

Caregivers of Younger Adults: A Focused Look at Those Caring for Someone Age 18 to 49



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A Focused Look at Caregivers of Younger Adults

This is the first of two companion reports to the full report of the study entitled *Caregiving in the U.S. 2015*. This companion report focuses on 159 unpaid family caregivers who provide care to an adult age 18 to 49 – we call them “caregivers of younger adults” – and includes a comparison to 1,087 caregivers of older adults, when significantly different. The other companion report provides detail on caregivers of older adults (ages 50+). All family caregivers were interviewed using GfK’s web-enabled KnowledgePanel®, a probability-based panel designed to be representative of the U.S. population, between September 11 and November 5, 2014. To see complete study results, or for more information about the questionnaires or the methodology, please reference the full report and Appendices A and B.

Reading this Report

All figures have been weighted and rounded. In addition, “don’t know” or “refused” responses are not always presented in charts and tables. For these reasons, some charts and tables will not add to 100%. The results for multiple- response questions may also add to greater than 100%.

The n sizes shown in each table or graphic represent the unweighted number of respondents who answered each question. All demographic information about the caregiver is in reference to their current situation if currently caregiving, or their situation at the time they last provided care if not a current caregiver.

A. Prevalence of Caregiving

We estimate at least 5.6 million adults in the United States have provided unpaid care to an adult family member or friend who is 18 to 49 years of age in the prior 12 months.²

B. Basics of the Caregiving Situation

Nearly nine in 10 caregivers of younger adults take care of only one care recipient (86%). Four in 10 are currently providing care (44%) and nearly six in 10 (56%) have provided care in the past year, but are no longer doing so. In comparison, those caring for older adults ages 50+ are more often currently providing care (57%).

Caregivers of younger adults tend to be female (61%). Their recipients are close to half female and half male (55% and 45%, respectively). The share of female recipients tends to rise in relation to the age of the recipient.

Figure 1: Gender of Care Recipient by Age of Recipient

	Recipient Age 18 to 49 (n=159)	Recipient Age 50 or older (n=1,087)
Female	55%	67%* ³
Male	45*	33

On average, caregivers of younger adults are 42.8 years old and care for someone 36.4 years of age. Caregivers of younger adults are, on average, about 7 years younger than caregivers of older adults (50.3 years old, on average).

While the majority of caregivers of younger adults care for a relative (79%), they are less likely to do so than caregivers of older adults (86%). More care for their own adult child (32%) than any other relation (32%), followed by a spouse or partner (17%), sibling or sibling-in-law (13%), or parent (9%).

Most caregivers of younger adults have been providing care for less than five years (72%), including 42% who have provided care for less than 6 months (more common than among caregivers of older adults – 28%). Of note, though, 19% have provided care for 10 years or more,⁴ bringing the average duration of care to 5.8 years – considerably

² This estimate is based on the total number of adult caregivers in the United States (39.8 million), subtracting out those who care for someone age 50+ (34.2 million). This is a minimum estimate, as some caregivers are known to be caring for both someone age 50+ and someone age 18-49. The questionnaire did not ask whether the caregiver provided care to *any* person of this age, but if it had, the estimate would be larger.

³ Throughout this report, an asterisk (*) indicates a numerical result that is significantly higher than the comparison group.

⁴ Most (65%) of these long-duration (10 years or longer) caregivers are caring for an adult child.

longer than caregivers of older adults (3.7 years). By contrast, the *typical* caregiver of a younger adult has given 0.8 years of care (as measured by the median), similar to caregivers of older adults (1.0 years).

When asked if they felt they had a choice in taking on their caregiving responsibility, half (50%) say they had no choice. Those caring for a nuclear family member, such as a spouse (64%) or adult child (57%), are more likely to feel they had an obligation to provide care for their loved one, more so than those caring for a nonrelative (29%).

C. Living Situation

Most caregivers of a younger adult report their loved one does not live alone (84%), more so than caregivers of older adults (66%).

Half of caregivers of younger adults live with their care recipient (49%), while three in 10 say their loved one lives in his or her own home (31%). Caregivers of an older adult are less likely to report they reside with their care recipient (32%) and more likely to report that their recipient lives in his or her own home (51%).

Figure 2: Where Care Recipient Lives by Age of Recipient

	Recipient Age 18 to 49 (n=156)	Recipient Age 50 or older (n=1,078)
In caregiver's household	49%*	32%
In his or her own home	31	51*
In someone else's home	14*	5

Among the 49% of caregivers who share their household with their younger adult recipient, most (66%) are taking care of their own adult child or their spouse. Of caregivers of younger adults who do not live with their care recipient, 73% visit their loved one at least once a week.

D. Care Recipient Condition

Types of Care Recipient Conditions

Caregivers of younger adults most commonly say their recipient has a short-term physical condition (43%), emotional or mental health problem (36%), or a long-term physical condition (32%). Many care recipients have more than one ongoing problem or illness (37%). These conditions or reasons for care differ greatly by the age of the recipient.

Figure 3: Types of Care Recipient Conditions by Age of Recipient

	Recipient Age 18 to 49 (n=159)	Recipient Age 50 or older (n=1,087)
Any physical condition(s)	71%	87%*
Short-term physical condition(s)	43%*	34%
Long-term physical condition(s)	32%	63%*
Emotional or Mental health problems	36%*	19%
Behavioral issues	17%*	5%
Developmental/Intellectual Disorder, Mental Retardation	11%*	3%
Memory problems	11%	29%*
<i>Average Number of Conditions</i>	1.5	1.5

Care Recipient’s Main Problem or Illness

When caregivers are asked what they perceive to be the *main* problem or illness for which their younger adult care recipient needs care, the top three named are mental or emotional illness (18%), surgery/wounds (12%), and cancer (6%). This is quite different from the top three mentions among caregivers of older adults, which are: “old age”/aging issues (16%), Alzheimer’s or dementia (9%), and mobility issues (8%).

One in four (23%) caregivers of younger adults feels it is *somewhat* or *very* difficult to coordinate the various health care and service providers who give care or treatment to their loved one.

E. Caregiving Activities and Burden of Care

Hours of Care Provided

On average, caregivers of younger adults spend 26.9 hours a week providing care to their loved one.⁵ Four in 10 are in situations where their time commitment is modest, no more than eight hours each week (42%). On the other end of the scale, 27% provide more than 40 hours of care per week.

Help with Activities of Daily Living (ADLs)

How is caregivers’ time spent? Just over half of caregivers of younger adults help their loved one with at least one Activity of Daily Living (ADL, 54%); most commonly helping

⁵ Any caregiver who typed in hours of care in excess of 98 hours per week is capped at this level, equivalent to 14 hours per day. Caregivers who selected constant care were capped at 77 hours per week, the mean hours of care derived from an imputation model predicting hours of care provided. For more details on the imputation model, see Appendix B: Detailed Methodology.

their care recipient get in and out of beds and chairs (34%). On average, they help with 1.4 of the six ADLs, fewer than caregivers of adults ages 50 or older (1.7 ADLs).

In particular, caregivers of younger adults are less likely than those caring for older recipients to aid their loved one with getting in and out of beds and chairs, toileting, and incontinence.

Figure 4: Help with Activities of Daily Living (ADLs) by Age of Recipient

	Recipient Age 18 to 49 (n=159)	Recipient Age 50 or older (n=1,087)
Get in and out of beds and Chairs	34%	45%*
Get dressed	28%	32%
By feeding him or her	24%	23%
Bathe or shower	24%	26%
Get to and from the toilet	20%	28%*
By dealing with incontinence/diapers	9%	18%*

Among caregivers of younger adults who perform ADLs, 28% find it difficult.

Help with Instrumental Activities of Daily Living (IADLs)

Caregivers of younger adults help with 4.1 out of seven Instrumental Activities of Daily Living (IADLs), on average. Most commonly they help with transportation (78%) and housework (75%). Caregivers of younger adults are more likely to help with preparing meals than those caring for someone 50 or older, but are less likely to arrange outside services.

Figure 5: Help with Instrumental Activities of Daily Living (IADLs) by Age of Recipient

	Recipient Age 18 to 49 (n=159)	Recipient Age 50 or older (n=1,087)
Transportation	78%	78%
Housework	75%	72%
Grocery or other shopping	73%	76%
Preparing meals	71%*	59%
Managing finances	52%	54%
Giving medicines, pills, or injections	44%	47%
Arranging or supervising services	20%	33%*

Other Key Activities

Caregivers’ responsibilities often extend beyond the traditional ADLs and IADLs, to interacting with various providers, agencies, and professionals on their care recipient’s behalf. About three in five caregivers of younger adults monitor the severity of their loved one’s condition in order to adjust care accordingly (57%), while about half communicate with health care professionals or advocate for their recipient.

Caregivers of younger adults are less likely to be monitoring conditions and communicating with care professionals than are those caring for older adults.

Figure 6: Help with Key Activities by Age of Recipient

	Recipient Age 18 to 49 (n=159)	Recipient Age 50 or older (n=1,087)
Monitoring severity of recipient’s condition to adjust care accordingly	57%	68%*
Communicating with health care professionals (doctors, nurses, social workers) about his/her care	50%	66%*
Advocating for him/her with health care providers, community services, government agencies	45%	51%

Burden of Care

Two out of five caregivers of younger adults are in high burden situations (42%), 18% have a medium burden, and 40% have a low burden.⁶

F. Medical/Nursing Tasks

Recent research⁷ revealed that in addition to ADLs and IADLs, family caregivers are increasingly performing tasks that nurses typically perform. Known now as “medical/nursing tasks,” these skilled activities include injections, tube feedings, catheter and colostomy care, and many other complex care responsibilities. Half of caregivers of younger adults assist with medical/nursing tasks (51%), including 38% who are performing these tasks *without any* prior preparation and 12% who did have some sort of prior preparation.

⁶ “Burden of care” is an index that is based on the number of hours of care provided by the caregiver, the number of Activities of Daily Living performed, and the number of Instrumental Activities of Daily Living. Points are assigned for each of these, and ultimately, these points are consolidated into three burden categories: low, medium, and high. See Appendix B, Detailed Methodology for the details of creating the index.

⁷ Reinhard, S.C., Levine, C., & Samis, S. (2012) “Home Alone: Family Caregivers Providing Complex Chronic Care.” AARP Public Policy Institute & United Hospital Fund.

Among caregivers of younger adults who provide medical/nursing tasks, 14% find it difficult to do so (rated 4 or 5 on 5-point scale).

When caregivers of younger adults are asked to select the ways in which they would prefer to learn how to perform medical/nursing tasks, should they be needed, the most-preferred learning methods are to have a qualified person *show* them how to perform it (53%) and to perform it themselves while a qualified person watches (*hands-on*, 48%).

G. Hospitalization

Only about two out of five caregivers of younger adults report their loved one had been hospitalized at least once in the past year (44%), significantly less common than among caregivers of older adults (55%).

Caregivers of younger adults are five times more likely (10%, compared with 2% among caregivers of older adults) to report that they were not included by health care workers in discussions about their loved one’s care when they should have been.

H. Presence of Other Caregivers

Just four in 10 caregivers of younger adults say someone else has also provided unpaid care to their loved one within the past 12 months (39%). Three out of four (76%) caregivers of younger adults consider themselves to be the primary unpaid caregiver, including 60% who are sole caregivers and 16% who report that there are other caregivers but that they provide most of the unpaid care. Caregivers of older adults are less likely to be the primary caregiver (61%).

Figure 7: Primary Caregiver Status by Age of Recipient

	Recipient Age 18 to 49 (n=159)	Recipient Age 50 or older (n=1,087)
Primary caregiver (Sole or provides most unpaid care)	76%*	61%
Sole caregiver	60%*	44%
Provides most of unpaid care	16%	16%
Not primary caregiver	23%	39%*

Among caregivers of younger adults, those caring for a spouse/partner (86%) and those caring for an adult child (83%) are especially likely to be the primary caregiver.

In addition, just one in five (19%) reports their younger adult care recipient had paid help in the past 12 months, from any aides, housekeepers, or other paid helpers.

Caregivers of older adults are more likely to report their loved one receives paid help (34%).

I. Stress and Strain of Caregiving

Caregiver Health

Half of caregivers of young adults consider their health to be *excellent* or *very good* (51%), 31% evaluate their health as *good*, and 17% say it is *fair* or *poor*. By comparison, 10% of the U.S. adult population describes their health as *fair* or *poor*.⁸ Nearly one in four feel caregiving has made their health worse (24%), although 66% say their health has not been affected, and 9% claim it has improved as a result of caregiving.

Strain and Stress

Six in 10 caregivers of younger adults report that they experience little to no physical strain in caring for their loved one (59% rating it 1 to 2 on a 5-point scale), 19% experience moderate strain (a rating of 3), and 22% report the level of physical strain is high (a rating of 4 or 5).

Emotional stress is more common among caregivers of young adults. Fewer than four in 10 say there is little to no emotional stress (38% rating it 1 or 2), while slightly more feel a high level of emotional stress (40% rating 4 or 5 on 5-point scale). Caregivers of an adult age 18 to 49 with an emotional or mental health issue are more likely to report feeling emotional stress (57%) than are those caring for someone without such problems (30%).

One in five caregivers of a younger adult experiences financial strain (22% rating 4 or 5 on a 5-point scale). Caregivers of older adults are more likely to report little to no financial strain (63% vs. 53% among caregivers of younger adults).

J. Impact of Caregiving on Work

Concurrence of Work and Caregiving

A majority (65%) of caregivers of younger adults were employed at some point in the past year while caregiving. Among them, half work full time (49%) and on average, they work 34.7 hours a week. One in six is self-employed or owns a business (18%). In comparison, 9.4% of U.S. workers are self-employed.⁹

⁸ CDC/NCHS, National Health Interview Survey, January–June 2014, Family Core component.

⁹ Current Population Survey, Annual Social and Economic Supplement, 2012 data, presented in Bureau of Labor Statistics Monthly Labor Review article “Female self-employment in the United States: An update to 2012” (October 2014).

Employer Support

What are employers doing to support caregivers? Six in 10 working caregivers of younger adults say their supervisor knows they provide care (61%). In terms of the benefits and support that their employer provides, 49% have flexible work hours, and 21% report having programs like information, referrals, counseling, or an employee assistance program to help caregivers.

Just 12% of working caregivers of younger adults say they are able to telecommute or work from home, fewer than caregivers of older adults (24%).

Workplace Impacts

When it becomes difficult to balance caregiving with work, or if the demands of work come into conflict with one’s caregiving responsibilities, sometimes caregivers choose to make changes to their work situation. Six in 10 caregivers of a younger adult report having to make a workplace accommodation as a result of caregiving, such as cutting back on their working hours (19%), taking a leave of absence (18%), or other such impacts.

Caregivers of younger adults are more likely (15%) to report having received a warning about performance or attendance than those caring for older adults (5%).

Figure 8: Primary Caregiver Status by Age of Recipient

	Recipient Age 18 to 49 (n=103)	Recipient Age 50 or older (n=621)
Went in late, left early, took time off to provide care	49%	49%
Went from working full to part-time or cut back hours	19%	13%
Took leave of absence	18%	14%
Received a warning about performance or attendance at work	15%*	5%
Give up working entirely	8%	6%
Retired early	6%	4%
Turned down a promotion	6%	5%
Lost any job benefits	3%	3%

Caregivers of younger adults are more likely to report that they have ever been fired from any job as a result of being a caregiver for their loved one (7% compared to 2% among caregivers of older adults).

K. Information Needs and Caregiving Support

Information Needs

A large majority (78%) of caregivers of younger adults feel they need more help or information about at least one topic related to caregiving. Most commonly, caregivers of younger adults would like assistance with managing their own emotional and physical stress (45%). One in three would like help or information about keeping their loved one safe at home (32%)—less than the demand for this assistance among caregivers of older adults (43%). Caregivers of younger adults are less likely to want help or information about making end-of-life decisions (12% vs. 24% among caregivers of adults age 50+).

Figure 9: Help and Information Needs by Age of Recipient

	Recipient Age 18 to 49 (n=159)	Recipient Age 50 or older (n=1,087)
Managing your emotional and physical stress	45%	42%
Keeping your loved one safe at home	32%	43%*
Making end-of-life decisions	12%	24%*
Managing his/her challenging behaviors	11%	13%
Managing his/her incontinence or toileting problems	7%	11%
Finding non-English language educational materials	4%	5%

Conversations about Recipient and Self-Care

Only a small proportion of caregivers of younger adults report having had conversations with health care providers—like doctors, nurses, or social workers—about what is needed to provide care to their care recipient (23%) or for their own care (16%). Caregivers of younger adults are less likely to have had conversations about what is needed to care for their recipient than caregivers of older adults (33%).

When asked if these kinds of conversations with health care providers would be helpful, one in three (33%) caregivers of younger adults think conversations about needs for recipient care would be helpful, while 24% say conversations about self-care needs would be helpful.

Services Used

Just half of caregivers of younger adults report having done at least one support service or request, including things like requesting information about financial help for their loved one (31%), making modifications to their loved one’s home (20%), using outside

transportation services (17%), or using respite services (12%). Caregivers of younger adults are less likely to have made modifications or used outside transportation services than caregivers of older adults.

Figure 10: Support Services or Requests Made by Age of Recipient

<i>In your experience as a caregiver, have you ever...</i>	Recipient Age 18 to 49 (n=159)	Recipient Age 50 or older (n=1,087)
Requested information about how to get financial help for care recipient	31%	27%
Had modifications made in the home where recipient lives	20%	36%*
Had outside service provide transportation for recipient instead of you providing the transportation	17%	24%*
Used a respite service or sitter to take care of recipient to free up your time	12%	16%

One in four (26% rating 4 or 5 on 5-point scale) caregivers of younger adults report it is difficult to get affordable services in their loved one’s local area or community.

Policy Reactions

When asked to gauge their perception of how helpful several policy proposals might have been to their caregiving experience, caregivers of younger adults are less likely to feel each of the four policies would be helpful to their experiences. They are most commonly (40%) supportive of requiring health care providers to include their own name on their loved one’s medical chart.

Figure 11: Helpfulness of Policy Proposals Made by Age of Recipient

	Recipient Age 18 to 49 (n=159)	Recipient Age 50 or older (n=1,087)
Requiring health care providers to include your name on recipient’s medical chart	40%	50%*
Requiring hospitals or other facilities to instruct or demonstrate any medical/nursing tasks	35%	45%*
Requiring hospitals to inform you about major decisions	32%	43%*
Having respite services available	26%	35%*

When asked to select the most helpful potential policy focused on providing financial support to caregivers (out of three potential policies), one in three (33%) caregivers of younger adults selected an income tax credit to offset the cost of care. About one in four (23%) selected a program where caregivers could be paid for at least some of the hours they provide care, fewer than caregivers of older adults (32%). The third policy – a

partially paid leave of absence from work for employed caregivers – was deemed helpful by just 13% of caregivers of younger adults.

About seven in 10 caregivers of younger adults are in favor of banning workplace discrimination against workers who have caregiving responsibilities (69%).

L. Long-Range Planning

About one in three (36%) caregivers of younger adults expects to be a caregiver for some adult (either their current loved one or someone else) during the next five years, with roughly equal proportions saying they would not be a caregiver (31%) or who were not sure (33%). Caregivers of older adults are more likely to expect to continue their role (54%).

Figure 12: Expectation of Future Caregiving by Age of Recipient

	Recipient Age 18 to 49 (n=159)	Recipient Age 50 or older (n=1,087)
Yes – expects to care for adult in next 5 years	36%	54%*
No – does not expect to provide care	31%*	22%
Not sure	33%*	23%

Less than one in four caregivers of younger adults report their loved one has plans in place for his or her future care, such as instructions for handling financial matters, health care decisions, or living arrangements (23%). Caregivers of older adults are more likely (50%) to report their recipient has these kinds of arrangements.

Four in 10 caregivers of younger adults have plans in place for their own future care (40%).

M. Respondent Profile

Six in 10 caregivers of younger adults are female and they are 42.8 years old, on average – younger than caregivers of older adults. About six in 10 are white, and 22% are Hispanic. Four in 10 have a high school education or less (43%), which is higher than the number who have a college degree (24%).

Figure 13: Demographic Summary by Care Recipient Age

	Recipient Age 18 to 49 (n=159)	Recipient Age 50 or older (n=1,087)
Caregiver Gender		
Male	39%	40%
Female	61	60
Age of Caregiver		
18 to 34	40%*	21%
35 to 49	22	24
50 to 64	26	35*
65 to 74	7	12*
75 or older	5	8
<i>Mean age</i>	<i>42.8</i>	<i>50.3*</i>
Race/Ethnicity of Caregiver		
White	59%	62%
African American	12	13
Hispanic	22	16
Asian American ¹⁰	3	7*
Other	4	2
Caregiver Education		
Less than high school	13%*	7%
High school graduate	29	28
Some college	25	21
Technical school	8	7
College graduate	16	20
Graduate school	8	16*

Note: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated.

¹⁰ Asian American is inclusive of those caregivers who are of Asian origin, background, or descent, including the regions of the Indian subcontinent, Far East, Southeast Asia, or Pacific Islands.

Caregivers of younger adults have a median household income of \$53,900, comparable to \$53,046 for the United States overall.¹¹ Most are married or living with a partner, and 33% have a child or grandchild under the age of 18 living in their household.

Profile of Respondents (continued)

	Recipient Age 18 to 49 (n=159)	Recipient Age 50 or older (n=1,087)
Caregiver Marital Status		
Married	57%	57%
Living with a partner	13*	7
Widowed	6	5
Separated	1	2
Divorced	5	8
Single, never married	17	20
Caregiver Household Income		
Less than \$50,000 (net)	47%	46%
Less than \$15,000	13	12
\$15,000 to \$29,999	18	16
\$30,000 to \$49,999	16	19
\$50,000 or more (net)	53	54
\$50,000 to \$74,999	16	18
\$75,000 to \$99,999	15	13
\$100,000 or more	21	23
<i>Median Household Income</i>	<i>\$53,900</i>	<i>\$55,000</i>
Children/Grandchildren in Caregiver's Household		
Yes	33%	28%
No	67	71

Note: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated.

¹¹ U.S. Census Bureau, American Community Survey, 2013.

About two in three caregivers of younger adults are employed, and most live in an urban or suburban setting. Fourteen percent have served in the armed forces, and just 3% report their care recipient has served, fewer than caregivers of older adults. Eight percent self-identify as lesbian, gay, bisexual, or transgender (LGBT).¹²

Profile of Respondents (continued)

	Recipient Age 18 to 49 (n=159)	Recipient Age 50 or older (n=1,087)
Care Recipient Living Location		
Urban/Suburban	71%	71%
Rural	28	28
Caregiver Living Location		
Urban/Suburban	81%	85%
Rural	19	15
Caregiver Employment Status		
Employed in past year while caregiving	65%	59%
Not employed	35	41
Caregiver Service in Armed Forces		
Served on active duty	14%	10%
Did not ever serve	85	89
Care Recipient Service in Armed Forces		
Served on active duty	3%	15%*
Did not ever serve	94*	83
Caregiver LGBT status		
Yes	8%	9%
No	92	91

Note: Letters in superscript indicate a figure is significantly higher than the figure in the column indicated.

¹² 6.9% of all screened respondents in *Caregiving in the U.S. 2015* self-identify as LGBT. In addition, we find that caregiving for an adult is more common among those who identify as LGBT (20.4% vs. 16.5% not identifying as LGBT). Nationally, Gallup estimates 5.6% of Americans are LGBT. Gates, G.J. (October 2014) "LGBT Demographics: Comparisons among population based surveys," The Williams Institute.

About the National Alliance for Caregiving

Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, the Alliance supports a network of 80+ state and local caregiving coalitions and serves as Secretariat for the International Alliance of Carer Organizations. Learn more at www.caregiving.org.

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