Use of the Palliative Performance Scale to estimate survival among home hospice patients with heart failure

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Abstract

Aims Estimating survival is challenging in the terminal phase of advanced heart failure. Patients, families, and health-care organizations would benefit from more reliable prognostic tools. The Palliative Performance Scale Version 2 (PPSv2) is a reliable and validated tool used to measure functional performance; higher scores indicate higher functionality. It has been widely used to estimate survival in patients with cancer but rarely used in patients with heart failure. The aim of this study was to identify prognostic cut-points of the PPSv2 for predicting survival among patients with heart failure receiving home hospice care.

Methods and results This retrospective cohort study included 1114 adult patients with a primary diagnosis of heart failure from a not-for-profit hospice agency between January 2013 and May 2017. The primary outcome was survival time. A Cox proportional-hazards model and sensitivity analyses were used to examine the association between PPSv2 scores and survival time, controlling for demographic and clinical variables. Receiver operating characteristic curves were plotted to quantify the diagnostic performance of PPSv2 scores by survival time. Lower PPSv2 scores on admission to hospice were associated with decreased median (interquartile range, IQR) survival time [PPSv2 10 = 2 IQR: 1–5 days; PPSv2 20 = 3 IQR: 2–8 days] IQR: 55–207. The discrimination of the PPSv2 at baseline for predicting death was highest at 7 days [area under the curve (AUC) = 0.802], followed by an AUC of 0.774 at 14 days, an AUC of 0.736 at 30 days, and an AUC of 0.705 at 90 days.

Conclusions The PPSv2 tool can be used by health-care providers for prognostication of hospice-enrolled patients with heart failure who are at high risk of near-term death. It has the greatest utility in patients who have the most functional impairment.

Keywords Hospice; Palliative care; Heart failure; Prognosis; Palliative performance scale; End-of-life care

Introduction

Heart failure is a progressive disease characterized by high symptom burden that primarily affects older adults with multiple co-morbid conditions.1 In the terminal phase (Stage D), estimating survival is challenging because it has a non-linear disease trajectory.2,3 As such, less than half of physicians accurately estimate survival,4 and the error is systematically optimistic.5

Although national guidelines recommend using population-based risk calculators6-8 to estimate survival for patients with heart failure,8,9 these models have limited ability to prospectively identify the vast majority of heart failure patients who will die in the next year.2,10 Prognostication is thus hampered by limited tools, wide variation in time to death between patients,2 and poor accuracy of clinician-derived survival estimates.4,5 thus adversely affecting patient quality of life near the end of life.9

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For patients and families, knowing how much time remains is important for decision-making, closure for personal and family matters, and shared decision-making focused on patient goals of care.\textsuperscript{2} A clear prognosis is also informative for hospice organizations who need to allocate end-of-life services and select therapies most consistent with a patient’s estimated survival time. To handle the high symptom burden at the end of life, an intensification of services is often necessary. Given the high error in survival estimates for patients with heart failure,\textsuperscript{4,5} having objective data demonstrating a high risk of mortality within a specified time frame would be informative for patients, patient families, and hospice agencies alike.

Palliative Performance Scale Version 2 (PPSv2) has been widely utilized across palliative care patient populations, yet limited data are available on its prognostic value in patients with heart failure. The PPSv2 is a modified version of the Karnofsky performance scale and is used to measure functional status in palliative care\textsuperscript{11,12} and predict survival among terminally ill patients.\textsuperscript{13} Two systematic literature reviews report that the PPSv2 is highly predictive of survival in mixed palliative care populations.\textsuperscript{14,15,16} The relationship between a lower PPSv2 score and shorter length of survival has been reported most commonly for patients with cancer.\textsuperscript{17} To our knowledge, this is the first study to use the PPSv2 to estimate survival time among home hospice heart failure patients. The purpose of this study is to identify prognostic cut-points of the PPSv2 for predicting survival among patients with heart failure receiving home hospice care.

**Methods**

**Study setting and data sources**

This retrospective cohort study included 1114 adult patients with a primary diagnosis of heart failure served from a not-for-profit hospice agency in New York between January 2013 and May 2017. This home hospice agency has an average daily census of >1000 patients in its hospice programme across all five New York City boroughs. The inclusion criterion for this study was patients with a primary diagnosis of heart failure over 18 years of age. For patients with multiple episodes of hospice care during the study period (i.e. two or more admissions), the first episode was selected. The sample included patients with complete data on all study measures.

Patient data were obtained from the electronic medical record database. This database has a diverse set of variables that includes socio-demographics, severity of illness, co-morbid conditions, admission disposition, PPSv2 scores that were collected by nurses at the time of enrolment, and date of death or discharge from hospice services. For patients who enrolled in and out of hospice on multiple occasions, we included the first episode of hospice care only. The home hospice agency and Columbia University Medical Center institutional review boards approved the conduct of this study, and the study complies with the Declaration of Helsinki. The Strengthening the Reporting of Observational Studies in Epidemiology guidelines for the reporting of observational studies were followed.\textsuperscript{18}

**Measures**

The primary outcome in our study was survival time. This variable was calculated as the difference in days between the date of hospice admission and the date of death in hospice. Socio-demographic characteristics included sex, age, race/ethnicity, insurance, marital status, the absence of a primary caregiver, and the absence of a health-care proxy. International Classification of Diseases, 9th revision, Clinical Modification and 10th revision codes were used to calculate Charlson Comorbidity Index scores.\textsuperscript{19} Hospice referral source, which distinguished those who entered hospice following a hospitalization vs. non-hospital settings, was also collected.

The PPSv2 is a reliable and validated tool used to measure functional performance across five domains: ambulation, activity and evidence of disease, independence in self-care, oral intake, and level of consciousness.\textsuperscript{13,20} (Table 1). The PPSv2 is divided into 11 categories between 0% and 100% in 10% increments, in which higher scores indicate higher functionality.\textsuperscript{13} Because PPSv2 scores ranged from 0 to 60 in this cohort, we used six discrete PPS scores (10, 20, 30, 40, 50, and 60). For all patients of the Visiting Nurse Service of New York hospice programme, the PPSv2 is completed as part of a comprehensive admission assessment at admission to hospice care and then every 2 months as a measure of functional status and ongoing change.

**Data analysis**

Means and percentages were used to describe the study population, including demographic and clinical characteristics, and crude mortality rates by PPSv2 score. Medians and interquartile ranges (IQRs) were used to describe survival time by PPSv2 score (among patients who died in hospice), and differences in survival by the PPSv2 were evaluated using the Kruskal–Wallis rank sum test. Receiver operating characteristic curves were plotted for all patients to quantify the diagnostic performance of PPSv2 scores. Sensitivity analyses were also conducted to examine whether diagnostic performance of PPSv2 scores varied by survival time. A Cox proportional-hazards model was used to examine associations of survival time with PPSv2 scores, controlling for patient socio-demographic and clinical characteristics.\textsuperscript{21} Patients who were discharged alive from hospice were
were performed using R Version
trolled for all covariates in the regression model. All analyses
– death. The Kaplan
the date of discharge if patients left hospice prior to their
83
primary caregiver (\( \times \))
Survival time was top coded to
Present the threshold for determining statistical signi-
63
Their majority of home hospice patients in our analysis were
Study population

Results
Study population
The majority of home hospice patients in our analysis were
were female (56.6%) with a mean age of 86 years and had a
primary caregiver (83.8%) (Table 2). All patients lived in
New York City and were racially and ethnically diverse
(22.4% Hispanic, 17.8% African American, and 7.6% Asian).
Most patients were insured through Medicare (63.4%) or
Managed Medicare (e.g. Medicare Advantage; 29.4%) and
were admitted into hospice from the hospital (53.6%). PPSv2
scores at admission to hospice ranged from 10 to 60. The
modal PPSv2 score was 40 (36.2% of all patients). The mean
Charlson Comorbidity Index score was relatively low
(2.8, SD = 1.1). The five most frequent co-morbidities among
patients included renal failure (25.0%), Type II diabetes
without clinical complications (20.4%), chronic pulmonary
disease (18.8%), dementia (16.1%), and stroke (9.5%). While
the majority of patients died while under hospice care
(72.3%), over a quarter of patients were discharged alive
(27.7%). Among those who were discharged alive (n = 309),
the reasons for discharge included acute hospitalization
(49.5%), elective revocation to pursue disease-directed
treatments (21.0%), disqualification (16.2%), or transfer to
another hospice or care setting (13.3%). There was minimal
missing data (<5%) for all study measures.

Percentage of hospice deaths and survival time
by palliative performance scale score

There was a higher mortality rate among patients admitted
to hospice with low PPSv2 scores. Nearly all patients admit-
ted to hospice with a PPSv2 score of 10 or 20 died during
their hospice stay (96% and 92%, respectively). In contrast,
a smaller percentage of those admitted with PPSv2 scores
of 50 or 60 died in hospice (56% and 37%, respectively)
(Figure 1A).

The median survival time was significantly shorter for
patients with lower PPSv2 scores compared with those with
higher PPSv2 scores at the time of admission (\( P < 0.001 \)).
Among the 805 patients who died in hospice, the median
survival time was 2 IQR: 1–5 and 3 IQR: 2–8 days for patients
admitted with a PPSv2 score of 10 and 20, compared with a
median survival time of 80 IQR: 55–207 days for patients with
a PPSv2 score of 60 (Figure 1B).

Accuracy of Palliative Performance Scale Version
2 scores at admission in predicting hospice
survival

While the overall predictive accuracy of the PPSv2 for our
sample was modest [area under the curve (AUC) = 0.69],
the predictive accuracy of PPSv2 scores varied according to

Table 1 Palliative Performance Scale Version 2 (PPSv2)

| PPS level, % | Ambulation         | Activity and evidence of disease                  | Self-care | Intake     | Conscious level |
|-------------|--------------------|---------------------------------------------------|-----------|------------|----------------|
| 100         | Full               | Normal activity and work                           | Full      | Normal     | Full           |
| 90          | Full               | Normal activity and work                           | Full      | Normal     | Full           |
| 80          | Full               | Normal activity and work                           | Full      | Normal or reduced | Full |
| 70          | Reduced            | Unable normal job/work                              | Full      | Normal or reduced | Full |
| 60          | Reduced            | Unable hobby/house work                            | Occasional assistance necessary | Normal or reduced | Full |
| 50          | Mainly sit/lie     | Unable to do any work                              | Considerable assistance required | Normal or reduced | Full |
| 40          | Mainly in bed      | Unable to do most activity                         | Mainly assistance | Minimal to sips | Full |
| 30          | Totally bed bound  | Unable to do any activity                          | Total care | Mouth care only | Full |
| 20          | Totally bed bound  | Unable to do any activity                          | Total care | Mouth care only | Full |
| 10          | Totally bed bound  | Unable to do any activity                          | Total care | Mouth care only | Full |
| 0           | Death              | —                                                  | —         | —          | —              |

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survival time. The PPSv2 had greater accuracy in predicting survival within the first weeks of hospice enrolment (AUC for hospice survival at 7 days = 0.80; 14 days = 0.77; 30 days = 0.74; 90 days = 0.71; 180 days = 0.69) (Figure 2).

**Factors predicting hospice survival time from a multivariable Cox proportional-hazards model**

Results from the multivariate Cox proportional-hazards regression predicting hospice survival time model indicate that PPSv2 scores on admission independently predict survival time among hospice patients with heart failure. Compared with those with a PPSv2 score of 60, those with PPSv2 scores ≤20 had particularly higher hazard of mortality: 18.6 (95% confidence interval = 8.5 to 40.7) and 10.2 (95% confidence interval = 4.6 to 22.6) among hospice patients with PPSv2 scores of 10 and 20, respectively (Table 3). Kaplan–Meier survival curves plotted for each value of the PPSv2 using Cox regression estimates and average covariate values indicate a graded increase in mortality risk from higher to lower PPSv2 scores (Figure 3).

**Discussion**

This is one of the largest and most recent studies in the USA to evaluate the use of the PPSv2 for end-of-life prognostication among patients enrolled in hospice services with a primary diagnosis of heart failure. We found that the PPSv2 can be used to predict survival time for patients with heart failure who are enrolled in hospice. Predictive accuracy for death of the PPSv2 was incrementally improved among patient groups with low PPSv2 scores.

The PPSv2 is widely used in other patient populations for end-of-life prognostication, but there is limited research establishing its utility in the heart failure population. The
The findings of this study support the use of the PPSv2 score at admission for estimating survival in the first 30 days of hospice enrolment. The diagnostic accuracy was greatest among those with low scores, specifically scores of 10 and 20, which correlated with a survival of under a week. This finding is consistent with Harrold et al. who reported that, among a heterogeneous cohort of patients enrolled in a community hospice programme, PPSv2 scores are most accurate in predicting mortality within 1 week (AUC: 0.8~0.85). As such, the PPSv2 can be informative for patients and families who ask health-care providers to predict anticipated life expectancy. Given the poor accuracy of clinician-derived survival estimates, the PPSv2 can be used as supporting evidence and a ‘reality check’ for the prognosis. The PPSv2 can also be used by hospice agencies to support the allocation of appropriate resources, such as more extensive symptom management support, to individuals for whom death is imminent.

This is the largest study of patients with heart failure to report Kaplan–Meier survival curves by initial PPSv2 scores among cardiac home hospice patients. In this sample, there were distinct survival curves for each discrete value of the PPSv2 (10, 20, 30, 40, 50, and 60). Our findings extend observations by Lau et al. and Downing et al. who similarly demonstrated that survival curves differed according to PPSv2 scores among a range of non-heart failure diagnoses. Given that the association between PPSv2 scores and survival may vary between different patient populations, our study has established normative survival data for patients with heart failure. This is critical for building an evidence-base that can be applied to patients with similar diagnoses and sociodemographic characteristics. Finally, there are mixed perspectives on whether the PPSv2 score should be used as categorical (i.e. groups of PPSv2 scores) or discrete (i.e. individual PPSv2 score values) variables for prognostication. Our study demonstrates that each PPSv2 score has a unique trajectory of survival time and supports the value of reporting individual discrete scores.

Patients with advanced heart failure often experience uncontrolled symptoms and rapid changes in their disease trajectories. Despite this, palliative care for patients with heart failure often lags behind that for other diseases such as cancer. Consistent with an American Heart Association guideline, we recommend that palliative approaches occur earlier in the disease process, ideally timing conversations about advance care planning between patients and providers with the initial diagnosis of heart failure. Given the potential for improved prognostication and low burden on providers, our study findings indicate that there may be utility in using PPSv2 scores at hospice admission. Future research steps include the evaluation of the PPSv2 as part of informing hospice eligibility at the time of hospital discharge. Finally,
almost a quarter of the population dis-enrolled from hospice. This is a large and important segment of the population. Future research should explore predictors of discharge in this population, including PPSv2 scores. More research is also needed on the clinical utility of repeated PPSv2 measurements and whether they can be used to evaluate trajectories of change for patients. The clinical implication of this finding for health-care providers within cardiac home hospice programmes is that this short, provider completed questionnaire can be a helpful indicator of survival in the next 30 days, which can be extremely valuable information for patients, families, and providers.

**Limitations**

There are some important limitations to consider. First, survival time is limited to the period of time that patients were enrolled in hospice and does not include data for patients who were discharged from hospice and admitted to local hospitals. We had limited data on patient socio-economic status including income and education. Another limitation is that co-morbid conditions may be underreported in this sample. Medicare regulations changed in 2014, implemented in 2015, mandating that hospices code for both the terminal illness and other coexisting diagnoses that support the terminal condition. These regulations may lead...
to an underreporting of co-morbid conditions, which may explain why the Charlson Comorbidity Index is relatively low in this sample of patients. Very few participants in our sample had PPS scores of 60 raising questions about the validity of prognostication for scores in this range. This was also expected because it is a cohort of hospice-enrolled patients. Finally, our data were derived from a single non-profit hospice agency, albeit one that is located in a highly urban and culturally diverse setting.

Conclusions

Our study demonstrates that the PPSv at admission to hospice has high predictive accuracy for survival in the first 30 days among patients with heart failure, with incremental value at lower PPSv scores. These findings provide evidence that this tool can be used to estimate time to death among heart failure patients enrolled in hospice, which may be helpful for patients and families who frequently request accurate predictions of prognosis and for hospice agencies who may benefit from utilizing these data to better identify patients that require intensification of their services.

Conflict of interest

None declared.

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