



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

Primary vs. Non-Primary

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Welcome to the Inaugural Transamerica Caregivers Survey

Welcome to this compendium of insights and findings from the Inaugural *Transamerica Institute Survey on Caregiving in the United States*

This report is an exploration of the nature of non-professional family caregiving in the U.S., offering portraits of caregivers and care recipients as well as perspectives on caregiving responsibilities and the impact caregiving has on caregivers' health, finances and well-being.

It is comprised of these chapters:

- *Primary vs. Non-Primary.* This chapter contains a portrait of today's caregivers based 26 key indicators measuring caregiving's impacts on both the caregiver and care recipient.
- *Influences of Demographics on Caregiving.* These chapters are demographic segmentation analyses by voluntary status, employment status, gender, generations, household income, and ethnicity.

Each chapter presents a concise set of 26 key measures for each demographic segment.

We hope that you find this compendium to be a helpful source of caregiving research and survey data.

If you are seeking survey data that you do not find in this report, please contact Transamerica Institute at info@transamericacenter.org and we will do our best to assist you.

Thank you.

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.

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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
- The Health Effects of Being a Caregiver
- Ways to Help Caregivers with Their Responsibilities

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 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 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



A Portrait of Today's Caregivers: Primary vs. Non-Primary

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

Executive Summary

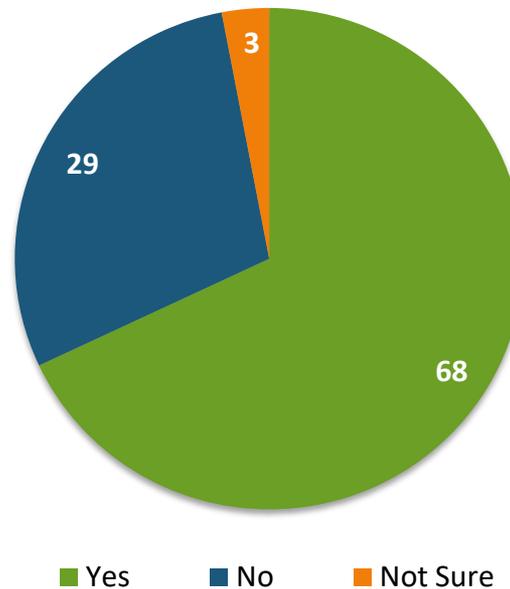
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- Ways to Help Caregivers with Their Responsibilities

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?” (%)

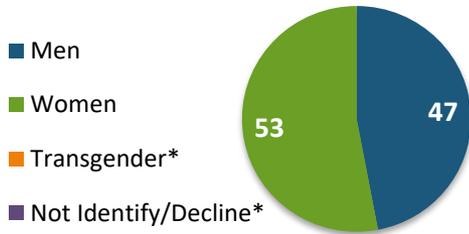


A Portrait of Caregivers

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-two percent are employed either full-time or part-time. Caregivers' household income is \$57,000 (estimated median).



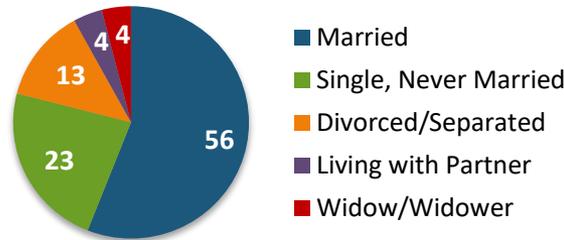
GENDER



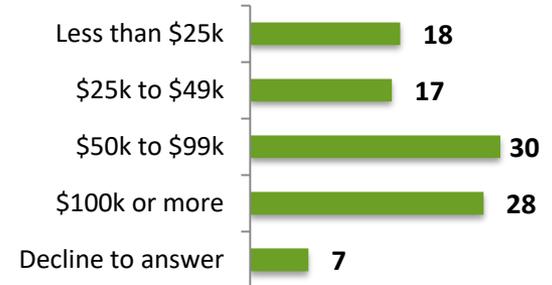
*Note: Sample size for Transgender and Not Identify/Decline too small to report



MARITAL STATUS



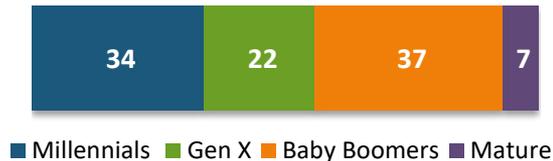
HOUSEHOLD INCOME



Estimated Median: \$ 57,000



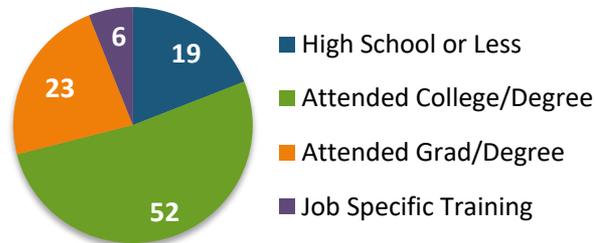
GENERATION



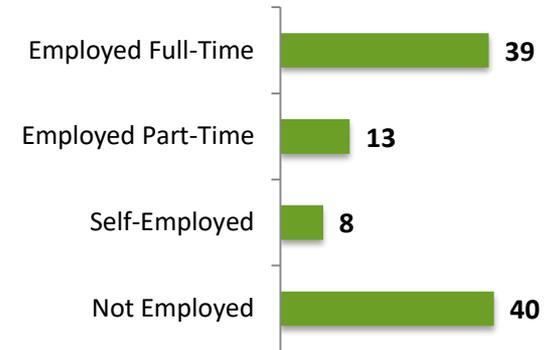
Median Age: 48



EDUCATION



EMPLOYMENT



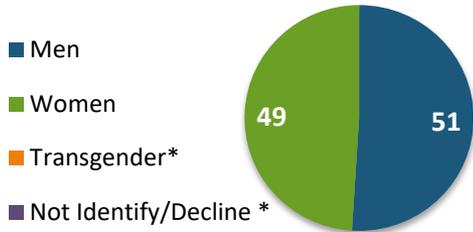
A Portrait of Primary Caregivers

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 (%)



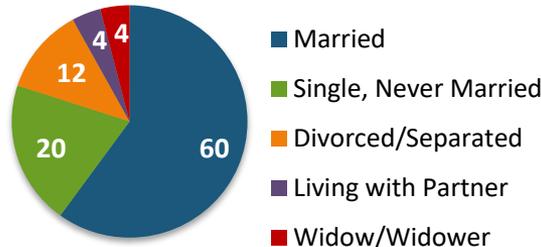
GENDER



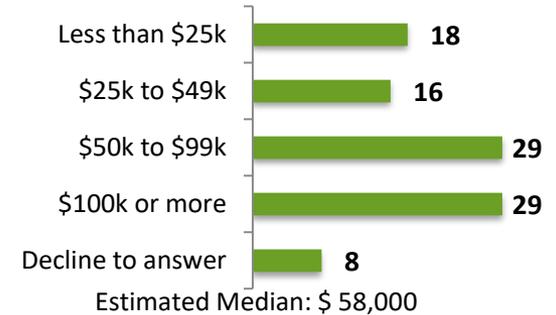
*Note: Sample size for Transgender and Not Identify/Decline too small to report



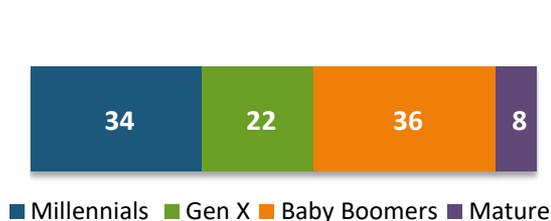
MARITAL STATUS



HOUSEHOLD INCOME



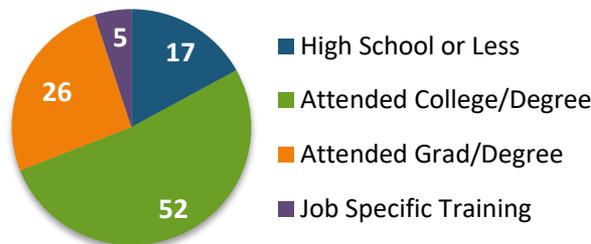
GENERATION



Median Age: 47



EDUCATION



EMPLOYMENT



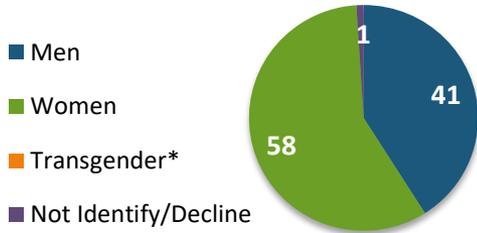
A Portrait of Non-Primary Caregivers

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 (%)



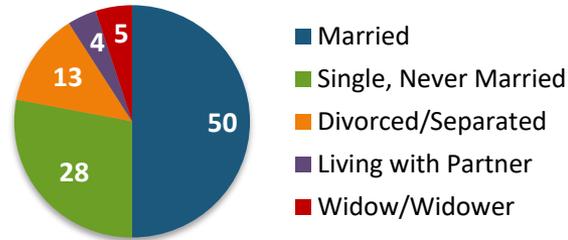
GENDER



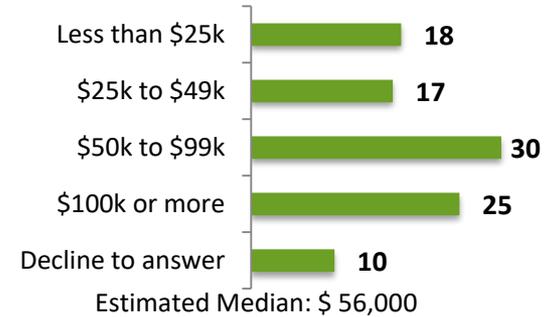
*Note: Sample size for Transgender too small to report



MARITAL STATUS



HOUSEHOLD INCOME



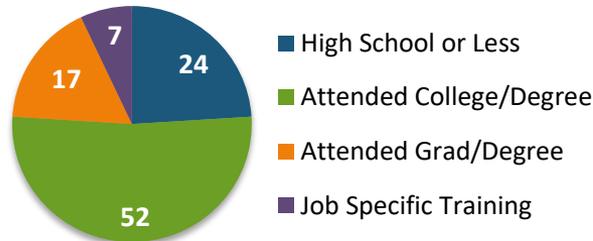
GENERATION



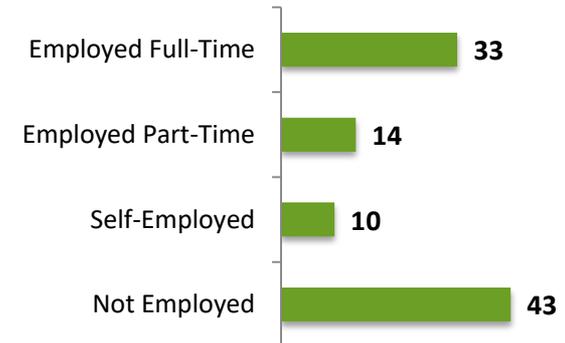
Median Age: 49



EDUCATION



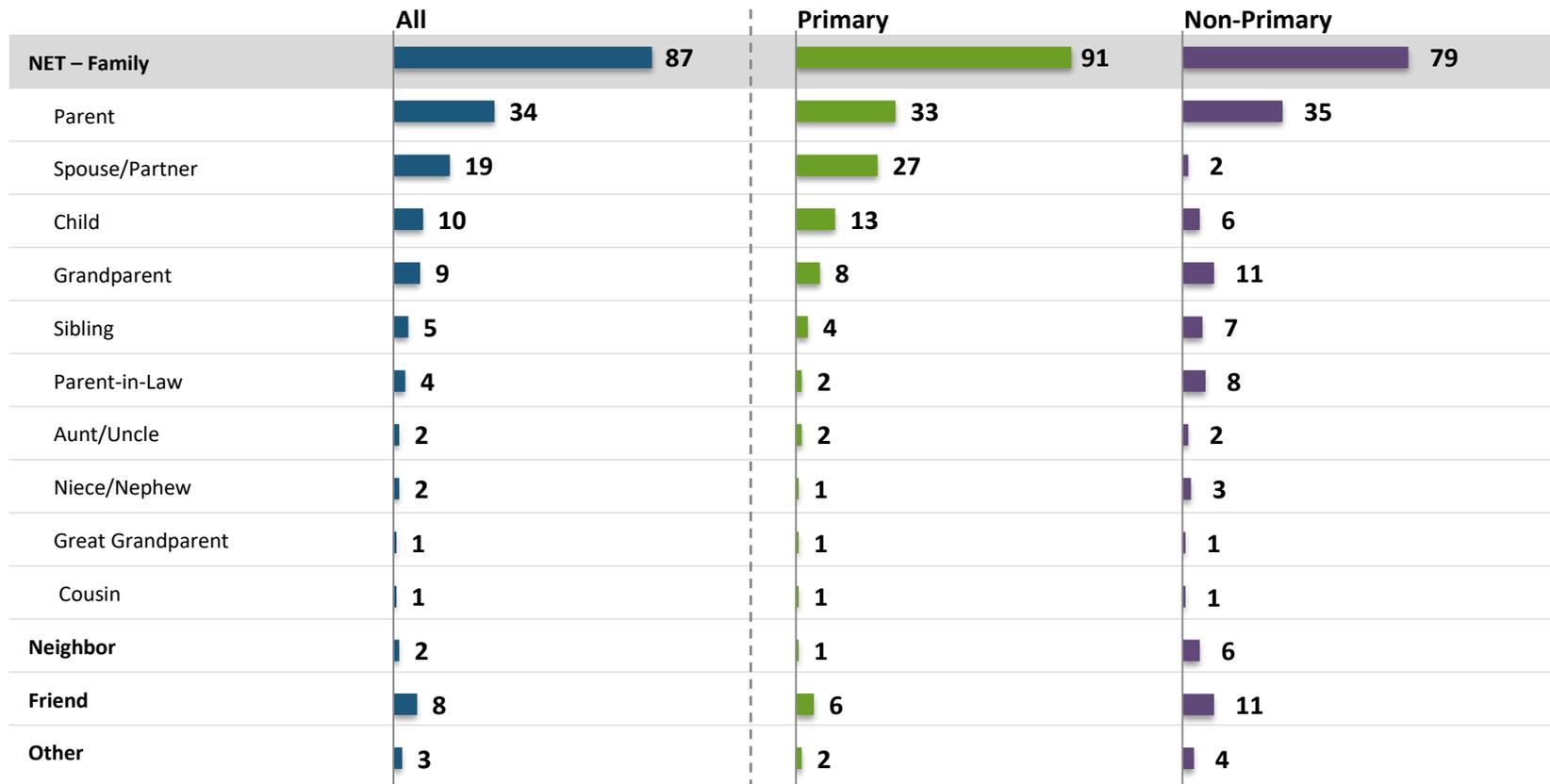
EMPLOYMENT



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).

Relationship to Care Recipient (%)



BASE: ALL QUALIFIED RESPONDENTS

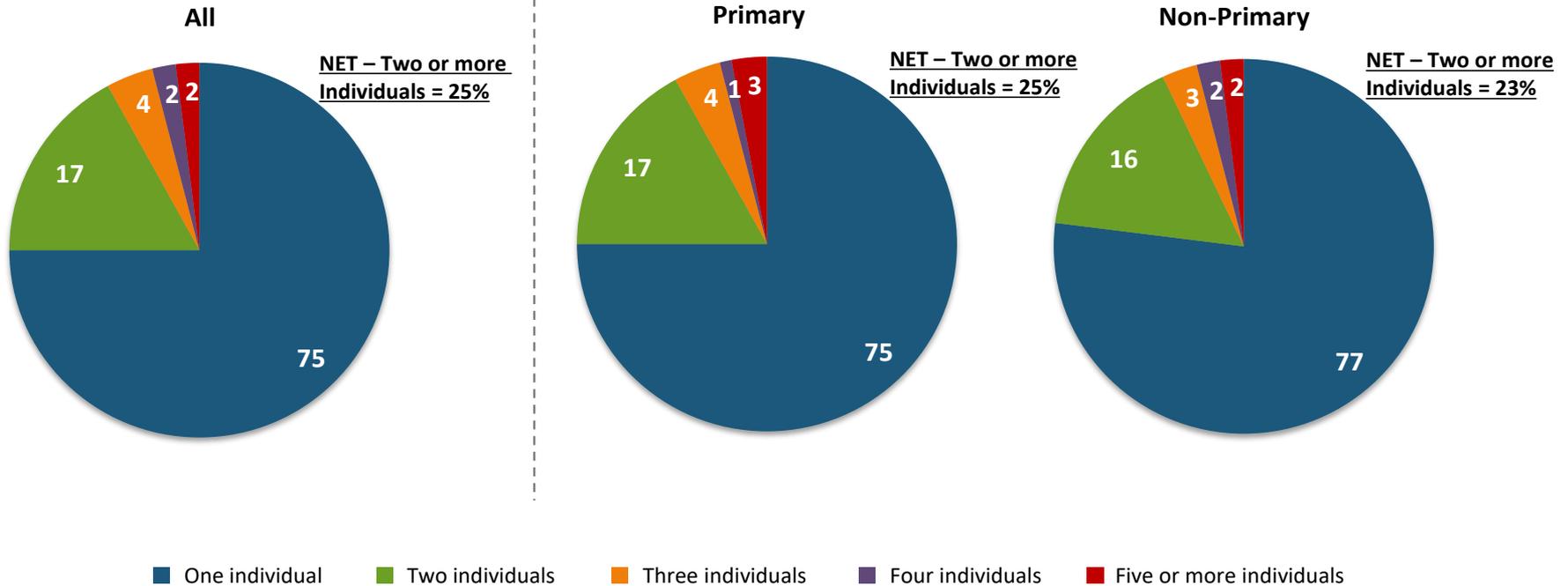
Q700. You mentioned providing care for [INSERT ANSWER FROM Q610] individual(s).

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

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.

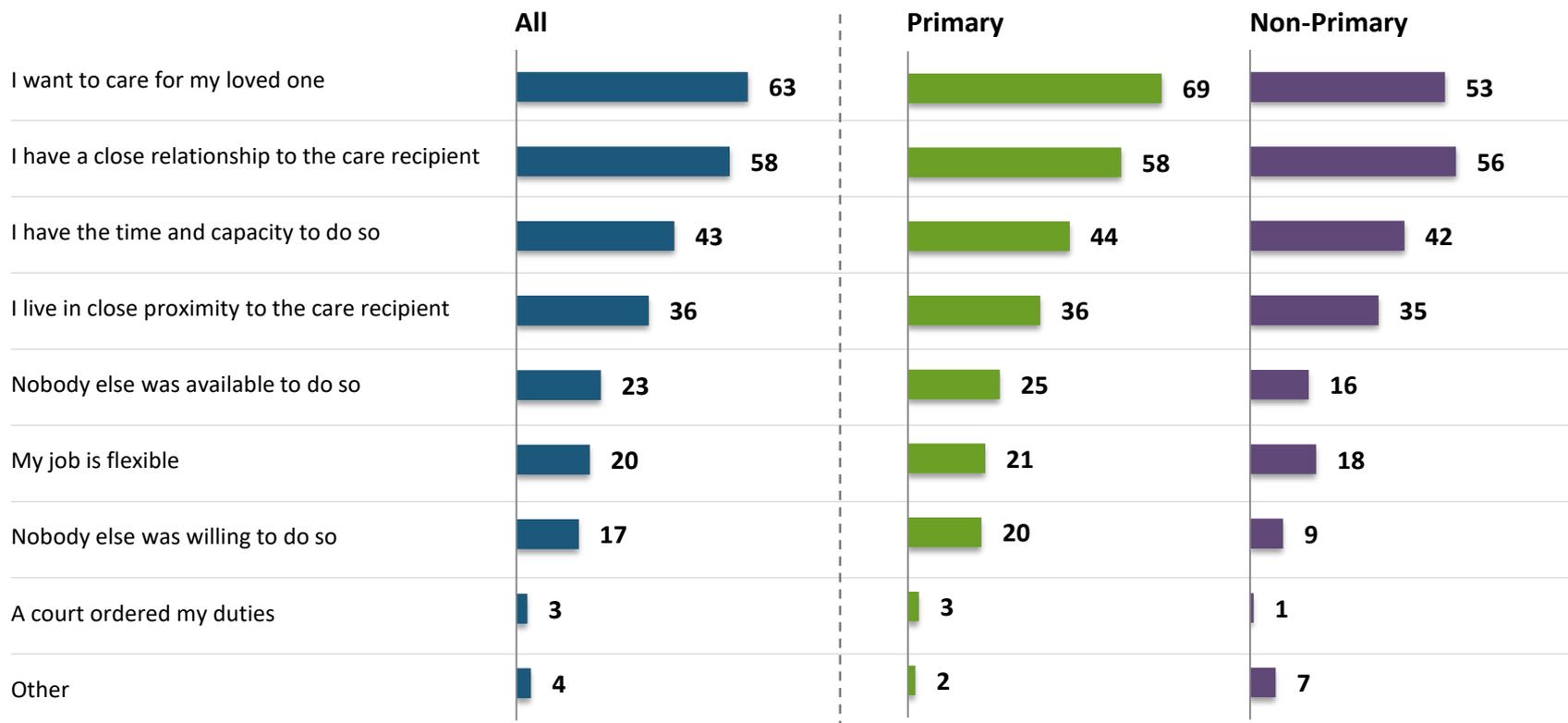
Number of Individuals Cared for in the Past 12 Months (%)



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, respectively) or that nobody else was willing to do so (20 percent vs. 9 percent respectively).

Reasons for Becoming a Caregiver (%)



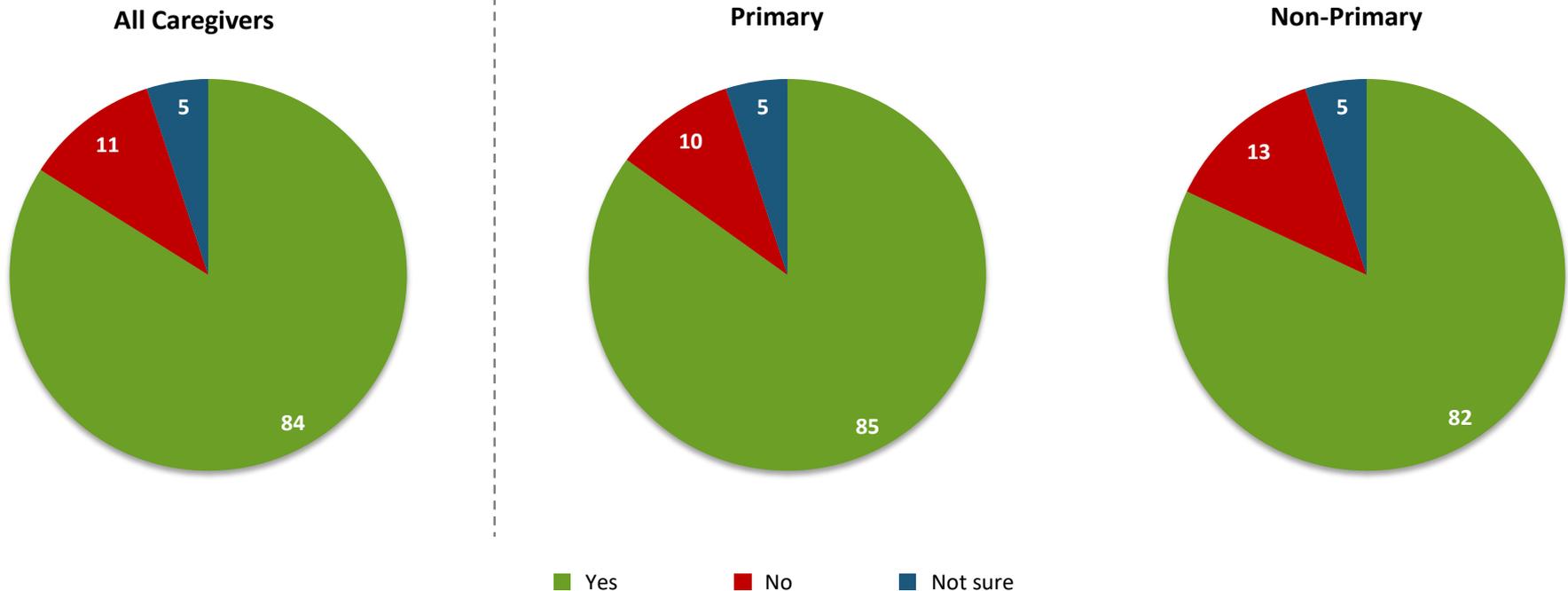
BASE: ALL QUALIFIED RESPONDENTS

Q815. How did you come to be a caregiver? Please select all that apply.

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.”

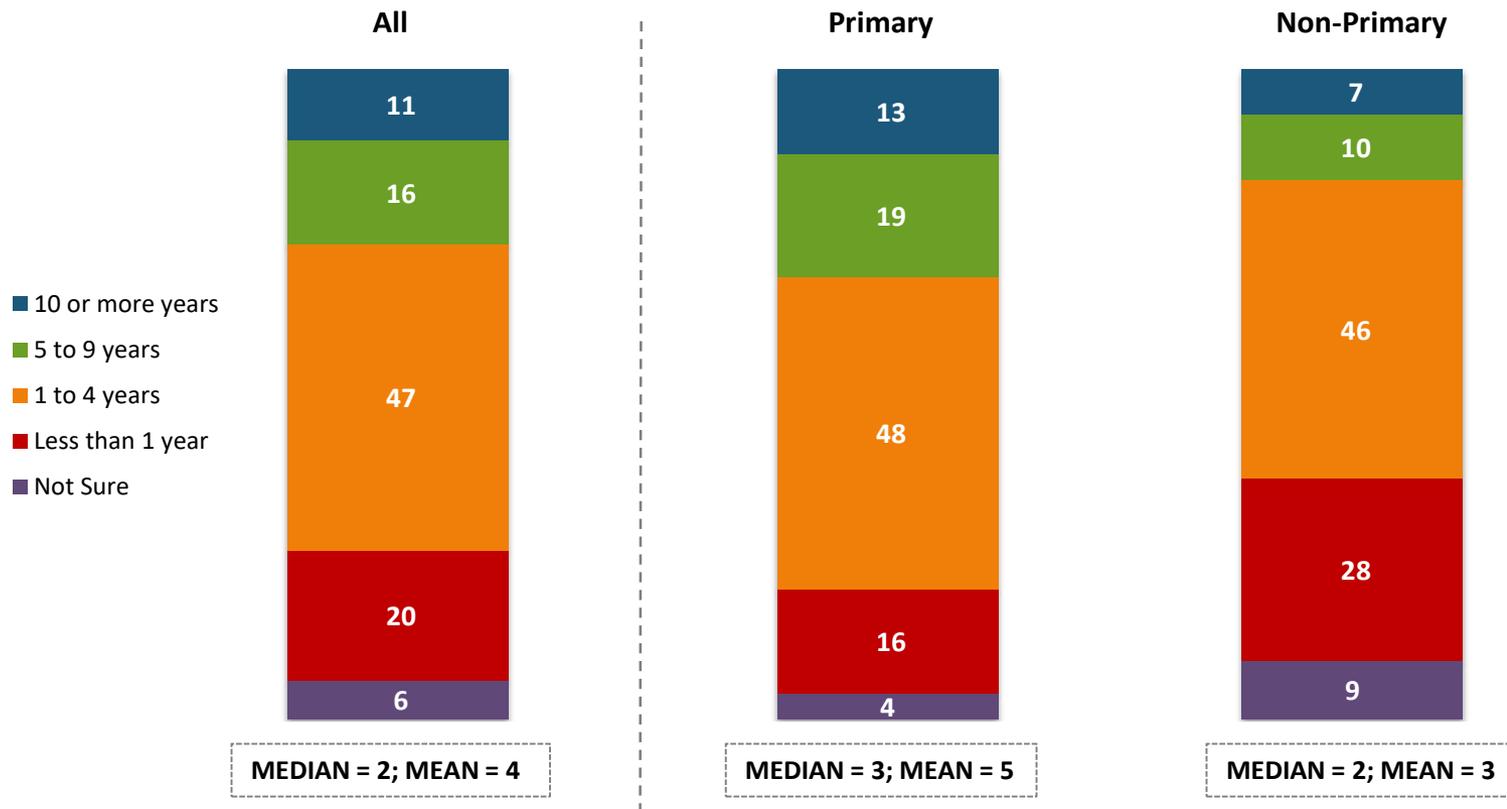
“Do you feel that you became a caregiver voluntarily?” (%)



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.

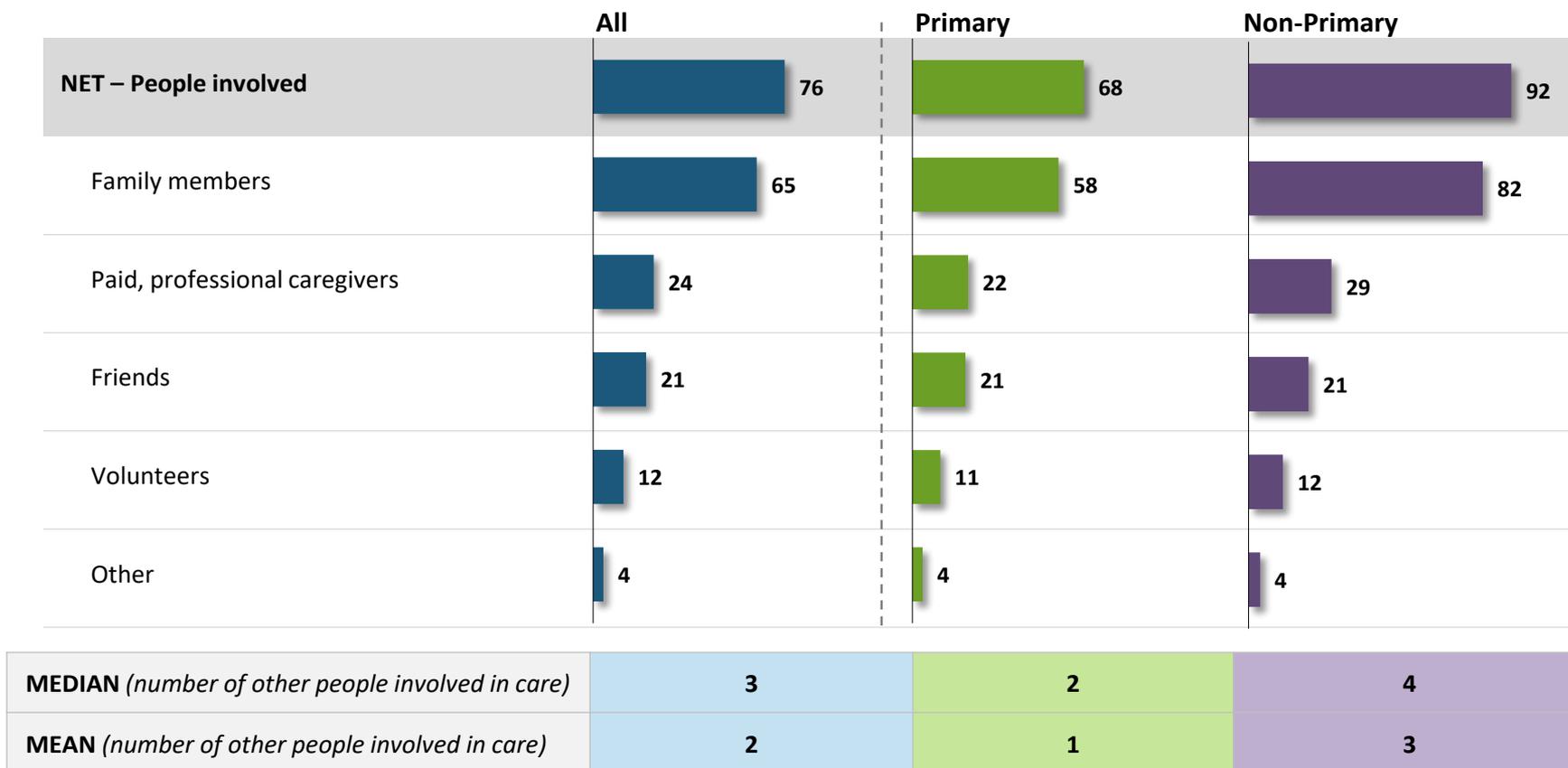
Duration of Time as a Caregiver (%)



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 (%)



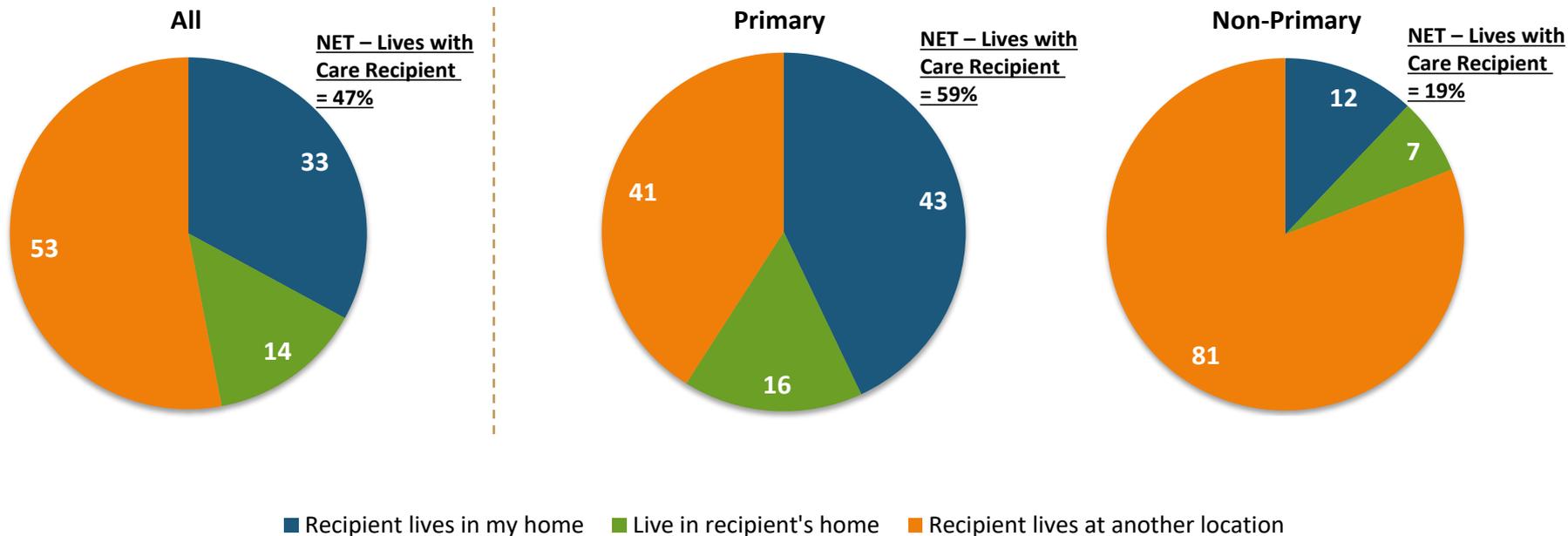
BASE: ALL QUALIFIED RESPONDENTS

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.

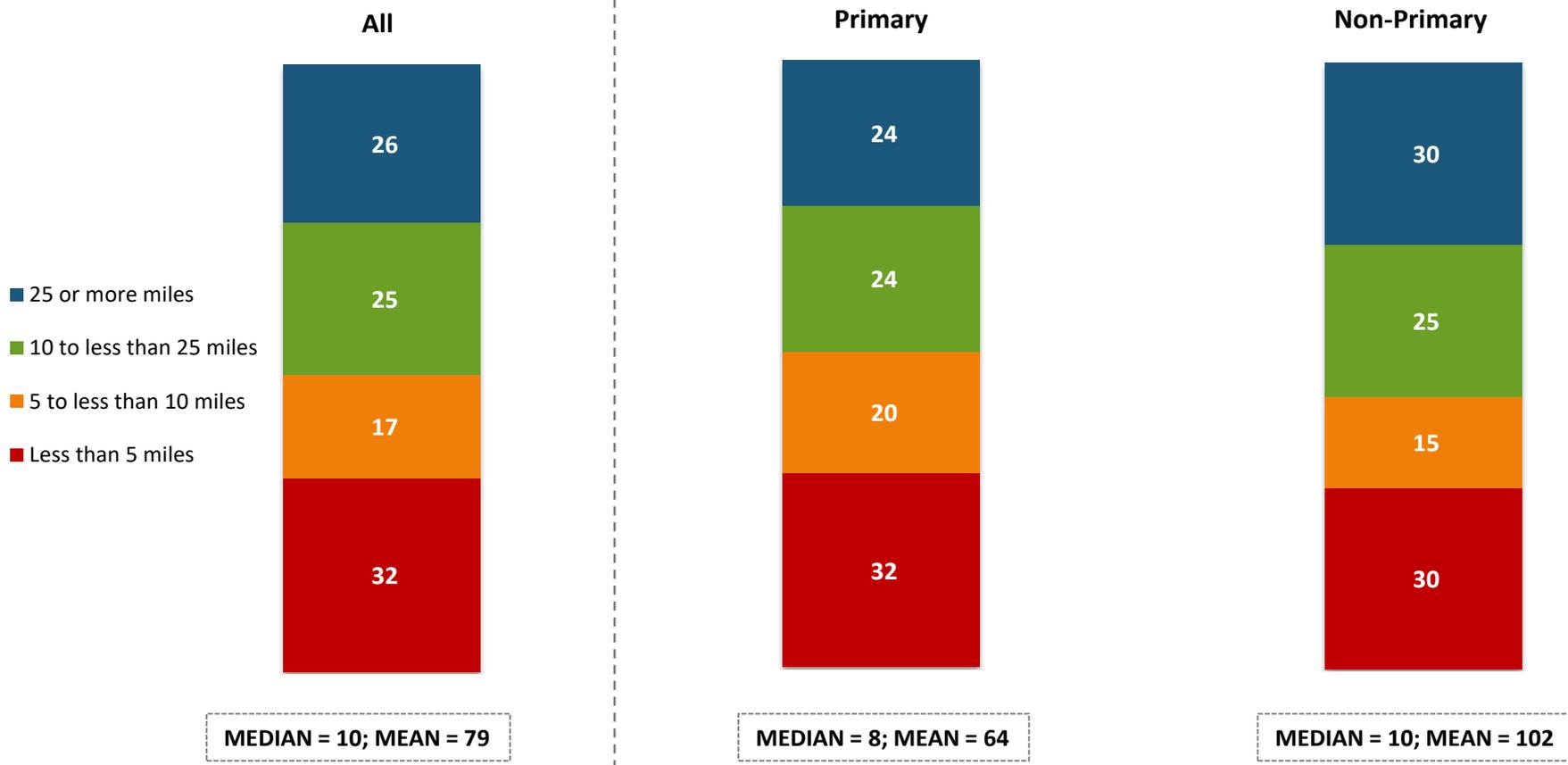
Where Care Recipients Live (%)



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.

Distance to Care Recipient (%)



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

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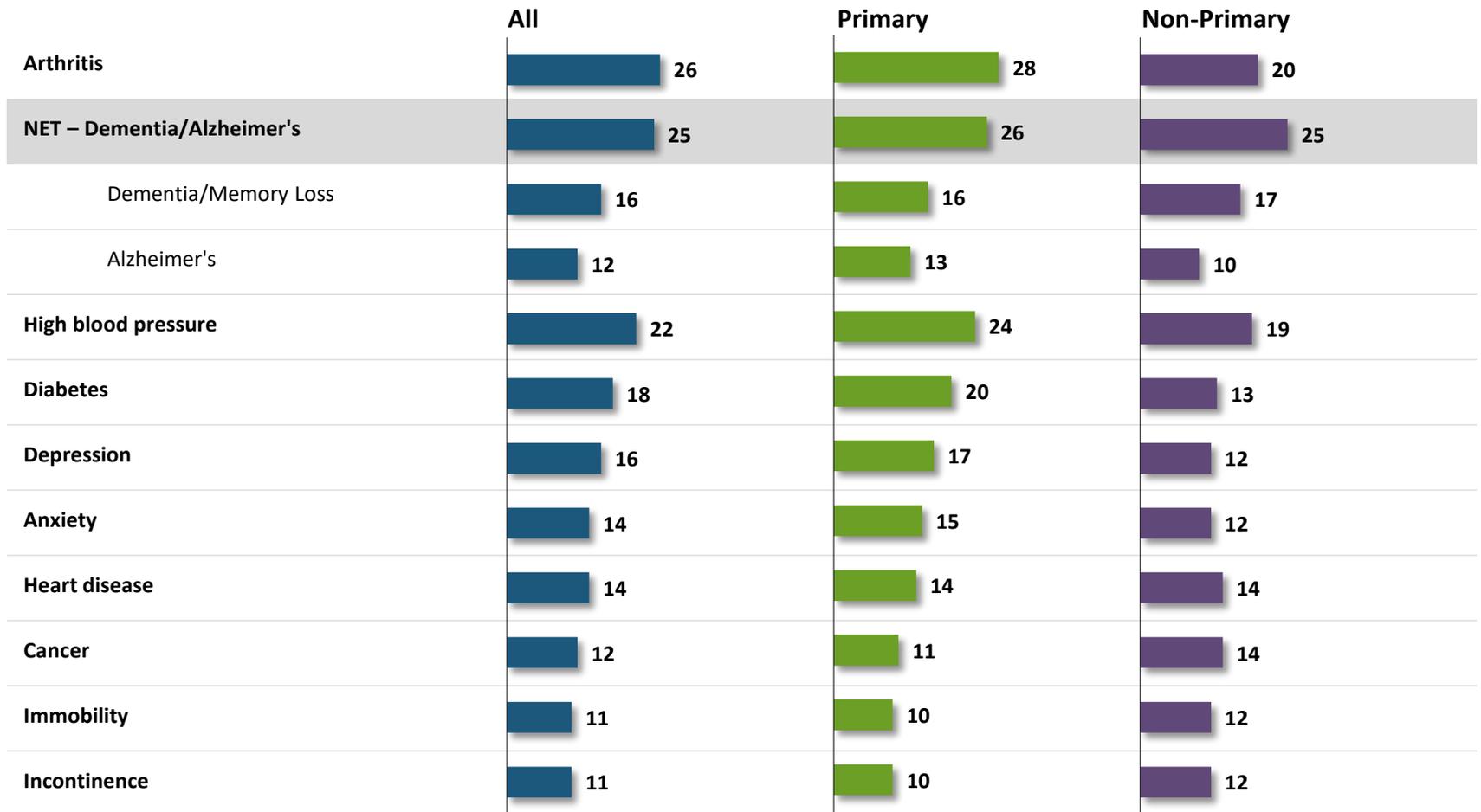
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Care Recipients Have a Range of Conditions

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.

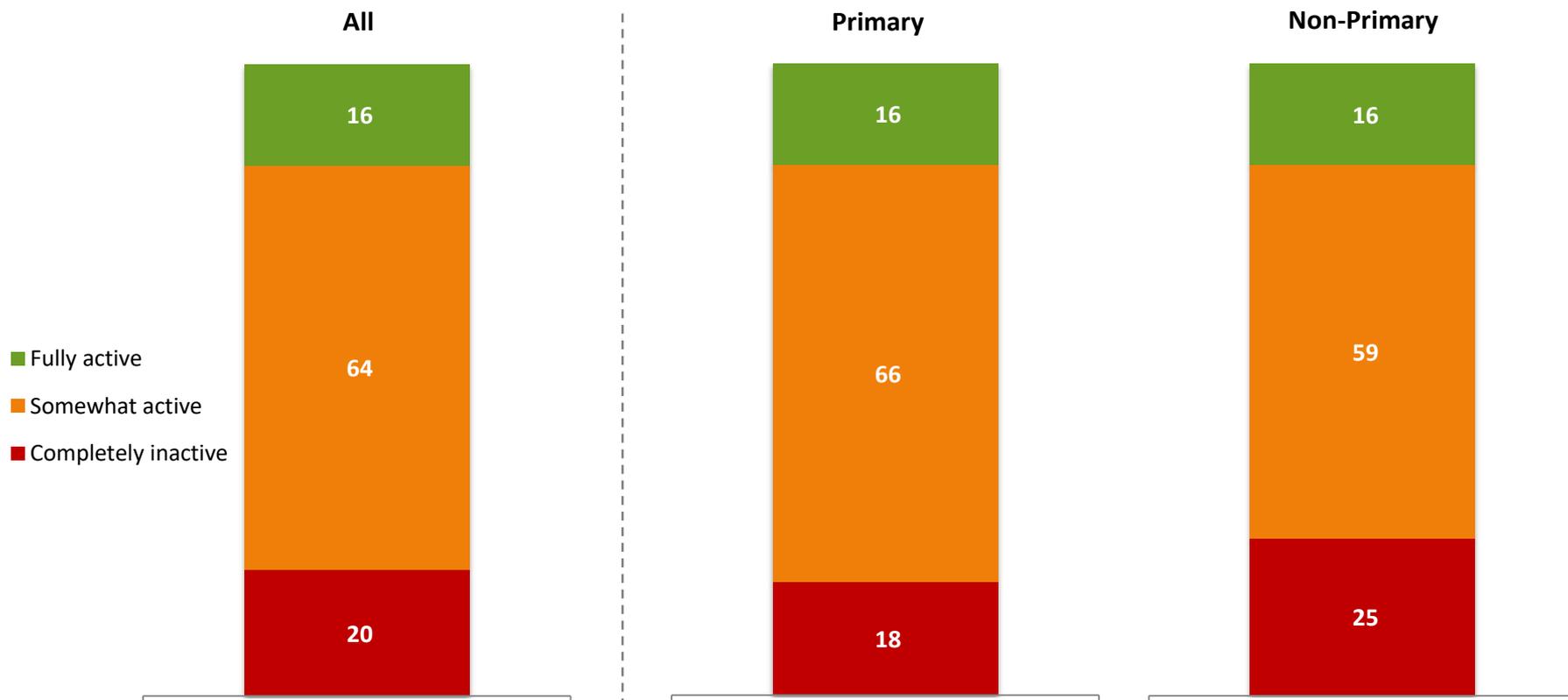
Top 10 Most Frequently Cited Conditions of Care Recipient (%)



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 (%)



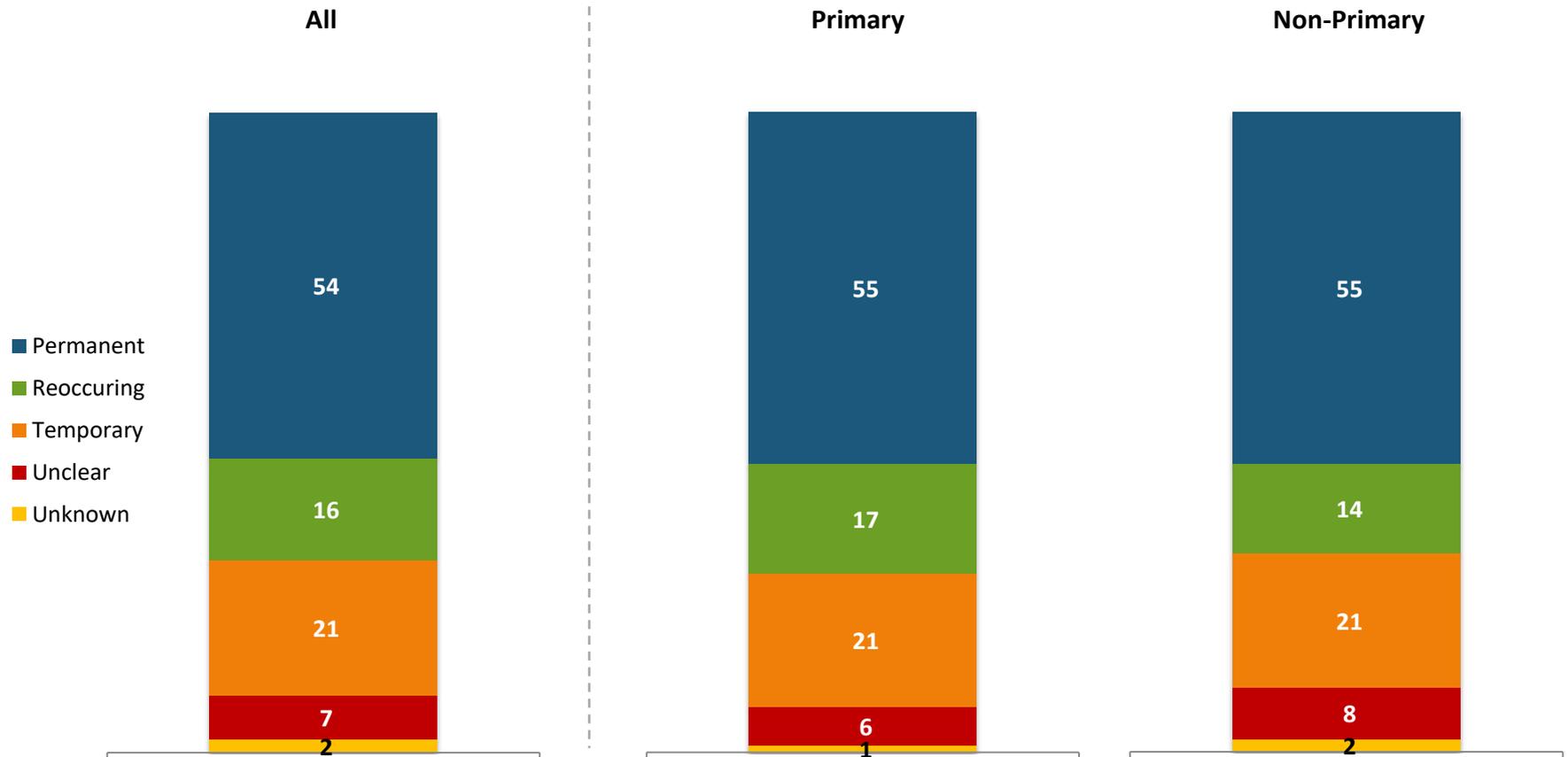
BASE: ALL QUALIFIED RESPONDENTS

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.

Condition of the Care Recipient (%)



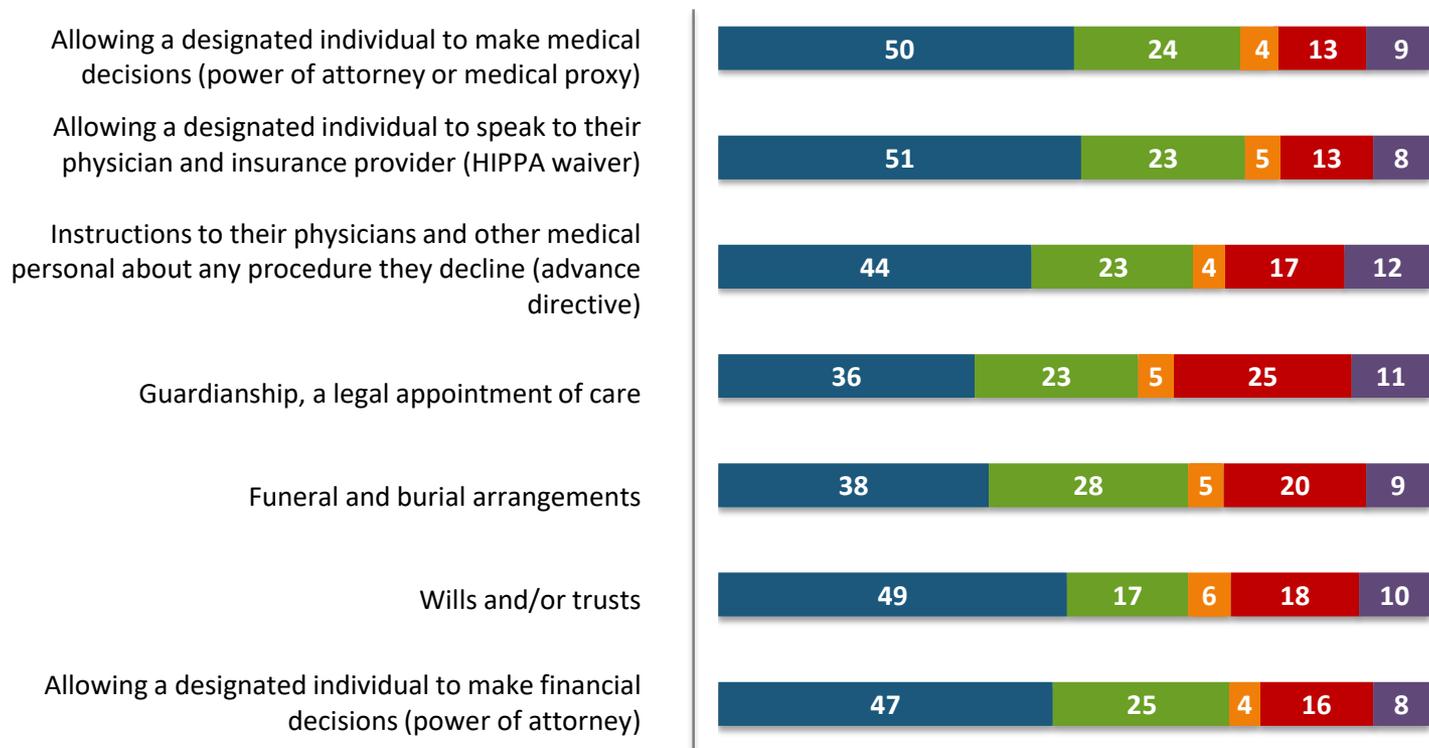
BASE: ALL QUALIFIED RESPONDENTS

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 (%)

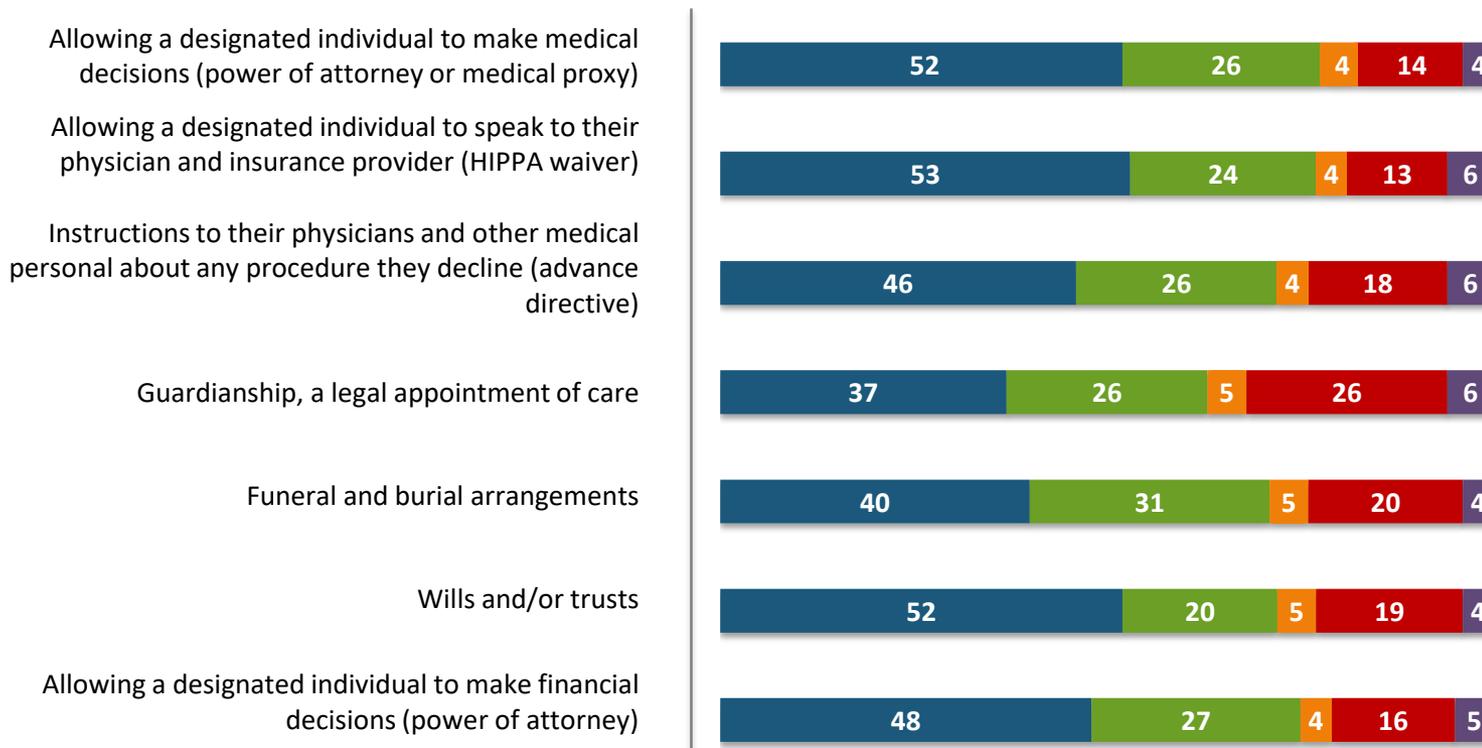


■ Discussed and written ■ Discussed but not written ■ Not discussed, but written ■ Not discussed and not written ■ Don't Know

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 (%)

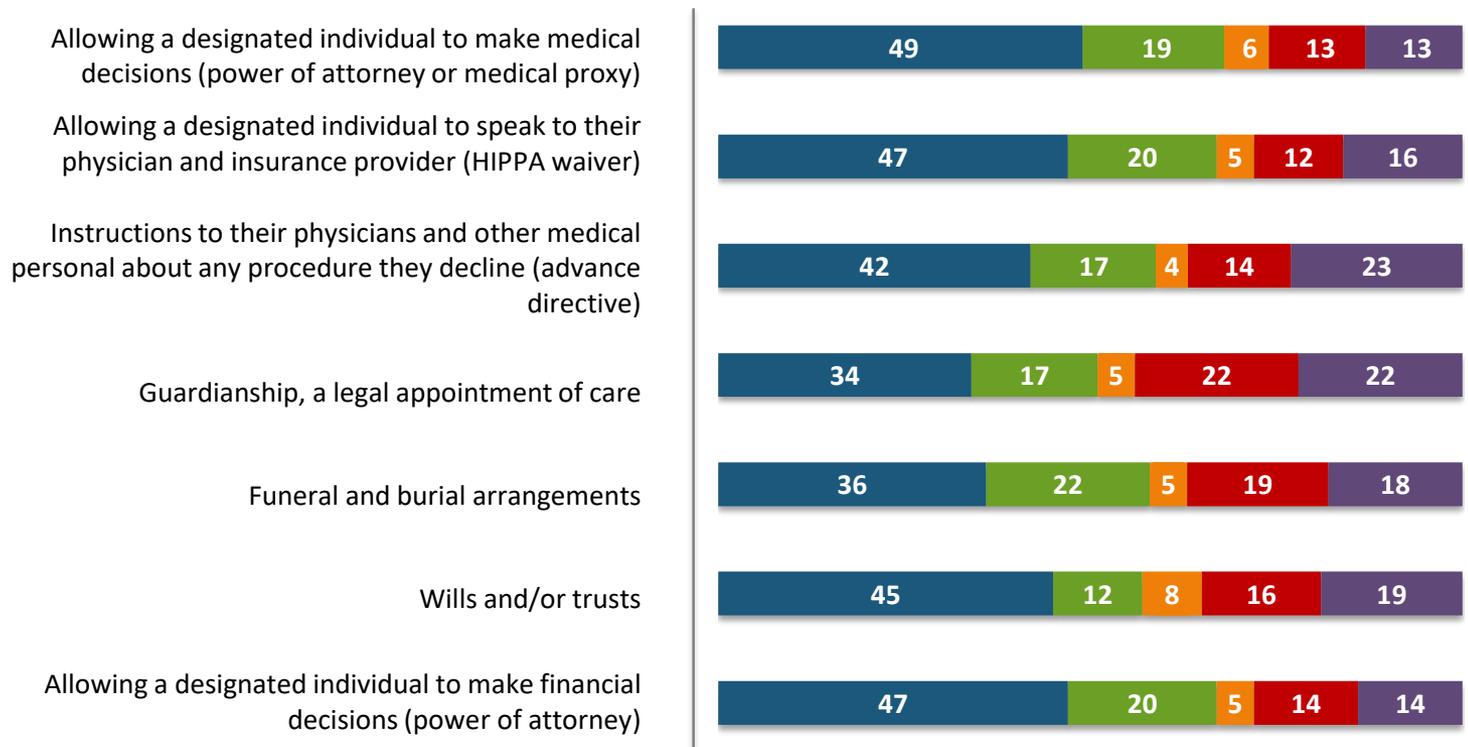


■ Discussed and written ■ Discussed but not written ■ Not discussed, but written ■ Not discussed and not written ■ Don't Know

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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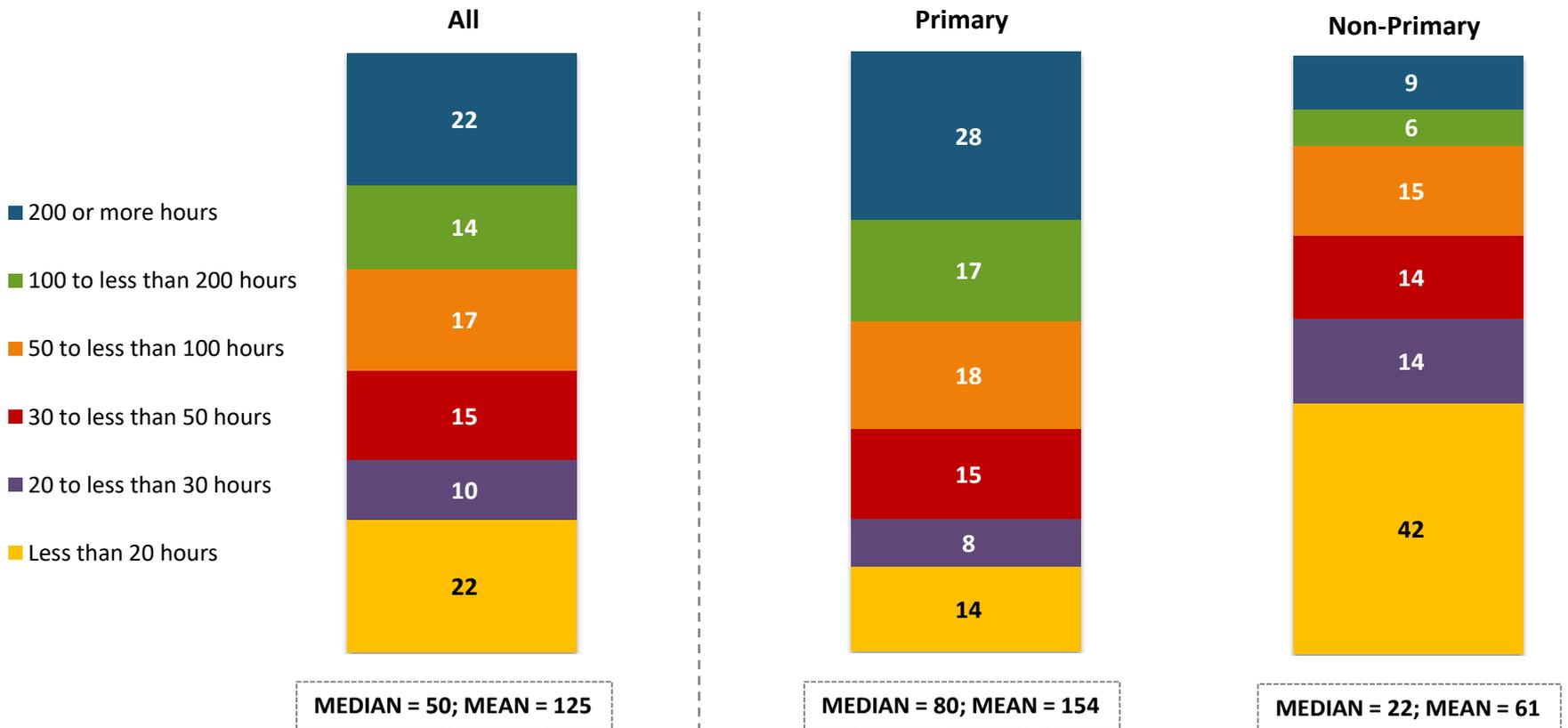
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Caregiving Is a Full-Time Job for Many

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

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.

Time Spent On Caregiving Duties Each Month (hours per month)	All		Primary		Non-Primary	
	Median	Mean	Median	Mean	Median	Mean
Household						
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
Social/Communication						
Companionship	33	92	50	114	16	42
Basic communications	10	46	12	52	6	23
Language translation	5	15	5	14	4	17
Health-Related						
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
Personal Care						
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
Medical-Related						
Medication management	5	16	5	17	4	10
Medical treatment administration	5	18	5	18	3	11
Paying bills/Managing finances	3	9	4	10	2	4
Other	5	63	8	50	5	83

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

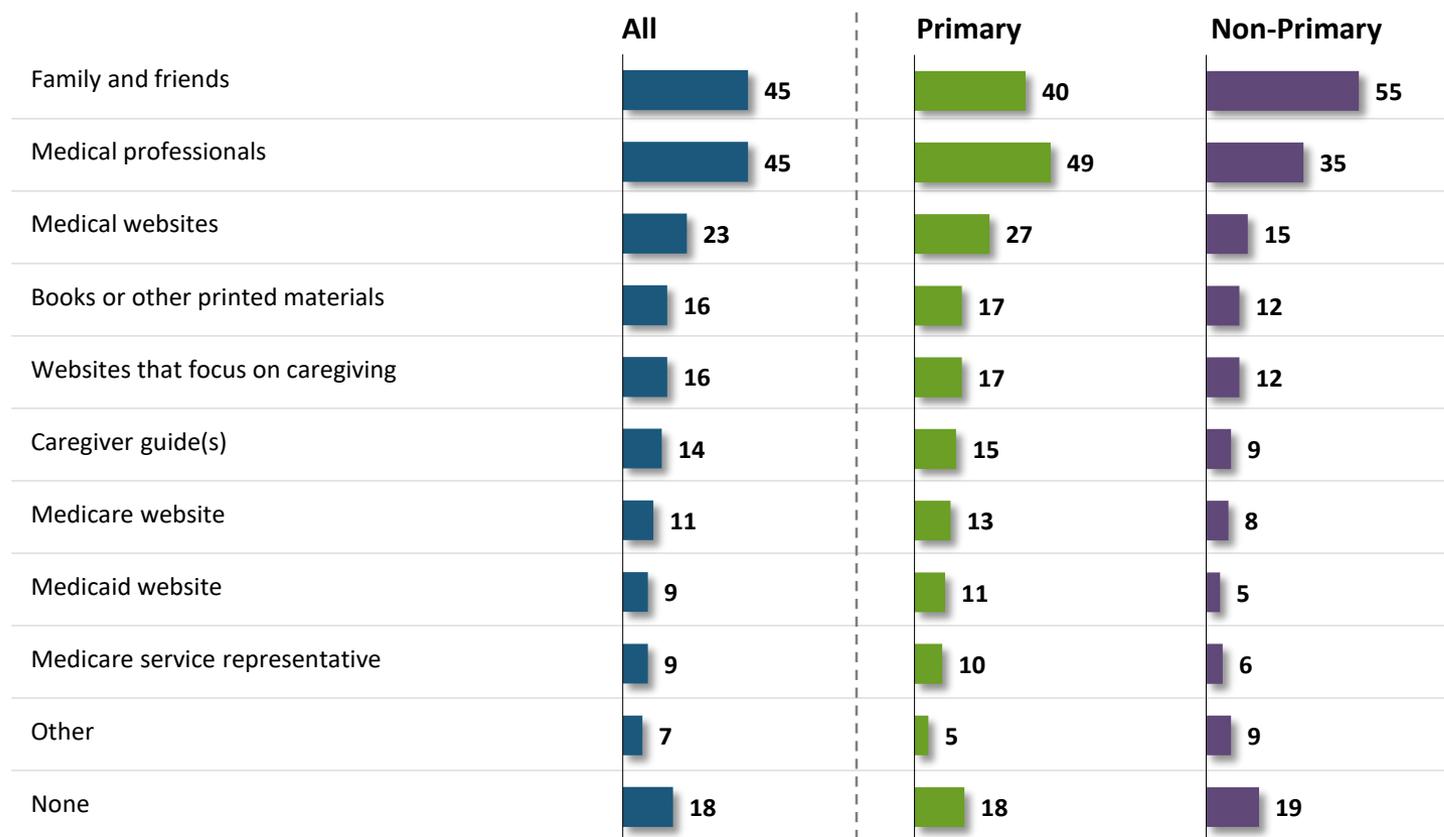
BASE: ALL QUALIFIED RESPONDENTS

Q830. On average, approximately how many hours per month do you spend performing the following duties for the care recipient?

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 (%)



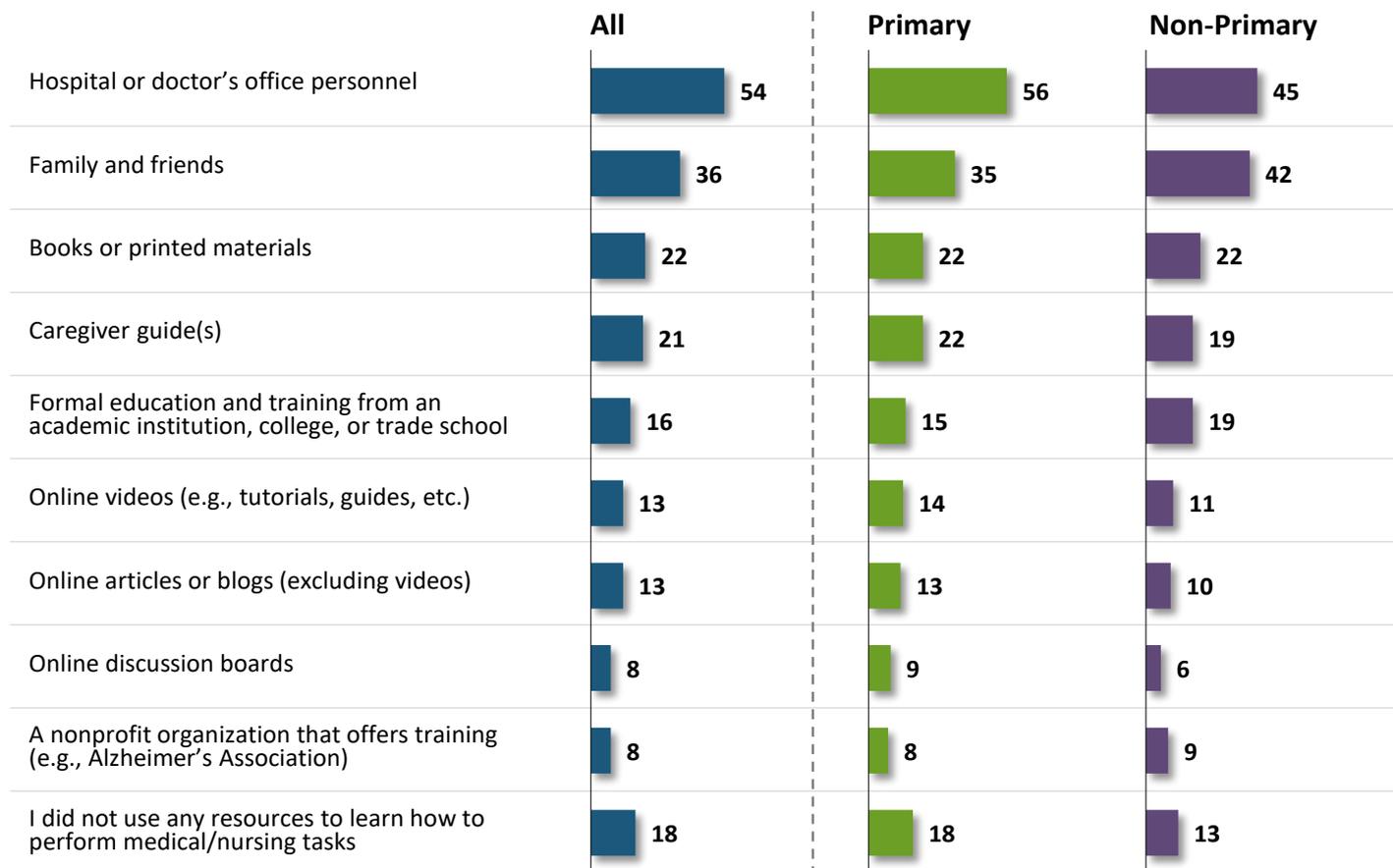
BASE: ALL QUALIFIED RESPONDENTS

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%

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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
NET – Employed	52	53	47
Employed full-time	39	41	33
Employed part-time	13	12	14
NET – Self-employed	8	8	10
Self-employed full-time	5	5	6
Self-employed part-time	3	3	4
NET – Not employed	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
NET – Employed	30	28	36
Full-time employed	18	18	16
Part-time employed	15	12	23
Self-employed	7	9	5
Never employed	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 (%)

	All	Primary	Non-Primary
NET – Reduced hours or job responsibilities	26	30	16
Reduced my hours	18	20	12
Reduced job responsibilities	10	12	5
Switched to a less demanding job	8	8	6
NET – Taken leave	18	22	9
Taken an unpaid leave of absence from my employer covered by the Family and Medical Leave Act	10	12	4
Taken a paid leave of absence from my employer	6	8	3
Taken an unpaid leave of absence from my employer not covered by the Family and Medical Leave Act	6	7	4
NET – Retired early/quit job	14	16	12
Retired early	8	9	7
Quit a job	7	8	6
Used vacation, sick days, and/or personal days off to be a caregiver	30	30	29
Missed days of work	26	29	15
Began working an alternative schedule	15	17	9
Began to work remotely	9	11	6
Took on additional hours to pay for cost of caregiving	8	9	4
None	24	18	38

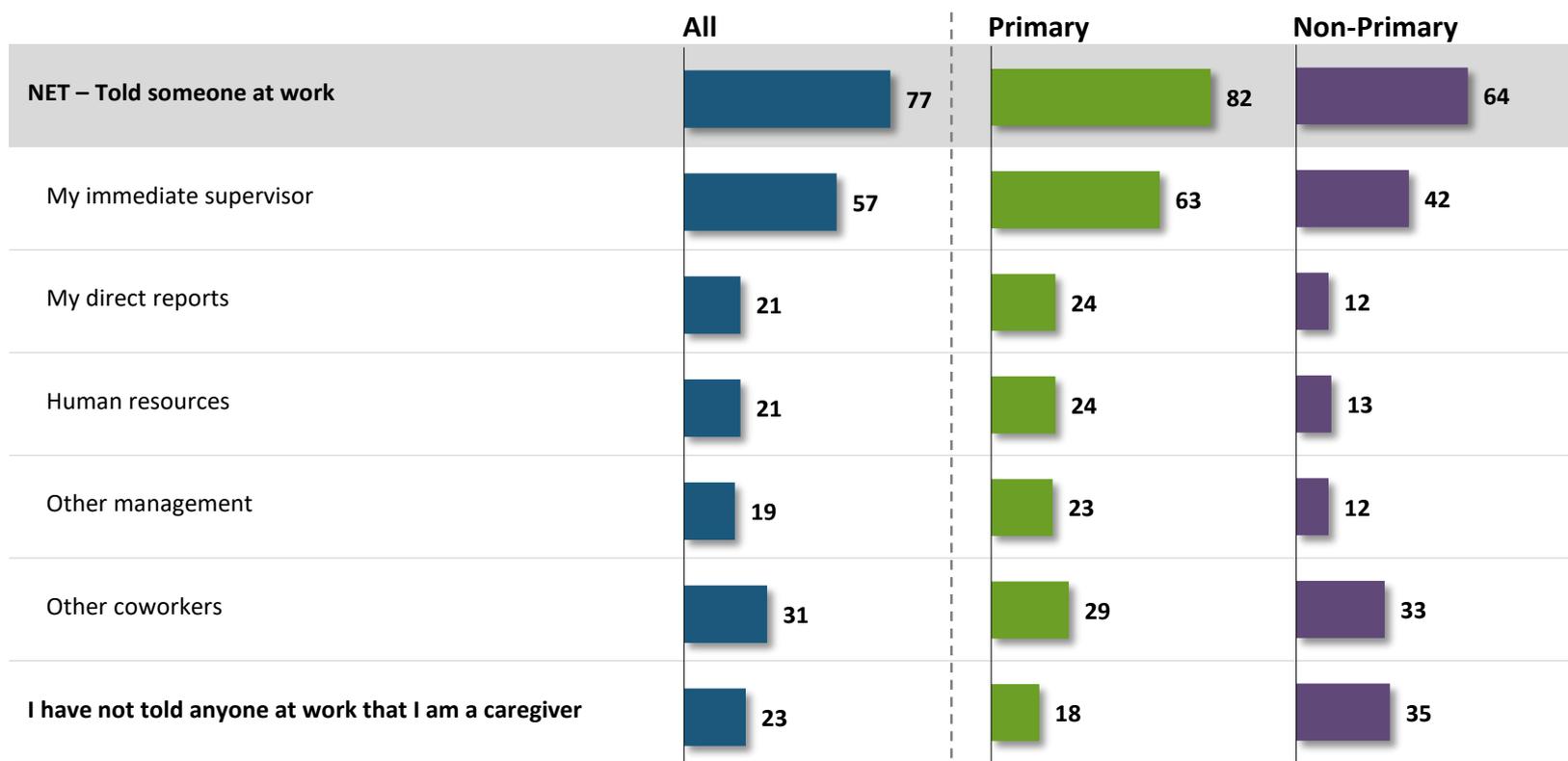
NOTE: Thirteen most commonly selected sources shown.

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.

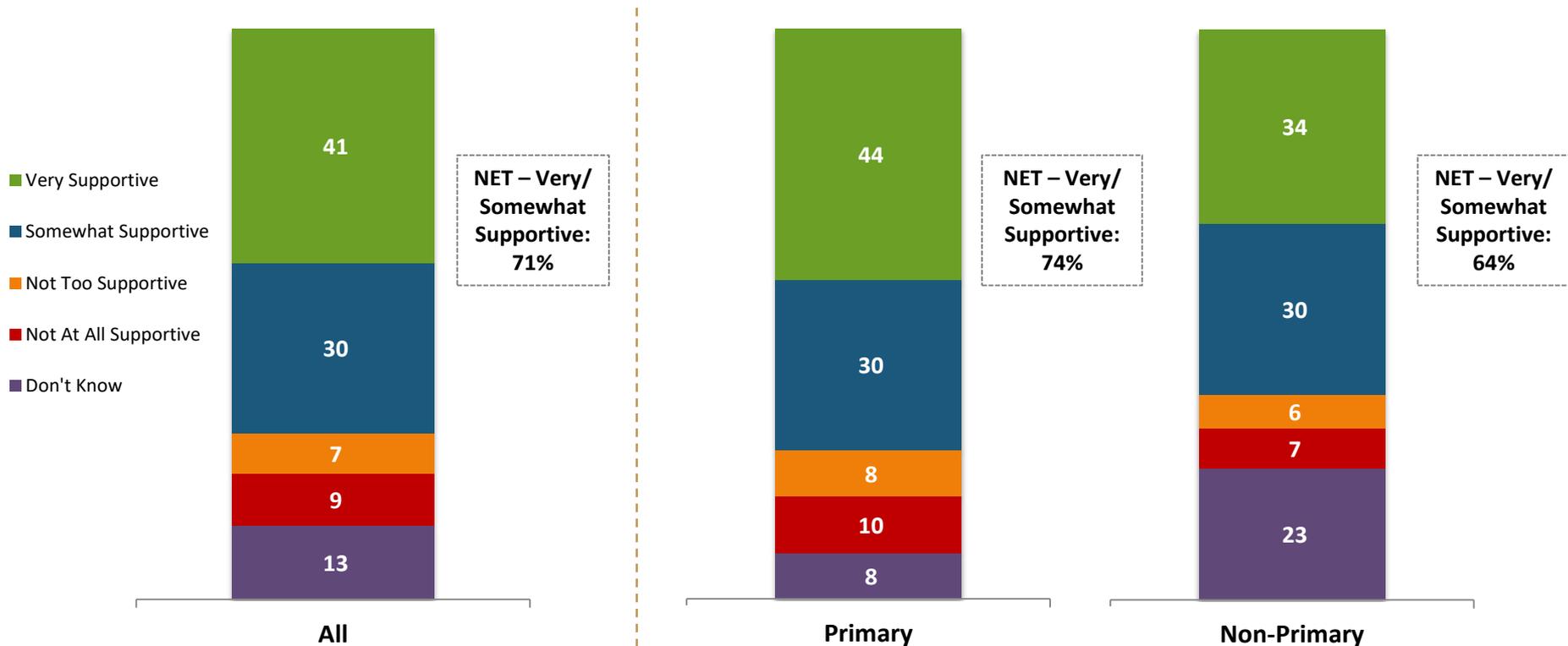
BASE: EMPLOYED FULL-TIME OR PART-TIME

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.

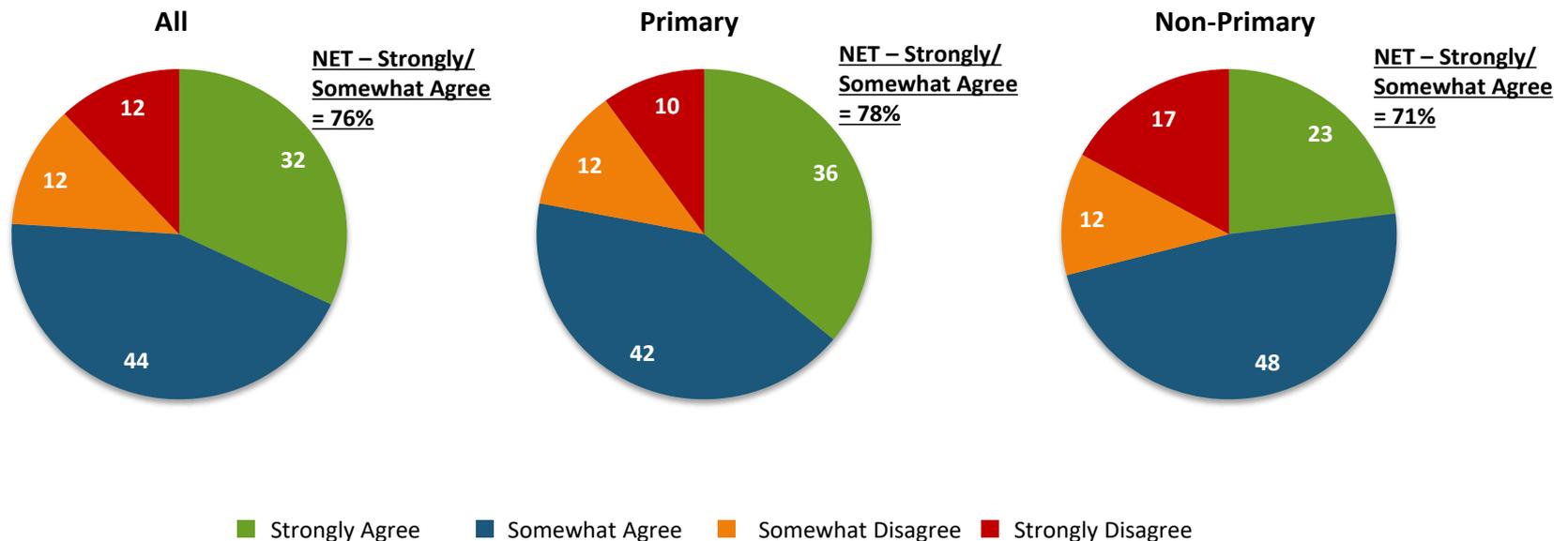
BASE: CURRENTLY EMPLOYED FULL-TIME OR PART-TIME

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.

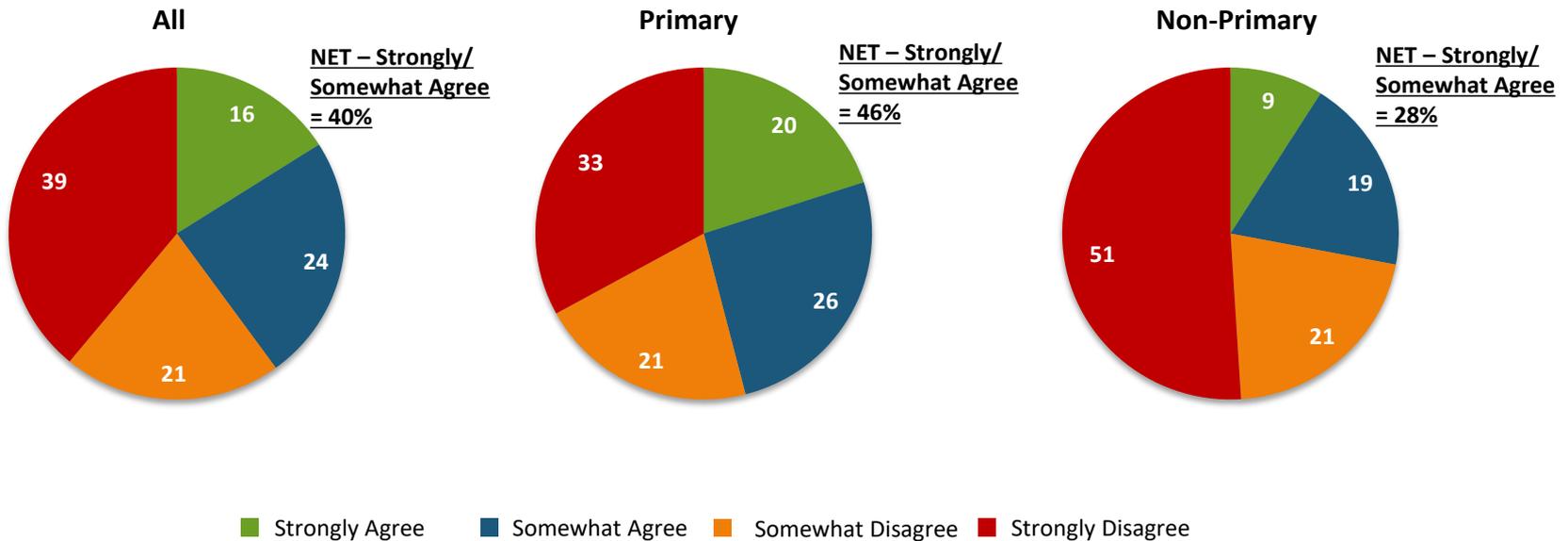
BASE: CURRENTLY EMPLOYED FULL-TIME OR PART-TIME

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.

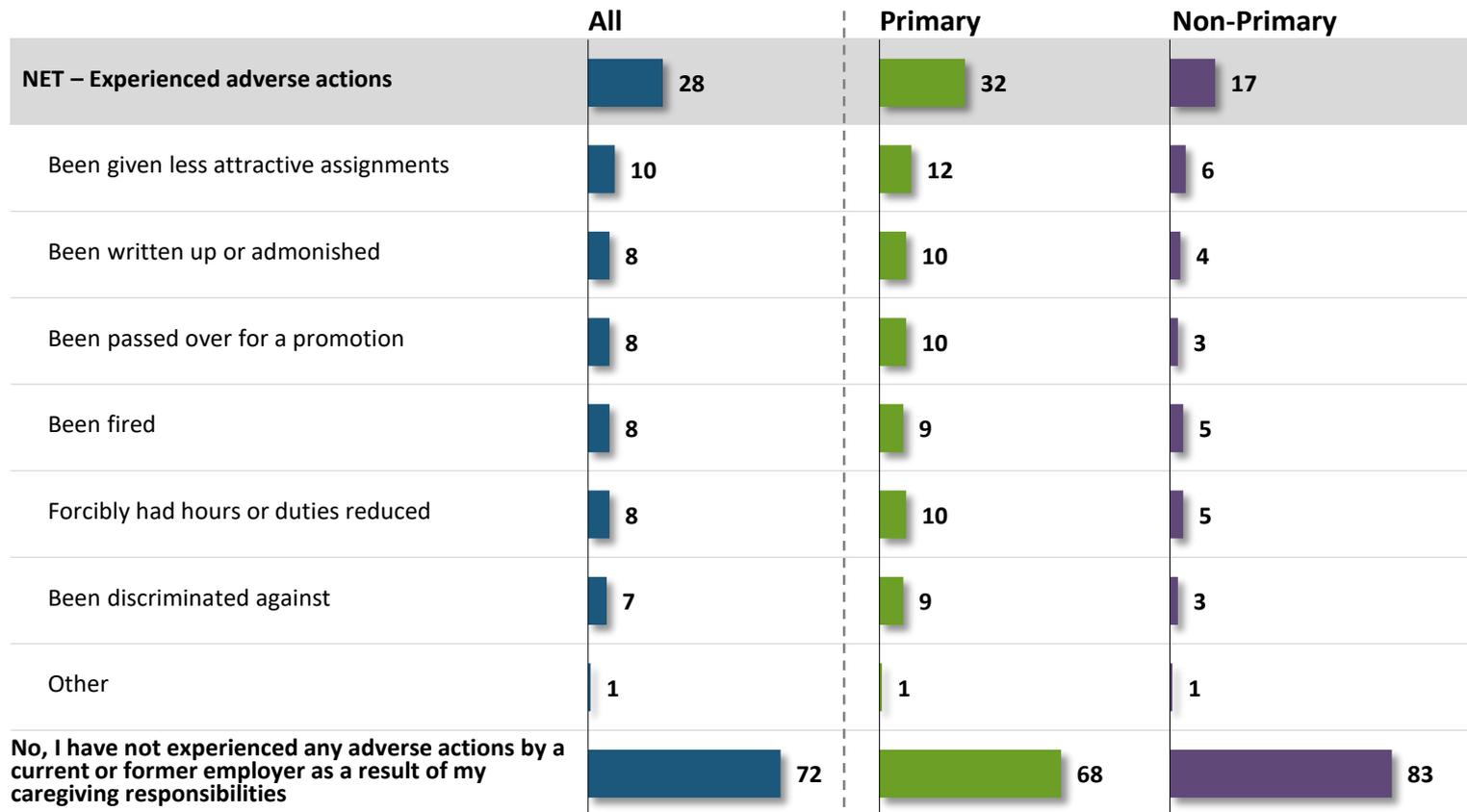
BASE: CURRENTLY EMPLOYED FULL-TIME OR PART-TIME

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).

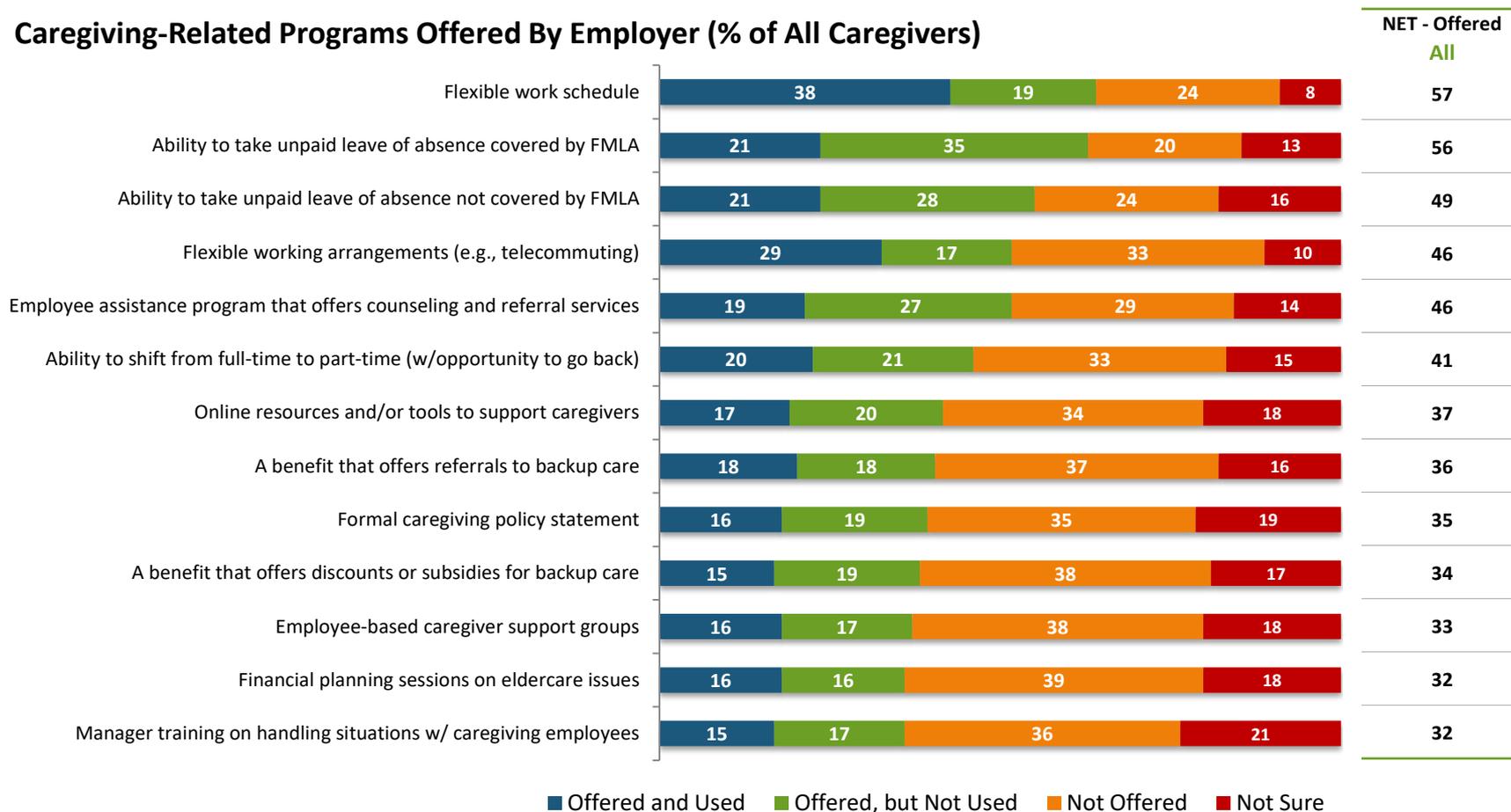
Adverse Employment Actions Experienced As a Result of Caregiving Duties (%)



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)



■ Offered and Used ■ Offered, but Not Used ■ Not Offered ■ Not Sure

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

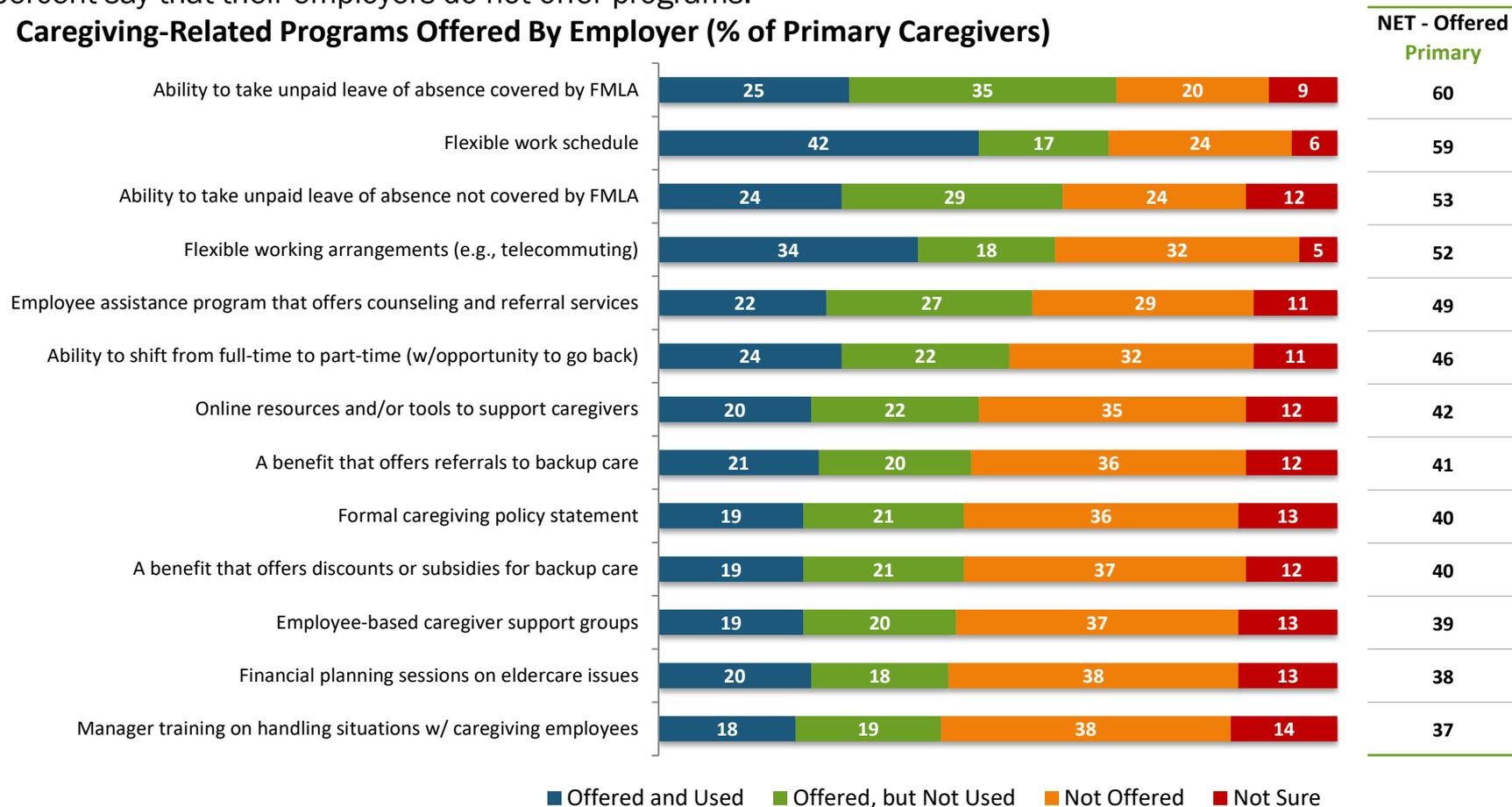
BASE: EMPLOYED FULL-TIME OR PART-TIME

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)



■ Offered and Used ■ Offered, but Not Used ■ Not Offered ■ Not Sure

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

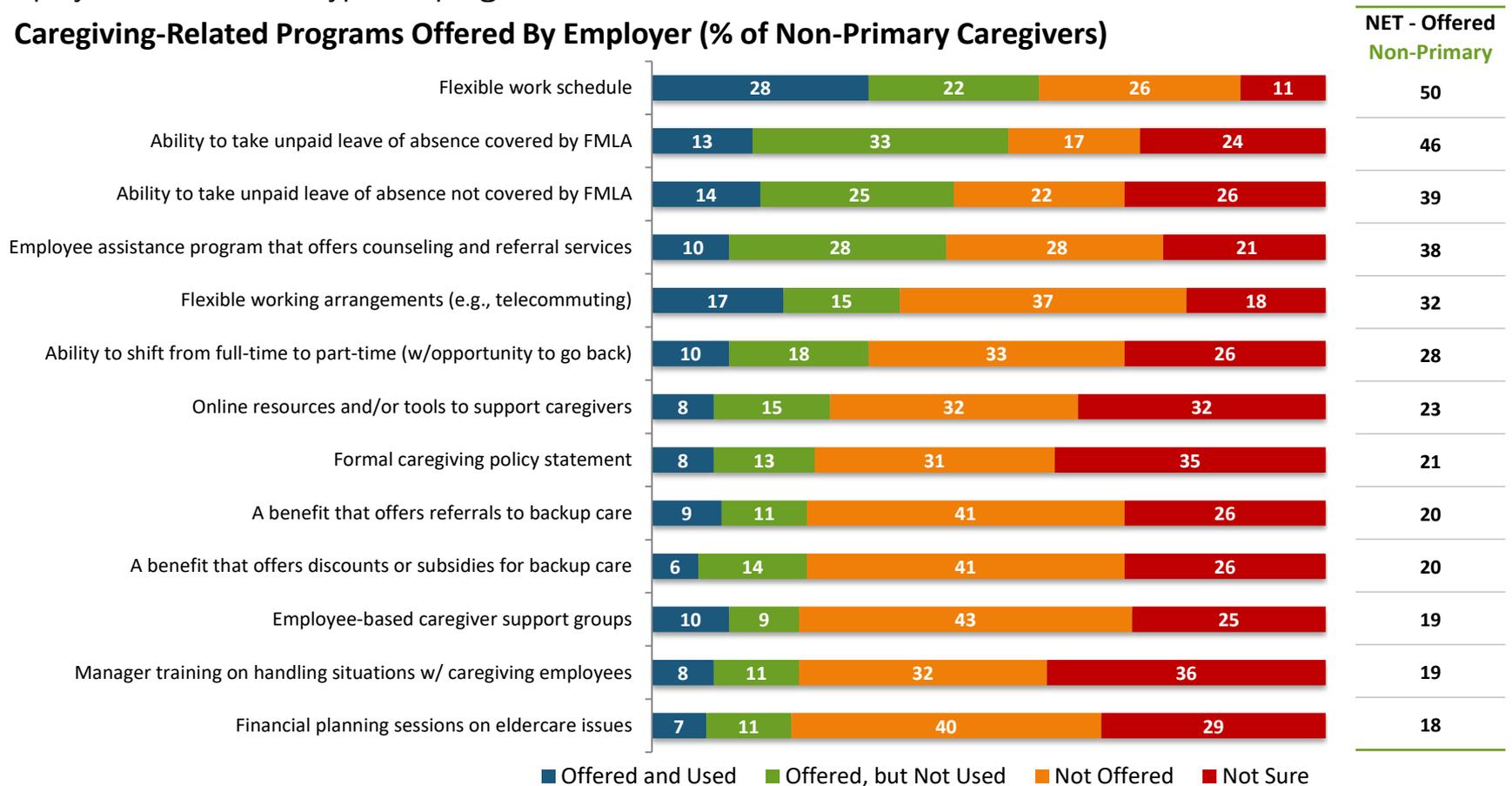
BASE: EMPLOYED FULL-TIME OR PART-TIME

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)



■ Offered and Used ■ Offered, but Not Used ■ Not Offered ■ Not Sure

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

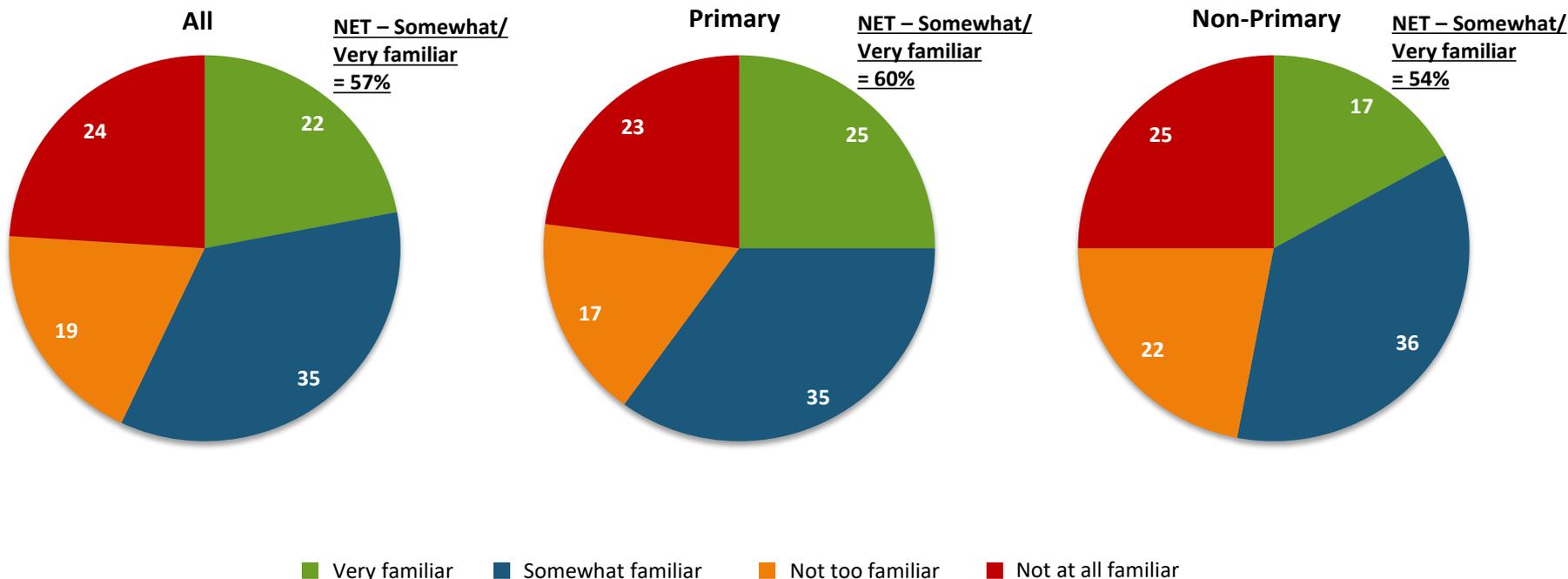
BASE: EMPLOYED FULL-TIME OR PART-TIME

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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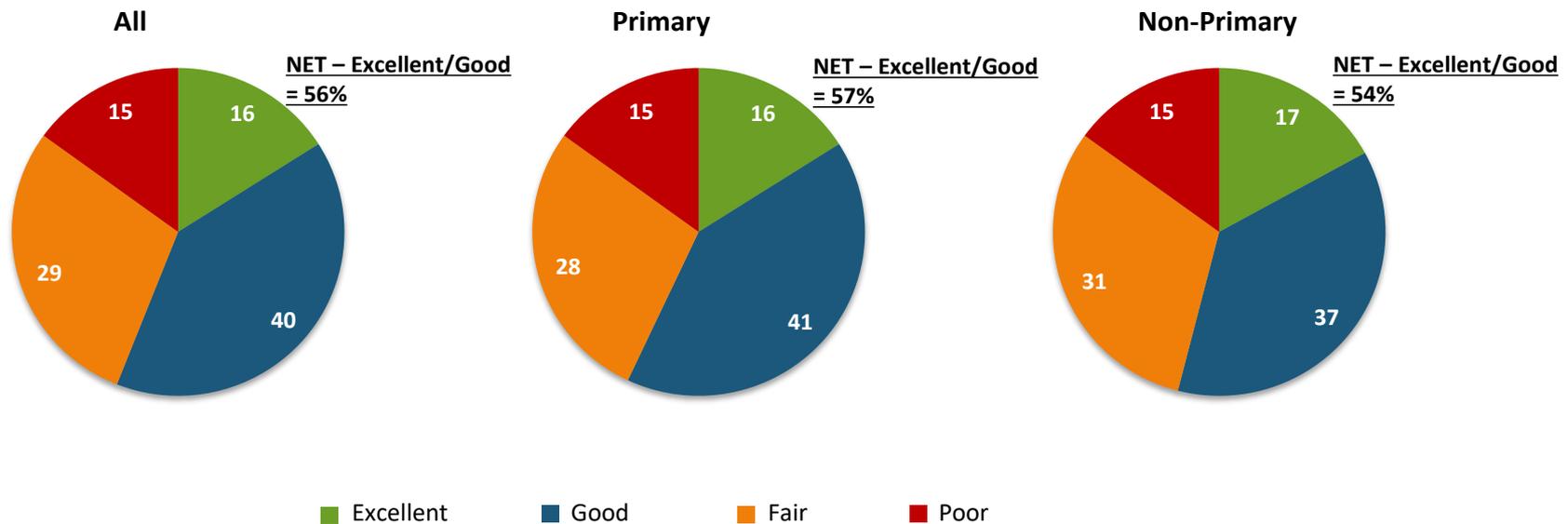
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Caregivers' Financial Well-Being

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.

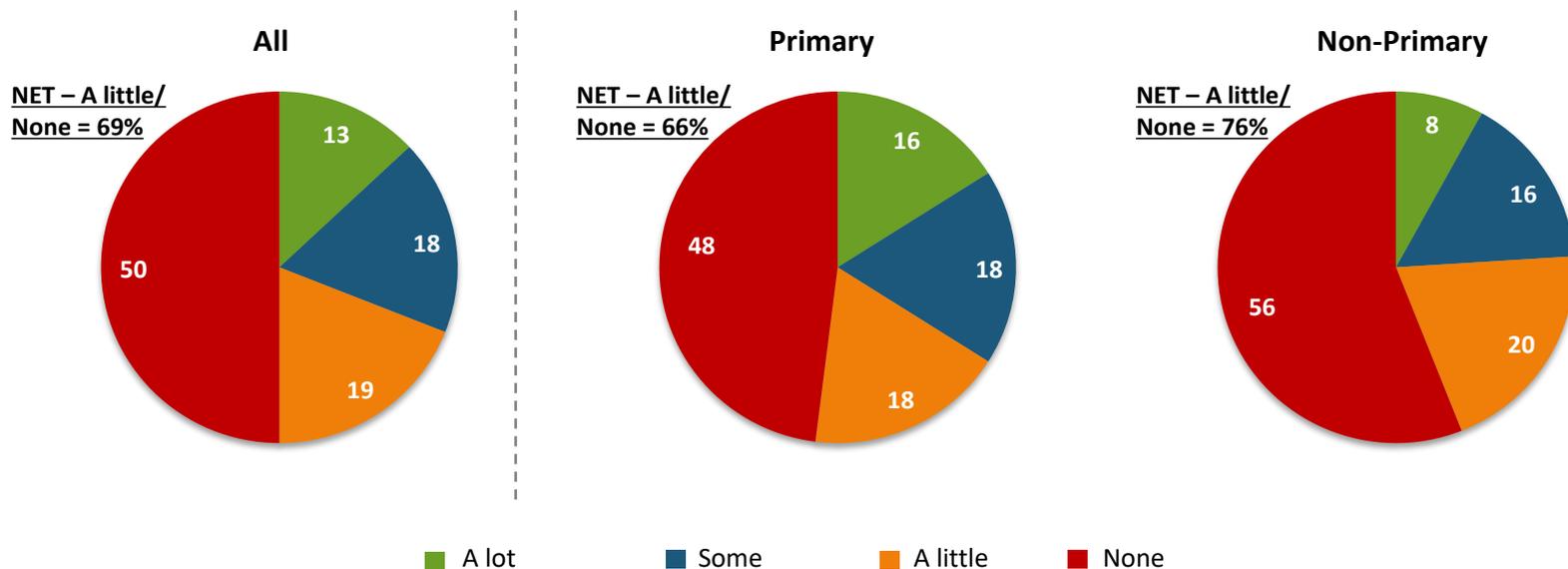
“How would you describe your own financial well-being?” (%)



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.

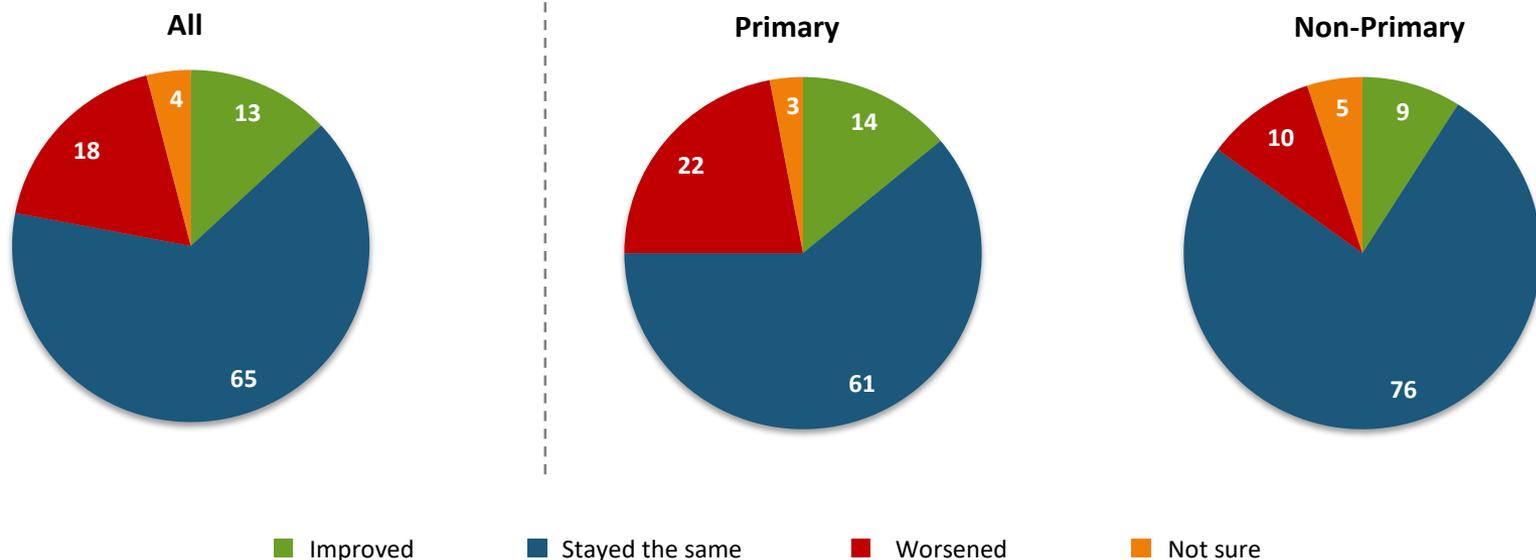
“To what extent did you consider your own financial situation when deciding to become a caregiver?” (%)



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.

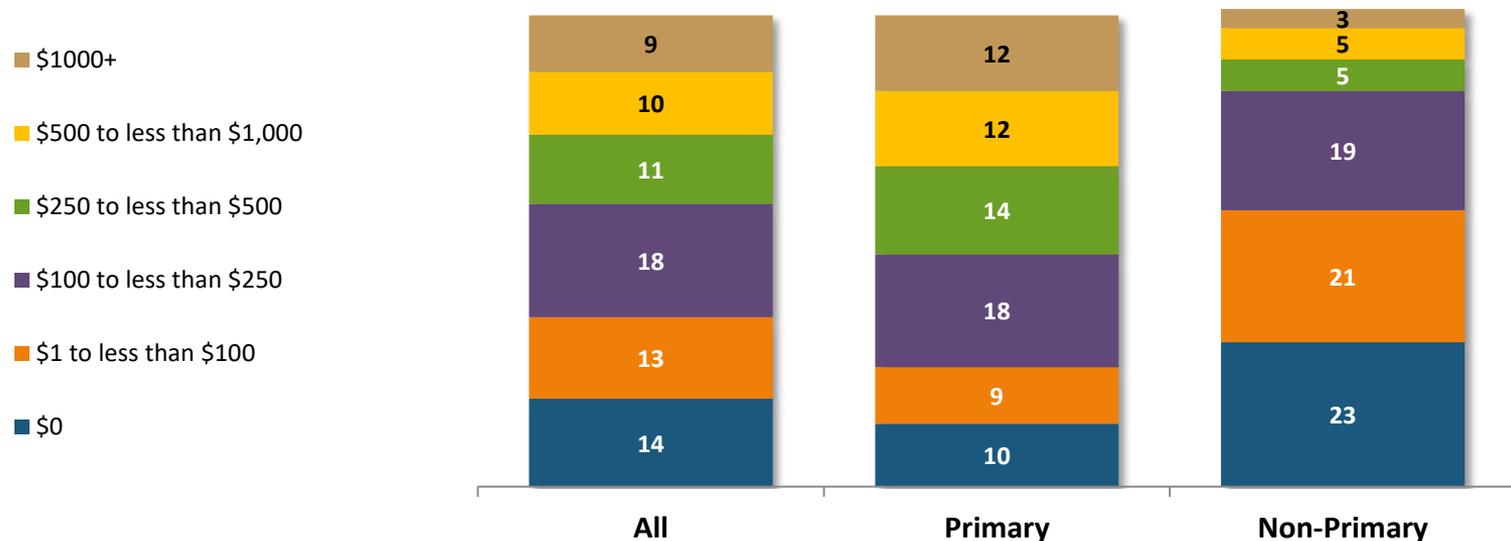
“How has your financial situation changed as a result of becoming a caregiver?” (%)



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 (%)



Median	\$150	\$250	\$50
Not Sure (%)	25	25	24

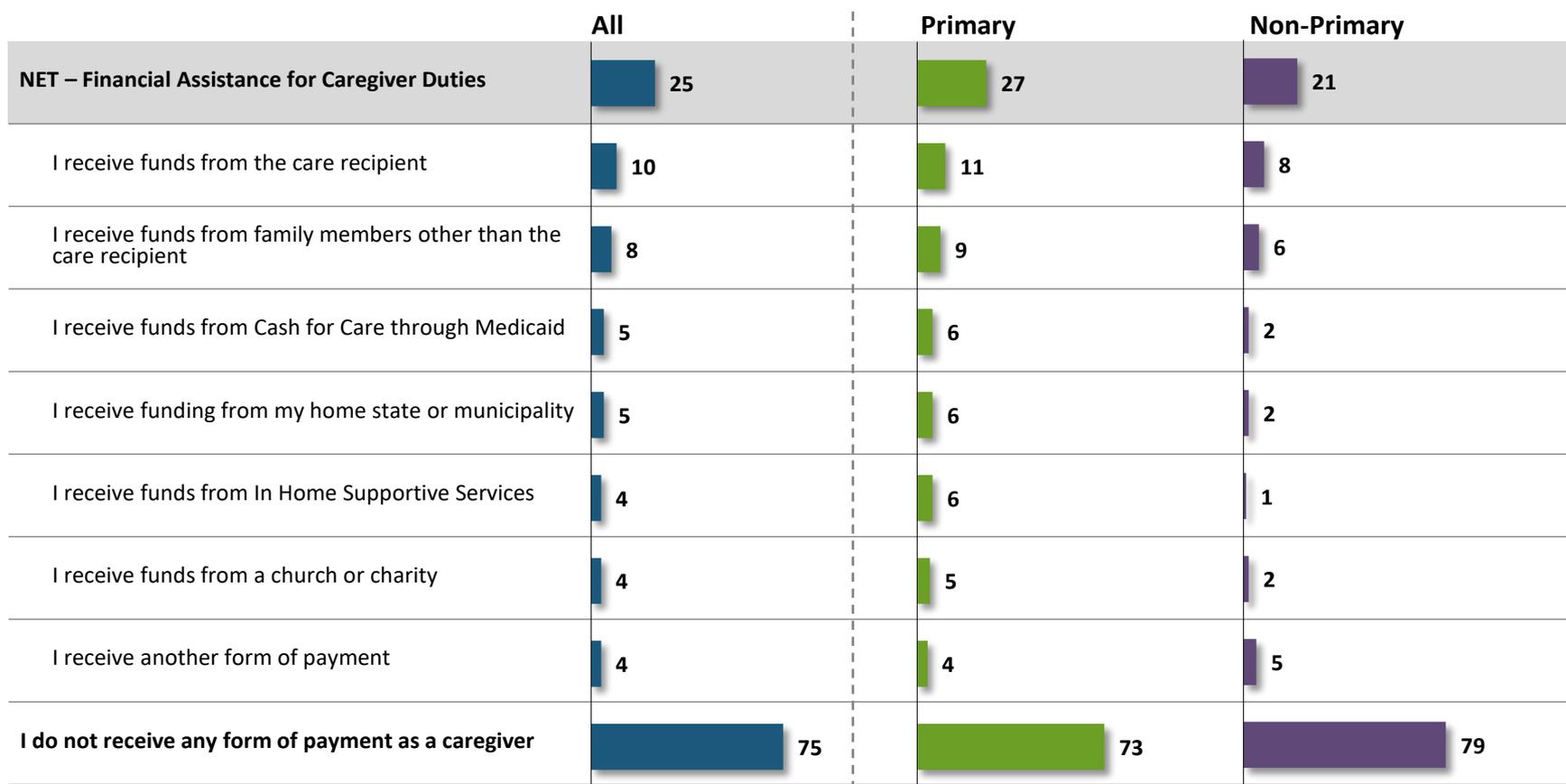
BASE: ALL QUALIFIED RESPONDENTS

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.

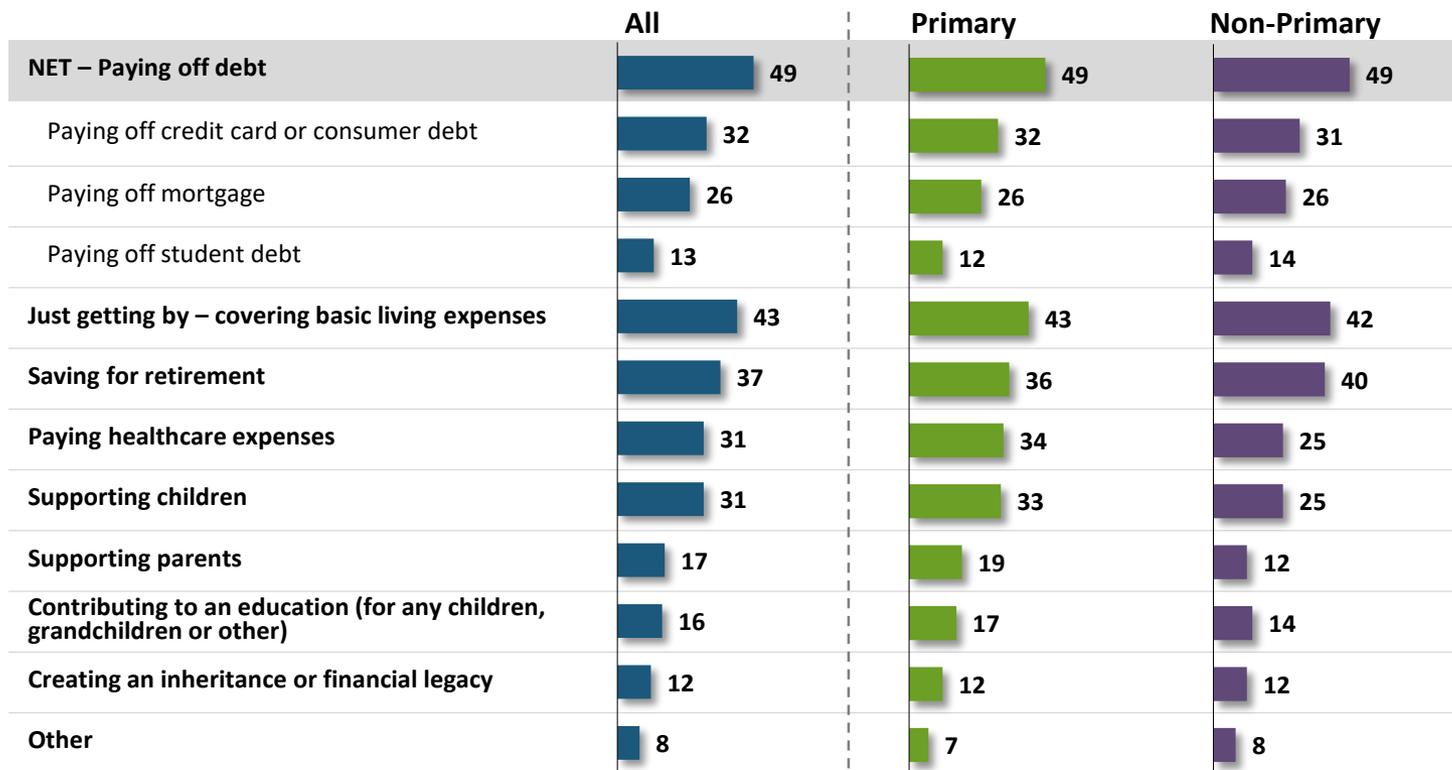
Sources of Financial Assistance Received for Caregiving Duties, If Any (%)



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.

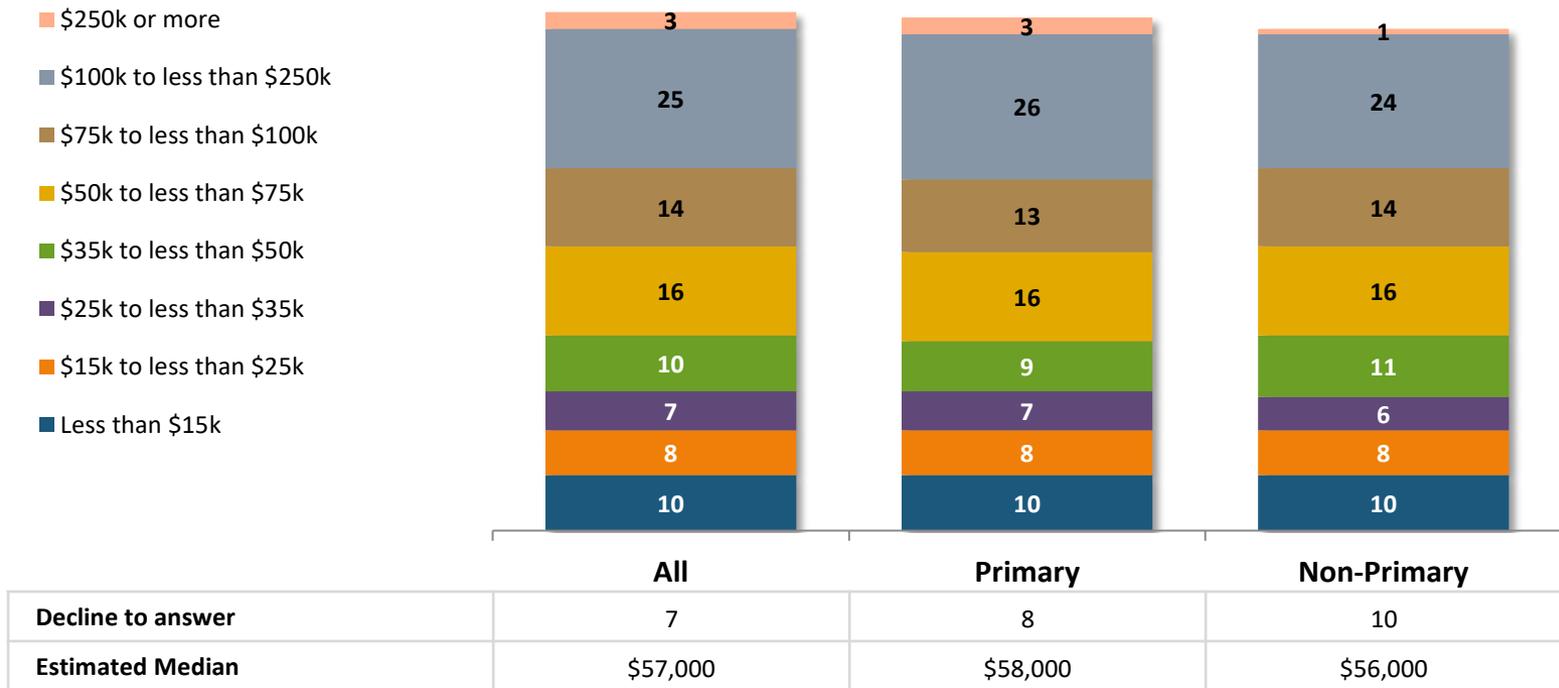
“Which of the following are your financial priorities right now?” (%)



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

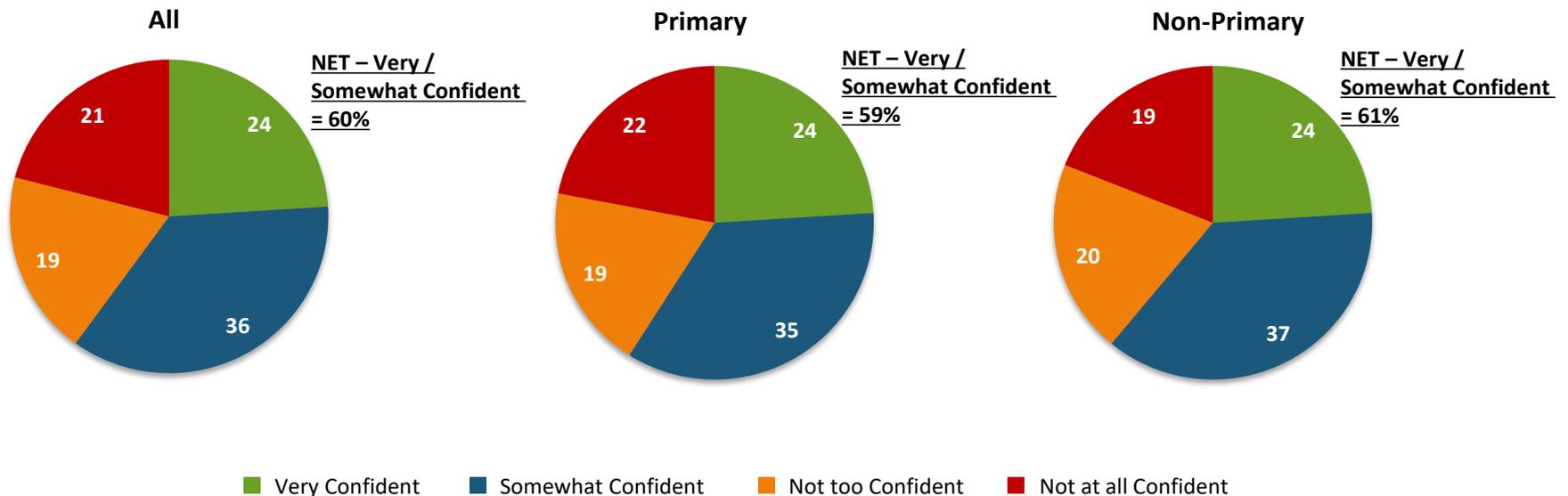
BASE: ALL QUALIFIED RESPONDENTS

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.

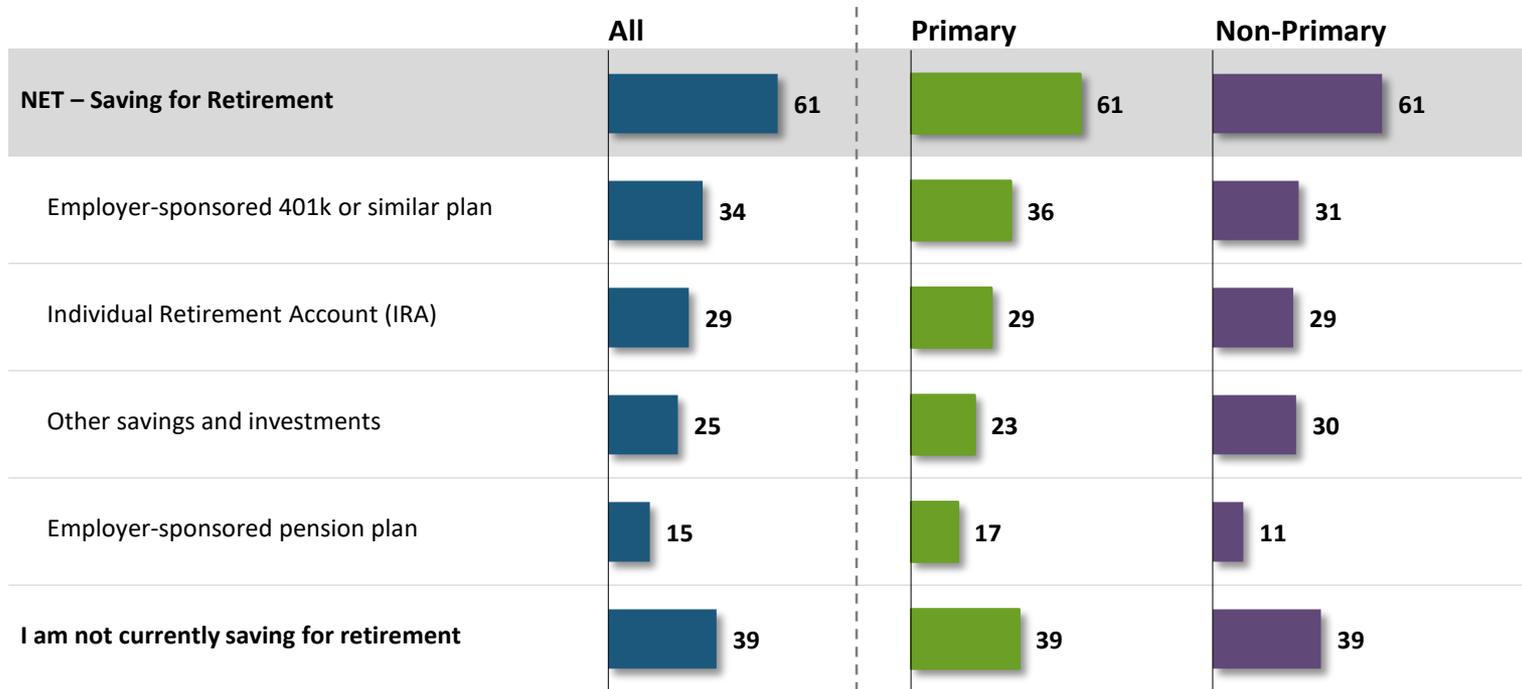
“How confident are you that you will be able to fully retire with a lifestyle you consider comfortable?” (%)



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.

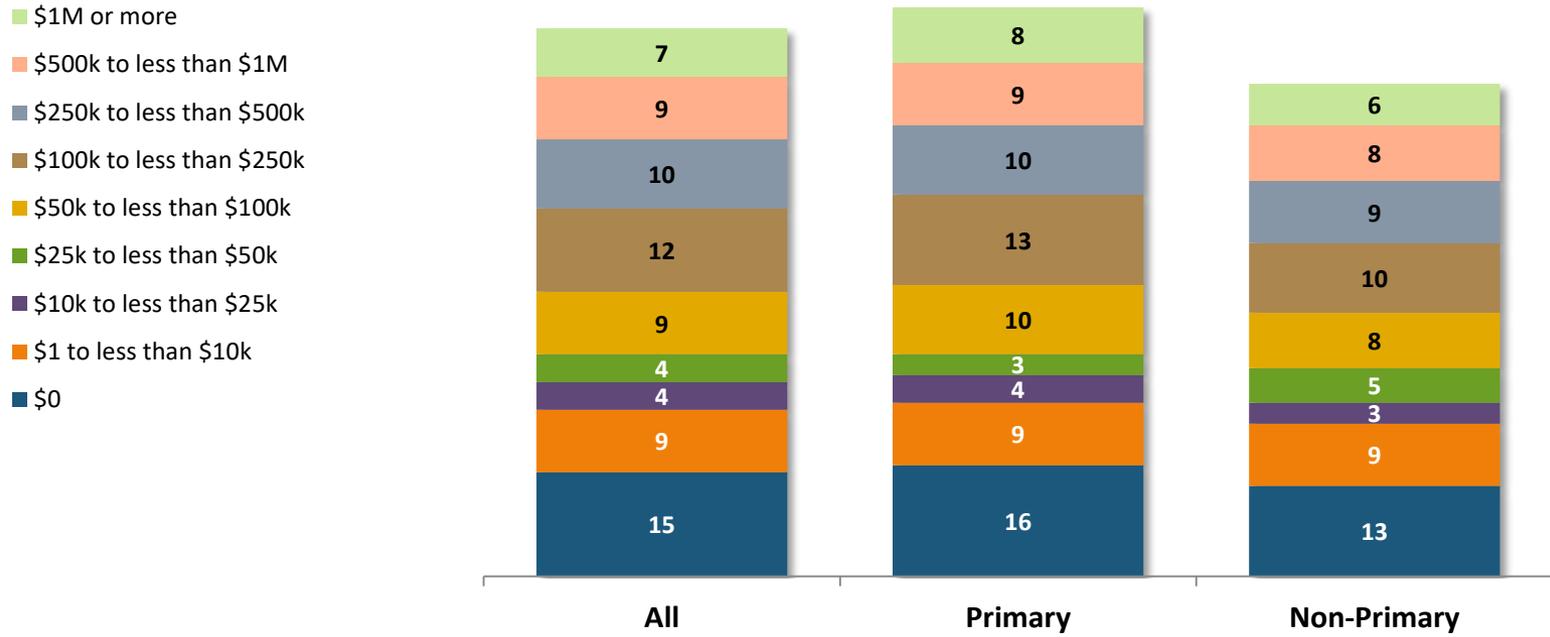
Saving For Retirement (%)



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 (%)



	All	Primary	Non-Primary
Not Sure	11	8	17
Decline to answer	10	10	12
Estimated Median	\$68,000	\$71,000	\$62,000

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

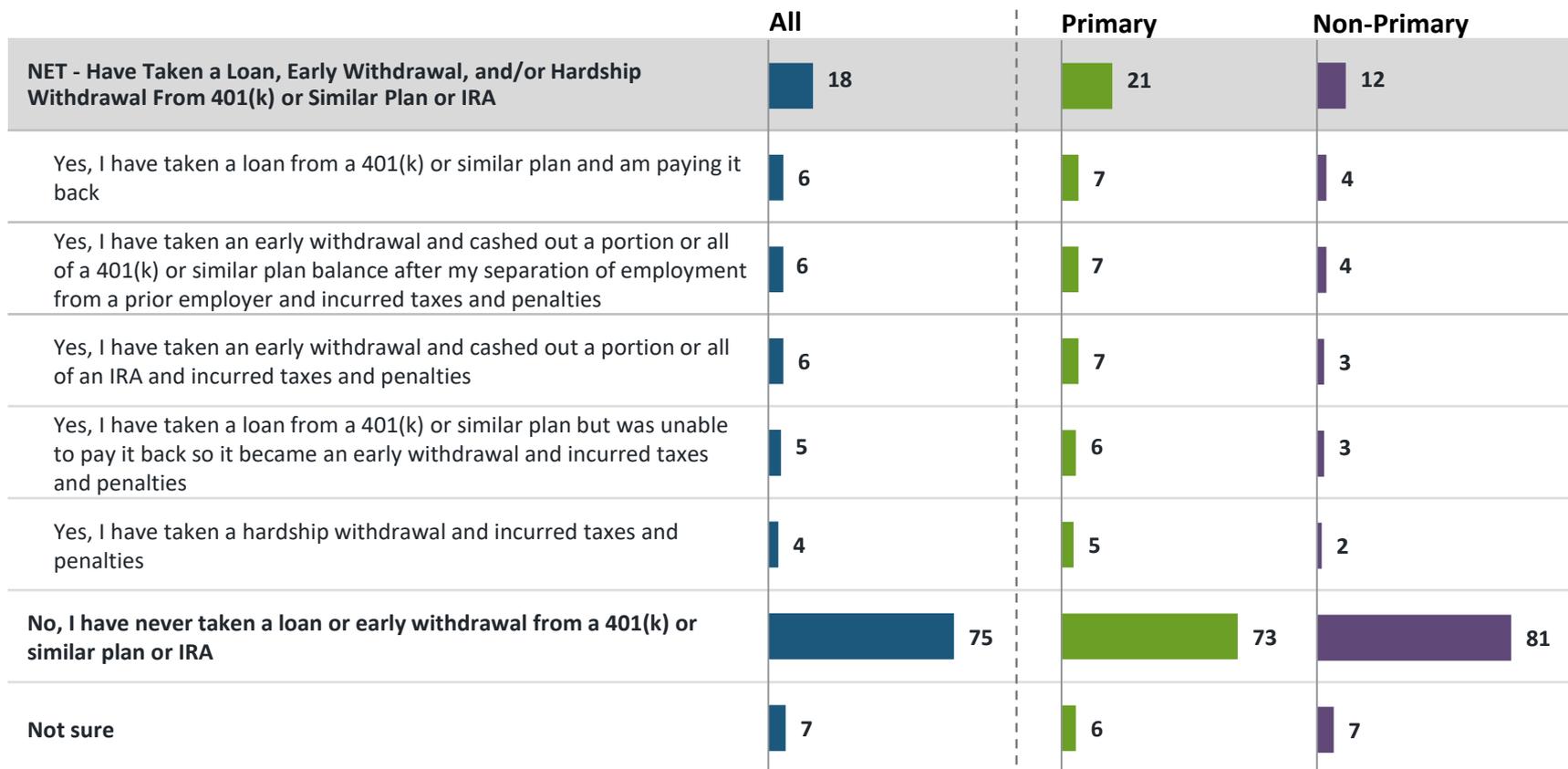
BASE: ALL QUALIFIED RESPONDENTS

Q1270. What is your total household retirement savings in all accounts?

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.

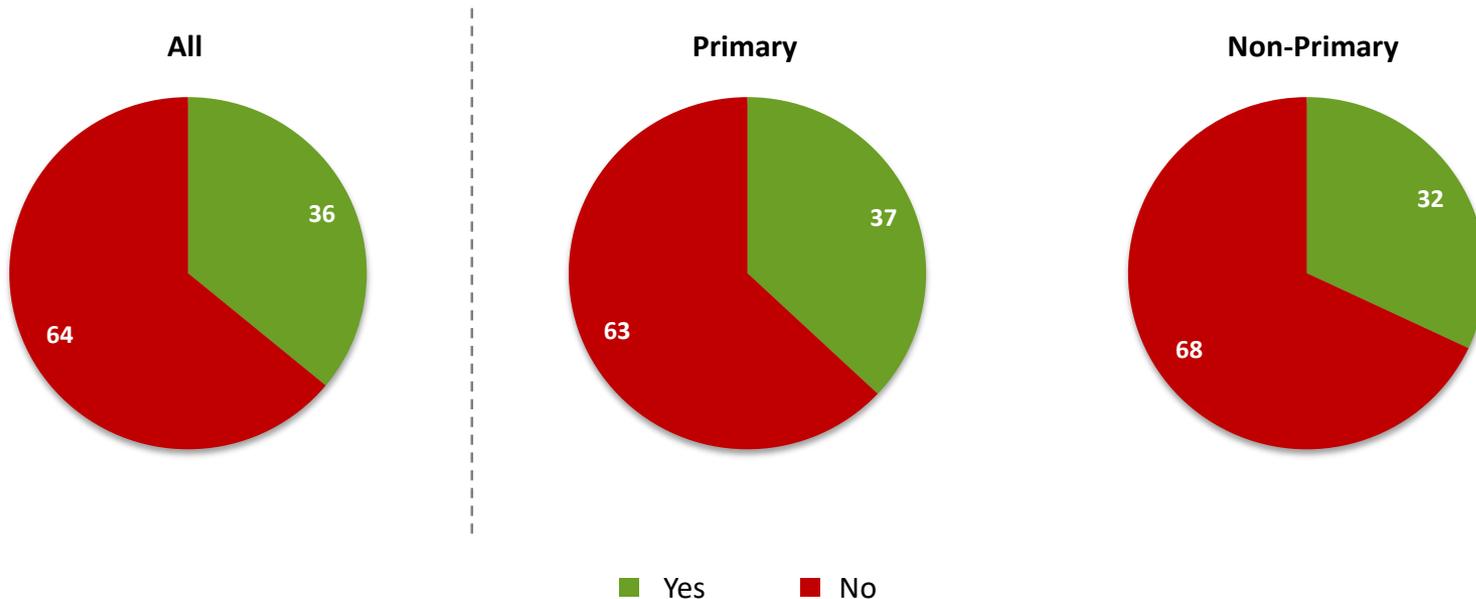
Loans, Hardship Withdrawals, and/or Early Withdrawals From Retirement Accounts Taken as a Result of Caregiving Duties (%)



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?” (%)



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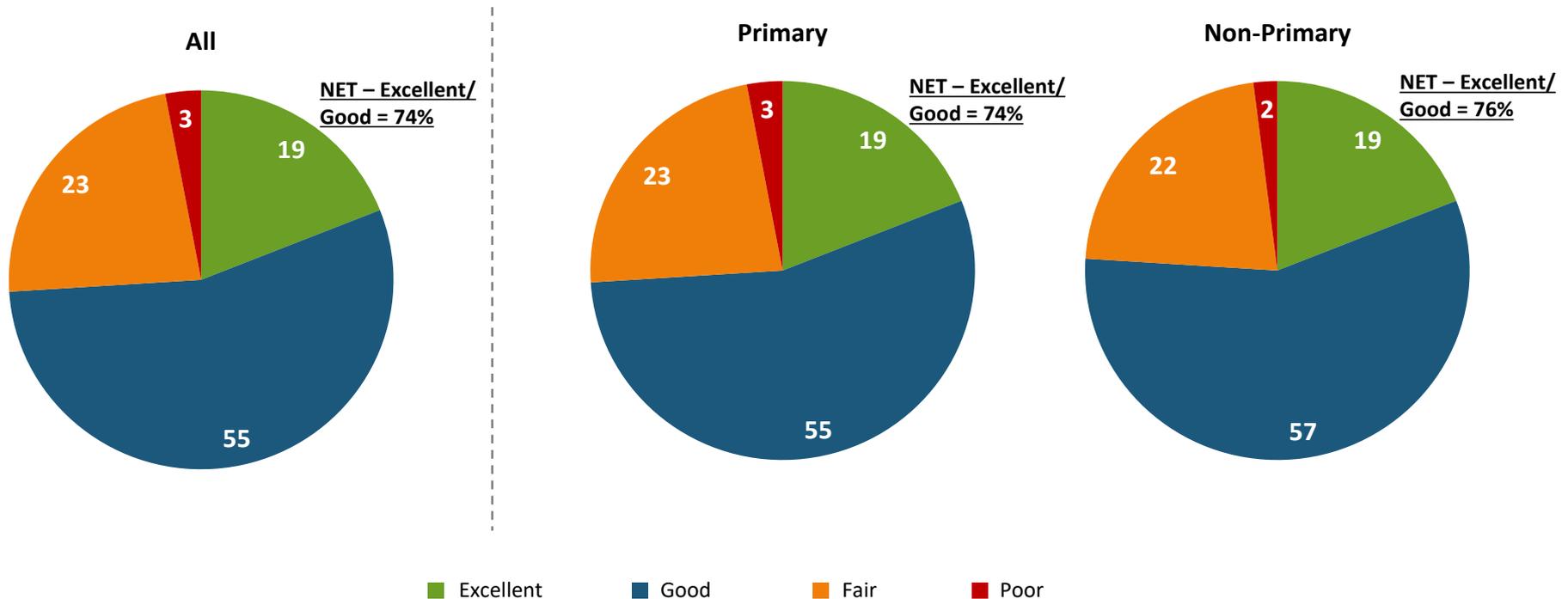
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Most Caregivers Consider Themselves to Be in Excellent/Good Health

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.

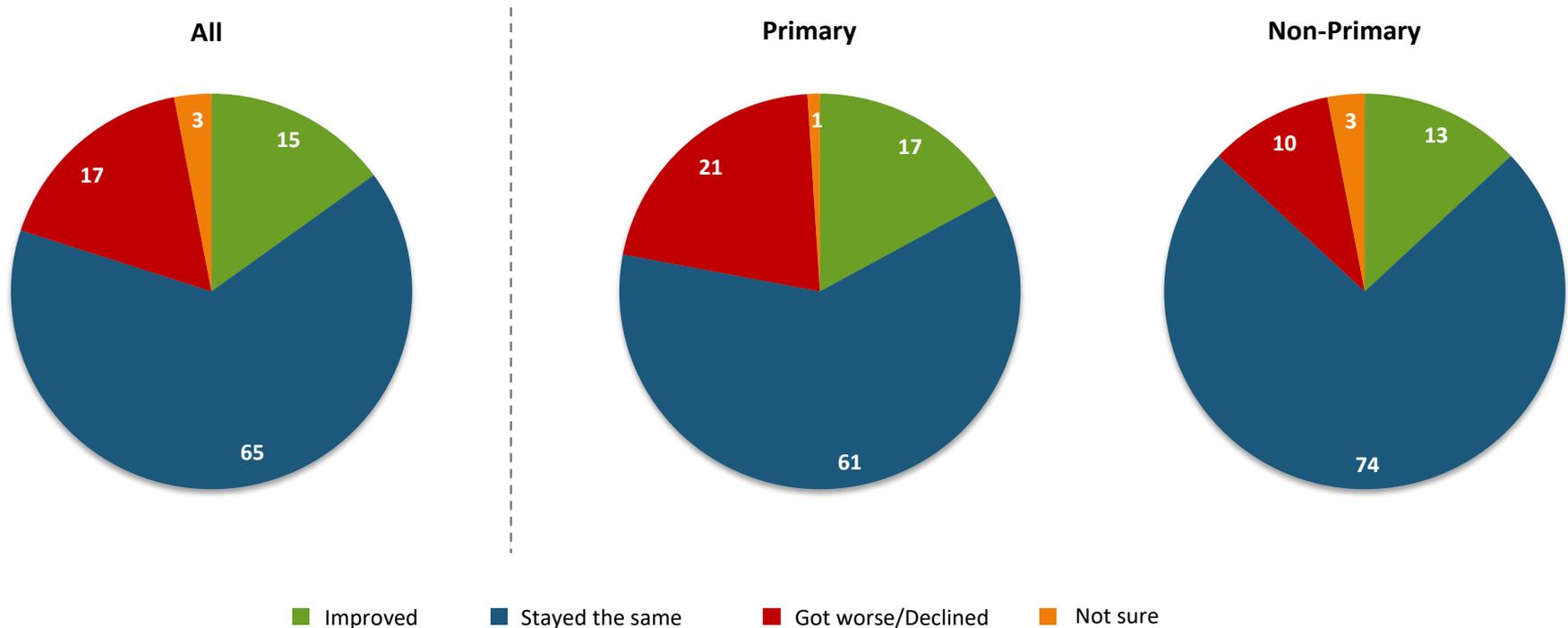
Caregivers' Self-Described Health Status of Their Own Health (%)



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.

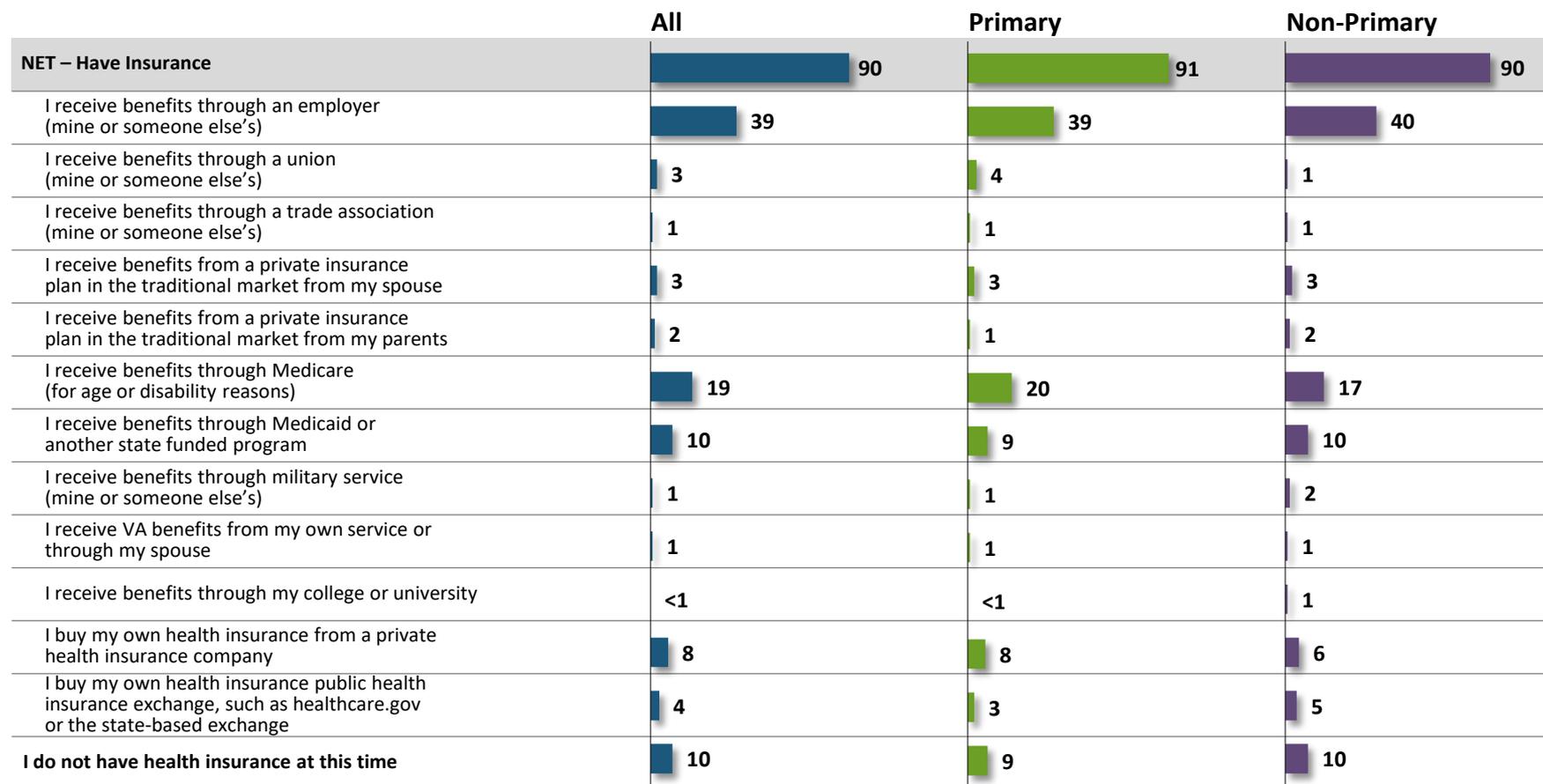
Changes in General Health Since Becoming a Caregiver (%)



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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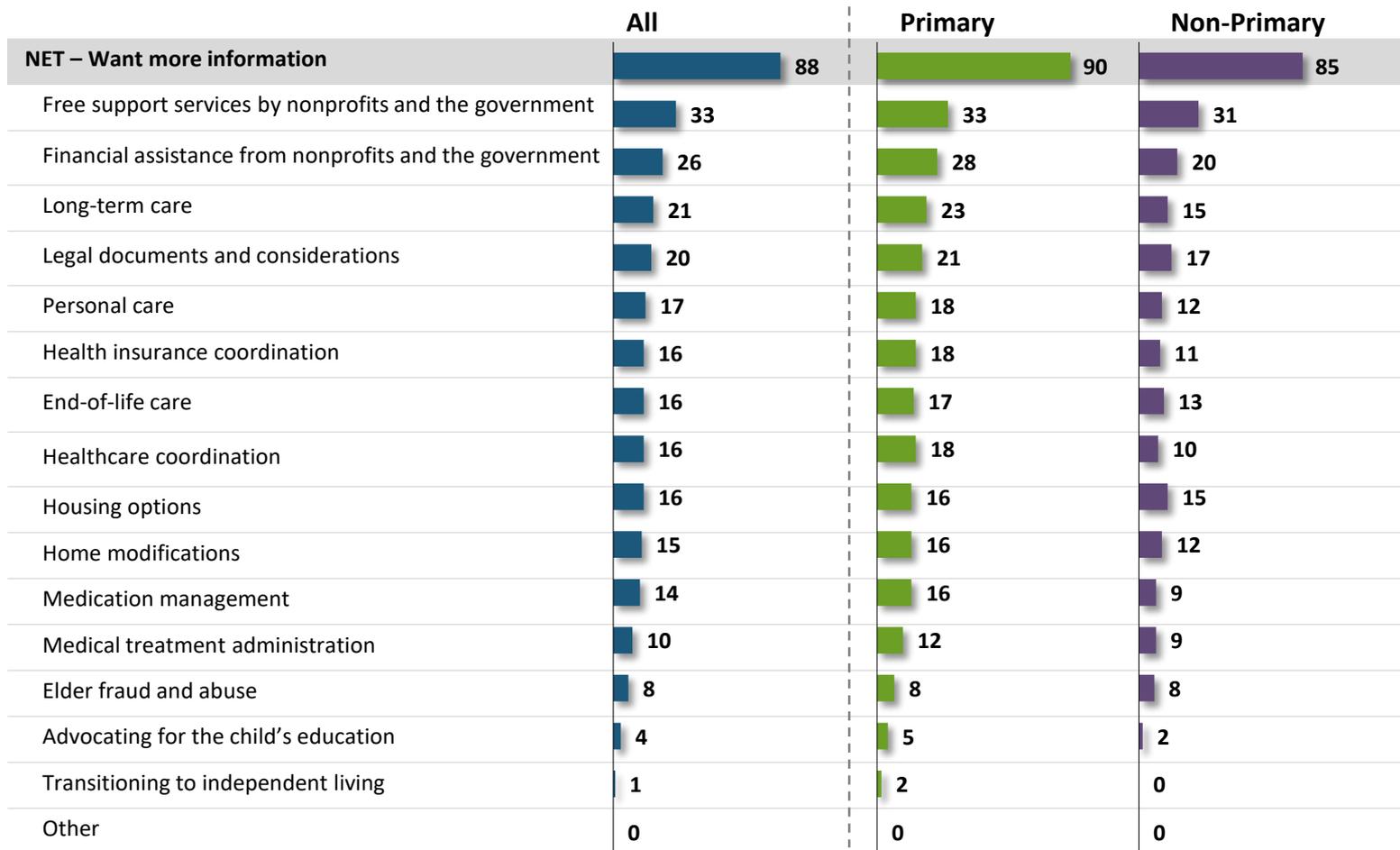
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Caregivers Want More Information to Help with Their Duties

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

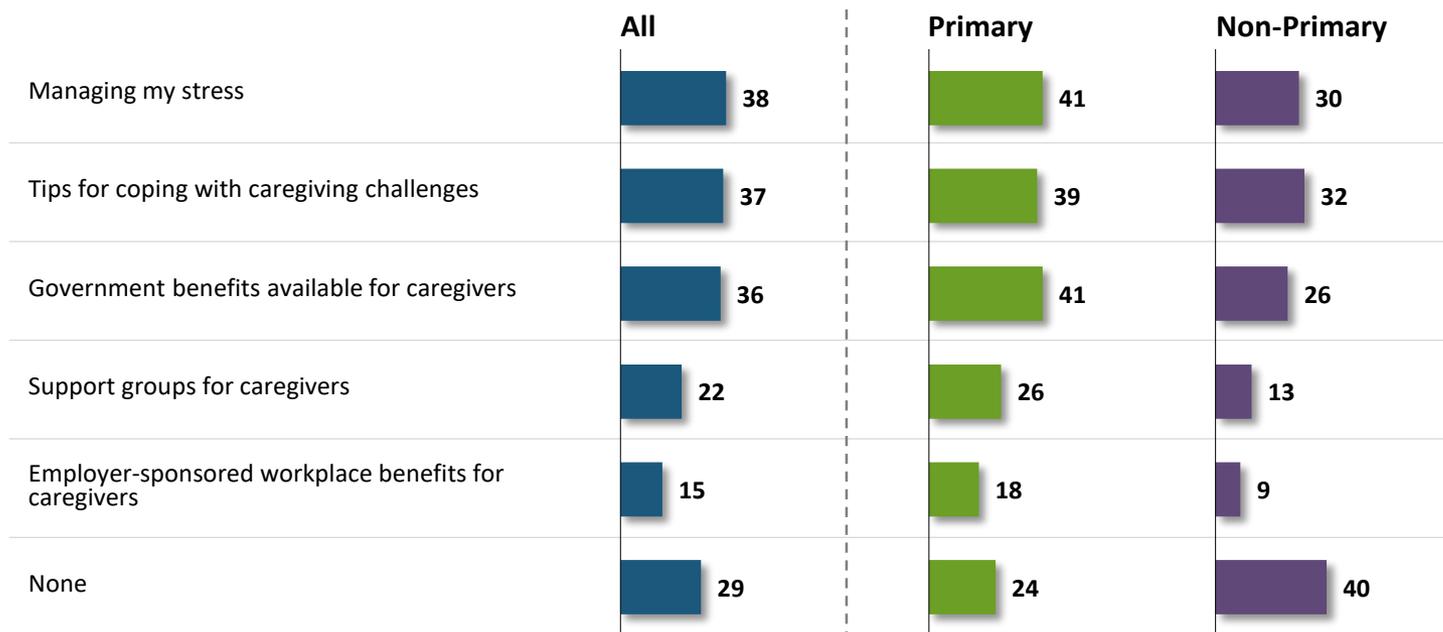
Q845. Which of the following topics would you like more information about to help you with your caregiving responsibilities? I would like more information about...

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

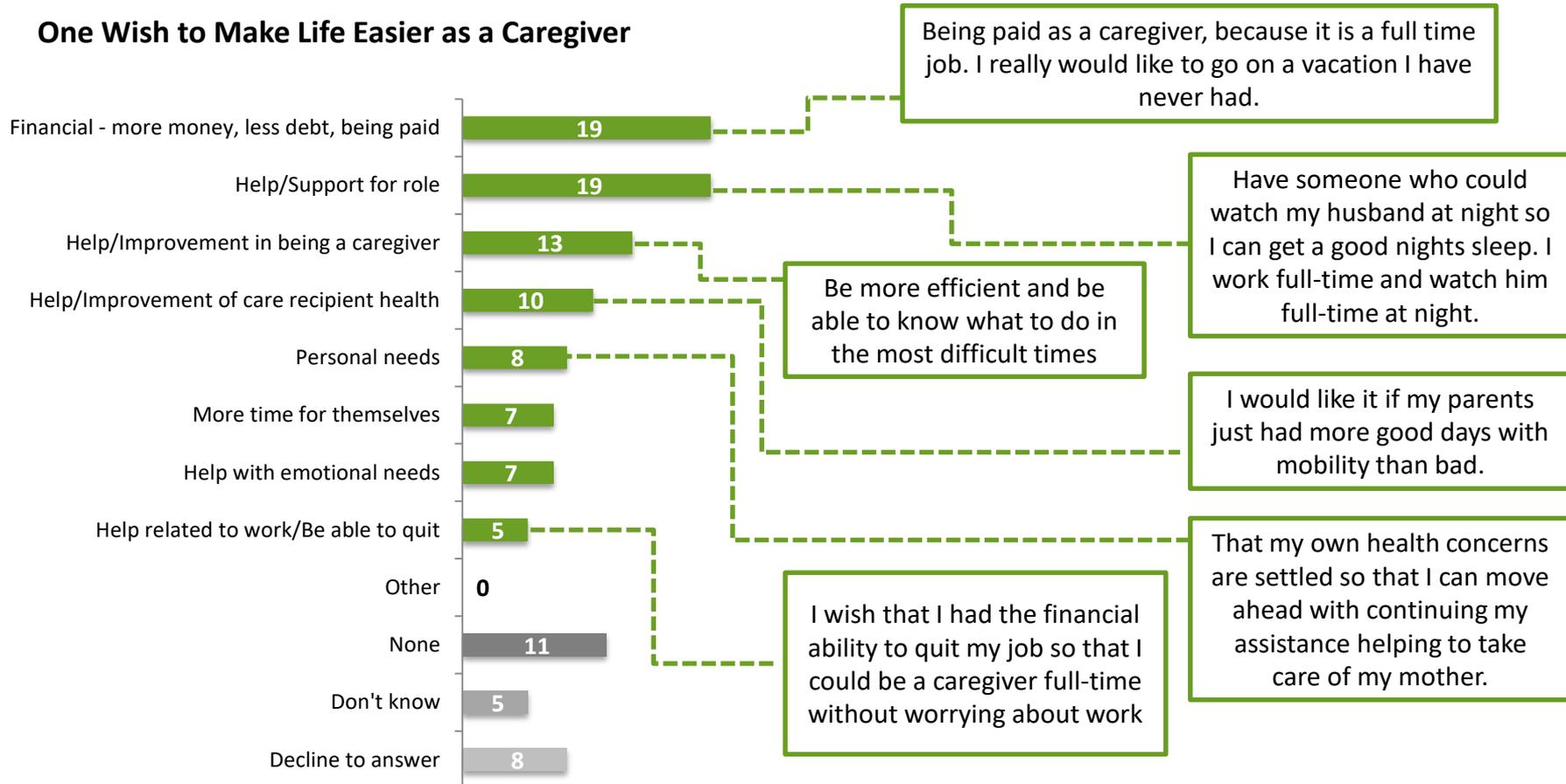
Q850. Which of the following topics would you like more information to help you personally with your caregiving responsibilities? I would like more information about...

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.

One Wish to Make Life Easier as a Caregiver



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