## Cost of informal caregiving for patients with heart failure



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

**Methods** We used a study sample of noninstitutionalized US respondents aged  $\geq$ 50 years from the 2010 HRS (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 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 2-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. (Am Heart J 2015;169:142-148.e2.)

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 with those without heart

failure.<sup>4</sup> Total cost of heart failure in adults aged  $\geq$ 18 years, 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 most 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 (ADLs) 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.

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## Figure



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 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 sociodemographic 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 noninstitutionalized respondents aged  $\geq$ 50 years without missing data; 19,762 respondents (Figure) 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 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 that 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

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