



## Addressing the Costs of Informal Caregiving in the United States

- Estimates suggest that, without intervention or policy change, the prevalence of cardiovascular disease (CVD) will rise dramatically in the coming decades.<sup>1</sup>
- In addition to creating greater strain on our health system, this projected increase in CVD prevalence will impose greater demands on informal caregivers. Yet while older populations grow—by 2030 more than 1 in 5 US residents will be 65 or older<sup>2</sup>—the informal caregiver pool is shrinking. As more adults divorce or never marry and as people have fewer children now than in previous generations, there are fewer spouses and children, traditional sources of informal caregiving.<sup>2</sup>
- Caregivers come from all generations, income and educational levels, family types, sexual orientations, gender identities, and racial/ethnic groups. In fact, 61 percent of caregivers are non-Hispanic White, 17 percent are Hispanic or Latino, 14 percent Black, 5 percent Asian American and Pacific Islander, and 3 percent multiracial or other race/ethnicity.<sup>3</sup>
- Caregivers for those with CVD and other chronic diseases are at risk for their own deteriorating health and burnout from the prolonged distress, physical demands, and economic costs of caregiving.<sup>4</sup>
- The burden of informal caregiving for both patients with CVD and their caregivers is significant and can vary by racial and ethnic groups. For example, African-American caregivers provide on average 31.2 hours of care per week while Hispanic caregivers provide 26 hours each week, Asian-American caregivers 24.1, and White caregivers 21.2.<sup>3</sup>
- In 2020, 24 percent of people caring for adults cared for more than one person, compared with 18 percent in 2015.<sup>3</sup> Caregivers in a rural area provide care for more than one person more often than caregivers who live in a suburban or urban area.<sup>3</sup>
- Caregivers with lower income are more often in high-intensity caregiving situations than caregivers whose household income is at least \$50,000. The same is true for caregivers with less than a college degree compared to those who have at least a bachelor's degree.<sup>3</sup>
- Nearly half (47%) of caregivers have an annual household income below \$50,000, with a median income of \$54,700.<sup>5</sup> More than 60% of African-American and Hispanic caregivers report an annual household income less than \$50,000 compared to 42% of whites and 30% of Asians.<sup>5</sup>
- The economic value of activities forgone, as a result of caregiving, such as lost wages, is estimated at \$522 billion annually, while the costs of replacing this care by unskilled and skilled paid care are \$221 billion and \$642 billion, respectively.<sup>6</sup>
- Caregivers with a household income of less than \$50,000 are more likely to experience financial impacts from caregiving than caregivers whose income is at least \$50,000.<sup>3</sup>
- Caregivers of rural residents have a more difficult time finding affordable services compared to caregivers of suburban or urban residents, so caregivers of rural residents may be filling in for unobtainable services.<sup>3</sup> Nearly a third of care recipients live in a rural area.<sup>3</sup>



## Policy At-A-Glance: Informal Caregiving

A variety of federal and state legislative proposals have emerged in recent years to mitigate challenges confronted by caregivers and to help address support-system shortfalls.

**The American Heart Association supports policy initiatives that address caregivers' needs such as strong family and medical leave policies, appropriations for training and support programs, increased access to palliative care, the development of a national caregiving strategy, consideration of caregivers in payment and delivery systems of care, and tax credits.**

For more information and resources from the American Heart Association's policy research department on stroke registries please visit: <https://www.heart.org/en/about-us/policy-research>.

### Fast Facts:

1. In a 2018 report, AHA estimated that medical costs and productivity losses of cardiovascular disease (CVD) are expected to grow from \$555 billion in 2015 to \$1.1 trillion in 2035.<sup>7</sup> Although this burden is significant, the estimate does not include the costs of informal or unpaid caregiving provided to patients with CVD.
2. The costs of informal caregiving for patients with CVD were estimated to be \$61 billion in 2015 and are projected to increase to \$128 billion in 2035.<sup>7</sup> Accounting for these costs increases total CVD costs by 11% to \$616 billion in 2015 and \$1.2 trillion in 2035.<sup>7</sup>
3. Costs of informal caregiving to stroke patients constitute more than half of the total costs of CVD informal caregiving (\$31 billion in 2015 and \$66 billion in 2035). At the per person level, the burden of informal caregiving of CVD is the greatest among Blacks and persons ages 80 years or older.<sup>7</sup>

For more information and resources from the American Heart Association's policy research department, please visit [www.heart.org/en/about-us/policy-research](http://www.heart.org/en/about-us/policy-research).

### References

- <sup>1</sup> Khavjou, O., Phelps, D., Leib, A. Projections of cardiovascular disease prevalence and costs: 2015-35. RTI International. November 2016. Accessed online October 16, 2020 at <https://healthmetrics.heart.org/wp-content/uploads/2017/10/Projections-of-Cardiovascular-Disease.pdf>
- <sup>2</sup> National Academies of Sciences, Engineering, and Medicine. *Families caring for an aging America*. National Academies Press, 2016. <https://doi.org/10.17226/23606>.
- <sup>3</sup> *Caregiving in the U.S. 2020 - AARP Research Report* AARP and National Alliance for Caregiving. *Caregiving in the United States 2020*. Washington, DC: AARP. May 2020. <https://doi.org/10.26419/ppi.00103.001>.
- <sup>4</sup> Schulz R, Sherwood PR. Physical and mental health effects of family caregiving. *Journal of Social Work Education*. 2008 Sep 1;44(sup3):105-13.
- <sup>5</sup> *Caregiving in the U.S. 2015 - AARP Research Report* AARP and National Alliance for Caregiving. *Caregiving in the United States 2015*. Washington, DC: AARP. June 2015.
- <sup>6</sup> Chari AV, Engberg J, Ray KN, Mehrotra A. The opportunity costs of informal elder-care in the United States: new estimates from the American Time Use Survey. *Health Serv Res*. 2015;50:871-882
- <sup>7</sup> Dunbar SB, Khavjou OA, Bakas T, Hunt G, Kirch RA, Leib AR, Morrison RS, Poehler DC, Roger VL, Whitsel LP; on behalf of the American Heart Association. Projected costs of informal caregiving for cardiovascular disease: 2015 to 2035: a policy statement from the American Heart Association. *Circulation*. 2018;137:e558-e577. DOI: 10.1161/CIR.0000000000000570.