Prognostication in palliative care

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Predictions of less than 1 year

The surprise question was developed to identify patients who may benefit from a palliative approach to future care or who may need referral to specialist palliative care. To use the surprise question, clinicians should ask themselves, ‘Would I be surprised if this patient were to die in the next 6–12 months?’ It is used in routine clinical practice in a variety of settings and forms part of the Gold Standards Framework (GSF) proactive identification guidance (PIG), which is supported by NICE guidance. In GSF PIG, the surprise question is intended to be considered in combination with other (general and disease-specific) prognostic factors. A systematic review found the accuracy of the surprise questions is variable; there is a wide range of sensitivity (the ability to recognise patients who are dying; 11.6 to 95.6%), specificity (the ability to recognise patients who are not dying; 13.8 to 98.2%) and positive predictive value (the proportion of patients who die when the clinician predicts that they will die; 13.9 to 78.6%). The negative predictive value (the proportion of patients who survive when clinicians predict that they will

Importance of prognostication

Being able to provide an accurate prognosis for survival is important for patients, carers and clinicians. For patients, it allows time to prepare for approaching death, for example, by making financial plans or saying goodbye. For clinicians, an awareness and consideration of prognosis may be important for informing decision making surrounding medical interventions, achieving preferred place of care and advance care planning. Open discussion about prognosis can facilitate patient-centred care and shared decision making. The recently published NHS Long Term Plan acknowledges that, for an ageing society with multiple long-term conditions and increasing complexity, it is important to identify patients in the last year of life with the aim of achieving proactive and personalised care plans. Table 1 summarises how current guidance, policies and funding streams for patients rely, to some extent, on estimated prognoses.

Key points

Prognostic information is frequently helpful for patients, their carers, and for healthcare professionals.

Understanding patients’ prognoses can facilitate access to certain services and benefits.

Clinical predictions of survival are widely used and are helpful for identifying patients at different stages of their disease trajectory. Clinicians should be aware of the risk of overestimation, especially in temporal estimates.

Prognostic scores may provide more objective and/or more accurate prognoses than clinician predictions alone.

Whichever method for formulating a prognosis is used, it is important that information is communicated sensitively and with an appropriate degree of uncertainty.

KEYWORDS: Palliative care, terminal care, prognosis, communication, algorithm
Predictions of weeks to months

Clinical predictions of survival come in many forms. Clinicians may state that they expect a patient to live for a specific period of time such as 5 days, 3 weeks or 4 months. These are known as continuous temporal predictions. Alternatively, clinicians may provide a survival estimate in discrete categories such as 0 to 2 days, 3 to 7 days, or greater than 7 days. These are known as categorical temporal predictions. Finally, clinicians may frame their predictions in terms of probabilities, such as the likelihood a patient will die in the next week or the next month. These are known as probabilistic estimates of survival.

Clinicians’ temporal predictions (either categorical or temporal) are frequently inaccurate and unreliable, with a systematic tendency to over-estimate.10,11 Although individual studies have suggested that accuracy may depend on experience, specialty or level of acquaintance with the patient, there is no consistent evidence that a particular group or sub-group of clinicians are more accurate than others. There is a suggestion that probabilistic predictions may be more accurate than temporal estimates, but fewer studies use this method.12

There is some evidence the accuracy and consistency of survival predictions can be improved by using algorithms and/or prognostic scoring systems. Table 2 provides examples of prognostic tools that have been validated in palliative care settings (hospital, hospice and community).13 Most of these tools have been developed predominantly (or exclusively) in advanced cancer populations. Therefore, clinicians caring for patients with advanced organ failures, degenerative neurological conditions and frailty should use these tools with caution.

A limitation of some prognostic tools is that they rely, to a greater or lesser extent, on the clinicians’ own prediction of survival. This can be a drawback for clinicians who wish to use a prognostic tool to provide an ‘objective’ estimate uncontaminated by their own subjective judgement. Some prognostic tools incorporate blood test results and although this can improve prognostic accuracy it can reduce their practical usefulness in palliative care practice where the philosophy is generally to minimise unnecessary procedures. Finally, although clinician predictions are known to be inaccurate, very few existing prognostic tools have consistently been shown to provide a superior performance.

Predictions of imminent death (<72 hours)

A phenomenon known as the ‘horizon effect’ suggests it is easier to predict events expected to happen imminently in contrast to those further in the future. For example, a weather prediction 3 days in advance is likely to be more accurate than one of 1/4 days. By the same logic it ought to be easier to predict when death is imminent than when death is still a few weeks or months away. Very few studies have systematically addressed this question. However, a systematic review found some evidence to support this hypothesis.10

Several studies have tried to understand factors that may predict imminent death. A range of methods have been used in this pursuit: by identifying signs and symptoms that forecast the last 72 hours of life, by asking clinicians what information they use to predict the last days of life and by studying subconscious clinical decision-making processes.

Patients with palliative performance scale (PPS) levels of 10%, 20%, and 30% (ie bed bound, needing all care, reduced oral intake and drowsy) have a median survival of 2, 4 and 13 days, respectively, thus probably making the PPS the most suitable prognostic tool for identifying patients at risk of imminent death.14

Prospective studies have monitored clinical signs in advanced cancer patients approaching death and found 13 indicators with high sensitivity (>95%) and positive likelihood ratios (>5) in the last 72 hours of life.15 These signs were pulselessness of radial
artery, respiration with mandibular movement, urine output <100 ml/12 hours, Cheyne-Stokes breathing, audible airway secretions, non-reactive pupils, decreased response to verbal or visual stimuli, inability to close eyelids, drooping of nasolabial fold, hyperextension of neck, grunting of vocal cords and upper gastrointestinal bleed. This is an area of ongoing research and caution must be exercised when interpreting results until they have been replicated. Some of the purported signs may be difficult to spot and the sensitivity of some were quite low, which means their absence does not exclude the possibility of imminent death. Moreover, it is unclear whether rigorous assessment of these clinical features would be any more accurate than relying on clinicians’ predictions.

Using a Delphi survey of international palliative care experts the factors used in conscious decision making were explored. There was over 50% consensus that pattern of breathing, level of consciousness and cognition, emotional state, general deterioration, intake of fluid and food, and skin changes are clinical aspects most commonly used to predict the last hours and days of life.14

Understanding intuition in predicting imminent death is a difficult area to study. Clinicians themselves are often unable to articulate the subconscious thought processes underlying their decisions, often referring to it as a ‘sixth sense’. A recent study used judgement analysis to try to understand doctors’ prognostic decision-making processes. From an original group of 99 palliative care doctors, the best 14 prognosticators were identified. Their subconscious decision-making strategies were probed by determining how their judgments altered in certain experimental conditions. The PPS was the most influential factor, followed by the presence of Cheyne-Stokes breathing, a decline in the patient’s overall condition and their level of agitation or sedation. 17

Communication of prognosis
Regardless of the method used to develop a prognostic estimate, there is always an element of uncertainty, which may be more pronounced in conditions with a variable illness trajectory. This uncertainty is one of the barriers to initiating conversations about the future with patients; the belief being that inaccuracy will decrease trust and bad news may lead to depression and loss of hope. However, evidence suggests this is not the case if conducted in a sensitive manner.18

| Table 2. Examples of prognostic tools validated in palliative care settings |
|-----------------------------|------------------------------------|-----------------------------|---------------------------------|-----------------|
| Prognostic tool  | Validated populations | Type of prediction | Factors included in score | Comments |
| Palliative Prognostic Score (PaP) | Mixed advanced disease: cancer and non-cancer | Probability of surviving 30 days – score assigns patients to one of three groups with < 30%, 30–70% or > 70% probability of survival | Symptoms of dyspnoea and anorexia | A hybrid assessment method which combines clinicians’ survival estimates with clinical features and blood results |
| Palliative Performance Scale (PPS) | Mixed advanced disease: cancer and non-cancer | Each decreasing PPS level (deciles from 100 to 0 %) is associated with a shorter survival; a study has derived median survival in days for PPS levels 10–70% | Functional status based on ambulation activity and evidence of disease self-care intake (food and fluid) conscious level | Does not rely on blood results or clinician predictions of survival. Not specifically developed as a prognostic tool and may therefore be missing some key prognostic variables. |
| Prognosis in Palliative care study (PiPS-A) score | Advanced incurable cancer | Provides a probability of surviving days (0–14 days), weeks (15–56 days) or months (>56 days) | Clinical information on diagnosis Sites of metastases Presence or absence of key symptoms Cognitive status Functional status | Does not rely on clinician predictions of survival. In one study was found to be better than a doctor’s or a nurse’s survival prediction |
| Prognosis in Palliative care study (PiPS-B) score | Advanced incurable cancer | Provides a probability of surviving days (0–14 days), weeks (15–56 days) or months (>56 days) | Performance score Oral intake Clinical signs of oedema and delirium Symptoms of dyspnoea | Does not rely on blood results or clinician predictions of survival |
| Palliative Prognostic Index (PPI) | Advanced incurable cancer | Probability of surviving < 3 weeks or < 6 weeks | | |

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Like the ways in which clinicians make survival estimates, the manner of explaining prognosis can be done in a variety of ways: by providing time frames (eg weeks to months) or by providing the likelihood of being alive for certain events. No approach has been found to be superior, but a consistent finding is that exact timeframes should be avoided.

It is also important to bear in mind that estimated prognosis may change over time, as well as the patient’s wish for prognostic information. In this dynamic situation, conversations involving disclosure of prognostic information can happen over several care settings and with different clinicians. Therefore, it is important to ensure adequate documentation and communication with other healthcare providers.

Guidelines (including examples of useful phrases) on how to communicate prognosis and discuss end of life issues are available.18,19 There is renewed focus with the recent Royal College of Physicians’ report aiming to advise and support healthcare providers.20

A summary of these recommendations is detailed in Table 3. ■

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