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Use of the Palliative Performance Scale to Estimate Survival among Home Hospice Patients with

Heart Failure

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(2) Abstract

Background: Estimating survival is challenging in the terminal phase of advanced heart failure. Patients, families and healthcare 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.

Aim: 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: This retrospective cohort study included 1,114 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 examine the association between PPSv2 scores and survival time, controlling for demographic and clinical variables. Receiver Operating Characteristic (ROC) curves were plotted to quantify the diagnostic performance of PPSv2 scores by survival time.

Results: Lower PPSv2 scores on admission to hospice were associated with decreased median (IQR) survival time (PPSv2 10 = 2 (IQR: 4) days; PPSv2 20 = 3 (IQR: 6) days; PPSv2 30 = 13 (IQR: 48) days). The discrimination of the PPSv2 at baseline for predicting death was highest at 7 days (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 healthcare 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.

Journal subject terms: hospice, palliative care, heart failure, prognosis, palliative performance scale, end-of-life care

Abbreviations:

PPSv2: Palliative Performance Scale Version 2

VNSNY: Visiting Nurse Service of New York

STROBE: Strengthening the Reporting of Observational Studies in Epidemiology

ICD: International Classification of Diseases

ROC: Receiver Operating Characteristic

AUC: Area under the curve

(3) Introduction

Heart failure is a progressive disease characterized by high symptom burden that primarily affects older adults with multiple comorbid conditions.[1] In the terminal phase (stage D), estimating survival is challenging because it has a nonlinear disease trajectory.[2,3] As such, less than half of physicians accurately estimate survival,[4] and the error is systematically optimistic.[5] Though national guidelines recommend using population-based risk-calculators [6-8] 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.[5]

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.[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,[4,5] having objective data demonstrating a high risk of mortality within a specified timeframe would be informative for patients, patient families, and hospice agencies alike.

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Palliative Performance Scale Version 2 (PPSv2) has been widely utilized across palliative care patient populations, yet limited data is 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[11,12] and predict survival among terminally ill patients.[13] In the most recent review of the PPSv2, Downing and colleagues reported that it is highly predictive of survival in a mixed palliative care population.[14] The relationship between a lower PPSv2 score and shorter length of survival has been reported most commonly for patients with cancer.[15] 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.

(4) Methods

Study Setting and Data Sources

This retrospective cohort study included 1,114 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 more than 1,000 patients in its hospice program across all five New York City boroughs. The inclusion criteria for this study was patients with a primary diagnosis of heart failure over 18 years of age. For patients with

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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 which includes socio-demographics, severity of illness, comorbid conditions, admission disposition, PPSv2 scores which were collected by nurses at the time of enrollment, 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.[16]

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 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 healthcare proxy. *International Classification of Diseases*, 9th revision, Clinical Modification (ICD-9-CM) and 10th revision (ICD-10) codes were used to calculate Charlson comorbidity index scores.[17] Hospice referral

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source, which distinguished those who entered hospice following a hospitalization versus 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[13,18] **(Table 1)**. The PPSv2 is divided into 11 categories between 0% and 100% in 10% increments, in which higher scores indicate higher functionality.[13] Since PPSv2 scores ranged from 0-60 in this cohort, we used six discrete PPS scores (10, 20, 30, 40, 50 and 60). For all patients the VNSNY hospice program, the PPSv2 is completed as part of a comprehensive admission assessment at admission to hospice care and then every two 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, crude mortality rates by PPSv2 score. Medians and interquartile ranges were used to describe survival time by PPSv2 score (among patients who died in hospice), and differences in survival by PPSv2 were evaluated using the Kruskal-Wallis rank sum test. Receiver Operating Characteristic (ROC) 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-

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hazards model was used to examine associations of survival time with PPSv2 scores, controlling

for patient socio-demographic and clinical characteristics.[19] Patients who were discharged alive

from hospice were censored at the date of discharge. A p-value of 0.05 represented the threshold

for determining statistical significance. Survival time was top-coded to one year and censored as

of the date of discharge if patients left hospice prior to their death. The Kaplan–Meier event-free

survival graphs controlled for all covariates in the regression model. All analyses were

performed using R version 3.4.3.

(5) Results

Study Population

The majority of home hospice patients in our analysis were female (56.6%) with a mean age of

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 comorbidities 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

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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 admitted 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 to 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: 4] and 3 [IQR: 6] days for

patients admitted with a PPSv2 score of 10 and 20, compared to a median survival time of 80

days [IQR: 152] for patients with a PPSv2 score of 60 **(Figure 1b)**.

Accuracy of PPSv2 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 survival time. The PPSv2 had greater accuracy in predicting survival within the first weeks of hospice enrollment (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).

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 to those with a PPSv2 score of 60, those with PPSv2 scores ≤20 had particularly higher hazard of mortality; 18.6 (95% CI= 8.5 to 40.7) and 10.2 (95% CI= 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)**.

(6) Discussion

This is one of the largest and most recent studies in the United States 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

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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 findings of this study support the use of the PPSv2 score at admission for estimating survival in the first 30 days of hospice enrollment. 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 and colleagues who reported that, among a heterogeneous cohort of patients enrolled in a community hospice program, PPSv2 scores are most accurate in predicting mortality within one week (AUC: 0.8~0.85).[20] As such, the PPSv2 can be informative for patients and families who ask healthcare providers to predict anticipated life expectancy. Given the poor accuracy of clinician derived survival estimates,[4,5] 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[21] and Downing et al[14] who similarly demonstrated that survival

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curves differed according to PPSv2 scores among a range of non-HF 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 socio-demographic characteristics.[21] Finally, there are mixed perspectives on whether the PPSv2 score should be used as a categorical [22,23] (i.e., groups of PPSv2 scores) or discrete (i.e. individual PPSv2 score values) variables for prognostication. [24-26] 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.[27] Consistent with an American Heart Association guideline,[2] 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.[28,29] 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 implications of this finding for healthcare providers within cardiac home hospice programs 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 socioeconomic status including income and education. Another limitation is that comorbid conditions may be underreported in this sample. Medicare regulations changed in 2014, implemented in 2015, mandating that hospices code for both the terminal illness as well as other coexisting diagnoses which support the terminal condition. These regulations may lead to an underreporting of comorbid 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

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single nonprofit hospice agency, albeit one that is located in a highly urban and culturally diverse setting.

Conclusions

Our study demonstrates that the PPSv2 at admission to hospice has high predictive accuracy for survival in the first 30-day among patients with heart failure, with incremental value at lower PPSv2 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.

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(9) Conflicts of interest

Conflicts of Interest: none declared

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Figure 1a. Death in hospice by PPSv2 scores

Legend: Figure 1a represents the proportion of people who died in hospice by PPSv2 score at admission to hospice.

Figure 1b: Length of survival in days by PPSv2 scores

Legend: Figure 1b represents a box plot of the median length of survival in days by PPSv2 score at admission to hospice.

Figure 2. Receiver Operating Characteristic (ROC) Curve by Length of Service Group

Legend: Figure 2 displays the ROC curve predicting survival based on PPSv2 score values measured on hospice admission across five groups (i.e., 7 days, 14 days, 30 days, 90 days, 180 days).

Figure 3. Adjusted Kaplan-Meier survival curves from Multiple Cox Regression

Legend: Figure 3 displays adjusted Kaplan-Meier survival curves plotted for each value of the PPSv2 using Cox regression estimates and average covariate values.

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(13) Tables

Table 1: Palliative Performance Scale (PPSv2) version 2					
PPS Level	**Ambulation**	**Activity and Evidence of Disease**	**Self-care**	**Intake**	**Conscious Level**
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
80%	Full	Normal activity & work No evidence of disease	Full	Normal or Reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or Reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or Reduced	Full Or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or Reduced	Full Or Confusion

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40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Minimal to sips	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care		Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care		Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

Table 2: Characteristics of the Study Population by PPSv2 at Admission

Characteristics	Total	10%	20%	30%	40%	50%	60%	p-value
No. of participants, (%)	1114 (100)	82 (7)	79 (7)	288 (26)	403 (36)	243 (22)	19 (2)	
Female sex	630 (57)	40 (49)	44 (56)	190 (66)	224 (56)	126 (52)	6 (32)	0.001
Age, years								
18 to 64	48 (4)	5 (6)	5 (6)	4 (1)	15 (3.7)	17 (7)	2 (11)	<0.001
65 to 74	107 (10)	17 (21)	6 (8)	22 (8)	30 (7)	27 (11)	5 (26)	
75 to 84	248 (22)	23 (28)	21 (27)	53 (18)	88 (22)	57 (24)	6 (32)	
85 +	711 (64)	37 (45)	47 (60)	209 (73)	270 (67)	142 (58)	6 (32)	
Race/Ethnicity								0.162
Hispanic	250 (22)	20 (24)	17 (22)	55 (19)	96 (24)	57 (24)	5 (26)	
Non-Hispanic Black	198 (18)	11 (13)	13 (17)	44 (15)	68 (17)	56 (23)	6 (32)	
Non-Hispanic White	581 (52)	45 (55)	45 (57)	160 (56)	211 (52)	115 (47)	5 (26)	
Other	85 (8)	6 (7)	4 (5)	29 (10)	28 (7)	15 (6)	3 (16)	
Marital Status								0.176
Not Married	756 (68)	48 (59)	50 (63)	210 (73)	269 (67)	166 (68)	13 (68)	

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Married	358 (32)	34 (41)	29 (37)	78 (27)	134 (33)	77 (32)	6 (32)	
Primary Caregiver (none)	181 (16)	10 (12)	19 (24)	52 (18)	55 (14)	42 (17)	3 (16)	0.188
Advanced Directives (none)	196 (18)	23 (28)	28 (35)	49 (17)	64 (16)	26 (11)	6 (32)	<0.001
Payer Source								0.356
Commercial/Other	44 (4)	5 (6)	4 (5)	4 (1)	19 (5)	10 (4)	1 (5)	
Managed Medicaid	16 (1)	2 (2)	1 (1)	2 (1)	4 (1)	6 (2)	1 (5)	
Managed Medicare	327 (29)	27 (33)	21 (27)	91 (32)	114 (28)	71 (29)	4 (21)	
Medicaid	21 (2)	1 (1)	1 (1)	2 (1)	12 (3)	4 (2)	1 (5)	
Medicare	706 (63)	47 (57)	52 (66)	189 (66)	254 (63)	152 (63)	12 (63)	
Charlson Comorbidity Score, mean (SD)	2.82 (1)	2.63 (1)	2.82 (1)	2.90 (1)	2.83 (1)	2.83 (1)	2.32 (1)	0.198
Comorbidities, mean %								
Renal failure	278 (25)	16 (20)	27 (34)	60 (21)	103 (26)	68 (28)	4 (21)	0.1
Type II Diabetes	227 (20)	12 (15)	11 (14)	52 (18)	97 (24)	50 (21)	5 (26)	0.119
Pulmonary Disease	209 (19)	4 (5)	12 (15)	54 (19)	80 (20)	55 (23)	4 (21)	0.022
Dementia	179 (16)	10 (12)	15 (19)	62 (22)	59 (15)	33 (14)	0 (0)	0.02
Stroke	106 (10)	12 (15)	9 (11)	29 (10)	36 (9)	18 (7)	2 (11)	0.445

Referral Source							<0.001
Hospital	597 (54)	70 (85)	59 (75)	150 (52)	190 (47)	116 (48)	12 (63)
Other Setting	517 (46)	12 (15)	20 (25)	138 (48)	213 (53)	127 (52)	7 (37)
Discharge Reason							<0.001
Acute Hospitalization	153 (14)	1 (1)	2 (3)	23 (8)	69 (17)	53 (22)	5 (26)
Disqualification	50 (4)	0 (0)	0 (0)	9 (3)	23 (6)	16 (7)	2 (11)
Revocation	65 (6)	2 (2)	3 (4)	9 (3)	26 (6)	22 (9)	3 (16)
Transfer	41 (4)	0 (0)	1 (1)	6 (2)	18 (4)	14 (6)	2 (11)
Death	805 (72)	79 (96)	73 (92)	241 (84)	267 (66)	138 (57)	7 (37)

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Table 3: Cox Proportional Hazards Model Predicting Hazard of Mortality among Hospice Patients with Heart Failure (N=1,114)

Variable	Unadjusted HR (95% CI)	*p*-Value	Adjusted HR (95% CI)	*p*-Value
PPSv2 10%	16.48 (7.59-35.80)	<.001	18.57 (8.47-40.72)	<.001
PPSv2 20%	11.05 (5.08-24.07)	<.001	10.20 (4.61-22.57)	<.001
PPSv2 30%	3.89 (1.84-8.26)	<.001	4.18 (1.94-9.01)	<.001
PPSv2 40%	2.51 (1.19-5.32)	0.02	2.65 (1.24-5.69)	0.01
PPSv2 50%	1.77 (0.83-3.78)	0.14	1.90 (0.88-4.10)	0.10
PPSv2 60%	1 [Reference]		1 [Reference]	
Age	1.00 (1.00-1.00)	0.58	1.00 (0.98-1.00)	0.01
Gender				
Female	1.03 (0.90-1.19)	0.66	1.16 (1.00-1.37)	0.07
Race/Ethnicity				
African American	0.60 (0.50-0.74)	<.001	0.53 (0.43-0.66)	<.001
Hispanic	0.72 (0.60-0.87)	<.001	0.60 (0.49-0.73)	<.001
Other	0.79 (0.61-1.04)	0.08	0.72 (0.55-0.95)	0.02
Marital Status				
Married	1 [Reference]		1 [Reference]	
Not Married	0.86 (0.74-1.00)	0.04	0.82 (0.70-0.98)	0.03
Primary Caregiver				

|				
Yes	1 [Reference]		1 [Reference]	
No	1.20 (0.99-1.46)	0.07	1.41 (1.16-1.72)	<.001
Advance Directive				
No	1 [Reference]		1 [Reference]	
Yes	2.18 (1.81-2.62)	<.001	2.07 (1.70-2.52)	<.001
Referral source				
Hospital	1 [Reference]		1 [Reference]	
Other Setting	0.80 (0.69-0.91)	0.001	0.84 (0.72-0.98)	0.02
Payer Source				
Medicare	1 [Reference]		1 [Reference]	
Commercial/Other	0.869 (0.59-1.28)	0.48	0.829 (0.55-1.25)	0.37
Managed Medicaid	0.633 (0.30-1.34)	0.23	0.613 (0.28-1.30)	0.22
Managed Medicare	0.968 (0.83-1.13)	0.68	1.059 (0.90-1.25)	0.50
Medicaid	0.596 (0.33-1.08)	0.09	0.384 (0.21-0.72)	0.002
Charlson Comorbidity Score	0.925 (0.87-0.99)	0.02	0.937 (0.88-0.10)	0.05

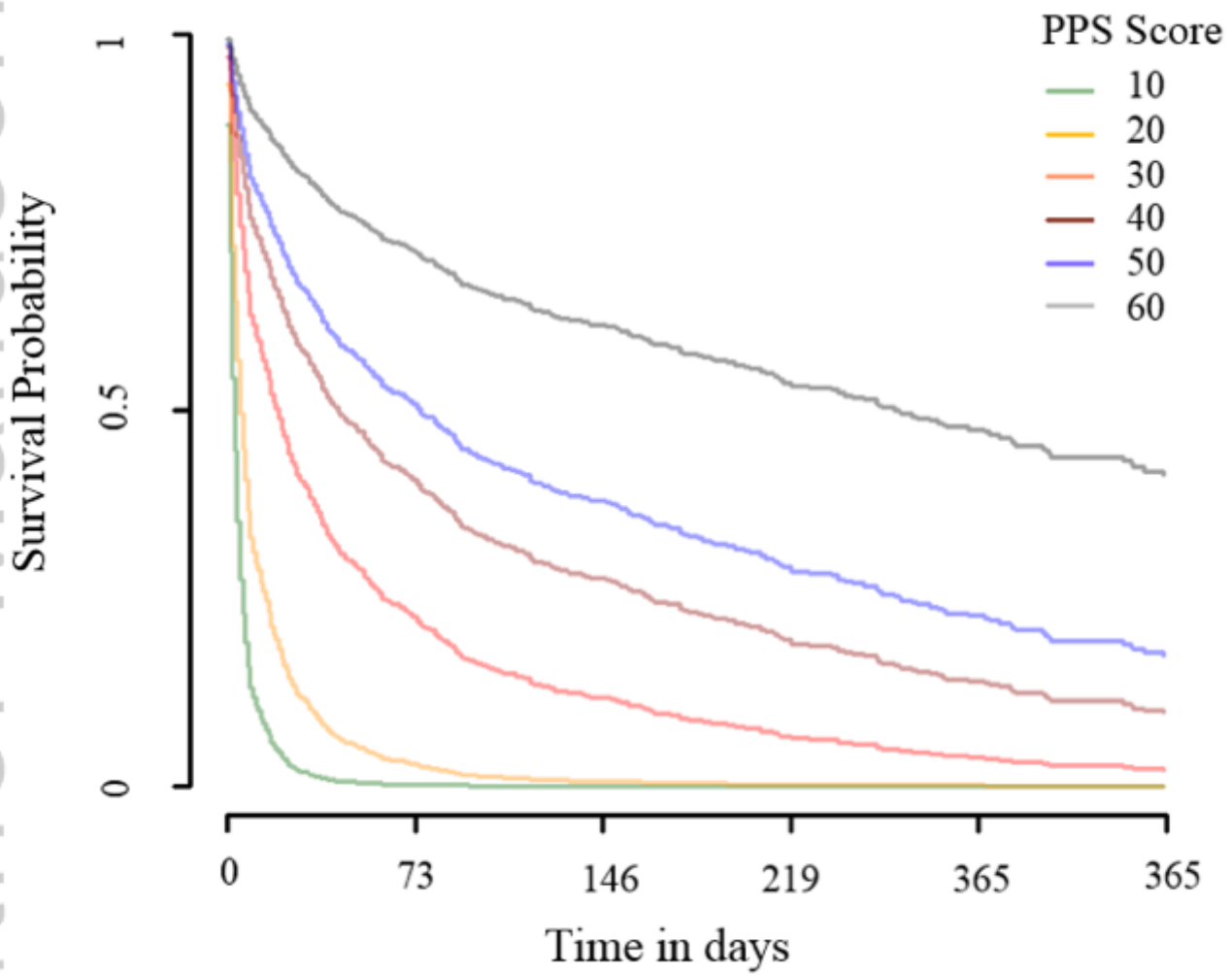**Abbreviations:** PPSv2: Palliative Performance Scale version 2; CI: Confidence Interval; HR: hazard ratio
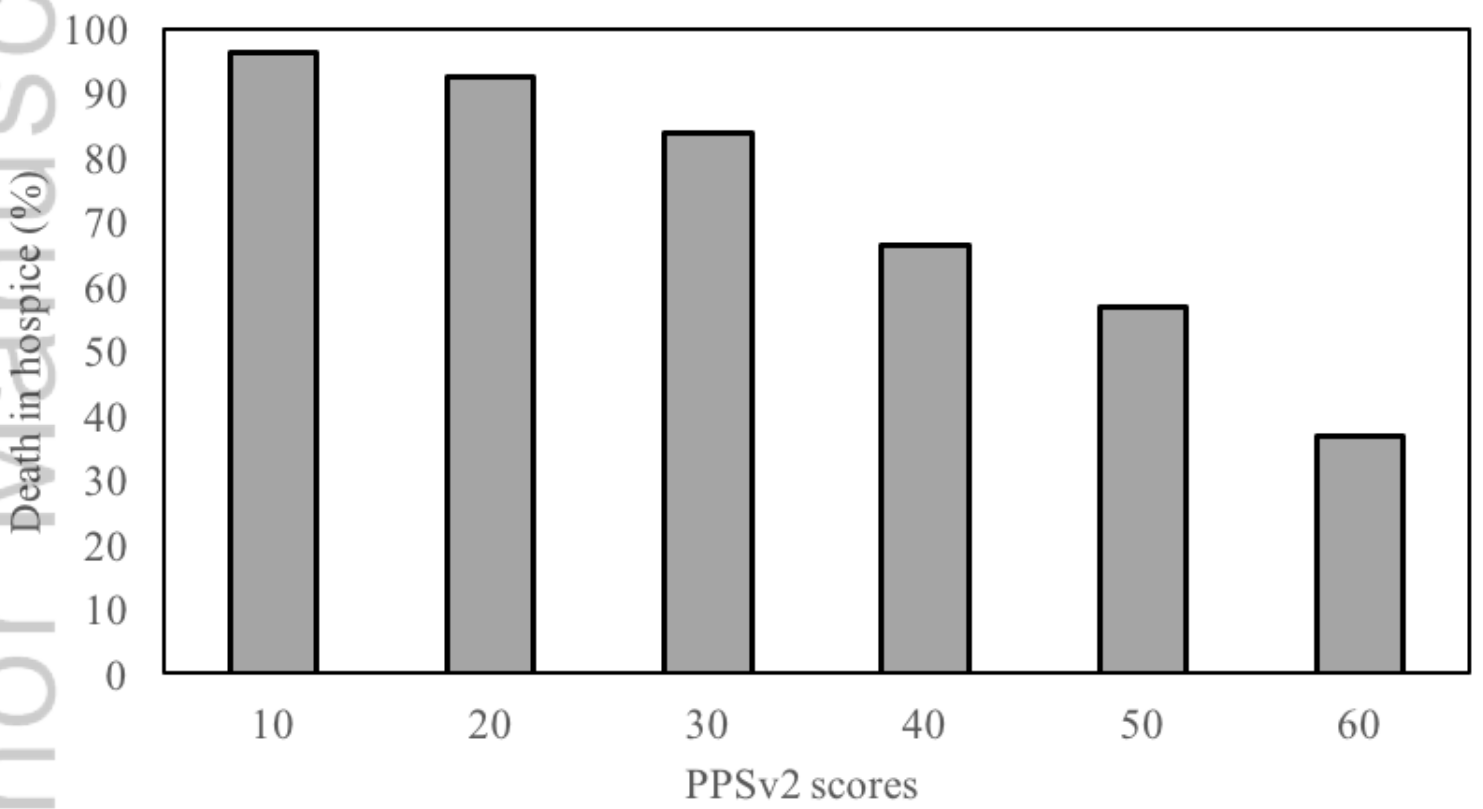
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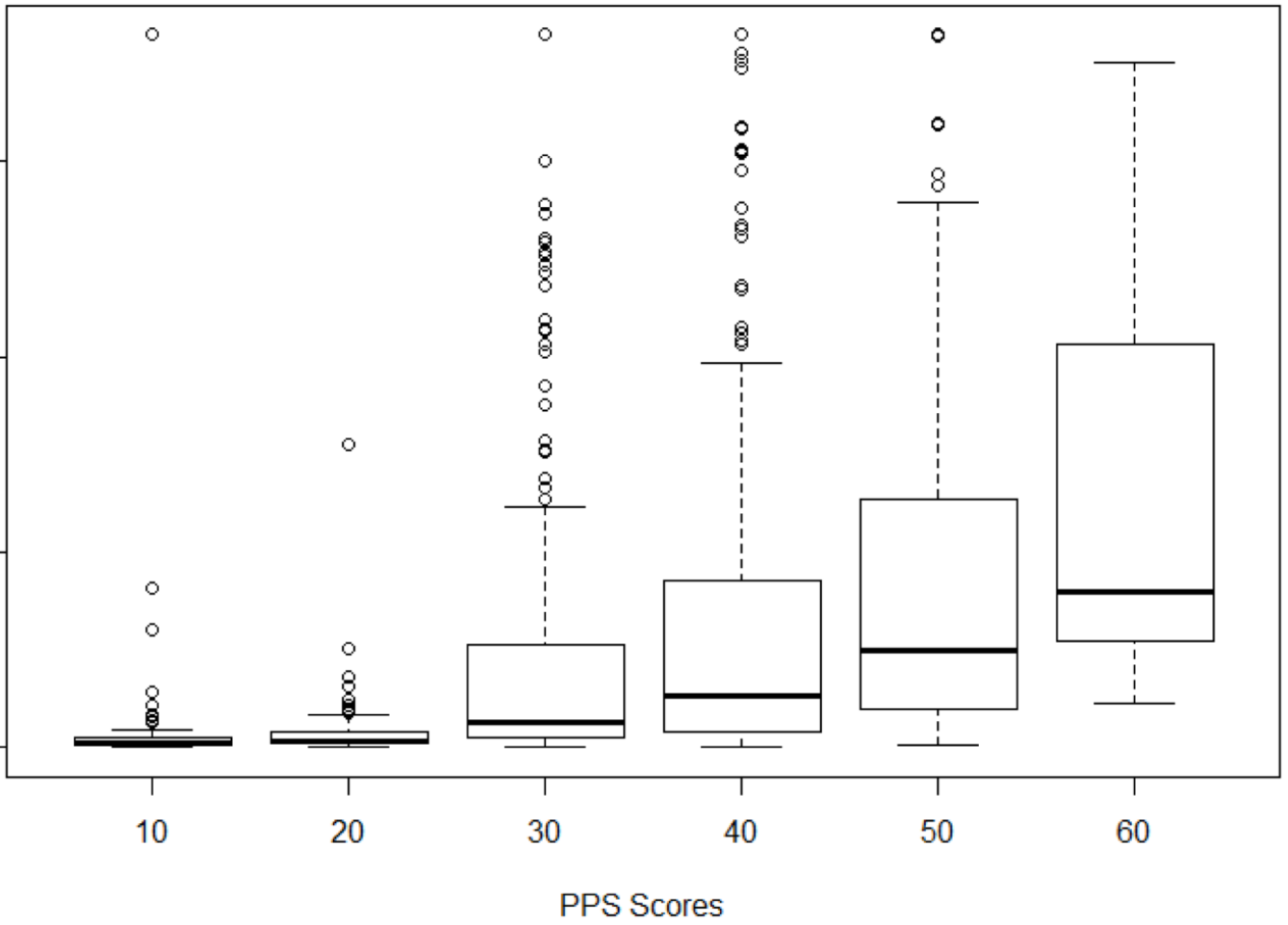
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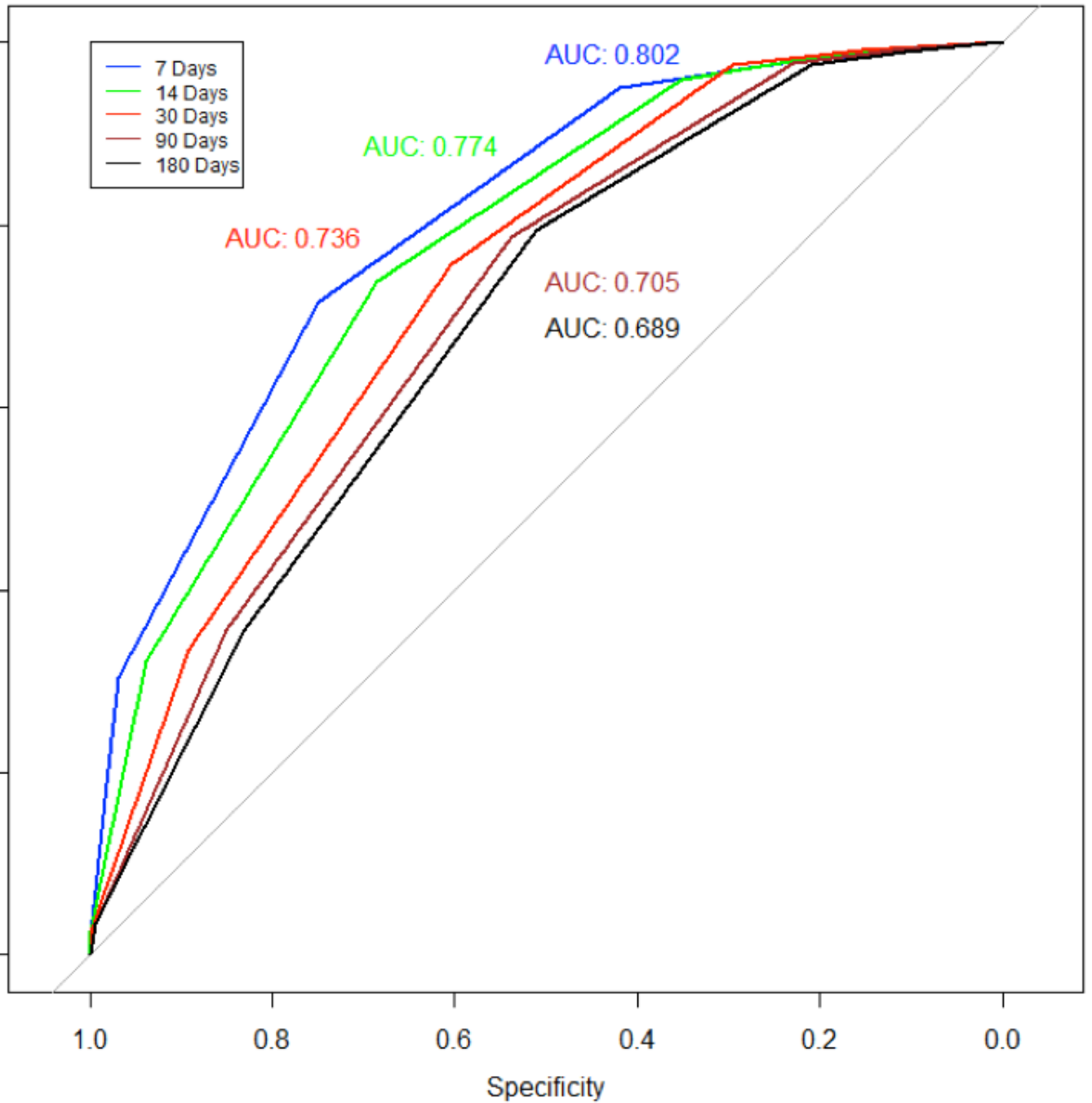
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