

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

Executive Summary



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The Many Faces of Caregivers

is a comprehensive examination of the state of non-professional caregiving in America. Non-professional family 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 research uncovers the various challenges caregivers are facing as well as insight into their health, both physical and financial, and the support they desire.

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

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

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**Catherine Collinson,
Transamerica Institute**

Transamerica Institute’s national survey of 3,000+ non-professional caregivers examines their duties and the impact caregiving has on their personal health and well-being, employment, finances and retirement preparations. It offers an in-depth analysis and demographic portraits of caregivers by employment status, gender, generation, household income, race/ethnicity, whether they are the primary caregiver, and whether they became a caregiver voluntarily. It also has detailed findings about care recipients, including their health status and financial situation.

A Portrait of Today's Caregivers

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

To illustrate the diversity of the caregiver population, the survey finds:

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

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

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

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

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

The Daily Lives and Duties of Caregivers

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

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

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

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

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

Hector De La Torre,
Transamerica Institute

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

The Precarious Employment Situation of Caregivers

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

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

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

The Potential Negative Financial Implications of Being a Caregiver

“Caregiving responsibilities can impact a caregiver’s finances, ranging from lost income due to time off the job to incurring out-of-pocket expenses on behalf of the care recipient. Over time, it can negatively impact the caregiver’s own future retirement,” said Collinson. Caregivers spend \$150 per month (median) out-of-pocket to cover expenses for their care recipient, a finding which increases with a caregiver’s household income. For example, caregivers with an HHI of less than \$25k spend \$100 (median) per month compared to those with an HHI of \$100k or more who spend \$300 (median) per month. Across all caregivers, 75 percent receive no financial assistance or payment for their work. Paradoxically, caregivers with an HHI of \$100k or more (32 percent) are more likely to receive some financial assistance for their caregiving duties, compared to only 20 percent of those with an HHI of less than \$25k.

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

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

The Health Effects of Being a Caregiver

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

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

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

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

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

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

- Thirty-two percent of Primary caregivers have been providing care for five or more years compared to 17 percent of Non-Primary caregivers;
- Primary caregivers spend more time per month caregiving (80 hours median) compared to Non-Primary caregivers (22 hours median). Forty-five percent of Primary caregivers spend 100 or more hours per month caregiving compared to 15 percent of Non-Primary caregivers;
- Among caregivers who are currently employed or have been employed during their time as a caregiver, Primary caregivers (82 percent) are far more likely than Non-Primary (62 percent) to have made some form of adjustment to their employment. Primary caregivers (32 percent) are also more likely than Non-Primary caregivers (17 percent) to have experienced some form of adverse actions taken by their employers;

- Sixty-one percent of Primary caregivers indicate their own health takes a backseat to that of their care recipient, compared to only 41 percent of Non-Primary caregivers. And 21 percent of Primary caregivers say their health has declined since becoming a caregiver, a finding that is double that of Non-Primary caregivers (10 percent); and,
- Twenty-two percent of Primary caregivers say their financial situation has worsened since becoming a caregiver, compared to 10 percent of Non-Primary caregivers.

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

Types of Help Caregivers Seek

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

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

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

For full survey results, additional information, as well as tools and resources for caregivers, please visit www.transamericainstitute.org.

About Transamerica Institute®

Transamerica Institute® 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 comprises 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 Survey

An online survey was conducted by Harris Poll between March 13 and April 21, 2017 among 3,074 caregivers from a subset of a nationally representative sample of the general population. Caregivers met the following criteria: U.S. residents, age 18 or older, non-professional/unpaid caregivers who provided care for a relative or friend at any time in the past 12 months. The sample included 2,137 Primary caregivers and 829 Non-Primary caregivers.

Results 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, employment status; and,
- 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.

About this Executive Summary

This Executive Summary is derived from the report, *The Many Faces of Caregivers: A Close-Up Look at Caregiving and Its Impacts*, which was prepared internally by the research team at Transamerica Institute. See www.transamericainstitute.org for the full report, caregiving resources, fact sheet, and additional materials.