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## Cost of Informal Caregiving for Patients with Heart Failure

Heesoo Joo, PhD, Jing Fang, MD, Jan L. Losby, PhD, MSW, and Guijing Wang, PhD

Division for Heart Disease and Stroke Prevention, US Centers for Disease Control and Prevention (CDC), 4770 Buford Hwy NE, Mailstop F-72, Atlanta, GA 30341

### Abstract

**Background**—Heart failure is a serious health condition that requires a significant amount of informal care. However, informal caregiving costs associated with heart failure is largely unknown.

**Methods**—We used a study sample of non-institutionalized US respondents aged 50 and older from the 2010 Health and Retirement Study (n=19,762). Heart failure cases were defined by using self-reported information. The weekly informal caregiving hours were derived by a sequence of survey questions assessing (1) whether respondents had any difficulties in activities of daily living or instrumental activities of daily living, (2) whether they had caregivers or not because of reported difficulties, (3) the relationship between the patient and the caregiver, (4) whether caregivers were paid, and (5) how many hours per week each informal caregiver provided help. We used a two-part econometric model to estimate the informal caregiving hours associated with heart failure. The first part was a logit model to estimate the likelihood of using informal caregiving, and the second was a generalized linear model to estimate the amount of informal caregiving hours used among those who used informal caregiving. Replacement approach was used to estimate informal caregiving cost.

**Results**—The 943 (3.9%) respondents who self-reported as ever being diagnosed with heart failure used about 1.6 more hours of informal caregiving per week than those who did not have heart failure ( $P < .001$ ). Informal caregiving hours associated with heart failure were higher among non-Hispanic blacks (3.9 hours/week) than non-Hispanic whites (1.4 hours/week). The estimated annual informal caregiving cost attributable to heart failure was \$3 billion in 2010.

**Conclusion**—The cost of informal caregiving was substantial and should be included in estimating the economic burden of heart failure. The results should help public health decision makers in understanding the economic burden of heart failure and in setting public health priorities.

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Corresponding authors: Guijing Wang, PhD, Division for Heart Disease and Stroke Prevention, US Centers for Disease Control and Prevention (CDC), 4770 Buford Hwy NE, Mailstop F-72, Atlanta, GA 30341, Tel: 770-488-4846, Fax: 770-488-8151, gbw9@cdc.gov.

The findings and conclusions of this article are those of the authors and do not necessarily represent the official position of the US Centers for Disease Control and Prevention (CDC).

## Introduction

In the United States, heart failure is a serious public health issue among the elderly. Hospitalizations for heart failure have tripled in past 3 decades, and heart failure is one of the most common reasons for hospitalization in this age group.<sup>1</sup> In 2012, the prevalence of heart failure was 2.42% in adults and was expected to increase 46% by 2030, resulting in 8 million or more adult heart failure patients.<sup>2</sup> The mortality rate of patients with heart failure in the United States remains high; almost half of patients diagnosed with heart failure will die within 5 years.<sup>3</sup> Moreover, surviving patients with heart failure have high morbidity burden compared to those without heart failure.<sup>4</sup> Total cost of heart failure in adults 18 years or older, including direct medical costs and productivity loss, was \$31 billion in 2012.<sup>2</sup>

Previous studies have indicated that the hospitalization and mortality rates associated with heart failure have been decreasing among Medicare beneficiaries,<sup>1,3,5</sup> but the impact of these trends on the economic burden of heart failure is unclear. The improvement of survival rates for heart failure may shift the burden from mortality to morbidity and long-term care.<sup>1</sup> Lower mortality rates may reduce productivity loss due to death, although the majority of people with heart failure are older Americans with low productivity. For patients with advanced stages of heart failure, improved medical care can lead to longer life expectancy, but patients may not be able to perform activities of daily living and need formal and informal caregiving. Thus, lower mortality rates may increase the need for formal and informal caregiving. Intensive informal caregiving may help lower hospitalization rates and reduce direct medical costs but can lead to greater informal caregiving burden. For instance, adherence to heart failure treatment guidelines can lower hospitalization rates but may require more use of informal caregiving.

To better understand the economic burden of heart failure, it is important to study informal caregiving hours used and associated costs. Although many previous studies have investigated direct medical costs of heart failure,<sup>2,6,7</sup> informal caregiving costs associated with heart failure have been largely ignored. We attempt to fill this gap by specifying an econometric model to estimate the hours and economic value of informal caregiving for patients with heart failure.

## Data and Methods

### Data

For our analysis, we used cross-sectional data from the 2010 Health and Retirement Study (HRS).<sup>8</sup> HRS is a biennial longitudinal household survey for monitoring the health and well-being of people who are near or older than retirement age in the United States. It contains abundant socio-demographic information as well as self-reported health status, and has often been used to estimate informal caregiving costs associated with chronic diseases including cancer, diabetes, stroke, and dementia.<sup>9–13</sup> From the respondents who participated in the 2010 interview (N = 22,034), we limited the sample to non-institutionalized respondents aged 50 or older without missing data; 19,762 respondents (Figure 1) had complete information, of which 943 self-identified as having heart failure.

We used a sequence of questions from the HRS to verify whether a respondent used any (formal or informal) caregiving services. The first question was about whether a respondent had a functional disability that limited his or her ability to perform activities of daily living (ADLs) or instrumental activities of daily living (IADLs).<sup>14</sup> The HRS included 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. When respondents reported they had any difficulties with doing ADLs or IADLs due to a health or a memory problem, they were asked whether they had caregivers. Those who reported having caregivers were asked about their relationship with each caregiver and payment status. Informal caregivers were defined as those who were family caregivers or volunteers without payment.<sup>12</sup>

Weekly informal caregiving hours were estimated by multiplying the number of days per week by the number of hours per day of caregiving from an informal caregiver. When a respondent reported multiple informal caregivers, we summed weekly informal caregiving hours from all informal caregivers per respondent. For respondents who reported no use of caregivers, we assumed zero hours of informal caregiving.

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### Two-part model

We applied a two-part model to estimate the incremental informal caregiving hours associated with heart failure. This is because the distribution of informal caregiving hours is skewed; most of the study sample (90.4%) did not use informal caregiving. This model has been used in estimating informal caregiving costs of several chronic diseases such as cancer, diabetes, stroke, and dementia and well explained in previous literature.<sup>4, 10-12</sup>

The first part of a two-part model is a binary choice model for the estimation of probability of observing zero versus positive outcome. We applied a logit model in the first part to estimate the effect of heart failure on the likelihood of receiving informal caregiving. The second part is regression model conditional on a positive outcome. A generalized linear model (GLM) with the log link and gamma distribution was used in this paper to estimate the effect of heart failure on logged informal caregiving hours among those who received informal caregiving.<sup>15, 16</sup> The independent variables were race, age, gender, marital status, education, self-reported chronic conditions, and usage of formal caregiving. These variables were controlled for in both the logit model and the linear regression model. We ran a two-part model with the whole sample for a national estimate. To investigate the health disparities in informal caregiving burden, we also ran the two-part models for non-Hispanic whites and non-Hispanic blacks, separately. We did not run the model for Hispanic population because of too few of them had heart failure (n=84). The average marginal effect of heart failure on weekly informal caregiving hours was estimated from the combined results of both parts. The STATA (StataCorp, College Station, TX) command “tpm” was used for the two-part model estimation.<sup>15</sup>

## Cost estimation

We estimated the economic value associated with informal caregiving by using a replacement approach, which assumes that informal care activities substitute for activities of formal (paid) caregivers.<sup>12, 17</sup> We used the median wage of home health aide workers (\$9.89/hour) in 2010 from the US Bureau of Labor Statistics as the hourly cost for informal caregiving.<sup>12</sup> We estimated the national level of informal caregiving cost associated with heart failure by using the heart failure prevalence estimates among those who were 50 or older from the 2010 HRS.<sup>12</sup> We translated weekly per-patient cost into annual national cost by multiplying the weekly per patient informal caregiving cost, the number of heart failure cases, and 52 weeks.

## Results

Among 19,762 respondents, 943 reported having ever been diagnosed with heart failure (Figure 1), for a weighted prevalence of 3.9%. Overall, those who ever had heart failure have different socio-demographic characteristics, and health conditions compared to those who never had heart failure (Table 1). The heart failure group was more likely to use both informal caregiving than the non-heart failure group. Overall, 33.0% of the respondents in the heart failure group used informal caregiving, compared to 8.6% of respondents without heart failure ( $P < .001$ ). Among those who used informal caregiving, the heart failure group used an average of 32.1 hours of informal caregiving per week, compared to 25.1 hours per week for the non-heart failure group ( $P = .002$ ). Detailed caregiving statistics were shown in Appendix Table 1. The similar patterns were observed within non-Hispanic white and non-Hispanic black sub-race groups.

The two-part model with total population showed that people in the heart failure group were more likely to use informal caregiving than those in the non-heart failure group (odds ratio [OR], 1.99;  $P < .001$ ) (Table 2). An average of 1.63 total weekly hours was associated with heart failure ( $P < .001$ ). For non-Hispanic whites, respondents with heart failure were more likely to use informal caregiving than those in the non-heart failure group (OR, 1.97;  $P < .001$ ); but among those who used informal caregiving, informal caregiving hours were not significantly different between the heart failure and non-heart failure groups. Informal caregiving hours attributable to heart failure were 1.36 hours per week ( $P < .001$ ). For non-Hispanic blacks, people in the heart failure group also were more likely to use informal care than those without heart failure (OR 1.75;  $P = .072$ ). Weekly informal caregiving hours attributable to heart failure were 3.87 hours ( $P = .001$ ).

Using the median wage of home health aid workers in 2010 (\$9.89 per hour) and the incremental weekly informal caregiving hours associated with heart failure, the annual average informal caregiving cost associated with heart failure was \$836 per patient for total population (Table 2). We estimated average annual incremental cost associated with heart failure per patient to be \$699 for non-Hispanic whites and \$1,988 for non-Hispanic blacks (Table 2). By using the estimated prevalence of heart failure from the 2010 HRS of 3.6 million, the national cost of informal caregiving associated with heart failure among those who were non-institutionalized and aged 50 or older was \$3.0 billion (95% CI, \$1.9 billion to \$4.2 billion) in 2010. For non-Hispanic whites ( $n = 2.8$  million), the annual informal

caregiving cost associated with heart failure as \$2.0 billion (95% CI, \$1.0 billion to \$2.9 billion). For non-Hispanic blacks (n = 0.5 million), the informal caregiving cost for heart failure in 2010 was \$1.0 billion in (95% CI, \$0.4 billion to \$1.6 billion).

## Discussion

Our estimates suggest a high economic burden due to informal caregiving for patients with heart failure. In 2010, ever having a diagnosis of heart failure was associated with 1.63 hours per week of informal caregiving. This finding was consistent with a previous study using 2000 HRS data for respondents who were at least 65 years old, which showed that those with heart failure used an additional 1.6 hours of informal caregiving per week compared with those who never had any heart problems.<sup>4</sup> Heidenreich et al. showed that the productivity loss associated with heart failure, which did not include informal caregiving costs, was \$8.6 billion in 2012 for those who were 45 years or older in the United States.<sup>2</sup> Although our age group differed slightly ( 50 y), our cost estimate of \$3.0 billion per year for informal caregiving associated with heart failure represents an additional 35% in indirect costs, on the basis of the estimate from Heidenreich et al.

Some authors have proposed that mortality and morbidity costs associated with heart failure, which take into account lost productivity, are less than direct medical costs among older Americans because of their low employment rate.<sup>2</sup> The informal caregiving cost associated with heart failure, which is a part of indirect cost but is not affected by the employment status of heart failure patients, can be significant among older heart failure patients. Thus, the indirect cost of heart failure is substantially underestimated if informal caregiving cost is not taken into account.

We found that the incremental cost of informal caregiving for heart failure among non-Hispanic blacks was 2.8 times higher than the cost among non-Hispanic whites. Several factors may account for this difference. First, cultural traditions and strong informal caregiving networks among non-Hispanic blacks may increase the use of informal caregiving.<sup>18–21</sup> Our results suggest that non-Hispanic blacks are more likely to use informal caregiving than non-Hispanic whites for both the heart failure and non-heart failure groups.

Second, low access to formal caregiving may lead to the extensive use of informal caregiving among non-Hispanic blacks. It is well-known that racial/ethnic minorities face barriers to health services.<sup>22</sup> The older non-Hispanic black population is less likely to use formal caregiving, including paid in-home services and nursing home care, than older non-Hispanic whites.<sup>23</sup> Less use of formal caregiving may explain the high level of informal caregiving use among non-Hispanic blacks. Finally, because non-Hispanic black patients with heart failure have higher hospitalization and re-hospitalization rates and a lower mortality rate at 30 days and 1 year due to heart failure than non-Hispanic whites,<sup>2, 3, 24</sup> they may need more informal caregiving.

When informal caregiving costs are not included in cost-of-illness estimates, heart failure costs among non-Hispanic blacks can be highly underestimated and can contribute to inaccurate assessment of racial/ethnic disparities in total heart failure costs. Another serious

issue among non-Hispanic black is the onset of heart failure at young age.<sup>25</sup> The early onset of heart failure increases overall indirect costs, including informal caregiving cost and productivity loss, associated with heart failure because of longer life expectancy. Therefore, managing and preventing heart failure in middle-aged non-Hispanic blacks should be a public health priority.

The use of the two-part model enabled us to properly estimate the informal caregiving hours and cost associated with heart failure. Another method often used in literature is a comparison of informal caregiving use before and after the onset of a disease.<sup>26</sup> This method may have a benefit when (1) the moment of disease onset is easy to verify, (2) the onset itself has a significant effect on informal caregiving, and (3) the onset of the disease causes long-term permanent disability. However, heart failure usually is diagnosed after several years of onset, and the moment of onset is hard to verify. The moment of diagnosis can be observed, but the diagnosis itself does not affect informal caregiving needs as much as diseases such as stroke, which usually require immediate surgery or treatment after diagnosis. Also, level of disability among patients with heart failure depends on the management of overall health conditions and can improve over time after diagnosis.

The use of nationally representative data to estimate the cost of informal caregiving was an additional strength of this study. In previous HRS waves, respondents were asked whether a doctor has told you that you have heart failure in the last two years. The question potentially allowed patients with very mild or well-managed heart failure to be categorized in the non-heart failure group. The 2010 HRS asked whether a doctor ever told you that you have heart failure. Thus, we were able to estimate the national level of informal caregiving burden associated with heart failure based on the self-reported diagnosis of heart failure. This dataset, providing sufficient socio-demographic variables, make use of the two-part model possible. The model reduced possible sample selection bias by adjusting for adequate numbers of sample characteristics.

A limitation of this study is that we cannot incorporate the severity of heart failure into our analysis because the survey does not provide that information. Patients with minor symptoms of heart failure may use less informal caregiving than patients with symptomatic stages of heart failure. Another limitation is that the HRS relies on self-reported information and does not have detailed medical diagnosis and treatment information for heart failure. Informal caregiving hours were also self-reported and exposed to the possible reporting errors. Our data is cross-sectional. The cost consequences should be interpreted as associated with, rather than caused by, heart failure. We did not include the population who were staying in long-term care facilities at the time of the survey because 97% of them had zero survey weight and national representativeness of the population was unclear. Although we considered socio-demographic characteristics and multiple chronic conditions as confounders, other unknown characteristics could have led to increased informal caregiving needs.

Despite these limitations, our study proposes a robust estimate of the cost of informal caregiving for heart failure. This information will be useful to public health decision makers

who must rank public health priorities and develop strategies for reducing the health and economic burdens of heart failure.

## Conclusion

In this study, we estimated that the annual informal caregiving cost for non-institutionalized US patients with heart failure aged 50 or older was \$3.0 billion in 2010. This is 35% of one current estimate of mortality and morbidity costs for heart failure in the literature. This information should be taken into account when considering the economic burden of heart failure and developing intervention strategies for heart failure prevention. We also found that non-Hispanic black patients used 2.8 times more informal caregiving cost than non-Hispanic white patients. This information should be considered when developing intervention programs to reduce racial disparities in heart failure cost and prevalence.

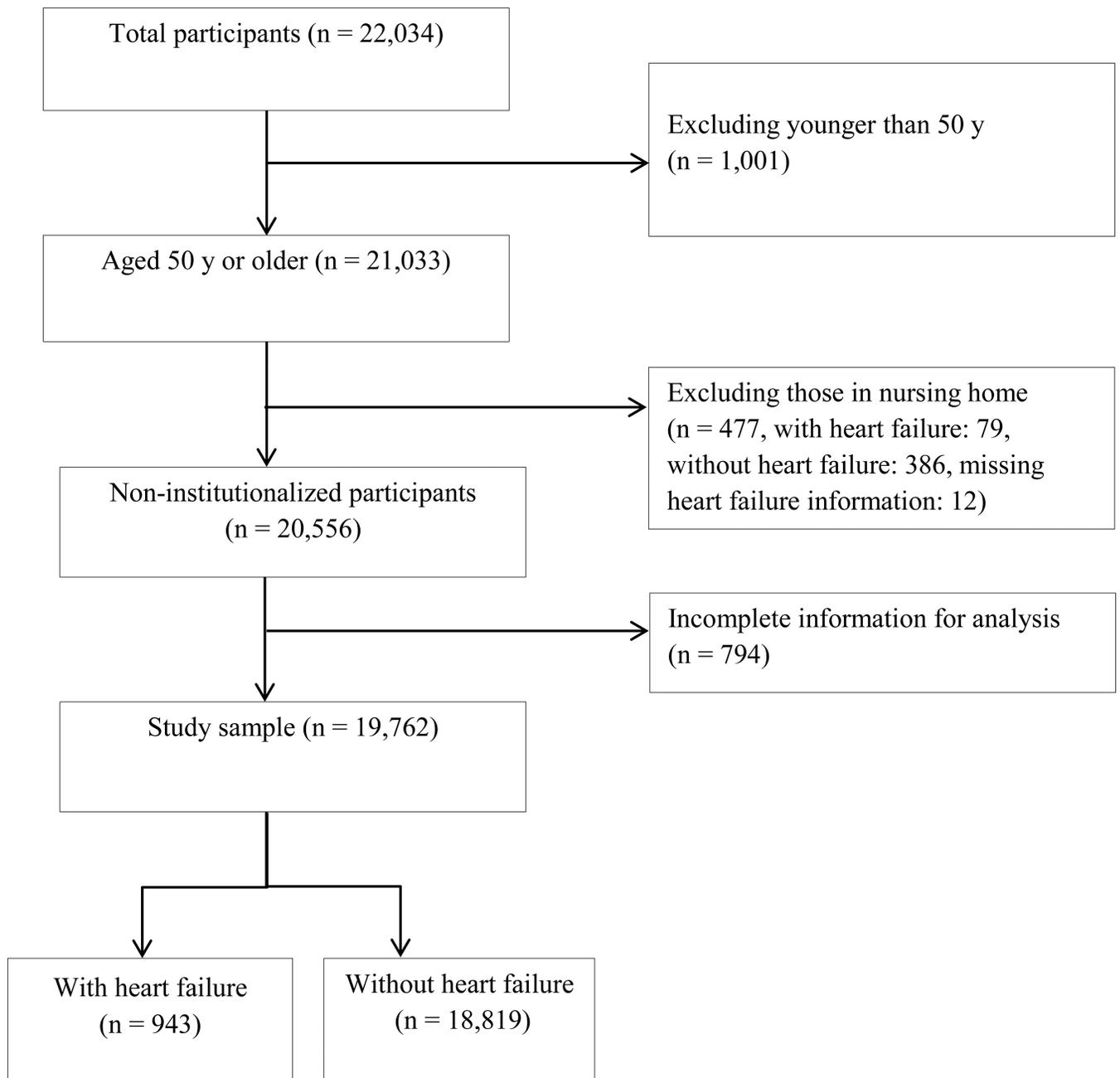
## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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**Figure 1.**  
Study Population Selection Process from the 2010 Health and Retirement Study

Characteristics of Study Sample, by Race and Heart Failure Status, 2010 Health and Retirement Study (%)

Table 1

	Total population (n=19,762)				Non-Hispanic white (n=12,849)		Non-Hispanic black (n=3,744)		
	Without heart failure (n=18,819)	With heart failure (n=943)	P-value	Without heart failure (n=12,213)	With heart failure (n=636)	P-value	Without heart failure (n=3,540)	With heart failure (n=204)	P-value
Races/ethnicities									
	Non-Hispanic white	78.9	.289	-	-	-	-	-	-
	Non-Hispanic black	9.8	.004	-	-	-	-	-	-
	Hispanic	8.6	.071	-	-	-	-	-	-
	Other	2.6	.949	-	-	-	-	-	-
Gender	Male	45.9	.119	46.2	52.3	.009	43.0	33.3	.043
Age, y	50-64	59.5	<0.001	56.6	27.3	<0.001	68.1	66.2	.729
	65-74	22.8	0.004	23.8	32.7	.002	19.4	16.9	.532
	75-84	12.9	<0.001	14.1	26.9	<0.001	9.7	11.9	.419
	85 over	4.8	<0.001	5.4	13.1	<0.001	2.8	5.0	.180
Married		62.2	<0.001	64.8	50.2	<0.001	38.9	32.6	.172
Education	Less than high school	15.1	<0.001	10.3	19.4	<0.001	24.9	30.7	.193
	High school graduate	30.7	0.139	32.0	35.8	.156	28.9	31.6	.541
	Some college	24.9	0.649	25.7	26.5	.717	27.0	29.5	.651
	College and more	29.3	<0.001	31.9	18.4	<0.001	19.2	8.2	<0.001
Self-reported chronic conditions	Hypertension	53.8	<0.001	51.8	81.9	<0.001	69.7	97.0	<0.001
	Diabetes	19.2	<0.001	16.7	45.5	<0.001	27.0	61.4	<0.001
	Cancer	13.1	<0.001	14.2	22.9	<0.001	9.9	16.3	.078
	Chronic lung disease	8.6	<0.001	9.2	31.9	<0.001	7.2	33.1	<0.001
	Stroke	5.0	<0.001	4.7	23.0	<0.001	7.8	21.1	<0.001
	Psychiatric disorders	17.9	<0.001	18.7	30.0	<0.001	14.1	36.7	<0.001
	Arthritis	52.2	<0.001	53.8	77.5	<0.001	52.7	75.6	<0.001
Informal caregiving	Utilization	8.6	<0.001	7.7	30.0	<0.001	12.7	37.9	<0.001
	Weekly hours <sup>a</sup>	25.1	0.002	23.1	30.6	0.023	31.3	43.2	0.027

	Total population (n=19,762)		Non-Hispanic white (n=12,849)		Non-Hispanic black (n=3,744)				
	Without heart failure (n=18,819)	With heart failure (n=943)	P-value	Without heart failure (n=12,213)	With heart failure (n=636)	P-value			
# of caregivers <sup>a</sup>	1.7	1.9	0.007	1.6	1.7	0.037	2.1	2.5	0.234
Formal caregiving									
Utilization	1.5	9.1	<0.001	1.3	7.5	<0.001	2.9	13.8	<0.001
Weekly hours <sup>a</sup>	29.1	31.1	0.783	33.0	35.1	0.852	20.7	23.0	0.788
# of caregivers <sup>a</sup>	1.2	1.4	0.172	1.3	1.4	0.467	1.2	1.3	0.305

Notes: All statistics are properly weighted.

<sup>a</sup> All numbers are from those who utilized caregiving.

**Table 2**

Heart Failure-Associated Informal Caregiving Use and Cost among People Aged 50 or Older, by Race, 2010 Health and Retirement Survey

	<b>Total population (n=19,762)</b>	<b>Non-Hispanic white (n=12,849)</b>	<b>Non-Hispanic black (n=3,744)</b>
Odds ratio of using informal caregiving (With vs. Without heart failure)	1.992* [1.567–2.533] <sup>a</sup>	1.968* [1.468–2.638]	1.747 [0.950–3.214]
Heart failure associated use of informal caregiving (hours/week) <sup>b</sup>	1.625* [1.009–2.242]	1.359* [0.709–2.009]	3.866* [1.552–6.179]
Annual informal caregiving costs associated with heart failure			
Per patient estimates (\$) <sup>c</sup>	836 [519–1,153]	699 [365–1,033]	1,988 [798–3,178]
National estimates (\$ billion) <sup>d</sup>	3.030 [1.881–4.181]	1.950 [1.017–2.883]	0.998 [0.400–1.595]

Notes:

\* p<0.01.

<sup>a</sup>Numbers in squared brackets are 95% confidence interval.

<sup>b</sup>Estimated results are from survey weighted two-part models with adjustment of gender, age, marital status, education, self-reported chronic conditions (hypertension, diabetes, cancer, chronic lung disease such as chronic bronchitis or emphysema, stroke, psychiatric disorders, and arthritis), and usage of formal caregiving.

<sup>c</sup>Per patient annual informal caregiving costs associated with heart failure were estimated by using total weekly hours associated with heart failure multiplied by 52 weeks and median wages of health aide workers (\$9.89/hour) from the 2010 U.S. Labor Statistics.

<sup>d</sup>National estimates were derived by per capita annual informal caregiving costs multiplied with national estimate of patients with HF aged 50 and older from 2010 HRS.