Activities of Daily Living and Outcomes in Heart Failure

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Background—Chronic disease can contribute to functional disability, which can degrade quality of life. However, the prevalence of functional disability and its association with outcomes among patients with heart failure requires further study.

Methods and Results—Southeastern Minnesota residents with heart failure were enrolled from September 2003 through January 2012 into a cohort study with follow-up through December 2012. Difficulty with 9 activities of daily living (ADLs) was assessed by a questionnaire. Patients were divided into 3 categories of ADL difficulty (no/minimal, moderate, severe). The associations of ADL difficulty with mortality and hospitalization were assessed using Cox and Andersen-Gill models. Among 1128 patients (mean age, 74.7 years; 49.2% female), a majority (59.4%) reported difficulty with one or more ADLs at enrollment, with 272 (24.1%) and 146 (12.9%) experiencing moderate and severe difficulty, respectively. After a mean (SD) follow-up of 3.2 (2.4) years, 614 patients (54.4%) had died. Mortality increased with increasing ADL difficulty; the hazard ratio (95% confidence interval) for death was 1.49 (1.22–1.82) and 2.26 (1.79–2.86) for those with moderate and severe difficulty, respectively, compared to those with no/minimal difficulty ($P_{\text{trend}}$<0.001). Patients with moderate and severe difficulty were at an increased risk for all-cause and noncardiovascular hospitalization. In a second assessment, 17.7% of survivors reported more difficulty with ADLs and patients with persistently severe or worsening difficulty were at an increased risk for death (hazard ratio, 2.10; 95% confidence interval, 1.71–2.58; $P<0.001$) and hospitalization (hazard ratio, 1.51; 95% confidence interval, 1.31–1.74; $P<0.001$).

Conclusions—Functional disability is common in patients with heart failure, can progress over time, and is associated with adverse prognosis. (Circ Heart Fail. 2015;8:261-267. DOI: 10.1161/CIRCHEARTFAILURE.114.001542.)

Key Words: epidemiology ■ heart failure ■ morbidity ■ mortality ■ survival

Physical disability and loss of independence can complicate the care of patients with chronic diseases such as heart failure (HF), and it can degrade their quality of life. The ability to perform activities of daily living (ADLs) is often used as a surrogate for the more difficult-to-measure construct of functional disability. Despite the ease of estimating functionality through patient-reported outcomes, little is known about the prevalence and severity of ADL deficits and functional disability in patients with HF.

Our limited understanding of functional disability among patients with HF is problematic for several reasons. First, disease-specific treatment options depend on a patient’s functional capabilities. Second, although functional disability has been associated with increased mortality in general elderly populations, its association with outcomes, including mortality and hospitalization in patients with HF, is unclear.

To address these gaps in knowledge, we investigated the prevalence and progression of difficulty with ADLs and their associations with mortality and hospitalization in a community-based cohort of patients with HF.

Methods

Study Design

This study was a cohort study conducted in southeastern Minnesota. This area is relatively isolated from other urban centers, and a limited number of providers, the largest of which is the Mayo Clinic, deliver the vast majority of medical care to local residents. The Rochester Epidemiology Project, a medical record linkage system, allows the indexing of medical care for residents of southeastern Minnesota, thus enabling the comprehensive capture of health-related events for the community’s residents.

Patient Population

Potential patients with HF were identified using natural language processing of the electronic medical record text. Following a clinical visit, documentation is transcribed and appears in the electronic record within 24 hours, making prompt identification of patients with HF possible. The search was restricted to patients who were ≥20 years old and who were residents of Olmsted, Dodge, and Fillmore Counties in Minnesota. This approach yielded 100% sensitivity compared with

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billing data, which is the desired methodology for case finding.5 Medical records were then reviewed by experienced research nurses to determine whether patients had active HF meeting Framingham criteria.6 Patients were approached to provide their consent to participate in the study from September 2, 2003, through January 31, 2012, which included an echocardiogram and blood draw. Hospitalized patients were contacted in the hospital, and patients seen in the outpatient setting were approached at their next scheduled clinical encounter. All patients provided written authorization to participate in the study, which was approved by the Mayo Clinic Institutional Review Board.

Data Collection

Patient Baseline Characteristics

Patient baseline characteristics were collected from the patients’ medical records. A physician’s diagnosis was used to define a history of cerebrovascular disease, peripheral vascular disease, chronic obstructive pulmonary disease, dementia, and malignancy. A history of hypertension was defined as systolic blood pressure ≥140 mmHg, diastolic blood pressure ≥90 mmHg, or use of antihypertensive medications. Diabetes mellitus was defined using American Diabetes Association criteria or use of diabetes medications. Body mass index was calculated using the last outpatient weight before study enrollment and the earliest adult height. Estimated glomerular filtration rate was calculated based on the creatinine level at study enrollment.7 Anemia was defined as hemoglobin <12 mg/dL in women or <13 mg/dL in men.8 The Charlson comorbidity index was used to assess the degree of comorbidity.10 Resting left ventricular ejection fraction was collected from transthoracic echocardiograms performed within 6 months before 2 months after study enrollment. Preserved ejection fraction was defined as ≥50%. Marital status was obtained from a self-administered annual survey. Resuscitation preference was defined as either Full Code or Do Not Resuscitate based on documentation in the electronic medical record.11 Activities of Daily Living

A patient’s ability to perform ADL is requested annually for all patients at the Mayo Clinic by a self-administered survey sent to the patient’s home address. During a hospital admission, patients are asked to complete the survey if they have not completed one within the past 6 months. Patients are asked to identify whether they have difficulty performing the following tasks on their own: feeding themselves, dressing, using the toilet, housekeeping, climbing stairs, bathing, walking, using transportation, and managing medications. The response options are binary (Yes/No). Similar activity-based items with binary response options have been used for functional assessment in other populations.12-14 As this was self-administered, proxy responses were allowed, but their frequency could not be assessed. To be eligible for inclusion in this analysis, participants were required to have responded to the survey near the time of study enrollment (6 months before to 3 months after). Marital status was obtained from the same annual survey.

Ascertainment of All-Cause Mortality and Hospitalizations

Participants were followed through December 31, 2012, for death from any cause and for all-cause hospitalization. Mortality follow-up was available on all patients; hospitalization data were available in 95% of patients, and those without hospitalization data were excluded from that portion of the analysis. The date of death was determined using death certificates filed in Olmsted County, obituary notices, and electronic files of death certificates obtained from the State of Minnesota Department of Vital and Health Statistics. Information on hospitalizations in Olmsted County was obtained using local administrative sources. Transfers between hospitals were considered a single hospitalization. The principal discharge diagnosis was categorized based on the primary International Classification of Diseases, Ninth Revision (ICD-9) code as HF (ICD-9 428) other cardiovascular/renal (ICD-9 390–459, 580–89) or noncardiovascular (all other codes). Patients who were alive at the last follow-up were censored at their date of last medical contact.

Statistical Analysis

Negative binomial regression was used to examine the predictors of the number of ADLs for which patients had difficulty. To obtain a parsimonious multivariable model, all potential predictors shown in Table 1 (with the exception of Charlson comorbidity index) were entered into the model and backward selection was performed while retaining only significant predictors of difficulty with ADLs. Rasch analysis was used to identify the order of difficulty of ADLs.15 Rasch analysis is a 1-parameter item response theory model for analyzing categorical data, such as questionnaire responses. The probability of a respondent providing a positive answer to an item is a function of the respondent’s ability and the item’s difficulty. Item difficulties are determined not only by the frequency with which an item gets a positive response but also by the ability levels of subjects who have a positive response. For example, when applied to educational tests, easier test items should be answered correctly by most subjects, including those with limited proficiency in the subject matter; whereas the probability of a correct response to more difficult questions would be much higher in those test-takers with high proficiency. In this way, difficult items are those items that are generally given positive responses by those with high-ability levels and negative responses by those with low-ability levels. Similarly, when applied to ADL difficulties, Rasch analysis identifies the level of difficulty of each ADL based on the response patterns of patients with varying levels of functionality. Once ADL difficulties were established with Rasch analysis, subjects were assigned a numeric grade based on the least difficult ADL that a subject could not perform. Other groups, such as those who developed the physical function item bank for the Patient Reported Medical Information System, have used item response theory-based approaches to model physical function as a unidimensional construct—an approach similar to ours—without the requirement for subdomains such as applied cognition and mobility.16 Patients were then divided into 1 of 3 categories (minimal, moderate, severe difficulty) based on their difficulty with ADLs. Kaplan–Meier curves and Cox proportional hazard regression models were used to examine the association between ADL difficulty and mortality. We checked the proportional hazard assumption using the scaled Schoenfeld residuals, and it was found to be valid. To examine the association between ADL difficulty and hospitalization, we used Andersen–Gill models, which account for the repeated nature of hospitalizations.17-18 Complete case analysis was used in all modeling. A P value <0.05 was used as the level of significance for all analyses. Analyses were performed using SAS Version 9.3(Cary, NC) and WinSteps software (Rasch analysis).

Results

A total of 2331 patients were invited to participate in the study, and 1476 patients were enrolled (63.3% consent rate).
Of those, 1128 (76.4%) provided information on their ability to perform ADLs around the time of enrollment (median, 17 days earlier), and are included in the analysis. The majority of questionnaires assessing ADL difficulty were collected in the outpatient setting (69%), whereas the others were collected while the patient was hospitalized. The baseline characteristics of the study population are shown in Table 1. Patients were elderly (mean age, 74.7 years), 50.8% were men, 51.7% had preserved ejection fraction, and comorbidities such as hypertension, diabetes mellitus, and cerebrovascular disease were common. Patients who were not eligible for inclusion in the analysis because they lacked ADL information or did not consent to participate were more often older (78.2 versus 74.7 years; \( P < 0.001 \)) and women (55.1% versus 49.2%, \( P = 0.004 \)). At the time of enrollment, a majority of patients (n=670; 59.4%) had difficulty with one or more ADLs.

### Predictors of Difficulty With ADLs

The associations between patient clinical characteristics and the number of ADLs for which patients reported difficulty are shown in Table 2. The independent predictors of difficulty with ADLs were older age, female sex, diabetes mellitus, cerebrovascular disease, dementia, anemia, morbid obesity, and unmarried status. Dementia was one of the factors most strongly associated with ADL difficulty; adjusting for other factors, patients with dementia have a more than 2-fold increase in the number of ADLs for which they report difficulty compared with a patient without dementia. For example, if the average patient without dementia reported difficulty with 2 ADLs, adjusting for other factors, on average, patients with dementia would report difficulty with 4.3 ADLs.

### Hierarchy of Difficulty With ADLs

The difficulty hierarchy of the 9 ADLs was found to be in order from the easiest to the most difficult: eating, toileting, dressing (severe ADL difficulty=highest order and level of ADL difficulty were similar in both men and women. For all ADLs more difficult than eating, the majority of patients who could perform each ADL could perform all easier ADLs (Table 3). The ADL that performed the least well in this regard was walking, as 26.5% of people who could walk without assistance could not complete all easier ADLs.

### Difficulty With ADLs, Hospitalizations, and Death

After a mean (SD) follow-up of 3.2 (2.4) years, 614 (54.4%) patients had died and 910 patients had been hospitalized a total of 4024 times (median 2 hospitalizations per person, 25th–75th percentile 1–5, 38.1% cardiovascular). The most common reasons for hospitalizations were HF (ICD-9 428, n=741 hospitalizations, 18.4% all hospitalizations), arrhythmia (ICD-9 427, n=187, 4.7% all hospitalizations), and pneumonia (ICD-9 486, n=174, 4.3% all hospitalizations). When patients were categorized by the easiest ADL that they had difficulty completing, we found a similar mortality risk in patients who had difficulty with eating, toileting, and dressing (severe ADL difficulty=highest...
Difficulty with activities of daily living (ADLs) over time (Table 4). Patients with persistently severe or worsening difficulty with ADLs over time (worse from minimal to moderate/severe) were at the highest risk for out-of-hospital death, such that they may die without being hospitalized. When we performed a sensitivity analysis where we assumed that patients were hospitalized on their date of death, the HR for hospitalization for those with moderate and severe difficulty with ADLs was similar (1.57 versus 1.57). The association between ADL difficulty and HF hospitalization followed a similar pattern in all-five hospitalization, with a stronger association in those with moderate difficulty. Using the previously established categories of minimal, moderate, and severe difficulty with ADLs was similar (1.57 vs. 1.57). Patients with moderate and severe ADL difficulty were at an increased risk for noncardiovascular hospitalization.

<table>
<thead>
<tr>
<th>Outcome</th>
<th>No/Minimal</th>
<th>Moderate</th>
<th>Severe</th>
<th>Adjusted* P for Trend</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mortality</td>
<td>1 (referent)</td>
<td>1.98 (1.65–2.37)</td>
<td>2.81 (2.26–3.48)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>All-cause hospitalization</td>
<td>1 (referent)</td>
<td>1.49 (1.22–1.82)</td>
<td>2.26 (1.79–2.86)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>HF Hospitalization</td>
<td>1 (referent)</td>
<td>1.53 (1.32–1.78)</td>
<td>1.45 (1.19–1.75)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Noncardiovascular hospitalization</td>
<td>1 (referent)</td>
<td>1.37 (1.17–1.59)</td>
<td>1.22 (1.00–1.49)</td>
<td>0.001</td>
</tr>
</tbody>
</table>

*Adjusted for age, sex, Charlson comorbidity index, and location of questionnaire completion (hospital vs outpatient).

Figure 3. Change in independence with activities of daily living (ADLs) over time. Patients (n, %) are categorized by their level of difficulty with ADLs at study enrollment and during follow-up assessment (performed a median of 9 months later). Patients with stable difficulty over time are shown in yellow, less difficulty in green, and increasing difficulty in red.
with serial ADL assessments), the risk of death (unadjusted HR, 2.44; 95% CI, 2.00–2.98; \( P<0.001 \)) and readmission (HR, 1.64; 95% CI, 1.41–1.91; \( P<0.001 \)) were markedly increased. Adjusting for age, sex, Charlson comorbidity index, and time between surveys, patients with persistently severe or worsening difficulty with ADLs were at an increased risk of subsequent mortality (HR, 2.10; 95% CI, 1.71–2.58; \( P<0.001 \)) and readmission (HR, 1.51; 95% CI, 1.31–1.74; \( P<0.001 \)).

**Association Between ADL Difficulty and Resuscitation Preferences**

Information on resuscitation preferences was available in the 517 patients enrolled after September 2007. At enrollment, 390 (75.4%) were Full Code, 73 (14.1%) elected to be DNR, and 54 (10.4%) had unknown resuscitation preference. Patients reporting moderate or severe difficulty with ADLs more often elected Do Not Resuscitate status at enrollment (22.0% versus 12.5%; \( P=0.009 \)). Among those who were Full Code at enrollment, patients reporting moderate or severe difficulty with ADLs were more likely to change to Do Not Resuscitate during follow-up (40.8% versus 24.7%; \( P<0.001 \)).

**Discussion**

In this large community cohort of patients with HF, the majority of patients had difficulty with one or more ADLs. A clear hierarchy in the order of ADL difficulty existed, which allowed patients to be categorized as having minimal, moderate, and severe difficulty with ADLs. Within this framework, there was an increase in mortality and hospitalization risk with increasing difficulty with ADLs. Although most patients reported similar functionality a year later, persistently severe or worsening difficulty with ADLs was associated with increased mortality and hospitalization risk.

The ability to perform ADLs is a commonly used method of assessing a person’s functionality. ADLs include daily self-care activities that a person would routinely encounter in their residence or when interacting with their external environment. ADLs are sometimes divided into basic, which include self-care tasks such as eating, dressing, and bathing, and instrumental, which allow a person to live independently, such as housekeeping, managing medications, and using transportation. Our assessment included a combination of both basic and instrumental ADLs. By contrast, another commonly used form of ADL assessment, the Katz ADL index, includes only 6 basic ADLs (eating, continence, transferring, toileting, dressing, bathing). Though the ADLs we assessed differed slightly from the Katz index, there was consistency in the order of difficulty among the common ADLs compared with previous reports, with eating being the easiest of the 6 Katz ADLs and bathing requiring the highest level of function to be completed. These data, which define a meaningful hierarchy of ADL difficulty, also suggest an expected pattern of functional decline or recovery that may be of clinical utility.

Accordingly, there was consistency to the order of difficulty with ADLs in a second assessment, with eating, toileting, and dressing representing the easiest items, and walking/climbing stairs being the most difficult items to be completed. This hierarchy of difficulty will enable clinicians to easily assess a patient’s current level of function, and to provide insights into the types of activities that would represent signs of decline or improvement in function in individuals.

We found that moderate or severe difficulty with ADLs was common in community patients with HF. We suspect that the decreased functionality observed is not entirely attributable to HF, as most patients had other comorbidities, such as diabetes mellitus, peripheral vascular disease, and cerebrovascular disease, all of which can impact a person’s mobility and ability to perform self-care activities. In the contemporary era, most patients with HF are elderly and have multi-morbidity, and care needs to be comprehensive, and include consideration of their functional status and comorbidity burden.

Some patients experienced a progression in functional disability over time. Anticipating the needs of patients is an important component in providing patient-centered care. Functional independence is highly valued by patients and increasing difficulty with ADLs has been associated with worse health-related quality of life, which can, in turn, affect disease management and impact outcomes. Further work is needed to address whether there are interventions that could be performed to prevent progression. Care by disease-specific subspecialists and physical therapy interventions have been demonstrated to slow or halt functional decline in other disease states, but their role in patients with HF remains to be explored.

In addition to its potential impact on quality of life and care needs, difficulty with ADLs was associated with an increased risk of hospitalization and death. HF is a clinical syndrome with an overall poor prognosis, with a 5-year survival of only 50% in community studies. However, the prognosis can be highly variable based on the clinical characteristics of the patient, and prognostication can be difficult. Although risk scores have been developed, they are often complex and can be challenging to implement in a busy clinical practice. Here, we observed that patients who reported severe difficulty with ADLs had a dismal median survival of only 1.5 years, thus representing a high risk subgroup of patients. Ascertainment of information on ability to perform ADLs may thus serve several clinically relevant functions. In addition to supplying information that may help anticipate care needs of the patient, it may also provide a quick idea of a patient’s global prognosis, which can help in guiding discussions and determining the appropriateness of therapeutic options.

Though we saw a clear graded increase in the risk of death with increasing ADL difficulty, the relationship between ADL difficulty and hospitalization was more complex. Taking into account the potential impact of out-of-hospital death on risk, patients with both moderate and severe difficulty had a 57% increased risk for hospitalization compared with those with no or minimal difficulty. These findings suggest that though patients with functional limitations are at a higher risk for hospitalization than those who are functionally independent, the level of difficulty does not necessarily determine risk. There are several factors that may contribute to this observation. First, one of the strongest predictors of ADL difficulty was dementia. It may be that many patients with severe ADL difficulty are known to have a poor prognosis and have made choices to avoid...
hospitalization or be cared for in settings that limit their likelihood of hospitalization. In addition, the ADLs associated with poor outcomes in this study, such as self-feeding, are those characterized by integrated multi-step tasks that must be accurately sequenced and executed through higher-level cognitive processes. Walking and stair climbing, the ADLs least associated with poor outcomes, in contrast, require intact neuromuscular function but impose limited cognitive demands. It is possible that the construct most strongly associated with death and hospitalization among patients with HF is a cognitive one that is related to, but imperfectly reflected by ADL performance and a diagnosis of dementia. Enhanced predictive capability and more targeted therapeutic interventions may be achieved through efforts to more accurately characterize functional domains that are causally linked to poor outcomes in HF.

A similar combination of basic and instrumental ADLs has been used to assess older populations in a variety of settings.20–32 In the Cardiovascular Health Study (participants age ≥65 years),30 the Medicare Current Beneficiary Survey (age, ≥65 years),29,32 and a large Swedish cohort (age, 70–76 years),31 the prevalence of difficulty with one or more ADLs ranged from 17% to 26%, much lower than the 59% observed in our study. However, the prevalence of ADL difficulty was similar to that reported in patients aged ≥70 years discharged from a general medical service after an acute hospitalization,33 where 59% reported difficulty with one or more ADLs. In each of these studies, a graded increase in mortality with increasing difficulty with ADLs was observed, similar to our findings. These results suggest that though community patients with HF may have a higher burden of ADL difficulty than the general elderly population, the associated increase in mortality risk with ADL difficulty is likely generalizable to patients in a variety of settings.

**Limitations and Strengths**

There are limitations to be acknowledged that aid in interpretation of these data. First, as in any prospective study, participation rates must be taken into account in interpreting study results. Difficulty with ADLs may be underestimated, as participants, on average, were younger than nonparticipants. As the questionnaire used to assess ADLs is self-administered, it is unclear how often it was completed by a proxy informant, rather than the patient. This may be of particular relevance for the subset of patients with dementia, where self-report of ADL difficulty may be less accurate. Hospitalizations occurring outside of the county were not captured. However, a comparison with Medicare data would suggest that only 5% of all hospitalizations for elderly patients living in Olmsted County occur outside of the county. Conversely, this study has several notable strengths. We were able to capture serial ADL information on a large community cohort of patients with HF who are well characterized and have extensive longitudinal follow-up. This allowed us to characterize functionality and its association with outcomes, which, to the best of our knowledge, has not yet been reported. This information is of critical value in planning care for the growing population of elderly patients with HF, and had been previously lacking from the literature.

**Clinical Applicability**

These data have important clinical implications. The ability to complete ADLs can be easily assessed during an office visit and may be helpful in real-time prognostication to inform patient-provider discussions about goals of care and expected functional trajectory. Furthermore, if a patient is identified as having difficulty with one or more ADLs or has a progression in dysfunction over time, this may represent an important trigger to pursue a more thorough assessment and physical therapy evaluation.

**Conclusions**

In summary, we found that difficulty with ADLs was common in patients with HF, progressed over time in many individuals, and was a powerful marker of adverse prognosis. These findings provide new insight into the burden of functional disability in patients with HF. Routine assessment of patient-reported difficulty with ADLs may aid in prognostication and tailoring of therapeutic options.

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**Disclosures**

None.

**References**


Activities of Daily Living in Heart Failure


**CLINICAL PERSPECTIVE**

The heart failure population is growing and changing—patients are surviving longer, but are more often plagued by multiple comorbidities, which place them at an increased risk for development of impairments in functionality. Though scarcely studied in heart failure, functional impairment can dramatically affect a person’s quality of life and is an important patient-reported outcome. In this study of a large community cohort of patients with heart failure, we found that 37% of individuals reported moderate or severe difficulty with activities of daily living (ADL), which was associated with an increased risk of death and hospitalization. The impairments were not static, as many patients experienced progression of ADL difficulty over time, which was also a marker of poor prognosis. Progressive ADL difficulty followed a clear hierarchy, where more advanced skills such as climbing stairs and housekeeping were lost first, whereas the ability to perform basic ADLs such as eating and toileting were preserved until patients developed more widespread functional impairment. There are several important clinical implications of these data. First, patient-reported difficulty with ADLs is easy to assess during a routine clinical visit, and it may provide valuable information to guide patient-clinician discussions around prognosis and decision-making. Second, patients who report impairments may be candidates for a more thorough assessment and physical therapy evaluation.
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