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Utah Caregiving Perspectives

A Survey Exploring Utah Caregivers' Employment, Challenges, and Support Needs

Many caregivers share experiences and needs, but differences arise based on factors like age, gender, employment status, caregiving hours, and living situation.

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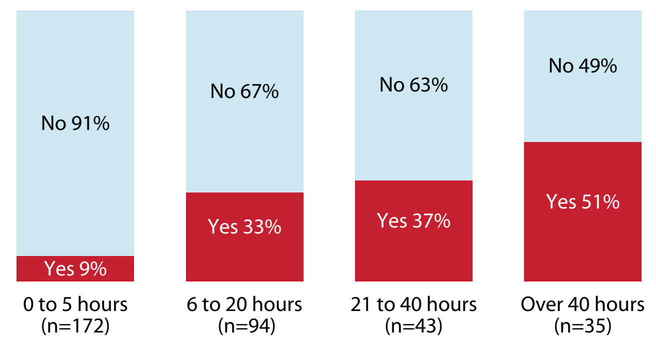
Analysis in Brief

Utah caregivers are a heterogeneous group and they provide care for friends and family members in a variety of ways. Although many Utah caregivers are balancing the demands of work, family, and caregiving in ways they feel are acceptable, certain subsets of caregivers defined by age, gender, income, employment status, hours of caregiving, and living situation need more support.

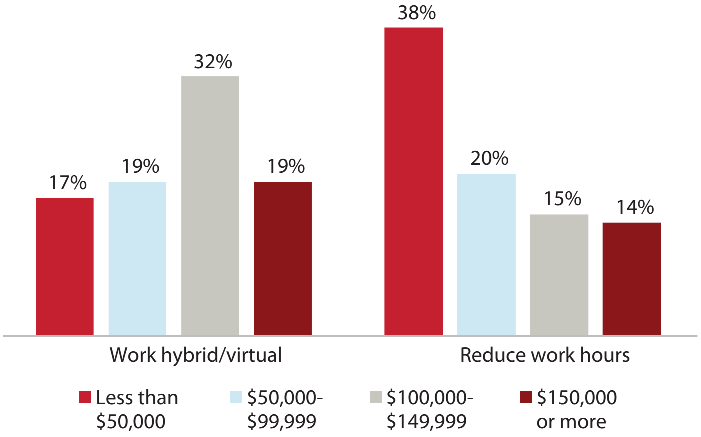
Time commitments and caregiving arrangements vary widely. Whereas half (50%) of caregivers devote five hours or less each week to caregiving, one in ten spends more than 40 hours weekly. One third (34%) of caregivers live in the same household as their care recipient and just over a quarter (26%) cared for someone living on their own.

- **More than 4 in 10 caregivers report financial stress.** Even more report mental health concerns. Both types of concern are reported at higher rates by caregivers who devote more time to caregiving.
- **Most Utah caregivers work.** Forty-nine percent of caregivers work full-time,16% part-time, and a little over a third are not currently employed. Though most caregivers are satisfied with their current work level, some (both full-time and not currently working) would ideally prefer to work part-time.
- **Hybrid/virtual work and reduced hours are the most frequent work-related changes related to caregiving.** Two in five employed caregivers (40%) made a work-related change due to caregiving. Of the two most common changes, lower income caregivers most often reduced their work hours while higher earning caregivers shifted to remote or hybrid work (See Figure 50).
- **Utah caregivers rely on friends and family for support.** More than half of caregivers (52%) turned to family or friends for help caregiving while only 11% paid for assistance or a home health service. Additionally, 11% found support through government or community programs. Forty-two percent indicate that financial support through a government caregiver program would be helpful.

By Caregiving Hours: During the past twelve months, have you delayed any healthcare for yourself as a result of your caregiving responsibilities? n=347



By Income: What work-related changes did you experience due to caregiving? n=226



- **Likelihood of delaying personal healthcare increases with hours of caregiving.** Over half of caregivers who provide over 40 hours of care have delayed healthcare for themselves in the past year. A third or more who provided 6-40 hours of caregiving have also delayed their own healthcare.

Table of Contents

The Family Caregiving Collaborative contributed to and sponsored this report.

The **Family Caregiving Collaborative** is a University of Utah College of Nursing-led interdisciplinary initiative whose mission is to create a future where caregivers of all ages, races, ethnicities, and gender are seen, heard, understood, valued, connected, and supported. Collaborative work focuses in 4 key areas: research, education, clinical practice, and community engagement/policy. To learn more, visit nursing.utah.edu/FCC.

Introduction

There is no simple way to define Utah caregivers or their caregiving experience. According to several measures, most caregivers are comfortable with their situation. However, for almost every measure, there are segments of the population who are more likely to struggle. This report examines both the summary responses for all caregivers and notable differentiations in caregiving experience depending on age, gender, income, employment status, hours of caregiving, and living situation.

According to the survey, Utah caregivers are more likely to be women (61%), married (78%), White (90%), and living in a household with no children (56%). However, this broad description doesn't capture the complexities of the group. For instance, male caregivers are more likely to be 65 and older (28% compared to 21% women), and earn more than $100,000 a year (41% compared with 34% of women). The balancing act required for caregiving also looks different depending on factors such as whether a caregiver works full-time (43%) and their weekly caregiving time commitment (ranging from 0-5 hours (50%) to over 40 hours (11%)).

Utah caregivers provide diverse insights into their need for support and the challenges they face due to their caregiving responsibilities. The vast majority of Utah caregivers are unpaid (97%) and have not received caregiving support from the state or county (91%), yet 42% indicate that financial support through a government caregiver program would be helpful. Only sixteen percent of caregivers always or almost always have difficulty balancing family life and caregiving. However, when looking at specific demographics, over a quarter (28%) of caregivers ages 55-64 and those providing more than 20 hours of caregiving (28%), struggle with this balance. Differences like these underscore the unique challenges for subsets of caregivers.

Given the survey sample size (347 total caregivers, of which 226 are employed), and the potential for caregivers with certain characteristics to be over or underrepresented in the survey, statistical significance is not attributed to the findings. However, the data does reveal caregiver characteristics that often coincide with variations in caregiving experience.

When cross-tabulating variables with demographic questions, a linear relationship occasionally emerges. One example is the relationship between the number of hours of care a caregiver provides and whether they have delayed health care for themselves in the last 12 months. The more hours of care a caregiver provides, the more likely they are to have delayed health care for themselves. In contrast, most relationships lack a consistent trajectory. For example, although the highest percentage of caregivers who say caregiving and work balance is acceptable are those making $150,000 or more (88%), the second most likely income category is those making between $50,000 and $99,999 (81%), rather than the next highest income group of $100,000 to $149,999 (73%).

The survey does not offer a definitive explanation of reasons behind these trends and variations, but the relationships suggest an ebb and flow of life demands at different ages, variations in life demands based on income, variations in work demands based on job type, and differences between employed caregiver's support needs and the support needs of homemakers or retirees.

Figure 1: Surveyed Caregivers by County

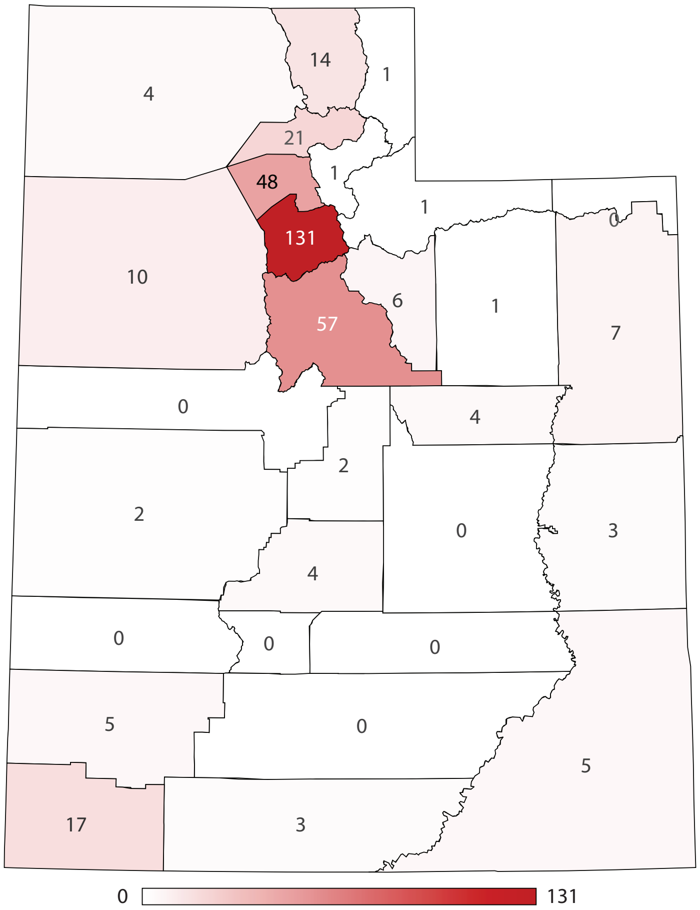


Figure 2: Surveyed Caregivers by Marital Status

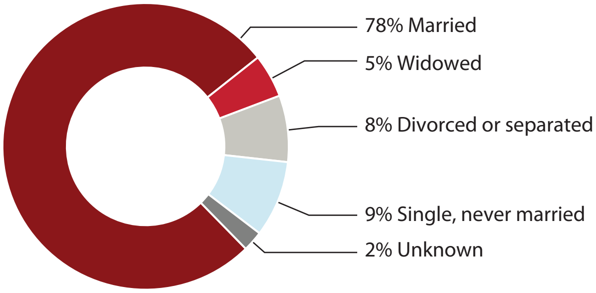


Table 1: Demographic Characteristics of Surveyed Caregivers and Utah Population

Demographics		Survey	State
Gender	Male	38.3%	50.6%
	Female	61.4%	49.4%
Age	18 to 24	3.5%	11.2%
	25 to 34	9.2%	14.6%
	35 to 44	18.4%	13.9%
	45 to 54	24.5%	10.4%
	55 to 64	20.5%	9.5%
	65 to 74	15.6%	6.8%
	75 and older	8.4%	4.3%
Marital Status	Married	78.5%	55.5%
	Widowed	5.0%	3.5%
	Divorced or Separated	7.7%	10.1%
	Single, Never Married	8.8%	30.8%
Race	Hispanic or Latino	3.8%	14.4%
	American Indian or Alaskan Native	0.3%	0.8%
	Asian or Asian American	1.5%	2.3%
	Black or African American	0.0%	1.1%
	Pacific Islander or Native Hawaiian	0.3%	0.9%
	White	89.7%	77.3%
	Multiple Races or Ethnicities	3.5%	3.0%
	Other	0.6%	0.3%

Demographics		Survey	State
Household Size	1-person	9.6%	19.6%
	2-person	30.7%	30.3%
	3 or 4-person	38.3%	29.7%
	5+ person	21.3%	20.4%
Children	0	55.7%	67.1%
	1	16.8%	10.8%
	2	14.2%	10.6%
	3+	13.3%	11.5%
Education	Some High School	0.3%	6.9%
	High School Diploma or G.E.D.	9.8%	22.7%
	Some College or Associate's Degree	38.5%	35.0%
	Bachelor's Degree	33.1%	23.5%
	Graduate or Professional Degree	18.3%	12.0%
Income	Less than $25,000	7.0%	11.3%
	$25,000 to $49,999	15.3%	17.7%
	$50,000 to $74,999	20.3%	18.1%
	$75,000 to $99,999	20.7%	15.1%
	$100,000 to $149,999	18.7%	20.3%
	$150,000 to $199,999	9.0%	8.8%
	$200,000 or more	9.0%	8.5%

Note: All Utah comparisons were taken from the 2021 ACS 5-Year Estimates, except for household size and presence of children, which were sourced from the U.S. Census Bureau 2020 Demographic Housing Characteristics File (DHC). Data describing number of children per household sourced from ACS Microdata. Shares may not sum to 100% due to respondents who were unsure or chose not to answer.

Overview of Employment and Caregivers

Most caregivers also work. Almost half of surveyed caregivers (49%) work full-time, while 16% work part-time, and more than a third (35%) are not employed (Figure 3). Of those who are either employed part- or full-time, 17% are self-employed.

According to the survey, a larger share of males and aged 45-54 caregivers work full-time while respondents 65 and older, women, and those caring for someone more than 40 hours a week are less likely to be employed when compared to other categories.

- 65% of male caregivers work full-time compared to 39% of female caregivers
- 69% of respondents aged 45-54 work full-time compared to 17% of those 65 and older and 55%-56% of respondents in other age groups
- 66% percent of respondents 65 or older are not employed compared to 18%-34% of adults in other categories
- 49% of those caring for someone for more than 40 hours a week are not employed compared to 31%-37% of those working less than 40 hours a week

Ideally, more caregivers would like to work part-time. While 49% of caregivers are currently employed full-time, only 43% express a preference for full-time employment. Notably, there is a higher preference for part-time employment (27%) compared to the current part-time employment rate of 16%, indicating that some caregivers presently engaged in full-time or non-employment roles would prefer part-time work. A substantial portion (30%) of caregivers expressed a desire not to be employed (35% of respondents are currently not employed) (Figure 4).

Flexibility is key for those who would like to work more. Caregivers who indicated they would like to work more (n=27) were asked what would be needed to achieve their ideal work level. About a quarter of them indicated they would need flexibility in hours and/or schedule for their ideal work level (Figure 5).

Given a list of employer policies, the twenty-seven caregivers wanting to work more underscore the importance of a flexible schedule, remote work, and better-paying part-time jobs (Figure 6).

Few non-working caregivers stopped working due to caregiving. Only 2% of respondents not currently working stopped due to caregiving. Of 120 unemployed caregivers, 58% stopped working for a reason other than caregiving (such as retirement), and 28% chose to be homemakers (Figure 7).

Nearly a quarter of caregivers (23%) devote more than 20 hours each week to caregiving. Half of respondents (50%) provide care for less than 6 hours a week. More than a quarter of respondents (27%) provide 6-20 hours of care each week. Another 13% provide 21-40 hours of weekly care, while only 10% provide over 40 hours of care a week (Figure 8).

Figure 3: Which of the following describes your current employment status? (n=347)

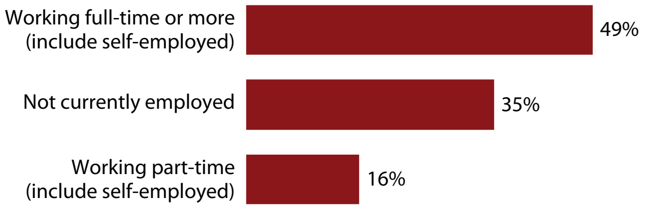


Figure 4: Current and Ideal Employment Status n=346

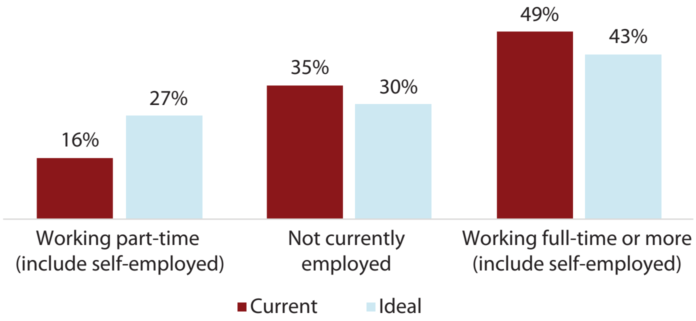


Figure 5: What is necessary to allow your ideal work level? n=27 *(reported by actual number responding)*

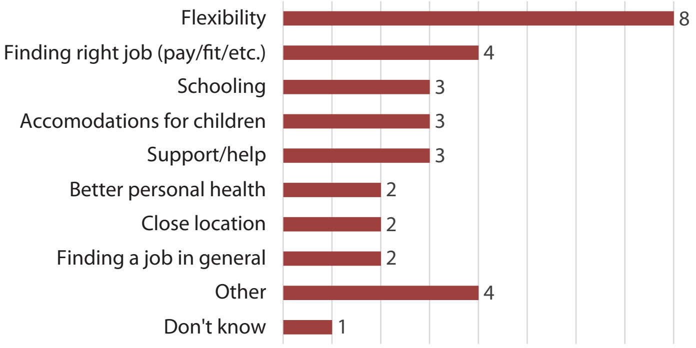


Figure 7: Non-working Caregivers: Which best describes your employment situation? n=120

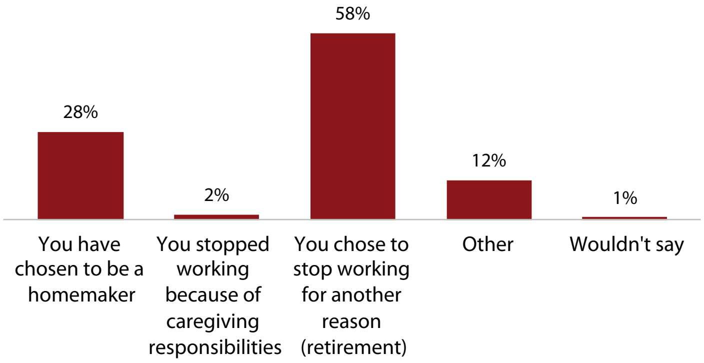


Figure 8: In a typical week, about how many hours do/did you spend caring for this person? n=344

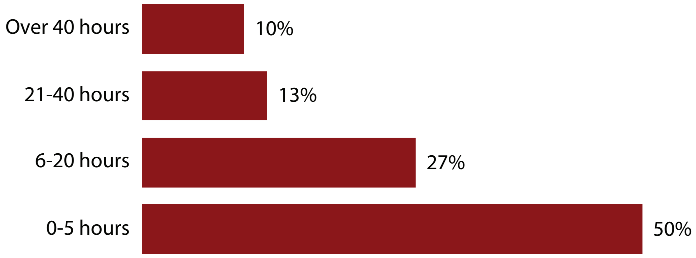


Figure 9: Are you paid for the hours that you spend helping this person? n=347

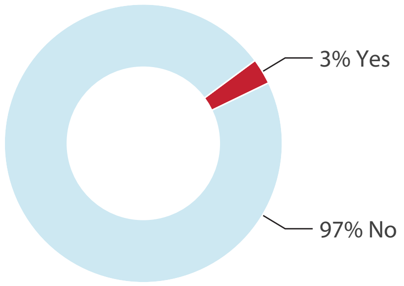
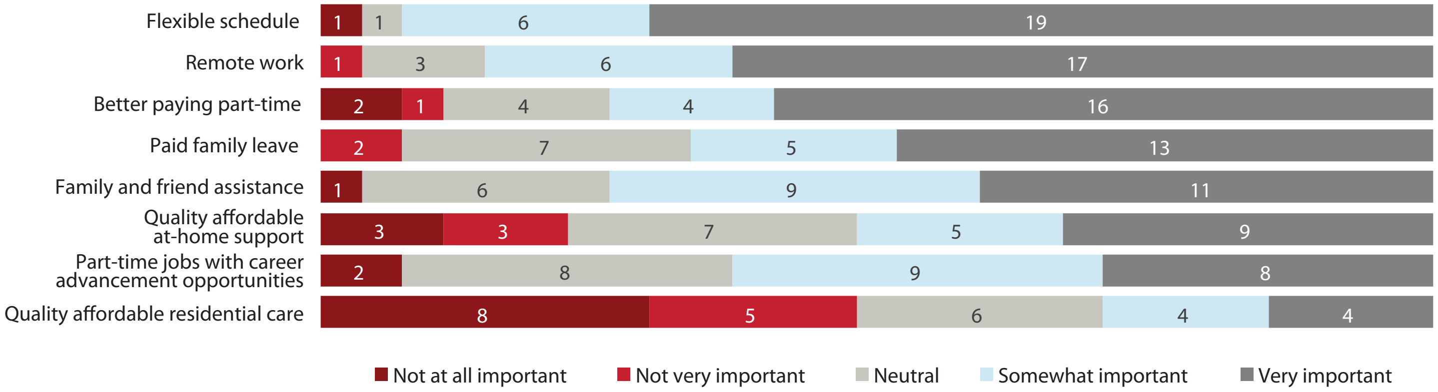


Figure 6: How Important are the Following to Achieve your Ideal Work/Caregiving Balance? n=27 *(reported by actual number responding)*



Additional Caregiver Characteristics

The vast majority of caregivers are unpaid. Ninety-seven percent of caregivers are not paid for their caregiving (Figure 9).

Few caregivers seek or receive support services from the government. Only a small proportion of caregivers have looked for (15%) or received (9%) support services from the state or county (Figures 10 and 11).

Residential facility care is not typical. Caregivers are equally likely (34%) to have the person they are caring for live with them or with a friend or family member. A quarter (26%) of caregivers care for someone who lives alone, and 4% care for someone who lives in a residential care facility (Figure 12).

Most caregivers have a short drive. For those not living with the person they care for, most (67%) are within a 20-minute drive. Twenty-two percent are between a 20-minute and 59-minute drive, leaving 12% who drive one or more hours (Figure 13).

Caregivers typically visit a few times each week or month. Over 70% of caregivers who care for someone not living with them make the trip several times a week (39%) or a few times a month (32%). Twelve percent of caregivers not living with the person they are caring for make the trip at least daily (Figure 14).

For a demographic profile of caregivers interviewed in this survey, please see Appendix 2.

Caregivers providing care for more than 40 hours a week

Although a small number of respondents (35) provide care for more than 40 hours a week, survey results suggest these caregivers may differ from other caregivers in important ways:

- 69% are women compared to 61% of caregivers overall
- 49% are not employed compared to 35% of caregivers overall
- 29% are employed part-time, compared to 16% of caregivers overall
- 62% had bachelor's degrees or above compared with 51% for caregivers overall
- 37% are aged 65 or older compared with 24% for caregivers overall
- 43% with incomes under $50,000 compared with 22% of caregivers overall
- Caregivers who spent more than 40 hours giving care were less likely to live in Salt Lake County (17%) compared to those spending 40 hours or less caregiving (37 to 41%)

Figure 10: Have you looked for caregiving support services from the state or county? n=347

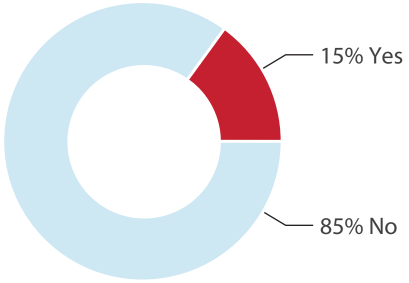


Figure 11: Have you received caregiving support services from the state or county? n=347

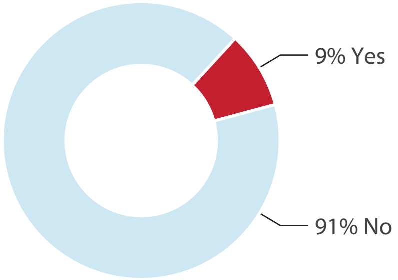


Figure 12: What best describes the living situation of the person you are/were caring for? n=346

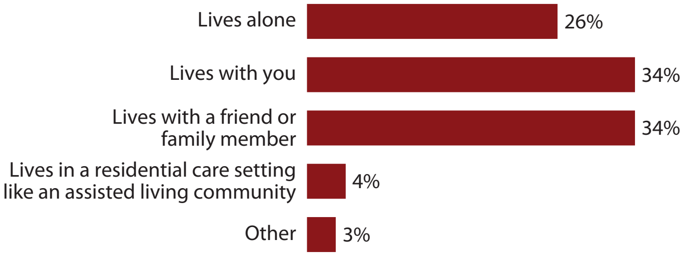
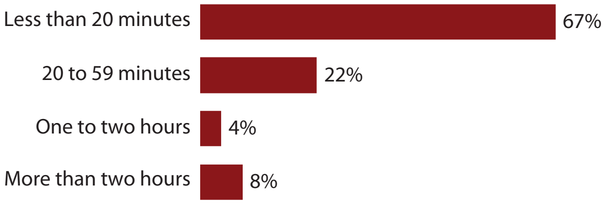


Figure 13: How long does it take to travel from your resident to this person's home? n=228



How are caregivers impacted by caregiving?

Most caregivers say their physical health is good. The majority of caregivers (80%) report being in good health themselves, with four in five caregivers describing their health as good, very good, or excellent. Only 4% of caregivers indicate their health is poor (Figure 15).

According to survey results, non-employed and lower wage earners are more likely to report their health is poor or fair.

- 30% of those not currently employed compared to 15% of full time and 18% of part time workers
- 37% with incomes of less than $50,000 compared with 6% to 16% of those with higher incomes

Nearly a quarter of caregivers (23%) delay their own health care due to caregiving responsibilities (Figure 16).

Survey results show that personal health care is more likely to be delayed by those living with the person they care for and/or those providing more care each week.

- 37% of caregivers who live with the person they care for compared to 16% of caregivers whose friend or loved one lives outside their home
- 51% of those giving care for 40 or more hours each week compared to 37%, 33%, and 9% in descending caregiving hours (Figure 17)

Mental Health

Mental health concerns related to caregiving affect 45% of all caregivers. More than 1 in 4 caregivers (27%) report mild concerns resulting from their caregiving duties, while another 14% report moderate concerns, and 4% experience serious mental health concerns (Figure 18).

Responses to the survey indicate that caregivers who suffer the least from mental health concerns live with the individual they care for and/or give 0-5 hours per week giving care.

- 9% of those spending 0- 5 hours per week caregiving compared to 24%-29% in ascending order of caregiving hour categories (Figure 19)
- 25% living with the individual they care for had serious or moderate concerns compared to15% of all other living arrangements

> *"I was too tired and it wiped me out. I had my own health problems and work to manage. It was exhausting and I had to see a therapist."*

Figure 14: About how often do you make this trip? n=228

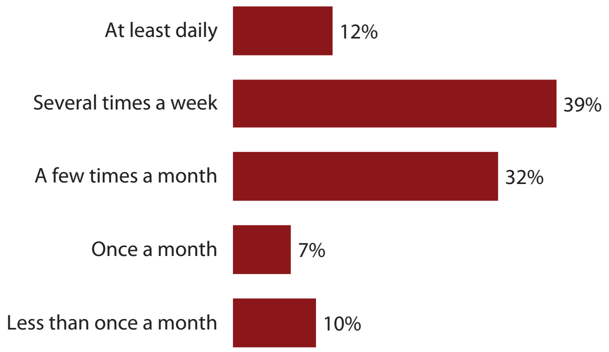


Figure 15: In general, would you say your own health is "excellent," "very good," "fair," or "poor"? n=347

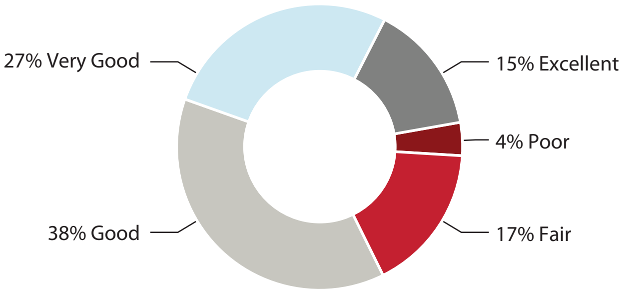


Figure 16: During the past twelve months, have you delayed any health care for yourself as a result of your caregiving responsibilities? n=347

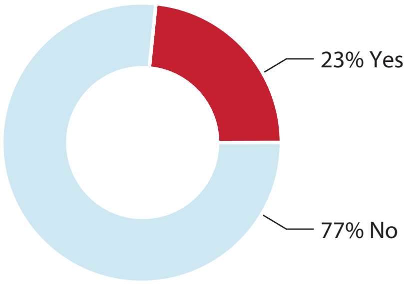


Figure 17: By Caregiving Hours: During the past twelve months, have you delayed any healthcare for yourself as a result of your caregiving responsibilities? n=347

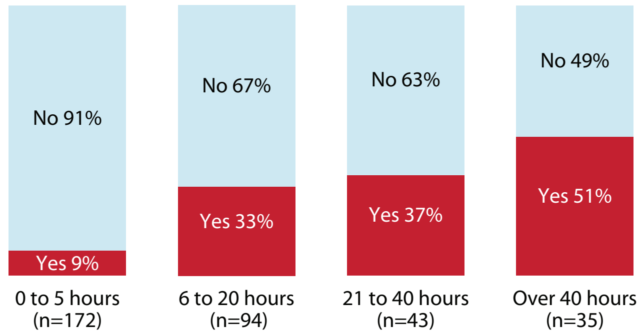


Figure 18: During the past twelve months, have you suffered any mental health concerns as a result of providing care to this person? n=346

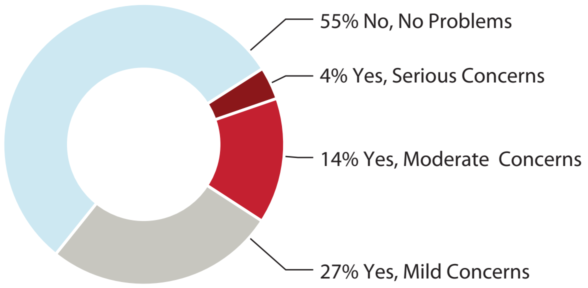


Figure 20: During the past twelve months, have you suffered any financial stress yourself as a result of providing care to this person? n=347

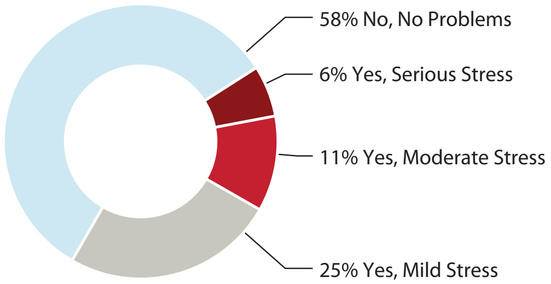


Figure 19: By Caregiving Hours: During the past twelve months, have you suffered any mental health concerns as a result of providing care to this person? n=344

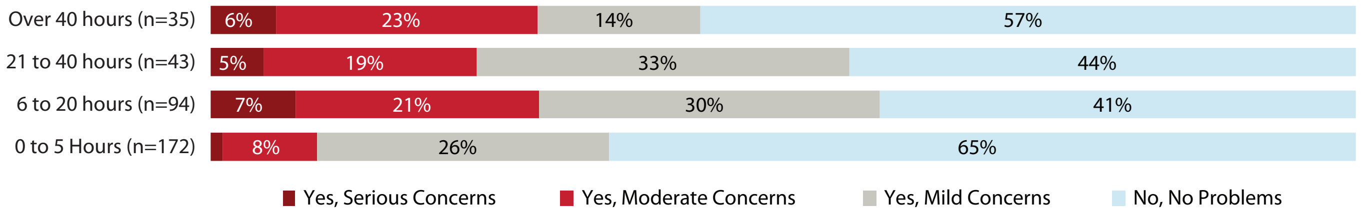
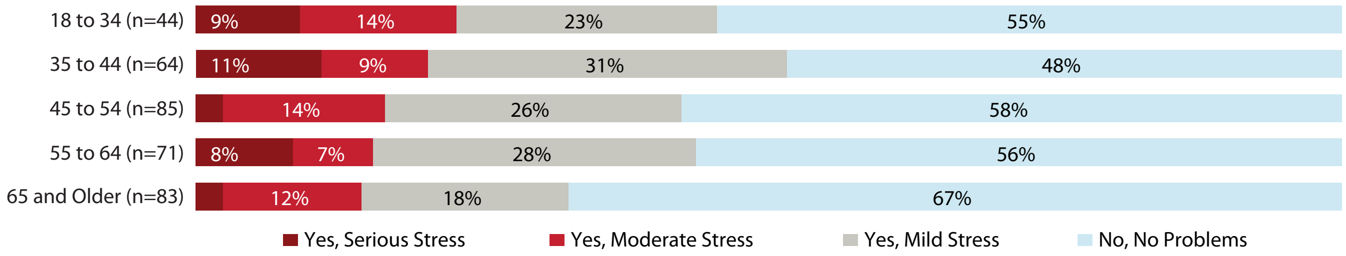


Figure 21: By Age: During the past twelve months, have you suffered any financial stress yourself as a result of providing care to this person? n=347



Financial Stress

Financial stress is a challenge for many Utah caregivers. More than 4 in ten caregivers (42%) experience financial stress due to caring for their friend or family member. A quarter (25%) of all caregivers report mild financial stress, 11% report moderate financial stress, and 6% report serious financial stress (Figure 20).

According to the survey, caregivers who experience serious or moderate financial stress are more likely to be: younger; spending more than 5 hours per week caregiving; living with the person they provide care for, and/or earning a lower income.

> *"The biggest challenge is money."*

<u>Categories where a higher percentage of caregivers face serious or moderate financial stress:</u>

- 23% of caregivers age 18 to 34 experience serious or moderate financial stress compared to 20%, 16%, 15%, and 14% of other age categories in ascending order (See Figure 21)
- More than 25% of those who spend more than 5 hours weekly caregiving face financial stress, compared to 7% of those who spend 5 hours or less
- 33% of those who live with the person they are providing care for compared to 8%-23% of those in other living arrangements
- 34% of caregivers earning annual household incomes below $50,000 face stress compared to 6% - 17% in ascending order of income categories

Caregiving Balance, Strategies, and Support

While over half (57%) of caregivers report never or almost never having difficulty balancing caregiving with family life, 16% face this challenge often (Figure 22). On a scale from one to five, with one being never and five being always, 27% of caregivers chose a rating of a three, indicating they experience difficulty balancing family life and caregiving, but not frequently.

Survey results indicate that caregivers aged 55-64, those with the lowest incomes, and caregivers spending more than 20 hours caring weekly are more likely to report having trouble balancing caregiving with family life (giving ratings of 4 or 5 on the scale).

> *“Trying to spend time with MY family and care for the person I’m caring for at the same time. I’m split in two.”*

<u>Categories where a higher percentage of caregivers have trouble balancing caregiving with family life (assigning ratings of 4 or 5):</u>

- 28% of 55–64-year-old caregivers compared to 14% of those 65 and older and 7%-17% in younger age categories in ascending order
- 21% of caregivers who earn less than $50,000 , compared to 13%-16% of caregivers in higher income categories
- 28% of caregivers who spend 21 or more hours weekly providing care, compared to 9% of those who spend 0 to 5 hours and 20% of those who spend 6-20 hours

Analysis reveals unique family life balance response patterns among the 13 respondents with loved ones in residential care compared to caregivers navigating other living situations.[1] Caregivers with loved ones in residential care are the least likely to say it is never difficult to balance family life and caregiving but are also the least likely to say this balance is always difficult. Instead, their ratings tend towards the middle categories, with the highest shares of respondents assigning difficulty ratings of 2 and 4 (Figure 23).

More than six in ten caregivers (63%) report some level of difficulty balancing caregiving and self-care (ratings of 2-5 on 5-point scale), with 18% indicating this is frequently challenging by assigning ratings of 4 or 5 (Figure 24).

Caregivers more likely to experience difficulty balancing caregiving with caring for themselves tend to be those who live with the person they care for, have household incomes less than $100,000, and spend more hours each week providing care (Figure 25).

Figure 22: During the past twelve months, how frequently was it difficult for you to balance your family life and caregiving? Use a 1 to 5 scale where 1 means "never" and 5 means "always." n=346

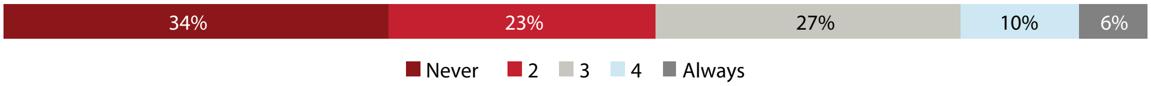


Figure 23: By Living Situation: During the past twelve months, how frequently was it difficult for you to balance your family life and caregiving? Use a 1 to 5 scale, with 1 being "never" and 5 being "always." n=345

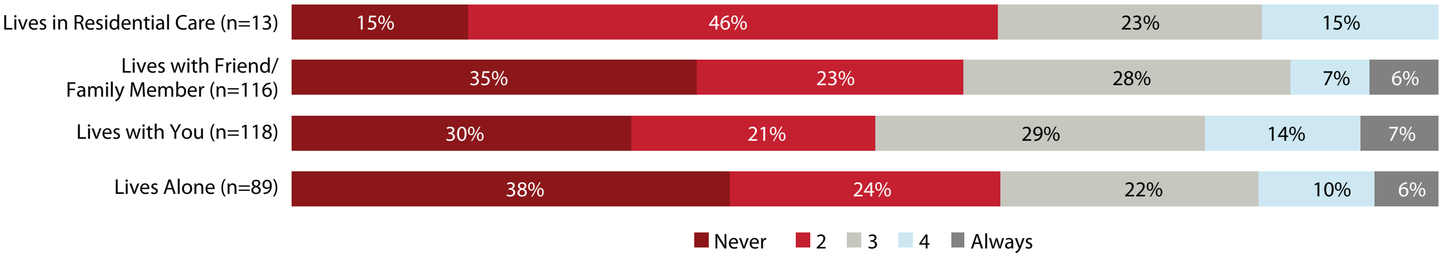
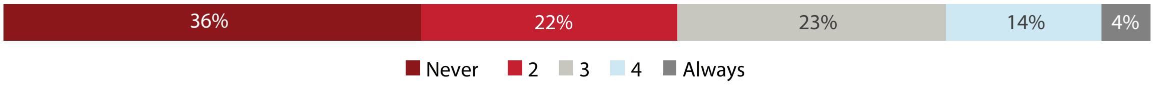


Figure 24: During the past twelve months, how frequently was it difficult for you to balance caring for yourself and caregiving? Use a 1 to 5 scale where 1 means "never" and 5 means "always." n=346



Categories where a higher percentage of caregivers have trouble balancing caregiving with caring for themselves (4 or 5 selected on the 5-point scale)

- 27% of caregivers living with the person they care for in contrast to 12%-16% of caregivers who live apart from the person they provide care for
- 21%-22% of those with household incomes less than $100,000 compared to 8%-11% for those with household incomes of $100,000 or more
- 34% of caregivers providing care for more than 40 hours, compared with 25% caring for 6-40 hours and 9% of those caring for under 0-5 hours

Strategies for Managing Caregiving

Getting help from friends and family is important. Slightly more than half of caregivers (52%) have requested help from friends or family members to handle their caregiving responsibilities. About 1 in ten respondents (11%) have paid for assistance or utilized a home health service to manage their caregiving duties. The same percentage have used a government or community program in their caregiving efforts (Figure 26). Fewer respondents mention alternative strategies, such as utilizing insurance, Alcoholics Anonymous, physical therapy, cleaning assistance, hospice care/respite care, and adjusting personal schedules (see Appendix 3 for all "other" comments).

Among the 11% (n=37) of caregivers who paid for caregiving assistance, most received these services from a family member or a professional caregiver. A smaller number paid for services provided by a non-professional caregiver.

According to the survey, caregivers are more likely to ask family or a friend for unpaid help if they are younger, live with the person they care for, provide more hours of care each week, or have higher incomes.

Categories where a higher percentage of caregivers are likely to ask family or a friend for unpaid help

- 59%-61% of caregivers aged 18-54 compared to 48% for older age groups of 55-64 and 41% for 65 and older (Figure 27)
- 58%-69% provide care for six or more hours per week compared to 43% caring for 0-5 hours (Figure 28)
- 59% for those earning $150,000 or more compared to 49% earning under $50,000 (the percent descends from highest to lowest income though it is the most common strategy used across all incomes)
- 58% of caregivers live with the person they care for compared to 47% with the person living alone, 49%, living with a friend/family member, and 54% living in residential care

Figure 25: By Caregiving Hours: During the past twelve months, how frequently was it difficult for you to balance caring for yourself and caregiving? Use a 1 to 5 scale, with 1 being "never" and 5 being "always." n=343

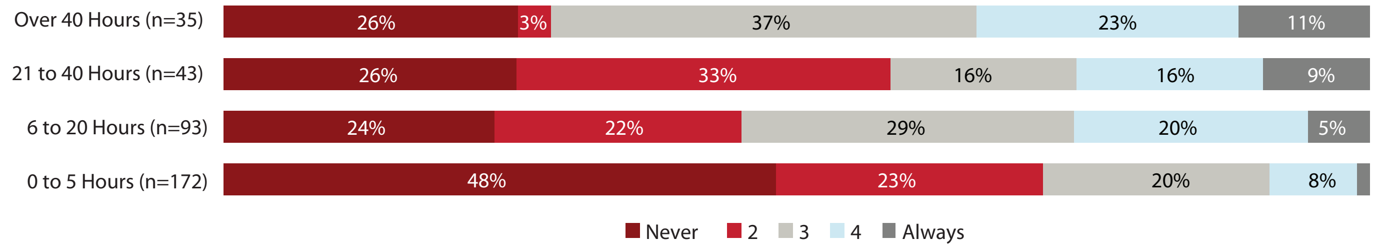


Figure 26: Which of the following strategies did/are you using to manage caregiving? (Yes responses shown) n=347

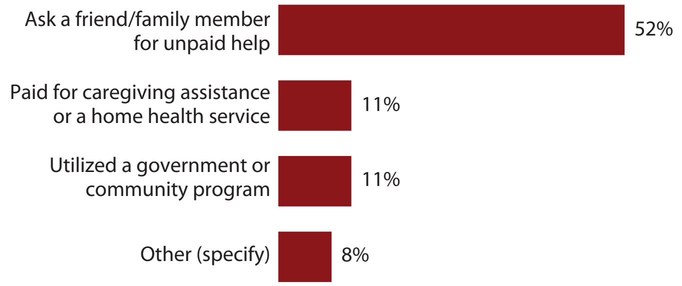


Figure 27: By Age: Which strategies are you using to manage caregiving? "Asked a friend or family member for unpaid help" ("Yes" responses by caregiver age)

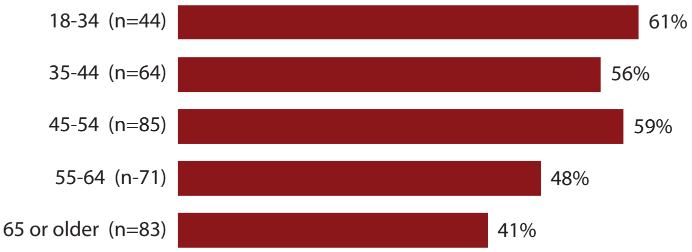


Figure 28: By Caregiving Hours: Which strategies are you using to manage caregiving? "Asked a friend or family member for unpaid help" ("Yes" responses by hours caregiving per week) n=180

Figure 29: During the past 12 months, did you ever feel unsupported or inadequate as a caregiver? n=347

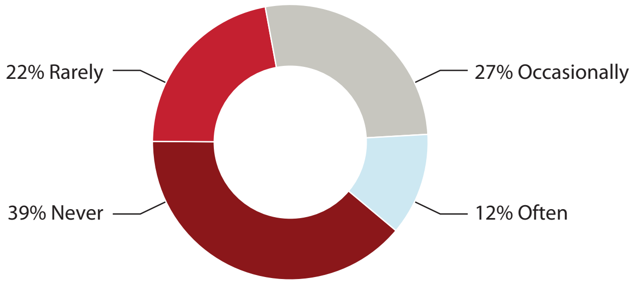


Figure 30: By Caregiving Hours: During the past 12 months, did you ever feel unsupported or inadequate as a caregiver? n=347

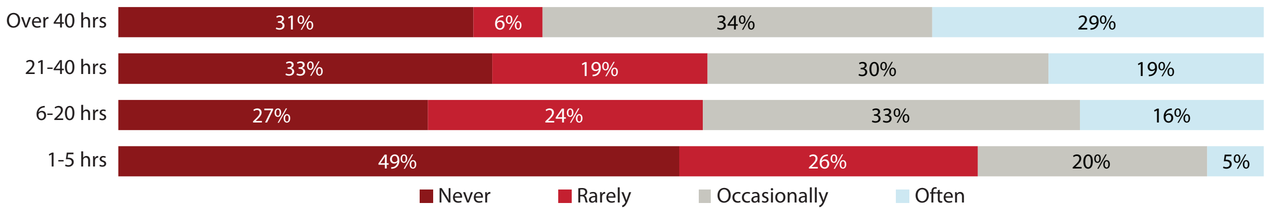
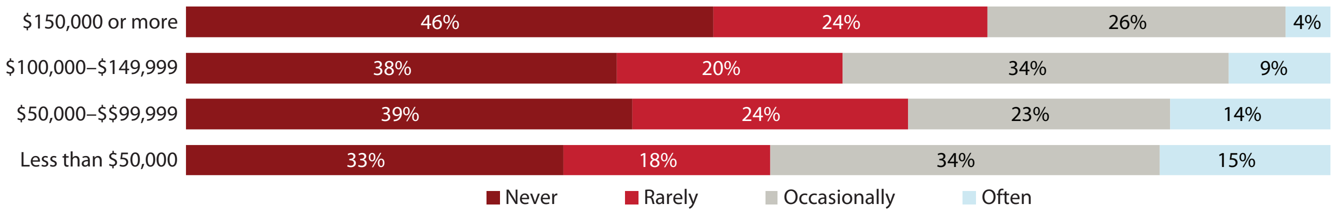


Figure 31: By Income: During the past 12 months, did you ever feel unsupported or inadequate as a caregiver? n=347



Support for Caregivers

There is no one-size-fits-all answer to how caregivers feel about the adequacy of the care they provide. Overall, most caregivers seldom or never experience feelings of inadequacy or lack of support. Roughly 1 in ten survey respondents (12%) often felt unsupported or inadequate in their role as a caregiver during the past year. Around a quarter (27%) responded that they felt this way "occasionally." The majority of respondents indicate they "never" (39%) or "rarely" (22%) experienced feelings of being unsupported or feeling inadequate as a caregiver during the past year (Figure 29).

According to the survey, caregivers who provide more hours of care are more likely to feel inadequate or unsupported.

<u>Categories where a higher percentage of caregivers "often" feel inadequate/unsupported:</u>

- 18% of caregivers employed part-time compared to 11% of full-time working caregivers and 12% of those not employed
- 29% of those providing over 40 hours of care compared with 19% of 21-40 hour caregivers, 16% for of 6-20 hour caregivers, and 5% of less than 5 hours of caregiving (Figure 30)

Many caregivers never feel unsupported. Caregivers who are men, older, not employed, caring for 0-5 hours, earning $150,000 or more, or who provide care for someone living on their own or with friends or family are most likely to say they never feel unsupported.

<u>Categories where a higher percentage of caregivers "never" feel inadequate/unsupported:</u>

- 51% of those aged 65 and older compared to 37%, 36%, and 32% of caregivers ages 55-64, 35-54, and 18-34, respectively.
- 45% of caregivers that are not employed compared with 33% of part-time and 36% of full-time caregivers
- 47% of men care providers as opposed to 34% of women
- 49% caring for the person 0-5 hours a week versus 31% providing over 40 hours, 33% caring for 21-40 hours, and 27% giving 6-20 hours of care each week (Figure 30)
- 46% of those earning $150,000 or more compared with 33%-39% of caregivers in the lower income categories (Figure 31)
- 46% of those caring for a person that lives with a friend/family and 42% with a loved one living independently

Figure 32: By Living Situation: During the past 12 months, did you ever feel unsupported or inadequate as a caregiver? n=347

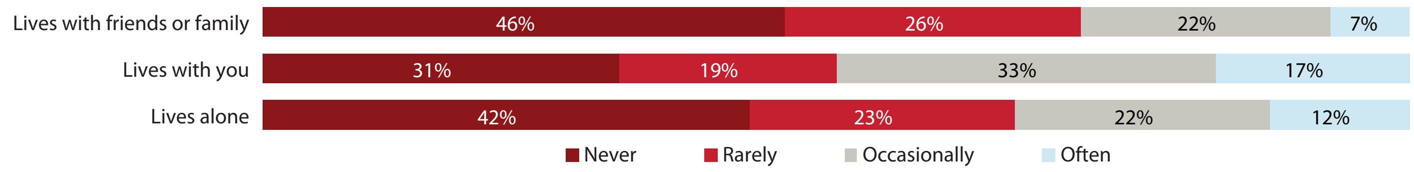
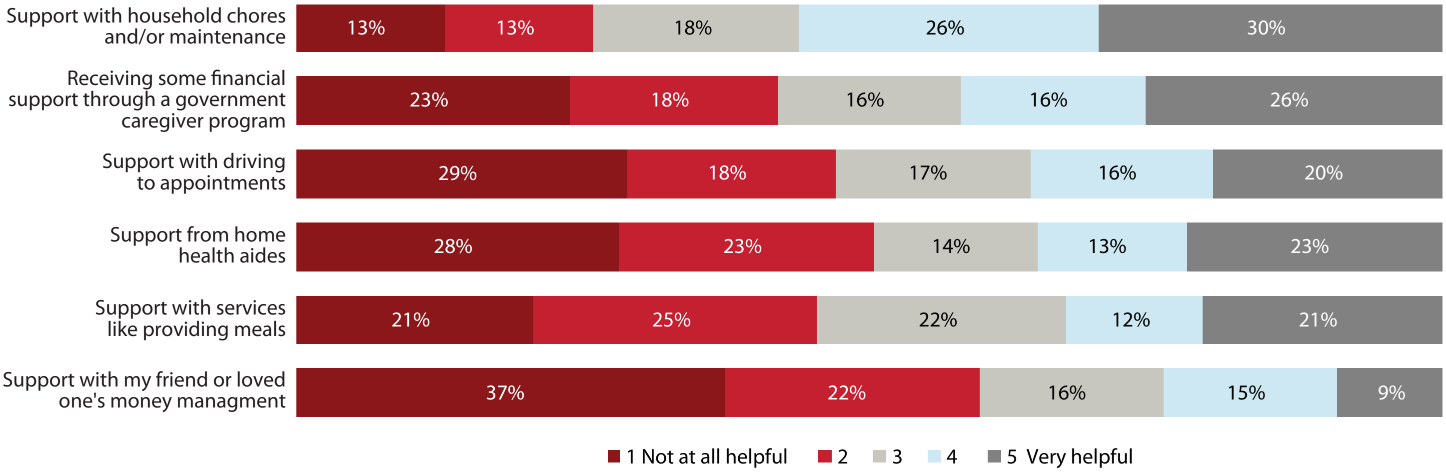


Figure 33: Using a 1-5 scale, with 1 being not at all helpful and 5 being very helpful, how helpful would the following be in allowing you to provide care for your friend or loved one outside of a residential care setting? n=199-202



> *"…support with food support, bills, rides, you name it. When you are down on your luck and there's nobody there to help, whether you're the single caregiver or not, it would help if you knew somebody was behind you backing you up."*

in contrast with 31% of caregivers who reside with the person they are caring for, and 31% of those caring for someone in residential care (Figure 32)

Caregivers who experienced feelings of inadequacy or lack of support in the past year offer a variety of responses when asked about the types of assistance that would have been beneficial to them. The most frequent responses include support from family and friends (39%), financial support (11%), and medical support (10%). Several other ideas were mentioned, including things like training and resources, mental healthcare, respite care, emotional support, etc. A complete list of verbatim comments is available in Appendix 3.

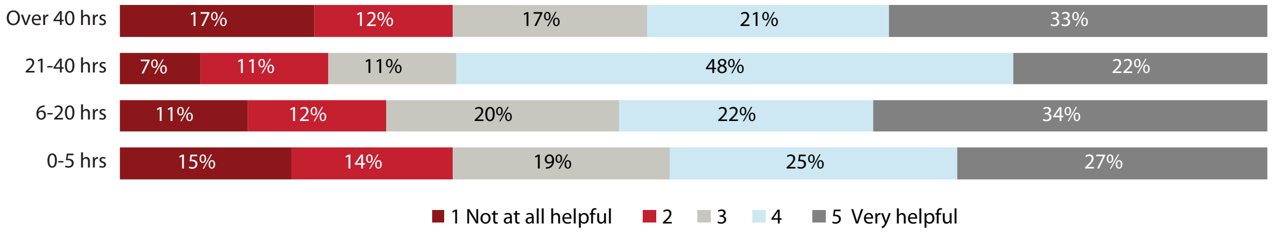
Helpfulness of Caregiving Supports

Assistance with household chores and financial support are most helpful. Caregivers who felt unsupported or inadequate in the past 12 months ranked "support with household chores and maintenance" as the most helpful form of support to allow them to continue to provide care to their friend or loved one outside of a residential care setting. Over half of the respondents (56%) rate this option as helpful (combined responses of 4 and 5 on the scale).

Table 2: Think about a specific time you felt unsupported… what kind of support would have helped? This could include support from family, friends, government services, medical support, or others. n=212

Support mentioned		n=
Support from family, friends	39%	(82)
Financial support	11%	(23)
Medical support	10%	(22)
Government support	9%	(19)
Training, resources, information	6%	(12)
Mental healthcare	6%	(12)
Emotional support, a listening ear	5%	(11)
Meals	4%	(8)
Nothing	4%	(8)
Respite care, support for overwhelm	3%	(7)
Any and all support	3%	(6)
Appreciation, acknowledgment	3%	(6)
Community, social support	3%	(6)
General help, support	3%	(6)
Help around the house, yard	3%	(6)
Transportation	3%	(6)
Help with hygiene, physical needs	2%	(5)
Miscellaneous responses	5%	(10)
Don't know	4%	(9)

Figure 34: By Caregiving Hours: *Support with household chores. n=200*



Forty-two percent of caregivers view financial aid through government programs as beneficial support, though an equal percentage (42%) said it would not assist them. About a third of respondents believe that services such as driving to appointments (36%), home health aides (35%), and services providing meals (33%) would contribute significantly to maintaining their current situation. Nearly a quarter of the respondents (24%) identify help with money management as a factor, while the majority (60%) believe it wouldn't significantly aid in providing care outside of a residential setting (Figure 35).

According to the survey, different types of support are likely to be valued by different categories of caregivers.

Categories where a higher percentage of caregivers rate "support with household chores and/or maintenance" as helpful

- 63% of 35-44 year olds and 61% of 55-64 year olds compared with other age groups 41%-56%
- 70% caregiving for 21-40 hours each week compared to those providing 0-5 hours at 52%, 6-20 hours at 56%, and over 40 hours, 45% (See Figure 34)
- 69% of those caring for a person living alone compared with situations where the person resides with the respondent or other caregiver (51%-52%)

Categories where a higher percentage of caregivers rate "receive some financial support through a government program" as helpful

- 55% of aged 18-34 and 57% of 35–44-year-olds contrasted with older caregivers (22%-40%)
- 67% of those providing over 40 hours of care and 52% between 21-40 hours, as opposed to those working fewer hours (31%-42%) (See Figure 35)

Categories where a higher percentage of caregivers rate "support with driving to appointments" as helpful

- 47% of aged 55-64 caregivers compared with 34% to 38% of younger age categories and 23% of those 65 and older
- 43% of those earning over $150,000 compared to 24%-39% of other income categories

Categories where a higher percentage of caregivers rate "support from home health aides" as helpful

- 45% of those between 35-45 compared with other age groups ranging from 25%-39%
- 41% of men contrasted with 33% of women caregivers.
- 45% of those providing care for 21-40 hours per week compared to other caregivers ranging from 33%-36% (See Figure 36)

Categories where a higher percentage of caregivers rate "support with services like providing meals" as helpful (4 or 5 selected on the 5-point scale)

- 44% who provide care for 21-40 hours per week compared with other caregivers' scores ranging from 25%-39% (See Figure 37)
- 46% of those caring for a person who lives alone compared with those in other living situations ranging from 25%-31%

Categories where a higher percentage of caregivers rate "support with person's money management" as helpful (4 or 5 selected on the 5-point scale)

- 33% of caregivers earning between $50,00-$99,999 compared to other income categories ranging from 15%-25%

Of note, fewer than a quarter of respondents overall found money management support to be beneficial.

A notable observation is that respondents aged 65 and older were more inclined to rate certain aspects as 'not helpful' (scoring 1 or 2 on the 5-point scale) compared to other age groups. Specifically:

- Assistance with providing meals: 55% (compared to the overall percentage for all groups of 46%)
- Support with managing their friend or loved one's finances: 82% (compared to the overall finding for all age groups of 59%)
- Receiving financial support through a government caregiver program: 65% (compared to the overall percentage of 42%)

Figure 35: By Caregiving Hours: *Financial support through a government caregiver program. n=198*

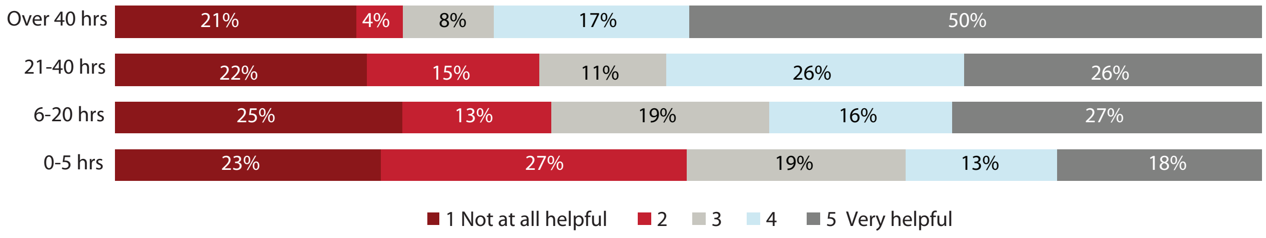


Figure 36: By Caregiving Hours: *Support from home health aides. n=198*

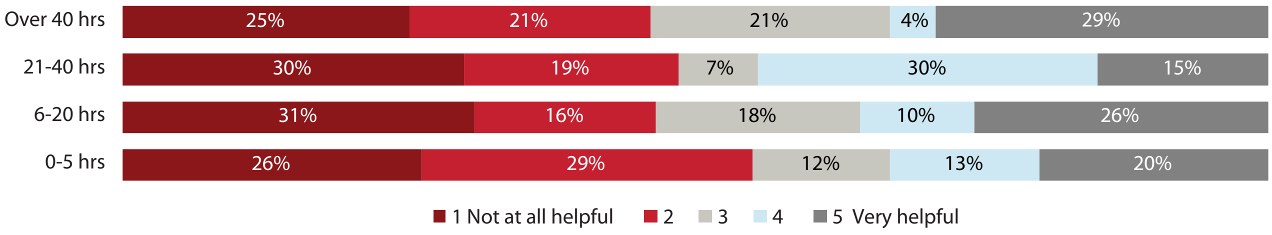
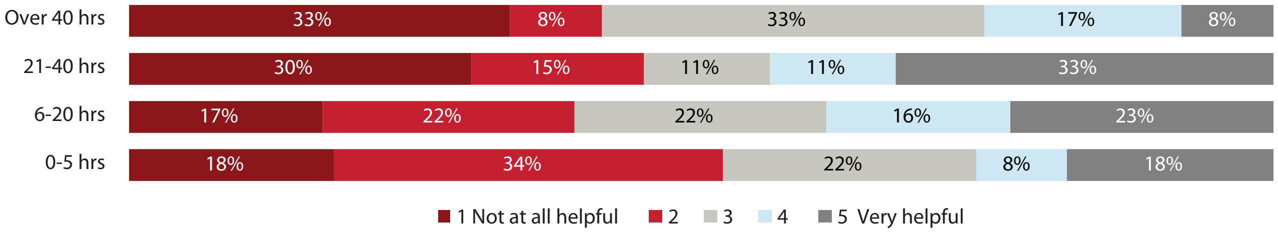


Figure 37: By Caregiving Hours: *Support with services like providing meals. n=200*



Caregivers' Future Outlook

A majority of caregivers are confident in their ability to continue caring for their friend or loved one, but a sizeable group anticipate alternate caregiving arrangements will be required in the future. Seventy-two percent of caregivers said they can sustain caring for their friend or loved one in their current state of health (combining responses of 4 and 5 on a 5-point scale) while 14% indicated they are not currently in a position to provide care as long a their loved one will require it. About 1 in 10 caregivers (11%) express concerns that their physical or mental health might hinder their ability to continue providing care. Nearly 1 in 5 caregivers perceive a residential care setting as the best option for their friend or loved one, although financial constraints may prevent this choice.

Opinions among caregivers differ regarding their expectations for the future care needs of their friend or loved one. While 38% anticipate the care required will surpass what they can provide in the future, 42% do not foresee this circumstance (Figure 38).

According to the survey, caregivers who are employed, who have higher household incomes, whose loved one or friend lives with them or a family member or friend, or who are men are more likely than other caregivers to say they are in a position to continue caregiving. Comparatively, part-time workers and those caregiving for someone who lives alone are more likely than other caregivers to say a residential care setting would be the best option for their friend or loved one. Caregivers providing 6-20 hours of care, aged 45-54, earning a higher household income, or caring for someone living alone are more likely than other caregivers to say they anticipate their friend or loved one requiring more care than they can provide in the future.[2]

Categories where a higher percentage of caregivers say they agree with the statement: "I am in a position to continue providing care to my friend or loved one as long as needed in their current state of health" (4 or 5 selected on the 5-point scale):

- 70%-80% of caregivers in income categories above $50,000 ranging in ascending order for higher income levels compared with 63% for those with incomes of less than $50,000
- 83% of those who live with the person they are caring for and 73% whose loved one lives with a friend or family member compared with 60% for other living situations
- 76% of men compared with 69% of women
- 76% of part-time employees and 74% of full-time compared to 66% of those caregivers who are not employed

Categories where a higher percentage of caregivers say they agree with the statement: "For many reasons, a residential care setting (assisted living, board and care, memory care, or a skilled nursing facility) would be the best situation for my friend or loved one, but it isn't an option financially" (4 or 5

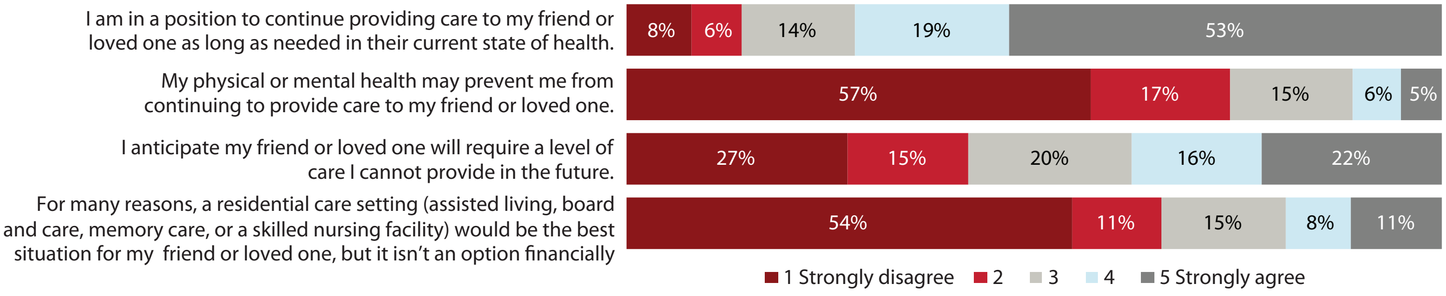


Figure 38: Using a 1 to 5 rating scale with 1 being "Strongly Disagree" and 5 being "Strongly Agree," please indicate your level of agreement with the following statements: n=331-344

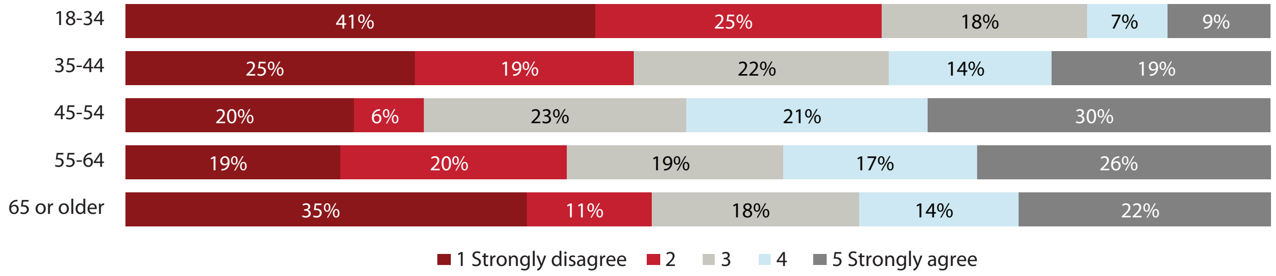


Figure 39: By Age: Do you anticipate a friend or loved one will require a level of care you cannot provide in the future? n=344

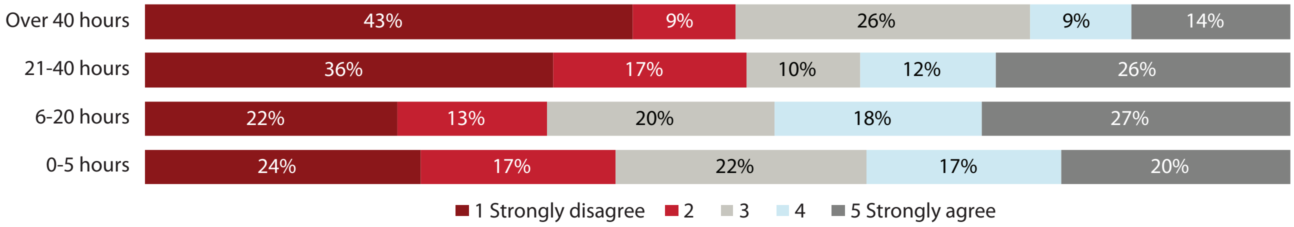


Figure 40: By Caregiving Hours: Do you anticipate a friend or loved one will require a level of care you cannot provide in the future? n=341

selected on the 5-point scale). (Asked only of respondents who give care to someone not in a care facility)

- 28% of part-time working caregivers compared with 17% of full-time and 19% of those not employed
- 28% of those caring for a person who lives alone versus 15%-16% of caregivers supporting the person in other living situations

Categories with a higher percentage of caregivers who say they agree with the statement: "I anticipate that my friend or loved one will require a level of care I cannot provide in the future" (4 or 5 selected on the 5-point scale).

- 51% of caregivers aged 45-54 and older compared to 16% for 18-34 year olds). Middle aged respondents have the most concern that they will not be able to provide care in the future. (See Figure 39)
- 45% of those caregiving 6-20 hours per week agreed, compared to 37%, 38%, and 23% of those who care 0-5 hours, 21-40 hours, and over 40 hours weekly. Those providing 21 or more hours of care are more likely to disagree than other caregivers (Figure 40)
- 45% of caregivers in each of the higher income categories of $100,000-149,000 and $150,000 or more compared to the lower income categories (35%-37%)
- 52% of those caring for a person who lives alone compared to 27%-46% in other living situations

Caregivers prefer a home setting. Most caregivers (71%) prefer a home setting over a residential setting to provide routine daily health support for the person they are caring for. Only 12% of respondents say residential care is their choice if daily regular care becomes necessary. Approximately 1 in five (18%) respondents are uncertain about their preferred care setting (Figure 41).

Categories with a higher percentage of caregivers who prefer a home setting:

- 77% each for age categories of 55-64 and 65 and older compared to 63%-69% in younger age groups
- 83% of those providing care for 21-40 hours per week compared to 66%-74% for the other caregiving categories

Figure 41: If the person you are caring for currently requires routine daily support from health professionals or requires this level of support in the future, would your preference be a home setting or a residential care setting? n=339

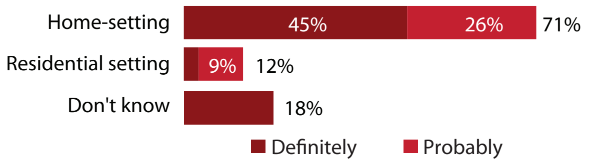


Figure 42: Including yourself, how many employees does your your company or organization have? n=226

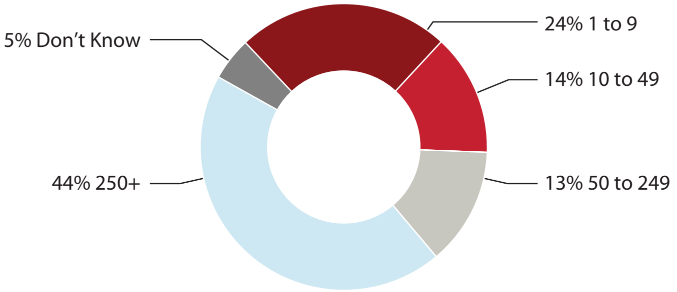


Figure 43: By Income: Including yourself, how many employees does your your company or organization have? n=226

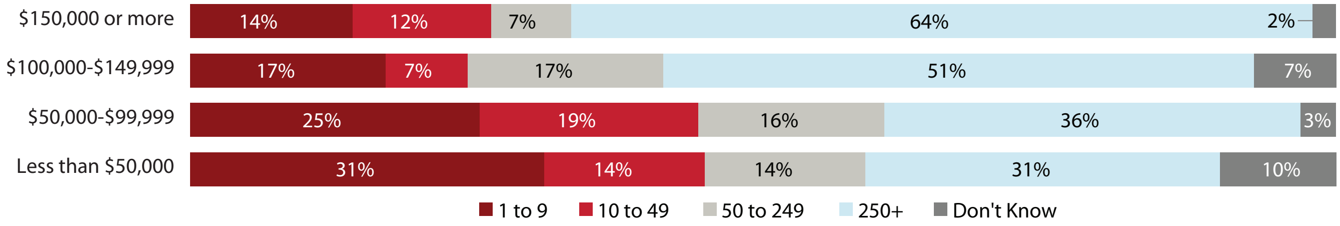
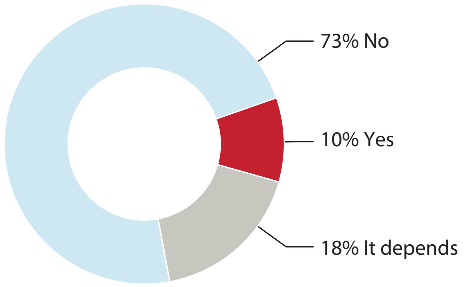


Figure 44: Is caregiving preventing you from working as much as you desire or need? n=226



Employed Caregivers: Balancing Work and Caregiving

Employed caregivers most likely work for a large employer. According to the survey, caregivers are most likely to either work in an organization with more than 250 employees (44%) or with 1-9 employees (24%) (Figure 42).

Categories with a higher percentage of employed caregivers who work for employers with 250 plus employees:

- 51% of full-time workers compared to 22% part-time
- 64% of those earning $150,000 or more compared with 31%-51% in ascending order of other income categories (See Figure 43)
- 57% of caregivers provide 6-20 hours of care compared to 30%-43% for other caregiving hour categories

Categories with a higher percentage of employed caregivers who work for employers with 1-9 employees:

- 44% of caregivers work part-time compared to 18% full-time
- 31% of those with incomes less than $50,000 compared to 14%-25% for other income categories (See Figure 43)

A greater percentage of women (27%) than men (19%) work for companies with between one and nine people, but both are most likely to work for organizations with 250 or more people (47% of men and 43% of women).

One in ten caregivers say caregiving prevents them from working. A large percentage (73%) of employed caregivers say caregiving is not preventing them from working as much as they desire or need. An additional 18% said "it depends" (Figure 44).

Figure 45 shows there may be a relationship between income and the likelihood a caregiver feels their caregiving prevents them from working as much as they desire or want.

Difficulty managing work and caregiving varies. Most employed caregivers either never (33%) or infrequently (23%), found it difficult to manage work and caregiving in the past 12 months. Only about 1 in five always or frequently find it difficult (9% and 12%) (Figure 46).

Figure 45: By Income: Is caregiving preventing you from working? n=226

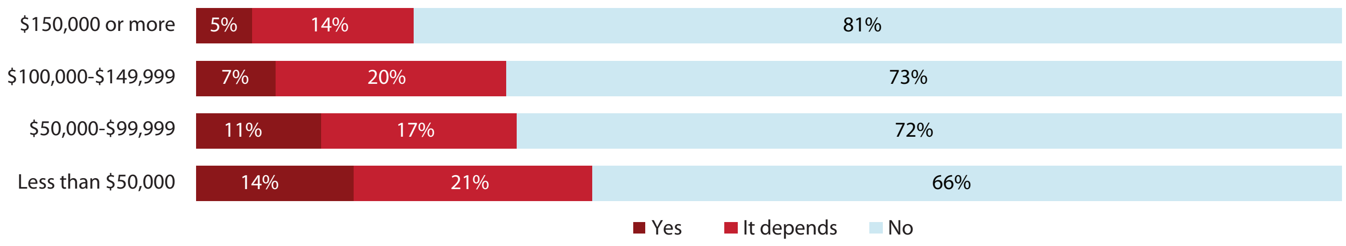


Figure 46: How frequently was it difficult to manage work and caregiving in the past 12 months? n=226

Figure 47: By Caregiving Hours: How frequently was it difficult to manage work and caregiving in past 12 months? n=226

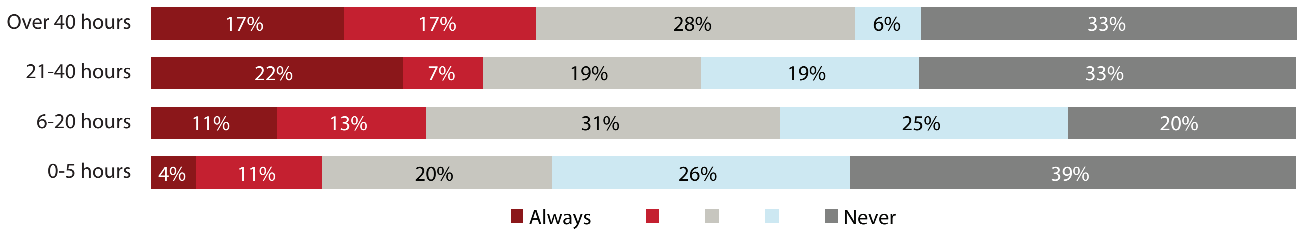


Figure 48: By Full-time/Part-time: How frequently was it difficult to manage work and caregiving in past 12 months? n=226

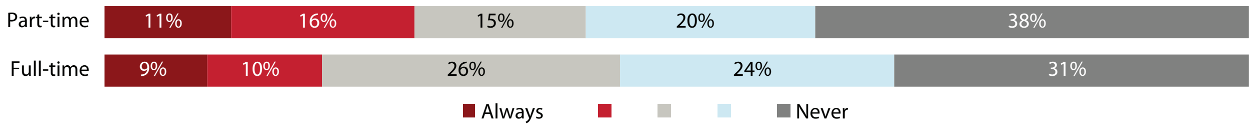


Figure 49: By Income: How frequently was it difficult to manage work and caregiving in the past 12 months? n=226

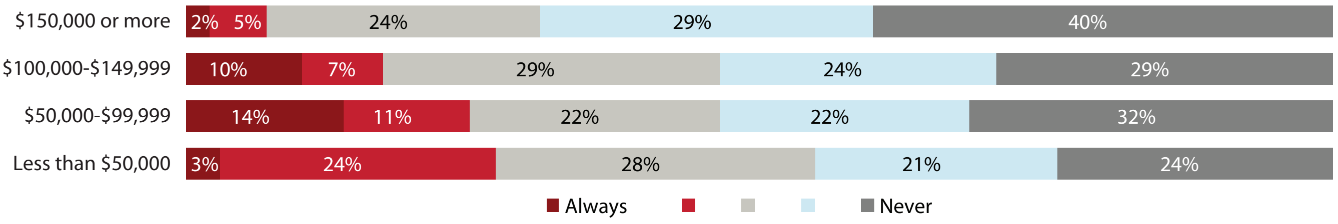
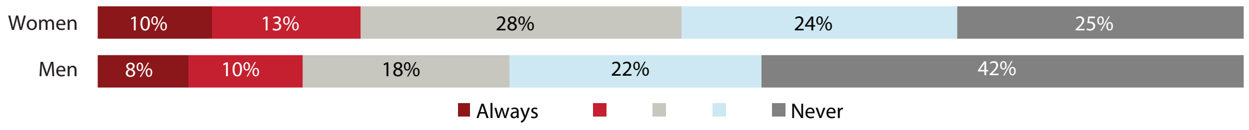


Figure 50: By Women/Men: How frequently was it difficult to manage work and caregiving in the past 12 months? n=226



Categories with a higher percentage of employed caregivers who almost always have difficulty (4 or 5 selected on the 5-point scale):

- 34% of those providing over 40 hours of care a week compared to 15%-29% of those providing fewer hours of weekly care (See Figure 47)
- 27% who are work part-time compared to 19% of caregivers working full-time (Figure 48)
- 25%-27% of caregivers with incomes less than $100,000 compared to 7%-17% for the upper-income categories (Figure 49)

Categories with a higher percentage of employed caregivers who almost *never* have difficulty (1 and 2 selected on the 5-point scale):

- 64% of men compared to women at 49% (See Figure 50)

Some respondents have made work-related changes due to caregiving. While no single work related change was reported by a majority of caregivers, Figure 51 shows that more than 1 in 5 have begun working virtually (or hybrid) and/or reduced their work hours. Additionally, 40% of caregivers indicated they changed something related to their work (as opposed to 60% who selected none).

According to the survey, full-time employees, caregivers in households earning between $100,000-$149,999, and women were more likely than other categories of caregivers to begin working hybrid as a result of caregiving. Comparatively, part-time workers, those providing over 40 hours of care, those in households with less than $50,000 household income, and women are more likely to have reduced work hours due to caregiving.

Categories with a higher percentage of employed caregivers who began working hybrid/remote due to caregiving:

- 24% of full-time employees compared to 15% of part-time
- 27% of women caregivers compared to 15% of men
- 32% of those earning between $100,000 -$149,999 compared to 17%-19% in the other income categories

Categories with a higher percentage of employed caregivers who reduced work hours due to caregiving:

- 35% of part-time employees versus 16% of full-time employees
- 23% of women caregivers compared to 17% of men
- 44% of those providing care over 40 hours a week compared to 13%-30% of those providing fewer hours of care per week
- 38% with incomes of less than $50,000 compared to 14%-20% of those in higher income categories

Figure 52 shows that caregivers' incomes less than $50,000 are more likely to reduce their work hours due to caregiving whereas caregivers with incomes of $100,00 or greater are change to hybrid or remote work (Figure 52).

Figure 51: What work-related changes did you experience due to caregiving? n=226

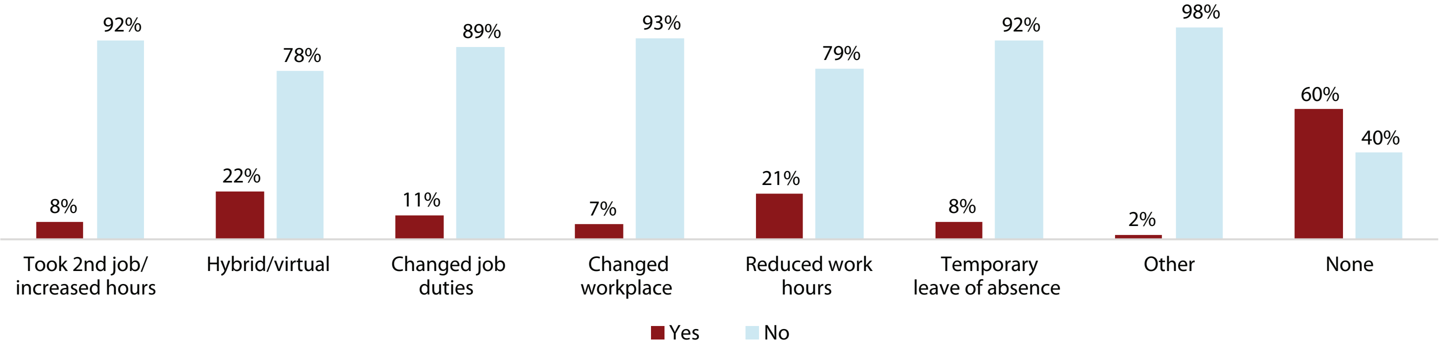


Figure 52: By Income: What work-related changes did you experience due to caregiving? n=226

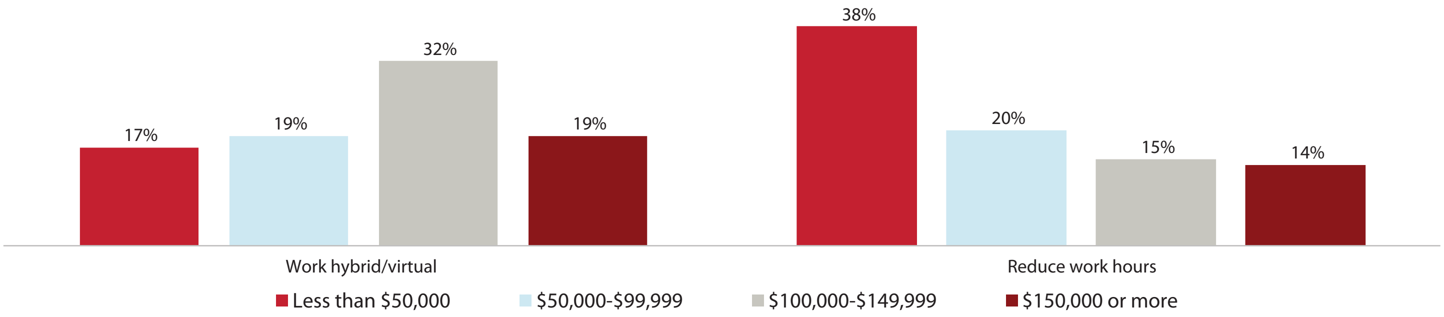


Figure 53: Which of the following three statements best describes your current situation? n=226

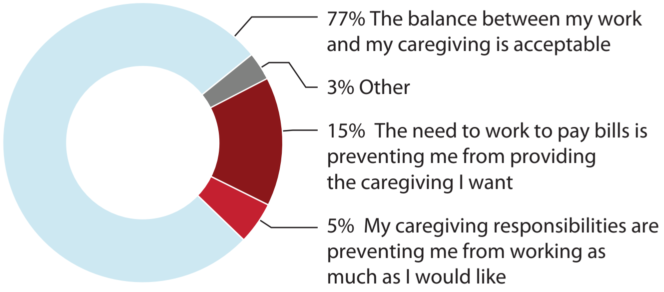


Figure 54: By Income: "Caregiving and work balance is acceptable" best describes the current situation n=155

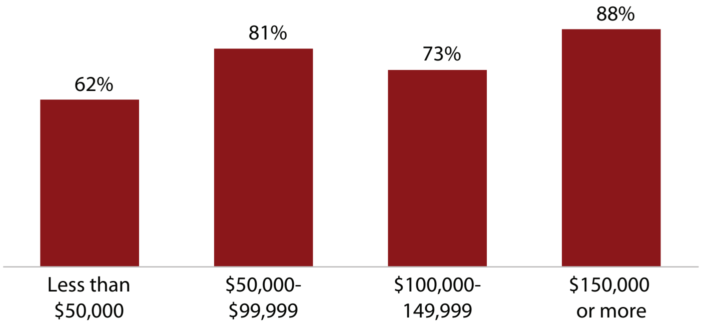
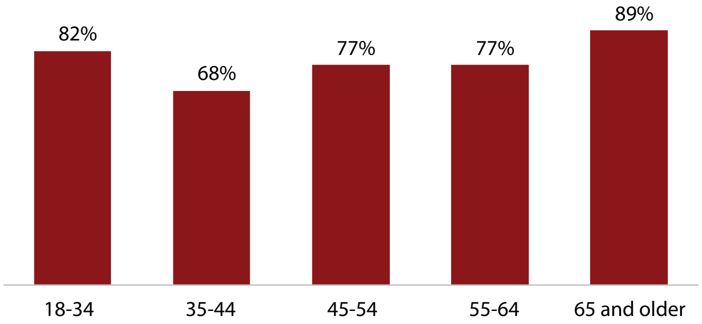


Figure 55: By Age: "Caregiving and work balance is acceptable" best describes the current situation n=174

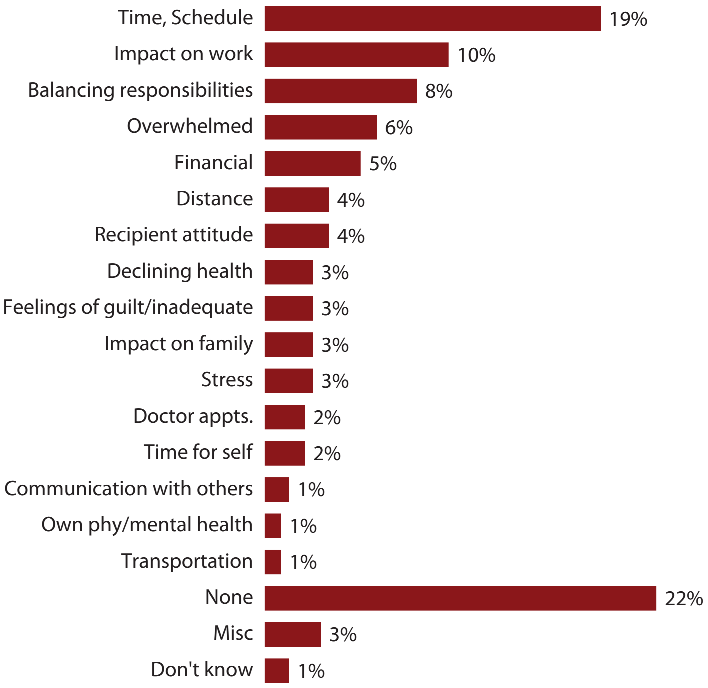


The balance between caregiving and work is acceptable for most (77%) caregivers, however noteworthy differences exist between demographic groups. (Figures 53, 54, 55). Men and women are similarly likely to find the balance acceptable (79% of men and 76% of women), as are full-time and part-time workers (76% and 80%), but differences by age and income are more notable.

<u>Categories with a higher percentage of employed caregivers who find their balance between caregiving and work acceptable:</u>

- 88% of caregivers in the highest income category of $150,000 or more followed by 81% in the $50,000-$99,999 category, 73% earning $100,000-$149,999, and 62% with incomes less than $50,000 (See Figure 54).

Figure 56: What is the most difficult part of managing work and caregiving responsibilities? n=226 (open-ended)



- 82% and 89% of the youngest and oldest caregivers, respectively, say the balance is acceptable compared to 68%-77% of the middle-aged categories (See Figure 55).

If managing work and caregiving is difficult, time and scheduling are often involved. Respondents mention a variety of difficulties in managing work and caregiving responsibilities. Time and schedule is the most common difficulty mentioned, while more than a fifth of respondents responded "none" (Figure 56).

At work, respondents are most likely to talk to a coworker about their caregiving situation. Forty-two percent of working respondents have talked to a coworker about their caregiving situation, with much smaller shares talking to management (17%), a supervisor, (24%), or human resources (5%). Variations in the response "not applicable" reflect the demographics of different workplace structures (Figure 57).

According to the survey, full-time workers are more likely to talk to management, supervisors, human resources, and co-workers than part-time workers. In comparison, part-time workers, women, those 65 and older, and those in the lower income categories are more likely than other caregivers to say talking to someone in the workplace is "not applicable," suggesting these groups do not have the same access to employer support that other caregivers have.

Figure 57: Have you talked with any of the following at your workplace about your caregiving situation? n=226

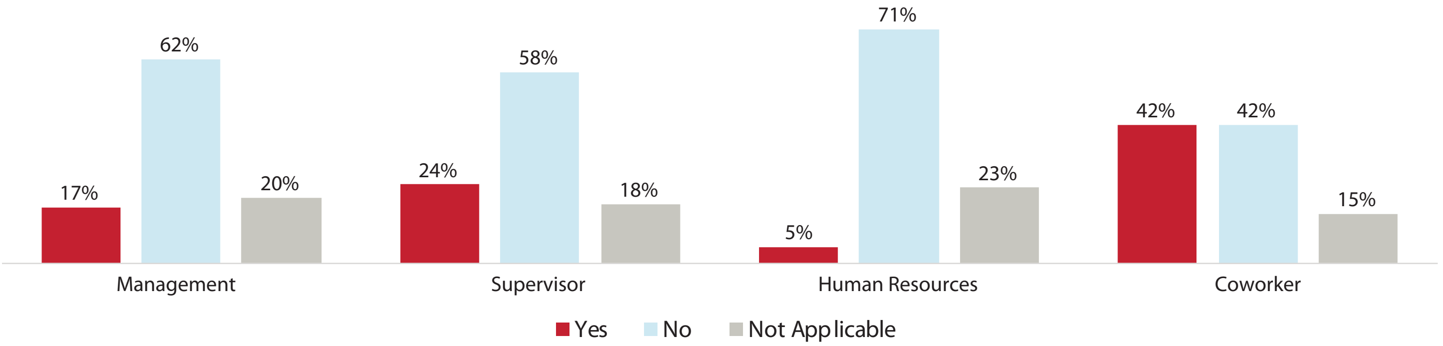


Figure 58: By Income, *Management*: Have you talked with any of the following at your workplace about your caregiving situation? n=226

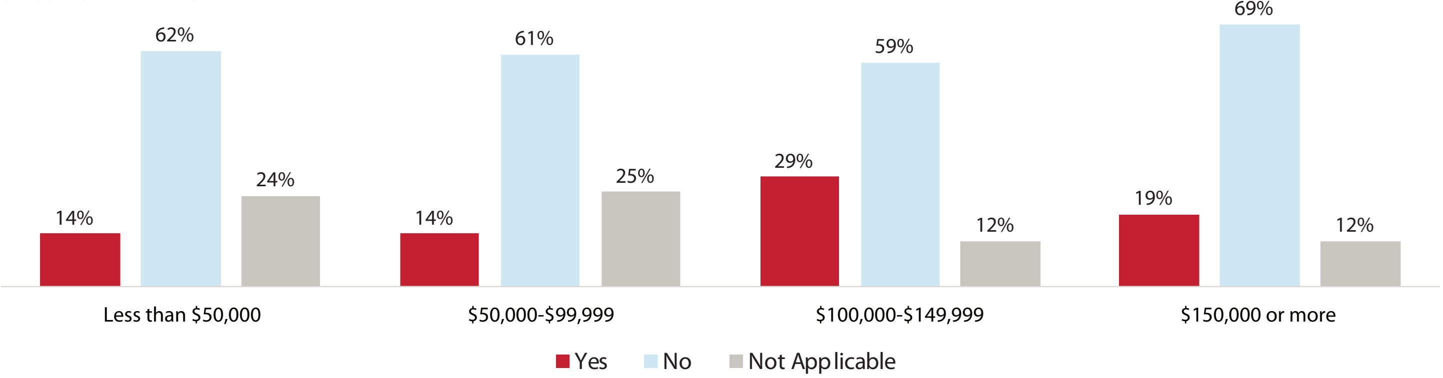
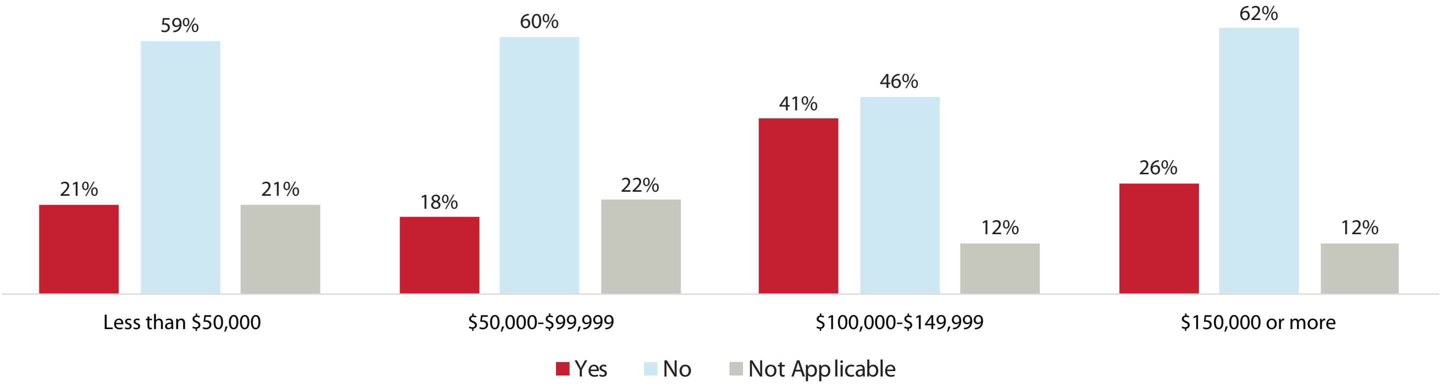


Figure 59: By Income, *Supervisor*: Have you talked with any of the following at your workplace about your caregiving situation? n=226



Categories with a higher percentage of employed caregivers who have talked to management:

- 20% of full-time working caregivers compared to 7% for part-time
- 19%-21% of those in the middle age categories (35-44 and 45-64) compared to 12% for ages 18-34 and 11% for 65 and older
- 22%-26% of caregivers who provide care for 6 or more hours each week spoke to management, compared to 12% of those who cared for 0-5 hours
- 29% of caregivers with incomes between $100,000-$149,999 compared to 19% who earn $150,000 or more, and 14% in the lower income categories (See Figure 58)

Categories with a higher percentage of employed caregivers who have talked to a supervisor:

- 29% of full-time employees compared to 11% of part-time
- 29% and 32% of employees aged 45-54 and 55-64 years compared to 12%-23% for the other categories
- 37%-43% provide care for 6-20 hours and 21-40 hours a week compared to 14% for those giving care 0-5 hours and 11% for over 40 hours.
- 41% of those with an income between $100,000-$149,999 compared to 26% of those earning $150,000 or more and 18% and 21% for lower two income categories under $100,000. (See Figure 59)

Figure 60: By Income, *Human Resources*: Have you talked with any of the following at your workplace about your caregiving situation? n=226

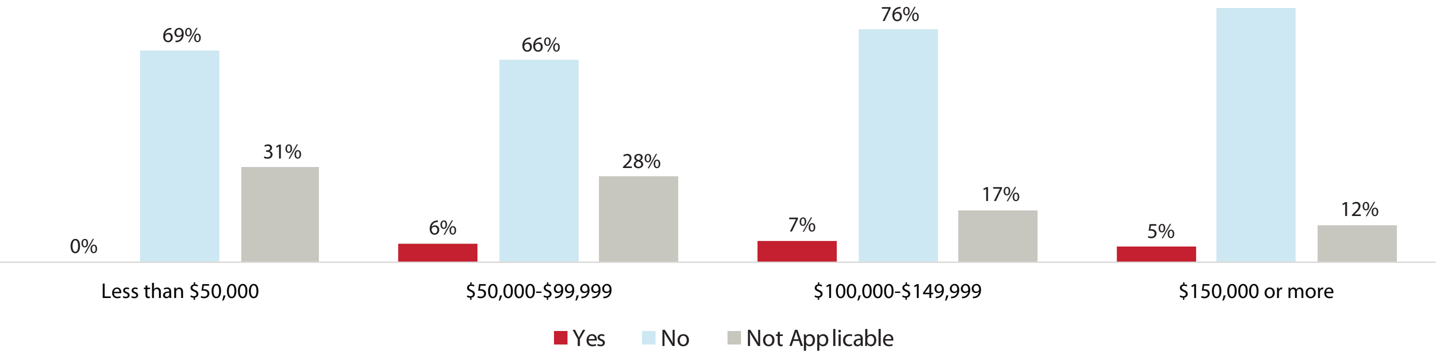
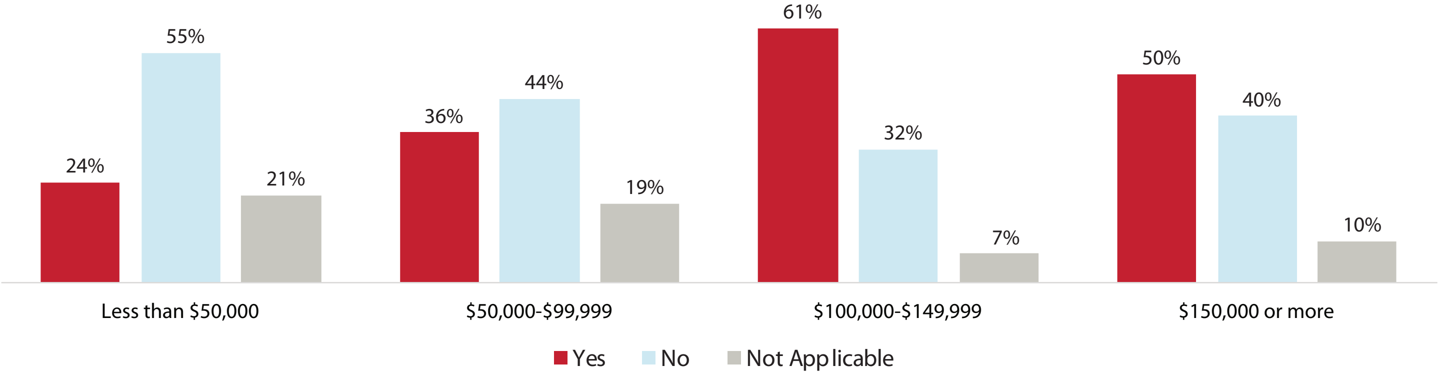


Figure 61: By Income, *Coworker*: Have you talked with any of the following at your workplace about your caregiving situation? n=226



Categories with a higher percentage of employed caregivers who have talked to a coworker:

- 51% of caregivers employed full-time versus 15% of part-time employees
- 43% and 52% of those in the middle age groups (ages 35-64) compared to 30% for both 18-34 and 65 and older
- 48% of those caregiving for 6-40 hours a week compared to 39% of other groups.
- 61% of caregivers earning from $100,000-$149,999 contrasted to 50% for those with incomes of $150,000 or more and 24% and 36% for the two lower income categories (See Figure 61)

Caregivers whose loved one lives in residential care are more likely to have spoken with managers, supervisors, human resource, and co-workers, but these differences may be overstated due to a small sample size (n=7).

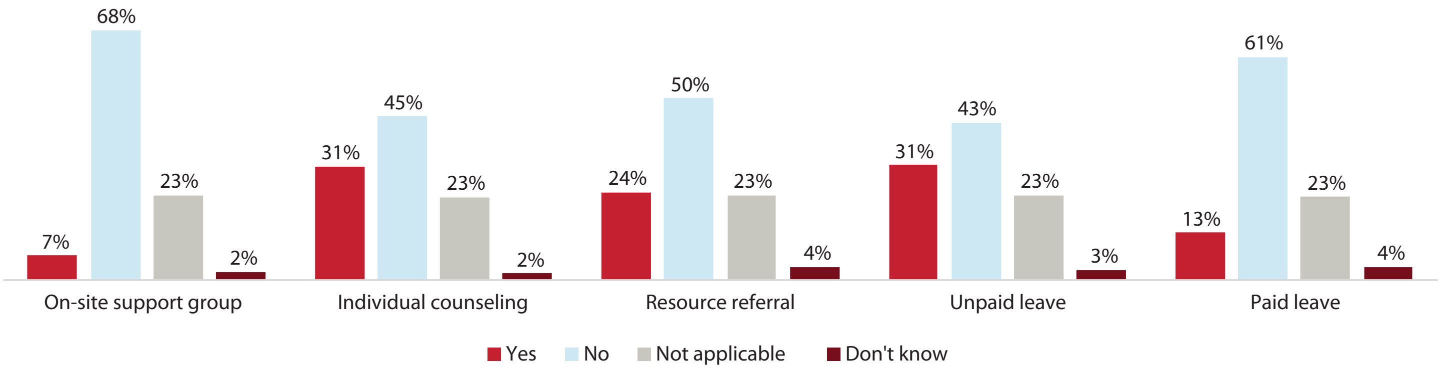
Categories with a higher percentage of employed caregivers who answered "not applicable" to human resources:

- 38% of those working part-time compared to 19% of full-time working caregivers
- 30% of women caregivers compared to 16% of men.
- 32% of employees aged 65 or older compared to 21%-23% for other age categories
- Caregivers earning lower incomes, with 31% of those earning less than $50,000 selecting "not applicable" and rates decreasing to 12% for those earning $150,000 or more (Figure 60)

Individual counseling and unpaid leave are the most frequently offered employee supports. Almost a third of employed respondents work at organizations offering individual counseling and/or unpaid leave. A quarter are offered resource referral, and the large majority do not have access to on-site support groups and paid leave (Figure 62).

According to the survey, full-time employees and caregivers with higher incomes were more likely to have access to all supports, except that those making $100,000-149,999 consistently had more access to support than those making $150,000 or more. Caregivers caring for someone who was in residential care were more likely to have all types of employer supports than those caring for people in other residential situations. There is a variation among the age and hours of care categories most likely to have specific supports.

Figure 62: Does your employer offer these supports/benefits for caregiving? n=226



Categories with a higher percentage of employed caregivers who work for an employer who offers on-site support:

- 15% of those employees earning $100,000-$149,000 compared with other income groups with 0% to 7%
- 11% of those aged 55-64 compared with younger employees 18-54 (6%-7%) and 0% for those working caregivers 65 years and older
- 9% of those employed full-time compared to 0% of part-time employees

Categories with a higher percentage of employed caregivers who work for an employer who offers individual counseling:

- 46% for employees earning $100,000-$149,999 and 33% earning $150,000 or more compared with 14% and 26% in lower income groups.
- 48% of those providing care for 6-20 hours a week compared to other hours caring categories (22%-33%)
- 37% of those aged 45-54 and 34% aged 55-64 compared with younger age categories and 27% and 29% and employees 65 and older with 18% having individual counseling
- 37% of full-time employed caregivers compared to 13% part-time

Categories with a higher percentage of employed caregivers who work for an employer who offers resource referral:

- 34% of those with incomes $100,000 -$149,999 and over $150,000 (29%) compared to those at $99,999 or less (17%-20%)
- 33% of those providing care for 6-20 hours a week compared with caregivers in other categories (17%-24%)
- 23%-29% in all age categories except 65 and older at 14%
- 32% of employed men versus 17% of women
- 30% of employees working full time compared to 5% part-time

Categories with a higher percentage of employed caregivers who work for an employer who offers unpaid leave:

- 44% of employees making $100,000-149,999 and 19% of those earning over $150,000, compared to 8% of caregivers earning $50,000 to $99,999 and 3% of those earning less than $50,000
- 61% of those caregiving for over 40 hours a week with other groups ranging from 26%-36%
- 31%-38% in 35-64 year group compared to 24%-25% for the youngest and oldest age groups
- 35% of those employed full-time compared to 18% part-time

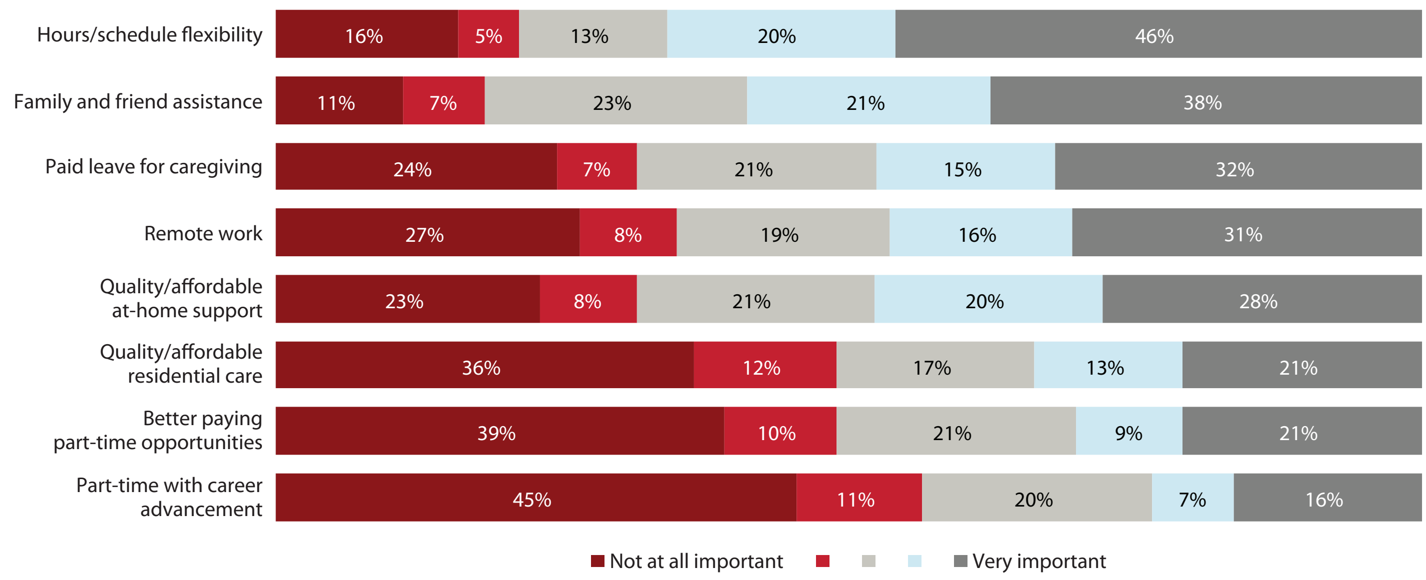
Categories with a higher percentage of employed caregivers who work for an employer who offers paid leave:

- 25% of employees making $100,000-149,999 and 19% of those earning over $150,000, compared to 8% of caregivers earning $50,000 to $99,999 and 3% of those earning less than $50,000
- 23% of employed respondents providing care for 6-20 hours a week with other groups ranging from 8%-15%
- 19% of employees age 35-44 and 14% of 45-54 year olds with other age categories between 7%-12%
- 19% of employed male caregivers compared to 7% of women
- 15% of full-time employees compared to 5% part-time

Flexibility is key. Hours and schedule flexibility is the most important support for successfully balancing work and caregiving, according to 66% of respondents saying it is important or very important. Family and friend assistance (59%), quality affordable at-home support (48%), paid leave for caregiving (47%) and remote work (47%) closely follow (Figure 63).

According to the survey, caregivers who are 65 and older are less likely to rate many of the supports as important. Some of the most highly ranked supports – hours and flexibility, family and friend assistance, quality affordable at-home support, and paid leave caregiving – show the varied levels of importance given by other caregiver subsets. Of interest, older caregivers are also less likely to say access to quality affordable residential care is important.

Figure 63: How important are these to you successfully balancing work and caregiving? n=226



Categories with a higher percentage of employed caregivers who say hours and flexibility is important (sum of 4 and 5 ratings)

- 65%-76% of employed caregivers in the four age categories under 65 compared to 32% for 65 and older
- 71% of employed women verses 59% of men
- 72% of employees earning $150,000 or more, and 70% making $50,000-$99,999 compared with 62% earning less than $50,000 and 59% in the $100,000-$149,999 income categories

Categories with a higher percentage of employed caregivers who say family and friend assistance is important (sum of 4 and 5 ratings)

- 57%-69% in the age categories under 65 compared to 18% for employees 65 and older
- 67% of women compared with 48% of men
- 64% of those employed full-time compared with 44% of part-time employees

Categories with a higher percentage of employed caregivers who say quality affordable at-home support is important (sum of 4 and 5 ratings):

- 45%-60% of caregivers under age 65 in contrast to 25% of 65 and older
- 51% of full-time working caregivers compared to 40% part-time
- 53% of women compared to 41% of employed men
- 52%-56% of caregivers providing 21 or more hours of care compared to 46%-47% for those providing fewer hours of care
- 46%-51% of those with incomes above $50,000 compared to 38% of caregivers with incomes under $50,000

Categories with a higher percentage of employed caregivers who say paid leave caregiving is important (sum of 4 and 5 ratings):

- 44%-61% for age groups under 65 years compared to 18% for employees 65 and older
- 51% making $50,000-$99,999 and 47% earning $100,000 -$149,999 compared with 42% of $150,000 or more and 41% of employees in the lowest income category
- 67% of those providing over 40 hours of caregiving per week compared to 40%-56% in lower caregiving hour categories
- 50% of caregivers employed full-time versus 40% part-time

Categories with a higher percentage of employed caregivers who say remote work is important (sum of 4 and 5 ratings)

- 47%-54% of ages groups under 65 compared to 22% for 65 and older
- 50% of women compared to 42% of men
- 56% of caregivers providing 21-40 hours of care compared to 44%-47% for the other hours of care categories
- 42%-53% for incomes above $50,000 compared to 31% for caregivers with incomes under $50,000

Conclusion

Although Utah's caregivers' experiences and needs are varied, some common themes emerge. Caregivers are likely to look to family and friends for support. About half of all caregivers have asked for assistance from family and friends, and over half of employed caregivers say it is important to balancing work and caregiving. Support from family and friends is also the most frequently identified form of support for caregivers who have felt inadequate or in need of support.

Flexibility is important for caregivers who are employed. Two-thirds of these caregivers identified flexible work hours and schedules as an important support to balance work and caregiving. Almost half identify remote/hybrid work, a work policy option that also frequently allows for greater scheduling flexibility. The possibility of part-time work is another way to increase flexibility, with some caregivers indicating they would work part-time if they could choose their ideal employment scenario.

Both of these themes suggest challenges for caregivers who do not have family and friends who are able or willing to support caregiving and caregivers with jobs that don't allow for flexible schedules or remote work. For instance, about one in five working caregivers have changed to hybrid work and a similar percentage have reduced work hours due to caregiving, but these choices don't fall evenly across income categories. A greater percentage of caregivers with lower incomes reduce their work hours due to caregiving compared with caregivers with higher incomes. Comparatively, a greater percentage of upper-middle-income earners choose remote/hybrid work. These differences likely highlight the disparity in flexibility options available to caregivers in differing jobs and economic positions. Furthermore, part-time workers are less likely to have discussed their caregiving situation with someone at their workplace, suggesting less employer support for caregivers working part-time positions.

Caregivers contributed $5.1 billion in economic value to Utah in 2020.[3] The survey findings suggest that while many are adjusting their lives in ways they can manage, some groups need additional support – from family and friends, workplace policies, and/or government programs – to effectively meet the needs of their loved ones and themselves. Different subsets of caregivers experience different challenges. Further research is needed on specific caregiver subsets to understand the factors contributing to their particular concerns.

Endnotes

1. Nine respondents answered "other." Their responses are not included in this analysis.
2. The small sample size of the caregiver population (12% overall) agreeing with the statement "My physical or mental health may prevent me from continuing to provide care to my friend or loved one" makes it challenging to draw conclusions about the opinions of different subgroups.
3. https://d36oiwf74r1rap.cloudfront.net/wp-content/uploads/Family-Caregivers-FCC-Oct2022.pdf

Appendix 1: Methodology

In 2023, the University of Utah Family Caregiving Collaborative enlisted the services of the Kem C. Gardner Policy Institute to conduct a comprehensive statewide survey of caregivers in Utah. The primary aim of this research was to gain a deeper understanding of the caregiving experience, with a specific focus on the preferences of individuals balancing work and caregiving responsibilities, and to identify how to best support these caregivers.

Working with the Family Caregiving Collaborative, the Gardner Institute developed a survey questionnaire tailored to address these objectives. The telephone survey averaged 10-12 minutes and had four open-ended questions. The Gardner Institute pretested the survey to ensure the clarity and flow of questions and the accuracy of the computer program. The survey questionnaire is provided in the Appendix for reference.

The Gardner Institute engaged Lighthouse Research to conduct the survey. From July 7 to July 21, 2023, Lighthouse Research collected interviews using a mixed-mode methodology. Initially, Lighthouse distributed online survey links to a random sample of known Utah email addresses. Next, Lighthouse conducted telephone interviews to achieve the desired response level. Over 95% of survey responses were obtained through telephone interviews. Lighthouse Research draws from multiple sources, including their own continuously updated 25+ year-old database, public records from list vendors, and Utah voter registration lists.

The survey sample included individuals aged 18 and above who have offered short-term or long-term assistance to a family member or friend with a serious or chronic illness or disability during the past 12 months. Although the precise number of these caregivers in Utah remains unknown, the survey's margin of error is estimated to be +/- 5% at the 95% confidence level. It is worth noting that the error rate may vary for specific questions, influenced by skip patterns and or when considering responses from distinct demographic categories.

The report delves into both percentages and means. Percentage responses illuminate the distribution of answers, while means, where applicable, denote the average value derived from the overall range of responses to a given question.

Limitations

The sample may not fully represent the entirety of the current and recent caregiver population in Utah, potentially leading to over-representation or under-representation of certain groups.

Telephone surveys may inadvertently exclude individuals or demographic groups without phone access, those lacking an established phone number, or those who actively screen their calls. Furthermore, some individuals might be disinclined to participate in phone surveys due to time constraints or a lack of interest in the survey topic.

When the analysis delves into specific subsets of respondents, there is increased uncertainty regarding the extent to which their preferences likely reflect the views of others in the subset who were not surveyed.

This report provides an analysis of the survey results. Conducting further analysis with additional variables from this survey would provide an even greater understanding of Utah caregivers' experiences. Additional analysis with a more extensive and diverse sample would be valuable to learning more about the caregiving experiences of specific population groups and establishing the significance of the observed associations noted in this report.

Appendix 2: Caregiver Demographics

For this survey, caregivers are defined as individuals who, in the last 12 months, have provided short or long-term help to family members or friends who have serious or chronic illnesses or disabilities. Caregivers responding to this survey are representative of the state population in how they are geographically distributed across Utah's counties, however, they differ from the state population overall in marital status, household size, household income, education, and race and ethnicity (Table 1). The survey sample, collected in July 2023, includes 347 individuals who acted as caregivers at some point during the previous 12 months. This sample of caregivers includes 133 males (38%), 213 females (61%), and 1 individual who identified outside these two categories, compared to a near 50/50 male/female split for Utah's population according to the 2020 Census. Caregivers range in age from 22 to 91, with a median age of 52.5, tending to be older than the Utah population generally.

The caregivers surveyed live in 22 counties within Utah, with 74% of respondents living within the four Wasatch Front counties (Davis, Salt Lake, Utah, and Weber), aligning with 2020 Census results showing 76% of Utah's total population lives in these four counties (Figure 1).

Approximately 4 in 5 (80%) survey respondents live in urban areas. Another 5% of respondents live in rural areas, and the remaining 15% of respondents live in zip codes that include both urban and rural residences, making accurate categorization difficult.

Nearly 90% of caregivers surveyed identify as White, a much less racially diverse group than the population generally, which is 77% White according to the 2020 Census. The 35 non-White caregivers identify as the following race and ethnicities: Hispanic or Latino (13), multiracial (12), Asian (5), Pacific Islander or Native Hawaiian (1), American Indian or Alaskan Native (1), Middle Eastern (1) and European (1).

More than three in four (266) of the caregivers surveyed are married (Figure 2). The next largest group, comprising 9%, are single and have never been married (30), followed by 8% (26) who are divorced or separated. An additional 5% (17) are widowed. The marital status is unknown for the remaining 2% (8) of respondents. This composition differs from Utah's population overall, in which married residents make up a much smaller share (56%), and those who are single and never married compose a much larger share (31%).

Surveyed caregivers live in a range of household sizes, with 10% living alone, 31% living with one other person, 38% living in 3 or 4-person households, and 21% living in households with 5 or more people. Four in ten (44%) caregivers in the sample had children under the age of 18 living with them. In Utah overall, a much higher share of the population lives alone, a smaller share lives in households with 3 or 4 people, and a smaller share lives in households with children.

The caregivers reflected in the survey sample were more highly educated compared to the state population overall. Over half of the respondents held bachelor's degrees or higher (52%) compared to only 35% of the Utah population aged 25 and older. Respondents also reported higher incomes than the state population in general. Similar shares of caregivers and Utah residents reported household incomes of $100,000 or above, but among the sample of caregivers, higher shares reported incomes between $50,000 and $99,999, and smaller shares reported incomes below $50,000.

Noteworthy Differences among Caregivers Surveyed

Male caregivers are more likely to be:

- Age 65 or older
- Earning $100,000 or more in household income per year

Caregivers earning $100,000 or more in household income are more likely to be:

- Married
- Male
- Living along the Wasatch Front

Caregivers earning under $100,000 are more likely to be:

- Age 65 or older
- Living alone

Appendix 3: Questionnaire with Complete Results

Number Responding – 347
Fieldwork Dates – July 7-23, 2023

Hello, this is ________________ calling from Lighthouse Research. We are conducting a brief survey to better understand residents' thoughts about family caregiving.

For this research, a caregiver is a person who provides short-term or long-term help to a family member or friend who has a serious or chronic illness or disability.

---

1. During the past 12 months, did you provide any such help to a family member or friend? This may include help with baths, medicines, household chores, paying bills, driving to doctor's visits or the grocery store, arranging for medical and support services, or just regular check-ins to see how they are doing.

		(*n*-347)
Yes	100%	(347)
No **(Thank & Terminate)**		

First, a couple of background questions that will help us analyze date.

2. What is your gender?

		(n-347)
Male	38%	(133)
Female	61%	(213)
Self-identify (specify)	<1%	(1)

---

3. What is your age? _______
(COLLAPSED INTO CATEGORIES FOR ANALYSIS)

		(n-347)
18 to 24	3%	(12)
25 to 34	9%	(32)
35 to 44	18%	(64)
45 to 54	24%	(85)
55 to 64	20%	(71)
65 to 74	16%	(54)
75 or older	8%	(29)

---

4. What county do you live in? (n-347) Very Rural / Rural / Urban

Beaver	0%	Juab	0%	Tooele	3%
Box Elder	1%	Kane	1%	Uintah	2%
Cache	4%	Millard	1%	Utah	16%
Carbon	1%	Morgan	<1%	Wasatch	2%
Daggett	0%	Piute	0%	Washington	5%
Davis	14%	Rich	<1%	Wayne	0%
Duchesne	<1%	Salt Lake	38%	Weber	6%
Emery	0%	San Juan	1%		
Garfield	0%	Sanpete	1%		
Grand	1%	Sevier	1%		
Iron	1%	Summit	<1%		

---

5. Which of the following best describes your current employment status?

		(n-347)
Working full-time/or more (includes self-employed)	49%	(171)
Working part-time (includes self-employed)	16%	(55)
Not currently employed	35%	(121)

---

6. *If employed (a or b) to Question 5 ask:* Are you self-employed?

		(n-226)
Yes	17%	(39)
No	75%	(169)
Both – self-employed & employed with a company	8%	(18)

---

7. Which of the following best describes your ideal employment situation?

		(n-346)
Working full-time/or more (includes self-employed)	43%	(148)
Working part-time (includes self-employed)	27%	(94)
Not employed	30%	(104)

For the next set of questions, please think about the person for whom you provided the most care in the last twelve months.

8. Do you currently provide care for this person?

		(n-347)
Yes	65%	(226)
No	35%	(121)

9. In a typical week, about how many hours on average {do/did} you spend, caring for this person (for example, if the care you are providing had to be replaced, how many hours would be needed per week)?

___ hours (1 to 168)
1 = One hour or less
999 Wouldn't Say
(COLLAPSED INTO CATEGORIES FOR ANALYSIS)

		(n-344)
0 hours	1%	(4)
5 or less	19%	(65)
2 to 5 hours	30%	(103)
6 to 10 hours	13%	(53)
11 to 25 hours	14%	(53)
26 to 50 hours	13%	(42)
Over 50 hours	7%	(24)

10. {Are/Were} you paid for any of the hours that you spent helping this person? This could be payment from a public program, a family member, or directly from the care recipient.

		(n-347)
Yes	3%	(10)
No	97%	(337)

11. Have you looked for caregiving support services from the state or county?

		(n-347)
Yes	15%	(52)
No	85%	(295)

12. Have you received caregiving support services from the state or county?

		(n-347)
Yes	9%	(31)
No	91%	(316)

13. What best describes the living situation of the person you are/were caregiving for?

		(n-346)
Lives alone	26%	(90)
Lives with you	34%	(118)
Lives with a friend or family member	34%	(116)
Lives in a residential care setting like an assisted living community, a board and care home, memory care, or a skilled nursing facility	4%	(13)
Other (specify)	3%	(9)

14. *If a, c, d, or e in Question 13, ask:* How long does it take you to travel from your residence to this person's home?

		(n-228)
Less than 20 minutes	67%	(152)
20 to 59 minutes	22%	(50)
1 to 2 hours	4%	(8)
More than 2 hours	8%	(18)

15. *If a, c, d, or e in Question 13, ask:* About how often do you make this trip?

		(n-228)
At least daily	12%	(28)
Several times a week	39%	(88)
A few times a month	32%	(73)
Once a month	7%	(17)
Less than once a month (please specify)	10%	(22)

Now we want to ask you some questions about how caregiving has impacted you.

16. In general, would you say your own health is Excellent, Very Good, Good, Fair, or Poor?

		(n-347)
Poor	4%	(13)
Fair	17%	(58)
Good	38%	(131)
Very good	27%	(94)
Excellent	15%	(51)

17. During the past 12 months, how frequently was it difficult for you to balance your family life and caregiving? Please use a 1 to 5 scale with 1 being never and 5 being always.

		(n-346)
1 – Never	34%	(116)
2	23%	(81)
3	27%	(92)
4	10%	(36)
5 – Always	6%	(21)
Mean score (1-5 scale)	2.32	
Median	2.00	

18. During the past 12 months, how frequently was it difficult for you to balance caring for yourself and caregiving? Again, use the 1 to 5 scale with 1 being never and 5 being always.

		(n-346)
1 – Never	36%	(126)
2	22%	(77)
3	23%	(81)
4	14%	(47)
5 – Always	4%	(15)
Mean score (1-5 scale)	2.27	
Median	2.00	

19. *If employed (a or b) to Question 5 ask:* During the past 12 months, how frequently was it difficult for you to manage work and caregiving responsibilities? Again, use the 1 to 5 scale with 1 being never and 5 being always.

		(n-226)
1 – Never	33%	(74)
2	23%	(52)
3	23%	(53)
4	12%	(26)
5 – Always	9%	(21)
Mean score (1-5 scale)	2.42	
Median	2.00	

20. During the past 12 months, have you suffered any financial stress yourself as a result of providing care to this person?

		(n-347)
Yes, Serious stress	6%	(21)
Yes, Moderate stress	11%	(39)
Yes, Mild stress	25%	(87)
No, no problems	58%	(200)

21. During the past 12 months, have you suffered any mental health concerns yourself as a result of providing care to this person?

		(n-346)
Yes, Serious concerns	4%	(13)
Yes, Moderate concerns	14%	(50)
Yes, Mild concerns	27%	(92)
No, no concerns	55%	(191)

22. During the past 12 months, have you delayed any health care for yourself as a result of your caregiving responsibilities?

		(n-347)
Yes	23%	(81)
No	77%	(266)

23. Which of the following strategies did/are you using to manage caregiving? Have you…
(“YES” RESPONSES SHOWN)

Yes		(n-347)
Asked a friend or family member for unpaid help	52%	(181)
Paid for caregiving assistance or a home health service	11%	(37)
Utilized a government or community program (e.g. senior center, Meals on Wheels, Ride program)	11%	(38)
Other (specify)	8%	(29)

24. *If “yes” to B in Question 23, ask:* Was the assistance you paid for provided by:

		(n-37)
A family member/friend	41%	(15)
A professional caregiver,	46%	(17)
A hired support person that’s not a professional caregiver	22%	(8)
Other (specify)	3%	(1)
Don’t know	3%	(1)

25. During the past 12 months, did you ever feel unsupported or inadequate as a caregiver? Would you say . . .

		(n-347)
Often	12%	(43)
Occasionally	27%	(92)
Rarely	22%	(77)
Never	39%	(135)

26. *If a, b, or c in Question 25, ask:* Think about a specific time you felt unsupported. What kind of support would have helped? This could include support from family, friends, government services, and medical support.
(Coded by ALL MENTIONS)

Support from family, friends	39%	(82)
Financial support	11%	(23)
Medical support	10%	(22)
Government support	9%	(19)
Training, resources, information	6%	(12)
Mental healthcare	6%	(12)
Emotional support, a listening ear	5%	(11)
Meals	4%	(8)
Nothing	4%	(8)
Respite care, support for overwhelm	3%	(7)
Any and all support	3%	(6)
Appreciation, acknowledgment	3%	(6)

Community, social support	3%	(6)
General help, support	3%	(6)
Help around the house, yard	3%	(6)
Transportation	3%	(6)
Help with hygiene, physical needs	2%	(5)
Miscellaneous responses	5%	(10)
Don't know	4%	(9)

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27. *If a, b, or c in Question 25 and not d in Question 13, ask:* Using a 1 to 5 rating scale with 1 being not at all helpful and 5 being very helpful, would the following allow you provide care for your friend or loved one outside of a residential care setting …

A…. support from home health aides.

		(n-199)
1 – Not at all helpful	28%	(55)
2	3%	(45)
3	14%	(28)
4	13%	(26)
5 – Very helpful	23%	(45)
Mean	2.80	
Median	2.00	

B… support with driving to appointments.

		(n-203)
1 – Not at all helpful	29%	(59)
2	18%	(36)
3	17%	(35)
4	16%	(32)
5 – Very helpful	20%	(40)
Mean	2.79	
Median	3.00	

C … support with services like providing meals.

		(n-202)
1 – Not at all helpful	21%	(42)
2	25%	(50)
3	22%	(44)
4	12%	(24)
5 – Very helpful	21%	(42)
Mean	2.87	
Median	3.00	

D … support with household chores and/or maintenance.

		(n-202)
1 – Not at all helpful	13%	(26)
2	13%	(26)
3	18%	(37)
4	26%	(53)
5 – Very helpful	30%	(60)
Mean	3.47	
Median	4.00	

E … support with my friend or loved one's money management.

		(n-203)
1 – Not at all helpful	37%	(75)
2	22%	(44)
3	16%	(33)
4	15%	(31)
5 – Very helpful	9%	(19)
Mean	2.38	
Median	2.00	

F …receiving some financial support through a government caregiver program.

		(n-200)
1 – Not at all helpful	23%	(47)
2	18%	(36)
3	16%	(33)
4	16%	(32)
5 – Very helpful	26%	(52)
Mean	3.03	
Median	3.00	

Q27 A-F	Num resp.	Not at all 1	2	3	4	Very 5	Mean 1-5 scale
A. Support from home health aides	*199*	28%	23%	14%	13%	23%	2.80
B. Support with driving to appointments	*203*	29%	18%	17%	16%	20%	2.79
C. Support with services like providing meals	*202*	21%	25%	22%	12%	21%	2.87
D. Support with household chores and/or maintenance.	*202*	13%	13%	18%	26%	30%	3.46
E. Support with my friend or loved one's money management	*203*	37%	22%	16%	15%	9%	2.38
F. Receiving some financial support through a government caregiver program.	*200*	23%	18%	16%	16%	26%	3.03

28. Using a 1 to 5 rating scale with 1 being "Strongly Disagree" and 5 being "Strongly Agree," please indicate your level of agreement with the following statements:

A. I am in a position to continue providing care to my friend or loved one as long as needed in their current state of health.

		(n-340)
1 – Strongly Disagree	8%	(26)
2	6%	(22)
3	14%	(48)
4	19%	(65)
5 – Strongly Agree	53%	(179)
Mean	4.03	
Median	5.00	

B. My physical or mental health may prevent me from continuing to provide care to my friend or loved one.

		(n-344)
1 – Strongly Disagree	57%	(196)
2	17%	(59)
3	15%	(51)
4	6%	(21)
5 –Strongly Agree	5%	(17)
Mean	1.85	
Median	1.00	

C. *If d in Question 13, SKIP:* For many reasons, a residential care setting (assisted living, board and care, memory care, or a skilled nursing facility) would be the best situation for my friend or loved one, but it isn't an option financially.

		(n-331)
1 – Strongly Disagree	54%	(180)
2	11%	(36)
3	15%	(50)
4	8%	(28)
5 – Strongly Agree	11%	(37)
Mean	2.11	
Median	1.00	

D. I anticipate my friend or loved one will require a level of care I cannot provide in the future.

		(n-344)
1 – Strongly Disagree	27%	(93)
2	15%	(51)
3	20%	(69)
4	16%	(54)
5 – Strongly Agree	22%	(77)
Mean	2.92	
Median	3.00	

28. (A-D)	Num resp.	Str Disag. 1	2	3	4	Str. Agree 5	Mean 1-5 scale
A. I am in a position to continue providing care to my friend or loved one as long as needed in their current state of health.	340	8%	6%	14%	19%	53%	4.03
B. My physical or mental health may prevent me from continuing to provide care to my friend or loved one.	344	57%	17%	15%	6%	5%	1.85
C. (this Q. skipped if currently in care setting) For many reasons, a residential care setting (asst. living, board & are, memory care, skilled nursing facility) would be the best situation for my friend or loved one, but it isn't an option financially.	331	54%	11%	15%	8%	11%	2.11
D. I anticipate my friend or loved one will require a level of care I cannot provide in the future.	344	27%	15%	20%	16%	22%	2.92

29. If the person you are caring for currently requires routine daily support from health professionals or requires this level of support in the future, would your preference be a home setting or a residential care setting?

		(n-339)
Definitely home-setting	45%	(151)
Probably home-setting	26%	(88)
Probably a residential care setting	9%	(29)
Definitely a residential care setting	3%	(11)
Don't know	18%	(60)

The next several questions relate to your employment.

30. *If not employed (option c) to Question 5 ask:* Which best describes your employment situation?

		(n-120)
I have chosen to be a homemaker.	28%	(33)
I stopped working because of caregiving responsibilities.	2%	(2)
I chose to stop working for another reason. (e.g. retired)	58%	(70)
Other (specify)	12%	(15)

31. *If not employed (option c) on Question 5 and a or b on Question 7, ask:* Earlier you mentioned that ideally you would work (full/part) time. What would be necessary to make that possible? (*Coded by all comments mentioned and reported by actual responses*)

	(n-27 responses)
Flexibility	(8)
The right job (pay, fit, qualifications)	(4)
Schooling	(3)
Support/help	(3)
Accommodations for children	(3)
Better personal health	(2)
Finding a job, in general	(2)
Close location	(2)
Other responses	(4)
Don't know	(1)

32. *If not employed (option c) on Question 5 and a or b on Question 7, ask:* Using a 1 to 5 rating scale where 1 is "not at all important," 2 is "not very important," 3 is "neutral", 4 is "somewhat important" and 5 is "very important." How important are the following for you to achieve your ideal balance of work and caregiving? [Do not rotate first three]

A. Access to quality affordable at-home caregiving support

		(n-27)
1 – Not at all important	11%	(3)
2 - Not very important	11%	(3)
3 - Neutral	26%	(7)
4 – Somewhat important	19%	(5)
5 – Very important	33%	(9)

B. Access to quality affordable residential care, such as nursing homes

		(n-27)
1 – Not at all important	30%	(8)
2 - Not very important	19%	(5)
3 - Neutral	22%	(6)
4 – Somewhat important	15%	(4)
5 – Very important	15%	(4)

C. Assistance with caregiving from friends and family

		(n-27)
1 – Not at all important	4%	(1)
2 - Not very important	0%	(0)
3 - Neutral	22%	(6)
4 – Somewhat important	33%	(9)
5 – Very important	41%	(11)

D. Ability to work remotely

		(n-27)
1 – Not at all important	0%	(0)
2 - Not very important	4%	(1)
3 - Neutral	11%	(3)
4 – Somewhat important	22%	(6)
5 – Very important	63%	(17)

E. Flexibility in work hours or schedule

		(n-27)
1 – Not at all important	4%	(1)
2 - Not very important	0%	(0)
3 - Neutral	4%	(1)
4 – Somewhat important	22%	(6)
5 – Very important	70%	(19)

F. Better paying part-time job opportunities

		(n-27)
1 – Not at all important	7%	(2)
2 - Not very important	4%	(1)
3 - Neutral	15%	(4)
4 – Somewhat important	15%	(4)
5 – Very important	59%	(16)

Q 32 A-H	Num resp.	Not at all 1	Not very 2	Neutral 3	Somewhat 4	Very 5
A. Access to quality, affordable at-home caregiving support	27	11%	11%	26%	19%	33%
B. Access to quality affordable residential care, such as nursing homes	27	30%	19%	22%	15%	15%
C. Assistance with caregiving from friends and family	27	4%	0%	22%	33%	41%
D. Ability to work remotely	27	0%	4%	11%	22%	63%
E. Flexibility in work hours or schedule	27	4%	0%	4%	22%	70%
F. Better paying part-time job opportunities	27	7%	4%	15%	15%	59%
G. Part-time job opportunities that allow career advancement	27	7%	0%	30%	33%	30%
H. Paid family leave for care	27	0%	7%	26%	19%	48%

G. Part time job opportunities that allow career advancement

		(n-27)
1 – Not at all important	7%	(2)
2 - Not very important	0%	(0)
3 - Neutral	30%	(8)
4 – Somewhat important	33%	(9)
5 – Very important	30%	(8)

H. Paid family leave for caregiving

		(n-27)
1 – Not at all important	0%	(0)
2 - Not very important	7%	(2)
3 - Neutral	26%	(7)
4 – Somewhat important	19%	(5)
5 – Very important	48%	(13)

33. *If employed (a or b) to Question 5 ask:* Including yourself, how many employees does your company or organization have? [If local office is part of a national organization, include the national organization size]

		(n-226)
1 to 9 employees	24%	(54)
10 to 49 employees	14%	(31)
50 to 249 employees	13%	(30)
250 employees or more	44%	(100)
Don't know	5%	(11)

34. *If employed (a or b) to Question 5 ask:* Have you experienced any of the following work-related changes due to your caregiving role? Did you… ("YES" RESPONSES SHOWN)

		(n-226)
A. Take a second job or Increase hours with your current job?	8%	(18)
B. Work hybrid or virtually?	22%	(49)
C. Change your job duties?	11%	(25)
D. Change your place of work?	7%	(15)
E. Reduce your number of work hours?	21%	(47)
F. Take a temporary leave of absence?	8%	(19)
G. Other (specify)	2%	(5)
H. None of the above	60%	(136)

35. If employed (a or b) to Question 5 ask: Is caregiving preventing you from working as much as you desire or need?

		(n-226)
Yes	10%	(22)
No	73%	(164)
It depends	18%	(40)

36. *If employed (a or b) to Question 5 ask:* Which of the following three statements best describes your current situation?

		(n-225)
The need to work to pay bills is preventing me from providing the caregiving I want.	15%	(34)
My caregiving responsibilities are preventing me from working as much as I would like.	5%	(11)
The balance between my work and my caregiving is acceptable.	77%	(174)
Other (specify) _______	3%	(6)

37. If employed (a or b) to Question 5 ask: In the last 12 months, what was the most difficult part of managing your work and caregiving responsibilities? (Coded to represent each time a theme was mentioned in comments)

None	22%	(49)
Time, scheduling	20%	(45)
Impact on work	13%	(30)
Balancing responsibilities	12%	(26)
Exhaustion, overwhelm	8%	(19)
Financial	5%	(12)
Impact on family	5%	(12)
Doctor appointments	5%	(11)
Distance, travel	4%	(9)
Time for self	4%	(9)
Attitude of recipient	4%	(8)
Feelings of inadequacy, guilt	3%	(7)
Declining health, passing	3%	(6)
Stress	3%	(6)
Own physical and mental health	2%	(5)
Communication with others	2%	(4)
Transportation	1%	(3)
Miscellaneous responses	3%	(7)
Don't know	1%	(3)

38. *If employed (a or b) to Question 5 ask:* Have you talked with any of the following at your workplace about your caregiving situation?

A. Management		(n-226)
Yes	17%	(39)
No	62%	(141)
Not applicable	20%	(46)

B. Supervisor		(n-226)
Yes	24%	(55)
No	58%	(130)
Not applicable	18%	(41)

C. Human Resources Officer		(n-226)
Yes	5%	(12)
No	71%	(161)
Not applicable	23%	(53)

D. Coworker		(n-225)
Yes	42%	(95)
No	43%	(96)
Not applicable	15%	(34)

Q38 A-D	Num resp.	Yes	No	Not Applic
A. Management	226	17%	62%	20%
B. Supervisor	226	24%	58%	18%
C. Human Resources Officer	226	5%	71%	23%
D. Coworker	225	42%	43%	15%

39. *If employed (a or b) to Question 5 ask:* Does your employer offer any of the following support or benefits for caregivers?

A. On-site support group		(n-226)
Yes	7%	(15)
No	68%	(154)
Not applicable	23%	(52)
Don't know	2%	(5)

B. Individual counseling		(n-226)
Yes	31%	(70)
No	45%	(101)
Not applicable	23%	(51)
Don't know	2%	(4)

C. Referrals to needed resources		(n-226)
Yes	24%	(54)
No	50%	(112)
Not applicable	23%	(52)
Don't know	4%	(8)

D. Unpaid leave for caregiving		(n-226)
Yes	31%	(71)
No	43%	(97)
Not applicable	23%	(52)
Don't know	3%	(6)

E. Paid leave for caregiving		(n-225)
Yes	13%	(29)
No	61%	(137)
Not applicable	23%	(51)
Don't know	4%	(8)

Q 39 A-E	Num resp.	Yes	No	Not applic.	Don't know
A. On-site support group	226	7%	68%	23%	2%
B. Individual counseling	226	31%	45%	23%	2%
C. Referrals to needed resources	226	24%	50%	23%	4%
D. Unpaid leave for caregiving	226	31%	43%	23%	3%
E. Paid leave for caregiving	225	13%	61%	23%	4%

40. *If employed (a or b) to Question 5 ask:* Using a 1 to 5 rating scale where 1 is "not at all important," and 5 is "very important." How important are the following for you to successfully balance work and caregiving? [Do not rotate first three]

A. Access to quality, affordable at-home caregiving support

		(n-226)
1 – Not at all helpful	23%	(52)
2	8%	(19)
3	21%	(47)
4	20%	(45)
5 – Very helpful	28%	(63)
Mean	3.21	
Median	3.00	

B. Access to quality affordable residential care, such as nursing homes

		(n-225)
1 – Not at all helpful	36%	(82)
2	12%	(28)
3	17%	(39)
4	13%	(29)
5 – Very helpful	21%	(47)
Mean	2.69	
Median	3.00	

C. Assistance with caregiving from friends and family

		(n-226)
1 – Not at all helpful	11%	(25)
2	7%	(16)
3	23%	(52)
4	21%	(48)
5 – Very helpful	38%	(85)
Mean	3.67	
Median	4.00	

D. Remote work

		(n-226)
1 – Not at all helpful	27%	(60)
2	8%	(19)
3	19%	(42)
4	16%	(36)
5 – Very helpful	31%	(69)
Mean	3.15	
Median	3.00	

E. Flexibility in hours or schedule

		(n-226)
1 – Not at all helpful	16%	(36)
2	5%	(12)
3	13%	(29)
4	20%	(45)
5 – Very helpful	46%	(104)
Mean	3.75	
Median	4.00	

F. Better paying part-time job opportunities

		(n-225)
1 – Not at all helpful	39%	(88)
2	10%	(22)
3	21%	(47)
4	9%	(21)
5 – Very helpful	21%	(47)
Mean	2.63	
Median	2.38	

G. Part-time job opportunities that allow career advancement

		(n-225)
1 – Not at all helpful	45%	(102)
2	11%	(25)
3	20%	(45)
4	7%	(16)
5 – Very helpful	16%	(37)
Mean	2.38	
Median	2.00	

H. Paid leave for family caregiving

		(n-225)
1 – Not at all helpful	24%	(55)
2	7%	(16)
3	21%	(47)
4	16%	(35)
5 – Very helpful	32%	(72)
Mean	3.24	
Median	3.00	

I. Other

Q40 A-H	Num resp.	Not at all 1	2	Neut.- 3	4	Very Helpful 5	Mean 1-5 scale
A. Access to quality affordable at-home caregiving support	226	23%	8%	21%	20%	28%	3.21
B. Access to quality affordable residential care, such a nursing homes	225	36%	12%	17%	13%	21%	2.69
C. Assistance with caregiving from friends and family	226	11%	7%	23%	21%	38%	3.67
D. Remote work	226	27%	8%	19%	16%	31%	3.15
E. Flexibility in work hours or schedule	226	16%	5%	13%	20%	46%	3.75
F. Better paying part-time job opportunities	225	39%	10%	21%	9%	21%	2.38
G. Part-time job opportunities that allow career advancement	225	45%	11%	20%	7%	16%	2.38
H. Paid family leave for care	225	24%	7%	21%	16%	32%	3.24

41. We know there are a lot of challenges associated with caregiving. What have we missed? Tell me what the greatest challenge of caregiving is for you.
(ALL MENTIONS CODED)

None, nothing	22%	(77)
Time commitment, scheduling	9%	(32)
Support, respite needed	8%	(28)
Meeting demands, being enough	6%	(22)
Balancing responsibilities	6%	(22)
Financial challenges	5%	(19)
Declining health, passing	5%	(18)
Education, training, resources	5%	(16)
Help is not accepted or appreciated	4%	(14)
Exhaustion, overwhelm	3%	(12)
Impact on family	3%	(11)
Distance, travel	3%	(10)
Own physical and mental health	3%	(10)
Dealing with government and healthcare entities	2%	(8)
Loneliness, sadness	2%	(8)
Difficulty having a patient, positive mindset	2%	(8)
Neglecting self, time for self	2%	(7)
Physical limitations	2%	(6)
Miscellaneous responses	11%	(37)
Don't know	8%	(29)

Thank you for sharing your caregiving experience with me. To conclude the survey, I have some questions about yourself and your family.

42. How many people live in your household, including yourself?

		(n-342)
1	10%	(33)
2	31%	(105)
3	17%	(58)
4	21%	(73)
5	8%	(29)
6	10%	(33)
7 or more	3%	(11)

43. *If two or more in Question 42, ask:* How many children younger than 18 years of age live in your household?

		(n-309)
None	56%	(172)
1	17%	(52)
2	14%	(44)
3	6%	(18)
4	6%	(19)
5	1%	(2)
6	1%	(2)
7 or more	0%	(0)

44. What is your zip code?

45. What level of school or educational degree have you completed?

		(n-338)
Some schooling, no high school degree	<1%	(1)
High school degree/GED credential	10%	(33)
Some college/post-secondary courses	28%	(93)
Associate degree	11%	(37)
Bachelor's degree	33%	(112)
Master's degree	14%	(46)
Professional or Doctorate degree	5%	(16)

46. What is your marital status?

		(n-339)
Married or part of a domestic partnership	78%	(266)
Widowed	5%	(17)
Divorced	7%	(25)
Separated	<1%	(1)
Single/never married	9%	(30)

47. With which racial/ethnic identity do you most identify?

		(n-339)
Hispanic/Latino	4%	(13)
American Indian or Alaska Native	<1%	(1)
Asian or Asian-American	1%	(5)
Black or African American	0%	(0)
Pacific Islander/Native Hawaiian	<1%	(1)
White	90%	(304)
Multiracial	4%	(12)
Other (Please specify)	1%	(2)
Don't know	<1%	(1)
Collapsed race/ethnicity		
White	90%	(304)
All other	10%	(34)
Don't know	<1%	(1)

48. Which of these describes your household income last year?

		(n-300)
Less than $25,000	7%	(21)
$25,000-49,999	15%	(46)
$50,000-74,999	20%	(61)
$75,000-99,999	21%	(62)
$100,000-149,999	19%	(56)
$150,000- 199,999	9%	(27)
$200,000-249,000	4%	(11)
$250,000 or more	5%	(16)

Appendix 4: Verbatim Comments

Question 13: What best describes the living situation of the person you are/were caring for? "Other" responses

- Family member and aide.
- Senior living community.
- Deceased.
- Neighbor.
- Group home.
- Injured neighbor.
- Was a friend whom we had escorted off the property for drug use.
- Died.
- We were married but he passed away in April.

Question 15: About how often do you make this trip? "Less than once a month (specify)"

- Rarely.
- Once a year. (2)
- A few times a year.
- Three times a year. (3)
- Twice a year. (2)
- Every few months. (2)
- The person is my 94-year-old mother who lives alone in San Juan County. She has many people who are available to help. The primary issue is that we, her children, decided that she should not drive anymore. I only help when I am visiting.
- On occasion.
- Every three months.
- Every once in a while. (2)
- Every two months.
- Every two to three months.
- Once or twice a year.
- Every four months.
- When needed.
- Not necessary for me to be there.

Question 23: Which of the following strategies did/are you using to manage caregiving? "Other" responses

- I tried taking them to an AA meeting and getting them involved and group therapy, tried talking to see what they might think is their best solution. I tried helping them get back on their feet, letting them stay at my home and getting them cleaned up.
- I arranged to be mostly home.
- Physical therapy.
- Using the VA.
- Introduce them to my family so that they have some association with each other.
- I have used the hospital.
- Hospice.
- We have personal aides that come in during the day, through the new choice waiver we also have hospice care coming in.
- Friends have provided meals on occasion.
- Pay someone to help clean the person's home.
- Medicare or Medicaid provided respite care for 3-4 days per month, and I used it twice.
- Someone to clean my house.
- We use our local church congregation.
- Using the internet to try and get their needs met.
- She passed away last month.
- Used contact through my church.
- Paid for some things to assist.
- If I get overwhelmed, I just slow down, do one thing at a time and realize I have the time and energy, I just have to pace myself.
- Insurance.

Question 26: Think about a specific time you felt unsupported. What would have helped? This could include support from family, friends, government services, medical support etc.
(Individual comments may encompass multiple themes, with each theme contributing to the overall percentage. However, for categorization purposes, comments are exclusively placed under the category of the first theme mentioned in each comment)

Support from family, friends - 39%

- A friend to call on.
- Additional family support.
- Any family member, but mainly my sister, to reach out and come to help me.
- Arguments from family members who live thousands of miles away and don't know the situation at all.
- Extra family help.
- Family and friends; there were times when family wouldn't step up.
- Family being around more.
- Family help. (2)
- Family or friends.
- Family support (i.e., caring for the yard).
- Family support, occupational therapy, and medical support.
- Family support. (6)
- Family, government services, medical support.
- Family, government, medical.
- Family. (9)
- Financial, more help from family help with medication.
- Friend/family support.
- Friends.
- Friendship and understanding, medical, and financial.
- Having a family member step in for a few minutes so I could have a minute to myself and regroup.
- Having my daughter take care of her own children.
- Help from family and friends.
- Help from friends/family, relief of the financial burden of it, more support in school or social situations.
- Help from sons and daughters.
- I remember one particular time when I was taking care of my grandmother and my brother with special needs while my mother was out of the country. I was left alone to take care of them, despite my other siblings being available. I could have definitely appreciated support from these family members.

- If I ever felt unsupported, all I had to do was pick up the phone and a neighbor was right there.
- If my family would step up a little more to evenly distribute caregiving responsibilities.
- Involvement of other family members in decision-making.
- It would be helpful if his girlfriend was closer.
- It would definitely help if I could get more physical help from family, friends, and healthcare professionals. It would also really help to get slight financial help to pay for the extra expenses.
- Knowing what options are available in our area, congruent decision-making between family members.
- Moral support from relatives involved.
- More family and friends.
- More family support from siblings.
- More family support. (3)
- More family.
- More help from family, more help financially.
- More help from family.
- More help from my own children.
- More support from family and some financial support.
- More support from their family.
- Patience and understanding from other family members.
- Probably from family and from the government, I guess.
- Professional caregiving would help. There are so many barriers and support from friends would be most beneficial.
- Support and acknowledgement from family.
- Support from additional family.
- Support from family and community.
- Support from family, but it really is more just the feeling of making sure you're doing the right thing.
- Support from family. (10)
- Support from friends and family.
- Support from friends.
- Support from siblings to care for my parents.
- The individual's family.
- The other siblings live too far away, so the care is mostly done by the few who live nearby. It would be nice if the others lived closer.
- Visiting teacher helps by a phone call or in person visit.
- When one family member complains about the help being given to the cared for member.
- Wish my son had a friend.

Financial support - 11%

- Anything, money.
- Financial and mental support would help.
- Financial assistance.
- Financial security/disposable income.
- Financial, more help from family help with medication.
- Financial. (4)
- Friendship and understanding, medical, and financial.
- Help from friends/family, relief of financial burden of it, more support in school or social situations.
- It would definitely help if I could get more physical help from family, friends, and healthcare professionals. It would also really help to get slight financial help to pay for the extra expenses.
- Just having a listening ear. It was when my elderly father broke his hip earlier this year. I was quite alone figuring out his financial care and sometimes it was just hard. I made it!
- Loss of a family member's job as the sole breadwinner. Unemployment could be better while they search for other jobs so that those of us who help don't need to provide a financial bridge in the meantime.
- Medical support, financial support.
- More help from family, more help financially.
- More support from family and some financial support.
- Someone to help manage finances.
- The government. However, since the ACA has been passed, I have found that healthcare for seniors disproportionately decreases each year they are alive. My mother-in-law is 83 years old and has brain tumors that are operable with a high percentage of probable success (70%), even at her age, to remove her tumors. Medicare has denied all treatment except several drugs. Hospice is available when it's time for her to die. The biggest fraud perpetrated on Americans is the ACA. The government isn't helping the elderly. They are letting them die. If we could afford the surgery, she would most likely live another 8 to 10 years. That's coming from her doctor, not a hopeful family.
- There are not a lot of services to support elderly parents that are affordable. My parents are fortunate to have pensions from the state. It is enough to put them over the financial line for all programs, but not enough to provide them assistance they need.
- Universal basic income, universal healthcare.

Medical support - 10%

- Better coordination between many doctors.
- Doctors.
- Family support, occupational therapy, and medical support.
- Family, government services, medical support. (4)
- Financial, more help from family help with medication.
- Friendship and understanding, medical, and financial.
- Government assistance and help with rent and medical bills.
- Help taking her to the doctor.
- Helping with getting to doctor appointments, house cleaning, and meal making.
- I have used medical support.
- In-home medical support/services.
- Maybe medical/government. (2)
- Medical assistance.
- Medical support, financial support.
- Medical support. (6)
- Medical.
- Minor disability funds to help someone who is hoping to recover and get a job, but as of now, can't.
- Probably from family and from the government, I guess.
- Professional caregiving would help. There are so many barriers and support from friends would be most beneficial.
- State level recognition and support for running a nonprofit elective healthcare practice.
- Support from government services.
- The government. However, since the ACA has been passed, I have found that healthcare for seniors disproportionately decreases

each year they are alive. My mother-in-law is 83 years old and has brain tumors that are operable with a high percentage of probable success (70%), even at her age, to remove her tumors. Medicare has denied all treatment except several drugs. Hospice is available when it's time for her to die. The biggest fraud perpetrated on Americans is the ACA. The government isn't helping the elderly. They are letting them die. If we could afford the surgery, she would most likely live another 8 to 10 years. That's coming from her doctor, not a hopeful family.
- There are not a lot of services to support elderly parents that are affordable. My parents are fortunate to have pensions from the state. It is enough to put them over the financial line for all programs, but not enough to provide them assistance they need.
- Universal basic income, universal healthcare.
- Unsure. This person has a hoarding disorder. There is NO help for this from the government. Alternative therapies are helping a lot.
- Working with the IRS to get errors on their end corrected for my mom has been extremely challenging. Having anyone from the government offices actually take responsibility for getting things corrected would be very helpful. Instead, everyone seems to be quick to hand us off to another person. This issue still has NOT been resolved and it was not caused by any of our actions.

Government support - 9%
- Government assistance and help with rent and medical bills.
- Government help would be great.
- Government help.
- Government services. (3)
- Government support, mental health support.
- Government support.

Training, resources, information - 6%
- Accurate information to answer questions.
- Communication about what is best and why.
- Having valuable info that was easily accessible.
- I have never cared for another person in this manner. I know many friends and family who have over the years, but never have I been in their shoes.
- Information on private services that help widows with household chores and maintenance.
- Just knowing that someone is available to help out.
- Knowing available resources.
- Knowing what options are available in our area, and congruent decision-making between family members.
- Knowledge.
- More resources or classes or something to offer education for myself.
- More training on how to deal with a difficult patient.
- Resources to help me help them.

Mental healthcare - 6%
- Dementia, anger, hygiene, therapy, food, conversation.
- Financial and mental support would help.
- Government support, mental health support.
- Housekeeping and mental support services.
- I felt unqualified to offer appropriate support for the person's mental health.
- I was just in a moment of mental weakness, being overstimulated by other stuff.
- Mental health counseling.
- Mental health support for me as a caregiver.
- Professional mental health counseling.
- Someone else being a mental support person.
- Support from a mental health professional to help me deal with my mother's emotional state (either to help me learn strategies to help deal with the stress or to learn ways to help my mother deal with the stress).
- The recipient is showing signs of dementia and is becoming increasingly unkind. Not much that can be done about it.

Emotional support, a listening ear - 5%
- Another person to listen.
- Emotional support.
- Emotional.
- Just having a listening ear. It was when my elderly father broke his hip earlier this year. I was quite alone figuring out his financial care and sometimes it was just hard. I made it!
- Just knowing that someone is available to help out.
- Just someone regularly checking on me without me having to ask.

Meals - 4%
- All of the above support with food support, bills, rides, you name it. When you're down on your luck and there's nobody there to help, whether you're the single caregiver or not, it would help if you knew somebody was behind you backing you up.
- Dementia, anger, hygiene, therapy, food, conversation.
- Groceries.
- Help with cleaning and meals or just calling or texting to see how we are doing.
- Helping with getting to doctor appointments, house cleaning, and meal making.
- Meals.
- There were a couple of times he fell, and I had to call the fire department, there were times when I was gone, and he didn't feed himself and it would have been nice to have someone there to feed him.
- Vanpool for grocery acquisition vs me having to spend hours between driving to my mother's home, going to the grocery store.

Nothing - 4%
- No answer. (5)
- None related to caregiving.
- None. (2)

Respite care, support for overwhelm - 3%
- A break.
- Help to give me a break.
- I was so overwhelmed with all of the person's needs. I couldn't take care of everything for the person and myself. I had to find help for the person so I could reduce the amount of stress I was under.

- I'm just burned out.
- More free time to be available to help more.
- Someone to step in and give me a break.
- Watching them so I can sleep.

Any and all support - 3%

- All of the above support with food support, bills, rides, you name it. When you're down on your luck and there's nobody there to help, whether you're the single caregiver or not, it would help if you knew somebody was behind you backing you up.
- All of the above. (2)
- All.
- Any and all.
- Anything, money.

Appreciation, acknowledgment - 3%

- A little appreciation on her part would be nice.
- Acknowledgement for the effort it takes to offer the care.
- Acknowledgment that I'm providing care.
- Feeling like I put my time, heart, and soul into being the best friend to this person, but trying to be there for her. She has made me feel like I am.
- I remember one particular time when I was taking care of my grandmother and my brother with special needs while my mother was out of the country. I was left alone to take care of them, despite my other siblings being available. I could have definitely appreciated support from these family members.
- Support and acknowledgement from family.

Community, social support - 3%

- A community program.
- Available programs.
- I help different people with different problems, but from what I've seen, the social services in Utah could be much better.
- Social interaction with outside sources.
- Support from family and community.
- Support from government services.

General help, support - 3%

- Help from others.
- I have no one to help.
- Just another adult to help.
- Just some help.
- Just someone else to do it.
- Professional or someone else who would be paid to give care.

Help around the house, yard - 3%

- Family support (i.e., caring for the yard).
- Help with cleaning and meals or just calling or texting to see how we are doing.
- Help with household chores.
- Helping with getting to doctor appointments, house cleaning, and meal making.

Transportation - 3%

- Help taking her to the doctor.
- Helping with getting to doctor appointments, house cleaning, and meal making.
- If there was a trusted rideshare.
- Someone to drive her to appointments.
- Transportation of family.
- Vanpool for grocery acquisition vs me having to spend hours between driving to my mother's home, going to the grocery store.

Help with hygiene, physical needs - 2%

- Dementia, anger, hygiene, therapy, food, conversation.
- Hygiene (bath).
- Physical help.
- Someone to come in and shower and help aid and do exercises.
- There were a couple of times he fell, and I had to call the fire department, there were times when I was gone, and he didn't feed himself and it would have been nice to have someone there to feed him.
- Housekeeping and mental support services.
- Information on private services that help widows with household chores and maintenance.

Miscellaneous responses - 5%

- A return phone call, moral support.
- Computer support.
- Employers who understand that work-life balance matters so that people can be available to help care for family members, who "come first" and "matter more than anything," but only when the ask is simply more thoughts and prayers and Facebook posts, but not actually reducing workload or hours or increasing pay.
- Help with the paperwork and red tape that both the federal and state demand.
- Same-gender helper.
- Some type without paperwork.
- Someone to help me with my own health issues.
- The recipient is showing signs of dementia and is becoming increasingly unkind. Not much that can be done about it.
- There is no one that my parents will trust or allow to help.

Don't know - 4%

- I don't know. (4)
- Not sure.
- Not too sure about that one.
- Unknown. (2)
- Unsure. This person has a hoarding disorder. There is NO help for this from the government. Alternative therapies are helping a lot.

Question 30: (If not currently employed) Which best describes your employment situation? "Other" responses

- Had to close our business.
- I had to quit for all the reasons above, including that I had to stop work to care give, but I also had to quit because I was driving for Lyft and the car got broken and I couldn't get it fixed.
- Disabled.

- Can't find suitable work.
- Full-time student.
- Disabled.
- Student.
- I need a part-time job, but haven't found one yet that works around being a homemaker.
- Have MS and am on disability.
- Disability.
- I am physically unable to work. I help give care by default because I am home and available as a result.

Question 31: Earlier you mentioned that ideally you would work. What would be necessary to make that possible? (n= 27 respondents)

Flexibility – 8 responses

- A job that allows me to work from home.
- A medical miracle, or a position I can do from home with no fixed schedule.
- Find an in-home, part-time job.
- I would love to own my own business making soaps and candles. I would need to be able to still be home and still make a living at the same time.
- Job that can be flexible.
- Just need to find the right fit. Flexible and not too many hours in a week. I have a child at home.
- People to accept your schedule.
- Remote work from home.

The right job (pay, fit, qualifications) – 4 responses

- Decent pay employment.
- Employment that matches my qualifications, knowledge, and is nearby.
- Find a job I felt like I can do well and that I love. I worked as a custodian for 16 years, but when I got hurt, I couldn't keep doing it, so I quit and got another job. They fired me for not being good enough. I would love to be able to sell my books online and work part time somewhere where I felt like I was doing a good job.
- The right opportunity.

Schooling – 3 responses

- Employment that matches my qualifications, knowledge, and is nearby.
- Finish school.
- I am a full-time college student. When I have completed my degree or when I feel I'm ready, I'll start an internship or part-time job.

Support / help - 3 responses

- My own health to improve and for Mother's needs to be taken care of since she is blind and lives alone; she needs help with many things.
- Steady services that others are willing and able to pay for.

Accommodations for children – 3 responses

- Childcare.
- Just need to find the right fit. Flexible and not too many hours in a week. I have a child at home.
- When my kids are older.

Better personal health – 2 responses

- A medical miracle, or a position I can do from home with no fixed schedule.
- My own health to improve and for Mother's needs to be taken care of since she is blind and lives alone; she needs help with many things.

Finding a job, in general – 2 responses

- Available jobs.
- Find a job.
- Support help on a regular basis for a loved one.

Close location – 2 responses

- Employment that matches my qualifications, knowledge, and is nearby.
- Find a job close enough to walk to, a mile or so.

Miscellaneous responses – 4 responses

- A new and better healthcare system.
- I'd have to be able to start driving.
- Nothing.
- Settle the estate.

Don't know – 1 response

- Wouldn't say.

Question 34: Have you experienced any of the following work-related changes due to your caregiving role? "Other" responses

- It changed my career, where I'm working now is in the career I want to be but it took me a while to get here.
- Flex hours.
- Work longer and harder.
- Side eyes, frowns, and passive-aggressive remarks.
- Rearranged schedule.

Question 36: (If caregiving is preventing respondent from working as much as desired or needed) Which of the following statements best describes your current situation? "Other" responses

- It wasn't working out and my needs are more important to me.
- They passed away.
- Death.
- I cut a neighbor's grass.
- Mostly it works fine. Rarely I'm unable to get him where he needs to go.
- Usually, the balance is acceptable, but there have been some times that I need to work more hours than I am able to.

Question 37: In the last twelve months, what was the most difficult part of managing your work and caregiving responsibilities?

(Individual comments may encompass multiple themes, with each theme contributing to the overall percentage. However, for categorization purposes, comments are exclusively placed under the category of the first theme mentioned in each comment)

None - 22%

- Don't have any.
- Eventually, it all works out. I think that's the mindset we all need to have looking at the picture as a whole.
- I did not have any difficulties.
- I haven't had any difficulties.
- It's acceptable.
- My caregiving does not take much time, so there have not been any issues.
- N/A (5)
- No difficulty. (3)
- No issues. (2)
- No problem. (3)
- No real difficulties, occasionally I need a day or two off, but I have plenty of paid leave to do that.
- None. (8)
- Nothing difficult.
- Nothing. (16)
- The caregiving was very little, so it was definitely manageable.
- There really hasn't been difficulty.
- There was no difficulty.

Time commitment, scheduling - 20%

- Being interrupted at critical times.
- Continuous interruptions.
- Doing it regularly.
- Enough time in the day.
- Event deadlines.
- Finding the time outside of two jobs.
- Finding time to do it all.
- If I were full-time at home, I could better be available when needed.
- Just finding the time to do it.
- Just finding time in a generally busy life.
- Just time management.
- Lack of overall time.
- Limited time.
- Making sure I am available when needed.
- Managing money and time.
- Money and time.
- Not enough time to do everything.
- Not having the time and patience to really be available and listening to what my mom needs.
- Schedule.
- Scheduling and finding childcare during the summer.
- Scheduling conflicts.
- Scheduling, transportation, and appointments.
- Scheduling. (2)
- She needs someone with her all the time. We take turns as a family to rotate care.
- Sometimes my friend needed something that I could not help with because it was during working hours.
- Takes a lot of time.
- Taking off chunks of time.
- Time and distance.
- Time and energy.
- Time and/or lack of it.
- Time commitments.
- Time management between work, caregiving, and social life.
- Time management for appointments.
- Time management. (4)
- Time to do things.
- Time to do what was needed at both homes.
- Time. (7)
- Trying to work and care for someone at the same time. There is not enough time in the day to get everything done.

Impact on work - 13%

- Appointments during work hours.
- Being able to concentrate on work without interruption.
- Being there for the person and working was very difficult in January and February.
- Days off have to be changed.
- Dealing with my job.
- Finding time to break away from work, including outside of office hours, to care for family.
- Getting my work schedule and having to work with/around doctors' appointments.
- Giving adequate care and working adequately.
- Going to work when she was in the hospital.
- Having my day "chunked-up" between working and running to appointments, rather than having focused time to work.
- Having to change my schedule to be there to help when needed.
- Having to leave work to pick them up.
- Having to shift work schedules around frequently and work extra hours to make up for time away for caregiving.
- Having to take time off during the middle of the workday, then make up the hours later in the evening.
- Having too much to do before I go to work and being overwhelmed.
- I have some out-of-town jobs that I haven't been able to take care of because of my caregiving responsibilities.
- I need to be in the office to complete my work.
- I need to work more to pay for my caregiving responsibilities.
- I travel for work, so it can be challenging or worrisome.
- I work for an hour each morning and then return in the afternoon for another hour.
- Just long days at work.
- Losing job.
- Making sure I had enough paid time off to provide care.
- My work schedule is not flexible.
- Needing to take the time off work to go to doctor appointments.
- Sometimes I don't sleep well, which makes working and caregiving more difficult.

- Stress of missing some work time to give care.
- Taking off chunks of time.
- Taking time off to travel to doctor appointments.
- The needs of caregiving are not always coming at the times that I can be flexible with my workload.
- The timing of doctor's appointments and work meetings.
- Trying to manage and balance time-sensitive work projects while also attending to time-sensitive needs for my mom.

Balancing responsibilities - 12%
- Balancing other family relationships.
- Balancing properly.
- Being there for the person and working was very difficult in January and February.
- Family balance.
- Finding the time outside of two jobs.
- Finding time to do it all.
- Giving adequate care and working adequately.
- Going to school.
- Having a baby while working my main job while running a nonprofit healthcare facility.
- Having to balance the two.
- Having to shift work schedules around frequently and work extra hours to make up for time away for caregiving.
- Having to take time off during the middle of the workday, then make up the hours later in the evening.
- Having too much to do before I go to work and being overwhelmed.
- I have some out-of-town jobs that I haven't been able to take care of because of my caregiving responsibilities.
- I need to work more to pay for my caregiving responsibilities.
- Juggling tasks.
- Just feeling stretched thin between all of my responsibilities.
- Managing my schedule, work, and caring for myself, time alone/away.
- Scheduling conflicts.
- School.
- Time management between work, caregiving, and social life.
- Time to do what was needed at both homes.
- Trying to balance taking care of someone else but also needing to take care of myself and my other responsibilities.
- Trying to do it all alone while trying to manage my own health issues.
- Trying to manage and balance time-sensitive work projects while also attending to time-sensitive needs for my mom.
- Trying to work and care for someone at the same time. There is not enough time in the day to get everything done.

Exhaustion, overwhelm - 8%
- All of the doctors' appointments. My parents have so many that making sure they get to them, having someone there to translate what is needed, and making sure they do the follow-up tests/appointments is overwhelming. Right now, it is moderately manageable. But will quickly become unmanageable as they get older and/or health deteriorates.
- Being worn out from one or the other, slight reduction in capacity in one or the other.
- Burnout.
- Emotional and mental stress on my health, trying to take care of both.
- Energy.
- Having days that are very overwhelming.
- Having too much to do before I go to work and being overwhelmed.
- I was too tired, and it wiped me out. I had my own health problems and work to manage. It was exhausting and I had to see a therapist.
- It's just exhausting.
- Lack of sleep.
- Mostly the mental toll it has taken on me.
- Not a lot of sleep.
- Not getting enough sleep.
- Physically draining.
- Sleep.
- Sleeping enough.
- Sometimes I don't sleep well, which makes working and caregiving more difficult.
- Stress and sleep.
- Time and energy.

Financial - 5%
- Finances. (2)
- Financial. (2)
- Financials.
- I need to work more to pay for my caregiving responsibilities.
- Inflation of the cost of things is making things hard to manage.
- Lack of income.
- Managing money and time.
- Money and time.
- Money stress.
- Money.

Impact on family - 5%
- Balancing other family relationships.
- Being away from home when I needed to be here.
- Family balance.
- Finding time to break away from work, including outside of office hours, to care for family.
- Less time at home.
- Navigating the family issues on who gives the care.
- Not being home at certain times.
- She needs someone with her all the time. We take turns as a family to rotate care.
- The demand from my parents is leaving little time for my children.
- The person doesn't admit she needs more help than others at home can provide.
- The stress of it being a family member.
- Trying to spend time with MY family and care for the person I'm caring for at the same time. I'm split in two.

Doctor appointments - 5%

- All of the doctors' appointments. My parents have so many that making sure they get to them, having someone there to translate what is needed, making sure they do the follow up tests/appointments is overwhelming. Right now, it is moderately manageable. But will quickly become unmanageable as they get older and/or health deteriorates.
- Appointments during work hours.
- Appointments that overlap.
- Getting my work schedule and having to work with/around doctors' appointments.
- Having my day "chunked-up" between working and running to appointments, rather than having focused time to work.
- Needing to take the time off work to go to doctor appointments.
- Not being able to be at all the appointments.
- Scheduling, transportation, and appointments.
- Taking time off to travel to doctor appointments.
- The timing of doctor's appointments and work meetings.
- Time management for appointments.

Distance, travel - 4%

- 1.5 hours away allows me to help only once a month.
- Commuting.
- Difficulties associated with travel.
- Distance. I provide supportive care for my mother who is cared for primarily by my father. Living
- I travel for work, so it can be challenging or worrisome.
- Mainly the distance between her home and her doctors and my job.
- Taking time off to travel to doctor appointments.
- The driving time back and forth.
- The person I wanted to help was in another state.
- Travel time and communication with others.
- Travel.

Time for self - 4%

- I do not have much time for myself.
- I was too tired, and it wiped me out. I had my own health problems and work to manage. It was exhausting and I had to see a therapist.
- It is sometimes difficult to find the necessary time for myself.
- Lack of acknowledgment for the effort it takes and lack of time for myself.
- Managing my schedule, work, and caring for myself, time alone/away.
- Not as much time for outside exercise.
- Taking time for myself.
- The most difficult part is a little bit more selfish. I like to paint and draw, and I have to put my hobbies and interests on the backburner at times. Since I'm an introvert and I work with people all day, I value this time to myself, so I sometimes get frustrated when I don't get this time.
- Trying to balance taking care of someone else but also needing to take care of myself and my other responsibilities.

Attitude of recipient - 4%

- Attitude of recipient.
- Figuring out when my grandma needs help and when she will accept help.
- Getting the individual to agree to doing things.
- Helping my daughter take her health serious and take care of herself.
- Lack of acknowledgment for the effort it takes and lack of time for myself.
- The attitude of the one receiving the care.
- The one in need isn't receptive.
- The person doesn't admit she needs more help than others at home can provide.

Feelings of inadequacy, guilt - 3%

- Doing a good job.
- Giving adequate care and working adequately.
- Guilt.
- Making sure I'm adequate.
- Not being there when I needed to be there.
- Not sure what to do sometimes.
- The constant worry of knowing I'm not meeting all the obligations, and that they're happy.

Declining health, passing - 3%

- Getting older.
- Having that person die.
- Just watching a loved one deteriorate.
- Watching the decline of their health.
- When I had to quit caring for my husband.
- When she fell and broke her hip.

Stress - 3%

- Stress and sleep.
- Stress of missing some work time to give care.
- Stress. (2)
- The stress and constant having to help with basic things.
- The stress of it being a family member.

Own physical and mental health - 2%

- Being injured.
- Being sick.
- Emotional and mental stress on my health, trying to take care of both.
- Mostly the mental toll it has taken on me.
- Physically draining.

Communication with others - 2%

- Coordinating between doctors that will not talk to each other.
- Travel time and communication with others.
- Working with doctor and understanding what I need to do to provide the best care.
- Working with government and insurance.

Transportation - 1%

- Getting my son where he needs to go.
- Scheduling, transportation, and appointments.
- Transportation.

Miscellaneous responses - 3%

- Everything was harder.
- Having enough room in the house we live in.
- I only visit on occasion.
- I would have liked to help my sister more, but it wasn't possible.
- Mostly medical reasons (pharmacy), cooking and preparing meals for a diabetic can be challenging.
- This survey.
- Working with government and insurance.

Don't know - 1%

- Don't know.
- I can't say specifically.
- I'm not sure.

Question 41: We know there are a lot of challenges associated with caregiving. What have we missed? Tell me the greatest challenge of caregiving is for you.

None, nothing - 22%

- Cannot think of anything. (4)
- Caregiving is an opportunity, not a challenge.
- I can't think of anything. I could be too tired to think of something though.
- I cared for my wife for three months after her knee replacement. It was a pleasure. A lot of work but not a burden at all.
- I don't believe you missed anything.
- I don't find it a challenge.
- I don't have any challenges. My mother only needed minimal support for a short period of time when she got Covid and when she sprained her ankle.
- I really don't think there is much of anything right now.
- I think you covered it.
- I thought it hit on everything.
- I'm happy to help whenever I can.
- No challenges at this time.
- No challenges, the caregiving I do is very minimal.
- No challenges (2)
- No issues.
- None. (21)
- Not many.
- Not really a challenge at all.
- Nothing comes to mind.
- Nothing I can think of. (2)
- Nothing offhand.
- Nothing with caregivers. No challenges, I am just blessed to be able to help.
- Nothing, good job.
- Nothing, it felt thorough.
- Nothing, she is a friend.
- Nothing. (21)
- The survey hit everything I could think of!
- These questions have been great.
- Think you got it covered.
- This was a thorough survey.
- Unknown
- Very good.

Time commitment, scheduling - 9%

- Balancing my time as an employee, caregiver, wife, and mother to my children.
- Enough time.
- Finding the time with a busy family schedule.
- Having time.
- I love helping out but wish I had more time.
- Lack of time, flexibility in doctor appointments.
- Making time.
- Managing my time and communicating with my spouse.
- Not enough hours in the day.
- Paid time off.
- Taking the time to go to her house, giving her meds, and visiting her.
- The amount of time and effort and not knowing the best thing to do.
- The fact that I have my own stressors to worry about, both time and financially.
- The fact that many times caregiving is an ongoing task that may last for years or decades.
- The greatest challenge is giving all of my time and energy. They need more than just food and the basics. Keeping optimistic is hard.
- The greatest challenge is transportation and time management with my life and theirs.
- The hardest part was having to adjust mentally to doing it all the time.
- The time it takes to care for them and just managing when you need to feed them and everything, just mostly time.
- Time and lack of extra time.
- Time and resources.
- Time and the strain on my mental health due to dealing with a difficult person.
- Time management. (2)
- Time to do it.
- Time vs money.
- Time, money, the will to do what is needed sometimes.
- Time. (4)
- Time. It's hard to take care of my own family and help my dad. He passed away from cancer but while he was sick; it was hard to balance at times.
- Work schedule, and proximity to my parents.

Support, respite needed - 8%

- Access to respite care.
- Being able to support the person mentally and help the person stay positive about their limitations.
- Doing it alone.
- Emotional support.

- Encouragement that I can do it.
- Feeling like you're on call all the time, so just not having the freedom, just not having the burden off your shoulders so you just have to create breaks for yourself.
- Feeling supported. The toll of caregiving and being the sole breadwinner for a family of 5 is heavy on my physical and mental health. It doesn't seem like there are any other options available.
- Figuring out how to get the help my son will need when I'm too old or unable to do it.
- Finding people to sit with him while I run errands or go to a movie.
- Getting a break.
- Getting breaks from care giving from siblings.
- Having support from other family members.
- Helping other loved ones, who are caring for a family member.
- How to best support and help someone while still maintaining healthy boundaries.
- I'm the disabled one caregiving for my son with little support.
- I'm the only one of his family that lives here, so it's all on me.
- Infrequent (occasional) support groups to talk to would be helpful.
- Just being the only person who is there all the time.
- Lack of community/government assistance.
- My family member had Alzheimer's, and she passed last September. We had no help until she was put on hospice the last two weeks of her life. Medicare was useless during the time we cared for her.
- No services close by for support.
- Not having support.
- Not much is needed from me personally. I'm not the best person to ask about this complicated situation. More support for others in a much more difficult situation would be a huge benefit to society.
- Residential help for remote or rural areas.
- Social/emotional support for caregivers.
- Support from extended family.
- Understanding from family and friends.
- Why do some people just not want to get involved?

Meeting demands, being enough - 6%

- Being able to support the person mentally and help the person stay positive about their limitations.
- Being available when needed.
- Being aware of their needs.
- Feeling responsible for someone else.
- I can't help everyone.
- I would say just knowing how to help make a good decision. I always worry if we are doing the right thing.
- Keeping up with the demands.
- Knowing if someone is struggling.
- Making decisions when you know what's right even if it's against what they want.
- Making sure I am doing enough.
- Making sure that I am doing it in a peaceful, wonderful way.
- Meeting the needs of the person as the needs increase.
- My mom is dependent on me for everything, and I do my best to manage. It is difficult to take some time for myself.
- Not being able to fix everything myself is also inconvenient.
- Not getting enough work done, having appointments get off "wait list" and trying to slice them in.
- Not much is needed from me personally. I'm not the best person to ask about this complicated situation. More support for others in a much more difficult situation would be a huge benefit to society.
- Probably the greatest challenge is not being able to leave or have a family life.
- The amount of time and effort and not knowing the best thing to do.
- The challenge is to make the best decision for the family member's care.
- The greatest challenge is myself and the personal commitment that it takes.
- The mental aspect of having to accept that my loved one will eventually need more care than I can give.
- The most difficult is knowing what my person needs when they do not communicate it effectively.

Balancing responsibilities - 6%

- Balancing family and caregiving.
- Balancing it all.
- Balancing my time as an employee, caregiver, wife, and mother to my children.
- Balancing paying for livable situations and caretaking.
- Balancing time. (2)
- Feeling responsible for someone else.
- Finding a balance between home, work, and caregiving, as well as finding time for yourself.
- Finding the time with a busy family schedule.
- How to best support and help someone while still maintaining healthy boundaries.
- I think it is the life balance.
- Life balances with the needs of who I am caring for.
- My own mental health and balancing caregiving with my other responsibilities outside of work and caregiving.
- Not getting enough work done, having appointments get off "wait list" and trying to slice them in.
- The greatest challenge is navigating work and appointments.
- The time it takes to care for them and just managing when you need to feed them and everything, just mostly time.
- Time management between work, caregiving, and social life.
- Time spent between two families (mine and care person). Keeping care person motivated to continue getting stronger and healthier.
- Time. It's hard to take care of my own family and help my dad. He passed away from cancer but while he was sick; it was hard to balance at times.
- Trying to coordinate everything is complicated.
- Trying to manage everything.
- Work/life balance.

Financial challenges - 5%

- At times financial assistance.
- Caregiver has become a term only associated with people who provide care for the elderly with disabilities and the severely infirm, and that is not at all the case. Plenty of people provide substantial care to others who appear to be "well" by many metrics. How I provide care provides substantial but unquantifiable peace of mind to someone who does not have that in many aspects of life. That the toll or price of caregiving must be quantifiable in terms of a monetary cost or apply only to actions related to someone's physical well-being is ludicrous, particularly in a world where we understand how crucial good mental health and positive state of mind are for overall positive health outcomes. I may have done a few things that cost me money I really did not have, but I am glad to be able to provide a service using a skill I possess to someone who honestly has been unable to learn that skill herself, which has lessened her own stress levels and increased her positivity in a time of grief and intense physical pain and difficult transition and loss of independence. But that service is never going to be recognized as "caregiving," just as going to have dinner with her once a week when she can still fix dinner for 20 people herself will never be recognized as "caregiving," even though she is alone for the first time in 86 years and has never had to take care of only herself. We live in a society hell bent on insisting we care about ourselves (our own masks first) when we are designed for connection, and we fight that impulse with every fiber of our beings because it isn't profitable, and the results are unpredictable, and the outcomes are often unquantifiable. We need to be caring for one another, all of us, always. The qualitative results of serving and connecting with one another demonstrate that maybe helping someone.
- Cost of help in the home.
- else put their mask on first because they're struggling and panicking, and we are not; maybe that's something worth trying. And continued insistence from the federal and state level that caregiving is a burden to be relieved rather than an opportunity to be encouraged is the absolute wrong approach.
- Expense, insurance companies, the privatization of care.
- Finances.
- Financial burden.
- Financial.
- Is there a possibility for a family member to be paid as a full-time caregiver?
- Managing finances and getting to appointments.
- Managing her finances, transportation for doctors and errands, support in her home so she can remain there as long as possible, and activities for the blind.
- Mental and financial wellbeing.
- Money.
- The biggest challenge is money.
- The biggest support is financial assistance. The survey did not ask much about that.
- The cost of healthcare and medical services in this country is astronomically high.
- The fact that I have my own stressors to worry about, both time and financially.
- The legal challenge, making sure there's proper legal guidance. Mental stability, getting answers, financial problems, expenses, no financial help. Watching them go through changes because they need to make changes they're not used to. Trying to keep them positive can be challenging.
- Time vs money.
- Time, money, and the will to do what is needed sometimes.

Declining health, passing - 5%

- I think it is hard to see the person I care about suffer.
- It's just hard to see older folks' age; I'll be there soon.
- Just the sadness of watching my dad get old. Knowing that he's not the same, and that it's not going to get any better. Getting him to meet needed changes is also difficult. For instance, we finally got him new hearing aids, but it's a struggle to get him to wear them regularly. It's also hard knowing how to prepare for the future. I'm very on top of things and we've done everything we can at this point, but I know that the future may bring difficulty we can't predict right now. And that's just hard and sad because I love my dad so much. (My mom passed away many years ago.)
- Just watching a loved one suffer.
- Losing the one that I help.
- My friend's passing kept it from becoming too time-consuming and difficult.
- My husband passed away.
- My mother has since passed. But at the time I was assisting with her care, it was making sure we had enough family to share the load of her care. For me, I enjoyed caring for my mom and will care for my dad if or when the time comes, he needs assistance.
- Not seeing progress in the one needing care.
- Seeing someone you love so deeply struggles immensely.
- The emotional challenge is the hardest. My mother has dementia and is in a memory care facility. The greatest challenge is she does not remember her posterity. It's hard to see her struggle with simple tasks. I feel like we have already lost her in many ways.
- The feeling of not being able to make it all go away for the person. I feel helpless when he is in pain, can't move, or stumbles.
- The person I cared for is now deceased.
- They were elderly and died of old age a month ago. It would be nice if the questions had a way to answer by saying it had happened but was over. I wasn't sure what to answer for some of it as me and my family don't provide care for them anymore.
- Watching my husband decline.
- Watching my loved one's decline.
- When it is your spouse.
- I was my husband's caregiver until he passed away on 01/05/23. It became increasingly more and more difficult. While he was hospitalized, I kept going over and over in my mind: "How am I going to do this when we get home?" My son was trying to make arrangements for him to go to an assisted living facility. We had to make the decision to take him off all the machinery to let him pass peacefully. It would have been helpful to have someone to talk to and to ask numerous questions.

Education, training, resources- 5%

- Being prepared by learning things younger in school.
- Education on how best to help support. So that I don't push too hard or too soft in their healing. When is it okay to let them rest all day and when do I need to get them up and moving?
- I am not familiar with the programs that are out there, so I need to really educate myself.
- I'm not certified.
- I'm not sure of other resources that may be an acceptable solution before moving to nursing home facility. Additional information regarding that kind of a resource would be appreciated.
- Information about assistance.
- Infrequent (occasional) support groups to talk to would be helpful.
- Lack of resources, knowing where to go for health, long wait lists, and finding what would be the most helpful.
- Learning medical stuff.
- Medical knowledge, education for me to understand what this person is going through and how to best help them.
- Not knowing what to do.
- Not knowing where to find the services my mom needs that I can't give her as she declines.
- Our child has a chronic condition that doesn't have a lot of medical knowledge or treatments because it is rare.
- Resources to help elderly individuals understand the Medicaid benefits. They are very confusing and complex.
- The information about services available is somewhat difficult to find, for instance HUD housing voucher programs and available spaces at other apartments/centers.
- Understanding options and resources that are available.

Help is not accepted or appreciated - 4%

- Getting the person to realize they might have to go into a nursing facility to get more specialized help.
- Getting them to accept what I tell them or help them with.
- Having the care that I was providing, being treated with disregard and ingratitude.
- Having the family member refuse care and be mentally challenging.
- Helping someone who isn't ready to admit they need help.
- I often feel underappreciated, especially when I suggest something that will help.
- I'm a nurse. Right now, we all agree on what is happening with my mother-in-law. Everyone is good to help, and she is 92 and has DNR with health issues she does not want treated. We will honor those wishes.
- Just getting my stubborn mother to listen and let us help her.
- Mine is unique. I care for my stepmother since my father's death over ten years ago. She is just ornery and unappreciative. I can live with it.
- My aging father refuses to pay anyone to help out. Family members don't expect to be paid, of course, but he won't hire outside sources for anything. And he has plenty of money, so that's not the issue.
- Reasoning with the one needing help!
- The actual person needing to be cared for does not accept that they need help or that they are getting older and need to be cared for.
- The greatest challenge for me was the person's inability to want to take care of themselves.
- Trying to get her to understand.

Exhaustion, overwhelm - 3%

- Being too lazy/lack of energy. Sometimes I just want to leave the house, but I still go.
- Finding the energy and desire to keep showing up for work.
- I didn't see where caring for a spouse (loved one) was indicated. Perhaps I missed it. Taking time for self and not feeling guilty about doing so. Keeping up with caring for him and myself is exhausting.
- It consumes me and I'm losing my own life, purpose, and happiness. It is just so much.
- I've been able to manage, except for my own exhaustion.
- Loss of sleep.
- Mental and physical exhaustion.
- Overload.
- Stress.
- The fact that I have my own stressors to worry about, both time and financially.
- The greatest challenge is giving all of my time and energy. They need more than just food and the basics. Keeping optimistic is hard.
- The lack of sleep.

Impact on family - 3%

- Balancing family and caregiving.
- Family issues and being opposite gender.
- Feeling supported. The toll of caregiving and being the sole breadwinner for a family of five is heavy on my physical and mental health. It doesn't seem like there are any other options available.
- Finding the time with a busy family schedule.
- I'm the only one of his family that lives here, so it's all on me.
- My family member had Alzheimer's, and she passed last September. We had no help until she was put on hospice the last two weeks of her life. Medicare was useless during the time we cared for her.
- Probably the greatest challenge is not being able to leave or have a family life.
- The challenge is to make the best decision for the family member's care.
- The time away from your own family.
- The time that everything takes away from my young children.
- Time. It's hard to take care of my own family and help my dad. He passed away from cancer but while he was sick; it was hard to balance at times.

Distance, travel - 3%

- Distance to relative.
- Distance.
- Managing her finances, transportation for doctors and errands, support in her home so she can remain there as long as possible, and activities for the blind.
- Residential help for remote or rural areas.
- The distance.
- The greatest challenge is transportation and time management with my life and theirs.
- Transportation.
- Travel time to and from.
- Travel to loved one.
- Traveling.

Own physical and mental health - 3%

- Dealing with my own illness and sacrificing my own time and health.
- Feeling supported. The toll of caregiving and being the sole breadwinner for a family of 5 is heavy on my physical and mental health. It doesn't seem like there are any other options available.
- Mental and financial wellbeing.
- Mental health.
- Mental wellness.
- My own health.
- My own mental health and balancing caregiving with my other responsibilities outside of work and caregiving.
- The greatest challenge for me in caregiving is that it is tasking emotionally and mentally.
- The mental toll it has taken on me, the caregiver, feeling so lonely.
- Time and the strain on my mental health due to dealing with a difficult person.

Dealing with government and healthcare entities - 2%

- Dealing with hospice and home aid nurses because they never provided the care we needed. They had a set standard.
- Having to follow up with people that help to make sure things got done.
- Lack of community/government assistance.
- My interactions with government entities, i.e., Social Security, IRS, Medicare has been the biggest challenge. Nobody seems to want to take ownership of anything, so my mom's issues get passed around like a hot potato. There are issues with the IRS that I have been working to get resolved since March 2020 that as of today have yet to be resolved. We've done phone calls, chat sessions, on-location visits, virtual Zoom calls and even had an advocate assigned to help with getting things corrected, and still have not been able to get things resolved. In my opinion, this is unacceptable.
- The enormous ignorance and problems with the ability of government to honor its obligations for approved levels of need.
- The government. They need to get out of the healthcare business. Americans need to be able to negotiate with insurance companies directly without legal protections safeguarding unfair competitive practices that protect the insurance companies. You know it's a horrible situation when every single doctor says the same thing, "The passage of the ACA has destroyed healthcare for American citizens and has restricted doctors from performing treatments needed to help their patients." At least the myriad of doctors we regularly deal with.
- The greatest challenge has been the state trying to shut down my wife's healthcare facility while she is having a baby.
- The legal challenge, making sure there's proper legal guidance. Mental stability, getting answers, financial problems, expenses, no financial help. Watching them go through changes because they need to make changes they're not used to. Trying to keep them positive can be challenging.

Loneliness, sadness - 2%

- Being a caregiver can be a very lonely, thankless job. People definitely need to remember this and offer to help caregivers more often.
- Being lonely.
- Caregivers should not be left behind and forgotten, they need care as well. It's the feeling of loneliness and lack of support that has a caregiver's mind going someplace else when they have to do caregiving. And afterwards when there's nobody to care for anymore, they're forgotten and left behind.
- Feeling tied to home.
- Never leaving the house. We have to stay away from crowds ever since COVID. I have had heart attacks and related issues since 2009 and my husband had brain surgery and got epilepsy in 2020 and has had seizures yearly since. I look forward to having mini visits from Meals on Wheels when they deliver the food.
- Ongoing sadness, worry, anxiety, and depression.
- Outside social interaction for a person who is limited due to lots of pain when moving/walking.
- The mental toll it has taken on me, the caregiver, feeling so lonely.

Difficulty having a patient, positive mindset - 2%

- Being able to support the person mentally and help the person stay positive about their limitations.
- Being patient with his disabilities (MD, memory and hearing loss).
- Being patient.
- Lack of patience, I just can't get anything done.
- Maintaining the mindset to do it.
- Staying positive.
- The greatest challenge for me in caregiving is that it is tasking emotionally and mentally.
- The legal challenge, making sure there's proper legal guidance. Mental stability, getting answers, financial problems, expenses, no financial help. Watching them go through changes because they need to make changes they're not used to. Trying to keep them positive can be challenging.

Neglecting self, time for self - 2%

- I didn't see where caring for a spouse (loved one) was indicated. Perhaps I missed it. Taking time for self and not feeling guilty about doing so. Keeping up with caring for him and myself is exhausting.
- My mom is dependent on me for everything, and I do my best to manage. It is difficult to take some time for myself.
- Neglecting my own needs to take care of the other person.
- Self-care.
- Taking care of myself.
- The greatest challenge is myself and the personal commitment that it takes.
- Time for myself and my grandchildren. Little flexibility in the care I provide, and the variable time involved.

Physical limitations - 2%

- Helping them in and out of the car by myself.
- Hygiene (bath).
- Mobility.
- Physical limitations.
- The biggest challenge is that my sister is not mobile, and if she falls, we cannot pick her up and have to call the paramedics. Also, it has been hard to convince her that she needs residential care.
- The physical responsibilities.

Miscellaneous responses - 11%

- Caregiver has become a term only associated with people who provide care for the elderly with disabilities and the severely infirm, and that is not at all the case. Plenty of people provide substantial care to others who appear to be "well" by many metrics. How I provide care provides substantial but unquantifiable peace of mind to someone who does not have that in many aspects of life. That the toll or price of caregiving must be quantifiable in terms of a monetary cost or apply only to actions related to someone's physical well-being is ludicrous, particularly in a world where we understand how crucial good mental health and positive state of mind are for overall positive health outcomes. I may have done a few things that cost me money I really did not have, but I am glad to be able to provide a service using a skill I possess to someone who honestly has been unable to learn that skill herself, which has lessened her own stress levels and increased her positivity in a time of grief and intense physical pain and difficult transition and loss of independence. But that service is never going to be recognized as "caregiving," just as going to have dinner with her once a week when she can still fix dinner for 20 people herself will never be recognized as "caregiving," even though she is alone for the first time in 86 years and has never had to take care of only herself. We live in a society hell bent on insisting we care about ourselves (our own masks first) when we are designed for connection, and we fight that impulse with every fiber of our beings because it isn't profitable, and the results are unpredictable, and the outcomes are often unquantifiable. We need to be caring for one another, all of us, always. The qualitative results of serving and connecting with one another demonstrate that maybe helping someone.
- Caregiving is not just about the elderly. In my case my wife and I are not near retirement, but her cancer required a high level of care that challenged my ability to work and manage her needs.
- Does family have any responsibility to care for the members of their own family or should the government pay for it all?
- else put their mask on first because they're struggling and panicking, and we are not; maybe that's something worth trying. And continued insistence from the federal and state level that caregiving is a burden to be relieved rather than an opportunity to be encouraged is the absolute wrong approach.
- Finding employment training for high-functioning, autistic grandson.
- Food.
- Getting substandard care at nursing home facilities, nobody checking on my mother-in-law for hours on end, sitting in her diaper, and throwing up sitting on her. Not getting proper medication, not giving proper antibodies even though they were prescribed, it wasn't until we threatened to take her out of there that they even tried to change. The place was Rocky Mountain.
- Having to take surveys.
- HIPAA Laws that limit the amount of information I can have regarding current health issues for someone in the beginning stages of dementia/Alzheimer's.
- I assist a friend who has been experiencing homelessness for three years. She is currently in housing but has no income, has little support from her own family, has obstacles with technology which limits her ability to find and apply for resources, and has severe mental illness on top of some physical illnesses. The housing situation, although better than the street, is in constant disrepair and she does not feel safe. I feel like she could be successful if she had a medical provider who could address all of her physical and mental needs and offer a compassionate and tolerant approach to the unique situation that homelessness creates, but it seems like our current system is so disjointed that by the time she bounces from one specialist to another, she gets too overwhelmed and discouraged and ends up letting it all crumble. She goes into crisis for a month or two before she gets the energy to start again. I do her laundry once a week and offer rides upon occasion, but the thing she seems to need the most is someone who sees her value.
- I'm a nurse. Right now, we all agree on what is happening with my mother-in-law. Everyone is good to help, and she is 92 and has DNR with health issues she does not want treated. We will honor those wishes.
- It is difficult to make decisions sometimes due to emotions.
- It's chronic nature.
- It's important that disabled people and elderly people have the ability to live in their own homes, but yet have the ability to travel out into the community and be part of the same community as others that are not disabled or elderly. The state of Utah needs to sign onto that DIA, the Disability Integration Act. There needs to be opportunities for people to have freedom and independence, but yet have that help needed to help them achieve the goals they want.

- It's the unknown of what the future is going to look like, we are in a unique situation that we are caregiving for someone who is younger, so we don't know what that timeline is going to look like.
- Keeping him up on drinking water.
- Managing the judgement, I feel from time to time because I have no interest in a career outside the home.
- My aging father refuses to pay anyone to help out. Family members don't expect to be paid, of course, but he won't hire outside sources for anything. And he has plenty of money, so that's not the issue.
- My caregiving is not to the level considered for most of these questions.
- My challenges are minor in comparison to other people I've talked to, as my grandmother is capable cognitively and physically. That being said, the greatest challenge is that I have a hard time drawing boundaries, and since I tend to say yes, a lot, I am often the go-to person to provide assistance when my siblings can as well.
- My family members will more than likely heal, that factor helps me know I won't be care giving at this level forever.
- No ages were ever specific to who we cared for.
- Not having advanced warning.
- Some questions, we're very vague.
- Sometimes it's not someone who needs a nursing home or full-time care that can put a strain on the caregiver.
- The challenge this time is death, funeral expenses, and settling bills and the estate.
- The city of SLC needs to do more for the homeless and elderly. We need to become the beacon on the hill.
- The comfort of the person being cared for.
- The hoops someone like me who has autism and taking care of grandma with Alzheimer's makes it impossible to navigate.
- The unknown.
- There is still a lot of work to do after death!
- This survey seems geared to the elderly only. You should have made it more neutral and less age restricted. We had my wife's friend staying with us after her rent doubled and she had had two surgeries and needed somewhere to recover. Unbeknownst to us she was also an illegal drug user, and the police were involved in escorting her from our house.
- Those silly PSA regarding caregiving should not be heard by me. They make me feel like I am taking someone's paying job.
- We should be paid by the state to provide such care.
- When my husband moved back to Texas to be 5 minutes from cancer care instead of 3 hours to Salt Lake City.

Don't know - 8%

- Don't know. (8)
- N/A (17)
- No comment. (3)
- Unknown.

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