

EDITORIALS

Predicting and communicating prognosis in palliative care

Prognostic tools can help, but should not be applied blindly

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When Abdelbaset Ali al-Megrahi, convicted of the Lockerbie bombing, was released from a Scottish prison in August 2009, he was freed on compassionate grounds. His doctors pronounced that he was terminally ill with prostate cancer and thought he had only a few months to live. He is still alive today. How Meghari's prognosis was formulated is not known, but its accuracy may have been improved if his doctors had had access to a tool like the one developed in the linked study by Gwilliam and colleagues (doi:10.1136/bmj.d4920).¹

Diagnosis, prognosis, and therapeutics are the three essential clinical skills and prognosis is the least well done. Doctors are rarely trained in formulating prognoses, and nor do they like doing it, so they try to avoid it.² But in the 21st century much of clinical practice involves caring for patients with advanced, progressive, life limiting illness. Prognosis needs to be restored as a core clinical skill, to optimise the patient's treatment and planning.

A new science of prognosis is emerging in palliative care. There are two components to the skill of prognosis—formulating the prediction and communicating it to the patient. Formulation of the prediction may be based on personal clinical judgment or an actuarial one, whereby the human element is eliminated and the prediction rests solely on statistics.³ Some guidance is available for clinicians who wish to formulate the prognosis in their head. It can be formulated as a temporal prediction (expressed as a date or in units of time) or a probabilistic one (expressed as the percentage chance of reaching a certain time point). So called death trajectories have been described⁴; the pattern of decline seen in terminal cancer is monophasic and easier to anticipate than for other end stage diseases.⁵ Patient related factors such as performance status, symptoms, and laboratory parameters are more predictive of imminent death from cancer than are tumour related factors such as grade, stage, or genetic signatures.⁶

Temporal predictions based on clinical judgment are notoriously inaccurate and usually overoptimistic.⁷ Although probabilistic predictions are more accurate, approaching that of other clinical predictions,⁸ actuarial judgment of survival is now recommended.⁹ Several statistical models that predict survival

have been developed over the past 25 years,¹⁰ but none has entered routine clinical practice. Most came from single institutions, had small sample sizes, evaluated limited panels of variables, and were never validated. They have rarely been compared head to head with clinical judgment.

Gwilliam and colleagues' study overcomes many of these methodological deficiencies. From a list of 80 demographic, clinical, and biochemical variables sampled in more than 1000 patients from 18 different palliative care programmes across the United Kingdom, the authors identified the 23 parameters that are independently associated with a poor prognosis. When combined in mathematical models, these variables can clearly discriminate three different prognostic subgroups that have median survivals of about one week, one month, and three months. The models have been developed with and without blood tests, so that they can be adapted to a range of palliative care situations. They are well calibrated, and correctly predict whether the patient will live for days, weeks, or months about 60% of the time. They have been internally validated via robust statistical techniques, and they performed as well as human judges, if not better. External validation is now needed, both in other palliative care populations and in patients with advanced cancer who have not yet been referred to a palliative care service.¹¹

On the down side, the authors admit that their models are arcane and not easily calculated at the bedside. An electronic "app" is in the pipeline, but a nomogram should also be developed. Because about a third of patients were in the best prognostic group and a quarter of them were still alive at six months, a broader range of specific temporal and probabilistic predictions should be provided.

Because the predictions are easily affected by confounders, palliative care clinicians will need to avoid applying the tool arbitrarily. For example, a prediction of "days" that would be accurate for a natural death at home would probably be inaccurate in an acutely ill patient who is admitted to hospital with a life threatening complication and opts for aggressive life sustaining treatment in the intensive care unit.

Ultimately, however, even a state of the art prognostic tool like the Prognosis in Palliative care Study (PiPS) predictor model will often be inaccurate. This is not surprising because previous work indicated that the kind of variables evaluated in this model fail to explain a large proportion of the variance seen in actual survival.⁷ New prognostic factors need to be identified and evaluated. A starting point would be to look at cases where expert clinicians formulated different prognoses to the tool. Outlier cases that fall at the extremes of the survival curves may also provide insights that minimise the amount of unexplained error in future prognostic models.

Until this inherent inaccuracy is mitigated, doctors will continue to resist prognosticating; those who do will be scorned by their colleagues and accused of “playing God.” Patients’ preferences for prognostic information vary during the course of the illness, so communicating the prediction to the patient is as important as forecasting it.¹²

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