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