select all.

# Informing Coworkers About Their Caregiving Duties

Among caregivers who are employed, many have told their immediate supervisor that they are a caregiver, including those with an HHI under \$25k (49 percent), an HHI between \$25k and \$49k (53 percent), an HHI between \$50k and \$99k (56 percent), and those with an HHI of \$100k+ (60 percent). To a lesser extent, caregivers have told their coworkers about their caregiving responsibilities, including 40 percent of caregivers with an HHI under \$25k, 37 percent of those with an HHI between \$25k and \$49k, 20 percent of those with an HHI of \$50k to \$99k, and 19 percent of those with an HHI of \$100k+.

## “Which of the following people at work have you told that you are a caregiver?” (%)



NOTE: Self-employed and not employed were excluded from this question.

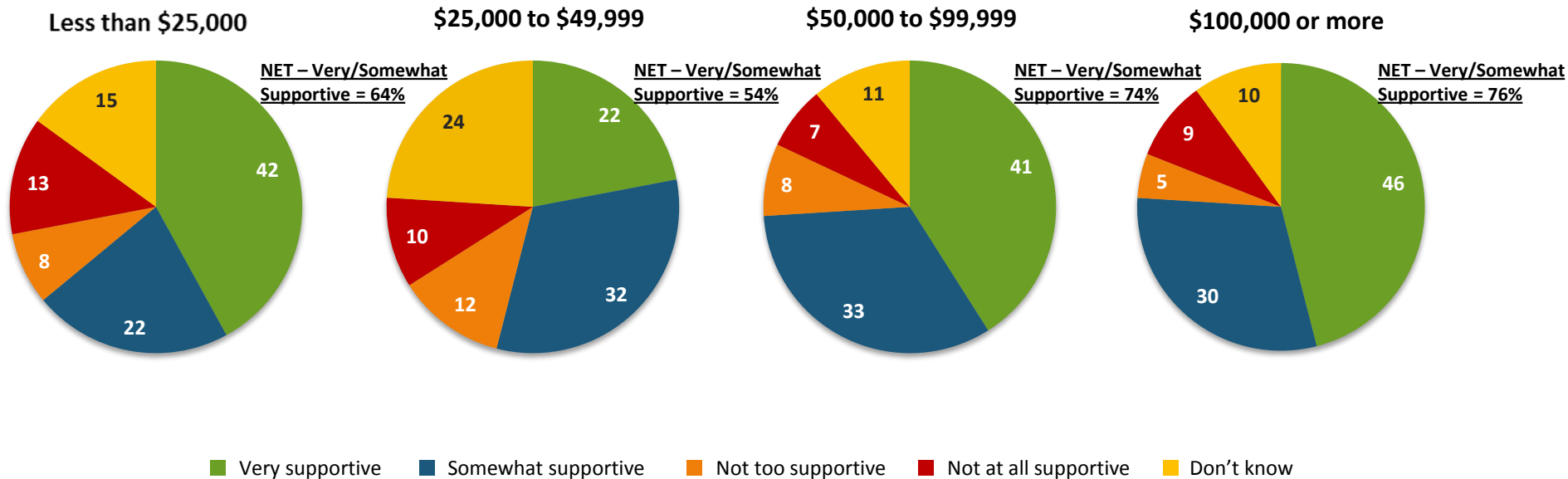
BASE: EMPLOYED FULL-TIME OR PART-TIME

Q1035. Which of the following people at work have you told that you are a caregiver? Select all.

# Employer Support of Caregiving Duties

Across levels of HHI, fewer caregivers with an HHI of less than \$25k (64 percent) and caregivers with an HHI between \$25k and \$49k (54 percent) feel that their employers are supportive of their caregiving responsibilities, compared to caregivers with an HHI between \$50k and \$99k (74 percent) and caregivers with an HHI of \$100k+ (76 percent).

**“How supportive is your employer of your caregiving responsibilities?” (%)**



NOTE: Self-employed and not employed were excluded from this question.

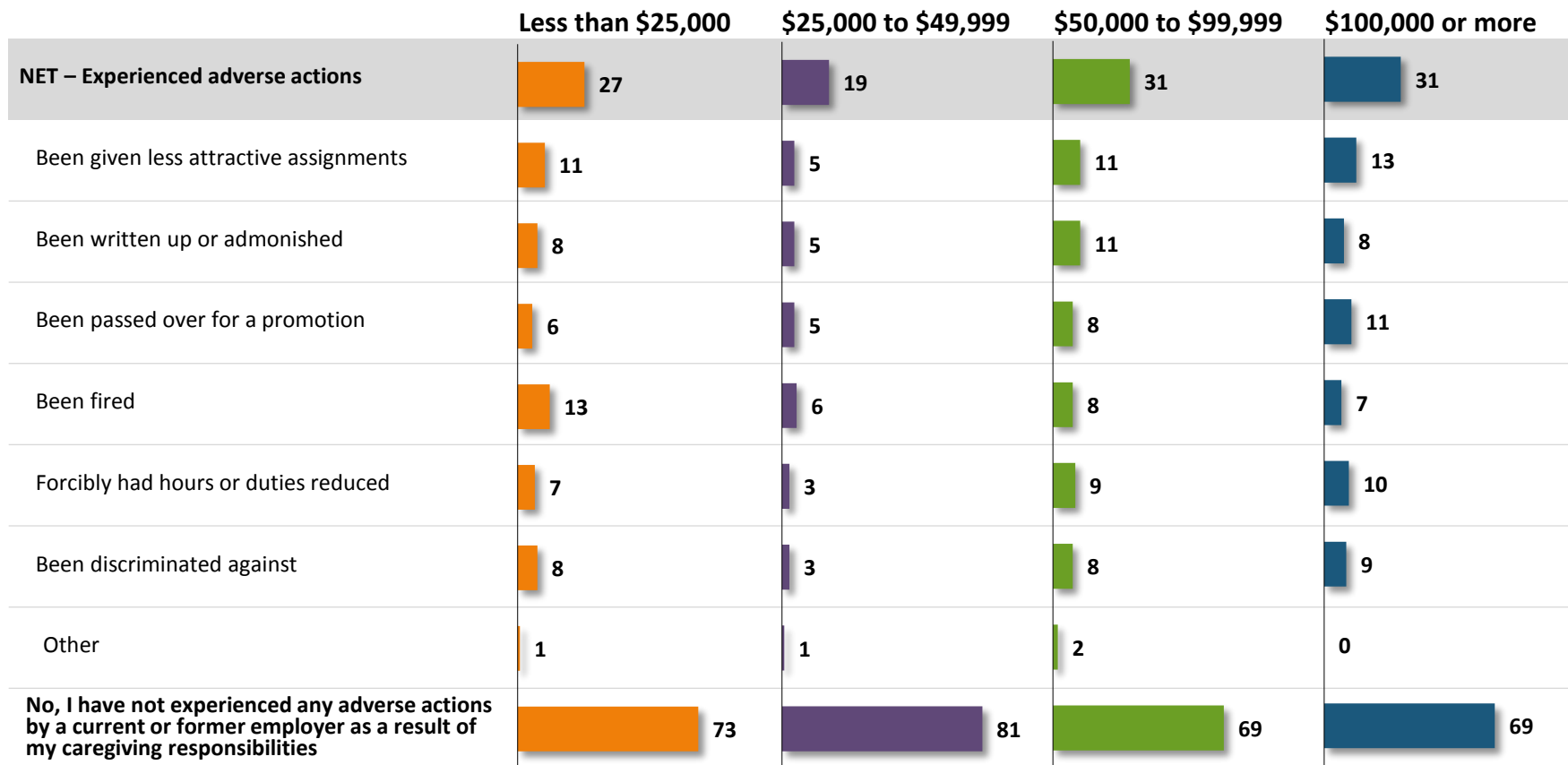
BASE: EMPLOYED FULL-TIME OR PART-TIME

Q1045. How supportive is your employer of your caregiving responsibilities?

# Adverse Actions Taken by Employers

Caregiving duties may conflict with job responsibilities, which can lead to adverse actions taken by employers. Among caregivers who are currently employed or who have been employed during their time as a caregiver, some have experienced adverse actions by a current or former employer, including 27 percent of caregivers with an HHI less than \$25k, 19 percent of caregivers with an HHI between \$25k and \$49k, and 31 percent of caregivers with an HHIs of \$50k to \$99k and \$100k+.

**Adverse Employment Actions Experienced as a Result of Caregiving Duties (%)**

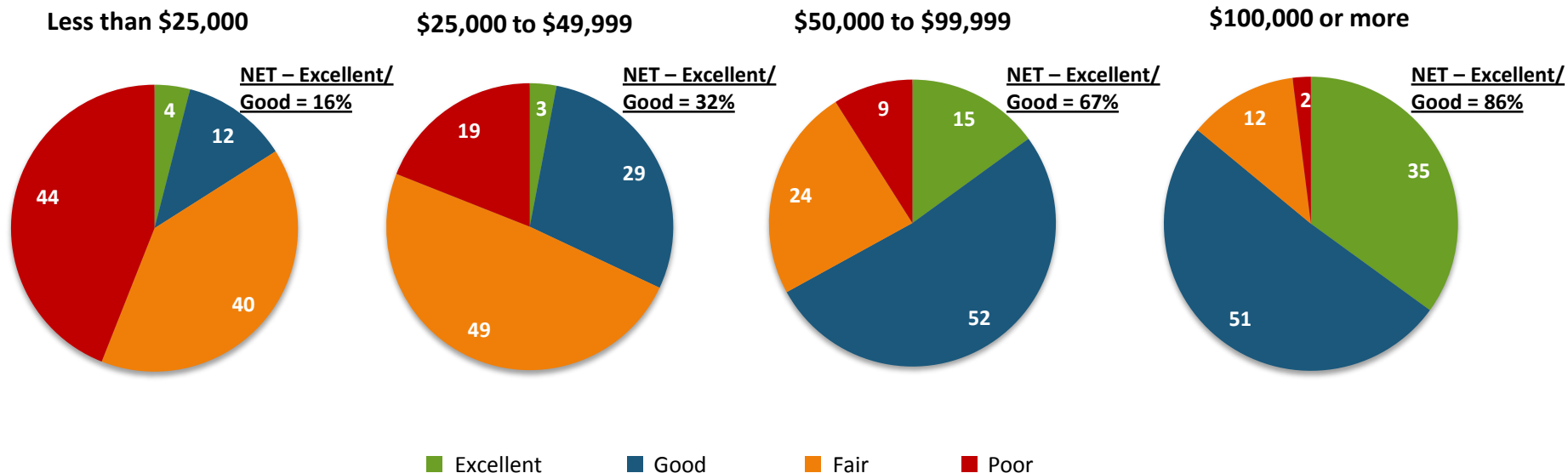




# Caregivers' Financial Well-Being

Caregivers' sense of financial well-being increases with HHI. Caregivers with an HHI of less than \$25k (16 percent) are far less likely to describe their financial well-being as excellent or good, compared to those with an HHI between \$25k and \$49k (32 percent), between \$50k and \$99k (67 percent), or \$100k+ (86 percent). An alarming 44 percent of caregivers with an HHI of less than \$25k describe their financial well-being as poor.

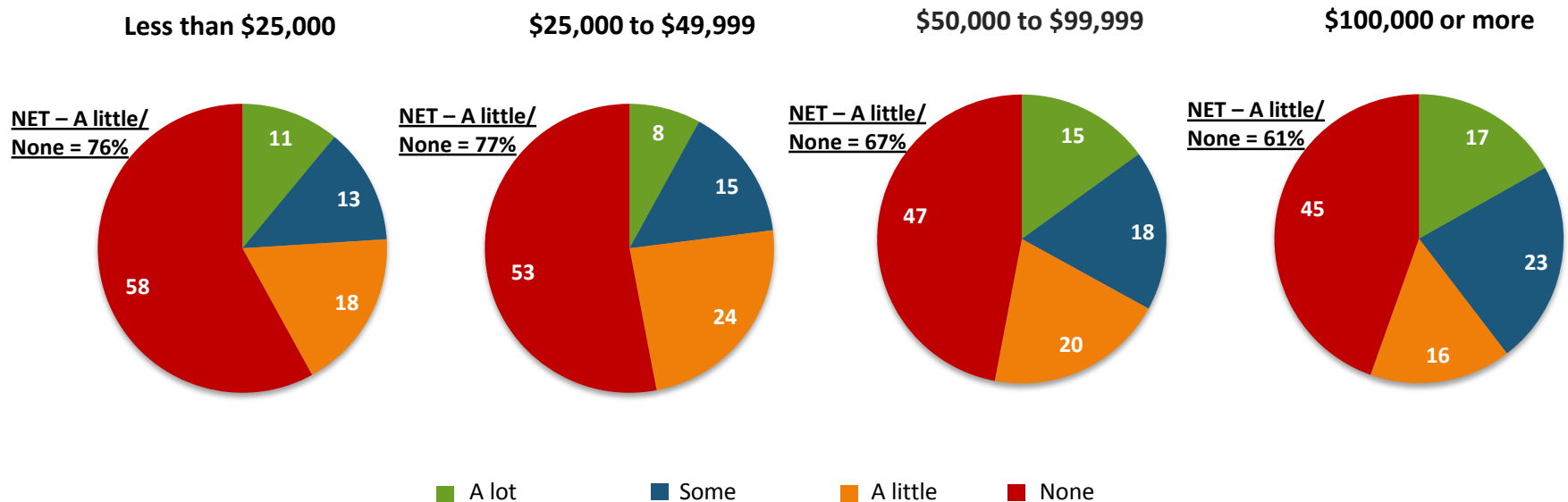
**"How would you describe your own financial well-being?" (%)**



# Financial Considerations Before Becoming Caregivers

Most caregivers gave little or no consideration to their financial situation when deciding to become a caregiver, including those with HHIs of less than \$25k (76 percent), \$25k to \$49k (77 percent), \$50k to \$99k (67 percent), and \$100k+ (61 percent). Moreover, caregivers with an HHI of less than \$25k (58 percent) and caregivers with an HHI between \$25k and \$49k (53 percent) did not consider their financial situation at all, compared to caregivers with an HHI between \$50k and \$99k (47 percent) and caregivers with an HHI of \$100k+ (45 percent).

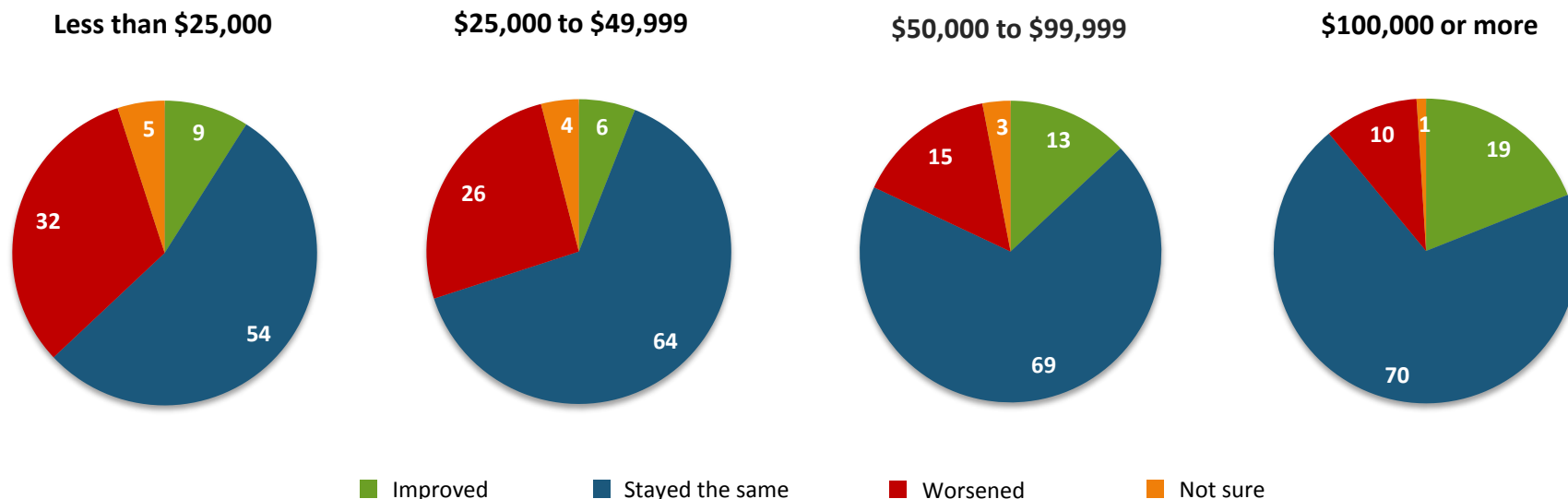
**“To what extent did you consider your own financial situation when deciding to become a caregiver?” (%)**



# Change in Financial Situation as a Result of Caregiving

The majority of caregivers across all levels of HHI say that their financial situation has remained the same as a result of becoming a caregiver. However, the size of the majority increases with levels of HHI, ranging from HHIs of \$25k (63 percent), \$25k to \$29k (70 percent), \$50k to \$99k (82 percent), to \$100k+ (82 percent). It is alarming and noteworthy that caregivers with lower HHIs are more likely to say their financial situation worsened due to their caregiving responsibilities. Specifically, 32 percent of those with an HHI of less than \$25k say their financial situation worsened, compared to only 10 percent of those with an HHI of \$100k+.

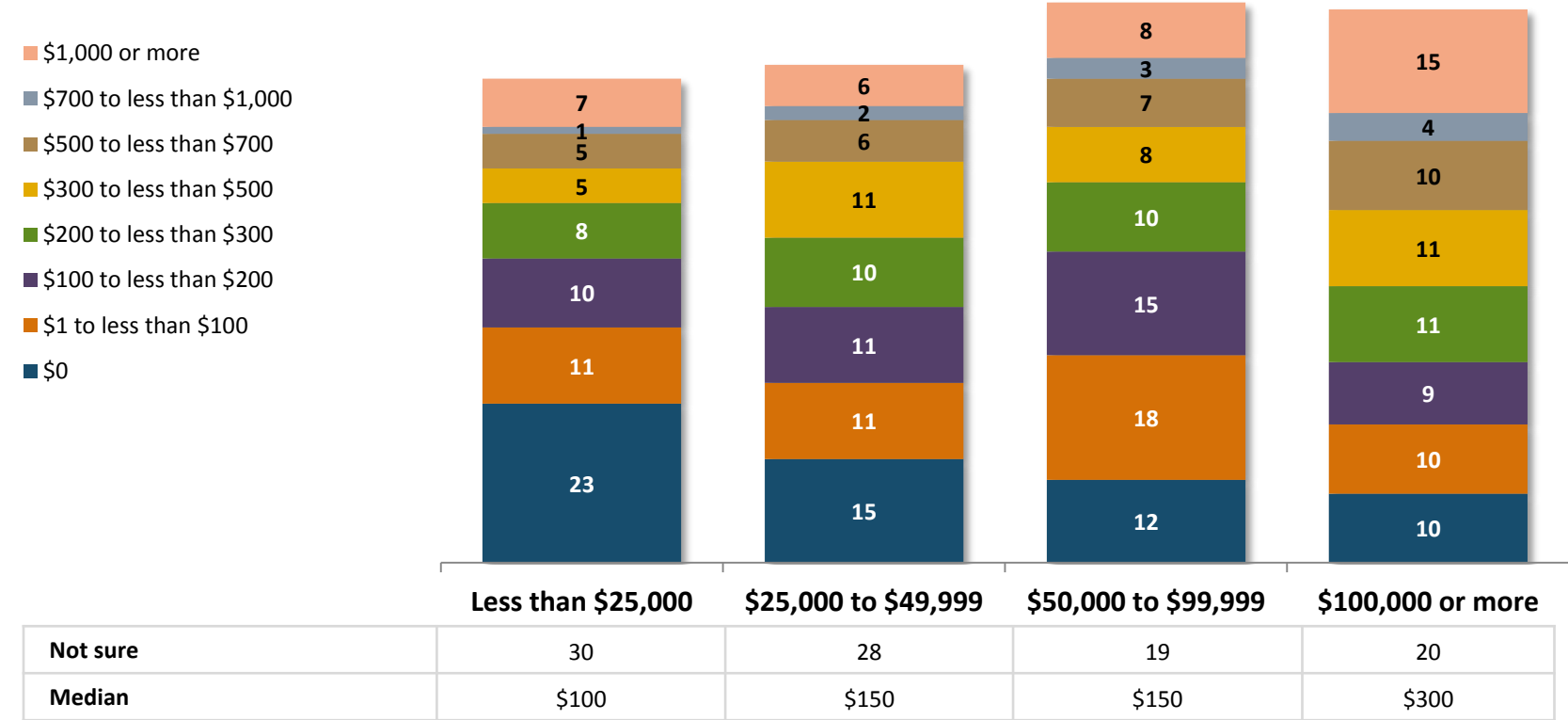
**“How has your financial situation changed as a result of becoming a caregiver?”**



# Monthly Personal Expenditures for Caregiving

Caregivers across levels of HHI find themselves paying out-of-pocket expenses for their care recipient. Caregivers with an HHI of less than \$25k spend roughly \$100 (median) on monthly expenditures for the care recipient, while those with HHIs of \$25k to \$49k and \$50k to \$99k both spend \$150 per month (median), and an HHI of \$100k+ spend \$300 (median) per month.

Monthly Personal Expenditures to Cover Expenses for Care Recipient (%)



Note: The median is the midpoint of the range of each response category. Non-responses are excluded from the estimate.

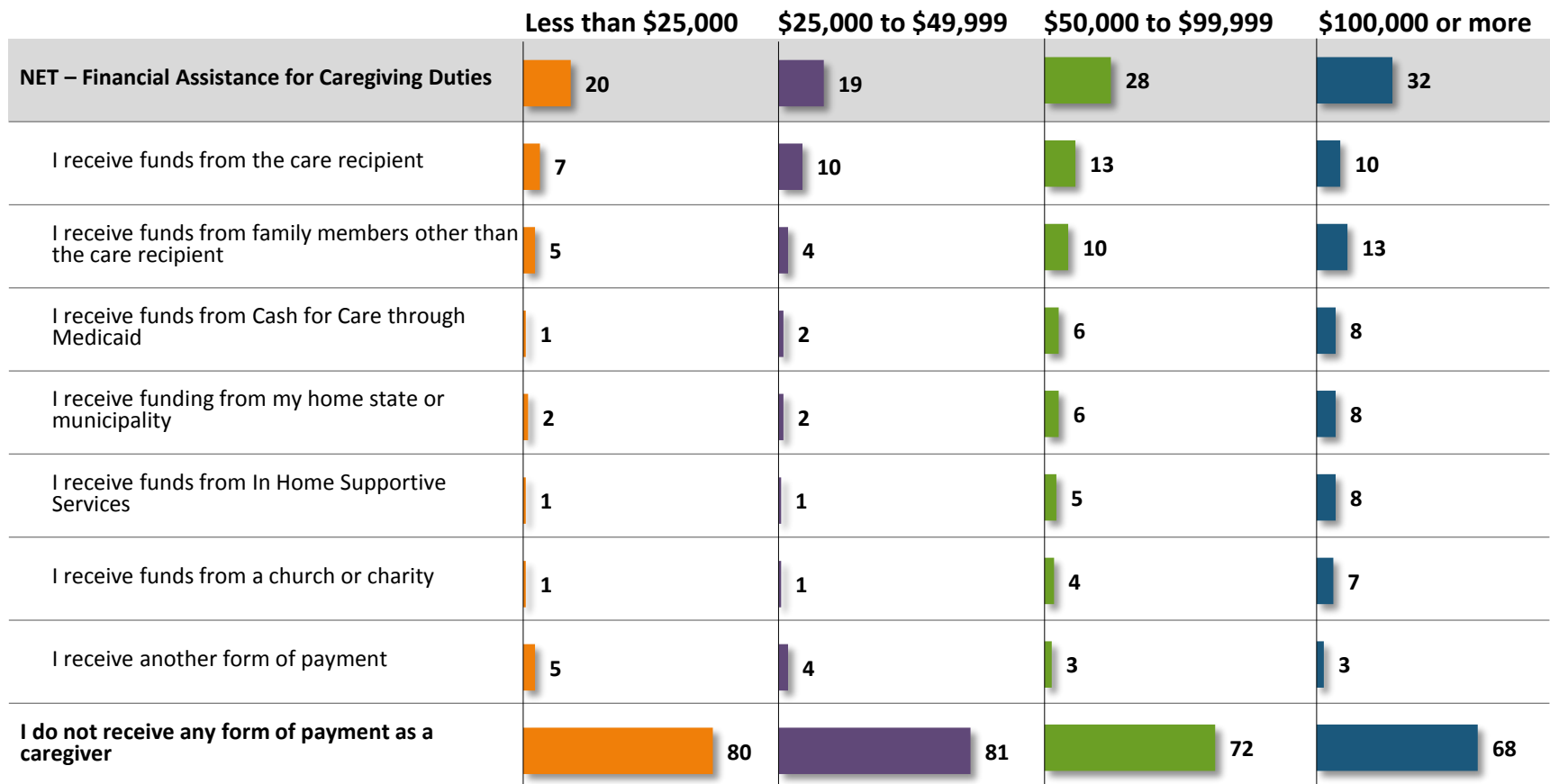
BASE: ALL QUALIFIED RESPONDENTS

Q1120. On average, approximately how much money do you spend each month paying out-of-pocket to cover expenses for the care recipient (e.g. for groceries, over-the-counter medications, gas, parking)?

# Financial Assistance for Caregiving Duties

Most caregivers do not receive compensation for their caregiving duties across all levels of HHI, including caregivers with an HHI of less than \$25k (80 percent), an HHI between \$25k and \$49k (81 percent), an HHI between \$50k and \$99k (72 percent), and an HHI of \$100k+ (68 percent). Among those receiving some form of payment, the most frequently cited sources are funds from the care recipient and family members.

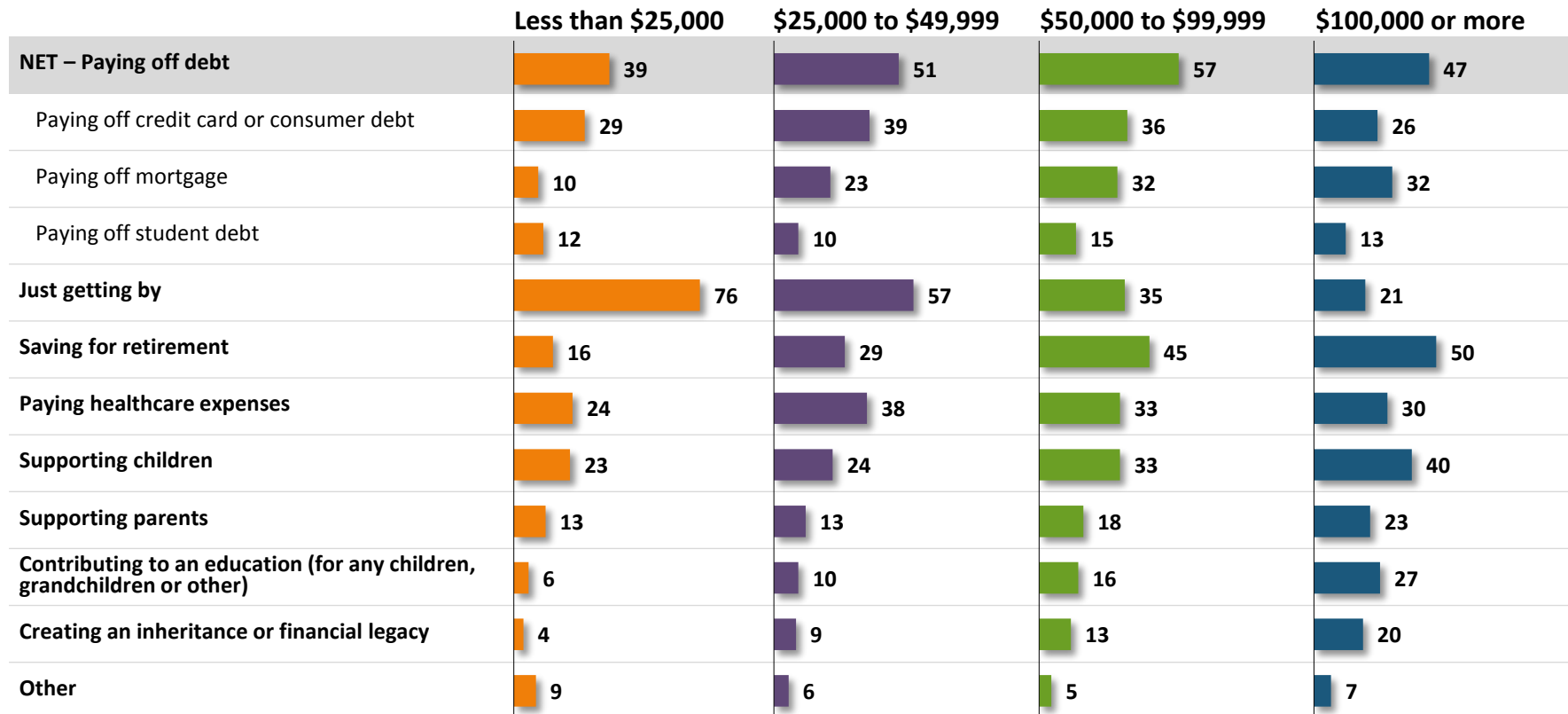
**Sources of Financial Assistance Received for Caregiving Duties, If Any (%)**



# Financial Priorities Among Caregivers

Caregivers' financial priorities vary across levels of HHI. Caregivers with an HHI less than \$25k (76 percent) and those with an HHI between \$25k and \$49k (57 percent) most frequently cite “just getting by” as a financial priority. In contrast, caregivers with HHIs of \$50k to \$99k (57 percent) most frequently cite paying off some form of debt (net) as a financial priority. Caregivers with an HHI of \$100k+ (50 percent) most frequently cite saving for retirement as a financial priority.

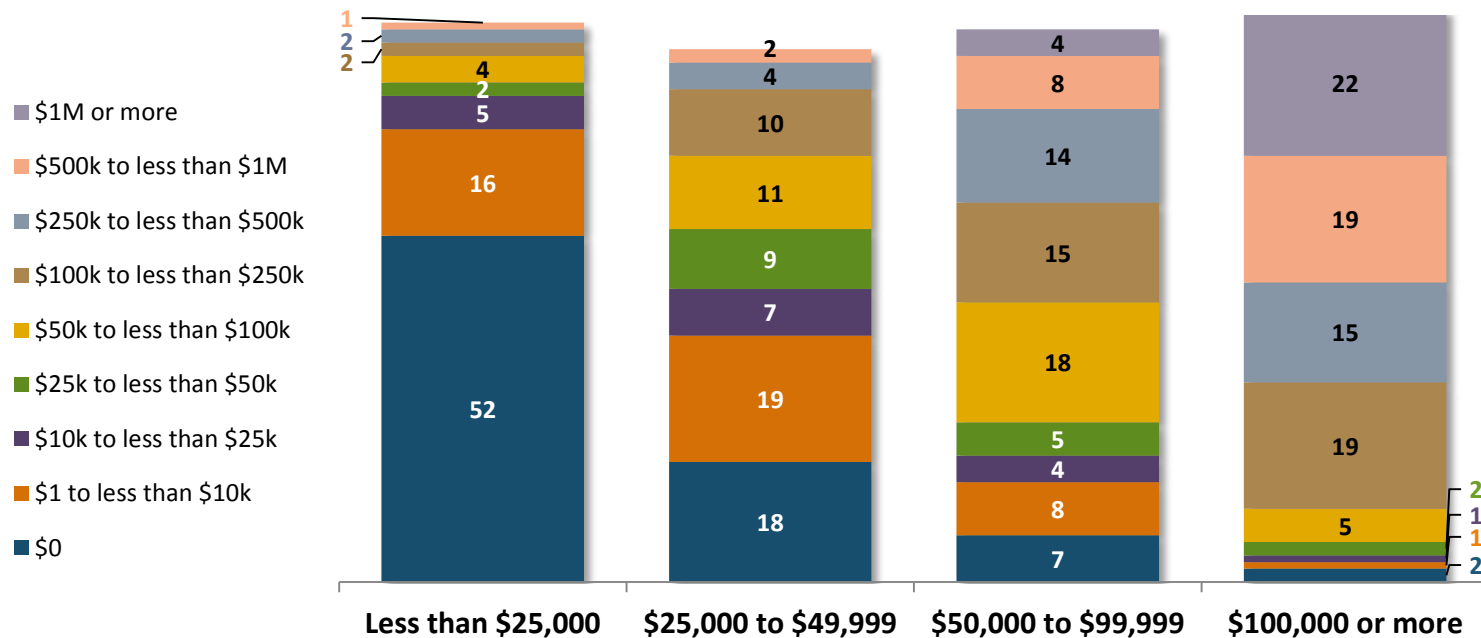
## “Which of the following are your financial priorities right now?” (%)



# Total Household Retirement Savings Among Caregivers

Caregivers' retirement savings increase with their level of HHI. Fifty-two percent of caregivers with an HHI of less than \$25k say that they have no retirement savings. Caregivers with an HHI between \$25k and \$49k have saved \$11,000 (estimated median), while those with an HHI between \$50k and \$100k have saved \$74,000 (estimated median) and those with an HHI of \$100k+ have saved \$347,000 (estimated median).

**Total Household Retirement Savings in All Accounts (%)**

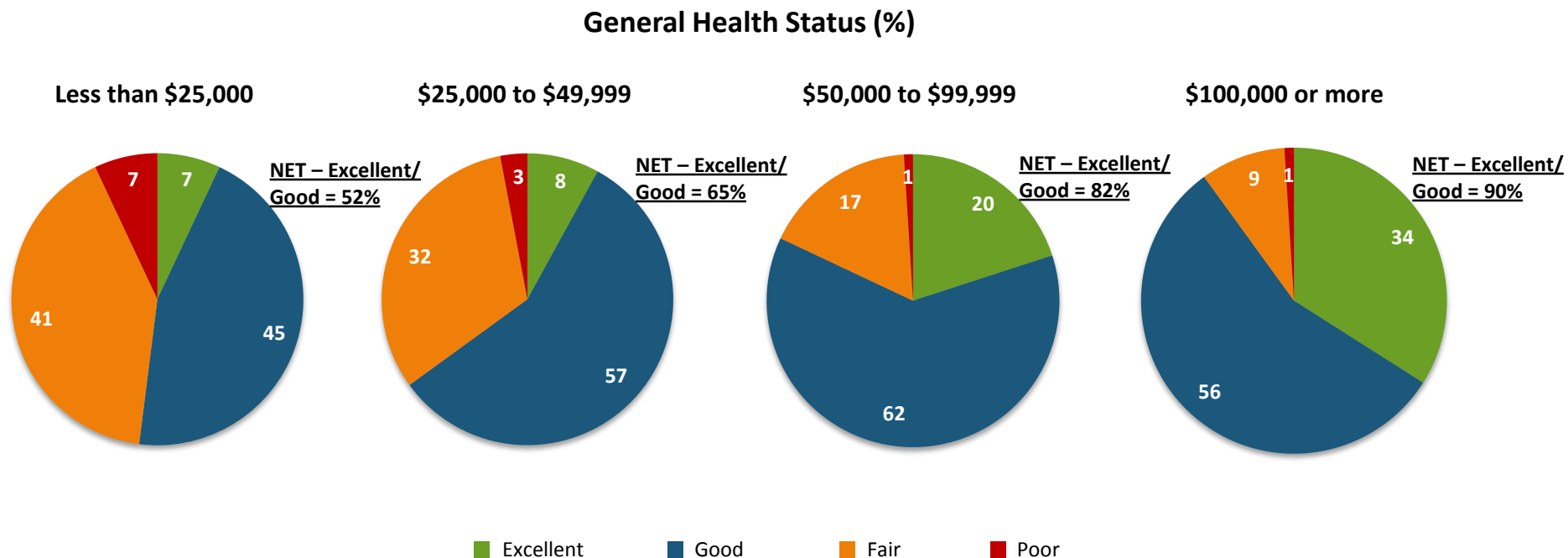


Not sure	10	14	12	10
Decline to answer	6	6	5	4
Estimated Median	\$0	\$11,000	\$74,000	\$347,000

Note: The median is estimated based on the approximate midpoint of the range of each response category. Non-responses are excluded from the estimate.

# Caregivers' Self-Described General Health

Caregivers' self-described general health varies dramatically across levels of HHI. Only 52 percent of caregivers with an HHI under \$25k describe their general health as excellent or good, compared to 65 percent of caregivers with an HHI of \$25k to \$49k, 82 percent of those with an HHI of \$50k to \$99k, and 90 percent of those with an HHI of \$100k+. Furthermore, fewer than 10 percent of caregivers with an HHI of less than \$50k report their general health as being excellent, compared to 20 percent of those with an HHI of \$50k to \$99k and 34 percent of those with an HHI of \$100k+.

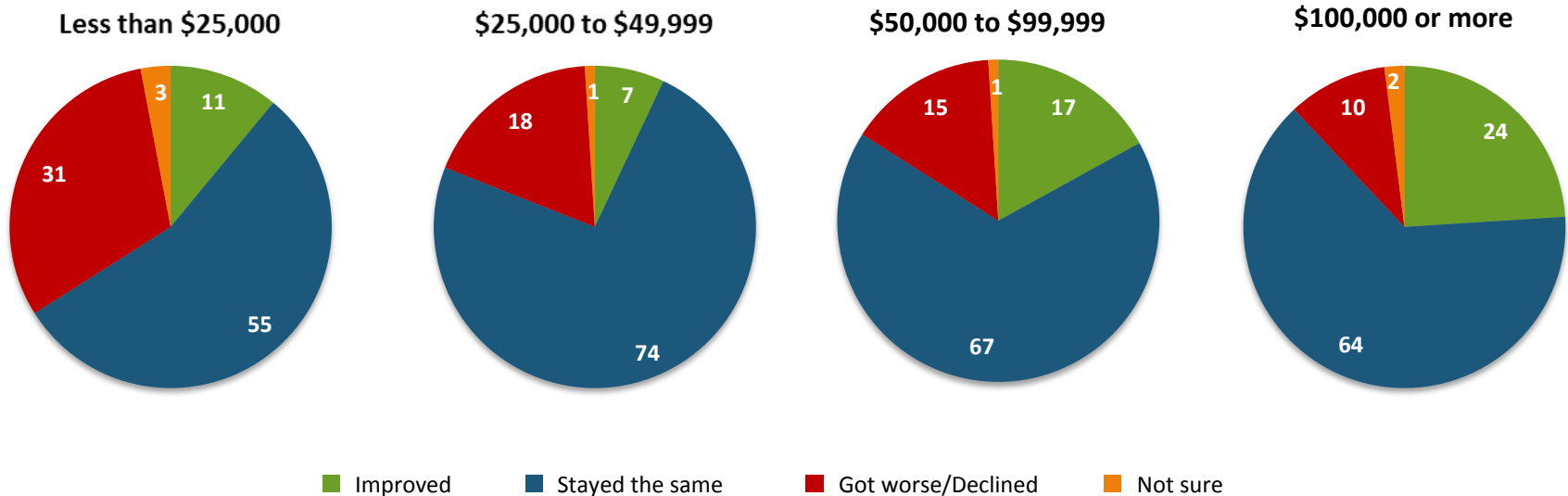




# Changes in General Health Since Becoming a Caregiver

Most caregivers say that their general health has stayed the same since becoming a caregiver, including those with HHIs of less than \$25k (55 percent), \$25k to \$49k (74 percent), \$50k to \$99k (67 percent), and \$100k+ (64 percent). However, an alarming 31 percent of caregivers with an HHI of less than \$25k say that their health has declined since becoming a caregiver. This compares to just 18 percent of caregivers with an HHI of \$25k to \$49k, 15 percent of caregivers with an HHI of \$50k to \$99k, and 10 percent of caregivers with an HHI of \$100k+.

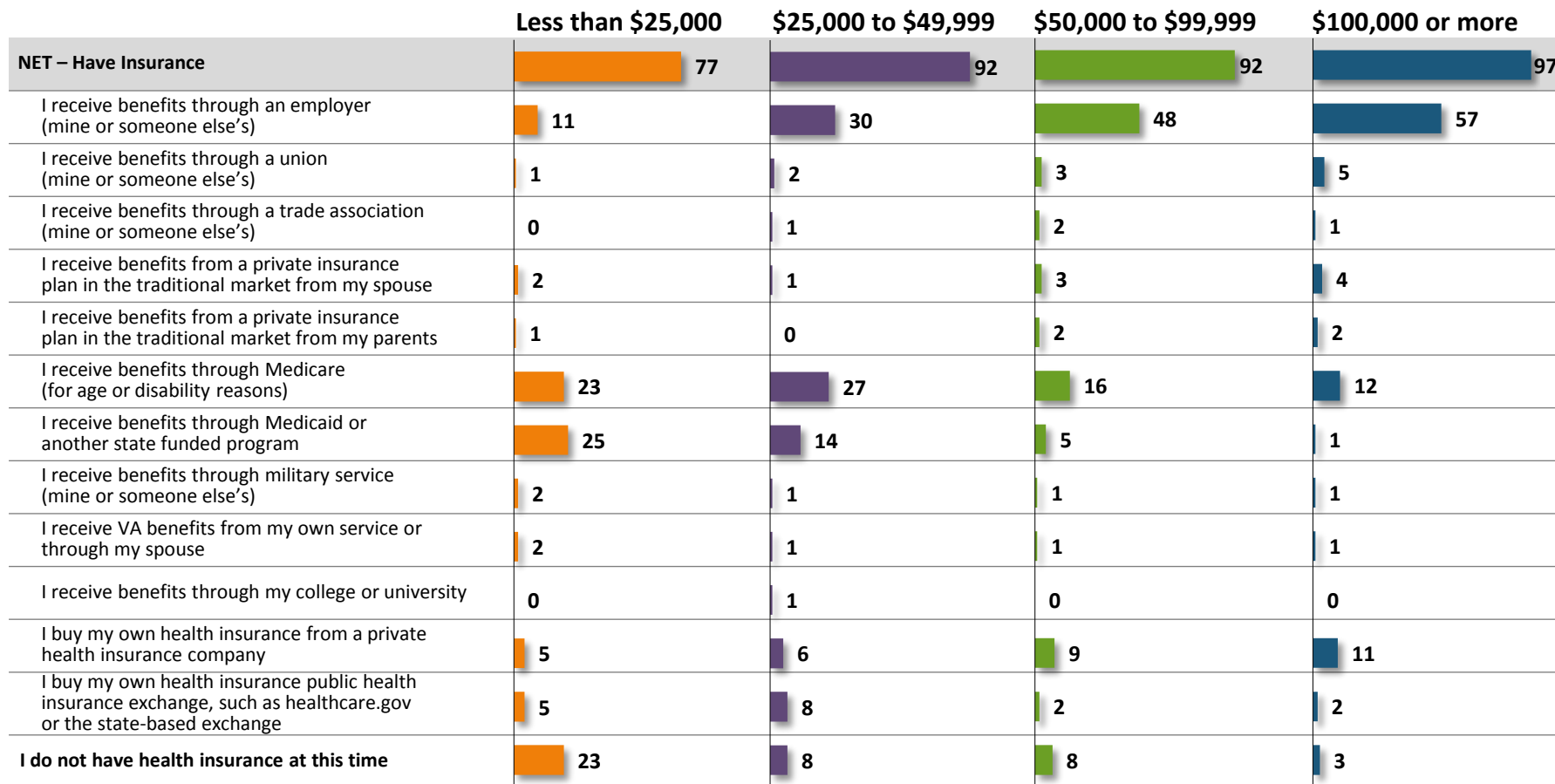
Changes in General Health Since Becoming a Caregiver (%)



# Caregivers' Health Insurance

Most caregivers across all levels of household income (HHI) indicate that they have health insurance. However, caregivers with an HHI of \$25k or less (77 percent) are less likely to have health insurance, compared to those with an HHI \$25k and \$49k (92 percent), an HHI \$50k and \$99k (92 percent), and an HHI \$100k+ (97 percent). Caregivers of higher income households are more likely to receive their health insurance through an employer while those of lower income households are more likely to receive benefits from Medicare or Medicaid.

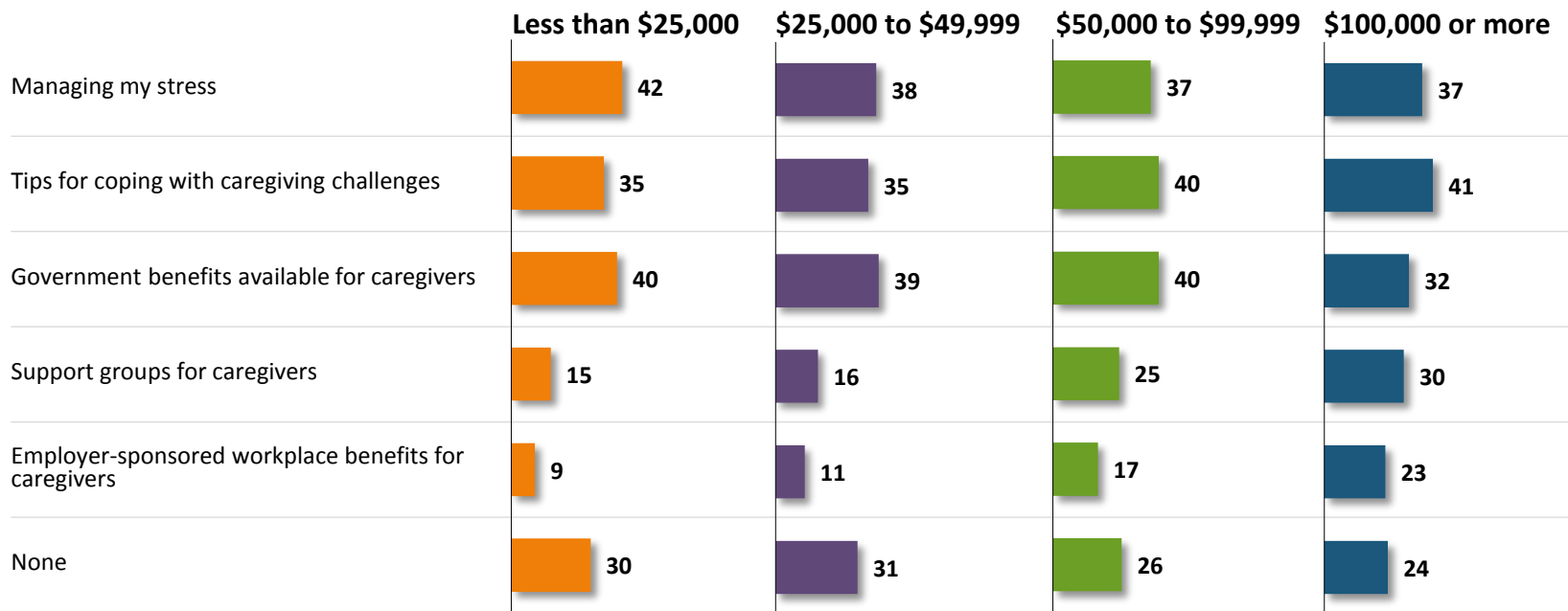
## “Which of the following best describes how you primarily receive health insurance?” (%)



# Caregivers Would Like More Information to Help Them Personally

Across all levels of HHI, approximately four in 10 caregivers would like more information on managing stress, coping with caregiving challenges, and government benefits available for caregivers. Caregivers with an HHI of \$50k to \$99k (25 percent) and those with an HHI of \$100k+ (30 percent) would like more information about support groups for caregivers, more so than those with an HHI of \$25k to \$49k (16 percent) and those with an HHI of less than \$25k (15 percent).

**“Which of the following topics would you like more information to help you personally with your caregiving responsibilities?” (%)**



NOTE: Five most commonly selected sources shown.

BASE: ALL QUALIFIED RESPONDENTS

Q850. Which of the following topics would you like more information to help you personally with your caregiving responsibilities? I would like more information about... Select all.



## Demographic Perspectives By Race/Ethnicity

# ***The Many Faces of Family Caregivers: A Close-Up Look at Caregiving and Its Implications***

## **A Portrait of Today's Caregivers**

- Demographic Perspectives
- Voluntary Status
- Employment Status
- Generations
- Gender
- Household Income

### **➤ *Race/Ethnicity***

## **Appendix: Caregiver and Care Recipient Demographics**

## **Acknowledgements**



# Demographic Perspectives by Race/Ethnicity

In this chapter, the survey explores the similarities and differences of caregiving responsibilities and the impact on caregivers by their race/ethnicity. The survey finds that 72 percent of caregivers are White, 15 percent are Hispanic, seven percent are African-American, four percent are Asian or Pacific Islander, one percent are some other race/ethnicity, and one percent declined to answer.

Across ethnicities, caregivers share much in common including their reasons for becoming a caregiver, specifically the desire to care for their loved one, and their commitment to ensuring the care recipient has a good quality of life. They perform similar caregiving duties and are similarly likely to rely on various sources of information to assist with their caregiving duties. They are also similarly likely to self-report as being in excellent or good health. Lastly, they are similarly likely to be employed.

The survey also found some noteworthy differences by race/ethnicity. Hispanic caregivers spend significantly more time each month caregiving compared to other ethnicities. Asian/Pacific Islander and White caregivers report higher levels of household income and retirement savings and they are more likely to self-describe their financial well-being as good or excellent, compared to Hispanic and African-American caregivers. They are also more likely to have health insurance coverage. African-American caregivers are more likely to cite paying off some form of debt as a financial priority, compared to other necessities. More than half of African-American caregivers cite “just getting by” as a financial priority.

## *Twenty-Six Facts About Caregivers by Race/Ethnicity*

- **Most Consider Themselves to Be the Primary Caregivers.** Approximately two-thirds of caregivers consider themselves to be the Primary caregiver of their care recipient, including 69 percent of White, 68 percent of Hispanic, 65 percent of Asian/Pacific Islander, and 62 percent of African-American caregivers.
- **The Majority of Caregivers Are Caring for a Family Member.** The vast majority of caregivers are caring for a family member, a finding which is higher among White and Asian/Pacific Islander caregivers (both 89 percent) and African-American caregivers (88 percent) than for Hispanic caregivers (78 percent). Approximately one in three caregivers are caring for a parent, a finding which is consistent across ethnicities. Approximately one in ten are caring for a child. Of note, White (23 percent) and Asian/Pacific (18 percent) caregivers are more likely to be caring for a spouse/partner, compared to Hispanic and African-American caregivers (both 9 percent).
- **Reasons for Becoming a Caregiver.** Approximately six in 10 caregivers across ethnicities cite wanting to care for their loved one and having a close relationship with the care recipient as reasons for becoming a caregiver. More Asian/Pacific Islander caregivers (52 percent) became a caregiver because they have the time and capacity to do so, compared to 44 percent of White, 43 percent of Hispanic, and 42 percent of African-American caregivers. Hispanic caregivers (25 percent) are somewhat more likely than those of other ethnicities to say that nobody else was willing to do so.

# Demographic Perspectives by Race/Ethnicity

- **Total Caregiving Hours per Month.** Hispanic caregivers spend the most time on caregiving at 80 hours per month (median), compared to White caregivers (50 hours), and Asian/Pacific Islander and African-American caregivers (both 45 hours). Hispanic caregivers (47 percent) are also more likely to spend 100 hours or more each month, compared to other ethnicities.
- **Caregiver Duties Performed.** Caregiving encompasses a broad range of duties – duties that are consistent performed across ethnicities.
  - Approximately nine in 10 caregivers across ethnicities perform various household-related tasks for the caregiver (i.e., running errands, housework, meal preparation, home repairs, home modifications).
  - Approximately seven in 10 caregivers across ethnicities perform various health-related tasks (i.e., accompanying to medical appointments, healthcare coordination, health insurance coordination).
  - Hispanic caregivers (73 percent) are more likely to perform personal care duties (i.e., mobility, personal care, and feeding) for the care recipient, compared to the other ethnicities (60 percent).
- **Hours Spent Caregiving by Types of Duties.** Caregivers spend the most amount of time per month providing companionship to the care recipient, including 40 hours (median) by White caregivers, 30 hours by both Hispanic and African-American caregivers, and 20 hours by Asian/Pacific Islander caregivers. Caregivers spend the second most amount of time per month on meal preparation. Hispanics spend 24 hours (median) per month preparation, a finding that is higher than found among African-American (20 hours median), White (19 hours median), and Asian/Pacific Islander caregivers (15 hours median).
- **Sources of Information Relied on to Assist in Caregiving Duties.** Caregivers across ethnicities most frequently rely on family and friends and medical professionals as sources of information to assist them with their caregiving duties. More Asian/Pacific Islander (58 percent) and African-American caregivers (52 percent) rely on family and friends compared to Hispanic caregivers (47 percent) and White caregivers (43 percent). Hispanic caregivers (38 percent) are somewhat less likely to rely on medical professionals compared to Asian/Pacific Islander (47 percent), White (46 percent), and African-American caregivers (45 percent).
- **Sources for Learning About Medical/Nursing Tasks.** Among caregivers currently performing medical-related tasks and across ethnicities, the most frequently cited sources for learning such tasks are hospital or doctor's personnel. More Asian/Pacific Islander caregivers (64 percent) use hospital or doctor's office personnel as sources for learning these tasks, compared to Hispanic (59 percent), White (54 percent), and African-American (44 percent) caregivers.

# Demographic Perspectives by Race/Ethnicity

- **Caregivers' Sentiments About Their Caregiving Duties.** Almost all caregivers agree that it is important to provide a good quality of life for the care recipient – including 96 percent of White, 95 percent of Asian/Pacific Islander, 93 percent of African-American, and 88 percent of Hispanic caregivers. Approximately nine in 10 caregivers across ethnicities say they like helping and enjoy spending time with the care recipient. Many caregivers say that their own health takes a backseat to the health of the care recipient, including 60 percent of Asian/Pacific Islander, 56 percent of White, 52 percent of Hispanic, and 48 percent of African-American caregivers.
- **Employment Status of Caregivers.** Employment status is similar across ethnicities. Approximately half of caregivers are employed, including 58 percent of Asian/Pacific Islander caregivers and 51 percent of White, Hispanic, and African-American caregivers. Approximately four in 10 caregivers across ethnicities are not employed, including 43 percent of Hispanic, 40 percent of both White and African-American, and 35 percent of Asian/Pacific Islander caregivers. Slightly fewer than one in 10 caregivers are self-employed.
- **Disruptions to Employment as a Result of Caregiving.** Caregiving responsibilities can be disruptive to a caregiver's employment. Many caregivers who are currently employed or who have been employed during their time as caregivers have adjusted their work life to accommodate their caregiving duties.
  - Approximately one in four caregivers across ethnicities have reduced their work hours or job responsibilities.
  - Approximately three in 10 caregivers across ethnicities have used vacation, sick days, and/or personal days off to be a caregiver.
  - African-American (19 percent), White (15 percent), and Hispanic (13 percent) are more likely than Asian/Pacific Islander caregivers (6 percent) to have retired early or quit a job.
- **Informing Coworkers About Their Caregiving Duties.** Many employed caregivers have told their immediate supervisor that they are a caregiver, including Asian/Pacific Islander (62 percent), White (58 percent), African-American (51 percent), and Hispanic caregivers (47 percent). Among ethnicities, African-American caregivers (36 percent) are more likely to have not to tell anyone at work that they are a caregiver, compared to Hispanic (31 percent), Asian/Pacific Islander (23 percent), and White caregivers (20 percent).
- **Employer Support of Caregiving Duties.** Most employed caregivers believe that their employers are supportive of their caregiving duties. White (74 percent) and African-American and Asian/Pacific Islander caregivers (both 71 percent) are more likely to believe their employers are very or somewhat supportive, compared to Hispanic caregivers (57 percent). Across ethnicities, some caregivers feel that their employers are not at all supportive of their caregiver responsibilities, including 9 percent of White, Hispanic, and Asian/Pacific Islander caregivers and 4 percent of African-American caregivers.



# Demographic Perspectives by Race/Ethnicity

- **Adverse Actions Taken by Employers.** Caregiving duties may conflict with job responsibilities which, in turn, may lead to adverse actions taken by employers such as being given less attractive assignments, being discriminated against, or being passed over for a promotion, among others. Most caregivers have not experienced any adverse actions as a result of their caregiving duties. However, among those currently employed or have been employed during their time as a caregiver, Hispanic and White caregivers (31 and 29 percent, respectively) are more likely to have experienced adverse actions, compared to Asian/Pacific Islander (16 percent) and African-American (12 percent) caregivers.
- **Caregivers' Financial Well-Being.** Asian/Pacific Islander (61 percent) and White caregivers (59 percent) are more likely to describe their financial well-being as excellent or good, compared to Hispanic (46 percent) and African-American caregivers (41 percent). In contrast, 19 percent of African-American, 17 percent of Hispanic, 15 percent of Asian/Pacific Islander, and 14 percent of White caregivers describe their financial well-being as poor.
- **Financial Considerations Before Becoming Caregivers.** Most caregivers across ethnicities gave little or no consideration to their financial situation when deciding to become a caregiver, including 74 percent of Hispanic, 72 percent of African-American, 69 percent of Asian/Pacific Islander, and 68 percent of White caregivers.
- **Change in Financial Situation as a Result of Caregiving.** The majority of caregivers across ethnicities say their financial situation as stayed the same since becoming a caregiver, including 66 percent of White and Hispanic caregivers, 62 percent of African-American caregivers, and 56 percent of Asian/Pacific Islander caregivers. However, approximately one in five caregivers say that their financial situation worsened as a result of becoming a caregiver, including White (19 percent), Hispanic (16 percent), African-American (19 percent), and Asian/Pacific Islander caregivers (22 percent).
- **Monthly Personal Expenditures for Caregiving.** Caregivers often find themselves paying out-of-pocket expenses for the care recipient (e.g., groceries, over-the-counter medications, gas, parking). Asian/Pacific Islander caregivers spend more money out-of-pocket per month (\$250 median) to cover expenses for their care recipient, compared to White (\$150 median), Hispanic (\$150 median), and African-American caregivers (\$120 median).
- **Financial Assistance for Caregiving Duties.** The majority of caregivers across ethnicities do not receive any form of payment for their caregiving duties. However, more Hispanic caregivers (31 percent) receive compensation for their caregiving duties, compared to Asian/Pacific Islander caregivers (27 percent), White caregivers (25 percent) and African-American caregivers (18 percent). Among those receiving payment, the most frequently cited sources of funds are from the care recipient and family members.

# Demographic Perspectives by Race/Ethnicity

- **Financial Priorities Among Caregivers.** Paying off some form of debt (i.e. mortgage, credit card, consumer, or student debt) is the most frequently referenced financial priority among caregivers, including African-American (59 percent), Hispanic (50 percent), White (48 percent), and Asian/Pacific Islander caregivers (47 percent). More than half of African-American caregivers (52 percent) cite “just getting by” as a financial priority, a finding that is higher than found among Hispanic (46 percent), White (42 percent), and Asian/Pacific Islander caregivers (34 percent).
- **Total Household Income Among Caregivers.** Asian/Pacific Islander caregivers report the highest HHI at \$83,000 (estimated median) in 2016, followed by White at \$63,000, Hispanic at \$41,000, and African-American at caregivers at \$40,000. Forty-two percent of Asian/Pacific Islander caregivers and 31 percent of White caregivers report an HHI of \$100k+, whereas approximately half of African-American (50 percent) and Hispanic caregivers (48 percent) report an HHI of less than \$50k.
- **Total Household Retirement Savings Among Caregivers.** White caregivers report the highest total household retirement savings in all accounts at \$99,000 (estimated median), a finding that is higher than found among Asian/Pacific Islander caregivers at \$65,000, Hispanic caregivers at \$12,000, and African-American caregivers at only \$4,000. Of concern, 23 percent of Hispanic caregivers and 20 percent of African-American caregivers report having no household retirement savings, compared to 13 percent of White and 11 percent of Asian/Pacific Islander caregivers.
- **Caregivers’ Self-Described General Health.** The majority of caregivers across ethnicities self-describe their general health as excellent or good, including 77 percent of White, 70 percent of Hispanic, 69 percent of African-American, and 67 percent of Asian/Pacific Islander caregivers. White caregivers (21 percent) are more likely to self-describe their health as excellent compared to other ethnicities. Asian/Pacific Islander caregivers (10 percent) are more likely than other ethnicities to self-describe their general health as poor.
- **Changes in General Health Since Becoming a Caregiver.** Approximately two-thirds of caregivers indicate that their general health has stayed the same since becoming a caregiver, including 67 percent of both Hispanic and Asian/Pacific Islander caregivers, 66 percent of African-American caregivers, and 63 percent of White caregivers. Caregivers across ethnicities are also similarly likely to indicate their general health has declined, including 19 percent of White, 16 percent of Asian/Pacific Islander, 14 percent of Hispanic, and 13 percent of African-American caregivers.
- **Caregivers’ Health Insurance.** While the vast majority of caregivers have health insurance, Asian/Pacific Islander (96 percent) and White caregivers (94 percent) are more likely to have insurance compared to African-American (86 percent) and Hispanic caregivers (75 percent). Across ethnicities, caregivers most frequently receive benefits through an employer.

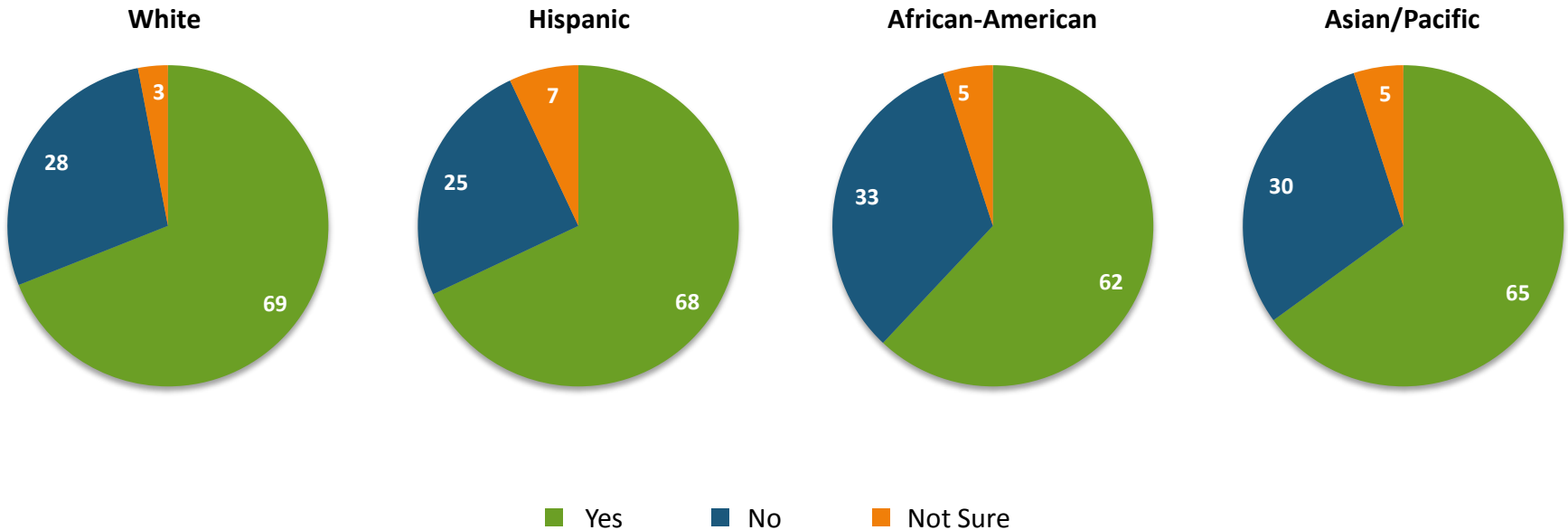
# Demographic Perspectives by Race/Ethnicity

- **Caregivers Would Like More Information to Help Them Personally.** Across ethnicities, approximately four in 10 caregivers would like more information about stress management, tips for coping with caregiving challenges, and government benefits available for caregivers. Hispanic (30 percent) and Asian/Pacific Islander caregivers (27 percent) are slightly more likely than African-American (24 percent) and White caregivers (20 percent) to want information about support groups for caregivers. Hispanic caregivers (23 percent) are slightly more likely than other ethnicities to want information about employer-sponsored workplace benefits for caregivers.

# Most Consider Themselves to Be the Primary Caregivers

Approximately two-thirds of caregivers consider themselves to be the Primary caregiver of their care recipient, including 69 percent of White, 68 percent of Hispanic, 65 percent of Asian/Pacific Islander, and 62 percent of African-American caregivers.

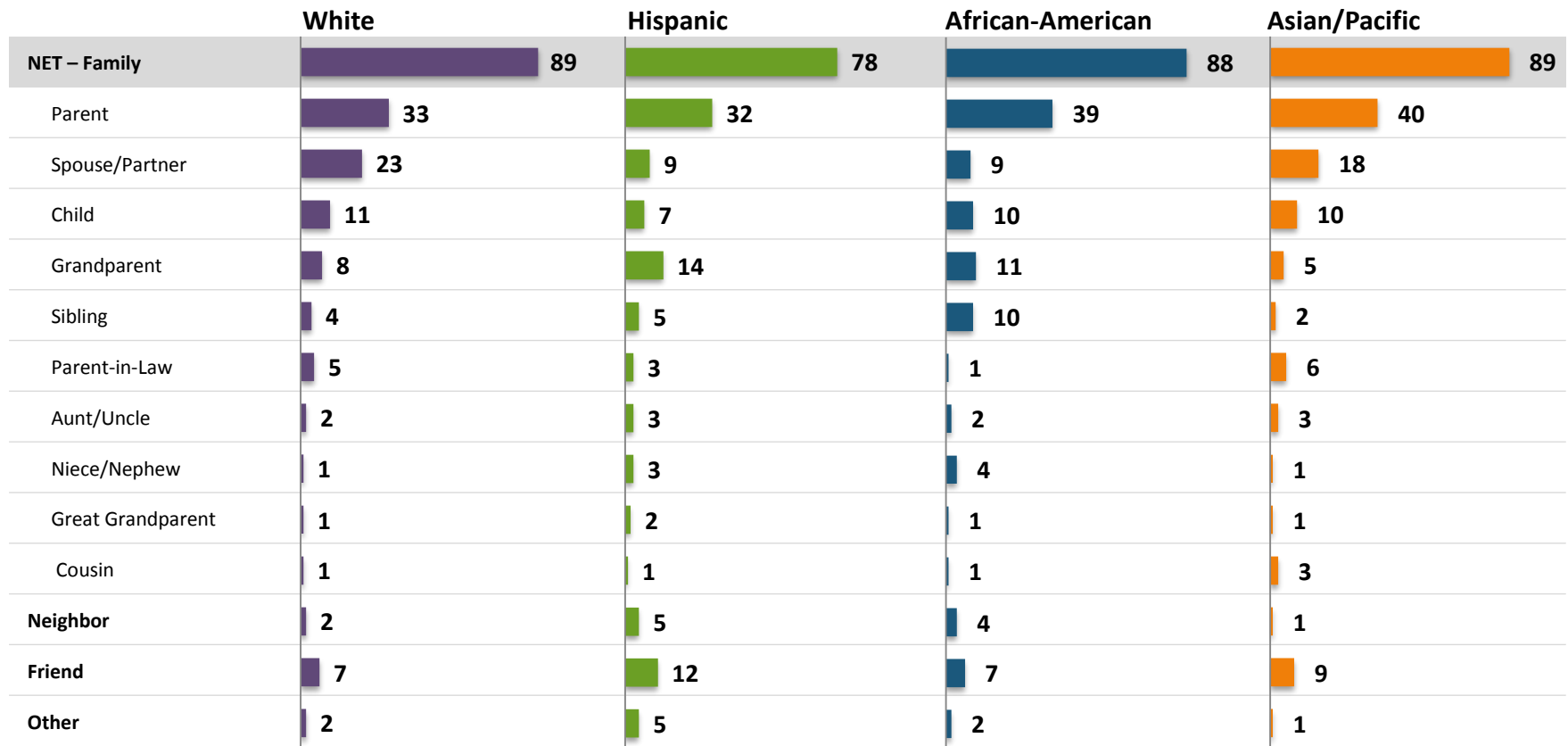
“Would you consider yourself to be the Primary caregiver?” (%)



# The Majority of Caregivers Are Caring for a Family Member

The vast majority of caregivers are caring for a family member, a finding which is higher among White and Asian/Pacific Islander caregivers (both 89 percent) and African-American caregivers (88 percent) than for Hispanic caregivers (78 percent). Approximately one in three caregivers are caring for a parent, a finding which is consistent across ethnicities. Approximately one in ten are caring for a child. Of note, White (23 percent) and Asian/Pacific (18 percent) caregivers are more likely to be caring for a spouse/partner, compared to Hispanic and African-American caregivers (both 9 percent).

Relationship to Care Recipient (%)



BASE: ALL QUALIFIED RESPONDENTS

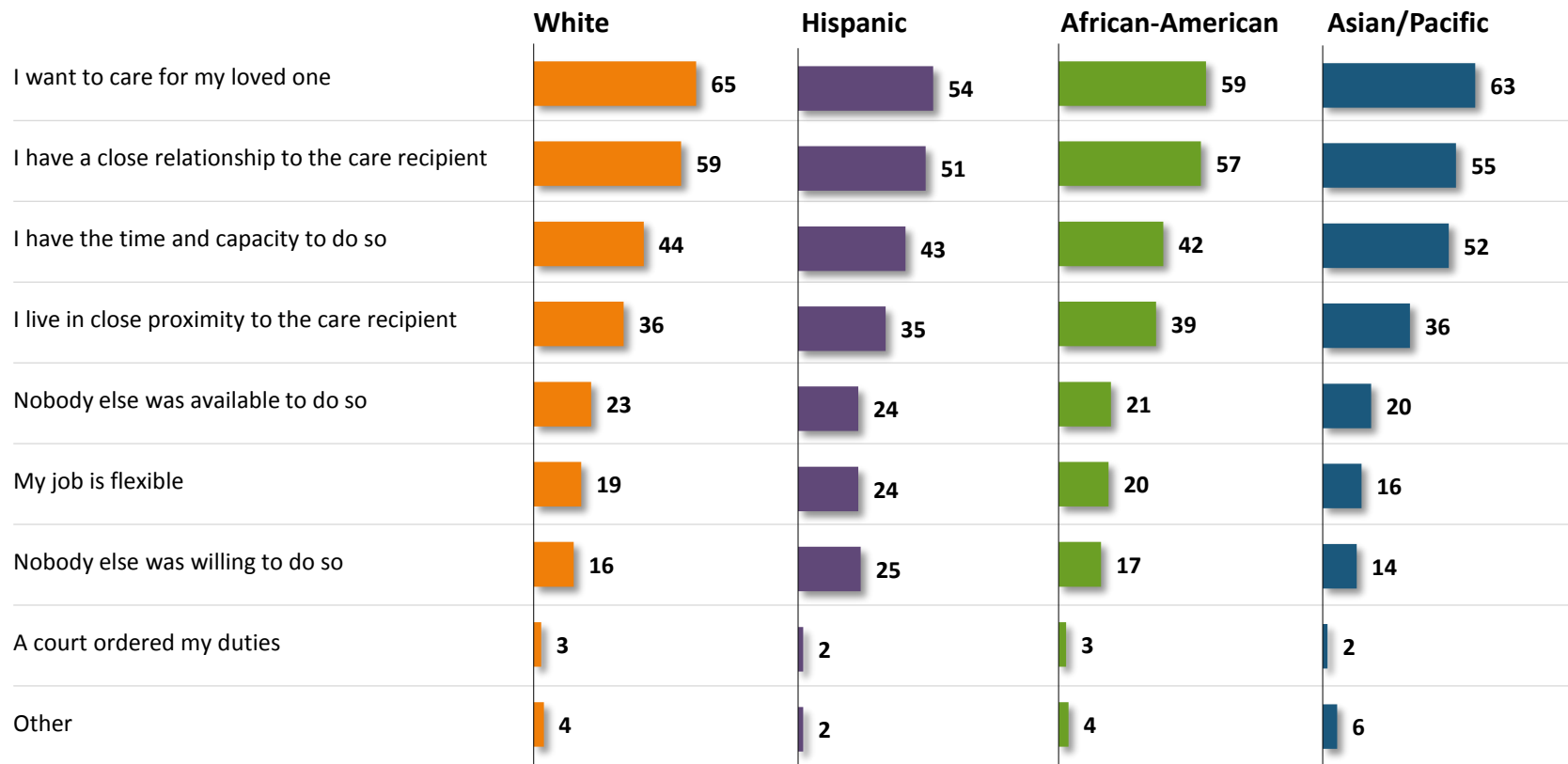
Q700. You mentioned providing care for [INSERT ANSWER FROM Q610] individual(s).

Please let us know your relationship to the person, their age, and their gender.

# Reasons for Becoming a Caregiver

Approximately six in 10 caregivers across ethnicities cite wanting to care for their loved one and having a close relationship with the care recipient as reasons for becoming a caregiver. More Asian/Pacific Islander caregivers (52 percent) say they became a caregiver because they have the time and capacity to do so, compared to 44 percent of White, 43 percent of Hispanic, and 42 percent of African-American caregivers. Hispanic caregivers (25 percent) are somewhat more likely than caregivers of other ethnicities to indicate that nobody else was willing to do so.

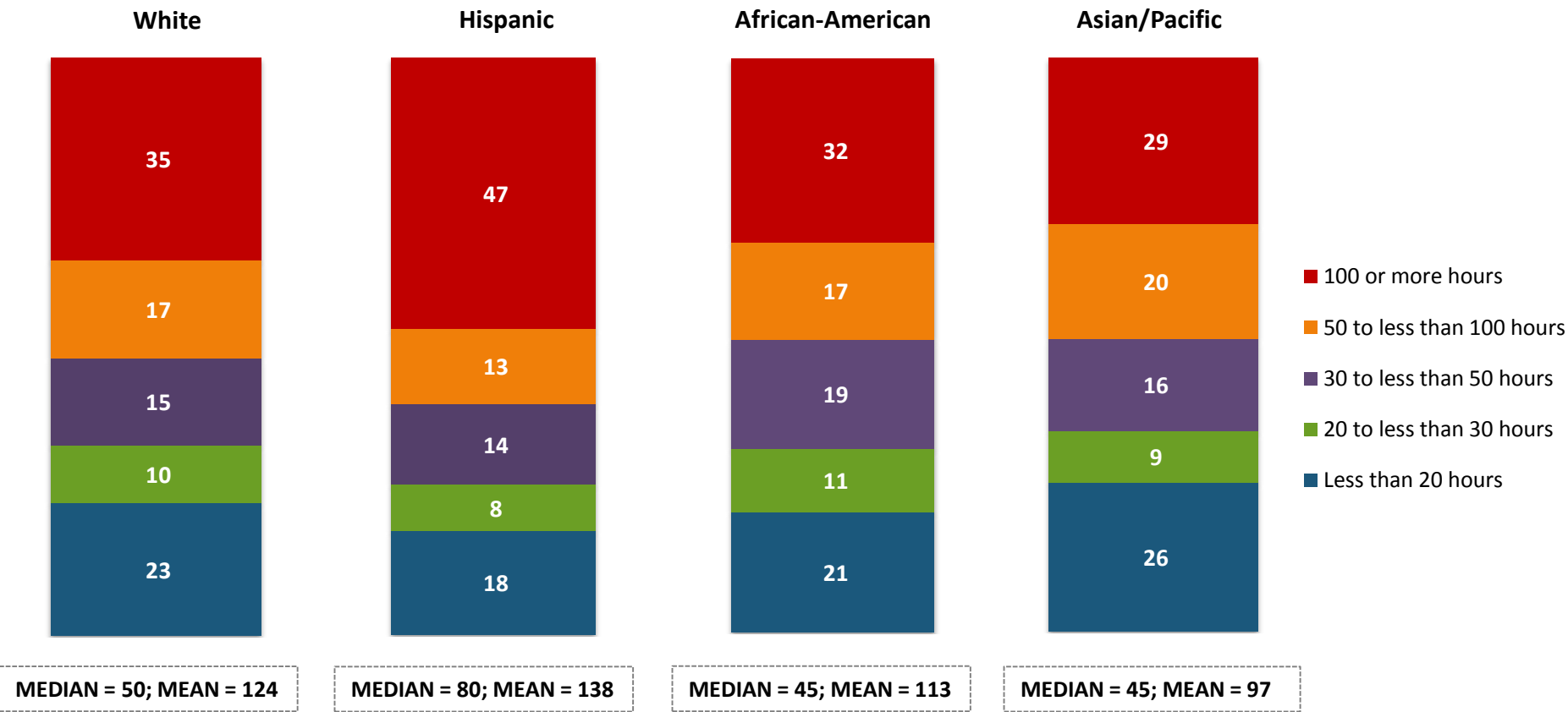
**Reasons for Becoming a Caregiver (%)**



# Total Caregiving Hours per Month

Hispanic caregivers spend the most time on caregiving at 80 hours per month (median), compared to White caregivers (50 hours), and Asian/Pacific Islander and African-American caregivers (both 45 hours). Hispanic caregivers (47 percent) are also more likely to spend 100 hours or more each month, compared to other ethnicities.

Total Hours Spent Caregiving Each Month (%)



Note: The median is the midpoint of the range of each response category. The mean is the average of all responses.

BASE: ALL QUALIFIED RESPONDENTS

Q832. In total, approximately how many hours per month do you spend caring for the care recipient?

# Caregiver Duties Performed

Caregiving encompasses a broad range of duties – duties that are consistent performed across ethnicities.

Approximately nine in 10 caregivers across ethnicities perform various household-related tasks for the caregiver (i.e., running errands, housework, meal preparation, home repairs, home modifications).

Approximately seven in 10 caregivers across ethnicities perform various health-related tasks (i.e., accompanying to medical appointments, healthcare coordination, health insurance coordination, health insurance coordination).

Hispanic caregivers (73 percent) are more likely to perform personal care duties (i.e., mobility, personal care, and feeding) for the care recipient, compared to the other ethnicities (60 percent).

Caregiving Duties	White	Hispanic	African-American	Asian/Pacific
<b>NET – Household</b>	<b>89%</b>	<b>88%</b>	<b>90%</b>	<b>80%</b>
Running errands	68%	65%	74%	56%
Housework	59%	65%	61%	51%
Meal preparation	58%	60%	64%	47%
Home repairs	32%	23%	21%	26%
Home modifications	20%	20%	12%	25%
<b>NET – Social/Communication</b>	<b>72%</b>	<b>71%</b>	<b>73%</b>	<b>73%</b>
Companionship	63%	55%	62%	56%
Basic communications	30%	31%	39%	35%
Language translation	4%	20%	5%	23%
<b>NET – Health-Related</b>	<b>69%</b>	<b>69%</b>	<b>68%</b>	<b>73%</b>
Accompanying to medical appointments	61%	60%	61%	66%
Healthcare coordination	44%	40%	47%	55%
Health insurance coordination	32%	19%	24%	44%
<b>NET – Personal Care</b>	<b>60%</b>	<b>73%</b>	<b>60%</b>	<b>60%</b>
Mobility	39%	43%	32%	39%
Personal care	34%	42%	34%	30%
Feeding	23%	48%	28%	22%
Incontinence care	14%	15%	20%	16%
<b>NET – Medical-Related</b>	<b>50%</b>	<b>46%</b>	<b>49%</b>	<b>43%</b>
Medication management	45%	44%	47%	42%
Medical treatment administration	17%	15%	10%	8%
<b>Paying bills/Managing finances</b>	<b>45%</b>	<b>34%</b>	<b>45%</b>	<b>43%</b>
<b>Other</b>	<b>4%</b>	<b>4%</b>	<b>4%</b>	<b>3%</b>



# Hours Spent Caregiving by Types of Duties

Caregivers spend the most amount of time per month providing companionship to the care recipient, including 40 hours (median) by White caregivers, 30 hours by both Hispanic and African-American caregivers, and 20 hours by Asian/Pacific Islander caregivers.

Caregivers spend the second most amount of time per month on meal preparation. Hispanics spend 24 hours (median) per month preparation, a finding that is higher than found among African-American (20 hours median), White (19 hours median), and Asian/Pacific Islander caregivers (15 hours median).

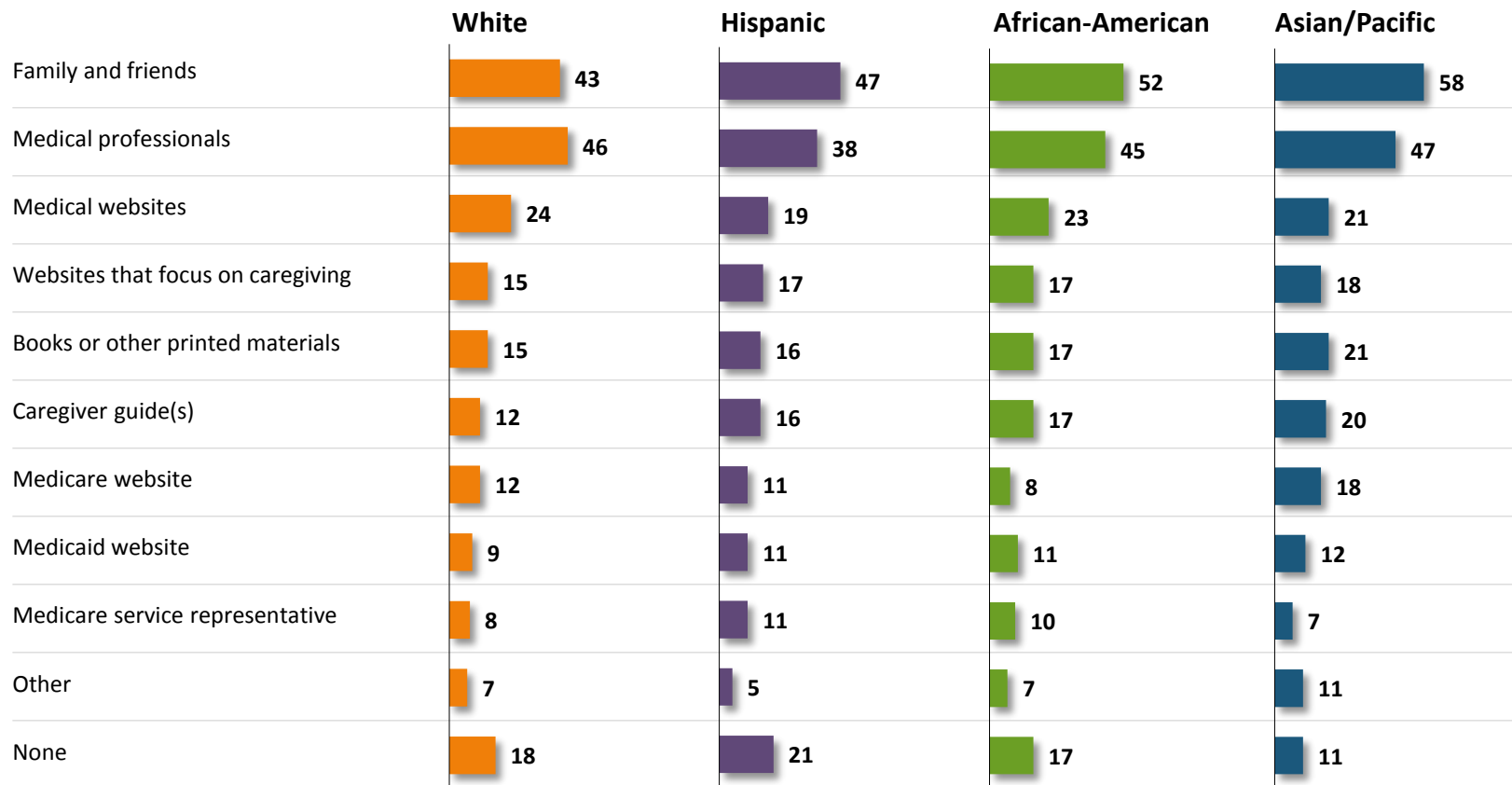
*Note: The median is the midpoint of the range of each response category. The mean is the average of all responses.*

Time Spent On Caregiving Duties Each Month (hours per month)	White		Hispanic		African-American		Asian/Pacific	
	Median	Mean	Median	Mean	Median	Mean	Median	Mean
<b>Household</b>								
Running errands	8	18	10	15	8	25	8	13
Housework (e.g., cleaning, laundry)	10	28	12	25	10	27	8	20
Meal preparation	19	31	24	32	20	38	15	29
Home repairs	3	9	6	12	2	18	2	7
Home modifications	2	8	10	12	2	6	2	3
<b>Social/Communication</b>								
Companionship	40	97	30	70	30	97	20	61
Basic communications	10	45	18	37	20	70	10	40
Language translation	5	16	5	10	2	34	3	18
<b>Health-Related</b>								
Accompanying to medical appointments	4	11	5	11	4	15	3	7
Healthcare coordination	3	9	5	8	3	20	2	5
Health insurance coordination	2	9	4	6	2	10	2	4
<b>Personal Care</b>								
Mobility	8	23	10	25	12	28	7	18
Personal care	10	26	20	25	20	29	10	19
Feeding	10	35	20	34	10	26	10	27
Incontinence care	5	23	10	24	10	17	5	14
<b>Medical-Related</b>								
Medication management	5	16	7	19	5	26	2	8
Medical treatment administration	5	18	9	18	5	13	2	10
<b>Paying bills/Managing finances</b>	3	9	4	7	4	15	3	4
<b>Other</b>	10	85	1	6	6	10	8	9

# Sources of Information Relied on to Assist in Caregiving Duties

Caregivers across ethnicities most frequently rely on family and friends and medical professionals as sources of information to assist them with their caregiving duties. More Asian/Pacific Islander (58 percent) and African-American caregivers (52 percent) rely on family and friends compared to Hispanic caregivers (47 percent) and White caregivers (43 percent). Hispanic caregivers (38 percent) are somewhat less likely to rely on medical professionals compared to Asian/Pacific Islander (47 percent), White (46 percent), and African-American caregivers (45 percent).

**Sources of Information to Assist in Caregiving Duties (%)**



NOTE: Nine most commonly selected sources shown.

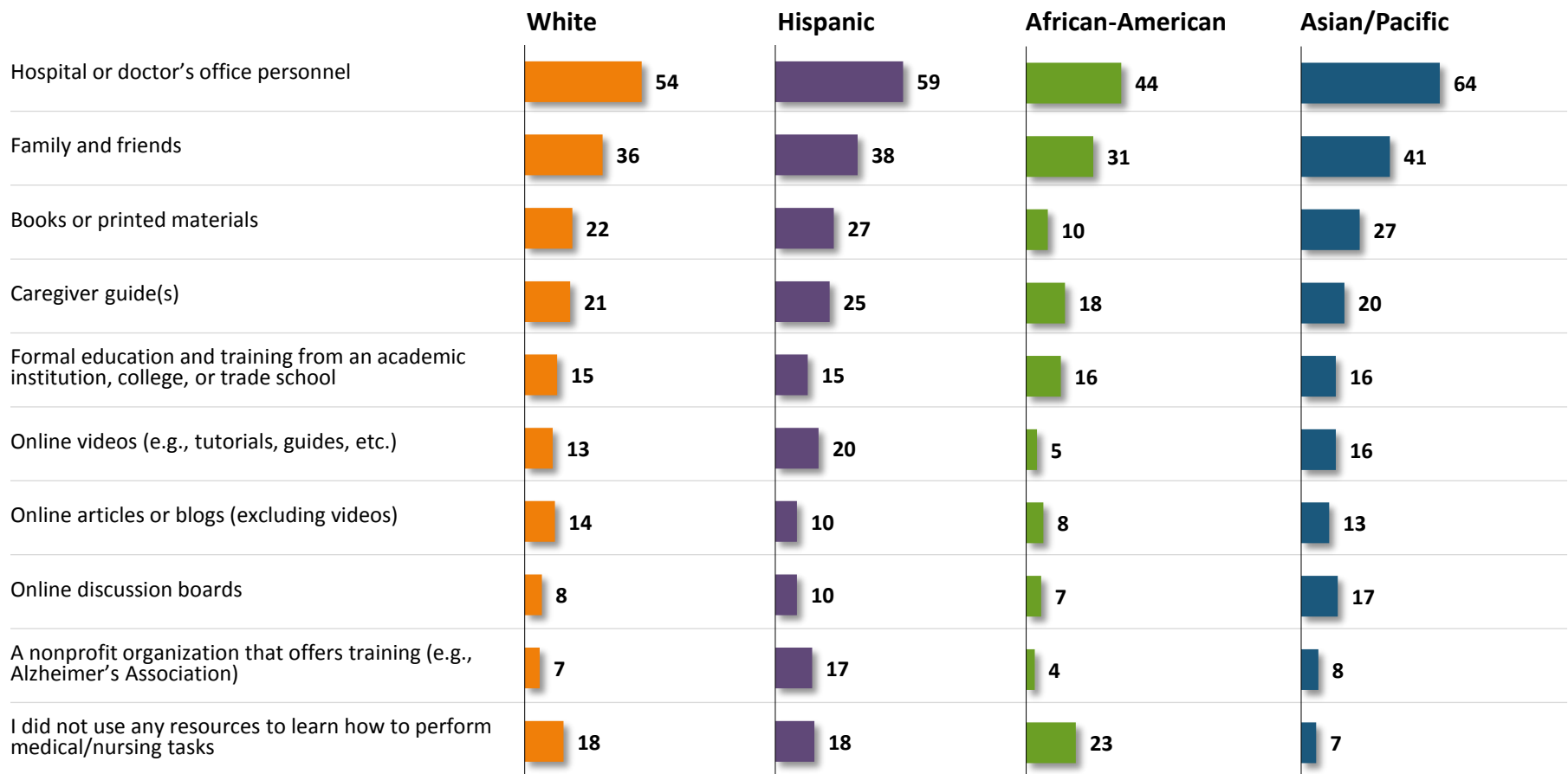
BASE: ALL QUALIFIED RESPONDENTS

Q840. Which of the following do you rely on as sources of information to assist in your caregiving duties? Select all.

# Sources for Learning About Medical/Nursing Tasks

Among caregivers currently performing medical-related tasks and across ethnicities, the most frequently cited sources for learning such tasks are hospital or doctor's personnel. More Asian/Pacific Islander caregivers (64 percent) use hospital or doctor's office personnel as sources for learning these tasks, compared to Hispanic (59 percent), White (54 percent), and African-American (44 percent) caregivers.

**Sources for Learning Medical/Nursing Tasks Related to Being a Caregiver (%)**



NOTE: Nine most commonly selected sources shown.

BASE: IF ADMINISTERING MEDICATIONS AND MEDICAL TREATMENTS

Q835. You mentioned you perform medication management or medical treatment administration for the care recipient. Where did you learn how to perform medical/nursing tasks related to being a caregiver? Select all.

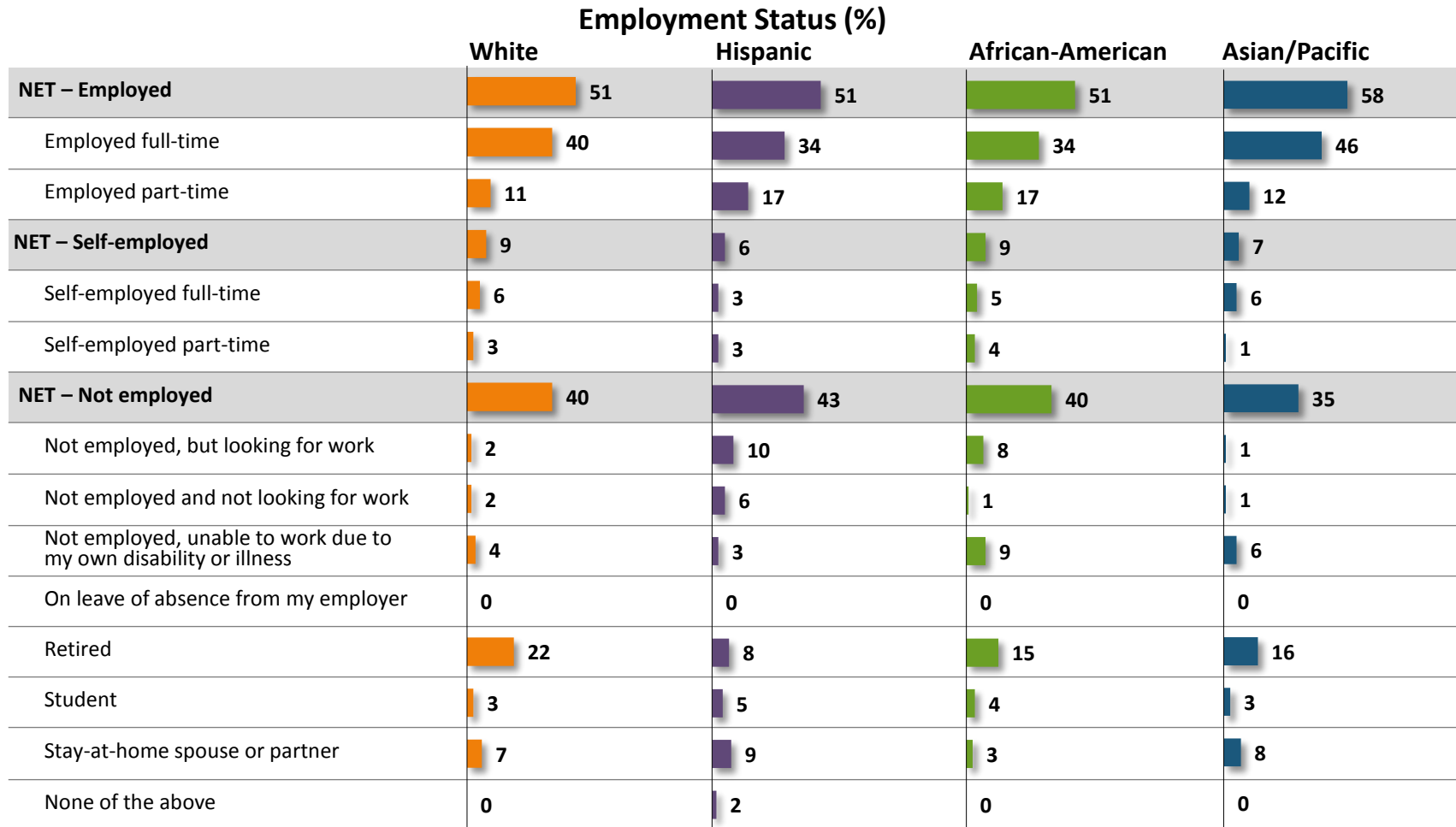
# Caregivers' Sentiments About Their Caregiving Duties

Almost all caregivers agree that it is important to provide a good quality of life for the care recipient – including 96 percent of White, 95 percent of Asian/Pacific Islander, 93 percent of African-American, and 88 percent of Hispanic caregivers. Approximately nine in 10 caregivers across ethnicities say they like helping and enjoy spending time with the care recipient. Many caregivers say that their own health takes a backseat to the health of the care recipient, including 60 percent of Asian/Pacific Islander, 56 percent of White, 52 percent of Hispanic, and 48 percent of African-American caregivers.

Caregivers' Sentiments About Their Caregiving Duties	White	Hispanic	African-American	Asian/Pacific
	Strongly/Somewhat Agree (NET)			
Positive				
It's important for me to provide a good quality of life for the care recipient	96	88	93	95
I like helping the care recipient	91	90	88	92
I enjoy spending time with the care recipient	91	90	86	89
Being a caregiver gives me a strong sense of purpose	83	80	83	90
Being a caregiver has led me to take better care of my own health	69	70	73	83
Being a caregiver has inspired me to document my own health and legal wishes	66	66	65	70
Negative				
My own health takes a backseat to the health of my care recipient	56	52	48	60
My caregiving duties leave me feeling physically exhausted	54	58	50	57
My caregiving duties leave me feeling emotionally exhausted	55	50	50	62
I need more help with my caregiving duties	46	54	47	58
With all of my caregiving duties, I barely have time for anything else	45	50	43	51
My caregiving duties leave me feeling completely overwhelmed	44	41	39	49

# Employment Status of Caregivers

Employment status is similar across ethnicities. Approximately half of caregivers are employed, including 58 percent of Asian/Pacific Islander caregivers and 51 percent of White, Hispanic, and African-American caregivers. Approximately four in 10 caregivers across ethnicities are not employed, including 43 percent of Hispanic, 40 percent of both White and African-American, and 35 percent of Asian/Pacific Islander caregivers. Slightly fewer than one in 10 caregivers are self-employed.



# Disruptions to Employment as a Result of Caregiving

Caregiving responsibilities can be disruptive to a caregiver's employment.

Many caregivers who are currently employed or who have been employed during their time as caregivers have adjusted their work life to accommodate their caregiving duties.

Approximately one in four caregivers across ethnicities have reduced their work hours or job responsibilities.

Approximately three in 10 caregivers across ethnicities have used vacation, sick days, and/or personal days off to be a caregiver.

African-American (19 percent), White (15 percent), and Hispanic (13 percent) are more likely than Asian/Pacific Islander caregivers (6 percent) to have retired early or quit a job.

"Which of the following have you done as a result of becoming a caregiver?" (%)

	White	Hispanic	African-American	Asian/Pacific
<b>NET – Reduced hours or job responsibilities</b>	26	26	21	27
Reduced my hours	18	15	16	20
Reduced job responsibilities	11	10	7	8
Switched to a less demanding job	7	10	7	7
<b>NET – Taken leave</b>	18	19	10	21
Taken an unpaid leave of absence from my employer <u>covered by the Family and Medical Leave Act</u>	10	11	6	9
Taken a paid leave of absence from my employer	7	6	4	7
Taken an unpaid leave of absence from my employer <u>not covered by the Family and Medical Leave Act</u>	6	5	3	6
<b>NET – Retired early/quit job</b>	15	13	19	6
Retired early	9	6	7	1
Quit a job	7	8	13	5
<b>Used vacation, sick days, and/or personal days off to be a caregiver</b>	30	25	30	24
<b>Missed days of work</b>	25	26	35	16
<b>Began working an alternative schedule</b>	14	16	12	16
<b>Began to work remotely</b>	10	6	11	15
<b>Took on additional hours to pay for cost of caregiving</b>	7	10	8	5
<b>None</b>	25	23	25	18

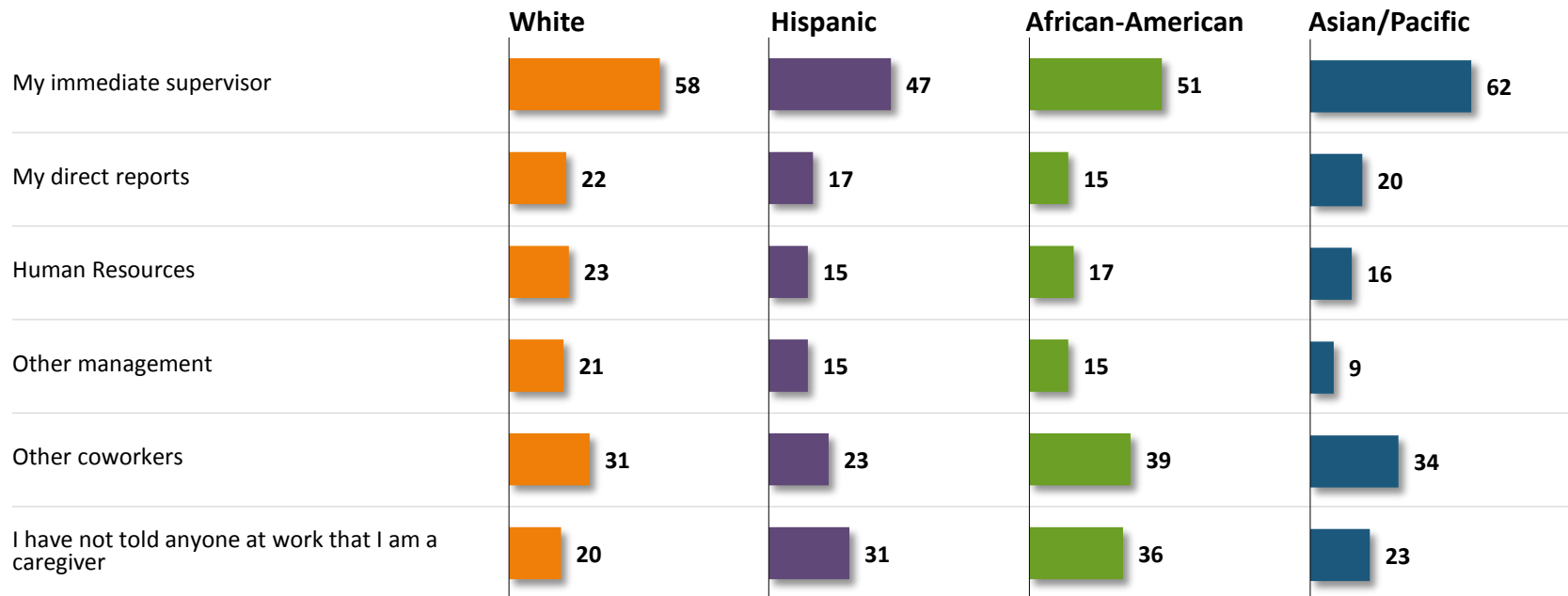
NOTE: Thirteen most commonly selected sources shown.

BASE: ALL EMPLOYED OR HAVE BEEN EMPLOYED DURING THEIR TIME AS A CAREGIVER  
Q1025. Which of the following have you done as a result of becoming a caregiver? Select all.

# Informing Coworkers About Their Caregiving Duties

Many employed caregivers have told their immediate supervisor that they are a caregiver, including Asian/Pacific Islander (62 percent), White (58 percent), African-American (51 percent), and Hispanic caregivers (47 percent). Among ethnicities, African-American caregivers (36 percent) are more likely to have not to tell anyone at work that they are a caregiver, compared to Hispanic (31 percent), Asian/Pacific Islander (23 percent), and White caregivers (20 percent).

**“Which of the following people at work have you told that you are a caregiver?” (%)**



NOTE: Self-employed and not employed were excluded from this question.

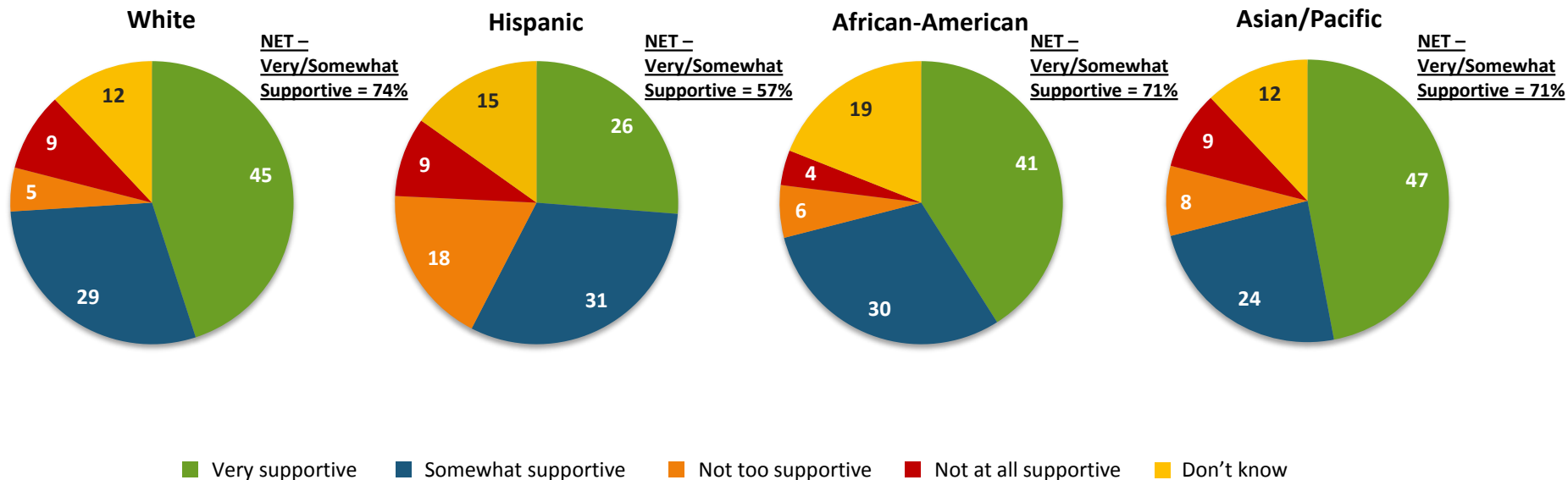
BASE: EMPLOYED FULL-TIME OR PART-TIME

Q1035. Which of the following people at work have you told that you are a caregiver? Select all.

# Employer Support of Caregiving Duties

Most employed caregivers believe that their employers are supportive of their caregiving duties. White (74 percent) and African-American and Asian/Pacific Islander caregivers (both 71 percent) are more likely to believe their employers are very or somewhat supportive, compared to Hispanic caregivers (57 percent). Across ethnicities, some caregivers feel that their employers are not at all supportive of their caregiver responsibilities, including 9 percent of White, Hispanic, and Asian/Pacific Islander caregivers and 4 percent of African-American caregivers and 4 percent of African-American caregivers.

**“How supportive is your employer of your caregiving responsibilities?” (%)**



NOTE: Self-employed and not employed were excluded from this question.

BASE: EMPLOYED FULL-TIME OR PART-TIME

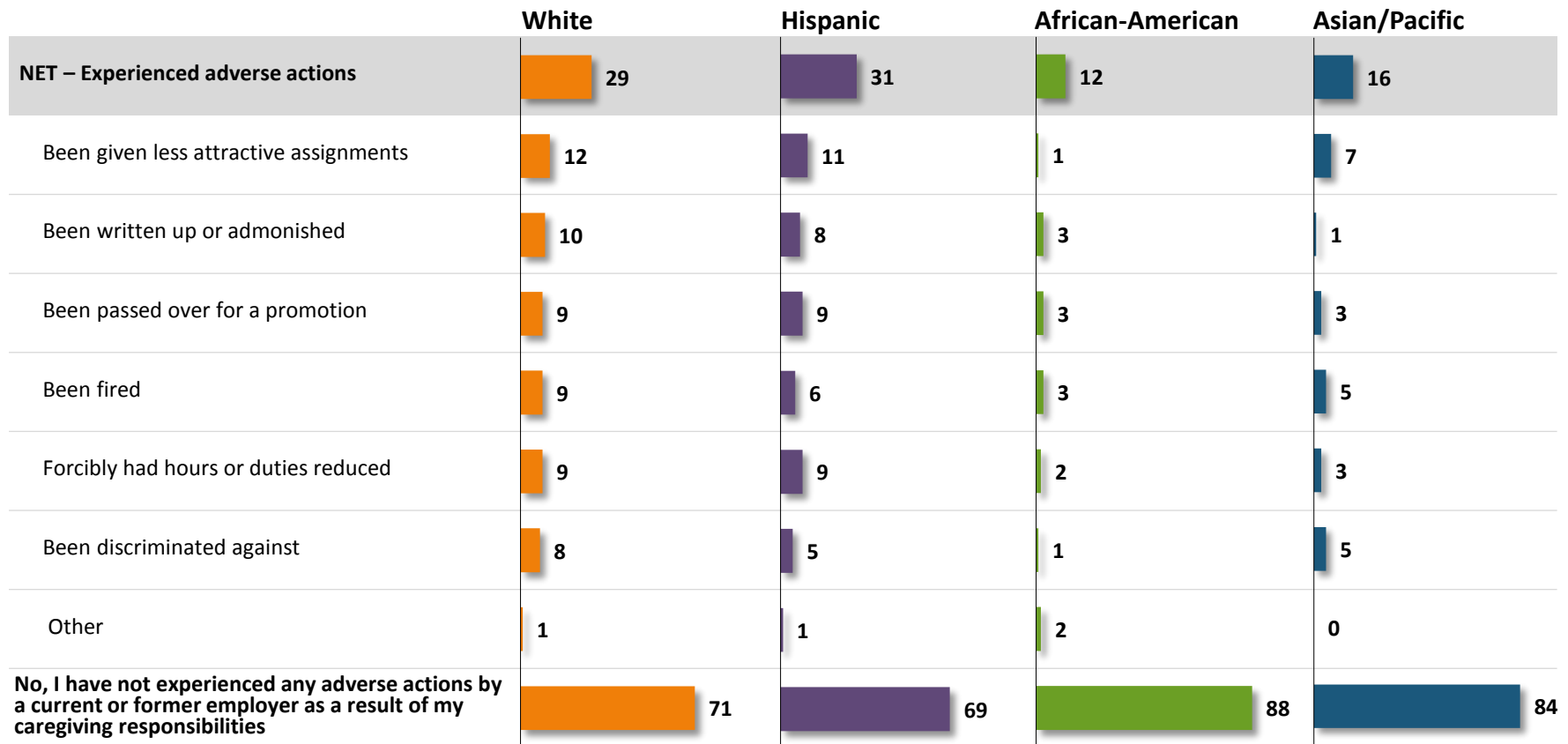
Q1045. How supportive is your employer of your caregiving responsibilities?



# Adverse Actions Taken by Employers

Caregiving duties may conflict with job responsibilities which, in turn, may lead to adverse actions taken by employers such as being given less attractive assignments, being discriminated against, or being passed over for a promotion, among others. Most caregivers have not experienced any adverse actions as a result of their caregiving duties. However, among those currently employed or have been employed during their time as a caregiver, Hispanic and White caregivers (31 and 29 percent, respectively) are more likely to have experienced adverse actions, compared to Asian/Pacific Islander (16 percent) and African-American (12 percent) caregivers.

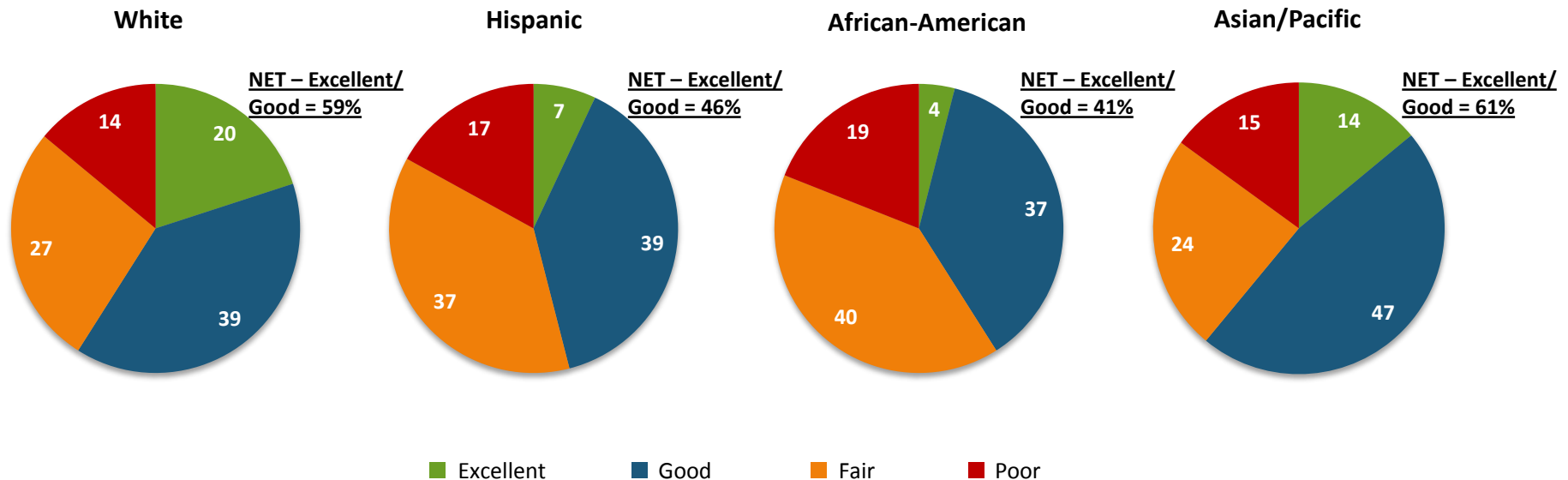
## Adverse Employment Actions Experienced as a Result of Caregiving Duties (%)



# Caregivers' Financial Well-Being

Asian/Pacific Islander (61 percent) and White caregivers (59 percent) are more likely to describe their financial well-being as excellent or good, compared to Hispanic (46 percent) and African-American caregivers (41 percent). In contrast, 19 percent of African-American, 17 percent of Hispanic, 15 percent of Asian/Pacific Islander, and 14 percent of White caregivers describe their financial well-being as poor.

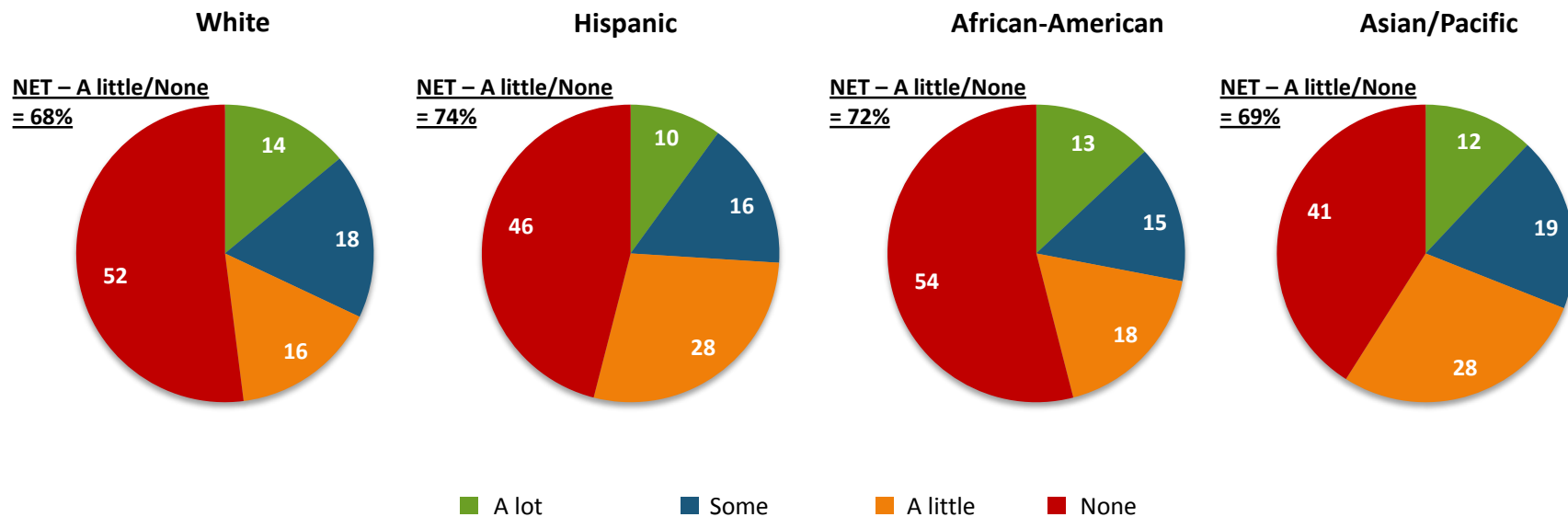
**“How would you describe your own financial well-being?” (%)**



# Financial Considerations Before Becoming Caregivers

Most caregivers across ethnicities gave little or no consideration to their financial situation when deciding to become a caregiver, including 74 percent of Hispanic, 72 percent of African-American, 69 percent of Asian/Pacific Islander, and 68 percent of White caregivers.

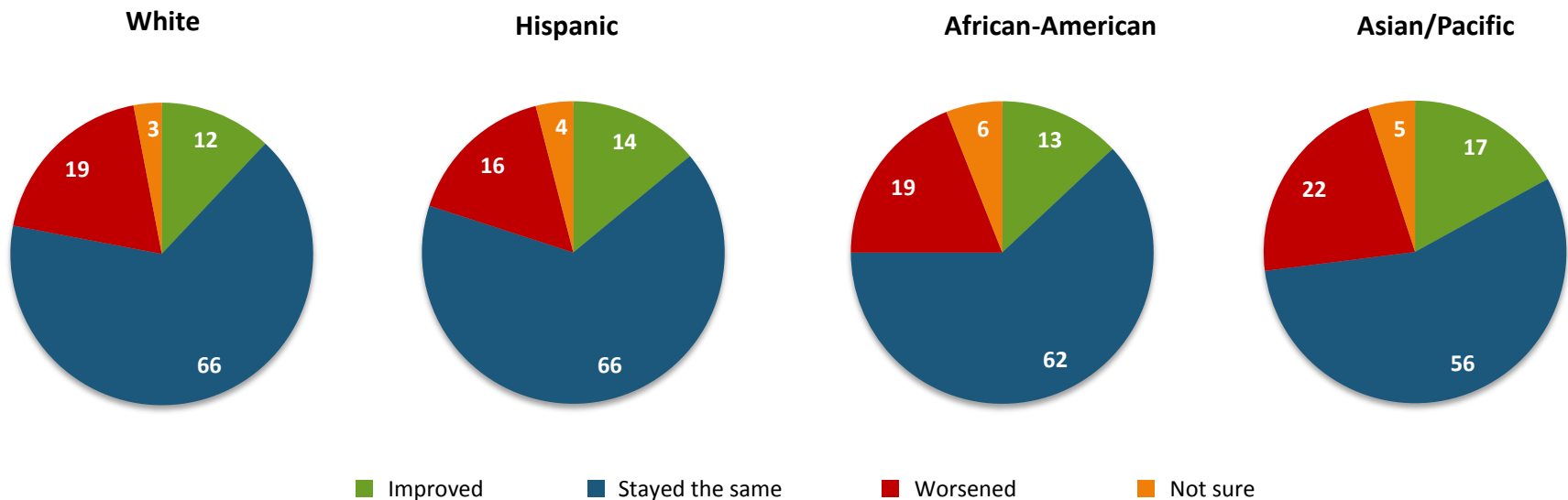
**“To what extent did you consider your own financial situation when deciding to become a caregiver?” (%)**



# Change in Financial Situation as a Result of Caregiving

The majority of caregivers across ethnicities say their financial situation as stayed the same since becoming a caregiver, including 66 percent of White and Hispanic caregivers, 62 percent of African-American caregivers, and 56 percent of Asian/Pacific Islander caregivers. However, approximately one in five caregivers say that their financial situation worsened as a result of becoming a caregiver, including White (19 percent), Hispanic (16 percent), African-American (19 percent), and Asian/Pacific Islander caregivers (22 percent).

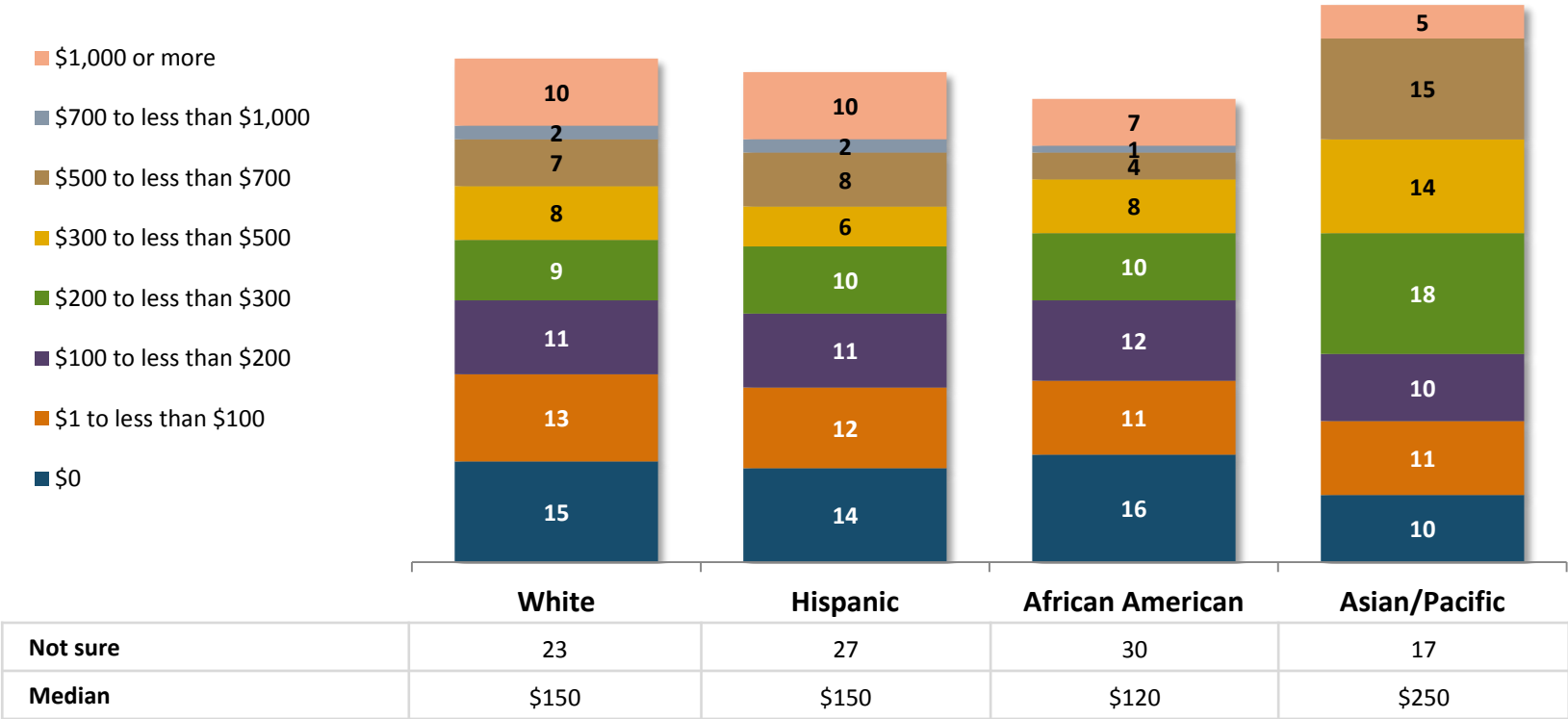
**“How has your financial situation changed as a result of becoming a caregiver?”**



# Monthly Personal Expenditures for Caregiving

Caregivers often find themselves paying out-of-pocket expenses for the care recipient (e.g., groceries, over-the-counter medications, gas, parking). Asian/Pacific Islander caregivers spend more money out-of-pocket per month (\$250 median) to cover expenses for their care recipient, compared to White (\$150 median), Hispanic (\$150 median), and African-American caregivers (\$120 median).

Monthly Personal Expenditures to Cover Expenses for Care Recipient (%)



Note: The median is the midpoint of the range of each response category. Non-responses are excluded from the estimate.

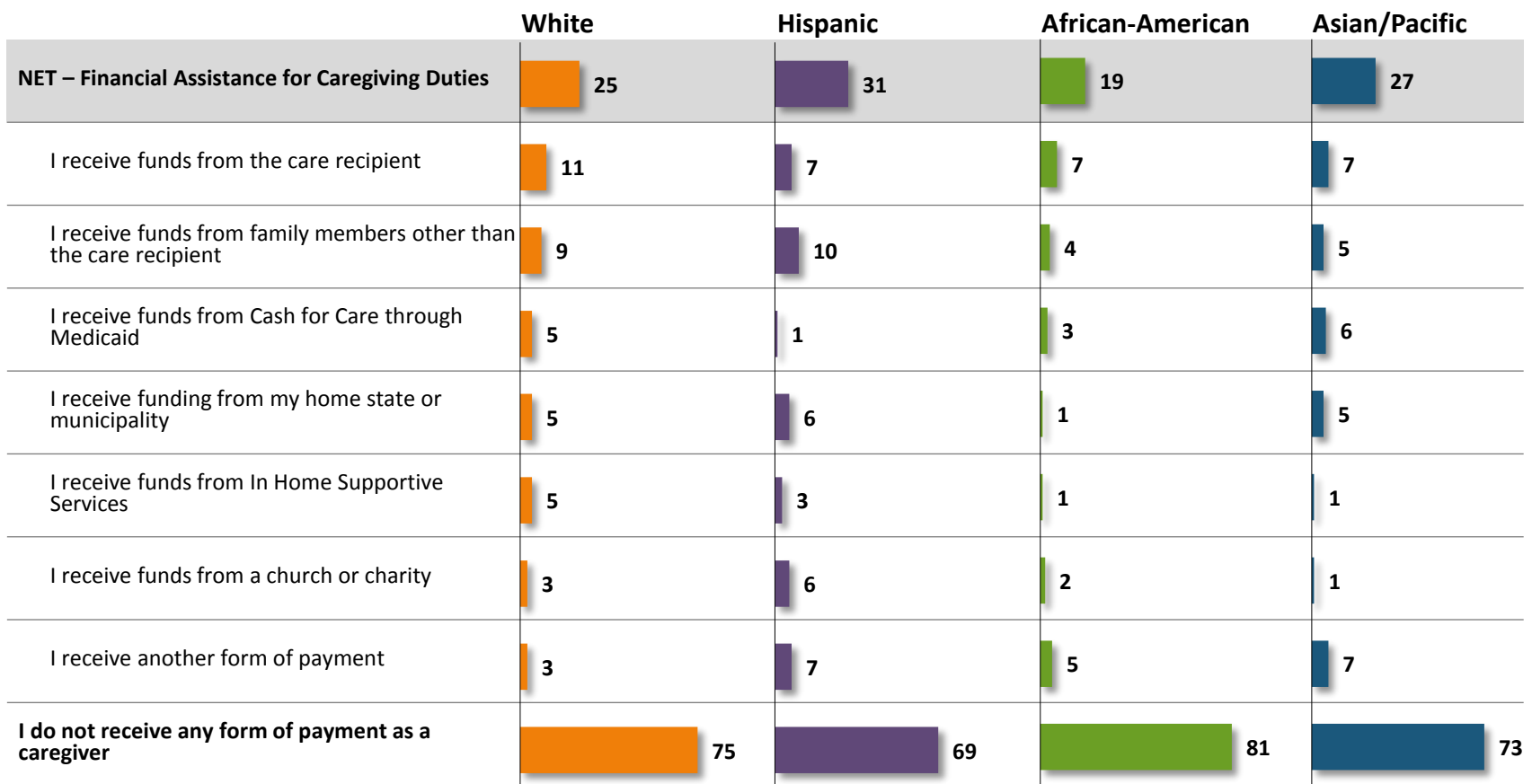
BASE: ALL QUALIFIED RESPONDENTS

Q1120. On average, approximately how much money do you spend each month paying out-of-pocket to cover expenses for the care recipient (e.g. for groceries, over-the-counter medications, gas, parking)?

# Financial Assistance for Caregiving Duties

The majority of caregivers across ethnicities do not receive any form of payment for their caregiving duties. However, more Hispanic caregivers (31 percent) receive compensation for their caregiving duties, compared to Asian/Pacific Islander caregivers (27 percent), White caregivers (25 percent) and African-American caregivers (18 percent). Among those receiving payment, the most frequently cited sources of funds are from the care recipient and family members.

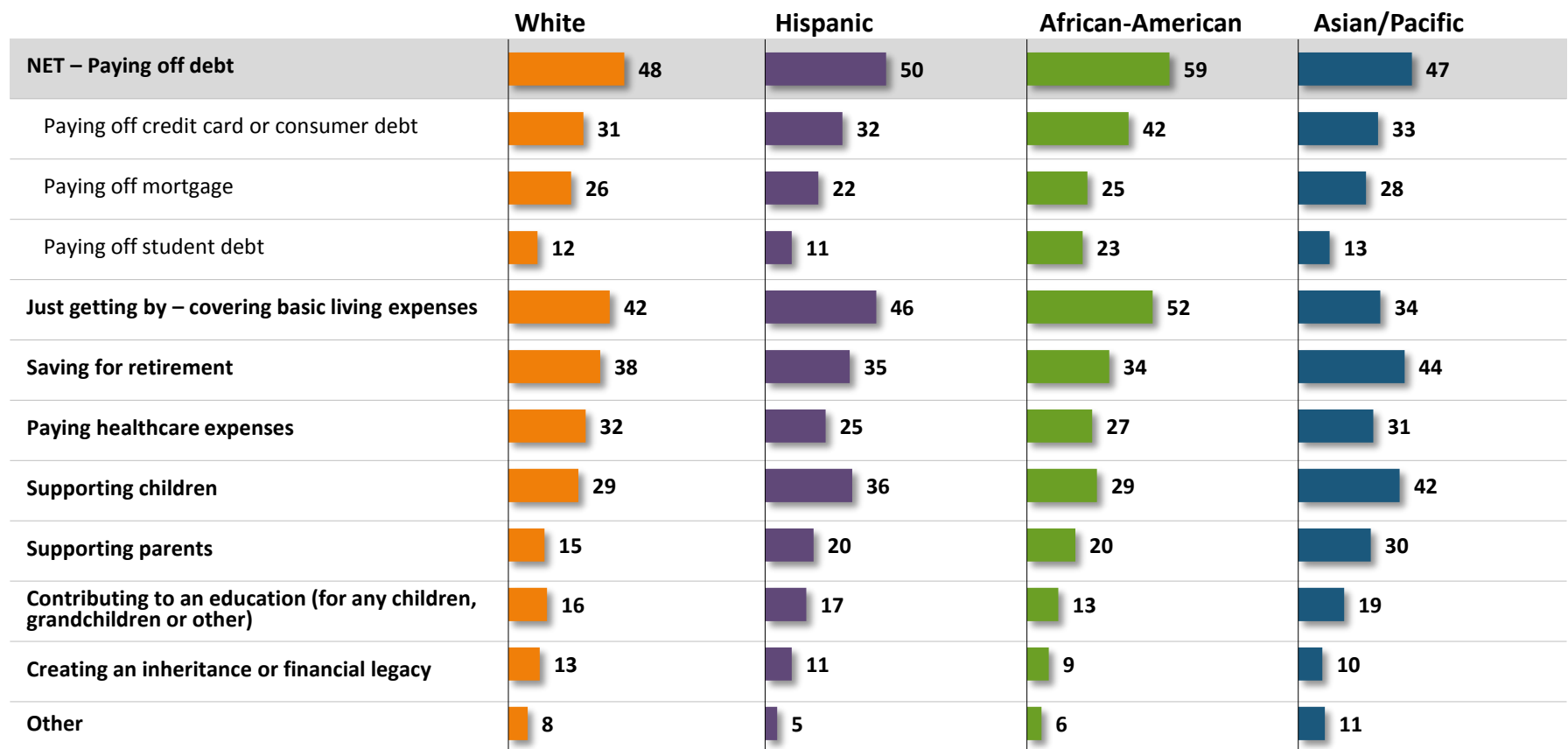
Sources of Financial Assistance Received for Caregiving Duties, If Any (%)



# Financial Priorities Among Caregivers

Paying off some form of debt (i.e. mortgage, credit card, consumer, or student debt) is the most frequently referenced financial priority among caregivers, including African-American (59 percent), Hispanic (50 percent), White (48 percent), and Asian/Pacific Islander caregivers (47 percent). More than half of African-American caregivers (52 percent) cite “just getting by” as a financial priority, a finding that is higher than found among Hispanic (46 percent), White (42 percent), and Asian/Pacific Islander caregivers (34 percent).

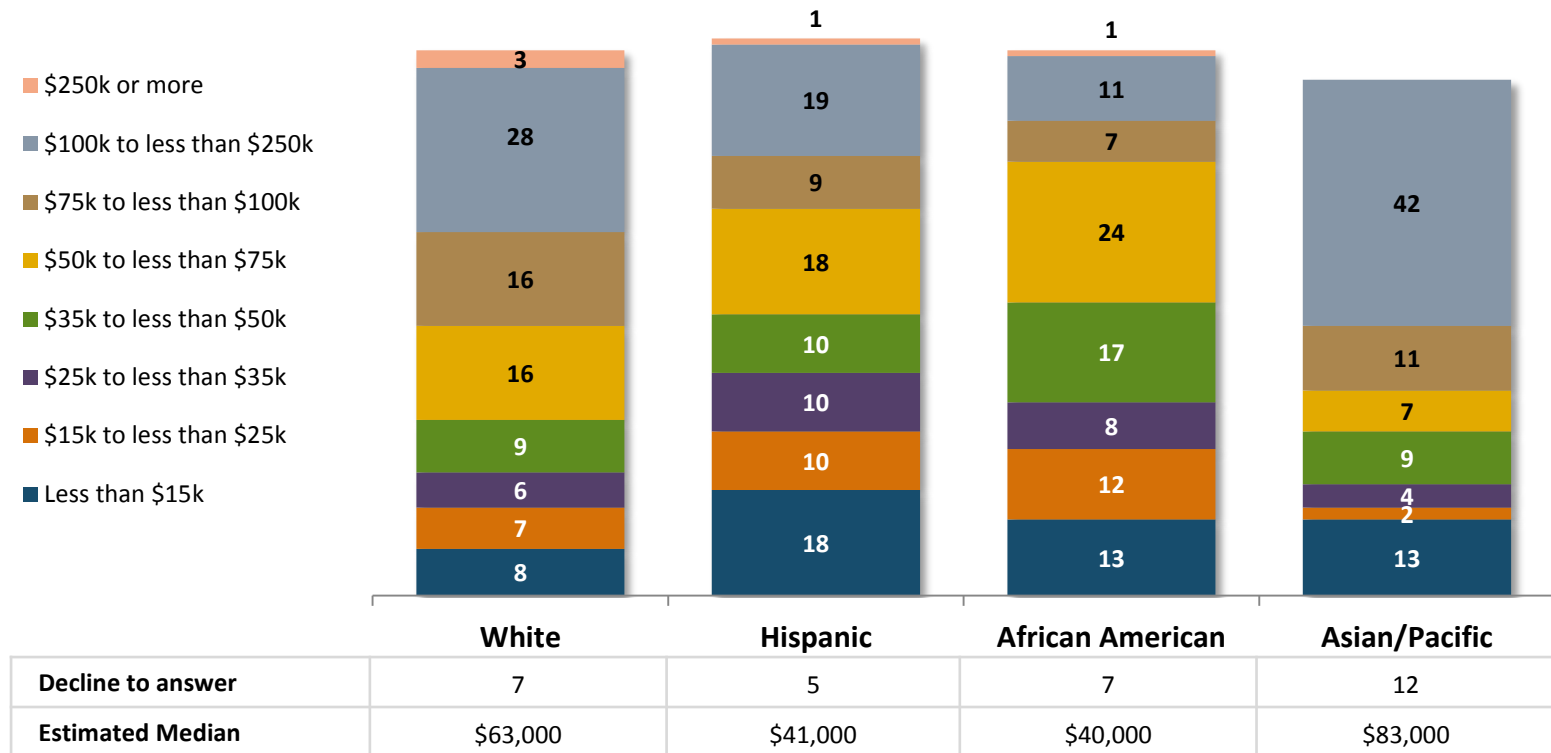
**“Which of the following are your financial priorities right now?” (%)**



# Total Household Income Among Caregivers

Asian/Pacific Islander caregivers report the highest HHI at \$83,000 (estimated median) in 2016, followed by White at \$63,000, Hispanic at \$41,000, and African-American at caregivers at \$40,000. Forty-two percent of Asian/Pacific Islander caregivers and 31 percent of White caregivers report an HHI of \$100k+, whereas approximately half of African-American (50 percent) and Hispanic caregivers (48 percent) report an HHI of less than \$50k.

**Total Household Income in 2016 (%)**



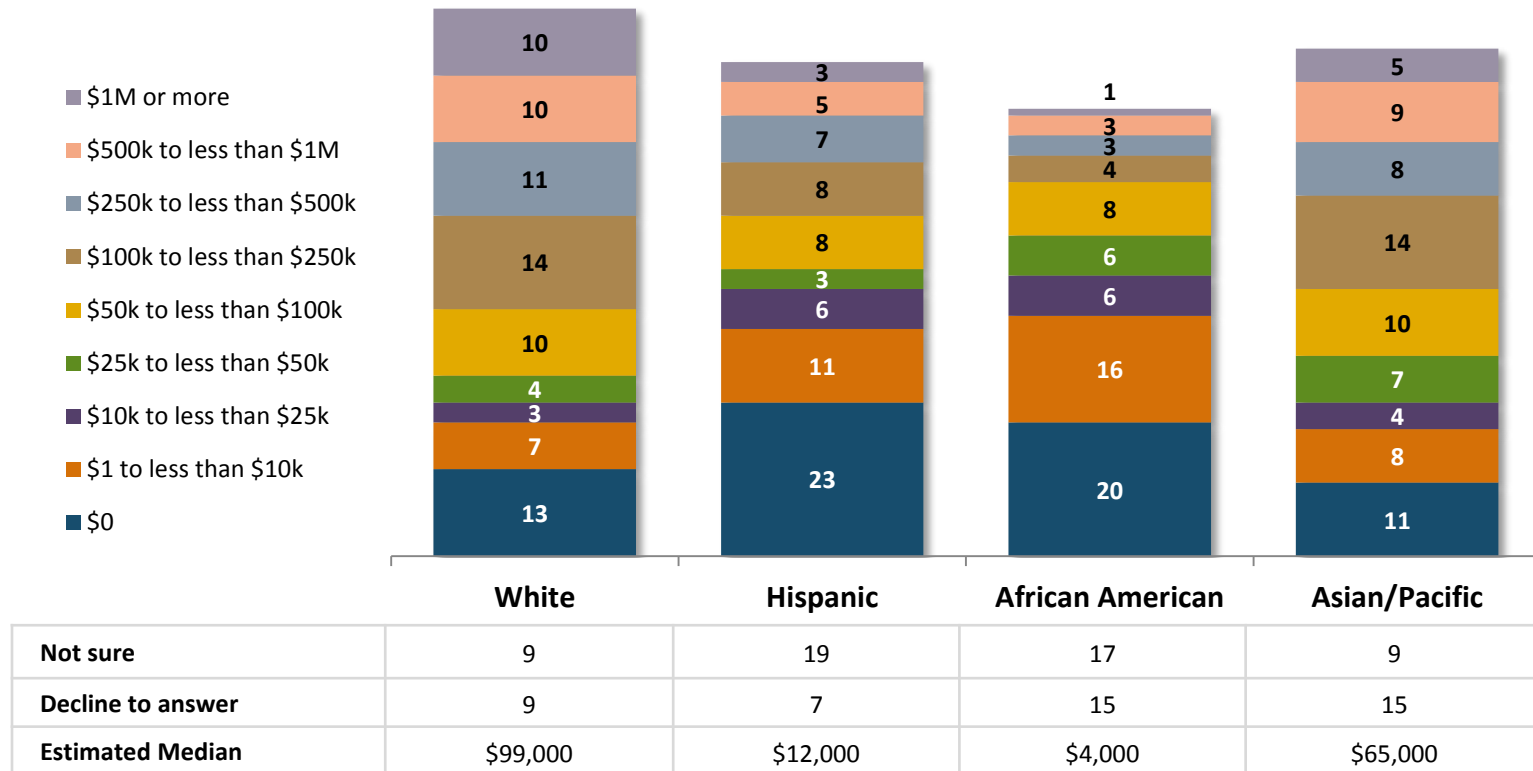
Note: The median is estimated based on the approximate midpoint of the range of each response category. Non-responses are excluded from the estimate.



# Total Household Retirement Savings Among Caregivers

White caregivers report the highest total household retirement savings in all accounts at \$99,000 (estimated median), a finding that is higher than found among Asian/Pacific Islander caregivers at \$65,000, Hispanic caregivers at \$12,000, and African-American caregivers at only \$4,000. Of concern, 23 percent of Hispanic caregivers and 20 percent of African-American caregivers report having no household retirement savings, compared to 13 percent of White and 11 percent of Asian/Pacific Islander caregivers.

**Total Household Retirement Savings in All Accounts (%)**

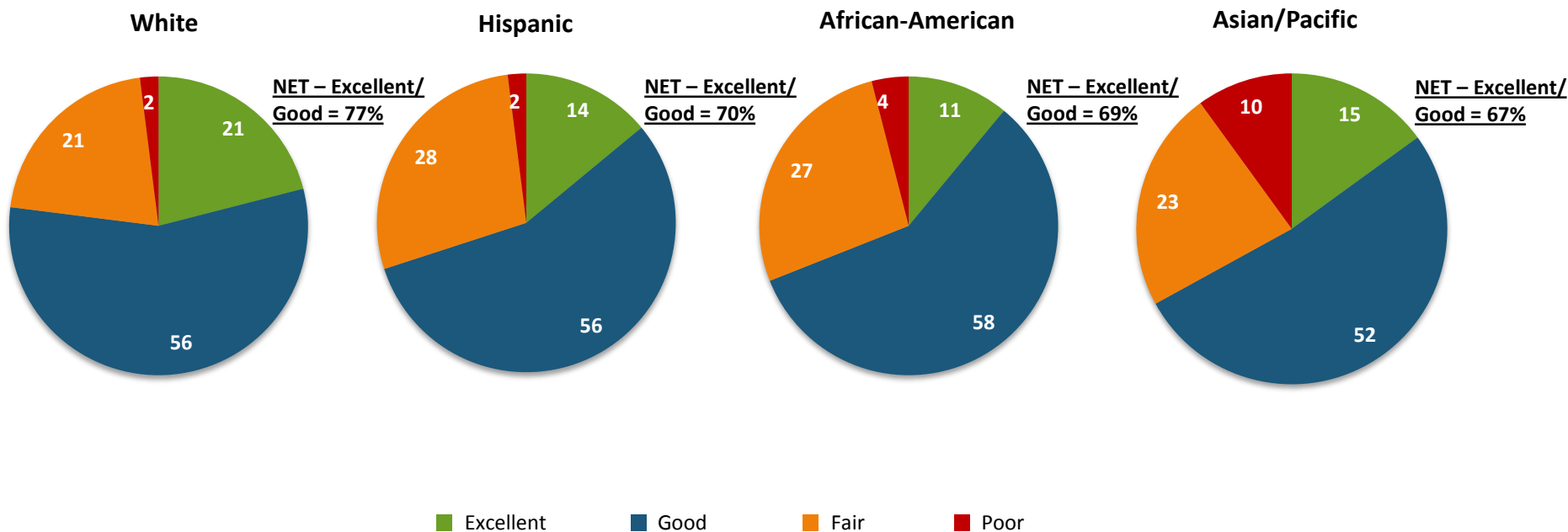


*Note: The median is estimated based on the approximate midpoint of the range of each response category. Non-responses are excluded from the estimate.*

# Caregivers' Self-Described General Health

The majority of caregivers across ethnicities self-describe their general health as excellent or good, including 77 percent of White, 70 percent of Hispanic, 69 percent of African-American, and 67 percent of Asian/Pacific Islander caregivers. White caregivers (21 percent) are more likely to self-describe their health as excellent compared to other ethnicities. Asian/Pacific Islander caregivers (10 percent) are more likely than other ethnicities to self-describe their general health as poor.

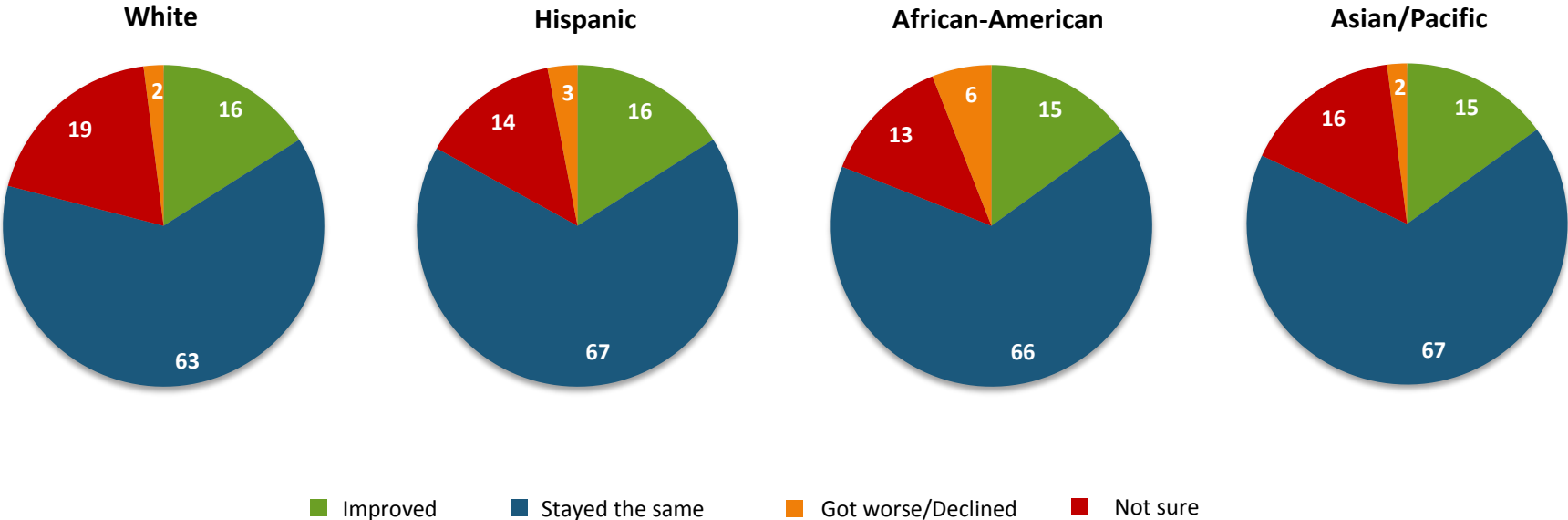
General Health Status (%)



# Changes in General Health Since Becoming a Caregiver

Approximately two-thirds of caregivers indicate that their general health has stayed the same since becoming a caregiver, including 67 percent of both Hispanic and Asian/Pacific Islander caregivers, 66 percent of African-American caregivers, and 63 percent of White caregivers. Caregivers across ethnicities are also similarly likely to indicate their general health has declined, including 19 percent of White, 16 percent of Asian/Pacific Islander, 14 percent of Hispanic, and 13 percent of African-American caregivers.

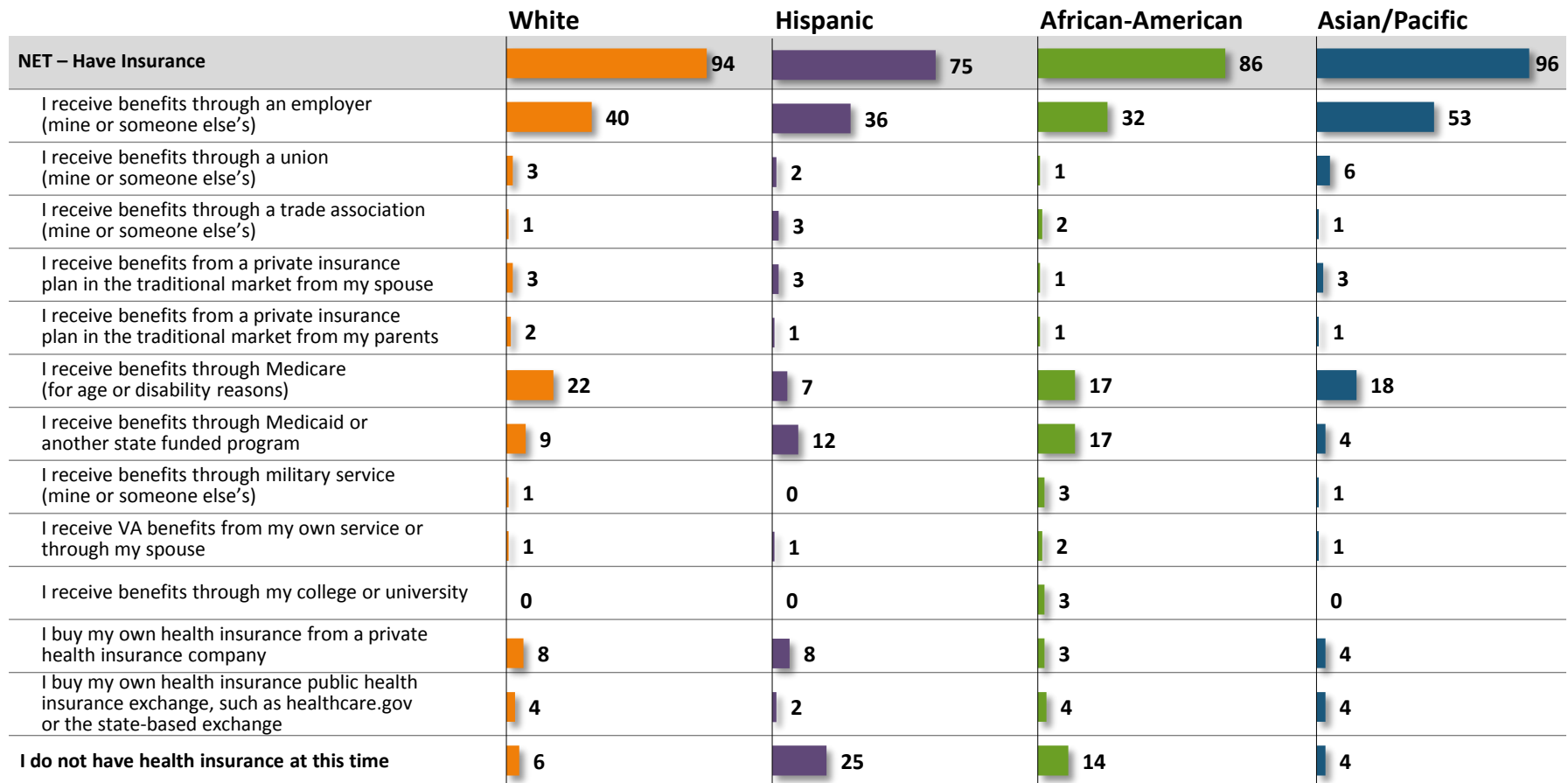
Changes in General Health Since Becoming a Caregiver (%)



# Caregivers' Health Insurance

While the vast majority of caregivers have health insurance, Asian/Pacific Islander (96 percent) and White caregivers (94 percent) are more likely to have insurance compared to African-American (86 percent) and Hispanic caregivers (75 percent). Across ethnicities, caregivers most frequently receive benefits through an employer.

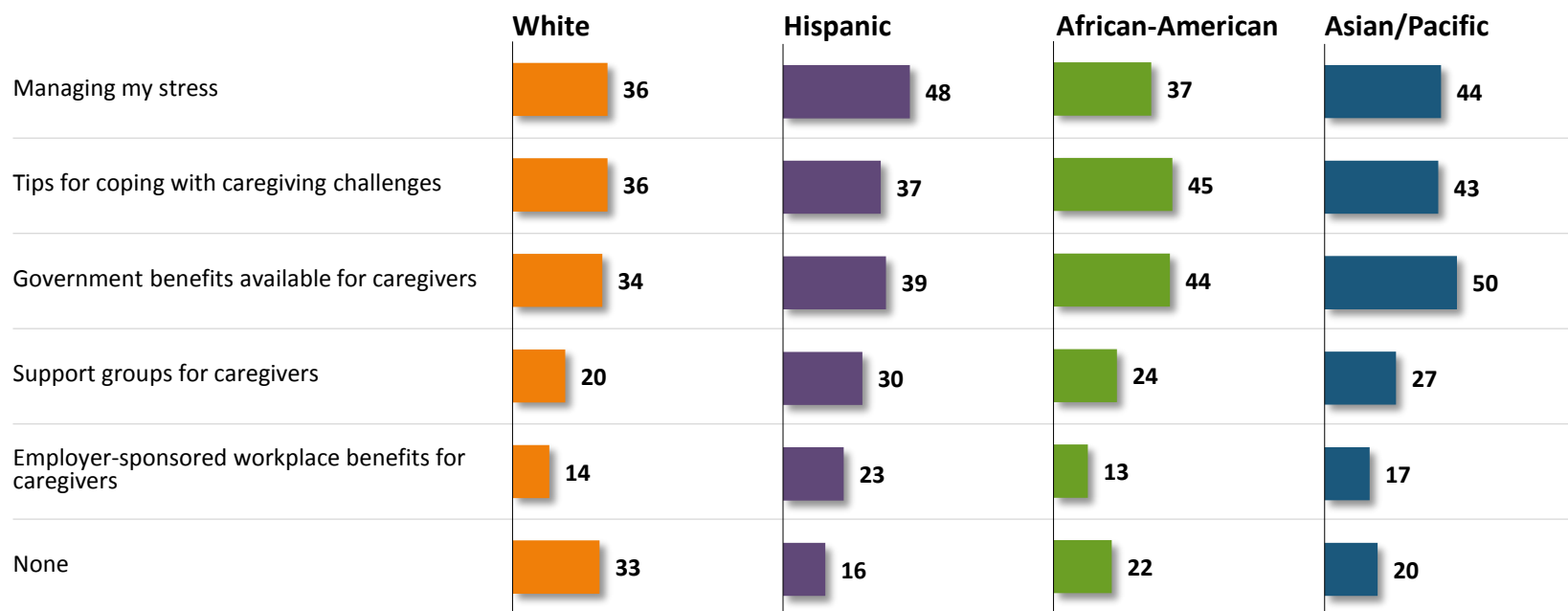
**“Which of the following best describes how you primarily receive health insurance?” (%)**



# Caregivers Would Like More Information to Help Them Personally

Across ethnicities, approximately four in 10 caregivers would like more information about stress management, tips for coping with caregiving challenges, and government benefits available for caregivers. Hispanic (30 percent) and Asian/Pacific Islander caregivers (27 percent) are slightly more likely than African-American (24 percent) and White caregivers (20 percent) to want information about support groups for caregivers. Hispanic caregivers (23 percent) are slightly more likely than other ethnicities to want information about employer-sponsored workplace benefits for caregivers.

**“Which of the following topics would you like more information to help you personally with your caregiving responsibilities?” (%)**



NOTE: Five most commonly selected sources shown.

BASE: ALL QUALIFIED RESPONDENTS

Q850. Which of the following topics would you like more information to help you personally with your caregiving responsibilities? I would like more information about... Select all.



## Appendix

# ***The Many Faces of Family Caregivers: A Close-Up Look at Caregiving and Its Implications***

## **A Portrait of Today's Caregivers**

### **Demographic Perspectives**

- Voluntary Status
- Employment Status
- Generations
- Gender
- Household Income
- Race/Ethnicity

➤ ***Appendix: Caregiver and Care Recipient Demographics***

## **Acknowledgements**



# Caregiver Demographics

Gender	%
Male	47
Female	53
Other	0

Age	
18-24	6
25-34	20
35-44	18
45-54	18
55-64	20
65+	18
MEAN	48
MEDIAN	48

Race/Ethnicity	
White	72
Black/African-American	7
Hispanic	15
Asian/Pacific Islander	4
Other	1
Decline to answer	1

Education	
High school or less	19
Attended/ college degree	52
Attended/grad degree	23
Job specific training	6

Urbanicity	
Urban	39
Suburban	37
Small town/Rural	24

Marital Status	%
Never married	23
Married or civil union	56
Divorced/Separated	13
Widow/Widower	4
Living with partner	4

Sexual Orientation	
Heterosexual	93
Lesbian	1
Gay	2
Bisexual	3
Other	1
Decline to answer	-

Employment Status	%
Full time	38
Part time	13
Self employed	9
Leave of Absence	0
Retired	19
Student	3
Unemployed/Not working (Net)	11
Homemaker	7

Employer Size	
Less than 10	9
10-24	6
25-49	7
50-99	14
100-499	21
500-999	15
1000 or More	28

Small Business Size	
1	-
2	17
3	11
4	8
5	18
6	11
7	9
8	13
9	13
MEAN	5.4
MEDIAN	5

BASE: ALL QUALIFIED RESPONDENTS

Q268. Gender, Q280. Age, Q485. Race/Ethnicity, Q434. Education, Q1250. Urbanicity, Q364. Marital Status, Q498. Sexual Orientation, Q1000. Employment Status, Q1005. Employer Size, Q1010. Small Business Size



# Care Recipient Demographics

Gender	%
Male	44
Female	56
Other	0

Age	
<18	11
18-29	5
30-39	5
40-49	4
50-59	8
60-69	14
70-79	20
80-89	22
90-99	8
100+	1
Not sure	2
MEAN	63.3
MEDIAN	79

Race/Ethnicity*	
White	74
Black/African-American	8
Hispanic	13
Other	4
Decline to answer	1

Urbanicity	
Urban	39
Suburban	37
Small town/Rural	24

Marital Status	%
Married or civil union	46
Never married	15
Divorced/Separated	13
Widow/Widower	23
Living with partner	3
Don't know	0

Sexual Orientation	
Heterosexual	93
Lesbian	0
Gay	1
Bisexual	1
Other	0
Not sure	4
Decline to answer	1

Type of Dwelling	
Single Family	72
Multi-Unit Condo/Apt	13
Independent Community	3
Assisted Living Facility	3
Skilled Nursing Facility	3
Life-Care Community	1
Group Home	2
Other	3

Health Insurance	%
Major Medical	75
Life	26
Dental	26
Vision	24
Disability	15
Long-term care	11
Critical illness	6
Cancer	4
Other	3
Don't know	7
No Health Insurance	3

Types of Major Medical	%
Medicare	69
Private insurance through employer/spouse's employer/former employer	28
Medicaid	21
Private insurance purchased through the individual insurance market	14
Medigap	6
VA Care	6
Medicare Savings Program (MSP)	5
Armed Services Tricare	4
A plan through a Health Insurance Exchange	2
Other	3
I don't know	3

\*Please note: Asian/Pacific Islander was not a specific response for care recipient race/ethnicity

BASE: ALL QUALIFIED RESPONDENTS

Q703. Gender, Q702. Age, Q1210. Race/Ethnicity, Q1220. Urbanicity, Q1200. Marital Status, Q1215. Sexual Orientation, Q1225. Type of Dwelling, Q735. Health Insurance, Q740. Types of Major Medical

# Conditions Affecting Care Recipients

## Conditions (%)

ALL CONDITIONS	%
<b>PHYSICAL HEALTH (NET)</b>	<b>71%</b>
Arthritis	26
High blood pressure	22
Diabetes	18
Heart disease	14
Cancer	12
Immobility	11
Incontinence	11
Deafness/Hearing impairment	10
Blindness/Vision impairment	7
Chronic respiratory diseases	7
Stroke	7
Major injury	6
Lung disease/Emphysema/COPD	6
Kidney diseases	5
Paralysis	2
Chronic liver disease and Cirrhosis	1
<b>HIV/AIDS</b>	<b>1</b>

ALL CONDITIONS	%
<b>NEUROLOGICAL (NET)</b>	<b>35%</b>
<b>ALZHEIMER'S/ DEMENTIA (SUB-NET)</b>	<b>25%</b>
Dementia/Memory loss	16
Alzheimer's	12
Developmental disabilities	3
Epilepsy/Seizures	3
Communication disorder	3
Parkinson's Disease	2
Multiple sclerosis	2
Cerebral Palsy	1
<b>MENTAL HEALTH (NET)</b>	<b>27%</b>
Depression	16
Anxiety	14
Bipolar	5
Autism spectrum disorder	4
<b>Surgery/Post surgery</b>	<b>2</b>
<b>Age</b>	<b>1</b>
<b>Back problems</b>	<b>1</b>
<b>Broken bones/Fractures</b>	<b>1</b>
<b>Cold/Flu/Fever/Cough</b>	<b>1</b>
<b>GI/Bowel conditions</b>	<b>1</b>
<b>Pain/Chronic pain</b>	<b>1</b>
<b>Replacements</b>	<b>1</b>

Only responses selected by 1% or more shown

BASE: ALL QUALIFIED RESPONDENTS

Q725. Which of the following condition(s) apply to the care recipient? Please select all that apply.

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