Circulation

AHA POLICY STATEMENT

Projected Costs of Informal Caregiving for Cardiovascular Disease: 2015 to 2035

A Policy Statement From the American Heart Association

INTRODUCTION: In a recent report, the American Heart Association 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 the burden is significant, the estimate does not include the costs of family, informal, or unpaid caregiving provided to patients with CVD. In this analysis, we estimated projections of costs of informal caregiving attributable to CVD for 2015 to 2035.

METHODS: We used data from the 2014 Health and Retirement Survey to estimate hours of informal caregiving for individuals with CVD by age/sex/race using a zero-inflated binomial model and controlling 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 noninstitutionalized adults ≥54 years of age. The value of caregiving hours was monetized by the use of home health aide workers' wages. The per-person costs were multiplied by census population counts to estimate nation-level costs and to be consistent with other American Heart Association analyses of burden of CVD, and the costs were projected from 2015 through 2035, assuming that within each age/sex/racial group, CVD prevalence and caregiving hours remain constant.

RESULTS: 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. Costs of informal caregiving of patients with stroke constitute more than half of the total costs of CVD informal caregiving ($31 billion in 2015 and $66 billion in 2035). By age, costs are the highest among those 65 to 79 years of age in 2015 but are expected to be surpassed by costs among those ≥80 years of age by 2035. Costs of informal caregiving for patients with CVD represent an additional 11% of medical and productivity costs attributable to CVD.

CONCLUSIONS: The burden of informal caregiving for patients with CVD is significant; accounting for these costs increases total CVD costs to $616 billion in 2015 and $1.2 trillion in 2035. These estimates have important research and policy implications, and they may be used to guide policy development to reduce the burden of CVD on patients and their caregivers.

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Understanding trends in the escalating costs of cardiovascular disease (CVD) is important to develop informed policy that ultimately reduces the economic impact of CVD on health care and society. A recent analysis by the American Heart Association suggests that total direct (medical) and indirect (lost productivity) costs of CVD, the most costly of all chronic diseases, are expected to grow from $555 billion in 2015 to $1.1 trillion in 2035.[1] Although this 20-year projected growth is significant, the estimate does not include the costs associated with informal caregiving provided to patients with CVD. To provide a more complete representation of CVD costs, this analysis of projected costs of informal caregiving for individuals with CVD for 2015 to 2035 was undertaken to determine the influence of CVD caregiving on incremental costs of CVD to inform relevant policy recommendations.

In the United States, >65 million people currently provide care for a chronically ill, disabled, or aged family member.[2] Informal caregivers are most often family members such as spouses, adult children or other relatives, partners, neighbors, and friends or multiple caregivers who may or may not live in the same household and provide care in an unremunerated status. 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. Informal caregiving is defined as home care that is provided without payment by family members or friends of the care recipient.

We acknowledge that despite the term *informal*, this type of caregiving is not informal or simple. Informal caregivers who provide care for loved ones with chronic illness such as CVD are essential, and the protracted stress and toll on their quality of life and health status have been well documented.[3,4] The total opportunity cost of unpaid elder care, that is, the economic value of activities forgone as a result of caregiving such as lost wages, has been estimated at $522 billion annually, whereas the costs of replacing this care by unskilled and skilled paid care are $221 billion and $642 billion, respectively.[5] A recent review of family caregiver website conversations by the Coalition to Transform Advanced Care confirmed the stresses of informal caregiving by family members who reported issues such as a compromised career (>50%), inability to work (48%), deprioritization of work (33%), and negative impact on their disposable income and financial health (94%).[6] Although traditionally more women have served as caregivers than men, women's greater and longer participation in the workforce has resulted in a smaller pool of women readily available to assume caregiving roles,[7,8] and men currently represent ≈40% of informal caregivers.[9] Informal caregiving of elders and those with chronic conditions is a significant and costly phenomenon in the United States; a greater understanding of the magnitude of the burden of informal caregiving for patients with CVD and its projected growth is essential.

FACTORS INFLUENCING COST

Informal caregivers play an essential part in maintaining the health and well-being of individuals coping with serious illness like CVD. The care they provide may be episodic, daily, occasional, and of short or long duration. Responsibilities of caregiving are also varied, ranging from helping with household tasks or self-care activities to handling coordination of multiple medical appointments and complex medical regimens that were once delivered only by licensed healthcare personnel in a hospital or other settings.[10–13] Often, informal caregivers must undertake these activities without needed information and training.[12] 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 well-being.[3,14–16] These burdens are particularly evident among caregivers who provide higher-intensity assistance with healthcare activities that involve more supervision and longer hours of care.[3,14]

More than half of informal caregivers hold jobs, and the "invisible work" of providing healthcare services that is not compensated often requires making workplace accommodations that have been associated with productivity loss.[12,14] Informal caregivers provide almost $470 billion in unpaid care, with an additional average of $7000/y in out-of-pocket costs for home modifications, transportation, reduced worktime, unpaid leave, and reduced savings.[17] Previous studies have gleaned some insights by estimating informal caregiving costs and economic burden associated with heart failure[18] and stroke.[19] One study of patients with end-stage congestive heart failure found that 23% of families had lost all or most of their savings by the time the patient died.[20] A recent *Families Caring for an Aging America* report from the National Academy of Sciences Engineering and Medicine (NASEM)[12] identified a number of factors that can place caregivers at financial risk. They may lose income, Social Security or other retirement benefits, and career opportunities when they cut back on work hours or stop working. They may also incur substantial out-of-pocket expenses that draw from the caregivers' savings and undermine their own future financial security. The report also detailed other factors associated with financial harm, including coresidence or residing a long distance from the individual needing care; lack of other family members to share responsibilities and costs; and, if employed, limited access to paid leave or a flexible workplace.

The impact of informal caregiving on employers includes the replacement costs for employees who must leave their job because of caregiving duties, costs of absenteeism and workday interruptions, and management and administrative costs based on the time supervisors spend handling issues of employed caregivers. The NASEM report[12] highlighted the existence of some workplace programs for caregiving employees and the anecdotal evidence suggesting their value in supporting caregivers and retaining workers. The NASEM report explicitly called out the need for additional data and research assessing the costs and outcomes of workplace programs for employers and the extent to which they help working caregivers juggle their caregiving and job responsibilities.

CURRENT POLICIES AFFECTING INFORMAL CAREGIVING FOR CVD

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. These initiatives are important because Medicare and Medicaid programs generally have not focused on providing direct caregiver services and supports other than Medicaid's home- and community-based services waiver, which gives states an option to cover respite care and caregiver education and training.[12] Proposals pending in the current Congressional session seek to reinforce the importance of informal caregiving and to reduce burdens by creating medical leave insurance benefits, training and support services programs, and tax credits, including, for example, the following:

- The Family and Medical Insurance Leave Act establishes an Office of Paid Family and Medical Leave within the Social Security Administration and creates a "family and medical leave insurance" benefit payment for individuals providing caregiving services who meet qualifying criteria.[21]
- The Community-Based Independence for Seniors Act establishes Community-Based Institutional Special Needs demonstration programs with select Medicare Advantage plans for providing long-term care services benefits involving homemaker services, meal delivery, transportation, respite care, adult day care, and safety or other equipment.[22]
- The Credit for Caring Act of 2017 establishes a tax credit of up to $3000 annually for working family caregivers. The eligible caregiver must have incurred expenses caring for a qualified recipient and have earned income of at least $7500 for the year. A qualified recipient is defined as someone who bears a relationship to the caregiver and has been certified as having long-term needs.[23]
- The Recognize, Assist, Include, Support, and Engage Family Caregivers Act directs the Department of Health and Human Services secretary to develop, maintain, and periodically update a National Family Caregiving Strategy that includes information on palliative care, care planning, financial security, etc. Public input is required in the development of the strategy.[24] The Recognize, Assist, Include, Support, and Engage Family Caregivers Act was signed into law on January 23, 2018.
- The Americans Giving Care to Elders Act provides financial relief to family caregivers by creating a tax credit for the costs of caring for an aging or ailing relative. The legislation would help offset elder care expenses of up to $6000/y that include medical care, lodging away from home, adult day care, custodial care, respite care, assistive technologies and devices, environmental modifications, and counseling or training for a caregiver.[25]
- Federal tax benefits amend the Internal Revenue Code by providing tax credits on expenses incurred for caregiving services necessary for maintaining employment, which may include obtaining household services, respite care, or other needed assistance.[26]
- The Caregiver Advise, Record, Enable Act enacted by >30 states assists family caregivers as their loved ones go into the hospital and as they transition home, transitions that often are stressful times in the CVD experience for caregivers.[11,27–29] The Caregiver Advise, Record, Enable Act elevates the prominence of informal caregivers and their critical role as partners in care delivery by requiring hospitals to be accountable for (1) recording the name of the family caregiver(s) in the patient's medical record, (2) informing the family caregivers when the patient is to be discharged, and (3) providing the family caregiver with education and instruction in the medical tasks he or she will need to perform for the patient at home.[30]
- The Alzheimer's Caregiver Support Act authorizes grant programs expanding caregiver training and support services for families and caregivers of individuals living with Alzheimer disease or related dementia.[31]

State and local governments may provide a number of programs and services that are supported by appropriations or implemented with legislation and regulation. These include assistance in gaining access to programs and services, respite care to temporarily relieve caregivers from their responsibilities, and supplemental services such as a personal emergency response system, assistive technology, home-delivered meals, transportation, or home modifications. These kinds of support can be impactful and essential.

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 on which a more cohesive and comprehensive set of health reform policies and practices can be designed to meet the specific CVD care needs, to minimize the burdens experienced by informal caregivers, and to address the total economic impact of CVD.

METHODS

Overview

Estimated baseline and projected costs of informal caregiving for patients with CVD were generated with the methods detailed below. We used data from the 2014 wave of the HRS (Health and Retirement Study) to estimate baseline costs of informal caregiving for CVD. The HRS is a longitudinal project sponsored by the National Institute on Aging and the Social Security Administration that includes nationally representative data on Americans ≥54 years of age. The survey includes information on the respondent's physical and mental health, insurance coverage, financial status, family support systems, labor market status, and retirement planning.

Our analysis sample included 16 731 noninstitutionalized respondents ≥54 years of age with an age range of 54 to 104 years, including 46% men and 32% minority respondents. We defined CVD conditions using responses to the question, "Has a doctor ever told you that you have/had [hypertension, angina, heart attack, congestive heart failure, stroke, abnormal heart rhythm, or other heart problems]?" Thus, the estimates are based on self-reported prevalence of the conditions (questions are listed in Appendix Table A1). We conducted the analyses by age, race/ethnicity, and sex using age groups of 54 to 64, 65 to 79, and ≥80 years. The racial/ethnic groups were white non-Hispanic, white Hispanic, black, and other race/ethnicity. The white Hispanic group included individuals of Hispanic origin who identified themselves to be of white race. We refer to this group as Hispanics. The black group included individuals of Hispanic and non-Hispanic origin. The race/ethnicity definitions are driven by data availability and are consistent with our previous report of projected CVD burden.[1] We used sample weights provided by the HRS to produce nationally representative estimates.

Prevalence of CVD

We estimated the prevalence of each CVD condition using logit regression models controlling for demographics (age, race/ethnicity, and sex), consistent with previous methodology for generating CVD prevalence estimates.[1,32] We predicted prevalence of each condition in each age/race/ethnicity/sex cell for 2014 using coefficients from the logit regressions.

Hours of Informal Caregiving for Patients With CVD

We used an algorithm similar to the one reported by Joo et al[18] to identify respondents who received informal caregiving and to quantify the weekly hours of informal caregiving received. We used a series of questions to identify respondents who reported at least 1 functional limitation in activities of daily living (ADLs) and in instrumental ADLs (IADLs) resulting from a physical, cognitive, or memory problem. The HRS includes 6 items for ADLs—bathing, eating, dressing, walking across a room, using the toilet, and getting in or out of bed—and another 5 tasks for IADLs: preparing a hot meal, shopping for groceries, using a telephone, taking medication, and managing money.

For respondents who reported at least 1 limitation in ADLs or IADLs, we used the question "Does anyone ever help you with [ADL/IADL]?" to identify patients who reported receiving help from a caregiver. For respondents who reported having caregivers, we used the questions on their relationship with each caregiver and payment status to further identify respondents who received care from informal caregivers. Specifically, we identified informal caregivers as caregivers who were family members or volunteers who were not paid for their caregiving.[33,34]

Next, for each informal caregiver, we calculated the weekly number of informal caregiving hours by multiplying the number of days per week by the number of hours per day of caregiving. We set the maximum number of daily hours of caregiving that 1 caregiver provided to 16 hours, assuming 8 hours of sleep.[35–37] For respondents who reported multiple informal caregivers, we summed the weekly hours of caregiving across all informal caregivers per respondent.

We used a zero-inflated binomial model to estimate the weekly number of caregiving hours as a result of CVD as a function of each CVD condition, other costly and prevalent conditions (diabetes mellitus, cancer, arthritis, depression, high cholesterol, lung disease, mental health, and Alzheimer disease), and sociodemographic variables (age, age squared, sex, race/ethnicity, education, region of residence, marital status, and household income determined as total respondent and spouse earnings from all sources). For respondents with comorbid CVD conditions, we included a separate control for each condition. We then predicted the number of caregiving hours attributable to each CVD condition by age/sex/race/ethnicity.

Dollar Value of Informal Caregiving for Patients With CVD

We quantified the monetary value of informal caregiving using a replacement cost approach in which caregiving time is valued by the market value for services performed. This approach assumes that if informal caregivers were not available, a person would need to pay someone for these services.[18,19,34] We used 2015 median wage data for home health aide workers and inflated it by 46% as recommended by Neumann et al[38] to account for fringe benefits.[38–40] We calculated the annual per-person cost of informal caregiving of CVD by age/sex/race/ethnicity as a product of weekly hours of informal caregiving for an individual with CVD by age/sex/race/ethnicity, median hourly wage of health aid workers, and 52 weeks.

Projected Costs

We generated projections of costs of informal caregiving of CVD using an assumption that within each of the age/sex/racial/ethnic groups, the prevalence of the condition and informal caregiving hours will remain constant.[1,32] Baseline average costs per person for each demographic category are allowed to grow in real terms on the basis of the historical rate of growth of real wages. These projections reflect expected changes in population demographics but assume no change in policy that would affect prevalence and relative cost within a demographic category. We generated a projected number of people with each condition by age/sex/race/ethnicity in each year (2015–2035) by multiplying the baseline prevalence of each condition by age/sex/race/ethnicity by the 2010 census projections of population counts by age/sex/race/ethnicity for 2015 through 2035. We obtained projected population counts for 2015 through 2035 from the 2014 population projections of the US resident population by age, sex, race, and Hispanic origin generated by the US Census Bureau.[41]

We calculated projections of annual costs of informal caregiving of each CVD condition for the years 2015 through 2035 by age/sex/race/ethnicity by multiplying the annual per-person cost of informal caregiving of CVD by age/sex/race/ethnicity by the number of people with each condition for years 2015 to 2035 by age/sex/race/ethnicity. We used assumptions from the Congressional Budget Office on the average annual growth rate of real earnings and applied an annual growth rate of 1.29% to the caregiving costs in each year through 2035.[42] Finally, we aggregated annual costs across age/sex/racial/ethnic groups to calculate total projected costs of informal caregiving of CVD in each year (2015–2035).

RESULTS

The estimated weekly per-person hours of informal caregiving attributable to each CVD condition (hypertension, coronary heart disease, heart failure, stroke, and other heart disease) and breakdown by sex, race/ethnicity, and age group are presented in Table 1. Across conditions, the number of informal caregiving hours ranges from 0.10 h/wk for patients with coronary heart disease to 6.12 h/wk for patients with stroke. On average, white non-Hispanics with CVD receive fewer hours than other groups, and given the aging of the population, individuals ≥80 years of age receive more hours of caregiving than those <80 years of age.

Per person, the average annual cost of informal caregiving for a patient with CVD is the highest among blacks with an estimated cost of $1600/y in 2015 and increasing to $2300/y in 2035. The lowest average annual cost is found among white non-Hispanics with $890/y in 2015 and increasing to $1300/y in 2035 (Figure 1). Looking at condition-specific costs reveals that for hypertension, per-person costs are the highest among Hispanics with an estimated annual cost of $420 in 2015 and increasing to $550 in 2035 and the lowest among white non-Hispanics with an estimated cost of $220 in 2015 and increasing to $300 in 2035 (Figure 2). At the person level, stroke is the most expensive CVD condition in terms of informal caregiving, with blacks incurring the highest informal caregiving cost of $7200 in 2015 and increasing to $10 000 in 2035 (Figure 3).

Projected total annual informal caregiving costs attributable to CVD are presented in Table 2. The costs of informal caregiving for patients with CVD were estimated at $61 billion in 2015 and are projected to more than double to $128 billion in 2035 (Table 2). Total costs of informal caregiving for patients with stroke constitute more than half of the total costs of informal caregiving of patients with CVD ($31 billion in 2015 and $66 billion in 2035). Although at the per-person level the informal caregiving provided to patients with hypertension appears minimal at 0.31 h/wk (Table 1), aggregated to the national level, the burden is significant ($14 billion in 2015 and $29 billion in 2035; Table 2) because of the high prevalence of hypertension. At the national level, the cost of informal caregiving provided to patients with CVD is the highest among white non-Hispanics with an estimate of $38 billion in 2015 and increasing to $70 billion in 2035 (Figure 4). In 2015, CVD informal caregiving costs were highest among individuals 65 to 79 years of age ($24 billion); however, by 2035, they are expected to be surpassed by the costs among individuals ≥80 years of age ($53 billion; Figure 5). By sex, total costs of informal caregiving are higher among women with CVD ($35 billion in 2015 and $73 billion in 2035) than men ($26 billion in 2015 and $55 billion in 2035; Figure 6).

DISCUSSION

Results of our analysis present the additional costs of total direct and indirect CVD costs from 2015 to 2035. The results assume that CVD prevalence and infor-

Table 1. Estimated Per-Person Weekly CVD-Attributable Hours of Informal Caregiving

Category	Mean Weekly Hours (95% Confidence Interval)				
	Hypertension	CHD	HF	Stroke	Other Heart Disease
All	0.31 (0.30–0.32)	0.10 (0.04–0.17)	1.95 (1.91–2.00)	6.12 (5.79–6.44)	0.98 (0.92–1.04)
Male	0.27 (0.25–0.28)	0.16 (0.12-.20)	1.70 (1.63–1.77)	5.39 (5.35–5.43)	0.80 (0.76–0.84)
Female	0.35 (0.34–0.37)	0.04 (0.02–0.05)	2.17 (2.03–2.32)	6.83 (6.59–7.07)	1.14 (1.10–1.19)
White	0.26 (0.25–0.28)	0.15 (0.14–0.16)	1.76 (1.72–1.80)	5.38 (5.25–5.51)	0.84 (0.80–0.87)
Black	0.46 (0.42–0.50)	0.00	2.95 (2.88–3.01)	8.78 (8.57–8.99)	1.97 (1.88–2.05)
Hispanic	0.52 (0.46–0.58)	0.00	2.70 (2.64–2.76)	7.79 (7.48–8.10)	1.79 (1.69–1.89)
Other race	0.40 (0.39–0.41)	0.00	2.04 (1.88–2.21)	6.34 (6.09–6.60)	1.25 (1.20–1.30)
Age 54–64 y	0.26 (0.26–0.27)	0.03 (0.00–0.05)	1.79 (1.70–1.87)	5.20 (5.18–5.21)	0.76 (0.69–0.83)
Age 65–79 y	0.31 (0.30–0.32)	0.20 (0.20–0.21)	1.82 (1.80–1.84)	5.03 (4.96–5.10)	0.81 (0.73-.088)
Age ≥80 y	0.43 (0.39–0.47)	0.00	2.35 (2.24–2.46)	9.23 (8.68–9.79)	1.56 (1.51–1.61)

Confidence intervals were estimated from bootstrapped standard errors. Estimates that were not statistically significant (*P*>0.05) were replaced with zeroes and confidence intervals were not reported. CHD indicates coronary heart disease; CVD, cardiovascular disease; and HF, heart failure.

mal caregiving hours within each age/sex/racial/ethnic group remain constant and take into account expected changes in population demographics and real wage growth. The projected cost of informal caregiving attributable to CVD is $61 billion in 2015 with a projected increase to $128 billion in 2035. At the per-person level, the burden of informal caregiving for CVD is greatest among blacks and individuals ≥80 years of age. Aggregated to the national level, informal caregiving costs for those with CVD are the highest among white non-Hispanics and women. The burden of informal caregiving for patients with CVD is significant, and accounting for these costs increases total CVD costs by 11% to $616 billion in 2015 and $1.2 trillion in 2035.

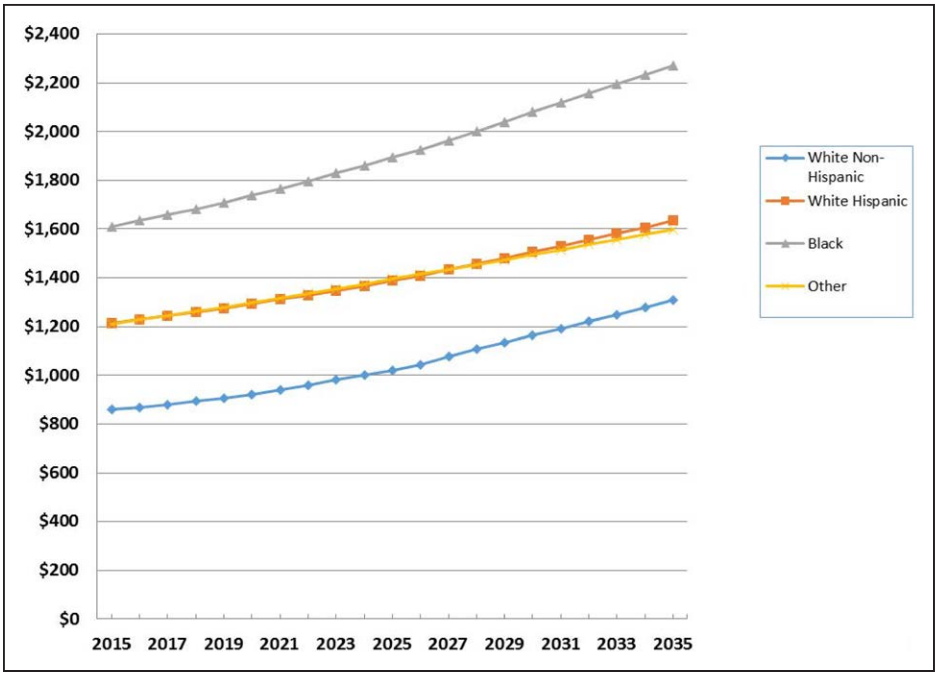

Figure 1. **Projected per-person informal caregiving costs of cardiovascular disease by race (2015 US dollars).**

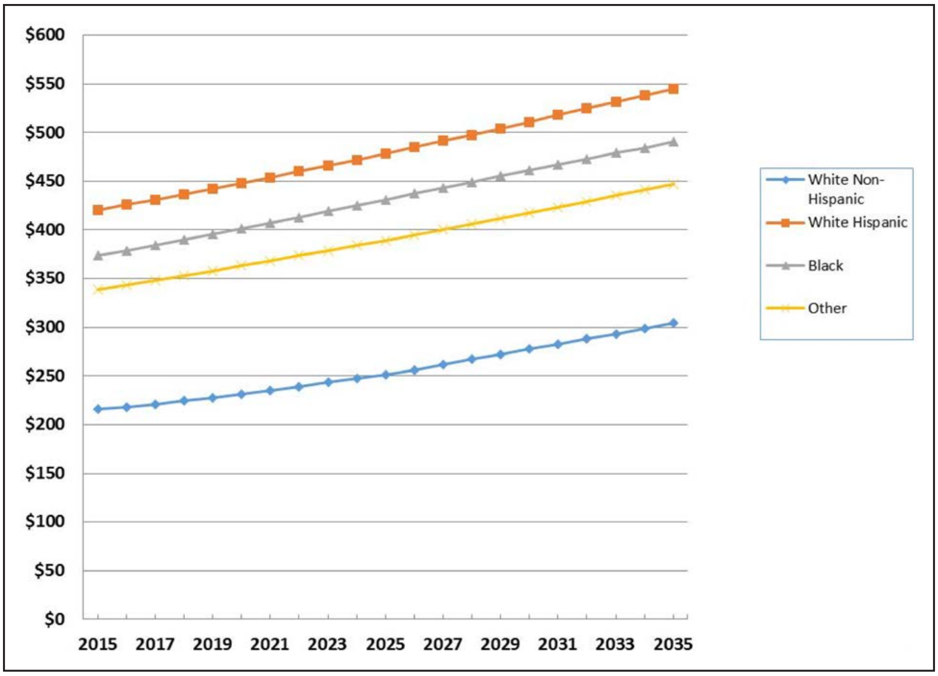

Figure 2. **Projected per-person informal caregiving costs of hypertension by race (2015 US dollars).**

Aside from this study and that reported by Joo and colleagues,[18,19,43] costs of informal caregiving associated with CVD are not well documented. Our estimates of the per-person hours of informal caregiving attributable to heart failure and stroke are consistent with previous studies.[18,19] For patients with heart failure, Joo et al[18] used methodology similar to that in the present study but used data from the 2010 HRS that included adults ≥50 years of age; our analysis included adults ≥54 years of age. For patients with stroke, Joo et al[19] focused on adults ≥65 years of age and used an approach that quantified hours of informal caregiving for patients with stroke in the past 2 years (rather than ever having a stroke as in the present analysis). Our estimates of total informal caregiving costs, however, are twice as high as the costs previously reported for patients with heart failure and stroke.[18,19] The main reason for that difference is that, following recommendations by Neumann et al,[38] we valued the hours of an informal caregiver using a wage of home health aide workers that was inflated to account for fringe benefits, whereas previous studies did not.

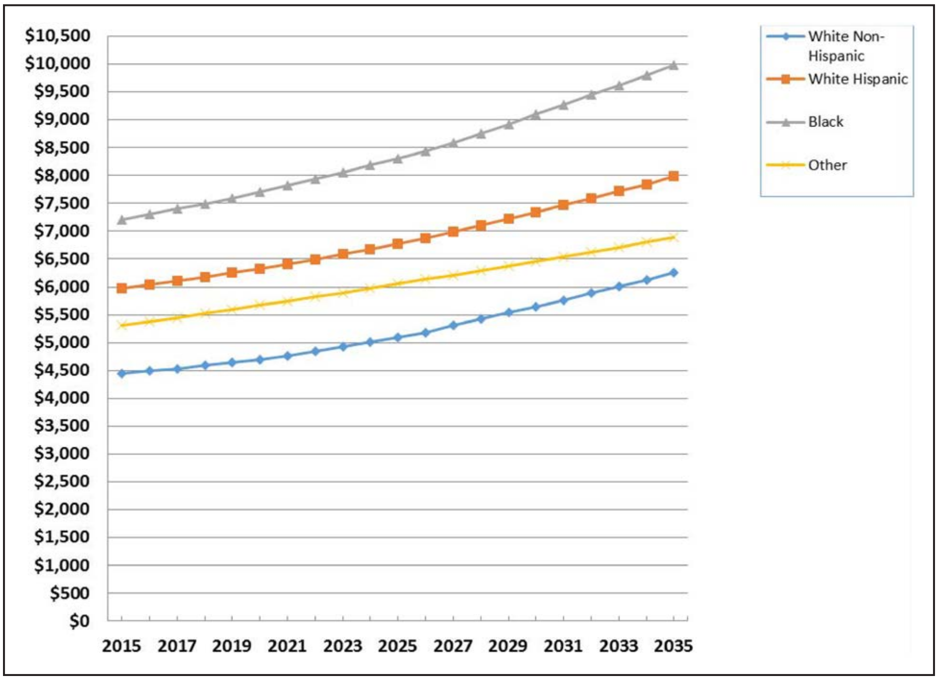

Figure 3. **Projected per-person informal caregiving costs of stroke by race (2015 US dollars).**

Table 2. **Projected Total Costs of Informal Caregiving Attributable to CVD (2015 US Dollars in Billions)**

Year	Total CVD	Hypertension	CHD	HF	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

CHD indicates coronary heart disease; CVD, cardiovascular disease; and HF, heart failure.

As a result of chronic stress, caregivers themselves are faced with emotional and health impacts of caregiving, loss of employment, and significant changes in their lives as a result of providing care.[3,15,44,45] From a financial standpoint, caregivers often incur out-of-pocket costs when they provide care (eg, paying for medical, household, or personal care items for the caregiving recipient).[17] Life changes encompass changes in social functioning, subjective well-being, and health as a result of providing care.[15,44] Caregiver health and well-being are important because of the impact that caregivers and patients have on each other within dyadic relationships.[46,47] Several studies have shown that caregiver self-esteem, optimism, and anxiety are associated with outcomes for patients with CVD (eg, depressive symptoms, quality of life).[46–48] Our analysis does not quantify emotional or health burden, job loss, life changes, healthcare use, or out-of-pocket costs incurred by informal caregivers. Frequently referred to as spillover effects,[49] limited research exists on the economic spillover effects on CVD caregivers.

How Caregiving Costs Add to the Burden of Heart Disease and Stroke Through 2035

The epidemiology of CVD has changed substantially over the past 2 decades.[50] These profound changes are exemplified by a decline in the incidence of myocardial infarction,[51,52] a preponderance of non–ST-segment–elevation myocardial infarctions, and a shift in the mix of heart failure cases with more patients presenting with preserved ejection fraction.[53] The impact of this evolution is amplified by 2 key factors: incident manifestations of CVD occurring at older ages and the aging of the population, which leads to a larger pool of candidates for CVD. As a consequence, CVD is now materializing within the complexities of old age, and cardiac care is increasingly entering the domain of geriatric care.[54] Accordingly, caregiving needs are growing and are most often fulfilled by informal caregivers. Because CVD has increasingly become integrated with geriatric conditions and manifests more often alongside other diseases, the complexity of managing multiple chronic conditions increases the magnitude of the demands on caregivers.

Given the aging of the US population, caregiving requirements are expected to markedly escalate by 2035. Because caregivers experience substantial stress and

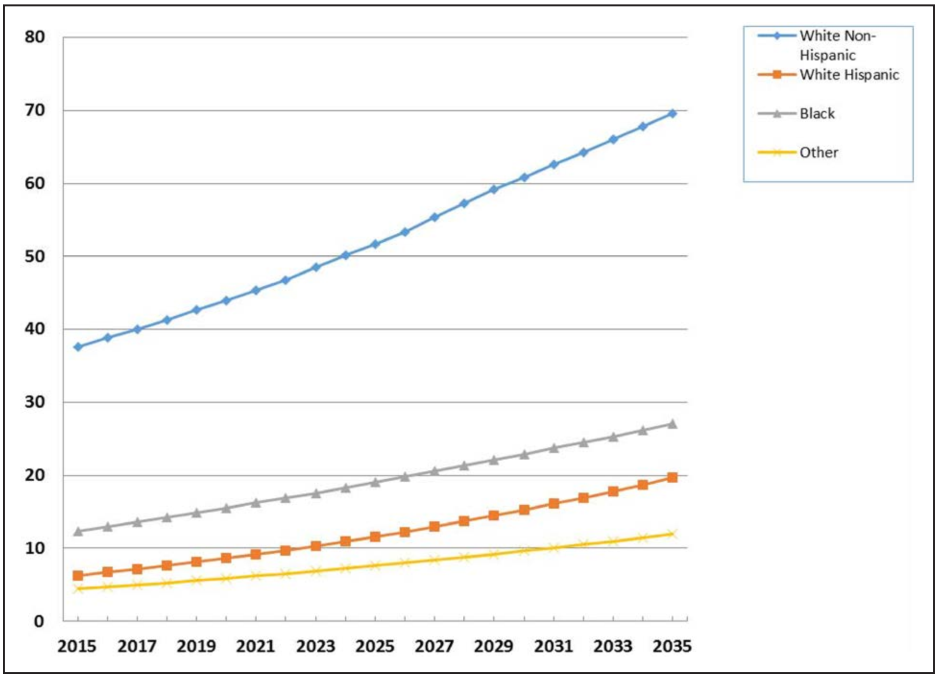

Figure 4. **Projected total informal caregiving costs of cardiovascular disease by race (2015 US dollars in billions).**

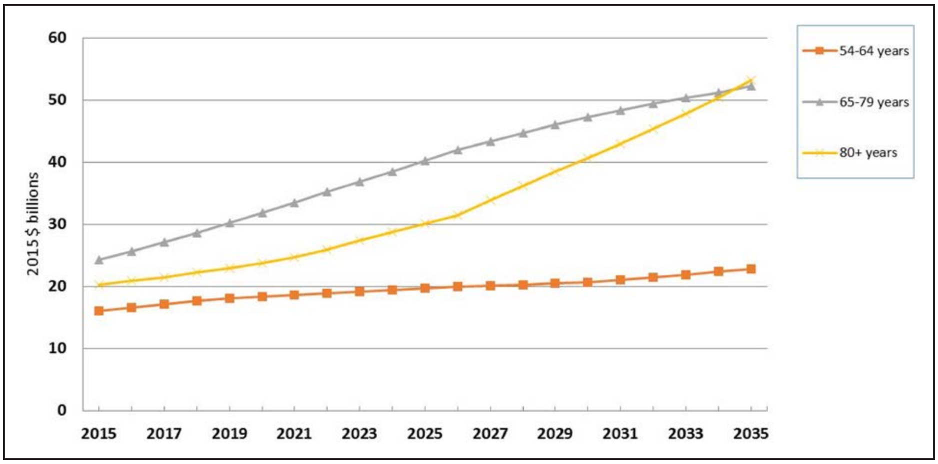

Figure 5. Projected total informal caregiving costs of cardiovascular disease by age groups (2015 US dollars in billions).

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 the impact of CVD. However, the conceptual importance of measuring caregiving costs contrasts sharply with the scarcity of data on the topic and the lack of an agreed-on methodological framework that would inform this matter with the necessary rigor and accuracy. A recent review outlined the limitations of existing studies, including reliance on different methods, numerous biases, and small sample size.[43] Nevertheless, the estimated costs of informal care are high. As the need for methodological work is increasingly recognized, approaches to valuation of informal care are now being proposed, which will greatly contribute to addressing the recognized gaps in methodological knowledge and will therefore enhance the robustness of future analyses.[55] One example is the need for approaches for valuation of informal care that quantify the spillover effects on caregivers, including the emotional, financial, and health burden.

Special Concerns for Patients With Stroke

Compared with other types of CVD, the higher costs of providing care for stroke survivors are not surprising ($31 billion in 2015 and $66 billion in 2035). Stroke is a leading cause of disability, with 50% of survivors having hemiparesis, 46% with cognitive deficits, 19% with aphasia, and 35% experiencing depressive symptoms.[56] Because of the suddenness of stroke, informal caregivers struggle with finding information about stroke, managing emotions and behaviors of the survivor, providing personal care, providing instrumental care, and dealing with their own emotions and life

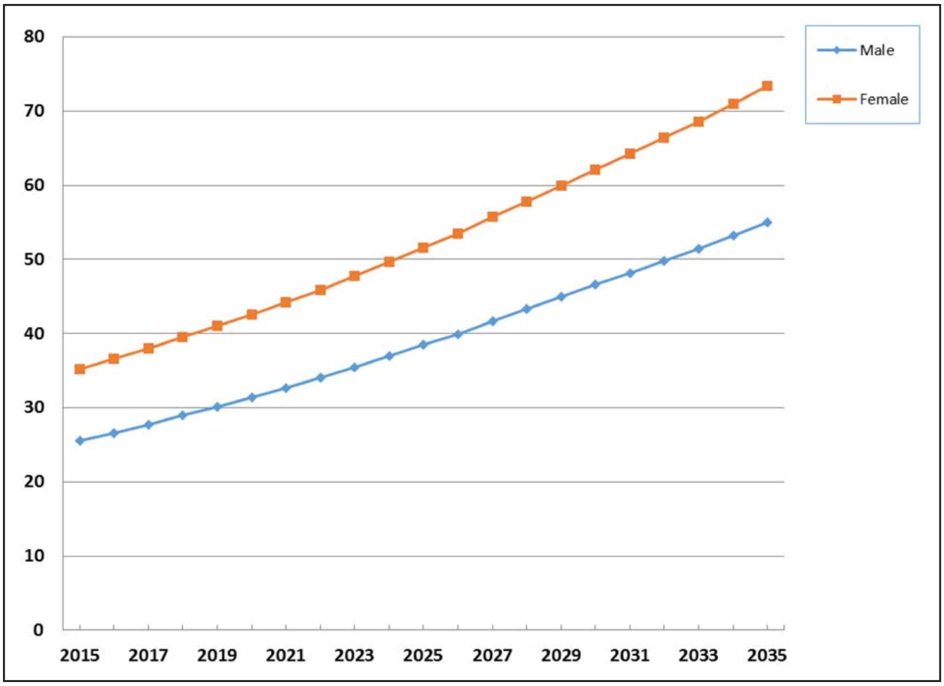

Figure 6. Projected total informal caregiving costs of cardiovascular disease by sex (2015 US dollars in billions).

changes.[44,57] The most difficult aspect of providing care is managing emotions and behaviors of the survivor, particularly depressive symptoms and personality changes as a result of the stroke.[44,57] Informal caregivers of survivors with aphasia, compared with those without, have reported more difficulty with providing care and worse life changes, with lack of time to spend with family and friends.[58] With 50% of stroke survivors having hemiparesis and 30% being unable to walk without assistance, informal caregivers must suddenly learn how to assist with ADLs and mobility issues, with falls being a major concern. Financial issues, transportation, and finding respite care are also central issues for stroke caregivers.[44,57] The complexity of care and the impact of stroke on the lives of survivors and their informal caregivers make stroke very time-consuming and costly.

Special Considerations in Heart Failure

Although less costly than stroke, the burden of informal caregiving for patients with heart failure is also significant (around $7 billion in 2015 and $14 billion in 2035), as noted in Table 2. In heart failure, the challenges of aging and multimorbidity leading to complex care needs are well known. Family caregivers of individuals with heart failure are engaged in providing direct care and assisting with self-care. They monitor and support complex medical regimens, dietary restrictions, medications, symptom assessment/management, psychological health, and quality of life.[13] In addition to providing transportation to multiple appointments, they are confronted with the stresses and uncertainty associated with frequent hospital admissions.[15,45,59–63] Few effective interventions to support family caregivers of patients with heart failure have been reported.[13]

Cognitive impairment associated with heart failure is one of several issues that compound family caregivers' responsibilities.[64] Although not studied specifically in patients with heart failure, a study has shown that Alzheimer disease and related dementias increase costs through effects on the management of comorbid illnesses, which is of particular relevance for heart failure given its self-management requirements.[65] It has been documented that increasing life expectancy leads to an increasing burden of comorbid conditions in aging populations, in particular CVD and dementia. These 2 diseases are likely to coexist, and there is substantial evidence that atherosclerosis and cognitive impairment share common risk factors and pathophysiology.[66] This is particularly salient for heart failure because the prevalence of cognitive impairment in heart failure is high, interfering with its management and imposing a particularly high burden on caregivers.

Special Concerns by Age, Sex, and Race/Ethnicity

The results reveal significant disparities in the burden of CVD caregiving by age, sex, and race/ethnicity. As expected, CVD prevalence increases with age, and as noted above, the increasing aging population shifts costs of CVD to older ages.[54] In 2015, 90% of people ≥80 years of age were estimated to have at least 1 form of CVD.[1] Informal caregiving costs of CVD were the highest among those 65 to 79 and >80 years of age, reflecting the increasing frailty and required assistance with ADLs and IADLs.

In 2014, the prevalence of hypertension, heart failure, stroke, and other heart conditions such as atrial fibrillation was higher among women than men.[50] In this analysis, the increased projected caregiving costs for women likely reflect these trends and the increased age of women for CVD events.

Aggregated to the national level, the total caregiving costs are the highest among whites because they represent the largest racial/ethnic group. At the per-person level, blacks bear the highest burden of caregiving. The effect of race/ethnicity on the use of paid or informal caregivers for individuals with CVD has received little attention in the literature. The declines seen in CVD in recent years have been smaller among blacks than whites, accompanied by increased severity of CVD among blacks.[67] The prevalence of hypertension, heart failure, and stroke is highest among blacks, with CVD initially occurring at younger ages and being more resistant to treatment.[50,68,69] For example, 47% of blacks were estimated to have hypertension in 2015 compared with 40% of white non-Hispanics, consequently increasing their risk for stroke and heart failure.[1,70–72]

Studies of traumatic spinal cord injury and other chronic conditions suggest that blacks were more likely to receive informal care from other family members, friends, church support, and others, whereas whites were more likely to receive informal or family care from spouses.[73] Level of income was most directly related to the use of paid versus unpaid care. A study of 270 patients[74] to determine indicators of 6-month healthcare use after hospitalization for ischemic stroke found that blacks had more home healthcare visits than whites. Thus, the underuse of health care after stroke was not associated with worse long-term stroke outcomes for blacks. Living with an available caregiver was associated with less postacute healthcare use, and coresiding caregiver availability was reduced in women, black women in particular.[74]

We further assessed the issue of racial/ethnic differences in caregiving using the HRS data and found that blacks, regardless of CVD status, received more caregiving than whites, including both paid and informal caregiving. The portion of the paid caregiving hours attributable to CVD was similar across blacks and whites, so we cannot conclude that blacks used more informal caregiving because they had less access to paid caregiving than whites. These estimates controlled for age and other sociodemographic characteristics, so it is likely that severity of disease contributed to the higher use of caregiving reported by black patients with CVD (and we were unable to control for it in our data). We also found that black patients with CVD were more likely to report ADL limitations (which is a qualifier for receiving caregiving in our analysis), with 34% of black patients with CVD versus 23% of white patients with CVD reporting at least 1 ADL limitation. This finding suggests that black patients with CVD may be in need of more caregiving hours (formal and informal) than white patients with CVD.

Caregiving Costs in Noncardiovascular Chronic Conditions

Caregiving costs have been studied to some extent in noncardiovascular conditions. A systematic review of the inclusion of informal care in the economic evaluation of Alzheimer disease, colon cancer, Parkinson disease, and rheumatoid arthritis evaluated how often and how informal care was addressed in cost-effectiveness studies of these chronic diseases.[75] Although in Alzheimer disease informal cost was included in 64% of economic evaluations, it was addressed in only 13% of the studies of Parkinson disease and 14% of the studies pertaining to rheumatoid arthritis and was not mentioned in studies focusing on metastatic colorectal cancer. Furthermore, studies that reported informal care costs did not discuss their methodology. Because methods could conceptually differ across studies, the ability to compare across diseases is limited.

In oncology, reports on caregiving depict the breadth of caregiving activities and their far-reaching impact on families,[76,77] yet studies directly addressing the related economic implications and costs have been infrequent.[78] For diabetes mellitus, the estimated annual costs of caregiving were reported to range from $1162 to $5082 per person.[43] As expected, the caregiving needs of Alzheimer disease bring the highest cost compared with those of stroke, mental illness, cancer, and multiple sclerosis.[55] However, detailed comparisons with other diseases that rely on consistent methodology are lacking. Hence, it is challenging to examine how caregiving costs for other chronic diseases compare with costs for CVD.

Taken collectively, these observations identify a significant gap in our knowledge about caregiving and thus a research opportunity of critical societal urgency. An agreed-on methodological framework is a requisite for the field to move forward and to conduct comparisons across diseases.

LIMITATIONS

This analysis is subject to several limitations. As with most surveys, the data and projections are subject to sampling error. However, the large number of participants and national representativeness of the sample mitigate these concerns. Although geographic variation has been studied extensively in patients with stroke,[50] region-level subgroup analyses were not conducted because of small subsample sizes. Studies have shown higher rates of stroke mortality for patients living in the stroke belt (ie, the southeastern United States), indicating geographic disparities.[50] These disparities may also be evident in terms of resource use and the resultant need for more caregiving hours for patients who survive a severe stroke. Although other specific cardiovascular conditions with caregiving needs (eg, peripheral vascular disease, congenital heart disease) were not analyzed separately, they were likely captured in the “other heart diseases” category. Future work should attempt to address these conditions more specifically.

This analysis did not capture informal caregivers who provide personal and other care for institutionalized patients with CVD. Although this type of caregiving was beyond the scope of this study, it is an important aspect to consider in future analyses.

This analysis includes adults ≥54 years of age; younger groups also may have caregiver needs. We previously estimated that the medical costs of CVD among those 18 to 44 years of age constituted <5% of medical costs among those ≥18 years of age ($15 billion of $318 billion).[1] Thus, given the relatively low prevalence of CVD in this younger age group, we do not expect that excluding them from the analysis significantly underestimated the total costs of informal caregiving for patients with CVD. Although costs for younger populations may be relatively low, they likely need care over a longer period of time, for the remainder of their lives for some patients. Stroke is also occurring at earlier ages in young adults[79]; thus, further consideration of these caregiving needs is warranted.

Some participants reported zero hours of receipt of informal caregiving. It is not clear whether that reflects low or zero need, that they did not have an informal caregiver available, or that they used a paid caregiver. In addition, we cannot always identify whether the informal caregiver was living in the same household. However, we do know that most of the informal caregivers were family members. Among those with at least 1 CVD condition who received informal caregiving, 90% reported having a family member as at least 1 of the caregivers.

The number of caregiving hours was self-reported by the recipients of care, potentially introducing bias because there could be reporting discrepancies if caregivers were the respondents.[43] However, the estimates presented here are likely conservative because care recipients usually understate impairment or disability compared with assessments by caregivers.[80–82] Furthermore, the self-reported data used in this analysis have also been previously used to estimate informal costs of caregiving for patients with heart failure, stroke, dementia, depression, and diabetes mellitus.[18,19,33,35,83]

We did not examine the spillover effects on caregivers; it is well documented that prolonged and intense caregiving effort exerts a devastating toll on caregiver health manifested as burden, depression, reduced quality of life, and increased risk for CVD events and other chronic conditions[14,15] compared with noncaregivers of the same age. The true economic burden of CVD caregiving may be greater in that caregivers who report higher levels of caregiving distress have greater consumption of health services.[84,85] We also did not capture productivity losses and out-of-pocket expenses incurred by the caregivers. Our analysis did not account for the state or county assistance that some informal caregivers may be receiving.

FUTURE RESEARCH OPPORTUNITIES AND POLICY IMPLICATIONS

Research Opportunities

According to a recent review on costs associated with informal care for patients with CVD and diabetes mellitus, research is limited by recall bias, small samples, and differing methodology.[43] Joo and colleagues[43] recommended that future studies standardize methods for estimating costs of informal caregiving by (1) estimating disease-attributable cost rather than overestimating from multiple diseases per patient, (2) collecting patient-level data that include informal caregiver burden, (3) assessing a set of help areas rather than relying on memory, and (4) conducting sensitivity analyses. Of particular importance is collecting accurate hours of informal care with proper ways to estimate costs.[43] Integration of informal caregiving costs into economic evaluations of illnesses such as CVD will help to avoid underinvesting for intervention strategies for these conditions.[43] For example, several studies have been designed and tested with informal caregivers of individuals with heart failure[13,62–64,86–89] and stroke,[90–92] with some including cost analyses or estimated costs of intervention delivery.[93,94] Scientific guidelines recommend that informal caregivers be included in the care of individuals with CVD,[86,90,95] yet implementation of evidence-based strategies to support informal caregivers remains a challenge in today's healthcare system, primarily because of a lack of allocated resources within healthcare systems.

Although this analysis and policy discussion has centered on informal caregiving, it is important to acknowledge that many patients with cardiovascular issues also receive care from paid nonprovider caregivers in their home or nonacute setting in the form of home health aides, companions, and homemaker assistants. Limited information is available on the role that these paid caregivers play in the care of patients such as assistance with ADLs or more extensive roles, including medication management, selection of meals and diet, communication with healthcare professionals, and symptom monitoring. The relationship and substitutability among informal caregiving, formal caregiving provided at home or in a community, and institutional care have been studied extensively but with varying results. A consistent finding is the inverse relationship between informal care and institutionalized care. Receipt of informal care reduces the probability of or delays nursing home entry.[96–98] However, the findings on the relationship between informal care and paid home care are mixed. Some researchers predict that informal care and paid home care are substitutes,[98,99] whereas others find no significant effects.[100] We explored controlling for the use of formal caregiving in our regression model but did not find that adding this variable changed our results. A greater understanding of the interaction between unpaid and paid caregiving and the type of care provided would help inform and possibly reduce variances in state Medicaid policies/reimbursement and variances in Medicaid plan coverage.

Policy Guidance

Caregiving has become a critical issue of public policy, requiring holistic health reform solutions that account for the specific needs of both patients and their informal caregivers as the unit of care within systems of care delivery. Elderly individuals are known to prefer to stay in their homes and communities rather than in a nursing home; they also prefer to receive care from a family member rather than from a home health aide.[101] Thus, informal caregiving is an important component of improved well-being of the aged individuals.

CVD is already our nation's costliest disease, and the projected dramatic rise in CVD prevalence and costs between now and 2035[1] portends increased strain on the capacity of the health system and demands imposed on informal caregivers at the same time that the caregiver pool is shrinking.[12] These circumstances place CVD caregivers at risk for their own health deterioration and burnout from the prolonged distress, physical demands, and costs of caregiving,[3,102] and as demonstrated in this analysis, our nation will bear the costs.

We propose 4 strategic steps to prioritize family-focused care alongside person-centered care at a level commensurate with caregivers' critical contributions to quality care delivery:

1. **Develop and deploy a national caregiving strategy.** Implement the consensus recommendation of the NASEM caregiving expert committee calling for the departments of Health and Human Services, Labor, and Veterans Affairs to work with private-sector stakeholders in developing and executing a national caregiving strategic action plan to preserve caregiver health, well-being, and financial security. This plan would explicitly and systematically detail how to adapt aspects of the nation's systems for health care, workplaces, and long-term services and supports to engage informal caregivers and to support their health, values, and social and economic well-being, as well as address the needs of the increasingly culturally and ethnically diverse caregiver population. The strategy should at a minimum accomplish the following:
    - Develop, test, and implement effective mechanisms within Medicare, Medicaid, and Veterans Affairs to ensure that informal caregivers are routinely identified, assessed, and supported
    - Direct the Centers for Medicare & Medicaid Services to develop, test, and implement provider payment reforms that motivate providers to engage caregivers in delivery processes
    - Explore, evaluate, and adopt federal policies that provide economic support for working and nonworking caregivers to offset the costs of caregiving, lost wages, and other costs
    - Evaluate the few existing state initiatives and experiences addressing caregiver needs through support programs to identify opportunities for implementing similar successful programs more broadly and across all states.[12]

    The Recognize, Assist, Include, Support, and Engage Family Caregivers Act[24] and other similar pieces of federal legislation provide helpful legislative vehicles for advancing these priorities.

2. **Expand palliative care access.** Implement the American Heart Association and American Stroke Association recommendations[103] calling for palliative care integration early in the disease trajectory for advanced CVD and stroke by expanding palliative care access in all hospital and community-based settings. The palliative care needs of symptomatic patients with heart failure are comparable to those of patients with advanced cancer.[104,105] These burdens also affect caregiver quality of life.[13,27,87,102,106–108] However, patients and caregivers with heart failure access palliative services far less often than patients with cancer.[105,109] Even in cases when patients with heart failure are referred for palliative care, consultations are initiated only very late in the care trajectory.[109]

    Although not synonymous, end-of-life care and palliative care overlap in many ways. A recent study of older adults' caregivers at the end of life examined 900 000 community-dwelling Medicare beneficiaries who received support from 2.3 million caregivers.[110] Ninety percent were unpaid and provided almost twice as many hours of care per week as other caregivers. However, older adults at the end of life were not significantly more likely than other older adults to receive caregiving funded by government, state, or private insurance, underscoring the need for both greater recognition and expanded access to supportive services.[110]

    Palliative care focuses on maximizing quality of life for both the patient and caregiver at any age and any stage of serious illness, providing an extra layer of support in these circumstances.[103] It uses a team-based approach to relieve the pain, symptoms, and distress of a serious illness like CVD.[111] By determining patient and caregiver goals of care through skilled communication, treating distressing symptoms while coordinating care, providing practical support for patients and caregivers, and mobilizing community support and resources to ensure a secure and safe living environment, palliative care teams help meet patient and caregiver needs so that they can avoid unwanted and expensive crisis care.[112–114]

    Many large US hospitals now have palliative care services, but availability across settings is highly variable by region and by state. Only a small fraction of the patients and families who could benefit receive it.[115] Extending palliative care integration in the community and expanding primary palliative care core competencies across the workforce through communication and symptom management skills training are vital steps to reliably meet the quality of life and support needs of patients and caregivers where they live.[116–118] Advocating for enactment of legislation that expands palliative care awareness, access, training, and research is an important action that stakeholders can take to help increase palliative care availability and accessibility for patients with CVD and their caregivers.

3. **Embed caregiver engagement and outcomes in performance and payment reforms.** Caregivers should be assessed for unmet needs throughout the course of CVD. Given the scope and complexity of their caregiving role, ensuring that they feel well prepared and supported in fulfilling their responsibilities is essential. The proliferation of shared risk payment models encouraging shorter hospital stays and reduced readmission has increased health system, payer, and provider

reliance on informal and family caregivers as critical partners in the treatment and support of seriously ill individuals. However, the availability and adequacy of caregiving are often assumed instead of assessed, discussed, or trained.[12] Responding to this reality, pay-for-performance reforms through Medicare Access and CHIP (Children's Health Insurance Program) Reauthorization Act implementation, advancement of various alternative payment models, and development of associated quality measures should specifically include accountability for engaging informal caregivers and assessing their specific needs across system, institutional, and provider performance metrics. Quality improvement initiatives should include clearly articulated performance standards that hold providers accountable for caregiver engagement, training, and support by explicitly including caregiver-reported outcomes in quality measures. These could include caregiver satisfaction with provider encounters, adequacy of training and instructions provided, caregivers' confidence and efficacy in performing required tasks, and the adequacy of support services provided.

4. **Invest in caregiving research.** The NASEM report consensus recommendations highlighted several priority research areas for investment, including funding for health services research to transform population health and care delivery focused on preserving caregiver well-being, quality of life, and workforce productivity.[12] Specific to caregivers of patients with heart failure or other CVD, research priority is also strongly warranted for intervention development and testing to enhance caregiver support and education.[12,87] The national strategy development recommended above should include expert consideration and identification of additional caregiving research priority areas.

Focused efforts to address the above 4 priorities will enable the United States to address the rising costs of informal caregiving while also offering needed caregiver education and support. The outcomes will be improved quality of life for patients with CVD and family caregivers and improved productivity of the workforce.

Although different payer systems must be considered, established national or provincial caregiver strategies from several other countries might provide important insights for approaches to be considered or adapted for the United States. Notable examples of the components of these strategies include government-funded community support groups (Australia); respite and age-appropriate resources for informal caregivers (Australia); financial support to pay for care after an assessment of needs (United Kingdom); flexible work arrangements for informal caregivers such as compressed work weeks, flex time, and work from home (New Zealand); and income replacement for family caregivers comparable to the provisions for care personnel in the formal caregiving sector (Sweden, United Kingdom, Canada).[119]

CONCLUSIONS

Combining our estimates of informal caregiving costs ($61 billion in 2015) with the medical and indirect cost of CVD burden analysis ($555 billion in 2015) adds 11% to the projected costs of heart disease and stroke (totaling more than $616 billion in 2015). According to CVD prevalence projections, 45% of the US population will have CVD in 2035; thus, the escalation of caregiving needs must be considered in planning. Attention to the need for family-focused approaches and the development of sound caregiver policy are critical to ultimately reduce the burden of CVD. Collaboration among professional organizations, patient and family advocacy groups, and policy makers could have a profound effect on changing this concerning landscape.

ARTICLE INFORMATION

The American Heart Association makes every effort to avoid any actual or potential conflicts of interest that may arise as a result of an outside relationship or a personal, professional, or business interest of a member of the writing panel. Specifically, all members of the writing group are required to complete and submit a Disclosure Questionnaire showing all such relationships that might be perceived as real or potential conflicts of interest.

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This table represents the relationships of writing group members that may be perceived as actual or reasonably perceived conflicts of interest as reported on the Disclosure Questionnaire, which all members of the writing group are required to complete and submit. A relationship is considered to be "significant" if (a) the person receives $10 000 or more during any 12-month period, or 5% or more of the person's gross income; or (b) the person owns 5% or more of the voting stock or share of the entity, or owns $10 000 or more of the fair market value of the entity. A relationship is considered to be "modest" if it is less than "significant" under the preceding definition.

*Significant.

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*Significant.

APPENDIX

Table A1. Questions Used to Define CVD Conditions in HRS

Condition	Qualifying Questions From HRS
Hypertension	Has a doctor ever told you that you have high blood pressure or hypertension?
CHD	Has a doctor ever told you that you have angina? OR Has a doctor ever told you that you have had a heart attack?
Congestive HF	Has a doctor ever told you that you have congestive HF?
Stroke	Has a doctor ever told you that you had a stroke?
Other heart conditions	Has a doctor ever told you that you have an abnormal heart rhythm? OR Has a doctor ever told you that you had a heart attack, CHD, angina, congestive HF, or other heart problems? (Use this question to identify other heart conditions if respondent answered “yes” to this question but “no” to all the questions above.) OR What type of heart disease do you have? Qualifying responses: 1. Abnormal heart rhythm (includes “heart skips,” atrial fibrillation, palpitations, tachycardia, pacemaker) 2. Blockage in arteries (includes clogged arteries, hardening in the arteries, build-up in the arteries, collapsed artery, arteriosclerosis, bundle-branch block) 3. Valve problems (includes mitral valve prolapse, leaky heart valve, valve wearing out, narrowing of a valve, aortic stenosis, leaking heart problem, heart murmurs) 4. HF (includes enlarged heart, congestive HF, enlarged chamber)

CHD indicates coronary heart disease; CVD, cardiovascular disease; HF, heart failure; and HRS, Health and Retirement Study.

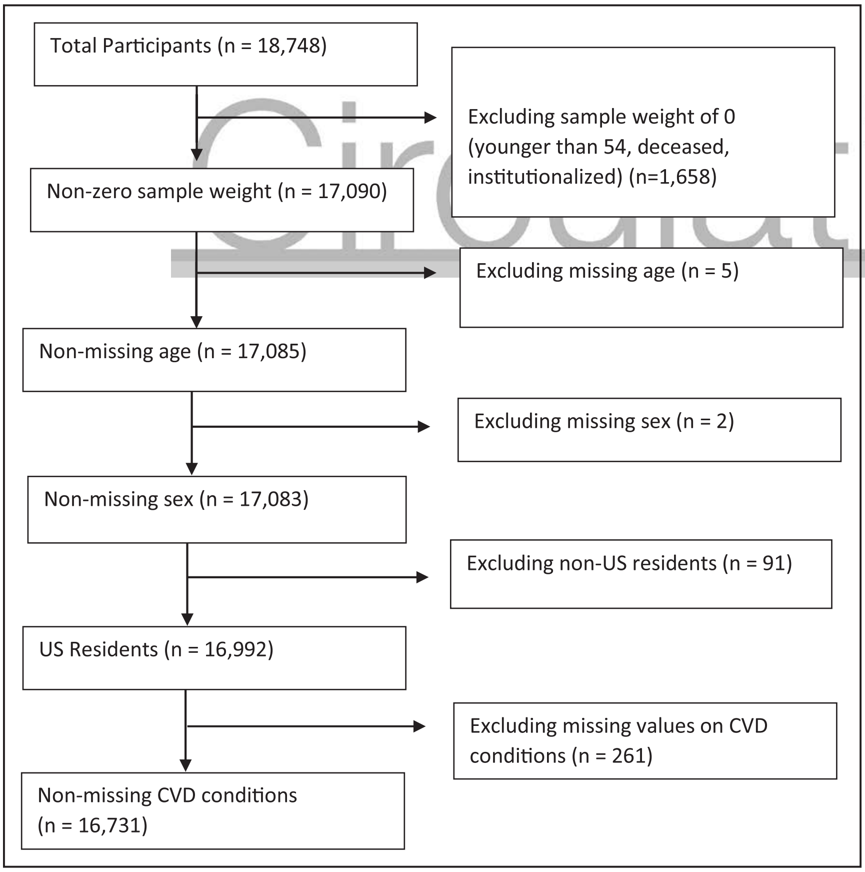

Figure A1. Study population selection process from 2014 HRS (Health and Retirement Study). CVD indicates cardiovascular disease.

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