Degree of Disability and Patterns of Caregiving among Older Americans with Congestive Heart Failure

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OBJECTIVES: Although congestive heart failure (CHF) is a common condition, the extent of disability and caregiving needs for those with CHF are unclear. We sought to determine: (1) prevalence of physical disability and geriatric conditions, (2) whether CHF is independently associated with disability, (3) rates of nursing home admission, and (4) formal and informal in-home care received in the older CHF population.

METHODS: We used cross-sectional data from the 2000 wave of the Health and Retirement Study. We compared outcomes among three categories of older adults: (1) no coronary heart disease (CHD), (2) CHD, without CHF, and (3) CHF.

RESULTS: Compared to those without CHF, respondents reporting CHF were more likely to be disabled ($P<0.001$) and to have geriatric conditions ($P<0.001$). Respondents reporting CHF were more likely to have been admitted to a nursing home ($P<0.05$). CHF respondents were more functionally impaired than respondents without CHF. The adjusted average weekly informal care hours for respondents reporting CHF was higher than for those reporting CHD but without CHF and those reporting no CHD (6.7 vs 4.1 vs 5.1, respectively; $P<0.05$). Average weekly formal caregiving hours also differed among the three groups (1.3 CHF vs 0.9 CHD without CHF vs 0.7 no CHD; $P>0.05$).

CONCLUSIONS: CHF imposes a significant burden on patients, families, and the long-term care system. Older adults with CHF have higher rates of disability, geriatric conditions, and nursing home admission.

KEY WORDS: CHF; disability; formal and informal caregiving.
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INTRODUCTION

Congestive heart failure (CHF) is increasing in prevalence among older adults because of the aging of the US population and the greater survival of patients [1–4]. Consequently, many people will be aging with CHF and its complications, leading to greater disability and greater need for home and community-based services as well as nursing home care [4]. This substantial increase in the prevalence of CHF will generate additional burdens on older patients, their family members, and the health care system to provide the substantial daily care required by individuals with CHF [5–7]. Although many aspects of CHF care have been extensively studied, we do not have good estimates of the extent of disability suffered by people with CHF nor their use of in-home caregiving. This study is the first to characterize disability in the older community-dwelling CHF population and the utilization of in-home services using a nationally representative sample. This information is essential in planning for the long-term care needs of this growing segment of the older adult population.

To assess the clinical and social impact of CHF on older Americans, we examined cross-sectional data from the 2000 wave of the Health and Retirement Study (HRS), comparing respondents who report CHF with those who report coronary heart disease (CHD) without CHF and those who report no CHD, to answer the following four research questions: (1) What is the extent of physical disability and geriatric conditions among older adults with CHF? (2) Is CHF independently associated with disability? (3) How much formal and informal in-home care is utilized by older adults with CHF? (4) What is the likelihood of nursing home admission among older adults with CHF? We hypothesized that older adults with CHF would be more disabled and require more in-home services than older adults with CHD alone and those without CHD.

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MATERIALS AND METHODS

Data

We used cross-sectional data from the 2000 wave of the HRS, a biennial, longitudinal survey of a nationally representative cohort of US adults aged 50 years or older [8]. The HRS 2000 cohort is representative of approximately 34.5 million adults in this age group in the USA. This survey provides detailed self-report information on chronic diseases, cognitive impairment, and task-specific disabilities. Interviews were conducted with all HRS respondents every 2 years, either by telephone or in person, with the latter mode used preferentially for those age 80 years or older. The interviews conducted in 2000 were conducted in 10,371 households (82% survey

response rate; see the HRS website at http://hrsonline.isr.umich.edu for more information on the organization and design of the HRS).

Of the 19,850 respondents to the 2000 survey, our analysis was limited to the 11,093 respondents age 65 and above. Proxy respondents (n=1,068, 9.3%: 8.3% [n=669] of no CHD respondents, 10.1% [n=309] of CHD, without CHF respondents, and 20.6% [n=90] of CHF respondents) completed surveys in some cases when participants were unable to respond. Current nursing home residents (n=240) were excluded from the analysis. Seventeen respondents had missing data for heart condition categories; thus, we excluded them from the analysis.

Classification of Heart Disease Categories

All respondents were asked: "Has a doctor ever told you that you had a heart attack, coronary heart disease, angina, congestive heart failure, or other heart problems?" Those who responded "yes" were further asked "Has a doctor told you that you have congestive heart failure in the last 2 years." The responses from these two questions were used to sort respondents into three mutually exclusive heart problem categories: (1) no CHD, (2) CHD but without CHF, and (3) CHF.

Independent Variables

The sociodemographic variables included in the analysis as independent variables were: age (65–74, 75–84, ≥85), race, gender, income, living arrangement (married, unmarried living with others, and unmarried living alone), household net worth [9], and level of education. Self-reported comorbid illnesses included were: hypertension, lung disease (asthma or chronic obstructive pulmonary disease), stroke, cancer, diabetes, and psychiatric problem. Geriatric conditions are defined as clinical conditions that are highly prevalent in older, particularly frail adults. Self-report of urinary incontinence, injury by fall, and dementia were the variables utilized in this analysis to capture geriatric conditions. The presence and severity of dementia for self-respondents was defined using a modified version of the Telephone Interview for Cognitive Status (TICS), a validated cognitive screening instrument patterned on the Mini-Mental State Examination, which is specifically designed for population-based studies [10–12]. The TICS was not administered to those respondents represented by a proxy, but rather each proxy was asked questions to assess respondent's overall memory and change in memory compared to prior waves. Based on prior validation studies, we defined a cutoff score of 8 (2 standard deviations below the mean) on the 35-point TICS scale as the level of cognitive impairment consistent with "dementia"[13,14]. Cognitive impairment consistent with dementia was defined based on a report of "fair or poor memory" as assessed by a proxy respondent [15].

Dependent Variables

We evaluated several dependent variables relevant to our research questions: activities of daily living (ADL) and instrumental activities of daily living (IADL) disability (using composite variables), the utilization of formal and informal in-home caregiving, and the number of hospital and nursing home admissions in the 2 years before the interview. A respondent was considered to have a disability in an ADL (bathing, dressing, eating, toileting, and walking) if they reported having difficulty performing the ADL or required assistance. Disability in an IADL (grocery shopping, preparing meals, taking medication, managing money, and making phone calls) was defined as having difficulty performing the IADL without help or not doing an IADL because of a health problem.

We classified respondents as receiving informal care if in-home care was provided by a relative (paid or not) or unpaid nonrelative with no organizational affiliation in the past month. Formal care was identified for those reporting in-home care performed by a paid nonrelative or someone with an organizational affiliation in the past 2 years [16]. Presence or absence of formal and/or informal caregiving and the weekly hours of each were also evaluated.

The occurrence of a hospitalization for each heart disease category was determined by respondent self-report. Respondents were asked "In the last 2 years, have you been in the hospital overnight?" Prior residence in a skilled nursing facility or nursing home was identified if respondents answered "yes" to the following question: "In the last 2 years, have you been a patient overnight in a nursing home, convalescent home or other long-term health care facility?"

Data Analyses

The demographic, medical condition, and disability characteristics of the three heart disease groups (CHF, CHD without CHF, and no CHD) were compared using standard descriptive statistics including chi-square and chi-square test for statistical trend. The unadjusted disability rates were calculated for each heart disease category using survey-weighted values.

We used negative binomial regression with a three-level categorization of ADL (none, 1–3, and 4–6) and IADL (none, 1–3, and 4–5) disability to estimate unadjusted and adjusted incident rate ratios to determine if CHF is independently associated with disability. The model was adjusted for attributes known to be associated with disability: age, race, gender, level of education, net worth, living arrangement, and certain medical conditions. We used bootstrapping to estimate 95% confidence intervals for the incident rate ratios of ADL and IADL limitations.

To determine the association between heart disease category and type of caregiving, a multivariable logistic regression model was used. Because a substantial proportion of the respondents did not receive informal and formal care in the month before the administration of the survey and the distribution of informal and formal care hours among recipients was highly skewed, a two-part regression model was used for this analysis [17]. In the first part of the two-part model, we used logistic regression to determine the likelihood of receiving informal and formal home care by estimating the association between each type of in-home care and the heart problem categories, controlling for other covariates. In the second part of the two-part model, ordinary least squares regression was utilized to examine the association between the natural log of informal and formal care hours and the heart disease category. The results from each part of the model were then combined to obtain an estimate of the average effect of the heart disease category on weekly hours of informal and formal in-home caregiving. Results were retransformed back into hours, the natural units. We used bootstrapping to estimate the confidence intervals for the predicted average weekly informal and formal hours [18].

We controlled for potentially confounding sociodemographic and health status attributes in the prediction of average formal and informal care hours by heart disease category. Among the three groups, we compared the probabilities of reported hospitalization and nursing home admission in the prior 2 years using descriptive methods and logistic regression, interpreting coefficients as proportions rather than odds ratios, for multivariate analysis. Multivariate analyses controlled for demographic and disease variables. These and all analyses used were weighted and adjusted for the complex sampling design of HRS using STATA 9.0 [19].

RESULTS

Characteristics of the Study Population

The characteristics of the study population are shown in Table 1. Of the 10,626 respondents reporting heart problem status in the 2000 survey, 7,363 (69.3%) reported no CHD, 2,863 (26.8%) reported a CHD without CHF, and 400 (3.8%) reported CHF. Those with CHF were older, had lower levels of education, and were less likely to be married. In addition, those with CHF were more likely to be living alone and to have the lowest net worth of all three groups.

Individuals with CHF were more likely to report a history of hypertension, lung disease, diabetes, arthritis, cancer, stroke, and psychiatric issues. Geriatric conditions were more prevalent among those respondents with CHF; they were more likely to have injury by fall, urinary incontinence, and cognitive impairment consistent with dementia.

ADL and IADL Impairments

Table 2 shows that CHF respondents were significantly more functionally impaired with more ADL and IADL impairments ($P<0.001$, χ^2 for trend) than respondents without CHF. Specifically, those with CHF were significantly more likely to have at least one and ≥ four ADL and IADL impairments.

Table 2 also shows the specific ADL and IADL impairments associated with respondents by heart disease category. The most prevalent ADL limitation was "walking across a room" among 41.8% of respondents with CHF, 21.1% of respondents with CHD, no CHF, and 12.5% of respondents with no CHD.

Table 1. Characteristics of Respondents by Heart Disease Category (*n*=10,626)

Variable	Heart disease category			
	No CHD (*N*=7,363)	CHD, no CHF (*N*=2,863)	CHF (*N*=400)	*P* value
Age				<0.001
65–74	4,275 (57.7)	1,271 (43.6)	147 (36.8)	
75–84	2,407 (33.7)	1,156 (42.1)	177 (45.3)	
≥85	681 (8.6)	436 (14.3)	76 (18.0)	
Age: mean±SD	74.0±0.1	76.4±0.16	77.6±0.43	<0.001
Gender				<0.001
Men	2,970 (39.6)	1,443 (49.5)	172 (42.2)	
Women	4,393 (60.4)	1,420 (50.5)	228 (57.8)	
Race				0.9
White	6,185 (88.3)	2,423 (88.8)	347 (88.5)	
Black	989 (8.8)	373 (8.4)	45 (8.3)	
Other	236 (3.0)	85 (2.8)	10 (2.6)	
Education (year)				<0.001
<12	2,368 (29.6)	1,058 (35.6)	186 (46.6)	
12	2,501 (35.0)	918 (32.5)	117 (29.0)	
≥13	2,494 (35.4)	887 (31.9)	97 (24.4)	
Living arrangement				0.01
Married	4,341 (56.4)	1,658 (55.2)	202 (47.5)	
Unmarried living with other	907 (12.2)	369 (13.9)	66 (16.1)	
Unmarried living alone	2,115 (31.3)	836 (31.7)	132 (36.4)	
Net worth				<0.001
≤49,200	1,615 (20.4)	758 (25.4)	108 (26.7)	
49,201–151,000	1,823 (24.4)	728 (25.2)	137 (33.3)	
151,001–370,000	1,893 (26.9)	724 (26.1)	86 (21.7)	
≥370,001	2,003 (28.4)	642 (23.4)	69 (18.4)	
Medical conditions				
Hypertension	3,711 (59.6)	1,829 (63.0)	293 (73.0)	<0.001
Lung disease	597 (8.0)	385 (13.9)	130 (31.8)	<0.001
Stroke	476 (6.3)	391 (13.2)	89 (22.7)	<0.001
Cancer	1,034 (14.4)	495 (17.3)	75 (19.1)	<0.001
Psychiatric problem	780 (10.5)	466 (15.2)	106 (28.3)	<0.001
Arthritis	610 (8.4)	281 (10.0)	66 (17.0)	<0.001
Diabetes	1,051 (13.5)	622 (20.8)	141 (33.3)	<0.001
Geriatric conditions				
Urinary incontinence	1,363 (18.7)	652 (23.3)	145 (36.1)	<0.001
Injury by fall	4,449 (60.2)	2,018 (70.3)	321 (78.3)	<0.001
Dementia	413 (5.0)	227 (7.1)	72 (17.3)	<0.001

Percentages (in parentheses) are weighted using the HRS respondent population weights to adjust for the complex sampling design of the HRS. Percentages are column percents, for example 36.8% of people with CHF are aged 65–74, but may not add to 100% because of rounding.

Table 2. Number and Specific Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) Limitations, by Heart Disease Category (*n*=10,626)

Variable	Heart disease category			
	No CHD (*N*=7,363)	CHD, no CHF (*N*=2,863)	CHF (*N*=400)	*P* value
Number of ADLs impaired (M±SD)	0.43±0.02	0.71±0.03	1.49±0.11	<0.001[a]
0	5,864 (80.3)	1,930 (68.3)	181 (45.7)	<0.001
1–3	1,222 (16.2)	741 (25.2)	148 (37.6)	
4–6	277 (3.5)	192 (6.5)	71 (16.8)	
Type of ADL impairment				
Walking across a room	961 (12.5)	632 (21.1)	169 (41.8)	<0.001
Dressing	669 (8.6)	417 (14.2)	119 (41.8)	<0.001
Bathing	531 (6.9)	330 (11.6)	107 (27.3)	<0.001
Transferring	528 (6.8)	345 (11.3)	105 (24.4)	<0.001
Toileting	376 (4.9)	245 (8.7)	74 (18.1)	<0.001
Eating	227 (2.9)	133 (4.5)	39 (8.8)	<0.001
Number of IADLs impaired (M±SD)	0.26±0.01	0.43±0.03	1.05±0.08	<0.001[a]
0	6,377 (87.0)	2,249 (79.1)	221 (55.2)	<0.001
1–3	814 (10.8)	520 (17.7)	133 (34.5)	
4–5	172 (2.2)	94 (3.2)	46 (10.2)	
Type of IADL impairment				
Grocery shopping	619 (8.1)	424 (14.6)	141 (35.6)	<0.001
Managing money	440 (5.7)	249 (8.4)	88 (22.4)	<0.001
Cooking	442 (5.7)	275 (9.5)	95 (23.2)	<0.001
Taking medication	229 (3.1)	139 (4.8)	51 (12.2)	<0.001
Using the telephone	298 (3.7)	178 (5.6)	58 (13.4)	<0.001

Percentages (in parentheses) are weighted using the HRS respondent population weights to adjust for the complex sampling design of the HRS.
[a]*Test for trend*

The most prevalent IADL limitation was "grocery shopping" among 35.6% of respondents with CHF, 14.6% of respondents with CHD, no CHF, and 8.1% of respondents with no CHD.

Table 3 describes the incident rate ratio (RR) of ADL and IADL limitations, by heart disease category. In the unadjusted analyses, CHF was associated with a greater number of ADL (incident RR 3.50; 95% confidence interval [CI], 3.05–4.01) and IADL (incident RR 3.99; 95% CI 3.39–4.69) limitations. Although the risk ratios were attenuated after adjustment for demographics and certain chronic diseases, CHF remained significantly independently associated with a higher risk of ADL and IADL limitations.

Table 3. Incident Rate Ratio of the Association of ADL and IADL Limitations, by Heart Disease Category with 95% Confidence Intervals, Controlled for Covariates that are also Associated with Disability

Heart disease category	ADL	IADL
Unadjusted		
No CHD	Ref.	Ref.
CHD, no CHF (RR; 95% CI)	1.68 (1.53–1.83)	1.64 (1.49–1.80)
CHF (RR; 95% CI)	3.50 (3.05–4.01)	3.99 (3.39–4.69)
Adjusted[a]		
No CHD (RR; 95% CI)	Ref.	Ref.
CHD, no CHF (RR; 95% CI)	1.22 (1.1–1.39)	1.21 (1.1–1.37)
CHF (RR; 95% CI)	1.51 (1.33–1.71)	1.67 (1.35–2.06)

[a]*Adjusted for age, gender, race, education, living arrangement and net worth, incontinence, blood pressure, cancer, stroke, arthritis, fall-injured, diabetes, lung disease, psychiatric problem, dementia, and nursing home and hospital admission*

Patterns of In-home Caregiving

Of the 400 respondents with CHF, 42.2% received informal in-home care, while 13% received formal in-home care. In contrast, 18.3% of respondents with CHD without CHF received informal care and 3.9% of formal care. Those respondents with no CHD had the lowest rates of informal and formal care with 11 and 2.2%, respectively (Table 4).

The unadjusted weekly hours of informal and formal care were also greatest for the CHF group. After adjustment for the other covariates, weekly informal in-home caregiving hours for those with CHF were significantly greater than those of the other two heart disease categories ($P<0.05$; Table 4). However, there was no significant difference in formal in-home caregiving hours between the CHF group and the other two groups.

Hospital and Nursing Home Admission

Table 4 shows that 69.5% of individuals with CHF were hospitalized in the prior 2 years, as compared to 43% of those with CHD without CHF and 22.1% of those without CHD. Approximately 10.0% of respondents with CHF were in a nursing home in the prior 2 years, compared to 3.0% of respondents with CHD without CHF and 2% of those without CHD.

Additionally, Table 4 shows the unadjusted and adjusted hospitalization and nursing home admission rates by heart disease category. A higher proportion of CHF patients were hospitalized compared to respondents with CHD without CHF and no CHD. Adjustment for sociodemographics and health condition variables using logistic regression did not alter the differences in rates among the groups, which remained significant ($P<0.05$). Nursing home admission was most common among those with CHF. After adjusting for socio-

Table 4. Receipt and Intensity of Caregiving and Proportion that were Hospitalized or Admitted to a Nursing Home, by Heart Disease Category

Characteristics	Heart disease category		
	No CHD (*N*=7,363)	CHD, no CHF (*N*=2,863)	CHF (*N*=400)
Receiving care (%)			
Informal*	11.0	18.3	42.2
Formal*	2.2	3.9	13.0
Weekly informal care hours			
Unadjusted (hours±SD)**[a, c]	3.5±0.23	5.0±0.43	15.9± 1.45
Adjusted (hours; 95% CI)**[a, b, c]	5.1 (4.4–5.9)	4.1 (3.5–4.7)	6.7 (5.5–7.9)
Weekly formal care hours			
Unadjusted (hours±SD)[a, c]	0.5±0.09	1.1±0.21	3.8±1.2
Adjusted (hours; 95% CI)[a, b, c]	0.7 (0.5–0.9)	0.9 (0.6–0.2)	1.3 (0.7–1.8)
Hospitalized in last 2 years			
N (%)	1,646 (22.1)	1,231 (43.0)	283 (69.5)
Unadjusted (probability±sd)**[c]	0.221±0.005	0.43±0.01	0.695±0.026
Adjusted (probability; 95% CI)**[b, c]	0.234 (0.23–0.24)	0.397 (0.38–0.14)	0.605 (0.57–0.64)
Lived in a nursing home in last 2 years			
N (%)	118 (1.6)	86 (3.1)	36 (9.5)
Unadjusted (probability±sd)**[c]	0.016±0.001	0.031±0.003	0.095±0.015
Adjusted (probability; 95% CI)**[b, c]	0.018 (0.016–0.021)	0.026 (0.022–0.029)	0.055 (0.044–0.067)

Percentages for receipt of formal and informal caregiving and for hospital and nursing home admission are weighted using the HRS respondent population weights to adjust for the complex sampling design of the HRS.

*$P<0.001$

**$P<0.05$

[a]*Using the two-part model*

[b]*Adjusted for age, gender, race, education, living arrangement and net worth, incontinence, blood pressure, cancer, stroke, arthritis, fall-injured, diabetes, lung disease, psychiatric problem, dementia, and nursing home and hospital admission.*

[c]*Using logistic regression with coefficients interpreted as probabilities*

demographics and health condition using logistic regression, those with CHF still had significantly higher rates of nursing home admission ($P<0.05$).

DISCUSSION

As the US population ages, the prevalence of CHF among older Americans is anticipated to increase significantly. Our study demonstrates a significantly greater burden of illness in geriatric conditions, functional limitations, in-home caregiving needs, and nursing home admission among older adults with CHF, as compared to those with CHD without CHF and those without CHD in a community-dwelling, nationally representative cohort. This analysis sheds greater light on the extent of disability in this highly vulnerable group.

The substantial burden of noncardiac comorbid illness in the CHF population has been well described by other investigators [20–23]. Our study documents that, in addition, there is a high prevalence of geriatric conditions among older adults with CHF including, urinary incontinence, injury by fall, and dementia. Each of these conditions suggests the presence of a high degree of disability and often requires a multifaceted approach to effectively manage. For example, it is well known that dementia has an important impact on function, an older patient's need for informal and formal support, and nursing home entry [13,24]. A multidisciplinary approach to dementia care management and care coordination across healthcare delivery systems has been shown to improve patient care and caregiver support as well as delay institutionalization [25,26]. The presence of CHF in a cognitively impaired individual further increases CHF-related morbidity and affects functional outcomes and the need for institutional care [27–29]. A clinician's failure to recognize cognitive deficits in a CHF patient could directly affect their clinical outcomes and quality of care.

To our knowledge, our study is the first to explicitly characterize the pattern of care utilized by the older CHF population and the significant time commitment that it imposes on family members. Families spend a substantial amount of time addressing the daily needs of this disabled population. Similarly, this population is also utilizing formal or paid sources of care; however, there was no statistically significant difference between the weekly hours of formal care compared to the other heart problem categories. This finding could be explained by two primary factors. First, compromised access to such services likely occurred because of the reduction in public spending for home- and community-based services in the late 1990s. The use of informal care by the CHF population in the setting of limited availability of formal services may represent substitution of informal services to address an unmet need. Second, physicians and other members of the healthcare team who participate in home care service referrals may be missing opportunities to refer eligible older patients [30,31]. Improved methods to appropriately identify patients for home-based services and promote sound care coordination for older adults are likely needed.

Our study has some limitations that warrant comment. The proportion of respondents with CHF in our cohort was approximately 4%, which contrasts with other epidemiologic studies estimating the prevalence of CHF in older adults at 9–12% [32,33]. Our low estimate could be explained by misclassification of respondents by heart disease category because of recall bias or the lack of full understanding of the CHF question by respondents. Although respondents were specifically asked if a physician had told them they had CHF, it is conceivable that respondents could have been misclassified by

heart disease category because of a lack of familiarity with the diagnosis [34]. CHF diagnoses were not confirmed by medical records of symptoms, medical therapy, or ejection fraction. Additionally, the CHF respondents captured in this HRS cohort may represent those with the greatest disease severity and, therefore, greater functional limitations. For all of these reasons, self-report of CHF as a diagnosis in this cohort likely represents a lower bound of the true prevalence; thus, our estimates of disability, caregiving, and other health outcomes could be over- or understated.

To date, the HRS survey questions concerning heart disease diagnoses have not been validated as a reliable means of identifying patients with CHF. Adjudication by an expert panel is considered to be the gold standard for establishment of CHF as a diagnosis [4]. Prior work by Tisnado et al. [35] reported fair concordance between self-report of CHF and ambulatory managed care records, but no clinical databases have been used with the HRS to date. Nevertheless, self-report data such as our HRS data is an important data source for monitoring patient and caregiver experiences and perceptions, which are not routinely found in clinical databases. Future work is needed to compare the self-reported prevalence of CHF with the prevalence derived from Medicare data using HRS data linked to Medicare administrative files once available for public use.

Our study documents that older adults reporting CHF have a significantly higher prevalence of geriatric conditions, caregiving needs, and nursing home admission compared to those in the other heart disease categories. Additionally, CHF is independently associated with disability, even when other comorbidities are taken into account. These data suggest that the current approach of disease-specific care, for example a CHF disease management clinic, may be insufficient to care for this medically complex, frail population [21,23,36]. Promoting care delivery systems that provide a coordinated, multidisciplinary approach to older adults with high medical complexity, like those with CHF, will be necessary to optimize care.

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