



PROJECTED COSTS OF INFORMAL CAREGIVING FOR CARDIOVASCULAR DISEASE: 2015-2035

3 THINGS TO KNOW

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In a recent 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. Although this burden is significant, the estimate does not include the costs of family, informal or unpaid caregiving provided to patients with CVD.

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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. Accounting for these costs increases total CVD costs by 11% to \$616 billion in 2015 and \$1.2 trillion in 2035. 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.

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The burden of informal caregiving for both patients with CVD and their caregivers is significant. A variety of federal and state legislative proposals have emerged in recent years to mitigate challenges confronted by caregivers and help address support system shortfalls including medical leave insurance benefits, training and support services programs, and tax credits but much more needs to be done.

With the aging of the U.S. population, caregiving requirements are expected to markedly escalate by 2035. In the United States, over 65 million people currently provide care for a chronically ill, disabled or aged family member. Older individuals are known to prefer to stay in their homes and community rather than in a nursing home; they also prefer to receive care from a family member rather than from a home health aide. This report¹ estimates the costs of informal caregiving for patients with CVD in order to inform policy development in support of this important component of care for aging individuals.

“... the projected dramatic rise in CVD prevalence and costs between now and 2035 portends increased strain on health system capacity and demands imposed on informal caregivers at the same time the caregiver pool is shrinking. These circumstances place CVD caregivers at risk for their own health deterioration and burnout from the prolonged distress, physical demands, and costs of caregiving.”

Informal caregivers are most often family members or other relations, partners, neighbors, and friends who may or may not live in the same household and provide care without paid compensation. The term “informal” is frequently used to distinguish these unpaid caregivers from paid professional caregivers who provide formal home or community-based care or institutionalized care, but this type of caregiving is not informal or simple. The care provided may be episodic, daily, occasional, and of short or long duration. Responsibilities range from helping with household tasks or self-care activities to handling coordination of multiple medical appointments and complex medical regimens once only delivered by licensed health care personnel in a clinical





setting. Often, informal caregivers must undertake these activities without needed information and training. Although some report positive aspects of this role, caregiving responsibilities are also associated with distressing physical, emotional, and economic effects that strain health, financial security, and wellbeing. These burdens are particularly evident among caregivers who provide higher-intensity assistance with health care activities that involve more supervision and longer hours of care. The economic value of activities forgone, as a result of caregiving, such as lost wages, has been 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. As caregivers experience substantial stress and personally endure large social, economic and health care costs, studying how caregiving costs augment the burden of heart disease and stroke is of direct and central relevance to the assessment of CVD's impact.

Informal caregivers play an essential part in maintaining the health and wellbeing of individuals coping with serious illness like CVD, and caregiving has become a critical issue of public policy. Proposed policy solutions include paid family medical leave, tax credits, technical assistance, training and support services, and community-based demonstration programs funded through insurance plans that provide long term care services. State and local governments may provide programs



and services supported by appropriations including assistance in finding programs and services, respite care for caregivers, and supplemental services such as a personal emergency response system, assistive technology, home-delivered meals, transportation, or home modifications.

Such policy proposals offer important initial steps in raising the profile of informal caregivers and recognizing their integral supporting role in the care delivery process. Within this context, the estimated projections of CVD for caregiving costs will provide data upon which a more cohesive and comprehensive set of health reform policies and practices can be designed to meet the specific CVD care needs, minimize the burdens experienced by informal caregivers, and address the total economic impact of CVD.

Projected Costs of Informal Caregiving Attributable to CVD (2015 \$ billions)

Year	Total CVD	Hypertension	Coronary Heart Disease	Heart Failure	Stroke	Other Heart Disease
2015	60.7	14.4	1.0	6.5	30.5	8.3
2020	74.0	17.6	1.3	7.9	37.2	10.0
2025	90.0	21.3	1.5	9.6	45.5	12.1
2030	108.7	25.2	1.7	11.6	55.5	14.7
2035	128.3	29.2	1.9	13.5	66.3	17.4
% change from 2015 to 2035	111%	103%	84%	107%	117%	110%

Methodology

- We used data from the 2014 Health and Retirement Survey to estimate hours of informal caregiving due to CVD by age/sex/race using a zero-inflated binomial model and controlled for sociodemographic factors and health conditions.
- Costs of informal caregiving were estimated separately for hypertension, coronary heart disease, heart failure, stroke, and other heart disease.
- We analyzed data from a nationally-representative sample of 16,731 non-institutionalized adults aged 54 or older.
- The value of caregiving hours was monetized using home health aide worker's wages.
- The per person costs were multiplied by Census population counts to estimate national-level costs, and to be consistent with other AHA analyses of burden of CVD, the costs were projected from 2015 through 2035, assuming that within each age/sex/race group, CVD prevalence and caregiving hours remain constant.

¹Dunbar, SB., Khavjou, O. Bakas, T., Hunt, G., Kirch, R., Leib, A., Morrison, RS., Poehler, D., Roger, VL., Whitsel, LP. Projected costs of informal caregiving for cardiovascular disease: 2015-2035. *Circulation*. March 2018.