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Predicting survival in patients with advanced disease

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ABSTRACT

Prognostication is an important clinical skill for all clinicians, particularly those clinicians working with patients with advanced cancer. However, doctors can be hesitant about prognosticating without a fundamental understanding of how to formulate a prognosis more accurately and how to communicate the information with honesty and compassion. Irrespective of the underlying type of malignancy, most patients with advanced cancer experience a prolonged period of gradual decline (months/years) before a short phase of accelerated decline in the last month or two. The main indicators of this final phase are poor performance status, weight loss, symptoms such as anorexia, breathlessness or confusion and abnormalities on laboratory parameters (e.g. high white cell count, lymphopaenia, hyopalbuminaemia, elevated lactate dehydrogenase or C-reactive protein). The clinical estimate of survival remains a powerful independent prognostic indicator, often enhanced by experience, but research has only begun to understand the different biases affecting clinicians' estimates. More recent research has shown probabilistic predictions to be more accurate than temporal predictions. Simple, reliable and valid prognostic tools have been developed in recent years that can be used readily at the bedside of terminally ill cancer patients. The greatest accuracy occurs with the use of a combination of subjective prognostic judgements and objective validated tools.

Communicating survival predictions is an important part of cancer care and guidelines exist for improving delivery of such information. Important cultural differences may influence communication strategies and should be recognised in clinical encounters. More well-designed studies of prognosis and its impact on decision making are needed. The benefits and limitations of prognostication should be considered in many clinical decisions.

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1. Introduction

Diagnosis, treatment and prognosis are the three great clinical skills in medicine,[1] but prognosis diminished in importance during the 20th century as effective treatments became available for many previously fatal conditions.[2] Progress in palliative care over the past 40 years has encouraged a renaissance of prognostication as a clinical skill. Oncologists and palliative care clinicians need to be proficient at prognosis for various reasons:

- To provide patients and families with information for goal setting including priorities and expectations of care.[3–7]
- To assist with clinical decision making.[8,9]
- To compare similar patients with regard to outcomes.[10]
- To establish patients' eligibility for care programmes.[8,11]
- For the design and analysis of clinical trials.
- For policy making.[6–8]

Like the stages of cancer, prognosis can provide a common language for health care professionals involved in end of life care.

Despite the importance of prognosis as part of good end of life care, modern clinicians are often averse to predicting medical outcomes, particularly death. A survey of American physicians found that most respondents felt poorly trained for prognostication and faced difficulty in both formulating and communicating a prognosis.[12] They also found forecasting stressful, and worried about being judged poorly by patients and colleagues when predictions were incorrect. As a result they developed a number of coping strategies, including avoidance, optimism and vagueness.[13] Substantial progress in five aspects of the contemporary understanding of prognosis may help improve this difficult situation.

Firstly, prognosis is a much broader concept than just predicting survival. It is rightly defined as the 'relative probabilities of the various outcomes of the natural history of a disease'.[14] A useful taxonomy for the domains of prognosis is 'the 5D's of prognostication':[15]

- Disease progression/recurrence.
- Death.
- Disability/discomfort.
- Drug toxicity.
- Dollars (costs of health care).

All of these domains are relevant to palliative care, although predicting survival is the primary focus of this article. Examples of day-to-day prognostic questions faced by palliative care practitioners are shown in Table 1.

Secondly, prognostication in far advanced cancer is based on different predictive factors than prognosis in early stage disease. The diagnostic, pathological and treatment-related prognostic factors important in early stage cancer are less relevant in patients with advanced progressive disease than functional status, the anorexia–cachexia syndrome, systemic inflammation, lymphopaenia, poor quality of life and psychosocial factors.

Thirdly, the modern concept of 'death trajectories' makes predicting survival in far advanced cancer easier to conceptualise.[16] The typical 'cancer' trajectory involves a gradual decline in health status over a period of months or years, with an accelerated decline in the final weeks to months (Fig. 1). The challenge for clinicians caring for advanced cancer patients is identifying when the accelerated, irreversible decline is occurring rather than an acute and reversible event.

Table 1 – 5D's: examples from palliative care

'D'	Example
Disease progression/recurrence	Will she become hypercalcaemic again?
Death	Is there time for my sister to come from out of town?
Disability	Will I walk again?
Drug toxicity	Won't morphine make me an addict?
Dollar cost	Is more expensive to treat cancer pain according to the guidelines?

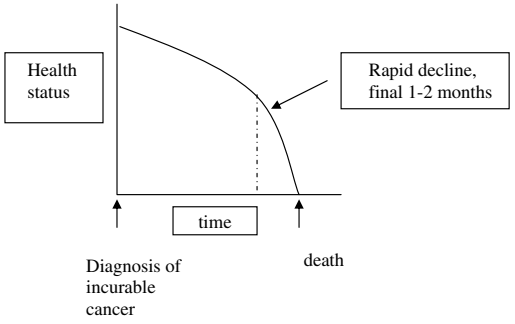

Fig. 1 – Conceptual model of cancer death trajectory.[122,123]

Fourthly, proponents of prognostication need to counter criticism of survival predictions being too inaccurate to be helpful. Of course there are many uncertainties when predicting future outcomes, especially when considering the complex dynamic of the human body and the multiple interactions between the human body and illness. However, the accuracy of survival predictions depends on the type of prediction being made, with probabilistic predictions (the percentage chance of surviving to a certain time) (50–75% accuracy) being superior to traditional temporal predictions (the estimate of time the patient will survive), accurate only 25% of the time.[3,17–21] As Table 2 shows, the accuracy of probabilistic cancer survival predictions is comparable with that of other medical predictions and meteorological forecasting.

Lastly, prognosis is often misunderstood as a static phenomenon, reinforced by the research studies focusing on one point in time (e.g. survival after admission to hospital or referral to hospice). The illness trajectory changes over time, so that as the illness evolves, new issues must be considered and the prognosis should be revised.

2. Prognostic factors in advanced cancer

2.1. *Performance status*

Almost 150 different variables have been evaluated for their ability to predict survival (Table 3).[22–24] Of all of them,

Table 2 – Accuracy of oncologic prognoses and other medical predictions and forecasts

Prediction	Accuracy (%)	Reference
Cancer: curability	91	29
Survive an ICU admission	90	28
Rain in next 12 h	87	29
Cancer: survive 3 months	75	29
5-day forecast (rain)	73	29
Positive blood culture	69	30
Cancer: survive 1 year	57	29
Palliative care: date ± 33	26	31

performance status has been the most extensively studied and consistently shows an association with survival duration. A Karnofsky Performance Scale (KPS) score <50% is associated with a short survival,[6,7,22,25–27] although it accounts for only a small amount of the variability in observed survival.[64] Patient-rated KPS scores can provide independent prognostic information to physician-rated ones.[25]

The KPS definitions used at lower performance scores (need for hospitalisation, special care) do not reflect modern health care delivery. Two modifications have attempted to address these wording issues: the Palliative Performance Scale (PPS) and the Australian modification of the KPS (AKPS).[28,29] The PPS adds categories for oral intake and conscious level (Table 4).[30] PPS scores correlate strongly with KPS scores[31] and are also a strong predictor of survival. There is some disagreement about whether PPS scores represent distinct survival deciles[32] or fall into three bands (PPS 10–20%, PPS 30–50%, PPS 60–70%).[74,75] Typically, palliative care patients in these bands have a median survival of a week, a month and 3 months, respectively. Negative-change serial PPS scores in hospitalised patients predict decline towards death, whilst stable scores result in discharge consideration.[33] PPSv2, a minor wording clarification, has high inter- and intra- rater reliability.[34] The PSS is available online at http://web.his.uvic.ca/research/NET2/index.php.

The Eastern Cooperative Oncology Group–Performance Status (ECOG-PS) Scale has also been shown to be predictive of survival in advanced cancer.[25,35,36] Activity of daily living scores are associated with survival of cancer patients,[37] but have not been investigated as extensively as performance status.

2.2. *Symptoms*

Symptoms are recognised as indicators of poor survival in patients with advanced cancer.[23,35] The US National Hospice Organisation (currently the NHPCO) study showed that symptoms can improve the accuracy of KPS score in predicting survival.[38] The strongest association between any symptom and survival is for anorexia and/or weight loss (Table 3). The anorexia–cachexia syndrome has been labelled the 'final common pathway' of cancer by some.[25,39–41] Dyspnoea[8,36,42–44] and confusion/cognitive failure[26,43,45,46] are other symptoms that have been shown consistently to predict a poor survival in far advanced cancer.

Even though episodes of severe, uncontrollable pain have been reported to be more common in the last few weeks of life,[47] pain is not usually considered to be predictive of poor survival.[38,48] This may reflect a lead-time bias in prognostic studies, most of which have not involved true inception cohorts, as pain is often a trigger for palliative care referral. Similarly, treatment with opioids does not have any impact on survival rate according to several groups of investigators.[36,49,50]

Many questions remain to be answered about symptoms and survival. Is severity important? Is having multiple symptoms worse? What about symptom distress? With regard to the last, a Canadian study of recently diagnosed, advanced cancer patients (median survival 1 year) found that Symptom

Table 3 – The extent to which various clinical variables appear to be predicative of survival in patients with far advanced cancer[121]

Variable	Number of positive studies[a]	Total number of studies evaluating	Strength of association
Poor performance status	14	14	Definite
Anorexia	8	9	Definite
Clinical prediction of survival	7	7	Definite
Cognitive failure	7	8	Definite
Dyspnoea	7	8	Definite
Dry mouth	5	6	Definite
Weight loss	4	5	Definite
Dysphagia	4	5	Definite
Primary site	5	10	Possibly yes
Pain	5	10	Possibly yes
Serum albumin	3	4	Possibly yes
Tachycardia	3	4	Possibly yes
Gender (male)	3	11	Possibly yes
Marital status	2	5	Probably not
Nausea	2	5	Probably not
Age	2	9	Probably not
Fever	1	4	Probably not
Anaemia	0	4	Probably not

a Positive on either univariate or multivariate analysis.

Table 4 – Palliative Performance Scale v2[30]

PPS level (%)	Ambulation	Activity level	Evidence of disease	Self-care	Intake	Conscious level
PPS 100	Full	Normal activity	No evidence of disease	Full	Normal	Full
PPS 90	Full	Normal activity	Some evidence of disease	Full	Normal	Full
PPS 80	Full	Normal activity with effort	Some evidence of disease	Full	Normal or reduced	Full
PPS 70	Reduced	Unable normal job/work	Some evidence of disease	Full	Normal or reduced	Full
PPS 60	Reduced	Unable hobby/ house work	Significant disease	Occasional assistance necessary	Normal or reduced	Full or confusion
PPS 50	Mainly sit/lie	Unable to do any work	Extensive disease	Considerable assistance necessary	Normal or reduced	Full or drowsy or confusion
PPS 40	Mainly in bed	Unable to do any work	Extensive disease	Mainly assistance	Normal or reduced	Full or drowsy or confusion
PPS 30	Totally bed bound	Unable to do any work	Extensive disease	Total care	Reduced	Full or drowsy or confusion
PPS 20	Totally bed bound	Unable to do any work	Extensive disease	Total care	Minimal sips	Full or drowsy or confusion
PPS 10	Totally bed bound	Unable to do any work	Extensive disease	Total care	Mouth care only	Drowsy or coma
PPS 0	Dead	–	–	–	–	–

Instructions: PPSv2 level is determined by reading left to right to find a 'best horizontal fit.' Begin at left column reading downwards until current ambulation is determined, then, read across to next and downwards until each column is determined. Thus, 'leftward' columns take precedence over 'rightward' columns. Also, see definitions of terms to interpret PPSv2 accurately. With permission Victoria Hospice Society.

Distress Scores (SDS) were highly correlated with survival ($r = -0.49$).[51] Fatigue, insomnia, frequent pain and 'outlook' were the symptoms most commonly attributed with high distress. The physical symptom subscale scores of the Rotterdam Symptom Checklist[52] and the Memorial Symptom Assessment Scale[53] can also predict survival in selected populations.

2.3. *Quality of life*

An association has been demonstrated between the survival of advanced cancer patients and scores on a number of quality of life (QOL) instruments, including the Functional Living Index-Cancer (FLIC),[54] Spitzer QLI,[55,56] the EORTC QLQ C30,[57] and even the SF-36.[58] This association has not been studied much in patients with far advanced disease and its nature is unclear.[59] Furthermore, the content and length of these surveys does not make them well suited for use in this population. A study of the Therapeutic Impact Questionnaire (TIQ), which has subscales for global well-being, physical symptoms, function, psychological state and family/social relationships found that only global well-being and patient-rated cognitive function showed independent prognostic value in palliative care patients. Whilst these two subscales are hardly representative of quality of life, median survival was 137, 50 and 17 days, respectively, when there was impairment on neither, one, or both scores.[46]

2.4. *Biological parameters*

The idea of being able to prognosticate from the results of a simple blood test is very appealing to clinicians. A large Italian study found reduced survival in palliative care patients with high total WBC, high neutrophil percentage, low lymphocyte percentage, low serum pseudocholinesterase, low serum albumin and elevated proteinuria.[60] On multivariate analysis, only high total WBC and lymphopaenia retained independent prognostic significance. Many similar studies have been conducted subsequently. Most current interest is in the prognostic import of elevated lactate dehydrogenase (LDH),[20,61,62] the pro-inflammatory cytokines such as interleukin-6,[63] and C-reactive protein (CRP).[64–66]

3. Formulating a survival prediction

There are two components to the clinical act of prognostication. The first is formulating the prediction (i.e. foreseeing). The second is communicating the prediction to the patient, family or other medical professionals (i.e. foretelling). Both foreseeing and foretelling are areas for research and quality improvement.[67]

The two approaches to formulate the prognosis are (a) the clinical prediction of survival (CPS) and (b) the use of statistical tools. Research commencing within the field of clinical psychology has shown that statistical methods are generally superior to clinical judgement in predicting human behaviour and other outcomes,[68] but the subjective or clinical prediction of survival remains important in daily clinical practice. The two approaches are not mutually exclusive and the European Association of Palliative Care's recent Working Group on Prognostication has recommended that both may be used in a clinical situation to reduce uncertainty.[69] CPS has been retained as an independent predictor of survival on multivariate

analysis of prognostic variables by several different investigators.[42,70]

3.1. Clinical prediction of survival (CPS)

The main advantage of CPS is flexibility, as validated prognostic tools may not always be available or appropriate to the patient's immediate clinical situation. Unfortunately, CPS is subject to many cognitive biases including the framing effect, anchoring, confirmation bias and selective recall.[71,72] The accuracy of CPS has been the subject of many studies.[6,7,26,45,48,55,70,73–78] A systematic review found that temporal CPS consistently overestimates actual survival (AS) by 45%, being correct to within one week in only 25% cases.[79] But despite the discrepancy, CPS and AS were highly correlated.

Recent studies in non-Western countries not included in the meta-analysis have found less over-estimation.[80,81] As mentioned previously, probabilistic predictions are less inaccurate than temporal ones.[48,55] Repeated estimates are thought to be more accurate.[6,78,82] Results are conflicting as to whether CPS is more accurate closer to death.[74,9,20,83] No consistent differences have been found in the prognostic abilities of health care workers from different disciplines.[6,26,73,74,76,84,78] Experience seems to improve prognostic accuracy, but the stronger the doctor–patient relationship, the lower the prognostic accuracy.[3]

To construct a prognosis using CPS, one relies on experience, but this depends on having seen a lot of similar cases and having a reliable memory. Understanding clinicians' reasoning behind their estimates of life expectancy might provide useful insights into consideration and valuation of select clinical and social information,[85] but has not been well studied. A survey of Italian oncologists found that they mainly relied on tumour-related factors when formulating predictions in patients with advanced disease.[86] Other research found that CPS and KPS scores were closely correlated ($r = 0.61$),[87] suggesting that experienced clinicians rely on performance status when making predictions. A useful framework for a structured CPS that takes these factors into account is shown in Fig. 2.[88,89]

3.2. Statistical estimate of survival

Many studies published in the last 10 years use multiple regression models for determining the association between prognostic factors and survival, but few have tested the predicative accuracy of their final models, a key step in prognostic model building. A recent systematic review of survival prediction tools for use in a palliative population focused on those where some validation was evident.[90]

Of an original screening of 975 citations, only 28 studies met the inclusion criteria and were reviewed. Just 15 studies involving some 10 tools (five of which are used in cancer) had adequate quality to permit synthesis. Some tools that the authors of the review consider clinically useful are briefly described here.

Readers should familiarise themselves with a selection of tools that meet their prognostic needs then test them in their patient population. One useful method for comparing these tools is the calculation of likelihood ratios (LR). LR represents the likelihood that a given prognostic score would be expected

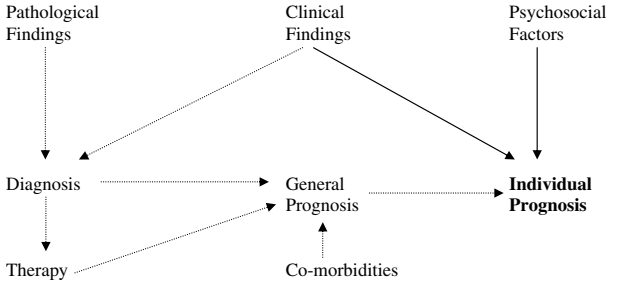

Fig. 2 – Formulating a prognosis – adapted from reference.[88]

in a patient who will die within a specific time interval, compared to the likelihood that that same prognostic score would be expected in a patient who will not die (or not survive) within that interval. 'Positive likelihood ratios' (LR+) tell us how much to increase a 'suspected' probability of dying (pre-test probability), whilst the 'negative likelihood ratios' (LR–) tell us how much to decrease it given a specific score or cut-off.[91]

(a) Palliative Prognostic (PaP) Score[42]: This tool combines KPS score, symptoms, white cell count, lymphocyte percentage and CPS.[60] Points are allocated for each of these factors and these sub-scores are summed to give a final score, known as the palliative prognostic (PaP) score, which predicts for short-term survival (Table 5). The scores (0–5.5; 6–11 and 11.5–17.5) split populations of far advanced cancer patients into three iso-prognostic groups with high (>70%), intermediate (30–70%) and low (<30%) chances of surviving 30 days, respectively. The PaP score has been validated in hospitalised palliative care patients,[92] community care patients,[49] and hospitalised oncology patients.[93]

(b) Palliative Performance Index (PPI): This combines PPS score, oral intake, oedema, dyspnoea and delirium[43] (see Table 6). It does not require a CPS. Like the PaP score, three risk groups are calculated, in this case with median survivals of >6 weeks (PPI <2.0), 3–6 weeks (PPI 2.0–4.) and <3 weeks (>4.0).[94] It is not as widely validated as the PaP score.

(c) Cancer Prognostic Score[95]: This tool predicts short-term survival (1 and 2 weeks) using a 7-item scale including liver and lung metastases, functional performance status, weight loss, oedema, cognitive impairment, tiredness and ascites.

(d) Intra-hospital Cancer Mortality Risk Model (ICMRM)[62]: This could be a useful tool for clinicians to predict the likelihood of dying of cancer following hospital admission. It uses ECOG-PS, duration of illness, type of admission, haemoglobin and LDH. It had more than 80% accuracy in the derivation and the validation cohorts, with a median survival of 8 days.

(e) Scores based on biological makers: The Glasgow Prognostic Score (GPS) combines CRP and albumin and also stratifies patients into three groups based on elevated CRP and/or hypoalbuminaemia. It has been used to predict survival in recently diagnosed advanced lung or upper gastrointestinal malignancies[65,66] The B-12/CRP index (BCI)[96] takes the product of serum vitamin B12

Table 5 – How to compute PaP score:[42]

	Partial score
Dyspnoea	
No	0
Yes	1
Anorexia	
No	0
Yes	1.5
Karnofsky performance status	
⩾30%	0
10–20%	2.5
Clinician's estimate of survival (weeks)	
>12	0
11–12	2
7–10	2.5
5–6	4.5
3–4	6
1–2	8.5
Total white cell count	
⩽ 8.5	0
8.6–11.0	0.5
>11	1.5
Lymphocyte percentage	
20–40%	0
12–19.9%	1
<12%	2.5
Risk groups	Total score
A (30 day survival probability >70%)	0–5.5
B (30 day survival probability 30–70%)	5.6–11
C (30 day survival probability <30%)	11.5–17.5

Table 6 – Calculation of the Palliative Performance Index

Factor	Partial score
PPS 10–20%	4
PPS 30–50%	2.5
PPS >50%	0
Delirium	4
Dyspnoea at rest	3.5
Oral intake mouthfuls or less	2.5
Oral intake reduced but more than mouthfuls	1
Oral intake normal	0
Oedema	1
Total score (sum of partial scores) and expected survival	
• Group A (total score <2.0): greater than 6 weeks	
• Group B (2.0–4): 3–6 weeks	
• Group C (>4.0): less than 6 weeks	

level (pmol/l) and serum CRP level (mg/l) and stratifies patients with advanced cancer into 3 groups based on pre-determined cut-off points (10,000 and 40,000).

3.3. *Future prognostic tools*

Progress in statistical computing in the past decade strengthens evidence for survival prediction risk calculators or prognostic models. Some notable examples in advanced cancer include:

- Prognostat: a web-based tool for survival prediction. It includes a calculator, survival tables and nomogram. It is located via http://web.his.uvic.ca/research/NET2/index.php or a link at www.victoriahospice.org.
- Adjuvant!: a web-based algorithm database used to provide accurate 10-year morbidity/mortality outcome prediction in breast and lung cancer.[97] It can be located at www.adjuvantonline.com.
- Memorial Sloan Kettering Cancer Centre (MSKCC) nomograms: The MSKCC group has developed a number of survival risk calculators for several cancers. For example, the prostate cancer nomogram for hormone refractory stage is derived from age, Karnofsky score, PSA, haemoglobin, ALK, LDH and albumin levels.[98] It then calculates survival probability for 1-year, 2-year and median survival in months. It may be located at http://www.mskcc.org.
- Updated links to online prognostic tools is maintained by one of the authors at http://prognosis.pallimed.org/.

4. Communicating a prognosis

Both formulating and communicating prognoses to patients with advanced cancer are complex and difficult processes. Episodes of poor communication are often vividly remembered. However, communication is a skill and can be honed. It is incumbent on all health professionals to ensure that they are trained adequately to break this prototypical example of 'bad news'.

4.1. *Why communicate the formulated prognosis to the patient?*

Talking to patients about prognosis is difficult and stressful,[12] and the evidence suggests that clinicians are poor at this type of communication.[99] So why do it? Most cancer patients want a high level of prognostic information.[100–104] In one study 81% of patients with recently diagnosed metastatic cancer wanted information about average survival times.[103] They want this information to optimise the time remaining, finish uncompleted tasks and prepare for their death.

Giving patients prognostic information also affects patient outcomes. An 'explicit terminal diagnosis' reduced admission rates to hospital and increased the chances of dying at home.[105] Advance care planning for patients at the end of life requires frank yet tactful disclosure about prognosis. Without such explicit prognostic information patients may find themselves being managed in the curative care setting at the end of life rather than a more palliative environment. Other studies have found that patients with unrealistic or inaccurate expectations of survival are more likely to undergo aggressive and probably futile treatments.[106,107]

4.2. *What prognostic information do patients want?*

In general, cancer patients want to have all available information about their cancer and chances of cure,[108] and palliative care patients are no exception. For example, a large UK study found that 85% patients wanted as much information as possible, both good and bad news.[109] Notably, only 7% wanted

just to hear good news. In terms of what sort of information palliative patients want, two themes consistently emerge: prognosis and maintenance of hope.[101,110] This is clearly a challenging demand for doctors to be honest yet optimistic and patients acknowledge this difficulty themselves, being caught between wanting to know what is going on and fearing the answers they might receive. Strategies for maintaining hope in the face of poor prognosis have been identified.[110]

Many studies stress the importance of individualised content and timing of prognostic discussions.[103,111–113,108,109,114] Individual patients' information needs can change during the course of the illness. Unfortunately, patient characteristics (age, gender, race and social status) do not predict how much information patients want or how such information should be delivered.[101] There is also a poor correlation between patients' and doctors' perceptions of decision-making preferences.[115] In one study,[103] approximately half the patients wanted specialists to initiate discussions about prognosis, 20% only wanted specialists to tell them about survival 'if asked' and 10% never wanted to discuss it. Moreover, although most patients preferred words and numbers to diagrams and pie charts, older patients were significantly more likely to prefer 100-person diagrams and patients with more years of education were more likely to prefer pie charts. Patients also prefer optimistic or positively framed statements such as 'chance of living for five years' and 'longest survival without treatment' rather than 'chance of living for one year' or 'shortest survival without treatment'.

4.3. *How to communicate the formulated prognosis to the patient?*

Although patients generally want to know their prognosis, the best way to communicate it is not always clear. Some important attributes relating to the process of information-giving[110] are shown in Table 7a. The National Health and Medical Research Council of Australia have recently produced and published evidence-based guidelines on communicating prognosis to adults with advanced life-limiting illnesses.[116] The guidelines cover eight processes and can be remembered by the use of the mnemonic **P.R.E.P.A.R.E.D.** (Table 7b).

Table 7a – Attributes of good communication of prognostic information

Playing it straight (the need for clinicians to be honest and direct)
Making it clear (providing information in an understandable format)
Showing you care (the use of empathetic words and non-verbal communication)
Giving time (allowing patients not to feel rushed)
Pacing information (providing information at a rate appropriate to the individual)
Staying the course (the need for clinicians to convey the message that they will not abandon the patient as the illness progresses)

Table 7b – P.R.E.P.A.R.E.D. mnemonic for communicating a prognosis

Prepare for the discussion
Check facts
Ensure appropriate environment
Relate to the person
Develop rapport and show empathy
Elicit patient and care-giver preferences
Clarify baseline understanding
Check what patient wants to know
Provide information
Pace the information
Use clear language
Explain uncertainty, limitations and unreliability of prognostic estimates
Ensure consistency of information
Acknowledge emotions and concerns
Acknowledge and respond to distress
(Foster) Realistic hope
But avoid giving unrealistic or false information
Encourage questions
Check patient's understanding
Be prepared for further discussions in the future
Document
Write a clear summary in the medical notes
Communicate with other professionals

4.4. *Cultural issues and communicating prognosis in palliative care*

There is evidence of cultural differences between English-speaking/Northern European countries and other countries, with a tendency for patients from other countries to want less detailed information.[104] However, a Dutch study also found that doctors and patients from that country often collude to avoid discussing the prognosis.[117] The attitudes and beliefs of culturally diverse palliative care specialists (Europe, South America and Canada) regarding communication with the terminally ill has been studied.[118] Respondents from all three regions believed that cancer patients should be informed of their diagnosis and the terminal nature of their illness, and that the proportions of patients who knew this information were similar in the three regions. Likewise, respondents from all regions agreed that 'do not resuscitate' orders should be present and should be discussed with the patient in all cases. Differences were found, however with regard to the proportions of palliative care physicians who believed that most of their patients wanted to know about the terminal stage of their illness – more than 90% of Canadians compared with 18% of South American and 26% of European physicians. Similar results were found when the physicians were asked the percentage of families who want patients to know the terminal stage of their illness. However, almost all of the physicians agreed that if they had terminal cancer they would like to know.

There was a significant association between patient-based decision making and female sex, older age and being a physician in Canada or South America. Finally, South American physicians were significantly more likely to support beneficence and justice as compared with autonomy. Canadian physicians were more likely to support autonomy as compared with beneficence. This survey suggests that major regional differences in the attitudes and beliefs of physicians regarding communication at the end of life exist. Much more research is needed on this topic, but in the meantime physicians need to be aware of their personal attitudes towards

discussing diagnosis, prognosis and any other sensitive issue (e.g. sexuality, spirituality) and endeavour not to impose their own values on those of the patient.

5. Conclusion

Prognostication remains a challenging topic. In the past 20 years, much research has been undertaken to identify the ways of improving the accuracy and precision of clinicians' estimates and many tools are now available to improve prognostication. Research is now needed to show how these tools aid clinical decision making.

Whilst we are now in a better position to give the patient 'x % chance of surviving for y weeks/months', we are not yet able to propose any of the existing tools as the ideal one to be recommended for widespread use. Most of the existing tools focus on performance status, symptoms and simple laboratory markers; whilst these are helpful, they have individual drawbacks in the lack of accessibility, applicability and knowledge they provide. Novel objective prognostic factors need to be identified and functional status and biomarkers are the main focus of current research.

Notwithstanding this progress, clinical judgment remains important, in the authors' opinion. The clinical data needed to use a tool to calculate the prognosis (e.g. recent laboratory parameters) may not be available, tools may not provide the prognostic information required, and they may not have been validated in the population to which the individual patient belongs. Clinical judgement alone may be sufficient if the issue is acknowledging a probability of dying from an illness in the foreseeable future. The SUPPORT study showed that patients may change their planning behaviour once they understand that the chance of surviving beyond six months is small.[119] Furthermore, models predicting survival should be thought of like any diagnostic test, i.e. they should not be interpreted in isolation but as a way of improving the pre-test probability of survival, which is based on clinical judgement.

The concept of 'sentinel events' may be important in prognosis in palliative care. The prognostic models described above can provide improved clarity, but still provide a general, non-individualised prognosis. What happens to palliative patients who appear otherwise stable then suddenly decline or even die? Examples may include severe renal dysfunction (with bacteraemia, amputation and acute myocardial event) or dementia (dysphagia, decubiti and aspiration pneumonia).[120] Various biological markers like CRP may also help. Clarification of such sentinel events may provide more individualised focus on prognosis as illness progresses and complications occur.

Even if precise and accurate individual predictions of survival duration become available, this alone should never drive treatment plans. What ultimately is needed is not so much an accurate prediction of time but an acknowledgement of the possibility of dying, communicated carefully by the compassionate and skilful physician.

Conflict of interest statement

None declared.

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