

2023 NORTH CAROLINA DEMENTIA CAREGIVER DATA BRIEF: COSTS, UNIQUE CHALLENGES AND FUTURE IMPLICATIONS

Executive Summary

Like much of the country, North Carolina is facing a multi-pronged dilemma of rising formal and informal care costs, a growing population of older adults, increases in the prevalence of Alzheimer's disease and related dementias (ADRD) and simultaneous shortages in the healthcare workforce and declines in the number of potential family caregivers. Those caring for a loved one with dementia may face disproportionately higher medical and care costs and a wider array of challenges unique to dementia. As the state continues its efforts to address ADRD, consideration should be given to the undue costs and additional challenges which may be encountered by those with dementia and their families and caregivers.

Introduction

Caregivers are defined as those who tend to the needs of a person who is unable to care for themselves due to a chronic illness, health problem, injury or disability. This data brief focuses on caregivers tending to their friends or family members with cognitive impairment^a (CI) or ADRD. Dementia is the collective term used for a disorder caused by a number of brain diseases or by a brain injury. The disorder manifests as a myriad of symptoms that get worse over time and that include memory loss, confusion, difficulty with reasoning and problem-solving and changes in behavior and personality. This brief also focuses on the informal care costs, health outcomes and unique challenges faced by dementia caregivers especially in comparison with other types of caregivers and includes demographic and related details about caregivers in North Carolina.

Scope

There is limited aggregated data available on the prevalence of cognitive impairment and all types of dementia in North Carolina, but the Alzheimer's Association estimates that in 2021 there were 180,000 people in the state with Alzheimer's Disease, the most common form of dementia.¹ Likewise, there is little data available on the number of caregivers in NC who provide care for a loved one with CI and any type of dementia. However, the Alzheimer's Association reports that in 2021 there were an estimated 356,000 caregivers in North Carolina who provided 514 million hours of unpaid care valued at \$7.3 billion for Alzheimer's Disease alone.¹

CALCULATING THE VALUE OF INFORMAL CARE

Informal care is the term used to describe the unpaid care given by family members and friends. Researchers typically calculate its value using replacement costs (the cost of replacing informal care with formal care) or as foregone wages (the difference between achieved earnings and the earnings that could have been achieved if the caregiver's paid work had not been interrupted or otherwise affected). However, a more comprehensive way of estimating the cost of informal caregiving is referred to as the "welfare cost" which, in addition to the cost of foregone wages, includes the "value of lost leisure and the implications for future employability and wages."² Calculations that include only replacement costs or foregone wages without consideration of these and other factors likely underestimate the value of informal care.

The Cost of Informal Care

A 2018 study comparing the costs of informal caregiving found that the average cost in foregone wages was estimated at \$24,500; the welfare cost was estimated at \$180,000.³ Other studies have demonstrated significant differences in the annual and lifetime costs associated with the informal care of those with dementia vs. those with other diseases and conditions. Given additional findings indicating that informal care comprises up to 75% of the care given to a person with dementia,³ the manner in which the value of informal care is calculated may be of particular importance for policy and programmatic considerations in the dementia realm.

Caregiver Burden

The concept of caregiving typically refers to the activities and experiences involved in caring for someone with an illness, injury or disability. Caregiver burden has been defined as “a multidimensional response to the physical, psychological, emotional, social, and financial stressors associated with the caregiving experience.”⁴ Caregivers tending to loved ones with dementia often experience higher levels of caregiver burden, stress, anxiety and depression and are more likely to view their caregiving as highly stressful.⁵ Compared to other types of caregivers, dementia caregivers also report higher caregiver burden levels in multiple areas (including financial, emotional and physical).⁵ Greater caregiver burden is associated with increased risk of institutionalization of the care recipient.^{6,7,8} When caregivers are unable or no longer able to care for their loved one at home and opt for placement in a nursing home or other institutionalized form of care, this, in turn, puts them at risk for increased feelings of caregiver burden and depression.⁶

Caregiver Challenges

Caregivers face a wide array of potential challenges (financial, emotional, mental and physical) as a result of their caregiving role, but those caring for loved ones with dementia often face even greater challenges and experience poorer health outcomes than caregivers overall.^{3,6,7,8,10,11,12} People with dementia are more likely to display neuropsychiatric symptoms (NPS) that include (in descending order of prevalence) apathy, mood disturbances (depression and anxiety), agitation, aggression, sleep disorders, delusions, hallucinations and disinhibition.^{6,12,13,14} NPS are often erratic and unsettling, may be humiliating or abusive and may disrupt both

DEMENTIA CARE COSTS VS. THOSE OF OTHER CONDITIONS

The cost of informal care for a person with dementia is higher than that of other diseases. A 2015 retrospective cohort study of Medicare fee-for-service beneficiaries ≥ 70 years of age found that, when measured by replacement costs, informal care costs were 2.17 times higher for Alzheimer’s Disease (\$83,022) than for other diseases (\$38,272).³ Another 2015 study found that total health care spending in the last five years of life for people with ADRD was 57% greater than the costs associated with other diseases, including cancer and heart disease.⁹



A 2017 study that assessed the cost of care over a lifetime for a person with dementia found that the lifetime costs were \$184,500 greater than for someone without dementia. Most of this amount (86%) was not covered by Medicare or Medicaid and was incurred by the families.¹⁰

IMPACT OF CAREGIVING ON DEMENTIA CAREGIVER HEALTH

Because people with dementia are more likely than those with other conditions to display NPS, dementia caregivers are more likely to face a greater number of challenges over and above those typically faced by caregivers generally (such as lack of privacy, financial strain, feelings of isolation, family disputes and stress, the management of multiple roles and competing demands on time.¹²) This increased caregiver burden can result in chronic stress and exhaustion that put dementia caregivers at risk for cardiovascular diseases, substance use and abuse, rheumatoid arthritis, insomnia and weakened immune systems.^{3,6}



A 2015 study assessed the two-year incidence of major depressive and anxiety disorders in dementia caregivers who, at baseline, were free of symptoms or in whom the disorders were not identifiable through diagnosis. Its findings included 60% incidence of either disorder (37% depression and 55% anxiety) and a high cumulative incidence (one-third) of comorbid anxiety and depressive disorders.^{6,11}

care recipient and caregiver sleep. Several studies have found neuropsychiatric symptoms to be the most troublesome for caregivers to manage^{5,13,14} with agitation, aggression, resistiveness to care and disinhibition, particularly inappropriate sexual behaviors, being the most likely to damage the caregiver/recipient bond.^{12,14}

North Carolina Caregivers

The Behavioral Risk Factor Surveillance System (BRFSS) survey is a random telephone survey of state residents aged 18 and older that collects data on a variety of health behaviors and preventive health practices. The Caregiver module is a set of optional questions that may be added by participating states and territories to the core questions of the BRFSS survey; it was included in North Carolina's BRFSS survey in 2021, 2017 and 2011.^b The information and graphs that follow summarize the 2021 findings for North Carolina and provide 2017 and 2011 estimates for comparison, when appropriate. (Significant revisions were made to the Caregiver module after its implementation in 2011, including revisions to the phrasing of the caregiver screening question itself. See Appendix Notes.^c When 2011 data is cited, survey incongruencies will be noted.)

The 2021 BRFSS caregiver screening question asked all survey participants whether they had provided "regular care or assistance to a friend or family member who has a health problem or disability." In 2021, fewer respondents self-reported as caregivers (17.6%)¹⁵ than in 2017 (19.9%)¹⁶ or in 2011 (19.7%).¹⁷ Respondents who self-reported as caregivers were then asked additional questions and caregiver module data was analyzed along with other BRFSS data to provide estimates of the number of caregivers who reported being Veterans or having a functional disability^d themselves (Table 1).

Table 1.

	2011	2017	2021
Caregivers who reported having a functional disability ^{15,16,17}	33.1% N=996	35.6% N=753	38.6% N=734
Caregivers who reported having Veteran status ^{15,16,17}	10.7% N=999	14.7% N=755	11.5% N=740

Among caregivers, variation was noted between years in distribution by their sex (Figure 1), level of education, household income and rural vs. urban residential classification. College educated caregivers was 32.1% in 2011 and 40.1% in 2021,^{15,17} while those in the high school/GED category decreased from 30.2% in 2011 to 22.4% in 2021.^{15,17} Findings related to household income indicate that caregivers generally had higher amounts of household income in 2021 than in 2011. In 2021, only 36.5% of caregivers had annual household incomes less than \$50,000 compared with 53.5% in 2011.^{15,17} Caregivers with annual household incomes of \$50,000 to \$75,000 remained consistent from 2011 (13.0%) to 2021 (14.3%).^{15,17} Caregivers with annual household incomes of more than \$75,000 increased from 19.1% in 2011 to 28.8% in 2021.^{15,17} (See Figure 2 for more detailed caregiver household income comparison data.)

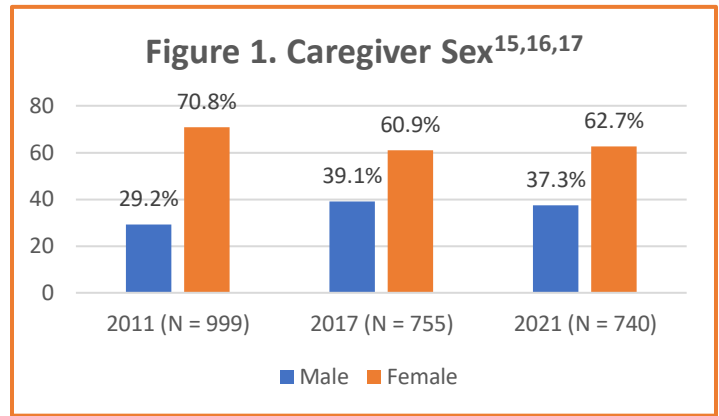
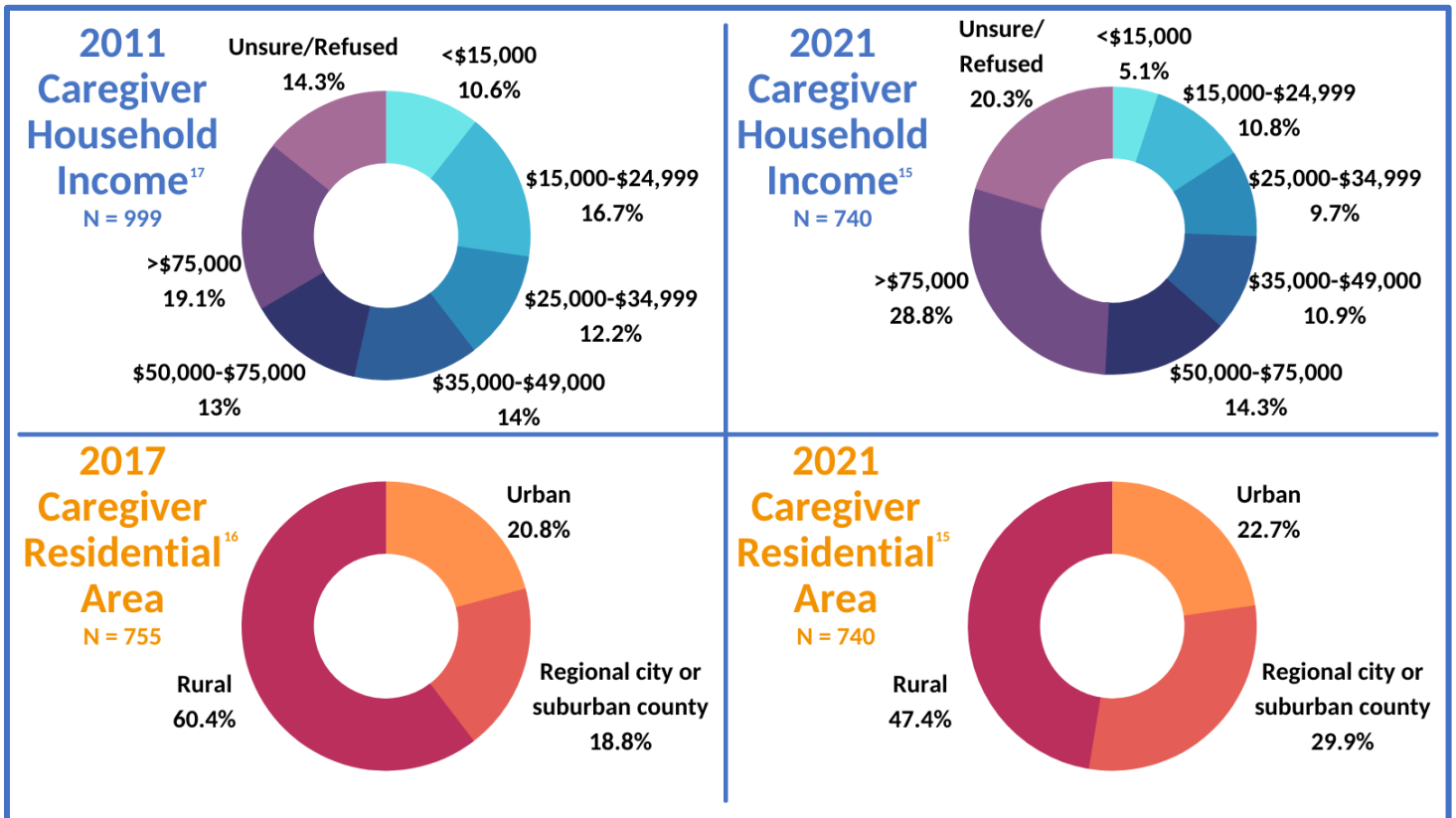


Figure 2.

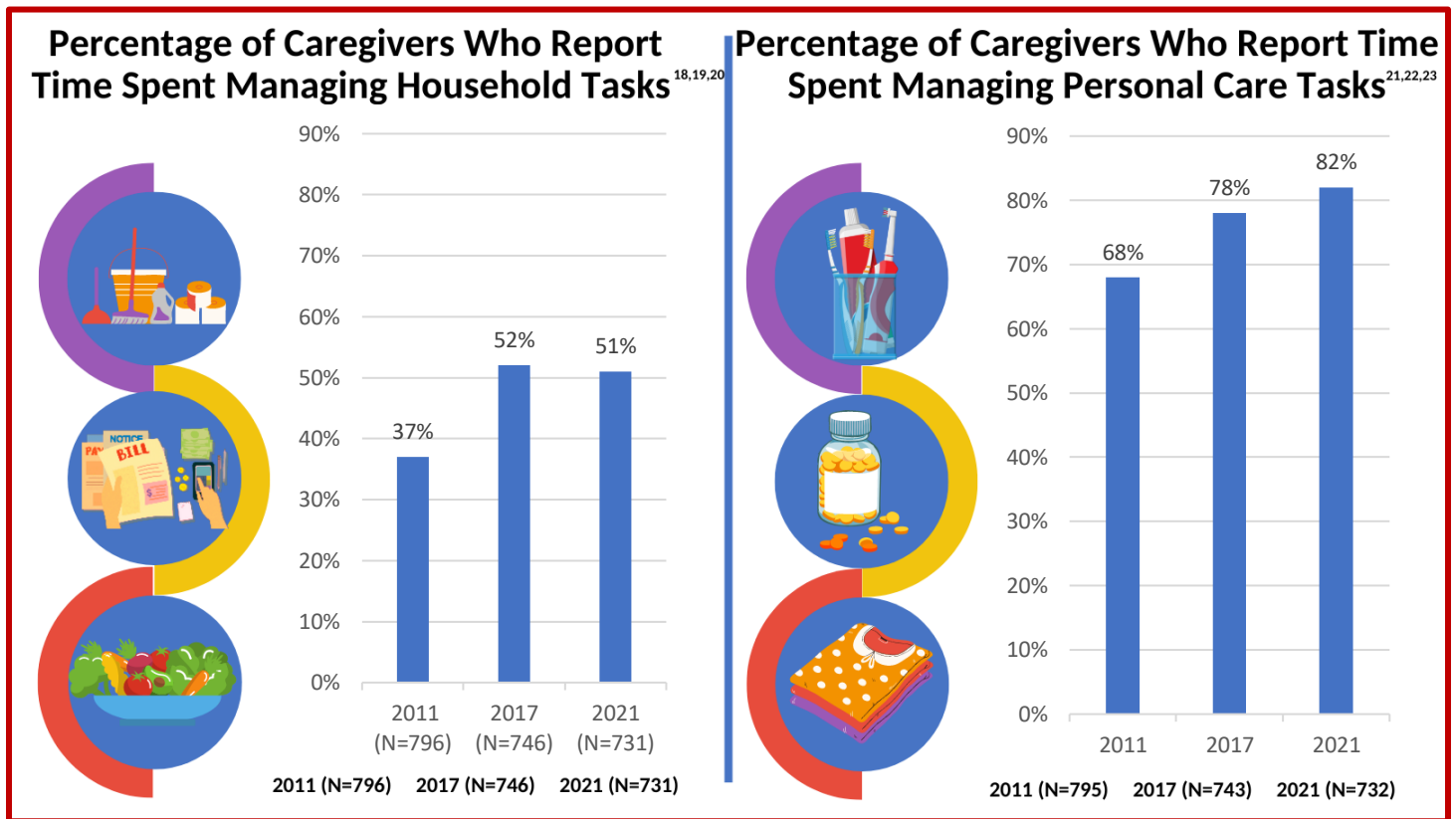


Residential classification (rural/suburban/urban) findings reflected variation in the percent of caregivers classified as living in rural and suburban areas^{15,16} (Figure 2 above). (County of residence is coded using the North Carolina Rural Center’s county classification.)

Respondents who self-reported as caregivers were also asked two questions in 2011, 2017 and 2021 about the type of tasks they were managing for the care recipient.^c The survey delineates two categories of tasks:

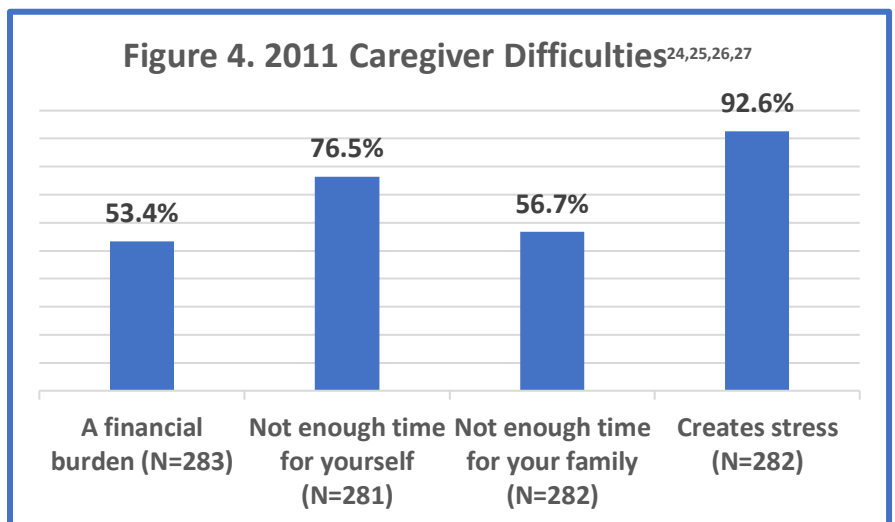
personal care tasks which include “giving medications, feeding, dressing or bathing” and household tasks which include “cleaning, managing money or preparing meals.” Figure 3 shows the estimates of caregiver management of these tasks from 2011 to 2021.^{18,19,20,21,22,23}

Figure 3.



In the 2011 BRFSS, caregivers were given a “list of difficulties you may have faced” and were asked to “please tell me yes or no whether you have faced each one” (Figure 4).^{24,25,26,27} These questions about caregiver difficulties were not asked in the 2017 and 2021 iterations of the survey. Given the rates of difficulties experienced by caregivers reflected in these findings, more research is needed into the specific challenges faced by NC caregivers so that informed decisions may be made regarding policies, funding

allocations and programming. (Note: the data shown in Figure 4 includes responses from all caregivers, not just those caring for someone with dementia. Disaggregated data by care recipient illness/condition is not available)



WORKFORCE SHORTAGES

There are currently 158 geriatricians in North Carolina. In order to meet the future care needs of NC's older adults (65+ years), the number of geriatricians needs to increase 238% by 2050. (This calculation is based on how many geriatricians will be needed to serve those projected to have Alzheimer's disease in 2050, assuming that the percentage of people 65 and older with Alzheimer's remains at approximately 10%. The calculation assumes that each geriatrician can care for up to 700 patients.) Shortages in the dementia care workforce can result in delayed and inaccurate diagnosis which can result in delays in treatment, care delivery and other services.²⁸



A 2020 study aptly surmised, “[T]he middle class, who neither qualify for Medicaid-funded home care nor have the means to pay for significant paid caregiving out of pocket, face a unique challenge: They must either rely solely on family caregivers to meet their needs or pay out of pocket for paid caregivers until their wealth is exhausted and they become Medicaid eligible.”³⁶

for persons with dementia are approximately 25% higher³⁴ or \$4,982 and \$9,354, respectively, making either of these care options unaffordable for the majority of American families (80%) with annual household incomes of \$150,000 or less.³⁵

Future Implications and Considerations

Similar to trends seen nationwide, North Carolina adults aged 60+ years outnumber children under 18 years due to increases in life expectancy and concomitant declines in birth rates.^{29,30,31} As the “boomer” cohort ages and the proportion of older adults across the state continues to grow, more caregivers will be needed to support them with household tasks and their personal care and health needs. However, a simultaneous decline in family caregivers has been noted by the American Association of Retired Persons (AARP) who reports that, in 2010, there were seven potential family caregivers for every person aged 80+ years; they estimate that, by 2030, the number of potential family caregivers could be as few as four per person.³² The decline in the rate of North Carolinians self-reporting as caregivers (from 19.9% in 2017 to 17.6% in 2021)^{15,16} reflected in state BRFSS data may be further evidence of this trend.

BRFSS data estimating that more than 80% of caregivers in 2021 spent time managing personal care tasks for care recipients indicate this is a common area of need that could be prioritized for legislative efforts and resource allocation. Likewise, differences in the rates of female (63%) vs. male (37%) caregivers, although it has decreased since 2011 (71% vs. 29%, respectively), may suggest that the caregiving role is impacted by stigma, gender socialization or some other factor(s) that warrants consideration.

Projected shortages in the healthcare workforce, exacerbated by the aforementioned declines in caregivers, may also impact dementia caregivers and their loved ones and will likely make aging in place more challenging to achieve. Costs vary across the state, but, in 2021, the median monthly cost for home care (home health aide) was \$3,986 (40 hours per week for four weeks) and \$7,483 for a semi-private nursing home room.³³ Due to the need for increased support and supervision, the monthly costs

Summary

The incidence of Alzheimer's disease and related dementias in North Carolina is increasing as are health care costs and the costs of both formal and informal care. Numerous studies have documented the disproportionately higher costs of caring for a person with dementia compared with other conditions and the wider array of challenges that are unique to caregiving for someone with dementia. As the state continues its efforts to address ADRD, consideration should be given to the undue costs and additional challenges which may be encountered by those with dementia and their families and caregivers.

Appendix

Notes:

^a Cognitive impairment is defined as difficulty “remembering, learning new things, concentrating, or making decisions that affect their everyday life.” Cognitive impairment ranges from mild to severe.³⁷

^b Questions related to caregiving were administered as part of the national BRFSS core survey in 2000 but were not repeated. To improve caregiver surveillance, the Centers for Disease Control and Prevention (CDC) provided funds to the University of Florida in 2004 to develop a caregiver module to collect data on the characteristics and health of caregivers. Module development was based on previous research and was influenced by key national stakeholders that were convened by AARP in 2005. North Carolina was selected as the site for piloting the module because of its large BRFSS sample size and administrative capacity. The following caregiver screening question was administered in the 2005 North Carolina BRFSS survey: "People may provide regular care or assistance to someone who has a long-term illness or disability. During the past month, did you provide any such care or assistance to a family member or friend?" Persons who responded "yes" to the question were classified as caregivers and were asked additional questions in the caregiver module about themselves and their primary care recipient. ³⁸

^c Revisions to the BRFSS caregiver screening question and questions about caregiver management of household and personal care tasks:

2011: “People may provide regular care or assistance to a friend or family member who has a health problem, long-term illness, or disability. During the past month, did you provide any such care or assistance to a friend or family member?”¹⁷

2017 & 2021: “During the past 30 days, did you provide regular care or assistance to a friend or family member who has a health problem or disability?”^{15,16}

2011 household tasks: "Please tell me yes or no whether the person you care for needs help with any of the following: taking care of his/her residence or personal living spaces, such as cleaning, managing money or preparing meals."¹⁸

2017 & 2021 household tasks: "In the past 30 days, did you provide care for this person by managing household tasks such as cleaning, managing money or preparing meals?"^{19,20}

2011 personal care tasks: "Please tell me yes or no whether the person you care for needs help with any of the following: taking care of himself/herself, such as eating, dressing or bathing."²¹

2017 & 2021 personal care tasks: "In the past 30 days, did you provide care for this person by managing personal care such as giving medications, feeding, dressing, or bathing?"^{22,23}

^d Functional Disability - The BRFSS survey includes six questions recommended by the U.S. DHHS as the national standard for identifying disabilities in population-health based surveys.

Data that did not meet statistical reliability standards was suppressed.

Some “Don’t know/Not Sure/Refused” data was not cited in this report.

Data Source & Methods:

The Behavioral Risk Factor Surveillance System (BRFSS) is the nation’s “system of health-related telephone surveys that collect state data about U.S. residents regarding their health-related risk behaviors, chronic health conditions, and use of preventive services.”³⁹ The Caregiver module is an optional set of questions that is periodically added to the core survey. The caregiver screening question asks survey participants if they have provided “regular care or assistance to a friend or family member...” The remaining questions are asked only of participants responding ‘yes’ to the screening question. For more information about BRFSS or the Caregiver module and for general information about the CDC, visit: <https://www.cdc.gov/brfss/index.html>, <https://www.cdc.gov/brfss/questionnaires/index.htm> and <https://www.cdc.gov/>.

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