Original Article

Using the Palliative Performance Scale to Provide Meaningful Survival Estimates

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Abstract

Although there is a growing body of knowledge on survival prediction in populations with advanced cancer receiving palliative care using the Palliative Performance Scale (PPS), this literature has focused on disease, gender, and care location, and less is known about how to apply such knowledge to be clinically meaningful. To address this issue, we evaluated a database comprising 13 years of initial PPS scores on 6066 patients, which were recorded on their first assessment by the Victoria Hospice palliative care team in the home or palliative care unit setting. Our results reaffirmed PPS as a significant predictor of survival, with increasing survival times associated with higher PPS levels. We explored survival time distributions, a life expectancy table, and a survival nomogram as three potential ways to assist in estimating survival times in palliative care. We also evaluated the concept of Kaplan-Meier survival curve "nose-tail" refinement, and observed that this approach requires more research. More work is needed to better identify those who live "longer than expected" or die "sooner than expected" to provide clinical utility in discussion with patients and families. J Pain Symptom Manage 2009;38:134–144.

Key Words

Survival estimates, palliative care, Palliative Performance Scale, prognostication

Introduction

In 1996, Anderson et al.[1] reported the development and trial use of the Palliative Performance Scale (PPS) as a new tool for measuring functional status in palliative care. The PPS is a modification of the Karnofsky Performance Scale[2] with five functional dimensions: ambulation, activity level and evidence of disease, self-care, oral intake, and level of consciousness. The PPS is divided into 11 levels, from PPS 0% to PPS 100%, in 10% increments—a patient at PPS 0% is dead and at 100% is ambulatory and healthy. Since its publication, numerous studies have

Funding for this study was provided by the Canadian Institutes for Health Research New Emerging Team grant in palliative and end-of-life care.

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Accepted for publication: June 16, 2008.

0885-3924/09/$—see front matter
doi:10.1016/j.jpainsymman.2008.05.017

evaluated its use in survival prediction of terminally ill cancer and noncancer patients.[3–9]

Although the PPS has been found to be predictive of survival, there have been differences in how the PPS was used and reported, and in other significant predictors. For instance, Morita et al.[3] reported three PPS groups (i.e., PPS 10%−20%, PPS 30%−40%, and PPS ≥50%) with different survival curves, but Virik and Glare[4] and Lau et al.[5] did not reveal such groupings. Although Lau et al.[5] found that gender and age affected survival, Virik and Glare[4] observed no such relationship, and Harrold et al.[6] reported an association between the PPS and mortality in nursing home and cancer patients.

In the meta-analysis by Downing et al.[10] on the survival patterns of 1808 patients from four independent studies, the PPS was confirmed as a strong predictor of survival for palliative care patients; higher PPS levels were associated with increased lengths of survival. After adjustment for study differences, females were also found to live longer, especially if not diagnosed with cancer. Although these results are the strongest evidence to date on the use of the PPS in survival prediction of patients receiving palliative care, the study also identified the value of providing survival probabilities and lengths of survival in a way to assist clinicians in meaningful communication with patients and families.

The challenge in providing meaningful survival estimates is further illustrated by a recent systematic review of prognostic tools in palliative care,[11] which revealed wide variability in how results are currently reported. For instance, the Italian Palliative Prognostic Score[12] uses three risk groups with different 30-day survival probabilities (i.e., Group A, >70%; Group B, 30%−70%; and Group C, <30%). The Palliative Prognostic Index (PPI)[13] from Japan uses survival time cutoffs of less than three weeks for PPI greater than 6 and less than six weeks for PPI greater than 4. Even for the PPS, different forms of survival estimates have been used. For example, Head et al.[7] reported the median survival times for five admission PPS categories (PPS 10%−20%, PPS 30%, PPS 40%, PPS 50%, and PPS 60%−70%) and five diagnosis groups (cancer, lung disease, debility/dementia, heart disease, and others), whereas Harrold et al.[6] reported mortality rates at 7, 30, 90, and 180 days for PPS 10%−20%, PPS 30−40%, and PPS 50−70% by site of care (nursing home vs. community) and diagnosis (cancer vs. noncancer). In contrast, Lau et al.[5] used mortality rates for each PPS level with increasing time intervals up to one year (e.g., 1, 3, 5, 7, 14, 30 days, and so on). These reporting variations make it difficult to compare survival estimates derived using different methods and populations. There is a need for clinicians to convey to patients their estimated survival time intervals in a simple yet meaningful manner.

We undertook a retrospective study on a cohort of 6066 patients receiving palliative care enrolled at the Victoria Hospice Society (VHS) in British Columbia, Canada, over a 13-year period to determine how the PPS could be used to provide survival estimates in a more useful manner. First, we outline the program, design, sample, and analyses. Subsequently, we explore different ways of providing survival estimates using the PPS and related variables that are considered significant predictors. We conclude with a discussion of the issues surrounding meaningful use of these survival estimates and their overall implications.

Methods

Program Description

The VHS is located in Victoria, British Columbia, Canada. VHS operates a 17-bed Palliative Care Unit (PCU) with seven acute/tertiary care, nine extended palliative care, and one respite care beds. The VHS offers a wide range of palliative care services, including pain and symptom management, palliative medical consultation to homes and hospitals, palliative response team (PRT) 24-hour crisis intervention at home, counseling and emotional services for dying patients and families, as well as spiritual, volunteer, grief and bereavement support, education, and research. At any given time, approximately 350 patients are registered with Victoria Hospice. In fiscal 2006/2007, there were 524 admissions to the VHS 17-bed PCU, with an average length of stay of eight days in the palliative acute/tertiary care beds, 17.4 days in the extended care beds and seven days in the respite bed. Approximately 22% of these patients were able to return home once their symptoms

improved. Overall, in 2007, there were 350 deaths in the PCU, 331 at home, and 110 in hospitals and facilities. VHS provided care in 26% of all deaths and 65% of all cancer deaths in Greater Victoria. The average time from initial registration to death was 105 days for cancer patients and 88 days for noncancer patients.

It should be recognized that the palliative care programs have unique organizational aspects in providing clinical services and demographic variations. In this study, patients admitted to the PCU beds have a very short length of stay, which is, in part, because of the ability of PRT to keep most patients at home. PRT is called to homes by home nursing or the family physician when either the patient is imminently dying at home or management of uncontrolled symptoms is needed. PRT is involved at home for an average of only 3.2 days, compared with the overall VHS average time from registration to death of approximately 100 days.

Design and Sample

This was a retrospective study to examine the survival patterns of a 13-year cohort of patients receiving palliative care, registered in the VHS database during March 1993 and February 2005. Patients' data were collected beginning at first admission to the tertiary palliative care, extended palliative care, or respite beds, or from first PPS score taken at home by PRT. A "tertiary"-care bed is also sometimes referred to as an "acute"-care bed, where patients are admitted for either investigation and treatment or imminent death. "Extended palliative care" beds refer to designated beds for patients who are unable to return home, but may have a longer anticipated length of stay than those admitted to an acute or tertiary unit. It also can be called a "residential hospice" connected to a chronic care, long-term care facility, nursing home, or a "free-standing hospice." "Home" in this context means one's personal home (house, condominium, apartment, or assisted living care home).

VHS maintained an electronic database where selected patient data, such as demographics and admission/consult details, including their PPS scores, were routinely collected by VHS physicians and nurses. The anonymized data extracted for this study consisted of the patient's age, gender, primary diagnosis, specific disease, death date, and initial PPS score, as well as the date and location that the initial PPS was recorded. The outcome variable for this study was survival time, which was defined as the difference in days between the date/time on which the patient's initial PPS was recorded until death. Censored patients with unknown survival status were included with their survival time calculated to the last known discharge or assessment date.

This study received ethics approval on the use of the anonymized data set from the VHS, the Joint Ethics Review Committee of the Vancouver Island Health Authority, and the University of Victoria (VIHA/UVic Joint Ethics Application, Protocol No. 2005-96b).

Data Analysis and Reporting

Descriptive statistics included median, mean, and range to summarize the characteristics of the cohort in relation to the initial PPS, age, gender, location, and diagnosis. Diagnosis was recoded into three types (i.e., cancer, noncancer, and not recorded) and 21 diagnosis categories. These 21 categories were made consistent with the coding schemes used by both VHS and the Capital Health Regional Palliative Care Program in Alberta to allow multicenter comparison in a subsequent validation study. Kaplan-Meier (KM) survival curves were computed and graphed by PPS and by covariates (i.e., age, gender, location, and diagnosis category). Log-rank tests were used to determine significant differences between survival curves, and for differences between adjacent PPS pairs (e.g., PPS 10% vs. PPS 20%, PPS 20% vs. PPS 30%, and others). We used the Cox proportional hazards model to identify the relationship between the hazard ratios for death with initial PPS, age, gender, location, and diagnosis category. We also analyzed extreme survival outcome behaviors, labeled as the "nose-tail" effects, using Chi-squared tests and logistic regression. All statistical computations were performed using SPSS version 15 (SPSS Inc., Chicago, IL) and R version 2.5.1 (www.r-project.com).

For reporting of survival estimates, we explored three types of outputs in different presentation formats based on the statistical analyses done. These are in the form of: 1) a survival time table showing the frequency

distribution of survival duration by PPS and other covariates; 2) a life expectancy table showing the cumulative survival rates by days for each PPS level based on the KM survival curves; and 3) a nomogram[14] for calculating survival probabilities for an individual patient based on the Cox proportional hazards models fitted to the data.

Results

Patient Characteristics

The characteristics of the retrospective cohort considered in this study are shown in Table 1. There were 6281 eligible patients registered in the VHS database during March 12, 1993 and February 8, 2005. A total of 215 patients were excluded from the cohort; 193 of these patients had an initial PPS 0%, 11 had an initial PPS 80% or greater, seven had hospital ward as initial care location, and four had data-coding errors. PPS 0% was recorded when patients either died on arrival to the PCU or, more commonly, when the crisis PRT team was called to the home but the patient died before they arrived. These exclusions led to 6066 (96.6%) eligible patients with a mean age of 71.5 years selected for the final analysis. Only 191 or 3.2% of these patients were censored with unknown death dates; the remaining 5875 patients (96.8%) were all followed up until death. The cohort consisted of 2892 males (47.7%), 3156 females (52.0%), and 18 (0.3%) with unknown gender. Over two-thirds (4092 or 67.5%) of the patients had their initial PPS recorded while at home by PRT. The primary diagnosis type included 5097 (84.0%) cancer and 756 (12.5%) noncancer patients. As part of the analysis, these patients were further grouped into 14 common cancer categories and four noncancer categories, with two "other" and one "not recorded" categories created for miscellaneous/unrecorded diagnoses and those with small sample sizes. The two most common cancer categories were gastrointestinal and respiratory cancers, with 1331 (21.9%) and 1255 cases (20.7%), whereas the most common noncancer category was cardiovascular disease, with 328 (5.4%) cases.

Overall Survival Patterns

The mean, median, and range of the survival times for the patients by predictor variables

Table 1
Patient Characteristics

Variables	Result
No. of patients considered in this study	
Total no. of eligible patients	6281 (100%)
Excluded patients with following criteria	
Initial PPS score 0%	193 (3.1%)
Initial PPS score >70% (i.e., 10 patients at PPS 80%, 1 at PPS 90%)	11 (0.2%)
Initial care location being hospital ward	7 (0.1%)
Data coding error (e.g., female with prostate cancer)	4 (0.1%)
Total no. of selected patients included in final analysis	6066 (96.6%)
Total no. of censored patients with unknown death date (as % of selected patients)	191 (3.2%)
No. of patients per age group (based on earliest consult/admission date)	
<45	280 (4.6%)
45–64	1326 (21.9%)
65–74	1525 (25.1%)
75–84	1981 (32.6%)
85+	951 (15.7%)
Unknown	3 (0.1%)
Mean age (years)	71.5 (SE: 0.179)
Median age (years)	74
No. of patients by gender	
Male	2892 (47.7%)
Female	3156 (52.0%)
Unknown	18 (0.3%)
No. of patients per location type	
Tertiary care	1264 (20.8%)
Extended palliative care	710 (11.7%)
Home crisis by PRT	4092 (67.5%)
No. of patients with cancer/noncancer primary diagnosis type	
Cancer	5097 (84.0%)
Noncancer	756 (12.5%)
Not recorded	213 (3.5%)
No. of patients with diagnosis category (at time of consult/admission)	
Cancer	
Breast	556 (9.2%)
Eye, brain, and central nervous system	134 (2.2%)
Gastrointestinal—colorectal	599 (9.9%)
Gastrointestinal—esophagus	137 (2.3%)
Gastrointestinal—pancreas	294 (4.8%)
Gastrointestinal—stomach	147 (2.4%)
Gastrointestinal—other	154 (2.5%)
Genital—female	296 (4.9%)
Genital—male	369 (6.1%)
Head and neck	79 (1.3%)
Hematopoietic	351 (5.8%)
Respiratory	1255 (20.7%)
Skin	107 (1.8%)
Urinary	228 (3.8%)
Other	391 (6.4%)
Noncancer	
AIDS	75 (1.2%)
Cardiovascular	328 (5.4%)
Neurological	69 (1.1%)
Respiratory	157 (2.6%)
Others	127 (2.1%)
Not recorded	213 (3.5%)

PPS, age, gender, location, diagnosis type, and diagnosis category are shown in Table 2. The overall mean survival time excluding censored patients was 40 days (95% confidence interval [CI]: 37, 43), median of eight days (95% CI: 8, 9), and a range of less than 1−2497 days. The KM survival curves stratified by PPS level are shown in Fig. 1. The PPS survival curves were all well separated from each other. The log-rank test for the equality of survival curves

Table 2
Survival Time by Age, Gender, Location, Diagnosis, and Initial PPS

	Survival Times (in Days)				Log Rank
Variables	Mean (95% CI)	Median (95% CI)	Range	No. of Patients (%)	*P*-value
Overall	40 (37, 43)	8 (8, 9)	<1−2497	6066	
Age (years)				6063	<0.001
<45	74 (56, 92)	25 (18, 33)	<1−1199	280 (4.6%)	
45−64	45 (39, 51)	13 (11, 15)	<1−1378	1326 (21.9%)	
65−74	40 (34, 46)	8 (7, 9)	<1−1633	1525 (25.1%)	
75−84	38 (32, 43)	8 (7, 9)	<1−1976	1981 (32.6%)	
85+	29 (21, 38)	5 (4, 6)	<1−2497	951 (15.7%)	
Gender				6038	<0.001
Female	47 (42, 52)	9 (8, 10)	<1−2497	3156 (52.2%)	
Male	33 (30, 37)	7 (6, 8)	<1−1633	2892 (47.8%)	
Location				6066	<0.001
Tertiary care	42 (35, 49)	10 (9, 11)	<1−1976	1264 (20.8%)	
Extended palliative care	45 (34, 56)	13 (11, 15)	<1−2497	710 (11.7%)	
Home crisis by PRT	39 (35, 43)	7 (6, 8)	<1−1959	4092 (67.5%)	
Diagnosis type				6058	<0.001
Cancer	39 (36, 42)	9 (8, 10)	<1−2497	5117 (84.5%)	
Noncancer	48 (37, 59)	4 (3, 5)	<1−1622	941 (15.5%)	
Diagnosis category				6066	<0.001
Cancer					
Breast	64 (52, 75)	16 (12, 20)	<1−1092	556 (9.2%)	
Eye, brain, and central nervous system	37 (26, 47)	13 (9, 17)	1−480	134 (2.2%)	
Gastrointestinal					
Colorectal	39 (31, 47)	11 (9, 13)	<1−1199	599 (9.9%)	
Esophagus	26 (4, 35)	7 (5, 9)	<1−309	137 (2.3%)	
Pancreas	34 (19, 49)	8 (6, 10)	<1−1959	294 (4.8%)	
Stomach	50 (26, 74)	11 (8, 14)	<1−1063	147 (2.4%)	
Other	36 (30, 41)	5 (3, 7)	<1−400	154 (2.5%)	
Genital—female	49 (37, 60)	17 (12, 22)	<1−962	296 (4.9%)	
Genital—male	53 (39, 67)	12 (8, 16)	<1−1305	369 (6.1%)	
Head and neck	22 (14, 30)	8 (6, 10)	<1−177	79 (1.3%)	
Hematopoietic	57 (28, 86)	6 (5, 7)	<1−2497	351 (5.8%)	
Respiratory	26 (23, 29)	8 (7, 9)	<1−518	1255 (20.7%)	
Skin	30 (19, 42)	9 (6, 12)	<1−422	107 (1.8%)	
Urinary	39 (27, 52)	10 (6, 14)	<1−1103	228 (3.8%)	
Other	27 (20, 34)	8 (6, 10)	<1−968	391 (6.4%)	
Noncancer					
AIDS	62 (32, 93)	13 (5, 21)	<1−652	75 (1.2%)	
Cardiovascular	51 (32, 69)	3 (2, 4)	<1−1119	328 (5.4%)	
Neurological	53 (0, 109)	5 (3, 7)	<1−1622	69 (1.1%)	
Respiratory	40 (19, 60)	4 (3, 5)	<1−1111	157 (2.6%)	
Others	36 (14, 58)	4 (3, 5)	<1−787	127 (2.1%)	
Not recorded	54 (28, 81)	4 (3, 5)	<1−1633	213 (3.%)	
Initial PPS				6066	<0.001
PPS 10%	3 (1, 5)	1 (1, 1)	<1−429	570 (9.4%)	
PPS 20%	7 (4, 11)	2 (2, 2)	<1−851	737 (12.1%)	
PPS 30%	20 (16, 24)	5 (5, 5)	<1−1274	1420 (23.4%)	
PPS 40%	39 (34, 44)	13 (12, 14)	<1−1119	1647 (27.2%)	
PPS 50%	76 (64, 88)	28 (25, 31)	<1−2497	1055 (17.4%)	
PPS 60%	92 (80, 105)	43 (38, 48)	1−1199	487 (8.0%)	
PPS 70%	141 (92, 190)	63 (48, 78)	1−1959	150 (2.5%)	

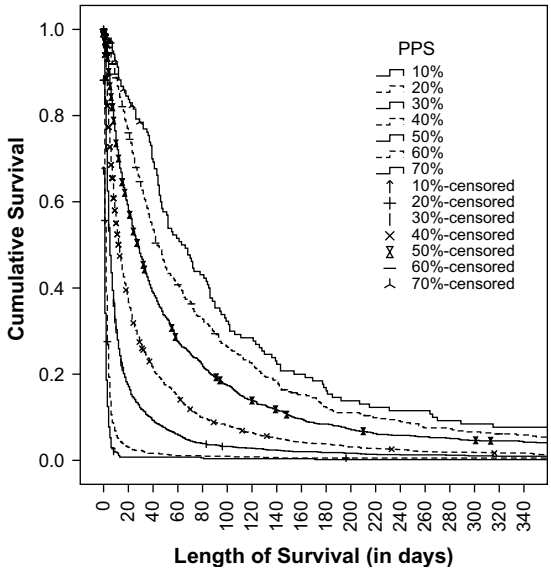

Fig. 1. Kaplan-Meier survival curves by initial PPS.

was highly significant at $P < 0.001$, suggesting that there were significant differences among these curves. Pair-wise log-rank tests for PPS 10−20%, PPS 20%−30%, PPS 30%−40%, PPS 40%−50%, PPS 50%−60%, and PPS 60%−70% showed these adjacent curves to be significantly different from each other ($P < 0.001$). Although the survival curves for PPS 10% and PPS 20% showed similar rates of decrease initially, there was a noticeable "tail effect" for approximately 20% of patients with longer survival duration at PPS 20%. Conversely, a "nose effect" could be observed at higher PPS levels, such as PPS 40% and PPS 50%, where approximately 20% of patients had abrupt, short survival duration.

Exploration of Nose-Tail Effects

Further exploratory analysis was carried out for the "nose-middle-tail" patients from the KM survival curves using Chi-squared tests and logistic regression. "Nose" patients are those with relatively short survival times (with the converse holding true for "tail" patients), and "middle" patients are neither nose nor tail. The exploratory results indicated that factors such as gender and diagnosis likely played some role in predicting whether a patient would fall into a nose or tail category. As an example, for patients who were admitted at PPS 10%, more males tended to be in the nose category. Logistic regression models also produced statistically significant results. However, these did not accurately predict nose and tail patients, indicating there were other explanations, such as sentinel events, for these abrupt or lengthy survival times.

Survival by Palliative Performance Scale and Covariates

The Cox proportional hazards model was used to examine the relationship between the hazard ratio of death for age, gender, location, diagnosis category, and initial PPS. The results shown in Table 3 indicate that all of these variables were significantly related to the hazard for death. Patients who were 85 years and older had significantly higher hazard than all other age groups. Male patients had higher hazard than female. Patients first seen at home by PRT had higher hazard than those assessed on admission to the PCU. Many cancer and noncancer categories had lower hazards for death when compared with those with respiratory cancer. These included cancer categories for breast, eye−brain−central nervous system, gastrointestinal, male genital, and urinary system, and noncancer categories for cardiovascular and neurological systems. Patients with higher initial PPS levels than PPS 10% all had significantly lower hazards. There was also a clear ordering effect showing lower hazard ratios at higher PPS levels, as evident from the mostly nonoverlapping 95% CIs for the relative risks reported (except for PPS 60% and PPS 70%). We found no significant interaction effects among the covariates, such as between cancer and gender.

Survival Rates and Nomogram

The cumulative survival rates in days by initial PPS for this cohort are summarized in Table 4. These were extracted from the respective survival tables produced as part of the KM survival analysis outputs. In this table, the survival rates are expressed in probabilities of surviving patients in the cohort given defined time periods. The time periods began with fairly tight intervals of 1, 3, 5, 7, and 14 days, then increasing to wider intervals of 30, 45, 60, and 90 days, ending at 180 and 365 days in duration. For example, at PPS 10%, one would expect 34% of patients to survive for one day and 13% for at least three days, but only 1% would be expected

Table 3
Hazard Ratios for Age, Gender, Location, Diagnosis, and Initial PPS[a]

Variables	Hazard Ratio	95% CI for Hazard Ratio		*P*-value
		Lower	Upper	
Age group (years) (vs. 85+)				<0.001
<45	0.733	0.631	0.851	<0.001
45–64	0.830	0.757	0.909	<0.001
65–74	0.905	0.830	0.987	0.025
75–84	0.861	0.793	0.934	0.001
Gender (vs. male)	0.802	0.757	0.851	<0.001
Location (vs. home crisis by PRT)				<0.001
Tertiary care	0.775	0.725	0.829	<0.001
Extended palliative care	0.725	0.666	0.790	<0.001
Diagnosis category (vs. cancer—respiratory)				<0.001
Cancer				
Breast	0.753	0.677	0.839	<0.001
Eye, brain, and central nervous system	0.618	0.515	0.742	<0.001
Gastrointestinal				
Colorectal	0.903	0.818	0.997	0.043
Esophagus	1.061	0.887	1.269	0.518
Pancreas	0.923	0.811	1.050	0.225
Stomach	0.802	0.672	0.956	0.014
Other	0.987	0.834	1.168	0.880
Genital—female	0.874	0.765	0999	0.048
Genital—male	0.654	0.578	0.740	<0.001
Head and neck	1.009	0.801	1.271	0.941
Hematopoietic	0.996	0.881	1.125	0.947
Skin	0.872	0.714	1.066	0.183
Urinary	0.754	0.653	0.869	<0.001
Other	0.885	0.789	0.994	0.039
Noncancer				
AIDS	0.799	0.620	1.028	0.081
Cardiovascular	0.650	0.570	0.742	<0.001
Neurological	0.634	0.493	0.815	<0.001
Respiratory	0.884	0.746	1.048	0.157
Others	0.844	0.697	1.023	0.084
Not recorded	0.800	0.688	0.932	0.004
Initial PPS (vs. PPS 10%)				<0.001
PPS 20%	0.542	0.485	0.606	<0.001
PPS 30%	0.247	0.222	0.274	<0.001
PPS 40%	0.144	0.130	0.160	<0.001
PPS 50%	0.091	0.081	0.102	<0.001
PPS 60%	0.070	0.061	0.080	<0.001
PPS 70%	0.056	0.046	0.069	<0.001

[a]This model is based on 6045 patient cases; 21 other cases were omitted because of missing data.

to survive for at least 14 days. In contrast, at PPS 40% level, one would expect 94% of patients to survive for one day, 82% for at least three days and 46% for 14 days, with 27% still alive in 30 days. Even patients at PPS 20% would be expected to have higher survival rates for the same time intervals compared with those at PPS 10%.

A survival nomogram was constructed to provide a graphical summary of the fitted Cox model that could be used to determine the survival probabilities of an individual patient, as shown in Fig. 2. The nomogram shows a model of median and 25th and 75th percentile survival in days given a set of covariate values. Points for each covariate value are determined from the specific covariate scales. These points are summed and the total value is located on the Total Points scale. Median and quartile survival estimates lie directly below the total value on the Total Points scale. As an example, consider an 86-year-old male patient with initial PPS of 20%, admitted from home PRT with a noncancer cardiovascular disease. The covariate points are: AGE = 10, GENDER = 8, LOCATION = 10,

Table 4
Survival Rates by Initial PPS

	Survival Rate (%) in Days											
PPS Level	1	3	5	7	14	30	45	60	90	180	365	Total Cases
PPS 70%	99	97	96	95	87	77	62	**51**	35	16	7	150
PPS 60%	99	97	95	92	83	64	**49**	41	29	12	5	487
PPS 50%	97	93	87	82	67	**47**	36	28	19	8	4	1055
PPS 40%	94	82	73	66	**46**	27	19	15	9	4	1	1647
PPS 30%	84	63	**48**	40	23	12	8	6	4	2	1	1420
PPS 20%	**56**[a]	28	15	9	4	2	2	1	1	0	0	737
PPS 10%	34%	13	5	3	1	0	0	0	0	0	0	570

[a]Boldfaced numbers represent approximately 50% survival rates at a given PPS level.

diagnosis (DX) = 3, PPS = 77 points, for a total of 108 points. This yields a median survival of just over two days, and first and third quartiles of just over one day and four days, respectively.

Discussion

Providing Meaningful Survival Estimates

This is the largest known retrospective study on the use of PPS in survival prediction within

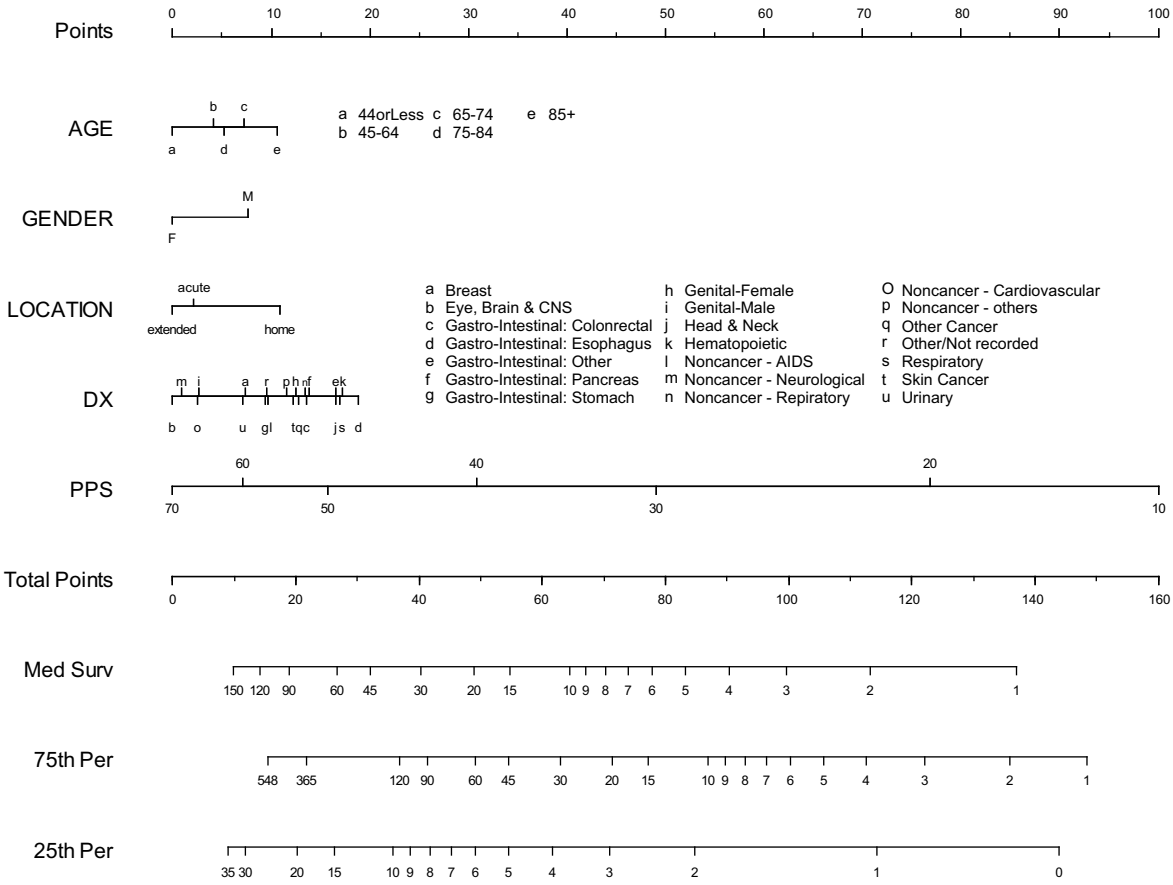

Fig. 2. A survival nomogram based on age, gender, location, diagnosis, and PPS. To illustrate its use, consider the example of an 86-year-old male patient with initial PPS of 20%, admitted from home PRT with noncancer cardiovascular disease. The covariate points are: AGE = "e" for 10 points, GENDER = "M" for 8 points, LOCATION = "home PRT" for 10 points, DX = "o" for 3 points, PPS = "20%" for 77 points, for total points of 108. Then, drawing a vertical line downward from the total points calculated yields a median survival of just over two days, first (75th) quartile of just over four days, and third (25th) quartile of one day.

the palliative care setting. In particular, we have reaffirmed the strong association found in earlier studies between the survival time of palliative care patients and their functional status, as measured by the PPS when first seen by the palliative care team. We also found age, gender, location, and diagnosis to be significant predictors of survival time in palliative care, thus substantiating earlier findings that were otherwise somewhat contradictory, likely because of smaller sample sizes. Note that the overall mean and median survival times of our cohort from initial PPS assessment at admission to the PCU or PRT were 40 and 8 days, respectively. When compared with the four PPS studies with known median survival times in the meta-analysis by Downing et al.,[10] the current (crisis) cohort had the shortest survival, which suggests that our patients were more seriously ill than those in the other studies. However, we should emphasize that the mean and median survival times from registration with the overall Victoria Hospice program to death were much longer at 82 and 32 days, respectively. Thus, the median survival times for a given palliative care setting should always be interpreted in the context of the patient population under study.

Drawing on these findings, we presented three ways of reporting survival estimates by PPS and related predictors for palliative care patients. These are survival time distributions, life-expectancy table, and survival nomogram. The respective KM survival time distributions, shown in Table 2, provide details on the mean, median, range of survival duration for a cohort of patients from a given palliative care setting by their age, gender, location, diagnosis, and initial PPS. When using these distributions, clinicians should be aware that the survival times were computed separately for each variable independent of the others. For instance, the survival times by PPS represent the mean, median, and range of survival duration at each PPS level aggregated over all ages, gender, locations, and diagnoses. Similarly, the survival times for each age group are aggregated across all PPS levels and the remaining variables. Last, the number/percentage of patients tallied under each variable category allows clinicians to determine how closely this cohort matches with their local setting and patient population.

The life expectancy table is based on the cumulative survival rates of our cohort over time, as shown in Table 4. In its current form, this table allows clinicians to use the initial PPS level of a given patient to "look up" his/her survival rates (in percentages) across different time intervals starting with one day up to one year. The "Total Cases" column on the right side shows how many patients were used to compute the respective survival rates at each PPS level. When larger numbers of cases are present, the clinicians should have a higher degree of confidence in the survival estimates provided. Again, we emphasize that the survival rates over time at a given PPS level in this table were aggregated across all ages, gender, locations, and diagnoses for the cohort. In contrast, the survival nomogram is based on the Cox regression model that has been adjusted for all the variables present. As such, the total points for a given patient in the survival nomogram represents the survival time in days adjusted by his/her age, gender, location, diagnosis, and initial PPS level.

Caution is needed when using our results for survival estimation as both the location and type of care provided should be considered. Where clinical services are similar to those of the VHS, the results are likely transferable. Because our data are recorded at the time and date of admission to a tertiary unit (i.e., patient not stable or symptoms uncontrolled) and PRT (urgent or crisis issues at home), our results may provide inaccurate estimates for those patients who are seen at an earlier stage of illness. We are currently investigating data for less critically ill patients, and two sets of prognostic tools may eventually emerge from our research—one for crisis patients and another for more stable palliative patients.

Implications

Additional investigation is needed into underlying causes for the "nose-tail effects" observed. These are often high stress points for patients, families, and staff where death occurs in a timeframe not quite as expected. Many family members often become exhausted when providing vigil that "goes on and on." If we are better able to predict who these patients are, families may be able to adjust time spent at the bedside, reduce emotional stress that

sometimes leads to requests to "get it over with," and possibly improve memories surrounding the death for the bereaved. Similarly, although general physical decline may be occurring and a reasonable clinical prediction of survival shared, there are some patients whose condition suddenly changes and they die well before predicted. Had family members been aware, travel plans for those at a distance may be expedited to be able to arrive before death. At such times, staff may occasionally be criticized for such "errors" or questions resurface as to what else could have been done.

Performance status as measured by the PPS is highly predictive of survival. However, we believe that our predictions can be improved by incorporating other factors, such as disease variations, identified sentinel events, and clinicians' predictions. This is an area of our ongoing research.

More work also is needed on the proposed reporting formats for survival estimates. Rather than adding to the repertoire of output options, we are exploring the use of a dynamic Web-based life expectancy table that allows clinicians to select matching patient cases in real time according to the age, gender, diagnosis, and initial PPS entered. Lastly, it is essential that our proposed reporting methods be evaluated independently by others to determine their meaningfulness and utility in the palliative care setting.

Study Limitations

There are several limitations to this study that should be mentioned. First, this study was based on just one palliative care program in British Columbia, Canada. As such, these findings may not be applicable to other palliative care settings, and likely not directly generalizable to the wider non-palliative care populations. Second, the use of initial PPS to estimate survival is simple but does not take into account the time course of the illness. In particular, the initial PPS scores were obtained at times of crisis (admission to tertiary unit and PRT home crisis service), not at an earlier point in the illness. A more accurate but complex approach is to examine dying trajectories with multiple PPS scores over time. Clinically, illness trajectories do change over time, so that, as the illness evolves, new issues must be considered and the prognosis revised accordingly.[15] Third, this is a retrospective analysis and not yet tested in a prospective study. Fourth, we recognize other factors affect survival, including symptom distress, biologic markers, quality of life, and care options. Therefore, the use of initial PPS alone in survival estimation must be viewed with caution.

Conclusion

Current means of reporting survival estimates in the palliative care setting is variable at best. Drawing on our study findings, three methods of providing survival estimates using performance status and simple demographic indices have been suggested. These are the use of survival time distribution, life expectancy table, and survival nomogram based on initial PPS, age, gender, location, and diagnosis as the significant predictors. This study is the largest known retrospective survival prediction study using the PPS in the palliative care setting. The proposed methods of reporting survival estimates could improve the ability of clinicians to have meaningful discussion on prognosis with palliative care patients and their families.

Acknowledgments

The anonymized data set and management/staff support received from the VHS are greatly appreciated.

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