

## **Clinician estimates of prognosis: accuracy and impact—a retrospective inpatient hospice study**

### **AUTHORS:**

Dr Simon Tavabie, Palliative Medicine Registrar, Barts Health NHS Trust, London UK.

(Corresponding author: [simon.tavabie@nhs.net](mailto:simon.tavabie@nhs.net) orcid.org/0000-0001-9420-8168)

Dr Anya Hargreaves, Internal Medicine Trainee, West Hertfordshire NHS Trust, UK.

Dr Adrian Tookman, Medical Director & Consultant in Palliative Medicine, Marie Curie Hospice Hampstead

Professor Patrick Stone, Departmental head, Marie Curie Palliative Care Research Department, Division of Psychiatry, University College London (orcid.org/0000-0002-5765-9047)

### **DISCLOSURES:**

No funding sought and no conflicts of interest for any authors.

### **AUTHOR CONTRIBUTIONS:**

PS & ST conceived the project. ST & AH collected the data. All authors oversaw the production and revisions of the manuscript.

### **ETHICS AND GOVERNANCE:**

The project, its aims and collection methods were discussed and approved at the June 2020 Marie Curie Hospice Hampstead Local Audit and Governance group. The project was processed using the NHS HRA REC decision tool and was found not to need NHS REC review.

### **WORD/FEATURE COUNTS:**

Abstract: 199;

Manuscript: 1405 (1502-97 in titles and tables etc)

Tables: 1;

References: 15;

Appendices: 3

**Keywords:** Prognosis, hospice care, terminal care, survivorship, service evaluation

### **ABSTRACT:**

**OBJECTIVE:**

To evaluate the accuracy and impact of clinicians' estimates of prognosis (CEP) in patients referred for hospice inpatient care.

**METHODS:**

Retrospective review of twelve months' referrals to a London hospice unit. Data extracted included date of referral, admission and death and CEP.

**RESULTS:**

N=383. Mean age 72 years (range 24-101).

CEP accuracy:

Median survival where CEP was 'days' (n=141) was 7 days (0-164); CEP 'weeks' (n=167) was 14 days (1-538); CEP 'months' (n=75) was 32 days (2-507). Kaplan-Meier survival curves showed significant difference between CEP of 'months' and 'weeks' ( $p < 0.0001$ ); 'months' and 'days' ( $p < 0.0001$ ); but not 'days' and 'weeks' ( $p = 0.1$ ).

CEP impact:

Admission waiting time increased with increasing CEP: CEP 'days' (n=105) median 1 day (0-14); CEP 'weeks' (n= 154) median 2 days (0-46); CEP 'months' (n=69) median 3 days (0-46). No significant difference was demonstrated in the number of discharge planning conversations between groups (0.9 per patient).

**CONCLUSIONS:**

CEP was accurate in over half of cases but did not adequately discriminate between those with prognoses of days or weeks. CEP may affect the prioritisation given to patients by hospices. Inaccurate CEP on referral forms may influence other aspects of care, however further research is needed.

**KEY MESSAGES BOX:**

**1. What was already known?**

Clinicians' estimates of prognosis (CEP) are often inaccurate.

**2. What are the new findings?**

CEP may influence prioritisation given for hospice admission.

**3. What is their significance?**

**A) Clinical**

CEP's appropriateness in prioritisation should be questioned.

**B) Research**

Further measures of impact should be evaluated on a wider scale to investigate the implications of inaccurate CEP.

## **INTRODUCTION:**

Palliative care clinicians commonly focus on quality, not quantity of life. However, estimates of prognosis are relevant to patients, framing decision-making about their care and preparation for dying and death<sup>1</sup> and influencing prioritisation of admissions and discharges to hospice inpatient units<sup>2</sup>.

Unfortunately, clinician estimation of prognosis (CEP) is often inaccurate, overestimating survival<sup>3,4</sup>. Accuracy may be influenced by clinicians' training, experience and familiarity with patients<sup>3</sup>. Consequently, some have called for less reliance on CEP<sup>5</sup>. Prognostic scores have been developed in order to improve objectivity, reliability and accuracy of predictions<sup>6,7</sup>, but they are used less commonly than CEP<sup>8</sup>.

There is limited evidence regarding the impact of CEP on patients in palliative care. We therefore undertook a retrospective evaluation of CEP accuracy for referrals to hospice, and its relationship with other aspects of patient care.

## **METHODS:**

### **Study setting:**

The Marie Curie Hospice, Hampstead is one of eight inpatient units across North London with a standardised referral *pro forma*, which includes CEP alongside demographic and clinical information. This study evaluated the accuracy of data included on this *pro forma* and potential impact on patient care.

### **Ethics/Governance:**

This service evaluation consisted of a retrospective review of referral forms and case-notes. Information was anonymised and maintained in a password-protected Microsoft Excel database on secure computers at Marie Curie Hospice, Hampstead. The project was

approved at the Marie Curie Hospice Hampstead Local Audit and Governance Group. The project was processed using the NHS HRA REC decision tool (did not require NHS REC review).

### **Patient population:**

Eligible patients were adults, referred for inpatient care at the hospice over a 12-month period with no restrictions to diagnoses or demography.

### **Study assessments:**

#### Accuracy of CEP:

Data were extracted on patient demographics, referral date and source, phase of illness<sup>9</sup>, CEP, date of admission, date of death or date last known to be alive. In cases where survival data were unknown, the date last known to be alive was recorded, otherwise survival was coded as 'unknown'.

As per Department of Health's Proactive Indicator Guidance within the Gold Standards Framework, referrers estimated prognosis using one of four categories: 'days', 'weeks', 'months' and 'years'<sup>10</sup>. In keeping with previous research<sup>11</sup>, prognosis of 'days' was taken to mean < 14 days; prognosis of 'weeks' as 2–8 weeks (14–55 days); prognosis of 'months' as 2-12 months (55-365 days) and prognosis of 'years' as >12 months. Due to the short study period and the small patient group with CEP of 'years', those with prognoses of months and years were grouped together as 'months+'.

#### Impact of CEP:

Data extracted from case-notes were used to analyse influence of CEP on patient care. Decisions for hospice admission and waiting time between referral and admission were seen as indicators of prioritisation for hospice admission. Preparation for dying and death was evaluated through number of discharge planning conversations held and whether a patient's stated 'preferred place of death' (PPD) was achieved. Due to resource constraints, this analysis was restricted to patients who inaccurately were assigned CEP of days or

months, as it was hypothesised that these patients were most likely to be adversely affected.

### **Statistical methods:**

Kaplan-Meier survival curves were plotted for each risk group (days, weeks months+), using log-rank testing for overall evaluation and area under receiver operating characteristic (AUROC) curve for pair-wise comparisons. Descriptive statistics were collated for time from referral to admission, discharge planning and PPD.

### **RESULTS:**

549 inpatient hospice referrals between 1<sup>st</sup> January 2019 and 31<sup>st</sup> December 2019 were identified of which 383 patients were eligible for inclusion (Appendix 1).

### **Demographics:**

Patients' mean age was 72 years (range 24-101). Patients were referred from hospital (183/383; 47.8%) and community specialist palliative care teams (182/383; 47.5%), the hospice day-therapy unit (12/383; 3.1%) and General Practitioners (6/383; 1.6%).

### **Accuracy of CEP:**

CEP accuracy was evaluated for those patients with known length of survival (Table 1). Of those excluded due to missing survival data (n=91), 36/91 had CEP of 'days', 33/91 of 'weeks' and 22/91 of 'months+'. Overall, CEP proved correct in 53% (202/383).

		Survival			
		Days (0-13d)	Weeks (14-55d)	Months+ (>55d)	Total
CEP	Days	106	32	3	141 (37%)
	Weeks	74	68	25	167 (44%)
	Months+	15	32	28	75 (19%)
	Total	195 (51%)	132 (34%)	56 (15%)	383

**Table 1: Clinician estimate of prognosis (CEP) compared with survival data**

Survivorship of patients in each CEP category was analysed (Appendix 2). Median survival for those with a CEP of 'days' (n =141) was 7 days (IQR = 3-14); 'weeks' (n=167) was 14 days (IQR 8-33); and 'months+' (n=75) was 32 days (IQR 16-93). There was a significant difference between the survival curves (log rank test: Chi square 118.6, df 2 p<0.0001). In pair-wise comparisons, patients with CEP of 'months+' had significantly different survival to those with CEP of 'days' (C =0.76, 95% CI 0.7-0.9, p<0.0001) or 'weeks' (C =0.67 95% CI 0.6-0.8 p<0.0001). There was no statistical difference between survival curves for those with CEP of 'weeks' and CEP of 'days' (C=0.59, 95% CI 0.5-0.7, p= 0.1).

#### **CEP and admission to hospice:**

Of those not admitted to hospice (n=56), 37 had CEP of 'days' (66%), 13 of 'weeks' (23%) and 6 of 'months+' (11%). 47 died within 'days' (84%), 8 in 'weeks' (14%) and 1 in 'months+' (2%).

Most patients (327/383; 85%) referred to hospice were admitted after a short wait. The group least likely to be admitted were patients with CEP of 'days', of whom 26% (37/141) died before admission. Odds ratios for admission based on CEP were: CEP 'days' 0.24 (95% CI 0.13-0.43); CEP 'weeks' 2.94 (95% CI 1.54-5.75); CEP 'months+' 2.23 (95% CI 0.94-5.07)). 14 patients assigned CEP of 'weeks' or 'months+' died at least one category sooner than predicted, before admission. Of those not admitted to hospice, a greater proportion died within days than in those admitted (47/56; 84% vs 195/383; 51%).

### **CEP and waiting times:**

Those with CEP of 'days' (n=105) waited a median of 1 day (IQR 1-5); those with CEP of 'weeks' (n=154) waited a median of 2 days (IQR 1-5); those with CEP of 'months+' (n=69) waited a median of 3 days (IQR 1-6).

### **CEP and discharge planning conversations and achievement of PPD:**

Of 141 patients admitted with a prognosis of 'days', 35/141 (25%) lived longer than predicted, of whom 19/35 (54%) achieved their PPD. Of 75 patients admitted with a CEP of 'months+', 47/75 (63%) had a shorter survival than predicted, of whom 16/47 (34%) achieved their PPD. Both groups had a mean of 0.9 discharge conversations.

### **DISCUSSION:**

#### **Key findings:**

In this exploratory, retrospective review of case-notes, only 53% of referrer CEPs aligned with survivorship. Clinicians accurately distinguished between patients with prognoses of months or shorter ( $p < 0.0001$ ), but were less able to distinguish between patients with prognoses of days versus weeks ( $p = 0.1$ ).

Patients with CEP of 'days' were least likely to be admitted to hospice. Those not admitted had shorter survival than those admitted. Explanations may be multifactorial, including late referrals, bed availability, and clinical factors influencing prioritisation for admission.

Generally, less prioritisation was given to patients with longer CEP. Some patients (n=60) were given inaccurately short prognoses and may have benefitted from shorter waiting-times, while others (n=121) were potentially disadvantaged through over-optimistic CEPs and delayed admissions.



The number of discharge planning conversations did not significantly differ between groups. Whilst attainment of PPD differed between those with inaccurate CEP of days and months, the significance is unclear without data for those with accurate CEP.

### **Strength and weaknesses:**

The single site, retrospective nature of the study limits the ability to draw broader conclusions. The use of routinely collected CEP data reflect clinical practice and lend our findings face validity. However, reliance on routinely collected data also meant that potentially relevant information (e.g. probability survival estimates or clinician confidence in CEP) were not captured. Moreover, CEPs were predominantly provided by specialist palliative care teams, potentially influencing their accuracy. The majority of exclusions comprised eligible patients not admitted, creating possible selection bias. Survival data were unknown for some patients and could have been improved by use of death registration data, rather than relying on hospice records.

### **In context:**

Although numerous palliative prognostic scores have been developed and validated<sup>6,7,8, 11,12,13,14,15</sup>, they are not in common usage and none have consistently shown superiority to clinical predictions of survival. In keeping with previously published data, we found that CEP was often inaccurate and over-optimistic<sup>4</sup>. To our knowledge, few studies have specifically explored the potential influence of inaccurate CEP on clinical care.

### **Unanswered questions and further research:**

The impact of CEP on care in the palliative setting would be more effectively evaluated in a prospective, multi-centre trial, with centres randomised to standard care or some form of enhanced prognostic determination or communication. This could be coupled with more in-depth evaluation using qualitative methods such as interviews with referrers, hospice clinicians, patients and their caregivers to best understand their experiences.

**CONCLUSION:**

CEP assigned to inpatient referrals to palliative care services is often inaccurate; this may affect prioritisation of admission and influence other aspects of patients' care.

## REFERENCES:

- 1 Adams E, Boulton M, Watson E. The information needs of partners and family members of cancer patients: a systematic literature review. *Patient Educ Couns* 2009;77:179-86.
- 2 Hardy J, Turner R, Saunders M, A'Hern R. Prediction of survival in a hospital-based continuing care unit. *European journal of cancer* 1994;30A;3:284-288
- 3 Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. *BMJ* 2000;320:469-72
- 4 White N, Reid F, Harris A, Harries P, Stone P. A Systematic Review of Predictions of Survival in Palliative Care: How Accurate Are Clinicians and Who Are the Experts? *PLoS ONE* 2016; 11(8): e0161407. doi:10.1371/journal.pone.0161407
- 5 Chiu N, Chiu L, Lutz S, Zhang N, Lechner B, Pulenzas N, et al. Incorporation of life expectancy estimates in the treatment of palliative care patients receiving radiotherapy: treatment approaches in light of incomplete prognostic models. *Annals of Palliative Medicine*. 2015;4(3):162–8.
- 6 Stone PC, Kalpakidou A, Todd C, Griffiths J, Keeley V, Spencer K, et al. The Prognosis in Palliative care Study II (PiPS2): A prospective observational validation study of a prognostic tool with an embedded qualitative evaluation. *PLoS ONE* 2021; 16(4): e0249297. <https://doi.org/10.1371/journal.pone.0249297>
- 7 Stone P, Vickerstaff V, Kalpakidou A, Todd C, Griffiths J, Keeley V, et al. Prognostic tools or clinical predictions: Which are better in palliative care? *PLoS ONE* 2021; 16(4): e0249763. <https://doi.org/10.1371/journal.pone.0249763>
- 8 Chu C, Anderson R, White N, Stone P. Prognosticating for Adult Patients With Advanced Incurable Cancer: a Needed Oncologist Skill. *Curr. Treat. Options in Oncol.* 2020; 21:5 DOI 10.1007/s11864-019-0698-2
- 9 Masso M, Allingham SF, Banfield M, Johnson CE, Pidgeon T, Yates P, Eagar K. Palliative Care Phase: inter-rater reliability and acceptability in a national study. *Palliat Med*. 2015 Jan;29(1):22-30. doi: 10.1177/0269216314551814
- 10 Thomas K, Wilson J. Gold Standards Framework: Proactive Indicator Guidance. 2016. [Accessed 16/3/21 <https://www.goldstandardsframework.org.uk/cd->

content/uploads/files/PIG/NEW%20PIG%20-%20%20%2020.1.17%20KT%20vs17.pdf].

- 11 Gwilliam B, Keeley V, Todd C, et al. Development of prognosis in palliative care study (PiPS) predictor models to improve prognostication in advanced cancer: prospective cohort study. *BMJ* 2011;343:d4920
- 12 Yourman LC, Lee SJ, Schonberg MA, Widera EW, Smith AK. Prognostic indices for older adults: a systematic review. *JAMA*. 2012;307(2):182-192
- 13 Maltoni M, Nanni O, Pirovano M, Scarpi E, Indelli M, Martini C, et al. Successful validation of the palliative prognostic score in terminally ill cancer patients. *J Pain Symptom Manage* 1999;17:240-7
- 14 Morita T, Tsunoda J, Inoue S, Chihara S. The palliative prognostic index: a scoring system for survival prediction of terminally ill cancer patients. *Support Care Cancer*. 1999;7(3):128–33.
- 15 Downing M, Lau F, Lesperance M, Karlson N, Shaw J, Kuziemy C, et al. Meta-analysis of survival prediction with Palliative Performance Scale. *J Palliat Care* 2007;23:245–254. doi:<https://doi.org/10.1177/082585970702300402>.