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The (un)availability of prognostic information in the last days of life: a prospective observational study

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Abstract

Objectives: The aims of this study were (1) to document the clinical condition of patients considered to be in the last two weeks of life and (2) to compare patients who did or did not survive for 72 hours.

Design: A prospective observational study.

Setting: Two sites in London, UK (a hospice and a hospital palliative care team).

Participants: Any inpatient, over 18 years old, English speaking, who was identified by the palliative care team as at risk of dying within the next two weeks was eligible.

Outcome measures: Prognostic signs and symptoms were documented at a one off assessment and patients were followed up 7 days later to determine whether or not they had died.

Results: Fifty participants were recruited and 24/50 (48%) died within 72 hours of assessment. The most prevalent prognostic features as death approached were a decrease in oral intake (60%) and a rapid decline of the participant's global health status (56%). Participants who died within 72 hours had a lower level of consciousness and had more care needs than those who lived longer. A large portion of data was unavailable, particularly that relating to the psychological and spiritual wellbeing of the patient, due to the decreased consciousness of the patient.

Conclusions: The prevalence of prognostic signs and symptoms in the final days of life has been documented between those predicted to die and those who did not. How doctors make decisions with missing information is an area for future research, in addition to understanding the best way to use the available information to make more accurate predictions.

Strengths and limitations of this study

- An observational study that prospectively documented prognostic signs and symptoms in relation to survival of 72 hours.
- The distinction between missing and unavailable data in palliative care.
- The results reflect only the participants that were recruited as part of this study, those who were referred to specialist palliative care. Other results might have been prevalent in a different population.

Background

Caring for a dying person is a core skill required of every doctor and healthcare professional.[1] Part of this competency is to be able to recognise when the person is dying in order to facilitate a "good death".[2] Recognising this terminal phase can enable the dying person to spend time with their loved ones in a location of their choice. The 'More Care; Less Pathway' report [3] alongside other research [4, 5] has highlighted that medical teams are not very accurate at recognising when patients are (or are not) imminently dying.

One way to improve this skill, is to teach staff which signs and symptoms are most prevalent at the end of life. There are a number of reports from organisations such as The National Council for Palliative Care and the National Institute for Health and Care Excellence (NICE), which present narrative summaries of the symptoms and signs that are most common during the last few days of life.[6-11] Previous research and systematic reviews have identified which signs and symptoms are prevalent among patients dying from cancer [12-18] or other diseases.[19-27] Interviews or surveys with health professionals have also been used to determine which signs or symptoms staff believe are most indicative of imminent death.[28-31] From the literature it appears that common signs include changes in breathing patterns, altered consciousness, agitation, changes to the appearance of the skin, incontinence or reduced urinary output. Common symptoms include tiredness, reduced appetite, confusion, changes in functional ability and social withdrawal.

Despite this body of evidence regarding signs and symptoms, these findings have not translated in to practice; medical teams continue to be inaccurate at recognising imminent death.[3] It has been highlighted from recent reports that evidence regarding the clinical presentation of people who were predicted to die, but subsequently did not, is lacking.[3, 4] Finally, findings from palliative care research highlight the high degree of missing or unavailable data.[32] If the common signs and symptoms identified from previous research are not available, or are missing, in the final days of life, then just how is death recognised?

Objectives:

1) To prospectively document the clinical condition of patients considered to be in the last two weeks of life.
2) To compaare the clinical condition of patients who did or did not survive for 72 hours.

Methods

A prospective observational study of patients referred to specialist palliative care. This study follows STROBE reporting guidelines (see Supplementary File 1). The original protocol for the study is in Supplementary File 2.

Settings

Recruitment took place at two palliative care services in London, UK (a hospice and a hospital) between January 2015 and October 2015.

Participants

All inpatient referrals to the palliative care team were screened by their respective clinical teams for eligibility. Palliative care was selected as the specialty to mitigate risk that the death would be sudden or unexpected.

Inclusion criteria:

1. 18 years old and over.
2. Identified by the palliative care team as likely to die in the next two weeks.
3. The patient or family could speak enough English for the researcher to discuss the study.

Exclusion criteria:

1. Assessed as not suitable to approach by the clinical team (i.e. discussing the research would cause too much distress)
2. Lacked capacity, and no personal consultee (family member) available
3. Refused to participate, either verbally or through an advance directive

Sample Size

This study formed part of a programme of research designed to devise a test for assessing clinicians' prognostic accuracy.[33] For the purpose of devising a prognostic test [34] it was necessary to obtain data from at least 20 patients (10 of whom died and 10 of whom survived for 72 hours). To ensure that at least 20 cases from this study were suitable for inclusion in the study to devise a prognostic test we aimed to recruit approximately 50 cases in total. The final sample was determined by the number of inpatient referrals who were eligible, suitable and willing to participate during the study recruitment period.

Patient & Public Involvement

Feedback on the protocol was sought from a consumer research panel (South West London Cancer Research Group). The suggestions from the group were reflected in the study protocol, specifically the study information sheets.

Ethical issues

This study received approval from West Midlands – Coventry and Warwickshire Research Ethics Committee in May 2014 (14/WM/0121).

Recruiting people who are at the ends of their lives presents ethical challenges. In both the hospice and hospital, this may have been the first time that the individual had been referred to palliative care. An inclusion criterion for the study was that the patient was considered to be likely to die within two weeks. This information had the potential to cause upset to both the family and the patient, unless it was handled sensitively by clinical staff. We addressed these concerns by allowing clinical teams to exclude potentially eligible patients if they judged that discussing the research would cause too much distress. Since this study did not require a consecutive series of patients, it was not felt to affect the integrity of the study to allow clinical teams the discretion to operate this form of research "gate-keeping".

Consent procedure

We expected a high number of participants to be unconscious or unresponsive and, as a consequence, to lack capacity. We adhered to the Mental Capacity Act [35] guidelines for recruiting patients without capacity. We also mirrored the approach taken in a similar study that had recruited patients admitted to the acute setting.[36]

If the clinician felt that involvement in the study would not cause distress, the clinician asked the patient, or their family member, if they wished to meet the researcher to discuss taking part in the study. If they agreed to this, the researcher briefed the patient and/or their family member about the research and obtained either informed consent or personal consultee agreement.

Due to the time sensitive nature of the research, there was no enforced delay between informing the patient about the study and seeking consent to participate. Each patient who entered the study was informed that they could withdraw at any time, without reason and without consequence to their care. It was possible to gain telephone advice from a personal consultee should they not live locally. If telephone advice was obtained, an information sheet and a "documentation of advice" form were posted to the family member with a return address. If the form was not returned, or was returned incomplete, the data pertaining to that patient were removed from the database and destroyed (see Supplementary File 3).

Procedure

All participants, upon entering the study, underwent a single observer-rated assessment of key prognostic features (see below), medications, and over all condition. Information regarding their medical history, their reason for admission, and their demographic details were extracted from the medical notes. Data regarding signs and symptoms over the last 24 hours were obtained from direct observation of the patient or from discussing their care with medical or nursing staff.

Measures

We collected data on prognostic variables that had previously been identified from the literature. We used validated measures to record agitation or sedation, functional ability, and co-morbidities.

Richmond Agitation Sedation Scale (RASS)

This scale assesses patients' level of agitation or sedation. The scale ranges from +4 (Combative) to -5 (unarousable). The RASS has high validity and reliability within a hospital setting.[37] This measure has previously been used in mortality research.[38] It distinguishes in greater detail than other scales the different levels of sedation.

Palliative Performance Scale

This scale is used to assess palliative care patients' functional ability.[39] It consists of five domains; Ambulation, Activity & Evidence of Disease, Self-Care, Intake and Conscious Level. Scores can range between 10% (fully dependent) - 100% (fully independent). A decrease in the patient's functional ability has been shown to predict death.[40]

Charlson Co-morbidity Index (CCI) score

This score summarises the severity of chronic comorbidities. It includes 19 diseases that are weighted by their association with mortality. Higher scores reflect a greater number and/or severity of comorbidities.[41] This was obtained from the patient's medical records. The CCI has been shown to predict short and long term mortality.[42]

Clinical signs and symptoms

Information was gathered about the following symptoms and signs, all of which have been previously identified as being potentially predictive of the dying phase:[12, 14-16, 19-22, 24-26, 28-30]

- Respiration (rate and character)
- Blood Circulation (pulse rate, blood pressure, peripheral perfusion, cyanosis)
- Physical Condition (performance status, mobility)
- Skin Integrity
- Excretion (continence, presence of indwelling catheter)
- Oral Intake
- Pain
- Consciousness (level of sedation or agitation)
- Psychological / Spiritual condition
- Other

The full list of clinical signs and symptoms recorded is shown in Supplementary File 4.

Missing data are common in palliative care studies.[32] For this reason, we set out to distinguish between missing data, that is data for which there was no retrievable answer, and data that were not available. For example, for several self-reported symptoms it was not possible to obtain an answer for patients who were unconscious, unless the patient's family members or attending nurse were able to act as a proxy provider of information. This was particularly common when assessing the psychological state of the participant. Equally, when a patient had a urinary catheter or a stoma, it was not possible to determine continence level. In these instances, data were recorded as "not available", rather than "missing".

Main Outcome

The main outcomes of interest were the characteristics of patients who did and did not die within 72 hours of assessment. Each participant was followed-up seven days after the day of observation. During this time, if the participant died, the date of death was recorded.

Analysis

The purpose of this study was to describe the presence or absence of key prognostic features in patients who were or were not dying, under the care of palliative care services rather than to test specific hypotheses about differences between sub-groups of participants. Therefore, to avoid over-interpretation of our data, no statistical tests have been performed to assess for such differences. Results have been summarised using descriptive statistics.

Results

Recruitment

In total, 60 patients were approached to participate in this study (see Figure 1). Ten were not included because; they had died before the researcher could see them (n=5); they had declined to participate (n=3); or they had no personal consultee available to provide advice (n=2).

Figure 1: Recruitment flowchart

Participant characteristics

The characteristics of participants recruited are presented in Table 1.

Table 1 Participant characteristics

Demographics	Total
	n (%)
Participants	50 (100)
Gender	
Male	30 (60)
Female	20 (40)
Age (mean, sd)	72.02 (16.60)
Ethnicity	
White British	36 (72)
Other	14 (28)
Cancer diagnosis?	
Yes	33 (66)
No	17 (34)
Charlson score (mean, sd)	5.43 (2.05)
Length of survival	
Fewer than 72 hours	24 (48)
More than 72 hours	26 (52)

By site

The patients in hospital were older [mean 76 years (sd 16) vs 64 (14)] with a higher prevalence of non-cancer diagnoses (48% vs 11%). They had fewer/less serious comorbidities than the patients from the hospice [mean 5.0 (sd 2.1) v 6.2 (sd 1.8)] and more patients died within 72 hours within the hospital (65% vs 21%).

By survival

Slightly more men than women died within 72 hours (58% vs 42%). The mean age of patients who died within 72 hours was higher (78, sd 13) than those who did not (67, sd 18). There was little difference in comorbidities between those who died within 72 hours (mean 5.2, sd 2.2) and those who did not (5.7, sd 1.9). Of those who died within 72 hours, 50% had cancer, and 50% did not.

Palliative Performance Scale (PPS)

The Palliative Performance Status (PPS) was assessed for every participant. The PPS scores ranged between 10% and 70%, with a median of 30% (IQR 10, 40). The participants who

died within 72 hours had a median PPS score of 10% (IQR 10, 30). Participants who survived beyond 72 hours had a median PPS score of 40% (IQR 20, 50).

Richmond Agitation Sedation (RASS)

Scores for the RASS ranged between +2 and -5. The median score for the total population was -1 (IQR -4, 0). The distribution of scores was bi-modal with most patients having either a score of 0 (n = 12, 24%) or a score of -5 (n = 9, 18%). The participants who died within 72 hours of assessment, were either deeply unconscious (62.5% scored either -4 or -5) or were agitated (20% scored +1 or +2) with a median score of -4 (IQR -4.5, -0.5). The participants who did not die within 72 hours were largely calm with mild agitation or sedation (70% scored between -1 and +1) and a median score of -0.5 (IQR -2, 0).

Clinical signs and symptoms prevalence

Table 2 details the prevalence of the signs and symptoms noted during the study. Participants who died within 72 hours were more frequently noted to have: a rapid decline of their global condition (75% vs 37%); decreased urine production (71% vs 23%); more concentrated urine (67% vs 31%); incontinence of faeces (71% vs 19%); noisy respiratory secretions (54% vs 15%); Cheyne-Stoke breathing (17% vs 4%); peripheral cyanosis (21% vs 4%); and refusal of food (21% vs 4%). There were two symptoms that were only seen in participants who died within 72 hours; respiration with mandibular movement (n = 2; 8%) and pulselessness of the radial artery (n = 2; 8%). Participants who survived longer than 72 hours were more frequently noted to have: a loss of appetite (69% vs 25%), pain (42% vs 4%), were more likely to express anxiety or fear (54% vs 17%) and were more accepting of their death (38% vs 8%).

Table 2 Prevalence of key prognostic features in patients who did or did not die imminently

	Present			Absent	Unavailable
	Total (n=50)	Died <72hrs (n=24)	Died > 72hrs (n=26)	Total (n=50)	
Respiration	n (%)				
Short of Breath	10 (20)	2 (8)	8 (31)	17 (34)	19 (38)*
Noisy Respiratory Secretions	17 (34)	13 (54)	4 (15)	33 (66)	0 (0)
Cheyne Stokes type breathing	5 (10)	4 (17)	1 (4)	45 (90)	0 (0)
Abdominal Swelling	13 (26)	4 (17)	9 (35)	37 (74)	0 (0)
Respiration with mandibular movement	2 (4)	2 (8)	0 (0)	48 (96)	0 (0)
Blood Circulation					
Pulselessness of the radial artery	2 (4)	2 (8)	0 (0)	37 (74)	7 (14)*
Peripheral Cyanosis	6 (12)	5 (21)	1 (4)	42 (84)	0 (0)*
Nose becomes more "pointed"	0 (0)	0 (0)	0 (0)	47 (94)	0 (0)*
Change in skin condition (moisture, colour, temperature)	16 (32)	8 (33)	8 (31)	34 (68)	0 (0)
Physical Condition					
Extreme tiredness	15 (30)	4 (17)	11 (42)	13 (26)	21 (42)*
Insomnia	7 (14)	1 (4)	6 (23)	21 (42)	21 (42)*
Surges of Energy	2 (4)	0 (0)	2 (8)	26 (52)	21 (42)*
Rapid degradation of general condition	28 (56)	18 (75)	10 (38)	22 (44)	0 (0)
Skin Integrity					
Wounds, ulcers or sores on the skin	13 (26)	6 (25)	7 (27)	37 (74)	0 (0)
Excretion					
Catheter	27 (54)	16 (67)	11 (42)	23 (46)	0 (0)
Stoma	7 (14)	1 (4)	6 (23)	43 (86)	0 (0)
Concentrated urine	24 (48)	16 (67)	8 (31)	19 (38)	4 (8)*
Incontinence (urinary)	10 (20)	5 (21)	5 (19)	13 (26)	27 (54)
Incontinence (faecal)	22 (44)	17 (71)	5 (19)	20 (40)	7 (14)*
Vomiting	12 (24)	3 (13)	9 (35)	38 (76)	0 (0)
Altered defecation – diarrhoea	10 (20)	4 (17)	6 (23)	38 (76)	1 (2)*
Altered defecation – constipation	19 (38)	9 (38)	10 (38)	29 (58)	1 (2)*
Decreased production of urine	23 (46)	17 (71)	6 (23)	18 (36)	6 (12)*
Oral Intake					
Decreased eating	30 (60)	13 (54)	17 (65)	5 (10)	15 (30)
Decreased drinking	26 (52)	13 (54)	13 (50)	10 (20)	14 (28)
Refusing food	6 (12)	5 (21)	1 (4)	23 (46)	21 (42)
Swallowing difficulty	12 (24)	4 (17)	8 (31)	17 (34)	20 (40)*
Loss of appetite	24 (48)	6 (25)	18 (69)	3 (6)	22 (44)*
Pain					
Patient reported pain	12 (24)	1 (4)	11 (42)	18 (36)	20 (40)
Clinician reported pain	13 (26)	3 (13)	10 (38)	37 (74)	0 (0)
Pain is less responsive to treatment	2 (4)	1 (4)	1 (4)	43 (86)	4 (8)*
Psychological Condition / Spiritual					
Confusion	13 (26)	6(25)	7 (27)	13 (26)	23 (46)*
Delirium	3 (6)	2 (8)	1 (4)	24 (48)	22 (44)*
Anxiety/fear	18 (36)	4 (17)	14 (54)	7 (14)	24 (48)*
Recoil behaviour (withdrawn)	1 (2)	0 (0)	0 (0)	25 (50)	23 (46)*
Acceptance of death	12 (24)	2 (8)	10 (38)	13 (26)	24 (48)*
Saying goodbye to family members	0 (0)	0 (0)	0 (0)	25 (50)	24 (48)*

*Missing data: shortness of breath (4) Pulselessness of the radial artery (4) Peripheral Cyanosis (2) Nose becomes more "pointed" (3) Extreme tiredness (1) Insomnia (1) Surges of Energy (1) Concentrated urine (3) Incontinence (faecal) (1) Altered defecation – diarrhoea (1) Altered defecation – constipation (1) Decreased production of urine (3) Swallowing difficulty (1) Loss of appetite (1) Pain is less responsive to treatment (1) Confusion (1) Delirium (1) Anxiety/fear (1) Recoil behaviour (withdrawn) (1) Acceptance of death (1) Saying goodbye to family members (1).

Missing and unavailable data

As shown in Table 2, there were some prognostic features for which almost half of the data were recorded as not available, or "unknown". In the cases where "unknown" was recorded, it was not "missing" (i.e. theoretically available but not recorded), it was simply not available (e.g. because the patient was unconscious, because of new staff on shift who were unfamiliar with the patient, or that no family were present). The aim of this study was to document key prognostic features in patients who were referred to specialist palliative care teams, and therefore the fact that data relating to some of these features were frequently "unknown" is a relevant finding.

Discussion

This study described the presence or absence of key prognostic features in palliative care patients who were thought to be in the last two weeks of life and who did or did not die within 72 hours of assessment.

In patients thought to be in the last two weeks of life, there was a reduction in physical ability, as measured by the palliative performance scale. Three symptoms affected at least half of the patients: reduced oral intake, a rapid decline in condition, and a change in excretions. This result is slightly inconsistent with other studies that have suggested that other symptoms such as fatigue and mental haziness are more prevalent in the last weeks of life.[43-45]

Different symptoms were prevalent in patients who died within 72 hours and in those who survived for longer. Patients who died within 72 hours had a lower palliative performance score and experienced either more agitation or more sedation than patients who survived

longer than 72 hours. Some symptoms were more prevalent in patients who died imminently, such as a rapid decline in global condition, decreased urine output, increased anxiety, incontinence, noisy respiratory secretions, Cheyne-Stoke breathing, and peripheral cyanosis. The small sample size of this study means that the estimates of the prevalence of particular symptoms should only be regarded as tentative. Two symptoms, although uncommon, were only noticed in patients who died imminently: respiration with mandibular movement and pulselessness of the radial artery. These symptoms have been previously suggested to predict imminent death.[12, 13, 16] One previous study reported that observations of the patient, such as heart rate and oxygen saturation, may also be predictive of imminent death.[17] However, most patients in our study did not have routine observations undertaken and so no such data were available.

This reiterates the importance of further research within a palliative care context particularly in the final days of life and about how to make prognostic decisions in the context of incomplete data.[32] We attempted to address the issue of missing data in this study by distinguishing between data that were truly missing and data that were not obtainable for a valid reason. For example, in patients who were comatosed, data about their subjective psychological state were simply not possible to obtain. A large volume of data was recorded as unavailable for patients in this study. This is an interesting finding and highlights the complicated landscape in which the medical team are asked to make predictions about imminent death based on information that is not always possible to obtain about the patient. The prevalence of prognostic factors in this study demonstrates the large amount of potential prognostic information that medical teams have to weigh up when making a decision about end of life care. Further research is required to determine how these decisions are made in practice.

Strengths and weaknesses

This study is one of the first, to the authors knowledge, to prospectively observe prognostic signs and symptoms in the final days of life whilst distinguishing between data that is not available rather than missing. However, this data is only taken from two london specialist palliative care teams. If a different population had been recruited, it is possible that other signs and symptoms may have been more prevalent. For example, patients who are not referred to specialist palliative care teams might present differently towards the end of life. This is an area for further research.

Conclusion

This study lends support to the usefulness of certain key prognostic features for predicting immnent death in palliative care inpatients. Further work is required to understand how clinicans should best integrate these prognostic features, with the volume of missing information, to refine their prognostic estimates of imminent death.

Declarations

Ethics approval and consent to participate

As described in the section “Patient & Public Involvement

Feedback on the protocol was sought from a consumer research panel (South West London Cancer Research Group). The suggestions from the group were reflected in the study protocol, specifically the study information sheets.

Ethical issues", this study received approval from West Midlands – Coventry and Warwickshire Research Ethics Committee in May 2014 (14/WM/0121).

Consent for publication

Not applicable

Conflict of Interest

None to declare

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Authors' contributions

NW developed the study concept, design and aims, designed data collection tools, completed the data collection for the whole study, cleaned and analysed the data, and drafted and revised the paper. FR developed the design and aims of the study, monitored the data collection tools for the observational study and data collection, aided in the analysis of the results, and revised the paper. AH developed the study concept, design, and aims, monitored data collection throughout the study, aided in the analysis plan and analysis of the results, and revised the paper. PL, CMG, OM, AT assisted in the study design, aided the data collection for the observational study, and revised the paper. PS & PH initiated the PhD study concept, developed the design and aims of the study, monitored the data collection tools for the entire

study and data collection, monitored the analysis of the results, and revised the paper. All authors approved the final version of the paper.

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Data Sharing

The dataset supporting the conclusions of this article is included within the article and its supplementary files.

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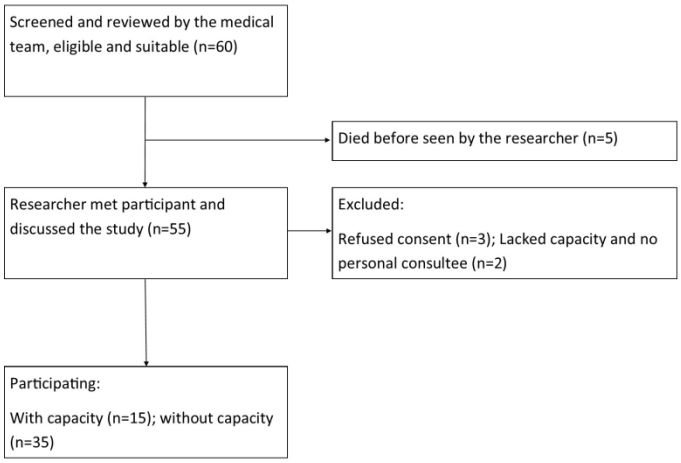
Supplementary Files

Supplementary File 1 STROBE guielines

Supplementary File 2 Original study protocol

Supplementary File 3 Study flow chart

Supplementary File 4 Symptoms gathered on each participant



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STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No.	Recommendation	Page No.	Relevant text from manuscript
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1-2	An observational study
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2	
Introduction				
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3-4	
Objectives	3	State specific objectives, including any prespecified hypotheses	4	
Methods				
Study design	4	Present key elements of study design early in the paper	4	
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	4	
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	5-7	
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case		
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	7-9	
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	7-9	
Bias	9	Describe any efforts to address potential sources of bias	9	Attempting to address "missing" data
Study size	10	Explain how the study size was arrived at	5	Sample Size heading

Continued on next page

Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	9	Analysis section
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	n/a	
		(*b*) Describe any methods used to examine subgroups and interactions	n/a	
		(*c*) Explain how missing data were addressed	9	Missing data
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy	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 analysed	10	Recruitment paragraph and figure 1.
		(b) Give reasons for non-participation at each stage	10	Figure 1
		(c) Consider use of a flow diagram		Figure 1
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	10-11	Participant characteristics section and Table 1
		(b) Indicate number of participants with missing data for each variable of interest	11-12	Table 2 & 3
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)		
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time		
		Case-control study—Report numbers in each exposure category, or summary measures of exposure		
		Cross-sectional study—Report numbers of outcome events or summary measures	11-12	Table 2 & 3.
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	n/a	
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a	

Continued on next page

Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	n/a	Data was summarised and not analysed to avoid over interpretation.
Discussion				
Key results	18	Summarise key results with reference to study objectives	13	
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	13-15	
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	13-15	
Generalisability	21	Discuss the generalisability (external validity) of the study results	13-15	
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	15	

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

University College London

Palliative Care: Clinicians' EstimateS (P:CES).

Improving the accuracy of health care professionals' predictions about clinical outcomes

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Summary

Doctors and nurses are inaccurate at predicting survival in patients who are seriously unwell. This lack of accuracy and consistency can have adverse consequences for patients and their families. Inaccurate prognoses can lead (for example) to delays in access to palliative care services, to patients dying in acute hospitals when they would rather die at home, to delays in access to NHS continuing care funding, and can cause psychological distress to patients and their carers.

This study has been developed in response to recent independent report ("More Care, Less Pathway") which made many recommendations about how to improve the care of the dying and in particular highlighted the need to for more evidence-based research when clinicians give a prognosis.

The aim of this study is to identify a group of 'experts' by presenting clinicians a series of case histories from real people admitted to the hospital and hospice, then asking them to predict the outcome. From the experts identified, we will then be able to understand what key information is being used to make an accurate prognosis. This novel approach will help to create a platform on which to improve novice clinicians' skills in prognosis. The case histories will help to test any future training interventions designed to improve outcome prediction.

Accuracy in predicting outcome can help to reduce unnecessary admissions and fast track much needed services. Ultimately this will enhance the quality of care received by patients who are reaching the end of their life.

Background

Overview

According to the report "Deaths in Older adults in England" (2010) there are currently 4.0 million people aged 75 and over. This is projected to increase to 7.2 million in the year 2033. This will increase the demand on the National Health Service and services such as palliative care. The Office of National Statistics reported that there were 499,331 deaths in England and Wales in 2012, a rise of 3.1% with the year before.

The National End of Life Strategy (2008) aims to get health professionals to identify individuals in the last year of their life in order to prepare for the eventual event of death through an Advance Care Plan. This will help to ensure that the patient's wishes are maintained and help reduce the costs and the burdens associated with unnecessary interventions.

The majority of patients wish to die in a familiar setting of a home or care home (Meeussen et al., 2009).The National Bereavement Survey (VOICES) (ONS, 2013) recently stated that whilst people wanted to die at home, hospital was the most common place of death (52%). Further evidence suggests that at least 40% of people dying in hospital had no medical reason to be there (Thomas et al, 2011).

The National Survey of Patient Activity Data for Specialist Palliative Care Services (2013) reported that of those receiving specialist palliative care services, only a quarter (23.9%) died in the acute setting.

These statistics highlight the importance of recognising the dying phase. When prognosis is discussed openly, it can alter the treatment offered. Allowing the family members, patients, and health professionals to engage fully and make informed decisions (Glare & Sinclair, 2008).

Accuracy in predicting outcome can help to reduce unnecessary admissions and fast track much needed services.

Prognosis

The crux of prognosis is the accurate recognition of death by health care professionals. The National End of Life Care Intelligence Network published a report 'Predicting Death' examined deaths in England and Wales (2011); comparing several reports, the 'unexpected death' figure lay between 22% - 42%.

For those who are recognised as dying within the next 72 hours, the Liverpool Care Pathway (LCP) was commonly used as a tool to help with symptom control (Ellershaw & Ward, 2003). It was one of three tools recommended as part of the National Institute for Health and Clinical Excellence guidelines (2004) for promoting high quality end-of-life care.

The recent independent report commissioned on the LCP ("More care, Less Pathway", 2013) has highlighted how imprecise the diagnosis of dying is. It highlighted frequent

problems with patients who are incorrectly placed on the LCP when they are not dying, and those who are not recognised as dying in time. This report suggested further research needs to be completed to improve the accuracy of recognition of death. This finding has been further supported by a review by Parry, Seymour, Whittaker, Bird, & Cox (2013) which concluded there is a lack of research in to the area of prognosis and imminent death.

Clinicians' Estimates

Currently, referrals to palliative services and access to continuing care funding support rely on a prognosis from a clinician. A common theme throughout the literature is that clinicians are inaccurate when it comes to providing these (Chow *et al*., 2001; Clarke *et al*., 2009; Glare *et al*., 2003). Becker *et al* (2007) noted that in a retrospective case note analysis, only a third (36.7%) of cases were recognised as 'dying' by the clinicians on an average of 3.8 days before death. This inaccuracy impacts the speed at which a patient is referred to palliative care services to receive specialist support both physical symptoms and for emotional support (Franks et al., 2000).

This study has been developed in response to recent reports which highlight the need for more evidence-based research in the area of prognosis and improving clinicians' estimates of survival. Previous studies have looked at how accurate clinicians are at predicting survival, but very few have concentrated on the last 72 hours of life. Previous studies have addressed what signs and symptoms are prevalent at the end of life and might predict the outcome, but none have looked at how clinicians use this information to formulate their prognosis. No previous study has specifically set out to identify which clinicians are best at prognostication, nor attempted to improve the performance of non-experts.

This 3 year PhD will be formed of two studies. The results of the study one will inform the development of the next study.

Study 1 – Creating the anonymous vignettes and identifying the 'expert' clinicians

The first phase will be a prospective observational cohort study of 50 patients referred to palliative services. The information gathered will be incorporated in to a series of case histories ("vignettes") to use in study 2. All patient identifiable information will be removed from the vignettes.

Each vignette will represent one participant and will contain information that clinicians usually have access to in order to predict an outcome.

This set of anonymous vignettes will provide the basis of the electronic survey for the PhD.

The vignettes will be administered to palliative care clinicians nationally. Each clinician will be asked to read the vignettes and give a percentage likelihood of survival for the next 72 hours.

From this, we aim to obtain an 'expert' population as well as identify potential symptoms and factors which may predict imminent death and/or how experts make their decisions.

Study 2 – Understanding how experts formulate a prognosis

Each expert will be interviewed briefly about what factors they feel are important when formulating a prognosis. The factors that are considered to be the most likely candidates will be developed in to a series of artificially constructed vignettes. The experts will then be presented with these artificial vignettes and asked to predict which patients they consider to have the worse prognosis. By statistically analysing the experts' responses to these vignettes we will be able to tease out which factors they are using to arrive at their judgments and how much importance they attach to each factor.

Research Objectives

Overall Objectives

The main aim of this PhD is to identify clinicians who are best at predicting survival and to investigate what factors they use to arrive at their predictions.

This will be completed through 3 stages:

- Creating a series of vignettes that reflect real patients who are referred to palliative care
- Identifying individuals who are deemed as 'experts' at predicting outcomes.
- Understanding what factors the 'experts' use to make decisions.

These insights will allow us to devise a training programme to teach other clinicians how to make a prognostic estimate like the "experts". Ultimately this will enhance the quality of care received by patients who are reaching the end of their life.

Specific Objectives for Study 1

- To produce a series of 50 suitable case vignettes of patients referred to palliative care services.
- Identify clinicians who are "experts" at giving a prognosis by asking them to read the anonymous case vignettes, through an electronic survey, and predict likelihood of surviving the next 72 hours.

Specific Objectives for Study 2

- To produce a series of artificial vignettes based on the factors the clinicians identify as being important when making a prognosis.
- Through Judgment Analysis, tease out the factors that clinicians are using when formulating a prognosis.

This is an application for study 1 only.
A separate ethics application will be made for study 2.

Methods

Location

Recruitment for the vignettes will take place at St George's Hospital in South London, and in the Marie Curie Hospice in North London. These two sites encompass an ethnically and socioeconomically diverse population.

Recruitment of clinicians will take place through an electronic survey, administered to Palliative Care Clinicians across the UK who are registered with the Association of Palliative Medicine (APM).

Sample Size

Vignettes

We require 50 case histories or "vignettes" (25 patients who died within 72 hours and 25 patients who survived 72 hours). This may require us to collect data on more than 50 patients.

When calculating the sample size for participants, we took various factors in to consideration:

Burden for participants

This was the main factor when considering how the number of vignettes to gather. We did not want to recruit participants unnecessarily.

Previous research

Rassafiani *et al* (2009) sampled 18 Occupational Therapists on a total of 110 case vignettes, which took two and a half hours to complete. We feel that this burden of time is not acceptable for the initial screening phase for experts. Particularly as we will be relying on the experts identified to be willing to sacrifice their time to participate further in study 2.

Implications for the Electronic Survey

Previous studies using the method of Judgement Analysis have varied widely in their sample sizes. In many of these studies (Harries, Tomlinson, Notley, Davies, & Gilhooly, 2012; Unsworth, 2007) the expert population have already been defined by years of employment. We are looking to identify the experts through these case vignettes, rather than assuming length of employment means better prognostication skills. If we assume a chance estimate of 50% for the clinicians correctly guessing death within 72

hours, we feel that gathering a cohort of 50 patients in study 1 will identify experts incorporating this.

The APM has approximately 1000 members across the UK. If we assume a response rate of approximately 40% (Corkum, Viola, Veenema, Kruszelnicki, & Shadd, 2011), this will give us a sample size of 400 clinicians from which to identify experts and invite to study 2.

Participant selection

Vignettes

It is expected that data collection should take place over a period of 12 months**.** Every referral that is made to the palliative care team will be screened for suitability. The referring clinician will be asked the following: "Would you be surprised if this patient died within the next two weeks?" For those where the answer is 'No', the palliative care team will speak with the patient or, if necessary, their relatives. Only if the patient or relative are willing to speak to the researcher, will the palliative care specialist contact the researcher.

Inclusion Criteria

- Over 18
- Referred to palliative care team
- "No" to surprise question
- Enough English language to understand the study

Exclusion Criteria

- Under 18
- "Yes" to surprise question
- Patients indicate they do not wish to participate either verbally or through an advanced directive
- Not enough spoken English language

Electronic Survey

Clinicians will be approached to participate based on their membership with the Association of Palliative Medicine (APM). This will be through an email invitation distributed through the membership network.

Consent Procedure

Vignettes

We seek to adopt the consent process of Gibbins et al (2013) and Scott, Jones, Blanchard, & Sampson (2011) in which a patient, who was admitted to hospital and identified as likely to die during the admission, was approached about participating and had their capacity assessed.

The consulting palliative care specialist will assess the patient before contacting the researcher. They will see if the patient is willing to meet and discuss the study with the researcher. In cases of unconsciousness, the palliative care specialist will contact the relatives to see if they are willing to discuss the study with the researcher.

If they are willing to discuss the study, the researcher will give the patient a short information sheet and explanation of what the study is and will ask the patient if they would like to participate. If they refuse at this point, no more contact will be made with them. If they agree, the researcher will assess their capacity to provide informed consent, using the Mental Capacity Act (MCA) guidelines.

They will be informed that they can withdraw at any point if they choose to without any effect on their care. Each participant will be given 24 hours to decide if they wish to participate. However, since this study is time sensitive and does not require participants to undergo any additional investigations / treatments or to complete any questionnaires / interviews, it is likely that many patients / relatives will prefer to provide consent / assent immediately. In these circumstances patients / relatives will not be required to wait 24 hours before giving consent / assent but will be able to withdraw at any point.

In the presence of capacity, they will be asked to sign a consent form if they are willing to participate. In the absence of capacity, the researcher will ask the patient for permission to contact the next of kin.

Assent from the next of kin shall be obtained from two methods:

Either

a) On the ward if they are present or due to attend with the patient. They will be given an Information Sheet about the study as well as the opportunity to ask questions. The researcher will ask them to consider the wishes of the patient regarding participation in research. They will be informed that they do not need to give an answer immediately if they do not wish to and that the researcher will return in 24 hours. If they assent for the patient to participate, they will be asked to sign an agreement form.

b) If the next of kin is unable to attend the hospital the researcher will seek verbal assent over the phone. This is due to the time sensitive nature of the research and need to obtain information from the healthcare professionals attending to the patient in a timely manner. Data collection will begin from the point of verbal agreement. An agreement form and Information Sheet will be sent to the next of kin with a prepaid envelope. If the agreement form is not returned within 2 weeks, a reminder letter shall be sent to the next of kin. If no response is received, it shall be assumed that consent has been withdrawn and the data collected will be destroyed in lines with GCP guidance.

The outcome of the participation will be documented in the patient's medical records to prevent duplication of approaching and to inform the medical team of the research involvement. (See Appendix 1 for consent procedure flowchart).

Once consented in to the study, one researcher (the PhD Student) will collect the data on all participants.

Electronic Survey

Before completing the electronic survey, clinicians will be asked to read through the electronic information sheet and to tick the box to indicate consent.

They will be asked to provide contact details for themselves and will be informed that there will be the potential to participate further. They will be asked some basic demographic questions: age, gender, geographic location, position held, and length of time working in palliative care.

The contact details of the Chief Investigator will be available to the clinicians if they have any questions and it will be explicit that they can withdraw or stop the survey at any time.

Measures

Vignettes

It is important that the data collected will reflect all aspects of the patient's condition in order for the clinicians to formulate a prognosis. All data will be derived from information collected from the medical team, no additional tests or interventions will be completed. This information will be collected for up to 7 days or until death, whichever occurs first.

The following information will be gathered:

1. Age and gender
2. Diagnosis and extent of disease
3. Extent of on-going treatment (e.g. IV fluids, antibiotics, other treatments)
4. Resuscitation status
5. Rapidity of change in condition
6. Conscious level
7. Oral intake
8. Symptom severity - pain, breathlessness, noisy breathing, restlessness, delirium
9. Performance status (using the palliative performance scale)
10. Full blood count and biochemistry results if available
11. Narrative description of patient's general condition

Before implementing this data collection tool, it will be examined by two senior palliative care clinicians to ensure face validity and that nothing obvious was missed. The same clinicians will then be asked to look over the first 3 participants in the study to ensure the validity and reliability of the data collected.

From the medical notes

Medical notes will be checked in order to gather the information stated above. Basic demographical data about each participant will be recorded.

From the healthcare professionals

The healthcare professionals assigned to care for the patient will be asked on the overall condition of the participant and whether they have noticed any changes in his/her condition. They will also be asked to estimate the participant's prognosis for the next 72 hours.

Construction of the Vignettes

Each vignette will represent one participant and will be a one page summary containing the above measures collected during each participant's admission. As previously mentioned, it is important that the information presented is representative of the information that a clinician would have access to when asked to make a prognosis.

Similarly to the data collection tools, the first 3 vignettes will be assessed by two senior palliative care consultants for face validity.

Construction of the Survey

An online assessment has been developed as the basis of the survey.

Prior to starting the assessment, there will be an introductory section that states:

Welcome to the P:CES website

Background

"Improving clinicians' ability to recognise the dying phase was one of the key priorities identified by the independent review into the Liverpool Care Pathway chaired by Baroness Neuberger. It is known that clinicians, in general, are inaccurate at estimating survival in palliative care patients. Despite this, there is no clear guidance about how clinicians can be taught to improve their performance on this clinical skill. This study will help us to identify those clinicians who are most accurate at prognosticating. We will then use this information to help to develop an educational package aimed at improving the prognostic skills of other clinicians.

This project has been reviewed and given favourable opinion by West Midlands - Coventry & Warwickshire Research Ethics Committee on 9th May 2014 (reference 14/WM/0121). This project is sponsored by University College London (UCL) and Marie Curie. This is a PhD project. The student is Nicola White. Professor Paddy Stone, Dr Adam Harris, and Professor Priscilla Harries are supervising this project.

Why have you been asked and what does it involve?

- You have been invited to participate in this assessment because you are a clinician with experience of caring for palliative care patients.
- The case studies that you will see are anonymised real cases of patients who were referred to Palliative Care Services.
- You will be presented with a series of case studies and you will be asked to provide an estimate for the probability that the patient will die within the next 72 hours.

- The task will take approximately 60 minutes to complete. However, you can take as long as you need for each case. You are also able to log out and return at a later time to complete the task.
- The accuracy of your estimates will be compared against the actual outcome of the cases.
- You will receive a certificate of participation on completion.
- The participants who are amongst the top performing clinicians will be contacted again after the survey."

The next page on the assessment will ask the participant to provide consent to participate and a contact email address.

The next page will ask clinicians for basic demographic information.

The next page is an instruction page to inform the clinicians how to complete the test:

"The case scenarios used in this assessment are all real patients who were referred to Palliative Care Services. Additional information relating to each case (for example: medication charts, blood test results and observations) are available at the end of each vignette.

We would like you to read each scenario and provide your response to the following question;

"What do you think the probability is that this patient will die within the next 72 hours?"

We appreciate that in routine practice, you would usually want to see the patient face-to-face before answering such a question. However, we are interested in your initial impressions based on the clinical information that is available to you. This may be similar to the situation that occurs when cases are discussed at a multi-disciplinary team meeting or when referral forms are considered at a hospice - or other situations when you need to make a prognostic estimate without the opportunity to undertake a clinical assessment yourself.

After the scenarios, at the bottom of each page, there is a box provided for you to indicate your estimate about the probability that the patient will die within the next 72 hours. You will not be able to move on to the next scenario until this information is provided.

Key Points:

- Please give each scenario a percentage score ranging from 0 (certain survival) to 100 (certain to die) for the next 72 hours.
- Please give each scenario a number ranging from 0 (you think the patient will die today) to >=365 (you think the patient will die after a year)
- There is no time limit for each case; however we are interested in your initial response to the information presented to you, so try not to spend too long on each one.
- Please judge each scenario as if it were your own case.
- You should undertake the task independently and not ask opinions from others during the task itself.
- It is best if you do the task without taking a break, however you are able to log off and return at a more convenient time if you need to.
- Please click on the continue button, not the back or refresh controls whilst working through the scenarios.
- You cannot return to earlier recommendations.

You will now have a practice scenario "

The clinician will then be asked to complete a practice vignette in order to familiarise themselves with the format of the assessment.

The clinician will be offered a certificate of completion.

Statistical Analysis

Analysis of the vignettes

An exploratory analysis will be conducted to examine the predictive power of the data collected and the occurrence of imminent death. Multiple regression analysis will be used with the outcome variable of death within 72 hours.

Analysis of the electronic survey

Each clinician will be asked to give a percentage of risk for each of the presented vignettes. Using a technique developed in weather forecasting (Brier, 1950), we will calculate a score for each clinician ranging from 0 to 1. This is known as the probability score or 'Brier Score'. This helps to calculate not only accuracy but consistency of decision making and discrimination between those who die and those who do not (Arkes et al., 1995; Mackillop & Quirt, 1997; Rakow, Vincent, Bull, & Harvey, 2005). A score of 0 indicates greater accuracy.

Experts will be judged as the top 10-25% scoring the closest to 0.

Exploratory analysis using multiple regression will also be able to highlight potential factors that the expert clinicians may be using to make their prognostic decision.

This information will help to form the basis of the next study.

Ethical Considerations

1. People who lack capacity

Duke & Bennett (2010) completed a systematic review of the issues involved with recruiting in palliative care. They discuss the issues of gate-keeping, vulnerability, and consent. As suggested by Gibbins et al. (2013) by refusing people the opportunity to participate in research, we are not providing a vulnerable population with the evidence-led care they deserve.

It is important that this study includes patients who lack capacity because many patients at the end of their lives become confused, semi-conscious or comatosed. Since the purpose of this study is to determine whether clinicians are able to predict which patients are likely to die, it is important that the study population is representative of the type of patients commonly seen in terminal care. We have

used guidance from the Mental Capacity Act and previous research that have recruited from a similar environment with a similarly vulnerable patient group. We do not wish to exclude a population for whom this study is aimed at helping. Therefore we have included a personal consultee to provide assent, which will be the designated next of kin.

2. The extra burden of participating in research when approaching the end of life and medically unwell

This study is not a trial or intervention. The measures taken are part of routine clinical care and should not increase the burden on the patients. The patient will not need to undergo any additional tests or interventions as a result of participating in this study. The patient, or their personal consultee, can withdraw at any time should they feel the burden is too much.

3. Knowledge and awareness of palliative care

Some patients or family members may not understand what palliative care means. All patients who are screened for eligibility to the study will have already been referred to the palliative care services and been assessed by a palliative care specialist prior to seeing the researcher. To avoid causing undue distress to potential participants, we have taken steps to ensure that the language used in the patient / carer information sheets is not insensitive. In the event that provision of information about the study were to cause distress, the patient and family member will be referred to the attending Doctor or nurse so that they have access to the necessary support.

4. Confidentiality

The vignettes will contain all relevant clinical data that the clinicians will look at routinely to provide a prognosis. All patient identifiable information will be removed. Since it is (at least theoretically) possible that patients with rare diseases or unusual clinical features may be identified inadvertently, care will be taken to exclude such patients from the study.

All data that is gathered from the patients and healthcare professionals will be anonymous in accordance with the Declaration of Helsinki. It will be stored on a password protected database and paper copies will be kept securely in a locked cabinet.

5. Follow up

The follow up for this study has been kept to a minimal to lessen the burden of participating in the research. Participation in the study is for seven days and the data will be collected from the medical notes or from the health care professionals.

Benefits of the study

Overall

This novel approach to assessing clinician's estimates will help us to understand what information expert clinicians use when they are formulating a prognosis. Creating a platform on which to improve novice clinicians' skills in prognosis, and test any future training interventions designed to improve outcome prediction.

Accuracy in predicting outcome can help to reduce unnecessary admissions and fast track much needed services. Ultimately this will enhance the quality of care received by patients who are reaching the end of their life.

Study 1 benefits

Study 1 will produce a series of genuine referrals to palliative care which will be able to test the effectiveness of future educational intervention designed to improve prognosis. The electronic survey will give preliminary information as to the factors that clinicians may be using to make a prognosis. It will also add to previous research by exploring potential predictive factors of imminent death.

Resources and costs

No payments will be made for participating in this study.

Insurance and indemnity

University College London holds insurance against claims from participants for harm caused by their participation in this clinical study. Participants may be able to claim compensation if they can prove that UCL has been negligent. However, if this clinical study is being carried out in a hospital, the hospital continues to have a duty of care to the participant of the clinical study. University College London does not accept liability for any breach in the hospital's duty of care, or any negligence on the part of hospital employees. This applies whether the hospital is an NHS Trust or otherwise.

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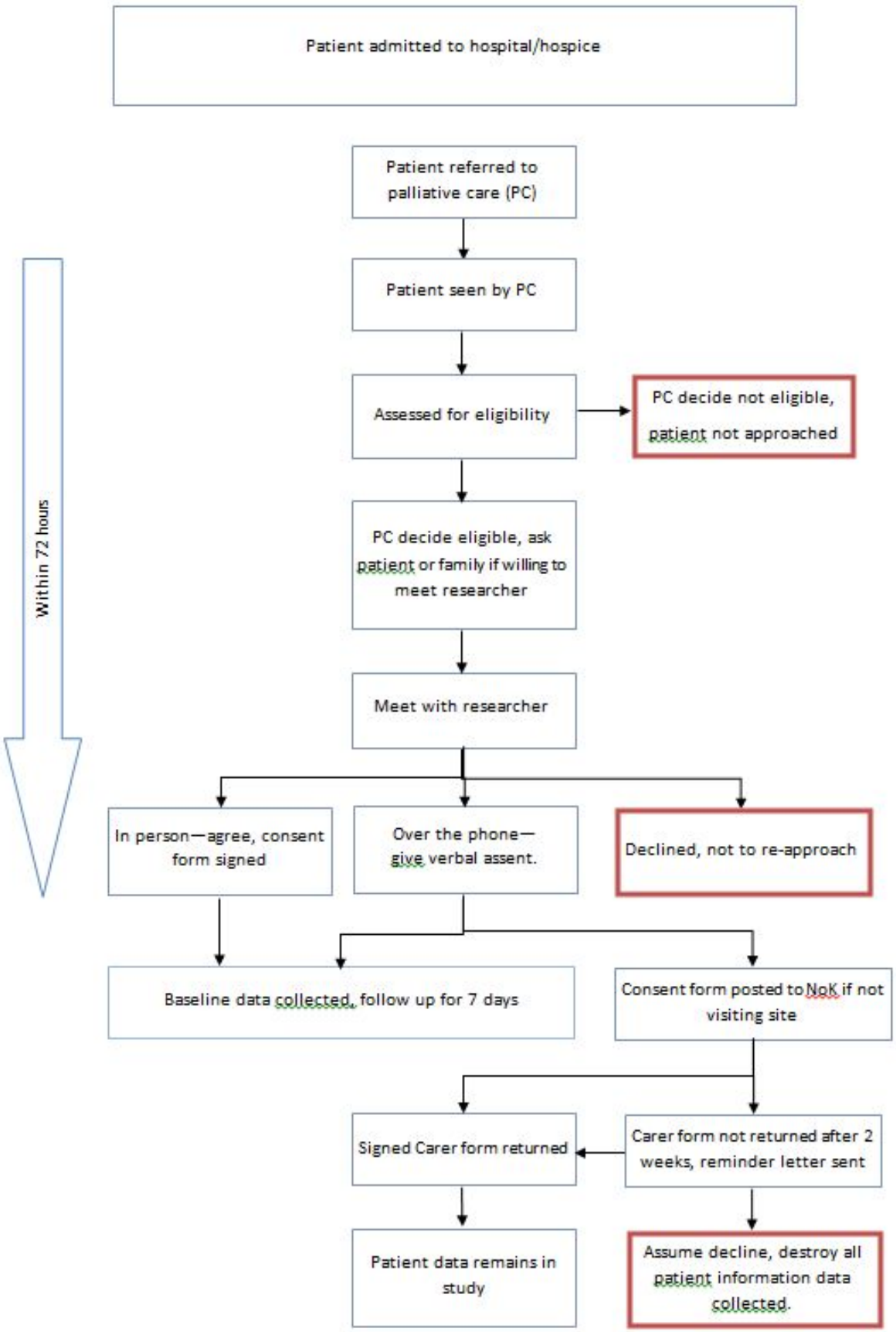
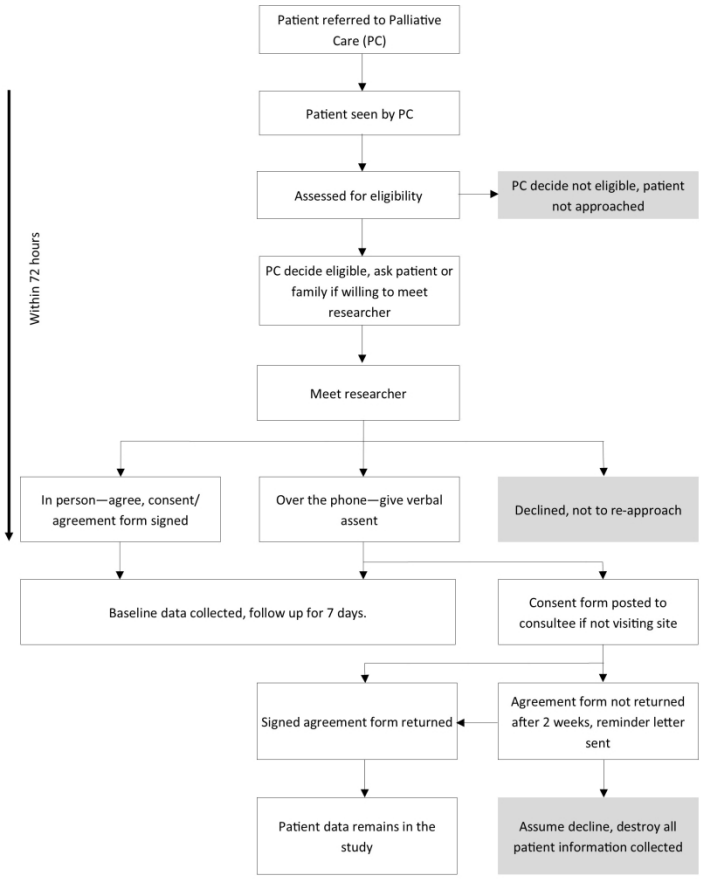
Appendix 1: Consent Flow Chart for Patient Recruitment





209x297mm (300 x 300 DPI)

P:CES Study

PID: _ _ **Site** *(circle):* **SGH / MCH** **Date:** _ _ / _ _ / _ _ _

Demographics

4. Age _ _ _ (years) **5. Gender** (*circle)* MALE / FEMALE **6. DOB:**

7. Date of Admission _ _ / _ _ / _ _ _ _ **8. Marital Status:** Single ☐ Widowed ☐ Married ☐ Divorced ☐

9a. Resuscitation Status: **9b. Date DNAR signed** *(if applicable)*

10. Ethnicity *(circle)*	**White**	**Mixed/Multiple ethnic group**	**Asian/Asian British**	**Black / African / Caribbean / Black British**	**Other ethnic group**
	English / Welsh / Scottish / Northern Irish / British	White and Black Caribbean	Indian	African	Arab
	Irish	White and Black African	Pakistani	Caribbean	Any other ethnic group, *(please describe)*
	Gypsy or Irish Traveller	White and Asian	Bangladeshi	Any other Black / African / Caribbean background, *(please describe)*	
	Any other White background *(please describe)*	Any other Mixed / Multiple ethnic background, *(please describe)*	Chinese		
			Any other Asian background *(please describe)*		

11a. Reason for admission: **11b. Source of admission** *(e.g. a+e, gp referral, clinic)*

12. Primary Diagnoses:

13. Charlson Co-Morbidity Index *(circle)*

Myocardial infarct	1	Hemiplegia	2
Congestive heart failure	1	Moderate or severe renal disease	2
Peripheral vascular disease	1	Diabetes with end organ damage	2
Cerebrovascular disease	1	Any tumour	2
Dementia	1	Leukaemia	2
Chronic pulmonary disease	1	Lymphoma	2
Connective tissue disease	1	Moderate or severe liver disease	3
Ulcer disease	1	Metastatic solid tumour	6
Mid liver disease	1	AIDS	6
Diabetes	1	TOTAL	

14. Medical Team prognosis of next 72 hours

"Do you think it is likely that this person will die in the next 72 hours?"

	Yes	No	Unsure		Yes	No	Unsure		Yes	No	Unsure
Nurse	☐	☐	☐	Doctor	☐	☐	☐	Palliative Care Specialist	☐	☐	☐

Percentage certainty:

Job title(s) of person/people stating prognosis:

P:CES Study

PID: _ _ **Site** *(circle):* **SGH / MCH** **Date:** _ _ / _ _ / _ _ _

15. Patient Symptoms

Please mark the following symptoms for the patient.
This information will be available from the medical notes, medical team, or from seeing the patient.

a. Respiration

	Yes	No	N/A
Complaint of shortness of breath	☐	☐	☐
0^2 sats	**Level:**		☐

	Yes	No
Noisy respiratory secretions	☐	☐
Cheyne-stokes respiration	☐	☐
Abdominal Swelling	☐	☐
Respiration with mandibular movement (jaw moving)	☐	☐

b. Blood Circulation

		N/A
Heart Rate	Pulse:	☐
Blood Pressure	BP:	☐
Fever	Temp:	☐

	YES	NO	N/A
Pulselessness of radial artery	☐	☐	☐
Peripheral Cyanosis (blue extremities)	☐	☐	☐
Pointed nose	☐	☐	☐

	Yes	No
Change in skin	☐	☐
Colour	☐	☐
specify		
Temperature	☐	☐
specify		
Moisture	☐	☐
specify		

c. Physical Condition

In consciousness:	Yes	No	N/A
Extreme tiredness	☐	☐	☐
Insomnia	☐	☐	☐
Surges of energy	☐	☐	☐
Rapid degradation of general condition in the last 24 hours	☐	☐	

Skin Integrity

	Yes	No
Infected wounds	☐	☐
Pressure Sores	☐	☐
Grade of Sore:		
Clinical signs of infection	☐	☐
Possible source?		

d. Excretion

	Yes	No	N/A
Is there a catheter in situ	☐	☐	
Is there a stoma in situ	☐	☐	
Urinary incontinence, *if applicable*	☐	☐	☐
Faecal incontinence, *if applicable*	☐	☐	☐
Concentrated urine	☐	☐	☐

	Yes	No	N/A
Vomiting	☐	☐	☐
Altered defecation - diarrhoea	☐	☐	☐
Altered defecation - constipation	☐	☐	☐
Decreased production of urine	☐	☐	☐
amount in last 24hrs			

e. Oral Intake

	Yes	No	N/A
Decreased eating	☐	☐	☐
Decreased drinking	☐	☐	☐

If the patient is conscious:	Yes	No	N/A
Refusal of food	☐	☐	☐
Swallowing Difficulty	☐	☐	☐
Loss of appetite	☐	☐	☐

f. Pain

In consciousness:	Yes	No	N/A
Patient complains of pain	☐	☐	☐
Do you think the patient has pain?	☐	☐	☐
Pain is less responsive to treatment	☐	☐	☐

Circle the pain level patient is reporting:
mild moderate severe

Circle the pain level you feel the patient is in:
mild moderate severe

P:CES Study

PID: _ _ **Site** *(circle):* **SGH / MCH** **Date: _ _ / _ _ / _ _ _**

g. Consciousness / Psychological Condition / Spiritual

Richmond Agitation Sedation Scale (RASS)

Please circle which category currently represents the patient

+4	Combative	Overtly combative, violent, immediate danger to staff	
+3	Very Agitated	Pulls or removes tube(s) or catheter(s); aggressive	
+2	Agitated	Frequent non-purposeful movement, fights ventilator	
+1	Restless	Anxious but movements not aggressive vigorous	
0	Alert and Calm		
-1	Drowsy	Not fully alert, but has sustained awakening (eye-opening/eye contact) to voice (>10 seconds)	Verbal Stimulation
-2	Light Sedation	Briefly awakens with eye contact to voice (<10 seconds)	
-3	Moderate Sedation	Movement or eye opening to voice (but no eye contact)	
-4	Deep sedation	No response to voice, but movement or eye opening to physical stimulation	Physical Stimulation
-5	Unarousable	No response to voice or physical stimulation	

How to complete the RASS:

1. Observe patient

a. Patient is alert, restless, or agitated. **(score 0 to +4)**

2. If not alert, state patient's name and *say* to open eyes and look at speaker.

b. Patient awakens with sustained eye opening and eye contact. **(score –1)**

c. Patient awakens with eye opening and eye contact, but not sustained. **(score –2)**

d. Patient has any movement in response to voice but no eye contact. **(score –3)**

3. When no response to verbal stimulation, physically stimulate patient by shaking shoulder and/or rubbing sternum.

e. Patient has any movement to physical stimulation. **(score –4)**

f. Patient has no response to any stimulation. **(score –5)**

	Yes	No	N/A		Yes	No	N/A
Confusion	☐	☐	☐	Recoil behaviour (withdrawn)	☐	☐	☐
Delirium	☐	☐	☐	Acceptance of death	☐	☐	☐
Anxiety/fear	☐	☐	☐	Patient is saying goodbye to family	☐	☐	☐

16. Narrative description of patient's overall condition and general presentation

P:CES Study

PID: _ _ **Site** *(circle):* **SGH / MCH** **Date: _ _ / _ _ / _ _ _**

17. Palliative Performance Scale

Please circle an option from each column which represents the patients current ability

Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious level
Full	Normal activity & work No evidence of disease	Full	Normal	Full
Full	Normal activity & work Some evidence of disease	Full	Normal	Full
Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
Reduced	Unable Normal Job/Work Some disease	Full	Normal or reduced	Full
Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or confusion
Mainly sit/lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or confusion
Mainly in bed	Unable to do any activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Reduced	Full or Drowsy +/- Confusion
Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or coma +/- Confusion
Death	-	-	-	-

18. Other

Please include any other information you feel may be relevant to the patient's condition e.g. family's intuitive feelings if offered, sudden change in the patient's condition.

19. Information about patient on admission

P:CES Study

PID: _ _ **Site** *(circle):* **SGH / MCH** **Date: _ _ / _ _ / _ _ _**

e.g. functional ability, treatments, number of previous admissions

BMJ Open

The (un)availability of prognostic information in the last days of life: a prospective observational study

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Primary Subject Heading:	Palliative care
Secondary Subject Heading:	Palliative care
Keywords:	PALLIATIVE CARE, Dying, Prognosis

The (un)availability of prognostic information in the last days of life: a prospective observational study

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Word count: 2,931

Abstract

Objectives: The aims of this study were (1) to document the clinical condition of patients considered to be in the last two weeks of life and (2) to compare patients who did or did not survive for 72 hours.

Design: A prospective observational study.

Setting: Two sites in London, UK (a hospice and a hospital palliative care team).

Participants: Any inpatient, over 18 years old, English speaking, who was identified by the palliative care team as at risk of dying within the next two weeks was eligible.

Outcome measures: Prognostic signs and symptoms were documented at a one off assessment and patients were followed up 7 days later to determine whether or not they had died.

Results: Fifty participants were recruited and 24/50 (48%) died within 72 hours of assessment. The most prevalent prognostic features observed were a decrease in oral food intake (60%) and a rapid decline of the participant's global health status (56%). Participants who died within 72 hours had a lower level of consciousness and had more care needs than those who lived longer. A large portion of data was unavailable, particularly that relating to the psychological and spiritual wellbeing of the patient, due to the decreased consciousness of the patient.

Conclusions: The prevalence of prognostic signs and symptoms in the final days of life has been documented between those predicted to die and those who did not. How doctors make decisions with missing information is an area for future research, in addition to understanding the best way to use the available information to make more accurate predictions.

Strengths and limitations of this study

- An observational study that prospectively documented prognostic signs and symptoms in relation to survival of 72 hours.
- Highlights the prevalence of missing data in palliative care.
- The results reflect only the participants that were recruited as part of this study, those who were referred to specialist palliative care. Other results might have been prevalent in a different population.

Background

Caring for a dying person is a core skill required of every doctor and healthcare professional.[1] Part of this competency is to be able to recognise when the person is dying in order to facilitate a "good death".[2] Recognising this terminal phase can enable the dying person to spend time with their loved ones in a location of their choice. The 'More Care; Less Pathway' report [3] alongside other research [4, 5] has highlighted that medical teams are not very accurate at recognising when patients are (or are not) imminently dying.

One way to improve this skill, is to teach staff which signs and symptoms are most prevalent at the end of life. There are a number of reports from organisations such as The National Council for Palliative Care and the National Institute for Health and Care Excellence (NICE), which present narrative summaries of the symptoms and signs that are most common during the last few days of life.[6-11] Previous research and systematic reviews have identified which signs and symptoms are prevalent among patients dying from cancer [12-18] or other diseases.[19-27] Interviews or surveys with health professionals have also been used to determine which signs or symptoms staff believe are most indicative of imminent death.[28-31] From the literature it appears that common signs include changes in breathing patterns, altered consciousness, agitation, changes to the appearance of the skin, incontinence or reduced urinary output, changes in functional ability and social withdrawal.. Common symptoms include tiredness, reduced appetite, and confusion.

Despite this body of evidence regarding signs and symptoms, these findings have not translated in to practice; medical teams continue to be inaccurate at recognising imminent death.[3] It has been highlighted from recent reports that evidence regarding the clinical presentation of people who were predicted to die, but subsequently did not, is lacking.[3, 4] Finally, findings from palliative care research highlight the high degree of missing or unavailable data.[32] If the common signs and symptoms identified from previous research are not available, or are missing, in the final days of life, then just how is death recognised?

This study was the first stage of a larger study investigating the recognition of dying [33].

Objectives:

1) To prospectively document the clinical condition of patients considered to be in the last two weeks of life.
2) To compare the clinical condition of patients who did or did not survive for 72 hours.

Methods

A prospective observational study of patients referred to specialist palliative care. This study follows STROBE reporting guidelines (see Supplementary File 1). The original protocol for the study is in Supplementary File 2.

Settings

Recruitment took place at two palliative care services in London, UK (a hospice and a hospital) between January 2015 and October 2015.

Participants

All inpatient referrals to the palliative care team were screened by their respective clinical teams for eligibility. Palliative care was selected as the specialty to mitigate risk that the death would be sudden or unexpected.

Inclusion criteria:

1. 18 years old and over.
2. Identified by the palliative care team as likely to die in the next two weeks.
3. The patient or family could speak enough English for the researcher to discuss the study.

Exclusion criteria:

1. Assessed as not suitable to approach by the clinical team (i.e. discussing the research would cause too much distress)
2. Lacked capacity, and no personal consultee (family member) available
3. Refused to participate, either verbally or through an advance directive

Sample Size

This study formed part of a programme of research designed to devise a test for assessing clinicians' prognostic accuracy.[34] For the purpose of devising a prognostic test [33] it was necessary to obtain data from at least 20 patients (10 of whom died and 10 of whom survived for 72 hours). To ensure that at least 20 cases were suitable for inclusion in the study to devise a prognostic test we aimed to recruit approximately 50 cases in total. The final sample was determined by the number of inpatient referrals who were eligible and willing to participate during the study recruitment period.

Patient & Public Involvement

Feedback on the protocol was sought from a consumer research panel (South West London Cancer Research Group). The suggestions from the group were reflected in the study protocol, specifically the study information sheets.

Ethical issues

This study received approval from West Midlands – Coventry and Warwickshire Research Ethics Committee in May 2014 (14/WM/0121).

Recruiting people who are at the ends of their lives presents ethical challenges. In both the hospice and hospital, this may have been the first time that the individual had been referred to palliative care. An inclusion criterion for the study was that the patient was considered to be likely to die within two weeks. This information had the potential to cause upset to both the family and the patient, unless it was handled sensitively by clinical staff. We addressed these concerns by allowing clinical teams to exclude potentially eligible patients if they judged that discussing the research would cause too much distress. Since this study did not require a consecutive series of patients, it was not felt to affect the integrity of the study to allow clinical teams the discretion to operate this form of research "gate-keeping".

Consent procedure

We expected a high number of participants to be unconscious or unresponsive and, as a consequence, to lack capacity. We adhered to the Mental Capacity Act [35] guidelines for recruiting patients without capacity. We also mirrored the approach taken in a similar study that had recruited patients admitted to the acute setting.[36]

If the clinician felt that involvement in the study would not cause distress, the clinician asked the patient, or their family member, if they wished to meet the researcher to discuss taking part in the study. If they agreed to this, the researcher briefed the patient and/or their family member about the research and obtained either informed consent or personal consultee agreement.

Due to the time sensitive nature of the research, there was no enforced delay between informing the patient about the study and seeking consent to participate. Each patient who entered the study was informed that they could withdraw at any time, without reason and without consequence to their care. It was possible to gain telephone advice from a personal consultee should they not live locally. If telephone advice was obtained, an information sheet and a "documentation of advice" form were posted to the family member with a return address. If the form was not returned, or was returned incomplete, the data pertaining to that patient were removed from the database and destroyed (see Supplementary File 3).

Procedure

All participants, upon entering the study, underwent a single observer-rated assessment of key prognostic features (see below), medications, and overall condition. Information regarding their medical history, their reason for admission, and their demographic details were extracted from the medical notes. Data regarding signs and symptoms over the last 24 hours were obtained from direct observation of, or discussion with, the patient or from discussing their care with medical or nursing staff.

Measures

We collected data on prognostic variables that had previously been identified from the literature. We used validated measures to record agitation or sedation, functional ability, and co-morbidities.

Richmond Agitation Sedation Scale (RASS)

This scale assesses patients' level of agitation or sedation. The scale ranges from +4 (combative) to -5 (unarousable). The RASS has high validity and reliability within a hospital setting.[37] This measure has previously been used in mortality research.[38] It distinguishes in greater detail than other scales the different levels of sedation.

Palliative Performance Scale

This scale is used to assess palliative care patients' functional ability.[39] It consists of five domains; Ambulation, Activity & Evidence of Disease, Self-Care, Intake and Conscious Level. Scores can range between 10% (fully dependent) to 100% (fully independent). A decrease in the patient's functional ability has been shown to predict death.[40]

Charlson Co-morbidity Index (CCI) score

This score summarises the severity of chronic comorbidities. It includes 19 diseases that are weighted by their association with mortality. Higher scores reflect a greater number and/or severity of comorbidities.[41] This was obtained from the patient's medical records. The CCI has been shown to predict short and long term mortality.[42]

Clinical signs and symptoms

As we wanted to provide a rich description of the patients who were potentially in the final days of life, we included all symptoms and signs that have previously been identified as being potentially predictive of the dying phase:[12, 14-16, 19-22, 24-26, 28-30]

- Respiration (rate and character)
- Blood Circulation (pulse rate, blood pressure, peripheral perfusion, cyanosis)
- Physical Condition (performance status, mobility)
- Skin Integrity
- Excretion (continence, presence of indwelling catheter)
- Oral Intake
- Pain
- Consciousness (level of sedation or agitation)
- Psychological / Spiritual condition
- Other

The full list of clinical signs and symptoms recorded is shown in Supplementary File 4.

We reported on the prevalence of missing data, which are common in palliative care studies.[32] For example, for several self-reported symptoms it was not possible to obtain an answer for patients who were unconscious, unless the patient's family members or attending nurse were able to act as a proxy provider of information. This was particularly common when assessing the psychological state of the participant. Similarly, when a patient had a urinary catheter or a stoma, it was not possible to determine continence level.

Main Outcome

The main outcomes of interest were the characteristics of patients who did and did not die within 72 hours of assessment. Each participant was followed-up seven days after the day of observation. During this time, if the participant died, the date of death was recorded.

Analysis

The purpose of this study was to describe the presence or absence of key prognostic features in patients who were or were not dying, under the care of palliative care services, rather than to test specific hypotheses about differences between sub-groups of participants. Therefore, to avoid over-interpretation of our data, no statistical tests have been performed to assess for such differences. Results have been summarised using descriptive statistics.

Results

Recruitment

In total, 60 patients were approached to participate in this study (see Figure 1). Ten were not included because; they had died before the researcher could see them (n=5); they had declined to participate (n=3); or they had no personal consultee available (n=2). Therefore 50 patients were included in this analysis, of whom 24 (48%) died within 72 hours of assessment.

Figure 1: Recruitment flowchart

Participant characteristics

The characteristics of participants recruited are presented in Table 1.

Table 1 Participant characteristics

Demographics	**Total**
	n (%)
Participants	50 (100)
Gender	
Male	30 (60)
Female	20 (40)
Age (mean, sd)	72.0 (16.60)
Ethnicity	
White British	36 (72)
Other	14 (28)
Cancer diagnosis?	
Yes	33 (66)
No	17 (34)
Charlson score (mean, sd)	5.43 (2.05)
Length of survival	
Less than 72 hours	24 (48)
More than 72 hours	26 (52)

By site

The patients in hospital were older compared to the hospice (mean 76 years, sd 16 vs 64, sd 14) with a higher prevalence of non-cancer diagnoses (48% vs 11%). They had fewer serious comorbidities than the patients from the hospice (CCI mean 5.0, sd 2.1 vs 6.2, sd 1.8) and more patients died within 72 hours within the hospital (65% vs 21%).

By survival

Slightly more men than women died within 72 hours (58% vs 42%). The mean age of patients who died within 72 hours was higher (78 years, sd 13) than those who did not (67, sd 18). There was little difference in comorbidities between those who died within 72 hours (CCI mean 5.2, sd 2.2) and those who did not (5.7, sd 1.9). Of those who died within 72 hours, 50% had cancer, and 50% did not.

Palliative Performance Scale (PPS)

The Palliative Performance Status (PPS) was assessed for every participant. The PPS scores ranged between 10% and 70%, with a median of 30% (IQR 10, 40). The participants who died within 72 hours had a median PPS score of 10% (IQR 10, 30). Participants who survived beyond 72 hours had a median PPS score of 40% (IQR 20, 50).

Richmond Agitation Sedation (RASS)

Scores for the RASS ranged between +2 and -5. The median score for the total population was -1 (IQR -4, 0). The distribution of scores was bi-modal; twelve patients (24%) had a score of 0 and nine (18%) had a score of -5. The participants who died within 72 hours of assessment were either deeply unconscious (n=15, 62.5% scored either -4 or -5) or were agitated (n=5, 20% scored +1 or +2) with a median score of -4 (IQR -4.5, -0.5). The participants who did not die within 72 hours were largely calm with mild agitation or sedation (n=18, 70% scored between -1 and +1) and a median score of -0.5 (IQR -2, 0).

Clinical signs and symptoms prevalence

Table 2 details the prevalence of the signs and symptoms noted during the study. Overall the most prevalent features observed were a decrease in oral food intake (60%) and a rapid decline of the participant's global health status (56%).

Participants who died within 72 hours were more frequently noted to have: a rapid decline of their global condition (75% vs 38%); decreased urine production (71% vs 23%); more concentrated urine (67% vs 31%); incontinence of faeces (71% vs 19%); noisy respiratory secretions (54% vs 15%); Cheyne-Stoke breathing (17% vs 4%); peripheral cyanosis (21% vs 4%); and refusal of food (21% vs 4%). There were two symptoms that were only seen in participants who died within 72 hours; respiration with mandibular movement (n = 2; 8%)

and pulselessness of the radial artery (n = 2; 8%). Participants who survived longer than 72 hours were more frequently noted to have: a loss of appetite (69% vs 25%), pain (42% vs 4%), were more likely to express anxiety or fear (54% vs 17%) and were more accepting of their death (38% vs 8%); however these data were more likely to be missing for patients who survived less than 72 hours.

Table 2 Prevalence of key prognostic features over the previous 24 hours in patients who did or did not die imminently

	Died <72 hours (n=24)			Died >72 hours (n=26)		
	Present	**Absent**	**Missing**	**Present**	**Absent**	**Missing**
	n (%)			n (%)		
Respiration						
Short of Breath	2 (8)	5 (21)	17 (71)	8 (31)	12 (46)	6 (23)
Noisy Respiratory Secretions	13 (54)	11 (46)	0 (0)	4 (15)	22 (85)	0 (0)
Cheyne Stokes type breathing	4 (17)	20 (83)	0 (0)	1 (4)	25 (96)	0 (0)
Abdominal Swelling	4 (17)	20 (83)	0 (0)	9 (35)	17 (65)	0 (0)
Respiration with mandibular movement	2 (8)	22 (92)	0 (0)	0 (0)	26 (100)	0 (0)
Blood Circulation						
Pulselessness of the radial artery	2 (8)	13 (54)	9 (38)	0 (0)	24 (92)	2 (8)
Peripheral Cyanosis	5 (21)	17 (71)	2 (8)	1 (4)	25 (96)	0 (0)
Nose becomes more “pointed”	0 (0)	21 (88)	3 (13)	0 (0)	26 (100)	0 (0)
Change in skin condition (moisture, colour, temperature)	8 (33)	16 (67)	0 (0)	8 (31)	18 (69)	0 (0)
Physical Condition						
Extreme tiredness	4 (17)	4 (17)	16 (67)	11 (42)	9 (35)	6 (23)
Insomnia	1 (4)	7 (29)	16 (67)	6 (23)	14 (54)	6 (23)
Surges of Energy	0 (0)	8 (33)	16 (67)	2 (8)	18 (69)	6 (23)
Rapid decline of global condition	18 (75)	6 (25)	0 (0)	10 (38)	16 (62)	0 (0)
Skin Integrity						
Wounds, ulcers or sores on the skin	6 (25)	18 (75)	0 (0)	7 (27)	19 (73)	0 (0)
Excretion						
Catheter	16 (67)	8 (33)	0 (0)	11 (42)	15 (58)	0 (0)
Stoma	1 (4)	23 (96)	0 (0)	6 (23)	20 (77)	0 (0)
Concentrated urine	16 (67)	7 (29)	1 (4)	8 (31)	12 (46)	6 (23)
Incontinence (urinary)	5 (21)	3 (13)	16 (67)	5 (19)	10 (38)	11 (42)
Incontinence (faecal)	17 (71)	6 (25)	1 (4)	5 (19)	14 (54)	7 (27)
Vomiting	3 (13)	21 (88)	0 (0)	9 (35)	17 (65)	0 (0)
Altered defecation – diarrhoea	4 (17)	19 (79)	1 (4)	6 (23)	19 (73)	1 (4)
Altered defecation – constipation	9 (38)	14 (58)	1 (4)	10 (38)	15 (58)	1 (4)
Decreased production of urine	17 (71)	5 (21)	2 (8)	6 (23)	13 (50)	7 (27)
Oral Intake						
Decreased eating	13 (54)	1 (4)	10 (42)	17 (65)	4 (15)	5 (19)
Decreased drinking	13 (54)	2 (8)	9 (38)	13 (50)	8 (31)	5 (19)
Refusing food	5 (21)	5 (21)	14 (58)	1 (4)	18 (69)	7 (27)
Swallowing difficulty	4 (17)	4 (17)	16 (67)	8 (31)	13 (50)	5 (19)
Loss of appetite	6 (25)	1 (4)	17 (71)	18 (69)	2 (8)	6 (23)
Pain						
Patient reported pain	1 (4)	8 (33)	15 (63)	11 (42)	10 (38)	5 (19)

Clinician reported pain	3 (13)	21 (88)	0 (0)	10 (38)	16 (62)	0 (0)
Pain is less responsive to treatment	1 (4)	20 (83)	3 (13)	1 (4)	23 (88)	2 (8)
Psychological Condition / Spiritual						
Confusion	6 (25)	2 (8)	16 (67)	7 (27)	11 (42)	8 (31)
Delirium	2 (8)	6 (25)	16 (67)	1 (4)	18 (69)	7 (27)
Anxiety/fear	4 (17)	2 (8)	18 (75)	14 (54)	5 (19)	7 (27)
Recoil behaviour (withdrawn)	0 (0)	7 (29)	17 (71)	1 (4)	18 (69)	7 (27)
Acceptance of death	2 (8)	4 (17)	18 (75)	10 (38)	9 (35)	7 (27)
Saying goodbye to family members	0 (0)	6 (25)	18 (75)	0 (0)	19 (73)	7 (27)

Missing data

As shown in Table 2, there were some prognostic features for which almost half of the data were recorded as missing. In general the proportion of missing data was higher in patients who died within 72 hours compared to those who survived. Measures such as the physical condition, oral intake, psychological well-being and whether they were experiencing shortness of breath were often not available either because there was no meaningful answer (i.e. the patient had a catheter/stoma or the patient was not alert enough to respond, with no proxy measure available) or the information was not recorded. The aim of this study was to document all previously identified prognostic features in patients who were referred to specialist palliative care teams. Whilst the diminished consciousness of the patient, which is an evidence-based prognostic indicator in its own right, could have limited the ability to collect some of this data; the fact that data relating to some of these features were frequently missing in those who died within 72 hours is a relevant and novel finding which has implications for clinical practice.

Discussion

This study described the presence or absence of key prognostic features in palliative care patients who were thought to be in the last two weeks of life and who did or did not die within 72 hours of assessment.

In patients thought to be in the last two weeks of life, there was a reduction in physical ability, as measured by the palliative performance scale. Three symptoms affected at least half of the patients: reduced oral intake, a rapid decline in condition, and a change in excretions. This result is slightly inconsistent with other studies that have suggested that other symptoms such as fatigue and mental haziness are more prevalent in the last weeks of life.[43-45]

Different symptoms were prevalent in patients who died within 72 hours and in those who survived for longer. Patients who died within 72 hours had a lower palliative performance score and experienced either more agitation or more sedation than patients who survived longer than 72 hours. Some symptoms were more prevalent in patients who died imminently, such as a rapid decline in global condition, decreased urine output, increased anxiety, incontinence, noisy respiratory secretions, Cheyne-Stoke breathing, and peripheral cyanosis. The small sample size of this study means that the estimates of the prevalence of particular symptoms should only be regarded as tentative. Two symptoms, although uncommon, were only noticed in patients who died imminently: respiration with mandibular movement and pulselessness of the radial artery. These symptoms have been previously suggested to predict imminent death.[12, 13, 16] One previous study reported that observations of the patient, such as heart rate and oxygen saturation, may also be predictive of imminent death but that for a large portion of patients, these vital signs were within a normal range in the last days of life.[17] Most of the patients in our study did not have routine observations undertaken and so no such data were available.

This reiterates the importance of further research within a palliative care context particularly in the final days of life and about how to make prognostic decisions in the context of incomplete data.[32] A large volume of data was recorded as missing for patients who died within 72 hours in this study. This is an interesting finding and highlights the complicated

landscape in which the medical team are asked to make predictions about imminent death based on information that is not always possible to obtain about the patient. The prevalence of prognostic factors in this study demonstrates the large amount of potential prognostic information that medical teams have to weigh up when making a decision about end of life care. Further research is required to determine how these decisions are made in practice.

Strengths and weaknesses

This study is one of the first, to the authors knowledge, to prospectively observe prognostic signs and symptoms in the final days of life. However, this data is only taken from two london specialist palliative care teams. If a different population had been recruited, it is possible that other signs and symptoms may have been more prevalent. For example, patients who are not referred to specialist palliative care teams might present differently towards the end of life. This is an area for further research. This study was not designed to demonstrate an association between the prevalence of symptoms at the end of life and death within days, and any apparent differences between groups need further confirmation in a comparative study.

Conclusion

This study lends support to the usefulness of certain key prognostic features for predicting immnent death in palliative care inpatients. Further work is required to understand how clinicans should best integrate these prognostic features, while taking into account the volume of missing information, to refine their prognostic estimates of imminent death.

Declarations

Ethics approval and consent to participate

As described in the section "Patient & Public Involvement

Feedback on the protocol was sought from a consumer research panel (South West London Cancer Research Group). The suggestions from the group were reflected in the study protocol, specifically the study information sheets.

Ethical issues", this study received approval from West Midlands – Coventry and Warwickshire Research Ethics Committee in May 2014 (14/WM/0121).

Consent for publication

Not applicable

Conflict of Interest

None to declare

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Authors' contributions

NW developed the study concept, design and aims, designed data collection tools, completed the data collection for the whole study, cleaned and analysed the data, and drafted and revised the paper. FR developed the design and aims of the study, monitored the data collection tools for the observational study and data collection, aided in the analysis of the results, and revised the paper. AH developed the study concept, design, and aims, monitored data collection throughout the study, aided in the analysis plan and analysis of the results, and revised the paper. PL, CMG, OM, AT assisted in the study design, aided the data collection for the observational study, and revised the paper. PS & PH initiated the PhD study concept, developed the design and aims of the study, monitored the data collection tools for the entire study and data collection, monitored the analysis of the results, and revised the paper. All authors approved the final version of the paper.

Acknowledgments

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Data Sharing

The dataset supporting the conclusions of this article is included within the article and its supplementary files.

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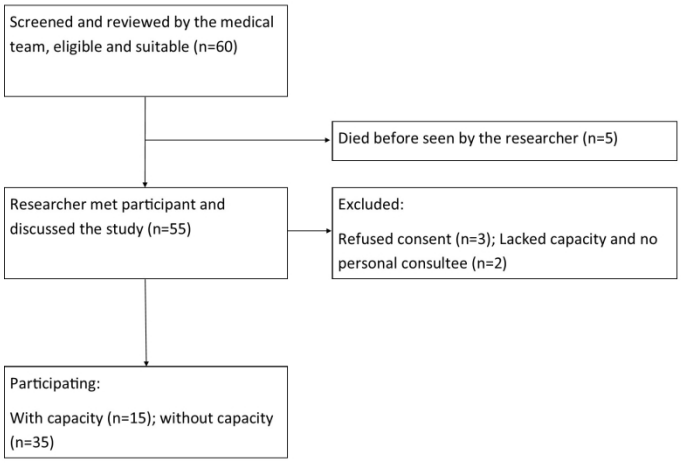
Supplementary Files

Supplementary File 1 STROBE guielines

Supplementary File 2 Original study protocol

Supplementary File 3 Study flow chart

Supplementary File 4 Symptoms gathered on each participant



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STROBE Statement—checklist of items that should be included in reports of observational studies

	Item No.	Recommendation	Page No.	Relevant text from manuscript
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1-2	An observational study
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2	
Introduction				
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3-4	
Objectives	3	State specific objectives, including any prespecified hypotheses	4	
Methods				
Study design	4	Present key elements of study design early in the paper	4	
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	4	
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	5-7	
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case		
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	7-9	
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	7-9	
Bias	9	Describe any efforts to address potential sources of bias	9	Attempting to address "missing" data
Study size	10	Explain how the study size was arrived at	5	Sample Size heading

Continued on next page

Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	9	Analysis section
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	n/a	
		(*b*) Describe any methods used to examine subgroups and interactions	n/a	
		(*c*) Explain how missing data were addressed	9	Missing data
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy	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 analysed	10	Recruitment paragraph and figure 1.
		(b) Give reasons for non-participation at each stage	10	Figure 1
		(c) Consider use of a flow diagram		Figure 1
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	10-11	Participant characteristics section and Table 1
		(b) Indicate number of participants with missing data for each variable of interest	11-12	Table 2 & 3
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)		
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time		
		Case-control study—Report numbers in each exposure category, or summary measures of exposure		
		Cross-sectional study—Report numbers of outcome events or summary measures	11-12	Table 2 & 3.
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	n/a	
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n/a	

Continued on next page

Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	n/a	Data was summarised and not analysed to avoid over interpretation.
Discussion				
Key results	18	Summarise key results with reference to study objectives	13	
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	13-15	
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	13-15	
Generalisability	21	Discuss the generalisability (external validity) of the study results	13-15	
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	15	

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

University College London

Palliative Care: Clinicians' EstimateS (P:CES).

Improving the accuracy of health care professionals' predictions about clinical outcomes

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Summary

Doctors and nurses are inaccurate at predicting survival in patients who are seriously unwell. This lack of accuracy and consistency can have adverse consequences for patients and their families. Inaccurate prognoses can lead (for example) to delays in access to palliative care services, to patients dying in acute hospitals when they would rather die at home, to delays in access to NHS continuing care funding, and can cause psychological distress to patients and their carers.

This study has been developed in response to recent independent report ("More Care, Less Pathway") which made many recommendations about how to improve the care of the dying and in particular highlighted the need to for more evidence-based research when clinicians give a prognosis.

The aim of this study is to identify a group of 'experts' by presenting clinicians a series of case histories from real people admitted to the hospital and hospice, then asking them to predict the outcome. From the experts identified, we will then be able to understand what key information is being used to make an accurate prognosis. This novel approach will help to create a platform on which to improve novice clinicians' skills in prognosis. The case histories will help to test any future training interventions designed to improve outcome prediction.

Accuracy in predicting outcome can help to reduce unnecessary admissions and fast track much needed services. Ultimately this will enhance the quality of care received by patients who are reaching the end of their life.

Background

Overview

According to the report "Deaths in Older adults in England" (2010) there are currently 4.0 million people aged 75 and over. This is projected to increase to 7.2 million in the year 2033. This will increase the demand on the National Health Service and services such as palliative care. The Office of National Statistics reported that there were 499,331 deaths in England and Wales in 2012, a rise of 3.1% with the year before.

The National End of Life Strategy (2008) aims to get health professionals to identify individuals in the last year of their life in order to prepare for the eventual event of death through an Advance Care Plan. This will help to ensure that the patient's wishes are maintained and help reduce the costs and the burdens associated with unnecessary interventions.

The majority of patients wish to die in a familiar setting of a home or care home (Meeussen et al., 2009).The National Bereavement Survey (VOICES) (ONS, 2013) recently stated that whilst people wanted to die at home, hospital was the most common place of death (52%). Further evidence suggests that at least 40% of people dying in hospital had no medical reason to be there (Thomas et al, 2011).

The National Survey of Patient Activity Data for Specialist Palliative Care Services (2013) reported that of those receiving specialist palliative care services, only a quarter (23.9%) died in the acute setting.

These statistics highlight the importance of recognising the dying phase. When prognosis is discussed openly, it can alter the treatment offered. Allowing the family members, patients, and health professionals to engage fully and make informed decisions (Glare & Sinclair, 2008).

Accuracy in predicting outcome can help to reduce unnecessary admissions and fast track much needed services.

Prognosis

The crux of prognosis is the accurate recognition of death by health care professionals. The National End of Life Care Intelligence Network published a report 'Predicting Death' examined deaths in England and Wales (2011); comparing several reports, the 'unexpected death' figure lay between 22% - 42%.

For those who are recognised as dying within the next 72 hours, the Liverpool Care Pathway (LCP) was commonly used as a tool to help with symptom control (Ellershaw & Ward, 2003). It was one of three tools recommended as part of the National Institute for Health and Clinical Excellence guidelines (2004) for promoting high quality end-of-life care.

The recent independent report commissioned on the LCP ("More care, Less Pathway", 2013) has highlighted how imprecise the diagnosis of dying is. It highlighted frequent

problems with patients who are incorrectly placed on the LCP when they are not dying, and those who are not recognised as dying in time. This report suggested further research needs to be completed to improve the accuracy of recognition of death. This finding has been further supported by a review by Parry, Seymour, Whittaker, Bird, & Cox (2013) which concluded there is a lack of research in to the area of prognosis and imminent death.

Clinicians' Estimates

Currently, referrals to palliative services and access to continuing care funding support rely on a prognosis from a clinician. A common theme throughout the literature is that clinicians are inaccurate when it comes to providing these (Chow *et al*., 2001; Clarke *et al*., 2009; Glare *et al*., 2003). Becker *et al* (2007) noted that in a retrospective case note analysis, only a third (36.7%) of cases were recognised as 'dying' by the clinicians on an average of 3.8 days before death. This inaccuracy impacts the speed at which a patient is referred to palliative care services to receive specialist support both physical symptoms and for emotional support (Franks et al., 2000).

This study has been developed in response to recent reports which highlight the need for more evidence-based research in the area of prognosis and improving clinicians' estimates of survival. Previous studies have looked at how accurate clinicians are at predicting survival, but very few have concentrated on the last 72 hours of life. Previous studies have addressed what signs and symptoms are prevalent at the end of life and might predict the outcome, but none have looked at how clinicians use this information to formulate their prognosis. No previous study has specifically set out to identify which clinicians are best at prognostication, nor attempted to improve the performance of non-experts.

This 3 year PhD will be formed of two studies. The results of the study one will inform the development of the next study.

Study 1 – Creating the anonymous vignettes and identifying the 'expert' clinicians

The first phase will be a prospective observational cohort study of 50 patients referred to palliative services. The information gathered will be incorporated in to a series of case histories ("vignettes") to use in study 2. All patient identifiable information will be removed from the vignettes.

Each vignette will represent one participant and will contain information that clinicians usually have access to in order to predict an outcome.

This set of anonymous vignettes will provide the basis of the electronic survey for the PhD.

The vignettes will be administered to palliative care clinicians nationally. Each clinician will be asked to read the vignettes and give a percentage likelihood of survival for the next 72 hours.

From this, we aim to obtain an 'expert' population as well as identify potential symptoms and factors which may predict imminent death and/or how experts make their decisions.

Study 2 – Understanding how experts formulate a prognosis

Each expert will be interviewed briefly about what factors they feel are important when formulating a prognosis. The factors that are considered to be the most likely candidates will be developed in to a series of artificially constructed vignettes. The experts will then be presented with these artificial vignettes and asked to predict which patients they consider to have the worse prognosis. By statistically analysing the experts' responses to these vignettes we will be able to tease out which factors they are using to arrive at their judgments and how much importance they attach to each factor.

Research Objectives

Overall Objectives

The main aim of this PhD is to identify clinicians who are best at predicting survival and to investigate what factors they use to arrive at their predictions.

This will be completed through 3 stages:

- Creating a series of vignettes that reflect real patients who are referred to palliative care
- Identifying individuals who are deemed as 'experts' at predicting outcomes.
- Understanding what factors the 'experts' use to make decisions.

These insights will allow us to devise a training programme to teach other clinicians how to make a prognostic estimate like the "experts". Ultimately this will enhance the quality of care received by patients who are reaching the end of their life.

Specific Objectives for Study 1

- To produce a series of 50 suitable case vignettes of patients referred to palliative care services.
- Identify clinicians who are "experts" at giving a prognosis by asking them to read the anonymous case vignettes, through an electronic survey, and predict likelihood of surviving the next 72 hours.

Specific Objectives for Study 2

- To produce a series of artificial vignettes based on the factors the clinicians identify as being important when making a prognosis.
- Through Judgment Analysis, tease out the factors that clinicians are using when formulating a prognosis.

This is an application for study 1 only.
A separate ethics application will be made for study 2.

Methods

Location

Recruitment for the vignettes will take place at St George's Hospital in South London, and in the Marie Curie Hospice in North London. These two sites encompass an ethnically and socioeconomically diverse population.

Recruitment of clinicians will take place through an electronic survey, administered to Palliative Care Clinicians across the UK who are registered with the Association of Palliative Medicine (APM).

Sample Size

Vignettes

We require 50 case histories or "vignettes" (25 patients who died within 72 hours and 25 patients who survived 72 hours). This may require us to collect data on more than 50 patients.

When calculating the sample size for participants, we took various factors in to consideration:

Burden for participants

This was the main factor when considering how the number of vignettes to gather. We did not want to recruit participants unnecessarily.

Previous research

Rassafiani *et al* (2009) sampled 18 Occupational Therapists on a total of 110 case vignettes, which took two and a half hours to complete. We feel that this burden of time is not acceptable for the initial screening phase for experts. Particularly as we will be relying on the experts identified to be willing to sacrifice their time to participate further in study 2.

Implications for the Electronic Survey

Previous studies using the method of Judgement Analysis have varied widely in their sample sizes. In many of these studies (Harries, Tomlinson, Notley, Davies, & Gilhooly, 2012; Unsworth, 2007) the expert population have already been defined by years of employment. We are looking to identify the experts through these case vignettes, rather than assuming length of employment means better prognostication skills. If we assume a chance estimate of 50% for the clinicians correctly guessing death within 72

hours, we feel that gathering a cohort of 50 patients in study 1 will identify experts incorporating this.

The APM has approximately 1000 members across the UK. If we assume a response rate of approximately 40% (Corkum, Viola, Veenema, Kruszelnicki, & Shadd, 2011), this will give us a sample size of 400 clinicians from which to identify experts and invite to study 2.

Participant selection

Vignettes

It is expected that data collection should take place over a period of 12 months**.** Every referral that is made to the palliative care team will be screened for suitability. The referring clinician will be asked the following: "Would you be surprised if this patient died within the next two weeks?" For those where the answer is 'No', the palliative care team will speak with the patient or, if necessary, their relatives. Only if the patient or relative are willing to speak to the researcher, will the palliative care specialist contact the researcher.

Inclusion Criteria

- Over 18
- Referred to palliative care team
- "No" to surprise question
- Enough English language to understand the study

Exclusion Criteria

- Under 18
- "Yes" to surprise question
- Patients indicate they do not wish to participate either verbally or through an advanced directive
- Not enough spoken English language

Electronic Survey

Clinicians will be approached to participate based on their membership with the Association of Palliative Medicine (APM). This will be through an email invitation distributed through the membership network.

Consent Procedure

Vignettes

We seek to adopt the consent process of Gibbins et al (2013) and Scott, Jones, Blanchard, & Sampson (2011) in which a patient, who was admitted to hospital and identified as likely to die during the admission, was approached about participating and had their capacity assessed.

The consulting palliative care specialist will assess the patient before contacting the researcher. They will see if the patient is willing to meet and discuss the study with the researcher. In cases of unconsciousness, the palliative care specialist will contact the relatives to see if they are willing to discuss the study with the researcher.

If they are willing to discuss the study, the researcher will give the patient a short information sheet and explanation of what the study is and will ask the patient if they would like to participate. If they refuse at this point, no more contact will be made with them. If they agree, the researcher will assess their capacity to provide informed consent, using the Mental Capacity Act (MCA) guidelines.

They will be informed that they can withdraw at any point if they choose to without any effect on their care. Each participant will be given 24 hours to decide if they wish to participate. However, since this study is time sensitive and does not require participants to undergo any additional investigations / treatments or to complete any questionnaires / interviews, it is likely that many patients / relatives will prefer to provide consent / assent immediately. In these circumstances patients / relatives will not be required to wait 24 hours before giving consent / assent but will be able to withdraw at any point.

In the presence of capacity, they will be asked to sign a consent form if they are willing to participate. In the absence of capacity, the researcher will ask the patient for permission to contact the next of kin.

Assent from the next of kin shall be obtained from two methods:

Either

a) On the ward if they are present or due to attend with the patient. They will be given an Information Sheet about the study as well as the opportunity to ask questions. The researcher will ask them to consider the wishes of the patient regarding participation in research. They will be informed that they do not need to give an answer immediately if they do not wish to and that the researcher will return in 24 hours. If they assent for the patient to participate, they will be asked to sign an agreement form.

b) If the next of kin is unable to attend the hospital the researcher will seek verbal assent over the phone. This is due to the time sensitive nature of the research and need to obtain information from the healthcare professionals attending to the patient in a timely manner. Data collection will begin from the point of verbal agreement. An agreement form and Information Sheet will be sent to the next of kin with a prepaid envelope. If the agreement form is not returned within 2 weeks, a reminder letter shall be sent to the next of kin. If no response is received, it shall be assumed that consent has been withdrawn and the data collected will be destroyed in lines with GCP guidance.

The outcome of the participation will be documented in the patient's medical records to prevent duplication of approaching and to inform the medical team of the research involvement. (See Appendix 1 for consent procedure flowchart).

Once consented in to the study, one researcher (the PhD Student) will collect the data on all participants.

Electronic Survey

Before completing the electronic survey, clinicians will be asked to read through the electronic information sheet and to tick the box to indicate consent.

They will be asked to provide contact details for themselves and will be informed that there will be the potential to participate further. They will be asked some basic demographic questions: age, gender, geographic location, position held, and length of time working in palliative care.

The contact details of the Chief Investigator will be available to the clinicians if they have any questions and it will be explicit that they can withdraw or stop the survey at any time.

Measures

Vignettes

It is important that the data collected will reflect all aspects of the patient's condition in order for the clinicians to formulate a prognosis. All data will be derived from information collected from the medical team, no additional tests or interventions will be completed. This information will be collected for up to 7 days or until death, whichever occurs first.

The following information will be gathered:

1. Age and gender
2. Diagnosis and extent of disease
3. Extent of on-going treatment (e.g. IV fluids, antibiotics, other treatments)
4. Resuscitation status
5. Rapidity of change in condition
6. Conscious level
7. Oral intake
8. Symptom severity - pain, breathlessness, noisy breathing, restlessness, delirium
9. Performance status (using the palliative performance scale)
10. Full blood count and biochemistry results if available
11. Narrative description of patient's general condition

Before implementing this data collection tool, it will be examined by two senior palliative care clinicians to ensure face validity and that nothing obvious was missed. The same clinicians will then be asked to look over the first 3 participants in the study to ensure the validity and reliability of the data collected.

From the medical notes

Medical notes will be checked in order to gather the information stated above. Basic demographical data about each participant will be recorded.

From the healthcare professionals

The healthcare professionals assigned to care for the patient will be asked on the overall condition of the participant and whether they have noticed any changes in his/her condition. They will also be asked to estimate the participant's prognosis for the next 72 hours.

Construction of the Vignettes

Each vignette will represent one participant and will be a one page summary containing the above measures collected during each participant's admission. As previously mentioned, it is important that the information presented is representative of the information that a clinician would have access to when asked to make a prognosis.

Similarly to the data collection tools, the first 3 vignettes will be assessed by two senior palliative care consultants for face validity.

Construction of the Survey

An online assessment has been developed as the basis of the survey.

Prior to starting the assessment, there will be an introductory section that states:

Welcome to the P:CES website

Background

"Improving clinicians' ability to recognise the dying phase was one of the key priorities identified by the independent review into the Liverpool Care Pathway chaired by Baroness Neuberger. It is known that clinicians, in general, are inaccurate at estimating survival in palliative care patients. Despite this, there is no clear guidance about how clinicians can be taught to improve their performance on this clinical skill. This study will help us to identify those clinicians who are most accurate at prognosticating. We will then use this information to help to develop an educational package aimed at improving the prognostic skills of other clinicians.

This project has been reviewed and given favourable opinion by West Midlands - Coventry & Warwickshire Research Ethics Committee on 9th May 2014 (reference 14/WM/0121). This project is sponsored by University College London (UCL) and Marie Curie. This is a PhD project. The student is Nicola White. Professor Paddy Stone, Dr Adam Harris, and Professor Priscilla Harries are supervising this project.

Why have you been asked and what does it involve?

- You have been invited to participate in this assessment because you are a clinician with experience of caring for palliative care patients.
- The case studies that you will see are anonymised real cases of patients who were referred to Palliative Care Services.
- You will be presented with a series of case studies and you will be asked to provide an estimate for the probability that the patient will die within the next 72 hours.

- The task will take approximately 60 minutes to complete. However, you can take as long as you need for each case. You are also able to log out and return at a later time to complete the task.
- The accuracy of your estimates will be compared against the actual outcome of the cases.
- You will receive a certificate of participation on completion.
- The participants who are amongst the top performing clinicians will be contacted again after the survey."

The next page on the assessment will ask the participant to provide consent to participate and a contact email address.

The next page will ask clinicians for basic demographic information.

The next page is an instruction page to inform the clinicians how to complete the test:

"The case scenarios used in this assessment are all real patients who were referred to Palliative Care Services. Additional information relating to each case (for example: medication charts, blood test results and observations) are available at the end of each vignette.

We would like you to read each scenario and provide your response to the following question;

"What do you think the probability is that this patient will die within the next 72 hours?"

We appreciate that in routine practice, you would usually want to see the patient face-to-face before answering such a question. However, we are interested in your initial impressions based on the clinical information that is available to you. This may be similar to the situation that occurs when cases are discussed at a multi-disciplinary team meeting or when referral forms are considered at a hospice - or other situations when you need to make a prognostic estimate without the opportunity to undertake a clinical assessment yourself.

After the scenarios, at the bottom of each page, there is a box provided for you to indicate your estimate about the probability that the patient will die within the next 72 hours. You will not be able to move on to the next scenario until this information is provided.

Key Points:

- Please give each scenario a percentage score ranging from 0 (certain survival) to 100 (certain to die) for the next 72 hours.
- Please give each scenario a number ranging from 0 (you think the patient will die today) to >=365 (you think the patient will die after a year)
- There is no time limit for each case; however we are interested in your initial response to the information presented to you, so try not to spend too long on each one.
- Please judge each scenario as if it were your own case.
- You should undertake the task independently and not ask opinions from others during the task itself.
- It is best if you do the task without taking a break, however you are able to log off and return at a more convenient time if you need to.
- Please click on the continue button, not the back or refresh controls whilst working through the scenarios.
- You cannot return to earlier recommendations.

You will now have a practice scenario "

The clinician will then be asked to complete a practice vignette in order to familiarise themselves with the format of the assessment.

The clinician will be offered a certificate of completion.

Statistical Analysis

Analysis of the vignettes

An exploratory analysis will be conducted to examine the predictive power of the data collected and the occurrence of imminent death. Multiple regression analysis will be used with the outcome variable of death within 72 hours.

Analysis of the electronic survey

Each clinician will be asked to give a percentage of risk for each of the presented vignettes. Using a technique developed in weather forecasting (Brier, 1950), we will calculate a score for each clinician ranging from 0 to 1. This is known as the probability score or 'Brier Score'. This helps to calculate not only accuracy but consistency of decision making and discrimination between those who die and those who do not (Arkes et al., 1995; Mackillop & Quirt, 1997; Rakow, Vincent, Bull, & Harvey, 2005). A score of 0 indicates greater accuracy.

Experts will be judged as the top 10-25% scoring the closest to 0.

Exploratory analysis using multiple regression will also be able to highlight potential factors that the expert clinicians may be using to make their prognostic decision.

This information will help to form the basis of the next study.

Ethical Considerations

1. People who lack capacity

Duke & Bennett (2010) completed a systematic review of the issues involved with recruiting in palliative care. They discuss the issues of gate-keeping, vulnerability, and consent. As suggested by Gibbins et al. (2013) by refusing people the opportunity to participate in research, we are not providing a vulnerable population with the evidence-led care they deserve.

It is important that this study includes patients who lack capacity because many patients at the end of their lives become confused, semi-conscious or comatosed. Since the purpose of this study is to determine whether clinicians are able to predict which patients are likely to die, it is important that the study population is representative of the type of patients commonly seen in terminal care. We have

used guidance from the Mental Capacity Act and previous research that have recruited from a similar environment with a similarly vulnerable patient group. We do not wish to exclude a population for whom this study is aimed at helping. Therefore we have included a personal consultee to provide assent, which will be the designated next of kin.

2. The extra burden of participating in research when approaching the end of life and medically unwell

This study is not a trial or intervention. The measures taken are part of routine clinical care and should not increase the burden on the patients. The patient will not need to undergo any additional tests or interventions as a result of participating in this study. The patient, or their personal consultee, can withdraw at any time should they feel the burden is too much.

3. Knowledge and awareness of palliative care

Some patients or family members may not understand what palliative care means. All patients who are screened for eligibility to the study will have already been referred to the palliative care services and been assessed by a palliative care specialist prior to seeing the researcher. To avoid causing undue distress to potential participants, we have taken steps to ensure that the language used in the patient / carer information sheets is not insensitive. In the event that provision of information about the study were to cause distress, the patient and family member will be referred to the attending Doctor or nurse so that they have access to the necessary support.

4. Confidentiality

The vignettes will contain all relevant clinical data that the clinicians will look at routinely to provide a prognosis. All patient identifiable information will be removed. Since it is (at least theoretically) possible that patients with rare diseases or unusual clinical features may be identified inadvertently, care will be taken to exclude such patients from the study.

All data that is gathered from the patients and healthcare professionals will be anonymous in accordance with the Declaration of Helsinki. It will be stored on a password protected database and paper copies will be kept securely in a locked cabinet.

5. Follow up

The follow up for this study has been kept to a minimal to lessen the burden of participating in the research. Participation in the study is for seven days and the data will be collected from the medical notes or from the health care professionals.

Benefits of the study

Overall

This novel approach to assessing clinician's estimates will help us to understand what information expert clinicians use when they are formulating a prognosis. Creating a platform on which to improve novice clinicians' skills in prognosis, and test any future training interventions designed to improve outcome prediction.

Accuracy in predicting outcome can help to reduce unnecessary admissions and fast track much needed services. Ultimately this will enhance the quality of care received by patients who are reaching the end of their life.

Study 1 benefits

Study 1 will produce a series of genuine referrals to palliative care which will be able to test the effectiveness of future educational intervention designed to improve prognosis. The electronic survey will give preliminary information as to the factors that clinicians may be using to make a prognosis. It will also add to previous research by exploring potential predictive factors of imminent death.

Resources and costs

No payments will be made for participating in this study.

Insurance and indemnity

University College London holds insurance against claims from participants for harm caused by their participation in this clinical study. Participants may be able to claim compensation if they can prove that UCL has been negligent. However, if this clinical study is being carried out in a hospital, the hospital continues to have a duty of care to the participant of the clinical study. University College London does not accept liability for any breach in the hospital's duty of care, or any negligence on the part of hospital employees. This applies whether the hospital is an NHS Trust or otherwise.

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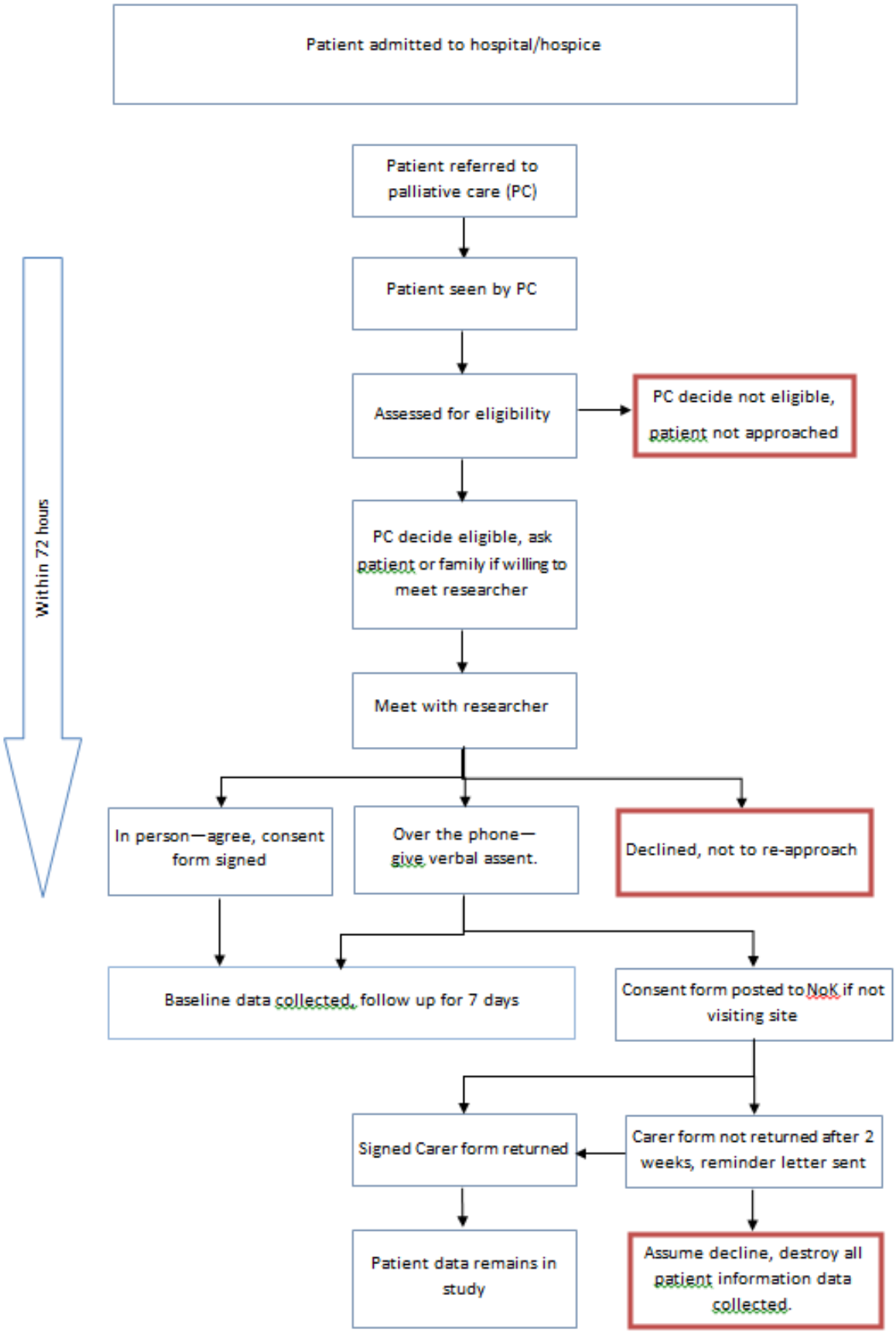
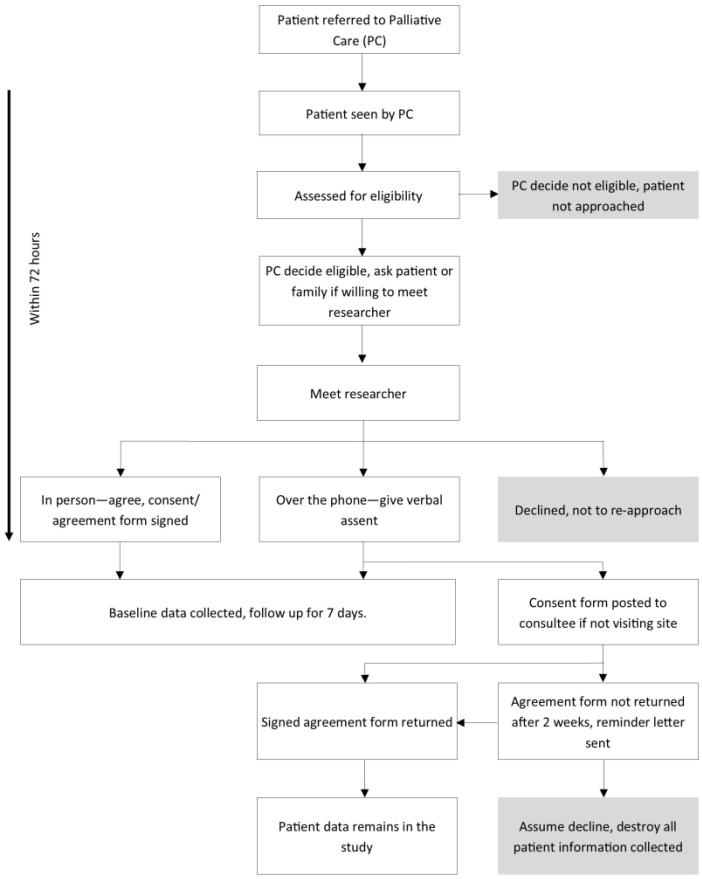
Appendix 1: Consent Flow Chart for Patient Recruitment





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P:CES Study

PID: _ _ **Site** *(circle):* **SGH / MCH** **Date:** _ _ / _ _ / _ _ _

Demographics

4. Age _ _ _ (years) **5. Gender** (*circle)* MALE / FEMALE **6. DOB:**

7. Date of Admission _ _ / _ _ / _ _ _ _ **8. Marital Status:** Single ☐ Widowed ☐ Married ☐ Divorced ☐

9a. Resuscitation Status: **9b. Date DNAR signed** *(if applicable)*

10. Ethnicity *(circle)*	**White**	**Mixed/Multiple ethnic group**	**Asian/Asian British**	**Black / African / Caribbean / Black British**	**Other ethnic group**
	English / Welsh / Scottish / Northern Irish / British	White and Black Caribbean	Indian	African	Arab
	Irish	White and Black African	Pakistani	Caribbean	Any other ethnic group, *(please describe)*
	Gypsy or Irish Traveller	White and Asian	Bangladeshi	Any other Black / African / Caribbean background, *(please describe)*	
	Any other White background *(please describe)*	Any other Mixed / Multiple ethnic background, *(please describe)*	Chinese		
			Any other Asian background *(please describe)*		

11a. Reason for admission: **11b. Source of admission** *(e.g. a+e, gp referral, clinic)*

12. Primary Diagnoses:

13. Charlson Co-Morbidity Index *(circle)*

Myocardial infarct	1	Hemiplegia	2
Congestive heart failure	1	Moderate or severe renal disease	2
Peripheral vascular disease	1	Diabetes with end organ damage	2
Cerebrovascular disease	1	Any tumour	2
Dementia	1	Leukaemia	2
Chronic pulmonary disease	1	Lymphoma	2
Connective tissue disease	1	Moderate or severe liver disease	3
Ulcer disease	1	Metastatic solid tumour	6
Mid liver disease	1	AIDS	6
Diabetes	1	TOTAL	

14. Medical Team prognosis of next 72 hours

"Do you think it is likely that this person will die in the next 72 hours?"

	Yes	No	Unsure		Yes	No	Unsure		Yes	No	Unsure
Nurse	☐	☐	☐	Doctor	☐	☐	☐	Palliative Care Specialist	☐	☐	☐

Percentage certainty:

Job title(s) of person/people stating prognosis:

P:CES Study

PID: _ _ **Site** *(circle):* **SGH / MCH** **Date:** _ _ / _ _ / _ _ _

15. Patient Symptoms

Please mark the following symptoms for the patient.
This information will be available from the medical notes, medical team, or from seeing the patient.

a. Respiration

	Yes	No	N/A
Complaint of shortness of breath	☐	☐	☐
0^2 sats	**Level:**		☐

	Yes	No
Noisy respiratory secretions	☐	☐
Cheyne-stokes respiration	☐	☐
Abdominal Swelling	☐	☐
Respiration with mandibular movement (jaw moving)	☐	☐

b. Blood Circulation

		N/A
Heart Rate	Pulse:	☐
Blood Pressure	BP:	☐
Fever	Temp:	☐

	YES	NO	N/A
Pulselessness of radial artery	☐	☐	☐
Peripheral Cyanosis (blue extremities)	☐	☐	☐
Pointed nose	☐	☐	☐

	Yes	No
Change in skin	☐	☐
Colour	☐	☐
specify		
Temperature	☐	☐
specify		
Moisture	☐	☐
specify		

c. Physical Condition

In consciousness:

	Yes	No	N/A
Extreme tiredness	☐	☐	☐
Insomnia	☐	☐	☐
Surges of energy	☐	☐	☐
Rapid degradation of general condition in the last 24 hours	☐	☐	

Skin Integrity

	Yes	No
Infected wounds	☐	☐
Pressure Sores	☐	☐
Grade of Sore:		
Clinical signs of infection	☐	☐
Possible source?		

d. Excretion

	Yes	No	N/A
Is there a catheter in situ	☐	☐	
Is there a stoma in situ	☐	☐	
Urinary incontinence, *if applicable*	☐	☐	☐
Faecal incontinence, *if applicable*	☐	☐	☐
Concentrated urine	☐	☐	☐

	Yes	No	N/A
Vomiting	☐	☐	☐
Altered defecation - diarrhoea	☐	☐	☐
Altered defecation - constipation	☐	☐	☐
Decreased production of urine	☐	☐	☐
amount in last 24hrs			

e. Oral Intake

	Yes	No	N/A
Decreased eating	☐	☐	☐
Decreased drinking	☐	☐	☐

If the patient is conscious:	Yes	No	N/A
Refusal of food	☐	☐	☐
Swallowing Difficulty	☐	☐	☐
Loss of appetite	☐	☐	☐

f. Pain

In consciousness:

	Yes	No	N/A
Patient complains of pain	☐	☐	☐
Do you think the patient has pain?	☐	☐	☐
Pain is less responsive to treatment	☐	☐	☐

Circle the pain level patient is reporting:
mild moderate severe

Circle the pain level you feel the patient is in:
mild moderate severe

P:CES Study

PID: _ _ **Site** *(circle):* **SGH / MCH** **Date: _ _ / _ _ / _ _ _**

g. Consciousness / Psychological Condition / Spiritual

Richmond Agitation Sedation Scale (RASS)

Please circle which category currently represents the patient

+4	Combative	Overtly combative, violent, immediate danger to staff	
+3	Very Agitated	Pulls or removes tube(s) or catheter(s); aggressive	
+2	Agitated	Frequent non-purposeful movement, fights ventilator	
+1	Restless	Anxious but movements not aggressive vigorous	
0	Alert and Calm		
-1	Drowsy	Not fully alert, but has sustained awakening (eye-opening/eye contact) to voice (>10 seconds)	Verbal Stimulation
-2	Light Sedation	Briefly awakens with eye contact to voice (<10 seconds)	
-3	Moderate Sedation	Movement or eye opening to voice (but no eye contact)	
-4	Deep sedation	No response to voice, but movement or eye opening to physical stimulation	Physical Stimulation
-5	Unarousable	No response to voice or physical stimulation	

How to complete the RASS:

1. Observe patient

a. Patient is alert, restless, or agitated. **(score 0 to +4)**

2. If not alert, state patient's name and *say* to open eyes and look at speaker.

b. Patient awakens with sustained eye opening and eye contact. **(score –1)**

c. Patient awakens with eye opening and eye contact, but not sustained. **(score –2)**

d. Patient has any movement in response to voice but no eye contact. **(score –3)**

3. When no response to verbal stimulation, physically stimulate patient by shaking shoulder and/or rubbing sternum.

e. Patient has any movement to physical stimulation. **(score –4)**

f. Patient has no response to any stimulation. **(score –5)**

	Yes	No	N/A		Yes	No	N/A
Confusion	☐	☐	☐	Recoil behaviour (withdrawn)	☐	☐	☐
Delirium	☐	☐	☐	Acceptance of death	☐	☐	☐
Anxiety/fear	☐	☐	☐	Patient is saying goodbye to family	☐	☐	☐

16. Narrative description of patient's overall condition and general presentation

P:CES Study

PID: _ _ **Site** *(circle):* **SGH / MCH** **Date: _ _ / _ _ / _ _ _**

17. Palliative Performance Scale

Please circle an option from each column which represents the patients current ability

Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious level
Full	Normal activity & work No evidence of disease	Full	Normal	Full
Full	Normal activity & work Some evidence of disease	Full	Normal	Full
Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
Reduced	Unable Normal Job/Work Some disease	Full	Normal or reduced	Full
Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or confusion
Mainly sit/lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or confusion
Mainly in bed	Unable to do any activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Reduced	Full or Drowsy +/- Confusion
Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or coma +/- Confusion
Death	-	-	-	-

18. Other

Please include any other information you feel may be relevant to the patient's condition e.g. family's intuitive feelings if offered, sudden change in the patient's condition.

19. Information about patient on admission

P:CES Study

PID: _ _ **Site** *(circle):* **SGH / MCH** **Date: _ _ / _ _ / _ _ _**

e.g. functional ability, treatments, number of previous admissions