Discordance Between Patient-Predicted and Model-Predicted Life Expectancy Among Ambulatory Patients With Heart Failure

Larry A. Allen, MD, MHS
Jonathan E. Yager, MD
Michele Jonsson Funk, PhD
Wayne C. Levy, MD
James A. Tulsky, MD
Margaret T. Bowers, RN, MSN
Gwen C. Dodson, RN, MSN
Christopher M. O'Connor, MD
G. Michael Felker, MD, MHS

Heart failure accounts directly for 55,000 deaths and indirectly for an additional 230,000 deaths in the United States each year. Despite advances in care, the prognosis for patients with symptomatic heart failure remains poor, with median life expectancy of less than 5 years. For those with the most advanced disease, 1-year mortality rates approach 90%. About half of these deaths are due to progressive pump failure, while the remainder are sudden. Prognosis is highly dependent on a multitude of patient characteristics, and a number of prognostic models have been developed to help predict survival in patients with heart failure.

Given the progressive nature of heart failure, its high mortality rate, and its predilection for affecting elderly persons, end-of-life issues should be at the forefront of heart failure management. In recognition of this, practice guidelines from major cardiovascular societies include sections on end-of-life considerations, which advocate ongoing patient and family education regarding prognosis for quality of life and survival.

Author Affiliations: Duke Clinical Research Institute and Division of Cardiology (Drs Allen, O’Connor, and Felker and Mss Bowers and Dodson) and Center for Palliative Care and Division of General Internal Medicine (Dr Tulsky), Duke University Medical Center, Durham, North Carolina; Cardiac Care Associates, Fairfax, Virginia (Dr Yager); Department of Epidemiology, University of North Carolina, Chapel Hill (Dr Jonsson Funk); and Division of Cardiology, University of Washington, Seattle (Dr Levy).

For editorial comment see p 2566.

©2008 American Medical Association. All rights reserved.
ure are sparse, especially in comparison with other morbid chronic diseases such as cancer.\textsuperscript{11,14} The extent to which patients with heart failure understand their prognosis remains poorly defined, and the few existing studies addressing end-of-life care in heart failure have largely involved resuscitation preferences.\textsuperscript{15-18} We are aware of no studies focusing specifically on patient perceptions of life expectancy in heart failure, although examples do exist in other disease settings.\textsuperscript{19,20}

Patient perception of prognosis is important because it fundamentally influences medical decision making regarding medications, devices, transplantation, and end-of-life care. Prior study in the field of oncology has shown that patients who believe they have a better chance for survival are more likely to favor aggressive therapy.\textsuperscript{22} With the increasing availability of potentially life-saving therapies that are also costly and invasive and that often involve increased risk of morbidity (eg, left ventricular assist devices), understanding patient perceptions of prognosis is vital for making appropriate care decisions.

The goals of this study were to quantify expectations of life expectancy in ambulatory patients with heart failure, to compare those expectations with model-estimated life expectancy and observed survival, and to identify patient-related factors associated with discrepancies between patient-predicted and model-predicted prognosis.

**METHODS**

**Patients**

This questionnaire survey was conducted between July and December 2004 at the Duke University Heart Failure Disease Management Program in Durham, North Carolina, a clinical program that provides heart failure care to a broad range of patients from the local community. On days determined by interviewer availability, all consecutive patients were approached and asked to participate in the study, which involved completing a questionnaire administered by a physician or nurse practitioner. Patients were excluded if they did not speak English, if they were cognitively impaired, if the interview would have occurred on the day of their initial encounter with the disease management program, or if they had previously participated in the survey. Patients had not previously met the interviewer. Interviews lasted approximately 15 minutes. Follow-up continued through February 2008. All patients provided written informed consent. The study was approved by the Duke University institutional review board.

**Questionnaire Design and Validity**

The questionnaire was composed of 63 multiple-choice and short-answer questions as well as a visual analog scale (VAS). Basic language was used to maximize understanding. Patient perceptions of remaining life expectancy were addressed with sequential items validated in prior studies.\textsuperscript{22-24} After a short introduction to the concept of prognosis, patients were asked, “What do you think the eventual outcome will be from your heart failure?” Possible answers were (1) It will be cured; (2) I will live a normal life span but will have heart failure the rest of my life; (3) Heart failure will likely shorten my life; (4) Don’t know; or (5) Refused to answer.

To quantify patient-perceived life expectancy, patients were asked, “While no one can ever say how much longer they might live, sometimes patients with chronic illnesses do think about this question. If you had to guess, how much longer do you think you will live?” Two sequential redundant responses were then recorded. In the first, quantitative ranges of patient-predicted remaining life expectancy were assessed with the following multiple-choice answers: more than 10 years, more than 5 years and up to 10 years, more than 2 years and up to 5 years, more than 1 year and up to 2 years, more than 6 months and up to 1 year, more than 3 months and up to 6 months, up to 3 months, don’t know, or refused to answer.\textsuperscript{22} Immediately following, a VAS of life expectancy was provided.\textsuperscript{23} The scale provided a time line composed of a 10-cm horizontal line with major hatch marks at each centimeter, labeled in 10-year increments from 0 to 100, and minor hatch marks at each millimeter. Patients were directed to “Put one mark on the line to indicate your current age. Put another mark on the line to indicate how old you think you might be when you die.” The difference between these 2 marks was recorded as the patient-predicted life expectancy. Visual analog scale instruments are well validated in a wide variety of clinical settings and may be less affected by level of numerical literacy than other probability-based methods of assessing patients’ expectations of survival.\textsuperscript{25-27}

Severity of heart failure symptoms was characterized using New York Heart Association (NYHA) functional class.\textsuperscript{29} Perceived quality of life was assessed using 2 general domain items adapted from the 36-item Short-Form Health Survey.\textsuperscript{29} Resuscitation preferences were recorded using items from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) project.\textsuperscript{33} Patients were screened for depression using the 2-question Patient Health Questionnaire.\textsuperscript{30-32} Religiosity was characterized using a modified Duke University Religion Index.\textsuperscript{33} Self-reported race was collected through a multiple-choice item on the questionnaire to assess whether patient expectations about prognosis differed based on racial background. Demographic information was recorded. Recent clinical, medication, laboratory, and imaging data were obtained from the electronic medical record.

**Model-Predicted Life Expectancy and Observed Survival**

The Seattle Heart Failure Model (SHFM), a prognostic tool that has been well validated in ambulatory patients with chronic heart failure, was used to estimate mean remaining life expectancy for each study participant.\textsuperscript{6,34-36} Although the SHFM...
was derived from a clinical trial population, it was initially validated in populations from 3 clinical trials and 2 registries of ambulatory patients with heart failure and has subsequently been validated in another large community-based population with heart failure, supporting the generalizability of the SHFM to the population used in this study. We used the electronic medical record to collect data on all variables required to calculate the SHFM score, including clinical characteristics (age, sex, NYHA functional class, systolic blood pressure, and weight), medications (angiotensin-converting enzyme inhibitor, angiotensin receptor blocker, β-blocker, statin, aldosterone blocker, loop diuretic dose, and allopurinol), device therapies (implantable cardioverter-defibrillator, cardiac resynchronization therapy), and results of diagnostic testing (ejection fraction, lymphocyte percentage, and levels of sodium, hemoglobin, uric acid, and total cholesterol). The most recent test results from within 12 months of the interview were used. Missing variables were imputed as the mean for all patients in the data set. The mean life expectancy provided by the SHFM for each individual participant was recorded as the model-predicted life expectancy.

Actuarial-predicted life expectancy based on age and sex alone was calculated for each patient in the cohort using life expectancy data from the Human Mortality Database (available at http://www.mortality.org). Observed survival was assessed through a search of the Social Security Death Index on February 12, 2008. To account for possible lag in recently deceased patients being available in the death index, we classified patients absent from our death index search as alive as of 6 months prior to the search or at their last documented clinical encounter, whichever was later.

**Statistical Analysis**

Baseline variables were reported as medians and interquartile ranges (IQRs) for continuous variables or as percentages for categorical variables. The internal consistency of prognostic assessments on the questionnaire was assessed by calculating the Cronbach α for intrapatient correlation of patient-predicted life expectancy from the VAS compared with patient-estimated life expectancy expressed using the multiple-choice item. The relationship of patient-predicted to model- and actuarial-predicted life expectancy was evaluated using linear regression analysis. The life expectancy ratio (LER) was defined as the simple ratio of patient-predicted to model-predicted life expectancy for each individual participant.

For descriptive purposes, patients were grouped into categories based on ranges of LER believed to define clinically meaningful categories: underestimated (LER < 0.7), concordant (LER 0.7–1.3), and overestimated (LER > 1.3). The univariate relationships of baseline patient characteristics across descriptive categories of LER were evaluated with Cochran-Mantel-Haenszel statistics for dichotomous variables and nonparametric Wilcoxon rank sum statistics for continuous variables.

To evaluate the validity of the SHFM in our population, we calculated the model accuracy (c statistic) in our cohort at 1 year and 3 years of follow-up and also assessed calibration of the model in our cohort by comparing predicted mortality with observed mortality by quintiles of predicted risk.

To identify characteristics associated with overestimation of survival, we performed multivariable linear regression with the log-transformed LER as the dependent variable. Based on cohort size, candidate variables considered for the model were limited to 12 and were selected using clinical assumptions of importance. These included age, sex, race, level of education, economic status, NYHA class, ejection fraction, ischemic etiology of heart failure, time since diagnosis of heart failure, recent hospitalization, presence of an implantable cardioverter-defibrillator, and depression. To identify nonlinear relationships between continuous covariates and LER, we first examined plots of each continuous covariate vs log-transformed LER to visually assess whether a nonlinear relationship was present and then evaluated the contribution of higher-order terms (squared and cubed) using a bivariate linear model; where higher-order terms were statistically significant at P < .10, we retained these for multivariable modeling. Backward stepwise selection was applied. Variables were retained in the model if the regression coefficient was significantly associated at the α = .10 level.

Cox proportional hazards analysis was used to assess the relationship between categories of LER and observed mortality after adjustment for other known predictors of mortality in heart failure (age, sex, race, NYHA functional class, ejection fraction, and ischemic etiology). We performed backward selection with LER forced into the model, retaining covariates with P < .10 or those for which removal of the covariate resulted in a 10% change in the parameter estimate for LER. All statistical analyses were performed using SAS version 9.1.3 (SAS Institute Inc, Cary, North Carolina).

**RESULTS**

**Cohort Characteristics**

During study enrollment, 154 patients were approached to participate in the study; 148 agreed. Of these 148 participants, 26 were unable or unwilling to estimate their life expectancy using the VAS and were therefore excluded from the current analysis. On the related multiple-choice answer for life expectancy, 21 of these excluded patients indicated that they felt unable to predict their life expectancy, and 5 answered that they would live more than 10 years. In comparison with the final study cohort, the 26 excluded patients were more likely to be African American (20 [77%]) and women (16 [61%]; observed mortality over median follow-up of 3 years was 31%, which was similar to that for the main cohort.
Baseline characteristics for the 122 patients in the final cohort are presented in Table 1. Our study cohort was racially diverse (47% African American) and included a significant proportion of elderly patients (45% aged >65 years). The cohort included a broad spectrum with regard to disease severity (58% NYHA class I/II, 42% class III/IV). Most patients had longstanding chronic heart failure (83% with heart failure for >1 year), and the use of guideline-recommended medical therapy for heart failure was high. Comorbid conditions were common, with hypertension, hyperlipidemia, and diabetes present in the majority of patients.

Data capture for baseline variables among the 122 patients in the final cohort was relatively complete; variables used in the SHFM were present for 118 (97%) of the study participants, with the exception of serum uric acid level (76 [62%]) and lymphocyte percentage (102 [84%]) (Table 1). Data used for the calculation of the SHFM score were relatively recent, with 78% of data obtained at the time of enrollment and 87% from within 1 month of enrollment.

Patient- and Model-Predicted Life Expectancies

The median patient-predicted life expectancy was 130.0 years (IQR, 8.21; range, 1-54 years). The intraparticipant reliability for patient-predicted expectancy was good (standardized Cronbach α=.92 for correlation between life expectancy from the VAS and that expressed using the multiple-choice item). In response to the qualitative question addressing the eventual outcome of their heart failure, 11 (9%) of study participants answered “It will be cured.” 62 (51%) answered “I will have a normal life expectancy but will have heart failure the rest of my life,” 144 (36%) answered “heart failure will likely shorten my life,” and 5 (4%) refused to answer.

The median survival predicted by the SHFM (ie, model-predicted life expectancy) was 10.0 years (IQR, 7.2-13.3 years; range, 2.0-25.2 years). Using actuarial life tables based on age and sex alone (without consideration for heart failure status), the median actuarial-predicted life expectancy was 20.5 years (IQR, 11.5-26.3 years; range, 3.5-52.6 years).

The majority of patients (77 [63%]) overestimated their life expectancy when compared with that predicted by the SHFM. The median LER (ie, ratio of patient-predicted to model-predicted life expectancy) was 1.4 (IQR, 0.8-2.5; range, 0.1-9.6). There was little relationship between patient-predicted and model-predicted life expectancy (R=0.02, slope=0.06, intercept=15.6 years; P=.80) (Figure 1A). Patient predictions of life expectancy were more similar to those predicted by empirically derived actuarial life tables based on age and sex alone, without regard for the presence of heart failure (R=0.53, slope=0.59, intercept=4.2 years; P<.001) (Figure 1B).

Observed Survival

Thirty-five patients (29%; 95% confidence interval [CI], 21%-37%) died over a median follow-up period of 3.1 years (IQR, 2.7-3.3 years). Additionally, 2 patients underwent heart transplantation, and 1 patient received a left ventricular assist device during follow-up. To assess the validity of the SHFM in our population, we analyzed the accuracy and calibration of SHFM predictions in the 35 patients who died during follow-up. Overall, the SHFM had accuracy in our population (C statistic=0.73 for 1-year survival, 0.64 for 3-year survival) that was comparable to previously published validation cohorts.6 Observed survival was similar to that predicted by the SHFM at 1 year (90% observed vs 92% predicted) and 3 years (72% observed vs 80% predicted). Comparison of observed survival with that predicted by the SHFM in our cohort is shown in Figure 2. In an exploratory analysis in the subgroup of patients who died, there was no relationship between patient-predicted life expectancy and observed survival (R=0.17, slope=1.54, intercept=11.1 years; P=.32).

To evaluate whether patients who overestimated life expectancy relative to that predicted by the SHFM experienced better survival during follow-up, we used Cox proportional hazards analysis to examine the relationship between survival and LER category (using concordant LER as the reference group). After adjusting for other likely predictors of mortality (age, sex, race, NYHA class, ejection fraction, and heart failure etiology), there was no relationship between LER category and survival (adjusted hazard ratio for overestimated LER, 1.05; 95% CI, 0.46-2.42; P=.91; for underestimated LER, 0.45; 95% CI, 0.17-1.21; P=.11). Kaplan-Meier curves of observed survival stratified by categories of LER are shown in Figure 3.

Patient Factors Associated With Prognostic Outlook

Given the discordance between patient predictions and model predictions of survival, we determined which patient characteristics were predictive of overestimation or underestimation of life expectancy. Table 1 shows univariate relationships of baseline characteristics across categories of LER. To assess whether patients who overestimated or underestimated survival were more common among patients with a concordant LER compared with those with underestimated and overestimated life expectancy.

Linear regression modeling identified patient factors independently associated with overestimated life expectancy (ie, higher LER) relative to that predicted by the SHFM. All of the continuous variables considered had a linear relationship with log-transformed
Table 1. Baseline Characteristics for the Study Cohort Stratified by Category of Life Expectancy Ratio (LER)a

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Overall</th>
<th>Underestimated (LER &lt; 0.7) (n = 26)</th>
<th>Concordant (LER 0.7-1.3) (n = 32)</th>
<th>Overestimated (LER &gt; 1.3) (n = 64)</th>
<th>P Valueb</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, median (IQR), y</td>
<td>122</td>
<td>122</td>
<td>122</td>
<td>122</td>
<td>.001</td>
</tr>
<tr>
<td>Men, No. (%)</td>
<td>76 (62)</td>
<td>16 (62)</td>
<td>21 (66)</td>
<td>39 (61)</td>
<td>.90</td>
</tr>
<tr>
<td>Race, No. (%)</td>
<td>61 (50)</td>
<td>17 (65)</td>
<td>20 (63)</td>
<td>24 (20)</td>
<td>.02</td>
</tr>
<tr>
<td>Other</td>
<td>4 (3)</td>
<td>2 (8)</td>
<td>0</td>
<td>2 (3)</td>
<td></td>
</tr>
<tr>
<td>College educated, No. (%)</td>
<td>61 (50)</td>
<td>20 (77)</td>
<td>13 (41)</td>
<td>28 (44)</td>
<td>.008</td>
</tr>
<tr>
<td>Comorbid conditions, No. (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td>122</td>
<td>100 (82)</td>
<td>22 (85)</td>
<td>26 (81)</td>
<td>.93</td>
</tr>
<tr>
<td>Diabetes</td>
<td>122</td>
<td>66 (54)</td>
<td>16 (58)</td>
<td>10 (31)</td>
<td>.84</td>
</tr>
<tr>
<td>Atrial fibrillation</td>
<td>122</td>
<td>36 (30)</td>
<td>6 (23)</td>
<td>15 (47)</td>
<td>.04</td>
</tr>
<tr>
<td>Stroke</td>
<td>122</td>
<td>20 (16)</td>
<td>4 (15)</td>
<td>10 (31)</td>
<td>.02</td>
</tr>
<tr>
<td>COPD</td>
<td>122</td>
<td>35 (29)</td>
<td>6 (23)</td>
<td>13 (41)</td>
<td>.22</td>
</tr>
<tr>
<td>Cancer other than skin</td>
<td>122</td>
<td>14 (11)</td>
<td>2 (8)</td>
<td>3 (9)</td>
<td>.63</td>
</tr>
<tr>
<td>Active smoker</td>
<td>122</td>
<td>15 (12)</td>
<td>3 (12)</td>
<td>4 (13)</td>
<td>.99</td>
</tr>
<tr>
<td>Heart failure NYHA class, No. (%)</td>
<td>122</td>
<td>13 (11)</td>
<td>5 (10)</td>
<td>2 (6)</td>
<td>.60</td>
</tr>
<tr>
<td>I</td>
<td>122</td>
<td>58 (48)</td>
<td>10 (36)</td>
<td>16 (55)</td>
<td>.30 (47)</td>
</tr>
<tr>
<td>II</td>
<td>122</td>
<td>42 (34)</td>
<td>9 (35)</td>
<td>11 (34)</td>
<td>22 (34)</td>
</tr>
<tr>
<td>III</td>
<td>122</td>
<td>9 (7)</td>
<td>2 (8)</td>
<td>1 (3)</td>
<td>.69</td>
</tr>
<tr>
<td>Ejection fraction, median (IQR), %</td>
<td>121</td>
<td>26 (20-35)</td>
<td>30 (25-35)</td>
<td>30 (20-40)</td>
<td>.10</td>
</tr>
<tr>
<td>Ischemic etiology, No. (%)</td>
<td>122</td>
<td>46 (38)</td>
<td>16 (61)</td>
<td>16 (50)</td>
<td>.44</td>
</tr>
<tr>
<td>Heart failure diagnosis ≥1 y, No. (%)</td>
<td>122</td>
<td>101 (83)</td>
<td>23 (88)</td>
<td>29 (91)</td>
<td>.49</td>
</tr>
<tr>
<td>Hospitalization in past 12 mo, No. (%)</td>
<td>120</td>
<td>73 (61)</td>
<td>16 (62)</td>
<td>15 (50)</td>
<td>.40</td>
</tr>
<tr>
<td>Current therapies, No. (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Implantable cardioverter-defibrillator</td>
<td>122</td>
<td>30 (25)</td>
<td>7 (27)</td>
<td>9 (28)</td>
<td>.76</td>
</tr>
<tr>
<td>Biventricular pacemaker</td>
<td>122</td>
<td>17 (14)</td>
<td>5 (20)</td>
<td>4 (13)</td>
<td>.64</td>
</tr>
<tr>
<td>ACE inhibitor or ARB</td>
<td>122</td>
<td>114 (93)</td>
<td>25 (96)</td>
<td>30 (94)</td>
<td>.30</td>
</tr>
<tr>
<td>β-Blocker</td>
<td>122</td>
<td>105 (86)</td>
<td>25 (96)</td>
<td>27 (84)</td>
<td>.24</td>
</tr>
<tr>
<td>Furosemide equivalents, mg/24 h, median (IQR)c</td>
<td>122</td>
<td>80 (20-160)</td>
<td>80 (20-160)</td>
<td>40 (15-120)</td>
<td>80 (40-160)</td>
</tr>
<tr>
<td>Statin</td>
<td>122</td>
<td>67 (55)</td>
<td>19 (73)</td>
<td>19 (59)</td>
<td>.25</td>
</tr>
<tr>
<td>Antidepressant</td>
<td>122</td>
<td>34 (28)</td>
<td>10 (38)</td>
<td>8 (25)</td>
<td>.40</td>
</tr>
<tr>
<td>Examination and laboratory data, median (IQR)</td>
<td>121</td>
<td>121</td>
<td>121</td>
<td>121</td>
<td>.01</td>
</tr>
<tr>
<td>Systolic blood pressure, mmHg</td>
<td>121</td>
<td>124 (110-140)</td>
<td>129 (114-138)</td>
<td>130 (116-150)</td>
<td>.05</td>
</tr>
<tr>
<td>Heart rate, beats/min</td>
<td>122</td>
<td>75 (66-84)</td>
<td>71 (66-80)</td>
<td>73 (62-78)</td>
<td>.69</td>
</tr>
<tr>
<td>Weight, kg</td>
<td>121</td>
<td>92 (78-109)</td>
<td>91 (73-106)</td>
<td>89 (73-106)</td>
<td>.45</td>
</tr>
<tr>
<td>Serum sodium, mEq/L</td>
<td>118</td>
<td>140 (138-142)</td>
<td>139 (138-141)</td>
<td>141 (138-142)</td>
<td>.30</td>
</tr>
<tr>
<td>Serum creatinine, mg/dL</td>
<td>118</td>
<td>1.2 (1.0-1.6)</td>
<td>1.2 (0.9-1.4)</td>
<td>1.3 (1.0-1.5)</td>
<td>.60</td>
</tr>
<tr>
<td>Hemoglobin, g/dL</td>
<td>122</td>
<td>12.8 (11.6-14.1)</td>
<td>13.5 (12.4-14.6)</td>
<td>12.9 (11.8-14.2)</td>
<td>.08</td>
</tr>
<tr>
<td>White blood cell count, ×10^3/L</td>
<td>121</td>
<td>6.7 (5.6-8.2)</td>
<td>7.3 (5.5-9.4)</td>
<td>6.7 (5.9-8.6)</td>
<td>.69</td>
</tr>
<tr>
<td>Lymphocyte percentage, %</td>
<td>102</td>
<td>23 (16-31)</td>
<td>25 (18-32)</td>
<td>24 (16-30)</td>
<td>.91</td>
</tr>
<tr>
<td>Uric acid, mg/dL</td>
<td>76</td>
<td>7.8 (6.1-9.5)</td>
<td>6.8 (5.6-9.2)</td>
<td>8.2 (6.9-9.8)</td>
<td>.28</td>
</tr>
<tr>
<td>Total cholesterol, mg/dL</td>
<td>118</td>
<td>166 (142-194)</td>
<td>168 (152-199)</td>
<td>163 (142-186)</td>
<td>.70</td>
</tr>
<tr>
<td>Serum NT-proBNP, ng/mL</td>
<td>99</td>
<td>1132 (370-2638)</td>
<td>1106 (407-2381)</td>
<td>1297 (491-2495)</td>
<td>.95</td>
</tr>
<tr>
<td>Psychosocial measures, median (IQR)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality of life (0 = low, 100 = high)</td>
<td>122</td>
<td>59 (40-75)</td>
<td>50 (38-75)</td>
<td>55 (45-75)</td>
<td>.44</td>
</tr>
<tr>
<td>Depression (0 = low, 7 = high)</td>
<td>122</td>
<td>1 (0-3)</td>
<td>2 (1-4)</td>
<td>1 (0-3)</td>
<td>.13</td>
</tr>
<tr>
<td>Religiosity (0 = low, 22 = high)</td>
<td>107</td>
<td>16 (13-19)</td>
<td>16 (12-19)</td>
<td>16 (13-19)</td>
<td>.06</td>
</tr>
<tr>
<td>Financially stable, subjective, No. (%)</td>
<td>122</td>
<td>41 (34)</td>
<td>8 (31)</td>
<td>11 (34)</td>
<td>.94</td>
</tr>
</tbody>
</table>

Abbreviations: ACE, angiotensin-converting enzyme; ARB, angiotensin receptor blocker; COPD, chronic obstructive pulmonary disease; IQR, interquartile range; NT-proBNP, N-terminal pro-brain natriuretic peptide; NYHA, New York Heart Association.

SI conversion factors: To convert creatinine values to µmol/L, multiply by 88.4; uric acid to µmol/L, by 59.485; total cholesterol to mmol/L, by 0.0259.

aLife expectancy ratio indicates the ratio of patient-predicted to model-predicted life expectancy.

bP values were calculated for categorical covariates using Cochran-Mantel-Haenszel statistics, whereas P values for continuous variables were calculated using nonparametric Wilcoxon rank sum statistics.

cFurosemide equivalents were estimated with the use of Micromedex as previously described.
LER except ejection fraction, which was modeled using quadratic and cubic terms to maximize the fit of the model. In the final multivariable model, independent predictors of higher log-transformed LER were younger age, higher NYHA class, lower ejection fraction, ischemic etiology of heart failure, and lower measures of depression (TABLE 2).

A linear relationship existed between decreasing age and increasing patient-predicted life expectancy, with progressively younger patients estimating progressively longer life expectancy despite model predictions that were similar across age groups (FIGURE 4). In contrast, model predictions were much more influenced by measures of disease severity (NYHA class, ejection fraction, and heart failure etiology) than by age. Figure 5 shows the association between patient-predicted life expectancy, model-predicted expectancy, and NYHA class, with higher NYHA classes having progressively decreasing model predictions of survival despite relatively static patient predictions. Patient predictions of life expectancy did not appear to be associated with symptom severity, with the same median patient-predicted expectancy of 12 years for patients who were minimally symptomatic (NYHA class I) as for those with advanced symptoms (NYHA class IV).

Since specific communication about prognosis between the clinician and the patient may have affected understanding of likely prognosis, we examined LERs for patients who reported having previously spoken to their clinician about prognosis (n=45) compared with those who had not (n=76) and found no significant difference in LER between these 2 groups (median LER, 1.34 vs 1.46, respectively; P=.55).

**COMMENT**

In ambulatory patients with heart failure, self-assessment of life expectancy was on average significantly greater than that predicted by a validated heart failure–specific model. When quantified as the LER (ie, ratio of patient-predicted to model-predicted life expectancy), the median overestimation of predicted future survival in the population was 40% (median LER, 1.4; IQR, 0.8-2.5). Overall, patient predictions of life expectancy correlated better with actuarial predictions (based on life tables using age and sex alone) than they did with expected survival based on the heart failure model. These data suggest that many patients with heart failure have survival expectations that differ markedly from the anticipated natural history of their disease.
Younger age, greater disease severity (higher NYHA class and lower ejection fraction), and measures of less depression were independently associated with higher LER. Patient expectations about their survival varied considerably with differences in age, and for unclear reasons patients appeared to predict similar life expectancy regardless of the objective severity of their heart failure. These associations resulted in particularly discordant predictions in younger patients and those with more severe disease and account for the seemingly paradoxical relationship between greater disease severity and higher LER. Both younger age and greater disease severity have been identified as being associated with greater discordance between patient and physician expectations about prognosis in patients with cancer. We also identified an association between lower measures of depression and higher LER, a relationship that seems intuitively valid (patients who are more depressed may be less likely to be optimistic in their prognostic outlook). The complex biological relationship between depression and heart failure has been increasingly recognized in recent years and is a subject of ongoing randomized trials.

These results underscore the complexity of identifying underlying reasons for the observed discordance between patient expectations and objective predictions of survival. One possible explanation of our findings may be that differences in perception about prognosis result from inadequate communication between clinicians and patients. The SUPPORT trial showed a high degree of incongruity between patients and their clinicians on end-of-life decisions. \(^\text{19}\) The root causes of inadequate transfer of prognostic information are almost certainly multifactorial but are likely related to clinician communication skills, patient-specific factors, and language and cultural differences. \(^\text{16}\) The lack of effective communication about prognosis may also be due in part to physicians’ self-perceived inability to predict risk of mortality in advanced heart failure. \(^\text{21}\) Recent data from the Evaluation Study of Congestive Heart Failure and Pulmonary Artery Catheter Effectiveness (ESCAPE) suggest that nurses may be better than physicians at estimating 6-month mortality in patients with advanced heart failure. \(^\text{12}\) Although we did not identify a clear relationship between LER and prior patient-physician discussions regarding prognosis, it seems likely that issues of communication play a substantial role in the way patients understand and interpret information about prognosis.

An alternative explanation for our findings may be that individuals’ predictions of longer life expectancy for themselves may simply reflect hope. When patients with advanced malignancy are asked whether they themselves stand to benefit from participating in a phase 1 trial, they tend to provide a much higher expected rate of benefit than when they are asked whether another person with the same level of disease is likely to benefit. \(^\text{15}\) The implication is that even when patients have a good understanding of prognosis, they may choose not to apply that information to themselves. In this study we asked patients only about self-assessed life expectancy, without regard to how they perceived prognosis for other individuals in the same situation.

Table 2. Multivariable Model of Independent Predictors of Higher Life Expectancy Ratio (LER)\(^\text{a}\)

<table>
<thead>
<tr>
<th>Clinical Characteristic</th>
<th>Parameter Estimate (95% CI)</th>
<th>(\chi^2)</th>
<th>(P) Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age per year</td>
<td>–0.028 (–0.038 to –0.018)</td>
<td>28.7</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>College educated</td>
<td>–0.22 (–0.47 to 0.29)</td>
<td>3.0</td>
<td>.08</td>
</tr>
<tr>
<td>NYHA class</td>
<td>0.22 (0.046 to 0.40)</td>
<td>6.1</td>
<td>.01</td>
</tr>
<tr>
<td>Ejection fraction, per %(^\text{b})</td>
<td>–0.29 (–0.47 to –0.12)</td>
<td>10.6</td>
<td>.001</td>
</tr>
<tr>
<td>Squared</td>
<td>0.008 (0.0032 to 0.014)</td>
<td>10.1</td>
<td>.002</td>
</tr>
<tr>
<td>Cubed</td>
<td>–0.00007 (–0.00012 to –0.00003)</td>
<td>9.6</td>
<td>.002</td>
</tr>
<tr>
<td>Ischemic etiology</td>
<td>–0.50 (–0.77 to –0.23)</td>
<td>12.8</td>
<td>&lt; .001</td>
</tr>
<tr>
<td>Depression score</td>
<td>–0.11 (–0.018 to –0.044)</td>
<td>10.6</td>
<td>.001</td>
</tr>
</tbody>
</table>

Abbreviations: CI, confidence interval; NYHA, New York Heart Association.

\(\text{a}\) The final reduced model shown here. Life expectancy ratio indicates ratio of patient-predicted to model-predicted life expectancy. The log-transformed LER was used as the dependent (outcome) variable with 12 clinical covariates considered in the initial model.

\(\text{b}\) Quadratic (ejection fraction squared) and cubic (ejection fraction cubed) terms were included in the final model due to the nonlinear relationship between ejection fraction and LER.
Physicians and family members frequently counsel patients on the importance of maintaining a positive optimistic outlook in the face of significant illness. While such an outlook may have psychological benefits for patients and their families, the extent to which an optimistic outlook may affect clinical outcomes in chronic illness remains inadequately characterized. Although our study was limited by the relatively small number of deaths in our cohort, patients’ overestimation of prognostic expectations were not associated with improved survival.

The oncology literature provides a foundation for end-of-life expectations in chronic illness. In contrast, relatively little work has been performed in end-of-life care in heart failure, despite a long-term prognosis comparable to that of many advanced forms of cancer. Patients with heart failure may be less informed about their disease process than those with lung cancer. In a qualitative study comparing illness trajectories of patients with class IV heart failure and those with metastatic lung cancer, patients with heart failure had less understanding about their disease and their prognosis. Whereas patients with lung cancer thought about dying as a direct result of their illness, those with heart failure tended to think about dying more in the context of aging. This is concordant with our findings that patients with heart failure estimated their survival to be more similar to actuarial survival based on age than that predicted by heart failure–specific models.

Our results suggest that the communication of prognostic information between physicians and patients with heart failure is an area in need of additional attention in terms of clinical care and research. Improvements in patient understanding of prognosis may refine decision making around resuscitation preferences, adherence to medical therapy, and consideration of advanced heart failure therapies such as implantable cardioverter-defibrillators, cardiac transplantation, or mechanical cardiac support. Efforts to better integrate palliative care into the treatment of selected patients with heart failure will require a more sophisticated appreciation of patient perceptions of prognosis. The increasing availability of Web-based clinical pre-
in other diseases such as early stage breast cancer, the use of prognostic models and decision tools has been shown to increase patient understanding of prognosis and treatment options, leading to higher degrees of satisfaction with the process of care.57

Our study has several important limitations. We compared patient perceptions of prognosis with estimates from the SHFM rather than with actual survival. Although the SHFM has been well validated in heart failure, survival estimates generated from the model may be inaccurate in individual patients. In the short term, the SHFM tended to slightly overestimate survival for our population (Figure 2), suggesting that overestimation of life expectancy by patients is in reality likely to be even greater than that calculated by LER.

Due to the lack of a control group, our data do not allow for a comparison of prognostic expectations between patients with and without heart failure. Consequently, we cannot determine to what extent our findings are unique to patients with heart failure or are generalizable to broader populations.

The study included a relatively small single-center sampling of patients with heart failure in a university disease management program, which may limit the generalizability of our findings to other settings. However, our cohort included a broad spectrum of disease severity as well as a significant proportion of elderly and African American patients and was generally similar to other unselected ambulatory cohorts with heart failure.35,48 We cannot exclude the possibility that patients’ perceptions of life expectancy may have been influenced by referral to an academic center, although the Duke Heart Failure Disease Management Program serves a diverse patient population through local satellite clinics. This study was performed in an ambulatory setting, and patient perceptions of life expectancy could be different during hospitalization for heart failure, a time when decisions regarding palliative care and advanced therapies are often made. Prior work in the inpatient setting has characterized predictors of referral to hospice but has not included patient perceptions of prognosis.69

We excluded 26 patients from our analysis who were unwilling or unable to provide an estimation of their life expectancy; such patients may have differed in relevant ways from study participants. Prior studies such as the SUPPORT study also have found that a significant proportion of patients are unwilling or unable to address expectations around end of life, suggesting that this potential for selection bias may be an unavoidable limitation of this type of research.51 We did not perform repeat questionnaires over time or other measures to validate the stability or consistency of the patient estimates of life expectancy; however, measures of the internal reliability of patient estimates of life expectancy on our questionnaire were quite high.

Although an exploratory analysis did not identify a relationship between higher LER and observed survival in our study, we did not have sufficient events to assess this relationship with much statistical power; a study design that assessed this relationship over the full range of actual survival would require very long-term follow-up to capture data on mortality in a substantial majority of the study population. Finally, our study did not assess clinician estimates of patient’s life expectancy, so we were not able to contrast the expectations of patients with those of their physicians.

CONCLUSIONS

In ambulatory patients with heart failure, the self-assessment of remaining life span was substantially longer than that predicted by heart failure survival models. This discordance was particularly marked in younger patients and those with more severe disease. The exact reasons for this incongruity are unknown but they may reflect hope or may result from inadequate communication between clinicians and their patients about prognosis. Because differences in expectations about prognosis could affect decision making regarding advanced therapies and end-of-life planning, further research into both the extent and the underlying causes of these differences is warranted. Whether interventions designed to improve communication of prognostic information between clinicians and patients would improve the process of care in heart failure should be tested in appropriately designed clinical trials.

Author Contributions: Dr Allen had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study concept and design: Allen, Yager, Tulsky, O’Connor, Felker.

Acquisition of data: Allen, Yager, Bowers, Dodson.

Analysis and interpretation of data: Allen, Yager, Funk, Levy, Tulsky, Felker.

Drafting of the manuscript: Allen, Yager, Funk, Felker.

Critical revision of the manuscript for important intellectual content: Allen, Yager, Funk, Tulsky, Bowers, Dodson, O’Connor, Felker.

Statistical analysis: Allen, Yager, Funk, Felker.

Administrative, technical, or material support: Yager, Dodson, O’Connor

Study supervision: Tulsky, Felker.

Financial Disclosures: The University of Washington holds the copyright for the Seattle Heart Failure Model. Dr Levy reported receiving royalties from the Seattle Heart Failure Model. No other disclosures were reported.

Funding/Support: While this study was unfunded, Dr Allen’s time was supported by National Institutes of Health grant NIH 2T32HL69749-04, and Dr Felker’s time was supported by National Institutes of Health/ National Heart, Lung, and Blood Institute grant K23 HL7257-01A.

REFERENCES


Eidinger RN, Schapira DV. Cancer patients’ in¬

evaluation.

Ambulatory patients referred for cardiac transplant
validation of a clinical index to predict survival in

PREDICTED LIFE EXPECTANCY AMONG AMBULATORY PATIENTS WITH HEART FAILURE

American College of Chest Physicians and the Inter-

Heart Failure): developed in collaboration with the

AHA 2005 Guideline Update for the Diagnosis and
Management of Chronic Heart Failure in the Adult: a
report of the American College of Cardiology/ American
Heart Association Task Force on Practice Guidelines (Writing Committee to Update the 2001 Guidelines for the Evaluation and Management of Heart Failure): developed in collaboration with the American College of Chest Physicians and the Inter¬

Heart Failure Society Of America. 2006 Compre¬

hensive Heart Fail Practice Guidance. J Card Fail.


Niemenen MS, Bohm M, Cowie MR, et al. Executive
summary of the guidelines on the diagnosis and
treatment of acute heart failure: the Task Force on

Eidinger RN, Schapira DV. Cancer patients’ in¬
sight into their treatment, prognosis, and unconven¬


Weeks JC, Cook EF, O’Day SJ, et al. Relationship

Sulmasy DP, Terry PB, Weisman CS, et al. The ac¬

Chapple NL. Awareness of death in the disen¬
gagement theory: a conceptualization and an empiri¬


2(7889):1127-1131.

McDowell I, Newell C. Measuring Health—A

Gigerenzer G, Edwards A. Simple tools for un¬