Determining timeframes to death for imminently dying patients: a retrospective cohort study.

O'CONNOR, T., LIU, W.M., SAMARA, J., LEWIS, J., STRICKLAND, K. and PATERSON, C.

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Determining timeframes to death for imminently dying patients: a retrospective cohort study

Tricia O'Connor[1,2*], Wai-Man Liu[3], Juliane Samara[1,4], Joanne Lewis[5], Karen Strickland[6,7,8,9] and Catherine Paterson[2,7,8,10]

Abstract

Background Clinicians are frequently asked 'how long' questions at end-of-life by patients and those important to them, yet predicting timeframes to death remains uncertain, even in the last weeks and days of life. Patients and families wish to know so they can ask questions, plan, make decisions, have time to visit and say their goodbyes, and have holistic care needs met. Consequently, this necessitates a more accurate assessment of empirical data to better inform prognostication and reduce uncertainty around time until death. The aims of this study were to determine the timeframes for palliative care patients (a) between becoming comatose and death, and (b) between being totally dependent and bedfast, and then comatose, or death, using Australia-modified Karnofsky Performance Status (AKPS) scores. The secondary aim was to determine if covariates predicted timeframes.

Method This is a large retrospective cohort study of 2,438 patients, 18 years and over, cared for as hospice inpatients or by community palliative care services, died between January 2017 and December 2021, and who collectively had 49,842 AKPS data points. An Interval-Censored Cox Proportional Hazards regression model was used.

Results Over 53% ($n=1,306$) were comatose (AKPS 10) for longer than one day before death (mean = 2 days, median = 1, SD = 2.0). On average, patients were found to be totally dependent and bedfast (AKPS 20) for 24 days, before progressing to being comatose. A difference in life expectancy was observed at AKPS 20 among people with cancer (mean = 14.4, median = 2, SD = 38.8) and those who did not have cancer (mean = 53.3, median = 5, SD = 157.1).

Conclusion Results provide clinicians with validated data to guide communication when answering 'how long' questions at end-of-life. Knowledge of projected time to death can prompt timely conversations while the patient can understand and engage in meaningful conversations. The importance of considering covariates such as location and diagnosis in determining timeframes has been highlighted. Shared decision-making and essential person-centered end-of-life care can be planned.

Keywords Australia-modified Karnofsky Performance Status, End-of-life, Palliative care, Prognostication, Timeframes to death.

*Correspondence:
Tricia O'Connor
ocon0316@flinders.edu.au

Full list of author information is available at the end of the article

Introduction

Good decision-making is the cornerstone of quality end-of-life care, and knowledge of life expectancy is essential for informing decisions [1–3]. Patient and family preparedness for death is often related to the clinicians' ability to predict dying and death [4, 5]. Evidence [6] suggests that when patients are aware that their death is close, their final wishes are more likely to be fulfilled, they are surrounded by loved ones, and have futile medications and interventions ceased. Families want to know how much time their dying loved one has left to ensure all those important to them have time to visit and say their farewells, and to ensure spiritual and cultural needs are met [7]. Many families wish to maintain a vigil and be present at the time of death. Previous research indicates that being present at the time of death is important to allay a sense of guilt and assist with bereavement [8].

Patients and families have expressed concern about poor and inadequate communication with clinicians regarding impending death [9, 10]. Furthermore, families and significant others are less likely to suffer complicated grief, more likely to have positive recollections of care, and report their loved one had a 'good death' when they are aware death is imminent [11]. Consequently, to empower patients and those important to them, clinician knowledge and insight into timeframes for when patients are likely to die is centrally important to achieving a good death.

The unpredictability of the disease trajectory, together with unforeseen complications (such as acute infections, catastrophic bleeds, etc.) means clinicians themselves continue to be uncertain when asked the 'how long' question. Being able to recognise and communicate that a patient is dying, and have those end-of-life conversations, is viewed as a care priority and an indicator of good end-of-life care [2]. Good decision-making, which is internationally recognised as a basis to good end of life care [1–3], must be generated by evidence-informed and accurate clinical data regarding the dying trajectories.

Predicting the timeframe to death, even for those who are unresponsive and actively dying, remains uncertain and problematic [12–17]. Clinician's accuracy in estimating time until death has had mixed results [16, 18, 19]. Previous research has examined anticipated timeframes to death, however they focused specifically only on the last three days of life [20–23] or focused on patients dying from cancer [18, 20, 21, 23, 24].

The Australia-modified Karnofsky Performance Status (AKPS) is a reliable and validated tool, where the main outcome measure for both cancer and non-cancer patients is performance status, through from when there is no evidence of disease to death [25, 26]. To accommodate more diverse care settings the gold standard Karnofsky Performance Status (KPS) tool was modified to become the AKPS [27]. Previous research has evaluated the KPS and the Palliative Performance Scale (PPS), a modification of the KPS [28], and found that they could be used interchangeably [29]. As with the PPS or KPS, a score of 10 in the AKPS represents the poorest functional status (comatose or barely rousable) [29]. There is little evidence of a definition for the term comatose in relation to AKPS 10. A recent systematic review to determine the conscious state of the dying patient defines coma in this instance as "does not awaken to any stimuli" [30]. The review authors however suggest patients are 'unresponsive', that is they may have a level of awareness but are unable to express themselves due to the dying process [31]. An AKPS 20 indicates the patient requires extensive nursing care [27], however a patient with an AKPS 20 may still be able to make their own decisions and say their goodbyes. Conversely a person scoring AKPS 30 may be 'almost completely bedfast' [27], yet still be independent with some care needs. These tools have been used in multiple studies for prognostication [17, 21, 25, 26, 32–35]. They have not however been used to predict the timeframe between patients having the ability to understand and to engage in decision-making and becoming comatose or unrousable [17], and then the time until death; nor have scores been reported consistently [36].

Methods

Aims

The aims of this research were to:

(a) determine timeframes to death for patients between becoming comatose or barely rousable (AKPS 10) and death (AKPS 0); and

(b) to explore timeframes between being totally bedfast and requiring extensive nursing care (AKPS 20), to then becoming:

- comatose or barely rousable (AKPS 10), or
- death (AKPS 0), using the Australia-modified Karnofsky Performance Status (AKPS) scale.

The secondary aim was to determine whether age, sex, primary diagnosis, or setting of care predicted timeframes to becoming comatose or barely rousable or timeframes from scoring AKPS 10 to death.

Design

This was a large retrospective cohort study which has been reported using the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) Guidelines (see Supplementary Table 1).

Setting

The specialist palliative care service involved in this study operated within a moderate sized metropolitan area and surrounding rural districts in Australia, which provided inpatient hospice and community specialist palliative care. The service's palliative care teams provided multiple other specialist palliative care services, such as out-patient clinics, in-reach to aged care homes, and hospital consultations. Due to variation in timing of clinical reviews in these settings, AKPS scores were not consistently recorded and therefore patients seen by these arms of the service were not included in this study.

Study cohort

The study population were patients who received specialist palliative care, and the inclusion criteria were:

i. patients with more than one recorded AKPS score for more than 24-hours; and
ii. were 18 years or over; and
iii. had a last episode of care which ended with death between 1 January 2017 and 31 December 2021; and
iv. were cared for as inpatients in a 19-bed inpatient hospice; or
v. were cared for in the community by a community specialist palliative care team.

Exclusion criteria.

i. patients cared for by other arms of the specialist palliative care service.

Data collection tool

The Australian National Palliative Care Strategy promotes research and nationally consistent data collection [37]. The Palliative Care Outcomes Collaboration (PCOC) is a benchmarking program that gathers data and measures the outcomes of palliative care delivered by 177 health services across Australia [25, 38]. As part of a suite of assessment tools used by PCOC, the Australia-modified Karnofsky Performance Status (AKPS) scale consists of an 11-point ordinal which measures patients' function and ability to perform daily tasks (100 = normal function, 0 = death) [27]. An AKPS score of 20 relates to patients who are totally bedfast and require extensive nursing care by professionals and/or family. An AKPS score of 10 indicates the patient is comatose or barely rousable [27] and in the terminal phase [39]. A palliative care phase denotes a particular period describing a patient's condition: stable, unstable, deteriorating, terminal, and bereavement phase [39]. Determining a palliative care phase requires a holistic clinical assessment considering the needs of the patient and their loved ones [39]. A phase change marks care points where the existing care plan is no longer effective [39]. The AKPS scale is a reliable and validated [27] internationally recognized tool in the palliative care context [38].

The specialist palliative care service where this study was undertaken was part of the PCOC and gathered data on patient care using the AKPS scale and other tools. The AKPS scores were documented electronically, generally by nurses during that shift and at the point-of-care provision, from the time of initial admission to the specialist palliative care service. All scores until death were reviewed and accounted for during the retrospective analysis. Although several scores may have been recorded over different shifts on the same day, a consensus agreement was made that only the last recorded AKPS score for each day for each patient was included in this study's dataset.

Data collection

Data were collected as part of routine patient care using PalCare (http://www.palcare.com.au/), a web-based pa lliative care patient information management system. A study specific report was commissioned, and data was extracted from the local PalCare patient information management system. Missing demographics, diagnoses, or other details were manually retrieved from clinical notes and reviewed independently by two research clinicians. Disagreements were discussed and a third researcher was consulted until agreement was reached.

Password protected MS Excel™ spreadsheets were used to manage de-identified extracted data which included the following: date and site of death, year of birth, sex, ethnicity, Aboriginal and Torres Strait Islander status, specialist palliative care service utilised, cancer or other diagnostic cohorts. Only the recorded primary diagnosis was included regardless of other co-existing comorbidities. All AKPS scores and dates of assessments from admission until death were extracted per patient.

To improve the integrity and accuracy of the data, researchers examined all clinical records to determine the clinical context of AKPS scores and interpret and explain clinically any outliers or anomalies. Final data were verified by all members of the research team to ensure agreement prior to analysis.

Statistical analysis

Descriptive statistics were used to summarize the study population's clinical characteristics and demographics. ANOVA was used for multi-group comparisons. In this retrospective study, no formal power calculations were attempted as a convenience sample was utilized. To estimate the probability of time to becoming comatose (AKPS 10) or time to death (AKPS 0), an Interval-Censored Cox Proportional Hazards regression model was used [40, 41]. A regression model was used as the specific

time patients became unrousable or transitioned from an AKPS 20 or 10 prior to assessment was not always certain. This model also allows consideration of multiple covariates. Data analyses and management were executed in STATA 16© statistical software (StataCorp LP, College Station, TX). A *p*-value equal to or less than 0.05 was considered statistically significant for all statistical tests.

Results

Participants

5,611 patients were cared for by the specialist palliative care service over five years, between 1 January 2017 and 31 December 2021. Based on inclusion criteria, 2,438 patients cared for by the two specialist palliative care teams; in the Community ($n = 986$, 40%) and as inpatients in the Hospice setting ($n = 1{,}452$, 60%), were included (see Fig. 1, Panel A). Associated with the 5,611 patients were 87,721 AKPS data points, and of these 49,842 AKPS data points represented the final included 2,438 patients (see Fig. 1, Panel B).

Clinical and demographic profile

More patients were male (52%, $n = 1{,}265$), and 38% ($n = 932$) of all patients were over the age of 80 years old. 75% of the population had a cancer diagnosis of which 52% ($n = 950$) were male. 64% ($n = 598$) of those over 80 years of age had a cancer diagnosis, whereas 89% ($n = 320$) of those aged 60 years and younger had cancer. Within the hospice setting 22.7% of all in-patients had a non-cancer diagnosis, compared to 29.3% of those cared for in the community. The most prevalent non-cancer diagnosis was solid organ failure ($n = 230$, 9%) followed by cardiovascular disease ($n = 124$, 5%) (see Table 1).

Australia-modified Karnofsky performance status scores

Overview across the whole patient cohort

The average AKPS score was lower among those who had a non-cancer diagnosis at the initial point of referral and throughout the illness journey (see Fig. 2, Panel A). There was an observed change in AKPS scores at around 20–30 days before death for those with a cancer diagnosis, with a rapid decline observed from 20 days until death. Although those who were in-patients in the Hospice generally had a slightly lower function level, for both cohorts there was a tipping point where a rapid decline occurred around 30 days prior to death (Panel B). Equally, regardless of age a decline was noted around 20 days prior to death (Panel C).

Time from AKPS 10 to death

From the first AKPS 10 score, 53.6% ($n = 1{,}306$) of patients were comatose or barely rousable for longer than one day. The mean (median [standard deviation]) time to death after the first recorded AKPS score of 10 was 2.1 (1 [2.0]) days which was not statistically significantly different across location (see Table 2 Panel A and B). Adjusting for covariates, the likelihood of death within three days of becoming comatose or barely rousable was greater than 70%, and within one week was greater than 90% (see Fig. 3, Panel A).

Outliers

2% ($n = 26$) of those patients with an AKPS score of 10 ($n = 1{,}306$) survived longer than seven days, with the longest being 15 days (see Supplementary Table 2). Among these outliers 18 patients (69%) had a cancer diagnosis and eight (31%) had a non-cancer diagnosis.

Time from AKPS 20 to AKPS 10

Of the included patients, 1,739 (71.3%) were recorded as having at least one AKPS 20 score during their admission. Of the 1,739 patients who scored 20 on the AKPS scale, 999 (57%) patients went from AKPS 20 to AKPS 10 and death. The mean (median [SD]) time to move from first recorded AKPS score of 20 to first recorded AKPS score of 10 was 24 (4 [86.3]) days. There was no statistically significant difference across the two locations ($p = 0.36$) (Hospice 22.5 (4 [87.0]) and Community 28.1 (3 [84.3]) (see Table 3, Panels A, B). The average number of days however, for non-cancer patients to transition from AKPS 20 to AKPS 10, was more than three times longer than those patients who had a cancer diagnosis, which was statistically significant $p < 0.01$ (see Table 3, Panel C). After the first change from AKPS 20 to AKPS 10 for patients dying with cancer, the mean was 14.4 (2 [38.8]) days, whereas the mean for non-cancer patients was 53.3 (5 [157.1]) days.

The likelihood of being assessed as comatose or barely rousable (AKPS 10) after being first recorded an AKPS score of 20 was around 80% within two weeks (see Fig. 3, Panel B). The likelihood of transition from AKPS 20 to AKPS 10 was higher among patients with cancer. On average there was a 50% chance that patients with cancer would move from AKPS 20 to an AKPS 10 four days prior to death, whereas for those with a non-cancer diagnosis it was six days prior to death (see Fig. 3, Panels C and D).

Time to death after change to AKPS 20 – including variation in AKPS scores

Not all patients moved directly to an AKPS 10 after a score of AKPS 20. There was movement between AKPS scores as patients' health deteriorated (to AKPS 10 or death), improved (to AKPS 30 or above), and deteriorated again (returned to AKPS 20 or 10 or death). As previously stated, of the 2,438 patients included, 1,739 (71.3%) were recorded as having at least one AKPS 20 score during their admission. The mean (median) time

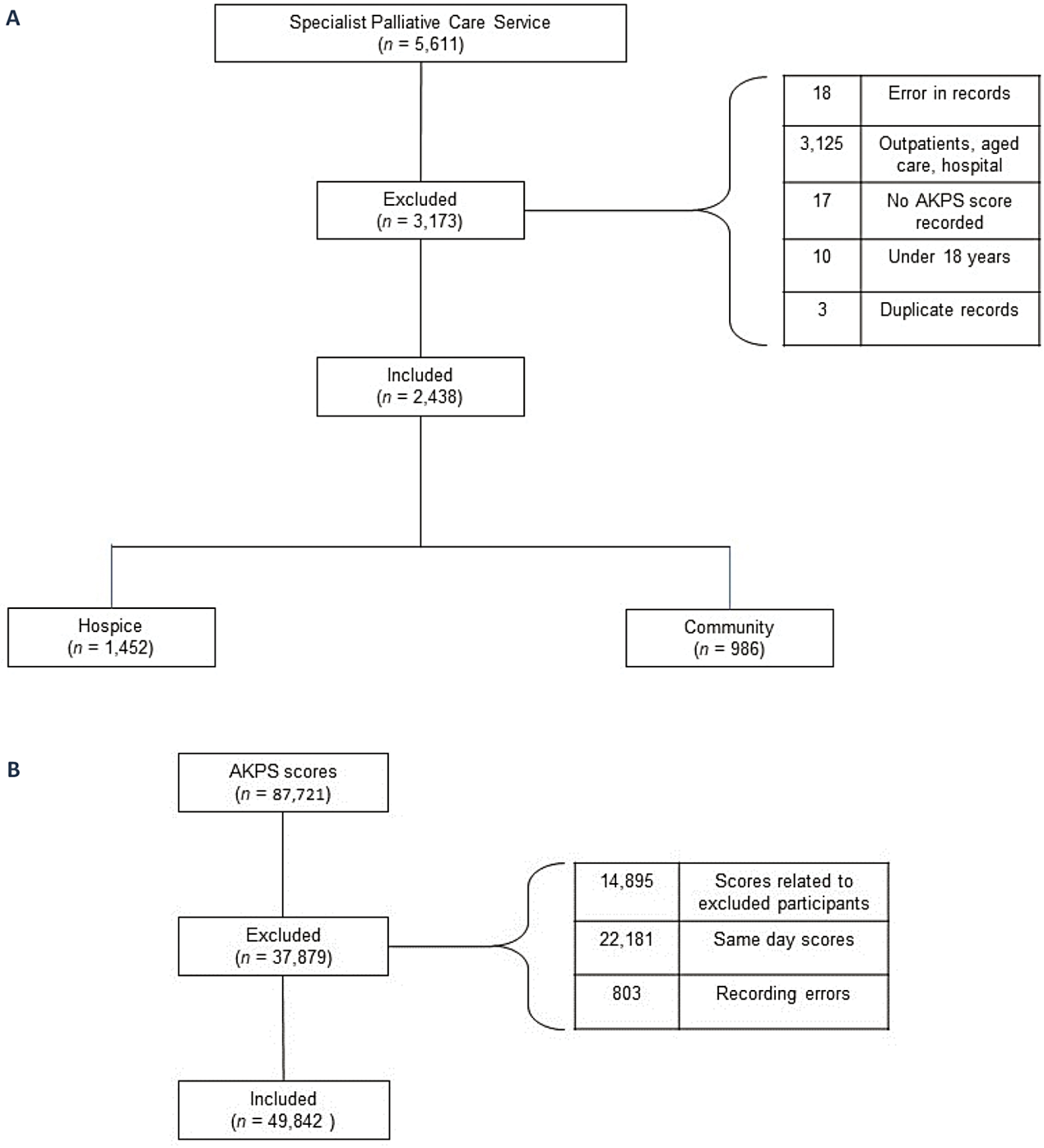

Fig. 1 Flow diagram. Panel **A**: Participants. Panel **B**: Australia-modified Karnofsky Performance Status

to death after first recorded AKPS score of 20 was 26.1 (5) days with a significantly high variation [99.5 days] (see Table 4, Panel A).

The time to death after the first recorded AKPS score of 20 was almost twice as long among the patient cohort who died in the Community compared to those who died at the Hospice (mean time = 39.1 days (5 [143.6]) versus 20.4 days (5 [71.7]), with a p-value < 0.01)) (see Table 4, Panel B).

Examining cancer diagnosis in relation to time to death after change to AKPS 20, there was minimal difference across the two locations ($p = 0.18$) (see Table 4, Panel C). Non-cancer patients who received palliative care in the Community however had a statistically significant longer time between AKPS 20 and death (82.5 (8) [235] vs.

Table 1 Demographics

	Full sample	
	n	**%**
Total number of patients	2438	-
Hospice	1452	60
Community	986	40
Age[a]	74.17	13.8
18–60	361	15
61–80	1145	47
> 80	932	38
Sex		
Male	1265	52
Female	1172	48
Missing data	1	0
Primary Diagnosis		
Cancers	1819	75
Hospice - Cancer	1122	46
Hospice - Non-cancer	330	14
Community - Cancer	697	29
Community - Non-cancer	289	11
Solid organ failure	230	9
Neurological conditions	108	4
Cardiovascular disease	124	5
Alzheimer's disease/dementia	65	3
Other[b]	92	4

[a] Mean and SD (instead of *n* and %) are reported

[b] This includes for example, sepsis, type 2 diabetes mellitus, mental disorder, fracture, etc.

43.1 (5) [138]) with a *p*-value of 0.03 (see Table 4, Panel D). There was a higher percentage of non-cancer patients cared for in the Community than in the Hospice (29.3% versus 22.7%) (see Table 1, Demographics).

Discussion

This research evaluated data collected at point-of-care until death, of a large retrospective cohort of patients who were cared for in the community and an in-patient hospice setting. An association between AKPS scores and timeframes to death was found. AKPS scores of 20 and 10, and a range of clinical and demographic covariates were explored with the aim of informing decision-making at end-of-life. More than half of the included population died on the second day of being assessed as comatose or barely rousable regardless of location, and most people had died within 4 days. The results of this study validate similar results using the PPS [42, 43] where a PPS 10 and AKPS 10 score [17] indicate an average life expectancy of one day with a mean of 2.1 days. Previous research of a smaller cohort produced similar findings, but that research did not include data from AKPS 20 [17].

Scoring an AKPS 20 indicates the patient requires extensive nursing care [27], but cognitively may still be able to talk and make their own decisions, which is important for person-centered care when planning for end-of-life. Results from the current research revealed that there was a high probability of patients who had

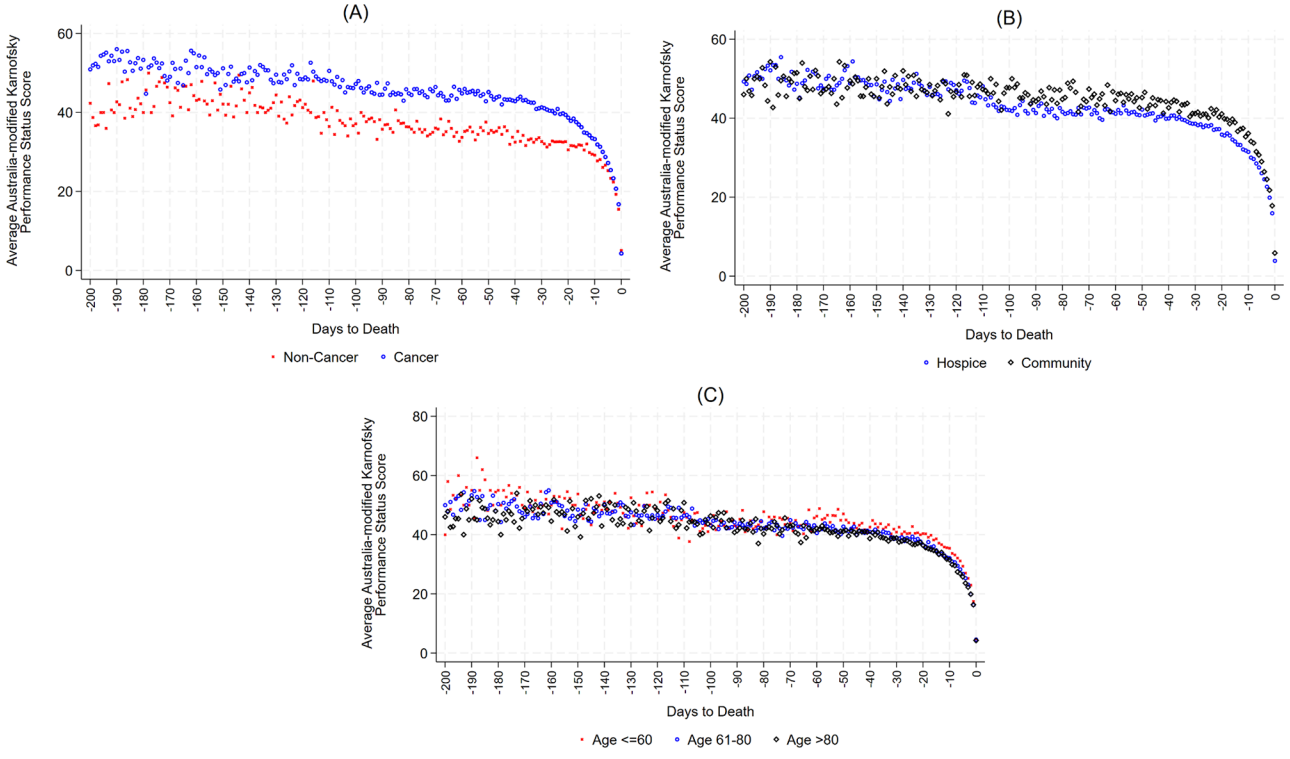

Fig. 2 Average AKPS score (49,842 AKPS data points for 2,438 patients)

Table 2 Time to death after change to AKPS 10 ($n = 1,306$)

Panel A: Overall

	Time to Death (Days)		
	Mean	Median	SD
After first change to:			
AKPS 10	2.1	1	2.0

Panel B: Across 2 locations: Hospice and Community

	Time to Death (Days)						ANOVA *p*-value
	Hospice			Community			
	Mean	Median	SD	Mean	Median	SD	
After first change to:							
AKPS 10	2.1	1	2.0	2.1	1	2.1	0.78

become bedbound and required extensive nursing care (AKPS 20) would be comatose or barely rousable within a month, however a variation in timeframes was acknowledged. The findings are in keeping with the generally accepted seminal work on patterns of functional decline for chronic non-cancer illness where fluctuating patterns of decline are experienced [44]. The average number of days non-cancer patients were bed bound and requiring extensive nursing care - that is, AKPS 20 - prior to death was more than three times longer than that of a patient affected by cancer. Further groupings of cancer and non-cancer diagnosis by type was not done in our study, however a previous study found that survival for some cancer groups such as prostate, colorectal, and breast cancer were similar to survival for patients with a non-cancer diagnosis [43, 45]. Another study examining survival in those with both cancer and non-cancer diagnosis did not find a logical association between PPS 10% and 20% scores and median survival time in non-cancer patients [34]. A further study of patients with heart failure, which obtained PPS 10% and 20% scores at the time of enrolment and on the date of death or discharge, found similar median survival time for PPS 10%, but just 2–8 days for PPS 20% [42].

A systematic review exploring median time until death for patients of mixed diagnosis (cancer and non-cancer) reported similar time ranges as the current study [36], however scores were only recorded one week apart [46], once on initial assessment [43, 45], and with only a total of between one and 13 scores for each of 666 patients during the study [47]. The present research in contrast presented AKPS scores from the initial admission to the palliative care service until death, with scores being captured in real-time at each point-of-care, providing a more robust account of deterioration and the time trajectory in last weeks and days of life.

Our study found that patients with an AKPS score of 20 had a high likelihood of scoring an AKPS 10 within a month – that is, being comatose or barely rousable and no longer able to make decisions for themselves. Unlike previous research that combined PPS ratings of 20% and below [20, 21], 30% and below [32], or scores only obtained at change of phase resulting in an average score [48], this study separately accounted for all AKPS 20 and 10 scores, which advances understanding further. From a clinical practice perspective, highlighting the use of the AKPS 20 as a predictor of dying, this research provides clinicians, patients and those important to them with a clear indicator that death may be imminent and provides a trigger to commence those essential timely end-of-life conversations. From an organisational perspective, more accurate prognostication (including information comparing mean/median days to death in the community versus the hospice, and cancer versus non-cancer diagnosis) can be helpful in determining the level of urgency in establishing services, transferring care to an inpatient setting, allocating resources, and setting priorities related to goals of care [49, 50].

Using all gathered AKPS scores, our research found that there was a distinct overall change of score or 'tipping point' preceding death when controlling for variables. This work confirms Morgan et al. [48] study which found that AKPS scores dropped by 15–26 points in the last 14–22 days of life for all diagnostic cohorts. This observation adds to the predictive capabilities of the AKPS. Our study advances this previous research by including all AKPS scores rather than a 'modelled average score' [48].

The literature indicates that end-of-life conversations often occur too late, and nearly a third of bereaved families perceive a need for improvement in clinicians' discussion around impending death [9]. Having the communication skills to transmit this knowledge to patients and families in a timely, compassionate, and sensitive manner is essential [4, 6, 9, 51–54]. Practical training and mentoring are required to assist healthcare professionals

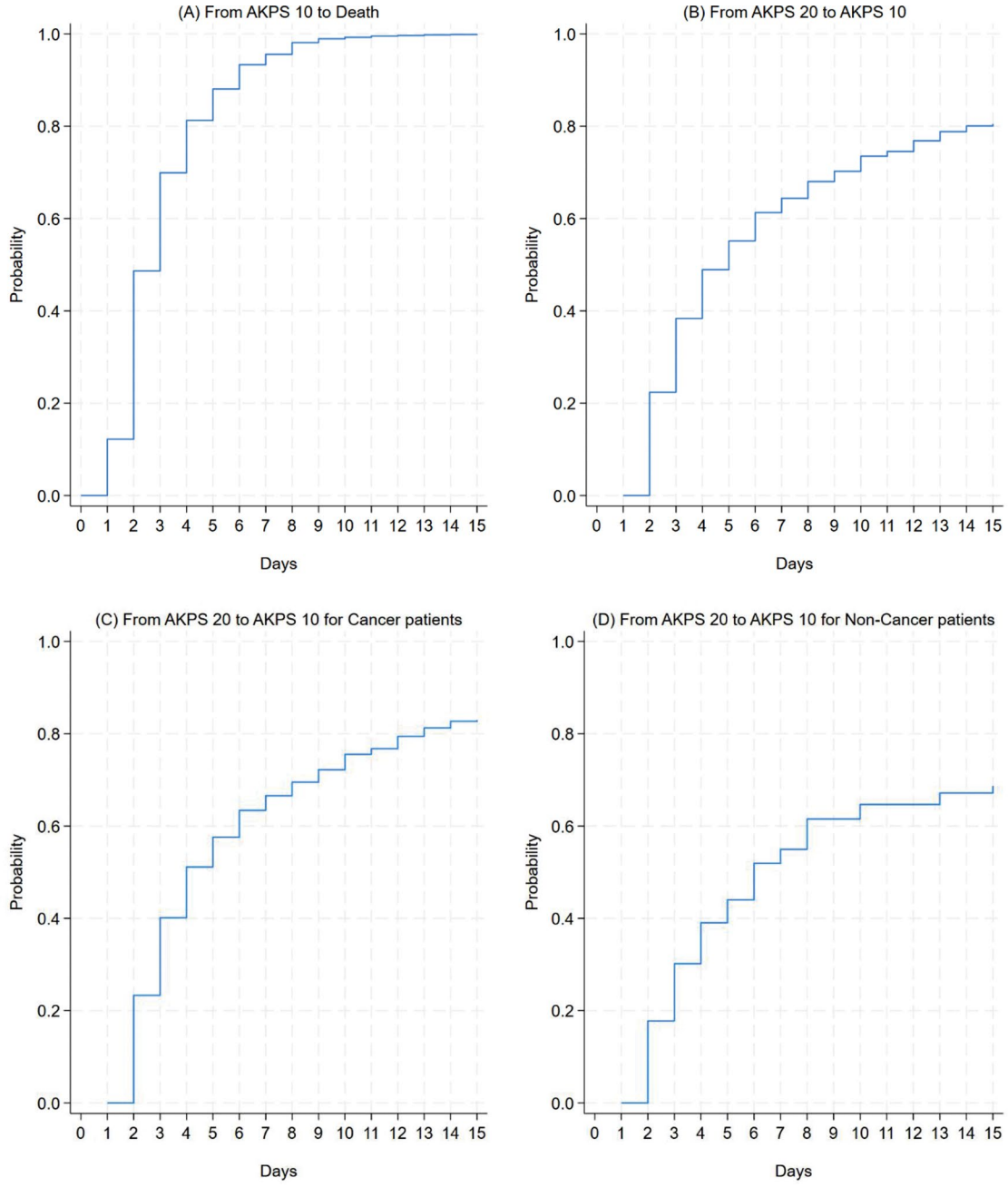

Fig. 3 Adjusted failure functions. Panel **A** - Adjusted failure function from AKPS 10 to death ($n=1,306$). Panel **B** - Adjusted failure function from AKPS 20 to AKPS 10 ($n=999$). Both are adjusted for age, sex, cancer diagnosis, standard deviation of AKPS score for the past 7 days, and location. Panel **C** and **D** - Adjusted failure function from AKPS 20 to AKPS 10 ($n=1,306$) respectively for cancer and non-cancer patients. Both are adjusted for age, sex, standard deviation of AKPS score for the past 7 days, and location

work through their own emotional needs, and to translate communication guidelines and recommendations into practice [4, 54, 55]. Results of this study provide clinicians with validated data when answering 'how long' questions at end-of-life. Knowledge of projected time to death can prompt timely conversations between clinicians, patients and those important to them to discuss and plan essential person-centered end-of-life care.

Almost 50% of patients did not become comatose or unrousable, they either died suddenly or were comatose or unrousable for less than 24 h. In contrast some who did have an AKPS of 10 lived for longer than one week. Family awareness of uncertainty around dying has been explored previously, and findings revealed that families gave clinicians permission to express uncertainty [4, 54, 56]. Conversely, knowledge of uncertainty about death

Table 3 Time to AKPS 10 after change to AKPS 20 ($n = 999$)

Panel A: Overall

	Time (Days)		
	Mean	Median	SD
After first change: From AKPS 20 to AKPS 10	24.0	4	86.3

Panel B: Across 2 locations: Hospice and Community

	Time (Days)						ANOVA *p*-value
	Hospice			Community			
	Mean	Median	SD	Mean	Median	SD	
After first change: From AKPS 20 to AKPS 10	22.5	4	87.0	28.1	3	84.3	0.36

Panel C: Between cancer and non-cancer patients

	Time (Days)						ANOVA *p*-value
	Cancer patients			Non-Cancer patients			
	Mean	Median	SD	Mean	Median	SD	
After first change: From AKPS 20 to AKPS 10	14.4	2	38.8	53.3	5	157.1	<0.01

has been cited as a reason for clinicians' reluctance to discuss dying [56, 57]. Estimates to death, grounded in evidence provided by this research can offer clinicians greater confidence when making clinical decisions and answering 'how long' questions at end-of-life.

Strengths and limitations

Larger studies have used the AKPS to examine and prognosticate at end-of-life, however only AKPS scores at change of phase were used [48] or average scores were assessed [21, 34, 42]. Uniquely this study accounted for all AKPS scores from date of admission to the specialist palliative care service, across cancer and non-cancer disease trajectories, age, sex and in two palliative care settings until death. Specific diagnostic groupings such as types of cancer etc. were not included, this can be viewed as a limitation of this study. Uncertainty around when the patients' AKPS score changed was addressed by using an Interval-Censored Cox Proportional Hazards model. Time of death was not recorded; however, all scores were for 24 h (one day) periods. Although data examined retrospectively is a limitation, this study used data that included all AKPS scores recorded in real-time at the point-of-care provision throughout the palliative disease trajectory. Some bias may exist as AKPS scores are based on subjective assessments by individual clinicians. Similarly, patients scoring AKPS 10 may have been sedated, had delirium, been sleeping, etc. The correlation between the use of sedating medications at end-of-life, such as opioids or benzodiazepines, was not possible in this study as data was not available. Although the researchers made every effort to ensure the data was accurate, the data is retrospective, and inferences were made from clinical notes. Data regarding ethnicity was not included as collection of this raw data was inconsistent. This study only included data from one specialist palliative care service, and only those who were referred to specialist palliative care were included in this study, the results should therefore be read accordingly. Equally, this study is not representative of all dying patients scoring an AKPS of 20 – 10 who may require specialist palliative care in other settings or in other regions.

Conclusion

This study adds to the body of knowledge on end-of-life care by providing clinicians with validated data to guide communication when answering 'how long' questions at end-of-life. Clinician knowledge and insight into timeframes for when patients are likely to die is centrally important to achieving a good death. AKPS scores determining timeframes to death can offer clinicians additional confidence when answering patient and family 'how long' questions at end-of-life. The importance of considering the primary diagnosis (cancer vs.

Table 4 Time to death after change to AKPS 20 ($n = 1,739$)

Panel A: Overall

	Time to Death (Days)		
	Mean	Median	SD
After first change to:			
AKPS 20	26.1	5	99.5

Panel B: Across 2 locations: Hospice and Community

	Time to Death (Days)						ANOVA *p*-value
	Hospice			Community			
	Mean	Median	SD	Mean	Median	SD	
After first change to:							
AKPS 20	20.4	5	71.7	39.1	5	143.6	<0.01

Panel C: Cancer patients across 2 locations: Hospice and Community

	Time to Death (Days)						ANOVA *p*-value
	Hospice			Community			
	Mean	Median	SD	Mean	Median	SD	
After first change to:							
AKPS 20	14.3	5	34.2	17.4	4	45.1	0.18

Panel D: Non-Cancer patients across 2 locations: Hospice and Community

	Time to Death (Days)						ANOVA *p*-value
	Hospice			Community			
	Mean	Median	SD	Mean	Median	SD	
After first change to:							
AKPS 20	43.1	5	138.0	82.5	8	235.0	0.03

Appendix 1 Australia-modified Karnofsky Performance Status (AKPS)

AKPS ASSESSMENT CRITERIA	SCORE
Normal; no complaints; no evidence of disease	100
Able to carry on normal activity; minor sign of symptoms of disease	90
Normal activity with effort; some signs or symptoms of disease	80
Cares for self; unable to carry on normal activity or to do active work	70
Able to care for most needs; but requires occasional assistance	60
Considerable assistance and frequent medical care required	50
In bed more than 50% of the time	40
Almost completely bedfast	30
Totally bedfast and requiring extensive nursing care by professionals and/or family	20
Comatose or barely rousable	10
Dead	0

https://documents.uow.edu.au/content/groups/public/@web/@chsd/documents/doc/uow272194.pdf

non-cancer) and patients cared for in the community versus hospice have been highlighted when determining timeframes. Knowledge of estimated time to death can assist clinicians, patients and families with planning and decision-making. From an organisational perspective more accurate prognostication can aid decisions, policy making and resource allocation. Further research is needed to determine the value of these timeframes in clinical decision-making in other contexts.

Abbreviations

AKPS	Australia-modified Karnofsky Performance Status.
KPS	Karnofsky Performance Status.
PCOC	Palliative Care Outcomes Collaboration.
PPS	Palliative Performance Scale.
STROBE	Strengthening the Reporting of Observational Studies in Epidemiology.

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

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Not applicable.

Author contributions
All authors contributed to the design of the study. TO'C, W-ML, JS collected the data. TO'C and W-ML analysed the data. All authors were involved in the interpretation of the data. TO'C drafted the manuscript. All authors critically revised the manuscript and approved the final version of the manuscript and agreed to be accountable in all aspects of the work. The corresponding author attests that all authors meet authorship criteria.

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Data availability
No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate
Calvary Healthcare Human Research Ethics Committee approved the study (10-2022) and cross institutional approval was granted from the University of Canberra and Australian National University Ethics Committees. Routinely collected clinical data was de-identified and aggregated. Individual patient consent was not required.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

Author details
[1]Clare Holland House, North Canberra Hospital, 40 Mary Potter Cct, Bruce, Canberra 2617, Australia
[2]Caring Futures Institute, Flinders University, Sturt Rd, Bedford Park, Adelaide, South Australia 5042, Australia
[3]Research School of Finance, Actuarial Studies and Statistics, Australian National University, Canberra, Australia
[4]NSW Health Southern NSW Local Health District, NSW Health, Moruya, NSW, Australia
[5]School of Nursing and Health, Avondale University, Wahroonga, NSW, Australia
[6]School of Nursing and Midwifery, Edith Cowan University, Perth, Western Australia, Australia
[7]Faculty of Health, School of Nursing, Midwifery and Public Health, University of Canberra, Bruce, ACT 2617, Australia
[8]Robert Gordon University, Aberdeen, Scotland, UK
[9]School of Clinical Sciences, Faculty of Health and Environmental Sciences, Auckland University of Technology, Auckland, New Zealand
[10]Central Adelaide Health Network, 1 Port Rd, Adelaide, South Australia 5000, Australia

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Publisher's note

Supplementary Table 1. STROBE Statement—Checklist for cohort studies.

	Item No	Recommendation	Page No
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2-3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	4-5
Objectives	3	State specific objectives, including any prespecified hypotheses	5
Methods			
Study design	4	Present key elements of study design early in the paper	6
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	7
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	7
		(*b*) For matched studies, give matching criteria and number of exposed and unexposed	n/a
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	9
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	8-9
Bias	9	Describe any efforts to address potential sources of bias	8-9
Study size	10	Explain how the study size was arrived at	8
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	8-9

Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	9-10
		(*b*) Describe any methods used to examine subgroups and interactions	9
		(*c*) Explain how missing data were addressed	8-9
		(*d*) If applicable, explain how loss to follow-up was addressed	n/a
		(*e*) Describe any sensitivity analyses	n/a
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analyzed	10-18
		(b) Give reasons for non-participation at each stage	
		(c) Consider use of a flow diagram	11
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	10
		(b) Indicate number of participants with missing data for each variable of interest	n/a
		(c) Summarize follow-up time (eg, average and total amount)	n/a
Outcome data	15*	Report numbers of outcome events or summary measures over time	10-18
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	n/a
		(*b*) Report category boundaries when continuous variables were categorized	
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	10-18
Discussion			

Key results	18	Summarize key results with reference to study objectives	19-21
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	21-22
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	19
Generalizability	21	Discuss the generalizability (external validity) of the study results	21
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	23

Supplementary Table 2. Outliers

Days in AKPS 10	Age	Sex (M/F)	Cancer / Non-cancer	Diagnosis	Hospice / Community
8	67	F	Cancer	Metastatic large cell lung cancer with brain metastases	Hospice
8	67	F	Cancer	Glioblastoma multiforme	Hospice
8	77	M	Cancer	Liver failure secondary to hepatocellular carcinoma + NASH cirrhosis	Community
8	76	F	Cancer	SCC of oesophagus	Hospice
8	87	F	Non-cancer	Functional decline and chronic kidney disease	Hospice
8	84	M	Cancer	Metastatic lung cancer with brain metastases	Hospice
8	89	M	Cancer	Colon cancer, dementia	Hospice
8	72	M	Cancer	Duodenal adenocarcinoma	Community
8	77	M	Cancer	Colorectal cancer, liver metastasis	Community
9	88	F	Non-cancer	Epilepsy and dementia	Hospice
9	69	F	Non-cancer	Alzheimer's dementia	Community
9	79	M	Cancer	Glioblastoma multiforme	Hospice
9	76	M	Cancer	Head and neck cancer- SCC base of the tongue	Community
10	71	M	Cancer	Pancreatic adenocarcinoma	Hospice
10	94	M	Non-cancer	Vascular dementia	Community
10	72	M	Non-cancer	Fractured neck of femur and alcoholic cirrhosis	Hospice
11	63	M	Cancer	Glioblastoma multiforme	Hospice
11	66	M	Cancer	Advanced pancreatic adenocarcinoma	Community
12	64	F	Cancer	Subglottic carcinoma. CT brain … suggestive of vascular dementia	Hospice
12	74	M	Non-cancer	Hepatic encephalopathy	Hospice
12	75	F	Non-cancer	End stage Parkinson's disease	Hospice
12	67	F	Cancer	Metastatic malignant meningioma	Hospice
13	65	F	Non-cancer	Peripheral neuropathy and urosepsis	Hospice
13	48	F	Cancer	Glioblastoma multiforme	Hospice
14	56	F	Cancer	Metastatic endometrial carcinoma with leptomeningeal disease	Hospice
15	59	F	Cancer	Glioblastoma multiforme	Community