



# **The Economic Value Of Informal Caregiving For Persons With Dementia: Results From 38 States, The District Of Columbia, And Puerto Rico, 2015 And 2016 BRFSS**

By: Kristina M. Rabarison, **Erin D. Bouldin**, Connie L. Bish, Lisa C. McGuire, Christopher A. Taylor, and Kurt J. Greenlund

## **Abstract**

**Objectives.** To estimate the economic value from a societal perspective of informal caregiving of persons with dementia in 38 states, the District of Columbia, and Puerto Rico. **Methods.** Using a cost replacement method and data from the 2015 and 2016 Behavioral Risk Factor Surveillance System caregiver module, the US Bureau of Labor Statistics May 2016 Occupation Profiles, and the US Department of Labor, we estimated the number and economic direct cost of caregiving hours. **Results.** An estimated 3.2 million dementia caregivers provided more than 4.1 billion hours of care, with an average of 1278 hours per caregiver. The median hourly value of dementia caregiving was \$10.28. Overall, we valued these caregiving hours at \$41.5 billion, with an average of \$13069 per caregiver. **Conclusions.** Caregivers of persons with dementia provide care that has important economic implications. Without these efforts, many people would either not receive needed care or have to pay for that support. Surveillance data can be used to estimate the contributions of informal caregivers and the economic value of the care they provide.

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# The Economic Value of Informal Caregiving for Persons With Dementia: Results From 38 States, the District of Columbia, and Puerto Rico, 2015 and 2016 BRFSS

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**Conclusions.** Caregivers of persons with dementia provide care that has important economic implications. Without these efforts, many people would either not receive needed care or have to pay for that support. Surveillance data can be used to estimate the contributions of informal caregivers and the economic value of the care they provide.

without informal caregivers, people with dementia may not receive some of the assistance they need to maintain their health and well-being.<sup>9</sup> Although family members and friends currently provide substantial care for older adults with dementia, the need for informal care may increase as Medicare reduces reimbursement for home health services.<sup>10,11</sup> We estimated the number of informal caregiving hours received by and their economic value to persons with dementia. We also explored the potential effects of providing informal caregiving on the health of these caregivers.

## METHODS

The District of Columbia, Puerto Rico, and 38 states implemented the caregiver module of the 2015 and 2016 Behavioral Risk Factor Surveillance System (BRFSS).<sup>12</sup> We used data from the BRFSS caregiver module to identify informal caregivers for persons with dementia, characterize these caregivers' demographic and health status, and characterize the informal care they provided.

BRFSS is a state-based telephone (land-line and cell phone) survey supported by the Centers for Disease Control and

**D**ementia is a form of cognitive decline that progresses over time.<sup>1</sup> Alzheimer's disease is the most common form, with an estimated 5.7 million persons in the United States living with Alzheimer's.<sup>2,3</sup> In addition, Alzheimer's is the sixth leading cause of death in the United States and accounted for 3.6% of all deaths in 2014.<sup>4</sup> By 2025, an estimated 7.1 million people aged 65 years and older will be living with Alzheimer's disease or other dementias.<sup>3</sup>

As a result of the progressive nature of dementia and the impaired function and loss of independence it leads to, many people with dementia need assistance from formal and informal caregivers. Formal caregivers are paid caregivers, such as home health aides and nurse aides, who provide care at home or in residential facilities.<sup>5-7</sup> Informal caregivers

are unpaid family members or friends who regularly care for or assist a person with a chronic health problem or disability.<sup>8</sup> These informal caregivers provide a wide range of assistance, such as help with personal care (e.g., giving medications, feeding, dressing, or bathing) and household tasks (e.g., cleaning, managing money, or preparing meals).

Informal caregivers are a vital component of long-term support in US communities<sup>8</sup>;

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**Note.** *The opinions expressed by the authors do not necessarily reflect the opinions of the US Department of Health and Human Services, the Public Health Service, the Centers for Disease Control and Prevention, or the authors' affiliated institutions.*

Prevention; it asks adults in community living environments who are aged 18 years and older about a variety of health behaviors and experiences. BRFSS includes optional modules that states may choose to include in their annual survey. The optional caregiver module included 9 questions designed to assess the prevalence of informal caregiving and characteristics of these caregivers' experience.<sup>13,14</sup>

We weighted data to state population estimates using an iterative proportional fitting (or raking) method and combined them. Our analyses accounted for the complex sampling design of the BRFSS (following guidance available at [http://www.cdc.gov/brfss/data\\_documentation/index.htm](http://www.cdc.gov/brfss/data_documentation/index.htm)). To estimate the hourly cost of caregiving for persons with dementia, we used (1) state-specific hourly wage data from the US Bureau of Labor Statistics' May 2016 State Occupational Employment and Wage Estimates<sup>15</sup> for home health aides as well as maids and housekeeping cleaners, and (2) states' minimum wage from the US Department of Labor.<sup>16</sup> All data sources in this study are publicly available.

## Definition and Number of Informal Caregivers

BRFSS survey respondents were asked the following: "People may provide regular care or assistance to a friend or family member who has a health problem or disability. 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?" We identified informal caregivers as those who answered "yes" and non-caregivers as people who answered "no" or who reported that the care recipient had died during the past 30 days. We excluded persons from our analysis who did not provide a response.

All informal caregivers were asked to identify "the main health problem, long-term illness, or disability that the person you care for has." We defined informal caregivers for persons with dementia as those whose response was categorized as "dementia and other cognitive impairment disorders" rather than as 1 of the 13 other possible categories.

## Characteristics of Care Provided by Informal Caregivers

We categorized persons receiving informal care by relationship to caregiver as parent or parent-in-law, spouse or partner (husband, wife, or same-sex partner), other relative (child, sibling or sibling-in-law, grandparents, grandchild, or others not listed), or non-relative. The BRFSS categorized the average number of hours providing informal care per week as 0 to 8 hours, 9 to 19 hours, 20 to 39 hours, or 40 or more hours. We categorized the types of informal care provided in the past 30 days as personal care only (giving medications, feeding, dressing, or bathing), household tasks only (cleaning, managing money, or preparing meals), both personal care and household tasks, or neither.

## Number of Informal Caregiving Hours

To determine the number of informal caregiving hours that caregivers reported, we calculated the weighted percentage of each BRFSS weekly hours category. We multiplied these percentages by the median number of hours within each category to estimate the total number of dementia informal caregiving hours per week. The median number of hours for those who reported 40 hours or more was 84 hours when calculated using data from 2012 and 2013 BRFSS data and when the question was asked with a continuous response option (0–168 hours). Last, we multiplied the total number of informal dementia caregiving hours per week by 52 weeks to estimate the annual number of hours. We multiplied the amount of time caregivers spent providing care in the past week by 52 weeks because we assumed that the prevalence and experience of caregivers captured at the time of the survey accurately represented the prevalence in the states, the District of Columbia, and Puerto Rico, including both long- and short-term caregivers.

## Economic Value of Informal Caregiving

From a societal perspective that accounts for informal care as a complement to formal care and other unmeasured informal costs (e.g., caregiver early retirement), we

estimated the economic value of dementia caregiving using a cost replacement approach, which assumes that the type of care caregivers provide substitutes for care that would otherwise be provided by paid workers.<sup>17–20</sup> The BRFSS type of care categories were household tasks only, personal care only, both, or neither (activities not identified). The paid worker categories we used were (1) home health aides and (2) maids and housekeeping cleaners. For each state, we obtained the state-level median hourly wages from the 2016 US Bureau of Labor Statistics and the state-level minimum wage from the US Department of Labor. We conducted the cost replacement for each type of care as follows:

- We substituted household task cost with the state-level median hourly wage of maids and housekeeping cleaners;
- We substituted personal care cost with the state-level median hourly wage of home health aides;
- We substituted cost of providing both household task and personal care with the combined average of maids and housekeeping cleaners, and home health aides' state-level median hourly wages; and
- We substituted the cost of unidentified activities with the median state minimum wage.

To estimate the hourly economic value of informal dementia caregiving, we used the sum of each cost replacement multiplied by the weighted percentage of the types of care provided for each state, the District of Columbia, and Puerto Rico. We multiplied this hourly value estimate by the annual number of informal dementia caregiving hours to estimate the annual economic value, which we then divided by the number of informal dementia caregivers to estimate the economic value per caregiver per year. Dollar amounts are in 2016 US dollars.

## Demographics and Health Status of Informal Caregivers

Examined demographic characteristics included sex; age group (18–34, 35–44, 45–54, 55–64, and ≥ 65 years); race/ethnicity (non-Hispanic White, non-Hispanic Black, Hispanic, non-Hispanic Asian, and other/multiracial,

i.e., American Indian, Alaska Native, multiracial, or other not listed); marital status (married or coupled, i.e., married or a member of an unmarried couple, vs not married or not coupled, i.e., divorced, widowed, separated, or never married); education level (no high school diploma, high school graduate or general equivalency diploma, some college, and college graduate); employment status (employed or self-employed, homemaker, student, retired, out of work, and unable to work); and annual household income (<\$15 000, \$15 000–\$24 999, \$25 000–\$49 999, \$50 000–\$74 999, and ≥\$75 000).

Examined health status characteristics included frequent physical distress (physical illness and physical injury for ≥ 14 days in the past 30 days); frequent mental distress (stress, depression, and problems with emotions for ≥ 14 days in the past 30 days); body mass index (BMI, which is weight in kg divided by height in meters squared; normal weight [BMI < 25 kg/m<sup>2</sup>], overweight [25 ≤ BMI < 30], or obese [BMI ≥ 30]); having at least 1 of 7 chronic diseases (i.e., heart disease, stroke, diabetes, asthma, chronic pulmonary disease, arthritis, or nonskin cancer); health care cost was a barrier to care in the past 12 months (i.e., needed to see a doctor but could not because of cost); and had any health care coverage (i.e., health insurance, prepaid plans such as health maintenance organizations, government plans such as Medicare, or Indian Health Service).

## RESULTS

In 38 states, the District of Columbia, and Puerto Rico, we identified 4645 adults as informal dementia caregivers from the 2015 and 2016 BRFSS caregiver module, with a population estimate of 3 175 104. More than half of these caregivers were White (69.2%; 95% confidence interval [CI] = 65.4%, 72.9%), women (65.2%; 95% CI = 61.5%, 68.7%), married (61.4%; 95% CI = 55.9%, 66.6%), and employed (55.7%; 95% CI = 50.1%, 61.2%; Table 1). The percentages of informal dementia caregivers reporting frequent physical distress and frequent mental distress were 12.8% (95% CI = 10.5%, 15.5%) and 17.8% (95% CI = 12.3%, 24.9%), respectively (Table 2).

**TABLE 1—Demographic Characteristics of Dementia Caregivers: 2015–2016 Behavioral Risk Factor Surveillance System Caregiver Module, 38 States, District of Columbia, and Puerto Rico**

Characteristics	Dementia Caregivers (n = 4645), <sup>a</sup> Weighted % (95% CI) <sup>b</sup>
Women	65.2 (61.5, 68.7)
Age group, y	
18–24	10.0 (5.2, 18.3)
25–34	7.7 (6.2, 9.7)
35–44	9.8 (7.6, 12.5)
45–54	21.8 (18.6, 25.4)
55–64	25.1 (22.6, 27.7)
≥ 65	25.6 (21.2, 30.4)
Race/ethnicity	
Non-Hispanic White	69.2 (65.4, 72.9)
Non-Hispanic Black	13.6 (10.1, 18.1)
Hispanic	13.2 (8.1, 20.7)
Non-Hispanic Asian	1.8 (0.9, 3.2)
Non-Hispanic other <sup>c</sup>	2.2 (1.6, 3.1)
Marital status	
Married/coupled <sup>d</sup>	61.4 (55.9, 66.6)
Not married/not coupled <sup>e</sup>	38.6 (33.4, 44.1)
Education	
No high school diploma	6.2 (4.9, 7.8)
High school graduate	22.5 (20.1, 25.1)
Some college	40.9 (36.9, 45.1)
College graduate	30.4 (27.2, 33.8)
Employment status	
Employed/self-employed	55.7 (50.1, 61.2)
Homemaker	5.8 (4.7, 7.1)
Student	4.0 (2.1, 7.6)
Retired	23.6 (19.5, 28.2)
Out of work	4.1 (3.1, 5.4)
Unable to work	6.8 (5.3, 8.9)
Annual household income, \$	
< 15 000	8.8 (6.7, 11.5)
15 000–24 999	13.7 (10.9, 17.2)
25 000–49 999	23.8 (20.4, 27.7)
50 000–74 999	17.7 (13.5, 22.8)
≥ 75 000	36.0 (29.6, 42.8)

Note. CI = confidence interval. The 38 states are AL, AZ, AR, CA, CO, CT, FL, GA, HI, ID, IL, IN, IA, KY, LA, ME, MD, MN, MS, MO, MT, NE, NV, NJ, NY, ND, OH, OR, PA, SC, SD, TN, TX, UT, VA, WV, WI, and WY.

<sup>a</sup>Unweighted sample size was not design adjusted.

<sup>b</sup>Design-adjusted percentages and CIs.

<sup>c</sup>American Indian, Alaska Native, multiracial, or other not listed.

<sup>d</sup>Married or a member of an unmarried couple.

<sup>e</sup>Divorced, widowed, separated, or never married.

## Amount and Type of Informal Caregiving

Informal dementia caregivers most frequently provided care to a parent or a parent-in-law (49.1%; 95% CI = 45.3%, 53.0); for

0 to 8 hours per week (55.6%; 95% CI = 51.8%, 59.4%); for between 2 and 5 years (28.6%; 95% CI = 23.9%, 33.7%). On average, informal dementia caregivers provided assistance with both household tasks

**TABLE 2—Health Status Characteristics of Dementia Caregivers: 2015–2016 Behavioral Risk Factor Surveillance System Caregiver Module, 38 States, District of Columbia, and Puerto Rico**

Characteristics	Dementia Caregivers (n = 4645), <sup>a</sup> Weighted % (95% CI) <sup>b</sup>
<b>Frequent physical distress<sup>c</sup></b>	
No (< 14 d)	87.2 (84.5, 89.5)
Yes (≥ 14 d)	12.8 (10.5, 15.5)
<b>Frequent mental distress<sup>d</sup></b>	
No (< 14 d)	82.2 (75.1, 87.7)
Yes (≥ 14 d)	17.8 (12.3, 24.9)
<b>BMI</b>	
Normal weight (< 25 kg/m <sup>2</sup> )	33.3 (27.5, 39.8)
Overweight (25 to < 30 kg/m <sup>2</sup> )	34.5 (30.6, 38.6)
Obese (≥ 30 kg/m <sup>2</sup> )	32.2 (27.2, 37.6)
<b>Chronic disease<sup>e</sup></b>	
Yes	52.2 (46.4, 57.9)
No	47.8 (42.1, 53.6)
<b>Health care cost barrier to care</b>	
Yes	11.7 (9.9, 13.8)
No	88.3 (86.2, 90.1)
<b>Has any health coverage<sup>f</sup></b>	
Yes	90.2 (87.2, 92.6)
No	9.8 (7.4, 12.8)

Note. BMI = body mass index; CI = confidence interval. The 38 states are AL, AZ, AR, CA, CO, CT, FL, GA, HI, ID, IL, IN, IA, KY, LA, ME, MD, MN, MS, MO, MT, NE, NV, NJ, NY, ND, OH, OR, PA, SC, SD, TN, TX, UT, VA, WV, WI, and WY.

<sup>a</sup>Unweighted sample size was not design adjusted.

<sup>b</sup>Design-adjusted percentages and CIs.

<sup>c</sup>Had physical illness or physical injury ≥ 14 d during the past 30 d.

<sup>d</sup>Experienced stress, depression, and problems with emotions for ≥ 14 d during the past 30 d.

<sup>e</sup>At least 1 of the following: heart disease, stroke, diabetes, asthma, chronic pulmonary disease, arthritis, or nonskin cancer.

<sup>f</sup>Had any health care coverage, such as health insurance, prepaid plans such as health maintenance organizations, government plans such as Medicare, or Indian Health Service.

and personal care (56.1%; 95% CI = 50.3%, 61.7%; Table 3).

## Economic Value of Informal Caregiving

An estimated 3.2 million informal dementia caregivers provided more than 4.1 billion hours of care each year, with an average of 1278 hours per caregiver annually (Table 4). California had the most informal caregivers (393 320) and the lowest annual number of informal caregiving hours per caregiver (788).

The median hourly value of informal dementia caregiving across all participating locations was \$10.28, ranging from \$8.70 in Puerto Rico to \$14.99 in the District of

Columbia. In total, the annual value of these informal caregiving hours was \$41.5 billion, averaging \$13 069 per caregiver per year (Table 4).

## DISCUSSION

Public health surveillance data, such as BRFSS data, allow practical and approachable methods to estimate the contributions of informal dementia caregivers and the economic value of the care they provide. With an average of \$13 069 per caregiver (range: \$8420 [Iowa] to \$22 462 [Hawaii]) for 38 states, the District of Columbia, and Puerto Rico, our findings were consistent with previous studies and showed that

dementia caregiving is lengthy, personal, and costly.<sup>9,17–25</sup> For example, a 2010 study using data from the Health and Retirement Study (HRS) estimated the annual unadjusted cost of informal dementia caregiving at \$33 329 (range: \$23 578–\$38 049) per person receiving care for all adults who needed both formal and informal care in the United States.<sup>20</sup> Our analysis estimated only the replacement cost of informal care provided and did not include formal care services, forgone wages, or any other indirect cost to the estimates, which, therefore, is lower than is the per care recipient estimate calculated in the HRS-based study.<sup>20</sup>

Considering the aging US population and the substantial projected increase of dementia prevalence and its associated costs, understanding the characteristics of dementia caregivers is an important public health issue.<sup>3,8,17–20</sup> Caregivers play an important role in ensuring that older adults receive the help and assistance they need.<sup>8</sup> Evidence shows that persons with Alzheimer's are more likely to need informal caregivers as their health declines.<sup>23</sup> Many people being cared for by family members or friends, if they were not receiving this care, might use formal caregiving services to remain in their homes.<sup>9</sup> Alternatively, some people with dementia would no longer receive the care or support they need,<sup>9</sup> which could exacerbate the severity of their condition and further increase their health care costs and might result in institutionalization.

Because of demographic trends and policy changes, the demand for informal caregivers for people with dementia may increase. Recent policy changes reduced Medicare payments to home health service providers by 3.5% per year from 2014 to 2017.<sup>10,11</sup> This change was part of the Centers for Medicare and Medicaid Services' rebasing efforts that updated Medicare's home health services prospective payment system to reflect the most current data on costs and use of services and the impacts of care provided on patient outcomes.<sup>10,11</sup> A reduction in home health service provision for vulnerable patients with complex conditions could shift their care from formal to informal caregiving. Golberstein et al. found that reductions in Medicare home health care payments are followed by subsequent increases in the number of

**TABLE 3—Characteristics of the Care Dementia Caregivers Provided: 2015–2016 Behavioral Risk Factor Surveillance System Caregiver Module, 38 States, District of Columbia, and Puerto Rico**

Characteristics	Dementia Caregivers (n = 4645), <sup>a</sup> Weighted % (95% CI) <sup>b</sup>
<b>Person receiving care</b>	
Parent/parent-in-law	49.1 (45.3, 53.0)
Spouse/partner <sup>c</sup>	12.2 (9.7, 15.3)
Other relative <sup>d</sup>	27.4 (23.9, 32.1)
Nonrelative	11.3 (8.5, 14.8)
<b>No. h providing care per wk</b>	
0–8	55.6 (51.8, 59.4)
9–19	13.1 (11.0, 15.6)
20–39	10.7 (8.8, 13.0)
≥ 40	20.6 (17.9, 23.6)
<b>Length of time as caregiver</b>	
< 30 d	14.3 (9.1, 21.7)
1 mo to < 6 mo	10.1 (8.0, 12.6)
6 mo to < 2 y	22.5 (19.6, 25.6)
2 y to < 5 y	28.6 (23.9, 33.7)
≥ 5 y	24.6 (21.5, 28.0)
<b>Type of care provided</b>	
Household tasks only <sup>e</sup>	23.0 (20.2, 26.0)
Personal care only <sup>f</sup>	7.6 (6.1, 9.4)
Both <sup>g</sup>	56.1 (50.3, 61.7)
Neither <sup>h</sup>	13.3 (8.4, 20.6)

Note. CI = confidence interval. The 38 states are AL, AZ, AR, CA, CO, CT, FL, GA, HI, ID, IL, IN, IA, KY, LA, ME, MD, MN, MS, MO, MT, NE, NV, NJ, NY, ND, OH, OR, PA, SC, SD, TN, TX, UT, VA, WV, WI, and WY.

<sup>a</sup>Unweighted sample size was not design adjusted.

<sup>b</sup>Design-adjusted percentages and CIs.

<sup>c</sup>Husband, wife, or same-sex partner.

<sup>d</sup>Child, sibling or sibling-in-law, grandparents, grandchild, or others not listed.

<sup>e</sup>Household tasks such as cleaning, managing money, or preparing meals.

<sup>f</sup>Personal care such as giving medications, feeding, dressing, or bathing.

<sup>g</sup>Household tasks and personal care.

<sup>h</sup>Other activities not identified.

beneficiaries relying on informal care, particularly those with lower incomes.<sup>26</sup>

Most informal dementia caregivers in our study had at least 1 chronic health condition, and more than half were women. In general older women (aged 65 years and older) are more likely than are men to have chronic health conditions—with heart disease as their leading cause of death—and limitations in daily living activities.<sup>27,28</sup> Previous research has shown that female informal caregivers provide care for longer periods and provide more personal care than do male informal caregivers.<sup>21,24,29</sup> In the final stages of the disease, people with dementia require more intense and constant care—whether they are cared for by family members and friends or

formal caregivers either at home or in a residential facility.<sup>9,23,30</sup> The increased intensity of the care provided can negatively affect the health status of informal dementia caregivers and lead to increased personal health care costs—particularly for older female caregivers.<sup>30,31</sup> Furthermore, caregivers in poor health may have more difficulty tending to the needs of care recipients<sup>31</sup> and may even need to stop providing care to manage their own health.<sup>32</sup>

### Contributions to the Literature

Our results are consistent with those of previous studies<sup>3,17,19,20</sup> that used a replacement cost method to estimate the cost of informal dementia caregiving. These studies

used the average hourly wage of home health aides,<sup>17,20</sup> the average hourly wage of maids and housekeeping cleaners,<sup>19</sup> or the average hourly wage of home health aides and federal minimum wage<sup>3</sup> to substitute for the hourly cost of dementia caregiving. By contrast, we used a large survey of people residing in 38 states, the District of Columbia, and Puerto Rico, which allowed us to use accessible methods with population-based data from the same period to estimate the hourly cost of dementia caregiving.

Occupational wages are not normally distributed across states, thus the median is a more appropriate measure of centrality than is the average.<sup>33</sup> In our cost replacement approach, we used median hourly wages from each state, the District of Columbia, and Puerto Rico instead of the composite average hourly wages that previous studies used. In addition, instead of taking the average of the cost replacements, we applied state-based weighted percentages of each type of care provided to the appropriate cost substitute. These approaches allowed us to obtain state-level estimates of the value of informal dementia caregiving.

### Limitations

All BRFSS data were self-reported by caregivers; care recipients were not surveyed. Informal caregivers may not have self-identified as caregivers, resulting in an underestimate in the number of caregivers. Additionally, informal caregivers likely do not keep formal records of the hours of care they provide, and so the estimates we report are approximations of the time and therefore value of this care. The survey also collected limited information about care recipients and did not include age, sex, residence (e.g., whether they lived alone, with their informal caregivers, in a long-term care facility), or a complete picture of their caregiving arrangement (e.g., whether they also had formal caregivers and whether they had more than 1 informal caregiver). Our estimates assume that informal caregivers provided care to 1 care recipient. Providing informal caregiving to multiple care recipients is not a response option in the survey. This means that the estimated value of informal caregiving per caregiver might be underestimated. Similarly,

**TABLE 4—Estimated Number of Informal Dementia Caregivers, Caregiving Hours, and Their Economic Values: 2015–2016 Behavioral Risk Factor Surveillance System Caregiver Module, 38 States, District of Columbia, and Puerto Rico**

State	Informal Caregivers <sup>a</sup>	Annual Informal Caregiving Hours		Value of Informal Caregiving per Hour <sup>d</sup> , \$	Annual Value of Informal Caregiving, \$	
		Total <sup>b</sup>	Per Caregiver <sup>c</sup>		Total <sup>e</sup>	Per Caregiver <sup>f</sup>
AL	72 954	79 387 426	1 088	8.76	695 351 285	9 531
AZ	88 814	172 935 817	1 947	10.09	1 744 308 471	19 640
AR	31 719	47 472 348	1 497	8.94	424 307 843	13 377
CA	393 320	309 816 302	788	11.11	3 443 366 542	8 755
CO	53 923	62 514 920	1 159	10.93	683 564 396	12 677
CT	53 923	59 099 663	1 096	11.49	678 765 239	12 588
DC	6 344	6 638 855	1 047	14.99	99 495 853	15 684
FL	171 284	221 787 892	1 295	10.22	2 265 989 147	13 229
GA	72 954	93 966 351	1 288	9.34	877 485 032	12 028
HI	22 204	34 266 305	1 543	14.55	498 730 302	22 462
ID	12 688	14 637 149	1 154	9.51	139 147 326	10 967
IL	133 221	167 576 241	1 258	10.74	1 800 103 977	13 512
IN	69 783	88 759 592	1 272	9.86	874 728 439	12 535
IA	25 375	20 872 230	823	10.24	213 666 509	8 420
KY	50 751	89 868 816	1 771	9.90	889 811 822	17 533
LA	69 783	108 303 720	1 552	8.88	962 161 588	13 788
ME	22 204	23 352 605	1 052	10.32	241 070 806	10 857
MD	72 954	83 465 579	1 144	11.12	928 013 711	12 720
MN	60 267	54 701 689	908	11.34	620 064 435	10 289
MS	47 579	82 297 471	1 730	9.13	751 370 557	15 792
MO	66 611	100 228 811	1 505	9.93	995 622 896	14 947
MT	6 344	9 220 338	1 453	10.53	97 117 825	15 309
NE	22 204	18 678 274	841	10.14	189 443 083	8 532
NV	15 860	25 715 460	1 621	13.23	340 325 980	21 459
NJ	101 502	142 540 253	1 404	10.86	1 547 831 782	15 249
NY	266 442	369 277 349	1 386	11.87	4 381 483 136	16 444
ND	6 344	9 522 015	1 501	12.60	119 978 145	18 912
OH	196 660	251 168 412	1 277	9.74	2 445 312 863	12 434
OR	41 235	54 121 346	1 313	11.09	600 303 689	14 558
PA	168 112	208 868 928	1 242	10.39	2 170 475 039	12 911
SC	63 439	94 853 978	1 495	9.25	877 593 746	13 834
SD	6 344	5 946 435	937	10.39	61 775 725	9 738
TN	111 018	178 071 404	1 604	9.46	1 684 779 853	15 176
TX	317 193	382 117 637	1 205	8.88	3 392 337 208	10 695
UT	25 375	39 444 529	1 554	10.34	407 723 501	16 068
VA	79 298	128 065 983	1 615	10.06	1 287 840 489	16 240
WV	34 891	59 170 340	1 696	9.27	548 797 503	15 729
WI	63 439	65 578 690	1 034	10.39	681 514 732	10 743
WY	6 344	8 154 163	1 285	10.95	89 305 780	14 078

*Continued*

TABLE 4—Continued

State	Informal Caregivers <sup>a</sup>	Annual Informal Caregiving Hours		Value of Informal Caregiving per Hour <sup>d</sup> , \$	Annual Value of Informal Caregiving, \$	
		Total <sup>b</sup>	Per Caregiver <sup>c</sup>		Total <sup>e</sup>	Per Caregiver <sup>f</sup>
PR	44 407	85 546 551	1 926	8.70	744 643 374	16 769
Total	3 175 104	4 058 011 863	1 278 <sup>g</sup>	. . .	41 495 709 629	13 069 <sup>h</sup>
Median	57 095	80 842 448	1 291	10.28	719 997 329	13 650
Minimum	6 344	5 946 435	788	8.70	61 775 725	8 420
Maximum	393 320	382 117 637	1 947	14.99	4 381 483 136	22 462

Note. The 38 states are AL, AZ, AR, CA, CO, CT, FL, GA, HI, ID, IL, IN, IA, KY, LA, ME, MD, MN, MS, MO, MT, NE, NV, NJ, NY, ND, OH, OR, PA, SC, SD, TN, TX, UT, VA, WV, WI, and WY. Dollars are 2016 US dollars.

<sup>a</sup>Weighted percentage of dementia caregivers multiplied by design-adjusted population size.

<sup>b</sup>Weighted percentage of each category of hours that care was provided per week, for 52 wk multiplied by number of caregivers.

<sup>c</sup>Annual hours divided by number of caregivers.

<sup>d</sup>Weighted percentage of household task, personal care, both, and neither multiplied by their estimated hourly costs, which are on the basis of the hourly wages of housekeepers and maids, home health aides, and state minimum wage.

<sup>e</sup>Annual hours multiplied by value of informal caregiving per hour.

<sup>f</sup>Annual value of informal caregiving divided by number of caregivers.

<sup>g</sup>Average informal caregiving hours per caregiver: total of caregiver hours divided by total caregivers.

<sup>h</sup>Average value of informal caregiving hours per caregiver: total of annual value of informal caregiving divided by total caregivers.

respondents were limited to reporting 1 condition for the care recipient, so it is possible that dementia or cognitive decline was underestimated if caregivers reported another condition.

Another limitation is our focus on the value of the care that informal dementia caregivers reported providing and not on the full economic cost of providing this care. Specifically, previous research has demonstrated that although people who provide care may do so in place of working for wages,<sup>34,35</sup> people who are unemployed or who have low income from wages more frequently become informal caregivers than do people employed full time at higher wages.<sup>36,37</sup> Therefore, the value of informal caregiving we report may overestimate the full economic costs of providing care because some of these caregivers are not forgoing wages to provide this care. Last, intangible costs might also affect the economic value of informal caregiving and the health of these caregivers.

## Public Health Implications

Informal dementia caregiving is an important public health issue. Overall, we valued the informal dementia caregiving in 38 states, the District of Columbia, and Puerto Rico at \$41.5 billion, with an average of \$13 069 per caregiver, which represents an

indirect cost of dementia. Without the efforts of informal caregivers, many people would either not receive needed care or would have to pay for that support. Local and state public health departments might identify and provide evidence-based caregiver support services to promote good mental and physical health while providing informal care. Policymakers and government agencies may want to consider the impact of Medicare funding cuts or changes on the demand for and burden on informal caregivers and people with long-term care needs in the community.

From a data use perspective, our study shows that public health professionals can use population estimates from surveillance data to estimate the contributions of informal caregivers and the economic value of the care they provide. Health policy planners can use this information to assess state needs, including physical, mental, and social supports, for informal caregivers as well as needed links between clinical and community systems to address the needs of both patients and their caregivers. Furthermore, the methods we used could be used to estimate the direct cost economic value of informal caregiving for other health conditions. *AJPH*

## CONTRIBUTORS

K. M. Rabarison and E. D. Bouldin initiated and designed the study, performed the statistical analysis, and

interpreted the data. C. L. Bish, L. C. McGuire, C. A. Taylor, and K. J. Greenlund provided input to and approved the study design and interpreted data findings and results. All authors provided substantive suggestions, drafted and revised the article, and gave final approval for the article.

## HUMAN PARTICIPANT PROTECTION

Human participant protection was not required because this study uses secondary publicly available data.

## REFERENCES

- Wilson RS, Segawa E, Boyle PA, Anagnos SE, Hibel LP, Bennett DA. The natural history of cognitive decline in Alzheimer's disease. *Psychol Aging*. 2012;27(4):1008–1017.
- Hebert LE, Weuve J, Scherr PA, Evans DA. Alzheimer disease in the United States (2010–2050) estimated using the 2010 census. *Neurology*. 2013;80(19):1778–1783.
- Alzheimer's Association. 2018 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2018;14(3):367–429.
- Heron M. Deaths: leading causes for 2014. *Natl Vital Stat Rep*. 2016;65(5):1–96.
- Beck C, Ortigara A, Mercer S, Shue V. Enabling and empowering certified nursing assistants for quality dementia care. *Int J Geriatr Psychiatry*. 1999;14(3):197–211; discussion 211–212.
- McCabe MP, Davison TE, George K. Effectiveness of staff training programs for behavioral problems among older people with dementia. *Aging Ment Health*. 2007;11(5):505–519.
- Nguyen M, Pachana NA, Beattie E, Fielding E, Ramis MA. Effectiveness of interventions to improve family-staff relationships in the care of people with dementia in residential aged care: a systematic review protocol. *JBI Database Syst Rev Implement Rep*. 2015;13(11):52–63.
- Talley RC, Crews JE. Framing the public health of caregiving. *Am J Public Health*. 2007;97(2):224–228.



9. Zhu CW, Torgan R, Scarmeas N, et al. Home health and informal care utilization and costs over time in Alzheimer's disease. *Home Health Care Serv Q*. 2008;27(1):1–20.
10. Office of the Federal Register. Medicare and Medicaid programs; home health prospective payment system rate update for CY 2014, home health quality reporting requirements, and cost allocation of home health survey expenses. 2013. Available at: <https://www.federalregister.gov/documents/2013/12/02/2013-28457/medicare-and-medicaid-programs-home-health-prospective-payment-system-rate-update-for-cy-2014-home>. Accessed April 2, 2018.
11. Office of the Federal Register. Medicare and Medicaid Programs; CY 2017 home health prospective payment system rate update; home health value-based purchasing model; and home health quality reporting requirements. 2016. Available at: <https://www.federalregister.gov/documents/2016/11/03/2016-26290/medicare-and-medicaid-programs-cy-2017-home-health-prospective-payment-system-rate-update-home>. Accessed April 2, 2018.
12. Mokdad AH. The Behavioral Risk Factors Surveillance System: past, present, and future. *Annu Rev Public Health*. 2009;30:43–54.
13. Centers for Disease Control and Prevention. Behavioral Risk Factor Surveillance System (BRFSS) caregiver module. 2018. Available at: <https://www.cdc.gov/aging/healthybrain/brfss-faq-caregiver.htm>. Accessed April 2, 2018.
14. Centers for Disease Control and Prevention. BRFSS questionnaires. 2018. Available at: <https://www.cdc.gov/brfss/questionnaires/index.htm>. Accessed April 2, 2018.
15. US Department of Labor. May 2015 state occupational employment and wage estimates. Available at: <https://www.bls.gov/oes/2015/may/oessrcst.htm>. Accessed April 2, 2018.
16. US Department of Labor. Changes in basic minimum wages in non-farm employment under state law: selected years 1968 to 2017. Available at: <https://www.dol.gov/whd/state/stateMinWageHis.htm>. Accessed April 2, 2018.
17. Rhee Y, Degenholtz HB, Lo Sasso AT, Emanuel LL. Estimating the quantity and economic value of family caregiving for community-dwelling older persons in the last year of life. *J Am Geriatr Soc*. 2009;57(9):1654–1659.
18. Langa KM, Chernew ME, Kabeto MU, et al. National estimates of the quantity and cost of informal caregiving for the elderly with dementia. *J Gen Intern Med*. 2001;16(11):770–778.
19. Harrow BS, Mahoney DF, Mendelsohn AB, et al. Variation in cost of informal caregiving and formal-service use for people with Alzheimer's disease. *Am J Alzheimers Dis Other Dement*. 2004;19(5):299–308.
20. Hurd MD, Martorell P, Delavande A, Mullen KJ, Langa KM. Monetary costs of dementia in the United States. *N Engl J Med*. 2013;368(14):1326–1334.
21. Navaie-Waliser M, Spriggs A, Feldman PH. Informal caregiving: differential experiences by gender. *Med Care*. 2002;40(12):1249–1259.
22. McCann JJ, Hebert LE, Beckett LA, Morris MC, Scherr PA, Evans DA. Comparison of informal caregiving by Black and White older adults in a community population. *J Am Geriatr Soc*. 2000;48(12):1612–1617.
23. Zhu CW, Scarmeas N, Torgan R, et al. Clinical characteristics and longitudinal changes of informal cost of Alzheimer's disease in the community. *J Am Geriatr Soc*. 2006;54(10):1596–1602.
24. Anderson LA, Edwards VJ, Pearson WS, Talley RC, McGuire LC, Andresen EM. Adult caregivers in the United States: characteristics and differences in well-being, by caregiver age and caregiving status. *Prev Chronic Dis*. 2013;10:E135.
25. Schulz R, Martire LM. Family caregiving of persons with dementia: prevalence, health effects, and support strategies. *Am J Geriatr Psychiatry*. 2004;12(3):240–249.
26. Golberstein E, Grabowski DC, Langa KM, Chernew ME. The effect of Medicare home health care payment on informal care. *Inquiry*. 2009;46(1):58–71.
27. Centers for Disease Control and Prevention. Leading causes of death in females, 2014. 2017. Available at: <https://www.cdc.gov/women/lcod/2014/race-ethnicity/index.htm>. Accessed April 2, 2018.
28. Crescioni M, Gorina Y, Bilheimer L, Gillum RF. Trends in health status and health care use among older men. *Natl Health Stat Rep*. 2010;(24):1–18.
29. Pinquart M, Sörensen S. Gender differences in caregiver stressors, social resources, and health: an updated meta-analysis. *J Gerontol B Psychol Sci Soc Sci*. 2006;61(1):33–45.
30. Zhu CW, Leibman C, McLaughlin T, et al. The effects of patient function and dependence on costs of care in Alzheimer's disease. *J Am Geriatr Soc*. 2008;56(8):1497–1503.
31. Thorpe JM, Thorpe CT, Schulz R, Van Houtven CH, Schleiden L. Informal caregiver disability and access to preventive care in care recipients. *Am J Prev Med*. 2015;49(3):370–379.
32. Afram B, Stephan A, Verbeek H, et al. Reasons for institutionalization of people with dementia: informal caregiver reports from 8 European countries. *J Am Med Dir Assoc*. 2014;15(2):108–116.
33. MacGillivray HL. Mean, median, and mode. 2014. Available at: <https://onlinelibrary.wiley.com/doi/abs/10.1002/9781118445112.stat00622>. Accessed July 23, 2018.
34. Nguyen HT, Connelly LB. The effect of unpaid caregiving intensity on labour force participation: results from a multinomial endogenous treatment model. *Soc Sci Med*. 1982;100:115–122.
35. Van Houtven CH, Coe NB, Skira MM. The effect of informal care on work and wages. *J Health Econ*. 2013;32(1):240–252.
36. Heitmueller A. The chicken or the egg? Endogeneity in labour market participation of informal carers in England. *J Health Econ*. 2007;26(3):536–559.
37. Carmichael F, Charles S, Hulme C. Who will care? Employment participation and willingness to supply informal care. *J Health Econ*. 2010;29(1):182–190.