

**National Rehabilitation
Research and Training Center
on Family Support (NCFS)
Caregiver Profile: A Closer Look
at Spousal Caregivers**

Executive Summary

Millions of Americans provide care to others each day, supporting aging parents, young and adult children and grandchildren, spouses and partners, siblings, and other friends and relatives. Each population can experience different burdens and benefits associated with caregiving, depending on their own unique circumstances and the needs of the care recipient. While much research has been done to try to enhance our understanding of the needs and experiences of caregivers, data collection processes are inconsistent across caregiver populations. In a series of policy briefs, including this one, the University of Pittsburgh National Rehabilitation Research and Training Center on Family Support (NCRFS) leverages large, national datasets to construct a detailed profile of different types of caregivers, highlighting both current knowledge and key gaps. The goal of these policy briefs is to provide a more granular understanding of the unique needs of caregiver sub-populations to inform program supports and future policy development.

Utilizing data from the Behavioral Risk Factor Surveillance System (BRFSS) and National Health and Aging Trends Study (NHATS) National Study of Caregiving (NSOC), this brief outlines the demographics and key indicators of the physical, mental, emotional, and financial health of spousal caregivers. This brief also identifies spousal caregivers in both younger (<65) and older (65+) age cohorts with disability and provides insight into factors such as health status, income and employment, and access to services among these subgroups.

NATIONAL DATASETS: OVERVIEW OF METHODOLOGY

BRFSS: The BRFSS is a telephone-based survey of U.S. residents, sponsored by the Centers for Disease Control and Prevention (CDC). The survey collects information on health behaviors, chronic conditions, and preventive practices.

Caregiver population: BRFSS participants must be aged 18 and over. Caregivers were identified by asking if the individual provided regular care or support for a friend or family member with a health problem or disability during the past 30 days.

Care recipient population: BRFSS does not restrict the age of the care recipient, so care recipients could be of any age.

Years: 2015-2017

Sample size: Data was combined from 44 non-overlapping states and the District of Columbia from 2015 to 2017 (using data from the year first administered). With 54,076 total caregivers identified, we focused on the subset of 9,955 caregivers providing care for a spouse. Caregiver sample sizes in the four main subsets analyzed here were: younger / non-disabled (n = 2,786); younger / disabled (= 1,421); older / non-disabled (n = 3,617); older / disabled (n = 2,131).

Disability status determination: Caregiver disability was measured in the BRFSS using the six-question disability sequence used in the American Community Survey and many other surveys. This consists of six yes / no questions asking about ambulatory, self-care, independent living, cognitive, vision, and hearing difficulties.

NHATS/NSOC data: NHATS is an annual in-person survey which uses the Medicare enrollment frame for sampling, and NSOC is a nationally representative sample of family caregivers. NHATS respondents who report needing help with a variety of self-care, mobility, and instrumental tasks of daily living provide a roster of helpers which then serves as the sampling frame for the NSOC caregiver sample.

Caregiver population: Caregivers in NSOC may be adults of any age.

Care recipient population: NHATS surveys adults age 65 and older, so all care recipients are 65 or older.

Years: 2017

Sample size: A total of 2,361 caregivers were interviewed in the 2017 wave of NSOC. We focused on the subset of caregivers providing care for a spouse, for a total of 429 caregivers. Among the 429 caregivers, 239 reported any disability, while 190 reported no disability.

Disability status determination: Caregiver disability was measured in the NSOC with three items asking about upper extremity limitations; lower extremity limitations; and breathing problems.



➤ Background

To inform the overview of key characteristics of spousal caregivers in comparison to other types of caregivers, this section highlights some of the current knowledge about the unique experience of spousal caregivers.

Along with adult children caring for adult parents, spousal caregivers are more likely than other categories of caregivers to express a lack of choice associated with becoming a caregiver.¹ A majority of older adults live either alone or with a spouse or partner, and only 20 percent live with an adult of another generation, such as adult children or grandchildren, and in-laws or parents.² Compared to other types of caregiver, spousal caregivers are more likely to provide care alone, without paid or unpaid assistance.³ Spousal caregivers are also more likely than other types of caregivers to provide medical and nursing care, such as administering injections, tube feeding, or providing wound care, to their spouse or partner.⁴

Previous research on spousal caregivers has noted the risk of negative physical and mental health outcomes associated with caregiving.^{5,6} Though some researchers have found the close nature of the relationship between spouses can exacerbate feelings of stress and burden on the part of the caregiver, others have noted positive impacts associated with spousal caregiving, including improvements in well-being and relationship quality, as well as feelings of accomplishment and personal growth.^{7,8,9,10}

Despite the increased likelihood of age-related functional limitations and poorer health, studies have shown that the age of a spouse caregiver does not have an impact on the selection of the spouse as the primary caregiver.¹¹ The transition into the spousal caregiver role is associated with increasing physical frailty and a decline in functional health over time.^{12,13} For spousal caregivers with chronic disease, directing resources toward caregiving can reduce the time and resources available for the caregiver to engage in care for their own health, and physical exertion associated with caregiving can worsen symptoms associated with the caregiver's own underlying chronic conditions.^{14,15}

Compared to adult children caring for aging parents, spousal caregivers are more likely to experience negative job-related impacts associated with caregiving, such as arriving late or leaving early, and are specifically more likely to cut back on work hours, give up work entirely, or retire early.¹⁶

FINDINGS

BFRSS data indicates that the most common types of family caregiver and recipient relationships are adult children supporting parents (38 percent) and spouses supporting partners (14.5 percent). Caregivers supporting a friend or other non-relative comprise 15 percent of the caregiver population. Spousal caregivers are generally older than other types of caregivers, with nearly half over 65 years old. Comparatively, less than 10 percent of adult children caring for aging parents are over 65. Per BRFSS data, spousal caregivers are also more likely to report a disability than other types of caregivers.

Spousal caregivers tend to have worse self-rated health than other types of caregivers, and close to one-third report at least four days in the last month in which physical health was not good or that health issues prevented engagement in usual activities.

Table 1.
Age Distribution of Spousal Caregivers by %

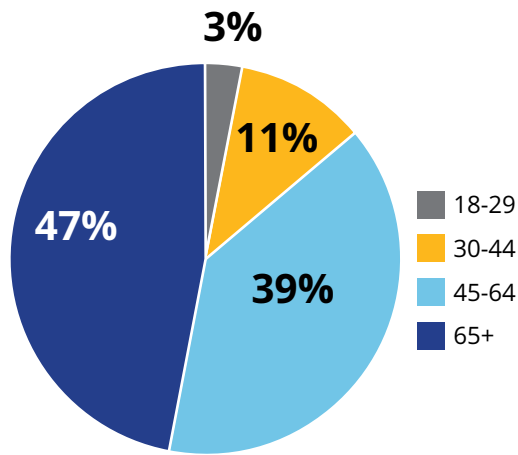
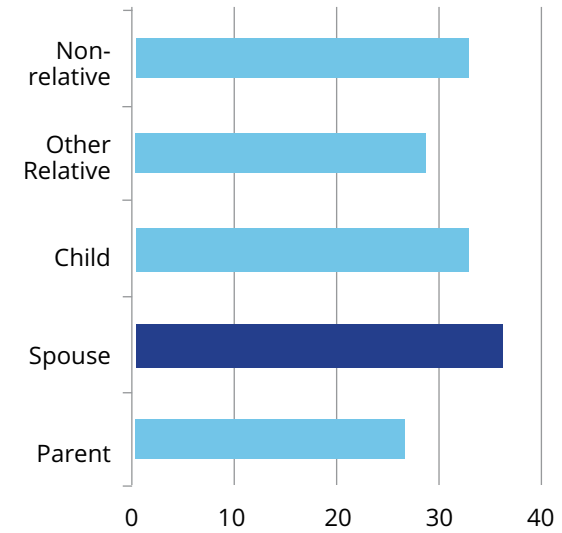


Table 2.
% of Caregivers with Disability by Care Recipient Relationship with Caregiver

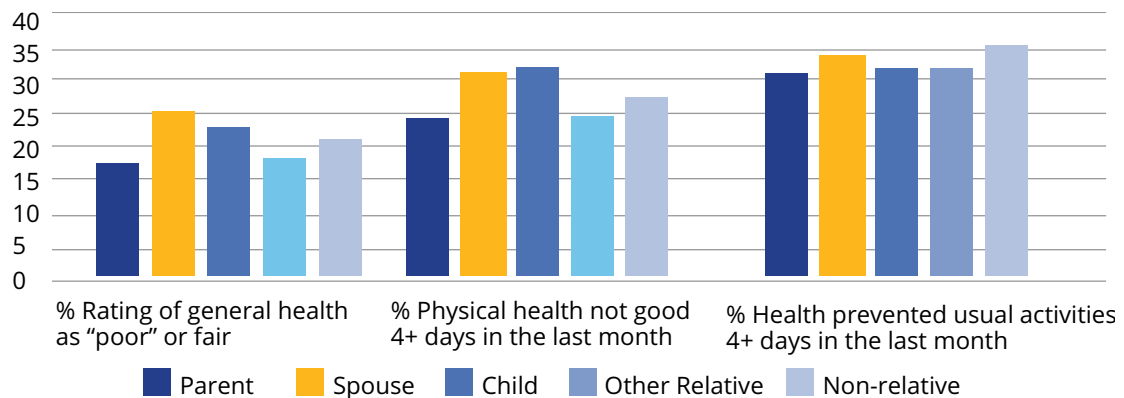


Source: University of Pittsburgh National Rehabilitation Research and Training Center on Family Support Analysis of Data from the Centers for Disease Control and Prevention Behavioral Risk Factor Surveillance System survey

CHRONIC DISEASE

With the exception of stroke and asthma, spousal caregivers have a higher prevalence of many chronic diseases compared to other types of caregivers, which is consistent with the generally older age of the spousal caregiver population.

Table 3.
Self-Reported Physical Health Indicators, % Caregivers by Relationship with Care Recipient



Source: University of Pittsburgh National Rehabilitation Research and Training Center on Family Support Analysis of Data from the Centers for Disease Control and Prevention Behavioral Risk Factor Surveillance System survey

Table 4.
Self-Reported Physical Health Indicators, % Caregivers by Relationship with Care Recipient

Self-Reported Chronic Disease	Parent	Spouse	Child	Other Relative	Non-relative
High blood pressure	32.1	51.4	36.1	31.3	38.7
High cholesterol	35.4	50.2	42.0	34.2	41.4
Heart attack	2.9	8.5	5.8	3.8	5.8
Angina / coronary heart disease	3.3	9.0	5.0	4.0	5.2
Stroke	2.0	5.8	6.1	2.7	4.7
Asthma	18.1	15.7	17.4	18.2	16.5
Skin cancer	5.2	13.3	7.1	5.2	6.9
Other type of cancer	5.7	13.7	7.8	6.0	8.3
COPD, emphysema or chronic bronchitis	6.7	11.7	9.5	8.0	9.0
Arthritis, rheumatoid arthritis, gout, lupus, or fibromyalgia	29.5	48.2	35.2	26.1	34.5
Kidney disease	2.2	4.4	4.1	2.0	3.3
Diabetes	8.3	18.8	12.1	9.5	11.7
Overweight or obese	67.6	71.1	68.2	65.2	66.6

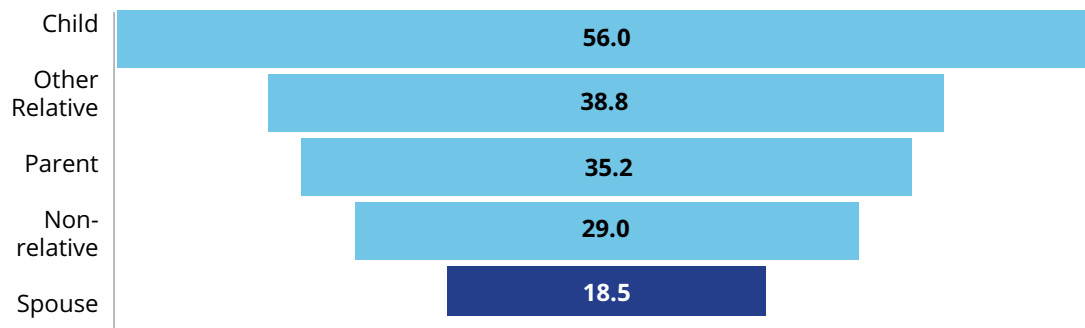
Source: University of Pittsburgh National Rehabilitation Research and Training Center on Family Support Analysis of Data from the Centers for Disease Control and Prevention Behavioral Risk Factor Surveillance System survey



➤ “Sandwich” Generation Caregivers

As the population ages, an increasing number of adult children are caring for their aging parents while raising young children. In the chart below, we show that approximately 35 percent of individuals providing care to a parent are also in a household with a child under the age of 18. However, these so called “sandwich” generation caregivers are not alone—other caregivers supporting relatives, friends, and spouses or partners of all ages are also living in a household with children. Potentially due to age, spousal caregivers are the least likely to have a child residing in the household.

Table 5.
Presence of Child in Household, % Caregivers by Relationship with Care Recipient



Source: University of Pittsburgh National Rehabilitation Research and Training Center on Family Support Analysis of Data from the Centers for Disease Control and Prevention Behavioral Risk Factor Surveillance System survey

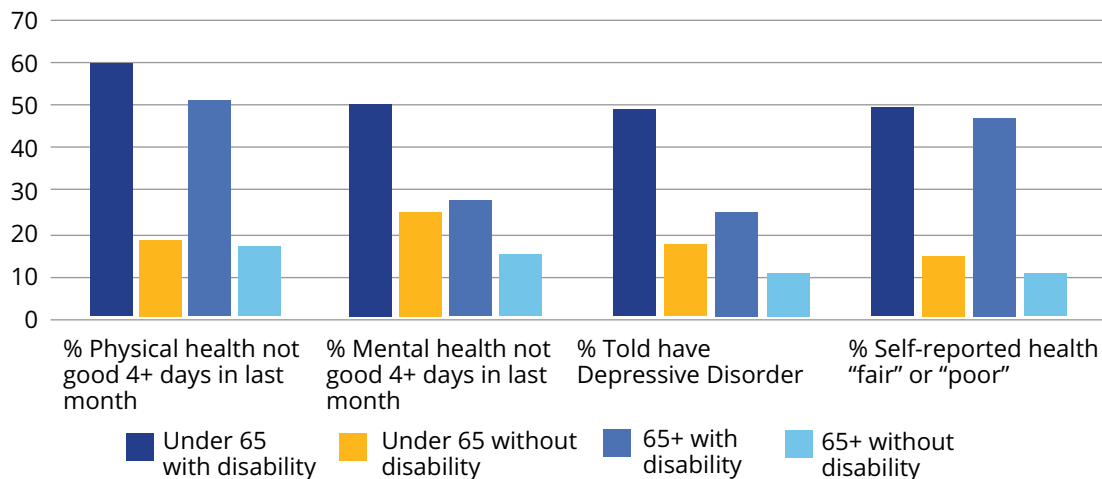
➤ Impacts of Disability on Spousal Caregivers

This section of the brief discusses the presence of disability among spousal caregivers by age, noting key differences in population subgroups across indicators such as physical and mental health, income and education, and utilization of services. As noted above, NSOC provides data on caregiver and care recipient pairs in which the recipient is at least 65 years of age, while BRFSS provides data on caregivers age 18 and above. For measures that are only available in NSOC, limited information is available on younger caregivers.

While the prevalence of disability for the U.S. population is approximately 13 percent in 2020, the prevalence of disability among all caregivers as identified in BRFSS data was nearly 30 percent. Per BRFSS data, the prevalence of disability among spousal caregivers is higher than other caregiver subgroups and increases with age, from 33.8 percent of spousal caregivers age 18 to 64 to 37.1 percent of spousal caregivers over 65.

In each age cohort, spousal caregivers with disabilities were more likely to report worse physical and mental health than those without disabilities. Poor self-reported physical and mental health was particularly pronounced among younger spousal caregivers with disabilities. More than half of all younger spousal caregivers with disabilities reported four or more days per month where physical health or mental health were not good, and close to half of all younger spousal caregivers with disability self-reported a diagnosis of depression.¹⁷

Table 6.
Physical and Mental Health Indicators Among Spousal Caregivers by Age and Disability Status



Source: University of Pittsburgh National Rehabilitation Research and Training Center on Family Support Analysis of Data from the Centers for Disease Control and Prevention Behavioral Risk Factor Surveillance System survey

CHRONIC DISEASE

The prevalence of many chronic diseases is higher among caregivers with disabilities. The difference between occurrence of chronic disease among younger spousal caregivers with disabilities is more pronounced than among older spousal caregivers with disabilities. As noted above, caregivers with chronic disease may struggle to balance the activities required to maintain their own health while providing support to a spouse or partner. Additionally, poor health can inhibit the ability of the caregiver to provide high quality informal care to the care recipient.

Table 7.
Self-Reported Chronic Disease, % Caregivers by Age and Disability Status

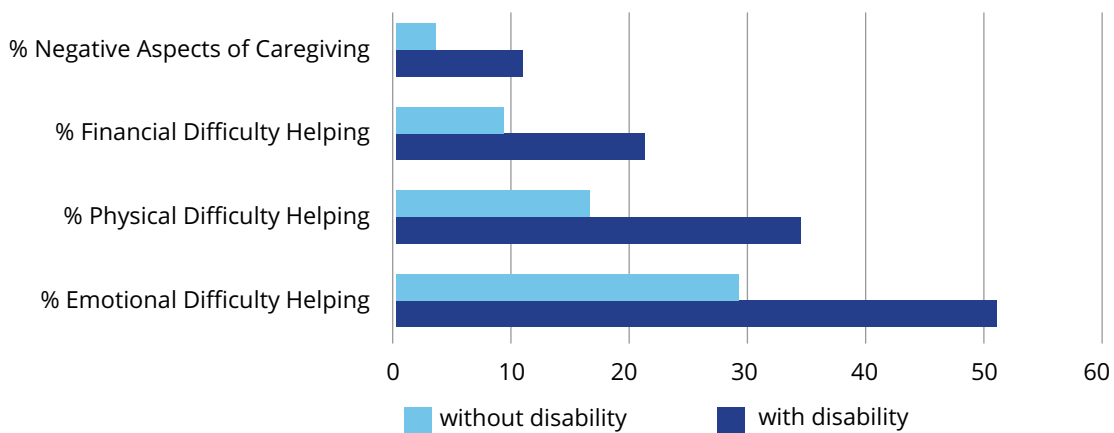
	Under 65 with disability	Under 65 without disability	65+ with disability	65+ without disability
High blood pressure	54.8	35.8	71.5	55.4
High cholesterol	53.8	39.6	61.2	52.6
Heart attack	12.1	3.1	14.5	8.5
Angina	11.7	2.5	18.9	8.6
Stroke	6.7	1.9	13.2	5.3
Asthma	26.1	15.2	19.6	7.7
Skin cancer	7.7	5	24.4	19.4
Other cancer	7.5	6.3	20.1	22.1
COPD	26.4	4.7	18.8	6.3
Arthritis	62.5	25.4	74.4	48.9
Kidney disease	5.9	1.2	10.1	3.8
Diabetes	24.4	10.4	28.8	19
Obesity	51	38.4	39	23.3

Source: University of Pittsburgh National Rehabilitation Research and Training Center on Family Support Analysis of Data from the Centers for Disease Control and Prevention Behavioral Risk Factor Surveillance System survey

➤ Caregiver Burden

The presence of disability among spousal caregivers has a significant impact on indicators of caregiver burden. Compared to spousal caregivers without disability, individuals with disability are nearly twice as likely to report financial, physical, and emotional difficulties providing assistance to their spouse or partner, as well as to report substantial negative aspects of caregiving, such as feeling exhausted when going to bed, having more things to do than you can handle, and having no time for yourself. Additionally, per NSOC, spousal caregivers with disabilities are more likely to meet the criteria for risk of depression (19 vs. 9 percent) and anxiety (16 vs. 8 percent) than those without disabilities.

Table 8.
Indicators of Caregiver Burden Among Spousal Caregivers of Care Recipients Age 65+ by Disability Status



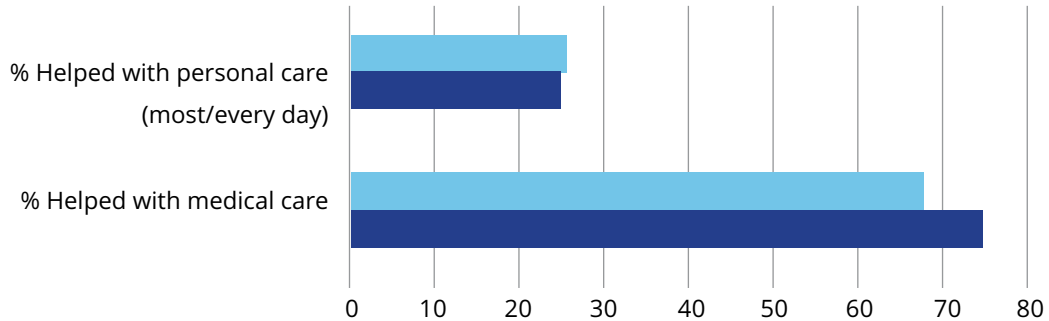
Source: University of Pittsburgh National Rehabilitation Research and Training Center on Family Support Analysis of Data from the Centers for Disease Control and Prevention Behavioral Risk Factor Surveillance System survey



➤ Caregiver Tasks and Intensity

Spousal caregivers with disabilities are more likely than those without disabilities to report providing medical care but are slightly less likely to provide personal care most or every day. Per NSOC data, on average, spousal caregivers with disabilities spent approximately 18.5 hours caregiving per week, while spousal caregivers without disabilities spent 21.8 hours per week caregiving.

Table 9.
Types of Caregiving Task Provided by Spousal Caregivers of Care Recipients Age 65+ by Disability Status

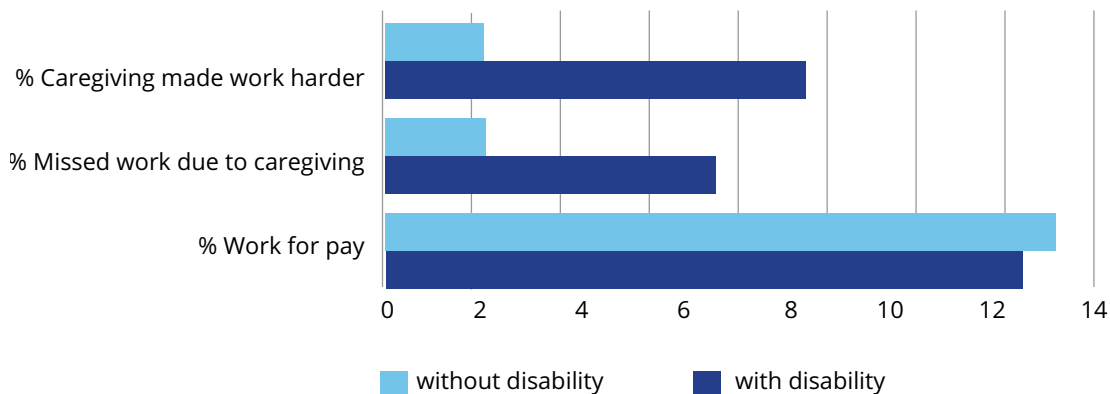


Source: University of Pittsburgh National Rehabilitation Research and Training Center on Family Support Analysis of data from National Health and Aging Trends Study (NHATS) National Study of Caregiving (NSOC). Data on caregivers supporting care recipients under 65 is not available through NHATS/NSOC

➤ Employment

Among spousal caregivers, caregivers without disabilities are only slightly more likely to report paid employment. However, spousal caregivers with disability are more likely to report missed work due to caregiving (6.5 vs 2 percent) and that caregiving responsibilities made work more difficult (8.5 vs 2 percent).

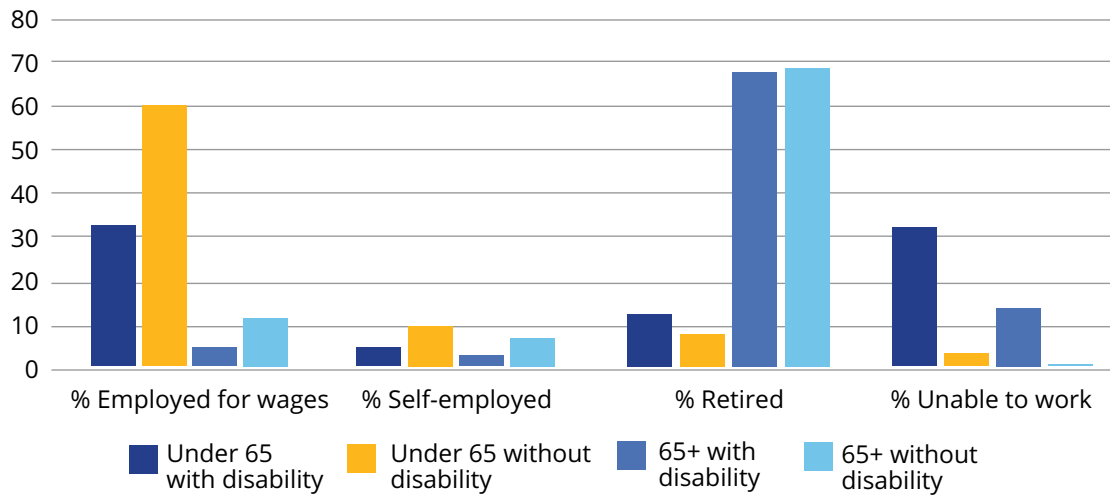
Table 10.
Employment Impacts Among Spousal Caregivers of Care Recipients Age 65+



Source: University of Pittsburgh National Rehabilitation Research and Training Center on Family Support Analysis of data from National Health and Aging Trends Study (NHATS) National Study of Caregiving (NSOC). Data on caregivers supporting care recipients under 65 is not available through NHATS/NSOC.

Among older spousal caregivers, the most common employment status is retired. The likelihood of retirement status is similar for older spousal caregivers with and without a disability. However, for spousal caregivers under 65, individuals without disabilities are significantly more likely to work, with 70 percent reporting employment for wages or self-employment, compared to only 37 percent of spousal caregivers with a disability.

Table 11.
Employment Status of Spousal Caregivers by Age and Disability Status



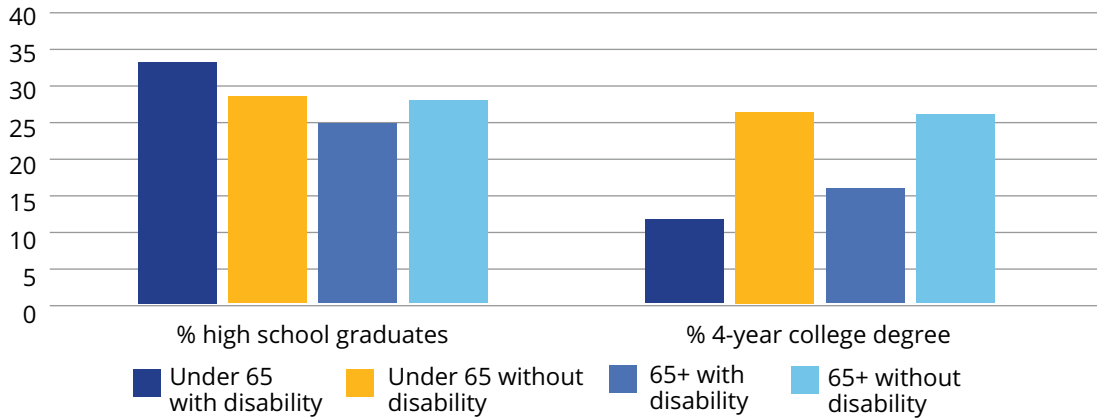
Source: University of Pittsburgh National Rehabilitation Research and Training Center on Family Support Analysis of data from National Health and Aging Trends Study (NHATS) National Study of Caregiving (NSOC). Data on caregivers supporting care recipients under age 65 is not available through NHATS/NSOC.

Education

Younger spousal caregivers with disabilities are more likely to be high school graduates than spousal caregivers without disabilities and older spousal caregivers with disabilities. Spousal caregivers with disabilities are less likely to have completed a four-year college degree, and younger spousal caregivers with disabilities are the least likely to have a four-year degree.



Table 12.
Educational Attainment of Spousal Caregivers by Age and Disability Status

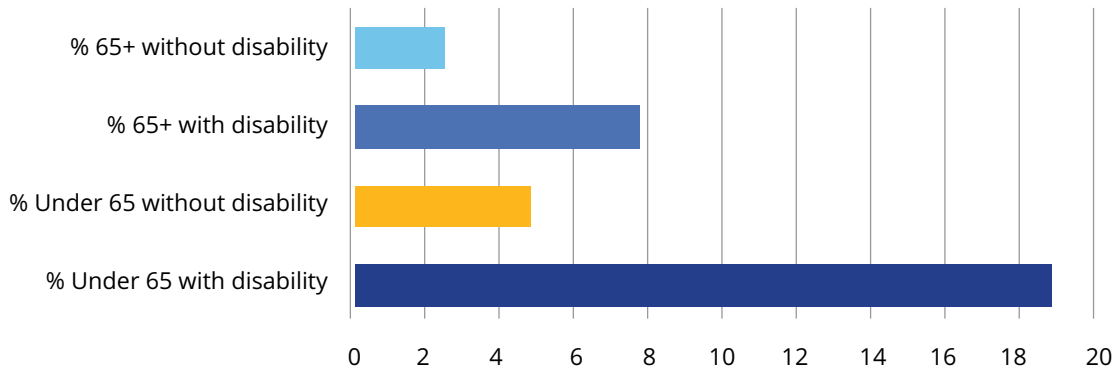


Source: University of Pittsburgh National Rehabilitation Research and Training Center on Family Support Analysis of Data from the Centers for Disease Control and Prevention Behavioral Risk Factor Surveillance System survey

Income

Spousal caregivers with disabilities are more likely to have annual incomes less than \$15,000, below the 2022 poverty line of \$18,130 for a household of two.¹⁸ Close to 20 percent of younger spousal caregivers with disabilities live below the poverty line, compared to only 4.8 percent of younger spousal caregivers without disabilities and 7.6 percent of older spousal caregivers with disabilities. According to BRFSS data, among younger spousal caregivers, 28.5 percent of those with disabilities and 10.6 percent of those without disabilities have an annual income of \$20,000 or less.

Table 13.
% Spousal Caregivers With Income Below \$15,000 Annually by Age and Disability Status

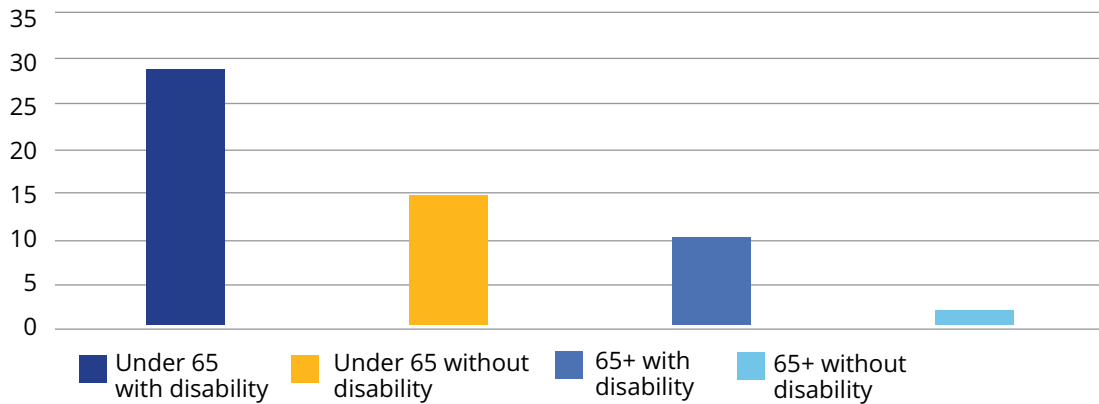


Source: University of Pittsburgh National Rehabilitation Research and Training Center on Family Support Analysis of Data from the Centers for Disease Control and Prevention Behavioral Risk Factor Surveillance System survey

Access to Care

According to BRFSS data, approximately 10 percent of younger spousal caregivers reported a lack of health insurance coverage, compared to slightly over one percent of older spousal caregivers. Younger spousal caregivers were more likely to report an inability to see a doctor when needed due to cost. Spousal caregivers with disability were more likely to report cost-related access to care challenges than those without disabilities within the same age range. Challenges in access to care were the most severe among younger spousal caregivers with disability, with more than 1 in 4 reporting a cost related challenge to accessing a doctor.

Table 14.
% Unable to See Doctor Due to Cost in the Past Year by Age and Disability Status

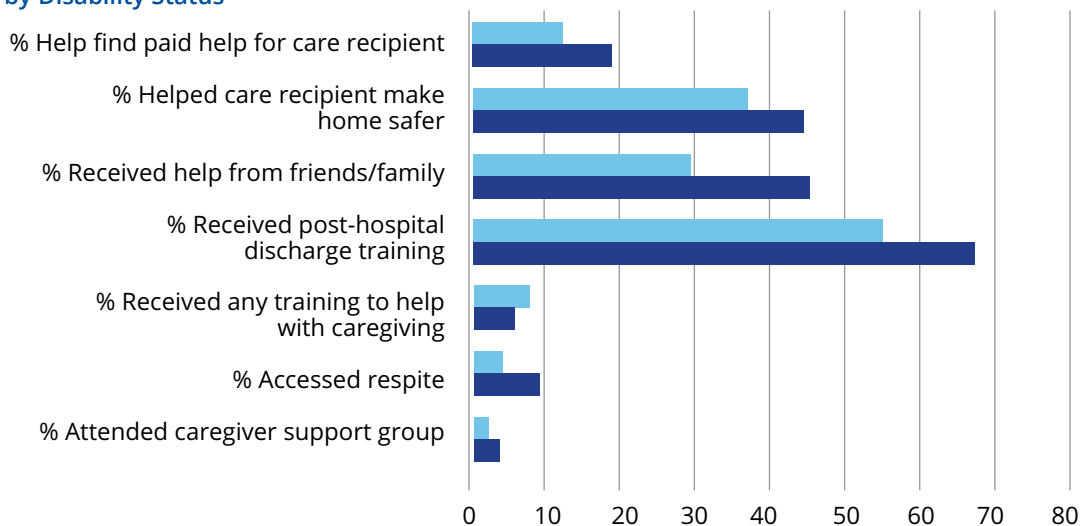


Source: University of Pittsburgh National Rehabilitation Research and Training Center on Family Support Analysis of Data from the Centers for Disease Control and Prevention Behavioral Risk Factor Surveillance System survey

➤ Access to Caregiver Support Services

Spousal caregivers utilize a variety of supportive services to help with caregiving responsibilities. Per NSOC, a majority of spousal caregivers report receiving training on how to care for their spouse or partner post hospital discharge, but comparatively few receive training through other means. Spousal caregivers with a disability are more likely to report use of caregiver supports, such as seeking out paid care, respite services, or caregiver support groups, and receiving help from friends or family. Overall, utilization of key caregiver support services, such as respite, training, and support groups, is relatively low, at less than 10 percent of spousal caregivers both with and without disabilities.

Table 15.
Services and Assistance Received by Spousal Caregivers of Care Recipients Aged 65+ by Disability Status



Source: University of Pittsburgh National Rehabilitation Research and Training Center on Family Support Analysis of Data from the Centers for Disease Control and Prevention Behavioral Risk Factor Surveillance System survey

➤ Conclusion

This brief analyzes recent BFRSS and NHATS/NSOC data to identify and explore the presence of disability among caregivers of different age groups, highlighting the strong linkages between disability and caregiving. Nationally, the prevalence of disability among caregivers is substantially higher than among the general population. Though spousal caregivers with disabilities are slightly more likely to utilize support such as help from friends or family or services such as respite and support groups, overall utilization of caregiver support services is low. Compared to spousal caregivers without disability, spousal caregivers with disability are also significantly more likely to report physical, emotional, and financial burdens associated with caregiving, as well as negative employment related impacts, including missing work.

This brief also highlights needs and potential gaps in support for caregivers with disabilities under age 65. Across many indicators, including mental health, obesity, and depressive disorder, younger caregivers with disabilities report poorer health than older caregivers with disabilities. Younger caregivers with disabilities are also more likely than older caregivers and younger caregivers without disabilities to live below the poverty line, and less likely than younger caregivers without disabilities to be employed. These findings indicate a need to target caregivers with disabilities for support, with a particular emphasis on supporting younger spousal caregivers with disabilities.



Endnotes

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