

Burden of Cirrhosis on Older Americans and Their Families: Analysis of the Health and Retirement Study

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Prevalence of cirrhosis among older adults is expected to increase; therefore, we studied the health status, functional disability, and need for supportive care in a large national sample of individuals with cirrhosis. A prospective cohort of individuals with cirrhosis was identified within the longitudinal, nationally representative Health and Retirement Study. Cirrhosis cases were identified in linked Medicare data via ICD-9-CM (International Classification of Diseases, Ninth Revision, Clinical Modification) codes and compared to an age-matched cohort without cirrhosis. Two primary outcome domains were assessed: (1) patients' health status (perceived health status, comorbidities, health care utilization, and functional disability as determined by activities of daily living and instrumental activities of daily living), and (2) informal caregiving (hours of caregiving provided by a primary informal caregiver and associated cost). Adjusted negative binomial regression was used to assess the association between cirrhosis and functional disability. A total of 317 individuals with cirrhosis and 951 age-matched comparators were identified. Relative to the comparison group, individuals with cirrhosis had worse self-reported health status, more comorbidities, and used significantly more health care services (hospitalizations, nursing home stays, physician visits; $P < 0.001$ for all bivariable comparisons). They also had greater functional disability ($P < 0.001$ for activities of daily living and instrumental activities of daily living), despite adjustment for covariates such as comorbidities and health care utilization. Individuals with cirrhosis received more than twice the number of informal caregiving hours per week ($P < 0.001$), at an annual cost of US \$4700 per person. **Conclusion:** Older Americans with cirrhosis have high rates of disability, health care utilization, and need for informal caregiving. Improved care coordination and caregiver support is necessary to optimize management of this frail population. (HEPATOLOGY 2012;55:184-191)

The prevalence of cirrhosis among older adults is expected to increase,¹ in part due to the rising incidence of nonalcoholic fatty liver disease and the aging of the hepatitis C population.^{2,3} Patients with cirrhosis, especially those with age-related comorbidities, experience several potentially debilitating complications that can have a significant impact on activities of daily living (ADLs), such as the ability

to dress oneself, and instrumental activities of daily living (IADLs), such as the ability to manage shopping or housework. These impairments, combined with the associated regimen of dietary restrictions, medications, laboratory testing, and clinic visits, make management of cirrhosis in the elderly very complex.⁴ Furthermore, optimal home-based care is limited without caregivers who can help supplement the care

Abbreviations: ADL, activities of daily living; CMS, Center for Medicare and Medicaid Services; HRS, Health and Retirement Study; IADL, instrumental activities of daily living; ICD-9-CM, International Classification of Diseases, Ninth Revision, Clinical Modification; IRR, incident rate ratio; PPV, positive predictive value.

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that clinicians provide.⁵ Figure 1 presents a conceptual framework demonstrating how cirrhosis-related complications, underlying psychosocial/behavioral issues, and aging might contribute to increased caregiver time and burden.

The importance of informal caregiving by family members has been well described for patients with other chronic diseases such as diabetes, congestive heart failure, and stroke. Caregiver involvement improves patient outcomes,⁶ and interventions can increase caregiver effectiveness.⁷⁻⁹ Informal caregiving for these conditions has also been shown to cause significant economic and health burdens for the caregivers.¹⁰⁻¹⁶ For older adults with cirrhosis, the degree of functional impairment and involvement of informal caregivers has not been well described. The current study used a unique, large national data set to assess health status and functional disability of older individuals with cirrhosis and its complications, as well as estimate the burden and cost of informal caregiving in this population.

Patients and Methods

Human Subjects

This study was conducted using prospectively collected data from the Health and Retirement Study (HRS) linked to the Center for Medicare and Medicaid Services (CMS) standard analytic files. The HRS is a biennial, longitudinal survey of a nationally representative cohort of US adults older than 50 years of age. The HRS includes more than 22,000 Americans, with interviews performed every 2 years, providing detailed information on participants' functional condition, health status, and caregiver assistance. The HRS has been used previously to characterize the functioning and caregiver support for individuals with chronic diseases such as congestive heart failure and diabetes.^{10,17} HRS respondents who met the following criteria were included in the study population: (1) community-dwelling (i.e., those living in skilled nursing facilities or nursing homes were excluded), (2) completed an interview some time between 1998-2008, and (3) age ≥ 65 years at the time of the interview. Because HRS surveys may not accurately identify patients with cirrhosis, we linked surveys to Medicare claims using International Classification of Diseases (ICD) codes, as

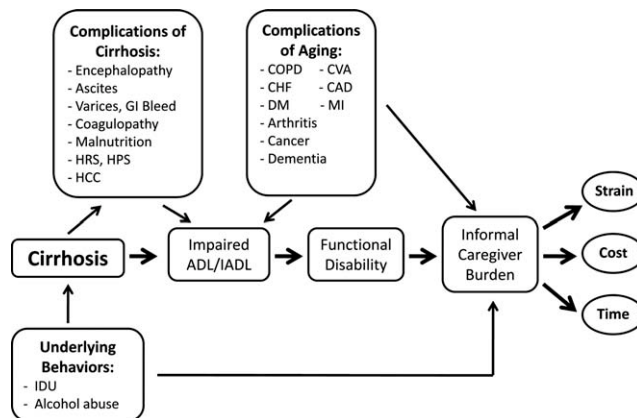


Fig. 1. Conceptual framework demonstrating how cirrhosis-related complications, underlying psychosocial/behavioral issues and aging contribute to increased informal caregiver burden. CAD, coronary artery disease; CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease; CVA, cerebrovascular accident; DM, diabetes mellitus; GI, gastrointestinal; HCC, hepatocellular carcinoma; HPS, hepatopulmonary syndrome; HRS, hepatorenal syndrome; IDU, injection drug use; MI, myocardial infarction.

described below. The first CMS claim date on which a cirrhosis diagnosis was identified is referred to as the "index date." The HRS interview following the index date is referred to as the "index HRS interview," and was the source of information for the current study. Median time from "index date" to "index HRS interview" was 370 days (range, 1-1090 days); cases without an interview within 3 years of the index date were excluded from the analysis.

Cirrhosis Cases. A set of ICD-9-CM (ICD, Ninth Revision, Clinical Modification) codes were used to identify cases with cirrhosis and its complications. Individuals with cirrhosis were identified from all available Medicare claims files (carrier, inpatient, outpatient, skilled nursing, home health, and hospice) between 1995-2007 as those individuals having at least one of the following ICD-9-CM claims for cirrhosis (alcoholic cirrhosis, 571.2; cirrhosis not due to alcohol, 571.5) or complications of cirrhosis (hepatic encephalopathy, 572.2; ascites, code 789.5 until 2007, then 789.59; hepatorenal syndrome, 572.4; esophageal varices with bleeding, 456.0, 456.2; esophageal varices without bleeding, 456.1, 456.2; portal hypertension, 572.3; hepatocellular carcinoma, 155.0; and spontaneous bacterial peritonitis, 567.23). Individuals identified solely by ascites code were included only if they had two or more ascites claims on different days in a 1-year period.

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This algorithm was then externally validated by reviewing patient charts for a sample of patients identified by ICD-9-CM codes and receiving care at the University of Michigan in 2008. Positive predictive value (PPV) of the ICD-9-CM codes was determined using a random sample of 100 outpatients and inpatients with these billing codes seen at the University of Michigan in 2008. A diagnosis of cirrhosis was determined by chart audit performed by a hepatologist, on the basis of compatible histologic analysis; imaging showing a cirrhotic liver with splenomegaly and a platelet count of $<120,000/\text{mm}^3$; or evidence of decompensated cirrhosis with hepatic encephalopathy, hepatorenal syndrome, ascites, or variceal bleeding. Of those with a verified diagnosis of cirrhosis, further chart review was performed to determine if cirrhosis was compensated or decompensated at the time the ICD-9-CM code was billed. A second cohort of patients was used to determine sensitivity of the ICD-9-CM codes. Inpatient and outpatient billing codes were assessed over the past 2 years for a random sample of 100 patients from another study for which patients with cirrhosis had been enrolled prospectively. The above validity tests showed that our algorithm of ICD-9-CM codes had a PPV of 88% and a sensitivity of 67%. Of the patients with a diagnosis of cirrhosis verified by chart review, 43% had compensated and 57% had decompensated cirrhosis at the time of coding, indicating that our algorithm of ICD-9-CM codes identified patients with both compensated and decompensated cirrhosis.

Comparison Group. An age-matched cohort of HRS respondents who did not have cirrhosis served as a comparison group. Each cirrhosis case was matched by age with three comparators, drawn from the pool of HRS respondents completing surveys during the same period and enrolled in Medicare Parts A and B FFS (Fee-For-Service) in the month of the index date, but without any Medicare claims indicating cirrhosis.

Data Analysis

Two primary outcome domains were assessed: patients' health status (perceived health status, comorbidities, health care utilization, and functional disability) and informal caregiving (hours of caregiving provided by a primary informal caregiver and associated cost). In order to determine degree of functional decline over time, change in functional disability and hours of informal caregiving was measured over the time period between the HRS interview before and after the index date (first date of cirrhosis detection by ICD-9-CM code).

Self-reported comorbid medical illnesses included hypertension, diabetes, cancer, chronic lung disease (asthma, chronic obstructive lung disease), heart disease, stroke, and arthritis. Cognitive function was measured by using a validated screening test for cognitive function (35-point scale including tests of memory, serial 7 subtractions, naming, and orientation).¹⁸ Although objective testing was used for cognitive assessment, it is important to note that these tests do not differentiate between impairment due to hepatic encephalopathy or competing etiologies such as Alzheimer's disease or alcohol-related dementia. On the basis of these tests, cognitive function was categorized using accepted cut-points into three levels of functioning: normal, mild-to-moderate impairment, and severe impairment. Health care utilization was measured by the number of subjects that required hospitalization, nursing home stay, or home health services during the 2 years prior to the index HRS survey. Number of physician visits as well as out-of-pocket medical expenses over the duration of 2 years was also recorded.

Subjects' ability to perform tasks of daily living was assessed within the two commonly recognized domains of ADLs and IADLs. ADLs include the following six activities: eating, dressing, bathing, toileting, getting in and out of bed, and mobility inside own residence. ADLs were considered impaired if the subject reported difficulty performing or receiving help with any of the above six activities. IADLs include the following five activities: cooking, grocery shopping, taking medications, managing money, and using the telephone. IADLs were considered impaired if the subject reported difficulty performing or receiving help with any of the above five activities.

An informal caregiver was defined as a family member or unpaid relative with no organizational affiliation who provided in-home care to the respondent. Data recorded for the caregiver included sex and relationship to the respondent. The number of hours per week of informal caregiving was calculated using the average number of days per week and the average number of hours per day that the subject reported receiving informal care in the past month. The hours of caregiving were averaged across all subjects, including those who did not receive any caregiving.

Demographic data included sex, age, race, ethnicity, living situation (married, unmarried living with others, unmarried living alone), presence of children who live within 10 miles, years of education, insurance other than Medicare/Medicaid, and household net worth.

Cost of Informal Care. The annual cost of informal caregiving can be estimated using opportunity cost,

which accounts for the cost of hours sacrificed by the informal caregiver in order to care for a patient by applying a market wage rate to caregiving activities.^{19,20} Opportunity cost can be estimated using the wage of an equivalent service, such as that of a home health aide. The yearly opportunity cost of informal caregiving for individuals with cirrhosis was estimated by multiplying the median hourly national wage for a home health aide (US \$9.85)²¹ × the weekly hours of informal caregiving × 52 (weeks per year). Upper and lower bound cost estimates for informal caregiving were created using 10th and 90th percentile hourly wage for a home health aide, respectively (10th percentile: US \$7.67; 90th percentile: US \$14.13). Cost estimates were averaged across all subjects, including those who did not receive any caregiving.

Statistical Analysis. Descriptive bivariate statistics were analyzed using chi-squared and F-tests for categorical and continuous variables, respectively. Negative binomial regression was used to estimate the independent effect of cirrhosis on number of impaired ADLs (and IADLs). On the basis of regression results, we calculated incident rate ratios (IRR), which is the ratio of the incidence rate of impaired ADLs (or IADLs) in individuals with cirrhosis relative to the rate of impairment among individuals without cirrhosis. An IRR > 1 indicates that cirrhosis is associated with increased impairment in functional status compared to their age-matched controls. The model was adjusted for potential confounders known to be associated with cirrhosis and independently associated with poor functional status (age, sex, race, ethnicity, schooling, net worth, living arrangement, comorbidities, and insurance other than Medicare/Medicaid). Comorbidities were entered into the model as seven separate binary indicators, one for each comorbid condition. Cognitive impairment was intentionally excluded from this model, because neurocognitive dysfunction may directly result from cirrhosis and thus be a pathway to disability rather than a confounder. To determine whether health care utilization confounded the association between cirrhosis and disability, a sensitivity analysis was performed by creating an interaction variable between presence of cirrhosis and number of physician visits (over the duration of 2 years) and including it as a covariate in the regression model. All analyses were carried out using SAS version 9.1.3 (SAS Institute, Cary, NC) and were adjusted for the matched case-comparator design. The study protocol conformed to the ethical guidelines of the 1975 Declaration of Helsinki as reflected in *a priori* approval by the appropriate institutional review committee.

Table 1. Demographic Characteristics of Patients with Cirrhosis and Comparison Group*

Variable	Cirrhosis Cases (n = 317)	Comparison Group (n = 951)	P Value
Age (years)	74.7 ± 0.4	74.7 ± 0.2	0.68
Sex (Male)	143 (45.1)	393 (41.3)	0.24
Race/ethnicity			
White	227 (71.6)	797 (83.8)	<0.001
Black	45 (14.2)	98 (10.3)	
Hispanic	40 (12.6)	49 (5.2)	
Other	5 (1.6)	7 (0.7)	
Education (years)	11.0 ± 0.2	11.7 ± 0.1	0.001
Living arrangement			
Married, living with spouse	172 (54.3)	553 (58.2)	0.35
Unmarried, living with others	50 (15.8)	117 (12.3)	
Unmarried, living alone	95 (30.0)	281 (29.6)	
Children within 10 miles	203 (65.1)	555 (59.7)	0.14
Household net worth (US\$)†	102,439 (27,600-292,500)	181,513 (43,926-493,178)	0.04

*Data presented as (mean ± standard error) for continuous variables, n (%) for categorical variables.

†Median (interquartile range).

Results

Study Population Characteristics

We identified 317 cases with cirrhosis and 951 comparators in the linked HRS-Medicare data. Relative to the comparison group, individuals with cirrhosis were more likely to be Hispanic ($P < 0.001$), have less education ($P = 0.001$), and have lower net worth ($P = 0.040$) (Table 1). The two groups were similar with respect to the proportion of individuals with insurance other than Medicare/Medicaid ($P = 0.091$).

Health Status and Functional Disability

Individuals with cirrhosis had a greater number of medical comorbidities ($P < 0.001$) than those in the comparison group, worse perceived health status ($P < 0.001$), and more severe cognitive impairment ($P = 0.001$) (Table 2). They also required more than double the health care services (hospitalizations, nursing home stays, and physician visits; $P < 0.001$ for all) and had significantly higher out-of-pocket medical expenses ($P = 0.001$) compared to those without cirrhosis, yet only 25% reported receiving home health services. One-quarter of individuals with cirrhosis reported their health status as “poor”, compared to only 11% of those without cirrhosis ($P < 0.001$ for the trend; Table 2).

Individuals with cirrhosis had greater impairment of ADLs compared to the comparison group ($P < 0.001$), with 38% indicating at least one impaired ADL (Table 3). Overall, 14% of individuals with cirrhosis could perform only 0-2 of their ADLs (i.e., 4-6

Table 2. Self-Reported Health Status and Medical Conditions of Patients with Cirrhosis and Comparison Group*

Variable	Cirrhosis Cases (n = 317)	Comparison Group (n = 951)	P Value
Perceived health status			
Excellent	16 (5.1)	96 (10.1)	<0.001
Very good/good/fair	223 (70.6)	747 (78.6)	
Poor	77 (24.3)	107 (11.3)	
Perceived pain			
None	187 (59.0)	669 (70.7)	<0.001
Mild/moderate	96 (30.3)	212 (22.4)	
Severe	34 (10.7)	65 (6.9)	
Medical comorbidities§			
Hypertension	185 (58.4)	534 (56.3)	0.55
Diabetes	97 (30.6)	169 (17.8)	<0.001
Cancer	74 (23.4)	153 (16.1)	0.005
Lung disease	56 (17.7)	96 (10.1)	<0.001
Heart disease	133 (42.1)	290 (30.6)	<0.001
Stroke	51 (16.1)	105 (11.1)	0.02
Arthritis	212 (66.9)	589 (62.0)	0.10
Number of medical comorbidities	2.6 ± 0.08	2.0 ± 0.04	<0.001
Cognitive impairment			
None	175 (55.4)	635 (66.8)	0.001
Mild-moderate	92 (29.1)	204 (21.5)	
Severe	49 (15.5)	112 (11.8)	
Hospital stay†	212 (66.9)	311 (32.7)	<0.001
Nursing home stay†	55 (17.4)	53 (5.6)	<0.001
Home health services†	74 (24.8)	98 (10.6)	<0.001
Number of physician visits†	20.5 ± 2.4	10.8 ± 0.5	<0.001
Out-of-pocket medical expenses (US\$)†,‡	2150 (526-5379)	1459 (433-3709)	0.001

*Data presented as (mean ± standard error) for continuous variables, n (%) for categorical variables.

†Over the past 2 years, self-reported.

‡Median (interquartile range).

§Patient could indicate more than one comorbidity.

impaired ADLs). IADLs were similarly impaired, with 10% of individuals with cirrhosis able to perform only 0-1 IADLs (i.e., 4-5 impaired IADLs). The most common ADL and IADL impairments among those with cirrhosis were “dressing” and “grocery shopping”, respectively. After adjusting for covariates associated with functional disability, having cirrhosis was independently associated with impaired ADLs (adjusted IRR = 1.50, *P* = 0.004) and impaired IADLs (adjusted IRR = 1.72, *P* < 0.001) (Table 4). In other words, after adjustment, those with cirrhosis experienced 1.50 times more ADL impairments and 1.72 times more IADL impairments compared to those without cirrhosis. Sensitivity analysis using an interaction variable between cirrhosis and number of physician visits revealed no significant interaction between cirrhosis and health care utilization (ADL model: *P* = 0.33; IADL model: *P* = 0.80). In fact, greater use of health care services correlated more strongly with disability among the comparison group than among the cirrhosis group (data not shown). Thus, health care

Table 3. Functional Status of Patients with Cirrhosis and Comparison Group*

Variable	Cirrhosis Cases (n = 317)	Comparison Group (n = 951)	P Value
Number of impaired ADLs			
0	195 (61.5)	722 (75.9)	<0.001
1-3	79 (24.9)	166 (17.5)	
4-6	43 (13.6)	63 (6.6)	
Type of ADL impairment§			
Walking across room	63 (19.9)	110 (11.6)	0.001
Dressing	76 (24.0)	139 (14.6)	<0.001
Bathing	71 (22.4)	114 (12.0)	<0.001
Transferring	46 (14.6)	86 (9.1)	0.005
Toileting	52 (16.5)	91 (9.6)	<0.001
Eating	36 (11.4)	58 (6.1)	0.002
Loss of ADLs over time†,‡			
< 0	25 (8.6)	66 (7.7)	0.001
0	180 (62.1)	641 (74.7)	
1	32 (11.0)	76 (8.9)	
>2	53 (18.3)	75 (8.7)	
Number of impaired IADLs			
0	204 (64.4)	753 (79.3)	<0.001
1-3	80 (25.2)	146 (15.5)	
4-5	33 (10.4)	50 (5.3)	
Type of IADL impairment§			
Grocery shopping	91 (30.3)	135 (14.8)	<0.001
Managing money	65 (21.5)	96 (10.5)	<0.001
Cooking	63 (21.7)	102 (11.6)	<0.001
Taking medication	41 (13.1)	47 (5.1)	<0.001
Using the telephone	38 (12.1)	77 (8.2)	0.026
Loss of IADLs over time†,‡			
< 0	13 (4.5)	42 (5.0)	<0.001
0	187 (64.9)	673 (79.3)	
1	35 (12.2)	68 (8.0)	
>2	53 (18.4)	66 (7.8)	

*Data presented as (mean ± standard error) for continuous variables, n (%) for categorical variables.

†Category of < 0 indicates gain in ADLs (functional improvement); >0 indicates loss of ADLs (functional decline).

‡Median = 2.1 years (time between pre-index date survey and post-index date survey). Cirrhosis cases: n = 290; comparison group: n = 858.

§Patients could have more than one ADL or IADL impairment.

utilization does not confound the independent association between cirrhosis and disability.

Receipt of Informal Care

One-third of individuals with cirrhosis identified a caregiver (formal or informal), with less than 10% of

Table 4. Incident Rate Ratio (IRR) of the Association Between Cirrhosis and Functional Disability

IRR*	Cirrhosis	No Cirrhosis	P Value
Impaired ADLs			
Unadjusted	1.73 (1.38-2.15)	Ref.	<0.001
Adjusted†	1.50 (1.14-1.97)	Ref.	0.004
Impaired IADLs			
Unadjusted	1.95 (1.55-2.46)	Ref.	<0.001
Adjusted†	1.72 (1.30-2.29)	Ref.	<0.001

*IRR >1 indicates that cirrhosis is associated with higher incidence rate of functional disability (impaired ADL or IADL) compared to no cirrhosis.

†Adjusted for age, sex, race, ethnicity, schooling, net worth, living arrangement, medical comorbidities, and insurance other than Medicare/Medicaid.

Table 5. Patterns of Receiving Care for Patients with Cirrhosis and Comparison Group*

Variable	Cirrhosis Cases (n = 317)	Comparison Group (n = 951)	P Value
Receiving care			
Informal	99 (31.2)	157 (16.5)	<0.001
Formal	29 (9.2)	47 (4.9)	0.006
Any (formal or informal)	105 (33.1)	170 (17.9)	<0.001
Sex of informal caregiver			
Male	38 (38.4)	66 (42.0)	0.56
Female	73 (73.7)	114 (72.6)	0.84
Relationship of informal caregiver to patient†			
Child/children	57 (57.6)	93 (59.2)	0.79
Spouse	41 (41.4)	55 (35.0)	0.30
Grandchild	6 (6.1)	14 (8.9)	0.41
Other caregiver	20 (20.2)	31 (19.8)	0.93
Informal care received (hours per week)	9.14 ± 1.42	4.00 ± 0.59	<0.001
Increase in informal care received over time‡ (hours per week)	6.78 ± 1.32	2.75 ± 0.56	<0.001

*Data presented as (mean ± standard error) for continuous variables, n (%) for categorical variables.

†Patient was able to indicate more than one informal caregiver; Among those with at least one informal caregiver

‡Median = 2.1 years (time between pre-index date survey and post-index date survey). Cirrhosis cases: n = 290; comparison group: n = 858.

patients receiving formal (paid) care. Individuals with cirrhosis received more than twice the informal caregiving hours relative to the comparison group ($P < 0.001$), with informal care most often provided by the subjects' children (Table 5).

Change in Functional Status and Caregiving Over Time

Change in functional status and caregiving was determined using data from the HRS interview before and after the index date (i.e., first date of cirrhosis detection by ICD-9-CM code). Median time from the pre-index date interview until the post-index date interview was 775 days (2.1 years), with a range of 474-1853 days. Cases without an interview within 3 years prior to the index date were excluded from this pre- and post-index analysis. All cirrhosis cases and comparators completed an HRS survey after the index date; however, some did not have an HRS survey performed prior to the index date. Therefore, 9% of patients with cirrhosis and 10% of controls were excluded from these analyses, leaving a sample of 290 cases with cirrhosis and 858 comparators. Nearly 30% of patients with cirrhosis demonstrated functional decline over the pre- to post-index time period (median 2.1 years), as defined by loss of at least one or more ADLs. Moreover, 18% of individuals with cir-

rhosis had severe functional decline (loss of two or more ADLs), doubling that of the age-matched comparison group (Table 3). A similar rate of functional decline was seen for IADLs (Table 3). Over the pre- and post-index time period, individuals with cirrhosis received 6.8 additional hours of informal caregiving per week, more than twice as much as the increase in the age-matched comparison group (Table 5).

Annual Cost of Informal Caregiving

Using the 2009 median national wage for a home health aide (US \$9.85 per hour²⁰), the annual cost of informal caregiving for elderly individuals with cirrhosis was US \$4700 per person, compared to US \$2100 for age-matched elderly individuals without cirrhosis. Using the 10th and 90th percentile hourly national wage for a home health aide, annual cost of informal caregiving ranged from US \$3700 to US \$6700 for patients with cirrhosis and from US \$1600 to US \$2900 for patients without cirrhosis.

Discussion

In this nationally representative sample of older Americans, we found that individuals with cirrhosis had significantly worse health status and greater functional disability compared to those without cirrhosis, requiring nearly twice the amount of informal caregiving at an annual societal cost of approximately US \$4700 per individual. Nearly 20% of subjects with cirrhosis experienced severe functional decline (loss of two or more ADLs) over a median of approximately 2 years, more than doubling that of age-matched individuals without cirrhosis. As the incidence of nonalcoholic fatty liver disease increases and the population infected with hepatitis C virus ages, cirrhosis among the elderly will become increasingly prevalent and is expected to impose a significant burden to patients and their caregivers.

In addition to the potential burden to caregivers, individuals with cirrhosis also strain the health care system. Annually, cirrhosis results in 50,000 hospitalizations²²; of those who survive hospitalization, approximately 20% are readmitted within 30 days.²³ Our findings show that more than two-thirds of individuals with cirrhosis report being admitted to the hospital within the prior 2 years, an incidence twice that of age-matched individuals without cirrhosis. Moreover, fewer than one-quarter of individuals with cirrhosis received home health care services after hospital discharge, indicating a potentially lost opportunity for improved care transitions. In other diseases, improving patient and caregiver knowledge about

chronic disease management and integrating caregivers in the health care process have been shown to significantly decrease hospital admission rates.^{24,25} Our findings suggest that applying these concepts and services among patients with cirrhosis has the potential to result in significant cost savings.

It is important to emphasize this study compared subjects with cirrhosis to age-matched individuals, not healthy controls. As expected with advancing age, individuals in the comparison group had several comorbidities (e.g., arthritis in 62%, cardiac disease in 31%, diabetes in 18%, and cancer in 16%; Table 2), all of which can be independently associated with significant functional decline and cost. Thus, the current study highlights the incremental disability, cost, and caregiver burden of cirrhosis, even relative to other serious chronic illnesses. Future research is needed to examine the role that specific cirrhosis-related complications (such as muscle wasting, hepatic encephalopathy, and ascites) contribute to the overall disability found in this study.

To our knowledge, this is the first study to use a population-based sample to quantify functional disability and the impact on formal and informal care of individuals with cirrhosis. For comparison, a similar study of the HRS data set showed that individuals with congestive heart failure require an average of 6.7 hours of informal care per week, which is 2.5 fewer hours per week than the care requirements of those with cirrhosis.¹⁰ Data such as these have been used to demonstrate the need and potential efficacy of innovative programs that provide caregiver training and education,^{26,27} improve communication between provider and patients or caregivers (e.g., telemedicine),^{8,28} and create infrastructure for comprehensive chronic disease management²⁹ and postdischarge transitional care.^{30,31} As evidenced by our findings, patients with cirrhosis require similar support for basic activities such as bathing and taking medications, thereby necessitating the intervention of informal caregivers to help prevent potential poor outcomes (e.g., falls, missed appointments, medication noncompliance). Moreover, the significantly lower education level found in our study emphasizes that individuals with cirrhosis may have poor knowledge and coping strategies for managing their chronic disease, further contributing to functional disability. At present, there are few structured services that promote patient education and self-care or caregiver support for the population with cirrhosis.

Our study has some limitations that warrant comment. Although there are several studies that have defined cirrhosis using ICD-9 codes,³²⁻³⁵ prior methods have not been validated. In order to maximize

specificity, we selected a narrow spectrum of ICD-9-CM codes, and therefore may have excluded patients with well-compensated cirrhosis that are either unaware of diagnosis, asymptomatic with no prior history of decompensation, or who have limited interaction with the health care system. Similarly, it is possible that a small percentage of the comparison group may have undiagnosed cirrhosis. In addition, our study population may have excluded patients who lack comorbidities that would prompt medical care for reasons other than cirrhosis. However, we would expect a similar phenomenon in the comparison group, and therefore, both groups may equally consist of "sicker" patients. Also, the current study lacked histological, laboratory, or imaging data to confirm cirrhosis diagnosis. Although data such as medical comorbidities and health care utilization (hospitalization, nursing home, physician visits) were self-reported, several studies have demonstrated the accuracy of self-reported diagnoses.³⁶⁻³⁹ Finally, because cases were identified via linkage with the CMS database, our findings are limited to individuals with cirrhosis who are aged 65 or older.

Other limitations of our study involve our method for estimating cost, which likely resulted in an underestimate of the cost of informal caregiving. Estimates were based on caregiving from family members only, and did not include costs associated with caregiving from nonfamily members (e.g., friends, neighbors). Moreover, cost estimates were based only on assistance with ADLs and IADLs and did not include other time-consuming caregiving activities such as transportation to a hospital for clinic visits, laboratory tests, paracenteses, or variceal banding. Similarly, our cost estimates do not include other significant caregiving costs such as out-of-pocket expenses related to medications, medical supplies, or lost wages (patient or caregiver) related to cirrhosis. A recent study by Bajaj et al. highlighted these other cirrhosis-related expenses and the detrimental effect they can have on patients' ability to adhere to medical recommendations.⁴

This population-based study confirms the significant burden and cost that cirrhosis and its complications places upon the patient and caregiver, as well as the health care system. Clinicians should be aware of the increased need for informal caregiving among patients with cirrhosis, especially older individuals with other age-related comorbidities. In addition, health care economists and policy makers should consider the significant functional limitations of this population as well as the substantial hours of informal caregiving required to help avert preventable poor outcomes related to the patients' inability to independently

manage their disease. Greater focus on a comprehensive delivery of care for patients with cirrhosis, including involvement of caregivers and improved care coordination, is necessary to optimize management of this frail population.

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